Curating 'soul' in health data: A practical investigation of Arts Based Health Research examining the efficacy of public and patient engagement.

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Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Abstract

This study is a practical investigation of Arts-Based Health Research exploring levels of participation, quality of engagement, and audience reach. It examines how ABHR can stimulate and foster meaningful and transformative participation in health research. Arts-based health research is a growing field, and researchers have long recognised that photography, visual and performing arts have benefits for patients and offer insights that cannot be expressed, documented, or shared in other ways. This research study scopes arts-based research being used in a variety of clinical and community settings, emphasising the prominence of photovoice in the field.

The research was conducted in the north of England, over a period of five academic years with two research groups: i) people living with dementia, and ii) older people in isolation during a global pandemic. The research was clearly bound by context, and the theoretical framework was underpinned by a Freirean philosophy, rooted in the idea that minority groups hold key information about how different forms of oppression can maintain power.

The methodology includes the co-creation of visual art labyrinth installations to share and gather data about lived experiences and ethnocomedy theatre was used to present findings and explore the audiences' perceptions. The data was collected over a period of four academic years and analysed collectively using an interactive thematic approach. Through the lens of participatory research methods, the analysis, interpretation, and discussion of data were completed in collaboration with co-researchers.

Arts-based methods revealed the capacity of creative approaches to offer psychosocial benefits, such as enhanced social engagement, positive impact on relationships, and improved wellbeing. A blended arts-based approach with participatory action research provided a person-centred approach to health research, reflecting the global call to humanise healthcare and offering a framework where people are valued, and their preferences and needs are respected.

The study concludes that arts-based health research can furnish us with the resources to analyse societal issues, develop solutions, implement change in health services, improve the patient experience and transform people's lives.

Figure 1: Lost and Found Labyrinth – Open Eye Gallery 2017
Ryan-McNeill, 2017

Chapter One: Introduction

*"Art enables us
to find ourselves and
lose ourselves
at the same time."
– Thomas Merton*

Chapter One: Introduction

1.1 Background

The arts have a long history of adding value to our lives, bringing people together, and increasing our understanding of the human experience. For centuries, the arts have supported communities in creating, maintaining, and sharing stories. There is a growing appreciation of the role the arts can play in helping communities identify strengths and assets for patient benefit. More recently with the rise of co-design methods we are beginning to see how the arts can not only support the healing process but can help patients imagine, realise and shape future health services. In 2015, Public Health England published a paper in which they described how participatory approaches are an important resource in our path to building stronger connections and directly addressing the marginalisation and powerlessness caused by deep-rooted health inequalities (Public Health England 2015). The paper also suggests that the arts can act as a gateway to link communities (Public Health England 2015) but the arts can also increase our understanding of experiences related to health conditions and services. There is no doubt that the arts have an important role to play in health research, and there are indications that the arts can increase engagement and enhance patient benefit, While 'Public Patient Involvement' is embedded within NHS policy (NHS England, Public Participation Team 2017), and the Arts-Based Health Research (ABHR) field is gaining respect and growing in breadth and depth, arts based health approaches are still not considered mainstream within the UK and worldwide.

Research is considered art-based, when an expressive art-making activity supports one or more stages of the research process (Leavy, 2020, McNiff, 1998). The involvement of the art form within the research process provides an additional quality that relates to the experience of art, such as, an appeal to the senses or emotions, in a way that arts methods are able to, but traditional research methods are not. For example, a newly qualified doctor using a dialectic method of questions to develop a patient narrative is distinct from an arts-informed narrative approach to understand patient experience on an emotional and visceral level. The development of patient narratives is where the boundaries are most blurred, in determining whether research is art-based. When we hear the term 'patient narrative' we might consider

it an arts-based research method, but are we truly talking about an art form? i.e., creative writing or poetry? Unquestionably, the patient narratives that are required during clinical trials should not be considered arts-based because they are a simply a written summary of adverse events that occur in a patient during a trial. However, other patient narratives may involve an element of storytelling, which is where the lines become blurred. Clark's observation of the narrative in patient centred care, tells us that although it enables the patient to express themselves, *'and their ideas, concerns, and expectations addressed'* (Clark 2008), there is often a disconnect between the doctor and the patient. Frequently medical practitioners try to fit the patient's individual experience into a singular truth of any said medical condition, but a patient's unique story may not fit the medical narrative of a particular health condition. Acknowledging Kant's 'Theory of experience', Clark suggests, that because we all perceive things differently, advice to one patient about their cardiac rehabilitation could mean something very different to another patient. Clark therefore concludes that '*reason, logic, and direct questions'* from a doctor to a patient, should be woven into a narrative and the doctor could even incorporate a story to entertain the patient, in order for them to be fully appreciated and understood (Clark 2008). This suggests that a traditional patient narrative within a medical consultation would not necessarily be considered as an arts-based method merely because it involves narrative; only when creative methods are applied, such as the use of storytelling to connect and gain a deeper understanding, should it be considered an art-based health method. Researchers using creative writing arts-based methods in health suggest that it generates a deeper emotional response from patients. (Look et al. 2012; Lapum et al. 2012; Lapum 2013) However, this research is not questioning the legitimacy or quality of the art form being used as a research method, it aims to explore the usefulness of the arts-based method and benefit for the patient.

The role of creativity and arts has a long history of supporting and promoting health in communities, but it is over the last 60 years, with the proliferation of evidence and campaigning that we have seen an increase in the numbers of clinicians and health practitioners who recognise and accept the impact arts and creativity can have on health outcomes (Clift and Camic, 2018). Much has been written about the growth of arts and health and the relationship between the creative arts and health outcomes, specifically in relation to therapeutic arts and/or arts and health interventions in the UK and internationally (Clift and Camic, 2018,

Stuckey and Noble, 2010). To a large extent, changes in the arts, health and wellbeing policy environment over the last 30 years have shaped the landscape for arts and health practice. When the All-Party Parliamentary Group on Arts, Health and Wellbeing published their substantial report: *Creative Health: The Arts for Health and Wellbeing*, in 2017 (APPGAHW, 2017), it provided comprehensive evidence and numerous examples of practice which demonstrate the beneficial impact of the arts and creativity on health outcomes.

There are several reasons as to why we have seen a growth of interest in arts and health over the last 10 years. At the first Culture, Health and Wellbeing conference in the UK in 2013, Lord Howarth references the 'pathology of the west as a driving force behind the growth of the arts and health movement' (Clift and Camic, 2018). In 2018, Matt Hancock's address to the King's Fund about the benefits of social prescribing (as former UK's Secretary of State for Health and Social Care), highlights how the arts and health agenda had become a government priority when he announced the three key messages from the APPG Creative Health report,

- *The arts can help keep us well, aid our recovery and support longer lives better lived.*
- *The arts can help meet major challenges facing health and social care: ageing, long-term conditions, loneliness and mental health.*
- *The arts can help save money in the health service and social care.*

A couple of years earlier, Clift and Camic published the Oxford Textbook of Creative Arts, Health and Wellbeing offering a global perspective on achievements, developments, opportunities for future growth and challenges (Clift and Camic, 2016). These ground-breaking publications, events and the increase of peer reviewed articles that demonstrate robust evidence of the benefits of arts and health practice, have evidently built confidence amongst health commissioners, practitioners, and researchers, and laid the foundations for arts and health development at local and regional level.

In 2017, Liverpool established an Advice on Prescription service because GPs observed that patients had social issues that were impacting their health and wellbeing and recognised this wasn't something that a medical prescription could resolve. This developed into an Arts on Prescription social prescribing model in 2019/20 when the Department of Health PHE also funded 20,000 link workers across the UK.   The correlation between the growth of arts and health interventions and arts-based health research is more apparent in the literature, as we

see researchers employing arts-based research methods to assess and evaluate the impact of social prescribing or arts on prescription programmes (Stickley and Hui 2012b, 2012a).

1.2 Medicine and visual art

There is also a long record of the relationship between visual art and medicine. For hundreds of years artists or scientists have used art to document health sciences. Leonardo da Vinci's work is still the subject of much research and teaching in various disciplines such as chemistry, dentistry, neuroscience, optics, medical anatomy and psychology. His Vitruvian Man (around 1490), one of the most recognisable drawings in the world, exemplifies the practice and teaching of the anatomy and medicine. Leonardo da Vinci's contributions to physiology, often inspired by his artistic interests, surely qualifies him as an early pioneer of arts-based health research. Throughout his artwork, he investigated blood flow, muscles and physiology of breathing and Mark D. Williams describes how the Vitruvian Man, symbolises "the three essential attributes of a 'compleat' physician - science, humanitarianism, and artistry." (Gorman, 2002)

Figure 2: "The Vitruvian Man" by Leonardo da Vinci, circa 1492.
Sourced from Wikimedia Commons under the public domain license from the Gallerie dell'Accademia, Venice.
Materials used: Pen, ink, watercolor and metal point on paper.
Available at: https://en.wikipedia.org/wiki/Vitruvian_Man
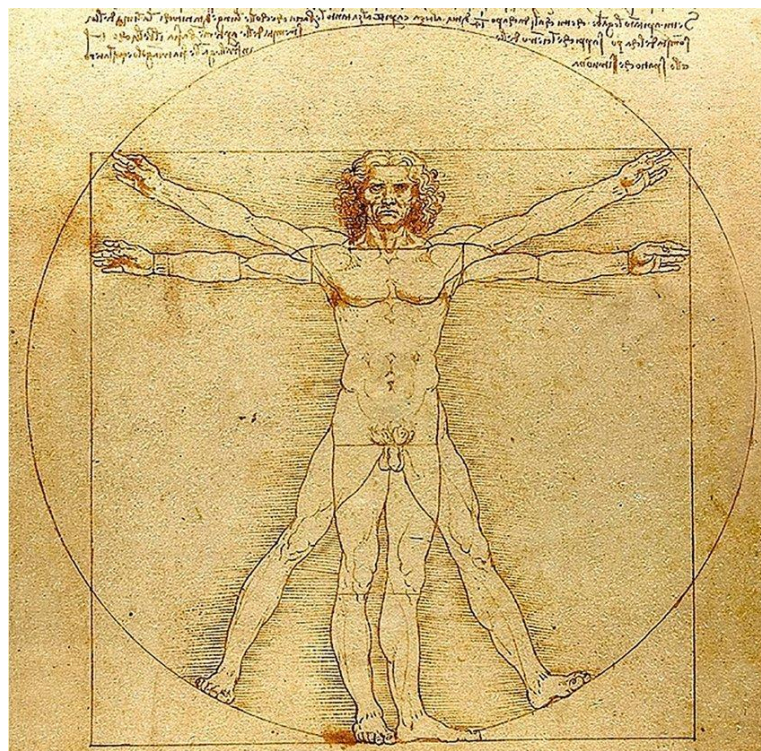
Leonardo da Vinci's Mona Lisa also comes under much discussion and debate within the medical community. During the painting's 300 years of existence the medical diagnosis of the female subject, identified as Lisa Gherardini, has been scrutinised in depth. Dr Vito Franco, from Palermo University, suggests that the Mona Lisa shows clear signs of a build-up of fatty acids under the skin, caused by too much cholesterol. He also suggests there seems to be a lipoma, or benign fatty-tissue tumour, in her right eye. This demonstrates that the intensive observation skills of an artist, can reveal illness within the body, that otherwise might have gone unseen.

Figure 3: A selection of published medical diagnosis on Mona Lisa by Leonardo da Vinci.
Image Cropped and relevelled from File: Mona Lisa, by Leonardo da Vinci, from C2RMF retouched.jpg (no date) Wikimedia Commons. Available at: https://en.wikipedia.org/wiki/Mona_Lisa

No eyebrows or eyelashes may represent madarosis
Ashrafian 2016

Skin lesion at the end of the upper eyelid similar to xanthelasma
Dequeker 2004 et al

Facial muscle contracture - facial nerve has undergone partial wallerior degeneration follow... Bell's Palsy.
Dr Ardour 1989

Scar on lip area possibly due to application of blunt force.
Changes in the perioral area occur when antier teeth are lost.
Borkowski 1992

Idiopathic facial paralysis during pregnancy.
Dr Hellebrand 2006

Puffy neck (goitre) caused by enlarged thyroid gland, most likely due to pregna... Dr Keele 1959

Swelling of the dorsum of the right hand suggests subcutaneous lipoma.
Dequeker et al 2004

Throughout history, there have been examples of drawings being used in medical science which could also be argued as early examples of visual art-based health research. The use of art is particularly relevant in plastic surgery. Sepehripour's survey of plastic surgeons concludes that most plastic surgeons have a background in art (Fernandes, 2020). Harold Gillies, a plastic surgeon cited as the creator of plastic surgery as a discipline (and trained hundreds of young surgeons) was foremost an artist.

Similarly, Santiago Ramon y Cajal (1852-1934) conducted his neuroscience research as both an artist and a pathologist. Creating remarkable drawings of neurons, Cajal documented his discoveries, calling upon both his artistic and medical training he illustrated what he observed through his microscope. Cajal produced meticulous drawings that proved far more accurate than anything that could be produced by the microscopic tools available at the time. Cajal viewed slices of the brain through a microscope treated with a stain developed by Camillo Golgi, which showed neurons sharply etched in black. Seeing this new level of detail, Cajal was able to make some of the first fundamental discoveries in neuroscience, and show that the brain is made up of neurons that are separated from one another by microscopic gaps (later called synapses). This led Cajal to develop what became known as the neuron doctrine. (Neuroscientifically Challenged, 2018)

Figure 4: Axon of Purkinje neurons in the cerebellum of a drowned man. Cajal Institute (CSIC), Madrid
Public domain, via Wikimedia Commons
Available at: https://commons.wikimedia.org/wiki/File:Santiago_Ramon_y_Cajal_nerve_cells_in_the_brain.jpg

Cajal exemplifies the lost connection between medical science and art, likely due to technological developments no longer necessitating it. Cajal spent hours meticulously sketching by hand what he saw through his microscope, leading to him to develop a better understanding of neurons, and enabling the discoveries that still influence medical neuroscience today. Posthumously, the Weisman Art Museum at the University of Minnesota presented The Beautiful Brain: The Drawings of Santiago Ramón y Cajal (January 28, 2017– May 21, 2017). For several months, this exhibition toured university galleries across America and Canada, potentially reaching a broader audience than if it had stayed at the Instituto Cajal in Madrid. This is a perfect example of the ways in which artists and curators can collaborate with medical researchers to create a compelling experience that relates to and connects to the lives and interests of a diverse audience.

1.3 Arts Therapy

The use of art is central to the process of analysis and treatment in arts therapy. In art therapy, the art is often used to create the patients' medical narrative and to support the healing process. It's not surprising that researchers evaluating the impact of therapeutic arts activities, would naturally adopt art-based research methods. McCaffrey advocates for the use of music and visual art-based research methods in a mental health music therapy study (McCaffrey 2015), in '*Hitting the right note for child and adolescent mental and emotional wellbeing*', Harkins et al use drawing within a multi genre approach to evaluate Sistema Scotland's "*Big Noise*" orchestral programme (Harkins et al. 2016). Firmly rooted in the view the arts can be used to communicate the emotional and social complexities of vulnerable people to inform critical debates. MacLeod et al uses a participatory arts-based research approach to examine – Visible Voices, an innovative program '*Connecting Seniors with others through Expressive Arts Making'* (MacLeod, 2016).

In therapeutic settings, art is used to help people express thoughts, emotions, and experiences that may be difficult to speak about. Visual art has been found to be particularly useful with children and young people, who are not literate or have language difficulties, and therefore, provide a child-centred structure to enable them to describe their health experiences and environments (NE-CF, 2005; The National Network for the Arts in Health, 2005). Guillemin promotes the use of drawing to gain a better understanding of illness and states, '*The use of*

drawings in the study of health and illness is limited, confined mostly to children. Drawings with children are most predominantly used for diagnostic or therapeutic purposes in psychology and psychoanalysis' (Guillemin, 2004). However, this conclusion is based on research prior to 2001 and we are now seeing an increased use of drawing arts-based research approaches that involve children and young people, not just in diagnosis or therapy interventions, but also in the co-design of health environments such as hospital wards (Stålberg et al. 2016; Lambert et al. 2013) to improve on health services (Latimer 2018) and to create effective public health information (Montgomery et al. 2012).

1.4 Background to Arts Based Health Research

Innovative approaches such as photovoice, narrative storytelling and other arts-based interventions have previously been reviewed by Catalani and Minkler (2009), Fraser and Sayah (2011), Boydell et al (2012). These valuable reviews focus on methodological, theoretical and ethical issues faced by those doing ABHR (Fraser and Sayah, 2011, Cox and Boydell, 2015) and the strengths of photovoice to enhance an understanding of community assets and needs (Catalani and Minkler, 2009).

This research builds upon this valuable work and focuses on the successes and challenges of ABHR over the last ten years 2010-2020, to gain an understanding of how ABHR can increase meaningful patient and public participation, gain an authentic understanding of the lived experience and successfully disseminate findings to wide audiences. This study examines participatory creative practice as a methodological approach to arts-based health research. The study includes a scope and review of ABHR currently undertaken across a variety of disciplines and health contexts; a discussion of the participation, quality of engagement, and reach of ABHR; the development of 'Labyrinth installations' as an ABHR method, and further development of two theatre-based health research projects.

1.5 Problem Statement

Public Patient Involvement and Engagement (PPIE) is the latest term used to describe the role of members of the public in health research projects. Patient and public involvement (PPI) as it was previously known, has become increasingly important in the development, delivery, and improvement of healthcare.

The National Institute for Health and Care Research (NIHR) recognises that research projects would benefit from first-hand knowledge of patients of illness, disease, or services. Public Involvement (PI) can also provide researchers with insights into the lived experience of illnesses, treatments, and health services. These insights help to improve patient outcomes because the research is more relevant to the needs of patients, carers, and service users.

The existing PI in health research typically uses group meetings and discussions, however difficulties can arise when there are communication challenges or patients are reluctant to engage. Diversity in PI is important for several reasons, firstly all communities should be able to contribute and give their voice on health decisions that affect their lives. Secondly, and more importantly, the people who face more inequalities tend to suffer the worst health. The NIHR website cites research highlighting there is a '*lack of alignment between* [research] *recruitment and disease prevalence*' (Bower et al., 2020). Art-based research has demonstrated successes working with diverse communities, approaches such as photovoice overcome language barriers and effectively represent authentic voices. More innovative approaches that immediately meet the needs of patients from deprived areas need to be examined and adopted.

This study explores ABHR in relation to two health contexts, Dementia and the Covid-19 global pandemic and strategies that people used in each of these contexts to maintain a reasonable quality of life.

1.5.1 People Living with Dementia

Dementia is present in all areas of our society, from family relations to policy making. The need to address the health and social problems that Dementia is creating globally appears simultaneously in many different disciplines including pharmacology, psychology, health, economics, arts and culture. One-third of people with mild-to-moderate dementia experience loneliness; 30% are moderately lonely and 5% are severely lonely, reports one of the first major studies to look at the issue (Victor et al., 2020). These figures are comparable with the general population of older people. People with dementia who live alone, and who experience social isolation, depression and lower quality of life are more likely to feel lonely. Evidence shows that arts interventions help older adults reduce the risk of dementia and cognitive decline as evidenced in the WHO report, "*Going to museums, galleries, the theatre, concerts or the opera every few months or more often in older age has been associated with a slower rate of cognitive decline and a lower risk of developing dementia*" (Fancourt and Finn, 2019,

p.24). With no known cure for dementia and limited treatments, research into living well with dementia is vital.

Dementia is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people. There are currently 944,000 people with dementia in the UK, 1 in 11 people over 65 have dementia. It is difficult to know the exact number of people with dementia, often there is a gradual nature to recognising the symptoms in the early stages and there are reports of a low diagnosis rate following the pandemic (Smith, A, 2021). The most recent national audit of Memory Assessment Services in England and Wales, conducted between January and August 2021 by the Royal College of Psychiatrists and supported by Alzheimer's Society, has revealed the average waiting time from referral to dementia diagnosis has increased. Data suggests that waiting times across the NHS have almost doubled since the global pandemic and memory clinics are continually being underfunded and overlooked. Reports from the UK Meeting Centre Support Programme suggest that waiting times for a diagnosis in Powys Wales is up to two years (Association of Dementia Studies, 2022).

The progression of cognitive, behavioural, and social changes that occur following a diagnosis, Alzheimer's disease (AD) and related dementias affect individuals' quality of life' in profound ways. Social interaction can slow down the progression of the patients' memory deficit by increasing synaptic plasticity and enhances neurogenesis and cognitive functions (Hsiao et al, 2018). A recent study examined the benefits of shared activities during an art engagement activity at Andy Warhol Art Museum and emphasised the important role that humour can play. '*People with cognitive impairments were able to engage in humor during social interactions.... Humor and laughter allowed the group to provide a safe social environment to talk about the activity and their illness'* (Liptak, 2014, p.10).

There is much stigma associated with dementia and it can impede gaining a diagnosis and seeking treatment (Herrmann et al., 2018) but there is growing evidence that persons with dementia are able to adapt to functional changes, find ways to remain active, and create meaning in their lives as they live well with this disease (Dupuis et al 2021).

1.5.2 Wellbeing and isolation during the Covid-19 pandemic

Coronavirus disease-2019 (COVID-19) had an unprecedented effect all over the world, especially in older adults. The risk of developing a serious and often deadly disease led to restrictions including social distancing, staying at home, businesses being closed and no gatherings of more than two people. This had a detrimental effect on the psychological wellbeing of older adults. Although it's hard to measure social isolation and loneliness precisely, there is strong evidence that many adults aged 50 and older who were socially isolated put their health at risk. Several studies have found that:

- *Social isolation was associated with about a 50% increased risk of dementia.*
- *Poor social relationships (characterized by social isolation or loneliness) was associated with a 29% increased risk of heart disease and a 32% increased risk of stroke.*
- *Loneliness was associated with higher rates of depression, anxiety, and suicide.*
- *Loneliness among heart failure patients was associated with a nearly 4 times increased risk of death, 68% increased risk of hospitalization, and 57% increased risk of emergency department visits.*

(Centers for Disease Control and Prevention, 2021)

1.6 What is examined within this study?

This study aims to develop, define, and investigate participatory arts-based approaches that support effective engagement and increase participation in health research. These aims were developed during the participatory action research process established to address the purpose of the study which was to explore and examine the impact of arts on the lived experience of people living with dementia. The literature review serves to present examples of arts-based research methods and how the approaches benefit patients and public involved. This provides the framework for the methodology that was selected to work with people living with dementia and older people during a pandemic.

The richness of the opportunities presented by the use of arts in conducting and reporting research outcomes are examined within this thesis, together with, how the ABHR effectively engages patients and increases audience reach. The challenges of the ethics and informed

consent particularly when engaging patients who are vulnerable is carefully considered. The study also questions where ABHR sits within global health research policy, regional and national health research strategies.

1.7 What it is not

This study does not investigate the quality of the arts-based genre used within health research.

Despite including ABHR projects that aim to improve the wellbeing of participants, this thesis does not discuss creative health projects health interventions, where the aim is to seek psychotherapeutic outcomes. It was also not intended to measure participants wellbeing as part of this study however the anecdotal evidence volunteered by participants relating to their wellbeing is discussed within the findings.

1.8 Purpose of the Study

The purpose of this study was to illuminate the lived experiences of people living with dementia and examine the isolation of older adults during the global pandemic in Liverpool, UK.

Dementia is the umbrella term for a range of brain diseases that cause progressive cognitive decline and are chronic in their nature. Symptoms include deterioration in cognitive function, behavioural changes, and functional limitations. The illness has a profound impact on society, according to the WHO dementia has physical, psychological, social and economic impacts (WHO, 2022), not only for people living with dementia, but also for their carers, families and communities they live in.

Loneliness and social isolation in older adults are serious public health risks affecting a significant number of people in the UK. Social isolation and/or loneliness is linked to reduced quality of life, neuropsychiatric symptoms, and psychotropic drug use in people living with dementia. Interventions, including physical activity, should be individualised and patient centred. By taking a closer look at the issues that affect quality of life of older adults and PWD, we have been able to identify effective research methods to meet the needs of this group and improve their health outcomes. While exploring the lived experiences of PWD and Older

adults, the impact of lockdowns and restrictions during the global pandemic was evident and included in this study.

1.9 Significance of the Study

This research presents:

- An up-to-date scope (40 years) and systematic review (25 years) of arts-based health research.
- An analysis of levels participation and audience reach in relation to each art-based method used within this study.
- Examples of arts-based research activities that reveal direct and indirect evidence of the benefit for patients engaging in health research.
- The development of a Framework for effective Participatory Art-Based Health Research.

This study makes contribution and advances the field of knowledge in arts, health, creative health, qualitative and participatory research methods, it also has specific relevance to public and patient involvement and engagement in health research (PPIE).

In addition, this research has received several funding awards and holds implications for policy makers and future strategies to engage communities within heath research especially within Public and Patient Involvement and Engagement (PPIE).

1.10 Researcher position/background

As a creative practitioner, I have co-created several arts and health projects in partnership with artists and service providers. Prior to this PhD, I spent a year supporting a hospital art programme and witnessing the benefits that arts can play within the healing process. I have produced several arts events in collaboration with community members, arts and media organisations and I am especially keen to be involved in projects that provide community members with a voice and the tools to reach their full potential, to thrive and transform their lives.

In 2016, I was invited to become a researcher for the Liverpool John Moores University Medical Humanities Research Group. I engaged a group of older people, some of whom had

early stages of dementia, to experience a Tate Liverpool's art exhibition titled 'An Imagined Museum'. The research activity sought to promote an understanding of ageing minds in relation to arts activities, memory, curatorship, and critical review. The art- viewing and discussion event invited older people and people living with dementia (early stages) to explore how they feel about art exhibitions at Tate Liverpool, what was really important to them and what had little impact.

During our visit to the Tate, we used a participatory cultural probe method. All participants were provided with a toolkit to help record their experience during their arts and cultural activities. This consisted of an easy-to-use digital recorder, notebook and pen. Following the visit all participants took part in a recorded focus group to discuss the experience. Data was collected by transcribing the recording and interviews following the visit. The group was took part in 2053: A Living Museum. During the exhibitions concluding weekend, all artworks were removed and replaced by a person or group remembering or performing each of the artworks that were once on display.

I presented the findings from our art viewing activity with a comedy performance, which was inspired the groups response to by Elaine Sturtevant's *'Warhol's Flowers'*. The comedy performance paid homage to Sturtevant's reconstructions, the repetition of works by other artists, and comedy sketches set in art galleries by Monty Python and '*Pete and Dud*'. The comedy text was interwoven with the stories/data collected as part of the art viewing experience. It was performed using a persona named 'Aimee', a character interpretation from the hyperreality TV show Towie. Throughout the text, other artworks were referenced that were also featured in the exhibition, this demonstrated the groups experience of the art viewing activity.

Whilst developing the script for the performance I had an increasing awareness of how I was learning more about the participant experience. The performance highlighted the possibilities of reaching wider audiences to raise awareness of limitations of health conditions. This experience informed the PhD research rational and guided the development of the research aim and research questions.

1.11 Research Questions

This study was guided by three research questions,

1. What are the benefits of participatory arts-based research (PABR) methods for patients?

2. Which art-based research methods in health increase engagement and help us gain a better understanding of the lived experience of public and patients?

3. How effective are arts-based dissemination methods in reaching audiences and raising awareness of health conditions?

These questions were explored during two distinct phases:

a) PABR exploring the lived experience of PLWD and how the arts can improve quality of life.

b) PABR to investigate the impact of lockdowns on the wellbeing of older adult during the global pandemic.

1.12 Overview of the theoretical framework

This research study aims to develop new theories through the inductive analysis of data collected from participants, rather than pre-existing theoretical frameworks. However, it is recognised that this thesis traverses several pre-existing theoretical frameworks associated with ABR, social theory, and PAR and these supported the development of the research methodology.

1.12.1 Arts Based Research

Previous evaluations of ABR suggest that it is firmly established within conventional qualitative methodologies, such as grounded theory, phenomenology, ethnography, and narrative inquiry. (Leavy, 2020). Arts-based research involves a range of research approaches and strategies that use one or more of the arts during the research stages. Such approaches have evolved from understandings that life and experiences of the world are multifaceted, and that art offers ways of knowing the world that involve sensory perceptions and emotion as well as intellectual responses. Researchers have used arts for various stages of research. It may be to collect or create data, to interpret or analyse it, to present their findings, or some combination of these. Arts-based research has been used to investigate art making itself, or to explore the lived experience. In other research ABR is used to explore issues in the wider social sciences. The field is a constantly evolving one, and researchers have evolved diverse ways of using the communicative and interpretative tools that processes with the arts allow. These include techniques to overcome language barriers and eliminating the need for verbal expression, whilst also capturing and expressing ambiguities, and complexities. This study

examined ABR within a social theoretical framework to analyse how individuals interpret the world to create meaning. Social constructivism, established by Russian psychologist Lev Vygotsky, asserts that people actively engage in the creation of their own knowledge (Schreiber & Valle, 2013). Vygotsky posited that knowledge acquisition occurs predominantly within social and cultural contexts, rather than being an isolated process within the individual (Schreiber & Valle, 2013). The participant groups in this study aligned with social constructivism theory, where arts-based activities were employed to stimulate and facilitate discussion by leveraging the natural flow of conversation within the research group.

1.12.2 Constructive Grounded Theory

Jonassen (1999) suggested that a constructivist learning environment is essential for offering learners a meaningful, stimulating, and significant experience that leads to effective problem solving and social change (Jonassen, 1999). ABR facilitated an enhanced constructivist learning environment, creating a significant and genuine context for social and collaborative activities to thrive. According to constructivist grounded theorists, a constructivist approach to grounded theory is both possible and desirable. The theory is co-created between the participants and the researcher during interactions (Charmaz, 2006) and collective discoveries. Therefore, in this study, the merging theory guided the literature review (McCann and Clark, 2003). The CGT framework complemented co-production within the PAR iterations and the creative process in ABR assisted the transformation process.

1.12.3 PAR

Underpinned by a Freirean philosophy relating to critical consciousness, participants enquire about the origins of their problems and develop solutions guided by critical analysis that are grounded in their lived experiences. This Freirean approach is rooted in the premise that minority groups had critical insights into the systems of oppression that sustain power; empowered people and groups would gain greater control throughout the research study and, consequently, over their identities and lives. Freire addressed themes of power, voice, conflict, and class by employing dialogue as the principal instrument for liberation, urging participants to critically reflect on their experiences and acknowledge the potential for change (Freire, 2017). Freire's notion that passivity perpetuates oppression while action might overcome it permeates the spirit of this research.

1.13 Definition of key terms

There is no single home for the variety of ideas relating to a participatory arts and health practice. Concepts such as arts, creativity, community, co-design, health, practice or participation are very differently understood by researchers from different disciplines (Broderick, 2011). Consequently, there are multiple terms across the range of arts and humanities, social science and health fields for the same or similar concept. Terms that have been used in reference to arts-based health research, include:

- arts-based knowledge transfer (Spagnol et al., 2019),
- visual methodologies (Pink 2012), Mitchell et al., 2017), (Mitchell 2011),
- cultural animation (Kelemen et al., 2018),
- action media (Parker 1997),
- an arts-based health communication method, and
- some examples of Community Based Participatory Research (CBPR) may also be considered ABR because occasionally where arts techniques are embedded to encourage participation (Minkler and Wallerstein 2008).

An understanding of these terms proved valuable to this thesis especially during the scoping and system review of the literature. CBPR emerged over the last few decades as an alternative research paradigm, but it is important to recognise that CBPR has a long history. CBPR has roots in transformational research practices such as action research and participatory action research. Social psychologist Kurt Lewin developed the action research school during the 1940s (Reason and Bradbury, 2008) and it's evident that the principles of participatory action research can be seen in several ABHR methods, encouraging participants to engage in an art making activity is of itself participatory. In addition, several photovoice health articles describe CBPR as a complementary method (Cheezum 2019; Sidibe et al., 2018; Reid et al., 2018). Although not all CBPR incorporate arts within the participatory research process.

1.13.1 Abbreviations

This is a list of abbreviations that appear in this thesis.

ABR – Arts Based Research

ABHR – Arts Based Health Research

HRA – Health Research Authority (UK)

LCCG – Liverpool Clinical Commissioning Group (Now known as ICB – Integrated Care Board)

LJMU – Liverpool John Moores University

NHS – National Health Service (UK)

NIHR – National Institute for Health and Care Research (UK)

PABR – Participatory Arts Based Research

PAR – Participatory Action Research

PLWD – People Living with Dementia (Includes the carer and the person with dementia)

PWD – Person or people with Dementia

1.14 Summary

The opening of Chapter One captures the need for a greater understanding of the development of arts-based health research over the last 20 years. After providing background and context, the statement of the problem, purpose, and the significance of the study follows the research questions to guide the dissertation study and theoretical frameworks that offer a purposeful lens to gather, conceptualise, and analyse the findings. Additionally, insight and personal motivation for this dissertation topic, research bias, and definitions of key terms are provided.

1.15 Organisation of Thesis

Chapter Two explores the literature and presents a visual map scoping the field of Arts Based Health Research.

Chapter Three outlines the methodology and arts-based research methods used in the study. It describes a methodological approach which would both embrace and challenge the multifaceted and multidisciplinary essence of arts-based health research.

Chapter Four is a presentation of case studies and data, from the emergent arts-based methods: PAR using cultural activities as stimulus, the Labyrinth Exchange as a vehicle for dissemination and public engagement, and theatre-based health methods to reach diverse audiences.

Chapter Five offers a discussion around the discoveries during the research journey and the significance of the findings in relation to the literature.

Chapter Six - Concludes the thesis by providing recommendations as well as outlining the implications of the study and suggestions for further research.
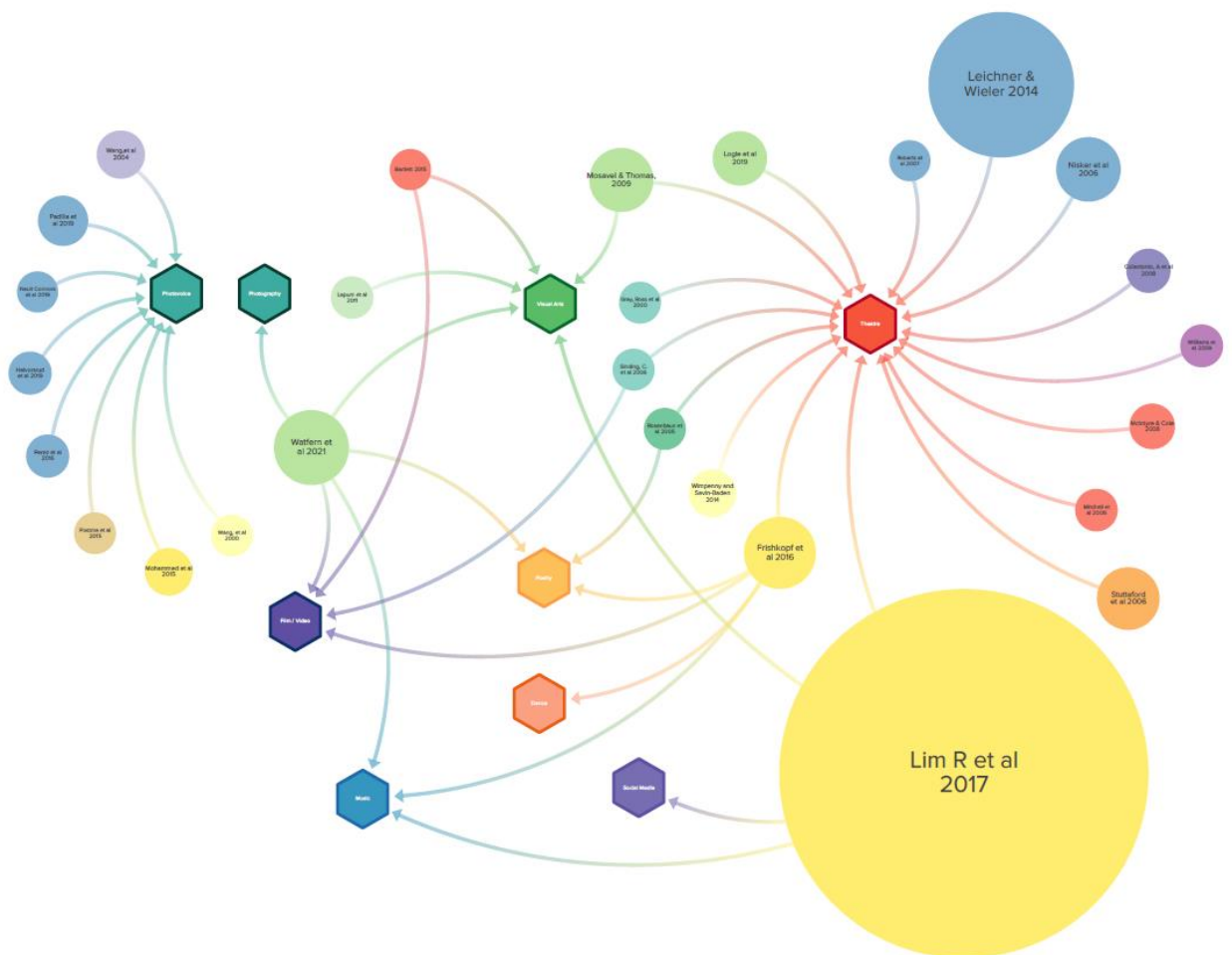
Figure 5: Systems map of ABHR systematic review
Ryan-McNeill, 2023 Available at: https://kumu.io/ElaineRyMc/abhrliteraturereviewmap

CHAPTER TWO: Visual Scoping Map and Systematic Review of Arts-Based Health

Arts-based researchers are not 'discovering' new research tools. They are carving them.

Leavy, 2020

Chapter Two: Visual Scoping Map and Systematic Review of Arts-Based Health Research

2.1 Introduction

Arts-based methods started to appear in health research towards the end of the 20th century. Inspired by the inadequacy of positivistic science, researchers began to investigate the scope of patients' visual, sensory, embodied, and emotional experiences using arts-based health methods. In 'Fiction as Research', Leavy argues that the use of art within research offers authenticity, accessibility, and reach and without doubt, Leavy's work of fiction has had far greater reach than her academic peer-reviewed papers (Leavy, 2013).

This chapter scopes and presents the burgeoning 40 years of ABHR, offering an introductory overview of this nascent field of research. The literature scoped and analysed as part of this review is presented in a visual format to depict the popular art genres used in health research, enhance the analysis, and illustrate the patterns that emerged.

2.2 Organisation of the Literature Review

The literature review is presents in three sections. Firstly, the literature revealed from an initial scoping activity is presented visually (1985-2020 Figures 7 and 8; 2010-2020 Figures 9 and 10). The second section provides an analysis of ABHR within health contexts in relation to health conditions and services. The third discusses ABHR methods, the specific patient population it is used with and the stages of research in which it is applied. In the final section, we discuss and analyse public engagement and dissemination events in greater detail. In particular, the systematic review of 27 studies looks at how ABHR can enhance the quality of engagement, increase participation, and increase audience reach. The major tenets of ABHR are articulated, along with its ability to enhance the patient experience of health research.

2.3 Scoping map and Systematic Review

A systematic review approach was chosen because of its origins in the medical sciences. The systematic review produced a complete and impartial summary of arts-based health research.

According to Petersen et al. (2008), a precursor to the systematic review in software engineering is systematic mapping, where the objective is to build a classification scheme and structure a research area. Prior to a systematic review, systematic mapping can provide an overview of a research area and scrutinise the quantity, type, and results of published literature within it. This systematic mapping process consists of three steps: (1) identifying relevant literature; (2) composing a classification scheme; and (3) visualising the literature. Healthcare researcher Donna Zucker, who self-identifies as a visual learner, developed maps or models to visualise and interpret the data (Leavy, 2020). This approach is relevant to the analysis of ABHR literature because of the diversity of art forms, health conditions, and outcomes.

Academics have effectively laid out where and how researchers have applied arts-based methods (Barone 2012; Leavy 2019; Knowles and Cole 2007; McNiff 2005) and visual methodologies (Prosser 2011; Pink 2012; Mitchell, De Lange, and Moletsane 2017). Mitchell's collection of visual methodologies in global public health explores visual methodologies that advocate for social change and policy influence. Few studies in the field of arts-based research focus on public and patients as participants (Kelemen, Surman, and Dikomitis 2018). Mitchell's collection of visual methodologies was published in Global Public Health Journal volume 11, however not all health research using these methodologies involved patient participation. Pink's collection of advances on visual methodology only includes one chapter dedicated to health, Ethnomemesis, likewise, Leavy's Handbook on Art-Based Research has one chapter, '*Deepening the Mystery of Arts Based Research in the Health Sciences*' by Lapum (Lapum, 2018; cited in Leavy). During this PhD study Hinsliff-Smith published, Arts Based Health Care Research: A Multidisciplinary Perspective, devoted to the practical application of arts, health and wellbeing research (Hinsliff-Smith, 2022). This provides a glimmer of hope and a sign of progress in the advancement of the field.

Most reviews of arts-based health research focus on the benefits (Leavy 2019), (Boydell 2012), methodology (Barone 2012), (Knowles and Cole 2007), ethics (Boydell and Hodgins, 2016), but little has been written about the development and growth of ABHR, particularly from a cross-disciplinary perspective.

The following databases were searched: CINAHL, ERIC, Medline, PubMed, PsychINFO, and Scopus, using different combinations of several keywords. The initial search identified 1906

papers, of which only 229 were relevant. 216 studies met the inclusion criteria, but after the first review, this number dropped to 211. A final review of the literature detected 209 papers that met the criteria. All relevant studies were analysed by year, author, art method, health condition, journal, and research aim.

2.4 Inclusion Criteria

For this literature review, the inclusion criteria are as follows:

- Participatory art-based research, arts-based knowledge transfer, and CPBR as examples of ABR approaches in health.
- Any art form, including storytelling, visual arts, music, dance, theatre, and photovoice, is considered relevant. Social media platforms were considered relevant forms of art as a sexual health information research project with young people demonstrates the creation of social media content required storytelling (Byron et al. 2013).
- Patients or people with lived experience had to be involved (if they weren't involved in the art-making process, they at least had to participate in the design or curatorial process). I.e., Stålberg, used a co-design approach where patients contributed their perspectives to designing an interactive app (Stålberg, 2016), and similarly, Wolpin et al. invited patients to discuss and design pictographs for health information on smartphones (Wolpin et al., 2016).

Studies were included if they engaged patients in public health promotion and projects that improved knowledge of the patient experience and patient wellbeing but studies on the periphery of health services were not included, such as sanitisation and clean water, healthy eating projects, and exercise studies. Similarly, studies relating solely to disability research and not a specific health service were omitted. Any articles that evaluated creative health using traditional research methods, i.e., surveys, questionnaires, focus groups, and interviews, were not deemed relevant to this review, unless they employed arts-based research methods to evaluate their impact.

Figure 5. Scoping and systematic review search and retrieval process flow chart

Articles displayed in database searches
496

Non-English Articles
109

English articles included
387

Non relevant articles
101

Articles retrieved and reviewed for visual mapping
286

Articles that did not meet the inclusion criteria
42

Articles retrieved and reviewed for visual mapping
244

Further articles identified that did not meet the criteria
34

Articles retrieved and reviewed for visual mapping
210

Visual mapping articles
2010 - 2021
118

Studies included in Systematic Review (focusing on participation, quality of engagement and audience reach)
27

"The arts" in ABHR are broadly understood to include not only traditional forms such as theatre, dance, music, painting, and sculpture, but also more recent additions such as film, photography, and performance art, as well as crafts, digital and electronic production, and various aspects of popular culture such as social media. ABHR has embraced several art forms, including performing arts (e.g., activities in the genres of music, dance, theatre, singing, and film); visual arts, design, and craft (e.g., crafts, design, painting, photography, sculpture, and textiles); and creative writing (e.g., poetry, storytelling, and life history narratives). The breadth of arts used in health research is extensive and innovative, such as the construction of an aerial and contemporary dance to narrate the lived experience of patients with epilepsy (Spagnol et al., 2018).

Figure 6: Arts-based knowledge translation in aerial silk to promote epilepsy awareness Spagnol et al 2018, p.62

2.5 Scoping the field: a visual map of ABHR over the last 40 years

The visual map of the literature review was created to consider whether visualising data can enhance analysis and synthesis. The first data analysts realised the absolute necessity of visualising data to get their message across. More recently, with the development of big data, data visualization has become a huge concern. The exponential growth of data collection has been spurred by the prevalence of the internet and the growing number of data-generating devices, including smart phones and wearable electronics. The battle between letting the data speak for itself and creating a visualisation that grabs the audience began over two hundred

years ago when William Playfair, an engineer, political economist, and pioneer of visualisation in the early 19th century, invented the time series graph or line chart, the bar chart, and the pie chart. In understanding how visual data grabs an audience, Playfair said, "nothing is drier and more tedious as statistics," and data must "set the mind and imagination to work". (Costigan-Eaves and McDonald-Ross, 1990). He recognised that, while raw data is invaluable, it must be transformed into something else to make a difference. Chishtie et al. conclude that 'visual analysis' is a rapidly expanding method for handling complex health care data. What makes VA innovative is its capability to process multiple, varied data sources to demonstrate trends and patterns for exploratory analysis, leading to knowledge generation and decision support' (Chishtie et al., 2019).

Using a visual approach to analyse and synthesise ABHR provided instantaneous insight into a large amount of data and also helped to distinguish errors in the data, such as duplications and papers that did not meet the criteria for closer analysis. The colour coding of art genres helped to immediately recognise the patterns emerging in the data, particularly the dominance and growth of art-based health research methods particularly photovoice. Visualising data within a literature review presents a unique opportunity to effectively convey a vast amount of information and enables an analysis of the outputs, challenges, and benefits described in numerous studies. Visual analysis initially provided a thorough inspection of all potentially relevant articles.

For the visual maps of ABHR articles a colour code for art genres was created:

Performing arts–Drama and theatre, Dance (including creative movement)

Creative Writing (poetry, fiction) / Storytelling (including digital storytelling)

Multi-genre (applied more than one art form)

Visual Arts (including drawing, painting, decoupage, collage)

Photography (including Photovoice, Photo Elicitation, Photo Novella)

Music and Film/Video

Graphic Design

A sub-category was created within the visual arts for Photovoice to represent a more accurate account of ABHR methods. Previous ABHR reviews present the visual arts as the most commonly used genre, followed by performance arts and literary arts (Fraser and Sayah, 2011, Lapum 2018). When photovoice is distinguished within the visual arts genre, it can be determined that the Photovoice method equates to 64% of all ABHR in the last 10 years and other visual arts only 13%. This is notable within the visual representation of literature. The prolific use of photovoice among health researchers suggests this requires further discussion.

Figures 7 and 8 are visual representations of the initial scope of arts-based health research since the first peer-reviewed article in 1985. This visual scoping review has systematically mapped the literature chronologically and distinguished the art genres used. It identifies gaps in the field of ABHR, such as music, which is not represented here, and what is striking is the prevalence of photovoice, from the creation of the method by Wang and Burries in the 1990s to its dominance of the field over the last ten years. The visual scope indicates that the inaugural ABHR genre published in peer-reviewed journals was visual arts, beginning with drawing, followed by photography, which subsequently dominated the field of health research.

The earliest ABHR article to appear in a peer review journal was Stravnicky-Myland's study using drawing with children of alcoholics. Clinicians first used drawings as a diagnostic aid, but they quickly recognised that these illustrations could enhance the research methodology by providing profound insights into their lived experiences (Stravnicky-Myland, 1986). This demonstrates that the recognition of arts-based health research as an effective health research methods is still in a nascent phase of development, with its inclusion in peer-reviewed journals dating back less than 40 years.

Building upon previous art-based health research reviews, this review provides a brief overview of the categories of health research using arts-based approaches, the successes and challenges of theatre and visual arts-based approaches in health research, and how ABHR might increase meaningful participation, the quality of engagement, and audience reach.

Figure 7. Visual map of Arts Based Health Research 1985 – 2009
Ryan-McNeill, 2019

Rich et a. (2006) Effects of creating visual illness narratives on quality of life with asthma: a pilot intervention study.

Rich et al (2005) Visual narratives of the pediatric illness experience: Children communicating with clinicians through video.

Stewart, S et al (2008) Expanding health literacy: Indigenous youth creating videos.
Shapiro, D. et al (2009)

Patients as teachers, medical students as filmmakers: The video slam, a pilot study

Lopez, E. D. S., et al (2005) Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: Blending the techniques of photovoice and grounded theory.
McAllister, C. L., et al (2005) "Come and take a walk": Listening to Early Head Start parents on school-readiness as a matter of child, family, and community health.
Smith, B K.; et al (2006) Facilitating narrative medical discussions of type 1 diabetes with computer visualizations and photography.
Baker & Wang (2006) Photovoice: use of a participatory action research method to explore the chronic pain experience in older adults
Hergenrather, K C., et al (2006) Windows to work: Exploring employment-seeking behaviors of persons with HIV/AIDS through Photovoice
Hussey, W. (2006) Slivers of the journey: The use of photovoice and storytelling to examine female to male transsexuals 'experience of health care access.
Nowell, B. L. et al (2006) Revealing the cues within community places: Stories of identity, history, and possibility.
Short, R. V. (2006) New ways of preventing HIV

infection: Thinking simply, simply thinking.
Stevens, C. A. (2006) Being healthy: Voices of adolescent women who are parenting.
Wang, C. C. (2006) Youth participation in photovoice as a strategy for community change
Bader, R. et al (2007) Global youth voices: Engaging Bedouin youth in health promotion in the Middle East.
Smith, B. K.; et al (2007) Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices.
Frith & Harcourt (2007) Using photographs to capture women's experiences of chemotherapy: Reflecting on the method
Fournier, B. et al (2007) Nursing care of AIDS patients in Uganda.
Grosselink & Myllykangas (2007) The leisure experiences of older US women living with HIV?AIDS.
Oliffe & Bottorff (2007) Further than the eye can see? Photo elicitation and research with men

Jurkowski & Paul-Ward (2007) Photovoice with vulnerable populations: Addressing disparities in health promotion among people with intellectual disabilities.
Levin, T; at al. (2007). Aphasia talks: Photography as a means of communication, self-expression, and empowerment in persons with aphasia.
Mamary, E. et al. (2007). Our lives: An examination of sexual health issues using photovoice by non-gay identified African American men who have sex with men.
Rhodes & Hergenrather (2007) Recently arrived immigrant Latino men identify community approaches to promote HIV prevention.
Schwartz at al (2007) Using photovoice to improve family planning services for immigrant hispanics.
Washington at al (2008) Telling my story: From narrative to exhibit in illuminating the lived experience of homelessness among older African American women.
Bender, D. et al (2008) Perceptions of quality of reproductive care services in Bolivia: Use of photo prompts and surveys as an impetus for change
Oliffe, et al (2008)

Analyzing participant produced photographs from an ethnographic study of fatherhood and smoking.
Jacobs & Harley (2008) Finding voice: The photovoice method of data collection in HIV and AIDS-related research
Thompson et al (2008) The experience of living with chronic mental illness: A photovoice study
Vaughn et al (2008) Picturing" health A photovoice pilot of Latina girls' perceptions of health
Fleming et al (2009) An ethnographic approach to interpreting a mental illness photovoice exhibit.
Poudrier & Mac-Lean (2009) We've fallen into the cracks: Aboriginal women's experiences with breast cancer through photovoice
Boxall & Ralph (2009) Research ethics and the use of visual images in research with people with intellectual disability.
Angus et al (2009) Context and Cardiovascular Risk Modification in Two Regions of Ontario, Canada: A Photo Elicitation Study

Rich, M (2004) Health literacy via media literacy—**Video** intervention/prevention assessment.

Rich, M. et al (2000). Asthma in life context: **Video** Intervention/prevention Assessment (VIA).

Rich, M et al (2000). **Video** intervention/prevention assessment: a patient-centered methodology for understanding the adolescent illness experience.

Wang, et al (2004). Exploring professional values and health policy through **photovoice**

Wang, et al (2004). Family, maternal, and child health through **photovoice**

Streng, J. M et al (2004). Realidad Latina: Latino adolescents, their school, and a university use **photovoice** to explore immigration.

Wang, et al (2004). Flint **photovoice**: Community building among youths, adults, and policymakers.

Dyches, T (2004). **Snapshots** of life: Perspectives of school-aged individuals with developmental disabilities.

Graziano, K. J. (2004). Oppression and resiliency in a post-apartheid South Africa: Unheard voices of Black gay men and lesbians.

Herman & Larkey (2006) Effects of an art-based curriculum on clinical trials attitudes and breast cancer prevention knowledge.
Morgan, M. et al (2009) Drawing the experience of chronic vaginal thrush and complementary and alternative medicine.
Nowicka-Sauer, Katarzyna

(2007) Patients' perspective: Lupus in patients' drawings—Assessing drawing as a diagnostic and therapeutic method.
Pelander et al (2007) Children in the hospital Elements of quality in drawin

Piko & Bak (2006) Children's perceptions of health and illness: Images and lay concepts in preadolescence.
Rollins. (2005) Tell me about it: Drawing as a communication tool for children with cancer
Walker, K. et al (2009) "I Like to jump on my trampoline": An analysis of

drawings from 8- to 12-year-old children beginning a weight-management program.
Stuckey, H. L. (2009) Creative expression as a way of knowing in diabetes adult health education: An action research study

Allotey, P. et al (2003). The DALY, context and the deter- minants of the severity of disease: An exploratory comparison of paraplegia.

Booth & Booth (2003). In the frame: **Photovoice** and mothers with learning difficulties

Radley & Taylor (2003) Images of recovery: A **photo-elicitation** study on the hospital ward

Radley, & Taylor (2003) Images of recovery: A **photo-elicitation** study on the hospital ward.

Pietrzyk, Susan (2009) Talking wellness: A description of a community academic personnel project to engage an African-American community about depression through the use of poetry, film, and photography

Chung, et al (2009) Talking wellness: A description of a community academic personnel project to engage an African-American community about depression through the use of poetry, film, and photography

Coad, J (2007) Using art-based techniques in engaging children and young people in health care consultations and or research?

Wang, et al (2001). **Photovoice** ethics: Perspectives from Flint.

LeClerc, C M, et al (2002). Falling short of the mark: Tales of life after hospital discharge

Clarke, J. et al (2005) Poetry and prose: Telling the stories of formerly homeless mentally ill people.

Furman et al (2006). Inside a provider's perspective: Using practitioner poetry to explore the treatment of

Furman, Rich (2006) Poetic forms and structures in qualitative health research.
Lapum, Jennifer (2005)

Women's experiences of heart surgery recovery: A poetical dissemination.

Killion & Wang (2000). **Linking African American mothers across life stage and station through photovoice.**

Wang, et al (2000). Who knows the streets as well as the homeless? Promoting personal and community action through **photovoice**.

Kontos & Naglie (2007) Expressions of personhood in Alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool.
McIntyre & Cole (2008) Love stories about caregiving and Alzheimer's disease—A performative methodology.
Mitchell, G. J et al (2006) Research-based theatre: The making of I'm still here!

Mosavel & Thomas (2009) Project REECH: Using theatre arts to authenticate local knowledge.
Nisker, J. et al (2006) Theatre as a public engagement tool for health-policy development.
Roberts, G. et al (2007) On the edge: A drama-based mental health education programme on early psychosis for schools.
Rosenbaum, M. et al (2005) in their own words:

Rossiter, K. et al (2008) Staging data: Theatre as a tool for analysis and knowledge transfer in health research
Sandelowski, M. et al (2006) From synthesis to script: Transforming qualitative research findings for use in practice.
Sinding, C. et al (2006) Audience responses to a research-based drama about life after breast cancer.

Stuttaford, M. (2006) Use of applied theatre in health research dissemination and data validation: a pilot study from South Africa.
Williams, E. M. (2009) Behind the fence forum theater: An arts performance partnership to address lupus and environmental justice.
Broadbent et al. (2006) Psychosomatic Research Changes in patient drawings of the heart identify slow recovery after myocardial infarction

Wang, et al. (1998). **Photovoice** as a participatory health promotion strategy.

Guillemin, M (2004). Understanding illness: Using **drawings** as a research method.

Guillemin, M (2004). Embodying heart disease through **drawings**

Wang, et al (1994) Empowerment through photo novella: Portraits of participation.

Wang, et al (1997). Photovoice: Concept, methodology, and use for participatory needs assessment.

Henare, D et al (2003). Chronic pain: Gaining understanding through the use of **art**

Broadbent et al. (2004) A picture of health – myocardial infarction patients' **drawings** of their hearts and subsequent disability.

Hanna & Jacobs (1993) The use of **photography** to explore the meaning of health among adolescents with cancer

Hanna, Jacobs & Guthrie (1995) Exploring the concept of health among adolescents with diabetes using photography

Gray, R. et al (2003). Reactions of health professionals to a research-based **theatre** production.

Kidd & Tusaie (2004) Disconfirming beliefs: The use of **poetry** to know the lived experience of student nurses in mental health clinics

Bosompra, Kwadwo (2007-2008). The potential of **drama** and songs as channels for AIDS education in Africa: A report on focus group findings from Ghana.

Colantonio, A et al (2008). After the crash: Research-based theater for knowledge transfer.

Cox, S et al (2009). Genetics on **stage**: Public engagement in health policy development on preimplantation genetic diagnosis.s

Stravinsky-Mylant (1986) The use of drawings in the assessment and treatment of children

Rollins (1990) Childhood cancer: Siblings **draw and tell**

Power (1996) Evaluating health knowledge: An alternative approach

Gray, Ross et al (2000). The use of research-based **theatre** in a project related to metastatic breast cancer.

Sinding, C. et al (2002) **Staging** breast cancer, rehearsing metastatic disease.

Picard, Carol (2008) **Creative movement** and transformation to choreography: A mode of research presentation.

Gavaravarapu, S (2009) Nutrition education for student volunteers using a videotaped folk **dance** format.

Eakin, et al (2009) Knowledge translation through research-based theatre

1990 - 1999

2000-2009

Figure 8. Visual map of Arts Based Health Research 2010 - 2020
Ryan-McNeill, 2019

Trop and Withers 2017 Visions and Voices: Using Photovoice to Document International Migrants ' Health Needs in Santiago, Chile

Brandt et al 2016 Planting Healthy Roots: Using Documentary Film to Evaluate Participatory Research

Shortt et al 2017 Place and recovery from alcohol dependence: a journey through photovoice

Jih et al 2018 Application of Photovoice with Focus Groups to Explore Dietary Behaviors of Older Filipino Adults with Cardiovascular Disease.

Capous-Desyllas, M. C. (2013) Using photovoice with sex workers: The power of art, agency and resistance

Musoke et al 2015 Using photovoice to examine community level barriers affecting maternal health in rural Wakiso

Williams et al 2016 A snapshot of the lives of women with polycystic ovary syndrome: A photovoice investigation

Moya et al 2017 Adults experiencing Homelessness in the US-Mexico Border region: A Photovoice project

Georgievsk et al 2018 Through our eyes: A photovoice intervention for adolescents on active cancer treatment.

Vallesi S et al 2018 Incorporating Underlying Social Determinants into Aboriginal Health Promotion Programs.

Cabassa LJ 2013 Health and wellness photovoice project: engaging consumers with serious mental illness in health care

Zemits et al 2014 Moving Beyond "Health Education": Participatory Filmmaking for Cross-Cultural Health Communication

Mizock et al 2015 Recovery narrative photovoice: Feasibility of a writing and photography intervention for serious mental illnesses

Belon et al 2016 Perceived community environmental influences on eating behaviors: A Photovoice analysis

Werremeyer et al 2016 Using Photovoice to explore patients' experiences with mental health medication: A pilot

Lightfoot et al 2017 Using photovoice with immigrant Latino adolescents to explore barriers to healthcare

Creighton et al 2018 Photovoice Ethics: Critical Reflections From Men's Mental Health Research.

Gabarron E et al 2018 Social media for health promotion in diabetes: study protocol for a participatory public health

Bredesen et al 2013 Using photovoice methodology to give voice to the health care needs of homeless families.

Byron P et al 2013 Young people's use of social media and the risk of sharing sexual health information.

Mitchell et al 2015 Exploring Creole women's mental health using ethnography and Photovoice in Bluefields,

Ardrey et al 2016 The Cooking and Pneumonia Study in Malawi: A Nested Pilot of Photovoice Participatory Method

Walker et al 2016 Type 1 diabetes. comparing adolescent and parental perspectives with photovoice.

Leung et al 2017 A pilot study using photovoice to explore health perceptions among migrant youth in Beijing, China

Chew and Lopez 2018 Empowered to Self-Care: A Photovoice Study in Patients With Heart Failure

Irby MB et al 2018 Violence as a health disparity: Adolescents' perceptions of violence depicted through photovoice.

Jui et al 2019 A community-based diabetes group pilot incorporating a community health worker and photovoice methodology

Bukowski et al 2011 Making the invisible visible: A photovoice exploration of homeless women's health in central Auckland.

Postma et al 2014 Mexican-American caregivers 'perceptions about asthma management: a photovoice

MacFarlane et al 2015 Implications of participatory methods to address mental health needs / Climate

Wolpin et al 2016 Redesigning pictographs for patients with low health literacy

Rose et al 2016 Exploring wellbeing and agency among urban youth through photovoice

Kim et al 2017 Experiences of Korean mothers of children with cancer: A Photovoice study

Carroll et al 2018 Using PhotoVoice to Promote Land Conservation and Indigenous Well-Being in Oklahoma.

Velez-Grau, Carolina 2018 Using Photovoice to examine adolescents 'experiences receiving mental health services

Halvorsrud et al 2019 Capturing ethnic minority people's lived experiences of severe mental illness and its treatment

Taylor P 2020 The Process of Women's Help-Seeking for Suicidality After Intimate Partner Violence:

Yi & Zebrack (2010) Self-portraits of families with young adult cancer survivors: Using photovoice

Mann Woith et al 2014 Feasibility of a Photovoice Study Promoting Respirator Use among Russian

Kowitt et al 2015 Using Photovoice to Understand Barriers to and Facilitators of Cardiovascular Health

Stålberg et al 2016 Young children as co-designers in the design of an interactive application

Tang et al 2016 The big picture unfolds: Using photovoice to study user participation in mental health services

Esau et al 2017 Engaging youth in rural Uganda in articulating health priorities through Photovoice

Bates et al 2018 Enhanced patient research participation: a Photovoice study in Blantyre Malawi.

Sun et al 2018 Perceptions of Needs, Assets, and Priorities Among Black Men Who Have Sex With Men With HIV

Gullón et al 2019 Using Photovoice to Examine Physical Activity in the Urban Context and Generate Policy Recommendations

O'Donovan et al 2020 Exploring perceptions, barriers, and enablers for delivery of primary ear and

Wallis et al 2010 "This is not a well place": Neighborhood and stress in Pigtown".

Kovacic et al 2014 Beginning a partnership with PhotoVoice to explore environmental health and

Iskander D 2015 Re-imaging malaria in the Philippines: how photovoice can help to re-imagine malaria.

Grieb et al 2016 ¡Vive!: Designing an Intervention to Improve Timely HIV Diagnosis Among Latino Immigrant Men.

Musoke et al 2016 Reflections on participatory research on maternal health in Wakiso district, Uganda

Edwards and Greeff 2017 Emotional cancer challenges experienced in South Africa: 316 photovoice interviews

Bates et al 2018 Household concepts of wellbeing and the contribution of palliative care for cancer: Blantyre, Malawi

Sidibe et al 2018 Using Photovoice to Understand African American Female Adolescents 'Perspectives on Sexual Risk

Ferlette et al 2019 Using Photovoice to Understand Suicidality Among Gay, Bisexual, and Two-Spirit Men

Nguyen-Truong et al 2020 Cultural Narratives of Micronesian Islander Parent Leaders: Maternal and Children's Health.

Capous-Desyllas, M. C. (2013) Using photovoice with sex workers: The power of art, agency and resistance

Bayer & Alburqueque 2014 Adolescents use photovoice to speak their mind on adolescent health in Lima, Peru.

Hermanns et al 2015 Visions of Living with Parkinson's Disease: A Photovoice Study

Wolpin et al 2016 Redesigning pictographs for patients with low health literacy.

Maratos et al 2016 Exploring the Lived Experience of High-Functioning Stroke Survivors Using Photovoice

Creighton et al. 2017 Retrospectives on a Canadian rural male youth suicide using an instrumental photovoice case study.

Latimer et al 2018 Creating a safe space for First Nations youth to share their pain

Roger et al 2018 Living with Parkinson's disease – perceptions of invisibility in a photovoice study

Drainoni et al 2019 Perspectives on photovoice among people who inject drugs

Tömbom et al 2019 Life after stroke - A photovoice study on participation in Sweden

Wells, F. et al (2012) A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies

Balbale et al 2014 Using photovoice to explore patient perceptions of patient-centered care in the Veterans Affairs Health

Helm et al 2015 Using Photovoice with youth to develop a drug prevention program in a rural Hawaiian community.

Hirsch and Philbin 2016 Insights from the use of life history drawings in research with a migrant community

Mabry et al 2016 Healthy Eating in Rural Women of Childbearing Age: Findings From a PhotoVoice Study

Bashore et al 2017 Improving health in at-risk youth through Photovoice

Anderson et al 2018 Using participatory risk analysis to develop a song about malaria for young children in Limpopo

Reid & Alonso 2018 Imagining Inclusion: Uncovering the Upstream Determinants of Mental Health

Cheezum et al 2019 Using PhotoVoice to Understand Health Determinants of Formerly Homeless Individuals Housing in

Soriano-Ayala et al 2019 Identification of Cultural and Transcultural Health Assets Among Adolescents

Yi & Zebrack (2010) Self-portraits of families with young adult cancer survivors: Using photovoice

Thomas et al 2013 Written and spoken narratives about health and cancer decision making: a novel application of photovoice.

Hammer et al. 2015 Perceptions of Healthy Eating in Four Alberta Communities: A Photovoice Project

Gilbert,et al 2016 Portrait of a process: Arts-based research in a head and neck cancer clinic.

Han & Oliffe 2016 Photovoice in mental illness research: A review and recommendations.

Balbale et al 2017 Examining Participation among Persons with Spinal Cord Injuries and Disorders

Nguyen 2018 The Creative and Rigorous Use of Art in Health Care Research

Peña-Purcell et al 2018 Photovoice Stories From African Americans and Hispanic/Latinos Living With Diabetes

Cardarelli et al 2019 The Mountain Air Youth Photovoice Project.

Skoy & Werrenmeyer 2019 Using Photovoice to Document Living With Mental Illness on a College Campus

Haines et al 2010 "The missing picture": Tobacco use through the eyes of smokers.

Teti et al 2013 Photovoice as a tool to facilitate empowerment among poor and racial/ethnic minority women with HIV.

Fortin et al 2015 I WAS HERE: young mothers who have experienced homelessness use Photovoice

Yi-Frazier et al 2015 Using Instagram & Photovoice for Storytelling in Adolescents With Type 1 Diabetes

Gill et al 2016 Photovoice: A Strategy to Better Understand the Reproductive and Sexual Health Needs of Young Mothers

Kia-Keating et al 2017 Photography and Social Media Use with Youth: Ethical Considerations

Gameirol et el 2018 DrawingOut – An innovative drawing workshop to support the dissemination of research findings

Padilla et al 2018 PhotoVoice methodology to promote policy dialog among street-based drug

Baig et al 2019 Using photovoice to promote diabetes self-management in Latino patients.

Ronzi et al 2019 Using photovoice to advance clean cooking and improve health: The LPG adoption in Cameroon

Cooper & Yarbrough (2010) Tell me-show me: Using combined focus group and photovoice methods to gain understanding of health issues in rural Guatemala.

Panazzola & Leipert 2014 Exploring mental health issues of rural senior women residing in Ontario, Canada

Florian et al 2015 Using Photovoice and Asset Mapping to Inform a Community-Based Diabetes Intervention, Boston

Yankelow et al 2015 "Another Day in Paradise": A Photovoice Journey of Rural Older Adults Living With Diabetes

Ghosh et al 2016 Photovoice exploration with mothers from the Indian Sundarbans.

Govender et al 2017 Secrecy, empowerment and protection: positioning PrEP in KwaZulu-Natal, South Africa

Limaye NP et al 2018 Designing a novel digital story intervention to improve maternal and child health in the

Overby et al 2018 PhotoVoice: Engaging School Communities in Wellness Efforts

Joensson K et al 2019 Listening to the patients: using participatory design in the development of a cardiac rehab web portal.

Nitzinger et al 2019 Latino Health Perceptions in Rural Montana: Engaging Promotores de Salud Using Photovoice/Facebook.

Montgomery M et al 2012 The Native Comic Book Project: native youth making comics and healthy decisions.

Mohammed et al 2013 Harnessing Photovoice for tuberculosis advocacy in Karachi, Pakistan

Bisung et al 2015 Using Photovoice as a Community Based Participatory Research Tool for Water, in Usoma, Kenya

Woda et al 2016 Factors influencing self-care behaviors of African Americans with heart failure: A photovoice project

Evans-Agnew, Robin 2016 Asthma Management Disparities: A Photovoice Investigation With African American Youth

Wieland ML et al 2017 Digital Storytelling Intervention for Immigrant and Refugee Adults With Diabetes.

Farre AGMC et al 2018 Adolescent health promotion based on community-centered arts education

Musoke et al 2018 Reflecting strategic experiences of community health workers using photovoice in rural

Arcia A et al 2019 Pictograms for a Web App to Help Hispanic Caregivers Learn About the Functional Stages of Dementia.

Nault Connors et al 2019 Use of Photovoice to engage stakeholders patient-centered outcomes research.

Stuckey & Tisdell 2010 The role of creative expression in Diabetes: An exploration into the meaning-making process.

LeBron AM et al 2014 Storytelling in community intervention research: lessons from the walk your heart to health.

McLeod et al 2015 Connecting Socially Isolated Older Rural Adults with Volunteers through Expressive Arts

True et al 2015 Understanding Barriers to Mental Health Care for Recent War Veterans Through Photovoice

Evans et al 2016 Use of photovoice with people with younger onset dementia

Kaholokula JK et al 2017 Cultural Dance Program Improves Hypertension Management for Native Hawaiians

Spagnol et al 2018 Arts-based knowledge translation in aerial silk to promote epilepsy awareness

Mitchell, Felicity 2018 Using Photovoice to Document American Indian Perspectives on Water and Health

Cordova et al 2019 A multilevel mHealth drug abuse and STI/HIV intervention for clinic settings in the United States.

Leung et al 2019 Motivating Diabetic Patients to Engage in Regular Physical Activity: A Multi-

Lambert et al 2013 Young children's perspectives of ideal physical design features for hospital-built environments

Rix EF et al 2014 Aboriginal people's experience of haemodialysis in rural Australia.

Mohatt et al 2015 Case studies of participatory public art as a pathway to wellness for persons with behavioral health challenges

Switzer et al 2015 Visualizing harm reduction: Methodological and ethical considerations

Cooper and Yarbrough 2016 Asian-Indian Students: A Photovoice Study of Health and Adaptation

Schroeder K et al 2017 Dance for Health: An Intergenerational Program to Increase Access to Physical Activity.

Atkins R et al 2018 Using a Participatory Action Research Model to Evaluate the Impact of Dance for Health.

Lennon-Dearing & Price 2018 Women living with HIV tell their stories with photovoice

Moore AP et al 2019 Designing (HEAL-D) self-management and support programme for UK African and Caribbean communities.

Lam et al 2019 Exploring the Relationship between School Gardens, Food Literacy and Mental Well-Being in Youths

Look MA et al 2012 Developing a culturally based cardiac rehabilitation program: the HELA study.

Leichner & Wieler 2014 maladjusted: Participatory theatre about human-centred care

Njeru et al 2015 Stories for change: development of a diabetes digital storytelling intervention for refugees

Saimon et al 2015 A Photovoice Analysis of Factors Influencing Physical Activity Behavior Among Malaysian

Chan et al 2016 An Age-Friendly Living Environment as Seen by Chinese Older Adults: A "Photovoice" Study.

Lim R et al 2017 Drama as a community engagement strategy for malaria in rural Cambodia.

Frauenberger C et al 2018 Thinking OutsideTheBox - Designing Smart Things with Autistic Children.

LaVela et al 2018 Using the Participatory Research Method, Photovoice, in Individuals With Spinal Cord Injury.

Logie et al 2019 Exploring the Participatory Theatre to Reduce Stigma and Promote Health Equity for LGBT in Swaziland.

Keefe et al 2019 Prioritizing Health Equity: Patient Perspectives from a Clinic-Based

2010-2020

Catalani and Minkler (2009), Fraser and Sayah (2011), and Boydell et al. (2012) reviewed innovative approaches such as photovoice, narrative storytelling, and other arts-based interventions. While there have been more recent reviews of photovoice and its effect on working with specific cohorts, i.e., learning disabilities (Chin and Baolota, 2023) and indigenous young people (Anderson et al., 2023).

This scoping review demonstrates clearly through this visual approach that Photovoice grew in prominence during 2016. This coincided with Global Health Journal dedicating two issues of the publication to participatory visual approaches.

Catalani and Minkler's review provides a better understanding of how photovoice combined CBPR methods to enhance the understanding of community assets and needs (Catalani and Minkler 2010), whereas Fraser and Sayah's review focuses on methodological, theoretical, and ethical issues within the field of ABHR (Fraser and Sayah, 2011, Hodgins 2014).

Recognising the lack of systematic reviews over the last 15 years, Figures 9 and 10 presents a visual map of ABHR between 2010 and 2021, illustrating the development of ABHR and the most popular art genres used over the last 13 years (see Figures 9 and 10).

2.6 Health Conditions and Health Services

Various fields of health, including mental, physical, social, and environmental, have used arts-based health research approaches. Previous reviews have highlighted the use of the arts in medicine, nursing, epidemiology, health policy, sociology, psychology, neuroscience, and rehabilitation science (Boydell et al., 2012; Fancourt and Joss, 2015). In this review, health categories were analysed using the '*Health Research Classification System'*. There are 21 separate categories, which encompass all diseases, conditions, and areas of health. Of the 21 categories, 19 refer to specific areas of health or disease, plus there are two additional categories: 'Generic Health Relevance' to capture research that is relevant to all diseases and conditions or to general health and well-being, and 'Public Health' for studies that explored effective communication and public health promotion with no focus on a specific disease or condition.

Although this provided a list that marries categories used within the health system, this system does not differentiate between adult and child health. An additional criterion was added to this scoping review to analyse ABHR used in studies for adults or children.

2.7 A summary of health categories

In previous Arts-Based Health Research (ABHR) reviews, the health contexts of ABHR studies were not analysed. Figure 11 presents a scope of the data in this study and indicates that arts-based health research covers almost all health contexts. The health conditions that have not been explored or investigated using ABHR are ear deafness and normal ear development and function, eye diseases and normal eye development and function, and musculoskeletal. This gap offers Arts Based Health Researchers an opportunity to explore the benefits for patients within these health contexts further.

Generic health relevance has the highest proportion at 18%, followed by mental health at 15%, reproductive health and childbirth at 11%, and public health research at 10%. It's possible that ABHR covers almost all health situations because health researchers recognise the benefits and know how useful it is to reach people from different backgrounds and languages. ABHR methods are most likely being used in new health situations to meet the criteria for peer review health journal themes.

Figure 11: Table of Health Categories represented in Arts-Based Health Research review

Health Category	Description	No of ABHR papers
Blood	Haematological diseases, anaemia, clotting (including thromboses and venous embolisms) and normal development and function of platelets and erythrocytes	1 (Nr A = 1)
Cancer and neoplasms	All types of neoplasms, including benign, potentially malignant, or malignant (cancer) cancer growths. This includes leukaemia and mesothelioma.	16 (Nr A = 13 / YP = 3)
Cardiovascular	Coronary heart disease, diseases of the vasculature and circulation including the lymphatic system, and normal development and function of the cardiovascular system	15 (Nr A = 12 / YP = 2 / A+ YP = 1)
Congenital disorders	Physical abnormalities and syndromes that are not associated with a single type of disease or condition including Down's syndrome and cystic fibrosis	1 (Nr A = 1)
Ear	Deafness and normal ear development and function	0
Eye	Diseases of the eye and normal eye development and function	0
Infection	Diseases caused by pathogens, acquired immune deficiency syndrome, sexually transmitted infections and studies of infection and infectious agents	18 (Nr A = 15 / YP = 2 / A+ YP = 1)
Inflammatory and immune system	Rheumatoid arthritis, connective tissue diseases, autoimmune diseases, allergies and normal development and function of the immune system	3 (Nr A = 3)
Injuries and accidents	Fractures, poisoning and burns	4 (Nr A = 4)
Mental health	Depression, schizophrenia, psychosis and personality disorders, addiction, suicide, anxiety, eating disorders, learning disabilities, autistic spectrum disorders and studies of normal psychology, cognitive function and behaviour	30 (Nr A = 26 / YP = 4)
Metabolic and endocrine	Metabolic disorders (including Diabetes) and normal metabolism and endocrine development and function. This includes all research on the pineal, thyroid, parathyroid, pituitary and adrenal glands.	15 (Nr A = 12 / YP = 3)
Musculoskeletal	Osteoporosis, osteoarthritis, muscular and skeletal disorders and normal musculoskeletal and cartilage development and function	0
Neurological	Dementias, transmissible spongiform encephalopathies, Parkinson's disease, neurodegenerative diseases, Alzheimer's disease, epilepsy, multiple sclerosis and studies of the normal brain and nervous system	9 (Nr A = 8 / YP = 1)
Oral and gastrointestinal	Inflammatory bowel disease, Crohn's disease, diseases of the mouth, teeth, oesophagus, digestive system including liver and colon, and normal oral and gastrointestinal development and function	1 (Nr A = 1)
Renal and urogenital	Kidney disease, pelvic inflammatory disease, renal and genital disorders, and normal development and function of male and female renal and urogenital system	1 (Nr YP = 1)
Reproductive health and childbirth	Fertility, contraception, abortion, in vitro fertilisation, pregnancy, mammary gland development, menstruation and menopause, breast feeding, antenatal care, childbirth and complications of new-borns.	23 (Nr A = 19 / YP = 4)
Respiratory	Asthma, chronic obstructive pulmonary disease, respiratory diseases and normal development and function of the respiratory system.	3 (Nr YP = 3)
Skin	Dermatological conditions and normal skin development and function	0
Stroke	Include both ischaemic stroke (caused by blood clots) and haemorrhagic stroke (caused by cerebral/intercranial haemorrhage).	4 (Nr A = 13 / YP = 3)
Generic health relevance	Research applicable to all diseases and conditions or to general health and well-being of individuals.	37 (Nr A = 19 / YP = 18)

2.8 Art-based research in the research stages

The use of arts in research can be applied at any phase of the research process. However, existing literature indicates that the incorporation of art methods in research is commonly seen during the data gathering stage or when disseminating findings through exhibitions or performances. This is supported by studies conducted by Lapum (2018), cited in Leavy, Cox, and Boydell, Clift and Camic (2016), and Furman (2006). Public health research commonly utilises the arts as a means of presenting and distributing findings, acknowledging the significance of effectively promoting these findings as public health messages (Boydell et al., 2012). Arts practitioners are frequently recruited to participate in health research during its concluding phases, with the purpose of enhancing data using graphics or making it more easily understandable through illustrations, exhibitions or performances. The arts are rightfully acknowledged as being efficacious in conveying information, particularly when aiming to engage broader audiences and create a significant influence. Several researchers in the literature contend that the arts are primarily employed during the data collection and sharing phases, while the utilisation of ABHR is infrequent during literature reviews and the analysis stage of research.

Several ABHR studies, such as those by Törnbom K and KS (2019), Soriano-Ayala et al., 2020), Padilla et al. (2019), Nitzinger (2019), Ferlatte et al. (2019), Baig et al. (2019), and Vélez-Grau (2019), investigate the use of data analysis techniques in the theatre creation and photovoice process. Nguyen (2018) observes that the literature review phase of a health research project seldom includes arts approaches, and there has been limited debate on the advantages of these techniques in data analysis. Consequently, it is imperative to examine the advantages of employing artistic methods to augment analysis and synthesis at every phase of the research process.

2.9 Visual arts

Visual arts are the most prolific genre within arts-based health research. Photography accounts for over 70% of all participatory arts-based health research, but visual arts-based health research also involves a wide range of artistic methods, from traditional painting (Nguyen 2018), drawing (Gilbert et al. 2016), (Lambert et al. 2013), (MacLeod

et al. 2016), (Govender et al., 2017), sculpture and digital media graphic design (Montgomery et al. 2012), (Wolpin et al. 2016), photography (Limaye et al. 2018), film (Zemits et al. 2015), and social media (Nitzinger 2019).

2.10 Photography

Photography has been used in a variety of ways within health research. Photo-elicitation involves showing photographs to participants during interviews to provoke a response about a specific issue, cultural matter, or ritual (Hurworth et al., 2005). The participant may take the photographs or obtain them from other sources. The photographs prompt participants to talk about difficult or abstract concepts, encouraging the gathering of rich data. Photographs gives participants agency and the option to consider what they want to talk about at the research interview while also producing a storyboard of photos to be discussed (Olliffe and Bottorff, 2007).

Figure 12: Photovoice brochure of participant reflections
Halvorsrud et al, 2019, p.14-15 Available at: https://legacy.synergicollaborativecentre.co.uk/wp-content/uploads/2019/02/Synergi_Photovoice_Brochure_Updated-Nov-2018.pdf

Photovoice is a participatory action research (PAR) method based on health promotion principles, educational theories for critical consciousness, feminist theory, and a community-based approach to documentary photography (Wang and Burris, 1997; Wang et al., 1996). This approach has three main goals:

- *To enable people to record and reflect their community's strengths and concerns,*

- *To promote critical dialogue and knowledge about important issues through large and small group discussions of photographs, and*
- *To reach policymakers*

(Wang and Burris, 1997).

Rooted in Freirean democratic ideals, the methodology provides people with cameras so that they can photograph their everyday realities and represent their experiences. Photovoice is based on the concepts that images teach; pictures can influence policy; and community members ought to participate in creating and defining the images that shape healthy public policy (Wang, 1999).

Figure 13: Photovoice: concept, methodology, and use for participatory needs assessment Wang and Burries, 1999, p.381
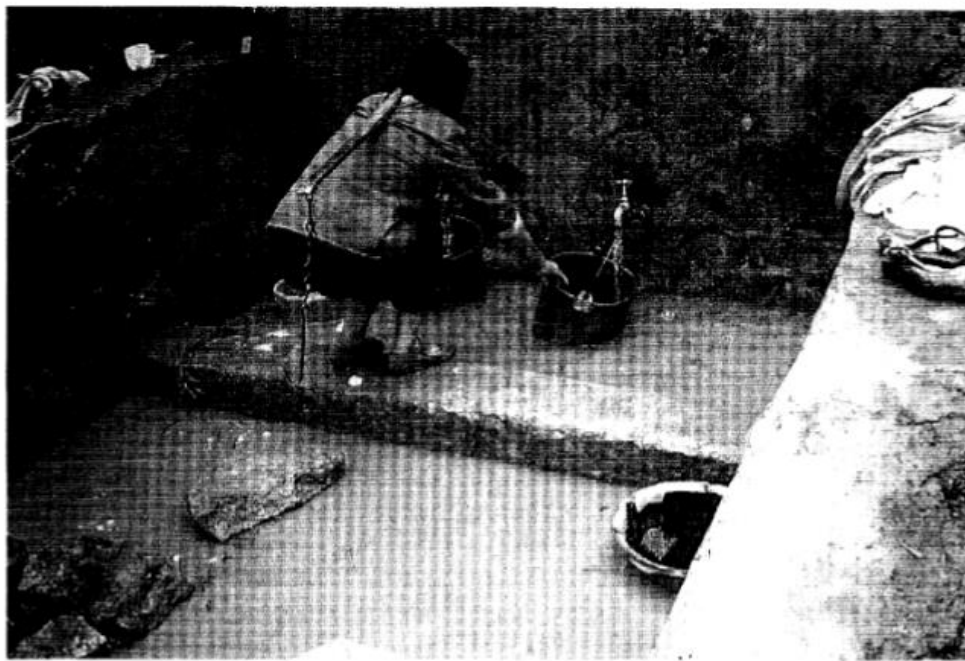
Figure 3. "Drinking water is a problem in our mountainous area. The water is not very clean. The water the woman is getting flows from two faucets. The faucet water is pumped up from the pond by the electric power station. Whenever there is a power blackout in our mountain areas, even the water from these faucets is not available. I wanted to show the difficulty of getting drinking water." Photograph and caption by Li Cui Zhen, a Chengjiang County farmer, age 34.

Frequently, health research studies use photography to understand the patient experience. However, one of the notable advantages of photovoice is its capacity to stimulate a dialogue and expression that shapes the narrative, and spurs action for change. Ideally, the photovoice technique should include participants in all stages of

the research process, especially in the initial phases to influence the study questions. Upon closer analysis of the photovoice publications, it becomes evident that there is an inconsistency in how researchers used this method.

Wang and Burries defined the three stages of photovoice studies in their seminal paper, Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment (Wang and Burries, 1997). More than 90% of the photovoice papers analysed in this scoping review (n109) cite at least one photovoice work by Wang. Nevertheless, not all photovoice projects adhere to the Wang and Burries photovoice principles. Studies discuss the benefits of Photovoice to enhance patient experience (Ferlette et al., 2019; Reid and Allonso, 2018), overcome language and literacy barriers (Perez et al., 2016; Esau et al., 2016), and empower participants to acquire new skills and enhance their sense of control over their health and well-being (Leung et al., 2019; Baig et al., 2019). A limited number of Photovoice research projects reviewed in this analysis specifically address the process of engaging policymakers, indicating that often researchers use Photovoice to achieve one or two thirds of the goals defined by Wang and Burries. Studies that exclusively utilise photography to examine the patient experience inaccurately label the research as a photovoice study, while it should be correctly identified as photo-elicitation.

## 2.11 Drawing, painting, and graphic arts

Visual art-based health research with children and adolescents has been used for a variety of health contexts: to describe pain (Latimer et al. 2018), wellbeing (Harkiss et al. 2016), heart disease, and understand children and young people's hospital inpatient experience (Pelander, 2007).

Figure 14: Artwork from 'Creating a safe space for First Nations youth to share their pain' Latimer et al 2018, p.6

The Department of Health in the UK highlighted an increase in participation and consultation among children between 1994 and 2004 (Coad et al. 2008). Over the last decade, evidence of visual arts in co-designing health apps (Stålberg et al. 2016), hospital environments (Lambert et al. 2013), and service improvement (Latimer 2018) has been reported.

Figure 15: Ideal hospital room by girl aged 7
Lambert at al, 2013, p. 64
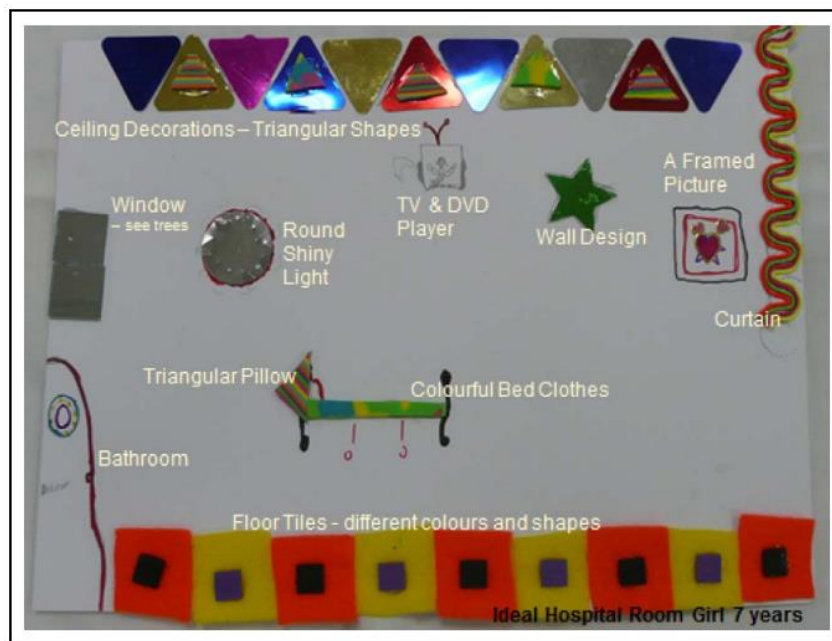
Health research with children and adolescents most commonly uses drawing and painting to complement verbal modes of expression, facilitate children's communication, and shape the data. In the 1990s, Rollins published a study that analysed children's drawings of their families to understand their experience of cancer. Since the 1990's, there has been an interest in effective ways of using art-based methods to involve children and young people in health research. Graphic arts have been used to produce public health messages. Montgomery et al. (2012) describe the co-creation of an interactive comic, with young people becoming active producers to encourage healthy choices. Researchers discuss how arts-based techniques can liberate and frame data generated by children, and several arts-based researchers highlight how visual artwork can capture people's imaginations unlike a written report or publication.

Figure 16: Comic strip evaluation tool
Montgomery et al 2012, p. S44
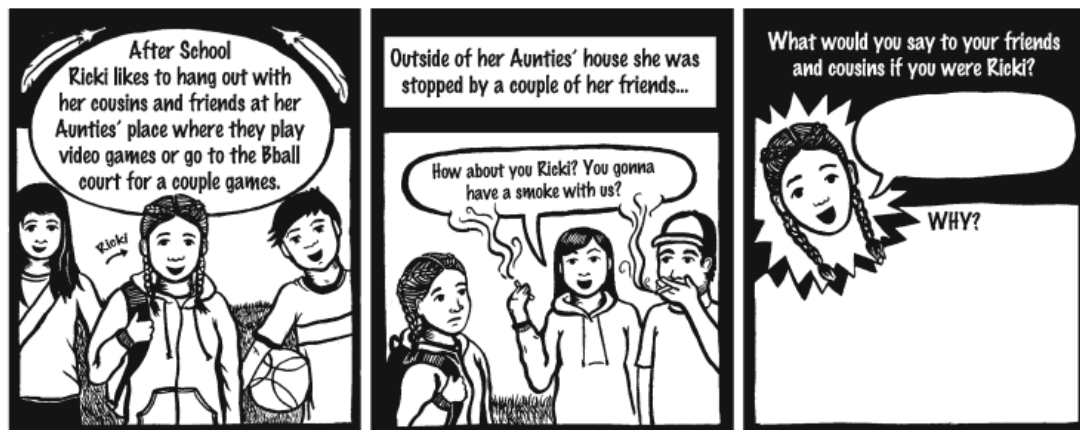
Visual arts have proved to be effective with adult patients to increase an understanding of the lived experience. Drawing-based methods have reportedly increased the patients understanding of their own health conditions and recovery (Broadbent et al., 2017). In some studies, visual arts are used to co-produce effective public health messages (Govender et al., 2017). In Govender et al's research study visual arts are combined with participatory action research to engage participants in an ongoing dialogue to understand often complex, diverse, and dynamic features of their lived experience and uses this to promote more effective health care practices.

Figure 17: Co-designed public health campaign
Govender et al 2017, p. 1279

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2.12 Theatre-Based Health Research

The majority of health research conducted using theatre methods is showcased through live performances. These performances offer healthcare professionals and the public valuable insights into the lived experiences of patients experiencing various health conditions, including cancer, heart disease, HIV, injuries, mental health, and dementia. The use of theatre performances as a knowledge transmission approach has proven highly effective due to the ability to captivate and entertain audiences, while also being widely accepted as a culturally appropriate activities across various countries and cultures (Hall et al., 2019). Gray's work discusses the use of research-based theatre in a project focused on metastatic breast cancer. He explains that theatre has the ability to portray research findings in a manner that enhances comprehension and alters societal perceptions (Gray et al. 2000).).

Figure 17: 'Inside Out of Mind' theatre play about life on a dementia ward
Photo by Fletcher, A, 2013 Meeting Ground Theatre Company Available at:
https://meetinggroundtheatrecompany.co.uk/projects/inside-out-of-mind

Participatory theatre in ABHR, demonstrates that it can help people understand and empathise complex feelings. This can greatly reduce cultural barriers and stigma by addressing both the social and personal factors that cause them. Frishkopf et al. suggests that co-produced video broadcasts developed using drama techniques can produce cost-effective public health campaigns in regions with high illiteracy and poverty rates. The data evidences significant changes in knowledge, attitudes, and behaviours (Frishkopft et al., 2016).

Figure 18 is a visual map that illustrates prominent theatre practitioners, philosophers, and academics who have influenced theatre-based health research. The connections emphasise the influences referenced in their studies. The fusion of ethnography and theatre, as well as the pioneering 'ethnodrama' research by Jim Mienczakowski and colleagues, serve as inspiration for several academics. Scholars also cite Saldana's extensive contributions to the development of 'ethnotheatre' and Goldstein's work in converting ethnographic data into playscripts as influential. Others cite leading figures from the participatory action research movement, specifically Freire, Fals Borda, and Boal (Logie et al., 2019; Leichner and Wieler, 2014; Nisker et al., 2006; and Williams et al., 2014). In these studies, the researchers apply techniques such as Forum Theatre from Boal's Theatre of the Oppressed. Using this approach, actors portray a local issue and invite audience members, or spect-actors (Boal, 1985), to propose and evaluate potential solutions through live performance. Similarly, Fox and Salas' Playback and Readers Theatre utilise comparable methods to foster a critical dialogue within communities (Moran & Alon, 2011). Some researchers fail to reference 'ethnodrama' or theatre practitioners in their papers, i.e., McIntyre and Cole, Barnes, but refer to other leaders relating to the health context they are researching, including Kitwood's dementia-person-centred care (McIntyre and Cole, 2008) and Marmot's important work in relation to health inequities (Barnes, 2013).

In this figure, health contexts - **Infection**, **Cancer, and Neoplasms**, **Public Health**, **Neurology**, **Mental Health**, **Injuries and Accidents**, **Inflammatory and Immune**, **General Health** are depicted by the corresponding colours and the size of the research study (diamond shaped) in relation to audience reach.

Figure 18: Systems map of theatre-based health research connected by influences cited in studies Ryan-McNeil

Legend
- Infection
- Cancer and neoplasms
- Public health
- Neurological
- Mental health
- Injuries and accidents
- Inflammatory and immune
- General health
- Infection
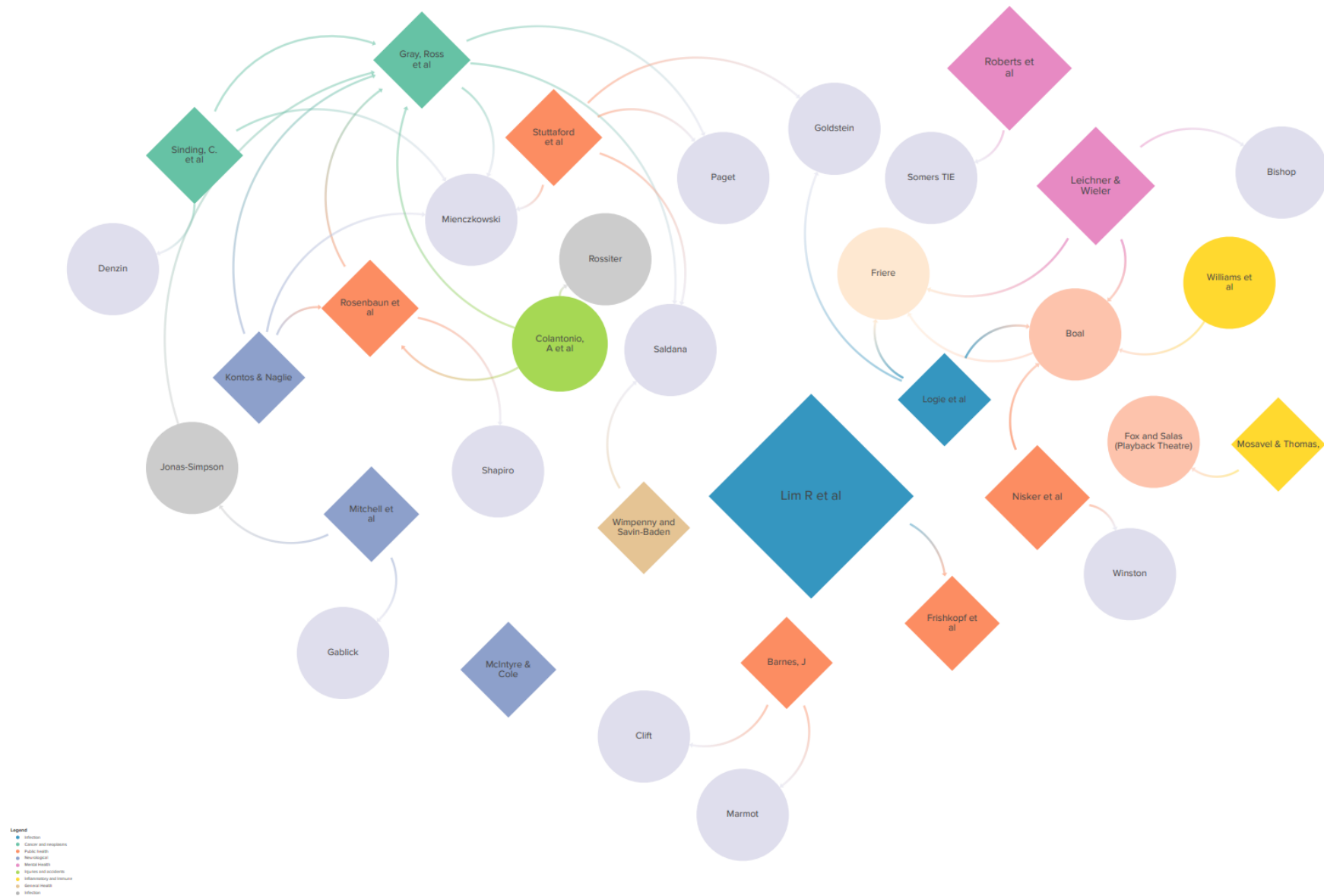
2.13 Systematic Review of–public engagement and audience reach in Arts Based Health Research (2000 – 2022)

This systematic review explores the impact of arts-based methods on public engagement in health research, with a particular focus on participation, quality of engagement, and audience reach. Study papers were selected if they discussed these criteria. The studies that met the criteria either used performing arts as the arts-based method (n = 17, 63%), photovoice (29%), or mixed arts methods (n = 5, 18.5%). Four papers integrated theatre with other art forms, such as visual arts and poetry (Lapum, 2012) and visual arts and film (Bartlett, 2015).

Most of the studies included in this focused review take place in the same country as the origin of the researchers (81%): Australia (n = 1), Canada (n = 8), Pakistan (n = 1), the UK (n = 4), and the United States (n = 8), although in two of the US studies the participants were from South America but lived in the US. Four of the papers led by international research teams took place in Cambodia, the Dominican Republic, Ghana, Swaziland, and Lesotho, and universities were predominantly from western countries (partnering with academics or health professionals from the participants' native countries), and one UK research team's study was in South Africa.

The studies involved patients with a variety of health conditions. Twelve papers (44%) focused on long-term health conditions, including cancer (n = 2), cardiovascular (n = 1), Lupus (n = 1), severe mental health (n = 1), dementia (n = 3), respiratory (n = 1), stroke (n = 1), and traumatic brain injuries (n = 1). Additionally, one study used creative writing as an innovative training approach for medical students, where the patients had a variety of long-term conditions (n = 1). The remaining fifteen papers focused on infectious diseases (n = 3), mental health (n = 6), and general health (n = 5). In the general health category, arts-based methods were predominantly used to gain a better understanding of diverse community's health needs, i.e., older people, the homeless, children and families, LGBT, and ethnically diverse communities. One study discusses how eight clinical academic groups with specific cultural, social, and environmental health issues partnered with artists in residence to co-create art installations with service providers, consumers, and carers (Watfern et al., 2021).

Figure 19a: Table 2 ABHR studies included in systematic literature review

Year	Author	Title	Art-based method	Participants	Audience Reach	Citations
2000	Gray et al	The use of research-based theatre in a project related to metastatic breast cancer.	Theatre	4	Unknown	145
2000	Wang, et al	Who knows the streets as well as the homeless? Promoting personal and community action through photovoice.	Photovoice	11	500+	749
2004	Wang,et al	Family, maternal, and child health through photovoice	Photovoice	60	Unknown	467
2005	Rosenbaun et al	In their own words: Presenting the patient's perspective using research-based theatre.	Theatre	Unknown	413	74
2006	Mitchell et al	Research-based theatre: The making of I'm still here!	Theatre	Unknown	279+	115
2006	Nisker et al	Theatre as a public engagement tool for health-policy development.	Theatre	12	1000+	87
2006	Sinding, C. et al	Staging breast cancer, rehearsing metastatic disease.	Theatre	4	Unknown	40
2006	Sinding, C. et al	Audience responses to a research-based drama about life after breast cancer.	Theatre	70	396+	16
2006	Stuttaford et al	Use of applied theatre in health research dissemination and data validation: a pilot study from South Africa.	Theatre	313	390	7
2007	Kontos & Naglie	Expressions of personhood in Alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool.	Theatre	40	43+	138
2007	Roberts et al	On the edge: A drama-based mental health education programme on early psychosis for schools.	Theatre	313	2500	54
2008	Colantonio, A et al	After the crash: Research-based theater for knowledge transfer.	Theatre	29	283+	122
2008	McIntyre & Cole	Love stories about caregiving and Alzheimer's disease—A performative methodology.	Theatre	40	300	32
2009	Fleming, et al	An ethnographic approach to interpreting a mental illness photovoice exhibit.	Photovoice	15	unknown	76
2009	Mosavel & Thomas,	Project REECH: Using theatre arts to authenticate local knowledge.	Theatre	180	180+	8
2009	Williams et al	Behind the fence forum theater: An arts performance partnership to address lupus and environmental justice.	Theatre	19	80	14

Figure 19b: Table 2 ABHR studies included in systematic literature review continued

Year	Author	Title	Art-based method	Participants	Audience Reach	Citations
2011	Lapum et al	Employing the Arts in Research as an Analytical Tool and Dissemination Method: Interpreting Experience Through the Aesthetic	Visual Arts	16	1200	11
2014	Leichner & Wieler	maladjusted: Participatory theatre about human- centred care	Theatre	24	2020	5
2014	Wimpenny and Savin-Baden	Using theatre and performance for promoting health and wellbeing amongst the 50+ community: an artsinformed evaluation	Theatre	55	55	18
2015	Bartlett	Visualising dementia activities - One banner features labyrinth maze in head	Visual Arts	7	63000+	49
2015	Mohammed et al	Harnessing Photovoice for tuberculosis advocacy in Karachi, Pakistan	Photovoice	55	1000	15
2015	Postma et al	Mexican-American caregivers' perceptions about asthma management: a photovoice study	Photovoice	10	60	15
2016	Frishkopf et al	Performing arts as a social technology for community health promotion in northern Ghana	Theatre	241	300+	6
2016	Perez et al	A Community-Engaged Research Approach to Improve Mental Health Among Latina Immigrants: ALMA Photovoice	Photovoice	21	146	8
2017	Lim R et al	Drama as a community engagement strategy for malaria in rural Cambodia.	Theatre	29	8620	46
2019	Logie et al	Exploring the Potential of Participatory Theatre to Reduce Stigma and Promote Health Equity for Lesbian, Gay, Bisexual, and Transgender (LGBT) People in Swaziland and Lesotho.	Theatre	106	100	59
2019	Nault Connors et al	Use of Photovoice to engage stakeholders in planning for patient-centered outcomes research.	Photovoice	6	20	13
2019	Padilla et al	Adaptation of PhotoVoice methodology to promote policy dialog among street-based drug users in Santo Domingo, Dominican Republic.	Photovoice	75	Unknown	24
2021	Watfern et al	The HIVE: a co-created art installation about health	Mixed-media	75	Unknown	4

Most studies were keen to demonstrate the efficacy of the arts-based method in relation to participant engagement, and some described the efficacy of the arts method to engage patients from a certain demographic or to gain knowledge about the lived experience of a particular health condition. Some focused solely on the dissemination stage and evaluated the impact on audiences (Sinding, 2006; Nisker, 2006) or health professionals and clinicians with the aim of improving their medical education (Rosenbaum et al., 2006; Colantonio et al., 2008).

Six papers used the arts to explore the social determinants of health, including environmental, social, and emotional impacts on wellbeing, but only one used the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) scale alongside an arts-informed evaluation to assess participants wellbeing before and after the arts activities. (Wimpenny and Savin-Baden, 2014).

A systems map (Figure 17) demonstrates the capacity of participatory theatre to involve a significant number of participants by utilising Forum Theatre techniques to integrate audience perspectives into the research study. Each study within this review has been colour coded according to the health context and grouped by art form. The sized indicates the number of participants.

The studies that engaged the most participants (n = 100+) all used theatre-based participatory action research approaches. These included interactive drama techniques (Frishkopf et al., 2016, Roberts et al. 2007) and participatory theatre methods (Logie et al., 2019, Mosavel and Thomas, 2009). Watfern et al's study (2021) describes the Hive, which is another example of large participant engagement, their co-created art installation engaged approximately 263 people. The audience and participants included researchers, service providers, service managers, service users, and the wider community, engaged in eight health initiatives, each partnering with artists from various art genres (Watfern et al., 2021).

Studies also use traditional research methods such as interviews and focus groups, in some cases to develop content for the arts-based outputs, and questionnaires are used to evaluate the impact of performances. Two of the studies with small numbers were continuations of prior qualitative health research (Gray et al., 2000; Bartlett, 2015), hence

the reduction of numbers because they were limited to recruiting previous research
participants.

Figure 20: Systems map of ABHR systematic review
Image by Elaine Ryan-McNeill Available at: https://kumu.io/ElaineRyMc/abhrlitertaurereviewmap
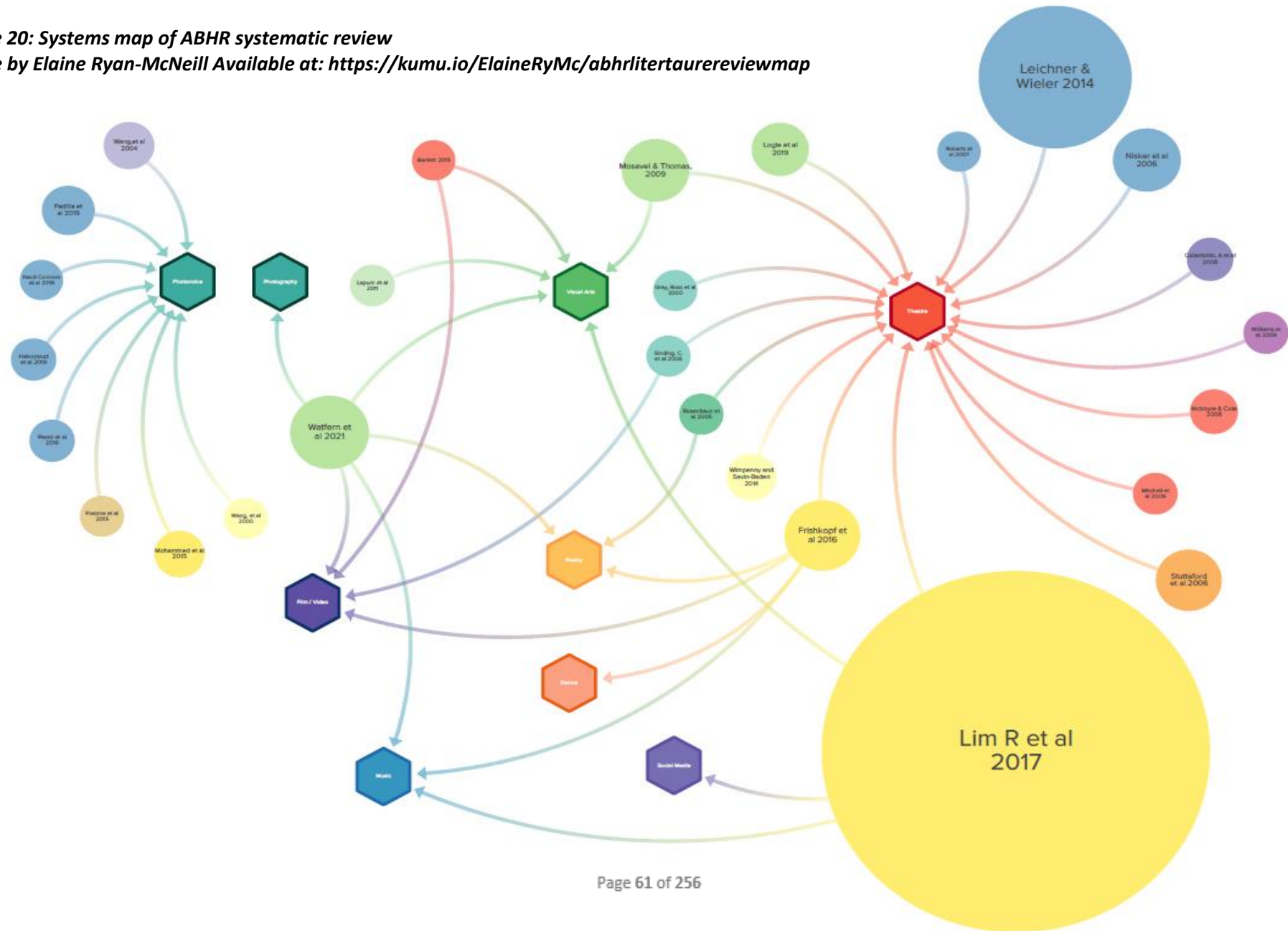
2.13.1 Participation

The analysis revealed that visual arts and mixed media projects had the lowest participation rates, which is unusual for visual arts methodologies. Power's study engaged 587 students aged 11-14, demonstrating the potential of visual arts to reach a large number of young people and gain their perspectives about HIV transmission (Power, 1996). Nonetheless, various factors influence the sample size in qualitative investigations. Multiple researchers have debated the ideal number of participants, especially when examining the lived experience, and discuss how it is preferable to delve deeply into narratives with a smaller number of participants. The inclusion of large groups only tends to provide a broad, shallow, and descriptive study. Typically, in participatory qualitative research, facilitators aim for 12–20 participants to ensure significant involvement. Photovoice studies sometimes involve a smaller number of participants to facilitate in-depth talks and an effective co-production of a final exhibition. The photovoice participants in this review range in age from 6 to 75. This shows that photovoice can involve a lot of people and give a lot of different perspectives on lived experiences, which isn't always possible with qualitative studies. Participatory arts research frequently sees the number of participants fluctuate, as new participants may join throughout a study and others leave before completion. Additionally, audience members can become research participants. For instance, Forum Theatre invites audiences to comment during a public engagement event and incorporates their input into final recommendations or research reports. In Leichner and Wieler's description of Forum Theatre, 2020 audience members contribute to a 32-point policy report on mental health care, demonstrating the success of widening participation through interactive theatre approaches. Figure 18 illustrates the fluctuation of participation figures in this study. Initially, we invited participants (n = 191) to submit stories about their lived experiences with mental health. 44 of these were selected to come for an interview to assess their suitability for the theatre performance. This resulted in 24 participants plus a creative team developing a theatre play. During the performances, the facilitator engaged a further 2020 audience members, using the Legislative Theatre technique and interactive Forum Theatre, inviting the audience to comment and contribute to policy reports or legislation (Leichner and Wieler, 2014). However, Leichner and Wieler recognise the

limitations to the knowledge generated through theatre as a participatory art, given that it will only attract a select audience of those who appreciate theatre (Leichner and Wieler, 2014).

Figure 21: Example of fluctuating participant timeline for maladjusted: theatre-based study
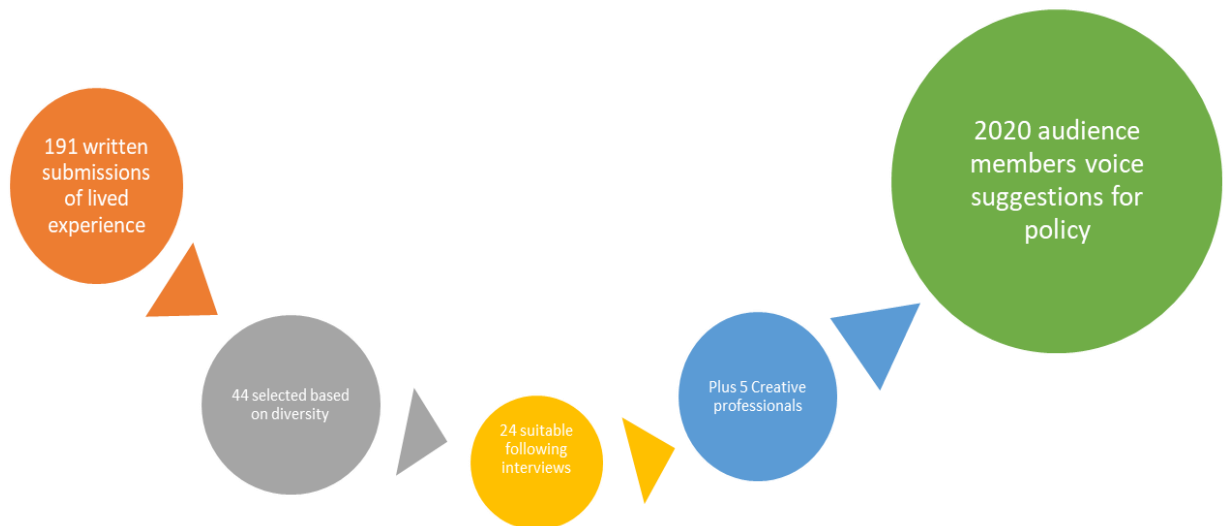
In Lim et al.'s study, a core drama group used participatory approaches to engage villagers to create content; their stories were integrated into drama performances with schoolchildren participating in songs about malaria. These inclusive arts-based participatory approaches resulted in an average participation rate of 66% of the village population reached. This was achieved through 20 three-day performance workshops, which involved a total of 5689 people. Although theatre was found to be a highly effective technique for engaging people, Lim et al. discovered multiple barriers to involvement, such as transportation limitations and deteriorating road conditions caused by weather (Lim et al., 2017).

2.13.2 Recruitment

Multiple studies examine purposive sampling and snowballing approaches as recruiting strategies (Mohammed et al., 2015; Logie et al., 2019; Mitchel et al., 2006). One study by Wimpenny and Savin-Baden (2014) suggested arts-based activities generated a curiosity and fascination among the participants, attracting them to join the study. However, another article implied that the arts method may have reduced engagement because participants reported they did not know what to expect from the title of the project and found it unnerving. According to Perez et al., promotoras

(lay health advisors) found the name '*FotoVoz*' (in Spanish) intimidating (Perez et al., 2016).

One-third of the studies examined how arts-based research enhanced recruitment of participants from diverse populations. Wang et al. (2004) noted that photovoice is effective because it does not require academic skills. This is especially crucial for fostering the involvement of various communities with low educational attainment. Postma et al. (2015) found that the majority of the participants in their study left school at an average age of 8.7 years, as a result, the use of photovoice effectively eliminated obstacles to engagement for this community group.

Challenges involving patients was also discussed in two of the studies, particularly people with dementia. McIntyre and Cole overcame this by weaving direct quotes from research participants into the theoretical concepts that emerge within the research findings. In Mitchell et al.'s study, all the researchers within the creative team had personal experience with dementia, and they aligned their intentions to develop theatre performances based on personal contributions with Gablik's views on reality-making (Mitchell et al., 2006). By incorporating real-life experiences and perspectives, the researchers believed they could construct a realistic worldview of living with dementia. The performance evaluations suggest that both plays had a meaningful impact and made a difference in the lives of others living with dementia, with some claiming they had a positive impact on their relationships (Mitchell et al., 2006).

2.13.3 Quality of Engagement

It's evident that the flexibility of creativity in ABHR allowed researchers to proactively respond to needs identified by participants during the research process. Several papers discuss addressing the participants' needs during the research process including the implementation of a food and clothing bank for street drug users (Padilla et al., 2019), the adoption of Kitwood's care paradigm to meet the needs of people with dementia (McIntyre, 2008) and revising the research process to improve engagement (Wang et al. 2000). This review discovered that the plasticity of ABHR, gives participants the freedom and flexibility to go beyond the research's focus, often

related to data affecting wider determinants of health (Wang et al., 2000; Roberts et al., 2007).

The Healthcare Improvement Studies Institute's (THIS Institute) review emphasises two primary justifications for employing arts-based research approaches. S. Ball et al. (2021) recognise ABHR as an efficient method for involving stakeholders and improving public engagement, discussing its potential to increase research outcomes and meet funder expectations. Several studies evidence the importance of participants' subjective experience in shaping outcomes and impact, as this review acknowledges.

2.13.4 Participant experience

The benefits of using arts-based approaches for participants were discussed in several studies. Bartlett's study identified that artmaking improved participants' confidence, motivation, and self-efficacy, with one participant stating, "I think I've got a bit more 'get up and go' since I've started coming to these workshops." (Bartlett, 2007). There is substantial evidence indicating that individuals derive psychosocial advantages from participating in arts-based activities (Fancourt and Finn, 2019). Therefore, we can argue that research participants can immediately benefit from arts-based approaches. However, only a limited number of arts-based health research studies specifically address well-being as a positive outcome. In all the studies, only one measured the participants' well-being using WEMWBS, in which the results showed that individuals scored significantly higher after participating in arts interventions, specifically theatre and performance. This suggests that art interventions provided opportunities for diverse, marginalised members of a community to connect and transform their self-perception in ways that were beneficial for their health and well-being (Wimpenny and Savin-Baden, 2014). The qualitative narratives in photovoice studies highlight the benefits that participants experience from their involvement. Participants reported feeling empowered when using photography to communicate sensitive issues (Halvorsrud et al., 2019). Photovoice also taught promotoras (health advisors) to reflect on critical issues that could motivate people to take action (Perez et al., 2016). Additionally, the homeless participants gained a sense of empowerment by recognising their values and

providing extensive knowledge and historical information about their town. They also formed a peer-to-peer support group where they shared survival tips with each other (Wang et al., 2000). Several photovoice studies looked at how looking at pictures together helped people find a common way to communicate and understand each other, which led to more support for each other and a stronger commitment to the project. Participants in drama-based techniques identify with the feelings and behaviours of others, leading to the normalisation of their experience with cancer (Gray et al., 2000).

The findings of this study indicate that involvement in arts-based activities enhances the participants' sense of identity and facilitates their integration into the group, thereby providing further enrichment. This indicates that ABHR provides an immediate benefit to research participants, often exceeding the research's objectives and purposes.

2.14 Audience and reach

2.14.1 Presenting the data

The dissemination of data involved visual art exhibitions, theatre performances, and digital media. A particularly novel approach was a labyrinth installation for Lapum's "The 7,024th Patient" project. Lapum presented poetry and photography as a winding labyrinth path, engaging viewers physically and emotionally in an immersive experience of heart patients' narratives. The labyrinth exhibition reached 1,200 visitors (patients and their loved ones, practitioners, administrators, researchers, and students) at two events, one of which was the International Congress of Qualitative Inquiry in Illinois. Audience figures from other studies imply that festivals and conference events are a successful way of reaching wide audiences. Bartlett's exhibition of dementia activism toured three cities in the United Kingdom: Bradford (the British Science Festival), Glasgow (the Scottish Mental Health Arts Festival), and Liverpool (the Dementia Care Congress). The touring exhibition was supplemented with a website, and a film was uploaded to Vimeo once the exhibition had closed. Each event reaches from 1000 to 10,000 people, and the Vimeo video of Agnes and

Nancy has had 3.5k views. It's estimated that Bartlett's arts-based research reached of over 4,000.

Mixed media and comedy proved to effectively reach and engage audiences in Lim et al.'s co-produced public health education strategy for malaria in rural Cambodia. The mixed media approach art and use of social media (Facebook and YouTube) to share photos and videos reached 8620 in total (Lim et al., 2017).

2.14.2 Audience reach and impact

Eleven of the review papers (40%) did not specify the audience numbers, making the analysis a challenge. To overcome this, a conservative estimated figure (20% of total attendance) was derived based on the type of event. Some papers named the conferences, festivals, events, and public exhibitions or performances, and attendance figures were calculated using data obtained via the event websites and the following table of attendance figures was used to estimate average attendance figures, where data relating to audience figures was not available in the studies reviewed.

Figure 22. Estimated audience figures for public events

Event type	Total attendance figure	Estimated audience reach
International conference	1,000-2,000	200-400
National Festival event	500-1000	100-200
Local exhibition/performance	50-100 per day	10-20

Without doubt, broadcast media attracts the highest audience numbers. At The Indus Hospital, Pakistan, Mohammed et al., showcased a Photovoice exhibition for tuberculosis advocacy in two languages, Urdu and English. The event attracted around 1000 key stakeholders. Furthermore, the show garnered coverage on seven prominent news channels in Pakistan, as well as eight major English daily newspapers, nine Urdu newspapers, and several internet platforms. The project also served as an influential lobbying tool for policymakers, prompting the Programme Manager of Pakistan's National TB Control Programme to request nationwide expansion of the project (Mohammed et al., 2015). Similarly, Wang's photovoice study involving homeless individuals revealed that, after the exhibition and the

presence of policymakers, the city contemplated a $3 million investment in a new institution for the homeless (Wang et al., 2000).

2.14.3 Audience experience

As previously discussed, forum-style theatre has undoubtedly proved its effectiveness in engaging audience members in health research or policy recommendations. Photovoice studies also examine audience engagement in conversation circles, focus groups, or individual interviews and several studies discussed the importance of sharing the research arts outputs with the patients involved in the co-creation of the performance or exhibition to authenticate the data (Wimpenny and Savin-Baden 2014). Stuttaford argues that the 'final contribution of applied theatre is towards validity. One way of assessing validity is by returning to respondents and presenting research material to them.' (Stuttaford, 2006).

2.15 Challenges of arts-based health research

There is growing discussion around the efficacy of ABHR's to represent the lived experience authentically, but some studies question if patient narratives can become misrepresented during the curation process. While ABHR may amplify participants voices so they resonate more strongly in the research output, Bartlett raised concerns about how the arts may have a detrimental effect on original research by diverting attention away from the research (Bartlett, 2015). Bartlett claims the professional artist exerted excessive control over the exhibition's curation, which allowed them to manipulate the interpretation of the study and distract from the authentic research, '…*key quotes show how art-based research communication can pique curiosity about the creative process but not necessarily the scholarly work behind it.*' (Bartlett, 2015, P.762). Conversely, several Photovoice studies, emphasise the significance of co-curation, encouraging participants to choose images and narratives for the exhibition, preventing any one artist from having complete control over the curatorial process.

Although ABHR has experienced significant growth in the past four decades and there is increasing proof of its usefulness, its current state as a research method is still in its infancy. Thus far, published research has not fully examined all aspects of ABHR and

has not thoroughly documented the field's progress. Further research is therefore required to establish its credibility and this scoping review attempts to address some of these gaps.

2.16 Gaps in existing literature

In this study, few ABHR explore or discuss the impact of patient engagement on the development or improvement of health services. Researchers and policymakers can learn and share expertise through various methods, including inviting policymakers to stakeholder events and exhibitions, and creating videos, booklets, or toolkits. In this scoping review, more than half of the ABHR fail to discuss a stakeholder event or sharing; however, it is acknowledged that in some studies, an exhibition or public event would not have been appropriate due to the primary aim of learning more about the patient's illness, and in some studies, confidentiality and the protection of people's identities were ethical considerations.

Undoubtedly, Photovoice presents the most rigorous research design within arts-based health. The global health community has clearly accepted it as an effective research method to learn about the patient experience and make effective changes. However, there is insufficient literature for other ABHR art genres to establish their trustworthiness as participatory qualitative health inquiry. While still in small numbers, some studies have begun to demonstrate effectiveness of participatory theatre approaches in terms of participation, quality of engagement, and reach.

2.17 Conclusion

Researchers often combine ABHR methods, which are qualitative in nature, with methodologies like action research and cooperative inquiry (Reason and Bradbury, 2008). The emphasis on intuition, empathy, and self-awareness within the creative process, means that arts-based research benefits from a phenomenological research approach. Braud and Anderson identify that phenomenological and other transpersonal research methods help researchers delve into the subtle dimensions of human experience. They discuss how transpersonal research methods recognise the human experience as spacious and multi-dimensional. Braud and Anderson help us better understand these in-depth approaches and propose that they 'tend to better

suit the idiographic and personal nature of transpersonal experience' (Braud 1998). Similarly, incorporating the arts into the research process provides an authentic and deeper understanding of the human experience, which increases our understanding of health conditions and experience of services. Projects that focus on human problems or issues often employ art to capture the unfolding nature of life. As a powerful and accessible form of communication, the arts have enormous potential to enhance health research for patient benefit.

Leavy argues that a creative research approach offers ways to describe, explore, discover, and problem-solve (Leavy, 2018); using the arts within health research can help to develop new insights and raise awareness and within a participatory arts-based framework, problem solving is embedded within the iterative process. The evidence in this review demonstrates that not only does an arts-based approach invigorate a curiosity about the human experience, but it also illuminates alternative perspectives that have the potential to bring about immediate changes while working towards longer-term transformations for diverse groups of patients.

This review confirms that within the nascent field of ABHR, there is a disparate nature of analysis between the artforms. As the field has been evolving, ABH researchers have explored diverse ways of using communicative, illustrative, and interpretative tools that arts methods allow, resulting in a field of research that is multifaceted and often limited in explanations and definitions. The diversity of the data does not enable effective analysis. The complexity of the ABHR field needs further refining to identify an academic framework, and Archibald (2022) goes some way towards developing a continuum of arts-based research and translation, suggesting an ongoing consideration of arts-based research in health is needed. However, we must approach this with sensitivity and not lose sight of the holistic dimensions of the creativity process essential to ABHR. The creative process, which can often uncover and present the frailty and multidimensional quality of the human experience, has been described as having an ineffable quality, presenting us with additional challenges and questions around what can be gained by 'effing the ineffable'.

Preliminary evidence indicates an increasing realisation of the potentials of arts-based health research; however, this research often remains hidden in obscurity, thereby limiting its potential use. There is still plenty of opportunity to expand and strengthen ABHR's research base. ABHR can significantly improve the experience of patients participating in research, offering immediate psychosocial benefits to patients and address issues related to participation. While arts dissemination can reach wider audiences and authentically represent the lived experience of patients to influence policymakers and service providers.
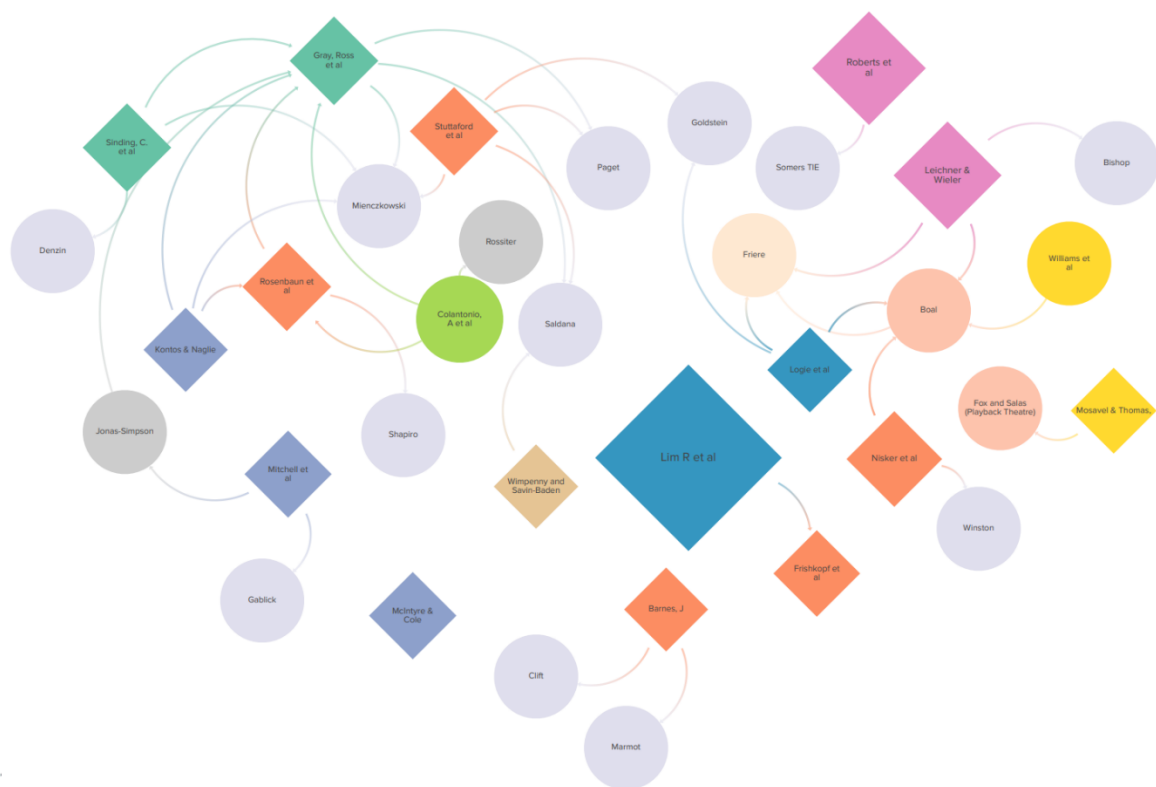
Figure 23: Systems map of theatre-based health research and methodology
Ryan-McNeill, 2023 Available at: https://kumu.io/ElaineRyMc/theatre-based-health-research-map

CHAPTER THREE: Methodology and Arts Based Methods

*"No research

without action,

no action

without research"*

- Kurt Lewin

Chapter Three: Methodology and Arts Based Methods

3.1 Introduction to Research Methods

This chapter discusses the arts-based approaches to data collection and analysis used in this study. In Chapter 2, it is evident that ABHR can provide immediate benefit to patients during the research process and offer an opportunity for patients to gain a greater awareness of the condition they are living with and how to adapt. This study initially sought to illustrate the lived experiences of people living with dementia, in particular, how arts engagement can enhance the quality of life and aid patients in adapting to their health condition.

A methodological approach was required that would both embrace and challenge the multifaceted and multidisciplinary essence of arts-based health research while providing a safe, inclusive, and accessible way of engaging older people, patients with dementia, and the public to bring about change. Conducting health research with patients can be challenging due to the potentially divergent disciplinary philosophical and paradigmatic stances. The literature review employed a methodology with origins in the medical sciences, but because of the social health nature of the inquiry, a social science methodology was adopted.

The following section explores definitions of methodology, including an introduction to arts-based participatory action research approaches. The thesis then presents the participatory methodology and explains its rationale. The chapter also considers the arts-based dissemination strategy for the study findings. It is important to highlight that, while often used synonymously, the terms 'methodology' and 'methods' relate to distinctly different aspects of research.

This study was an exemplary fit for participatory qualitative research focused on knowledge and action, as it examined the advantages of ABHR while also seeking to comprehend the lived experiences of people with dementia. This study used participant experiences to inform, guide, and focus the research outcomes.

3.2 Organisation of Chapter Three

Chapter Three is organised with subsections to detail relevant information. The order is as follows: Methodology, Research Design, Research Questions, Inquiry Strategy, Setting and Environment, Ethics NIHR Protocol and Procedures, Participants and Sample, Sampling Procedures and Participation Selection, Data Collection Procedures, Triangulation, Data Analysis and Management, Trustworthiness, and Summary.

3.3 What is methodology?

Abraham Kaplan defines methodology for behavioural sciences as the study—the description, the explanation, and the justification—of methods, not the methods themselves (Kaplan 1964, p. 18). Crotty also suggests that we need to put considerable effort into four questions around methods, methodology, theoretical perspective, and epistemology when developing a research plan. He describes methodology as 'the strategy, plan of action, process, or design lying behind the choice,' whereas methods are 'the techniques or procedures used to gather and analyse data' (Crotty, 1998). In clarifying the distinction within creative research methods, Kara theorises that methodology provides a contextual framework "a coherent and logical scheme based on views, beliefs, and values that guides the choices researchers make" (Kara, 2015). People often use the terms "method" and "methodology" interchangeably, often failing to distinguish between the two. Indeed, methodology is sometimes confused with research strategies and design. Methodological definitions are not always so clear-cut. This is certainly true of the participatory research. Unlike nomothetic research, which can operate under almost any social conditions and generalise populations of individuals, participatory research necessitates a democratic social and political context. Many writers and researchers have been suggesting that a fundamental shift is occurring in the western worldview and that new patterns of thought are emerging that will transform experience, thinking, and action (Minkler and Wallerstein, 2008). This shift necessitates an extended epistemology that acknowledges research in which everyone participates in the design of the inquiry, determines the action under investigation, and contributes to the process of making sense and drawing conclusions. Heron and Reason argue for

a radical epistemology where a knower participates in the known, communicating their experience of the world in four different ways.

- Experiential knowing is acquired through direct face-to-face encounters with the person, place, or thing; it is knowing through empathy and resonance—that kind of in-depth knowing that is almost impossible to put into words.
- Presentational knowing grows out of experiential knowing and provides the first form of expression through aesthetic imagery, drawing, sculpture, movement, dance, drama, etc.
- Propositional knowing draws on concepts, ideas, and theories expressed in informative statements.
- Practical knowing is knowing 'how to do something', the skills and competence that can lead to the act of transformation.

(Heron and Reason, 2001)

The issue of participation in health research has been crucial since the Alma Ata conference in 1978, but critics often point to participatory action research's lack of rigor and validity. Recently, health systems have adopted an asset-based approach that stems from people's communities within their social contexts, emphasizing the importance of community participation in improving health conditions (Wallerstein and Duran, 2010). We have seen developments around asset building in the UK over the last 20 years and UK Research and Innovation funding has focused on mobilising community asset over the last 3 years. In 1989, "Working for Patients" reforms introduced wide-ranging proposals, setting out the most radical changes in the NHS since its creation. The introduction of an "internal market' and a departure from providing services to purchasing and commissioning them, alongside the establishment of stand-alone trusts to manage the provision of hospital and community services, opened the NHS up to the market economies (Greengross et al., 1999). The Department of Health incorporated patient involvement into its Research and Development policy by the year 2000, following the introduction of the Citizens Charter in 1991, which promoted patient voice (Pandya-Wood and Robinson, 2014).

The NHS five-year forward view published in 2014 highlights that 'the health service has been prone to operating a 'factory' model of care and repair, with limited

engagement with the wider community, a short-sighted approach to partnerships, and underdeveloped advocacy and action on the broader influencers of health and wellbeing.' (NHS England, 2014)

Negative comments and conversations linked to dementia, particularly in the news and media, often stereotype and discriminate against people living with dementia. Research is required to support better public awareness, inclusion, and acceptance of people affected by dementia.

3.4 Research Design

In 2006, MoMA (Museum of Modern Art) in New York began an innovative approach to serving people with dementia and their carers through art discussion, and this gave rise to numerous 'Meet me at...' events at museums and galleries around the world (Rosenberg et al., 2009). Several studies have since observed and evidenced how visits to the gallery can provide much relief, a sense of purpose, and stimulation for people living with dementia (Macpherson et al., 2009; Camic et al., 2014; Fancourt et al., 2018).

Although this study examines how society can have a positive impact on people living with dementia, there is little research on how people living with dementia can themselves have a positive impact on society. A limited understanding of dementia can lead to misconceptions, resulting in society viewing dementia as a degeneration of 'normal' brain activity rather than considering how the ageing process might have a positive effect on society. Behavioural and psychological symptoms often isolate and stigmatise individuals living with dementia, causing them to fear negative reactions from neighbours and relatives. Several research papers indicate that using a collaborative approach for people living with dementia ensures they are involved in the design and process of research and encourages a focus on their views. (Scottish Dementia Working Group, 2014; Wang, 2019) Over the last fifteen years, dementia research debates and discussions have focused not on whether people with dementia should participate in research but rather on the most effective methods for doing so (Hellström et al., 2007). Liverpool has encouraged people living with dementia to participate in research and innovation, as well as service-related

projects. Liverpool John Moores University's Innovate Dementia project is a testament to this and has resulted in several spin-off projects within the dementia community, namely SURF (the Service Users Reference Forum), run by and for people living with dementia.

The goal of participatory and arts-based research methods is to comprehend and create meaning from the experiences of dementia patients and to explore how engaging in artistic activities could enhance their quality of life. Participatory Arts-Based Research (PABR) fuses the principles of participatory action research with arts-based methods. PAR aims to make the research process more democratic and collaborative. In this participatory arts-based research study, choices were made to use research methods that would bring immediate benefit to the research group of people living with dementia. We grounded each purposeful choice in the literature and adopted an agile research approach, where learning along the way guided the next stages of the research process (2001).

On behalf of the WHO-ESCEO Working Group, de Wit et al., outlined the significance of patient-centred research in The Lancet,

"Engaging with patients helps bridge the gap between health research, policy, and patient-centred practice, increases transparency, and leads to more meaningful outcomes. Patient engagement should be initiated in a stepwise manner through which all parties can learn together."

(de Wit et al., 2019, p.911)

Participatory Action Research (PAR) allows for the collection of firsthand perspectives and subsequent analysis of the process. An arts and culture group activity programme was developed for community-dwelling adults living with dementia and family carers using a Participatory Action Research (PAR) approach. PAR, or Participatory Action Research, has been used by nurses to perform community assessments, establish community collaborations, engage the target population, and integrate reflection into the process (Kelly, 2005). McIntyre outlines PAR's essential concepts, which are participatory, transformative, and grounded in the lives of research participants. For McIntyre, the process of questioning, reflecting,

dialoguing, and decision making involves 'a spiral of adaptable steps that include the following:

- *Questioning a particular issue*
- *Reflecting upon and investigating the issue*
- *Developing an action plan*
- *Implementing and refining said plan*

(McIntyre, 2015, p.6)

The PAR projects described by McIntyre are linked to a set of activities (e.g., painting, sculpting, storytelling, collage-making, and photography) and involves community people and researchers as equal collaborators. The process of mutual learning should act as an empowering process that allows participants to have more control over their lives, and a harmonious integration of research and action (Minkler and Wallerstein, 2008). PAR strives to addressing major challenges by fostering a collaborative culture and engaging communities in research activities as equal partners. This approach develops novel research perspectives and effective solutions.

PAR was established by a consortium of intellectuals who were growing more alarmed by the intolerable circumstances in various global communities. This initiative was launched during the 1997 World Congress held in Cartagena, Columbia. Their objective was to create research methods and strategies that actively include individuals and are dedicated to promoting social and political change, resulting in significant and necessary actions. In *The Handbook of Action Research*, Fals-Borda also identified Paulo Freire's influential book, Pedagogy of the Oppressed, as one of the ideas that shaped the development of Participatory Action Research (Fals-Borda, 2001). While PAR predates Freire's influential work, it provides the epistemological basis for PAR as a liberating practice (Campos and Anderson, 2021), which involves initiating positive change.

3.5 Freire's influence on Participatory Action Research and this study

Freire (1970–1994) has demonstrated both in his writing and in community projects that transformation implies an act of transforming an oppressive society through

participatory opportunities. This concept is also applicable in this research project, as its purpose is to explore the transformative qualities of participatory arts-based research for patients. According to Freire, education is centred around developing learners who are critically aware and humanised. These learners actively work to liberate themselves and the world from injustice, ultimately promoting social transformation. Despite originating in an era of authoritarianism, the concepts of political consciousness-raising developed by Freire are essential to Participatory Action Research (PAR). These concepts are applicable in any situation where a society is dealing with a conflict regarding its development model, which includes the protection, creation, and distribution of wealth, as well as the involvement of its members in this process (Suzina and Tufte, 2020). Freire recognised that the process of freedom required a dual approach. To bring about a transformation in society, individuals must alter their perspective on the world. Additionally, he maintained the conviction that individuals could not attain freedom as a bestowed present or honour; rather, they had to assert their own entitlement to it. To foster autonomy, a pedagogy (or research approach) that promotes liberation should empower individuals to determine what is best for them. Inequitable social hierarchies create oppressive practices and social arrangements, some ABH researchers have adopted liberating approaches in their research methods. Wang and Burris created Photovoice in the 1990s by integrating Paulo Freire's critical pedagogy, feminist theory, and documentary photography. This combination has shown to be the most effective arts-based health research strategy. At the core of photovoice lies Freire's concept, which emphasises individuals expressing themselves based on their personal experiences, critically examining their circumstances to gain a more profound comprehension and create solutions. Photovoice employed feminist theory to incorporate collaborators as equal stakeholders in the research and advocacy process, highlighting their personal experiences and fundamental issues in policymaking (Wang et al., 1996). Community-based documentary photography techniques prioritise a grassroots methodology for representing lived experiences, while also using photography as a means of personal expression. This study used the photovoice principles in combination with various art forms, and the participants

engaged in artistic activities to facilitate conversations on the lived experiences of adults with dementia.

PAR projects encompass a range of research approaches and communicate findings through multiple mediums, including visual and performance arts. The research group of PLWD will be equipped with the necessary tools and abilities to examine their experiences using a Participatory Action Research (PAR) methodology and an arts-based research method. The ultimate goal is to bring about positive changes and enhancements in their lives.

3.6 Participatory Action Research

Participatory action research (PAR) is a methodology that involves collaboration to develop a process through knowledge building and social change. In a health context, PAR converts patients, who make up "traditional" participants, into researchers, and "traditional" researchers become participants, promoting team cohesion, equity, and effective communication. Given that it is focused on action, reflection, and iterative change, PAR aims to improve health and inequities by involving people who, in turn, take actions to improve their own health. The initial overarching question explored how the arts can improve the quality of life for people living with dementia and initiated the research process, helping to define the inquiry strategy and research methods. Within the iterative and flexible PAR approach, research questions evolved along the research journey as discoveries were made.

The following tenets of participatory action research underpinned the arts-based methods within this study:

- Develop an equitable research approach that enables participants to record and reflect on their strengths and concerns.
- Encourage critical dialogue and collective knowledge about important issues, large and small.
- Collectively agree on action to take.
- Take action to support transformation.

These tenets are particularly important when seeking to address health inequalities and provide the relatively powerless and voiceless with tools to improve their situation.

3.7 Arts-Based Research

A notable aspect of this study was the integration of the arts into the PAR methodology. Art based research strengthen PAR, by promoting and amplifying marginalised voices, providing accessibility to non-academic audiences, and enriching communication, all of which can lead to sensuous, embodied, and affective ways of knowing (Nunn, 2020).

Researchers see the early 21st century as "a dynamic and exciting time for research methods" (Kara, 2015), with methodological boundaries expanding across all social science and health disciplines. Researchers from various disciplines have successfully adopted creative research methods to enhance their research processes. According to Leavy, researchers who use arts-based methods are developing a 'holistic, integrated practice'. (Leavy, 2020)

Art-based research (ABR) is about constructing meaning through art, but it is also about designing a process that enhances the study (Leavy, 2018) and the experience of participants. The capability of the arts to capture experiences mirrors the unfolding nature of social life; therefore, there is alignment between subject matter and method. Problem-centred or issue-centred projects often employ ABR, where the central problem guides the research approach. By combining the principles of PAR with ABR, the research group effectively identifies the problems or issues to address throughout the research process.

ABR brings art and science together for the purpose of asking new questions and developing new insights (Barone, 2012). A transdisciplinary approach to knowledge building, ABR combines the tenets of the creative arts in research contexts (Leavy, 2009, 2016; McNiff, 2005). A researcher uses ABR for a purpose that is often associated with art activities or to better understand the human experience (Leavy, 2018; Merriam and Tisdell, 2016). Art provides a platform for rich discourse, enhancing meaning and providing additional data during interviews with participants (Leavy,

2018). This section will detail the arts-based research (ABR) methods used within the design of this study and how they aided the research group.

This study's design incorporated ABR to explore multiple meanings, fostering multiplicity in meaning-making rather than promoting influential assertions (Leavy, 2020). A piece of art stimulates a dialogue that focuses on evoking meanings. ABR is particularly useful for research projects that aim to describe, explore, or discover, or that require attention to processes (Leavy, 2020).

3.8 Participatory action research with artistic activities as a stimulus

This study used art as a stimulus to extract the essence of dementia patients' experiences and explore community-based solutions to improve quality of life. This participatory arts-based study used the experience of the arts as an elicitation device.

There were two phases to this study: (i) an initial exploration of arts-based methods to explore the lived experience and impact of arts on the quality of life for people living with dementia; and (ii) testing the efficacy of arts-based methods in the context of a global pandemic with older people. In the second phase of the study, the lockdown restrictions impacted a large section of the world's population; therefore, the focus shifted to the use of the arts to improve wellbeing during the induced social isolation caused by lockdowns.

Figure 24: PAR focus group at The British Music Experience
Ryan-McNeill, 2018

Initially, a participatory action research group of people living with dementia was established to visit arts and cultural venues around the Liverpool City Region. Exposing people to new ideas, stories, or images is one of PABR's goals in cultivating social consciousness. Health professionals often use ABR due to its inclusive configuration and ability to challenge people's perspectives and thinking (Lambert, 2013). During arts activities, observations, focus groups, and interviews, we captured the complexity of living with dementia, the barriers faced, and the opportunities that exist locally to improve wellbeing while using inquiry strategies, a theoretical framework, and questions to guide the study. Arts-based methods were also used to disseminate findings to enhance public and stakeholder engagement in the research.

3.9 Role of the facilitator in PAR

The role of the facilitator in a participatory action research project is vital to ensuring parity in the collaborative approach. In PABR, facilitators guide individuals through analysis and action against systems that oppress them, building an understanding of those mechanisms in their everyday lives, a process that Freire termed conscientização (critical consciousness) (Freire, 2017). Through this consciousness-raising, problem-posing education, the oppressed will come to see themselves as no longer oppressed or oppressors, "but humans in the process of achieving freedom" (Freire, 2017). Freire remarks that pedagogy for the oppressed is one that "makes oppression and its causes objects of reflection by the oppressed, and from that reflection will come their necessary engagement in the struggle for their liberation." By taking action to change these systems, people from minority groups can learn more about the root causes of their conditions and deepen their analysis. The dementia community may not consider themselves oppressed, but they are certainly vulnerable and face discrimination every day in terms of negative attitudes and exclusion from wider society.

Freire's notions of conscientização (critical consciousness) help us understand who we are or who we might be, and, more importantly, how to work with others to create and develop systems and societies that work for everyone. Dialogue is Freire's central mechanism for change. Constructive, deliberative, engaging, and transformative dialogue requires the inner depths of humility in order to transform

our lived realities, and this is part of the conceptual thinking that Freire imparts throughout his work.

3.9.1 Dialogue, empathy, love, and hope

According to Freire, true dialogue cannot exist unless the partners engage in love, humility, faith, trust, hope, and critical thinking. Humility for Freire is a specific requirement in recognising that people are knowledgeable (Suzina and Tufte, 2020) and within education people are not just the passive recipients of knowledge. Applying Freire's vision of humility to this research methodology means knowing that research begins with the participants or community you are investigating, not the researcher. Researchers who approach communities with a genuine desire to learn from and understand them facilitate much more effective relationships than those who adopt a traditional research approach that is based on the researcher's own knowledge, education, and experience. A humble approach that acknowledges the community's powerful role is a great way to ensure improved community participation as well as improved outcomes. We can draw some parallels with Kurtz's principle of 'organicity' in the body-mind-centred psychotherapy Hakomi, which sees individuals as inherently wise living systems capable of self-organisation, self-correction, and self-maintenance (Kurtz, 2007). The researcher's role, then, is to facilitate and support the community's natural restorative ability.

Freire's principle of hope is about trusting a new just social order. In community-based PAR, believing in the research and its possibilities is a key principle. A combination of high expectations and effective outcomes can instil hope in the researchers, along with a belief that they can bring about change. Photovoice has come under some criticism for overpromising and not delivering (Leibenberg, 2018). It's therefore important that the facilitator's words of encouragement and hope are not empty. They must communicate effectively and earnestly, backed by proof of their accomplishments. Belief in the community's capacity to improve their situation can help them believe it themselves.

According to Suzina and Tufte (2019), Freire's empathy acknowledges the inequalities faced by those undergoing education and views them as collective issues, not as a result of individual effort or merit. Freire also adopts a radical view of empathy and

enters 'into the situation of those with whom one is in solidarity' (Freire 2000). For a researcher, having the means to experience the feelings of another, or metaphorically "put oneself in their shoes," could certainly act as a precursor to the potential development of critical consciousness.

The principle of love emphasises the cultural nature of Freire's pedagogy, whereby he places the value of relationships over the rigour of discipline (Suzina and Tufte, 2020). This approach to research recognises the community's plenitude and knowledge. Acknowledging the importance of love can be difficult for a researcher because it requires them to be vulnerable, but love is an essential element to any meaningful relationship, especially for relationships seeking growth and learning. Communication happens verbally and non-verbally, and one of the most effective ways to express love of any kind is through our actions. Freire's acknowledgement of the role of love within dialogue is akin to the practice of 'loving presence' in the psychotherapy model, Hakomi by Ron Kurtz (Kurtz, 2007). People often describe 'living presence' as the relationship between a happy and contented mother and her peaceful new-born baby. Applying this within PAR aims to help co-researchers feel safe, heard, appreciated, and understood. This is not the usual state of consciousness for traditional researchers yet adapting the five core principles of Hakomi Therapy (mindfulness, organicity, non-violence, mind-body integration, and unity) provides techniques for a PAR facilitator with PLWD. An effective PAR facilitator creates an environment for co-researchers to trust the process and feel safe enough so we can learn about their lived experience. It was important to attend dementia awareness training sessions, becoming a dementia friend and dementia friend champion to understand and support the PAR group's needs.

The Hakomi principles particularly for the PAR group activities included mindfulness and observing one's own actions to help get a clear picture of reality and identify what is working and what is not. Recognising that the simple actions we take can encourage connection—praise, smiles, words of encouragement, signs of respect, genuine interest, and concern—resulting in a more meaningful dialogue. The state of mindfulness helps to reduce distraction and quiet the mind, enhancing our ability to detect sensations, emotions, and thoughts arising in the moment. Research suggests

a direct relationship between creativity and mindfulness, correlating the act of doing art, being surrounded by art, and mindfulness (Langer, 2007).

3.10 Using ABR to disseminate findings, analyse and gather new data

Data was gathered from grey literature of first-hand experiences of living with dementia. Two arts-based researchers from Liverpool Screen School joined the PAR group; both had lived with dementia as carers, and both had experience working with labyrinths. PLWD were invited to share their lived experiences, and the stories were analysed to create themes, which instructed the aesthetic creation of the labyrinth path.

A narrative interviewing approach was used to elicit stories of PLWD's experiences. The collection of multiple narratives manifests in extremely rich data, as no two interviews are alike (Lieblich et al., 1998). The literature and interview data created textual vignettes of short written texts. Artists developed some of the texts into illustrations and cartoons to represent a visual narrative.

Figure 25: Illustration of 'Al - Mr Zheimers' story
*Image by Laura Chafer, 2017*
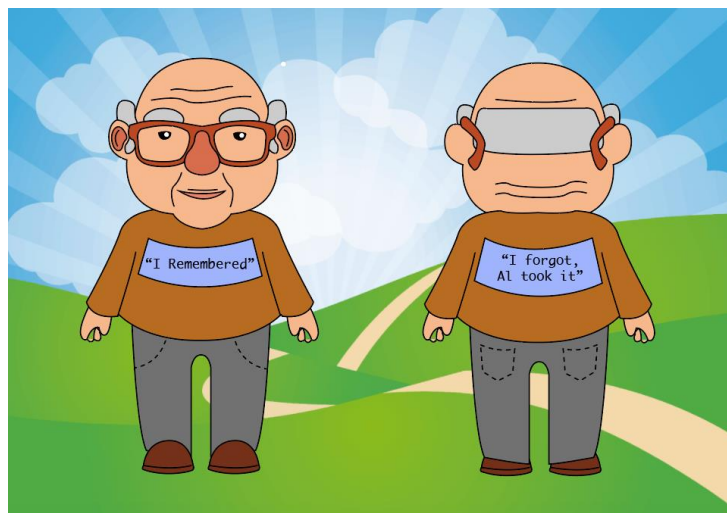
The artworks and vignettes were presented using postcards and inserted into card holders positioned along the labyrinth path.

Figure 26. Illustration of an amusing story about person with dementia singing in the shower Ryan-McNeill, 2017


Figure 27. Stories shared by labyrinth audience members who became research participants. Ryan-McNeill, 2018
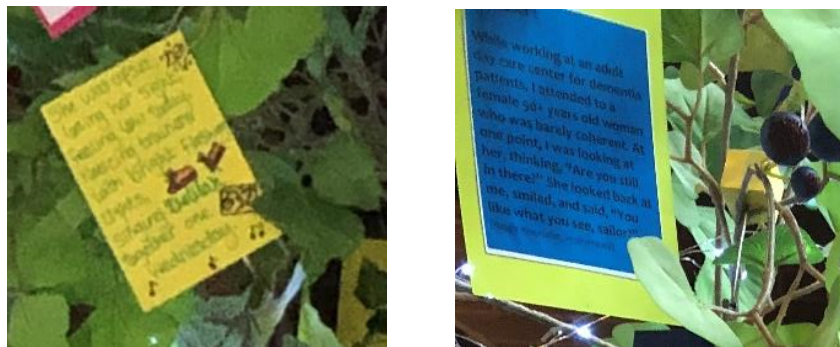
A labyrinth art installation was co-created to disseminate findings about living well with dementia. This was titled 'The Lost and Found Labyrinth'. Labyrinths are historical and cultural symbols; they have existed for approximately 4,000 years and have been found in all corners of the world. The labyrinth's unicursal path is outlined on the floor, using a classical labyrinth shape it takes audience participants into the centre and back out again, rarely are they used as an arts-based method.

Figure 28: Classical Labyrinth (3 circuit)
Ryan-McNeill and Irving, 2019

Entrance
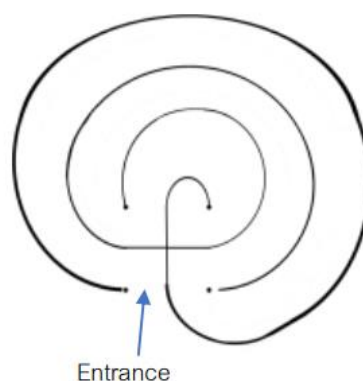
3.10.1 Classical Labyrinths

Dating back to at least 2000 BCE, and found worldwide, these are the oldest and most widespread type of labyrinth. Installation art creates a complete, multi-sensory, immersive experience (Leavy 2020). Audiences were invited to walk labyrinth paths, transforming their experience from observer to participant. Many have found walking labyrinths to be potentially powerful and deeply peaceful experiences, and the meditative path can provide the opportunity for fresh insights, introspection, and contemplation. This was particularly relevant for reflections on experiences of living with dementia, which are likely to be sensitive and emotionally charged. While this meditative and self-reflective method can offer therapeutic value, it can also carry the risk of inducing distress, so it is important to nurture safe research methods and spaces. Some arts-based approaches have been particularly effective at communicating complex or sensitive topics, whether visually, using stories, or through drama.

Creating a labyrinth installation to share patient experiences has previously been used by Lapum (2012), in her project titled 'The 7,024th Patient'. The installation was 1,700 square feet wide and 91/2 feet tall; it exhibited hanging textiles, poetry, and photographic images. The labyrinth design and aesthetic were chosen to invoke an emotive and visceral experience from the audience that emulated the experience of having heart surgery (Leavy, 2020). The materials outlining our 'Lost and Found' labyrinth path were deliberately no larger than 20cm; this encouraged the audience participating in the labyrinth installation to quiet the mind, calm anxieties, and encourage meditation as they looked downward to follow the one path. In addition, we invited audience members to share their own experiences living with dementia and add them to the labyrinth via postcards or donated artifacts. Any audience member shifting from observer to participant was presented with the participatory information and asked to give consent in accordance with the ethics approval process.

Figure 29: Lost and Found Labyrinth – Open Eye Gallery 2017
Ryan-McNeill, 2017

The labyrinth experience was designed to be a calm, mindful, winding journey in which it's impossible to get 'lost', creating a safe, immersive experience for PWLD and the public. The labyrinth was large enough to allow everyone to walk to the centre and back out again.

Maggie O'Neill discusses collectively walking as an arts-based research method and how the process encouraged reflection that was 'relational, sensuous, kinaesthetic, democratic, and participatory' (O'Neill, 2012). O'Neill's participants took part in arts and research workshops, and then led guided walks with a variety of key stakeholders, including policymakers. Equally our co-created Lost and Found Labyrinth installation invited stakeholders to walk the path and learn about the lived experiences of PLWD.

Arts-based methods as an approach to gather data and disseminate findings were tested during the pandemic to explore and investigate the impact of social isolation on people's wellbeing. Potential participants were reached by developing several online resources, sharing them via Online Survey (formerly BOS) tools, and connecting with participants via telephone and video software, i.e., Zoom.

3.10.2 Theatre-Based Arts Research

During the data gathering process, we observed several experiences related to the use of humour as a coping strategy. Goodenough and Low's (2012) study was one of the first rigorous studies to explore humour therapy in dementia patients. SMILE, a randomised controlled trial, studied the impact of comedic and improvisation skills on a range of improvements in wellbeing, including the easing of depression, anxiety, loneliness, hopelessness, stress, and increased self-esteem among residents of residential aged care facilities. The study found a 20% reduction in agitation using humour therapy (Goodenough et al., 2012).

Merrick et al. (2016) discuss how humour acts as a saviour for people living with dementia. Focusing on the present and laughing at a situation can help to sustain a sense of self (Merrick et al, 2016). This highlighted how the use of humour can be a useful tool, if used appropriately, to help cope with challenging situations for people living with dementia. Ganz and Jacobs (2014) suggest that coping with humour can decrease stress and increase social support. Comedy performances will bring data to life, making it more accessible to policymakers, arts and cultural organisations, and the general public. Recognising humour throughout the PAR process led to participants having a pleasant experience. Incorporating humour at this stage also helped us to highlight how humour can act as a coping strategy and support the improvement of mental and physical health.

3.10.3 The creation of an ethno-comedy theatre play

The production of a comedy theatre play aimed to attract a distinct audience from that of the Lost and Found Labyrinth. The theatre play's development consisted of several stages. Co-designing and delivering the performance in partnership with people living with dementia (PLWD) was crucial.

The play was developed using a verbatim theatre technique. The initial aim was to present people's experiences of living with dementia by developing and presenting a series of comedy sketches in a comedy club venue as part of the Being Human Festival, a celebration of humanities research through public engagement. Tony Robinson pioneered the technique known as 'Verbatim Theatre', which ideally fits within a qualitative research framework by transforming text or data into a

performance (Paget, 1987). The writers, actors, or performers would usually take part in the data gathering process. In our approach, some performers were telling their own stories.

A writer and director developed the ABHR theatre production 'Inside Out of Mind', based on participant observation in dementia wards, to produce a powerful yet non-naturalistic representation of life on a dementia ward from the perspective of the patients, staff, and visitors. A research evaluation concluded that this was a powerful medium to share results from qualitative research; it reinforced professional carers' pride in their work and their understanding of their role in the wider narrative of dementia (Schneider, 2017). The PAR group expressed how important it was to represent people living well with dementia. ABHR theatre was evidently an effective way to break the stigma around dementia and reach audiences in a much quicker timeframe than traditional research dissemination processes (Hall et al., 2019).

The Labyrinth Installation process had previously gathered and analysed rich data. An additional stage of analysis divided this data into smaller research themes suitable for the comedy performance. Collectively, the arts researchers agreed on the narrative and stories to tell. The PAR group verified the authenticity of the selected stories. According to Belfield (2018), the narrative in verbatim work is the structure; the story is something more profound; and it is a way of expressing what lies at the heart of the piece or research. Once the narrative and stories were selected, drama improvisation methods were used to bring the scenes to life and, where possible, show rather than tell the audience the stories at the heart of the play.

The theatre performance invited co-researchers, who were also carers, to perform alongside professional performers and share their personal stories. The research facilitator, fully immersed in the PAR project, initially directed the piece.

Comedy theatre and humour were used to reduce the stigma amongst adults with the aim of increasing those benefiting from an early diagnosis, building on von Gorp and Vercuysses' research on the effects of media language and the need for positive experiences despite a dementia diagnosis to destigmatize the condition (Wolverson et al., 2016). The use of humour might have been morally problematic, so we

established ground rules and applied the kindness and respect principles previously discussed in the facilitator role discussion.

During the global pandemic, we produced a COVID-safe comedy play to explore the impact of social isolation on the wellbeing of the older generation in Liverpool. The exact same approach was used as described previously, but the data gathering stage took place online using video meeting software and by telephone.

3.11 Qualitative research methods

This participatory arts-based study employed four qualitative instruments: (1) focus groups; (2) semi-structured interviews; (3) observations; and (4) documents, photographs, and artwork reviewed as sources of data.

3.11.1 Focus Groups

Focus groups are a viable method that qualitative researchers use to gather information about a particular event or phenomenon from the perspectives of individuals connected to the event or experience. For several decades, the social sciences have widely used the focus group as a qualitative method of data collection. Focus groups are useful for bringing together groups of participants with relevant expertise and experience on a given topic to share detailed information. The group dynamics of the focus groups allowed the research facilitator to extract rich data about the arts and culture experiences collectively and revisit the findings discussed in the initial focus group that took place immediately after the experience. It also enabled the research group to discuss the impact of the experience in the days following the event. During the focus groups, there was an opportunity to observe body language and other non-verbal cues that may convey emotion to establish a rapport to inform future decisions within the research (Merriam and Tisdell, 2016).

We conducted a total of 12 focus groups in this study to collect data from people living with dementia who had participated in an arts activity. Six were held immediately after a visit to a local gallery or museum exhibition. Six took place one week after the art experiences in a university venue. Three focus groups were conducted in Independent Living Schemes to collect stories from older people about their social isolation during lockdown.

3.11.2 Semi-structured interviews

Semi-structured interviews are an effective method for data collection within a PAR project. As they flow more naturally, like a conversation, there is a familiarity. They enable the researcher to collect qualitative, open-ended data and explore participant thoughts, feelings, and beliefs about a particular topic. Not all semi-structured interviews were face-to-face; during the COVID lockdown, this was the most effective method to interview older people who were shielding. Many researchers have some scepticism about using the telephone in qualitative studies for in-depth interviews and serious consideration needs to be given to the interview context (Holt, 2010). According to Cachia and Milward (2011), telephone conversations and interview modes are complementary. We found that the interview transcripts provided rich textual data that we subsequently analysed to produce the theatre performance exploring the experiences of older people during lockdown.

3.11.3 Observation

This PABR study used observations to gather additional data on the phenomenon it explored. Participant observation can take different forms; for example, it could be covert, where the participant does not disclose that he or she is a researcher. Observations were discussed during focus groups within the PABR approach. All participants became co-researchers, and everyone had the role of observing and feeding back to the group. The facilitator, fully immersed in all group activities, fostered an immersive perspective of the group members' worldview through their daily experiences.

Observations of specific incidents or behaviours served as a reference point for discussions within the focus groups. The research group was invited to reflect on and respond to these observations, enabling clarification of the observations, a better understanding of the context, and the ability to triangulate emergent themes (Merriam and Tisdell, 2016, p. 139).

3.11.4 Document and Artefact Review

Documents, artefacts, and artworks submitted to the research were important sources of data. The curation of the labyrinths and the composition of the comedy

performances guided the review and analysis of the documents. The documents reviewed for this study included photographs, letters, artworks, evaluation comments, and feedback. Literature and grey material were also reviewed during the data analysis stage and incorporated into the creative outputs (see Appendix 1).

The artworks themselves were analysed alongside the artist's descriptions, interview transcripts, and conceptual analysis of the images. The artists were asked about their concepts during the interview session about their artworks. Within the artworks, common images, ideas, and themes were recorded, with a focus on the subject matter, the context, and the mood of the artwork and how it related to social isolation and their wellbeing. The curation process of the lockdown labyrinth included a thematic analysis of the artists' responses.

3.12 Setting and Environment

The capacity of venues, specifically the number of co-researchers comfortably accommodated in arts and cultural venues and the Liverpool School of Art and Design facilities for group discussions, was a crucial consideration. During the COVID lockdown restrictions, it was important to adhere to government guidelines on social distancing. This was true for the Lockdown Labyrinth and COVID-safe theatre performances for older members of the community.

3.13 Participants

This study was interested in exploring the experiences of people living with dementia and how older people experienced social isolation during lockdown. To gain a deeper understanding of these experiences, research participants were selected based on the following criteria:

PAR group with PLWD

- people with mild to medium dementia,
- living in the Liverpool area
- are able to give informed consent
- are able to take part in arts and cultural activities across the Liverpool City Region.

Lockdown Wellbeing Study

- Who has been or is in social isolation due to the UK's COVID-19 lockdown?

- individuals, couples, families with children, students, or creative practitioners

- willing to take part in lockdown labyrinth arts activities before June 20th

- happy to communicate in English

3.13.1 Informed Consent for People Living With Dementia (PLWD)

Research indicates that there are no easy solutions to support the process of gaining informed consent for PWD, but there are numerous measures that can be taken to support the process (as outlined above), and this helped to assess whether co-researchers with dementia were making informed decisions about taking part in the research. Several researchers who have tried to address these issues recommend participatory research approaches and practical methods of process consent. Research involving people living with dementia raises questions regarding informed consent, with memory problems and concentration difficulties associated with the condition suggesting a need to refer to the Mental Capacity Act, 2005 (Gov.uk 2014). Although an increasing number of researchers believe that people diagnosed with "mild" or "moderate" dementia are capable of giving consent, the ethical considerations regarding consent and mental capacity for people living with dementia pose some challenges.

Given that all co-researchers had 'mild' or 'moderate' dementia and were still living independently, it was understood that the co-researchers with dementia were entitled to be regarded and treated as being able to make choices. The assumption of presumed capacity enshrines consent, unless proven otherwise. Additionally, this research has adopted a number of recommendations from Alzheimer Europe's dementia ethics research project to support the assessment of informed consent. When providing information, core researchers will be aware of the differences between participants and take into account cultural backgrounds and other factors such as level of education, linguistic matters, differences in perceived power, impairments, psychological state, etc. The use of visual or other aids has been considered and has been incorporated into the research process.

The participatory research approach established the conditions for person-centred relationships between the research facilitator and co-researchers; it allowed the focus on consent to be a process that runs throughout the research project rather than taking place merely at the beginning (Dewing, 2007). In addition, this process relates to person-centred care and stresses the importance of interdependence and connectedness through relationships. Care was taken during the research process to become mindful of non-verbal signals in relation to participation and wellbeing. The principles of person-centred nursing provide five necessary conditions for person-centred research. The conditions are informed flexibility, sympathetic presence, negotiation, mutuality, and transparency comprise these conditions. Dewing's work (2008) incorporates these five conditions into the process consent method, and this influenced the process consent method for older persons with cognitive impairment (usually through dementia) and changes in their capacity that would likely prevent them from giving informed consent.

The Mental Capacity Act (2005) presents certain challenges when dealing with dementia; however, researchers have developed the participatory research method to address these challenges. Informed consent assumes that a study participant is capable of making a free and voluntary conscious decision based on adequate information about the study, its risks, benefits, and procedures. Although dementia may affect a person's decision-making capacity at some point, defining the capacity to give informed consent is multifaceted. The challenge in including people with dementia in research is to determine their capacity to give informed consent or assent in a way that secures their rights and maintains their autonomy. People with dementia and their family members may be considered vulnerable because dementia affects many domains of a patient's life, threatening identity, autonomy, and independence. Dementing diseases also pose significant challenges to family members. When researchers focus on sensitive issues in research studies, it can have an impact on the emotional wellbeing of all participants and co-researchers. Researchers acknowledge that research interviews can potentially benefit study participants by offering a platform to discuss and interpret their experiences, thereby instilling a sense of purpose.

Before each research activity, the research group facilitator checked in with the participants to ensure that the person with dementia had understood the information about the study and their participation in it. When seeking consent, particular attention was paid to environmental factors (such as noise level, time of day, and lighting), wording and sentence structure, jargon was avoided, and the amount of information provided at the time was limited to ensure clarity.

The co-researchers confirmed their voluntary participation, signed a consent form, and received information at each stage of the research activity. Participants were made aware that they could withdraw from the study at any time, freely and without having to provide justification for their decision. In addition, researchers were attentive to signs of distress linked to participation, and if necessary, we checked with the PWD to see whether they wished to withdraw from the study. Researchers followed up with participants who withdrew from a study in case they were experiencing any negative effects from the study or resulting from their withdrawal. Researchers were alert to signs of distress and were willing to stop the consent process with that person, either temporarily or permanently. Engagement in the research was continually monitored to ensure that co-researchers were happy to participate.

The research group treated all participants equally and provided them with the same information sheets. Informed consent took place as a reflexive and ongoing process whereby the researcher's goal was to ensure that participation was voluntary in each phase of the study.

The key ethical principles guiding this study are kindness, respect, and fairness for people living with dementia. These principles were embedded using the principles of Freire and Kurtz. I was prepared in advance to adopt strategies that prevent or minimise risk and, during group discussions, to respond actively to emotional distress due to my training in mindful body-centred psychotherapy (Hakomi and being a dementia champion).

3.13.2 HRA: ethical approval

The Liverpool John Moores University research ethics committee, the Health Research Authority National and Regional Ethics Committee, and Merseycare NHS

Trust provided ethical approval for the recruitment of study participants. Ethical approval was obtained from Liverpool John Moores University in March 2016, an application submitted to HRA REC in November 2016, and approval was received in January 2017. A research passport was obtained from the local dementia health services provider, Merseycare NHS Trust, in June 2017, which enabled the recruitment process of people living with dementia.

3.13.3 Sampling Procedures and Participant Selection

For phase 1, two gatekeepers delivering dementia services (Merseycare NHS Trust and SURF – Service Users Reference Forum for PLWD). A university academic referred a father and son because she thought it would benefit them. With agreement from managers, people living with dementia were sent written information about the study. They were asked to contact the research facilitator if they wished to find out more and take part. In phase 2, participants were invited to take part via an online platform (onlinesurveys.ac.uk) and older people's housing scheme manager became gatekeepers for the older adults who were invited to engage in interviews.

The number of co-researchers was calculated by assessing what was reasonably practical to enable a meaningful discussion. In Merrick et al's study of the lived experience, they acknowledged it is better to investigate the stories of fewer participants in more depth than to include more participants but give a broad, shallow, and descriptive analysis. A sample size of 4 to 10 was considered ideal due to the likelihood of people withdrawing from the study, therefore, it was considered advantageous to overrecruit.

3.14 Triangulation within ABR

According to Merriam and Tisdell (2015), the most effective strategy to ensure internal validity is known as triangulation.

'by using three methods of data collection — interviews, observations, and documents…means comparing and cross-checking data collected through observations at different times or in different places, or interview data collected from people with different perspectives or from follow-up interviews with the same people.'

Triangulation implies the use of multiple methods or data sources in qualitative research to develop a comprehensive understanding of phenomena (Patton, 2002). People also view triangulation as a qualitative research strategy that tests validity by combining information from various sources. In this study, multiple participants were interviewed, and four different methods of data collection were employed to ensure triangulation of the data: interviews, art submissions, observation, and document review.

Corroborating mixed methods and strategies against one another results in methodological triangulation (Scott, 2016). Interviews, art creation, artifact and document reviews, and observations provided data from multiple methods to triangulate the study. Data was collected from multiple participants using arts-based approaches to evoke emotional engagement. Focus groups and interviews were documented and reviewed, along with artefacts created and submitted throughout the study.

3.15 Data Analysis and Management

Conducting qualitative research is about attempting to see the world from another person's perspective; therefore, the most important part of data analysis and management is to be true to the participants (Merriam and Tisdale, 2016; Saldana, 2013).

At all times, the participants' voices remained central to the research. Their perspectives have been justly interpreted and reported in such a way that others will be able to access and glean new learning. The content of arts-based dissemination has been authenticated by sharing with the participants themselves and gaining their approval.

3.16 Data Analysis

Following a participatory framework, after each activity the co-researchers took part in a table discussion to present findings, giving co-researchers the chance to provide context and input on data or recommendations. The follow-up focus group received

preliminary data from each art and culture activity with PLWD in the form of a series of "placemats"—photographs printed out for the group. Each placemat presented data through images and quotes, displayed in a visually pleasing, easy-to-follow format. The placemat's purpose was to use visuals to trigger their response to the previous week's activity and give people living with dementia the opportunity to independently ponder and analyse the data. This process helped identify which findings and recommendations were the most meaningful. This applies particularly to participatory research because it ensures that the various perspectives flow into the interpretation during the data analysis process and that the co-researchers gain insight into the background to their own viewpoints and that of the other members. At this level of analysis, co-researchers identified three dimensions that emerged from the dialogue process: issues, themes, and theories. The research facilitator was able to share information about how their experience and responses related to the evidence outlined in the literature review concerning the use of arts to live well with dementia.

3.16.1 Data Analysis Protocol

A data analysis protocol was created in order to systematically consider all sources of data collected. Initial readings of interview transcripts and reviews of all sources of data enabled early identification of commonalities or connections between sources.

3.16.2 Thematic Analysis

Thematic analysis is the process of identifying patterns or themes within qualitative data. According to Braun and Clarke, learning thematic analysis should be the first qualitative method because it *provides core skills that will be useful for conducting many other kinds of analysis'* (Braun and Clarke, 2006, p. 78).

The accessibility of Thematic Analysis is another advantage. For people new to qualitative research, TA provides a way of doing research that otherwise can seem vague, mystifying, conceptually challenging, and overly complex. Using an inductive TA method, the data drove the research analysis. The creation of a research question for ethical approval did not dictate the data gathered during the PAR process. The research groups adopted a flexible approach to benefit the research outcomes. Equally, preconceived concepts, ideas, or topics were considered when coding and

interpreting the data. Analysis produces the answer to a question, even if, as in some qualitative research, the specific question that is being answered only becomes apparent through the analysis. Any data set can reveal numerous patterns, and the goal of analysis is to pinpoint those that are pertinent to addressing a specific research question. The data analysis yielded new research questions for further exploration and investigation.

Master themes that occurred during the focus group were identified to highlight how the activities influenced reflections on the lived experience. Braun and Clarke's six-step process for identifying, analysing, and reporting qualitative data in thematic analysis was used to determine the overarching themes that emerged from the data. (Braun and Clarke, 2006)

As the PAR research group facilitator, I transcribed recorded focus group verbatim in word documents and imported these into a spreadsheet to analyse.

The transcripts were read several times to gain familiarity, highlighted sections of text, and coded under these initial descriptive titles: activities, advice, challenges, digital tech, loneliness, recommendations, social interaction. Preliminary themes were constructed from codes: accessibility, enjoyment, experience, humour, isolation, loss, and reminiscence.

The two new researchers, who formed part of the Creative Team for Arts-Based Methods, independently reviewed these preliminary themes and either agreed with code assignment or offered alternative perspectives.

The research group facilitator conducted four iterative interviews, each themed and coded to capture participant experiences related to the topics of interest. The data reached saturation when no new codes or themes surfaced.

The two researchers from the creative team met with the research facilitator to further refine the themes and codes to be used within the creative outputs, the 'Lost and Found Labyrinth' and 'On Cloud 79' comedy theatre performances.

3.16.3 Arts-based data analysis

An interdisciplinary analysis team, including artist practitioners and researchers, convened several times to analyse the data in relation to curating a labyrinth arts

installation and producing a comedy performance. The analysis team systematically analysed visual images, interviews, literature text analysis, and transcribed qualitative focus group data.

Data analysis was an iterative process; data was gathered variably throughout the study. It was necessary to analyse the data at different stages to meet the requirements of the creative outputs (Lost and Found Labyrinth, On Cloud 79 theatre performance, Silver Bells and Cocktails: A Life in Lockdown Theatre Performance, Lockdown Labyrinth, and Solstice Exhibition).

The first cycle involved becoming immersed in the data by reading and rereading textual and visual data (e.g., transcripts of interviews, text from grey literature, and photo submissions). During this stage, aspects that were relevant to the research study were highlighted. Co-researchers and artists, who were involved in the co-design or co-creation stage of the art, shared notes. Artists selected the vignettes that they developed into illustrations and cartoons. During the second cycle, data was coded and labels were identified for data that was potentially relevant to the research question or creative output.

The coding stage led to the evolution of themes, identifying and overlapping areas of similarity between codes. The unifying features recognised were shared and presented in a way that reflected the data authentically and meaningfully. Dialogue with participants and colleagues resulted in the generation, scrutiny, and vetting of the identified emerging themes. The coding and tagging processes are important aspects of data analysis. The researcher interprets the revealed topics, issues, similarities, and differences through participant narratives, a process known as coding (Merriam and Tisdale, 2016; Saldana, 2013). This process helped the artistic research team understand the world from the perspective of the co-researchers.

3.17 Data Management

Data from all sources was managed using a mix of manual and computer management. Audio recordings were stored in a password-secured computer programme and deleted after transcripts were completed. All data was handled,

stored, and destroyed in accordance with the LJMU Research Data Management Policy and GDPR (General Data Protection Regulation).

3.18 Trustworthiness

To maximise the trustworthiness of the qualitative data, this study uses multiple data gathering methods (i.e., interviews, focus groups, and analysis of artworks, photos, and text submissions). Visual images offer multiple meanings, creating rich narrative data and deepening the understanding of the research topic. This data triangulation, examining sources, and identifying similar characteristics blended the data into themes and meta-narratives.

This study aimed to better understand people living with dementia and older people's experiences of social isolation during a global pandemic. The study adhered to a thoughtfully constructed research design and effectively used an ABR framework to interpret and present the findings. This approach provided and accurately captured the rich and descriptive detail of how an arts-based research approach can bring immediate benefit to the participants. Participatory arts-based research methods confirmed the consensus around emerging themes and supporting evidence.

3.19 Summary

This chapter provided an overview of the qualitative and arts-based research methods employed in this study. Using a participatory arts-based research study approach, we illuminated the experiences of people living well with dementia and explored the use of art to overcome isolation during the pandemic.

This chapter also reviewed methods of arts-based research, research design, research method protocols, and processes for data collection.

"People's stories are data with soul…

the stories that our communities tell in five years, is probably the most powerful measure of success."

- NHS director of inequalities

Prof. Bola Owolabi

Figure 30: Photovoice 2018 Exhibition at the 5th Global Health Systems Symposium Liverpool Ryan-McNeill, 2018

CHAPTER FOUR -   Arts-Based Health Research – in practice: Findings

Chapter Four: Arts based practice as health research – Findings

4.1 Introduction

This chapter discusses the data pertaining to the effectiveness of arts-based research approaches, namely in terms of participation and audience reach. The findings delve deeper into how art-based methods improve participation, quality of engagement, and audience impact. Several arts-based practices were used and developed to gather and share data in relation to knowledge of the lived experience of people with dementia (phase 1). These were later tested during the global pandemic (phase 2) by exploring the use of the arts to support the wellbeing of older adults in lockdowns during a global pandemic.

This chapter presents and analyses data based on research findings related to:

1. Levels of participation using arts-based research methods in phases 1 and 2.
2. Quality of engagement for co-researchers (prominent themes relating to the perceived benefits of ABHR approaches for PLWD and older adults during the pandemic).
3. Audience reach and impact by an art-based dissemination approach (The Exchange Labyrinth, ethnocomedy theatre, stakeholder event with film presentation, and digital media).

Figure 31 is a visual timeline of the entire research study, and the arts-based methods used within each phase. The two research phases took place between September 2017 and June 2021. Phase 1 began in September 2017 to March 2020 and phase 2 in April 2020 during the Covid-19 lockdown and finished in June 2021. The ABR activity and research stage are outlined in the table in Figure 30.

Figure 31: Research activity timeline
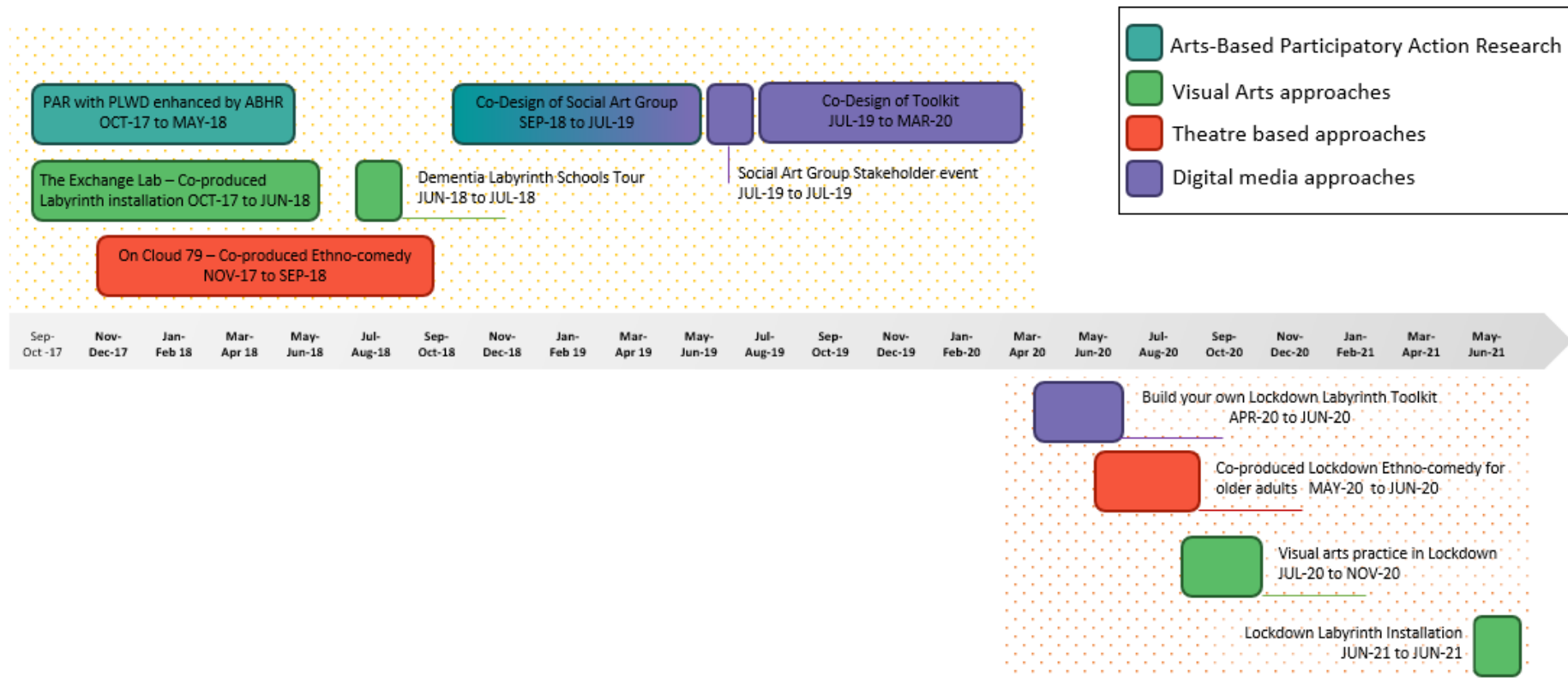
Figure 32: Table of arts-based research activities

Art-Based Research Practice	Stages/ Phases	ABR	Description	Dates	Research activity
• Participatory Action Research enhanced by ABR methods with PLWD	1a / 1	PAR	PAR (stage 1) Art viewing activities (visits to arts and cultural venues) to explore benefits for PLWD	Oct 2017 – May 2018	Data gathering
	1b / 1	PAR	PAR (stage 2) Co-Design of an arts social group, development of a short film and social media content.	Jan 2019 – June 2019	Co-design, data gathering and dissemination
	1c / 1	PAR	Stakeholder event with presentation of PAR findings using photography and film to promote further development of Made Up to Meet Up	June 2019	Data gathering and dissemination
• The Exchange Lab – Using a labyrinth art installation to present findings and increase public engagement with health research.	2a / 1	Visual Arts	The Lost and Found Labyrinth – an arts installation of a labyrinth path, created using donated knitwear, photographs and postcards to present lived experiences of dementia	Oct 2017 – June 2018	Data gathering and dissemination
	2b / 1	Visual Arts	The Dementia Labyrinth Schools Tour – an adaptation of the Lost and Found Labyrinth to promote age friendly communities around schools	July 2018	Co-production and dissemination
	2c / 2	Visual Arts	The Lockdown Labyrinth – a collaborative arts installation using a labyrinth path shape to present data from interviews about wellbeing during the covid-19 pandemic	June 2021	Co-production and dissemination
• Ethno-Comedy Theatre Performances to share research findings and promote wellbeing	3a / 1	Theatre	Tangled Veil and the Cloud of Unknowing / On Cloud 79 comedy theatre performances to share findings and promote living well with dementia	Nov 2017/ Sept 2018	Data analysis and dissemination
	3b / 2	Theatre	Silver Bells and Cocktails – a life in Lockdown covid safe theatre tour to share lockdown stories and promote wellbeing during a pandemic	May 2020	Data analysis and dissemination
• Creative Toolkits to encourage engagement in arts-based research and social prescription activities	4a / 1	Digital	Made Up to Meet Up Toolkit - a step by step guide to develop arts based social groups supporting social prescribing in the Liverpool City Region	June 2019 / June 2022	Co-design and dissemination
	4b / 2	Digital	Build Your Own Lockdown Labyrinth – a how to guide to support artists, schools, and home schoolers to produce their own labyrinth and explore wellbeing during lockdown	April 2020	Participant recruitment

Data was collected during different art-based research activities, including audience evaluation during dissemination activities, as part of the iterative approach to this project. The discoveries outlined in this chapter provide a demonstration of how arts-based methods influenced involvement, the level of involvement, and the reception from the audience. The iterative procedure, that provided flexibility in addressing the needs of the research participants and shaped the design of each successive research phase, is also explained.

4.2 Phase one

### 4.2.1 Phase one participation

Between October 2017 and April 2020, a total of 82 people engaged with Phase 1 of the research study exploring living with dementia and how the arts can improve quality of life. Of these, 64 confirmed they had lived experience; most of those who didn't were students or artists engaged to support the creative outputs. Eight participants had a diagnosis of dementia; 44 were unpaid carers, and nearly all took part in two or more research activities. Of those who had lived experience, there were 24 males and 39 females, and one participant identified as 'they', with ages ranging from 20 to 74 years. 11 were mental health student nurses. An additional 84 participated in evaluations of the creative outputs, On Cloud 79

4.2.2 Phase one recruitment

Purposive sampling involved recruiting 82 participants from various organisations, including people living with dementia, SURF (Service Users Reference Forum for PWD), Liverpool John Moores University staff, and students with lived experience. Throughout the research process, all participants were from the Northwest of the UK. Figure 25 details the levels of participation in phase 1 in relation to the arts-based research activity. The theatre performance gained the most participation, which was mainly due to the cumulative effect of the iterative process. The inclusion of all participant stories and contributions in the succeeding arts-based outputs led to an increase in participant numbers at successive research stages. All the data gathered throughout the iterative research processes was analysed and incorporated into the

development of the Labyrinth installation 'Lost and Found' and the ethno-comedy drama performance 'On Cloud 79'.

Figure 33: Phase 1 research activities map with participant characteristics. Ryan-McNeill, 2024
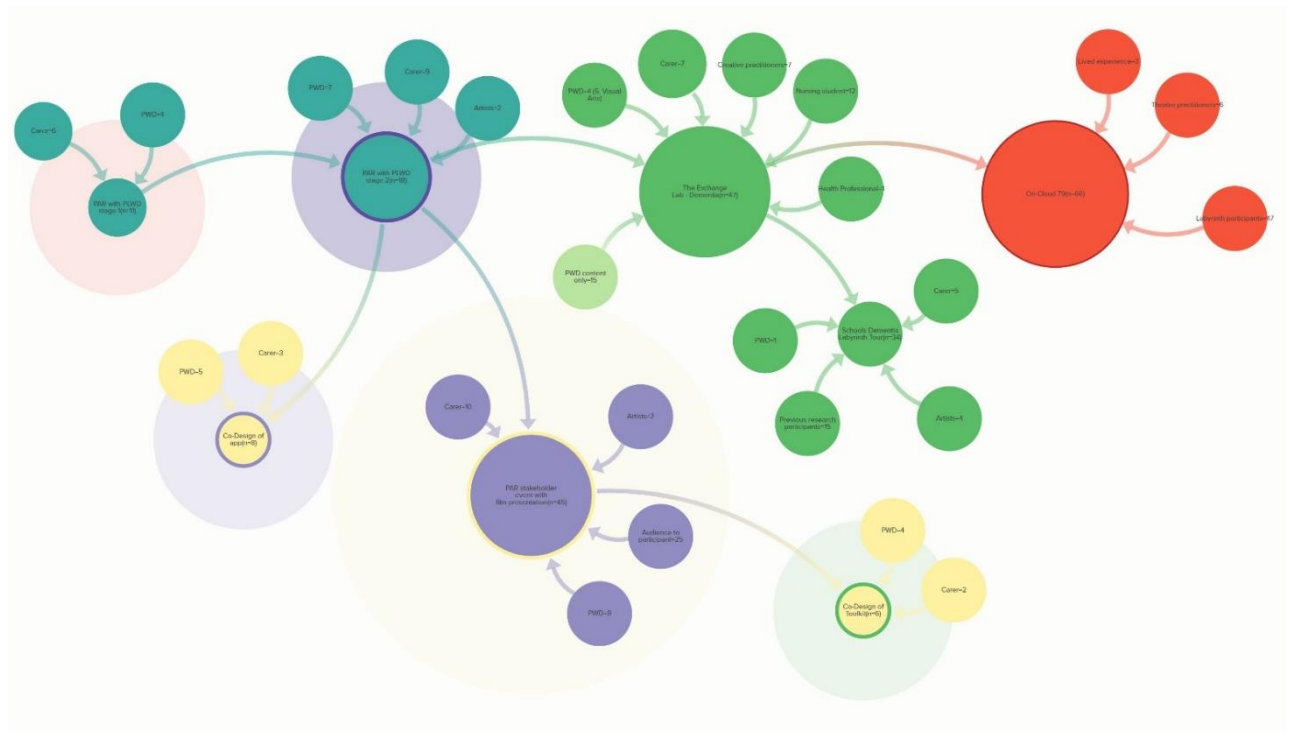
In Figure 31, the elements have been colour coordinated in relation to the art form used, corresponding to the visual scoping map in Chapter 2. The size indicates the no. of participants.

Both the PAR stage 2 and the stakeholder events have different coloured borders to represent the additional arts-based methods that featured within these research activities, Arts-based PAR and digital respectively. The number of participants almost doubled for Stage 2 of the PAR study, (n = 18) indicating that the art viewing activity attracted new participants. Equally the opportunity to be part of a co-design process to support the dementia community's engagement with arts and culture in the Liverpool City Region was considered a benefit. The following anonymised quotes from members of the PAR stages 1 and 2 group demonstrate this:

"Sarah mentioned at SURF how much fun it was being involved in this research project, me and Billy are coming along because we loved getting involved in music

and art activities, I still play and have recorded a few songs about my living with dementia."

"I've discovered places in Liverpool that I didn't even know existed. It's important to keep busy and active. Everyone with a diagnosis should know about this. It's important to meet and share these social experiences with people in the same boat as you".

"SURF has changed, we don't do any social activities, that's what people with dementia really need. We want to be having fun and living our lives to the full."

As per the participants' feedback, the arts-based study offered a vital social engagement and the chance to connect with others facing similar circumstances. Most participants (n = 71) actively participated in many art-based research activities, suggesting that arts-based methods were more accessible and appealing to participants compared to traditional research methods. This was not applicable to research conducted during the COVID lockdown, as digital methods and telephone interviews were required due to the self-isolation restrictions imposed because of the pandemic.

Several supplementary research activities involved limited participant cohorts. The activities consisted of the School Dementia Labyrinth Tour (n = 6), the Co-design of a Dementia Wellbeing app (n = 8), and the Made Up to Meet up Toolkit (n = 10). The co-designed research activities were created in response to the findings that were revealed during the iterative stages of the research process.
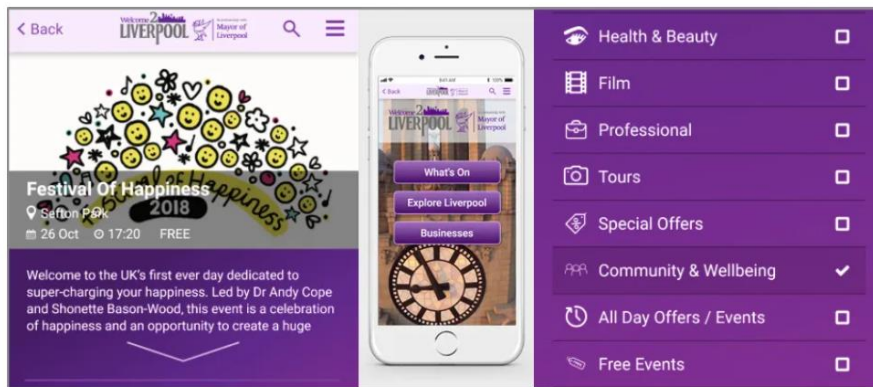
4.3 Co-design

4.3.1 Co-design of a wellbeing app

Eight members from the PAR group collaborated with the digital tech business 'Welcome 2 Liverpool' to co-design a wellbeing app. The app was being developed to showcase free arts and cultural events happening in Liverpool in 'real time'. The PAR group recognised the potential of using this approach to promote dementia-friendly events and enhance participation in social arts activities. They were enthusiastic about assisting others in living well with dementia and determined to challenge the negative perception associated with a diagnosis. This project was supported and

funded by the Dementia Connect Development Lab led by University of West of England.

Figure 34: Dementia Connect Wellbeing app Image by Welcome to Liverpool
Welcome to Liverpool, 2018
Available at: https://dementiaconnect.dcrc.org.uk/projects/whats-on-dementia/

4.3.2 Co-design of the social arts group for social prescribing

Six members from the PAR group collaborated with artists and health professionals (n = 10) to co-design a toolkit. The purpose of this toolkit is to promote sustainable social prescribing models by disseminating the research findings of the PAR group. After discussions on the advantages of art viewing activities for PWD at a stakeholder event, 'Made Up to Meet Up' was established as a model for an arts and culture social group. It secured financing from the National Lottery, Liverpool John Moores University, and a health commissioner. A local GP practice managers contributed to the development of the concept by providing suggestions on how it may be implemented inside Primary Care Networks.

Figure 35: Illustration from the Made Up to Meet Up Toolkit
Image by Andrea Stables

4.4 Accessibility

The issue of accessibility was addressed in phase 1, while phase 2 focused on the inaccessibility of businesses, services and leisure activities that people were unable to participate in due to the extensive lockdown measures. Accessibility of research activities was crucial for participation, and this was taken into consideration in both phases. Three institutions, including the Walker Art Gallery, World Museum Liverpool, and Tate Liverpool, visited during the PAR activities, are ranked among the top 20 most accessible venues. In general, the locations used in the PAR research were of a high standard for disability access, however, transportation to and from these venues posed challenges for several participants and the rotating doors at Tate Liverpool were problematic for some co-researchers. PWD can present with diverse impairments, including perceptual difficulties. Unfortunately, a lack of awareness regarding these challenges has led to the many facilities being inaccessible. The research group commented how revolving doors create difficulties and risk of injury. Tate Liverpool had an accessible door to the right and to the left of the two revolving doors, but the group remarked that it was not clearly signposted, *"For people with dementia these aren't ideal; we should rename them revolving doors! I didn't realise there was an accessible door it isn't very clear at all."* (PWD from PAR 1 and 2 group)

Figure 36: Tate Liverpool's revolving doors
*Ryan-McNeill, 2017*

4.5 Phase 2

4.5.1 Phase 2 participation

Between April 2020 and June 2021, a total of 63 people engaged with Phase 2 of the research study. The Covid-19 pandemic was the health context of which all 63 had lived experience. Participants identified as creative practitioners (*n* = 42), older adults aged 60+(*n* = 18) (5 were also creative practitioners), older person specialists (*n* = 3) and one schoolteacher (*n* = 1). Of all those who participated 11 were male and 52 were female.

Figure 37: Phase 2 research activities with participation numbers and characteristics Ryan-McNeill, 2024 using Kumu. Available at: https://kumu.io/
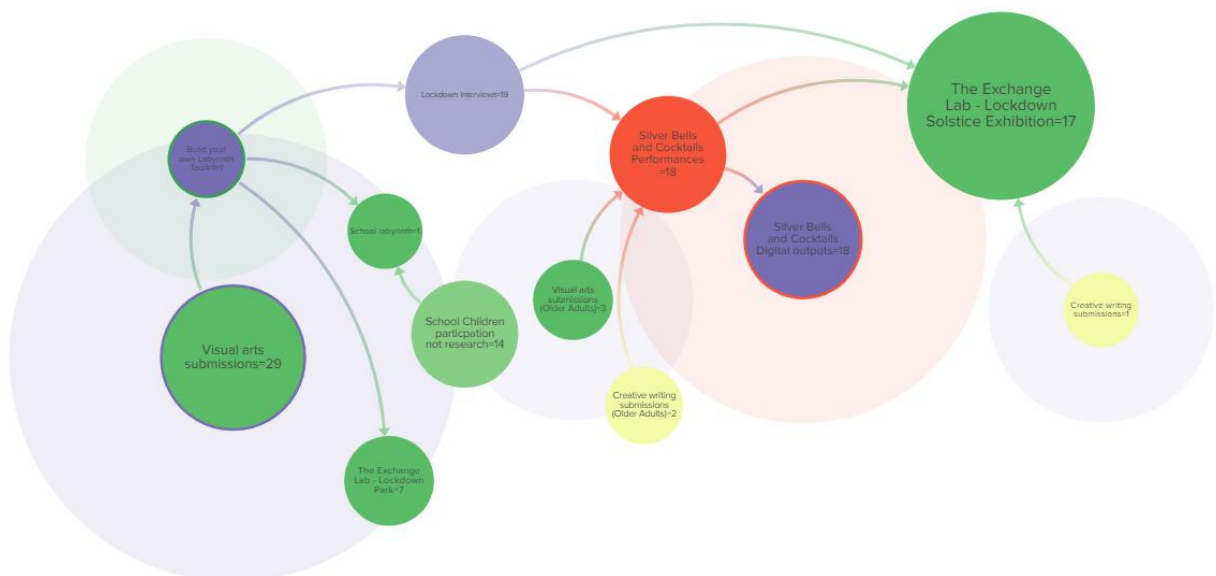
4.5.2 Phase 2 recruitment

The recruitment process for Phase 2 was challenging due to the implementation of a nationwide lockdown in the UK in March 2020. Since the majority of the population's interactions and encounters occurred online and practically everyone in the UK was improving their digital skills, digital methods were used to recruit participants. Shifting to engagement via a digital platform presented difficulties, as there were limitations on the participatory element of PAR. The types of discussions that establish a strong connection and ignite innovative thoughts, which frequently occur during informal interactions in a physical workshop, were noticeably lacking. The implementation of the new protocols and adherence to the health and safety rules proved to be a significant distraction for many professionals.

A digital Creative Labyrinth Toolkit was sent out with the purpose of recruiting research participants to engage in discussions regarding the use of arts and labyrinths amid a global pandemic. People were invited to investigate how the arts contributed to their health and wellbeing during this extraordinary period. They could construct their own labyrinths or contribute artworks that could be incorporated into a labyrinth exhibition once the restrictions were lifted. The toolkit was disseminated to more than 400 schools through email, and creative practitioners were also encouraged to provide information about their professional activities. Invitations were distributed through social media platforms such as Facebook and WhatsApp, as well as via direct emails to schools, artists, housing associations, and University networks. This approach recruited the highest number of participants (n = 32).

Figure 38: Build Your Own Labyrinth Toolkit title page
McNeill and Irving, 2020 Image by Loughlin, K 2019

A variety of arts-based methods were explored to support research engagement, including the collaborative creation of a solstice labyrinth in a nearby park with families. However, only individuals who already had an established relationship with the researcher (n = 5) took part in this activity.

Figure 39: Solstice Lockdown Labyrinth Sefton Park
Ryan-McNeill, 2020

4.6 Engagement

4.6.1 Levels of engagement

The arts engagement activities resulted in a significant increase in participation throughout phase one. However, in phase 2, the Covid pandemic and the measures imposed by the UK Government had a detrimental impact on the number of participants. Although a large number of people were contacted digitally, only a small percentage of them participated in the study. A mail merge was used to contact more than 600 schools. However, only fourteen schoolteachers downloaded the Labyrinth toolkit, and only one of them submitted photos of a co-designed labyrinth that had been installed. This reduced the efficacy of any analysis. Other schools indicated interest in joining in the project but were unable to allocate time for extracurricular activities due to the necessity to modify their teaching techniques to comply with the government's Covid pandemic requirements.

In phase 2, the participants who showed interest and engaged, were primarily those who already had a prior connection with the researcher. These links were established either during phase 1 (n = 6), through artist networks (n = 17), or university connections (n = 20). The level of participation in the research varied among individuals. For example, 20 creative practitioners provided artwork, 35 participated in semi-structured interviews, and 18 agreed to both. As a result of difficulties encountered in phase 2, it became necessary to modify the recruitment strategy in order to cater to the requirements of potential participants. After conducting online interviews with three experts who specialise in older individuals, it became evident that isolation has a negative effect on the well-being of our older population. Consequently, the research altered its focus to address the loneliness experienced by older adults due to the steps implemented to combat the spread of Covid-19. Numerous arts institutions promptly responded and devised innovative methods to involve the public, despite the difficulties encountered in 2020 and 2021. Based on this incentive, the research study was modified, and Arts Council England granted

funds to involve older individuals in the co-production of a COVID-safe theatre performance. The aim was to engage older adults, gather data (stories) about their experiences during lockdown and share this using ethnocomedy theatre. Initially, older adults were invited to write letters and share ways they were manging their wellbeing during the lockdowns. Posters were placed in Independent Living Schemes, only three letters were submitted out of the 500+ residents reached.

A new approach to engaging older adults emerged from interviews with older people specialists; telephone interviews proved to be more effective in this regard. Many participated because it alleviated their feelings of isolation. The housing association scheme managers recruited four older adults, and after the first four interviews, a snowball effect led to more older adults agreeing to participate (n = 14). In addition, five older adults shared art works as submissions. Traditional research methods (telephone/zoom interviews and online questionnaires) were the most effective ways to recruit participants during the lockdown periods in phase 2, but several interviewees (n = 39) engaged because they had the opportunity to have their stories or artworks included in a theatre performance or exhibition.

Figure 41: Letters from participants about life in Lockdown
Ryan-McNeill, 2020
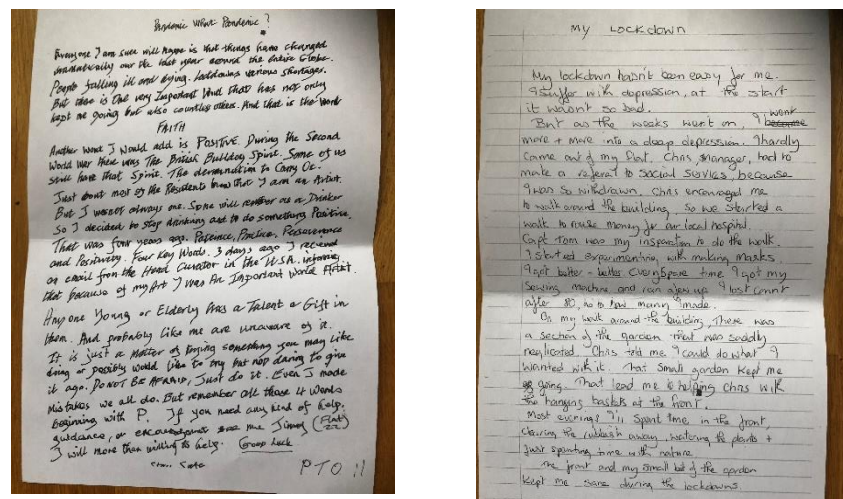
On several occasions, arts activities were cited by participants as a reason to engage and remain involved in the research. In some instances, participants engaged following a visit to an art exhibition or performance by taking part in an evaluation. Figure 39 demonstrates the cumulative number of participants attracted to engage

by arts-based activities: PAR 2 (*n* = 7), The Exchange Lab (*n* = 13), On Cloud 79 (*n* = 88, 82 evaluation + 6 artists), Schools Labyrinth (*n* = 2), stakeholder event (*n* = 12) a total of 125 participants. 74% of these participants were audience members who participated in evaluations and offered feedback. Figure 40 represents the number of participants engaged in phase 2.

Figure 42: No. of new participants with each arts-based activity phase
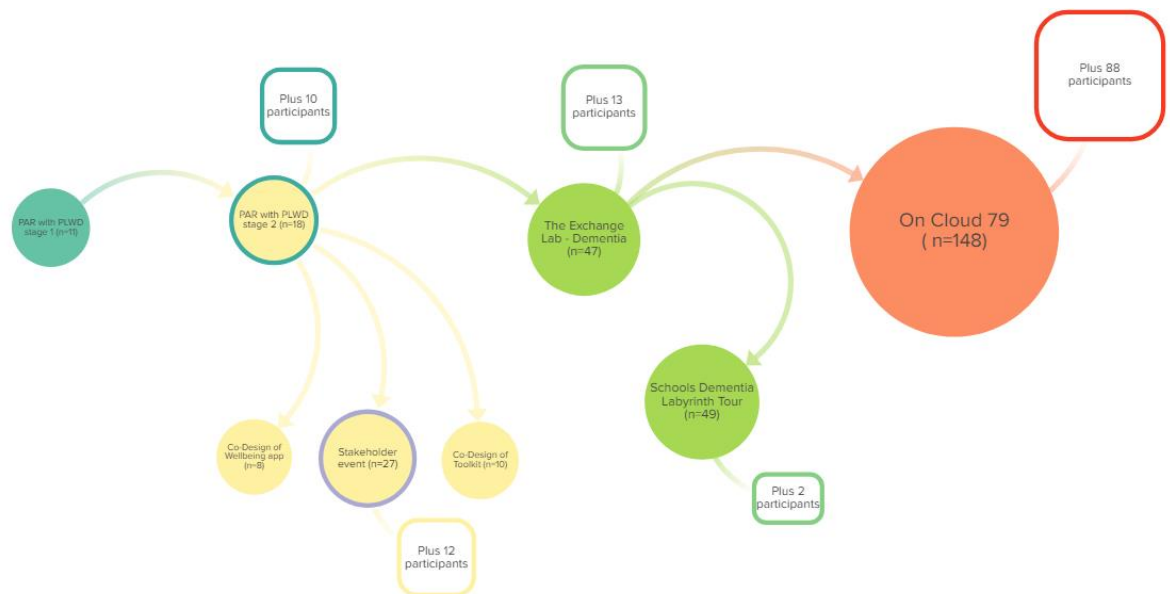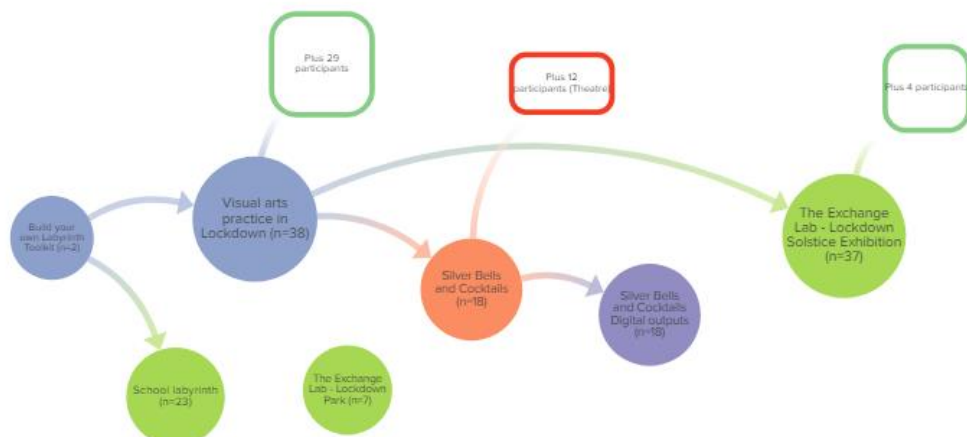*Ryan-McNeill, 2024 using Kumu. Available at: https://kumu.io/*

Figure 43: No. of new participants with each arts-based activity phase 2
Ryan-McNeill, 2024 using Kumu. Available at: https://kumu.io/

4.7 Quality of Engagement

In this section, the data analysis is presented and organised under the overarching themes of "Adaptation", "Sense of loss", and "Social isolation" and explores the key ingredients within the arts-based research approach that helped to address these concerns.

These three themes derived from concepts identified during the thematic analysis stage of the research. The initial concepts in phase 1 included: accessibility, advocating for active lives, pride in community and heritage, reminiscence, loss of identity, adapting to a diagnosis, benefit of digital tech and humour. In phase 2 the concepts included: lack of physical contact, importance of ritual, pride in city and environment, resilience, art as therapy, adapting to lockdown restrictions, loss of lives and community connections, digital tools, and humour.

The themes that appeared in both research phases and related to the arts engagement are discussed further. Quotes from participants are included to illustrate each of the overarching themes.

4.7.1 Adaptation

A challenging theme in phases 1 and 2 of the study was adaptation and need for change in response to a dementia diagnosis, or a global health pandemic. Humour resonated as a source of strength and coping strategy for stress, anxiety, or discomfort caused by the health context, in both participant groups.

4.7.2 Humour

A participant from the Labyrinth Exchange produced illustrations to portray the significant impact that his father's dementia had on their connection. Despite undergoing enormous changes, humour would nevertheless serve as a unifying force for them. He recounted how, following his father's passing, he depicted his father's progression through dementia in a collection of cartoons. He explained this was the only way he knew how to cope with his experience. He published his work to raise awareness and inspire others.

Participants living with dementia discussed how humour helped maintain relationships and acted as a coping strategy for carers. One carer talked about her father-in-law having a cheeky sense of humour which she likened to a 70s television sitcom.

...Caring for my in laws with dementia has been hard work but I find moments of joy in some of the funny situations. One day Dad (father-in-law) chased me round the coffee table, Benny Hill style, I could almost hear the Benny Hill theme tune in my head it made me giggle...(Phase 1 Labyrinth Exchange Interviewee)

They also spoke of how being playful and using humour reduced sensations of paranoia and agitation which one of the symptoms of her mother-in-law.
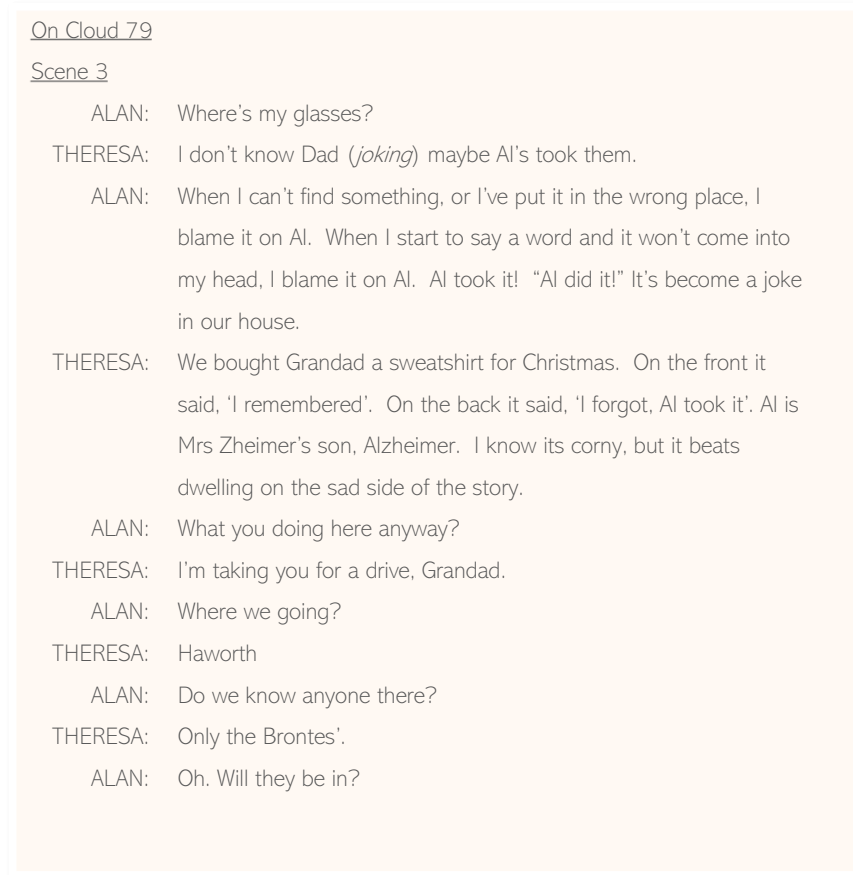
...Mum (mother-in-law) was different to Dad (father-in-law) her dementia affected her differently, she would get agitated quite easily and I knew she was developing symptoms when she couldn't remember how to make Lasagne any more. Whenever she got anxious or frightened Dad would jump up and take her in a dance hold, making her giggle...(The Labyrinth Exchange Interviewee Phase 1)

Other spoke about how humour was the one thing that would connect them with their loved ones, as the disease was progressing.

...Her sense of humour was the one thing that remains of her. She would light up a room when she walked in. She always had a twinkle in her eye...(PAR stage 1 and 2 participant Phase 1)

Several carers spoke of their relatives (PWD) as having twinkle in their eye in relation to their sense of humour and this was incorporated as a key theme in the theatre

Figure 46: Comedy data represented in 'On Cloud 79' theatre script

On Cloud 79
Scene 3

ALAN: Where's my glasses?

THERESA: I don't know Dad (*joking*) maybe Al's took them.

ALAN: When I can't find something, or I've put it in the wrong place, I blame it on Al. When I start to say a word and it won't come into my head, I blame it on Al. Al took it! "Al did it!" It's become a joke in our house.

THERESA: We bought Grandad a sweatshirt for Christmas. On the front it said, 'I remembered'. On the back it said, 'I forgot, Al took it'. Al is Mrs Zheimer's son, Alzheimer. I know its corny, but it beats dwelling on the sad side of the story.

ALAN: What you doing here anyway?

THERESA: I'm taking you for a drive, Grandad.

ALAN: Where we going?

THERESA: Haworth

ALAN: Do we know anyone there?

THERESA: Only the Brontes'.

ALAN: Oh. Will they be in?

In phase 2 one of the creative practitioners working with older adults via an online platform talked about how humour alleviated the stress of the covid lockdowns and helped to relax groups engaging in online creative activities.

… the (drama) activity gave them confidence to think about their experiences more positively…after a 6-week break, the group was relaxed and playful, even jovial at times. They were feeling a lot more comfortable and eager to get back to the drama activities and be creative… when the group were talking about difficulties or challenges it was approached with a bit more optimism… (Drama practitioner for older people interviewee phase 2)

An actor in the phase 2 Ethnocomedy, 'Silver Bells and Cocktails', also talk about drama games and improvisations providing much needed catharsis by offering a

comical view of the pandemic, this and the importance of human connection is described in her quote:

…It's been really important for us as performers to connect, within the guidelines of course…I've never been away from people this long ever. On our first day of rehearsals, we belly laughed, cried and laughed some more, it was joyful. You forget how good this) is for the soul. It's been as beneficial for us as it has been for the older people, we are performing to… (Ethnocomedy performer phase 2)

Figure 47: Actors during an outdoor rehearsal of Silver Bells and Cocktails
Ryan-McNeill, 2020

The need for a good sense of humour was recognised as a valuable life asset for participants in both research phases. The participants experience during the pandemic reflected what was happening globally as many resorted to creative activities and humour, evidenced by the outpouring of gags, memes, and funny videos on social media.

4.7.3 Relationships

Both research groups emphasised the influence of the health context on the quality of their relationships.

A person with dementia in PAR stage 2, expressed that when he and his wife was telling his friends about his condition, they made him feel as if he had acquired an extraordinary ability.

"I didn't realise that when I was diagnosed with dementia, I also got a superpower. When people heard that I had dementia they would direct the conversation to my wife. They would talk straight to her and blank me, I became invisible." (PWD PAR stage 2)

Participants talked about the impact of dementia on their family relationships, and how the memory loss and confusion can make communication difficult. A daughter talked about her relationship with her mother and how it affected their relationship:

"Ours roles have always been reversed. Mary has been sick for a long time I've cared for her since I was 8 years old. I have to call my mum Mary not mum. That's the best way for us to communicate otherwise she gets confused." (Carer PAR stage 1 and 2)

Several participants described the art activities as being supportive of relationships with family and friends. The statements below, are illustrations of improved communication and interactions due to the arts activities:

"Made Up to Meet Up is great. Everyone is really friendly, and we look forward to attending activities, being with other people who understand the difficulties faced with socialising for people who are living with dementia makes me feel more part of the community. My dad doesn't like modern art, but it has given us something to talk about. It's reminded us of how great Liverpool is." (Carer from PAR 1 and 2)

"Mary looks forward to coming for a whole week, it doesn't half improve her mood. It really gives us a break from being stuck in. When she's anxious she can be hard work, but when we get out and about, she's much better. We had a right laugh over the big doll (part of an exhibition) Mary'll tell you straight." (Carer from PAR 1 and 2)

For many of the older adults during phase 2, the most important relationships were with children and grandchildren, and one participant appreciated the value of theatre.

"It breaks my heart; my grandchildren are growing. I feel like I'm missing out. It's like they are going away from me." (Older adult lockdown interview)

"If I could I'd book a train to London, I'd go give my son a hug. I'm longing to hug him. I'm going to get upset now." (Older adult lockdown interview)

"I've tried using that zoomy thing on the i-pad my son got me but it's no use. Hey I've enjoyed all the theatre though isn't it amazing I've watched loads online – the big shows from London – what you can watch now online eh. Still you can't beat live theatre – that's what I say anyway." (Older adult lockdown interview)

4.7.4 Social isolation

During phase 1 it was evident that PWD were concerned about being misunderstood and becoming isolated. The concern from the co-researchers was that reduced social activity could result in the dementia journey progressing quickly and being less able to live independently.   Several of the participants spoke of the importance of remaining active following a diagnosis to manage their adaptation and psychosocial benefits. The importance of being social engaged and active was reiterated in several PAR stage 1 and 2 focus groups.

All of the older adults interviewed in phase 2 spoke of feeling lonely andisolated, even when they were trying to be upbeat you could hear the sadness in their voices. Some also spoke about the loss of physical contact.

"I'm not going to lie though – it's been tough – really tough -not seeing my kids and grandkids. I mean they've come to the front gate and we've chatted but nothing beats a good hug does it?"

In phase 1, participants were concerned about social isolation and the impact on their dementia.

"If you feel lonely and you get depressed any condition can deteriorate." (PWD PAR stage 1 and 2)

The discussions during the PAR focus groups steered towards the importance of social activities for PWD, some participants preferred arts and cultural activities to the usual offer for older adults. The research arts activities supported PLWD need to remain socially active:

"Jimmy goes to a centre and that is the best thing for him. It's really important to be stimulated. That's why we join this research group." (Carer from PAR stage 1 and 2)

"I would get involved in anything and everything - exactly that. Staying at home on your own then it's a rapid downhill slide. But this is great, I love art, its better than bingo" (PWD from PAR stage 1and 2)

Although the project did not intend to be therapeutic, participants' overwhelming response was that arts engagement created a space in which they found an opportunity to reflect on how living with dementia could impact their social lives or how the global pandemic was affecting their wellbeing. Comments about the isolation during phase 2 included worrying about others, and concerns about low mood and depression. Mostly interviewees would refer to other residents in the housing scheme than speak about their own loneliness.

"I'm quite an upbeat person but some of the others (residents) they liked the days out or going the Bingo. They'd arrange little trips out, but they can't do that now. Some of them aren't that mobile. They're just stuck in, withering away. It's sad really." (Older adult during lockdown)

Figure 48: Character portraying sadness and loss in Silver Bells and Cocktails Ryan-McNeill, 2020

One older adult even told us an interesting way he tried to alleviate the loneliness he felt.

"I just bought a teddy bear from the Asda. Sounds daft but I'll just put it on the couch. It won't be able to talk like it's just for company… You have to laugh don't yer. Still there are others far worse off than me." (Older adult during lockdown)

Participants in phase 2 described several ways of maintaining their wellbeing during the pandemic uncertainties, they spoke about exercising, and healthy eating:

"I keep myself busy. Usually some yoga or gentle exercise in the garden. Healthy eating is really important. We help out and look out for everyone in here. (Older adult during lockdown)*"*

Figure 49: Character depicting healthy approaches to wellbeing
Ryan-McNeill, 2020

Several creative practitioners spoke about the use of arts to explore their emotions and feelings during the first lockdown period. One fine art student used her practice to reflect on her experience of the lockdown measures:

"I wanted to explore the sense of isolation in the artwork I created during lockdown. I started out during the first lockdown totally shocked about the 2m distance - absolutely shocked. I had to create art to do with the imposed physical restriction. I felt like I didn't have much space – lack of freedom." (Student artist interviewed during lockdown).

One drama practitioner shared poems on Facebook to reflect on their experience of the lockdown restrictions and how they were affecting her and the community.

Figure 51: Extract from 'These Days of Strange' Poems by drama practitioner
Simms, P, 2029

I got to thinking about the
little ones
And thinking about
memories
When present meets the
future
And they look back
On these days of strange

Maybe
I thought
They wont see things that
way
At all
As normal is normal
And days just are what
they are
As they unfold
For brains
That are small

Like
Maybe some will look back
And say ...

Oh!!
We made cakes
And pies
And paper frogs
And played games
And grown-ups were there
Like
All the time
And then maybe
what seems like an age
To us
Adults
Will simply pass
Like a blink of an eye
And might even need a jog
Of the memory
To remind them

Time moves in mysterious
ways
In these days of strange

But then
A dark cloud appeared
In my not so small brain

Some homes could turn
into prisons
For some small brains
That fill up
With tears
And scars

I couldn't bear the
thoughts

I had to pick up a book
And stroke my cat

Later

We moved from my bed
And went outside
And looked up
At the moon

And we prayed...

Another drama practitioner described how using arts approaches online supported the processing and expression of emotions for the older adults she was working with.

…The drama activities helped the group discuss their experience of lockdown…it gave them a place to be social, a place to feel normal, valued, respected. An opportunity to express their feeling in whatever artform. Opportunity to use arts to explore emotions and feelings and help with processing that – a safe space where people came together, made them feel less isolated…(Drama Practitioner during lockdown)

One of the arts and health practitioner spoke of a resilience developed by people with mental health based on their experience which helped them cope during lockdown.

…People on furlough didn't know what to do with their time. They realised they had not considered their mental health before. People who have struggled with mental health had a resilience, especially artists and others could learn from that. Others without that resilience possible the first lockdown hit them hard…(Arts and Health Practitioner from UK during lockdown)

The data collected during lockdown revealed that a significant number of participants resorted to engaging in arts and crafts activities. This involvement in the arts was found to have a crucial impact on boosting their overall well-being. Practitioners working with older adults used creative techniques to enhance engagement and ease their anxieties. The artistic activities helped people in dealing with and regulating their emotions.

4.8 Arts as research dissemination

This section explores the audience reach of each arts-based dissemination method used and discusses the audience perception, including: the Labyrinth Exchange, Ethnocomedy drama performances, and stakeholder event with film presentation.

4.8.1 The Labyrinth Exchange

Figure 52: The Lost and Found Labyrinth Liverpool Biennial, Liverpool's Cathedral Ryan-McNeill, 2018

4.8.2 The Lost and Found (Dementia Labyrinth)

4.8.3 Audience analysis

The labyrinth exchange visual art installation had the largest audience reach (n = 2290) with 18 exhibition days. It was first exhibited in an open public pace outside the Open Eye Gallery in Liverpool, UK, as part of the Being Human Festival in October 2017 reaching 258 people (n = 258). It was also exhibited twice at the Royal Liverpool Hospital Dementia Conference 2018 (n = 53), 2019 (n = 45), at a Museum of Science and Industry Manchester Late night event (n = 320), at spent five days at Liverpool Anglican Cathedral for Liverpool Independents Biennial (n = 897). The largest audience figures correlated with the venue's footfall, i.e., Liverpool's Anglican Cathedral has 600,000 visitors per year. Working with schools as partners also increased audience reach. The labyrinth schools tour engaged 717 young people with challenging and complex information about dementia to raise awareness within the community.

4.8.4 Audience experience

Carers were the main contributors of text for the labyrinth postcards. They provided anecdotes, experiences, amusing incidents, memories, and sincere emotions

regarding their family member with dementia. The images, along with the participants' narratives, left a lasting impact and offered a detailed portrayal of the disease and its complexity. The inclusion of art in the Lost and Found labyrinth stimulated deep thought and self-reflection.

Several postcards were created as homage to family members or loved ones suffering from dementia. The venue where the Labyrinth Exchange was exhibited had an impact on the content of the postcard submitted. For example, the majority of the postcards composed within the Cathedral were usually dedicated to the memory of a deceased individual or featured encouraging messages for someone afflicted with dementia. The postcards' content reflected the expected behaviour in a religious building.

Figure 53: Labyrinth content postcards collected at the Liverpool's Cathedral Photographed by Ryan-McNeill, 2018
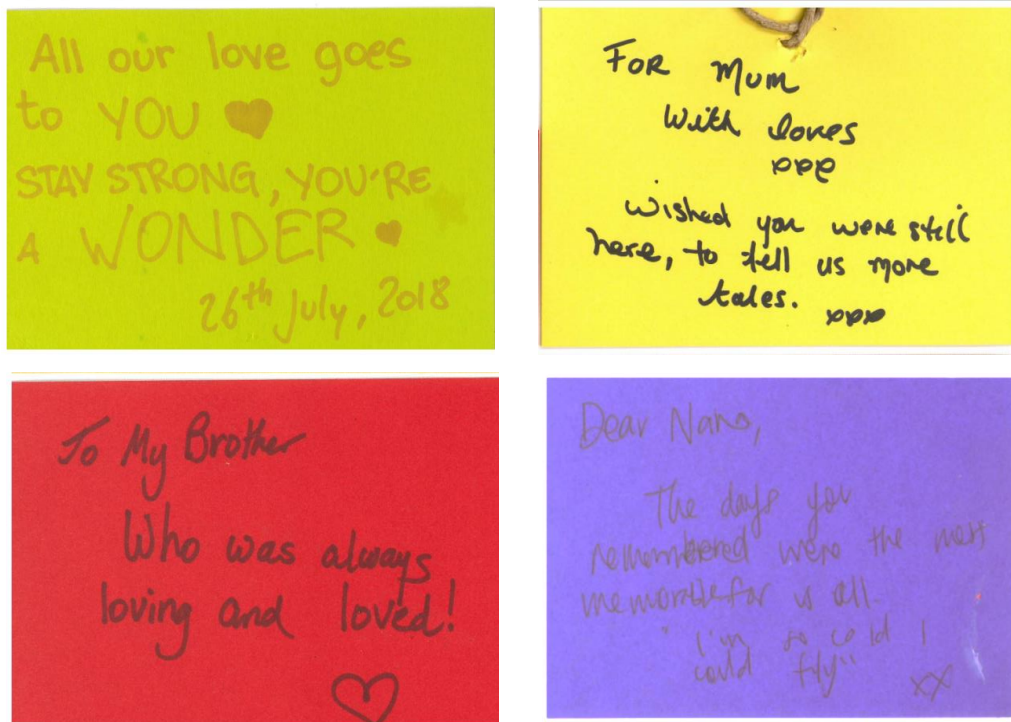
4.8.5 Evaluation of the Lost and Found (Dementia) Labyrinth

Members of the public were invited to provide feedback about their experience of the *Lost and Found Labyrinth* installation by writing comments and adding to an evaluation tree, designed by a carer living with dementia.

Figure 54: Positive Roots Evaluation Tree by carer of PWD
Welch, J, 2017 Photographed by Ryan-McNeill, 2018

The evaluation comments highlighted how interaction with the Lost and Found Labyrinth stirred recollections of departed loved ones. One participant found great solace in photographs of her father being 'joyful and beaming' while in the labyrinth. Feedback from others indicated that labyrinth art installations have the capacity to engage a broader audience by presenting thought-provoking content, serving as a reminder that individuals are not alone.

"Thought provoking"

"Wow melts my heart beautiful"

"The stories on the postcards are beautiful and sweet"

"Well done funny and profound"

"It was a nice experience"

"A reminder that no one is alone in the struggle – Let love light the way"

 (Quotes from audience members - Lost and Found Labyrinth installation – Open Eye Gallery 2017)

Comments from audiences in Spanish suggested that the labyrinth installation had the ability to crossed language barriers:

"Nuncate olvides de ti" – Never forget about you. (Audience member - Lost and Found Labyrinth Liverpool Independents Biennial - Anglican Cathedral 2018)

4.9 The Lockdown Labyrinth

4.9.1 Audience analysis

The lockdown labyrinth had several iterations, it began as a '*Rainbow Labyrinth'*, a home-schooling project to pilot and develop the Labyrinth Toolkit (*n* = 1).

Figure 56: The Rainbow Labyrinth, developed with children as a home-school activity Co-produced with young people. Photographed by Ryan-McNeill, 2018

'*The Park Solstice Labyrinth',* a co-produced park labyrinth with children and parents (*n* = 18). Finally, the Lockdown Labyrinth, which was a culmination of all the research gathered, featured in a covid safe outdoor exhibition in June 2020 reaching 53 people (*n* = 53).

Figure 58: The Lockdown Labyrinth Solstice Exhibition, Back Quarter Collective Chester Co-produced by exhibiting artists. Photographed by Ryan-McNeill, 2020

4.9.2 Audience experience

Fourteen audience members, who were artists also exhibiting, became participants by engaging with the labyrinth installation, recognising the context they began sharing their own experiences during lockdown. The aesthetic of the lockdown labyrinth took on a non-classical shape because the centre was 2 x 2-meter square representative of social distancing guidance and therefore was not representative of the labyrinth archetypal form. Fewer audience members walked the labyrinth than previous installations. The greatest engagement came from other exhibiting artists who discussed their own art practice during lockdown.

4.10 Ethnocomedy – Theatre-based dissemination

4.10.1 'On Cloud 79' - Ethnocomedy exploring themes of living well with dementia

4.10.2 Audience analysis

The ethnocomedy, 'On Cloud 79', had seven performances, six were live theatre and one was an exert broadcast on local radio (BBC Radio Merseyside). The radio has the largest audience with an estimated 147k listeners. The theatre performance collectively reached 435 people, these figures are broken down per venue: twice at Laughterhouse Comedy Club 2017 ($n = 70$), 2018 ($n = 89$), twice at the Royal Liverpool Hospital Dementia Conference 2018 ($n = 93$), 2019 ($n = 63$), open dress rehearsal for University staff ($n = 11$).

Figure 59: Image from On Cloud 79 in rehearsals September Loughlin, K 2018

The Ethnocomedy theatre piece helped to reach a different audience from that attracted by the Exchange Labyrinth. Theatre enabled the research to be communicated across disciplinary and professional boundaries and authentic stories resonated with people's experiences dementia (predominantly from a caring perspective) and at conferences the performance assisted discussions which challenged the dominant narrative of fear of a diagnosis.

4.10.3 Audience impact

Northwest Coast Strategic Clinical Network gathered feedback from the audience at the dementia conference 2018. 82 of the 93 audience members completed the evaluation. This data was anonymised, no individuals were identifiable, and therefore the data did not fall within the scope of the GDPR. Conference attendees used a Likert scale of 5 (Poor – Fair – Good – Very good – Excellent). Overall, the performance received 4.9 out of 5 and a standing ovation. This was collated and analysed with feedback gathered at theatre performances (*n*=15). The comments provided a clear indication as to why the audience scored the performance so highly. Primarily audiences found the 'On Cloud 79' performance to be an authentic representation of living with dementia.

"Dementia portrayed so accurately, very moving and emotional. Blown away by the performance!" / "Brilliant acting and story lines of getting dementia across, and how hard it must be for individual's families living with dementia. Amazing" / "Fun. Enthusiastic. Good act that portrays dementia from a patient's point of view." / "Amazing performance. Such an intimate and heart-warming perceptive." / "Very accurate and highlights the funny side. Amazing." (Ethnocomedy audience members at Dementia Conference 2018).

Some feedback suggested that the performance captured different perspectives and diverse experiences of living with dementia.

"Amazing. So engaging and very good how they managed to reflect multiple different stories and the good and the bad." / "Portrays the effects of dementia well, emphasising different cases." / "Performance was a perfect way to express dementia

from perspectives of different people." (Ethnocomedy audience members at Dementia Conference 2018).

Feedback also suggested that the use of humour was effective and supported the authenticity.

"Brilliant, very relatable and eye opening. An emotional performance, yet funny." / "Thoroughly enjoyed on Cloud 79 - some very accurate acting with some humour as well. Very moving." (Ethnocomedy audience members at Dementia Conference 2018).

"Entertaining - made me aware of symptoms of Dementia." (Ethnocomedy audience members at Dementia Conference 2018).

4.10.4 '*Silver* Bells *and Cocktails'* – a life in lockdown (covid-safe performances)

4.10.5 Audience figures

The ethnocomedy, 'Silver Bells and Cocktails', about a life in lockdown had 13 covid-safe outdoor theatre performances, collectively reaching 310 people (*n* = 310).

Figure 58: Silver Bells and Cocktails Halton Housing July 2020
Ryan-McNeill, 2020

In phase 2 there were two digital performances, one online conference (n = 53), You Tube videos (n = 79) and a exert broadcast on local radio (BBC Radio Merseyside) (n = 257k). Once again, the radio broadcast had the largest audience with radio figures being greater during the pandemic.

Figure 59: Performance of Silver Bells and Cocktails with residents watching from their balcony (the 'Royal Box' as it was comically referred to)
Ryan-McNeill, 2020

4.10.6 Audience impact

To address the emotional distress experienced by older folks during lockdown, a graphic designer was commissioned to design a poster for the performance. The poster was displayed at each of the Independent Living Schemes for individuals over the age of 55.

The poster was superfluous to the marketing campaign since the events were provided free of charge at each housing scheme. Nevertheless, scheme managers indicated that the poster elicited enthusiasm among the residents. Several scheme managers enhanced the experience of the theatre performance by providing fancy dress accessories to create a festive atmosphere.

Figure 61: Residents in courtyard waiting for performance July 2021
Ryan-McNeill, 2021

Several scheme managers reported how the '*Silver Bells and Cocktails'* performance created a positive atmosphere and increased sense of community among the

residents. The comments also suggest that the performance authentically represented the lived experience of their residents.

"You and the team have been fantastic, and the feedback has been amazing – please pass on my sincere thanks to all the group. You nailed it."

"Thank you so much for the performance the customers really enjoyed, and it lifted them greatly after such a challenging year. The performers got it so right …please pass on our thanks and good luck to you all."

For some it was their first social interaction in over 12months. One performance had to be delayed because a resident was waiting for her support worker so she could attend. We learnt that she hadn't been out of her flat for 15 months. When the resident arrived in her wheelchair, she punched the air and shouted, *'Freedom!'* Audiences reported that the theatre performances brought enjoyment, entertainment and made them feel valued and listened to, those who had shared stories watch the show with pride and even mouthed the words when it came to their narratives.

4.11 Stakeholder event

The stakeholder event effectively engaged a wide range of participants to promote and obtain varied perspectives on enhancing involvement in the arts for the purpose implementing social prescribing across Liverpool. The stakeholder event successfully attracted new partners who could offer assistance in implementing the arts and culture social group. A total of 46 participants representing various sectors including arts and culture organisations, health and social care workers, artists, researchers, voluntary organisations, and health commissioners were in attendance. The event was co-produced with PLWD and engaged a total of 17 additional research participants. (Arts Organisations *n* = 4, creative practitioners *n* = 2, Health and Social Care professionals *n* = 5, Health commissioner *n* = 1, Local Authority *n* = 2, academic researchers *n* = 2 voluntary sector *n* = 1). The film showed the benefits of engaging in arts and culture as part of a social group and enabled PWD who were unable to attend to still have a voice.

Figure 62: Made Up to Meet Up Film created by John Burton using logo designed by MADM Burton, J, 2019

You Tube: https://www.youtube.com/watch?v=LEbZJEmv8dw

4.12 Dissemination beyond the study

Research activities within this study had national and international reach with creative outputs featuring in several arts and research festivals (Liverpool Independents Biennial, Being Human Festival of Humanities and Late at the Museum) and publications:

'The Labyrinth Exchange', has been recognised by The Association of Arte Útil and included in an international archive of replicable useful art projects.

Figure 63: The Labyrinth Exchange in the Arte Útil archive
Ryan-McNeill, 2018 Available at: https://www.arte-util.org/projects/the-labyrinth-exchange/
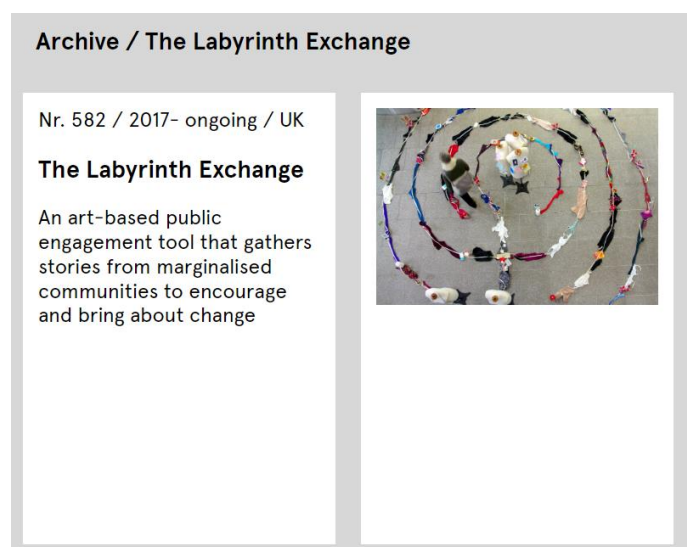
The Lockdown Labyrinth project was featured in a TCCE (The Cultural Capital Exchange) blog and publication June 2020.

Figure 64: Doing Arts Research in a Pandemic- featuring the Lockdown Labyrinth project Ryan-McNeill, 2020 Available at: https://tcce.co.uk/wp-content/uploads/2020/06/Doing-Arts-Research-in-a-Pandemic-final-edit.pdf

The development of a '*Build your own labyrinth*' toolkit contributed to supporting educators and home schoolers during lockdown and the '*Made up to Meet up*' Social Arts Group model will be further tested in rural areas; toolkits will be distributed to social prescribing link workers and contribute to supporting the social prescribing infrastructure 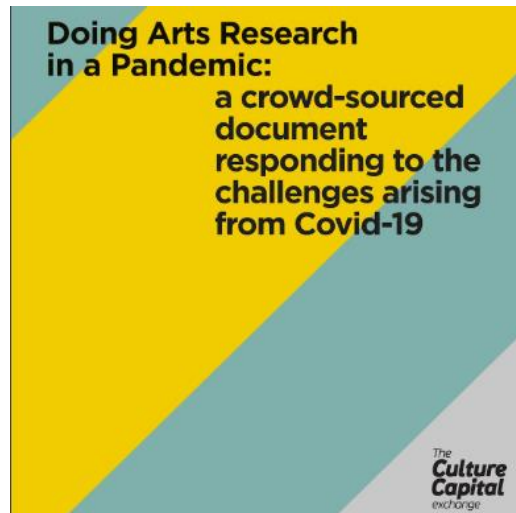for creative health initiatives across the UK. A poster for the toolkit is being presented at the 5th International Social Prescribing Conference, London June 2025.

4.13 Summary

The findings indicate that ABHR acts as a motivation for patients to engage in research, it offers flexibility to address issues related to participation and can significantly improve the experience of participants by offering immediate psychosocial benefits to patients.

The arts-based dissemination approaches were particularly effective at communicating complex or sensitive topics in a way that a target audience can relate to. The labyrinth Exchange provided a mindful space where assumptions can be challenged and explored, the Ethnocomedy theatre was especially helpful in shaping otherwise dry, formal prose into something people can easily engage with, and the

co-created film effectively reached stakeholders prompting action with the commissioning the Made up to Meet up toolkit to support social prescribing across Liverpool.

ABHR was also successful in engaging people outside of academia with important information about living well with dementia.

Figure 65: Illustrators adaptation of PAR focus group photo for the Made up to Meet up Toolkit Stables, A, 2021

CHAPTER FIVE -   Discussion

"Art is not a mirror

held up to reality,

but a hammer

with which to shape it."

- Berthold Brecht

Chapter Five – Discussion

5.1 Introduction

These findings add a new level of understanding to ABHR in relation to participation, quality of engagement and audience reach. The findings confirm earlier analyses of the benefits of ABHR and its ability to increase participation and improve the experience of research engagement. They also offer new insights about the use of arts approaches with research participants, and outline the key ingredients revealed in this study for ABHR to encourage psychosocial benefits for participants.

This study investigated a variety of arts-based approaches as innovative tools for public engagement in health research. The findings showed that both visual and performing arts are powerful and effective tools for increasing participation, raising awareness, and engaging members of the public in discussions relating to health conditions that are morally complex, emotionally charged, and controversial.

The literature review summarised the empirical research on the burgeoning area of ABHR, it highlighted possibilities for advancement while acknowledging the limitations and obstacles of the distinctive arts-based methodologies. It also illustrates the multifaceted character of ABHR, which can often be confusing and is commonly misinterpreted by professionals and academics working in this field from both arts and health sectors.

This study acknowledges the tension between the varied arts-based methodologies that sit within the rigorous demands of health research. A comprehensive narrative that provides suitable guidance and a rich contextual understanding is required to bring ABHR into the mainstream. This discussion presents a framework that effectively captures the fundamental essence of the participatory arts-based research used in this practice-based study. It provides a clear and simple map that will enable arts-based health researchers from both arts and health disciplines to compare interventions, capture their outcomes and further develop best practice.

5.2 Visualising data

The researcher found that using unique diagrams and graphics allowed for a more thorough review of the data, leading to fresh perspectives that helped identify anomalies. As discussed in the introduction, Leonardo da Vinci and Santiago Ramón y Cajal, two early medical painters, utilised their remarkable creative ability to reveal medical aspects that could have otherwise been overlooked. This discovery is consistent with Nguyen's personal experience, in which her artistic approach involved a meticulous and perceptive analysis of the material, uncovering deficiencies in the research (Nguyen, 2018). While it is commonly believed that visualising complex data can effectively convey information, there is limited knowledge about how readers perceive the visual narrative. Although this study found that systematic mapping techniques are useful at illustrating patterns and connections, further research is needed to determine how well this is perceived. The use of visual data is of great significance in the health sector due to the active promotion by NHS England to use data in decision-making, planning, contracting, and monitoring of primary care services (Jager et al, 2023). Incorporating this into the patient narrative is vital as the NHS transitions to a data-oriented approach for tailoring treatment and care according to the patient's need (Health Education England, 2021). Lapum suggests that with the NHS in crisis this presents an opportunity for ABHR (Lapum, 2018). The use of arts as a research method could increase public and patient involvement in health research but the discourse around PPI tends to focus on co-production methods and arts-based approaches rarely feature within this discussion. A recent article recognises the strengths of arts-based PPI methods, especially for adults, kids, and people with language and memory impairments. A common misperception regarding the use of creative approaches is that they necessitate significant amounts of time, financial resources, and effort, and are limited to specific patient groups (Phillips et al., 2024). This research demonstrates that arts-based health study methods can been used in a wide range of health context, showing that they can be used successfully with almost any patient group.

5.3 Participation

Understanding the efficacy of arts-based approaches in health research to enhance patient involvement is dependent on a deeper comprehension of ABHR participant motivations. The scarcity of research on this topic, limits our understanding of how ABHR attracts patients and public to engage with a health research study. The findings in this research provided some insight into the factors that draw people to ABHR. Participants volunteered their reasons for participating with the study during PAR focus groups, and it is evident that they were motivated by the social aspect as well as the arts activities.

The participation figures suggest that arts activities may give rise to participant numbers with the largest number of participants recorded for the On Cloud 79 ethnocomedy theatre activity in phase 1. This is a result of the cumulative effective of PAR and the number of participants engaged during the previous arts-based research activities. A similar approach was used by Lim et al to engage 5689 members of the community (66% participation by 8260 audience members) as part of a co-produced Cambodian drama using caricatures for comic value (Lim et al, 2017). A team of professional drama practitioners worked with village leaders and provincial health authorities to incorporate key messages about preventing Malaria.

The role of professional artists in ABHR has been questioned in the literature with regards to their efficacy and impact on the authenticity of the study (Bartlett, 2014). Where studies describe an effective relationship between patient and artists these use a combination of participatory action research principles within the art method (Wang et al, 2000; Govender et al., 2017). However, the role of artists in ABHR, who do not have lived experience relating to the health context, requires careful consideration to ensure the group dynamic and power balance remains equals between all members of the group.

Seventy percent of the participants actively engaged in a variety of arts-based research activities. Discussions during these activities indicated an enjoyment of the research process and participants valued psychosocial benefits. The combination of participatory action research and arts-based research practice enabled the collection of diverse data from multiple sources. The thematic analysis, enhanced by the artistic

process (curation of labyrinth art installations and development of theatre plays), helped merge multiple perspectives into a cohesive message for the creative outputs. When Govender et al. organised a community dialogue in their South African HIV Prep public health art-based PAR study they brought together different stakeholders to establish a collective consensus (Govender et al., 2017). In this study, the data acquired from each arts-based PAR activity was examined collectively to inform and guide the next iteration or cycle of the study. Multiple stories authenticated the data and audiences with lived experience of the health context validated the merging of micro narratives into a meta narrative, because of this iterative cyclical approach. Combining participatory action research with arts allows for an ongoing conversation and a deeper understanding of the complicated, varied, and changing aspects of the patients' lived experience. Ideally this knowledge could be used to improve the way health care is provided.

Essentially, most research activities were preplanned, but two of the co-design activities were carried out in response to the developing data narrative (2 x co-design activities: Made up to Meet up & Dementia Connects). Wang (2000) and Perez et al. (2016) emphasise the advantages of employing a flexible participatory research approach in their photovoice studies. Having this adaptability increased engagement with a wider range of stakeholders and provided opportunities to capitalise on funding and partnerships (such as the National Lottery, Higher Education Institutions, regional and national festivals). Additionally, this implied that participants played a crucial role in shaping the iterative research activity. Roger et al (2018) examined the advantages of acquiring a deeper understanding of the patient experience through the use of a photovoice and by engaging patients in the early stages of the research process to determine the primary concerns of individuals with Parkinson's disease. The inclusion of patients in the planning and design of a research study is uncommon, this is partly due to outlining the research methods and design in a research ethics application prior to engaging participants. The ethical approval process states that you must wait for ethical approval before approaching participants in research conducted in the UK. This is particularly relevant for research involving individuals who have used NHS and adult social care services in the past or present. To obtain ethical approval, researchers must use the Integrated Research Application System

(IRAS). Recent advancements in Public and Patient Involvement and Engagement have prompted researchers to actively involve patient groups, service users, or specific audiences in health research. To facilitate this, various minor grant schemes have been established to provide financial support. Public advisory programmes with similar objectives have been established by regional health research teams.

5.4 Engagement

The aim of this research study was to ensure that the selected methods would offer immediate benefits to the patients and public involved. Feedback from participants during the research phases indicates that this goal was achieved. The study participants reported several psychosocial benefits, such as enhanced social engagement, positive impact on relationships, and improved wellbeing. Unlike the study conducted by Wimpenny and Savin-Baden (2014), this study did not use the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) to evaluate participants' well-being, it was never the intention to measure participants wellbeing. Nonetheless, wellbeing has been discussed and self-reported benefits indicate the effect of ABHR on participant wellbeing. Research methods that offer psychosocial benefits to public and patients should be considered, just like McIntyre and Cole's theatre-based dementia study where they incorporated a framework of 'Loving Research' based on Kitwood's person-centred care approach to ensure their research was person centred (McIntyre and Cole 2008).

5.5 Quality of Audience Experience

5.5.1 Content

The use of diverse methodologies for data collection resulted in a wide range of narratives. The PAR focus groups primarily discussed the firsthand experience of those living with dementia. The interviews and labyrinth approaches mostly gathered data from carers, offering insights on the challenging behaviours displayed by PWD. The contents of the labyrinth may have had an impact on the additional narratives and information that were gathered during public exhibits. The data collection methodology had a cumulative impact as data accumulated at each iterative stage of the study process and through the use of artistic methodologies.

5.5.2 Authenticity

Delivering several iterations of the labyrinth in both phase 1 and 2, help us reach wider audiences and gather many additional stories which increased confidence in the authenticity of the data, this approach provided us with a rich data source to analyse and develop into a script for a theatre performance.

Both ethnocomedy theatre performances helped audiences to recognise themselves and see a different perspective from their own. Risks were taken to tell truths resulting in authentic recognisable voices. One of the aims of the theatre-based health research was to remind audiences that they were not alone. There were several moments when audience members genuinely conversed with the characters and actors had to improvise as audience members sparked up conversations with their characters.

5.5.3 Comedy

Ethnocomedy theatre used performance to effectively evoke emotional responses from audiences. The performance attempted to highlight the profound themes uncovered by Thematic Analysis, including the experience, enjoyment of life, grief, relationships, and reminiscence. By eliciting laughter from the audience, we cultivated a sense of empathy towards the characters and provided an opportunity for contemplation about their own lived experience.

5.6 Challenges

5.6.1 People with dementia as performers

It was difficult to include people with dementia as performers in the ethnocomedy. The research project did not provide sufficient time frames to train and incorporate PWD as performers. McIntyre and Cole acknowledge the same problem (McIntyre and Cole, 2014). However, it is important to note that this decision to use professional actors was by no means a reflection of the capabilities of PWD in the group. The objective of the theatrical production was to effectively communicate a research message on living well with dementia to a wide audience. Consequently, professional actors were selected to perform in live shows. Whenever feasible, individuals with live experience were incorporated into the performance. 60% of the

creative team for the theatre production had personal experience with dementia. Lapum also explores the collaboration with an interdisciplinary team to guarantee thorough analysis and sensitivity to the nature of knowledge throughout the process (Lapum, 2012).

5.7 Art-based dissemination

Arts helped to reach wider audiences and authentically represent the lived experience of patients to influence policymakers and service providers. The arts activities helped to give people validation in their experience, something they had not encountered elsewhere. The actors discussed how important connection is within live performance. Sharing an experience with live actors and live audience members is not only valuable, but also necessary for human connection.

It is important to note that not all distribution efforts need to target a big number of people, but rather focus on reaching the appropriate individuals. Depending on the study objectives, there are instances where it is equally crucial to raise awareness among policy makers as it is to communicate a health message to communities. The presence of commissioners and decision makers in the stakeholder event had a significant influence on future development and strategy. Wang's study involving homeless individuals showcased the advantages of involving policy and decision makers. Although it did not succeed in persuading them to alter their plans and construct the new $3 million accommodation nearer to the workplace of the users, it did prompt board members, planners, community members, and community leaders to reconsider the issues from the standpoint of the homeless. (Wang et al., 2000)

5.8 Media

Creating a short film with PWD proved to be highly impactful, as PWD were not always able to participate in stakeholder events. The video allowed them to have a prominent role in further discussions. It also allowed PWD to effectively communicate even when they may have difficulty articulating their experiences. In addition to the video footage, we also emphasised the presence of PLWD at events. Video images from research interviews were used but again researchers appreciated that this is not the same as connecting face-to-face with someone living with

dementia (Mitchell et al., 2006). Bartlett's video garnered a total of 3,500 viewers on YouTube, in addition to the number of views it received at the festivals where her study was showcased (Bartlett, 2015).

5.9 Participatory ABHR with benefits – The key ingredients

The findings contributed to an understanding of the key ingredients that facilitated psychosocial benefits for participants in a participatory ABHR process. This provided a framework of six principles, accessibility, creating a safe space, creative flexibility, social connectivity, common cause of helping others, and enjoyment. These principles are underpinned by the values of participatory action research, which have proven effective in ABHR, these include the core attributes of photovoice which encompass equality, empowerment, and social change.

The key ingredients within this framework will enable arts-based health researchers to achieve high-quality projects that have the potential to improve participants' health and well-being throughout the research process. All ABHR should apply these framework principles to optimise participant experience and health outcomes during the research process.

Figure 66: The key ingredients for supporting psychosocial benefits for participants in participatory ABHR
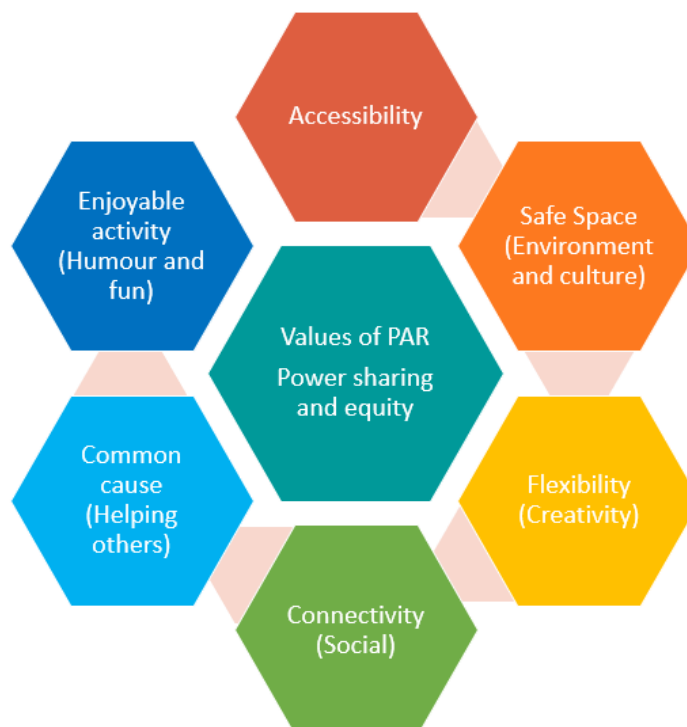
The six principles are discussed further to illustrate the key ingredients of the ABHR framework presented. This framework offers a pathway to promote best practice and enable comparisons of various arts interventions, potentially leading to the acknowledgement of arts-based research as a valid and effective method in health.

5.9.1 Accessibility

Research activities must be carefully designed and tailored to individuals in order to gain new knowledge about their lived experience in health conditions and services. A significant portion of the discussion regarding accessibility in research focuses on people with disabilities. However, to tackle health inequalities, it is crucial to also address the barriers faced by disadvantaged communities, and actively promote their participation and inclusion in the data narrative. PAR researchers universally acknowledge the significance of ensuring research activities are accessible and inclusive. This study examined the accessibility of research activities within an arts context. The participants discussions around accessibility of the venues we visited are discussed in Chapter four.

5.9.2 Safe space (Environment and Culture)

This principle addresses the creation of safe environments and spaces that enable participants to speak openly and honestly. Creating safer spaces for participants to talk about their experiences led to genuine reflections and a deeper understanding of the lived experience of the health condition. Consideration must also be given to the culture established within the group. Participants valued their inclusion in a group with shared lived experiences. Being with others who experienced similar issues provided comfort and support. During phase 2, significant emphasis was placed on ensuring that all activities adhered to Covid safety protocols and complied with government safety guidelines.

It is also important to develop a shared agreement of engagement, where all participants, researchers, artists, and organisations, irrespective of backgrounds, collectively agree the ground rules. Culture, language, and neurodiversity are some of the reasons why people may understand or act on guidelines differently but within the research group we agreed to be respectful, kind and mindful of language. Further approaches to this within this research study are discussed in Chapter three.

5.9.3 Flexibility (Creativity)

Participatory ABH research activities should be conducted using a flexible approach. Ideally in PAR activities are co-designed from the beginning with participants or modified to ensure effective engagement. In contrast to other ABHR studies, multiple art forms were adopted throughout the research stages of this study, and these were selected based on the strengths, skills and talents within the research group membership. Audiences also engaged as research participants and offered new data within the participatory arts-based dissemination approaches.

Benefits of the iterative process were apparent throughout this research study. people with lived experience, artists, creative practitioners and health professionals, established an effective "co-producing relationship" that refined and redirected the data throughout the research process. Where possible we acted upon participants needs as they arose within the iterative research process. The adaptations to the research plan have been discussed earlier in this chapter and is illustrated in Figure 29: Research activity timeline.

5.9.4 Connectivity (Social interactions)

Meaningfully connecting with others is critical to the well-being of individuals. The use of participatory arts-based methods facilitated the integration of individuals, resulting in the merging of varied perspectives and fostering empathy and cohesion within the study group. Participants in Phase 1 noted that being with others who had similar health issues was a beneficial aspect of the group. Pratt et al. (2023) investigate the person-centred research principle of connectivity. This concept aims to empower research participants by allowing them to communicate and perhaps elaborate on their experiences through the way interactions are performed, with attention given to factors such as place, time, and human connection (Pratt et al., 2023). The arts activity evoked reminiscence as the participants spoke about their lives past and present, this contributed to regaining a clear sense of personal identity and group bonding. During phase 2, participants expressed a strong desire for human connection. The use of artistic approaches served as a reminder that others were facing similar circumstances, and the theatre performances fostered a sense of connection among everyone involved.

5.9.5 Common cause (Helping others)

The research findings demonstrated that participants were enthusiastic about promoting awareness of living a fulfilling life with dementia in order to eliminate the negative stereotypes and stigma associated with a dementia diagnosis. In both phases of this study, having a common goal (living with dementia or maintaining a healthy wellbeing during a global pandemic), which everyone could agree on, effectively drew people together. It gave differing parties some sense of common identity and purpose. This served as a substantial catalyst and source of resilience throughout the research process. In studies by Perez et al., 2016 and Bartlett, 2015, the participants cooperated to advocate and address a shared difficulty, while also establishing peer support systems alongside the research objectives. Facilitating change by doing research and sharing knowledge is anticipated to be achieved through the collection and distribution of information. The fundamental principles of participatory ABHR are aligned with the goals of improving society, establishing a harmony with the participants' motivations for engagement.

5.9.6 Enjoyable activity (Humour and fun)

In phase 1 of the study humour enabled carers and PWD to connect, often in the face of considerable challenge. Participants expressed how laughter helped those in caring roles recognise PWD can remain active partners in their close relationships, rather than passive recipients of care. A systematic review of positive lived experiences in dementia confirmed that humour is a salient and meaningful aspect of people's attempts to cope positively (Wolverson et al., 2016). Liptak et al (2014) found that humour, silliness, and sarcasm helped in focus groups of people with mild cognitive impairment and Alzheimer's disease when commenting about the difficulties in dementia (Liptak, 2014). As the research and this study's findings suggest people with dementia can engage in humour and actively use it as a coping mechanism despite cognitive impairments. During phase 2 humour was also recognised as a copy strategy and participants hugely appreciated being given the space and opportunity to laugh.

This study has evidenced that the enjoyable and fun aspect of the arts approach was a motivation for engagement and the playful quality of the creative process led to

greater insights. According to Phillips and colleagues' review of creative methods in PPI, '*Individuals are permitted and encouraged to explore a creative self, which can lead to the exploration of new ideas and an overall increased enjoyment of the process*' (Phillips et al., 2024). The use of arts has undoubtedly been recognised with arts-based health and hospital arts programmes for children and young people but there need not be an age limit on creativity and being playful.

In this framework, the latter key ingredients relate to the 5 ways to wellbeing (Aked et al, 2008) and could explain why the group reported psychosocial benefits. The principles outlined in the framework are interrelated and collectively form the essential components for effective participatory ABHR. For example, the provision of enjoyable and accessible arts activities increased social connectivity among the research participants. Equally, the flexibility inherent in a creative approach transformed the research culture into one that was inclusive, helping to facilitate an authentic collaborative partnership with participants and propelled the research into action, which is essential to PAR.

Person-centred approaches to practice recognise the global call to humanise healthcare, where people are valued, and their preferences and needs are respected (WHO, 2015). This study did not establish that any arts approach is better suited to specific project aims, situations or audiences than others: choosing the best approach to use is context specific. However, the findings revealed through the data analysis provide us with some insight into the principal characteristics of participatory arts health research that could be developed into a quality framework for ABHR to ensure successful engagement of patients.

"Art is not a mirror

held up to reality,

but a hammer

with which to shape it."

\- Berthold Brecht

Figure 67: Performers singing during a Silver Bells and Cocktails theatre show
Ryan-McNeill, 2020

CHAPTER SIX -   Conclusion

Chapter Six: Conclusion

This thesis study has summarised, reviewed, and evaluated the published literature, considering the benefits and implications of arts-based activities for engaging patients and the public in health research. The review demonstrated that all ABHR papers, spanning 40 years, observed some form of social, relational, psychological/cognitive, or emotional health-based benefit(s) of participatory arts activities for research participants. This conclusion reflects on the research process and findings, and what emerges from them may have implications beyond the PhD project itself.

In terms of the study design, the chosen methodology successfully addressed the research questions, and the arts methods provided the platform to meet the needs of the research groups while exploring the efficacy of ABHR. Employing an iterative design and grounding art-based methods in a participatory action research model proved to be a favourable combination, as it allowed for unexpected discoveries and the flexibility to address them collectively. The researcher's absolute participation allowed for immersion and absorption, enabling a comprehensive understanding of the participant's experience. Phase 1's longevity and the use of several arts' engagement platforms facilitated the collection of substantial quantities of data, enabling the production of creative outputs with authentic content. New data emerged during arts-based iterations in each phase of the project, offering validation and providing a deeper understanding of the meta-narrative that emerged from the collection of individual micro-narratives.

This research study was an attempt to investigate three research questions:

a) What are the benefits of participatory arts-based research methods?
The arts-based methods aimed to promote active and effective engagement, facilitate fair and honest collaboration, and generate authentic artworks for dissemination. The participatory ABHR initiatives built trusting relationships between the participants and the research facilitator; they also helped alleviate some of the participants' concerns around their health conditions. Additional benefits included

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the cultivation of interpersonal skills such as confidence, empathy, and teamwork, which strengthened social relationships throughout the research process.

Researchers widely recognise the effectiveness of arts-based techniques for eliciting empathic responses and fostering a connection to patients' experiences. For participants, having both a voice and the freedom to discuss issues and concerns about their lived experiences beyond the research questions proved to be beneficial. ABHR enhanced patients' understanding of their daily lives and increased knowledge among health system commissioners and policymakers. Participatory ABHR methods have the potential to dismantle the obstacles that exist between academic institutions, healthcare settings, and communities.

b) Which art-based research methods in health increase engagement and help us gain a better understanding of the lived experiences of the public and patients?
Selecting the research methodology was a crucial step in ensuring the success of a research project, and it involved defining the problem, reviewing existing literature, and understanding the philosophical approach. When embarking on a research project, often the intention is to identify facts through an investigation to help solve a problem or deal with a situation. In health research, the aim is to generate new knowledge and improve patients' lives. The research group collectively chose the arts-based methods for this study, taking into account their skills and experiences. The creative approaches provided patients' psychosocial benefits during the research process.

In Chapter 4 the benefits described by participants are discussed in detail, and this knowledge helped develop a framework for a successful participatory arts-based health research (PABHR) study. The six principles have been refined and developed into the ACCESS (Participatory Arts-Based Health Research) framework:

- **A**ccessibility—Making the research activities accessible to promote inclusivity and equity.

- **C**ommon cause—Defining and developing an understanding of the common cause that unites participants and is explored and addressed through the research.

- **Cr**eative flexibility—Choosing a flexible creative approach to meet the needs of participants and invite content beyond the research study.

- **E**njoyment—Offering an engaging, fun, and enjoyable experience.

- **S**afe space—Producing a safe space where participants feel supported, can build trusting relationships, and are able to voice sensitive topics.

- **S**ocial—Providing opportunities for participants to connect with others.

These principles are underpinned by PAR fundamentals that promote equity, empowerment, and social transformation. The PAR methods used in this study showed significant benefits for participants and were essential for creating narratives around improving health services, co-production, and problem-solving. These person-centred approaches fostered and enhanced community relationships and trust, proving essential for initiating social transformation. This indicates that the foundational PAR techniques are as significant as the arts-based activities in ABHR.

The suitability of the art genre depended on the preferences and experiences of the members of the research group; however, no art form exhibited a greater or lesser capacity to deepen the understanding of patients' lived experiences in this research. This study was unable to ascertain if a particular art-based research method contributed to increased engagement, given that various artistic methods were used, and participant involvement unfolded as a cumulative process, with individuals frequently interacting with multiple art forms.

The Health Research Authority states that the goal of patient and public involvement aims to improve studies so that they:

- are more relevant to participants,
- are designed in a way that is acceptable to participants,
- have participant information that is understandable to participants,

- provide a better experience of research,

- have better communication of results to participants at the end of the study.

<div align="right">(Health Research Authority, n.d.)</div>

Beyond ethical approval, which guarantees the research's honesty, rigorousness, transparency, respect, and protection of all participants, there are few recommendations for designing research that will immediately benefit patients' well-being. This study provides evidence of the psychosocial benefits of using participatory arts-based methods for participants, highlighting the need to advocate for these approaches in future health research projects.

The benefits of arts-based approaches in health research need to be further reinforced, as identified by NIHR in the Best Research for Best Health: The Next Chapter strategy 2021. In several areas of health, public health, and social care research, the pace of development needs to accelerate if they are to fully address the changing needs of people and communities in the 21st century (NIHR, 2021). NIHR's research strategy highlights the need to improve ways of working, making it easier for people to understand and work with health researchers, access evidence, and evaluate impact. The NIHR is committed to strengthening communications in order to engage and involve stakeholders, support the dissemination of research findings, and promote the value of health and social care research more broadly. This study evidences the importance of creativity in PPIE (Patient and Public Involvement and Engagement), and the ACCESS framework of participatory arts-based methods qualifies as a necessary component that could overcome the inadequacies emphasised in reviews of PPIE. Primarily, there is a lack of awareness of research engagement opportunities for the public and patients; barriers still need to be removed to make the research process and methods less daunting, and frequently research participant groups lack diversity (Ocloo, 2021).

The ACCESS framework of six principles underpinned by PAR uncovered in this study should be adopted by NIHR as an example of public involvement to shape the future of health and social care research. The table below maps the ACCESS Framework

established during this arts-based health research study alongside the UK Standards for Public Involvement developed as the hallmark of good public involvement (UK Public Involvement Standards Development Partnership, 2017) to demonstrate how an arts-based approach with PAR enhances public and patient involvement with health research.

Figure 67: ACCESS Framework mapped alongside the UK Standards for Public Involvement

UK Standards for Public Involvement	ACCESS Framework
Inclusive Opportunities - Public involvement partnerships are accessible and include a range of people and groups, as informed by community and research needs.	The principle of accessibility relates to engagement barriers. Recruitment and involvement is further enhanced with the use of artistic outputs that reach large numbers of diverse participants, providing inclusive engagement opportunities.
Working Together - Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships. Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected.	The common cause principle defines an understanding of the collective issues that unites participants. This is further explored and addressed through the creative research process. The safe space principle relates to the collective creation of a safe space where participants feel supported, can build trusting relationships, and are able to voice sensitive topics.
Support and Learning - Promote support and learning that builds confidence and skills for public involvement in research. We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.	The social principle provides opportunities for participants to connect with others. The flexible creative principle enables the researcher to meet the needs of participants and remove barriers. The arts-based methods also provide opportunities for skills development and confidence building amongst participants.
Governance - Involve the public in research management, regulation, leadership and decision making. Public involvement in research governance can help research be more transparent and gain public trust.	The underpinning of PAR within this framework empowers participants giving them ownership of the research process. Flexible approaches provide opportunities for participants to direct the focus of the research.
Communication - Use plain language for well-timed and relevant communications, as part of involvement plans and activities. Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing.	Co-created outputs reaches large numbers of public and patients using relevant language, raising awareness of ways to engage in this health research projects. Media and broadcast had the largest reach whereas theatre and visual arts provided engagement opportunities.
IMPACT - Seek improvement by identifying and sharing the difference that public involvement makes to research. Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public.	Creative flexibility enables research that meets the needs of participants and invites content beyond the research study focus. Arts-based methods enhance the perceptions of a community's health priorities and foster a deeper understanding of the communities lived experience of health conditions or contexts which can be shared widely using creative dissemination approaches.

The ACCESS Framework principles are likely to improved participant wellbeing because they fuse with evidence-based actions known as the 5 steps to wellbeing: **Connect**, **Be Active**, **Take Notice**, **Keep Learning**, and **Give** (NHS, 2022). The activities that make a positive difference to people lives should be embedded into an arts-based research approach to improve the wellbeing of participants during the research process:

- Accessibility - **(Be Active – by making research activities creative and accessible participants became more active)**
- Common cause – **(Give - Offer support to people going through difficult times)** the common cause that unites participants and is explored and addressed through this research framework.
- Creative flexible approaches - **(The arts-based activities encourage participants to take notice, be in the moment and take time to enjoy the moment)**
- Enjoyment - **(Keep learning – engaging in enjoyable participatory research gave participants a sense of achievement, fun, learning opportunities, agency and choice)**
- Safe space - Producing a safe space where participants feel supported, can **build trusting relationships**, and are able to voice sensitive topics.
- Social - **Providing opportunities for participants to connect with others.**

One could argue that research studies involving patient participants should also strive to include techniques that increase well-being and quality of life.

c) How effective are arts-based dissemination methods in reaching audiences and raising awareness of health conditions?

In contrast with traditional methods, the study shows that art-based approaches successfully recruit people with lived experience from a larger demographic group, and increases audience reach. Research findings can be effectively disseminated through the use of arts-based strategies, according to increasing evidence. Beyond the influence of conventional textual presentations, the use of theatre as a medium for disseminating research findings can not only promote audience participation but

also influence social understanding. One example of how a creative public engagement initiative involves diverse communities and reaches broad audiences is the NIHR Multiverse Lab. To find out what was important to people in terms of their health and well-being, Unfolding Theatre was commissioned by health and social care partners in 2020 to construct Multiverse Lab, a pop-up project that reached over 3,000 people (NIHR Newcastle Biomedical Centre, 2022). In order to provide more in-depth analysis and validation, the arts-based methods used in this study were intended to increase curiosity, trigger emotional reactions, promote conversation, and make it easier for people to share their lived experiences. Innovative art methods also made it possible to reach a wide range of people with messages that were enjoyable and didn't require a specific knowledge. But reaching wider audiences with digital media—like broadcasting on radio to more than 150K listeners—leads to a lack of understanding as to how the listener perceives the research. Further research could be done to learn more about the effects of digital audience outreach.

Implications for the sector, research, and policy

In the health sector, there is a growing appetite for innovative approaches; however, arts-based methods, creative health, and even population health have been considered 'pink and fluffy' by some senior leaders in the NHS. Nevertheless, a comprehensive WHO report that reviews over 3,500 published studies on the health benefits of participating in the arts (Fancourt and Finn, 2019) proves it is highly logical to integrate arts-based approaches into PPI research and would enable participants to experience the intrinsic benefits of engaging in artistic activities while improving research outcomes. The dynamic engagement in this study that created the ACCESS Framework not only enriched the data collection but also empowered participants, giving them a sense of ownership over the research process. Consequently, a shift towards the use of this framework will not only enhance the validity of research findings but also foster a deeper understanding of the communities involved, thus improving the quality and consistency of public involvement in research.

In the arts sector, the ACCESS framework provides creative practitioners who are engaging in health research with a road map to successful use of arts to engage public and patients in health research. It also offers a unified structure by which to evaluate and assess the efficacy of ABHR. Therefore, it is recommended that a global community network of ABHR be established to develop a transnational framework. This would emphasise the significance of international information exchange and professional development, particularly in overcoming language obstacles. Interactions between professionals in various settings might provide motivation for communities of ABH professionals to recoup lost momentum or seek direction from ABH scholars specialising in different creative forms. For example, combining participatory action research (PAR) with photography to create the photovoice approach could be beneficial to other art forms. Similarly, the use of the forum theatre as an engagement method in visual arts shows could enhance audience participation and foster more substantive conversations. Every genre of art-based research has the potential to cultivate a meticulous research methodology that can be recorded and disseminated.

At a policy level, the NHS England Research Ethics System should recognise and embrace the advantages of innovative research methods to improve the use of public and patient engagement (PPI). Encouraging university ethics to promote the recognition of ABHR worldwide could enhance international dialogues, networking, and collaboration, therefore fostering support for innovative research methodologies that improve public engagement. The inherent interdisciplinary character of PABHR can be used to increase the recognition and awareness of the practice in other sectors, including social justice, education, and biomedical sciences. In addition, ethics committees should investigate the absence of an ABHR in PPI (Patient Public Involvement) and prioritise participant well-being.

This research study emphasised that during times of crisis and isolation, the significance of art grew increasingly prominent in our lives, whether it was through virtual discussions about the newest binge-watch drama, the sharing of painted rainbows, or musical tributes dedicated to the NHS. During the lockdown, we had the

opportunity to enjoy a diverse range of live streaming theatre, concerts, and virtual art exhibitions. However, many viewers felt a lack of connection during digital content. During the live performances, theatre enthusiasts expressed their longing for theatre and revealed that they had not witnessed a live performance in over a year. This study examined how a collaborative outdoor display addressed the demands of artists experiencing digital art fatigue after only being limited to the creation of digital works during the global pandemic. The opportunity to collaboratively organise a COVID-safe outdoor exhibition satisfied the desire of numerous artists to showcase their work in a public setting and connect with audiences and other artists. The arts not only provide society with the opportunity to reflect but also equip us with the means to empower individuals and effect profound changes in their lives. The arts furnish us with the resources that enable us to analyse societal issues, develop solutions, and implement transformation. It is imperative that leaders in health research recognise ABHR as a mainstream method that has the capability to improve patient well-being during the research process and can reach diverse communities to address health inequalities.

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Appendices

Catalogue of Creative Outputs:

Illustrating a journey of participatory creative practice in health research, developing arts based methods including labyrinth art installations and theatre performances.

The beginning... the seed...
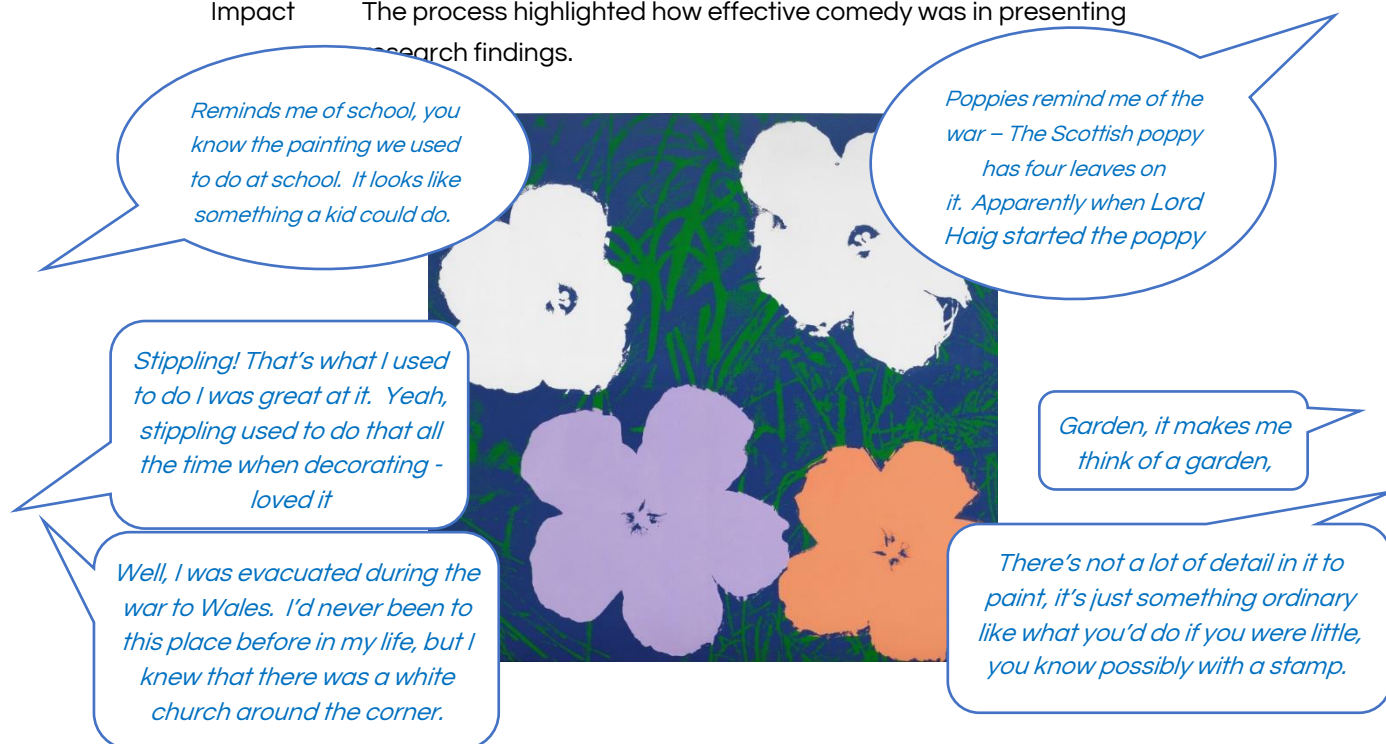
Date:	February 2016
Title:	Looting the Cultural Supermarket
Art form/s:	Comedy Performance
Where:	Tate Liverpool
About:	The performance featured as part of Tate Liverpool's 'Imagine Museum'

2053: A Living Museum was the extraordinary conclusion of Tate Liverpool's special exhibition, An Imagined Museum: works from the Centre Pompidou, Tate and MMK collections. The exhibition closed on Sunday 14 February 2016, and reopened on 20 February 2016 with the artworks removed, replaced by a person or group remembering or performing each of the artworks that were once on display. A Living Museum drew on Ray Bradbury's book, Fahrenheit 451 (1953), where characters become a living library of banned books to preserve their content for future generations.

The research activity sought to promote an understanding of ageing minds in relation to arts activities, memory, curatorship, and critical review. The art- viewing and discussion event invited older people and people living with dementia (early stages) to become co-researchers and explore how they feel about art exhibitions at Tate Liverpool, what is really important to them and what had little impact.

I presented the findings from our art viewing activity by way of a comedy performance. Inspired by Elaine Sturtevant's reconstructions, the repetition of works by other artists, the performance paid homage to comedy sketches set in art galleries by Monty Python and Pete and Dud. The comedy text was interwoven with the stories/data collected as part of the art viewing experience. (Text highlighted in blue below) It was

performed using a character called 'Amee' as a representation of the hyperreality TV show - Towie. Throughout the text, other artworks were referenced that were also featured in the exhibition, this demonstrated the whole experience of the art viewing activity.

Research method/s:	PAR, Cultural probes, focus groups, interviews, small element of co-design
Challenges:	Gaining ethical approval to work with people with dementia, could have used more co-design to develop and perform the data.
Impact	The process highlighted how effective comedy was in presenting research findings.

Reminds me of school, you know the painting we used to do at school. It looks like something a kid could do.

Poppies remind me of the war – The Scottish poppy has four leaves on it. Apparently when Lord Haig started the poppy

Stippling! That's what I used to do I was great at it. Yeah, stippling used to do that all the time when decorating - loved it

Garden, it makes me think of a garden,

Well, I was evacuated during the war to Wales. I'd never been to this place before in my life, but I knew that there was a white church around the corner.

There's not a lot of detail in it to paint, it's just something ordinary like what you'd do if you were little, you know possibly with a stamp.

Elaine-Sturtevant-1924-2014-Warhol-Flowers-1990-Silkscreen-and-acrylic-on-canvas-2950-x-

Date:	September 2017
Title:	Participatory Action Research Group: Cultural inquiry exploring how the arts can support living well with dementia.
Art form/s:	Cultural Experiences (Gallery & Museum Visits) & Storytelling
Where:	Various cultural venues across Liverpool City Region
About:	The PAR project was launched in November 2017 with the primary aim to investigate, describe and increase the understanding of PWD lived experienced of cultural engagement. By placing people living with dementia at the heart of the research process we explored how arts and cultural activities can offer emotional, social, psychological, and practical support. The objective was to create a positive perspective of how people can live well with dementia and engage in society.
	The people living with dementia became co-researchers and investigated the experience of an arts and culture programme of activities. We explored how and why we engaged, the challenges and barriers we faced, the benefits and impact. As the project developed, we recognised barriers to visiting cultural venues, and decided to co-design a Made Up to Meet Up social group.
Research method/s:	PAR, Cultural probes, focus groups, co-design
Challenges:	Recruiting participants once ethical approval was achieved. Managing ethical process of research engagement as PWD conditions worsened.
	Maintaining a collaborative approach to research. The group naturally looked toward the research facilitator as a leader, it was important to share responsibility for the direction of the research.
Impact	The research group co-designed a social group model that could support others living with dementia and the wider social prescribing initiative.
	The project received funding from Dementia Connect, Awards for All Lottery, LJMU QR Funding and (formerly known as) Liverpool Clinical Commissioning Group to develop outputs such as Dementia Friendly app for wellbeing, toolkit, and website for the development of Made Up to Meet Up Social Groups.

Made Up To Meet Up

Date:	October 2017
Title:	Lost and Found Labyrinth Installation
Art form/s:	Art installation, curation, poetry, storytelling, photography, illustration, comedy, participatory art
Where:	Open Eye Gallery, Liverpool
About:	The Lost and Found Labyrinth is an art installation co-designed and co-ordinated by research academics in partnership with people living with dementia. The installation creates a labyrinth path to share stories and experiences of those living with dementia.

The artwork is not only aesthetically pleasing but also thought-provoking, with the labyrinth form acting as a metaphor for the brain. Made up of donated knitwear and postcards from those living with dementia, the labyrinth aims to bring individual narratives to the public while providing the opportunity for contributors to relive their memories, honouring loved ones. The artwork sets out to invoke joy in its participants and explores the use of humour as a coping strategy. Smiling and laughing can have a positive effect on PWD and has been recognised as a good and effective complementary and alternative intervention in the treatment of dementia patients. (Takeda, 2010)

Research method/s:	Co-design, art-based research methods including creative writing, storytelling, visual arts and curation.
Challenges:	The initial set up of a labyrinth installation can take several hours, it requires a large space.
Impact	Public installations of the labyrinth provides a way of including the wider public views and insights into living with dementia.

It enabled us to reach wider audiences by exhibiting at museum and arts events, health conferences, and schools.

Date: November 2017,

Title: Comedy Sketch show 'The Tangled Veil and the Cloud of Unknowing'

Art form/s: Theatre, comedy, performance, storytelling

Where: Laughterhouse Comedy Club, Hope Street Theatre, Liverpool, Liverpool Royal Hospital's annual dementia conference.

About: The Tangled Veil and the Cloud of Unknowing took the stories gathered for the L&F Labyrinth to produce an sketch show about living well with dementia. It was first performed at Laughterhouse Comedy Club 2017 as part of the Being Human Festival, subsequently we were invited to perform at Liverpool Royal Hospital's annual dementia conference 2017 & 2018, and Hope Street Theatre 2018. Reaching audiences numbers of 586.

The play was co-produced with people living with dementia touching on individual journeys.

Research method/s: Co-production, art-based research methods including theatre, creative writing, storytelling, and curation.

Challenges: Funding costs to cover actors and theatre professionals' fees.

Impact   Raising awareness in performance venues reaching alternative audience to labyrinth helping more people gain insights into living with dementia.

Tommy Dunne (PWD): One of the best pieces of theatre I have seen about dementia.

Supporting PWD in developing their own theatre piece.

Date: February 2018,

Title: Labyrinth Installation at Museum of Science and Industry and Liverpool's Anglican Cathedral as part of Liverpool Independents Biennial

Art form/s: Art installation, curation, poetry, storytelling, photography, illustration, comedy, participatory art

Where: Museum of Science and Industry, Manchester

Liverpool's Anglican Cathedral, Liverpool Biennial

About: The Lost and Found Labyrinth toured various cultural venues. The labyrinth path presented a mindful experience for audiences as we shared stories and experiences of those living with dementia.

Along with artists, students and academics, the labyrinth continued to be co-designed and delivered in partnership with people living with dementia (PLWD) in support of the view that they can continue to make a significant contribution to health research and innovative projects. We created a positive empowering experience for PLWD by placing them at the heart of the research and creative process. Being artful, mentally active and socially engaged has a positive effect on cognitive skills. (Young et al, 2015) Our objective is to increase opportunities for engagement, reduce the social isolation associated with living with dementia and improve quality of life.

Research   Co-design, art-based research methods including creative writing,
method/s: storytelling, visual arts and curation.

Challenges: The initial set up of a labyrinth installation can take several hours, and it requires a large space.

Impact   Public installations of the labyrinth provides a way of including the wider public views and insights into living with dementia.

It enabled us to reach wider audiences by exhibiting at museum and arts events, health conferences, and schools.
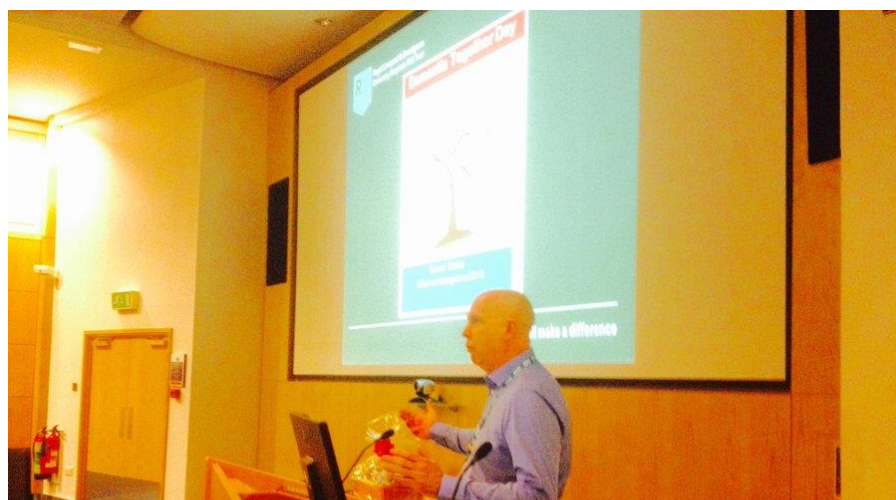
Date:	May – July 2018
Title:	School Tour of Labyrinth to raise awareness of living with dementia
Art form/s:	Art installation, curation, poetry, storytelling, photography, illustration, comedy, participatory art
Where:	Various school across Liverpool
About:	We develop a Labyrinth schools tour to help children and their families to better understand dementia gaining vital support in the development of age friendly communities.
	Building on the Alzheimer's Society's resources for young people the Labyrinth workshops were delivered to 3,000 children aged 6-11, in partnership with PLWD, Liverpool Dementia Action Alliance and health researchers.
Research method/s:	Co-design, art-based research methods including creative writing, storytelling, visual arts and curation.
Challenges:	The initial set up of a labyrinth installation can take several hours, and it requires a large space.
Impact	We learnt that schools are more likely to book dementia information sessions when combined with the interactive labyrinth.
	LJMU in partnership with SURF, Dementia Action Alliance Liverpool, Alzheimer's Society, Greenbank Primary School, Liverpool City Council and endorsed by Liverpool's Mayor – Joe Anderson
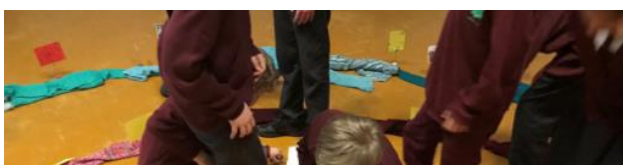
MsRowlandsGb
@MsRowlandsGb

A big thank you to @FreemonkeyMc and the team for bringing the dementia labyrinth to @GreenbankSchool The sense of calm created was inspiring and the information shared was enlightening, for both staff and pupils. Thank you to @Jokennedy81 and Cllr Jeremy Wolfson for joining us

Date:	May 2018 & 2019,
Title:	Comedy Performance 'The Tangled Veil and the Cloud of Unknowing' & 'On Cloud 79' 2019
Art form/s:	Theatre, comedy, performance, storytelling
Where:	Liverpool Royal Hospital's annual dementia conference.
About:	We were invited to perform The Tangled Veil and the Cloud of Unknowing at The Royal Liverpool and Broadgreen Hospitals & North West Coast Strategic Clinical Networks '*Dementia Matters*' Conference. Using humour we aimed to raise awareness of an authentic lived experience and reduce the stigma amongst adults with the aim of increasing those benefiting from an early diagnosis. We also aim to build on von Gorp and Vercuysses' research on the effects of media language and the need for positive experiences despite a dementia diagnosis to destigmatise the condition (Wolverson, Clarke and Moniz-Crook, 2016).
	The stigma against people with dementia is widespread and its consequences far reaching. Team members experiencing dementia tell us how vital humour is in coping with the challenges they face. Our key message is to adopt a positive attitude and keep a sense of fun.
Research method/s:	Co-production, art-based research methods including theatre, creative writing, storytelling, and curation.
Challenges:	Funding costs to cover actors and theatre professionals' fees.
Impact	Raising awareness in performance venues reaching alternative audience to labyrinth helping more people gain insights into living with dementia.
	Tommy Dunne (PWD): One of the best pieces of theatre I have seen about dementia.
	Invited to support other PWD in developing their own theatre piece.

Date:	October 2019,
Title:	HSR 2018 Photovoice Exhibition at 5th Global Symposium on Health Systems Research
Art form/s:	Curation, Photography
Where:	ACC Liverpool
About:	HSR 2018 Photovoice was a multi-project Photovoice exhibition, inviting delegates to submit their Photovoice images for ongoing or completed projects that were in line with the Symposium sub-themes. The Photovoice exhibition created a platform for critical dialogue and learning throughout the symposium, as we advanced health systems with the vision of 'Health for All' in the SDG era, and universal coverage.
	Photovoice is a participatory action research methodology that involves the taking of images by individuals, the discussion and analysis of these images and the use of the images to communicate the lived experiences, strengths and challenges of the photographers.
	32 projects were included from 28 different countries.
	https://healthsystemsresearch.org/hsr2018/photovoice/
	https://healthsystemsresearch.org/hsr2018/photovoice/index.html
Research method/s:	Photovoice, Creative Evaluation Tree
Challenges:	Questioned the co-design of the exhibition without patients from the project having a say. Therefore, original participants not involved in the exhibition. Representing the context to the photographs to highlight the research.
Impact	Reached 2247 actors involved in health systems and policy research and practice from more than 125 countries.
	Developed a deeper understanding of the range of photovoice projects across the globe

Date:	September 2018,
Title:	Comedy Theatre Performance 'On Cloud 79
Art form/s:	Theatre, comedy, performance, storytelling
Where:	Hope Street Theatre, Liverpool, Liverpool Royal Hospital's annual dementia conference.
About:	After receiving ACE funding, I worked with a professional writer and director to develop the comedy sketches into a theatre play 'On Cloud 79'

40% of the creative team were living with dementia, we used their stories and experiences to develop the piece.

On Cloud 79' was developed using verbatim interviews and stories of people experiencing dementias. The play features characters from different backgrounds, and different presentations of the condition. The play takes the audience through a range of emotional experiences including loss, sadness and humour which provides authenticity to the characters and demonstrates what it is like to live with dementia including family members and friend's perspectives. The play promotes the view that PLWD can continue to make a significant contribution to society. |
| Research method/s: | Co-production, art-based research methods including theatre, creative writing, storytelling, and curation. |
| Challenges: | Funding costs to cover actors and theatre professionals' fees. |
| Impact | Raising awareness in performance venues reaching alternative audience to labyrinth helping more people gain insights into living with dementia.

Tommy Dunne (PWD): One of the best pieces of theatre I have seen about dementia.

Supporting PWD in developing their own theatre piece. |

Date: Sept 2018, - July 2019

Title: Made Up to Meet Up Development Project/Stakeholder Event

Art form/s: Cultural Experiences (Gallery & Museum Visits) & Storytelling, Film, photography, creative content, social media

Where: Various cultural venues across Liverpool

About: Every social prescribing programme is different because it responds to the needs of each unique community. To develop a sustainable and successful social prescribing strategy we need to understand what is already there within the community and what works well. A co-design approach will help to ensure Liverpool's social prescribing programme is inclusive and has a shared vision. With this Beyond the Prescription event, we aim to bring key stakeholders together to discuss where we are at, see what works and plan how we can move forward together.

Research method/s: Co-design, focus groups, cultural probes, stakeholder event

Challenges: Bringing the right people round the table, selecting key speakers

Impact   Toolkit commission – support Social Prescribing across the region

200

Date: Feb – Mar 2020,

Title: The Bird Lime Labyrinth

Art form/s: Art installation, curation, poetry, storytelling, collage, participatory art

Where: HMP Walton,

About: The Bird Lime Labyrinth was an art installation co-designed and co-produced with prisoners to represent their approaches to wellbeing whilst in prison.

Due to suspected covid I was unable to complete the installation in the three prisons instead I developed instructions for the arts lead to install with the prisoners.

Research method/s: Co-design, art-based research methods including creative writing, storytelling, visual arts and curation.

Challenges: Covid 19 start of lockdown and isolation.

Impact

Date:	May – July 2020
Title:	Labyrinth Lockdown Toolkit to support school and home schooling
Art form/s:	PAR, art installation, curation, poetry, storytelling, photography, illustration, comedy, participatory art
Where:	Virtual/Remote
About:	The Lost and Found Labyrinth is an art installation co-designed and co-ordinated by research academics in partnership with people living with dementia. The installation creates a labyrinth path to share stories and experiences of those living with dementia.
	The artwork is not only aesthetically pleasing but also thought-provoking, the labyrinth form acts as a metaphor for the brain. Made up of donated knitwear and postcards from those living with dementia, the labyrinth functions to bring individual narratives to the public while providing the opportunity for contributors to relive their own memories. The artwork sets out to invoke joy in its participants, since smiling and laughing has positive effects in helping to engage the brain.
Research method/s:	Co-design, art-based research methods including creative writing, storytelling, visual arts and curation.
Challenges:	Delivering participatory action research during covid restrictions. Reaching out to relevant contacts during lockdown.
Impact	

Build Your Own Lockdown Labyrinth Toolkit

By Elaine McNeill & Alex Irving

Date:	May – June 2021,
Title:	Covid Safe Doorstep Theatre Performance 'Silver Bells and Cocktails'
Art form/s:	Theatre, comedy, performance, storytelling
Where:	Various Independent Living Schemes and Care Homes across Liverpool City Region.
About:	During Lockdown, I raised funding to produce a doorstep theatre piece. In collaboration with some of Liverpool's finest actors and writers, we set out to give older people the chance to be heard, demonstrating that we recognise their worth as valuable members of society. Working with people from Independent Living Schemes, we created an authentic yet mischievous comedy guaranteed to get everyone laughing, singing, and tapping their feet - Silver Bells and Cocktails – a life in lockdown.
	We toured Liverpool City Region's Independent Living Schemes and Care Homes during April and May, and 'Silver Bells and Cocktails', became the first social activity many had taken part in over 12/15 months.
Research method/s:	Co-production, art-based research methods including theatre, creative writing, storytelling and music.
Challenges:	Funding costs to cover actors and theatre professionals' fees.
Impact	We realised that the tour was for many, the first social activity older people had taken part in over 12/15 months. *Thank you so much for the performance the customers really enjoyed, and it lifted them greatly after such a challenging year. The performers got it so right …please pass on our thanks and good luck to you all.* Linda Murray – Scheme Manager at Hawthorne Court
	Finalist for Liverpool City Region Culture and Creativity Impact Award – Covid-19 Creative Response (individual) for producing doorstep theatre, in collaboration with some of Liverpool's finest actors and writers. In partnership with Independent Living Scheme residents across the city, we created – 'Silver Bells and Cocktails – a life in lockdown'. The award was to recognise an individual who has used culture and creativity to make a significant impact on people's lives during the Covid 19 pandemic.

Date:	June 2021
Title:	Lockdown Labyrinth Installation
Art form/s:	Art installation, curation, poetry, storytelling, photography, illustration, comedy, participatory art
Where:	Back Quarter Outdoor Venue, Chester
About:	The Lost and Found Labyrinth is an art installation co-designed and co-ordinated by research academics in partnership with people living with dementia. The installation creates a labyrinth path to share stories and experiences of those living with dementia.
	The artwork is not only aesthetically pleasing but also thought-provoking, the labyrinth form acts as a metaphor for the brain. Made up of donated knitwear and postcards from those living with dementia, the labyrinth functions to bring individual narratives to the public while providing the opportunity for contributors to relive their own memories. The artwork sets out to invoke joy in its participants, since smiling and laughing has positive effects in helping to engage the brain.
Research method/s:	Co-design, art-based research methods including creative writing, storytelling, visual arts and curation.
Challenges:	The initial set up of a labyrinth installation can take several hours, and it requires a large space.
Impact	Public installations of the labyrinth provides a way of including the wider public views and insights into living with dementia.
	It enabled us to reach wider audiences by exhibiting at museum and arts events, health conferences, and schools.

Date:	March – June 2022
Title:	Post Covid Theatre Performance 'Shaken Rattled and Rolled'
Art form/s:	Theatre, comedy, performance, storytelling
Where:	Various Independent Living Schemes and Care Homes across Liverpool City Region.
About:	Following the success of Silver Bells Doorstep theatre tour, we received additional funding from ACE to produce another tour post lockdown.
	The residents from Meadowlands Court are back to share their ups and downs post-lockdown. The communal lounges are open again and this promises to be the party of all missed parties. Featuring Eithne Browne (Emmerdale, Brick Up the Mersey Tunnel, Mam I'm Ere), Liam Tobin (Homebaked – The Musical, The Menlove Avenue Murder Mystery, Sweeney Todd) and Mulu lead singer Laura Campbell.
Research method/s:	Co-production, art-based research methods including theatre, creative writing, storytelling and music.
Challenges:	Funding costs to cover actors and theatre professionals' fees. Staff/management covid sickness in schemes – cancellations and limited of bookings
Impact	

Date:	May – September 2022,
Title:	QR Funding and LCCG Commission to produce toolkit for Made Up to Meet Up Social Groups
Art form/s:	Graphic Design and Illustration, Storytelling
Where:	Various cultural venues across Liverpool City Region
About:	The Made Up to Meet Up toolkit outlines methods and techniques for ensuring the social participation of people living with dementia and other health contexts, in the design, implementation, monitoring and evaluation of an arts social group to improve their health. Using arts and cultural activities, people living with dementia were placed at the heart of the research process. The aim was to create a positive perspective of how people can live well with dementia and engage in society.
	The 'Made Up to Meet Up' social groups were co-designed with people living with dementia in 2017/18, our process and findings were shared as part of a stakeholder event in 2019. A GP Practice Manager stated that every GP surgery should have a Made Up to Meet Up group and Clare Mahoney Social Prescribing Lead at Liverpool Clinical Commissioning Group, pledged to support the development of local Made Up to Meet Up groups as part of the social prescribing provision in the city.
Research method/s:	PAR, Cultural probes, focus groups, co-design
Challenges:	Co-design with artists who have been commissioned
Impact	The Made Up to Meet Up toolkit will be disseminated to all Link Workers and GP Practices, Medical Centres initially across Liverpool. A digital version will be made available to all Link Workers across the UK via the Future NHS Collaboration Platform. It will also be shared with the Northwest Social Prescribing Network co-chair – Jo Ward.

Appendix 2. Performance Scripts

Looting the Cultural Supermarket A Living Museum at Tate Liverpool

(Data and stories collected as part of the art viewing event highlighted below)

Oh here you all **Amee:** *are... I thought we were meeting by the Duchamp. No of course, I said when I came out of the Dan Graham that I was going to turn left at the Fontana, walk past the Deitman and meet you here at the Sturtevant.* (Shouts across the gallery at son) *Marnie get off that Avenza before you break it.*

Sorry about that, I'm Aimee it's lovely to be here at Tate Liverpool - I'm from a little show called Towie some of you may or may not heard of it. Between you and me, I think there's a right load of rubbish in here. And you think they'd have tidied up (referencing Pawel Althamer's Self-Portrait as a Businessman) *But this 'ere flowers one's not bad* (points at Sturtevant's Warhol's Flowers). *My aunt Frances says it reminds her of school, you know the painting they used to do at school. It looks like something a kid could do. She said she'd see that and think of her school days. She loved art at school.*

My aunt Marian gave me a lovely description of this last week, she said imagine a poppy, then imagine four poppies. The background is very dark with light green strokes of paint, two white poppies an orange and a lilac, with little bits marked in the centre yer know. Each poppy has five rounded leaves on it just as a poppy would be.

Then my Uncle Andrew would say, Poppies remind him of the war - mind you he is an ex-serviceman, and he was telling me that the Scottish poppy has four leaves on it. Apparently when Lord Haig started the poppy appeal it never covered Scotland, but Lady Haig sorted that one out.

White poppies though? now there's a new one - don't think I've ever seen a real white poppy. I guess they represent peace lovely that in't it? I'm gonna get me one of them yeah peace - it'd go lovely with my bright pink Ted Baker Mac. Oy Marnie get away from Polke's Pasadena with that marker pen!

Still this artwork by Sturtevant reminds me of a garden yeah that's what my Aunt Marian would say, she just thought of a garden right away, a garden. But my Aunt Frances, as I said before, reckons it reminds her of sitting in school and doing art, you know. There's not a lot of detail in it to paint, it's just something ordinary like what you'd do if you were little, you know possibly with a stamp. Stippling! Now my Aunt Frances was great at stippling used to do that all the time when decorating - loved it.

Hang on where's our Marnie gone? I don't reckon he likes it here, earlier I caught him spitting at the Bridget Riley next door. And I tell you something for nothing - he's not a bad shot, he can hit a Dan Flavin at 30 yards. but you know you show him an exhibition of op art from the 1960's and he goes all bothered and confused - I mean it don't half make you go funny. But people love it don't they? All that funny eye stuff. I heard one of Riley's went for over £2.5 million. Jeepers that's nearly as much as what Footballer Torres is worth. Why would pay that much, for a piece of art? I mean how do you know if it's any good. I know there's those where the eyes follow you round the room of course there very very good, and if it don't follow you

round the room then it ain't. There's an absolutely brilliant piece in the other room, in fact its reem. I was in there yesterday and it felt like someone was watching me - you know eyes boring into the back of me neck. I whipped round quickly in a flash and I see the Reg Butler - all 78 eyes staring at me. Give me the willies still this one's alright cos it's just a bowl of pansies.

My Aunt Frances loves pansies, all the coloured pansies you can get in winter and summer. All the lovely colours you can see in the pansies, they're beautiful colours. My aunt Frances would say this painting looks more like a pansy and she would draw a dark line around each of them making it neat you know.

Makes you think about how Sturtevant did this... I heard that Andy Warhol gave her the original silk screen. Then when he was asked about his technique for his flower paintings, he supposedly replied, "I don't know. Ask Elaine Sturtevant." Oo oo funny eh well jel that she copied him but Sturtevant didn't like to see it as copy though oh no she said her work was more like repetition. She was sort of saying nothing comes from nothing. Nothing is original and everything has been done before you know...

My Aunt Frances reckons she's been here before. She told me that when she was evacuated during the war to Wales. She'd never been to this place before in her life yet she knew that there was a white church around the corner. Never been there in her life before - as true as god she'd say, on her children's life. Another tale she told was that whilst she was there one morning the kids were excited and shouted about a film star coming down their road. It was only her mum who had come to fetch them home. She was flaxen blonde though with a big fur coat and crocodile skin shoes. I can just picture it now. My Aunt Frances reckons as you get older you can see it more clearly. You sit there thinking about it and memories become more clear.

Do you know that much of Sturtevant's work was created from memory - exact replicas from memory pretty impressive. Replicas, repetitions, simulacra whatever you want to call it – simulacra... yeah I know! No I don't mean hairspray, I mean simulacra as in the hyper real. You know? What she was saying, back in the olden days, is everything's being copied from something, by someone, and this was way before Kanye West did that version of Bohemian Rhapsody at Glastonbury. Yeah, she was on it, probably more on it than Warhol really. I mean everyone said Warhol understood like, but Sturtevant reckoned he didn't give an 'effin jeff'.

I'll tell you who needs to give an elfin jeff though. That lady in the photo over there with a nest as a what'ya a ma call it. I'd love to know who did her vajazzle. I'd be swerving that Salon. Another thing that has been bothering me is Tanning's Poppy Hotel Room eh? How are supposed to tell if it a good piece of art when the nudes are facing away from you? Where are the eyes to see if it is following you? Cos they've got their bloody backs to you. I guess the only way you can tell it a good piece, when it's like that, is if the bottom follows you around the room. Not sure I like the sound of that. Anyway, I've kept you long enough, so catch yer later. I need to get a selfie with some artist's shit. Ta ra xxx

On Cloud 79 Ethnocomedy Script

'On Cloud 79' is based on detailed research and dementia stories. The piece concentrates primarily on the early stages of dementia, its impact on family members and care workers. This is illustrated verbatim through true life-narratives and fiction. We also show the progression of the condition.

Imagine a desolate landscape, a Yucca tree, as painted by Magritte, inhabited by a people in exile.

Set in a Care Home, a Family Home, a Day Care Centre and a Residential Home.

MUSIC Mr Men Original Theme tune theme.

SCENE 1

Lights up.

SALLY enters. She takes her time. She spots a rug. She skirts around it, afraid. She sees some chocolates, puts them in her bag. Decides to sit in a chair she's not used to sitting in. SALLY has a twinkle in her eye. She was an original hippy and went to the first Glastonbury.

ENID enters…she's on the top deck of the Queen Mary. In her own head. ENID has delusions of grandeur. She walks right across the rug, no problem.

ENID

Ahoy, there?! That's my chair.

SALLY moves into her own chair.

ALAN enters. He puts a strange hat on his head, settles down.

Cissie enters. She speaks directly to the audience. CISSY takes centre stage with a presence that's both larger-than-life and also at the same time a deeply revealing and authentic character study of a fiercely determined elderly woman with a fabulously timed scouse wit.

CISSIE

It's my duty today to welcome you and tell you a little bit about what you're going to be seeing here today and what's been going on. I've come to talk to yer about On Cloud 79, about dementia and the things that affect yer, you now as you get older. And let's be honest you don't even have to be that old.

I can see you're all looking thinking oh no it won't happen to me, I've done my exams, I've got a degree. I keep myself active doing puzzles and crosswords. But one day you'll find yourself sitting doing the Times Crossword colouring in the squares in with a coloured pen instead of writing letters. Oh eye happens to the best of us.

I shouldn't even be here you know, oh no I'm not meant to be here in this home I've got a lovely little flat, I've got a lovely little flat and I'd be there soon as ever, as being in this place I tell yer. It's just having a bit of a clean up at the moment you know, a little bit of a sparkle being added to it. Well the walls were getting on me nerves they were painted in that Mongolia, so I've had to move into here while the decorators are in. and no its not a euphemism for having jam in my waffle. Oh no hat ship sailed quite some time ago no the decorator… painters are literally in my little flat and I'm gonna be in there as soon as I can. Cos I can't wait to get meself out of here. OOoo you don't know the half of what goes on. They are supposed to be looking after yer, but half the time you don't know what's coming back in yer wash basket or nothing anyway.

I'll tell you a little bit about the people you'll be seeing an all today – keep your eye on them because they'll be telling their stories and these stories are true you know, Oh ey for all the joking and laughing aside, cos life's like that, funny, sad. you laugh, you cry, oh ey these are true stories oh ey I remember. *(Pause as she loses herself in a memory)*

Oh ey yeah so anyway… where was I… oh the people, the dramatis personae:

Now we've got moony June, you see her standing there looking out of the window and you don't know if she's looking at her future or her past, well she was a police woman you know, oh ey yeah she worked for the police, she used to drive the cars, I mean she was supposed to, it was her job like, she didn't just take them or nothing like that.

And then we've got Lacarno lil oooo Sally keep your eyes on 'er. Honest to god sticky fingers, it's like she's got feckin' blu tac on the end of em. Oh excuse me swearing, I've got like a pensioners tourettes. Yeah she ain't half got sticky fingers that one, anything that comes around 'er she'll have that in 'er bag . I've seen her hanging around my little door as well.

And then we've got the queen ere, lady muck that's what I call 'er, Enid her name is. She thinks she lives in a castle you know she does. And she always thinks she's on the Queen Mary, well why not I say? You might as well be there as living in this place, might'n yer? Cos if your living in yer mind you might as well be somewhere lovely as sitting here waiting for .. you know waiting for…well just waiting for somat to happen. Thinks she lives in a castle with servants. I'd quite like to spend an afternoon in her head. Be lovely to visit that castle she thinks she lives in, even though she comes from Everton, used to live by the water tower there. I think that's given her yer know ideas of grandeur.

Ah and Grandad, Grandad here, he's still in his home you know well for the time being. He keeps things going although he spends most of the day on his own, what kind of a life is that eh? But he looks after himself as best he can. I tell yer he's got a few tales to tell, well we all have haven't we all and he's got a lovely sense of humour.

Oh there's another one as well Dirty Dora the top floor explorer oh god you wanna see her, well if you get the chance, she'll probably be on the top floor where the men are. She's supposed to have lost her memory but she still knows where the men are kept. Oh god, honest to god she'd be hanging outside Ann Fowler home for fallen women. If they hadn't knocked it down - advertising. (She laughs) oh your not s'posed to talk about stuff like that are yer a bit of jiggery-pokery, you know doing the hibbety-dibbety, putting the bread in the oven ey cos when you get to a certain age – we're meant to be past it aren't we we're meant to be past bringing an al dente noodle to the spaghetti house – well even if it is more like cleaning the cobwebs with the broom.

Addresses a member of the audience: Oh you've got a nice face haven't you? It's nice and clean. Ah bless yer. Oh sod this *(exits stage)*

ENID

Charming spot. *(Pause)* Should we go?

SALLY

We can't.

ENID

Why not?

SALLY

Cos we're meant to wait.

ENID

Who said?

SALLY

You know....thingy....what's her name? Godzilla?

ENID

Ah! *(Pause)* You're sure we're meant to be here?

SALLY

What?

ENID

Are you sure we're meant to be here?

SALLY

She said by the Yucca. *(They look around)* But are there others?

ENID

Other what?

SALLY

Yuccas.

ENID

I don't think so. It's a funny looking yucca, what's it called?

SALLY

Jarvis

ENID

Jarvis?

SALLY

Jarvis Yucca

Pause.

ENID

Charming today, isn't it?

SALLY

If you say so

ENID

And it's not over yet.

SALLY

apparently not

ENID

It's only the beginning

SALLY

It's awful

ENID

Worse than being at the dentist.

SALLY

The hospital.

ENID

The theatre.

SALLY

The theatre?

Beat.

ENID

Nurse!

SCENE 3

A smartly dressed lady enters.

SMART LADY

*Can you press that button? I need the toilet. This is supposed to be a care-home, but
I've not seen much caring going on in here.*

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Pause.

SCENE 4

Birdcage with towel over it, parrot inside.

CARE-WORKER

(Takes the plastic bag off Alan's head. Trying to put his slippers on)

Lift your foot up.

ALAN

Where have you been?

CARE WORKER

I told you. I was going to do some shopping for the old lady down the road.

ALAN

Old lady? She's younger than you.

Alan puts the plastic bag back on his head.

CARE WORKER

You cheeky bugger, I'm 45. And you're lucky to have me, anyway

(She takes the plastic bag off Alan's head again) What are you doing with that on your head?

ALAN

It's to keep the kangaroos away.

CARE WORKER

How's that working exactly?

ALAN:

Well, I haven't seen one yet.

CARE WORKER

(Joking)

You talk as much nonsense as your Parrot.

ALAN

What, potty mouthed Charlie? I don't know what you've been teaching him but it's X-rated.

CARE WORKER

Whatever that birds learnt he's learnt it form you.

PARROT

(*Off)*

Fat Arse

CARE WORKER

I beg your pardon?

PARROT

Fat Arse

CARE WORKER

Who's got a fat arse?

ALAN

Clare Balding (pointing at the telly)

CARE WORKER

Clare Baldings' got a fat arse?

ALAN

No. Clare Balding she's on the telly again.

CARE WORKER

Clare Balding oh you know she married a woman her…

ALAN

What's wrong with that. So, did I…. And very entertaining she was.

ALAN (as PARROT)

Put a sock in it, put a sock in it.

SCENE 5

Kingswood Manor Care Home

Care home entertainer enters

CARE HOME ENTERTAINER

Afternoon ladies, what should we do today, a bit of drawing? Some arts and crafts?

Don't forget busy days...restful nights.

(They ignore her)

Who fancies a good ole knees up eh? Come on Sally. Sally, it's right up your Alley eh?

SALLY

Here we go again.

CARE HOME ENTERTAINER (*Sings*)

Keep the Home Fires Burning,

While your hearts are yearning,

Though your lads are far away

They dream of home.

ENID

Do you know anything a bit more recent.?

CARE HOME ENTERTAINER

Of course, how about, (*sings*) We'll meet again don't know where don't know when...

SALLY

I think she meant something more upbeat.

CARE HOME ENTERTAINER

Will this do?

(Sings) Happy and I'm smilin', walk a mile to drink your water
You know I'd love to love you and above you there's no other
We'll go walking out while others shout of war's disaster

Oh, we won't give in, let's go living in the past.

SALLY

Jesus I think I'm having a flashback

CARE HOME ENTERTAINER

I'll just pop up to the top floor to see if the men in the big lounge fancy a sing song.

Care Home Entertainment leaves

ENID

She's a lovely person and she's got a lovely approach.

SALLY

Her departures' even better.

ENID

Ha ha. Thank goodness she didn't get us doing the Hokey Cokey again

SALLY

Hmmm…. but Enid? What if the Hokey Cokey really is what it's all about?

Pause. Enter Sally's daughter, Lynne. She goes to her mum.

LYNNE

Exactly. What if the hokey cokey really is what it's all about?

Sally enjoys Lynne's touch.

When I found first out about my mum's dementia I was devastated, all you hear in the media is that people are suffering, battling the disease, the thing is you just don't know how you are going to react until it happens to you. I think it's the guilt that gets you the most. Guilt that you can't visit enough, that you can't make any of it better, that when you visit you always have to leave, that you're letting others do the 'caring', that you haven't moved closer.…the list just goes on.

And then there's the fear, a nagging, almost paralyzing fear, that it's going to happen to you. Because when your nan, mum and two uncles all have it, you realise that the odds are probably not stacked in your favour. You know, my mum always used to say if anything like that happens to me, lock me up and throw away the key.

I've spent years with her not recognizing me. The last six years she hasn't known who any of us are. She wasn't aware when my daughter was born - the child she so desperately wanted me to have. She isn't aware that Tom her youngest, has graduated and become a successful lawyer. And she's also not aware that dad has sat with her every single day holding her hand - whilst she just sat there existing. The care home do their best but…. Well, the other day we played some music to her, she used to love Fat's Waller. Her mum used to play it to her, she roared with laughter when she heard it. It was a beautiful moment. Although me mum does take it a bit too far … she still has a twinkle in her eye you know. When we were little she told us our gran used to pretend to be Doris Day and sing Que Sera, Sera, but our mum would

change the words saying it was more like 'Kiss me arse, me arse...we sang it last week and she gave us this big beaming smile. Ah, it was lovely.

SALLY

(SINGS)

Kiss me arse, me arse...

(*She suddenly stops, remembers her Mum and starts to cry*)

LYNNE

Ah now then, what's to do?

SALLY

I miss my mum

LYNNE

I know *(pause)* so do I.

(LYNNE holds SALLY's hand and finds herself getting upset).

I'm sorry I've got to go.

LYNNE leaves

SALLY

(about her daughter)

She was a very attractive woman, wasn't she?

SCENE 6

CARE HOME ENTERTAINER

(washing her hands with hand gel)

They're on lock down up there, C Difficile. Did I hear someone having a sing song?

(Sings) When I was just a little girl I asked my mother what should I be, will I be handsome, Will I be Rich? Here's what she said to me...

SALLY puts her headphones on, starts listening to, "Has he lost his mind - can he see or is he blind,

ENID

No!

SALLY

(Iron Man) Da da - dee dee dee, da da dee dee - dee dee dee

ENID

What are you listening to?

SALLY

Black Sabbath

Care Home Entertaining leaves. Pause. Transition movement.

SCENE 7

TONY

Where have you been, love? You've been ages.

JUNE

I went to get petrol, I couldn't find the Garage.

Tony goes to hug June, she rejects him. She goes to sit with the others in the care home.

SCENE 8

SALLY

I once went on a date with a lady, she used to work on Fenwick Street.

ENID

Don't you mean a man.

SALLY

No, she was definitely a woman.

ENID

Have you seen my chocolates? Black magic?

                              JUNE

No, she'll of had em.

                              SALLY

I once went on a date with a lady, she used to work on Fenwick Street.

CISSY enters sits in chair center.

                              ENID

Don't you mean a man?

                              SALLY

No, she was definitely a woman.

                              ENID

Have you seen my chocolates? Black magic?

                         JUNE (enters)

I've told you she'll have em!

                              CISSY

Beam me up Scotty

                              ENID

Isn't a Fenwick a tree?

                              SALLY

Perhaps they're not the season.

                              ENID

It's always the season for a good days' run.

                              SALLY

Eh?

                              ENID

On the Queen Mary, definitely

                              SALLY

Are you suggesting? That we're in the wrong place?

                              ENID

Hmmm…well, there are usually people here.

SALLY

Where are they, then?

ENID

They'll come, they'll come. Well, maybe tomorrow we'll give it a wide berth.

SALLY

Ok, we'll come back tomorrow.

ENID

After two

SALLY

More than likely.

ENID

Oh.

Pause

SALLY

What did we do yesterday?

CISSY

The same friggin' thing you do every day.

ENID

I'm guessing we were here.

SALLY

(Looking round). You think? Does this place look familiar?

CISSY

Frig this where's that bloody taxi!

ENID

I didn't say that.

SALLY

Well?

ENID

It doesn't matter.

SALLY

All the same . . . that yucca . . . the pond . . .

ENID

The smell of the sea

JUNE

What? Are you on about?

ENID

Is it today?

JUNE

Is what today?

ENID

That we're meant to wait.

SALLY

They said Saturday. *(Pause)* I think.

ENID

You think.

JUNE

You think.

SALLY

I wrote it on one of my post it notes. *(She fumbles in pockets, amongst a range of things - bursting with miscellaneous rubbish, chocolates appear then she places then back in the bag)*

ENID

But what Saturday? This Saturday? Is it a Saturday? Could it be a Sunday? *(Pause)* Or a Monday? *(Pause)* Or Friday?

SALLY

How will we find out?

ENID

Wait and see?

SALLY

But you said we were here yesterday.

JUNE

In Newcastle, you don't say Fenwick you say Fenwick.

ENID

(Shouting) Can we just stop talking for a minute, do you mind?

Smart Lady enters.

SMART LADY

I'm expecting a visitor will you let me know when they arrive?

Enid becomes TINA and narrates Alan's story

TINA

Yes of course love.

Scene 9

THERESA

My Grandad is ninety-one, (*She takes his plastic hat off*) Lancashire Lad through and through; steam train engineer in his working days on the East Lancs' railway; merchant navy in the war; played saxophone as a young lad, loves his jazz and big band music. He just can't get out much anymore. We had to have the conversation about him stopping driving: we were worried about his safety and others. *(ALAN puts the hat back on)* Not so long ago he contacted the mechanic and he was told his car needed some parts that were only available on the internet which would take a long time.

ALAN

TINA, I have a job for you. Drive me to the internet.

TINA

Alright Grandad, I will. Eventually we agreed that it would go to scrap: it was in reasonable nick but had seen better days.

My Aunt Sarah came up to sort out the car and…. It's gone, vanished. Nothing on the street outside his house, not in the garage round the back. I mean where can you hide a purple Nissan micra? We looked everywhere, all the usual places –

ALAN

Did you look down the back of the couch?

TINA

We're talking about your car, love. Aunt Sarah asks my Grandad, but he gets a bit vague.

ALAN

I've asked someone to look after it for me because the resident permit's charge is too expensive.

TINA

Why didn't you put it in your own garage? Another vague response.

ALAN

Bats

TINA

We are now all on the hunt for the mystery purple Micra. I mean, it's not like it should be difficult to miss? Finally, we track it down to one of his friends. He said my Grandad had given it to him. Aunt Sarah had to explain what had happened, the chap ended up buying it. I love hearing about how mischievous my Grandad had been. I picture the twinkle in his blue eyes as he tried to trick us. He might not quite remember who I am anymore, but he can still hide a car!

Last week I was at the day centre watching an old black and white western with him.

ALAN

Who's that?

THERESA

It's John Wayne, Grandad.

ALAN

Who's that?

THERESA

It's John Wayne.

ALAN

Who's that?

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JUNE

It's John fucking Wayne.

ALAN

Where's my glasses?

THERESA

I don't know Dad (joking) maybe Al's took them.

ALAN

When I can't find something, or I've put it in the wrong place, I blame it on Al. When I start to say a word and it won't come into my head I blame it on Al. Al took it! "Al did it!" It's become a joke in our house.

THERESA

We bought Grandad a sweatshirt for Christmas. On the front it said, 'I remembered'. On the back it said, 'I forgot, Al took it'. Al is Mrs Zheimer's son, Alzheimer. I know its corny, but it beats dwelling on the sad side of the story.

ALAN

What you doing here anyway?

THERESA

I'm taking you for a drive, Grandad.

ALAN

Where we going?

THERESA

Haworth

ALAN

Do we know anyone there?

THERESA

Only the Brontes'.

ALAN

Oh. Will they be in?

Spike Jones – All I Want for Christmas intro… fade after intro

ALAN

Hey, I love this one. All I want for Christmas is some new false teeth.

THERESA

New false teeth New false teeth

TOGETHER

All I want for Christmas is my mem or ree….then I could wish you Merry Christmas.

ALAN

You're wonderful you, look at you.

THERESA

Ah, Grandad you're wonderful, you've been wonderful.

ALAN

You've been a wonderful grand-daughter. And I had a wonderful Wife… but what about that Bloody Hitler?

Scene 10

A younger June and her mates, Sue (SALLY), Emma (ENID), are on a night out, at the bar.

JUNE

Didn't we raid this place, a couple of years ago? As part of that big drugs bust… Operation…??

EMMA

Colorado.

SUE

No. You're thinking of that place over by the Strand. The one that they knocked down.

JUNE

See, this is how I get.

EMMA/SUE

Everyone gets like that/I can't remember what I was doing on my last shift.

Pause. Slightly awkward.

EMMA

This is the place where that newbie nearly shit himself when you told him it was haunted. Remember? The good-looking fella, who came over from traffic.

JUNE

Oh aye, yeah. Anyone fancy a shot?

SUE

Easy tiger, the night is long.

JUNE

But life is short. *(To an imaginary bar man)* Three Tequilas, please.

EMMA

We've got to get home, remember?

JUNE

But that's my problem, isn't it? I can't remember.

Awkward.

EMMA

June, I'm sorry, I didn't mean anything/

JUNE

/Aw catch yourself on. It is what it is. *(Pause)* Seriously, Tony's doing my head in. He watches my every move. I intend to make the most of tonight. (*Three more shots. June downs hers)* And I don't give a toss what anyone says.

SUE

OK. Sod it. *(The other two down theirs)* Three more!

JUNE

That's the spirit. Eh? Where can we score a bit of *(She mines snorting coke)*? We could go dancing.

EMMA

Behave yourself, you!

JUNE

I will not! I'm making this night count.

SUE

You're going to get us into trouble.

JUNE

Ah…but I've got a get out clause, haven't I? "What do think you were doing?" "Haven't got a clue, can't remember." *(Laughter)* I'm gonna milk this bastard while I still can. Seriously, I would like to go dancing. Before I end up in some bloody dementia disco dancing to Boney M. I hate Boney M.

EMMA

What are you like?

SUE

If you want to go dancing babes, we'll go dancing.

JUNE

I do. *(Pause)*

EMMA

Do they really have dementia discos?

JUNE

Oh yeah, they have all sorts. I got in the taxi after being at the support group the other day, but it wasn't one of the usual drivers. He said 'whereabouts do you live?' I was like "It's no good asking me, I've just come out of the Don't Remember Society, haven't I?" Dozy twat.

SUE

Oh my God.

EMMA

What did he say?

JUNE

You should have seen his face….I felt a bit sorry for him.

SUE

She takes no prisoners, does she?

JUNE

What do you mean, it was a great training opportunity for him? I said "look love, I'm not sure where I live, I've got dementia, so you're gonna have to help me, here." Poor bugger was mortified. He goes "I'm sorry about that, sweetheart." I went "Not as sorry as me. And don't call me sweetheart." He said "I'll tell you what I'll keep driving round, give us a shout if you see anything familiar. I won't charge you any extra." Eventually, I recognized the garage at the end of our road, so I yelled 'STOOOOOP!' The taxi came to a screeching halt, did a quick u turn and he dropped me right at my door.

EMMA

But you know, I get lost in my own house.

SUE

Me too, I've got a shocking memory. Sometimes I find myself on the landing, and I can't remember whether I was going up the stairs or down the stairs.

JUNE

(A serious realization)

The other day I caught myself with a jar of mayonnaise in my hand, standing in front of the fridge. Couldn't remember whether I was putting it away or about to make a sandwich.

The truth brings them all down to earth. Sue tries to make light of it.

SUE

Luckily, I don't have that problem, touch wood. *(She raps her knuckles on the bar-it's a joke)* Oh, that must be the door. I'll get it.

They laugh.

JUNE

Just nipping the loo. Pass us me bag.

EMMA

Aren't you passed all that?

JUNE

I'm not after a tampon, you fool. It's a bloody Tena Lady. And it's your round. I'll have

a G & T.

June leaves. Awkward pause.

SUE

Oh God.

EMMA

I know.

SUE

She's handling it so well, isn't she brilliant?

EMMA

You don't know what to say for the best do you? If it was me…

SUE

…I'd be sat in the corner going wibble wibble.

The inference being…

EMMA

Don't! *(Pause)* It's mad isn't it?

SUE

The whole world is mad.

EMMA

You've got to laugh, haven't you?

SUE

Absolutely. Let's all have a drink and a laugh, eh?

SCENE 1

CISSIE

Oh are you still 'ere? so am I. I come from me home, well I've just been to have a little check up on things. From a home to this home. Makes you wonder what a home is and how you can lose it, I'm not losing mine. You won't catch me staying here with them, oh god no, no, no. They're doing well on it me little flat you know. It's got a nice bit of colour on it. Her from the landings came to have a look at it. Oh its very nice I suppose but its not to my taste. I threw the eye on her – she'll never know the taste of fresh milk ever again. Well here we are again I can't tell you about the state of this place – it leaves a lot to be desired. Its not your home is it, its not your home and I don't half feel sorry for the ones who haven't got a clue where they are, where there home is. No wonder they get confused, cos there's all sorts going on every day.

Some people complain about there being people from different parts of the world and they are all working dead hard you know. There's all different voices, colours and accents, I like it. It makes me think I'm on holiday you do you know I like it here. They work very hard an all you know.

Honestly this place it's like Miami Vice. You wouldn't believe the goings on og god almighty, you could write a book about it, if you could remember half of what you wanted to put in it. There's a fella who's coming in and out a nephew of one of the ladies, she on about the second landing. He's in and out, in and out. And everyone say ah isn't he lovely he's always coming to see his aunty how sweet is that, he a good boy isn't he coming to see his aunty isn't he? Isn't he lovely? But I'm not so daft. You can't keep me behind that door. He's only taking her medication and selling outside at the bus stop. And I know that for fact, I've got that from the horses mouth and call me feckin dobbin. That's what it was, and then there was another panick the other day cos of them drugs. They found a big stash, in the wardrobe, the woman in no. 23, oh go dthere was murder. They had the doctor in and everything. They thought she was going to kill herself. She was like that, You stupid bastards that's two week in Rhyl that.
 (She goes for a moment) Did I or did I not say, I'm not one for jangling?!

She leaves. Change.

SCENE 3

TINA

(She takes his hat off)

When Dad was still at home he would insist on the TV being on, constantly in the background. It's like it grounded him in some way, he would fall asleep then wake and stare at the afternoon gardening programs.

Hello, Dad, how are you? Oh, you're watching Charlie Dimmock again?

ALAN

All she does is talk about sex. Can you get me a boiled egg love? *(She goes to get the egg)* Do you know three things happen when you get to my age. One you start to lose your memory… and… I've forgotten the other two. I often find myself looking at lady's bottoms just can't remember why, anymore.

(passes Alan the egg. Alan puts his hat back on)

TINA

Here you go, Dad.

ALAN

What's that?

TINA

It's an egg.

ALAN

What am I supposed to do with that?

TINA

Eat it.

ALAN

Give it to the man who stole all the memories. I hate boiled eggs.

ALEX

Come on, dad.

SCENE 5

TINA

During Dad's assessment, he was really polite. His dementia has affected him in such a way he had become a sweet and gentle old man but a little bit fruity in a Carry-On kind of way. Crikey, one day I caught him chasing one of the home helps around the coffee table. (BEAT) It got too much. We had to put him into a home.

ALAN

Now thank you very much now bye bye bye. Yes, thank you very much now bye bye bye bye.

SMART LADY

Who's he?

TINA

This is my Dad, he's called Alan, my name is Tina. Nice to meet you, what's your name?

SMART LADY

I'm not telling you. I don't want to.

TINA

That's all right.

SMART LADY

Who is he? Who is he?

TINA

This is my Dad his name is Alan.

(Alan laughs)

ALAN

(Tarzan)

Ah ah ah ah…

SMART LADY

I will tell you my name.

SMART LADY

It's the Royal Bank of Scotland, Miss

SALLY

Bank of Scotland? Royal bank of Scotland? Ha! Kiss me arse me arse, me arse. Haha

JUNE

What are you on about?

SALLY

It's awful

Worse than being at the dentist.

JUNE

The hospital. (BEAT)

Fuck off

SCENE 7

CISSY

Oh hello again... It's funny I can't remember what happened last Tuesday but I can remember when our Theresa didn't bring that cake stand back and that's why she wasn't invited to the bloody wedding. Still you never know what's going on in here from one minute to the next but the staff do try you know. They try to make it lovely for yer. There's young girl who looks after me ah bless her and she comes in and she got eyebrows like she's just won the 2:30 at Kempston. But she smiles and she's lovely. Do you know they take all your washing away for you and it's a bloody gamble what you get back. Honest to god you never know what's gonna be in the friggin basket. And I noticed light fingered Lil walking round with a sheep dog look on. You know sheep dog – light em up and point them in the right direction and my new pearly corselet from TJ Hughes. What can you do about that? I tell yer I can't wait till my flats been sorted. I'm straight off even if I have to drive that taxi meself.

Last time I was at my flat I didn't half get a fright. There I was sitting nice and tidy watching Countdown whne suddenly there's a ran tan tan on me door. Well I nearly shit a brick. It was only nonnie from across the landings. There she was gave me the fright of me life, she'd only gone and won herself one of those fake bakes at the Bingo. Well she looked like a chewed toffee.

Sometimes I do feel sorry for our nonnie. Well there's been this fella hanging around hasn't there? We all know he a bit of a lothario but not poor nonnie, well he's got his eye on her cos she nice and tidy she looks after herself you know, got a few bob she's been looking after her pension. And the next thing you know her bus pass has gone missing and he's been seen riding around on the top of the 60 with hat and a matinee coat that he got from the Oxfam shop.

Movement to denote Tony is visiting June.

JUNE

Who do I have to speak to get out of here? *(Turns to TONY)* Do you work here?

TONY

It's me love. It's me.

June goes back to the door.

TONY

My wife June has dementia - she was diagnosed around six years ago. I met June at my sister's 21st birthday. She was a police-officer, and came straight from a shift – but she threw herself into the party. At the end of the night she said, "I'm going canoeing in Richmond in the morning, meet me there." And that was it. We have been married ever since.

June was adventurous and sporty, and we spent our holidays walking and camping. She loved a drink and a laugh. My wife had a big family and we were always at parties.   June was the centre of attention when she walked into a room.

A few years ago, I started noticing changes in her. The thing is…it effects everyone differently. If you meet a person with dementia…you've met one person with dementia. I became her main carer. For a while we had a nurse who came to wash her hair and do other bits but that was only temporary. A couple of years in, it was clear I couldn't cope with it at home. The first place she was in had a square building and for exercise and activity they would get them to march around the corridor. It was awful leaving her there. But now we've got her in a lovely place it is an amazing home, they do make the effort to keep the people happy. It's really important to keep your sense of humour. I guess June's sense of humour is the one thing that remains of her.

For me, it's very lonely. Your life shrinks. Our families live quite far away and they rarely visit now because she gets agitated in the lounge or with other people in the home. Some days when I visit June struggles to hold a conversation. We watch TV, but I don't know how much she understands.

My worst fear is that something will happen to me. If I am not with her, she can get agitated and distressed. We are still as close as we can be in the circumstances. Of course, I still love her. I know that her essence is still there, even though the June that was, has gone.

Getting Jun into a nursing home wasn't half as bad as getting a diagnosis. We sat in the clinic while the doctor conducted a series of cognitive tests. One was a verbal questionnaire about general knowledge and current affairs:

SCENE 7 R&D FINAL SCENE TO INSERT CLICHES/PHRASES AND SONG LYRICS

DOCTOR (Laura)

What's your name?

SMART LADY

Royal Bank of Scotland

DOCTOR

Where do you live?

ENID

Hartsheath Castle - the servants will show you to the dining room.

DOCTOR

What year is it?

SALLY

1967-9 - where's my mum? I was there when Tommy Cooper Died

DOCTOR

Who's the Prime Minister?

ALAN

I don't know but I don't like him.

DOCTOR

Do you know where we are?

ALAN

Well, if you don't know, God help the rest of us.

SALLY

We weren't always old we just got that way.

ENID

It's far-fetched this writing of my life. I must tell you the tale of my life, madam, but I don't want my tea to get cold.

SALLY

I'm suffering from a monkey-puzzle. The Monkey-puzzle is this place.

SMART LADY

I was a dancer with the Ballet Rambert

Henry Mancini Moon River Piano fade up slowly until dance with it

ALAN

The brilliance of my brain slipped away when I wasn't looking.

TINA

My Dad's GP was a close friend, an extraordinary man – he offered the best advice to my Dad. He urged him to stop assaulting Alzheimer's head on.

DOCTOR

You can't win in a head butt. That doesn't work. You just have to learn to dance with it.

SMART LADY

Don't put the cart before the horse. Tune the guitar first.

ALAN

He who sells an ox today, will have an egg tomorrow.

ENID

In real life, one must look out of the window.

JUNE

What doesn't kill you makes you stronger.

ALAN

One must always think of everything.

ENID

Take it to the top, One should always take it to the top

SALLY

Know your onions

ALAN

Boy is that woman a fatty! Hey sweetheart—lay off the cupcakes!"

SALLY

When are we going home?

ENID

Well, we can't set off today, but we will go tomorrow.

JUNE

Nevertheless, You can't teach an old dog new tricks

ENID

When I'm in the country, I love the solitude and the quiet.

SALLY

Oh yes I do too, the grass is always greener.

JUNE

Are we going home? I won't be any trouble. I'll sleep on the floor.

ENID

What day is it?

SALLY

Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday.

ALAN

Where's my keys?

ALL

Al's took 'em.

JUNE

The road to hell is paved with good intentions

ENID

I'll climb to the highest steeple and tell the world he's mine

SMART WOMAN

I'll give you my mother-in-law's slippers if you'll give me your husband's coffin.

JUNE

Are we going home?

ENID

I'm looking for a priest to marry to our maid.

SALLY

My uncle lives in the country, but that's none of the midwife's business.

ALAN

I've got loads of bricks, just no cement.

SALLY

What goods a man in your bed if he can't remember anything?

JUNE

Working class hero, working class traitor.

SALLY

We weren't always old we just got that way.

ENID

It's far-fetched this writing of my life. I must tell you the tale of my life, madam, but I don't want my tea to get cold.

SALLY

The puzzle is - How do I cope with the monkeys?

SMART LADY

I was a dancer with the Ballet Rambert.

SALLY

Can I come home? I'll sleep on the floor.

ALAN

The brilliance of my brain slipped away when I wasn't looking.

SALLY

I won't be any trouble.

ENID

My Dad's GP was a close friend an extraordinary man – he offered the best advice to my Dad. He urged him to stop assaulting Alzheimer's head on.

DOCTOR

You can't win in a head butt. That doesn't work. You just have to learn to dance with it.

Lights down.

SILVER BELLS AND COCKTAILS – A Life in Lockdown Play Script

SCENE ONE

Edie and Evelyn residents from Meadowland Court break into the unauthorised part of the garden during curfew (lockdown). They are setting up for a party away from the prying eyes of the neighbours in the road.

Edie – are you in or are you out? Let's face it last year we were in and out of lockdown like the blooming hokey cokey.

They continue setting up putting up the bunting and places the boxes around the performance space while having a bit of a song and a laugh.

"Up for a party, flower? You're not gonna grass us up to the rozzers are you? Look at the nose on him! You look as if you like a drink, love. Have you got any drugs? Jesus, with a face like hers…giz that back, I'm uninviting you."

Are you happy to be out love? – tell your face then…Blah blah. Oh you've maxed your Matalan card haven't you. How have you been coping with TJs love?

They introduce other characters and argue over the rules – what they can and can't do – Edie bosses Evelyn and takes charge. Evelyn wants to party but she's worried about what people will think (especially her daughter).

Both carry on setting up… sing a song from one of Joe's mix tapes.

Jimmy Ruffin's What Becomes Of The Broken hearted

As I walk this land with broken dreams

I have visions of many things

But happiness is just an illusion

Filled with sadness and confusion

What becomes of the broken-hearted

Who had love that's now departed?

I know I've got to find

Some kind of peace of mind

Maybe

The roots of love grow all around

But for me they come a-tumblin' down

Every day heartaches grow a little stronger

I can't stand this pain much longer

I walk in shadows searching for light

Cold and alone, no comfort in sight

Hoping and praying for someone to care

Always moving and goin' nowhere

What becomes of the broken-hearted

Who had love that's now departed?

I know I've got to find

Some kind of peace of mind

Help me

I'm searching, though I don't succeed

But someone look, there's a growing need

Oh, he is lost, there's no place for beginning

All that's left is an unhappy ending

Now, becomes of the broken-hearted

Who had love that's now departed?

I know I've got to find

Some kind of peace of mind

I'll be searching everywhere

Just to find someone to care

I'll be looking everyday, I know I'm gonna find a way

Nothing's gonna stop me now

I'll find a way somehow

And I'll be searching everywhere

I know I gotta find a way

I'll be looking

Big Truck comes in and turns the music off.

Big Truck: You can hear that down the street - what you trying to do? Get the bizzies after us?

Edie: What are you doing down the street anyway? Al right mate we'll be on our way (winks at Evelyn)

They crack on they're going to leave but they don't.

Big Truck introduces Mabel.

SCENE 2

MABEL   Mabel. Number 26. I've not been here that long. I moved in just before Christmas, 2019. Before the Big Lockdown. I've only got the one son, Kelvin, he's down south, I didn't want him to have to worry about what would happen to me in future, so I thought 'best jump while you've still got your faculties and before you're pushed'.

To tell you the truth I wasn't looking forward to it one bit, but wow! I absolutely love it here. Best thing I ever did, apart from my divorce. It's brilliant here. I've never had a better social life. There's a big community space downstairs. I hadn't even finished unpacking my boxes when I got invited to the Christmas party. My God, what a 'do' that was.

Joe Jive Teddy is teaching the cha cha cha to Evelyn.

Everyone was so welcoming, like they'd known me forever. There was a Christmas dinner laid on, entertainment, a table full of drink, you name it. I've never danced so much in my life, only got to bed after 2. I've made so many friends. Good friends. We go on day trips,

Joe: Friday's fish and chips nights, and there's bingo,

MABEL: Honestly you would not believe it. Of an afternoon we'd be down here for a jangle with a pot of tea and a packet of biscuits on the go. I absolutely love it. BEAT. I say love it I

mean I *loved* it. Everything has had to stop, hasn't it? It may sound selfish, but it feels cruel, all these new friends, this new life and then…

Kelvin calls "How are you doing, mum?

MABEL: Great, love, I'm doing great. (back to audience) He'd only worry. At least I can get out for a walk. It's the ones with health issues I feel sorry for. Some of them have never been over the doorstep in almost a year and they're frightened of people bringing stuff in so…a few of us ring round checking on people but it's not the same.

And that rule of 6 thing could never work here. How could you choose just 6 people and leave so many others out?

BEAT.

But not long now, eh? It sounds daft but the first thing I'm going to do is get on a bus. I've really missed catching the bus. All those different faces, listening to all the chatter, people smiling just for the sake of it. I even miss the screaming kids. I don't know what it is but when I …BEAT…I think it's that feeling of going somewhere with lots of different people, all carrying our own lives, our own stories. But together. When I get a bit low that's what I look forward to. I can't wait. Not long now, eh?

SCENE 3

ELLA   Dad, Dad?   (has to shout cos he's hard of hearing.   Goes through his post and passes him the newspaper.)

MALLY: Mally Number 10, ground floor.

ELLA: I pop in most days. Mores the pity. He's always been a cantankerous old bugger, my dad, but this has made him much worse. All we do is argue, it's really getting me down. My daughter says, "He's horrible to you, leave him to it." I wish I could, but he's my dad. We used to have a laugh. BEAT. It's the rules that do his head in the most. And the fact it's the Tories making them. Every time Boris is on the telly with his 'Hands, Face, Space' it sets him off.

Mally: How about fist, boot, arse? Now, fuck off.

ELLA I refuse to take him shopping anymore. Every time we came to use hand gel in public he'd go…

MALLY: (SPITS ON HANDS) This is how I wash my hands. I don't need chemicals. They can frig off. You need a bit of dirt for your immune system."

ELLA: And he's quite loud so I'd be mortified. I do a shop for him on a Friday now, anything else he can get himself from the corner shop. It sounds awful that I'm leaving an 86-year-old to go out to the shops while all this is going on but there's no stopping him. Believe me I've tried, you don't what he's like.

MALLY: Since when has the flu stopped people going about their business?

ELLA Erm…when you're ill, in bed with the flu, dad?

MALLY: And NO. I am not wearing that flamin' face rag. Who do you think I am, Batman and soddin' Robin?"

ELLA: I try to reason with him, but it always ends up in row. With me turning into a 6-year-old again. Sometimes I go home in tears. I think, that's it. I'm not going back. BEAT. Then I can't sleep all night for worrying about him.

(During the first lockdown, he was brough home in a police car. He'd only been caught playing crown green bowls! Can you imagine? A load of geriatrics running off in different directions, trying to escape arrest! Luckily, he got off with a caution. I've tried to explain that it's selfish.

MALLY: Selfish? You've got years ahead of you, you can write this one off as if it's nothing. Do you know what one year means to me? Do you think I want to spend it like this? 'Think about other people'? According to our 'great and merciful leader' I'm not the granny killer."

ELLA: I know he doesn't mean it. I know he's just worried because when I went round the other day, after he'd told me not to bother coming back for the umpteenth time this month,

there was a massive, and I mean massive, like bigger than me massive, teddy bear sat on the chair. I said, "What the hell is that?" He goes,

MALLY: What's it look like? It's company And unlike you, it won't answer me back."

ELLA: Sometimes I hate him! (feels bad for saying this)

We went for a walk the other day, to Camphill Woods. We didn't talk or anything, just walked through the woods, taking it all in. When we got back he started crying. I asked him why he was so upset.

MALLY: I'm not upset. I'm happy.

EDIE: (to Ella) How is he today? He'll soon cheer up love. Cissy lines. (Filler for Liam to change and enter as Paul)

Paul passes

PAUL (wearing a high vis):   I don't live here! Crikey, how old do you think I am? I'm a DPD delivery driver so I know the area well. Can you guess where I'm from? (BANTER WITH AUDIENCE) St Helens.

Edie: Wool!

Paul: Before you say anything, I've heard it all before. 'The place where ideas go to die", that was the latest. Oh, how we laughed. I deliver round here a lot. It's quite nice but… it's funny….we've never been busier or on a tighter leash where time is concerned, and I get that everybody is worried about their own situation. But these past few months have been very weird. We've all had to find our own rhythm, haven't we? We're getting used to it but…not sure if that's a good thing. I used to like my job but there's so much pressure…still…can't complain. It's a job isn't it? I'm lucky I can get out and about. Not that everyone is pleased to see me, round here. Most people are fine, a few pleasantries, make the drop and get out of there. But some people are scared to open the door, I have to coax them, all the time I've got my eye on the clock. And it's brought out the worst in some. Delivered a parcel the other day, a box about this big. It was heavy enough for me, the old lady would have struggled to pick it up from the floor and, understandably, she was worried about me getting too close, so I said, "if you step back, love, I'll put it on that little table for you." Which is what I did. Just trying to help out.

She only went and reported me for going into the house. I got carpeted for that. My sister-in-law works in the Asda, someone rang up to complain about her not wearing a mask. She was

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behind a screen. I dunno. I'm beginning to think it suits that lot in charge, to have us all at each other's throats. "Oi get away from that van you little get."

SCENE 3

Evelyn: He's a lovely bloke Paul isn't he?

Edie: Eye he was telling me that he'd set up a spinning centre just before lockdown. Couldn't get a penny poor sod.

What about pilot as a decorated or is this too cliched?

Edie and Evelyn set up a shrine in the garden to remember those who have died.

Edie: I do miss a good funeral.

Evelyn: Oh I do too. Sitting at the back and checking out the sandwiches.

Edie: Yeah that and casual sex BEAT the two biggest losses during lockdown. (or is this more a line for Tracey?)

Big Truck has found an invite and approaches Edie about it. He threatens to report her to the police but she stands up to him and calls his bluff. (They talk about the NHS, the law, lockdown) – Edie takes a political stance and makes a stand. He can't go through with it – he'll never be a grass. He leaves her to it. Evelyn enters. She gets a phone call from her daughter. EVELYN'S DAUGHTER DOESN'T WANT HER TO GO TO THE FESTIVAL. SHE GIVES HER AN ULTIMATUM. 'IF YOU'RE GOING TO PUT YOURSELF AT RISK LIKE THIS, WHY SHOULD I COME ROUND TO SEE YOU?'

SONG – Stand by your gran

Ideas for Stand by your man lyrics

Sometimes it's hard to be a grandma
When the little sods come cap in hand

You'll have your uppers, and you'll have your downers
Summat the kids don't understand
Cos when you love her, you forgive her

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Even when her tourettes gets out of hand

Although she curses, They know where her purse is

'Cause after all, she's yer bloody Nan

Stand by your Nan

She not too old to visit

It's not her fault is it?

The nights are cold and lonely

Stand by your Nan

And show the world you love her

Keep givin' all the love you can

Stand by your nan

Stand by your Nan

She's not just any old has been

She's a Liverpool queen

Who's spent many a night at the Grafton

Stand by your Nan

And show the world you love her

Keep givin' all the love you can

SYLIE: Sylvie, number 49. *(She is doing yoga via zoom?)*

I shouldn't be here…I shouldn't. I should be sitting on a beach in Goa with Pete and all our mates, watching the sunrise. I'd have perfected my downward dog by now I'm sure. Pete and I were free spirits - but it wasn't to be. I broke my bleeding hip, I was shopping one morning in Marksies for some holiday bits and what did I do? Decided to take the stairs instead of the

escalator. I had my head in the clouds, daydreaming of Shiva…and I only went and fell right down them. – Miss "Thinks she's so invincible" definitely wasn't!

We decided to put India on hold and we moved in here…five years ago that was. It took a while to adjust but we grew to enjoy it, made some good friends. Unfortunately, as soon as we got settled, Pete passed away – a pulmonary embolism – it was such a shock, we'd been married 45 years… he was my soul mate.   (She lights a candle for Pete)

I'm so glad he hasn't had to go through all this lockdown nonsense. I can just imagine what he'd have to say about the way it's all been handled! He was never Mr Johnson's biggest fan.

My daughter, Amy, is a nurse in Aintree, she's calling me every day to make sure I'm behaving myself. I've told her I'm fine, to leave me be and make sure she's getting plenty of rest after all the extra shifts she's doing. BEAT

Big Truck: Hey Sylvie didn't I see you come out of Tracey's last night?

SYLVIE/TRACEY: Me nooooooo!/It was only for 5 mins.

I keep myself busy. Plenty of Vitamin D helps apparently and turmeric… I bung it in everything! I made a huge curry yesterday and left a bowl on Joe's doorstep next door, …he's an angel, bless him. **(impro)** He checks up on all the residents, organising quizzes and things to keep us busy… Tracy has a huge crush on him so she wasn't too happy when he was raving about my spicy chicken dahl. I said Tracy, I'm not trying to entice him! I'm just being bloody nice" **(Tracy – yeah whatever)** She's not been here too long so she never met Pete…if she did she'd realise there's no room in this heart for any other man…

That's the hardest thing about this isolation – gives me too much time to think – think about the past, and all the memories….

(sitar/yoga music and yoga poses – invite is put into her hand)

TRACY   Number 45, Tracy Anne Jones. And it's Anne with a E…Nobody ever remembers the Anne though– it really gets on my wick. My mother gave me a middle name for a reason! I decided to come here because I got fed up of waiting for husband number 5 so I thought I'd meet some new people. I can't stand being on my own you see. I hate it…My mother used to call me a social butterfly. My dad just called me slut. I don't have much family left now

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though, not since my brother died. And I never had any kids, it just didn't happen unfortunately.

My niece and nephew do keep in touch but they've got busy lives.

So I thought, "right Tracy Anne, you can't sit around the flat moping, you need to get out there and meet people". I looked around, visited a few places and well, Meadowland seemed to be the one. As soon as I walked in, I got a warm, fuzzy feeling. **(Joe- I'll say you did!)** I was having a ball until the bloody lockdown. I really felt like I'd won the lottery getting a room overlooking the gardens and of course having Jivin Joe next door. He's hilarious, full of beans that one. He has a chat with me everyday and he's sent me some youtube dance links so I can practice my cha cha cha. He reminds me of husband number 3 – Nick. My Nicky was perfect, we had such a laugh together and we'd have continued living in married bliss if he hadn't been run over by a friggin Ice cream Van – Mr Whippy! Of all things! He was mortified. It didn't kill him but it set off all his health problems and definitely caused the stroke he died of a year later. He was so young, only 53. My Nicky… His eldest, Adam still keeps in touch, sends me a text every now and then and I always get a beautiful Christmas bouquet. After Nick, came Jim – well the less said about Jim the better. That swine swindled me out of thousands he did. He was as dodgy as they come and I'm sure he's having fun in his new pad down at Kirkham prison.

 You'd think it would put me off meeting someone new wouldn't it…but no, I'm still a hopeless romantic and there's plenty of passion in these veins. Speaking of passion, I was telling Joe yesterday to watch "Bridgerton" **(audience interaction – have you seen it?)** but he didn't seem too fussed. He was too busy singing the praises of Sylvia's curry. She say's she's not interested in him but she didn't leave a bowl on anybody else's bloody doorstep! She's one of those…full of good karma and dead spiritual. She goes outside of a morning and medidates. Tells me I should try it. Maybe I will. She's not too bad and I need to stop watching the telly! I think I've been through everything on Netflix twice now. Oh but that Duke, what a sight for sore eyes he is. I'd certainly choose his naked arse over Mr Darcy's wet shirt any day of the week I can tell you! **(*starts to sing voulez vous couche avec moi – ce soir into slut drop*)**

SCENE 4

JOE   Oh ey up. I love music…it's the thing that has really kept me going through all of this– spinning my tunes. Number 47, Joseph Williams, I'm 76 years young I am! I'm forever getting warnings from Big Truck. He's always telling me to lower the volume or he'll get me done for noise pollution! We have a bit of banter we do - He's just got terrible taste in music. I tell him. "You wouldn't know a quality piece of vinyl if it jumped up and smacked you in the face fella". I'm trying to educate him but he's having none of it. I caught him dancing to some boy band on the telly last year – before we were all put under house arrest and I had to have a few words. I gave him a mixed tape with my… "essential must listen to and appreciate before you die songs!" **(He sings a line from motown songs – my girl, ain't too proud to beg, abc, Saturday night at the movies and jimmy mack)**

I'm the head of light entertainment here at Meadowland. I love organising all the quiz nights, jive dancing, games, afternoon teas – you name it, I've done it. So I've tried me best to keep it all going… Big Truck kindly prints out the weekly quiz and then I post them through everyone's door. Keeps the spirits up. **(Alright Alright, show off)** They love it.

I'm not going to lie though – it's been tough – really tough -not seeing my kids and grandkids. I mean they've come to the front gate and we've chatted but nothing beats a good hug does it? I'm a hugger me you see. Why do you think I got into the dancing? I just want to grab them in my arms and give them a bloody huge big bear hug. It's such a simple gesture isn't it – that we take for granted.

I honestly didn't think it'd last as long as it has, the social distancing, the masks, all the rules but we've got to take it seriously haven't we, otherwise we'll never bloody get back to normal. All these young ones meeting up in groups down by the beach and bending the rules….it's just going to keep us inside for longer. **(receives the invite)** And I need to get out, get back to normality**….(reads it)** I want me hugs back!...I'm counting down the days.

Jo invites Edie and Evelyn who are drinking and smoking weed through a bong – chatting about their families.

Finale song: Ain't no mountain high enough

Ain't No Mountain High Enough

Marvin Gaye, Tammi Terrell

Listen, baby

Ain't no mountain high

Ain't no valley low

Ain't no river wide enough, baby

If you need me, call me

No matter where you are

No matter how far (Don't worry baby)

Just call my name

I'll be there in a hurry

You don't have to worry

'Cause baby

There ain't no mountain high enough

Ain't no valley low enough

Ain't no river wide enough

To keep me from getting to you babe

Remember the day

I set you free

I told you

You could always count on me darlin'

From that day on I made a vow

I'll be there when you want me

Some way, some how

'Cause baby

There ain't no mountain high enough

Ain't no valley low enough

Ain't no river wide enough

To keep me from getting to you babe

Ho no darlin'

No wind, no rain

Or winters cold can stop me baby, na na baby

'Cause you are my goal

If you're ever in trouble

I'll be there on the double

Just send for me, oh baby, ha

My love is alive (Hoo)

Way down in my heart

Although we are miles apart

If you ever need a helping hand

I'll be there on the double

Just as fast as I can

Don't you know that

There ain't no mountain high enough

Ain't no valley low enough

Ain't no river wide enough

To keep me from getting to you babe

Don't you know that

There ain't no mountain high enough

Ain't no valley low enough

Ain't no river wide enough

Ain't mountain high enough

Ain't no valley low enough

THE END

Appendix 3

Participation Information Sheets and Consent forms

LIVERPOOL JOHN MOORES UNIVERSITY

RESEARCH GROUP PARTICIPANT INFORMATION SHEET

Title of Project: How arts and culture impact on people living well with dementia?

Ref: (LJMU REF:)

Dear Sir/Madam,

You are being asked to take part in a research study on the suitability of the cultural offer of arts activities for people living with dementia in Liverpool. The LJMU Research Ethics Committee has approved this project.

In this study, you will be asked to become a co-researcher and explore your experience of a variety of arts and cultural activities. A number of arts organisations such as Tate Liverpool, FACT Cinema, Merseyside Dance Initiative and The Royal Court Theatre are offering activities for people with dementia and you will be invited to suggest your own activities. We will be discovering what is really important to you and what has little impact. You will be provided with a camera, note book and mini voice recorder to assist you as you experience each activity. After each activity you will be asked to take part in a group discussion where we will all share our views.

TIME COMMITMENT

This research will take place over six months. You will be invited to five arts activities one a month starting from June. Immediately after the activity you will be provided with refreshments and we will hold a group discussions. You will also be required to attend a further group discussion a week later again refreshments will be provided.

During the final month we will be developing an exhibition and comedy performance of our experiences to share with decision makers, policy makers, friends and family.

COST, REIMBURSEMENT AND COMPENSATION

Your participation in this study is voluntary. You will receive free entry to all of the activities and refreshments will be provided.

PARTICIPANTS' RIGHTS

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed.

You have the right to omit or refuse to answer or respond to any question that is asked of you.

You have the right to have your questions about the procedures answered (unless answering these questions would interfere with the study's outcome). If you have any questions as a result of reading this information sheet, you should ask the researcher or your scheme manager before the study begins.

BENEFITS AND RISKS

There are no known physical risks for you in this study. There may be some emotional issues if you are experiencing issues with memory problems and concentration difficulties. We will be supported by community health nursing practitioners who have experience in working with older people.

CONFIDENTIALITY/ANONYMITY

The data we collect does not contain any personal information about you except. No one will link the data you provided to the identifying information you supplied (e.g. name, address, email, contact telephone number).

It is expected that part of the work will be developed into an exhibition and performance, all data will be anonymous unless otherwise instructed and agreed by participants. In addition part of the work will be published in academic journals and/or in the form of an academic book. It is also part of the creation of academic knowledge, to present and discuss the outcome of the research in academic seminars and conferences. You will be advised where to access any journal or conference papers published from the work. You will also be offered the

opportunity to receive a summary of the results. In doing so, individual participants will not be identifiable.

FOR FURTHER INFORMATION

Elaine McNeill the research facilitator will be glad to answer your questions about this study at any time. You may contact her on tel 0151 904 1140 or email e.mcneill@ljmu.ac.uk

If you want to find out about the final results of this study, you should contact Elaine McNeill.

If you any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

Contact details of Research Group Coordinator:

Elaine McNeill MSc, BA hons FHEA
Student Development Coordinator, Liverpool School of Art and Design

The John Lennon Art and Design Building, Duckinfield Street, Liverpool, L3 5RD
t: 01519041140 e: E.McNeill@ljmu.ac.uk

Participant Consent Form

(Focus Groups)

Ref: (LJMU REF:)

LIVERPOOL JOHN MOORES UNIVERSITY

PARTICIPANT CONSENT FORM

Title of Project: **How arts and culture impact on people living well with dementia?**

Ref: (LJMU REF:)

Name of Researcher and School/Faculty: Elaine McNeill (Liverpool School of Art and Design)

Material gathered during this research will be treated as confidential and securely stored. Please answer each statement concerning the collection and use of the research data.

Read carefully		
Items	yes	no
I confirm that I have read and understand the information provided for the above study. I have also had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without a reason and that this will not affect my legal rights.	☐	☐
I understand that any personal information collected during the study will be anonymised and remain confidential.	☐	☐
I agree to have my statements audio/video recorded and activity (if undertaken) photographed, and its contents being used for research Purposes	☐	☐
I agree to the use of anonymous quotations in any publication that derives from this research.	☐	☐

I would like to receive information regarding the outcome of the research project.	☐	☐
I agree to take part in the above project.	☐	☐

Name of Participant: Date   Signature

Name of Researcher   Date   Signature

Name of Person taking consent   Date   Signature

(if different from researcher)

<u>Focus Groups Consent to recording and photographs</u>

Title of Project: How arts and culture impact on people living well with dementia?

Ref: (LJMU REF:)

Section one

General and Demographic information to support themes:-

Demographic	
Title	
Gender	
Age	

Organisation	
Position	
Department	
Day	
Start time	
End Time	
Email (optional)	
Contact number (optional)	
Agree or did not to be recorded	
Agree or did not to be on video	
Agree or did not to be photographed	

Participant Information Sheet for Lockdown Labyrinth Arts Activities

The Usefulness and Significance of Arts-Based Lockdown Labyrinths during Epidemics

LJMU's Research Ethics Committee Approval Reference:

Thank you for your interest in the Lockdown Labyrinth study. Here is some further information regarding the nature of the study, along with the answers to some questions you may wish to ask. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

** If you decide to take part in this study the activities must be completed with members of the household that you are socially isolating with or alone.

If you have any questions or wish to talk through being involved in the study, please do not hesitate to contact:

Elaine McNeill on: **07782482733** or Email: E.McNeill@ljmu.ac.uk

Elaine is a PhD Student Researcher at Liverpool School of Art and Design

What is the purpose of the study?

The primary aim of this study is to investigate the experience of using arts activities to reflect on our experiences of social isolation during the lockdown. The COVID-19 pandemic found many of us adjusting to a very different way of life. The arts sector devised a host of imaginative ways to help to improve the mental health and wellbeing of communities during social isolation. With this study we hope to explore what arts activities have been useful during epidemics.

Why have I been invited to participate?

You have been invited because you showed an interest in taking part in the Lockdown Labyrinth project.

This study is looking for people:

- aged 18+
- have been/are in social isolation due to the UK's Covid-19 Lockdown
- individuals/couples
- families with children
- students
- creative practitioners
- willing to take part in lockdown labyrinth arts activities before 20th June
- happy to communicate in English

Unfortunately, if you fit any of the following criteria you will not be able to take part:

- If you are not willing to give signed consent
- If you cannot adhere to the study protocol
- If you are not able to read English

Do I have to take part?

No. It is up to you to decide whether or not to take part. This study is completely voluntary. All aspects of this study are described in this information sheet and a copy will be given to you. I will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

There are four aspects to this study.

1. Arts activities

You will be invited to take in an arts activity based on experiences of being in social isolation during the UKs lockdown.

2. Activity Evaluation Questionnaire

Following the arts activity, you will be invited to complete an online questionnaire with 9 questions asking you about your experiences during the arts/labyrinth activity. This should take approx. 15mins.

3. Semi-structured interview

You will be asked to participate in a single 20-30min interview to talk about your experiences of

Lockdown arts activity either using an online communication tool such as Zoom or Skype, or over the phone with as many breaks as required by yourself. Interviews will be audio recorded on a password protected audio recording device and as soon as possible the recording will be transferred to secure storage and deleted from the recording device. Once the recording has been transcribed it will be deleted entirely.

The interview will last about 20 minutes and will include questions like:

• What did you learn from taking part in the Lockdown Labyrinth arts activity?
• How would you describe your experience?
• What worked well? why?
• What did not work well? why not?
• What was your understanding of your experience of social isolation prior to taking part?
• How do you think this type of activity can help people in social isolation?

You will be able to skip questions if you wish. Once the interview has been written up, you will be given the chance to review the data, to test accuracy of interpretations and conclusions.

Are there any possible disadvantages or risks from taking part?

There is a possibility that some of the reflections whilst engaging in the arts activities and/or topics discussed in the interview may cause distress, although every effort has been made to

minimize the chances of this happening. If you are personally affected by participating in any part of this study, you may wish to seek support/advice.

Mental Health UK provides information for managing your mental health during the coronavirus outbreak. https://mentalhealth-uk.org/help-and-information/covid-19-and-your-mental-health/

For children Emerging Minds have produced a list of useful age appropriate resources for children

https://emergingminds.org.uk/recommended-resources-supporting-children-and-young-people-with-worries-and-anxiety-links/?fbclid=IwAR1QZU3WXwt0ZagioIrQtj_e2hKLttkAuY9WzpzE5nkeIyn1oIzWjKnY7mw

What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in the study, it is recognised that creative activities can be useful for improving health and wellbeing, particularly if feeling isolated, anxious or depressed. It is hoped that this work will support many others who are socially isolated due to epidemics in the future.

What will happen to the data provided and how will my taking part in this project be kept confidential?

When you agree to take part in this study, we will use your personal data (e.g. name, contact details) so we can contact you with regards to the study activities. Personal data will only be accessible to myself the PhD Researcher and investigator. No personal identifiable data will be transferred outside of the European Economic Area. You will not be identifiable in any reports or publications. Pseudonyms will be used in transcripts and reports to help protect the identity of individuals and organisations unless you tell us that you would like to be attributed to artwork, information or direct quotes.

When we no longer need to use personal data, it will be deleted. However, your consent form, contact details and any interview audio recording will be retained until 2026. Should you

withdraw from the study, your research data will be destroyed, and subsequently your data will not be included in any publications.

Limits to confidentiality

Please note that confidentiality cannot always be guaranteed. In certain exceptional circumstances where you or others (i.e. children) may be at significant risk of harm, we may need to report this to an appropriate authority. For example, if:

- The investigator believes you are at serious risk of harm, either from yourself or others

- You pose a serious risk of harm to, or threaten or abuse others

What will happen to the results of the study?

The investigator intends to publish the results in a PhD thesis and a peer reviewed journal article.

Who is organising and [If applicable] funding/commissioning the study?

This study is organised by Liverpool John Moores University and funded/commissioned by BBCArt and Arts Council England (may include if necessary)

Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the Liverpool John Moores University Research Ethics Committee (Reference number: xxx).

What if something goes wrong?

If you have a concern about any aspect of this study, please contact the relevant investigator who will do their best to answer your query. The investigator should acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you wish to make a complaint, please contact the chair of the Liverpool John Moores University Research Ethics Committee (researchethics@ljmu.ac.uk) and your communication will be re-directed to an independent person as appropriate.

Data Protection Notice

Liverpool John Moores University is the sponsor for this study based in the United Kingdom. We will be using information from you and in order to undertake this study and will act as the data controller for this study This means that we are responsible for looking after your information and using it properly. Liverpool John Moores University will process your personal data for the purpose of research. Research is a task that we perform in the public interest. Liverpool John Moores University will keep identifiable information about you for 5 years after the study has finished in 2021.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the study to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at by contacting secretariat@ljmu.ac.uk.

If you are concerned about how your personal data is being processed, please contact LJMU in the first instance at secretariat@ljmu.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Thank you for reading this information sheet and for considering to take part in this study.

Please keep a copy of this participant information sheet along with a copy of the signed consent form, if you choose to participate in any of the study activities described in this Information Sheet.