Integrated Care for Patients Following Acute Stroke: Evidence Synthesis and Development of a Novel Holistic Approach to Stroke Care

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Dedication

I would like to dedicate this PhD to those inspirational stroke survivors who willingly gave up their time to share their stories with extraordinary freedom, frankness and clarity during my research journey.

Abstract

Background

Integrated care is an emerging concept that improves patient outcomes and satisfaction and reduces healthcare costs and resource utilisation. There is limited evidence on the benefit of integrated care in people with stroke. This study aims to determine what components of integrated care are considered important for patients and HCPs and to use the information gained to generate a new person-centred integrated care pathway.

Methods

This study comprised two distinct work packages. Work package 1 was a systematic review and meta-analysis of published studies on integrated care in stroke. Work package 2 was an innovative mixed methods study comprising two Phases (Phase 1: focus groups to explore stroke survivors' experiences of stroke recovery; Phase 2: a Delphi survey to gain consensus on which components of care patients and HCPs believe should be included in an integrated stroke pathway.

Results

The systematic review demonstrated that patients receiving integrated stroke care had significant improvements in quality of life and significantly reduced incidence of depression. There were no significant differences in mortality, recurrent stroke or major bleeding.

Four themes were identified in the stroke survivor focus groups through Reflexive Thematic Analysis: 1) Recognising stroke, 2) Loss of identity, 3) Life after stroke – Feeling lucky and 4) Dealing with the past and looking to the future. Based on the findings of the study, a new holistic integrated care pathway for stroke was created (RACE: R – Recognition of stroke and its associated symptoms, A – Acute and appropriate treatment of stroke, C – Control of cardiovascular risk and other comorbidities, and E – Education and training on care in post-stroke life and prevention of subsequent stroke).

Conclusions

The involvement of stroke survivors and HCPs in a novel mixed methods study has allowed the creation of a new holistic integrated care pathway based on clinical evidence and the priorities of patients and clinicians. Future research should focus on testing the RACE pathway and on further characterising the benefits of integrated care in people with stroke.

1 Chapter One: Introduction

1.1 Overview of the thesis

This PhD thesis describes a series of work packages including a mixed methods study which aimed to investigate the integrated care of people following stroke and to use the knowledge gained to develop a new model of care that meets the needs of this population. These aims were achieved in two work packages by 1) undertaking a systematic review and meta-analysis of the literature, 2) Phase 1 exploring the experiences of adult men and women following their recovery from stroke and 3) Phase 2 employing a Delphi survey to gain consensus on the components of care that should be incorporated into an integrated stroke care pathway. Previous research in stroke has focussed on integrated care and rehabilitation interventions delivered in the acute setting whereas this study aimed to understand the barriers and enablers people with stroke experience during their recovery following hospital discharge.

This chapter will provide context to the care and treatment of people following stroke, discuss the aims for the PhD project, provide an overview of the study design, and explain how the thesis will enhance the body of knowledge in this field. Chapter Two introduces the background and rationale for the study and discusses the theoretical framework upon which the research is based. In Chapter Three, the philosophical viewpoint or research paradigms will be discussed and the rationale for the choice of research paradigm is given, in addition to my philosophical perspectives as a researcher. Chapter Four provides an introduction to the phenomenon of stroke and discusses the concept of holistic care. Subsequent chapters in the thesis are dedicated to the study itself. The systematic review and meta-analysis, focus groups and Delphi survey are integral parts of the study and are covered in Chapters Five, Six and Seven, respectively. In Chapter Eight, the findings of all the studies are brought together and synthesised in a detailed discussion and in Chapter Nine the new integrated care pathway is presented. Chapter Ten provides a concise conclusion to the research and discusses future implications for this work.

1.2 Background to stroke

Stroke is often considered the cerebral equivalent of a myocardial infarction since both conditions are life-threatening vascular events involving blockage of or restriction of blood flow in an artery causing ischaemic necrosis of downstream tissue (Widimský et al., 2013), which results from an interruption of blood supply to the brain either through a blockage in a blood vessel or bleeding into the brain (National Heart Lung and Blood Institute, 2023). If the cause of the stroke is a blockage, cells in the brain are starved of oxygen and nutrients delivered

to them by the blood and start to die within minutes. If the stroke is caused by bleeding into the brain, the pressure exerted by the escaping blood damages the cells (National Heart Lung and Blood Institute, 2023). More detailed information of the pathophysiology of stroke can be found in Chapter Four.

Stroke is classed as a medical emergency since it can lead to prolonged brain damage, long-term disability, or even death (National Heart Lung and Blood Institute, 2023). Stroke signs can range from mild weakness or numbness to paralysis on one side of the face or body (National Heart Lung and Blood Institute, 2023). Other signs may include a sudden and severe headache, sudden weakness, visual and speech problems (National Heart Lung and Blood Institute, 2023).

Stroke is a common condition with more than 11.9 million events recorded worldwide in 2021 (Feigin et al., 2025) and a lifetime risk of 25% from the age of 25 years onwards (Feigin et al., 2018). Globally, stroke is the second-leading cause of death and the third-leading cause of death and disability combined (Feigin et al., 2025). The socioeconomic burden of stroke is substantial; globally the cost of stroke is estimated at more than US$890 billion (0.66% of global gross domestic product [GDP]) (Feigin et al., 2025) and in the UK alone, it is estimated that the societal costs of stroke are approximately £26bn annually (Patel et al., 2020), with a mean estimated cost per patient of £46,000 every year over the first 5 years (Xu et al., 2018). Individuals surviving an initial stroke are at substantially increased long-term risk of subsequent stroke (Edwards et al., 2017), with 11% having a recurrent stroke within 1 year and 26% having a recurrent stroke within 5 years (Mohan et al., 2011). Recurrent strokes are associated with poorer outcomes and higher mortality compared with the initial stroke (Samsa et al., 1999; Modrego et al., 2000; Buckley et al., 2022).

The Global Burden of Disease (GBD) study 2021 estimated that the mortality rate from stroke decreased by 22% between 1990 and 2021 and that the global incidence of stroke remained largely unchanged from 2015 onwards (Feigin et al., 2024). There were some increases in incidence, death, prevalence and disability in southeast Asia, east Asia, sub-Saharan Africa and Oceania, attributed to poor control of risk factors such as hypertension and insufficiently effective stroke service provision and accessibility in these regions (Feigin et al., 2024). Between 2010 and 2017, data from the GBD report that global prevalence of stroke had increased by 19.3%, incidence by 5.3% and mortality by 5.3% in this time period, driven mostly by China and Eastern Europe (Goldstein, 2020; Feigin et al., 2021; Saini et al., 2021), with the absolute number of people affected by stroke almost doubling between 1990 and 2016.

Worryingly, the risk of stroke is increasing in young adults between the ages of 20 and 45 (Goldstein, 2020). In a recent analysis of the Oxford Vascular (OXVASC) study of almost 95,000 people registered with GP practices across Oxfordshire for the last 20 years, there was a 67% increase in stroke incidence among younger adults (under 55 years) between 2002-2010 and 2010-2018 (incidence rate ratio [IRR], 1.67; 95% confidence intervals [CI], 1.31-2.14) (Li et al., 2022). There was a significant increase in the proportion of younger adults who had stroke working in skilled occupations, especially professional or managerial jobs, which suggests that work-related stress, low physical activity and long working hours might be factors as these were more strongly associated with risk of stroke than myocardial infarction (MI) (Li et al., 2022). Low levels of physical activity and long working hours were each strongly associated with risk of stroke. The prevalence of traditional vascular risk factors (diabetes, hypertension, smoking and obesity) in young people with stroke was also high, emphasising the importance of identifying and managing these risk factors as they tend to be undertreated in younger people (Li et al., 2022).

Despite these alarming observations, there has been a marked improvement in the management of acute stroke in recent years in some countries such as the UK, one of the reasons for which is the development of effective post-stroke management and prevention strategies. These include centralised models of acute stroke care with associated reductions in mortality and length of hospital stay (Elameer et al., 2018; Morris et al., 2019), the adoption of hyperacute stroke interventions such as reperfusion (thrombolysis and thrombectomy), imaging by computed tomography (CT) or magnetic resonance imaging (MRI) (Campbell, 2024) and movement towards a more holistic and integrated care approach (Lip et al., 2022b; Lip and Ntaios, 2022). These strategies have improved stroke outcomes across the Western world including Europe, Canada and North America in spite of the increasing incidence of stroke in some countries, with stroke treatment guidelines recommending them as standard care (Ahmed et al., 2019; Kleindorfer et al., 2021; Alamowitch et al., 2023; Campbell, 2024). However, stroke management and outcomes are worsening in lower- and middle-income countries (LMICs) in certain regions such as East Asia, Southeast Asia and Oceana. In these countries, the burden of stroke is high and there is a substantial disparity in access to modern, effective treatments compared with high income countries (HICs). Poorer outcomes are often attributed to social deprivation, lack of access to stroke care and poor awareness of stroke prevention strategies (Aguirre et al., 2023).

The centralisation of stroke services in parts of the UK and the formation of hyperacute stroke units (HASUs) offering equitable, around-the-clock access to stroke specialists, investigations, imaging and, if indicated, thrombolysis, (Liu et al., 2011) and can be considered to represent integrated care of stroke in the acute setting. The treatment of stroke patients in HASUs has been associated with reductions in mortality (absolute reduction -1.1% at 90 days, indicating 168 fewer deaths) and length of hospital stay (-2.0 days in Greater Manchester and -1.4 days in London), contributing to significant cost savings (for example £156,118 per 1,000 patients in Greater Manchester) compared with traditional stroke units (Hunter et al., 2013; Morris et al., 2014). Improvements in the quality of stroke care delivered by HASUs are supported by data from the Sentinel Stroke National Audit Programme (SSNAP) (Elameer et al., 2018) . However one challenge with centralised stroke units is that there is no standardised care pathway in HASU implementation and intervention outcomes differ significantly depending on the type of care model used and the priorities of the stroke unit (Ramsay et al., 2015; Fulop et al., 2016). Additionally, the formation of HASUs across the UK is the exception rather than the rule, with uneven distribution of units across the country. London has the highest density of HASUs and further North there is a tendency for fewer units by comparison (Liu et al., 2011). Elsewhere, people with suspected stroke are most often diagnosed and treated for stroke at their local hospital A&E department in the first instance before being transferred to an acute stroke ward or stroke unit (NHS, 2021a). Recent data from NHS England showed that hospital admissions for stroke have risen by 28% between 2004 and 2024, with a 55% increase in people aged 50-59, driven in part by hypertension, obesity, poor diet and lack of exercise (NHS England, 2024). In addition, the 2024 SSNAP report highlights that the median time from stroke onset to arrival at first hospital increased from 3 hours 55 minutes to 4 hours in 2022/2023, a trend that has been steadily increasing since 2013, indicating a pressing need for better collaboration between stroke networks and ambulance providers, especially in rural areas (NHS, 2021a; Sentinel Stroke National Audit Programme [SSNAP], 2024).

There are many challenges remaining in stroke care, including a lack of consensus on the optimal care pathway for patients as evidenced by the high variability in the practical application of treatment guidelines and adherence to quality indicators (Norrving et al., 2018; McMahon et al., 2020). High heterogeneity among stroke treatment centres influences the quality of care (Ali et al., 2018), and there is continuing need to develop good quality evidence for non-pharmacological rehabilitation interventions for prevention of secondary vascular

events and risk factor management after stroke (Mackay-Lyons et al., 2013; Stinear et al., 2020; Kleindorfer et al., 2021).

In addition, discontinuity of care from hospital to home has been reported in the literature (Chen et al., 2020; de Mooij et al., 2021; NHS Rightcare, 2021). An integrative review of 23 stroke studies from a range of countries was undertaken to identify challenges faced by stroke survivors and carers in hospital to home transition care. The review reported a compromised transition of care due to disjointed service provision, which caused unmet needs and increased the potential for re-hospitalisation and institutionalisation (Chen, Xiao and Chamberlain, 2020). Another study from the Netherlands found that discontinuation of care occurred to a varying extent throughout transmural (coordinated and collaborative) care in patients with a first stroke who were discharged home (de Mooij et al., 2021). In the UK, it has been reported that there is a lack of continuity of care for stroke patients, with 1 in 3 areas of England, Wales and Northern Ireland not commissioning ongoing support for patients and carers; 70% of patients did not receive a six-month follow-up review, with 30% of clinical commissioning groups (CCGs) not commissioning any follow-up review (NHS Rightcare, 2021).

It is therefore clear that much of the progress in stroke management has been made in the setting of acute care with less focus on the post-acute stroke care pathway (Gilham, 2021) where integrated care plans such as early mobilisation as part of early supported discharge (Langhorne et al., 2014; Brandal et al., 2019; Rafsten, 2019; Jee et al., 2022) are often well documented. However, less is known about the care of patients following discharge back into the community. Across Europe, few countries appear to publish data on provision of stroke services in the community and there is substantial variation in the provision of post-discharge care for stroke survivors (Stroke Alliance for Europe, 2020). In some countries (for example Austria, Latvia, Italy, Portugal and Macedonia), formal pathways between different phases of stroke care (acute, inpatient rehabilitation, community rehabilitation) do not exist, are incomplete, are not fully implemented, and/or vary between localities. There are also regional and rural versus urban variations in access to community-based rehabilitation (for example patients in some regions of Ireland, Portugal, Sweden and Spain do not have access to outpatient and/or domiciliary rehabilitation) (Stroke Alliance for Europe, 2020). In the USA, access to post-discharge care is unevenly distributed throughout the country, with poorer access to specialist care in rural locations, among black and Hispanic patients, and for patients without health insurance (He et al., 2025). In the UK, a recent SSNAP annual report identified a decline in the proportion of patients receiving a 6-month review (Sentinel Stroke National Audit

Programme [SSNAP], 2022). The report highlighted the need for an adequately resourced multidisciplinary team of healthcare professionals (HCPs) required to deliver the recommended amount of rehabilitation of patients according to their need, especially in the community setting (Sentinel Stroke National Audit Programme [SSNAP], 2022).

There is recent robust evidence to suggest that the implementation of simplified, holistic, integrated care pathways in conditions sharing the same cardiovascular risk factors as stroke are associated with reduced risk of mortality and morbidity (Lip and Ntaios, 2021; Romiti et al., 2021) and may be a suitable framework to develop and implement in stroke care.

Briefly, integrated care and holistic care refer to a number of core concepts including embracing person-centred care, delivered by a team of HCPs who collaborate closely with each other, providing high quality and consistent care for the patient (Costa et al., 2020; Ski et al., 2023). Integrated care and holistic care are discussed in much more detail in Chapters Two and Four, respectively.

1.3 Outline of the research project

The precise nature of a holistic integrated stroke care pathway is currently unknown, hence there is a need to review the published literature, explore patient experiences of stroke recovery and gain consensus from stroke survivors and those individuals who care for them as to what the creation of an integrated care pathway for stroke survivors should involve.

The aim of this PhD research is to construct a streamlined holistic integrated care pathway for people with stroke based on published literature and the experiences of recovery in people with stroke. The research is divided into two distinct yet iterative studies:

- **Study 1 (Work package 1)**: Identify interventions within integrated care which provide tangible benefits to patients and the HCPs who deliver them by conducting a systematic review and meta-analysis of the literature.
- **Study 2 (Work package 2)**: A mixed methods study in 2 phases:
    - **Phase 1:** Through patient focus groups, explore the experiences of stroke survivors during their recovery from stroke, and explore the barriers and enablers that patients experience during stroke rehabilitation and the components of care that they believe would enhance recovery. The information gained will be used to identify potential components of integrated care.
    - **Phase 2**: Using the data collected from the systematic review and the focus groups, undertake a Delphi survey to gain consensus regarding the components of care that

patients and stroke professionals believe should be included in an integrated stroke pathway.

The data obtained from these studies will be used to construct an integrated, patient-centred, holistic pathway for the care of people with stroke.

1.4 Research question

What components of an integrated care pathway for people with stroke are considered important for patients and healthcare professionals?

1.5 Summary of theory and rationale for the research programme

The rationale for the research is based upon studies of integrated care in a range of chronic conditions including those sharing risk factors with stroke such as cardiovascular disease and atrial fibrillation (Lip, 2017; Ski et al., 2023). These studies indicate that integrated care is effective in the care of people with these conditions however there is limited information on the holistic aspect of these pathways. For this reason, the mixed methods study involving stroke survivors is a key component of the research to ensure that the creation of the integrated care pathway is holistic and reflects the needs of those people who will benefit from it. The philosophy and theoretical framework of the mixed methods study is discussed in detail in Chapter Two.

1.6 Contribution of the programme to current research and knowledge

Because there is currently no accepted standard of care for people following stroke, as evidenced by high heterogeneity in treatment guidelines (Norrving et al., 2018; McMahon et al., 2020) and delivery of care in stroke treatment centres (Ramsay et al., 2015; Fulop et al., 2016; Ali et al., 2018), this research will aim to bring together the findings of published literature, patient experiences and HCP views on what an integrated stroke recovery pathway should resemble. This will be achieved through a systematic review of the published literature to identify components of integrated care that benefit patients, a series of focus groups involving stroke survivors to listen to their experiences of recovery and determine their priorities, and a Delphi survey of HCPs and patients to identify what components should be included in an integrated care pathway and how that pathway should be delivered. The research will allow the creation of a streamlined and patient-centred pathway, the aim of which is to ultimately improve care and outcomes for people with stroke.

2 Chapter Two: Theoretical Framework and Integrated care

Chapter One introduced the PhD thesis, its research question, aims, rationale summary and potential contribution to current knowledge and understanding of integrated care in people with stroke. This chapter includes a thorough discussion of integrated care, the theoretical framework upon which the study is based and a discussion of previous studies and concepts which have formed the basis of the study. This chapter also introduces the key element of holism, described in detail in Chapter Four.

2.1 Integrated Care

2.1.1 What is integrated care?

There are multiple definitions of integrated care but in its simplest form it can be described as *"care that is planned with people who work together to understand the service user and their carer(s), puts them in control and coordinates and delivers services to achieve the best outcomes"* (NHS, 2024). Over the last 20 years, numerous models and approaches to integrated care have been documented and applied across a range of settings (Satylganova et al., 2016). A literature review conducted in 2009 by Armitage and colleagues identified 175 overlapping concepts and definitions of integrated care, indicating a lack of consensus as to what integrated care actually means (Armitage et al., 2009). This multiplicity arises from the polymorphic nature of the integrated care concept that has been applied from multiple disciplinary perspectives such as public administration, social science, psychology and in addition, differing professional points of view, for example clinical versus managerial, holistic care versus disease management and public health versus long-term care. Integrated care is, therefore, associated with a wide range of different objectives (Nolte and McKee, 2008; Satylganova et al., 2016). The absence of a unifying definition of integrated care compounds the current difficulty in its assessment (Satylganova et al., 2016). However there are common themes associated with definitions of integrated care in the management of long-term health conditions such as personalised, joined-up, coordinated health and social care, and reducing inequalities (Department of Health and Social Care, 2022; Ski et al., 2023)

Ski and colleagues (2023) have proposed the following definition of integrated care for people with cardiovascular disease: *"Integrated care is the coordinated organization of a continuum of care delivery across settings, responsive to the needs of each person to achieve enhanced quality of care, optimal quality of life and health equality"* (Ski et al., 2023 p.2). This definition is similar to NHS and WHO definitions (Satylganova et al., 2016; NHS, 2024): **Integrated**

care is a patient-centred approach which involves multiple teams of healthcare providers communicating with each other and the patient and family to provide the best possible care for the patient across their journey. It is this latter definition that underpins this thesis.

The philosophy of integrated care is based on the idea that healthcare should be seamless and patient-centred, with the goal of improving outcomes for people with complex needs (Valentijn et al., 2013). This is an evolution of the Chronic Care Model (CCM) (Wagner, 1998), a framework upon which this study is based is designed to improve the care of people living with chronic diseases by emphasising the importance of an informed patient interacting with a proactive healthcare team within a supportive health system. The CCM is described in more detail in Section 2.2.

The objectives of integrated care revolve around the need to provide seamless continuous care for an ageing population with a growing prevalence of comorbidity and chronic disease, rather than fragmented health care services, when a patient's care is spread out among multiple providers, often across different systems and clinics (Prior et al., 2023; Kern et al., 2024). Fragmentation is important because it can lead to a loss of continuity of care and poorer clinical outcomes (Prior et al., 2023; Kern et al., 2024). Integrated care reflects a need to involve stakeholders (including service users, carers, clinicians, managers, and policy makers) in the development of programmes designed to achieve greater efficiency, value for money and equality (Czypionka et al., 2020; Department of Health and Social Care, 2022; Garattini et al., 2022). In the UK and Europe, integrated care systems have been developed to provide community-based care, reduce hospital admissions, waiting times and the length of hospital stay, speed up and shorten treatments and clinic visits, avoid duplication of diagnostic tests, improve patient satisfaction, and ensure care is person-centred and coordinated (Johri et al., 2003; Baxter et al., 2018; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b). These systems bring different parts of the health service, local government, and voluntary and community sector closer together to improve the health of the community and tackle healthcare inequalities (Baxter et al., 2018; Garattini et al., 2022).

This approach requires a transdisciplinary workforce (one that transcends traditional disciplinary boundaries to encourage professionals to collaborate closely, sharing knowledge and skills to provide a comprehensive and holistic intervention, promoting a unified and interconnected model of care) that is flexible, agile, willing and able to be redeployed and rapidly retrain to learn new skills (Manley et al., 2016; Kritanshu, 2024). Transdisciplinary healthcare models require multiple disciplines (for example, nurses, physicians,

physiotherapists, occupational therapists) to work collaboratively towards shared goals (Lip et al., 2022b; Lip and Ntaios, 2022; Martin et al., 2023) and placing the patient at the centre of the care model.

2.1.2 Integrated care and person-centred care

Person-centred care (PCC) is an evolving concept, originally described by Edith Balint in 1969 as examining the person as a whole and understanding the patient as a unique human being (Balint, 1969). PCC is based on a philosophical ideology to acknowledge and endorse the individual's resources, needs, and preferences (Ski et al., 2023). PCC simply means bringing back the person into care, and by that reinforcing the ever-present ethical demand to uphold dignity, providing autonomy, choice and control, respecting decision making and doing good (Edvardsson, 2015). PCC is holistic, flexible, creative, personal and unique (Edvardsson, 2015).

PCC is an integral component of integrated care; wrapping care around the person is also key to a user-friendly, seamless, joined-up approach (Ski et al., 2023). From a PCC perspective, HCPs view patients as partners in the planning and performing of the care process, inclusive of shared responsibility, coordinated care and treatment (Connolly et al., 2017; Greutmann et al., 2018). Patients are therefore viewed as a partner within integrated care, the focal point around which services are integrated, not just a victim of disease or a passive 'object' that receives integrated care services (Coulter and Oldham, 2016). Before patient care can be 'integrated' (in the way the system perceives integration), it needs to be person-centred; without this the patient is often left feeling segregated and uncertain (Ski et al., 2023).

The advancement of the biomedical model of healthcare has led to a shift away from the patient to a focus on the disease, without consideration of the evolving context in which people live and work (Starfield, 2011; Hagendijk et al., 2025). Indeed, Peterson-Burch and colleagues (2017) highlight that current treatments for stroke focus on the condition and not the person (Peterson-Burch et al., 2017). Care is better with the recognition of a person's problems rather than a diagnosis of their illness and PCC must be accessible, comprehensive, continuous and coordinated, something which is more likely to be found in primary care and the result of a long-standing and trusting relationship between patients and healthcare provider (Ahmed et al., 2022; Khatri et al., 2023).

2.1.3 Integrated Care and Shared Decision Making

Shared decision making (SDM) is a collaborative approach whereby patients and HCPs work collaboratively to select the best course of action in the management of the patient's condition (Dennison Himmelfarb et al., 2023; Montori et al., 2023). SDM is a relatively simple process which comprises a series of steps (Dennison Himmelfarb et al., 2023). Step 1 involves clearly communicated, unbiased medical evidence on the risks and benefits of the medical intervention and reasonable alternatives, including no intervention. Step 2 involves clinical expertise provided in a way that tailors the evidence for individual patients. In Step 3 SDM is supported through inclusion of patient values, goals, and preferences, as well as treatment burdens, in the decision process (Dennison Himmelfarb et al., 2023).

Paternalistic healthcare is based on the concept that clinicians are expected to use their expert knowledge to make the 'best' decisions on behalf of their patients (Thomas et al., 2021). The legal premise of informed consent recognises that patients have the right to autonomy when making choices regarding their treatment (Appelbaum et al., 1987). PCC ensures that each patient's specific health needs, including access and desired health outcomes drive all health decisions (Dennison Himmelfarb et al., 2023). SDM is a communication process by which patients and clinicians collaborate to choose tests, treatments and care plans that most align with an individual patient preferences and values (Dennison Himmelfarb et al., 2023).

A growing body of evidence suggests that the benefits of SDM include improved patient knowledge, engagement and confidence, better outcomes, increased adherence to treatment and improved patient satisfaction (Royal College of Surgeons, 2023). A 2011 Cochrane review by Stacey and colleagues (2011) reported that SDM increases patients' expectations of benefits and harms, stimulates involvement in decision making and improves patients' agreement between values and treatment choice (Stacey et al., 2011). In an updated analysis by Stacey and colleagues (2024) involving 209 studies and 107,698 patients, SDM resulted in substantially improved knowledge, expectations of benefits and harms, and participation in making the decision, with participants feeling better informed and clearer on what mattered most to them (Stacey et al., 2024). SDM is also thought to benefit healthcare providers by promoting evidence-based practice and reducing costs (Lee and Emanuel, 2013; Royal College of Surgeons, 2023). SDM is now considered as a marker of quality care and is recommended for reimbursement in many healthcare services (Centers for medicare and Medicaid Services, 2016; Spatz et al., 2017; Chen et al., 2023).

There are also challenges associated with the implementation of SDM. These include low adoption rates (below 10%; Royal College of Surgeons, 2023), insufficient time, a noisy and busy environment with a lack of private spaces to conduct SDM conversation, uncertainty over clinical benefits and a need for additional studies (Waddell et al., 2021; Elwyn et al., 2023a). Initiatives to incentivise SDM using payment programs have so far failed to shift practices towards SDM (Elwyn et al., 2023b). A systematic review of 28 studies of SDM in older people with multiple chronic conditions identified 149 barriers and 67 perceived facilitators (Pel-Littel et al., 2021). Perhaps most importantly, there is the attitude of many clinicians who find it difficult to adopt this approach, particularly in those whose attitudes are shaped by training, mentorship, and role models who have historically paid less attention to the views and wishes of patients (Royal College of Surgeons, 2023).

2.1.4 Integrated care and holistic care

As discussed in depth in Chapter Four, the concept of holistic care involves treating the patients as a whole (mind, body and spirit) and can incorporate natural and non-invasive treatments in addition to conventional treatment (Papathanasiou, 2013). Integrated care is a multidisciplinary coordinated approach and as part of the approach to medical treatment generally employs the use of conventional medical treatments but can also include complementary therapy (IDCC Health Services, 2023). Integrated care is often known as integrative care in the literature and indeed the term 'integrative care' is used more often than integrated care in some cases (Frisch and Rabinowitsch, 2019). In a review of published articles on integrated care and holistic care from a nursing viewpoint, there was found to be substantial overlap between the two definitions; the terms 'integrative' and 'holistic'; both have similarities between their philosophical and/or theoretical foundations and the incorporation of alternative or complementary treatments but it is currently difficult to distinguish between the two terms and further research is necessary to clarify these definitions (Frisch and Rabinowitsch, 2019).

Definitions aside, what is clear however, is that holistic care and integrated care are fundamentally linked concepts and there is increasing consensus that integrated care of people with complex needs cannot exclusively address physical health problems but needs to adopt a holistic view of the person (Boult and Wieland, 2010; Corser, 2011; Ivbijaro et al., 2014; Lin et al., 2014; Morgan et al., 2015; Czypionka et al., 2020). This consensus is based on the recognition that physical health, mental health and social circumstances are interconnected and should therefore not be dealt with independently. A qualitative analysis of 17 European integrated care programmes for people with complex health needs identified two key sub-

themes for a focus on holistic care; 1) consideration of mental health and 2) consideration of the social situation of patients (Czypionka et al., 2020). In accordance with this holistic view, most of the 17 integrated care programmes accounted for mental health in the care process and many provided corresponding services as an integrated part of the programme such as counselling and psychotherapy. Most of the programmes also emphasised the social situation of the individuals in their care and some were designed to actively target social problems by providing social workers, counselling and even community centres. Personal contact with patients in their own environment during their assessment was considered important in order to fully capture the social situation of people with complex needs, allowing for a better understanding of the individual's situation and the scale and complexity of the need (Czypionka et al., 2020).

Integrated care provides the means for a holistic approach to patient care but in order to implement both concepts, HCPs and policymakers must recognise the need to shift from the paternalistic and service-centric model of 'physician knows best' to a more collaborative and consultative approach with patients about their needs and experiences as users of health services (Wong et al., 2022a). Targeting the specific factors and behaviours influencing attitudes to integrated and holistic care should improve buy-in from HCPs (Wong et al., 2022a).

2.1.5 Putting integrated care into practice

Integrated care is a worldwide initiative that has been adopted due to the recognition that global demand for healthcare is increasing due to the burden of chronic conditions and multimorbidity, necessitating a change in the delivery of healthcare to improve outcomes and sustainability (World Health Organization, 2015; Trankle et al., 2019; Czypionka et al., 2020; European Commission: Consumers and Food Executive, 2020; Kearney et al., 2020; Hu et al., 2021; Sullivan-Taylor et al., 2022). Implementing integrated care is a policy priority with the aim of bringing health and social care closer together in order to streamline services, conserve resources, tackle inequalities and provide value for money (World Health Organization, 2015; European Commission: Consumers and Food Executive, 2020; Pett, 2022; Exley et al., 2024; NHS, 2024).

Integrated care pathways and policies exist for a range of chronic conditions (Briggs et al., 2019) including cancer (Ouwens et al., 2009; Cortis et al., 2017; Soo et al., 2023), cardiovascular disease (CVD) (Lip, 2017; Ski et al., 2023), diabetes/endocrine disorders (Jaffe et al., 2015; Lancet Diabetes and Endocrinology [Editorial], 2015; Tan et al., 2021; Zarora et al., 2022; Kumari et al., 2023), respiratory conditions (Nici and ZuWallack, 2018; Koff et al.,

2021; Patel, 2021) and mental health (Sunderji et al., 2017; Wells et al., 2018; Brown et al., 2021). The potential benefits of integrated care are manyfold: it allows the patient to tell their story just once, they have a single point of contact for all of their care needs and the quality and delivery of their care will remain unchanged and seamless wherever and whenever they choose to receive that care (NHS, 2024). Benefits of implementing integrated care in these conditions for patients include better treatment tolerance and completion (Ski et al., 2023; Soo et al., 2023), improvements in quality of life (Ouwens et al., 2009; Ski et al., 2023; Soo et al., 2023), self-management (Nici and ZuWallack, 2018; Ski et al., 2023), physical functioning, health and fitness (Wells et al., 2018; Koff et al., 2021; Ski et al., 2023), risk factors such as systolic blood pressure (SBP), cholesterol and glycated haemoglobin (HbA1c) (Zarora et al., 2022), reductions in depression/anxiety (Ouwens et al., 2009), costs (Wells et al., 2018; Kumari et al., 2023), and hospitalisations (Nici and ZuWallack, 2018; Wells et al., 2018; Koff et al., 2021; Zarora et al., 2022; Ski et al., 2023).

2.2 Integrated Care and the Chronic Care Model

The CCM serves as a foundation for integrated care programs to support patients to self-manage their chronic illness (Otieno et al., 2023). CCM is an organisational framework first proposed by Wagner in 1998 with an aim to improve healthcare for people with chronic diseases, using a holistic approach involving interventions at multiple levels, including those directed at the patient, healthcare providers, and the overall healthcare system (Vallente, 2023). Wagner's original proposed model for improvement of chronic illness care assumed that "*the locus of care remains with the personal physician, supported by an integrated (and perhaps expanded) practice team"* (Wagner, 1998 p.3), for coordination of care and medical oversight (Boult et al., 2008) but included behaviourally sophisticated self-management support that prioritised the increase in patient confidence and improvement in skills to be able to manage their own illness (Wagner, 1998). The interactions between patients and healthcare providers should consist of well-developed processes and incentives that allowed changes in the delivery of healthcare. Additionally, these CCMs focussed on self-management support, offering priority to enhancing patients' confidence and skills, ultimately allowing them to take control of their own illnesses (Wagner, 1998). CCM comprises six key components; 1) health system or a health organisation (HSHO), 2) clinical information systems (CIS), 3) decision support (DS), 4) delivery system design (DSD), 5) self-management support (SMS) and 6) community-including organisations and resources for patients (CORP), with the last two components being focussed on the patient (Yeoh et al., 2018; Vallente, 2023). CCM has been shown to improve

outcomes in a range of chronic conditions including diabetes, CVD, chronic obstructive pulmonary disease (COPD) and hypertension and reduce unnecessary medical burden, for example by avoiding hospitalisation through implementation of CCM components such as self-management training for HCPs and patients (Yeoh et al., 2018). Implementing CCM also improves knowledge and awareness among patients of their condition, enhances training of HCPs through team working, and reduces the social and medical burden by effective disease management (Yeoh et al., 2018).

Integrated care evolved from CCM by expanding its principles beyond the health and social well-being of whole communities and populations (Otieno et al., 2023) down to individual level. CCM promotes collaboration between HCPs for specific conditions whereas integrated care goes further by fostering extensive collaboration between different healthcare providers, social care, and community services to create a single system of care (NHS, 2023b). CCM supports patient self-management, a key component of the model. Integrated care places the patient at the centre of decision-making and empowers them with knowledge and resources for their overall well-being, not just their condition (Dunn, 2003; Coulter and Oldham, 2016; NHS, 2023b). Whilst CCM provides a framework for disease-specific care, integrated care recognises the complexity of modern healthcare challenges, such as an ageing population and people with multiple comorbidities, and integrated care aims to address these needs in a more holistic manner (Borgermans et al., 2017). The evolution from CCM to integrated care is associated with increased use of clinical information systems and eHealth support tools to improve coordination of care and access to information across different providers (Pomey et al., 2024). Strong policy leadership is often required with integrated care to encourage innovation and service transformation. Initiatives like the Integrated Care Systems (ICSs) in the UK were developed to bring local organisations together with a mandate to collaborate on improvement of the health and wellbeing of their local populations (NHS, 2023b).

The CCM provides a strong foundation for coordinated care for people with chronic conditions (Wagner, 1998). Integrated care has evolved from CCM and improved upon it by focussing on a broader population, expanding collaboration between providers of care, introducing PCC, accounting for complexity, incorporating health technology and infrastructure, and engendering strong policy leadership and governance (Dunn, 2003; Coulter and Oldham, 2016; Borgermans et al., 2017; NHS, 2023b; Otieno et al., 2023; Pomey et al., 2024). CCM was chosen as the theoretical framework for this study as it incorporates all the key elements of care upon which integrated care has developed and this study is itself an integrated care project.

2.3 Integrated Care Models in Stroke

There are few models of integrated care that have been developed specifically for stroke and there is no universally recognised or standardised model of integrated care in people with any long-term medical condition (Liu et al., 2025). A review of integrated care in Canada by Suter and colleagues (2009) identified 10 universal principles of successfully integrated healthcare systems that may be used by decision-makers to assist with integration efforts (Suter et al., 2009). These principles comprise 1) comprehensive services across the care continuum, 2) patient focus, 3) geographic coverage and rostering, 4) standardised care delivery through interprofessional teams, 5) performance management, 6) information systems, 7) organisational culture and leadership, 8) physician integration, 9) governance structure and 10) financial management. In a recent systematic review of integrated care models for stroke, Liu and colleagues (2025) used the 10 Suter principles as the basis for their research and identified just 15 randomised studies that were fully adherent, with varying degrees of adherence to individual principles (Liu et al., 2025), indicating that Suter's model is not routinely incorporated into stroke integrated care.

In the UK, the Integrated Community Stroke Service (ICSS) was part of the NHS National Stroke Service Model announced in 2021 (NHS, 2021a). This model highlights coordinated care of stroke patients by a specialist team and emphasises the need for a responsive and intensive service available seven days a week and driven by patient need (NHS, 2021a). Similarly, the Integrated Life after Stroke Support (ILASS) model was developed by the Stroke Association in collaboration with NHS England to provide best practice guidance on support services required to deliver practical, emotional and social input to people affected by stroke (Stroke Association, 2023b). The principles of the ILASS model include integrated care delivered on the basis of need, with outcomes to improve quality of life, physical and mental wellbeing, to reduce the risk of subsequent stroke and enhance the patient experience (Stroke Association, 2023b). However, there are currently no published studies of implementation of either the ICSS or ILASS models and the only literature that exists is a series of single-patient case studies where parts of the ILASS model have been implemented (Stroke Association, 2023b).

The Improving Primary Care After Stroke (IPCAS) research study was a complex mixed methods study designed to improve stroke care in the community (Mullis et al., 2024; Aquino et al., 2025). The study comprised five components: a structured review; a direct point of contact; improving communication between primary and secondary care; local service

mapping; and training of primary care professionals. The 'My Life After Stroke' (MLAS) self-management programme for people with stroke comprised an initial individual session, four weekly group-based sessions and a final individual session. The coprimary end points for the study were two subscales (emotion and participation) of the Stroke Impact Scale (SIS) v3.0 at 12 months after randomisation. Secondary endpoints included SIS Short Form and EuroQol-5 Dimension (EQ-5D) questionnaire (Mullis et al., 2024). The study was conducted in general practice and 1040 patients were randomised and at 12 months there was a 0.64 (97.5% CI: -1.7 to +2.8) improvement in the emotion outcome and a 1.3 (97.5% CI: -2.0 to +4.6) increase in participation in the intervention group compared with control however there was no improvement in quality of life as measured by SIS or EQ-5D. More than 80% of participants received a review but only a third of participants attended MLAS and the direct contact service was seldom used. Local service mapping had variable take-up by HCPs, communication between primary and secondary care was not possible, although training rates among primary care professionals were high. Some participants did not feel the intervention was relevant for them due to their recovery and the time that had passed since their stroke. The study identified that the most commonly identified need among stroke survivors was fatigue and while IPCAS did not address this need, it did acknowledge the importance of addressing long-term needs of stroke survivors in the community (Mullis et al., 2024; Aquino et al., 2025).

The Longer-Term Stroke care (LoTS) care study was a comprehensive UK research programme that developed, tested and implemented strategies to improve life after stroke and address unmet needs at six months post-stroke (Forster et al., 2021). The programme included the development of an intervention called New Start based on unmet needs prioritised by stroke survivors and their carers through semi-structured interviews, literature reviews, and exploration of current stroke services. The intervention was refined and piloted with three stroke services (case studies) and a larger cluster randomised feasibility trial was conducted in 10 stroke services across England and Wales (five received the intervention and five continued with standard care). Key components of New Start included problem-solving self-management with survivors and carers, assistance with obtaining usable information, and helping survivors and their carers build sustainable, flexible support networks. One component of New Start was the development of Longer-term Unmet Needs after Stroke monitoring tool (LUNS), which was tested and validated in a cohort of 850 stroke survivors (LoTs care LUNS Study Team, 2013).

Criteria to progression to a full LoTS trial (red, amber, green) included target stroke survivor recruitment rates achieved, on average, across sites (24.1 per site over 6 months, green); 216 (80.3%) registered stroke survivors returning follow-up questionnaires at 9 months (84.1% in the intervention arm and 75.8% in the usual care arm, green); 95.2% of registered stroke survivors offered at least one session of the intervention (green); all five intervention sites having at least two facilitators deemed competent, delivering the New Start intervention and providing it to stroke survivors (green). There were concerns at some trial centres over the number of stroke survivors being offered, accepting and receiving the intervention. After testing the New Start intervention, the authors concluded that further refinement of the target population and optimisation of the intervention materials were needed before the initiation of a full randomised controlled trial (Forster et al., 2021).

There is published evidence to support the benefit of multidisciplinary interventions aimed at rehabilitation for stroke survivors, early supported discharge (ESD) and approaches to support the transition of patients back into the community following acute stroke (Langhorne and Baylan, 2017; Langhorne et al., 2020a; O'Callaghan et al., 2022; Todhunter-Brown et al., 2025). A network meta-analysis of organised inpatient (stroke unit) care showed moderate evidence of a higher likelihood of survival, independence and living at home a year after stroke (Langhorne et al., 2020b). ESD is generally considered to be beneficial as a systematic review showed that ESD with coordinated multidisciplinary team input provided for a selected group of stroke patients can reduce long-term dependency and admission to institutional care as well as reducing the length of hospital stay (Langhorne and Baylan, 2017). Other aspects of integrated care in stroke are more controversial. For example, a systematic review of the effectiveness of interventions to support the transition back to the community after stroke demonstrated improvements in functional status but the certainty of this evidence was low (O'Callaghan et al., 2022). This review also demonstrated that support interventions could improve quality of life and reduce depression but the level of heterogeneity between studies was high and the essential components of effective transition of care interventions were still unknown (O'Callaghan et al., 2022). More recently, a systematic review of approaches to physical rehabilitation with the aim of improving function and mobility after stroke concluded that these approaches, together with additional physical rehabilitation, were likely to improve recovery of function and mobility after stroke (Todhunter-Brown et al., 2025). Whilst this review was comprehensive and included 267 studies with 21,838 participants, the authors noted that the certainty of their findings was limited due to substantial heterogeneity, with mainly

small studies, poor follow-up and notable differences between study populations and interventions (Todhunter-Brown et al., 2025).

With no currently accepted standard model of integrated care in stroke and a paucity of published data on stroke integrated care models, there is a need for an integrated and holistic pathway for stroke survivors that is evidence-based and includes direct input from patients.

2.3.1 The ABC Concept of Integrated Care in Stroke

A novel "ABC" concept for the management of patients following stroke has recently been proposed (ABC_{STROKE}) with the three main 'pillars' outlined as A — Appropriate Antithrombotic therapy; B — Better functional and psychological status; and C — Cardiovascular risk factors and Comorbidity optimisation (including lifestyle changes) (Lip and Ntaios, 2022). The ABC_{STROKE} pathway was itself developed from an ABC pathway for people with atrial fibrillation (AF) (the ABC_{AF} pathway) on the basis that both conditions share a number of common cardiovascular risk factors, including advancing age, male sex, hypertension, diabetes mellitus, valvular heart disease, heart failure, coronary heart disease, chronic kidney disease, inflammatory disorders, sleep apnoea, and tobacco use (Kamel et al., 2016).

The three pillars of ABC_{AF} are A — avoid stroke (with anticoagulants); B — better symptom management, with patient-centred decisions on rate or rhythm control; C — cardiovascular and comorbidity risk optimisation (Lip, 2017). The ABC_{AF} pathway has been tested and validated in a series of post-hoc and prospective studies. In a recent systematic review of more than 285,000 patients, those with AF treated according to the ABC_{AF} pathway showed significantly lower risks of all-cause death (odds ratio ([OR)]: 0.42, 95% CI: 0.31–0.56), cardiovascular death (OR: 0.37, 95% CI: 0.23–0.58), stroke (OR: 0.55, 95% CI: 0.37–0.82), and major bleeding (OR: 0.69, 95% CI: 0.51–0.94) compared with those receiving standard care (Romiti et al., 2022). The hypothesis for the ABC_{STROKE} pathway was that its implementation could be associated with similar benefits in lowered risks to those demonstrated by the ABC_{AF} pathway.

The ABC_{STROKE} pathway fits with the key components of the CCM (Wagner, 1998) as it requires the presence of a multidisciplinary team of specialists such as stroke consultants, neurologists, surgeons, nurses, GPs and rehabilitation specialists providing care across primary and secondary care (HSHO) (Lip and Ntaios, 2022), and the presence of clinical information systems allowing HCPs to collaborate with each other (CIS) (Islam et al., 2018). Given the common cardiovascular risk factors between stroke and AF (including advancing age, male

sex, hypertension, diabetes mellitus [DM], valvular heart disease, heart failure, coronary heart disease, chronic kidney disease, inflammatory disorders, sleep apnoea, and tobacco use), there are clear similarities between the ABC_{STROKE} and ABC_{AF} pathways.

The ABC_{STROKE} pathway concept is shown in Figure 1 and represents the delivery system design (DSD). In the A pillar, recurrent stroke is minimised with the use of antithrombotic therapy delivered by a specialist physician according to the patient's status and comorbidities (Lip and Ntaios, 2022). In Pillar B, the aim is to provide the best improvement in functional and psychological status possible through a multidisciplinary approach with rehabilitation and allied HCPs. The rehabilitation packages that need to be put into place here should be designed around the patient and their needs both in hospital, during rehabilitation and post-discharge (DS) (Lip et al., 2022b).

Similar to the C pillar for the ABC_{AF} pathway, Pillar C for the ABC_{STROKE} pathway has the goal of lowering the associated cardiovascular risk burden in these patients, to reduce the risks of recurrent stroke or other major adverse cardiovascular events by encouraging patients to adopt positive lifestyle changes such as healthy diet, regular exercise, alcohol and tobacco use reduction, and weight loss, giving them control over their condition (SMS).

The ABC_{STROKE} pathway recognises the importance of stroke recovery from the patient perspective, acknowledging the psychological and social impact of stroke in addition to the physical impairments (Lip et al., 2022b). Ongoing support, listening to the patient and providing personalised education, information, and advice in simple terms with consistent messages are important throughout the patient journey and continuity of care is essential (CORP). Greater involvement of the patient and family/caregiver in planning and co-producing support packages and input and feedback on optimising stroke care pathways are critical to success (Lip et al., 2022b).

The ABC_{STROKE} pathway has been tested and validated in real world observational studies; the Athens Stroke Registry (Sagris et al., 2024) and a Hong Kong stroke patient cohort (Tsang et al., 2024). The findings from these studies are summarised in Section 2.3.2.

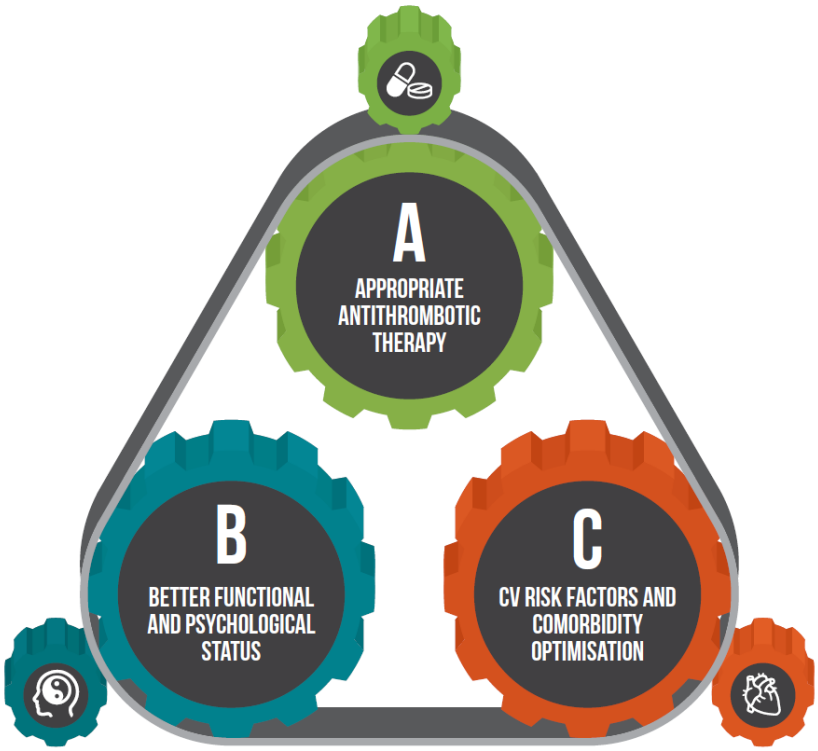


Figure 1 The ABC Concept for Integrated Care in Stroke

A - Appropriate Antithrombotic Therapy. Anticoagulants and antiplatelet therapies play an important role in preventing subsequent stroke and clinical trials have demonstrated the efficacy and safety of anticoagulants for cardioembolic stroke prevention and antiplatelet therapies for non-cardioembolic (large artery atherosclerosis) stroke prevention (Kapil et al., 2017). Stroke treatment guidelines recommend the antiplatelet therapy aspirin in the acute management of ischaemic stroke, antiplatelet therapy (aspirin, clopidogrel, dipyridamole) in the secondary prevention of non-cardioembolic ischaemic stroke, and anticoagulants (warfarin or direct-acting oral anticoagulants [DOAC]) in the secondary prevention of cardioembolic (most commonly AF-related) ischaemic stroke (Shrestha et al., 2017).

The choice of antithrombotic therapy is also dependent upon comorbidities, cost, patient adherence and the balance of risk between stroke prevention and increased potential for bleeding, and as yet, there is no 'one size fits all' therapy (Bir and Kelley, 2021). Antithrombotic therapy needs to be approached on an individual patient basis according to their specific characteristics, values and preferences (Ntaios and Lip, 2016).

B – Better Functional and Psychological Status

<u>Functional status</u>

Stroke is generally considered to be a condition which causes functional deficit, manifesting as weakness and paralysis (the largest cause of disability) (Poomalai et al., 2023), however, up to 20% of patients have no weakness and others experience clinically silent stroke (Gilham, 2021). Therapeutic interventions that have been shown to improve functional status in people with stroke include thrombolysis (Wardlaw et al., 2014) and endovascular therapy (Roaldsen et al., 2021a), with some low-level evidence for muscle anti spasticity agents (Demetrios et al., 2013; Synnot et al., 2017; Creamer et al., 2018a; Creamer et al., 2018b). Beneficial non-therapeutic rehabilitation interventions include functional electrical stimulation (FES), mirror therapy (Thieme et al., 2018), electromechanical and robot-assisted arm/gait training (Mehrholz et al., 2017; Mehrholz et al., 2018), virtual reality (VR) training (Veerbeek et al., 2017), treadmill training (Mehrholz et al., 2017), physical rehabilitation and cardiorespiratory fitness training (Pollock et al., 2014b; Pollock et al., 2014c; Saunders et al., 2014; Saunders et al., 2020b; Buckley et al., 2021b), ESD (Gonçalves-Bradley et al., 2017), multidisciplinary packages for post-acute care (PAC) (Chiu et al., 2021) and the management of fever, sugar and swallowing dysfunction (Middleton et al., 2011). There is, however, increasing recognition of the wide heterogeneity in rehabilitation of people with stroke (Hakiki et al., 2021) and the capacity for spontaneous recovery (Cramer, 2008; Campbell and Khatri, 2020; Grefkes and Fink, 2020).

All patients with cerebrovascular disease are at risk of cognitive impairment (Gilham, 2021) and some degree of cognitive impairment is present in up to 74% of patients following acute stroke, with disorders in executive functioning, abstract reasoning, verbal memory and/or language being most common (Nys et al., 2007). A systematic review and meta-analysis of non-randomised studies of psychological interventions to address post-stroke cognitive impairment showed a small positive effect on cognition, including domains such as memory and attention (Merriman et al., 2019), however the evidence for randomised controlled studies of memory training reports only short-term benefits (Das Nair et al., 2016a), whereas randomised controlled studies of interventions for spatial neglect and executive dysfunction are of insufficient quality to demonstrate any clear benefit (Chung et al., 2013; Longley et al., 2021).

Psychological status

Mood disturbance is common following a stroke and may present as depression or anxiety (Gilham, 2021). Left untreated, psychological mood disturbance is associated with higher rates

of mortality, long-term disability, readmission to hospital, suicide and outpatient service utilisation (Pohjasvaara et al., 2001; Williams, 2005).

Up to 30% of people with stroke experience depression (Bowen et al., 2016), which has been shown to be an independent predictor of poor long-term functional outcome post-stroke and is also associated with increased mortality (Pohjasvaara et al., 2001; Ayerbe et al., 2014). Although depression is an important morbidity associated with stroke that impacts on recovery, it is often undetected or inadequately treated and a Cochrane systematic review demonstrated only low-level evidence for the benefit of pharmacological, psychological, and non-invasive brain stimulation interventions in stroke patients (Allida et al., 2020). Despite this, other studies of comprehensive, multidisciplinary interventions in people with stroke (including professional psychology sessions, exercise, early rehabilitation training and cognitive training) that were included in the systematic review have shown reductions in depression in participants who received the interventions (Wu et al., 2012a; Cheng, 2018; Lee, 2018; Brandal et al., 2019; Yu, 2019; Zhang et al., 2019; Lin, 2020; Feng et al., 2021; Gun Young, 2021; Jung et al., 2021).

Anxiety is also common in people with stroke, affecting approximately 20% of patients, but as with post-stroke depression, there is only low-level evidence in systematic reviews to support the use antidepressants or relaxation therapy for the treatment of post-stroke anxiety (Knapp et al., 2017), although other studies included in the review have shown benefit (Cheng, 2018; Yu, 2019; Zhang et al., 2019; Feng et al., 2021).

Dementia is one of the major causes of dependency following stroke and is often under-recognised, due in part to delays of at least 6 months in obtaining a diagnosis, a lack of harmonisation of definition and classification of post-stroke dementia, approaches to neurocognitive assessment, and duration of follow-up after stroke (Mijajlović et al., 2017; Rost et al., 2022). The prevalence of post-stroke dementia is approximately 30% and is set to increase due to improved stroke survival and an ageing population (Leys et al., 2005; Lip and Ntaios, 2021). Post-stroke dementia should be recognised and treated since these patients may have greater functional impairment and higher mortality rates post-stroke (Leys et al., 2005).

Psychological support is multifaceted and involves a number of different healthcare providers, (health, social care and voluntary), and a clear jointly developed pathway of care is essential to optimise service delivery, but substantial improvements in psychological and emotional care can be achieved by ensuring that psychological support is considered by the multidisciplinary team to be as important to stroke recovery as physical rehabilitation (Gilham, 2021).

C - Cardiovascular Risk Factors and Comorbidity Optimisation (Including Lifestyle Changes)

One of the objectives for integrated care in stroke is to manage risk factors since many people with stroke may have a number of multiple comorbidities (Buckley et al., 2022). The appropriate management of comorbidities such as AF, atherosclerosis, dyslipidaemia, arterial hypertension, heart failure, diabetes, sleep apnoea and cardiac ischaemia will reduce the burden of cardiovascular risk in this patient population (Lip and Ntaios, 2021; Lip and Ntaios, 2022).

Pharmacological blood pressure lowering for primary and secondary prevention of CVD has a substantial effect on reducing the risk of major cardiovascular events. In a meta-analysis of 48 clinical trials with data from more than 34,000 patients, the 'Blood Pressure Lowering Treatment Triallists' Collaboration reported that a 5 mm Hg reduction in SBP lowered the relative risk of major cardiovascular events by 10%. The risks for stroke, heart failure, ischaemic heart disease, and death from CVD were reduced by 13%, 13%, 8%, and 5%, respectively (Blood Pressure Lowering Treatment Trialists, 2021). Importantly, the study found that the proportional effects of blood pressure-lowering on cardiovascular outcomes were similar in people with or without previous cardiovascular disease and across categories of baseline SBP, emphasising the need to consider antihypertensive medication as treatment options for prevention of CVD irrespective of blood pressure level and prior history of CVD (Blood Pressure Lowering Treatment Trialists, 2021).

Obstructive sleep apnoea (OSA) indirectly increases the risk of stroke by an effect upon other risk factors such as blood pressure and AF (Sharma and Culebras, 2016), but it is also independently associated with a doubling of the risk of stroke and all-cause mortality, even when controlling for other risk factors including hypertension, AF, smoking, diabetes and hyperlipidaemia (Yaggi et al., 2005). The prevalence of OSA in people with acute ischaemic stroke is approximately 3% and a recent study showed that AF and changes in ambulatory status were associated with worsening neurological outcomes (Sanders et al., 2021). Sleep apnoea may also be associated with an increased risk of vascular dementia (Sharma and Culebras, 2016). Data from a non-randomised study indicate that treatment of OSA with continuous positive airway pressure (CPAP) may reduce mortality and prevent new nonfatal vascular events in ischaemic stroke patients with OSA (Martinez-Garcia et al., 2005; Martinez-Garcia et al., 2009; Martinez-Garcia et al., 2012), although more studies are required to confirm these observations.

Obesity is one of the most common modifiable risk factors for stroke and in the Norwegian HUNT study (Trøndelag Health Study) (Brumpton et al., 2022), obesity was not an independent risk factor, rather conditions such as hypertension, diabetes and dyslipidaemia were associated with increased risk of stroke (Horn et al., 2021). Whilst weight loss is associated with improvements in blood pressure, triglycrides and high-density lipoprotein (HDL), insulin sensitivity and markers of inflammation, with a direct relationship between the extent of improvement and the amount of weight loss (Kernan et al., 2013), the beneficial effects of weight loss on stroke risk are controversial. A large population-based study of more than 111 million people in South Korea showed that the risk of ischaemic stroke was gradually increased in those who lost or gained more than 5% of their weight over four years, but those who maintained their weight had the lowest risk (Cho et al., 2019). In another study of healthy male volunteers, increased weight during early life was associated with increased risk of stroke however there was no increased risk with weight gain in midlife (Prestgaard et al., 2020). These studies highlight a phenomenon known as the **Obesity Paradox**, a counterintuitive finding that overweight and obese people with a particular disease may have better outcomes than their normal weight or underweight counterparts (Amundson et al., 2010; Dramé and Godaert, 2023). The obesity paradox has been observed in people with CVD including heart failure, coronary heart disease, AF and hypertension (Tutor et al., 2023) and according to some reviews, the majority of post-stroke studies suggest that overweight and obese people have lower mortality rates and better functional outcomes compared with normal weight and underweight patients, suggesting the existence of an obesity paradox in stroke (Forlivesi et al., 2021; Quiñones-Ossa et al., 2021).

It is, however, important to acknowledge that, although the obesity paradox remains controversial in CVD and people with stroke, many of the studies are limited by methodological concerns including a lack of randomised trials, retrospective design, assessment of obesity with BMI, non-linear relationship between BMI and outcome, and short follow-up times (Forlivesi et al., 2021; Tutor et al., 2023). Indeed, a study re-examining cardiovascular outcomes data using waist-to-height ratio instead of BMI in patients with heart failure and reduced ejection fraction all but eliminated the effect of the obesity paradox on mortality (Butt et al., 2023). Weight loss or lower weight may in fact be due to disease progression, resulting in a bias which may serve to increase mortality risk in the normal weight group, creating the appearance that overweight is protective, a phenomenon known as reverse causality (Banack and Stokes, 2017; Tobias, 2017). Collider stratification bias is another

possible explanation for the obesity paradox, in which the bias can create false conclusions about the factors causing and caused by obesity. This bias occurs when an exposure and outcome each influence a third variable (Banack et al., 2023). For example, mortality from smoking-related diseases is compared in people with obesity versus those without. Obesity and smoking are both risk factors, but smoking is the stronger of the two risk factors for mortality. Collider stratification bias would state that obesity is protective whereas the reality is that smoking is a more dangerous risk factor (Obesity Medicine Association, 2023). Additionally, the importance of weight loss initiatives cannot be overlooked as obesity is a strong independent risk factor for the development of CVD and stroke (Forlivesi et al., 2021; Quiñones-Ossa et al., 2021; Tutor et al., 2023). To conclude, the obesity paradox has been largely debunked by more recent studies showing the effects of BMI misclassification, reverse causality and collider stratification bias (Banack and Stokes, 2017; Tobias, 2017; Banack et al., 2023; Butt et al., 2023; Obesity Medicine Association, 2023).

Heavy alcohol consumption (defined as >3 drinks daily) has been shown to increase the risk of stroke in a systematic review and meta-analysis of 26 studies (n=82-107,137 per study), with a higher risk of haemorrhagic and ischaemic stroke in women compared with men (Patra et al., 2010). The authors recommended avoidance of heavy alcohol consumption with a limit of ≤2 drinks per day (Patra et al., 2010). A systematic review and meta-analysis of more than 300,000 individuals demonstrated a 60% overall increased risk of stroke in smokers compared with non-smokers, and a dose-response relationship that increased the stroke risk by 12% for every increment of 5 cigarettes smoked per day (Pan et al., 2019). Unsurprisingly, persistent smokers have an increased risk of recurrent stroke that rises with increasing number of daily cigarettes; the relative risk (RR) ranged from 1.68 (95% CI: 1.14–2.48) in those who smoked 1 to 20 cigarettes daily to 2.72 (95% CI: 1.36–5.43) in those who smoked more than 40 cigarettes daily ($P < 0.001$) (Chen et al., 2019). Smoking cessation decreases the risk of stroke after 2 to 4 years of quitting and the risk returns to the level of non-smokers after 5 years (Wolf et al., 1988; Kawachi et al., 1993; Pan et al., 2019).

Physical activity and fitness levels in people following a stroke are low, and these low levels are associated with common post-stroke functional limitations (Saunders et al., 2020b). Therefore, increasing physical activity (including exercise) following a stroke could improve fitness and ameliorate common post-stroke functional limitations. A retrospective analysis of 2,909 people with stroke undergoing exercise-based cardiac rehabilitation (CR) was associated with a 53% risk reduction in all-cause mortality, a 12% risk reduction in recurrent stroke, and

a 36% risk reduction in rehospitalisation at 2 years compared with standard care (Buckley et al., 2021a).

A systematic review and meta-analysis of physical fitness training programs for patients with stroke reported a low mortality rate and suggested that exercise is safe in this patient population (Saunders et al., 2020b). Cardiorespiratory fitness training (in particular walking) can improve fitness, balance and walking after stroke and may reduce the risk of stroke hospitalisation by 7%. Exercise in people with stroke may also be associated with other benefits such as improved cognitive function, mood and quality of life, although further studies are needed to confirm these benefits and to determine the optimal amount of exercise (Saunders et al., 2020a; Saunders et al., 2020b).

Lifestyle modifications including weight loss, healthy diet, regular physical activity, smoking cessation, and low-to-moderate alcohol consumption may reduce risk of incident and recurrent stroke and these behaviours should be targeted because of their positive effect on cardiovascular risk factors (Niewada and Michel, 2016; Bailey, 2018). The American Heart Association's 'Life's Essential 8' concept identified an enhanced approach to assessing cardiovascular health throughout a patient's entire life course, with eight components including diet, physical activity, nicotine exposure, sleep health, BMI, blood lipids, blood glucose, and blood pressure (Lloyd-Jones et al., 2022). Life's Essential 8 identifies modifiable risk factors for heart and brain health and the prevention of cognitive decline, which includes psychosocial factors and behaviours, conditions and lifestyles that can emerge in childhood and adolescence, all of which can be routinely identified and managed in primary care (Lloyd-Jones et al., 2022). However, long-term behavioural change is challenging and is sometimes only achievable with intensive long-term patient support and education programs (Bailey, 2018). The EUROASPIRE survey is an example of poor adherence to recommendations in patients with congestive heart disease, with just 29% of 16,259 patients achieving goals for smoking cessation, weight loss and exercise (De Bacquer et al., 2022). The reasons for such poor adherence include lack of self-confidence, no experience in having participated in a cardiac rehabilitation programme, lack of information and understanding of the disease characteristics and a perception that the recommended change would be less enjoyable than their current lifestyle (Burell, 2021).

There are many theories and models relating to health behaviour change and a few examples of these are described. Social Cognitive Theory (SCT) is commonly used and based on a core set of determinants that include knowledge of health risks and benefits of different health

practices, perceived self-efficacy that people can exercise control over their own health habits, outcome expectations about the expected costs and benefits for different health habits, the health goals people set for themselves and the concrete plans and strategies for achieving them, and the perceived facilitators and social and structural impediments to the changes they seek (Bandura, 2004; Burell, 2021). Acceptance and commitment therapy (ACT) is an adapted form of cognitive behavioural therapy (CBT), focussing on how thinking affects behaviour and promotes psychological flexibility (Rashidi et al., 2021). The prevalence of psychological distress among people living with CVD and/or type 2 diabetes mellitus (T2DM) is high, and ACT may offer an alternative treatment approach however additional research is required to investigate the effectiveness of this approach in this patient group (Rashidi et al., 2021). Patient education is a critical component of comprehensive cardiac rehabilitation (Jaiswal et al., 2022) and improves disease-related knowledge, physical activity and adherence to lifestyle modifications such as diet and exercise (Ghisi et al., 2020; Arrieta-Bartolomé et al., 2022). Cardiac rehabilitation is a supervised programme recommended for people recovering from cardiovascular events and typically includes physical training, cardiovascular risk factor modification, and psychosocial support (Taylor et al., 2022). Regular structured cardiovascular exercise programs such as those recommended by the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) in the UK been shown to reduce hospitalisations and cardiovascular mortality while improving quality of life (British Association for Cardiovascular Prevention and Rehabilitation, 2023), highlighting the benefits of patient education to improve adherence to lifestyle modifications and comprehensive cardiac rehabilitation to improve fitness and reduce cardiovascular risk.

2.3.2 The ABC$_{\text{STROKE}}$ Concept for Integrated Stroke Care in Practice

Two recent studies have reported findings following implementation of the ABC$_{\text{STROKE}}$ pathway (Sagris et al., 2024; Tsang et al., 2024). The study by Sagris and colleagues was a post-hoc analysis of data from the Athens Stroke Registry to determine adherence to the pathway and outcomes (Sagris et al., 2024). Adherence to the A pillar was defined as appropriate antithrombotic treatment at discharge following stroke, adherence to the B pillar was defined as a degree of deficit at discharge based on the modified Rankin scale (mRS) ≥1 with any kind of physiotherapy, speech therapy or ergotherapy, and adherence to the C pillar was defined as the use of statins, treatment of hypertension and diabetes and revascularisation in ≥70% of people with carotid artery stenosis. Full adherence to all three pillars of the pathway was observed in 156/2,513 (6.2%) patients in the study and was independently associated with

lower risks of stroke recurrence, major adverse cardiovascular events (MACE) and mortality (Sagris et al., 2024).

The study by Tsang and colleagues was a retrospective cohort study of 9,669 patients with ischaemic stroke in Hong Kong between 2006 and 2022 (Tsang et al., 2024). Definitions of adherence to the three pillars were similar to that of the study by Sagris and colleagues with the exception of the B pillar, where deficit at discharge was defined as mRS >2, although patients with mRS ≤2 also qualified. The primary endpoint of this study was a composite outcome of recurrent stroke, incident TIA, incident haemorrhagic stroke, incident myocardial infarction (MI), incident heart failure and all-cause mortality. After 12 months of follow-up, full adherence to the ABC_{STROKE} pathway was observed in 58.1% of patients and full adherence was associated with a lower risk of the primary composite endpoint (hazard ratio (HR): 0.80; 95% CI: 0.72–0.88), as well as a lower risk of haemorrhagic stroke (sub-distribution hazard ratio [SHR]: 0.50; 95% CI: 0.38–0.67), heart failure (SHR: 0.771; 95% CI: 0.596–0.998), cardiovascular death (SHR: 0.64; 95% CI: 0.45–0.90), and all-cause mortality (HR: 0.72; 95% CI: 0.62–0.85) (Tsang et al., 2024).

These two studies indicate that full adherence to the ABC_{STROKE} pathway results in lower risks of recurrent stroke, MACE and mortality however there are substantial differences in the rates of full adherence (6.2% in the Sagris study versus 58.1% in the Tsang study) (Sagris et al., 2024; Tsang et al., 2024). This is explained in part by the difference in the proportion of patients prescribed statins in the studies (20.1% versus 78.6% in the Sagris and Tsang studies, respectively), implying that the majority of patients in the Sagris study were non-adherent. In addition, the sample size of the Tsang study was noticeably larger than (n=9,669) that of the Sagris study (n=2,513) and the data analysis in the Tsang study was more extensive.

Although both studies have limitations; they were both retrospective in design and there were differences in the ABC criteria between studies. For example, the Sagris study defined the B criterion as mRS ≥1 whereas in the Tsang study this was defined as mRS >2, and for the C criterion, the Tsang study provides information on the treatments used for management of hypertension and diabetes whereas the Sagris study does not. Despite these limitations, they nonetheless highlight the potential benefits of an ABC approach to stroke care (Sagris et al., 2024; Tsang et al., 2024).

These two studies also highlight the complexity of post-stroke care, which is a highly dynamic and multifactorial process requiring a personalised, multi-disciplinary approach and a long-

term commitment to address a range of pathophysiological, sociodemographic and therapeutic factors that influence recovery (Alawieh et al., 2018; Morone and Pichiorri, 2023). The low levels of full adherence to the ABC_{STROKE} pathway suggest that integrated care in stroke is difficult to implement fully (Sagris et al., 2024) and that a transfer of the ABC concept from AF to stroke is insufficient without recognising the differences between the two conditions. AF management primarily focuses on stroke prevention and symptom control (Lip, 2017), whereas post-stroke care involves managing the immediate and long-term physical, cognitive, and psychological consequences of brain injury, in addition to secondary prevention (Lip et al., 2022b). Future integrated care pathways for stroke should recognise the differences in complexity between stroke and AF and also address knowledge gaps. In this study, the results of the systematic review and meta-analysis (discussed in full in Chapter Five) identify current knowledge gaps in stroke management.

2.3.3 The Holistic Element of the Research

The ABC concept of integrated care is outlined in detail for AF and stroke in this chapter and many of the published articles state that the pathways involved are intended to be holistic in nature (Lip, 2017; Lip et al., 2022b; Lip and Ntaios, 2022; Sagris et al., 2024; Tsang et al., 2024). However, the majority of sources provide no information on how these pathways are considered holistic. For example, the position paper on integrated care for stroke of the European Society of Cardiology Council on Stroke mentions the word 'holistic' in relation to the stroke ABC pathway on 12 occasions but does not state anywhere what this actually means (Lip et al., 2022b). The only published article that hints at what holistic care means is the paper by Lip (2017) on the ABC_{AF} pathway concept, where pillar B involves better control of symptoms through patient-centred and symptom directed decisions, and pillar C states that control of cardiovascular risk factors and comorbidities should include a consideration of patient values and preferences (Lip, 2017), indicating a potential involvement of the patient in decisions about their care. However, even in this article, there is no indication of how these elements within the pillars of the pathway were conceived. Was there a series of patient interviews, a focus group, or a questionnaire, or was it just perhaps a decision by the author? This question remains unanswered.

The systematic review of models of integrated care by Liu and colleagues involved a meta-analysis to identify the effects of integrated care on health-reported quality of life (HRQoL), activities of daily living and depression, which the authors described as important patient-reported outcomes that reflect the holistic effects of an intervention on physical, mental, and

social domains (Liu et al., 2025). However, the reference to holism in this sense refers to the beneficial outcomes and not to the involvement of patients in decisions about their care, which would reflect a holistic approach to integrated care in stroke.

The ILASS model proposed by the Stroke Association states that all stroke survivors as well as carers and family members, should have access to personalised support that is proactively offered in addition to standard stroke rehabilitation (Stroke Association, 2023b). By involving patients in decisions about their care through personalised support, the ILASS is holistic in nature but to date has not been implemented in clinical studies.

The ICSS model of stroke care documents a range of pathways of care tailored to patient need (NHS, 2021a). These pathways include home discharge with ICSS input seven days a week, home discharge with ICSS input combined with daily social care support and discharge to a residential or nursing home (NHS, 2021a). While this might also be considered a holistic approach, ICSS is a guidance model only and its implementation is not currently reported in the published literature.

The IPCAS study of stroke care in the community was an initiative aimed at developing a novel primary care model to better address the longer-term needs of stroke survivors compared with standard care (Mullis et al., 2024). The intervention included the development of a primary care model, a 'Managing Life After Stroke' programme (including self-management) and was developed through a multiprofessional group including patients. This approach allowed a holistic understanding of the perspectives of stroke survivors and carers on experiences of health and care services since discharge from specialist services (Mullis et al., 2024).

The LoTS2 study was a comprehensive research programme the included five workstreams, one of which was an exploration of the predictors of longer-term unmet needs and participation post stroke through semi structured interviews with stroke survivors and their carers (Forster et al., 2021). A qualitative study aimed at identifying longer-term-unmet needs in stroke survivors with the aim of developing patient-centred services as part of the intervention demonstrates a holistic approach to the research programme (Forster et al., 2021).

The 10 key principles of integrated care according to Suter (Suter et al., 2009) include principle #2 (patient focus), which refers to focussing on patient needs and patient engagement and participation in their care. In the review by Liu and colleagues, who used these principles to identify fully adherent integrated care models for stroke, there is no specific reference in their

findings to this principle (Liu et al., 2025), indicating that current integrated care models in stroke are not holistic.

2.4 Chapter Summary

In this chapter, the concept of integrated care has been introduced, which is essentially care that is delivered by a multidisciplinary team of HCPs with the patient at the centre of care, sharing the decision making. Integrated care is an evolution of the Chronic Care Model (CCM), the theoretical framework underpinning this study, with a greater focus on health and social wellbeing of communities and populations while recognising the complexity of modern healthcare (Borgermans et al., 2017; Otieno et al., 2023). The rationale for this study comprises the ABC_{AF} and ABC_{STROKE} integrated care pathways, meeting the six key components of CCM, with this process identifying the importance of the holistic element of integrated care pathways. There is little published evidence to suggest that current approaches to integrated care in stroke are holistic in nature.

In the next chapter, the philosophical viewpoint or worldview that underpins this study will be discussed and the rationale for choosing a research paradigm will be provided.

3 Chapter Three: Philosophical Viewpoint for the Research Project

This chapter introduces the concept of the philosophical worldview or paradigm and discusses the research paradigms underpinning the theoretical framework for this research project. The mixed methods study comprises a series of stroke survivor focus groups, which are qualitative in nature, and a quantitative Delphi survey. The challenge was to choose a research paradigm which fits both qualitative and quantitative elements.

3.1 The Philosophical Worldview or Paradigm

In order to ensure a strong research design, the published literature states the need to adopt a research paradigm, a philosophical framework that is consistent with the researcher's beliefs about the nature of reality, knowledge and how to acquire it (Guraya et al., 2023). A research paradigm is a set of common beliefs about research shared between scientists about how problems should be understood and addressed (Kuhn, 1962). A paradigm can be defined as an assumption about how things work and is commonly expressed as a worldview involving shared understandings of reality (Szyjka, 2012; Rossman and Rallis, 2017). Paradigms are important as they guide the planning and execution of the research process (Guraya et al., 2023). Before undertaking research, assumptions are made by all researchers about the state of the world. Regardless of whether the research is quantitative or qualitative in nature, these assumptions are important as they impact upon the interpretation of a study's results (Brown and Dueñas, 2020).

There are four main components of a research paradigm: ontology, epistemology, methodology and axiology (Lincoln and Guba, 1985; Abdul Rehman and Alharthi, 2016). Ontology refers to the study of the nature of reality or of being and attempts to determine whether reality actually exists or whether it is constructed from our thoughts (Crotty, 2015). Ontology is an important component of a research paradigm since philosophical assumptions about the nature of reality affect the understanding of research data and influence thoughts about the research problem and how to solve it (Guraya et al., 2023). Epistemology relates to the study of knowledge and how we know what we know and can either be positivist or interpretivist in nature (Crotty, 2015; Guraya et al., 2023). Positivist and interpretivist paradigms are discussed in more detail below. Methodology relates to the way in which researchers approach and solve their research problems, in other words it is all about the processes, principles and procedures of their research (Guraya et al., 2023). Axiology relates to the philosophical study of values and ethics and is an important component of a research paradigm as it considers what elements of research are

valuable, why they are valuable and how to go about conducting research in an ethical manner (Brown and Dueñas, 2020; Guraya et al., 2023).

3.1.1 The Positivist Paradigm

The positivist research paradigm emerged during the Enlightenment period of the 17th and 18th centuries, inspired by philosophers such as Locke and Descartes (Park et al., 2020). Positivism was formalised by the scientist August Comte in the 19th century, who believed that society operated according to scientific laws that could be discovered (Crotty, 2015). The positivist paradigm is based on the assumption that there is a single objective reality that can be understood through observation and experimentation (Park et al., 2020). The epistemology of positivism is based on the discovery of observable and measurable facts (Alharahsheh and Pius, 2020). In the positivist paradigm, the researcher bases their knowledge on the external existence of reality and uses a clear hypothesis, objectives and methodology, with reproducible and reliable quantitative methods and statistics to analyse their research data (Brown and Dueñas, 2020; Park et al., 2020; Guraya et al., 2023). Positivism is associated with dualism in addition to objectivity; put simply this means that researchers can be detached from participants (dualism) and by following strict research protocols, the risk of study bias can be minimised (objectivity) (Park et al., 2020). The disadvantages of the positivist paradigm are related to its narrow view of the human experience, which can lead to superficial findings and a failure to capture subjective phenomena and complexity of individual experiences (Alharahsheh and Pius, 2020).

3.1.2 The Post-Positivism Paradigm

The positivist paradigm is heavily dependent upon experimentation to prove a hypothesis based on data and statistical analysis, however the paradigm has been widely criticised, mainly by interpretivists and critical theorists (Crotty, 2015; Abdul Rehman and Alharthi, 2016; Ryan, 2018; Alharahsheh and Pius, 2020). The most common criticism is that the positivist paradigm is not suitable for studying individuals and social phenomena since it is based on observable and empirical evidence (Abdul Rehman and Alharthi, 2016; Panhwar et al., 2017). The philosopher Popper (Popper, 1935) challenged the positivist paradigm on the basis that scientists conducted their research in a continual process of conjecture and falsification, acknowledging that a scientific theory can never be absolutely certain and can always be improved or falsified by new evidence (Crotty, 2015). Early proponents of post-positivism included the sociologist Weber (Weber, 1947) and his concept of understanding or 'verstehen' (Tucker, 1965) (p.158). Weber's post-positivist approach was further developed in the mid-20th

century and first linked to phenomenology by Schutz (Schutz, 1932; Schutz, 1967), further developed by Luckmann, one of Schutz's students, (Schutz and Luckmann, 1979) and by Luckmann in collaboration with Berger (Berger and Luckmann, 1966). This seminal body of work underpins multiple elements of post-positivist research, which include the main components of constructivism, interpretivism and reflexivity, in addition to many elements within the sociology of science and technology (Fox, 2008).

The post-positivist paradigm is based on the assumption that the absolute truth does not exist as humans are not infallible but unlike positivism it accepts that researchers' views of reality are shaped by values, cultures and beliefs and therefore accounts for human error (Berger and Luckmann, 1966; Schutz, 1967; Michael, 2025). Post-positivism emphasises a proper understanding of the directions of a research study from a multi-dimensional and multi-method perspective. The post-positivist paradigm offers greater flexibility than positivism as a variety of methods, including both quantitative and qualitative approaches, can be used to gain a better understanding of complex phenomena (Panhwar et al., 2017; Michael, 2025). However, whilst post-positivism aligns philosophically with qualitative research, some argue that using qualitative methods does not necessarily make the research post-positivist as the underlying assumptions and objectives may still be positivist in nature (Ryan, 2006) and there may also be a lack of coherence if criteria for choosing between competing explanations are unclear (Loughlin, 2012; Musa and Aldiabat, 2024).

3.1.3 The Pragmatic Research Paradigm

The pragmatic research paradigm is a philosophical approach developed in the 1870s by American classical pragmatists such as Sanders Peirce (1839-1914), James (1842-1910) and Dewey (1859-1952), treating ideas and concepts as tools that could be evaluated according to how useful they were at practical problem solving (Dewey, 1916; Weinel, 2023). The epistemology of pragmatism is underpinned by the notion that knowledge is always based on experience, that the perceptions of the world are influenced by social experience, and that knowledge is unique to the individual (Kaushik and Walsh, 2019). Pragmatism uses the most appropriate methods to address a research question, regardless of whether these methods are qualitative or quantitative (Tashakkori and Teddlie, 1998; Kaushik and Walsh, 2019; Allemang et al., 2022). Pragmatism is suitable for mixed methods research and real-world problem-solving, as it focuses on what works best to achieve a desired outcome (Kaushik and Walsh, 2019). Morgan (2014) identified three ideas of pragmatism that highlight the pragmatic focus on the nature of experience rather that the nature of reality (Morgan, 2014a). Firstly, *"actions*

cannot be separated from the situations and contexts in which they occur" (p. 26), meaning that our beliefs are created by the repeated experiences of predictable outcomes. Secondly, *"actions are linked to consequences in ways that are open to change"* (p. 26), implying that if actions change, the consequences also change. According to pragmatist philosophy, it is not possible to experience the exact same situation twice, meaning that beliefs are inherently provisional. Thirdly, "*actions depend on worldviews that are socially shared sets of beliefs"* (p. 27). Pragmatism states that no two people can share identical experiences, meaning that their worldviews cannot be identical either however there are varying degrees of experience that can be shared between people, so in this way worldviews can be individually unique and shared socially (Morgan, 2014a).

Pragmatism rejects the traditional philosophical dualism of objectivity and subjectivity and also allows the researcher to abandon post-positivism and constructivism (Kaushik and Walsh, 2019). In pragmatism, empirical enquiry is preferred over idealistic or rationalistic approaches (Frega, 2011). Rather than assigning post-positivism and constructivism in two different ontological and epistemological camps, pragmatic researchers focus on the two different approaches to inquiry (Morgan, 2014b).

Disadvantages of the pragmatic research paradigm include the concern that it has become a paradigm of convenience for mixed methods research, that prioritising flexibility and practicality over principles sacrifices the ability to provide guidance for researchers, and it risks methodological concerns when translating epistemological ideas into practice, potentially creating more problems (Hampson and McKinley, 2023).

3.1.4 The Interpretivist Paradigm

The interpretivist paradigm originated as a challenge to positivism in social science, focussing on subjective, social and cultural construction of reality rather than objective facts, by the philosopher Vico (1668-1744) in the 18th century (Crotty, 2015; Open University, 2016). Other key influencers of interpretivism include Weber (1864-1920) with his concept of *"verstehen"* (Tucker, 1965 p.158). Interpretivism assumes that there are a number of socially constructed multiple realities and that truth and reality are not discovered, rather they are created (Abdul Rehman and Alharthi, 2016). The epistemology of interpretivism is subjective rather than objective (Alharahsheh and Pius, 2020). People interact with one another and society and ascribe meaning to different social phenomena (Abdul Rehman and Alharthi, 2016). Grix (2004) states that *"researchers are inextricably part of the social reality being researched, in other words they are not 'detached' from the subject they are studying"* (Grix, 2004 p.83).

Different researchers bring different perspectives to the same research problem and the aim of interpretivist research is to attempt to understand the interpretations of individuals about the social phenomena they interact with (Abdul Rehman and Alharthi, 2016; Alharahsheh and Pius, 2020). Cohen and colleagues (Cohen et al., 2007) state that social phenomena should be observed and understood *"through the eyes of the participants rather than the researcher"* (p.21). The research methodology for interpretivism involves qualitative techniques such as interviews and focus groups, collecting verbal rather than statistical data (Redman-MacLaren et al., 2014; Abdul Rehman and Alharthi, 2016; Alharahsheh and Pius, 2020). The main disadvantages of interpretivism lie with its subjective nature, the potential for researcher bias as it relies heavily on the researcher's interpretation of the data, and a focus on a deeper knowledge and understanding of the phenomena being studied rather than generalising the results to other contexts and individuals (Mack, 2010; Cohen et al., 2011; Pham, 2018).

3.1.5 Summary of the Research Paradigms

The research paradigms outlined in this chapter cover a range of philosophical viewpoints: positivist or interpretivist, objective or subjective, a single reality versus multiple realities, and are summarised in Table 1.

Table 1 Summary of the positivist, postpositivist, interpretivist and pragmatic paradigms

Paradigm	**Ontology** ***(What is reality?)***	**Epistemology** ***(How can I know reality?)***	**Theoretical perspective** ***(Which approach do you use to know something?)***	**Methodology** ***(How do you go about finding out?)***	**Method** ***(What techniques do you use to find out?)***
Positivist	There is a single reality or truth (more realist)	Reality can be measured and hence the focus is on reliable and valid tools to obtain that	Positivism Post-positivism	Experimental research Survey research	Usually quantitative, could include: Sampling Measurement and scaling Statistical analysis Questionnaire Focus group Interview
Interpretivist	There is no single reality or truth. Reality is created by individuals in group (less realist)	Reality needs to be interpreted. It is used to discover the underlying meaning of events and activities	Interpretivism (reality needs to be interpreted) • Phenomenology • Symbolic interactionism • Hermeneutics Critical enquiry Feminism	Ethnography Grounded theory Phenomenological research Heuristic enquiry Action research Discourse analysis	Usually qualitative, could include: Qualitative interview Observation Participant Non-participant Case study Life history Narrative Theme identification
Pragmatist	Reality is constantly renegotiated, debated, interpreted in light of its usefulness in new unpredictable situations	The best method is one that solves problems. Finding out is the means, change is the underlying aim	Deweyan pragmatism Research through design	Mixed methods Design-based research Action research	Combination of any of the above and more, such as data mining, expert review, usability testing, physical prototype

Source: (Crotty, 2015; Patel, 2015)

3.1.6 Choice of Paradigm

The research studies contained both qualitative and quantitative elements and so it was necessary to choose a paradigm which could address both the subjective and objective nature of the studies. Choosing the most suitable research paradigm is critical since it provides the fundamental philosophical framework, aligning the research question, methodology, and interpretation of results (Kaushik and Walsh, 2019; Brown and Dueñas, 2020). The correct paradigm ensures coherent, philosophically sound research, capable of producing meaningful, rigorous, and valid conclusions. A well-chosen paradigm guides decisions on what knowledge to seek, how to gather and analyse the data, and can even shape the researcher's worldview and ethical considerations, ultimately impacting the quality and relevance of the study (Kaushik and Walsh, 2019; Brown and Dueñas, 2020; Guraya et al., 2023). The systematic review uses a rigorous, transparent and reproducible process to synthesise and analyse research data (Ahn and Kang, 2018; Mengist et al., 2020). A positivist or post-positivist paradigm would fit here as the systematic review has clear objectives and methodology aimed at proving a hypothesis

from observable and empirical evidence in the published literature (Abdul Rehman and Alharthi, 2016; Panhwar et al., 2017). This approach would answer the research question for the systematic review however, the qualitative questions in the mixed methods study would not be answered with such an approach as the research questions are subjective and would require a different and more suitable paradigm.

The purpose of a mixed methods research is to provide a more complex understanding of a phenomenon that would otherwise not have been accessible by using one approach alone (Morse and Niehaus, 2009; Creswell and Clark, 2011). It is likely that there is no one research paradigm that fits mixed methods studies given their quantitative and qualitative nature. Rather, mixed methods studies span multiple single paradigms (Hall, 2013; Shannon-Baker, 2016). The mixed methods study in this research project is pragmatic in the sense that the approach uses the most appropriate methods to answer the research questions and the methods can be quantitative or qualitative, offering a balance between objectivity and subjectivity (Tashakkori and Teddlie, 1998; Shannon-Baker, 2016; Kaushik and Walsh, 2019; Allemang et al., 2022).

The choice of paradigm that best fits this research is a pragmatic paradigm as it allows for a combination of research methods that span other paradigms (including for example, interpretivist) and is suited to mixed methods studies.

3.2 Perspectives from a researcher

My own lived experiences as a patient with AF gives me a unique insight into the world of being a patient with a long-term medical condition. From this perspective one could argue there is a degree of understanding and empathy (von Knorring et al., 2025). Being a patient can often elicit responses from other patients who may not otherwise divulge what may be sensitive and personal information to researchers who do not have a long-term medical condition. In this sense, a patient-to-patient dialogue is unique and can be invaluable and highly informative, facilitating a better understanding of the condition and what it really means for those who suffer from it (Halpern, 2012). However, my beliefs as a person must be independent of the philosophical standpoint of myself as a researcher in order to avoid personal bias when interpreting data generated during the study. This was achieved through reflexivity, defined as the practice of self-conscious critique appraisal by researchers and evaluation of how subjectivity and context can influence the research process (Olmos-Vega et al., 2023); this involved questioning and challenging my own thoughts and beliefs and how these might influence the research and positionality, understanding of myself, who I am, and what I bring to the research (Darwin Holmes, 2020).

My recent background is based in business, having run my own limited company for more than 20 years. This background influences how I behave as a researcher as I have a natural sense of urgency to get things done as my business activities are associated with deadlines, which are often short and non-negotiable. This has caused frustration where I have requested support and that support had not been immediately forthcoming. I have worked in the public sector previously (I was a laboratory technician at the University of Nottingham for more than five years) so I am familiar with the culture of academia but there is sometimes a clash between the cultures of business and academia, which I have worked hard to mitigate and bring some sense of order to my work by focusing on the goal of completing my research journey over the long-term rather than my own short-term personal frustrations.

3.3 Chapter Summary

This chapter has introduced the concept of a research paradigm, a philosophical worldview and a set of lenses through which to view the research. Four paradigms have been discussed; positivist, post-positivist, pragmatic and interpretivist. Each paradigm has a unique set of properties, ranging from positivist to interpretivist, objective to subjective. The paradigm that was chosen for this research is the pragmatic paradigm as the most appropriate methods have been used to answer the research question. The pragmatic paradigm allows for a combination of quantitative and qualitative research methods, making it particularly suitable for mixed methods studies.

4 Chapter Four: Stroke and Holistic Care

This chapter provides an overview of stroke: what it is, what types of strokes exist, how stroke is recognised and treated, and what the likely outcomes are for patients.

4.1 Stroke

A stroke is defined as a condition in which blood supply to the brain is interrupted either by a blockage or a narrowing of a blood vessel (stenosis) in the case of ischaemic stroke, or bleeding into the brain caused by a ruptured blood vessel in the case of haemorrhagic stroke (Kleindorfer et al., 2021). Strokes can be divided into three main types; ischaemic stroke, intracerebral haemorrhage (ICH) and subarachnoid haemorrhage (Kleindorfer et al., 2021). The most common type of stroke is ischaemic stroke, which accounts for approximately 62% of all incident strokes worldwide (World Stroke Organization, 2022).

Intracerebral haemorrhage accounts for approximately 28% of all incident strokes worldwide (World Stroke Organization, 2022). Intracerebral haemorrhage changes quickly, fluctuates substantially, has extremely high mortality (40-50%) and disability rates (only 12-39% of patients have any functional independence after six months and most will experience some lifelong disability) (Faghih-Jouybari et al., 2021; Rajashekar and Liang, 2023).

Subarachnoid haemorrhage (SAH) is a bleed into the space between arachnoid membrane and the pia mater of the brain, consisting of the cerebrospinal fluid and the blood vessels that supply different areas of the brain (Ziu et al., 2023). SAH accounts for approximately 10% of all strokes and regardless of cause, SAH is frequently devasting with high morbidity and mortality (40-60%) despite advances in diagnostic and therapeutic development (Yamada et al., 2003).

4.1.1 Stroke recovery outcomes

It is estimated that between 3% and 18% of people with ischaemic stroke and 22-45% of people with haemorrhagic stroke die in hospital, with factors such as stroke severity, comorbidities such as heart disease and complications such as sepsis influencing these rates (Ong et al., 2016; Bustamante et al., 2017; Ranasinghe et al., 2023). The variation in mortality rates is partly due to geographical location and provision of stroke services, with higher mortality rates in lower income countries and those with poorer quality stroke care provision (Bustamante et al., 2017; Feigin et al., 2025). Of those individuals who survive their stroke, approximately 10% recover almost completely, 25% recover with minor impairments, 40% experience moderate-to-severe impairment requiring specialist care and 10% require long-term care (American Stroke Association, 2025; Northwestern Medicine, 2025).

4.1.2 Post stroke cardiovascular risk

Post-stroke patients are at substantial risk of new onset cardiovascular events, termed stroke-heart syndrome, and are associated with a significantly worse 5-year prognosis in terms of major adverse cardiovascular events (MACE) (Buckley et al., 2022; Hoad et al., 2025). In a retrospective cohort study of 365, 383 patients with ischaemic stroke with 5-year follow-up, 11.1% developed acute coronary syndrome, 8.8% AF/flutter, 6.4% heart failure, 1.2% severe ventricular arrythmias, and 0.1% Takotsubo syndrome within four weeks of incident ischaemic stroke (Buckley et al., 2022). In a similar analysis of 171,489 patients with ICH and five-year follow-up, 15% (n=26,449) experienced ⩾1 newly diagnosed cardiovascular complication within four weeks and this was associated with a significantly higher risk of five-year MACE (HR 1.35 [95% CI: 1.32–1.38]), (Hoad et al., 2025).

These studies also showed that people with stroke and newly diagnosed cardiovascular complications were at higher risk of recurrent stroke (both ischaemic and ICH). For example, people with ischaemic stroke and stroke-heart syndrome had >50% prevalence of recurrent stroke at five years (Buckley et al., 2022). These observations support the need for a comprehensive integrated care pathway in people with stroke to reduce the risks associated with MACE and recurrent stroke (Lip et al., 2022b).

4.2 Holistic and person-centred care

4.2.1 Holistic health: Definition and brief history

The words ‘Holism’ and ‘Holistic’ are derived from “ Όλος” (holos), a Greek word meaning all, whole, entire, total (Papathanasiou, 2013). The concept of holistic healthcare is a different philosophy to the biomedical model and deals with the patient as a whole, involving a multi-faceted approach. Importantly, the individual is the focus of interest not the disease, and unlike traditional mechanistic approaches, holistic management includes psychological, sociological (biopsychosocial) and mental health support in addition to disease control (Figure 2).

Holistic health is an ancient concept and dates back to the time of Hippocrates, the father of medicine, in 400 BCE, who believed in the healing power of nature (Mantri, 2008). The philosopher Socrates stated in 380 BCE that *“the part can never be well unless the whole is well”* (Jowett, 380 BCE p.16) and this is a reference to the philosophy of holistic health, which is to consider the person as a whole and not just individual symptoms, body parts or ailments (Jowett, 380 BCE).

The earliest examples of holistic healthcare include Chinese herbal medicine, which dates back almost 5,000 years, and the Indian medical practice of Ayurveda, which originated in the 6th century BCE (Mantri, 2008; Adams et al., 2024). Following the discovery of microorganisms such as bacteria and viruses as the causes of disease, Western medicine has focussed almost entirely upon the development of medical treatments such as penicillin to destroy these disease-causing organisms, with much less emphasis on the lifestyle, environment and emotional wellbeing of the person being treated. Fortunately, in more recent times, there has been a renewed interest in the philosophy of holistic care and how it benefits those who receive it (Mantri, 2008).

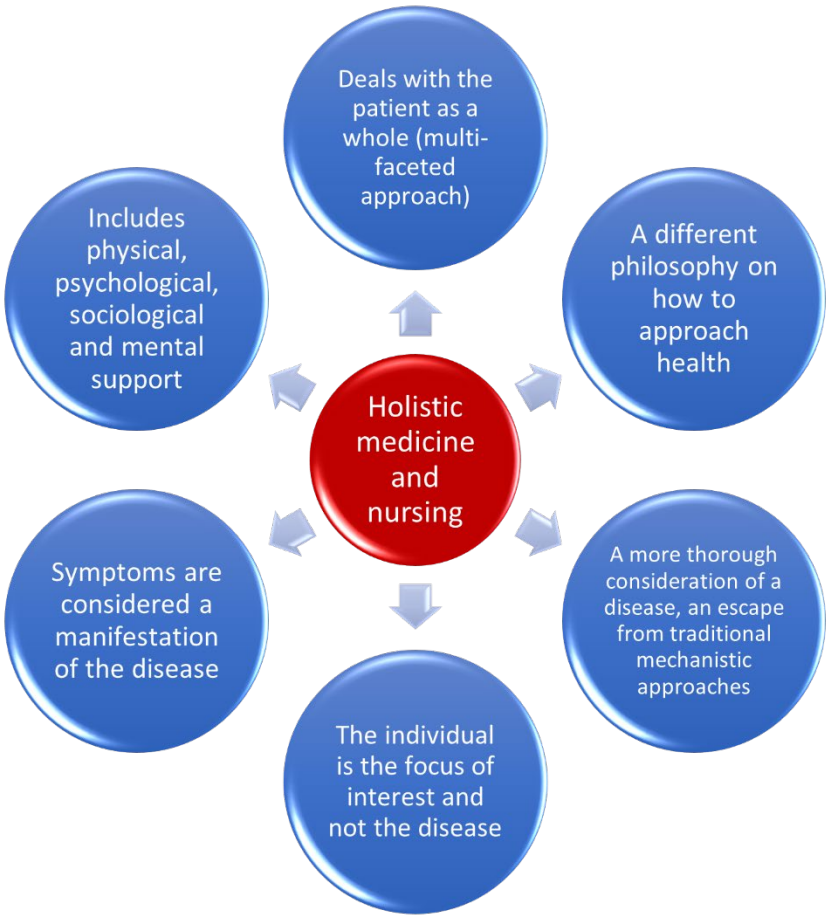


Figure 2 The concept of holistic care

Reproduced with permission from Papathanassiou (Papathanasiou, 2013)

The concept of holistic care is documented predominantly within the nursing profession since nursing has been inherently associated with holistic principles since the 1700s (Thornton, 2019; Nursing and Midwifery Council, 2024). Nursing education is based on consideration of the whole person and focusses on the physiological, psychological, sociological, emotional, relational and spiritual aspects of people (Thornton, 2019; Ambushe et al., 2023). Caring and

healing have always been a foundation of nursing practice (Thornton, 2019; Nursing and Midwifery Council, 2024).

Florence Nightingale was the founder of modern nursing practice and she realised the importance of cleanliness, natural light, pure air and water in the process of healing (Thornton, 2019). An extract from her notes expresses these principles clearly: *"It is often thought that medicine is the curative process. It is no such thing; medicine is the surgery of functions, as surgery proper is that of limbs and organs. Neither can do anything but remove obstructions; neither can cure; nature alone cures. Surgery removes the bullet out of the limb, which is an obstruction to cure, but nature heals the wound. So it is with medicine; the function of an organ becomes obstructed; medicine, so far as we know, assists nature to remove the obstruction, but does nothing more. And what nursing has to do in either case, is to put the patient in the best condition for nature to act upon him. Generally, just the contrary is done. You think fresh air, and quiet and cleanliness extravagant, perhaps dangerous, luxuries, which should be given to the patient only when quite convenient, and medicine the sine qua non, the panacea. If I have succeeded in any measure in dispelling this illusion, and in showing what true nursing is, and what it is not, my object will have been answered.*" (Nightingale, 1859 pp.96-97). Nightingale's principles have substantially influenced modern nursing practice through her innovative approaches to healthcare and dedication to improving patient outcomes. This has resulted in reduced mortality rates through improved sanitation, pioneering use of data analysis in healthcare and the establishment of nursing education standards laying the foundation for the modern nursing profession (Turkowski and Turkowski, 2024).

In the 1900s, the principles of holistic nursing care were largely abandoned in countries such as the USA, due in part to the relentless pursuit of curative medicines but also because of a change in the paradigm of healthcare from a service provision model to a business-like for profit model (Thornton, 2019; Natural Healers, 2024). This was also driven in Europe by the Theory of Germs, which originated in the late 19th century, where Koch established that diseases were caused by germs, leading to the criteria of Koch's postulates, still in modern-day use (National Research Council, 2004; Al-Shura, 2014). In the early 1980s, the first holistic nursing groups were formed, such as the American Holistic Nurses Association (AHNA) in order to move the focus back towards delivering quality care and tending to the needs of the person as a whole. In 2006, the American Nurses Association (ANA) officially recognised holistic nursing as a distinct speciality within the discipline (Thornton, 2019).

4.2.2 Principles of holistic care

Medical care has advanced to the extent that diseases previously considered incurable can now be treated successfully. However, medical treatment success does not necessarily mean that the patient perceives themselves as cured following treatment (Papathanasiou, 2013). Health extends beyond whether a person has a particular disease or medical condition (defined by pathology and biomedicine) and encompasses the well-being of an individual in their environment, which comprises psychological, social and cultural elements as well as the physical aspects. The WHO constitution states that "*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."* (World Health Organization, 2025). In a holistic sense, an illness or a disease can be thought of as an imbalance in the harmony of these elements in an otherwise healthy individual and holistic care aims to restore this balance by addressing all of the factors (such as physical, mental emotional and spiritual) that are negatively impacted by illness (Jasemi et al., 2017).

The holistic approach is governed by a number of principles including the capability of the individual to improve their knowledge and skills and change their behaviour towards themselves and others, a natural inclination towards being healthy, taking responsibility to maintain that health, and ownership of decisions and developments (Papathanasiou, 2013). Providing holistic care respects the person as an individual and considers their own needs and priorities. It also allows the health care practitioner to better understand the impact of an illness on the individual and how to better respond to their true needs (McCormack, 2003).

Holism is considered to be a critical element of patient care for improving long-term outcomes and empowering patients to take an active role in self-management (Brew, 2024; McIlvennan and Howie-Esquivel, 2025). Holistic care provides patients with the comprehensive understanding and tools needed to manage their health autonomously, improving quality of life and reducing the risk and impact of complications (Brew, 2024; McIlvennan and Howie-Esquivel, 2025).

4.2.3 Holistic care in people with stroke

Despite being well described in the literature, holistic care remains a vague and subjective concept with no clear definition (McEvoy and Duffy, 2008; Bullington and Fagerberg, 2013; Jasemi et al., 2017; Frisch and Rabinowitsch, 2019). Perhaps as a consequence of this, holistic care is sometimes described in the literature without a clear knowledge of its meaning (Bullington and Fagerberg, 2013; Jasemi et al., 2017). The body of evidence for the benefit of holistic care in stroke is poorly represented and comprises studies which are generally small

and of low quality with interventions such as art therapy and acupuncture (Farmer, 2015; Kristensen et al., 2015; Sit et al., 2017; Pang et al., 2022).

Although there are no published studies showing a definitive holistic care approach in people with stroke, there is evidence to suggest a move to a more person-centred care model (Morgan and Yoder, 2012; Gluyas, 2015). Concerted efforts have been made to move from a model of care where patients are passive recipients to one in which patients and their family members are active participants in the planning their care and decision making (Gluyas, 2015). However, in an analysis of 51 qualitative studies of 168 stroke patients and 328 caregivers by Pindus and colleagues (2018), stroke survivors and their caregivers perceived that the services that were provided to them were passive rather than proactive, described as an absence of proactive follow-up by either primary or secondary care, with feelings of dissatisfaction, frustration and abandonment expressed by stroke survivors and caregivers. When community support from healthcare services was provided, these services were appreciated and were associated with feelings of confidence and reassurance (Pindus et al., 2018).

The provision of stroke care is often perceived by patients as being incomplete (McKevitt et al., 2011; Andrew et al., 2014; Olaiya et al., 2017a; Jamison et al., 2018; Abrahamson and Wilson, 2019). In a systematic review of qualitative studies involving community dwelling stroke survivors, unmet needs regarding information, physical recovery and activity/participation, social environmental resources and psycho-emotional support were identified (Guo et al., 2021). A recent position paper published by the European Society of Cardiology Council on Stroke summarises the evidence for an integrated approach to stroke care that is intended to be more holistic (Lip et al., 2022a).

The term *"patient-centred care"* is used interchangeably with *"person-centred care"* (Morgan and Yoder, 2012 p.6), a holistic (bio-psychosocial-spiritual) approach that is tailored to the individual, and offers choice and negotiation of care by that individual, who is empowered to be involved in health decisions at whatever level is needed by the person receiving the care (Morgan and Yoder, 2012). Carers or family members are often central to the management of people with stroke, becoming part of the care team, especially in developing countries where resources such as nursing staff and physiotherapists are often limited (Pedapati et al., 2021b). Family-centred care encourages collaboration and partnership among patients, families, and healthcare providers with respect to the planning, delivery, and evaluation of health care (Creasy et al., 2015; Lobo et al., 2021).

Governments and healthcare organisations have committed to this paradigm, since person-centred care models have been shown to result in improved outcomes for patients, better use of resources, reduced health care costs, and increased patient and HCP satisfaction with care (Gluyas, 2015). For example, in the UK, the NHS is committed to involving people in their own care by proposing and implementing a number of initiatives including personalised care and support planning, a process of active participation by the patient, caregivers and NHS services which leads to an agreed personalised care and support plan (NHS, 2021b).

4.3 Chapter Summary

The concept of holistic health is ancient, dating back millennia, and extends beyond physical health to include the whole person, focussing on them rather than the disease (Papathanasiou, 2013). Holistic care was abandoned in the 1900s due to a drive to eradicate disease through the development of new medicines (Al-Shura, 2014; Thornton, 2019), however holistic care is now enjoying a resurgence in many long-term conditions such as stroke, with evidence of person-centred care models improving outcomes for patients and reducing healthcare costs (Gluyas, 2015; NHS, 2021b).

This research study used a holistic approach by seeking direct input and feedback from stroke survivors as to what an integrated care pathway for stroke should include following some critical input from a personal and public involvement (PPI) group. The findings from stroke survivors informed the creation of a new person-centred care pathway.

The next chapter reports the findings of the first research work package (Study 1), which was the systematic review and meta-analysis of published literature on integrated care in people with stroke.

5 Chapter Five: Study 1 - Systematic Review and Meta-Analysis of the Literature

5.1 Purpose of systematic review

The purpose of the systematic review was to answer the following research questions:

1. What types of integrated care management strategies exist for people with stroke?
2. Do integrated care management pathways for stroke impact patient outcomes?
3. What elements of integrated care management for stroke are effective at improving patient outcomes?

5.2 The selection of a systematic review for Study 1

Stroke is a complex medical condition and its treatment is associated with many challenges. The management of stroke is continually evolving, with movement towards more holistic integrated care. Given the complexity and challenging nature of stroke management, the scientific rigour provided by a review of published studies on integrated care in stroke was considered appropriate choice for Study 1, which was based on clearly defined research questions on a known gap in the knowledge base. The reason for choosing a systematic review for this research project is based on several factors. In August 2025, typing the word “stroke” into PubMed yielded nearly 500,000 results, indicating that this is an extensively researched topic. The objective was to obtain a comprehensive and reliable understanding of the published literature on integrated care in stroke to provide a strong evidence base for the research project and it was felt that a systematic review would identify the most relevant studies and that including a meta-analysis would ensure a robust, reliable and reproducible review whilst minimising bias and the effects of high study heterogeneity. Additionally, a systematic review with meta-analysis was considered more desirable than other types of review, such as scoping review or narrative review, for submission and publication in a peer-reviewed journal.

5.3 Step 1: Systematic review protocol and registration

A protocol was written and approved by the supervisory team before being registered in PROSPERO in November 2021 (reference CRD42021290240) and conducted in accordance with the PRISMA guidelines (Page et al., 2021). A copy of the protocol is provided in Appendix A.

5.4 Study inclusion/exclusion criteria

Studies that reported integrated care in stroke patients were included in the review based on a definition of integrated care used by the NHS and the WHO (World Health Organization, 2015; NHS, 2024):

Integrated care is a patient-centred approach which involves multiple teams of healthcare providers communicating with each other to provide the best possible care for the patient across their journey.

Stroke was defined according to a conceptual representation of subtypes in the American Heart Association/American Stroke Association (AHA/ASA) guidelines (ischaemic stroke, intracerebral haemorrhage or subarachnoid haemorrhage [further information on stroke types is provided in Section 4.1.1]) (Kleindorfer et al., 2021).

5.4.1 Inclusion criteria

Patients with any acute stroke or TIA of any age, and any pathological type of stroke (ischaemic, venous, ICH) were included. All randomised controlled trials, uncontrolled comparative trials, observational cohort studies, mixed methods and quantitative case studies were considered for inclusion. In order for the systematic review to be comprehensive and thorough, non-randomised uncontrolled trials were included provided they had a control group for comparative purposes. For sample groups including mixed diagnoses, for example transient ischaemic attack or traumatic head injury, in addition to stroke, the authors were contacted for data specific to the stroke cohort.

5.4.2 Exclusion criteria

Studies involving patients for which stroke was not the primary event or where a definitive diagnosis of stroke could not be confirmed were excluded.

5.5 Intervention(s), exposure(s)

Interventions of interest which may or may not have been part of a structured plan of care included (pharmacological or non-pharmacological) secondary stroke prevention measures, for example anticoagulation, management of stroke risk factors such as hypertension, overweight/obesity, management of comorbidities such as CVD, respiratory disease or diabetes, non-pharmacological interventions such as exercise programmes, physiotherapy, occupational therapy, mental health support, dietary advice, weight loss, smoking and alcohol use, delivered within inpatient or outpatient settings.

5.6 Comparator(s)/control

Comparator or control groups comprised standard management of patients following acute stroke. If there were data for patient adherence or non-adherence to elements of the care pathway, these data were documented.

5.7 Main outcome(s)

Primary outcomes included all-cause mortality, cardiovascular mortality, recurrent stroke, and major bleeding. These outcomes were chosen as the systematic review was based on the primary outcomes assessed in the ABC_{AF} pathway and the shared risk factors between stroke and AF. The hypothesis for the current study and the ABC_{STROKE} pathway, upon which this research was also based, was that its implementation could be associated with similar benefits in lowered risks to those demonstrated by the ABC_{AF} pathway (reduced all-cause mortality, cardiovascular mortality, stroke and major bleeding, Section 2.3.1).

Secondary outcomes included quality of life, rehospitalisation, mental wellbeing/depression/anxiety, and treatment adherence.

5.8 Step 2: Electronic database search

The search strategy was developed by the review team using MeSH terms and synonyms for 'stroke' and 'integrated care'. These terms were combined with Boolean operators, truncations and wildcards. MEDLINE®, EMBASE®, CINAHL®, Web of Science, and the Cochrane Central Register of Controlled Trials were searched from 01 January 2012 to 01 January 2022 for relevant studies (Appendix B). A search of grey literature was also undertaken, and the search was extended to Google Scholar. The search was initially conducted in MEDLINE® and CINAHL® and was then adapted for the remaining databases. There were no language restrictions (article titles written in foreign language were translated using Google Translate and assessed for relevance) however the availability of a full-text article was required for inclusion. Search results were imported into and managed using Endnote 20.6 (Clarivate Analytics, 2023). Attempts were made to contact authors of published full-text versions of studies to request additional study data, when required.

5.9 Step 3: Title and abstract screening

Two reviewers (I.E-B. and I.K.) independently and in duplicate screened the titles and abstracts of the retrieved studies in Endnote 20.6 (Clarivate Analytics, 2023). Regular communication regarding the progress of screening was maintained between reviewers to ensure that screening

was completed in a timely fashion. The number of full text articles to be retrieved was discussed and agreed between reviewers.

5.10 Step 4: Review of full text articles

The full texts of all potentially relevant articles were retrieved and independently assessed by the reviewers (I.E-B, I.K. and B.J.R.B.). Any disagreement was resolved through discussion with B.J.R.B. Those articles for which no full text publication was available were excluded from the analysis.

5.11 Step 5: Hand searching

Supplementary sources for full text articles were searched for additional information such as study protocols, statistical analysis plans (SAPs) and supplementary information. In some cases, protocols and SAPs were published as separate articles and these were used in the risk of bias assessments.

5.12 Step 6: Data extraction and quality

Data extraction was conducted independently by I.E-B., with at least 20% checked by B.J.R.B. to ensure consistency and accuracy. Data extracted included the following: a) authors, year of publication, country of origin, reference; b) study design with inclusion/exclusion criteria; c) study aims and objectives; d) demographic data of study populations (including n=, age, sex, ethnicity, disease characteristics, comorbidities); e) description of intervention and/or comparator; f) outcomes (effectiveness and safety); g) results; h) conclusions and i) risk of bias assessment.

An Excel spreadsheet was used to capture the data during the data extraction process and was populated in duplicate by I.E-B and I.K (Appendix C). This spreadsheet served as the DET.

5.13 Risk of bias assessment

Risk of bias was independently assessed in duplicate by two reviewers for randomised trials (I.E-B. and I.K.) and by multiple reviewers (I.E-B., K.H., B.J.R.B, G.Y.H.L. and I.D.J.) for non-randomised trials. Any discrepancies were discussed and resolved with B.R.J.B. Risk of bias was assessed using the Cochrane Risk of Bias v.2 (RoB2) tool (Sterne et al., 2019) and the Risk Of Bias In Non-randomised Studies – of Interventions (ROBINS-I) tool (Sterne et al., 2016) for randomised and non-randomised trials, respectively.

5.14 Data synthesis

Results of the systematic review were summarised descriptively and grouped according to the target outcome (primary: mortality, recurrent stroke, major bleeding; secondary: quality of life, rehospitalisation, mental wellbeing/depression/anxiety, treatment adherence).

5.15 Meta-analysis

Meta-analyses were conducted for comparable studies where sufficient data were present. Primary and secondary outcome effect measures with 95% confidence intervals were pooled using RevMan 5.4 software (Cochrane Collaboration, 2020). Random effects models were used, allowing for between-study variability by weighting studies using a combination of intra- and inter-study variance. Results were presented visually using Forest plots. Heterogeneity was assessed visually and using the I^2 statistic with 25%, 50% and 75% considered moderate, substantial and considerable heterogeneity, respectively.

To measure the overall treatment effects, the Der Simonian & Laird method for both binary, (for example, mortality), and continuous (for example, quality of life) outcomes were used (DerSimonian and Laird, 1986). If continuous data were not homogeneous, an estimate of the standardised mean difference (SMD) with 95% confidence intervals was calculated. If quantitative data were too few or too heterogeneous, then a narrative synthesis approach was undertaken.

Randomised controlled trials (RCTs) were meta-analysed separately to non-randomised controlled trials (NRCTs). Randomised study results were reported using risk ratio (RR). For studies with continuous data (for example quality of life assessment scales), mean differences were used to compare outcomes of studies that used the same assessment scales and standardised mean differences (SMD) were used to combine results from studies across scales.

For studies reporting standard errors (SE), these were converted into standard deviation (SD) using the formula SD=SE×√N, where N is the sample size of a particular group (Higgins et al., 2019). For studies reporting means and confidence intervals only, SD was calculated from 95% confidence intervals (CI) using the following formula (Higgins et al., 2019):

$$\text{SD}=\surd=\surd=\surd N \times \frac{(upper\ limit - lower\ limit)}{3.92}$$

For studies with two control or intervention groups, these were combined using the following formula (Higgins et al., 2019):

Mean=$\frac{N_1M_1+N_2M_2}{N_1+N_2}$ where N and M are sample size and mean for each group. SD for the combined groups was calculated as follows (Higgins et al., 2019):

SD=$\sqrt{\frac{(N1-1)SD1^2+(N2-1)SD2^2+\frac{N1N2}{N1+N2}(M1^2+M2^2-2M1M2)}{N1+N2-1}}$

5.16 Analysis of subgroups or subsets

If the necessary data were available, analysis of the following subgroups were undertaken using stratified meta-analysis for 1) primary outcomes of all-cause death, cardiovascular death and recurrent stroke, (for example CHA_2DS_2-VASc score groups and HAS-BLED scores for bleeding risk); 2) geographic region (Asia, Europe, North America); 3) study design (real-world data versus randomised controlled trials; short versus long-term follow-up, prospective versus retrospective) and 4) patient subgroups (aged >75 and <75 years, health conditions, adherence/non-adherence with interventions). Mortality and other outcomes (where applicable) were analysed according to length of follow-up, via sub-group analyses to stratify for different follow-up time points. Further, quality of life and depression/anxiety data were grouped and analysed according to the type of measurement tool employed (e.g., VAS, EQ-5D, HADS). Where feasible, standardised mean differences were used to meta-analyse similar scales. Meta-analyses of RCTs and NRCTs were conducted separately.

5.17 Stage 7: Creating the report. Updated systematic review following submission of manuscript to Quarterly Journal of Medicine February 2024

On 02 February 2024, a completed systematic review manuscript was submitted to the Quarterly Journal of Medicine (QJM) for review with a view to acceptance and publication. Reviewer comments resulted in substantial amendments to the original search strategy and data analysis. These amendments included:

- Extended searches to include all studies on integrated care published between 01 January 2012 and 01 January 2024
- The addition of search terms ‘long-term stroke management’, ‘post-stroke disease management’ and ‘post-stroke care pathways’. The additional outcomes of three-month or 12-month functional status as measured by the modified Rankin Scale (mRS), recurrent risk of cardiovascular disease and ‘unplanned’ readmission rates (instead of readmission rates)

In order to complete the amendments within the timeframe specified by the journal (which was originally three months but was extended by request to nine months), two additional reviewers

(K.H.) and (M.F-R.) were engaged to assist with data extraction and risk of bias assessment. The revised manuscript was submitted to QJM on 10 January 2025 and was accepted for publication on 14 January 2025. The results section in this chapter includes the data from the revised manuscript containing the amended data analysis required by the journal. A copy of the accepted article is provided in Appendix D.

5.18 Review Findings

An initial search yielded 27,271 records. After removal of duplicates, 18,142 records were screened in duplicate by I.E-B. and I.K. Following close collaboration and regular discussion, 17,812 records were excluded, and the remaining 330 full text articles were assessed for eligibility against the inclusion/exclusion criteria. The main reason for excluding full text articles (74%) at this stage was that the intervention(s) being studied was/were not considered to be part of integrated care according to our definition. Other studies were excluded if there was no control or comparator arm, if the study outcomes did not match the criteria specified in the protocol, the study populations were not people with stroke, or if the studies were only published as an abstract. Of the 330 full text articles, 99 (30%) were included in the systematic review (Figure 3) and 63 (19%) were included in meta-analysis.

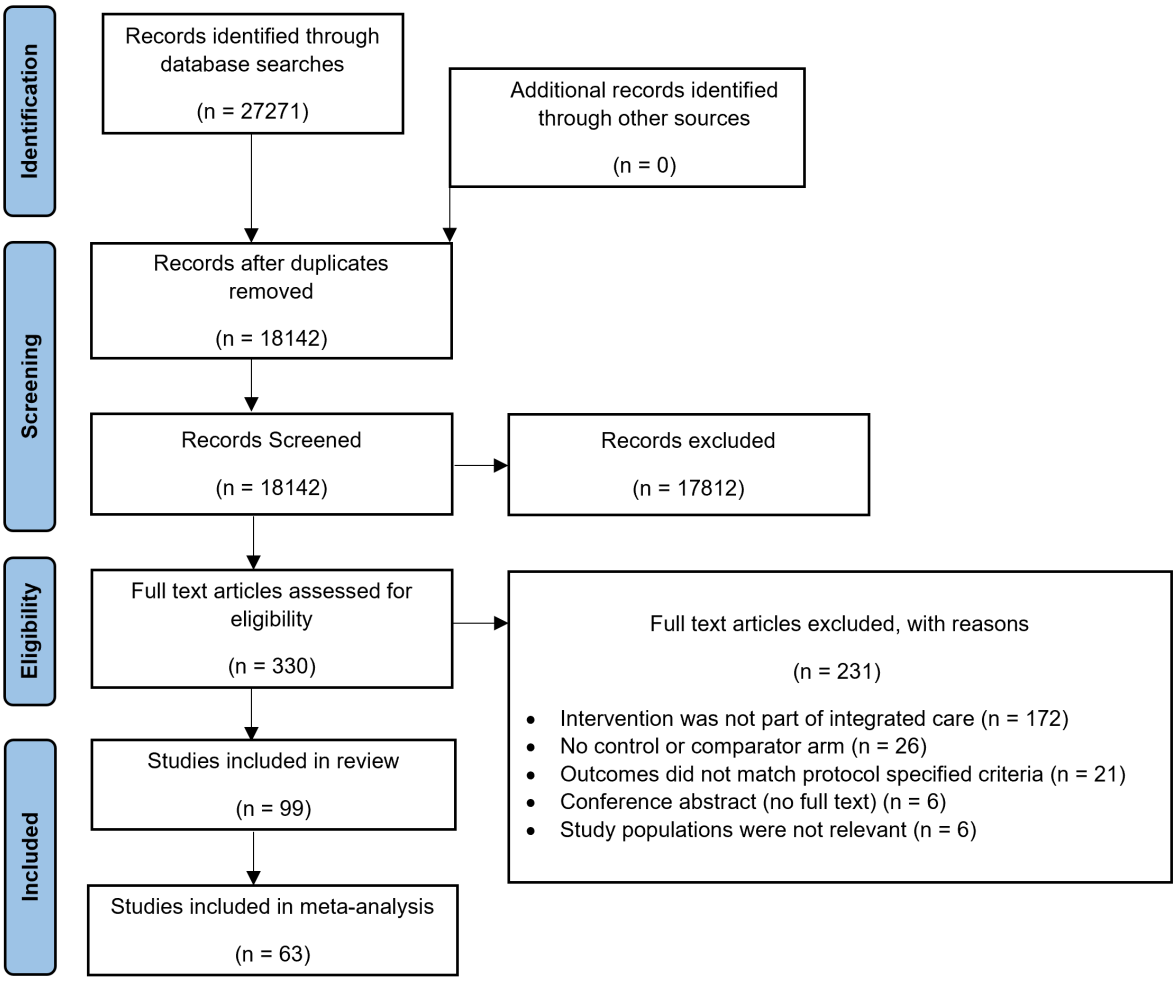


Figure 3 PRISMA chart for systematic review

5.18.1 Characteristics of the included studies

The studies included in the review were published between January 2012 and January 2024. Of the 99 studies, the majority (n=64) were RCTs (Appendix E). The total number of participants included in the review was 88,435, of which 40,475 received an integrated care intervention or pathway comprising multiple interventions. Mean/median patient age ranged from 53 (Chen et al., 2016; Xi, 2017; Lee et al., 2018; Pedapati et al., 2021a) (18-21) to 83 years (Swanson, 2019) and the proportion of females ranged from 23% (Long Weijan and Zhang, 2017) to 70% (Vluggen, 2021).

A data extraction spreadsheet serving as the DET was created using Microsoft Excel which included all relevant details for every included study and was populated in duplicate by I.E-B and I.K (Section 5.11). The use of this spreadsheet allowed rapid and effective sorting of parameters for analysis and for verification of data between researchers (Appendix C).

5.18.2 Study settings

The settings for the studies ranged from acute care only prior to discharge from the hospital or stroke unit, transitional care in which the study was conducted both pre-and post-discharge into the community, and those that were conducted entirely in the community (post-discharge).

5.18.2.1 Acute setting (pre-discharge)

Of the 99 studies in the review, 22 were conducted in acute care. These studies included early (mobilisation or passive exercise within 48h of admission) or very early rehabilitation (mobilisation or passive exercise within 24h of admission) (Liu et al., 2014; Bernhardt et al., 2015; Nakibuuka et al., 2016; Langhorne et al., 2017; Brandal et al., 2019; Cumming, 2019; Lin et al., 2020).

Post-acute care (PAC) programs comprised individually tailored rehabilitation programs including physiotherapy, activities of daily living, and speech and swallowing therapy (Chiu et al., 2021; Chang et al., 2022).

Intensive antiplatelet combination treatment was provided as a secondary prevention intervention (Bath et al., 2018). Nurse-led rapid rehabilitation interventions included airway and nutrition management, mobilisation and passive exercise and counselling following mechanical thrombectomy (He et al., 2023).

One study compared primary stroke centres and comprehensive stroke centres for in-hospital outcomes such as thrombectomy rates and mortality (Man et al., 2018), whilst another evaluated carotid endarterectomy, a surgical procedure to remove plaques in stroke patients with carotid artery stenosis (Mofidi et al., 2018).

A novel telestroke program for thrombolysis in acute stroke involving a telephone-based stroke service managed by a dedicated neurologist was the intervention in one study (Nguyen-Huynh et al., 2018). Another study included a structured educational intervention (SEI) comprising information on stroke, secondary prevention, post-stroke complications and a video showing range of motion exercises for caregivers (Pedapati et al., 2021a).

The self-rehabilitation video exercises (SAVE) study comprised a series of bedside exercise videos designed to implement 60 minutes of exercise every day for four weeks (Jung et al., 2021). Finally, a horticultural intervention for stroke inpatients that comprised horticultural activities including the motions of reaching–grasping, squatting, stepping, and stooping, implemented for 60 minutes three times weekly for six weeks in patients (Lee et al., 2018).

5.18.2.2 Transitional care studies

Thirty-five (35) studies were considered to represent transitional care, where interventions were delivered to participants in the pre- and post-discharge settings. These studies included the Stroke East Saxony care project, a post-stroke pathway implemented by case managers comprising educational discussions, quarterly checkups for vascular risk factors and adherence to antithrombotic/anticoagulant medication in addition to standard care (Bodechtel et al., 2016).

The Integrated Care for the Reduction of Secondary Stroke (ICARUSS) study was a shared care initiative between primary and secondary care, directly involving patients and carers in stroke risk factor management (Joubert et al., 2020). The Comprehensive Post-Acute Stroke Services – Transitional Care (COMPASS-TC) study comprised a post-acute care pathway follow-up with the advanced practice provider and nurse coordinator in clinic within 7 to 14 days post-discharge, an individualised electronic care plan, and referral to community services (Duncan et al., 2020; Bushnell et al., 2021)

Nurse-led care pathways included personalised plans, health education, nutritional advice, psychological counselling and follow-up (Liu, 2018; Lin, 2022), and some studies evaluated early, very early supported discharge or PAC programs with additional community support (Peng et al., 2017; Rafsten, 2019; Tung et al., 2021; Huang et al., 2023).

The multidisciplinary STROKE-CARD study was a comprehensive disease management program delivered by a multidisciplinary team that included risk factor management and patient education (Willeit et al., 2020). Training programs included self-care comprising multi-joint coordinated exercise based on standard care (Li et al., 2023). Comprehensive nursing training for caregivers was delivered by trained nurses (Long Weijan and Zhang, 2017), cognitive rehabilitation training comprised patient and family member education, cognitive training, rehabilitation training, and regular follow-up (Cheng et al., 2018a). Family-centred care programs consisted of four steps; needs assessment, educating families based on patients' needs, follow-ups by short phone interviews, and a referral service (Nayeri et al., 2014). Intensive patient and caregiver education programs included comprehensive psychoeducation and psychonursing for patients and caregivers, with a cognitive rehabilitation training and mobile communication application known as WeChat (Yu et al., 2019; Zhang et al., 2019).

5.18.2.3 Post-discharge community studies

The majority (42) of the studies included in the review were conducted in the community post-discharge. The community locations included patients' own homes (Jones et al., 2016; Olaiya et al., 2017b; Sharma et al., 2019; Deutschbein et al., 2020; Døhl et al., 2020; Feng et al., 2021), university research premises (Brouwer et al., 2018; Koch et al., 2020; Wang et al., 2021; Lo et al., 2023), urban and rural community centres (Ellis-Hill et al., 2019; Bragstad et al., 2020; MacKay-Lyons et al., 2022), primary care (Olaiya et al., 2017b; Luengo-Fernandez et al., 2022), outpatient clinics (Gao et al., 2017; Olaiya et al., 2017b; Teuschl et al., 2017; Cuccurullo et al., 2019; Ahmadi et al., 2020; Shaw et al., 2020; Greger et al., 2021; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b; Schwarzbach et al., 2023) and care homes (Swanson, 2019; Fu et al., 2020). Some studies were conducted at multiple locations such as community centres, outpatient clinics and patients' homes (Saal et al., 2015; Olaiya et al., 2017b; Xi, 2017; Hjelle et al., 2019; Swanson, 2019; Minshall et al., 2020; Towfighi et al., 2021; Luengo-Fernandez et al., 2022; Lu et al., 2023b).

These studies included interventions such as exercise and aerobic training programs (Graven et al., 2016; Døhl et al., 2020; Koch et al., 2020; Buckley et al., 2021a; MacKay-Lyons et al., 2022), risk factor management and secondary prevention studies (Olaiya et al., 2017b; Teuschl et al., 2017; Cuccurullo et al., 2019; Sharma et al., 2019; Greger et al., 2021; Towfighi et al., 2021; Wang et al., 2021; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b; Luengo-Fernandez et al., 2022; Schwarzbach et al., 2023). Other interventions included group discussion, counselling, antidepressants, CBT, art and creativity to improve psychosocial wellbeing (Gao et al., 2017; Ellis-Hill et al., 2019; Hjelle et al., 2019; Bragstad et al., 2020; Minshall et al., 2020; Gun Young, 2021). Some studies used self-management programs comprising one-to-one needs-based analysis, and goal setting using workbooks (Jones et al., 2016; Fu et al., 2020), internet/virtual interventions such as consultations, clinics, or telemedicine for people with disabilities or living in remote areas (Xi, 2017; Feng et al., 2021; Yan et al., 2021; Feng et al., 2023; Lo et al., 2023; Lu et al., 2023b), and post-discharge follow-up support programs conducted in person or by telephone (Saal et al., 2015; Brouwer et al., 2018; Swanson, 2019; Deutschbein et al., 2020).

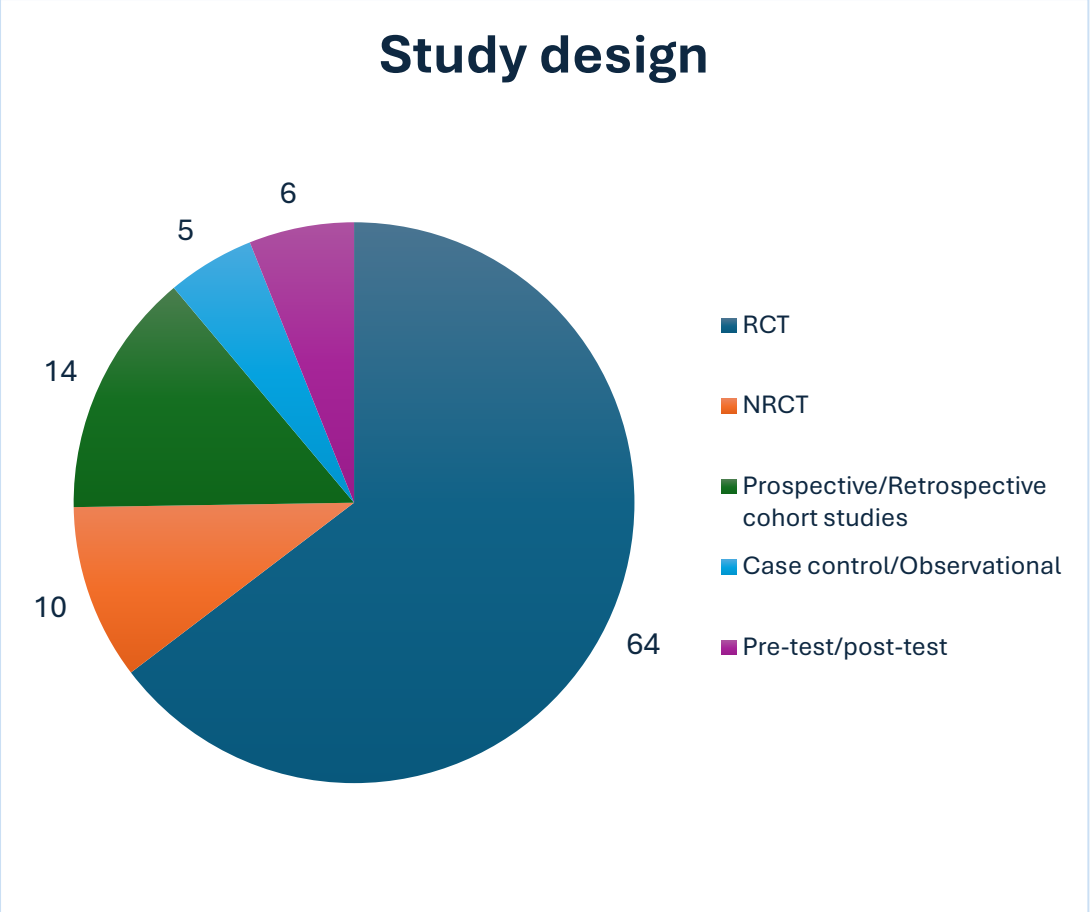
5.18.3 Study design

The 99 studies in the review comprised the following design (Figure 4):

- **Randomised controlled trials: 64** (Liu et al., 2014; Nayeri et al., 2014; Bernhardt et al., 2015; Saal et al., 2015; Wong and Yeung, 2015; Graven et al., 2016; Jones et al.,

2016; Rasmussen et al., 2016; Gao et al., 2017; Langhorne et al., 2017; Long Weijan and Zhang, 2017; Olaiya et al., 2017b; Teuschl et al., 2017; Xi, 2017; Bath et al., 2018; Brouwer et al., 2018; Cheng et al., 2018b; Lewthwaite et al., 2018; Liu, 2018; Cumming, 2019; Ellis-Hill et al., 2019; Geng et al., 2019; Hjelle et al., 2019; Rafsten, 2019; Rodgers et al., 2019; Sharma et al., 2019; Yu et al., 2019; Zhang et al., 2019; Abdul Aziz et al., 2020; Ahmadi et al., 2020; Bragstad et al., 2020; Chu et al., 2020; Deng et al., 2020; Deutschbein et al., 2020; Døhl et al., 2020; Duncan et al., 2020; Fu et al., 2020; Joubert et al., 2020; Koch et al., 2020; Lin et al., 2020; Minshall et al., 2020; Shaw et al., 2020; Willeit et al., 2020; Wu et al., 2020; Bushnell et al., 2021; Feng et al., 2021; Khramov et al., 2021; Pedapati et al., 2021a; Towfighi et al., 2021; Vluggen, 2021; Wang et al., 2021; Yan et al., 2021; Chang et al., 2022; Freburger et al., 2022; Kalav et al., 2022; Lin, 2022; MacKay-Lyons et al., 2022; Mohammadi et al., 2022; Wong et al., 2022b; Demir Avci and Gözüm, 2023; Huang et al., 2023; Li et al., 2023; Lo et al., 2023; Schwarzbach et al., 2023)

- **Non-randomised controlled trials: 10** (Chen et al., 2016; Nakibuuka et al., 2016; Lee et al., 2018; Man et al., 2018; Reeves et al., 2019; Gun Young, 2021; Jung et al., 2021; Feng et al., 2023; He et al., 2023; Lu et al., 2023b)
- **Retrospective/prospective cohort studies: 14** (López-Liria et al., 2016; Chen et al., 2017; Chang et al., 2018; Mofidi et al., 2018; Cuccurullo et al., 2019; Swanson, 2019; Chiu et al., 2021; Greger et al., 2021; Tung et al., 2021; Chang et al., 2022; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b; Yoo et al., 2022; Bergh et al., 2023)
- **Pre-test/post-test studies using the same groups before and after the intervention: 6** (Nguyen-Huynh et al., 2018; de Belvis et al., 2019; Markle-Reid et al., 2020; Brouns et al., 2021; Dello et al., 2021; Luengo-Fernandez et al., 2022)
- **Case-controlled or retrospective observational studies: 5** (Bodechtel et al., 2016; Peng et al., 2017; Brandal et al., 2019; Cecchi et al., 2020; Buckley et al., 2021a).



RCT, randomised controlled trial; NRCT, non-randomised controlled trial.

Figure 4 Summary of study design

In the current study, randomised controlled trials (RCTs) were those that showed clear evidence of a randomisation process in the methods where participants were allocated by chance to study groups using a validated randomisation procedure and had at least two study arms, one of which represented control or standard care. Non-randomised controlled trials (NRCTs) were those in which participants were not assigned by chance to different study groups but were assigned by the researchers as in quasi-experimental studies.

The 99 studies included were distributed across the following countries:

- **China: 24** (Wong and Yeung, 2015; Chen et al., 2016; Gao et al., 2017; Long Weijan and Zhang, 2017; Xi, 2017; Cheng et al., 2018a; Liu, 2018; Geng et al., 2019; Yu et al., 2019; Zhang et al., 2019; Chu et al., 2020; Deng et al., 2020; Wu et al., 2020; Feng et al., 2021; Wang et al., 2021; Yan et al., 2021; Lin, 2022; Wong et al., 2022b; Feng et al., 2023; He et al., 2023; Huang et al., 2023; Li et al., 2023; Lu et al., 2023b)
- **USA: 16** (Cheng et al., 2018b; Lewthwaite et al., 2018; Man et al., 2018; Nguyen-Huynh et al., 2018; Cuccurullo et al., 2019; Reeves et al., 2019; Duncan et al., 2020; Koch et al., 2020; Bushnell et al., 2021; Greger et al., 2021; Towfighi et al., 2021; Wang et al., 2021; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b; Freburger et al., 2022; Lo et al., 2023)
- **UK: 8** (Jones et al., 2016; Bath et al., 2018; Mofidi et al., 2018; Ellis-Hill et al., 2019; Rodgers et al., 2019; Shaw et al., 2020; Buckley et al., 2021a; Luengo-Fernandez et al., 2022)
- **Taiwan: 7** (Chen et al., 2017; Peng et al., 2017; Chang et al., 2018; Lin et al., 2020; Chiu et al., 2021; Tung et al., 2021; Chang et al., 2022)
- **Germany: 5** (Bodechtel et al., 2016; Ahmadi et al., 2020; Deutschbein et al., 2020)
- **Norway: 5** (Hjelle et al., 2019; Swanson, 2019; Bragstad et al., 2020; Døhl et al., 2020; Bergh et al., 2023)
- **Australia: 4** (Bernhardt et al., 2015; Graven et al., 2016; Olaiya et al., 2017b; Joubert et al., 2020)
- **Canada: 4** (Brouwer et al., 2018; Sharma et al., 2019; Markle-Reid et al., 2020; MacKay-Lyons et al., 2022)
- **International Multicentre: 3** (Langhorne et al., 2014; Saal et al., 2015; Rasmussen et al., 2016; Cumming, 2019; Minshall et al., 2020; Schwarzbach et al., 2023),
- **Korea: 3** (Lee et al., 2018; Gun Young, 2021; Jung et al., 2021)
- **Austria: 2** (Teuschl et al., 2017; Willeit et al., 2020)
- **Iran: 2** (Nayeri et al., 2014; Mohammadi et al., 2022)
- **Italy: 2** (de Belvis et al., 2019; Cecchi et al., 2020)
- **Netherlands: 2** (Brouns et al., 2021; Vluggen, 2021)
- **Sweden: 2** (Brandal et al., 2019; Rafsten, 2019),
- **Turkey: 2** (Kalav et al., 2022; Demir Avci and Gözüm, 2023).
- **Belgium: 1** (Dello et al., 2021)
- **Denmark: 1** (Rasmussen et al., 2016)
- **India: 1** (Pedapati et al., 2021a)
- **Malaysia; 1** (Abdul Aziz et al., 2020)
- **New Zealand: 1** (Fu et al., 2020)
- **Russia: 1** (Khramov et al., 2021)
- **Spain: 1** (López-Liria et al., 2016)
- **Uganda: 1** (Nakibuuka et al., 2016)

Forty percent of the studies were conducted in China or the USA, with China accounting for 24% of studies. The majority of these were small studies with between 40 participants (Liu,

2018) and 1,226 participants (Yan et al., 2021). Thirty-three (33) studies were conducted in the UK and Europe.

5.18.4 Study interventions

Of the 99 studies included in the review, the majority (42/99, 42%) comprised multiple components of care as part of an integrated care pathway or package. Twenty-eight studies included an exercise or physical activity component (9 of which used this as the sole intervention in addition to standard care) (Liu et al., 2014; Bernhardt et al., 2015; Langhorne et al., 2017; Lee et al., 2018; Cumming, 2019; Døhl et al., 2020; Lin et al., 2020; Buckley et al., 2021a; Jung et al., 2021), 24 studies included an educational or training component (one of which used this as the sole intervention) (Saal et al., 2015), 17 studies included a psychological or mental health component (including three studies which used this component as the sole intervention) (Ellis-Hill et al., 2019; Hjelle et al., 2019; Bragstad et al., 2020), 15 studies used interventions to address lifestyle and risk factors, and three studies involved mHealth technology (Figure 5). A total of 19 studies were considered patient-centred or individualised/personalised to each participant.

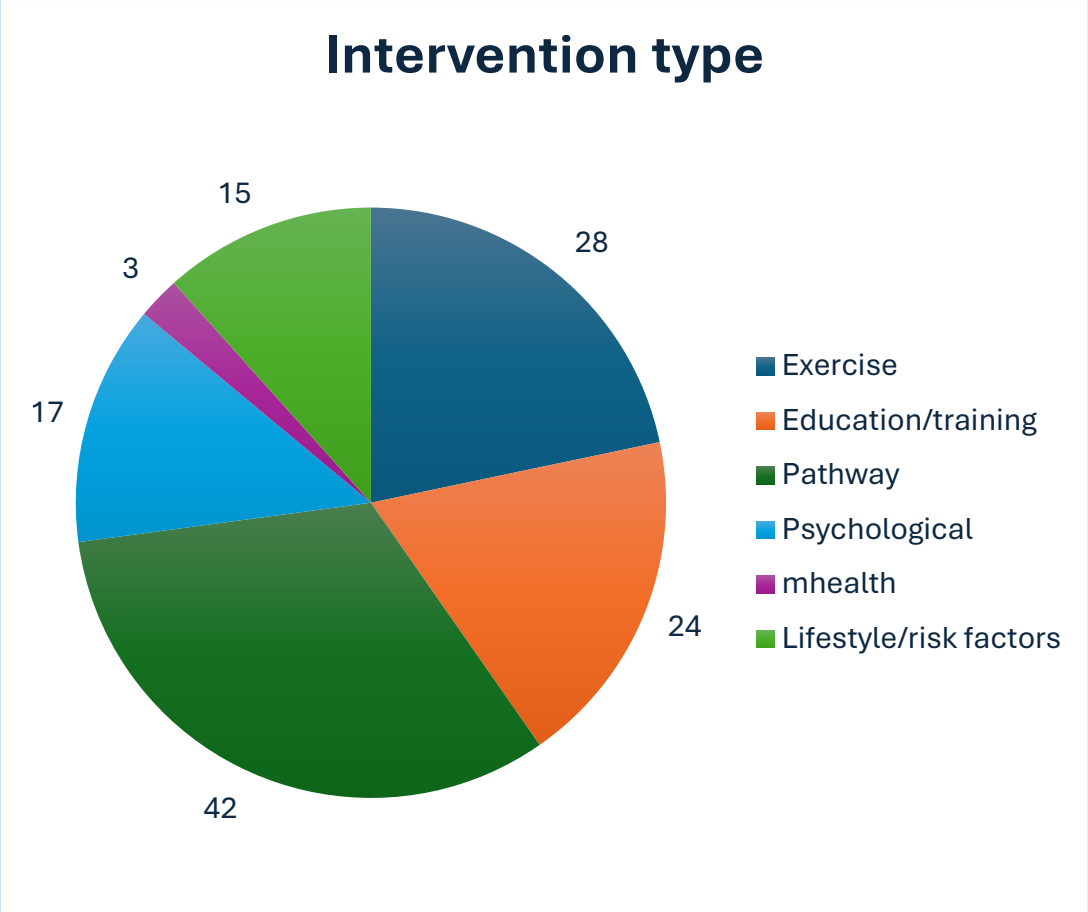


Figure 5 Types of intervention

5.18.4.1 Integrated care pathways or packages

Studies that included pathways or packages comprised multiple components of care. These components included pathways based on national guidelines (Bergh et al., 2023), post-acute care pathways (PAC) (Peng et al., 2017; Bushnell et al., 2021; Chiu et al., 2021; Tung et al., 2021; Chang et al., 2022), exercise, education and training, counselling and psychological/mental health support, lifestyle advice and risk factor management.

In Italy, the stroke recovery program (SRP) was designed to provide a supportive framework for the transition of care from the inpatient hospital setting to an outpatient community level of care. Through structured physician visits, outpatient therapies and a medically supervised interval cardiovascular conditioning protocol, the SRP provided an innovative healthcare delivery model designed to promote stroke rehabilitation and improve medical outcomes (Cuccurullo et al., 2019; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b).

The PAC studies comprised comprehensive multidisciplinary care pathways implemented in patients who were discharged into the community following acute care. For example, the COMPASS-TC intervention was a transitional care model that included education, secondary prevention, rehabilitation, recovery, referrals to community-based resources, and caregiver support services (Duncan et al., 2020). The intervention included telephone follow-up within two business days of hospital discharge and a clinic visit targeted to occur 7 to 14 days post-discharge. Standardised clinical assessments that included social and functional determinates of health informed an individualised care plan (COMPASS-CP), delivered at the point of care (Duncan et al., 2020). The structured ambulatory post-stroke care program for outpatient aftercare in patients with ischaemic stroke in Germany (SANO) study was a 1-year patient-centred integrated care intervention including regular follow-up, lifestyle advice, risk factor control, goal setting and motivational interviewing (Schwarzbach et al., 2023). Details of other PAC studies can be found in Appendix E.

5.18.4.2 Exercise

Several studies that included exercise as an integrated care component implemented the intervention as a managed exercise program or schedule implemented and monitored by HCPs such as physiotherapists (Døhl et al., 2020; Wu et al., 2020; Brouns et al., 2021; Buckley et al., 2021a; Gun Young, 2021; Pedapati et al., 2021a; MacKay-Lyons et al., 2022; Wong et al., 2022b). In some studies, exercise was delivered through early supported discharge or very early mobilisation in hospital or on the stroke unit and comprised sitting, standing, and walking (out-of-bed) activity that was conducted under supervision more often and earlier than for standard

care (Liu et al., 2014; Bernhardt et al., 2015; Langhorne et al., 2017; Brandal et al., 2019; Cumming, 2019; Rafsten, 2019; Rodgers et al., 2019; Lin et al., 2020; Shaw et al., 2020; Huang et al., 2023).

In general, exercise was aimed at improving strength, balance, coordination, mobility, endurance, stability, speech or aerobic capacity (Brouwer et al., 2018; Brouns et al., 2021; Chiu et al., 2021; Wong et al., 2022b). The type of exercise included range of motion (ROM) activities (Chiu et al., 2021; Gun Young, 2021; Pedapati et al., 2021a), stretching (Gun Young, 2021), aerobic exercises and resistance training using bicycles or gym equipment (Cuccurullo et al., 2019; Koch et al., 2020; Brouns et al., 2021). In one study, the exercise centred around horticulture activity motions of specific functional tasks such as reaching–grasping, squatting, stepping, and stooping (Lee et al., 2018). Another study employed activities of daily living as the exercise intervention (Peng et al., 2017).

One study used a battery of standard tests including the timed Up and Go (TUG) test, which requires participants to stand from a seated position on a chair with armrests, walk 3m, turn around, and return to a seated position; the 6-minute walk test (6MWT) for endurance, where participants are instructed to walk as far as possible on an indoor track over 6 minutes with rests as needed, and the distance travelled is recorded; and stair mobility, assessed as the time taken to ascend and descend four stairs of standard rise (17.8cm) and run (27.9cm) dimensions (Brouwer et al., 2018). Two studies focussed on exercise-based cardiac rehabilitation (Cuccurullo et al., 2019; Buckley et al., 2021a).

Information on the intensity and frequency of exercise was not always specified but where data were available this showed that exercise was tailored and the dose delivered according to ability (Cuccurullo et al., 2019; Koch et al., 2020; Brouns et al., 2021; Chiu et al., 2021). Intensity varied from low through moderate to high intensity or vigorous (Askim et al., 2018; Cheng et al., 2018b; Cuccurullo et al., 2019; Døhl et al., 2020) and in some cases increased as patients progressed (Koch et al., 2020; Wong et al., 2022b). Frequency ranged from 2-3 sessions per week to three times daily and duration was between 15 and 90 minutes (Askim et al., 2018; Cheng et al., 2018b; Cuccurullo et al., 2019; Døhl et al., 2020; Lin et al., 2020; Chiu et al., 2021; Jung et al., 2021; Wong et al., 2022b), which may or may not have included additional warm-up or cooldown time (Cuccurullo et al., 2019; Koch et al., 2020; Gun Young, 2021).

In general, exercise interventions were delivered and monitored in person by trained nurses or allied HCPs (namely, nurses, physiotherapists and occupational therapists) (Langhorne et al.,

2017; Peng et al., 2017; Lewthwaite et al., 2018; Cuccurullo et al., 2019; Cumming, 2019; Brouns et al., 2021; Chiu et al., 2021). In most cases, patients performed the exercise individually, either at home or in rehabilitation centres however some studies delivered the intervention in a group setting (Teuschl et al., 2017; Askim et al., 2018; Cuccurullo et al., 2019; Døhl et al., 2020) and others used video or virtual reality to deliver remote exercise programs (Lin et al., 2020; Jung et al., 2021; Pedapati et al., 2021a).

The overall duration of the exercise intervention was generally between 4 and 16 weeks (Lewthwaite et al., 2018; Gun Young, 2021; Jung et al., 2021; Wong et al., 2022b) but varied widely from as little as 14 days or until discharge from the acute stroke unit, whichever was sooner for very early mobilisation (Langhorne et al., 2017; Cumming, 2019) to 24 months (Teuschl et al., 2017).

Further details of exercise interventions can be found in Appendix E.

5.18.4.3 Education and training

Educational and training components of integrated care included rehabilitation training for patients and/or their carers delivered both in hospital/rehabilitation ward (Chen et al., 2017; Liu, 2018; Kalav et al., 2022; Mohammadi et al., 2022) and after discharge during periods of follow-up for up to 12 months (Nayeri et al., 2014; Saal et al., 2015; Cheng et al., 2018a; Liu, 2018; Zhang et al., 2019; Fu et al., 2020; Kalav et al., 2022; Mohammadi et al., 2022). In some studies, caregivers were educated separately and given training on how best to care for their patients (Nayeri et al., 2014; Zhang et al., 2019). In other studies, educational interventions were delivered face-to-face by trained HCPs (including nurses, physicians, pharmacists and community health workers) either in the hospital or the patient's home (Long Weijan and Zhang, 2017; Olaiya et al., 2017b; Xi, 2017; Zhang et al., 2019; Chu et al., 2020; Pedapati et al., 2021a; Towfighi et al., 2021; Vluggen, 2021; Kalav et al., 2022; Mohammadi et al., 2022).

Education on lifestyle and addressing the risk factors for stroke (for example Life's Simple 7 [now updated to Life's Simple 8]) which included the following: smoking cessation, weight management, physical activity, optimal nutrition, cholesterol control, blood pressure management and blood sugar control (Cuccurullo et al., 2022b)) was common in studies, (Nayeri et al., 2014; Saal et al., 2015; Olaiya et al., 2017b; Deng et al., 2020; Duncan et al., 2020; Pedapati et al., 2021a; Wang et al., 2021; Kalav et al., 2022), as was self-care (Chu et al., 2020; Deng et al., 2020; Duncan et al., 2020; Minshall et al., 2020; Towfighi et al., 2021; Wang et al., 2021; Lo et al., 2023). The importance of medication adherence was stated in some

studies (Towfighi et al., 2021; Wang et al., 2021). Advice on seeking community support services was also provided (Brouwer et al., 2018; Duncan et al., 2020).

Education and training resources were sometimes provided as printed materials (workbooks and booklets) (Nayeri et al., 2014; Cheng et al., 2018a; Duncan et al., 2020; Fu et al., 2020; Minshall et al., 2020; Pedapati et al., 2021a; Kalav et al., 2022) and in other studies, education and training was delivered online through the use of email, social platforms or specifically designed websites (Saal et al., 2015; Fu et al., 2020; Wang et al., 2021; Demir Avci and Gözüm, 2023; Lo et al., 2023).

5.18.4.4 Psychological interventions

Psychological interventions in studies included screening for depression (Abdul Aziz et al., 2020), dialogue-based interventions which comprised counselling sessions to identify problems and promote psychosocial wellbeing (Gao et al., 2017; Hjelle et al., 2019; Reeves et al., 2019; Ahmadi et al., 2020; Bragstad et al., 2020; Minshall et al., 2020; Wong et al., 2022b). Other studies used cognitive training, focussing on improving concentration, logic, memory, processing speed and executive function (Gao et al., 2017; Cheng et al., 2018a; Yu et al., 2019; Koch et al., 2020; Brouns et al., 2021). Two studies employed the use of motivational training (Lewthwaite et al., 2018; Mohammadi et al., 2022), one study sought to improve psychosocial wellbeing using art classes (Ellis-Hill et al., 2019) and in one study pharmacological therapy (citalopram) was administered in an attempt to reduce depression (Gao et al., 2017).

These interventions were delivered in person by psychologists or other HCPs (such as nurses, therapists or social workers with suitable training) (Gao et al., 2017; Cheng et al., 2018a; Lewthwaite et al., 2018; Hjelle et al., 2019; Reeves et al., 2019; Yu et al., 2019; Bragstad et al., 2020; Wong et al., 2022b) and in some cases, group activities were performed in order to encourage patients to interact with other (Gao et al., 2017; Ellis-Hill et al., 2019).

Psychotherapy sessions ranged in duration from 1-2 hours with a frequency of between three times a week and once a month. The interventions were delivered over a total time period ranging from 14 weeks to 18 months (Gao et al., 2017; Ellis-Hill et al., 2019; Reeves et al., 2019; Yu et al., 2019; Bragstad et al., 2020; Koch et al., 2020; Minshall et al., 2020).

5.18.4.5 mHealth

Three studies used a mobile health (mHealth) based platform to deliver integrated care. The system-integrated and technology-enabled model of care (SINEMA) was a mobile app-based intervention aimed at stroke survivors in rural China, where stroke rehabilitation resources

were limited (Yan et al., 2021). Brouns and colleagues used a comprehensive digital eRehabilitation intervention which included cognitive/physical exercises, activity-tracking and psycho-education using a platform known as Fast@home, accessed either with a smartphone, laptop/PC or tablet (Brouns et al., 2021). One of the three components in the intensive patient care program (IPCP) study was a mobile app using a software platform called WeChat, which encouraged stroke patients to communicate both with the healthcare team and with other patients (Yu et al., 2019).

5.18.4.6 Lifestyle and risk factors

A total of 15 studies included addressing stroke risk factors and encouraging stroke survivors to adopt healthier lifestyles in order to reduce the risk of recurrent stroke or other complications. The interventions focussed on risk factors such as blood pressure, diabetes, cholesterol, smoking and alcohol use. The interventions were delivered by HCPs such as nurses, doctors, pharmacists and community health workers either in person or by telephone using educational materials and counselling or motivational interviewing sessions (Teuschl et al., 2017; Bath et al., 2018; Cheng et al., 2018b; Geng et al., 2019; Ahmadi et al., 2020; Dello et al., 2021). Regular monitoring of blood pressure, blood sugar, cholesterol and lipids was performed in some studies and measured against secondary prevention targets (Bath et al., 2018; Sharma et al., 2019; Ahmadi et al., 2020; Joubert et al., 2020; Towfighi et al., 2021; Luengo-Fernandez et al., 2022). In some studies, participants engaged in managed exercise programmes (Teuschl et al., 2017; Cuccurullo et al., 2019; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b) or were offered advice on healthy eating and nutrition (Teuschl et al., 2017; Cumming, 2019; Geng et al., 2019; Ahmadi et al., 2020; Greger et al., 2021). Several studies assessed the impact of antiplatelet and/or antithrombotic treatment over time on rates of subsequent stroke or cardiovascular complications (Bath et al., 2018; Sharma et al., 2019; Luengo-Fernandez et al., 2022).

The total duration over which the interventions were delivered was generally longer than that of other types of interventions and was typically 12 months (Cuccurullo et al., 2019; Joubert et al., 2020; Greger et al., 2021; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b) but ranged from 72 hours (Dello et al., 2021) in the case of a short study to improve management of blood glucose levels, body temperature and dysphagia to as long as 10 years in a study that evaluated the impact of long-term anticoagulant/antiplatelet treatment on secondary prevention (Luengo-Fernandez et al., 2022).

5.18.5 Risk of bias assessment

Risk of bias was conducted in duplicate with RCTs and NRCTs analysed separately using the Cochrane v.2 (RoB2) (Sterne et al., 2019) and the Risk Of Bias In Non-randomised Studies – of Interventions (ROBINS-I) tools (Sterne et al., 2016), respectively. Risk of bias assessments were conducted by I.E. in parallel with I.K., K.H. or M.F-R. The findings for each study were discussed, debated where necessary and agreed prior to including in a risk of bias summary table.

RCTs Of the 64 RCTs, 10 were at low risk of bias, 33 were moderate risk and 21 studies were at high risk of bias due to small numbers, study design, confounding factors or missing data. A full summary of risk of bias assessment for RCTs is provided in Appendix F Figure S1.

NRCTs Of 35 NRCTs, 20 were considered at moderate risk of bias and 15 studies were at high risk of bias. A full summary of risk of bias assessment for NRCTs is provided in Appendix F Figure S2.

5.18.6 Studies demonstrating a positive benefit in favour of integrated care

Of the 99 studies in the review, 66% showed a positive benefit in favour of integrated care and these are summarised below.

5.18.6.1 Primary outcomes

5.18.6.1.1 Mortality

A total of 24 studies included mortality as an endpoint, of which 8 (33%) demonstrated a benefit in favour of integrated care. The Italian stroke recovery program (SRP) was a prospective cohort study of a comprehensive integrated care package comprising home visits, outpatient therapy, modified cardiac rehabilitation, risk factor management and lifestyle advice (Cuccurullo et al., 2019; Cuccurullo et al., 2022b). A feasibility study of SRP in 142 participants demonstrated a reduction in 1-year mortality of 13.9% versus control (HR 0.11, SE = 1.07 [95% CI: 0.01 to 0.90], P = 0.039) (Cuccurullo et al., 2019). A later analysis of an enhanced SRP with a higher number of participants (n=449) demonstrated an even greater benefit on mortality reduction in favour of integrated care (RR 0.24 [95% CI: 0.08 to 0.71], P = 0.0046) (Cuccurullo et al., 2022b). Further details of these studies can be found in Appendix G.

5.18.6.1.2 Recurrent stroke

Fourteen studies included in the review evaluated recurrent stroke as an outcome, with three showing a positive benefit in favour of integrated care. Of these studies, one was at low risk of bias (Sharma et al., 2019) and two were considered moderate risk of bias (Buckley et al., 2021a;

Luengo-Fernandez et al., 2022) The prospective, population-based (before/after) EXPRESS study of rapid assessment and treatment initiation with high-dose aspirin or clopidogrel and intensive and regular follow-up demonstrated a reduction in stroke risk and disability (defined as mRS ≥2) even after 10 years (Luengo-Fernandez et al., 2022). Similarly, the double-blind, randomised, double dummy COMPASS study of combined anticoagulant and antiplatelet therapy significantly reduced the risk of ischaemic/unknown stroke in 1,032 patients with prior stroke (HR, 0.33 [95% CI: 0.14 to 0.77], P = 0.01) (Sharma et al., 2019). A retrospective observational study of exercise-based cardiac rehabilitation in 5,818 propensity-match participants demonstrated a 12% reduction in the odds of recurrent stroke in favour of the intervention (OR 0.88 [95% CI 0.79 to 0.98]) (Buckley et al., 2021a). Conversely, 11/14 (79%) of studies in this analysis showed no difference in recurrent stroke rates between integrated care and control despite the observation that none of them were at high risk of bias (two were low risk and nine were moderate risk). Of these 11 studies, eight were RCTs (Saal et al., 2015; Bath et al., 2018; Cheng et al., 2018b; Reeves et al., 2019; Ahmadi et al., 2020; Fu et al., 2020; Willeit et al., 2020; Schwarzbach et al., 2023) and three were NRCTs (Mofidi et al., 2018; Nguyen-Huynh et al., 2018; Reeves et al., 2019; Deutschbein et al., 2020).

5.18.6.1.3 Major bleeding

A total of six studies included major bleeding as an outcome. Amongst these studies were the INSPiRE-TMS, an open-label, multicentre, international randomised controlled trial of a support programme which included counselling, lifestyle changes, and support for medication adherence with 2-year follow-up (Ahmadi et al., 2020); the Triple Antiplatelets for Reducing Dependency after Ischaemic Stroke (TARDIS) study of intensive antiplatelet versus guideline antiplatelet therapy (Bath et al., 2018); the structured ambulatory post-stroke care program (SANO) study, a 1-year patient-centred integrated care intervention including regular follow-up, lifestyle advice, goal setting and motivational interviewing (Schwarzbach et al., 2023); and the STROKE-CARD study, a comprehensive disease management program delivered by a multidisciplinary team that included risk factor management and patient education (Willeit et al., 2020). Despite the robust design of these studies, only the COMPASS study showed a significant reduction in the risk of major bleeding with rivaroxaban compared with aspirin (HR 3.84 [95% CI: 1.08 to 13.6], P = 0.04) (Sharma et al., 2019). Further details of these studies can be found in Appendix G.

5.18.6.2 Secondary outcomes

5.18.6.2.1 Quality of life

Quality of life was the most studied outcome in the review, being evaluated in 37/99 studies. Many of these studies were robust and well-designed including INSPIRE-TMS (Ahmadi et al., 2020); TARDIS (Bath et al., 2018); EXPRESS (Luengo-Fernandez et al., 2022); AVERT (Langhorne et al., 2017; Cumming, 2019); the Accelerated Skill Acquisition Program (ASAP) comprising skill acquisition through task-specific practice, impairment mitigation to increase capacity, and motivational enhancements to build self-confidence (Lewthwaite et al., 2018) The Michigan Stroke Transitions Trial (MISTT) was a home-based social worker–led case management (SWCM) program with or without a website, comprising biopsychosocial assessment followed by development of a personalised plan to address unmet needs (Reeves et al., 2019). The Early supported discharge reviews (EXTRAS) trial included mobility, self-care, mood, and cognitive function interventions (Rodgers et al., 2019; Shaw et al., 2020); other studies included STROKE-CARD (Willeit et al., 2020); and the SINEMA study of mHealth (Yan et al., 2021). The majority of other studies were of non-randomised design, many of which had small numbers of participants (less than 100 in total) and which placed them at moderate-to-high risk of bias (Wong and Yeung, 2015; Jones et al., 2016; Long Weijan and Zhang, 2017; Xi, 2017; Liu, 2018; Geng et al., 2019; Chu et al., 2020; Deng et al., 2020; Markle-Reid et al., 2020; Wu et al., 2020; Kalav et al., 2022; Mohammadi et al., 2022; Wong et al., 2022b).

A total of 16 studies showed an improvement in quality of life (QoL) in favour of integrated care and in 14 studies the differences between groups were statistically significant ($P < 0.05$) (Wong and Yeung, 2015; Long Weijan and Zhang, 2017; Xi, 2017; Lewthwaite et al., 2018; Liu, 2018; Geng et al., 2019; Reeves et al., 2019; Fu et al., 2020; Willeit et al., 2020; Khramov et al., 2021; Yan et al., 2021; Mohammadi et al., 2022; Wong et al., 2022b; He et al., 2023). It is important to note that of these 14 studies, the majority (13) were RCTs (Wong and Yeung, 2015; Long Weijan and Zhang, 2017; Xi, 2017; Lewthwaite et al., 2018; Liu, 2018; Geng et al., 2019; Reeves et al., 2019; Fu et al., 2020; Willeit et al., 2020; Khramov et al., 2021; Yan et al., 2021; Mohammadi et al., 2022; Wong et al., 2022b) and 6 were considered at high risk of bias and excluded from the meta-analysis (Long Weijan and Zhang, 2017; Xi, 2017; Liu, 2018; Khramov et al., 2021; Mohammadi et al., 2022; He et al., 2025). Further details of these studies can be found in Appendix G.

5.18.6.2.2 Readmission

Sixteen studies in the review evaluated readmission as an outcome, of which nine (56%) showed a benefit in favour of integrated care. Beneficial interventions included interviews and web-based training for caregivers and patients (Demir Avci and Gözüm, 2023), exercise-based cardiac rehabilitation (Buckley et al., 2021a), PAC (Peng et al., 2017), individualised care packages including transitional care (Chen et al., 2016; Deutschbein et al., 2020), the Italian SRP (Cuccurullo et al., 2022a), internet-based home care (Lu et al., 2023b), and care/education programs delivered by nurses or pharmacists (Swanson, 2019; Wang et al., 2021). Of these nine studies, the difference was significant in eight ($P < 0.05$), with significance not being stated in one study (Demir Avci and Gözüm, 2023). Two of these studies were RCTs (Wang et al., 2021; Demir Avci and Gözüm, 2023) and seven were non-randomised or propensity-matched cohort studies (Chen et al., 2016; Peng et al., 2017; Swanson, 2019; Deutschbein et al., 2020; Buckley et al., 2021a; Cuccurullo et al., 2022a; Lu et al., 2023b). All nine studies were assessed as moderate risk of bias. Further details of these studies can be found in Appendix G.

5.18.6.2.3 Anxiety and depression

Anxiety and depression were the second-most frequently assessed outcomes in the review, with 28 studies evaluating anxiety, depression or both as an outcome. The larger, more robust studies that assessed anxiety/depression included the Program of Rehabilitative Exercise and Education to Avert Vascular Events After Non-Disabling Stroke or Transient Ischemic Attack (PREVENT) trial, a multi-modal, case-managed program of exercise and education (MacKay-Lyons et al., 2022); early supported discharge interventions (Brandal et al., 2019; Rodgers et al., 2019; Shaw et al., 2020); and the COMPASS-TC trial (Duncan et al., 2020).

A number of validated depression and anxiety scoring tools were used including the Hospital Anxiety and Depression Score-Anxiety/Depression subscales (HADS-A, HADS-D) (Jones et al., 2016; Cheng et al., 2018a; Ellis-Hill et al., 2019; Rafsten, 2019; Rodgers et al., 2019; Yu et al., 2019; Zhang et al., 2019; Minshall et al., 2020; Shaw et al., 2020; MacKay-Lyons et al., 2022), Zung's Self-rating Anxiety Scale (SAS) and Self-rating Depression Scale (SDS) (Liu et al., 2014; Cheng et al., 2018a; Zhang et al., 2019; Feng et al., 2021), Geriatric Depression Score (GDS) (Saal et al., 2015; Graven et al., 2016; Lee et al., 2018; Lo et al., 2023), Patient Health Questionnaire two or nine-item scale (PHQ-2, PHQ-9) (Reeves et al., 2019; Abdul Aziz et al., 2020; Duncan et al., 2020), Yale-Brown single item questionnaire (Hjelle et al., 2019; Bragstad et al., 2020), Beck depression inventory (BDI: Gun Young, 2021; Jung et al., 2021; Khramov et al., 2021), Short Form 36 (SF-36) Mental Component Summary (MCS) (Wong and Yeung,

2015; Jung et al., 2021), Warwick-Edinburgh Mental Well-being Scale (Ellis-Hill et al., 2019), Hamilton Depression (HAMD) 17-item scale (Gao et al., 2017), Bech-Rafaelsen Melancholia Scale (MES) (Gao et al., 2017), Centre for Epidemiologic Studies Depression Scale (CES-D) (Teuschl et al., 2017), and patient-reported outcome measures (PROMS) (Brandal et al., 2019).

The Hospital Anxiety and Depression Score (HADS) is a validated 14-item, self-administered questionnaire for screening and measuring the severity of anxiety and depression symptoms in patients, particularly those with physical illnesses. It consists of two subscales; one for anxiety and one for depression, each subscale with 7 items rated on a 4-point Likert scale. Scores for each subscale range from 0 to 21, with higher scores indicating greater severity, and specific cut-off points help interpret results as mild (8-10), moderate (11-14), or severe (15-21) (Zigmond and Snaith, 1983; Stern, 2014).

Zung's self-rating depression and anxiety scales are 20-item questionnaires designed to measure the impact of anxiety and depression. Similar to HADS, each scale uses a 4-point Likert scale. Ranges for mild, moderate, and severe depression or anxiety are 50–59, 60–69, and over 70, respectively (Zung, 1965; Zung, 1971).

The Geriatric Depression Scale (GDS) is a 15- or 30-item scale for rating depression in older people using yes/no answers for each question (Yesavage et al., 1982). The 15-item scale is equally effective and is used in preference to the 30-item scale, with scores of 5-8, 9-11 and 12-15 indicating mild, moderate and severe depression, respectively (Conradsson et al., 2013).

The Patient Health Questionnaire 2- and 9-item scales are self-administered tools to assess depression. The PHQ-2 comprises the first two items of the PHQ-9 and its purpose is to inquire about the degree to which an individual has experienced depressed mood over the past two weeks. Those individuals who screen positive for PHQ-2 should be further evaluated with the PHQ-9 to determine whether they meet criteria for a depressive disorder (Gilbody et al., 2007). PHQ-9 scores each of the 9 DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, fourth edition) criteria as "0" (not at all) to "3" (nearly every day). Scores of 5, 10, 15, and 20 represent mild, moderate, moderately severe, and severe depression, respectively (Kroenke et al., 2001; Gilbody et al., 2007).

The Yale-Brown single item questionnaire for depression is part of the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) and asks whether an individual feels sad or depressed, with a simple yes/no answer (Watkins et al., 2007). The Beck Depression Inventory (BDI) is a 21-item self-reporting questionnaire for evaluating the severity of depression in normal and

psychiatric populations. Each item is ranked on a 4-point scale from 0 (symptom absent) to 3 (severe symptoms), with scores ranging from 0-63. In those individuals diagnosed with depression, scores of 14-19, 20-28 and 29-63 indicate mild, moderate and severe depression, respectively (Jackson-Koku, 2016).

The Short-Form 36-item scale (SF-36) is a health survey covering a total of eight domains with scale score ranges from 0 to 100 (percent of maximum sum score), covering four physical health perceptions (physical functioning—PF, role limitations because of physical health problems—RP, bodily pain—BP, general health—GH), and four mental health concepts (vitality—VT, social functioning—SF, role limitations because of personal or emotional problems—RE, and mental health perceptions—MH) (Grassi et al., 2010). The mental component summary (MCS) of the SF-36 measures a person's mental health and emotional well-being by combining scores from four of its eight subscales: Vitality, Social Functioning, Role-Emotional, and Mental Health. Total scores range from 0-100, with scores above 50 indicating better mental health (Ding et al., 2021).

The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) is a 14-item scale, with each item scoring between 1 (none of the time) to 5 (all of the time), resulting in a total score of 14-70. Higher scores indicate higher levels of positive mental well-being (Tennant et al., 2007).

The Hamilton Depression Rating Scale (HAM-D or HDRS) is a 17-21 item clinician administered questionnaire, with the first 17 items measuring symptoms experienced over the past week and the additional four items identifying a subtype of depression (Renemane and Vrublevska, 2021). It is scored between 0 (not present) and 4 (severe) points using either a three-point or a five-point scale and summed up to obtain the total score. Total scores of 8-16, 17-23 and ≥24 indicate mild, moderate and severe depression, respectively (Renemane and Vrublevska, 2021).

The Bech-Rafaelsen Melancholia Scale (MES) is an 11-item, observer-rated scale used to measure the severity of depression, in particular melancholic states, and to assess a patient's response to treatment, originally developed from the HDRS (Bech, 2002). It comprises items assessing various depressive symptoms with item being rated on a 5-point scale, rated 0 (not present) to 4 (description varies between each item but indicates severe or constant symptoms), with a range of 0-44. Scores of 11-14, 15-24 and 25-44 indicate mild, moderate and severe depression, respectively (2012).

The Center for Epidemiologic Studies Depression Scale (CES-D) is a 20-item self-reporting questionnaire, with each item rated on a four-point Likert scale from 0 (rarely or some of the time) to 3 (most or all of the time), giving a score range of 0-60, with higher scores indicating worse mental health (Radloff, 1977). A cut-off score of 16 on CES-D is normally considered indicative of clinical depression (Covic et al., 2007).

Patient-Reported Outcome Measures (PROMS) is a tool used to collect information about a patient's own health and quality of life status before and after they receive treatment for a chronic condition. The questions are spread across two surveys, completed before and after treatment, and include symptom reporting, satisfaction with care and treatments, self-rated health, and health-related quality of life (Jones et al., 2007). The value of PROMS is that it provides insight into the effectiveness of healthcare interventions for patients and supports the reduction of healthcare inequalities (NHS England Digital, 2025).

A total of 9/28 (32%) studies were considered to be at high risk of bias (Gao et al., 2017; Cheng et al., 2018a; Lee et al., 2018; Ellis-Hill et al., 2019; Yu et al., 2019; Zhang et al., 2019; Minshall et al., 2020; Jung et al., 2021; Khramov et al., 2021) and were excluded from the meta-analyses. Fifteen of 28 studies (54%) showed a positive benefit in favour of integrated care either in reduced numbers of participants reporting anxiety/depression or in reduced scores for anxiety/depression. In both cases this indicated an improvement through the interventions and in 11 studies the differences between groups were statistically significant ($P < 0.05$) (Liu et al., 2014; Wong and Yeung, 2015; Graven et al., 2016; Teuschl et al., 2017; Cheng et al., 2018a; Lee et al., 2018; Brandal et al., 2019; Yu et al., 2019; Zhang et al., 2019; Lin et al., 2020; Feng et al., 2021; Gun Young, 2021; Khramov et al., 2021; MacKay-Lyons et al., 2022; Lo et al., 2023). Of note, two studies that assessed anxiety/depression at two different timepoints (3/months and 12/24 months) reported that the differences in favour of integrated care were significant at the first timepoint but were not significant at the second timepoint (Teuschl et al., 2017; MacKay-Lyons et al., 2022). Interventions that were associated with significant reductions in anxiety/depression included ESD (Liu et al., 2014; Brandal et al., 2019), lifestyle advice, risk factor management, exercise, education, cognitive training (Teuschl et al., 2017; Cheng et al., 2018a; Lin et al., 2020; Gun Young, 2021; Khramov et al., 2021; MacKay-Lyons et al., 2022; Lo et al., 2023), inpatient horticulture (Lee et al., 2018), transitional care programs (Wong and Yeung, 2015) and individualised integrated care pathways delivered by healthcare providers (Graven et al., 2016; Feng et al., 2021). Further details of these studies can be found in Appendix G.

5.18.6.2.4 Lifestyle and risk factors

Eleven of 99 studies evaluated cardiovascular risk factors or lifestyle advice as outcomes, 10 of which were RCTs. The single NRCT was a retrospective review of pharmacist-led medication advice and was the only study considered to be at high risk of bias (Greger et al., 2021). The RCTs included TARDIS (Bath et al., 2018), ICARUSS (Joubert et al., 2020), PREVENT (MacKay-Lyons et al., 2022), SANO (Schwarzbach et al., 2023) and SUCCEED, a multifactorial pathway comprising tailored educational materials; vascular risk factor goal tools; and Chronic Disease Self-Management Program (CDSMP) workshops, medication adherence and self-management delivered by Advanced practice physician (APC) and community health workers (CHW) (Towfighi et al., 2021).

Interventions included blood pressure control (Olaiya et al., 2017b; Teuschl et al., 2017; Cheng et al., 2018b; Geng et al., 2019; Towfighi et al., 2021), lipid management (Olaiya et al., 2017b; Teuschl et al., 2017; Cheng et al., 2018b; Geng et al., 2019; Towfighi et al., 2021), lifestyle advice (Teuschl et al., 2017; Geng et al., 2019; Greger et al., 2021), education (Olaiya et al., 2017b; Towfighi et al., 2021), exercise (Olaiya et al., 2017b; Teuschl et al., 2017; Cheng et al., 2018b; Towfighi et al., 2021), alcohol and tobacco use (Olaiya et al., 2017b; Teuschl et al., 2017; Cheng et al., 2018b; Geng et al., 2019; Towfighi et al., 2021), cognitive training (Teuschl et al., 2017), and medication adherence (Greger et al., 2021).

Despite comprehensive evaluation of lifestyle and cardiovascular risk factors, only one study reported significant differences for all of the parameters measured (Greger et al., 2021) however this study was at high risk of bias, so it was not included in the meta-analysis, and there were only 30 participants in each group. Multiple significant beneficial effects were observed in three other studies (Teuschl et al., 2017; Geng et al., 2019; MacKay-Lyons et al., 2022) however these benefits were not observed across all parameters and the beneficial effects of one study at 12 months were diminished at 24 months (Teuschl et al., 2017). Of the studies that included alcohol and smoking status, two reported that the incidences of smoking and/or alcohol consumption were significantly lower in the control group (Teuschl et al., 2017; Geng et al., 2019). Further details of these studies can be found in Appendix G.

5.18.6.2.5 Adherence to intervention

Six studies included adherence to intervention as an outcome (Chen et al., 2016; Jones et al., 2016; Bath et al., 2018; Ellis-Hill et al., 2019; Koch et al., 2020; Greger et al., 2021), four of which were RCTs. Interventions included arts and health practitioner-led group sessions (Ellis-Hill et al., 2019), combined exercise and cognitive training (Koch et al., 2020), triple

antiplatelet therapy (Bath et al., 2018), home-based transitional care (Chen et al., 2016), a self-management program comprising one-to-one rehabilitation sessions and a stroke workbook (Jones et al., 2016), and pharmacist led medication review, counselling, and risk factor management (Greger et al., 2021). Three studies were at high risk of bias and were not included in the meta-analysis (Ellis-Hill et al., 2019; Koch et al., 2020; Greger et al., 2021).

All six studies showed improved adherence to intervention in favour of integrated care with adherence rates of between 14% to 98% in the intervention groups compared with 3% to 79% in the control groups. These differences were statistically significant in four studies ($P < 0.01$) (Chen et al., 2016; Bath et al., 2018; Koch et al., 2020; Greger et al., 2021) however it is worth noting that in the TARDIS study, the significant difference disappeared at seven days (Bath et al., 2018). Further details of these studies can be found in Appendix G.

5.18.6.3 Exploratory outcomes

5.18.6.3.1 Favourable outcome

A total of 12 studies (of which nine were RCTs) included assessment of functional status using the modified Rankin Scale (mRS). The mRS is an evolution of the Rankin Scale introduced by Rankin in 1957 (Quinn et al., 2008) and has become the primary outcome scale for the majority of acute stroke clinical trials. The mRS is a 7-point scale that measures the degree of functional disability from 0 (no symptoms) to 6 (dead), with a score of 3 indicating moderate disability, with people in this category requiring some help, but able to walk unassisted (Broderick et al., 2017).

These studies included TARDIS (Bath et al., 2018), AVERT (Bernhardt et al., 2015; Langhorne et al., 2017), EXPRESS (Luengo-Fernandez et al., 2022), COMPASS (Sharma et al., 2019) and STROKE-CARD (Willeit et al., 2020). One study was considered to be at high risk of bias and was excluded from the meta-analysis (He et al., 2023).

The way in which mRS data were presented varied substantially between studies; in some cases, mRS was given as a range of scores (for example, 0-1, 2-3, 4-5) (Bath et al., 2018; Bergh et al., 2023), in others mRS was expressed as favourable outcome (mRS ≤2) (Langhorne et al., 2017; Fu et al., 2020; Willeit et al., 2020; Pedapati et al., 2021a) and disability/dependency/death (mRS ≥2) (Dello et al., 2021; Luengo-Fernandez et al., 2022), or mRS could be shown as Mean (SD) values (Sharma et al., 2019; He et al., 2023), making it difficult to compare studies.

Of the 12 studies, six showed an improvement in functional status either as an increase in the proportion of participants with favourable outcome or a reduction in the proportion of patients with death or disability (Rasmussen et al., 2016; Fu et al., 2020; Willeit et al., 2020; Dello et al., 2021; Luengo-Fernandez et al., 2022; He et al., 2023). Of note, the AVERT study of very early mobilisation showed a reduction in the proportion of patients with favourable outcome post-intervention (Bernhardt et al., 2015; Langhorne et al., 2017). Further details of these studies can be found in Appendix G.

5.18.6.3.2 Risk of recurrent cardiovascular disease

Three RCTs (SANO, STROKE-CARD and TARDIS) recorded MI as an outcome (Bath et al., 2018; Willeit et al., 2020; Schwarzbach et al., 2023). Only the STROKE-CARD study reported a significantly reduced risk of MI in the intervention group at 12 months (HR, 0.32 [95% CI: 0.13 to 0.80, P = 0.014) (Willeit et al., 2020).

Three RCTs (INSPiRE-TMS, STROKE-CARD and TARDIS) recorded vascular death as an outcome (Bath et al., 2018; Ahmadi et al., 2020; Willeit et al., 2020). As with MI, only the STROKE-CARD study reported a significantly reduced risk of vascular death in the intervention group at 12 months (HR, 0.32 [95% CI: 0.16 to 0.66, P = 0.002) (Willeit et al., 2020). Further details of these studies can be found in Appendix G.

5.18.7 Meta-analysis

The findings of the meta-analysis are summarised in Table 2 and discussed in detail below.

Table 2 Summary of findings table for meta-analysis of Integrated care studies

Outcomes	Relative effect (95% CI)	Number of participants (studies)	Comments
Primary			
Mortality	RCTs: RR 0.88 (0.70 to 1.12) NRCTs: RR 0.84 (0.47 to 1.51)	23,088 (13) 28,618 (7)	There were fewer death events in the integrated care groups compared with control but no significant overall difference in mortality in RCTs or NRCTs. The only significant difference in death events was observed in a subgroup analysis of long-term mortality in NRCTs (>2 years, 6,799 participants, 3 studies, RR = 0.51, P = 0.02)
Recurrent stroke	RCTs: RR 0.84 (0.69 to 1.02) NRCTs: RR 1.08 (0.64 to 1.82)	12,987 (10) 8,013 (5)	There were fewer recurrent strokes associated with RCTs of integrated care compared with control however this did not reach statistical significance (P = 0.08) There was a significant reduction in recurrent stroke with NRCTs in favour of integrated care (P = 0.007)
Major bleeding	RR 1.35 (0.56 to 3.22)	8,210 (4)	There were more major bleeding events in the integrated care groups compared with

Outcomes	Relative effect (95% CI)	Number of participants (studies)	Comments
			control but the difference was not statistically significant (P = 0.50)
Secondary			
Quality of life	SMD: 0.34 (0.17 to 0.51)	9,953 (14)	Integrated care interventions significantly improved quality of life (P < 0.0001), with the greatest difference in QoL scoring observed with the EQ-5D and SF-36 general health questionnaire scoring tools
Unplanned readmission	RCTs: RR 0.92 (0.78 to 1.09) NRCTs: RR 0.76 (0.37 to 1.57)	6,956 (9) 6,370 (5)	There were fewer unplanned readmission events associated with integrated care interventions however the differences were not significant in either RCTs (P = 0.34) or NRCTs (P = 0.34)
Anxiety and depression	Depression: RR 0.95 (0.91 to 0.99)	31,226 (6)	The proportion of patients with depression was significantly lower with integrated care compared with control (P = 0.0002)
Lifestyle and cardiovascular risk factors	SMD -0.17 (-0.25 to -0.09)	4,538 (9)	Overall, integrated care was associated in a significant improvement in cardiovascular risk factors (P < 0.0001), with significant reductions in SBP and LDL-cholesterol (both P ≤ 0.03) however there were no differences between groups for total cholesterol, BMI or the proportion of patients stopping smoking.
Adherence to intervention	RR 1.27 (0.70 to 2.29)	3,515 (3)	Integrated care was associated with higher rates of adherence compared with control however the difference was not statistically significant (P = 0.43)
Exploratory			
Favourable outcome (mRS ≤2)	RR 1.02 (0.98 to 1.07)	4,751 (4)	There was no difference in the proportion of patients with favourable outcome between integrated care and control (P = 0.35)
Recurrent risk of cardiovascular disease:			There were fewer events of myocardial infarction and vascular death associated with integrated care however these differences were not statistically significant (MI, P=0.07; vascular death, P=0.30)
Myocardial infarction	RR 0.60 (0.34 to 1.05)	7,733 (3)	
Vascular death	RR 0.58 (0.21 to 1.60)	4,221 (2)	

BMI, body mass index; CI, confidence interval; HADS-A, hospital anxiety and depression scale-anxiety component; LDL, low density lipoprotein; MI, myocardial infarction; mRS, modified Rankin Scale; NRCT, nonrandomised controlled trial; RCT, randomised controlled trial, RR, risk ratio; SBP. Systolic blood pressure; SMD, standardised mean difference.

5.18.7.1 Primary outcomes

5.18.7.1.1 Mortality

Meta-analyses of mortality for RCTs (Figure 6) and NRCTs (Figure 7) are presented below. Each analysis includes all eligible studies and compared integrated care with control or standard treatment for each outcome.

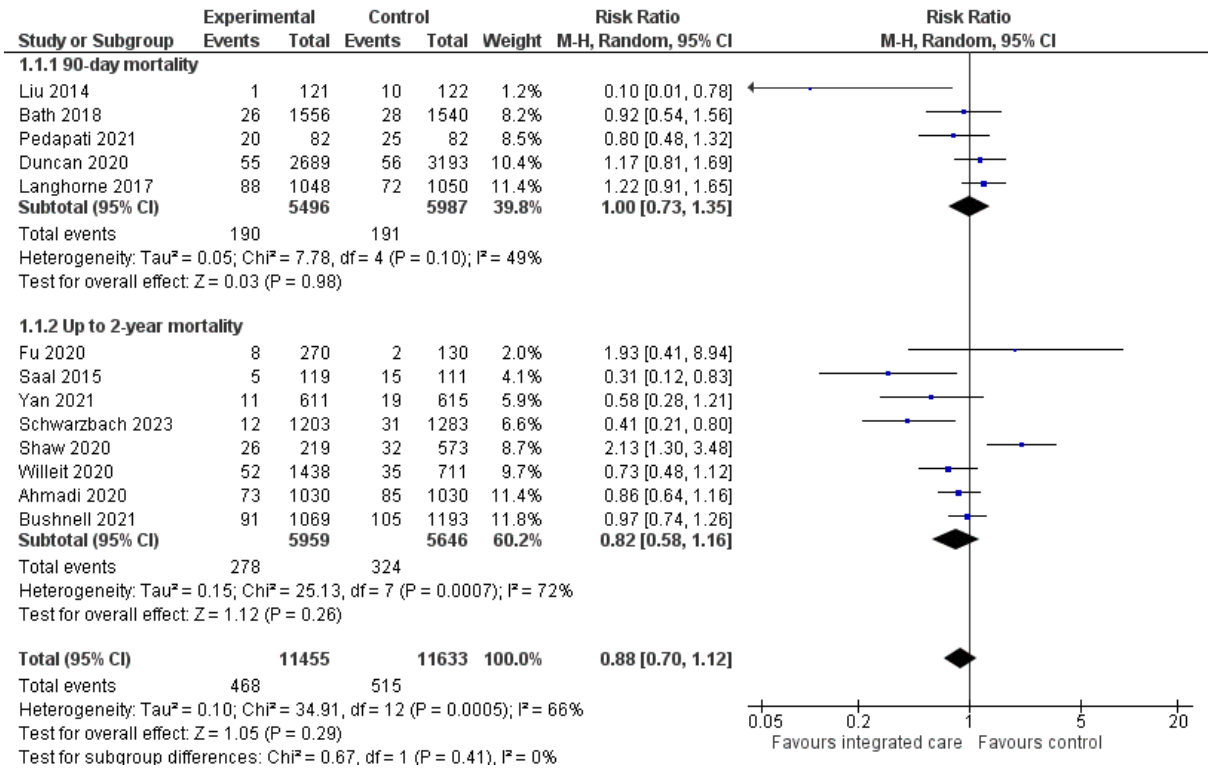


Figure 6 Forest plot of mortality: RCTs

A total of 13 (n=23,088) RCTs compared integrated care with control for mortality. Compared with control, integrated care was not associated with reduced mortality (RR 0.88, 95% CI: 0.70 to 1.12, I^2 = 66%, P = 0. 29). This was regardless of short-term (90-days) and long-term (up to 1 year) analysis of mortality.

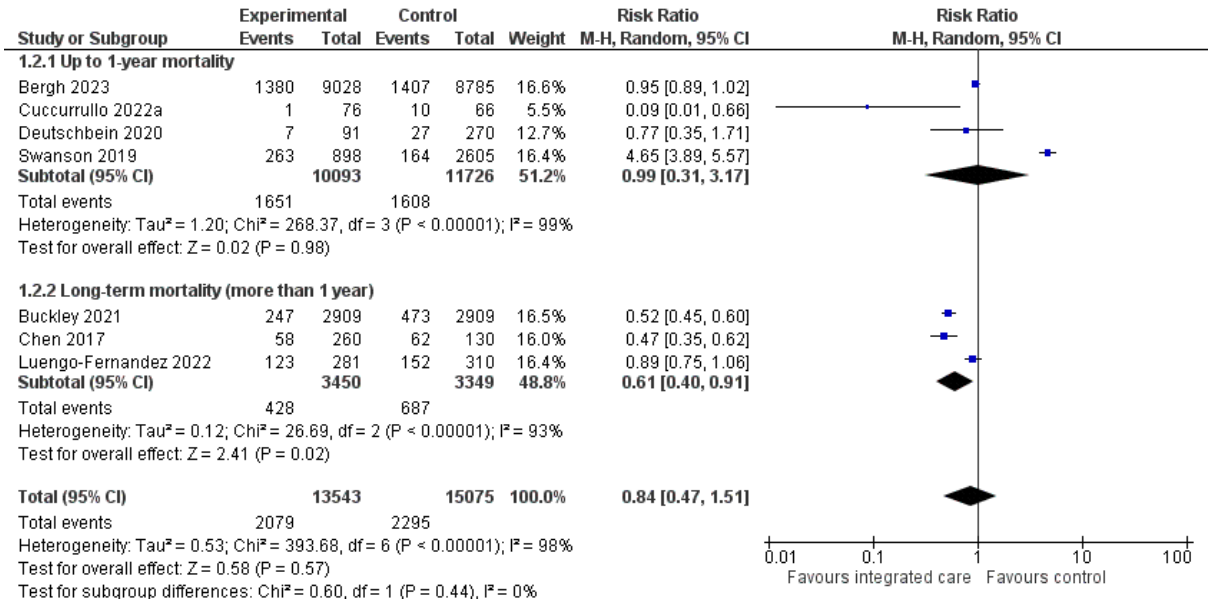


Figure 7 Forest plot of mortality: NRCTs

A meta-analysis of mortality in 7 (n=28,618) NRCTs also showed no overall reduction in mortality with integrated care (RR 0.84 [95% CI: 0.47 to 1.51], I^2 = 98%, P = 0.57). Sub-group analysis indicated a significant reduction in long-term (>2 year) mortality in favour of integrated care (RR 0.61 [95% CI: 0.40 to 0.91], I^2 = 93% P = 0.02) however there were only 3 studies (n=9,404) included in this analysis (Figure 7).

5.18.7.1.2 Recurrent stroke

Meta-analyses for recurrent stroke are presented for RCTs (Figure 8) and NRCTs (Figure 9) below. A total of 10 (n=12,987) RCTs showed a difference in recurrent stroke in favour of integrated care (RR 0.84 [95% CI: 0.69 to 1.02], I^2 = 42%, P = 0.08, Figure 8) however this difference did not reach statistical significance regardless of follow-up time.

A total of 5 (n=8,013) NRCTs showed a significant reduction in recurrent stroke in favour of integrated care (RR 0.92 [95% CI: 0.87 to 0.98], I^2 = 11%, P = 0.007, Figure 9).

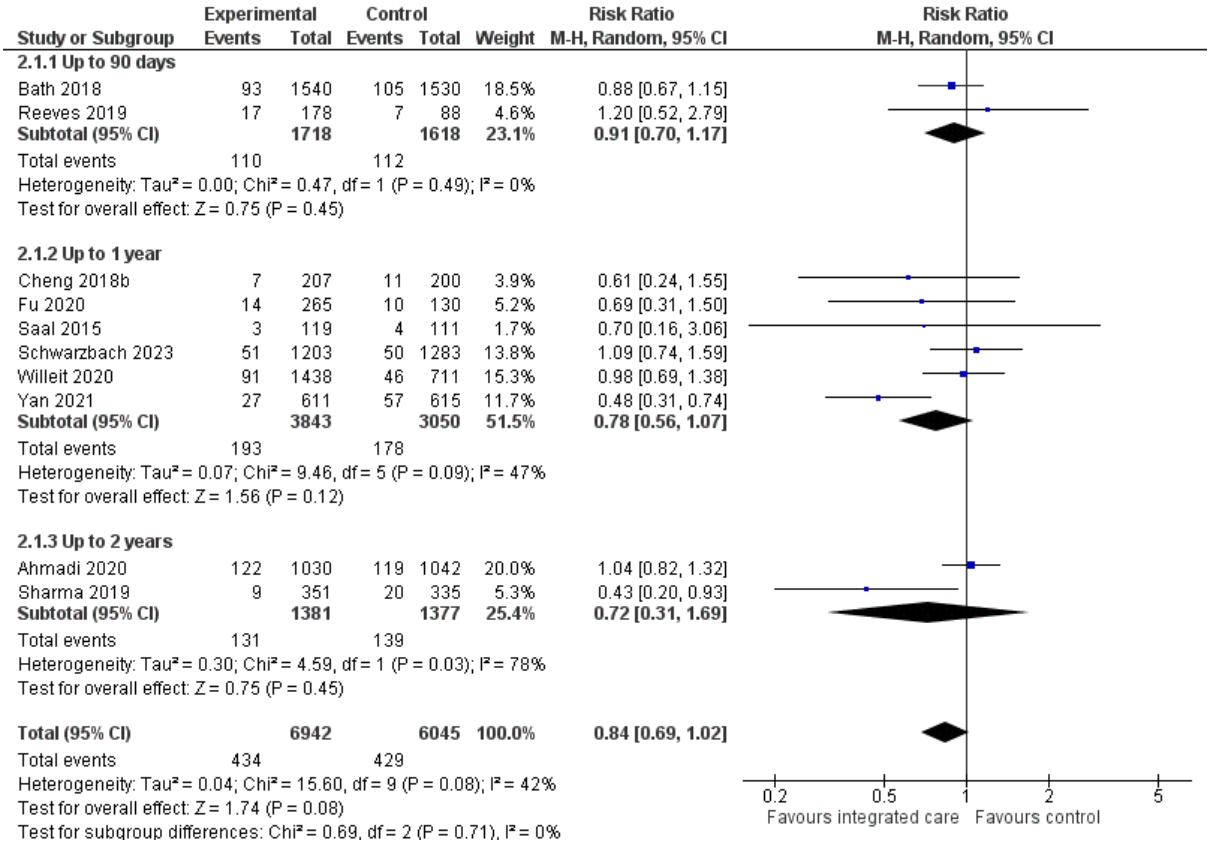


Figure 8 Forest plot of recurrent stroke: RCTs

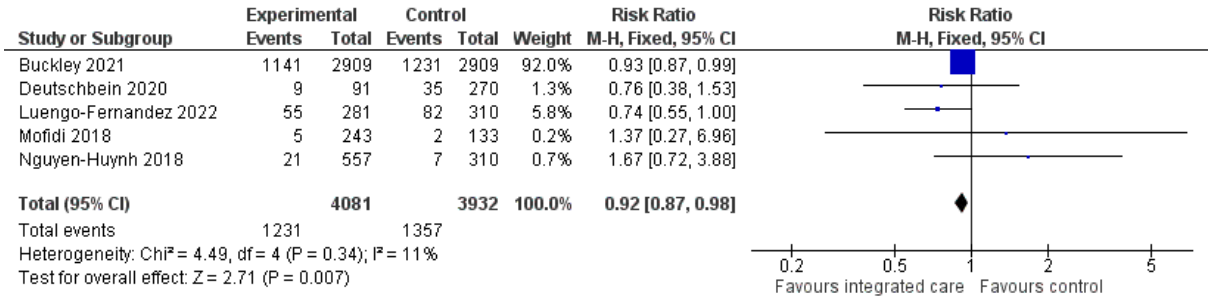


Figure 9 Forest plot of recurrent stroke: NRCTs

5.18.7.1.3 Major bleeding

A total of 4 RCTs (n=8,210) compared integrated care with control for major bleeding. (Figure 10). There were more bleeding events associated with integrated care versus control (RR 1.35 [95% CI: 0.56 to 3.22], I^2 = 84%), however the difference was not statistically significant (P = 0.50).

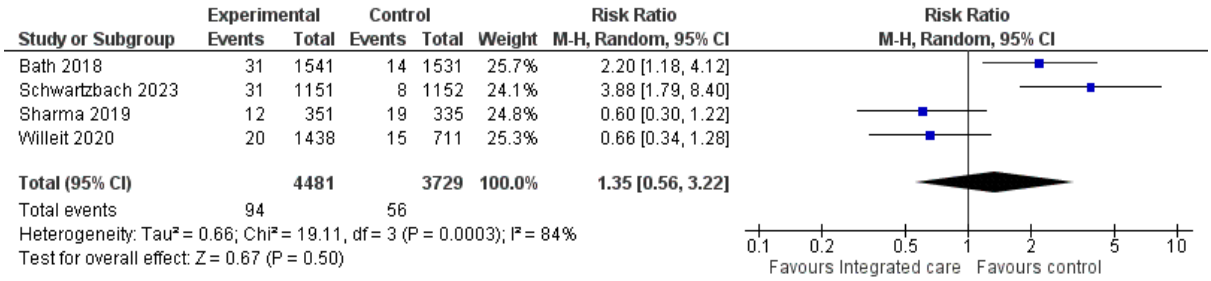


Figure 10 Forest plot of major bleeding: RCTs

5.18.7.2 Secondary outcomes

5.18.7.2.1 Quality of life

Meta-analysis was conducted on a total of 14 studies (n=9,953) using standardised mean difference (SMD) to combine different quality of life (QoL) scales (Figure 11).). Overall, there were significant improvements in QoL in favour of integrated care (SMD = 0.34 [95% CI: 0.17 to 0.51], I^2 = 92%, P < 0.0001).

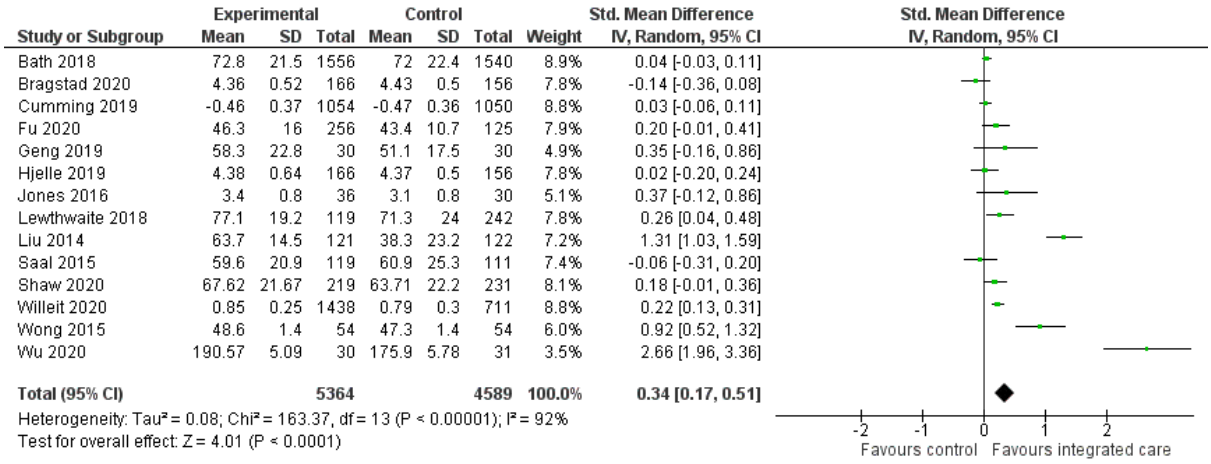


Figure 11 Forest plot of quality of life (combined QoL scales)

Subgroup meta-analysis by QoL measurement scale showed that the greatest differences in QoL between integrated care and control were observed with EQ-5D (2 studies [n=811], mean difference [MD] 4.74 [95% CI: 1.70 to 7.78, I^2 = 0%, P = 0.002, Figure 12) and SF-36 General Health questionnaire (2 studies [n=303], MD 16.89 [95% CI: -0.91 to 34.69, I^2 = 90%, P = 0.06, Figure 13).

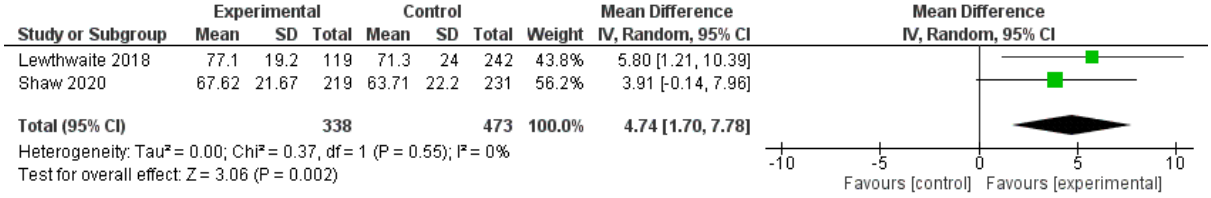


Figure 12 Forest plot of quality of life by EQ-5D General Health scale

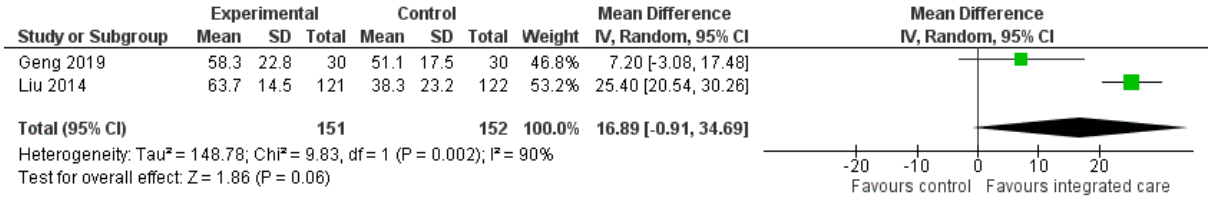


Figure 13 Forest plot of quality of life by SF-36 General Health scale

There were-non-significant trends in improved QoL in favour of integrated care in SF-36 physical component score (PCS) (5 studies [n=627], MD 1.70 [95% CI: -0.69 to 4.10, I^2 = 97%, P = 0.16, Figure 14) and SF-36 mental component score (MCS) (3 studies [n=261], MD 1.62 [95% CI: -2.25 to 5.49, I^2 = 98%, P = 0.41, Figure 15).

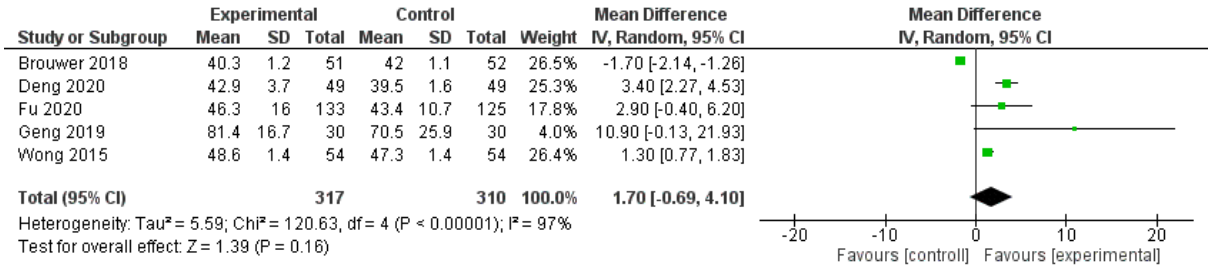


Figure 14 Forest plot of quality of life by SF-36 Physical Component Score (PCS)

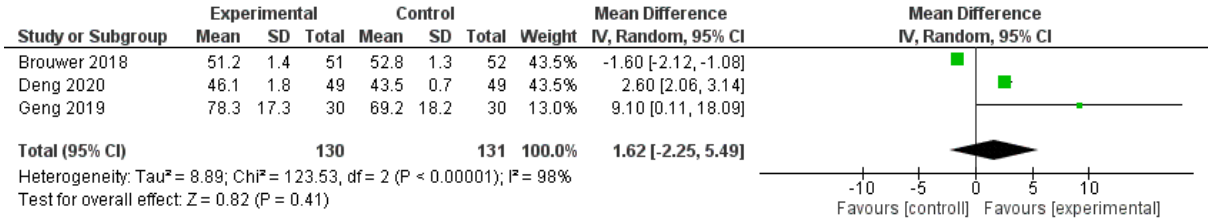


Figure 15 Forest plot of quality of life by SF-36 Mental Component Score (MCS)

5.18.7.2.2 Readmission

Readmission was considered to be unplanned based on the assumption that the majority of readmissions were due to complications or events such as subsequent stroke or MI that could not have been predicted. Meta-analyses for readmission are presented for RCTs in Figure 16 and in Figure 17 for NRCTs.

A non-significant trend for reduction in readmission in favour of integrated care was observed in 9 (n=6,956) RCTs (RR 0.92 [95% CI: 0.78 to 1.09, I^2 = 61%, P = 0.34, Figure 16). There was no difference in readmission rates in a meta-analysis of 5 (n=5,712) NRCTs (RR 0.71 [95% CI: 0.35 to 1.44, I^2 = 97%, P = 0.34, Figure 17).

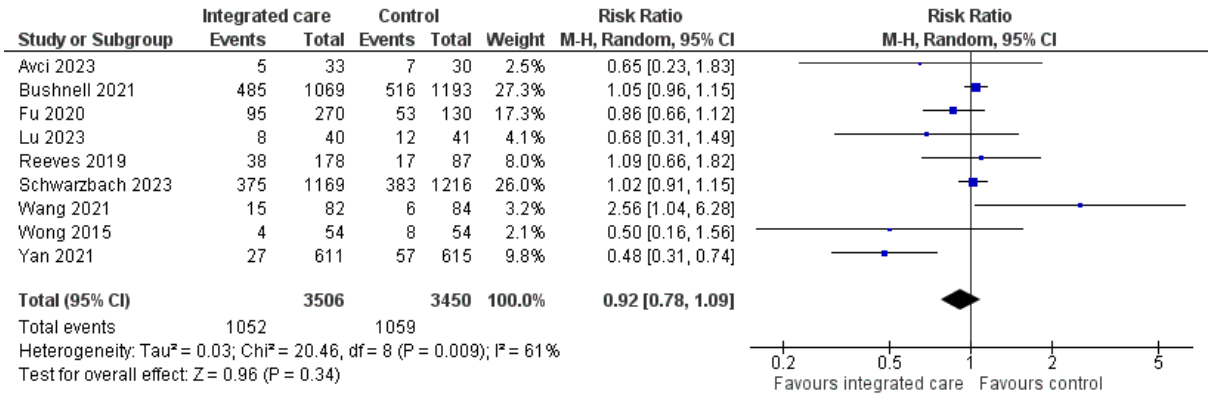


Figure 16 Forest plot of unplanned readmission (RCTs)

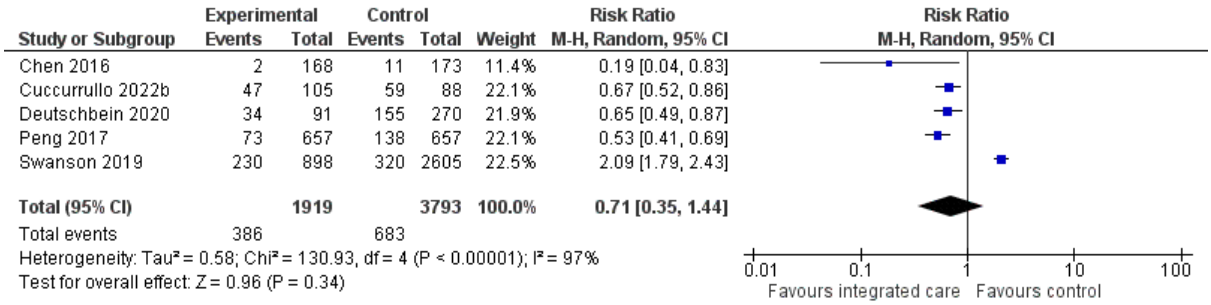


Figure 17 Meta-analysis of unplanned readmission (NRCTs)

5.18.7.2.3 Anxiety and depression

Meta-analysis was conducted on 5 (n=35,606) RCTs reporting proportions of patients with depression using Yale-Brown, PROMS, PHQ2, and GDS scales. Integrated care was associated with a significant reduction in the proportion of patients with depression compared with control (RR 0.96 [95% CI: 0.93 to 0.98, I^2 = 6%, P = 0.0002, Figure 18). Subgroup analysis showed that this association was significant with follow-up times to 6 months (P = 0.02) but was non-significant in studies with 12 months of follow-up (P = 0.38).

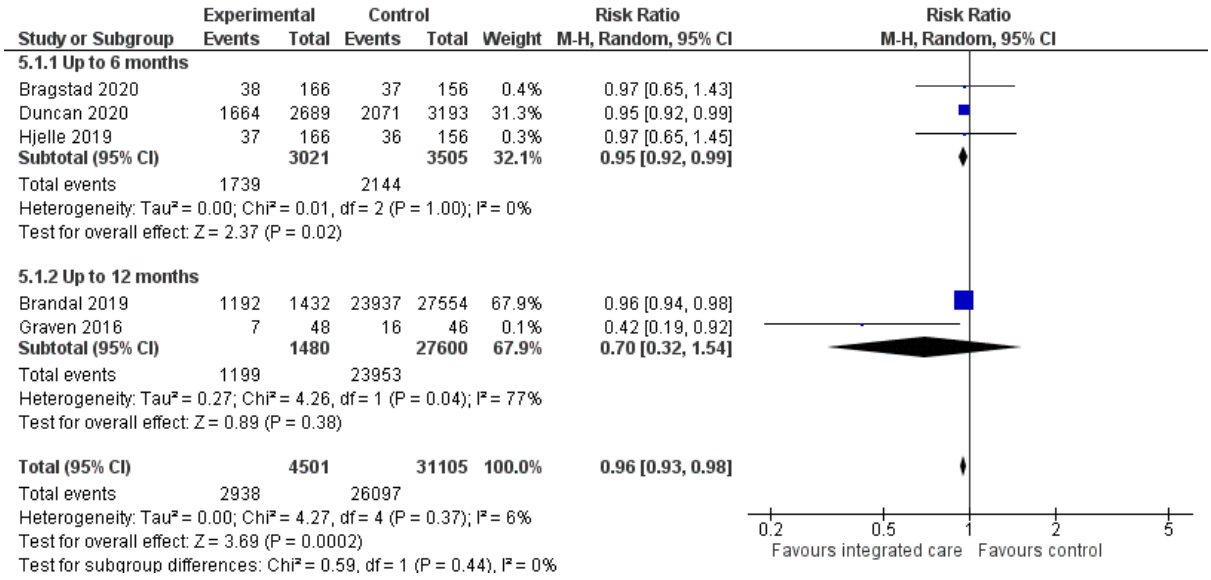


Figure 18 Forest plot of proportion of participants with depression

Meta-analysis also showed that depression scores were significantly lower with integrated care than control regardless of the scale being used (SMD = -0.17 [95% CI: -0.27 to -0.07, I^2 = 0%, P = 0.001, Figure 19).

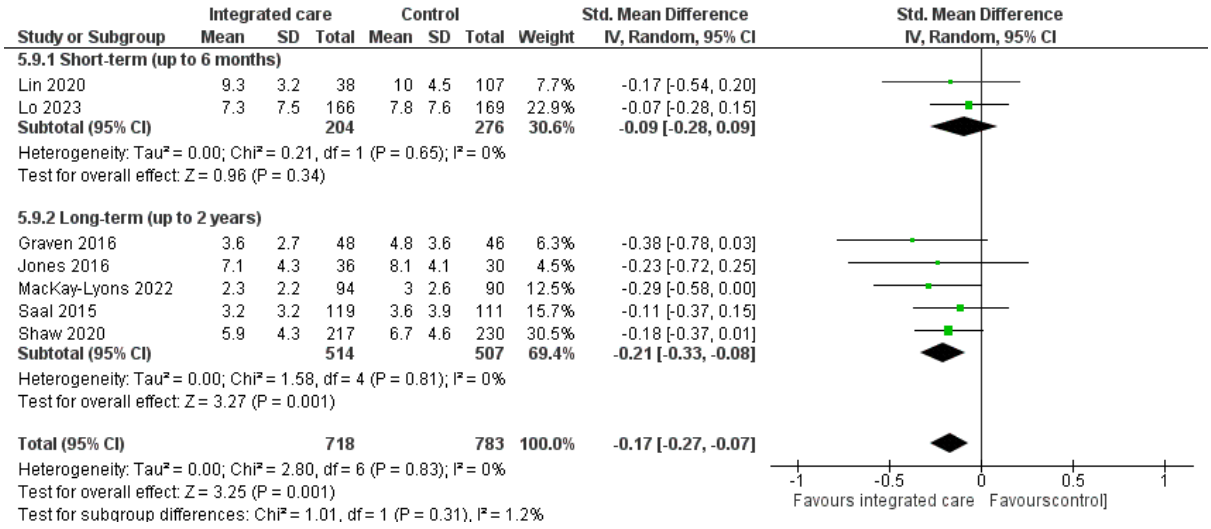


Figure 19 Forest plot of depression scores

Anxiety scores using the HADS-A and Zung's SAS were also significantly lower with integrated care interventions according to a meta-analysis of 5 studies (n=1,050). SMD was -0. 05 (95% CI: -0.89 to 0.11, I^2 = 88%, P = 0.01, Figure 20).

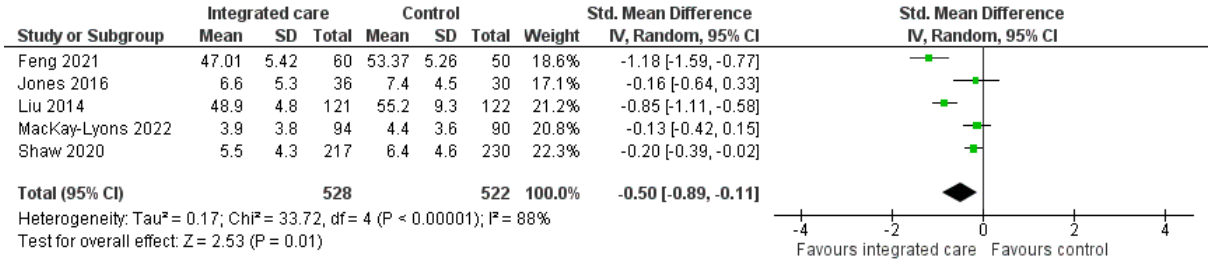


Figure 20 Forest plot of anxiety scores

5.18.7.2.4 Lifestyle and cardiovascular risk factors

Meta-analysis was conducted on lifestyle and risk factors including systolic blood pressure (8 studies, n=4,477), smoking cessation (3 studies, n=1,346), total cholesterol (4 studies, n=993) LDL-cholesterol (5 studies, n=3,318) and BMI (4 studies, n=738). Overall, integrated care was associated with a significant benefit compared with control (SMD -0.17 [95% CI: -0.25 to -0.09], I^2 = 63%, P < 0.0001, Figure 21) and there were significant reductions in SBP and LDL-cholesterol (P = 0.009 and P = 0.01, respectively), but not for total cholesterol (P = 0.29) or BMI (P = 0.35). Four studies (n=1,869) evaluated rates of smoking cessation however there was no difference between the proportion of patients stopping smoking between groups (RR 1.10 [95% CI: 0.93 to 1.31, I^2 = 91%, P = 0.27, Figure 22).

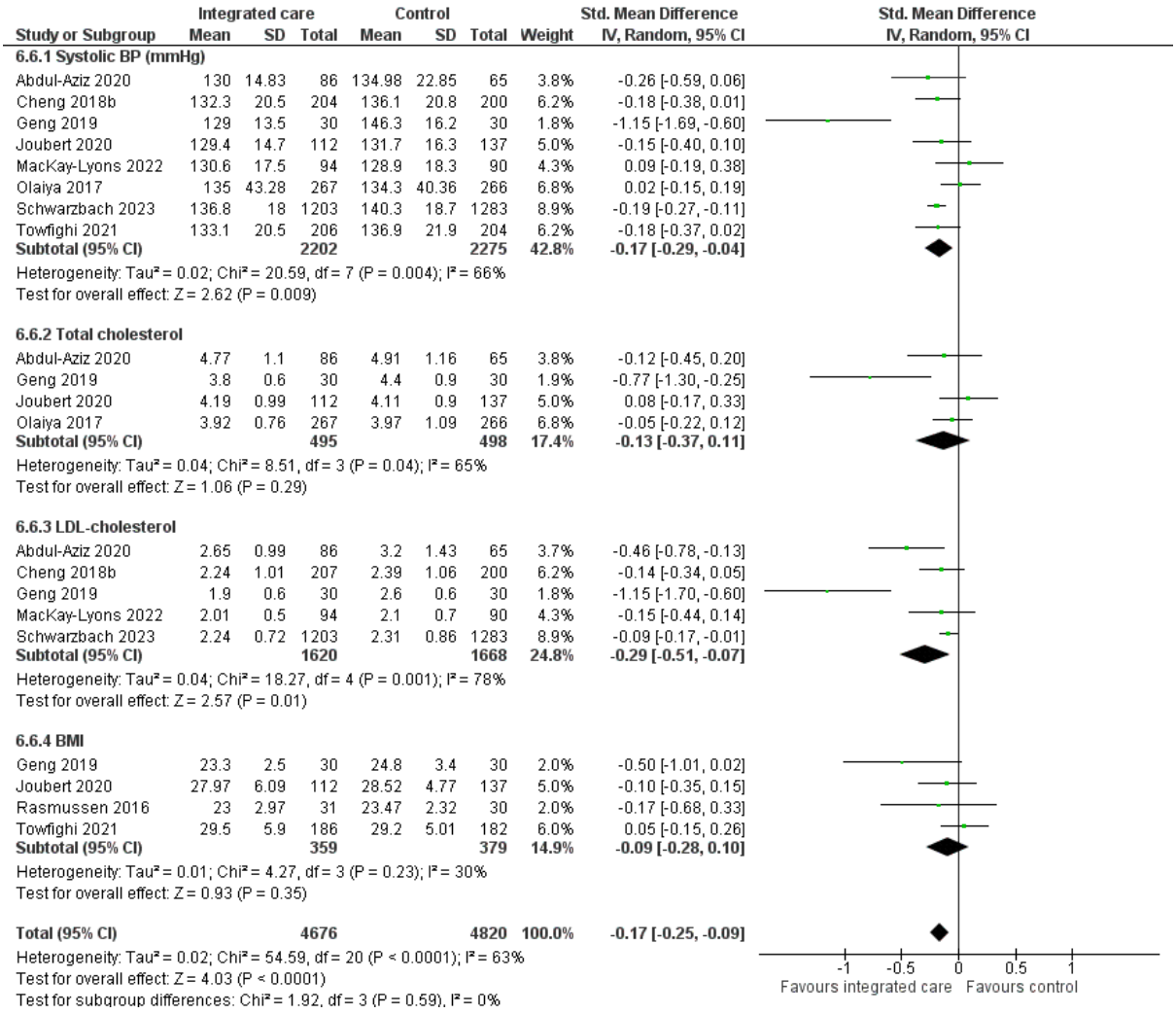


Figure 21 Forest plot of cardiovascular risk factors

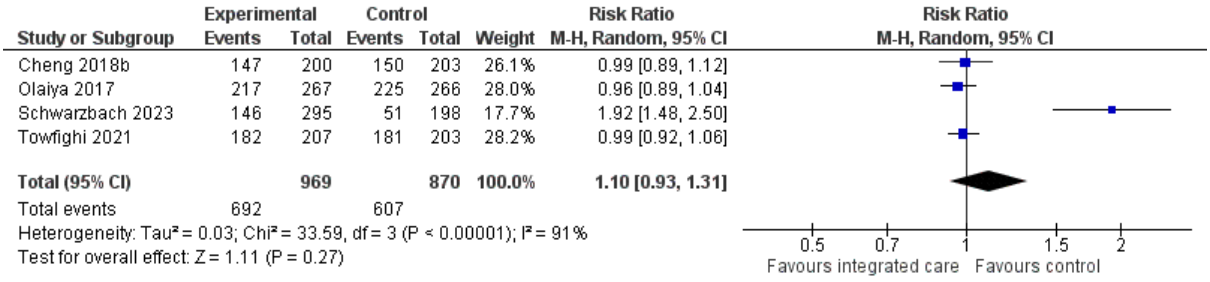


Figure 22 Meta-analysis of smoking cessation

5.18.7.2.5 Adherence to intervention

Three (3) studies (n=3,515) included adherence to intervention as an outcome. Integrated care was associated with higher rates of adherence compared with control however the difference was not statistically significant (RR 1.27 [95% CI: 0.70 to 2.29], $I^2 = 99\%$, P = 0.43, Figure 23).

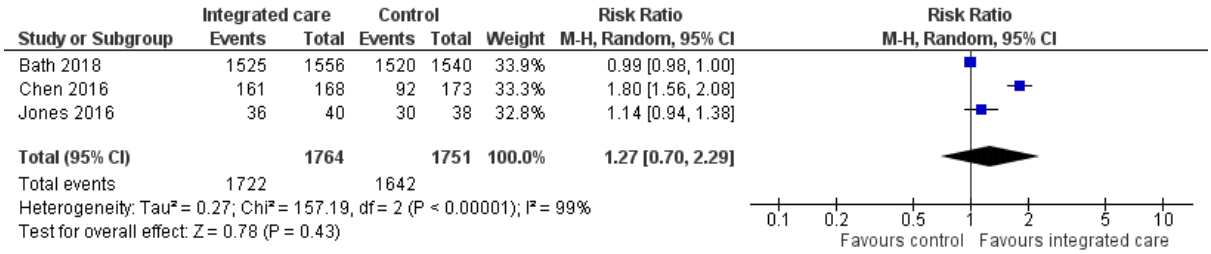


Figure 23 Meta-analysis of adherence to intervention

5.18.7.3 Exploratory outcomes

5.18.7.3.1 Favourable outcome

Four studies included favourable outcome (defined as mRS ≤2). Overall, there was no significant difference in rates of favourable outcome between groups (RR 1.02 [95% CI: 0.98 to, 1.07], I^2 = 77%, P = 0.35, Figure 24).

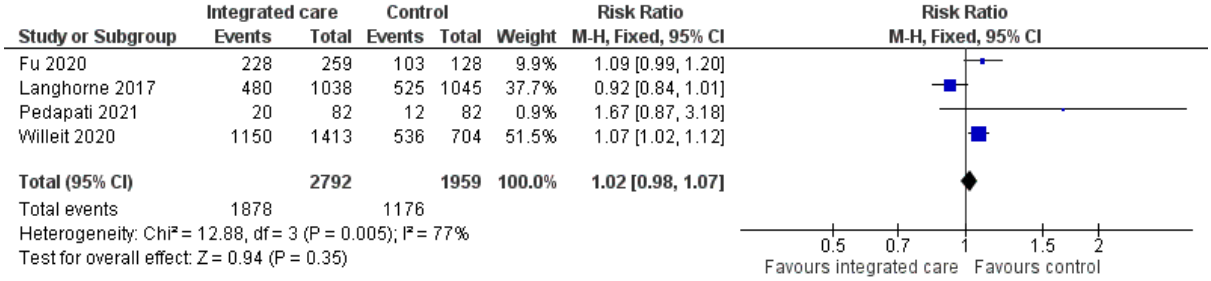


Figure 24 Forest plot of favourable outcome

Two NRCTs included disability or death (defined as mRS ≥2). Overall, there was a significant difference in rates of disability or death in favour of integrated care (RR 0.85 [95% CI: 0.73, 1.00], I^2 = 0%, P = 0.04, Figure 25)

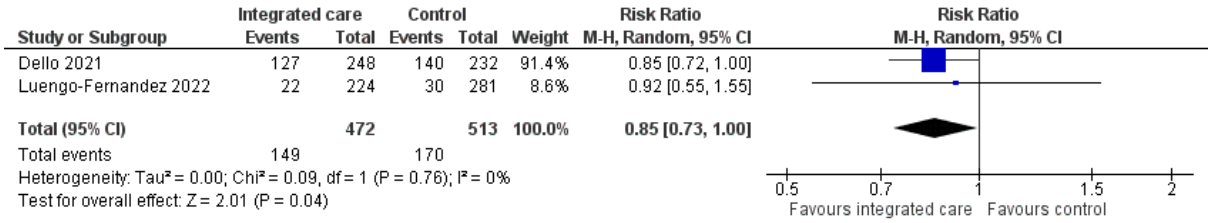


Figure 25 Forest plot of disability or death

5.18.7.3.2 Risk of recurrent cardiovascular disease

Meta-analysis was conducted for MI (3 studies, n=7,733, Figure 26) and vascular death events (2 studies, n=4,221, Figure 27). Although there were fewer events associated with integrated care in both of these analyses, the differences were not statistically significant (MI, P = 0.07; vascular death, P = 0.30).

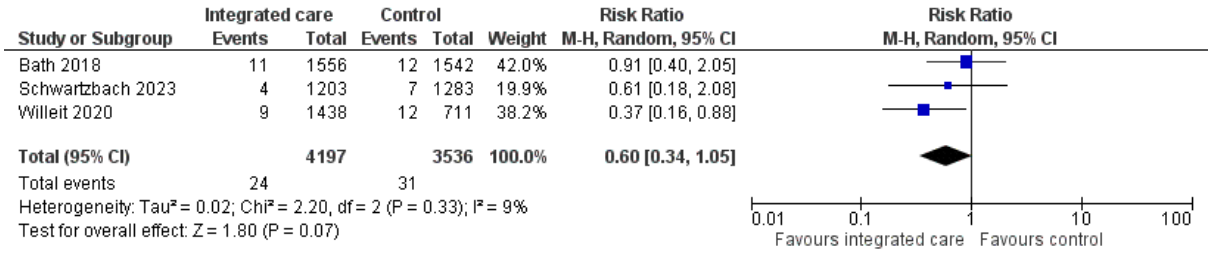


Figure 26 Forest plot of myocardial infarction risk

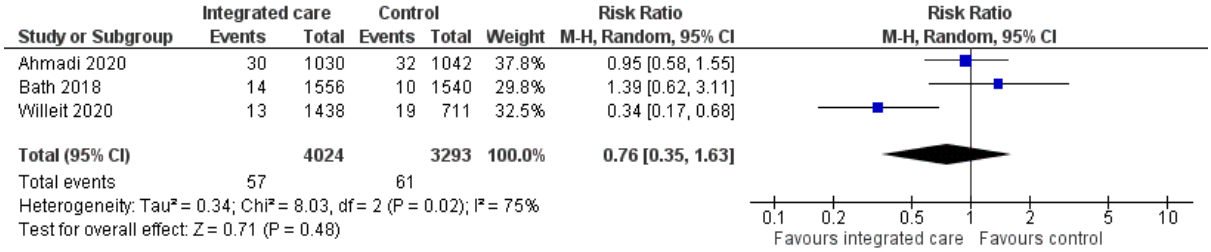


Figure 27 Forest plot of vascular death

5.19 Chapter summary

The systematic review addresses the research question for the study, that is 'What components of an integrated care pathway for people with stroke are considered important for patients and healthcare professionals?'. In the first published systematic review and meta-analysis of integrated care in stroke, this study showed that integrated care in stroke is effective in improving outcomes for stroke survivors and that integrated care pathways should include exercise and interventions addressing lifestyle and stroke risk factors as a priority. Given the considerable heterogeneity between studies, there is no consensus on how to best design such a pathway although the results of the current study provide some indication of which interventions should be included.

In the next chapter, the first part of Work Package 2, the stroke survivor focus groups, is discussed.

6 Chapter Six: Study 2 Phase 1 – Stroke Survivor Focus Groups

6.1 Introduction to Focus Groups

Focus groups are a qualitative research method that originated in the 1940s in an attempt to move away from interviewer-dominated research techniques and were initially widely used in urban planning, marketing and other social sciences (Leung and Savithiri, 2009; Barbour, 2018). They bring together a group of individuals for an informal discussion to explore their shared opinions and experiences on a particular research topic. Focus groups have become increasingly popular in healthcare research as they allow a rich insight into patient experiences, encourage communication and engagement among participants, can reach groups of participants who may be difficult to access or are vulnerable, and uncover hidden issues that individual interviews or questionnaires might miss. Focus groups can also provide a wealth of information in a short time period and the researcher can interact directly with the participants to allow, for example, the clarification of responses (Leung and Savithiri, 2009; Stewart and Shamdasani, 2015; Barbour, 2018).

There are a number of limitations associated with focus groups. These include 1) the potential for bias, where one or more individuals may dominate the group and influence the discussion, 2) a phenomenon known as the social desirability effect, where participants provide the information they think the researchers want (Bergen and Labonté, 2020; Gower et al., 2022), or 3) the researcher may inadvertently bias the discussion by providing clues about the nature of the data being sought (Stewart and Shamdasani, 2015). Other limitations associated with focus groups include limited data gathering if the focus groups are small, lethargy or unwillingness to participate, lack of control during the meeting that may lead to the discussion of irrelevant topics, complex and time-consuming organisation, and the potential to cause distress in vulnerable participants or if discussing sensitive issues (Then et al., 2014; Stewart and Shamdasani, 2015).

In order to mitigate the effects of the limitations associated with focus groups outlined above, each meeting in the current study was run using a clear discussion guide prior to the commencement of the meeting and participants were provided with detailed information about the focus groups before they were approached subsequently to provide informed consent among those who agreed to participate (Section 6.2.4 and Section 6.2.6).

The purpose of this qualitative study was to understand the priorities of care from the perspective of stroke survivors. Despite the Department of Health recommendations (NHS,

2021a) that we should be providing a more holistic approach to stroke care, there is little published evidence to suggest that stroke care is currently person-centred and that factors such as patient and carer involvement, and health inequalities, are seldom considered (Lowther et al., 2021).

6.2 Methods

6.2.1 Holistic Care Perspectives from a Stroke Survivor Personal and Public Involvement Group

In this section, the informal discussions in February 2022 between myself and three stroke survivors who were part of a PPI Group are summarised. The three individuals were all of different ages and backgrounds; one was a white male in his early 60s who experienced an ICH, one was a middle-aged black female working as a volunteer in a stroke support group who had her stroke (ischaemic stroke following carotid dissection) at the age of 30, and the third was a young (under 30) white female athlete who experienced an ICH. The informal discussion presented a fascinating opportunity to learn more about their individual stroke recovery journeys and to present my proposed research in more detail so that collectively we could shape the research into a more patient-focussed framework. The experiences for each individual were unique and each of them highlighted elements of their care that went well and other elements that could have been improved. A summary of the key points recorded following the meeting is listed below.

Key discussion points

- Lack of information (stroke cause, what would happen next, no or incomplete answers to important questions) *"What caused my stroke?"*
- Lack of dignity and respect (listening to what healthcare assistants [HCAs] were talking about but not being able to speak in response, HCAs viewing patients as difficult or uncooperative)
- Lack of staff education/training (one nurse could not read the label on the medicine when the patient asked what it was)
- Non-specialist care (HCPs not aware that a specific condition upon readmission was possibly stroke-related and not being aware of most recent patient history)
- Communication – lack of communication between primary and secondary care, no patient voice *("our opinion doesn't count")*
- Empathy and understanding – no concept of patient viewpoint from clinicians

- Discontinuity of care – no indication of what would happen after discharge from hospital
- Emotional support and mental health care provision was almost non-existent
- One-size fits all approach despite different types of stroke (ICH/ischaemic stroke)
- Patient education: information provided was difficult to read/confusing
- Lack of verbal communication *("what has happened, what will happen from now on?")*
- Low expectations of recovery from HCPs
- Low self-confidence, onus on the individual to make things happen
- Difference in perception of recovery: doctor: *"your recovery is a miracle"*; patient "*I have just got back what I lost"*

The meeting was crucial for the development of the research project in that it provided an opportunity to hear the patient voice and to shape the research design. The PPI group recommended a focus group strategy where stroke survivors could provide their opinions on their stroke care and share their experiences with each other and that the duration of each focus group should be between 60 and 90 minutes. This recommendation was adopted into the current study as a mixed methods study, containing stroke survivor focus groups and a Delphi survey to seek opinions from stroke survivors and HCPs on the importance of elements of stroke care in a proposed integrated care pathway.

6.2.2 Ethics submission through the Integrated Research Application System

Given that stroke survivors for the qualitative focus groups were going to be recruited through NHS outpatient clinics, an NHS Ethics submission was prepared through the Integrated Research Application System (IRAS, No. 317528) and submitted on 28 June 2023. The Research Ethics Committee (REC) approved the application on 26 July 2023 and issued a letter of approval. A copy of the IRAS-approved protocol is provided in Appendix H.

6.2.3 Purposive sampling

Purposive sampling is widely used in qualitative research and is a technique where participants are selected based on their relevance to the research question and their ability to provide rich and diverse perspectives for the most effective use of limited resources (Palinkas et al., 2015; Campbell et al., 2020; Richard, 2020; Nyimbili and Nyimbili, 2024). This approach involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Creswell and Plano Clark, 2011). In addition to knowledge and experience, Bernard (2017) notes the importance of availability and

willingness to participate, and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner (Bernard, 2017). It was for these reasons that purposive sampling was used in this study to find stroke survivors who were willing and able to tell their story in a group of like-minded individuals. This approach would also ensure that potential participants would meet the study inclusion criteria.

6.2.4 Recruitment of focus group participants

Participants for the stroke survivor focus groups were recruited from two clinical areas according to the criteria for inclusion and exclusion set out in the study protocol:

1. Stroke outpatient clinics at a district general hospital, Merseyside
2. Contact with research nurses at a University Teaching hospital, Merseyside

I attended the outpatient clinics at the district hospital in person. Clinic staff, who included consultants, registrars and stroke nurses, identified potential participants meeting the study inclusion criteria. Those stroke survivors who were willing to learn more about the study were invited to a face-to-face discussion with myself following the initial approach by the clinical teams. This meeting took place in a separate meeting room for privacy, or in a clinic room with the doctor or nurse present. It was at this meeting that potential participants were given information to take away and consider if they wished to participate in the study. The information pack comprised an invitation letter (Appendix I), Participant Information Sheet (PIS, Appendix J), and an informed consent form (ICF, Appendix K).

In the case of the University Teaching Hospital, two research nurses provided a list of eligible stroke survivors who had previously participated in stroke research and had indicated on consent forms that they were willing to be contacted regarding participation in other research studies. I contacted these individuals by phone using the contact details provided and took address details for those who expressed interest for them to be sent study information.

Permission was sought for me to contact all participants a second time within seven days after of the initial contact to check interest and then obtain informed consent over the telephone if they were still willing to participate. At second contact, I asked each individual if they were willing to participate in the study and for those that indicated they were willing to participate, I discussed informed consent and gained verbal consent from the participant, with the discussion being recorded to document that consent was given. When this was granted, I discussed the content of the ICF with the participant to check for understanding. I requested that the participant complete and return the consent form in an SAE provided with the study

information pack. Alternatively, written informed consent was taken in person on the day of arrival prior to the commencement of the focus group. A copy of the signed ICF was given to each participant for their records.

Recruitment took place between 25 October 2023 and 03 December 2023. During this time, a total of 92 stroke survivors meeting the study criteria were contacted (56 in outpatient clinics and 36 through the Teaching Hospital). A total of 34 patients did not respond at attempted second contact (either not returning a call following a voicemail message or not responding to email), 23 declined to participate at second contact leaving 35 patients who gave informed consent over the telephone (24 patients from clinics and 11 patients from the hospital). Following this conversation a confirmation letter was sent to each participant with details of the meeting venue, timings and travel options. A follow-up telephone call was made to confirm attendance a week prior to the focus group meeting date.

6.2.5 Focus group characteristics

A total of four focus groups were planned and implemented. Purposive sampling was used to ensure heterogeneity in each group regarding age, gender, stroke type, time since stroke and level of post-stroke disability. A summary of the demographics and characteristics of all 35 consented participants is provided in Table 3.

Table 3 Characteristics of consented focus group participants (n=35)

Median age* (min, max), years	64 (24, 89)
Male, n (%)	22 (63)
Female, n (%)	13 (37)
Ethnicity, n (%)	
White/British	34 (97)
Any other white background	1 (3)
Geographical location (local borough), n (%)	
Liverpool city region	10 (29)
Sefton	3 (9)
Knowsley	6 (17)
St Helens	8 (23)
Halton	4 (11)
Warrington	4 (11)
Stroke diagnosis, n (%)	
Lacunar syndrome (LACS)	15 (43)
Partial anterior circulation syndrome (PACS)	2 (6)
Thalamic	3 (9)
Occipital	1 (3)
Posterior circulation syndrome (POCS)	5 (14)
Middle cerebral artery (MCA)	3 (9)
Posterior cerebral artery (PCA)	1 (3)
Total anterior circulation syndrome (TACS)**	2 (6)
Carotid artery dissection	1 (3)
Cardioembolic stroke	1 (3)
Other	1 (3)
Median length of stay (min, max), days	5 (2, 202)
Median time since discharge* (min, max), days	333 (160, 1786)

*At time of focus group meeting date.
** One participant was diagnosed with intracerebral haemorrhage (ICH) in addition to TACS.

The median age of participants was 64 years, 8 were aged 55 and under and the youngest was 24. Two thirds of the participants were male and the majority (52%) were from Liverpool city or St Helens. Of note, all participants were white, with no other ethnicities being recruited. People from Asian and Afro Caribbean backgrounds were approached by outpatient clinic staff but none of these individuals were willing to participate or even know more about the study. The most common stroke diagnosis (43%) was lacunar syndrome (LACS). Median length of stay in hospital was 5 days and participants had been discharged from hospital for a median of 333 days.

6.2.6 Focus group allocation and attendance

In accordance with published literature on focus groups, the proposed number of participants for each focus group was between 6 and 10 (Liamputtong, 2011; Barbour, 2018). This number is recommended to generate an appropriate level of participant involvement and to provide rich contextual data which can then be analysed (Liamputtong, 2011; Stewart and Shamdasani,

2015). Participants were allocated to a total of four focus groups according to age, gender and level of post-stroke disability to ensure as even a balance of as possible across groups. This was not always possible due to some participants being reallocated to a different group than originally planned due to illness or conflicting commitments.

Each focus group was conducted using a clear discussion guide (Appendix L), which introduced the researcher, outlined the purpose of the group and provided a set of ground rules to be observed during the meeting. These ground rules were devised according to Kreuger's guide on running focus groups (Kreuger, 2002), were displayed on a flip or wall chart for the duration of the meeting, and summarised opening questions (Kreuger, 2002). An atmosphere of trust and openness was created by warmly welcoming the participants, thanking them in advance for their important contributions and stressing that each participant shared something in common with other participants in the room; they were all stroke survivors on a recovery journey. This important statement was aimed at defining a common purpose for each participant in the room to help to explain to them why their input was being sought. It was also aimed at creating an open and informal discussion since none of the participants in any of the groups knew each other. Participants were informed at the start of the meeting according to the ground rules that their opinions were highly valued, that there are no wrong answers, and that each individual's opinions could be freely expressed and should be respected by the other participants. They were advised not to say anything that might be upsetting or cause embarrassment, that my role was to act as a facilitator and that they should talk to each other (Kreuger, 2002; Liamputtong, 2011). They were also informed that the meeting was to be recorded for research purposes and data gathering but that the recording would be handled in strictest confidence in accordance with university guidance on data handling and storage.

The discussion was focussed on a series of primary questions, with additional questions serving as prompts that were used, if necessary, by the researcher to keep the discussion flowing and to allow the researcher to keep the discussion 'on topic'(Table 4). The researcher assisted with equipment and refreshments, arranged the room, and welcomed the participants as they arrived (Kreuger, 2002).

Each member of the focus group was given the opportunity through facilitation and a round robin approach to speak to the group and contribute to the discussion, being mindful that some individuals could have been hesitant in a group setting and others would have been dominant and attempted to control the discussion (Liamputtong, 2011).

Table 4 Focus group questions

Research Question 1	***"Can you tell me about your experiences of recovering from a stroke?"***
Interview Questions	Can you tell me about your stroke recovery journey (from when you were admitted to hospital to where you are now)?
Prompts	What was your experience of: • The time up until you were discharged (early supported discharge)? • The time after you arrived home (what happened afterwards with your care)?
Research Question 2	***"Can you tell me what went well and what didn't go so well during your recovery?"***
Interview questions	Did you encounter any problems during your stroke recovery? If so, can you talk about them? Can you think of anything that helped your stroke recovery? If so, can you talk about them? Looking back at your stroke recovery journey, is there anything you would want to change about the way you were cared for? If so, can you talk about them
Prompts	Was there something during your recovery that you found especially difficult to manage? Was there any part of your care that really stood out/really made a difference in your recovery? Thinking about how you were cared for, what do you think could have been done differently that would have made a real difference?

The focus groups were held every alternate Wednesday between 24 January and 06 March 2024. Of the 35 consented participants, 27 (77%) attended and 8 (23%) did not attend on the date of the meeting. Each focus group comprised between 6 and 8 participants. The proposed duration for each focus group was 90 minutes and this was dependent on the group recognising that they were post stroke patients and they could become easily fatigued. For many stroke survivors the ability to concentrate and communicate may have been problematic and regular breaks and checking in with the participants to ensure they were able to continue was an important part of managing the groups (Liamputtong, 2011; Barbour, 2018). Each meeting lasted for 90 minutes between 11:00 and 12:30 and was run according to a series of ground rules outlined in a discussion guide, which was on permanent display on a flip chart during each meeting. After outlining some very general questions on recovery from stroke, an informal and freeform discussion was allowed to develop with minimal interaction from the researchers. All of the focus groups were held at Exchange Station in Liverpool, an accessible building in central Liverpool converted into offices with good public transport links and onsite parking. Each meeting room was spacious, well lit, free from interruption, and with accessible toilets in close proximity. Focus group attendees were provided with refreshments and the option of a buffet lunch after the meeting had finished.

6.2.7 A note on focus group discussions

Before engaging in the analysis of data in depth, it is important to note that during the first focus group meeting the participants were aware that the main purpose of the discussion was centred on their recovery after discharge however the majority of participants felt that it was important to share their experiences of stroke with the group as a prelude to their acute treatment and ongoing management. This proved to be a critical discussion point as much of the conversation around recovery was linked to individual stroke experiences and in addition the uniqueness of each individual's stroke experience was highlighted. With this in mind, I explained to the participants of subsequent focus groups that they were at full liberty to share their experiences of stroke with others. This had the result of improving cohesiveness within the groups and allowed for informal, meaningful and frank discussions.

6.2.8 Focus group meeting recording and transcription

Each focus group meeting was recorded using high quality digital recording equipment and wired microphones. Each recording was imported into Word and transcribed using the transcribe feature in the Word desktop app. The transcript was checked for accuracy against the recording and edited where necessary.

Coding for each transcript was conducted line by line within Microsoft Word, using the highlighting and comment features (Appendix M). Once each of the transcripts were coded, a second coding took place in order to ensure that all codes were captured. The codes generated in Word were then compared and verified using NVivo (Dhakal, 2022) (Appendix N).

6.3 Data Analysis

6.3.1 Reflexive Thematic Analysis

Reflexive thematic analysis is a flexible, interpretive approach to qualitative data analysis that identifies themes by focusing on the active and critical self-reflection of the researcher throughout the entire process (Braun and Clarke, 2019; Braun and Clarke, 2022). Reflexive thematic analysis views the researcher's personal, theoretical, and disciplinary background as a valuable resource that helps to form their understanding and interpretation of the data. This process involves the acknowledgement of the researcher's own biases and preconceptions in an open and transparent manner to produce a more insightful and nuanced analysis of patterns and meanings within a dataset (Byrne, 2022; Delve and Limpaecher, 2024).

While most thematic analysis focuses on pattern identification, reflexive thematic analysis (Braun and Clarke, 2022) goes further by layering in the active role of the researcher in the

process, identifying overarching themes and examining how the researcher's own subjectivity influences what they see, offering a more honest and nuanced analytical process. Reflexive thematic analysis allows a unique perspective on qualitative research through the creation of insightful and transparent themes that reflect both the data and the researcher's analytic lens. Reflexive thematic analysis is built upon six phases (Braun and Clarke, 2022). These are:

1. Familiarisation with the data	Transcribing data: reading and re-reading, noting down initial codes
2. Generating initial codes from the data	Coding interesting features in the data in a systematic fashion across the data set, collating data relevant to each code
3. Initial theme generation	Collating codes into potential themes, gathering all data relevant to each theme
4. Theme development and review	Checking if the themes work in relation to the coded extracts and the entire data set; generating a thematic map
5. Refining, defining and naming themes	Ongoing analysis to refine the specifics of each theme; generation of clear names for each theme
6. Writing up	Final opportunity for analysis selecting appropriate extracts; discussion of analysis, relating back to the research question or literature, producing the report

The six phases of reflexive thematic analysis are not a linear process and can be conducted in any order and repeated any number times to fully analyse and make sense of the data. The way in which thematic analysis is conducted is entirely up to the researcher (Braun and Clarke, 2022).

6.3.1.1 The Choice of Reflexive Thematic Analysis

After consideration of a number of qualitative data analysis techniques, reflexive thematic analysis was selected for this study on the basis that it would be able to provide rich data analysis to answer the research questions for the focus groups and also to gain some understanding of how people with stroke make sense of their experience, as would be the case with interpretative phenomenological analysis (IPA). However, the value of IPA lies with its in-depth exploration focussed on individuals and would have been the most appropriate choice had the study used semi-structured interviews rather than focus groups (Delve and Limpaecher, 2023). The design of the study was originally intended to employ semi-structured interviews but this was changed to include focus groups instead, due to time constraints. Thematic analysis is flexible and can be used to analyse a variety of data types, including interviews, focus groups and text documents. It can also be used to identify broader patterns within a dataset (Braun and Clarke, 2022; Delve and Limpaecher, 2023). This flexibility and ability to identify broad patterns made it the most suitable data analysis method for this study. The aims of the

qualitative study were to gain an appreciation of the elements of stroke care that are important to patients and why, by analysing data collected in a group setting rather than individually (Smith and Osborn, 2015; Smith, 2022).

6.4 Findings

This section presents the findings from the focus groups following qualitative analysis of the data using reflexive thematic analysis, which are presented as a series of diagrams showing overarching themes, subthemes, the codes that make up these subthemes and extracts from meeting recording transcripts that inform the codes.

6.4.1 Focus Group Participant Characteristics

A total of 35 participants from the city of Liverpool and surrounding districts were recruited to take part in a total of 4 focus groups. Purposive sampling was used to ensure heterogeneity in each group regarding age, gender, stroke type, time since stroke and level of post-stroke disability. Of the 35 participants who agreed to participate, a total of 27 attended the focus groups (17 males and 10 females), with 6-8 participants in each group. Table 5 below summarises the participants' demographics in each of the focus groups. Of those who participated in the focus groups, 7 were aged 55 and under, with the youngest aged 45. The oldest participant was 89. The majority were able to attend the meetings by themselves, either through the use of public transport or travelling with a relative or carer. Five participants attended the meetings with either a family member (spouse or partner) or carer present.

Table 5 Participants for stroke survivor focus groups

Participant pseudonym allocated	Gender	Age	Stroke type	Time since stroke (days)*	Level of post-stroke disability/impairment†
Focus Group 1					
Ernest	Male	75	Right LACS	169	None
Edgar	Male	54	Cardioembolic	198	Moderate disability (can walk unassisted)
Allison	Female	57	Right MCA infarct	523	None
Alice	Female	78	Bilateral LACS	207	One-sided weakness
Alana	Female	79	Left PACS	216	Limited mobility
Jeffrey	Male	86	POCS	234	Impaired balance, walks with stick
Focus Group 2					
Francis	Male	51	POCS	244	Limited mobility (uses wheelchair)
Gavin	Male	68	Right thalamic infarct	199	None
Gracie	Female	75	LACS	324	None
Amee	Female	74	Posterior circulation	308	None
Kirk	Male	46	Right LACS	413	None
Dennis	Male	73	Right LACS	447	None
Focus Group 3					
Keith	Male	73	LACS	1,786	None
Marcus	Male	44	Right LACS	218	None
Harold	Male	56	Right LACS	324	Limited mobility, requires carer present
Maggie	Female	77	Left LACS	857	Limited mobility
Michele	Female	70	LACS	610	None
Jack	Male	49	Left sided ICH	252	Moderate disability (can walk unassisted)
Travis	Male	64	Left LACS	590	None
Focus Group 4					
Roger	Male	54	POCS	524	None
Aaron	Male	71	Right LACS	160	Impaired balance
Rose	Female	89	Left thalamic	240	Neurological deficit
Philip	Male	60	Carotid dissection	734	Visual problems
Michael	Male	58	Left MCA	344	None
Peggy	Female	64	Multiple right-side infarcts	373	Visual problems, walks with stick
Mariah	Female	53	LACS	538	None
Henry	Male	63	Right LACS	333	None

ICH, intracerebral haemorrhage; LACS, lacunar syndrome; MCA, middle cerebral artery; PACS, partial anterior circulation syndrome; POCS, posterior circulation syndrome.

*Time since discharge date and focus group meeting date inclusive. For participants who experienced more than one stroke, time since stroke is measured from discharge following the most recent event.

†Levels of post-stroke disability are those observed by the researcher of participants upon arrival or during the focus groups or those announced by the participants themselves during the discussion.

6.4.2 Identification of Themes

During the coding process, codes were represented in thematic maps as separate bubbles. As the analysis progressed, these codes were consolidated into themes and subthemes. The initial thematic map is shown in Appendix O. The initial mapping was consolidated into definitive themes, subthemes and associated codes (Figure 28).

A total of four themes were identified from an in-depth analysis of the focus group data: recognising stroke, loss of identity, Life after stroke –, 'Feeling lucky' and dealing with the past and looking to the future. Each theme is summarised in a thematic diagram showing some transcript quotes as part of the main codes used in the analysis. The codes are then grouped into sub-themes, which are themselves linked to the overarching theme. The sub-themes and codes are described in the text below for each individual theme.

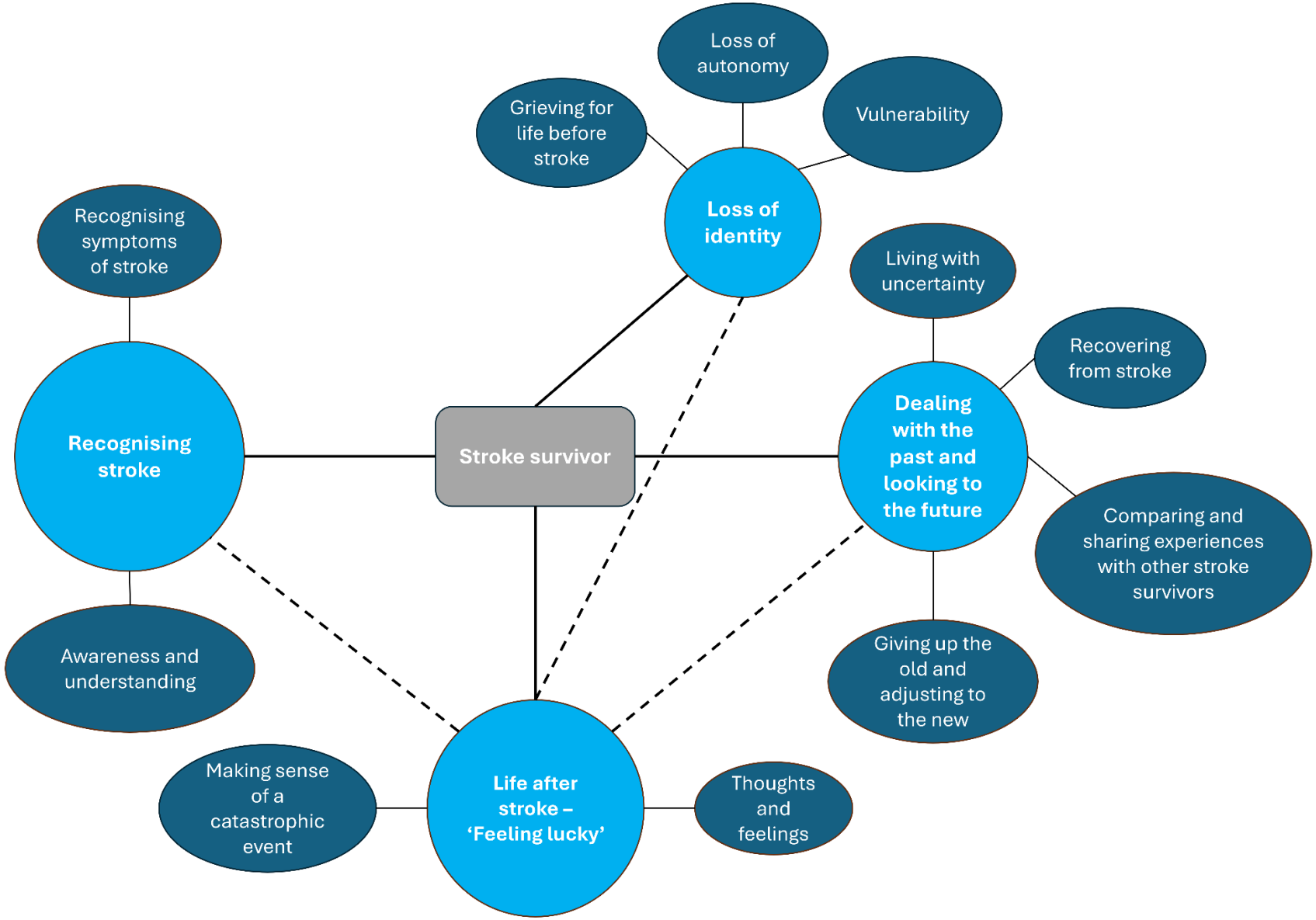


Figure 28 Thematic Mapping: Consolidation

6.4.2.1 Theme 1: Recognising stroke

The theme recognising stroke evolved around two main sub-themes: 1) recognising the symptoms stroke, and 2) awareness and understanding (Figure 29).

6.4.2.1.1 Recognising the symptoms of stroke

Participants had a knowledge of stroke that was often based on what they had seen in the media. The most commonly referred media source mentioned by participants in each of the groups was the FAST advert (Face, Arms, Speech, Time to call 999) (Bietzk et al., 2012; Dombrowski et al., 2013; Flynn et al., 2014) and the well-recognised symptoms of facial droop, arm weakness and slurred speech. However, participants did describe other symptoms that would not normally be associated with stroke, for example pins and needles and numbness. These symptoms were often mistaken for other non-serious conditions and participants often chose not to act on them as they assumed they would only be temporary. At some point, either when symptoms were still present or had become more severe, participants realised that there was something wrong and would seek medical advice from HCPs. This was a first step toward being diagnosed with a stroke. The recognition of stroke was predominantly diagnosed by an HCP (doctor or stroke nurse). However, in some instances the participants themselves or a relative realised the signs and symptoms of a stroke and acted. A number of participants during the focus groups expressed their annoyance and frustration in situations where they were not believed by HCPs. Participants described instances where they believed they were having a stroke or where they felt that opportunities to diagnose and treat stroke earlier had been missed.

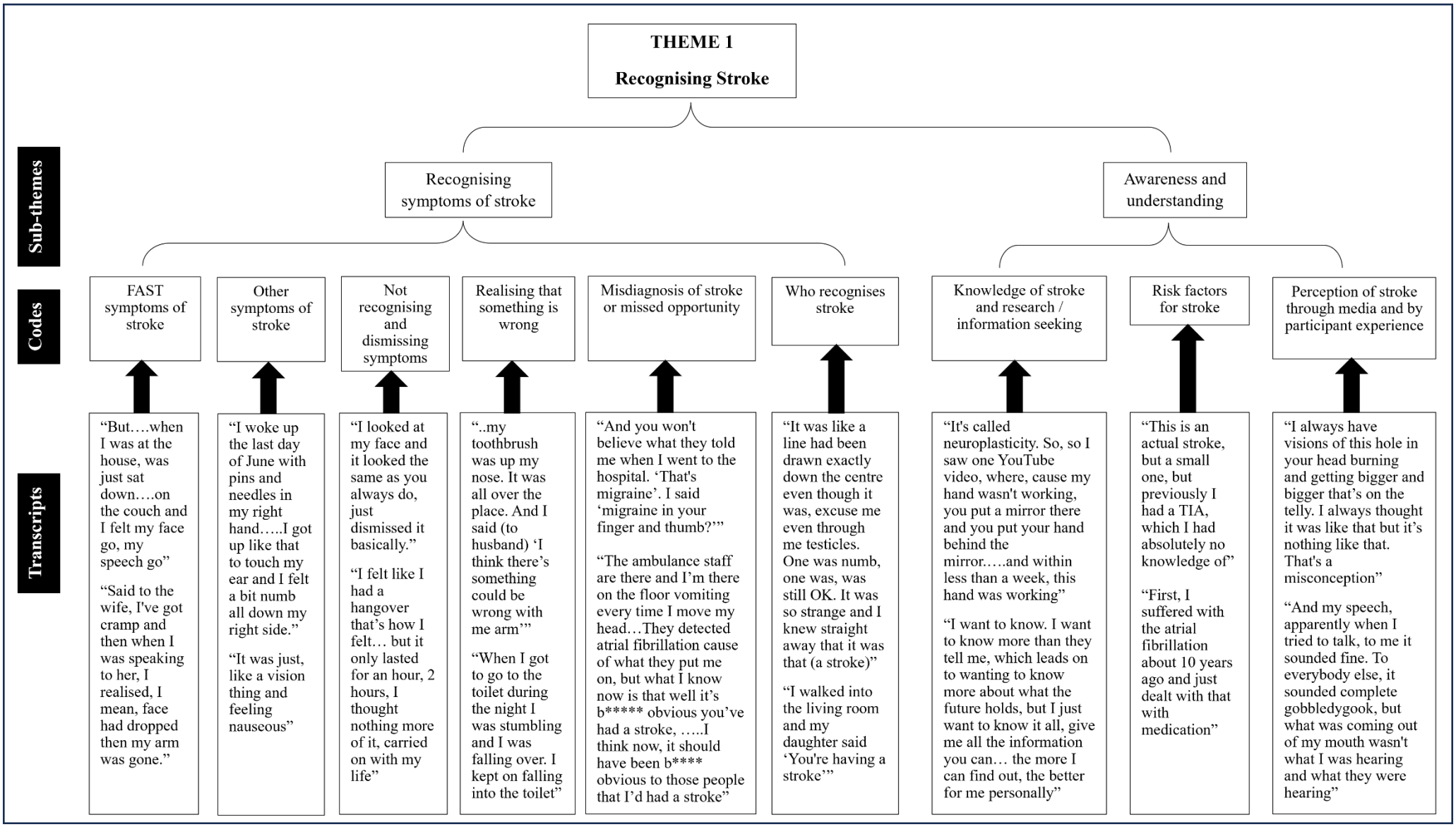


Figure 29 Theme 1, Recognising Stroke

FAST symptoms of stroke

Some participants recalled that during their experience of having a stroke, they were aware of the well-recognised FAST symptoms of facial droop, arm weakness and slurred speech or complete loss of speech (Bietzk et al., 2012; Dombrowski et al., 2013; Flynn et al., 2014). The awareness of the FAST signs and symptoms of stroke was often accompanied by the realisation that the participants knew what was happening to them.

> *"But when I was having, when I was at the house, was just sat down in the, on the couch and I felt my face go, my speech go and I had like a hot sensation behind the eyes like my eyes are burning from, from the back." (Marcus, 44 years, focus group 3)*

> *"I woke up in the middle of the night on a Saturday and…I thought I had cramp in this leg, my right leg. Said to the wife, 'I've got cramp' and then when I was speaking to her, I realised, face had dropped then my arm was gone." (Travis, 64 years, focus group 3)*

Other symptoms of stroke

Other symptoms of stroke that were commonly reported by the participants included neurological problems, such as numbness, pins and needles or muscle weakness, sometimes limited to a single limb and at others involving one side of the body. A 78-year-old lady called Alice in focus group 1 recalls her experience:

> *"I woke up the last day of June with pins and needles in my right hand which is still there and just thought I'd been sleeping on my arm, so my husband rubbed it. I got up like that to touch my ear and I felt a bit numb all down my right side." (Alice, 78)*

Other participants described visual problems, feeling sick, also just a vague feeling of being unwell, like having a hangover:

> *"It was just, like a vision thing and feeling nauseous" (Roger, 54 years, focus group 4)*

> *"I got up and I was thinking to myself, 'oh, my God, my head hurts so much'. And I felt like I'd had a really bad night on the ale. And I haven't drunk for five years." (Mariah, 53 years, focus group 4)*

Not recognising and dismissing symptoms

Since many participants described less well-known symptoms of stroke such as pins and needles or numbness, there was no recognition of the possibility that these symptoms could be the initial stages of a stroke. Inevitably, the participants dismissed the symptoms as a temporary

problem that would resolve with time, often after an overnight sleep, and they would continue with their lives as normal, as Edgar, a 54-year-old gentleman from focus group 1 states:

> *"I was at work playing pool at lunch, had to sit down, I felt unwell. Ten minutes later, I drove myself home, took the afternoon off, and that was on a Friday and actually by 7 or 8 o'clock at night I was right as rain, went out to see some friends…..I felt like I had a hangover that's how I felt, but it only lasted for an hour, 2 hours, I thought nothing more of it, carried on with my life." (Edgar, 54)*

The way in which symptoms were dealt with gives the impression that some of the participants thought that going to seek help from an HCP was unnecessary as they would eventually disappear.

> *"I looked at my face and it looked the same as you always do, just dismissed it basically. So he (husband) said 'Do you think you should go to [hospital]' and I said 'What on a Friday? You must be joking', so, just didn't bother." (Alice, 78)*

Realising that something is wrong

Participants often described symptoms of stroke other than those in FAST as vague and without making a connection to the condition. They tended to ignore these symptoms until either they became more severe, or they were still present after dismissing them for some time, typically overnight. Once participants had realised that something was wrong, they took action by contacting the emergency services. An example of this is Amee, a 74-year-old lady in focus group 2, who initially told the focus group how her stroke symptoms started:

> "*I thought, oh, a bit of a funny face and my mouth, it was like there was a line in it, I thought Ohh it'll go off and then gradually it was my leg like tingling right side and my arm and I thought ohh something might go off. So, I went to bed. Yeah, I thought it might go off during the night …" (Amee, 74)*

Like other participants Amee dismissed her symptoms thinking that they would disappear after a night's sleep but when she woke, there was still a problem. Amee describes a loss of arm coordination that prompted a call to the emergency services and she was subsequently diagnosed as suffering from a stroke:

> *"I went to clean my teeth and it was (moves hand randomly over face) I thought hmm hasn't gone. …..my toothbrush was up my nose. It was all over the place. And I said (to husband) 'I think there's something could be wrong with me arm'" (Amee, 74)*

Misdiagnosis of stroke or missed opportunity

During the focus group discussions, the subjects of how participants' strokes were misdiagnosed in their opinion and how they thought opportunities to diagnose their stroke earlier had been missed were mentioned frequently. Many participants described how a lack of awareness by HCPs of symptoms that can be associated with a stroke resulted in delays in stroke diagnosis or misdiagnosis.

Specific examples of cases where participants felt their stroke had been misdiagnosed included migraine, as described by Rose, an 89-year-old lady in focus group 4. Rose arrived at a district general hospital complaining of pins and needles in her arm and hand and after these symptoms had persisted, she felt that she was having a stroke, however it appears that her symptoms were dismissed by the doctors:

> *"And you won't believe what they told me when I went to the hospital. 'That's migraine'. I said 'migraine in your finger and thumb?'...I said 'I think I've had a stroke'. 'No, it's migraine'. So that was one doctor, then I see another doctor and he said the same thing. And I kept saying 'is that migraine?' I said 'migraine's up here (pointing to head) not down there (pointing to hands)'" (Rose, 89)*

The delays in diagnosis and treatment (in some cases no treatment at all was given) resulted in feelings of anger and frustration at opportunities lost for early or timely intervention. This is demonstrated by Edgar when being assessed by an ambulance crew:

> *"The ambulance staff are there and I'm there on the floor vomiting every time I move my head…They detected atrial fibrillation cause of what they put me on, but what I know now is that well it's b***** obvious you've had a stroke, ...I think now, it should have been b**** obvious to those people that I'd had a stroke" (Edgar, 54)*

Some participants described having TIAs prior to their stroke diagnosis and they felt that these were clear warning signs of an impending stroke that were sometimes not detected or treated, representing a missed opportunity, as Marcus, a 44-year-old gentleman in focus group 3 describes:

> *"I'm a bit annoyed about it really, cause basically it was a TIA. I think it was a TIA looking back now. I know everyone's doing their best and by the time I got to hospital it had totally resolved so there was no evidence left if that makes any sense ..... you can't blame them really, but I felt like I should have been probably treated better, more quickly, really." (Marcus, 44)*

Who recognises stroke

Not surprisingly, most participants state that their diagnosis of stroke was made by HCPs. However, there were incidences where stroke was recognised by relatives, acquaintances, and neighbours. The recognition of stroke in this way implies some knowledge or assumptions about what a stroke looks like.

In the case of Ernest, a 75-year-old gentleman in focus group 1, a hairdresser told him that he thought Ernest was having a stroke, although Ernest was aware that he was dragging his foot:

> *"I got out of bed and I'm dragging my foot behind me……Went down, got me haircut, and he (hairdresser) said 'What are you up to? I think you've had a bit of a stroke'. So I rang my surgery and I said 'I think I've had a stroke I'm dragging my foot.'" (Ernest, 74)*

Keith, a 73-year-old gentleman in focus group 3, describes how he realised that he was having a stroke one morning and this appears to be based on knowledge of stroke and his experience of observing his father suffering from a TIA. Keith took immediate action, and got himself to a nearby general hospital:

> *"I felt a numbness just down the right-hand side into me thigh and my feet.. And I mean it was strange because it was like a line had been drawn exactly down the centre even through me testicles. One was numb, one was still OK. It was so strange, and I knew straight away that it was that (a stroke).……And I made my way down to the hospital by cab…… But I realised that what I had was, it wasn't a TIA cause I'd seen a TIA with me father, so I knew the difference." (Keith, 73)*

Alana, a 79-year-old lady in focus group 1, recalled how a next-door neighbour had been called to her house by her husband:

> *"I was moving from chair to chair and I just collapsed. My husband didn't know what was wrong with me and the coronation was going on, on the television and we have two doctors that live next door to us, they're not GPs or anything like that, but my husband rang one of them and he came round he said straight away, 'she's had a stroke, get the ambulance'". (Alana, 79)*

6.4.2.1.2 Awareness and understanding

This sub-theme relates to the participant's knowledge of stroke and how they perceive stroke through their own understanding and through their own experiences. A clear knowledge of risk

factors for stroke was demonstrated as several participants talked freely about AF and TIA, which are both well documented stroke risk factors.

Knowledge of stroke and research/information seeking

For some participants, the experience of having a stroke provoked a desire to learn more about the condition and how it could be managed. This was voiced clearly by Edgar after recovering from his stroke, who felt that knowing more about stroke could help him with his recovery in the future:

> *"I want to know more than they tell me, which leads on to wanting to know more about what the future holds, but I just want to know it all, give me all the information you can… the more I can find out, the better for me personally" (Edgar, 54)*

Dennis, a 73-year-old gentleman from focus group 2 explained that he regularly researched treatments for stroke rehabilitation and cited one example of a technique called mirror therapy, which has been shown to be beneficial for limb recovery after stroke. This was not something that was offered to him through the NHS but clearly it seems to have worked for him:

> *"It's called neuroplasticity. So, so I saw one YouTube video, where, cause my hand wasn't working, you put a mirror there and you put your hand behind the mirror. You can't see it but you put your other hand there and it looks to your brain as though that's your left hand. So I started moving this the way I wanted it to go with the….and within less than a week, this hand was working*" *(Dennis, 73)*

Risk factors for stroke

Participants demonstrated a knowledge and awareness of many risk factors for stroke including AF, TIA, CVD and diabetes. Atrial fibrillation and TIA were mentioned most frequently as participants described having these conditions prior to the onset of stroke. Aaron described having both of these risk factors prior to his stroke:

> *"First, I suffered with the atrial fibrillation about 10 years ago and just dealt with that with medication and I had a TIA in 2018. I lost my right arm and my right leg in in the middle of the night, 2:00 in the morning and the speech went and everything. I couldn't, just garbage was coming out of my mouth and then after about an hour when they phoned for the, the ambulance, we went to….hospital, which is only 5 minutes away." (Aaron, 71)*

Perception of stroke through media and by participant experience

Many of the participants in the focus groups were aware of the public information films on UK television regarding stroke. They recalled the original NHS FAST video showing the well-recognised symptoms of stroke (facial droop, arm weakness and slurred speech) (Bietzk et al., 2012; Dombrowski et al., 2013; Flynn et al., 2014) but for those who had experienced other symptoms of stroke, participants felt that this video was not representative of their experience. The later NHS FAST video of a person with a burning hole in their head getting larger as the stroke progressed (Flynn et al., 2014) was also criticised for not being an accurate representation of the experience of many of the participants. This sentiment is summarised by Jeffrey, an 86-year-old gentleman in focus group 1:

> *"I always have visions of this hole in your head burning and getting bigger and bigger that's on the telly. I always thought it was like that but it's nothing like that. That's a misconception" (Jeffrey, 86)*

There were also clear examples that the way in which participants perceived their behaviour whilst they were having their stroke was often different to the behaviour that was observed by others, as recalled by Philip:

> "*And my speech, apparently when I tried to talk, to me it sounded fine. To everybody else, it sounded complete gobbledygook, but what was coming out of my mouth wasn't what I was hearing and what they were hearing" (Philip, 60)*

6.4.2.2 Theme 2: Loss of Identity

The theme loss of identity is based on 3 sub-themes: 1) Grieving for life before stroke; 2) Loss of autonomy; and 3) Vulnerability (Figure 30). Loss of identity was an important theme and participants were found to reflect on the person they used to be and the life they had before the stroke. Recollections of the past were frequent in the focus group discussions as were the expression of strong emotions such as anger, frustration, guilt and fear, as discussed below.

6.4.2.2.1 Grieving for life before stroke

When participants described their experience of stroke, they made frequent reference to their pre-stroke life and their stories often started with descriptions of how their life used to be and some expressed that they were trying to become that person once more even though they realised that this was not possible due to the disabling effects of their stroke. An overwhelming sense of loss was felt when participants recounted their stories.

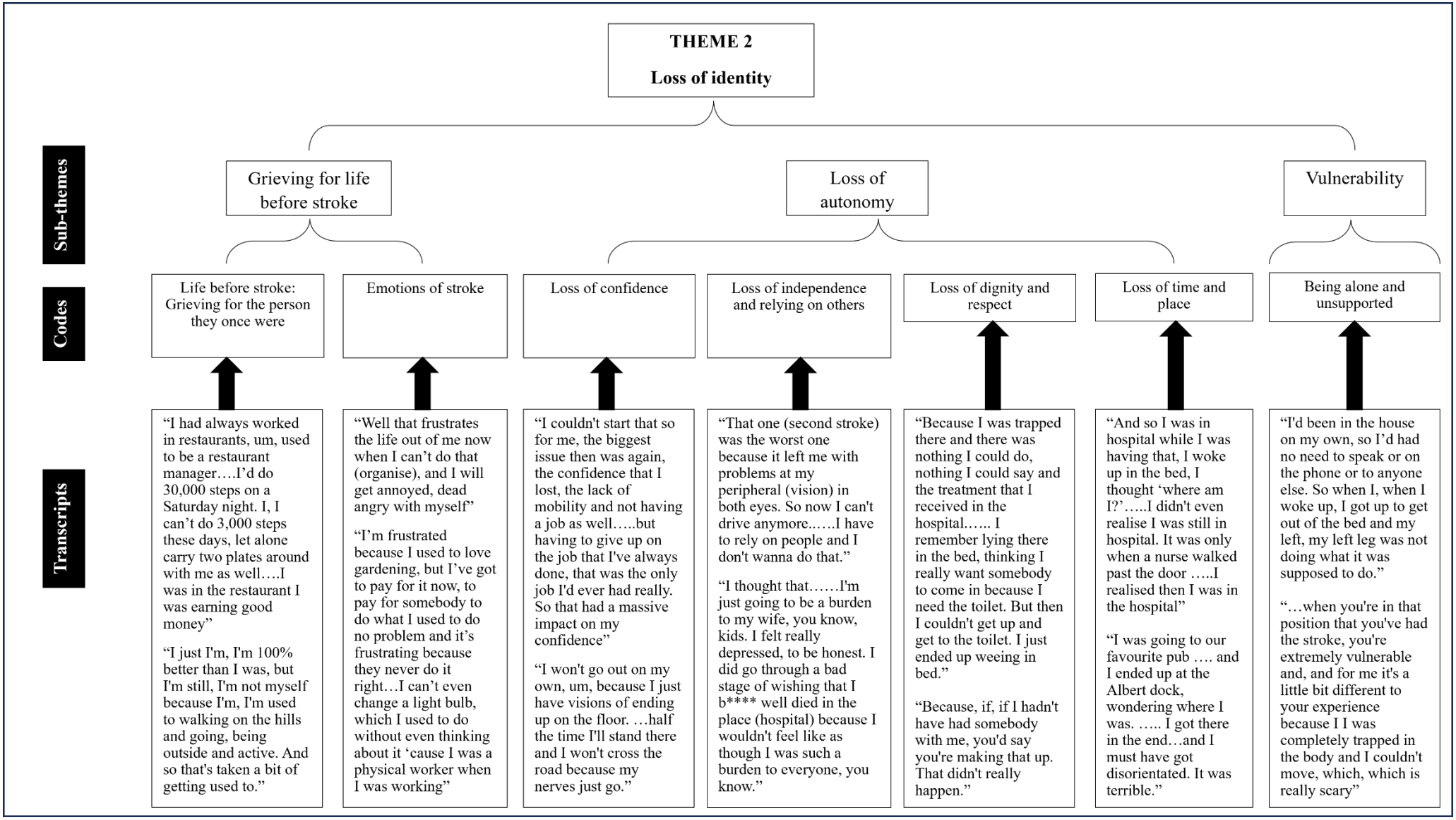


Figure 30 Theme 2, Loss of Identity

Life before stroke: Grieving for the person they once were

Reflecting back to a life before stroke was a common activity in which most of the participants indulged; this involved remembering how they used to be and how the stroke had affected them. Participants often compared their past life with their current life and highlighted the differences in a negative way (losing something). Kirk reflects on how stroke has changed his life:

> *"I had always worked in restaurants, um, used to be a restaurant manager so that I was due to start a new job in January…but quickly realised that I couldn't…I used to work on a Saturday night. I'd do 30,000 steps on a Saturday night. I can't do 3,000 steps these days, let alone carry two plates around with me as well…." (Kirk, 46)*

Emotions of stroke

Recalling experiences of stroke often evoked strong emotions; commonly it was frustration at not being able to do the activities they could do prior to the stroke event and anger at how their life had changed for the worse. There were feelings of guilt after they had recovered from stroke, knowing that their symptoms could have been a lot worse and life limiting. Being exposed to people whose strokes were much more serious while either on the stroke wards or in the stroke unis had reaffirmed this belief. This is summarised by Allison, a 57-year-old lady in focus group 1:

> *"Well that frustrates the life out of me now when I can't do that (organise), and I will get annoyed, dead angry with myself,…. but when I calm with down myself, I think, 'God there's people on that ward, you know, who didn't get all their movement back. I did and I can still go out, I've got my (driving) licence back'……..and then I feel guilty then and think……. 'I'm lucky, really lucky compared to some of them in there." (Allison, 57)*

Jeffrey voiced his frustration about being unable to perform simple tasks that he did not think twice about prior to his stroke and his inability to engage in one of his enjoyable hobbies:

> *"I'm a lot slower and it's frustrating. I'm frustrated because I used to love gardening, but I've got to pay for somebody to do what I used to do no problem and it's frustrating because they never do it right, never do it as good as you used to do….. I get frustrated that I can't do anything over skirting board level……I can't even change a light bulb, which I used to do without even thinking about it 'cause I was a physical worker when I was working" (Jeffrey, 86)*

6.4.2.2.2 Loss of autonomy

Participants described a sense of loss of control and confidence and many found it difficult to adapt to the change and accept that there were some things that they could no longer do as they had done before. Loss of independence was a major element of the discussions and was often associated with feelings of guilt for being reliant upon others.

Loss of confidence

Participants talked about a loss of confidence following their stroke that had far reaching consequences, impacting on their social and financial activity. Kirk described the situation where he was unable to start a new job because of his stroke:

> *"I couldn't start that so for me, the biggest issue then was again, the confidence that I lost, the lack of mobility and not having a job as well. And in addition to all that the, fact that I would probably well, I still haven't returned to that industry, but having to give up on the job that I've always done, that was the only job I'd ever had really. So that had a massive impact on my confidence. Obviously, a big impact on finances." (Kirk, 46)*

A loss of confidence prevented some participants from engaging in normal pre-stroke social activity. Mariah and Peggy described feelings of anxiety when considering going out alone:

> "*And sort of in a nutshell really and, and my anxieties and I'm scared if I go out, is it (the stroke) gonna happen again?" (Mariah, 53)*

> *"I'm on the phone with a psychologist um just the depression and anxiety because I won't go out on my own, um, because I just had visions of ending up on the floor. Um. And I have to keep looking, you know, if I'm crossing the road and half the time I'll stand there and I won't cross the road because my nerves just go." (Peggy, 64)*

Loss of independence and relying on others

Loss of independence was a common discussion point amongst the participants. Many of them owned a car and had driving licences before they had a stroke. Many strongly viewed the loss of their driving licence as a loss of their independence, particularly those who were living by themselves, even if they had friends and family close by. This was summarised by Peggy:

> *"That one (second stroke) was the worst one because it left me with problems at my peripheral (vision) in both eyes. So now I can't drive anymore. I've had to return my driver's licence to DVLA and that has, you know, knocked me for 10 because I'd drive*

down to my daughter's in Lincoln. I can't do that now. I could just jump in the car, go to friends' houses and again, I have to rely on people and I don't wanna do that…" Peggy, 64)

Peggy's experience also highlighted the dependency of stroke survivors on others when they no longer had the freedom that they enjoyed pre-stroke. This was associated with feelings of guilt, anger, depression and frustration at not being able to control their own lives. Francis, a 51-year-old gentleman in focus group 2, described how his dependence on his family made him feel like a burden after his stroke had left him confined to a wheelchair and reliant on his family:

*"I thought that this is how things are gonna be, you know, you're gonna be moved around. I'm just going to be a burden to my wife, you know, kids. I felt really depressed, to be honest. I did go through a bad stage of wishing that I b**** well died in the place (hospital) because I wouldn't feel like as though I was such a burden to everyone, you know." (Francis, 51)*

Loss of dignity and respect

Francis described a particularly traumatic experience of his stroke management in hospital; his stroke was severe and had left him paralysed and unable to communicate with hospital staff, which affected his care. He described his experience as being trapped in his own body:

"I was trapped there and there was nothing I could do, nothing I could say and the treatment that I received in the hospital. I remember a night staff and trying to say to him that I needed the toilet. Get some sleep, turn the lights off. Close the door. Put the buzzer out of reach. ….. I remember lying there in the bed, thinking I really want somebody to come in because I need the toilet. But then I couldn't get up and get to the toilet. I just ended up weeing in bed." (Francis, 51)

Francis stated that there were situations in which he felt he was not listened to or respected. He described how he was a type 2 diabetic and needed water after he became dehydrated in hospital, but the staff appeared to ignore his requests and treated him in what appeared to be a disrespectful and contemptable manner:

"That they've since looked at the records to find I was severely dehydrated. They hadn't been giving me the water, but she'd (nurse) written in the notes that she'd given me 3 litres of water, so I had a, a really, really bad experience with this…..I was asking for water and couldn't get none but my blood test clearly proved that I wasn't telling lies. I

was dehydrated for over 5 days and while I had this tube in I was begging and pleading with people. And it was like a running joke in that 'Here he is, waterman, he's always crying out for water'". (Francis, 51)

Francis believes that if his wife hadn't been in hospital with him to witness his care, he would not have been believed:

"Because, if I hadn't have had somebody with me, you'd say 'you're making that up. That didn't really happen'. My wife experienced it all and even a, a doctor experienced it…..but my blood test proved that I wasn't telling lies" (Francis, 51)

Loss of time and place

Participants often mentioned that the stroke had left them with memory problems during and after their experiences. This resulted in them losing their sense of time and place, as Jack, a 49-year-old gentleman in focus group 3 describes:

"I was in hospital while I was having that, I woke up in the bed, I thought 'where am I?', I didn't even realise I was still in hospital. It was only when a nurse walked past the door because you could see through the door, seeing me in the hospital gown I realised then I was in the hospital" (Jack, 49)

These episodes of loss of time and place occurred both during acute treatment for stroke and after discharge from the stroke unit or hospital, so in this sense loss of time and place appears to be an ongoing issue that stroke survivors must face.

6.4.2.2.3 Vulnerability

Several participants described a sense of vulnerability both during and after stroke. Travis mentioned that vulnerability was one feeling he experienced following his stroke in addition to feeling depressed:

"The initial feelings were vulnerable, depressed, then I had fatigue, as we've all had, which I still have now, but not as bad." (Travis, 64)

Francis also described feelings of vulnerability based on his own experience of being unable to move or communicate with others:

"When you're in that position that you've had the stroke, you're extremely vulnerable, and for me it's a little bit different to your experience because I was completely trapped in the body and I couldn't move, which, which is really scary" (Francis, 51)

His feelings of vulnerability were compounded when he heard others talking about end-of-life care, which led him to question his own mortality:

> *"And I could also hear people talking about palliative care, which made me think that this is it for me and this is - I'm going to die in here at some point" (Francis, 51)*

Being alone and unsupported

Francis, who had a severe stroke and a particularly traumatic experience in hospital, made a very clear point that he thought he was treated without respect and dignity but he was also left unattended for long periods of time and he had very limited ability to communicate. He felt that he ought to complain about the way in which he was treated, especially as he was in such a vulnerable position:

> *"I don't want to do anything about it, I just don't want it to happen to anyone else, because when you're in that position that you've had the stroke, you're extremely vulnerable and, and for me it's a little bit different to your experience because I was completely trapped in the body and I couldn't move, which is really scary." (Francis, 51)*

Roger described experiencing two strokes, both of which occurred while he was alone in his house. Fortunately, he was able to get help himself on both occasions as the symptoms appeared to come on gradually. He was aware that he might have been suffering from a stroke on the first occasion:

> *"I thought 'I'm not going to A&E at midnight on Friday night. I'll go in the morning' and just slept like a baby…..I'd been in the house on my own, so I'd had no need to speak or on the phone or to anyone else. So when I woke up, I got up to get out of the bed and my left leg was not doing what it was supposed to do…..and that's when I thought 'Yeah, I think you've had a stroke'" (Roger, 54)*

On the second occasion, Roger had experienced some visual disturbance that he attributed to migraine (a condition he suffered from occasionally) and at home he described feelings of nausea and dizziness with subsequent vomiting, something he didn't equate with a stroke:

> *"I was standing in the kitchen and just felt myself fall back and it, actually just knocked me out, I did fall over a couple of times that weekend and it wasn't till I actually went to the GP on the, I still didn't know it was a stroke. Went to the GP on the Tuesday*

afternoon and she just said 'get to the hospital now'. They did all the tests and it was a stroke." (Roger, 54)

Other participants expressed concern for those living alone with stroke as the majority of participants had support for spouses, family and friends to help them whilst they were experiencing stroke and also during the recovery process. There was a fear of being alone and unsupported in the future. The sentiment is summed up by Maggie, a 77-year-old lady in focus group 3:

"I'm lucky because I've got some friends that are close by and I've got two nephews who are excellent, you know. While they live a little bit away, they, they're fantastic. But I can imagine if I was on my own, there is no support at all." (Maggie, 77)

6.4.2.3 Theme 3: Life After Stroke – 'Feeling Lucky'

The theme Life after stroke – 'Feeling lucky' arose from two main sub-themes: 1), making sense of a catastrophic event, and 2) thoughts and sentiments (Figure 31). This theme encompasses the ways in which stroke survivors make sense of the experience by reflecting on their experiences and vocalising how it impacted on their lives and captures their thoughts and sentiments during and after the event or events.

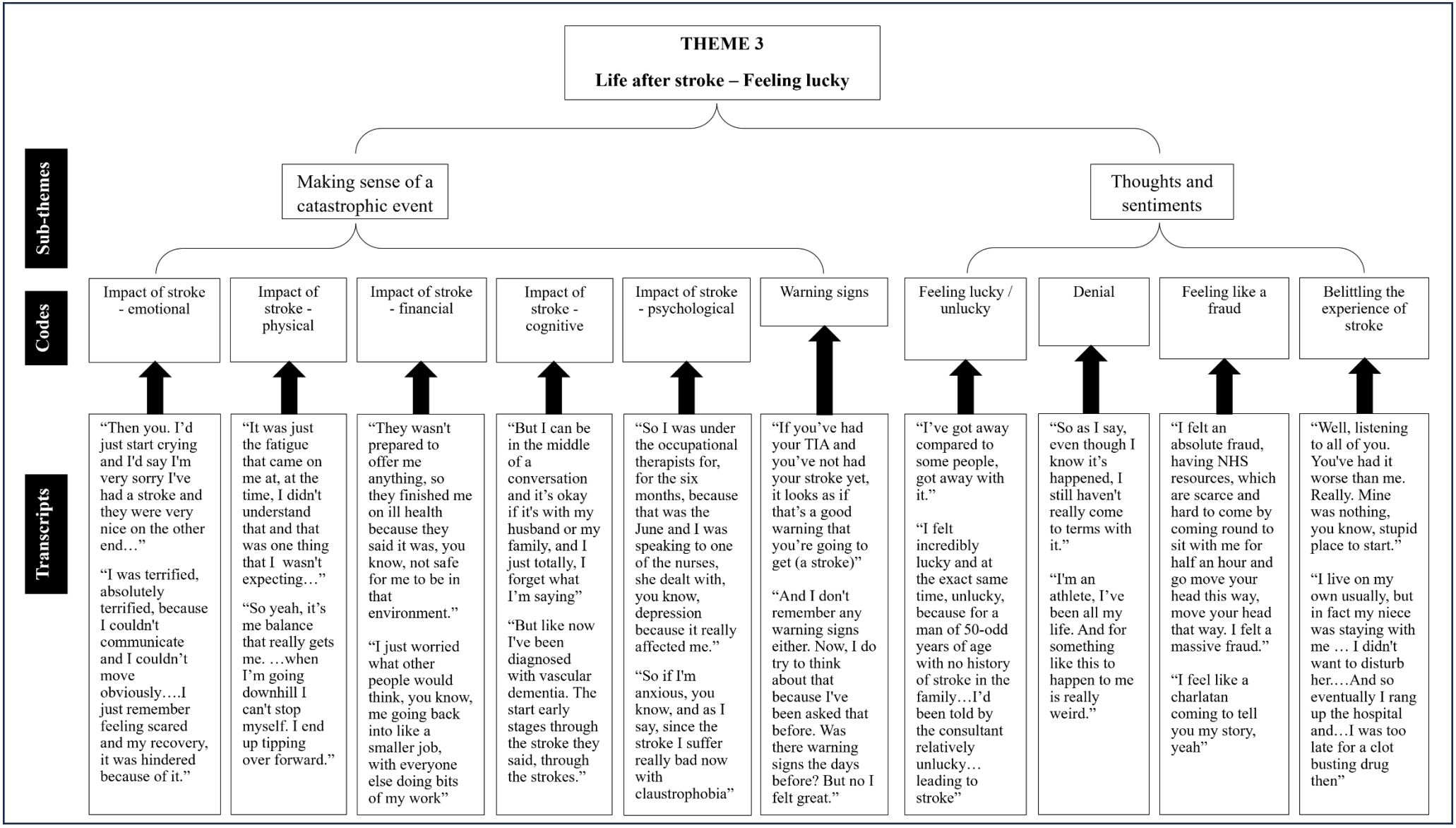


Figure 31 Life after Stroke – "Feeling Lucky"

6.4.2.3.1 Making sense of a catastrophic event

From discussions with focus groups, it was clear that the impact of stroke was far reaching, and participants had to make sense of the impact of stroke and how it had changed their lives. Stroke negatively impacted on many domains; these included emotional, physical, financial, cognitive and psychological and these are described in more depth below.

Impact of stroke – Emotional

Stroke negatively impacted the emotional status of participants, who recalled strong responses such as tearfulness and fear. Maggie described a time when she was on the phone to a customer service agent and after a minute or so she became overwhelmed with emotion and burst into tears, making it difficult to explain what she needed:

> *"I'd just start crying and I'd say 'I'm very sorry I've had a stroke' and they were very nice on the other end but……I would never have been able to explain what I wanted or what problems were, you know" (Maggie, 77)*

Another strong emotion brought on by stroke was fear, as articulated by Mariah, whose recovery was impacted by this feeling:

> *"I just remember feeling so scared, not knowing what was going on and I could hear the word 'stroke', but it wasn't sinking in. I was terrified, absolutely terrified, because I couldn't communicate and I couldn't move obviously. I just remember feeling scared and my recovery, it was hindered because of it." (Mariah, 53)*

Impact of Stroke -Physical

The most frequently reported impact of stroke upon participants were the physical symptoms and these often negatively affected recovery. Post-stroke fatigue was very common amongst participants and its impact was far reaching, as Keith states:

> *"I think it was the third week I was doing some weeding out in the garden and …. I did one, and I couldn't do the second one. I just, total exhaustion. It was just the fatigue that came on me at the time, I didn't understand that and that was one thing that I wasn't expecting, I didn't expect it at all." (Keith, 73)*

Henry, a 63-year-old gentleman in focus group 4, described his post-stroke fatigue as very distinct:

> *"I think I found like a kind of a very distinct fatigue that I had. That's what it was. It wasn't what, like I'd done something. Well, I put it down to that because I've thought*

I've probably over trained and I felt so fatigued and that, but it was a real…..It's really hard to explain. It's like a fatigue I've never had before." (Henry, 63)

Participants frequently spoke about balance problems following their stroke, which increased the likelihood of falls. Aaron, a 71-year-old gentleman in focus group 4, recalled how he had been affected by balance problems:

"So yeah, it's my balance that really gets me. And when I hit a rise in the road or whatever, I slow down, my legs don't seem to be working properly either and then when I'm going downhill I can't stop myself. I end up tipping over forward." (Aaron, 71)

Impact of stroke – Financial

For those participants who were working at the time of their stroke, the impact of stroke on financial and work continuity was often substantial. Marcus recalls remaining in the same role but having to reduce his working hours, and that he struggled to adapt to this change:

"Well, I did a couple of weeks where I was doing mornings so like nine till one and then just got back in with the team. So it was different really. I just worried what other people would think, you know, me going back into like a smaller job, with everyone else doing bits of my work, that's my worry really. I did struggle with that change really." (Marcus, 54)

Other participants were unable to return to work following stroke, and were made redundant by their employer as Francis describes:

"Because I'm on the maintenance team I would service and repair all the cleaning machines that you drive round. They weren't prepared to offer me anything, so they finished me on ill health because they said it was, you know, not safe for me to be in that environment" (Francis, 51)

After redundancy, those affected participants lost their financial independence and often had to resort to using savings and claiming benefits to make ends meet.

Impact of stroke - Cognitive

Participants stated how stroke had negatively impacted on their cognitive function, resulting in memory problems or more serious issues such as dementia. Allison described how she frequently lost the thread of a conversation and became angry and embarrassed as a result, especially if this happened in a public place such as a shop.

"I can be in the middle of a conversation and it's okay if it's with my husband or my family, and I just totally, I forget what I'm saying…..Nine times out of ten it's the punchline and people are looking at me and I'm just going – the word's there but I can't get it and.... I get dead red and dead angry with myself, and I'll go out of the shop and say 'I'm sorry' and walk out, phone me husband to come and pick me up I'm coming home." (Allison, 57)

Impact of stroke - Psychological

Stroke had a substantial negative impact on the psychological wellbeing of the participants as depression and anxiety were commonly reported post-stroke conditions. Participants stated how they struggled with their mental health, especially if there was no support for them, and some highlighted that they were still trying to cope with mental health problems. Peggy describes how she managed her depression following stroke:

"I was under the occupational therapists for the six months, because that was the June and I was speaking to one of the nurses, she dealt with, you know, depression because it really affected me." (Peggy, 64)

Mariah described how she had become claustrophobic since her stroke:

"So, if I'm anxious, you know, and as I say, since the stroke I suffer really bad now with claustrophobia" (Mariah, 53)

Warning signs

Focus group participants were asked to reflect on their experiences of stroke and to state if they were aware of any warning signs that indicated that they were likely to suffer a stroke. This reflection was often linked to a previous diagnosis of a stroke or TIA following a scan and a discussion with the treating clinician, prompting participants to recall how they felt or what they were doing at the time of the event. For example, Alice recalled being told by a clinician following a scan she had a TIA about six months prior to her stroke and she tried to remember where she was and what she was doing at that time:

"Up till then, because I'd been for the scan, she actually said 'you had a TIA 6 months ago'… and I'm thinking well that would have been round about Christmas, and we were away at Christmas at my daughter's and I don't remember anything at all that made me feel, and we do drink a lot at my daughter's, so if I was feeling unsteady on my feet I wouldn't have been putting it down to a TIA that's for sure…. I tried thinking in my brain did I feel any different then?" (Alice, 78)

There was a feeling that experiencing one or more TIAs could have been a warning sign for a stroke, as Jeffrey surmises:

> *"If you've had your TIA and you've not had your stroke yet, it looks as if that's a good warning that you're going to get (a stroke)" (Jeffrey, 86)*

This was a subject that was discussed in several focus groups and for others, the stroke was completely unexpected with no warning signs in advance, as Mariah states:

> *"I don't remember any warning signs either. Now, I do try to think about that because I've been asked that before. Was there warning signs the days before? But no, I felt great." (Mariah, 53)*

6.4.2.3.2 Thoughts and sentiments

The sub theme 'thoughts and sentiments' captures the thought processes and feelings frequently expressed by participants during the focus group discussions.

Feeling lucky/unlucky

One of the most frequently reported sentiments was that of 'feeling lucky'. All participants had recovered from their stroke sufficiently to be able to willingly attend and participate in a focus group and feelings of being lucky were made in comparison with other stroke patients. These were individuals, some with severe disabilities, that the participants observed whilst they were in hospital or on a stroke unit themselves. This led to participants feeling grateful that they had recovered and the realisation that the outcome could have been much worse. This is summed up by Aaron:

> *"I've got away compared to some people, got away with it." (Aaron, 71)*

Edgar described conflicting feelings of being lucky at having recovered completely from a stroke but also unlucky after experiencing a stroke as he was otherwise healthy with no obvious risk factors:

> *"I felt incredibly lucky and at the exact same time, unlucky, because for a man of 50-odd years of age with no history of stroke in the family, relatively healthy lifestyle, some exercise although you can always do a bit better, um, I'd been told by the consultant relatively unlucky, atrial fibrillation, blah blah blah, leading to stroke. Feeling lucky and unlucky at the same time is really weird.*" (Edgar, 54)

Denial

While many participants stated that they had come to terms with having a stroke, there were some individuals who found it difficult to accept that they had experienced this life-changing event and were still struggling to cope as a result. Mariah described her experience of stroke and of her refusal to accept it:

> *"So as I say, even though I know it's happened, I still haven't really come to terms with it." (Mariah, 53)*

Henry stated that, during his recollection of his own stroke experience, he was a martial arts instructor and a fit and healthy individual. He experienced symptoms of stroke one morning:

> *"I just woke up one morning and my wife was out at the time and I tried to get out of bed and all the left side wasn't working with me. I just thought this is weird, this, you know, because, I mean, I'm an athlete, I've been all my life. And for something like this to happen to me is really weird. I train six days a week. I just got up to go and have a shower and as I came out, I remember I fell over as well. And I found it really hard to get back up and I thought this is crazy what's going on". (Henry, 63)*

Philip described feelings of guilt when he was in a stroke unit with other patients:

> *"I felt a bit guilty being in there because I looked, ...they put me on the stroke ward obviously, but I was looking at the state of some of the people, and I'm thinking 'I feel fine' you know" (Philip, 60)*

Feeling like a fraud

Participants often stated that their strokes had been mild in severity, allowing them to recover but this was linked with feelings of being a fraud. Participants were aware of limited NHS resources, and they felt embarrassed and guilty at having taken up those resources whilst they were being diagnosed and treated for stroke. Again, comparisons were made with other patients who had severe strokes and disabilities that left them partially or wholly dependent on others. The sentiment of feeling like a fraud was voiced by Edgar:

> *"I felt an absolute fraud, having NHS resources, which are scarce and hard to come by coming round to sit with me for half an hour and go move your head this way, move your head that way. I felt a massive fraud." (Edgar, 54)*

Dennis felt uncomfortable talking about his experience of stroke in his focus group as he expected others to have experienced more severe strokes than him:

"I feel like a charlatan coming to tell you my story, yeah" (Dennis, 73)

Belittling the experience of stroke

Some participants felt they had to belittle or trivialise their own stroke experience, indicating a reluctance to take their experience seriously. This sometimes occurred after individuals had listened to the experiences of several others and had decided that their experience was somehow less important, as Rose describes:

> *"Well, listening to all of you. You've had it worse than me. Really. Mine was nothing, you know, stupid place to start." (Rose, 89)*

Maggie described her stroke experience in a trivial manner and this appears to have resulted in a delay in her seeking help:

> *"Well, ... it's a bit silly really, but I woke up in the middle of the night. ....And when I went to wash, I was a bit unsteady and I looked at myself in the mirror ....and I decided that I was alright. It was just the fact it was in the middle of the night, which ...was absolutely stupid because it of course I knew all the stuff about face and arm and leg and whatever....and I live on my own usually, but in fact my niece was staying with me ... Stupid the way your brain works..... So I didn't want to disturb her. How daft can you get? And so eventually I rang up the hospital and....I woke my niece up and I said to ring my nephew, which is all silly because I was too late for a clot busting drug then" (Maggie, 77)*

6.4.2.4 Theme 4: Dealing with the past and looking to the future

This theme is based on 4 sub-themes: 1) recovering from stroke, 2) giving up the old and adjusting to the new, 3) living with uncertainty and 4) comparing and sharing experiences with other stroke survivors (Figure 32).

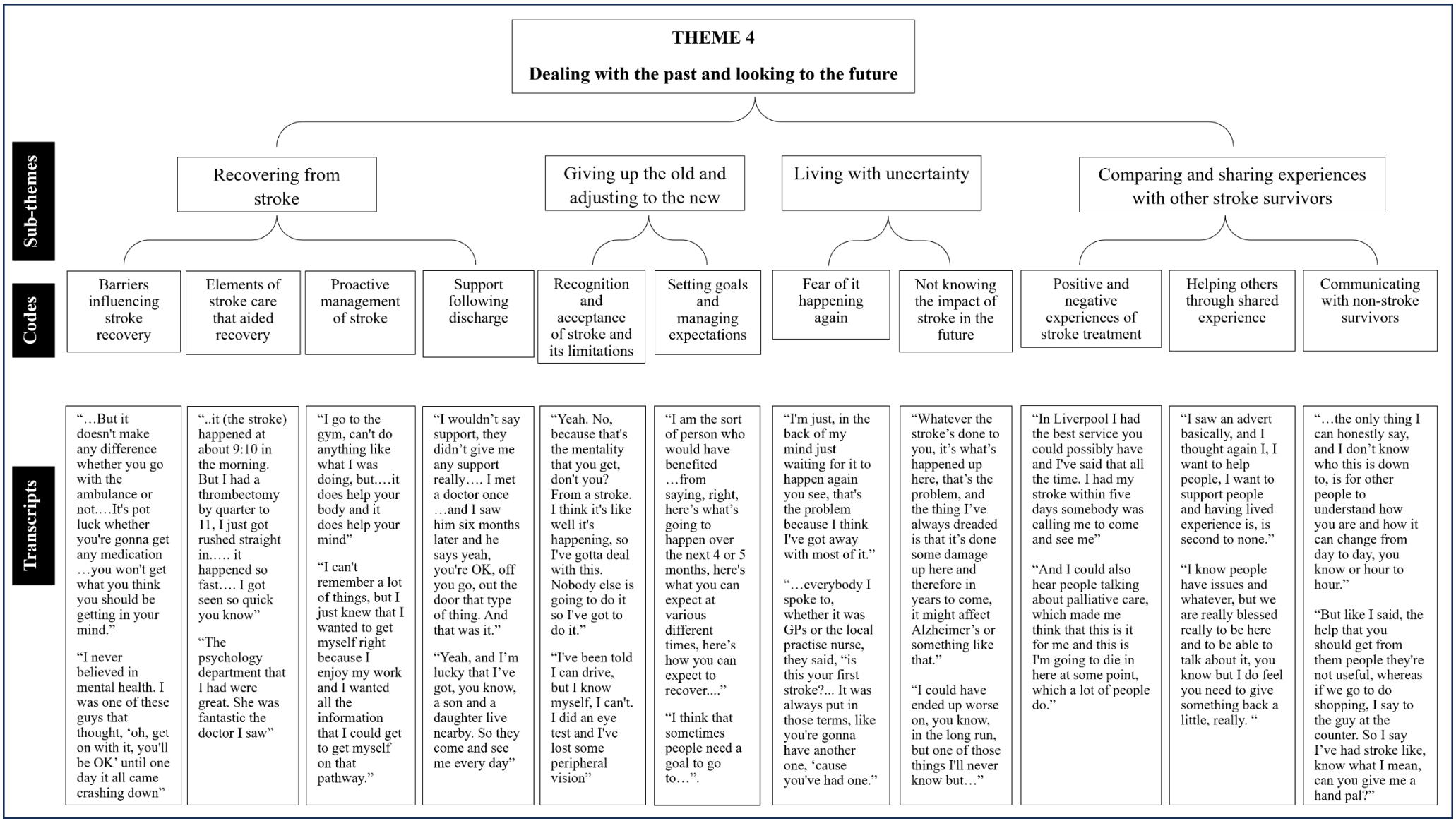


Figure 32 Dealing with the past and looking to the future

6.4.2.4.1 Recovering from stroke

Participants described their own experiences of recovering from stroke and some mentioned specific barriers that they felt hindered their recovery. Conversely, participants also identified elements of their stroke care that made a positive difference to their recovery. The focus groups discussed ways in which they managed their stroke recovery themselves and these were frequently referred to as being proactive and taking charge of their lives. Participants also discussed aspects of the support that they received following discharge from the hospital or stroke unit.

Although some participants found it difficult to accept having a stroke (see Section 6.4.2.3.2), most recognised that life would not be the same and they would have to make allowances and adjustments to cope with the impact of stroke. For some, this involved setting goals or managing their expectations. Participants also described the uncertainty of their future following stroke, which involved an expectation of subsequent strokes and concerns about the long-term effects of stroke. There were positive and negative experiences of stroke treatment and many participants found sharing their stories with other stroke survivors was beneficial. There was also a need for understanding from non-stroke survivors about the difficulties some participants faced in daily life.

Barriers influencing stroke recovery

Participants cited that a lack of clear information on aspects of stroke recovery was a barrier to their improvement. These aspects included the use of aspirin in the acute treatment of stroke, post-stroke, and the timing of stroke treatment. A number of participants discussed the uncertainty when it came to taking aspirin for the treatment of stroke. Medical guidance seemed to the participants be advising against using aspirin and changing to other antiplatelet drugs such as clopidogrel. Marcus remembered high-dose aspirin from an advert he saw on the television on stroke treatment:

> *"It's annoying, because, like we've all got access to aspirin over the counter. So it's part of the advert based on, you know the FAST thing. Give them a certain amount of aspirin straight away. Yeah, we've all got that in the house haven't we. But I didn't know that's what they treat you with straight away and that's what they did. It takes all that time because you're thinking you need medical intervention when you can as a sufferer, you could have done it yourself sort of thing you know. Or you could have made it easier." (Marcus, 44)*

There was uncertainty about the dose of aspirin that should be used in treatment of a stroke, as Keith explained:

> *"I kept a box (of aspirin) in the house, it was 75 milligram, we get 75 milligrams, isn't it the tablets that you get? And the dose for a stroke I believe was 300 milligram." (Keith, 73)*

Keith's experience also highlighted a lack of clear information about the timing of stroke treatment; he had expectations that he would receive medication himself. This was a sentiment also expressed by Roger.

> *"They, always say, you know, if you think you've had a stroke then call 999 and get an ambulance out, right. But it doesn't make any difference whether you go with the ambulance or not. It's potluck whether you're going to get any medication when you get there you won't get what you think you should be getting in your mind. I think most people think 'Ohh we'll go there and they'll give us some magic pill' and take that and that will sort something out do you know what I mean, to stop it getting any worse because the whole idea is, is to stop it getting worse." (Keith, 73)*

> *"I was in for longer, I think than I needed to be especially as they don't actually treat you in there, they just sort of wait for it to get better don't they?" (Roger, 54)*

The effects of stroke on mental health were frequently discussed as a barrier to recovery. Participants freely talked about anxiety and depression and how they struggled to cope with it. Philip described how he was surprised by depression following his stroke:

> *"But what I wasn't prepared for was the mental side of what had happened to me. And I can remember that the physios that came, they kept saying to me 'Are you OK?' 'Yeah, I'm fine', because I never believed in mental health. I was one of these guys that thought, 'oh, get on with it, you'll be OK' until one day it all came crashing down." (Philip, 60)*

Elements of stroke care that aided recovery

Participants also described elements of their stroke care that made a real difference to their recovery from stroke. Michael, a 58-year-old gentleman in focus group 4, explained how rapid diagnosis and treatment allowed him to make a full and quick recovery:

> *"And then me mate drove round the corner straight away, blew through to the operators and then they got an ambulance and it happened at about 9:10 in the morning. But I had a thrombectomy by quarter to 11, I just got rushed straight into the treatment centre.*

Yeah, and straight in and had the thrombectomy that was the Monday. I came out of hospital dinner time-ish on a Wednesday" (Michael, 58)

Speed of treatment was also mentioned by Alana as she was convinced that rapid diagnosis by neighbours, who were doctors, and a rapid CT scan were critical to the speed of her recovery:

"One of the doctors on the stroke unit, you know, we were discussing this point that I went straight to a CT scan and she said 'well that has helped you with your recovery'....but she said they've tried to train the paramedics and the ambulance staff that when it is somebody with a suspected stroke, that they don't take them to A&E, they take them straight to the CT scanner....that could be a crucial thing in the training of the paramedics and the ambulance service, you know, if they were able to recognise first and get that early treatment, it would save a lot of people." (Alana, 79)

The effects of stroke on the mental health of participants were a frequent and recurrent topic and the majority had experienced depression or anxiety. Psychological support in the form of counselling was one element of care that really made a difference, as Philip and Mariah state:

"But I thought, 'or maybe I do need to see somebody.' But since then I've had a few sessions and it's been fantastic what it does for you. I, once I've admitted it (depression) to myself, then they were great with me. Once I put my hand up and said 'yeah, there's something wrong here.' The psychology department that I visited were great. She was fantastic the doctor I saw, but it took, everybody, everybody else could see it apart from me because I didn't believe it." (Philip, 60)

"I had a stroke psychiatrist and she was lovely, and she was patient and you know, we learned a lot from each other and she stayed with me for the year. So if I ever struggle again to just get in touch with the stroke centre and you know. So, I feel like if I do need that help again, which I probably will, it's there" (Mariah, 53)

Participants also described how physiotherapy had a positive impact on their recovery, allowing them to move and regaining their independence. Maggie benefited so much from her 6 months of physiotherapy that she continued to receive treatment from a private physiotherapist after the NHS resource had ended:

"I pay for a private physio to come whenever, every two weeks or something like that, and then there's a what's it called. There's a guy. He's a trainer to do with, I can't remember the name now, but he's to do with, he specialises in strokes. So, he, does exercise with me as well and gives me things to do…" (Maggie, 77)

Proactive management of stroke

The majority of participants had taken control of their own stroke recovery and they described the ways in which exercise helped them to maintain or improve their recovery. Participants viewed exercise as an important part of their life even if it was more difficult to perform post-stroke, as Gracie describes:

> *"I go to the gym, can't do anything like what I was doing, but I still do it and, and I do think going to the gym. This is why I said to this gentleman (other participant), it does help your body and it does help your mind" (Gracie, 75)*

Participants also discussed taking responsibility for their own recovery and this was accompanied with a clear self-determination to get better. Michele, a 70-year-old lady in focus group 4, articulated this:

> *"I can't remember a lot of things, but I just knew that I wanted to get myself right because I enjoy my work and I wanted all the information that I could get to get myself on that pathway." (Michele, 70)*

Support following discharge.

In the focus groups, participants described the level of support they received upon being discharged from the hospital or stroke unit back to home. Regular follow-up healthcare support was sometimes lacking as Travis mentions below and in some cases the participants described the follow-up they did receive was disorganised, with appointments at different locations and at times which made it difficult to attend all of them, as Jack states.

> *"I wouldn't say support, they didn't give me any support really, but in terms of the support mechanisms other than the occupational health therapist and the physio, you were just....I met a doctor once and I saw him six months later and he says 'yeah, you're OK, off you go', out the door that type of thing. And that was it." (Travis, 64)*

> *"I got two appointments, sometimes I've got 3 on the same day, 10 minutes for each of them but miles apart. ...., so I've had to go around, cancel certain ones, I mean, because that's hard, I don't know what the hell I was doing…" (Jack, 49)*

Support from friends and family post-stroke was an important element mentioned by several participants, as Aaron and Edgar describe below.

> *"Yeah, I'm lucky that I've got, you know, a son and a daughter who live nearby. So, they come and see me every day." (Aaron, 71)*

"I didn't need that much physio, I didn't need that much help at all as I've got family at home that could help me so I managed to maintain any kind of independence" (Edgar, 54)

Participating in stroke research clinical trials was a topic raised by several participants. In their experiences, participating in clinical trials allowed them to give something back to the team who had helped them through recovery and to contribute to the knowledge base. Gracie's motivation for participating in clinical trials appears to be through her recovery and feeling lucky:

"I count myself very lucky indeed. And this is why I do this research. I've done four up to now I feel I need to give something back for people in the future you know, because that day I went in there …. the other two people died that day." (Gracie, 75)

In some cases, the care and support the participants received from the clinical trials research team was perceived to be better than that provided by the NHS and frequent contact from the researchers provided reassurance, as Keith describes:

"I think was the best thing that's ever happened to me because all it was, was two people and it was a girl called Sarah and John and, and they just chatted to me in a room and they just did the tests and mental health tests visual tests all that stuff but what I liked about it at that time was I could have someone. They said 'you can phone us up 24 hours a day' but then every so often they'd phone me up. I felt reassured that no matter what happened, I could fall back on them." (Keith, 73)

Dennis's experience of being involved in clinical trials led him to believe that there was a difference in the quality of care he received during the trial compared with his NHS treatment. He described numerous NHS follow-up appointments which were repeatedly cancelled and resulted in him seeing nobody from the hospital team after discharge. In contrast, his care during the research was superior in his opinion:

"Spent all day in the hospital doing my exercise and everything that was fantastic. So, I felt as though I was being cared for but only because it was the research study with the Professor. I felt as though the NHS hadn't followed up on me at all." (Dennis, 73)

6.4.2.4.2 Giving up the old and adjusting to the new

During their discussions, many participants accepted that they had suffered a stroke and that they would have to change their lifestyles in order to adapt to a different life. This process

involved recognising that the stroke would restrict their normal lives in some way. Some of the participants mentioned that setting goals helped them to focus and have something to aim for; this was an important part of their recovery journey.

Recognition and acceptance of stroke and its limitations

The participants discussed how they had come to terms with their stroke. One topic that was discussed commonly was the ability to drive, which in some cases was regained after recovery but lost in others due to permanent loss of some peripheral vision and an inability to pass the vision test required for regaining a driving licence. Philip spoke very frankly about his own stroke experience, which involved some permanent peripheral sight loss, and even though he had retaken his driving test and passed, he felt that he could not continue to drive safely and that he had accepted this limitation:

> *"I've been told I can drive, but I know myself, I can't. I did an eye test and I've lost some peripheral vision so I don't know whether I fluked it or whatever, but they passed me and they've said I can drive, which is absolutely ridiculous because I can't. But there's nothing to stop me. I've got my driving licence back. The only thing that's stopping me driving is me because I know I can't." (Philip, 60)*

Setting goals and managing expectations

Edgar stated that it was important for him to have an idea from a person in authority about how he might expect to recover from his stroke and how long this recovery might take:

> *"I think I am the sort of person who would have benefited at the start from saying, right, here's what's going to happen over the next 4 or 5 months, here's what you can expect at various different times, here's how you can expect to recover at various different times and what that would have meant for me individually." (Edgar, 54)*

Allison agreed that setting goals was beneficial for some people but highlighted the danger of not achieving the goals set and how that would make her feel about herself:

> *"Everyone's different aren't they. I think that sometimes people need a goal to go to, personally I'd have felt very disheartened because if they'd have said to me you know, you'll be here in 6 months and I was only here, I'd have thought 'well this isn't going right', you know, I wouldn't have felt good about it, um, so I just used to say to them 'I'll see how things are', how me progress is myself, because I'd feel disheartened ." (Allison, 57)*

6.4.2.4.3 Living with uncertainty

When talking about managing stroke in the future, the majority of participants expressed uncertainty over how their stroke could affect their health and well-being and there was a fear (sometimes an expectation) that they would have another stroke, expressed by those who knew of no obvious reason why they had suffered their stroke, as Dennis described:

> *"I've had absolutely no, zero history. I've been fit and healthy all my life and all of a sudden, just like that, that one episode". (Dennis, 73)*

Fear of it happening again

There was a perception among some participants that if they had experienced a mild stroke with a full recovery, that they were expecting a subsequent stroke that might be more severe, as Aaron described:

> *"I'm just, in the back of my mind just waiting for it to happen again you see, that's the problem because I think I've got away with most of it." (Aaron, 71)*

Some participants mentioned that the expectation of subsequent strokes wasn't restricted to patients and that HCPs often spoke to them in a manner that suggested subsequent or multiple strokes:

> *"The things that were getting to me is everybody I spoke to, whether it was GPs or the local practise nurse, they said, 'Is this your first stroke?' It was always put in those terms, like you're gonna have another one, 'cause you've had one." (Dennis, 73)*

Not knowing the impact of stroke in the future

This was a frequent topic of discussion in the focus groups, with previously healthy participants concerned about developing new problems in the future and some of the older participants reporting that their pre-existing conditions, such as diabetes and arthritis, were worse or more difficult to control post-stroke. Participants thought of a stroke as a form of brain damage and their concerns were related to what this brain damage could result in, as Jeffrey describes:

> *"Whatever the stroke's done to you, it's what's happened up here, that's the problem, and the thing I've always dreaded is that it's done some damage up here and therefore in years to come, it might affect Alzheimer's or something like that." (Jeffrey, 86)*

Often, the concern about what would happen in the future was linked to how participants were managed and treated for their stroke. This was expressed by participants who had experienced TIA before being diagnosed with stroke. Gavin had a series of TIAs before being diagnosed

with stroke and on one occasion was expecting some medication before the clinician reversed the decision and Gavin was discharged without treatment. In his discussion, Gavin wondered whether that decision not to provide treatment could have affected the subsequent outcome:

> *"It was only the 4th time they said 'you've actually had a stroke' but said 'it's nothing we've missed. The other times we did the check must have been a little blockage and it's finally made its way up to your brain'. But the first time I went the doctor said 'we'll give him some aspirin and send him home.' When I went up to check out, I said 'What about the aspirin?' He said 'I've had a rethink, and we think you don't need it'. So, whether that would have stopped it altogether in its tracks, I don't know. I could have ended up worse in the long run, but one of those things I'll never know." (Gavin, 68)*

6.4.2.4.4 Comparing and sharing experiences with other stroke survivors

The feedback from attending focus group participants to the researcher was positive and many had expressed excitement at being able to share their experiences with other stroke survivors. Participation appeared for some to be therapeutic as some of the older participants said they otherwise rarely left their homes and had limited social interaction.

Positive and negative experiences of stroke treatment

Individual experiences of stroke treatment and care following discharge were different. Most were positive and complimentary about the care they had received and those who had delivered that care. Gracie was positive about all aspects of her care:

> *"In Liverpool I had the best service you could possibly have and I've said that all the time. I had my stroke within five days somebody was calling me to come and see me. The Stroke Society came out to me I don't know how many times in the month, right. There were people ringing me up, dieticians and different people. I had a councillor that came out within three months of this all happening right? Since then people ring me up every now and again. Two weeks ago I had a lady who rang me and said 'I'm a counsellor.' She rang me yesterday and spoke to me and asked me how I was. She was on the phone 45 minutes, talking things through with me and whatever. So she said 'well, my number's here. I'll leave it open. You need me, you ring me.' I can hold my hands up and say I am so thankful for Liverpool Council for the, you know, the treatment I've had." (Gracie, 75)*

Not all participants had a positive experience of stroke treatment in hospital. Francis described how hospital staff behaved in his vicinity whilst he was unable to move or speak following his stroke:

> *"I could also hear people talking about palliative care, which made me think that this is it for me and I'm going to die in here at some point, which a lot of people do. So, it's not unusual that they would turn around and say 'we've done everything we can for him.'" (Francis, 51)*

Helping others through shared experience

Throughout the focus groups, there appeared to be a willingness for participants to help each other through their own shared experiences and the researcher noted high energy and enthusiasm levels during the meetings. Whilst the impact of stroke on the life of participants was very clear from their experiences, some saw the adaptation and acceptance of a new norm as an opportunity to use their experiences to benefit others. A good example of this is Kirk, who previously worked in the restaurant business, a career that he was unable to return to post-stroke. Instead, he decided to work for the Stroke Association in Liverpool, his lived experience of stroke providing a unique insight for helping others:

> *"I saw an advert basically, and I thought I want to help people, I want to support people and having lived experience is second to none.… so I work in the Liverpool team, I'm the only stroke survivor there. (Kirk, 46)*

Communicating with non-stroke survivors

One topic that was discussed frequently by participants was a need for the public to understand the issues faced by stroke survivors in everyday life and to make allowances for them. Once participants had made others aware that they were stroke survivors, people were generally sympathetic and helpful. Participants described difficulties they'd experienced during social conversations with friends and family and when trying to communicate with customer service advisors for banks or energy companies by telephone. Allison explained in her focus group that her speech often became slurred during conversation and that she felt it was important for people to understand that this was a consequence of stroke:

> *"I don't know who this is down to, is for other people to understand how you are and how it can change from day to day, you know or hour to hour. One minute, you know, I sound like I'm drunk and then another minute I'm fine, well fine as can be." (Allison, 57)*

Maggie recalled difficult situations when she would struggle trying to speak to a customer service agent on the telephone and would become emotional and unable to communicate with that person what she wanted. Maggie felt that all of the menus she had to negotiate and buttons she had to press were confusing and frustrating for a stroke survivor and that an advocacy service would be useful:

> *"I mean, I know when I first had my stroke and for a while I used to get on the telephone, say to the, the gas or the electricity or somebody and you'd talk for about a minute and you'd be all right. The banks, all sorts because nothing is, well, it's not user friendly and you get so frustrated, you know if you're pressing button A and then you go through to somebody who's a machine and it's not a person, so it goes on and on and on. So it would good if there was some sort of advocacy service for the things that you need." (Maggie, 77)*

6.4.3 Reflexivity

Throughout the focus groups, I kept a reflexivity journal in accordance with my choice of reflexive thematic analysis as a method of analysing the data from this study. I recorded my thoughts and feelings at the conclusion of each of the four focus groups and some of these are summarised in this section.

My initial thoughts revolved around the concept of qualitative research. As a hard-wired quantitative researcher with a previous career full of hard facts (statistics, tables, graphs and charts), how would I deal with the concept of qualitative research? This question took me a long time to get to grips with, and even though I have read numerous books on the philosophy of research and how qualitative and quantitative research differ, I admit that even now I have only a basic understanding of its principles.

With no experience of qualitative data analysis, I turned to numerous people for support including my supervisor, whose own PhD work was based on qualitative research, and other PhD researchers who were using the same analysis method. I even asked a group of fellow PhD students from all disciplines (including engineering and psychology) to try and code part of a transcript from my first focus group meeting to see if they would interpret the data in the same way as I had done. Most of these students had never been involved in qualitative research before but after being schooled in the method of coding, they produced a series of codes and themes which matched those that I had produced, which provided me with some validation that the approach I was taken was the right one.

The meetings all achieved their objectives with very little input from me. I found myself acting purely as a facilitator to make sure everybody contributed and nobody dominated the group. In this way, I had a unique perspective from each person and this provided me with very rich data, which took me seven months to analyse.

It was clear to me from that first group meeting that participants felt the need to tell the group about how, when and where they had experienced their stroke. The focus of my research was on the quality and duration of their care post-discharge but the experience of stroke was equally important in their eyes, almost as if it was a right of passage in a group meeting, so I ensured that every person who attended a focus group was given the opportunity to talk about what had happened to them before they were admitted and treated. This had the effect of participants comparing their experiences with each other and in some cases trivialising their own experience if they considered it to be less serious than others they heard.

Although the majority of focus group participants were relatively able bodied and attended the meeting in person without the need for aid, one individual arrived with a carer as he had developed post-stroke dementia, several arrived with wives and husbands who were also their caregivers, and one person attended in a wheelchair. In the majority of cases, the caregivers remained silent during the discussions however there was one participant whose wife kept contradicting some of his statements and I made a note in my transcripts where this had happened so that it did not adversely influence my data analysis.

6.4.4 Chapter Summary

A total of four separate focus groups were held during the research study. Four themes emerged from the data analysis involving 27 participants (17 males, 10 females). These themes were as follows: 1) recognising stroke, 2) loss of identity, 3) Life after stroke – 'Feeling Lucky' and 4) dealing with the past and looking to the future.

There were clear disparities in the symptoms of stroke experienced by participants and well-recognised symptoms of stroke; facial droop, arm weakness and slurred speech, the symptoms of which are associated with stroke and known to the wider public through the media. Those participants experiencing other symptoms such as numbness, pins and needles, muscle weakness or general malaise did not associate these with stroke and dismissed them until the symptoms persisted or became more serious. Arguably, the well-recognised symptoms are displayed only when a person is having a stroke and there is a lack of awareness that other symptoms may present in the buildup to a stroke. The experience of stroke survivors

demonstrate that stroke is sometimes misdiagnosed or diagnosed late and this can lead to missed opportunities for early recognition and intervention. These findings need to be considered in the context of a series of small-scale focus groups. Whilst the participants in the present study commonly described symptoms not associated with the public perception of stroke, the experiences of these individuals are unique to each person and may therefore not reflect those of the wider stroke population.

Although there appears to be a good level of knowledge amongst participants of the well-recognised symptoms of and risk factors for stroke, these were not always described in participants' experiences. It appears that earlier recognition and a greater understanding of a broad range of symptoms that can lead to stroke would be beneficial for patients and HCPs alike to provide earlier diagnosis and more rapid intervention.

Loss of identity was frequently discussed in the focus groups, with participants remembering how life was prior to their stroke and how this catastrophic event had left them with a lack of autonomy, confidence, dignity and respect. Consequently, many participants spoke about reliance on others and how this further contributed to their feelings of vulnerability. Reliving these events in the focus groups evoked strong emotions such as anger, guilt, tearfulness and frustration and a fear of being alone and unsupported.

Participants frequently described themselves as 'feeling lucky', in that their recovery from stroke seemed relatively straightforward and uncomplicated when compared with other stroke victims they had observed on the stroke units. There was a feeling amongst the participants that they expected to be more disabled than they were and so they felt grateful that they had made a successful recovery. The impact of stroke was wide-ranging and affected participants emotionally, financially, physically and psychologically. A number of the participants regularly described 'feeling like a fraud' as they considered their strokes to be mild in severity and felt guilty about using precious NHS resources to help them towards recovery. Participants would also trivialise their experiences of stroke, often after listening to the experiences of other participants in their focus group, as if a mild stroke was not worthy of discussion.

The recovery from stroke appeared to be dependent upon a number of factors. These included acceptance of stroke and its associated limitations, a proactive approach to recovery, the level of support received post-discharge and taking responsibility for their own recovery. Elements of stroke care that aided recovery included rapid diagnosis and treatment, psychological support and physiotherapy. Support following discharge was varied, with some participants

describing fragmented or minimal follow-up, limited community support such as access to physiotherapy and psychological support. Of those who participated in stroke research clinical trials, the experience was positive with some participants stating that they felt their care as a research participant was better than their standard care.

The majority of participants believed that the future following stroke was uncertain and there was a fear, and in some cases an expectation, that they would experience another stroke in the future. Others were concerned that having a stroke might lead to other brain-related condition such as Alzheimer's.

Overall, participants found that sharing their experiences in a focus group was beneficial, with some saying that they rarely had any form of social interaction post-stroke. There was a strong desire to use their own experiences to help others, whether through research or working directly with other stroke survivors. There was also a recommendation of the need for the public to acknowledge stroke survivors and to make allowances for them in everyday life.

In Chapter Seven, the second part of work package 2, the Delphi survey, is covered.

7 Chapter Seven: Study 2 Phase 2 – Delphi Survey

7.1 The Delphi Survey Technique

The Delphi technique is a method of gathering expert opinion by working with a group of people with specialist knowledge and experience of a particular research subject to reach a consensus position, and has been widely used in healthcare research (Keeney et al., 2006; Barrett and Heale, 2020). The Delphi technique was first developed in the 1950s by Dalkey and Helmer of the RAND Corporation to gain reliable expert consensus for military forecasting during the Cold War (Dalkey, 1969; Keeney et al., 2011). Specifically, they developed an approach named after the Ancient Greek Oracle of Delphi, who could predict the future, which promoted anonymity and avoided direct confrontation between experts, so that the methods employed *"...appear to be more conducive to independent thought on the part of the experts and to aid them in the gradual formation of a considered opinion"* (Dalkey and Helmer, 1963 p.2). The Delphi technique gained popularity in the 1960s onwards and is widely used in corporate management, information systems, E-commerce, marketing, internet banking, health and tourism research (Dalkey, 1969; Keeney et al., 2011).

Although the Delphi technique has evolved over time, the fundamental characteristics remain unchanged, and the overarching approach is a series of 'rounds' during which a group of experts

are asked for their opinions on a particular subject. The questions for each round are based in part of the findings of the previous one, allowing the study to evolve over time in response to earlier findings (Keeney et al., 2006; Barrett and Heale, 2020). Participants are able to see the results of previous rounds with the productions of a report – including their own responses – an approach which allows them to reflect on the views of other participants and reposition their own opinions accordingly if desired (Keeney et al., 2006). This also provides participants with the opportunity to consider and feedback on what they perceive to be the strengths and weaknesses of other participants' responses. The findings of each round are always shared with the broader group anonymously, avoiding any bias that might result from participants being concerned about their own views being viewed negatively or from their own opinions being biased by personal factors. This framework of expert opinion rounds, with each round built on previous findings and each allowing for responses to be reconsidered by participants, is designed to allow the development of a consensus view that answers the research question (Barrett and Heale, 2020).

7.2 The Choice of Delphi Type

There are a variety of different types of Delphi survey, which highlights the flexibility of this method. The main types are summarised in Table 6.

Table 6 Types of Delphi Surveys and Main Characteristics

Type	Process
Classical Delphi	Conducted in a series of rounds Round 1 starts with a questionnaire to elicit opinions and gain consensus Subsequent rounds are used to evaluate responses Can be conducted by post or email
Modified Delphi	Modification usually involves replacing Round 1 with pre-generated ideas from the literature or face-to-face meetings, interviews, or focus groups
Decision Delphi	Same process as classical Delphi but focusses on making decisions rather than reaching consensus
Policy Delphi	Same as classical Delphi but focus is to reach consensus on future policy on a particular topic
Real time Delphi	Same as classical Delphi except that participants may be in the same location and consensus is reached in real time Often a single questionnaire with no rounds is used
e-Delphi	Same as classical Delphi but conducted online through a web portal or by email
Technological Delphi	Similar to real-time Delphi but uses special polling software and keypads for participants to provide immediate real time responses
Online Delphi	Same as classical Delphi but questionnaires are complete online
Argument Delphi	A derivative of the Policy Delphi Focussed on the generation of relevant factual arguments Non-consensus design

Type	Process
Disaggregative Delphi	Non-consensus design Conducts various scenarios of the future for discussion Uses cluster analysis

Source: (Keeney et al., 2011; Varndell et al., 2021)

The choice of a Delphi survey for this study was made based on the flexibility of the approach to gathering views from experts in the area of stroke care, including those who are beneficiaries of that care, the ability for the participants to reflect on their views in the light of the opinions of others, and the anonymity of the survey which promotes honesty among participants (Barrett and Heale, 2020). Importantly, the Delphi technique allows the co-construction of an integrated care pathway by involving those who implement and receive care.

The type of Delphi survey was chosen according to the target population, accessibility and ease of use. The HCPs who were involved in the recruitment of focus group participants and the stroke survivors who agreed to participate in the focus groups were asked about their preferences for completing a short Delphi survey. The majority of HCPs and stroke survivors had access to and were regular users of the internet and this was the preferred method of delivery of the survey since an internet-based survey was considered convenient and participants could choose when to complete it. This observation is supported by research showing that stroke survivors with more than one hour of daily digital media usage preferred digital communication such as email (Schmidt et al., 2023). Some stroke survivors indicated that they would prefer a postal survey.

Of the available types of Delphi survey, the Classical Delphi technique was chosen since participants would be providing responses to a series of statements about components of integrated care in a series of rounds to gain consensus and this was implemented as an online or e-Delphi as the majority of participants indicated that they preferred an internet-based survey and a postal survey was designed and implemented for those who preferred this option.

A key issue in any Delphi survey is the percentage agreement among participants that would be accepted by the researcher as consensus (Keeney et al., 2006). There is no agreement in the published literature as to what level the percentage for consensus should be set and it is partly dependent upon the research topic (a life-or-death issue would require a consensus set at 100%). The range of consensus in the literature ranges from 51%-100% although a 1% difference between consensus and no consensus at the lower end of this range seems difficult to justify. A figure of 75% appears more robust and values of 70-80% have been used successfully in several studies (Green et al., 1999; McKenna et al., 2001; McKenna and

Hasson, 2002). This also matches the upper interquartile range of statistical analysis (75%) (Beiderbeck et al., 2021). For this study, consensus was set at 75% as this appears to be the minimal level that is sufficiently rigorous with the understanding that there is currently no obvious scientific rationale for this (McKenna et al., 2001; Keeney et al., 2006).

7.3 Methods

7.3.1 Feedback from PPI Group on Delphi Survey

The feedback from the PPI group on the Delphi was positive in that participants found it easy to navigate and quick to complete. One comment that was made was that there were no components that addressed visual impairment, which was an issue experienced by one of the PPI members. This was not included as it did not appear in the list of components identified by the systematic review or mixed methods study.

7.3.2 Recruitment of Survey Participants

Participants for the Delphi survey included registered HCPs. These were people with at least 12 months' experience, knowledge and expertise in the management of stroke and those invited included physicians, neurologists, stroke physicians, neurosurgeons, general practitioners, specialist stroke nurses, ward nurses, community nurses, physiotherapists, occupational therapists, speech and language therapists, and pharmacists. Criteria for entry of HCPs into the Delphi survey were listed on a start web page prior to entry into the study, which included a check box for time in post. Those who had less than 12 months experience were excluded from the survey.

Invitations to HCPs were sent by email to NHS stroke care teams in Merseyside and were also distributed to major stroke research organisations based in London, Nottingham, Leeds, Bristol, Aberystwyth, Oxford and Cambridge. Nationally, invitations to HCPs were distributed through Getting it Right First Time for Stroke (GIRFT), and the British and Irish Association of Stroke Physicians (BIASP), which included details of the survey in their December 2024 and January 2025 monthly newsletters. A copy of the invitation letter is provided in Appendix P and the PIS is provided in Appendix Q.

Stroke survivors who participated in the focus groups were invited to participate in the survey at the end of each focus group, requesting permission to contact them by telephone when the survey was ready to be implemented, and an information pack comprising an invitation letter (Appendix R) and PIS (Appendix S) was provided to them. Invitations were also distributed through the Stroke Association. A paper-based survey was provided as an option to those

individuals who requested it and a separate ICF (Appendix T) was included for the participant to complete and return together with their completed survey in an SAE. A help sheet explaining some of the terms in the survey was also provided (Appendix U). The contents of the help sheet were also provided as links within the online survey.

A poster advertising the Delphi survey was distributed to both HCPs and stroke survivors through the channels described above (Appendix V). To improve completion rates, all participants who completed each round of the survey in full were entered into a prize draw with first, second and third prizes of £100, £75 and £50 in gift cards, respectively, awarded to individuals drawn at random after the survey was closed.

7.3.3 Survey Design and Implementation

The first round of the survey was constructed around a series of components that were derived from the findings of the systematic review (comprising interventions that improved outcomes for patients) and the analysis of the qualitative focus groups. The components of care identified from the systematic review that provided a benefit to patients or HCPs were added to the table, together with details of the studies from which they were identified. In the case of the qualitative findings from the focus groups, elements of the discussion which were considered important by the participants and could be identified as components of integrated care, were added to the table. In the case of the systematic review, these components were grouped according by cost effectiveness, acute and post-discharge interventions and those components which positively impacted education and training. Individual components that were part of the same study were listed separately.

In the case of focus group components, these were similarly grouped according to awareness and knowledge, acute and post-discharge components and those components that were important for education and training, in line with the themes that were identified in the qualitative analysis.

These components are summarised in Table 7.

Table 7 Summary of components of integrated care from systematic review and focus groups

From systematic review	Component	References
Economic	Cost-effective stroke management programs	(Abdul Aziz et al., 2020)
Acute stroke management	Early supported discharge	(Brandal et al., 2019; Rodgers et al., 2019; Shaw et al., 2020)
	Exercise	(Gun Young, 2021)
	Speech therapy	(Chen et al., 2017; Cuccurullo et al., 2022a)
	Dysphagia treatment	(Chen et al., 2017)
	High intensity rehabilitation (4 or more sessions/week)	(Chang et al., 2018; Yoo et al., 2022)
	Nurse-led rehabilitation program following thrombectomy	(He et al., 2023)
	Early rehabilitation and nursing	(Liu et al., 2014; Huang et al., 2023)
	Group physiotherapy sessions	(Li et al., 2023)
	Acute medical treatment (Early clinic referral and imaging, antiplatelet, statin and BP lowering therapy)	(Luengo-Fernandez et al., 2022)
Stroke management following discharge	Exercise-based cardiac rehabilitation	(Buckley et al., 2021a; Cuccurullo et al., 2022a)
	Regular follow-up	(Bodechtel et al., 2016; Cheng et al., 2018b)
	High intensity rehabilitation	(Chang et al., 2018)
	Physician visits	(Joubert et al., 2020; Cuccurullo et al., 2022b)
	Home visits from healthcare professionals	(Joubert et al., 2015; Cuccurullo et al., 2022b)
	Management of risk factors (blood pressure, cholesterol, blood sugar, weight loss, smoking cessation)	(Bodechtel et al., 2016; Teuschl et al., 2017; Cuccurullo et al., 2019; Joubert et al., 2020; Willeit et al., 2020; Dello et al., 2021; MacKay-Lyons et al., 2022)
	Individual tailored care program including regular monitoring and program adjustment	(Deutschbein et al., 2020; Feng et al., 2021; Mohammadi et al., 2022)
	Psychosocial and wellbeing support (eg, art classes, horticulture)	(Lee et al., 2018; Ellis-Hill et al., 2019)
	Counselling	(Wong and Yeung, 2015; Willeit et al., 2020)
	Adherence to antithrombotic/anticoagulant medication	(Bodechtel et al., 2016)
	Antithrombotic/anticoagulant medication	(Bath et al., 2018; Sharma et al., 2019)
	Exercise programs	(Rasmussen et al., 2016)
	Group physiotherapy sessions	(Li et al., 2023)
	Goal setting	(Bodechtel et al., 2016; Graven et al., 2016; Rasmussen et al., 2016; Fu et al., 2020; Khramov et al., 2021)
	Pharmacist delivered care program	(Wang et al., 2021)
	Case manager delivered care program	(Bodechtel et al., 2016)
	Physiotherapy	(Graven et al., 2016; Døhl et al., 2020; Li et al., 2023)
	Massage therapy	(Khramov et al., 2021)
	Occupational therapy	(Aziz et al., 2020; Bragstad et al., 2020)

	Social support	(Reeves et al., 2019; Khramov et al., 2021; Wong et al., 2022b)
	Medication review	(Greger et al., 2021)
	Medical treatment for depression	(Gao et al., 2017)
	Continuous nursing or nurse-led care pathway	(Xi, 2017)
	Post-acute care program (PAC) measuring activities of daily living, nutrition, exercise, mobility and language	(Peng et al., 2017)
	Individual assessment of stroke patient needs	(Nayeri et al., 2014; Wong and Yeung, 2015)
	Home based rehabilitation using videoconferencing	(Willeit et al., 2020; Wu et al., 2020; Lu et al., 2023b)
	mHealth training using an app	(Yan et al., 2021)
Education and training	Patient and family member education	(Chu et al., 2020)
	Cognitive training	(Gao et al., 2017; Koch et al., 2020; Gun Young, 2021)
	Rehabilitation training	(Chu et al., 2020; Feng et al., 2021)
	Lifestyle advice	(Geng et al., 2019)
	Self management	(Deng et al., 2020)
	Motivational training	(Lewthwaite et al., 2018)
	Nurse-led education and follow-up	(Liu, 2018)
	Medication management	(Wang et al., 2021)
	Rehabilitation training for carers	(Long Weijan and Zhang, 2017; Li et al., 2023)
	Training program for HCPs	(Long Weijan and Zhang, 2017)
	Virtual reality training	(Lin et al., 2020)
	Caregiver training (nursing for caregivers)	(Zhang et al., 2019; Feng et al., 2023)
	Written patient information on stroke (leaflets and booklets)	(Saal et al., 2015)
	Regular organised educational and information sessions	(Saal et al., 2015)

From focus groups	Components
Awareness and knowledge	Awareness of well-known symptoms of stroke according to the media (facial droop, arm weakness, slurred speech)
	Awareness of less well-known symptoms of stroke (pins and needles, muscle weakness, dizziness, general feeling of malaise)
	Risk factors for stroke (atrial fibrillation, TIA, diabetes, cardiovascular disease)
	A greater understanding from the public about the problems that stroke survivors face
Acute stroke management	Rapid diagnosis of stroke
	Rapid scanning in suspected stroke
	Physiotherapy
	Acute medical treatment (eg, clot busting drugs, anticoagulants)
	Occupational therapy
	Psychological support
Stroke management following discharge	Regular follow-up
	Physiotherapy
	Occupational therapy
	Psychological support
	Stroke survivor advocacy services
	Support from family and friends
	Support from charities (eg, Stroke Association)
Education	Role of aspirin in stroke management
	Side effects of other treatments (eg, statins for control of lipids)
	Lifestyle advice
	Participating in research studies on stroke

The survey was developed electronically and implemented through QuestionPro® (https://www.questionpro.com), an online web-based portal which was fully compliant with General Data Protection Regulation (GDPR) with encrypted data transfer for security between data servers and survey participants. The survey was constructed in such a way that participants had to provide informed consent before they could access the survey or any information relating to it. Participants were also given the option to complete a paper-based survey by post as an alternative, with a separate ICF being provided for this option. The published literature indicates that offering both online and paper-based surveys can improve participation rates, as it caters to different preferences and abilities, with participation rates for paper-based surveys often higher than that for online surveys in older participants (Kelfve et al., 2020; Anhang Price et al., 2022; Ceccato et al., 2024). Individuals who contacted the researcher and were willing to participate were informed of exactly what they would be asked to do, how much time they would be expected to contribute, and how the information that they provided would be used (Hasson et al., 2000). They were also advised that their participation was entirely voluntary, and they were free to withdraw from the survey at any time.

The survey was constructed according to guidance provided by published articles (de Villiers et al., 2005; Beiderbeck et al., 2021). A panel of participants possessing knowledge of stroke care delivery, members of multidisciplinary stroke teams and patients with experience of stroke recovery, were requested to participate and the planned panel size was a minimum of 30 members to provide sufficient rigour for statistical analysis (de Villiers et al., 2005).

Components for Round 1 and subsequent rounds were grouped under 4 main questions which reflected the patient journey from experiencing stroke through to recovery and rehabilitation. These were:

1. Thinking about the acute management of stroke (from recognition of symptoms or diagnosis to hospital or stroke unit treatment), how important do you think each of these elements are for an integrated care pathway for stroke?
2. Thinking about the management of stroke survivors following discharge from the hospital or stroke unit, how important do you think each of these elements are for an integrated care pathway for stroke?
3. Thinking about potential education and training of stroke survivors and their carers following discharge from the hospital or stroke unit, how important do you think each of these elements are for an integrated care pathway for stroke?
4. Thinking about the ways in which to better understand how stroke affects people who suffer from it and how to prevent further strokes in the future, including awareness and knowledge of stroke, how important do you think each of these elements are for an integrated care pathway for stroke?

Each component was rated using a 4-point Likert Scale (Cooper and Johnson, 2016) between 1 (very important), 2 (important), 3 (unimportant) and 4 (very unimportant). A period of one month was given for each round of the survey to be completed by participants, with a reminder being issued after two weeks following an amendment to the IRAS Ethics submission.

The Round 1 questionnaire responses were analysed providing interim results demonstrating consensus and non-consensus items. The components upon which consensus had been reached based upon a single response (≥75% scoring very important, important, unimportant or very unimportant) were taken to inform the construction of a stroke integrated care pathway concept and removed from subsequent questionnaires. A second questionnaire containing the remaining non-consensus components (Round 2), and the Round 1 results (Appendix W) were sent out to the participants. Participants were given the option to compare their initial opinions with the group result and to reconsider their response from Round 1 if desired (Keeney et al., 2006). Subsequent rounds continued until an acceptable level of consensus was achieved, no further consensus issue emerged or until the response rate was too low (Figure 33). The final consensus presented issues upon which the participants agreed (consensus), along with the items which remained controversial (non-consensus) (de Villiers et al., 2005).

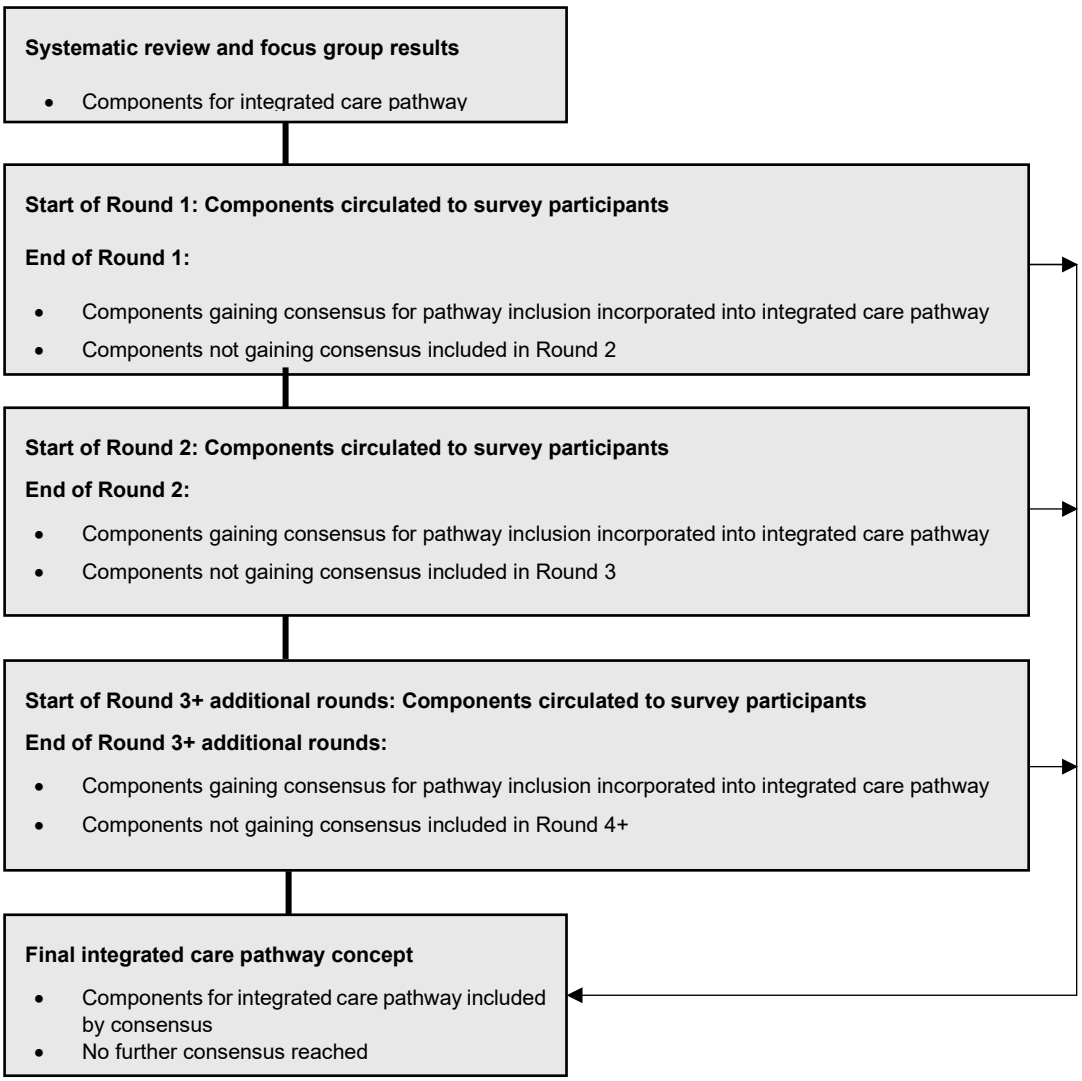


Figure 33 Modified Delphi Methodology (Eubank et al., 2016)

7.4 Results

The Delphi survey was conducted in three rounds and participants were given four weeks to complete each round of the survey, with a reminder at two weeks. A total of 42 participants completed Round 1 of the survey between 21 January and 14 March 2025 (the participation period was extended due to slow initial uptake of the survey and the requirement to reach a minimum number of 30 participants for scientific robustness). Of the 42 participants, 35 completed the online survey and seven (all stroke survivors) completed postal surveys.

The Round 1 participants comprised stroke survivors and HCPs and formed the survey panel. Details of the participants across the three survey rounds are shown in Table 8.

Table 8 Characteristics of Delphi survey participants

	Round 1 (Panel)	Round 2	Round 3
Total, n*	**42**	**31**	**34**
Stroke survivors, n	20	15	15
HCPs, n	22	16	19
Nurse	7	6	7
Doctor	5	5	5
PT	8	5	7
OT	1	0	0
Other	1	0	0
Online survey completion time, median (range), seconds			
Overall	426 (144-4180)	521 (214-1999)	405 (86-1286)
HCPs	371 (144-4180)	437.5 (214-933)	276 (86-864)
Stroke survivors	573 (387-1588)	386 (302-1999)	528 (264-1286)
Online survey non-completion, n			
Overall	25	7	5
HCPs	14	1	2
Stroke survivors	11	6	3

* Includes postal survey participants. HCP, healthcare professional; OT, occupational therapist; PT, physiotherapist

Of the 42 participants in the panel, 31/42 (74%) and 34/42 (81%) participated in Rounds 2 and 3, respectively, exceeding the 70% compliance limit specified in the protocol. The proportion of HCPs completing the survey ranged from 52-56%. The majority of HCP responders in each round were nurses (32-37%) and physiotherapists (31-37%). Overall, the median time taken to complete the online survey was between 405 and 521 seconds, with the shortest median time (405 seconds) for Round 3, although there were substantial variations in completion time range (from 86 seconds to 4,180 seconds). In general, HCPs completed the survey in shorter times than stroke survivors, although the opposite was true for Round 2.

A total of 37 participants started but did not complete the online survey and the most common reasons for this were not providing an email address, which resulted in survey termination (11/37, 30%) or answering the first question (*please indicate if you are a stroke survivor or a stroke healthcare professional*) but not proceeding further than this (11/37, 30%). In the case of stroke survivors, some individuals made repeated attempts to complete the survey without success, with two individuals making two separate attempts across rounds and one individual making three separate attempts in the same survey round. Of these three individuals, one completed the survey successfully for all three rounds, one completed the survey successfully for Rounds 1 and 3, and the third individual requested a postal survey but only completed Round 1.

In terms of geographical location, the majority of participants (35/42, 83%) were based in Merseyside. However, as the invitations to participate in the survey were distributed nationally, there were also participants based in Greater Manchester (three participants), West Yorkshire (Leeds, three participants) and Scotland (Dundee, one participant).

7.4.1 Statements Achieving Consensus

Fourteen statements reached consensus (defined as a score of ≥75%) following three rounds of the Delphi survey, all of which were rated as 'very important' by the majority of participants. A total of nine statements achieved consensus on single responses in Round 1 (Table 9). A further four statements achieved consensus in Round 2. However, only one additional statement achieved consensus in Round 3. Seven statements in Round 1 and one statement in Round 3 were part of question 1 in the survey, which related to acute stroke care. All four consensus statements in Round 2 were part of question 2, which related to post-discharge care. Two statements in Round 1 were part of question 4, which related to awareness, understanding and prevention of subsequent stroke. Of note, there were no statements that reached a single response consensus in Question 3, which related to post-discharge education and training for stroke survivors and their carers, in any of the three survey rounds. Given that only one additional statement reached consensus after Round 3, it seemed unlikely that additional survey rounds would provide further consensus based on single responses and the decision was made to close the survey after three rounds.

Table 9 Summary of consensus achieved on single responses (all rated as 'very important')

Question #	Statement	Round 1	Round 2	Round 3	Very important
1	Rapid diagnosis of stroke	✓			100%
	Rapid brain scanning in suspected stroke	✓			98%
	Acute medical treatment (for example, clot busting drugs, thrombectomy, anticoagulants, antiplatelet drugs, high blood pressure treatment)	✓			91%
	Speech therapy			✓	82%
	Treatment for dysphagia (difficulty in swallowing)	✓			79%
2	Control of stroke risk factors (blood pressure, cholesterol, blood sugar, weight loss, smoking cessation)	✓			86%
	Ongoing occupational therapy		✓		77%
	Physiotherapy including exercise		✓		87%
	Early rehabilitation		✓		77%
	An individual assessment of stroke patient needs		✓		77%
	Taking antiplatelet/anticoagulant medication	✓			76%
	Adherence to antiplatelet and anticoagulant medication	✓			76%
4	Awareness of the well-known symptoms of stroke according to media campaigns such as FAST (Face, Arms, Speech, Time to call 999)	✓			79%
	Awareness of the risk factors for stroke (for example atrial fibrillation, transient ischaemic attack [TIA], diabetes, cardiovascular disease)	✓			81%

7.4.2 Consensus by type of participant

When the results of the Delphi survey were analysed according to the type of participant (stroke survivor vs HCPs) a very clear disparity between the groups was observed, which is summarised below in Table 10.

Table 10 Statements Reaching Consensus by Type of Participant

Delphi Round #	Number of statements reaching consensus	
	Stroke survivors	HCPS
1	6	18
2	0	12
3	1	6

All consensus was reached on the single response 'very important' with the exception of the only statement to reach consensus by stroke survivors in Round 3 (*stroke survivor self-care programs*, rated as 'important' by 80% of participants compared with 22% of HCPs). In total, responses from HCPs reached consensus on 36 statements across all three rounds, whereas in stroke survivors, there were only 6 statements reaching consensus in Round 1, none reaching consensus in Round 2, and only one in Round 3, implying that the rates of consensus for the combined responses were being driven by HCPs.

7.5 Chapter Summary

The Delphi survey was constructed through a secure online platform and based on a series of four questions that represented the stroke patient journey from diagnosis through treatment to post-discharge recovery. Both HCPs and stroke survivors were invited to participate and the option of a paper-based questionnaire was provided for those who preferred it.

In total, 42 participants (including seven stroke survivors) completed Round 1 of the survey. Two further rounds were conducted and participation rates were 74% and 81% in Rounds 2 and 3, respectively. Fourteen of 55 (25%) statements reached consensus based on a single response scoring ≥75%. The majority (12/14) of consensus components were from questions 1 (which related to acute stroke care) and 2 (which related to post-discharge care), highlighting the importance participants placed on rapid stroke diagnosis, acute treatment, rehabilitation and secondary prevention. Awareness of the well-known symptoms of stroke according to the FAST campaign and the risk factors for stroke were also considered high priority for any integrated care pathway for people with stroke.

8 Chapter Eight: Discussion of Findings

This chapter brings together the findings of the systematic review, focus groups and Delphi survey to synthesise and discusses the results in detail, with each element being discussed in turn. The chapter summary brings together all of the critical findings from the research, which are combined into a new integrated care pathway outlined in Chapter Nine.

8.1 Systematic Review and Meta-Analysis

Work Package 1 of this research comprised the systematic review and meta-analysis. To our knowledge, this was the first comprehensive systematic review with meta-analysis of published studies on integrated care in stroke. Of the 99 studies in the review, the majority (64) were RCTs and 35 were either NRCTs (10), retrospective/prospective cohort studies (14), pre-test/post-test studies using the same groups before and after the intervention (6), or case-controlled or retrospective observational studies (5). Of the 63 studies included in the meta-analysis, 51 were RCTs. Meta-analysis was conducted separately for RCTs and NRCTs and summarised in Table 2. Regarding the primary and secondary outcomes, data were analysed in NRCTs for mortality, recurrent stroke and unplanned readmission only. All other outcomes were analysed solely for RCTs due to insufficient NRCTs or missing data in NRCTs, that precluded meta-analysis.

The findings of the review showed that integrated care was associated with improvements in QoL, reductions in anxiety and depression and positive benefits on some cardiovascular risk factors but did not impact mortality, recurrent stroke, major bleeding or readmission rates. Other published systematic reviews have evaluated interventions such as organised inpatient stroke care (Langhorne et al., 2020a), exercise (Mehrholz et al., 2011; Pollock et al., 2014a; Mehrholz et al., 2017; Saunders et al., 2020b), ESD (Goncalves-Bradley et al., 2017; Jee et al., 2022; Williams et al., 2022) and interventions for cognitive rehabilitation (das Nair et al., 2016b), depression (Allida et al., 2020) and anxiety (Knapp et al., 2017) however none of these reviews were conducted in the setting of integrated care.

Whilst some studies in the review demonstrated a benefit in outcomes with integrated care interventions, other studies using similar interventions did not. These observations highlight considerable heterogeneity and a lack of consensus over which components should form part of an integrated stroke pathway and how they should be implemented. Indeed, individual studies demonstrated that interventions such as exercise, rehabilitation, risk factor management, and mental health initiatives were likely to have a positive effect in improving

outcomes in people with stroke. These included studies of cardiovascular exercise and high-intensity rehabilitation that were associated with significantly lower mortality rates (Buckley et al., 2021a; Chang et al., 2022; Cuccurullo et al., 2022b). Within this review, exercise was the only intervention that was associated with a beneficial effect on all of the following outcomes: mortality, recurrent stroke, readmission, QoL, depression/anxiety and adherence to intervention (Table 11). Complete pathways and interventions aimed at addressing depression/anxiety impacted on all but one of these outcomes. These observations suggest that the most effective single intervention for integrated care in stroke is likely to be exercise. There is published evidence supporting the value of exercise in stroke rehabilitation. More than 70% of stroke survivors experience impairment of movement or other neurological functions (Zhang et al., 2022) and exercises used in rehabilitation place the utmost emphasis on functional and psychological recovery (Shahid et al., 2023). Personalised exercise plans delivered by physiotherapists have been shown to improve motor function, reduce disability, increase physical activity and fitness levels, and improve QoL for stroke patients. In addition, physiotherapy, defined as any physical treatment including therapeutic exercise, has been associated with structural brain remodelling, which may contribute to improved motor function following stroke, and improvements in mental health, with reduced incidence of depression. Therefore, physiotherapy is an essential component of stroke management and recovery (Gordon et al., 2018; Shahid et al., 2023). The most recent NICE guidance for stroke recommends early mobilisation as soon as the patients' clinical condition permits and they can move from a bed to a chair independently or with assistance, as part of an active management programme in a specialist stroke unit. This care should be prolonged following discharge for as long as it continues to help them to achieve their treatment goals (National Institute for Health and Care Excellence, 2022; National Institute for Health and Care Excellence, 2023a).

Table 11 Summary of interventions associated with a positive effect on outcomes

Intervention	Effect on outcomes					
	Mortality	**Recurrent stroke**	**Readmission**	**QoL**	**Depression/anxiety**	**Adherence**
Exercise	+	+	+	+	+	+
Education			+	+	+	
Complete pathway	+	+	+	+	+	
Psychological / psychosocial				+	+	+
Lifestyle/risk factors*	+		+	+	+	+
mHealth		+		+	+	

The STROKE-CARD study, a comprehensive disease management program delivered by a multidisciplinary team that included risk factor management and patient education, reported reduced cardiovascular risk and improved QoL (Willeit et al., 2020). Studies employing interventions such as ESD, regular community follow-up, education, cognitive and motivational training, and goal setting reported significant reductions in the proportions of participants with depression or anxiety and improvements in QoL (Graven et al., 2016; Rasmussen et al., 2016; Lewthwaite et al., 2018; Brandal et al., 2019; Hjelle et al., 2019; Yu et al., 2019; Zhang et al., 2019; Bragstad et al., 2020), with individualised care pathways and mHealth technology providing substantial improvements in these outcomes (Xi, 2017; Yu et al., 2019; Wu et al., 2020; Yan et al., 2021; Mohammadi et al., 2022).

Conversely, there are large and well-designed randomised trials of comprehensive integrated care interventions that did not demonstrate any substantial benefit over standard care. The structured ambulatory post-stroke care program (SANO) study, a 1-year patient-centred integrated care intervention including regular follow-up, lifestyle advice, goal setting and motivational interviewing, demonstrated positive benefits in controlling cardiovascular risk factors such as blood pressure and LDL cholesterol, but did not reduce the rate of major cardiovascular events (Schwarzbach et al., 2023). In the Triple Antiplatelets for Reducing Dependency after Ischaemic Stroke (TARDIS) study, significantly more bleeding events were reported overall in the TARDIS group (19.8%) compared with control (9.1%, $P < 0.001$), prompting the study to be stopped early (Bath et al., 2018). INSPiRE-TMS was an open-label, multicentre, international randomised controlled trial of a support programme which included counselling, lifestyle changes, and support for medication adherence. Despite a 2-year follow-up, there was no difference in the composite primary endpoint of major vascular events consisting of stroke, acute coronary syndrome, and vascular death between the intervention and control groups (Ahmadi et al., 2020). The Very Early Rehabilitation Trial for stroke study (AVERT) showed that significantly fewer participants in the AVERT group had favourable outcome and there was no difference in mortality or QoL (Bernhardt et al., 2015; Langhorne et al., 2017; Cumming, 2019).

The authors of these studies cited numerous factors for these unexpected results. In the SANO study, the follow-up period of 1 year may have been too short to properly assess the long-term effects of the intervention and patients in the intervention group were probably more likely to report symptoms of recurrent stroke than were patients in the control group due to the regular assessment by specialised stroke physicians (detection bias) (Schwarzbach et al., 2023). In the

TARDIS study, the authors noted that participants with a severe stroke (presenting with cortical strokes) tended to do better on standard therapy whereas intensive antiplatelet treatment favoured those with mild stroke. The type of standard (guideline) parameter appeared to be important as there was a non-significant tendency for intensive therapy to have beneficial effects on the primary outcome in comparison with combined aspirin and dipyridamole, but not when compared with clopidogrel alone. The authors also suggested that the use of thrombolysis 24h prior to study intervention may have increased the difference in bleeding between the study groups (Bath et al., 2018).

In the INSPiRE-TMS study, factors discussed by the authors included higher primary outcome rates of patients not attending the scheduled visits, different study and healthcare settings in the study sites (Germany and Denmark), and fading motivation both among participants and researchers in this long-term (2-year) study (Ahmadi et al., 2020). In the AVERT trial, a lack of improvement in QoL was partly explained by the observation that, although there is an association between mRS and QoL after stroke, this association suffers from substantial variability and at three months post-stroke, QoL at a given mRS level was highly heterogeneous, prompting efforts to develop a utility-weighted mRS to better reflect patient perception of QoL (Cumming, 2019). The lack of difference in favourable outcome in AVERT compared with standard care was explained by a very high level of recovery overall. Despite having more than one-quarter of participants aged >80 years and 45% recording a moderate or severe stroke, almost 50% had a favourable outcome in terms of independence at 3 months. Across both groups, the case fatality rate averaged only 8% and there was no significant difference between the groups (Bernhardt et al., 2015; Langhorne et al., 2017).

Overall, the results of this systematic review are inconsistent, with 34% of reviewed studies showing no benefit over comparator treatment and considerable heterogeneity between studies. Factors influencing a lack of benefit or mixed findings over standard care include insufficient time during the study to show a benefit, better outcomes in the control group compared with the intervention group, declining motivation during long-term studies and high heterogeneity associated with the measurement of some study outcomes.

The centralisation of stroke services and the creation of HASUs has improved outcomes for patients compared with traditional stroke units, reflected in reduced mortality rates and hospital length of stay (Hunter et al., 2013; Morris et al., 2014) however there is currently no standard HASU care pathway and outcomes vary widely as a result (Ramsay et al., 2015; Fulop et al., 2016). In general, much of the more robust published data on stroke care management are in

the acute setting (Gilham, 2021), where integrated care plans such as ESD (Langhorne et al., 2014; Brandal et al., 2019; Rafsten, 2019; Jee et al., 2022; Williams et al., 2022) are often clearly defined. However, less is known about patient care following discharge back into the community and studies show that care from this point onwards is often discontinuous (de Mooij et al., 2021; NHS Rightcare, 2021; Chen et al., 2022), which can result in unmet needs and increased potential for hospitalisation and institutionalisation (Chen et al., 2020). A recent Sentinel Stroke National Audit Programme (SSNAP) annual report identified a decline in the proportion of patients receiving a 6-month review from 42.4% in 2020-2021 to 38.5% in 2021-2022 and highlighted the need for an adequately resourced multidisciplinary team of healthcare professionals required to deliver the recommended amount of rehabilitation of patients according to their need, especially in the community setting (Sentinel Stroke National Audit Programme [SSNAP], 2022).

8.1.1 Meta-analysis: Primary outcomes

8.1.1.1 Mortality

Meta-analysis showed no difference overall in mortality between integrated care and control or standard care. Although subgroup analysis showed a significant reduction in long-term mortality in favour of integrated care, there were only 3 studies in this subgroup and the findings must be interpreted with caution. One of the studies was a large retrospective analysis with nearly 6,000 participants (Buckley et al., 2021a) which may have skewed the results.

The overall findings are consistent with the published literature with systematic reviews of ESD and exercise showing no significant differences in mortality rates compared with standard care (Saunders et al., 2020b; Jee et al., 2022; Williams et al., 2022). These reviews contained numerous studies with small sample sizes (the majority with <50 participants per group), some of which had lacking follow-up data for mortality, and interventions tended to be of short duration (Saunders et al., 2020b; Jee et al., 2022; Williams et al., 2022).

A Cochrane systematic review by Saunders and colleagues (Saunders et al., 2020b) included 75 studies which comprised cardiorespiratory (32 studies, 1,631 participants), resistance (20 studies, 779 participants), and mixed training interventions (23 studies, 1,207 participants) in a meta-analysis. Mortality was not positively impacted by any of the interventions; risk differences were all 0.00 (low-certainty evidence). There were few deaths overall (19/3,017 at end of intervention and 19/1,469 at end of follow-up) (Saunders et al., 2020b). A systematic review and meta-analysis of ESD and transitional care by Jee and colleagues (Jee et al., 2022) identified a total of 20 RCTs, 18 conducted in Western countries and 2 conducted in Eastern

countries. Meta-analysis of mortality showed no significant difference between the intervention and control groups (OR 0.80 [95% CI: 0.56 to 1.17, P = 0.25) (Jee et al., 2022). Williams and colleagues (Williams et al., 2022) conducted a smaller systematic review and meta-analysis of five ESD studies. Mortality was a secondary outcome of the review and three studies were evaluated. There was no difference in risk of mortality between the ESD group (n=398) and the control group (n=361) (fixed effects model [FEM], RR 0.98 [95% CI: 0.63 to 1.53], I^2 = 0%, P = 0.93) (Williams et al., 2022).

8.1.1.2 Recurrent stroke

Overall, there was no difference in recurrent stroke between integrated care and control with RCTs (P = 0.08) however there was a significant difference observed with NRCTs (P = 0.007). Few systematic reviews have directly assessed the impact of interventions on recurrent stroke as an outcome however the interventions in this analysis that were associated with reductions in recurrent stroke (lifestyle and cardiovascular risk factor management) have also been shown to reduce recurrent stroke rates in other meta-analyses of interventions including intensive blood pressure control, statin therapy, and complete secondary prevention programmes (Kitagawa et al., 2019; Lambert et al., 2021; Yin et al., 2022).

An updated meta-analysis of intensive BP management (defined as <120/80 mm Hg) which included the RESPECT RCT of 1,280 participants and 3 other RCTs, reported a 22% reduction in recurrent stroke in favour of intensive treatment (RR 0.78 [95% CI: 0.643 to 0.96; P = 0.02) (Kitagawa et al., 2019). A meta-analysis of the effect of statin treatment as secondary prevention demonstrated significantly reduced odds of stroke of any type in people with ischaemic stroke in 11 RCTs (OR 0.87 [95% CI: 0.77 to 0.97], P = 0.002) and 12 cohort studies (OR 0.80 [95% CI: 0.66 to 0.96], P = 0.02) (Yin et al., 2022).

A systematic review of stroke secondary prevention programmes was conducted by Lambert and colleagues (Lambert et al., 2021). This review identified a total of 31 studies, 13 of which were classified as effective and 18 of which were considered not effective. Of the 13 effective studies, five demonstrated long-term effectiveness (significant improvement in outcome measure at >6 months post-randomisation) and eight demonstrated short-term effectiveness (at ≤6 months post-randomisation). The three main intervention strategy categories were improving adherence to the care plan (16/31 studies), improving education (14/31), and increasing physical activity (7/31). Similar to findings of this review, the majority of the effective studies (11/31) used more than one core intervention strategy and therefore received more than one classification: two studies mixed education and physical activity, eight mixed

education and improving adherence to the care plan, two mixed education and physical activity, one mixed physical activity and improving adherence to the care plan, and no program combined all three core strategies. The review by Lambert and colleagues identified clear lessons to be learned from the current prevention programs included: 1) offer tailored care for underserved groups, 2) control blood pressure, 3) provide opportunities for medication dosage titration, 4) establish the care plan prior to discharge, 5) invest in supervised exercise programs, 6) remove barriers to accessing care in low resource settings, and 7) improve the transition of care (Lambert et al., 2021).

8.1.1.3 Major bleeding

Integrated care was associated with more major bleeding events compared with standard care however the difference was not statistically significant (P = 0.50). In this review, the TARDIS and COMPASS studies reported increased major bleeding events with triple therapy versus conventional guideline therapy and reduced events with low-dose rivaroxaban and aspirin treatment, respectively (Bath et al., 2018; Sharma et al., 2019). In the TARDIS study the difference in major bleeding events was sufficiently high in the intervention group to justify stopping the study early to prevent further harm to participants (Bath et al., 2018).

There are numerous meta-analyses in the published literature comparing oral anticoagulants for stroke prevention in patients with AF and in general direct oral anticoagulants (DOAC) have a lower bleeding risk than Vitamin K agonists (VKA) (Cameron et al., 2014; Tawfik et al., 2016; Cohen et al., 2018; Lei et al., 2018). Combination treatment with anticoagulant and antiplatelets is associated with increases in the risk of major bleeding in CVD (Barnes, 2020; Szapary et al., 2022).

Meta-analyses of major bleeding risk in stroke survivors are currently lacking in the published literature and as a result, no definitive conclusions can be drawn.

8.1.2 Meta-analysis: Secondary outcomes

8.1.2.1 Quality of life

Overall, integrated care was associated with significant improvements in QoL (P < 0.0001 vs control) and the magnitude of improvement was greatest with the SSQOL and SF-36 General Health questionnaire assessment tools, however these findings must be interpreted in the presence of substantial (>75%) heterogeneity between studies.

Improvements in QoL are documented in the literature with meta-analyses of interventions such as organised stroke care (Langhorne et al., 2020a) and exercise (Chen and Rimmer, 2011;

Saunders et al., 2020b; Ali et al., 2021) however the degree of improvement in QoL is difficult to define due to lack of information (Saunders et al., 2020b).

Generally, the literature suggests that integrated care in people with chronic conditions improves QoL by improving access to services, increasing patient satisfaction, and providing more coordinated and person-centred care (Baxter et al., 2018). However, the evidence is not always conclusive, and the degree of improvement may depend on successful implementation, such as strong collaboration between providers and a focus on patient needs (Gavaldà-Espelta et al., 2023; Zhang et al., 2025).

8.1.2.2 Readmission

Whilst there was a trend in favour of reduced unplanned readmission for integrated care versus control in this meta-analysis, the trend was not statistically significant. Outside of this review, there is little published information about hospital readmission rates in stroke survivors. An observational study in a cohort of 1,235 Asian patients demonstrated readmission rates of 24% at one year and 7% at up to three years (Tay, 2021). The authors suggested that interventions, such as fall risk assessments, vaccinations, meticulous catheter care, intensified secondary risk factor interventions and continued post-discharge rehabilitation, could reduce readmission rates within the first year, where rates were highest (Tay, 2021).

In countries such as the USA, where readmissions associated with any medical condition are associated with substantial healthcare cost pressures, a combination of multiple interventions such as patient needs assessment, medication reconciliation, patient education, arranging timely outpatient appointments, and providing telephone follow-up, have successfully reduced readmission rates for patients discharged to home (Kripalani et al., 2014). This multi-component approach has also been implemented successfully in people with ischaemic stroke, with one study showing 30-day readmission rates decreasing from 7.4% to 2.8% over a six-month period (Leonhardt-Caprio et al., 2022). A second study in 155 stroke patients with persistent impairment and disability showed significantly lower six-month readmission rates in people who received follow-up visits from either physicians or physiotherapists compared with people receiving standard care (26-35% versus 44%, P = 0.028) (Andersen et al., 2000).

8.1.2.3 Depression and anxiety

Meta-analysis also showed that integrated care was associated with statistically significant reductions in the proportion of patients with depression (P = 0.007). In this review, the analysis has also demonstrated that the assessment tools used showed changes in depression scores and

consistently demonstrated a positive benefit of integrated care over control. In the case of depression, this appeared to be regardless of the scoring system used and anxiety scores were improved with the HADS-A and Zung's SAS scales.

The prevalence of anxiety and depression is substantially higher among stroke survivors compared with the general population and up to one third of all stroke patients suffer from one or more psychosocial impairments (van Nimwegen et al., 2023; Lei et al., 2025), highlighting the importance of managing these comorbidities. Recent systematic reviews of interventions such as CBT, supportive psychotherapy, music and art therapy, and exercise therapy have been shown to improve psychological wellbeing and physical rehabilitation in people with stroke (Zhao et al., 2024; Lei et al., 2025) and many of these interventions can be delivered by nurses or other HCPs (van Nimwegen et al., 2023).

8.1.2.4 Lifestyle and Cardiovascular Risk Factors

The meta-analysis demonstrated that interventions aimed at reducing the impact of cardiovascular risk factors and positively impacting lifestyle in people stroke were associated with a significant benefit overall (SMD -0.17 [95% CI: -0.25 to -0.09], I^2 = 63%, P < 0.0001, Figure 21), with a statistically significant benefit for the cardiovascular risk factors of SBP and LDL cholesterol (P = 0.009 and P = 0.01, respectively).

The benefits of lowering blood pressure, managing OSA with interventions such as CPAP, reducing weight in obesity, healthy diet, regular physical activity, smoking cessation, and low-to-moderate alcohol consumption may include reducing risk of incident and recurrent stroke (Niewada and Michel, 2016; Bailey, 2018) and these are discussed in more detail in Chapter Two.

8.1.2.5 Adherence to Intervention

Although there were limited studies that assessed adherence to intervention in this review and there was no significant difference in adherence rates to interventions between integrated care and control groups, there are published data that suggest that integrated care can improve intervention adherence. In a systematic review of integrated care models for mental health conditions that included 12 studies, patients receiving integrated care reported higher treatment adherence and a greater sense of support from multidisciplinary teams (Alnasser et al., 2025). A meta-review of integrated care programmes for adults with chronic conditions including chronic heart failure, diabetes, COPD and asthma showed that integrated care was associated with improved adherence to treatment guidelines (Martínez-González et al., 2014).

The studies suggest that integrated care can improve adherence to interventions by using a more coordinated, person-centred approach. Models such as CCM use multidisciplinary teams, patient education, and case managers to increase patient engagement and help them adhere to their treatment plans (Wagner, 1998; Mansour et al., 2022).

8.1.3 Meta-analysis: Exploratory Outcomes

8.1.3.1 Favourable outcome

The were mixed results in the meta-analysis that showed a significant improvement in functional status as measured by mRS in NRCTs but not in RCTs (Chapter Five Section 5.17.7.3.1). Overall, the published literature suggest that integrated care can improve functional status as measured by mRS, with evidence showing a significant reduction in disability scores compared with standard care, particularly in stroke survivors (Tan et al., 2025). However, as with the findings from the meta-analysis, the effectiveness of integrated care on functional status is variable, with some studies reporting no significant improvement in functional status (Langhorne et al., 2017; Willeit et al., 2020) or finding that other factors such as integrated care pathways did not provide any benefit over multidisciplinary teams (Sulch et al., 2002).

8.1.3.2 Risk of recurrent cardiovascular disease

The meta-analysis showed that there were fewer recurrent cardiovascular events associated with integrated care but the difference was not statistically significant (Chapter Five Section 5.17.7.3.2). In an eight-year follow-up of an integrated cardiovascular risk management program comprising lipid modifying and blood pressure lowering medication, mean SBP and LDL cholesterol were significantly lowered in a higher proportion of patients at high risk of CVD, reducing the risk of subsequent cardiovascular events (Smits et al., 2023). In a meta-analysis of integrated care in patients with chronic heart failure, integrated care was associated with reduced risk for all-cause mortality (RR 0.90, 95% CI 0.86–0.95), cardiovascular mortality (RR 0.73, 95% CI 0.60–0.88), all-cause hospital readmission (RR 0.95, 95% CI 0.91–1.00), heart failure-related hospital readmission (RR 0.84, 95% CI 0.79–0.89), and all-cause emergency department visits (RR 0.91, 95% CI 0.84–0.98) (Yang et al., 2023). Full adherence to the ABC$_{\text{STROKE}}$ integrated care pathway has also been associated with lower risks of stroke recurrence, MACE and mortality (Sagris et al., 2024; Tsang et al., 2024).

Collectively, these studies indicate that integrated care can reduce the risk of recurrent CVD by improving risk factor control and patient outcomes through coordinated, personalised, and holistic treatment plans, leading to reduced rates of mortality, hospital readmissions, and

cardiovascular events, along with better management of blood pressure, cholesterol, and other risk factors.

8.1.4 Strengths

The systematic review has many strengths. First, it was a comprehensive and thorough undertaking which used a broad definition of integrated care to capture the majority of studies representing contemporary care over a 12-year period from 01 Jan 2012 to 01 Jan 2024 inclusive. Second, many of the processes within the review including screening and risk of bias assessment were conducted simultaneously in duplicate where required and the findings were compared, discussed and agreed. Third, the review was accepted and published in a high impact factor journal and represents a major contribution to the evidence base as, to our knowledge, it was the first comprehensive systematic review and meta-analysis of integrated care in stroke.

8.1.5 Limitations

There are several limitations to this review. The primary outcomes of mortality, recurrent stroke and major bleeding were selected on the basis of research conducted on integrated care in AF, a condition closely linked to stroke with shared cardiovascular risk factors in which an integrated care approach (ABC_{AF}) has been documented and resulted in substantial reductions in the risk of all-cause death (58%), cardiovascular death (61%), stroke (45%) and major bleeding (Romiti et al., 2022). The hypothesis was that integrated care for stroke would be associated with similar positive effects on mortality, recurrent stroke and major bleeding. However, the priorities of stroke patients may extend beyond these parameters. In a survey of stroke survivors, psychological difficulties, cognitive impairment and communication difficulties were identified as the three most important aspects of stroke rehabilitation and long-term care as perceived by patients (James Lind Alliance, 2022). In addition, stroke is considered a medical emergency (National Heart Lung and Blood Institute, 2023) and the care of stroke patients is both complex and resource-intensive, requiring rapid, often immediate, multidisciplinary intervention to prevent lasting brain damage (Futrell and Millikan, 1996; Campbell, 2024; Salehi et al., 2024). By contrast, AF is a chronic condition and while also complex, management is focussed on stroke prevention over the long-term with regular monitoring of stroke and bleeding risk (Chao et al., 2024). Thus, the priorities for stroke patients may differ with those of AF patients, which may reflect on different emphasis placed on primary outcomes such as mortality.

There is currently no standard or unifying definition of integrated care and delivery is likely to be influenced by views and expectations of various stakeholders in the health system (Satylganova et al., 2016), an observation that has been confirmed in studies of hyperacute stroke care where different outcomes were reported due to differences in care models and priorities (Ramsay et al., 2015; Fulop et al., 2016). For example, centralisation of stroke services in London resulted in a significant reduction in mortality rates since almost all London patients were treated in a HASU and were more likely to receive evidence-based care whereas stroke patients in Manchester were far less likely to be treated in a HASU and receive evidence-based care, resulting in unchanged mortality rates (Fulop et al., 2016).

The WHO reports large variations in the definition of integrated care and for the purposes of this review, we used a definition of integrated care developed by the NHS and WHO (Appendix B) and included studies where there was evidence of an integrated care approach according to this definition, however some studies could have been missed during the literature searches if they were not considered to be integrated care per definition. Due to the volume of published studies in stroke, the search was restricted to 12 years however it is possible that some important studies could have been missed if they fell outside of the search window.

Meta-analysis of outcomes indicates high heterogeneity between studies, in particular those evaluating QoL, which confounds interpretation of the findings. Due to the majority of studies having small patient numbers and the paucity of data available for some outcomes, the systematic review did not exclude studies considered to be at moderate or high risk of bias and these studies may have influenced the results of the meta-analyses.

The current study did not account for differences according to setting and acknowledgement is made of the substantial differences in design that may exist between those studies conducting entirely in the acute setting versus those conducted entirely in the community post-discharge. For example, when conducting meta-analysis, no distinction was made between studies of different design (Figure 7). Of the 13 RCTs meta-analysed for mortality, 4 were conducted in the acute setting, 3 in the transitional care setting and 6 in the community setting. Another limitation with the systematic review is that 42/99 (42%) studies evaluated more than one component of stroke care as part of an integrated care pathway or package. In these studies, it is not usually possible to determine the effect of individual components as the results are only reported for the combined interventions. Individual components such as physiotherapy or exercise as part of integrated care pathways represent a subset of the evidence base, and as a consequence the findings of this review provide limited evidence of the effectiveness of these

interventions when compared with studies evaluating them individually (Shepperd et al., 2009). High heterogeneity between studies compounds the analysis of multiple interventions, particularly with observational studies (Hilton Boon et al., 2022).

8.1.6 Systematic Review and Meta-analysis: Conclusions

The findings of this systematic review demonstrate that integrated care improves quality of life, reduces depression and is associated with a positive benefit on cardiovascular risk factors but does not impact mortality, recurrent stroke or readmission rates.

Individual studies in the review demonstrate that interventions such as exercise, rehabilitation, risk factor management, and mental health initiatives are effective in improving outcomes in people with stroke however the results of studies are inconsistent, with 34% of reviewed studies showing no benefit over comparator treatment and considerable heterogeneity between studies.

This is the first systematic review and meta-analysis of integrated care in people with stroke however further research is necessary to determine which elements of integrated care provide the most benefit to people with stroke.

8.2 Focus Groups

8.2.1 Introduction

The primary aims of the focus groups were to explore the experiences of stroke survivors during their recovery from stroke and to explore the barriers and enablers that patients experience during stroke rehabilitation and the components of care that would enhance recovery. The information gained was used to identify potential components of integrated care.

The four main themes that were identified through analysis of the focus group data using Braun and Clarke's (2022) reflexive thematic analysis (Braun and Clarke, 2022) were 1) recognising stroke, 2) loss of identity, 3) Life after stroke – 'Feeling lucky' and 4) dealing with the past and looking to the future. This chapter aims to discuss these themes in depth and situate these findings within the current body of literature.

8.2.2 Theme 1: Recognising stroke

During the focus group discussions, participants demonstrated a good level of knowledge about the signs, symptoms and risk factors for stroke after they had experienced the event however there was a clear perception of what a stroke should look like. This perception was the result of remembering a series of NHS public information films and adverts first launched in 2009 displaying the FAST mnemonic; F= facial weakness, A = arm weakness and S =speech

disturbance and the desired behavioural response and T= time to call emergency services if any one of these stroke symptoms was recognised (Dombrowski et al., 2013; Flynn et al., 2014). The campaign ran in the UK from 2009 to 2014 in a series of phases to raise awareness of the symptoms of stroke and the need for a rapid emergency response from the public. The damage to the brain from stroke was illustrated with an image of a fire burning a hole in the head of an older adult depicted in the advert. The need for a rapid response was further emphasised with the words 'ACT FAST' along with the key message *"The faster you act the more of the person you save"* (Flynn et al., 2014 p.2).

A survey of public awareness of the FAST campaign in the UK conducted in 2013 showed a high awareness of the three common symptoms of stroke; facial weakness 89%, arm weakness 83%, speech problems 91%. However, poor recognition of other important signs, including leg weakness (57%) and visual loss (44%) were observed (Robinson et al., 2013). The authors of the survey stated that the FAST campaign only focussed on three symptoms resulting in the public perception that symptoms such as leg weakness and visual loss were not related to stroke. The authors concluded that poor recognition of important stroke symptoms such as these may lead to delays in presentation, specialist assessment and secondary prevention, and such stroke symptoms should be included in future public health campaigns (Robinson et al., 2013). A survey of 356 adults in Birmingham to determine the level of knowledge of the FAST campaign was conducted by Bietzk and colleagues (Bietzk et al., 2012). This study demonstrated that 65% of participants were aware of the FAST campaign but of these, 32% were unaware of the meaning of any of the letters and only 28% knew the meaning of all 4 letters. Of those questioned, only 54% were aware of diabetes, hypertension and high cholesterol as risk factors for stroke and general understanding was poorest in the youngest (18-30) and oldest (81+) age groups and non-white participants, highlighting an educational need for greater awareness of stroke (Bietzk et al., 2012).

In the wider literature, public health campaigns during the COVID-19 pandemic were initially effective in persuading the public that following the recommended guidance regarding social distancing and preventative measures for infection control were worthwhile (British Medical Association, 2022) however, over the course of the pandemic, people cited news fatigue as a reason for engaging less with COVID-19 information (McClaughlin et al., 2023). The repetition of public health messaging, confusion from inconsistent guidance, misinformation and constant updates on death and infection rates associated with messaging fatigue (McClaughlin et al., 2023) increased the likelihood of non-compliance with recommended

guidance such as the wearing of face coverings and vaccinations (British Medical Association, 2022). A 12-month multimedia public campaign in Switzerland aimed at people with chest pain resulted in a significant reduction in mean pre-hospital time delay from 180 minutes prior to the campaign to 155 minutes during the campaign ($P < 0.001$) (Gaspoz et al., 1996). The study also reduced the diagnosis time of acute MI from 195 to 155 minutes ($P < 0.002$) and increased the number of weekly emergency department visits, implying an increased awareness among the public of the potential implications of chest pain (Gaspoz et al., 1996).

These studies indicate that public health campaigns are effective in raising awareness amongst the public, promoting positive behavioural change and improving diagnosis and treatment rates. These positive benefits must be tempered against news and messaging fatigue in prolonged campaigns, misinformation, and inconsistent guidance, all of which can contribute to a lack of engagement and potential non-compliance with official government guidance.

The published literature correlates well with the findings from the focus groups during which participants frequently described non-FAST symptoms associated with their strokes such as pins and needles, numbness, muscle weakness and a general feeling of malaise. Since these were less common symptoms of stroke not described by FAST, the participants dismissed them and only acted on them if the symptoms persisted or worsened. Some of the participants criticised the FAST campaign for being unrepresentative of their experience and one participant even described the advert as a misconception.

The literature and findings from the focus groups highlight an educational need to include additional possible stroke symptoms in future campaigns but without increasing the complexity of the FAST test aimed at raising public awareness (Robinson et al., 2013) and to increase awareness of stroke in the younger and older age groups (Bietzk et al., 2012). The literature states that public health campaigns are most effective with simple and memorable messages across multiple media platforms that people can recall and take action that is consistent with the campaign (Randolph and Viswanath, 2004; Ratner and Riis, 2014). In the case of the COVID-19 public health campaigns in the UK, small and repetitive slogans such as *"stay home, protect the NHS, save lives"* (British Medical Association, 2022 p.38) were effective at conveying the behaviours that the public were expected to adopt during the pandemic.

Stroke education campaigns such as FAST are part of public health policy and are aimed at increasing public awareness of stroke (NHS, 2021a). The impact of these campaigns has been

an increase in stroke symptom recognition and intention to call emergency medical services (Tan et al., 2022) however awareness of stroke remains low among the public and HCPs.

There is a clear need to educate healthcare practitioners as suboptimal recognition of stroke symptoms has been recently reported in a study of Emergency Department HCPs in Cyprus in which only 46% were knowledgeable about stroke (Rossis et al., 2024). This contrasts with greater but still suboptimal levels of stroke knowledge amongst Emergency Department HCPs including nurses and paramedics in the USA (58%) (Traynelis, 2012), nurses in Brazil (68.5%) (Sbampato dos Santos et al., 2017), Emergency Department HCPs in Saudi Arabia (64%) (Shire et al., 2017) and India (68.8%) (Baby et al., 2019). A nationwide study from Malaysia, conducted with an online questionnaire among HCPs, found that 76% of respondents demonstrated a solid understanding of stroke (Albart et al., 2022).

Furthermore, one interesting consequence of public meetings in Leicestershire designed to promote public awareness following the survey by Robinson and colleagues (2013) revealed that the East Midlands Ambulance Service would not triage a patient reporting acute leg weakness as having possibly suffered a stroke as this symptom was not part of the FAST Campaign. This perception changed because of the survey. An audit of stroke recognition policy in other ambulance services revealed two other regions which would not classify leg weakness as being a possible stroke symptom (Robinson et al., 2013).

8.2.3 Theme 2: Loss of identity

Broadly, loss of identity can occur in anyone suffering from trauma (Horowitz, 2018) or living with a chronic illness as the sense of personal identity is dynamic throughout the lifespan and changes constantly with normative biographical transitions (Bonino et al., 2025). These changes are intensified when a person is confronted with non-normative transitions, such as the diagnosis of a chronic disease, which disrupts the function and perceptions of the body, resulting in a strong sense of discontinuity with the past. As a consequence, life plans, goals and the social roles in which individuals are involved can change dramatically and people have to redefine their personal identity (Bonino et al., 2025).

When focus group participants described their experiences of stroke, in most cases they reflected on how their life used to be prior to the event and they often lamented on what they had lost from their previous life. Loss of identity is a frequently reported phenomenon in people who have suffered a life-changing event such as a stroke (Tyerman and Humphrey, 1984; Wright and Telford, 1996; Ellis-Hill and Horn, 2000; Ellis-Hill et al., 2000; Carroll and Coetzer,

2011; Anderson and Whitfield, 2013; Levack et al., 2014; Lapadatu and Morris, 2019), MI (Fredriksson-Larsson et al., 2013; Dreyer et al., 2021) or cancer (Park et al., 2009).

Loss of identity has been described in the stroke literature as *"loss of me"* (Murray and Harrison, 2004 p.811) and feeling distanced from their new sense of identity, which is perceived as strange and unfamiliar and survivors are still dealing with the consequences of stroke five years after the event (Pallesen, 2014). People often view themselves more negatively after stroke and this view is unrelated to any physical impairment or disability (Ellis-Hill and Horn, 2000). As Ellis-Hill and colleagues (2000) describe following their narrative interviews of stroke survivors, participants expressed feelings of having gone through a fundamental change that could be likened to entering a new foreign world and in one case a participant described a sense of no return, of not being able to get back to where he was before, and feeling that his normal life had come to an end (Ellis-Hill and Horn, 2000). This description is like many accounts recalled by participants in this study.

Loss of identity impacts both upon people with traumatic brain injury and their families (Landau and Hissett, 2008). It engenders a sense of threat to self (Gracey, Longworth, & Psaila, 2015) and provokes attempts to restore identity-related functions (Lapadatu and Morris, 2019). When this goal cannot be achieved, an adjustment to loss of functioning is triggered according to a model proposed by Brands and colleagues (Brands et al., 2012). Consequently, there may be grieving for the lost identity and a striving to reconstruct self-identity (Levack et al., 2010).

8.2.3.1 Grieving for life before stroke

The UK Stroke Association states that coming to terms with a stroke diagnosis is akin to a bereavement and can affect both the stroke survivor and their family (Stroke Association, 2023a). The findings from the current study indicate that focus group participants experienced a profound sense of loss and appeared to enter a grieving process for the person they were prior to the event. The sense of loss and emotional distress is not restricted to stroke survivors but has also been observed in other chronic illnesses such as MI (Liljeroos et al., 2023), diabetes (Bateman, 2018) and cancer (Macmillan Cancer Support, 2025). One of the more commonly used models for the grieving process is the model comprising five stages described by Elisabeth Kübler-Ross in her book On Grief and Grieving (Kübler-Ross and Kessler, 2014):

- **Stage 1: Denial.** In this stage the person's mind tries to reject what has happened to them and they simply cannot believe it. Denial is a way of coping with loss associated with a traumatic event such as stroke and it often manifests itself as questioning whether

the event actually happened. When the person knowingly accepts the loss, the healing process begins and the denial fades (Kübler-Ross and Kessler, 2014, pp.8-11). In stroke survivors, denial could involve refusing to accept help or using aids to perform daily activities in the belief that nothing is wrong (Stroke Association, 2023a).

Examples from Study

In the current study there were clear examples of denial in stroke focus group participants during the event (not believing that they were experiencing a stroke because the symptoms they were experiencing were not what they considered to be characteristic of stroke) and after (refusing to accept a diagnosis of stroke or that subsequent life would have to change substantially).

- **Stage 2: Anger.** This is a necessary stage of the healing process and anger presents itself in multiple ways; the person is angry at themselves for being unable to stop the traumatic event from happening, angry at the doctors for not diagnosing the condition earlier or treating sooner, angry at the situation in which they find themselves, and angry at God for allowing it to happen to them. Anger manifests after denial and once the person realises that they are going to survive their traumatic event. Expressing anger also means that the person is progressing through their healing process their and anger should not be suppressed. Conversely, some may experience guilt, which is anger turned in on itself. Anger eventually subsides and the feelings of loss change their form once more (Kübler-Ross and Kessler, 2014, pp 11-16).

  Examples from Study

  In the current study there were multiple examples of anger, guilt and frustration in which participants described being unable to engage in activities of normal daily living such as carrying out a conversation, DIY or gardening. The guilt was expressed when they realised that they had at least made a full recovery from their stroke unlike other patients they had seen with more severe stroke and associated disability.

- **Stage 3: Bargaining**. The bargaining stage of grief revolves around *"if only"* or *"what if"* statements, for example "*if only I had seen the doctor sooner"* or "*what if I had done something about my symptoms earlier?"* (Kübler-Ross and Kessler, 2014, pp 17-20) accompanied by a strong desire to go back to the past and to change things.

Bargaining can be an important reprieve from the pain associated with grief and it evolves over time, moving from the past to the future. A person may bargain that nobody else in their family suffers a traumatic event or illness as they have done. At the end of the bargaining process, the person concludes that their previous life is gone (Kübler-Ross and Kessler, 2014).

Examples from Study

Reflection on past events and asking 'if only' questions were expressed frequently by the focus group participants, for example wondering if there were warning signs of an impending stroke that they could have picked up on earlier and what might have been different if they had.

- **Stage 4: Depression.** In this sense, depression means a deep sadness rather than clinical depression (Stroke Association, 2023a). The person withdraws from life and wonders whether there is any point in going on living. In grief however, depression is a necessary step in the healing process even though it may appear to some as endless, but it disappears once it has served its purpose in loss. Depression is helpful in grief as it allows the sufferer to slow down, take stock of the loss and start to rebuild their lives and sense of self (Kübler-Ross and Kessler, 2014, pp 20-24).

  Examples from Study

  In the current study, depression was one of the most frequently discussed topics amongst participants; some had difficulty acknowledging that they were suffering from it and others needed psychological support in order to manage it. Sharing their experiences of depression with other stroke survivors in the focus groups was beneficial for many of the participants, especially those who had never shared their experiences of depression previously.

- **Stage 5: Acceptance.** This stage is about accepting the reality of a new norm that is here to stay and making adjustments to live in that new reality. Acceptance might mean nothing more than experiencing more good days than bad days and the sufferer might never be happy about acceptance, however individuals learn to live again through acceptance and grow with the grief (Kübler-Ross and Kessler, 2014, pp 24-28).

  Examples from Study

Some of the focus group participants explained how they dealt with the grief of the loss of their normal life by engaging in activities that they could perform within their capabilities in their new post-stroke life and which gave them a sense of achievement and purpose, such as going to the gym or participating in stroke research clinical trials.

8.2.3.1.1 Models of Grieving

Kubler-Ross's five stages of grief is one of many models for understanding loss and dealing with grief (Kübler-Ross and Kessler, 2014). The Dual Process Model by Stroebe and Schut (Stroebe and Schut, 1999) looks at two types of activities in grief: those that are loss oriented and those that are restoration oriented. Essentially a healthy grief includes both activities and an individual will move between the two; this is a normal process and probably both need to be conducted as the individual adjusts to their grief and mixed feelings. In this model, grief involves a dynamic oscillation between these two orientations, with healing requiring integration of both (Stroebe and Schut, 1999). The loss-orientated activities include denial or avoidance of restoration changes and the restoration-orientated activities doing new things and creating new identities and relationships. These behaviours have been observed in the current study however the Dual Process model was developed around the actual loss of a loved one.

Worden's Four Tasks of Mourning (Worden, 2018) offers a more active, proactive framework for navigating grief. The four tasks include 1) *Accepting the reality of the loss:* acknowledging that the death has occurred, 2) *Processing the pain of grief:* experiencing and working through the emotional pain associated with the loss, 3) *Adjusting to a world without the deceased:* adapting to the practical and emotional changes in life after the loss, and 4) *Finding an appropriate place for the deceased while building a new life:* establishing a lasting connection to the deceased while also creating a new life (Worden, 2018). Worden's task-based approach has been used to support people bereaved by COVID-19 (Khosravi, 2021). Some parallels with Worden's Four Tasks of Mourning can be seen in the current study. Focus group participants described how they eventually accepted that the person they once were before their stroke had gone and that they had to adjust to a new reality based on their new circumstances. They often referred back to the person the used to be by comparing what they could do then with what they could do in the present time. As with the Dual Process model, Worden's Four Tasks of Mourning is a model based on the actual loss of a loved one.

Dr Lois Tonkin, a grief counsellor, developed the 'Growing around Grief' theory after speaking to a client about the death of their child (Tonkin, 1996). The client told Tonkin that at first grief

filled every part of her life. She drew a picture with a circle to represent her life and shading to indicate her grief. It was all consuming. She had thought that as time went by the grief would shrink and become a much smaller part of her life. But what happened was different. The grief stayed just as big, but her life grew around it. There were times where she felt the grief as intensely as when her child first died. But there were other times where she felt she lived her life in the space outside the circle (Tonkin, 1996). Tonkin's theory of grief explains that the grief never disappears but that sufferers can grow a new life which includes the loss (Tonkin, 1996). Tonkin's theory is one of the most popular theories of grief. In the current study, focus group participants talked about creating a new life post-stroke but they did not discuss this in the context of the grief they had suffered.

In considering the models of loss and grieving outlined above, there are some similarities between the current study findings and each model, however, the participants in the present study described their emotional responses following stroke in the context of loss of the person they once were, whereas the Dual Process model, Worden's Four Tasks of Mourning and Tonkin's theory of grief highlight behaviours surrounding the actual loss of a loved one rather than the emotional responses associated with loss of identity.

Although Kubler-Ross's five stage model of grieving is still highly popular and regularly accepted, there are a number of criticisms against its adoption as a guideline for grieving (Corr, 2020; Avis et al., 2021). These include the criticisms that the model is too rigid and linear and does not reflect the true, non-linear disrupted nature of grief, that it is an over-simplification of the grieving process and that it does not recognise individual differences in personality, culture and support systems. Many critics argue that the Kubler-Ross model is too prescriptive, implying that individuals are not grieving properly if they do not follow the stages in the order they are portrayed (Corr, 2020; Avis et al., 2021). Criticisms aside, of the models of grieving described in this chapter, the Kubler-Ross model appears to be the best fit with the findings of the current study.

In a study by Levack and colleagues (2010), the reconstruction of a lost or disrupted sense of identity or self-following traumatic brain injury appeared to be an essential part of the recovery process but was complex, involving factors such as retraining skills, acceptance of disability, revising personal narrative and redefining what was meant by 'success'(Levack et al., 2010). Therefore, reconstruction of self-identity involved both improving a person's capacity (through activity involving effort) and changing self-perception. There was a tension between acceptance of the current situation and striving for a better one. Acceptance of loss was often

considered as a requirement to move on although this was not something that all participants in the current study felt ready or able to do. Complete acceptance of loss also appeared to be detrimental; too much like giving up, and some desire for ongoing improvement was considered beneficial for motivation and for retaining a positive outlook on life (Levack et al., 2010).

Self-identity is a complex, multidimensional concept and can be defined as an integrated sense of self that develops during adolescence and emerging adulthood, serving as a guiding mechanism for life pathways and decisions, and is associated with well-being and adaptive functioning (Bailey, 2003; Meca et al., 2023). In her book entitled "Good Days Bad Days: The Self in Chronic Illness and Time", Kathy Charmaz describes the crossroads between chronic illness and the constructions of self-identity (the self) (Charmaz, 1997). In Chapter 9 of the book, Charmaz (1997) explains the importance of time and its relationship to the concept of self; time plays a pivotal role in shaping the concept of self as chronic illness ties the concept of self to the past, present or future. The concept of self may shift and evolve with time, changing and restructuring parts of the past, present and future in a kaleidoscopic fashion. New events result in the recombination of past, present and projected future selves in different and changing ways (Charmaz, 1997).

The participants in the current study demonstrated a shift and change in how they perceived self-identity when speaking about stroke, their conversation including events from the past, present and future. The participants' own perception of self-identity had been altered dramatically by this life changing event (stroke) and this was evident by the creation of a new identity, coping with the limitations of stroke and trying to make the best of things.

8.2.3.2 Loss of autonomy

In healthcare, autonomy is the principle that individuals have the right to self-determination and to make informed decisions about their own health and medical care without being unduly influenced by healthcare providers when making decisions about treatments (Ubel et al., 2018). This principle underpins the requirement for informed consent and shared decision making before any medical procedure, as well as the right of a patient to refuse treatment (Pietrzykowski and Smilowska, 2021).

Autonomy is an important component of rehabilitation and includes the right to take part in the decision-making that concerns a person's health. Autonomy is considered necessary to achieve full participation in life (Cardol et al., 2002). Loss of autonomy in stroke is well documented

in the literature, rendering individuals unable to make decisions about their own health and life choices (Proot et al., 2000; Greenwood et al., 2010; Lou et al., 2017; Palstam et al., 2019; Westerlind et al., 2020; Lu et al., 2023a) and it affects caregivers as well as patients (Greenwood et al., 2010). Stroke has been shown to result in substantial disruptions in autonomy, independence, social life and relationships (Lou et al., 2017). A longitudinal observational study conducted by Palstam and colleagues (2019) investigated participation and autonomy in a group of patients five years after stroke using a specific questionnaire known as the Impact of Participation and Autonomy-questionnaire (IPA-E) (Palstam et al., 2019). The authors found restricted participation and autonomy in people with stroke even after five years and that the most restricted domains in the survey (autonomy outdoors [ability to plan and pursue recreational activities and engage in social events], work/education and social life/relationships [quality of social life and the individual's capabilities of establishing and maintaining relationships with friends and acquaintances]) were those that required high levels of physical, social and cognitive abilities (Palstam et al., 2019).

In a qualitative study of carers of stroke survivors by Greenwood and colleagues (2010), a purposive sample of 31 carers described reductions in their autonomy and independence within the first three months following discharge of the stroke survivor they cared for. This was due to substantial changes in their lifestyles following the responsibility of caring for a stroke survivor and an increasing dependence on help from others, however they also identified strategies to manage these changes and take back control of their lives. These strategies included selection, optimisation, compensation, asking for and accepting help and negotiation (Greenwood et al., 2010).

As stroke survivors recover, they regain some degree of autonomy. In a qualitative study of stroke patients receiving rehabilitation in nursing homes, Proot and colleagues (2010) reported that patients experienced an improvement in their autonomy (particularly in self-determination, independence and self-care) in the final weeks before discharge. The change in autonomy was found to be related to regained abilities and self-confidence, and to patients' strategies, for example taking the initiative and being assertive (Proot et al., 2000). In the current study, there were numerous examples of participants describing a loss of autonomy after having their stroke and then regaining some independence after recovering, for example in some cases participants were able to reclaim their driving licences or return to work. Regaining autonomy meant that they were less reliant on others and were able to make their own decisions about their care.

8.2.3.3 Vulnerability

The 2014 Care Act defines a vulnerable adult as an individual who has needs for care and support, who is experiencing, or at risk of, abuse or neglect and, as a result of their care needs, is unable to protect themselves (UK Government, 2014). The definition of vulnerability with people experiencing stroke differs in the sense that it arises from loss of control, functional impairment or disability, a negative perception of health and identity, and a dependency on others (Carlsson et al., 2009; Green and King, 2009; Croot et al., 2014; Taule and Råheim, 2014).

In the published literature, a heightened awareness of vulnerability has been identified by stroke survivors (Wolfenden and Grace, 2015; Crowfoot et al., 2018) and in a qualitative literature review by Crowfoot and colleagues (2018) a theme entitled *"the vulnerable self"* emerged (Crowfoot et al., 2018 p.1381). In this review (Crowfoot et al., 2018), vulnerability appears to occur at the onset of TIA or minor stroke and is a pivotal component that initiates a process of reshaping the self (Taule and Råheim, 2014). Vulnerability has been associated in some studies with the suddenness of the event (Green and King, 2009; Gibson and Watkins, 2012), a loss of control (Taule and Råheim, 2014) the emotional response to experiencing a TIA or minor stroke and a dependency on others (Carlsson et al., 2009; Croot et al., 2014; Taule and Råheim, 2014). Vulnerability had a negative impact on the way individuals perceived their health and identity (Green and King, 2009; Taule and Råheim, 2014), often leading to the belief that they were less physically able due to functional impairment (Green and King, 2009). People who compared their pre- and post-minor stroke physical capabilities also appeared to have a negative self-perception of their health (Taule and Råheim, 2014).

Patients suffering a stroke can be especially vulnerable because a sudden event has disrupted their lives and reminded them of their mortality (Loft et al., 2019). Indeed, a study by Gaynor and colleagues (2018) in stroke patients from Action on Secondary Prevention Interventions and Rehabilitation in Stroke (ASPIRE-S) study followed up five years after stroke assessed vulnerability using the Vulnerable Elders Score (VES) (Gaynor et al., 2018). Vulnerability in this study, defined as a VES score of ≥3, was associated with a five-fold higher risk of mortality compared with individuals who were nonvulnerable (Gaynor et al., 2018).

Several participants in the current study described feelings of vulnerability post-stroke and one individual had particularly strong feelings of vulnerability as he was unable to move or communicate during and immediately after his stroke and listening to conversations around him about palliative care led him to consider his own mortality.

8.2.4 Theme 3: Life after stroke – 'Feeling lucky'

Despite the observation in this study that most participants repeatedly stated how lucky they felt after recovering from stroke, arising from witnessing more severely disabled individuals either in hospital or stroke unit during their experience, there are few published studies on this phenomenon in the literature. A single published article documenting a thematic analysis on receiving bad news in stroke survivors by Maddern and Kneebone (2019) identified a theme entitled *"lucky to be alive"* (Maddern and Kneebone, 2019 p.271). The study was conducted in the context of patients being given the bad news of a stroke diagnosis by a medical practitioner and this theme arose from participants having received a sharp reminder of their mortality. Feeling lucky to have survived the stroke inspired people to make the most of their lives, but was never said to erase the earlier effects of bad news when it was poorly delivered by medical practitioners (Maddern and Kneebone, 2019). Elsewhere in the literature, the theme of feeling lucky is represented only in narrative descriptions by individual stroke survivors and these generally provide little or no context. For example, in the UK Stroke Association newsletter Stroke News (Spring, 2023), an article on loneliness after stroke describes how Tracey (aged 52) received thrombolysis and was discharged from hospital after six days after her stroke: *"Despite feeling lucky in her recovery, the lasting effects of stroke have affected her social life and mental health"* (Stroke Association, 2023c p.30). In this case, Tracey may have felt lucky in her recovery because she was in hospital for a relatively short period of time however it is important to understand why people with stroke feel that they are lucky and it is clear that this area of stroke is under-researched and merits further investigation.

More broadly, individuals who survive other potentially fatal medical events such as sepsis or MI often express that they feel lucky to have survived and are grateful for the medical support they have received (Ahmed and Masood, 2019; Duda, 2025; East Kent Hospitals University NHS Foundation Trust, 2025). As with stroke, there is very little published research about this phenomenon and most of the information exists as anecdotal evidence (East Kent Hospitals University NHS Foundation Trust, 2025) or case studies (Ahmed and Masood, 2019; Duda, 2025).

8.2.4.1 Making sense of a catastrophic event

This sub-theme arose from discussions with focus group participants who had effectively accepted that their lives had been changed by stroke and were managing their recovery. Participants described difficulties in coming to terms with having had a stroke, including sudden emotional outbursts, debilitating fatigue, struggling to conduct a conversation, suffering bouts of depression, questioning their rate of recovery and worrying about how they would cope financially.

Stroke has been described in the literature as a catastrophe and an overwhelmingly transformative event that leaves survivors with a feeling of loss, uncertainty, and social isolation (Salter et al., 2008). This in turn affects their sense of self, emotions, personality, abilities, activities, roles, and social relationships (Salter et al., 2008; Taule and Råheim, 2014).

The impact of stroke is far-reaching as it affects emotional, physical, financial, cognitive, and psychological domains. Strong emotions such as anger, fear, impatience, tearfulness and sadness following stroke are reported in the literature and these emotional reactions are often unpredictable and are linked to a sense of vulnerability (Taule and Råheim, 2014; Crowfoot et al., 2018). In the focus groups, participants described sudden outbursts of emotion such as bursting into tears or wanting to shout and scream.

Among the physical impacts of stroke, fatigue was the problem that was most frequently reported in the current study. Post-stroke fatigue (PSF) is well documented in the literature (Acciarresi et al., 2014; Nadarajah and Goh, 2015; Wu et al., 2015; Aali et al., 2020; Zhang et al., 2021) and has been described as *"an early exhaustion after physical or mental activity, weariness, and aversion to effort"* (Staub and Bogousslavsky, 2001 p.78). Despite being well documented, PSF is poorly understood (Acciarresi et al., 2014; Nadarajah and Goh, 2015), with few interventions shown to provide any benefit according to a Cochrane systematic review of the literature (Wu et al., 2015). Importantly, PSF impacts negatively on QoL, has a strong association with depression and has been shown to a predictor of post-stroke mortality (Acciarresi et al., 2014; Nadarajah and Goh, 2015; Zhang et al., 2021). Participants in the current study described the uniqueness of PSF and a need to be educated and informed about PSF as several described its unexpected onset and a far greater than anticipated impact of PSF on their daily lives. The literature also highlights a need for additional studies to learn more about PSF and how it can be effectively managed (Acciarresi et al., 2014; Nadarajah and Goh, 2015; Zhang et al., 2021).

Balance problems were another issue that was raised by participants in the current study, and it was associated with falls and fear of falling. Balance impairment in stroke survivors is common and the prevalence has been estimated at 48% in a study of 83 stroke survivors (Khan and Chevidikunnan, 2021). In a small study of 75 stroke survivors in the UK, a total of 83% were found to have a balance disability, 27% of whom could sit but not stand, 40% could stand but not step, and 33% could step and walk but still had limited balance (Tyson et al., 2006). The most common intervention for recovery of balance is physiotherapy (61%), however, other interventions including virtual reality (20%), robotic devices (6%) and Tai-Chi (4%) have been documented (Arienti et al., 2019). Physiotherapy appears to be the most effective intervention with the highest quality studies (An and Shaughnessy, 2011; Arienti et al., 2019), with exercise therapy, physical fitness training, care-mediated exercise in addition to usual care, and repetitive task training all showing evidence of significant beneficial effect (Arienti et al., 2019). There were clear examples of how participants in the current study described how they had benefited from physiotherapy to improve their balance, with one individual opting to pay for private treatment after her NHS care had expired, so that she could continue with her recovery. These observations must be interpreted with caution as they relate to individual experiences from a small group of participants and may not reflect the experiences of the wider stroke population.

The estimated societal cost of stroke in the UK is £26 billion per year, with new onset stroke costing approximately £45,000 per patient during the first year and £25,000 in subsequent years (Patel et al., 2019). According to a briefing in 2012 by the Stroke Association, one in four people in the UK with stroke are under the age of 65 and stroke can have a sudden and unexpected effect on the finances of those in work (Stroke Association, 2012b). Income declines whilst bills and expenses tend to increase, putting a strain on family relationships. For some, the financial impact of stroke is lifelong, financial support is minimal and claiming benefits is often fraught with difficulty (Stroke Association, 2012b). Those participants in the current study who were of working age and in employment at the time of their stroke experienced similar problems, struggling to make ends meet and at times being unable to claim additional financial support, relying on savings, benefits and the sale of personal items to cover their costs.

Cognitive impairment and memory dysfunction are common symptoms following stroke that can have a substantial impact on quality of life and activities of daily living (Al-Qazzaz et al., 2014; Oros et al., 2016; Tang et al., 2020; Lee et al., 2021). Memory dysfunction occurs in over

a third of stroke survivors (O'Sullivan et al., 2023) and the activities that typically tend to be affected by memory problems include remembering important dates and difficulties in carrying out a conversation (Tang et al., 2020). Cognitive recovery occurs in most stroke survivors within 12-18 months however the mechanisms of recovery are not fully understood and as a result, strategies to treat memory dysfunction are lacking (O'Sullivan et al., 2023). In the current, study participants frequently discussed experiences of memory dysfunction, such as losing the thread of a conversation or ending up in an unfamiliar location without knowing how they got there.

The psychological impact of stroke includes depression, anxiety, post-traumatic stress disorder (PTSD), mania, psychosis, irritability, and apathy, among other emotional and behavioural conditions such as personality changes (Lanza, 2006; Robinson and Jorge, 2016; Devereux and Berns, 2023). Left untreated, psychological mood disturbance is associated with higher rates of mortality, long-term disability, readmission to hospital, suicide and outpatient service utilisation (Pohjasvaara et al., 2001; Williams, 2005). Up to 30% of people with stroke experience depression (Bowen et al., 2016), which has been shown to be an independent predictor of poor long-term functional outcome post-stroke and is also associated with increased mortality (Pohjasvaara et al., 2001; Ayerbe et al., 2014). Although depression is an important morbidity associated with stroke that impacts on recovery, it is often undetected or inadequately treated and a Cochrane systematic review demonstrated only low-level evidence for the benefit of pharmacological, psychological, and non-invasive brain stimulation interventions in stroke patients (Allida et al., 2020). Despite this, other studies of comprehensive, multidisciplinary interventions in people with stroke (including professional psychology sessions, exercise, early rehabilitation training and cognitive training) that were not included in the current study meta-analysis have shown reductions in depression in participants who received the interventions (Wu et al., 2012b; Cheng et al., 2018a; Lee et al., 2018; Brandal, 2019; Yu et al., 2019; Zhang et al., 2019; Lin et al., 2020; Feng et al., 2021; Gun Young, 2021; Jung et al., 2021).

The warning signs of a stroke are well documented and include TIA, which is itself termed a warning sign of a full-blown stroke (American Stroke Association, 2020; NHS, 2023a). Other warning signs include sudden numbness in the face arm or leg, often one-sided, sudden confusion, difficulty speaking or comprehending, visual disturbance, dizziness or loss of balance, or sudden severe headache (American Stroke Association, 2020; Stroke Association, 2023c). However, because these warning signs are not part of FAST, individuals who

experience them do not associate these with a stroke and do not act unless, as in the case of the participants in the current study, the symptoms persist or worsen. This was particularly common for participants who described their experiences of their first stroke. Participants who had experienced more than one stroke were more likely to recognise the signs of a subsequent stroke and act earlier. The observations highlight the importance of extending the FAST message to include the lesser-known symptoms and warning signs.

Prevention of stroke recurrence is well documented in the literature by minimising the impact of cardiovascular risk factors such as hypertension, AF and diabetes (Lip, 2017; Lip et al., 2022b). Lifestyle modifications including weight loss, healthy diet, regular physical activity, smoking cessation, and low-to-moderate alcohol consumption may reduce risk of incident and recurrent stroke (Lip et al., 2022b; Govori et al., 2024); these behaviours should be targeted because of their positive effect on cardiovascular risk factors (Niewada and Michel, 2016; Bailey, 2018). The American Heart Association's 'Life's Essential 8' concept identified modifiable risk factors for brain health and prevention of cognitive decline that include behaviours, conditions and lifestyles that can emerge in childhood and adolescence, all of which can be routinely identified and managed in primary care (Lloyd-Jones et al., 2022). However, long-term behavioural change is challenging and is sometimes only achievable with intensive long-term patient support and education programs (Bailey, 2018). There are numerous examples of lifestyle modifications to reduce the risk of recurrent stroke in the current study. After initially struggling to cope with a diagnosis of stroke and its consequences, participants began to realise and understand the importance of secondary stroke prevention. They talked about smoking cessation, healthy eating and regular exercise as ways to reduce their risk of cardiovascular complications.

8.2.4.2 Thoughts and sentiments

Apart from feeling lucky, which is discussed above, there is little published information about why some stroke survivors might feel like frauds for using NHS resources prior to diagnosis and why they belittle their stroke experiences. A stroke survivor's story on the site Different Strokes UK mentions the experience of Greet, a physiotherapist who suffered an ischaemic stroke (Different Strokes UK, 2024a). Greet's experience encompasses many of the concepts that are discussed in this chapter. He had non-classical symptoms of stroke including headache, feeling rough and tingling sensations and did not act on them until they worsened. He was in denial about having a stroke because his symptoms were atypical and importantly Greet states *"it made me feel like a fraud right up until my diagnosis"* (Different Strokes UK, 2024a p.4).

In the current study, there were many participants who stated that they felt like frauds and they appeared to do this out of a sense of guilt for using scarce NHS time and resources and that they did not realise that they were having a stroke because their symptoms did not fit with FAST. Instead, they thought that whatever they were suffering from was trivial and did not merit the time and attention they received.

This behaviour may be linked to a lack of awareness of symptoms that indicate a serious health-related event, which can result in a delay in seeking help. In a study of decision-making behaviour in acute cardiac patients during the COVID-19 pandemic, the number of admissions to hospital for MI reduced substantially (Burton et al., 2022). This was partly due to a lack of awareness of cardiac symptoms but also a reliance on informal support networks and a reluctance to seek medical treatment because of concerns of COVID-19 infection (Burton et al., 2022). Patient delay with symptoms of acute coronary syndrome (ACS) is common and associated with increased mortality (Farquharson et al., 2023). A study of an intervention designed to change behaviour of patients with symptoms of ACS resulted in significant increases in intention to phone an ambulance immediately for ACS symptoms (Farquharson et al., 2023). These studies highlight the need for informed public health messaging to ensure those in need of treatment can recognise their symptoms and access care in a timely fashion.

A blog post on the business networking site LinkedIn introduces the concept of imposter syndrome in stroke (A Stroke of Grace, 2024). Imposter syndrome is a psychological phenomenon in which people doubt their accomplishments and fear being exposed as a "fraud" despite evidence of success or competence. In stroke recovery, imposter syndrome may manifest itself as survivors minimising their progress, feeling unworthy of their achievements, or fearing that others will view their recovery as inadequate. Survivors may question their improvements, compare their progress unfavourably with others, or feel undeserving of support and praise. Imposter syndrome has other profound effects on stroke recovery, leading to anxiety or depression and disrupting the reconstruction of self-identity (Different Strokes UK, 2024a). There are examples of participants in the current study displaying behaviour that suggests imposter syndrome given that many of them trivialised their own experience, especially after hearing the experiences of others in the same room, and this seemed to be related to the observations that they considered their stroke was mild in severity and not a 'proper' stroke. This area of behaviour post-stroke is clearly under-researched and merits further investigation.

8.2.5 Theme 4: Dealing with the past and looking to the future

8.2.5.1 Recovering from stroke

In a broader sense, the term 'recovery' is a general concept referring to the process of regaining health, well-being, or a lost ability, including the ability to work and perform in society (Friedman, 2021). The term recovery is used widely in both professional contexts and daily life and is generally thought to have been achieved when a patient who experienced an illness comes back to his or her former health state (Friedman, 2021). However, the concept of recovery as defined here has been criticised for being too general since it incorporates different ideas of recovery without differentiating between them, and as being inaccurate since the concept of recovery is used extensively when patients have not come back to their former sound state (Friedman, 2021). In a debate about recovery and mental health, Slade and Longden (2015) state that recovery is best judged by the person living the experience and they define recovery as *"full symptom remission, full or part-time work or education, independent living without supervision by informal carers, and having friends with whom activities can be shared, all sustained for a period of two years"* (Slade and Longden, 2015 p.3).

However, in stroke the literature suggests that only about 25% of stroke survivors make a full recovery, in other words a return to the level of everyday participation and physical functioning of community-matched people who have not had a stroke, and the likelihood of recovery is dependent upon the severity of any disability (Dobkin, 2005). Approximately 35% of stroke survivors with initial leg paralysis never regain useful function, and 20-25% are unable to walk without full physical assistance. Approximately 65% of patients cannot incorporate an affected hand into their usual activities six months after stroke (Dobkin, 2005).

Factors influencing post-stroke motor recovery and improvements in QoL include socio-demographic factors (age, gender, race, socioeconomic status), clinical factors (comorbidities such as diabetes, depression, infection, white matter disease), the type of stroke and rehabilitation/physiotherapy (timing, type, dose, merged therapy) (Nichols-Larsen et al., 2005; Milinavičienė et al., 2007; Alawieh et al., 2018). For those people who require it, thrombolysis is a significant predictor of functional recovery from stroke, as are activities of daily living (ADL) function on the day of discharge (Koositamongkol et al., 2013).

As outlined in Section 4.1.2.3, stroke rehabilitation is a comprehensive, multidimensional process that assists stroke survivors in recovering or adapting to loss of physiological or psychological function following stroke when reversal of the underlying pathological process is incomplete. Comprehensive rehabilitation involves physiological activities such as exercise

to improve strength, coordination, balance and mobility, with occupational therapy allowing stroke survivors to regain their ability to perform ADL (Li et al., 2024). Psychological counselling and support are key components in addressing emotional and cognitive challenges that may arise during rehabilitation (Li et al., 2024).

In the current study there were numerous examples of how focus group participants had used rehabilitation, in particular, exercise and physiotherapy, as an integral part of their physical recovery. There were also examples of how counselling had helped them through periods of depression, allowing them to navigate negative emotional responses to an altered life post-stroke.

8.2.5.2 Giving up the old and adjusting to the new

As discussed in Section 8.2.3.1, one of the stages of grieving for life before stroke is acceptance of a new norm post-stroke (Kübler-Ross and Kessler, 2014), meaning that stroke survivors have to accept that their life has changed permanently before they can attempt to rebuild their identity.

The participants in the current study recalled multiple examples of how they had accepted the limitations that stroke had placed upon them. One common example of this was independence based upon the continued ability to drive. Some participants had recovered sufficiently to regain their driving licences whilst other had to accept that they would no longer be able to drive due to permanent loss of some peripheral vision, which meant that they could not pass the vision test required for regaining a UK driving licence and had to rely on others to drive for them. Some individuals expressed that they no longer felt confident enough to drive even though they had regained their licences.

Visual field loss is common in stroke survivors, with estimates of prevalence of between 8% and 67% (Rowe et al., 2013). In a prospective study of 915 stroke survivors in the UK, 479 participants (52%) had visual field loss. Almost half of symptomatic participants (n=226) experienced only visual field loss: almost half (n=226) also had reading difficulty, blurred vision, diplopia, and perceptual difficulties. Thirty one percent (31%, n=151) had visual field loss as their only visual impairment and 69% (n=328) had low vision, eye movement deficits, or visual perceptual difficulties. This study demonstrated that visual field loss in stroke survivors requires accurate assessment in order to define the type of visual loss and to provide targeted treatment (Rowe et al., 2013).

A study of adaptive behaviour in stroke survivors showed that individuals realised change, knowing and accepting the physical, psychological, and social changes caused by stroke (Choi et al., 2022). Individuals took on an optimistic view, having a positive meaning in life by hoping for recovery. They restructured daily activities to suit themselves, modifying them in order to safely and smoothly carry out daily life in their new, stroke-altered physical, psychological, and social situations. Stroke survivors established their own new normal and lived their daily lives, performing functional activities to their fullest potential, including healthy behaviours such as taking medications or rehabilitating exercises, and participating in family or community activities to reintegrate into society (Choi et al., 2022).

The participants in the current study also provided multiple examples of how they had taken control of their recovery after accepting the limitations that stroke had imposed upon them. A number of participants talked about being proactive, learning more about their condition and demonstrating a willingness to engage in self-management strategies such as goal setting.

Self-management is a concept that involves an individual actively managing a chronic condition in partnership with their social network and healthcare providers and is different to self-care, defined as the ability of individuals, families, and communities to promote health, prevent disease, and cope with illness and disability, with or without the support of a health worker (Kitson and Lawless, 2025). There is evidence that self-management strategies improve outcomes post-stroke and these strategies include patient education and information provision, goal setting, action planning, self-monitoring and social support (Pearce et al., 2015; Warner et al., 2015; Klockar et al., 2023; Sahely et al., 2023). A qualitative systematic meta-review of stroke self-management strategies by Pearce and colleagues (2015) reported on the devastating impact of stroke on peoples' self-image; the fact that informational, physical, psychological and social support needs evolve as survivors move through the different stages of recovery from acute stroke through rehabilitation to looking towards the future; and the potential benefits of goal-setting and action-planning underpinned by good patient-professional communication potentially supported by groups for stroke survivors (Pearce et al., 2015). Despite the benefits of self-management programs and the observation that stroke survivors perceive them as a valuable addition to their recovery, they remain underutilised in routine clinical practice (Pearce et al., 2015; Warner et al., 2015; Klockar et al., 2023; Sahely et al., 2023). One qualitative study reported that stroke survivors continue to feel unprepared with managing everyday activities following discharge and they are largely left to work things out for

themselves, indicating an overlooked opportunity to initiate self-management support earlier in the recovery process (Klockar et al., 2023).

8.2.5.3 Living with uncertainty

Living with uncertainty in illness is well documented in the literature (Mishal, 1988; Mishal, 1990; Gursahani, 2021; Eppel-Meichlinger et al., 2024) and an early protagonist was Merle Mishel, who developed an Uncertainty in Illness theory (UIT) in 1988 (Mishal, 1988). According to Mishel, uncertainty is defined as the *"inability to determine meaning to illness-related events"* (Mishel, 1988, p.225). Through the UIT, Mishel outlined how patients cognitively structure a subjective interpretation of uncertainty regarding treatment and outcomes in 3 central pillars: 1) Antecedents generating uncertainty (in other words, the stimuli frame [symptom pattern, event familiarity, and event congruence]), cognitive capacities, and structure providers (education, social support, and credible authorities), 2) Appraisal, and 3) Coping with uncertainty (Mishal, 1988). Mishal's UIT was refined and reconceptualised to incorporate the experience of continuous uncertainty, for example, in chronic illness or with regard to a possible recurrence (Mishal, 1990). In 2021, Gursahani proposed four pillars of illness uncertainty in stroke survivors based on Mishel's UIT (Gursahani, 2021): 1) Unpredictability of illness course; 2) Lack of information; 3) Perceived complexities of information, treatment and the relationship with healthcare system/providers; and 4) Ambiguity about the illness state itself. Uncertainty is associated with anxiety and depression, heightened stress levels, impaired coping and poor health outcomes. Much of this uncertainty in stroke can be addressed by prediction of further deterioration, estimation of functional recovery, requirements of long term rehabilitation, possible dependence on others and life expectancy (Gursahani, 2021).

The participants in the current study expressed uncertainty about the likelihood of recurrent stroke and the impact of stroke on their future health, with clear concerns about the possibility of developing dementia. These observations fit with pillars 1 and 4 of Gursahani's adaptation of Mishel's UIT (Gursahani, 2021). Regarding Pillar 1, from the focus group discussions, it was clear that individual experiences of both the event and the recovery were unique to each participant and the uncertainty about the future varied as a consequence. Those individuals who experienced multiple strokes or whose stroke was preceded by TIA were less certain about what would happen in their future and this was confounded by a lack of information in some cases from HCPs about their likely disease course, which partly fits with Pillar 2. Focus group participants were also concerned about the possibility of recurrent stroke or the development

of other post-stroke brain conditions such as dementia due to a perception that stroke had damaged their brain function. In fact, one participant explained to the group that he had developed post-stroke dementia and he ascribed this directly to experiencing two strokes six months apart, with the second stroke being substantially more serious than the first.

Regarding Pillar 4, ambiguity in chronic illness stems from a lack of clarity about diagnosis, treatment and prognosis of a particular chronic condition (Boss and Couden, 2002). Given the value placed on predictability in Western culture, uncertainty is viewed as aversive because it disrupts an individual's sense of control (Hoth et al., 2015). In the current study, some participants stated that the cause of their stroke had never been made clear to them by their healthcare providers, leading to uncertainty about whether they would experience future strokes if the cause was still present and unknown. Whether this was due to a lack of knowledge of the cause by HCPs or just that clinicians knew the cause but did not communicate this is unknown, however it suggests that better communication between HCP and patient might reduce uncertainty. Others said that they were unsure of their prognosis because they had not been provided with clear information about this by HCPs or had not received treatment when they had expected it, which they thought could have influenced their recovery. There was an expectation that stroke survivors would experience further stroke, a sentiment that was also expressed by HCPs, who often spoke to them in a manner that suggested subsequent or multiple strokes.

8.2.5.4 Comparing and sharing experiences with other stroke survivors

Sharing experiences of stroke with other survivors is an important component of recovery (Stroke Association, 2012a; Kessler et al., 2014; Christensen et al., 2019; Hartford et al., 2019; Chen et al., 2022; Different Strokes UK, 2024b). Sharing experiences helps individuals by allowing them to identify with emotions, feelings and issues, minimises the impact of isolation and helps them to accept change and rebuild their identity. Sharing experiences is also an effective way of helping and inspiring others during their recovery, learning about different coping strategies, and is beneficial to carers as well (Stroke Association, 2012a; American Stroke Association, 2021; Different Strokes UK, 2024b).

Peer support groups have been shown to play an important role in stroke recovery by providing effective tools for coping with stroke, reducing anxiety and stress, and providing a forum for stroke survivors and families (Kessler et al., 2014; Christensen et al., 2019; Chen et al., 2022). Peer support visits for hospitalised stroke survivors provide encouragement and motivation for most individuals and allows them and their caregivers to prepare for post-discharge care and

for HCPs such as nurses to proactively enhance post-discharge care (Kessler et al., 2014; Chen et al., 2022).

In the current study, there were clear examples of the benefits of sharing experiences. Many participants were very enthusiastic about attending the focus groups so they could talk to others about their experiences. In particular, one individual attended a focus group because she wanted to share her experiences of post-stroke mental health problems with others, something she had not done before. She informed me later that her participation in the focus group had been invaluable as she had realised that her experiences with mental health difficulties were not unique to her. Some of the participants had attended previous focus groups and they had the confidence to contribute to the discussions early and encourage others who had no prior experience to speak. These individuals and others had been inspired to work directly with stroke survivors, either as volunteers for support groups, using their own experiences to help others, or to participate in clinical research studies. Eleven of the original 35 consented focus group participants had previously taken part in clinical research trials and had given their consent to be contacted regarding the current study.

Although the focus group participants in the current study wanted non-stroke survivors to have a better understanding of the issues that they face in everyday life and supported a stroke advocacy service, there is limited information on this subject in the literature and stroke advocacy services appear to be confined to Scotland within the UK (Scottish Independent Advocacy Alliance, 2021; EARS, 2024). Advocacy aims to support those individuals who are unable to speak for themselves or choose not to do so, safeguarding those who are vulnerable, and helping them to access information to allow them to make informed decisions about their care and support (Scottish Independent Advocacy Alliance, 2021). The Scottish Independent Advocacy Alliance provides free independent advocacy support across Scotland for individuals including stroke survivors and the EARS Independent Advocacy Service includes anyone aged over 16 with a diagnosis of stroke in Edinburgh and the Lothians (Scottish Independent Advocacy Alliance, 2021; EARS, 2024). Whilst this is an encouraging development in the support of stroke survivors, it appears that an equivalent stroke advocacy service does not exist in other parts of the UK, even though the participants in the current study stated that they would clearly benefit from such a service.

8.3 Focus Groups: Conclusions

The published literature supports some of the themes and subthemes identified in the current qualitative study however there were behaviours identified within the analysis that are poorly researched, with almost no published literature apart from anecdotal evidence. These behaviours include feeling lucky to have survived a stroke, feeling like a fraud for wasting NHS time and resources and trivialising stroke experiences. These behaviours were common amongst the study participants and warrant further investigation.

General awareness of stroke is good amongst the general public but the current study supports the clear educational need identified in the literature for campaigns which include other important but vague symptoms of stroke and to raise awareness of stroke further with the public and with HCPs to provide earlier recognition and treatment. Despite memorable stroke campaigns such as FAST, awareness amongst the public and HCPs regarding stroke remains stubbornly low. This approach is also needed to tackle delays in seeking medical assistance where there is uncertainty about whether individuals are having a stroke if they feel that their symptoms are not characteristic of this condition.

Stroke survivors experience a loss of identity and go through a multifactorial grieving process, which most closely follows the Kubler-Ross five-stage model of grieving. The grieving process relates to the loss of the person the stroke survivor once was rather than the actual loss of a loved one, so this differs in that stroke survivors experience the emotions of grieving associated with loss of identity. The grieving process ends when they accept that their life has changed permanently, allowing them to move on and rebuild their self-identity and regain their sense of autonomy. The current study has shown that the impact of stroke is far-reaching and affects emotional (sudden outbursts of emotion such as crying uncontrollably), physical (in particular, PSF and balance issues), financial (struggling to pay bills and to find support), cognitive (memory loss) and psychological (depression and anxiety) domains. The findings of the current study endorse what is documented in the literature about these domains but highlights the need for greater support for stroke survivors following their discharge back into the community since many individuals described that healthcare support was lacking.

Acceptance of stroke and its limitations allow stroke survivors to leave the past behind and concentrate on recovery but there is a sense of uncertainty about recurrent strokes and the possibility of cognitive decline such as dementia, and that the findings of this study support the literature. Some participants in the current study stated that they had never been told what had

caused their stroke and this served to heighten their anxiety of the possible outcomes in the future. If the cause was known to the clinician but this was not communicated to some of the participants, the current study highlights a need for improved communication between HCP and patient.

In general, stroke survivors in the current study benefited from sharing their stories with others however they desired a better understanding of the challenges they face in everyday life from the general public and they would value an advocacy service in England, although these are currently restricted to Scotland.

8.4 Delphi Survey

8.4.1 Survey Findings

8.4.1.1 Proportion of survey responses reaching consensus

The survey was conducted in three rounds and those statements achieving consensus on a single response were excluded from subsequent rounds. The result of this was a total of 14/55 (25%) statements reaching consensus (all considered 'very important') across three rounds. Nine of these statements reached consensus in Round 1, four statements reached consensus in Round 2 and one reached consensus in Round 3, with a fourth round considered unlikely to provide any further consensus. However, this approach excluded all of the statements that were considered to be 'important' by participants but did not reach consensus in their own right. This is particularly true for Question 3, where no statements reached consensus in any of the survey rounds. Since the statements included in subsequent rounds of the survey were dependent upon single response consensus, combining important and very important responses would have confounded the results and would also have invalidated the process of refining the survey questions for each successive round.

The single response consensus across the survey rounds indicates which interventions should be included into the integrated care pathway based on their perceived level of importance. There was a strong emphasis on the importance of rapid stroke diagnosis and scanning in suspected stroke, acute interventions such as thrombectomy, speech therapy and dysphagia treatment, and preventative treatment such as antihypertensives and anticoagulants/antiplatelet drugs. These were considered very important equally by stroke survivors and HCPs. Post-discharge rehabilitation interventions such as physiotherapy, occupational therapy and interventions to control the risk factors for stroke were considered very important, as were an awareness of the FAST campaign and the risk factors for subsequent stroke.

There were 15 statements under Question 3, which related to education and training of stroke survivors and their carers following discharge from the hospital or stroke unit. None of these statements reached consensus in any of the survey rounds but this finding requires explanation. Collectively, the proportion of participants who scored these Question 3 statements as either important or very important ranged from 76% to 100% across all three survey rounds. The only statement that did not reach ≥75% of important or very important responses in any of the rounds was the statement concerning training and education on stroke using virtual reality, which collectively scored between 59% and 71%. Clearly, interventions relating to training and education were considered to be important by the survey participants but because none of them reached the consensus threshold of ≥75% based on single responses, they were excluded from the integrated care pathway and combining the results would have invalidated the current findings and compromised the survey methodology.

8.4.1.2 Consensus achieved by participant type

The analysis of consensus by participant type (stroke survivors versus HCPs) showed that the achievement of consensus on single responses was driven by HCPs across all rounds of the survey (Table 10). Collectively, HCPs were associated with consensus for 36 statements whereas responses from stroke survivors reached consensus on just seven statements. The reasons for this are unclear.

In Round 1 especially, the low rate of consensus in stroke survivors might be partly due to confusion between the available responses (very important vs very unimportant) and difficulty in concentrating. This is reflected by direct feedback that I have received from several stroke survivors. Indeed, there were examples which have been outlined in Section 7.4 above of participants repeatedly attempting to complete the same survey in the same round. Personal communications from stroke survivors have indicated that in some cases the responses were confusing as the word 'important' was used too often. One individual stated that "*Might be 'easier for some of us, me included, if the choices were different words. Lots of importants in the choices and cognitively I struggle to differentiate*." Other stroke survivors commented verbally that they struggled due to an inability to concentrate and as a result they needed multiple attempts to complete the online survey. Conversely, the PPI feedback to the survey was that it was simple and easy to understand and complete, so these comments may reflect differences between individual participants in post-stroke impairments or the PPI group feedback may not be representative of the stroke population as a whole. Additionally, participation rates among stroke survivors were high; of the 13 stroke survivors who

participated online, all but two completed all three rounds, indicating a compliance rate of 85%. Of the seven stroke survivors who participated via postal surveys, 4/7 (57%) completed all three rounds.

This confusion may also be reflected by the number of started but not completed responses to the survey at Round 2 (six in stroke survivors and one in HCPs, although it should be noted that more HCPs [14] than stroke survivors [11] did not complete the survey in Round 1). In the case of stroke survivors, the uncompleted responses are from a small number of individuals making repeated unsuccessful attempts to complete the survey, some of whom eventually gave up. Others became familiar with the structure of the survey and the layout of the questions, which might explain why the completion time was substantially faster in Round 2 compared with Round 1. In the case of HCPs, the rate of non-completion was mainly due to participants not providing required information (email address) and the survey being terminated as a result.

The differences in consensus rates might reflect the way in which integrated care is perceived between different participant types. In the literature, patient perspectives on integrated care tend to focus on the patient-provider communication and personalised support (Stray et al., 2024), while clinicians may focus instead on organisational structures, collaboration, governance, leadership and delivery of services (Hussain and Dornhorst, 2015). In the case of HCPs in the current study, there appeared to be more decisiveness amongst them when prioritising components for integrated care and this could be due to a better understanding of the integrated care concept, especially if they are involved in delivering integrated care interventions, however there is no published evidence to directly support this notion. Stroke survivors may have reflected on their own unique experiences of treatment and recovery, as they did during the focus group meetings, and as a result they would likely have rated interventions in the survey by importance according to those experiences. This could perhaps explain why so few statements reached consensus among stroke survivors and this is supported by the observations that firstly, the spread of responses across the rounds was wider than that of HCPs and secondly, that the majority of individual responses scored as ‘very unimportant’ or ‘unimportant’ were made by stroke survivors. Again, there is no published evidence to directly support this theory and it warrants further investigation.

8.4.2 Choice of Likert Scale

Likert scales are widely used in research because of their ability to capture human sentiments in a standardised format and to transform qualitative data into quantitative data (Koo and Yang, 2025). A typical 5-point Likert scale would include options ranging from ‘Strongly Disagree’

to ‘Strongly Agree’, with intermediate responses such as ‘Disagree’, a neutral ‘Neither Agree nor Disagree’, and ‘Agree’. The term Likert-type scale encompasses both the original methodology introduced by Rensis Likert and its variations, including scales with different numbers of points (for example, four to seven points) (Koo and Yang, 2025). Over time, the original scale has evolved and adapted to meet diverse research requirements, including even-numbered scales which eliminate the neutral midpoint and compel respondents to take a definitive stance, as well as 7-point scales that offer greater granularity of response (Koo and Yang, 2025). Despite widespread adoption of Likert-type scales, controversies remain regarding their appropriate analysis and interpretation, particularly whether their response options should be treated as ordinal or interval data (Jamieson, 2004).

Even-numbered Likert-type scales have been used widely in research and a review of patient-reported outcome measures (PROMs) in 186 full-text articles reported a lack of consensus on the choice of scale but evidence that 5-point or 6-point verbal rating scales (VRS) were more informative (Gries et al., 2017). In this review, 4-point VRS were used in studies of children with asthma and people with depression (Liu et al., 2007; Preston et al., 2011). In the asthma study, children between the ages of four and 11 were able to understand and complete a 4-point VRS (childhood asthma control test [C-ACT]) assisted by facial graphics (Liu et al., 2007) and in the study of depression, the 5-point response options were not always equally spaced (in other words, they did not meet the assumptions of an equal interval scale) and 4-point response categories were as precise as five (Preston et al., 2011). In an analysis of Patient-Reported Outcome Measurement Information System (PROMIS) items; pain, fatigue, emotional distress, physical and social function, the optimal response set number was partially dependent on the item and construct. Four to six response options was typically optimal because these numbers both reduced cognitive burden for respondents and each option could provide unique information; investigators found that with response sets of greater than six choices, two or more options were typically collapsed to improve step-disorder and model fit (DeWalt et al., 2007). In a review of patient-reported sleep outcomes in alcohol and/or substance use disorder (SUD) clinical trials, frequently used validated sleep measures include the Pittsburgh Sleep Quality Index (PSQI), Epworth Sleepiness Scale (ESS), and Athens Insomnia Scale (AIS). All of these tools use a 4-point Likert-like scale and have high validity (Cronbach’s alpha = 0.73-0.89) and high test-retest reliability (r = 0.82-089) (Huhn et al., 2022).

The decision to use a 4-point Likert scale in the current study was based on the purpose of the survey, which was to identify which components of integrated care should be incorporated into

a pathway according to importance and therefore a 5-point Likert scale with a neutral 'neither unimportant nor important' response was rejected as the neutral response would not have been helpful in achieving the survey's aims, which were to obtain definitive responses from participants. At the same time, we wanted the survey to be as simple as possible to complete but equally, we wanted to avoid too many response points as this could potentially overwhelm participants, leading to respondent fatigue. This fatigue can manifest as reduced attention, rushed responses, or even survey abandonment, all of which can compromise data quality (Koo and Yang, 2025). The time taken for participants to complete the survey was measured to allow us to understand any potential impact of respondent fatigue.

8.4.3 Strengths

This Delphi survey has a number of strengths. Firstly, the high rate of initial participation and the consequently high rate of completion (exceeding 70%) in subsequent rounds provided robust data for analysis. Secondly, by allowing a diverse group of participants, (near equal proportions of HCPs and stroke survivors), the data are reflective of a range of disciplines and perspectives. Including stroke survivors as participants makes for a more holistic approach and a construction of an integrated care pathway equally suited to patients and HCPs alike by including their views on which components to include in an integrated care pathway. Thirdly, the provision of both online and paper-based surveys gave participants the opportunity to choose how they wanted to contribute to the research and likely contributed to the high compliance rates (Kelfve et al., 2020; Anhang Price et al., 2022; Ceccato et al., 2024). Fourthly, the geographical range of survey participant invitation was extended beyond the Northwest and whilst the majority of HCP participants were based in Merseyside, there were also respondents from Greater Manchester, Derbyshire, West Yorkshire and Scotland, providing a broader overview of attitudes and opinions towards integrated care.

8.4.4 Limitations

The Delphi survey also has limitations. While the majority of HCPs were unknown to the researchers and agreed to participate at random, all of the stroke survivors were known to me as they had all participated in the stroke survivor focus groups and were made aware of the survey at this time. Although invitations to participate in the survey were distributed widely to stroke survivors through the Stroke Association, no individuals from this organisation responded to the invitations or indicated any willingness to participate. The stroke survivors who participated in the focus groups were selected based on their ability to provide informed consent and to be able to complete either an online or paper-based survey, so they are not

representative of the entire stroke population. The fact that they were known to me also introduces the possibility of social desirability bias, a type of cognitive bias phenomenon that is well described in the literature in which participants might consciously or unconsciously tailor their answers to appear more socially acceptable, especially if they are known to the researcher (Bergen and Labonté, 2020; Gower et al., 2022).

The possibility of this type of bias was minimised by anonymising all of the survey response data and stating this approach clearly to all participants and also by the amount of time that had elapsed between the end of the last focus group (March 2024) and the start of the Delphi survey (January 2025).

The findings of the survey are also limited by constraints on the data collection period for the systematic review (from 01 Jan 2012 to 01 Jan 2024), that may have resulted in some relevant studies being excluded and those studies of individual or multiple components of stroke care that were excluded if they did not meet the criteria for integrated care. Further, the small scale of the stroke survivor focus groups provided data based on individual experiences that may not be representative of the wider stroke population. This is in addition to a small group of participating HCPs, the majority of whom were located in Merseyside. As a result, the components listed in Table 7 that were included in the survey may not be fully representative of all components of integrated stroke care that might be of benefit to patients and HCPs, and these components may not be generalisable to the wider geography of stroke management in the UK outside the North West.

Despite attempting to make the survey easy to navigate and complete, some stroke survivors still experienced confusion and difficulty in concentrating, often resulting in repeated attempts to complete the survey.

The Delphi survey used a 4-point Likert-type scale, eliminating the inclusion of a neutral response as it was deemed to be of little value given that the objective of the survey was to obtain specific and definitive responses from participants. Although the 4-point Likert scale is justified in this research, one disadvantage of such a scale is participants may have inadvertently been forced to provide an answer not truly representative of their opinion on a particular statement if a neutral response (neither unimportant nor important) was not available to them (Koo and Yang, 2025).

8.4.5 Conclusions: Delphi Survey

Delphi survey participants (HCPs and stroke survivors) indicated by consensus that 25% of components of integrated care laid out in the survey spanning acute stroke care, post-discharge care, post-discharge education and training for stroke survivors and their carers, and awareness, understanding and prevention of subsequent stroke, were very important elements to include in an integrated stroke care pathway. Together with the findings from the systematic review and meta-analysis of published studies on integrated care in stroke, the survey data will inform the development of a new holistic approach to integrated care in people with stroke. The next chapter will cover the production of the new integrated care pathway in people with stroke based on these findings.

8.5 Chapter Summary

In this chapter, the key findings from the two work packages of this research project (systematic review and mixed methods study) have been extensively discussed and compared in the context of published literature. In summary, integrated care has been shown in the systematic review and meta-analysis to improve quality of life, reduce depression and is associated with a positive benefit on cardiovascular risk factors but does not impact mortality, recurrent stroke or readmission rates. Interventions that include exercise and mental health initiatives were associated with a positive impact on the primary and secondary outcomes that were evaluated in the study however more than a third of studies in the analysis demonstrated no benefit over standard care and there was considerable heterogeneity between individual studies. There are limitations to the systematic review. These include a 12-year data collection period, no distinction between study setting (acute, transitional or community), high heterogeneity between studies, the difficulty in evaluating the benefit of individual components as part of a combined intervention, and individual components as part of integrated care representing a subset of the evidence base. These limitations may impact the generalisability of the findings.

The focus group findings supported the need for greater awareness of the symptoms of stroke amongst the public and HCPs documented in the literature, in particular regarding the less well known and more vague symptoms of stroke that include numbness, muscle weakness and visual problems. Despite effective and impactful public health campaigns such as FAST in the UK, awareness of stroke remains low and can result in delays in seeking medical assistance. The physical and psychological burden in people following stroke is substantial and they experience a range of emotions that can be likened to a process of bereavement. The level of support stroke survivors receive to deal with the burden of stroke after discharge into the

community is often lacking or disorganised and can lead to feelings of frustration, isolation or abandonment. It is important to consider these findings in the context of a small-scale group study of stroke survivors whose individual experiences may not reflect those of the wider population.

When asked for their opinions on what key components should be included in an integrated care pathway for people with stroke, HCPs and stroke survivors indicated that rapid diagnosis and acute medical treatment were critical elements in the early recognition and management of stroke. The control of risk factors to prevent secondary stroke recurrence, rehabilitation including speech therapy, physiotherapy and occupational therapy, medication adherence and the need to provide individualised treatment were critical elements during the recovery phase. From an educational perspective, an awareness of the well-known symptoms of stroke according to media campaigns such as FAST and of the risk factors for stroke such as AF, TIA, CVD and diabetes are also high priority components of integrated care. These results were obtained from a small-scale group study of stroke survivors and HCPs, most of whom were based in Merseyside and the Northwest, therefore the findings may be limited by demographics and stroke survivor characteristics, reflecting local attitudes and experiences rather than those of the wider community.

These findings support future research on integrated care in people with stroke that should focus on further clarity on the interventions that would provide the most benefit to patients, to ensure that delivery of care extends beyond acute treatment and continues to support people following discharge back to the community, and that the voice of the stroke survivor is paramount in ensuring that integrated care is truly holistic in nature, with them at the centre of care.

9 Chapter Nine: Production of Integrated Care Pathway

The proposed integrated care pathway brings together the results of the systematic review and meta-analysis with the findings from the stroke survivor focus groups and the results of the Delphi survey. There are some similarities between the proposed pathway and the ABC$_{\text{STROKE}}$ pathway originally proposed by Lip and colleagues in that both pathways share an A and C pillar relating to antithrombotic therapy and control of cardiovascular and other comorbidities, respectively (Lip et al., 2022b; Lip and Ntaios, 2022) (Chapter Two). The proposed pathway is more extensive and includes four pillars according to a stroke survivor's journey from recognition and diagnosis through treatment and rehabilitation to post-discharge care. The mnemonic RACE is proposed; R – Recognition of stroke and its associated symptoms, A – Acute and appropriate treatment of stroke, C – Control of cardiovascular risk and other comorbidities and E – Education and training on care in post-stroke life and prevention of subsequent stroke. The components of the mnemonic and their supporting evidence are discussed below. A summary of the proposed pathway is provided in Figure 34.

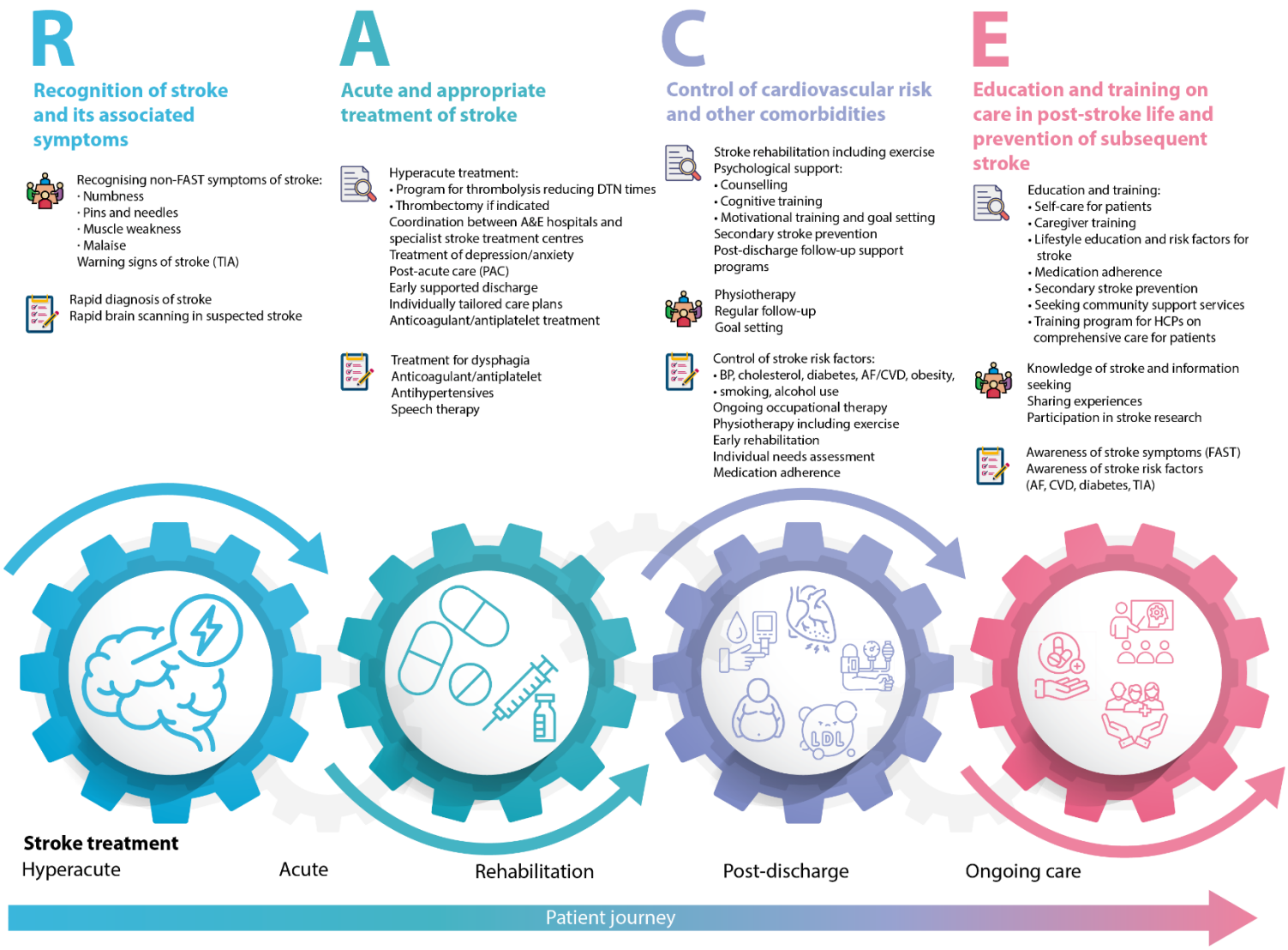


Figure 34 Proposed RACE Integrated Care Pathway in People with Stroke

A&E, accident and emergency; AF, atrial fibrillation, BP, blood pressure; CVD, cardiovascular disease, DTN, door-to-needle; FAST, face-arms-speech-time to call 999; HCP, healthcare professional; PAC, post-acute care; TIA, transient ischaemic attack.

9.1 R – Recognition of stroke and its associated symptoms

In the stroke survivor focus groups, the participants made a strong recommendation for the importance of recognising symptoms other than facial droop, arm weakness and slurred speech typically shown in the FAST stroke recognition campaign (Dombrowski et al., 2013; Flynn et al., 2014). These symptoms included numbness, pins and needles, muscle weakness and a feeling of general malaise. The participants also stressed the importance of recognising these other symptoms of stroke and acting on them if they did not resolve or worsened with time.

A lack of awareness or recognition of key symptoms of potentially catastrophic events such as stroke or MI can result in delays in seeking appropriate medical assistance, which can result in worse outcomes (Robinson et al., 2013; Burton et al., 2022; Farquharson et al., 2023), highlighting the need for informed public health messaging to ensure those in need of treatment can recognise their symptoms and access care in a timely fashion. Stroke survivors whose diagnosis was made early reported better outcomes. Rapid diagnosis by medically qualified neighbours, thrombectomy within three hours, and being taken straight to a CT scanner were examples participants gave of how prompt recognition and treatment of stroke had made a real difference to their recovery (Chapter Six Section 6.4.2.4.1). Some focus group participants described experiencing TIA before stroke, some on multiple occasions and felt that these were clear warning signs of an impending stroke and current guidelines recommend treatment with high-dose aspirin (300 mg daily) following TIA and secondary prevention as soon as the diagnosis is confirmed (National Institute for Health and Care Excellence, 2022).

TIA is often referred to as a warning sign for stroke in treatment guidelines (American Stroke Association, 2020; NHS, 2023a) and the experiences of stroke survivors with TIA and their descriptions of non-FAST symptoms of stroke highlight the importance of extending the FAST message to include the lesser known symptoms and warning signs.

In the Delphi survey, two statements from Question 1 (relating to acute stroke care) reached consensus. These were:

- *Rapid diagnosis of stroke*, rated as very important by 100% of survey participants
- *Rapid brain scanning in suspected stroke*, rated as very important by 98% of survey participants

Clearly, these two interventions were given high importance by both stroke survivors and HCPs alike, therefore public education is important to recognise stroke symptoms. This is supported by the 2023 National Clinical Guideline for Stroke, which states that *"the evidence for a direct*

link between awareness and recommended behaviour is weak, especially among older members of the population, minority ethnic groups and those with lower levels of education, all of which are population groups at greater risk of stroke" (Jones et al., 2010; Sentinel Stroke National Audit Programme [SSNAP], 2023 p.12). The guidelines recommend that public and professional education programmes should be implemented to increase awareness of stroke and the need for urgent diagnosis and treatment. However, they also state that campaigns aimed at the public and HCPs may have more impact on HCPs than the public and that further research on improving public awareness of stroke and taking appropriate action is required (Lecouturier et al., 2010; Sentinel Stroke National Audit Programme [SSNAP], 2023).

Imaging is a critical component of stroke diagnosis and decision-making and guidelines recommend imaging as soon as possible but within three-to-twenty-four hours of onset of symptoms (Latchaw et al., 2009; Rehani et al., 2020; National Institute for Health and Care Excellence, 2022).

9.2 A – Acute and appropriate treatment of stroke

According to our systematic review, interventions that were delivered in the acute setting (following hyperacute interventions such as thrombolysis and scanning) that benefitted stroke survivors included interventions to treat anxiety and depression, ESD, post-acute care (PAC), individually tailored care plans and anticoagulation/antiplatelet treatment.

Hyperacute treatment in stroke involves interventions such as reperfusion (thrombolysis and thrombectomy) which are delivered in a time-limited window (Campbell, 2024). In the systematic review and meta-analysis, hyperacute treatment is covered in some of the studies. In one study, the introduction of a standardised modified Helsinki protocol of thrombolysis across 21 hospitals using telestroke management was associated with increased alteplase administrations, significantly shorter door-to-needle (DTN) times, and no increase in adverse outcomes. However there was no significant difference in symptomatic ICH rates before and after implementation (Nguyen-Huynh et al., 2018). According to a Cochrane systematic review, thrombolysis within six hours of stroke reduces mortality and dependency, with those people treated in the first three hours deriving substantially more benefit than with later treatment (Wardlaw et al., 2014). A second Cochrane review evaluated the effectiveness of endovascular thrombectomy in ischaemic stroke due to large artery occlusion. This review reported that endovascular thrombectomy improved the likelihood of survival with a good feunctional outcome and reduced the risk of mortality (Roaldsen et al., 2021b). As a consequence, thrombolysis is now administered to patients with acute stroke in the UK within

a guideline time window of 4.5 hours, and endovascular thrombectomy for large artery occlusion within six hours (Sentinel Stroke National Audit Programme [SSNAP], 2023).

The type of treatment centre to which a patient with a stroke presents may also influence the outcomes. In the USA, the Brain Attack Coalition proposed the establishment of two levels of stroke centres: primary stroke centres (PSCs) with the necessary staffing, infrastructure and programs to stabilise and treat most patients with acute stroke, and comprehensive stroke centres (CSCs) providing care to patients experiencing the most complex strokes that require specialised testing and interventions (Man et al., 2018). This model is similar to that of a two-centre model for European countries with stroke units and stroke centres (Ringelstein et al., 2013). It is generally accepted that acute stroke care is best conducted in dedicated stroke units and there is evidence from numerous RCTs that outcomes for patients with stroke and TIA are better if they are managed in stroke units compared with general medical or neurological wards (Kjellström et al., 2007; Terént et al., 2009; Langhorne et al., 2020a). This is supported by guidelines. In the UK, the NICE guidance on treatment of stroke and TIA and National Clinical Guidelines recommend admitting anyone with a suspected stroke directly to a hyperacute stroke or specialist stroke unit staffed by a specialist stroke multidisciplinary team after initial assessment, from either the community, the emergency department, or outpatient clinics (National Institute for Health and Care Excellence, 2022; Sentinel Stroke National Audit Programme [SSNAP], 2023).

Numerous published studies have shown a positive benefit in favour of integrated care either in reduced numbers of participants reporting anxiety/depression or in reduced scores for anxiety/depression. Further details of these interventions and studies are provided in Section 5.17.7.2.3 and Appendix G. These results also supported by the findings of the stroke survivor focus groups as some participants were substantially negatively affected by depression and anxiety post-stroke (Section 6.4.2.3.1) and where psychological support was offered to participants, this made a substantial positive difference to their recovery (Section 6.4.2.4.1). A Cochrane systematic review demonstrated only low-level evidence for the benefit of pharmacological, psychological, and non-invasive brain stimulation interventions in stroke patients (Allida et al., 2020). Despite this, the UK National Clinical Guidelines for stroke recommend psychological care being provided by stroke services both in the acute and community settings, however national audits indicate a need for service improvement (Sentinel Stroke National Audit Programme [SSNAP], 2023).

Whilst very early supported discharge (Rafsten, 2019) or very early mobilisation (Bernhardt et al., 2015; Langhorne et al., 2017; Cumming, 2019) has been shown to be detrimental to recovery, early rehabilitation including mobilisation and exercise started within weeks of admission may result in improved quality of life, better functional independence and less depression (Coleman et al., 2017; Brandal et al., 2019; Rodgers et al., 2019; Lin et al., 2020; Shaw et al., 2020; Huang et al., 2023). Early supported discharge is now considered an integral component of inpatient stroke care in patients where appropriate according to guidelines (Sentinel Stroke National Audit Programme [SSNAP], 2023; National Institute for Health and Care Excellence, 2024).

Post-acute care programs, which include interventions such as nutrition advice, exercise, physiotherapy, speech therapy, occupational therapy have been shown to improve quality of life, functional status, and reduce the risk of hospital readmissions (Peng et al., 2017; Chiu et al., 2021; Chang et al., 2022). These are key components of comprehensive rehabilitation programmes recommended by guidance, initiated and coordinated in the acute setting and delivered in the community by multidisciplinary services, tailored to goals and outcomes of inidivudual stroke survivors (Sentinel Stroke National Audit Programme [SSNAP], 2023). A Cochrane review of cardiorespiratory and mixed training indicated that these interventions reduce disability during or after usual stroke care and that their incorporation into rehabilitation programmes improves fitness, balance, and walking speed and capacity (Saunders et al., 2020b).

Integrated care plans for rehabilitation initiated in the acute setting with individually tailored interventions such as exercise (which are individualised according to ability) but also including active follow-up, management of risk factors and comorbidities and promotion of a healthy lifestyle are associated with reduced mortality, improved adherence to interventions, increased physical strength and better functional status (Cuccurullo et al., 2019; Koch et al., 2020; Brouns et al., 2021; Chiu et al., 2021).

Medical treatment with anticoagulant/antiplatelet therapy following stroke has been shown to substantially reduce the risk of recurrent stroke, even after 10 years of follow-up (Luengo-Fernandez et al., 2022), however, according to the evidence base for ABC_{STROKE}, the choice of therapy needs to be made on an individual patient basis to balance the risk between stroke prevention and increased potential for bleeding (Ntaios and Lip, 2016; Bath et al., 2018). Current recommendations state that anticoagulant treatment should be considered within 5 days of onset for mild stroke and 5-14 days of onset for moderate or severe stroke. Those individuals

with ICH, TIA or minor stroke should be considered for antiplatelet therapy for secondary prevention (Sentinel Stroke National Audit Programme [SSNAP], 2023).

In the Delphi survey, three statements that were part of Question 1 and related to acute stroke care reached consensus. These were:

- *Acute medical treatment (for example, clot busting drugs, thrombectomy, anticoagulants, antiplatelet drugs, high blood pressure treatment)*, rated as very important by 91% of survey participants
- *Speech therapy*, rated as very important by 82% of survey participants
- *Treatment for dysphagia*, rated as very important by 79% of survey participants

The Delphi survey findings support the need for antithrombotic therapy and secondary stroke prevention measures identified by the systematic review. In the stroke survivor focus groups, there was one individual who was incapacitated following his stroke and described in detail how speech therapy and treatment for his dysphagia had helped him to recover.

Adherence to the A pillar could be demonstrated using validated depression and anxiety scoring tools to measure change in proportion of patients with psychological comorbidities or by monitoring changes in scores as a positive improvement. Adherence to PAC, individually tailored care plans or ESD could be shown by documenting the initiation of the interventions included in them, such as exercise programs, speech therapy, treatment for dysphagia, and psychotherapy/counselling. The prescription of anticoagulant/antiplatelet and/or antihypertensive therapy for secondary stroke prevention during acute treatment would also demonstrate adherence to this pillar.

9.3 C – Control of cardiovascular risk and other comorbidities

Risk factors for stroke include hypertension, diabetes, cardiovascular risk factors such as AF and CVD, obesity, smoking and alcohol use. The systematic review results demonstrated that rehabilitation including exercise was effective in reducing the risk of mortality, recurrent stroke and rehospitalisation (Cuccurullo et al., 2019; Buckley et al., 2021a; Cuccurullo et al., 2022a; Cuccurullo et al., 2022b). Comprehensive psychological support including counselling, cognitive training, motivational training and goal setting was associated with reduced cognitive impairment, depression and anxiety, improved functional status, adherence to intervention and QoL (Wong and Yeung, 2015; Gao et al., 2017; Cheng et al., 2018a; Lewthwaite et al., 2018; Reeves et al., 2019; Yu et al., 2019; Koch et al., 2020; Brouns et al., 2021; Mohammadi et al., 2022) (Section 5.17.4.4 and Section 5.17.6.2.3). Post-discharge follow-up support programs,

which included telephone calls and in-person home visits, improved the management of risk factors through educational sessions, and were associated with reduced mortality risk and lower rehospitalisation rates (Saal et al., 2015; Deutschbein et al., 2020).

The identification of risk factors for stroke and TIA should be part of the initial assessment during the acute phase according to guidance, with regular review and secondary prevention in primary care, which may require additional resources (Sentinel Stroke National Audit Programme [SSNAP], 2023; National Institute for Health and Care Excellence, 2024).

In the stroke survivor focus groups, participants who received physiotherapy during hospitalisation and continued to receive it post-discharge described how helpful this had been in improving their functional status and rehabilitation. One participant benefited so much from her initial physiotherapy that she continued to receive treatment from a private physiotherapist after the NHS resource had ended (Section 6.4.2.4.1). Regular follow-up after discharge was often lacking and left participants feeling confused and frustrated, highlighting the importance of regular follow-up and communication in any integrated stroke care pathway (Section 6.4.2.4.1). Given that stroke is a life-changing event, some participants mentioned the importance of setting goals, giving them focus and having something to aim for, which was considered an important part of their recovery journey (Section 6.4.2.4.2).

These observations are supported by current recommendations, which state that higher doses of physiotherapy are associated with better recovery (Sentinel Stroke National Audit Programme [SSNAP], 2023). A needs-based assessment should be undertaken at 6 months post-discharge, with regular follow-up in order to address any unmet needs and provide longer-term support. (Sentinel Stroke National Audit Programme [SSNAP], 2023).

In the Delphi survey, a total of six statements relating to post-discharge stroke care reached consensus. These were:

- *Control of stroke risk factors (blood pressure, cholesterol, blood sugar, weight loss, smoking cessation)*, rated as very important by 86% of survey participants
- *Ongoing occupational therapy*, rated as very important by 77% of survey participants
- *Physiotherapy including exercise*, rated as very important by 87% of survey participants
- *Early rehabilitation*, rated as very important by 77% of survey participants
- *An individual assessment of stroke patient needs*, rated as very important by 77% of survey participants

- *Adherence to antiplatelet and anticoagulant medication*, rated as very important in 76% of survey participants

The findings of the Delphi survey support the importance of secondary stroke prevention through the control of risk factors such as hypertension, diabetes, cardiovascular risk factors such as AF and CVD, obesity, smoking and alcohol use. Many of these risk factors are modifiable and can be managed through active treatment of hypertension and diabetes, weight loss and lifestyle modification, education and counselling (Lip, 2017). This approach was a common component of studies in the systematic review (Nayeri et al., 2014; Saal et al., 2015; Olaiya et al., 2017b; Deng et al., 2020; Duncan et al., 2020; Pedapati et al., 2021a; Wang et al., 2021; Kalav et al., 2022), and the meta-analysis showed that management of these risk factors significantly reduced SBP and LDL-cholesterol but did not significantly impact total cholesterol, BMI or smoking cessation (Section 5.17.7.2.4).

There are clear recommendations in stroke management guidelines regarding management of risk factors. People with ischaemic stroke or TIA should be offered personalised advice and support on lifestyle factors to reduce cardiovascular risk, including diet, physical activity, weight reduction, alcohol moderation and smoking cessation (Sentinel Stroke National Audit Programme [SSNAP], 2023). Blood pressure should be measured and managed in primary care to achieve an SBP of ≤130 mm Hg, with at least annual review once this target has been reached (Sentinel Stroke National Audit Programme [SSNAP], 2023). Lipid lowering treatment is also considered an effective intervention for secondary prevention and all stroke survivors should be offered statin treatment unless contraindicated or no evidence of atherosclerosis is identified. Treatment should aim to reduce LDL-cholesterol below 1.8 mmol/l (Sentinel Stroke National Audit Programme [SSNAP], 2023).

Occupational therapy is a component of rehabilitation that is also delivered and monitored by trained occupational therapists (Langhorne et al., 2017; Peng et al., 2017; Lewthwaite et al., 2018; Cuccurullo et al., 2019; Cumming, 2019; Brouns et al., 2021; Chiu et al., 2021). The length of occupational or physiotherapy therapy support according to stroke survivor focus group discussions may end at six months, even if it is providing benefit, which may cause frustration due to a perceived lack of follow-up, however stroke survivors do benefit from ongoing physiotherapy (whether paid for privately or provided by the NHS in some circumstances) as outlined in Section 6.4.2.4.1.

The dose of therapy is multi-faceted with variation in dose, duration and frequency, and the optimal intensity of therapy is unclear and stroke therapy is rarely delivered at high intensity (Sentinel Stroke National Audit Programme [SSNAP], 2023). In the UK, the ability to deliver guideline-recommended levels of therapy is challenging. In the SSNAP report for 2022, the proportion of stroke survivors receiving the target equivalent of 45 minutes of therapy per day 5 days per week was just 32% for physiotherapy and 34% for occupational therapy, highlighting a substantial shortfall in service delivery (Sentinel Stroke National Audit Programme [SSNAP], 2022). Whilst small in size, with limited generalisability, the findings of the focus groups in the current study support the observations in guidelines of a shortfall in therapy provision.

The Delphi survey findings also support the need for individualised care, for example an exercise program based on individual ability with regular monitoring (Cuccurullo et al., 2019) and the importance of adherence to medication for secondary prevention of stroke such as antiplatelet/anticoagulant treatment and antihypertensives (Bath et al., 2018; Greger et al., 2021). According to stroke management guidelines, individualised plans are an integral part of care for stroke survivors, with shared decision making facilitated by clinicians and, for example, rehabilitation programmes tailored to individual needs accounting for comorbidities, baseline activity levels, post-stroke fatigue, tolerance, goals and preferences (Sentinel Stroke National Audit Programme [SSNAP], 2023).

Adherence to the C pillar could be demonstrated by regular documentation of an individualised care plan agreed between the patient and HCPs which could include interventions such as rehabilitation, exercise, psychological support, secondary prevention, diet and lifestyle guidance, goal setting and repeated follow-up. Some studies in the systematic review included workbooks in which activities were recorded (Nayeri et al., 2014; Jones et al., 2016; Cheng et al., 2018a; Duncan et al., 2020; Fu et al., 2020; Minshall et al., 2020; Pedapati et al., 2021a; Kalav et al., 2022). The effectiveness of psychological interventions could be measured using validated depression and anxiety assessment tools such as HADS, SDS and Zung's SAS and SDS scales (Section 5.17.6.2.3). Adherence to management of stroke risk factors should be assessed against target values for blood pressure, cholesterol, HbA1c, and BMI (Section 5.17.6.2.4).

9.4 E – Education and training on post-stroke care and prevention of subsequent stroke

The systematic review included education and training interventions including patient self-care, training for caregivers, lifestyle education and secondary prevention advice, medication

adherence, advice on seeking community support services, and training for HCPs on comprehensive care for patients. These interventions were associated with improved QoL (Long Weijan and Zhang, 2017; Deng et al., 2020; Li et al., 2023), better functional status (Chu et al., 2020), higher adherence to intervention (Nayeri et al., 2014), reduced depression (Yu et al., 2019; Zhang et al., 2019; Feng et al., 2023; Lo et al., 2023) and lower rehospitalisation rates (Wang et al., 2021; Demir Avci and Gözüm, 2023). Healthcare professionals who received training through their institutions had improved skills and experience when guiding and advising patients and their caregivers on how to manage stroke (Long Weijan and Zhang, 2017; Olaiya et al., 2017b; Xi, 2017; Zhang et al., 2019; Chu et al., 2020; Pedapati et al., 2021a; Towfighi et al., 2021; Vluggen, 2021; Kalav et al., 2022; Mohammadi et al., 2022).

In the stroke survivor focus groups, there was a clear desire to learn more about stroke and how to manage their own condition. In some cases, participants conducted research themselves and found interventions that were not offered to them by the NHS but were perceived to have had a positive impact on their recovery (Section 6.4.2.1.2). There was a strong willingness to share individual experiences with others and this had a positive benefit in terms of knowledge, understanding, helping others and improving social interaction (Section 6.4.2.4.4). Of those who participated in stroke research clinical trials, there was a sense of wanting to give something back to the team who had helped them through recovery and to contribute to the knowledge base. It was also an opportunity to receive novel treatments and a different level of care (Section 6.4.2.4.1).

A Cochrane systematic review of self-management programmes in stroke survivors reported that these interventions could benefit individuals living in the community, improving quality of life and self-efficacy, well recognised goals for people with stroke (Fryer et al., 2016). Current guidelines indicate that people with stroke should be offered self-management support based on self-efficacy, aimed at the knowledge and skills needed to manage life after stroke, with particular attention given to this at reviews and transfers of care (Sentinel Stroke National Audit Programme [SSNAP], 2023).

In the Delphi survey, two statements relating to Question 4 (awareness, understanding and prevention of subsequent stroke) reached consensus. These were:

- *Awareness of the well-known symptoms of stroke according to media campaigns such as FAST (Face, Arms, Speech, Time to call 999)*, rated as very important by 79% of participants

- *Awareness of the risk factors for stroke (for example atrial fibrillation, transient ischaemic attack [TIA], diabetes, cardiovascular disease)*, rated as very important by 81% of participants

The findings of the survey support the importance of knowledge and education identified in the systematic review and stated clearly by focus group participants in recognising the symptoms of stroke and being aware of and actively managing the risk factors for stroke to prevent recurrence.

The quality of post-stroke care is partly dependent upon the level of knowledge, awareness, competence and skill of individuals to be able to deliver that care and there is a need for continued post-stroke training and development for both HCPs and patients/caregivers to enhance knowledge and understanding (Chu and Choi, 2020; Melnikov, 2020; Liang et al., 2023). A recent systematic review of health literacy in the prevention of stroke found relatively low literacy levels among patients, highlighting a need for improved stroke education (Ymeraj et al., 2025). Improved knowledge of stroke in patients can also improve self-esteem and empower engagement in health-promoting behaviours (Mun and Shim, 2024).

The educational elements of the E pillar are supported by National guidelines in all settings. Acute stroke services should have an education programme for all HCPs providing acute stroke care (including ambulance services and the emergency department as appropriate) and should provide training for HCPs in the specialty of stroke (National Institute for Health and Care Excellence, 2023a; Sentinel Stroke National Audit Programme [SSNAP], 2023). Education should be provided for carers of stroke survivors who are dependent in personal activities such as toileting or dressing, as part of a transitional care package, with telephone support and advice for 3 months. Education regarding stroke and its impacts on physical and mental functioning in the medium-to-long term (for example, education on psychosocial and cognitive aspects, post-stroke fatigue, activities of daily living) should also be part ongoing needs for stroke recovery, and should not be time-limited (National Institute for Health and Care Excellence, 2023a; Sentinel Stroke National Audit Programme [SSNAP], 2023).

Adherence to the E pillar could be demonstrated by recording of any educational and training activities agreed between patients and HCPs using resources such as a workbook or a patient diary as was the case in some of the studies included in the systematic review (Nayeri et al., 2014; Jones et al., 2016; Cheng et al., 2018a; Duncan et al., 2020; Fu et al., 2020; Minshall et al., 2020; Pedapati et al., 2021a; Kalav et al., 2022). Participation in lifestyle changes such as

healthy eating, reducing weight, tobacco and alcohol consumption, and the equivalent of cardiac rehabilitation exercise programmes could also be documented in this manner. Demonstration of knowledge and awareness of the symptoms of stroke and the risk factors among patients, caregivers and HCPs could be shown through the use of questionnaires.

9.5 RACE and the Chronic Care Model

Integrated care is an evolution of the Chronic Care Model (CCM), an organisational framework first proposed in 1998 (Wagner, 1998). CCM is the theoretical framework that underpins this study and therefore the RACE pathway must be aligned with all six key components of the CCM. RACE is intended to be conducted within primary and secondary care. The RACE pathway itself is a clear representation of delivery system design (DSD) as it shows how each pillar of the pathway should be implemented and the components that are part of each pillar (Figure 36). In addition to clear components for each pillar, the RACE pathway includes the patient journey from diagnosis through acute treatment, rehabilitation, post-discharge and ongoing care, emphasising that stroke care should be a seamless process throughout this journey.

During the A pillar of the pathway, patients should be able to determine what interventions they receive and how they receive them. This will be achieved where feasible through collaborative discussions between healthcare providers and patients, co-ordination of care between hospital A&E departments, specialist stroke units and primary care, and shared decision-making between patient and provider to create individually tailored care plans (DS).

Self-management support (SMS) starts in Pillar C with stroke survivors receiving psychological support including motivational training and goal setting as a step towards self-management. Regular follow-up and review of progress in goal setting will ensure achievement of personal targets set by the patient. Decision support continues in Pillar C with assessment of individual needs for care post-discharge.

The E pillar focuses on education and training for patients and carers, which includes lifestyle changes such as regular exercise, medication adherence, strategies to prevent recurrent stroke, healthy eating, weight loss, and reduction in alcohol and tobacco use, giving them control over their condition (SMS). Healthcare professionals should receive training on providing comprehensive care and support for stroke survivors throughout their recovery journey and how to manage patient expectations. Stroke survivors are also encouraged in Pillar E to seek community support services and to share their experiences with others (CORP). This could be

achieved through stroke survivors engaging with other patients through stroke charities, patient advocacy and support groups and participating in stroke research clinical trials. Stroke survivors should also be encouraged to learn more about stroke and interventions that could benefit them individually, such as mirror therapy, through resources such as the internet, research publications and social media. The RACE pathway is therefore fully compliant with the principles of CCM.

9.6 Conclusions

The combined results of the systematic review and meta-analysis, stroke survivor focus groups and the Delphi survey have informed the creation of a new proposed integrated care pathway underpinned by the CCM termed RACE, comprising four pillars: R – Recognition of stroke and its associated symptoms, A – Acute and appropriate treatment of stroke, C – Control of cardiovascular risk and other comorbidities, and E – Education and training on care in post-stroke life and prevention of subsequent stroke. This new pathway builds on the ABC_{STROKE} care pathway (Lip et al., 2022b; Lip and Ntaios, 2022) and is distinct from Suter's 10 principles of integrated care and the ICSS and ILASS models of integrated care developed in the UK. The main difference between the pathways is that RACE includes the patient journey from diagnosis of stroke and hyperacute treatment, acute treatment, rehabilitation, post-discharge through to ongoing care and complements the findings of the IPCAS study in primary care and the New Start study programme by highlighting the need for long-term support in stroke care (Forster et al., 2021; Mullis et al., 2024).

RACE has also been designed based on published evidence and with direct input from stroke survivors, making it a holistic approach. This highlights the importance of continued stroke care throughout the patient's journey; the C and E pillars contain numerous interventions that could potentially be implemented for the remaining life of the patient. The four pillars of the pathway are supported by recommendations for comprehensive stroke care in the UK provided by National guidelines (National Institute for Health and Care Excellence, 2022; National Institute for Health and Care Excellence, 2023a; Sentinel Stroke National Audit Programme [SSNAP], 2023). These pillars are especially important given the results of recent studies and guidance showing that awareness of stroke and its implications remains low among patients and indeed with HCPs, and that post-discharge follow-up of stroke patients needs to be improved (Chu and Choi, 2020; Melnikov, 2020; Forster et al., 2021; Liang et al., 2023; Sentinel Stroke National Audit Programme [SSNAP], 2023; Mullis et al., 2024; Sentinel Stroke National Audit Programme [SSNAP], 2024; Aquino et al., 2025; Ymeraj et al., 2025).

The findings of the current study should be interpreted with caution due to the limitations of the systematic review data collection period (01 Jan 2012 to 01 Jan 2024), and the small size of the mixed methods study (27 stroke survivors and 22 HCPs), which limits generalisability of the findings to a broader stroke patient population and a more geographically diverse population of HCPs. Nonetheless, it is envisaged that this new pathway will result in improved educational and training initiatives to enhance the awareness and management of stroke in the future.

10 Chapter Ten: Conclusions and Implications

10.1 Introduction

This final chapter presents the conclusions of the research study, outlines the next steps for future research, highlights challenges for implementation of integrated care in stroke going forward, summarises the contribution of this research to current knowledge, and indicates how the study data will be disseminated.

10.2 Study Conclusions

The objective of this study was to determine which components of an integrated care pathway for people with stroke are considered important for patients and HCPs. This study was the first to systematically review the published literature on integrated care in stroke and the meta-analysis concluded that integrated care in stroke improves quality of life, reduces depression and is associated with a positive benefit on cardiovascular risk factors but does not impact mortality, recurrent stroke or readmission rates. Interventions that include exercise and mental health initiatives were associated with a positive benefit on the primary and secondary outcomes that were evaluated in the study however more than a third of studies in the analysis demonstrated no benefit over standard care and there was considerable heterogeneity between individual studies.

The innovative mixed methods study was the first of its kind to directly involve stroke survivors in the ultimate creation of a new integrated care pathway for stroke. Firstly, inviting them to participate in a series of focus groups allowed individuals to describe the challenges they faced during their recovery and outline which parts of their care benefited them the most. Secondly, stroke survivors were invited to participate in a survey so that they could provide direct input on which components of care should be included in an integrated care pathway. This approach ensured that the pathway would be holistic, something that appears to be lacking so far in this particular field of research. The involvement of stroke survivors in this research highlights the need for ongoing support following discharge from the hospital or stroke unit and a need for increased awareness amongst the public and HCPs about the symptoms of stroke and what action to take.

The findings of this study culminated in the creation of a new patient-focussed integrated care pathway, the RACE pathway.

10.3 Implications for Future Research

The systematic review and meta-analysis indicated the potential benefits that are associated with integrated care in stroke however one third of studies showed no benefit over standard care and there was considerable heterogeneity between studies. Further research should be conducted to determine more precisely which elements of integrated care provide benefits for patients. In addition, there is no unifying definition of integrated care, which confounds the difficulty in its assessment (Satylganova et al., 2016).

The mixed methods study was the first of its kind to involve stroke survivors in the process of creating a new integrated pathway however the Delphi survey participants were known to me and this could have created social desirability bias (Bergen and Labonté, 2020; Gower et al., 2022). The focus group findings showed that individuals experienced a range of emotions during their experience of the event and also when recovering. These experiences were unique to each person and these individuals were selected based on their ability to participate and to give informed consent, so they are not representative of the entire stroke population. Therefore, further research studies on this topic should focus on gathering additional information from a more diverse group of individuals who are not previously known to researchers.

The RACE integrated care pathway is newly created and the next research step would be to test it to determine the precise benefits that would be associated with its implementation. The ABC_{AF} and ABC_{STROKE} integrated pathways, upon which RACE is based, have already been tested and have shown benefits in reducing mortality rates, recurrent stroke and cardiovascular events in patients who are fully adherent to the pillars of each pathway (Romiti et al., 2022; Sagris et al., 2024; Tsang et al., 2024). Potential RACE study designs could include analysis of stroke patient registries or cohorts as in the studies that tested the ABC_{AF} and ABC_{STROKE} pathways. This could be a potentially efficient and rapid way of determining the potential benefits of RACE. Alternatively, a feasibility study could be conducted and if findings are positive, this could lead to a randomised controlled trial.

10.4 Future Challenges for Integrated Care

In stroke care, there is a lack of consensus on the optimal care pathway for patients as evidenced by the high variability in the practical application of treatment guidelines and adherence to quality indicators (Norrving et al., 2018; McMahon et al., 2020). There is currently a discontinuity between hospital care and community care, with up to 70% of stroke survivors in the UK not receiving a six-month follow-up (NHS Rightcare, 2021). The absence of follow-up

leads to feelings of dissatisfaction, frustration and abandonment expressed by stroke survivors and caregivers (Pindus et al., 2018).

Integrated care is complex and involves multidisciplinary teams of HCPs collaborating with each other to provide high quality and seamless care to patients. It is therefore resource intensive and despite the benefits of integrated care that have been demonstrated in the literature, adoption rates are low (Kozlowska et al., 2018). Barriers to successful implementation of integrated care include a lack of commitment across organisations, limited resources, poorly functioning information technology (IT), poor coordination of finances and care pathways, conflicting objectives, and conflict within teams (Kozlowska et al., 2018). Even with substantial investment and commitment, progress is likely to be slow and difficult (Miller et al., 2021). Layering of numerous policy initiatives is confusing and can distract from the important work of relationship building. Ultimately, integrated care cannot by itself address major inadequacies in the underlying resources and structural inequalities (Miller et al., 2021).

Lower- and middle-income countries often have limited resources with which to implement this type of care and stroke outcomes are worsening in some cases (Aguirre et al., 2023). Even in high-income countries such as the UK, there is a need for an adequately resourced multidisciplinary team of healthcare professionals required to deliver the recommended amount of rehabilitation of patients according to their need, especially in the community setting (Sentinel Stroke National Audit Programme [SSNAP], 2022). With such disparities in stroke care provision between countries according to income, it is likely that the implementation of a pathway like RACE would be very different in lower- and middle-income countries compared with high-income countries. Further research would be needed to quantify these differences.

The NHS has committed to the concept of integrated care through the formation of Integrated Care Systems (ICSs), emphasising the need for collaboration and support (NHS, 2023b). There have also been two integrated care initiatives created by NHS and the Stroke Association (ICSS and ILASS) but these have not been implemented according to current knowledge. There has also been a recent shift away from focussing on stroke as a national priority medical condition as outlined in the NHS Long-term Plan published in 2019 (NHS England, 2019). The milestones for stroke care published in this plan included delivering a 10-fold increase in the proportion of patients who receive a thrombectomy after a stroke by 2022 so that each year 1,600 more people will be independent after their stroke, and by 2025 having amongst the best performance in Europe for delivering thrombolysis to all patients who could benefit (NHS England, 2019). Now in 2025, there is no published evidence to show that these milestones

have been reached. The 2025 NHS 10-year plan, Fit for the Future, published by the current government (NHS England, 2025) refers to stroke only twice in the document; firstly in the context of partnering with industry to impact outcomes that really matter for patients, such as fewer heart attacks, strokes or cancer diagnoses, and secondly in the context of tobacco smoking as a risk factor for stroke (NHS England, 2025). These observations imply that stroke is no longer a current national priority.

According to the British Medical Association, the NHS is experiencing some of the most extreme pressures in its 77-year history, with decades of chronic under-resourcing and under-funding, shortages of medical staff, increasing rates of attrition in the medical workforce, increased demand for healthcare services and an ageing population (BMA, 2025). With these extreme pressures, it is difficult to envisage the implementation of comprehensive integrated stroke care within the NHS at present. Recent reports from SSNAP appear to support evidence for a health system struggling to cope, reporting increases in the median time from stroke onset to arrival at first hospital every year since 2013 (Sentinel Stroke National Audit Programme [SSNAP], 2024) and a decline in the proportion of stroke patients receiving a six-month review (Sentinel Stroke National Audit Programme [SSNAP], 2022).

10.5 Contribution to Current Knowledge

Integrated care is a well-documented concept and has evolved from the CCM, developed in 1998 (Wagner, 1998). This study adds the first systematic review and meta-analysis of integrated care in people with stroke and identifies which components of integrated care benefit patients and are associated with a positive impact on outcomes. It provides the basis for future research to further establish the benefits of integrated care in people with stroke.

The novel mixed methods study involves direct patient feedback, through focus groups and a Delphi survey, to inform the creation of a new integrated care pathway for people with stroke. The mixed methods study has confirmed observations that the post-stroke journey is complex and has a high physiological and psychological burden, involving a range of emotions and a sense of grieving for a life as it was before the event. Longer-term support and care are commonly lacking, and the findings of the study support published literature and guidelines highlighting the need for continued support and resources post-discharge to allow stroke survivors to manage their recovery in the most efficient manner.

The new RACE integrated care pathway has been developed based on clinical evidence, input from HCPs and comprehensive feedback from stroke survivors, so it can be considered as a

more holistic approach to integrated care for people with stroke. It serves as a basis for future research on the implementation of holistic, person-centred care.

10.6 Dissemination of Findings

The findings of the systematic review and meta-analysis were published in January 2025 (Eustace et al., 2025) and a copy of the publication is included in Appendix D. A further three manuscripts based on the current study to submit for publication in high-impact peer-reviewed journals are planned, which will include the qualitative findings from the stroke survivor focus groups, a manuscript summarising the findings of the Delphi survey and a manuscript describing the new RACE integrated care pathway.

The thesis will be disseminated through the online repository at Liverpool John Moores University and those individuals who participated in the research such as HCPs and stroke survivors will be provided with the opportunity to receive the study results through the university.

Further dissemination of the findings of the study could be achieved through presentations, posters and abstracts at conferences such as the UK Stroke Forum, World Stroke Congress and the ESC Heart and Stroke conference.

11 References

A Stroke of Grace. (2024) *Imposter Syndrome and Stroke Recovery: Navigating the Hidden Challenges* [online]

Available at: https://www.linkedin.com/pulse/imposter-syndrome-stroke-recovery-navigating-hidden-of-grace-ktowc?trk=public_post_main-feed-card_feed-article-content

[Accessed: Sep 2024]

Aali, G., Drummond, A., das Nair, R. and Shokraneh, F. (2020) Post-stroke fatigue: a scoping review. *F1000Res*, 9, 242.

Abdul Aziz, A.F., Mohd Nordin, N.A., Muhd Nur, A., Sulong, S. and Aljunid, S.M. (2020) The integrated care pathway for managing post stroke patients (iCaPPS©) in public primary care Healthcentres in Malaysia: impact on quality adjusted life years (QALYs) and cost effectiveness analysis. *BMC Geriatrics*, 20 (1), 1–10.

Abdul Rehman, A. and Alharthi, K. (2016) An introduction to research paradigms. 3.

Abrahamson, V. and Wilson, P.M. (2019) How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res*, 19 (1), 480.

Acciarresi, M., Bogousslavsky, J. and Paciaroni, M. (2014) Post-stroke fatigue: epidemiology, clinical characteristics and treatment. *Eur Neurol*, 72 (5-6), 255–261.

Adams, C., Harrison, R. and Wolf, J.A. (2024) The Evolution of Patient Experience: From Holistic Care to Human Experience. *Patient Experience Journal*, 11 (1), 4–13.

Aguirre, A.O., Rogers, J.L., Reardon, T., Shlobin, N.A., Ballatori, A.M., Brown, N.J.et al. (2023) Stroke management and outcomes in low-income and lower-middle-income countries: a meta-analysis of 8535 patients. *Journal of Neurosurgery*, 139 (4), 1042–1051.

Ahmadi, M., Laumeier, I., Ihl, T., Steinicke, M., Ferse, C., Endres, M.et al. (2020) A support programme for secondary prevention in patients with transient ischaemic attack and minor stroke (INSPiRE-TMS): an open-label, randomised controlled trial. *Lancet Neurol*, 19 (1), 49–60.

Ahmed, A., van den Muijsenbergh, M. and Vrijhoef, H.J.M. (2022) Person-centred care in primary care: What works for whom, how and in what circumstances? *Health Soc Care Community*, 30 (6), e3328–e3341.

Ahmed, N., Audebert, H., Turc, G., Cordonnier, C., Christensen, H., Sacco, S.et al. (2019) Consensus statements and recommendations from the ESO-Karolinska Stroke Update Conference, Stockholm 11–13 November 2018. *European Stroke Journal*, 4 (4), 307–317.

Ahmed, N. and Masood, J. (2019) When Life Changes Forever: Life After a Myocardial Infarction. *JACC Case Rep*, 1 (4), 684–685.

Ahn, E. and Kang, H. (2018) Introduction to systematic review and meta-analysis. *Korean J Anesthesiol*, 71 (2), 103–112.

Al-Qazzaz, N.K., Ali, S.H., Ahmad, S.A., Islam, S. and Mohamad, K. (2014) Cognitive impairment and memory dysfunction after a stroke diagnosis: a post-stroke memory assessment. *Neuropsychiatric Disease and Treatment*, 10 (null), 1677–1691.

Al-Shura, A.N. (2014) Chapter 1 - History of Health Communications. In: Al-Shura, A. N. (ed.) *Health Communication in Traditional Chinese Medicine.* Boston: Academic Press. pp. 3–12.

Alamowitch, S., Turc, G., Palaiodimou, L., Bivard, A., Cameron, A., De Marchis, G.M.et al. (2023) European Stroke Organisation (ESO) expedited recommendation on tenecteplase for acute ischaemic stroke. *Eur Stroke J*, 8 (1), 8–54.

Alawieh, A., Zhao, J. and Feng, W. (2018) Factors affecting post-stroke motor recovery: Implications on neurotherapy after brain injury. *Behav Brain Res*, 340, 94–101.

Albart, S.A., Yusof Khan, A.H.K., Abdul Rashid, A., Wan Zaidi, W.A., Bidin, M.Z., Looi, I.et al. (2022) Knowledge of acute stroke management and the predictors among Malaysian healthcare professionals. *PeerJ*, 10, e13310.

Alharahsheh, H.H. and Pius, A. (2020) A review of key paradigms: positivism VS interpretivism. *Global Academic Journal of Humanities and Social Sciences*, 2 (3), 39–43.

Ali, A., Tabassum, D., Baig, S.S., Moyle, B., Redgrave, J., Nichols, S.et al. (2021) Effect of Exercise Interventions on Health-Related Quality of Life After Stroke and Transient Ischemic Attack. *Stroke*, 52 (7), 2445–2455.

Ali, M., Salehnejad, R. and Mansur, M. (2018) Hospital heterogeneity: what drives the quality of health care. *The European Journal of Health Economics*, 19 (3), 385–408.

Allemang, B., Sitter, K. and Dimitropoulos, G. (2022) Pragmatism as a paradigm for patient-oriented research. *Health Expectations*, 25 (1), 38–47.

Allida, S., Cox, K.L., Hsieh, C.-F., Lang, H., House, A. and Hackett, M.L. (2020) Pharmacological, psychological, and non-invasive brain stimulation interventions for treating depression after stroke. *Cochrane Database of Systematic Reviews*.

Alnasser, I.M., Alharbi, M.O., Albishr, N.N., Alghafes, N.J., Khobrani, M.A.H., Alharthi, A.K.et al. (2025) Effectiveness of integrated care models for mental health conditions in family medicine in terms of outcomes, including access to care, treatment adherence, and patient quality of life. *International Journal of Medicine in Developing Countries*, 9 (1), 205–214.

Ambushe, S.A., Awoke, N., Demissie, B.W. and Tekalign, T. (2023) Holistic nursing care practice and associated factors among nurses in public hospitals of Wolaita zone, South Ethiopia. *BMC Nurs*, 22 (1), 390.

American Stroke Association (2020) Stroke, TIA and warning signs. [online],

Available at: https://www.stroke.org/en/help-and-support/resource-library/lets-talk-about-stroke/stroke-tia-and-warning-signs

[Accessed: Sep 2024]

American Stroke Association. (2021) *The power of sharing your story* [online]

Available at: https://www.stroke.org/en/stroke-connection/stroke-onward/the-power-of-sharing-your-story

[Accessed: Sep 2024]

American Stroke Association. (2025) *Stroke Rehabilitation* [online],

Available at: https://www.stroke.org/en/life-after-stroke/stroke-rehab

[Accessed: Jul 2025]

Amundson, D.E., Djurkovic, S. and Matwiyoff, G.N. (2010) The obesity paradox. *Crit Care Clin*, 26 (4), 583–596.

An, M. and Shaughnessy, M. (2011) The Effects of Exercise-Based Rehabilitation on Balance and Gait for Stroke Patients: A Systematic Review. *Journal of Neuroscience Nursing*, 43 (6), 298–307.

Andersen, H.E., Schultz-Larsen, K., Kreiner, S., Forchhammer, B.H., Eriksen, K. and Brown, A. (2000) Can Readmission After Stroke Be Prevented? *Stroke*, 31 (5), 1038–1045.

Anderson, S. and Whitfield, K. (2013) Social identity and stroke: 'they don't make me feel like, there's something wrong with me'. *Scand J Caring Sci*, 27 (4), 820–830.

Andrew, N.E., Kilkenny, M., Naylor, R., Purvis, T., Lalor, E., Moloczij, N.et al. (2014) Understanding long-term unmet needs in Australian survivors of stroke. *Int J Stroke*, 9 Suppl A100, 106–112.

Anhang Price, R., Quigley, D.D., Hargraves, J.L., Sorra, J., Becerra-Ornelas, A.U., Hays, R.D.et al. (2022) A Systematic Review of Strategies to Enhance Response Rates and Representativeness of Patient Experience Surveys. *Med Care*, 60 (12), 910–918.

Appelbaum, P.S., Lidz, C.W. and Meisel, A. (1987) *Informed Consent: Legal Theory and Clinical Practice*. Oxford University Press.

Aquino, M.R.J., Turner, G., Kreit, E., Blatchford, E.G., Grant, J., Johnson, V.et al. (2025) Implementing a new model of primary care for stroke survivors living in the community: a mixed-methods process evaluation. *Trials*, 26 (1), 249.

Arienti, C., Lazzarini, S.G., Pollock, A. and Negrini, S. (2019) Rehabilitation interventions for improving balance following stroke: An overview of systematic reviews. *PLOS ONE*, 14 (7), e0219781.

Armitage, G.D., Suter, E., Oelke, N.D. and Adair, C.E. (2009) Health systems integration: state of the evidence. *Int J Integr Care*, 9, e82.

Arrieta-Bartolomé, G., Supervia, M., Velasquez, A.B.C., Delgado-Montero, A., Méndez, I., Orduñez, M.Á.O.et al. (2022) Evaluating the effectiveness of a comprehensive patient education intervention in a hybrid model of cardiac rehabilitation: A pilot study. *PEC Innovation*, 1, 100054.

Askim, T., Langhammer, B., Ihle-Hansen, H., Gunnes, M., Lydersen, S., Indredavik, B.et al. (2018) Efficacy and Safety of Individualized Coaching After Stroke: the LAST Study (Life After Stroke): A Pragmatic Randomized Controlled Trial. *Stroke*, 49 (2), 426–432.

Avis, K.A., Stroebe, M. and Schut, H. (2021) Stages of Grief Portrayed on the Internet: A Systematic Analysis and Critical Appraisal. *Front Psychol*, 12, 772696.

Ayerbe, L., Ayis, S., Crichton, S., Wolfe, C.D. and Rudd, A.G. (2014) The long-term outcomes of depression up to 10 years after stroke; the South London Stroke Register. *J Neurol Neurosurg Psychiatry*, 85 (5), 514–521.

Aziz, A.F.A., Nordin, N.A.M., Nur, A.M., Sulong, S. and Aljunid, S.M. (2020) The integrated care pathway for managing post stroke patients (iCaPPS (c)) in public primary care Healthcentres in Malaysia: impact on quality adjusted life years (QALYs) and cost effectiveness analysis. *BMC Geriatrics*, 20 (1), 10.

Baby, P., Srijithesh, P.R., Ashraf, J. and Kannan, D. (2019) Emergency nurses' knowledge about tissue plasminogen activator therapy and their perception about barriers for thrombolysis in acute stroke care. *International Journal of Noncommunicable Diseases*, 4 (4), 121–126.

Bailey, J.A., 2nd (2003) Self-image, self-concept, and self-identity revisited. *J Natl Med Assoc*, 95 (5), 383–386.

Bailey, R.R. (2018) Lifestyle Modification for Secondary Stroke Prevention. *American Journal of Lifestyle Medicine*, 12 (2), 140–147.

Balint, E. (1969) The possibilities of patient-centered medicine. *J R Coll Gen Pract*, 17 (82), 269–276.

Banack, H.R., Mayeda, E.R., Naimi, A.I., Fox, M.P. and Whitcomb, B.W. (2023) Collider Stratification Bias I: Principles and Structure. *American Journal of Epidemiology*, 193 (2), 238–240.

Banack, H.R. and Stokes, A. (2017) The 'obesity paradox' may not be a paradox at all. *International Journal of Obesity*, 41 (8), 1162–1163.

Bandura, A. (2004) Health Promotion by Social Cognitive Means. *Health Education & Behavior*, 31 (2), 143–164.

Barbour, R. (2018) *Doing Focus Groups*. Second Edition ed. London: Sage.

Barnes, G.D. (2020) Combining antiplatelet and anticoagulant therapy in cardiovascular disease. *Hematology Am Soc Hematol Educ Program*, 2020 (1), 642–648.

Barrett, D. and Heale, R. (2020) What are Delphi studies? *Evidence Based Nursing*, 23 (3), 68–69.

Bateman, J. (2018) When diabetes is diagnosed: How to use the grief cycle to provide emotional support. *Diabetes & Primary Care*, 20 (5), 189–192.

Bath, P.M., Woodhouse, L.J., Appleton, J.P., Beridze, M., Christensen, H., Dineen, R.A.et al. (2018) Triple versus guideline antiplatelet therapy to prevent recurrence after acute ischaemic stroke or transient ischaemic attack: the TARDIS RCT. *Health Technol Assess*, 22 (48), 1–76.

Baxter, S., Johnson, M., Chambers, D., Sutton, A., Goyder, E. and Booth, A. (2018) The effects of integrated care: a systematic review of UK and international evidence. *BMC Health Serv Res*, 18 (1), 350.

Bech, P. (2002) The Bech-Rafaelsen Melancholia Scale (MES) in clinical trials of therapies in depressive disorders: a 20-year review of its use as outcome measure. *Acta Psychiatr Scand*, 106 (4), 252–264.

Bech, P. (2012) Appendix 3d: The Bech-Rafaelsen Melancholia Scale (MES). In: (ed.) *Clinical Psychometrics.* pp. 136–139.

Beiderbeck, D., Frevel, N., von der Gracht, H.A., Schmidt, S.L. and Schweitzer, V.M. (2021) Preparing, conducting, and analyzing Delphi surveys: Cross-disciplinary practices, new directions, and advancements. *MethodsX*, 8, 101401.

Bergen, N. and Labonté, R. (2020) "Everything Is Perfect, and We Have No Problems": Detecting and Limiting Social Desirability Bias in Qualitative Research. *Qual Health Res*, 30 (5), 783–792.

Berger, P.L. and Luckmann, T. (1966) *The Social Construction of Reality: a Treatise in the Sociology of Knowledge*. New York: Anchor Books.

Bergh, E., Askim, T., Rønning, O.M., Šaltyteė Benth, J., Fjærtoft, H. and Thommessen, B. (2023) Does implementation of a standardized pathway of stroke care affect functional outcome after stroke? *International journal of stroke : official journal of the International Stroke Society*, 18 (5), 578–585.

Bernard, H.R. (2017) *Research Methods in Anthropology: Qualitative and quantitative approaches*. 6 ed. London: Rowman & Littlefield.

Bernhardt, J., Langhorne, P., Lindley, R.I., Thrift, A.G., Ellery, F., Collier, C.et al. (2015) Efficacy and safety of very early mobilisation within 24 h of stroke onset (AVERT): a randomised controlled trial. *The Lancet*, 386 (9988), 46–55.

Bietzk, E., Davies, R., Floyd, A., Lindsay, A., Greenstone, H., Symonds, A.et al. (2012) FAST enough? The U.K. general public's understanding of stroke. *Clin Med (Lond)*, 12 (5), 410–415.

Billinger, S.A., Arena, R., Bernhardt, J., Eng, J.J., Franklin, B.A., Johnson, C.M.et al. (2014) Physical activity and exercise recommendations for stroke survivors: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*, 45 (8), 2532–2553.

Bir, S. and Kelley, R.E. (2021) Antithrombotic Therapy in the Prevention of Stroke. *Biomedicines*, 9 (12).

Blood Pressure Lowering Treatment Trialists, C. (2021) Pharmacological blood pressure lowering for primary and secondary prevention of cardiovascular disease across different levels of blood pressure: an individual participant-level data meta-analysis. *Lancet*, 397 (10285), 1625–1636.

BMA. (2025) *An NHS under pressure* [online]

Available at: https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/an-nhs-under-pressure

[Accessed: Oct 2025]

BMJ Publishing Group (2025) Overview of stroke. *BMJ Best Practice* [online],

Available at: https://bestpractice.bmj.com/topics/en-gb/1080

[Accessed: Jul 2025]

Bodechtel, U., Barlinn, K., Helbig, U., Arnold, K., Siepmann, T., Pallesen, L.-P.et al. (2016) The stroke east Saxony pilot project for organized post-stroke care: a case-control study. *Brain and behavior*, 6 (5), e00455.

Bonino, S., Calandri, E. and Cattelino, E. (2025) Living with a chronic illness as a challenge to psychological development: The role of personal identity, sense of coherence and perceived self-efficacy. *Social Sciences & Humanities Open*, 11, 101620.

Borgermans, L., Marchal, Y., Busetto, L., Kalseth, J., Kasteng, F., Suija, K.et al. (2017) How to Improve Integrated Care for People with Chronic Conditions: Key Findings from EU FP-7 Project INTEGRATE and Beyond. *Int J Integr Care*, 17 (4), 7.

Boss, P. and Couden, B.A. (2002) Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples, and families. *Journal of Clinical Psychology*, 58 (11), 1351–1360.

Boult, C., Karm, L. and Groves, C. (2008) Improving chronic care: the "guided care" model. *Perm J*, 12 (1), 50–54.

Boult, C. and Wieland, G.D. (2010) Comprehensive primary care for older patients with multiple chronic conditions: "Nobody rushes you through". *JAMA*, 304 (17), 1936–1943.

Bowen, L., James, M. and Young, G. (2016) National clinical guideline for stroke. *The Intercollegiate Stroke Working Party*.

Bragstad, L.K., Hjelle, E.G., Zucknick, M., Sveen, U., Thommessen, B., Bronken, B.A.et al. (2020) The effects of a dialogue-based intervention to promote psychosocial well-being after stroke: a randomized controlled trial. *Clinical Rehabilitation*, 34 (8), 1056–1071.

Brandal, A., Eriksson, M., Glader, E.L. and Wester, P. (2019) Effect of early supported discharge after stroke on patient reported outcome based on the Swedish Riksstroke registry. *BMC Neurol*, 19 (1), 40.

Brandal, A.E., M. Glader, E. L. Wester, P. (2019) Effect of early supported discharge after stroke on patient reported outcome based on the Swedish Riksstroke registry. *BMC neurology*, 19.

Brands, I.M., Wade, D.T., Stapert, S.Z. and van Heugten, C.M. (2012) The adaptation process following acute onset disability: an interactive two-dimensional approach applied to acquired brain injury. *Clin Rehabil*, 26 (9), 840–852.

Braun, V. and Clarke, V. (2019) Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11 (4), 589–597.

Braun, V. and Clarke, V. (2022) *Thematic Analysis: A Practical Guide*. Sage.

Brew, L. (2024) Integrating Holistic Care in Nursing Practice: Approaches and Benefits. *Journal of Advanced Practices in Nursing*, 9 (4), 391.

Briggs, A., M, Jennifer, G.P., Marie, L.D., Samantha, B., Brigitte, T., Yuka, S.et al. (2019) Integrated prevention and management of non-communicable diseases, including musculoskeletal health: a systematic policy analysis among OECD countries. *BMJ Global Health*, 4 (5), e001806.

British Association for Cardiovascular Prevention and Rehabilitation (2023) The BACPR Standards and Core Components for Cardiovscular Disease Prevention and Rehabilitation 2023. [online],

Available at: https://www.bacpr.org/resources/publications

[Accessed: Oct 2025]

British Medical Association (2022) The public health response by UK governments to COVID-19. [online],

Available at: https://www.bma.org.uk/media/5980/bma-covid-review-report-4-28-july-2022.pdf

[Accessed: Oct 2025]

British National Formulary (2025) Stroke. [online],

Available at: https://bnf.nice.org.uk/treatment-summaries/stroke/

[Accessed: July 2025]

Broderick, J.P., Adeoye, O. and Elm, J. (2017) Evolution of the Modified Rankin Scale and Its Use in Future Stroke Trials. *Stroke*, 48 (7), 2007–2012.

Brouns, B., Van Bodegom-Vos, L., De Kloet, A.J., Tamminga, S.J., Volker, G., Berger, M.A.M.et al. (2021) EFFECT OF A COMPREHENSIVE EREHABILITATION INTERVENTION ALONGSIDE CONVENTIONAL STROKE REHABILITATION ON DISABILITY AND HEALTH-RELATED QUALITY OF LIFE: A PRE-POST COMPARISON. *Journal of Rehabilitation Medicine (Stiftelsen Rehabiliteringsinformation)*, 53 (3), 1–12.

Brouwer, B., Bryant, D. and Garland, S.J. (2018) Effectiveness of Client-Centered “Tune-Ups” on Community Reintegration, Mobility, and Quality of Life After Stroke: A Randomized Controlled Trial. *Archives of Physical Medicine & Rehabilitation*, 99 (7), 1325–1332.

Brown, M., Moore, C.A., MacGregor, J. and Lucey, J.R. (2021) Primary Care and Mental Health: Overview of Integrated Care Models. *The Journal for Nurse Practitioners*, 17 (1), 10–14.

Brown, M.E.L. and Dueñas, A.N. (2020) A Medical Science Educator's Guide to Selecting a Research Paradigm: Building a Basis for Better Research. *Med Sci Educ*, 30 (1), 545–553.

Brumpton, B.M., Graham, S., Surakka, I., Skogholt, A.H., Løset, M., Fritsche, L.G.et al. (2022) The HUNT study: A population-based cohort for genetic research. *Cell Genomics*, 2 (10), 100193.

Buckley, B.J.R., Harrison, S.L., Fazio-Eynullayeva, E., Underhill, P., Lane, D.A., Thijssen, D.H.J.et al. (2021a) Exercise-Based Cardiac Rehabilitation Associates with Lower Major Adverse Cardiovascular Events in People with Stroke. *Cerebrovascular Diseases*, 51 (4), 488–492.

Buckley, B.J.R., Harrison, S.L., Fazio-Eynullayeva, E., Underhill, P., Lane, D.A., Thijssen, D.H.J.et al. (2021b) Exercise-Based Cardiac Rehabilitation and All-Cause Mortality Among Patients With Atrial Fibrillation. *Journal of the American Heart Association*, 10 (12).

Buckley, B.J.R., Harrison, S.L., Hill, A., Underhill, P., Lane, D.A. and Lip, G.Y.H. (2022) Stroke-Heart Syndrome: Incidence and Clinical Outcomes of Cardiac Complications Following Stroke. *Stroke*.

Bullington, J. and Fagerberg, I. (2013) The fuzzy concept of 'holistic care': a critical examination. *Scand J Caring Sci*, 27 (3), 493–494.

Burell, G.K. (2021) What's the secret of behaviour change? *European Journal of Preventive Cardiology*, 29 (2), 380–382.

Burton, S., Hayes, J.A., Morrell-Scott, N., Sanders, J., Walthall, H., Wright, D.J.et al. (2022) Should I stay or should I go? An exploration of the decision-making behavior of acute cardiac patients during the COVID-19 pandemic. *Heart Lung*, 52, 16–21.

Bushnell, C.D., Kucharska-Newton, A.M., Jones, S.B., Psioda, M.A., Johnson, A.M., Daras, L.C.et al. (2021) Hospital Readmissions and Mortality Among Fee-for-Service Medicare Patients With Minor Stroke or Transient Ischemic Attack: Findings From the COMPASS Cluster-Randomized Pragmatic Trial. *J Am Heart Assoc*, 10 (23), e023394.

Bustamante, A., Giralt, D., García-Berrocoso, T., Rubiera, M., Álvarez-Sabín, J., Molina, C.et al. (2017) The impact of post-stroke complications on in-hospital mortality depends on stroke severity. *Eur Stroke J*, 2 (1), 54–63.

Butt, J.H., Petrie, M.C., Jhund, P.S., Sattar, N., Desai, A.S., Køber, L.et al. (2023) Anthropometric measures and adverse outcomes in heart failure with reduced ejection fraction: revisiting the obesity paradox. *European Heart Journal*, 44 (13), 1136–1153.

Byrne, D. (2022) A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity*, 56 (3), 1391–1412.

Cameron, C., Coyle, D., Richter, T., Kelly, S., Gauthier, K., Steiner, S.et al. (2014) Systematic review and network meta-analysis comparing antithrombotic agents for the prevention of stroke and major bleeding in patients with atrial fibrillation. *BMJ Open*, 4 (6), e004301.

Campbell, B.C. (2024) Hyperacute ischemic stroke care-Current treatment and future directions. *Int J Stroke*, 19 (7), 718–726.

Campbell, B.C.V. and Khatri, P. (2020) Stroke. *Lancet*, 396 (10244), 129–142.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S.et al. (2020) Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing*, 25 (8), 652–661.

Cardol, M., De Jong, B.A. and Ward, C.D. (2002) On autonomy and participation in rehabilitation. *Disabil Rehabil*, 24 (18), 970–974; discussion 975–1004.

Carlsson, G.E., Möller, A. and Blomstrand, C. (2009) Managing an everyday life of uncertainty – A qualitative study of coping in persons with mild stroke. *Disability and Rehabilitation*, 31 (10), 773–782.

Carroll, E. and Coetzer, R. (2011) Identity, grief and self-awareness after traumatic brain injury. *Neuropsychol Rehabil*, 21 (3), 289–305.

Ceccato, V., Gliori, G., Näsman, P. and Sundling, C. (2024) Comparing responses from a paper-based survey with a web-based survey in environmental criminology. *Crime Prevention and Community Safety*, 26 (2), 216–243.

Cecchi, F., Diverio, M., Arienti, C., Corbella, E., Marrazzo, F., Speranza, G.et al. (2020) Development and implementation of a stroke rehabilitation integrated care pathway in an Italian no profit institution: an observational study. *European journal of physical and rehabilitation medicine*, 56 (6), 713–724.

Centers for medicare and Medicaid Services. (2016) *Beneficiary Engagement and Incentives Models: Shared Decision Making Model* [online]

Available at: https://www.cms.gov/newsroom/fact-sheets/beneficiary-engagement-and-incentives-models-shared-decision-making-model

[Accessed: November 2025]

Chang, K.-C., Hung, J.-W., Lee, H.-C., Yen, C.-L., Wu, C.-Y., Yang, C.-L.et al. (2018) Rehabilitation Reduced Readmission and Mortality Risks in Patients With Stroke or Transient Ischemic Attack: A Population-based Study. *Medical care*, 56 (4), 290–298.

Chang, K.-V., Chen, K.-H., Chen, Y.-H., Lien, W.-C., Chang, W.-H., Lai, C.-L.et al. (2022) A multicenter study to compare the effectiveness of the inpatient post acute care program versus traditional rehabilitation for stroke survivors. *Scientific reports*, 12 (1), 12811.

Chao, T.F., Potpara, T.S. and Lip, G.Y.H. (2024) Atrial fibrillation: stroke prevention. *Lancet Reg Health Eur*, 37, 100797.

Charmaz, K. (1997) *Good Days Bad Days: The Self in Chronic Illness and Time*. Second Edition ed. Rutgers University Press.

Chen, C.-M., Yang, Y.-H., Chang, C.-H. and Chen, P.-C. (2017) Effects of Transferring to the Rehabilitation Ward on Long-Term Mortality Rate of First-Time Stroke Survivors: A Population-Based Study. *Archives of physical medicine and rehabilitation*, 98 (12), 2399–2407.

Chen, J., Li, S., Zheng, K., Wang, H., Xie, Y., Xu, P.et al. (2019) Impact of Smoking Status on Stroke Recurrence. *Journal of the American Heart Association*, 8 (8).

Chen, L., Sit, J.W. and Shen, X. (2016) Quasi-experimental evaluation of a home care model for patients with stroke in China. *Disabil Rehabil*, 38 (23), 2271–2276.

Chen, L., Xiao, L.D. and Chamberlain, D. (2020) An integrative review: Challenges and opportunities for stroke survivors and caregivers in hospital to home transition care. *J Adv Nurs*, 76 (9), 2253–2265.

Chen, L., Xiao, L.D. and Chamberlain, D. (2022) Exploring the shared experiences of people with stroke and caregivers in preparedness to manage post-discharge care: A hermeneutic study. *J Adv Nurs*, 78 (9), 2983–2999.

Chen, M., Sepucha, K., Bozic, K.J. and Jayakumar, P. (2023) Value-based Healthcare: Integrating Shared Decision-making into Clinical Practice. *Clin Orthop Relat Res*, 481 (3), 448–450.

Chen, M.D. and Rimmer, J.H. (2011) Effects of exercise on quality of life in stroke survivors: a meta-analysis. *Stroke*, 42 (3), 832–837.

Chen, P.H., Gao, S., Wang, Y.J., Xu, A.D., Li, Y.S. and Wang, D. (2012) Classifying Ischemic Stroke, from TOAST to CISS. *CNS Neurosci Ther*, 18 (6), 452–456.

Cheng, C., Liu, X., Fan, W., Bai, X. and Liu, Z. (2018a) Comprehensive Rehabilitation Training Decreases Cognitive Impairment, Anxiety, and Depression in Poststroke Patients: A Randomized, Controlled Study. *J Stroke Cerebrovasc Dis*, 27 (10), 2613–2622.

Cheng, C.L., Xin Fan, Wenjun Bai, Xue Liu, Zhaojun (2018) Comprehensive Rehabilitation Training Decreases Cognitive Impairment, Anxiety, and Depression in Poststroke Patients: A Randomized, Controlled Study. *Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association*, 27 (10), 2613–2622.

Cheng, E.M., Cunningham, W.E., Towfighi, A., Sanossian, N., Bryg, R.J., Anderson, T.L.et al. (2018b) Efficacy of a Chronic Care-Based Intervention on Secondary Stroke Prevention Among Vulnerable Stroke Survivors: a Randomized Controlled Trial. *Circulation. Cardiovascular quality and outcomes*, 11 (1), e003228.

Chiu, C.C., Lin, H.F., Lin, C.H., Chang, H.T., Hsien, H.H., Hung, K.W.et al. (2021) Multidisciplinary Care after Acute Care for Stroke: A Prospective Comparison between a Multidisciplinary Post-Acute Care Group and a Standard Group Matched by Propensity Score. *Int J Environ Res Public Health*, 18 (14).

Cho, J.-H., Rhee, E.-J., Park, S.E., Kwon, H., Jung, J.-H., Han, K.-D.et al. (2019) Maintenance of body weight is an important determinant for the risk of ischemic stroke: A nationwide population-based cohort study. *PLOS ONE*, 14 (1), e0210153.

Choi, H., Lim, A. and Song, Y. (2022) Adaptive Behavior in Stroke Survivors: A Concept Analysis. *Asian Nursing Research*, 16 (4), 231–240.

Christensen, E.R., Golden, S.L. and Gesell, S.B. (2019) Perceived Benefits of Peer Support Groups for Stroke Survivors and Caregivers in Rural North Carolina. *N C Med J*, 80 (3), 143–148.

Chu, K., Bu, X., Sun, Z., Wang, Y., Feng, W., Xiao, L.et al. (2020) Feasibility of a Nurse-Trained, Family Member-Delivered Rehabilitation Model for Disabled Stroke Patients in Rural Chongqing, China. *Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association*, 29 (12), 105382.

Chu, Y.M. and Choi, K.S. (2020) Effectiveness of patient education in acute stroke: a comparison between a customised computer system and a pictorial information booklet. *BMJ Health Care Inform*, 27 (3).

Chung, C.S., Pollock, A., Campbell, T., Durward, B.R. and Hagen, S. (2013) Cognitive rehabilitation for executive dysfunction in adults with stroke or other adult non-progressive acquired brain damage. *Cochrane Database Syst Rev*, 2013 (4), Cd008391.

Cochrane Collaboration (2020) *Review Manager (RevMan), Version 5.4.*

Cohen, A.T., Hill, N.R., Luo, X., Masseria, C., Abariga, S.A. and Ashaye, A.O. (2018) A systematic review of network meta-analyses among patients with nonvalvular atrial fibrillation: A comparison of efficacy and safety following treatment with direct oral anticoagulants. *Int J Cardiol*, 269, 174–181.

Cohen, L., Manion, L. and Morrison, K. (2007) *Research Methods in Education*. London: Routledge.

Cohen, L., Manion, L. and Morrison, K. (2011) *Research Methods in Education*. 7 ed. Routledge.

Coleman, E.R., Moudgal, R., Lang, K., Hyacinth, H.I., Awosika, O.O., Kissela, B.M.et al. (2017) Early Rehabilitation After Stroke: a Narrative Review. *Curr Atheroscler Rep*, 19 (12), 59.

Connolly, S.B., Kotseva, K., Jennings, C., Atrey, A., Jones, J., Brown, A.et al. (2017) Outcomes of an integrated community-based nurse-led cardiovascular disease prevention programme. *Heart*, 103 (11), 840–847.

Conradsson, M., Rosendahl, E., Littbrand, H., Gustafson, Y., Olofsson, B. and Lövheim, H. (2013) Usefulness of the Geriatric Depression Scale 15-item version among very old people with and without cognitive impairment. *Aging Ment Health*, 17 (5), 638–645.

Corr, C.A. (2020) Elisabeth Kübler-Ross and the “Five Stages” Model in a Sampling of Recent American Textbooks. *OMEGA - Journal of Death and Dying*, 82 (2), 294–322.

Corser, W.D. (2011) Increasing primary care comorbidity: a conceptual research and practice framework. *Res Theory Nurs Pract*, 25 (4), 238–251.

Cortis, L.J., Ward, P.R., McKinnon, R.A. and Koczwara, B. (2017) Integrated care in cancer: What is it, how is it used and where are the gaps? A textual narrative literature synthesis. *Eur J Cancer Care (Engl)*, 26 (4).

Costa, D.G.D., Moura, G., Pasin, S.S., Costa, F.G.D. and Magalhaes, A.M.M. (2020) Patient experience in co-production of care: perceptions about patient safety protocols. *Rev Lat Am Enfermagem*, 28, e3272.

Coulter, A. and Oldham, J. (2016) Person-centred care: what is it and how do we get there? *Future Hospital Journal*, 3 (2), 114–116.

Covic, T., Pallant, J.F., Conaghan, P.G. and Tennant, A. (2007) A longitudinal evaluation of the Center for Epidemiologic Studies-Depression scale (CES-D) in a rheumatoid arthritis population using Rasch analysis. *Health Qual Life Outcomes*, 5, 41.

Cramer, S.C. (2008) Repairing the human brain after stroke: I. Mechanisms of spontaneous recovery. *Ann Neurol*, 63 (3), 272–287.

Creamer, M., Cloud, G., Kossmehl, P., Yochelson, M., Francisco, G.E., Ward, A.B.et al. (2018a) Intrathecal baclofen therapy versus conventional medical management for severe poststroke spasticity: results from a multicentre, randomised, controlled, open-label trial (SISTERS). *J Neurol Neurosurg Psychiatry*, 89 (6), 642–650.

Creamer, M., Cloud, G., Kossmehl, P., Yochelson, M., Francisco, G.E., Ward, A.B.et al. (2018b) Effect of Intrathecal Baclofen on Pain and Quality of Life in Poststroke Spasticity. *Stroke*, 49 (9), 2129–2137.

Creasy, K.R., Lutz, B.J., Young, M.E. and Stacciarini, J.M. (2015) Clinical Implications of Family-Centered Care in Stroke Rehabilitation. *Rehabil Nurs*, 40 (6), 349–359.

Creswell, J.W. and Clark, V.L.P. (2011) *Designing and Conducting Mixed Methods Research*. SAGE Publications.

Creswell, J.W. and Plano Clark, V.L. (2011) *Designing and conducting mixed methods research*. 2 ed. Thousand Oaks, CA: Sage.

Critical Appraisal Skills Programme. (2025) *What are Systematic Reviews?* [online]

Available at: https://casp-uk.net/news/what-is-a-systematic-review/

[Accessed: Mar 2025]

Croot, E.J., Ryan, T.W., Read, J., Campbell, F., O'Cathain, A. and Venables, G. (2014) Transient ischaemic attack: a qualitative study of the long term consequences for patients. *BMC Fam Pract*, 15, 174.

Crotty, M. (2015) *The Foundations of Social Research: Meanings and Perspective in the Research Process*. London: Sage Publications.

Crowfoot, G., van der Riet, P. and Maguire, J. (2018) Real-life experiences of people with transient ischaemic attack or minor stroke: A qualitative literature review. *J Clin Nurs*, 27 (7-8), 1381–1398.

Cuccurullo, S.J., Fleming, T.K., Kostis, J.B., Greiss, C., Eckert, A., Ray, A.R.et al. (2022a) Impact of Modified Cardiac Rehabilitation Within a Stroke Recovery Program on All-Cause Hospital Readmissions. *Am J Phys Med Rehabil*, 101 (1), 40–47.

Cuccurullo, S.J., Fleming, T.K., Kostis, W.J., Greiss, C., Gizzi, M.S., Eckert, A.et al. (2019) Impact of a Stroke Recovery Program Integrating Modified Cardiac Rehabilitation on All-Cause Mortality, Cardiovascular Performance and Functional Performance. *American Journal of Physical Medicine & Rehabilitation*, 98 (11), 953–963.

Cuccurullo, S.J., Fleming, T.K., Zinonos, S., Cosgrove, N.M., Cabrera, J., Kostis, J.B.et al. (2022b) Stroke Recovery Program with Modified Cardiac Rehabilitation Improves Mortality, Functional & Cardiovascular Performance. *J Stroke Cerebrovasc Dis*, 31 (5), 106322.

Cumming, T.B.C., Leonid Collier, Janice Donnan, Geoffrey Ellery, Fiona Dewey, Helen Langhorne, Peter Lindley, Richard I. Moodie, Marj Thrift, Amanda G. Bernhardt, Julie (2019) Early mobilization and quality of life after stroke: Findings from AVERT. *Neurology*, 93 (7), e717–e728.

Czypionka, T., Kraus, M., Reiss, M., Baltaxe, E., Roca, J., Ruths, S.et al. (2020) The patient at the centre: evidence from 17 European integrated care programmes for persons with complex needs. *Bmc Health Services Research*, 20 (1), 1102.

Dalkey, N. (1969) An experimental study of group opinion: The Delphi method. *Futures*, 1 (5), 408–426.

Dalkey, N. and Helmer, O. (1963) An experimental application of the Delphi method for the use of experts. *Management Science*, 9, 458–467.

Darwin Holmes, A.G. (2020) Researcher Positionality - A Consideration of Its Influence and Place in Qualitative Research - A New Researcher Guide. *Shanlax International Journal of Education*, 8 (4), 1–10.

Das Nair, R., Cogger, H., Worthington, E. and Lincoln, N.B. (2016a) Cognitive rehabilitation for memory deficits after stroke. *Cochrane Database of Systematic Reviews*, 2016 (9).

das Nair, R., Cogger, H., Worthington, E. and Lincoln, N.B. (2016b) Cognitive rehabilitation for memory deficits after stroke. *Cochrane Database Syst Rev*, 9 (9), CD002293.

De Bacquer, D., Astin, F., Kotseva, K., Pogosova, N., De Smedt, D., De Backer, G.et al. (2022) Poor adherence to lifestyle recommendations in patients with coronary heart disease: results from the EUROASPIRE surveys. *Eur J Prev Cardiol*, 29 (2), 383–395.

de Belvis, A.G., Lohmeyer, F.M., Barbara, A., Giubbini, G., Angioletti, C., Frisullo, G.et al. (2019) Ischemic stroke: clinical pathway impact. *International Journal of Health Care Quality Assurance (09526862)*, 32 (3), 588–598.

de Mooij, M.J., Ahayoun, I., Leferink, J., Kooij, M.J., Karapinar-Carkit, F. and Van den Berg-Vos, R.M. (2021) Transition of care in stroke patients discharged home: a single-center prospective cohort study. *BMC Health Serv Res*, 21 (1), 1350.

de Villiers, M.R., de Villiers, P.J. and Kent, A.P. (2005) The Delphi technique in health sciences education research. *Med Teach*, 27 (7), 639–643.

Dello, S., Lemmens, R., Demeestere, J., Michiels, D., Wellens, L., Weltens, C.et al. (2021) A nurse-led multicomponent intervention supported by advanced electronic health records to improve the acute management of stroke patients: A pre- and post-intervention study. *INTERNATIONAL JOURNAL OF NURSING STUDIES ADVANCES*, 3.

Delve, H.L. and Limpaecher, A. (2023) Thematic Analysis vs. Interpretative Phenomenological Analysis in Qualitative Research. [online],

Available at: https://delvetool.com/blog/interpretative-phenomenological-analysis-vs-thematic-analysis

[Accessed: Sep 2025]

Delve, H.L. and Limpaecher, A. (2024) Reflexive Thematic Analysis (RTA) in Qulaitative Research. [online],

Available at: https://delvetool.com/blog/reflexive-thematic-analysis

[Accessed: Sep 2025]

Demetrios, M., Khan, F., Turner-Stokes, L., Brand, C. and McSweeney, S. (2013) Multidisciplinary rehabilitation following botulinum toxin and other focal intramuscular treatment for post-stroke spasticity. *Cochrane Database Syst Rev* (6), CD009689.

Demir Avci, Y. and Gözüm, S. (2023) Effects of Transitional Care Model-Based Interventions for Stroke Patients and Caregivers on Caregivers' Competence and Patient Outcomes: Randomized Controlled Trial. *Computers, informatics, nursing : CIN*, 41 (10), 805–814.

Deng, A.W., Yang, S.D. and Xiong, R.B. (2020) Effects of an integrated transitional care program for stroke survivors living in a rural community: a randomized controlled trial. *Clinical Rehabilitation*, 34 (4), 524–532.

Dennison Himmelfarb, C.R., Beckie, T.M., Allen, L.A., Commodore-Mensah, Y., Davidson, P.M., Lin, G.et al. (2023) Shared Decision-Making and Cardiovascular Health: A Scientific Statement From the American Heart Association. *Circulation*, 148 (11), 912–931.

Department of Health and Social Care (2022) Joining up care for people, places and populations. [online],

Available at: https://assets.publishing.service.gov.uk/media/620e4c65d3bf7f4f0399cffc/joining-up-care-for-people-places-and-populations-web-accessible.pdf

[Accessed: Jan 2025]

DerSimonian, R. and Laird, N. (1986) Meta-analysis in clinical trials. *Control Clin Trials*, 7 (3), 177–188.

Deutschbein, J., Grittner, U., Schneider, A. and Schenk, L. (2020) Community care coordination for stroke survivors: results of a complex intervention study. *Bmc Health Services Research*, 20 (1), 1143.

Devereux, N. and Berns, A.M. (2023) Evaluation & Treatment of Psychological Effects of Stroke. *Dela J Public Health*, 9 (3), 62–69.

DeWalt, D.A., Rothrock, N., Yount, S. and Stone, A.A. (2007) Evaluation of item candidates: the PROMIS qualitative item review. *Med Care*, 45 (5 Suppl 1), S12–21.

Dewey, J. (1916) *Democracy and Education*. United States of America: Macmillan.

Dhakal, K. (2022) NVivo. *J Med Libr Assoc*, 110 (2), 270–272.

Different Strokes UK. (2024a) *Greet's story* [online]

Available at: https://differentstrokes.co.uk/stories/greets-story/

[Accessed: Sep 2024]

Different Strokes UK. (2024b) *Stroke Survivor Stories* [online]

Available at: https://differentstrokes.co.uk/what-we-do/survivors-stories/

[Accessed: Sep 2024]

Ding, X., Abner, E.L., Schmitt, F.A., Crowley, J., Goodman, P. and Kryscio, R.J. (2021) Mental Component Score (MCS) from Health-Related Quality of Life Predicts Incidence of Dementia in U.S. Males. *J Prev Alzheimers Dis*, 8 (2), 169–174.

Dobkin, B.H. (2005) Clinical practice. Rehabilitation after stroke. *N Engl J Med*, 352 (16), 1677–1684.

Døhl, Ø., Halsteinli, V., Askim, T., Gunnes, M., Ihle-Hansen, H., Indredavik, B.et al. (2020) Factors contributing to post-stroke health care utilization and costs, secondary results from the life after stroke (LAST) study. *Bmc Health Services Research*, 20 (1), 288.

Dombrowski, S.U., Mackintosh, J.E., Sniehotta, F.F., Araujo-Soares, V., Rodgers, H., Thomson, R.G.et al. (2013) The impact of the UK 'Act FAST' stroke awareness campaign: content analysis of patients, witness and primary care clinicians' perceptions. *BMC Public Health*, 13 (1), 915.

Dramé, M. and Godaert, L. (2023) The Obesity Paradox and Mortality in Older Adults: A Systematic Review. *Nutrients*, 15 (7).

Dreyer, R.P., Pavlo, A.J., Horne, A., Dunn, R., Danvers, K., Brush, J.et al. (2021) Conceptual Framework for Personal Recovery in Patients With Acute Myocardial Infarction. *Journal of the American Heart Association*, 10 (19), e022354.

Duda, J. (2025) The walking wounded: sepsis survivors grapple with post-sepsis syndrome. *The Lancet Respiratory Medicine*, 13 (9), 786–788.

Duncan, P.W., Bushnell, C.D., Jones, S.B., Psioda, M.A., Gesell, S.B., D'Agostino, R.B., Jr.et al. (2020) Randomized Pragmatic Trial of Stroke Transitional Care: The COMPASS Study. *Circulation. Cardiovascular quality and outcomes*, 13 (6), e006285.

Dunn, N. (2003) Practical issues around putting the patient at the centre of care. *J R Soc Med*, 96 (7), 325–327.

EARS. (2024) *EARS Independent Advocacy Service (SCIO)* [online]

Available at: https://www.ears-advocacy.org.uk/

[Accessed: Sep 2024]

East Kent Hospitals University NHS Foundation Trust. (2025) [online]

Available at: https://www.facebook.com/EastKentHospitals/posts/a-grandfather-who-spent-four-weeks-in-a-coma-after-contracting-sepsis-said-he-is/1349473490515674/

[Accessed: Oct 2025]

Edvardsson, D. (2015) Notes on person-centred care: What it is and what it is not. *Nordic Journal of Nursing Research*, 35 (2), 65–66.

Edwards, J.D., Kapral, M.K., Fang, J. and Swartz, R.H. (2017) Long-term morbidity and mortality in patients without early complications after stroke or transient ischemic attack. *CMAJ*, 189 (29), E954–E961.

Elameer, M., Price, C., Flynn, D. and Rodgers, H. (2018) The impact of acute stroke service centralisation: a time series evaluation. *Future Healthc J*, 5 (3), 181–187.

Ellis-Hill, C., Thomas, S., Gracey, F., Lamont-Robinson, C., Cant, R., Marques, E.M.R.et al. (2019) HeART of Stroke: randomised controlled, parallel-arm, feasibility study of a community-based arts and health intervention plus usual care compared with usual care to increase psychological well-being in people following a stroke. *BMJ Open*, 9 (3), e021098.

Ellis-Hill, C.S. and Horn, S. (2000) Change in identity and self-concept: a new theoretical approach to recovery following a stroke. *Clin Rehabil*, 14 (3), 279–287.

Ellis-Hill, C.S., Payne, S. and Ward, C. (2000) Self-body split: issues of identity in physical recovery following a stroke. *Disabil Rehabil*, 22 (16), 725–733.

Elwyn, G., Price, A., Franco, J.V.A. and Gulbrandsen, P. (2023a) The limits of shared decision making. *BMJ Evidence-Based Medicine*, 28 (4), 218–221.

Elwyn, G., Sierpe, A. and Forcino, R. (2023b) Do payment programs incentivize shared decision making in US healthcare? *Patient Education and Counseling*, 113, 107798.

Eppel-Meichlinger, J., Kobleder, A. and Mayer, H. (2024) Refining Mishel's Reconceptualized Uncertainty in Illness Theory: Explaining the Development of Uncertainty in Chronic Illness. *Res Theory Nurs Pract*, 38 (2), 171–192.

European Commission: Consumers, H.A. and Food Executive, A. (2020) *Integrated care – Improving health care coordination and delivery*. Publications Office of the European Union.

Eustace, I., Buckley, B.J.R., Kaya, I., Hoad, K.L., France-Ratcliffe, M., Hill, A.R.et al. (2025) Integrated care management for patients following acute stroke: a systematic review. *QJM: An International Journal of Medicine*.

Exley, J., Glover, R., McCarey, M., Reed, S., Ahmed, A., Vrijhoef, H.et al. (2024) Governing Integrated Health and Social Care: An Analysis of Experiences in Three European Countries. *International Journal of Integrated Care*.

Faghih-Jouybari, M., Raof, M.T., Abdollahzade, S., Jamshidi, S., Padegane, T., Ehteshami, S.et al. (2021) Mortality and morbidity in patients with spontaneous intracerebral hemorrhage: A single-center experience. *Curr J Neurol*, 20 (1), 32–36.

Farmer, C. (2015) Bringing Holistic Treatments to the Attention of Medicine: Acupuncture as an Effective Poststroke Rehabilitation Tool. *Journal of Evidence-Based Complementary & Alternative Medicine*, 20 (2), 120–125.

Farquharson, B., Johnston, M., Williams, B., Smith, K., Dombrowski, S., Jones, C.et al. (2023) Reducing patient delay in acute coronary syndrome: Randomized controlled trial testing effect of behaviour change intervention on intentions to seek help. *British Journal of Health Psychology*, 28 (1), 188–207.

Feigin, V.L., Abate, M.D., Abate, Y.H., Abd ElHafeez, S., Abd-Allah, F., Abdelalim, A.et al. (2024) Global, regional, and national burden of stroke and its risk factors, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *The Lancet Neurology*, 23 (10), 973–1003.

Feigin, V.L., Brainin, M., Norrving, B., Martins, S.O., Pandian, J., Lindsay, P.et al. (2025) World Stroke Organization: Global Stroke Fact Sheet 2025. *Int J Stroke*, 20 (2), 132–144.

Feigin, V.L., Nguyen, G., Cercy, K., Jonson, C.O., Alam, T., Parmar, P.G.et al. (2018) Global, Regional, and Country-Specific Lifetime Risks of Stroke, 1990 and 2016. *New England Journal of Medicine*, 379 (25), 2429–2437.

Feigin, V.L., Stark, B.A., Johnson, C.O., Roth, G.A., Bisignano, C., Abady, G.G.et al. (2021) Global, regional, and national burden of stroke and its risk factors, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Neurology*, 20 (10), 795–820.

Feng, W., Yu, H., Wang, J. and Xia, J. (2021) Application effect of the hospital-community integrated service model in home rehabilitation of stroke in disabled elderly: a randomised trial. *Ann Palliat Med*, 10 (4), 4670–4677.

Feng, X.H., Deng, A.W., Chen, J.H. and Xiong, R.B. (2023) Health-related outcomes 6 months after integrated care of older people with stroke in 2 different primary care settings. *Family Practice*, 6.

Flynn, D., Ford, G.A., Rodgers, H., Price, C., Steen, N. and Thomson, R.G. (2014) A time series evaluation of the FAST National Stroke Awareness Campaign in England. *PLOS ONE*, 9 (8), e104289.

Forlivesi, S., Cappellari, M. and Bonetti, B. (2021) Obesity paradox and stroke: a narrative review. *Eat Weight Disord*, 26 (2), 417–423.

Forster, A., Ozer, S., Crocker, T.F., House, A., Hewison, J., Roberts, E.et al. (2021) Longer-term health and social care strategies for stroke survivors and their carers: the LoTS2Care research programme including cluster feasibility RCT. *Programme Grants for Applied Research*, 9 (3).

Fox, N.J. (2008) Post-positivism. In: Given, L. M. (ed.) *The SAGE Encyclopaedia of Qualitative Research Methods.* London: Sage.

Freburger, J.K., Pastva, A.M., Coleman, S.W., Peter, K.M., Kucharska-Newton, A.M., Johnson, A.M.et al. (2022) Skilled Nursing and Inpatient Rehabilitation Facility Use by Medicare Fee-for-Service Beneficiaries Discharged Home After a Stroke: Findings From the COMPASS Trial. *Archives of physical medicine and rehabilitation*, 103 (5), 882.

Fredriksson-Larsson, U., Alsen, P. and Brink, E. (2013) I've lost the person I used to be—Experiences of the consequences of fatigue following myocardial infarction. *International Journal of Qualitative Studies on Health and Well-being*, 8 (1), 20836.

Frega, R. (2011) *Pragmatist Epistomologies*. Lexington Books.

Friedman, Y. (2021) On recovery: re-directing the concept by differentiation of its meanings. *Med Health Care Philos*, 24 (3), 389–399.

Frisch, N.C. and Rabinowitsch, D. (2019) What's in a Definition? Holistic Nursing, Integrative Health Care, and Integrative Nursing: Report of an Integrated Literature Review. *Journal of Holistic Nursing*, 37 (3), 260–272.

Fryer, C.E., Luker, J.A., McDonnell, M.N. and Hillier, S.L. (2016) Self management programmes for quality of life in people with stroke. *Cochrane Database of Systematic Reviews* (8).

Fu, V., Weatherall, M., McPherson, K., Taylor, W., McRae, A., Thomson, T.et al. (2020) Taking Charge after Stroke: A randomized controlled trial of a person-centered, self-directed rehabilitation intervention. *International journal of stroke : official journal of the International Stroke Society*, 15 (9), 954–964.

Fulop, N.J., Ramsay, A.I., Perry, C., Boaden, R.J., McKevitt, C., Rudd, A.G.et al. (2016) Explaining outcomes in major system change: a qualitative study of implementing centralised acute stroke services in two large metropolitan regions in England. *Implement Sci*, 11 (1), 80.

Futrell, N. and Millikan, C.H. (1996) Stroke is an emergency. *Dis Mon*, 42 (4), 199–264.

Ganti, L. (2025) Management of acute ischemic stroke in the emergency department: optimizing the brain. *International Journal of Emergency Medicine*, 18 (1), 7.

Gao, J., Lin, M., Zhao, J., Bi, S., Ni, Z. and Shang, X. (2017) Different interventions for post-ischaemic stroke depression in different time periods: a single-blind randomized controlled trial with stratification by time after stroke. *Clinical Rehabilitation*, 31 (1), 71–81.

Garattini, L., Badinella Martini, M. and Nobili, A. (2022) Integrated Care in Europe: Time to Get it Together? *Applied Health Economics and Health Policy*, 20 (2), 145–147.

Gaspoz, J.M., Unger, P.F., Urban, P., Chevrolet, J.C., Rutishauser, W., Lovis, C.et al. (1996) Impact of a public campaign on pre-hospital delay in patients reporting chest pain. *Heart*, 76 (2), 150–155.

Gavaldà-Espelta, E., Del Mar Lleixà-Fortuño, M., Baucells-Lluis, J., Ferré-Ferraté, M., Tomàs-Navarro, B., Curto-Romeu, C.et al. (2023) Innovative Health and Social Integrated Care Model Effectiveness to Improve Quality Care for Chronic Patients: A Single Group Assignment Clinical Trial. *Int J Integr Care*, 23 (4), 2.

Gaynor, E., Rohde, D., Large, M., Mellon, L., Hall, P., Brewer, L.et al. (2018) Cognitive Impairment, Vulnerability, and Mortality Post Ischemic Stroke: A Five-Year Follow-Up of the Action on Secondary Prevention Interventions and Rehabilitation in Stroke (ASPIRE-S) Cohort. *Journal of Stroke and Cerebrovascular Diseases*, 27 (9), 2466–2473.

Geng, G.L., He, W., Ding, L., Klug, D. and Xiao, Y.H. (2019) Impact of transitional care for discharged elderly stroke patients in China: an application of the Integrated Behavioral Model. *Topics in Stroke Rehabilitation*, 26 (8), 621–629.

George, E. and Arya, S. (2020) Non-Atherosclerotic Vascular Causes of Stroke. *American College of Cardiology* [online],

Available at: https://www.acc.org/latest-in-cardiology/articles/2020/05/04/11/53/non-atherosclerotic-vascular-causes-of-stroke

[Accessed: July 2025]

Ghisi, G.L.M., Rouleau, F., Ross, M.K., Dufour-Doiron, M., Belliveau, S.L., Brideau, J.R.et al. (2020) Effectiveness of an Education Intervention Among Cardiac Rehabilitation Patients in Canada: A Multi-Site Study. *CJC Open*, 2 (4), 214–221.

Gibson, J. and Watkins, C. (2012) People's experiences of the impact of transient ischaemic attack and its consequences: qualitative study. *J Adv Nurs*, 68 (8), 1707–1715.

Gilbody, S., Richards, D., Brealey, S. and Hewitt, C. (2007) Screening for depression in medical settings with the Patient Health Questionnaire (PHQ): a diagnostic meta-analysis. *J Gen Intern Med*, 22 (11), 1596–1602.

Gilham, S.C., L. (2021) Psychological care after stroke: Improving stroke services for people with cognitive and mood disorders. *NHS Improvement - Stroke*.

Gluyas, H. (2015) Patient-centred care: improving healthcare outcomes. *Nursing Standard*, 30 (4), 50–59.

Goldstein, L.B. (2020) Introduction for Focused Updates in Cerebrovascular Disease. *Stroke*, 51 (3), 708–710.

Gomez, C.R. (2018) Time Is Brain: The Stroke Theory of Relativity. *Journal of Stroke and Cerebrovascular Diseases*, 27 (8), 2214–2227.

Goncalves-Bradley, D.C., Iliffe, S., Doll, H.A., Broad, J., Gladman, J., Langhorne, P.et al. (2017) Early discharge hospital at home. *Cochrane Database Syst Rev*, 6 (6), CD000356.

Gonçalves-Bradley, D.C., Iliffe, S., Doll, H.A., Broad, J., Gladman, J., Langhorne, P.et al. (2017) Early discharge hospital at home. *Cochrane Database of Systematic Reviews*, 2021 (7).

Gordon, B.R., McDowell, C.P., Hallgren, M., Meyer, J.D., Lyons, M. and Herring, M.P. (2018) Association of Efficacy of Resistance Exercise Training With Depressive Symptoms: Meta-analysis and Meta-regression Analysis of Randomized Clinical Trials. *JAMA Psychiatry*, 75 (6), 566–576.

Gore, M., Bansal, K., Khan Suheb, M.Z., Lui, F. and Asuncion, R.M.D. (2024) Lacunar Stroke. [online],

Available at: https://www.ncbi.nlm.nih.gov/books/NBK563216/

[Accessed: July 2025]

Govori, V., Budinčević, H., Morović, S., Đerke, F. and Demarin, V. (2024) Updated Perspectives on Lifestyle Interventions as Secondary Stroke Prevention Measures: A Narrative Review. *Medicina (Kaunas)*, 60 (3).

Gower, T., Pham, J., Jouriles, E.N., Rosenfield, D. and Bowen, H.J. (2022) Cognitive biases in perceptions of posttraumatic growth: A systematic review and meta-analysis. *Clin Psychol Rev*, 94, 102159.

Grant, M.J. and Booth, A. (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26 (2), 91–108.

Grassi, M., Nucera, A. and European Community Respiratory Health Study Quality of Life Working, G. (2010) Dimensionality and summary measures of the SF-36 v1.6: comparison of scale- and item-based approach across ECRHS II adults population. *Value in Health*, 13 (4), 469–478.

Graven, C., Brock, K., Hill, K.D., Cotton, S. and Joubert, L. (2016) First Year After Stroke: An Integrated Approach Focusing on Participation Goals Aiming to Reduce Depressive Symptoms. *Stroke*, 47 (11), 2820–2827.

Green, T.L. and King, K.M. (2009) Experiences of male patients and wife-caregivers in the first year post-discharge following minor stroke: A descriptive qualitative study. *International Journal of Nursing Studies*, 46 (9), 1194–1200.

Greenwood, N., Mackenzie, A., Cloud, G. and Wilson, N. (2010) Loss of autonomy, control and independence when caring: a qualitative study of informal carers of stroke survivors in the first three months after discharge. *Disabil Rehabil*, 32 (2), 125–133.

Grefkes, C. and Fink, G.R. (2020) Recovery from stroke: current concepts and future perspectives. *Neurol Res Pract*, 2, 17.

Greger, J., Wojcik, R., Westphal, E., Aladeen, T., Landolf, K., Boyce, S.et al. (2021) Pharmacist intervention and anti-platelet medication monitoring in patients following stroke and transient ischemic attack. *JOURNAL OF THE AMERICAN COLLEGE OF CLINICAL PHARMACY*, 4 (3), 311–317.

Greutmann, M., Theile, G. and Tobler, D. (2018) Holistic Care and Palliation. In: Swan, L. and Frogoudaki, A. A. (ed.) *Heart Failure in Adult Congenital Heart Disease.* Cham: Springer International Publishing. pp. 241–250.

Gries, K., Berry, P., Harrington, M., Crescioni, M., Patel, M., Rudell, K.et al. (2017) Literature review to assemble the evidence for response scales used in patient-reported outcome measures. *J Patient Rep Outcomes*, 2, 41.

Grix, J. (2004) *The Foundations of Research*. New York: Palgrave Macmillan.

Gun Young, Y. (2021) The Effects of an Integrated Management Program on Physical Function, Cognitive Function, and Depression in Patients with Subacute stroke. *Korean Critical Care Nursing*, 14 (1), 50–62.

Guo, Y., Zhang, Z., Lin, B., Mei, Y., Liu, Q., Zhang, L.et al. (2021) The Unmet Needs of Community-Dwelling Stroke Survivors: A Systematic Review of Qualitative Studies. *Int J Environ Res Public Health*, 18 (4).

Guraya, S.S., Harkin, D.W., Yusoff, M.S.B. and Guraya, S.Y. (2023) Paradigms unfolded - developing, validating, and evaluating the Medical Education e-Professionalism framework from a philosophical perspective. *Front Med (Lausanne)*, 10, 1230620.

Gursahani, R. (2021) Coping with uncertainty of deterioration-stroke. *Journal of the Neurological Sciences*, 429.

Hagendijk, M.E., Zipfel, N., Melles, M., van der Wees, P.J., Hulshof, C.T.J., Çölkesen, E.B.et al. (2025) Towards person-centred work-focused healthcare for people with cardiovascular disease: a qualitative exploration of patients' experiences and needs. *Disability and Rehabilitation*, 47 (1), 194–206.

Hakiki, B., Paperini, A., Castagnoli, C., Hochleitner, I., Verdesca, S., Grippo, A.et al. (2021) Predictors of Function, Activity, and Participation of Stroke Patients Undergoing Intensive Rehabilitation: A Multicenter Prospective Observational Study Protocol. *Front Neurol*, 12, 632672.

Hall, R. (2013) Mixed Methods: In search of a paradigm. In: (ed.). pp. 71–78.

Halpern, J. (2012) Gathering the patient's story and clinical empathy. *Perm J*, 16 (1), 52–54.

Hampson, T. and McKinley, J. (2023) Problems posing as solutions: Criticising pragmatism as a paradigm for mixed research. *Research in Education*, 116 (1), 124–138.

Hartford, W., Lear, S. and Nimmon, L. (2019) Stroke survivors' experiences of team support along their recovery continuum. *Bmc Health Services Research*, 19 (1), 723.

Hasson, F., Keeney, S. and McKenna, H. (2000) Research guidelines for the Delphi survey technique. *J Adv Nurs*, 32 (4), 1008–1015.

He, E., Prabhakaran, S., Golani, S., Mehendale, R., Morales, J. and Siegler, J.E. (2025) Stroke Discharge Care Navigation: A Compass in Need of a Captain. *Stroke: Vascular and Interventional Neurology*, 5 (2), e001623.

He, Y., Wang, R., Dong, S., Long, S., Zhang, P. and Feng, L. (2023) Nurse-led rapid rehabilitation following mechanical thrombectomy in patients with acute ischemic stroke: A historical control study. *Medicine*, 102 (28), e34232.

Higgins, J.P., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J.et al. (2019) *Cochrane Handbook for Systematic Reviews of Interventions*. Chichester: John Wiley & Sons.

Hilton Boon, M., Burns, J., Craig, P., Griebler, U., Heise, T.L., Vittal Katikireddi, S.et al. (2022) Value and Challenges of Using Observational Studies in Systematic Reviews of Public Health Interventions. *Am J Public Health*, 112 (4), 548–552.

Hjelle, E.G., Bragstad, L.K., Kirkevold, M., Zucknick, M., Bronken, B.A., Martinsen, R.et al. (2019) Effect of a dialogue-based intervention on psychosocial well-being 6 months after stroke in Norway: a randomized controlled trial. *Journal of rehabilitation medicine*, 51 (8), 557–565.

Hoad, K.L., Jones, H., Miller, G., Abdul-Rahim, A.H., Lip, G.Y. and Buckley, B.J. (2025) Stroke-heart syndrome: Incidence and clinical outcomes of cardiac complications following intracerebral haemorrhage. *Eur Stroke J*, 10 (1), 100–107.

Hogge, C., Goldstein, L.B. and Aroor, S.R. (2024) Mnemonic utilization in stroke education: FAST and BEFAST adoption by certified comprehensive stroke centers. *Front Neurol*, 15, 1359131.

Hollist, M., Morgan, L., Cabatbat, R., Au, K., Kirmani, M.F. and Kirmani, B.F. (2021) Acute Stroke Management: Overview and Recent Updates. *Aging Dis*, 12 (4), 1000–1009.

Horn, J.W., Feng, T., Mørkedal, B., Strand, L.B., Horn, J., Mukamal, K.et al. (2021) Obesity and Risk for First Ischemic Stroke Depends on Metabolic Syndrome: The HUNT Study. *Stroke*, 52 (11), 3555–3561.

Horowitz, M. (2018) Redefining Identity after Trauma or Loss. *Psychodyn Psychiatry*, 46 (1), 135–144.

Hoth, K.F., Wamboldt, F.S., Ford, D.W., Sandhaus, R.A., Strange, C., Bekelman, D.B.et al. (2015) The social environment and illness uncertainty in chronic obstructive pulmonary disease. *Int J Behav Med*, 22 (2), 223–232.

Hu, L., Glavin, Y.-F.W., Yan, R., Pei, C., Yan, M., Zhang, Y.o.et al. (2021) Integrating Health and Care in China: Lessons Learned and Future Outlook. *International Journal of Integrated Care*.

Huang, J., Zuo, J., Tang, X., Zou, J., Zeng, Y., Chen, S.et al. (2023) Early Rehabilitation and Nursing Intervention (ERNI) Accelerates the Recovery of Patients With Ischemic Stroke. *The neurologist*, 28 (6), 409–412.

Huhn, A.S., Ellis, J.D., Dunn, K.E., Sholler, D.J., Tabaschek, P., Burns, R.et al. (2022) Patient-reported sleep outcomes in randomized-controlled trials in persons with substance use disorders: A systematic review. *Drug Alcohol Depend*, 237, 109508.

Hunter, R.M., Davie, C., Rudd, A., Thompson, A., Walker, H., Thomson, N.et al. (2013) Impact on clinical and cost outcomes of a centralized approach to acute stroke care in London: a comparative effectiveness before and after model. *PLOS ONE*, 8 (8), e70420.

Hussain, S. and Dornhorst, A. (2015) Integrated care: the clinicians' view. *Future Hosp J*, 2 (2), 83–85.

IDCC Health Services. (2023) *What is the difference between holistic and integrative medicine* [online]

Available at: https://idcchealth.org/blogs/understanding-the-distinction-between-holistic-health-and-integrative-medicine/#:~:text=Treatment%20Modalities%3A%20Holistic%20medicine%20leans,from%20different%20disciplines%20working%20together

[Accessed: Jun 2024]

Islam, M.M., Poly, T.N. and Li, Y.J. (2018) Recent Advancement of Clinical Information Systems: Opportunities and Challenges. *Yearb Med Inform*, 27 (1), 83–90.

Ivbijaro, G.O., Enum, Y., Khan, A.A., Lam, S.S. and Gabzdyl, A. (2014) Collaborative care: models for treatment of patients with complex medical-psychiatric conditions. *Curr Psychiatry Rep*, 16 (11), 506.

Jackson-Koku, G. (2016) Beck Depression Inventory. *Occupational Medicine*, 66 (2), 174–175.

Jaffe, A., Yoselis, A. and Tripto-Shkolnik, L. (2015) Better together: a community- hospital integrative model of healthcare as a practical solution for providing excellence in endocrinology care in an era of limited resources. *Israel Journal of Health Policy Research*, 4 (1), 28.

Jaiswal, V.C., Parmar, L. and Ghodey, S. (2022) Patient Education Strategies for Coronary Heart Disease in a Cardiac Rehabilitation Setting: A Scoping Review. *Journal of Datta Meghe Institute of Medical Sciences University*, 17 (1), 152–165.

James Lind Alliance. (2022) *Stroke Rehabilitation and Long-Term Care Top 10 Priorities* [online]

Available at: https://www.jla.nihr.ac.uk/priority-setting-partnerships/stroke/stroke-rehabilitation-and-long-term-care-top-10-priorities.htm

[Accessed: Mar 2023]

Jamieson, S. (2004) Likert scales: how to (ab)use them. *Medical Education*, 38 (12), 1217–1218.

Jamison, J., Ayerbe, L., Di Tanna, G.L., Sutton, S., Mant, J. and De Simoni, A. (2018) Evaluating practical support stroke survivors get with medicines and unmet needs in primary care: a survey. *BMJ Open*, 8 (3), e019874.

Jasemi, M., Valizadeh, L., Zamanzadeh, V. and Keogh, B. (2017) A Concept Analysis of Holistic Care by Hybrid Model. *Indian J Palliat Care*, 23 (1), 71–80.

Jee, S., Jeong, M., Paik, N.J., Kim, W.S., Shin, Y.I., Ko, S.H.et al. (2022) Early Supported Discharge and Transitional Care Management After Stroke: A Systematic Review and Meta-Analysis. *Front Neurol*, 13, 755316.

Johri, M., Beland, F. and Bergman, H. (2003) International experiments in integrated care for the elderly: a synthesis of the evidence. In: (ed.) *Database of Abstracts and Reviews of Effects (DARE): Quality-assessed Reviews [Internet]*. University of York. Available at: https://www.ncbi.nlm.nih.gov/books/NBK69752/

[Accessed: Jul 2024]

Jones, F., Gage, H., Drummond, A., Bhalla, A., Grant, R., Lennon, S.et al. (2016) Feasibility study of an integrated stroke self-management programme: a cluster-randomised controlled trial. *BMJ Open*, 6 (1), e008900.

Jones, J.B., Snyder, C.F. and Wu, A.W. (2007) Issues in the design of Internet-based systems for collecting patient-reported outcomes. *Qual Life Res*, 16 (8), 1407–1417.

Jones, S.P., Jenkinson, A.J., Leathley, M.J. and Watkins, C.L. (2010) Stroke knowledge and awareness: an integrative review of the evidence. *Age Ageing*, 39 (1), 11–22.

Joubert, J., Davis, S.M., Donnan, G.A., Levi, C., Gonzales, G., Joubert, L.et al. (2020) ICARUSS: An effective model for risk factor management in stroke survivors. *INTERNATIONAL JOURNAL OF STROKE*, 15 (4), 438–453.

Joubert, J., Davis, S.M., Hankey, G.J., Levi, C., Olver, J., Gonzales, G.et al. (2015) ICARUSS, the Integrated Care for the Reduction of Secondary Stroke trial: rationale and design of a randomized controlled trial of a multimodal intervention to prevent recurrent stroke in patients with a recent cerebrovascular event, ACTRN=12611000264987. *INTERNATIONAL JOURNAL OF STROKE*, 10 (5), 773–777.

Jowett, B. (380 BCE) *Charmides, or Temperance* [online].

Available at: https://classics.mit.edu/Plato/charmides.html [Accessed Aug 2025].

Jung, S.H., Park, E., Kim, J.H., Park, B.A., Yu, J.W., Kim, A.R.et al. (2021) Effects of Self RehAbilitation Video Exercises (SAVE) on Functional Restorations in Patients with Subacute Stroke. *Healthcare (Basel)*, 9 (5).

Kalav, S., Bektas, H. and Unal, A. (2022) Effects of Chronic Care Model-based interventions on self-management, quality of life and patient satisfaction in patients with ischemic stroke: A single-blinded randomized controlled trial. *JAPAN JOURNAL OF NURSING SCIENCE*, 19 (1).

Kamel, H., Okin, P.M., Elkind, M.S. and Iadecola, C. (2016) Atrial Fibrillation and Mechanisms of Stroke: Time for a New Model. *Stroke*, 47 (3), 895–900.

Kapil, N., Datta, Y.H., Alakbarova, N., Bershad, E., Selim, M., Liebeskind, D.S.et al. (2017) Antiplatelet and Anticoagulant Therapies for Prevention of Ischemic Stroke. *Clinical and Applied Thrombosis/Hemostasis*, 23 (4), 301–318.

Kaushik, V. and Walsh, C.A. (2019) Pragmatism as a Research Paradigm and Its Implications for Social Work Research. *Social Sciences*, 8 (9), 255.

Kawachi, I., Colditz, G.A., Stampfer, M.J., Willett, W.C., Manson, J.E., Rosner, B.et al. (1993) Smoking cessation and decreased risk of stroke in women. *JAMA*, 269 (2), 232–236.

Kearney, L.K., Zeiss, A.M., McCabe, M.A., Thistlethwaite, J.E., Chana, N., Chen, S.et al. (2020) Global approaches to integrated care: Best practices and ongoing innovation. *Am Psychol*, 75 (5), 668–682.

Keeney, S., Hasson, F. and McKenna, H. (2006) Consulting the oracle: ten lessons from using the Delphi technique in nursing research. *J Adv Nurs*, 53 (2), 205–212.

Keeney, S., Hasson, F. and McKenna, H. (2011) *The Delphi Technique in Nursing and Health Research*. Wiley-Blackwell.

Kelfve, S., Kivi, M., Johansson, B. and Lindwall, M. (2020) Going web or staying paper? The use of web-surveys among older people. *BMC Med Res Methodol*, 20 (1), 252.

Kern, L.M., Bynum, J.P.W. and Pincus, H.A. (2024) Care Fragmentation, Care Continuity, and Care Coordination-How They Differ and Why It Matters. *JAMA Intern Med*, 184 (3), 236–237.

Kernan, W.N., Inzucchi, S.E., Sawan, C., Macko, R.F. and Furie, K.L. (2013) Obesity. *Stroke*, 44 (1), 278–286.

Kessler, D., Egan, M. and Kubina, L.A. (2014) Peer support for stroke survivors: a case study. *BMC Health Serv Res*, 14, 256.

Khan, F. and Chevidikunnan, M.F. (2021) Prevalence of Balance Impairment and Factors Associated with Balance among Patients with Stroke. A Cross Sectional Retrospective Case Control Study. *Healthcare (Basel)*, 9 (3).

Khatri, R.B., Wolka, E., Nigatu, F., Zewdie, A., Erku, D., Endalamaw, A.et al. (2023) People-centred primary health care: a scoping review. *BMC Primary Care*, 24 (1), 236.

Khosravi, M. (2021) Worden's task-based approach for supporting people bereaved by COVID-19. *Curr Psychol*, 40 (11), 5735–5736.

Khramov, V.V., Kogaeva, K.P., Arkhipova, L.U., Alekseeva, V.O. and Lukyanova, M.I. (2021) EFFECTIVENESS OF POST-STROKE SOCIAL REHABILITATION IN PATIENTS WITH MODERATE IMPAIRMENTS. *BULLETIN OF RUSSIAN STATE MEDICAL UNIVERSITY* (2), 62–68.

Kim, H., Kim, J.-T., Lee, J.S., Kim, B.J., Kang, J., Lee, K.-J.et al. (2022) Stroke of Other Determined Etiology: Results From the Nationwide Multicenter Stroke Registry. *Stroke*, 53 (8), 2597–2606.

Kitagawa, K., Yamamoto, Y., Arima, H., Maeda, T., Sunami, N., Kanzawa, T.et al. (2019) Effect of Standard vs Intensive Blood Pressure Control on the Risk of Recurrent Stroke: A Randomized Clinical Trial and Meta-analysis. *JAMA Neurol*, 76 (11), 1309–1318.

Kitson, A.L. and Lawless, M.T. (2025) Why We Need to Think Differently About Self-Care and Self-Management. *Nursing Inquiry*, 32 (2), e70013.

Kjellström, T., Norrving, B. and Shatchkute, A. (2007) Helsingborg Declaration 2006 on European stroke strategies. *Cerebrovasc Dis*, 23 (2-3), 231–241.

Kleindorfer, D.O., Towfighi, A., Chaturvedi, S., Cockroft, K.M., Gutierrez, J., Lombardi-Hill, D.et al. (2021) 2021 Guideline for the Prevention of Stroke in Patients With Stroke and Transient Ischemic Attack: A Guideline From the American Heart Association/American Stroke Association. *Stroke*, 52 (7), e364–e467.

Klockar, E., Kylén, M., Gustavsson, C., Finch, T., Jones, F. and Elf, M. (2023) Self-management from the perspective of people with stroke – An interview study. *Patient Education and Counseling*, 112, 107740.

Knapp, P., Campbell Burton, C.A., Holmes, J., Murray, J., Gillespie, D., Lightbody, C.E.et al. (2017) Interventions for treating anxiety after stroke. *Cochrane Database of Systematic Reviews*, 2017 (5).

Koch, S., Tiozzo, E., Simonetto, M., Loewenstein, D., Wright, C.B., Dong, C.et al. (2020) Randomized Trial of Combined Aerobic, Resistance, and Cognitive Training to Improve Recovery From Stroke: Feasibility and Safety. *Journal of the American Heart Association*, 9 (10), e015377.

Koff, P.B., Min, S.J., Freitag, T.J., Diaz, D.L.P., James, S.S., Voelkel, N.F.et al. (2021) Impact of Proactive Integrated Care on Chronic Obstructive Pulmonary Disease. *Chronic Obstr Pulm Dis*, 8 (1), 100–116.

Koo, M. and Yang, S.-W. (2025) Likert-Type Scale. *Encyclopedia*, 5 (1), 18.

Koositamongkol, S., Sindhu, S., Pinyopasakul, W., Nilanont, Y. and Redman, R.W. (2013) Factors influencing functional recovery in patients with acute ischemic stroke. *Collegian*, 20 (4), 207–213.

Kozlowska, O., Lumb, A., Tan, G.D. and Rea, R. (2018) Barriers and facilitators to integrating primary and specialist healthcare in the United Kingdom: a narrative literature review. *Future Healthc J*, 5 (1), 64–80.

Kreuger, R.A. (2002) Designing and Conducting Focus Group Interviews. [online],

Available at: https://www.eiu.edu/ihec/Krueger-FocusGroupInterviews.pdf

[Accessed: Apr 2023]

Kripalani, S., Theobald, C.N., Anctil, B. and Vasilevskis, E.E. (2014) Reducing hospital readmission rates: current strategies and future directions. *Annu Rev Med*, 65, 471–485.

Kristensen, H.K., Lund, H., Jones, D.L. and Ytterberg, C. (2015) Achieving a holistic perspective in stroke rehabilitation: An overview of the use of the ICF by Danish physiotherapists and occupational therapists. *International Journal of Therapy & Rehabilitation*, 22 (10), 460–469.

Kritanshu, K. (2024) *Multidisciplinary vs Transdisciplinary Approach in Healthcare* [online]

Available at: https://www.totalcommunication.com.sg/post/multidisciplinary-vs-transdisciplinary-approach-in-healthcare

[Accessed: Jan 2025]

Kroenke, K., Spitzer, R.L. and Williams, J.B. (2001) The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*, 16 (9), 606–613.

Kübler-Ross, E. and Kessler, D. (2014) *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. Simon & Schuster.

Kuhn, T.S. (1962) *The structure of scientific revolutions*. Chicago and London.

Kumar, A., Unnithan, A., Das, J.M. and Mehta, P. (2023) Hemmorhagic Stroke. [online],

Available at: https://www.ncbi.nlm.nih.gov/books/NBK559173/

[Accessed: Jul 2025]

Kumari, Y., Bai, P., Waqar, F., Asif, A.T., Irshad, B., Raj, S.et al. (2023) Advancements in the Management of Endocrine System Disorders and Arrhythmias: A Comprehensive Narrative Review. *Cureus*, 15 (10), e46484.

Lambert, C.M., Olulana, O., Bailey-Davis, L., Abedi, V. and Zand, R. (2021) "Lessons Learned" Preventing Recurrent Ischemic Strokes through Secondary Prevention Programs: A Systematic Review. *J Clin Med*, 10 (18).

Lancet Diabetes and Endocrinology [Editorial] (2015) Care integration for endocrine disorders in cancer survivors. *The Lancet Diabetes & Endocrinology*, 3 (7), 487.

Landau, J. and Hissett, J. (2008) Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems, & Health*, 26 (1), 69–85.

Langhorne, P. and Baylan, S. (2017) Early supported discharge services for people with acute stroke. *Cochrane Database Syst Rev*, 7 (7), Cd000443.

Langhorne, P., Coupar, F. and Pollock, A. (2009) Motor recovery after stroke: a systematic review. *Lancet Neurol*, 8 (8), 741–754.

Langhorne, P., Jepsen, B.G. and Larsen, T. (2014) Early home-supported discharge after stroke. *International Journal of Rehabilitation Research*, 37 (2), 192–194.

Langhorne, P., Ramachandra, S. and Stroke Unit Trialists, C. (2020a) Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database Syst Rev*, 4 (4), CD000197.

Langhorne, P., Ramachandra, S. and Stroke Unit Trialists, C. (2020b) Organized Inpatient (Stroke Unit) Care for Stroke: Network Meta-Analysis. *Stroke*, 51 (12), e349–e350.

Langhorne, P., Wu, O., Rodgers, H., Ashburn, A. and Bernhardt, J. (2017) A Very Early Rehabilitation Trial after stroke (AVERT): a Phase III, multicentre, randomised controlled trial. *Health Technol Assess*, 21 (54), 1–120.

Lanza, M. (2006) PSYCHOLOGICAL IMPACT OF STROKE: A RECOVERING NURSE'S STORY. *Issues in Mental Health Nursing*, 27 (7), 765–774.

Lapadatu, I. and Morris, R. (2019) The relationship between stroke survivors' perceived identity and mood, self-esteem and quality of life. *Neuropsychol Rehabil*, 29 (2), 199–213.

Latchaw, R.E., Alberts, M.J., Lev, M.H., Connors, J.J., Harbaugh, R.E., Higashida, R.T.et al. (2009) Recommendations for Imaging of Acute Ischemic Stroke. *Stroke*, 40 (11), 3646–3678.

Lecouturier, J., Rodgers, H., Murtagh, M.J., White, M., Ford, G.A. and Thomson, R.G. (2010) Systematic review of mass media interventions designed to improve public recognition of stroke symptoms, emergency response and early treatment. *BMC Public Health*, 10, 784.

Lee, A.Y.P., S. A. Park, H. G. Son, K. C. (2018) Determining the Effects of a Horticultural Therapy Program for Improving the Upper Limb Function and Balance Ability of Stroke Patients. *HORTSCIENCE*, 53 (1), 110–119.

Lee, E.O. and Emanuel, E.J. (2013) Shared Decision Making to Improve Care and Reduce Costs. *New England Journal of Medicine*, 368 (1), 6–8.

Lee, P.H., Yeh, T.T., Yen, H.Y., Hsu, W.L., Chiu, V.J. and Lee, S.C. (2021) Impacts of stroke and cognitive impairment on activities of daily living in the Taiwan longitudinal study on aging. *Sci Rep*, 11 (1), 12199.

Lee, S.A., Park, H.G. and Son, K.C. (2018) Determining the Effects of a Horticultural Therapy Program for Improving the Upper Limb Function and Balance Ability of Stroke Patients. *Hortscience*, 53 (1), 110–119.

Lei, H., Yu, L.T., Wang, W.N. and Zhang, S.G. (2018) Warfarin and the Risk of Death, Stroke, and Major Bleeding in Patients With Atrial Fibrillation Receiving Hemodialysis: A Systematic Review and Meta-Analysis. *Front Pharmacol*, 9, 1218.

Lei, X.Y., Chen, L.H., Qian, L.Q. and Lu, X.D. (2025) Psychological interventions for post-stroke anxiety and depression: Current approaches and future perspectives. *World J Psychiatry*, 15 (6), 103270.

Leonhardt-Caprio, A.M., Sellers, C.R., Palermo, E., Caprio, T.V. and Holloway, R.G. (2022) A Multi-Component Transition of Care Improvement Project to Reduce Hospital Readmissions Following Ischemic Stroke. *Neurohospitalist*, 12 (2), 205–212.

Leung, F.H. and Savithiri, R. (2009) Spotlight on focus groups. *Can Fam Physician*, 55 (2), 218–219.

Levack, W.M., Boland, P., Taylor, W.J., Siegert, R.J., Kayes, N.M., Fadyl, J.K.et al. (2014) Establishing a person-centred framework of self-identity after traumatic brain injury: a grounded theory study to inform measure development. *BMJ Open*, 4 (5), e004630.

Levack, W.M., Kayes, N.M. and Fadyl, J.K. (2010) Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disabil Rehabil*, 32 (12), 986–999.

Lewthwaite, R., Winstein, C.J., Lane, C.J., Blanton, S., Wagenheim, B.R., Nelsen, M.A.et al. (2018) Accelerating Stroke Recovery: Body Structures and Functions, Activities, Participation, and Quality of Life Outcomes From a Large Rehabilitation Trial. *Neurorehabilitation & Neural Repair*, 32 (2), 150–165.

Leys, D., Henon, H., Mackowiak-Cordoliani, M.A. and Pasquier, F. (2005) Poststroke dementia. *Lancet Neurol*, 4 (11), 752–759.

Li, L., Scott, C.A. and Rothwell, P.M. (2022) Association of Younger vs Older Ages With Changes in Incidence of Stroke and Other Vascular Events, 2002-2018. *JAMA*, 328 (6), 563–574.

Li, X., He, Y., Wang, D. and Rezaei, M.J. (2024) Stroke rehabilitation: from diagnosis to therapy. *Front Neurol*, 15, 1402729.

Li, Y., Wang, Q., Liu, X.L., Hui, R. and Zhang, Y.P. (2023) Effect of the physical rehabilitation program based on self-care ability in patients with acute ischemic stroke: a quasi-experimental study. *FRONTIERS IN NEUROLOGY*, 14.

Liamputtong, P. (2011) *Focus Group Methodology: Principles and Practice*. London: Sage.

Liang, J., Luo, C., Ke, S. and Tung, T.-H. (2023) Stroke related knowledge, prevention practices and associated factors among stroke patients in Taizhou, China. *Preventive Medicine Reports*, 35, 102340.

Liljeroos, T., Humphries, S., Puthoopparambil, S.J., Norlund, F. and Olsson, E.M.G. (2023) Management of emotional distress following a myocardial infarction: a qualitative content analysis. *Cognitive Behaviour Therapy*, 52 (1), 47–64.

Lin, E.H., Von Korff, M., Peterson, D., Ludman, E.J., Ciechanowski, P. and Katon, W. (2014) Population targeting and durability of multimorbidity collaborative care management. *Am J Manag Care*, 20 (11), 887–895.

Lin, R.C., Chiang, S.L., Heitkemper, M.M., Weng, S.M., Lin, C.F., Yang, F.C.et al. (2020) Effectiveness of Early Rehabilitation Combined With Virtual Reality Training on Muscle Strength, Mood State, and Functional Status in Patients With Acute Stroke: A Randomized Controlled Trial. *Worldviews Evid Based Nurs*, 17 (2), 158–167.

Lin, R.C.C., Shang-Lin Heitkemper, Margaret McLean Weng, Shu-Min Lin, Chi-Feng Yang, Fu-Chi Lin, Chia-Huei (2020) Effectiveness of Early Rehabilitation Combined With Virtual Reality Training on Muscle Strength, Mood State, and Functional Status in Patients With Acute Stroke: A Randomized Controlled Trial. *Worldviews on Evidence-Based Nursing*, 17 (2), 158–167.

Lin, Y. (2022) Effect of multi-disciplinary clinical nursing pathway on self-efficacy and self-management behavior i patients with cerebral infarction. *Acta Medica Mediterranea*, 38 (5), 3133–3138.

Lincoln, Y.S. and Guba, E.G. (1985) *Naturalistic Enquiry*. Thousand Oaks, California, USA: Sage.

Lip, G.Y.H. (2017) The ABC pathway: an integrated approach to improve AF management. *Nat Rev Cardiol*, 14 (11), 627–628.

Lip, G.Y.H., Lane, D.A., Lenarczyk, R., Boriani, G., Doehner, W., Benjamin, L.A.et al. (2022a) Integrated care for optimizing the management of stroke and associated heart disease: a position paper of the European Society of Cardiology Council on Stroke. *Eur Heart J*, 43 (26), 2442–2460.

Lip, G.Y.H., Lane, D.A., Lenarczyk, R., Boriani, G., Doehner, W., Benjamin, L.A.et al. (2022b) Integrated care for optimizing the management of stroke and associated heart disease: a position paper of the European Society of Cardiology Council on Stroke. *European Heart Journal*, 43 (26), 2442–2460.

Lip, G.Y.H. and Ntaios, G. (2021) "Novel Clinical Concepts in Thrombosis": Integrated Care for Stroke Management-Easy as ABC. *Thromb Haemost*.

Lip, G.Y.H. and Ntaios, G. (2022) "Novel Clinical Concepts in Thrombosis": Integrated Care for Stroke Management-Easy as ABC. *Thrombosis and Haemostasis*, 122 (03), 316–319.

Liu, A.H., Zeiger, R., Sorkness, C., Mahr, T., Ostrom, N., Burgess, S.et al. (2007) Development and cross-sectional validation of the Childhood Asthma Control Test. *J Allergy Clin Immunol*, 119 (4), 817–825.

Liu, B., Cai, J. and Zhou, L. (2025) Effectiveness of integrated care models for stroke patients: A systematic review and meta-analysis. *Journal of Nursing Scholarship*, 57 (2), 266–297.

Liu, L.M. (2018) EFFECTS OF TRANSITIONAL CARE ON FUNCTIONAL EXERCISE: COMPLIANCE AND HEALTH STATUS OF STROKE PATIENTS. *Acta Medica Mediterranea*, 34 (4), 959–965.

Liu, N., Cadilhac, D.A., Andrew, N.E., Zeng, L., Li, Z., Li, J.et al. (2014) Randomized controlled trial of early rehabilitation after intracerebral hemorrhage stroke: difference in outcomes within 6 months of stroke. *Stroke (00392499)*, 45 (12), 3502–3507.

Liu, S.D., Rudd, A. and Davie, C. (2011) Hyper acute stroke unit services. *Clinical Medicine*, 11 (3), 213–214.

Lloyd-Jones, D.M., Allen, N.B., Anderson, C.A.M., Black, T., Brewer, L.C., Foraker, R.E.et al. (2022) Life's Essential 8: Updating and Enhancing the American Heart Association's Construct of Cardiovascular Health: A Presidential Advisory From the American Heart Association. *Circulation*, 146 (5), e18–e43.

Lo, S.H.S., Chau, J.P.C., Lau, A.Y.L., Choi, K.C., Shum, E.W.C., Lee, V.W.Y.et al. (2023) Virtual Multidisciplinary Stroke Care Clinic for Community-Dwelling Stroke Survivors: A Randomized Controlled Trial. *Stroke*, 54 (10), 2482–2490.

Lobo, E.H., Abdelrazek, M., Grundy, J., Kensing, F., Livingston, P.M., Rasmussen, L.J.et al. (2021) Caregiver Engagement in Stroke Care: Opportunities and Challenges in Australia and Denmark. *Front Public Health*, 9, 758808.

Loft, M.I., Martinsen, B., Esbensen, B.A., Mathiesen, L.L., Iversen, H.K. and Poulsen, I. (2019) Call for human contact and support: an interview study exploring patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions. *Disability and Rehabilitation*, 41 (4), 396–404.

Long Weijan and Zhang, J. (2017) Patient Caregiver Comprehensive Rehabilitation Nursing Training Joint Continued nursing care for ischemic stroke patients at home Impact on quality of life and activities of daily living. *Chinese Nursing Research*, 31 (20), 2456–2461.

Longley, V., Hazelton, C., Heal, C., Pollock, A., Woodward-Nutt, K., Mitchell, C.et al. (2021) Non-pharmacological interventions for spatial neglect or inattention following stroke and other non-progressive brain injury. *Cochrane Database of Systematic Reviews*, 2021 (7).

López-Liria, R., Vega-Ramírez, F.A., Rocamora-Pérez, P., Aguilar-Parra, J.M. and Padilla-Góngora, D. (2016) Comparison of Two Post-Stroke Rehabilitation Programs: A Follow-Up Study among Primary versus Specialized Health Care. *PLOS ONE*, 11 (11), e0166242.

Lorenzetti, D.L. and Ghali, W.A. (2013) Reference management software for systematic reviews and meta-analyses: an exploration of usage and usability. *BMC Medical Research Methodology*, 13 (1), 141.

LoTs care LUNS Study Team (2013) Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. *Clin Rehabil*, 27 (11), 1020–1028.

Lou, S., Carstensen, K., Jorgensen, C.R. and Nielsen, C.P. (2017) Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disabil Rehabil*, 39 (3), 301–313.

Loughlin, N. (2012) The Benefits and Disadvantages of Post-positivism in International Theory. [online],

Available at: https://www.e-ir.info/2012/01/20/what-are-the-benefits-and-disadvantages-of-post-positivism-for-international-theory/#:~:text=However%2C%20whilst%20this%20essay%20argues,post%2Dmodernism%20and%20critical%20theory.

[Accessed: Aug 2025]

Lowther, H.J., Harrison, J., Hill, J.E., Gaskins, N.J., Lazo, K.C., Clegg, A.J.et al. (2021) The effectiveness of quality improvement collaboratives in improving stroke care and the facilitators and barriers to their implementation: a systematic review. *Implementation Science*, 16 (1).

Lu, H., Tan, X., Wang, X., Lin, Q., Huang, S., Li, J.et al. (2023a) Basic psychological needs satisfaction of stroke patients: a qualitative study. *BMC Psychol*, 11 (1), 64.

Lu, L.X., Wei, S.Y., Huang, Q.Y., Chen, Y.K., Huang, F.X., Ma, X.A.et al. (2023b) Original Article Effect of "Internet plus tertiary hospital-primary hospital-family linkage home care" model on self-care ability and quality of life of discharged stroke patients. *AMERICAN JOURNAL OF TRANSLATIONAL RESEARCH*, 15 (12), 6727–6739.

Luengo-Fernandez, R., Li, L., Silver, L., Gutnikov, S., Beddows, N.C. and Rothwell, P.M. (2022) Long-Term Impact of Urgent Secondary Prevention After Transient Ischemic Attack and Minor Stroke: Ten-Year Follow-Up of the EXPRESS Study. *Stroke*, 53 (2), 488–496.

Lui, F., Khan Suheb, M.Z. and Patti, L. (2025) Ischemic Stroke. *StatPearls* [online],

Available at: https://www.ncbi.nlm.nih.gov/books/NBK499997/

[Accessed: July 2025]

Mack, L. (2010) The Philosophical Underpinnings of Educational Research. [online],

Available at: https://en.apu.ac.jp/rcaps/uploads/fckeditor/publications/polyglossia/Polyglossia_V19_Lindsay.pdf

[Accessed: Aug 2025]

MacKay-Lyons, M., Gubitz, G., Phillips, S., Giacomantonio, N., Firth, W., Thompson, K.et al. (2022) Program of Rehabilitative Exercise and Education to Avert Vascular Events After Non-Disabling Stroke or Transient Ischemic Attack (PREVENT Trial): a Randomized Controlled Trial. *Neurorehabilitation and neural repair*, 36 (2), 119–130.

Mackay-Lyons, M., Thornton, M., Ruggles, T. and Che, M. (2013) Non-pharmacological interventions for preventing secondary vascular events after stroke or transient ischemic attack. *Cochrane Database Syst Rev* (3), CD008656.

Macmillan Cancer Support. (2025) *Your feelings when someone has cancer* [online]

Available at: https://www.macmillan.org.uk/cancer-information-and-support/supporting-someone/emotional-support-for-family-and-friends/your-feelings-when-someone-has-cancer

[Accessed: Oct 2025]

Maddern, R. and Kneebone, II (2019) Receiving Bad News: A Thematic Analysis of Stroke Survivor Experiences. *J Patient Exp*, 6 (4), 271–277.

Magee, W.L., Clark, I., Tamplin, J. and Bradt, J. (2017) Music interventions for acquired brain injury. *Cochrane Database Syst Rev*, 1 (1), CD006787.

Maguida, G. and Shuaib, A. (2023) Collateral Circulation in Ischemic Stroke: An Updated Review. *J Stroke*, 25 (2), 179–198.

Man, S., Zhao, X., Uchino, K., Hussain, M.S., Smith, E.E., Bhatt, D.L.et al. (2018) Comparison of Acute Ischemic Stroke Care and Outcomes Between Comprehensive Stroke Centers and Primary Stroke Centers in the United States. *Circulation. Cardiovascular quality and outcomes*, 11 (6), e004512.

Mangiardi, M., Bonura, A., Iaccarino, G., Alessiani, M., Bravi, M.C., Crupi, D.et al. (2023) The Pathophysiology of Collateral Circulation in Acute Ischemic Stroke. *Diagnostics (Basel)*, 13 (14).

Manley, K., Martin, A., Jackson, C. and Wright, T. (2016) Using systems thinking to identify workforce enablers for a whole systems approach to urgent and emergency care delivery: a multiple case study. *BMC Health Serv Res*, 16 (a), 368.

Mansour, M.H.H., Pokhrel, S. and Anokye, N. (2022) Effectiveness of integrated care interventions for patients with long-term conditions: a review of systematic reviews. *Integr Healthc J*, 4 (1), e000083.

Mantri, S. (2008) Holistic Medicine and the Western Medical Tradition. *Virtual Mentor* [online], 10 (3), 177–180

Available at: https://journalofethics.ama-assn.org/article/holistic-medicine-and-western-medical-tradition/2008-03

[Accessed: Aug 2024]

Markle-Reid, M., Valaitis, R., Bartholomew, A., Fisher, K., Fleck, R., Ploeg, J.et al. (2020) An integrated hospital-to-home transitional care intervention for older adults with stroke and multimorbidity: A feasibility study. *Journal of Comorbidity*, 10, 1–21.

Martin, A.K., Green, T.L., McCarthy, A.L., Sowa, P.M. and Laakso, E.L. (2023) Allied health transdisciplinary models of care in hospital settings: A scoping review *J Interprof Care*, 37 (1), 118–130.

Martinez-Garcia, M.A., Campos-Rodriguez, F., Soler-Cataluna, J.J., Catalan-Serra, P., Roman-Sanchez, P. and Montserrat, J.M. (2012) Increased incidence of nonfatal cardiovascular events in stroke patients with sleep apnoea: effect of CPAP treatment. *Eur Respir J*, 39 (4), 906–912.

Martinez-Garcia, M.A., Galiano-Blancart, R., Roman-Sanchez, P., Soler-Cataluna, J.J., Cabero-Salt, L. and Salcedo-Maiques, E. (2005) Continuous positive airway pressure treatment in sleep apnea prevents new vascular events after ischemic stroke. *Chest*, 128 (4), 2123–2129.

Martinez-Garcia, M.A., Soler-Cataluna, J.J., Ejarque-Martinez, L., Soriano, Y., Roman-Sanchez, P., Illa, F.B.et al. (2009) Continuous positive airway pressure treatment reduces mortality in patients with ischemic stroke and obstructive sleep apnea: a 5-year follow-up study. *Am J Respir Crit Care Med*, 180 (1), 36–41.

Martínez-González, N.A., Berchtold, P., Ullman, K., Busato, A. and Egger, M. (2014) Integrated care programmes for adults with chronic conditions: a meta-review. *International Journal for Quality in Health Care*, 26 (5), 561–570.

McClaughlin, E., Vilar-Lluch, S., Parnell, T., Knight, D., Nichele, E., Adolphs, S.et al. (2023) The reception of public health messages during the COVID-19 pandemic. *Applied Corpus Linguistics*, 3 (1), 100037.

McCormack, B. (2003) A conceptual framework for person-centred practice with older people. *Int J Nurs Pract*, 9 (3), 202–209.

McEvoy, L. and Duffy, A. (2008) Holistic practice--a concept analysis. *Nurse Educ Pract*, 8 (6), 412–419.

McIlvennan, C.K. and Howie-Esquivel, J. (2025) Back to Basics: Self-Care Education to Empower Patients With Heart Failure. *Journal of Cardiac Failure*, 31 (8), 1115–1117.

McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., Rudd, A.R.et al. (2011) Self-reported long-term needs after stroke. *Stroke*, 42 (5), 1398–1403.

McMahon, N.E., Bangee, M., Benedetto, V., Bray, E.P., Georgiou, R.F., Gibson, J.M.E.et al. (2020) Etiologic Workup in Cases of Cryptogenic Stroke. *Stroke*, 51 (5), 1419–1427.

Meca, A., Allison, K., Cruz, B., Ayers, K., Webb, T. and Patel, P. (2023) Who am I? Identity and its implications for health and psychosocial functioning. In: Halpern-Felsher, B. (ed.) *Encyclopedia of Child and Adolescent Health (First Edition).* Oxford: Academic Press. pp. 64–78.

Mehrholz, J., Kugler, J. and Pohl, M. (2011) Water-based exercises for improving activities of daily living after stroke. *Cochrane Database Syst Rev*, 2011 (1), CD008186.

Mehrholz, J., Pohl, M., Platz, T., Kugler, J. and Elsner, B. (2018) Electromechanical and robot-assisted arm training for improving activities of daily living, arm function, and arm muscle strength after stroke. *Cochrane Database Syst Rev*, 9 (9), Cd006876.

Mehrholz, J., Thomas, S. and Elsner, B. (2017) Treadmill training and body weight support for walking after stroke. *Cochrane Database Syst Rev*, 8 (8), CD002840.

Melnikov, S. (2020) The need for knowledge and skills in the care of post-stroke patients. *Eur J Cardiovasc Nurs*, 19 (6), 456–457.

Mengist, W., Soromessa, T. and Legese, G. (2020) Method for conducting systematic literature review and meta-analysis for environmental science research. *MethodsX*, 7, 100777.

Merriman, N.A., Sexton, E., McCabe, G., Walsh, M.E., Rohde, D., Gorman, A.et al. (2019) Addressing cognitive impairment following stroke: systematic review and meta-analysis of non-randomised controlled studies of psychological interventions. *BMJ Open*, 9 (2), e024429.

Michael, R. (2025) Postpositivism. *EBSCO Research Starters* [online],

Available at: https://www.ebsco.com/research-starters/religion-and-philosophy/postpositivism#:~:text=Postpositivism%20claims%20that%20people's%20natural,and%2C%20thus%2C%20inherently%20untrustworthy.

[Accessed: Aug 2025]

Middleton, S., McElduff, P., Ward, J., Grimshaw, J.M., Dale, S., D'Este, C.et al. (2011) Implementation of evidence-based treatment protocols to manage fever, hyperglycaemia, and swallowing dysfunction in acute stroke (QASC): a cluster randomised controlled trial. *Lancet*, 378 (9804), 1699–1706.

Mijajlović, M.D., Pavlović, A., Brainin, M., Heiss, W.-D., Quinn, T.J., Ihle-Hansen, H.B.et al. (2017) Post-stroke dementia – a comprehensive review. *BMC Medicine*, 15 (1), 11.

Milinavičienė, E., Rastenytė, D. and Kriščiūnas, A. (2007) Factors influencing outcomes in patients with stroke. *Medicina*, 43 (4), 269.

Miller, R., Glasby, J. and Dickinson, H. (2021) Integrated Health and Social Care in England: Ten Years On. *Int J Integr Care*, 21 (4), 6.

Minshall, C., Castle, D.J., Thompson, D.R., Pascoe, M., Cameron, J., McCabe, M.et al. (2020) A psychosocial intervention for stroke survivors and carers: 12-month outcomes of a randomized controlled trial. *Topics in Stroke Rehabilitation*, 27 (8), 563–576.

Mishal, M.H. (1988) Uncertainty in Illness. *Journal of Nursing Scholarship*, 20 (4), 225–232.

Mishal, M.H. (1990) Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship*, 22 (4), 252–262.

Modrego, P.J., Pina, M.A., Mar Fraj, M. and Llorens, N. (2000) Type, causes, and prognosis of stroke recurrence in the province of Teruel, Spain. A 5-year analysis. *Neurological Sciences*, 21 (6), 355–360.

Mofidi, R., Thomas, M., Wong, P.F., Bergin, A. and Young, G. (2018) Do Integrated Systems of Stroke Care Improve Symptom to Surgery Times in Patients with Symptomatic Carotid

Stenosis? A Single Centre Decision Tree Analysis. *European Journal of Vascular and Endovascular Surgery*, 56 (6), 784–792.

Mohammadi, E., Hassandoost, F. and Mozhdehipanah, H. (2022) Evaluation of the "partnership care model" on quality of life and activity of daily living in stroke patients: A randomized clinical trial. *Jpn J Nurs Sci*, 19 (1), e12448.

Mohan, K.M., Wolfe, C.D., Rudd, A.G., Heuschmann, P.U., Kolominsky-Rabas, P.L. and Grieve, A.P. (2011) Risk and cumulative risk of stroke recurrence: a systematic review and meta-analysis. *Stroke*, 42 (5), 1489–1494.

Montori, V.M., Ruissen, M.M., Hargraves, I.G., Brito, J.P. and Kunneman, M. (2023) Shared decision-making as a method of care. *BMJ Evid Based Med*, 28 (4), 213–217.

Morgan, A., Sinnott, S.J., Smeeth, L., Minassian, C. and Quint, J. (2021) Concordance in the recording of stroke across UK primary and secondary care datasets: a population-based cohort study. *BJGP Open*, 5 (2).

Morgan, D.L. (2014a) *Integrating Qualitative and Quantitative Methods: A Pragmatic Approach*. Sage Publications, Inc.

Morgan, D.L. (2014b) Pragmatism as a Paradigm for Social Research. *Qualitative Inquiry*, 20 (8), 1045–1053.

Morgan, M.A., Coates, M.J. and Dunbar, J.A. (2015) Using care plans to better manage multimorbidity. *Australas Med J*, 8 (6), 208–215.

Morgan, S. and Yoder, L.H. (2012) A Concept Analysis of Person-Centered Care. *Journal of Holistic Nursing*, 30 (1), 6–15.

Morone, G. and Pichiorri, F. (2023) Post-Stroke Rehabilitation: Challenges and New Perspectives. *J Clin Med*, 12 (2).

Morris, S., Hunter, R.M., Ramsay, A.I., Boaden, R., McKevitt, C., Perry, C.et al. (2014) Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis. *BMJ*, 349, g4757.

Morris, S., Ramsay, A.I.G., Boaden, R.J., Hunter, R.M., McKevitt, C., Paley, L.et al. (2019) Impact and sustainability of centralising acute stroke services in English metropolitan areas: retrospective analysis of hospital episode statistics and stroke national audit data. *BMJ*, 364, l1.

Morse, J.M. and Niehaus, L. (2009) *Mixed Method Design: Principles and Procedures*. Left Coast Press.

Mukherjee, D., Levin, R.L. and Heller, W. (2006) The cognitive, emotional, and social sequelae of stroke: psychological and ethical concerns in post-stroke adaptation. *Top Stroke Rehabil*, 13 (4), 26–35.

Mullis, M., Aquino, M.R.J., Kreit, E., Johnson, V., Grant, J., Blatchford, E.et al. (2024) Developing primary care services for stroke survivors: the Improving Primary Care After Stroke (IPCAS) research programme. *Programme Grants for Applied Research*, 12 (1).

Mun, G. and Shim, J. (2024) Stroke knowledge and health-promoting behaviors: Mediating effect of patient self-esteem. *Patient Education and Counseling*, 129, 108398.

Murray, C.D. and Harrison, B. (2004) The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disabil Rehabil*, 26 (13), 808–816.

Musa, M. and Aldiabat, K. (2024) RECONSIDERING THE USE OF POST-POSITIVIST PARADIGM IN SOCIAL SCIENCES: IS IT POSSIBLE? *European Journal of Education Studies*, 11 (7), 101–110.

Nadarajah, M. and Goh, H.-T. (2015) Post-stroke fatigue: a review on prevalence, correlates, measurement, and management. *Topics in Stroke Rehabilitation*, 22 (3), 208–220.

Nakibuuka, J., Sajatovic, M., Nankabirwa, J., Ssendikadiwa, C., Kalema, N., Kwizera, A.et al. (2016) Effect of a 72 Hour Stroke Care Bundle on Early Outcomes after Acute Stroke: A Non Randomised Controlled Study. *PLOS ONE*, 11 (5), e0154333.

National Heart Lung and Blood Institute. (2023) *What is a stroke?* [online]

Available at: https://www.nhlbi.nih.gov/health/stroke

[Accessed: Jun 2024]

National Institute for Health and Care Excellence (2022) NG128 Stroke and transient ischaemic attack in over 16: diagnosis and initial management. [online],

Available at: https://www.nice.org.uk/guidance/ng128/resources/stroke-and-transient-ischaemic-attack-in-over-16s-diagnosis-and-initial-management-pdf-66141665603269

[Accessed: Jul 2025]

National Institute for Health and Care Excellence (2023a) NG236 Stroke rehabilitation in adults. [online],

Available at: https://www.nice.org.uk/guidance/ng236/resources/stroke-rehabilitation-in-adults-pdf-66143899492549

[Accessed: Oct 2024]

National Institute for Health and Care Excellence. (2023b) *What are Strokes and TIAs?* [online]

Available at: https://cks.nice.org.uk/topics/stroke-tia/background-information/definition/

[Accessed: May 2024]

National Institute for Health and Care Excellence (2024) Stroke Rehabilitation in Adults. [online],

Available at: https://www.nice.org.uk/guidance/ng236/resources/stroke-rehabilitation-in-adults-pdf-66143899492549

[Accessed: Jul 2025]

National Research Council, U. (2004) A Theory of Germs. In: (ed.) *Science, Medicine, and Animals.* Washington DC: National Academies Press.

Natural Healers. (2024) *A History of Holistic Health* [online]

Available at: https://www.naturalhealers.com/blog/holistic-health-history/

[Accessed: May 2024]

Nayeri, N.D., Mohammadi, S., Razi, S.P. and Kazemnejad, A. (2014) Investigating the effects of a family-centered care program on stroke patients' adherence to their therapeutic regimens. *Contemporary Nurse*, 47 (1-2), 88–96.

Neves, G., Cole, T., Lee, J., Bueso, T., Shaw, C. and Montalvan, V. (2022) Demographic and institutional predictors of stroke hospitalization mortality among adults in the United States. *eNeurologicalSci*, 26, 100392.

Nguyen-Huynh, M.N., Klingman, J.G., Avins, A.L., Rao, V.A., Eaton, A., Bhopale, S.et al. (2018) Novel Telestroke Program Improves Thrombolysis for Acute Stroke Across 21 Hospitals of an Integrated Healthcare System. *Stroke*, 49 (1), 133–139.

NHS (2021a) National Stroke Service Model: Integrated Stroke Delivery Networks. [online], PAR406,

Available at: https://www.england.nhs.uk/wp-content/uploads/2021/05/national-stroke-service-model-integrated-stroke-delivery-networks-may-2021.pdf

[Accessed: July 2025]

NHS (2021b) Personalised Care and Support Planning. [online],

Available at: https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/

[Accessed: Mar 2024]

NHS. (2023a) *Overview: Transient ischaemic attack (TIA)* [online]

Available at: https://www.nhs.uk/conditions/transient-ischaemic-attack-tia/#:~:text=You%20should%20be%20referred%20to,the%20chances%20of%20that%20happening.

[Accessed: Sep 2024]

NHS. (2023b) *What are integrated care systems?* [online]

Available at: https://www.england.nhs.uk/integratedcare/what-is-integrated-care/

[Accessed: Mar 2023]

NHS. (2024) *Integrated care* [online]

Available at: https://www.hee.nhs.uk/our-work/integrated-care

[Accessed: Jan 2024]

NHS England (2019) The NHS Long Term Plan. [online],

Available at: https://webarchive.nationalarchives.gov.uk/ukgwa/20230418155402/https:/www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

[Accessed: Mar 2023]

NHS England. (2024) *Hospital admissions for strokes rise by 28% since 2004 – as NHS urges the public to 'Act FAST'* [online]

Available at: https://www.england.nhs.uk/2024/11/hospital-admissions-for-strokes-rise-by-28-since-2004-as-nhs-urges-the-public-to-act-fast/

[Accessed: July 2025]

NHS England (2025) Fit for The Future: 10 Year Health Plan for England. [online],

Available at: https://www.england.nhs.uk/long-term-plan/

[Accessed: Oct 2025]

NHS England Digital. (2025) *Uses of PROMS* [online]

Available at: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/patient-reported-outcome-measures-proms/a-guide-to-proms-methodology/uses-of-proms

[Accessed: Sep 2023]

NHS Health Education England. (2024) *Integrated care* [online]

Available at: https://www.hee.nhs.uk/our-work/integrated-care#:~:text=It%20is%20care%20that%20is,to%20achieve%20the%20best%20outcomes.

[Accessed: January]

NHS Rightcare (2021) RightCare Pathway: Stroke. [online],

Available at: https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2017/09/stroke-pathway.pdf

[Accessed: Mar 2024]

Nichols-Larsen, D.S., Clark, P.C., Zeringue, A., Greenspan, A. and Blanton, S. (2005) Factors Influencing Stroke Survivors' Quality of Life During Subacute Recovery. *Stroke*, 36 (7), 1480–1484.

Nici, L. and ZuWallack, R. (2018) Integrated Care in Chronic Obstructive Pulmonary Disease and Rehabilitation. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, 15 (3), 223–230.

Niewada, M. and Michel, P. (2016) Lifestyle modification for stroke prevention: facts and fiction. *Curr Opin Neurol*, 29 (1), 9–13.

Nightingale, F. (1859) Observation of the Sick. In: (ed.) *Notes on Nursing: What it is and what it is not.* pp. 105–126.

Nolte, E. and McKee, M. (2008) *Caring for People with Chronic Conditions: A Health System Perspective*. Open University Press.

Norrving, B., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A.et al. (2018) Action Plan for Stroke in Europe 2018–2030. *European Stroke Journal*, 3 (4), 309–336.

Northwestern Medicine. (2025) *Life after Stroke* [online]

Available at: https://www.nm.org/conditions-and-care-areas/neurosciences/comprehensive-stroke-centers/life-after-stroke#:~:text=Recovery%20facts,impairments%20that%20require%20special%20care

[Accessed: July 2025]

Ntaios, G. and Lip, G.Y. (2016) Difficult situations in anticoagulation after stroke: between Scylla and Charybdis. *Curr Opin Neurol*, 29 (1), 42–48.

Nursing and Midwifery Council. (2024) *Seeing the Whole Person Supports Better Care* [online]

Available at: https://www.nmc.org.uk/standards/guidance/holistic-care/#:~:text=It%20empowers%20us%20to%20do,assess%20whether%20medication%20is%20working.

[Accessed: Sep 2025]

Nyimbili, F. and Nyimbili, L. (2024) Types of Purposive Sampling Techniques with Their Examples and Application in Qualitative Research Studies. *British Journal of Multidisciplinary and Advanced Studies*, 5 (1), 90–99.

Nys, G.M., van Zandvoort, M.J., de Kort, P.L., Jansen, B.P., de Haan, E.H. and Kappelle, L.J. (2007) Cognitive disorders in acute stroke: prevalence and clinical determinants. *Cerebrovasc Dis*, 23 (5-6), 408–416.

O'Callaghan, G., Fahy, M., Murphy, P., Langhorne, P., Galvin, R. and Horgan, F. (2022) Effectiveness of interventions to support the transition home after acute stroke: a systematic review and meta-analysis. *BMC Health Serv Res*, 22 (1), 1095.

O'Sullivan, M.J., Li, X., Galligan, D. and Pendlebury, S.T. (2023) Cognitive Recovery After Stroke: Memory. *Stroke*, 54 (1), 44–54.

Obesity Medicine Association. (2023) *The Obesity Paradox Explained: Is It Still Valid?* [online]

Available at: https://obesitymedicine.org/blog/the-obesity-paradox/

[Accessed: Oct 2025]

Olaiya, M.T., Cadilhac, D.A., Kim, J., Nelson, M.R., Srikanth, V.K., Andrew, N.E.et al. (2017a) Long-term unmet needs and associated factors in stroke or TIA survivors: An observational study. *Neurology*, 89 (1), 68–75.

Olaiya, M.T., Kim, J., Nelson, M.R., Srikanth, V.K., Bladin, C.F., Gerraty, R.P.et al. (2017b) Effectiveness of a shared team approach between nurses and doctors for improved risk factor management in survivors of stroke: a cluster randomized controlled trial. *Eur J Neurol*, 24 (7), 920–928.

Olmos-Vega, F.M., Stalmeijer, R.E., Varpio, L. and Kahlke, R. (2023) A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 45 (3), 241–251.

Ong, C.-T., Sung, S.-F., Wong, Y.-S., Wu, C.-S., Hsu, Y.-C., Su, Y.-H.et al. (2016) Risk Factors for In-Hospital Mortality among Ischemic Stroke Patients in Southern Taiwan. *International Journal of Gerontology*, 10 (2), 86–90.

Open University (2016) Introduction to positivist, interpretivism & critical theory. [online], Available at: https://oro.open.ac.uk/49591/17/49591ORO.pdf [Accessed: Aug 2025]

Oros, R., Popescu, C., Iova, C., Mihancea, P. and Iova, S. (2016) The impact of cognitive impairment after stroke on activities of daily living. *Human & Veterinary Medicine*, 8 (1), 41–44.

Otieno, P., Agyemang, C., Wao, H., Wambiya, E., Ng'oda, M., Mwanga, D.et al. (2023) Effectiveness of integrated chronic care models for cardiometabolic multimorbidity in sub-Saharan Africa: a systematic review and meta-analysis. *BMJ Open*, 13 (6), e073652.

Ouwens, M., Hulscher, M., Hermens, R., Faber, M., Marres, H., Wollersheim, H.et al. (2009) Implementation of integrated care for patients with cancer: a systematic review of interventions and effects. *International Journal for Quality in Health Care*, 21 (2), 137–144.

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D.et al. (2021) The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, 372, n71.

Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N. and Hoagwood, K. (2015) Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy Ment Health*, 42 (5), 533–544.

Palstam, A., Sjödin, A. and Sunnerhagen, K.S. (2019) Participation and autonomy five years after stroke: A longitudinal observational study. *PLOS ONE*, 14 (7), e0219513.

Pan, B., Jin, X., Jun, L., Qiu, S., Zheng, Q. and Pan, M. (2019) The relationship between smoking and stroke: A meta-analysis. *Medicine (Baltimore)*, 98 (12), e14872.

Pang, P.C.P., Cheung, D.S.K. and Chiang, V.C.L. (2022) Visual Art Intervention for People With Stroke on Holistic Well-Being: A Critical Review. *Journal of Holistic Nursing*, 40 (2), 123–145.

Panhwar, A.H., Ansari, S. and Shah, A.A. (2017) Post-Positivism: An effective paradigm for social and educational research. *International Research Journal of Arts and Humanities*, 45 (45), 253–259.

Papathanasiou, I. (2013) Holistic Nursing Care: Theories and Perspectives. *American Journal of Nursing Science*, 2 (1), 1.

Park, C.L., Zlateva, I. and Blank, T.O. (2009) Self-identity after cancer: "survivor", "victim", "patient", and "person with cancer". *J Gen Intern Med*, 24 Suppl 2 (Suppl 2), S430–435.

Park, Y.S., Konge, L. and Artino, A.R., Jr. (2020) The Positivism Paradigm of Research. *Acad Med*, 95 (5), 690–694.

Patel, A., Berdunov, V., Quayyum, Z., King, D., Knapp, M. and Wittenberg, R. (2019) Estimated societal costs of stroke in the UK based on a discrete event simulation. *Age and Ageing*, 49 (2), 270–276.

Patel, A., Berdunov, V., Quayyum, Z., King, D., Knapp, M. and Wittenberg, R. (2020) Estimated societal costs of stroke in the UK based on a discrete event simulation. *Age and Ageing*, 49 (2), 270–276.

Patel, I. (2021) Integrated respiratory care. *Clinics in Integrated Care*, 6, 100053.

Patel, S. (2015) The research paradigm - methodology, epistomology and ontology - explained in simple language. [online],

Available at: https://salmapatel.co.uk/academia/the-research-paradigm-methodology-epistemology-and-ontology-explained-in-simple-language/

[Accessed: Aug 2025]

Patra, J., Taylor, B., Irving, H., Roerecke, M., Baliunas, D., Mohapatra, S.et al. (2010) Alcohol consumption and the risk of morbidity and mortality for different stroke types - a systematic review and meta-analysis. *BMC Public Health*, 10 (1), 258.

Pearce, G., Pinnock, H., Epiphaniou, E., Parke, H.L., Heavey, E., Griffiths, C.J.et al. (2015) Experiences of Self-Management Support Following a Stroke: A Meta-Review of Qualitative Systematic Reviews. *PLOS ONE*, 10 (12), e0141803.

Pedapati, R., Bhatia, R., Shakywar, M., Gupta, A., Vishnubhatla, S., Srivastava, M.V.P.et al. (2021a) Educating Caregivers to Reduce Complications and Improve Outcomes of Stroke Patients (ECCOS)-A Cluster-Randomized Trial. *JOURNAL OF STROKE & CEREBROVASCULAR DISEASES*, 30 (9).

Pedapati, R., Bhatia, R., Shakywar, M., Gupta, A., Vishnubhatla, S., Srivastava, M.V.P.et al. (2021b) Educating Caregivers to Reduce Complications and Improve Outcomes of Stroke Patients (ECCOS) - A Cluster-Randomized Trial. *J Stroke Cerebrovasc Dis*, 30 (9), 105966.

Pel-Littel, R.E., Snaterse, M., Teppich, N.M., Buurman, B.M., van Etten-Jamaludin, F.S., van Weert, J.C.M.et al. (2021) Barriers and facilitators for shared decision making in older patients with multiple chronic conditions: a systematic review. *BMC Geriatr*, 21 (1), 112.

Peng, L.-N., Lu, W.-H., Liang, C.-K., Chou, M.-Y., Chung, C.-P., Tsai, S.-L.et al. (2017) Functional Outcomes, Subsequent Healthcare Utilization, and Mortality of Stroke Postacute Care Patients in Taiwan: A Nationwide Propensity Score-matched Study. *Journal of the American Medical Directors Association*, 18 (11), 990.e997–990.e912.

Peterson-Burch, F., Reuter-Rice, K. and Barr, T.L. (2017) Rethinking Recovery. *Holistic Nursing Practice*, 31 (1), 3–6.

Pett, W.B., A. (2022) The state of integrated care systems 2021/22. *NHS Confederation*.

Pham, L.T.M. (2018) Qualitative Approach to Research: A review of advantages and disadvantages of three paradigms: positivism, interpretivism and critical enquiry. [online],

Available at: https://www.researchgate.net/profile/Lan-Pham-3/publication/324486854_A_Review_of_key_paradigms_positivism_interpretivism_and_critical_inquiry/links/5acffa880f7e9b18965cd52f/A-Review-of-key-paradigms-positivism-interpretivism-and-critical-inquiry.pdf

[Accessed: Aug 2025]

Pieper, D., Heß, S. and Faggion, C.M. (2021) A new method for testing reproducibility in systematic reviews was developed, but needs more testing. *BMC Medical Research Methodology*, 21 (1), 157.

Pietrzykowski, T. and Smilowska, K. (2021) The reality of informed consent: empirical studies on patient comprehension—systematic review. *Trials*, 22 (1), 57.

Pillai, A.A., Tadi, P. and Kanmathareddy, A. (2023) Cardioembolic Stroke. [online], Available at: https://www.ncbi.nlm.nih.gov/books/NBK536990/ [Accessed: July 2025]

Pindus, D.M., Mullis, R., Lim, L., Wellwood, I., Rundell, A.V., Abd Aziz, N.A.et al. (2018) Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services – A systematic review and meta-ethnography. *PLOS ONE*, 13 (2), e0192533.

Pohjasvaara, T., Vataja, R., Leppavuori, A., Kaste, M. and Erkinjuntti, T. (2001) Depression is an independent predictor of poor long-term functional outcome post-stroke. *Eur J Neurol*, 8 (4), 315–319.

Pollock, A., Baer, G., Campbell, P., Choo, P.L., Forster, A., Morris, J.et al. (2014a) Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database Syst Rev*, 2014 (4), CD001920.

Pollock, A., Baer, G., Campbell, P., Choo, P.L., Forster, A., Morris, J.et al. (2014b) Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database Syst Rev* (4), CD001920.

Pollock, A., Gray, C., Culham, E., Durward, B.R. and Langhorne, P. (2014c) Interventions for improving sit-to-stand ability following stroke. *Cochrane Database Syst Rev* (5), CD007232.

Pomey, M.-P., Schaad, B., Lasserre-Moutet, A., Böhme, P. and Jackson, M. (2024) Towards a New Integrated Model for Taking Into Account the Experiential Knowledge of People With Chronic Diseases, Integrating Mediation, Therapeutic Education and Partnership: The Expanded Chronic Care Patient–Professional Partnership Model. *Health Expectations*, 27 (5), e70054.

Poomalai, G., Prabhakar, S. and Sirala Jagadesh, N. (2023) Functional Ability and Health Problems of Stroke Survivors: An Explorative Study. *Cureus*, 15 (1), e33375.

Popper, K. (1935) *Logik der Forschung*. Vienna: Verlag von Julius Springer.

Prestgaard, E., Mariampillai, J., Engeseth, K., Erikssen, J., Bodegård, J., Liestøl, K.et al. (2020) Change in Body Weight and Long-Term Risk of Stroke and Death in Healthy Men. *Stroke*, 51 (5), 1435–1441.

Preston, K., Reise, S., Li Cai, n. and Hays, R.D. (2011) Using the Nominal Response Model to Evaluate Response Category Discrimination in the PROMIS Emotional Distress Item Pools. *Educational and Psychological Measurement*, 71 (3), 523–550.

Prior, A., Vestergaard, C.H., Vedsted, P., Smith, S.M., Virgilsen, L.F., Rasmussen, L.A.et al. (2023) Healthcare fragmentation, multimorbidity, potentially inappropriate medication, and mortality: a Danish nationwide cohort study. *BMC Medicine*, 21 (1), 305.

Proot, I.M., Crebolder, H.F., Abu-Saad, H.H., Macor, T.H. and Ter Meulen, R.H. (2000) Stroke patients' needs and experiences regarding autonomy at discharge from nursing home. *Patient Educ Couns*, 41 (3), 275–283.

Prust, M.L., Saylor, D., Zimba, S., Sarfo, F.S., Shrestha, G.S., Berkowitz, A.et al. (2022) Inpatient Management of Acute Stroke of Unknown Type in Resource-Limited Settings. *Stroke*, 53 (3), e108–e117.

Quinn, T.J., Dawson, J. and Walters, M. (2008) Dr John Rankin; his life, legacy and the 50th anniversary of the Rankin Stroke Scale. *Scott Med J*, 53 (1), 44–47.

Quiñones-Ossa, G.A., Lobo, C., Garcia-Ballestas, E., Florez, W.A., Moscote-Salazar, L.R. and Agrawal, A. (2021) Obesity and Stroke: Does the Paradox Apply for Stroke? *Neurointervention*, 16 (1), 9–19.

Radloff, L.S. (1977) The CES-D Scale:A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, 1 (3), 385–401.

Rafsten, L.D., Anna Nordin, Asa Björkdahl, Ann Lundgren-Nilsson, Asa Larsson, Maria E. H. Sunnerhagen, Katharina S. (2019) Gothenburg Very Early Supported Discharge study (GOTVED): a randomised controlled trial investigating anxiety and overall disability in the first year after stroke. *BMC neurology*, 19 (1), 277.

Rajashekar, D. and Liang, J.W. (2023) Intracerebral Hemorrhage. [online],

Available at: https://www.ncbi.nlm.nih.gov/books/NBK553103/

[Accessed: July 2025]

Ramsay, A.I., Morris, S., Hoffman, A., Hunter, R.M., Boaden, R., McKevitt, C.et al. (2015) Effects of Centralizing Acute Stroke Services on Stroke Care Provision in Two Large Metropolitan Areas in England. *Stroke*, 46 (8), 2244–2251.

Ranasinghe, V.S., Pathirage, M. and Gawarammana, I.B. (2023) Predictors of in-hospital mortality in stroke patients. *PLOS Glob Public Health*, 3 (2), e0001278.

Randolph, W. and Viswanath, K. (2004) Lessons Learned from Public Health Mass Media Campaigns: Marketing Health in a Crowded Media World*. *Annual Review of Public Health*, 25 (Volume 25, 2004), 419–437.

Rashidi, A., Whitehead, L., Newson, L., Astin, F., Gill, P., Lane, D.A.et al. (2021) The Role of Acceptance and Commitment Therapy in Cardiovascular and Diabetes Healthcare: A Scoping Review. *Int J Environ Res Public Health*, 18 (15).

Rasmussen, R.S., Østergaard, A., Kjær, P., Skerris, A., Skou, C., Christoffersen, J.et al. (2016) Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: a randomised controlled trial. *Clinical Rehabilitation*, 30 (3), 225–236.

Ratner, R.K. and Riis, J. (2014) Communicating science-based recommendations with memorable and actionable guidelines. *Proceedings of the National Academy of Sciences*, 111 (supplement_4), 13634–13641.

Redman-MacLaren, M., Mills, J. and Tommbe, R. (2014) Interpretive focus groups: a participatory method for interpreting and extending secondary analysis of qualitative data. *Glob Health Action*, 7, 25214.

Reeves, M.J., Fritz, M.C., Woodward, A.T., Hughes, A.K., Coursaris, C.K., Swierenga, S.J.et al. (2019) Michigan Stroke Transitions Trial. *Circulation. Cardiovascular quality and outcomes*, 12 (7), e005493.

Rehani, B., Ammanuel, S.G., Zhang, Y., Smith, W., Cooke, D.L., Hetts, S.W.et al. (2020) A New Era of Extended Time Window Acute Stroke Interventions Guided by Imaging. *Neurohospitalist*, 10 (1), 29–37.

Renemane, L. and Vrublevska, J. (2021) Chapter 17 - Hamilton depression rating scale: Uses and applications. In: Martin, C. R., Hunter, L.-A., Patel, V. B., Preedy, V. R. and Rajendram, R. (ed.) *The Neuroscience of Depression.* Academic Press. pp. 175–183.

Richard, V. (2020) *How to choose a qualitative research design* [online]

Available at: https://dissertationbydesign.com/how-to-choose-a-qualitative-research-design/

[Accessed: Mar 2025]

Ringelstein, E.B., Chamorro, A., Kaste, M., Langhorne, P., Leys, D., Lyrer, P.et al. (2013) European Stroke Organisation recommendations to establish a stroke unit and stroke center. *Stroke*, 44 (3), 828–840.

Roaldsen, M.B., Jusufovic, M., Berge, E. and Lindekleiv, H. (2021a) Endovascular thrombectomy and intra-arterial interventions for acute ischaemic stroke. *Cochrane Database Syst Rev*, 6, CD007574.

Roaldsen, M.B., Jusufovic, M., Berge, E. and Lindekleiv, H. (2021b) Endovascular thrombectomy and intra-arterial interventions for acute ischaemic stroke. *Cochrane Database Syst Rev*, 6 (6), CD007574.

Robinson, R.G. and Jorge, R.E. (2016) Post-Stroke Depression: A Review. *Am J Psychiatry*, 173 (3), 221–231.

Robinson, T.G., Reid, A., Haunton, V.J., Wilson, A. and Naylor, A.R. (2013) The face arm speech test: does it encourage rapid recognition of important stroke warning symptoms? *Emerg Med J*, 30 (6), 467–471.

Rodgers, H., Howel, D., Bhattarai, N., Cant, R., Drummond, A., Ford, G.A.et al. (2019) Evaluation of an Extended Stroke Rehabilitation Service (EXTRAS): A Randomized Controlled Trial and Economic Analysis. *Stroke*, 50 (12), 3561–3568.

Romiti, G.F., Pastori, D., Rivera-Caravaca, J.M., Ding, W.Y., Gue, Y.X., Menichelli, D.et al. (2021) Adherence to the 'Atrial Fibrillation Better Care' Pathway in Patients with Atrial Fibrillation: Impact on Clinical Outcomes—A Systematic Review and Meta-Analysis of 285,000 Patients. *Thrombosis and Haemostasis*.

Romiti, G.F., Pastori, D., Rivera-Caravaca, J.M., Ding, W.Y., Gue, Y.X., Menichelli, D.et al. (2022) Adherence to the 'Atrial Fibrillation Better Care' Pathway in Patients with Atrial Fibrillation: Impact on Clinical Outcomes—A Systematic Review and Meta-Analysis of 285,000 Patients. *Thrombosis and Haemostasis*, 122 (03), 406–414.

Rosner, J., Reddy, V. and Lui, F. (2023) Neuroanatomy, Circle of Willis. [online],

Available at: https://www.ncbi.nlm.nih.gov/books/NBK534861/

[Accessed: July 2025]

Rossis, C., Michail, K.A., Middleton, N., Karanikola, M., Papathanassoglou, E. and Mpouzika, M. (2024) Knowledge on Stroke Recognition and Management among Emergency Department Healthcare Professionals in the Republic of Cyprus. *Healthcare*, 12 (1), 77.

Rossman, G.B. and Rallis, S.F. (2017) The Researcher as Learner. In: (ed.) *An Introduction to Qualitative Research: Learning in the Field.* Fourth ed. Available at]

Rost, N.S., Brodtmann, A., Pase, M.P., van Veluw, S.J., Biffi, A., Duering, M.et al. (2022) Post-Stroke Cognitive Impairment and Dementia. *Circulation Research*, 130 (8), 1252–1271.

Rowe, F.J., Wright, D., Brand, D., Jackson, C., Harrison, S., Maan, T.et al. (2013) A prospective profile of visual field loss following stroke: prevalence, type, rehabilitation, and outcome. *Biomed Res Int*, 2013, 719096.

Royal College of Surgeons, o.E. (2023) Shared Decision Making: an essential step in optimal patient care. [online],

Available at: https://www.rcsed.ac.uk/news-resources/rcsed-blog/2023/september/shared-decision-making-an-essential-step-in-optimal-patient-care

[Accessed: Sep 2024]

Ryan, A.B. (2006) Post-Positivist Approaches to Research. In: (ed.) *Researching and Writing Your Thesis: A Guide for Postgraduate Students.* MACE: Maynooth Adult and Community Education. pp. 12–26.

Ryan, G. (2018) Introduction to positivism, interpretivism and critical theory. *Nurse Res*, 25 (4), 14–20.

Saal, S., Becker, C., Lorenz, S., Schubert, M., Kuss, O., Stang, A.et al. (2015) Effect of a stroke support service in Germany: a randomized trial. *Topics in Stroke Rehabilitation*, 22 (6), 429–436.

Sagris, D., Lip, G.Y.H., Korompoki, E., Ntaios, G. and Vemmos, K. (2024) Adherence to an integrated care pathway for stroke is associated with lower risk of major cardiovascular events: A report from the Athens Stroke Registry. *European Journal of Internal Medicine*, 122, 61–67.

Sahely, A., Giles, D., Sintler, C., Soundy, A. and Rosewilliam, S. (2023) Self-management interventions to improve mobility after stroke: an integrative review. *Disabil Rehabil*, 45 (1), 9–26.

Saini, V., Guada, L. and Yavagal, D.R. (2021) Global Epidemiology of Stroke and Access to Acute Ischemic Stroke Interventions. *Neurology*, 97 (20 Supplement 2), S6–S16.

Salehi, V., Veitch, B., Smith, D. and McCarthy, J. (2024) Understanding the complexity of a stroke care system through functional modelling and analysis. *Human Factors in Healthcare*, 6, 100084.

Salter, K., Hellings, C., Foley, N. and Teasell, R. (2008) The experience of living with stroke: a qualitative meta-synthesis. *J Rehabil Med*, 40 (8), 595–602.

Samsa, G.P., Bian, J., Lipscomb, J. and Matchar, D.B. (1999) Epidemiology of recurrent cerebral infarction: a medicare claims-based comparison of first and recurrent strokes on 2-year survival and cost. *Stroke*, 30 (2), 338–349.

Sanders, C.B., Knisely, K., Edrissi, C., Rathfoot, C., Poupore, N., Wormack, L.et al. (2021) Obstructive sleep apnea and stroke severity: Impact of clinical risk factors. *Brain Circ*, 7 (2), 92–103.

Sataloff, R.T., Bush, M.L., Chandra, R., Chepeha, D., Rotenberg, B., Fisher, E.W.et al. (2021) Systematic and other reviews: criteria and complexities. *J Otolaryngol Head Neck Surg*, 50 (1), 41.

Satylganova, A., Tello, J. and Barbazza, E. (2016) Integrated Care Models: An Overview. *World Health Organization* [online],

Available at: https://www.researchgate.net/publication/315493946_Integrated_care_models_an_overview_Copenhagen_WHO_Regional_Office_for_Europe_2016

[Accessed: Sep 2023]

Saunders, D.H., Greig, C.A. and Mead, G.E. (2014) Physical Activity and Exercise After Stroke. *Stroke*, 45 (12), 3742–3747.

Saunders, D.H., Sanderson, M., Hayes, S., Johnson, L., Kramer, S., Carter, D.et al. (2020a) Physical Fitness Training for Patients With Stroke. *Stroke*, 51 (11), e299–e300.

Saunders, D.H., Sanderson, M., Hayes, S., Johnson, L., Kramer, S., Carter, D.D.et al. (2020b) Physical fitness training for stroke patients. *Cochrane Database Syst Rev*, 3, CD003316.

Saver, J.L. (2006) Time Is Brain—Quantified. *Stroke*, 37 (1), 263–266.

Sbampato dos Santos, J.V., Aparecida de Melo, E., Lopes da Silveira Junior, J., Nascimento Vasconcelos, N., de Castro Lima, M. and Moreira Damázio, L.C. (2017) THE EFFECTS OF NURSING TRAINING ON THE EVALUATION OF PATIENTS WITH CEREBROVASCULAR ACCIDENT. *Journal of Nursing UFPE / Revista de Enfermagem UFPE*, 11 (5), 1763–1768.

Schmidt, R., Geisler, D., Urban, D., Pries, R., Franzisket, C., Voigt, C.et al. (2023) Stroke survivors' preferences on assessing patient-reported outcome measures. *J Patient Rep Outcomes*, 7 (1), 124.

Schutz, A. (1932) *Der sinnhafte Aufbau der sozialen Welt: Eine Einleitung in die verstehende Soziologie.* Vienna: Julius Springer.

Schutz, A. (1967) *The Phenomenology of the Social World*. Northwestern University Press.

Schutz, A. and Luckmann, T. (1979) *Strukturen der Lebenswelt*. Frankfurt: Suhrkamp.

Schwarzbach, C.J., Eichner, F.A., Rücker, V., Hofmann, A.L., Keller, M., Audebert, H.J.et al. (2023) The structured ambulatory post-stroke care program for outpatient aftercare in patients with ischaemic stroke in Germany (SANO): an open-label, cluster-randomised controlled trial. *Lancet Neurol*, 22 (9), 787–799.

Scottish Independent Advocacy Alliance (2021) Stroke Advocacy Stories. [online],

Available at: https://www.siaa.org.uk/wp-content/uploads/2021/02/SIAA_Stroke_Advocacy_Stories.pdf

[Accessed: Sep 2024]

Sentinel Stroke National Audit Programme [SSNAP] (2022) The Road to Recovery: The Ninth SSNAP Annual Report. [online],

Available at: https://www.strokeaudit.org/Documents/National/Clinical/Apr2021Mar2022/Apr2021Mar2022-AnnualReport.aspx

[Accessed: Sep 2024]

Sentinel Stroke National Audit Programme [SSNAP] (2023) National Clinical Guideline for Stroke for the United Kingdom and Ireland. [online],

Available at: https://www.strokeguideline.org/

[Accessed: July 2025]

Sentinel Stroke National Audit Programme [SSNAP] (2024) State of the Nation Report 2024. [online],

Available at: https://www.hqip.org.uk/resource/ssnap-nov24/

[Accessed: Mar 2025]

Shaheen, N., Shaheen, A., Ramadan, A., Hefnawy, M.T., Ramadan, A., Ibrahim, I.A.et al. (2023) Appraising systematic reviews: a comprehensive guide to ensuring validity and reliability. *Frontiers in Research Metrics and Analytics*, Volume 8 - 2023.

Shahid, J., Kashif, A. and Shahid, M.K. (2023) A Comprehensive Review of Physical Therapy Interventions for Stroke Rehabilitation: Impairment-Based Approaches and Functional Goals. *Brain Sci*, 13 (5).

Shannon-Baker, P. (2016) Making Paradigms Meaningful in Mixed Methods Research. *Journal of Mixed Methods Research*, 10 (4), 319–334.

Sharma, M., Hart, R.G., Connolly, S.J., Bosch, J., Shestakovska, O., Ng, K.K.H.et al. (2019) Stroke Outcomes in the COMPASS Trial. *Circulation*, 139 (9), 1134–1145.

Sharma, S. and Culebras, A. (2016) Sleep apnoea and stroke. *BMJ*, 1 (4), 185–191.

Shaw, L., Bhattarai, N., Cant, R., Drummond, A., Ford, G.A., Forster, A.et al. (2020) An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT. *HEALTH TECHNOLOGY ASSESSMENT*, 24 (24), 1–+.

Shepperd, S., Lewin, S., Straus, S., Clarke, M., Eccles, M.P., Fitzpatrick, R.et al. (2009) Can we systematically review studies that evaluate complex interventions? *PLoS Med*, 6 (8), e1000086.

Shire, F., Kasim, Z., Alrukn, S. and Khan, M. (2017) Stroke awareness among Dubai emergency medical service staff and impact of an educational intervention. *BMC Research Notes*, 10 (1), 255.

Shrestha, S., Coy, S. and Bekelis, K. (2017) Oral Antiplatelet and Anticoagulant Agents in the Prevention and Management of Ischemic Stroke. *Curr Pharm Des*, 23 (9), 1377–1391.

Sit, J.W.H., Chan, A.W.H., So, W.K.W., Chan, C.W.H., Chan, A.W.K., Chan, H.Y.L.et al. (2017) Promoting Holistic Well-Being in Chronic Stroke Patients Through Leisure Art-Based Creative Engagement. *Rehabilitation Nursing*, 42 (2), 58–66.

Ski, C., Cartledge, S., Foldager, D., Thompson, D., Fredericks, S., Ekman, I.et al. (2023) Integrated care in cardiovascular disease: a statement of the Association of Cardiovascular Nursing and Allied Professions of the European Society of Cardiology. *European Journal of Cardiovascular Nursing*, 22.

Slade, M. and Longden, E. (2015) Empirical evidence about recovery and mental health. *BMC Psychiatry*, 15 (1), 285.

Smith, J.A., Flowers, P., Larkin, M. (2022) *Interpretative Phenomenological Analysis: Theory, Method and Research*. 2nd ed. Sage.

Smith, J.A. and Osborn, M. (2015) Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *Br J Pain*, 9 (1), 41–42.

Smits, G., van Doorn, S., Bots, M.L. and Hollander, M. (2023) Cardiovascular risk reduction with integrated care: results of 8 years follow up. *BMC Prim Care*, 24 (1), 66.

Soo, W.K., Yin, V., Crowe, J., Lane, H., Steer, C.B., Dārziņš, P.et al. (2023) Integrated care for older people with cancer: a primary care focus. *The Lancet Healthy Longevity*, 4 (6), e243–e245.

Spatz, E.S., Elwyn, G., Moulton, B.W., Volk, R.J. and Frosch, D.L. (2017) Shared decision making as part of value based care: New U.S. policies challenge our readiness. *Z Evid Fortbild Qual Gesundhwes*, 123-124, 104–108.

Stacey, D., Bennett, C.L., Barry, M.J., Col, N.F., Eden, K.B., Holmes-Rovner, M.et al. (2011) Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* (10), CD001431.

Stacey, D., Lewis, K.B., Smith, M., Carley, M., Volk, R., Douglas, E.E.et al. (2024) Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*, 1 (1), Cd001431.

Starfield, B. (2011) Is patient-centered care the same as person-focused care? *Perm J*, 15 (2), 63–69.

Staub, F. and Bogousslavsky, J. (2001) Fatigue after stroke: a major but neglected issue. *Cerebrovasc Dis*, 12 (2), 75–81.

Stern, A.F. (2014) The Hospital Anxiety and Depression Scale. *Occupational Medicine*, 64 (5), 393–394.

Sterne, J.A., Hernan, M.A., Reeves, B.C., Savovic, J., Berkman, N.D., Viswanathan, M.et al. (2016) ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ*, 355, i4919.

Sterne, J.A.C., Savovic, J., Page, M.J., Elbers, R.G., Blencowe, N.S., Boutron, I.et al. (2019) RoB 2: a revised tool for assessing risk of bias in randomised trials. *BMJ*, 366, l4898.

Stewart, D.W. and Shamdasani, P.N. (2015) *Focus Groups*. Thousand Oaks, California, USA: Sage.

Stinear, C.M., Lang, C.E., Zeiler, S. and Byblow, W.D. (2020) Advances and challenges in stroke rehabilitation. *Lancet Neurol*, 19 (4), 348–360.

Stray, K., Wibe, T., Debesay, J. and Bye, A. (2024) Older adults' perceptions and experiences of interprofessional communication as part of the delivery of integrated care in the primary healthcare sector: a meta-ethnography of qualitative studies. *BMC Geriatr*, 24 (1), 146.

Stroebe, M. and Schut, H. (1999) The dual process model of coping with bereavement: rationale and description. *Death Stud*, 23 (3), 197–224.

Stroke Alliance for Europe (2020) 5.6 Rehabilitation After Dishcarge from Hospital. *The Burden of Stroke in Europe* [online],

Available at: https://strokeeurope.eu/index/rehabilitation-and-long-term-support/5-6-rehabilitation-after-discharge-from-hospital/

[Accessed: July 2025]

Stroke Association (2012a) *My stroke victory: inspiring stories from stroke survivors and their families*.

Stroke Association (2012b) *Short changed by stroke: The finincial impact of stroke on people of working age*.

Stroke Association. (2023a) *Feelings of grief after stroke* [online]

Available at: https://www.stroke.org.uk/blog/feelings-grief-after-stroke

[Accessed: Sep 2024]

Stroke Association (2023b) National Guidance for an Integrated Life After Stroke Support Model. [online],

Available at: https://www.stroke.org.uk/sites/default/files/policy/ilass_may_2023_-_final_version_nhsesa_v2.pdf

[Accessed: Nov 2025]

Stroke Association (2023c) *Stroke News*. United Kingdom.

Sulch, D., Melbourn, A., Perez, I. and Kalra, L. (2002) Integrated care pathways and quality of life on a stroke rehabilitation unit. *Stroke*, 33 (6), 1600–1604.

Sullivan-Taylor, P., Suter, E., Laxton, S., Oelke, N.D. and Park, E. (2022) Integrated People-Centred Care in Canada - Policies, Standards, and Implementation Tools to Improve Outcomes. *Int J Integr Care*, 22 (1), 8.

Sunderji, N., Ion, A., Ghavam-Rassoul, A. and Abate, A. (2017) Evaluating the Implementation of Integrated Mental Health Care: A Systematic Review to Guide the Development of Quality Measures. *Psychiatric Services*, 68 (9), 891–898.

Suter, E., Oelke, N.D., Adair, C.E. and Armitage, G.D. (2009) Ten key principles for successful health systems integration. *Healthc Q*, 13 Spec No (Spec No), 16–23.

Swanson, J.O.M., Tron Anders (2019) Comparisons of readmissions and mortality based on post-discharge ambulatory follow-up services received by stroke patients discharged home: a register-based study. *Bmc Health Services Research*, 19 (1), 4.

Synnot, A., Chau, M., Pitt, V., O'Connor, D., Gruen, R.L., Wasiak, J.et al. (2017) Interventions for managing skeletal muscle spasticity following traumatic brain injury. *Cochrane Database Syst Rev*, 11 (11), Cd008929.

Szapary, L., Tornyos, D., Kupo, P., Lukacs, R., El Alaoui El Abdallaoui, O. and Komocsi, A. (2022) Combination of antiplatelet and anticoagulant therapy, component network meta-analysis of randomized controlled trials. *Front Cardiovasc Med*, 9, 1036609.

Szyjka, S. (2012) Understanding Research Paradigms: Trends in Sciende Education Research. *Problems of Education in the 21st Century*, 43, 110–118.

Tan, G.D., Kozlowska, O. and Rea, R.D. (2021) Integrated care and diabetes: challenges, principles and opportunities. *Clinics in Integrated Care*, 4, 100037.

Tan, J., Ramazanu, S., Liaw, S.Y. and Chua, W.L. (2022) Effectiveness of Public Education Campaigns for Stroke Symptom Recognition and Response in Non-Elderly Adults: A Systematic Review and Meta-Analysis. *Journal of Stroke and Cerebrovascular Diseases*, 31 (2).

Tan, S.Y.J., Lee, S.C., Rusli, K.D.B., Woo, B.F.Y., Ang, S.G.M., Zhou, W.et al. (2025) Effectiveness of Multidisciplinary Transitional Care Interventions on Functional Status,

Quality of Life and Readmission Rates in Stroke Patients: A Systematic Review and Meta-Analysis. *Journal of Clinical Nursing*, n/a (n/a).

Tang, E.Y.H., Price, C., Stephan, B.C.M., Robinson, L. and Exley, C. (2020) Impact of Memory Problems Post-stroke on Patients and Their Family Carers: A Qualitative Study. *Front Med (Lausanne)*, 7, 267.

Tashakkori, A. and Teddlie, C. (1998) *Mixed Methodology: Combining Qualitative and Quantitative Approaches*. Sage Publications, Inc.

Taule, T. and Råheim, M. (2014) Life changed existentially: a qualitative study of experiences at 6–8 months after mild stroke. *Disability and Rehabilitation*, 36 (25), 2107–2119.

Tawfik, A., Bielecki, J.M., Krahn, M., Dorian, P., Hoch, J.S., Boon, H.et al. (2016) Systematic review and network meta-analysis of stroke prevention treatments in patients with atrial fibrillation. *Clin Pharmacol*, 8, 93–107.

Tay, M.R.J. (2021) Hospital readmission in stroke survivors one year versus three years after discharge from inpatient rehabilitation: Prevalence and associations in an Asian cohort. *J Rehabil Med*, 53 (6), jrm00208.

Taylor, R.S., Dalal, H.M. and McDonagh, S.T.J. (2022) The role of cardiac rehabilitation in improving cardiovascular outcomes. *Nat Rev Cardiol*, 19 (3), 180–194.

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S.et al. (2007) The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes*, 5 (1), 63.

Terént, A., Asplund, K., Farahmand, B., Henriksson, K.M., Norrving, B., Stegmayr, B.et al. (2009) Stroke unit care revisited: who benefits the most? A cohort study of 105,043 patients in Riks-Stroke, the Swedish Stroke Register. *J Neurol Neurosurg Psychiatry*, 80 (8), 881–887.

Teuschl, Y., Matz, K., Firlinger, B., Dachenhausen, A., Tuomilehto, J., Brainin, M.et al. (2017) Preventive effects of multiple domain interventions on lifestyle and risk factor changes in stroke survivors: Evidence from a two-year randomized trial. *Int J Stroke*, 12 (9), 976–984.

Then, K.L., Rankin, J.A. and Ali, E. (2014) Focus group research: what is it and how can it be used? *Can J Cardiovasc Nurs*, 24 (1), 16–22.

Theofanidis, D., Savopoulos, C. and Hatzitolios, A. (2016) Global specialized stroke care delivery models. *Journal of Vascular Nursing*, 34 (1), 2–11.

Thieme, H., Mehrholz, J., Pohl, M., Behrens, J. and Dohle, C. (2013) Mirror therapy for improving motor function after stroke. *Stroke*, 44 (1), e1–2.

Thieme, H., Morkisch, N., Mehrholz, J., Pohl, M., Behrens, J., Borgetto, B.et al. (2018) Mirror therapy for improving motor function after stroke. *Cochrane Database Syst Rev*, 7 (7), Cd008449.

Thomas, E.C., Bass, S.B. and Siminoff, L.A. (2021) Beyond rationality: Expanding the practice of shared decision making in modern medicine. *Soc Sci Med*, 277, 113900.

Thornton, L. (2019) A Brief History and Overview of Holistic Nursing. *Integr Med (Encinitas)*, 18 (4), 32–33.

Tobias, D.K. (2017) Addressing Reverse Causation Bias in the Obesity Paradox Is Not "One Size Fits All". *Diabetes Care*, 40 (8), 1000–1001.

Tocco, S. (2011) Identify the vessel, recognize the stroke. *American Nurse Today*, 6 (9), 8–11.

Todhunter-Brown, A., Sellers, C.E., Baer, G.D., Choo, P.L., Cowie, J., Cheyne, J.D.et al. (2025) Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database Syst Rev*, 2 (2), Cd001920.

Tonkin, L. (1996) Growing around grief—another way of looking at grief and recovery. *Bereavement Care*, 15 (1), 10–10.

Towfighi, A., Cheng, E.M., Ayala-Rivera, M., Barry, F., McCreath, H., Ganz, D.A.et al. (2021) Effect of a Coordinated Community and Chronic Care Model Team Intervention vs Usual Care on Systolic Blood Pressure in Patients With Stroke or Transient Ischemic Attack The SUCCEED Randomized Clinical Trial. *JAMA NETWORK OPEN*, 4 (2).

Trankle, S.A., Usherwood, T., Abbott, P., Roberts, M., Crampton, M., Girgis, C.M.et al. (2019) Integrating health care in Australia: a qualitative evaluation. *Bmc Health Services Research*, 19 (1), 954.

Traynelis, L. (2012) Emergency Department Nurses' Knowledge of Evidence-Based Ischemic Stroke Care. *Kaleidoscope*, 10, 44.

Tsang, C.T.W., Choi, S.E., Ren, Q.W., Huang, J.Y., Gu, W.L., Guo, R.et al. (2024) Integrated care using the ABC-stroke pathway improves cardiovascular outcomes and survival in patients with recent ischaemic stroke: a population-based cohort study. *European Heart Journal*, 45 (Supplement_1).

Tucker, W.T. (1965) Max Weber's Verstehen. *The Sociological Quarterly*, 6 (2), 157–165.

Tung, Y.-J., Lin, W.-C., Lee, L.-F., Lin, H.-M., Ho, C.-H. and Chou, W. (2021) Comparison of Cost-Effectiveness between Inpatient and Home-Based Post-Acute Care Models for Stroke Rehabilitation in Taiwan. *International Journal of Environmental Research and Public Health*, 18 (8).

Turkowski, Y. and Turkowski, V. (2024) Florence Nightingale (1820-1910): The Founder of Modern Nursing. *Cureus*, 16 (8), e66192.

Tutor, A.W., Lavie, C.J., Kachur, S., Milani, R.V. and Ventura, H.O. (2023) Updates on obesity and the obesity paradox in cardiovascular diseases. *Progress in Cardiovascular Diseases*, 78, 2–10.

Tyerman, A. and Humphrey, M. (1984) Changes in self-concept following severe head injury. *Int J Rehabil Res*, 7 (1), 11–23.

Tyson, S.F., Hanley, M., Chillala, J., Selley, A. and Tallis, R.C. (2006) Balance Disability After Stroke. *Physical Therapy*, 86 (1), 30–38.

Ubel, P.A., Scherr, K.A. and Fagerlin, A. (2018) Autonomy: What's Shared Decision Making Have to Do With It? *Am J Bioeth*, 18 (2), W11–w12.

UK Government (2014) Care Act 2014. [online],

Available at: https://www.legislation.gov.uk/ukpga/2014/23/contents

[Accessed: Nov 2025]

Uman, L.S. (2011) Systematic reviews and meta-analyses. *J Can Acad Child Adolesc Psychiatry*, 20 (1), 57–59.

Valentijn, P.P., Schepman, S.M., Opheij, W. and Bruijnzeels, M.A. (2013) Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care. *Int J Integr Care*, 13, e010.

Vallente, R.U. (2023) Chronic Care Model (CCM). [online],

Available at: https://www.ebsco.com/research-starters/health-and-medicine/chronic-care-model-ccm

[Accessed: July 2025]

van Nimwegen, D., Hjelle, E.G., Bragstad, L.K., Kirkevold, M., Sveen, U., Hafsteinsdóttir, T.et al. (2023) Interventions for improving psychosocial well-being after stroke: A systematic review. *International Journal of Nursing Studies*, 142, 104492.

Varndell, W., Fry, M. and Elliott, D. (2021) Applying real-time Delphi methods: development of a pain management survey in emergency nursing. *BMC Nursing*, 20.

Veerbeek, J.M., Langbroek-Amersfoort, A.C., van Wegen, E.E., Meskers, C.G. and Kwakkel, G. (2017) Effects of Robot-Assisted Therapy for the Upper Limb After Stroke. *Neurorehabil Neural Repair*, 31 (2), 107–121.

Vluggen, T.P.M.M.v.H., Jolanda C. M. Tan, Frans E. Verbunt, Jeanine A. van Heugten, Caroline M. Schols, Jos M. G. A. (2021) Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial. *BMC Geriatrics*, 21 (1), 134.

von Knorring, J., Lehti, A., Lindvall, K. and Semb, O. (2025) I Want to be Known as a Whole Human Being: A Qualitative Study About Patients' Experiences of Empathy in Health Care. *J Patient Exp*, 12, 23743735251369702.

Waddell, A., Lennox, A., Spassova, G. and Bragge, P. (2021) Barriers and facilitators to shared decision-making in hospitals from policy to practice: a systematic review. *Implementation Science*, 16 (1), 74.

Wade, D.T. and de Jong, B.A. (2000) Recent advances in rehabilitation. *BMJ*, 320 (7246), 1385–1388.

Wafa, H.A., Marshall, I., Wolfe, C.D.A., Xie, W., Johnson, C.O., Veltkamp, R.et al. (2024) Burden of intracerebral haemorrhage in Europe: forecasting incidence and mortality between 2019 and 2050. *The Lancet Regional Health – Europe*, 38.

Wagner, E.H. (1998) Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract*, 1 (1), 2–4.

Walters, R., Collier, J.M., Braighi Carvalho, L., Langhorne, P., Katijjahbe, M.A., Tan, D.et al. (2020) Exploring post acute rehabilitation service use and outcomes for working age stroke

survivors (≤65 years) in Australia, UK and South East Asia: data from the international AVERT trial. *BMJ Open*, 10 (6), e035850.

Wang, J., Wang, J., Qiu, S., Zhou, C., Zhang, H., Li, Q.et al. (2021) Pharmaceutical care program for ischemic stroke patients: a randomized controlled trial. *Int J Clin Pharm*, 43 (5), 1412–1419.

Wang, S., Zou, X.-L., Wu, L.-X., Zhou, H.-F., Xiao, L., Yao, T.et al. (2022) Epidemiology of intracerebral hemorrhage: A systematic review and meta-analysis. *FRONTIERS IN NEUROLOGY*, Volume 13 - 2022.

Wardlaw, J.M., Murray, V., Berge, E. and del Zoppo, G.J. (2014) Thrombolysis for acute ischaemic stroke. *Cochrane Database Syst Rev*, 2014 (7), Cd000213.

Warner, G., Packer, T., Villeneuve, M., Audulv, A. and Versnel, J. (2015) A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors. *Disability and Rehabilitation*, 37 (23), 2141–2163.

Watkins, C.L., Lightbody, C.E., Sutton, C.J., Holcroft, L., Jack, C.I., Dickinson, H.A.et al. (2007) Evaluation of a single-item screening tool for depression after stroke: a cohort study. *Clin Rehabil*, 21 (9), 846–852.

Weber, M. (1947) *The Theory of Social and Economic Organization*. New York: Oxford University Press.

Weinel, I. (2023) Dewey applies pragmatism to education. [online],

Available at: https://www.ebsco.com/research-starters/religion-and-philosophy/dewey-applies-pragmatism-education

[Accessed: Aug 2025]

Wells, R., Kite, B., Breckenridge, E. and Sunbury, T. (2018) Community Mental Health Center Integrated Care Outcomes. *Psychiatric Quarterly*, 89 (4), 969–982.

Westerlind, E., Persson, H.C., Tornbom, K. and Sunnerhagen, K.S. (2020) Return to work predicts perceived participation and autonomy by individuals with stroke. *Disabil Rehabil*, 42 (25), 3673–3678.

Widimský, P., Kožnar, B., Vaško, P., Peisker, T. and Štětkářová, I. (2013) Acute myocardial infarction and acute stroke: What are the differences? Focus on reperfusion therapy. *Cor et Vasa*, 55 (2), e111–e116.

Willeit, P., Toell, T., Boehme, C., Krebs, S., Mayer, L., Lang, C.et al. (2020) STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: A randomised clinical trial. *EClinicalMedicine*, 25, 100476.

Williams, L.S. (2005) Depression and stroke: cause or consequence? *Semin Neurol*, 25 (4), 396–409.

Williams, S., Morrissey, A.M., Steed, F., Leahy, A., Shanahan, E., Peters, C.et al. (2022) Early supported discharge for older adults admitted to hospital with medical complaints: a systematic review and meta-analysis. *BMC Geriatr*, 22 (1), 302.

Wolf, P.A., D'Agostino, R.B., Kannel, W.B., Bonita, R. and Belanger, A.J. (1988) Cigarette smoking as a risk factor for stroke. The Framingham Study. *JAMA*, 259 (7), 1025–1029.

Wolfenden, B. and Grace, M. (2015) Vulnerability and Post-Stroke Experiences of Working-Age Survivors During Recovery. *Sage Open*, 5 (4), 2158244015612877.

Wong, E., Mavondo, F., Horvat, L., McKinlay, L. and Fisher, J. (2022a) Healthcare professionals' perspective on delivering personalised and holistic care: using the Theoretical Domains Framework. *Bmc Health Services Research*, 22 (1), 281.

Wong, F.K. and Yeung, S.M. (2015) Effects of a 4-week transitional care programme for discharged stroke survivors in Hong Kong: a randomised controlled trial. *Health Soc Care Community*, 23 (6), 619–631.

Wong, F.K.Y., Wang, S.L., Ng, S.S.M., Lee, P.H., Wong, A.K.C., Li, H.Y.et al. (2022b) Effects of a transitional home-based care program for stroke survivors in Harbin, China: a randomized controlled trial. *Age and Ageing*, 51 (2).

Worden, J.W. (2018) *Grief Counseling and Giref Therapy: A Hanbook for the Mental Health Practitioner*. Springer.

World Health Organization (2015) WHO global strategy on integrated people-centre health services 2016-2026: Executive Summary. [online],

Available at: https://interprofessional.global/wp-content/uploads/2019/11/WHO-2015-Global-strategy-on-integrated-people-centred-health-services-2016-2026.pdf

[Accessed: Feb 2025]

World Health Organization. (2025) *Health and Well-Being* [online]

Available at: https://www.who.int/data/gho/data/major-themes/health-and-well-being

[Accessed: Sept 2025]

World Stroke Organization (2022) Global Stroke Fact Sheet 2022. [online],

Available at: https://www.world-stroke.org/assets/downloads/WSO_Global_Stroke_Fact_Sheet.pdf

[Accessed: July 2025]

Wright, J.C. and Telford, R. (1996) Psychological problems following minor head injury: a prospective study. *Br J Clin Psychol*, 35 (3), 399–412.

Wu, D.Y., Guo, M., Gao, Y.S., Kang, Y.H., Guo, J.C., Jiang, X.L.et al. (2012a) Clinical effects of comprehensive therapy of early psychological intervention and rehabilitation training on neurological rehabilitation of patients with acute stroke. *Asian Pac J Trop Med*, 5 (11), 914–916.

Wu, D.Y., Guo, M., Gao, Y.S., Kang, Y.H., Guo, J.C., Jiang, X.L.et al. (2012b) Clinical effects of psychological intervention and drug therapy against peptic ulcer. *Asian Pac J Trop Med*, 5 (10), 831–833.

Wu, S., Kutlubaev, M.A., Chun, H.Y.Y., Cowey, E., Pollock, A., Macleod, M.R.et al. (2015) Interventions for post-stroke fatigue. *Cochrane Database of Systematic Reviews* (7).

Wu, Z., Xu, J., Yue, C., Li, Y. and Liang, Y. (2020) Collaborative Care Model Based Telerehabilitation Exercise Training Program for Acute Stroke Patients in China: A Randomized Controlled Trial. *Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association*, 29 (12), 105328.

Xi, W.D., Yamei Wang, Ai'ping (2017) Influence of continuing nursing outside hospital on rehabilitation effect and quality of life in patients with stroke. *Chinese Nursing Research*, 31 (29), 3760–3762.

Xu, X.M., Vestesson, E., Paley, L., Desikan, A., Wonderling, D., Hoffman, A.et al. (2018) The economic burden of stroke care in England, Wales and Northern Ireland: Using a national stroke register to estimate and report patient-level health economic outcomes in stroke. *Eur Stroke J*, 3 (1), 82–91.

Yaggi, H.K., Concato, J., Kernan, W.N., Lichtman, J.H., Brass, L.M. and Mohsenin, V. (2005) Obstructive Sleep Apnea as a Risk Factor for Stroke and Death. *New England Journal of Medicine*, 353 (19), 2034–2041.

Yaghi, S. and Elkind, M.S. (2014) Cryptogenic stroke: A diagnostic challenge. *Neurol Clin Pract*, 4 (5), 386–393.

Yamada, S., Koizumi, A., Iso, H., Wada, Y., Watanabe, Y., Date, C.et al. (2003) Risk Factors for Fatal Subarachnoid Hemorrhage. *Stroke*, 34 (12), 2781–2787.

Yan, L.J.L., Gong, E.Y., Gu, W.B., Turner, E.L., Gallis, J.A., Zhou, Y.et al. (2021) Effectiveness of a primary care-based integrated mobile health intervention for stroke management in rural China (SINEMA): A cluster-randomized controlled trial. *Plos Medicine*, 18 (4), 20.

Yang, Y.F., Hoo, J.X., Tan, J.Y. and Lim, L.L. (2023) Multicomponent integrated care for patients with chronic heart failure: systematic review and meta-analysis. *ESC Heart Fail*, 10 (2), 791–807.

Yeoh, E.K., Wong, M.C.S., Wong, E.L.Y., Yam, C., Poon, C.M., Chung, R.Y.et al. (2018) Benefits and limitations of implementing Chronic Care Model (CCM) in primary care programs: A systematic review. *International Journal of Cardiology*, 258, 279–288.

Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M.et al. (1982) Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res*, 17 (1), 37–49.

Yin, Y., Zhang, L., Marshall, I., Wolfe, C. and Wang, Y. (2022) Statin Therapy for Preventing Recurrent Stroke in Patients with Ischemic Stroke: A Systematic Review and Meta-Analysis of Randomized Controlled Trials and Observational Cohort Studies. *Neuroepidemiology*, 56 (4), 240–249.

Ymeraj, M., Kotica, F., Bozzolan, G., Rocco, G., Virgolesi, M., Alvaro, R.et al. (2025) Health literacy in stroke disease: A systematic review. *Journal of Vascular Nursing*, 43 (1), 33–45.

Yoo, D.-Y., Choi, J.-K., Baek, C.-Y. and Shin, J.-B. (2022) Impact of intensive rehabilitation on long-term prognosis after stroke: A Korean nationwide retrospective cohort study. *Medicine*, 101 (38), e30827.

Yu, H.L., Cao, D.X. and Liu, J. (2019) Effect of a novel designed intensive patient care program on cognitive impairment, anxiety, depression as well as relapse free survival in acute ischemic stroke patients: a randomized controlled study. *Neurol Res*, 41 (9), 857–866.

Yu, H.L.C., D. X. Liu, J. (2019) Effect of a novel designed intensive patient care program on cognitive impairment, anxiety, depression as well as relapse free survival in acute ischemic

stroke patients: a randomized controlled study. *NEUROLOGICAL RESEARCH*, 41 (9), 857–866.

Zarora, R., Immanuel, J., Chivese, T., MacMillan, F. and Simmons, D. (2022) Effectiveness of Integrated Diabetes Care Interventions Involving Diabetes Specialists Working in Primary and Community Care Settings: A Systematic Review and Meta-Analysis. *Int J Integr Care*, 22 (2), 11.

Zhang, L., Zhang, T. and Sun, Y. (2019) A newly designed intensive caregiver education program reduces cognitive impairment, anxiety, and depression in patients with acute ischemic stroke. *Braz J Med Biol Res*, 52 (9), e8533.

Zhang, S., Cheng, S., Zhang, Z., Wang, C., Wang, A. and Zhu, W. (2021) Related risk factors associated with post-stroke fatigue: a systematic review and meta-analysis. *Neurol Sci*, 42 (4), 1463–1471.

Zhang, S., Xie, H., Wang, C., Wu, F. and Wang, X. (2022) Effectiveness of Physiotherapy to Promote Motor Recovery in Individuals with Stroke: A Systematic Review Protocol. *Research Square*.

Zhang, Y., Stokes, J., Anselmi, L., Bower, P. and Xu, J. (2025) Can integrated care interventions strengthen primary care and improve outcomes for patients with chronic diseases? A systematic review and meta-analysis. *Health Research Policy and Systems*, 23 (1), 5.

Zhao, B., Yao, Y. and Gao, T. (2024) The effect of psychological intervention on the quality of life and rehabilitation outcome of stroke patients with anxiety and depression: A systematic review. *Medicine (Baltimore)*, 103 (45), e40439.

Zigmond, A.S. and Snaith, R.P. (1983) The hospital anxiety and depression scale. *Acta Psychiatr Scand*, 67 (6), 361–370.

Ziu, E., Khan Suheb, M.Z. and Mesfin, F.B. (2023) Subarachnoid Hemorrhage. [online],

Available at: https://www.ncbi.nlm.nih.gov/books/NBK441958/

[Accessed: July 2025]

Zung, W.W.K. (1965) A Self-Rating Depression Scale. *Archives of General Psychiatry*, 12 (1), 63–70.

Zung, W.W.K. (1971) A Rating Instrument For Anxiety Disorders. *Psychosomatics*, 12 (6), 371–379.

12 Appendices

12.1 Appendix A: Systematic Review Protocol

NIHR | National Institute for Health Research

PROSPERO
International prospective register of systematic reviews

Review methods were amended after registration. Please see the revision notes and previous versions for detail.

Citation

Ian Eustace, Karen Higginbotham, Ian Jones, Benjamin Buckley, Deirdre Lane, Gregory Y H Lip. Integrated care management for patients following acute stroke: a systematic review and meta-analysis. PROSPERO 2021 CRD42021290240 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021290240

Review question

1. What types of integrated care management strategies exist for people with stroke?

2. Do integrated care management pathways for stroke impact patient outcomes?

3. What elements of integrated care management for stroke are effective at improving patient outcomes?

Searches [1 change]

A comprehensive search of electronic databases (Cochrane Central Register of Controlled Trials, MEDLINE, EMBASE, CINAHL, Cochrane Library and Web of Science), based on a pre-defined search strategy, developed and conducted in collaboration with an Information Specialist. Medical subject heading (MeSH) terms and synonyms for the different terms will be used and combined with Boolean operators, proximity operators, truncations and wildcards. The search will initially be conducted in MEDLINE and CINAHL and will then be adapted for the remaining databases. Databases will be searched for relevant publications restricted to the last 5 years (to ensure adequate representation of contemporary post-stroke care), with no language or geographical limitation. The reference list of articles that meet the inclusion criteria after full-text review will be hand-searched to identify additional articles. A search of grey literature will be undertaken and the search will extend to Google Scholar. An attempt will be made to contact authors of published abstracts to request full-text versions of studies and/or study data, if required. For quality control purposes, a second reviewer will confirm the relevance of searched articles and a third reviewer may be involved in the event of disagreements between reviewers.

A systematic search of the published literature will be conducted with groups of key words used, related to: "stroke" OR "thrombotic stroke" OR "embolic stroke" OR "ischemic stroke" or "transient isch*" OR "intracranial haemorrhage" OR "cerebral intraventricular haemorrhage" OR "cerebral haemorrhage" OR "cerebral infarction" OR "brain infarction" OR "anterior cerebral artery infarction" OR "middle cerebral artery infarction" OR "posterior cerebral artery infarction"

AND

"integrated care" OR "stroke rehabilitation" or "integrated health" OR "coordinated care" OR "comprehensive care" OR "seamless care" OR "transmural care" OR “multidisciplinary care” OR “patient-centred care” OR “patient care” OR “patient care management” OR “managed care programs”.

Types of study to be included

Randomised controlled trials, uncontrolled comparative trials, observational cohort studies, mixed methods and quantitative case studies.

Condition or domain being studied

Stroke patients as outlined in the searches. The goal of this systematic review is to investigate interventions available for patients following acute stroke in the hospital, rehabilitation or home environment, and to establish if, in comparison with usual care or other comparative active interventions, integrated support

services offered to patients can achieve better patient outcomes.

Participants/population
Inclusion criteria:

Patients with any acute stroke or transient ischaemic attack (TIA) of any age, and any pathological type of stroke (ischaemic, venous, intracerebral haemorrhage). Stroke will be defined according to American Heart Association/American Stroke Association (AHA/ASA) guidelines (Kleindorfer DO et al., 2021).

Exclusion criteria:

Patients in which stroke is not the primary event or where a definitive diagnosis of stroke cannot be confirmed. For sample groups including mixed diagnoses (e.g., transient ischaemic attack or traumatic head injury, in addition to stroke), we will contact the authors for data specific to the stroke cohort.

Intervention(s), exposure(s)
Interventions of interest which may or may not be part of a structured plan of care will include (pharmacological or non-pharmacological) secondary stroke prevention measures (e.g. anticoagulation), management of stroke risk factors such as hypertension, overweight/obesity, management of co-morbidities such as cardiovascular disease, respiratory disease or diabetes, non-pharmacological interventions such as exercise programmes, physiotherapy, occupational therapy, mental health support, dietary advice, weight loss, smoking and alcohol use, delivered within inpatient or outpatient settings.

Comparator(s)/control
Standard management of patients following acute stroke. If there are data for patient adherence or non-adherence to elements of the care pathway, these data will be documented.

Context
Patients with any type of acute stroke or transient ischaemic attack.

Main outcome(s)
Primary outcomes

All-cause mortality, cardiovascular mortality, recurrent stroke, major bleeding.

Secondary outcomes

Quality of life, rehospitalisation, mental wellbeing/depression/anxiety, treatment adherence.

Measures of effect

Rates, Proportions, Hazard Ratios, Odds Ratios, Risk Ratios, as appropriate for the available data.

Additional outcome(s)
Not applicable

Data extraction (selection and coding)
All articles by title/abstract will be imported into Endnote™ 20.1 bibliographic software (Clarivate Analytics, 2021), and duplicates will be removed. An initial screen of titles and abstracts will be performed in duplicate, and full-text versions potentially eligible articles will be retrieved. Screening of full-text articles will then be completed in duplicate by two independent reviewers.

Using a predefined data extraction form, the following data will be extracted from each included study:

1. Study characteristics: author details, title of study, journal of publication, year of publication, country of origin, study design, time-period of data collection, and inclusion and exclusion criteria.

2. Study population (intervention and control groups, where applicable): sample size, demographic characteristics including age (mean or median and range), sex, ethnicity, proportion of participants with

chronic health conditions, baseline physiological/clinical measurements, CHA2DS2-VASc score, and HAS-BLED score, QoL measures.

3. Results: outcomes measures (all-cause mortality, cardiovascular mortality, ischaemic stroke, major bleeding), effect measures (unadjusted and adjusted, and factors adjusted for if applicable), and follow-up time point for each measure.

Risk of bias (quality) assessment

Two reviewers will independently assess the risk of bias and disagreements will be resolved by consensus or consultation with a third reviewer. For randomised controlled trials, the Cochrane Risk of Bias (RoB 2) tool will be used. For non-randomised studies, the Risk of Bias In Non-Randomized Studies – of Interventions (ROBINS-I) tool (Sterne et al, 2016) will be used.

Strategy for data synthesis

The results of the systematic review will be summarized descriptively. Results will be grouped according to the target outcome (i.e., all-cause mortality, cardiovascular mortality, ischaemic stroke, major bleeding).

If sufficient data are available, then meta-analyses will be conducted. If two (or more) studies use the same databases and populations, only the most appropriate/largest of the studies will be included in meta-analyses. Primary and secondary outcome effect measures with 95% confidence intervals will be pooled using RevMan software. Random effects models will be used, which allow for between-study variability by weighting studies using a combination of intra- and inter-study variance. Results will be presented visually using Forest plots. Heterogeneity will be assessed visually and using the I^2 statistic with 25%, 50% and 75% considered moderate, substantial and considerable heterogeneity, respectively.

To measure the overall treatment effects, we will use the Der Simonian & Laird method for both binary (e.g., mortality) and continuous (e.g., quality of life) outcomes. If continuous data is not homogeneous, an estimate of the standardised mean difference with 95% confidence intervals will be calculated. If quantitative data are too few or too heterogeneous, then a narrative synthesis approach will be undertaken.

Analysis of subgroups or subsets

If the necessary data are available, analysis of the following subgroups will be undertaken using stratified meta-analysis for i) primary outcomes of all-cause death, CV death and ischemic stroke, (e.g., CHA2DS2-VASc score groups and HAS-BLED scores for bleeding risk); ii) geographic region (Asia, Europe, North America); iii) study design (real-world data versus randomised controlled trials; short versus long-term follow-up, prospective versus retrospective) and iv) patient subgroups (aged >75 and <75 years, health conditions, adherence/non-adherence with interventions). Mortality and other outcomes (where applicable) will be analysed according to length of follow-up, via sub-group analyses to stratify for different follow-up time points. Further, quality of life and depression/anxiety data will be grouped and analysed according to the type of measurement tool employed (e.g., VAS, EQ-5D, HADS). Where feasible, standardised mean differences may be used to meta-analyse similar scales.

Contact details for further information

[redacted]

Organisational affiliation of the review

Liverpool John Moores University
https://www.ljmu.ac.uk/

Review team members and their organisational affiliations [1 change]

Mr Ian Eustace. Liverpool John Moores University
Dr Karen Higginbotham. Liverpool John Moores University
Professor Ian Jones. Liverpool John Moores University
Dr Benjamin Buckley. University of Liverpool
Dr Deirdre Lane. University of Liverpool
Professor Gregory Y H Lip. University of Liverpool

Type and method of review
Systematic review

Anticipated or actual start date
30 November 2021

Anticipated completion date
30 November 2022

Funding sources/sponsors
The review is funded by Liverpool John Moores University

Conflicts of interest
IDJ is a consultant and speaker for Bristol-Myers Squibb (BMS)/Astra-Zeneca. No fees are received personally. BJRB has received research funding from BMS/Pfizer. DAL has received investigator-initiated educational grants from BMS, has been a speaker for Boehringer Ingeheim, and BMS/Pfizer and has consulted for BMS, Boehringer Ingelheim, and Daiichi-Sankyo. GYHL is a consultant and speaker for BMS/Pfizer, Boehringer Ingelheim and Daiichi-Sankyo. No fees are received personally.
Yes

Language
English

Country
England

Stage of review
Review Ongoing

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
Delivery of Health Care, Integrated; Humans; Risk Factors; Stroke

Date of registration in PROSPERO
09 November 2021

Date of first submission
08 November 2021

Stage of review at time of this submission [1 change]

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Revision note

Search strategy updated and refined to reduce number of search results

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.
The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

09 November 2021
19 November 2021
26 June 2022

12.2 Appendix B: Systematic Review Search Strategy

Full search strategies for Medline/CINAHL, Web of Science and Cochrane database of randomised controlled trials

Summary of hits

12203 identified

2785 duplicates removed

9418 screened for full text review

Medline/CINAHL = 5,248

(MM "Stroke") OR (MM "Ischemic Stroke") OR (MM "Hemorrhagic Stroke") OR (MM "Embolic Stroke") OR (MM "Thrombotic Stroke") OR (MM "Intracranial Hemorrhages") OR (MM "Intracranial Thrombosis") OR (MM "Intracranial Embolism") OR (MM "Intracranial Embolism and Thrombosis") OR (MM "Cerebral Infarction") OR (MM "Cerebral Hemorrhage") OR (MM "Brain Infarction") OR (MM "Infarction, Posterior Cerebral Artery") OR (MM "Infarction, Anterior Cerebral Artery") OR (MM "Infarction, Middle Cerebral Artery")

AND

(MM "Delivery of Health Care, Integrated") OR (MM "Rehabilitation") OR (MM "Stroke Rehabilitation") OR (MM "Patient Care") OR (MM "Patient-Centered Care") OR (MM "Patient Care Management") OR (MM "Managed Care Programs") OR (MM "Patient Care Team")

Web of Science = 4,221

"stroke" OR "thrombotic stroke" OR "embolic stroke" OR "ischemic stroke" or "transient isch*" OR "intracranial haemorrhage" OR "cerebral intraventricular haemorrhage" OR "cerebral haemorrhage" OR "cerebral infarction" OR "brain infarction" OR "anterior cerebral artery infarction" OR "middle cerebral artery infarction" OR "posterior cerebral artery infarction"

AND

"integrated care" OR "stroke rehabilitation" or "integrated health" OR "coordinated care" OR "comprehensive care" OR "seamless care" OR "transmural care" OR “multidisciplinary care” OR “patient-centred care” OR “patient care” OR “patient care management” OR “managed care programs”

Cochrane Database of randomised controlled trials = 2,734

Stroke OR stroke rehabilitation OR ischemic stroke OR thrombotic stroke OR cerebral artery stroke OR transient ischemic attack OR intracranial hemorrhage

AND

diet therapy - DH, drug therapy - DT, methods – MT, mortality - MO, nursing - NU, prevention & control - PC, psychology - PX, rehabilitation - RH, therapy – TH

Definition of integrated care

Integrated care in this review is defined according to NHS Health Education England (NHS Health Education England, 2024), thus: *"It is care that is planned with people who work together to understand the service user and their carer(s), puts them in control and coordinates and delivers services to achieve the best outcomes."*

12.3 Appendix C: Systematic Review Data Extraction Table

Study ID (surname of first author and year first full report of study was published e.g. Smith 2001)	Article title	Author	Reference citation	Study author contact details	Country of origin	Name/ID of person extracting data	Date of data extraction (dd/mm/yy)	Aim/objectives of the study	Study design	Study inclusion and exclusion criteria	Recruitment procedures used (e.g. details of randomisation, blinding)	Unit of allocation (e.g. participant, GP practice etc.)	Age	Gender	Ethnicity	Socio-economic status	Disease characteristics	Co-morbidities	Setting in which the intervention is delivered	Description of the intervention(s) and control(s) (e.g. dose, route of administration, number of cycles, duration of cycle, care provider, how the intervention was developed, theoretical basis [where relevant])	OUTCOMES	Unit of assessment/ analysis	Statistical techniques used	Numb partic enroll
Abdul Aziz 2020	The integrated care pathway fc	Abdul Aziz Aznida Firzah	Abdul Aziz, A.F	Correspor	Malaysia	IE	18/07/2022	The aim of this stu	Pragmatic cluster randomised controlled tr	Patient inc	Patients were rec	Patient, Primar	Mean (SD	Control; M	Control; M	Annual inc	Sub-type not spec	Smoking n=9 (	Primary care	Assessment/treatment for both g	Primary: Qualit	EuroQoL EQ-	Mann Whitne	Contr
Ahmadi 2020	A support programme for seco	Michael Ahmadi	Ahmadi M et a	Correspor	Germany	IE	09/08/2022	To assess the effe	Prospective, randomised, open-label, blind	We includ	Patients were rar	Participant	Mean (SD	Control: fe	Not report	Not report	Index event: Isch	Arterial hypert	Hospital outpa	In the support programme, patier	Primary: comp	All n (%): BP <	The outcomes	Contr
(Demir) Avci 202	Effects of Transitional Care Mo	Demir Avci	Avci, Y.D. and	ydemir@a	Turkey	KH	12/08/2024	This study was cor	This study is a parallel-group, assessor-blin	Inclusion f	Computerised ra	patients, hospi	The mean	female cat	not report	not report	Ischaemic n = 29	Intervention: 3	Hospital and H	Caregivers were interviewed with	Primary: levels	Sociodemogr	Intention-to-t	Total
Bath 2018	Triple versus guideline antiplat	Philip M Bath	Bath, P. M., W	philip.batl	UK	MFR	19/07/2024	The main objectiv	International (UK, Denmark, Georgia, NZ) p	>50 years	Patients allocatec	Patient, Primar	69.0 ± 10.	Intensive (	Intensive (	NR	Intensive Group:	NR	Primary care	Intensive treatment group given c	Primary:	modified Ran	Death was an	Inten
Bergh 2023	Does implementation of a stan	Elin Bergh	Bergh, E., Askir	elin.josefi	Norway	MFR	22/07/2024	Aim was to evalua	Repeated measures analysis from a retrosp	≥18 regist	Patient data colle	Patient in publi	72.5 ± 12.	(n=4744 (4	NR	NR	Ischaemic stroke	Previous strok	Primary care	New 2018 SCP: The aim of the	Primary outcor	modified Ran	Cluster effect	17813
Bernhardt 2015	Efficacy and safety of very earl	Julie Bernhardt	Bernhardt, J., I	julie.bernl	Australia	MFR	24/07/2024	Aimed to compare	Single-blind RCT in 56 acute stroke units in	Between J	Patients were rar	Patient in hosp	Interventi	Interventi	NR	Living arra	Stroke history- Fir	Risk Factors: Hy	Primary care	Components of usual care, includ	The primary o	modified Ran	Primary effica	2104
Bodechtel 2016	The stroke east Saxony pilot pr	Ulf Bodechtel	Bodechtel U, B	kepplinge	Germany	MFR	24/07/2024	Aimed to determi	Retrospective database case-control study	SOS (Strok	Intervention pati	Patient, primar	Interventi	Interventi	NR	NR	Acute ischemic st	Arterial hypert	Primary care	Intervention: Consecutive	Functional ind	Modified Ran	tudent t test, '	
Bragstad 2020	The effects of a dialogue-basec	Line Kildal Bragstad	Bragstad LK et	Email: e.g.	Norway	IE	21/07/2022	To evaluate the eff	Multicenter, prospective, randomized, asse	Inclusion:	A computer-gene	Participant, hos	Mean (SD	Control;	Male 58.3%	Not report	Stroke classificati	Intervention: I	Community, pr	Dialogue-based intervention to pi	Primary: Psych	Pyschosocial	SPSS. The stat	Gave
Brandal 2019	Effect of early supported disch	Anna Brådal	Brandal A et al	Correspor	Sweden	IE	21/07/2022	To compare patier	Case controlled, observational study using	Inclusion:	All patients regist	Patient, univers	Mean (SD	Control; M	Not report	Education	Stroke subtype In	Intervention: I	Stroke units, pa	Modern unit stroke care followed	Primary: satisfa	3-month follc	Independent	
Brouns 2021	EFFECT OF A COMPREHENSIVE	Berber Brouns	Brouns B et al.	Correspor	Netherlan	IE	23/07/2022	To compare the ef	Pre-post test, controlled, pragmatic clinical	Inclusion (	Eligible people wi	Participant	Mean (SD	Control: M	Not recorc	Living alor	Stroke type, n ha	Not reported	Inpatient, outp	web-based erehabilitation compr	Primary: Stroke	impact scale	Patient charac	Contr
Brouwer 2018	Effectiveness of Client-Centere	Brenda Brouwer	Brouwer B et a	Brenda Br	Canada	IE	23/07/2022	To explore the eff	A multicenter randomized controlled trial v	First majo	After entering the	Participants, co	Mean (SD	Control: M	Not report	Living stat	Stroke characteri	Not reported	Home and labc	Tune-up interventions comprised	Primary: Comn	Primary: Subj	Chi square, st	
Buckley 2021	Exercise-Based Cardiac Rehabi	Benjamin Buckley	Buckley B et al.	Benjamin	UK	IE	23/07/2022	To investigate the	Retrospective observational study	Patients w	Exercise-based c	Participant	Propensity	Propensity	Propensity	Not report	Stroke populatior	Propensity sco	Not specified	Exercise-based cardiac rehabilitat	All-cause mort	n (%) of even	Chi square, t-t	
Bushnell 2021	Hospital Readmissions and Mo	Cheryl D bushnell	Bushnell CD et	Correspor	USA	IE	10/08/2022	Our aim was to in	COMPASS was a cluster-randomized trial o	Inclusion:	Randomization o	Hospital	Mean (SD	Female: cc	White: cor	Urban-rur	Stroke diagnosis,	Hypertension:	Hospital stroke	COMPASS-TC (Comprehensive Po	Thirty- and 90-	Thirty- and 9(	Mixed logistic	Partic
Cecchi 2020	Development and implementa	Francesca Cecchi	Cecchi, F., Dive	apaperini(	Italy	MFR	29/07/2024	The purpose of th	Prospective observational study	Patients a	All patients on ad	Patient in hosp	2015-2017	2015-2017	NR	NR	RANKIN score at a	CIRS (cumulati	Primary care	An evidence-based stroke rehabil	Feasibility and	Feasibility an	Shapiro-Wilk t	2015-
Chang 2022	A multicenter study to compar	Ke-Vin Chang	Chang, K.V., Ch	Senior aut	Taiwan	MFR	02/08/2024	Aimed to determi	Cohort study	(1) be old	Patients who join	Patient, Primar	Unweight	Unweight	NR	NR	UnweightedType	UnweightedDi	Primary care	PAC program. Rehabilitation in th	Primary: perfo	Primary: Bart	Inverse proba	
Chang 2018	Rehabilitation Reduced Readm	Ku-Chou Chang	Chang, K.C., Hs	Husei-Che	Taiwan	MFR	02/08/2024	To investigate the	Retrospective cohort study using National I	Admitted	Data from the Lo	Patient, Primar	Total: 66.7	Total: 56.7	NR	NR	Stroke type:	Subs Diabetes	No re	Primary care	Subjects categorised into 3 groups:	OE1) Vascular	Vascular ever	Stepwise mult	
Chen 2016	Quasi-experimental evaluation	Lu Chen	Chen, L., Sit, J.	gycc2011	China	KH	12/08/2024	Evaluate outcome	Quasi-experimental controlled study	Inclusion:	Noted participan	Patients, dische	53.34 yrs	(96:77 mal	not report	assess dur	Ischaemic stroke	not reported	Within Home f	Control: received routine postdisc	satisfaction wit	BI	T-test and Chi	Interv
Chen 2017	Effects of Transferring to the R	Chien-Min Chen	Chen C-M et al	Chien-Min	Taiwan	IE	25/07/2022	To assess the long	Retrospective cohort study	Inclusion:	Subjects with inp	Participant	RR Group:	RR group:	Not report	Insured ar	Type of stroke Ha	Not reported	Hospital stroke	Rehabilitation delivered by physi	Primary: 5-yea	5-years after	Cox proportio	
Cheng 2018	Comprehensive Rehabilitation	Chunmei Cheng	Cheng C et al.	Address c	China	IE	25/07/2022	To explore the eff	Randomised controlled trial	Inclusion:	Patients were rar	Participant, hos	Mean (SD	CRT group	Not report	Education	Lesion location, n	Smoking (n/%)	Hospital	Patient and family member educa	Cognitive impa	Montreal cog	SPSS 22.0 soft	
Cheng 2018	Efficacy of a Chronic Care–Base	Eric M. Cheng	Cheng EM et a	Correspor	USA	IE	25/07/2022	to test the efficacy	Randomised controlled trial	Inclusion (	Before initiation (	Participant	Mean (SD	Male: con	Non-Hispa	Education	NIHSS score, n (%	Systolic BP, ave	Community, ou	The research team collaborated v	Change in SBP	Interviews to	We compared	
Chiu 2021	Multidisciplinary Care after Acu	Chong-Chi Chiu	Chiu C-C et al.	Correspor	Taiwan	IE	25/07/2022	The main objectiv	Large-scale prospective cohort study	Inclusion:	Patients divided i	Participant, hos	After Prop	After Prop	Not report	After Prop	After Propensity S	After Propensi	Hospital	The PAC therapy was delivered in	Functional disa	Individual pa	Generalised e	
Chu 2020	Feasibility of a Nurse-Trained, I	Kun Chu	Chu K et al. J	School of	China	IE	26/07/2022	This study aimed t	Single-centre randomised controlled trial	Inclusion (	Eligible patients v	Participants	Mean (SD	Control: M	Not report	Household	Stroke type Isch	Smoking n (%)	Hospital, home	Primary: Physic	Primary: Bart	Analysis of va		
Cuccurullo 2022	Stroke Recovery Program with	Sara J. Cuccurullo	Cuccurullo, S.J.	Sara.Cucc	USA	KH	12/08/2024	The objectives of t	Retrospective analysis of data from a prosp	Inclusion:	Participants recru	patients, cardia	Entire Coh	Male: Enti	Hispanic:	n/a	Entire: haemorrh	Entire Cohort:	outpatient	full SRP (physician visits, outpatie	functional perf	AM-PAC, ME	student's 2 sa	n= 16
Cuccurullo 2022	Impact of Modified Cardiac Rel	Sara J. Cuccurullo	Cuccurullo, S.J.	Sara.Cucc	USA	IE	12/08/2024	The primary objec	Prospective matched cohort study	Inclusion:	All patients were	Participant	Matched	Matched (	Matched	Matched	Matched cohort	Matched	outpatient the	full SRP (physician visits, outpatie	Primary: readn	Ordinal value	Chi -square, t	SRPP:
Cuccurullo 2019	Impact of a Stroke Recovery Pr	Sara J Cuccurullo	Cuccurullo SJ e	All corres	USA	IE	26/07/2022	To investigate the	Prospective cohort study: feasibility study f	Inclusion (	The JFK Johnson	Participant	Matched g	NP: Male :	Hispanic: I	Education	Type of stroke Ha	Atrial fibrillatic	rehabilitation a	Enhanced SRP Includes Three Cor	Feasibility stud	1-year morta	Mortality: dire	
Cumming 2019	Early mobilization and quality (	Toby B Cumming	Cumming TB e	Correspor	Internatio	IE	26/07/2022	To determine whe	A Very Early Rehabilitation Trial (AVERT) wa	Eligible pa	Participants were	Participant	Mean (SD	Female: C	Not report	Education	Oxfordshire Stro	Not reported	Hospital	For both intervention and control	Primary: good	Primary: moc	multivariable,	
de Belvis 2019	Ischemic stroke: clinical pathw	Antonio Giulio de Belvis	de Belvis AG et	Correspor	Italy	IE	26/07/2022	To determine whe	pre-post retrospective observational study	All patient	No randomisatior	Participant	Mean (SD	Male: Con	Not report	Not report	Patients with pre	Not reported	Hospital stroke	The clinical pathway introduces cl	The clinical pat	Percentages	A descriptive	
Dehghan Nayeri	Investigating the effects of a fa	Nahid Dehghan Nayeri	Dehghan Naye	No report	Iran	KH	09/09/2024	The aim of this stu	Posttest-only randomised controlled trial s	Inclusion:	Patient and caref	cluster random	Caregiver	Caregiver	Not report	Patient: In	mRS (n (%)):	4 - E	Not reported /	Hospital-based	Experiment group: Need assessm	Adherence reg	Adherence to	Descriptive stu	n = 75
Dello 2021	A nurse-led multicomponent ir	Simon Dello	Dello, S., Lemr	simon.del	Belgium	KH	12/08/2024	The aim of this stu	Single-centre pre- and post-intervention sti	Inclusion:	Recruited from th	Patients, stroke	Age (years	Male 59.6	n/a	n/a	Pre: NIHSS on Adı	Diabetes: 23.4	Stroke Unit	The standard electronic care plan	Primary: death	NIHSS,mRS, t	Multiple logis	n = 49
Deng 2020	Effects of an integrated transiti	Aiwen Deng	Deng A et al. C	Ribo Xiong	China	IE	26/07/2022	To evaluate the ef	A pilot randomized controlled trial	Patients w	Blinded assessm	Participant	Mean (SD	Control: m	Not report	Education	Ischemic stroke: (	Not reported	Stroke unit, ho	For the intervention group, a mul	Quality of life (	Quality of life	Data were do	
Deutschbein 202	Community care coordination	Johannes Deutschbein	Deutschbein J	Correspor	Germany	IE	26/07/2022	To evaluate the ef	Pragmatic non-randomised controlled trial	Eligible pa	Patients were cor	Participant	Mean (SD	Interventi	Not report	Not report	Stroke type, n (%	Diabetes: Inte	Community, pr	The main purpose of the interven	The analysis of	Incidence rat	van den Buss	N=365
Dohl 2020	Factors contributing to post-str	Øystein Døhl	Dohl O et al. B	Correspor	Norway	IE	26/07/2022	To evaluate whet	multicentre, pragmatic, single-blinded, ran	Those incl	Patients were eni	Participant	Mean (SD	Interventi	Not report	Living alor	Not reported	Not reported	Hospital, prima	Participants randomized to the in	Cost analysis, r	Costs expres	Differences be	
Duncan 2020	Randomized Pragmatic Trial of	Pamela W Duncan	Duncan PW. C	Pamela W	USA	IE	26/07/2022	The objectives of t	pragmatic cluster-randomized trial	Eligible pa	Hospitals were ra	Hospital unit	Mean (SD	Female: in	White: rac	Geograph	Stroke diagnosis,	Not reported	Hospital	The intervention was delivered w	The primary o	Primary: SIS-	ITT analysis in	6024
Ellis-Hill 2019	HeART of Stroke: randomised c	Caroline Ellis-Hill	Ellis-Hill C et al	Correspor	UK	IE	27/07/2022	To evaluate (1) th	Two-centre, 24-month, parallel-arm RCT wi	Participan	Participants were	Participant	Mean (SD	Control: fe	White Eng	Level of ec	Stroke type, n (%	Not reported	Community	The HoS intervention comprised t	The outcomes	Primary: War	Quantitative a	
Feng 2021	Application effect of the hospit	Weijiao Feng	Feng W et al. A	Correspor	China	IE	27/07/2022	To explore the eff	Randomised controlled trial	The inclus	From September	Participant	Mean (SD	Control: m	Not report	Family inc	Stroke type Ischae	Not reported	Hospital and h	HCISM intervention was applied i	The changes of	Self care abili	Statistical ana	
Feng 2024	Health-related outcomes 6 mo	Xuehuan Feng	Feng, X., Deng,	xiongribo	China	KH	13/08/2024	Aim is to explore t	6-month follow-up of an open, prospectiv	Inclusion:	IHSC was set up i	participants, pr	ALL: 68.8y	Males ALL	n/a	Annual Hc	Diagnosis Ischaer	All Groups: 97	Primary health	The model, based on the Chronic	Functional perf	mBI, SF-36, C	Shapiro-Wilk t	Over
Freburger 2022	Skilled Nursing and Inpatient R	Janet K. Freburger	Freburger, J.K.,	janet_freb	USA	KH	13/08/2024	Aim is to examine	Randomised Multi-location control trial	Inclusion:	Randomization o	patients, outpa	Age in yea	Female, n	n/a	n/a	Stroke Diagnosis,	n (%)	Home via telep	The intervention included telephc	Primary: skillec	Medicare FFS	Intent-to-trea	Hospi
Fu 2020	Taking Charge after Stroke: A r	Vivian Fu	Fu V et al. Int J	Correspor	New Zeala	IE	27/07/2022	To confirm wheth	This was a prospective, randomized, open	Participan	Participants were	randomized in	Mean (SD	Male: con	NZ Europe	Lives alon	Stroke severity: m	Diabetes mellit	Home	Following baseline assessments ir	The primary o	SF-36 PCS	The primary a	
Gao 2017	Different interventions for pos	Jie Gao	Gao J et al. clin	Correspor	China	IE	27/07/2022	To determine the	A single-blind, randomized, controlled trial	The subje	Randomization ir	Group (A,B or c	Mean (SD	Male: Gro	Not report	Marital sta	HAMD17, mean (	Cardiovascula	Hospital rehabi	Group A: Patients received placeb	Depression, m	Depression: I	The SPSS 19.0	Grou
Geng 2019	Impact of transitional care for	Giuling Geng	Geng G et al. T	CONTACT	China	IE	27/07/2022	To investigate the	Randomised controlled trial	Inclusion (	Between August	Hospital ward	Mean (SD	Male: inte	Not report	Marital sta	Type of stroke Her	Number of cor	Hospital ward,	Intervention and control groups r	Health promot	Health prom	Data were ana	
Graven 2016	First Year After StrokeAn Integr	Christine Graven	Graven, C., Brc	Christine.(	Australia	KH	13/08/2024	The aim of this stu	Prospective randomised controlled trial	Inclusion:	The participants (	patient, inpatie	Age, mear	Male: n =	n/a	n/a	Stroke type, n (SD	history of depi	Home via telep	The intervention group received a	Primary:level o	GDS-15	Independent	N=11
Greger 2021	Pharmacist intervention and ar	Jessica Greger	Greger J et al. J	Correspor	USA	IE	10/08/2022	The primary objec	Single-centre retrospective chart review	Inclusion:	Retrospective dat	Participant	Mean (SD	Male: con	Not report	Not report	Previous stroke: c	Diabetes mellit	Pharmacist pra	Following initial consultation with	The primary o	Nonresponsi	McNemar's te	Contr
Gun Young 2021	The Effects of an Integrated M	Geun-Young Yang	Yang GY and N	Address re	Korea	IE	12/08/2022	This study examin	Open label non-randomised study with a n	Inclusion:	Blinded allocatior	Participant	Mean (SD	Female: cc	Not report	Education	Type of CVA Infarc	Comorbidity**	Hospital ward,	16 sessions over 8 weeks compris	Physical functi	Physical func	Chi-square tes	
He 2023	Nurse-led rapid rehabilitation f	Yueyue He	He, Y., Wang, F	fengling21	China	KH	13/08/2024	The aim of thisstu	a non-randomized, historically controlled c	Inclusion:	not reported - no	Inpatient, Hosp	Mean (SD	Female, n	n/a	not report	NIHSS score at ad	Hypertension,	Rehabilitation P	The intervention outlines a "Rapic	Primary: disabi	mRS, mBI, EC	Wilcoxon ranl	Contr
Hjelle 2019	EFFECT OF A DIALOGUE-BASED	Ellen G Hjelle	Hjelle EG et al.	Correspor	Norway	IE	12/08/2022	To evaluate the ef	Multicentre, prospective, randomized cont	Patients w	A computer-gene	Participant	Mean (SD	Female: cc	Not report	Living with	Stroke aetiology (	No comorbidit	acute treatmer	The dialogue-based intervention (	Primary: Psych	Primary: Psych	Chi square regres	Enroll
Huang 2023	Early Rehabilitation and Nursin	J Huang	DOI: 10.1097/NRL.000000(	China	IK			Control vs early re	Randomised control trial?	Ischamic s	Randomised but	patients	> 60 years	N/A	N/A	N/A	N/A	N/A	Hospital	ICN (internet + continued nursing	Fugl-Meyer Assessment Scal	X2 for qualitat		
Jones 2016	Feasibility study of an integrate	Fiona Jones	http://dx.doi.org/10.113	United Kin	IK			To test the feasibil	Cluster randomised controlled trial: Feasibi	Site: Com	Randomised with	Participant	Int: 61.79	Male: Int :	N/A	N/A	N/A	N/A	Community (o	individualised approach to self-m	Activities of da	Fisher's exact test. Multi lev		

Data extraction form columns_QJM update

12.4 Appendix D: Systematic Review and Meta-Analysis Publication

OXFORD

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Review

Review

Integrated care management for patients following acute stroke: a systematic review

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Abstract

Contemporary stroke care is moving towards more holistic and patient-centred integrated approaches, however, there is need to develop high quality evidence for interventions that benefit patients as part of this approach. This study aims to identify the types of integrated care management strategies that exist for people with stroke, to determine whether stroke management pathways impact patient outcomes and to identify elements of integrated stroke care that were effective at improving outcomes. The study is a systematic review with meta-analysis. The review was conducted using Medline, CINAHL, Web of Science and the Cochrane Database of randomized controlled trials from January 2012 to January 2024. Studies that evaluated interventions as part of integrated care against a control or standard treatment group were included. Primary outcomes included mortality, recurrent stroke and major bleeding. Secondary outcomes included quality of life, unplanned readmission, anxiety and depression, lifestyle and cardiovascular risk factors, and adherence to intervention. In total, 99 studies were included and 63 were meta-analysed. Patients receiving integrated stroke care had significant reductions in recurrent stroke (RR 0.79, 95% CI: 0.63–1.00, $P = 0.05$, $I^2 = 39\%$), significant improvements in quality of life (SMD = 0.41, 95% CI: 0.26–0.56, $P < 0.00001$, $I^2 = 91\%$) and reduced incidence of depression (RR 0.95, 95% CI: 0.92–0.99, $P = 0.007$, $I^2 = 22\%$). There were no significant differences in mortality or major bleeding. The findings of this study show that integrated care post-stroke is associated with better quality of life and reduced depression and recurrent stroke.

Introduction

Effective stroke care needs an organizational structure that facilitates best treatments at the right time.[1] Contemporary stroke care commonly involves a multidisciplinary team of healthcare professionals.[2] Integrated care in stroke has been defined as a project network technique involving interdisciplinary interventions to improve communication and co-ordination between disciplines, providing a time frame for patient care, with regular monitoring of patient progression.[3] However, there is no unifying definition or common conceptual understanding of integrated care, and the perspectives that construct the concept can be shaped by views and expectations of various health system stakeholders.[4]

The centralization of stroke services in parts of the UK and the formation of hyperacute stroke units (HASUs) offering continual access to stroke specialists, investigations and interventions[5] can be considered to represent integrated care in acute stroke. The treatment of stroke patients in HASUs has resulted in reductions in mortality and length of hospital stay compared with traditional stroke units.[6,7]

Recently, there has been a move towards a more integrated or holistic management pathway for patients following acute stroke, which might prevent recurrent stroke and could also improve patient functional status, symptoms and comorbidities[2,8] however many challenges remain. These include a lack of consensus on the optimal care pathway for patients,[9,10] high heterogeneity among stroke treatment centres[11] and the continuing need to develop high quality evidence for prevention of secondary vascular events and risk factor management after stroke.[12–14]

With no clear definition of integrated care in stroke and no consensus on optimal patient management in the acute and post-acute settings, some clarification on which integrated care strategies are most beneficial to patients is needed. In this study, we aimed to identify the types of integrated care management strategies that exist for people with stroke, to determine whether stroke management pathways impact patient outcomes and to identify elements of integrated care that improved patient outcomes.

Methods

This systematic review was conducted in accordance with the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA).

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Inclusion and exclusion criteria

Studies of integrated care in stroke patients were included in the review based on NHS/WHO definitions (Supplementary Material S1). Stroke was defined using the American Heart Association/American Stroke Association (AHA/ASA) guidelines.[12] Patients with any acute stroke or transient ischaemic attack (TIA) of any age, and any pathological type of stroke (ischaemic, venous, intracerebral haemorrhage) were included. All randomized controlled trials (RCTs), uncontrolled comparative trials, observational cohort studies, mixed methods and quantitative case studies were considered for inclusion whereas studies involving patients for which stroke was not the primary event or where a definitive diagnosis of stroke could not be confirmed were excluded.

Search strategy

The search strategy used medical subject headings (MeSH) terms and synonyms for "stroke" and "integrated care". These terms were combined with Boolean operators, truncations and wildcards. Studies with evidence of a multidisciplinary approach to care with or without a patient-centred focus were included. MEDLINE, CINAHL, Web of Science and the Cochrane Central Register of Controlled Trials were searched from 1 January 2012 to 1 January 2024 for relevant studies (Supplementary Material S1).

Data extraction

Data extraction was conducted independently by I.E., K.L.H., M.F-R. and I.K. using a bespoke data extraction tool and included: (a) authors, publication year, country of origin, reference; (b) study design with inclusion/exclusion criteria; (c) aims and objectives; (d) demographic data (including *n*=, age, sex, ethnicity, disease characteristics, co-morbidities); (e) description of intervention and/or comparator; (f) outcomes (effectiveness and safety); (g) results; (h) conclusions and (i) risk of bias assessment.

Risk of bias assessment

Risk of bias was independently assessed in duplicate by I.E. and I.K., K.L.H. or M.F-R. and discrepancies were discussed and resolved with a third reviewer (B.R.J.B). The Cochrane Risk of Bias v.2 (RoB2) tool[15] and the Risk Of Bias In Non-randomized Studies—of Interventions (ROBINS-I)[16] were used for randomized and non-randomized trials, respectively.

Data synthesis

Results of the systematic review were grouped by outcome (primary: mortality, recurrent stroke, major bleeding; secondary: quality of life, unplanned readmission, depression/anxiety, treatment adherence). Meta-analyses were conducted for comparable studies where sufficient data were present. Primary and secondary outcome effect measures with 95% confidence intervals (CI) were pooled using RevMan software version 5.4.[17] Random effects models were used, allowing for between-study variability by weighting studies using a combination of intra- and inter-study variance. Results were presented visually using Forest plots. Heterogeneity was assessed visually and using the I^2 statistic with 25%, 50% and 75% considered moderate, substantial and considerable heterogeneity, respectively.

To measure overall treatment effects, the Der Simonian & Laird method for both binary (e.g. mortality) and continuous (e.g. quality of life) outcomes was used. If continuous data were not homogeneous, an estimate of the standardized mean difference (SMD) with 95% CI was calculated. If quantitative data were too few or too heterogeneous, then a narrative synthesis approach was undertaken.

Analysis of subgroups or subsets

Mortality and other outcomes (where applicable) were analysed according to length of follow-up, via sub-group analyses to stratify for different follow-up time points. Quality of life and depression/anxiety data were grouped and analysed according to type of measurement tool (e.g. VAS, EQ-5D, HADS). Where feasible, SMDs were used to meta-analyse similar scales. Meta-analyses of randomized controlled trials (RCTs) and non-randomized trials (NRCTs) were conducted separately.

Results

An initial search yielded 27 271 records. After removal of duplicates, 330 papers were assessed for eligibility against the inclusion/exclusion criteria. Of these, 99 (30%) were included in the systematic review (Figure 1) and 63 (19%) were included in meta-analysis.

Characteristics of the included studies

The studies included in the review were published between January 2012 and January 2024. Of the 99 studies, the majority (64) were RCTs (Supplementary Material S2). The total number of participants included in the review was 88 435, of which 40 475 received an integrated care intervention or pathway comprising multiple interventions. Mean/median patient age ranged from 53 years[18–21] to 83 years[22] and the proportion of females ranged from 23%[23] to 70%[24].

Of the 64 RCTS, 10 were considered at low risk of bias, 33 were moderate risk and 21 studies were at high risk of bias due to small numbers, study design, confounding factors or missing data. Of 35 NRCTs, 20 were considered at moderate risk of bias and 15 studies were at high risk of bias (Supplementary Material S3).

Of the 99 individual studies, 28 included an exercise intervention, 28 included an educational component, 17 included a psychological intervention and 16 assessed lifestyle and cardiovascular risk factors. Forty-two (42) studies included multiple interventions or complete pathways and 19 studies were considered patient centred. Of the intervention types, exercise, lifestyle and mental health interventions positively impacted on the majority of protocol-specified primary and secondary outcomes across studies however only exercise positively impacted all outcomes.[18,25–36]

Overall, the results of the studies were inconclusive, with 34% showing no significant benefit of the intervention over the control or comparator group and there was substantial heterogeneity between studies.

Meta-analysis

The findings of the meta-analysis are summarized in Table 1.

Primary outcomes

Mortality

A total of 13 ($n=21\,533$) RCTs compared integrated care with control for mortality (Figure 2A). Integrated care was not associated with reduced mortality (relative risk [RR] 0.79, 95% CI: 0.59–1.06, $I^2=74\%$). Sub-group analysis of NRCTs indicated a significant reduction in long-term (>1 year) mortality in favour of integrated

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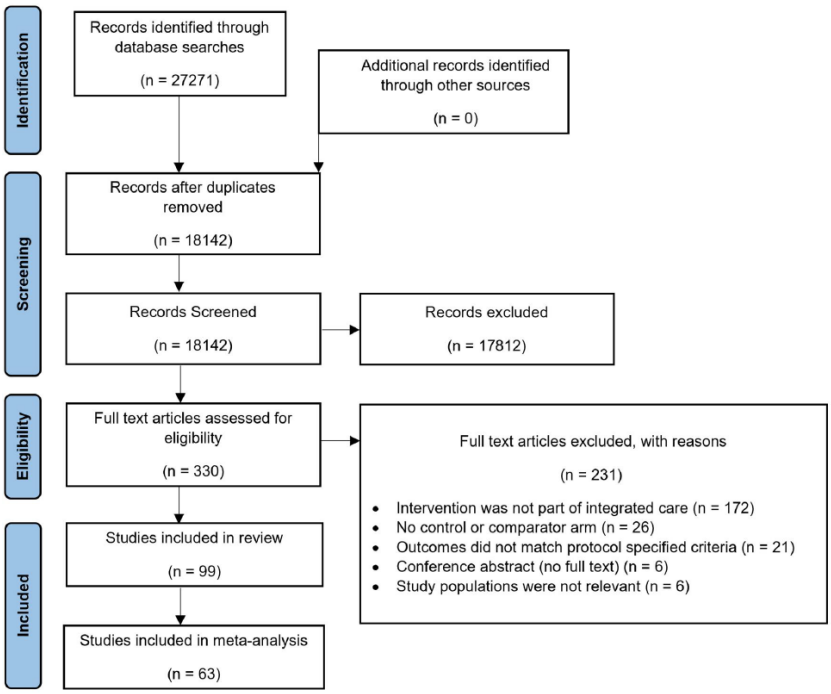


Figure 1. PRISMA chart for systematic review of integrated care in stroke.

care (RR 0.58, 95% CI: 0.43–0.80, $P = 0.0007$, $I^2 = 86\%$) however there were only three studies ($n = 9404$) included in this analysis (Figure 2B).

Recurrent stroke

A total of nine ($n = 10\,915$) RCTs showed a statistically significant reduction in recurrent stroke in favour of integrated care (RR 0.79, 95% CI: 0.63–1.00, $P = 0.05$, $I^2 = 39\%$, Figure 3A) however there was no difference in recurrent stroke between groups in NRCTs (RR 1.08, 95% CI: 0.64–1.82, $P = 0.78$, $I^2 = 4\%$, Figure 3B).

Major bleeding

A total of four RCTs ($n = 8210$) compared integrated care with control for major bleeding (Figure 4). There were more bleeding events associated with integrated care versus control (RR 1.35, 95% CI: 0.56–3.22, $I^2 = 84\%$), however the difference was not statistically significant ($P = 0.50$).

Secondary outcomes

Quality of life

Meta-analysis was conducted on a total of 21 studies ($n = 10\,653$) using SMD to combine different quality of life (QoL) scales (Figure 5). Overall, there were significant improvements in QoL in favour of integrated care (SMD = 0.41, 95% CI: 0.26–0.56, $P < 0.00001$, $I^2 = 91\%$). Subgroup meta-analysis showed that the greatest differences in QoL were observed with SF-36 and SSQOL (Supplementary Material S4).

Unplanned readmission

There was no significant difference in unplanned (based on the assumption that the majority of readmissions were due to complications or events such as subsequent stroke or myocardial infarction [MI] that could not be predicted) readmission rates in nine ($n = 7236$) RCTs (RR 0.88, 95% CI: 0.73–1.05, $P = 0.15$, $I^2 = 71\%$, Figure 6A) or in five ($n = 6370$) NRCTs (RR 0.76, 95% CI: 0.37–1.57, $P = 0.46$, $I^2 = 97\%$, Figure 6B).

Anxiety and depression

Meta-analysis was conducted on seven ($n = 36\,044$) RCTs reporting proportions of patients with depression using Yale-Brown, GDS, PROMS, PHQ2 and HADS-D scales (Figure 7). Integrated care was associated with a significant reduction in the proportion of patients with depression (RR 0.95, 95% CI: 0.92–0.99, $P = 0.007$, $I^2 = 22\%$, Figure 7) regardless of follow-up time (up to 6 months or up to 12 months). Meta-analysis also showed that anxiety and depression scores were significantly lower with integrated care regardless of scale or follow-up time (Supplementary Material S4).

Lifestyle and cardiovascular risk factors

Overall, integrated care was associated with a significant improvement in cardiovascular risk (Table 1). Further information can be found in Supplementary Material S4.

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Table 1 Summary of findings table for systematic review of integrated care

Outcomes	Relative effect (95% CI)	Number of participants (studies)	Comments
Primary			
Mortality	RCTs: RR 0.79 (0.59–1.06) NRCTs: RR 0.82 (0.45–1.49)	21 533 (13) 31 223 (9)	There were fewer death events in the integrated care groups compared with control but no significant overall difference in mortality in RCTs or NRCTs. The only significant difference in death events was observed in a subgroup analysis of long-term mortality in NRCTs (>1 year, 9404 patients, three studies, RR = 0.58, $P = 0.0007$)
Recurrent stroke	RCTs: RR 0.79 (0.63–1.00) NRCTs: RR 1.08 (0.64–1.82)	10 915 (9) 1604 (3)	There were significantly fewer recurrent strokes associated with RCTs of integrated care compared with control ($P = 0.05$) however there were no differences in NRCTs
Major bleeding	RR 1.35 (0.56–3.22)	8210 (4)	There were more major bleeding events in the integrated care groups compared with control but the difference was not statistically significant ($P = 0.50$)
Secondary			
Quality of life	SMD: 0.41 (0.26–0.56)	10 653 (21)	Integrated care interventions significantly improved quality of life ($P < 0.00001$), with the greatest difference in QoL scoring observed with the SF-36 general health questionnaire and the SSQOL scoring tools
Unplanned readmission	RCTs: RR 0.88 (0.73–1.05) NRCTs: RR 0.76 (0.37–1.57)	7236 (9) 6370 (5)	There were fewer unplanned readmission events associated with integrated care interventions however the differences were not significant in either RCTs ($P = 0.15$) or NRCTs ($P = 0.46$)
Anxiety and depression	Depression: RR 0.95 (0.92–0.99) Anxiety (HADS-A): RR 0.75 (0.57–0.99)	36 044 (7) 606 (3)	The proportion of patients with depression was significantly lower with integrated care compared with control ($P = 0.007$). An analysis of anxiety using the HADS-A assessment tool showed that the proportion of patients with anxiety was significantly lower with integrated care ($P = 0.04$)
Lifestyle and cardiovascular risk factors	SMD −0.17 (−0.25 to −0.09)	4538 (9)	Overall, integrated care was associated in a significant improvement in cardiovascular risk factors ($P < 0.0001$), with significant reductions in SBP and LDL-cholesterol (both $P \leq 0.03$) however there were no differences between groups for total cholesterol, BMI or the proportion of patients stopping smoking
Adherence to intervention	RR 1.31 (0.77–2.23)	3646 (4)	Integrated care was associated with higher rates of adherence compared with control however the difference was not statistically significant ($P = 0.32$)
Exploratory			
Favourable outcome (mRS ≤ 2)	RR 1.02 (0.98–1.07)	4751 (4)	There was no difference in the proportion of patients with favourable outcome between integrated care and control ($P = 0.35$)
Recurrent risk of cardiovascular disease: Myocardial infarction Vascular death	RR 0.60 (0.34–1.05) RR 0.58 (0.21–1.60)	7733 (3) 4221 (2)	There were fewer events of myocardial infarction and vascular death associated with integrated care however these differences were not statistically significant (MI, $P = 0.07$; vascular death, $P = 0.30$)

Patient or population: people with stroke.
Setting: during and after care.
Intervention: Integrated care.
Comparison: Control; end of intervention.
BMI, body mass index; CI, confidence interval; HADS-A, hospital anxiety and depression scale-anxiety component; LDL, low density lipoprotein; MI, myocardial infarction; mRS, modified Rankin Scale; NRCT, nonrandomized controlled trial; RCT, randomized controlled trial, RR, risk ratio; SBP, systolic blood pressure; SMD, standardized mean difference.

Adherence to intervention

Overall, adherence rates were higher with integrated care but the difference was not statistically significant ($P = 0.32$, Table 1). Further information can be found in Supplementary Material S4.

Exploratory analysis: functional status

An exploratory meta-analysis was conducted on four RCTs ($n = 4751$) that included data on functional status according to the modified Rankin Scale (mRS). This analysis showed no significant difference in favourable outcome (defined as mRS ≤ 2) between integrated care and control (RR 1.02, 95% CI: 0.98–1.07, $P = 0.35$, $I^2 = 77\%$, Figure 8).

Exploratory analysis: recurrent risk of cardiovascular disease

Meta-analysis was conducted for MI (three studies, $n = 7733$) and vascular death events (two studies, $n = 4221$). Although there were fewer events associated with integrated care, these differences were not statistically significant (Table 1). Further information can be found in Supplementary Material S4.

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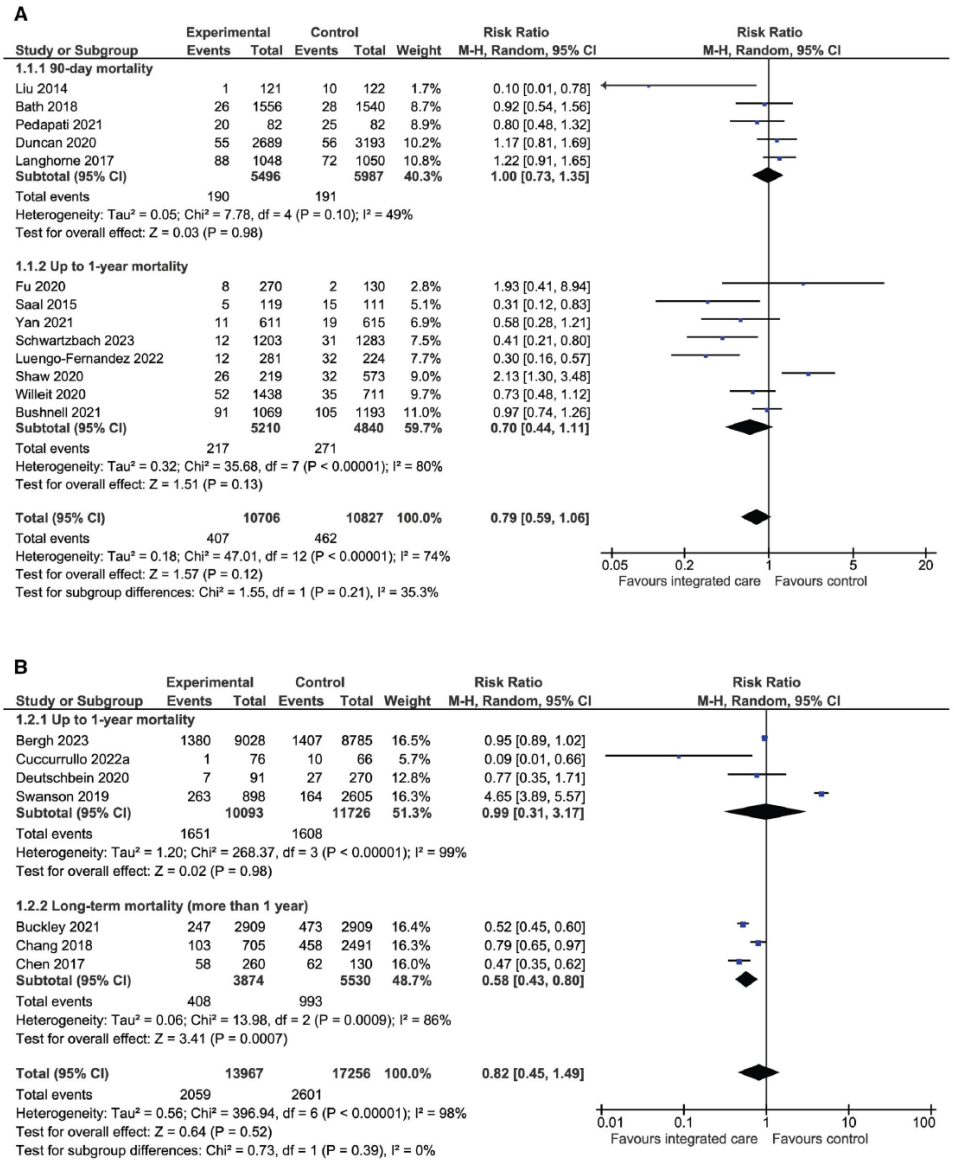


Figure 2. Comparison of integrated care with control for mortality (A, randomized controlled trials; B, nonrandomized trials).

Discussion

To our knowledge, this is the first comprehensive systematic review with meta-analyses of integrated care in stroke showing that integrated care was associated with improvements in QoL, reductions in recurrent stroke, anxiety and depression and positive benefits on some cardiovascular risk factors but did not impact mortality, major bleeding or readmission rates. Other systematic reviews have evaluated interventions such as organized inpatient stroke care,[37] exercise,[38–41] early supported discharge[42–44] and interventions for cognitive rehabilitation,[45] depression[46] and anxiety[47] however none of these reviews were conducted in the setting of integrated care.

Whilst some studies demonstrated a benefit in outcomes with integrated care interventions, other studies using similar

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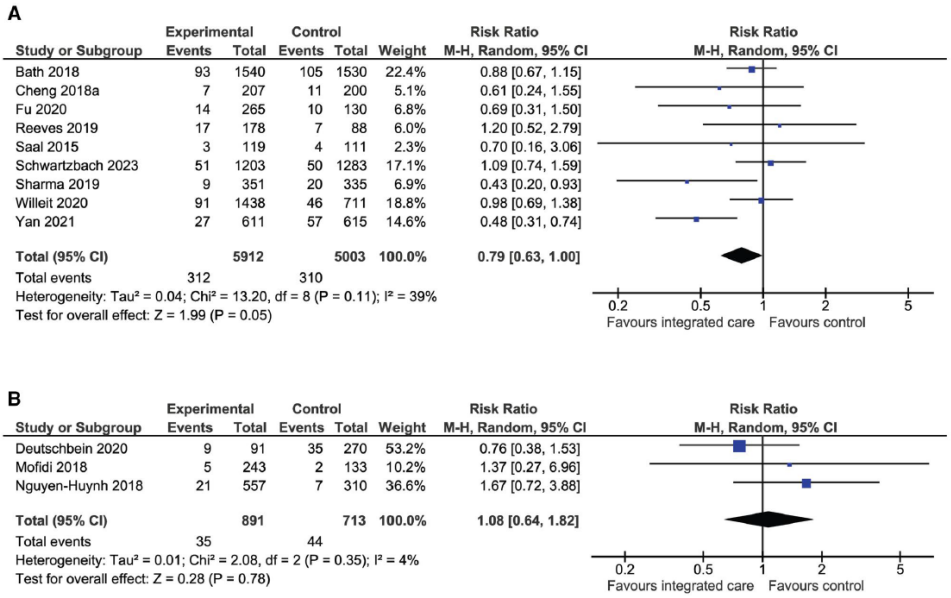


Figure 3. Comparison of integrated care with control for recurrent stroke (A, randomized controlled trials; B, nonrandomized controlled trials).

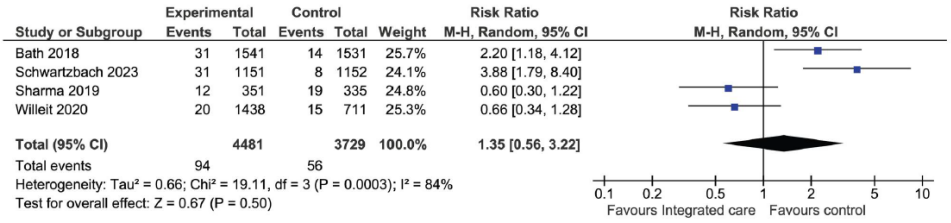


Figure 4. Comparison of integrated care with control for major bleeding (randomized controlled trials).

interventions did not. These observations highlight a lack of consensus over which components should form part of an integrated stroke pathway and how they should be implemented. Indeed, individual studies demonstrated that interventions such as exercise, rehabilitation, risk factor management and mental health initiatives were most effective at improving outcomes in people with stroke. These included studies of cardiovascular exercise and high-intensity rehabilitation that were associated with significantly lower mortality rates.[25,35,48] The EXPRESS study of rapid assessment and treatment initiation with high-dose aspirin or clopidogrel and intensive and regular follow-up demonstrated a reduction in stroke risk and disability (mRS ≥ 2) even after 10 years.[49] Similarly, the COMPASS study of combined anticoagulant and antiplatelet therapy significantly reduced the risk of ischaemic/unknown stroke in 1032 patients with prior stroke (HR, 0.33, 95% CI: 0.14–0.77, $P = 0.01$).[50] The STROKE-CARD study, a comprehensive disease management program delivered by a multidisciplinary team that included risk factor management and patient education, reported reduced cardiovascular risk and improved QoL.[51] Studies employing interventions such as early supported discharge, regular community follow-up, education, cognitive and motivational training, and goal setting reported significant reductions in the proportions of participants with depression or anxiety and improvements in QoL,[30,36,52–57] with individualized care pathways and mhealth technology providing substantial improvements in these outcomes.[20,55,58–60]

Conversely, there are large and well-designed randomized trials of comprehensive integrated care interventions that did not demonstrate any substantial benefit over standard care. The structured ambulatory post-stroke care program (SANO) study, a 1-year patient-centred integrated care intervention including regular follow-up, lifestyle advice, goal setting and motivational interviewing, demonstrated positive benefits in controlling CV risk factors such as blood pressure and LDL cholesterol, but did not reduce the rate of major cardiovascular events.[61] In the Triple Antiplatelets for Reducing Dependency after Ischaemic

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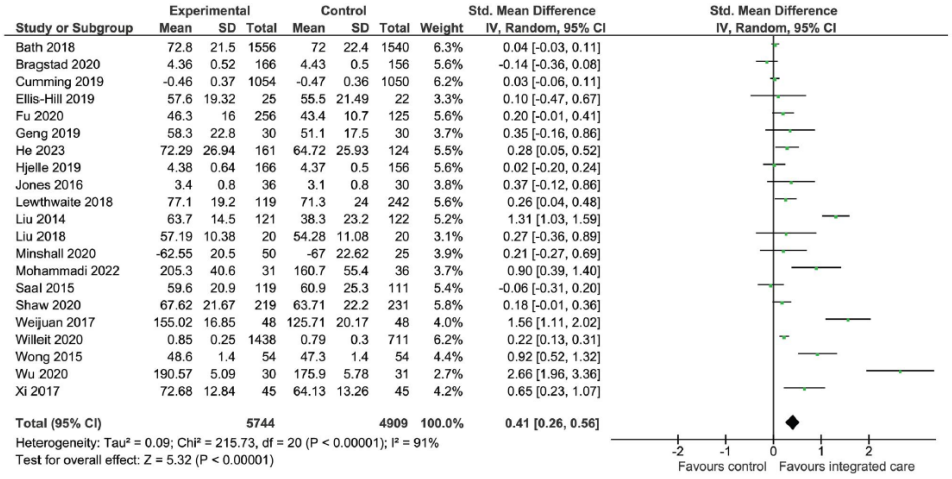


Figure 5. Comparison of integrated care with control for quality of life (randomized controlled trials).

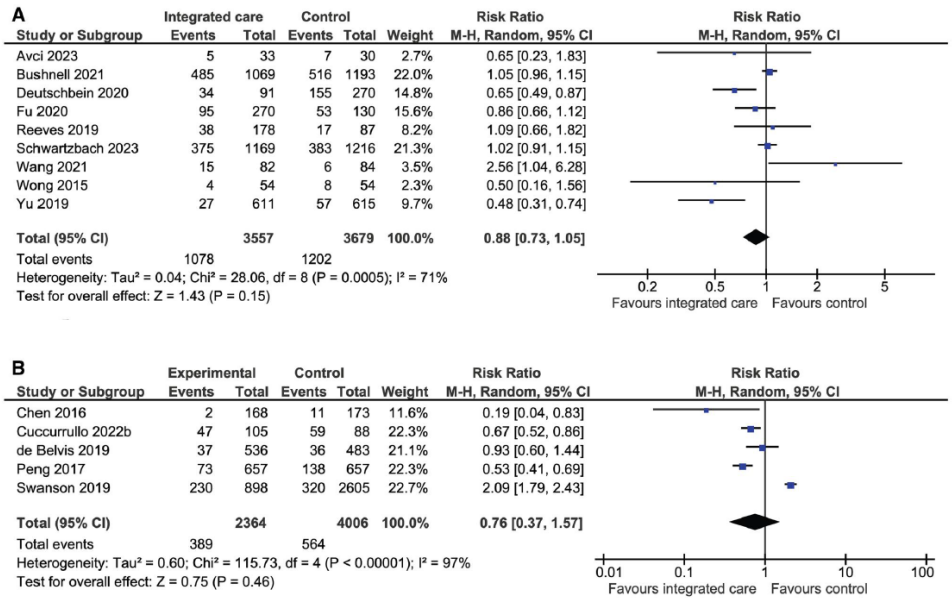


Figure 6. Comparison of integrated care with control for unplanned readmission (A, randomized controlled trials; B, nonrandomized controlled trials).

Stroke (TARDIS) study, significantly more bleeding events were reported overall in the TARDIS group (19.8%) compared with the control group (9.1%, $P < 0.001$), prompting the study to be stopped early.[62] The Very Early Rehabilitation Trial for stroke study (AVERT) showed significantly fewer participants in the AVERT group had favourable outcome and there was no difference in mortality or QoL.[63–65]

Overall, the results of this systematic review are inconsistent, with 34% of reviewed studies showing no benefit over comparator treatment and substantial heterogeneity between studies.

The centralization of stroke services and the creation of HASUs has improved outcomes for patients compared with traditional stroke units, reflected in reduced mortality rates and hospital length of stay[6,7] however there is currently no standard

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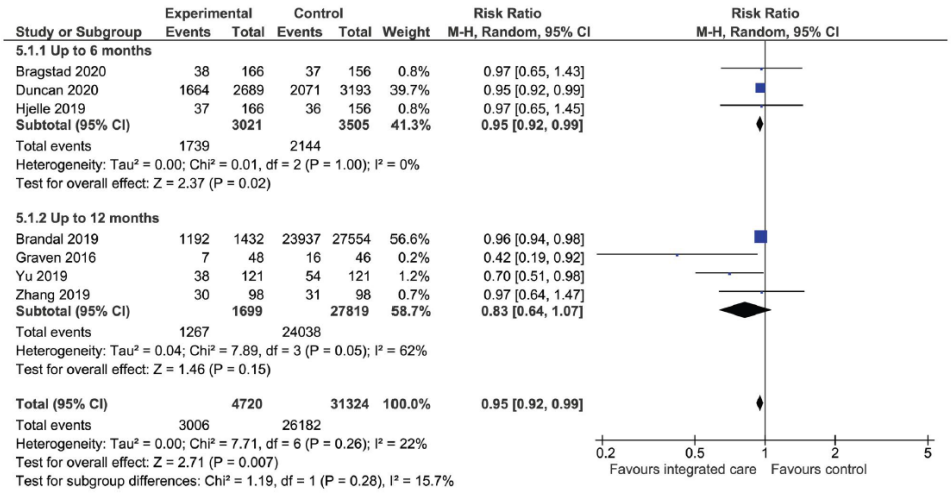


Figure 7. Comparison of integrated care with control for proportion of patients with depression by follow-up time.

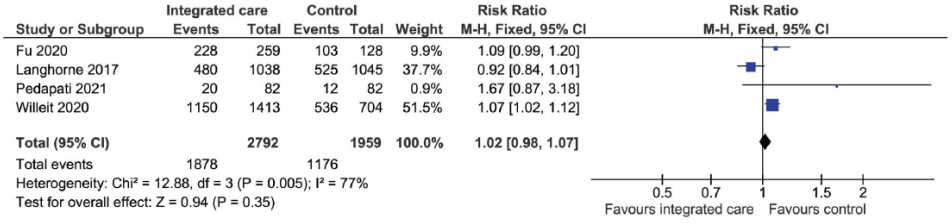


Figure 8. Comparison of integrated care with control for proportion of patients with favourable outcome (mRS ≤ 2).

HASU care pathway and outcomes vary widely as a result.[66,67] Much of the published data on stroke care management is in the acute setting,[68] where integrated care plans such as early supported discharge[43,44,53,69,70] are often clearly defined however less is known about patient care following discharge back into the community and studies show that care from this point onwards is often discontinuous,[71–73] which can result in unmet needs and increased potential for hospitalization and institutionalization.[72] A recent Sentinel Stroke National Audit Programme (SSNAP) annual report identified a decline in the proportion of patients receiving a 6-month review and highlighted the need for an adequately resourced multidisciplinary team of healthcare professionals required to deliver the recommended amount of rehabilitation of patients according to their need, especially in the community setting.[74]

Primary outcomes

Meta-analysis showed no difference overall in mortality between integrated care and control or standard care. Although subgroup analysis showed a significant reduction in long-term mortality in favour of integrated care, there were only three studies in this subgroup and the findings must be interpreted with caution. The overall findings are consistent with the published literature with systematic reviews of early supported discharge and exercise showing no significant differences in mortality rates compared with standard care.[43,44,75]

A statistically significant reduction in recurrent stroke in favour of integrated care was observed with RCTs but not with NRCTs. Few systematic reviews have directly assessed the impact of interventions on recurrent stroke as an outcome however the interventions in this analysis that were associated with reductions in recurrent stroke (lifestyle and cardiovascular risk factor management) have also been shown to reduce recurrent stroke rates in meta-analyses.[76–78]

Integrated care was associated with more major bleeding events compared with standard care however the difference was not statistically significant ($P = 0.50$). There are numerous meta-analyses comparing oral anticoagulants for stroke prevention in patients with atrial fibrillation (AF) and in general direct oral anticoagulants (DOAC) have a lower bleeding risk than Vitamin K agonists (VKA).[79–82] Combination treatment with anticoagulant and antiplatelets is associated with increases in the risk of major bleeding in cardiovascular disease (CVD).[83,84] In this review, the TARDIS and COMPASS studies reported increased major bleeding events with triple therapy and reduced events with low-dose rivaroxaban and aspirin treatment, respectively.[50,62] Meta-analyses of major

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bleeding risk in stroke survivors are currently lacking in the published literature.

Secondary outcomes

Overall, integrated care was associated with improvements in QoL and the magnitude of improvement was greatest with the SF-36 and SSQOL assessment tools however these findings must be interpreted in the presence of substantial (>75%) heterogeneity between studies. Meta-analysis also showed that integrated care was associated with statistically significant reductions in the proportion of patients with anxiety and depression, with a statistically significant benefit for the cardiovascular risk factors of systolic blood pressure (SBP) and LDL cholesterol.

Improvements in QoL are documented in the literature with interventions such as organized stroke care[37] and exercise[75,85,86] however the degree of improvement in QoL is difficult to define due to lack of information.[75]

Limitations

There is currently no standard or unifying definition of integrated care and delivery is likely to be influenced by views and expectations of various stakeholders in the health system,[4] an observation that has been confirmed in studies of hyperacute stroke care where different outcomes were reported due to differences in care models and priorities.[66,67] For example, centralization of stroke services in London resulted in a significant reduction in mortality rates since almost all London patients were treated in a HASU and were more likely to receive evidence-based care whereas stroke patients in Manchester were far less likely to be treated in a HASU and receive evidence-based care, resulting in unchanged mortality rates.[66] The WHO reports large variations in the definition of integrated care and for the purposes of this review, we used a definition of integrated care developed by the NHS and WHO (Supplementary Material S1) and included studies where there was evidence of an integrated care approach according to this definition however some studies could have been missed during the literature searches if they were not considered to be integrated care per definition. Due to the volume of published studies in stroke, the search was restricted to 12 years however it is possible that some important studies could have been missed if they fell outside of the search window. Most of the integrated care trials in this review included multiple interventions or comprised complete pathways and the effect of individual interventions could not be assessed.

Meta-analysis of outcomes indicates high heterogeneity between studies, in particular those evaluating QoL, which confounds interpretation of the findings. Due to the majority of studies having small patient numbers and the paucity of data available for some outcomes, the systematic review did not exclude studies considered to be at moderate or high risk of bias and these studies may have influenced the results of the meta-analyses.

Conclusions

The findings of this systematic review demonstrate that integrated care improves quality of life, reduces recurrent stroke, anxiety and depression and is associated with a positive benefit on some cardiovascular risk factors but does not impact mortality or readmission rates. Further research is necessary to fully determine which elements of integrated care provide the most benefit to people with stroke.

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Author contributions

Ian Eustace (Conceptualization [equal], Data curation [lead], Formal analysis [lead], Investigation [lead], Methodology [lead], Project administration [lead]), Benjamin Buckley (Conceptualization [equal], Data curation [supporting], Formal analysis [supporting], Investigation [supporting], Methodology [supporting], Project administration [supporting], Supervision [equal]), Isik Kaya (Data curation [supporting], Formal analysis [supporting]), Katie Hoad (Formal analysis [supporting]), Madeleine France-Ratcliffe (Formal analysis [supporting]), Andrew M. Hill (Investigation [supporting]), Ian Jones (Conceptualization [equal], Methodology [supporting], Supervision [equal]), Karen Higginbotham (Conceptualization [equal], Methodology [supporting], Supervision [equal]), and Gregory Lip (Conceptualization [equal], Investigation [supporting], Methodology [supporting], Supervision [equal])

Supplementary material

Supplementary material is available at *QJMED* online.

Conflict of interest: G.Y.H.L. is a consultant and speaker for BMS/Pfizer, Boehringer Ingelheim, Daiichi-Sankyo, Anthos. No fees are received personally. He is a National Institute for Health and Care Research (NIHR) Senior Investigator and co-principal investigator of the AFFIRMO project on multimorbidity in AF, which has received funding from the European Union's Horizon 2020 research and innovation programme under grant Agreement No. 899871. B.J.R.B. has received research grants from BMS/Pfizer. I.D.J. has received investigator-initiated funds from Bristol Myers Squibb and Astra Zeneca. No fees are received personally. A.M.H., K.H., I.E., I.K., K.L.H. and M.F-R. have no conflicts of interest to declare.

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References

1. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke for the UK and Ireland. 2023. https://www.strokeguideline.org/
2. Lip GYH, Ntaios G. "Novel clinical concepts in thrombosis": integrated care for stroke management-easy as ABC. *Thromb Haemost* 2022; **122**:316–9.
3. Sulch D, Kalra L. Integrated care pathways in stroke management. *Age Ageing* 2000; **29**:349–52.
4. Satylganova A, Tello J, Barbazza E. Integrated care models: an overview. World Health Organization [Internet]. 2016. https://www.researchgate.net/publication/315493946_Integrated_care_models_an_overview_Copenhagen_WHO_Regional_Office_for_Europe_2016
5. Liu SD, Rudd A, Davie C. Hyper acute stroke unit services. *Clin Med (Lond)* 2011; **11**:213–4.

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6. Hunter RM, Davie C, Rudd A, Thompson A, Walker H, Thomson N, *et al.* Impact on clinical and cost outcomes of a centralized approach to acute stroke care in London: a comparative effectiveness before and after model. *PLoS One* 2013; **8**:e70420.
7. Morris S, Hunter RM, Ramsay AI, Boaden R, McKevitt C, Perry C, *et al.* Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis. *BMJ* 2014; **349**:g4757.
8. Lip GYH, Lane DA, Lenarczyk R, Boriani G, Doehner W, Benjamin LA, *et al.* Integrated care for optimizing the management of stroke and associated heart disease: a position paper of the European Society of Cardiology Council on Stroke. *Eur Heart J* 2022; **43**:2442–60.
9. McMahon NE, Bangee M, Benedetto V, Bray EP, Georgiou RF, Gibson JME, *et al.* Etiologic workup in cases of cryptogenic. *Stroke* 2020; **51**:1419–27.
10. Norrving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, *et al.* Action plan for stroke in Europe 2018–2030. *Eur Stroke J* 2018; **3**:309–36.
11. Ali M, Salehnejad R, Mansur M. Hospital heterogeneity: what drives the quality of health care. *Eur J Health Econ* 2018; **19**:385–408.
12. Kleindorfer DO, Towfighi A, Chaturvedi S, Cockroft KM, Gutierrez J, Lombardi-Hill D, *et al.* 2021 Guideline for the prevention of stroke in patients with stroke and transient ischemic attack: a guideline from the American Heart Association/American Stroke Association. *Stroke* 2021; **52**:e364–467.
13. Mackay-Lyons M, Thornton M, Ruggles T, Che M. Non-pharmacological interventions for preventing secondary vascular events after stroke or transient ischemic attack. *Cochrane Database Syst Rev* 2013; Mar 28(3):CD008656.
14. Stinear CM, Lang CE, Zeiler S, Byblow WD. Advances and challenges in stroke rehabilitation. *Lancet Neurol* 2020; **19**:348–60.
15. Sterne JAC, Savovic J, Page MJ, Elbers RG, Blencowe NS, Boutron I, *et al.* RoB 2: a revised tool for assessing risk of bias in randomised trials. *BMJ* 2019; **366**:l4898.
16. Sterne JA, Hernan MA, Reeves BC, Savovic J, Berkman ND, Viswanathan M, *et al.* ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ* 2016; **355**:i4919.
17. The Cochrane Collaboration. Review Manager (RevMAN) [Computer program]. Version 5.4, 2020.
18. Lee A-Y, Park S-A, Park H-G, Son K-C. Determining the effects of a horticultural therapy program for improving the upper limb function and balance ability of stroke patients. *Horts* 2018; **53**:110–9.
19. Pedapati R, Bhatia R, Shakywar M, Gupta A, Vishnubhatla S, Srivastava MVP, *et al.* Educating caregivers to reduce complications and improve outcomes of stroke patients (ECCOS) – a cluster-randomized trial. *J Stroke Cerebrovasc Dis* 2021; **30**:105966.
20. Xi W, Duan Y, Wang A. Influence of continuing nursing outside hospital on rehabilitation effect and quality of life in patients with stroke. *Chin Nurs Res* 2017; **31**:3760–2.
21. Chen L, Sit JW-H, Shen X. Quasi-experimental evaluation of a home care model for patients with stroke in China. *Disabil Rehabil* 2016; **38**:2271–6.
22. Swanson JO, Moger TA. Comparisons of readmissions and mortality based on post-discharge ambulatory follow-up services received by stroke patients discharged home: a register-based study. *BMC Health Serv Res* 2019; **19**:4.
23. Long W, Zhang J. Patient caregiver comprehensive rehabilitation nursing training joint continued nursing care for ischemic stroke patients at home impact on quality of life and activities of daily living. *Chin Nurs Res* 2017; **31**:2456–61.
24. Vluggen TPMM, van Haastregt JCM, Tan FE, Verbunt JA, van Heugten CM, Schols JMGA. Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial. *BMC Geriatr* 2021; **21**:134.
25. Buckley BJR, Harrison SL, Fazio-Eynullayeva E, Underhill P, Lane DA, Thijssen DHJ, *et al.* Exercise-based cardiac rehabilitation associates with lower major adverse cardiovascular events in people with stroke. *Cerebrovasc Dis* 2022; **51**:488–92.
26. Chen CM, Yang YH, Chang CH, Chen PC. Effects of transferring to the rehabilitation ward on long-term mortality rate of first-time stroke survivors: a population-based study. *Arch Phys Med Rehabil* 2017; **98**:2399–407.
27. Yang GY, Min HS. The effects of an integrated management program on physical function, cognitive function, and depression in patients with subacute stroke. *J Korean Crit Care Nurs* 2021; **14**:50–62.
28. Wong FKY, Wang SL, Ng SSM, Lee PH, Wong AKC, Li H, *et al.* Effects of a transitional home-based care program for stroke survivors in Harbin, China: a randomized controlled trial. *Age Ageing* 2022; **51**:afac027.
29. Khramov W, Kogaeva KP, Arkhipova LU, Alekseeva VO, Lukyanova MI. Effectiveness of post-stroke social rehabilitation in patients with moderate impairments. *BRSMU* 2021; **2**:62–8.
30. Lewthwaite R, Winstein CJ, Lane CJ, Blanton S, Wagenheim BR, Nelsen MA, *et al.* Accelerating stroke recovery: body structures and functions, activities, participation, and quality of life outcomes from a large rehabilitation trial. *Neurorehabil Neural Repair* 2018; **32**:150–65.
31. Lin RC, Chiang SL, Heitkemper MM, Weng SM, Lin CF, Yang FC, *et al.* Effectiveness of early rehabilitation combined with virtual reality training on muscle strength, mood state, and functional status in patients with acute stroke: a randomized controlled trial. *Worldviews Evid Based Nurs* 2020; **17**:158–67.
32. Peng LN, Lu WH, Liang CK, Chou MY, Chung CP, Tsai SL, *et al.*, Taiwan Stroke Postacute Care (PAC) Study Group. Functional outcomes, subsequent healthcare utilization, and mortality of stroke postacute care patients in Taiwan: a nationwide propensity score-matched study. *J Am Med Dir Assoc* 2017; **18**:990.e7–12.
33. Teuschl Y, Matz K, Firlinger B, Dachenhausen A, Tuomilehto J, Brainin M, ASPIS Study Group. Preventive effects of multiple domain interventions on lifestyle and risk factor changes in stroke survivors: evidence from a two-year randomized trial. *Int J Stroke* 2017; **12**:976–84.
34. Cuccurullo SJ, Fleming TK, Kostis JB, Greiss C, Eckert A, Ray AR, *et al.* Impact of modified cardiac rehabilitation within a stroke recovery program on all-cause hospital readmissions. *Am J Phys Med Rehabil* 2022; **101**:40–7.
35. Cuccurullo SJ, Fleming TK, Zinonos S, Cosgrove NM, Cabrera J, Kostis JB, *et al.* Stroke recovery program with modified cardiac rehabilitation improves mortality, functional & cardiovascular performance. *J Stroke Cerebrovasc Dis* 2022; **31**:106322.
36. Rasmussen RS, Østergaard A, Kjær P, Skerris A, Skou C, Christoffersen J, *et al.* Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: a randomised controlled trial. *Clin Rehabil* 2016; **30**:225–36.
37. Langhorne P, Ramachandra S, Stroke Unit Trialists C. Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database Syst Rev* 2020; **4**:CD000197.

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38. Mehrholz J, Kugler J, Pohl M. Water-based exercises for improving activities of daily living after stroke. *Cochrane Database Syst Rev* 2011; **2011**:CD008186.
39. Mehrholz J, Thomas S, Elsner B. Treadmill training and body weight support for walking after stroke. *Cochrane Database Syst Rev* 2017; **8**:CD002840.
40. Pollock A, Baer G, Campbell P, Choo PL, Forster A, Morris J, *et al.* Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database Syst Rev* 2014; **2014**:CD001920.
41. Saunders DH, Sanderson M, Hayes S, Johnson L, Kramer S, Carter D, *et al.* Physical fitness training for patients with stroke. *Stroke* 2020; **51**:E299–300.
42. Goncalves-Bradley DC, Iliffe S, Doll HA, Broad J, Gladman J, Langhorne P, *et al.* Early discharge hospital at home. *Cochrane Database Syst Rev* 2017; **6**:CD000356.
43. Jee S, Jeong M, Paik NJ, Kim WS, Shin YI, Ko SH, *et al.* Early supported discharge and transitional care management after stroke: a systematic review and meta-analysis. *Front Neurol* 2022; **13**:755316.
44. Williams S, Morrissey AM, Steed F, Leahy A, Shanahan E, Peters C, *et al.* Early supported discharge for older adults admitted to hospital with medical complaints: a systematic review and meta-analysis. *BMC Geriatr* 2022; **22**:302.
45. das Nair R, Cogger H, Worthington E, Lincoln NB. Cognitive rehabilitation for memory deficits after stroke. *Cochrane Database Syst Rev* 2016; **9**:Cd002293.
46. Allida S, Cox KL, Hsieh C-F, Lang H, House A, Hackett ML, Cochrane Stroke Group. Pharmacological, psychological, and non-invasive brain stimulation interventions for treating depression after stroke. *Cochrane Database Syst Rev* 2020; **1**:CD003437.
47. Knapp P, Campbell Burton CA, Holmes J, Murray J, Gillespie D, Lightbody CE, *et al.*, Cochrane Stroke Group. Interventions for treating anxiety after stroke. *Cochrane Database Syst Rev* 2017; **5**:CD008860.
48. Chang K-V, Chen K-H, Chen Y-H, Lien W-C, Chang W-H, Lai C-L, *et al.* A multicenter study to compare the effectiveness of the inpatient post acute care program versus traditional rehabilitation for stroke survivors. *Sci Rep* 2022; **12**:12811.
49. Luengo-Fernandez R, Li L, Silver L, Gutnikov S, Beddows NC, Rothwell PM. Long-term impact of urgent secondary prevention after transient ischemic attack and minor stroke: ten-year follow-up of the EXPRESS study. *Stroke* 2022; **53**:488–96.
50. Sharma M, Hart RG, Connolly SJ, Bosch J, Shestakovska O, Ng KKH, *et al.* Stroke outcomes in the COMPASS trial. *Circulation* 2019; **139**:1134–45.
51. Willeit P, Toell T, Boehme C, Krebs S, Mayer L, Lang C, *et al.*, STROKE-CARD study group. STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: a randomised clinical trial. *EClinicalMedicine* 2020; **25**:100476.
52. Bragstad LK, Hjelle EG, Zucknick M, Sveen U, Thommessen B, Bronken BA, *et al.* The effects of a dialogue-based intervention to promote psychosocial well-being after stroke: a randomized controlled trial. *Clin Rehabil* 2020; **34**:1056–71.
53. Brandal A, Eriksson M, Glader EL, Wester P. Effect of early supported discharge after stroke on patient reported outcome based on the Swedish Riksstroke registry. *BMC Neurol* 2019; **19**:40.
54. Hjelle EG, Bragstad LK, Kirkevold M, Zucknick M, Bronken BA, Martinsen R, *et al.* Effect of a dialogue-based intervention on psychosocial well-being 6 months after stroke in Norway: a randomized controlled trial. *J Rehabil Med* 2019; **51**:557–65.
55. Yu HL, Cao DX, Liu J. Effect of a novel designed intensive patient care program on cognitive impairment, anxiety, depression as well as relapse free survival in acute ischemic stroke patients: a randomized controlled study. *Neurol Res* 2019; **41**:857–66.
56. Zhang L, Zhang T, Sun Y. A newly designed intensive caregiver education program reduces cognitive impairment, anxiety, and depression in patients with acute ischemic stroke. *Braz J Med Biol Res* 2019; **52**:e8533.
57. Graven C, Brock K, Hill KD, Cotton S, Joubert L. First year after stroke: an integrated approach focusing on participation goals aiming to reduce depressive symptoms. *Stroke* 2016; **47**:2820–7.
58. Wu Z, Xu J, Yue C, Li Y, Liang Y. Collaborative care model based telerehabilitation exercise training program for acute stroke patients in China: a randomized controlled trial. *J Stroke Cerebrovasc Dis* 2020; **29**:105328.
59. Yan LL, Gong E, Gu W, Turner EL, Gallis JA, Zhou Y, *et al.* Effectiveness of a primary care-based integrated mobile health intervention for stroke management in rural China (SINEMA): a cluster-randomized controlled trial. *PLoS Med* 2021; **18**:e1003582.
60. Mohammadi E, Hassandoost F, Mozhdehipanah H. Evaluation of the "partnership care model" on quality of life and activity of daily living in stroke patients: a randomized clinical trial. *Jpn J Nurs Sci* 2022; **19**:e12448.
61. Schwarzbach CJ, Eichner FA, Rücker V, Hofmann AL, Keller M, Audebert HJ, *et al.*, SANO study group. The structured ambulatory post-stroke care program for outpatient aftercare in patients with ischaemic stroke in Germany (SANO): an open-label, cluster-randomised controlled trial. *Lancet Neurol* 2023; **22**:787–99.
62. Bath PM, Woodhouse LJ, Appleton JP, Beridze M, Christensen H, Dineen RA, *et al.* Triple versus guideline antiplatelet therapy to prevent recurrence after acute ischaemic stroke or transient ischaemic attack: the TARDIS RCT. *Health Technol Assess* 2018; **22**:1–76.
63. Cumming TB, Churilov L, Collier J, Donnan G, Ellery F, Dewey H, *et al.*, AVERT Trial Collaboration group. Early mobilization and quality of life after stroke: findings from AVERT. *Neurology* 2019; **93**:e717–28.
64. Langhorne P, Wu O, Rodgers H, Ashburn A, Bernhardt J. A very early rehabilitation trial after stroke (AVERT): a phase III, multicentre, randomised controlled trial. *Health Technol Assess* 2017; **21**:1–120.
65. Bernhardt J, Langhorne P, Lindley RI, Thrift AG, Ellery F, Collier J, *et al.* Efficacy and safety of very early mobilisation within 24 h of stroke onset (AVERT): a randomised controlled trial. *Lancet* 2015; **386**:46–55.
66. Fulop NJ, Ramsay AI, Perry C, Boaden RJ, McKevitt C, Rudd AG, *et al.* Explaining outcomes in major system change: a qualitative study of implementing centralised acute stroke services in two large metropolitan regions in England. *Implement Sci* 2016; **11**:80.
67. Ramsay AI, Morris S, Hoffman A, Hunter RM, Boaden R, McKevitt C, *et al.* Effects of centralizing acute stroke services on stroke care provision in two large metropolitan areas in England. *Stroke* 2015; **46**:2244–51.
68. Gilham SC, Clark L. Psychological care after stroke: improving stroke services for people with cognitive and mood disorders. NHS Improvement—Stroke. 2021. NHS Improvement, Leicester, UK.
69. Langhorne P, Jepsen BG, Larsen T. Early home-supported discharge after stroke. *Int J Rehabil Res* 2014; **37**:192–4.
70. Rafsten L, Danielsson A, Nordin A, Björkdahl A, Lundgren-Nilsson A, Larsson M, *et al.* Gothenburg very early supported discharge study (GOTVED): a randomised controlled trial

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12.5 Appendix E: Characteristics of Studies included in Systematic Review

Summary of study characteristics including study design, patients, interventions, outcome measures, results and conclusions

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Abdul Aziz, 2020 (1)	Pragmatic cluster randomised controlled trial-within trial at public primary care health centres Control n=65, iCaPPS n=86	Screening for complications, QoL, depression	QoL (primary) EQ-5D-5L at 6 months Cost/QALY (secondary)	6-month EQ-5D-5L score changes: Improvement: Intervention 36.1%, control 23.1% No change: Intervention 39.5%, control 69.2% Deterioration: Intervention 24.4%, control 7.7% Cost/QALY Intervention USD469.60 Control USD538.41	The iCaPPS© is a very cost effective method for monitoring post stroke patients who are residing at home
Ahmadi et al, 2020 (INSPiRE-TMS) (2)	Prospective, randomised, open-label, blinded endpoint, event--driven trial Control n=1042, intervention n=1030	Counselling, lifestyle changes, medication adherence	Composite of vascular events, ACS, vascular death (primary) Secondary: each component of primary, readmission, recurrent stroke, major bleeding	Vascular mortality (ITT): Intervention n=30 (2.9%), control n= 32 (3.1%) HR 0·94 (0·57–1·54) All-cause mortality (ITT): Intervention n=73 (7·1%), control n=85 (8·2%) HR 0·85 (0·62–1·17) Stroke (ITT): 11.8% intervention, 11.4% control (HR 1·02, 95% CI: 0·79–1·32)	Provision of an intensified secondary prevention programme in patients with non-disabling stroke or transient ischaemic attack was associated with improved achievement of secondary prevention targets but did not lead to a significantly lower rate of major vascular events
Avci and Gozum, 2023 (3)	Parallel-group, assessor-blind, monocenter randomized controlled trial Control n = 60 (30 patients and 30 caregivers), Intervention n = 66 in (33 patients and 33 caregivers)	Interviews and education (web-based training) for caregivers and patients	Readmission rates	Hospital return status of stroke patients: Intervention Group (n = 33): Yes = 5 (15.2%), no = 28 (84.8%) Control Group (n = 30): Yes = 7 (23.3%), no = 23 (76.7%)	Interventions based on the transitional care management (TCM) increased caregiver competence, prepared them for caregiving and e-health literacy, and prevented the progression of burnout. Transitional Care Model–based interventions also improved patient outcomes. Readmission and pressure ulcers were less common in stroke patients in the intervention group compared with the control group.
Bath et al., 2018 (TARDIS) (4)	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily). Guideline treatment received combined aspirin and dipyridamole or clopidogrel	Primary: Incidence and severity of any recurrent stroke (ischaemic, haemorrhagic; assessed using the modified Rankin Scale) or TIA within 90 days by blinded telephone follow-up. Secondary: bleeding and its severity, death, myocardial infarction, disability, mood, cognition, QoL	The incidence and severity of recurrent stroke or TIA did not differ between intensive and guideline therapy [adjusted common odds ratio (acOR) 0.90, 95% confidence interval (CI) 0.67 to 1.20; p = 0.47]. Major (encompassing fatal) bleeding increased with intensive as compared with guideline therapy (adjusted hazard ratio (aHR) 2.23, 95% CI 1.25 to 3.96; p = 0.006) and the difference only developed during the active treatment phase. Quality of life and mood did not differ between the treatment groups.	The TARDIS trial found that there was no significant reduction in the recurrence of stroke or TIA, or their severity, with intensive antiplatelet therapy based on three agents as compared with guideline therapy. However, triple antiplatelet therapy was associated with increased major bleeding. Overall, there was no effect on the net balance between harm and

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
		alone, using the loading and maintenance doses; these treatments were given for 30 days, after which routine treatment was taken.			benefit confirming the overall neutral finding of the trial.
Bergh, 2023 (5)	Repeated measures analysis (pre-post) from a retrospective cohort of patients registered in the Norwegian Stroke Register (NSR). N = 11009 included in study comparing functional outcome (5388 in 2017 and 5621 in 2019)	Standardised Care Pathway for stroke (SCP) based on National guidelines	Primary: change in mRS at 90 days Secondary: Mortality at 90 days	No significant in change in mRS between the 2 years (OR=1.06, 95%CI 0.86, 1.30). Overall, 1407 (16%) of 8785 patients had died within 90 days in 2017, and 1380 (15.3%) of 9028 in 2019, no significant difference between groups.	No significant improvement in function outcome after the introduction of an SCP. However, significantly more patients were discharged directly home from hospital, and more patients with stroke were treated in a dedicated stroke unit after the implementation (in 2019).
Bernhardt et al., 2015 (AVERT) (6)	Single-blind randomised controlled trial in 56 acute stroke units in 5 countries (Aus, NZ, Malaysia, Singapore, UK -Eng, Scot, Wales, NI) Control n=1050, intervention n=1054	Very early mobilisation (exercise and movement therapy)	Primary: favourable outcome (mRS) Secondary: Change in mRS, mortality	Favourable outcome: intervention 480 (46%), control 525 (50%) (adjusted OR 0.73 [95% CI: 0.59-0.90]), p=0.004 Mortality: Intervention 88/1048 (8%), control 72/1050 (7%), OR 1.34 (95% CI: 0.93-1.93), p=0.113	Significantly fewer participants in the AVERT group had favourable outcome and there was no difference in mortality
Bodechtel et al., 2016 (Stroke East Saxony [SOS] care project) (7)	Retrospective database case-control study Control: n=45, Intervention n=45	Intervention: Post-stroke care pathway managed by case manager Control: usual care that was provided by primary care physicians after discharge	Functional independence, recurrent stroke, mortality, QoL, risk factors	The following target goals were more frequently achieved in SOS Care patients than in controls: blood pressure (100% vs. 46.2%, P < 0.001), cholesterol (100% vs. 74.4%, P < 0.001), and body mass index (67.4% vs. 46.2%, P = 0.052). More patients in the intervention group were functionally independent at 12 months after the index event than patients receiving only usual care (75.6% vs. 48.9%; P = 0.009). Quality of life measured by the EQ5D questionnaire was rated significantly higher in SOS Care patients than in controls (median index: 0.887 [IQR, 0.099] vs. 0.788 [0.0625]; P = 0.049).	Pilot data suggest that organized post-stroke care enhances achievement of secondary prevention goals
Bragstad et al., 2020 (8)	Multicenter, prospective, randomized, assessor-blinded, controlled trial with two parallel groups Gave consent n=353, randomised n=322 Control n=156, intervention n=166	Dialogue-based intervention to promote psychosocial wellbeing (psychological)	Primary: psychosocial wellbeing Secondary: HRQoL, depression	Between-group differences at 12 months (mean, SE): Physical domain 0.06 (−0.07, 0.20), P=0.36 Communication domain 0.06 (−0.05, 0.16), P=0.27 Psychosocial domain 0.07 (−0.11, 0.25), P=0.45	The dialogue-based intervention implemented in this RCT did not lead to lower levels of emotional distress and anxiety at 12 months post-stroke. The intervention did not lead to higher levels of health-related quality of life or higher sense of coherence at 12 months post-stroke. Based on the outcome measures used in this study, there is insufficient evidence to support implementation of the intervention in its current form.
Brandal, 2019 (9)	Prospective, randomised, open-label, blinded endpoint, event--driven trial	Early supported discharge (ESD)	Primary: Satisfaction with rehab after discharge Secondary: Depression	Significantly improved satisfaction with rehab after discharge (OR: 1,78, 95% CI:1.17-2.49), independence in mobility (OR: 1.50, 95% CI: 1.17-1.92), toileting (OR: 1.30, 95% CI: 1.06-	Patients that received ESD after stroke were more satisfied with rehabilitation after discharge and experienced less depression than

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
	N=99833 (Control n=27554, intervention n=1432)			1.61) and dressing (OR: 1.23, 95% CI: 1.02-1.48), significantly less dysthymia/depression (OR: 0.68, 95% CI: 0.55-0.84)	patients that received other health care and/or rehabilitation care
Brouns, 2021 (10)	Pre-post test, controlled, pragmatic clinical trial Control n=258, intervention n=310	Web-based e-rehabilitation comprising physical exercise and cognitive exercise (psychological) programmes (mhealth)	Primary: level of disability (SIS) Secondary: QoL EQ-5D-5L at 3 and 6 months	Primary: Between T3 and T6, the change in scores for the SIS subscales Communication (control group/ intervention group –1.7/–0.3) and Physical strength (–5.7/3.3) were significantly greater in the total intervention group (all mean differences< minimally clinically important differences). No significant differences were found for other SIS subscales or secondary outcomes, or between T0–T3 and T0–T6. Secondary: Within group EQ-5D-5L changes (mean, SD): 3 months Intervention 0.07 (0.2), control 0.07 (0.2), between group P=0.19 6 months Intervention 0.01 (0.2), control –0.01 (0.2), between group P=0.38 LMM (0-6 months) P-value 0.50 (95% CI: 0.0–0.1)	eRehabilitation alongside conventional stroke rehabilitation had a small positive effect on communication and physical strength on the longer term, compared to conventional rehabilitation only No difference in QoL at 3 or 6 months
Brouwer et al., 2018 (11)	Multicenter randomized controlled trial with 2 groups: an intervention ("tune-up") group and a control group having the same exposure to assessment N=132 (Control n=52, Intervention n=51)	Patient-centred treatment sessions comprising strength/power, balance, cardiovascular endurance (exercise), motor coordination, and education about relevant community resources, as well as how to monitor their mobility and activities	Primary: community reintegration Secondary: QoL (SF-36) at 12 months	At 12 months, both groups showed significant improvement in community reintegration (P<.05), a trend evident at all time points, with no difference between groups (mean difference, -0.5; 95% confidence interval, -1.8 to 2.7; P=0.68). Similarly, a main effect of time reflected improvement in mobility-related and quality of life outcomes for both groups (P≥.0.5), but no group differences (P≥0.30).	All participants in the tune-up group met or exceeded at least 1 mobility-related goal; however, the intervention did not differentially improve community reintegration. The improvements in mobility and quality of life over the 15-month postdischarge period may be secondary to high activity levels in both study groups and exposure to regular assessment.
Buckley et al., 2022 (12)	Retrospective observational study N=836,923 Propensity matched cohorts: Control n=2909, intervention n=2909	Exercise-based cardiac rehabilitation	2-year mortality, recurrent stroke, rehospitalisation	Mortality: 8.5% Intervention, 16.5% control, (OR 0.47, 95% CI 0.40-0.56) Recurrent stroke: 39.2% intervention, 42,3% control (OR 0.88, 95% CI 0.79-0.98) Rehospitalisation at 2-years was proportionally lower with 40.7% (n=1,185 of 2,909 patients) in the exercise-based cardiac rehabilitation cohort compared to 51.8% (n=1,507 of 2,909 patients) in the controls (OR 0.64, 0.58-0.71)	Exercise-based cardiac rehabilitation prescribed for people following a stroke associated with significantly lower odds of major adverse cardiovascular events at 2-years, compared to usual care
Bushnell et al., 2021 (13)	COMPASS was a cluster-randomized trial of the effectiveness of the COMPASS-TC intervention (INV) compared with usual care (UC) Participating hospitals: control n=20, inv n=20 Patients: Control n=1193, inv n=1069	Post-acute care pathway (full pathway) follow-up with the advanced practice provider and nurse coordinator in clinic within 7 to 14 days post discharge, an individualized electronic care plan, and referral to community services	1-year mortality, 30- and 90-day unplanned readmissions, 1 year all-cause readmissions	Mortality: 8.5% intervention, 8.8% control (OR, 0.93; 95% CI, 0.68–1.26) Rehospitalisation: 30d admissions: Intervention 105 (9.9%), control 103 (8.7%), OR 1,20 (95% CI: 0.83-1.74) 60d readmissions: Intervention 210 (19.9%), control 222 (18.9%), OR 1.10 (95% CI: 0.84-1.41) 1 year all-cause readmissions: Intervention 485 (45.4%), control 516 (43.3%), HR 1.06 (95% CI: 0.95-1.77) 1 year stroke readmission: Intervention 67 (6.3%), control 62 (5.2%), HR 1.26 (95% CI: 0o.0-1.77)	The risk of unplanned all-cause readmission was similar between INV versus UC at 30 (9.9% versus 8.7%) and 90 days (19.9% versus 18.9%), respectively. No significant differences between randomization groups were seen in 1-year all-cause readmissions, stroke-specific readmissions, or mortality
Cecchi et al., 2020 (14)	Prospective observational study Control n=443; intervention n=84	Evidence-based stroke rehabilitation integrated care pathway (ICP)	Mortality	Mortality: 2015-17: 4 (0.9%), 2018: 1 (1.2%), p=0.803	Compared to prior practice, ICP implementation was associated to a significant improvement in some patient-oriented outcomes at discharge: recovery of trunk control, bladder catheter removal,

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					and pressure sore resolution. However, there was no difference in mortality
Chang et al., 2018 (15)	Retrospective cohort study using National Health Insurance database Control n=2491, intervention 2103	High intensity rehabilitation (inpatient, outpatient or both) versus no rehab	All-cause mortality	Model 1 Control: 18.4%, low-intensity 17.9%, high intensity 14.6% (p=0.0062) Model 2 Control: 18.4%, inpatient + outpatient 10.2%, inpatient only 25.2%, outpatient only 12.6% (p<0.0001)	Rehabilitation use was associated with reduction of readmissions/mortality risks following stroke or TIA.
Chang et al., 2022 (16)	Multi-centre cohort study Control n=212, intervention n=122	Post acute care (PAC) program	Quality of Life (EQ-5D)	EQ5D Non-PAC: before 0.03±0.32, after 0.20±0.32, P-value <0.001 PAC: before 0.15±0.35, after 0.38±0.32, P-value <0.001	Traditional inpatient post-stroke rehabilitation and PAC programs are both helpful for post-stroke functional recovery. Compared to traditional inpatient rehabilitation, the PAC program showed significantly more improvement in basic and instrumental activities of daily living, nutrition, quality of life, and cognition.
Chen et al., 2016 (17)	Quasi-experimental controlled study Control n=173, intervention n=168	Individualised transitional care model based at home	Adherence to medication, readmission	Medication compliance rates: intervention 161 (95.83%) vs. control 92 (53.18%), p = 0.004 Readmission: Intervention 2 (1.19%) vs. control 11 (6.36%), $Chi^2 = 5.30$, p = 0.02)	The intervention was associated with significantly higher medication compliance and satisfaction with acute hospitalisation and lower readmission rates.
Chen, 2017 (18)	Retrospective cohort study N=11,419 Propensity matched group n=390 (RR n=130, NtR n=130, NoR n=130)	Rehabilitation for hospitalised patients including mobilisation (exercise), speech therapy and dysphagia treatment	5-year all-cause mortality	Rehab + rehab ward (RR) 17.7% Rehab no rehab ward (NtR) 26.9% (HR 2.2 95% CI 1.36-3.57; P<.01 vs RR) No rehab (NR) 47.7% (HR, 4.00; 95% CI, 2.55-6.27; P<.01 vs RR)	Among first-time stroke survivors, the 5-year mortality HR reported in this study indicates that subjects who underwent rehabilitation in the rehabilitation ward had 2.2 times lower mortality risk than those who received rehabilitation without transfer to the rehabilitation ward, and had 4 times lower mortality risk than those who did not receive rehabilitation
Cheng, 2018 (19)	Randomised controlled trial N=201 (CRT n=84, control n=84)	Patient and family member education, cognitive training (psychological), rehabilitation training, regular follow-up	HADS anxiety/depression score SAS anxiety score, SDS depression score	Both montreal cognitive assessment score change (Month12 [M12]-baseline; P = .001) and minimum mental state examination score change (M12-baseline) were higher in CRT group than that in control group (P = .004), and the percentage of cognitive impairment by montreal cognitive assessment score ≤26 was lower (P = .003) in CRT group compared to control group at month 12. HADS anxiety score change at 12 months: -0.23 ± 0.20 (CRT) vs 0.62 ± 0.17 (control), p=0.002 SAS anxiety score change at 12 months: -0.23 ± 0.20 (CRT) vs 2.00 ± 0.77 (control), p=0.006 HADS depression score change at 12 months: -0.71 ± 0.23 (CRT) vs 0.44 ± 0.18 (control), p<0.001	CRT contributes to the recovery of cognitive impairment, and decreases anxiety and depression in poststroke patients

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				SDS depression score change at 12 months: -2.10 ± 1.10 (CRT) vs 2.30 ± 0.88 (control), p=0.002	
Cheng et al., 2018 (20)	Randomised controlled trial N=407 (Control n=200, int n=207)	Medication modification relevant to stroke risk factors, tobacco cessation, physical activity, depression, and medication adherence	Change in SBP, LDL cholesterol, Physical activity, smoking cessation, 10-year risk of CV events	Differences in Changes From Baseline Between Control and Intervention Arms* (95% CI): SBP −3.6 mm Hg (−9.3 to 2.2) p=0.55 LDL mg/dL, mean (SD) −10.2 mg/dL (−21.1 to −0.6) p=0.03 Smoking cessation 0.6 OR (0.3 to 1.3), p=0.58 Physical activity assessed as exercise ≥3 d per wk, n (%):0.9 OR (0.5 to 1.8), p=0.84 10 year risk of CV events: %, mean (SD) -0.8 (−3.1 to 1.6), p=0.98 *Repeated-measures mixed-effect models included baseline, 3-mo, and 12-mo values.	This intervention did not improve SBP control beyond that attained in usual care among vulnerable stroke survivors. A community-centered component could strengthen the intervention impact.
Chiu, 2021 (21)	Large-scale prospective cohort study N=1786 (PAC n=273, non-PAC n=273)	Post-acute care (PAC): physical exercise (physical, occupational, or speech-swallowing therapy) in multiple sessions	Functional disability, cognitive status, functional status, QoL, functional balance	From 12 weeks after rehabilitation to 1 year after rehabilitation, the PAC group had higher total scores for BI, FOIS, IADL, BBS, and MMSE compared to the non-PAC group. That is, the PAC group had larger improvements in all functional status measures except EQ-5D. According to the DID values (with mean and standard errors) for the PAC group and non-PAC group, the PAC program had significant ($p < 0.001$) positive net effects on BI, FOIS, IADL, BBS, and MMSE but had a significant ($p < 0.001$) negative net effect on EQ-5D during the study period.	Although the incidence of stroke is high, PAC provided early after stroke can improve restoration of function.
Chu, 2020 (22)	Single-centre randomised controlled trial N=61 (Control n=30, intervention n=31)	Training for caregivers (education), personalised training plan for patients for recovery of physical function (mobility, self-care, bowel/toilet control)	Primary: Physical function Secondary: QoL EQ-5D at 6 months	Compared with that in the control group, BI increased more at 3 months and decreased less at 6 months in the intervention group, there was a significant difference in mean BI scores across the three time points ($F = 21.96$, $p = 0.0001$), but no significant between-group difference ($F = 0.94$, $p = 0.3371$). In the intervention group, BI scores at 3-and 6-months post-discharge were higher than that before discharge ($t = 8.38$, $p = 0.0001$; $t = 4.14$, $p = 0.0003$). In the control group, BI scores at 3 months were higher than that before discharge ($t = 5.29$, $p = 0.0001$), but no significant difference at 6 months. At 6 months post-discharge, the intervention group and the control group had similar EQ-5D scores ($p = 0.91$), and similar CBI scores (3.67 vs 3.68, $p = 0.98$).	The study showed that the novel nurse-trained, family member-delivered rehabilitation model improved physical recovery indicated by BI scores without increasing caregiver burden, compared to usual care, for rural stroke patients in southwest China.
Cuccurullo et al., 2022 (23)	Prospective matched cohort study Control n=88, intervention n=105	SRP program: Physician Visits, Outpatient Therapy, and Modified Cardiac Rehabilitation (management of blood pressure (BP), cholesterol control, reduction of blood sugar, getting active, eating better, losing weight, and smoking cessation) Lifestyle	Readmission rates	All cause readmission: control 59 (67%), intervention 47 (45%), difference in proportion 22%, HR 0.51 (0.31-0.83), p=0.006	Acute care hospital readmissions were reduced in stroke survivors who participated in SRP.
Cuccurullo et al., 2022 (24)	Prospective matched cohort study: feasibility study followed by matched group subanalysis	Enhanced SRP program including home visits,	1-year mortality	Mortality: Control 10/66 (15.2%), intervention 1/76 (1.3%), difference 13.9%, HR 0.11 (95% CI: 0.01-0.90), p=0.039	Stroke survivors receiving a SRP integrating modified cardiac rehabilitation may potentially

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
	Control n=66, intervention n=76	outpatient therapy and modifies cardiac rehabilitation			benefit from reductions in all-cause mortality and improvements in cardiovascular performance and function
Cuccurrullo, 2019 (25)	Prospective cohort study: feasibility study followed by matched group sub-analysis N=783 (SRP feasibility study n=136, matched NP n=66, matched SRP n=76)	Physician Visits, Outpatient Therapy, and Modified Cardiac Rehabilitation (management of blood pressure (BP), cholesterol control, reduction of blood sugar, getting active, eating better, losing weight, and smoking cessation) Lifestyle	1-year mortality	The feasibility study showed the SRP to have the following (a) excellent safety, (b) markedly low 1-yr poststroke mortality from hospital admission (1.47%) compared with national rate of 31%, (c) improved cardiovascular performance over 36 sessions (103% increase in metabolic equivalent of tasks times minutes), (d) improved function in Activity Measure of Post-Acute Care domains ($P < 0.001$), (e) positive re- views from SRP-participants/staff. Subgroup analysis showed the SRP to (a) positively impact mortality, nonparticipants had a 9.09 times higher hazard of mortality ($P = 0.039$), and (b) improve function in Activity Measure of Post-Acute Care domains ($P < 0.001$).	Stroke survivors receiving a SRP integrating modified cardiac rehabilitation may potentially benefit from reductions in all-cause mortality and improvements in cardiovascular performance and function
Cumming, 2019 (26)	International, multicenter (56 sites), pragmatic single-blind phase 3 randomized controlled trial, spanning 2006–2015 N=2104 (Intervention n=1054, control n=1050)	Very early mobilisation (physical activity within 24 hours) exercise	Primary: Good functional outcome Secondary: QoL AQoL 4D at 12 months	No significant difference in quality of life at 12 months between intervention (median 0.47, interquartile range [IQR] 0.07–0.81) and usual care (median 0.49, IQR 0.08–0.81) groups was identified ($p = 0.86$), nor were there any group differences across the 4 AQoL-4D domains. The same lack of group difference in quality of life was observed at 3 months. When cohort data were analyzed (both groups together), quality of life was strongly associated with acute length of stay, independence in activities of daily living, cognitive function, depressive symptoms, and anxiety symptoms (all $p < 0.001$). Quality of life in AVERT participants was substantially lower than population norms, and the gap increased with age.	Early and more frequent mobilisation after stroke does not have a marked influence on QOL over the subsequent year
de Belvis, 2019 (27)	Pre-post retrospective observational study N=1,009 Control n=483, intervention n=526	5-stage clinical pathway: (1) initial framing; (2) evaluation/staging; (3) treatment; (4) rehabilitation; and (5) follow-up/monitoring (full pathway)	30-day readmission and mortality	An increase context-sensitive in-patient numbers with more severe cerebrovascular events and an increase in patient transfers from the Stroke to Neurology Unit within three days (70 percent, p 0.25) were noted. Clinical pathway implementation led to an increase in patient flow from the Emergency Department to dedicated specialized wards such as the Stroke and Neurology Unit (23.7 percent, $p < 0.001$). Results revealed no statistically significant decrease in readmission rates within 30 days (5.7 percent, $p=0.85$) and no statistically significant differences in 30-day mortality.	Clinical pathway implementation showed an overall positive effect on patient management and service efficiency owing to the standardised application in time-dependent protocols and multidisciplinary/integrated care implementation, which improved all phases in acute ischemic stroke care
Deng 2020 (28)	A pilot randomized controlled trial Control n=49, intervention n=49	Multidisciplinary poststroke consultation team providing home visits, ongoing rehabilitation, medication reconciliation, self-management education	QoL	Mean values of Physical Components Summary and Mental Components Summary, integral components of Short-Form Health Survey-36, were significantly better in the intervention group at four and eight weeks (40.2 ± 6.3 and 42.9 ± 3.7 for the former; 43.9 ± 2.6 and 46.1 ± 1.8 for the later). The same trend was observed in Modified Barthel Index (87.1 ± 9.2 and 92.5 ± 6.7 at four and eight weeks, respectively). But the significant improvement in Caregiver Strain Index was only observed at four weeks. There were significant differences between groups in these scores.	The transitional care program has been proven to be feasible and improve health-related outcomes

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Dello et al., 2021 (29)	Single-centre pre- and post-intervention study Control n=238, intervention n=257	Nurse-led management of temperature, glycaemia and swallowing (risk factors)	Mortality and functional status	The rates of 90-day death and dependency (mRS ≥2) were lower in the post-intervention period (51%) compared to the pre-intervention period (60%), adjusted OR 0.63, 95% CI: 0.41-0.97.	The intervention in the study was associated with significantly lower death and dependency compared with control
Deutschbein, 2020 (30)	Pragmatic non-randomised controlled trial N=361 (intervention n=145, control n=270)	Individualised case management, with regular face-to-face visits as part of a comprehensive individualised programme (PT, OT, support required), regular monitoring and adjustment (full pathway)	Recurrent stroke, readmission, 1-year mortality	In the first year post-stroke, the incidence rate per 100 person-months of visiting a community neurologist was 6.41 (95% CI: 5.00–8.20) in the intervention group, com- pared to 3.32 (95% CI: 2.73–4.04) in the control group. In the intervention group, 9.9% suffered from another stroke within 12 months compared to 13% in the control group. Readmissions to a hospital were recorded for 37.4% in the intervention group and 57.4% in the control group. Participants had an incidence rate of 4.03 (95% CI: 2.58–6.28) readmissions per 100 person-months, standard care patients 9.56 (95% CI: 7.99–11.43). Patients with a higher number of comorbidities were admitted to a hospital more frequently. The number of readmissions was accompanied by substantially lower hospital costs in the intervention group (median 6 months costs: €0, IQR: €0–1910) compared to those in the control group (median 6 months costs: €938, IQR: €0–4375). This difference was also confirmed in the linear mixed model. The 12-month survival rate for the intervention group was 0.92 (95% CI: 0.87–0.98) compared to 0.90 (95% CI: 0.87–0.94) in the control group	This study showed the beneficial potential of care coordination for a vulnerable patient population: the utilization rate of important health services was increased, and the rate of hospital readmissions decreased as a result. Future research should focus on the risk of recurrent strokes and the long-term effects of improved care
Døhl, 2020 (31)	Multicentre, pragmatic, single-blinded, randomized controlled trial N=380 (Intervention n=186, control n=194)	A follow-up program comprising monthly individualized coaching by a physiotherapist, physical activity and exercise schedule, training diary	Cost analysis, need variables (primary= MAS, secondary HRQoL)	The average grand total cost were 23,126 Euro in the intervention group, of this in average 1480 Euro were costs related to the intervention. In the control group the average grand total cost were 20,412 Euro. The hospital costs constituted nearly 41% of the total costs in the intervention group and 45% in the control group. The primary care costs constituted 41% of the total costs in the intervention group and 42% in the control group. The higher cost of physiotherapy in the intervention group is due to the cost of the intervention. In intervention group there were a smaller pro- portion of elderly above 80 years, but there were a higher proportion of females and those living alone. There were higher total health care costs in the intervention group than the control group, related to the intervention cost. For the primary care and hospital care there were no cost differences between the intervention and control group. For the GP's there were indication (p = 0.09) of lower costs in the intervention group. In the specification using clinical outcome measures, MAS and Gait speed were both strongly associated with the use of health care services, whereas there was no such association for Barthel. MMSE was associated with the use of primary care costs. Gait speed, on the other hand was negatively associated with all types of health care services, except hospital care. Implying that increased Gait speed reduced the use of health care services, and thereby costs.	Long term, regular individualized coaching did not reduce health care costs compared to standard care. We found that MAS, Gait speed, HADS and mRS were significant predictors for future health care use. The generic EQ-5D-5 L performed equally well as the more detailed battery of outcome measures, suggesting that HRQoL measures may be a simple and efficient way of identifying patients in need of health care after stroke and targeting groups for interventions

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Duncan, 2020 (32)	Pragmatic cluster-randomized trial 6024 patients, 41 hospitals (Hospitals n=40, patients intervention n=2689, control n=3193)	Education, secondary prevention, rehabilitation, recovery, referrals to community-based resources, and caregiver support services by telephone follow-up	Primary: Functional status Secondary: 90-day mortality, depression	Of intervention hospitals, 58% had uninterrupted intervention delivery. Thirty-five percent of patients at intervention hospitals attended a COMPASS clinic visit. The primary outcome was measured for 59% of patients and was not significantly influenced by the intervention. Mean Stroke Impact Scale-16 (±SD) was 80.6±21.1 in TC versus 79.9±21.4 in usual care. Home blood pressure monitoring was self-reported by 72% of intervention patients versus 64% of usual care patients (adjusted odds ratio, 1.43 [95% CI, 1.21–1.70]). No other secondary outcomes differed.	Although designed according to the best available evidence with input from various stakeholders and consistent with Centers for Medicare and Medicaid Services TC policies, the COMPASS model of TC was not consistently incorporated into real-world health care. No significant effect of the intervention on functional status at 90 days post-discharge was found
Ellis-Hill, 2019 (33)	Two-centre, 24-month, parallel-arm RCT with qualitative and economic components N=56 (Control n=25, intervention n=22)	Arts and health practitioner-led group sessions (psychosocial and wellbeing)	The outcomes were self-reported measures of well-being, mood, capability, health-related quality of life, self-esteem and self-concept (baseline and 5 months post randomisation)	Despite a low recruitment rate (14%; 95% CI 11% to 18%), 88% of the recruitment target was met, with 29 participants randomised to HoS and 27 to UC (57% male; mean (SD) age=70 (12.1) years; time since stroke=9 (6.1) months). Follow-up data were available for 47 of 56 (84%; 95% CI 72% to 91%). Completion rates for a study-specific resource use questionnaire were 79% and 68% (National Health Service and societal perspectives). Five people declined HoS post randomisation; of the remaining 24 who attended, 83% attended ≥6 sessions. Preliminary effect sizes for candidate primary outcomes were in the direction of benefit for the HoS arm. Participants found study processes acceptable. The intervention cost an estimated £456 per person and was well-received (no intervention- related serious adverse events were reported).	Findings from this first community- based study of an arts and health intervention for people poststroke suggest a definitive RCT is feasible.
Feng et al., 2023 (34)	6-month follow-up of an open, prospectively comparative study Control n=94, intervention n=95	Full integrated care pathway for older stroke patients including nursing and caregiver support	Quality of life	Significant improvement in mental component of SF-36 SF-36 PCS baseline: Control 31.7 ± 0.6, intervention 32.0 ± 0.8 After 3 months: Control 39.5 ± 2.8, intervention 40.4 ± 3.1 After 6 months: Control 41.7 ± 3.0, intervention 42.2 ± 1.6 (between group difference 9.63, p=0.105) SF-36 MCS baseline: Control 35.4 ± 3.2, intervention 35.2 ± 2.9 After 3 months: Control 42.1 ± 3.8, intervention 41.7 ± 6.6 After 6 months: Control 46.2 ± 2.9, intervention 51.5 ± 0.7 (between group difference 8.44, p<0.001)	Older people with stroke who received IHSC services, maintained higher levels of mental aspect of quality of life and experienced less disease burden during 6-month follow-up, compared with those who received usual integrated care.
Feng, 2021 (35)	Randomised controlled trial N=120 (Control n=60, intervention n=60)	Trained multidisciplinary team providing an intervention plan based on the patient's condition and treatment-related information, and arranging specific plans for family visits and telephone follow-ups,	The changes of self-care ability, compliance behavior, self-efficacy, and adverse mood before and after intervention were compared between the two groups	The modified Barthel Index (MBI) score of the observation group after 3 months of intervention was higher than that of the control group (P<0.05). In the observation group, the changes in the proportion of medication, reasonable diet, moderate exercise, and regular return visits after 3 months were higher than those in the control group (P<0.05). The General Self-efficacy Scale (GSES) score of the observation group was	HCISM applied to the home rehabilitation of the disabled elderly with stroke can improve life self-care ability and self-efficacy, improve medical compliance behavior, and reduce

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
		continued support and follow-up in the community (full pathway)		higher than that of the control group after 3 months of intervention (P<0.05). Zung's Self-rating Anxiety Scale (SAS) and Self-rating Depression Scale (SDS) scores in the observation group were low after 3 months of intervention than those in the control group (P<0.05).	negative emotions, and is thus worthy of further promotion
Freburger et al., 2022 (COMPASS) (36)	Randomised Multi-location controlled trial Control n=1193, intervention n=1069	Telephone follow-up and clinic visit with individualised care plan	Readmission, mortality	Skilled nursing facility or inpatient rehabilitation facility: Patients with one or more admissions, n (%): Intervention 150 (14.0); Control 142 (11.9) Skilled nursing facility: Patients with one or more admission, n (%): Inervention 133 (12.4); control 123 (10.3) Inpatient rehabilitation facility Patients with one or more admission, n (%): Intervention 28 (2.6); control 32 (2.7) Mortality: Intervention 88/1069 (8.2%), control 105/1193 (8.8%)	No difference in readmission rates or mortality between intervention and control groups
Fu, 2020 (37)	Prospective, randomised, open trial of two active and one control interventions with blinded endpoint assessment N=400 (Primary analysis: control n=125, T1 n=123, t2 n=133)	One-to-one qualitative assessment of patient views and needs, education and goal setting	Primary: QoL Secondary: Mortality, recurrent stroke, rehospitalisation at 12 months	Twelve months following stroke, participants in either of the TC groups (i.e. TC1 TC2) scored 2.9 (95% confidence intervals (CI) 0.95 to 4.9, p 0.004) points higher (better) than control on the Short Form 36 Physical Component Summary. This difference remained significant when adjusted for pre-specified baseline variables. There was a dose effect with Short Form 36 Physical Component Summary scores increasing by 1.9 points (95% CI 0.8 to 3.1, p < 0.001) for each extra Take Charge session received. Exposure to the Take Charge intervention was associated with reduced odds of being dependent (modified Rankin Scale 3 to 5) at 12 months (TC1 + TC2 12% versus control 19.5%, odds ratio 0.55, 95% CI 0.31 to 0.99, p = 0.045).	Confirming the previous randomized controlled trial outcome, Take Charge—a low-cost, person- centered, self-directed rehabilitation intervention after stroke—improved health-related quality of life and independence. Two sessions, six weeks apart, were better than a single session. Improvements were also seen in basic and advanced activities of daily living and independence.
Gao, 2017 (38)	A single-blind, randomised, controlled trial that compared three intervention groups, with subgroups stratified by time after stroke N=273 (Group A n=91, Group B n=91, group C n=92) Analysis groups: Group A n=86, Group B n=85, Group C n=87	Citalopram, psychological intervention for depression, cognitive behavioural education	Depression, melancholia, side-effects, activities of daily living, functional impairment	When stratification was not considered, the scores of Group B on the Melancholia Scale were lower than those of Group A (P = 0.02); when the four time-based subgroups were analysed, significant differences were observed between Groups A and B (PMES = 0.02, PHAMD17 = 0.02) in the group recruited six months after discharge and between Groups A and C (PMES = 0.01) in the last time period nine months after discharge	The effects of citalopram or cognitive behavioural therapy is similar to the effect of rehabilitation alone for early-onset post-ischaemic depression; rehabilitation and citalopram for delayed-onset post-ischaemic depression; and rehabilitation and cognitive behavioural therapy for late-onset post- ischaemic depression are more effective than rehabilitation alone
Geng, 2019 (39)	Randomised controlled trial N=101 (Control n=30, intervention n=30)	Physical function, emotional function, lifestyle, medication adherence	Systolic blood pressure, BMI, cholesterol, physical activity, smoking and alcohol consumption at 6 months	The TC intervention improved the discharged elderly stroke patients' health behaviors, activities of daily living, quality of life, and stroke knowledge. The intervention also controlled the patients' systolic blood pressure, body mass index, total cholesterol, triglycerides, and low-density lipoprotein cholesterol.	This study provided evidence of concurrent self-reported and objective clinical indicators in discharged elderly stroke patients for the impact of the IBM-based 3-month TC intervention, which can be recommended for clinical practice

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Graven et al., 2016 (40)	Prospective randomised controlled trial Control n=46, intervention n=48	Physiotherapist-led comprehensive multifactorial care pathway individualised to each participant	Depression (Geriatric depression score [GDS-15])	At 12 months, the mean GDS-15 score was lower in the intervention group (3.6) compared to the control group (4.8). A lower proportion of participants in the intervention group (14.6%) had significant depressive symptoms (GDS-15 ≥6) at 12 months compared to the control group (34.8%). At 12 months.	Positive impact of individualised, goal-centered, comprehensive poststroke management for reducing depressive symptoms during the first year poststroke.
Greger, 2021 (41)	Single-centre retrospective chart review Control n=4516, inv n=1274 Matched groups: Control n=171, inv n=171	Pharmacist led medication review, counselling, risk factor management (lifestyle)	Primary: change in responsiveness to antiplatelet medication Secondary: Lifestyle (including adherence)	At the first visit, a total of 168 instances of optimizing antiplatelet therapy or counseling patients on adherence were identified in the PFT group while 35 instances were identified in the non-PFT group. Over the course of 1 year, 24 patients in the PFT group were counseled on adherence while only five patients in the non-PFT group were counseled (P = .0008). Similarly, 47 drug-drug interactions were identified by pharmacists compared with 10 identified by providers (P < .0001). All intervention data collected resulted in statistically significantly more pharmacist interventions than provider interventions, except decreasing the dose of aspirin. PFT results were reviewed for patients in the PFT group (n = 171). Baseline antiplatelet response results revealed 27% (n = 46) of patients were responsive to their current antiplatelet therapy and 73% (n = 125) were nonresponsive (Figure 1). A total of 25% (n = 43) of PFT patients were unable to be tested during their first visit generally due to drug-drug interactions with their antiplatelet therapy, a drug-test interaction, technical difficulties, or medication non- adherence.	Pharmacist interventions optimized secondary stroke/TIA prophylaxis therapy, decreased drug-drug interactions, and increased adherence counseling. Patients who underwent PFT and pharmacist intervention transitioned from non- responsive to responsive to their antiplatelet therapy regimen
Gun Young, 2021 (42)	Open label non-randomised study with non-equivalent control group design N=50 (Control n=23, inv n=20)	Integrated management programme assessing physical function (structured exercise), cognitive function, and depression	Depression (Beck Depression inventory at 4 and 8 weeks)	The interaction between group and time was significant, indicating that the experimental group showed improvement in gait speed, balance ability, cognitive function (linguistic ability, linguistic memory, reasoning), and a decrease in depression compared to the control group	These results indicate that the integrated management program developed herein was beneficial in restoring physical function, cognitive function, and depression in subacute stroke patients.
He et al., 2023 (43)	Randomized, historically controlled clinical trial Control n=124, intervention n=161	Rapid recovery implementation process to optimise patient recovery post-surgery	Functional status (mRS), QoL (EQ-5D)	mRS score at discharge: 2.52 (1.89) Control, 3.61 (5.74) intervention, p<0.001 mRS score 3 month after discharge: 2.38 (1.77) (control), 2.01 (1.95) (intervention), p = 0.097 EQ-5D-5 L: Mobility 1.69 (0.78) (control),1.6 (0.82) (intervention), p=0.349 Self-care 1.56 (0.78) (control), 1.65 (0.82) (intervention), p=0.394 Usual activities 1.6 (0.76) (control), 1.61 (0.78) (intervention), p=0.897 Pain/discomfort 1.27 (0.48) (control),1.33 (0.58) (intervention), p=0.383 Anxiety/depression 1.39 (0.56) (control), 1.23 (0.43) (intervention), p=0.013 Visual analog scale 64.72 (25.93) (control), 72.29 (26.94) (intervention), p=0.017	Statistically significant differences in mRS were seen at discharge but not at 3 months. Significant differences were found in anxiety/depression and overall quality of life, with the intervention group showing better outcomes.

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Hjelle, 2019 (44)	Multicentre, prospective, randomized controlled trial Enrolled n=353, randomised n=322 (Control n=156, inv n=166)	Dialogue-based intervention delivered in patient home by nurse/OT (psychological)	Primary: Psychosocial wellbeing. Secondary: depression, QoL, sense of coherence	After controlling for the baseline values, no significant benefit was found in the intervention group over the control group (odds ratio (OR): 0.898: 95% confidence interval (95% CI): 0.54-1.50, p = 0.680) 6 months post-stroke	Psychosocial well-being improved during the first 6 months after stroke in both arms of the trial, but no statistically significant benefit of the dialogue-based intervention was found compared with usual care.
Huang et al., 2023 (ERNI) (45)	Randomised non-blinded controlled trial Control n=45, intervention n=45	Early rehabilitation and nursing intervention (ERNI), internet + continuous nursing program	QoL (SS-QoL)	QoL scores Control before intervention 31.8±4.3, after 42.5±3.7, p<0.005 ERNI group before intervention 31.5±4.0, after 50.1±3.1, p<0.001 Between group difference after intervention, p<0.001	ERNI was associated with significantly better QoL
Jones et al., 2016 (46)	Cluster randomised controlled trial Control n=30, intervention n=36	Bridges self-management program (SMP) comprising one-to-one rehabilitation sessions and stroke workbook	Hospital anxiety and depression scores, QoL (SAQOL), adherence to intervention	HADS-A scores: Baseline: control 7.4±5.1, intervention 7.5±5.3 6 weeks: control 7.3±4.9, intervention 7.5±4.9 12 weeks: control 7.4±4.5, intervention 6.6±5.3 HADS-D scores: Baseline: control 7.1±3.4, intervention 6.9±4.2 6 weeks: control 8.2±4.1, intervention7.1±4.5 12 weeks: control 8.1±4.1, intervention 7.1±4.3 SAQOL mean scores: Baseline: control 3.2±0.8, intervention 3.4±0.8 6 weeks: control 3.1±1.0, intervention 3.3±0.8 12 weeks: control 3.1±0.8, intervention 3.4±0.8 Thirty-nine participants (98%) completed baseline measures and 36 participants completed week 12 outcome measures (90%) in intervention sites, compared with 35 (92%) completing baseline outcomes and 30 (79%) completing week 12 outcomes measures in control sites.	No significant differences in QoL or anxiety/depression but responsiveness to intervention was shown
Joubert et al., 2020 (ICARUSS) (47)	Double blind randomized controlled trial Control n=137, intervention n=112	ICARUSS (Integrated Care for the Reduction of Secondary Stroke) intervention involving personalizing stroke risk factors for the stroke survivor and ongoing support from a stroke specialist and primary care physician vs usual care.	Risk factors (blood pressure, cholesterol, BMI, alcohol)	At the 12-month evaluation, there was a significant decrease in systolic blood pressure (129.4 [14.7]) from baseline (134.6 [16.7]) in the intervention group of 5.2mmHg (p<0.01), control 133.7 (17.0) at baseline to 131.7 (16.3) at 12 months, p=0.29. Fasting total cholesterol (mmol/l): Intervention: Baseline 5.00 (1.17), 12 month 4.19 (0.99) Control: Baseline 4.36 (1.14), 12 month 4.11 (0.90) BMI: Intervention: Baseline 27.78 (5.38), 12 month 27.97 (6.09), p=0.50 Control: Baseline 27.45 (4.94), 12 month 28.52 (4.77), p=0.02 Alcohol (no o drinks per week) Intervention: Baseline 8.4 (16.5), 12 month 4.8 (10.1), p=0.04 Control: Baseline 6.0 (10.2), 12 month 4.6 (7.2), p=0.26	In stroke survivors, the ICARUSS model was superior to usual care with respect to best-practice recommendations for traditional risk factors as well as behavioral and functional outcomes.
Jung, 2021 (48)	Non-randomised single arm trial with historical control group	Exercise based intervention tailored to each patient	The primary outcome measurements used were Berg	Differences in BBS, MBI, and PCS components in SF-36 were more statistically significant in the SAVE group than that in the	This evidence-based SAVE intervention can optimize patient

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
	N=313 (Control n=96, int n=227) Analysis: Control n=96, int n=88		Balance Scale (BBS), Mini-Mental State Examination (MMSE), Modified Barthel Index (MBI), physical component summary (PCS), and the mental component summary (MCS) of the Short-Form Survey 36 (SF-36), and Beck Depression Inventory (BDI) according to the WHO's International Classification of Functioning, Disability, and Health (ICF).	control group ($p < 0.05$). Patients in the SAVE group showed more significant improvement in BBS, MBI, and PCS components in SF-36 as compared to that in the control group	recovery after a subacute stroke while keeping the available resources in mind.
Kalav, 2022 (49)	Single centre, single-blinded randomised controlled experimental study N=210 (Control n=34, int n=34)	Individualised patient education with follow-up	Primary: Self efficacy, QoL, patient satisfaction Secondary: healthy eating habits, physical activity (lifestyle), BP (risk factors)	No significant differences were found between the two groups with respect to self-efficacy and QoL. Patient satisfaction was significantly higher in the IG. Positive feedback percentages of the patients in the IG regarding stroke knowledge level and consuming whole-grain food at the end of the 12 weeks increased significantly. This protocol had no significant effects on the secondary outcomes.	The CCM-based interventions may increase the satisfaction level of the patients and help to raise awareness of the risk of a secondary stroke. More studies are needed to examine the effects of these interventions
Kam Yuet Wong et al., 2022 (50)	Randomised controlled trial N=2612 (Control n=58, int n=58)	Holistic MDT-based exercise training programme with psychological and social support	The primary outcome was EQ-5D-5L (Chinese). Secondary: SIS, ADL, self-efficacy	Both intervention and control groups showed improvement in EQ-5D-5L from baseline to post-intervention (0.66 versus 0.83, $P < 0.001$) and (0.66 versus 0.77, $P < 0.001$), respectively, and there was significant group-by-time interaction in EuroQol-Visual Analogue Scale from baseline to post-intervention at 90 days and follow-up at 180 days with the intervention group experiencing better improvement. Similarly, significant interaction effects were also found in the Stroke Impact Symptom scale, self-efficacy and modified Barthel Index	Home-based transitional care was effective in improving QOL, symptoms, self-efficacy and activities of daily living
Khramov, 2021 (51)	Prospective randomized controlled parallel-group study N=122 (Control n=59, int n=63)	Exercise, massage, PT and OT, social adaptation, goal setting	QoL, depression	The functional, cognitive, psychological and emotional states and the level of social activity were monitored for 6 months. Group 2 demonstrated more pronounced improvement than group 1 after 6 months of follow-up, confirmed by higher Rivermead ($p = 0.011$) and SS-QOL ($p < 0.05$) scores and lower DASH and Beck scores ($p = 0.015$ and $p < 0.001$, respectively). In both groups, MMSE (cognitive function) scores slightly increased, but the differences between the groups were insignificant.	The proposed post-stroke rehabilitation program is effective in helping patients regain their independence and improve social adaptation. The scales and scores used in the study, especially DASH and SS-QOL, are sensitive to changes in the functional state of stroke survivors with moderate impairments
Koch, 2020 (52)	Prospective randomised study N=131 (control n=45, int n=86)	Combined exercise and cognitive training (psychological)	The primary outcomes were feasibility and adherence to the 12-week intervention and safety. The principal secondary outcome was global cognition. Other secondary cognitive outcomes included multiple tests measuring working memory, processing speed, verbal/visual learning	The observed-over-expected visit ratio was significantly higher in the intervention than in the control group (0.74±0.30 versus 0.54±0.38; P=0.003). A total of 99 adverse events were reported by 59 participants, none of which were serious and related to the intervention. Greater gains in physical, cognitive, and mood outcomes were found in the CARET+CTI group than in the control group, but were not statistically significant after adjustments. The most common reason for withdrawal was lack of time/having to return to work, newly arising	A CARET+CTI intervention, after stroke, is safe, feasible, and has satisfactory participant adherence over 12 weeks

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			and memory, and executive function with the Hopkins Verbal Learning Test Revised, Hopkins Verbal Learning Test Revised Delayed Recall, Grooved Pegboard, Stroop Delis Kaplan Executive Function Test, WAIS-IV Coding Digit Symbol Substitution Test, Brief Visuospatial Memory Test-R, Brief Visuospatial Memory Test-R Delayed Recall Digit Span Backwards, and the CogState Brief Battery	medical issues, and that the control intervention was not challenging enough	
Langhorne et al., 2017 (53)	Pragmatic, prospective, parallel-group, multicentre, international, RCT with blinded assessment of outcomes and an intention to treat analysis N=2104 (Control n=1050, int n=1054)	Very early mobilisation (within 24h of stroke onset) Exercise	The primary outcome was survival without major disability [modified Rankin scale (mRS) score of 0–2] at 3 months after stroke. Secondary efficacy outcomes were an assumption-free ordinal shift across the range of the mRS, time (days) to walk 50 m unassisted and the proportion of patients achieving unassisted walking by 3 months.	Compared with UC, VEM patients mobilised 4.8 hours [95% confidence interval (CI) 4.1 to 5.7 hours; $p < 0.0001$] earlier, with an additional three (95% CI 3.0 to 3.5; $p < 0.0001$) mobilisation sessions per day. Fewer patients in the VEM group (n = 480, 46%) had a favourable outcome than in the UC group (n = 525, 50%) (adjusted odds ratio 0.73, 95% CI 0.59 to 0.90; $p = 0.004$). Results were consistent between Australasian and UK settings. There were no statistically significant differences in secondary outcomes at 3 months and QoL at 12 months. Dose–response analysis found a consistent pattern of an improved odds of efficacy and safety outcomes in association with increased daily frequency of out-of-bed sessions but a reduced odds with an increased amount of mobilisation (minutes per day).	Patients in the VEM group were mobilised earlier and with a higher dose of therapy than those in the UC group, which was already early. This VEM protocol was associated with reduced odds of favourable outcome at 3 months cautioning against very early high-dose mobilisation. At 12 months, health-related QoL was similar regardless of group. Shorter, more frequent mobilisation early after stroke may be associated with a more favourable outcome
Lee, 2018) (54)	Open-label parallel group study N=31 (Control n=17, int n=14)	Horticulture-based exercise therapy	Upper limb function, grip strength, pinch force, fine motor skills, balance, ADL, depression, rehabilitation stress, rehabilitation motivation, fall efficacy.	Stroke patients in the HT group showed significantly improved upper limb function, hand force, balance, fall efficacy, activities of daily living, and decreased depression ($P < 0.05$). By contrast, no significant change was noted in the control group. In addition, 85.7% of the stroke patients in the HT group reported being very satisfied or satisfied with the HT program	In conclusion, the HT program based on task-oriented training improved the patients' physical and psychological function after stroke rehabilitation. These study results suggest that implementing an HT program in a rehabilitation hospital will effectively contribute to functional recovery after stroke
Lewthwaite, 2018 (55)	Parallel group, three-arm, single blind, superiority randomized controlled trial of a theoretically-defensible, upper extremity rehabilitation program N=361 (UCC n=122, DEUCC n=120, ASAP n=119)	Accelerated Skill Acquisition Program (ASAP) comprising skill acquisition through task-specific practice, impairment mitigation to increase capacity, and motivational enhancements to build self- confidence (exercise, psychological)	The log-transformed WMFT time score at the 1 year endpoint is the primary outcome measure for the trial and the basis of a priori sample size and sensitivity estimates. The SIS hand domain and full SIS constitute the secondary outcome measures.	Across all groups, most improvement occurred during the treatment phase, followed by change more slowly during follow-up. Compared with DEUCC and UCC, ASAP group gains were greater during treatment for Stroke Impact Scale Hand, Strength, Mobility, Physical Function, and Participation scores, self-efficacy, perceived health, reintegration, patient-centeredness, and quality of life outcomes. ASAP participants reported higher Motor Activity Log–28 Quality of Movement than UCC posttreatment and perceived greater study- related improvements in quality of life. By end of study, all groups reached similar levels with only limited group differences	Customized task-oriented training can be implemented to accelerate gains across a full spectrum of patient- reported outcomes. While group differences for most outcomes disappeared at 1 year, ASAP participants achieved these outcomes on average 8 months earlier

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Li et al., 2023 (56)	Randomised controlled trial Control n=80, intervention n=80	Physiotherapy group rehabilitation (We chat) updates in outpatient setting every 2 weeks where a combination of doctors, nurses and rehabilitation therapists continued follow up	QoL (SS-QoL)	SS-QoL scores: Baseline: Control 117.59±17.99, intervention 119.94±22.78 1 month: Control 120.10±18.11, intervention 130.83±22.30 3 months: Control 121.89±16.89, intervention 137.46±21.70 Between group p=0.001 (1 month), p<0.001 (3 months)	Significant SS-QOL score differences between intervention group and control
Lin, 2022 (57)	Randomised controlled trial Control n=83, intervention n=83	Intervention group had a multi-disciplinary clinical nursing pathway (CNP) formed and followed until 11 days post-stroke	Anxiety and depression (45-point scale)	Anxiety scores (A1): Baseline: Control (G1) 20.98±2.63, intervention 20.68±2.57 After intervention: Control 18.63±2.10, intervention 15.08±2.00 (p<0.05) Depression scores (A2): Baseline: Control 33.08±3.52, intervention 33.62±4.03 After intervention: Control 29.73±3.92, intervention 22.47±2.64 (p<0.05)	Anxiety and depression were significantly reduced in the intervention group compared with control
Lin, 2020 (58)	Randomised controlled trial N= 152 (control n=114, int n=38) Analysis: Control n=107, int n=38	Supervised virtual reality training in addition to early rehabilitation exercise	Outcome data including muscle strength, mood state (depression, anxiety), and functional status were collected at baseline (within 4 hr following admission) and on the day of discharge (7 to 21 days).	Participants in the EG reported increased muscle strength of upper and lower limbs in both affected and unaffected sides, decreased depression and anxiety, and increased functional status at discharge. When the group–time interaction was examined, the EG had greater increased upper limb muscle strength of the unaffected side (ß = 0.34, p < .001) and decreased depression and anxiety scores (ß = −2.31, p = .011; ß = −1.63, p = .047) at discharge compared with the CG. However, there was no difference in the functional status change scores from baseline between EG and CG	A poststroke program that includes both early rehabilitation and VR training has greater benefit in relation to mood state and muscle strength at discharge than early rehabilitation alone. Therefore, an early physical rehabilitation program that includes VR training for acute stroke inpatients should be considered for implementation in clinical settings
Liu et al., 2014 (59)	Multi centre randomized controlled trial Control n=122, intervention n=121	Early intervention: Standard care but at 48 hours following ICH onset.	Mortality, HrQoL, anxiety	Mortality: 3 months: Control 10/122, intervention 1/121 6 months: Control 12/122, intervention 3/121 SF-36 Mean differences between components at 3 months varied were -2.5 to 5.8 between groups, 6.4-25.5 at 6 months Zung's self rating anxiety scale: 3 months: control 51.8 (5.8), intervention 51.8 (4.9), mean difference = 0 6 months: control 55.2 (9.3), intervention 48.9 (4.8), mean difference -6.4	Commencement of rehabilitation within 48 hours of ICH significantly reduced hospital length of stay and improved long-term survival and morbidity outcomes when compared with standard practices
Liu, 2018 (60)	Randomised trial N=40 (control n=20, int n=20)	Nurse-led personalised education and follow-up	Functional exercise compliance, health status	No significant between-group differences were observed in functional exercise compliance or health status before the intervention was conducted. One month after the intervention, functional exercise compliance and health status were significantly improved in the intervention group, with significant between-group differences in all but one dimension: social functioning. Three months after the intervention, functional exercise compliance and four dimensions of health status – physical functioning (PF), role limitations due to physical health problems (RP), general health perceptions	A nurse-led transitional care intervention effectively improved the early functional exercise compliance and health status of stroke patients. However, the intervention effect decreased with time after the intervention, and the long-term effect was not ideal

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
				(GH), and mental health (MH) – were significantly improved in the intervention group compared with the control group. Six months after the intervention, only the active advice-seeking of functional exercise compliance and the GH of health status were significantly improved in the intervention group compared with the control group.	
Lo et al., 2023 (61)	Randomised controlled trial Control n=169, intervention n=166	Virtual multidisciplinary stroke clinic including monthly follow-up calls and educational videos	Primary: self-efficacy Secondary: depression (GDS)	Depression level (GDS): Baseline (T0): control 8.4 (6.9), intervention 10.2 (6.7) 3 months (T1): control 7.1 (6.7), intervention 8.2 (6.9) 6 months (T2): control 7.8 (7.6), intervention 7.3 (7.5), effect size 0.36 (95% CI: 0.13-0.60)	The intervention reduced depression but not significantly
López-Liria et al., 2016 (62)	Prospective cohort study Control n=67, intervention n=78	Home-based rehabilitation including physiotherapy versus hospital based rehabilitation (standard care)	QoL (SF-36)	PCS-36 Pre-test: intervention 26.76 (5.07), control 26.15 (5.35), p=0.482 Post-test: intervention 31.95 (8.01), control 32.17 (8.18), p=0.870 MCS-36 Pre-test: Intervention 29.67 (7.48), control 33.41 (13.22), p=0.034 Post-test 35.44: Intervention (10.70), control 37.30 (13.17), p=0.349	No statistically significant differences between groups
Lu et al., 2023 (63)	Randomised controlled trial Control n=41, intervention n=40	Internet-based home care model (multidisciplinary)	Readmission, QoL (SS-QoL), anxiety and depression (HADS), adherence to intervention	Rehospitalisation = 16 in control group vs 8 in intervention p=0.043 After 3 months of nursing, there was no significant difference in SS-QOL scores between the intervention group and the control group (P>0.05). After 6 months and 12 months of nursing, the SS-QOL score of the intervention group was statistically higher than that of the control group (P<0.05) There was no significant difference in HADS scores between the two groups after 3 months of nursing (P>0.05). After 6 months and 12 months of nursing, the HADS score of the intervention group was significantly lower than that of the control group (both P<0.05) The scores of standardized drug use, rehabilitation training and reasonable diet in the intervention group were higher than those in the control group (all P<0.05)	The intervention was associated with significantly lower readmission rates. Better QoL, lower depression and anxiety rates were observed in the intervention group but only at 6 and 12 months. Adherence to intervention was higher in the intervention group.
Luengo-Fernandez et al., 2022 (EXPRESS) (64)	Prospective population-based before (phase 1: April 2002–September 2004; n=310) versus after (phase 2: October 2004–March 2007; n=281) study EXPRESS: Phase 1 n=310, Phase 2 n=281; Control: Phase 1 n=167, Phase 2 n=224	EXPRESS Phase 1: Clinic referral (1-2 days), brain imaging and ECG, ultrasound/echo, primary care treatment protocol comprising antiplatelet, statin, BP lowering. Phase 2: As Phase 1 but treatment initiated immediately instead of by primary care, high-dose aspirin or clopidogrel, CT scan during clinic. Follow-up 1, 6, 12, 60, and 120 months after the index	Mortality, functional statust (mRS), recurrent stroke, quality of life (EQ-5D)	Death, n (%): 1 month: Control Phase 1 14/167 (8), Phase 1 7/310 (2), Control Phase 2 15/224 (7%), Phase 2 4/281 (1) 6 months: Control Phase 1 16/167 (10), Phase 1 14/310 (5), Control Phase 2 23/224 (10%), Phase 2 9/281 (3) 1 year: Control Phase 1 26/167 (16), Phase 1 24/310 (8), Control Phase 2 32/224 (14), Phase 2 12/281 (4) 5 years: Control Phase 1 77/167 (46), Phase 1 89/310 (29), Phase 2 control 89/224 (40), Phase 2 62/281 (22) 10 years: Control Phase 1 109/167 (65), Phase 1 152/310 (49), control Phase 2 132/224 (59), Phase 2 123/281 (44) Disability (mRS>2), n (%):	Urgent assessment and treatment of patients with transient ischemic attack or minor stroke resulted in a long-term reduction in recurrent strokes and improved outcomes, with little atrophy of the early benefit over time, representing good value for money even with a 10-year time horizon. A reduction in stroke risk in phase 2 was still evident at 10 years (55/23.3% versus 82/31.6%; hazard ratio=0.68 [95% CI, 0.48–

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
		event in both Phases. Control: standard care (not referred to study clinic)		1 month: Control Phase 1 47/167 (33), Phase 1 55/310 (18), control Phase 2 58/224 (32), Phase 2 34/281 (13) 6 months: Control Phase 1 47/167 (34), Phase 1 71/310 (24), control Phase 2 50/224 (29), Phase 2 34/281 (13)* 1 year: Control Phase 1 43/167 (33), Phase 1 60/310 (22), Control Phase 2 47/224 (29), Phase 2 36/281 (14)** 5 years: Control Phase 1 27/167 (34), Phase 1 51/310 (25), Control Phase 2 37/224 (32), Phase 2 50/281 (29) 10 years: Control Phase 1 9/167 (21), Phase 1 44/310 (36). Control Phase 2 22/224 (35), Phase 2 30/281 (27) Statistically significant at: *p<0.001 & ** p<0.050 when compared to phase 1 Recurrent stroke, n (%) 90 days: Phase 1 32/310 (10%), Phase 2 6/281 (2%) 10 years: Control Phase 1 39/167 (23%), Phase 1 82/310 (26%), Control Phase 2 55/224 (25), Phase 2 55/281 (20%)	0.95]; P=0.024), as was the impact on risk of disabling or fatal stroke (17/7.7% versus 32/13.1%; hazard ratio=0.54 [0.30–0.97]; P=0.036).
MacKay-Lyons et al., 2022 (PREVENT) (65)	Three-site, single-blinded, randomized controlled trial Control n=90, intervention n=94	Participants randomized to the PREVENT group engaged in a multi-modal, case-managed program of exercise and education.	CV risk factors including systolic BP, cholesterol, anxiety and depression (HADS)	Resting SBP mmHg: Baseline: PREVENT 131.8±15.7, Control 131.7±18.4 Post-treatment: PREVENT 125.9±16.7, Control 129.3±18.1 6-months: PREVENT 126.8±15.1, control 128.2±16.8 12 months: PREVENT 130.6±17.5, control 128.9±18.3 Change from baseline between groups -3.5 (-8.8, 1.8) Resting DBP mmHg Baseline: PREVENT 76.6±11.1, control 74.9±9.8 Post-treatment: PREVENT 72.2±12.0, control 73.7±14.6 6 months: PREVENT 71.8±8.1, control 73.8±9.0 12 months: PREVENT 73.0±9.7, control 72.5±9.9 Change from baseline between groups -3.2 (-6.3, -.2), p<0.05 LDL-C Mmol/L: Baseline: PREVENT 2.24±0.8, control 2.24±0.9 Post-treatment: PREVENT 1.94±0.8, control 2.23±0.8 6 months: PREVENT 1.96±0.6, control 2.21±0.8 12 months: PREVENT 2.01±0.5, control 2.10±0.7 Change from baseline between groups -.31 (-.42, -.20), p<0.05 HADS-A 0-21: Baseline: PREVENT 5.2±4.1, control 5.5±4.0 Post-treatment: PREVENT 5.1±4.1, control 4.4±3.8 6 months: PREVENT 4.6±3.8, control 4.5±3.9 12 months: PREVENT 3.9±3.8, control 4.4±3.6 Change from baseline between groups: -.9 (-2.1, 0,3) HADS-D 0-21: Baseline: PREVENT 3.4±2.8, control 3.5±3.2 Post-treatment: PREVENT 3.1±2.9, control 3.4±3.1 6 months: PREVENT 2.9±2.6, control 3.3±2.9 12 months: PREVENT 2.3±2.2, control 3.0±2.6	Significant between-group differences at post-intervention favored PREVENT group over UC: DBPrest (mean difference [MD]: -3.2 mmHg, 95% confidence interval [CI]: -6.3, -.2, P = .04) and LDL-C (MD: -.31 mmol/L, 95% CI: -.42, -.20, P = .02). Trends of improvement in PREVENT group were noted in several variables between baseline and 6-month follow-up but not sustained at 12-month follow-up. Impact of PREVENT on vascular risk factor reduction was more modest than anticipated, possibly because several outcome variables approximated normative values at baseline and training intensity may have been sub-optimal.

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
				Change from baseline between groups: -.2 (-1.1, .7)	
Man, 2018 (66)	Nonrandomized comparative group study CSC n=134 (patients n=159,000), PSC n=1047 (patients n=563,941)	Comparison of stroke care in in-hospital outcomes between primary stroke centers (PSC) and comprehensive stroke centers (CSC) (pathway comparisons)	In-hospital mortality, smoking cessation	Both CSCs and PSCs had good conformity to 7 performance measures and the summary defect-free care measure. Among emergency department admissions, CSCs had higher intravenous tPA (tissue-type plasminogen activator) and endovascular thrombectomy rates than PSCs (14.3% versus 10.3%, 4.1% versus 1.0%, respectively). Door to intravenous tPA time was shorter at CSCs (median, 52 versus 61 minutes; adjusted risk ratio, 0.92; 95% confidence interval, 0.89–0.95). More patients at CSCs had door to intravenous tPA time ≤60 minutes (79.7% versus 65.1%; adjusted odds ratio, 1.48; 95% confidence interval, 1.25–1.75). For transferred patients, CSCs and PSCs had comparable overall performance in defect-free care, except higher endovascular thrombectomy therapy rates. The overall in-hospital mortality was higher at CSCs in both emergency department admissions (4.6% versus 3.8%; adjusted odds ratio, 1.14; 95% confidence interval, 1.01–1.29) and transferred patients (7.7% versus 6.8%; adjusted odds ratio, 1.17; 95% confidence interval, 1.05–1.32). In-hospital outcomes were comparable between CSCs and PSCs in patients who received intravenous tPA or endovascular thrombectomy	CSCs and PSCs achieved similar overall care quality for patients with acute ischemic stroke. CSCs exceeded PSCs in timely acute reperfusion therapy for emergency department admissions, whereas PSCs had lower risk-adjusted in-hospital mortality. This information may be important for acute stroke triage and targeted quality improvement
Markle-Reid, 2020 (67)	Prospective one-group pre-test/post-test pragmatic study N=45 (participated n=30)	Multidisciplinary transitional care intervention delivering training and support to older stroke patients at home with regular consultation and follow-up (pathway)	The primary objective was to determine the feasibility of implementing the TC intervention. The secondary objectives were to (i) explore the preliminary effectiveness of the intervention based on changes in patient-reported health outcomes, and the costs of use of health and social services, from baseline to 6-month follow-up; (ii) determine the feasibility of the study methods; and (iii) determine the most appropriate primary outcome measure for a future RCT.	The intervention was feasible and acceptable to both older adults and providers. From baseline to 6 months, there was no statistically significant difference in health outcomes. However, there was a significant reduction in the total per person use and costs of health services.	This study established the feasibility of conducting a larger randomized controlled trial of this intervention.
Minshall, 2020 (68)	Randomised controlled trial N=458 (Control: stroke patients n=39, carers n=40. 12-month assessment patients n=25, carers n=23 Int: stroke patients n=50, carers n=44. 12-month assessment patients n=27, carers n=18)	Program of personalized psychosocial support – Stroke Care Optimal Health Program (SCOHP) comprising education, self-management and reflective exercises	Primary outcomes were QoL and self-efficacy. Secondary outcomes were anxiety and depression, coping, illness perceptions, work and social adjustment, carer strain and carer satisfaction	Of the 173 participants recruited (89 stroke survivors; 84 carers), a total of 137 participants – 73 stroke survivors (intervention n = 42; usual care n = 31) and 64 carers (intervention n = 35; usual care n = 29) – underwent analysis up to 12 months. No statistically significant differences were found in the primary outcomes between groups over time, though a significant improvement in carer satisfaction was found at 6 months in the intervention group compared to the usual care group.	No significant differences between groups for QoL
Mofidi et al., 2018 (69)	Retrospective registry study	Integrated stroke care pathway for patients with carotid artery	Symptom to surgery time, major bleeding, mortality, cost	Median symptom to surgery time was 11 (0-66) days for the former and 15 (3-90) days for the latter (p < .001). There was	An integrated stroke system of care is cost-effective and associated

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	Control n=133, intervention 243	stenosis undergoing carotid endarterectomy (CEA). Within 60 minutes: CT scan, stroke team evaluation, thrombolysis is needed; within 24 hours carotid duplex, MR angiogram, diffusion weighted MRI; within 48 hours vascular surgeon review; within 2 weeks carotid endarterectomy, all cases discussed in MDT	effectiveness, risk of recurrent stroke	no significant difference in peri-operative stroke death rate between integrated (5/243, 2.1%) and standard (2/133, 1.5%) pathways (chi-square = 0.14, p = .73). Major bleeding: Intervention 6/243 (2.5%), control 3/133 (2.3%) Recurrent stroke: Intervention 5/243 (2.1%), control 2/133 (1.5%) CEA through the integrated pathway improved quality adjusted life expectancy by an additional 0.13 (0.64 QALYs [integrated pathway] to 0.51 QALYs [standard pathway]) and was associated with an incremental lifetime cost benefit of £2203.4.	with significant improvements in quality adjusted life years.
Mohammadi, 2022 (70)	Single-blind RCT N=80 (Control n=36, int n=31)	Personalised care plan providing education, diet, activity, anxiety level, medication with follow-up	QoL (SSQOL) at 3 and 6 months, activities of daily living (ADL)	The results show that the mean scores of the QOL significantly increased after the intervention in the intervention group (before = 130.80; 3 months = 172.19; 6 months = 205.29) compared to the control group (before = 150; 3 months = 144.86; 6 months = 160.66). Also, the mean scores of the ADL significantly increased after the intervention in the intervention group (before = 1.96; 3 months = 3.64; 6 months = 4.87) compared to the control group ($p < .05$). The effect size is equal to 0.501 and 0.245 for QOL and ADL, respectively.	The findings show that the care program based on a PCM recovered the QOL and ADL of stroke participants more than other interventions.
Nakibuuka et al., 2016 (71)	Non-randomised controlled Control n=125, intervention n=126	Stroke care bundle including rapid screening, scans, antiplatelet therapy and physiological monitoring	Mortality at 7, 30 days, in-hospital mortality	Mortality within 7 days was higher in the intervention group compared to controls (RR 13.1, 95% CI 3.3–52.9). There was no difference in 30-day mortality between the two groups (RR 1.2, 95% CI 0.5–2.6). There was better 30-day survival in patients with severe stroke in the intervention group compared to controls (P = 0.018). The median survival time was 30 days (IQR 29–30 days) in the control group and 30 days (IQR 7–30 days) in the intervention group. In the intervention group, 41patients (32.3%) died in hospital compared to 23 (18.1%) in controls (P < 0.001).	While implementing elements of a stroke-focused ICP in a Ugandan national referral hospital appeared to have little overall benefit in mortality and functioning, patients with severe stroke may benefit on selected outcomes.
Nayeri et al., 2014 (72)	Posttest-only randomised controlled trial study Control n=30, intervention n=30	Family centred care program including education for patients and caregivers	Adherence to intervention, readmission, stroke recurrence	Readmission: Control 8/30 (26.6%), intervention 3/30 (10%) Stroke recurrence: Control 3/30 (10%, intervention 2/30 (6.6%), p<0.64 Adherence to the therapeutic regimen in 3 areas of rehabilitation, dietary and medicine regime [n (%) & Mean +/- SD]: ARR: Good (84–66): Ex Group - 29 (96.66%) & 72.73 ± 4.08. Con Group- 0 (0%) & 51.96 ± 5.04 Average: (65–47): Ex group - 1 (3.34%) ; Con Group - 24 (80%) Weak: (18–11): Ex group - 0 (0%); Con group - 2 (6.27) t = 17.51; p <0.000 ADR:	Face-to-Face individual education has effective enhanced adherence to ATRs among patients and caregivers. This approach taken for the experimental group has improved both physical and mental health status of patients and reduced complicaitons, and it is recommended to be routine to enhance care quality.

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
				Good (33–27): Ex group - 28 (93.33%) & 29.63 ± 2.32; Con group - 0 (0%) & 22.43 ± 2.29 Average (26–19): Ex group - 2 (6.27%); Con Group -28 (93.33%) Weak (18–11): Ex group - 0 (0%); Con group - 2 (6.27) t = 12.5; p <0.000 AMR: Good (18–15): Ex group - 30 (100%) & 17.13 ± 0.89; Con group - 24 (80%) & 15.26 ± 1.04 Average (14–11): Ex group - 0 (0%); Con group - 6 (20%) Weak (10–6): Ex group - 0 (0%); Con group - 0 (0%) t = 7.40; p<0.000	
Nguyen-Huynh, 2018 (73)	Sequential pre-post intervention group study N=867 (Control n=310, int n=557)	Telestroke program for thrombolysis through a dedicated tele-neurologist to advise on alteplase delivery (pathway)	Primary: DTN time for alteplase Secondary: Symptomatic ICH	This study included 310 patients treated with alteplase in the pre–EXpediting the PRrocess of Evaluating and Stopping Stroke period and 557 patients treated with alteplase in the EXpediting the PRrocess of Evaluating and Stopping Stroke period. After implementation, alteplase administrations increased to 62/mo from 34/mo at baseline (P<0.001). Median DTN time decreased to 34 minutes after implementation from 53.5 minutes prior (P<0.001), and DTN time of <60 minutes was achieved in 87.1% versus 61.0% (P<0.001) of patients. DTN times <30 minutes were much more common in the Stroke EXpediting the PRrocess of Evaluating and Stopping Stroke period (40.8% versus 4.2% before implementation). There was no significant difference in symptomatic intracranial hemorrhage rates in the 2 periods (3.8% versus 2.2% before implementation; P=0.29).	Introduction of a standardized modified Helsinki protocol across 21 hospitals using telestroke management was associated with increased alteplase administrations, significantly shorter DTN times, and no increase in adverse outcomes
Olaiya et al., 2017 (74)	Pragmatic multicentre, cluster-randomised, controlled trial, with blinded assessment of outcomes and intention-to-treat analysis N=2516 (Control n=266, int n=267)	Individualised management programme comprising a chronic disease management (CDM) plan and education	Framingham risk score (modified for secondary outcomes). FRS includes cholesterol levels, systolic BP, use of antihypertensives, smoking status and uncontrolled diabetes	From January 2010 to November 2013, 156 general practices (280 patients) were randomly assigned to usual care (control) and 159 (283 patients) to the intervention. The median age was 70.1 years; 65% were male. Overall, >80% of participants were prescribed recommended secondary prevention therapies at baseline. The primary efficacy analysis comprised 533 participants, with 30 either dying or lost to follow-up. In adjusted analyses, no significant between-group difference was found in the cardiovascular risk score at 12 months (0.04, 95% confidence interval -1.7, 1.8).	The effectiveness of an organized secondary prevention programme for stroke may be limited in patients from high-performing hospitals with regular post-discharge follow-up and communication with general practices.
Pedapati et al., 2021 (75)	Prospective single-centre, cluster-randomised, open-label, blinded endpoint superiority trial N=164 (Int n=82, control n=82)	Education and exercise plan tailored to the home needs of patients	Primary: In-hospital mortality Disability, 3-month mortality (secondary)	Among 164 patients recruited, 82 received intervention, and standard care each. The mean (Standard deviation) Glasgow coma scale of patients was 11.01 (3.4), and National Institute of Health Stroke Scale was 19.17 (8.54). The incidence of complications (72 in the intervention versus 81 in the control group; p=0.56) was not different. Ten patients (12.2%) in the intervention group and 16 (19.5%) in the control group (p=0.20) died in-hospital. Twenty patients (27.8%) in the intervention and twelve (18.2%) in the control group attained modified Rankin Scale 0-2 at three months (p=0.12). The mortality at three months (20 [24.4%] in the intervention versus 25 [30.5%] in the control group) was not different (p=0.38). The intervention group had fewer complications (42	A structured educational intervention did not reduce the incidence of hospital-acquired complications, mortality, or morbidity. However, there was a trend towards fewer complications in the initial days of hospital stay. Extended hospital stay, caregiver fatigue, and dilution of the intervention over time might be reasons for the apparent lack of effect

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				versus 68 in the control group; p=0.01) during the initial ten days of hospital stay, but adjusted analysis revealed no difference.	
Peng, 2017 (76)	Propensity score-matched case-control study using the National Health Insurance data Original cohort: control n=3159, int n=1480 Matched Cohort: control n=657, int n=657	PAC program measuring activities of daily living, nutrition, exercise, mobility and language	90-day mortality, readmission	After propensity score matching, baseline characteristics, stroke severity, and status of healthcare utilization before index stroke admission were similar between cases and controls. After PAC services, the case group obtained significant improvement in all functional domains and may have reduced subsequent disability. Among all functional assessments, balance was the most significantly improved domain and was suggestive for the reduction of subsequent falls risk and related injuries. Compared with controls, patients receiving PAC services had significantly lower 90-day hospital re-admissions [11.1% vs 21.0%, adjusted odds ratio (aOR) 0.47 with 95% confidence interval (CI) 0.34-0.64], stroke-related re-admissions (2.1% vs 8.8%, aOR 0.22, 95% CI 0.12-0.41), and emergency department visits (13.5% vs 24.0%, aOR 0.49, 95% CI 0.37-0.65), but the 90-day mortality rate remained similar between groups (1.4% case group vs 2.0% control group, aOR 0.68, 95% CI 0.29-1.62	PAC significantly improved the recovery of stroke patients in all functional domains through the program, with universal interorganizational staff training, periodic functional assessment, and high- intensity rehabilitation. Further longitudinal research is needed to evaluate the long-term survival benefits and healthcare utilization
Rafsten, 2019 (77)	Randomised controlled trial with blinded assessors N=140 (Control n=71, int n=69)	Very early supported discharge comprising person-centred goal setting for achievement of identified aims (pathway)	The primary outcome as stated in the protocol was anxiety. The secondary outcome was the patients' degree of overall disability	No significant differences were found between the groups regarding anxiety at three or 12 months post-stroke (p = 0.811). The overall disability was significantly lower in the VESD group 3 months post-stroke (p= 0.004), compared to the control group. However, there was no significant difference between the groups 1 year post-stroke	The VESD does not affects the level of anxiety compared to ordinary rehabilitation. The VESD leads to a faster improvement of overall disability compared to ordinary rehabilitation.
Rasmussen et al., 2016 (78)	Interventional, randomised, safety/efficacy open-label trial Control n=30, intervention n=31	Multidisciplinary home-based pathway including exercise and goal setting	Primary: mRS at 90 days Secondary: DALYs, Motor Function, Cognitive Function, QOL, BMI, treatment-associated economy	mRS: Modified Rankin Scale: Intervention: 2 (2–3); Control: 3 (2–4) Modified Rankin Scale improvement: Intervention: 1 (1–2); Control: 1 (0–1) Body Mass Index (BMI): Intervention 23 (21–25); Control: 24 (22–25) Body Mass Index (BMI) improvement: Intervention: 0 (-0.5–0) Control: −1 (-2–0) EuroQol-5D™ score: Intervention: 0.77 (0.66–0.79), Control:0.66 (0.56–0.72) EuroQol-5D™ score improvement: Intervention: 0.19 (0.05–0.51); Control: 0.27 (0–0.49)	Early home-based rehabilitation reduced disability and increased quality of life. Compared to standard care, home-based stroke rehabilitation was more cost-effective.
Reeves, 2019 (79)	Open-label (unblinded) 3-group parallel-design clinical trial N=320 (Group 1 (UC): Global-10 n=77, PAM n=76, Group 2 (SWCM) Global-10 n=82, PAM n=79, Group 3 (SWCM + MISTT website) Global-10 n=81, PAM n=78)	Home-based social worker–led case management (SWCM) program with or without a website, comprising biopsychosocial assessment followed by development of a personalised plan to address unmet needs (pathway, psychological)	Primary: Anxiety Secondary: Disability	There were statistically significant changes in Patient-Reported Outcomes Measurement Information System Physical Health (P=0.003) and Patient Activation Measure (P=0.042), but not Patient-Reported Outcomes Measurement Information System Mental Health (P=0.56). The mean change in Patient-Reported Outcomes Measurement Information System Physical Health scores for group-3 (SWCM+MISTT Website) was significantly higher than both group-2 (SWCM; difference, +2.4; 95% CI, 0.46–4.34; P=0.02) and group-1 (usual care; difference, +3.4; 95% CI, 1.41–5.33; P<0.001). The mean change in Patient	An intervention that combined SWCM with access to online stroke-related information produced greater gains in patient-reported physical health and activation compared with usual care or case management alone. There was no intervention effect on mental health

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
	UC, usual care; MISTT, Michigan stroke transitions trial; PAM, pain activation measure; SWCM, social worker–led case management			Activation Measure scores for group-3 was significantly higher than group-2 (+6.7; 95% CI, 1.26–12.08; P=0.02) and marginally higher than group-1 (+5.0; 95% CI, −0.47 to 10.52; P=0.07).	
Rodgers, 2019 (80)	Parallel-group observer-blind multicenter individually randomized controlled trial N=573 (Control n=231, int n=219)	Early supported discharge reviews (EXTRAS) including mobility, self-care, mood (psychological), cognitive function (pathway)	The primary outcome was performance in extended activities of daily living. Secondary outcomes were health status, mood and experience of services.	Mean 24 month Nottingham EADL Scale scores were EXTRAS (n=219) 40.0 (SD 18.1) and usual care (n=231) 37.2 (SD 18.5) giving an adjusted mean difference of 1.8 (95% CI, –0.7 to 4.2). 1155/1338 (86%) of expected EXTRAS reviews were undertaken. Over 24 months, the mean cost of resource utilization was lower in the intervention group: –£311 (–$450 [95% CI, −£3292 to £2787; −$4764 to $4033]). EXTRAS provided more Quality Adjusted Life Years (0.07 [95% CI, 0.01 to 0.12]). At current conventional thresholds of willingness to pay (£20 000 [$28 940] per Quality Adjusted Life Years), there was a 90% chance that EXTRAS could be considered cost-effective.	EXTRAS did not significantly improve stroke survivors' performance in extended activities of daily living. However, given the impact on costs and Quality Adjusted Life Years, EXTRAS may be an affordable addition to improve stroke care.
Saal et al., 2015 (81)	Randomised controlled clinical trial Control n=111, intervention n=119	Post-discharge support including follow-up call and visit, education and training sessions	HRQoL BREF, depression (GDS), mortality, recurrent stroke	WHOQOL-BREF Physical: Intervention: Baseline - 68.5 (17.4); 12 months - 65.8 (18.5); Control: Baseline - 64.4 (20.0); 12 months 63.0 (21.8) Mean difference (95% CI) -0.7 (-4.7; 3.3) Psychological: Intervention: Baseline - 73.4 (14.9); 12 months 72.2 (17.8); Control: Baseline - 73.1 (16.8); 12 months -72.3 (18.9) Mean difference (95% CI) -1.5 (-5.4; 2.3) Social: Intervention: Baseline - 73.7 (15.0); 12 month - 73.3 (19.0); Control: Baseline - 75.2 (15.0); 12 months 75.8 (17.3) Mean difference (95% CI) -1.8 (-6.7; 3.1) Environment: Intervention: Baseline - 77.6 (12.0); 12 month - 78.9 (14.7); Control: Baseline- 81.3 (12.4); 12 month - 81.1 (14.5) Mean difference (95% CI) -0.7 (-4.4; 3.2) Global: Intervention: Baseline - 61.8 (17.5);l 12 month - 59.6 (20.9); Control: Baseline - 61.7 (19.6); 12 month - 60.9 (25.3) Mean difference (95% CI) -1.8 (-7.1; 3.6) GDS: Intervention: Baseline - 2.7 (2.2); 12 month - 3.2 (3.2), Control: baseline - 3.6 (3.3); 12 month - 3.6 (3.9) Mean difference (95% CI) 0.4 (-0.4; 1.1) Reinfarct Intervention: 3 (2.7); Control: 4 (3.8); RR (95% CI) 0.71 (0.16; 3.10); RD (95% CI) -0.01 (-0.09; 0.07) Mortality Intervention: 5 (3.9); Control: 15 (11.6); RR (95% CI): 0.34 (0.13; 0.90); RD (95% CI) - 0.06 (-0.13; 0.00)	No statistically significant differences were found between groups on HRQOL. No significant differences were observed between the intervention and control groups in depression and somatisation. No significant differences between groups in the number of recurrent strokes. The intervention group had a significantly lower mortality rate (3.9%) compared to the control group (11.6%) with a relative risk of 0.34 (95% CI, 0.13 to 0.90) and an adjusted hazard ratio of 0.32 (95% CI, 0.12 to 0.88).
Schwartzbach et al., 2023 (SANO) (82)	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	Recurrent stroke, MI, mortality, risk factors, major bleeding	First recurrent stroke: Control: 50 (3·9%); Intervention: 51 (4·2%); OR 1·00 (95% CI 0·58–1·73); aOR 1·03 (95% CI0·53–1·99) Myocardial infarction: Control 7 (0·5%); Intervention: 4 (0·3%); OR: 0·61 (95% CI 0·18–2·08)	This study demonstrated that the SANO programme had positive effects on the control of some cardiovascular risk factors in patients with stroke, but this did not translate into a reduction in the rate of major cardiovascular events

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
				All-cause death: Control: 31 (2·4%); Intervention: 12 (1·0%); OR 0·42 (95% CI 0·20–0·86) ; aOR 0·61 (95% CI 0·26–1·46) Readmission to hospital within 1 year of index stroke: Control: 383/1216 (31·5%); Intervention: 375/1169 (32·1%): OR 1·01 (95% CI 0·74–1·38); aOR: 0·99 (95% CI 0·73–1·37) Blood pressure (including self-reported by interview) <140/90 mm Hg: Control: 657/936 (70·2%); Intervention: 809/1103 (73·3%); OR 1·18 (95% CI 0·79–1·76), aOR 1·08 (95% CI 0·73–1·59) Blood pressure (physical examination only) <140/90 mm Hg† control: 468/679 (68·9%); intervention: 709/944 (75·1%); OR 1·34 (95% CI 0·86–2·09); aOR 1·34 (95% CI 0·88–2·04) Diabetes control‡ HbA1c ≤7% (53 mmol/mol) Control: 123/218 (56·4%); Intervention: 144/218 (66·1%); OR: 1·10 (95% CI 1·02–2·21); aOR: 1·45 (95% CI 0·94–2·26) Adherence to antithrombotic therapy targets§ Control: 1003 (88·3); Intervention: 1029 (89·4); OR 1·10 (95% CI 0·78–1·54); aOR 1·02 (95% CI 0·72–1·47) Hyperlipidaemia control¶ Achievement of LDL cholesterol targetsControl: 444/729 (60·9%); Intervention: 526/782 (67·3%), OR 1·36 (95% CI 1·00–1·85); aOR: 1·65 (95% CI 1·22–2·22) Smoking - Quit smoking - Control: 51/198 (25·8%); Intervention: 146/295 (49·5%); OR 3·13 (95% CI 1·72–5·70); aOR: 2·82 (95% CI 1·58–5·04) Bleeding: Control 8/1152 (0·7%), intervention 31/1151 (2·6%) Diagnosis of depression 13 (1·1%) 51 (4·3%)	1 year after the first ischaemic stroke. Since a 1-year follow-up period might be too short to demonstrate a positive effect on recurrent cardiovascular events, longer-term effects need to be considered.
Sharma et al., 2019 (COMPASS) (83)	COMPASS was a randomized, double-blind, double-dummy trial Prior stroke: rivaroxaban + aspirin n=351, rivaroxaban alone n=346, aspirin alone n=335. Total n=1032	Participants had stable coronary artery or peripheral artery disease and were randomly assigned to receive aspirin 100 mg once daily (n=9126), rivaroxaban 5 mg twice daily (n=9117), or rivaroxaban 2.5 mg twice daily plus aspirin (n=9152).	Primary: composite of CV death, MI and stroke	Recurrent stroke: R+A (n=351) 9/351, R (n=346) 18/346, A (n=335) 20/335 R+A vs A HR 0.42 (0.19-0.92) p=0.03 R vs A: HR 0.88 (0.47-1.67) p=0.70 Major bleeding R+A 12/351, R 26/346, A 19/335 R+A vs A HR 3.79 (1.07-13.4), p=0.04 R vs A: HR 3.84 (1.08-13.6), p=0.04 CV death, stroke or MI R+A 23/351, R 42/46, A 38/355 R+A vs A HR 0.57 (0.34-0.96), p=0.04 R vs A: HR 1.07 (0.69-1.66), p=0.77	In summary, low-dose rivaroxaban plus aspirin is an important new option for efficacious antithrombotic therapy for primary and especially secondary prevention of stroke in patients with atherosclerosis. The absolute risk reduction for secondary prevention is substantial and makes a compelling case favoring the use of 2.5 mg rivaroxaban twice daily plus aspirin in these patients.

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
				mRS at 7 days or discharge R+A (n=83) 2.4±2.0, R (n=115) 2.6±2.1, A (n=141) 2.2±1. R+A vs A mean difference (95% CI) 0.2 (–0.4 to 0.7), p=0.66 R vs A mean difference (95% CI) 0.3 (–0.1 to 0.8), p=0.29	
Shaw, 2020 (EXTRAS) (84)	Parallel-group observer-blind multicenter individually randomized controlled trial N=573 (Control n=231, int n=219)	Early supported discharge reviews (EXTRAS) including mobility, self-care, mood (psychological), cognitive function (pathway)	The primary outcome was performance in extended activities of daily living. Secondary outcomes were health status, mood and experience of services.	Mean 24-month Nottingham Extended Activities of Daily Living Scale scores were 40.0 (standard deviation 18.1) for EXTRAS (n = 219) and 37.2 (standard deviation 18.5) for usual care (n = 231), giving an adjusted mean difference of 1.8 (95% confidence interval –0.7 to 4.2). The mean intervention group Hospital Anxiety and Depression Scale scores were not significantly different at 12 and 24 months. The intervention did not improve patient health status or carer strain. EXTRAS patients and carers reported greater satisfaction with some aspects of care. The mean cost of resource utilisation was lower in the intervention group: –£311 (95% confidence interval –£3292 to £2787), with a 68% chance of EXTRAS being cost-saving. EXTRAS was associated with 0.07 (95% confidence interval 0.01 to 0.12) additional quality-adjusted life-years. At current conventional thresholds of willingness to pay for a quality-adjusted life-year, there is a 90% chance that EXTRAS is cost-effective	EXTRAS did not improve stroke survivors' performance in extended activities of daily living. The lack of effect on the primary outcome is likely to be a result of the concept of the intervention rather than the fidelity of the intervention. However, EXTRAS provided more quality-adjusted life-years and was associated with lower costs. In addition, patients and carers in the intervention group were more satisfied with aspects of their overall care. EXTRAS did not improve patients' health status or carers' quality of life or stress. A post hoc finding was that the intervention group had fewer cases of anxiety and depression than those who received usual care. Given the impact on costs and quality-adjusted life-years, there is a high chance that EXTRAS could be considered cost-effective at conventional thresholds of the NHS/UK society's willingness to pay for a quality-adjusted life-year (currently £20,000 per quality-adjusted life-year), despite there being no difference in the primary outcome.
Swanson, 2019 (85)	Retrospective cohort study Control: n-=2605, rehab only n=689, home nursing only n=535, home nursing and rehab n=898	Standalone home nursing or rehabilitation, or a combination of both, with or without GP follow-up visits (pathway)	90-day and 1-year mortality, readmission	There were no significant differences in readmission rates for early GP follow-up. Patients receiving home nursing and/or rehabilitation had higher unadjusted 90- and 365-day readmission rates than those without services (HR from 1.87 to 2.63 depending on analysis, $p < 0.001$), but the 90-day differences disappeared after risk adjustment, except for patients receiving only rehabilitation. There were no significant differences in mortality rates according to GP follow-up after risk adjustment. Patients receiving rehabilitation had higher mortality than those without services, even after adjustment (HR from 2.20 to 2.69, $p < 0.001$), whereas the mortality of patients receiving only home nursing did not differ from those without services.	Results indicate that the observed differences in unadjusted readmission and mortality rates according to GP follow-up and home nursing were largely due to differences in health status at admission, likely unrelated to the stroke. On the other hand, mortality for patients receiving ambulatory rehabilitation was twice as high compared to those without, even after adjustment and irrespective of also receiving home nursing.

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
					Hence, assessing the needs of these patients during discharge planning and providing careful follow-up after discharge seems important.
Teuschl et al., 2017 (86)	Prospective, Randomized, Open-Label, Blinded Endpoint multicenter, two-arm parallel group clinical trial N=202 (Control n=87, int n=80)	BP measurement, lifestyle advice, exercise, cognitive training on a regular basis	Primary: cognitive decline Secondary: depression, lifestyle (inc smoking cessation)	During the first 12 months, adherence to healthy lifestyle and adequately controlled physiological parameters (measured by summary scores) improved significantly in the intervention group compared to controls ($p < 0.01$). The consumption of reduced-fat milk ($p = 0.031$), reduced-fat spreads ($p = 0.007$), and fish ($p = 0.021$) increased in the intervention group from baseline to 12 months but not in controls. After 24 months, the group difference was significant for the lifestyle summary score but no longer for the combined laboratory lifestyle score	These results demonstrate that intensified individualized multidomain lifestyle interventions in stroke patients are effective in promoting healthy lifestyle in stroke care
Towfighi, 2021 (87)	Randomised controlled trial N=487 (Control n=246, int n=241)	Advanced practice physician (APC) and community health worker (CHW) visits, culturally and linguistically tailored educational materials; vascular risk factor goal tools; and Chronic Disease Self-Management Program (CDSMP) workshops, medication adherence, self-management (pathway)	Primary: Change in SBP Secondary: Lifestyle (smoking, diet, physical activity)	Mean (SD) systolic BP improved from 143 (17) mm Hg at baseline to 133 (20) mm Hg at 12 months in the intervention group and from 146 (19) mm Hg at baseline to 137 (22) mm Hg at 12 months in the usual care group, with no significant differences in the change between groups. Compared with the control group, participants in the intervention group had greater improvements in self-reported salt intake (difference, 15.4 [95% CI, 4.4 to 26.0]; P = .004) and serum CRP level (difference in log CRP, −0.4 [95% CI, −0.7 to −0.1] mg/dL; P = .003); there were no differences in other secondary outcomes. Although 216 participants (89.6%) in the intervention group received some of the 3 core components, only 35 participants (14.5%) received the intended full dose.	This randomized clinical trial of a complex multilevel, multimodal intervention did not find vascular risk factor improvements beyond that of usual care; however, further studies may consider testing the SUCCEED intervention with modifications to enhance implementation and participant engagement
Tung et al., 2021 (88)	Retrospective cohort study N=261 (Inpatient PAC: n=138, Home-based PAC n=59)	Post-acute care (PAC) delivering physical, OT and speech therapy in inpatient and home settings (pathway)	QoL: EuroQoL EQ-5D (ED5Q) Cost-effectiveness was calculated as the total cost divided by the improvement in Barthel index (BI), Lawton–Brody instrumental activities of daily life scale (IADL), ED5Q and mini nutritional assessment (MNA) scores	The total rehabilitative cost was cheaper in the home-based PAC group ($p < 0.001$), and the cost-effectiveness is USD 152.474 ± USD 164.661 in the inpatient group, and USD 48.184 ± USD 35.018 in the home group ($p < 0.001$). Lesser rehabilitative hours per 1-point increase of BI score was noted in the home-PAC group with similar improvements in daily activities, life quality and nutrition in both groups.	Home-based PAC is more cost-effective than inpatient PAC for stroke rehabilitation.
Vluggen, 2021 (89)	Two-arm multicenter randomised controlled trial N=190 (Control n=91, int n=99)	Inpatient neurorehabilitation treatment, home-based self-management training (patient and caregiver), education	Primary: Daily activity Secondary: QoL (SSQOL) at 6 months	Significant favourable effects for the programme were observed for the subscale autonomy outdoors of the IPA (−2.15, P = .047, and for the informal caregivers perceived care burden (1.23, P = .048. For the primary outcome daily activity and the other secondary outcomes, no significant effects were observed.	The integrated multidisciplinary programme had no effect on daily activity of older stroke patients. However, patients participating in the programme had a higher level of perceived autonomy of outdoor activities and their informal caregivers perceived a lower care burden. The programme might be promising in providing adequate (after) care, although adaptation of the programme is recommended to increase its feasibility and improve its effects

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
Wang et al., 2021 (90)	Randomised controlled trial N=184 (Control n=82, int n=84)	Pharmacist-delivered care program providing inpatient and outpatient care - education focused on medication therapy management (MTM), disease state management, and lifestyle for secondary prevention of ischemic stroke	Primary: modifiable risk factors, medication adherence rates Secondary: Readmission	Compared to CG, at the 6-month follow-up, medication adherence rates significantly increased regarding antihypertensive drugs (92.86% versus 78.57%, P = 0.031), anti-diabetic drugs (91.67% versus 69.7%, P = 0.02), and lipid-lowering drugs (77.38% versus 60.98%, P = 0.022) in IG. Compared to CG, more patients in IG attained the goal surrogate risk factor control markers of hemoglobin A1c (87.88% vs. 52.78%, P = 0.038) and low-density lipoprotein-C (66.67% vs. 48.78%, P = 0.02). Significantly fewer patients were re-admitted to the hospital in IG than CG (7.14% vs. 18.3%, P = 0.03).	Pharmaceutical care programs can improve risk factor control for the secondary prevention of stroke recurrence in ischemic stroke patients.
Long Weijan and Zhang, 2017 (91)	Randomised controlled trial N=96 (Control n=48, int n=48)	Training program for HCPs on comprehensive care for patients, rehabilitation training for caregivers (pathway)	QoL (SS-QOL) at 3 months posy-discharge	There was no significant difference in SS-QOL and Barthel scores between the two groups before discharge. 3 months after the intervention, the total score of SS-QOL in the intervention group (155.02 points ± 16.85 points) was higher than that before the intervention (123.46 points ± 13.23 points) and the control group after the intervention (125.71 points) ±20. Compared with the control group after the intervention, except for the three dimensions of thinking, vision, and work productivity, the scores of the other dimensions were significantly different (P<0.01); the intervention group The patient's Barthel score (62.71±6.76) was higher than that before the intervention (48.65±5.03) and the control group after the intervention (52.60±4.61)	The study of caregivers Comprehensive rehabilitation nursing training combined with continuous nursing after discharge can improve the quality of life of ischemic stroke patients at home.
Willeit et al., 2020 (STROKE-CARD) (92)	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	Stroke, MI, vascular death, QoL (EQ-5D-3L), functional status, major bleeding	Major cardiovascular disease events occurred in 78 patients in the STROKE-CARD care group (5.4%) and in 59 patients in the standard care group (8.3%) (hazard ratio, 0.63; 95% confidence interval: 0.45-0.88; P=0.007). Stroke or TIA: Intervention 91/1438 (6.3%), control 46/711 (6.5%), HR 0.96 (95% CI 0.67, 1.37), P=0.822 All-cause mortality: Intervention 52/1438 (3.6%), control 35/711 (4.9%), HR 0.72 (95% CI 0.47, 1.10), P=0.131 The median EQ-5D-3L health utility score was 0.783 (IQR 0.687-1.000) in the STROKE-CARD care group and 0.779 (IQR 0.573-1.000) in the standard care group (P < 0.001). A score of 1.0 indicating absence of problems in all five EQ-5D-3L dimensions was achieved by 43% in the STROKE-CARD care group and 32% in the standard care group (relative risk 1.36; 95% CI: 1.20-1.54; P < 0.001). Major bleeding: Intervention 20/1438 (1.4%), control 15/711 (2.1), HR 0.65 (0.33, 1.27), P=0.210 mRS ≤2: Intervention 1150/1413 (81.4%), control 536/704 (76.1%), HR 1.07 (1.02, 1.12), P=0.006	The pragmatic and easily implementable STROKE-CARD care programme reduced cardiovascular risk and improved health-related quality of life and functional outcome in patients with acute ischaemic stroke or TIA
Wong and Yeung 2014 (93)	Randomised controlled trial Control n=54, intervention n=54	The intervention group received the transitional care program (TCP) which was commenced before discharge and lasted for 4 weeks after discharge. The TCP had 3 components 1) holistic care delivered by	QoL (SF-36), depressive symptoms (CES-D), readmission	SF-36 PCS: After 4 weeks: Control 47.1 (1.2), intervention 47.9 (1.2) After 8 weeks: Control 47.3 (1.4), intervention 48.6 (1.4) F(P-value) after 4 weeks 13.76 (<0.001), after 8 weeks 37.60 (<0.001), interaction effect p=0.006 SF-36 MCS: After 4 weeks: Control 49.2 (1.1), intervention 49.9 (1.0)	The TCP improved QoL and reduced depression. Readmission rates in the intervention group were lower but this did not reach statistical significance

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
		holistic care managers (HCMS), 2) transitional care track and 3) holistic care managers.		After 8 weeks: Control 49.4 (1.4), intervention 49.9 (1.0) F(P-value) after 4 weeks 13.72 (<0.001), after 8 weeks 7.67 (0.007), interaction effect p=0.591 CES-D-HK (median [10^{th}-90^{th} percentile]): Total after 4 weeks: Control 4 (1.5–8), intervention 2 (0–5), p<0.001 Total after 8 weeks: Control 4 (0–7), intervention 2 (0–4), p<0.001 Readmission rates at 8 weeks: Control 14.8%, intervention 7.4% , p=0.358	
Wu, 2020 (94)	Randomised controlled trial N=64 (Control n=31, int n=30)	Home remote rehabilitation based on a collaborative care model creating a personalised plan delivered through videoconferencing (pathway)	Primary: Motor function, balance ability Secondary: quality of life	Both groups were significantly improved in terms of motor function and quality of life, but the intervention group showed greater improvement in Fugl-Meyer Motor Function Assessment (intervention group = 83.70 ± 4.44, control group = 75.29 ± 2.89), Berg Balance Scale (intervention group = 43.13 ± 2.32, control group = 38.29 ± 2.70) and Stroke-Specific Quality of Life Scale (intervention group = 190.57 ± 5.09, control group = 175.90 ± 5.78). Group-time interaction was significant in motor function and quality of life.	Collaborative care model based telerehabilitation exercise train-ing program can safely and effectively improve the recovery of motor function and improve the quality of life in patients with stroke.
Xi, 2017 (95)	Randomised controlled trial N=90 (Control n=45, int n=45)	Home remote rehabilitation based on a collaborative care model creating a personalised plan delivered through videoconferencing (pathway)	Out-of-hospital rehabilitation compliance, exercise rehabilitation effect and quality of life	Six months after discharge, the total score of rehabilitation training compliance (11.60 ± 1.67), Fugl-Meyer score (76.27 ± 10.23), Barthel index (72) in intervention group .08 ± 12.56 points) and overall health score (72.68 ± 12.84 points) than the control group (9.58 ± 1.74 points, 68.64 ± 9.88 points, 60 points .44 points ± 11.42 points, 64.13 points ± 13.26 points), the difference was statistically significant (P <0.05).	The out-of-hospital continuous nursing intervention improves the compliance of stroke patients with out-of-hospital rehabilitation, promotes the recovery of the patient's limb motor function and the improvement of daily living ability, and also improves the patient's quality of life
Yan et al., 2021 (96)	Open-label, two-arm cluster-randomized controlled trial villages n=50, participants n=1299 (Control n=615, int n=611)	Primary care based app (SINEMA) to improve communication between HCPs and patients (mhealth)	The primary outcome was the 12- month change in systolic blood pressure (BP). Secondary outcomes were predefined, including diastolic BP, health-related quality of life, physical activity level, self-reported medi- cation adherence (antiplatelet, statin, and antihypertensive), and performance in “timed up and go” test.	The program was implemented with high fidelity, and the annual program delivery cost per capita was US$24.3. There was a significant reduction in systolic BP in the intervention as compared with the control group with an adjusted mean difference: −2.8 mm Hg (95% CI −4.8, −0.9; p = 0.005). The intervention was significantly associated with improvements in 6 out of 7 secondary outcomes in diastolic BP reduction (p < 0.001), health-related quality of life (p = 0.008), physical activity level (p < 0.001), adherence in statin (p = 0.003) and antihypertensive medicines (p = 0.039), and performance in “timed up and go” test (p = 0.022). We observed reductions in all exploratory outcomes, including stroke recurrence (4.4% ver- sus 9.3%; risk ratio [RR] = 0.46, 95% CI 0.32, 0.66; risk difference [RD] = 4.9 percentage points [pp]), hospitalization (4.4% versus 9.3%; RR = 0.45, 95% CI 0.32, 0.62; RD = 4.9 pp), disability (20.9% versus 30.2%; RR = 0.65, 95% CI 0.53, 0.79; RD = 9.3 pp), and death (1.8% versus 3.1%; RR = 0.52, 95% CI 0.28, 0.96; RD = 1.3 pp).	In this study, a primary care-based mobile health intervention integrating provider-centered and patient-facing technology was effective in reducing BP and improving stroke secondary prevention in a resource-limited rural setting in China
Yoo et al., 2022 (97)	Register-based, retrospective cohort study	Intervention: Group 1 Physiotherapy whole; disorder	Mortality	Results of the Cox multivariate analysis of survival according to the treatment received:	Patients with stroke who received both PT and OT had a better long-

Study details	Design/Patients	Intervention	Outcomes	Results	Conclusions
	Control n=8337, intervention n=1298	of central nervous system (DCNS), mattress or mobilisation training (MMT), and Gait training (GT) or occupational therapy (OT) whole: CO, special OT (SO), activities of daily living training (ADLT), and rehabilitative dysphagia therapy (RDT); Group 2 PT: MMT and GT + OT whole; Group 3: PT whole + OT whole; Group 4: PT: DCNS and GT + OT whole. DCNS = >120 hours of PT		Control (no treatment): HR = 1.000 (reference) PT whole or OT whole: 1.348 (0.959–1.896), p=0.0856 PT: MMT and GT + OT whole: 1.538 (0.718–3.293), p-0.2682 PT whole + OT whole: 1.272 (0.910–1.778), p=0.1584 PT: DNCS and GT + OT whole: 0.361 (0.169–0.769), p=0.0082	term prognosis than those who received either treatment alone. Therapy performed by a physical therapist with more than 120 hours of training effectively improved the patients' long-term prognosis. Patients who received CO, SO, ADLT, and RDT in addition to DCNS and GT had a lower mortality rate (HR: 0.361, 95% CI: 0.169–0.769) than those who did not receive intensive treatment. Patients who received >10 sessions of DCNS per month had significantly lower mortality rates at 3 (HR: 0.709, 95% CI: 0.564–0.891) and 6 months (HR: 0.752, 95% CI: 0.587–0.962) post-stroke than those who received < 10 treatment sessions per month
Yu et al., 2019 (98)	Randomised controlled trial N=242 (Control n=121, int n=121)	Intensive patient care program (IPCP) on cognitive impairment, anxiety, depression including comprehensive psychoeducation and psychonursing, cognitive rehabilitation training and mobile communication application (psychological, mhealth)	Cognitive impairment, anxiety, depression, relapse-free survival	IPCP increased MMSE score at M12 and change of MMSE score (M12-M0), while decreased cognitive impairment rate at M12. For anxiety, decreased change of HADS-A score (M12-M0) and lower anxiety rate at M12 were observed in IPCP group compared to control group. For depression, decreased HADS-D score at M6 and M12, reduced change of HADS-D score (M12-M0) and lower depression rate at M12 were shown in IPCP group compared to control group. Besides, RFS was numerically longer in IPCP group compared to control group, but without statistical significance.	IPCP presents with a positive influence on improving cognitive impairment and decreasing anxiety as well as depression, while a less effect on improving RFS in AIS patients
Zhang et al., 2019 (99)	Randomised controlled trial N=196 (Control n=98, int n=98)	Intensive caregiver education program (ICEP) comprising intensive individualized education for patients and caregivers and psychological nursing for caregivers delivered by nurses in 1:1 sessions, caregivers received repeat sessions every 2 weeks	Patients' cognitive function, anxiety, and depression	Cognitive impairment score at M12 and cognitive impairment score change (M12–M0) were increased, while cognitive impairment rate at M12 was reduced in the ICEP group compared with the Control group. Anxiety score change (M12–M0), anxiety score at M12, and anxiety rate at M12 were decreased in the ICEP group compared with the Control group. Depression score change (M12–M0), depression score at M12, and depression rate at M12 were lower in the ICEP group compared with the Control group. Further subgroup analysis based on baseline features also provided similar results.	In conclusion, ICEP effectively reduced cognitive impairment, anxiety, and depression in AIS patients.

References

1. Abdul Aziz Aznida Furzah, Azlin MNN, Amrizal MN, Saperi S, Mohamed AS. The integrated care pathway for managing post stroke patients (iCaPPS ©) in public primary care Healthcentres in Malaysia: impact on quality adjusted life years (QALYs) and cost effectiveness analysis. BMC geriatrics. 2020;20(1):70.
2. Ahmadi M, Laumeier I, Ihl T, Steinicke M, Ferse C, Endres M, et al. A support programme for secondary prevention in patients with transient ischaemic attack and minor stroke (INSPiRE-TMS): an open-label, randomised controlled trial. The lancet Neurology. 2020;19(1):49-60.
3. Demir Avci Y, Gözüm S. Effects of Transitional Care Model-Based Interventions for Stroke Patients and Caregivers on Caregivers' Competence and Patient Outcomes: Randomized Controlled Trial. Computers, informatics, nursing : CIN. 2023;41(10):805-14.
4. Bath PM, Woodhouse LJ, Appleton JP, Beridze M, Christensen H, Dineen RA, et al. Triple versus guideline antiplatelet therapy to prevent recurrence after acute ischaemic stroke or transient ischaemic attack: the TARDIS RCT. Health Technol Assess. 2018;22(48):1-76.
5. Bergh E, Askim T, Rønning OM, Šaltyteė Benth J, Fjærtoft H, Thommessen B. Does implementation of a standardized pathway of stroke care affect functional outcome after stroke? International journal of stroke : official journal of the International Stroke Society. 2023;18(5):578-85.
6. Bernhardt J, Langhorne P, Lindley RI, Thrift AG, Ellery F, Collier J, et al. Efficacy and safety of very early mobilisation within 24 h of stroke onset (AVERT): a randomised controlled trial. Lancet. 2015;386(9988):46-55.
7. Bodechtel U, Barlinn K, Helbig U, Arnold K, Siepmann T, Pallesen L-P, et al. The stroke east Saxony pilot project for organized post-stroke care: a case-control study. Brain and behavior. 2016;6(5):e00455.
8. Bragstad LK, Hjelle EG, Zucknick M, Sveen U, Thommessen B, Bronken BA, et al. The effects of a dialogue-based intervention to promote psychosocial well-being after stroke: a randomized controlled trial. Clinical rehabilitation. 2020;34(8):1056-71.
9. Brandal A, Eriksson E, Glader, EL, Wester P. Effect of early supported discharge after stroke on patient reported outcome based on the Swedish Riksstroke registry. BMC NEUROLOGY. 2019;19.
10. Brouns B, Van Bodegom-Vos L, De Kloet AJ. Tamminga SJ, Volker G, Berger MAM, et al. Effect of a Comprehensive erehabilitation Intervention Alongside Conventional Stroke Rehabilitation on Disability and Health-related Quality of Life: a Pre-post comparison. Journal of Rehabilitation Medicine (Stiftelsen Rehabiliteringsinformation). 2021;53(3):1-12.
11. Brouwer B, Bryant D, Garland SJ. Effectiveness of Client-Centered "Tune-Ups" on Community Reintegration, Mobility, and Quality of Life After Stroke: a Randomized Controlled Trial. Archives of physical medicine and rehabilitation. 2018;99(7):1325-32.
12. Buckley BJR, Harrison SL, Fazio-Eynullayeva E, Underhill P, Lane DA, Thijssen DHJ, et al. Exercise-Based Cardiac Rehabilitation Associates with Lower Major Adverse Cardiovascular Events in People with Stroke. Cerebrovasc Dis. 2022;51(4):488-92.

13. Bushnell CD, Kucharska-Newton AM, Jones SB, Psioda MA, Johnson AM, Daras LC, et al. Hospital Readmissions and Mortality Among Fee-for-Service Medicare Patients With Minor Stroke or Transient Ischemic Attack: findings From the COMPASS Cluster-Randomized Pragmatic Trial. Journal of the American Heart Association. 2021;10(23):e023394.

14. Cecchi F, Diverio M, Arienti C, Corbella E, Marrazzo F, Speranza G, et al. Development and implementation of a stroke rehabilitation integrated care pathway in an Italian no profit institution: an observational study. EUROPEAN JOURNAL OF PHYSICAL AND REHABILITATION MEDICINE. 2020;56(6):713-24.

15. Chang K-C, Hung J-W, Lee H-C, Yen C-L, Wu C-Y, Yang C-L, et al. Rehabilitation Reduced Readmission and Mortality Risks in Patients With Stroke or Transient Ischemic Attack: A Population-based Study. Medical care. 2018;56(4):290-8.

16. Chang K-V, Chen K-H, Chen Y-H, Lien W-C, Chang W-H, Lai C-L, et al. A multicenter study to compare the effectiveness of the inpatient post acute care program versus traditional rehabilitation for stroke survivors. Scientific reports. 2022;12(1):12811.

17. Chen L, Sit JW-H, Shen X. Quasi-experimental evaluation of a home care model for patients with stroke in China. Disability & Rehabilitation. 2016;38(23):2271-6.

18. Chen CM, Yang YH, Chang CH, Chen PC. Effects of Transferring to the Rehabilitation Ward on Long-Term Mortality Rate of First-Time Stroke Survivors: A Population-Based Study. Archives of physical medicine and rehabilitation. 2017;98(12):2399-407.

19. Cheng C, Liu X, Fan W, Bai X, Liu Z. Comprehensive Rehabilitation Training Decreases Cognitive Impairment, Anxiety, and Depression in Poststroke Patients: A Randomized, Controlled Study. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association. 2018;27(10):2613-22.

20. Cheng EM, Cunningham WE, Towfighi A, Sanossian N, Bryg RJ, Anderson TL, et al. Efficacy of a Chronic Care-Based Intervention on Secondary Stroke Prevention Among Vulnerable Stroke Survivors: a Randomized Controlled Trial. Circulation Cardiovascular quality and outcomes. 2018;11(1):e003228.

21. Chiu C-C, Lin H-F, Lin C-H, Chang H-T, Hsien H-H, Hung K-W, et al. Multidisciplinary Care after Acute Care for Stroke: A Prospective Comparison between a Multidisciplinary Post-Acute Care Group and a Standard Group Matched by Propensity Score. International journal of environmental research and public health. 2021;18(14).

22. Chu K, Bu X, Sun Z, Wang Y, Feng W, Xiao, L, et al. Feasibility of a Nurse-Trained, Family Member-Delivered Rehabilitation Model for Disabled Stroke Patients in Rural Chongqing, China. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association. 2020;29(12):105382.

23. Cuccurullo SJ, Fleming TK, Kostis JB, Greiss C, Eckert A, Ray AR, et al. Impact of Modified Cardiac Rehabilitation Within a Stroke Recovery Program on All-Cause Hospital Readmissions. American journal of physical medicine & rehabilitation. 2022;101(1):40-7.

24. Cuccurullo SJ, Fleming TK, Zinonos S, Cosgrove NM, Cabrera J, Kostis JB, et al. Stroke Recovery Program with Modified Cardiac Rehabilitation Improves Mortality, Functional & Cardiovascular Performance. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association. 2022;31(5):106322.

25. Cuccurullo SJ, Fleming TK, Kostis WJ, Greiss C, Gizzi MS, Eckert A, et al. Impact of a Stroke Recovery Program Integrating Modified Cardiac Rehabilitation on All-Cause Mortality, Cardiovascular Performance and Functional Performance. American Journal of Physical Medicine & Rehabilitation. 2019;98(11):953-63.

26. Cumming TB, Churilov L, Collier J, Donnan G, Ellery F, Dewey H, et al. Early mobilization and quality of life after stroke: Findings from AVERT. Neurology. 2019;93(7):e717-e28.

27. de Belvis AG, Lohmeyer FM, Barbara A, Giubbini G, Angioletti C, Frisullo G, et al. Ischemic stroke: clinical pathway impact. INTERNATIONAL JOURNAL OF HEALTH CARE QUALITY ASSURANCE. 2019;32(3):588-98.

28. Deng A, Yang S, Xiong R. Effects of an integrated transitional care program for stroke survivors living in a rural community: a randomized controlled trial. Clinical rehabilitation. 2020;34(4):524-32.

29. Dello S, Lemmens R, Demeestere J, Michiels D, Wellens L, Weltens C, et al. A nurse-led multicomponent intervention supported by advanced electronic health records to improve the acute management of stroke patients: A pre- and post-intervention study. INTERNATIONAL JOURNAL OF NURSING STUDIES ADVANCES. 2021;3.

30. Deutschbein J, Grittner U, Schneider A, Schenk L. Community care coordination for stroke survivors: results of a complex intervention study. BMC health services research. 2020;20(1):1143.

31. Døhl Ø, Halsteinli V, Askim T, Gunnes M, Ihle-Hansen H, Indredavik B, et al. Factors contributing to post-stroke health care utilization and costs, secondary results from the life after stroke (LAST) study. BMC health services research. 2020;20(1):288.

32. Duncan PW, Bushnell CD, Jones SB, Psioda MA, Gesell SB, D'Agostino RB, et al. Randomized Pragmatic Trial of Stroke Transitional Care: The COMPASS Study. Circulation Cardiovascular quality and outcomes. 2020;13(6):e006285.

33. Ellis-Hill C, Thomas S, Gracey F, Lamont-Robinson C, Cant R, et al. HeART of Stroke: randomised controlled, parallel-arm, feasibility study of a community-based arts and health intervention plus usual care compared with usual care to increase psychological well-being in people following a stroke. BMJ open. 2019;9(3):e021098.

34. Feng XH, Deng AW, Chen JH, Xiong RB. Health-related outcomes 6 months after integrated care of older people with stroke in 2 different primary care settings. FAMILY PRACTICE. 2023.

35. Feng W, Yu H, Wang J, Xia J. Application effect of the hospital-community integrated service model in home rehabilitation of stroke in disabled elderly: a randomised trial. Annals of palliative medicine. 2021;10(4):4670-7.

36. Freburger JK, Pastva AM, Coleman SW, Peter KM, Kucharska-Newton AM, Johnson AM, et al. Skilled Nursing and Inpatient Rehabilitation Facility Use by Medicare Fee-for-Service Beneficiaries Discharged Home After a Stroke: Findings From the COMPASS Trial. Archives of physical medicine and rehabilitation. 2022;103(5):882.

37. Fu V, Weatherall M, McPherson K, Taylor W, McRae A, Thomson T, et al. Taking Charge after Stroke: A randomized controlled trial of a person-centered, self-directed rehabilitation intervention. International journal of stroke : official journal of the International Stroke Society. 2020;15(9):954-64.

38. Gao J, Lin M, Zhao J, Bi S, Ni Z, Shang X. Different interventions for post-ischaemic stroke depression in different time periods: a single-blind randomized controlled trial with stratification by time after stroke. Clinical rehabilitation. 2017;31(1):71-81.

39. Geng G, He W, Ding L, Klug D, Xiao Y. Impact of transitional care for discharged elderly stroke patients in China: an application of the Integrated Behavioral Model. TOPICS IN STROKE REHABILITATION. 2019;26(8):621-9.

40. Graven C, Brock K, Hill KD, Cotton S, Joubert L. First Year After Stroke: An Integrated Approach Focusing on Participation Goals Aiming to Reduce Depressive Symptoms. Stroke. 2016;47(11):2820-7.

41. Greger J, Wojcik R, Westphal E, Aladeen T, Landolf K, Boyce S, et al. Pharmacist intervention and anti-platelet medication monitoring in patients following stroke and transient ischemic attack. JOURNAL OF THE AMERICAN COLLEGE OF CLINICAL PHARMACY. 2021;4(3):311-7.

42. Gun Young Yang, Min HS. The Effects of an Integrated Management Program on Physical Function, Cognitive Function, and Depression in Patients with Subacute stroke. Journal of Korean Critical Care Nursing. 2021;14(1):50-62.

43. He Y, Wang R, Dong S, Long S, Zhang P, Feng L. Nurse-led rapid rehabilitation following mechanical thrombectomy in patients with acute ischemic stroke: A historical control study. Medicine. 2023;102(28):e34232.

44. Hjelle EG, Bragstad LK, Kirkevold M, Zucknick M, Bronken BA, Martinsen R, et al. Effect of a dialogue-based intervention on psychosocial well-being 6 months after stroke in Norway: A randomized controlled trial. Journal of rehabilitation medicine. 2019;51(8):557-65.

45. Huang J, Zuo J, Tang X, Zou J, Zeng Y, Chen S, et al. Early Rehabilitation and Nursing Intervention (ERNI) Accelerates the Recovery of Patients With Ischemic Stroke. The neurologist. 2023;28(6):409-12.

46. Jones F, Gage H, Drummond A, Bhalla A, Grant R, Lennon S, et al. Feasibility study of an integrated stroke self-management programme: a cluster-randomised controlled trial. BMJ OPEN. 2016;6(1).

47. Joubert J, Davis SM, Donnan GA, Levi C, Gonzales G, Joubert L, et al. ICARUSS: An effective model for risk factor management in stroke survivors. INTERNATIONAL JOURNAL OF STROKE. 2020;15(4):438-53.

48. Jung S-H, Park E, Kim J-H, Park, B-A, Yu J-W, et al. Effects of Self RehAbilitation Video Exercises (SAVE) on Functional Restorations in Patients with Subacute Stroke. HEALTHCARE. 2021;9(5).

49. Kalav S, Bektas H, Ünal A. Effects of Chronic Care Model-based interventions on self-management, quality of life and patient satisfaction in patients with ischemic stroke: A single-blinded randomized controlled trial. Japan Journal of Nursing Science. 2022;19(1):1-18.

50. Kam Yuet Wong F, Wang SL, Ng SSM, Lee PH, Wong AKC, Li H, et al. Effects of a transitional home-based care program for stroke survivors in Harbin, China: a randomized controlled trial. Age Ageing. 2022;51(2).

51. Khramov W, Kogaeva KP, Arkhipova, LU, Alekseeva, VO, Lukyanova, MI. EFFECTIVENESS OF POST-STROKE SOCIAL REHABILITATION IN PATIENTS WITH MODERATE IMPAIRMENTS. BULLETIN OF RUSSIAN STATE MEDICAL UNIVERSITY. 2021(2):62-8.

52. Koch S, Tiozzo E, Simonetto M, Loewenstein D, Wright CB, Dong C, et al. Randomized Trial of Combined Aerobic, Resistance, and Cognitive Training to Improve Recovery From Stroke: Feasibility and Safety. Journal of the American Heart Association. 2020;9(10):e015377.

53. Langhorne P, Wu O, Rodgers H, Ashburn A, Bernhardt J. A Very Early Rehabilitation Trial after stroke (AVERT): a Phase III, multicentre, randomised controlled trial. Health Technol Assess. 2017;21(54):1-120.

54. Lee A-Y, Park S-A, Park H-G, Son K-C. Determining the Effects of a Horticultural Therapy Program for Improving the Upper Limb Function and Balance Ability of Stroke Patients. HORTSCIENCE. 2018;53(1):110-9.

55. Lewthwaite R, Winstein CJ, Lane CJL, Blanton S, Wagenheim BR, Nelsen MA, Dromerick AW, et al. Accelerating Stroke Recovery: Body Structures and Functions, Activities, Participation, and Quality of Life Outcomes From a Large Rehabilitation Trial. Neurorehabilitation & Neural Repair. 2018;32(2):150-65.

56. Li Y, Wang Q, Liu XL, Hui R, Zhang YP. Effect of the physical rehabilitation program based on self-care ability in patients with acute ischemic stroke: a quasi-experimental study. FRONTIERS IN NEUROLOGY. 2023;14.

57. Lin Y. EFFECT OF MULTI-DISCIPLINARY CLINICAL NURSING PATHWAY ON SELF-EFFICACY AND SELF-MANAGEMENT BEHAVIOR IN PATIENTS WITH CEREBRAL INFARCTION. ACTA MEDICA MEDITERRANEA. 2022;38(5):3133-8.

58. Lin RC, Chiang SL, Heitkemper MM, Weng, SM, Lin CF, Yang FC, et al. Effectiveness of Early Rehabilitation Combined With Virtual Reality Training on Muscle Strength, Mood State, and Functional Status in Patients With Acute Stroke: A Randomized Controlled Trial. Worldviews on Evidence-Based Nursing. 2020;17(2):158-67.

59. Liu N, Cadilhac DA, Andrew NE, Zeng L, Li Z, Li J, et al. Randomized controlled trial of early rehabilitation after intracerebral hemorrhage stroke: difference in outcomes within 6 months of stroke. Stroke (00392499). 2014;45(12):3502-7.

60. Liu LM. EFFECTS OF TRANSITIONAL CARE ON FUNCTIONAL EXERCISE: COMPLIANCE AND HEALTH STATUS OF STROKE PATIENTS. ACTA MEDICA MEDITERRANEA. 2018;34(4):959-65.

61. Lo SHS, Chau JPC, Lau AYL, Choi KC, Shum EWC, Lee VWY, et al. Virtual Multidisciplinary Stroke Care Clinic for Community-Dwelling Stroke Survivors: A Randomized Controlled Trial. Stroke. 2023;54(10):2482-90.

62. López-Liria R, Vega-Ramírez FA, Rocamora-Pérez P, Aguilar-Parra JM, Padilla-Góngora D. Comparison of Two Post-Stroke Rehabilitation Programs: A Follow-Up Study among Primary versus Specialized Health Care. PloS one. 2016;11(11):e0166242.

63. Lu LX, Wei SY, Huang QY, Chen YK, Huang FX, Ma XA, et al. Original Article Effect of "Internet plus tertiary hospital-primary hospital-family linkage home care" model on self-care ability and quality of life of discharged stroke patients. AMERICAN JOURNAL OF TRANSLATIONAL RESEARCH. 2023;15(12):6727-39.

64. Luengo-Fernandez R, Li L, Silver L, Gutnikov S, Beddows NC, Rothwell PM. Long-Term Impact of Urgent Secondary Prevention After Transient Ischemic Attack and Minor Stroke: Ten-Year Follow-Up of the EXPRESS Study. Stroke. 2022;53(2):488-96.

65. MacKay-Lyons M, Gubitz G, Phillips S, Giacomantonio N, Firth W, Thompson K, et al. Program of Rehabilitative Exercise and Education to Avert Vascular Events After Non-Disabling Stroke or Transient Ischemic Attack (PREVENT Trial): a Randomized Controlled Trial. Neurorehabilitation and neural repair. 2022;36(2):119-30.

66. Man S, Zhao X, Uchino K, Hussain MS, Smith EE, Bhatt DL, et al. Comparison of Acute Ischemic Stroke Care and Outcomes Between Comprehensive Stroke Centers and Primary Stroke Centers in the United States. Circulation Cardiovascular quality and outcomes. 2018;11(6):e004512.

67. Markle-Reid M, Valaitis R, Bartholomew A, Fisher K, Fleck R, Ploeg J, et al. An integrated hospital-to-home transitional care intervention for older adults with stroke and multimorbidity: A feasibility study. Journal of Comorbidity. 2020;10:1-21.

68. Minshall C, Castle DJ, Thompson DR, Pascoe M, Cameron J, McCabe M, et al. A psychosocial intervention for stroke survivors and carers: 12-month outcomes of a randomized controlled trial. TOPICS IN STROKE REHABILITATION. 2020;27(8):563-76.

69. Mofidi R, Thomas M, Wong PF, Bergin A, Young G. Do Integrated Systems of Stroke Care Improve Symptom to Surgery Times in Patients with Symptomatic Carotid Stenosis? A Single Centre Decision Tree Analysis. Eur J Vasc Endovasc Surg. 2018;56(6):784-92.

70. Mohammadi E, Hassandoost F, Mozhdehipanah H. Evaluation of the "partnership care model" on quality of life and activity of daily living in stroke patients: A randomized clinical trial. Japan journal of nursing science : JJNS. 2022;19(1):e12448.

71. Nakibuuka J, Sajatovic M, Nankabirwa J, Ssendikadiwa C, Kalema N, Kwizera A, et al. Effect of a 72 Hour Stroke Care Bundle on Early Outcomes after Acute Stroke: A Non Randomised Controlled Study. PLOS ONE. 2016;11(5).

72. Nayeri ND, Mohammadi S, Razi SP, Kazemnejad A. Investigating the effects of a family-centered care program on stroke patients' adherence to their therapeutic regimens. Contemporary nurse. 2014;47(1-2):88-96.

73. Nguyen-Huynh MN, Klingman JG, Avins AL, Rao VA, Eaton A, Bhopale S, et al. Novel Telestroke Program Improves Thrombolysis for Acute Stroke Across 21 Hospitals of an Integrated Healthcare System. Stroke. 2018;49(1):133-9.

74. Olaiya MT, Kim J, Nelson MR, Srikanth VK, Bladin CF, Gerraty RP, et al. Effectiveness of a shared team approach between nurses and doctors for improved risk factor management in survivors of stroke: a cluster randomized controlled trial. Eur J Neurol. 2017;24(7):920-8.

75. Pedapati R, Bhatia R, Shakywar M, Gupta A, Vishnubhatla S, Srivastava MVP, et al. Educating Caregivers to Reduce Complications and Improve Outcomes of Stroke Patients (ECCOS)-A Cluster-Randomized Trial. JOURNAL OF STROKE & CEREBROVASCULAR DISEASES. 2021;30(9).

76. Peng LN, Lu WH, Liang CK, Chou MY, Chung CP, Tsai SL, et al. Functional Outcomes, Subsequent Healthcare Utilization, and Mortality of Stroke Postacute Care Patients in Taiwan: A Nationwide Propensity Score-matched Study. Journal of the American Medical Directors Association. 2017;18(11):990.e7-.e12.

77. Rafsten L, Danielsson A, Nordin A, Björkdahl A, Lundgren-Nilsson A, Larsson M, et al. Gothenburg Very Early Supported Discharge study (GOTVED): a randomised controlled trial investigating anxiety and overall disability in the first year after stroke. BMC neurology. 2019;19(1):277.

78. Rasmussen RS, Østergaard A, Kjær P, Skerris A, Skou C, Christoffersen J, et al. Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: a randomised controlled trial. Clinical Rehabilitation. 2016;30(3):225-36.

79. Reeves MJ, Fritz MC, Woodward AT, Hughes AK, Coursaris CK, Swierenga SJ, et al. Michigan Stroke Transitions Trial. Circulation Cardiovascular quality and outcomes. 2019;12(7):e005493.

80. Rodgers H, Howel D, Bhattarai N, Cant R. Drummond A, Ford GA, et al. Evaluation of an Extended Stroke Rehabilitation Service (EXTRAS): A Randomized Controlled Trial and Economic Analysis. STROKE. 2019;50(12):3561-8.

81. Saal S, Becker C, Lorenz S, Schubert M, Kuss O, Stang A, et al. Effect of a stroke support service in Germany: a randomized trial. TOPICS IN STROKE REHABILITATION. 2015;22(6):429-36.

82. Schwarzbach CJ, Eichner FA, Rücker V, Hofmann AL, Keller M, Audebert HJ, et al. The structured ambulatory post-stroke care program for outpatient aftercare in patients with ischaemic stroke in Germany (SANO): an open-label, cluster-randomised controlled trial. Lancet Neurol. 2023;22(9):787-99.

83. Sharma M, Hart RG, Connolly SJ, Bosch J, Shestakovska O, Ng KKH, et al. Stroke Outcomes in the COMPASS Trial. Circulation. 2019;139(9):1134-45.

84. Shaw L, Bhattarai N, Cant R, Drummond A, Ford GA, Forster A, et al. An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT. HEALTH TECHNOLOGY ASSESSMENT. 2020;24(24):1-+.

85. Swanson JO, Moger TA. Comparisons of readmissions and mortality based on post-discharge ambulatory follow-up services received by stroke patients discharged home: a register-based study. BMC health services research. 2019;19(1):4.

86. Teuschl Y, Matz K, Firlinger B, Dachenhausen A, Tuomilehto J, Brainin M, et al. Preventive effects of multiple domain interventions on lifestyle and risk factor changes in stroke survivors: Evidence from a two-year randomized trial. Int J Stroke. 2017;12(9):976-84.

87. Towfighi A, Cheng EM, Ayala-Rivera M, Barry F, McCreath H, Ganz D, et al. Secondary Stroke Prevention, Unitin. Effect of a Coordinated Community and Chronic Care Model Team Intervention vs Usual Care on Systolic Blood Pressure in Patients With Stroke or Transient Ischemic Attack The SUCCEED Randomized Clinical Trial. JAMA NETWORK OPEN. 2021;4(2).

88. Tung YJ, Lin WC, Lee LF, Lin HM, Ho CH, Chou W. Comparison of Cost-Effectiveness between Inpatient and Home-Based Post-Acute Care Models for Stroke Rehabilitation in Taiwan. INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH AND PUBLIC HEALTH. 2021;18(8).

89. Vluggen TPMM, van Haagstreg, JCM. Tan FE, Verbunt JA, van Heugten CM, Schols, JMG. A. Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial. BMC geriatrics. 2021;21(1):134.

90. Wang J, Wang J, Qiu S, Zhou C, Zhang H, Li Q, et al. Pharmaceutical care program for ischemic stroke patients: a randomized controlled trial. Int J Clin Pharm. 2021;43(5):1412-9.

91. Long Weijan, Zhang J. Patient Caregiver Comprehensive Rehabilitation Nursing Training Joint Continued nursing care for ischemic stroke patients at home Impact on quality of life and activities of daily living. Chinese Nursing Research. 2017;31(20):2456-61.

92. Willeit P, Toell T, Boehme C, Krebs S, Mayer L, Lang C, et al. STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: A randomised clinical trial. EClinicalMedicine. 2020;25:100476.

93. Wong FKY, Yeung SM. Effects of a 4-week transitional care programme for discharged stroke survivors in Hong Kong: a randomised controlled trial. Health & Social Care in the Community. 2015;23(6):619-31.

94. Wu Z, Xu J, Yue C, Li Y, Liang Y. Collaborative Care Model Based Telerehabilitation Exercise Training Program for Acute Stroke Patients in China: A Randomized Controlled Trial. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association. 2020;29(12):105328.

95. Xi W, Duan Y, Wang A. Influence of continuing nursing outside hospital on rehabilitation effect and quality of life in patients with stroke. Chinese Nursing Research. 2017;31(29):3760-2.

96. Yan LL, Gong E, Gu W, Turner EL, Gallis JA, Zhou Y, et al. Effectiveness of a primary care-based integrated mobile health intervention for stroke management in rural China (SINEMA): A cluster-randomized controlled trial. PLoS Med. 2021;18(4):e1003582.

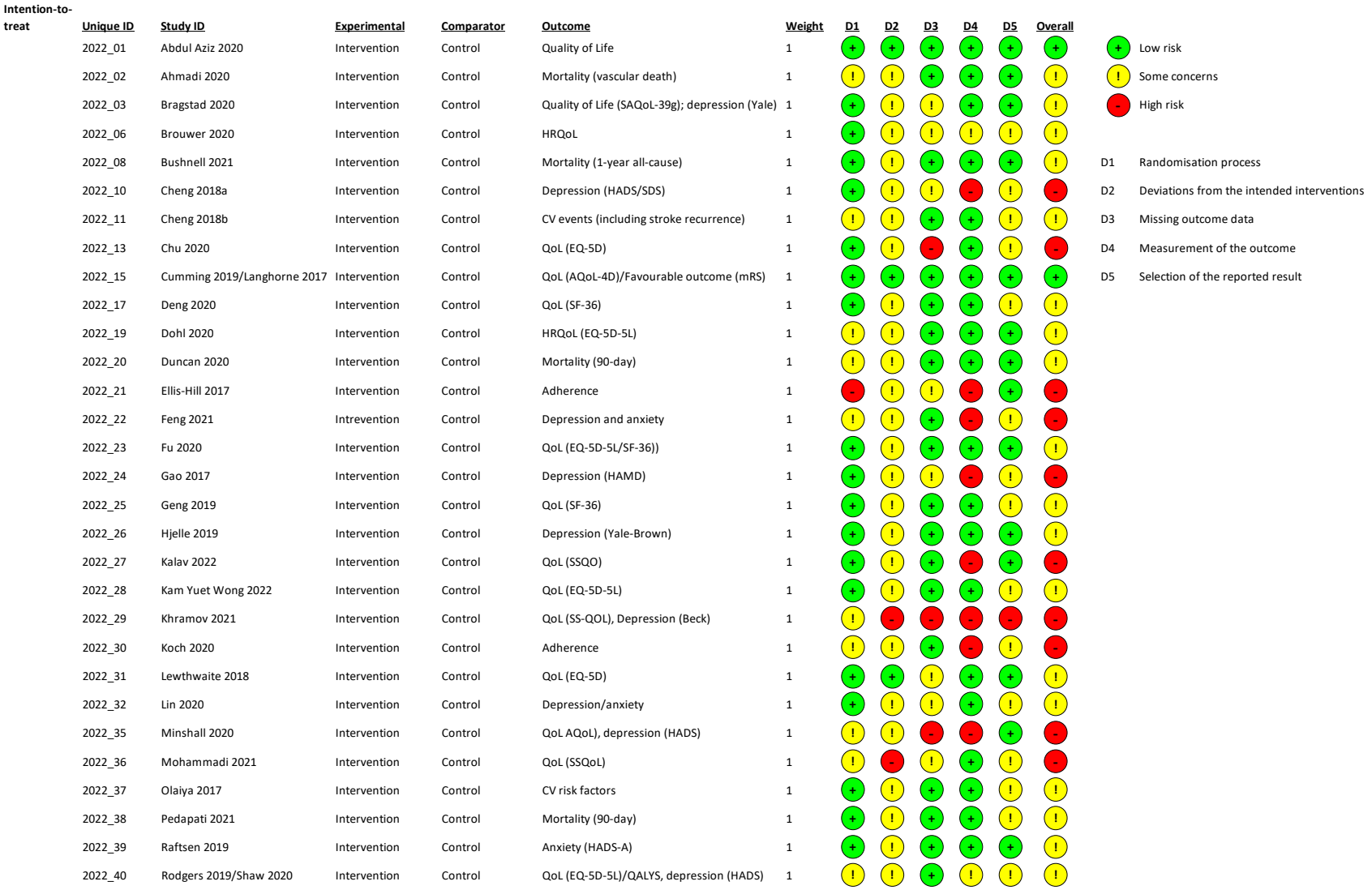
97. Yoo D-Y, Choi J-K, Baek C-Y, Shin J-B. Impact of intensive rehabilitation on long-term prognosis after stroke: A Korean nationwide retrospective cohort study. Medicine. 2022;101(38):e30827.

98. Yu HL, Cao DX, Liu J. Effect of a novel designed intensive patient care program on cognitive impairment, anxiety, depression as well as relapse free survival in acute ischemic stroke patients: a randomized controlled study. NEUROLOGICAL RESEARCH. 2019;41(9):857-66.

99. Zhang L, Zhang T, Sun Y. A newly designed intensive caregiver education program reduces cognitive impairment, anxiety, and depression in patients with acute ischemic stroke. Braz J Med Biol Res. 2019;52(9):e8533.

12.6 Appendix F: Risk of Bias Assessments (Randomised and Non-randomised Studies)

Figure S1. Risk of bias according to ROB2 tool (randomised studies)



Intention-to-treat

Unique ID	Study ID	Experimental	Comparator	Outcome	Weight	D1	D2	D3	D4	D5	Overall
2022_41	Teuschl 2017	Intervention	Control	depression (CESD)	1	+	!	!	+	+	!
2022_42	Towfighi 2021	Experimental	Control	CV risk factors	1	+	!	+	+	+	!
2022_43	Vluggen 2021	Intervention	Control	QoL (SSQoL)	1	-	!	!	+	+	-
2022_44	Wang 2021	Intervention	Control	Readmission to hospital	1	!	!	!	!	+	!
2022_45	Weijan Long 2017	Intervention	Control	QoL (SSQOL)	1	!	-	-	-	!	-
2022_46	Wu 2020	Intervention	Control	QoL (SSQOL)	1	!	!	+	+	!	!
2022_47	Xi 2017	Intervention	Control	QoL (SF-36)	1	!	!	!	-	!	-
2022_48	Yan 2021	Intervention	Control	QoL (EQ-5D-5L)/stroke recurrence	1	+	!	+	+	+	!
2022_49	Yu 2019	Intervention	Control	Anxiety/depression (HADS)	1	+	!	-	-	!	-
2022_50	Zhang 2019	Intervention	Control	Anxiety/depression (HADS)	1	+	!	!	-	+	-
2022_33	Liu 2018	Intervention	Control	QoL (SF-36)	1	!	-	+	-	!	-
2022_51	Reeves 2019	Intervention	Control	Quality of life (PROMIS-10)	1	!	!	+	!	+	!
2022_65	Avci 2023	Intervention	Control	Readmission	1	!	!	+	+	+	!
2022_66	Bath 2018	Intervention	Control	Recurrent stroke and major bleeding	1	+	+	+	+	+	+
2022_67	Bernhardt 2015	Intervention	Control	Favourable outcome	1	+	+	+	+	+	+
2022_68	Freberger 2022	Intervention	Control	Readmission	1	!	!	+	-	!	-
2022_69	Graven 2016	Intervention	Control	Depression (GDS)	1	+	!	+	+	!	!
2022_70	Huang 2023	Intervention	Control	QoL (SSQoL)	1	!	-	+	-	!	-
2022_71	Jones 2016	Intervention	Control	QoL (SF-12), anxiety/depression (HADS)	1	!	!	+	+	!	!
2022_72	Joubert 2020	Intervention	Control	Risk factors	1	+	+	+	+	+	+
2022_73	Li 2023	Intervention	Control	QoL (SS-QoL)	1	+	-	+	-	!	-
2022_74	Lin 2022	Intervention	Control	Anxiety/depression	1	!	-	+	-	!	-
2022_75	Liu 2014	Intervention	Control	Mortality/QoL/Anxiety	1	+	!	+	+	!	!
2022_76	Lo 2023	Intervention	Control	Depression (GDS)	1	+	+	+	+	+	+
2022_77	MacKay-Lyons 2022	Intervention	Control	Risk factors	1	+	+	+	+	+	+
2022_78	Nayeri 2014	Intervention	Control	Adherence to intervention/readmission	1	+	!	+	-	!	-
2022_79	Rasmussen 2016	Intervention	Control	Functional status (mRS)/QoI EQ-5D	1	+	+	+	!	+	!
2022_80	Saal 2016	Intervention	Control	Mortality/Recurrent stroke/QoL/depression	1	+	!	+	+	+	!
2022_81	Schwartzbach 2023	Intervention	Control	Mortality/recurrent stroke	1	+	!	+	+	+	!
2022_82	Sharma 2019	Intervention	Control	Recurrent stroke	1	+	+	+	+	+	+
2022_83	Willeit 2020	Intervention	Control	Mortality/QoL (EQ-5D)	1	+	+	+	+	+	+
2022_84	Wong 2015	Intervention	Control	QoL (SF-36)	1	+	+	+	+	!	!

+ Low risk
! Some concerns
- High risk

D1 Randomisation process
D2 Deviations from the intended interventions
D3 Missing outcome data
D4 Measurement of the outcome
D5 Selection of the reported result

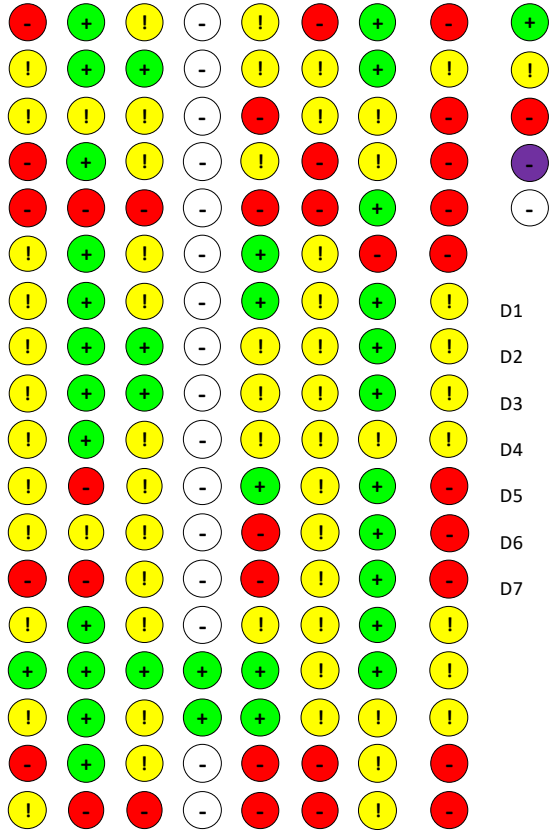
Figure S2. Risk of bias according to ROBINS-I tool (nonrandomised studies)

Unique ID	Study ID	Ref or label	Experimental	Comparator	Outcome	D1	D2	D3	D4	D5	D6	D7	Overall
2022_04	2022_04	Brandal 2019	Intervention	Control	Quality of life	!	+	+	+	+	!	+	!
2022_05	2022_05	Brouns 2021	Intervention	Control	Quality of life	!	+	!	+	+	!	+	!
2022_07	2022_07	Buckley 2021	Intervention	Control	All-cause mortality	!	+	!	-	+	!	+	!
2022_09	2022_09	Chen 2017	Intervention	Control	All-cause mortality	!	+	!	-	+	!	+	!
2022_12	2022_12	Chiu 2021	Intervention	Control	Quality of life	!	!	+	-	+	!	+	!
2022_14	2022_14	Cuccurrullo 2019	Intervention	Control	All-cause mortality	!	+	+	-	+	!	+	!
2022_16	2022_16	De Belvis 2019	Intervention	Control	30-day mortality	-	+	!	-	-	!	+	-
2022_18	2022_18	Deutschbein 2020	Intervention	Control	Readmission/mortality	!	+	+	+	+	!	+	!
2022_52	2022_52	Greger	Intervention	Control	Adherence	-	-	!	-	+	-	+	-
2022_53	2022_53	Gun Young 2021	Intervention	Control	Depression	!	+	+	-	+	+	+	!
2022_55	2022_55	Jung 2021	Intervention	Control	Depression	-	-	!	-	-	!	+	-
2022_56	2022_56	Man 2018	Intervention	Control	In-hospital mortality	!	+	!	-	+	!	+	!
2022_57	2022_57	Lee 2018	Intervention	Control	Depression	!	+	!	-	+	-	+	-
2022_58	2022_58	Markle-Reid 2020	Intervention	Control	Quality of life	-	+	!	-	+	-	+	-
2022_59	2022_59	Nguyen-Huynh 2018	Intervention	Control	Recurrent stroke	!	+	+	-	+	!	+	!
2022_60	2022_60	Peng 2017	Intervention	Control	90-day mortality	!	+	!	-	+	!	+	!
2022_61	2022_61	Swanson 2019	Intervention	Control	90-day mortality	!	+	!	-	!	!	+	!

+ Low risk
! Moderate risk
- Serious risk
- Critical risk
- No information

D1 Risk of bias due to confounding
D2 Risk of bias in selection of participants into the study
D3 Risk of bias in classification of interventions
D4 Risk of bias due to deviations from intended interventions
D5 Risk of bias due to missing data
D6 Risk of bias in measurement of outcomes
D7 Risk of bias in the reported results

Unique ID	Study ID	Ref or label	Experimental	Comparator	Outcome	D1	D2	D3	D4	D5	D6	D7	Overall
2022_54	2022_54	Tung 2021	Intervention	Control	Quality of life	-	+	!	-	!	-	+	-
2022_85	2022_85	Bergh 2023	Intervention	Control	90-day mortality	!	+	+	-	!	!	+	!
2022_86	2022_86	Bodechtel 2016	Intervention	Control	Recurrent stroke/mortality/QoI	!	!	!	-	-	!	!	-
2022_87	2022_87	Cecchi 2020	Intervention	Control	Mortality	-	+	!	-	!	-	!	-
2022_88	2022_88	Chang 2022	Intervention	Control	Quality of life	-	-	-	-	-	-	+	-
2022_89	2022_89	Chang 2018	Intervention	Control	Mortality	!	+	!	-	+	!	-	-
2022_90	2022_90	Chen 2016	Intervention	Control	Readmission	!	+	!	-	+	!	+	!
2022_91	2022_91	Cuccurrullo 2022	Intervention	Control	Mortality	!	+	+	-	!	!	+	!
2022_92	2022_92	Cuccurrullo 2022	Intervention	Control	Readmission	!	+	+	-	!	!	+	!
2022_93	2022_93	Dello 2021	Intervention	Control	Death and dependency	!	+	!	-	!	!	!	!
2022_94	2022_94	Feng 2024	Intervention	Control	Quality of life	!	-	!	-	+	!	+	-
2022_95	2022_95	He 2023	Intervention	Control	Functional status/QoL	!	!	!	-	-	!	+	-
2022_96	2022_96	Lopez 2016	Intervention	Control	Quality of life	-	-	!	-	-	!	+	-
2022_97	2022_97	Lu 2023	Intervention	Control	Readmission/QoL/depression	!	+	!	-	!	!	+	!
2022_98	2022_98	Luengo-Fernandez 2022	Intervention	Control	Recurrent stroke/functional status	+	+	+	+	+	!	+	!
2022_99	2022_99	Mofidi 2018	Intervention	Control	Mortality	!	+	!	+	+	!	!	!
2022_100	2022_100	Nakibuuka 2017	Intervention	Control	Mortality	-	+	!	-	-	-	!	-
2022_101	2022_101	Yoo 2022	Intervention	Control	Mortality	!	-	-	-	-	-	!	-



12.7 Appendix G: Analysis of Primary and Secondary Review Outcomes

Primary outcomes

Mortality

Table S12 Analysis of mortality

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Ahmadi et al, 2020 (INSPiRE-TMS) [1]	Prospective, randomised, open-label, blinded endpoint, event--driven trial Control n=1042, intervention n=1030	Counselling, lifestyle changes, medication adherence	Composite of vascular events, ACS, vascular mortality, all-cause mortality (2-year)	Vascular mortality (ITT): Intervention n=30 (2.9%), control n= 32 (3.1%) HR 0·94 (0·57–1·54) All-cause mortality (ITT): Intervention n=73 (7·1%), control n=85 (8·2%) HR 0·85 (0·62–1·17)	No significant difference in primary outcome between groups
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Secondary: death at 90 days	Events: Intervention 26/1556 (1.7%), control 28/1540 (1.8%)	No difference in mortality between groups
Bergh, 2023 [3]	Repeated measures analysis (pre-post) from a retrospective cohort of patients registered in the Norwegian Stroke Register (NSR). N = 11009 included in study comparing functional outcome (5388 in 2017 and 5621 in 2019)	Standardised Care Pathway for stroke (SCP) based on National guidelines	Secondary: Mortality at 90 days	Overall, 1407 (16%) of 8785 patients had died within 90 days in 2017, and 1380 (15.3%) of 9028 in 2019, no significant difference between groups.	No significant improvement in function outcome after the introduction of an SCP.
Bernhardt et al., 2015 (AVERT) [4]	Single-blind randomised controlled trial in 56 acute stroke units in 5 countries (Aus, NZ, Malaysia, Singapore, UK -Eng, Scot, Wales, NI) Control n=1050, intervention n=1054	Very early mobilisation (exercise and movement therapy)	Secondary: Change in mRS, mortality	Mortality: Intervention 88/1048 (8%), control 72/1050 (7%), OR 1.34 (95% CI: 0.93-1.93), p=0.113	Significantly fewer participants in the AVERT group had favourable outcome and there was no difference in mortality

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Cuccurrullo et al., 2022 [5]	Retrospective analysis of a prospective stroke database Control n=203, intervention n=246	Enhanced SRP program including home visits, outpatient therapy and modified cardiac rehabilitation	1-year mortality	Mortality: Control 14/203 (6.9%), intervention 4/242 (1.6%), RR 0.24 (95% CI: 0.08-0.71), p=0.0046	Stroke survivors receiving a SRP integrating modified cardiac rehabilitation may potentially benefit from reductions in all-cause mortality and improvements in cardiovascular performance and function
Buckley et al., 2022 [6]	Retrospective observational study N=836,923 Propensity matched cohorts: Control n=2909, intervention n=2909	Exercise-based cardiac rehabilitation	2-year mortality	8.5% Intervention (247/2909), 16.5% control (473/2909), (OR 0.47, 95% CI 0.40-0.56)	Significant (53%) reduction in mortality with intervention
Bushnell et al., 2021 [7]	COMPASS was a cluster-randomized trial of the effectiveness of the COMPASS-TC intervention (INV) compared with usual care (UC) Participating hospitals: control n=20, inv n=20 Patients: Control n=1193, inv n=1069	Post-acute care pathway (full pathway) follow-up with the advanced practice provider and nurse coordinator in clinic within 7 to 14 days post discharge, an individualized electronic care plan, and referral to community services	1-year mortality	8.5% intervention, 8.8% control (OR, 0.93; 95% CI, 0.68–1.26)	7% reduction in mortality with intervention (not significant)
Chang et al., 2018 [8]	Retrospective cohort study using National Health Insurance database Control n=2491, intervention 2103	High intensity rehabilitation (inpatient, outpatient or both) versus no rehab	All-cause mortality (average follow-up time = 32 months)	Model 1 Control: 458/2491 (18.4%), low-intensity 250/1398 (17.9%), high intensity 103/705 (14.6%) (p=0.0062 high intensity vs control)	Rehabilitation use was associated with reduction of readmissions/mortality risks following stroke or TIA.
Chen, 2017 [9]	Retrospective cohort study N=11,419 Propensity matched group n=390 (RR n=130, NtR n=130, NoR n=130)	Rehabilitation for hospitalised patients including mobilisation (exercise), speech therapy and dysphagia treatment	5-year all-cause mortality	Rehab + rehab ward (RR) 17.7% Rehab no rehab ward (NtR) 26.9% (HR 2.2 95% CI 1.36-3.57; P<.01 vs RR) No rehab (NR) 47.7% (HR, 4.00; 95% CI, 2.55-6.27; P<.01 vs RR)	Rehab with transfer to rehab ward significantly reduces 5-y mortality
Cuccurrullo, 2019 [10]	Prospective cohort study: feasibility study followed by matched group sub-analysis N=783 (SRP feasibility study n=136, matched NP n=66, matched SRP n=76)	Physician Visits, Outpatient Therapy, and Modified Cardiac Rehabilitation (management of blood pressure (BP), cholesterol control, reduction of blood sugar, getting active, eating better, losing weight, and smoking cessation) Lifestyle	1-year mortality	1.3% intervention, 15.2% control HR 0.11 (SE = 1.07, 95% CI = 0.01 - 0.90, P = 0.039)	Significant reduction in mortality with intervention
de Belvis, 2019 [11]	Pre-post retrospective observational study	5-stage clinical pathway: (1) initial framing; (2)	30-day mortality	9.7% intervention, 8.8% control (difference 18.9%)	Mortality higher in the intervention group

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	N=1,009 Control n=483, intervention n=526	evaluation/staging; (3) treatment; (4) rehabilitation; and (5) follow-up/monitoring (full pathway)			
Deutschbein, 2020 [12]	Pragmatic non-randomised controlled trial N=361 (intervention n=145, control n=270)	Individualised case management, with regular face-to-face visits as part of a comprehensive individualised programme (PT, OT, support required), regular monitoring and adjustment (full pathway)	1-year mortality	Intervention vs control HR 0.74 (95% CI: 0.32–1.68, P=0.57) unadjusted Intervention vs control HR 0.65 (95% CI: 0.28–1.49, P=0.39) adjusted	No difference in mortality between groups
Duncan, 2020 [13]	Pragmatic cluster-randomized trial 6024 patients, 41 hospitals (Hospitals n=40, patients intervention n=2689, control n=3193)	Education, secondary prevention, rehabilitation, recovery, referrals to community-based resources, and caregiver support services by telephone follow-up	90-day mortality	Survival to 90d, n (%): Intervention 2634 (98.0), control 3137 (98.2); OR 1.04 (0.62 to 1.75)	No difference in 90-day mortality
Fu, 2020 [14]	Prospective, randomised, open trial of two active and one control interventions with blinded endpoint assessment N=400 (Primary analysis: control n=125, T1 n=123, t2 n=133)	One-to-one qualitative assessment of patient views and needs, education and goal setting	Mortality at 12 months (secondary outcome)	Death at 12 months, N/N (%): Control 2/130 (1.5), TC1 4/132 (3.0), TC2 4/138 (2.9), Odds ratio difference (95% CI) TC2 + TC1 versus control 1.95 (0.41 to 9.34), p=0.40	No difference in 12-month mortality
Liu et al., 2014 [15]	Multi centre randomized controlled trial Control n=122, intervention n=121	Early intervention: Standard care but at 48 hours following ICH onset.	Mortality at 3 and 6 months	Mortality: 3 months: Control 10/122, intervention 1/121 6 months: Control 12/122, intervention 3/121	Commencement of rehabilitation within 48 hours of ICH significantly reduced hospital length of stay and improved long-term survival and morbidity outcomes when compared with standard practices
Luengo-Fernandez et al., 2022 (EXPRESS) [16]	Prospective population-based before (phase 1: April 2002–September 2004; n=310) versus after (phase 2: October 2004–March 2007; n=281) study EXPRESS: Phase 1 n=310, Phase 2 n=281; Control: Phase 1 n=167, Phase 2 n=224	EXPRESS Phase 1: Clinic referral (1-2 days), brain imaging and ECG, ultrasound/echo, primary care treatment protocol comprising antiplatelet, statin, BP lowering. Phase 2: As Phase 1 but treatment initiated immediately instead of by primary care, high-dose aspirin or clopidogrel, CT scan during clinic. Follow-up 1, 6, 12, 60, and 120 months after the index event in both Phases.	Mortality	Death, n (%): 1 month: Control Phase 1 14/167 (8), Phase 1 7/310 (2), Control Phase 2 15/224 (7%), Phase 2 4/281 (1) 6 months: Control Phase 1 16/167 (10), Phase 1 14/310 (5), Control Phase 2 23/224 (10%), Phase 2 9/281 (3) 1 year: Control Phase 1 26/167 (16), Phase 1 24/310 (8), Control Phase 2 32/224 (14), Phase 2 12/281 (4)	Urgent assessment and treatment of patients with transient ischemic attack or minor stroke resulted in a long-term reduction in recurrent strokes and improved outcomes, with little atrophy of the early benefit over time, representing good value for money even with a 10-year time horizon.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
		Control: standard care (not referred to study clinic)		5 years: Control Phase 1 77/167 (46), Phase 1 89/310 (29), Phase 2 control 89/224 (40), Phase 2 62/281 (22) 10 years: Control Phase 1 109/167 (65), Phase 1 152/310 (49), control Phase 2 132/224 (59), Phase 2 123/281 (44)	A reduction in stroke risk in phase 2 was still evident at 10 years (55/23.3% versus 82/31.6%; hazard ratio=0.68 [95% CI, 0.48–0.95]; P=0.024), as was the impact on risk of disabling or fatal stroke (17/7.7% versus 32/13.1%; hazard ratio=0.54 [0.30–0.97]; P=0.036).
Man, 2018 [17]	Nonrandomized comparative group study CSC n=134 (patients n=159,000), PSC n=1047 (patients n=563,941)	Comparison of stroke care in in-hospital outcomes between primary stroke centers (PSC) and comprehensive stroke centers (CSC) (pathway comparisons)	In-hospital mortality	CSC 5.5%, PSC 4.2% (standard difference -6.13%, P<0.05), OR 1.14 (95% CI: 1.01-1.19)	Lower mortality in primary stroke centre (PSC) compared with comprehensive stroke centre (CSC)
Mofidi et al., 2018 [18]	Retrospective registry study Control n=133, intervention 243	Integrated stroke care pathway for patients with carotid artery stenosis undergoing carotid endarterectomy (CEA). Within 60 minutes: CT scan, stroke team evaluation, thrombolysis is needed; within 24 hours carotid duplex, MR angiogram, diffusion weighted MRI; within 48 hours vascular surgeon review; within 2 weeks carotid endarterectomy, all cases discussed in MDT	Mortality at 30 days	There was no significant difference in peri-operative stroke death rate between integrated (5/243, 2.1%) and standard (2/133, 1.5%) pathways (chi-square = 0.14, p = .73).	No difference in mortality rates
Pedapati et al., 2021 [19]	Prospective single-centre, cluster-randomised, open-label, blinded endpoint superiority trial N=164 (Int n=82, control n=82)	Education and exercise plan tailored to the home needs of patients	In-hospital mortality, 90-day mortality	In-hospital mortality: 12.2% intervention, 19.5% control (P=0.2) 90-day mortality: 24.4% intervention, 30.5% control (p=0.38)	No significant differences in mortality between groups
Peng, 2017 [20]	Propensity score-matched case-control study using the National Health Insurance data Original cohort: control n=3159, int n=1480 Matched Cohort: control n=657, int n=657	PAC program measuring activities of daily living, nutrition, exercise, mobility and language	90-day mortality	1.4% intervention, 2.0% control (OR 0.68, 95% CI 0.29-1.62)	No significant differences in mortality between groups
Saal et al., 2015 [21]	Randomised controlled clinical trial Control n=111, intervention n=119	Post-discharge support including follow-up call and visit, education and training sessions	Mortality at 12 months	Mortality Intervention: 5 (3.9); Control: 15 (11.6); RR (95% CI): 0.34 (0.13; 0.90); RD (95% CI) - 0.06 (-0.13; 0.00)	The intervention group had a significantly lower mortality rate (3.9%) compared to the control group (11.6%) with a relative risk of 0.34 (95% CI,

Study details	Design/Patients	Intervention	Outcome	Results	Comments
					0.13 to 0.90) and an adjusted hazard ratio of 0.32 (95% CI, 0.12 to 0.88).
Schwarzbach et al., 2023 (SANO) [22]	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	All-cause death at 12 months	All-cause death: Control: 31/1283 (2·4%); Intervention: 12/1203 (1·0%); OR 0·42 (95% CI 0·20–0·86); aOR 0·61 (95% CI 0·26–1·46)	This study demonstrated that the SANO programme had positive effects on the control of some cardiovascular risk factors in patients with stroke, but this did not translate into a reduction in the rate of major cardiovascular events 1 year after the first ischaemic stroke.
Swanson, 2019 [23]	Retrospective cohort study Control: n-=2605, rehab only n=689, home nursing only n=535, home nursing and rehab n=898	Standalone home nursing or rehabilitation, or a combination of both, with or without GP follow-up visits (pathway)	90-day and 1-year mortality	Adjusted HR 90-day: Rehab 2.69 (95% CI: 1.80–4.03) Home nursing 0.81* (95% CI: 0.45–1.47) Rehab + Home nursing 2.54 (95% CI: 1.70–3.81) Adjusted HR 1-year: Rehab 2.38 (95% CI: 1.83–3.09) Home nursing 1.00* (95% CI: 0.71–1.41) Rehab + Home nursing 2.20 (95% CI: 1.68–2.89) *Significant difference to home nursing with rehabilitation, $p < 0.05$	90- and 365-day mortality rates were significantly higher in the intervention groups
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	All-cause mortality at 12 months	All-cause mortality: Intervention 52/1438 (3.6%), control 35/711 (4.9%), HR 0.72 (95% CI 0.47, 1.10), P=0.131	The pragmatic and easily implementable STROKE-CARD care programme reduced cardiovascular risk and improved health-related quality of life and functional outcome in patients with acute ischaemic stroke or TIA

Recurrent stroke

Table S13 Analysis of recurrent stroke

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Ahmadi et al., 2020 (INSPiRE-TMS) [1]	Prospective, randomised, open-label, blinded endpoint, event--driven trial Control n=1042, intervention n=1030	Counselling, lifestyle changes, medication adherence	2-year recurrent stroke (secondary)	Stroke (ITT): 11.8% intervention (122/1030), 11.4% control (119/1042) (HR 1·02, 95% CI: 0·79–1·32)	No difference in recurrent stroke between groups
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Primary: Incidence and severity of any recurrent stroke (ischaemic, haemorrhagic; assessed using the modified Rankin Scale) or TIA within 90 days by blinded telephone follow-up.	Ordinal stroke/TIA: Intervention 93/1540 (6.0%), control 105/1530 (6.9%). The incidence and severity of recurrent stroke or TIA did not differ between intensive and guideline therapy [adjusted common odds ratio (acOR) 0.90, 95% confidence interval (CI) 0.67 to 1.20; p = 0.47].	The TARDIS trial found that there was no significant reduction in the recurrence of stroke or TIA, or their severity, with intensive antiplatelet therapy based on three agents as compared with guideline therapy.
Buckley et al., 2022 [6]	Retrospective observational study N=836,923 Propensity matched cohorts: Control n=2909, intervention n=2909	Exercise-based cardiac rehabilitation	Recurrent stroke 2-year	39.2% intervention (1141/2909), 42.3% control (1231/2909)(OR 0.88, 95% CI 0.79-0.98)	12% lower odds of recurrent stroke with intervention
Cheng et al., 2018 [25]	Randomised controlled trial N=407 (Control n=200, int n=207)	Medication modification relevant to stroke risk factors, tobacco cessation, physical activity, depression, and medication adherence	12-month recurrent stroke (secondary)	Intervention 13%, control 14%, p=0.98	No difference in recurrent stroke between groups
Deutschbein, 2020 [12]	Pragmatic non-randomised controlled trial N=361 (intervention n=145, control n=270)	Individualised case management, with regular face-to-face visits as part of a comprehensive individualised programme (PT, OT, support required), regular monitoring and adjustment (full pathway)	Recurrent stroke 1-year	Intervention vs control IRR 0.78 (95% CI: 0.39–1.57, P=0.49) unadjusted Intervention vs control OR 0.76 (95% CI: 0.38–1.54, P=0.45) adjusted	No difference in recurrent stroke between groups
Fu, 2020 [14]	Prospective, randomised, open trial of two active and one control interventions with blinded endpoint assessment	One-to-one qualitative assessment of patient views and needs, education and goal setting	Recurrent stroke at 12 months (secondary outcome)	Recurrent stroke by 12 months, N/N (%): control 10/130 (7.7), TC1 10/129 (7.8), TC2 4/136 (2.9), Odds ratio difference (95% CI) TC2 + TC1 versus control 0.61 (0.25 to 1.45), p=0.26	No difference in recurrent stroke between groups

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	N=400 (Primary analysis: control n=125, T1 n=123, t2 n=133)				
Luengo-Fernandez et al., 2022 (EXPRESS) [16]	Prospective population-based before (phase 1: April 2002–September 2004; n=310) versus after (phase 2: October 2004–March 2007; n=281) study EXPRESS: Phase 1 n=310, Phase 2 n=281; Control: Phase 1 n=167, Phase 2 n=224	EXPRESS Phase 1: Clinic referral (1-2 days), brain imaging and ECG, ultrasound/echo, primary care treatment protocol comprising antiplatelet, statin, BP lowering. Phase 2: As Phase 1 but treatment initiated immediately instead of by primary care, high-dose aspirin or clopidogrel, CT scan during clinic. Follow-up 1, 6, 12, 60, and 120 months after the index event in both Phases. Control: standard care (not referred to study clinic)	Recurrent stroke at 10 years	Recurrent stroke, n (%) 90 days: Phase 1 32/310 (10%), Phase 2 6/281 (2%) 10 years: Control Phase 1 39/167 (23%), Phase 1 82/310 (26%), Control Phase 2 55/224 (25%), Phase 2 55/281 (20%) (P=0.024 Phase 2 vs Phase 1)	Urgent assessment and treatment of patients with transient ischemic attack or minor stroke resulted in a long-term reduction in recurrent strokes and improved outcomes, with little atrophy of the early benefit over time, representing good value for money even with a 10-year time horizon. A reduction in stroke risk in phase 2 was still evident at 10 years (55/23.3% versus 82/31.6%; hazard ratio=0.68 [95% CI, 0.48–0.95]; P=0.024), as was the impact on risk of disabling or fatal stroke (17/7.7% versus 32/13.1%; hazard ratio=0.54 [0.30–0.97]; P=0.036).
Mofidi et al., 2018 [18]	Retrospective registry study Control n=133, intervention 243	Integrated stroke care pathway for patients with carotid artery stenosis undergoing carotid endarterectomy (CEA). Within 60 minutes: CT scan, stroke team evaluation, thrombolysis is needed; within 24 hours carotid duplex, MR angiogram, diffusion weighted MRI; within 48 hours vascular surgeon review; within 2 weeks carotid endarterectomy, all cases discussed in MDT	Recurrent stroke at 30 days	Recurrent stroke: Intervention 5/243 (2.1%), control 2/133 (1.5%)	Recurrent stroke rates were higher in the intervention group
Nguyen-Huynh, 2018 [26]	Sequential pre-post intervention group study N=867 (Control n=310, int n=557)	Telestroke program for thrombolysis through a dedicated tele-neurologist to advise on alteplase delivery (pathway)	Symptomatic ICH at 9 months	There was no significant difference in symptomatic intracranial haemorrhage rates in the 2 periods (3.8% versus 2.2% before implementation; P=0.29).	No significant difference in recurrent stroke rates
Reeves, 2019 [27]	Open-label (unblinded) 3-group parallel-design clinical trial	Home-based social worker–led case management (SWCM) program with or without a	Stroke/TIA recurrence at 90 days	90-day stroke/TIA recurrence (n=265) UC 7 (8%) SWCM 5 (6%) OR 0.69 [0.21–2.26]	Recurrent stroke/transient ischemic attack occurred in 24 patients (9.1%), but rates

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	N=320 (Group 1 (UC): Global-10 n=77, PAM n=76, Group 2 (SWCM) Global-10 n=82, PAM n=79, Group 3 (SWCM + MISTT website) Global-10 n=81, PAM n=78) UC, usual care; MISTT, Michigan stroke transitions trial; PAM, pain activation measure; SWCM, social worker–led case management	website, comprising biopsychosocial assessment followed by development of a personalised plan to address unmet needs (pathway, psychological)		SWCM+MISTT Website 12 (13%) OR 1.76 [0.66–4.70] Type 3 $\chi 2$ global test: P=0.20	were similar across groups (P=0.20).
Saal et al., 2015 [21]	Randomised controlled clinical trial Control n=111, intervention n=119	Post-discharge support including follow-up call and visit, education and training sessions	Recurrent stroke (reinfarction) at 12 months	Reinfarct Intervention: 3 (2.7); Control: 4 (3.8); RR (95% CI) 0.71 (0.16; 3.10); RD (95% CI) -0.01 (-0.09; 0.07)	No significant differences between groups in the number of recurrent strokes.
Schwarzbach et al., 2023 (SANO) (22)	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	Recurrent stroke at 12 months	First recurrent stroke: Control: 50/1283 (3·9%); Intervention: 51/1203 (4·2%); OR 1·00 (95% CI 0·58–1·73); aOR 1·03 (95% CI0·53–1·99)	This study demonstrated that the SANO programme had positive effects on the control of some cardiovascular risk factors in patients with stroke, but this did not translate into a reduction in the rate of major cardiovascular events 1 year after the first ischaemic stroke.
Sharma et al., 2019 (COMPASS) [28]	COMPASS was a randomized, double-blind, double-dummy trial Prior stroke: rivaroxaban + aspirin n=351, rivaroxaban alone n=346, aspirin alone n=335. Total n=1032	Participants had stable coronary artery or peripheral artery disease and were randomly assigned to receive aspirin 100 mg once daily (n=9126), rivaroxaban 5 mg twice daily (n=9117), or rivaroxaban 2.5 mg twice daily plus aspirin (n=9152).	Recurrent stroke at 23 months	Recurrent stroke: R+A (n=351) 9/351, R (n=346) 18/346, A (n=335) 20/335 R+A vs A HR 0.42 (0.19-0.92) p=0.03 R vs A: HR 0.88 (0.47-1.67) p=0.70	In summary, low-dose rivaroxaban plus aspirin is an important new option for efficacious antithrombotic therapy for primary and especially secondary prevention of stroke in patients with atherosclerosis. The absolute risk reduction for secondary prevention is substantial and makes a compelling case favoring the use of 2.5 mg rivaroxaban twice daily plus aspirin in these patients.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	Recurrent stroke at 12 months	Stroke or TIA: Intervention 91/1438 (6.3%), control 46/711 (6.5%), HR 0.96 (95% CI 0.67, 1.37), P=0.822	The pragmatic and easily implementable STROKE-CARD care programme reduced cardiovascular risk and improved health-related quality of life and functional outcome in patients with acute ischaemic stroke or TIA
Yan et al., 2021 [29]	Open-label, two-arm cluster-randomised controlled trial villages n=50, participants n=1299 Control n=615, int n=611	Primary care based app (SINEMA) to improve communication between HCPs and patients (mhealth)	12-month recurrent stroke (exploratory)	4.4% intervention versus 9.3% control; (risk ratio [RR] = 0.46, 95% CI 0.32, 0.66; risk difference [RD] = 4.9 percentage points [pp]), p<0.0001	Significant reduction in recurrent stroke rate with intervention

Major bleeding

Table S14 Analysis of major bleeding

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Ahmadi et al., 2020 (INSPiRE-TMS) [1]	Prospective, randomised, open-label, blinded endpoint, event--driven trial Control n=1042, intervention n=1030	Screening for complications, QoL, depression	Major bleeding (2-year) secondary	Major bleeding (ITT) events/1000 patient years (possibly more than 1 event per patient): Intervention 32 (9; 6–12), control 38 (10; 7–14) IRR 0·84 (0·53–1·35)	No significant difference in major bleeding between groups
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Secondary: bleeding and its severity	Major bleeding events: Intervention 31/1541 (2.0%), control 14/1531 (0.9%) Major bleeding (NIHSS score) Score >3: Intervention 442/1540 (28.7%), control 435/1530 (28.4%) Score ≤3 or TIA: Intervention 1099/1540 (71.3%), control 1096/1530 (71.6%)	Significantly more bleeding events overall in TARDIS group (19.8%) compared with control (9.1%, p<0.001), prompting the study to be stopped early.
Mofidi et al., 2018 [18]	Retrospective registry study Control n=133, intervention 243	Integrated stroke care pathway for patients with carotid artery stenosis undergoing carotid endarterectomy (CEA). Within 60 minutes: CT scan, stroke team evaluation, thrombolysis is needed; within 24 hours carotid duplex, MR angiogram, diffusion weighted MRI; within 48 hours vascular surgeon review; within 2 weeks carotid endarterectomy, all cases discussed in MDT	Major bleeding at 30 days	Major bleeding: Intervention 6/243 (2.5%), control 3/133 (2.3%)	More patients in the intervention group were returned to theatre as a result of major bleeding
Schwarzbach et al., 2023 (SANO) [22]	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	Major bleeding events (SAEs) at 12 months	Bleeding Control 8/1152 (0·7%), Intervention 31/1151 (2·6%)	This study demonstrated that the SANO programme had positive effects on the control of some cardiovascular risk factors in patients with stroke, but this did not translate into a reduction in the rate of major cardiovascular events 1 year after the first ischaemic stroke.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Sharma et al., 2019 (COMPASS) [28]	COMPASS was a randomized, double-blind, double-dummy trial Prior stroke: rivaroxaban + aspirin n=351, rivaroxaban alone n=346, aspirin alone n=335. Total n=1032	Participants had stable coronary artery or peripheral artery disease and were randomly assigned to receive aspirin 100 mg once daily (n=9126), rivaroxaban 5 mg twice daily (n=9117), or rivaroxaban 2.5 mg twice daily plus aspirin (n=9152).	Major bleeding events at 23 months	Major bleeding: R+A 12/351, R 26/346, A 19/335 R+A vs A HR 3.79 (1.07-13.4), p=0.04 R vs A: HR 3.84 (1.08-13.6), p=0.04	In summary, low-dose rivaroxaban plus aspirin is an important new option for efficacious antithrombotic therapy for primary and especially secondary prevention of stroke in patients with atherosclerosis. The absolute risk reduction for secondary prevention is substantial and makes a compelling case favoring the use of 2.5 mg rivaroxaban twice daily plus aspirin in these patients.
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	Major bleeding events at 12 months	Major bleeding: Intervention 20/1438 (1.4%), control 15/711 (2.1), HR 0.65 (0.33, 1.27), P=0.210	The pragmatic and easily implementable STROKE-CARD care programme reduced cardiovascular risk and improved health-related quality of life and functional outcome in patients with acute ischaemic stroke or TIA

Secondary outcomes

Quality of life

Subgroup meta-analysis showed that the greatest differences in QoL were observed with EQ-5D (Figure S3) and SF-36 (Figure S4).

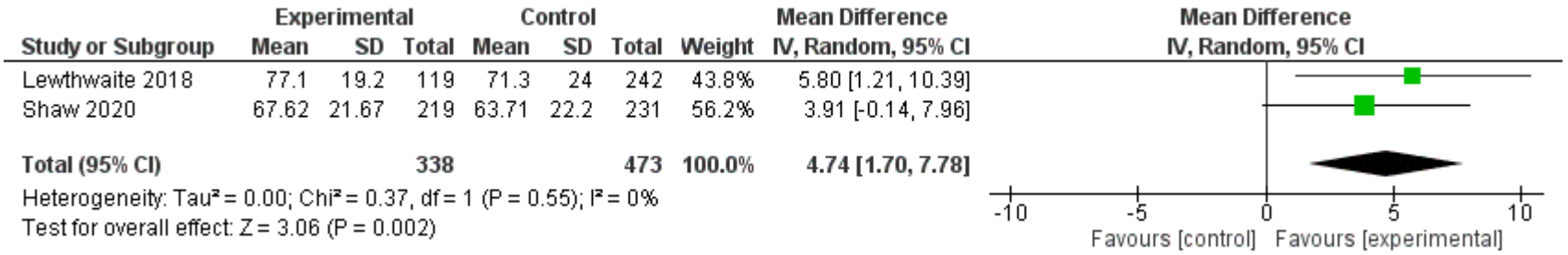


Figure S3: Comparison of integrated care with Control for QoL (EQ-5D)

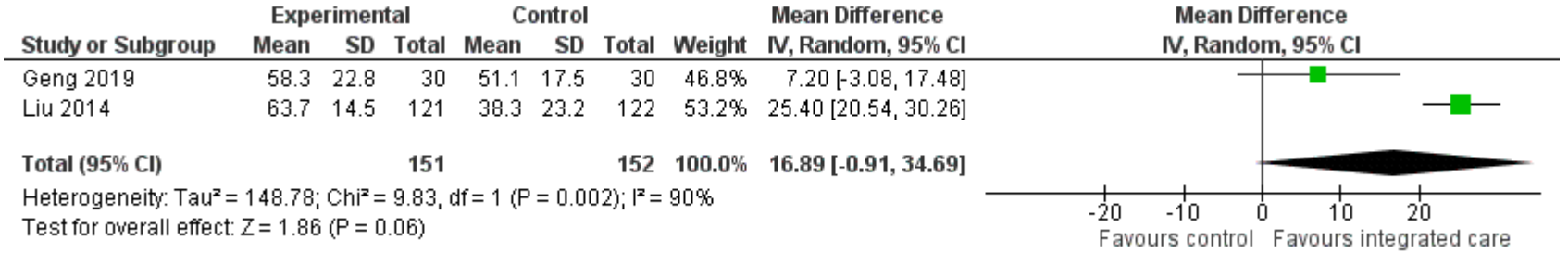


Figure S4: Comparison of integrated care with Control for QoL (SF-36 General Health questionnaire)

Table S15 Analysis of quality of life

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Abdul Aziz, 2020 [30]	Pragmatic cluster randomised controlled trial-within trial at public primary care health centres Control n=65, iCaPPS n=86	Screening for complications, QoL, depression	QoL (primary) EQ-5D-5L at 6 months Cost/QALY (secondary)	6-month EQ-5D-5L score changes: Improvement: Intervention 36.1%, control 23.1% No change: Intervention 39.5%, control 69.2% Deterioration: Intervention 24.4%, control 7.7%	No significant differences in EQ-5D-5L scores at baseline and at 6 months ($p > 0.05$) More cost-effective (12.7% lower)

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				Cost/QALY Intervention USD469.60 Control USD538.41	than standard care (cost/QALY)
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Secondary: QoL	EQ-5D-3L score, mean (SD) at 90 days: Intervention 0.7 (0.3), control 0.7 (0.3)	No difference in quality of life between groups
Bragstad et al., 2020 [31]	Multicenter, prospective, randomized, assessor-blinded, controlled trial with two parallel groups Gave consent n=353, randomised n=322 Control n=156, intervention n=166	Dialogue-based intervention to promote psychosocial wellbeing (psychological)	Stroke and Aphasia Quality of Life Scale (SAQOL) at 12 months	Between-group differences at 12 months (mean, SE): Physical domain 0.06 (−0.07, 0.20), P=0.36 Communication domain 0.06 (−0.05, 0.16), P=0.27 Psychosocial domain 0.07 (−0.11, 0.25), P=0.45	No difference in QoL at 12 months
Brouns, 2021 [32]	Pre-post post-test, controlled, pragmatic clinical trial Control n=258, intervention n=310	Web-based e-rehabilitation comprising physical exercise and cognitive exercise (psychological) programmes (mhealth)	QoL EQ-5D-5L at 3 and 6 months	Within group EQ-5D-5L changes (mean, SD): 3 months Intervention 0.07 (0.2), control 0.07 (0.2), between group P=0.19 6 months Intervention 0.01 (0.2), control –0.01 (0.2), between group P=0.38 LMM (0-6 months) P-value 0.50 (95% CI: 0.0–0.1)	No difference in QoL at 3 or 6 months
Brouwer et al., 2018 [33]	Multicenter randomized controlled trial with 2 groups: an intervention (“tune-up”) group and a control group having the same exposure to assessment N=132 (Control n=52, Intervention n=51)	Patient-centred treatment sessions comprising strength/power, balance, cardiovascular endurance (exercise), motor coordination, and education about relevant community resources, as well as how to monitor their mobility and activities	QoL (SF-36) at 12 months	SF-36 difference at 12 months Physical component -1.7 (-4.9 - 1.5), p=0.30 Mental component -1.6 (-5.4 - 2.1), p=0.40	No difference in QoL at 12 months
Chiu, 2021 [34]	Large-scale prospective cohort study N=1786 (PAC n=273, non-PAC n=273)	Post-acute care (PAC): physical exercise (physical, occupational, or speech-swallowing therapy) in multiple sessions	QoL EQ-5D at 12 months	Mean (SE) differences (PAC vs non-PAC) at 1 year after rehabilitation: -2.03 (-0.26)	No difference in QoL at 12 months
Chu, 2020 [35]	Single-centre randomised controlled trial	Training for caregivers (education), personalised	QoL EQ-5D at 6 months	Comparison of EQ-5D at 6 months post-hospital Intervention (n=26): EQ-5D 1.55 (0.39),	No difference in QoL at 6 months

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	N=61 (Control n=30, intervention n=31)	training plan for patients for recovery of physical function (mobility, self-care, bowel/toilet control)		Control (n=30): EQ-5D 1.56 (0.54), t: EQ-5D 0.11 P: EQ-5D 0.9125	
Cumming, 2019 [36]	International, multicenter (56 sites), pragmatic single-blind phase 3 randomized controlled trial, spanning 2006–2015 N=2104 (Intervention n=1054, control n=1050)	Very early mobilisation (physical activity within 24 hours) exercise	QoL AQoL 4D at 12 months	Adjusted median regression indicated no significant group difference in either total AQoL-4D scores (coefficient = −0.004; 95% confidence interval [CI] −0.043, 0.036; p = 0.86) or in any of the 4 domains at 12 months: Independent Living (coefficient = −0.007; 95% CI −0.038, 0.024; p = 0.66), Social Relationships (coefficient = 0.011; 95% CI −0.007, 0.030; p = 0.24), Physical Senses (coefficient = 0.009; 95% CI −0.004, 0.023; p = 0.16), and Psychological Well-being (coefficient = 0.001; 95% CI −0.011, 0.014; p = 0.85)	No significant difference in QoL at 12 months
Deng 2020 [37]	A pilot randomized controlled trial Control n=49, intervention n=49 Setting: Transitional care Duration: 8 weeks	Multidisciplinary poststroke consultation team providing home visits, ongoing rehabilitation, medication reconciliation, self-management education	QoL (SF-36)	Mean values of Physical Components Summary and Mental Components Summary, integral components of Short-Form Health Survey-36, were significantly better in the intervention group at four and eight weeks (40.2 ± 6.3 and 42.9 ± 3.7 for the former; 43.9 ± 2.6 and 46.1 ± 1.8 for the later). The same trend was observed in Modified Barthel Index (87.1 ± 9.2 and 92.5 ± 6.7 at four and eight weeks, respectively). But the significant improvement in Caregiver Strain Index was only observed at four weeks. There were significant differences between groups in these scores.	The transitional care program has been proven to be feasible and improve health-related outcomes
Døhl, 2020 [38]	Multicentre, pragmatic, single-blinded, randomized controlled trial N=380 (Intervention n=186, control n=194)	A follow-up program comprising monthly individualized coaching by a physiotherapist, physical activity and exercise schedule, training diary	QoL EQ-5D-5L at 18 months	Regression results* of individual cost coefficient measured as proportion increase in cost with one unit increase, with 95% CI. EQ-5D-5L as Need variable: Total costs: −3.50† (− 4.26 − − 2.75) Primary care: −3.48† (− 5.22 − − 1.74) Hospital care: −2.19† (− 3.14- -1.25) GP: −2.15 (− 3.05 − − 1.25) * Results from the regression †P < 0.05	No reduction in healthcare costs and no difference in QoL
Fu, 2020 [14]	Prospective, randomised, open trial of two active and one control interventions with blinded endpoint assessment N=400 (Primary analysis: control n=125, T1 n=123, t2 n=133)	One-to-one qualitative assessment of patient views and needs, education and goal setting	QoL SF-36 PCS at 12 months	Primary outcome SF-36 PCS 12 months, mean (SD): control 43.4 (10.7) n=125, TC1 45.4 (8.4) n=123, TC2 47.3 (8.4) n=133; difference (95% CI) TC2+TC1 minus control 2.9 (0.95 to 4.9), p=0.004 Secondary outcomes SF-36 PCS adjusted* 12 months: TC2+TC1 minus control 1.8 (0.15 to 3.5), p=0.032 SF-12 PCS six months mean (SD): control 41.9 (10.1) n=113, TC1 43.5 (8.9) n=113, TC2 45.1 (7.5) n=125;	Significantly improved QoL with intervention

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				difference (95% CI) TC2+TC1 minus control 2.4 (0.4 to 4.4), p=0.018 * Adjusted for Barthel Index five days after stroke, SF-12 PCS at baseline, age, sex, whether living alone	
Geng, 2019 [39]	Randomised controlled trial N=101 (Control n=30, intervention n=30)	Physical function, emotional function, lifestyle, medication adherence	QoL SF-36 at 6 months	QoL domain scores (mean [SD]) Physical functioning: Intervention 81.4 (16.7), control 70.5 (25.9); P<0.001 Role limitations due to physical problem: Intervention 85.3 (21.7), control 72.4 (23.5), P=0.004 Bodily pain: Intervention 78.1 (16.0), control 82.6 (16.4), P=0.835 General health: Intervention 58.3 (22.8), control 51.1 (17.5), P<0.001 Vitality: Intervention 77.2 (13.3), control 70.1 (13.1), P<0.001 Social functioning: Intervention 79.5 (21.9), control 67.1 (19.3), P=0.003 Role limitations due to emotional problems: Intervention 79.4 (22.6), control 54.0 (37.3), P=0.198 Mental health: Intervention 78.3 (17.3), control 69.2 (18.2), P<0.001	Significant differences in QoL domains in favour of intervention except for bodily pain and role limitations due to emotional problems
He et al., 2023 [40]	Randomized, historically controlled clinical trial Control n=124, intervention n=161	Rapid recovery implementation process to optimise patient recovery post-surgery	QoL (EQ-5D)	EQ-5D-5 L: Mobility 1.69 (0.78) (control),1.6 (0.82) (intervention), p=0.349 Self-care 1.56 (0.78) (control), 1.65 (0.82) (intervention), p=0.394 Usual activities 1.6 (0.76) (control), 1.61 (0.78) (intervention), p=0.897 Pain/discomfort 1.27 (0.48) (control),1.33 (0.58) (intervention), p=0.383 Anxiety/depression 1.39 (0.56) (control), 1.23 (0.43) (intervention), p=0.013 Visual analog scale 64.72 (25.93) (control), 72.29 (26.94) (intervention), p=0.017	Significant differences were found in anxiety/depression and overall quality of life, with the intervention group showing better outcomes.
Hjelle, 2019 [41]	Multicentre, prospective, randomized controlled trial Enrolled n=353, randomised n=322 (Control n=156, inv n=166)	Dialogue-based intervention delivered in patient home by nurse/OT (psychological)	SAQOL at 6 months	SAQOL between group differences (95% CI) Physical domain: –0.028 (–0.14 to 0.09), P=0.645 Communication domain: –0.031 (–0.10 to 0.04), P=0.437 Psychosocial domain: –0.004 (–0.21 to 0.20), P=0.967 Overall: –0.026 (–0.13 to 0.08), P=0.637	No significant between group differences in QoL
Jones et al., 2016 [42]	Cluster randomised controlled trial	Bridges self-management program (SMP) comprising one-to-one rehabilitation sessions and stroke workbook	QoL (SAQOL) at 12 weeks	SAQOL mean scores: Baseline: control 3.2±0.8, intervention 3.4±0.8 6 weeks: control 3.1±1.0, intervention 3.3±0.8 12 weeks: control 3.1±0.8, intervention 3.4±0.8	No significant differences in QoL

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	Control n=30, intervention n=36				
Kalav, 2022 [43]	Single centre, single-blinded randomised controlled experimental study N=210 (Control n=34, int n=34)	Individualised patient education with follow-up	SSQOL at 12 weeks	Changes in SSQOL domains, mean ±SD: Activities: control 0.62 ± 0.88, intervention 0.62 ± 0.88 (t=-0.82, p=0.4136) Social and family roles: control 0.60 ± 1.25, intervention 0.79 ± 1.18 (t= -0.77, p=0.4446) Language: Control 0.46 ± 1.04, intervention 0.92 ± 1.20 (t=-1.69, p=0.0959) Vision: control 0.36 ± 0.72, intervention 0.37 ± 1.00 (t=-0.05, p=0.9632) Energy: control 0.51 ± 1.14, intervention 0.54 ± 0.95 (t=-0.27, p=0.7861) Mood: control 0.01 ± 1.18, intervention -0.26 ± 1.40 (t= 0.76, p=0.4507) Personality: control 0.35 ± 1.02, intervention 0.09 ± 1.24 (t= 0.78, p=0.4375) SSQoL: control 0.44 ± 0.67, intervention 0.54 ± 0.79 (t=-0.71, p=0.4803)	No significant difference in QoL
Kam Yuet Wong et al., 2022 [44]	Randomised controlled trial N=2612 (Control n=58, int n=58)	Holistic MDT-based exercise training programme with psychological and social support	QOL: EQ-5D-5L at 3 and 6 months	GEE (mean, SE) EQ-5D-5L at 6 months: Baseline: Int 0.66 (0.01), control 0.66 (0.02); p=0.768 Post-intervention: Int 0.83 (0.02), control 0.77 (0.02); p=0.026	Significant improvements in QoL with intervention
Khramov, 2021 [45]	Prospective randomized controlled parallel-group study N=122 (Control n=59, int n=63)	Exercise, massage, PT and OT, social adaptation, goal setting	Stroke-specific QoL (SSQOL) at 6 months	SSQOL domain scores, M ± m Energy: Control 2.60 ± 0.17, Intervention 3.07 ± 0.15* Family roles: Control 2.43 ± 0.21, Intervention 3.72 ± 0.32* Language: Control 3.81 ± 0.16, Intervention 3.74 ± 0.26 Mobility: Control 2.92 ± 0.37, Intervention 4.31 ± 0.29* Mood: Control 2.85 ± 0.28, Intervention 4.34 ± 0.41* Personality: Control 3.13 ± 0.32, Intervention 3.32 ± 0.22 Self-care: Control 3.82 ± 0.20, Intervention 4.70 ± 0.19* Social role: Control 2.74 ± 0.17, Intervention 3.82 ± 0.25* Thinking: Control 2.51 ± 0.24, Intervention 2.61 ± 0.16 Upper extremity function: Control 4.03 ± 0.19, Intervention 4.74 ± 0.21* Vision: Control 2.72 ± 0.21, Intervention 2.92 ± 0.15	More pronounced improvement in SS-QOL ($p < 0.05$) scores for intervention group

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				Work, productivity: Control 2.41 ± 0.15, Intervention 3.20 ± 0.28* * — differences are significant ($p < 0.05$) relative to the comparison group (the Mann–Whitney U test).	
Langhorne et al., 2017 [46]	Pragmatic, prospective, parallel-group, multicentre, international, RCT with blinded assessment of outcomes and an intention to treat analysis N=2104 (Control n=1050, int n=1054)	Very early mobilisation (within 24h of stroke onset) Exercise	QoL (AQOL) at 12 months	The median AQoL IQR for the VEM group was 0.47 (95% CI 0.07 to 0.81) and in the UC group was 0.49 (95% CI 0.08 to 0.81; $p = 0.865$). The adjusted median regression result was –0.0036 (95% CI –0.045 to 0.038; $p = 0.865$).	No significant between group differences in QoL
Lewthwaite, 2018 [47]	Parallel group, three-arm, single blind, superiority randomized controlled trial of a theoretically-defensible, upper extremity rehabilitation program (47) N=361 (UCC n=122, DEUCC n=120, ASAP n=119)	Accelerated Skill Acquisition Program (ASAP) comprising skill acquisition through task-specific practice, impairment mitigation to increase capacity, and motivational enhancements to build self-confidence (exercise, psychological)	QoL (EQ-5D visual analogue scale [VAS]) at 3 months	End of treatment EQ-5D scores: Intervention (ASAP): 77.1 (73.6, 80.5)* Dose-equivalent usual care (DEUCC): 71.9 (68.6, 75.1) Usual care (UCC): 70.7 (66.8, 74.5) *P<0.05 vs DEUCC, P<0.001 vs UCC	Significant improvements in QoL at 3 months in intervention versus comparator groups
Liu, 2018 [48]	Randomised trial N=40 (control n=20, int n=20)	Nurse-led personalised education and follow-up	QoL (SF-36) at 1, 3 and 6 months	At month 1, 6/8 domains of SF-36 were significantly improved over control (P<0.05) excluding vitality (VT) and social functioning (SF) At month 3, 4/8 domains showed significance excluding bodily pain (BP), VT, SF and role limitations due to emotional problems (RE) At month 6, 1/8 domains (General health perceptions [GH]) were significant	QoL significantly improved versus control at 1 month but effect declined with continuing follow-up
Liu et al., 2014 [15]	Multi centre randomized controlled trial Control n=122, intervention n=121	Early intervention: Standard care but at 48 hours following ICH onset.	HRQoL (SF-36)	SF-36 Mean differences between components at 3 months varied were -2.5 to 5.8 between groups, 6.4-25.5 at 6 months	Commencement of rehabilitation within 48 hours of ICH significantly reduced hospital length of stay and improved long-term survival and morbidity outcomes when compared with standard practices
Luengo-Fernandez et al., 2022 (EXPRESS) [16]	Prospective population-based before (phase 1: April 2002–September 2004; n=310) versus after (phase 2: October	EXPRESS Phase 1: Clinic referral (1-2 days), brain imaging and ECG, ultrasound/echo, primary care	Quality of life (EQ-5D)	EQ-5D scores by time period, mean (SD): 1 month: Phase 1 0.751 (0.268), Control Phase 1 0.689 (0.279), Phase 2 0.784 (0.227). Control Phase 2 0.750 (0.249)	Urgent assessment and treatment of patients with transient ischemic attack or minor stroke

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	2004–March 2007; n=281) study EXPRESS: Phase 1 n=310, Phase 2 n=281; Control: Phase 1 n=167, Phase 2 n=224	treatment protocol comprising antiplatelet, statin, BP lowering. Phase 2: As Phase 1 but treatment initiated immediately instead of by primary care, high-dose aspirin or clopidogrel, CT scan during clinic. Follow-up 1, 6, 12, 60, and 120 months after the index event in both Phases. Control: standard care (not referred to study clinic)		1 year: Phase 1 0.759 (0.245), Control Phase 1 0.736 (0.247), Phase 2 0.765 (0.264), Control Phase 2 0.721 (0.271) 5 years: Phase 1 0.759 (0.262), Control Phase 1 0.754 (0.239), Phase 2 0.757 (0.269), Control Phase 2 0.719 (0.283) 10 years: Phase 1 0.705 (0.325), Control Phase 1 0.766 (0.307), Phase 2 0.718 (0.320), Control Phase 2 0.746 (0.271)	resulted in a long-term reduction in recurrent strokes and improved outcomes, with little atrophy of the early benefit over time, representing good value for money even with a 10-year time horizon. A reduction in stroke risk in phase 2 was still evident at 10 years (55/23.3% versus 82/31.6%; hazard ratio=0.68 [95% CI, 0.48–0.95]; P=0.024), as was the impact on risk of disabling or fatal stroke (17/7.7% versus 32/13.1%; hazard ratio=0.54 [0.30–0.97]; P=0.036).
Markle-Reid, 2020 [49]	Prospective one-group pre-test/post-test pragmatic study N=45 (participated n=30)	Multidisciplinary transitional care intervention delivering training and support to older stroke patients at home with regular consultation and follow-up (pathway)	HRQoL (SF-12) at 6 months	Difference in mean QoL scores (95% CI): HRQoL–Physical composite summary score (SF-12) 2.3 (2.2, 6.8), P=0.3 HRQoL–Mental composite summary score (SF-12) 0.3 (3.9, 4.4), P=0.9	No significant between group differences in QoL
Minshall, 2020 [50]	Randomised controlled trial N=458 (Control: stroke patients n=39, carers n=40. 12-month assessment patients n=25, carers n=23 Int: stroke patients n=50, carers n=44. 12-month assessment patients n=27, carers n=18)	Program of personalized psychosocial support – Stroke Care Optimal Health Program (SCOHP) comprising education, self-management and reflective exercises	Australian Assessment of Quality of Life-6 Dimensions (AQoL- 6D)33 and the 3-level EuroQoL-5-dimensions (EQ-5D-3 L) at 3, 6 and 12 months	Quality of life (AQOL), mean (SD) Stroke survivor Baseline: Int 0.61 (0.20), control 0.63 (0.24); p=0.71 3 months: Int 0.59 (0.18), control 0.62 (0.27); p=0.63 6 months: Int 0.58 (0.18), control 0.63 (0.27); p=0.40 12 months: Int 0.58 (0.19), control 0.64 (0.27); p=0.32 Stroke carer: Baseline: Int 0.71 (0.19), control 0.72 (0.21); p=0.96 3 months: Int 0.77 (0.13), control 0.71 (0.19); p=0.25 6 months: Int 0.70 (0.16), control 0.72 (0.22); p=0.74 12 months: Int 0.72 (0.18), control 0.69 (0.24); p=0.69 Quality of life (EQ-5D) Stroke survivor Baseline: Int 65.05 (18.01), control 58.72 (23.19); p=0.21	No significant differences between groups for QoL

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				3 months: Int 68.67 (20.34), control 65.45 (23.01); p=0.60 6 months: Int 64.03 (21.73), control 67.08 (18.24); p=0.58 12 months: Int 62.55 (20.50), control 67.00 (22.62); p=0.46 Stroke carer: Baseline: Int 73.88 (17.49), control 74.93 (17.00); p=0.81 3 months: Int 79.22 (13.19), control 71.29 (15.89); p=0.11 6 months: Int 70.13 (19.13), control 74.60 (19.02); p=0.45 12 months: Int 72.94 (19.94), control 69.83 (19.78); p=0.64	
Mohammadi, 2022 [51]	Single-blind RCT N=80 (Control n=36, int n=31)	Personalised care plan providing education, diet, activity, anxiety (psychological) level, medication with follow-up	QoL (SSQOL) at 3 and 6 months	QoL scores at 3 and 6 months (Mean ± SD): 3 months: Intervention 172.2 ± 40.7, control 144.9 ± 51.7, P<0.05 6 months Intervention 205.3 ± 40.6, control 160.7 ± 55.4, P<0.05	Significant improvements in QoL at 3 and 6 months in intervention versus control group
Reeves, 2019 [27]	Open-label (unblinded) 3-group parallel-design clinical trial N=320 (Group 1 (UC): Global-10 n=77, PAM n=76, Group 2 (SWCM) Global-10 n=82, PAM n=79, Group 3 (SWCM + MISTT website) Global-10 n=81, PAM n=78) UC, usual care; MISTT, Michigan stroke transitions trial; PAM, pain activation measure; SWCM, social worker–led case management	Home-based social worker–led case management (SWCM) program with or without a website, comprising biopsychosocial assessment followed by development of a personalised plan to address unmet needs (pathway, psychological)	PROMIS-10 global physical and mental health at 7 and 90 days	PROMIS-10 global physical health (n=434 observations) – difference in differences (D-in-D) analysis; test of group × time interaction: P=0.003 PROMIS-10 global mental health (n=434 observations) D-in-D analysis; test of group × time interaction: P=0.56	Significant difference in physical health but not mental health
Rodgers, 2019; Shaw, 2020 [52, 53]	Parallel-group observer-blind multicenter individually randomized controlled trial N=573 (Control n=231, int n=219)	Early supported discharge reviews (EXTRAS) including mobility, self-care, mood (psychological), cognitive function (pathway)	QALYs (EQ-5D-5L) at 1 and 2 years	Adjusted Difference* EXTRAS Minus Usual Care Mean (95% CI) Utility year 1: 0.05 (0.00 to 0.09) Utility year 2: 0.04 (0.01 to 0.07) Total as QALY: 0.07 (0.01 to 0.12)	EXTRAS provided more Quality Adjusted Life Years (0.07 [95% CI, 0.01 to 0.12]) but no difference in QoL
Saal et al., 2015 [21]	Randomised controlled clinical trial	Post-discharge support including follow-up call and	HRQoL BREF at 12 months	WHOQOL-BREF	No statistically significant differences

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	Control n=111, intervention n=119	visit, education and training sessions		Physical: Intervention: Baseline - 68.5 (17.4); 12 months - 65.8 (18.5); Control: Baseline - 64.4 (20.0); 12 months 63.0 (21.8) Mean difference (95% CI) -0.7 (-4.7; 3.3) Psychological: Intervention: Baseline - 73.4 (14.9); 12 months 72.2 (17.8); Control: Baseline - 73.1 (16.8); 12 months -72.3 (18.9) Mean difference (95% CI) -1.5 (-5.4; 2.3) Social: Intervention: Baseline - 73.7 (15.0); 12 month - 73.3 (19.0); Control: Baseline - 75.2 (15.0); 12 months 75.8 (17.3) Mean difference (95% CI) -1.8 (-6.7; 3.1) Environment: Intervention: Baseline - 77.6 (12.0); 12 month - 78.9 (14.7); Control: Baseline- 81.3 (12.4); 12 month - 81.1 (14.5) Mean difference (95% CI) -0.7 (-4.4; 3.2) Global: Intervention: Baseline - 61.8 (17.5);l 12 month - 59.6 (20.9); Control: Baseline - 61.7 (19.6); 12 month - 60.9 (25.3) Mean difference (95% CI) -1.8 (-7.1; 3.6)	were found between groups on HRQOL.
Tung et al., 2021 [54]	Retrospective cohort study N=261 (Inpatient PAC: n=138, Home-based PAC n=59)	Post-acute care (PAC) delivering physical, OT and speech therapy in inpatient and home settings (pathway)	EuroQoL EQ-5D (ED5Q) Cost-effectiveness was calculated as the total cost divided by the improvement in Barthel index (BI), Lawton–Brody instrumental activities of daily life scale (IADL), ED5Q and mini nutritional assessment (MNA) scores	Functional improvement in QOL between inpatient PAC and home-based PAC: p=0.769 Cost-effectiveness vs. ED5Q (USD): Inpatient PAC 25,476.70 ± 52,741.59 (849.22 ± 1758.05) Home-based PAC 15,623.60 ± 18,564.44 (520.79 ± 618.81); p<0.001	No significant difference between groups in QoL but home-based PAC was more cost-effective
Vluggen, 2021 [55]	Two-arm multicenter randomised controlled trial N=190 (Control n=91, int n=99)	Inpatient neurorehabilitation treatment, home-based self-management training (patient and caregiver), education	QoL (SSQOL) at 6 months	SSQOL domains Subscale physical functioning (Mean [SD]): Intervention 102.2 (19.9), control 99.2 (22.5), group effect 3.08, P=0.476 Subscale psychosocial functioning (Mean [SD]): Intervention 81.3 (17.1), control 78.7 (18.0), group effect 8.45, P=0.054	No significant difference between groups in QoL
Long Weijan and Zhang, 2017 [56]	Randomised controlled trial N=96 (Control n=48, int n=48)	Training program for HCPs on comprehensive care for patients, rehabilitation training for caregivers (pathway)	QoL (SS-QOL) at 3 months posy-discharge	SS-QOL components at 3 months, mean (SD), t-value, p=value physical fitness: Control 6.08±0.901, Intervention 6.92±0.991; t= -4.336, P=0.000 Family role: Control 6.48±0.80, intervention 7.33±1.121; t= -4.309, P=0.000 Language features: Control 14.08±3.231, intervention 18.29±2.141; t= -7.525, P=0.000	QoL was significantly higher in the intervention group overall at 3 months (P<0.01) and for all domains except thinking, vision and work productivity

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				Activity ability: Control 13.19±4.481, intervention 16.65±4.911; t= 3.605, P=0.001 Mood: Control 12.23±5.91, intervention 16.19±6.231; t= -3.193, P=0.002 Personality: Control 9.60±4.24, intervention 12.56±3.431; t= -3.759, P=0.000 Self-care ability: Control 13.71±5.69, intervention 17.91±5.691; t= -3.622, P=0.000 Social role: Control 10.33±5.31, intervention 14.23±7.181; t= -3.023, P=0.003 Thinking: Control 6.69±3.861, intervention 6.85±3.761; t=-0.214, P=0.831 Upper limb function: Control 14.04±6.07, intervention 18.23±6.601; t= -3.235, P=0.002 Vision: Control 10.23±2.75, intervention 10.52±2.581; t= -0.536, P=0.593 Work productivity: Control 9.04±1.66, intervention 9.33±1.621; t= -0.872, P=0.386 Total SSQOL score: Control 125.71±20.171, intervention 155.02±16.851; t= -7.727, P=0.000	
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	Stroke, MI, vascular death, QoL (EQ-5D-3L), functional status, major bleeding	The median EQ-5D-3L health utility score was 0.783 (IQR 0.687-1.000) in the STROKE-CARD care group and 0.779 (IQR 0.573-1.000) in the standard care group (P < 0.001). A score of 1.0 indicating absence of problems in all five EQ-5D-3L dimensions was achieved by 43% in the STROKE-CARD care group and 32% in the standard care group (relative risk 1.36; 95% CI: 1.20-1.54; P < 0.001).	The pragmatic and easily implementable STROKE-CARD care programme reduced cardiovascular risk and improved health-related quality of life and functional outcome in patients with acute ischaemic stroke or TIA
Wong and Yeung 2014 [57]	Randomised controlled trial Control n=54, intervention n=54	The intervention group received the transitional care program (TCP) which was commenced before discharge and lasted for 4 weeks after discharge. The TCP had 3 components 1) holistic care delivered by holistic care managers (HCMS), 2)	QoL (SF-36) at 4 and 8 weeks	SF-36 PCS: After 4 weeks: Control 47.1 (1.2), intervention 47.9 (1.2) After 8 weeks: Control 47.3 (1.4), intervention 48.6 (1.4) F(P-value) after 4 weeks 13.76 (<0.001), after 8 weeks 37.60 (<0.001), interaction effect p=0.006	The TCP improved QoL and reduced depression.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
		transitional care track and 3) holistic care managers.		SF-36 MCS: After 4 weeks: Control 49.2 (1.1), intervention 49.9 (1.0) After 8 weeks: Control 49.4 (1.4), intervention 49.9 (1.0) F(P-value) after 4 weeks 13.72 (<0.001), after 8 weeks 7.67 (0.007), interaction effect p=0.591	
Wu, 2020 [58]	Randomised controlled trial N=64 (Control n=31, int n=30)	Home remote rehabilitation based on a collaborative care model creating a personalised plan delivered through videoconferencing (pathway)	QoL (SSQOL) at 4,8 and 12 weeks	Overall SSQOL scores: 4 weeks: 148.97±5.22 intervention, control 137.23±4.57 8 weeks: 174.07±4.71 intervention, 155.52±4.44 control 12 weeks: 190.57±5.09 intervention, 175.90±5.78 control P<0.001	Significant improvements in QoL for intervention
Xi, 2017 [59]	Randomised controlled trial N=90 (Control n=45, int n=45)	Home remote rehabilitation based on a collaborative care model creating a personalised plan delivered through videoconferencing (pathway)	QoL (SF-36) at 6 months	Significant differences (P<0.05) versus control for 6/8 SF-36 domains excluding social functioning (SF) and bodily pain (BP)	Significant improvements in QoL
Yan et al., 2021 [29]	Open-label, two-arm cluster-randomized controlled trial villages n=50, participants n=1299 (Control n=615, int n=611)	Primary care based app (SINEMA) to improve communication between HCPs and patients (mhealth)	QoL (EQ-5D-5L) at 12 months	Change in health-related quality of life score, mean (SD)§ Intervention 0.01 (0.15), control −0.03 (0.14) Minimally adjusted model estimate (95% CI): 0.04 (0.01, 0.06), P=0.006 Fully adjusted model estimate (95% CI): 0.04 (0.01, 0.06), P=0.008 §Health-related quality of life was measured by using EQ5D-5L and was converted into a utility score based on the Chinese value set.	Significant improvements in QoL

Readmission

Table S16 Analysis of rehospitalisation

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Avci and Gozum, 2023 [60]	Parallel-group, assessor-blind, monocenter randomized controlled trial Control n = 60 (30 patients and 30 caregivers), Intervention n = 66 in (33 patients and 33 caregivers)	Interviews and education (web-based training) for caregivers and patients	Readmission rates (12 weeks)	Hospital return status of stroke patients: Intervention Group (n = 33): Yes = 5 (15.2%), no = 28 (84.8%) Control Group (n = 30): Yes = 7 (23.3%), no = 23 (76.7%)	Readmission and pressure ulcers were less common in stroke patients in the intervention group compared with the control group.
Buckley et al., 2022 [6]	Retrospective observational study N=836,923 Propensity matched cohorts: Control n=2909, intervention n=2909	Exercise-based cardiac rehabilitation	2-year incidence of rehospitalisation	Rehospitalisation at 2-years was proportionally lower with 40.7% (n=1,185 of 2,909 patients) in the exercise-based cardiac rehabilitation cohort compared to 51.8% (n=1,507 of 2,909 patients) in the controls (OR 0.64, 0.58-0.71)	Significant reduction in rate of rehospitalisation with intervention (36%)
Bushnell et al., 2021 [7]	COMPASS was a cluster-randomized trial of the effectiveness of the COMPASS-TC intervention (INV) compared with usual care (UC) Participating hospitals: control n=20, inv n=20 Patients: Control n=1193, inv n=1069	Post-acute care pathway (full pathway) follow-up with the advanced practice provider and nurse coordinator in clinic within 7 to 14 days post discharge, an individualized electronic care plan, and referral to community services	30- and 90-day unplanned readmissions, 1 year all-cause readmissions	30d admissions: Intervention 105 (9.9%), control 103 (8.7%), OR 1,20 (95% CI: 0.83-1.74) 60d readmissions: Intervention 210 (19.9%), control 222 (18.9%), OR 1.10 (95% CI: 0.84-1.41) 1 year all-cause readmissions: Intervention 485 (45.4%), control 516 (43.3%), HR 1.06 (95% CI: 0.95-1.77) 1 year stroke readmission: Intervention 67 (6.3%), control 62 (5.2%), HR 1.26 (95% CI: 0o.0-1.77)	No difference in readmission rates between groups
Chen et al., 2016 [61]	Quasi-experimental controlled study Control n=173, intervention n=168	Individualised transitional care model based at home	Readmission (1 month)	Readmission: Intervention 2/168 (1.19%) vs. control 11/173 (6.36%), $Chi^2 = 5.30$, p = 0.02)	The intervention was associated with significantly lower readmission rates.
Cuccurrullo et al., 2022 [62]	Prospective matched cohort study Control n=88, intervention n=105	SRP program: Physician Visits, Outpatient Therapy, and Modified Cardiac Rehabilitation (management of blood pressure (BP), cholesterol control, reduction of blood sugar, getting active, eating better, losing weight, and smoking cessation) Lifestyle	Readmission rates (1 year)	All cause readmission: control 59/88 (67%), intervention 47/105 (45%), difference in proportion 22%, HR 0.51 (0.31-0.83), p=0.006	Acute care hospital readmissions were reduced in stroke survivors who participated in SRP.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
de Belvis, 2019 [11]	Pre-post retrospective observational study N=1,009 Control n=483, intervention n=526	5-stage clinical pathway: (1) initial framing; (2) evaluation/staging; (3) treatment; (4) rehabilitation; and (5) follow-up/monitoring (full pathway)	30-day readmission rate (Patients not registered in the Italian NHS)	Pre-intervention (control) 7.4%, intervention 7.0%, Δ% -5.7, P=0.85	No statistically significant decrease in readmission rates within 30 days
Deutschbein, 2020 [12]	Pragmatic non-randomised controlled trial N=361 (intervention n=145, control n=270)	Individualised case management, with regular face-to-face visits as part of a comprehensive individualised programme (PT, OT, support required), regular monitoring and adjustment (full pathway)	Readmissions within 12 months (incidence ratio [IR]) per 100 person months	Intervention: 4.03 (95% CI: 2.58–6.28) Control: 9.56 (95% CI: 7.99–11.43) Incidence rate ratio (IRR) 0.45 (95% CI: 0.31-0.65) unadjusted, 0.42 (95% CI: 0.29-0.62), both P<0.001	Significantly lower rates of readmission in intervention group
Fu, 2020 [14]	Prospective, randomised, open trial of two active and one control interventions with blinded endpoint assessment N=400 (Primary analysis: control n=125, T1 n=123, t2 n=133)	One-to-one qualitative assessment of patient views and needs, education and goal setting	Readmission within 12 months (OR) secondary outcome	Readmission by 12 months, N/N (%): Control 53/130 (40.8), TC1 54/132 (40.9), TC2 41/138 (29.7), Odds ratio difference (95% CI) TC2 + TC1 versus control 0.79 (0.51 to 1.21), p=0.27	No difference in readmission rates
Lu 2023 [63]	Randomised controlled trial Control n=41, intervention n=40 Setting: Community (post-discharge) Duration: 6 months	Internet-based home care model (multidisciplinary)	Readmission	Rehospitalisation = 16 in control group vs 8 in intervention p=0.043	The intervention was associated with significantly lower readmission rates.
Peng, 2017 [20]	Propensity score-matched case-control study using the National Health Insurance data Original cohort: control n=3159, int n=1480 Matched Cohort: control n=657, int n=657	PAC program measuring activities of daily living, nutrition, exercise, mobility and language	90-day readmission event rates (events/total patient number)	90-d readmission events Original cohort Intervention: 161/1480 (10.9%), control: 674/3159 (21.3%), aOR 0.47 (95% CI: 0.39-0.57), P<0.01 Matched cohort Intervention: 73/657 (11.1%), control: 138/657 (21.0%), aOR 0.47 (95% CI: 0.34-0.64), P<0.01 90-d readmission events for stroke Original cohort Intervention: 41/1480 (2.8%), control: 254/3159 (8.0%), aOR 0.32 (95% CI: 0.23-0.45), P<0.01 Matched cohort Intervention: 14/657 (2.1%), control:	Significantly lower hospital 90-day readmissions and stroke-related readmissions

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				58/657 (8.8%), aOR 0.22 (95% CI: 0.12-0.41), P<0.01	
Reeves, 2019 [27]	Open-label (unblinded) 3-group parallel-design clinical trial N=320 (Group 1 (UC): Global-10 n=77, PAM n=76, Group 2 (SWCM) Global-10 n=82, PAM n=79, Group 3 (SWCM + MISTT website) Global-10 n=81, PAM n=78) UC, usual care; MISTT, Michigan stroke transitions trial; PAM, pain activation measure; SWCM, social worker–led case management	Home-based social worker–led case management (SWCM) program with or without a website, comprising biopsychosocial assessment followed by development of a personalised plan to address unmet needs (pathway, psychological)	Rehospitalisation at 90 days	90-day hospital readmissions (n=265) UC 17 (20%) SWCM 20 (23%) OR 1.21 [0.59–2.51] SWCM+MISTT Website 18 (20%) OR 1.03 [0.49–2.16] Type 3 $\chi 2$ global test: P=0.85	Hospital readmission occurred in 55 (20.8%) of the 265 subjects, but rates did not differ between treatment groups (P=0.85)
Schwarzbach et al., 2023 (SANO) (22)	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	Readmission to hospital at 12 months	Readmission to hospital within 1 year of index stroke: Control: 383/1216 (31·5%); Intervention: 375/1169 (32·1%): OR 1·01 (95% CI 0·74–1·38); aOR: 0·99 (95% CI 0·73–1·37)	This study demonstrated that the SANO programme had positive effects on the control of some cardiovascular risk factors in patients with stroke, but this did not translate into a reduction in the rate of major cardiovascular events 1 year after the first ischaemic stroke.
Swanson, 2019 [23]	Retrospective cohort study Control: n-=2605, rehab only n=689, home nursing only n=535, home nursing and rehab n=898	Standalone home nursing or rehabilitation, or a combination of both, with or without GP follow-up visits (pathway)	90-day and 1-year readmission	Adjusted HR 90-day: Rehab 1.45* (95% CI: 1.06–1.97) Home nursing 1.08 (95% CI: 0.74–1.57) Rehab + Home nursing 0.95 (95% CI: 0.67–1.34) Adjusted HR 1-year: Rehab 1.80* (95% CI: 1.45–2.22) Home nursing 1.31 (95% CI: 1.02–1.66) Rehab + Home nursing 1.46 (95% CI: 1.16–1.84) *Significant difference to home nursing with rehabilitation, $p < 0.05$	Patients receiving home nursing and/or rehabilitation had higher unadjusted 90- and 365-day readmission rates than those without services (HR from 1.87 to 2.63 depending on analysis, $p < 0.001$), but the 90-day differences disappeared after risk adjustment, except for patients receiving only rehabilitation
Wang et al., 2021 [64]	Randomised controlled trial N=184 (Control n=82, int n=84)	Pharmacist-delivered care program providing inpatient and outpatient care - education	Readmission was any event leading to hospitalization, including stroke recurrence or	Comparison of re-admission rates between the two groups at 6-month discharge (n = 166)	Significantly fewer patients were re-admitted to the

Study details	Design/Patients	Intervention	Outcome	Results	Comments
		focused on medication therapy management (MTM), disease state management, and lifestyle for secondary prevention of ischemic stroke	poor control of risk factors. The rates of re-hospitalizations were calculated and compared between groups at 6-month discharge.	Recurrent stroke, n (%): Intervention 3 (3.57), control 8 (9.76); p=0.11 Poor control of risk factors, n (%): intervention 1 (1.19), control 5 (6.10); p=0.20 Others, n (%): Intervention 2 (2.38), control 2 (2.44), p=1.00 Total, n (%): Intervention 6 (7.14), control 15 (18.30); p=0.03	hospital in IG than CG (7.14% vs. 18.3%, P = 0.03).
Wong and Yeung 2015 [57]	Randomised controlled trial Control n=54, intervention n=54	The intervention group received the transitional care program (TCP) which was commenced before discharge and lasted for 4 weeks after discharge. The TCP had 3 components 1) holistic care delivered by holistic care managers (HCMS), 2) transitional care track and 3) holistic care managers.	Readmission at 8 weeks	Readmission rates at 8 weeks: Control 8/54 (14.8%), intervention 4/54 (7.4%) p=0.358	Readmission rates in the intervention group were lower but this did not reach statistical significance
Yan 2021 [29]	Open-label, two-arm cluster-randomized controlled trial villages n=50, participants n=1299 (Control n=615, int n=611)	Primary care based app (SINEMA) to improve communication between HCPs and patients (mhealth)	Rehospitalisation (exploratory)	Hospitalisation rates at 1 year were 27/611 (4.4) in the intervention group and 57/615 (9.3%) in the control group (p<0.001)	Readmission rates were significantly lower in the intervention group

Depression and anxiety

Meta-analysis also showed that depression scores were significantly lower with integrated care than control regardless of the scale being used or the follow up time (SMD = -0.16, 95% CI: -0.26 to -0.06, p=0.001, I^2 = 0%, Figure S5).

Anxiety scores were also lower with integrated care interventions according to a meta-analysis of 4 studies (n=940) (Figure S6). SMD was -0.35 (95% CI: -0.70-0.01, p=0.05, I^2 = 84%).

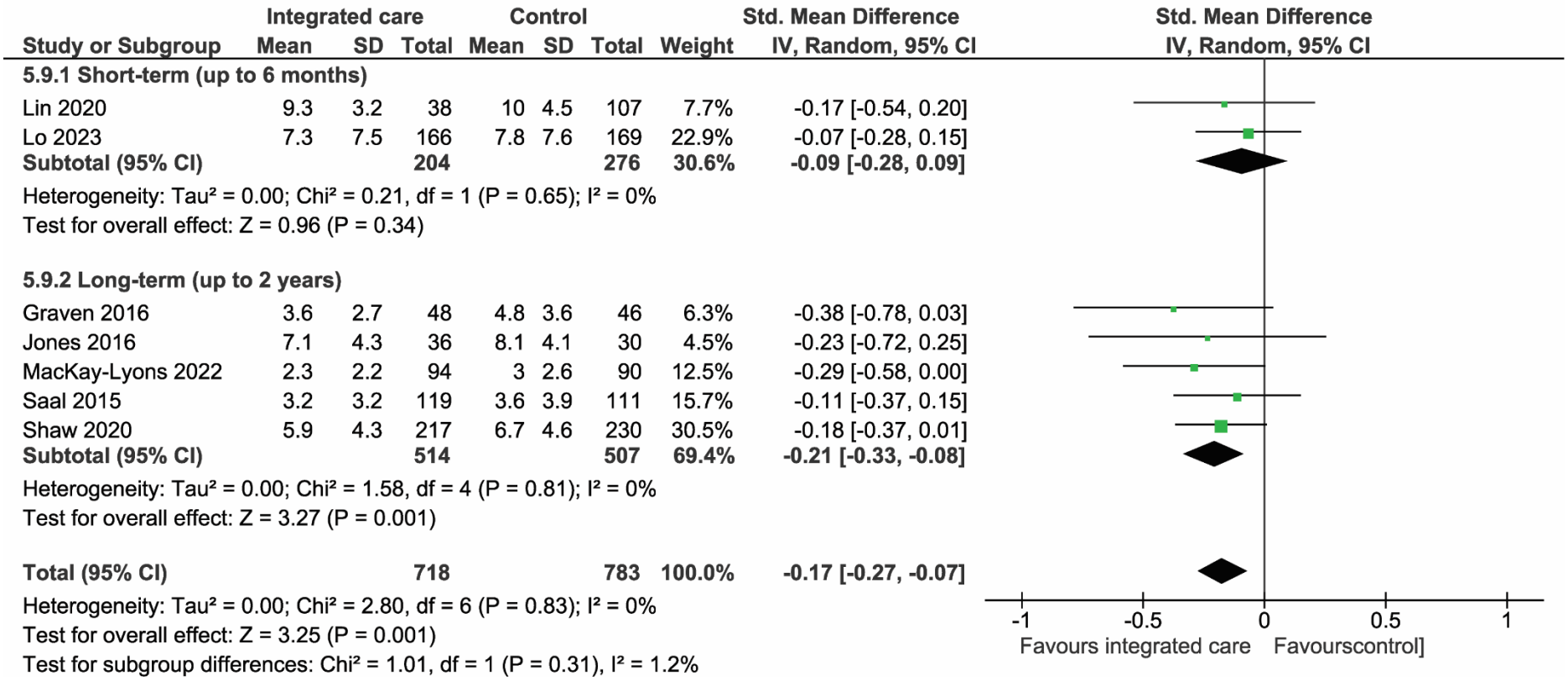


Figure S5: Comparison of integrated care with control for depression scores by follow-up time

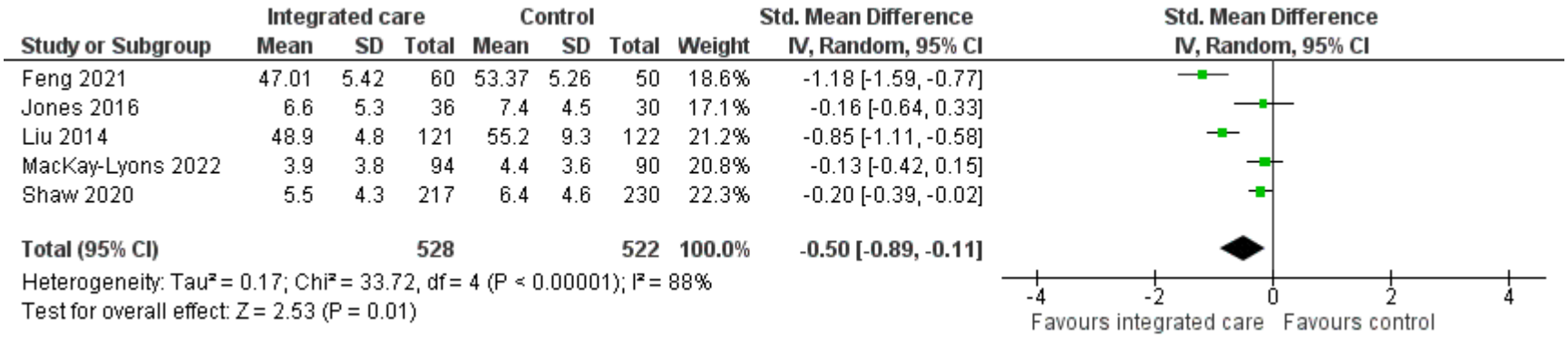


Figure S6: Comparison on integrated care with control for anxiety scores (SMD)

Table S17 Analysis of depression and anxiety

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Abdul Aziz, 2020 [30]	Pragmatic cluster randomised controlled trial-within trial at public primary care health centres Control n=65, iCaPPS n=86	Screening for complications, QoL, depression	Depression screen PHQ scores	Control: Baseline ≥10 6 (9.2%), <10 59 (90.8%) Exit ≥10 1 (1.2%), <10 85 (98.8%) Intervention: Baseline ≥10 6 (7.0%), <10 80 (93.0%) Exit ≥10 6 (7.0%), <10 80 (93.0%) Fisher's exact tests: Baseline 0.793 Exit 0.240	No significant difference in depression between groups
Bragstad et al., 2020 [31]	Multicenter, prospective, randomized, assessor-blinded, controlled trial with two parallel groups Gave consent n=353, randomised n=322 Control n=156, intervention n=166	Dialogue-based intervention to promote psychosocial wellbeing (psychological)	Yale-Brown single-item questionnaire	Feeling sad or depressed (Yale; N (%)b Intervention group T1 29 (17.4), T2 37 (22.3), T338 (22.9) Control group T1 43 (27.6), T2 36 (23.1), T3 37 (23.7) Between group differences at 12 months 0.96 (0.55, 1.68), OR 0.890c	No difference in depression at 12 months
Brandal, 2019 [65]	Prospective, randomised, open-label, blinded endpoint, event--driven trial N=99833 (Control n=27554, intervention n=1432)	Early supported discharge (ESD)	Patient recorded outcome measures (PROMS)	Depression n (%) Seldom Intervention 1083 (75.6), Control 20,819 (75.6) Often intervention109 (7.6), control 3118 (13.3), p=0.001 (OR 0.68 95% CI: 0.55 - 0.84) Missing: Intervention 240 (16.8), Control 3617 (13.1)	Significantly improved satisfaction with rehab after discharge, independence in mobility, toileting and dressing, significantly less depression
Cheng, 2018 [66]	Randomised controlled trial N=201 (CRT n=84, control n=84)	Patient and family member education, cognitive training (psychological), rehabilitation training, regular follow-up	HADS anxiety/depression score Zung's SAS anxiety score, Zung's SDS depression score	HADS anxiety score change at 12 months: -0.23 ± 0.20 (CRT) vs 0.62 ± 0.17 (control), p=0.002 SAS anxiety score change at 12 months: -0.23 ± 0.20 (CRT) vs 2.00 ± 0.77 (control), p=0.006 HADS depression score change at 12 months: -0.71 ± 0.23 (CRT) vs 0.44 ± 0.18 (control), p<0.001 SDS depression score change at 12 months: -2.10 ± 1.10 (CRT) vs 2.30 ± 0.88 (control), p=0.002	Significantly less cognitive impairment, anxiety and depression
Duncan, 2020 [13]	Pragmatic cluster-randomized trial 6024 patients, 41 hospitals (Hospitals n=40, patients intervention n=2689, control n=3193)	Education, secondary prevention, rehabilitation, recovery, referrals to community-based resources, and caregiver support services by telephone follow-up	Depression/no depression. Depression measured by the PHQ-2. Scores range from 0 to 6; higher scores corresponding to less	No depression, n (%): Intervention 1025 (78.3), control 1122 (76.6); OR 0.97 (0.74 to 1.26)	No difference in depression

Study details	Design/Patients	Intervention	Outcome	Results	Comments
			favourable outcomes. Absence of depression considered to be a score of ≤2.		
Ellis-Hill, 2019 [67]	Two-centre, 24-month, parallel-arm RCT with qualitative and economic components N=56 (Control n=25, intervention n=22)	Arts and health practitioner-led group sessions (psychosocial and wellbeing)	Warwick-Edinburgh Mental Well-being Scale (potential range 14–70, higher scores greater well-being) HADS	Warwick-Edinburgh Mental Well-being Scale Mean difference (95% CI) in change from baseline (unadjusted): 2.25 (−2.83 to 7.32), effect size 0.23 Mean difference (95% CI) in change from baseline (adjusted for centre and baseline score): 1.14 (−3.42 to 5.70), effect size 0.12 Hospital Anxiety and Depression Scale-anxiety subscale Mean difference (95% CI) in change from baseline (unadjusted): −0.47 (−2.48 to 1.54), effect size -0.12 Mean difference (95% CI) in change from baseline (adjusted for centre and baseline score): −0.55 (−2.39 to 1.28), effect size -0.14 Hospital Anxiety and Depression Scale-depression Mean (SD) n baseline: Control 5.0 (Mean difference (95% CI) in change from baseline (unadjusted): −1.82 (−3.42 to −0.22), effect size -0.56 Mean difference (95% CI) in change from baseline (adjusted for centre and baseline score): −1.46 (−3.12 to 0.21), effect size -0.45	Positive trend towards reduced depression and anxiety with intervention but not significant
Feng, 2021 [68]	Randomised controlled trial N=120 (Control n=60, intervention n=60)	Trained multidisciplinary team providing an intervention plan based on the patient's condition and treatment-related information, and arranging specific plans for family visits and telephone follow-ups, continued support and follow-up in the community (full pathway)	Zung's Self-rating Anxiety Scale (SAS) and Self-rating Depression Scale (SDS) scores	Comparison adverse mood between the two groups before and after intervention (x±s, points) Before the intervention: control SAS scores 58.27±6.03, SDS scores 61.06±5.37; intervention group SAS scores 58.41±5.98, SDS scores 61.28±5.62 t value SAS 0.128, SDS 0.219 P value SAS 0.899, SDS 0.827 3 months after the intervention: control SAS scores 53.37±5.26, SDS scores 55.34±6.11; intervention group SAS scores 47.01±5.14, SDS scores 48.71±5.42 t value SAS 6.698, SDS 6.288 P value SAS 0.000, SDS 0.000	Significantly lower anxiety and depression with intervention
Gao, 2017 [69]	A single-blind, randomised, controlled trial that compared three intervention groups, with subgroups stratified by time after stroke	Citalopram, psychological intervention for depression, cognitive behavioural education	HAMD 17-item scale, Bech-Rafaelsen Melancholia Scale (MES)	Comparison of outcome between the three groups – total sample MES, mean (SD): Group A 10.0 (2.8), Group B 9.0 (2.2), Group C 9.6 (2.1); Comparison (A, B, and C) p=0.02, comparison (A and B) p=0.02, Comparison (A and C) p=0.51 HAMD17, mean (SD): Group A	Significantly improved depression scores but only for MES and MES/HAMD at certain times in subgroup

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	N=273 (Group A n=91, Group B n=91, group C n=92) Analysis groups: Group A n=86, Group B n=85, Group C n=87			8.5 (3.4), Group B 8.1 (2.4), Group C 8.5 (2.7); Comparison (A, B, and C) p=0.60, comparison (A and B) p=0.79, Comparison (A and C) p=1.00 Outcome according to the depression scales with the stratified subgroups. 3-6 months after stroke MES and HAMD A vs B (both P=0.02) 6-9 months after stroke MES A, B and C (P=0.03), A vs C (P=0.01)	analysis (no difference in HAMD overall)
Graven et al., 2016 [70]	Prospective randomised controlled trial Control n=46, intervention n=48	Physiotherapist-led comprehensive multifactorial care pathway individualised to each participant	Depression (Geriatric depression score [GDS-15]) at 12 months	At 12 months, the mean GDS-15 score was lower in the intervention group (3.6±2.7) compared to the control group (4.8±3.6). A lower proportion of participants in the intervention group (14.6%) had significant depressive symptoms (GDS-15 ≥6) at 12 months compared to the control group (34.8%). At 12 months.	Positive impact of individualised, goal-centered, comprehensive poststroke management for reducing depressive symptoms during the first year poststroke.
Gun Young, 2021 [71]	Open label non-randomised study with non-equivalent control group design N=50 (Control n=23, inv n=20)	Integrated management programme assessing physical function (structured exercise), cognitive function, and depression	Beck Depression inventory at 4 and 8 weeks	Depression, mean (±SD) Pre-test Exp. 26.90±6.63, Control 24.26±6.13 Post-test (4 wk) Exp 19.05±4.49, control 21.00±4.72 Post-test (8 wk) Exp 12.00±2.60, control 17.826±4.76 G 1.62, p=0.211 T 171.35, p<.001 G*T 27.02, p<.001	Significant reduction in depression with intervention
Hjelle, 2019 [41]	Multicentre, prospective, randomised controlled trial Enrolled n=353, randomised n=322 (Control n=156, inv n=166)	Dialogue-based intervention delivered in patient home by nurse/OT (psychological)	Yale-Brown single-item questionnaire at 6 months	Depressed (Yale), n (%) T1: Intervention 29 (17.4), control 43 (27.6) T2: Intervention 37 (22.3), control 36 (23.1) Between group difference: OR 1.248 (95% CI: 0.64-2.41), P=0.507	No difference in depression between groups
Jones et al., 2016 [42]	Cluster randomised controlled trial Control n=30, intervention n=36	Bridges self-management program (SMP) comprising one-to-one rehabilitation sessions and stroke workbook	Hospital anxiety and depression scores at 12 weeks	HADS-A scores: Baseline: control 7.4±5.1, intervention 7.5±5.3 6 weeks: control 7.3±4.9, intervention 7.5±4.9 12 weeks: control 7.4±4.5, intervention 6.6±5.3 HADS-D scores: Baseline: control 7.1±3.4, intervention 6.9±4.2 6 weeks: control 8.2±4.1, intervention7.1±4.5 12 weeks: control 8.1±4.1, intervention 7.1±4.3	No significant differences in QoL or anxiety/depression

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Jung, 2021 [72]	Non-randomised single arm trial with historical control group N=313 (Control n=96, int n=227) Analysis: Control n=96, int n=88	Exercise based intervention tailored to each patient	Mental component summary (MCS) of the Short-Form Survey 36 (SF-36), and Beck Depression Inventory (BDI) at 4 weeks	BDI: T0: Intervention 12.08 ± 10.30, Control 14.45 ± 11.60 T1: Intervention 9.20 ± 9.18, Control 14.73 ± 12.18 P=0.087 (95% CI: −2.21 to 4.31) MCS: T0: Intervention 34.28 ± 9.48, control 35.56 ± 11.84 T1: Intervention 38.53 ± 10.19, control 37.32 ± 11.37 P=0.074 (95% CI: −9.39 to 0.45)	No significant differences in BDI or NCS between groups
Khramov, 2021 [45]	Prospective randomized controlled parallel-group study N=122 (Control n=59, int n=63)	Exercise, massage, PT and OT, social adaptation, goal setting	Beck depression inventory at 6 months	In the comparison group, the Beck Depression Inventory score declined to 15.3 ± 1.8 points at 3 months. The score was significantly lower in the main group (p = 0.008), equalling 12.7 ± 1.6 points. At 6 months, the situation was the same: group 1 scored 15.8 ± 1.4 points, group 2 scored 13.1 ± 0.9 points (p < 0.001)	More pronounced improvement in BDI scores for intervention group
Lee, 2018 [73]	Open-label parallel group study N=31 (Control n=17, int n=14)	Horticulture-based exercise therapy	Geriatric depression scale (GDS 5/15) at 6 weeks	GDS, mean (SD): Pre-test: control 6.5 (3.3), Intervention 7.0 (4.5) Post-test: Control 7.4 (3.4), Intervention 4.6 (3.7); P=0.044	Stroke patients in the HT group showed significantly improved upper limb function, hand force, balance, fall efficacy, activities of daily living, and decreased depression (P < 0.05)
Lin, 2020 [74]	Randomised controlled trial Control n=107, int n=38	Supervised virtual reality training in addition to early rehabilitation exercise	HADS at baseline and day of discharge (7-21 days)	Depression: Baseline: Int 12.1 ± 2.5, control 10.3 ± 4.8; t=5.13, p=0.025 After: Int 9.3 ± 3.2, control 10.0 ± 4.5; t=0.78, p<0.001	Significantly decreased anxiety and depression scores with intervention
Liu et al., 2014 [15]	Multi centre randomized controlled trial Control n=122, intervention n=121	Early intervention: Standard care but at 48 hours following ICH onset.	Anxiety (Zung's self rating anxiety scale)	Zung's self rating anxiety scale: 3 months: control 51.8 (5.8), intervention 51.8 (4.9), mean difference = 0 6 months: control 55.2 (9.3), intervention 48.9 (4.8), mean difference -6.4	Commencement of rehabilitation within 48 hours of ICH significantly reduced hospital length of stay and improved long-term survival and morbidity outcomes when compared with standard practices
Lo et al., 2023 [75]	Randomised controlled trial Control n=169, intervention n=166	Virtual multidisciplinary stroke clinic including monthly follow-up calls and educational videos	Primary: self-efficacy Secondary: depression (GDS)	Depression level (GDS): Baseline (T0): control 8.4 (6.9), intervention 10.2 (6.7)	The intervention reduced depression but not significantly

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				3 months (T1): control 7.1 (6.7), intervention 8.2 (6.9) 6 months (T2): control 7.8 (7.6), intervention 7.3 (7.5), effect size 0.36 (95% CI: 0.13-0.60)	
MacKay-Lyons et al., 2022 (PREVENT) [76]	Three-site, single-blinded, randomized controlled trial Control n=90, intervention n=94	Participants randomized to the PREVENT group engaged in a multi-modal, case-managed program of exercise and education.	Anxiety and depression (HADS)	HADS-A 0-21: Baseline: PREVENT 5.2±4.1, control 5.5±4.0 Post-treatment: PREVENT 5.1±4.1, control 4.4±3.8 6 months: PREVENT 4.6±3.8, control 4.5±3.9 12 months: PREVENT 3.9±3.8, control 4.4±3.6 Change from baseline between groups: -.9 (-2.1, 0,3) HADS-D 0-21: Baseline: PREVENT 3.4±2.8, control 3.5±3.2 Post-treatment: PREVENT 3.1±2.9, control 3.4±3.1 6 months: PREVENT 2.9±2.6, control 3.3±2.9 12 months: PREVENT 2.3±2.2, control 3.0±2.6 Change from baseline between groups: -.2 (-1.1, .7)	Significant between-group differences at post-intervention favored PREVENT group over UC: DBPrest (mean difference [MD]: -3.2 mmHg, 95% confidence interval [CI]: -6.3, -.2, P = .04) and LDL-C (MD: -.31 mmol/L, 95% CI: -.42, -.20, P = .02). Trends of improvement in PREVENT group were noted in several variables between baseline and 6-month follow-up but not sustained at 12-month follow-up. Impact of PREVENT on vascular risk factor reduction was more modest than anticipated, possibly because several outcome variables approximated normative values at baseline and training intensity may have been sub-optimal.
Minshall, 2020 [50]	Randomised controlled trial N=458 (Control: stroke patients n=39, carers n=40. 12-month assessment patients n=25, carers n=23 Int: stroke patients n=50, carers n=44. 12-month assessment patients n=27, carers n=18)	Program of personalized psychosocial support – Stroke Care Optimal Health Program (SCOHP) comprising education, self-management and reflective exercises	HADS at 3, 6 and 12 months	HADS, mean (SD) Depressive symptoms Stroke survivor Baseline: Int 6.31 (4.20), control 6.40 (5.42); p=0.93 3 months: Int 6.19 (4.44), control 6.88 (5.09); p=0.59 6 months: Int 6.71 (3.85), control 6.40 (5.38); p=0.80 12 months: Int 6.57 (5.07), control 6.72 (5.51); p=0.91 Stroke carer: Baseline: Int 5.14 (3.47), control 5.31 (4.27); p=0.86 3 months: Int 4.20 (2.64), control 6.10 (5.35); p=0.16	No significant differences between groups for QoL

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				6 months: Int 5.27 (3.80), control 5.52 (5.25); p=0.85 12 months: Int 5.33 (3.92), control 5.77 (5.01); p=0.76 Anxiety symptoms Stroke survivor Baseline: Int 7.33 (3.78), control 6.83 (4.55); p=0.62 3 months: Int 6.64 (3.58), control 7.00 (4.34); p=0.73 6 months: Int 7.35 (3.28), control 6.44 (5.05); p=0.41 12 months: Int 6.53 (3.72), control 6.96 (5.15); p=0.73 Stroke carer: Baseline: Int 6.97 (4.14), control 6.86 (4.32); p=0.91 3 months: Int 6.10 (3.38), control 6.90 (4.05); p=0.52 6 months: Int 6.22 (3.82), control 6.47 (5.20); p=0.85 12 months: Int 6.27 (3.35), control 7.54 (5.90); p=0.42	
Rafsten, 2019 [77]	Randomised controlled trial with blinded assessors N=140 (Control n=71, int n=69)	Very early supported discharge comprising person-centred goal setting for achievement of identified aims (pathway)	HADS-A at 3 and 12 months post-stroke	No significant differences were found between the groups regarding anxiety at three or 12 months post-stroke (p = 0.811)	No significant differences between groups
Reeves, 2019 [27]	Open-label (unblinded) 3-group parallel-design clinical trial N=320 (Group 1 (UC): Global-10 n=77, PAM n=76, Group 2 (SWCM) Global-10 n=82, PAM n=79, Group 3 (SWCM + MISTT website) Global-10 n=81, PAM n=78) UC, usual care; MISTT, Michigan stroke transitions trial; PAM, pain activation measure; SWCM, social worker–led case management	Home-based social worker–led case management (SWCM) program with or without a website, comprising biopsychosocial assessment followed by development of a personalised plan to address unmet needs (pathway, psychological)	PHQ-9 at 7 and 90 days	PHQ-9 (depression; n=378 observations)*– difference in differences (D-in-D) analysis; test of group × time interaction: P=0.97 Neuro-QOL anxiety (n=351 observations)* D-in-D analysis; test of group × time interaction: P=0.49 *Number of available observations differ between outcomes due to missing data	No differences in depression or anxiety
Rodgers, 2019; Shaw, 2020 [52, 53]	Parallel-group observer-blind multicenter individually randomized controlled trial N=573 (Control n=231, int n=219)	Early supported discharge reviews (EXTRAS) including mobility, self-care, mood (psychological), cognitive function (pathway)	HADS at 1 and 2 years	Adjusted Difference in means EXTRAS Minus Usual Care Mean (95% CI) Anxiety 12 months: −0.7 (−1.3 to 0.0) Anxiety 24 months: −0.6 (−1.4 to 0.1) Depression 12 months: −0.7 (−1.5 to 0.0) Depression 24 months: −0.7 (−1.4 to 0.0)	The mean intervention group Hospital Anxiety and Depression Scale scores were not significantly different at 12 and 24 months.
Saal et al., 2015 [21]	Randomised controlled clinical trial Control n=111, intervention n=119	Post-discharge support including follow-up call and visit, education and training sessions	Depression (GDS) at 12 months	GDS: Intervention: Baseline - 2.7 (2.2); 12 month - 3.2 (3.2), Control: baseline - 3.6 (3.3); 12 month - 3.6 (3.9) Mean difference (95% CI) 0.4 (-0.4; 1.1)	No significant differences were observed between the intervention and

Study details	Design/Patients	Intervention	Outcome	Results	Comments
					control groups in depression and somatisation.
Teuschl et al., 2017 [78]	Prospective, Randomized, Open-Label, Blinded Endpoint multicenter, two-arm parallel group clinical trial N=202 (Control n=87, int n=80)	BP measurement, lifestyle advice, exercise, cognitive training on a regular basis	Centre for Epidemiologic Studies Depression Scale (CES-D) at 12 and 24 months	Lifestyle summary score (LSS) and laboratory supported lifestyle score (LLSS) changes for CES-D at 12 and 24 months: LSS 12 months: coefficient 0.02, SE 0.01, p=0.015 24 Months: 0.02, SE 0.01, p=0.104 LLSS 12 months: coefficient 0.05, SE 0.01, p=0.002 24 months: coefficient 0.02, SE 0.01, p=0.09	Depression was significantly improved in the intervention group at 12 months but not at 24 months
Wong and Yeung 2015 [57]	Randomised controlled trial Control n=54, intervention n=54	The intervention group received the transitional care program (TCP) which was commenced before discharge and lasted for 4 weeks after discharge. The TCP had 3 components 1) holistic care delivered by holistic care managers (HCMS), 2) transitional care track and 3) holistic care managers.	QoL (SF-36), depressive symptoms (CES-D), readmission	CES-D-HK (median [10^{th}-90^{th} percentile]): Total after 4 weeks: Control 4 (1.5–8), intervention 2 (0–5), p<0.001 Total after 8 weeks: Control 4 (0–7), intervention 2 (0–4), p<0.001	The TCP improved QoL and reduced depression.
Yu et al., 2019 [79]	Randomised controlled trial N=242 (Control n=121, int n=121)	Intensive patient care program (IPCP) on cognitive impairment, anxiety, depression including comprehensive psychoeducation and psychonursing, cognitive rehabilitation training and mobile communication application (psychological, mhealth)	Hospital Anxiety and Depression Scale (HADS) anxiety (HADS-A) score, and HADS depression (HADS-D) score at 3, 6 and 12 months	HADS-A score change (M12-M0): control -0.4±1.6, int 0.4±1.5 (P<0.001), anxiety rate M0: control 24.0%, int 24.8% (P=0.881), M12: control 30.6%, int 17.4% (P=0.016) HADS-D score change (M12-M0): control -0.02±1.7, int -1.3±2.2 (P<0.001), depression rate M0: control 39.7%, int 43.8% (P=0.515), M12: control 44.6%, int 31.4% (P=0.034)	Proportion of patients with anxiety and depression was significantly lower at M12 with intervention compared with control. Changes in HADS-A and HADS-D scores were also significant in favour of intervention (both P<0.001)
Zhang et al., 2019 [80]	Randomised controlled trial N=196 (Control n=98, int n=98)	Intensive caregiver education program (ICEP) comprising intensive individualized education for patients and caregivers and psychological nursing for caregivers delivered by nurses in 1:1 sessions, caregivers received repeat sessions every 2 weeks	HADS-A, HADS-D, Zung's Self-rating Anxiety Scale (SAS), and Zung's Self-rating Depression Scale (SDS) at 3, 6 and 12 months	HADS-A score: change M12-M0 control 0.6±1.5, int -0.3±2.0 (P<0.001), anxiety M12: control 27.6%, int 29.6% (P=0.752) SAS score: change M12-M0 control 2.3±7.2, int -3.6±9.6 (P<0.001), anxiety M12: control 24.5%, int 12.2% (P=0.027) HADS-D score: change M12-M0 control 0.4±1.6, int -0.7±2.1 (P<0.001), depression rate M12: control 31.6%, int 30.6% (P=0.877)	Anxiety score change (M12–M0), anxiety score at M12, and anxiety rate at M12 were decreased in the ICEP group compared with the Control group. Depression score change (M12–M0), depression score at M12, and depression rate at M12 were lower in the ICEP

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				SDS score: change M12-M0 control 2.5±8.2, int -2.3±10.1 (P<0.001), depression rate M12: control 38.8%, int 23.5% (P=0.021)	group compared with the Control group. Further subgroup analysis based on baseline features also provided similar results.

Lifestyle and risk factors

Meta-analysis was conducted on lifestyle and risk factors including systolic blood pressure (8 studies, n=4,477), smoking cessation (3 studies, n=1,346), total cholesterol (4 studies, n=993) LDL-cholesterol (5 studies, n=3,318) and BMI (4 studies, n=738). Overall, integrated care was associated with a significant benefit compared with control (Table S7) SMD -0.17, 95% CI: -0.25, -0.09, p<0.0001, I^2 = 63%, Figure S7) and there were significant reductions in SBP and LDL-cholesterol (p=0.009 and p=0.1, respectively), but not for total cholesterol (p=0.29) or BMI (p=0.35). Four studies evaluated rates of smoking cessation however there was no difference between the proportion of patients stopping smoking between groups (RR 1.10, 95% CI: 0.93-1.31, p=0.27, I^2 = 91%, Figure S8).

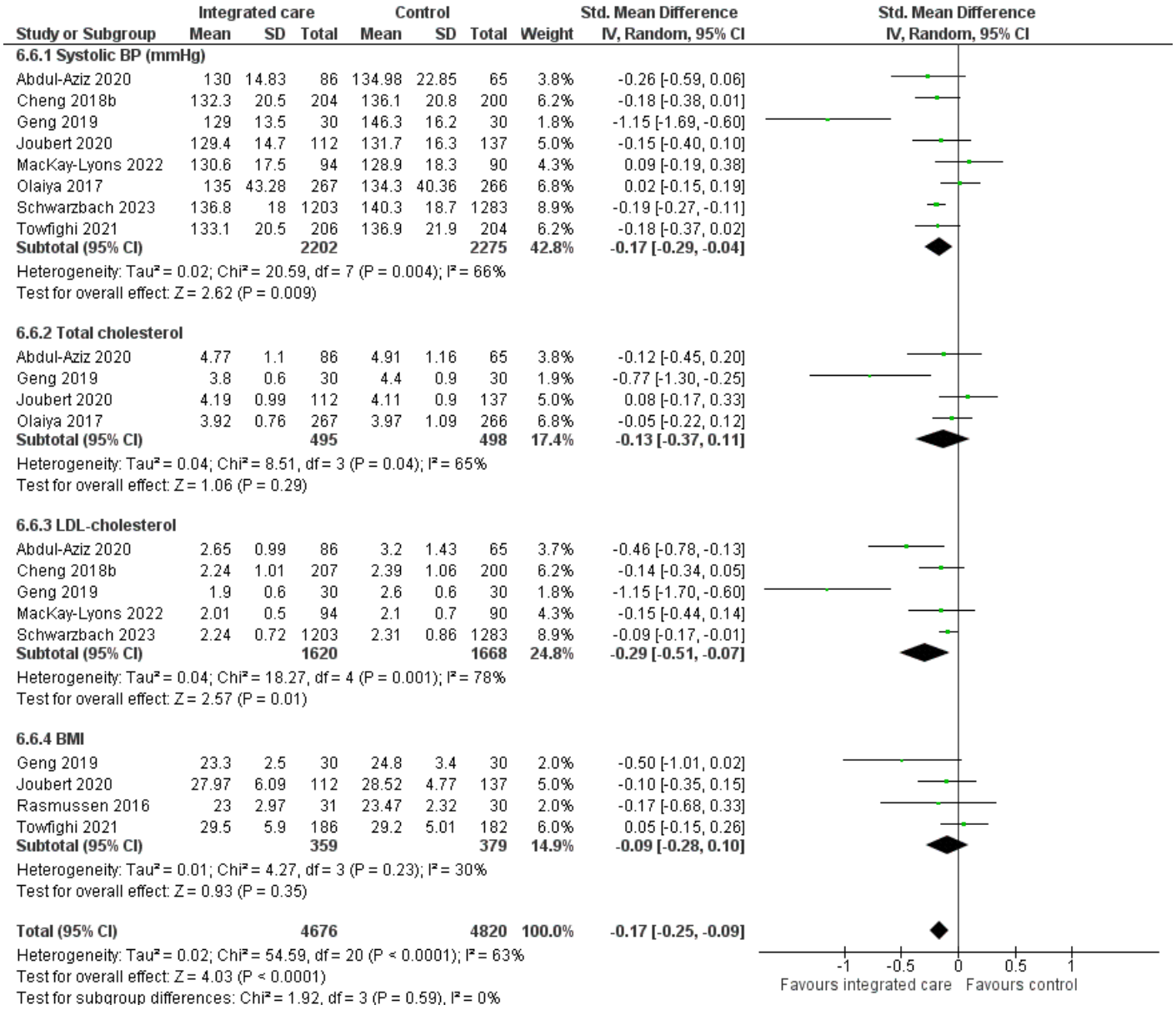


Figure S7: Comparison of integrated care with control for cardiovascular risk factors

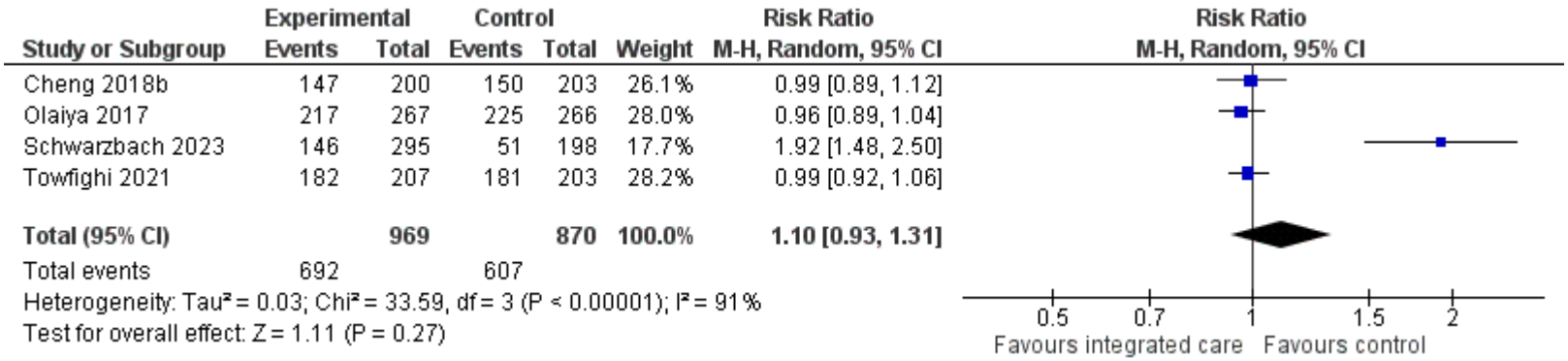


Figure S8: Comparison of integrated care with control for smoking cessation

Table S18 Analysis of lifestyle and/or cardiovascular risk factors

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Secondary: myocardial infarction at 90 days	Events: Intervention 11/1556 (0.7%), control 12/1540 (0.8%)	No difference in risk of recurrent cardiovascular disease
Cheng et al., 2018 [25]	Randomised controlled trial N=407 (Control n=200, int n=207)	Medication modification relevant to stroke risk factors, tobacco cessation, physical activity, depression, and medication adherence	Change in SBP, LDL cholesterol, Physical activity, smoking cessation, 10-year risk of CV events	Differences in Changes From Baseline Between Control and Intervention Arms* (95% CI): SBP −3.6 mm Hg (−9.3 to 2.2) p=0.55 LDL mg/dL, mean (SD) −10.2 mg/dL (−21.1 to −0.6) p=0.03 Smoking cessation 0.6 OR (0.3 to 1.3), p=0.58 Physical activity assessed as exercise ≥3 d per wk, n (%):0.9 OR (0.5 to 1.8), p=0.84 10 year risk of CV events: %, mean (SD) -0.8 (−3.1 to 1.6), p=0.98 *Repeated-measures mixed-effect models included baseline, 3-mo, and 12-mo values.	Among secondary outcomes, the only significant difference was that persons in the intervention arm were more likely to lower their low-density lipoprotein <100 md/dL (2.0 odds ratio; 95% CI, 1.1–3.5). All other between group differences were not significant Depression was not reported

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Geng, 2019 [39]	Randomised controlled trial N=101 (Control n=30, intervention n=30)	Physical function, emotional function, lifestyle, medication adherence	Systolic blood pressure, BMI, cholesterol, physical activity, smoking and alcohol consumption at 6 months	Outcomes 6 months after discharge (mean [SD]) SBP (mm Hg): Intervention 129.0 (13.5), control 164.3 (16.2); P<0.001 BMI (kg/m2): Intervention 23.3 (2.5), 24.8 (3.4); P<0.001 Total cholesterol (mmol/l): Intervention 3.8 (0.6), control 4.4 (0.9); P<0.001 Triglycerides (mmol/l): Intervention 1.1 (0.60, control 1.2 (0.5); P=0.007 LDL (mmol/l): Intervention 1.9 (0.6), control 2.6 (0.6); P<0.001 HDL (mmol/l): Intervention 1.4 (0.3), control 1.3 (0.4); P=0.227 Physical activity: Intervention: 19.5 (3.7), control 15.9 (4.2); P<0.001 Smoking: Intervention 3.3 (0.7), control 2.9 (0.7), P=0.009 Alcohol consumption: Intervention 3.6 (0.6), control 2.8 (0.7), P=0.035	Significant differences in SBP, BMI, cholesterol in favour of intervention but smoking and alcohol use were significantly lower in the control group
Greger, 2021 [81]	Single-centre retrospective chart review Control n=4516, inv n=1274 Matched groups: Control n=171, inv n=171	Pharmacist led medication review, counselling, risk factor management (lifestyle)	N (%) of patients counselled on medication adherence, added fish oil or vitamin C	Counselling on medication adherence: Platelet function test (PFT) group: 24 (14%), control 5 (3%); P=0.008 Added fish oil or vitamin C: PFT group 39 (23%), control 5 (3%); P=0.0001	Significantly improved medication adherence and added fish oil and vitamin C with intervention group
Joubert et al., 2020 (ICARUSS) [82]	Double blind randomized controlled trial Control n=137, intervention n=112	ICARUSS (Integrated Care for the Reduction of Secondary Stroke) intervention involving personalizing stroke risk factors for the stroke survivor and ongoing support from a stroke specialist and primary care physician vs usual care.	Risk factors (blood pressure, cholesterol, BMI, alcohol)	At the 12-month evaluation, there was a significant decrease in systolic blood pressure (129.4 [14.7]) from baseline (134.6 [16.7]) in the intervention group of 5.2mmHg (p<0.01), control 133.7 (17.0) at baseline to 131.7 (16.3) at 12 months, p=0.29. Fasting total cholesterol (mmol/l): Intervention: Baseline 5.00 (1.17), 12 month 4.19 (0.99) Control: Baseline 4.36 (1.14), 12 month 4.11 (0.90) BMI: Intervention: Baseline 27.78 (5.38), 12 month 27.97 (6.09), p=0.50 Control: Baseline 27.45 (4.94), 12 month 28.52 (4.77), p=0.02	In stroke survivors, the ICARUSS model was superior to usual care with respect to best-practice recommendations for traditional risk factors as well as behavioral and functional outcomes.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				Alcohol (no of drinks per week) Intervention: Baseline 8.4 (16.5), 12 month 4.8 (10.1), p=0.04 Control: Baseline 6.0 (10.2), 12 month 4.6 (7.2), p=0.26	
MacKay-Lyons et al., 2022 (PREVENT) [76]	Three-site, single-blinded, randomized controlled trial Control n=90, intervention n=94	Participants randomized to the PREVENT group engaged in a multi-modal, case-managed program of exercise and education.	CV risk factors including systolic BP, cholesterol, anxiety and depression (HADS)	Resting SBP mmHg: Baseline: PREVENT 131.8±15.7, Control 131.7±18.4 Post-treatment: PREVENT 125.9±16.7, Control 129.3±18.1 6-months: PREVENT 126.8±15.1, control 128.2±16.8 12 months: PREVENT 130.6±17.5, control 128.9±18.3 Change from baseline between groups -3.5 (-8.8, 1.8) Resting DBP mmHg Baseline: PREVENT 76.6±11.1, control 74.9±9.8 Post-treatment: PREVENT 72.2±12.0, control 73.7±14.6 6 months: PREVENT 71.8±8.1, control 73.8±9.0 12 months: PREVENT 73.0±9.7, control 72.5±9.9 Change from baseline between groups -3.2 (-6.3, -.2), p<0.05 LDL-C Mmol/L: Baseline: PREVENT 2.24±0.8, control 2.24±0.9 Post-treatment: PREVENT 1.94±0.8, control 2.23±0.8 6 months: PREVENT 1.96±0.6, control 2.21±0.8 12 months: PREVENT 2.01±0.5, control 2.10±0.7 Change from baseline between groups -.31 (-.42, -.20), p<0.05	Significant between-group differences at post-intervention favored PREVENT group over UC: DBPrest (mean difference [MD]: -3.2 mmHg, 95% confidence interval [CI]: -6.3, -.2, P = .04) and LDL-C (MD: -.31 mmol/L, 95% CI: -.42, -.20, P = .02). Trends of improvement in PREVENT group were noted in several variables between baseline and 6-month follow-up but not sustained at 12-month follow-up. Impact of PREVENT on vascular risk factor reduction was more modest than anticipated, possibly because several outcome variables approximated normative values at baseline and training intensity may have been sub-optimal.
Olaiya et al., 2017 [83]	Pragmatic multicentre, cluster-randomised, controlled trial, with blinded assessment of outcomes and intention-to-treat analysis N=2516 (Control n=266, int n=267)	Individualised management programme comprising a chronic disease management (CDM) plan and education	Framingham risk score (modified for secondary outcomes). FRS includes cholesterol levels, systolic BP, use of antihypertensives, smoking status and uncontrolled diabetes	Between group differences for primary outcome variables (95% CI): Systolic BP (mmHg) 0.05 (- 0.8, 1.6) HbA1c (%)0.08 (-0.3, 0.5) Total cholesterol (mmol/l) -0.008 (-0.1, 0.1) HDL cholesterol (mmol/l) 0.02 (-0.02, 0.06) Unadjusted and adjusted analyses of the effect of intervention on secondary outcomes, effect estimate (95% CI); p-value	No significant between group difference for any outcome

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				Systolic BP (per mmHg): unadjusted 1.1 (0.1, 22.1); p=0.974, adjusted 2.1 (0.1, 41.9); p=0.620 Current smoking Unadjusted 2.2 (1.1, 4.5), p=0.031, adjusted 1.9 (0.9, 4.0), p=0.078 Current risky drinking Unadjusted 1.2 (0.5, 2.7); p=0.670, adjusted 1.4 (0.6, 3.3); p=0.440 Healthy eating ≥5 servings of vegetables daily Unadjusted 0.6 (0.3, 1.2); p=0.171, adjusted 0.6 (0.3, 1.2); p=0.138 ≥2 servings of fruit daily Unadjusted 0.9 (0.6, 1.2); p=0.396, adjusted 1.0 (0.7, 1.4); p=0.843 <5 g salt daily Unadjusted 0.5 (0.2, 1.3); p=0.169, adjusted 0.6 (0.2, 1.4); p=0.216 Physically active Unadjusted 1.1 (0.6, 2.0); p=0.671, adjusted 1.1 (0.6, 2.0); p=0.719	
Rasmussen et al., 2016 [84]	Interventional, randomised, safety/efficacy open-label trial Control n=30, intervention n=31	Multidisciplinary home-based pathway including exercise and goal setting	Secondary: BMI at 90 days	Body Mass Index (BMI), median (IQR): Intervention 23 (21–25); Control: 24 (22–25) Body Mass Index (BMI) improvement: Intervention: 0 (-0.5–0) Control: −1 (-2–0)	Early home-based rehabilitation reduced disability and increased quality of life. Compared to standard care, home-based stroke rehabilitation was more cost-effective.
Schwartzbach et al., 2023 (SANO) [22]	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	Risk factors at 12 months	Blood pressure (including self-reported by interview) <140/90 mm Hg: Control: 657/936 (70·2%); Intervention: 809/1103 (73·3%); OR 1·18 (95% CI 0·79–1·76), aOR 1·08 (95% CI 0·73–1·59) Blood pressure (physical examination only) <140/90 mm Hg† control: 468/679 (68·9%); intervention: 709/944 (75·1%); OR 1·34 (95% CI 0·86–2·09); aOR 1·34 (95% CI 0·88–2·04) Diabetes control‡ HbA1c ≤7% (53 mmol/mol) Control: 123/218 (56·4%); Intervention: 144/218 (66·1%); OR: 1·10 (95% CI 1·02–2·21); aOR: 1·45 (95% CI 0·94–2·26) Adherence to antithrombotic therapy targets§ Control: 1003 (88·3); Intervention: 1029 (89·4); OR 1·10 (95% CI 0·78–1·54); aOR 1·02 (95% CI 0·72–1·47)	This study demonstrated that the SANO programme had positive effects on the control of some cardiovascular risk factors in patients with stroke, but this did not translate into a reduction in the rate of major cardiovascular events 1 year after the first ischaemic stroke. Since a 1-year follow-up period might be too short to demonstrate a positive effect on recurrent cardiovascular events, longer-term effects need to be considered.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				Hyperlipidaemia control¶ Achievement of LDL cholesterol targets: Control: 444/729 (60·9%); Intervention: 526/782 (67·3%), OR 1·36 (95% CI 1·00–1·85); aOR: 1·65 (95% CI 1·22–2·22) Smoking - Quit smoking - Control: 51/198 (25·8%); Intervention: 146/295 (49·5%); OR 3·13 (95% CI 1·72–5·70); aOR: 2·82 (95% CI 1·58–5·04)	
Teuschl et al., 2017 [78]	Prospective, Randomized, Open-Label, Blinded Endpoint multicenter, two-arm parallel group clinical trial N=202 (Control n=87, int n=80)	BP measurement, lifestyle advice, exercise, cognitive training on a regular basis	Healthy lifestyle (reduced fat milk and spreads, eating fish, alcohol intake, physical activity, BMI, smoking cessation, systolic BP, Non-HDL cholesterol and fasting blood glucose) at 12 and 24 months	Changes in healthy lifestyle habits, physiological parameters, and low-risk summary scores from baseline to 12 months, and to 24 months in the intervention and the control group Reduced fat milk 12 months: intervention +12.5% (p=0.031), control +5.8% (p=0.383), between group p=0.548 24 Months: intervention +12.5% (p=0.031), control -4.6% (p=0.503), between group p=0.062 Reduced fat spreads 12 months: intervention +16.3% (p=0.007), control +4.6% (p=0.481), between group p=0.273 24 Months: intervention +11.3% (p=0.108), control -2.3% (p=0.832), between group p=0.206 Fish ≥1/week 12 months: intervention +12.5% (p=0.021), control -4.6% (p=0.481), between group p=0.043 24 Months: intervention +10.0% (p=0.134), control +2.3% (p=0.832), between group p=0.616 Alcohol 1-6 times/week 12 months: intervention +7.5% (p=0.238), control -3.4% (p=0.648), between group p=0.323 24 Months: intervention 0.0% (p=1.000), control +5.8% (p=0.383), between group p=0.628 Physical activity 12 months: intervention +2.6% (p=0.754), control +1.1% (p=1.000), between group p=0.862	During the first 12 months, adherence to healthy lifestyle and adequately controlled physiological parameters (measured by summary scores) improved significantly in the intervention group compared to controls ($p < 0.01$). The consumption of reduced-fat milk ($p = 0.031$), reduced-fat spreads ($p = 0.007$), and fish ($p = 0.021$) increased in the intervention group from baseline to 12 months but not in controls. After 24 months, the group difference was significant for the lifestyle summary score but no longer for the combined laboratory lifestyle score. The number of smokers decreased significantly in the control but not in the intervention group.

Study details	Design/Patients	Intervention	Outcome	Results	Comments
				24 Months: intervention +1.3% (p=1.000), control -4.60.0% (p=1.000), between group p=0.862 Not currently smoking 12 months: intervention +2.5% (p=0.687), control +10.3% (p=0.004), between group p=0.118 24 Months: intervention +1.3% (p=1.000), control +9.2% (p=0.021), between group p=0.254 BMI 12 months: intervention -0.8 ± 2.0 (p=0.001), control -0.1 ± 2.1 (p=0.922), between group p=0.006 24 Months: intervention -0.8 ± 2.7 (p=0.007), control -0.2 ± 2.4 (p=0.938), between group p=0.036 Systolic BP (mm Hg) 12 months: intervention -1.6 ± 20.3 (p=0.529), control 2.4 ± 21.5 (p=0.494), between group p=0.397 24 Months: intervention -1.7 ± 20.1 (p=0.517), control -0.2 ± 22.9 (p=0.973), between group p=0.632 Non-HDL-C (mmol/l) 12 months: intervention -0.96 ± 1.16 (p<0.001), control -0.76 ± 1.64 (p<0.001), between group p=0.269 24 Months: intervention -0.97 ± 1.20 (p<0.001), control -0.88 ± 1.53 (p<0.001), between group p=0.732 Fasting blood glucose (mmol/l) 12 months: intervention -0.21 ± 1.51 (p=0.244), control -0.28 ± 2.01 (p=0.449), between group p=0.821 24 Months: intervention 0.01 ± 1.93 (p=0.611), control -0.06 ± 1.99 (p=0.600), between group p=0.499	
Towfighi, 2021 (SUCCEED) [85]	Randomised controlled trial N=487 (Control n=246, int n=241)	Advanced practice physician (APC) and community health worker (CHW) visits, culturally and linguistically tailored educational materials; vascular risk factor goal tools; and Chronic Disease Self-	Systolic BP: mm Hg; Non-HDL, mg/dL; HbA1c, %; Log CRP, mg/dL, physical activity, IPAQ (International Physical Activity Questionnaire), MET; servings of fruit/veg, n (%),	Differences in changes from baseline between usual care and intervention (95% CI): SBP ≤130 mm Hg −3.3 (−14.9 to 8.8); p=0.57 SBP, mm Hg −1.7 (−6.4 to 2.9); p=0.46 Non-HDL, mg/dL −3.3 (−14.9 to 8.3); p=0.57 HbA1c,% −0.2 (−0.5 to 0.2); p=0.36 Log CRP, mg/dL −0.4 (−0.7 to −0.1); p=0.003	Mean (SD) systolic BP improved from 143 (17) mm Hg at baseline to 133 (20) mm Hg at 12 months in the intervention group and from 146 (19) mm Hg at baseline to 137 (22) mm Hg at 12

Study details	Design/Patients	Intervention	Outcome	Results	Comments
		Management Program (CDSMP) workshops, medication adherence, self-management (pathway)	reduce/monitoring salt intake, n (%), not smoking and using antithrombotics, n (%) at 12 months	BMI 0.2 (−0.4 to 0.9); p=0.53 Physical activity, IPAQ, MET min/wk, median (IQR) 20 (−400 to 300); p=0.93 ≥5 daily servings of fruit/vegetables, No. (%)0.7 (−7.7 to 8.7); p=0.84 Reducing or monitoring salt intake, No. (%) 15.4 (4.4 to 26.0); p=0.004 Not smoking, No. (%)1.6 (−4.8 to 8); p=0.66 Using antithrombotic medication, No. (%)−0.6 (−6.7 to 5.3); p=0.80	months in the usual care group, with no significant differences in the change between groups. Compared with the control group, participants in the intervention group had greater improvements in self-reported salt intake (difference, 15.4 [95% CI, 4.4 to 26.0]; P = .004) and serum CRP level (difference in log CRP, −0.4 [95% CI, −0.7 to −0.1] mg/dL; P = .003); there were no differences in other secondary outcomes. Although 216 participants (89.6%) in the intervention group received some of the 3 core components, only 35 participants (14.5%) received the intended full dose.

Adherence to intervention

Three (3) randomised studies included adherence to intervention as an outcome in meta-analysis. Interventions included triple antiplatelet therapy (2), combined exercise and cognitive training (87), individual transitional care models based at home (61), and self-management sessions and a stroke workbook (41). More participants were adherent to integrated care than control but this difference was not statistically significant (RR 1.27 [95% CI: 0.70 to 2.29], I^2 = 99%, P = 0.43, Figure S9).

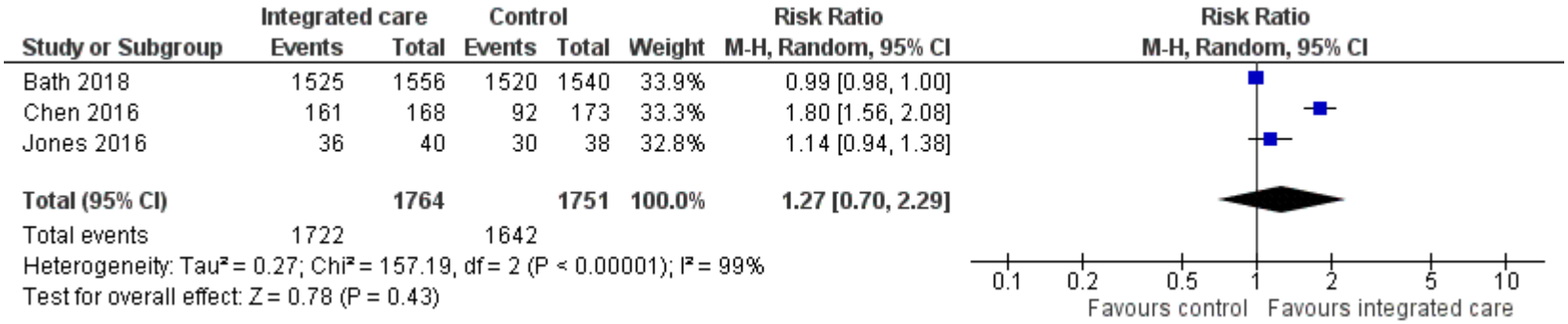


Figure S9: Comparison of integrated care with control for adherence to intervention

Table S19 Analysis of adherence to intervention

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Ellis-Hill, 2019 [67]	Two-centre, 24-month, parallel-arm RCT with qualitative and economic components N=56 (Control n=25, intervention n=22)	Arts and health practitioner-led group sessions (psychosocial and wellbeing)	Follow-up data and study completion rates in n (%) of patients	Study retention was good (with follow-up data available for 84% of participants) and high data completion rates (>80% for the candidate primary outcome measures).	High adherence rates to intervention
Greger, 2021 [81]	Single-centre retrospective chart review Control n=4516, inv n=1274 Matched groups: Control n=171, inv n=171	Pharmacist led medication review, counselling, risk factor management (lifestyle)	N (%) of patients counselled on medication adherence, added fish oil or vitamin C	Counselling on medication adherence: Platelet function test (PFT) group: 24 (14%), control 5 (3%); P=0.008 Added fish oil or vitamin C: PFT group 39 (23%), control 5 (3%); P=0.0001	Significantly improved medication adherence and added fish oil and vitamin C with intervention group

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Koch, 2020 [86]	Prospective randomised study N=131 (control n=45, int n=86)	Combined exercise and cognitive training (psychological)	Number of visits attended per week and any adverse events (AE)	The observed-over-expected visit ratio was significantly higher in the intervention than in the control group (0.74±0.30 versus 0.54±0.38; P=0.003).	Significantly higher adherence Intervention: 69/86 (80%) Control: 25/45 (56%)
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Adherence to intervention over the first 7 days	First treatment: Intervention 1391/1556 (89.4%), control 1193/1540 (77.5%), p<0.001 Any treatment: Intervention 1525/1556 (98.0%), control 1520/1540 (98.7%), p=0.14	Significantly more participants in the TARDIS group were adherent with the first treatment compared with control but at 7 days there was no significant difference in adherence rates.
Chen et al., 2016 [61]	Quasi-experimental controlled study Control n=173, intervention n=168	Individualised transitional care model based at home	Adherence to medication at 1 month	Medication compliance rates: intervention 161 (95.83%) vs. control 92 (53.18%), p = 0.004.	The intervention was associated with significantly higher medication compliance.
Jones et al., 2016 [42]	Cluster randomised controlled trial Control n=30, intervention n=36	Bridges self-management program (SMP) comprising one-to-one rehabilitation sessions and stroke workbook	Adherence to intervention	Thirty-nine participants (98%) completed baseline measures and 36 participants completed week 12 outcome measures (90%) in intervention sites, compared with 35 (92%) completing baseline outcomes and 30 (79%) completing week 12 outcomes measures in control sites.	No significant differences in QoL or anxiety/depression but responsiveness to intervention was shown

Functional status (modified Rankin scale)

Four studies included favourable outcome (defined as mRS≤2). Overall, there was no significant difference in rates of favourable outcome between groups (RR 1.02, 95% CI: 0.98, 1.07, p=0.35, I^2 = 77%, Figure S10).

	Integrated care		Control			Risk Ratio
Study or Subgroup	Events	Total	Events	Total	Weight	M-H, Fixed, 95% CI
Fu 2020	228	259	103	128	9.9%	1.09 [0.99, 1.20]
Langhorne 2017	480	1038	525	1045	37.7%	0.92 [0.84, 1.01]
Pedapati 2021	20	82	12	82	0.9%	1.67 [0.87, 3.18]
Willeit 2020	1150	1413	536	704	51.5%	1.07 [1.02, 1.12]
Total (95% CI)		**2792**		**1959**	**100.0%**	**1.02 [0.98, 1.07]**
Total events	1878		1176			

Heterogeneity: Chi² = 12.88, df = 3 (P = 0.005); I² = 77%
Test for overall effect: Z = 0.94 (P = 0.35)

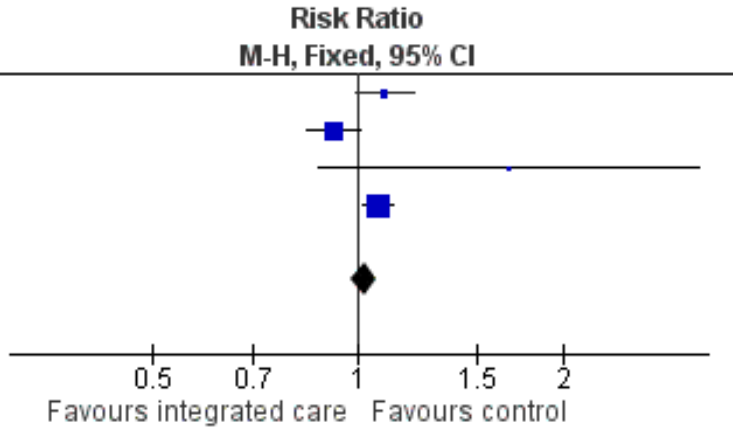


Figure S10: Comparison of integrated care with control for favourable outcome

Two non-randomised studies included disability or death (defined as mRS≥2). Overall, there was a significant difference in rates of disability or death in favour of integrated care (RR 0.85, 95% CI: 0.73, 1.00, p=0.0.04, I^2 = 0%, Figure S11).

	Integrated care		Control			Risk Ratio
Study or Subgroup	Events	Total	Events	Total	Weight	M-H, Random, 95% CI
Dello 2021	127	248	140	232	91.4%	0.85 [0.72, 1.00]
Luengo-Fernandez 2022	22	224	30	281	8.6%	0.92 [0.55, 1.55]
Total (95% CI)		**472**		**513**	**100.0%**	**0.85 [0.73, 1.00]**
Total events	149		170			

Heterogeneity: Tau² = 0.00; Chi² = 0.09, df = 1 (P = 0.76); I² = 0%
Test for overall effect: Z = 2.01 (P = 0.04)

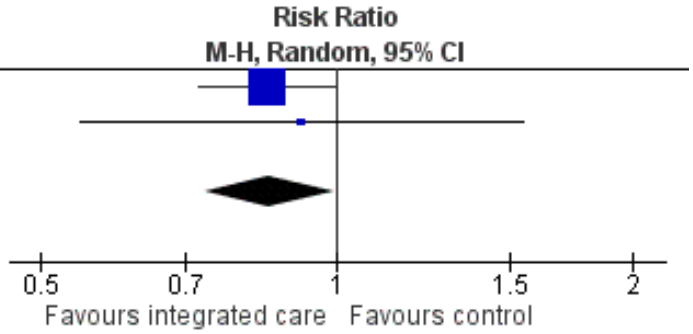


Figure S11: Comparison of integrated care with control for disability or death

Table S20 Analysis of functional status

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Primary: Incidence and severity of any recurrent stroke (ischaemic, haemorrhagic; assessed using the modified Rankin Scale) or TIA within 90 days by blinded telephone follow-up.	mRS at 90 days: Death (mRS score of 6): Intervention 13/1540 (0.7%), control 9/1530 (0.6%) mRS score of 4-5: Intervention 11/1540 (0.7%), control 9/1530 (0.6%) mRS score of 2-3: Intervention 22/1540 (101%), control 23/1530 (1.5%) mRS score of 0-1: Intervention 15/1540 (1.0%), control 18/1530 (1.2%) Median mRS score [IQR]: Intervention 1.0 [1.0, 2.0], control [1.0, 2.0]	No difference in mRS between groups
Bergh, 2023 [3]	Repeated measures analysis (pre-post) from a retrospective cohort of patients registered in the Norwegian Stroke Register (NSR). N = 11009 included in study comparing functional outcome (5388 in 2017 and 5621 in 2019)	Standardised Care Pathway for stroke (SCP) based on National guidelines	Primary: change in mRS at 90 days	mRS at 90 days: mRS score of 0-2: Intervention 4115/5621 (73.2%), control 3959/5388 (73.5%), p=0.77 mRS score of 3-5: Intervention 1504/5621 (26.8%), control 1429/5388 (26.5%)	No significant in change in mRS between the 2 years (OR=1.06, 95%CI 0.86, 1.30).
Bernhardt et al., 2015 (AVERT) [4]	Single-blind randomised controlled trial in 56 acute stroke units in 5 countries (Aus, NZ, Malaysia, Singapore, UK -Eng, Scot, Wales, NI) Control n=1050, intervention n=1054	Very early mobilisation (exercise and movement therapy)	Primary: favourable outcome (mRS) Secondary: Change in mRS, mortality	Favourable outcome: intervention 480 (46%), control 525 (50%) (adjusted OR 0.73 [95% CI: 0.59-0.90]), p=0.004	Significantly fewer participants in the AVERT group had favourable outcome and there was no difference in mortality
Dello et al., 2021 [87]	Single-centre pre- and post-intervention study Control n=238, intervention n=257	Nurse-led management of temperature, glycaemia and swallowing (risk factors)	Mortality and functional status (mRS ≥2) at 90 days	The rates of 90-day death and dependency (mRS ≥2) were lower in the post-intervention period (127/248 [51%]) compared to the pre-intervention period (140/232 [60%]), adjusted OR 0.63, 95% CI: 0.41-0.97.	The intervention in the study was associated with significantly lower death and dependency compared with control
Fu et al, 2020 [14]	Prospective, randomised, open trial of two active and one control interventions with blinded endpoint assessment	One-to-one qualitative assessment of patient views and needs, education and goal setting	mRS 0-2 versus 3-5 at 12 months	Control: 103/128 (80.5%) TC1: 108/126 (85.7) TC2: 120/133 (90.2)	Participants receiving either one or two Take Charge sessions were less likely to be dependent (mRS 3 to 5) at

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	N=400 (Primary analysis: control n=125, T1 n=123, t2 n=133)			TC2 + TC1 vs control: OR 0.55 (95% CI: 0.31 to 0.99), p=0.045	12 months compared to control, (TC1þTC2 12% versus control 19.5%, odds ratio (OR) 0.55, 95% CI 0.31 to 0.99, p=0.045).
He et al., 2023 [40]	Randomized, historically controlled clinical trial Control n=124, intervention n=161	Rapid recovery implementation process to optimise patient recovery post-surgery	Functional status (mRS)	mRS score at discharge: 2.52 (1.89) Control, 3.61 (5.74) intervention, p<0.001 mRS score 3 month after discharge: 2.38 (1.77) (control), 2.01 (1.95) (intervention), p = 0.097	Statistically significant differences in mRS were seen at discharge but not at 3 months.
Langhorne et al. 2017 [46]	Pragmatic, prospective, parallel-group, multicentre, international, RCT with blinded assessment of outcomes and an intention to treat analysis N=2104 (Control n=1050, int n=1054)	Very early mobilisation (within 24h of stroke onset) Exercise	The primary outcome was survival without major disability [modified Rankin scale (mRS) score of 0–2] at 3 months after stroke.	Fewer patients in the VEM group (n = 480, 46%) had a favourable outcome than in the UC group (n = 525, 50%) (adjusted odds ratio 0.73, 95% CI 0.59 to 0.90; p = 0.004).	This VEM protocol was associated with reduced odds of favourable outcome at 3 months cautioning against very early high-dose mobilisation.
Luengo-Fernandez et al., 2022 (EXPRESS) [16]	Prospective population-based before (phase 1: April 2002–September 2004; n=310) versus after (phase 2: October 2004–March 2007; n=281) study EXPRESS: Phase 1 n=310, Phase 2 n=281; Control: Phase 1 n=167, Phase 2 n=224	EXPRESS Phase 1: Clinic referral (1-2 days), brain imaging and ECG, ultrasound/echo, primary care treatment protocol comprising antiplatelet, statin, BP lowering. Phase 2: As Phase 1 but treatment initiated immediately instead of by primary care, high-dose aspirin or clopidogrel, CT scan during clinic. Follow-up 1, 6, 12, 60, and 120 months after the index event in both Phases. Control: standard care (not referred to study clinic)	Mortality, functional status (mRS), recurrent stroke, quality of life (EQ-5D)	Disability (mRS>2), n (%): 1 month: Control Phase 1 47/167 (33), Phase 1 55/310 (18), control Phase 2 58/224 (32), Phase 2 34/281 (13) 6 months: Control Phase 1 47/167 (34), Phase 1 71/310 (24), control Phase 2 50/224 (29), Phase 2 34/281 (13)* 1 year: Control Phase 1 43/167 (33), Phase 1 60/310 (22), Control Phase 2 47/224 (29), Phase 2 36/281 (14)** 5 years: Control Phase 1 27/167 (34), Phase 1 51/310 (25), Control Phase 2 37/224 (32), Phase 2 50/281 (29) 10 years: Control Phase 1 9/167 (21), Phase 1 44/310 (36). Control Phase 2 22/224 (35), Phase 2 30/281 (27) Statistically significant at: *p<0.001 & ** p<0.050 when compared to phase 1	Urgent assessment and treatment of patients with transient ischemic attack or minor stroke resulted in a long-term reduction in recurrent strokes and improved outcomes, with little atrophy of the early benefit over time, representing good value for money even with a 10-year time horizon. A reduction in stroke risk in phase 2 was still evident at 10 years (55/23.3% versus 82/31.6%; hazard ratio=0.68 [95% CI, 0.48–0.95]; P=0.024), as was the impact on risk of disabling or fatal stroke (17/7.7% versus 32/13.1%; hazard ratio=0.54 [0.30–0.97]; P=0.036).
Pedapati et al., 2021 [19]	Prospective single-centre, cluster-randomised, open-	Education and exercise plan tailored to the home needs of patients	Disability, 3-month mortality (secondary)	Twenty patients (27.8%) in the intervention and twelve (18.2%) in the control group attained	A structured educational intervention did not reduce the incidence of hospital-

Study details	Design/Patients	Intervention	Outcome	Results	Comments
	label, blinded endpoint superiority trial N=164 (Int n=82, control n=82)			modified Rankin Scale 0-2 at three months (p=0.12).	acquired complications, mortality, or morbidity.
Rasmussen et al., 2016 [84]	Interventional, randomised, safety/efficacy open-label trial Control n=30, intervention n=31	Multidisciplinary home-based pathway including exercise and goal setting	Primary: mRS at 90 days	mRS: Modified Rankin Scale: Intervention: 2 (2–3); Control: 3 (2–4) Modified Rankin Scale improvement: Intervention: 1 (1–2); Control: 1 (0–1)	Early home-based rehabilitation reduced disability and increased quality of life. Compared to standard care, home-based stroke rehabilitation was more cost-effective.
Sharma et al., 2019 (COMPASS) [28]	COMPASS was a randomized, double-blind, double-dummy trial Prior stroke: rivaroxaban + aspirin n=351, rivaroxaban alone n=346, aspirin alone n=335. Total n=1032	Participants had stable coronary artery or peripheral artery disease and were randomly assigned to receive aspirin 100 mg once daily (n=9126), rivaroxaban 5 mg twice daily (n=9117), or rivaroxaban 2.5 mg twice daily plus aspirin (n=9152).	Functional status (mRS) at 23 months	mRS at 7 days or discharge R+A (n=83) 2.4±2.0, R (n=115) 2.6±2.1, A (n=141) 2.2±1. R+A vs A mean difference (95% CI) 0.2 (–0.4 to 0.7), p=0.66 R vs A mean difference (95% CI) 0.3 (–0.1 to 0.8), p=0.29	In summary, low-dose rivaroxaban plus aspirin is an important new option for efficacious antithrombotic therapy for primary and especially secondary prevention of stroke in patients with atherosclerosis. The absolute risk reduction for secondary prevention is substantial and makes a compelling case favoring the use of 2.5 mg rivaroxaban twice daily plus aspirin in these patients.
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	Functional status (mRS) at 12 months	mRS ≤2: Intervention 1150/1413 (81.4%), control 536/704 (76.1%), HR 1.07 (1.02, 1.12), P=0.006	The pragmatic and easily implementable STROKE-CARD care programme reduced cardiovascular risk and improved health-related quality of life and functional outcome in patients with acute ischaemic stroke or TIA

Recurrent risk of cardiovascular disease

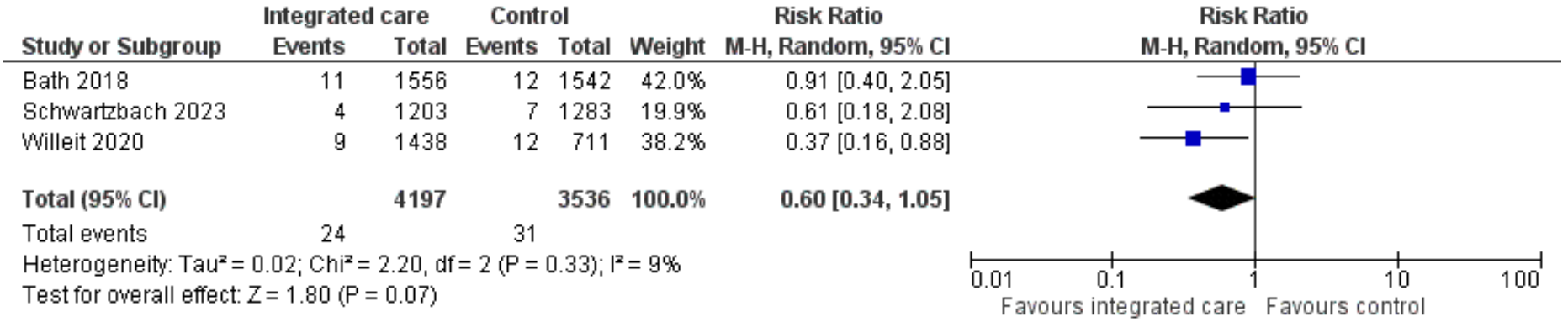


Figure S11: Comparison of integrated care with control for myocardial infarction

A meta-analysis of 3 studies (n=4,197) showed no significant difference in the recurrent risak of cardiovascular disease between groups (RR, 0.60, 95% CU: 0.34, 1.05, P=0.07, 1^2 = 9%, Figure S11).

A meta-analysis of 3 studies (n=7,317) showed no significant difference in the rates of vascular death between groups (RR, 0.76, 95% CI: 0.35, 1.63, P=0.48, I^2 = 75%, Figure S12).

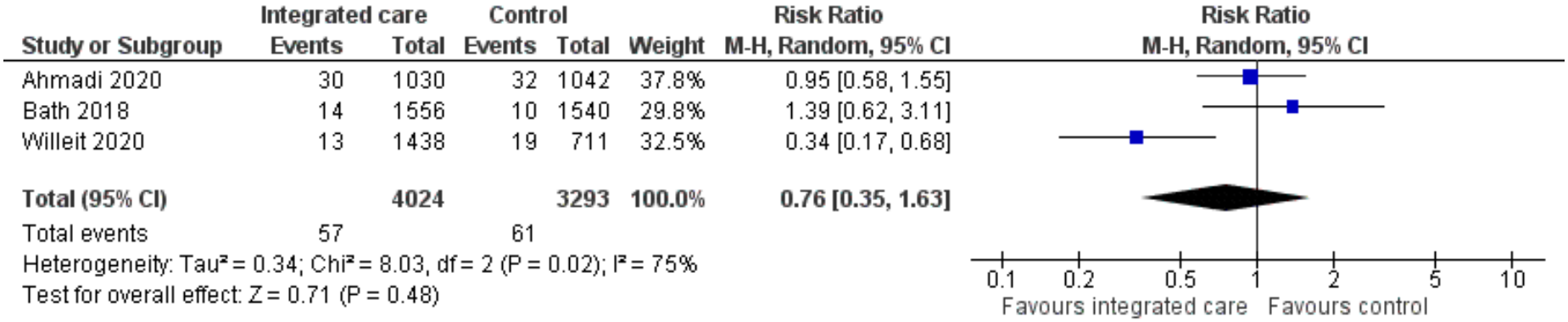


Figure S12: Comparison of integrated care with control for vascular death

Table S10: Analysis of recurrent risk of cardiovascular disease (myocardial infarction)

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	MI at 90 days	MI at Day 90, n (%): Intervention 11/1556 (0.7%) Control 12/1540 (0.8%)	No difference in MI between groups
Schwartzbach et al., 2023 (SANO) [22]	Prospective, open-label, cluster-randomised controlled trial Control n=1283, intervention n=1203	1-year patient-centred integrated care intervention including regular follow-up, lifestyle, goal setting and motivational interviewing (SANO)	MI at 12 months	MI at 12 months, n (%) Intervention: 4/1203 (0.3) Control: 7/1283 (0.5) OR, 0.61 (95% CI: 0.18-2.08)	No difference in MI between groups
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	MI at 12 months	MI at 12 months, n (%): Intervention: 9/1438 (0.6) Control: 12/711 (1.7) HR, 0.32, 95% CI: 0.13-0.80, p=0.014	Risk of MI was significantly lower in the STROKE-CARD group

Table S11: Analysis of recurrent risk of cardiovascular disease (vascular death)

Study details	Design/Patients	Intervention	Outcome	Results	Comments
Ahmadi et al., 2020 (INSPiRE-TMS) [1]	Prospective, randomised, open-label, blinded endpoint, event--driven trial Control n=1042, intervention n=1030	Screening for complications, QoL, depression	Vascular death (mean follow-up 3.6 years)	Vascular death, n (%): Intervention 30/1030 (2.9%) Control 32/1042 (3.1%) HR 0.94 (0.57-1.54)	No difference in vascular death rates between groups
Bath et al., 2018 (TARDIS) [2]	International (UK, Denmark, Georgia, NZ) prospective randomised open-label blinded end-point superiority clinical trial Guideline (control) n=1540, Intervention n=1556	Intensive treatment group given combined aspirin (load 300mg, maintenance 50-150mg daily, typically 75mg), clopidogrel (load 300mg, maintenance 75mg daily), and dipyridamole (200mg twice daily modified release, given orally; or 100mg three or four times daily).	Vascular death at Day 90	Vascular death at Day 90, n (%): Intervention 14/1556 (0.9%) Control 10/1540 (0.7%	No difference in vascular death rates between groups
Willeit et al., 2020 (STROKE-CARD) [24]	Pragmatic open-label two-centre randomised controlled trial with blinded outcome assessment of STROKE-CARD disease management programme and standard care Control n=711, intervention n=1438	STROKE-CARD care is a disease management programme by a multidisciplinary stroke team that comprises a standardised 3-month visit and access to a web-based patient portal targeting risk factor management, post-stroke complications, comorbidities and cardiovascular warning signs, rehabilitation demands, and patient education, counselling, and self-empowerment.	Vascular death at 12 months	Vascular death at 12 months, n (%): Intervention: 13/1438 (0.9) Control: 19/711 (2.7) HR, 0.32, 95% CI: 0.16-0.66, p=0.002	Risk of vascular death was significantly lower in the STROKE-CARD group

References

1. Ahmadi, M., et al., *A support programme for secondary prevention in patients with transient ischaemic attack and minor stroke (INSPiRE-TMS): an open-label, randomised controlled trial.* Lancet Neurol, 2020. **19**(1): p. 49–60.
2. Bath, P.M., et al., *Triple versus guideline antiplatelet therapy to prevent recurrence after acute ischaemic stroke or transient ischaemic attack: the TARDIS RCT.* Health Technol Assess, 2018. **22**(48): p. 1–76.
3. Bergh, E., et al., *Does implementation of a standardized pathway of stroke care affect functional outcome after stroke?* International journal of stroke : official journal of the International Stroke Society, 2023. **18**(5): p. 578–585.
4. Bernhardt, J., et al., *Efficacy and safety of very early mobilisation within 24 h of stroke onset (AVERT): a randomised controlled trial.* The Lancet, 2015. **386**(9988): p. 46–55.
5. Cuccurullo, S.J., et al., *Stroke Recovery Program with Modified Cardiac Rehabilitation Improves Mortality, Functional & Cardiovascular Performance.* J Stroke Cerebrovasc Dis, 2022. **31**(5): p. 106322.
6. Buckley, B.J.R., et al., *Exercise-Based Cardiac Rehabilitation Associates with Lower Major Adverse Cardiovascular Events in People with Stroke.* Cerebrovascular Diseases, 2021. **51**(4): p. 488–492.
7. Bushnell, C.D., et al., *Hospital Readmissions and Mortality Among Fee-for-Service Medicare Patients With Minor Stroke or Transient Ischemic Attack: Findings From the COMPASS Cluster-Randomized Pragmatic Trial.* J Am Heart Assoc, 2021. **10**(23): p. e023394.
8. Chang, K.-C., et al., *Rehabilitation Reduced Readmission and Mortality Risks in Patients With Stroke or Transient Ischemic Attack: A Population-based Study.* Medical care, 2018. **56**(4): p. 290–298.
9. Chen, C.-M., et al., *Effects of Transferring to the Rehabilitation Ward on Long-Term Mortality Rate of First-Time Stroke Survivors: A Population-Based Study.* Archives of physical medicine and rehabilitation, 2017. **98**(12): p. 2399–2407.
10. Cuccurullo, S.J.F., Talya K. Kostis, William J. Greiss, Christine Gizzi, Martin S. Eckert, Anne Ray, Arlen Razon Scarpati, Rosann Cosgrove, Nora M. Beavers, Traymon Cabrera, Javier Sargsyan, Davit Kostis, John B., *Impact of a Stroke Recovery Program Integrating Modified Cardiac Rehabilitation on All-Cause Mortality, Cardiovascular Performance and Functional Performance.* American Journal of Physical Medicine & Rehabilitation, 2019. **98**(11): p. 953–963.
11. de Belvis, A.G., et al., *Ischemic stroke: clinical pathway impact.* International Journal of Health Care Quality Assurance (09526862), 2019. **32**(3): p. 588–598.
12. Deutschbein, J., et al., *Community care coordination for stroke survivors: results of a complex intervention study.* BMC health services research, 2020. **20**(1): p. 1143.

13. Duncan, P.W., et al., *Randomized Pragmatic Trial of Stroke Transitional Care: The COMPASS Study.* Circulation. Cardiovascular quality and outcomes, 2020. **13**(6): p. e006285.

14. Fu, V., et al., *Taking Charge after Stroke: A randomized controlled trial of a person-centered, self-directed rehabilitation intervention.* International journal of stroke : official journal of the International Stroke Society, 2020. **15**(9): p. 954–964.

15. Liu, N., et al., *Randomized controlled trial of early rehabilitation after intracerebral hemorrhage stroke: difference in outcomes within 6 months of stroke.* Stroke (00392499), 2014. **45**(12): p. 3502–3507.

16. Luengo-Fernandez, R., et al., *Long-Term Impact of Urgent Secondary Prevention After Transient Ischemic Attack and Minor Stroke: Ten-Year Follow-Up of the EXPRESS Study.* Stroke, 2022. **53**(2): p. 488–496.

17. Man, S., et al., *Comparison of Acute Ischemic Stroke Care and Outcomes Between Comprehensive Stroke Centers and Primary Stroke Centers in the United States.* Circulation. Cardiovascular quality and outcomes, 2018. **11**(6): p. e004512.

18. Mofidi, R., et al., *Do Integrated Systems of Stroke Care Improve Symptom to Surgery Times in Patients with Symptomatic Carotid Stenosis? A Single Centre Decision Tree Analysis.* European Journal of Vascular and Endovascular Surgery, 2018. **56**(6): p. 784–792.

19. Pedapati, R., et al., *Educating Caregivers to Reduce Complications and Improve Outcomes of Stroke Patients (ECCOS)-A Cluster-Randomized Trial.* JOURNAL OF STROKE & CEREBROVASCULAR DISEASES, 2021. **30**(9).

20. Peng, L.-N., et al., *Functional Outcomes, Subsequent Healthcare Utilization, and Mortality of Stroke Postacute Care Patients in Taiwan: A Nationwide Propensity Score-matched Study.* Journal of the American Medical Directors Association, 2017. **18**(11): p. 990.e7–990.e12.

21. Saal, S., et al., *Effect of a stroke support service in Germany: a randomized trial.* TOPICS IN STROKE REHABILITATION, 2015. **22**(6): p. 429–436.

22. Schwarzbach, C.J., et al., *The structured ambulatory post-stroke care program for outpatient aftercare in patients with ischaemic stroke in Germany (SANO): an open-label, cluster-randomised controlled trial.* Lancet Neurol, 2023. **22**(9): p. 787–799.

23. Swanson, J.O.M., Tron Anders, *Comparisons of readmissions and mortality based on post-discharge ambulatory follow-up services received by stroke patients discharged home: a register-based study.* BMC health services research, 2019. **19**(1): p. 4.

24. Willeit, P., et al., *STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: A randomised clinical trial.* EClinicalMedicine, 2020. **25**: p. 100476.

25. Cheng, E.M., et al., *Efficacy of a Chronic Care-Based Intervention on Secondary Stroke Prevention Among Vulnerable Stroke Survivors: a Randomized Controlled Trial.* Circulation. Cardiovascular quality and outcomes, 2018. **11**(1): p. e003228.

26. Nguyen-Huynh, M.N., et al., *Novel Telestroke Program Improves Thrombolysis for Acute Stroke Across 21 Hospitals of an Integrated Healthcare System.* Stroke, 2018. **49**(1): p. 133–139.

27. Reeves, M.J., et al., *Michigan Stroke Transitions Trial.* Circulation. Cardiovascular quality and outcomes, 2019. **12**(7): p. e005493.

28. Sharma, M., et al., *Stroke Outcomes in the COMPASS Trial.* Circulation, 2019. **139**(9): p. 1134–1145.

29. Yan, L.J.L., et al., *Effectiveness of a primary care-based integrated mobile health intervention for stroke management in rural China (SINEMA): A cluster-randomized controlled trial.* Plos Medicine, 2021. **18**(4): p. 20.

30. Abdul Aziz, A.F., et al., *The integrated care pathway for managing post stroke patients (iCaPPS©) in public primary care Healthcentres in Malaysia: impact on quality adjusted life years (QALYs) and cost effectiveness analysis.* BMC Geriatrics, 2020. **20**(1): p. 1–10.

31. Bragstad, L.K., et al., *The effects of a dialogue-based intervention to promote psychosocial well-being after stroke: a randomized controlled trial.* Clinical rehabilitation, 2020. **34**(8): p. 1056–1071.

32. Brouns, B., et al., *EFFECT OF A COMPREHENSIVE EREHABILITATION INTERVENTION ALONGSIDE CONVENTIONAL STROKE REHABILITATION ON DISABILITY AND HEALTH-RELATED QUALITY OF LIFE: A PRE-POST COMPARISON.* Journal of Rehabilitation Medicine (Stiftelsen Rehabiliteringsinformation), 2021. **53**(3): p. 1–12.

33. Brouwer, B., D. Bryant, and S.J. Garland, *Effectiveness of Client-Centered "Tune-Ups" on Community Reintegration, Mobility, and Quality of Life After Stroke: A Randomized Controlled Trial.* Archives of Physical Medicine & Rehabilitation, 2018. **99**(7): p. 1325–1332.

34. Chiu, C.C., et al., *Multidisciplinary Care after Acute Care for Stroke: A Prospective Comparison between a Multidisciplinary Post-Acute Care Group and a Standard Group Matched by Propensity Score.* Int J Environ Res Public Health, 2021. **18**(14).

35. Chu, K., et al., *Feasibility of a Nurse-Trained, Family Member-Delivered Rehabilitation Model for Disabled Stroke Patients in Rural Chongqing, China.* Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association, 2020. **29**(12): p. 105382.

36. Cumming, T.B.C., Leonid Collier, Janice Donnan, Geoffrey Ellery, Fiona Dewey, Helen Langhorne, Peter Lindley, Richard I. Moodie, Marj Thrift, Amanda G. Bernhardt, Julie, *Early mobilization and quality of life after stroke: Findings from AVERT.* Neurology, 2019. **93**(7): p. e717–e728.

37. Deng, A.W., S.D. Yang, and R.B. Xiong, *Effects of an integrated transitional care program for stroke survivors living in a rural community: a randomized controlled trial.* Clinical Rehabilitation, 2020. **34**(4): p. 524–532.

38. Døhl, Ø., et al., *Factors contributing to post-stroke health care utilization and costs, secondary results from the life after stroke (LAST) study.* BMC health services research, 2020. **20**(1): p. 288.

39. Geng, G.L., et al., *Impact of transitional care for discharged elderly stroke patients in China: an application of the Integrated Behavioral Model.* Topics in Stroke Rehabilitation, 2019. **26**(8): p. 621–629.

40. He, Y., et al., *Nurse-led rapid rehabilitation following mechanical thrombectomy in patients with acute ischemic stroke: A historical control study.* Medicine, 2023. **102**(28): p. e34232.

41. Hjelle, E.G., et al., *Effect of a dialogue-based intervention on psychosocial well-being 6 months after stroke in Norway: a randomized controlled trial.* Journal of rehabilitation medicine, 2019. **51**(8): p. 557–565.

42. Jones, F., et al., *Feasibility study of an integrated stroke self-management programme: a cluster-randomised controlled trial.* BMJ Open, 2016. **6**(1): p. e008900.

43. Kalav, S., H. Bektas, and A. Unal, *Effects of Chronic Care Model-based interventions on self-management, quality of life and patient satisfaction in patients with ischemic stroke: A single-blinded randomized controlled trial.* JAPAN JOURNAL OF NURSING SCIENCE, 2022. **19**(1).

44. Wong, F.K.Y., et al., *Effects of a transitional home-based care program for stroke survivors in Harbin, China: a randomized controlled trial.* AGE AND AGEING, 2022. **51**(2).

45. Khramov, V.V., et al., *EFFECTIVENESS OF POST-STROKE SOCIAL REHABILITATION IN PATIENTS WITH MODERATE IMPAIRMENTS.* BULLETIN OF RUSSIAN STATE MEDICAL UNIVERSITY, 2021(2): p. 62–68.

46. Langhorne, P., et al., *A Very Early Rehabilitation Trial after stroke (AVERT): a Phase III, multicentre, randomised controlled trial.* Health Technol Assess, 2017. **21**(54): p. 1–120.

47. Lewthwaite, R., et al., *Accelerating Stroke Recovery: Body Structures and Functions, Activities, Participation, and Quality of Life Outcomes From a Large Rehabilitation Trial.* Neurorehabilitation & Neural Repair, 2018. **32**(2): p. 150–165.

48. Liu, L.M., *EFFECTS OF TRANSITIONAL CARE ON FUNCTIONAL EXERCISE: COMPLIANCE AND HEALTH STATUS OF STROKE PATIENTS.* ACTA MEDICA MEDITERRANEA, 2018. **34**(4): p. 959–965.

49. Markle-Reid, M., et al., *An integrated hospital-to-home transitional care intervention for older adults with stroke and multimorbidity: A feasibility study.* Journal of Comorbidity, 2020. **10**: p. 1–21.

50. Minshall, C., et al., *A psychosocial intervention for stroke survivors and carers: 12-month outcomes of a randomized controlled trial.* TOPICS IN STROKE REHABILITATION, 2020. **27**(8): p. 563–576.

51. Mohammadi, E., F. Hassandoost, and H. Mozhdehipanah, *Evaluation of the "partnership care model" on quality of life and activity of daily living in stroke patients: A randomized clinical trial.* Jpn J Nurs Sci, 2022. **19**(1): p. e12448.

52. Rodgers, H., et al., *Evaluation of an Extended Stroke Rehabilitation Service (EXTRAS): A Randomized Controlled Trial and Economic Analysis.* STROKE, 2019. **50**(12): p. 3561–3568.

53. Shaw, L., et al., *An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT.* HEALTH TECHNOLOGY ASSESSMENT, 2020. **24**(24): p. 1–+.

54. Tung, Y.-J., et al., *Comparison of Cost-Effectiveness between Inpatient and Home-Based Post-Acute Care Models for Stroke Rehabilitation in Taiwan.* International journal of environmental research and public health, 2021. **18**(8).

55. Vluggen, T.P.M.M.v.H., Jolanda C. M. Tan, Frans E. Verbunt, Jeanine A. van Heugten, Caroline M. Schols, Jos M. G. A., *Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial.* BMC geriatrics, 2021. **21**(1): p. 134.

56. Long Weijan and J. Zhang, *Patient Caregiver Comprehensive Rehabilitation Nursing Training Joint Continued nursing care for ischemic stroke patients at home Impact on quality of life and activities of daily living.* Chinese Nursing Research, 2017. **31**(20): p. 2456–2461.

57. Wong, F.K. and S.M. Yeung, *Effects of a 4-week transitional care programme for discharged stroke survivors in Hong Kong: a randomised controlled trial.* Health Soc Care Community, 2015. **23**(6): p. 619–31.

58. Wu, Z., et al., *Collaborative Care Model Based Telerehabilitation Exercise Training Program for Acute Stroke Patients in China: A Randomized Controlled Trial.* Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association, 2020. **29**(12): p. 105328.

59. Xi, W.D., Yamei Wang, Ai'ping, *Influence of continuing nursing outside hospital on rehabilitation effect and quality of life in patients with stroke.* Chinese Nursing Research, 2017. **31**(29): p. 3760–3762.

60. Demir Avci, Y. and S. Gözüm, *Effects of Transitional Care Model-Based Interventions for Stroke Patients and Caregivers on Caregivers' Competence and Patient Outcomes: Randomized Controlled Trial.* Computers, informatics, nursing : CIN, 2023. **41**(10): p. 805–814.

61. Chen, L., J.W. Sit, and X. Shen, *Quasi-experimental evaluation of a home care model for patients with stroke in China.* Disabil Rehabil, 2016. **38**(23): p. 2271–6.

62. Cuccurullo, S.J., et al., *Impact of Modified Cardiac Rehabilitation Within a Stroke Recovery Program on All-Cause Hospital Readmissions.* Am J Phys Med Rehabil, 2022. **101**(1): p. 40–47.

63. Lu, L.X., et al., *Original Article Effect of "Internet plus tertiary hospital-primary hospital-family linkage home care" model on self-care ability and quality of life of discharged stroke patients.* AMERICAN JOURNAL OF TRANSLATIONAL RESEARCH, 2023. **15**(12): p. 6727–6739.

64. Wang, J., et al., *Pharmaceutical care program for ischemic stroke patients: a randomized controlled trial.* Int J Clin Pharm, 2021. **43**(5): p. 1412–1419.

65. Brandal, A., et al., *Effect of early supported discharge after stroke on patient reported outcome based on the Swedish Riksstroke registry.* BMC Neurol, 2019. **19**(1): p. 40.

66. Cheng, C., et al., *Comprehensive Rehabilitation Training Decreases Cognitive Impairment, Anxiety, and Depression in Poststroke Patients: A Randomized, Controlled Study.* J Stroke Cerebrovasc Dis, 2018. **27**(10): p. 2613–2622.

67. Ellis-Hill, C., et al., *HeART of Stroke: randomised controlled, parallel-arm, feasibility study of a community-based arts and health intervention plus usual care compared with usual care to increase psychological well-being in people following a stroke.* BMJ Open, 2019. **9**(3): p. e021098.

68. Feng, W., et al., *Application effect of the hospital-community integrated service model in home rehabilitation of stroke in disabled elderly: a randomised trial.* Ann Palliat Med, 2021. **10**(4): p. 4670–4677.

69. Gao, J., et al., *Different interventions for post-ischaemic stroke depression in different time periods: a single-blind randomized controlled trial with stratification by time after stroke.* Clinical rehabilitation, 2017. **31**(1): p. 71–81.

70. Graven, C., et al., *First Year After Stroke: An Integrated Approach Focusing on Participation Goals Aiming to Reduce Depressive Symptoms.* Stroke, 2016. **47**(11): p. 2820–2827.

71. Gun Young, Y., *The Effects of an Integrated Management Program on Physical Function, Cognitive Function, and Depression in Patients with Subacute stroke.* Korean Critical Care Nursing, 2021. **14**(1): p. 50–62.

72. Jung, S.H., et al., *Effects of Self RehAbilitation Video Exercises (SAVE) on Functional Restorations in Patients with Subacute Stroke.* Healthcare (Basel), 2021. **9**(5).

73. Lee, S.A., H.G. Park, and K.C. Son, *Determining the Effects of a Horticultural Therapy Program for Improving the Upper Limb Function and Balance Ability of Stroke Patients.* Hortscience, 2018. **53**(1): p. 110–19.

74. Lin, R.C., et al., *Effectiveness of Early Rehabilitation Combined With Virtual Reality Training on Muscle Strength, Mood State, and Functional Status in Patients With Acute Stroke: A Randomized Controlled Trial.* Worldviews Evid Based Nurs, 2020. **17**(2): p. 158–167.

75. Lo, S.H.S., et al., *Virtual Multidisciplinary Stroke Care Clinic for Community-Dwelling Stroke Survivors: A Randomized Controlled Trial.* Stroke, 2023. **54**(10): p. 2482–2490.

76. MacKay-Lyons, M., et al., *Program of Rehabilitative Exercise and Education to Avert Vascular Events After Non-Disabling Stroke or Transient Ischemic Attack (PREVENT Trial): a Randomized Controlled Trial.* Neurorehabilitation and neural repair, 2022. **36**(2): p. 119–130.

77. Rafsten, L.D., Anna Nordin, Asa Björkdahl, Ann Lundgren-Nilsson, Asa Larsson, Maria E. H. Sunnerhagen, Katharina S., *Gothenburg Very Early Supported Discharge study (GOTVED): a randomised controlled trial investigating anxiety and overall disability in the first year after stroke.* BMC neurology, 2019. **19**(1): p. 277.

78. Teuschl, Y., et al., *Preventive effects of multiple domain interventions on lifestyle and risk factor changes in stroke survivors: Evidence from a two-year randomized trial.* Int J Stroke, 2017. **12**(9): p. 976–984.

79. Yu, H.L., D.X. Cao, and J. Liu, *Effect of a novel designed intensive patient care program on cognitive impairment, anxiety, depression as well as relapse free survival in acute ischemic stroke patients: a randomized controlled study.* Neurol Res, 2019. **41**(9): p. 857–866.

80. Zhang, L., T. Zhang, and Y. Sun, *A newly designed intensive caregiver education program reduces cognitive impairment, anxiety, and depression in patients with acute ischemic stroke.* Braz J Med Biol Res, 2019. **52**(9): p. e8533.

81. Greger, J., et al., *Pharmacist intervention and anti-platelet medication monitoring in patients following stroke and transient ischemic attack.* JOURNAL OF THE AMERICAN COLLEGE OF CLINICAL PHARMACY, 2021. **4**(3): p. 311–317.

82. Joubert, J., et al., *ICARUSS: An effective model for risk factor management in stroke survivors.* INTERNATIONAL JOURNAL OF STROKE, 2020. **15**(4): p. 438–453.

83. Olaiya, M.T., et al., *Effectiveness of a shared team approach between nurses and doctors for improved risk factor management in survivors of stroke: a cluster randomized controlled trial.* Eur J Neurol, 2017. **24**(7): p. 920–928.

84. Rasmussen, R.S., et al., *Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: a randomised controlled trial.* Clinical Rehabilitation, 2016. **30**(3): p. 225–236.

85. Towfighi, A., et al., *Effect of a Coordinated Community and Chronic Care Model Team Intervention vs Usual Care on Systolic Blood Pressure in Patients With Stroke or Transient Ischemic Attack The SUCCEED Randomized Clinical Trial.* JAMA NETWORK OPEN, 2021. **4**(2).

86. Koch, S., et al., *Randomized Trial of Combined Aerobic, Resistance, and Cognitive Training to Improve Recovery From Stroke: Feasibility and Safety.* Journal of the American Heart Association, 2020. **9**(10): p. e015377.

87. Dello, S., et al., *A nurse-led multicomponent intervention supported by advanced electronic health records to improve the acute management of stroke patients: A pre- and post-intervention study.* INTERNATIONAL JOURNAL OF NURSING STUDIES ADVANCES, 2021. **3**.

12.8 Appendix H: IRAS Approved Protocol for Mixed Methods Study

Date and version No: 20/07/2023 V1.1

Research Protocol for IRAS application - LJMU sponsored research

FULL/LONG TITLE OF THE STUDY:

Integrated care management for patients following acute stroke: evidence synthesis and development of a novel holistic approach to stroke care

SHORT STUDY TITLE/ACRONYM

Integrated care for patients following stroke

DATE AND VERSION NO:

20/07/2023
Version 1.1

RESEARCH REFERENCE NUMBERS

IRAS Number	317528
Sponsor reference number	23LJMUSPONSOR006
ISRCTN number	
REC reference number	23/EM/0171

This protocol has regard for the HRA guidance

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to adhere to the signed LJMU's Sponsorship CI declaration.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

Chief Investigator: Dr K Higginbotham
Signature: ..... Date: ...../...../.....

Name: (please print):.....

SPONSOR STATEMENT:

Where LJMU takes on the sponsor role for protocol development oversight, the signing of the IRAS form by the sponsor will serve as confirmation of approval of this protocol.

CONFIDENTIALITY STATEMENT

This document contains confidential information that must not be disclosed to anyone other than the Sponsor, the Investigator Team, HRA, host organisation, and members of the Research Ethics Committee, unless authorised to do so.

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KEY STUDY CONTACTS

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Sponsor:	Liverpool John Moores University
Funder:	Liverpool John Moores University
Chief Investigator Signature:	

No potential conflicts of interest declared.

TRAINING / CPD

Name of investigator (add	Date completed	Date completed LJMU research	Date completed research	Date completed	Date completed

new row if required)	LJMU REC training	integrity training	governance training	HTA training (or NA)	NIHR GCP training
Ian Eustace	01 Aug 2021	01 Aug 2021	01 Aug 2021	NA	08 Aug 2022

STUDY SUMMARY

Study Title	Integrated care management for patients following acute stroke: evidence synthesis and development of a novel holistic approach to stroke care	
Internal ref. no. / short title	Integrated care for patients following stroke	
Proposed start date	01 Aug 2023	
Proposed end date	01 Feb 2024	
Countries in which the study will take place	United Kingdom	
Lead NHS trust & R&D contact	Jeanette Anders St Helens and Knowsley Teaching Hospitals NHS Trust Research Department, Ground Floor, Whiston Hospital, Prescot. L35 5DR email: research@sthk.nhs.uk Tel@ 0151 430 2334/1218	
Study Design	Focus groups and Delphi survey	
Study Participants	People with stroke (Focus groups and Delphi survey) Healthcare practitioners (Delphi survey)	
Planned Sample Size	30 people with stroke (3 Focus groups) 30 healthcare practitioners and people with stroke (Delphi survey)	
Planned Study Period	6 months	
	Objectives	**Outcome Measures**
Primary	To explore the experiences of stroke survivors during their recovery from stroke To explore the barriers and enablers that patients experience during stroke rehabilitation and the components of care that would enhance recovery	Identification of themes arising from focus group discussions representing components of an integrated care pathway
Secondary	Using the data collected from a systematic review of the literature and the focus groups, undertake a Delphi survey to gain consensus regarding the components of care that patients and stroke professionals believe should be included in an integrated stroke pathway	Components for an integrated care pathway for which consensus has been reached for inclusion

FUNDING AND SUPPORT IN KIND

FUNDER	FINANCIAL AND NON-FINANCIAL SUPPORT GIVEN
Liverpool John Moores University School of Nursing and Advanced Practice Principal supervisor: Dr K Higginbotham RN, DProf, MPHIL, BSc (Hons), PGCAP, FHEA, Senior Lecturer in Adult Nursing, School of Nursing and Advanced Practice, Tithebarn Building, 81 Tithebarn Street, Liverpool, L2 2ER. Email: K.Higginbotham@ljmu.ac.uk	This research is fully funded by LJMU for a period of 3 years and includes: • A tax-free stipend • Tuition fees • Bench fees for research costs Supervisory time throughout the study period is provided as support in kind

ROLE OF STUDY SPONSOR AND FUNDER

As principal sponsor and funder, LJMU assumes overall responsibility for the initiation and management of the study and has oversight in the study design, conduct, data analysis and interpretation, manuscript writing, and dissemination of results through the supervisory team. LJMU controls the final decision regarding any of these aspects of the study.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS AND INDIVIDUALS

The researcher (Ian Eustace) will be responsible for conducting the study. The Chief Investigator (Dr K Higginbotham) will provide oversight and will be present at the first focus group meeting to provide support and guidance.

Patient & Public Involvement Group: Members of the Cheshire and Mersey Integrated Stroke Delivery Network (ISDN) Patient and Carer group have been consulted during the writing of the protocol (details of their involvement and input are described below)

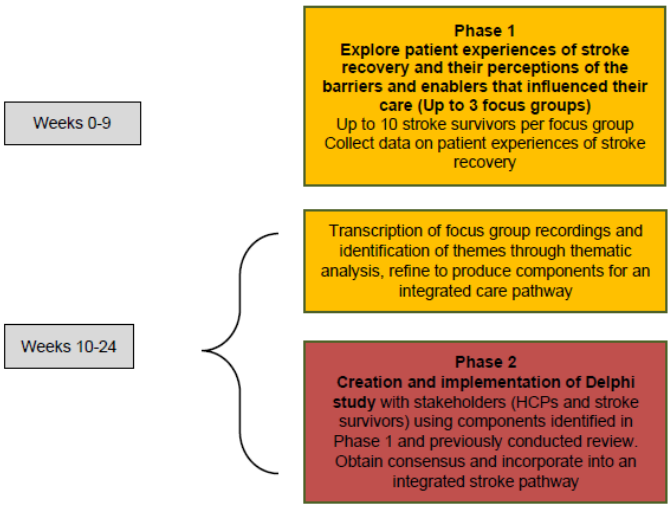
PROTOCOL CONTRIBUTORS

The protocol was written and finalised with input from the following contributors:

- The Chief Investigator and supervisory team provided review and comments on each draft of the protocol and approved the final version when all amendments had been made to their satisfaction.
- LJMU as the study sponsor and funder has oversight on study design, conduct, data analysis and interpretation, manuscript writing, and dissemination of results. LJMU also controls the final decision regarding any of these aspects of the study
- Members of the Cheshire and Mersey Integrated Stroke Delivery Network (ISDN) Patient and Carer group have been consulted during the writing of the protocol. Their contribution was instrumental in creating patient-driven elements of the research project such as the focus groups and involvement in surveys. They endorsed the focus group design of the study and approved the location where these meetings will be held. They also agreed with a focus group meeting duration of between 1 and 1.5 hours.

KEY WORDS: Integrated care, stroke, focus groups, Delphi survey.

STUDY FLOW CHART



ABBREVIATIONS

GCP	Good Clinical Practice
HRA	Health Research Authority
ICF	Informed Consent Form
LJMU REG	LJMU Research Ethics and Governance
NHS	National Health Service
NRES	National Research Ethics Service
PI	Principal Investigator
PIS	Participant/ Patient Information Sheet
PPI	Patient and public involvement
REC	Research Ethics Committee

1 BACKGROUND

Stroke is a common condition with more than 12 million events recorded worldwide in 2019 and a lifetime risk of 25% from the age of 25 years onwards (Feigin et al., 2018). Globally, stroke is the second-leading cause of death and the third-leading cause of death and disability combined (Feigin et al., 2021). The socioeconomic burden of stroke is substantial; in the UK alone, it is estimated that the societal costs of stroke are approximately £26bn annually (Patel et al., 2020), with a mean estimated cost per patient of £46,000 each year over the first 5 years (Xu et al., 2018). Individuals surviving an initial stroke are at substantially increased long-term risk of subsequent stroke (Edwards et al., 2017), with 11% having a recurrent stroke within 1 year and 26% within 5 years (Mohan et al., 2011). Recurrent strokes are associated with poorer outcomes and higher mortality compared with the initial stroke (Samsa et al., 1999; Modrego et al., 2000; Buckley et al., 2022).

The concept of "integrated care" was originally defined as a project network technique which, when applied to interdisciplinary care, provides the interdisciplinary team with prompts to initiate certain investigations,

referrals and treatments at predetermined intervals and checks to ensure that the patient is progressing as expected (Sulch and Kalra, 2000). Integrated care improves communication and coordination without necessarily changing the practice of individual disciplines (Pearson et al., 1995).

The interdisciplinary nature of stroke management in the acute and rehabilitation phases fits well with an integrated care approach (Sulch and Kalra, 2000). Integrated care pathways in stroke management were established in the 1990s (Falconer et al., 1993; Odderson and McKenna, 1993; Bowen and Yaste, 1994; Wentworth and Atkinson, 1996; Ross et al., 1997; Summers and Soper, 1998) and these studies included a plan for medical and nursing interventions and instructions on accessing other disciplines within the care team as a minimum requirement (Sulch and Kalra, 2000).

Since the initial studies in integrated care were conducted, there has been a marked improvement in the management of acute stroke in recent years as evidenced by the effectiveness of dedicated stroke unit care and the benefits of thrombolysis, which have transformed the treatment of stroke survivors, resulting in reduced mortality (Clarke and Forster, 2015; Morris et al., 2019; Heo et al., 2021).

The implementation of integrated care pathways in stroke management has been associated with reductions in mortality (Katzan et al., 2015; Ganesh et al., 2016; Buckley et al., 2021; Masiliunas et al., 2022), length of hospital stay (Vos et al., 2009; Heijnen et al., 2012; Katzan et al., 2015; Bindawas et al., 2017; Jang et al., 2020), recurrent stroke, cardiovascular events, blood pressure, lipids, alcohol consumption (Joubert et al., 2020; Willeit et al., 2020; Buckley et al., 2021), cost (van Exel et al., 2005; Baeten et al., 2010; Mofidi et al., 2018; Abdul Aziz et al., 2020; Markle-Reid et al., 2020), improvements in functional status and/or health-related outcomes of people with stroke (Bindawas et al., 2017; Cecchi et al., 2020; Deng et al., 2020; Joubert et al., 2020; Willeit et al., 2020), interdisciplinary communication and collaboration (Catangui and Slark, 2012; Reid et al., 2019), and improved health care quality and/or service delivery (Heijnen et al., 2012; Mofidi et al., 2018; de Belvis et al., 2019; Cecchi et al., 2020; Masiliunas et al., 2022).

The concept of integrated care has been characterised in more depth in other chronic health conditions related to stroke (Field et al., 2022; Lip and Ntaios, 2022). The ABC (Atrial fibrillation Better Care) pathway was proposed as an integrated holistic approach to improve the management of patients with atrial fibrillation (AF) that can be delivered by collaboration between health care professionals and comprises three main pillars: “A”—avoid stroke (with anticoagulants); “B”—better symptom management, with patient-centred decisions on rate or rhythm control; “C”—cardiovascular and comorbidity risk optimisation (Lip and Ntaios, 2022). The ABC pathway in AF has been tested and validated in a series of post-hoc and prospective studies. In a recent systematic review of more than 285,000 patients, those with AF treated according to the ABC pathway showed significantly lower risks of all-cause death (odds ratio ([OR)]: 0.42, 95% confidence interval ([CI)]: 0.31–0.56), cardiovascular death (OR: 0.37, 95% CI: 0.23–0.58), stroke (OR: 0.55, 95% CI: 0.37–0.82), and major bleeding (OR: 0.69, 95% CI: 0.51–0.94) compared with those receiving standard care (Romiti et al., 2022).

Cardiac and cerebrovascular disease (collectively termed CVD) are interlinked, and a combined action plan is required to identify, treat and facilitate patient recovery whilst also preventing future CVD events. Such collaboration between cardiac and stroke specialist teams within an integrated service care model will ensure effective and efficient management of people with stroke (Lip et al., 2022). The principles for integrated care in AF can be adapted to stroke care since stroke and AF share many common risk factors including advancing age, male sex, hypertension, diabetes mellitus (DM), valvular heart disease, heart failure, coronary heart disease, chronic kidney disease, inflammatory disorders, sleep apnoea, and tobacco use (Kamel et al., 2016; Lip et al., 2022). Indeed, an ABC pathway concept has been proposed as a more holistic approach for stroke, comprising three pillars; “A” – appropriate antithrombotic therapy, “B” – better functional and psychological status, and “C” – Cardiovascular risk factors and comorbidity optimisation but this concept is yet to be tested and the outcomes of the proposed study will inform the development of an integrated care pathway for stroke.

The development of effective post-stroke management and secondary prevention strategies includes movement towards a more holistic and integrated care approach (Lip et al., 2022). The concept of holistic medicine and nursing deals with the patient as a whole and involves a multi-faceted approach (Papathanasiou, 2013). Importantly, the individual is the focus of interest not the disease and the goal of holistic post-stoke care is to provide a patient-centred approach to achieve improvements in functional and psychological status, delivered by a multidisciplinary team of healthcare professionals, in order to meet the

expectations of patients and their carers for a good recovery and proper social re-integration (Papathanasiou, 2013; Lip et al., 2022).

2 RATIONALE

Despite improvements in outcomes there remain several challenges in contemporary stroke care. Much of the progress in stroke management has been made in the acute setting (Gilham, 2021) with discontinuity of care in the transition from hospital to home reported in the literature (Chen et al., 2020; Stroke Pathway, 2021; de Mooij et al., 2021). Governments and healthcare organisations are moving towards the concept of holistic, patient-centred stroke care, where patients and their family members are active participants in the planning of their care and decision making (Gluyas, 2015; NHS, 2021a; NHS, 2021b) However, there is currently limited published evidence that holistic stroke care is being delivered and some evidence that current stroke treatments seem to focus on the condition and not the individual (Peterson-Burch et al., 2017; Pindus et al., 2018; Guo et al., 2021). In a recent survey of lived experiences of stroke survivors conducted by the UK Stroke Association, those people who received holistic care felt involved in their treatment and diagnosis and were more likely to feel closer to recovery. However, 22% of stroke survivors were not involved in decisions regarding their recovery and support, leaving them feeling disempowered (Lived experience of stroke report, 2019), so for many stroke survivors, the holistic element of stroke care is absent.
The precise nature of a holistic integrated stroke care pathway is currently unknown, hence the need to review the published literature, explore patient experiences of stroke recovery and gain consensus from stroke survivors and those individuals who care for them as to what the creation of an integrated care pathway for stroke survivors should involve.

3 RESEARCH QUESTION

How can the management of patients with acute stroke be improved through integrated care pathways?

4 OBJECTIVES AND OUTCOME MEASURES

Quantitative research:

Objectives	**Outcome Measures**	**Timepoint(s) of evaluation of this outcome measure (if applicable)**
Primary Objective Underpinned by the data collected from a systematic review of the literature (previously undertaken) and the focus groups, undertake a Delphi survey to gain consensus regarding the components of care that patients and stroke professionals believe should be included in an integrated stroke pathway	Components for an integrated care pathway for which consensus has been reached for inclusion	Data will be collected at the end of each round of the survey

Qualitative research

Aim/Research Questions	**Objectives**
Primary Through patient focus groups, to explore the	Gather information about experience and treatment pathways for people with stroke following discharge

experiences of stroke survivors during their recovery from stroke Through patient focus groups, to explore the barriers and enablers that patients experience during stroke rehabilitation and the components of care that would enhance recovery	from hospital/stroke unit to home and identify components of integrated care through thematic analysis

5 STUDY DESIGN AND METHODS OF DATA COLLECTION AND DATA ANALYSIS

This is a mixed methods study with qualitative and quantitative elements, and will be conducted in two phases:

Phase 1: Patient focus groups

Stroke survivor focus groups (up to 3) will be held to explore the experiences of people recovering from stroke and their perceptions of the barriers and enablers that influenced their care. The focus groups will be audio recorded and the data analysed using reflexive thematic analysis (Braun and Clarke, 2022).

It is intended that participants for the focus groups will be selected using a purposive sampling strategy (Campbell et al., 2020) to include a cross-section of stroke survivors for example with different ages, ethnicity, cultures, geographic and socioeconomic backgrounds. This should allow the identification of common and differing experiences in the provision of stroke rehabilitation across the Northwest.

Each focus group will be conducted using a clear discussion guide, which will introduce the researcher, outline the purpose of the group, provide set of ground rules to be observed during the meeting. These ground rules will be displayed on a flip or wall chart for the duration of the meeting, and will summarise opening questions (Kreuger, 2002). An atmosphere of trust and openness will be created by warmly welcoming the participants, thanking them in advance for their important contributions and stressing that each participant shares something in common with other participants in the room; they are all stroke survivors on a recovery journey. Participants will be informed at the start of the meeting that their opinions are highly valued, that there are no wrong answers, and that each individual's opinions can be freely expressed and should be respected by the other participants (Kreuger, 2002; Liamputtong, 2011). They will also be informed that the meeting will be recorded for research purposes and data gathering but that the recording will be handled in strictest confidence in accordance with university guidance on data handling and storage.

The discussion will be focussed on a series of primary questions, with additional questions serving as prompts that can be used if necessary, by the researcher to keep the discussion flowing and to allow the researcher to keep the discussion "on topic" (Table 1). The researcher will assist with equipment and refreshments, arrange the room, welcome the participants as they arrive. The researcher will seek consent for the meeting to be recorded prior to commencement of the meeting. Each member of the focus group will be given the opportunity through facilitation to speak to the group and contribute to the discussion, being mindful that some individuals may be hesitant in a group setting and others may be dominant and may attempt to control the discussion (Liamputtong, 2011).

Table 1: Proposed focus group questions

Research Question 1	***"Can you tell me about your experiences of recovering from a stroke?"***
Interview Questions	Can you tell me about your stroke recovery journey (from when you were admitted to hospital to where you are now)?
Prompts	What was your experience of: • The time up until you were discharged (early supported discharge)? • The time after you arrived home (what happened afterwards with your care)?
Research Question 2	***"Can you tell me what went well and what didn't go so well during your recovery?"***

Interview questions	Did you encounter any problems during your stroke recovery? If so, can you talk about them? Can you think of anything that helped your stroke recovery? If so, can you talk about them? Looking back at your stroke recovery journey, is there anything you would want to change about the way you were cared for? If so, can you talk about them
Prompts	Was there something during your recovery that you found especially difficult to manage? Was there any part of your care that really stood out/really made a difference in your recovery? Thinking about how you were cared for, what do you think could have been done differently that would have made a real difference?

In accordance with published literature on focus groups, the proposed number of participants for each focus group will be between 6 and 10 (Liamputtong, 2011; Barbour, 2018). This number is recommended in order to generate an appropriate level of participant involvement and to provide a rich contextual data which can then be analysed (Liamputtong, 2011; Stewart and Shamdasani, 2015). The proposed duration for each focus group will be 1-1.5 hours and this will be dependent on the group recognising that they are post stroke patients and they could become easily fatigued. For many stroke survivors the ability to concentrate and communicate may be problematic and regular breaks and checking in with the participants to ensure they are able to continue will be an important part of managing the group (Liamputtong, 2011; Barbour, 2018).
The focus groups will be digitally audio recorded using an encrypted University recording device. The recordings will be transcribed verbatim by the researcher and anonymised for analysis by assigning a pseudonym to each participant. After transcription, the recording will be securely destroyed. Following each meeting, the researcher will make handwritten notes that will be used to document salient points made during the meeting and non-verbal communication or behaviour as part of group dynamics. Spatial maps of the meeting room layout will be included to show the location of participants, any observers and the researcher. Written materials on flipcharts will also be collected.
Following the end of each focus group meeting, the researcher will conduct a debriefing to capture the main outcomes of the meeting.
The data collected will be analysed using thematic analysis (Braun and Clarke, 2022) to generate themes arising from the focus group discussion. The themes representing potential components of an integrated pathway will then be incorporated with the results of the systematic review into the first-round questionnaire of the Delphi survey.

Phase 2: Development of components for stroke pathway and Delphi survey
Using the quantitative data generated from the systematic review and analysis of the qualitative themes that have been generated from the focus groups, a list of components of stroke care will be developed that will be used as the basis for a modified Delphi survey.
The first round will comprise a series of components of a proposed integrated care pathway that participants will rate according to importance. The survey will be developed electronically and run through an online web-based portal known as QuestionPro (https://www.questionpro.com), including obtaining informed consent before the participant can access the survey or any information relating to it. Participants will have the option to complete a paper-based survey by post as an alternative, with a separate consent form being provided for this option. People who have contacted the researcher and are willing to participate will be informed of exactly what they will be asked to do, how much time they will be expected to contribute, and how the information that they provide will be used (Hasson et al., 2000).
The survey will be constructed according to guidance provided by published articles (de Villiers et al., 2005; Beiderbeck et al., 2021). A panel of experts who possess knowledge of stroke care delivery, members of multidisciplinary stroke teams and patients with experience of stroke recovery, will be requested to participate and the planned panel size is a minimum of 30 members to provide sufficient rigour for statistical analysis (de Villiers et al., 2005).

A Delphi questionnaire will then be developed and sent to the participants to gather their opinions. The first questionnaire (Round 1) will comprise potential components of an integrated pathway concept based on the themes generated from the focus groups and the components identified from the systematic review. Items for Round 1 and subsequent rounds will be rated using a proposed 5-point Likert Scale (Cooper and Johnson, 2016) between 1 (extremely important), 2 (important), 3 (neutral [neither important or unimportant]), 4 (unimportant) and 5 (completely unimportant), with a "don't know" answer option also provided. However, the middle response may be problematic if participants are unsure what it means. The participant may be truly neutral, may not have enough information to make an informed choice or may choose this response to avoid giving an undesirable answer. Conversely, eliminating the neutral response may force participants to choose a response that is not truly reflective of their opinions (Cooper and Johnson, 2016). With this in mind, the Likert scale could be 4- or 5-point depending on the nature of the questions being posed.
The questionnaire responses will be analysed providing interim results demonstrating consensus and non-consensus items. The components upon which consensus has been reached to include will be taken to inform the construction of a stroke integrated care pathway concept. Another questionnaire containing the non-consensus components and the Round 1 results will be sent out to the participants (Round 2). This feedback will encourage the participants to compare their initial opinions with the group result and to reconsider their response from Round 1 if desired (Keeney et al., 2006). The expectation is that outlier responses will be adjusted and a level of agreement achieved. Round 2 will provide further data toward the interim results. Subsequent rounds will continue until an acceptable level of consensus is achieved, no further consensus issue is emerged, or until the response rate is too low. The final consensus will present issues upon which the experts agree (consensus), along with the items which remain controversial (non-consensus) (de Villiers et al., 2005).

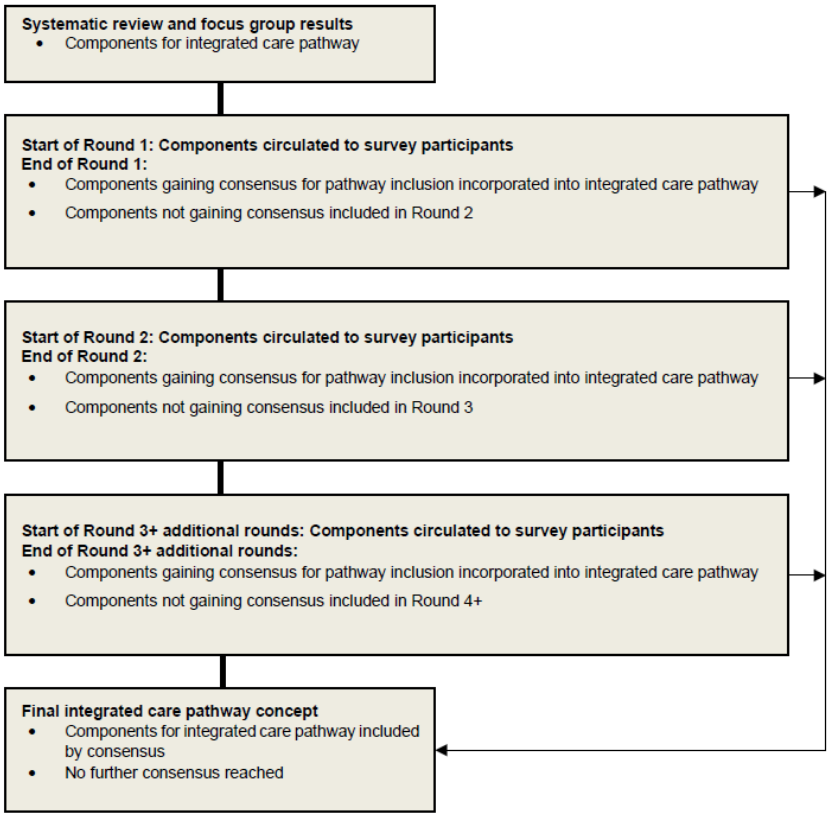


Figure 1: Modified Delphi Methodology (Eubank et al., 2016)

A key issue in any Delphi survey is the percentage agreement among participants that would be accepted by the researcher as consensus (Keeney et al., 2006). There is no agreement in the published literature as to what level the percentage for consensus should be set and it is partly dependent upon the research topic (a life-or-death issue would require a consensus set at 100%). The range of consensus in the literature ranges from 51%-100% although a 1% difference between consensus and no consensus at the lower end of this range seems difficult to justify. A figure of 75% appears more robust and values of 70-80% have been used successfully in several studies (Green et al., 1999; McKenna et al., 2001; McKenna and Hasson, 2002). This also matches the upper interquartile range of statistical analysis (75%) (Beiderbeck et al., 2021). For this study, consensus will be set at 75% as this appears to be the minimal level that is sufficiently rigorous with the understanding that there is currently no obvious scientific rationale for this (McKenna et al., 2001; Keeney et al., 2006).
Following the results from the Delphi survey, the identified components will be used to inform the development of an integrated stroke care pathway. The Delphi surveys for each round will be returned to the researcher when completed by the participant and each participant will be anonymised using an identification coding process.

5.1 Study setting

The focus groups will be held on university premises in a comfortable, spacious and private meeting room. The room has easy ingress and egress for disabled people having ramps into the building and lifts to all floors and is provisioned for recording equipment. Refreshments will be made available on arrival and toilets with disabled access are available in close proximity. Each focus group will be conducted in accordance with recommendations on running focus groups (Kreuger, 2002; Liamputtong, 2011; Stewart and Shamdasani, 2015; Barbour, 2018).
The Delphi survey will be developed electronically and run through an online web-based portal known as QuestionPro (https://www.questionpro.com).

5.2 Statistics and analysis

Focus groups

Thematic analysis is the process of identifying patterns or themes within qualitative data (Braun and Clarke, 2019; Braun and Clarke, 2022). The reflexive nature of the analysis is an important component as it accepts that data analysis is subjective and influenced by the researcher's own preconceptions, opinions and beliefs (Braun and Clarke, 2022). A reflective journal will be kept by the researcher which will serve as a repository for documenting and storing thoughts, critical analysis and meaning-making (Braun and Clarke, 2019; Braun and Clarke, 2022). A 6-phase guide based on the methods of Braun and Clarke (2022) will be used in order to analyse the data obtained from the focus groups. In Step 1 (familiarity with the data) the transcripts will be read and re-read to ensure complete familiarity with the data. In Step 2, the data will be organised in a meaningful and systematic manner and initial codes will be generated. Step 3 will involve organisation of the initial codes into broader themes which will be reviewed in Step 4 to ensure that they make sense and are supported by the data. Step 5 involves the final refinement of the themes and the aim is to 'identify the essence of what each theme is about.' Thematic maps will be generated to highlight the relationships between themes. Step 6 will involve writing up the data analysis for publication as conference abstracts or articles in per reviewed journals (Maguire and Delahunt, 2017; Braun and Clarke, 2022).

Thematic analysis for the focus group data is expected to be inductive (data-driven) in nature, with the inductive process beginning with observations and seeking to find a pattern within them (Proudfoot, 2022).
Participants will be assured that any personal data collected which could identify them such as their name will be treated as confidential and handled in line with General Data Privacy Regulation (GDPR), Data Protection Act (1998) and LJMU guidance. In order to maintain confidentiality of participants' personal data, the data will be coded, linked to information that can be used to identify the individual and the link will be stored in a folder on an encrypted university computer with access strictly limited to the researcher and the supervisory team.

Delphi survey

The Likert scale will be used for rating components of an integrated stroke care pathway. Descriptive statistics will be calculated using IBM SPSS Statistics version 28.0.1.1. The proportion of participants allocating a Likert score to each question will be summarised descriptively and expressed as percentages.
Final consensus data collected from the Delphi survey will be used to inform the selection and order of importance of components of an integrated stroke pathway.

6 PARTICIPANT RECRUITMENT

6.1 STUDY PARTICIPANTS

Focus groups
A sample of up to 30 people who have been diagnosed with stroke (up to 10 for each focus group and up to 3 focus groups) is planned. The following inclusion and exclusion criteria will be implemented.

6.2 INCLUSION CRITERIA

- Participant has capacity to give informed consent for participation in the study. Capacity to participate in a focus group will be determined by the clinician using a standard assessment tool as part of routine care
- Adults, aged 18 years or above
- Clinical condition: Diagnosed with stroke within the previous 5 years, with a minimum of 6 weeks post-discharge from stroke unit/hospital to home

6.3 EXCLUSION CRITERIA

The participant may not enter the study if ANY of the following apply:

- People with aphasia with no effective alternative means of communication, or severe cognitive impairment as assessed by the clinician, that would prevent them from providing informed consent or from participating in a focus group and Delphi survey.

Delphi survey
Participants for the Delphi survey will comprise registered healthcare professionals (HCPs). These will be people with at least 12 months' experience, knowledge and expertise in the management of stroke and will include physicians, neurologists, stroke physicians, neurosurgeons, general practitioners, specialist stroke nurses, ward nurses, community nurses, physiotherapists, occupational therapists, speech and language therapists, and pharmacists. Criteria for entry of HCPs into the Delphi survey will be listed on a start web page prior to entry into the study, which will include professional title/role, grade/banding and time in post. Participants will also include the stroke survivors who have already participated in the focus groups.
The literature provides a range of participant sample sizes for Delphi surveys (from 10 to 500) with no agreement on what the sample size should be (Keeney et al., 2011). For homogeneous samples, 10-15 participants are recommended (Keeney et al., 2011), but for the purposes of this study a target number of 30 participants is aimed for which will allow for sufficient scientific rigour.

6.4 RECRUITMENT TECHNIQUE

Focus groups
Participants for the focus groups will be recruited from NHS stroke follow up clinics in Liverpool (Liverpool University Hospitals NHS Foundation Trust and St Helens and Knowsley Teaching Hospitals NHS Trust) as patients attending these clinics will have been discharged from the stroke unit at least 6 weeks prior to recruitment. Up to 10 participants will be recruited purposively for each focus group and a planned number of 3 focus groups will be held.

Delphi survey
Recruitment for the Delphi study is planned by identifying eligible HCP participants (members of stroke management teams) from NHS stroke units at Liverpool University Hospitals NHS Foundation Trust and St Helens and Knowsley Teaching Hospitals NHS Trust).

6.5 PARTICIPANT IDENTIFICATION

Focus groups

Eligible participants for the focus groups will be identified by the clinician according to the inclusion criteria stated in Section 6.2. Those wishing to know more about the study will be introduced to the researcher, who will be present in the clinic and will provide an information pack including a participant information sheet and an informed consent form. The researcher will request permission to contact the participant by telephone 48-72 hours later to discuss informed consent. When telephoning, the researcher will discuss the content of the consent form with the participant to check for understanding. If they wish to continue, they will be invited to attend a focus group. Written informed consent will then be taken by the researcher in person on the day of arrival prior to the commencement of the focus group.

Delphi survey

The lead stroke clinician in each Trust will make their colleagues aware of the study via internal communications and the distribution of an invitation letter by email. The letter will include researcher contact details for all staff who wish to be considered for participation in the study. It will be made clear that due to the purposive nature of the sampling approach that not all staff will be invited to participate. In addition, invitations will be sent more widely to the British Association of Stroke Physicians (BASP), corresponding authors for the RCP National Clinical Guidelines for Stroke, Cochrane reviews for stroke care interventions, members of UK Stroke Research Groups (including for example, Cambridge, Bristol, Kings College London), and other relevant organisations such as Stroke Getting it Right First Time (GIRFT).

6.6 SCREENING AND ELIGIBILITY ASSESSMENT

Capacity of a stroke survivor to participate in the focus group and Delphi survey will be determined by the clinician. This may result in reference to assessments such as the Montreal Cognitive Assessment (MOCA), modified Rankin Scale (mRS) and National Institute of Health Stroke Scale (NIHSS) as examples, which will have been performed upon admission of the patient to the stroke unit and 24 hours later for some tests.

6.7 INFORMED CONSENT

Focus groups

Following identification of an eligible participant by their clinician and being introduced to the researcher, each participant will be provided with a participant information sheet outlining the study design and an informed consent form by the researcher. The researcher will describe the exact nature of the study; what it will involve for the participant; the implications and constraints of the protocol; and any risks involved in taking part the study. The participants will be given 48-72 hours to decide if they would like to participate in the study. The contact details of the researcher will be given should the participant have any questions about the study.

The researcher will request permission to contact the participant by telephone within 48-72 hours of the initial meeting to discuss informed consent and to gain verbal consent from the participant, with the discussion being recorded to document that consent has been given. When this is granted, the researcher will discuss the content of the consent form with the participant to check for understanding. Written informed consent will then be taken by the researcher in person on the day of arrival prior to the commencement of the focus group. A copy of the signed Informed Consent will be given to the participant.

Original signed consent forms will be retained by the researcher according to LJMU recommendations, stored in a locked cupboard or filing cabinet to which only authorised individuals (researcher and supervisors) have access.

Delphi survey

The electronic design of the survey will ensure that participants will initially have to go through a formal procedure (reading and understanding an informed consent statement and clicking on a check box) to indicate consent with participation before being able to access the survey and its associated information.

Participants will also include a purposive sample of the stroke survivors who participated in the focus groups. At the end of the focus groups participants will be provided with information about the Delphi survey and asked if they would like to be contacted at a future date to discuss their involvement. For those wishing to

know more about the Delphi survey, the researcher will make contact by telephone to outline the Delphi survey and discuss the content of the consent form with the participant to check for understanding. Informed consent will be gained verbally with the discussion being recorded to document that consent has been given. The participant will be asked to sign and date a consent form and return it to the researcher in a prepaid envelope if the participant wishes to complete a paper-based survey. For those wishing to complete the electronic survey, consent will be given by checking a tick box on a web start page prior to accessing the survey and its contents.

6.8 Discontinuation/withdrawal of participants from study

It will be clearly stated that the participant is free to withdraw from the study at any time for any reason without prejudice to future care, without affecting their legal rights, and with no obligation to give the reason for withdrawal. The reason for withdrawal by researcher (and by participant, if this information is volunteered) will be recorded in a study file.

7 DATA MANAGEMENT

7.1 Access to data

Direct access will be granted only to the research team, authorised representatives from the Sponsor and host institution for monitoring and/or audit of the study to ensure compliance with regulations.

7.2 Data recording and record keeping

All proposed data collection will be made explicit in the participant information sheet. Personal data will be handled according to GDPR regulations, involving pseudo-anonymisation by the co-investigator to protect the privacy of the participant. Any personal and recorded data obtained during the focus groups and administration of the Delphi survey will be kept in secure encrypted or password-protected files on the university server. The storage of data will be kept in accordance with the University retention of research data policy (5 years) and will be securely destroyed when not required.

8 SAFETY REPORTING

Due to the design and qualitative nature of the study and given that no interventions will be administered to participants, Adverse Events, Adverse Reactions and Serious Adverse Events are not expected. There is, however, the possibility that a participant may become distressed during the focus group meeting and this situation will be managed as outlined in section 10.2 below.

9 QUALITY ASSURANCE PROCEDURES

The study is subject to scrutiny by the sponsor who may monitor and evaluate whether the study is being conducted in accordance with the current approved protocol, GCP, relevant regulations and standard operating procedures, and that approved and correct versions of documents such as participant information sheets and informed consent forms are being used. The sponsor will also verify that study data are being stored correctly as per sponsor guidelines.

10 ETHICAL AND REGULATORY CONSIDERATIONS

10.1 Declaration of Helsinki

The researcher will ensure that this study is conducted in accordance with the principles of the Declaration of Helsinki and relevant regulations.

10.2 Assessment and management of risk

Stroke is a traumatic event and so there is the possibility that participants will become distressed when recalling past events. Should a participant become agitated or upset at any time when talking about their

experiences, the researcher will discreetly ask the participant if they wish to leave the focus group. The participant will be provided with support by a fellow member of the research team signposting to a suitable resource such as the Stroke Association. If they do not have a carer or family member present, they will be asked if they would like the researcher to contact the carer or their GP. A quiet space or separate quiet room will also be made available to the participant if needed. The participant is free to withdraw from the focus group and the study if they wish to do so.

10.3 Participant confidentiality

Participants will be assured that any personal data collected which could identify them such as their name will be treated as confidential and handled in line with General Data Privacy Regulation (GDPR), Data Protection Act (1998) and LJMU guidance. In order to maintain confidentiality of participants' personal data, the data will be coded, linked to information that can be used to identify the individual and the link will be stored in a folder on an encrypted university computer with access strictly limited to the researcher and the supervisory team.

10.4 Expenses and benefits

Focus groups

To facilitate participation, transportation to and from the meeting venue by taxi will be provided for each participant. Alternatively, any travel expenses incurred by the participant using their own preferred mode of transport, for example car or public transport, will be reimbursed via a claimant form and a payment in the form of a voucher or gift card (value £25) as an incentive to participate will be provided to the participant in accordance with university guidance.

Delphi survey

It is stated in the literature that one of the challenges of questionnaire-based research is low response rates, with some participants needing to be reminded repeatedly (McKenna et al., 2001; Keeney et al., 2006). As an incentive to participate in all rounds of the Delphi survey, participants will be advised that they will be entered into a prize draw after completing all of the survey rounds (first prize will be a £100 gift card, with a second prize of £75 and a third prize of £50). In addition, non-responders will be followed-up to promote high compliance and a target of 70% compliance is proposed to maintain rigour whilst accepting that there are no specific guidelines to define an appropriate response level for Delphi surveys (Keeney et al., 2011).

10.5 Other ethical considerations

The researcher involved in recruiting participants to this study will have completed the National Institute for Health Research (NIHR) Good Clinical Practice (GCP) training and will have achieved certification.

10.6 Research Ethics Committee (REC) and other regulatory review & reports

Before the start of the study, a favourable opinion will be sought from a REC for the study protocol, informed consent forms and other relevant documents such as advertisements. Approval will be obtained from LJMU REG (and Co-Sponsors) for any amendments to, or changes of status in the study **prior to** submission to the REC that ethically approved the study and any other regulatory authorities. All correspondence will be retained.

Upon the completion of the study (in this study, the date of the completion of analysis of all data collected during the study) an End of Study Declaration (within 90 days of the end of the study) and End of Study Report (within 12 months of the end of the study) will be submitted to the NHS REC which gave the favourable opinion and LJMU REG (sponsor@ljmu.ac.uk)

Early termination or suspension of the research will be reported to all relevant review bodies and the Sponsor (sponsor@ljmu.ac.uk) within 15 days.

11 SCIENTIFIC REVIEW

The study was reviewed by the PhD supervisory team (Level 2) comprising Dr K Higginbotham, Prof ID Jones, Br BJB Buckley and Prof GYH Lip. The study was also reviewed by the LJMU Ethics Committee as part of the sponsorship application.

Level 1 No Peer Review Required – minimal risk (no patient contact)	**Level 2 Review by project supervisor** (student projects with either no or minor patient/participant involvement)	**Level 3 Review by departmental colleague** (Low-risk projects with minimal patient involvement)	**Level 4 External, independent peer review**
Short questionnaire studies for use among hospital staff or GPs.	Human tissue samples [anonymous to investigator]	Human tissue samples [anonymous to investigator]	Clinical trial of an investigational medicinal product
Questionnaires asking patients about the quality of hospital services.	Study administering questionnaires	Study administering questionnaires	Clinical trial of a medical device
Use of data from medical notes by clinician looking after patient.	Qualitative study	Qualitative study	Performance Evaluation of an in vitro diagnostic device
	Study limited to working with data	Study limited to working with data	Other clinical trial or clinical investigation
		Non-intimate examination techniques, e.g. blood pressure measurement.	Research Tissue Bank
			Human tissue (tissue samples and data) [newly obtained, identifiable or obtained from surplus]

12 PATIENT & PUBLIC INVOLVEMENT

During the development of the protocol, members of a stroke PPI group were consulted about suitability of focus meeting facilities on LJMU campus and on the appropriate duration of the meetings.

13 PROTOCOL COMPLIANCE

Accidental protocol deviations can happen at any time. They will be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.
Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

14 INSURANCE

Table 11.1

The research study includes the following:	Please state YES or NO to at least one.
treating or preventing disease or diagnosing disease	
ascertaining the existence degree of or extent of a physiological condition	
assisting with or altering in any way the process of conception	
investigating or participating in methods of contraception	
inducing anaesthesia	
otherwise preventing or interfering with the normal operation of a physiological function	
None of the above	YES

LJMU has Public Liability insurance to cover the legal liability of the University as Research Sponsor in the eventuality of harm to a research participant arising from management and design of the research by the University and the activities here are included within that coverage.
LJMU's Public Liability and Professional Indemnity insurance policies provide an indemnity to our employees and students for their potential liability for harm to participants during the conduct of the research and the activities here are included within that coverage.

15 FINANCING

The cost of the study will be met by LJMU as the Funder.
University costs include the following:

- Payment of £25 in the form of a gift card to each focus group participant (maximum amount £750)
- Reimbursement of reasonable travel expenses incurred by focus group participants (estimated £500)
- Prize fund for participation in Delphi survey (total cost £225)

16 CONTRACTS AND AGREEMENTS

There is a requirement for a research passport (honorary research contract or letter of access) in order to undertake the research within the NHS in the following Trusts:

- Liverpool University Hospitals NHS Foundation Trust
- St Helens and Knowsley Teaching Hospitals NHS Trust

17 DEFINITION OF END OF STUDY

The end of study is the date of completion of the final analysis of all data collected during the study.

18 END OF STUDY AND ARCHIVING

The storage of data will be kept in accordance with the University retention of research data policy (5 years) and will be securely destroyed when not required.

19 ACCESS TO THE FINAL STUDY DATASET

The Investigator and the supervisory team will have full access to the final study data set without restriction. All patient documentation will reflect the future use of these data in research.

20 DISSEMINATION POLICY

The study findings will be disseminated to each individual participant by letter (postal or electronic depending on preference). An open invitation will be extended to all participants (including those participating in the Delphi survey) to join the researchers at the university, where the findings will be presented. The findings will be presented at conferences as abstracts or posters and manuscripts will be prepared for submission for

publication in healthcare journals. Presentations will not include personal details. Names will be changed to protect anonymity.

21 AUTHORSHIP ELIGIBILITY GUIDELINES AND ANY INTENDED USE OF PROFESSIONAL WRITERS

The Investigators and supervisory team will be involved in reviewing drafts of the manuscripts, abstracts, press releases and any other publications arising from the study. Authorship will be determined in accordance with the ICMJE guidelines and other contributors will be acknowledged.

22 REFERENCES

Abdul Aziz, A.F., Mohd Nordin, N.A., Muhd Nur, A., Sulong, S. and Aljunid, S.M. (2020) The integrated care pathway for managing post stroke patients (iCaPPS©) in public primary care Healthcentres in Malaysia: impact on quality adjusted life years (QALYs) and cost effectiveness analysis. *BMC Geriatrics*, 20 (1), 1-10.

Baeten, S.A., van Exel, N.J., Dirks, M., Koopmanschap, M.A., Dippel, D.W. and Niessen, L.W. (2010) Lifetime health effects and medical costs of integrated stroke services - a non-randomized controlled cluster-trial based life table approach. *Cost Eff Resour Alloc*, 8, 21.

Barbour, R. (2018) *Doing Focus Groups*. London: Sage.

Beiderbeck, D., Frevel, N., von der Gracht, H.A., Schmidt, S.L. and Schweitzer, V.M. (2021) Preparing, conducting, and analyzing Delphi surveys: Cross-disciplinary practices, new directions, and advancements. *MethodsX*, 8, 101401.

Bindawas, S.M., Vennu, V. and Moftah, E. (2017) Improved functions and reduced length of stay after inpatient rehabilitation programs in older adults with stroke: A systematic review and meta-analysis of randomized controlled trials. *NeuroRehabilitation*, 40 (3), 369-390.

Bowen, J. and Yaste, C. (1994) Effect of a stroke protocol on hospital costs of stroke patients. *Neurology*, 44 (10), 1961-1964.

Braun, V. and Clarke, V. (2019) Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11 (4), 589-597.

Braun, V. and Clarke, V. (2022) *Thematic Analysis*. London: Sage Publications.

Buckley, B.J.R., Harrison, S.L., Fazio-Eynullayeva, E., Underhill, P., Lane, D.A., Thijssen, D.H.J.et al. (2021) Exercise-Based Cardiac Rehabilitation Associates with Lower Major Adverse Cardiovascular Events in People with Stroke. *Cerebrovasc Dis*, 1-5.

Buckley, B.J.R., Harrison, S.L., Hill, A., Underhill, P., Lane, D.A. and Lip, G.Y.H. (2022) Stroke-Heart Syndrome: Incidence and Clinical Outcomes of Cardiac Complications Following Stroke. *Stroke*.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S.et al. (2020) Purposive sampling: complex or simple? Research case examples. *J Res Nurs*, 25 (8), 652-661.

Catangui, E.J. and Slark, J. (2012) Nurse-led ward rounds: a valuable contribution to acute stroke care. *British Journal of Nursing*, 21 (13), 801-805.

Cecchi, F., Diverio, M., Arienti, C., Corbella, E., Marrazzo, F., Speranza, G.et al. (2020) Development and implementation of a stroke rehabilitation integrated care pathway in an Italian no profit institution: an observational study. *European journal of physical and rehabilitation medicine*, 56 (6), 713-724.

Chen, L., Xiao, L.D. and Chamberlain, D. (2020) An integrative review: Challenges and opportunities for stroke survivors and caregivers in hospital to home transition care. *J Adv Nurs*, 76 (9), 2253-2265.

Clarke, D.J. and Forster, A. (2015) Improving post-stroke recovery: the role of the multidisciplinary health care team. *J Multidiscip Healthc*, 8, 433-442.

Cooper, I.D. and Johnson, T.P. (2016) How to use survey results. *J Med Libr Assoc*, 104 (2), 174-177.

de Belvis, A.G., Lohmeyer, F.M., Barbara, A., Giubbini, G., Angioletti, C., Frisullo, G.et al. (2019) Ischemic stroke: clinical pathway impact. *International Journal of Health Care Quality Assurance (09526862)*, 32 (3), 588-598.

de Mooij, M.J., Ahayoun, I., Leferink, J., Kooij, M.J., Karapinar-Carkit, F. and Van den Berg-Vos, R.M. (2021) Transition of care in stroke patients discharged home: a single-center prospective cohort study. *BMC Health Serv Res*, 21 (1), 1350.

de Villiers, M.R., de Villiers, P.J. and Kent, A.P. (2005) The Delphi technique in health sciences education research. *Med Teach*, 27 (7), 639-643.

Deng, A., Yang, S. and Xiong, R. (2020) Effects of an integrated transitional care program for stroke survivors living in a rural community: a randomized controlled trial. *Clinical Rehabilitation*, 34 (4), 524-532.

Edwards, J.D., Kapral, M.K., Fang, J. and Swartz, R.H. (2017) Long-term morbidity and mortality in patients without early complications after stroke or transient ischemic attack. *CMAJ*, 189 (29), E954-E961.

Eubank, B.H., Mohtadi, N.G., Lafave, M.R., Wiley, J.P., Bois, A.J., Boorman, R.S.et al. (2016) Using the modified Delphi method to establish clinical consensus for the diagnosis and treatment of patients with rotator cuff pathology. *BMC Med Res Methodol*, 16, 56.

Falconer, J.A., Roth, E.J., Sutin, J.A., Strasser, D.C. and Chang, R.W. (1993) The critical path method in stroke rehabilitation: lessons from an experiment in cost containment and outcome improvement. *QRB Qual Rev Bull*, 19 (1), 8-16.

Feigin, V.L., Nguyen, G., Cercy, K., Jonson, C.O., Alam, T., Parmar, P.G.et al. (2018) Global, Regional, and Country-Specific Lifetime Risks of Stroke, 1990 and 2016. *New England Journal of Medicine*, 379 (25), 2429-2437.

Feigin, V.L., Stark, B.A., Johnson, C.O., Roth, G.A., Bisignano, C., Abady, G.G.et al. (2021) Global, regional, and national burden of stroke and its risk factors, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Neurology*, 20 (10), 795-820.

Field, M., Kuduvalli, M., Torella, F., McKay, V., Khalatbari, A. and Lip, G.Y.H. (2022) Integrated Care Systems and the Aortovascular Hub. *Thromb Haemost*, 122 (2), 177-180.

Ganesh, A., Lindsay, P., Jiming, F., Kapral, M.K., Côté, R., Joiner, I.et al. (2016) Integrated systems of stroke care and reduction in 30-day mortality: A retrospective analysis. *Neurology*, 86 (10), 898-904.

Gilham, S.C., L. (2021) Psychological care after stroke: Improving stroke services for people with cognitive and mood disorders. *NHS Improvement - Stroke*.

Gluyas, H. (2015) Patient-centred care: improving healthcare outcomes. *Nursing Standard*, 30 (4), 50-59.

Green, B., Jones, M., Hughes, D. and Williams, A. (1999) Applying the Delphi technique in a study of GPs' information requirements. *Health Soc Care Community*, 7 (3), 198-205.

Guo, Y., Zhang, Z., Lin, B., Mei, Y., Liu, Q., Zhang, L.et al. (2021) The Unmet Needs of Community-Dwelling Stroke Survivors: A Systematic Review of Qualitative Studies. *Int J Environ Res Public Health*, 18 (4).

Hasson, F., Keeney, S. and McKenna, H. (2000) Research guidelines for the Delphi survey technique. *J Adv Nurs*, 32 (4), 1008-1015.

Heijnen, R., Limburg, M., Evers, S., Beusmans, G., van der Weijden, T. and Schols, J. (2012) Towards a better integrated stroke care: the development of integrated stroke care in the southern part of the Netherlands during the last 15 years (Special 10th Anniversary Edition paper). *International journal of integrated care*, 12, e123.

Heo, N.H., Lee, M.R., Yang, K.H., Hong, O.R., Shin, J.H., Lee, B.Y.et al. (2021) Short- and long-term mortality after intravenous thrombolysis for acute ischemic stroke: A propensity score-matched cohort with 5-year follow-up. *Medicine (Baltimore)*, 100 (44), e27652.

Jang, Y.J., Park, D., Kim, H.S., Lee, C.H., Byun, H.Y., Yoon, C.H.et al. (2020) Assessment of the Implementation of Critical Pathway in Stroke Patients: A 10-Year Follow-Up Study. *BioMed Research International*, 1-9.

Joubert, J., Davis, S.M., Donnan, G.A., Levi, C., Gonzales, G., Joubert, L.et al. (2020) ICARUSS: An effective model for risk factor management in stroke survivors. *INTERNATIONAL JOURNAL OF STROKE*, 15 (4), 438-453.

Kamel, H., Okin, P.M., Elkind, M.S. and Iadecola, C. (2016) Atrial Fibrillation and Mechanisms of Stroke: Time for a New Model. *Stroke*, 47 (3), 895-900.

Katzan, I.L., Youran, F., Speck, M., Morton, J., Fromwiller, L., Urchek, J.et al. (2015) Electronic Stroke CarePath: Integrated Approach to Stroke Care. *Circulation: Cardiovascular Quality & Outcomes*, 8, S179-S189.

Keeney, S., Hasson, F. and McKenna, H. (2006) Consulting the oracle: ten lessons from using the Delphi technique in nursing research. *J Adv Nurs*, 53 (2), 205-212.

Keeney, S., Hasson, F. and McKenna, H. (2011) *The Delphi Technique in Nursing and Health Research*. Wiley-Blackwell.

Kreuger, R.A. (2002) Designing and Conducting Focus group Interviews. [online], Available at: https://www.eiu.edu/ihec/Krueger-FocusGroupInterviews.pdf

Liamputtong, P. (2011) *Focus Group Methodology: Principles and Practice*. London: Sage.

Lip, G.Y.H., Lane, D.A., Lenarczyk, R., Boriani, G., Doehner, W., Benjamin, L.A.et al. (2022) Integrated care for optimizing the management of stroke and associated heart disease: a position paper of the European Society of Cardiology Council on Stroke. *Eur Heart J*.

Lip, G.Y.H. and Ntaios, G. (2022) "Novel Clinical Concepts in Thrombosis": Integrated Care for Stroke Management-Easy as ABC. *Thrombosis and haemostasis*, 122 (3), 316-319.

Lived experience of stroke report. (2019) *UK Stroke Association*.

Maguire, M. and Delahunt, B. (2017) Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars. *All Ireland Journal of Higher Education*, 9 (3), 3351-33514.

Markle-Reid, M., Valaitis, R., Bartholomew, A., Fisher, K., Fleck, R., Ploeg, J.et al. (2020) An integrated hospital-to-home transitional care intervention for older adults with stroke and multimorbidity: A feasibility study. *Journal of Comorbidity*, 10, 1-21.

Masiliunas, R., Vilionskis, A., Bornstein, N.M., Rastenyte, D. and Jatuzis, D. (2022) The impact of a comprehensive national policy on improving acute stroke patient care in Lithuania. *EUROPEAN STROKE JOURNAL*.

McKenna, H., Bradley, M. and Keeney, S. (2001) *Primary Care Nursing: A Study Exploring Key Issues for Future Developments*. Ulster, University of Ulster.

McKenna, H. and Hasson, F. (2002) A study of skill mix issues in midwifery: a multimethod approach. *J Adv Nurs*, 37 (1), 52-61.

McKenna, H.P. (1994) The essential elements of a practitioners' nursing model: a survey of psychiatric nurse managers. *J Adv Nurs*, 19 (5), 870-877.

Modrego, P.J., Pina, M.A., Mar Fraj, M. and Llorens, N. (2000) Type, causes, and prognosis of stroke recurrence in the province of Teruel, Spain. A 5-year analysis. *Neurological Sciences*, 21 (6), 355-360.

Mofidi, R., Thomas, M., Wong, P.F., Bergin, A. and Young, G. (2018) Do Integrated Systems of Stroke Care Improve Symptom to Surgery Times in Patients with Symptomatic Carotid Stenosis? A Single Centre Decision Tree Analysis. *European journal of vascular and endovascular surgery : the official journal of the European Society for Vascular Surgery*, 56 (6), 784-792.

Mohan, K.M., Wolfe, C.D., Rudd, A.G., Heuschmann, P.U., Kolominsky-Rabas, P.L. and Grieve, A.P. (2011) Risk and cumulative risk of stroke recurrence: a systematic review and meta-analysis. *Stroke*, 42 (5), 1489-1494.

Morris, S., Ramsay, A.I.G., Boaden, R.J., Hunter, R.M., McKevitt, C., Paley, L.et al. (2019) Impact and sustainability of centralising acute stroke services in English metropolitan areas: retrospective analysis of hospital episode statistics and stroke national audit data. *BMJ*, 364, l1.

NHS (2021a) *National Stroke Service Model: Integrated Stroke Delivery Networks* [online] Available at: https://www.england.nhs.uk/wp-content/uploads/2021/05/national-stroke-service-model-integrated-stroke-delivery-networks-may-2021.pdf [Accessed: December 2022]

NHS (2021b) *Personalised Care and Support Planning* [online] Available at: https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/ [Accessed: June 2022]

Odderson, I.R. and McKenna, B.S. (1993) A model for management of patients with stroke during the acute phase. Outcome and economic implications. *Stroke*, 24 (12), 1823-1827.

Papathanasiou, I. (2013) Holistic Nursing Care: Theories and Perspectives. *American Journal of Nursing Science*, 2 (1), 1.

Patel, A., Berdunov, V., Quayyum, Z., King, D., Knapp, M. and Wittenberg, R. (2020) Estimated societal costs of stroke in the UK based on a discrete event simulation. *Age and Ageing*, 49 (2), 270-276.

Pearson, S.D., Goulart-Fisher, D. and Lee, T.H. (1995) Critical pathways as a strategy for improving care: problems and potential. *Ann Intern Med*, 123 (12), 941-948.

Peterson-Burch, F., Reuter-Rice, K. and Barr, T.L. (2017) Rethinking Recovery. *Holistic Nursing Practice*, 31 (1), 3-6.

Pindus, D.M., Mullis, R., Lim, L., Wellwood, I., Rundell, A.V., Abd Aziz, N.A.et al. (2018) Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services – A systematic review and meta-ethnography. *PloS one*, 13 (2), e0192533.

Proudfoot, K. (2022) Inductive/Deductive Hybrid Thematic Analysis in Mixed Methids Research. *Journal of Mixed Methods Research*, 0 (0), 1-19.

Reid, M., Valaitis, R., Bartholomew, A., Fisher, K., Fleck, R., Ploeg, J.et al. (2019) Implementation and evaluation of an integrated hospital-to-home transitional care intervention for older adults with stroke and multimorbidity: a feasibility study. *International Journal of Integrated Care (IJIC)*, 19 (S1), 1-2.

Romiti, G.F., Pastori, D., Rivera-Caravaca, J.M., Ding, W.Y., Gue, Y.X., Menichelli, D.et al. (2022) Adherence to the 'Atrial Fibrillation Better Care' Pathway in Patients with Atrial Fibrillation: Impact on Clinical Outcomes-A Systematic Review and Meta-Analysis of 285,000 Patients. *Thromb Haemost*, 122 (3), 406-414.

Ross, G., Johnson, D. and Kobernick, M. (1997) Evaluation of a critical pathway for stroke. *J Am Osteopath Assoc*, 97 (5), 269-272, 275-266.

Samsa, G.P., Bian, J., Lipscomb, J. and Matchar, D.B. (1999) Epidemiology of recurrent cerebral infarction: a medicare claims-based comparison of first and recurrent strokes on 2-year survival and cost. *Stroke*, 30 (2), 338-349.

Stewart, D.W. and Shamdasani, P.M. (2015) *Focus Groups: Theory and Practice*. London: Sage.

Stroke Pathway. (2021) *NHS RightCare*. [online]. Available at: https://www.england.nhs.uk/rightcare/products/pathways/stroke-pathway/ [Accessed September 2022]

Sulch, D. and Kalra, L. (2000) Integrated care pathways in stroke management. *Age Ageing*, 29 (4), 349-352.

Summers, D. and Soper, P.A. (1998) Implementation and evaluation of stroke clinical pathways and the impact on cost of stroke care. *J Cardiovasc Nurs*, 13 (1), 69-87.

van Exel, N.J., Koopmanschap, M.A., Scholte op Reimer, W., Niessen, L.W. and Huijsman, R. (2005) Cost-effectiveness of integrated stroke services. *QJM*, 98 (6), 415-425.

Vos, L., Van Oostenbrugge, R.J., Limburg, M., Van Merode, G.G. and Groothuis, S. (2009) How to implement process-oriented care. *Accreditation and Quality Assurance*, 14 (1), 5-13.

Wentworth, D.A. and Atkinson, R.P. (1996) Implementation of an acute stroke program decreases hospitalization costs and length of stay. *Stroke*, 27 (6), 1040-1043.

Willeit, P., Toell, T., Boehme, C., Krebs, S., Mayer, L., Lang, C.et al. (2020) STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: A randomised clinical trial. *EClinicalMedicine*, 25, 100476.

Xu, X.M., Vestesson, E., Paley, L., Desikan, A., Wonderling, D., Hoffman, A.et al. (2018) The economic burden of stroke care in England, Wales and Northern Ireland: Using a national stroke register to estimate and report patient-level health economic outcomes in stroke. *Eur Stroke J*, 3 (1), 82-91.

23 APPENDICES

23.1 APPENDIX 1- REQUIRED DOCUMENTATION

Study protocol

Participant Information Sheet
Informed Consent Form
Study poster/flyer

23.2 Appendix 2 – schedule of procedures

Procedure	Timing	Average time per procedure
Participant information sheet	Initial recruitment	48-72 hours
Informed consent	Initial recruitment	30 minutes
Patient focus groups	Phase 1 (Weeks 0-9)	60-90 minutes
Delphi survey	Phase 2 (Weeks 10-24)	30-60 minutes

23.3 Appendix 3 – amendment history

Amendment No.	Protocol Version No.	Date issued	Author(s) of changes	Details of Changes made
1	1.1	20/07/2023	Ian Eustace	For HCPs, the wording has been amended in the protocol (version 1.1, Section 6.5, page 15/24) to state that *"The lead stroke clinician in each Trust will make their colleagues aware of the study via internal communications* ***and the distribution of an invitation letter by email.*** ~~*They will then provide a list of*~~ ***The letter will include researcher contact details*** *for all staff who wish to be considered for participation in the study"* **Section 5, page 11:** *"The focus groups will be digitally audio recorded using an encrypted University recording device. The recordings will be transcribed verbatim* ***by the researcher*** *and anonymised for analysis by assigning a pseudonym to each participant.* ***After transcription, the recording will be securely destroyed****."*

12.9 Appendix I: IRAS Approved Invitation Letter (Focus Groups)



LIVERPOOL JOHN MOORES UNIVERSITY

IRAS ID: 317528
LJMU's Research Ethics Committee Approval Reference:
NHS REC Reference: 23/EM/0171

Dear Patient,

We would like to invite you to participate in a focus group as part of a PhD research project. As a stroke survivor we are interested in hearing about your recovery journey from stroke as a participant in a focus group which will consist of other stroke survivors with whom you can share experiences. The information gained from this study will be used to inform the development of an integrated pathway aimed at improving the care of people with stroke.

In order to take part, we ask that you are aged 18 years or over, you are able to provide informed consent to participate in the study, you have been diagnosed with a stroke within the last 5 years and that you were discharged from hospital to home at least 6 weeks ago. If you choose to take part in the study, you will be invited to participate in a focus group with other stroke survivors. During the focus group you may be asked some questions about your stroke recovery and personal experiences. There are no right or wrong answers, we are just interested in your experiences and opinions. We will also contact your GP to inform them that you are participating in this research. The focus group will be audio-recorded, however if you do not feel comfortable with this, you are free to stop at any time and withdraw your participation. The focus group meeting will last for no more than 1.5 hours.

Expenses for travel such as taxi, public transport and car parking will be reimbursed for attending the focus group on production of receipts, or a mileage allowance provided as appropriate. You will also be reimbursed £25 as a gift card for attending the focus group to compensate for time.

Participation in this study is entirely voluntary and you can withdraw at any time without detriment to the care you receive. If you would like to participate in the focus group, please contact me using the details below.

Yours sincerely,

[redacted]

Version 1.0 29/06/2023

12.10 Appendix J: Participant Information Sheet (Focus Groups)

LIVERPOOL JOHN MOORES UNIVERSITY
Participant Information Sheet for Health Service User (Focus groups)

IRAS ID: 317528
LJMU's Research Ethics Committee Approval Reference:
NHS REC Reference: 23/EM/0171

Title of Study: Integrated care for patients following stroke

This study will look at what is important to people with stroke during their recovery journey. We will be bringing stroke survivors together to talk about their experiences using focus groups

You are being invited to take part in a research study. Before you decide it is important for you to understand why the study is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You do not have to take part if you do not want to. Please read this information, which will help you decide. Thank you for taking the time to read this.

1. What is the purpose of the study?
The care of people with stroke has improved dramatically in recent years, such as the establishment of acute stroke units and clot busting treatments. However, the management of people with stroke can be complicated since there are several different healthcare professionals involved in delivering the care across the hospital and home. This study aims to discover what really matters to people with stroke during their recovery. The information gained from this study will be used to inform the development of an integrated pathway aimed at improving the care of people with stroke.

This study is a PhD researcher-led study being conducted for the purpose of completing a doctorate degree programme and is funded by Liverpool John Moores University.

2. Why have I been invited to participate?
You have been invited because we are interested in hearing about your recovery journey from stroke as a participant in a focus group which will consist of other stroke survivors with whom you can share experiences. The inclusion criteria are:

- Provide informed consent to participate and be audio recorded during the focus group discussions
- Be aged 18-years and over.
- Have been diagnosed with a stroke within the last 5 years
- Have been discharged from the hospital to home at least 6 weeks ago

3. Do I have to take part?
No. It is up to you to decide whether or not to take part. You will be given this information sheet to take away and read.

4. What will happen to me if I take part?
If you choose to take part in the study, you will be invited to participate in a focus group with other stroke survivors. This will be held in a spacious and comfortable meeting room with easy access within the university building and will last for no more than 1.5 hours. During the focus

group you may be asked some questions about your stroke recovery and personal experiences. There are no right or wrong answers, we are just interested in your experiences and opinions. We will also contact your GP to inform them that you are participating in this research.

5. Payments, reimbursements of expenses or any other benefit or incentive for taking part

Expenses for travel such as taxi, public transport and car parking will be reimbursed for participants to attend the focus group on production of receipts, or a mileage allowance provided as appropriate. Participants will also be reimbursed £25 as a gift card for attending the focus group to compensate for time.

6. Will I be recorded and how will the recorded media be used?

The focus group will be audio-recorded, however if you do not feel comfortable with this, you are free to stop at any time and withdraw your participation. You will not be able to participate in the study if you later decide not to be audio recorded. The recording will be transcribed into a document by the research team and will be securely destroyed after transcription. Anything that identifies you individually will be deleted. All data collected will be securely stored on a password protected university server in an encrypted file. Only the research team will have access to the data to ensure confidentiality.

If you also wish to participate in the survey, any responses you provide will be anonymised and treated as strictly confidential.

7. Are there any possible disadvantages or risks from taking part?

Participating in the research is not anticipated to cause you any disadvantages or discomfort. However, discussing your stroke may bring about some uncomfortable conversations. Reliving events leading up to the stroke and living with stroke may cause you emotional distress. For this reason, you may choose not to participate in this study. If you do decide to participate, we can assure you that you will continue to be supported by contacting your health care team including your doctor and healthcare professionals who are expert in dealing with these matters. We will also make sure that you are put in touch with organisations who can help support you with your stroke recovery. If after taking part, you have any questions or concerns about stroke you can get information and advice from the organisations listed at the end of this sheet.

8. What are the possible benefits of taking part?

Whilst there will be no direct benefits to you for taking part in the study, it is hoped that this work will benefit other stroke survivors in the future by improving the care of people with stroke.

9. How will we use information about you?

We will need to use information from your patient notes by your doctor for this research project but we will not collect any of this information without your consent. This information will include race; ethnic origin; religion; age, ethnicity, sex, geographical location, name and address of your GP, and diagnosis. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. Your data will be stored in a password-protected university server. The researcher and the researcher's supervision team will be the only people that have access to the data. We will keep all information about you safe and secure.

Study data and records of consent will be kept securely for five years in line with university policy.

In addition, responsible members of Liverpool John Moores University may be given access to personal data for monitoring and/or audit of the study to ensure that the study is complying with applicable regulations.

We will not tell anyone (except informing your GP) that you have taken part in the focus group, although there is of course a possibility that another member of the group might recognise you. In addition, all participants in the focus group will be asked to respect the confidentiality of their fellow participants.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

With your consent, we would like to store your contact details so that we may contact you about the progress and the results of this study. Your details will be stored securely in a password-protected university server.

10. What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason. We will not collect any further information but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
You may withdraw from the study at any time by contacting the researcher by telephone, mobile [redacted] or email [redacted]

11. What will happen to the results of the study?
The researcher will use the results from this study to inform a new integrated care pathway for stroke patients. The study will also be published in the form of a thesis for the degree award of Doctor of Philosophy and as a journal article. The plan will be to write to you individually and let you know what we have found. We will also be sending out an invitation for you to join us here at the university where we can have an informal gathering and present informally the findings of this study.

12. Who has reviewed this study?
This study has been reviewed by, and received ethics clearance through, the university Research Ethics Committee (Reference number: EM/23/0171).

13. Whom do I contact if I have a concern about the study or I wish to complain?
If you have a concerns about any aspect of this study, please contact either myself on [redacted] or by email at [redacted] I will do my best to answer your query. You should expect a reply within 7 working days. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the university Research Ethics Committee who will seek to resolve the matter as soon as possible: Chair, university Research Ethics Committee; Email: FullReviewUREC@ljmu.ac.uk; Tel: 0151 231 2121; Research Innovation Services, Liverpool John Moores University, Exchange Station, Liverpool L2 2QP.

14. Where can you find out more about how your information is used?
Liverpool John Moores University is the data controller with respect to your personal data. More information about how we use your personal data is available from:

- https://www.ljmu.ac.uk/legal/privacy-and-cookies/external-stakeholders-privacy-policy/research-participants-privacy-notice
- www.hra.nhs.uk/information-about-patients/

- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the study team or contacting us using the information below

15. Contact for further information

[redacted]

If after taking part, you have any questions or concerns about stroke you can get information and advice from the following organisations:
Stroke Association: https://www.stroke.org.uk/

Thank you for reading this information sheet and for considering taking part in this study.

Note: A copy of the participant information sheet should be retained by the participant with a copy of the signed consent form.

12.11 Appendix K: Informed Consent Form (Focus Groups)

LIVERPOOL JOHN MOORES UNIVERSITY

Liverpool Centre for Cardiovascular Science

PARTICIPANT CONSENT FORM FOR FOCUS GROUPS (Patient)

Study title: Integrated care for patients following stroke
Research Ethics Committee Reference Number: 23/EM/0171

Principal Investigator: [redacted]
LJMU postgraduate research student
LJMU Email address: [redacted]

Supervisor Name: [redacted]

If you are happy to participate, please complete and sign the consent form below

		Please initial	
1.	I confirm that I have read the information sheet dated 24 May 2-23 (version 1.0) for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		
2.	I understand what taking part in the study involves		
3.	I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions I can withdraw from the study at any time, without giving a reason and without penalty or my legal rights being affected.		
4.	I understand that the process of informed consent will be undertaken on the telephone and will be audio recorded		
5.	I have been advised about potential risks associated with taking part in this study and have taken these into consideration before consenting to participate		
6.	I understand that the study involves taking audio recordings of me and I am happy to proceed. I understand that I will not be able to participate in the study if I later decide not to be audio recorded		
7.	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.		
8.	I understand that my information may be subject to review by responsible individuals from Liverpool John Moores University for monitoring and audit purposes		
9.	I agree for my contact details to be stored for the purpose of contacting me about this study	YES	NO
10.	I understand that personal data will remain confidential and that all efforts will be made to ensure I cannot be identified in reports or any further outputs		
11.	I understand that parts of our conversation will be used verbatim in future publications or presentations and that all efforts will be made to ensure I cannot be identified in reports or any further outputs		
12.	I agree to take part in this study		

Data Protection. Any personal information we collect and use to conduct this study will be processed in accordance with data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants.

Name of Participant Date Signature

For participants unable to sign their name, mark the box instead of signing ☐

I have witnessed the accurate reading of the consent form with the potential participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely

Name of Investigator Date Signature

Name of Person taking consent Date Signature
(if different from investigator)

12.12 Appendix L: Discussion Guide for Focus Group Meetings

Stroke Focus Group Discussion Guide

Welcome

Introductions (researcher and other research staff)

Our topic is: The journey of recovery from stroke

The purpose of this research is to discover what really matters to people with stroke during their recovery.
The information gained from this study will be used to inform the development of an integrated pathway aimed at improving the care of people with stroke
You have been invited because we are interested in hearing about your personal experiences of recovery from stroke

Guidelines

- There are no right or wrong answers, only differing opinions
- The meeting is being recorded, one person speaking at a time. If you are uncomfortable being recorded, please let us know
- You don't need to agree with others, but you must listen respectfully as others share their views
- We ask that you turn off your mobile devices or switch them to silent mode. If you must respond to a call, please do so as quietly as possible and rejoin us as quickly as you can
- Please avoid saying anything that may be upsetting for you or may cause you embarrassment
- Participation is entirely voluntary and you can withdraw at any time without detriment to the care you receive
- My role as a facilitator will be to guide the discussion
- Talk to each other

Questions

Can you tell me about your experiences of recovering from a stroke?

- Can you tell me about your stroke recovery journey (from when you were admitted to hospital to where you are now)?

Can you tell me what went well and what didn't go so well during your recovery?

- Did you encounter any problems during your stroke recovery? If so, can you talk about them?
- Can you think of anything that helped your stroke recovery? If so, can you talk about them?
- Looking back at your stroke recovery journey, is there anything you would want to change about the way you were cared for? If so, can you talk about them?

12.13 Appendix M: Example of Coding Using Word

Time since stroke Impact of stroke; balance problems Being in the right place Positive experience of stroke treatment Recovery from stroke Feeling lucky	00:05:38 Speaker 11 (ER): I'll go first. So my name's ER, I'm from Runcorn, um I'm 53 or 54, I'm at an age where I don't really pay much attention to those anniversaries and I had a stroke in June, um, which affected my balance, so among my physical attributes it was my balance that got messed up, um treated very well in Whiston, eventually, when I got to the right place, um and since then, uh, my recovery has been, I'm sure like you all, slow, sometimes forwards sometimes the odd step back but I'm in a better place than I was 5, 6 months ago. The contact I've had with the various different services that have helped me along the way have all been good and positive from the initial calls after the hospitals and physiotherapists, the Stroke Association have been getting in touch with me and seeing how I was doing really as much as anything else. I was in a lucky position, I didn't need that much physio, I didn't need that much help at all as I'd got family at home that could help me so I managed to maintain any kind of independence but nonetheless having that contact with somebody who was prepared to listen to you whinge if that's what you wanted to do or give you the right advice, that was all very positive. Looking back on the experience now, I think I am the sort of person who would have benefited at the start from saying, right, here's what's going to happen over the next 4 or 5 months;, here's what you can expect at various different times, here's how you can expect to recover at various different times and what that would have meant for me individually. Of course people are always willing to answer questions as best they could, um, but I think I would have benefited from a single point of contact saying here's where you are, here's where you got here maybe, and here's where you can expect to be in 6 months. Of course except that you can't always give guarantees, there aren't any guarantees in life especially when it comes to your body and whatnot but um, having that little glimmer of hope in the future from a voice of authority I think is, is uh, well I did get that eventually, that was beneficial to me, and here we are now. I'll enjoy the coffee and the cakes.
Not meeting expectations	00:08:26 Speaker 3 (AF): Can I ask you something. You know if they'd have told you that you'd have been there in 6 months' time and you wasn't, how would you have felt?
	00:08:35 Speaker 11 (ER): That is a problem, I full accept that is a problem with somebody in authority telling you exactly what's going to happen.
Not meeting expectations	00:08:44 Speaker 3 (AF): Yeah, or that the majority of people were there and you wasn't, wouldn't that have disheartened you?
	00:08:50 Speaker 11 (ER): Maybe, but I think I would, personally, the absence of uh anybody telling me that I found a bit more frustrating than knowing it and not reaching the target, you know if uh.....I fully understand why people couldn't tell me that, I get that, but if I could wave a magic wand, that's what I want. I want somebody saying here's where you are, if all things go well you can expect reasonably that within 6 months you will be in so and so position, but I do understand that's virtually impossible for anyone.

Coding	Transcript
Recognising that individual strokes are different Setting goals Not meeting expectations, demoralisation	00:09:49 Speaker 3 (AF): Everyone's different aren't they? I think that sometimes people need a goal to go to, personally I'd have felt very disheartened because if they'd have said to me you know, you'll be here in 6 months and I was only here, I'd have thought well this isn't going right, you know, I wouldn't have felt good about it, um, so I just used to say to them I'll see how things are, how me progress is meself, cause I'd feel disheartened me.
Recognising that individual strokes are different	00:10:12 Speaker 4 (JJ): Because everyone's different.
Recognising that individual strokes are different Setting goals	00:10:13 Speaker 3 (AF): Yeah everyone's different aren't they, some people just need a goal.
Fear Experiences of stroke Pre-stroke conditions Impact of stroke	00:10:27 Speaker 4 (JJ): Whatever the stroke's done to you, it's what's happened up here, that's the problem, and the thing I've always dreaded is that it's done some damage up here and therefore in years to come, it might affect Alzheimer's or something like that. That's my fear but I'll parallel exactly what's happened to you but my problem now is my pre stroke problems, I'm sort of feeling more than I did before. Uh, arthritis in the knee, balance problems which I had before the stroke are amplified now.
Impact of stroke	00:11:04 Speaker 11 (AF): Do you directly blame the stroke for.....?
Impact of stroke	00:11:08 Speaker 4 (JJ): Oh yes.
Impact of stroke	00:11:11 Speaker 3 (AF): Do you feel it's weakened a lot of other things?
Impact of stroke Pre-stroke conditions Positive experience of stroke treatment	00:11:18 Speaker 4 (JJ): Oh yes, I'm a lot slower and it's frustrating. I can't do the things.....I'm frustrated because I used to love gardening, but I've got to pay for it now, to pay for somebody to do what I used to do no problem and it's frustrating because they never do it right, never do it as good as you used to do, but those are the main things is that it's not so much the stroke as I think I've basically got round that, it's all these other things that I used to have cause I'm diabetic as well and you know it's played havoc with me at first. But I was up and walking around within 2 days of having the stroke at Whiston and I agree with you, it's first class they are, first class.
Positive experience of stroke treatment	00:12:15 Speaker 3 (AS): I agree with you there, can't fault the treatment in hospital.
Support	00:12:21 Speaker 4 (JJ): And I think the thing there is that you're in wards and you're in direct contact with the medical team, so they can see what's happening to you whereas at other hospitals you've got to wait until they come on their rounds.
Impact of stroke Being in the wrong place	00:12:38 Speaker 11 (ER): I agree with that. Whiston. I've got to admit that I had problems. It took a while to get to the right place for me because I had a couple of mini strokes first and then the big one here, so initially I got sent to Warrington.
Being in the wrong place	00:12:59 Speaker 4 (JJ): I refuse to go to Warrington.

reach for stroke recovery.

@mention or reply

Eustace, Ian

Expectations of stroke recovery, recognising limitations

@mention or reply

Eustace, Ian

Treatment of stroke, recognising limitations, expectations of stroke recovery, information seeking.

@mention or reply

Eustace, Ian

Impact of stroke, fear.

JJ is referring to the potential brain damage that

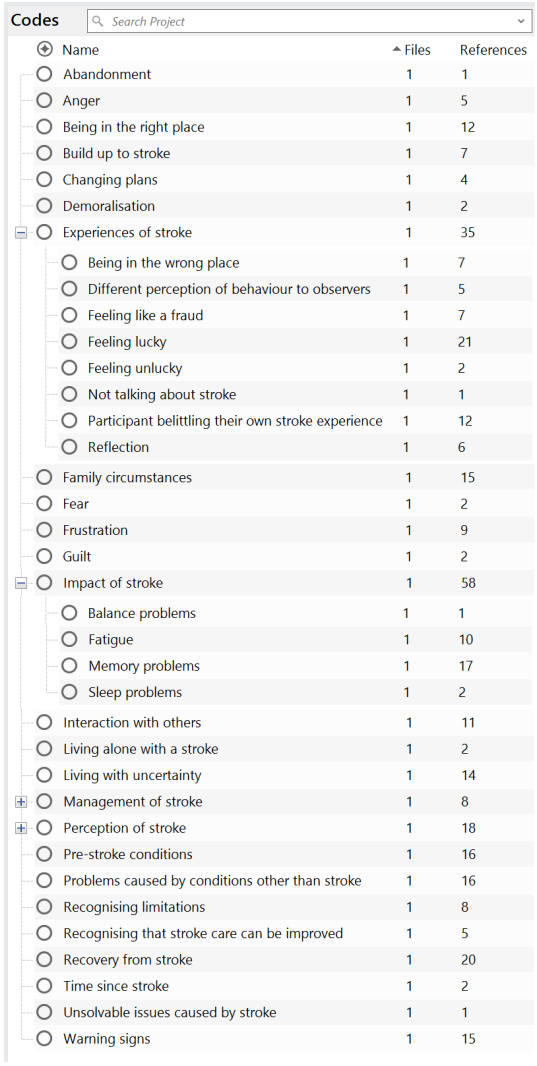
@mention or reply

Eustace, Ian

Frustration

This appears to be an example of loss of identity as JJ is remembering the person he used to be

12.14 Appendix N: Data Coding Comparison and Verification Using NVivo



IE: Yes we are.

ER: I'll go first. So my name's ER, I'm from Runcorn, um I'm 53 or 54, I'm at an age where I don't really pay too much attention to those anniversaries and I had a stroke in June, um, which affected my balance, so among my physical attributes it was my balance that got messed up, um treated very well in Whiston, eventually, when I got to the right place, um and since then, uh, my recovery has been, I'm sure like you all, slow, sometimes forwards sometimes the odd step back but I'm in a better place now than I was 5, 6 months ago. The contact I've had with the various different services that have helped me along the way have all been good and positive from the initial calls after I left hospital and physiotherapists, the Stroke Association have been getting in touch with me and seeing how I was doing really as much as anything else. I was in a lucky position, I didn't need that much physio, I didn't need that much help at all as I'd got family at home that could help me so I managed to maintain any kind of independence but nonetheless having that contact with somebody who was prepared to listen to you whinge if that's what you wanted to do or give you the right advice, that was all very positive. Looking back on the experience now, I think I am the sort of person who would have benefited at the start from saying, right, here's what's going to happen over the next 4 or 5 months, here's what you can expect at various different times, here's how you can expect to recover at various different times and what that would have meant for me individually. Of course people are always willing to answer questions as best they could, um, but I think I would have benefited from a single point of contact saying here's where you are, here's how you got here maybe, and here's where you can expect to be in 6 months. Of course except that you can't always give guarantees, there aren't any guarantees in life especially when it comes to your body and what not but um, having that little glimmer of hope in the future from a voice of authority I think is, is uh, well I did get that eventually, that was beneficial to me, and here we are now enjoying the coffee and the cakes.

AF: Can I ask you something. You know if they'd have told you that you'd have been there in 6 months' time and you wasn't, how would you have felt?

ER: That is a problem, I accept fully that is a problem with somebody in authority telling you exactly what's going to happen.

AF: Yeah, or that the majority of people were there and you wasn't, wouldn't that have disheartened you?

ER: Maybe, but I think I would, personally, the absence of uh anybody telling me that I found a bit more frustrating than knowing it and then not reaching the target, you know if uh.....I fully understand why people couldn't tell me that, I get that, but if I could wave a magic wand, that's what I'd want. I'd want somebody saying here's where you are, if all things go well you can expect reasonably that within 6 months you will be in so and so position, and in a year you'll be in so and so position, but I do understand that's virtually impossible for anyone.

AF: Everyone's different aren't they? I think that sometimes people need a goal to go to, personally I'd have felt very disheartened because if they'd have said to me you know, you'll be here in 6 months and I was only here, I'd have thought well this isn't going right, you know, I wouldn't have felt good about it, um, so I just used to say to them I'll see how things are, how me progress is meself, cause I'd feel disheartened me.

JJ: Because everyone's different.

AF: Yeah everyone's different aren't they, some people just need a goal.

JJ: Whatever the stroke's done to you, it's what's happened up here, that's the problem, and the thing I've always dreaded is that it's done some damage up here and therefore in years to come, it might affect Alzheimer's or something like that. That's my fear but I'll parallel exactly what's happened to you but my problem now is my pre-stroke problems, I'm sort of feeling more than I did before. Uh, arthritis in the knee, balance problems which I had before the stroke are amplified now.

AF: Do you directly blame the stroke for.....?

JJ: Oh yes.

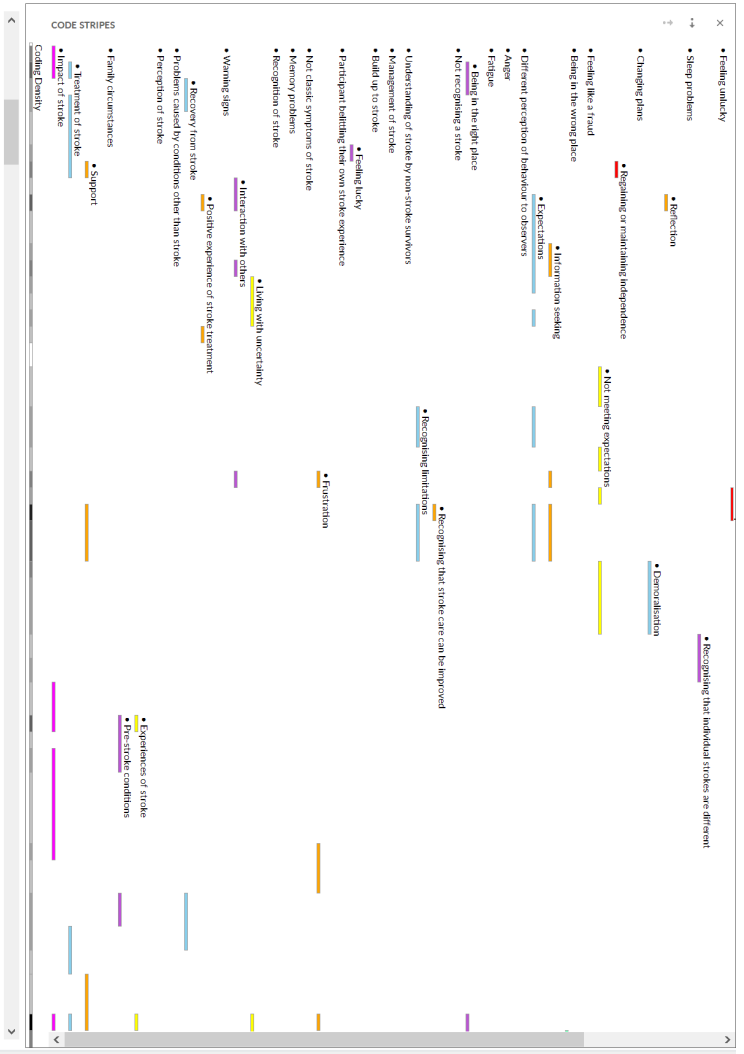
AF: Do you feel it's weakened a lot of other things?

JJ: Oh yes, I'm a lot slower and it's frustrating. I can't do the things.....I'm frustrated because I used to love gardening, but I've got to pay for it now, to pay for somebody to do what I used to do no problem and it's frustrating because they never do it right, never do it as good as you used to do, but those are the main things is that it's not so much the stroke because I think I've basically got round that, it's all these other things that I used to have cause I'm diabetic as well and you know it's played havoc with me at first. But I was up and walking around within 2 days of having the stroke at Whiston and I agree with you, it's first class they are, first class.

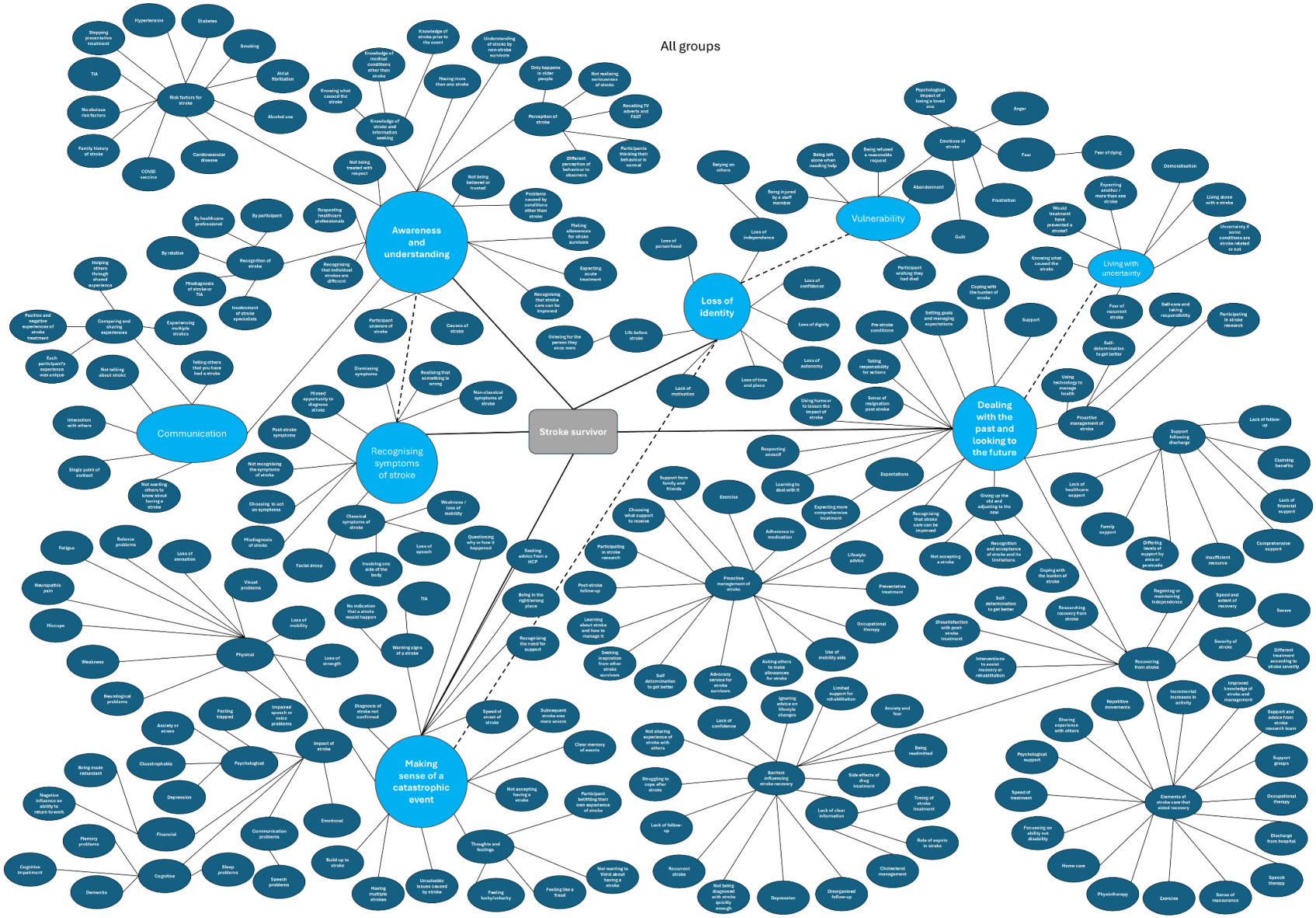
AS: I agree with you there, can't fault the treatment in hospital.

JJ: And I think the thing there is that you're in wards and you're in direct contact with the medical team, so they can see what's happening to you whereas at other hospitals you've got to wait until they come on their rounds.

ER: I agree with that. Whiston. I've got to admit that I had problems. It took a while to get to the right place for me



12.15 Appendix O: Thematic Mapping



12.16 Appendix P: Delphi Survey Invitation Letter (HCPs)



LIVERPOOL JOHN MOORES UNIVERSITY

IRAS ID: 317528
LJMU's Research Ethics Committee Approval Reference:
NHS REC Reference: 23/EM/0171

Dear Healthcare Professional,

We would like to invite you to participate in a Delphi consensus survey of integrated care in stroke as part of a PhD research project. As a healthcare professional with experience in the care of people living with stroke, we are keen to gain your views about how we should structure an integrated care pathway for stroke. Specifically, we would like to ask your views of proposed components of care that you would rate according to importance to include in the pathway.

All we ask is that you are a registered healthcare professional with a minimum of 12 months' experience in the management of people with stroke. If you choose to take part in the study, you will be invited to participate in a Delphi survey as a panel member. We realise that the professionals we are approaching are extremely busy in their respective fields, but because of the important input you can bring to the project we hope that you will agree to participate. In practical terms, we would require no more than two hours of your time, spread out over two to three separate occasions.

Each participant completing every round of the survey in full will be entered into a prize draw for the opportunity of winning first prize of a £100 gift card, with a second prize of £75 and a third prize of £50.

Participation in this study is entirely voluntary and you can withdraw at any time. If you would like to participate in the survey, please contact me by email or by using the contact details below.

Yours sincerely,

[redacted]

Version 1.0 29/06/2023

12.17 Appendix Q: Delphi Survey Participant Information Sheet (HCPs)

LIVERPOOL JOHN MOORES UNIVERSITY
Participant Information Sheet for Healthcare Professionals (Delphi survey)

IRAS ID: 317528
LJMU's Research Ethics Committee Approval Reference:
NHS REC Reference: 23/EM/0171

Title of Study: Integrated care for patients following stroke

This study will look at what is important to the management of people with stroke during their recovery journey from the viewpoint of healthcare professionals who care for them using a Delphi survey technique to obtain opinions on how integrated care in stroke should be structured and delivered.

1. What is the purpose of the study?
The care of people with stroke has improved dramatically in recent years, such as the establishment of acute stroke units and thrombolysis. However, the management of people with stroke can be complicated due to the multidisciplinary nature of healthcare professionals involved in delivering the care across the hospital and home. This study aims to discover the viable and feasible priorities of care for people with stroke during their recovery from the perspective of the healthcare professional. The information gained from this study will be used to inform the development of an integrated pathway for people with stroke.

This study is a PhD researcher-led study being conducted for the purpose of completing a doctorate degree programme and is funded by Liverpool John Moores University.

2. Why have I been invited to participate?
We would like to invite you to participate in a Delphi consensus survey. As a healthcare professional with experience in the care of people living with stroke we are keen to gain your views about how we should structure an integrated care pathway for stroke. Specifically, we would like to ask your views of proposed components of care that you would rate according to importance to include in the pathway. The inclusion criteria for the survey are:

- Registered healthcare professional with a minimum of 12 months' experience, in the management of stroke

3. Do I have to take part?
No. It is up to you to decide whether or not you wish to take part.

4. What will happen to me if I take part?
If you choose to take part in the study, you will be invited to participate in a Delphi survey as a panel member. The Delphi technique obtains consensus on the opinions of participants through a series of brief structured questionnaires. As part of the process, the responses from each questionnaire are fed back in summarised form to the participants who are then given an opportunity to respond again to the emerging data. This process would continue until a group consensus is achieved or four Delphi questionnaires have been completed. The Delphi is therefore an iterative multi-stage process designed to combine opinion into group consensus.
To allow timely conclusion of the study, we would respectfully request a response time of 2 weeks for completion of each questionnaire.

We realise that the professionals we are approaching are extremely busy in their respective fields, but because of the important input you can bring to the project we hope that you will agree to participate. In practical terms, we would require no more than two hours of your time, spread out over two to three separate occasions.

5. Payments, reimbursements of expenses or any other benefit or incentive for taking part

Each participant completing every round of the survey in full will be entered into a prize draw for the opportunity of winning first prize of a £100 gift card, with a second prize of £75 and a third prize of £50.

6. What are the possible benefits of taking part?

Whilst there will be no immediate benefits to you for taking part in the Delphi survey, it is hoped that this work will benefit healthcare professionals and stroke survivors in the future by improving the care of people with stroke with a new model of integrated care.

7. How will we use information about you?

We will need to use information from you for this research project but we will not collect any of this information without your consent. This information will include professional title/role, grade/banding and time in post. People will use this information to do the research or to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. The data will be stored in a password-protected university server. The researcher and the researcher's supervision team will be the only people that have access to the data.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Study data and records of consent will be kept securely for five years, in line with university policy.

In addition, responsible members of Liverpool John Moores University may be given access to personal data for monitoring and/or audit of the study to ensure that the study is complying with applicable regulations.

8. What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason. We will not collect any further information but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You may withdraw from the study at any time by contacting the researcher by telephone, mobile [redacted] or email [redacted]

9. What will happen to the results of the study?

The researcher will use the results from this study to inform a new integrated care pathway for stroke patients. The study will also be published in the form of a thesis for the degree award of Doctor of Philosophy and as a journal article.

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through the Integrated Research Application System (IRAS) (Reference number: 23/EM/0171).

11. Whom do I contact if I have a concern about the study or I wish to complain?
If you have a concerns about any aspect of this study, please contact either myself on [redacted] or by email at [redacted] I will do my best to answer your query. You should expect a reply within 7 working days. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the university Research Ethics Committee who will seek to resolve the matter as soon as possible: Chair, university Research Ethics Committee; Email: FullReviewUREC@ljmu.ac.uk; Tel: 0151 231 2121; Research Innovation Services, Liverpool John Moores University, Exchange Station, Liverpool L2 2QP.

11 Where can you find out more about how your information is used?
Liverpool John Moores University is the data controller with respect to your personal data. More information about how we use your personal data is available from:

- https://www.ljmu.ac.uk/legal/privacy-and-cookies/external-stakeholders-privacy-policy/research-participants-privacy-notice
- www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the study team or contacting us using the information below

12. Contact for further information
Researcher: [redacted]
Supervisor Name: [redacted]

Thank you for reading this information sheet and for considering taking part in this study.

12.18 Appendix R: Delphi Survey Invitation Letter (Stroke Survivors)



LIVERPOOL JOHN MOORES UNIVERSITY

IRAS ID: 317528
LJMU's Research Ethics Committee Approval Reference:
NHS REC Reference: 23/EM/0171

Dear Patient,

We would like to invite you to participate in a Delphi consensus survey of integrated care in stroke as part of a PhD research project. As a stroke survivor we are keen to gain your views about how we should structure an integrated care pathway for stroke. Specifically, we would like to ask your views of proposed components of care that you would rate according to importance to include in the pathway.

In order to take part, we ask that you are aged 18 years or over, you are able to provide informed consent to participate in the survey, you have been diagnosed with a stroke within the last 5 years and that you were discharged from hospital to home at least 6 weeks ago. If you choose to take part in the study, you will be invited to participate in a Delphi survey as a panel member. In practical terms, we would require no more than two hours of your time, spread out over two to three separate occasions.

Each participant completing every round of the survey in full will be entered into a prize draw for the opportunity of winning first prize of a £100 gift card, with a second prize of £75 and a third prize of £50.

With your permission, I would like to contact you by telephone to ask if you would like to participate in the survey and to discuss the consent form attached to this letter. Participation in this study is entirely voluntary and you can withdraw at any time without detriment to the care you receive. If you have any questions in the meantime, please feel free to contact me using the details below.

Yours sincerely,

[redacted]

12.19 Appendix S: Delphi Survey Participant Information Sheet (Stroke Survivors)

LIVERPOOL JOHN MOORES UNIVERSITY
Participant Information Sheet for Health Service User (Delphi survey)

IRAS ID: 317528
LJMU's Research Ethics Committee Approval Reference:
NHS REC Reference: 23/EM/0171

Title of Study: Integrated care for patients following stroke

This study will look at what is important to people with stroke during their recovery journey using a survey to allow them to express their opinions on how integrated care for people with stroke should be structured and delivered.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the study is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You do not have to take part if you do not want to. Please read this information, which will help you decide. Thank you for taking the time to read this.

1. What is the purpose of the study?
The care of people with stroke has improved dramatically in recent years, such as the establishment of acute stroke units and clot busting treatments. However, the management of people with stroke can be complicated since there are several different healthcare professionals involved in delivering the care across the hospital and home. This study aims to discover what really matters to people with stroke during their recovery. The information gained from this study will be used to inform the development of an integrated pathway aimed at improving the care of people with stroke.

This study is a PhD researcher-led study being conducted for the purpose of completing a doctorate degree programme and is funded by Liverpool John Moores University.

2. Why have I been invited to participate?
We would like to invite you to participate in a Delphi consensus survey. As a stroke survivor we are keen to gain your views about how we should structure an integrated care pathway for stroke. Specifically, we would like to ask your views of proposed components of care that you would rank in order of importance to include in the pathway. The inclusion criteria for the survey are:

- You are able to provide informed consent to participate in the survey
- You are aged 18-years and over.
- You have been diagnosed with a stroke within the last 5 years
- You were discharged from the hospital to home at least 6 weeks ago

3. Do I have to take part?
No. It is up to you to decide whether or not to take part. You will be given this information sheet to take away and read.

4. What will happen to me if I take part?

If you choose to take part in the study, you will be invited to participate in a Delphi survey as a panel member. The Delphi technique obtains consensus on the opinions of participants through a series of brief structured questionnaires. As part of the process, the responses from each questionnaire are fed back in summarised form to the participants who are then given an opportunity to respond again to the emerging data. This process would continue until a group consensus is achieved or four Delphi questionnaires have been completed.
To allow timely conclusion of the study, we would respectfully request a response time of 2 weeks for completion of each questionnaire.
In practical terms, we would require no more than two hours of your time, spread out over two to three separate occasions.
We will also contact your GP to inform them that you are participating in this research.

5. Payments, reimbursements of expenses or any other benefit or incentive for taking part

Each participant completing every round of the survey in full will be entered into a prize draw for the opportunity of winning first prize of a £100 gift card, with a second prize of £75 and a third prize of £50.

6. Are there any possible disadvantages or risks from taking part?

Participating in the Delphi survey is not anticipated to cause you any disadvantages or discomfort. If after taking part, you have any questions or concerns about stroke you can get information and advice from the organisations listed at the end of this sheet.

7. What are the possible benefits of taking part?

Whilst there will be no direct benefits to you for taking part in the Delphi survey, it is hoped that this work will benefit other stroke survivors in the future by improving the care of people with stroke.

8. How will we use information about you?

We will need to use information from you for this research project but we will not collect any of this information without your consent. This information will include your age, when you had your stroke and how long it has been since you were discharged from hospital. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Your data will be stored in a password-protected university server. The researcher and the researcher's supervision team will be the only people that have access to the data.

Study data and records of consent will be kept securely for five years in line with university policy. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

In addition, responsible members of Liverpool John Moores University may be given access to personal data for monitoring and/or audit of the study to ensure that the study is complying with applicable regulations.

We will not tell anyone that you have taken part in the Delphi survey. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

With your consent, we would like to store your contact details so that we may contact you about future opportunities to participate in studies. Your details will be stored securely in a password-protected university server The researcher and the researcher's supervision team will be the only people that have access to the data.

9. What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason. We will not collect any further information but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You may withdraw from the study at any time by contacting the researcher by telephone, mobile [redacted] or email [redacted]

10. What will happen to the results of the study?

The researcher will use the results from this study to inform a new integrated care pathway for stroke patients. The study will also be published in the form of a thesis for the degree award of Doctor of Philosophy and as a journal article. The plan will be to write to you individually and let you know what we have found. We will also be sending out an invitation for you to join us here at the university where we can have an informal gathering and present informally the findings of this study.

11. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through the Integrated Research Application System (IRAS) (Reference number: 23/EM/0171).

12. Whom do I contact if I have a concern about the study or I wish to complain?

If you have a concerns about any aspect of this study, please contact either myself on [redacted] or by email at [redacted] I will do my best to answer your query. You should expect a reply within 7 working days. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the university Research Ethics Committee who will seek to resolve the matter as soon as possible: Chair, university Research Ethics Committee; Email: FullReviewUREC@ljmu.ac.uk; Tel: 0151 231 2121; Research Innovation Services, Liverpool John Moores University, Exchange Station, Liverpool L2 2QP.

13. Where can you find out more about how your information is used?

Liverpool John Moores University is the data controller with respect to your personal data. More information about how we use your personal data is available from:

- https://www.ljmu.ac.uk/legal/privacy-and-cookies/external-stakeholders-privacy-policy/research-participants-privacy-notice
- www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the study team or contacting us using the information below

14. Contact for further information

[redacted]

[redacted]

If after taking part, you have any questions or concerns about stroke you can get information and advice from the following organisations:
Stroke Association: https://www.stroke.org.uk/

Thank you for reading this information sheet and for considering taking part in this study.

Note: A copy of the participant information sheet should be retained by the participant with a copy of the signed consent form.

12.20 Appendix T: Informed Consent Form (Paper-based Delphi Survey)

LIVERPOOL JOHN MOORES UNIVERSITY

Liverpool Centre for Cardiovascular Science

PARTICIPANT CONSENT FORM FOR DELPHI SURVEY (Patient)

Study title: Integrated care for patients following stroke
Research Ethics Committee Reference Number: 23/EM/0171

Principal Investigator: [redacted]

Supervisor Name: [redacted]

If you are happy to participate, please complete and sign the consent form below

		Please initial	
1.	I confirm that I have read the information sheet dated 22/05/2023 (version 1.0) for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		
2.	I understand what taking part in the study involves		
3.	I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions I can withdraw from the study at any time, without giving a reason and without penalty or my legal rights being affected.		
4.	I have been advised about potential risks associated with taking part in this study and have taken these into consideration before consenting to participate		
5.	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.		
6.	I understand that my information may be subject to review by responsible individuals from Liverpool John Moores University for monitoring and audit purposes		
7.	I agree for my contact details to be stored for the purpose of contacting me about this study	YES	NO
8.	I understand that personal data will remain confidential and that all efforts will be made to ensure I cannot be identified in reports or any further outputs		
9.	I understand that if I choose to complete a paper-based survey, the process of informed consent will be undertaken on the telephone and will be audio recorded		
10.	I agree to take part in this study		

Data Protection. Any personal information we collect and use to conduct this study will be processed in accordance with data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants.

Name of Participant Date Signature

For participants unable to sign their name, mark the box instead of signing ☐

I have witnessed the accurate reading of the consent form with the potential participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely

Name of Investigator	Date	Signature
Name of Person taking consent *(if different from investigator)*	Date	Signature

12.21 Appendix U: Delphi Survey Participant Help Sheet (Postal)

Delphi survey help sheet

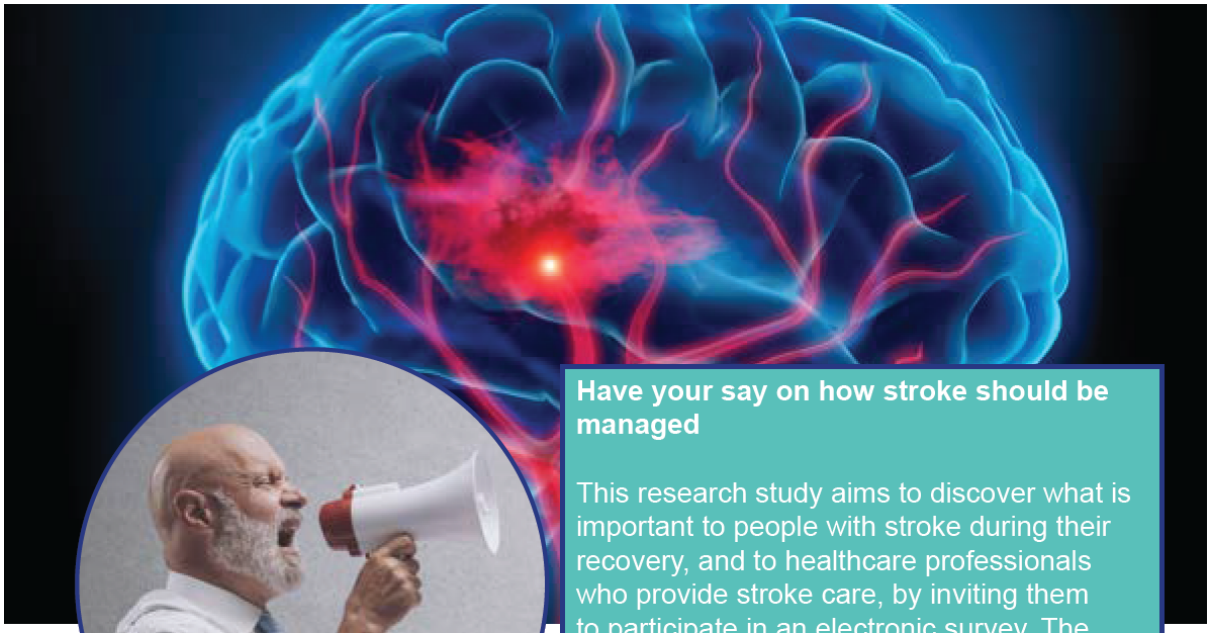
Term	Description
Question 1	
Delphi survey	The Delphi method is a process used to arrive at a group opinion or decision by surveying a panel of participants who either care for people with stroke or who have direct experience of living with stroke themselves. These participants respond to several rounds of questionnaires, and the responses are combined and shared with the panel after each round. The participants can adjust their answers after each round of the survey, based on how they interpret the group response provided to them. The final result of the survey is meant to be a true consensus of what the group thinks.
Healthcare professional	A healthcare professional is a qualified healthcare person registered with a professional organisation that allows them to provide health advice and treatment to patients who may suffer from physical or mental conditions.
Acute treatment	Acute treatment, or acute care, is a type of medical care that provides short-term treatment for a severe or urgent medical condition, injury, or illness such as a stroke. This often takes place in hospitals.
Integrated care	What we mean by the term "integrated care" is the care of people with stroke by a team of specialists including doctors, nurses, pharmacists, and therapists (occupational health, physiotherapy, speech and language therapy), all communicating with each other to provide high quality and consistent care centred around the patient.
Dysphagia	Dysphagia refers to difficulty in swallowing. Treatment for stroke survivors who have this problem will usually be given by a speech and language therapist.
Rehabilitation	Rehabilitation is a set of treatments and activities that can help with physical, emotional, social, and spiritual health. The goal of rehabilitation is to help people reach their optimal level of function in these areas. High intensity rehabilitation is typically used for patients who are recovering quickly and can benefit from additional therapy and can involve very frequent (even daily) access to a doctor or nurse practitioner, nursing care, and up to three hours of therapy per day.
Physiotherapy	Physiotherapy, also known as physical therapy, is a treatment that uses physical techniques to help restore, maintain, or improve a patient's movement, function, and well-being.
Occupational therapy	Occupational therapists focus on the things you want and need to do in your daily life. Occupational therapy uses everyday life activities (occupations) to promote health, well-being, and your ability to participate in the important activities in your life. They are specialists in mental and physical health and can recommend aids and adaptations that can promote your recovery
Thrombectomy	Thrombectomy is a surgical or mechanical procedure to remove a blood clot, or thrombus, from a blood vessel.

Question 2	
Term	**Description**
Medication	Medication is what we give to treat illness and is usually in the form of a tablet, pill or capsule.
Goal setting	Goal setting in stroke rehabilitation is a process where a patient and their therapy team identify and plan outcomes for the patient's recovery. It's a vital part of the rehabilitation process that can help patients stay motivated and encouraged.
Managed exercise program	This is an exercise program that is coordinated by a therapist (physiotherapist) that shows how hard and how often to exercise. They are usually planned around the patient and what they can do.
Exercise training	Also known as aerobic exercise, this is exercise aimed at increasing your heart rate and breathing and improving your blood flow. It can help to reduce your risk of heart disease, stroke, diabetes and some cancers, improve mood and sleep, and strengthen your heart, bones muscles and joints.
Adherence	Adherence refers to taking medicine in accordance with the agreed plans, following the correct dose and frequency (how much medicine to take and how often).
Antiplatelets	Antiplatelet drugs are medicines that prevent platelets (cells in the blood involved in clotting) from clumping together to form blood clots. Examples include aspirin and clopidogrel.
Anticoagulants	Anticoagulants are medicines that slow down the body's formation of blood clots. Examples include warfarin and apixaban.

Question 3	
Term	**Description**
Cognitive training	Cognitive training, also known as brain training, is a series of mental exercises and activities aimed at improving or maintaining cognitive abilities. It can help with a range of thinking skills and memory aspects, including: attention, logic and reasoning, memory, problem solving, and working memory. Examples include puzzle books and games.
Motivational training	Motivational training in stroke rehabilitation is a set of techniques and strategies that help patients stay engaged in their recovery. Motivation is a key factor in stroke rehabilitation because it's essential for patients to be active participants in their treatment.
Virtual reality	 Virtual Reality (VR) is a computer-generated environment with scenes and objects that appear to be real, making the user feel they are immersed in their surroundings. This environment is perceived through a device known as a Virtual Reality headset or helmet.

Question 4	
Term	**Description**
Malaise	In medical terms, malaise is a general feeling of discomfort, illness, or lack of well-being. It's also known as general ill feeling.
Atrial fibrillation	Atrial fibrillation or AF is an irregular and often abnormally fast heart rate.
Transient ischaemic attack	A transient ischaemic attack (TIA) or "mini stroke" is caused by a temporary disruption in the blood supply to part of the brain. It can cause sudden symptoms like a stroke but is short-lived, with the effects lasting a few minutes to a few hours.
Diabetes	Diabetes is a disease in which the body is unable to control the amount of sugar in the blood.
Cardiovascular disease	Cardiovascular disease (CVD) is a general term for any condition affecting the heart or blood vessels. Examples of CVD include coronary heart disease, where blood supply to the heart is reduced, stroke and TIA where blood supply to the brain is reduced.
Advocacy	Patient advocacy is the act of supporting a patient's rights and ensuring they receive the appropriate level of care. A patient advocate acts as a representative for the patient, helping them navigate the healthcare system and communicate with their healthcare providers. They can also help patients with financial, legal, and social support.

12.22 Appendix V: Delphi Survey Poster





Have your say on how stroke should be managed

This research study aims to discover what is important to people with stroke during their recovery, and to healthcare professionals who provide stroke care, by inviting them to participate in an electronic survey. The information gained from this survey will be used to inform the development of an integrated pathway aimed at improving the care of people with stroke

You may be eligible for this study if you:

- Are a stroke survivor and:
  - You are able to provide informed consent to participate in the survey
  - You are over 18 years of age
  - You have been diagnosed with a stroke within the last 5 years
  - You were discharged from the stroke unit to home at least 6 weeks ago

- Are a healthcare professional providing care for people with stroke and:
  - You are a physician, nurse, therapist or other healthcare professional providing direct stroke care
  - You have at least 1 year's experience in the management of people with stroke

The survey is expected to take no longer than 90 minutes in total
All participants completing the survey will be entered into a prize draw

- 1st Prize £100 gift card
- 2nd Prize £75 gift card
- 3rd Prize £50 gift card

Contact for further information

- Principal Investigator: [redacted]
- Supervisor: [redacted]

V1.0 24/05/2023. IRAS: 317528. REC: 23/EM/0171

LIVERPOOL JOHN MOORES UNIVERSITY

Liverpool Centre for Cardiovascular Science

12.23 Appendix W: Delphi Survey Report Example (Round 1)



A Delphi survey for Integrated Care Pathways in Stroke

Round 1 report

Dear participant,

Thank you for participating in the first round of the Delphi survey. The Delphi technique obtains consensus on the opinions of participants through a series of brief structured questionnaires. As part of the process, the responses from each questionnaire are fed back in summarised form to the participants who are then given an opportunity to respond again to the emerging data. This process will continue until a group consensus is achieved or four Delphi questionnaires have been completed.

The results for the first round are now complete and are summarised in this report. Consensus for the questions in this survey is set at 75%. This means that any question that is given the same answer by 75% or more of the participants is said to have reached consensus. For example, if 100% of participants answered that rapid diagnosis of stroke was very important, then this question will have reached consensus.

A total of 9 statements reached consensus after Round 1 of the survey (all rated as very important) and these are shown below:

Statement	Very important
Rapid diagnosis of stroke	100%
Rapid brain scanning in suspected stroke	98%
Acute medical treatment (for example, clot busting drugs, thrombectomy, anticoagulants, antiplatelet drugs, high blood pressure treatment)	91%
Treatment for dysphagia (difficulty in swallowing)	79%
Control of stroke risk factors (blood pressure, cholesterol, blood sugar, weight loss, smoking cessation)	86%
Taking antiplatelet/anticoagulant medication	76%
Adherence to antiplatelet and anticoagulant medication	76%
Awareness of the well-known symptoms of stroke according to media campaigns such as FAST (Face, Arms, Speech, Time to call 999)	79%
Awareness of the risk factors for stroke (for example atrial fibrillation, transient ischaemic attack [TIA], diabetes, cardiovascular disease)	81%

Next Steps

In Round 2 of the survey, you will have the opportunity to change your mind about these consensus statements if you hold a different opinion after seeing the results. The full survey results are also shown below for each survey question as a heat map. The colours in the heat map correspond to the proportion of participants who rated a question very unimportant, unimportant, important or very important. Darker colours indicate a higher percentage of participants giving a certain answer.

Each participant completing every round of the survey in full will be entered into a prize draw for the opportunity of winning first prize of a £100 gift card, with a second prize of £75 and a third prize of £50. Participation in this study is entirely voluntary and you can withdraw at any time without detriment to the care you receive. There is a help sheet with this survey that explains some of the terms used in the survey.

If you have any questions in the meantime, please feel free to contact me using the details below.



Question 1

Thinking about the acute management of stroke (from recognition of symptoms or diagnosis to hospital or stroke unit treatment), how important do you think each of these elements are for an integrated care pathway for stroke?

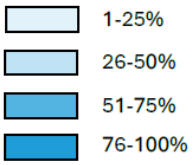
Statement	Very unimportant	Unimportant	Important	Very important
Rapid diagnosis of stroke	0.0%	0.0%	0.0%	**100.0%**
Rapid brain scanning in suspected stroke	2.4%	0.0%	0.0%	**97.6%**
Acute medical treatment (for example, clot busting drugs, thrombectomy, anticoagulants, antiplatelet drugs, high blood pressure treatment)	2.4%	0.0%	7.1%	**90.5%**
Occupational therapy	0.0%	2.4%	33.3%	64.3%
Speech therapy	0.0%	0.0%	31.0%	69.0%
Physiotherapy including exercise	2.4%	0.0%	26.2%	71.4%
Group physiotherapy sessions for stroke survivor inpatients	0.0%	14.3%	57.1%	28.6%
Treatment for dysphagia (difficulty in swallowing)	0.0%	2.4%	19.0%	**78.6%**
Psychological support or counselling	0.0%	0.0%	38.1%	61.9%
Early supported discharge (allowing stroke survivors to recover at home instead of the hospital or stroke unit)	0.0%	0.0%	31.0%	69.0%
High intensity rehabilitation (4 or more therapy sessions per week)	0.0%	2.4%	41.5%	56.1%
Rehabilitation program following thrombectomy	0.0%	2.4%	47.6%	50.0%
Early rehabilitation	0.0%	0.0%	28.6%	71.4%

1-25%
26-50%
51-75%
76-100%

Question 2

Thinking about the management of stroke survivors following discharge from the hospital or stroke unit, how important do you think each of these elements are for an integrated care pathway for stroke?

Statement	Very unimportant	Unimportant	Important	Very important
Regular follow-up of stroke survivors by healthcare professionals (for example, outpatient appointments, telephone or video calls every 3 or 6 months)	2.4%	2.4%	42.9%	52.4%
Home visits from healthcare professionals	2.4%	7.1%	45.2%	45.2%
Home-based rehabilitation using the internet or videoconferencing to communicate with the stroke care team	2.4%	14.3%	45.2%	47.6%
Home-based high intensity rehabilitation (4 or more therapy sessions per week)	0.0%	7.1%	45.2%	47.6%
Massage therapy	9.8%	36.6%	39.0%	14.6%
Ongoing physiotherapy (individual sessions)	0.0%	7.1%	47.6%	45.2%
Group physiotherapy sessions	0.0%	26.8%	51.2%	22.0%
Supported exercise programs (including information on exercise intensity and frequency)	0.0%	9.5%	47.6%	42.9%
Exercise training to improve health or fitness	0.0%	4.8%	59.5%	35.7%
Ongoing occupational therapy	0.0%	4.8%	52.4%	42.9%
Ongoing psychological support or counselling	0.0%	4.8%	47.6%	47.6%



Question 2 (continued)

Statement	Very unimportant	Unimportant	Important	Very important
Social and wellbeing support (for example art classes, horticulture)	4.8%	16.7%	50.0%	28.6%
Control of stroke risk factors (blood pressure, cholesterol, blood sugar, weight loss, smoking cessation)	0.0%	2.4%	11.9%	**85.7%**
An individual assessment of stroke patient needs	0.0%	0.0%	26.8%	73.2%
Stroke care and support using a mobile phone-based app	0.0%	34.1%	53.7%	12.2%
Individually tailored stroke patient care programs including regular monitoring and program adjustment	0.0%	2.4%	47.6%	50.5%
Continuous nursing support or a nurse-led stroke care pathway	0.0%	14.3%	54.8%	31.0%
Goal setting	0.0%	7.1%	45.2%	47.6%
Taking antiplatelet/anticoagulant medication	0.0%	0.0%	23.8%	**76.2%**
Adherence to antiplatelet and anticoagulant medication	0.0%	0.0%	23.8%	**76.2%**
Medical treatment for depression (for example antidepressants)	0.0%	9.5%	45.2%	45.2%
Review of medication by a healthcare professional (for example, a pharmacist)	0.0%	2.4%	31.0%	66.7%

1-25%

26-50%

51-75%

76-100%

Question 3

Thinking about potential education and training of stroke survivors and their carers following discharge from the hospital or stroke unit, how important do you think each of these elements are for an integrated care pathway for stroke?

Statement	Very unimportant	Unimportant	Important	Very important
Rehabilitation training for stroke survivors	0.0%	4.8%	38.1%	57.1%
Rehabilitation training for carers of stroke survivors	0.0%	2.4%	42.9%	54.8%
Stroke survivor and carer education about stroke	0.0%	0.0%	38.1%	61.9%
Cognitive training exercises (targeting memory and attention)	0.0%	0.0%	38.1%	61.9%
Stroke survivor self-care programs	0.0%	4.8%	47.6%	47.6%
Motivational training (confidence building)	0.0%	2.4%	42.9%	54.8%
Lifestyle advice (healthy diet, regular exercise or activity, maintaining a healthy weight, stopping or reducing smoking and drinking)	0.0%	4.8%	23.8%	71.4%
Nurse-led stroke education and follow-up	0.0%	11.9%	50.0%	38.1%
Nursing training for caregivers	0.0%	19.0%	38.1%	42.9%
Stroke support training programs for healthcare professionals	0.0%	4.8%	40.5%	54.8%
Information and education on medication (for example, the role of aspirin in stroke treatment, common side-effects of drug treatment)	0.0%	2.4%	40.5%	57.1%
Training and education on stroke care using virtual reality	0.0%	28.6%	40.5%	31.0%
Participation in stroke research studies	0.0%	2.4%	48.8%	48.8%
Written patient information on stroke (leaflets and booklets)	0.0%	4.9%	43.9%	51.2%
Regular organised educational and information sessions for stroke survivors	0.0%	9.8%	53.7%	36.6%

1-25%

26-50%

51-75%

76-100%

Question 4

Thinking about potential education and training of stroke survivors and their carers following discharge from the hospital or stroke unit, how important do you think each of these elements are for an integrated care pathway for stroke?

Statement	Very unimportant	Unimportant	Important	Very important
Awareness of the well-known symptoms of stroke according to media campaigns such as FAST (Face, Arms, Speech, Time to call 999)	0.0%	2.4%	19.0%	**78.6%**
Awareness of less well-known symptoms of stroke (for example pins and needles, muscle weakness, dizziness, general feeling of malaise)	0.0%	4.8%	21.4%	73.8%
Awareness of the risk factors for stroke (for example atrial fibrillation, transient ischaemic attack [TIA], diabetes, cardiovascular disease)	0.0%	0.0%	19.0%	**81.0%**
Understanding from the public about the problems that stroke survivors face in everyday life	2.4%	2.4%	38.1%	57.1%
Advocacy, a voice for the stroke patient	0.0%	4.8%	31.0%	64.3%

1-25%
26-50%
51-75%
76-100%