The role of the family in physical activity post-myocardial infarction

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A thesis submitted in partial fulfilment of the requirement of Liverpool John Moores University for the degree of Doctor of Philosophy

August 2019

Abstract

Engagement in physical activity (PA) post-myocardial infarction (MI) can reduce the risk of reoccurrence and mortality, whilst promoting improved health and wellbeing. However, uptake to PA through cardiac rehabilitation (CR) is poor. Family support has been suggested as a mechanism through which PA can be both promoted and sustained. However, little is known about how the family support patients' PA post-MI. Therefore, the aim of this PhD was to explore the role of the family in post-MI patients' PA experiences to make recommendations for how they can support positive PA engagement post-MI.

Study 1 drew on interpretative phenomenology to understand how MI patients and family members experienced, and made sense of PA post- MI. Six families (1 post-MI patient, 1 family member) engaged in longitudinal semi-structured interviews approximately 1, 4-and 9-months post MI. Post-MI, patients appeared to go on a journey of learning to re-engage with PA leaving "normality", (characterised as patients being able to do what they wanted and when) and transitioned to a "new normality", (being active but within parameters of their experiences of the MI. The family appeared to go on and influence how patients experienced this journey also. The journey comprised three superordinate themes, 'I can't do what I was doing before', 'finding my way' and 'accepting this way'. The family appeared to influence post-MI patients' PA, however because this was not always positive, it is worthwhile exploring how to support families support patients' PA.

Study 2 used semi-structured interviews with 14 cardiac rehabilitation practitioners (CRPs) to understand their views of family involvement in CR through the roles they can adopt in post-MI patients PA experiences. CRPs appeared positive about familial involvement in CR and identified three themes as roles family might adopt to influence post-MI patients PA engagement: 'being a second pair of ears', ''pulling back, pushing forward' - keeping the patient within PA boundaries' and 'providing social support'. A fourth theme 'factors that influence family support' was found that influenced the level and type of social support provided by families. Family involvement post-MI appeared to be supported and welcomed by CRPs, particularly in the early stages of recovery, thus integrating them into the CR pathway appeared favourable. However, given the influence families have can be negative, looking at ways to support families through building positive health beliefs is worthwhile.

Study 3 drew on the findings from studies 1 and 2 and adopted a co-production approach to develop a PA support resource for family members of MI patients and involved a series of development and acceptability meetings with post-MI patients, family members and CRPs. Findings led to the development of an information booklet and support pathway and were informed by qualitative data collected during the development and acceptability meeting/s. The information booklet included 4 key topics (‘your CR service’, ‘PA after a heart attack’, ‘what to expect this next year’ and ‘providing social support’). The support pathway offered a route to which the information could be delivered in practice. Co-production appeared an acceptable approach to resource development within cardiac care. However, given the early stage of the co-production, further work needs to be done to pilot and evaluate the resource in practice.

This thesis highlighted the importance of family in helping promote post-MI patients’ PA engagement. However, family support may not always be positive, and appeared influenced by families own health beliefs. Integrating the family into the CR pathway appeared favourable to help ensure the support family provide patients’ is optimal. The development of an evidence-based PA support information booklet for families of post-MI patients and support pathway appeared a feasible route for how this may be achieved in practice. To see whether integrating family into the CR pathway and offering support positively impacts on post-MI patients’ PA engagement, further work could pilot and evaluate the information booklet and support pathway in practice.

Acknowledgements

There are a number of people I wish to express gratitude to, as without them, this thesis would not have been possible.

First and foremost, a special thanks to my Director of Studies, Dr Paula Watson, whom to this day I still believe to be Wonder Woman! You have been the glue that has held both my thesis and me together, especially during the last push, amidst breakdowns aplenty! You truly are super and I hold you in the highest regard.

To my supervisors, Professor Ian Jones, Dr Rebecca Murphy and Dr Ivan Gee, thanks to each of you for your input over the last three years. Your contributions have been invaluable and I am forever grateful for the time you have given this PhD and me.

To my friends and colleagues, it has been the biggest pleasure getting to know you all. You are such a brilliant bunch of people who have provided much support and kindness in the most challenging of times. I wish you all the best in your future studies and endeavours.

A special thanks to my family, Mum, Dad, Emma, Joe, Jenny and Laura. Your support knows no bounds and I am grateful for each one of you.

A particular thank you to all the participants who took part in the studies in this PhD. Thank you for sacrificing your time so selflessly to speak to me. Without you, none of this would have been possible. I am both humbled and privileged for the opportunity to meet and get to know each of you over the last three years.

Many thanks to Liverpool John Moores University for awarding me the Scholarship to undertake this PhD, it would not have been possible with it.

Finally, I dedicate this thesis to my darling nieces, Briar and Margot. Thank you for bringing such sunshine into our lives. Auntie Sars loves you both very much.

Declaration

I declare that the work contained within this thesis is my own

Communications resulting from this PhD work:

Conference presentations (oral)

Birtwistle, SB., Murphy, R., Gee, I., Jones, I., & Watson, P.M, (2019), *What influences physical activity engagement post-myocardial infarction? A longitudinal qualitative study,* International Society of Behavioural Nutrition and Physical Activity Annual Meeting, Prague, Czech Republic, 4th – 7th June, 2019

Birtwistle SB., Murphy, R., Gee, I., Jones, I., & Watson, P.M, (2019), *Family involvement in the rehabilitation of heart attack patients – does it help?,* Liverpool John Moores University, Doctoral Academy Research Day, Liverpool

Birtwistle SB., Murphy, R., Gee, I., Jones, I., & Watson, P.M, (2019), *Family involvement in the rehabilitation of heart attack patients – does it help?,* Liverpool John Moores University Faculty of Science 3 Minute Thesis Competition, Liverpool (Faculty of Sport & Exercise Sciences winner)

Birtwistle, SB., Murphy, R., Gee, I., Jones, I., & Watson, P.M, (2018), *What influences physical activity engagement post-myocardial infarction? A longitudinal qualitative study,* 7th Congress of International Society for Physical Activity and Health, London, UK 15th – 17th October, 2018

Birtwistle, SB., Murphy, R., Gee, I., Jones, I., & Watson, P.M, (2018), *Family influences on post-MI patients physical activity, a qualitative study,* LJMU Faculty of Science Research Day, Liverpool

Conference presentation (poster)

Birtwistle, SB., Murphy, R., Gee, I., Jones, I., & Watson, P.M, (2019), *How do cardiac rehabilitation practitioners view the family in post-MI patients' PA experiences, a qualitative study,* International Society of Behavioural Nutrition and Physical Activity Annual Meeting, Prague, Czech Republic, 4th – 7th June, 2019

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List of abbreviations and glossary of terms

ARSI/s	Activity Referral Scheme Instructor/s
BACPR	British Association of Cardiovascular Prevention and Rehabilitation
BHF	British Heart Foundation
CHD	Coronary Heart Disease
CN/s	Cardiac Nurse/s
CR	Cardiac Rehabilitation
CRP/s	Cardiac Rehabilitation Practitioner/s
CVD	Cardiovascular Disease
EACPR	European Association for Cardiovascular Prevention and Rehabilitation
ECG	Electrocardiogram
ERS/s	Exercise Referral Schemes
HADS	Hospital Anxiety and Depression Scale
HP/s	Health Professional/s
IPA	Interpretative Phenomenological Analysis
NACR	National Audit of Cardiac Rehabilitation
NCDs	Non-communicable Diseases
NHS	National Health Service
Non-STEMI	Non-ST-Elevation Myocardial Infarction
MI	Myocardial Infarction
OT/s	Occupational Therapist/s
PA	Physical Activity
PIS	Participant Information Sheet
PPCI	Primary Percutaneous Coronary Intervention
SEM	Socio-Ecological Model
STEMI	ST-Elevation Myocardial Infarction
TIA	Transient Ischaemic Attack
UK	United Kingdom
WHO	World Health Organisation

Family = The term family is complex, however, for the purpose of this PhD it was used to refer to a group of people related either by blood, marriage or another form of connected relationship, characterised by a close emotional connection to one another

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Chapter 1 Introduction

1.1. Background

Cardiovascular disease (CVD) refers to a class of diseases that involve the heart and circulatory system (National Health Service (NHS), 2018), and has been labelled as a leading cause of death worldwide (World Health Organisation (WHO), 2017). In 2016, it was estimated that 17.9 million people died from CVD, which accounted for 31 % of all global deaths (WHO, 2017). There are multiple forms of CVD, one of which is Coronary Heart Disease (CHD). Recent figures from the British Heart Foundation ((BHF), 2019a) show that currently 2.3 million people in the United Kingdom (UK) are living with the disease, with more than 66,000 deaths being attributed to it. Myocardial infarction (MI) is a manifestation of CHD, and occurs when blood to the heart is partially reduced or blocked resulting in myocardial cell death.

Following a cardiac event (such as MI), patients are typically offered a programme of cardiac rehabilitation (CR). This is a multifaceted programme which aims to limit both the physiological and psychological impacts of cardiac disease, whilst also helping to manage and prevent further events (Dalal, Doherty and Taylor, 2015), and includes components on physical activity (PA), education and psychological support (BHF, 2016). In order to support the broad range of patient needs, CR comprises a multi-disciplinary team. Within the UK, CR usually occurs across four phases moving from a hospital to a community setting (Bethell, Lewin and Dalal, 2009). **Phase 1:** this phase occurs within a hospital setting and before hospital discharge. Once their condition is stable, patients are provided with information about their cardiac event, its causes and lifestyle advice to help manage and prevent further events (e.g. PA, dietary habits, smoking). During this phase, patients are also prescribed their medication, and a discussion surrounding their enrolment into the CR programme is had. **Phase 2:** this phase begins following patient discharge and typically takes place within patients' home. This phase is characterised through patients continued education and promotion of engagement in cardiovascular friendly health behaviours and is achieved through contact (either home visits or telephone calls) with a member of patients' CR team. **Phase 3:** this phase may occur at either an outpatient hospital or home setting, dependent on CR service and patient preference. In the outpatient hospital setting, patients typically engage in structured, supervised and group-based exercise, and is complemented with continued education and psychological support. Alternatively, home based programmes typically comprise written and audiotaped information and are supervised either over the phone or through home visits. **Phase 4**: this phase focuses on the long-term maintenance of healthy behaviours with a focus on continued exercise. Exercise classes are typically structured, supervised and group based and typically occur within community fitness centres.

Physical activity has been referred to within the literature as *"any bodily movement by the skeletal muscles that results in energy expenditure"* (Caspersen, Powell and Christenson, 1985, p.g.126). Engaging in PA has many benefits including preventing conditions such as CVD, diabetes, obesity and musculoskeletal conditions (Department of Health, 2011a), as well as enhancing psychological wellbeing (Johansson, Hartig and Staats, 2011). Within the context of MI, the benefits of sustained PA are well documented and include reduced cardiac mortality, hospital admissions, and improved psychological wellbeing and quality of life (British Association for Cardiac Rehabilitation and Prevention (BACPR), 2012, Dalal, Doherty and Taylor, 2015). However, for these benefits to occur, PA is recommended to be sustained over the longer term (Clark et al, 2012a). Despite this, current evidence suggests that mean uptake to CR within the UK is around 50% (Doherty et al, 2018), and following programme completion, the adherence and maintenance of PA is poor (Karmali et al, 2014).

Social support is frequently cited as a key influence on PA behaviour (Treiber et al, 1991, Kouvonen et al, 2012, Young et al, 2014, Wong et al, 2016, Smith et al, 2017). In particular, the family have been identified as a potential source of support because of their ability to help promote engagement in, and facilitate health behaviour change (Rosland et al, 2012) and have been considered as a valuable tool in patients extended care team (Mitnick, Leffler and Hood, 2010). However, little is known about the impact of the family in post-MI patients' PA experiences. Accordingly, this is an area of important exploration in order to promote patient health and wellbeing post-MI.

1.2 Study setting

The PhD took place within the Boroughs of Wigan and Leigh, which are geographical localities based within the Northwest of England. Evidence from Public Health England (PHE) (2018) highlights these localities to have a varied health profile in relation to the England average and is evident through a number of health indicators. The localities are characterised by high levels of obesity (27%) (PHE, 2015), and low levels of PA (50.9%) (PHE, 2015). Life expectancy is lower than the national average, although this appears to differ between socio-economic status and gender with life expectancy for men and women differing by 12 years and 9.8 years respectively in the most deprived areas compared to the least deprived (PHE, 2018). In addition, within these localities, CVD has also been reported to be responsible for the most common cause of early death (≤75) (PHE, 2018). The local CR service is delivered across both the Wigan and Leigh localities, and as described in section 1.1, follows a four-phase format moving from a hospital to community setting, full details of which can be found in chapter 2 in section 2.6.2.

1.3 Conception of PhD

This PhD was conceived following the findings of the primary researcher's MPhil project, which explored the barriers and facilitators to an Exercise Referral Scheme (ERS) in the boroughs of Wigan and Leigh (which incorporated phase 4 of the CR programme). Through this MPhil, it was found that family played a meaningful role in determining patients' decision to attend the ERS, and this appeared to be both positive and negative. The patients involved in the MPhil either had been diagnosed with a chronic but stable health condition, or were at risk of developing one. Therefore, the decision to focus upon MI patients was to understand the nature of family support within the context of an event that is perceived as being potentially life threatening, but where the recovery advocates for PA engagement (BACPR, 2017). The PhD was funded by a Liverpool John Moores University Scholarship awarded to Sarah Birtwistle.

1.4 Aims and objectives of PhD

The overarching aim of this PhD was to explore the role of the family in post-MI patients' PA experiences, with a view to making recommendations for how they can support positive PA engagement post-MI.

The aim was achieved through three studies, which addressed the following objectives:

1. To conduct longitudinal family interviews to explore post-MI patients' and family members' lived experiences of PA and how this changes over time (study 1)
2. To conduct semi-structured interviews to explore how cardiac rehabilitation practitioners (CRPs) view the family within the CR pathway through the roles they perceive family to adopt in shaping post-MI patients' PA experiences (study 2)
3. To involve multiple stakeholders in the co-production of a PA support resource for family members of MI patients (study 3)

Please refer to figure 1.1 for an overview of how the studies fit together and a timeline for data collection.

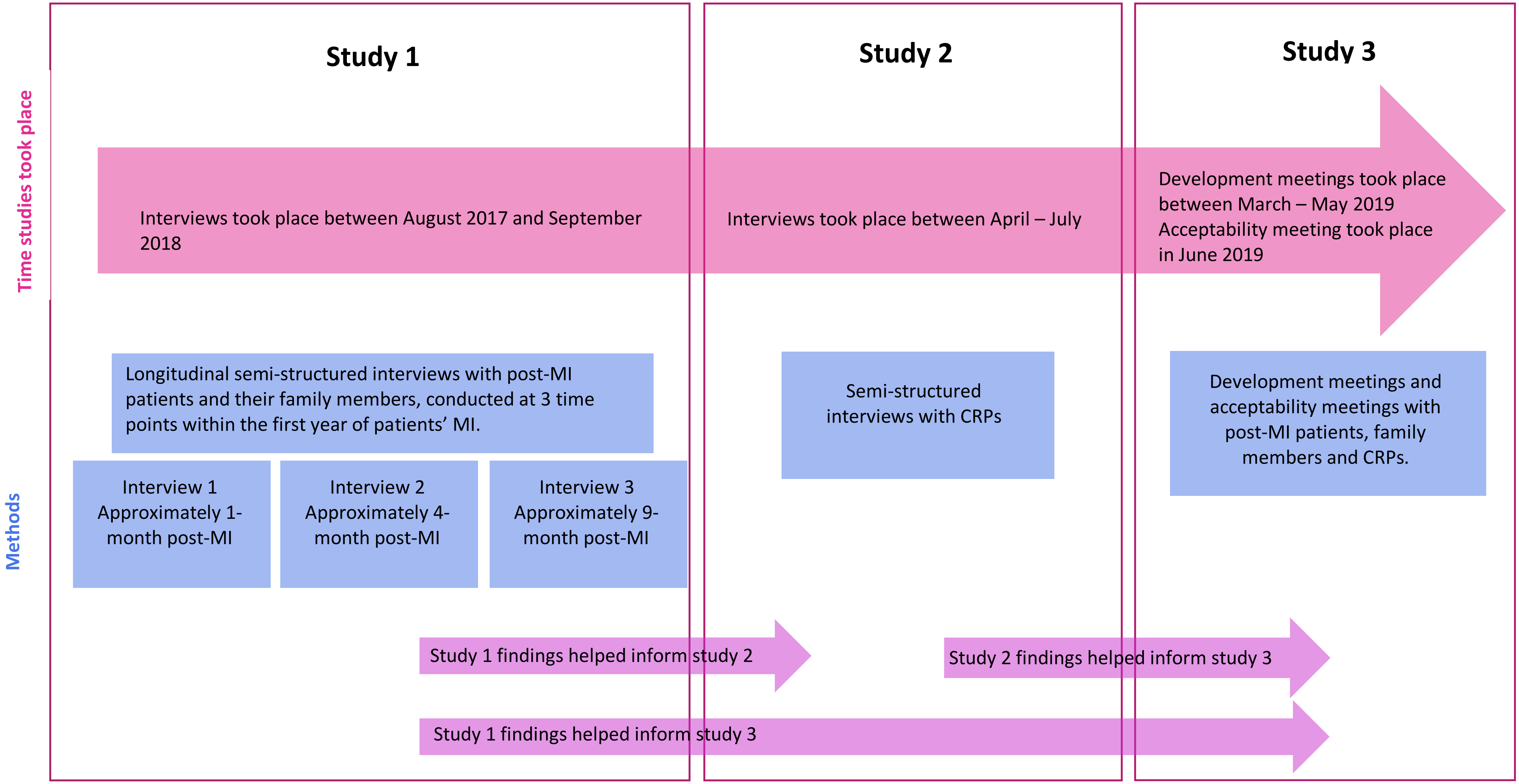


Figure 1.1 Overview of PhD studies

1.5 Organisation of thesis

Chapter 2 begins with a review of the literature, providing an overview and critique of the current literature within the fields of PA, CR and CVD (inclusive of CHD and MI), and family support and involvement in care. The review highlights gaps within the current literature and provides a rationale for the PhD. **Chapter 3** outlines the philosophical and methodological groundings of this PhD, and is followed with **chapters 4, 5 and 6,** which report the original studies of this PhD, all presented in the format of introduction, methods, results and discussion. Lastly, **chapter 7** provides a synthesis of the findings of the PhD, whilst also discussing strengths and limitations of the research, implications for both policy and practice and future research. The chapter concludes with the researcher's reflections of the research process and final PhD remarks.

1.6 Ethical approval

	Research ethics committee	**Reference number**
Studies, 1, 2 and 3	West of Scotland NHS Research Ethics Service	17/WS/0053
Ethics approval was granted for studies 2 & 3 through substantial amendments to study 1's original application		

Chapter 2 Literature review

2.1 Cardiovascular disease

2.1.1 Prevalence and health burden

Cardiovascular disease is an umbrella term used to describe a set of conditions that affect the heart and blood vessels (NHS, 2018). There are multiple types of CVD, although four main types have been identified and include, CHD, strokes and transient ischaemic attack (TIA), peripheral artery disease and aortic disease (NHS, 2018). It has been estimated that per annum, approximately 31% of worldwide deaths can be attributed to CVD (WHO, 2017), a percentage accounting for approximately 17.9 million individuals (WHO, 2017), with at least three quarters of these deaths being attributed to those in low to middle income countries (WHO, 2017).

Interesting trends can be witnessed when exploring the epidemiology of CHD. Data suggests the incidence of CHD has been steadily declining over the last 50 years (Scarborough et al, 2011a), with recent statistics supporting this trend (BHF, 2019b). Drawing on data from hospital episode statistics, GP registers and national health surveys, cardiac statistics collated by the BHF (2019b) suggest in England, total incidence has decreased. Their data shows that during the years 2005/2006 and 2016/2017 hospital admissions related to CHD declined from 428,262 to 396,316. With observable differences evident between genders, declining from 276,817 to 263,513 for men and 153,446 to 132,803 for women. Although, it is advisable to interpret such figures with caution given some individuals may not present at hospital (BHF, 2019). Regardless, CHD prevalence has appeared to remain consistent at 3% for England over a ten-year period (from 2004-2005 to 2014-2015) (Bhatnager et al, 2016), statistics that have been supported by PHE (2019) also. Reduced CHD incidence but consistent prevalence suggest that more people are surviving and living with CHD (Scarborough et al, 2011a) which could be explained through better treatment (e.g. medical interventions, medications) and management of these conditions.

However, as people are living longer within with CHD, it is worthwhile being mindful of the larger implications for society (Bhatnagar et al, 2017). From a health economics perspective, cardiovascular conditions cost the National Health Service (NHS) approximately £9 billion annually

(BHF, 2019a). Costs are further widespread to the economy also, costing approximately £19 billion a year (BHF, 2019a), through factors such as informal care costs (e.g. unpaid carers providing care to patients) (Luengo-Fernández et al, 2006). The impact to individuals can be huge also. Cardiovascular conditions can heighten the risk of developing further serious and complex health conditions, disability and a lowered quality of life (Million Hearts, no date (nd)), which can consequently lead to further pressures on the health service for treatment of secondary conditions. Thus, it is important to understand what can be done to help reduce the multiple burdens caused by heart conditions and promote healthy living.

2.1.2 Disease states and treatment

As stated above there are multiple different types of CVD. Some of the most common forms of CVD include stroke and TIAs, and aortic disease (NHS, 2018). Lastly there is CHD, which refers to a collection of diseases affecting blood supply to the heart (NHS, 2018), and is caused by a build-up of plaque in the coronary arteries, which can partially or completely block the blood flow to the heart (National Heart, Lung and Blood Institute, 2019). Coronary heart disease is a leading cause of death worldwide and within the UK. Last year alone 2.3 million were found to be living with the disease and 66,000 death were attributed to the disease (BHF, 2019). A manifestation of CHD is MI, which has been defined pathologically as *"myocardial cell death due to prolonged ischaemia"* (page 266) (Thygeson et al, 2018, page 266). Moreover, Thygeson and colleagues (2018) provide clinical criteria for further denoting MI as *"the presence of myocardial injury detected by abnormal cardiac biomarkers in the setting of evidence of acute myocardial ischaemia"* (page 266). Myocardial infarction is further divided into ST elevations MI (STEMI) and non-ST elevations MI (non-STEMI). A working diagnosis of MI is typically based on patient history and presenting electrocardiogram (ECG), as it is typical the patients may present with symptoms including persistent chest pain (Zeitz, Quinn, and Jones, in press). Presenting ST segment elevation with a rise in cardiac biomarkers greater than the 99th percentile (Zeitz, Quinn, and Jones, in press) provides a working definition of STEMI, whereby the absence of ST segment elevation on the ECG with respective rise in cardiac biomarkers suggest a non-STEMI. Medical treatment of acute MI is focused on restoring coronary blood flow as early as possible using either thrombolysis or primary percutaneous coronary intervention (PPCI). Whilst both therapies are time dependent, PPCI has been shown to provide superior outcomes if administered within 120minutes (Pinto et al, 2011). However, in Europe, thrombolysis is preferred if PPCI cannot be achieved within this timeframe (Ibanez et al, 2018).

A number of biological and behavioural risk factors have been cited in the literature as contributing to the onset of MI and can be classified as either modifiable (alcohol consumption, dietary behaviour, physical inactivity, smoking and stress) or non-modifiable (e.g. age, gender family history) (Joint British Societies 3 (JBS3), 2014). Behavioural risk factors can be modified and can help aid in the prevention and management of CHD. Cardiac rehabilitation is such a programme and includes elements on PA, cardiovascular risk reduction and psychological support (Dalal, Doherty and Taylor, 2015, BHF, 2016) to cardiac patients. Within the literature, CR has been described as a multifaceted intervention in secondary prevention, aiming to limit both the physiological and psychological impacts of CHD, helping manage symptoms and reduce the risk of future cardiac events (Dalal, Doherty and Taylor, 2015, Piepoli et al, 2016). Thus, helping improve patients' cardiovascular health through supporting modifications to lifestyle behaviours (e.g. PA, dietary habits, and concordance with medication). To support the broad range of patient needs (physiological, physical, psychological), CR is made up of a multidisciplinary team often including, cardiac specialists (cardiologists, cardiac nurses (CNs), physiotherapists, physiologists, occupational therapists (OTs), dieticians, psychologists and exercise referral specialists) (BHF, 2016).

Clinical guidance for the delivery of CR exist in a bid to ensure optimum effectiveness, but also to ensure the health and safety of those within the programme (Piepoli et al, 2014). Guidance outlined by the European Association for Cardiovascular Prevention and Rehabilitation (EACPR) (Piepoli et al, 2014), although for CVD rather than CHD specifically, provides direction to the implementation of CR services to ensure clinical outcomes are achieved. Given it is believed anyone diagnosed with CVD can benefit from CR, the importance of a comprehensive programme of CR being encouraged by CRPs to all appropriate patients in a timely manner (one to three weeks from patient diagnosis/discharge) is vital. Core components are the sum of activities aimed at providing patients with the best chances of either slowing down, or reversing the progression of their cardiac disease, thus it is of paramount importance these are delivered by appropriate and experienced staff members. As outlined in a recent policy statement from the EACPR (Piepoli et al, 2014) core components include administrative tasks (patient assessment and referral), education and support (vocational support, psychosocial management), medical management (lipid management, blood pressure monitoring/management) as well as behavioural risk factors (exercise prescription, PA and diet/nutritional counselling, weight control management and smoking cessation). Although formal rehabilitation programmes vary in both intensity and duration (Dalal, Doherty and Taylor, 2015), the adoption of guidance can be seen at national level within official documentation, including the BACPR (2017) and the National Institute for Health and Care Excellence ((NICE), 2013).

Various models of CR exist worldwide with evidence suggesting almost ¾ of countries offer supervised models and almost half offer alternative models (e.g. home-based) (Ghisi et al, 2018). Within the UK, CR is typically offered in a four-phase programme moving from a hospital to community setting (Bethell, Lewin and Dalal, 2009). **Phase 1:** once patients' medical condition is stable and before hospital discharge, a clinical member of staff (ideally from within patients' CR team) provides patients with information on their condition, causes and lifestyle advice. They also ensure patients have been prescribed their medication and look at enrolling them on to a CR programme. **Phase 2:** a member of patients' CR team provides continued education and promotion of positive health behaviours, either over the telephone or during face-to-face consultations. **Phase 3:** this phase may occur either over the telephone or at an outpatient hospital setting, dependent on both CR service and patient preference, and is typically 6 weeks in duration. Within an outpatient setting, patients are offered structured, supervised and group-based exercise, with is complimented with continued education and psychological support. Home based programmes usually involve a mixture of written and audiotaped guidance and are usually delivered by a member of patients' CR team either over the telephone or face to face. **Phase 4:** this phase focuses on the longer-term maintenance of healthy behaviours, in particular exercise, and may take place in a community setting and last approximately 12 weeks.

2.1.3 Cardiac rehabilitation – effectiveness, uptake, barriers and facilitators

Mixed evidence has been reported on the effectiveness of CR programmes. Recent evidence suggests that attending CR has the potential to reduce cardiovascular related mortality, improve health related quality of life (Sumner, Harrison and Doherty, 2017) and reduce hospital admissions (Anderson et al, 2016). Despite this, evidence suggests uptake to CR is below 50% worldwide (Piepoli et al, 2015), and within the UK specifically, has been recently recorded at around 50%, falling short of the national recommendations for all UK countries (Doherty et al, 2018). There is a wealth of evidence offering explanations to help understand the uptake of CR, which is important to understand to ensure services benefit those who are in need. Recent work by Thompson, Ski and Clark (2019) suggest that terms, aims and models of CR are outdated and propose for these to be revisited in order to ensure optimum effectiveness.

In regard to patient demographics, only 29% of females compared with 71% of men take up CR (Doherty et al, 2018). Such variance may be explained through women typically carrying a majority of family responsibilities (Supervia et al, 2017), which limits CR effectiveness and raises questions whether redesigning CR to meet the broad needs of patients is worthwhile. However, amongst women, age also appears to impact on CR attendance, with a higher proportion of over 75-year olds attending (Doherty et al, 2018). This may be in part to CR fostering cognition, socialization and independence in older patients (Schopfer and Forman 2016), factors that have been shown to act as a motivator for engagement in PA (Broderick et al, 2015). Although noteworthy is mixed results have been found in the context of age and CR participation, with some literature stating peak participation rates are for those aged between 50 – 65 years (Ruano-Ravina et al, 2016), whereas recent data found a higher mean age (67 years) (Doherty et al, 2018). This highlights the reach of older groups but is also worrying regarding the (lack of) engagement of younger populations. When looking at ethnicity, the predominant ethnic profile reported to be attending CR is White-British (Doherty et al, 2017). This is not surprising given evidence suggesting HPs’ reluctance to refer some patient groups, including those from ethnic minorities (Dalal, Doherty and Taylor, 2015). Marriage remains the dominant relationship status with 68% of CR attenders being in partnerships (Sumner, Grace and Doherty, 2016, Doherty et al, 2018). Those who are retired are more likely to attend (Peters and Keeley, 2017), however, this is not unusual given studies reporting that work acts as a barrier to the uptake of health and wellbeing initiatives (Birtwistle et al, 2018). Although one of the problems with using audit data in this case is that uptake to CR for many of the variables were reported collectively, not by individual condition. It is therefore difficult to establish the uptake to CR by patient demographics for MI patients specifically.

Although demographic factors are an important consideration, it is worthwhile acknowledging wider factors found to influence CR uptake, and numerous studies have adopted a qualitative lens to do so. Understanding influencing factors to CR within a qualitative context has the potential to improve uptake/maintenance through the provision of patients’ own lived experience. Qualitative studies by Cooper (2005), Holder (2015), Wong (2016) and Bäck (2017) and colleagues have used in-depth interviews with cardiac patients to understand their perspectives on the influencing factors to engagement in CR and/or healthy behaviours (e.g. PA) following a cardiac event. Findings from these studies found multiple influences occurring at different levels (namely intrapersonal, interpersonal and environmental) to influence attendance both positively and negatively. On an intrapersonal level, an increased awareness of mortality, increased physical fitness and improved heart health acted as facilitators to attending CR. Whereas factors such as patient identity (how they see themselves and the ‘types’ of people participating in CR), as identified in two qualitative systematic reviews exploring CR participation (Clark et al, 2012b and 2013), beliefs regarding CR, knowledge of the service (belief that it may be unsuitable) and negative views of the service were found to discourage attendance. Mixed results have been reported in regard to interpersonal factors, social support from family and peers, and referring health professionals (HPs) have found to be both barriers and facilitators

(Rogerson et al, 2012, Clark et al, 2013, Ghisi et al, 2013, Menezes et al, 2014, Schopfer and Forman, 2015, Wong et al, 2016). Social support is deemed positive when is plentiful and encouraging (Wong et al, 2016), whereas when it is lacking it can be potentially detrimental (Clark et al, 2013). In regard to HPs, when they engage with patients and offer support (choice regarding CR services, providing patient specific information), they were deemed as a facilitator to CR. However, a lack of endorsement and negative attitudes regarding CR had the undesired effect on attendance (Ghisi et al, 2013, Menezes et al, 2014, Schopfer and Forman, 2015). Numerous facilitators have been identified in relation to the environment. Factors such as monitoring and safety with CR through behaviours such as ongoing assessment appeared important to patients attending CR (Cooper et al, 2005, Clark et al, 2013), giving them the reassurance to be active. Whereas, CR services involving patients travelling long distances and a lack of transport appeared off putting (Menezes et al, 2014). Although these pieces of research provide insight into both the facilitators and barriers faced by patients to attend CR, a number of the studies included discussed uptake to CR in general, not the PA component in isolation, and nor focused specifically on MI patients. Myocardial infarction patients may experience different facilitators and barriers to PA (compared to general CR) (section 2.2.2).

2.2 <u>Physical activity in the treatment of CVD</u>

2.2.1 <u>PA guidelines, policy, public health and prevalence</u>

Physical activity is defined as *"as any bodily movement produced by the skeletal muscles that requires energy expenditure"* (Caspersen, Powell, and Christenson, 1985). Physical activity has been found to have numerous benefits to health including the prevention of cardiovascular, respiratory and musculoskeletal conditions (Warburton, Nicol and Bredin, 2006, Lee et al, 2012), as well as lowered depression and anxiety, (Williams et al, 2007, Johansson et al, 2011). Government guidelines recommend adults (aged 19 – 65 years) and older adults (aged 65+ years) should try and be active daily, and aim to engage in 150 minutes of moderate (e.g. brisk walking, cycling on level ground) or 75 minutes of vigorous (e.g. running, swimming fast) PA weekly. In addition, the guidance suggests engaging in strengthening activities on 2 days of the week also (Department of Health and Social Care, 2011a). It is also recommended that older adults who are at risk of falls, should incorporate activities that focus on improving balance and coordination (Department of Health and Social Care, 2011b). Finally, both groups are recommended to minimise the amount of time in a sedentary posture (time spent in a sitting, reclining or lying posture) for an extended period of time, given that this has been associated with an increased risk of heart and circulatory disease, as well as poor general health (BHF, 2017).

Although no specific PA guidelines exist for MI patients, guidance has been produced by recognised and established cardiac bodies such as the Australian Heart Foundation (2019) and the British Heart Foundation (2013) and provides advice on how to re-engage with PA post-MI. Although it is recommended to see a HP before starting any PA, patients are advised to be active daily, starting activity slowly and at a low intensity (walking is suggested as a starting point) and gradually build up levels of fitness. Patients are also advised to avoid sitting for long periods of time. The advice is holistic and aims to encourage patients to listen to their bodies and only engage in activities that feel right for them. However, it is advised that for activities requiring increased physical effort, such as cycling, swimming or tennis, to wait approximately 6 weeks and add them in gradually.

Despite the known benefits of PA, a recent report published by UK Government (2019a) found that in the UK, currently 25% of adults (reported as 16+ years) are classified as physically inactive, that is, doing less than 30 minutes of moderate PA per week, with PA levels appearing to decrease with age. Multiple non-communicable disease (NCDs) have been attributed to physical inactivity (Lee, 2012), which have been linked to increased morbidity and (premature) mortality (Joseph et al, 2017). In response to this, a call for action was led by the WHO, who launched the 'Global Action Plan for the Prevention and Control of NCDs' (2013), pledging to reduce premature mortality by 25% by the year 2025. The action plan outlines a comprehensive pathway for countries to adopt to help reduce NCDs and focuses on strengthening public policy and health services to prevent 4 major NCDs, CVD, cancer, chronic respiratory diseases and diabetes. Given these NCDs share behavioural risk factors (e.g. PA), addressing these as a means to help meet the target is of imperative importance, and are reflected in policy guidance such as the 'Global Action Plan on Physical Activity' (WHO, 2018a). The policies highlight a whole society approach to achieving a paradigm shift in both supporting and valuing all people being regularly active (WHO, 2018a), and this mentality is reflected in national policy. Within the UK, policies such as the 'NHS long-term care plan' (2019) and 'Moving Healthcare Professionals Programme' (Brannan et al, 2019), have looked to embed PA into the healthcare culture to help reduce the prevalence of sedentary lifestyles within society and therefore lessening NCD risk.

Cardiovascular diseases account for the most NCD deaths annually (WHO, 2018b). As the guidance suggests, PA is recommended for the prevention and management of cardiovascular conditions. Physical activity post-MI has been associated with numerous benefits including increased PA behaviour, improved physical and psychological wellbeing and quality of life (Taylor et al, 2014 Dalal, Doherty and Taylor, 2015, Anderson et al, 2016, BHF, 2017), and reduced risk of cardiac mortality (BACPR, 2012). A recent study by Ekblom and colleagues (2018) has added further evidence to support already existing statements that PA is beneficial to health following a cardiac event. Their study analysed data from 22,227 patients between the ages of 18-75 who were diagnosed with their first MI between December 2004 and October 2014, who had completed data for the SWEDEHEART registry, which included registries linked to subsequent MI related care (including PA). Physical activity was reported at 2 follow-up visits and based on patients' self-report on number of PA sessions (classified as 30 minutes or longer), during the previous 7 days. Patients were classified as inactive if they reported 0-1 number of sessions per week, whereas 2+ carried the active classification. Patients were further classified by changes made to their PA over the follow-up visits (constantly (in)active, reduced/increased activity). The study concluded that engaging in PA post-MI, compared with being inactive in the first year post-MI was related to reduced mortality. Yet one of the main limitations of the study was that PA was based on patients' self-report. Self-reported relies on the trustworthiness of participant accounts (Sallis and Sealens, 2015). It is therefore possible participants may not have provided accurate results, which could have impacted upon the reliability of the data. Regardless, such conclusions provide rationale to promote engagement in PA CR services post-MI.

2.2.2 PA engagement, barriers and facilitators to PA in cardiac populations

As discussed in section 2.1.2, being active is a fundamental component of CR. However, despite the benefits of continued involvement in PA following cardiac events, maintenance of PA following CR remains low (Dorn et al, 2001, Thompson et al, 2003, Karmali et al, 2014, Novella, Saunders and Reid, 2019). This appears to have elicited an argument within the literature questioning the effectiveness of CR programmes in their ability to improve the amount of PA performed outside of CR settings (Ter Hoeve et al 2015, 2017). To understand whether PA can be sustained post-CR, two recent randomised control trials (Fournier et al, 2018 and Ter Hoeve et al, 2018) were conducted to investigate the efficacy of interventions on the maintenance of PA behaviour in cardiovascular patients. Fournier and colleagues (2018) drew on habit formation theory to maintain PA. Cardiac patients were randomised to either two supervised PA sessions a week for 20 weeks, or a ‘progressively autonomous PA condition’ involving 10 weeks of twice weekly supervised PA, and then a further 10 weeks with one supervised PA session and were encouraged to add an additional 2 sessions in weekly. In Ter Hoeve et al’s (2018) study, participants were randomised to one of three conditions. Condition 1 involved 3-months standard CR-only, condition 2 involved 3-months standard CR with 3 face to face-based PA grouped counselling sessions followed by 9 months of aftercare with 3 face-to-face group-based lifestyle counselling sessions and condition 3, which involved 3 months standard CR followed by 9 months of aftercare with 5-6 telephonic counselling sessions. Fournier and colleagues (2018) concluded that regardless of randomisation, PA decreased following intervention completion, although individuals in the progressively autonomous PA group completed more PA sessions in the intervention. Whereas, in Ter Hoeve et al’s (2018) study, individuals whom received CR and face to face PA and lifestyle counselling saw improvements in step count and time spent in prolonged moderate to vigorous activity (MVPA) which was maintained at 18 months post-intervention. However, these studies did not explore participant experiences, therefore it is unknown what prevented the longer-term maintenance of PA behaviour and highlights the need for qualitative research to understand how PA can be promoted and sustained following a cardiac event.

Understanding the facilitators and barriers cardiac patients may face to being physically active is of important consideration when trying to understand why they may not maintain PA. Quantitative research through the use of questionnaires have found factors such as fatigue, worry of causing additional harm, competing priorities (work, family commitments) and PA motivation as barriers (Klompstra, Jaarsma and Strömberg, 2015). This has been verified through qualitative work through interviewing cardiac patients. Work by Tierney and colleagues (2011) and Albert and colleagues (2015) found that opportunities to be active with others experiencing similar conditions and meaningful support (positive reinforcement, verbal encouragement) encouraged PA. Whereas on the other hand, factors such as breathlessness and fatigue, deterioration of cardiac condition, a lack of personal drive to engage in PA, and overprotection of family members sometimes acted as deterrents. Although within a cardiac context, these studies were with patients with heart failure rather than MI, and it is worthwhile acknowledging how these conditions may exhibit themselves differently in relation to patients 'ability to engage in PA. A qualitative study by Rogerson and colleagues (2012) explored the barriers and facilitators to PA in patients following a cardiac event (MI included) through in-depth semi-structured interviews. Positive psychological benefits elicited through PA engagement (enhanced feelings of relaxation, distraction from other concerns, help in pain management, enhancing sense of achievement), having a PA purpose (someone worth fighting for), and social support from family and friends acted as encouragement to PA engagement. Psychological factors such as low mood (feeling teary and emotional) and lack of motivation (no interest or desire to be active), a fear to be active (scared to do themselves harm) and physical restrictions such as fatigue, were found to act as barriers to PA engagement post-MI, and have also been reported elsewhere (Yates, Price-Fowlkes and Agrawal, 2003, Crane, 2005).

2.3 Social support

2.3.1 Maslow’s hierarchy of needs

To understand the nature of social support and how connections with others may impact upon health and wellbeing, it is important to consider psychological theory. Many theories of human behaviour highlight the importance of significant others in our overall experiences of being, and how relationships can impact specifically upon human wellness. Maslow’s Hierarchy of Needs (1943) is a theory of human motivation comprising a five-tier model of human needs, often portrayed as hierarchical levels within a pyramid (figure 2.1). The theory posits in its most primary form that individuals’ basic needs must be satisfied before they become motivated to achieve ‘higher order’ level needs (Maslow, 1943) and become their fulfilled self (although one does not just become, this is always evolving). The basis of the pyramid is formed of physiological needs (e.g. food, water, air, warmth, shelter), and pertaining to Maslow, is the most basic need and if not satisfied the human body is unable to function optimally. Secondly, are the needs of safety (security and safety), thirdly, the need for love and belongingness (interpersonal relationships – friends and family), and fourthly, esteem (esteem for oneself – independence, mastery and respect from other – status). Lastly, at the top of the pyramid is ‘self-actualization’ and refers to a desire to be as capable as one can be (Maslow, 1987). Needs can be broken down further into basic needs for survival (stages 1 – 2), psychological needs for nourishment (stages 3 – 4) and self-fulfilment/growth needs (stage 5). Evidence suggests everyone has the ability to progress through the hierarchy to self-actualization, however progress may be stunted upon failure to meet needs lower in the hierarchy which may happen through life experiences (McLeod, 2007), such as illness or lack of social support.

Within Maslow’s hierarchy, the need for love and belongingness is of central importance for good health. A sense of belonging is the desire to establish meaningful relationships with others and as such may come from many different sources, and may include familial relationships, friendships and romantic partners. This need may be satisfied though compassion, care and empathy, and resultingly, one may feel a sense of acceptance, affection, love and trust (Maslow, 1943). However, if the need for love and belongingness is thwarted, this may lead individuals to feel a sense of maladjustment (Maslow, 1943) and ill health (Baumeister and Leary, 1995). Within a health context, Maslow's theory may be explained as such, the initial priority after having a traumatic health event (e.g. MI) is seeing to the basic needs (i.e. physiological and safety), and may be achieved through admittance to hospital and consequent treatment for the event, but next is the need for loved ones to show care, compassion, reassurance and support. If these needs are not met, this makes it challenging to make the lifestyle changes that may be associated with recovery (i.e. PA). Evidence suggests that the provision of love and care from a loved one following a health event is important given its promise in influencing chronically ill patients' quality of life (Rebin and Uchino, 2008).

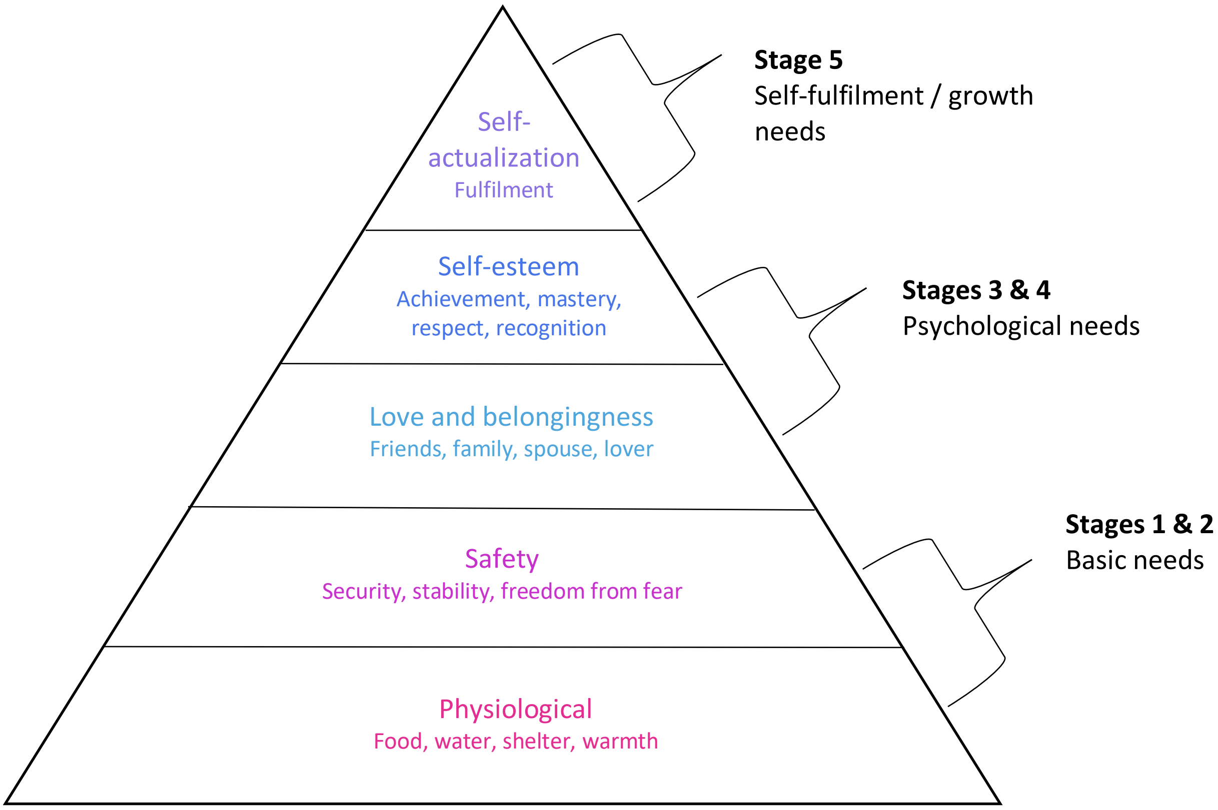


Figure 2.1 A visual overview of Maslow's Hierarchy of Needs, adapted from McLeod (2007)

2.3.2 Socio-ecological model

To help contextualise how love and belongingness fit within wider society, it is important to consider the Socio-Ecological Model (SEM) (Bronfenbrenner, 1979). Figure 2.2 provides a visual diagram of the SEM model. This model recognises that individuals are embedded within wider structural systems and as such suggests individual behaviour is an outcome of multiple different influences occurring at different levels, which closely interact with one another. Drawing on work by Sallis, Owen and Fisher (2008), the model includes the intrapersonal level (demographic and psychological factors), interpersonal (social relationships), organisational (local services), environmental (local service provision) and policy (governmental bodies/agencies). The need for love and belongingness as described by Maslow fits within the interpersonal sphere, focusing on how interpersonal relationships can influence health behaviours.

Within a cardiovascular setting many interpersonal factors have been associated with engagement in CR and have included support and motivation from friends, family (Bäck, Öberg and Krevers, 2017), and CR staff (Rogerson et al, 2013) interaction with others and having role models (Rogerson et al, 2013). Barriers included a lack of reassurance and guide from staff, lack of consultation with HPs about patient care (Tod, Lacey and McNeill, 2002) , social interaction with other patients (Cooper et al, 2005), and HPs attitudes and beliefs (i.e. not discussing PA with patients due to own belief they will not engage in PA) (Omura et al, 2018).

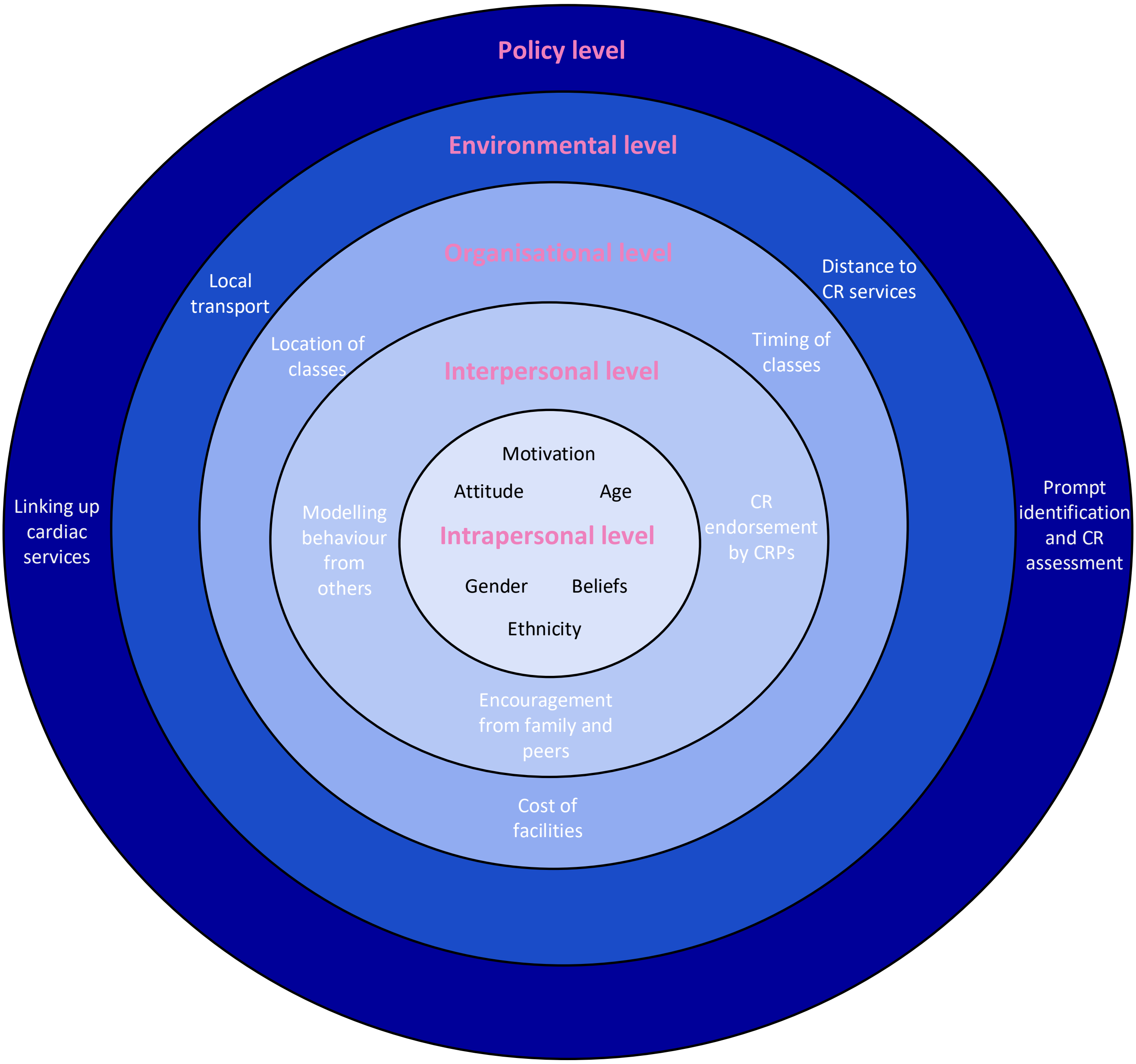


Figure 2.2 A visual representation of Socio-Ecological Model including factors influencing cardiac rehabilitation engagement for each level, adapted by Sallis, Owen and Fisher, (2008)

2.3.3 Social support and PA

Both Maslow (1943) and Bronfenbrenner (1979) highlighted the importance of social relationships as influencing overall health and wellbeing. It is well-established within the current literature base that social support is an important determinant of PA behaviour (Treiber et al, 1991, Fischer et al, 2008, Kouvonen et al, 2012, Bauman et al, 2012, Piwonski, Piwonska and Sygnowksa, 2012, Wong et al, 2016, Smith et al, 2017, Kang, Park and Wallace, 2018). Social support refers to 'the resources provided by another person' (Cohen and Syme, 1985), and is a multi-dimensional concept comprising of four distinct tenants and functions: emotional, informational, tangible and belonging (Uchino, 2004). Each of the tenants aim to assist individuals achieve a task/goal, however the methods in how this is achieved amongst the tenants differs. Emotional support is often defined as expressions of caring and concern and is said to be supportive by bolstering one's self-esteem during life challenges (Uchino, 2004), and may include behaviours such as listening, being present and providing encouragement. Informational support has been defined as the provision of advice or guidance (Uchino, 2004) and may prove useful because it provides direction. Tangible support is the provision of material aid (Uchino, 2004) and may include, in the context of PA, providing a lift to take a family member to a PA session. Lastly is belonging based support and refers to the presence of another to engage in social activities with (Uchino, 2004), and may include having a companion to be active with. Although distinct from each other, the tenants are highly interactive and not easily separated (e.g. providing informational support could be deemed as emotionally supportive given the provider of information has taken the time to find out the information and speak it through with an individual) (Uchino, 2004).

The mechanisms under which social support encourages PA are vast. Social support has been found to increase self-efficacy, self-esteem and perceived control, all of which have the potential to encourage individuals to engage in an active lifestyle (Stansfeld et al, 1998). Evidence suggests that PA levels are higher amongst those who receive social support (McAuley et al, 2003, Ayotte et al 2010), and many studies offer explanations for why this relationship exists. Support networks have been found to offer opportunities to be active, as well as providing praise and positive feedback (Laird, Fawkner and Niven, 2018), with such techniques being associated with increased motivation (Wong et al, 2016) and therefore the possibility of PA maintenance. Individuals have also been found to engage in PA if their close others do also (Darlow and Xu, 2011, Franks et al, 2012, Jackson, Steptoe and Wardle, 2015). It is therefore evident that the confidence to be active can come from those around us, and therefore provides further support for the utility of interpersonal relationships in promoting positive health engagement.

Due to the multiple tenants of social support, it is worth acknowledging how they may impact on PA behaviour given that different tenants may be more effective in encouraging PA. Tangible sources of support have been associated with increased likelihood of PA adoption (Kouvonen et al, 2012), whereas both emotional and tangible support has been associated with PA maintenance/engagement (Fischer et al, 2008, Kouvonen et al 2012). Although belonging forms of support in other studies has been found to influence PA engagement in women (Cavallo et al, 2014). Despite these findings highlighting how different tenants of support impact on PA, there are considerations to take on board. There is a great deal of heterogeneity in the definition of social support. Given the variance in reporting, caution must be taken when interpreting results as different support behaviours may be classified within different tenants of social support, making it difficult to understand the clear relationship between support tenant and PA.

2.3.4 Social support and cardiac populations

There is a wealth of research showing the impact of social support within a cardiovascular context. In regard to general engagement in healthy behaviours, a study by Ford and colleagues (2000), whom analysed National Health survey data in America, concluded that social relationships have a beneficial effect on reducing behaviours (in)directly associated with CVD. Within a post-MI population specifically, an early review from Mookadam and Arthur (2004) suggested a positive association between social isolation and MI mortality and morbidity post-MI. More recently, in a secondary analysis of cohort data, Fivecoat, Sayers and Rigel (2018) reported that increased social support (instrumental and emotional) was predictive of better self-care confidence in patients with heart failure, although did not specify exactly whom was the provider of the support. Likewise, within a study exploring the relationship between perceived social support from HPs amongst patients with coronary artery disease (Won and Son, 2017) findings suggested that plentiful support from HPs played a key role in promoting PA. In qualitative research, peer support has been found to positively impact on cardiac patients' PA. Findings in a study by Clark and colleagues (2012a) suggested patients who took up a peer support programme following the completion of a CR programme were at 12-months recorded as having similar activity levels as at CR completion. This was in comparison to patients who had declined the peer support programme, and who at 12-months follow-up PA had decreased by 211 minutes weekly. Such evidence provides a strong basis for the positive impact support can have on health outcomes, especially in reducing risk factors associated with CVD. Therefore, consideration should be given to incorporating social support into health promotion interventions. However, given that the providers of support in these studies were not solely focused on the family, this must be explored to understand whether similar benefits are apparent.

2.4 The family as a provider of social support

2.4.1 Theories

Individuals often seek out relationships with others based on shared interests and understanding (Cobb et al, 2016), therefore it is not unusual that in many relationships partners' health behaviours co-occur. Theories do exist that help explain the commonalities in behaviour in relationships. The shared resource hypothesis (Meyler, Stimpson and Peek, 2007) posits that over time spouses become like one another because of their shared social and physical environment, as well as access to resources, which leads to a concordance in behaviour. Social control hypothesis (Meyler, Stimpson and Peek, 2007) refers to controlling attempts by others to encourage engagement in behaviour (Tucker et al, 2002), however persons may engage in such behaviours out of feelings of obligation. It is worth noting that engaging in tasks out of obligation may not only impact upon the sustainability of the behaviour, but the mental impacts this has upon individuals also, as such controlling behaviour has been associated with increased psychological distress (Lewis and Rook, 1999). Lastly, convergence theory (Kiuru et al, 2012) suggests spouses simultaneously influence one another, and their behaviour converges to become similar over time. Evidence suggests that changes in health behaviours associated with risk of NCDs by one spouse can also lead to the promotion of similar changes in the other (Meyler, Stimpson and Peek, 2007, Falba and Sindelar, 2008). Within a PA domain, there are a number of studies that have examined the concordance of PA amongst couples and have reported that when one member of the couple is active, it increases the likelihood of the partner being active also (Wilson, 2002, Pettee et al, 2006). Such findings have been further verified by Cobb and colleagues (2016) who studied the concordance of 3,621 spousal pairs PA over a 6-year period to see whether change in one spouses' health behaviour impacted on that of the other. When one spouses PA increased, so did the others and concluded that when an individual's spouse increased his/her PA, the other individual's level was likely to increase also. However, it is important to note that the sample in the aforementioned studies were of married heterosexual couples, with little consideration given to other family structures. Regardless, findings do suggest that it may be worthwhile targeting PA promotion efforts to the wider social environment, but further work could be done to establish the relationship of support in different family contexts.

2.4.2 Family support and cardiac conditions

When looking at family as the providers of social support within the context of cardiovascular care, conclusions remain very positive. A study by Sayers and colleagues (2008) found that increased levels of social support from family (namely spouses) were predictive of heart failure patients' better self-care (medication and dietary adherence). Therefore, concluding that family support may help patients with heart failure have better health outcomes and advocating for family involvement in care. Likewise, a study by Franks and colleagues (2006) revealed that prospective analysis showed spousal support was associated with increased patient mental health, where spousal control predicted decreased patient health behaviour and mental health. Interestingly they concluded that despite spouses' efforts to help facilitate patients' healthy lifestyle, this may not always be as they intend (can sometimes be negative).

Further studies have demonstrated the effect of support provision on patient outcomes and have demonstrated that when these needs are supported by family members they promote positive health outcomes, and conversely, when needs are perceived to be unsupported outcomes are negative (Rosland et al, 2010, Rosland et al, 2012). Due to families' influence on health/illness management (Murray et al, 2012, Rosland et al, 2012, Clark et al, 2013), it is important to understand the factors that promote positive behaviour change and maintenance. Research exploring family behaviours of support have found that behaviours defined as overprotective, neglectful, controlling, critical, demanding and withdrawn as unsupportive (Kärner, Dahlgren and Bergdahl, 2004, Rosland et al, 2012). It is important to note that although perceived as negative by the patient, some family behaviours (i.e. being demanding) may be done out of concern for the patient, although still may negatively impact upon patients' ability to handle lifestyle changes (Kärner, Dahlgren and Bergdahl, 2004). Whereas family behaviours such as emphasis on self-reliance, encouragement without making demands, personal achievement, family cohesion and functioning and open/motivational communication have been associated with better patient outcomes, such as a sense of mastery, self-esteem, a better understanding of illness, rehospitalisation and perceived health (Ben-Sira and Eliezer, 1990, Kärner, Dahlgren and Bergdahl, 2004, Rosland et al, 2012, Karmali et al, 2014). Although these studies did not focus specifically on family support and PA engagement, or specifically on CR, they do provide a valuable insight into family behaviours that facilitate positive health management and outcomes, as well as behaviours that hinder this and consequently have negative effects on patient management outcomes.

2.5 Family involvement in cardiac care

2.5.1 Guidance for family involvement in patient care

Although no known guidance exists for involving the family in cardiac care specifically, some insight can be gained from guidance that has been developed within oncology settings. The TRIO guidelines (relating to the practitioner-patient-family trio) (Laidsaar-Powell et al, 2018a, 2018b) provide guidance that promotes the positive integration of family members into healthcare consultations and provide a useful starting point for promoting positive familial engagement. These guidelines aim to assist practitioners in fostering effective working relationships with patients' family, providing advice on how to overcome challenging interactions, as well as information on how to support family without derailing or losing focus of patients' healthcare needs.

2.5.2 Family member experiences and rationale for involving them in care

Given evidence suggesting the important role family can play in influencing the PA behaviours of patients with CHD, it is important to consider the experiences of those family members who provide support and the impact this may have on them. Research has focused on family behaviours in order to understand their responses to a cardiac event and consequent rehabilitation, which has led to understanding the support needs of families in order to optimise effective support to patients (O'Farrell et al, 2000, McLean and Timmons, 2007). The immediacy and often rapid occurrence of MI (American Heart Association [AHA], 2015) can lead family members of the patient to experience both physical and psychological burdens which can elicit conditions such as anxiety and depression (Reid, Ski and Thompson, 2013). O'Farrell and colleagues (2000) used questionnaires to measure psychological distress of partners of patients undergoing CR, and reported 66% were distressed (e.g. feeling tense, self-criticism and withdrawal). Distressed partners also reported lower levels of family functioning and implemented disengagement coping strategies such as avoidance. However, in the study, the sample was solely female therefore lacking generalisation for the whole population as men and women differ in levels of support they provide to patients (Kristofferzon et al, 2003). A recent qualitative study aimed to unpick the lived experiences of individuals caring for heart failure patients (Petruzzo et al, 2017). Results were mixed, and demonstrated that caring, although can be both psychologically and physically onerous, can also elicit feelings of contentment. On the one hand, carers expressed feelings of uncertainty over illness management, fear and worry related to the illness, restrictions to their life due to patient need and caring as being burdensome. However, they also felt helpful by helping patients to cope with the illness, providing encouragement for patients to engage in healthy behaviour and lastly, had a love and affection for the patients, which appeared as a coping factor to counteract the burdensome nature of care. Given the potential negative impact on individuals whom support chronically ill patients, McLean and Timmons (2007) qualitatively explored the information needs of partners/spouses. To prevent feelings of isolation, which was found to be crucial in order to successfully support the patient, McLean and Timmons (2007) suggested methods of support included self-help groups for partners/spouses supported and attended by HPs and telephone support systems. However, the above studies were cross-sectional in nature and therefore did not capture the changing levels of support that may occur throughout the recovery process (i.e. from the PA uptake to adherence stages), and how this may affect the management of health behaviours.

2.5.3 Perspectives of family involvement in care

2.5.3.1 Benefits of family involvement

Evidence exploring patient perspectives on family involvement in care appear positive, having benefits both in and outside of medical consultations. Patients have been found to be comforted with family presence given their ability to advocate for their care (Duran et al, 2007, Coyne, 2015), help facilitate patient decision making (Clayman et al, 2005, Wollf and Boyd, 2015), provide proximal support (i.e. emotional and informational support) and ability to promote adherence to treatment regimens (Shin et al, 2013). Yet in order for family involvement to operate smoothly, patients require to feel autonomous (i.e. to have control) during the consultation (Duran et al 2007, Laidsaar-Powell et al, 2013, Shin et al, 2013) and involves stating whom they want present, what information they want shared, and how treatment decisions are made. Primarily, family are there to support patients rather than to give their opinions. Autonomy supportive behaviours from family, such as clarifying health information, facilitating understanding, and prompting patients to engage in health-related discussions have been shown to promote encouragement in medical decision-making (Clayman et al, 2005).

The benefits of inviting family into patients' healthcare team extend beyond that of just patients, with evidence suggesting numerous benefits for the family involved also. Many qualitative studies have used face to face interviews, observation and focus groups to explore this and have found benefits to include an understanding of patients' condition and treatment plan, the ability to ensure important issues are addressed and understand the level of care being provided to patients (Duran et al, 2007, Sheehan et al, 2019). Behaviours which can provide family members with a sense of control over patients' condition by enhancing feeling of reassurance (Sheehan et al, 2019). Importantly, evidence suggests that family involvement can improve patient outcomes. A cross-sectional study by Rosland and colleagues (2011) and systematic review by Laidsaar-Powell and colleagues (2013) have explored the effect of family involvement in healthcare consultations on patient outcomes and the results were positive. Involvement increased patient understanding, the quality and quantity of the information exchanged and patients' ability to speak confidently during consultations. It is worthwhile considering the transferability of these findings to a MI population, given that the population in neither studies focused on this specific patient group, nor specifically looked at the role of the family within consultations within a PA promotion role. It is possible that roles could change dependent on both patient group and level of involvement in care.

From a HP perspective, many positives have been associated with the presence of family in care. Evidence suggests that HPs appreciate families' ability to share patients' health information, which they may have not otherwise had access to (Clayman et al, 2005, Wolff et al, 2017, Mackie, Marshall and Mitchell, 2017, Koren et al, 2018). Health professionals also see family as a means to help better their understanding through clarifying medical history or discussing medical topics, as well as being able to reinforce health information outside of healthcare consultations (Clayman et al, 2005, Wolff et al, 2017). Lastly, HPs feel that seeing family allows them to answer any questions or concerns they may have, which HPs deem reasonable given families' roles as patients' health advocate (Koren et al, 2018).

2.5.3.2 Challenges of family involvement

Although numerous benefits exist, it is important to consider the challenges of familial involvement in care also. Evidence from qualitative studies exploring experiences and/or perceptions of family involvement from the perspectives of patients, families and HPs have found multiple disadvantages. For patients, a lack of autonomy can present challenges. Autonomy distracting behaviours, characterised as interrupting, speaking for or criticising patients, have been found to have negative impacts on familial involvement in patient care, specifically in relation to shared decision making (Clayman et al, 2005). Evidence suggests that ensuring patient autonomy and that consultations remain patient centred are of paramount importance (Mackie, Marshall and Mitchell, 2017) however this can sometimes come with its own challenges, especially when there is disagreement between patients and their family. This is a worthwhile acknowledgement, especially given that family have been rated to be more beneficial to the patient when the patient has requested their involvement (Wolff et al, 2017).

For families, issues such as their motivation to be involved, competing priorities, intellectual capabilities and lack of confidence regarding knowledge of patients' condition and valued input have presented themselves as barriers to positive involvement (Laidsair-Powell et al, 2013, Laidsaar-Powell et al, 2016, Lee et al, 2017, Mackie, Marshall and Mitchell, 2017, Koren et al, 2018). In regard to roles, a lack of distinguished roles, unclear responsibilities, lack of guidance and hidden expectations (Laidsaar-Powell et al, 2013) can lead to feelings of stress and abandonment (Coyne, 2015). As roles often come with a sense of responsibility, it is not uncommon for families to experience emotional burdens when involved in patient care. Making treatment decisions on patients' behalf can cause negative feelings such as guilt, uncertainty and sadness (Laidsaar-Powell et al, 2016, Koren et al, 2018). However, given that ultimately family may have to make patients' healthcare decisions, it provides an argument for their important place as part of their healthcare team. In their study, Mackie, Marshall and Mitchell (2017) highlight sometimes HPs may only involve family if it works to their own advantage (i.e. to feed and/or shower patients) therefore saving them time. Yet, this narrow view of the advantages of involving family meant that when family attempted to engage with HPs, they were often viewed as a hindrance. These findings reflect that although HPs may acknowledge the family as part of the healthcare team this may only be in a superficial manner. This therefore may provide an explanation as to why family may at times feel at a loss in relation to the roles they can provide to patients (Coyne, 2015), and consequently highlights the importance of HPs 'buy in' to familial involvement to ensure its success.

From a HP perspective, given an extra individual in the consulting room, HPs noted time concerns, especially if they ask numerous questions, as well as concerns regarding the management of potential expectations families may have (Rosland et al, 2011). Health professionals have also expressed concerns over patient disclosure, noting that sometimes patients are reluctant to share important and necessary health information in the presence of family as they do not want to cause families additional worry (Isenberg et al, 2018) , as well as families potential to dominate and/or control consultations (Laidsaar-Powell et al, 2016). Difference in treatment decisions between patients and family members, as well as a desire for non-disclosure, put HPs in challenging situations. Although HPs understand families often have patients' best interests at heart, HP loyalties often lie with patients (Laidsaar-Powell et al, 2016).

Within a cardiovascular context, evidence suggests that although they viewed family as important, attitudes regarding actively involving them in care were less positive (Gusdal et al, 2017, Luttick et al, 2017). Both studies concluded that education for HPs was important to strengthen attitudes regarding familial involvement. However, given the quantitative nature of these studies, it is difficult to understand why such attitudes may exist.

2.5.4 Cardiac interventions involving family members

Two recent intervention studies have been conducted and have specifically focused on targeting both cardiac patients and their family members (Sher et al, 2014, Yates et al, 2015). In both studies participants were randomised to either the intervention (couples’ condition) or control group (patient condition), although interventions between studies differed slightly. In Sher and colleagues (2014) study, both conditions included 18 sessions over 24 weeks. In the couple condition both patient and spouse received information related to heart disease (nutrition, exercise, medication). Additionally, patients and spouses also received training in relationship skills (such as positive communication/collaboration). In the individual group, patients received the same training, education on cardiac risk reduction, but relationship skills was not provided. Whereas in Yates et al (2015) study both groups received patient individualized counselling/education/goal setting, however this was provided to partners in the intervention group also. Partners in the control group were invited to attend CR, but only offered education. Findings from both studies indicated PA increased for the duration of the intervention period in both the intervention and control groups. However, the PA behaviour for patients was not sustained 6 months following the intervention in both groups (Yates et al, 2015). However, the interventions, although offering education to patients and family members, there was no specific focus on understanding the health behaviours of the family members involved. Therefore, it is possible that the lack of maintenance of PA behaviour may be due to families only being involved to the extent of information sharer (Richards et al, 2018). Interventions that focus on both patients and family have been shown to be more effective for the longer-term maintenance of health behaviour (Burke et al, 2002). It is also worth noting that these interventions were designed with no input from those of whom they were intended to serve (patients and/or family members), which may have impacted upon the effectiveness of PA maintenance. A number of research studies exist that have developed community PA interventions using a collaborative approach involving service users (Buckley et al, 2018, McKay et al, 2018). Buckley and colleagues (2018) reported on the co-development of an ERS, concluding that involving services users in intervention design has the potential to improve implementation success. Likewise, Mckay and colleagues' (2018), research evaluated the effectiveness of a co-produced PA intervention for older adults, concluding co-produced interventions have the potential to positively impact upon PA. Such research indicates plausible methods to help encourage and sustain PA behaviour, but further work could be done to investigate whether these approaches work within cardiac populations given the more clinical setting.

2.6 Rationale for PhD

2.6.1 Health profile of geographical area

To give grounding to the research findings within this PhD, it is important to acknowledge the geographical profile in which the data was collected. The boroughs of Wigan and Leigh are geographical localities located in the North West of England and have a varied health profile in comparison to the England average (PHE, 2018). Many health-related indicators for the Wigan and Leigh Boroughs are lower than the average for England. It is an area characterised by high levels of obesity (27%) (PHE, 2015) and low levels of PA (50.9%) (PHE, 2015). Life expectancy is lower than the national average and appears to differ between socio-economic status and gender, with life expectancy for men and women differing by 12 years and 9.8 years respectively in the most deprived areas compared to the least deprived (PHE, 2018). Cardiovascular disease is reportedly the most common of cause of early death (75 years and younger), within the locality (PHE, 2018) also.

2.6.2 Outline of CR programme offered within geographical area

The CR service of study during the PhD was located within the Wigan and Leigh Borough and followed a four-phase format moving from a hospital to community setting, please refer to figure 2.3 below for visual overview of the CR service. Phase 1 involves an in-patient hospital visit from a member of patients' cardiac team, whom discuss diagnosis and treatment with the patient. Phase 2 begins on patient discharge and involves a home visit from a CN who discusses lifestyle behaviours with patients (PA, dietary habits, drinking, smoking, medication), and also discusses a referral to the physiotherapy led exercise sessions and stress management with an

OT. Phase 3 involves 6 weeks of supervised and individualised outpatient exercise sessions with a physiotherapist, which is run alongside 6 weeks of stress management classes with an OT. To determine patient need, a face-to-face consultation is arranged between patient and practitioner prior to the start of both the exercise and stress management classes. The last stage of the pathway is phase 4 and involves a 12-week programme of individualised and supervised exercise with an exercise referral practitioner, patients are referred to phase 4 through phase 3 physiotherapists. Prior to the start of phase 4, patients have a face-to-face consultation with an exercise referral practitioner to design a suitable programme of exercise.

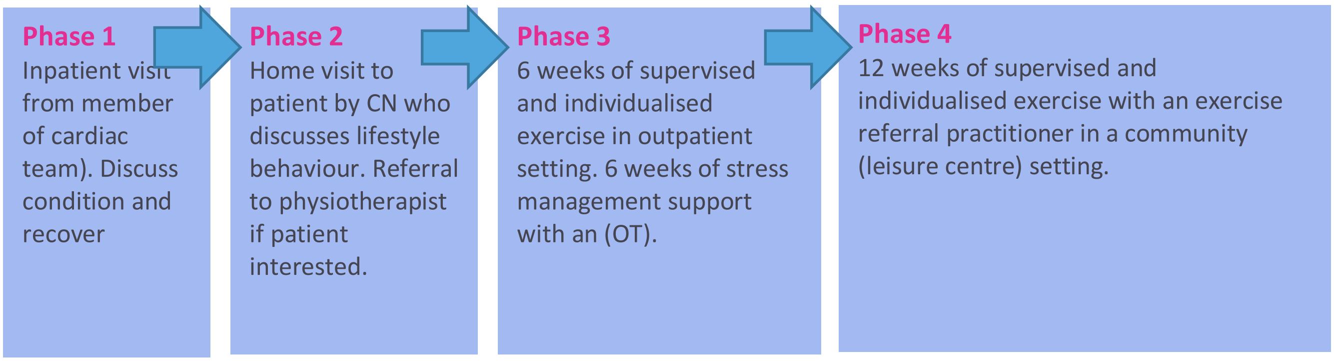


Figure 2.3 A visual overview of the cardiac rehabilitation service of study

2.6.3 Summary of why this PhD is needed and what it aimed to do

The research highlighted throughout this review has shown that CVD, especially CHD, is a pressing issue within current society, responsible for an overwhelming number of premature and preventable deaths each year. Physical activity has been presented as a beneficial and sustainable method in both the prevention and management of CHD, yet within an MI context, engagement appears poor. Evidence suggests that mobilizing patients’ social networks (in particular the family) is a worthwhile strategy in promoting PA, given that their support has been associated with increased PA engagement. Involving the family in healthcare promotion appears an acceptable strategy amongst patients, family members and HPs alike, although a number of challenges have also been noted. However, there appears minimal research on family support and PA within the context of an MI population. The NICE (2013) and BACPR (2017) guidance promotes involving supporting others (family/carers) in the care of cardiac patients, however little guidance exists highlighting how this is best achieved, nor the impact they have can have, specifically in relation to patients' PA experiences and how impact may change over time. Therefore, the aim of this PhD was to explore the role of the family in post-MI patients' PA experiences to make recommendations for how they can support positive PA engagement post-MI.

Chapter 3 Methodology

"…we construct knowledge through our lived experiences and through our interactions with other members of society...as such, as researchers, we must participate in the research process with our subjects to ensure we are producing knowledge that is reflective of their reality"

(Lincoln, Lynham and Guba, 2011, pg.103)

3.1 My background and philosophical positioning

In order to understand my positioning within the research, it is important to firstly outline my researcher background. As a researcher I consider myself as an interpretivist. I acknowledge that individuals create their own realities based on their own interaction with the world around them (Guba and Lincoln, 1985, Ponterotto, 2005), but also acknowledge my role in co-creating their realities. I believe that meanings are varied, complex, and specific to individual contexts (Guba, 1996) and the only way to access and come to understand another's world is through a process of interaction and interpretation (Creswell, 2003). As such, the interpretations made throughout this PhD may have been influenced by my own understandings and experiences, especially within the context of PA. It is therefore important to share relevant aspects of my past with the reader, and to acknowledge the interpretations presented in this PhD ought to be viewed as one of potentially many perspectives.

Academically, I have completed a degree in Sociology and have a taught Masters in Social Research and an MPhil in Sport and Exercise Sciences. It was through my MPhil project, which explored barriers and facilitators to an ERS, that this PhD was born. During this project it was found that family support acted as both a facilitator and barrier to patient attendance at the ERS. For me, this was quite interesting. I understood the logic in why family would act as a facilitator to engagement, but was intrigued by the notion of someone preventing a loved one from engaging in a behaviour that had the potential to improve health and quality of life. I therefore became interested in the role of the family in shaping patients' PA, and what could be done to ensure families were a positive influence on patients' PA engagement.

The MPhil project provided me with experience of PA with patients with a range of health conditions (e.g. cardiovascular, musculoskeletal, respiratory, and neurological). Therefore, before embarking on my PhD I had some knowledge of the barriers and facilitators to PA faced by a clinical population, however this was outside of a post-MI context specifically. Further to this, my academic background has not been positioned within a medical context, thus before this PhD I had limited knowledge of cardiovascular conditions and recovery pathways. Despite the potential to be viewed as a 'cultural outsider', this lack of expert knowledge has instead allowed me to adopt a genuine curiosity and openness throughout the research process to really understand post-MI patients, family members and CRP experiences of PA post-MI.

On a personal level, I have always seen myself as active and it forms part of my overall identity. Being active is something I see as an integral part of creating a healthy self. Consequently, I take great pleasure in being active and I will always make time for it, regardless of other commitments in my life. Running (especially with my dog) is one of my greatest pastimes, as is going to the gym. I have a structured exercise regime, typically aiming to be vigorously active at least 5 times per week, however I do make a conscious effort to try and be active daily. My relationship with PA started from a young age through dance, however has transformed over time. Although I no longer dance, I have found great pleasure in a number of other activities instead.

3.2 Philosophical positioning and methodological approaches within the PhD

Whilst I view the world through an interpretative lens, the overarching PhD aim is focussed on generating research insights to inform changes to practice, and thus is pragmatic in nature (Creswell and Creswell, 2018). Pragmatism is flexible and advocates methodological pluralism (Wildemuth, 1993), whereby the most appropriate methodology is adopted to answer the research question/s of interest. As such, each study in this PhD drew on a different methodological approach, each designed to answer a specific study question whilst contributing to an overarching aim of improving practice. Study 1 drew on the principles of IPA, through which I aimed to understand the realities of a single MI experience from multiple perspectives (post-MI patients and their family member) and explore how these changed over time. For study 2, I drew upon thematic analysis, whereby I aimed to understand how CRPs viewed the family in CR, through gathering in-depth insight into the roles family can adopt to shape post-MI patients' PA experiences. Lastly, for study 3 I adopted a co-production approach, whereby I aimed to understand multi-stakeholder views in the development of a PA support resource for families of MI patients.

Use of multiple qualitative methods allowed me to understand the role of the family in post-MI patients' PA experiences from the perspectives of those with lived experience. This in turn allowed me to authentically capture the social reality of the participants of study and therefore come to understand the phenomena in detail. In addition, using qualitative methods provided me with greater flexibility and ability to probe deeper into participant accounts (Patton, 2002), which helped further elicit a clearer understanding of participants' worlds. Adopting a qualitative approach also gave me the opportunity to immerse myself in individual stories, capturing the rich description of their lived experiences, and learning how these experiences could then help inform practice.

The section below provides an overview of the key principles underpinning each methodological approach and my rationale for its use in this PhD.

3.2.1 Interpretative phenomenology

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009) was drawn on as part of this PhD (study 1) as an in-depth qualitative approach to understand patient and family members' experiences of PA post-MI. This methodological approach aims to understand, in detail, how participants make sense of their personal and social world following phenomena (Smith and Osborn, 2008) and what meaning they attribute to the phenomena (Smith, Flowers and Larkin, 2009). That is, IPA research aims to understand 'an experience' as opposed to ‘experience’ (Smith, Flowers and Larkin, 2009). As study 1 aimed to understand how patients and family members experience PA post-MI, IPA was deemed as an appropriate methodology to draw from given that the experience of PA may have held more significance in their lives as it is connected to a potentially life changing event (the MI) (Smith, Flowers and Larkin, 2009).

Interpretative phenomenological analysis draws upon the phenomenological traditions of phenomenology (experience), hermeneutics (interpretation) and ideography (focus on the individual). The IPA approach is phenomenological in nature due to its focus on the close and detailed examination of participants’ life world and exploring their experience of a given phenomena (Smith and Osborn, 2008). In study 1, to ensure the phenomenological principle was followed, I gave myself the opportunity to immerse myself in participants’ stories, which allowed me to facilitate a deeper understanding of their experiences of PA post-MI. In IPA research, attempts to understand individuals’ social worlds is a largely dynamic and interpretative process (Smith and Osborn, 2008). Consequently, IPA relates to hermeneutics, which refers to going beyond the description of an event, and instead tries to make sense of an individuals’ being in the world (Neubauer, Witkop and Varpiom 2019), which requires multiple levels of interpretation. To ensure this principle was adhered to within the research process, I sought to make sense of participants’ subjective realities through multiple face-to-face in-depth interviews, which in turn, helped facilitate my understanding of MI patients and family members’ PA experiences post-MI. Lastly, IPA pertains to ideography, whereby there is a focus on the particular rather than the general (Smith, Flowers and Larkin, 2009). To ensure the idiographic principle was maintained throughout the study, I conducted interviews with each individual family, and ensured their individual stories were captured during the analysis and write-up phases through the use of verbatim quotations from their spoken accounts.

3.2.1.1 Longitudinal interviews

As an interpretivist researcher, I pertain to the beliefs that as well as realities being socially constructed, they are also fluid (Sparkes and Smith, 2014), and constantly developing and evolving based on interaction with the immediate and wider environment. Therefore, how experiences are seen at one time point may alter over successive time points, especially given experiences are often time specific (Charmaz, 2004), and are often reflected upon in the present. One of the research aims of study 1 was to understand how patient and family members' perceptions of PA changed over time. Using longitudinal interviews allowed me to capture temporal change, helping enhance the richness in individual accounts through being able to explore not only change, but also reasons for change and how changes were responded to (Hermanowicz, 2013). In other words, using longitudinal interviews allowed me to gain an in-depth insight and understanding into how PA experiences changed during patients' MI recovery, how these changes were interpreted and what they meant to participants.

3.2.1.2 Joint family interviews

As part of study 1, joint interviews between patients and family members were conducted. Although not originally intended, conducting these type of interviews provided me with an in-depth and unique understanding of the family dynamic (Reczek, 2014). Further, and in line with my own interpretivist epistemology, they helped reveal a collaborative family reality, whilst also demonstrating how each family member negotiated their own experience and reality. Therefore, providing me with an additional depth to their experiences. Although joint interviews can take multiple forms (Reczek, 2014) in this PhD, they were approached with either each member of the family being interviewed separately, but with the other member present, or a singular interview with both family members. It is recognised that joint interviews may compromise the authenticity of individual accounts through contamination or coercion (e.g. saying things to please the other) (Bennett and McAvity, 1992, Eisikovits and Koren, 2010). However, they can also elicit a complete and honest picture of individual experiences, given one family member can jog the memory of the other or challenge different versions of the experience (Reczek, 2014). For me, using joint interviews allowed me to obtain multifaceted truths, giving way to providing a holistic, deeper and more honest understanding of patients and their family members' experiences of PA post-MI.

3.2.2 Thematic analysis

Study 2 involved thematic analysis of semi-structured interviews as a means of exploring how CRPs viewed the role of the family within the CR process (focussing on PA specifically). As has been discussed throughout this chapter, I pertain to the belief that individuals create their own reality through the world they are interpreting, and as such, research requires the tools to allow participants to share their views (Creswell and Creswell, 2018). Semi-structured interviews offer a way of gaining an understanding of what the world means to individuals, through being able to enter their social world via a process of interaction (Charmez, 2004). This approach also gives participants the flexibility to talk about their experiences openly (Sparkes and Smith, 2014), which in turn allows for a greater depth and meaningful understanding of participant accounts. Thematic analysis has been proposed as an appropriate means to analyse such data because of its ability to report the experiences, meaning and reality of participants (Braun and Clarke, 2006) whilst focusing on developing meaning across cases, rather than within specific ones (Braun and Clarke, 2006). Thus, thematic analysis was deemed an appropriate methodological approach for study 2, where the focus was on understanding views across a sample of CRPS (rather than understanding their idiographic experiences).

3.2.3 Co-production

Within the Public Health literature, a co-production approach refers to 'the involvement of public service users in the design, management and/or evaluation of public services' (Osborne, Radnor and Strokosch, 2016), and was drawn upon for study 3 of this PhD. This approach was chosen due to its focus on collaboration with different participants, and a recognition that individuals with lived experience can play an important role in the development of interventions (Realpe and Wallace, 2010). To be able to capture the lived experiences of individuals, and therefore able to create an intervention that was both context sensitive and sustainable (Harden et al, 2016), I felt it was appropriate to use qualitative methods (informal meetings, multi-participant group meetings with post-MI patients, family members, and CRPs). Pertaining to my interpretivist views, conducting informal, multi-participant meetings allowed participants to discuss their own personal views, opinions and understandings, where co-participants could trigger memories/experiences that could help facilitate discussion (Wilkinson, 2009), and therefore being able to capture a range of thorough viewpoints.

As the co-production approach involved a multi-disciplinary group of participants, each were involved within different capacities. Local stakeholders (i.e. MI patients, family and CRPs) provided personal experiences to aid feasible resource development (Beierle, 2002), academic staff were involved in the capacity of providing theoretical knowledge and scientific evidence (Buckley et al, 2018). The co-production framework followed within the current PhD drew on elements from a co-production study by Buckley and colleagues (2018) which involved:

- Conducting a series of development meetings with stakeholders to gather their views on intervention development (topics broadly include format, content, delivery)
- Development of a draft intervention based on the data collected during development meetings, which was then shared with stakeholders and feedback sought
- Refinement of the intervention based on stakeholder feedback

Chapter 4 Understanding the lived experience of physical activity post-myocardial infarction

4.1 Introduction

As outlined in chapter 2, family support is an interpersonal mechanism that has the potential to influence the health behaviour (e.g. PA) and outcomes of cardiovascular patients (Franks et al, 2008, Sayers et al, 2008, Rosland et al, 2010, Rosland et al, 2011). With such outcomes potentially being determined through the provision of offering various forms of social support such as tangible (helping patients to look after themselves) or emotional (empathy, care, understanding) (Kärner, Dahlgren and Bergdahl, 2004, Barry et al, 2006).

Within a cardiac (including MI) and PA context, numerous studies have demonstrated the ways family can influence patients' experiences of PA (Kärner, Dahlgren and Bergdahl, 2004, Franks et al, 2006, Astin, Atkin and Darr, 2008). Family behaviours such as encouraging patients to make positive health choices, listening to patient concerns, taking a practical interest in patients' lifestyle changes, communicating empathetically and being encouraging without making demands have been associated with patients' engagement in healthy behaviours (e.g. PA) (Kärner, Dahlgren and Bergdahl, 2004, Franks et al, 2006, Astin, Horrocks and Closs, 2014, Karmali et al, 2014). Whereas family behaviours such as providing advice to control patients' behaviour, stopping engagement in behaviours through worry of perceived harm (e.g. overprotection) and a reluctance to be involved in patients' care have been associated with poorer health outcomes for patients (Kärner, Dahlgren and Bergdahl, 2004, Franks et al, 2006, Astin, Horrocks and Closs, 2014).

Given how the provision of family support can impact both positively and negatively upon patients' health outcomes, it is important to consider why there may be variance in support provision by family members. Work by Astin and colleagues (2008) has gone beyond describing roles and behaviours family may adopt and instead offered explanations as to why family may act in such ways. They suggested families may offer support because they have a personal belief that patients should engage in PA post-MI to help aid recovery. However, they also found families face challenges to supporting patients' PA, and included uncertainty regarding exactly what activity patients could do, but also patients own lack of motivation to be active. In addition, families own PA identity appeared to act as a mediating factor as to whether family supported patient PA. Further evidence (Dalteg et al, 2011, Reid, Ski and Thompson 2013, Saltmarsh et al, 2016), suggest it is not uncommon for family members to be emotionally affected and experience feelings of distress, such as depression and/or anxiety resulting from patients' cardiac event. With research speculating that within a MI context the often-unexpected nature of these events can be reasons for eliciting such feelings (Fosbøl et al, 2013).

Although the aforementioned studies provided insight into how and why families can influence PA following a cardiac event, they did not explore how post-MI patients and family make sense of the MI and how this influences PA, and how this may change over time. A growing body of evidence suggests that adopting a qualitative methodology is appropriate to understand the lived experiences of a phenomenon (Smith, Larkin and Flowers et al, 2009, Sparkes and Smith, 2014) and how this may unfold over time (McCoy, 2017). Within a health context, qualitative methodology allows researchers to draw on participant experiences to understand the mechanisms underpinning decisions to engage in healthy behaviours and how such processes may change over time. Therefore, such an approach is useful to gain an in-depth understanding of the influencing factors that promote positive engagement in health behaviours.

Thus, the aim of the current study was to understand the lived experiences of PA post-MI from the perspective of both patients and their family members. Data were collected over the course of 9 months (during the first year post-MI), with the aim of understanding how perceptions of PA may change over time.

4.2 Methods

4.2.1 Study design

This study was a qualitative longitudinal inquiry that drew upon the principles of IPA (Smith, Flowers and Larkin, 2009). Within the literature, IPA has been described as aiming to explore, in detail, the sense making activities of individuals in relation to their own subjective experiences (Smith and Osborn, 2003). Therefore, this approach focused on how individuals interpret and make sense of both their personal and social world and what meaning they attribute to experiences within their lives (Smith and Osborn, 2008). Data was collected using semi-structured interviews approximately 1, 4-and 9-months post patients' MI and involved joint interviews with patients and family members. This approach to data collection was adopted because it gave participants the flexibility to describe in detail and in their own words (Sofaer, 1999), their subjective experience of PA post-MI.

Figure 4.1 below provides a visual overview of the interview time points mapped onto the CR pathway as described in section 2.6.2. The time points chosen for the interviews were to reflect patients' journey through and post CR (i.e. before the start of phase 3 structured exercise classes, during phase 4 CR structured exercise classes and following completion of CR).

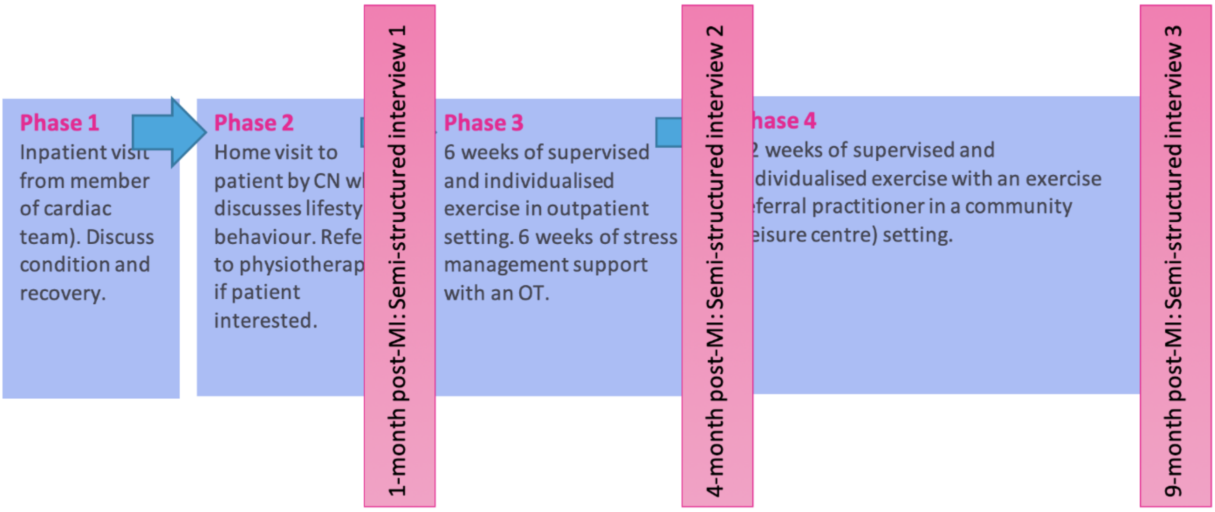


Figure 4.1 A visual overview of interview time points mapped on the cardiac rehabilitation pathway of study

4.2.2 Study setting

The study took place within a CR service located within the Northwest of England. Please refer to section 2.6.2 for a full overview of the current CR service provided in this location.

4.2.3 Participants and recruitment

4.2.3.1 Eligibility

To be eligible for the study, patients had to be classified as having had a MI within the previous month. Myocardial infarction diagnosis was determined by HPs on presentation to the hospital and was based on the 3rd definition of MI (Thygesen et al, 2012) which is in keeping with the 4th definition as defined in section 2.1.2. Patients also had to be aged 18 or over, speak fluent English and be present in the geographic region of interest for the study duration. However, patients were excluded if the MI had not been their first, had resulted in the need for coronary artery bypass graft surgery or were unable to engage in PA due to another co-morbidity, injury or ongoing investigation/s. However, due to slow recruitment, in October 2017, the eligibility criteria changed to include patients whom had multiple MIs. Patients were asked to recruit family members whom they deemed influential in their health and wellbeing. Both MI patient and at least one family member were required to take part in the study.

4.2.3.2 Sampling

This study drew on IPA principles to sample participants, which posits a small and homogenous sample (Smith and Osborn, 2008). Small because IPA is concerned with the idiographic mode of enquiry, understanding, in detail, each participant's experience, rather than making more generic and potentially surface level claims. Homogenous samples are important within this approach so the researcher is able to make detailed claims about a particular group and therefore, through a process of purposive sampling, can identify participants whom the research question/s will be relatable (Smith and Osborn, 2008). Therefore, in this study, purposive sampling was used to identify participants who could provide in-depth and relevant information to answer the research questions.

4.2.3.3 Participant recruitment

Cardiac nurses (x2) were responsible for identifying and recruiting MI patients during a routine home visit within 5 days of patients’ hospital discharge (this home visit is CR phase 2; please refer to section 2.6.2 for overview of CR pathway in study area). All patients had been referred to the CNs following their MI diagnosis.

Participant recruitment ran from May 2017 - December 2017. During this home visit, CNs screened patients for the inclusion and exclusion criteria outlined in section 4.2.3.1 and provided eligible patients with a study recruitment pack (if the patient consented to being given one) inclusive of a recruitment leaflet, reply slip and freepost envelope. The recruitment letter detailed reasons for contact, the purpose of the study and provided a brief overview of what participation would involve. Additionally, it informed participants that on completion of the third interview they would be given a £30 shopping voucher as a thank you. This amount was deemed appropriate to incentivise participants, but not enough to coerce them. Including freepost envelopes was to minimise the burden and cost to participants and increase the likelihood of responses. To help maximise the likelihood of the first interview with patients and family members taking place 1-month post-MI, participants who were interested in taking part were asked to return the reply slip to the primary researcher within 2 weeks of receiving the recruitment pack.

For each reply slip received, participants were sent a participant information sheet (PIS) and accompanying cover letter. The accompanying letter outlined the purpose of the PIS, whilst the PIS explained the interview procedure (including topics to be covered) and ethical considerations. It also outlined that the primary researcher would be in contact to discuss participation in the study and answer any questions about participation. During the follow-up telephone call, interviews were arranged on a day and time suitable for all participants, with the second and third interviews being arranged in person. If patients and family members were unable to be interviewed on the same day, an effort was made to ensure the interviews were as close as possible to ensure their experiences reflected the same timeframe. Before each interview, participants were sent a confirmation letter confirming the date, time and location of the interview. In addition, all participants were contacted via telephone the day before each interview was due to take place to confirm attendance. Any incomplete reply slips received (i.e. missing patient / family details), were followed up by the primary researcher and assessed for eligibility.

To ensure transparency in the recruitment procedure, both CNs were asked to complete a weekly recruitment checklist which recorded the number of MI patients they had seen that week, how many research packs they had given out and on what basis patients were not given a research pack. This data was then collated and transferred to a master copy by the primary researcher.

4.2.3.4 Final sample

Figure 4.2 details the recruitment flowchart and demonstrates how the final sample was reached. During the recruitment period (section 4.2.3.3), the number of MI patients reviewed by CNs was 176 patients. From this 55 were excluded on the basis of having multiple MIs (n = 21) (although patients were no longer excluded on this basis from October 2017), unable to participate in PA due to illness, injury or ongoing investigation (n = 21), heart surgery (n = 12) and transferred to a different CR service (n = 1). From the 121 patients being eligible for study participation, 21 were further excluded on the basis of declining the study information (n = 8) and forgetting to give out the study recruitment pack (n = 13). From the 100 patients given the recruitment pack, 8 responded to the study invite. However, a further 2 patients were excluded on the basis of not having a family member they deemed influential in their health and wellbeing (n = 1) and unresponsive to primary researcher contact (n = 1).

For an overview of patient characteristics, please refer to table 4.1. In total, 6 families took part in the research, consisting of 6 post-MI patients (3 females and 3 males) and 6 family members (3 male, 3 female, 5 spouses and 1 son), with the average age amongst patients being 68 years. Hospital Depression and Anxiety Scores (HADS) were collected from participants. Current evidence suggests in England, 72.5% of patients presented at CR with anxiety levels within the normal range (score range 0-7), with 16.1% presenting with borderline anxiety (score range 8-10) and 11.2% presenting with clinical (score range 11+) (Doherty et al, 2018). Whereas for depression, 82.1% presented at CR with levels in the normal range, 11.6% in the borderline range and 6.4% in the clinical range (Doherty et al, 2018). The HADS of the final sample therefore suggested they had comparable anxiety and depression levels to the general population.

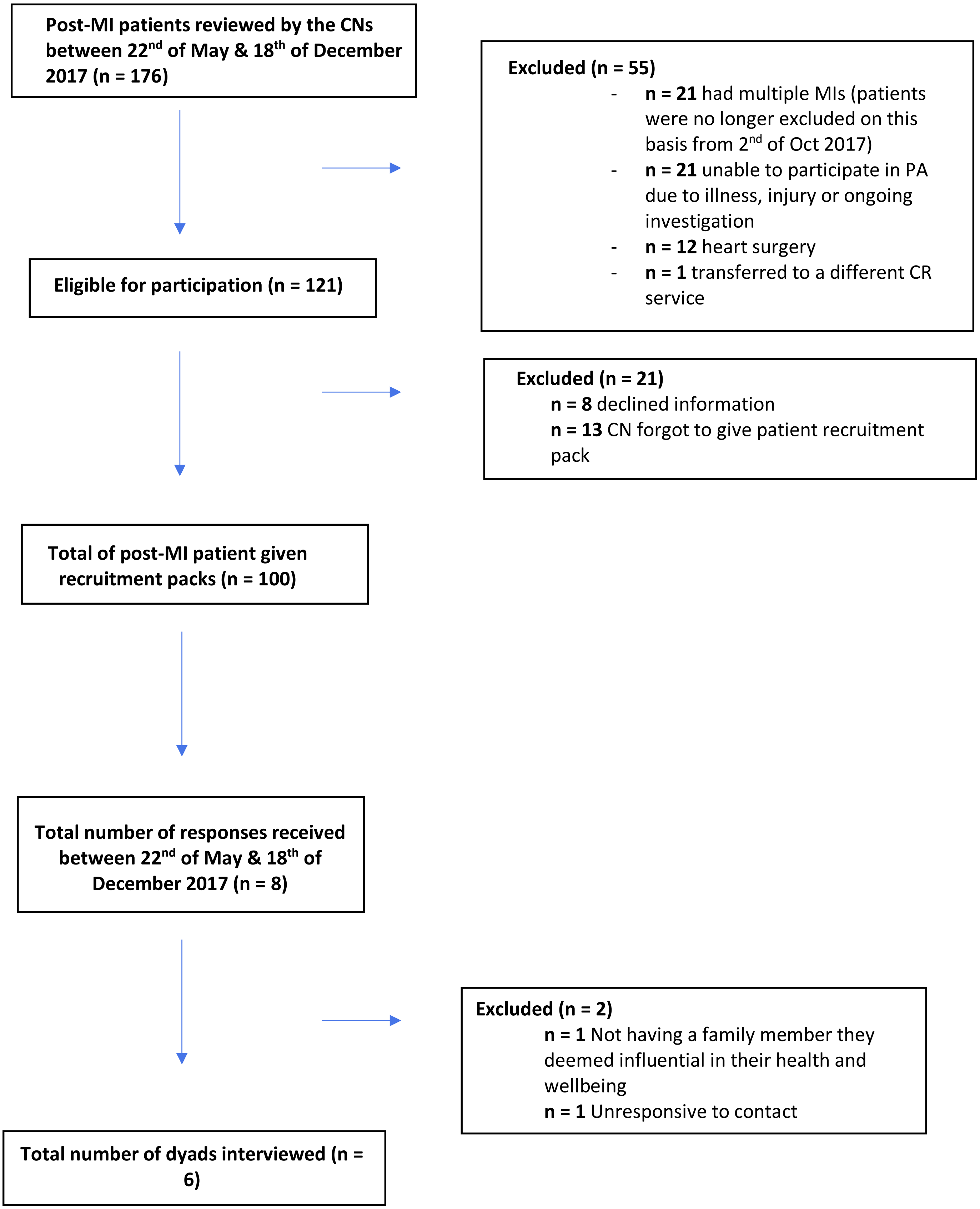


Figure 4.2 – Flowchart demonstrating the recruitment process of post-myocardial infarction patients

Table 4.1 Post-myocardial infarction patient demographic overview

Patient pseudonym	Family member pseudonym	Gender	Age	Ethnicity	Employment status	MI number	MI type	Attended exercise CR		HADS	
								Phase 3	Phase 4	Anxiety	Depression
Alex	Joanne	M	65	WB	Retired	1	ST elevation	✓	✗	4	2
Thomas	Mary	M	79	WB	Retired	1	Non ST - elevation	✗	✗	5	4
Doris	Anthony	F	73	WB	Retired	1	ST elevation	✓	✗	3	incomplete
Julia	George	F	60	WB	Retired	1	Non ST-elevation	✗	✗	10	8
Alice	David	F	69	WB	Retired	2	Non ST-elevation	✓	✗	8	7
Robert	Sarah	M	63	WB	Retired	3	Non ST-elevation	✗	✗	7	9

Key: M = Male, F = Female, WB = White British
HADS score key: For both anxiety and depression scales, normal range (0-7), borderline range (8-10), clinical range (11+)

4.2.4 Data collection

4.2.4.1 Procedure

The primary researcher conducted all interviews which took place between August 2017 and September 2018 in participants' homes and were recorded using a Dictaphone. The decision to interview participants in their homes was twofold. Firstly, it is advised that post-MI, patients refrain from driving in the weeks following their cardiac event (UK Government, 2019b), thus interviewing at home reduced participant burden. Secondly, interviewing in an environment where participants feel comfortable is said to increase the likelihood of participants opening up about their experiences (Bashir, 2017), and therefore was adopted to elicit rich and in-depth responses.

Written consent to participate in the study was obtained from all participants prior to the start of the study. Before the first interview, participants were asked to complete demographic forms, which included participant's gender, date of birth, ethnicity, residential address and employment status. As detailed in section 4.2.3.4, post-MI patients were also asked to complete the HADS (Zigmond and Snaith, 1983), and was done so to further understand the sample in relation to a wider cardiac population. Participants were also reminded that the focus of the interview was PA, and to aid participants understanding, the primary researcher outlined what this was prior to the start of each interview. The definition used was informed by Caspersen, Powell and Christenson's (1985) definition of PA as described in section 2.2.1. However, to ensure participant understanding, it was explained in lay language and to further aid understanding included an example and was referred to as *"…any movement made by your body where your heart rate feels raised, for example this could brisk walking".*

4.2.4.2 Interviews

4.2.4.2.1 Pilot interviews

Within this study, interviews were piloted with post-MI patients and their family members who had previously been offered CR but were not eligible for participation in the current study. Conducting pilot interviews is a multifunctional exercise (Kim, 2011). Pilot interviews allow researchers to understand the feasibility of the intended research process and how it will work in practice, ensure the research protocol is practical and realistic (Teijlingen and Hundley, 2001), that research questions are understandable and credible (Shenton, 2004) and to enhance researchers familiarity of the interview schedule. The latter allowing for both the refinement of interview techniques and increased confidence in the field of qualitative interviewing (Holloway, 1997).

Three face-to-face pilot interviews were conducted in participants' home, and one conducted over the telephone. Following the interview, participants were asked to feedback on the level of difficulty and tone of the questions asked, which is posited within the IPA tradition (Smith and Osborn, 2009), but also any topics they felt would be beneficial to explore that were absent from the guide, or about the interview process. From the feedback obtained from participants, there were a number of changes made to the interview and included refining questions so they had a broader and clearer focus, as well as a reminder to the primary researcher to make notes during the interview so not to forget to ask prompts that were not outlined within the interview guide. In addition, conducting the pilot interviews allowed the primary researcher to view the non-verbal responses of participants, providing valuable insight into whether participants were embarrassed either about the content or questions asked (Whelman and Kruger, 1999). Pilot interviews were reflected upon by the primary researcher and strengths and challenges discussed with members of the supervisory team and revised as appropriate.

4.2.4.2.2 Interview guide

Semi-structured interview guides were developed in collaboration with the research team for post-MI patients and their family members at each interview time-point. Interview guides explored PA and family support and were chosen because of their flexibility in allowing the researcher and participant to speak openly and build rapport, encouraging participants to speak about their subjective experiences (Smith and Osborn, 2008).

Techniques used to inform the semi-structured interview guides were in-line with the IPA tradition as outlined by Smith, Flowers and Larkin (2009) whereby questions were open to encourage participants to talk at length and also in a way that did not propel them to answer in particular ways. Guides opened with a question which allowed participants to narrate a descriptive experience, e.g. ‘to begin with, could you tell me what happened with your heart attack?’ (patient, interview 1), which allowed participants to settle into the interview. A “funnelled” approach was adopted for the guides, starting with broad questions and leading to more specific ones. Given the openness of the semi-structured interview guide, pre-determined prompts were devised to help the researcher further explore participant responses. However, due to each individual experience, in some cases, probing questions were determined by each individual participant responses. Table 4.2 provides an overview of the topics covered during the 3 interviews with post-MI patients and family members. Please refer to appendix 1 for a full overview of the patient interview guides used for data collection, and appendix 2 for a full overview of the family interview guides used for data collection.

Table 4.2 An overview of the interview topics covered during the longitudinal interviews

	Broad interview topics	
	Post-MI patients	**Family members**
Interview 1	- What happened with your heart attack (e.g. feelings, impact) - CR intentions - Own PA (e.g. ability, feelings, experiences, long-term PA) - Family response to MI (PA support, concerns, influence)	- Life since patients' heart attack (e.g. feelings, impact) - Patients' CR intentions (e.g. CR) - Own PA (e.g. attitudes, beliefs, behaviours) - Patients' PA (e.g. current ability, past-behaviour, support, future intentions)
Interview 2	- Reflection on time between last and most current interview (e.g. events, feelings, noticeable changes to lifestyle) - PA (e.g. CR participation, current behaviour, family response, future intentions)	- Reflection on time between last and most current interview (e.g. events, feelings) - Patients' PA (e.g. thoughts and feelings on their PA behaviour, support) - CR participation (e.g. future PA)
Interview 3	- Reflection on time between last and most current interview (e.g. events, feelings, noticeable changes to lifestyle) - PA (e.g. current behaviour, family responses, future intentions, impact of MI on PA) - Ideas for family to support post-MI patients' PA	- Reflection on time between last and most current interview (e.g. events, feelings) - Patients' PA (e.g. thoughts and feeling on their PA behaviour, future intentions, impact of MI on PA) - Ideas for family to support post-MI patients' PA

4.2.4.2.3 Conducting the interviews

Interviews lasted between 30 to 120 minutes in length and were conducted by the primary researcher. Participants were interviewed approximately 1, 4- and 9-month post patients MI, and done so to capture patients' PA journey through and after CR. However, due to differing participant circumstances this was not possible for all families, and the time between MI and first interview ranged from one to three months, although the time between interviews remained consistent (e.g. if a family were first interviewed at 3 months post-MI, their second interview was 6 months post-MI and their third 11 months post-MI). The initial objective was to interview patient and family members separately, so participants felt comfortable discussing their feelings and experiences. However, as the interviews progressed, multiple families requested to be interviewed together, and for the others who chose not to, the family member was present when the post-MI patient was interviewed and vice versa. Table 4.3 provides an overview of participants' interview timeline and interview format (i.e. interviewed together/separately).

The primary researcher led the interview, asking questions to try and discover how participants made sense of what had happened to them. Questions were asked one at a time, allowing each participant to think about their responses. For participants who were interviewed together, the primary researcher posed questions separately to allow each member of the family the opportunity and time to respond. However, because some of the topics were similar, participants often interjected one another with their thoughts and experiences. In these situations, to ensure participant responses were captured fully, the primary researcher made sure to go back to the question and ask if participants had anything further to add.

Although questions were asked in a way to maximise participant understanding, the primary researcher rephrased these if a participant expressed confusion over a question's meaning. The researcher's role while conducting the interviews was to create a relaxed and friendly environment and listen to the participant, allowing them to reflect on their thoughts and feelings in the context of their experience (Smtih, Flowers and Larkin, 2009), and to do so with ease. Having a semi-structured interview guide allowed for a flexible and open questioning approach, giving participants the opportunity to elaborate when answering. This in turn gave the researcher the chance to explore avenues that may have otherwise been unknown (Kinnafink, et al, 2014) giving the researcher a deeper insight and understanding into each experience. To ensure the primary researcher had understood what participants had said and in line with IPA, throughout the interviews, the primary researcher asked participants to confirm whether she had the understood participant accounts (Smith, Flowers and Larkin, 2009).

Table 4.3 An overview of post-myocardial infarction and family interview timeline and interview format

Patient pseudonym	**Family member pseudonym**	**Date of patient MI**	**Interview dates**			**Interview format** (i.e. were participant interviews conducted separately or together)		
			1	**2**	**3**	**1**	**2**	**3**
Alex	Joanne	May 2017	Aug 2017	Nov 2017	Apr 2018	S	T	T
Thomas	Mary	July 2017	Aug 2017	Nov 2017	Apr 2018	S	S	S
Doris	Anthony	Aug 2017	Sep 2017	Dec 2017	June 2018	S	S	T
Julia	George	Sep 2017	Nov 2017	Feb 2018	July 2018	S	T	T
Alice	David	Nov 2017	Jan 2018	Apr 2018	Sep 2018	T	T	T
Robert	Sarah	Nov 2017	Jan 2018	Apr 2018	Sep 2018	S	T	T

Key: S = participants interviewed separately, T = participants interviewed together

4.2.5 Data analysis

4.2.5.1 Transcription

The primary researcher transcribed each interview verbatim. A denaturalised approach was taken to transcription, meaning each pause, laugh ‘um’ and ‘ah’ was recorded within the transcript (Davidson et al, 2009) with this approach being likened to ‘real world’ speech (Oliver et al, 2005). As IPA was the approach adopted, it was considered important to include all verbal emotions (laugh, cries, etc…) and utterances in the transcript. This was not only because of there being a perceived link in IPA between verbal responses and underlying thoughts and feelings (Smith et al, 1996), but also because talk is peppered with utterances that can change a conversation’s meaning (Oliver et al, 2005). Although IPA recognises the interpretative role of the researcher when making sense of data by understanding that they will never completely understand participants’ personal worlds (Smith, Flowers and Larkin, 2009), choosing a denaturalised approach maximised the likelihood of interpreting each experience as accurately as possible.

Audio files were listened to and transcribed in Microsoft Office Word. To accurately capture each word, short phrases were listened and re-listened to. In cases where words or phrases were inaudible, the primary researcher thought back to the interview and tried to remember what was said. If this was unsuccessful, another member of the research team listened and tried to make sense of what was being said. Where it was not possible to understand what was said, the primary researcher noted this down in each transcript with the word 'inaudible' and the time in the audio file this occurred. As the aim was to understand participant experience, speculating what had been said was deemed inappropriate as this could have altered the meaning of their experience. To ensure each audio file had been transcribed accurately, the primary researcher listened to audio files alongside the finished transcript. Any inaccuracies were altered accordingly.

4.2.5.2 Analysis

Within this study, IPA was employed as means of exploring how patient and family members experienced and made sense of PA post-MI, and how these experiences transcended over time. Limited guidance exists outlining how to conduct an IPA analysis that captures experience over time (Farr and Nizza, 2019), instead a set of principles exist that can be applied flexibly, whilst still maintaining the emphasis on capturing participants lived and subjective experience. The principles for analysis followed within this study drew from an approach outlined by Smith, Flowers and Larkin (2009). who posit six analytical stages (1) reading and re-reading (transcripts), (2) initial noting, (3) developing emergent themes, (4) searching for connections across emergent themes, (5) moving to the next case and (6) looking for patterns across cases. However, it is worthwhile noting the analysis differed slightly in that this study looked at how themes manifested within and across cases over time. This combination of cross-case and longitudinal analysis has been shown useful as a means of portraying temporal change of how participants experience phenomena and how this unfolds and is made sense of through time as shown in McDonough and colleagues (2011) and Thomson, Martin and Sharples, (2017).

Interpretative phenomenological analysis is a dynamic process where researchers play an active role in exploring and understanding participants' social world. This involves researchers attempting to make sense of the participant who themselves is also trying to make sense of what is happening to them and is referred to as the 'double hermeneutic' (Smith, 2011). This demonstrates the subjective nature of IPA research, and how in this instance, the researchers may have influenced the data collection and analytical process given that it is seldom that interpretations develop outside of their own internal context and understanding (Hardcastle and Hagger, 2014). For the purposes of this study, it was therefore important to recognise the research teams' prior knowledge and expertise within the domains of PA, psychology and cardiac nursing. Within this study, bracketing was used by the primary researcher as a means to accept potential biases that may arise through the research teams' prior knowledge and experiences. By acknowledging these biases, it helped distinguish participant and researcher experiences, thus helping to ensure data presented was an authentic representation of participants. To further ensure transparency, the primary researcher reflected on her position within the research and also kept notes on the research process noting down challenges encountered during the research process and how these had the potential to impact on interpretation.

To help further counteract any interpretative bias, the research team were involved during all stages of the research process (from study development through to study analysis). During the analysis process the research team independently read over and coded six transcripts and came together to discuss these, helping to ensure the representation of developing themes, as done in other IPA studies (Newson et al, 2013). The research team also acted as 'critical' friends, with regular meetings held with them and used to discuss and debate themes until a consensus was reached, which has been used in other inductive qualitative studies (Williams, Smith and Papathomas, 2018).

4.2.5.2.1 Longitudinal analysis of family experiences

In an attempt to capture experiences within the context of each family's journey, transcripts from each family (i.e. patient and family member interviews at times 1, 2 and 3) were analysed as a whole. After several readings of each transcript, initial notes were added manually to margins to highlight utterances that pertained to the research questions (an effort was made to link notes closely with participants' spoken words to ensure their experiences were captured accurately). Initial notes were explored for meaning and developed into emergent themes, which represented themselves as small phrases grounded in the essence of what was found within the text, but also reflected the primary researcher's interpretation. Emergent themes were noted down on paper so the primary researcher could begin to search for connections between themes, and involved looking for associations, contradictions and changing meanings over time. Themes were then collapsed to form subthemes and super-ordinate themes, and names applied to capture the spirit of each theme. Theme development involved reviewing, removing, adding and changing codes, ensuring they fitted the data rather than forcing data into themes. This process was repeated for each family.

4.2.5.2.2 Cross case analyses

Themes developed from each family were manually noted on A4 paper and supported with verbatim quotes from the transcripts, (please refer to figure 4.3 for visual diagram). Each theme was then transferred to a post-it notes and mapped onto a pin board, which allowed the primary researcher to see patterns (e.g. convergence and divergence) across accounts. From this, a new pin board was created representing themes across dyads and created an overall synthesis of participant experiences (please refer to figure 4.4 for visual diagram). Themes were then written up and presented in narrative form. This process allowed themes to be expanded and further refined and developed so the longitudinal narrative could be explored and accurately represented, which involved multiple written drafts until the themes presented accurately represented participants' subjective experience (please refer to figure 4.5 for final analytical structure).

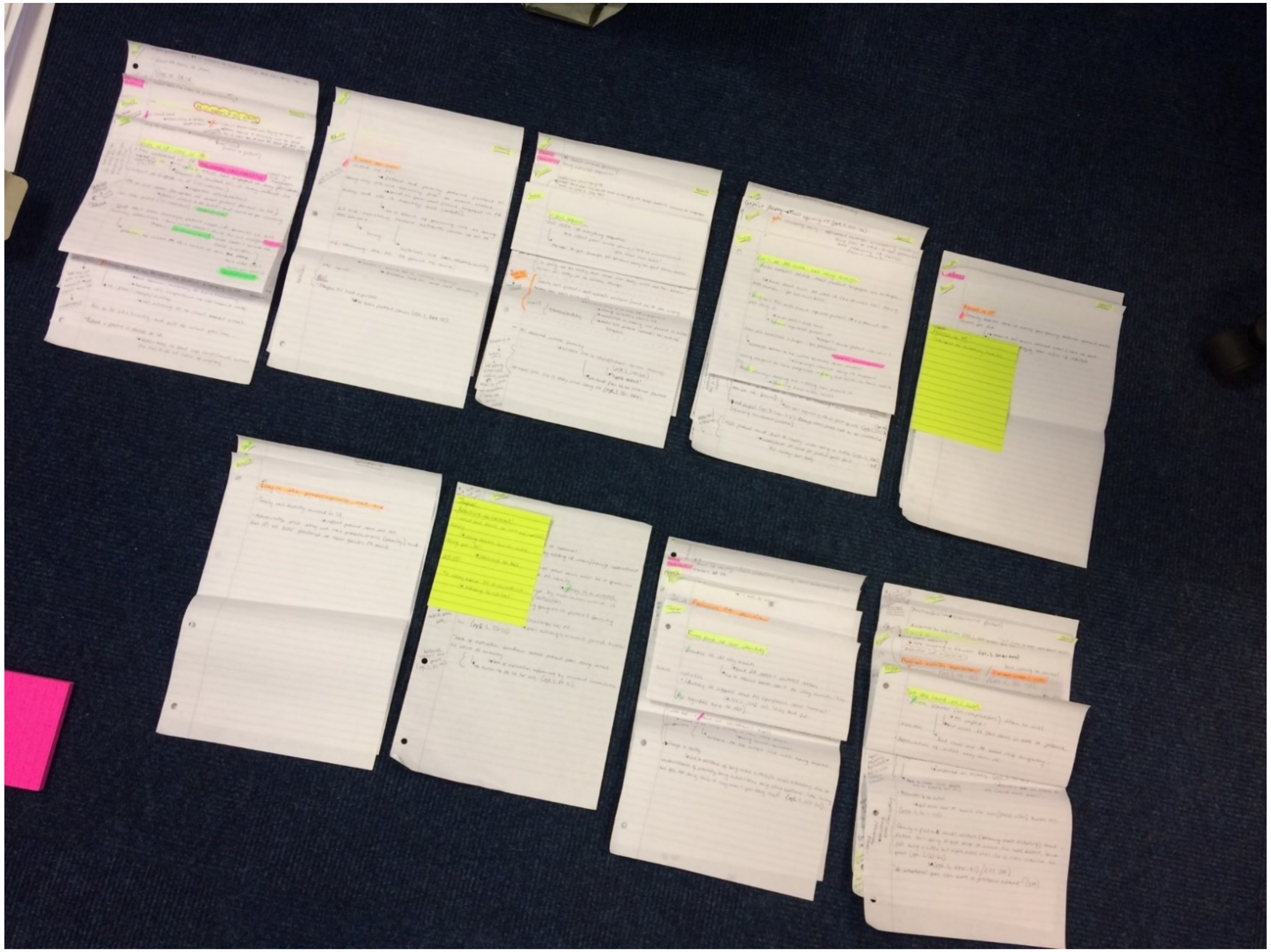


Figure 4.3 A visual representation of themes by family

Figure 4.4 A visual representation of synthesised themes on pin board

Figure 4.5 A visual representation of the final analytical structure of patients and family members experiences of physical activity post-myocardial infarction

4.3 Results

4.3.1 Overview of results

The findings presented within this section suggest that post MI, patients appeared to experience a journey of PA rediscovery, and family appeared to experience this journey with patients, but also appeared to shape the way it is experienced by them. The journey appeared characterised by leaving 'normality' (i.e. patients being able to do what they want and when they wanted to do it) and arriving at a 'new normality' (i.e. living life as a MI patient). This transition appeared to occur over sequential but overlapping stages, 'I can't do what I was doing before', 'finding my way' and 'accepting this way', with each stage being characterised by sub-themes. It is important to note that these stages are not bound by interview time (i.e. interview 1, 2, or 3). All families experienced these stages but not at the same pace, and the subthemes within stages transcended across time (i.e. occur at different stages) and interacted with one another (please refer to figure 4.6 for a visual diagram of the PA journey and associated subthemes).

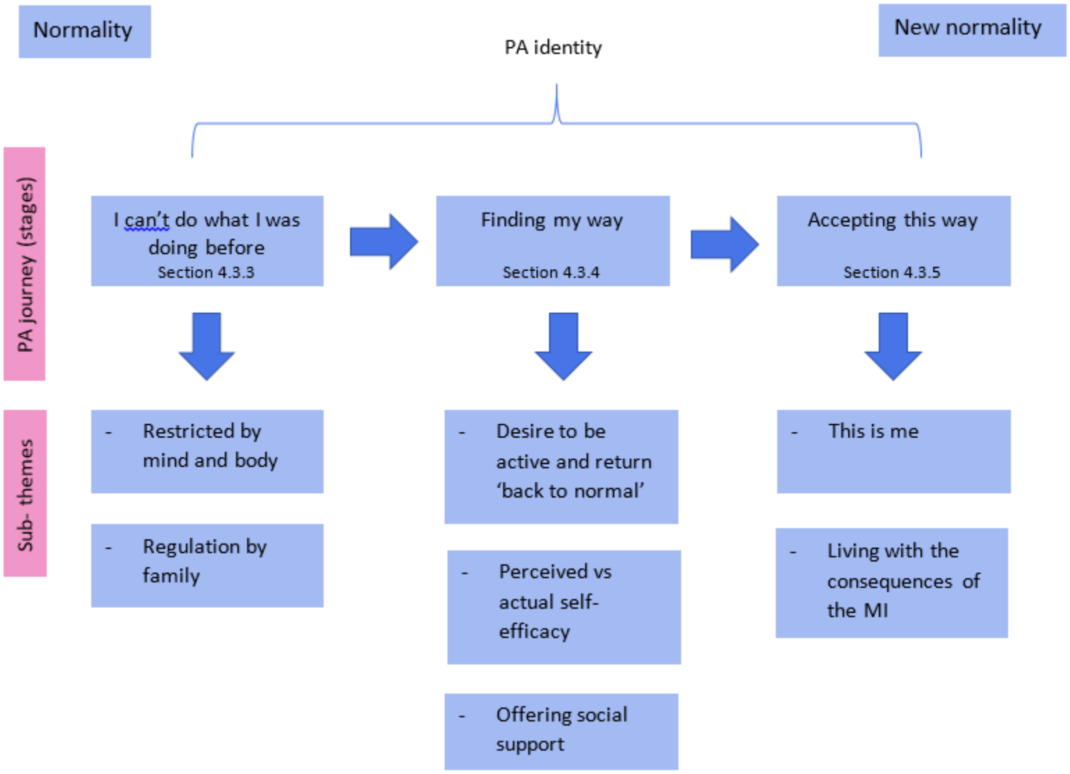


Figure 4.6 A Visual overview of the physical activity journey and associated subthemes

4.3.2 PA identities of families taking part

From the data, 5/6 families viewed themselves as active ("active families") and 1/6 (Thomas and Mary) viewed themselves as inactive ("inactive family"). It is important to note that how participants saw themselves in relation to activity appeared to influence their experiences of PA post-MI. In addition, despite how patients and families saw themselves in relation to activity, all patients and families experienced the three stages identified within the PA journey. However, the way in which it they experienced these stages differed and will be explained further in the narrative outlined within sections 4.3.3 – 4.3.5.

4.3.2.1 Active families

For families who considered themselves as active, PA aligned to their personal values and interests. They understood and bought into the belief activity was important and beneficial for health and consequently being active formed a regular part of these individuals' routine pre-MI. It is worth noting these families referred to PA rather than exercise per se, although some of the PA examples they provided were structured and fitness orientated (and thus would be defined as exercise according to Caspersen, Powell and Christenson's (1985) definition). For these families, patients' MI came as a shock (due to perceived healthy lifestyle), leaving patients experiencing feelings of disbelief - 'why me', cheated, and angry as they did not associate their identity with what they believed to be typical of "MI patients".

4.3.2.2 Inactive family

For the family who perceived themselves to be inactive (Thomas and Mary) they spoke about both exercise and PA during their interviews, although neither aligned with their values or interests, and consequently there was no intention to engage in PA or purposeful exercise post-MI. Whist both participants appeared to engage in incidental PA, this was not considered active nor the same as purposeful exercise. This family did not buy-in to the benefits of PA on health and due to patients perceived unhealthy behaviours (i.e. sedentary lifestyle), the MI did not come as a surprise to the patient.

The following section is a presentation of the patients and family members journey and is presented within the three phases as described in section 4.3.1.

4.3.3 I can't do what I was doing before

4.3.3.1 Restricted by mind and body

Patients experienced a sense of loss of autonomy over what their bodies could do as a result of the MI, which left many feeling frustrated. Active patients reported how their cardiac event had shaped and controlled their PA experiences as their bodies and mind restricted them from being able to engage in 'life as it were'.

The impact of the MI shifted active patients' physical identity from fit and healthy to slow, frail, breathless and lacking stamina, characteristics they were not accustomed to being associated with. Patients were aware of this shift and the interruptions it caused to their activities of daily living (e.g. unable to wash their car, go shopping, cut grass, walk dogs). This situation led patients to feel a sense of hopelessness, loss and decreased confidence, questioning whether to engage in physical tasks in case they caused harm, something that pre-MI did not cross their minds, highlighting patients' vulnerability to their condition and loss of freedom. Here Julia states her annoyance at how her MI was both physically and psychologically restrictive:

> *"I've always been fit and able to do anything I've wanted…it's like I would have never have done a bungee jump but now I definitely wouldn't do one… it's things like that where I'm thinking "is that putting me at risk" which is something I didn't really concentrate on that much before"* (1st interview).

Julia's statement highlights how the MI caused her to experience an identity crisis. This sense of uncertainty/insecurity appeared restraining on her PA experiences. In contrast, Thomas, who saw himself as inactive, took comfort from the physical restrictions placed on him by the MI, as it provided a rationale for him to do what he enjoyed:

> "*I was told to rest* [after MI] *as that was the best recuperation, I mean I didn't argue with that* [laughs], *that's what I enjoy, not exercise or nothing like that"* (1st interview).

Here, Thomas is accepting of what is expected of him during his initial recovery, informed by his own personal views of activity.

4.3.3.2 Regulation by family

All families recalled how during the early stages of recovery, the family regulated the patients' PA behaviour, which was not always positive, as it led to inadvertently promoting a sedentary lifestyle. As family cared for patients, they feared losing them to another MI, regulation was therefore used for preventative and protective purposes as told by Joanne (Alex's family member):

> *"I worry about him having another heart attack and I don't know how I'd cope without him I really don't, a heart attack, that could have been the end"* (1st interview).

However, clear distinctions were evident in how family regulated patients' behaviour and differed by PA identity. For Thomas and Mary, whom did not see themselves as active, Mary could be seen to protect Thomas through behaviours such as taking on household chores that traditionally he would have done pre-MI. Conversely, for families whom aligned themselves with activity and held the belief that PA was important and would benefit patient health, regulation translated as monitoring PA frequency, intensity, type and time, allowing patients to be active but within parameters accepted by the family. If family perceived tasks to be harmful to the patient (e.g. heavy lifting), or that patients had done enough (e.g. looking tired), they asked the patient to stop and rest. Many patients interpreted families' behaviour as an act of love, however, for some, these feelings co-existed with feelings of frustration at not being the ruler of their own destiny, which led to a loss of perceived autonomy, as highlighted by Doris:

> *"…it's 'careful Gran, be careful because there's this, be careful because there's that', which is a bit frustrating sometimes because they're only thinking about you…but they* [family] *do just watch me like a hawk"* (1st interview).

4.3.4 Finding my way

4.3.4.1 Desire to be active and return 'back to normal'

As time progressed, so did patients' relationship with PA. For patients whose personal values aligned with PA, PA made them feel better, healthier and as though they were doing something, and it played a meaningful role in their experience of recovery. Physical activity was multi-functional, acting as a vehicle for recovery to help re-build strength lost through the MI and increasing life quality and quantity, helping them reach their goals of 'returning to normal', which appeared valued and important to achieve. Alex stated that:

> *"…being active has always helped me feel better, it has helped me recover from injuries I've had in the past…I think it'll just help me get back to normal and be quite active again"* (1st interview).

For Alex, PA was purposeful, but his use of the phrase 'return back to normal' further intensified the dissonance between the reality of his current life and that of which he aspired to, which was also felt by many patients who identified as active.

It was important for patients who perceived themselves as active to have control of how they engaged in PA. Some patients opted to follow the traditional CR pathway, favourable due to the safe setting and knowledgeable staff. However, this only seemed apparent for phase 3, when asked about phase 4, many patients were not aware of its presence. Other patients opted to forgo PA CR phases 3 and 4, deciding to do PA that fitted into their pre-existing routines, a decision based on personal assumptions of CR expectations and requirements. Given the desire to ‘return to normal’ CR for these patients did not appear to be a constructive use of time. Robert had attended CR twice in the past recalling:

> *“I know the exercises, I know the regime they do it in…so I didn’t really think it would benefit me because I’ll do the exact same exercises* [in the gym*] it’ll just be without the physiotherapist”* (2nd interview).

Thus, for Robert, his previous experience acted as a deterrent for his most current involvement. Julia saw CR as a place for older and/or unfit MI patients, an image she dissociated with herself. Julia’s beliefs that CR was like *“one flew over the cuckoo’s nest”* (2nd interview) pertained to her belief she could achieve more from doing her own PA, than the perceived sedated activity prescribed during CR:

> *“I think CR is alright for somebody whose older and isn’t very fit…and that’s not me…cos from what I’ve been told it’s easy really…so if it’s not very physical there’s no point doing it”* (1st interview).

In contrast, and in line with Thomas’ dislike for activity, he expressed no desire to be active post-MI or ‘return back to normal’, especially given he felt the MI had no real impact on him. However, his PA behaviour differed from his spoken intentions. Although Thomas spoke about having a dislike in being active (*“…you may have already guessed, we* [Thomas and Mary] *aren’t big believers in exercise….do you see those chairs over there* [points to garden chairs*], that’s the type of activity we like”* (interview 1)), PA engagement was evident (“*I’ve been preoccupied finishing my fencing off, this is the activity I want, something which has a meaningful end to it…*

“(interview 2)). For Thomas PA appeared to be a bi-product of doing activities that served a valued purpose and therefore were done for enjoyment rather than for recovery:

> *“I’m out in the garden and I love it, no extreme activity for the sake of it, if I die I want to die happy, not healthy”* (interview 3).

This may therefore explain why he did not perceive himself as physically active, as he did not consciously decide to be active, instead it was a means to an end.

4.3.4.2 Perceived vs actual self-efficacy

Perceived vs actual self-efficacy focused on a difference of opinion between patients and family members regarding patients’ PA abilities. Responses to these differences varied, namely between accepting and challenging family advice.

Although Doris felt she could perhaps do a little more, she adhered to family advice of ‘slowing down’ (i.e. to only engage in activity deemed appropriate) and appeared to do so out of an obligation to ‘do the right thing’ by family members. She was aware the MI had impacted on her family, thus taking on advice ensured no harm could come to them and disrupt family life further:

> *“…you can’t be looked after* [by your family] *and then ignore what they are asking you to do, even if you think you can do different* [laughs], *so you take heed… I do what I’m told”* (3rd interview).

Doris’ feelings towards her family were evident. Her willingness to sacrifice her own PA wishes and be active within the parameters outlined by her family, demonstrated her care for others overrode her own sense of self, providing insight into how her own self-value in relation to others within her social network.

Challenges in PA behaviour arose for multiple reasons. Concerns were still present for family members over whether too much PA could prove harmful and consequently family continued to place restrictions on patients' PA (e.g. questioning activities, telling patients to stop, asking patients to slow down or take frequent breaks). Patients' rationale for challenging this train of thought was they felt best placed to make decisions about PA engagement as ultimately only they knew their bodies' ability, as stated by Sarah (Robert's family member):

> *"I sometimes think that when* [Robert] *is trying to do something he's pushing himself too hard and I have to try and say 'that's a bit too much for you' I guess at the moment it is always at the back of my mind is he going to have another one* [MI]" (Sarah, 2nd interview).

However, Robert felt otherwise:

> *"It's like when people tell me 'don't do too much', well what is too much…I feel like you've gotta push your body to understand what your limitations are"* (2nd interview).

Despite family concerns, deciding how far they could push themselves was important to patients and provided autonomy over their condition. These patients began experimenting with PA to help establish their own parameters, going through a process of trial and error (e.g. lowering PA expectations and intensity, slowing down, taking regular breaks and experimenting with new activities) to understand what their bodies could do. For some, trial and error appeared a product of reduced PA ability, which for patients who were active pre-MI caused feelings of frustrations and depression at their bodies' inability to work at the same capacity as before. In Julia's account, we see once more how comparisons between 'now' and 'then', were used to help her make sense of her PA ability, but also served as a reminder of being unable to meet her self-imposed PA expectations, which ignited feelings of frustration:

> *"…it's depressing when you get up every day and don't feel good as I thought I would…I thought I would feel like superwomen by now but I just don't… but I'm back walking the dogs but not like I used to, I keep getting breathless when doing hills, I've had to slow down"* (2nd interview).

4.3.4.3 Offering social support

As time progressed, family whose interests aligned with PA came to understand the important role PA played in patients' recovery and support for patients' PA became evident. Support included verbal encouragement, being active together, taking an interest, praising patients for PA, providing positive reinforcement (e.g. 'you can do it') and assisting patients with travelling to PA sessions. As many patients were active pre-MI, they noted they were self-motivating in terms of PA, but they did appreciate support as it acted as an additional encouragement, especially helpful if they faced barriers such as demotivation or fatigue. Instrumental support (e.g. being active with patients), allowed family to observe patients' PA also which helped inform family of patients' PA ability. The following statement details Robert's experience of support from his family member, Sarah:

> "[Sarah] *encourages me, sometimes I don't want to do anything, but* [Sarah] *will suggest going for a walk or to the gym…and* [as we have been going to the gym together] *she's more comfortable with what I do, she can see I don't do big weights…she can see I'm not doing much more than her"* (2nd and 3rd interview).

Robert's account displays how social support plays a dual purpose, not only shaping PA experiences but also how involvement may work to put families' mind at ease.

Although support in many cases was offered as a direct means to encourage patients to be physically active, this was not the case for all families. For Thomas, who engaged in PA for the purpose of achieving a meaningful outcome, his family member (Mary) helped him complete these tasks, and therefore support was for the final outcome, rather than for the sole purpose of encouraging PA.

4.3.5 Accepting this way

4.3.5.1 This is me

Acceptance occurred over time and focused on patients accepting the MI as part of their identity. However, the premise on which acceptance occurred differed amongst patients. For some patients, they experienced feelings of disappointment at coming to accept their PA ability may never be back to what it was, as felt by Alice:

> *"I know I'm not as fit as I was 12 months ago…it's depressing, but you've just gotta think…'the physical side isn't as good as it was but that's the way it has to be and that's the way it will be'…"* (3rd interview).

Here Alice is accepting of her new PA ability, although indicates the challenges she faced during this process. Namely, the loss of her 'old physical self', to which her current self does not fulfil, causing feelings of 'depression'.

Conversely, patients who had experienced additional health concerns during their recovery appeared more willing of the acceptance process. Doris, who had experienced multiple falls during her recovery noted:

> *"…do what you can with a happy heart…be strong enough to stay 'I've done enough now and I'm happy with that"* (3rd interview).

For Doris doing PA post-MI was about appreciating what her body could do as opposed to being disappointed in what it could not do, and this sense of acceptance allowed her to have positive appreciation of her body's ability.

4.3.5.2 Living with the consequences of the MI

Although physically the MI had happened to the patients, it left a lasting impact on the family also. For Thomas and Mary, the MI had led to the long-term change of family relationships. For Thomas whose daughter had forbidden him from engaging in any type of activity throughout the duration of his recovery, there lacked transparency between his actual behaviour and what he was telling his daughter. Internal conflicts were apparent with him not wanting to upset his daughter, but also wanting to do what he wished. To remain in control of his life, but also to adhere to his daughter's wishes, dishonesty was used as a means to manage the disagreements and was evident into the longer term:

> *"…my daughter's theory is that I should do nothing, you've had a heart attack…we* [Mary and I] *go along with it because we don't want to upset our daughter so I'm willing to put up with it* [being dishonest about activities] *for our daughter's sake*…so have to keep quiet about the things we do, we don't tell her everywhere we go now" (2nd interview).

Immediately following patients' MIs, family members feared MI reoccurrence, however for 'active' families, worry reduced as time went on, this being due them witnessing patients engaging in PA with no negative consequences, as displayed by George (Julia's family member):

> *"…no I'm not as worried as I was about* [Julia engaging in PA]*…she* [Julia] *been walking the dogs and nothing 'bad' has happened to her"* (2nd interview).

Here, patients' physical responses to PA gave indication to family members of patients' physical wellness, and therefore dictated how family should feel about them engaging in PA. Although worry decreased, it never totally dissipated. As the MI had come unexpectedly for many, family worried that it may occur again unexpectedly. Worrying about something that ultimately was beyond families' control was fruitless, and it appeared more important to enjoy every day rather than worrying about 'what ifs', as told by Joanne (Alex's family member):

> *"… because* [Alex] *had* [MI] *and we didn't see any of the warning signs…what will be will be…you can't put your life on hold and say "we can't do this" we just have to get on with things"* (3rd interview).

For Joanne and Alex, (referred through use of 'we') their positive outlook and attitude towards life influenced how they saw and managed worry. Living life for them outweighed living safely but living in fear.

4.4 Discussion

4.4.1 Findings overview

This study explored the lived experiences of PA post-MI from the perspective of both patients and their family members and how perceptions of PA may change over time. Findings suggested that post-MI, patients go on a journey of re-discovering how to re-engage in PA, and family appear to accompany patients on this journey and influence how it is experienced. Patients appear to leave 'normality', characterised as being able to do what they wanted and when and journey to a 'new normality', where patients are active but within parameters of their experiences of suffering with the MI.

4.4.2 Synthesis of results with wider literature

Within this study, the way in which patients saw themselves in relation to PA appeared to influence the ways in which they experienced their journey of PA post-MI. Patients who saw themselves as active pre-MI appeared to experience feelings of anger, loss and frustration in relation to how they saw themselves to PA post-MI. The experiences of those active pre-MI support the premise of Kübler-Ross' (1969) five stages of grief, a theoretical model proposing the progression through different emotional states (denial, anger, bargaining, depression and acceptance) following forms of personal loss. In this study, patients' loss appeared to centre on their pre-MI life and how they were restricted by their bodies to be active. In the aftermath of their MI, active families experienced disbelief, unable to understand how the MI had happened given their active lifestyle and were followed with feelings of frustration, anger and annoyance as patients began to realise the reality of the situation and impact on their lives. Bargaining followed and can be related to patients desire to 'return back to normal', living with a lowered PA ability in the hope it would help them return to their life as it were in the long run. The desire to 'return back to normal' has been reported elsewhere (Astin, Horrocks and Closs, 2014), and linked with a desire to readjust, a process which allowed patients to move from an unfamiliar to familiar self. Like in Astin and colleagues' synthesis (2014), some patients recognised that they were not able to engage in PA in the same way as pre-MI which led to accompanying negative moods, such as feelings of depression, despondent at their own PA inability. Overtime, however, patients came to accept what their bodies could do, understanding they may not be able to attain the same level of PA they had pre-MI, and therefore learning to live with their new PA identity. The process of grief and loss amongst chronically ill patients has been documented elsewhere (Charmez 1983, Astin et al, 2014). Evidence suggests trauma can be interpreted as an attack on the self, which can lead individuals to lose a sense of their personal identity (Thompson and Walsh, 2012). Within the current study, patients who saw themselves as active questioned their identity, as the MI undermined how they perceived themselves, and how they were perceived by others (as healthy and active).

Understanding the role of PA identity in shaping PA experiences following a cardiac event is an area which has been relatively unexplored. Evidence suggests identity is predictive of multiple factors of PA behaviour, including an intention to be active (Rhodes, Kaushal and Quinlan, 2016). Within this current study, patients who identified as active pre-MI displayed a motivation and intent to engage in PA during the course of their recovery, and as time progressed, their behaviour mirrored their intent. Identity acts as a self-regulating mechanism of motivation (Husband, Wharf-Higgins and Rhodes, 2019), which can act as a prompt to be active when people feel a disparity between their PA identity and PA behaviour. Many patients within the active family reported feeling a misalignment between their PA identity and PA behaviour post-MI and was evident through their desire to 'return back to normal'. Therefore, the mechanism that underpins identity (i.e. motivation) can be offered as an explanation as to why patients within the active family had a desire to re-engage in PA. Nevertheless, it is important to recognise how the MI impacted upon and changed how this group identified with PA. Following MI, patients attempt to 're-orientate towards the active self' (Brink, Karlson and Hallberg, 2006) whereby effort is made to live life as they had pre-MI. However, this is thwarted by illness restrictions, which ultimately lead patients to moderate/adapt their activities to regain a sense of their self. Given that findings from Brink, Karlson and Hallberg (2006) reflected patients readjustment 5 months post-MI, findings from the current study extend this proposed model by suggesting following the moderation/adjustment of PA behaviour, patients go on to accept they may never be able to engage in PA the same as pre-MI.

The patient within this study who did not see himself as active (Thomas) displayed a lack of intention to engage in PA. However, it is important to note that his identity and intention did not necessarily match. Explanation for this is offered by Adams, Leibbrandt and Moon (2011) and Smith and colleagues (2017) who suggest that older adults are more likely to engage in incidental PA (i.e. for leisure), which they may not perceive as activity. Within this study, Thomas and Mary, were in their late 70s and early 80s respectively and did not perceive themselves as being physically active, despite discussing numerous activities they had engaged in during Thomas' recovery (e.g. building a garden fence and pond). The primary reasons for engaging in these activities for this family were about the enjoyment gained from the primary task itself, rather than from the PA that was secondary to the task. Consequently, it is perhaps sensical that these activities were not perceived as being physically active. However, this highlights the importance of education around what constitutes PA following MI, from both the angle of enhancing PA and ensuring people do not overdo it early on.

Overprotection is considered a support style within the context of heart disease (De Ridder, Schreurs and Kuijer, 2005). One form of overprotection involves restricting patients in performing certain activities (Dalteg et al, 2011). Within this study, family members expressed concerns over how much and what activities patients should do, which led them to regulate patients' PA behaviour in fear of a reoccurring MI. Although overprotective behaviours often refer to one behaving in an intrusive manner, in this study overprotection was out of care for the patient. As with other studies exploring relationship dynamics in cardiac illness (Dalteg et al, 2011), this behaviour could be explained as a coping mechanism for families in order to avoid the emotional turmoil of seeing the patient go through another MI. However, given that PA following a cardiac event has numerous benefits including reduced cardiac mortality (Dalal, Doherty and Taylor, 2015) and improved long-term health (Heart Foundation, 2019) it may be worthwhile exploring potential avenues to support family concerns and worries on PA post-MI, so family feel in a position to support patients to becoming physically active.

Within this study, as patients' recovery progressed, family could be seen to support their PA behaviour and included emotional (providing a rationale for being active, encouragement without making demands, praise for being active and being active together), tangible (taking patients to CR PA classes) and belonging (being active together) forms of support (Uchino, 2004). These activities were in turn shown to have a positive impact upon many patients' PA engagement (i.e. encourage PA engagement). It is well documented that social support, when delivered in a constructive, nurturing and supportive manner, can elicit increased engagement in PA (Kärner, Dahlgren and Bergdahl, 2004, Rosland et al, 2012) and that appears no different when the source of support is family (Smith et al, 2017). Interestingly, it was family members whose own beliefs aligned with PA supported patients' PA engagement. Pertaining to familial theories that partners' health behaviours can co-occur through mutual interest (Frank et al, 2012, Cobb et al, 2016), it is possible that social support came from understanding the value of PA to help enhance health and cardiovascular risk factors. Given the important role patients' immediate social environment can have in supporting their activity, it posits the importance of mobilising family within CR to help promote PA engagement. However, given that the provision of support may depend on how family view themselves in relation to PA, it may also be worthwhile to explore ways to work with families to promote positive health beliefs.

4.4.3 Strengths and limitations

This study has a number of strengths. This appears to be one of the first longitudinal studies to explore the PA experiences of post-MI patients, providing insight into how PA may change over the duration of patients' recovery. In addition, it appears to be the first study to conduct interviews with both post-MI patients and family members within the aforementioned context, providing insight into families' roles in shaping patients' PA experiences.

The study is not however without limitations. Firstly, PA was not objectively measured and therefore participants' perceived PA behaviour may differ from their actual behaviour. Given the focus of IPA on lived experience however, perceptions are arguably the more important construct to study. Secondly, it is worthwhile considering that all participants in this study were over the age of 50 and of White British descent. Although the focus of IPA research is not the generalizability of the research findings (Smith and Osborn, 2008), it is worthwhile considering the application of the findings when looking at other populations. It is notable that 5 out of the 6 families interviewed saw themselves as being active, and therefore it is possible they were a compliant sample and therefore may not be representative of the MI population. Finally, it is worth acknowledging the low number of families who responded to the initial research invitation. Out of 100 research packs given to patients, only 8 responded. It was recently reported in the BHF's physical inactivity and sedentary report, in England, 76% of patients referred to CR were classified as inactive (2017). Given lack of motivation has been associated with lack of PA engagement (Klompstra, Jaarsma and Strömberg, 2015), this may provide insight into the low number of responses, especially given the research topic. Within this study, CNs allocated 5 minutes to provide patients with the research pack and explain the purpose of the research which was done at the end of a routine home visit. It is possible that this timeframe was insufficient to give the appropriate level of information to patients, especially those who lacked PA motivation. To help increase future uptake, it may be worthwhile those administering research packs to spend time with patients/family to discuss the research and topic, detailing that although about PA, listening to all experiences is important, so to encourage more of those who may be disinterested in PA to take part. However, it is worth considering that the low response rate may have also been due to the time between MI and recruitment. In this study, a recruitment pack was given out within 5 days of patient discharge to increase the likelihood of conducting the first interview 1-month post MI. Given that patients are given a large volume of information both as an inpatient and upon discharge, as well as making sense of their diagnosis (Astin, Horrocks and Closs, 2014), it is possible that both patients and family felt overwhelmed and therefore disinterested in taking part in the study at such an early timepoint. Going forward, it may therefore be helpful for researchers to consider the time between MI and interview.

4.4.4 Conclusion and recommendations

This study provided insight into the lived experiences of PA post-MI from the perspective of both patients and their family members and how PA experiences change over time. The findings suggested post-MI, patients go on a journey of PA rediscovery, and family accompany patients on this journey and influence how it is experienced. However, how the journey is experienced also appeared influenced by how families saw themselves in relation to PA. Families appeared to shape the ways in which patients experience PA post-MI, however as this was shown to be both positive and negative, it may be worthwhile exploring ways of helping support families support patients' PA. This could include involving family in patient conversations around PA, including what PA is appropriate and how this may relate to their pre-MI PA, and how this may change over time. Building on positive supportive behaviours such as verbal encouragement and being active together may also be worthwhile, as well as working with families to reduce temptation to regulate patient activity, which could be achieved through offering emotional support to families also.

Chapter 5 The roles of the family in post-myocardial infarction patients' physical activity experiences

5.1 Introduction

Findings from study 1 (chapter 4), told us how following MI, patients go on a journey of PA rediscovery, and family appeared to be on and shape the way this journey was experienced by patients (e.g. through regulating patients' PA and providing social support). How the journey was experienced also appeared informed by how families viewed themselves in relation to PA. What study 1 did not explore however, was families' involvement and role within the CR process. Understanding families' involvement in and roles of the family in the CR process is a worthwhile consideration because of the influence they can have upon patients' PA.

A recent systematic review by Albert (2016), suggests it is not uncommon practice for HPs to communicate health related information to patients' wider social networks (e.g. family members). In line with such thoughts, Mitnick and colleagues (2010) found that family have been described as valuable members of the healthcare team, who want to be involved in patient care (Coyne 2015, Laidsaar-Powell et al, 2013). Evidence suggests family involvement could be an effective intervention to help patients manage health conditions (Stenberg et al, 2018), however little is known about how the family can positively support PA engagement during MI patients' recovery.

Cardiac rehabilitation practitioners can be considered the "gatekeepers" to family involvement given they are often the first ones to see patients at the start of each CR phase and therefore have the potential to promote family support (Mackie, Mitchell and Marshall, 2017). Therefore, understanding how they perceive family in CR and the roles they adopt in shaping patients' PA behaviours is worthwhile. There is a wealth of evidence exploring HPs views on family involvement, however, is centred on other populations (e.g. cancer patients, older adults), where immediate family (i.e. spouses, parents) are involved beyond supporting lifestyle changes (e.g. PA) (Wollf et al, 2017, Koren et al, 2018).

Despite being quantitative in nature, studies by Shilling (2002), Clayman (2006) and Wolff and Roter (2008) and colleagues employed observations and surveys respectively to broadly understand the influence of ‘companions’ within healthcare consultations, and found numerous benefits, including the ability to absorb information, ask questions, provide health care information, facilitate patient understanding and enhance patient engagement with HP advice. In addition, findings from further survey studies by Shin and colleagues (2013) and Wolff and Boyd (2015), suggest the acceptability of involving others in care, by providing evidence suggesting patients appreciate the help provided within consultations. Families themselves have also reported benefits of being involved in patients’ healthcare, and suggest they experience increased feelings of helpfulness, decreased worry through an understanding of what is happening to patients, as well as being able to advocate for patient care (Duran et al, 2007).

As discussed above as well as in section 2.5.3.1 there is a wealth of evidence highlighting the benefits of involving family in patient care from the perspective of patients and family themselves. However, it is important to consider the perspectives of HPs, given they play a central role in patients’ care. Evidence suggests HPs views towards family involvement in care is well received, with benefits including families’ ability to share information and better understand patient concerns (Mackie, Marshall and Mitchell, 2017, Koren et al, 2018). However, within the context of cardiovascular care, although there is agreement that family involvement is welcomed, proactively inviting them to take part within patients’ care appear less positive (Gusdal et al, 2017, Luttik et al, 2017). Within these latter two studies, many challenges to familial involvement were observed, and included a lack of time to take care of families and seeing families as causing stress (i.e. seeing family as means to ‘check-up’ on HPs) (Luttik et al, 2017). As well as HPs working within an organisation with no approach to the care of families and lacking the competence to work with them (Gusdal et al, 2017). Although within a cardiovascular context, the studies by Luttik and colleagues (2017), and Gusdal, and colleagues (2017) were quantitative in nature and therefore lacked the in-depth and underlying thoughts of HPs. Therefore, this study adopted a qualitative approach to understand CRP views of family involvement in CR through exploring the roles they can adopt in post-MI patients’ PA experiences.

5.2 Methods

5.2.1 Study design and setting

A qualitative cross-sectional design was adopted for this study and was chosen due to its groundings in generating data that captures attitudes, beliefs and values of participants (Bertwits and Inui, 1998). Qualitative semi-structured interviews were used to collect data with participants. The study took place in the same Northwest Location as study 1. Please refer to section 2.6.2 for a full overview of the current CR service provided within this locality. Within this CR service it is important to recognise that family appear to only be involved reactively (i.e. if they happen to be present with patients at consultations they will be invited in (if agreed okay with patients)).

5.2.2 Participants and recruitment

5.2.2.1 Eligibility

Cardiac rehabilitation practitioners who had experience of working with MI patients within CR phases 2 – 4 within the CR service described in section 2.6.2, were eligible for participation in this study.

5.2.2.2 Sampling

As within the qualitative tradition (Sparkes and Smith, 2014), purposive sampling was used to recruit participants for the study who were identified through contacts known to the research team. Specifically, criterion-based sampling was used due to the desire to interview individuals whom had experience of working with MI patients in CR phases 2-4 and therefore it was important to interview participants whom could provide rich, in-depth and relevant data (Sparkes and Smith, 2014).

5.2.2.3 Participant recruitment

Gatekeeper consent was sought from the managers overseeing CR in their respective settings (hospital/community) before participants were contacted. Recruitment of participants was done through study gatekeepers whom during February 2018 emailed a recruitment leaflet detailing study purpose, reasons for contact, what the study involved and ‘next steps’ (for those interested in participating) to all eligible staff (n=3 CNs, n=3 physiotherapists, n=2 physiotherapist assistants, n=2 OTs and n=9 activity referral scheme instructors (ARSIs) total n = 19).

To invite them to participate in the study, after a period of 2 weeks, the primary researcher followed up with a second invitation email to those who had not responded. All CRPs who responded were sent a PIS detailing the interview procedure and ethical considerations and were given 7 days to decide upon participation. Following this period, the primary researcher contacted participants to establish their participation in the research and arrange an appropriate time and place for the interview.

5.2.2.4 Final sample

Figure 5.1 provides a visual overview of the recruitment flowchart. In total, out of the 19 CRPs invited to participate, 14 consented. Reasons given for non-participation included time constraints (n = 1), no longer in post (n = 1) and no interest (n = 3). The sample comprised 2 CNs (phase 2), 3 physiotherapists, 2 OTs (phase 3) and 7 ARSIs (phase 4), with a combined average of 7 years in their job roles.

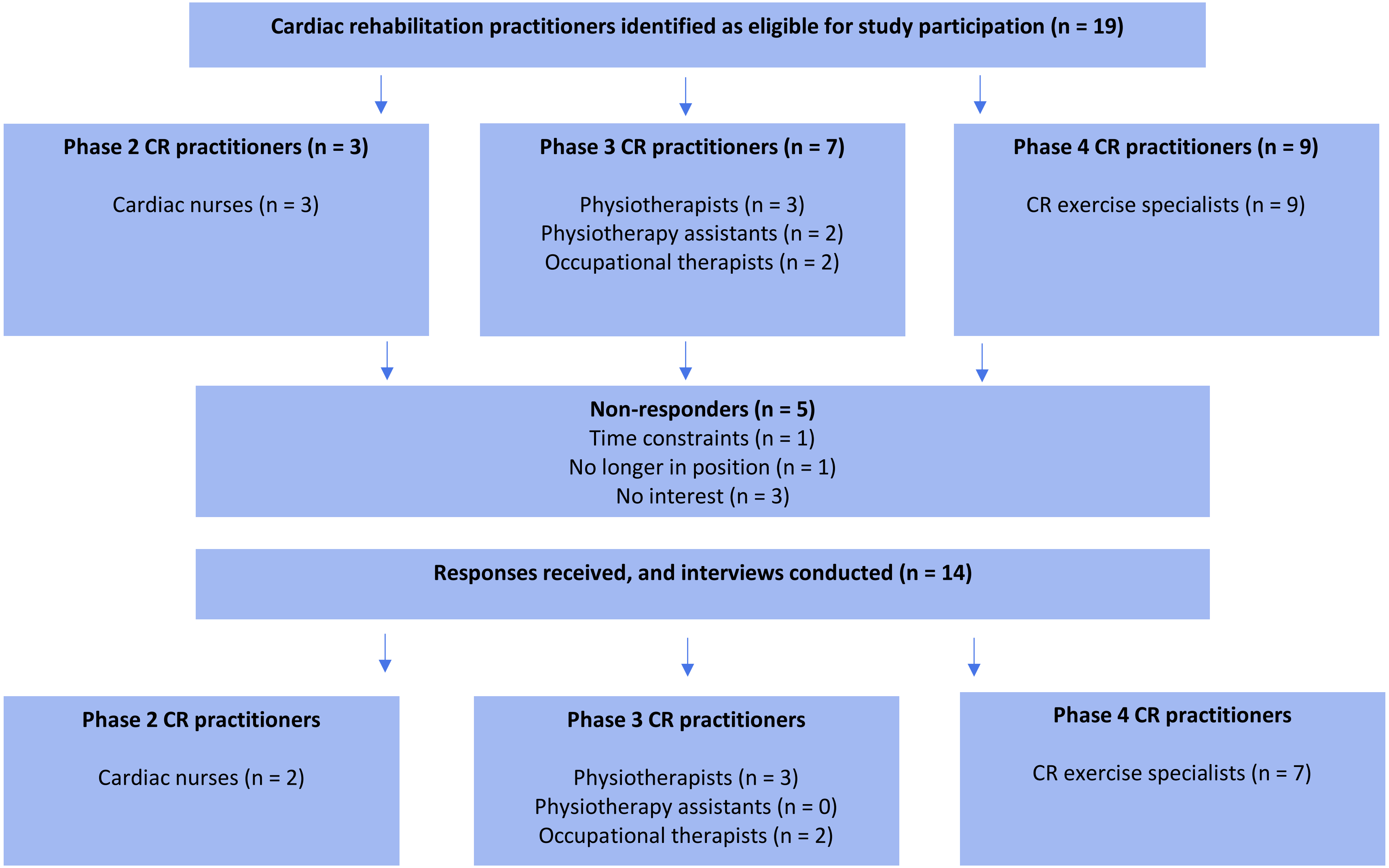


Figure 5.1 Flowchart demonstrating the recruitment process of cardiac rehabilitation practitioners

5.2.3 Data collection

5.2.3.1 Procedure

The primary researcher conducted interviews with CRPs between April and July 2018. Interviews took place at CRPs place of work and were recorded using a Dictaphone. The decision to interview CRPs in their place of work (either a community hospital or community gym setting) was to ensure the interview procedure was made as convenient as possible for all CRPs participating. Written consent was obtained from all CRPs before the start of each interview.

5.2.3.2 Interview guide

Semi-structured interviews were chosen for the method of data collection within this study due to their flexible nature in allowing participants to express their opinions, ideas, feelings and attitudes (Smith and Osborn, 2008, Sparkes and Smith, 2014). In line with semi-structured interviews an interview guide was developed to help direct points of discussion for the interview itself. The guide was informed through previous literature and developed through regular meetings with the research team where content was discussed and refined. Questions explored CRPs' thoughts on the roles and involvement of the family in post-cardiac care, familial influences (e.g. attitudes, beliefs, behaviours) on post-MI patients' PA engagement, and ideas on how family could support PA engagement in a post-MI population (please refer to appendix 3 for the full interview guide used for data collection). Specific probing questions were developed from these broader questions. However, these were used as prompts to use if the participant did not provide depth in their answer to the initial question, and thus were not used consistently.

5.2.3.3 Conducting the interviews

The interviews were conducted by the primary researcher and lasted between 20 and 50 minutes. Questions were asked one at a time, allowing for pause so participants had time to think about their responses. Although every effort was made during interview guide development to ensure questions were written, and consequently asked in lay language, the researcher re-phrased questions if participants expressed uncertainty over their meaning of any questions asked. In line with semi-structured interviewing, the role of the primary researcher was to guide, rather than dictate the interview (Smith and Osborn, 2008), thus allowing participants to reveal their views authentically. Asking open questions also allowed participants to elaborate on their responses, allowing the primary researcher to explore avenues that may not have otherwise become apparent if a more structured form of interviewing had been employed. To ensure participant accounts were reflected authentically, member checking was used throughout the interview process (Shaw, 2010) where the researcher reiterated her understanding of participant accounts to ensure a transparent and accurate understanding was held.

5.2.4 Data analysis

5.2.4.1 Transcription

Transcription was carried out by the primary researcher and followed the same process as described in section 4.2.5.1.

5.2.4.2 Analysis

The primary researcher analysed the transcripts following Braun and Clarke's (2006) framework for thematic analysis using NVivo 11 (QSR, 2015). This approach to analysis was adopted because of its flexible nature in analysing qualitative data (Braun and Clarke, 2006) to discover rich, pertinent and complex patterns within the data. Transcripts were analysed by CR phase to explore comparability of themes across phases, and to capture how family influences on patient PA engagement may change by CR phase. In the first instance, analysis involved reading and re-reading transcripts to ensure the primary researcher's familiarity with the data. Pieces of text relating to familial influence on post-MI patients' PA were then coded. Codes were based on the interpretation of the data achieved through conversations had between the primary researcher and participant. Once this process had been completed for each transcript, codes were explored for meaning and similar codes grouped together, a theme name representing the content within it was then applied (e.g. a second pair of ears). Individual themes were then explored further to look for nuances between codes, and related codes were grouped together to form specific sub-themes if appropriate. Lastly, themes across phases were explored for comparisons and contrasts to understand whether differences could be observed between practitioners working in different CR phases.

An inductive approach was adopted for analysis, however, due to the primary researcher's familiarity with the subject area, it was acknowledged that the interpretation of the data and developing themes did not occur in the absence of pre-existing knowledge (Hardcastle and Hagger 2011). To enhance credibility in the analysis, the primary researcher and research supervisor independently coded 3 transcripts (one from each CR phase) and came together to discuss and debate developing themes. To ensure each theme was distinct, meaningful and captured the essence of the extracts within it, themes were reviewed, refined and discarded until a consensus was reached.

5.3 Results

5.3.1 Overview of results

Figure 5.2 provides a visual overview of the themes and sub-themes that were identified as roles family may adopt to influence post-MI patients’ PA experiences.

The majority of CRPs were positive about involving the family in the CR process and felt family had an important role to play in patients’ post-MI PA experiences, particularly during the early stages of their rehabilitation. Cardiac rehabilitation practitioners did however note there was currently no formal process for involving families in consultations or CR activities and contact with families was more likely to result from chance encounters (i.e. with patients’ permission, CRPs invite family members into CR consultations if they are accompanying the patient). As a result, some CRPs expressed difficulties in providing meaningful answers to some questions. From the responses provided, 3 themes and 3 subthemes were identified that described the roles family may play in this process: ‘being a second pair of ears’, ‘pulling back, pushing forward - keeping the patient within PA boundaries’ and ‘providing social support’ (subthemes - role modelling, supporting practical engagement in PA and emotional support). A fourth theme was also identified and focussed on family factors deemed to influence the level and type of PA support provided by families and included 3 subthemes (family health beliefs, motivation to be active and perceptions of the patient’s post-MI condition). Each theme will be discussed in turn with illustrative quotes to support the narrative. Participant identifiers are also used and range from P1 to P14.

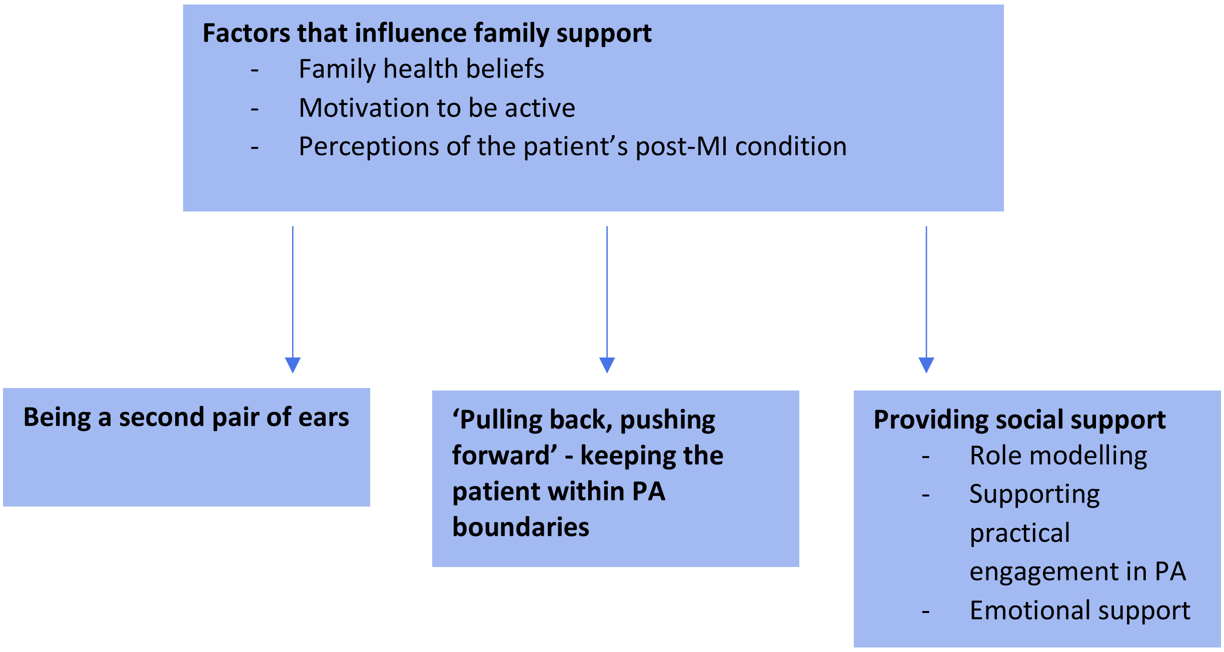


Figure 5.2 A visual overview of the themes and sub-themes identified as the roles family may adopt to influence post-myocardial infarction patients' physical activity experiences

5.3.2 Being a second pair of ears

Practitioners at phases 2 and 3 reported consistent thoughts on the advantages of having family members present during CR consultations. General advantages of family presence included providing CRPs with a realistic overview of patient health and behaviour, being able to answer CRP questions on behalf of the patient if the patient was unable to, which in turn could help inform treatment plans and reinforcing healthy behaviours when CRPs were not present. Specific to PA, CRPs mentioned family members' abilities to help patients make decisions regarding PA engagement and their ability to absorb information, relay this back to the patient and encourage PA participation, all useful if the patient appeared disengaged, distant or passive during consultations:

> *"…see*[ing] *family is helpful for us…it's another pair of ears to take on board advice and take on board information, and I think if it's the right type of family then they will help motivate and encourage them* [patient] *to keep active and do regular exercise"* (P1).

For some CRPs, family presence afforded them the opportunity to explain to the family what type and intensity of activity patients could do at home and help settle any fears the family may have surrounding patients' PA engagement:

> *"Sometimes it's good that spouses are in assessment because you can explain what level of activity you want patients to work at, the level of exertion and how much they should be doing"* (P5).

Although many phase 4 CRPs reported that they understood the benefits of family attending CR consultations (e.g. asking questions, providing answers/clarity to questions), they questioned whether family attending phase 4 CR consultations was necessary. This being that they felt because of patients' engagement in PA during phase 3 CR, by the time patients reach phase 4 they are more *"able and independent"* and therefore support from family was deemed unnecessary:

> *"It is rare people would come with somebody else unless they can't walk very far or something like that…* [patients] *have got used to the physio, so I think they've got to that point that they've left their family behind, so by the time they've done 12 sessions* [at physio]*, they are used to doing a little bit* [of exercise]" (P14).

Despite the overarching view of family involvement in CR consultations being positive, CRPs did note some challenges that occurred when family became "too involved". Too much involvement appeared to lead to the disruption of patient autonomy, where family would answer for them; one CRP noted that this appeared more common when females were the supporting family members:

> *"…very often if it's a gentleman that is the patient…half the time the wife will answer the questions which I actually have to say 'I need to hear it from him'…very often the women will take over the consultation and answer the questions"* (P5).

5.3.3 'Pulling back, pushing forward', keeping the patient within PA boundaries

CRPs across all phases described how family played a role in monitoring (and subsequently seeking to influence) PA behaviour amongst post-MI patients. Cardiac rehabilitation practitioners reported that in some situations, family sought to reign in the amount of PA patients were doing, with positive or negative effects depending on the patient's situation. For instance, CRPs reported how patients who were active pre-MI could become anxious at their lack or lowered levels of activity post-MI, and therefore attempt to throw themselves back into their pre-MI PA. In these circumstances, family were said to be instrumental to ensure patients did not overdo PA. Conversely, CRPs expressed concern that overprotective behaviour may negatively impact on the long-term PA engagement of the patient:

> *"…in the first few weeks the other half…will wrap* [patient] *up in cotton wool, they don't want them to do too much and it's that fear of it* [MI] *happening again…if you've got* [family] *like that then long term they may be reluctant to let* [patient] *do what they perceive as strenuous exercise"* (P2).

This overprotection by family members was perceived to be a result of worry that PA may bring on another cardiac event, something CRPs acknowledged was understandable. However, CRPs also recalled how reigning the patient in could lead to frustrations and arguments within the family:

> *"I get to hear a bit about family but it's more often than not 'they're tranna* [trying to] *stop me doing things' and* [patients] *can feel frustrated that family are always telling them not to do this and that…which causes a lot of frustrations and arguments really"* (P4).

For patients who lacked desire to engage in PA, the input of the family was perceived to be positive in encouraging PA and keeping patients on track. For example, some CRPs described family members as the "timekeeper" (i.e. monitoring how much PA patients were doing), and spoke of their positive role in encouraging patients to do more PA:

> "[I see] *those that really want to encourage their partner, mother, father, whoever to engage in activity because they may perceive that they are not doing enough"* (P3).

5.3.4 Providing social support

Cardiac rehabilitation practitioners recalled multiple types of social support behaviours that family could adopt to positively promote patients' engagement in PA, and included 'role modelling', 'supporting practical engagement in PA' and 'emotional support'.

5.3.4.1 Role modelling

Cardiac rehabilitation practitioners discussed how family who engaged in activity themselves could act as positive role models to patients. This view was noted frequently amongst phase 4 CRPs, who felt it was important for patients to have someone to look up to to promote PA engagement, especially if patients could see similarities to themselves:

> *"I suppose it's lead by example… if my wife can do it* [PA] *and she has a few health problems, that shows that he* [patient] *can do it …"* (P8).

5.3.4.2 Supporting practical engagement in PA

All CRPs interviewed recalled how the family could promote PA by providing practical support. Providing companionship-based forms of PA (i.e. patients and family being active together) was said to promote patients engage in PA. Alternatively, CRPs recalled how family could also help take patients to PA classes if patients were unable to get there themselves:

> *"…being willing to drive the patient to their cardiac rehab even if it's just initially…so in that way yeah, I've seen where patients have been supported by the family to actually physically get to a venue"* (P4).

5.3.4.3 Emotional support

Several CRPs mentioned that some patients may feel scared, anxious or unsure about whether to engage in PA post-MI and may require reassurance or support making PA decisions. Cardiac rehabilitation practitioners reported that patients sometimes ask family members their opinions about PA engagement both inside and outside of CR consultations. Additionally, they reported that nurturing behaviours such as providing encouragement and showing care and empathy were regarded as being positive to encourage PA behaviour. Conversely, if family members adopted negative behaviours (such as being critical), CRPs felt this could have psychological implications for the patient:

> *"…there's big psychological implications with any cardiac recovery and I think if* [family members] *are more critical that can heighten the negative psychological effects of the patient…and vice versa, if they are very encouraging and very caring…encouraging activity then obviously that's positive"* (P5)

To be able to provide emotional support, CRPs recognised that sometimes the family need support themselves, and was because the MI can psychologically impact upon family members also:

> *"…there should be a support group for family members…because they're traumatised by it* [MI] *quite often...sometimes the patient will be fine and we'll offer* [patient] *stress management, but really it's the spouse that needs it…they do get anxious…so the understanding of what an MI means and what that recovery means is massive for family because that emotional and psychological support is a lot easier for family if they can understand what is going on"* (P6).

5.3.5 Factors that influence family support

Three factors were identified by CRPs that were perceived to influence the type and level of support provided by families and included 'family health beliefs', 'motivation to be active', and 'perceptions of the patient's post-MI condition'.

5.3.5.1 Family health beliefs

Cardiac rehabilitation practitioners felt family members' personal health beliefs influenced how they supported patients to be active post-MI. They reported family health beliefs were both positive (e.g. valuing the importance of lifestyle behaviours in health) and negative (e.g. disinterest in engaging with healthy behaviours) and discussed health behaviours of family members as evidence of their underlying health beliefs. They reported that families who had positive health beliefs were more likely to encourage PA, through their own interest and engagement in it, whereas those with negative health beliefs were said to be less inclined to encourage PA through their own disinterest. Interestingly, CRPs reported that the link was not only made with PA, but there was a belief that if family had generally poor lifestyle habits (e.g. poor diet), they would be less likely to encourage PA. Cardiac rehabilitation practitioners perceived health beliefs to be influenced by socio-economic status and educational attainment (i.e. those at the higher end of the socio-economic scale were perceived to have positive health beliefs, whereas those at the lower end were perceived to have negative health beliefs).

> *"…. if family members are inclined to be fit and active or do regular exercise, I think they are more likely to try and influence the person who has had that heart attack. On the other hand, if they don't exercise and don't eat healthily…I think they are possibly unlikely to encourage the person who has had the heart attack to make any changes"* (P1).

5.3.5.2 Motivation to be active

Cardiac rehabilitation practitioners stated the importance of family members in motivating patients to engage in PA if patients were not motivated to engage themselves. However, CRPs went on to state that if the family were not motivated to engage in activity themselves, this would limit the patient's likelihood of PA engagement:

> *"…we're not able to motivate the ones that aren't motivated* [to engage in PA]*…family members are important…to encourage patients to do things like that* [PA]*…because if family members aren't motivated or disinterested* [to be active themselves] *then the patient has got no chance in terms of encouragement"* (P2).

5.3.5.3 Perceptions of the patient's post-MI condition

Cardiac rehabilitation practitioners recalled how families understanding of MI and recovery could impact upon the type and level of support provided. They recalled that some families worry about patients engaging in PA post-MI and put this down to a lack of understanding about PA post-MI, beliefs that they perceived to originate from the historical legacy of 'bedrest is best' following a cardiac event:

> *"I think people look at it 'you've had a heart attack, don't exert yourself', so the thought that you've been told that you have to do some exercise I guess that could worry other members of the family because you are putting exertion on the heart…but I guess that is back from the legacy where it was bedrest…and people think it's probably the best thing to do, but we know now with research that it isn't the best thing to do, it's about getting up and moving"* (P13).

In other cases, a number of CRPs recalled how some families can be unaware of the severity of patients MI, or perceive the patient as 'fixed' in the event of having a stent fitted, and therefore able to 'get on with life' as it were:

> *"…sometimes families don't understand the severity of an MI…you'll get patients who will say 'my wife doesn't realise that I've even had a MI, I've still got to do everything that I was doing before"* (P5).

5.4 Discussion

5.4.1 Findings overview

The findings presented in this study provided insight into how CRPs view the family within the CR pathway and the roles of the family in post-MI patients' PA experiences. Cardiac rehabilitation practitioners appeared to view family involvement as a positive factor in promoting PA amongst post-MI patients and identified multiple roles they can adopt ('being a second pair of ears', ''pulling back, pushing forward'' - keeping the patient within PA boundaries' and 'providing social support'). However, the level and type of social support offered by families for these roles appeared to be influenced by families own health beliefs, motivation to be active and their perceptions of patients' MI condition.

5.4.2 Synthesis of findings with wider literature

The findings within this study suggested that the level and type of social support offered by family to patients was dependent upon their own health beliefs, PA motivation and perceptions of patients' MI condition. It is established within the literature how families' health behaviour can be concordant (Cobb et al, 2016), through factors such as shared environment and access to facilities, control or through simultaneously influencing one another. In accordance with such theories, it is likely that if families are disinterested in positive health behaviours, it is likely the patient is also. Within spousal relationships, evidence suggests that when one partner makes a change, this increases the likelihood of the other making changes also (Falba and Sindelar, 2008 and Jackson, Steptoe and Wardle, 2015). Such evidence highlights the importance of understanding the family and their health beliefs, motivation, and perceptions of MI and designing interventions that target families as a collective unit when promoting engagement in healthy behaviours. However, given the focus within this literature on married couples, further work could be done to see whether other family members may be able to influence behaviour in the same way.

Within the current study, CRPs (primarily those in early CR phases) noted multiple benefits to involving the family in care, specifically in regard to attendance at consultations, and included families' ability to take on board information, relay information back to patients and ability to reinforce healthy behaviours within a home environment. The benefits of family involvement in care are well-documented (Duran et al, 2007, Coyne, 2015, Koren et al, 2018). However, given much of the evidence within the domain of familial involvement in healthcare is with populations where family are involved within a clinical capacity (e.g. making treatment decisions), the findings from the current study are novel given the focus on familial involvement within the context of lifestyle behaviour change. In addition, the findings suggest that involving family in the capacity of lifestyle behaviour change is valued and has the potential to be worthwhile.

It is noteworthy however that within this study, CRPs felt family involvement was particularly important during the early phases of CR. From CRPs perspectives, this was especially useful if patients did not appear fully engaged, as patients can sometimes appear passive and/or distant post-MI, and therefore the likelihood of them playing an active role during their consultation appeared low. Evidence suggests that following a cardiac event it is natural for patients to experience emotional distress (Wheatley, 2006, Jones et al, 2016), with feelings such as frustration, vulnerability and loss, as patients try and make sense and adapt to what has happened to them (Meredith, Wagstaff and Dicks, 2019). Such findings may explain why CRPs involved in the earlier phases of CR appreciated family involvement, because of their ability to speak and listen for the patient, and therefore provide information that CRPs may not have had access to otherwise (Laidsaar-Powell et al, 2016). A reason why family involvement could have been deemed more necessary in early CR phases could be explained through national audit data. Figures from the recent National Audit of Cardiac Rehabilitation (NACR) report (Doherty et al, 2018) suggest not everyone whom uptakes CR goes on to complete the programme (with most recent figures suggesting 76% of patients go on to complete CR). Therefore, it is possible that phase 4 CRPs are only seeing post-MI patients who are motivated to get to that stage of recovery and continue with

PA as part of their rehabilitation and may have the confidence to attend CR consultations on their own.

Despite CRPs feeling family involvement was generally positive, some challenges towards triadic consultations [referring to the clinician, family and patient trio] were noted. Cardiac rehabilitation practitioners recalled that family can become *"too involved"* during patient consultations. Numerous challenges to family involvement in care have been noted within the literature including requesting sensitive information and becoming aggressive during consultations (Laidsaar-Powell et al, 2016). Both of which can impact upon the delivery of patient care and harm patient autonomy. Within the literature, promoting patient autonomy appears key to ensure success of triadic consultations (Duran et al, 2007, Shin et al, 2013, Laidsaar-Powell et al, 2016), as ultimately, patients are often at the centre of the consultation and therefore should have an element of control over how it is run. Evidence suggests that the persistent thwarting of autonomy (e.g. being within a controlling environment) (Vansteenkiste, Niemiec and Soenens, 2010) has the ability to promote feelings of ill-being and lowered motivation (Gunnell et al, 2013). Given that CR comprises multiple consultations with different clinical staff at differing time points, it is possible that such controlling behaviour may impact negatively upon post-MI patients. Therefore, it is worth considering ways to work with CRPs, families and post-MI patients alike to help minimise controlling behaviour. However, it is worthwhile considering that not all patients and families will want to be involved in the same way, and therefore worth CRPs checking the willingness of families' involvement (Carmen et al, 2013) to ensure the consultation is optimum.

Within this study CRPs recalled how family can both hold back and push patients to engage in activity post-MI, however this also appeared mediated by how active patients were beforehand (i.e. for those who were very active pre-MI, family would be more predisposed to regulating their activity post-MI). It is well renowned that PA post-MI is beneficial (Dalal, Doherty and Taylor, 2015, Ekblom et al, 2018), however *"pulling patients back"* in this instance was perceived to limit patients' engagement in PA. This finding provides further rationale for CRPs to involve family and discuss with them PA related information (e.g. the appropriate amount of PA tailored specifically to patient need), so family can feel comfortable in the knowledge that the patient is not causing themselves undue harm. Evidence suggests opening up lines of communication to share information is important to promote patient health outcomes (Mackie, Mitchell and Marshall, 2018), and may involve a mixture of both verbal and written communication styles to help both patients and family absorb information (Australian Commission on Safety and Quality in Health [ACSQHC], 2014). Such guidance also provides an indication of how involving family within current practice could be achieved.

Lastly, all CRPs mentioned the importance of family in providing social support to post-MI patients to help promote PA engagement. It has been well documented within the literature that social support can encourage engagement in PA (Bauman et al, 2012, Smith et al, 2017, Birtwistle et al, 2018), and appears no different within the context of cardiac care. Cardiac rehabilitation practitioners noted family acting as role models could help enhance patient PA engagement. Within a PA context, offering guidance (informational support), especially from individuals' patients can relate to (i.e. in this instance if family could be active and had a health condition) can help promote mastery (Teixeira et al, 2012). It is common, especially amongst spousal pairs, for families to share similar health behaviours, therefore, to ensure role modelling is optimal, it is important to work with families to ensure their behaviour aligns positively to PA in order to promote positive engagement. Evidence suggests that tangible forms of support can encourage engagement in PA (Kouvonen et al, 2012). Within this study, tangible forms of support from family were also deemed important by CRPs and included families physically taking (e.g. by driving) post-MI patients to PA CR classes. Given that post-MI patients are advised to refrain from driving in the weeks following their MI (UK Government, 2019b) family being able to take patients to CR classes is an important area to promote. Cardiac rehabilitation practitioners also noted the important role family can adopt in providing emotional forms of support (showing empathy, care and encouragement). Within a health context, such nurturing forms of support have been found to help enhance patients' motivation to be active (Wong et al, 2016, Smith et al, 2017, Birtwistle et al, 2018). However, given data from the current study suggesting how families own beliefs (regarding health, PA motivation, and MI perceptions) may both positively and negatively impact upon the support they provide, it is arguably more important that CRPs ask questions to understand the family to establish health beliefs and help transform these where possible. However, it is also noteworthy that CRPs felt that family require support also. It has been well documented within the literature that following a cardiac event family may experience feelings of depression and/or anxiety (Randall, Molloy and Steptoe, 2009, Reid, Ski and Thompson, 2013) which may impact upon their adjustment to the event and functioning. Family functioning has been associated with health outcomes (Rosland, Heisler and Piette, 2012). Thus, before understanding their health beliefs, it may be more important to understand families' psychological health and support them to adjust to the cardiac event. This in turn may limit feelings of depression and anxiety, help improve their health and wellbeing, and thus be in a better position to provide support.

5.4.3 Strengths and limitations

Within the available literature to date, this is the first study to explore the role families can play in supporting PA engagement in post-MI patients, from the perspective of CRPs. Much of the literature exploring practitioner views on familial involvement in healthcare has been conducted within different contexts (e.g. oncology, critical care) (Coyne, 2015, Laidsaar-Powell et al, 2016 and 2017). Thus, the findings from the current study go some way in highlighting how CRPs view the family and the roles they can adopt within a post-MI context with specific regard to PA behaviour. Although this study only focused on post-MI patients' PA, and caution must be taken not to generalise, is possible that the findings identified may also be relevant to general cardiac care.

The sample was limited to practitioners who worked within a CR service located within the North West of England, therefore consideration must be taken when comparing the findings to other CR services as views between CRPs may differ. Not all practitioners invited to participate in the study did so. It is therefore important to acknowledge those who agreed to take part may have more of a positive outlook on, or acknowledge the benefits of, family involvement in helping shape post-MI patients' PA experiences, and therefore more willing to share their views. Finally, as the study focused on CRPs views only, conclusions cannot be drawn about the role families or patients themselves feel they can play. However, data from families themselves (chapter 4) suggests families do influence the way patients experience PA post-MI although do not appear to be actively involved in the CR process.

5.4.4 Conclusion and recommendations

Family involvement post-MI appeared to be supported and welcomed by CRPs, particularly in the early stages of recovery. The current study highlighted multiple roles the family can adopt that help shape post-MI patient PA experiences. However, despite the benefits of involving family in care, CRPs noted that in reality the interactions they had with family varied and often occurred by chance. Given the ways families can influence patients' PA post-MI, integrating them into the CR pathway appeared favourable. However, as the impact families have can also be negative, developing interventions focusing on building families' positive health beliefs, ensuring they understand their role in supporting patients' PA behaviour as well as making sure their needs are supported is important. Development of such an intervention might benefit from a co-production approach (Buckley et al, 2018), ensuring it addresses the needs of the patients, family and CRPs involved.

Chapter 6 The co-production of a physical activity support resource for families of post-myocardial infarction patients

6.1 Introduction

Interviews with CRPs (study 2, chapter 5) told us of the specific roles' family can adopt to influence post-MI patients' PA, and these can be both positive and negative in nature. It was also learnt that despite the influence family can have, the do not appear to be proactively involved within the CR pathway, although this appeared desirable by CRPs, they mentioned that currently interactions usually occur as a matter of chance. What study 2 did not tell us however was how the family could be incorporated into the CR pathway to ensure the influence they have on patients' PA is positive. Adopting a co-production approach is a possible method to help understand how to involve the family within the CR pathway which is acceptable to the CRPs, post-MI patients and families involved.

There is a wealth of evidence exploring the acceptability of family involvement within healthcare settings from patients, family members and HPs alike (section 2.5.3.1), and appears to be a widely accepted practice. Numerous benefits have been associated with family involvement in care. From a patient perspective, Duran and colleagues (2007) found having family present during medical encounters 'was the right thing to do', but also appreciated their involvement due to their ability to advocate for patient care. For families themselves, there are benefits such as learning about patients' conditions, understanding the level of care they receive, as well as the ability to ensure patients' health issues are being addressed (Coyne, 2015). Health professionals have noted their appreciation at families' ability to provide healthcare information that they may have otherwise missed, to reinforce health information and to gain a better understanding of the patient (Mackie, Marshall and Mitchell, 2017, Koren et al, 2018).

Within a cardiovascular setting, formal guidance stresses the importance of involving suitable support persons (e.g. family) during patients' cardiac recovery in roles of encouragement and support (NICE, 2013, BACPR, 2017). However, such guidance does not appear to consider how best to involve family, and perhaps arguably more important, consider the needs of family members and how their experience of the cardiac event may have impacted upon their ability to support patients. Evidence suggests that family support provided to patients following a cardiac event may not always be positive (Kärner, Dahlgren and Bergdahl, 2004, Rosland et al, 2010), and in some cases their support may be limited given their own psychological burdens brought on by the event (Reid, Ski and Thompson, 2013). Feelings of isolation have been found to inhibit the provision of effective support (McLean and Timmons, 2007) and support resources for support persons have been described as a viable means to overcome this barrier (McLean and Timmons, 2007), which in other studies have been found to lead to enhanced coping and increased confidence about making lifestyle changes (Stewart et al, 2001). Interventions focusing on the family within a cardiovascular and PA domain (Sher et al 2014, Yates et al, 2015), suggest that when interventions target both patients and family members an increase in PA can be observed, although mixed results have been seen when looking at longer-term PA maintenance.

It is worth acknowledging that none of the aforementioned studies (Sher et al, 2014, Yates et al, 2015) involved participants the intervention was intended to serve in the intervention design, which may, in part, have impacted upon their success. It has been said that public health interventions targeting lifestyle behaviours such as physical inactivity are often designed using a top-down approach (Leask et al, 2017) and do not acknowledge end-users (deliverers of the intervention and those in receipt of the intervention). This in turn can impact upon the effectiveness of such interventions. Adopting a co-production research approach, which promotes the active engagement of stakeholders involved in the intervention and its creation, has thus been promoted (Clarke et al, 2017, Leask et al, 2017, Leask et al, 2019) as a means to tackle such problems and to promote intervention effectiveness (Valaitis et al, 2018). Involving end-users in intervention development has many benefits, including the potential for increased effectiveness and sustainability of interventions (Leask et al, 2017), and improved satisfaction with care and improved health outcomes (Batalden et al, 2016, Lwemble et al, 2017). From a staff perspective, research suggests adopting a co-production approach can enhance staff wellbeing, increases the recognition to understand patients and their perspectives, and can alter their attitude of working with patients to improve services (Berwick et al, 2016, Lwemble et al, 2017). Adoption of a co-production approach has been used in the development of many health interventions (e.g. Buckley et al, 2018, McKay et al, 2018).

Results from studies 1 and 2 have suggested that family can play a meaningful role in shaping post-MI patients’ PA during the course of their recovery, but currently do not appear to be actively involved within the CR pathway. Thus, this study aimed to co-produce a PA-based support resource for families of post-MI patients in collaboration with CRPs, post-MI patients and their family members.

6.2 Methods

6.2.1 Study overview

The current study took place in the same North-West location as studies 1 and 2. Please refer to section 2.6.2 for a full overview of the current CR service provided in this location.

This section will provide an overview of the co-production approach adopted during this study. For a visual diagram of the co-production approach, please refer to figure 6.1. The co-production approach within this study comprised 4 stages, and as described in section 3.3.3 drew on an approach from a co-production study outlined by Buckley and colleagues (2018). The first stage of the co-production process involved conducting development meetings with post-MI patients, their family members and CRPs to gather participant views on resource design and development. The first development group meeting was held in March 2019 with post-MI patients and family members. Further development meetings were then held with CRPs (either individually or in pairs) and took place between April and May 2019. The second stage of this co-production study involved the primary researcher and research supervisor drafting a preliminary resource and pathway of how to deliver it based on the qualitative data collected during the development meetings. The third stage involved holding a multi-disciplinary acceptability meeting with all participants to review the drafted resources and took place in June 2019. During this meeting, feedback on the initial drafts was obtained from all participants. The final stage of this co-production study involved making refinements to the drafted documents from the qualitative feedback obtained during the acceptability meeting.

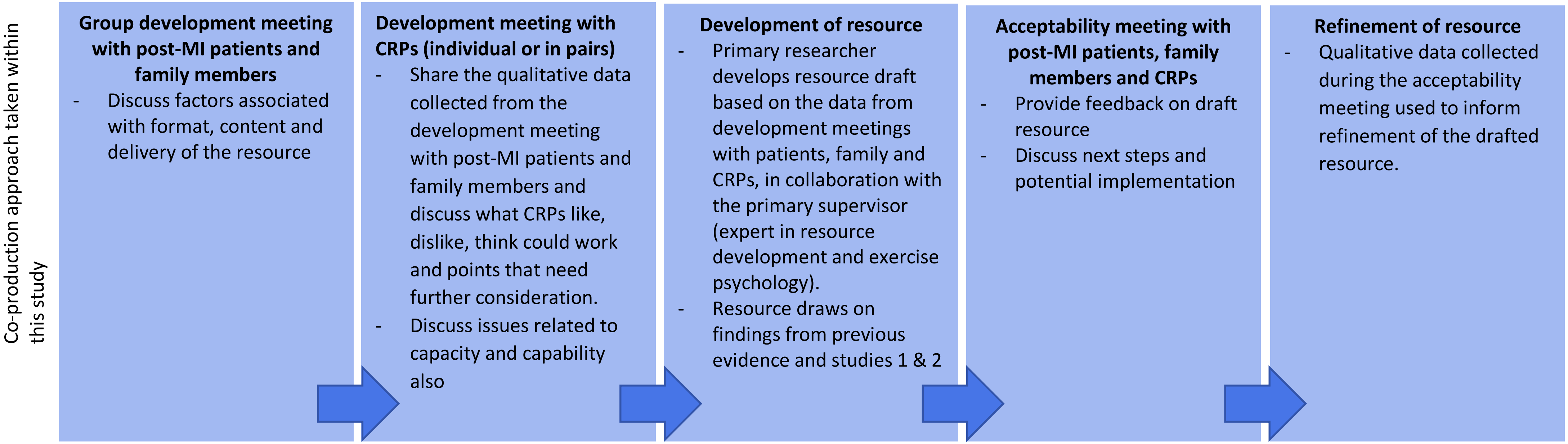
6.2.2 Participants and recruitment

6.2.2.1 Eligibility

Cardiac rehabilitation practitioners who had experience of working with MI patients within CR phases 2 - 4 working within the study location, and post-MI patients and their family members were eligible to take part in the study.

6.2.2.2 Recruitment

All participants were purposively sampled for this study and were identified through their prior involvement in studies 1 and 2, contacts of eligible participants, or through their contribution to the research team. Participants (post-MI patients, family members and CRPs) were initially approached about this study between April 2018 and September 2018 (on the completion of the preceding studies), where the primary researcher asked participants if they would be interested in taking part in a further co-production study. All participants who had stated their interest during this period (n=26) along with another CRP who was recruited via word of mouth (n=1) were contacted by telephone by the primary researcher in February 2019 to formally invite them to participate in the study. Before CRPs were contacted, gatekeeper consent was sought from the service manager(s) of CR phases 2 – 4. In addition, patients and their family members were informed they would each receive a £30 voucher for participation in the study (incentives were not offered to CRPs).



Co-production approach taken within this study

Group development meeting with post-MI patients and family members

- Discuss factors associated with format, content and delivery of the resource

Development meeting with CRPs (individual or in pairs)

- Share the qualitative data collected from the development meeting with post-MI patients and family members and discuss what CRPs like, dislike, think could work and points that need further consideration.
- Discuss issues related to capacity and capability also

Development of resource

- Primary researcher develops resource draft based on the data from development meetings with patients, family and CRPs, in collaboration with the primary supervisor (expert in resource development and exercise psychology).
- Resource draws on findings from previous evidence and studies 1 & 2

Acceptability meeting with post-MI patients, family members and CRPs

- Provide feedback on draft resource
- Discuss next steps and potential implementation

Refinement of resource

- Qualitative data collected during the acceptability meeting used to inform refinement of the drafted resource.

Figure 6.1 An outline of the co-production process

6.2.2.3 Final sample

From the 27 participants initially approached to participate in the study, 23 responded and 12 formally agreed to take part in the development and acceptability meetings. Reasons provided for non-participation included personal issues (patient and family members n=8) and lack of capacity (clinical staff n=3). Participants included 8 CRPS (1 CN, 2 physiotherapists, 1 OT, 3 ARSIs, 1 service manager), 2 post-MI patients and 2 family members. Of the 12 participants, 8 were female and 4 male.

6.2.3 Co-production process

6.2.3.1 Development meetings

The purpose of the development meetings was to collect qualitative data from participants to inform the development of a PA support resource for family members of post-MI patients. For the development stage, separate meetings were held with each participant group involved in the research (i.e. a development meeting was held with post-MI patients and their family members and development meetings held with CRPs in CR phases 2 - 4). The decision to hold the meetings by participant group was to ensure all participants could present their thoughts fully and comfortably. This approach also allowed the primary researcher to gain an in-depth understanding of the needs of each group. All development meetings were facilitated by the primary researcher.

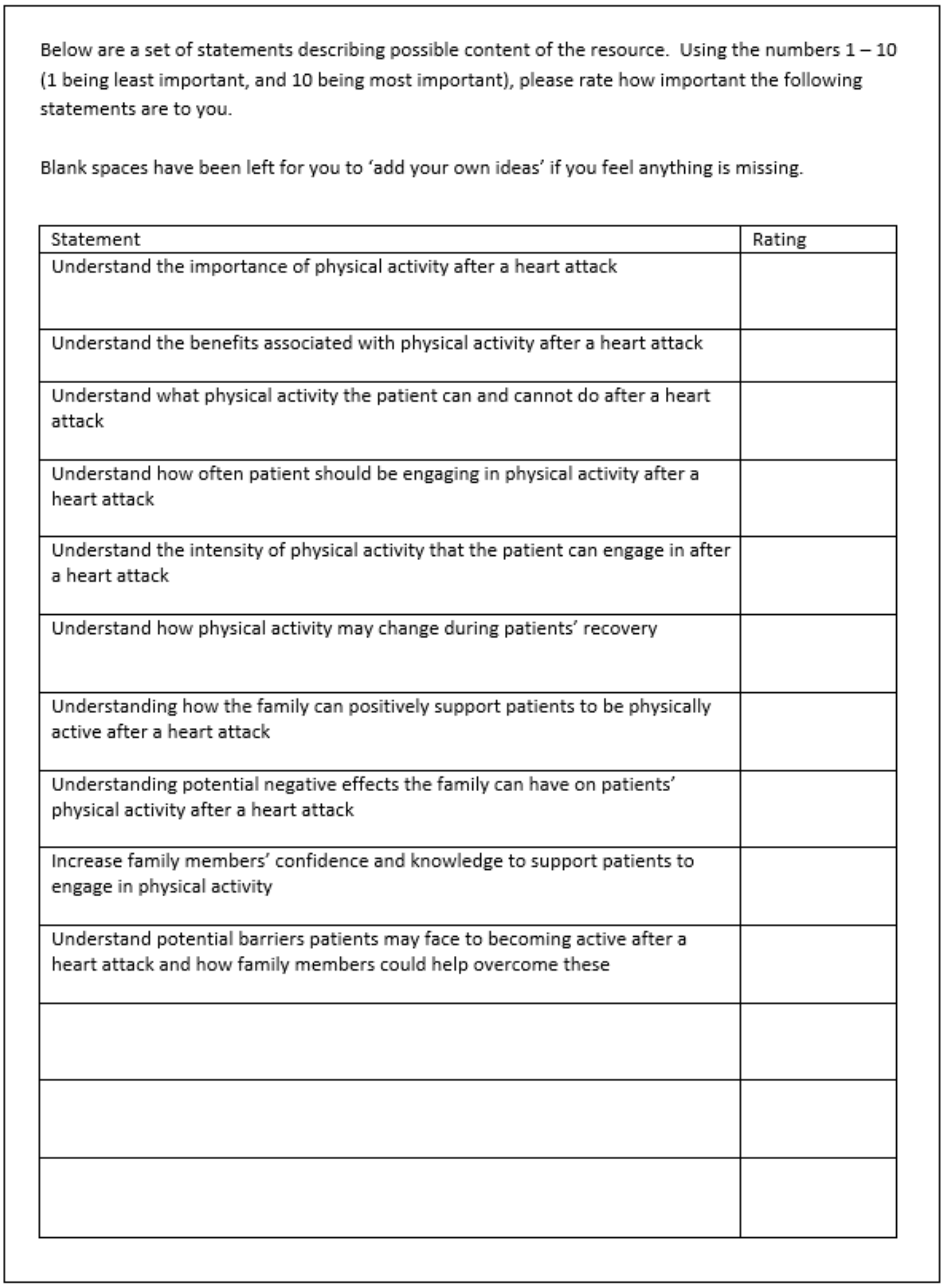
In total, five development meetings were organised and held between March and May 2019 in either leisure or healthcare facilities in the North West of England. Prior to each meeting, written consent was obtained and the primary researcher told the group the aim was to develop a support resource for family members to support post-MI patients' PA engagement, important given that poorly defined aims have the potential to jeopardise co-production success (Greenhalgh et al, 2016).

6.2.3.1.1 Patients and family members

Given the service user focus of the resource, the first meeting took place with patients and family members and included 2 post-MI patients and 2 of their family members (group total n = 4). To help ensure the aim of the session was met, a session structure (please refer to appendix 4) was developed, outlining meeting timings, discussion topics and tasks, all of which were developed through collaborative meetings with the research team (experienced in co-production). Discussion topics were used to help focus and facilitate discussion and drew on areas considered important within the literature for intervention design (including purpose, format, content and delivery). Using tasks to help facilitate discussions is not uncommon (Leask et al, 2017) and in this study, tasks were used to gather participant perceptions and reflections on their own personal experiences of PA post-MI and what they felt was missing/what information they would have liked to receive during the recovery phases.

To help determine resource content, participants were split by status (i.e. post-MI patient and family), and asked to collaboratively discuss questions including ‘what would you have liked to have known about PA?’, ‘what would you have liked your family/the patient to have known?’. Participants were asked to complete a written rating scales task, which asked them to rate statements in order of personal importance describing possible resource content (1 being least important and 10 being most important), (please refer to figure 6.2 for full written task). Statements were informed through the findings of studies 1 and 2, but participants were encouraged to add their own statements also if desired. In regard to format, participants were provided with multiple different resource formats (e.g. infographs, booklets, online resources), and asked to collectively discuss the pros and cons of each, thinking about aspects such as burden, feasibility, usability and accessibility. In terms of resource delivery, participants were asked to think about practical, verbal and visual aspects, which were facilitated through questions asked by the primary researcher, and included ‘when, by whom and how do you do think the resource is best delivered?’ and ‘what communication techniques are important to deliver the resource?'. Throughout the data collection process, participants were also encouraged to jot ideas down on flipchart paper, points which also acted as further points of discussion. In addition, a consensus was reached on each task before moving onto the next, this was to maintain focus on resource development.

The meeting with patients and family members was recorded using a Dictaphone and lasted approximately 2.5 hours in length.



Below are a set of statements describing possible content of the resource. Using the numbers 1 – 10 (1 being least important, and 10 being most important), please rate how important the following statements are to you.

Blank spaces have been left for you to 'add your own ideas' if you feel anything is missing.

Statement	Rating
Understand the importance of physical activity after a heart attack	
Understand the benefits associated with physical activity after a heart attack	
Understand what physical activity the patient can and cannot do after a heart attack	
Understand how often patient should be engaging in physical activity after a heart attack	
Understand the intensity of physical activity that the patient can engage in after a heart attack	
Understand how physical activity may change during patients' recovery	
Understanding how the family can positively support patients to be physically active after a heart attack	
Understanding potential negative effects the family can have on patients' physical activity after a heart attack	
Increase family members' confidence and knowledge to support patients to engage in physical activity	
Understand potential barriers patients may face to becoming active after a heart attack and how family members could help overcome these	

Figure 6.2 Written task given to patients and family members to help determine resource content

6.2.3.1.2 Cardiac rehabilitation practitioners

Following completion of the patient and family member development group, the primary researcher and research supervisor discussed and developed a meeting guide for CRPs, which was developed on the basis of findings from post-MI patients and family members (refer to appendix 5 for meeting guide). Topics explored included CRPs preferred format, content and delivery, but also considered factors relating to service capacity and capability. Meetings with CRPs were held either singularly or in pairs. Please refer to table 6.1 for CRPs involved during the development meetings and meeting format (i.e. meetings held singularly or in pairs). The primary researcher discussed what the meeting purpose and focus was and then went on to discuss what had been found during the meeting with post-MI patients and family members. Participants were then asked for feedback on these initial ideas with questions focusing on what they liked and what they did not, what they think may work in practice and solutions to any problems they identified, any other ideas they think could work and any conflicts they had with the ideas presented. Given that CRP meetings did not happen in a collective group, discussions from each development meeting with CRPs were fed into the next.

Each meeting with CRPs was recorded with a Dictaphone and varied in length lasting approximately 1 hour – 1.30 hours.

Table 6.1 Cardiac rehabilitation practitioners involved in the development meetings and format of meetings

CRPs involved in research study	Job role	Development meeting attendance
1	CN	✓
2	Physio	✓
3	Physio	✓
4	OT	✓
5	ARSI	✓
6	ARSI	✓
7	ARSI	✗
8	Service manager	✗
Meetings held singularly	Meetings held in pairs	Not involved in development meetings

6.2.3.2 Development of draft resources

In order to develop the resource, audio data collected from the development meetings with post-MI patients, family members and CRPs was listened to several times by the primary researcher and relevant and meaningful quotes pertaining to resource format, content and delivery (including capacity and capability) were extrapolated and coded in a Microsoft Office Word document. Once this had been done for each audio file, the primary researcher searched for patterns in the data, placing similar codes together and labelled with a theme name. Further investigation of themes allowed for further subthemes to be created. To ensure themes were distinct from one another, they were refined which included a process of collapsing, editing and discarding. Theme names were refined to ensure they accurately captured the quotes within them.

The process followed was similar to that of Braun and Clarke (2006). This process involved regular meetings with the primary supervisor, the purpose of which were to discuss and debate developing themes and aid in the development of the resources and planning of the acceptability meeting. These activities also enhanced rigour and acted as a means to verify themes, consequently increasing credibility and trustworthiness (Denzin, 2006).

The qualitative findings developed from the analysis of the data collected during the development meetings were used to inform the topics to be covered, the format and structure of the resource and how it should be delivered. However, to determine the content itself (i.e. within each topic identified by the participants to be included within the resource), findings from studies 1 and 2, as well as academic literature and evidence-based practitioner resources (i.e. from the BHF), were drawn upon. The development of the draft resource and associated pathway was an iterative process developed over a 2-month period. The resources were drafted in sections which were regularly reviewed by the primary supervisor and amended by the primary researcher, a cycle which continued until it was felt the resource and pathway captured the essence of the data collected and could be authentically presented to participants during the acceptability meeting.

6.2.3.3 Acceptability meeting

To gather feedback on the resources developed from the data collected during the development meetings, an acceptability meeting was held. The acceptability meeting included all participants who had taken part in the development meetings, with the exception of one physiotherapist, one ARSI and one family member because of work commitments and illness, respectively. In addition, another ARSI, service manager and the primary researcher’s second supervisor, with a background in cardiology, attended who had not taken part in a development meeting. The meeting took place in a health centre located within the North West of England in June 2019 and lasted approximately 2 hours and aimed to review the drafted resource and pathway, developed through the qualitative data collected during the development meetings.

It has been reported that power imbalances can occur during co-production research, usually favouring practitioners (Holland-Hart, 2019). In order to minimise this, numerous steps were taken to create an open environment where all participants felt free to share their thoughts without causing offence. To promote equality, fairness and a supportive atmosphere during the acceptability meeting, participants were reminded that although they came from a range of backgrounds with different experiences, there was a shared interest to promote PA post-MI. The primary researcher began by stating there were no right or wrong answers and all viewpoints shared were valid. In addition, during the acceptability meeting, participants were split into small groups, done to ensure everyone's voice was heard, and has been a technique used elsewhere (Buckley et al, 2018).

Table 6.2 refers to a summary session plan that was followed during the acceptability meeting. The meeting began with the primary researcher providing an overview of the findings that came through the development meetings. Following this, participants were split into two small groups (5-6), which where possible, aimed to have representatives for each participant group (e.g. patients, family, CNs, ARSIs). The reason for splitting participants into smaller groups was to complete two group tasks, which involved reviewing the drafted resource and pathway and providing feedback. The primary researcher was responsible for facilitating the 'drafted resource' task and research supervisor the 'pathway' task. All groups did both tasks, with each task lasting approximately 20 minutes. Before discussing the drafted resource and pathway, participants were given the opportunity to read over them. Participants were asked broad questions pertaining to what they liked about the resource and pathway and what they thought worked well, and what aspects they were unsure about and needed further consideration.

To enhance trustworthiness, participant feedback obtained during the tasks was shared during the summary discussion by both the primary researcher and research supervisor to participants. This process allowed participants to clarify any points potentially missed or misinterpreted and gave them the opportunity to contribute anything further, following similar principles to member checking (Birt et al, 2016). The final step of the acceptability meeting was to think about the 'next steps'.

Following completion of the acceptability meeting, audio files were transferred onto a desktop computer and listened to multiple times by the primary researcher. The analysis procedure followed similar steps as outlined within section 6.2.3.2, where verbatim quotes were extrapolated, coded, revised and placed and then presented in tables. Based on the findings of the acceptability meeting, a refined version of the drafted resource and pathway was then developed.

Table 6.2 Acceptability meeting summary session outline

Task duration			
20 minutes	Primary researcher gave presentation of PhD study 1 & 2 findings		
10 minutes	Outline aims of session	- Review drafted resource and pathway - Formulate tangible 'next steps' for taking resource forward	
10 minutes	Outline aims of resource	- To support family members support post-MI patients PA engagement	
40 minutes		**Broad questions asked to both small groups**	**Specific questions asked to each small group**
	Task 1 (small groups) review drafted resource	- What do you like about this / what do you think will work well? - What aspects are you not sure about / need some further consideration?	- Should the leaflet be specific to post-heart attack, or other cardiac conditions? (Bear in mind evidence has been collected with MI patients). - Thoughts on the term "family"?
	Task 2 (small groups) review pathway to deliver resource		- We suggested that the family member is initially contacted by phase 4 staff, then the face-to-face appointment with phase 4 staff involves both family member and patient – thoughts?
20 minutes	Summary discussion	- Summarise discussions had in each group - Discuss with participants the 'next steps' for taking resource forward	

6.3 Results

6.3.1 Overview of results

The results presented within this chapter are from the development and acceptability meeting(s) with post-MI patients, their family members, and CRPs. These meetings led to the development and refinement of a draft resource (and from here on in will be referred to as an information booklet) and pathway to deliver resource (which from here on in will be referred to as the support pathway). Therefore, the structure of this results section will be as follows; the presentation of the final information booklet and support pathway, factors were there was agreement between participants (which were used to inform the information booklet and support pathway), and factors in need of further consideration (before the information booklet and support pathway can be implemented in practice).

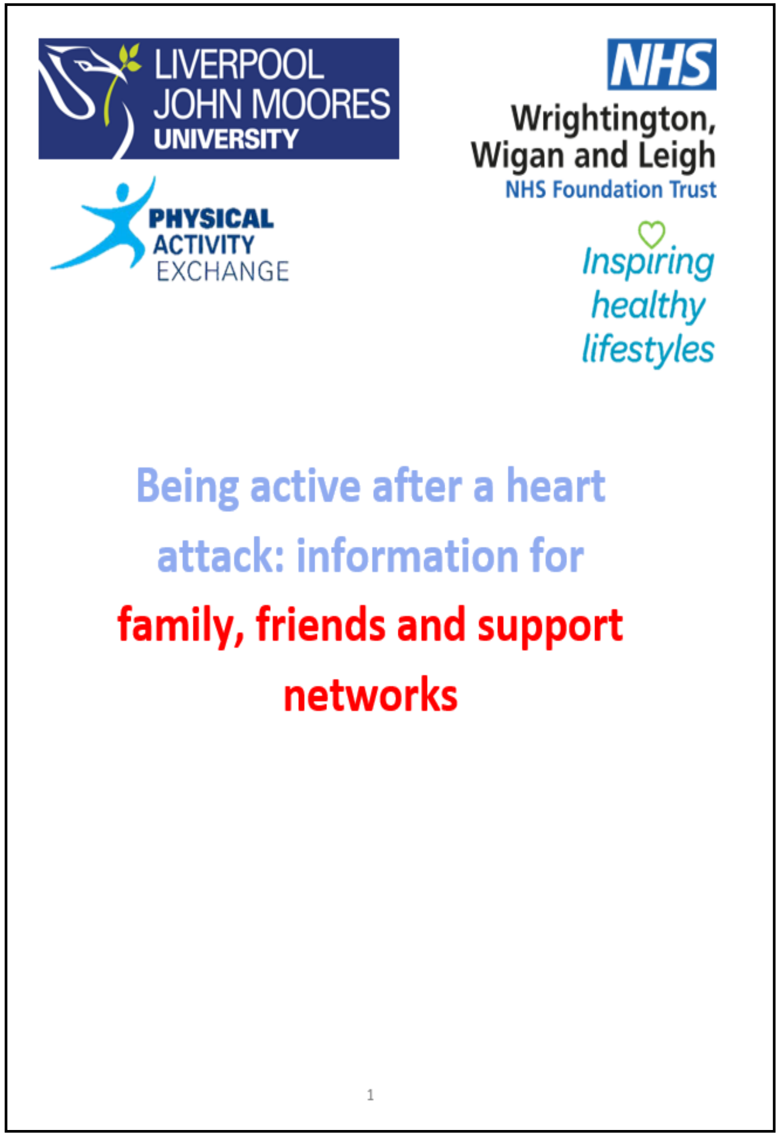
6.3.2 An overview of the information booklet and support pathway

As described in section 6.3.1 the co-production process led to the development of two documents a) an information booklet for family members of MI patients; and b) a support pathway, outlining how the information booklet could be delivered to family members. The refined documents are presented within this section, however, to view the original drafted documents please refer to appendix 6 for the information booklet and 7 for the support pathway.

6.3.2.1 Family information booklet

Please refer to figure 6.3 for a visual overview of the proposed information booklet that could be offered to family members of post-MI patients to help them support post-MI PA engagement.

The information booklet comprised 5 sections (1), your cardiac rehabilitation service (providing an overview of both patients and families' pathway through CR); (2) physical activity after a heart attack (overview of why PA is important and how much PA is appropriate post-MI); (3) what to expect this next year (details the PA journey patients and families may experience post-MI); (4) providing family support (outlining ways the family can support patients' PA); and (5) a summary page (a place to record discussions, goals and actions had during the "support chat"). As well as the qualitative data collected during the development and acceptability meeting(s), the information contained within the resource drew on findings from studies 1 and 2, as well as academic and evidence-based practitioner resources. Please refer to table 6.3 for an overview of how the information booklet mapped onto information sources.



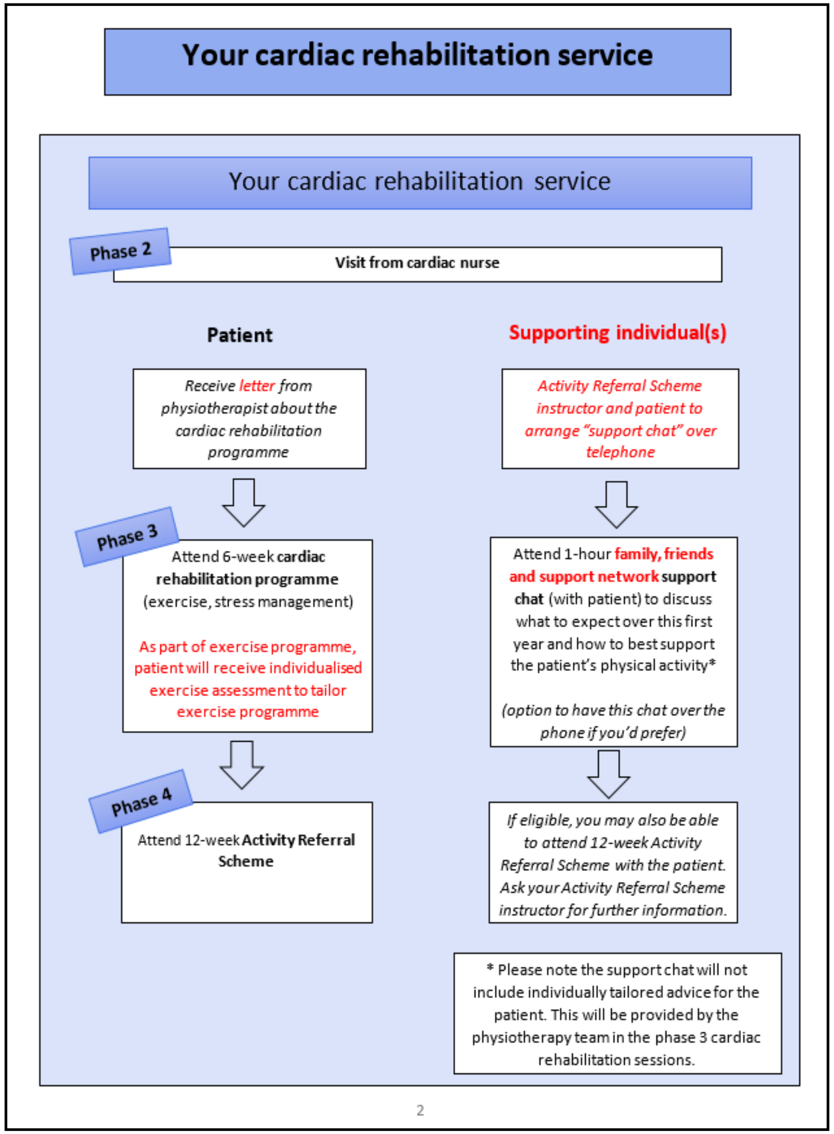
LIVERPOOL JOHN MOORES UNIVERSITY

PHYSICAL ACTIVITY EXCHANGE

NHS
Wrightington, Wigan and Leigh
NHS Foundation Trust

Inspiring healthy lifestyles

Being active after a heart attack: information for family, friends and support networks



Your cardiac rehabilitation service

Your cardiac rehabilitation service

Phase 2 Visit from cardiac nurse

Patient

Receive letter from physiotherapist about the cardiac rehabilitation programme

Phase 3 Attend 6-week **cardiac rehabilitation programme** (exercise, stress management)

As part of exercise programme, patient will receive individualised exercise assessment to tailor exercise programme

Phase 4 Attend 12-week **Activity Referral Scheme**

Supporting individual(s)

Activity Referral Scheme instructor and patient to arrange "support chat" over telephone

Attend 1-hour **family, friends and support network support chat** (with patient) to discuss what to expect over this first year and how to best support the patient's physical activity*

(option to have this chat over the phone if you'd prefer)

If eligible, you may also be able to attend 12-week Activity Referral Scheme with the patient. Ask your Activity Referral Scheme instructor for further information.

* Please note the support chat will not include individually tailored advice for the patient. This will be provided by the physiotherapy team in the phase 3 cardiac rehabilitation sessions.

Physical activity after a heart attack

What is physical activity?

"…any movement made by your body where your heart rate feels raised, for example this could brisk walking"

Why is physical activity important?

Research suggests that staying active will help people who have experienced a heart attack in many ways:

- It keeps them healthy
- It keeps them feeling good
- It improves life expectancy
- It reduces the chance of them having further heart problems

How much physical activity is appropriate after a heart attack?

Every patients' physical activity abilities will differ, and it is important patients listen to their bodies when engaging in activity.

When patients feel able, they may start engaging in activity slowly (walking). Over time, and when patients feel capable, they could try increasing their walking speed, or try different activities. It is important patients engage in activities they enjoy as this increases the likelihood of activity being sustained, and may be functional tasks such as gardening, washing the car or walking the dog.

If either you or the patient are unsure about activity, encouragement to attend cardiac rehabilitation consultations are advised.

Debugging myths!

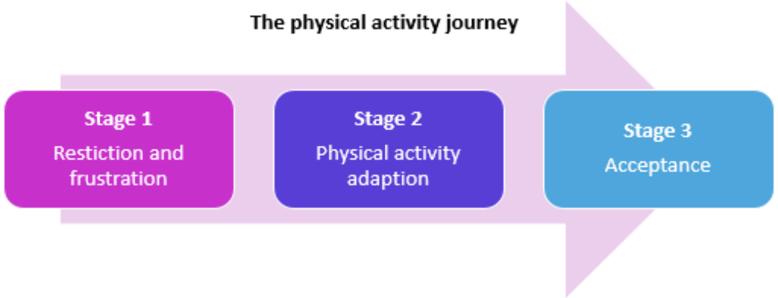
It is commonly believed that 'rest is best' following a heart attack. However, research shows that physical activity can be very good for patient health. If patients feel able, encourage them to engage in activity.

What to expect this next year

Research conducted by Liverpool John Moores University with heart attack patients and their family suggests after a heart attack patient go on a journey of learning how to re-engage with physical activity. Family go on the journey with patients also and influence how it is experienced by patients.

Every patient and families' experience of the journey will be individual and occur at different time points. Recovery is personal and that is okay, it is important patients engage in activity at a rate that is comfortable for them, something is better than nothing.

The physical activity journey

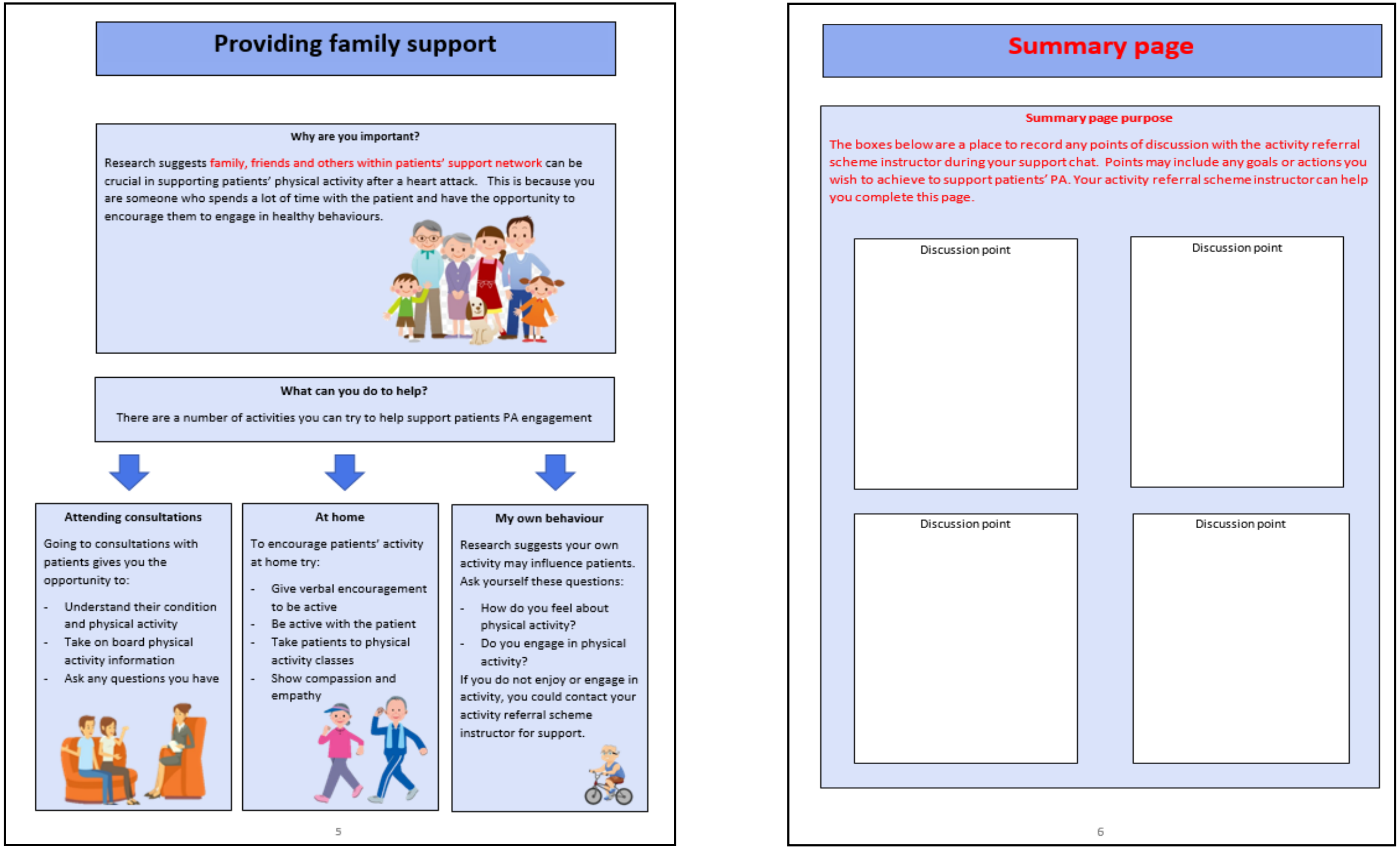


Stage 1
Restiction and frustration

Stage 2
Physical activity adaption

Stage 3
Acceptance

Stage 1	Stage 2	Stage 3
It is normal for patients to feel: - Vulnerable - Lack of control - Frustrated As a family member you may experience worry and feel like you want to stop patients from engaging in activity also.	As time progresses it is natural for patients to want to engage in physical activity. Patients may feel unable to engage in the same amount and intensity of activity as before their heart attack, but they may adapt their behaviour so they can do something.	Over time patients may come to accept their new relationship with physical activity. 



Providing family support

Why are you important?

Research suggests family, friends and others within patients' support network can be crucial in supporting patients' physical activity after a heart attack. This is because you are someone who spends a lot of time with the patient and have the opportunity to encourage them to engage in healthy behaviours.

What can you do to help?

There are a number of activities you can try to help support patients PA engagement

Attending consultations

Going to consultations with patients gives you the opportunity to:

- Understand their condition and physical activity
- Take on board physical activity information
- Ask any questions you have

At home

To encourage patients' activity at home try:

- Give verbal encouragement to be active
- Be active with the patient
- Take patients to physical activity classes
- Show compassion and empathy

My own behaviour

Research suggests your own activity may influence patients. Ask yourself these questions:

- How do you feel about physical activity?
- Do you engage in physical activity?

If you do not enjoy or engage in activity, you could contact your activity referral scheme instructor for support.

5

Summary page

Summary page purpose

The boxes below are a place to record any points of discussion with the activity referral scheme instructor during your support chat. Points may include any goals or actions you wish to achieve to support patients' PA. Your activity referral scheme instructor can help you complete this page.

Discussion point	Discussion point
Discussion point	Discussion point

6

Figure 6.3 A visual overview of the refined information booklet for family members of post-myocardial infarction patients
Key – The red writing pertains to refinements made to the information booklet following the qualitative data collected during the acceptability meeting

Table 6.3 An overview of how the information booklet mapped onto information sources

Information booklet page number	Page title and subsections	Information source	Evidence
2	**Your cardiac rehabilitation service**		
	Your cardiac rehabilitation service	CRPs	Face-to-face conversations with CRPs who detailed the CR pathway within the locality of study
3	**Physical activity after a heart attack**		
	- What is physical activity?	Study 1	Defined PA for a lay population which drew on the definition as outlined by Caspersen, Powell and Christenson (1985)
	- Why is physical activity important?	Academic and evidence-based practitioner resources	Evidence suggests that PA following MI can improve physical and mental health and reduce the risk of mortality and further cardiac events (Dalal, Doherty and Taylor, 2015, Anderson et al, 2016, BHF, 2017a)
	- How much physical activity is appropriate after a heart attack?	Heart pack provided to patients by CNs	Specified that following MI patients should start with gentle walking and then gradually introduce other physical activities when patients feel able (e.g. gardening)
	- Debugging myths	Study 2	CRPs recalled in study 2 how families' perception of 'bed rest is best' can negatively impact upon the type and level of support that they may provide to patients following MI
4	**What to expect this next year**		

	The ‘physical activity journey’	Study 1	Study 1 findings showed patients went through a process of not being able to do what they wanted (characterised by feelings of restriction and in some cases frustration), finding their own way with PA (adapting to engage in activity they could do) and then coming to accept this way (accepting a new relationship with PA)
5	**Providing support**		
	- Why are you important	Studies 1 and 2	Findings suggested that families can play an influential role in helping shape patients experiences of PA post-MI and can be positive in helping encourage PA engagement
	- What can you do to help?	Studies 1 and 2	Findings suggested that families can adopt multiple roles to help patients engage in PA post MI (e.g. being a second pair of ears, taking patients to CR classes, being active with patients) The findings also suggested that families own beliefs may impact upon the type and level of support, and therefore a focus on families own health behaviour was important
6	- Summary page	Acceptability meeting	Deemed important by participants to have a place to record any notes made during the delivery consultation

6.3.2.2 Support pathway

Please refer to figure 6.4 for a visual overview of the proposed support pathway showcasing how the information booklet could be delivered in practice.

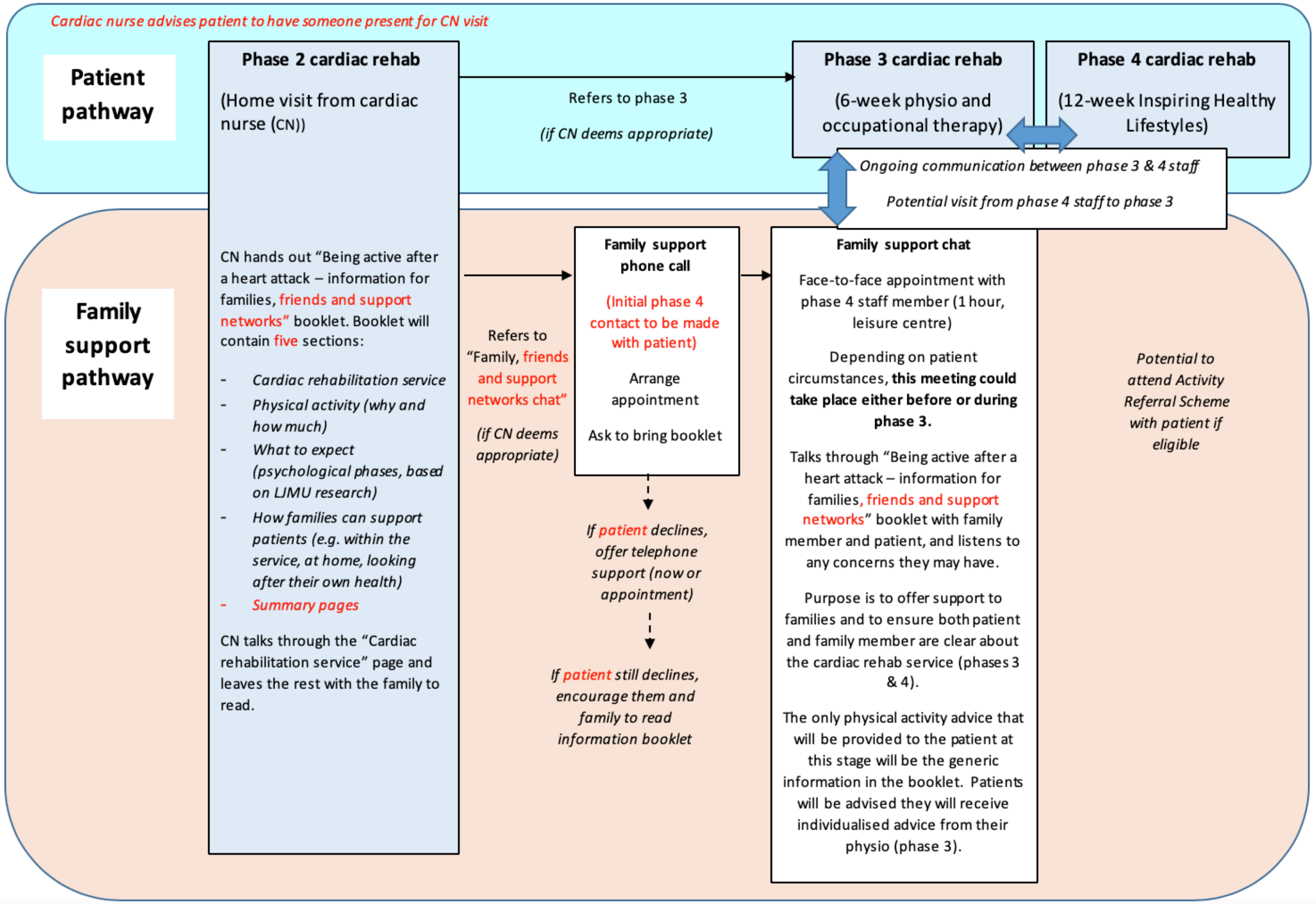
Through the development meetings it appeared important that for the information booklet to work in practice, it had to be part of a coherent pathway detailing how, when and by whom it would be delivered. The proposed pathway comprised 4 stages and was aligned to the existing CR pathway (section 2.6.2) and involved:

Stage 1: During a routine phone call to patient to arrange a home visit, CNs would ask patients to have family (or another support person/s) present during the appointment.

Stage 2: As part of CNs home visit to patients, CNs would be responsible for explaining the purpose of and handing out a hard copy of the information booklet to patients/family. During this visit CNs would also be responsible for referring patients to the “support chat”, on the basis of patients consenting to be referred and are deemed clinically able to engage in PA by CNs.

Stage 3: The next stage of the proposed pathway involved a telephone call between patients and ARSIs to arrange a face-to-face “support chat” for patients and their family. If during this telephone call patients decline the “support chat”, they would be offered telephone support, but if further declined would be encouraged that both themselves and their family read the information booklet.

Stage 4: During the “support chat” the role of the ARSIs would be to talk through the information within the booklet and answer any concerns or worries families may have. This meeting would also be a place where the ARSIs could encourage active involvement of family members who may be eligible for the phase 4 programme (which is part of a general activity referral programme for inactive individuals with health conditions).



Cardiac nurse advises patient to have someone present for CN visit

Phase 2 cardiac rehab

(Home visit from cardiac nurse (CN))

Phase 3 cardiac rehab

(6-week physio and occupational therapy)

Phase 4 cardiac rehab

(12-week Inspiring Healthy Lifestyles)

Ongoing communication between phase 3 & 4 staff

CN hands out "Being active after a heart attack – information for families, friends and support networks" booklet. Booklet will contain five sections:

- *Cardiac rehabilitation service*
- *Physical activity (why and how much)*
- *What to expect (psychological phases, based on LJMU research)*
- *How families can support patients (e.g. within the service, at home, looking after their own health)*
- *Summary pages*

CN talks through the "Cardiac rehabilitation service" page and leaves the rest with the family to read.

Refers to "Family, friends and support networks chat"

(if CN deems appropriate)

Family support phone call

(Initial phase 4 contact to be made with patient)

Arrange appointment

Ask to bring booklet

If patient declines, offer telephone support (now or appointment)

If patient still declines, encourage them and family to read information booklet

Family support chat

Face-to-face appointment with phase 4 staff member (1 hour, leisure centre)

Depending on patient circumstances, **this meeting could take place either before or during phase 3.**

Talks through "Being active after a heart attack – information for families, friends and support networks" booklet with family member and patient, and listens to any concerns they may have.

Purpose is to offer support to families and to ensure both patient and family member are clear about the cardiac rehab service (phases 3 & 4).

The only physical activity advice that will be provided to the patient at this stage will be the generic information in the booklet. Patients will be advised they will receive individualised advice from their physio (phase 3).

Potential to attend Activity Referral Scheme with patient if eligible

Figure 6.4 A visual overview of the refined support pathway of how the information booklet could be delivered in practice

Key – 'support pathway' refers to the CR pathway within the programme of study (as described in section 2.6.2). 'Family support pathway' refers to the pathway developed to demonstrate how the information booklet could be delivered in practice.

The red text pertains to refinements made to the support pathway following the qualitative data collected during the acceptability meeting

6.3.3 Findings that arose during the development and acceptability meetings

6.3.3.1 Overview

It appeared to be universally accepted by all participants that developing a PA support resource for family members had utility in practice, and reasons appeared twofold. Firstly, participants held the belief that such a resource would be helpful to aid family members' knowledge regarding PA engagement post-MI:

> *"…the family* [can] *hinder them* [patients] *in terms of 'no don't do that, that's a bit much… so I think if the relatives have a better understanding of the importance of regular exercise then yes it's going to be beneficial for the patient long-term"* (CRP 1, development meeting).

Secondly some participants believed designing a resource for families would make them feel part of the pathway and would therefore nurture family needs by providing information on how they can support patients, but also help them come to terms with what has happened to the patient:

> *"…cardiac events affects the whole family so it's important to include family during patients' recovery to help them understand what the patient is experiencing…but also how they can support which may help them feel more empowered and also help accept what is going on"* (CRP 4, development meeting).

During the development and acceptability meeting/s, a number of factors emerged, some where there was agreement (i.e. where there was consensus amongst participants), and some that required further consideration (i.e. where there was a differing of opinions). Table 6.4 details factors of agreement and provides a detailed overview of each factor of agreement amongst participants, provides an illustrative quote for each factor and how this was actioned within the resource by the research team. Table 6.5. details factors requiring further consideration and provides a detailed overview of each factor and also provide two contrasting quotes that demonstrate the differing perspective pertaining to each factor identified.

Within both tables, factors are categorised by resource format, content and delivery. It is worth noting that within the 'factors of agreement' table, factors for delivery are further subcategorised by the SEM for clarity as the factors identified spanned across different levels.

6.3.3.2 Factors of agreement

6.3.3.2.1 Resource format

It was considered important by all participants that the resource developed must be user-friendly. Patients recalled that as part of their recovery they are given a 'heart pack' (a 50+ page resource that details topics such as diet, PA, medication). Patients cited how this was too much information and requested something that was lesser in volume. Given external pressures (e.g. time), CRPs requested a resource that was relatively low burden and something that could fit easily within the existing CR pathway without causing disruption.

Table 6.4 Factors of agreement amongst participants relating to resource format, consent and delivery with illustrative quote and how factors were actioned

Factors of agreement	**Illustrative quote**	**How factors were actioned**
Resource format		
User friendly	*"…something what you can read and pick up…something that isn't too big*" (family member 2, development meeting)	• Limited information booklet to 6 pages long (including cover and summary page)
Low burden	*"…it* [resource] *must be something that can fit with the existing service that we offer" (*CRP 6, development meeting).	• Developed an information booklet that could fit into the existing CR pathway and did not add additional burden to staff and patients
Resource content		
Provide specific information on PA, family support, and what to expect	*"…from my own point of view it would've been good to know why* [it's important for patient to do PA] you know and *what* [patient] *could do cos I didn't know…and what I could've done to help"* (family member 2, development phase).	Ensured the information booklet included elements on: • Importance of PA (pg.3). • Appropriate amounts of PA post-MI (pg.3). • Information on how family can provide support to patients (pg.5). • PA 'journey' (pg. 4)
Highlight the importance of functional PA	*"… it's important to recognise functional activities…so activities like gardening and how family can support that"* (CRP 4, acceptability meeting).	• Refined information booklet to provide overview of functional activities (pg3).
Make information understandable, accurate and transparent	*"…explaining what it is* [resource]*…in a language what we understand"* (family member 1, development phase).	• Ensured the information booklet was written in lay language (e.g. instead of using the term myocardial infarction, the term heart attack was used).

Make individualised PA element clear	*"…the problem every heart attack is different, every patient is different, every recovery is different, so their activity is going to be different"* (family member 2, development meeting"	• Promoted attendance at CR consultations (throughout information booklet). • Used language explaining that every patient's PA experience will differ • Added a summary page to the information booklet to record personalised information discussed during the support chat, which may include goals and action plans (pg. 6).
Broad definition of "family"	*"…they* [patient] *may want to take a friend, it doesn't have to be a family member, just a key person"* (CRP 1, acceptability meeting).	• During refinement the term 'family' was broadened to include friends and support networks (which may refer to carers, support workers etc..).
Application of resource to other cardiac populations	*"I can't see how it* [resource] *couldn't be adapted because you're still wanting those patients to exercise…I think there's a place for it* [resource within other populations] *without a doubt"* (CRP 1, acceptability meeting).	• Decided it was important to trial the information booklet with MI patients and family first and then explore the possibility of the booklet being trialled with other cardiac populations.
Resource delivery		
Intrapersonal factors		
Ensuring staff are qualified to deliver	*"…I think sometimes* [phase 4 CRPs] *have a limited understanding of the kind of things we're looking for from a risk point of view because they don't have that specialist* [PA] *knowledge"* (CRP 3, development meeting).	• Within support pathway and information booklet (pg. 2) it was highlighted the only PA information provided during the support chat would be that included in the booklet, with any additional advice been given by physiotherapists during phase 3.

Patients as gatekeeper to family involvement	*“…I think it’s talking behind their* [patients’] *back if* you [resource deliverers] *contact the family member first…. it must be the patient* [service deliverers contact first]” (CRP 7, acceptability meeting).	Refined pathway to: - Outline CN would ask patients whether they want a referral to the phase 4 support chat (if CN deems appropriate based on individual presentation). - Support chat referral to be made through patients
Interpersonal factors		
Nurturing resource delivery	*“…it’s gotta be someone who can be sympathetic and enthusiastic …you can’t have someone who is shoving you through a door”* (family member 1, development meeting).	- Designed resource delivery to include a one-hour face-to-face consultation with phase 4 CRPs who can talk through the resource and listen to any concerns or worries and provide support.
Promotion of family involvement throughout pathway	*“…the patient is key, but always reiterating your family, bring them along, you need to be involved” (*CRP 1, acceptability meeting).	- CRPs within the family support pathway encouraged to promote bringing family to each consultation - Within the information booklet (pgs. 3 & 5) family attendance at consultations is encouraged.
Organisational factors		
Early involvement, but when is most appropriate?	*“…I think it would be beneficial getting family involved from an early start to motivate them to exercise”* (CRP 1, development phase)…[but] *it is about the timeliness of advice… there’s a danger of throwing too much information at people in the wrong setting”* (CRP 2, development meeting).	- Development of the support pathway - Obtained agreement from participants in the acceptability meeting that having the support chat between CR phases 2 – 3 was an appropriate time to involve family because they can start offering support to patients to engage in PA.

6.3.3.2.2 Resource content

All participants agreed that the information to be contained within the resource was understandable and accurate, so patients and family were able to make sense of the information provided. In addition to being understandable, CRPs highlighted the information to be accurate and transparent also. This was important to ensure patients and family were given a representative picture of CR (i.e. what the pathway looks like and what to expect), but from a risk perspective to ensure any information included within the resource was safe and appropriate for patients (i.e. not to prescribe specific PA that could cause harm).

For patients and family, it was important that the resource included specific information on PA (e.g. why it is important to engage in PA post-MI, detail activities they could try), family support (i.e. support techniques) post-MI, and appeared important to family in particular. Family recalled that following patients' MI they felt unaware of what PA the patient was able to do nor how best to help, and therefore any guidance that could be provided appeared helpful. Patients and family also recalled how, on reflection, it would have been helpful to understand what they could have expected during the course of recovery (i.e. their PA journey), this appeared especially important to help manage expectations and understand that they may not feel themselves or engage in PA in a similar manner as they had pre-MI straight away. It was acknowledged by all participants that every MI patients PA abilities will differ (dependent on factors such as age or other comorbidities). This was illustrated by patients and families who felt the (prescriptive) PA guidance provided in the heart pack given to patients currently (i.e. week 1, rest; week 2, try walking; etc…) can make patients feel disheartened if they are unable to reach certain milestones. However, it was also acknowledged by all participants that it was not possible to include individualised PA advice within a generic booklet, and therefore it appeared important to provide general advice but advocate attendance at consultations where individualised advice could be given. When discussing PA, it appeared important, especially to CRPs, the booklet detailed that engaging in PA can be done through functional activities (i.e. gardening). When discussed further it appeared important to demonstrate that PA could be done at home as well, oppose to a gym setting.

During the acceptability meeting it was discussed by participants to broaden the term “family” to include friends and wider social networks (e.g. carers or social workers). This was to ensure the term family, in the traditional sense (related through blood or marriage), did not exclude patients whom may not have any “family” (e.g. kin) they could rely on. It was also during the acceptability meeting where there was a consensus regarding the utility of the resource for other cardiac populations (i.e. stable angina), although it was agreed that in the first instance the resource needed to be trialled with MI patients and family and in the future consider expanding it.

6.3.3.2.3 Resource delivery

6.3.3.2.3.1 Intrapersonal factors

Ensuring staff were qualified to deliver the resource to patients was an important area of agreement by many phase 3 CRPs and appeared to be because of the risks associated with PA post-MI if incorrect advice is given. During the acceptability meeting, it became apparent that MI patients acted as the gatekeeper to family involvement. This was to ensure they were kept central considering the MI had happened to them and therefore was important they invited family into their care.

6.3.3.2.3.2 Interpersonal factors

Participants, especially patients and family, felt having someone sit and talk through the resource in a kind and compassionate manner was important, as was taking the time to walk through the information so it could be digested and understood. For this to be achieved, CRPs working within phase 4 proposed delivering the resource to family members through a one-hour support chat between patients’ visit from the CN and before starting phase 3. This being beneficial in two ways, firstly to integrate themselves into the service earlier, but also as a means to open up opportunities to encourage family members to be active also, by offering them PA sessions run by phase 4. To help encourage family involvement, it was deemed important by participants, especially CRPs, that family were encouraged throughout the CR pathway to be involved (e.g. through presence at different consultations (CN home visit, physiotherapist appointment) and saw themselves in that process (i.e. when communicating with patients encourage them to have family present).

6.3.3.2.3.3 Organisational factors

During the development meetings, all participants agreed that early resource delivery was important, but were unsure of what time point was best given the volume of information patients typically receive in the subsequent weeks post-MI. During the acceptability meeting, participants agreed the point of delivery specified within the support pathway (between CR phases 2 – 3) was an acceptable time to involve families as it allowed them to begin supporting the patients to become physically active.

6.3.3.3 Factors for further consideration

6.3.3.3.1 Resource format

For patients and family members, it appeared important that the resource developed was tangible in format (i.e. a physical document) and was important given that other formats (e.g. something accessed via a computer) may not be suitable given not everyone may not be able to access the internet. However, it was discussed by CRPs that although they understood why a tangible resource was optimal, they also had to consider practical restraints (i.e. lack of funding to print resources). Thus, although an information booklet was produced for the purpose of the PhD (and so it could be reviewed), it was discussed that further consideration would be needed to establish whether this would be accessed online or as a hard copy in the future.

6.3.3.3.2 Resource content

Within the acceptability meeting there was debate regarding the PA journey as outlined on page 4 of the resource. Cardiac rehabilitation practitioners expressed concern over whether the PA journey could be interpreted as negative (i.e. the journey states patients may come to accept their new level of PA, oppose to attaining similar levels of PA they may have had pre-MI), especially given that some MI patients can attain the same if not better PA levels. On the other hand, patients felt that the journey should be left as stated (i.e. restriction and frustration, adaption and acceptance) because they recalled how they did not get the same level of PA back and felt it was important to be transparent. It was however highlighted by the primary researcher and supervisor that the journey presented within the information booklet was based on data collected from MI patients and their family (study 1), and therefore represented the experiences of the families involved in this study. It was decided however, that this point needed further debate and discussion amongst all participants to reach a consensus.

Table 6.5 Factors requiring further consideration amongst participants relating to resource format, content and delivery with illustrative quotes

Factors requiring further consideration	Illustrative quote
Resource format	
Tangible resource	Developing a tangible resource *“…you want something with physical pages, something you can flick through”* (patient 1, development meeting). Counter opinion *“…what’s worth thinking about is recently the heart pack* [resource given out to patients to by CN on home visit] *has recently gone online…we don’t have the funding to print”* (CRP 1, acceptability meeting).
Resource content	
Framing of PA journey	Framing PA journey in a positive light *“I think at the beginning someone is so shocked they’ve had a heart attack…if someone were to say at that point ‘you’re never going to be able to do what you were doing before’…that would be a real ‘well you know what, I’ll give up now’…and some people do get a really good level of fitness back”* (CRP 4, acceptability meeting). Counter opinion *“…nobody ever said to me you’re not going to be as fit as you were before, and I’m not sure I wanted anyone to say that because I would think ‘yes, I’m going to get well’ and I worked really hard to get well…* [but] *you won’t* [get back to how you were] *and that’s what upset me ….and I’ve only just realised this you see this last 6 months”* (Patient 1, acceptability meeting).
Resource delivery	
Staffing capacity	Capacity as barrier to resource delivery *“I do think* [our staff delivering] *this resource is a really good idea and I do support it but we do have to think about capacity… ”* (CRP 8, acceptability meeting). *“A number of times we’ve looked at potential new ideas and then been worried about capacity and when it came down to it capacity didn’t become a problem because then we’ve not had as many people come through that system as we thought”* (CRP 8, acceptability meeting).

Who calls who to make initial support chat consultation	Activity referral scheme instructors to call patients *".. a phone call can be a good thing sometimes and the team contacting the patient…that goes a long way sometimes"* (patient 2, acceptability meeting). Counter opinion "[phase 4 currently operates through patient calling the service to book an appointment]…*I think it's worth further discussion because in some of our other programmes where, particularly working with vulnerable adults, we do it the other way around* [where we phone the patient to arrange a consultation]…*again, it's not a definite, it's a 'we can talk about it'"* (CRP 8, acceptability meeting).
How should support chats be delivered? Individual vs group consultations	Advantages of having group "support chats" "[having group support chats] *well it would provide a safe for you [patients] to see other people they would be active with so there's it's advantageous in that sense"* (CRP 8, acceptability meeting). Counter opinion *"…well I was just thinking whether it would be personal to yourself* [having group support sessions] but *not everyone would like that…I would have to think about that, it would depend on the person"* (patient 1, acceptability meeting).

6.3.3.3.3 Resource delivery

Another point of consideration was staffing capacity in regard to phase 4 whom had been proposed to deliver the resource. Although the organisation supported the idea of delivery, concern was raised over staffing capacity. However, it was also recognised that capacity should not be an issue in holding back something that has the potential to make a meaningful impact within society, and thus was discussed as a factor requiring further consideration. However, to help minimise issues associated with capacity suggestions were made to hold group support chats with multiple family members (and patients if they wished to join) oppose to individual ones. However, concerns relating to losing the individual nature of the chat and disclosure (i.e. individuals' ability to express worries they may have) were raised.

A further point of consideration was to establish who calls who to arrange the initial support chat consultation. Cardiac rehabilitation practitioners felt it should be patients' responsibility given that it shows a motivation to attend the chat and fits in with the existing approach adopted by phase 4 CRPs. However, there was concern that this approach could potentially limit the scope of how many people accessed the service, therefore there was an argument for service deliverers to call up patients whom at the very least could have a small chat with patients to understand what may be preventing them from attending the support chat. In addition, patients preferred someone calling them, given they felt a call can sometimes go a long way.

6.4 Discussion

6.4.1 Findings overview

The aim of this study was to co-produce a PA based support resource for family members of post-MI patients with CRPs, post-MI patients and their family members. From the qualitative data collected, an information booklet and support pathway were developed. The purpose of the support pathway was to demonstrate how the information booklet could be delivered in practice, whereas the purpose of the information booklet was to make family feel part of the CR pathway and provide them with support and guidance to help them promote PA engagement in post-MI patients. During the development and acceptability meetings a number of key factors determined the format, content and delivery of the information booklet. There was shared agreement on factors relating to resource format (user-friendly and low burden); content (provide PA/support information, accurate, understandable and transparent information, importance of functional activity, making individualised PA element clear, broad definition of "family", and applicability of resource to other cardiac populations); and delivery (ensuring staff are qualified to delivery, nurturing delivery, patients as gatekeepers, promotion of family throughout pathway and early involvement). Factors for further consideration related to resource format (tangible resource) content (framing of PA journey) and resource delivery (staffing capacity, who call**s** who to make initial support chat consultation and delivery of support chats).

6.4.2 Synthesis of findings with wider literature

Evidence suggests families' response to illness may affect patients' wellbeing and ultimately, recovery from the cardiac event (Beach et al, 1992). Therefore, it may prove sensical that developing a PA support resource for family members of post-MI patients appeared widely accepted and something viewed as having utility and value within practice. Although patients' social networks are highly regarded in the recovery process in the capacity of support provision (NICE, 2013, BACPR, 2017), there appears to be a lack of clarity and specific guidance on how this is best achieved in practice. The information booklet and support pathway co-produced as part of this study presented a possible mechanism through which the family may become more involved in patients' CR journey. In addition, as the information booklet and support pathway were developed with service users, their experiences are captured within the content and thus may be relatable to other post-MI patients and their families.

Patients, family members and CRPs passion for the resource may have also been reflected in their engagement through the co-production process. Adopting a sense of ownership during the co-production process has been offered as an explanation for good retention (Leask et al, 2017). A sense of ownership has been associated with knowledge production (Cook et al, 2012) evident in this study through participants' willingness to share their thoughts, ideas, opinions and experiences, during the intervention development and acceptability phases. Given the participants within this research were those with a lived experience of CR services, it is perhaps unsurprising they had an active interest in the development of such a resource. However, given their interest and willingness to engage, it suggests the utility of involving end-users in service design/delivery.

Although it was agreed amongst participants the information booklet had utility, issues relating to capacity to deliver the information booklet were factors requiring further consideration, especially amongst phase 4 CRPS (those who would be responsible to deliver the information booklet in practice). Capacity has been cited elsewhere as a barrier to the implementation of interventions within healthcare settings (Dodson, Baker and Brownson, 2010, Geerligs et al, 2018). However, within this study, despite capacity concerns, it was also recognised that capacity should not be a barrier that prevents something that has potential to have a meaningful impact upon service users. Acknowledging issues related to capacity when designing interventions is of utmost importance to ensure sustainability.

It is worthwhile acknowledging a number of disagreements were evident amongst participants through the co-production process (e.g. framing of PA journey, how support chats should be delivered). Disagreements within a co-production process have been widely acknowledged (Batalden et al, 2016) and may sometimes be a result of power imbalances. Having meetings where all participants were present appeared positive, providing a space to discuss conflicts and concerns with the hope of resolution. Creating spaces where individuals can share their views in an honest and open way has been promoted (Buckley et al, with editors), given it may help in the facilitation of identifying and overcoming problems in a proactive manner (Buckley et al, with editors).

All participants felt it was important that someone took the time to sit down and talk through the resource with family members (and patients) so they could make sense of the information, ask questions and discuss any worries or concerns, and in addition, noted deliverer qualities such as being kind and empathetic as important. Within a healthcare setting, empathy has been shown to build stronger patient/practitioner relationships positively impacting upon patient outcomes and satisfaction (Derksen et al, 2013). In addition, further evidence has demonstrated that as well as showing empathy and care, when practitioners take the time to sit down and listen to patient concerns, this can also result in an increased likelihood of engagement in healthy behaviours (Birtwistle et al, 2018). Phase 4 practitioners had spoken of resource delivery as a means to involve themselves within the CR process at an earlier stage and therefore potentially promoting better uptake to their service. When exploring organisational factors to influencing successful service collaboration, evidence suggests that when health services work together there is a greater benefit to population health (Valaitis, et al, 2018) through combined efforts of health promotion and the provision of support environments to carry out such behaviours (Van Avendork et al, 2012). Whereas, disjointed services have been shown to negatively impact upon the uptake of health initiatives (Birtwistle et al, 2018) through a lack of awareness of suitable programmes. Therefore, if transitions between CR phases can be improved (through involving phase 4 staff whilst patients undergo phase 3), this has the potential to have benefits for patient health and wellbeing.

Factors found to be important in resource development included ensuring it was user friendly, presented in lay language, provided relevant information and delivered in a kind, compassionate and empathetic manner. Within a health context, supportive communication styles have been associated with successful engagement in PA settings (Ntoumanis et al, 2017). However, given theemphasis on verbal communication, it is worth recognising that before this resource is implemented in practice, providing training workshops with individuals responsible for delivery may be worthwhile. This may help ensure their understanding of the resource, but also enhance their confidence to deliver it also.

One of the discussions that arose during the study was the use of terms and language, in particular the use of the word ‘family’. For participants this was not deemed inclusive given that some MI patients may not have what is deemed to be a ‘traditional’ family. Therefore, to aid inclusivity, the decision was made to refine the terminology to incorporate friends and support networks. Although recognising the need to broaden the term “family” to include wider social networks, it is worth recognising that the evidence on which the final resource was grounded within patients’ formal family networks (spouses/children). Therefore, it is worthwhile being mindful that the findings may have differed if wider social networks had been involved and is therefore worthy of further investigation to be able to make claims as to whether wider social networks have a similar impact.

6.4.3 Strengths and limitations

A main strength of this study lies in the co-production method adopted. Such an approach has been praised for its ability to involve end-users in intervention development and by listening to their lived experience can help enhance intervention effectiveness and sustainability (Wilton et al 2016), but also authenticity and richness that may have otherwise been lost if another approach adopted.

There were however some limitations of the study. Although the study involved representatives from CR phases 2 – 4, not all CR staff working within these phases in the CR service of study were involved, there was also a small number of patients and family members. Given participants' enthusiasm for study participation (as discussed in section 6.4.2), it is possible they present a biased view because of their interest in promoting PA engagement post-MI. Further to this, it is worth recognising that not all those involved during the CR pathway (i.e. phase 1 cardiac consultants whom are responsible for the provision of medical interventions (e.g. stents)), were invited, and consequently were not involved in the co-production study. Although the rationale to not include this group was because of their lack of interaction with the family, it does not discount that they may have been able to provide an additional perspective during the co-production process. Although qualitative research is not concerned with numbers, but rather individuals' lived experiences (Strauss and Corbin, 1999), it is worth recognising that if additional participants had been involved during the study, alternative perspectives could have been offered and consequently the findings may have looked different. Finally, it is also worth recognising that this study only comprised of one set of development meetings and one acceptability meeting. In their co-production study, Buckley and colleagues (2018), outline multiple stages of the co-production process, including obtaining further feedback on refined resource and discussions regarding intervention evaluation. The data collected as part of this current co-production study has laid the foundation for further ongoing development with a view to piloting and evaluating the resource in practice. However, before this is achieved further meetings are required to reach a consensus on points of further consideration.

6.4.4 Conclusion and recommendations

This study provided insight into the co-production of a support pathway and PA support resource for family members of MI patients, which has the potential to be used in practice to help promote PA post-MI. Co-production appeared to be an acceptable approach to intervention development within the context of cardiac care. However, despite the information booklet appearing to be widely accepted by the participants involved in the research, co-producing a resource is only part-way there, and it is also important to consider how this might be delivered in practice and align to existing service provision. Given, the early stages of the co-production process, further work is required to pilot and evaluate the resource in practice before its implementation.

Chapter 7 Synthesis of research findings

7.1 Overview of PhD study findings and synthesis overview

The aim of this PhD was to explore the role of the family in post-MI patients' PA experiences to make recommendations for how they can support positive PA engagement post-MI. To understand this overarching aim, three original qualitative studies (chapters 4, 5 and 6) were carried out by the primary researcher. The aim of this synthesis chapter is to bring together the key findings from each study, discuss the key strengths and limitations of the PhD, provide insight into avenues for potential future research, considerations for both policy and practice, researcher reflections on the research process, and lastly, a concluding statement. Firstly however, an overview of the key findings found throughout each study of the PhD will be provided and can be found in table 7.1 below.

Table 7.1 Overview of PhD study findings

Study and aim/s	Findings

Study 1
Aim 1
Understand the lived experiences of PA post-MI from the perspective of both patients and family members
Aim 2
Understand how perceptions of PA changed over time
	- Post-MI, patients go on a journey of re-discovery, learning how to re-engage with PA and family appear to accompany patients on this journey and influence how it is experienced by them
	- Patients leave 'normality' (being able to do what they want and when) and transition to a 'new normality', where patients are active but within the parameters of their experiences of suffering with the MI
	- The journey is characterised by 3 stages:
	  - 'I can't do what I was doing before'
	  - 'Regulation by family'
	  - 'Finding my way'
	- How patients and family identify with PA appears to influence the PA journey

Study 2 **Aim** Understand CRP views of family involvement in CR through exploring the roles they can adopt in post-MI patients PA experiences	- Cardiac rehabilitation practitioners appeared positive about involving the family within the CR process and that family had an important role to play in patients' post-MI PA experiences

	- Three roles were identified by CRPs as those that the family may adopt to influence post-MI patients PA and included:
	    - Being a second pair of ears
	    - 'Pulling back, pushing forward' – keeping the patient within PA boundaries
	    - Providing social support
	- 'Factors that influence family support' was a fourth theme identified and was said to influence the level and type of support provided by families

Study 3 **Aim** To co-produce a PA-based support resource for families of post-MI patients in collaboration with CRPS, post-MI patients and their family members	- The data collected during the development and acceptability meeting/s led to the development of an information booklet for family members and support pathway demonstrating how to deliver the information booklet in practice - The development of the information booklet and support pathway was based on a number of factors considered important by participants relating to format, content and delivery. - The support pathway developed emerged from findings suggesting in order for the information to work in practice it had to be part of a comprehensive pathway - Points for further consideration were also highlighted requiring further discussion before the piloting and evaluating the information booklet and support pathway in practice. Points for further consideration related to format, content and delivery.

7.2 Synthesis of PhD findings with wider literature

7.2.1 Patients' PA identity

Although this PhD was set within the context of the family, it is important to discuss post-MI patients in their individual entity. As found in study 1 patients whom saw themselves as active prior to having their MI showed an interest and desire to be active post-MI, whereas the inactive patient showed no desire to increase his activity levels following his MI.

Literature suggests that identity can play a role in individuals' PA decisions (Rhodes, Kaushal and Quinlan, 2016, Stevens et al, 2017). However, what the findings from this PhD have also told us is how identity may also act as a strong indicator to how patients choose to engage in PA post-MI, and how this may not always be positive. This may particularly be the case for older adults who have a strong sense of identity. This can be demonstrated by the inactive patient within study 1 whom was 79 and throughout the interviews continually stated that he "*wanted to die happy, not healthy".* Within the literature, 'identity and the self' have been reported to act as a barrier to PA uptake (Allendar, Cowburn and Foster, 2006) this being similar in CR settings also (Clark et al, 2012a, 2013). Possible explanations for this could be unhealthy behaviours that have been repeated over a lifetime are likely to have become embedded and form part of individuals' daily routines (Kelly and Barker, 2016), especially when they reach older age (Newsom et al, 2012). This, in turn, makes it difficult for individuals to make lifestyle changes, regardless of whether there is an imminent threat to health. From a Public Health perspective this is quite concerning, given the wealth of evidence suggesting the negative impacts of physical inactivity on health and wellbeing, as well as wider societal benefits such as implications to health services through increased risk of co-morbidities (Scarborough et al, 2011b) and society through loss of productivity due to premature mortality (Carter, Schofield and Shrestha, 2019). Thus, despite evidence suggesting that a diagnosis of a chronic health condition can act as a 'wake-up' for individuals to engage in lifestyle changes (Ades, 2001, McBride, Emmons and Lipkus, 2003, Schneider et al, 2014, Xiang, 2016) findings from this PhD suggest that this notion is incongruent with patients whom perceive themselves as inactive. Especially those who may be older in age where health and happiness do not go hand in hand. However, what was ironic in this patient's case was that he did seem to be active. Thus, in the future, for individuals whom may be in similar situations, it may be more about exploring ways of educating patients on what being healthy is and what PA is, which in turn may encourage them to do more of what they enjoy (i.e. in study 1 this included building fences/ponds). Given that happiness in older age is health protective (Chei, Lee and Malhotra, 2018), exploring routes to promote activities that create both enjoyment and are beneficial to health are worthwhile.

In isolation, these findings highlight the importance of early intervention to understand how patients perceive themselves in relation to PA and supports NICE (2013) guidance suggesting the importance of establishing patient health beliefs and illness perceptions before offering lifestyle advice. It is noteworthy however that focusing on the patients does not distract from the utility of the family in helping promote positive engagement in health behaviours (e.g. PA), but rather recognising that patients are active agents in their desire to engage in activity also.

7.2.2 Families' PA identity

As noted in sections 4.3.2.1 and 4.3.2.2 families' PA identities appeared aligned (i.e. family members of active patients saw themselves as being active also, whereas the family member of the inactive patient saw herself as being inactive also), with such findings supporting the premise of concordant health behaviours amongst families (Cobb et al, 2016). However, what is of worthy consideration is how CRPs during study 2 discussed how families own health beliefs (e.g. PA), had the potential to impact upon the type and level of PA offered to patients post-MI.

Within the literature, social support fits within the interpersonal sphere (Bronfenbrenner, 1979) and has been defined as *"the resources provided by another persons"* (Cohen and Syme, 1985). It can be considered a multi-dimensional concept in the different types of support offered (i.e. emotional, informational, tangible and belonging (Uchino, 2004)) and provision (e.g. family, friends, carers). As discussed in section 2.4.2, there is a wealth of evidence focusing upon the outcomes of family support provision on recipients' health (Kärner, Dahlgren and Bergdahl, 2004, Franks et al, 2006). However, little consideration appears to have been given to the health behaviours of support providers of MI patients and how this may impact upon support provision.

What has been learnt through this PhD is that within a MI and PA context, family support appears bound within an intrapersonal sphere also (i.e. family health beliefs) and has the potential to both positively and negatively influence post-MI patients' PA experiences.

Within study 2 it was found that families whom value the importance of, and engaged in PA themselves were more likely to have a positive impact upon encouraging patients to be active following MI. Whereas families who were not active or valued the outcomes of activity for health, were said to be less likely to encourage post-MI patients' PA engagement. These findings were corroborated with findings from study 1, where active families could be seen to support patients PA (in the later stages of their recovery), whereas this was not necessarily the case for the inactive family. When triangulating the findings from studies 1 and 2 it was shown that 'positive' health beliefs impacted upon the provision of offering tangible (e.g. assisting patients to CR classes), emotional (e.g. verbal encouragement) and companionship (e.g. being active together – which may also link with offering informational support given the opportunity to observe and learn) forms of social support. Family supporting patients following MI has been documented within the literature (Astin, Atkin and Darr, 2008, Astin, Horrocks and Closs, 2014), however understanding the role of familial health beliefs and consequent impact upon support provision appears, from the primary researchers knowledge, underexplored, which findings from this PhD suggest is an important area of consideration.

In light of such findings, within study 3, when developing the information booklet and support pathway, efforts were made to consider family health beliefs and their own PA behaviour (e.g. signposting to the phase 4 referral scheme, consideration of families' own PA and information on how being active themselves can help encourage patient PA). This was important given evidence suggesting although family based (in-particular spousal) interventions can be effective in promoting PA engagement (Richards et al, 2018), few have shown longer-term PA maintenance 1 year post-intervention (Burke et al, 2002, Sher et al, 2014), with potential effectiveness being offset by inattention on strategies to promote PA change in family members (Martire, 2005).

Thus, what this PhD contributes to the existing evidence base is that rather families being passive agents of support, it is in fact integral to learn about them and their health beliefs to ensure their health behaviours are aligned to those associated with cardiovascular risk reduction.

7.2.3 The importance of family support in cardiovascular care

One of the take home messages from this PhD is mobilising family in the promotion of PA post-MI is a worthwhile consideration. Findings from studies 1 and 2 demonstrated in what ways family influence post-MI patients' PA. This then led to the development of a potential support pathway for family integration into a pre-existing CR pathway as well as an information booklet for family members, providing information to help them feel supported to support post-MI patients' PA (study 3).

7.2.3.1 Family as mechanism to encourage engagement in PA post-MI

The findings from this PhD highlight the utility of family in positively influencing MI patients' PA through the provision of support (e.g. encouraging PA engagement, taking patients to CR classes, being a second pairs of ears). Given that within a cardiovascular context it is well established that family support can help improve patient health outcomes (Franks et al, 2006, Rosland et al, 2010, Rosland et al, 2012), the findings throughout this PhD provide further evidence of the importance of involving them in patients' care post-MI. However, despite the positive benefits family can have, it is worthwhile noting the negative impact they can have also. Within study 1, family were found to place restrictions on patients' PA, done to prevent a re-occurring MI, as well being unaware of what PA patients were able to do, with the negatives of family support being discussed by CRPs also during study 2. Restrictive and controlling family behaviours are not uncommon (Kärner, Dahlgren and Bergdahl, 2004, Rosland et al, 2012), but as found within this PhD, have the potential to limit patients' engagement in healthy behaviours.

Although guidance written by official cardiac bodies (NICE, 2013, BACPR, 2017) advocate for the involvement of family to support patients' recovery, there is little clarity on how this is best achieved in practice. This has the potential to be dangerous given current literature suggesting families are only superficially involved in cardiac patients' lifestyle changes (Rowland et al, 2019) and therefore potentially unaware of how to positively support PA engagement. This could perhaps explain why all participants involved in study 3 commented on the utility of the developed information booklet to be used in practice, given its ability to provide appropriate and relevant PA information, as well as strategies for family to support patients' engagement in PA.

7.2.3.2 Integrating the family into the CR pathway

To provide an understanding of how family could be integrated within the CR pathway, study 3 of this PhD aimed to co-produce a PA support resource for family members, which resulted in the development of an information booklet and support pathway. The latter detailing how the information booklet could be delivered in practice. Within this study, co-production appeared to be a viable means to ensure the information booklet developed met the needs of CR staff, post-MI patients and family alike. Although developed to support family in areas such as PA knowledge and support (intrapersonal), to help enhance their confidence to provide support to patients (interpersonal), it became evident during the co-production process that to ensure effectiveness in practice organisational elements had to be considered also (i.e. staffing capacity). Thus, suggesting that the integration of family in CR in fact requires a multi-level intervention.

Within the literature, multi-level interventions have been advocated for due to their increased effectiveness when compared to singular-level interventions (Sallis, 2018). They may also be more effective given that health behaviours are themselves complex (Kelly and Barker, 2016) and therefore are perhaps better targeted holistically. For example, throughout this PhD it was found that the provision of proficient and optimal family support (interpersonal) may be dependent upon families own attitudes and beliefs of health and wellness (intrapersonal). However, supporting family's health beliefs was something requiring collaboration from organisations within the CR service (i.e.one-hour support chat where family health beliefs would be considered), and therefore supports the premise that to ensure intervention effectiveness, mobilising multiple levels of the SEM is important (Sallis, 2018).

Although integrating the family in CR is worthwhile, it is also worth recognising the role of the patient within this process. Despite the information booklet being designed for families, it appeared important throughout the co-production process that patients were involved, especially for information booklet delivery (i.e. gatekeepers to family involvement, arrange support chat with patients). This can be linked to study 2, where CRPs discussed patients as being the focal point of care. These findings highlight that although family involvement has many benefits, it should be patients' decision firstly, to whether they would like any involvement at all, and secondly, if they do, they have the decision to whom they wish to be involved and to what extent (Laidsaar-Powell et al, 2013, 2016, Wolff et al, 2017). Thus, although in this PhD the information booklet was 'targeted' at the family (to support them to support patients), the findings suggest the importance of patient involvement in intervention development in the capacity of 'consenting' family in the recovery process.

7.3 Strengths of PhD

This PhD has several strengths which are worthy of further explanation. One of the main strengths lies within the research topic. Although numerous studies had been conducted within the area of family support and CHD, there was a scarcity of research specifically exploring the role of the family in post-MI patients' PA experiences. This PhD has therefore contributed to the evidence base and provided data of how family may influence post-MI patients PA over time, and what roles family can adopt to influence patients' PA. Whilst also co-producing an information booklet and support pathway, providing a realistic overview of how to involve families within a CR setting, which currently appears one of the first studies to do so.

The PhD drew up qualitative methods, which was seen as a strength. As discussed in chapter 3, these types of methods are exploratory and interactive, allowing the researcher to understand phenomena from individuals with lived experience. Using interactive methods allowed the primary researcher to 'enter' individuals' social world, providing the researcher with rich, thorough and meaningful data, and opportunity to make sense of individual experiences and the meaning they attribute to these (Sparkes and Smith, 2014). Being able to interact with participants allowed the primary researcher to build rapport with them which was also strengthened through the multiple interviews with patients and family members within study 1. The opportunity to build rapport increased the likelihood of participants becoming settled and comfortable (Elmir, Schmied and Jackson, 2011), which in turn may have led them to provide more thorough and authentic accounts of their experiences. Providing such authentic, rich and thorough accounts from participants lends itself to having a meaningful impact with practice arguably more so than using more scientific positivist approaches (e.g. surveys). Whilst positivist methods aim to establish trends and frequencies, this approach would not have captured the understanding into why such trends exist and what they mean to the participants experiencing them. Thus, qualitative methods allowed the researcher to capture the essence of participant experiences (Sparkes and Smith, 2014), whilst also capturing the delicacies and complexities that may have otherwise been missed if more scientific methods had been employed. Which in turn helped develop resources that are culturally appropriate and meaningful in practice.

An additional strength of this PhD can be taken from the longitudinal prospective design adopted as part of study 1. Longitudinal designs have long been called for within a healthcare and family context (Rosland et al, 2012) to understand how family support may change over time and the consequent impact this may have upon patient outcomes. Within this PhD, using a longitudinal prospective design allowed the researcher to understand the experiences of PA from the perspective of MI patients and their family as it was happening in real time, and thus gaining insight into the progression of change. This approach also limited the retrospective bias in accounts (Smith and Noble, 2014), as participants were able to recall their current experiences as they were experiencing them.

Another strength of the PhD is the collection of data from multiple stakeholders involved within CR, namely post-MI patients, their family and CRPs. Involving multiple participants within the research process allowed for a 360-degree view of the role of the family in post-MI patients' PA experiences to be obtained. In doing so, illuminating the broader meaning of this process and enabling understanding of its wider mechanisms (Larkin, Shaw and Flowers, 2019).

7.4 Limitations of research

Although multiple strengths have been identified, it is important to consider the limitations of this PhD research also. It is worthwhile recognising that all of the participants involved in this PhD were recruited from the same CR service located within the Northwest of England. Although this was convenient for participant recruitment and data collection purposes, it limited the number of participant accounts received. As discussed in section 2.1.2, CR can differ in both intensity and duration (Dalal, Doherty and Taylor, 2015). Consequently, if participation had been broader and included participants whom had experience (as both service users and staff), within different CR settings, it is possible the findings presented within this PhD may have differed. A high proportion of the patients involved in the research viewed themselves as active. Although this appeared positive concerning their PA engagement, it is worthwhile considering the applicability of the findings to a wider cardiac population. There are further limitations of the sample relating to participant demographics that are of worthy consideration. All participants involved within the PhD were of White British descent. Whilst there was an equal split in terms of gender for patients and family members (table 4.1), a majority of the CRPs involved were female. Therefore, the application of the findings to other ethnic groups, as well as genders must be a point of consideration.

As discussed in section 3.3.1 qualitative data is concerned with the subjective accounts of research subjects (Sparkes and Smith, 2014), and is considered a strength within the qualitative tradition. However, there are a number of challenges associated with the approach. As discussed in section 7.3, conducting qualitative interviews allowed for the researcher and participants to build rapport, which was strengthened during study 1 where the researcher had multiple contacts with the participants, and arguably got to know then quite well. Although this was positive in that it allowed the researcher to understand experiences in depth, social desirability cannot be discounted (Callegaro, 2008). It is possible that because of the rapport built, participants may have felt obliged to shape their answers to appease what they thought the researcher may have wanted to hear, which consequently may have impacted upon the trustworthiness of the data provided (Hutchinson and Wilson, 1992).

Lastly, the qualitative findings displayed within this PhD are from semi-structured interviews and informal meetings with post-MI patients, their family members and CRPs. Although it was recognised during the acceptability meeting in study 3 that the information for family should be extended to include ‘friends and support networks’ also, it is important to consider the application of research findings to these groups, given the family involved during this PhD were related to patients either through marriage or blood.

7.5 Future research

7.5.1 Triangulation of subjective data with other research methods

The findings of this PhD rely solely on the use of qualitative interviews and co-production meetings. As discussed within chapter 3, qualitative research has many strengths, however, also rely solely on subjective data. In study 1, 5/6 patients discussed how during their recovery they were engaging in bouts of PA. Going forward, it may be worthwhile using a combination of research methods to help triangulate participants’ accounts (e.g. accelerometery, observations). This may help spot (in)consistencies within accounts, and further help understand patients PA.

Further to this, it would be worthwhile doing a prospective study with a larger sample of participants to test out the hypotheses generated throughout this PhD (i.e. the PA "journey").

7.5.2 Going beyond "the family"

As mentioned in section 7.4 the family members involved in this study were related to the patient either by marriage (spouse) or through blood (child). To understand whether individuals who are deemed influential in patients care but are not deemed "family" (i.e. are not related in any way), share similar experiences to those expressed by family members in this PhD, it may be worthwhile conducting interviews with these groups also. In addition, to understand the PA experiences of patients who deem themselves to have no support, it may be worthwhile exploring research with these groups to see how they could be best supported.

7.5.3 Understand the effectiveness of the information booklet in practice

The information booklet and support pathway were developed through one set of development meetings and one acceptability meeting. The co-production framework outlined by Buckley and colleagues (2018), proposes multiple stages of the co-production process, with latter stages involving discussions regarding intervention evaluation. Future work could be done to conduct further meetings with the participants involved during study 3 to further refine the resource, with a view for it to be piloted within practice and evaluate whether it supports families to promote PA engagement in post-MI patients.

7.6 Implications for policy and practice

On the basis of the findings presented within this PhD, numerous changes could be made to both policy and practice and will be discussed below:

7.6.1 Policy

7.6.1.1 Designing of CR programmes to meet the needs of patients

Within study 1, some patients openly spoke about not choosing to attend the structured exercise sessions as provided within CR phase 3. For some patients this was because they believed it would be more constructive to do their own PA, whilst for the inactive patient, he decided not to participate because he showed no desire to be active post-MI. As discussed in section 4.3.2.1, ironically however, he was engaging in bouts of PA (which related to doing activities he enjoyed). Offering CR programmes that are perhaps more creative and truly patient centred (Thompson, Ski and Clark, 2019), may be a worthwhile consideration to help ensure that CR is perhaps more impactful and meets the needs of those it intends to serve.

7.6.1.2 <u>Implementing a support pathway for family members</u>

As discussed throughout this thesis, current CR guidance stipulates the importance of patients having a support person(s) who can encourage them to engage in health behaviours, engage, be involved in CR activities whenever possible, whilst also suggesting a focus on their own health behaviours (BACPR, 2017). Findings from this PhD support this premise, however, within current CR guidance little clarification is given on how best to involve them and how best to focus on their health behaviours. It is therefore proposed that establishing a support pathway for family members specifically to integrate them into the CR pathway, so they are able to support patients (as well as being supported themselves) is a worthwhile consideration.

7.6.1.3 <u>Expansion of the eligibility criteria for phase 4 programmes</u>

Phase 4 CR programmes typically occur in community settings with qualified exercise professionals (Bethell, Lewin and Dalal, 2009), and it is not atypical for these services to be provided within an ERS setting. Current eligibility for ERSs is the diagnosis of, or being at risk of developing, a chronic health condition (NICE, 2014), and therefore typically require a referral (to attend phase 4 CR it is integral to have completed phase 3). During study 3 of this PhD, it was suggested that family could be enrolled into appropriate classes offered by the ERS (whom are also responsible for delivering phase 4 CR) as a way of helping the family member/s to be active also. Reviewing current ERS guidance may be worthwhile so families of MI patients can attend these schemes by way of helping promote patients’ engagement in PA. Offering family places on ERSs could have wider benefits to society also. Evidence suggests spouses of patients with chronic illnesses are at an increased risk of disease also (Arden-Close and McGrath, 2017). Although within a spousal context, these findings may be applicable to wider family also, thus involving them in phase 4 programmes may reduce costs to healthcare settings, through lowering risk of morbidity.

7.6.2 Practice

7.6.2.1 Actively inviting family to participate in care

The findings suggested that involving family in patients' care to help promote PA has numerous benefits, although involvement must first be agreed by patients themselves. To help involve family within the CR pathway it may be worthwhile for CRPs to actively encourage them to be present during healthcare consultations. This may be achieved by CRPs first speaking with patients to understand whether they have support persons in their lives, and if so, obtaining consent for their involvement during CR. Patients could then be reminded through communications (either oral or written) they have with CRPs to have someone with them for consultations.

7.6.2.2 Taking time to understand the family

The findings from this PhD suggest the importance of families own health beliefs on the support they may provide. It is therefore worthwhile CRPs spending time with the family to understand them, their identity and how they see themselves in relation to PA. Given that evidence suggests that families (especially couples) show concordance for lifestyle and lifestyle changes (Wood, Roberts and Campbell, 1997, Jackson, Steptoe and Wardle, 2015, Cobb et al, 2016) investing time with the family has the potential to be very worthwhile in PA promotion post-MI.

7.7 Reflections on the research process

This section will reflect on some of the highlights and challenges I faced during the research process and drew on similar principles as outlined by Gibb (1988) in his reflection cycle.

Gibb’s (1988) reflective cycle posits six stages (description, feelings, evaluation, analysis, conclusion and action plan) and is a framework offered to examine experiences. In this case, I used it to help frame and explain the experiences I faced during the PhD, through describing the event, how it made me feel, what I learnt, and what I will take forward from the experience.

As appears to be the case when researchers reflect (Welsh, 2004, Morton, 2009) this section will be written in the first person in the hope of bringing to life some of the critical moments experienced during the research process, what I learnt from these and how I believe they have impacted upon my development as a researcher.

7.7.1 Development of the research topic

The initial research topic arose from my MPhil research, exploring uptake to an ERS in the Northwest of England (the same service responsible for delivering phase 4 CR within this PhD). The findings from this study suggested decisions to take up the ERS were influenced both positively and negatively by the family (Birtwistle et al, 2018), which opened up to further discussion of how the family may influence PA in patients with whom have had a medicalised event. My decision to focus on an MI population stemmed from evidence suggesting MIs are a life changing event (American Heart Association, 2016) and therefore may impact on how patients’ experiences PA afterwards. Given my interest in good health for all, and consequently an understanding of how to promote health and wellness for all groups within society, the development of this study aligned to my own interests and values.

Designing a research project which captured my personal interests was a considered a strength within this study. I believe it provided me with an inherent enjoyment and natural curiosity throughout the research process, with a desire to really understand post-MI patients’ PA experiences within a family context. It also lent itself to my interpretivist views, allowing me to further understand and develop my knowledge within the research area through in-depth discussion of participant experience.

However, it was through my own interest in the research topic and investment within the PhD that allowed me to build skills in learning the importance of being critically aware of myself as a researcher. Such skills have helped me understand the importance of establishing my professional boundaries and appreciating the potential impact I could have during the research process, skills I will take forward for future qualitative work.

7.7.2 The interview process

7.7.2.1 Adopting roles other than researcher

Although as discussed throughout section 3.4, there are multiple benefits to conducting joint interviews. As seen in study 1 many patients and family members choose to be interviewed together. On several occasions during the interviews, there appeared times they were used to resolve conflicts between families or air thoughts and feelings that had not been discussed. This can be demonstrated through one encounter I had with one family. During an early interview we were discussing family support, the patient recalled how she felt her husband was not being very supportive of her PA wishes through what she described as being ‘mothered’. This allowed her husband to see how his actions of what he perceived as being caring, was interpreted by his wife, and gave him an opportunity to provide a rationale for his actions (i.e. worried about her having a re-occurring MI, wanting to protect her from harm). At the time this made me feel awkward, firstly, I worried about asking questions that could potentially cause conflict and upset, and secondly, this open communication sometimes acted as a therapy session, for which I did not feel qualified to be giving. Although challenging for myself, I believed this encounter was beneficial to this couple (and other families), because it allowed them the opportunity to discuss thoughts and feelings encountered during the recovery process, which without my facilitation, may not have happened. Over time, I came to learn that these encounters were frequent and perhaps ‘normal’, given the sensitive nature of discussion. I learnt the importance of allowing participants to talk amongst themselves and make sense of what had and was continuing to happen to them, aligning to my own interpretivist views. I also learnt that these situations may be quite cathartic for families (Elmir et al, 2011), helping them reflect on their situation, and help them gain closure. These situations also helped me establish my professional boundaries, learning the importance of providing empathy as opposed to advice. I believe that although on occasion I found conducting dual interviews challenging, it has built my skills in facilitating small groups where participants have meaningful relationships, manage difficult situations and accept that it is okay to ask questions. Despite challenges, I believe this is also a valuable method of collecting data given the honesty that arose.

7.7.2.2 Being asked for my own opinion

Due to the nature of this PhD, I interviewed many of the same participants on multiple occasions (i.e. some participants from study 1 (who took part in repeat interviews) were involved in study 3 also, and a number of CRPs involved in study 2 were involved in study 3 also). Although this was positive as it allowed me to build rapport and get to know participants, it did not come without challenges. Whilst conducting interviews, participants would ask me what I thought of their response to questions asked. For example, during a discussion where a patient was talking about her experiences with clinical staff (which had not been very positive), she asked whether if I were in the same situation, would I feel the same way. I found this challenging for a number of reasons. Firstly, I felt she was looking for validation that she had the right to feel the way she did. Secondly although I could show empathy, as within the IPA tradition, I could not directly access her experiences, only try and make sense of her making sense of them (Smith, Flowers and Larkin, 2009). For me, these situations required careful management, I wanted to maintain rapport with participants but also honesty. Aligned to my own philosophical beliefs, I was aware how I responded may change the direction of the conversation and alter the interview dynamic. I learnt that during these situations it was okay to be honest and forgo the need to agree with all participants said (i.e. I understand why you must have felt that way, but I am unable to comment on how I would react in that situation because I have not experienced it). It also opened my eyes further to the vulnerabilities faced by qualitative researchers (e.g. blurring the line between being a researcher and participants' acquaintance/friend), but also seeing this as a strength, not weakness in so far as participants seeing you as someone to share such experiences with.

7.7.2.3 Managing worrisome situations

For me, conducting repeat interviews (study 1) was a strength of this PhD. It allowed me to collect rich and in-depth data, as well as building meaningful relationships. However, it is worth noting how this also encapsulated numerous concerns. During one particular interview, a patient recalled how she felt it necessary, because she had the MI, to cut out certain food groups from her diet. I remember feeling both worried and concerned, especially given that the patient in question was very frail. Given that this was the first interview I had with this patient I discussed this concern with my primary supervisor and how I was best to move forward. Luckily, on my next visit, the patients' family had intervened, and she seemed better. I learnt through this process to be more aware when interviewing (especially topics that are quite personal and health-related), that not all experiences are going to be positive and that is okay, and it is okay to confide in others and ask for advice on how best to move forward and manage the situation.

7.3.3 Challenging personal assumptions

One of the key things that I have learnt throughout this PhD process is the importance of challenging personal assumptions. Before embarking on this PhD, I had ideas of what an MI patient may look like (overweight, inactive, smoker and drinker), whom may lack the motivation to make lifestyle changes. It was through meeting the MI patients in this study and listening to their personal PA accounts with helped me change this perception. On the first meeting with the first patient I interviewed I recall knocking on this front door and opening the door this slight looking man. During the interview I recall frequent discussions pertaining to his active identity and remember thinking how he did not fit the perceived, and perhaps naïve stereotype I had. My assumptions were further challenged upon meeting the other MI patients within study 1. Even the inactive patient looked relatively well. It is through this PhD I have learnt the importance of ‘not judging a book by its cover’ and that although within society we can reduce the chances of having MI (through engagement in healthy behaviours), it does not diminish the absolute possibility it could happen, and therefore highlighted the importance of being open-minded.

7.8 Conclusion

The aim of this PhD was to explore the role of the family in post-MI patients’ PA experiences and to make recommendations for how they can support positive PA engagement post-MI. As such, this PhD demonstrated that families influence post-MI patients’ PA engagement, and this can be both positive and negative, with the type and level of support offered by families appearing influenced by their own health beliefs. To ensure optimal family support, understanding families’ health beliefs and educating them on the roles they can adopt to positively promote PA in post-MI patients are of is important. The PhD highlighted that one pathway this could be achieved is integrating family into the current CR pathway, as their current involvement appeared moreso to occur as a matter of chance. Consequently, to both integrate families into CR, and to help ensure they provide optimal support, a key output of this PhD was a draft family information booklet and support pathway that were evidenced based and deemed feasible in practice. To understand whether integrating the family into CR and offering support to family positively impacts upon post-MI patients PA engagement, further work could be done to pilot and evaluate how the support pathway and information booklet work with practice.

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Appendices

Appendix 1

Patient interview guides

Introduction

The interview will last approximately one hour and will address the following areas, your heart attack, cardiac rehab, physical activity and your family's response to your heart attack. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

**Give definition of physical activity*

"any movement made by your body where your heart rate feels raised, for example this could brisk walking"

To begin with, could you talk me through what happened with your heart attack?

***Prompts/probes**

- Feelings (before/during/now)
- Impact on self

1. Has someone discussed the cardiac rehab programme with you?

   ***Prompts/probes**

   - How was programme introduced
   - Awareness of doing exercise as part of treatment

2. At this point in time, are you intending on attending cardiac rehab?

   ***Prompts/probes**

   YES
   ↓
   - Thoughts/feelings about PA

   NO
   ↓
   - What are your reasons?
   ↓
   - Future PA intention

3. Please could you talk me through what your physical behaviours were like before you had your heart attack?

   ***Define physical activity**

   ***Prompts/probes**

   - Feelings/experiences about PA
   - PA & family (PA behaviours of family & is it something you've done together)

4. Please could you tell me how you feel about your ability to take part in physical activity following your heart attack?

   ***Prompts/probes**

  - Thoughts/feelings about ability
  - Provision of information about condition and PA
    - Satisfaction of information received

5. Can you tell me how your family have responded to your heart attack diagnosis?
   ***Prompts/probes**
   - How supportive do you feel your family are of you engaging in CR/activity around home?
   - Anything family do to encourage PA participation
     - How have encouragements been communicated?
   - Expressed concerns about PA
     - what concerns
     - how were they expressed
   - Influence PA participation

6. (If applicable) Finally, have you had any thoughts about your physical activity behaviour in the long-term (i.e. beyond cardiac rehab)?
   ***Prompts/probes**
   - Motivations to engage with PA
   - Daily lifestyle activity (house work/brisk walk)

*Prompts/Probes are there to be used as a guide for the interviewer. They are key words/phases to help the researcher ask questions and elicit responses from the participant. Prompting questions will be used in a conversational manner and only when deemed appropriate.

Patient interview 2

In order to collection in-depth data that is specific to each participant and their family, parts of interview 2 will be informed by the responses given during the first interview. Although some pre-determined probes/prompts will be used to elicit responses from participants (if necessary), some will also be formed through the experiences described by participants. As it is not known what participants will yet discuss this interview guide is broad and will be tailored accordingly prior to the interview.

Introduction

The interview will last approximately 1 hour and will address the following areas, what has happened in your life over the past couple of months, cardiac rehab, physical activity and family support. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

****Give definition of physical activity***

1. Please could you talk me through what has happened since our last interview?
   ***Prompts/probes**
   - Feeling self/family (during/now)
   - Noticeable changes to your lifestyle (feelings/influences)
   - Events

2. Did you attend cardiac rehab?

***Prompts/probes**

YES (completed)

↓

- Thoughts/experience of consultation
- Thoughts/feelings about PA
- Motivations to attend

YES (adhered)

↓

- Thoughts/experience of consultation
- Reasons for not completing

NO (*DNA)

↓

- Attend consultation?
    - Thoughts/experiences /why not attend?
- Reasons for not attending

3. Can you describe what your current physical activity behaviour is like?

   ****Define physical activity***

   ***Prompts/probes**

   - Engaging in PA?

   YES

   ↓

   - Type of PA
   - Feelings/thoughts
   - Motivation
   - Challenges to being as physically active as you'd like to have been?
   - Attended phase 4?

   NO

   ↓

   - What are your reasons?

   ↓

   - Future PA intentions

4. Can you discuss how your family have responded to your relationship with physical activity?

   ***Prompts/probes**

   - How supportive do you feel your family are of you engaging in PA/activity around the home?
   - Anything family have done/do to encourage your PA participation
   - Influence of family on PA
   - Concerns about PA participation

5. (If applicable) Can you discuss what your future intentions are regarding physical activity?

   ***Prompts/probes**

   - Motivations to engage with PA
   - Goals?
   - Daily lifestyle activity (house work)

*Prompts/Probes are there to be used as a guide for the interviewer. They are key words/phases to help the researcher ask questions and elicit responses from the participant. Prompting questions will be used in a conversational manner and only when deemed appropriate.

*DNA = Did not attend cardiac rehab

Patient interview 3

In order to collection in-depth data that is specific to each participant and their family, parts of interview 3 will be informed by the responses given during the first 2 interviews. Although some pre-determined probes/prompts will be used to elicit responses from participants (if necessary), some will also be formed through the experiences described by participants. As it is not known what participants will yet discuss this interview guide is broad and will be tailored accordingly prior to the interview.

Introduction

The interview will last approximately 1 hour and will address the following areas, what has happened in your life over the past couple of months, physical activity and family support. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

Give definition of physical activity

1. Please could you talk me through what has happened since our last interview?
   ***Prompts/probes**
   - Feelings self/family (during/now)
   - Noticeable changes to routine (influences)
   - Events

2. Please can you describe your current physical activity?
   Define physical activity
   ***Prompts/probes**
   - Currently physically active?

YES

↓

- What PA
- Thoughts/feelings about PA
- Motivations to engage
- Challenges to being as physically active as you'd like to have been?

NO

↓

- Reasons why not physically active

↓

- Future PA intentions

3. Can you discuss how your family have responded to your relationship with physical activity?
   ***Prompts/probes**
   - Support/encouragement (behaviours)
   - Concerns about PA participation
   - Family influence on PA participation

4. (If applicable) Can you discuss what your future intentions are regarding physical activity?
   ***Prompts/probes**
   - Motivations to engage with PA
   - Daily lifestyle activity (house work)
   - Sustainability of PA

        - How?
        - What?
        - Why?

5. Looking back now, what effect do you feel having the heart attack has had on your physical activity?
   ***Prompts/probes**
   - Have you learnt anything?
   - Comparisons (then/now)

6. Finally, the purpose of this PhD is to understand how the family can help support heart attack patients' physical activity. So, do you have any ideas about what would be helpful to support physical activity engagement following patients' MI?
   ***Prompts/probes**
   - Support based?
   - Any that would work/wouldn't?
     - Why?
   - How would it work?
   - What would it look like?

*Prompts/Probes are there to be used as a guide for the interviewer. They are key words/phases to help the researcher ask questions and elicit responses from the participant. Prompting questions will be used in a conversational manner and only when deemed appropriate

Appendix 2
Family interview guides

Introduction
The interview will last approximately 1 hour and will address the following areas, the time since [patient] heart attack, the cardiac rehab programme and physical activity. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

***Give definition of physical activity**

"any movement made by your body where your heart rate feels raised, for example this could brisk walking or gardening".

1. To begin with, could you talk me through what has happened with you since [patient]'s heart attack?
   ***Prompts/probes**
   - Feelings patient/self (before/during/now)
   - Impact of diagnosis on patient/self

2. Has someone discussed the cardiac rehab programme with [patient]?
   ***Prompts/probes**
   - Anyone discussed CR with you (and how you might play a role)?
   - Knowledge of programme
   - Provision of information (patients diagnosis/CR)

3. At this point in time, do you know about [patient]'s intentions to attend cardiac rehab?
   ***Prompts/probes**
   - Thoughts and feelings about patient's PA engagement (condition, ability)

4. Could you tell me about [patient]'s physical activity behaviour before they had their heart attack?
   ***Define physical activity**
   ***Prompts/probes**
   - Experience/feelings/habits PA

5. Please could you talk me through what your own physical activity is like?
   ***Prompts/probes**
   - Thoughts/feelings/experiences with PA

6. Please can you tell me how you feel about [patient]'s ability to take part in physical activity following their heart attack?
   ***Prompts/probes**
   - Thoughts feelings about ability (patient's PA behaviour before MI, amount family member feels they should/can do)
   - Support PA engagement
     - supportive/encouraging behaviours (discussion – approach/response/influence)
     - anything preventing being supportive
   - Concerns/worries

        - discussion with family member (approach/response/influence)

7. Have you or [patient] had any thoughts at this stage about their long-term physical activity (i.e. beyond cardiac rehab)?
   ***Prompts/probes**
    - Feelings/thoughts about PA engagement

*Prompts/Probes are there to be used as a guide for the interviewer. They are key words/phases to help the researcher ask questions and elicit responses from the participant. Prompting questions will be used in a conversational manner and only when deemed appropriate.

Family Interview guide 2

In order to collection in-depth data that is specific to each participant and their family, parts of interview 2 will be informed by the responses given during the first interview. Although some pre-determined probes/prompts will be used to elicit responses from participants (if necessary), some will also be formed through the experiences described by participants. As it is not known what participants will yet discuss this interview guide is broad and will be tailored accordingly prior to the interview.

Introduction

The interview will last approximately 1 hour and will address the following areas, the time since [patient]'s heart attack, the cardiac rehab programme and your feelings and thoughts towards your and [patient]'s physical activity. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

****Give definition of physical activity***

1. To begin with, could you talk what has happened in your life since our last interview?
   ***Prompts/probes**
    - Feelings patient/self (during/now)
    - Events

2. Can you describe what [patient]'s physical activity has been like since our last interview?
   ***Prompts/probes**
    - Thoughts/feelings about PA
    - Motivations
    - Changes past/present (what has influenced change)
    - Your own activities?
    - Support offered?

3. Can you discuss how [patient] got on at the cardiac rehab programme?
   ***Prompts/probes**
    - Thoughts/feeling about patients PA participation (during/now)
    - Patients current PA behaviour (thoughts/feelings)
        - Ability (health condition)
        - Concerns
        - Gone onto phase 4?
        - Future PA

*Prompts/Probes are there to be used as a guide for the interviewer. They are key words/phases to help the researcher ask questions and elicit responses from the participant. Prompting questions will be used in a conversational manner and only when deemed appropriate.

Family Interview guide 3

In order to collection in-depth data that is specific to each participant and their family, parts of interview 3 will be informed by the responses given during the first 2 interviews. Although some pre-determined probes/prompts will be used to elicit responses from participants (if necessary), some will also be formed through the experiences described by participants. As it is not known what participants will yet discuss this interview guide is broad and will be tailored accordingly prior to the interview.

Introduction

The interview will last approximately 1 hour and will address the following areas, what has happened in your life since our last interview and physical activity. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

****Give definition of physical activity***

1. To begin with, could you talk what has happened in your life since our last interview?

   ***Prompts/probes**
   - Feelings patient/self (during/now)
   - Noticeable changes in routine from then/now (what changes/influences)
   - Events

2. Please could you talk me through [patient]'s physical activity since our last interview?

   ****Define physical activity***

   ***Prompts/probes**
   - What activities?
     - Changes over last 9 months then/now (feelings/influences)
     - Anything preventing PA (influences on patient)
     - Your own activities?

3. Can you tell me how you feel about [patient]'s current physical activity?

   ***Prompts/probes**
   - Patients current PA behaviour (thoughts/feelings)
     - Ability (health condition)
     - Concerns

4. Please could you discuss how you feel about [insert name of patient] future physical activity intentions?

   ***Prompts/probes**
   - Feelings/thoughts about PA engagement

5. Finally, looking back now, what effects do you feel that [insert name of patient] heart attack has had on both your physical activity?

   ***Prompts/probes**
   - Feelings/thoughts
   - Have you learnt anything?

    - Comparisons (then/now)

6. Finally, the purpose of this PhD is to understand how the family can help support heart attack patients' physical activity. So, do you have any ideas about what would be helpful to support physical activity engagement following patients' MI?

   ***Prompts/probes**

    - Support based?
    - Any that would work/wouldn't?
        - Why?
    - How would it work?
    - What would it look like?

*Prompts/Probes are there to be used as a guide for the interviewer. They are key words/phases to help the researcher ask questions and elicit responses from the participant. Prompting questions will be used in a conversational manner and only when deemed appropriate.

Appendix 3
CRP interview guides

Introduction

The interview will last approximately one hour and will address your beliefs, thoughts and experiences about the family in post-cardiac care. Please answer in any way that you would like, there are no right or wrong answers, we are just interested to hear about and understand your experiences. Additionally, you do not have to answer any questions that you are uncomfortable with.

***Give definition of physical activity**

1. To begin with, could you talk me through what you believe is the role of family in post-cardiac care for post-MI patients?

   ***Prompts/probes**
   - How you see the family in the process of patient recovery
     - From phase 1 – phase 4

2. Can you describe how you think the family may influence physical activity engagement for post-MI patients?

   ***Prompts/probes**
   - Behaviours
   - Family attitudes/beliefs/thoughts towards PA

3. What family behaviours do you perceive as being positive and negative to support physical activity engagement in post-MI patients? (Participants will be asked to draw on personal experience if appropriate).

   ***Prompts/probes**
   - Actions/behaviours of patient/family members
     - Encouragement
     - Concerns/challenges for family being supportive?
   - Communications between patient/family member (how was support communicated)

4. Can you discuss what your thoughts are about involving the family in post-cardiac care for post-MI patients?

   ***Prompts/probes**
   - Interventions in cardiac-care that involves the family
     - What do these look like?
     - Thoughts on these
     - What works/what doesn't
     - Possible interventions
   - Family support needs

5. Finally, the purpose of my PhD is to understand what can be done to help increase physical activity amongst a post-MI population. Support from the family has been found to help encourage physical activity participation. Do you have any ideas on family based

interventions that may help encourage physical activity participation for a post-MI population?

***Prompts/probes**

- Feasibility / practicalities to have a support-based intervention?
- Appearance of the intervention?
    - What is good/bad about it?

***Prompts/Probes** are there to be used as a guide for the interviewer. They are flexible questions to try and elicit responses from the participant. They should be used in a conversational manner and only when deemed appropriate.

Appendix 4

Development meetings session structure for post-MI patients and family members

Time	**Activity**	**Resources/notes**
10.00am	**Arrive and refreshments**	Soft drinks and biscuits
10.00am – 10.40am	**Welcome and introduction** o Take consent o Sarah introduce self and participants to introduce themselves o Why are we doing workshop o Key messages from studies 1 & 2 o Explain **aim** of project and **objectives** of today o **Aim:** Work together to develop a resource for family members so they can support PA engagement in patients post-MI. o **Objectives:** ▪ Discuss purpose, format and delivery of resource ▪ Discuss resource content ▪ Discuss resource aesthetics o How today will work, structure of day: o Going to cover different elements of resource development. o Work together as a group (me as facilitator). Ask you to focus on specific question, discuss in groups afterwards (this may bring up further questions). o Finish with summary, next steps and questions. o Structure of study: o Have this meeting, then meeting CR practitioners and then review resource and then all come together to discuss feedback and future steps o Any questions at this stage?	Consent forms o Pens (biros) Resource o Overview of study 1 & 2 findings Flipchart paper and pens Resources

10.30am – 11.45am	**Practical task 1 – Content, purpose, format and delivery of resource** **Content** **What PA information do you think the resource should contain?** (Looking back, what information would have been helpful to know)? o Split participant by status (if appropriate) and ask **patients:** o What would you liked to have known about PA? o What would you have liked your family to know? o Ask **family:** o What would you have liked to know about PA? o What would you have liked the patient to have known? Come together and discuss **Other questions to consider** o PA expectations? o What, when, how much PA should patients be doing? o Myths/misconceptions? Rating scale task o Give out sheet with aim, ask to complete individually. Collect in and then discuss options rated highly and others that weren't rated. o Ask why they rated as they did. Also ask if there is anything else they feel is important and has been missed. **Format** **What format do you think the resource should take** (i.e. what should the resource look like, what form should it take?). o Show participants lists talk through each option noting the pros and cons of each and how burdensome they would be for the family. **Questions to consider** o In what capacity? o Think about feasibility (cost-effective), work within current CR model, deliverable, usability, accessibility, memorability.	My role will be to facilitate session Resources needed: o Dictaphones o Flipchart paper o Marker pens o Blue tack o Post-it notes & pins o Rating scale o Biros PA misconceptions post-MI - PA after a MI it may cause additional harm - Bedrest is best! Ratings scales **Pre-prepared on flipchart paper:** different options of potential resources (leaflet for patients, family & clinicians, video, internet resource). **NOTE:** that there may be other options as well which we can discuss also but

	○ Think about what you would have liked after patients' heart attack ○ Think about what is good about ideas suggested compared to other idea. **Delivery** **When and by whom and how do you think the resource is best delivered?** ○ Participants to work together! Come together and discuss **Other questions to consider** ○ At what time point do you think this should be delivered? ○ When do you think the information would be most beneficial? ○ Need to think about PA throughout recovery – when will resource be most appropriate and helpful? Information span recovery time? ○ Does it matter who gives you the leaflet? ○ Does it matter if it's given to the patient or the family? ○ Focus on delivery (left in a pile and pick up, or focused discussion direct to family member). ○ Question pros and cons! ○ What communication skills do you think are important during delivery?	reiterate the parameters of my PhD and ideas that may not be feasible currently but will be put forward as potential recommendations for the future. Ask participants to work together, give them sheet of flipchart paper and pens to note down ideas - Flip chart paper for each element (when, whom, how).
11.45am-12.00pm	**Break**	Drinks and biscuits
12.00-12.30pm	**Practical task 2 – content & deliverer of resource** **From what participants have identified as being important in the ratings task, discuss how each element of the content could be communicated.** - Focus on verbal and visual communication ○ Looks - show group different types of variety of leaflets etc and ask for options, note pros and cons of each and why they like some compared to other. **Think about** ○ Colour ○ Use of language (basic) Words/ing)	**NOTE:** Reiterate here that although supporting PA behaviour is the focus of my research, I'm aware that there may be other elements of recovery that may be helpful for support also. Open to speaking about these other factors, but these can go on for recommendations. Resources - Leaflets
12.30pm – 12.50pm	**Summary, next steps, questions**	

Appendix 5

CRP meetings guide for development meetings

Introduction

- Explain purpose of meeting (why we're here)
  - Research findings from studies 1 & 2 (discuss patient journey)
  - Ask you about your thoughts on resource
- What we hope to achieve from this study
  - Outline aims/objectives

Meeting focus

- Discuss what was found during development meeting with patient and family members
- Gather your initial ideas/feedback for resource
- Discuss format/delivery

Findings from development meeting with post-MI patients and family members

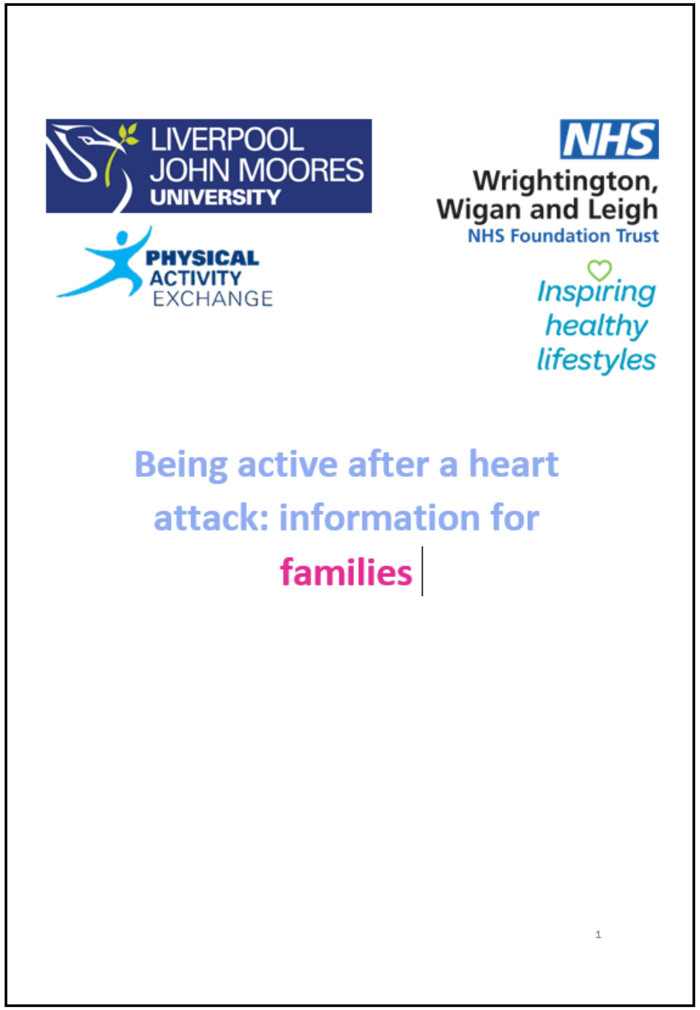
- Preferred format
- Content
  - PA
    - Why important and benefits post-MI (and why important to attend CR)
    - What patient can/can't do, intensity & frequency, specific exercises to enhance recovery
    - How family can support PA (positive and negative)
    - Increase family confidence to support patient PA
    - Aware of barriers patients can face to being active and how family can support to help overcome these
    - Physiological
  - Recovery
    - Individualised
- Delivery
  - By CNs that give specifically to family members (have separate 5 min consultation), important qualities (considerate, kind, empathetic)
- Practitioner feedback
  - Positive/negatives/challenges/solutions to participant ideas?
  - Any additions to the information provided you think is important to include?
  - Conflicts (anything you would change/don't agree with, if so, why?

Practitioner perspectives

- **Format/delivery**
  - Feasibility/capacity
    - Practical/achievable to give out within current pathway?
  - Any challenges identified, think about solutions, how can these be overcome?
  - Sustainability
    - Cost – other format options

Appendix 6

First draft of information booklet used in the acceptability meeting



LIVERPOOL JOHN MOORES UNIVERSITY

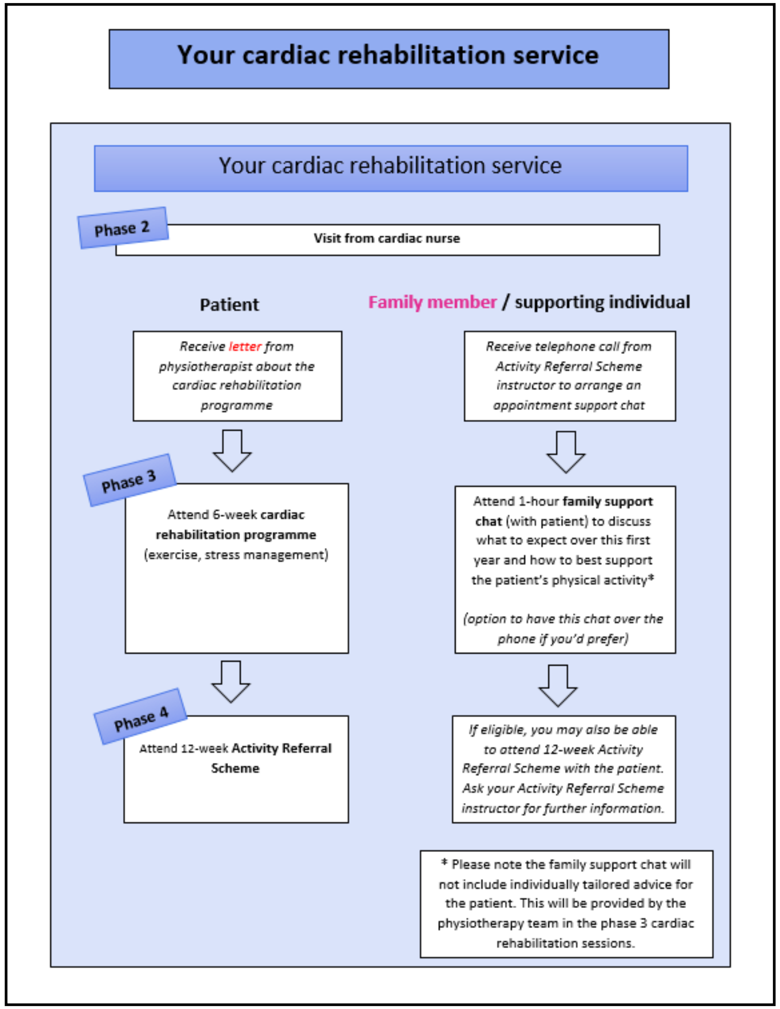
PHYSICAL ACTIVITY EXCHANGE

NHS
Wrightington, Wigan and Leigh
NHS Foundation Trust

Inspiring healthy lifestyles

Being active after a heart attack: information for families

1



Your cardiac rehabilitation service

Your cardiac rehabilitation service

Phase 2 **Visit from cardiac nurse**

Patient

Receive letter from physiotherapist about the cardiac rehabilitation programme

Phase 3 Attend 6-week **cardiac rehabilitation programme** (exercise, stress management)

Phase 4 Attend 12-week **Activity Referral Scheme**

Family member / supporting individual

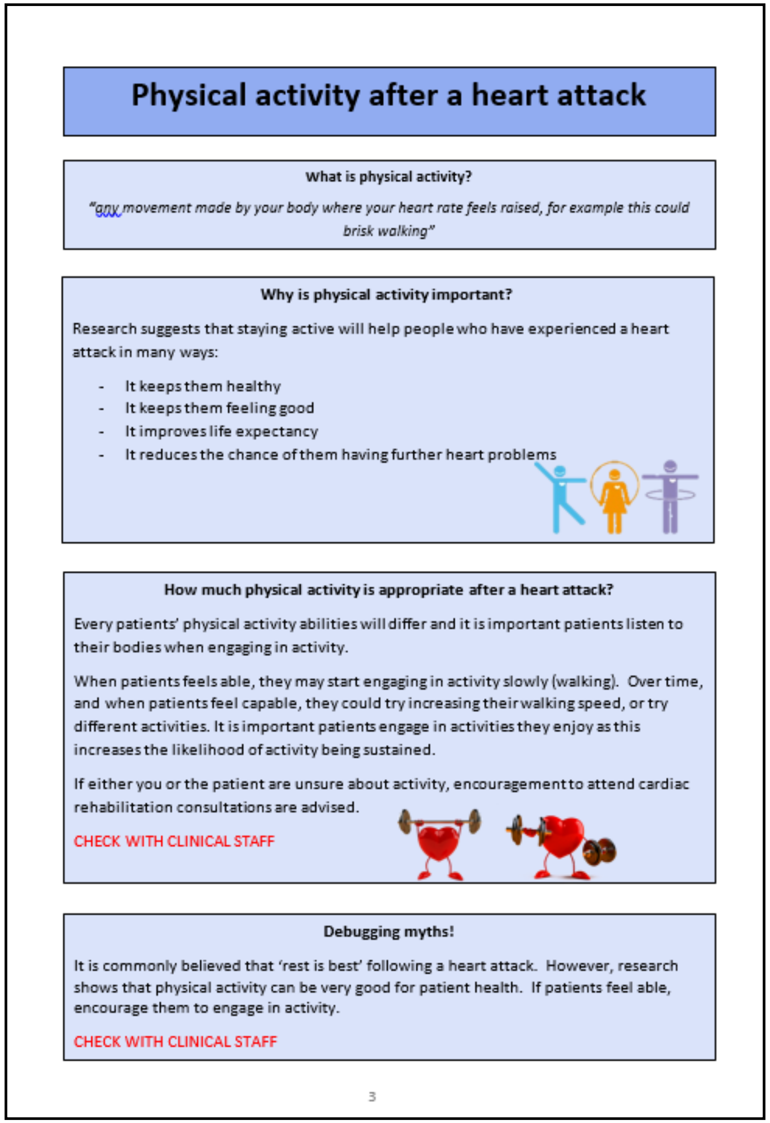
Receive telephone call from Activity Referral Scheme instructor to arrange an appointment support chat

Attend 1-hour **family support chat** (with patient) to discuss what to expect over this first year and how to best support the patient's physical activity*

(option to have this chat over the phone if you'd prefer)

If eligible, you may also be able to attend 12-week Activity Referral Scheme with the patient. Ask your Activity Referral Scheme instructor for further information.

* Please note the family support chat will not include individually tailored advice for the patient. This will be provided by the physiotherapy team in the phase 3 cardiac rehabilitation sessions.



Physical activity after a heart attack

What is physical activity?

"any movement made by your body where your heart rate feels raised, for example this could brisk walking"

Why is physical activity important?

Research suggests that staying active will help people who have experienced a heart attack in many ways:

- It keeps them healthy
- It keeps them feeling good
- It improves life expectancy
- It reduces the chance of them having further heart problems

How much physical activity is appropriate after a heart attack?

Every patients' physical activity abilities will differ and it is important patients listen to their bodies when engaging in activity.

When patients feels able, they may start engaging in activity slowly (walking). Over time, and when patients feel capable, they could try increasing their walking speed, or try different activities. It is important patients engage in activities they enjoy as this increases the likelihood of activity being sustained.

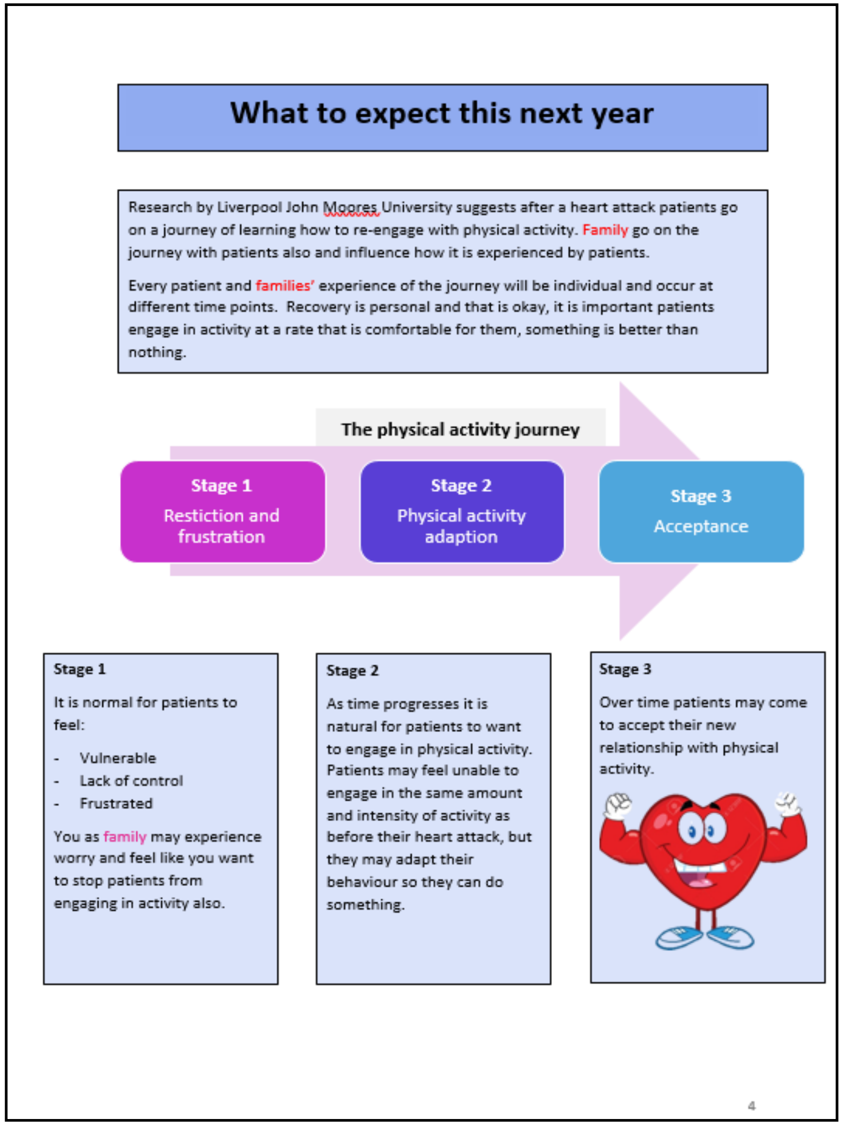
If either you or the patient are unsure about activity, encouragement to attend cardiac rehabilitation consultations are advised.

CHECK WITH CLINICAL STAFF

Debugging myths!

It is commonly believed that 'rest is best' following a heart attack. However, research shows that physical activity can be very good for patient health. If patients feel able, encourage them to engage in activity.

CHECK WITH CLINICAL STAFF



What to expect this next year

Research by Liverpool John Moores University suggests after a heart attack patients go on a journey of learning how to re-engage with physical activity. Family go on the journey with patients also and influence how it is experienced by patients.

Every patient and families' experience of the journey will be individual and occur at different time points. Recovery is personal and that is okay, it is important patients engage in activity at a rate that is comfortable for them, something is better than nothing.

The physical activity journey

Stage 1
Restiction and frustration

Stage 2
Physical activity adaption

Stage 3
Acceptance

Stage 1

It is normal for patients to feel:

- Vulnerable
- Lack of control
- Frustrated

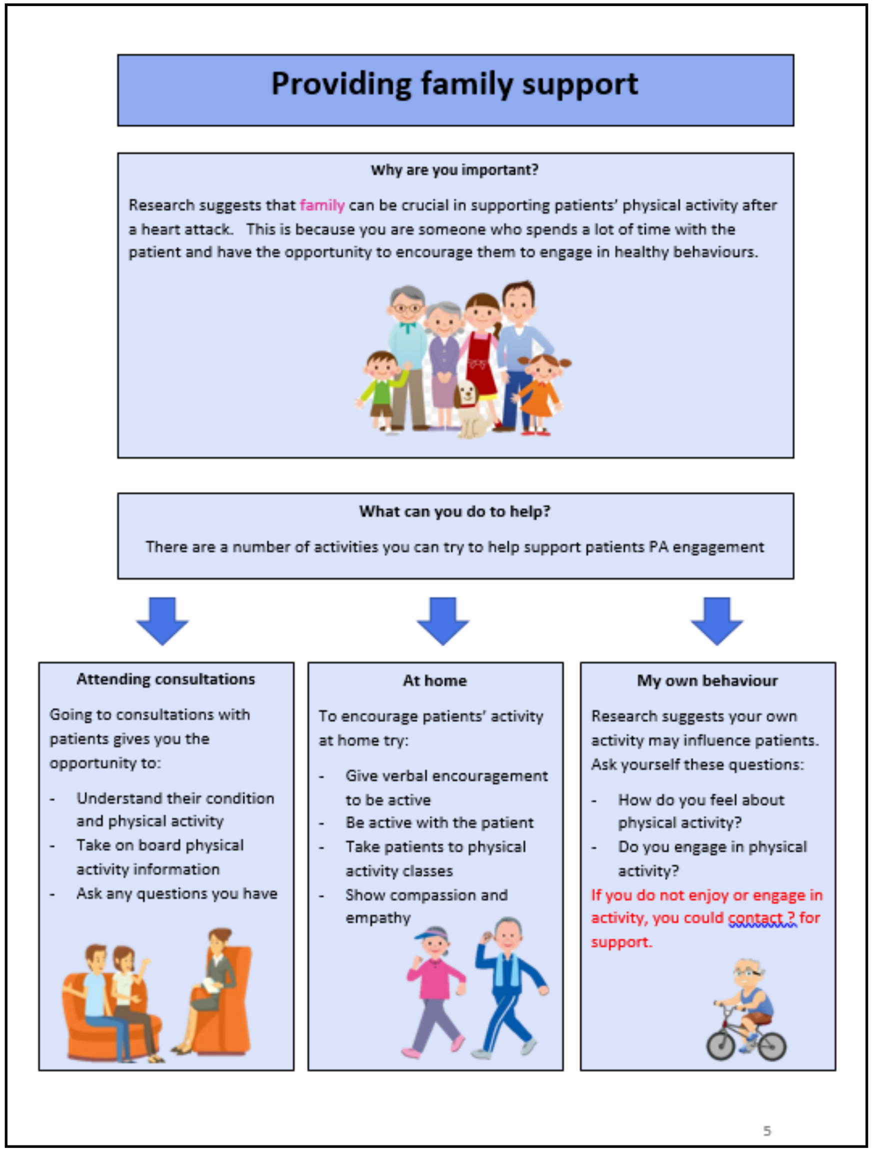
You as family may experience worry and feel like you want to stop patients from engaging in activity also.

Stage 2

As time progresses it is natural for patients to want to engage in physical activity. Patients may feel unable to engage in the same amount and intensity of activity as before their heart attack, but they may adapt their behaviour so they can do something.

Stage 3

Over time patients may come to accept their new relationship with physical activity.



Providing family support

Why are you important?

Research suggests that family can be crucial in supporting patients' physical activity after a heart attack. This is because you are someone who spends a lot of time with the patient and have the opportunity to encourage them to engage in healthy behaviours.

What can you do to help?

There are a number of activities you can try to help support patients PA engagement

Attending consultations

Going to consultations with patients gives you the opportunity to:

- Understand their condition and physical activity
- Take on board physical activity information
- Ask any questions you have

At home

To encourage patients' activity at home try:

- Give verbal encouragement to be active
- Be active with the patient
- Take patients to physical activity classes
- Show compassion and empathy

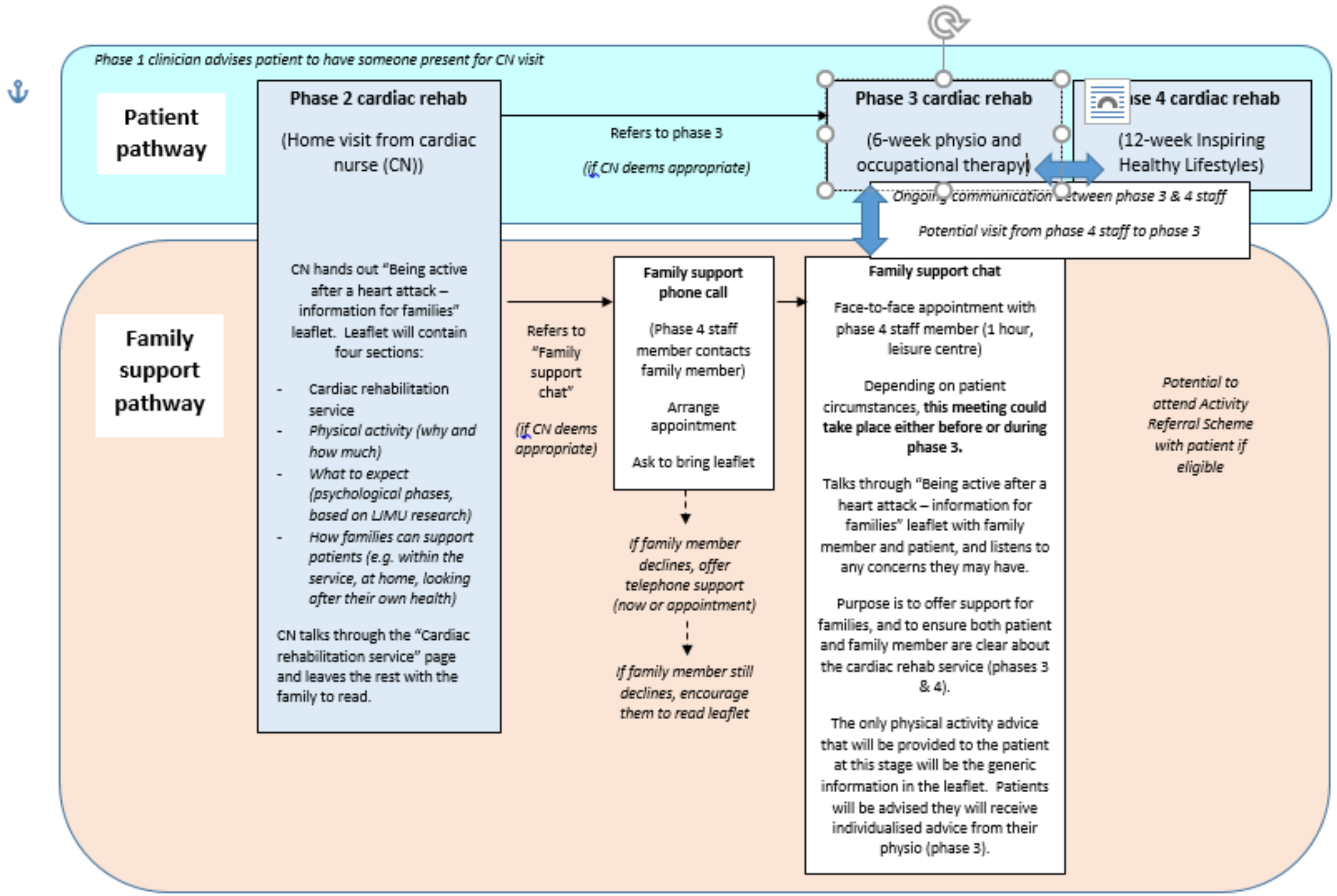
My own behaviour

Research suggests your own activity may influence patients. Ask yourself these questions:

- How do you feel about physical activity?
- Do you engage in physical activity?

If you do not enjoy or engage in activity, you could contact ? for support.

Appendix 7
First draft of support pathway used in the acceptability meeting



Phase 1 clinician advises patient to have someone present for CN visit

Phase 2 cardiac rehab

(Home visit from cardiac nurse (CN))

Refers to phase 3

(if CN deems appropriate)

Phase 3 cardiac rehab

(6-week physio and occupational therapy)

ase 4 cardiac rehab

(12-week Inspiring Healthy Lifestyles)

Ongoing communication between phase 3 & 4 staff

Potential visit from phase 4 staff to phase 3

CN hands out "Being active after a heart attack – information for families" leaflet. Leaflet will contain four sections:

- Cardiac rehabilitation service
- *Physical activity (why and how much)*
- *What to expect (psychological phases, based on LJMU research)*
- *How families can support patients (e.g. within the service, at home, looking after their own health)*

CN talks through the "Cardiac rehabilitation service" page and leaves the rest with the family to read.

Refers to "Family support chat"

(if CN deems appropriate)

Family support phone call

(Phase 4 staff member contacts family member)

Arrange appointment

Ask to bring leaflet

If family member declines, offer telephone support (now or appointment)

If family member still declines, encourage them to read leaflet

Family support chat

Face-to-face appointment with phase 4 staff member (1 hour, leisure centre)

Depending on patient circumstances, **this meeting could take place either before or during phase 3.**

Talks through "Being active after a heart attack – information for families" leaflet with family member and patient, and listens to any concerns they may have.

Purpose is to offer support for families, and to ensure both patient and family member are clear about the cardiac rehab service (phases 3 & 4).

The only physical activity advice that will be provided to the patient at this stage will be the generic information in the leaflet. Patients will be advised they will receive individualised advice from their physio (phase 3).

Potential to attend Activity Referral Scheme with patient if eligible