

Rehabilitation after myocardial infarction:
experiences and perspectives of people who do not use
cardiac rehabilitation and / or CHD 'self-help' groups
and their 'significant others'

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Declaration

I hereby declare that

- i. This thesis has been composed by myself
- ii. The work presented within this thesis is my own unless otherwise stated
- iii. This work has not been submitted for any other degree or professional qualification

Angela Mary Jackson

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Abstract

Background and goals:

This thesis explores the experience of rehabilitation following myocardial infarction (MI) from the perspective of people who did not attend either a cardiac rehabilitation programme (CR) or a CHD 'self-help' group and their 'significant others'. These resources are intended to support post-MI rehabilitation and readjustment and research identifies various benefits, yet many people do not use them. Given the scale of the population affected by CHD, the issues of why people do not use the resources, their experience and that of their family members, and the kinds of support people need and want, are of public health importance. These issues formed my investigative goals.

Methods:

The study used a qualitative methodology, informed by 'grounded theory'. A screening questionnaire identified non-participants from the post-MI population in Lothian, from which a sample of 'maximum diversity' was selected. In-depth interviews were conducted with twenty-seven post-MI people and seventeen 'significant others'. The analysis combined identifying emergent themes and searching the data for key issues relating to study objectives.

Findings:

Additional to the barrier of non-invitation, a spectrum of factors relating to people's 'lifeworld' circumstances, beliefs, and identity could either encourage or discourage participation. Factors were highly similar for both resources. Reasons for, and the process of non-participation could be grouped into three categories: "No need / no point", "Not worth it", or "Not possible". These were based on the way the factors that influenced individuals related to three key issues. Shifts between categories were also possible. A link between non-participation and a range of rehabilitation difficulties among post-MI people and family members is also demonstrated.

Conclusions and implications:

The study addresses a gap in understanding post-MI non-participation and its significance, providing insight into the process by which CR and CHD Group non-use occurs and the impacts for people who have had MI and family members. Recommendations are made, identifying realistic ways rehabilitation support might be improved, barriers and opportunities, and areas for further investigation.

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Abbreviations and terms

‘CHD’ – Coronary Heart Disease

‘MI’ – Myocardial Infarction (referred to in everyday speech as a 'heart attack')

‘STEMI’ - ‘ST Elevation MI’ (more severe, implying significant muscle tissue destruction)

‘N-STEMI’ - ‘Non ST Elevation MI’ (less severe, implying minimal or no tissue destruction)

‘CABG’ – Coronary Artery Bypass Graft (referred to in everyday speech as a ‘bypass’ or ‘bypass surgery’)

‘CR’ – Cardiac Rehabilitation programmes (Phase III, outpatient)

‘CHD Groups’ – CHD-focused 'self-help' groups

‘GP’ – General Practitioner

‘Significant other’ – Family member or close friend who plays a key role in a person’s life

Chapter One - Introduction

They tried to make me go to rehab

I said no, no, no.

Yes I been black, but when I come back

You wont know, know, know.

I ain't got the time

And if my daddy thinks I'm fine

He's tried to make me go to rehab

I won't go, go, go.

Lyrics from the song 'Rehab'

(Amy Winehouse, 2006)

Amy Winehouse's song 'Rehab' had a high media profile during the study period, and although relating to alcoholic rather than the cardiac rehabilitation that is the topic of my thesis, nonetheless the lyrics resonated with the issues I was considering. The lyrics made me think about the findings that were emerging from my data, particularly about the concept of non-participation as a choice. This seems to accord with the popular perception of non attendance at a resource such as cardiac rehabilitation programmes (CR), as was suggested by a comment from one of my family members when I first discussed the topic with them - "Well, it's their choice isn't it?" This off-the-cuff remark remained in my thoughts during the project, from reviewing the literature, to gathering and analysing my data. Contrary to this perception, the literature indicated that non-participation in CR and also CHD groups, the second resource on which my project focused, might not always be chosen; while even if people did choose not to participate it might be because they considered the resource inappropriate, inaccessible, or unappealing. However, the limitations of the previous research meant that the factors that influence non-participation, the process by which this occurs, the relation between the two resources, and the perspectives and rehabilitation experiences of non-participants,

were poorly understood. My study was undertaken to address these crucial gaps in understanding post-MI non-participation and its significance.

In essence my PhD is an exploration into the experiences and perspectives of people recovering from myocardial infarction (MI) who did not attend Cardiac Rehabilitation (CR) and / or a CHD group, and those of their family members. These two resources - the former, the main formal, health service, and the latter the main semi-formal resource, are specifically intended to support the rehabilitation of post-MI people. However, evidence shows that many people do not use them. Coronary Heart Disease (CHD) is a leading cause of death, illness, and disability in the UK and other industrialised countries and post-MI people form a sizeable population. Supporting the recovery of these people and managing their condition to prevent or mitigate further coronary events, morbidity, and negative impacts on quality of life, is in the interest of these people and their families, the health service, and wider society. The questions of why people do not use resources intended to fulfil these functions; the experience of people recovering without these resources and those of their family members, and the kinds of support that are needed and wanted are therefore of considerable public health importance. Additionally, as I go on to explain in my Methodology Chapter, my own previous experience of witnessing post-MI resource non-participation while working in primary care was a major part of my personal motivation to develop understanding of the support needs and preferences of post-MI people.

In Chapters Two, Three, and Four I engage with different areas of research literature relating to my topic. This provides the context for my study in terms of what previous research has found, but also highlights issues that hadn't been explored or fully explained, and the limitations of certain research perspectives. In each chapter I indicate how my study takes investigation forward to develop understanding of non-participation and non-participants.

Chapter Two sets the scene for the study. I explain the public health importance of CHD, post-MI rehabilitation, and secondary prevention. I then introduce the main formal and semi-formal health resources for post-MI people and critically appraise

the research. The broader system of primary and secondary care support and its limitations is outlined, following which I present and critique CR and CHD Groups, the two resources, whose absence is, ironically, pivotal to my study. Owing to the dearth of literature about the latter resource I also examine research on 'self-help' groups for other health issues. I then explain how my study relates to health promotion.

The fact that many people do not use these rehabilitation resources is the pivotal issue of my PhD. **Chapter Three** therefore examines key themes and perspectives taken on non-use of health resources generally and specifically regarding CR and CHD Groups (and other health self-help groups, as described above). I consider the shift in the medical view of non-use, and the challenges to medical perspectives and alternative insights from sociological research. I critique evidence on factors that may influence resource non-use and decision-making, identifying insights but also significant limitations, and describe how my study addresses important gaps to enhance understanding of post-MI non-participation.

Besides understanding why and how non-participation occurs, from a health promotion perspective the rehabilitation experience of non-participants and their families is a fundamental issue. In **Chapter Four** I examine research findings in relation to their significance and implications for my own study population, and identify areas where evidence and understanding is weak. The challenging and life-altering nature of post-MI experience is shown, but the available evidence indicates substantial diversity in the type and extent of impacts and the ways people respond. Yet because the evidence primarily relates to the general CHD population, it cannot be established whether the perspectives and responses of CR or CHD Group non-participants and their families differ in some way from those indicated and is related to their non-participation. My study addresses this question.

Chapter Five explains my methodology. Section One sets out the rationale for my methodology, design, and methods, explaining the theoretical premises and practical considerations underpinning my research. I describe the topic, reasons for investigation, and the PhD origin, then outline the case for selecting a qualitative

methodology, informed by ‘grounded theory’, in terms of its appropriateness to my ontological and epistemological stance regarding the research topic. I explain how a ‘social constructionist’ perspective, combined with certain practical considerations relating to recruitment, informed my design and methods choices. The principles that guided my sampling strategy are then discussed. Section Two documents the study implementation. In turn I describe the design and process of the two data collection stages and provide tables of the number and profile of participants: firstly for the screening questionnaire; and secondly, the in-depth interviews. Section Three outlines the methods and process of data analysis. I conclude by summarising the methodology and outcomes in terms of the study participants and data generated, and point to critical reflections about the methodological strengths and limitations that I undertake later in the thesis.

Chapters Six, Seven and Eight present my analysis and findings. Chapters Six and Seven address why people don’t participate in CR and CHD Groups. In Chapter Six I first identify non-opportunity, due to lack of invitation, information, and endorsement, as a barrier. I then identify a spectrum of wider factors related to people’s ‘lifeworld’ circumstances; beliefs; and identity, and show how these could influence resource use or non-use. I present new evidence showing how factors could influence people regarding both resources in a strikingly similar way, and could work in opposing directions - either to encourage or discourage resource use.

Chapter Seven takes forward understanding of the reasons for, and process of non-participation, addressing the crucial issues of the relative importance and inter-relation between competing factors and the different ways these combine to engender non-participation. Section One explains and illustrates my finding that the reasons for, and process of non-participation can be grouped into three broad categories, based on the way the factors that influenced individuals relate to three key issues. I also show how a person might shift between categories. In Section Two I present three case studies, exploring in depth the process and reasons for non-participation in CR and CHD Groups. Each provides an example of one of the three categories, drawing on the experiences and perspectives a post-MI interviewee and their family

member. The cases also illustrate the complexity of individual cases; the relation between non-participation in the two resources; contrasts between the three non-participation categories; and the link between non-participation and rehabilitation difficulties.

Chapter Eight focuses on the prominent issue of the difficulties non-participants and family members experienced. Although assessments of the recovery period varied considerably, all encountered hurdles on their recovery journeys. My findings indicate that if certain types of support had been available their rehabilitation experience might have been significantly better. I discuss the specific difficulties, the extent these related to CR and CHD Group non-participation, and the potential and limitations for these resources to address these unmet needs.

Chapter Nine concludes my thesis, drawing together key elements of the methodology, literature, and analysis to discuss the significance, limitations, and implications of my findings. I initially reflect critically on my methodology and the impact it may have had on my findings, focusing particularly on my sample in relation to the wider non-participant population, and considering the status of my findings in relation to the view of interview accounts as ‘social constructions’. The main section expands on the main analytical themes and new findings to show how my study adds to understanding of the reasons, process, and experience of non-participation. From a health promotion perspective I then identify and discuss a series of recommendations regarding ways that policy and practice might better support post-MI rehabilitation and CHD secondary prevention. Strategies to enhance the effectiveness of these measures and overcome implementation challenges are considered, including suggestions for further investigation regarding several issues.

Chapter Two - Setting the scene and introducing the resources

This first literature chapter sets the scene for the study. I explain why my PhD topic is relevant and important in terms of public health and health promotion. The significance of Coronary Heart Disease (CHD), and the importance of rehabilitation and secondary prevention for population health and health policy are described. I then introduce the main formal and semi-formal health resources for post-MI people and critically appraise the research relating to these. Initially, I outline the broader system of primary and secondary care support for post-MI people, based on the UK model, and highlight certain limitations. I then present and critique the two resources, the absence of which is (ironically) my study's central theme. First, I discuss Cardiac Rehabilitation (CR), the health service specifically for post-MI rehabilitation; then CHD Groups, the main semi-formal resource, which I consider in the context of 'self-help' groups relating to other health and illness conditions. I indicate how wider resources, particularly informal support, form an important further part of the picture in terms of understanding post-MI people's use and non-use of formal and semi-formal health resources. I conclude by explaining why my study topic is of importance from a health promotion perspective.

CHD as a major public health issue

Although CHD remains a major cause of death in industrialised countries, and rates in the UK and particularly Scotland are among the highest in Europe, mortality decreased dramatically during the last quarter of the 20th century. However, the incidence of heart disease has declined less rapidly (Petersen et al, 2003; Mackay et al, 2004) meaning that more people are surviving myocardial infarction (MI) and living with CHD as a chronic condition. CHD is a health policy priority in Scotland (Scottish Government, 2007), the UK (Department of Health, 2001) and other industrialised countries (Mackay et al, 2004). Besides primary prevention among the general population, secondary prevention amongst the growing number of people with established CHD is now of substantial importance, aiming to reduce their risk of

further cardiac incidents, morbidity, adverse impacts on quality of life, and social and economic costs (Scottish Government, 2007; Mackay et al, 2004). The scale of population need in this respect is considerable, particularly in Scotland. In Europe in 2002 CHD accounted for 11% of disability-adjusted life years lost from all causes (British Heart Foundation Health Promotion Research Group, 2005). In the UK CHD causes almost 114000 deaths annually and is the most common cause of premature death, while almost 260000 people have a heart attack each year and approximately 2 million people are suffering from angina, the most common form of CHD. CHD mortality in Scotland is amongst the highest and has fallen more slowly than other Western European and industrialised countries (British Heart Foundation Health Promotion Research Group, 2005). In Scotland every year an estimated 8000 people survive MI, 13000 people with angina require hospital admission, 6000 people undergo coronary revascularisation, and 6000 people suffer chronic heart failure (SIGN, 2002).

Health policy priorities

Additional to secondary prevention becoming a priority, the rising number of people living with CHD has contributed towards a policy emphasis, particularly in the last decade, on promoting self-management among people with chronic conditions and their families (Scottish Government, 2007; Department of Health, 2005). This is in the context of a substantial increase in other long-term conditions, and the associated health care costs of meeting this population's health needs. Also, enabling people to manage a significant portion of their own care as part of their day-to-day life is seen as a strand of the policy agenda in the UK and other countries of making health care more 'patient-centred' (Coulter & Redding, 2007). Yet, at present health service support is not fully meeting people's needs in this respect and requires further development (Richards & Coulter, 2007).

Health service treatment, care and support after MI

Guidelines set down the recommended treatment, care and support following MI. In Scotland these are the Scottish Intercollegiate Guidelines Network (SIGN) Guideline 57: 'Cardiac Rehabilitation', and 97: 'Risk and Prevention of Cardiovascular disease'. It is widely acknowledged that there is a disparity between the recommendations and practice, with considerable variation in the extent and models of implementation (Bethell et al, 2007; Thompson, 2002), although the guidelines do indicate the different elements of health service follow-up a person may receive. The period in hospital following MI is promoted as the first stage of rehabilitation support, where a person should receive reassurance, advice, education, information, and assistance with physical mobilisation, as well as medical assessment of their condition (SIGN, 2002). However some people report difficulty understanding and recalling information given in hospital after their MI (Smith & Liles, 2007; Gregory et al, 2005); or believe it was inappropriate to their personal situation (Helpard, 1998). Recent NHS hospital care evaluations (England) show unmet information needs regarding post-discharge rehabilitation and self-care (Richards & Coulter, 2007). Guidelines recognise that people may be emotionally vulnerable during the early post-discharge period as they come to terms with their MI, with many people feeling anxious and isolated. Support via home visits or telephone by health professionals and provision of information and guidance resources and in the UK is considered the second stage of rehabilitation (Bethell et al, 2007; SIGN, 2002). One example is the 'Heart Manual' - a 'home-based' rehabilitation resource, comprising an information manual and relaxation CDs, which may be accompanied by brief advice visits by a nurse. This is used in Lothian - where my study took place, and more widely the UK, and is recommended by Scottish guidelines (SIGN, 2002).

After hospital discharge a person will usually attend one or more outpatient consultations with a cardiac specialist. These are clinically focused - assessing a person's physical condition and physiological and lifestyle risk factors, and reviewing drug therapy. Yet, although people with complicated conditions may receive more of their care in hospital, primary care is recommended as the main locus for long-term follow-up for most post-MI people. Secondary prevention is the

principal goal of the recommended structured primary care follow-up, which entails condition monitoring and referral if necessary for specialist treatment; medication review; and supporting behavioural change via advice, information, monitoring, and, if relevant - nicotine replacement therapy. The follow-up model varies between areas and different professionals may be involved, particularly General Practitioners (GPs) and practice nurses, and possibly CHD-trained health visitors. Studies have suggested nurse-led clinics and home visits by CHD-trained health visitors can be effective in achieving secondary prevention outcomes (SIGN, 2002).

Certain limitations and problematic issues relating to primary and secondary care support have been indicated. Research shows lifestyle changes can be difficult to achieve and maintain even after secondary prevention support interventions (Campbell et al, 1998; Ebrahim & Davey-Smith, 1997), while provision of such post-discharge support is limited (Clark et al, 2005). Drug therapy uptake and compliance is also suboptimal (Kermode-Scott, 2008; SIGN, 2002; Johnson, 1999). Access to services may also be an issue. Tod et al's study (2001) found people with angina don't access, or may delay accessing primary care, and may consequently also miss out on referral to specialist cardiac services. It has been suggested that some post-MI people may similarly fail to access or receive the recommended follow-up (SIGN, 2002). Transport problems, distance, and associated financial costs have been identified as barriers to accessing specialist care (Chapple & Gatrell, 1998). There is evidence that post-discharge treatment plans may not be followed because staff wait for patients to consult rather than proactively inviting attendance (SIGN, 2002). Roebuck (2001) found some post-MI people's support and advice needs weren't met by their GP, which they perceived was due to the GP lacking time or not being sufficiently sensitive to their specific needs. Evidence from recent NHS evaluations suggests some people experience difficulty accessing GP advice due to the way services are organised (Richards & Coulter, 2007). Additionally, Gregory et al (2005) found people had unmet information needs because they felt some issues were insufficiently serious to consult their GP for, and hadn't been aware of alternative resources.

Transition between secondary and primary care and vice-versa has been highlighted as a particularly problematic aspect of post-MI care that may cause people to ‘slip through the net’ with negative consequences for their rehabilitation and secondary prevention outcomes (Clark et al, 2005, 2002; Dalal & Evans, 2003). The SIGN Guideline (2002, p. 17) reports there is, ‘plenty of opportunity for aspects of care to get lost during the transfer from secondary care to primary care, and plenty of evidence that this happens in practice’. Tod et al’s research (2001) suggests the reverse transition can also be problematic, identifying barriers to being referred to specialist cardiology services. Better communication between primary and secondary care and with patients; improved patient information, including a treatment plan; and further professional training and clarification of the role identities of professionals of different disciplines, have been advocated to address these issues (O’Driscoll et al, 2007; Clark et al, 2002; SIGN, 2002). Dalal & Evans (2003) report that cardiac nurses could be used to successfully bridge the primary and secondary care gap and improve follow-up and secondary prevention outcomes.

Additional to post-MI support in primary and secondary care, cardiac rehabilitation programmes (CR) are provided in many countries, and are advocated by policymakers, cardiac professionals, and heart-related voluntary organisations as a pivotal component of post-MI rehabilitation services. The recommended programmes are intended to address rehabilitation needs more comprehensively than primary and secondary care. However, the evidence outlined below indicates that CR generally fails to reach large numbers of post-MI people, while many programmes do not follow the recommended model and standards. This suggests that primary and secondary care might assume greater importance in terms of rehabilitation support for at least some non-participants and participants whose needs haven’t been sufficiently met by the programme. Yet, general primary and secondary care support lacks the range and depth of CR, and the problems outlined above may impede access to, and the effectiveness of these services. My study provides insight into the extent that CR non-participants’ needs are met by secondary and primary care.

Cardiac Rehabilitation (CR)

The World Health Organisation, and the Scottish Intercollegiate Guidelines Network (SIGN) - which sets down the recommended health service model for Scotland, view cardiac rehabilitation as a total process by which health professionals can help people recover and live with heart disease. The process encompasses disease prevention, condition management, and promoting the person's health and wellbeing in a holistic way, using different types of support.

‘...the sum of activities required to influence favourably the underlying cause of the disease, as well as to provide the best possible physical, mental and social conditions, so that the patients may, by their own efforts, preserve or resume when lost as normal a place as possible in the community’(WHO, 1993a, p. 3).

‘Cardiac rehabilitation is the process by which patients with cardiac disease, in partnership with a multidisciplinary team of health professionals, are encouraged and supported to achieve and maintain optimal physical and psychosocial health. Comprehensive cardiac rehabilitation consists of exercise training, behavioural change, education, and psychological support, to facilitate a return to normal living and to encourage patients to make lifestyle changes in order to prevent further events’ (SIGN, 2002, p. 1).

In the UK and most European countries four rehabilitation phases are generally identified. However, in some countries, notably the US, the stages are divided differently, and this has made comparisons problematic (Bethell et al, 2007; SIGN, 2002). Phase one - as an in-patient, and phase two - the early post-discharge period, entail support from primary and secondary care professionals. Primary care is also

seen as the lead service to support the fourth phase of longer-term health maintenance. Nonetheless, the term ‘cardiac rehabilitation’ – generally abbreviated to ‘CR’, is usually applied specifically to phase three. This entails a specialised, structured outpatient programme, guided by health professionals, generally lasting between six and twelve weeks (Thompson, 2002). It is these programmes that are the focus of this section, and people who do not participate in CR are one of the two non-participant groups my study investigates. It should be borne in mind however, that non-participants may have received in-patient rehabilitation support or used a home-based resource such as the 'Heart Manual' during the early post-discharge period. The non-participation figures thus underestimate use of health service-supported cardiac rehabilitation resources in a more general sense (SIGN, 2002). By taking a broad exploratory perspective into people’s rehabilitation experiences my study provides insight into the role such support had among CR non-participants, and whether this influenced use or non-use of these more structured resources.

The design and organisation of CR can vary considerably within as well as between countries, although in most countries the majority of programmes are hospital-based, including 75% of Scottish programmes (Scottish Needs Assessment Programme, 2001), and run on an outpatient basis (Bethell et al, 2007; SIGN, 2002; Dinnes et al, 1999). CR was originally exclusively exercise-focused, but international (WHO, 1993b) and national guidelines (for example, in the UK, most European countries, the USA, and Australia), increasingly advocate ‘Comprehensive CR’, as the Scottish Guideline definition above illustrates. ‘Comprehensive CR’ is a multidisciplinary intervention targeting a range of aspects of rehabilitation: exercise training, education, counselling, risk-factor modification, and psychosocial therapy and support. This model has been found to be more effective than ‘exercise-only’ CR. Firstly, in the breadth of outcomes – encompassing psychological and social recovery and biological risk factors, as well mortality and MI reoccurrence; and by offering greater scope for individualisation to patients’ needs (Rees et al, 2005; SIGN, 2002; Thompson & Lewin, 2000; Dinnes et al, 1999).

Effectiveness

The CR literature is vast, extending back to the mid 20th century and encompassing many countries (Bethell et al, 2007). A large proportion of the research has entailed assessing and comparing the effectiveness of different models for different patient groups. There is strong evidence that CR can be an effective intervention, particularly for reducing mortality and risk of MI recurrence (Bethell et al, 2007; Clark et al, 2005; Thompson et al, 2002; Jolliffe et al, 2001). Bethell et al state, ‘...an extensive evidence base... shows it to be one of the most beneficial and cost-effective treatments available to patients with coronary disease’ (2007, p. 58). Jolliffe et al’s Cochrane Review (2001) found a 26% reduction in cardiac mortality among attenders; while Clark et al’s meta-analysis (2005) shows a 38% decrease in non-fatal MI, and benefits for functional status and quality of life.

Reviews have additionally indicated that ‘Comprehensive’ CR can aid physical recovery, improve psycho-social wellbeing, reduce clinical and lifestyle-related ‘risk factors’, and increase participant knowledge, which may in turn contribute to reducing mortality and morbidity (Thompson, 2002; Dinnes et al, 1999). A caveat is that the evidence derives largely from study populations consisting overwhelmingly of white, middle-aged men, of lower risk of coronary complications - which could potentially limit generalisability to wider populations. Nevertheless, reviewers have concluded that although further research with more heterogeneous samples is necessary, there is no evidence to suggest lack of benefit for the wider population (Thompson, 2002; Jolliffe et al, 2001; Dinnes et al, 1999). The overall conclusion in the literature is that CR offers an effective secondary prevention strategy, contrasting with limited primary prevention success in reducing CHD in entire populations (Clark et al, 2002). This explains why CR non-participation and non-adherence is presented as a serious problem and has received considerable research attention (Cooper et al, 2007; Rees, 2005; Daly et al, 2002).

Non-participation and non-adherence

Considerable research energy has been expended attempting to quantify CR non-participation and non-adherence (non-completion). Variation in the measurements used, and between programmes based on differing models of CR and organised and

delivered in different ways, makes comparison problematic (Rees et al, 2005; Jolliffe, 2001; Thompson & de Bono, 1999). Nonetheless reviewers have concurred that while rates may vary substantially between people of different diagnoses, and between programmes, on the whole the international evidence shows that large proportions of eligible people do not attend or drop out (Cooper et al, 2002; Daly et al, 2002). Daly's review found only approximately a third of referred patients attended, while Cooper et al found an international average of 43%. Moreover these figures are for referred patients, whereas non-referral is also a major issue and total non-participation figures may therefore be higher. UK reviews similarly have indicated that fewer, and often considerably fewer, than fifty percent of referred people of various diagnoses attend (Bethell et al, 2007; Beswick et al, 2004). For example, Bethell et al's UK longitudinal survey found only a quarter of MI patients participated in CR, and drew attention to the contrast with the policy target of 85% enrolment.

Non-adherence is also substantial, with generally between two-thirds and half of attenders failing to complete (Daly et al, 2002; Oldridge, 1991). Specific Scottish data isn't available (Scottish Needs Assessment Programme, 2001), reflecting the widespread problem of limited and inconsistent data collection and lack of systems for audit and follow-up of non-attenders in UK CR services (Thompson & Lewin, 2000). Evidence from various countries has consistently shown that certain major population groups are under-represented: women, older people, people in socially deprived areas, minority ethnic patients, and people with greater functional impairment (Beswick et al, 2004; Dalal et al, 2004; Thompson & de Bono, 1999).

Problematic aspects of CR services

Yet, as Chapter Three will show, while there has been much investigation into the scale of the issue and certain associated factors have been identified, non-participation remains poorly understood (Thompson & Lewin, 2000). Thus, paradoxically, while it has been shown that CR can effectively assist rehabilitation and secondary prevention, at present these benefits do not reach many, and possibly most of the eligible population, for whom CR may be inaccessible, inappropriate, or

unacceptable. Problematic aspects of current services are a major theme. Thus, Bethell et al (2007, p. 69) state, ‘CR is an essential part of the care of cardiac patients but is poorly supported by clinicians and those planning and funding health services and as a result is often poorly organised, staffed and attended’. Evidence from various countries, including the UK, indicates that in practice many centres are not delivering ‘Comprehensive CR’ (Dalal et al, 2004; Henriksen, 2003; Dinnes et al, 1999). Campbell et al’s survey of Scottish outpatient CR (1996) found that while most offered exercise, relaxation and education, generally the programmes weren’t delivered effectively and so were unlikely to attain the secondary prevention outcomes reported by randomised control trials. The SIGN Guideline (2002) reports findings indicating that psychosocial factors were poorly assessed, and few programmes had input from a clinical psychologist.

It appears that the breadth of the vision and holistic goals for rehabilitation espoused in the definitions of cardiac rehabilitation cited above are not at present achieved by most programmes. Guidelines advocate that programmes should be menu-based - whereby participants select their preferred modules, to enable tailoring to individuals’ needs (Bethell et al, 2007; SIGN, 2002; Department of Health, 2001). Yet in practice CR delivery is often more rigid, with all patients receiving the same parts of a “one size fits all” fixed, regimented programme (Thorpe et al, 2005; Lau-Walker, 2004; Thompson, 2002; Thompson & Lewin, 2000). Calls for greater flexibility feature frequently in the conclusions of literature examining CR provision (Smith et al, 2004; Farley, 2003; Gassner, 2002; Daly et al, 2002; Thompson & de Bono, 1999).

Modifications, recommendations, and proposed reforms

In response to evidence of low uptake and access barriers (discussed in detail in Chapter Three), some centres now also offer alternative phase three CR delivery formats - primarily home or community-based programmes (Jolly et al, 2008; Bethell et al, 2007). National guidelines support this (SIGN, 2002), based on evidence that these may improve uptake and outcomes. For example, offering patients a choice between a home-based programme or hospital delivery ‘to suit their needs, preferences and circumstances’, is reported to have increased numbers of patients

achieving secondary prevention goals (Dalal & Evans, 2003) and sustaining lifestyle changes over time (Smith et al, 2004). Jolly et al (2008) report recent randomised trial results showing that home-based CR can engender similar benefits to traditional centre-based programmes outcomes. Home or community based programmes have also been found to augment uptake and adherence (Wingham et al, 2007; Grace et al, 2004; Dalal et al, 2004; Smith et al, 2004).

In the UK the failure of many programmes to meet national guidelines and provide the recommended service has commonly been attributed, at least partly, to under-resourcing. This has been suggested to result from historically having low priority within the NHS and within cardiac services, whereby clinical in-patient care has been prioritised. The origins of many CR programmes – having been developed by ‘local enthusiasts’, particularly nurses and physiotherapists, who have less power regarding budgets, has been identified as one reason for this; along with lack of support for CR by clinicians in the UK in contrast to other European countries (Bethell et al, 2007). In 2005 the Healthcare Commission, the independent NHS Inspectorate for England, described CR as a poorly funded and organised ‘cinderella service’ (Commission for Healthcare Audit and Inspection, 2005, p. 17).

Under-funding has also been identified as a key reason that UK services fail to meet guideline recommendations in terms of the numbers of people treated and the categories of people with established CHD referred to CR (Bethell et al, 2007; Thompson, 2002). Thus, while people with angina and heart failure could also benefit from CR, at present in the UK such people are generally not referred (Beswick et al, 2004). A high-profile campaign for increased CR funding is currently being conducted by a range of UK heart-related voluntary agencies, such as the British Heart Foundation and the British Association for Cardiac Rehabilitation. The aims are to enable improvements in service quality to meet national guidelines and better meet the needs of a wider range of patients; to improve access for currently excluded groups; and to address the ‘postcode lottery’ in service quality and availability between different regions (British Heart Foundation, 2007).

Nevertheless, research in the UK and various other countries has identified factors that suggest that notwithstanding funding issues, system functioning and organisation problems also impede effective CR delivery and underlie the gap between provision and the needs of people with CHD (O'Driscoll et al, 2007; Paquet et al, 2004; Henriksen, 2003; Clark et al, 2002; Daly et al, 2002). Researchers have suggested that further symptoms of the low priority accorded CR within the health care system are the lack of audit and quality indicators, which may contribute to poor referral and follow-up (Bethell et al, 2007; Beswick et al, 2004; Henriksen et al, 2003; Thompson, 2002). Unclear responsibility for CR, confusion regarding professional roles, and poor communication between different professional groups and parts of the system, are identified in the literature and suggested to result from poor system coordination (O'Driscoll et al, 2007; Scott et al, 2004; Henriksen et al, 2003; Clark et al, 2002; Thompson, 2002; Tod et al, 2002).

In conclusion there is a fundamental tension between the two most prominent themes in the CR literature: the potential effectiveness of CR as a rehabilitation and secondary prevention intervention, counterpoised against deficits in current provision in terms of the service model and the number and range of participants. The need for substantial changes has been acknowledged (Clark et al, 2002; Bethell et al, 2006), and it has commonly been proposed that alternatives might also be needed (Parkosewich, 2008; O'Driscoll et al, 2007; Paquet et al, 2004; Clark et al, 2002). Nonetheless, researchers and policymakers (Scottish Government, 2007; SIGN, 2002) evidently believe CR can be an important strategy to tackle the population health challenges posed by CHD. Understanding non-participation is therefore crucial.

'Self-help' groups for people with CHD

As described earlier, health policy and service-orientation in the UK and other industrialised countries increasingly promotes self-management by people and their families / carers, and places greater importance upon rehabilitation, to deal with the population health burden of long-term conditions (Scottish Government, 2007; Coulter & Redding, 2007; Department of Health, 2005). Encouraging the

community and voluntary sector role in supporting people with chronic conditions, and developing partnerships between these independent organisations / groups and statutory health services, is viewed by policymakers as a vital part of this. The existing contribution of 'self-help' groups and the need for government and statutory services to encourage and support the further development of this independent sector has specifically been highlighted (Scottish Government, 2007; WHO, 1986). UK cardiac rehabilitation guidelines advocate that 'self-help' groups should be encouraged, and recommend that health services should refer to, inform people about, and develop their relationship with, these groups (SIGN, 2002; Department of Health, 2001).

Health and illness-related 'self-help' groups

Since the 1970s groups independent of the formal health sector, established to support and assist people with particular health issues or illness conditions, have proliferated in many countries (Branckaerts & Richardson, 1992; Hatch, 1983). These independent, non-standardised and largely unregulated groups are heterogeneous in their origins, organisation, functions, and links with professionals and formal services. The varying terminology used: 'self-help groups', 'support groups', 'mutual support groups', 'mutual aid groups', 'community health clubs', and 'peer support groups', however makes comparison and generalisation problematic. (Branckaerts & Richardson, 1992; Lieberman, 1990).

Multiple definitions have been proposed and various attempts have been made to categorise different 'types' of group, particularly to differentiate between groups provided by professional services and those independent of formal provision (Galinsky & Schopler, 1994; Lock, 1986; Robinson, 1985; Levy, 1982; Gussow & Tracy, 1976). However, recent literature instead emphasises blurring between 'types' of groups. For example Davison et al (2000) describe 'fuzzy boundaries, with no hard and fast definitions'. Thus some community-based groups, organised independently of health or social services, may share as many features with, and appear more similar to some service-delivered groups than some that are independent. Additionally, researchers have challenged the previous assumption of complete dissociation between 'self-help' groups and professionals by showing that

many non-service based groups receive some degree of professional input and assistance (Adamsen & Rasmussen, 2001; Lieberman & Snowden, 1993).

Identified common features of 'self-help' type groups are: individuals sharing a common issue or problem, gathering regularly to exchange support, information and advice, and possibly undertaking other wellbeing-enhancing activities. Groups are predominantly community-based, and run independently of health service providers, although may have relationships with them. Recently Internet-based 'self-help' groups have also developed, replicating many functions of face-to-face groups, but with the important difference of being 'virtual' rather than a group people physically attend (Davison et al, 2000). My study focuses on face-to-face groups, but internet groups are potentially relevant as an alternative resource that CR and CHD Group non-participants might have used or wished to have used. Groups involve a high degree of member and wider community involvement, but not all are facilitated and organised by members or volunteers. Some are led or assisted by professionals acting as part of their statutory service remit, or employed by a voluntary organisation (Davison et al, 2000; Barath, 1991; Gray et al, 1996; Hedrick, 1988).

Various benefits have been reported, with apparent similarity between groups for diverse conditions. These include enhanced perceived social support – that is, availability of practical and emotional help, and the benefits this can entail for mental and emotional health (Lieberman & Goldstein, 2005; Kyrouz et al, 2002; Branckaerts & Richardson, 1992; Knight et al, 1980). Increased knowledge and learning about conditions and their management has been found to be important (Kyrouz, 2002; Branckaerts & Richardson, 1992; Lieberman, 1990; Trojan, 1989). This may result from 'formal' input, for example via speakers, official information sources, and professional helpers; and from 'experiential knowledge' – learning from the personal experiences of other members (Borkman, 1976), which receives particular emphasis in the literature. Enhanced coping and condition management (Kyrouz, 2002; Gussow & Tracy, 1976), and behaviour change and maintenance support and outcomes (Kyrouz, 2002; Subramanian et al, 1999; Gussow & Tracy, 1976), have also been reported. Some studies have found physiological and clinical benefits

(Kyrouz, 2002; Subramanian et al, 1999; Katz & Bender, 1976), but the evidence is sparser and less consistent (Branckaerts & Richardson, 1992).

Commentators nonetheless urge caution regarding reported effects and outcomes owing to certain limitations in the quality of evidence and variation between groups. The vast majority of studies have focused exclusively on existing group members and focus solely on positive benefits, ignoring the possibility of negative effects (Galinsky & Schopler, 1994). Davison et al (2000) suggest this participant focus creates an evaluation bias due to self-selection - whereby ongoing members must be at least reasonably satisfied, whereas dissatisfied people leave. Samples with limited diversity, low participation / return-rates, and 'convenience samples' in some studies also require their findings to be regarded cautiously (Klemm et al, 2003; Lieberman, 1990). Commentators have recommended well-designed research to address the uncertainties (Doull et al, 2005; Davison et al, 2000; Lieberman, 1990).

CHD-specific 'self-help' groups

Paradoxically, although CHD is a leading cause of death and disability, evidence on CHD groups is remarkably scarce. Although Scottish guidelines recommend CHD Groups should be encouraged, they acknowledge the dearth of direct evidence as problematic (SIGN, 2002). I conducted a literature search and found that even a generalised search for any heart-related group (including non-CHD conditions) identified only 97 electronic database 'hits' compared, for example, to 863 for cancer. Of the CHD-related literature approximately two-thirds reported hospital group interventions organised by health professionals as part of CR programmes, whereas only sixteen manifested 'self-help group' characteristics. Moreover, the range and quality of many studies is problematic. Almost half relate to one ongoing longitudinal study; one third were published pre-1990, and a third provide only anecdotal evidence. Well-designed studies thus constitute a very small body of evidence.

One possible explanation for the dearth of evidence is suggested by Davison et al's finding (2000) that there were considerably fewer CHD groups than groups for many other conditions, including conditions of far lower prevalence, for example, anorexia

– 1000 times less prevalent than cardiovascular disorders. Yet this relates to one study in one country (US), and further research is needed to ascertain whether this is replicated more widely and to explain any disparity. It is possible that the existence of formal CR programmes, for which there is no equivalent for most health conditions, may contribute to the comparatively low prevalence and profile of CHD Groups and the sparsity of related literature. Thus CR might attract participants, who, without formal provision might otherwise have attended a CHD Group, and also reduce their perceived need for further support after completing CR. Evidence presented by Hildingh et al (2000, 1995) suggests that non-referral and even active discouragement by health professionals may also discourage the development of CHD Groups. Wider findings confirm the influence professionals can have. Scottish survey results indicate that group facilitators considered endorsement and referral by health professionals a prerequisite for group success, while most participants had completed CR and received information about the group via CR (Bostock et al, 2007). Morland's secondary report (1992) reinforces these findings. The relationship between participation and non-participation in the two resources: CR and CHD Groups, therefore requires further investigation.

With similarity to the diversity in CR provision, research indicates that the structure and content of CHD Groups may vary within countries (Bostock et al, 2007; SIGN, 2002). Group functions may include: relaxation and information sessions, discussions, exercise, and informal interaction between members. The limited evidence suggests two different types of group: ones including exercise; and ones that do not, and instead emphasise peer support, information and education. Bostock et al (2007) found exercise was a central component of three-quarters of the 35 Scottish groups, and many of these groups' exercise programmes are supervised by professionals ranging from physiotherapists to fitness instructors (SIGN, 2002). Yet, exercise as a group function is not reported in the sparse literature from other countries, suggesting that non-exercise groups might be more common in other countries, although the sparsity of evidence means this currently cannot be ascertained.

Additional to the small number of studies, variations in the models and functions of groups mean that reported effects and outcomes of CHD Groups must be regarded as tentative. They appear broadly to reflect those of other health-related 'self-help' groups. Bostock et al's survey found considerable long-term membership among Scottish CHD Groups - illustrating that people perceive and receive benefits from participating. Positive impacts on psychological and emotional wellbeing have been identified. These include contact with similar people; reduced perceived isolation; increased perceived wellbeing, confidence, and self-esteem; affirmation; reassurance; comparison; health monitoring; becoming more relaxed about their condition; developing a more positive attitude; and helping people 'move on' from illness and diagnosis (Bostock et al, 2007; Gregory et al, 2006a; Hildingh & Fridlund, 2004; Hildingh et al, 1995; Wiggins, 1989). Mutual member support, particularly emotional support, has been found to be important - building confidence and developing coping ability, providing social companionship, enabling discussion of problematic issues, and reducing isolation (Bostock et al, 2007; Gregory et al, 2006a; Hildingh & Fridlund, 2001; Jackson, 2000; Hildingh et al, 1994; Klinger, 1985; Gilliland, 1979; Imhoff, 1976).

Several studies have reported that participating may support secondary prevention lifestyle changes: enhancing risk-factor knowledge (Hildingh et al, 1994); supporting smoking cessation and physical activity (Hildingh & Fridlund, 2004, 2001); and providing motivation and opportunity for exercise and informal lifestyle monitoring amongst members (Bostock et al, 2007; Gregory et al, 2006a, 2006b). Most studies have described education and information as a group function, yet evidence is limited. Hildingh & Fridlund (2001) found participants perceived greater informational support compared to non-participants, while Gregory et al (2006) report that members felt the group had increased their knowledge about their condition, its management, coping, and secondary prevention. Hildingh & Fridlund's longitudinal study (2001, 2003, 2004) examined clinical outcomes and physical effects, but the evidence is equivocal and too limited to draw conclusions.

In considering the present and potential role of CHD Groups for post-MI rehabilitation, an obvious but pivotal point is that any effects and outcomes apply

only to participants, and possibly their family members also (Bostock et al, 2007). If methodologically robust new quantitative and qualitative studies can corroborate the benefits tentatively indicated, this suggests either that non-participants may be disadvantaged, or their needs and available support may differ from participants. Thus in the light of the evidence suggesting that only a minority people with CHD attend (Bostock et al, 2007; SIGN, 2002; Hildingh & Fridlund, 2001; Davison et al, 2000) it appears important to ascertain the reasons for non-participation and examine the experience of non-participants and their families in the absence of such groups. Chapters Three and Four appraise the existing literature and demonstrate the need for my PhD study to address the gaps in understanding these issues.

Wider resources of support

This chapter has identified the contribution that CR, CHD Groups, and health services generally, can make to post-MI recovery, but also highlighted certain limitations. Yet, as Chapters Three and Four will illustrate, these resources are only part, and for some people not necessarily the most important part, of rehabilitation support. Informal resources play a significant role in helping people and their families manage chronic conditions and rehabilitate following MI, while other semi-formal resources may also be important. In recent years particularly, researchers and policymakers have identified the need to encourage and support families and carers in this role, identifying current deficits and the practical and therapeutic benefits of addressing the issue (for example, House of Commons Work and Pensions Committee, 2008; Thompson & Lewin, 2000). The Scottish Executive's Rehabilitation policy (2007) states that families and carers should be regarded not only as partners in long-term condition management but 'central members of rehabilitation teams'. UK national cardiac rehabilitation guidelines highlight the importance of involving family members and carers (SIGN, 2002; Department of Health, 2001). The role of these wider resources is important in the light of the issues at the heart of my PhD: the fact that CR and CHD Groups do not feature in the recovery experiences of many post-MI people, and the unknown extent and means by which these people and their families manage without them. By involving family members my study can provide insight on these issues, as my analysis will show.

Health Promotion – a means to promote health and prevent illness

The Ottawa Charter (1986) is regarded as seminal in terms of defining and shaping the philosophy and practice of health promotion (Tones & Tilford, 2001). The Charter defines health promotion as:

‘...the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being’ (WHO, 1986, p. 1).

The emphasis is upon the empowerment of individuals and communities, to enable them to gain control over aspects of their lives that affect their health. Recognition of the breadth of the factors that influence health, encompassing social, economic, political, and environmental factors necessitates a range of types of action across a wide spectrum of spheres. This is reflected in the five principal areas of action outlined in the charter. These encompass: building policies that support health; creating environments that support health; strengthening the capacity of communities to take action to improve health; developing the skills of individuals to enable them to make informed decisions about their health; and reorientating the emphasis of health services towards prevention. Rootman et al (2001) summarise the key principles of health promotion that underpin the Charter as: empowering, participatory, holistic, inter-sectoral, equitable, sustainable, and entailing multiple strategies. There are various models of health promotion, however a distinction is commonly made between primary, secondary and tertiary level activities (Gullotta &

Bloom, 2003; Tones & Tilford, 2001). Primary level activities address the determinants of health, aiming to support health and prevent disease. Secondary level activities entail early disease detection, followed by interventions to prevent conditions worsening and promote the health of affected people. Tertiary activities aim to reduce the impact of disease and promote quality of life.

Conclusion - CR and CHD Group non-participation as a Health Promotion issue

At the chapter's outset I identified the importance of CHD as a major population health concern in the UK and worldwide (British Heart Foundation, 2005; Petersen et al, 2003; Mackay et al, 2004). The number of people with established CHD means that secondary prevention has become a further public health policy priority alongside primary prevention among the general population (Scottish Government, 2007; Mackay et al, 2004). CR and CHD Groups are designed to support the rehabilitation of people with CHD, encompassing secondary and tertiary level health promotion. Consequently, in the light of evidence of substantial 'premature' death, morbidity, disability, economic loss, and impaired quality of life amongst people with CHD (British Heart Foundation, 2005; Petersen et al, 2003; Mackay et al, 2004) widespread non-use of these resources is an important health promotion issue. Understanding the reasons for non-use, non-users' experiences of rehabilitation, and how best to meet their needs, is essential to promote the health of people with CHD. The following literature chapters discuss what is already known about these topics and identify the gaps my study addresses.

Chapter Three - Non-use of health resources, CR, and CHD

Groups

The issue at the heart of my study is the fact that many eligible people do not use CR and CHD Groups, the two resources specifically for people recovering from MI. In this chapter I examine the key themes and different perspectives taken on non-use of health resources generally and then literature specifically relating to CR and CHD Groups. First, I consider the shift in the medical view of non-use, and the challenges to the medical standpoint and alternative insights provided by research from a sociological perspective, in terms of their significance and limitations for understanding non-use of post-MI resources. I critically examine the quantitative and qualitative evidence on factors that may influence health resource non-use and decision-making, identifying issues of potential significance, but highlighting the limitations and unanswered questions. I then consider the research specifically on CR and CHD Groups. Regarding the latter very few robust studies exist; whereas more research has been undertaken on CR yet the evidence is unclear on many areas, while studies that explain factors and provide insight into underlying processes are limited. I identify need for research to elucidate the relative importance and interaction of different influences that result in non-use, and to compare and explore the relation between non-participation in CR and CHD Groups.

Non-use of health resources

Perspectives on non-use

Investigating health service and treatment non-use has been a major research endeavour for several decades. Substantial proportions of patients do not follow medical recommendations about treatment, service use, and condition management (Sabre, 2003; Trostle, 2000; Cooper, 1998; Adams et al, 1997; Donovan, 1995). Until relatively recently the dominant view was of non-use as 'non-compliance' - that is, failure to use resources that professionals regard as beneficial; a negative behaviour, deviating from what professionals consider acceptable and sensible patient conduct. This view stems from the traditional 'medical model' of health care embodied in Talcott Parsons' work (1951). In reciprocity for being able to trust that clinically knowledgeable professionals

would act in their best interests, patients were expected to comply absolutely with their advice and instructions. Consequently 'non-compliance' was seen to represent deviance, as an irrational, irresponsible, and self-destructive behaviour – a view that dominated discourse and investigation on non-use for decades.

The 'non-compliance' perspective has now been superseded in medical and health policy. Non-use is now more commonly presented as 'non-adherence' or to a lesser extent 'non-concordance'. 'Non-adherence' is still seen as a problem - both as a lost opportunity to optimise individual and population health outcomes, and a waste of precious health care resources. However, the term is seen to have less connotations of patient blame than 'non-compliance', and to imply that non-use is recognised as a legitimate patient choice (Horne, 2006). Nonetheless, critics have suggested that 'non-adherence' continues to imply that professionals' knowledge and capacity for decisions are superior and although people are entitled not to follow this advice, it is imprudent to do so (Trostle, 2000). The concept of 'concordance' is primarily used in the UK and places greater emphasis on patient-professional partnership and negotiation regarding treatment decisions rather than a professional advising and a person opting to take or ignore advice. The emphasis on the need for professionals to help patients understand medical recommendations does however indicate that the goal continues to be for a person to make medically concordant decisions (Ferner, 2003; Paterson et al, 2001).

This shift has occurred partly in response to social and policy changes, particularly the development of patient consumerism - emphasising choice, autonomy, and the right to question sources of authority and information. The concepts of 'shared decision-making', 'patient participation', and the 'co-creation' of health reflect the move away from the traditional paternalistic health-care model to an emphasis on patient-professional partnerships (Cayton, 2006; Charles et al, 1999). A further factor in displacing the 'non-compliance' view is the major increase in people with chronic conditions, for which treatment decisions are less clear-cut, and self-management can play a major role (Horne, 2006; Donovan, 1995; Bury, 1991). Nevertheless, there are indications that the 'non-compliance' perspective persists to some extent, even if policies and semantics have shifted. Thus Britten (2007, p. 562) comments, 'many practitioners and academics have taken up the term concordance, not always in the ways originally intended. Its meaning is

subverted when it is used as a synonym for compliance'. Medical research continues to emphasise non-use as a negative and irrational behaviour (Trostle, 2000; Donovan, 1995), and this view still colours public discourse and media representations of the issue (for example, 'Case Notes', BBC Radio Four's, May 2006). Similar attitudes endure among some health professionals and may negatively influence service delivery to clients who do not follow recommendations (Chater, 1999; Fineman, 1991). Stevenson et al (2000) found that the traditional model of paternalistic decision-making persists in General Practice, even if GPs perceived value in enabling patients to take a greater role. Thus, from a medical perspective, following professionals' advice and using recommended resources continue to be advocated as the correct, responsible, and best options for someone who is ill.

Sociological research has challenged many of the assumptions underpinning the 'non-compliance' perspective and shown how the issue appears considerably different from the viewpoint of non-users. It has been shown that rather than objectively describing an actual behaviour 'non-compliance' instead is a socially constructed category based on the values and opinions of health professionals. From this perspective 'non-compliance' is a professionally created problem rather than one people experience, and negative attitudes towards 'non-compliers' represent the previously dominant view of health professionals and their influence in wider society. By ignoring professional recommendations patients are seen to openly challenge the ideology of medical expertise as the only valid strategy for managing health and illness and the only rational criterion for health decisions (Trostle, 2000; Donovan, 1995). Fineman (1991, p. 372) encapsulates this critical view: 'Non-compliance is not the neat diagnostic label of biomedical claims. Rather it is a complex, subjective, provider-created category of unacceptable client behaviours... as much to do with the values, attitudes, and beliefs underlying providers' expectations and assessments, as it does with their clients' behaviours.'

The sociological literature argues that the 'non-compliance' perspective cannot explain why people don't use health resources because it disregards certain fundamental aspects of health decision-making. People have been shown to be active decision-makers who make decisions in relation to their personal life context, beliefs and attitudes, rather than being passive 'blank sheets' awaiting professional guidance (Rogers et al, 1999; Donovan, 1995;

Bury, 1991). People's illness management and resource decisions encompass a substantially broader range of considerations than health / medical concerns, and other life issues may be judged to require higher or more immediate priority (Townsend et al, 2006; Horne & Weinman, 1999; Adams et al, 1997; Watson et al, 1996; Donovan, 1995). Conceptualisations, decisions, and actions relating to health and illness are located in the midst of, and intrinsically intertwined with, everyday life activities, patterns and structures (Blaxter, 2004; Gannik & Dalsted, 2006; 2002; Cunningham-Burley & Backett-Milburn, 1998). In contrast, contact with and the influence of health professionals and institutions may be relatively peripheral, even among people living with chronic illness, and so most health decisions are made by people rather than 'patients' (Gannik, 2002).

The 'non-compliance' assumption that not following medical recommendations is irrational has been robustly contested. Sociological research has shown that people make reasoned decisions in relation to a wide range of factors relating to their beliefs and life situations, in which context not following a more narrowly-defined medically-prescribed course of action may in their eyes be entirely rational (Paterson et al, 2001; Donovan, 1995; Bury, 1991; Trostle et al, 1983). Trostle described this as 'the logic of 'non-compliance''. Thus, balanced against various wider considerations, such as about employment, family obligations, prior health experiences, or negative resource perceptions, use of a treatment or service may not have priority or might be seen to entail negative consequences. From this standpoint, failure of the 'non-compliance' perspective to consider the broader context and consequences of resource use for an individual has been suggested to be limited, naïve, and unrealistic (Campbell et al, 2001; Paterson et al, 2001; Trostle, 2000, Donovan, 1995). Calls for an alternative understanding of decision-making that is grounded in the context of people's everyday lives (Gannik, 2002; Garro, 1998; Donovan, 1995) appear to have been heeded at least in terms of health policy (Scottish Executive, 2007).

The notion that medical advice is itself rational and relevant to people's situations has also been contested. Health professionals do not always impart clear and neutral information; treatment recommendations are not always rational and can be influenced by personal experience and commercial considerations; and professionals often lack full knowledge about their patients from which to recommend what is best for specific individuals

(Charles et al, 1999; Donovan, 1995). The unpredictability of chronic illness, from a professional as well as a patient perspective, also undermines the assumption that a clear outcome can be attained if a person complies with professionals' recommendations (Horne, 2006; Charles et al, 1999; Bury, 1991). So it can be argued that people can have legitimate and sensible grounds for adopting alternative courses of action, and drawing from a range of alternative resources and approaches.

People therefore do not consider health services the only or necessarily the most appropriate illness management strategies and contact with health professionals has been shown in sociological studies to be only a limited part of people's experience of managing health problems (Blaxter, 2004; Scambler, 2003; Gannik, 2002; Rogers et al, 1999; Cunningham-Burley, 1990). Scambler describes this as a 'significant clinical iceberg... the professional health services treat only the tip of the sum total of ill health' (2003, p. 3). People generally try to manage symptoms themselves as far as possible, or seek help from family and friends (Blaxter, 2004; Rogers et al, 1999). Indeed policy and services now promote self-management (Scottish Executive, 2007) and so people may be exposed to 'competing and often inconsistent messages' about using resources or managing a condition themselves (Rogers et al, 1999). People may also 'shop' from a range of alternative therapies and resources for a strategy they prefer, or believe will be more effective or fit their circumstances better than a medically-recommended option (Reilly, 2001; Trostle et al, 1983). Ziebland & Herxheimer (2008) describe how people also use information from other people's experiences to help them decide how best to respond to their illness. In terms of my investigation into non-use of CR and CHD Groups, it remains to be seen whether some people may view a CHD Group as an alternative to the formal resource of CR. It may be the case however, that while CR and CHD Groups are specifically designed to cater for people with CHD, and are viewed by professionals and other advocates such as voluntary organisations as important, people themselves may have other resources they prefer and that meet their needs sufficiently. In exploring the recovery experiences of people who haven't used these two resources my study seeks to shed light on this question.

Explaining health resource non-use

A sizeable volume of medical literature on treatment and resource non-use has employed the traditional ‘positivist’ approach of seeking associated traits, socio-demographic characteristics, and physiological variables. The theory underpinning this strategy is that it can identify population sub-groups who are more likely to deviate from medical recommendations, which may then be targeted with interventions, such as patient education. However, this approach has been criticised for several reasons. The hypothesis that non-use relates to specific characteristics or ‘types’ of people has been rebutted as a ‘myth’ (Horne, 2006; Calnan, 1987). Horne states, ‘...a typical non-adherent patient is something of a myth: most of us are non-adherent at some time’ (2006, p. 678). Cooper (1998) also reports that commonly people follow one aspect of advice but ignore another, thus cannot be classified either as someone who follows recommendations or does not. The quantitative evidence is equivocal (Horne, 2006; Trostle 2000). Moreover, sociological studies that have explored non-users’ experiences have suggested that all patients are potential ‘non-compliers’ when faced by particular circumstances and situations that make following medical recommendations problematic or undesirable (Calnan, 1987). Failure to adequately appreciate the crucial influence of everyday life circumstances and people’s beliefs on health decision-making has been seen to underpin health professionals’ unrealistic expectations about the degree patients will comply with their advice (Trostle 2000, 1983; Fineman, 1991).

More fundamentally, it has been argued that even if people ‘at risk’ of non-use might be identified it would have little value in that an associated factor cannot explain why non-use occurs. Without understanding the reasons for non-use it seems unlikely that strategies to address the issue among large and heterogeneous sections of the population will be successful (Horne, 2006; Sabre, 2003; Cooper, 1998; Trostle et al, 1983). Rather than asking *who* does not use health resources it has been suggested that the pertinent question is *why?* – to understand the meaning behind the behaviour (Calnan, 1987). Understanding the interaction of the individual, the condition and the treatment or resource has been suggested to be key to this (Horne, 2006). I now consider the existing evidence to identify findings of potential significance but also the limitations for understanding CR and CHD Group non-participation. Three areas of influence have been indicated as

important in facilitating or impeding resource use: people's beliefs; life circumstances; and the nature and organisation of the resource.

A range of reviews, including quantitative and qualitative studies, have indicated that people's beliefs are influential. A person's beliefs about their condition have been reported to be an important influence upon whether they use a resource or not (Horne, 2006; Sabre, 2003; Tod, 2001; Trostle, 2000; Cooper, 1998; Calnan, 1987; Amato & Bradshaw, 1985). The evidence relating to non-use of service or programme resources is however more limited than literature on medication non-use. Tod et al's study provides one example relating to people with angina, finding that fears and misconceptions about CHD could lead people to delay or avoid seeking help in primary care and so also miss out on referral to specialists. Social psychology models have also identified condition-related beliefs as an important contributory influence on whether someone perceives a health action necessary and potentially beneficial or not - including beliefs about the cause, nature, prognosis, consequences, and extent that a condition is curable or controllable (Tones & Tilford, 2001).

Condition-related beliefs have been suggested to interact with beliefs about a treatment or resource. Believing their condition is not a serious threat to current or future health has been identified as encouraging a person to perceive resource use is unnecessary (Horne, 2006; Campbell et al, 2001; Tones & Tilford, 2001; Cooper, 1998). If a person believes they can maintain key aspects of everyday life despite their symptoms then this may encourage a perception that they can manage without using a resource (Horne, 2006; Campbell et al, 2001; Britten, 1996). Yet conversely, fears and misunderstandings about a condition may lead a person to ignore or deny their condition's severity and so regard resources as irrelevant or unnecessary (Tod et al, 2001; Cooper, 1998 Adams et al, 1997). A perception that they lack control over their condition may also lead people to doubt a resource will be beneficial (Horne, 2006; Tones & Tilford, 2001; Cooper, 1998). It appears that a belief that a treatment / resource may be beneficial and effective for their condition can be particularly significant, but may be balanced against any perceived negative effects for health or their wider life roles and relationships (Horne, 2006; Campbell et al, 2001; Tones & Tilford, 2001; Cooper, 1998).

Horne (2006) highlights the importance of a person's own condition and treatment related beliefs in addition to information they may receive from professionals, '[people] evaluate whether the advice makes common sense in the light of their personal understanding and beliefs about the illness' (2006, p. 688). Qualitative exploration has suggested that people commonly have difficulty integrating information from health professionals into their 'personal disease model' (Gannik & Dalsted, 2006), and incongruity between people's illness beliefs with those that underpin health services and treatments has been identified as an important reason for non-use (Cooper, 1998). Ziebland & Herxheimer (2008) identify other people's experiences as an integral and important part of the evidence people use to make health care decisions. They indicate that people use this to interpret and assess information from professionals to help them negotiate the unfamiliar terrain of illness. This suggests that information about the experiences of others, either first-hand, or via sources such as informal Internet 'blogs' can play a powerful role in non-use decisions. This is an area my study explores regarding post-MI non-participants.

While professionals may believe that health considerations should be a person's priority, it is evident that health is actually only one of various priorities in people's lives. Broad exploratory sociological studies into how people manage health problems have reported that people commonly make 'trade-offs', whereby the perceived importance of wider 'lifeworld' issues, such as family, work, and social reputation, may mean these are given precedence over attending to health problems, even if this means tolerating problems or an impaired quality of life (Townsend et al, 2006; Bury, 1991). Some quantitative (Horne) and qualitative (Tod et al, 2001; Cooper, 1998) studies particularly relating to non-use, and social psychology models of health behaviour / action (Tones & Tilford, 2001), appear to reinforce this by indicating that a belief that resource use may impact negatively on wider aspects of their life may discourage resource use.

A person's self-concept is suggested to be important regarding health actions / decisions in Tones' 'Health Action Model' (Tones & Tilford, 2001). The aspects highlighted in the non-use literature primarily relate to a person's conception of their health in relation to their condition (discussed above) and self-reliance (discussed below). There are however examples of qualitative studies that have suggested that the interaction of broader aspects of self-conception and perceptions about resources can also be influential. Chater (1999)

found older people's sense of age identity deterred them from wishing to use resources they felt were for people older than themselves or were based on a model of age that didn't fit with their own. Also O'Brien et al (2005) found gender identity stereotypes were an important influence on men's reluctance to access GP services. Yet, it appears there have been relatively few such exploratory investigations specifically focused on non-use, and particularly regarding people with CHD.

People's beliefs about how they should manage their life and health appear influential regarding whether or not, and from which sources they seek or accept help with health problems. Desire to maintain self-reliance and autonomy, fuelled by the social importance of these values, has been identified as a deterrent for some people in qualitative (Tod, 2001; Chater, 1999 Adams et al, 1997), and to a lesser extent in quantitative studies (Amato & Bradley, 1985). Radley (1994) identified the stigma of being seen as not coping as a deterrent from help-seeking; while Chater and Adams found that some people viewed self-reliance as integral to their self-conception as well as a normal response to life situations, with the consequence that resource use could be seen as negative or unnecessary. Besides the influence of a strong local culture of self-reliance, Tod et al's study (2001) found people might be particularly inclined to rely on their personal resources if they also had negative beliefs and attitudes about health services or professionals. Amato & Bradley's survey findings also reflect this (1985).

A person's life circumstances might discourage health resource use, firstly, by providing alternative sources of support. Research, particularly exploratory qualitative studies, has suggested that generally people seek to manage health problems themselves as far as possible, using informal family help if assistance is necessary. 'Help-seeking' from wider sources has been indicated in studies relating to a wide range of health issues to be the exception rather than the rule, and a later strategy rather than a first resort (Blaxter, 2004; Tod, 2001; Cunningham-Burley & Irvine, 1987; Amato & Bradley, 1985). Whether this also applies following the potentially life-threatening event of an MI is examined later in this and the next chapter. It is possible that health service promotion of self-care may reinforce these beliefs and discourage resource use (Rogers et al, 1999). Yet conversely, lack of social support has also been identified by some qualitative (Anderson et al, 1996) and quantitative studies (Roberts, 1988; Shapiro, 1985) as contributing to non-use. This

may partly relate to absence of what Freidson (1970) originally described as the 'lay referral system', and which subsequent studies found could be important (Jepson et al, 2007; Schoenberg et al, 2003), whereby family and friends may act as informal 'consultants', recommending and encouraging use of various resources that may help the person's problem. However, further research is needed, particularly regarding CHD.

A person's life circumstances may also entail barriers that make use of formal and semi-formal resources problematic or non-preferable. As described above, the literature shows that people may decide not to use a resource if they perceive it might have negative consequences upon wider aspects of their life, such as losing income through time off work, or by disrupting family routines (Campbell et al, 2001; Donovan, 1995; Bury, 1991). Sociological findings suggest people make rational and legitimate decisions appropriate to their wider situations. However, while resource non-use may be a reasoned choice for some people who have other life priorities and alternative options, it is evident also that the problematic interaction of a person's personal circumstances and the inflexibility or inaccessibility of health resources for such people may prevent them carrying out their intention to use a resource (Tones & Tilford, 2001; Jepson, 2006; Jepson et al, 2005; Blaxter, 2004). Problems arising from the logistics of people's everyday lives, such as transport, travel distance, child-care, conflicting timing with existing activities / routines, and income constraints, may impede access to health resources that are not organised to accommodate these circumstances (Rogers et al, 1999; Amato & Bradley, 1985).

In terms of health services, barriers relating to service delivery have also been identified. Despite the flaws of the 'non-compliance' and 'non-adherence' medical perspectives, this body of research does identify certain obstacles that are seen as responsible for 'involuntary' treatment and resource non-use. These include inadequate patient knowledge, poor doctor-patient communication, unresolved patient concerns, and regime complexity (Donovan, 1995). Inadequate information stands out in the research and policy literature as a constraint on people's ability to make informed decisions and engage with professionals in 'shared decision-making' (Richards & Coulter, 2007; Rogers et al, 2007; Coulter, 1999). Qualitative research has suggested that people act based on the limited information available at the time (Jepson, 2006; Bury, 1991). Nonetheless

although good information has been identified as essential to facilitate resource use, people may not be able to pursue their preference regarding resource use if the service doesn't accommodate their life circumstances; certain options are locally unavailable; a person isn't invited; or the person doesn't understand or read information given (Jepson et al, 2007).

As Chapter Two described, there are notable differences between CR and CHD Groups. This suggests that the factors identified by previous research may have differing impacts with regard to the two resources. For example, one would expect the influence of health professionals and services to influence CR non-participation more than for CHD Groups, which are outwith health services. Their different functions, format, and organisation may also mean that issues relating to people's 'lifeworlds' differentially affect whether people attend CR or a CHD Group. My study appears to be unique in contrasting non-participation in both CR and CHD Groups and provides an opportunity to explore and compare the influences upon non-participation between the two, and indicate whether people deterred by one may be attracted to the other as an alternative and preferable option.

Non-use as a process

The literature suggests that the process that results in a person using a treatment or resource or not is often considerably more complex than a clear-cut, conscious decision taken at a single point in time, based solely on health-related considerations and the interaction between an individual and a health professional. Instead it appears that for many people the process may occur over time in response to a wide range of considerations relating to the individual, their life context and the resource; and various people - professionals of various disciplines and different parts of the healthcare system, members of a person's social network, and the wider community and society (Blaxter, 2004; Campbell et al, 2001; Charles et al, 1999; Bury, 1991). Again, my study can compare whether the process by which non-participation occurs in CR and CHD Groups is similar or different, and by employing an exploratory methodology can encompass the broader picture of the various influences upon individuals in their wider life and biographical context.

Qualitative research has suggested that people may ‘weigh up’ the relative personal ‘costs’ and ‘benefits’ of using or not using a resource. Some researchers have viewed this as a rational and conscious decision-making process (Campbell et al, 2001; Donovan, 1995). However, others suggest use and non-use may more commonly occur as the outcome of people’s unconscious responses to the information available and the considerations uppermost at a particular time (Blaxter, 2004; Paterson et al, 2001; Calnan, 1987). Bury’s review (1991) proposes that both analyses may be correct to some extent. Thus, having a chronic condition may mean people undertake a greater degree of conscious calculation in everyday life than people do ordinarily. Yet while people commonly assess the personal advantages and disadvantages of actions relating to their condition, they do not necessarily have clear goals, and due to limited information and the uncertainty of chronic conditions such evaluations are likely to be based on intuition as much as knowledge. However it has been suggested that while people may evaluate a particular resource option, the scope for most people to compare and make an informed choice between alternative resource options is considerably circumscribed due to lack information or understanding, or unavailability of certain options (Jepson et al, 2007; Rogers et al, 1999). My study provides insight into whether people’s non-participation in one resource may relate to their awareness, perceptions, and possibly their use or non-use of another resource.

Sociological researchers have highlighted the significance of the retrospective nature of people’s reflections on their illness experience. This raises an important consideration regarding non-use accounts, and the interpretation of my own interview data. Williams’ work on ‘narrative reconstruction’ (1984) suggests that accounts should be seen as an interpretive process whereby people seek to make sense of their condition by placing it in the context of their wider biographical experiences, beliefs, and self-conception. The research process affords opportunity for someone to reflect and construct a coherent account of why they acted in a certain way, that makes sense in terms of their wider biography and identity, and information they didn’t previously have. People might thereby present their actions as more deliberate and straightforward than they were at the time. Furthermore, people may use this process of narrative reconstruction to negotiate and resist criticism or stigma concerning their behaviour in relation to their illness (Throsby, 2007; Peel et al, 2005). The traditional dominance of the ‘medical model’ of acceptable illness behaviour, including ‘compliance’ with medical recommendations and

deference to health professionals might conceivably influence some people to emphasise or downplay certain reasons for non-use in order to present themselves as good citizens and patients. Also a person's presentation of their non-use as a rational choice based on the balance of influences on them at the time may represent a post-hoc effort to provide a coherent explanation rather than a factual description of a structured decision-making process at the time.

Non-participation and non-adherence in Cardiac Rehabilitation (CR)

CR has been advocated by researchers, policymakers, cardiac-related charitable and voluntary organisations, medical and health professional bodies, and practitioners of various disciplines in many countries as the 'gold standard' health service resource for post-MI rehabilitation, based on the evidence of effectiveness for CHD secondary prevention described in Chapter Two. It is therefore unsurprising that poor uptake and adherence are presented as serious concerns and substantial research has been undertaken to establish the scale of the problem and identify which people are missing out and why, thereby to design strategies to address this (Cooper et al, 2007; Bethell et al, 2007; Beswick et al, 2004). Yet, in terms of the crucial issue of understanding *why* CR currently fails to reach and benefit many people with CHD the research has substantial limitations, which inevitably impedes effective action to improve rehabilitation support.

Literature on CR non-participation is dominated by quantitative, epidemiological studies. Yet reviewers have concluded that while a large number of studies have been undertaken many are limited by their size and methodological quality (Jackson et al, 2005; Daly et al, 2002). There is substantial variation in the measurements used by different studies and trials, making findings difficult to compare (Bethell et al, 2007; Beswick et al, 2005; Rees et al, 2005; Thompson & de Bono, 1999). Comparison is further impeded by the differing models of CR found both within and between countries, for example some using 'comprehensive' CR, others using only selected elements; and some offering more flexible models, while most remain structured and hospital-based. Additionally, the different national contexts – for example, CR being available without charge to UK NHS patients, but only to people with adequate medical insurance in the US; and the varying classification of rehabilitation 'stages' between some countries (described in Chapter

Two) limit the extent that conclusions can reliably be drawn (Bethell et al, 2007; Daly et al, 2002). In parallel to evidence regarding CR effectiveness, the profile of non-participant study populations is also problematic: consisting overwhelmingly of white, middle-aged men, with lower clinical risk (such as uncomplicated MI); which limits generalisability to the wider CHD population (Jolliffe et al, 2001; Thompson & de Bono, 1999).

These studies have sought to identify factors associated with CR participation, non-participation, and non-adherence (non-completion or 'dropout'). However, the variables investigated have been limited to 'researcher-postulated barriers' and so cannot identify issues beyond those hypothesised by researchers and may thereby fail to encompass the influences and issues that exist in practice (Hagan et al, 2007). While evidence on certain factors points in a certain direction and readily suggests a plausible explanation, for example non-referral, evidence for many variables is equivocal (Daly et al, 2002). The quantitative research is important in identifying the breadth of influencing factors and suggesting the multi-factorial nature of non-participation (Jones et al, 2007), yet this approach cannot explain the process by which a factor found to be associated with non-participation influences an individual's behaviour. Further qualitative studies have been called for to examine the issues underlying the associations quantitative studies tentatively suggest and to elucidate the processes by which these may engender non-participation and non-completion (Clark et al, 2002; Daly et al, 2002; Farley, 2003; Oldridge, 1991).

There is a small but growing body of qualitative research, and although participants have been the primary focus, a number of studies have investigated non-participants' experiences and perspectives. These offer important insights into why and how non-participation may occur. However, their findings must be regarded cautiously and as requiring further substantiation because, as is the nature of qualitative research, most are localised and generally their samples are very small. Several studies have focused specifically on groups identified as less likely to attend CR and who have often been excluded from quantitative research. For example, Jones et al's recent study (2007) is unusual in including a sizeable number of non-participants (49), and focusing on women, ethnic minorities and older people. This adds important insight regarding these groups, but further research among the wider CHD population is needed. Additionally the sample

was drawn from people who agreed to participate in a CR trial, who cannot be assumed to be representative of non-participants generally. My study addresses the need for robust qualitative research with non-participants drawn from a broad spectrum of the CHD population.

The research generally reflects the medical perspective that dominates the wider literature on health resource non-use, whereby although non-participation may be accepted as an individual's prerogative and possibly an understandable choice given their circumstances, nonetheless it is considered inadvisable. This is underpinned by the assumption that CR is a suitable and effective option for most people with CHD, and consequently it has frequently been recommended that health service providers and professionals identify strategies to increase uptake and adherence. Yet there are important caveats to this. Firstly, a sizeable number of studies have advocated reform to make CR more accessible and better suited to people's needs and circumstances, and / or advocate provision of more flexible alternative modes of delivery (for example, Jolly et al, 2008; Beswick et al, 2005; Farley, 2003).

Additionally, as described in Chapter Two, the evidence of CR effectiveness predominantly relates to a subsection of the CHD population and clinical trial participants. Although reviewers have concluded that there is no evidence to suggest lack of benefit for the wider, potentially eligible population, nonetheless it is possible that the circumstances, needs and preferences of some people with CHD mean that CR may not be as effective or suitable as for the trial participants, and this might partly explain non-participation and non-adherence. Jolly et al's recent RCT evidence (2008) demonstrates that CR can benefit women, minority ethnic, and older patients, but their study participants may differ from people in these groups generally in that they had agreed to participate in a trial of alternative forms of CR. These important questions reinforce my study rationale - to explore the reasons for non-participation, experiences and perspectives of a broad spectrum of non-participants.

What influencing factors have been suggested by previous research?

The existing evidence has substantial limitations. Nonetheless, the quantitative research has pointed to a range of factors and suggested that the reasons for non-participation are

multi-factorial. The qualitative research has also provided insights regarding the processes by which some of these influences may contribute to non-participation.

Non-referral, non-invitation, non-encouragement

International reviews have identified non-referral as one important factor contributing to low CR participation, based on the number of studies that have reported this as strongly associated with non-participation (Beswick et al, 2005; Cortes et al, 2006 et al, 2000; Daly et al, 2002). Cortes et al encapsulate the general conclusion describing the ‘treatment gap’ between an eligible majority and the minority who are referred, despite guidelines that promote inclusiveness. For example, Beswick et al (2004) found only 45-67% of eligible English patients were referred (MI, unstable angina, revascularisation), with similar rates in Wales and lower referral in Northern Ireland. Specific Scottish statistics are unavailable. Reviews from different countries have found that people with certain demographic characteristics are less likely to be referred: women (Parkosewich, 2008; Jackson et al, 2005; Beswick et al, 2004; Scott et al, 2002; Dinnes et al, 1999); older people (Beswick et al, 2004; Cooper et al, 2002; Dinnes et al, 1999); people of minority ethnicity (Parkosewich, 2008; Beswick et al, 2004; Cortes et al, 2006, 2000); and in the US, people from disadvantaged areas (Parkosweich, 2007; Cortes et al, 2006 et al, 2000).

Certain clinical characteristics have also been associated with lower referral. Although guidelines in the UK, US and other countries recommend CR for people with angina and heart failure, in practice few programmes invite these patients. Moreover, at present large numbers of the core eligible groups of MI, CABG (bypass surgery), and angioplasty patients aren’t invited (Bethell et al, 2007; Parkosewich, 2008; Beswick et al, 2004). People whose condition is deemed more severe, or ‘higher risk’, for example, people who have had several MIs or have co-morbidity, are also less likely to be referred (Parkosewich, 2008; Beswick et al, 2004; Dinnes et al, 1999).

Yet, although the quantitative evidence for non-referral as a participation barrier may be strong, these studies don’t explain why this occurs, but only offer hypothetical suggestions based on associated variables (Beswick et al, 2004; Dinnes et al, 1999). There are few qualitative studies to offer further insight from the perspective of professionals (Beswick et al, 2004; Henriksen, 2003). The available evidence has suggested that several factors

relating to referral systems and service provision contribute to lower referral of people with certain characteristics. Reviews have identified a context and culture of services not focused on following national guidelines, based on a widespread lack of knowledge of guidelines among staff (Bethell et al, 2007; Parkosewich, 2008; Beswick et al, 2004). It has also been suggested that CR is undervalued within the health care system. For example, CR referral is not often a quality indicator, and combined with lack of audit, this has been identified as contributing to the failure to refer according to guidelines (Bethell et al, 2007; Parkosewich, 2008; Beswick et al, 2004). A number of qualitative studies have also reported that service failings contribute to low and non-protocol referral. Scott et al (2004) found unclear responsibility for CR and lack of patient follow-up partly responsible for low referral of women; while Henriksen et al (2003) similarly found fragmentation and lack of coordination and communication of the cardiac follow-up system exacerbated poor referral practices. Tod et al (2002) found poor information flow between staff of different disciplines and parts of the system, and between staff and patients could impede referral and engender non-participation. Broader studies that have critically examined CR operation have reinforced these indications of service implementation problems (for example, O'Driscoll et al, 2007; Clark et al, 2002, Thompson, 2002).

UK and US reviews (Bethell et al, 2007; Parkosewich, 2008; Beswick et al, 2004) have suggested that economic constraints from managing programmes on insufficient resources is an important factor underlying these general service deficiencies that create the conditions for sub-optimal referral. More directly however it has been suggested that non-referral can be a deliberate strategy whereby service providers faced by inadequate budgets seek to maintain capacity to deliver a service to people they perceive as their core clients. This has been identified as one reason that local protocols are often more conservative than guidelines and exclude patients clinically deemed 'higher risk' and people with angina and heart failure (Bethell et al, 2007). CR staff in Tod et al's qualitative study (2002) identified this as a key reason that existing services met the needs of only a minority of patients, while non-participants said long waiting lists had meant that CR hadn't been available when they most needed it. Clark et al (2002) found that while health professionals didn't explicitly acknowledge older age as an exclusion criterion, subtler constraints based on assumptions about older people and efforts to limit service expenditure resulted in older people being invited less. It was assumed that older people's

health and physical abilities would be poorer than younger clients and so more resource intensive, requiring more staff time, transport, and location flexibility.

Low awareness of protocols, limited knowledge about CR, and doubts about its effectiveness for certain people, among referring health professionals have also been identified as important contributory influences - by quantitative reviews (Bethell et al, 2007; Parkosewich, 2008; Beswick et al, 2004; Daly et al, 2002; Cortes et al, 2006 et al, 2000) and several qualitative studies (Mitoff et al, 2005; Scott et al, 2004; Henriksen, 2003). Jolly et al's quantitative study (2005) and Cortes et al's review (2006) found referrers' perceptions of linguistic access a key reason for low referral of non-English speakers. However, these studies didn't reveal whether this reflected limitations in language provision and economic factors that may underlie this, inadequate knowledge about provision, or incorrect assumptions that all people of minority ethnicity require such provision. Qualitative investigation is needed to understand the underlying factors.

Some reviewers have advocated introducing automatic referral systems to surmount the human and organisational referral barriers and ensure that national guidelines are followed and all eligible people are invited (Bethell et al, 2007; Parkosewich, 2008). Grace et al's prospective study (2007) found 50% more people enrolled when referred by an automated computerised system compared to usual referral at physician discretion. Yet studies have shown that even when referral is high or even universal - as in some clinical trials and certain national health systems, such as Australia, this hasn't automatically engendered greater participation (Cortes et al, 2006; Farley, 2003). For example, Mazzini et al's (2008) study found that a 'Get with the Guidelines' intervention to encourage centres to use the American Heart Association pathway engendered significantly higher referral, yet most referred patients didn't enrol. Thus while referral is essential, it is only one factor.

The importance of information and encouragement from health professionals has been highlighted. Physician recommendation is the factor that has been most consistently found to be associated with participation in the quantitative research, while weak or no recommendation is reported to be strongly linked to non-participation (Jackson et al, 2005; Yates, 2003; Jones et al, 2003; Scott et al, 2002; Dinnes et al, 1999). Qualitative studies also have reported that professional recommendation and encouragement generally

increases likelihood of participation (Mitoff et al, 2005; McSweeney & Crane, 2001; Ostergaard-Jensen & Pettersen, 2003). Wyer et al's exploratory study (2001) found a doctor's recommendation carried great weight, although nurses could also be influential. However, Mitoff et al (2005) found that physician recommendation was a powerful influence on some but not all patients – indicating that wider factors relating to the person, particularly their beliefs, could be as, if not more, influential. While the importance of positive recommendation and encouragement has most commonly been highlighted, Parkosewich's review (2007) also reports that negative endorsement from a physician, suggesting people had no need to attend, could also deter participation.

Inadequate information has been highlighted in reviews (Parkosewich, 2008; Dinnes et al, 1999) and many of the qualitative studies (Jones et al, 2007; Clark et al, 2004; Ostergaard-Jensen & Pettersen, 2003; Tod et al, 2002; Henriksen, 2002) as a factor preventing people making an informed choice about whether to attend. Jones et al's qualitative study found some invitees were confused by the generic information they received, and didn't perceive they had been personally invited, while Tod et al found people misunderstood what CR was due either to lack of information or lack of information that made sense to them. Clark et al found non-participants had negative perceptions about information previously received from health professionals and suggested this may also have deterred them about CR. Other qualitative studies have indicated that patients informed about CR while in hospital shortly after their MI and newly adjusting to medication may have difficulty assimilating and retaining information and so may fail to consider attending (Mitoff et al, 2005; McSweeney & Crane, 2001). Limited opportunity to discuss their decisions, barriers, and possible solutions with health staff also has been identified as a contributory factor to non-participation decisions (Hagan et al, 2007; McSweeney & Crane, 2001). Helpard & Meagher-Stewart's study of older women (1998) found they often felt that the standardised hospital information didn't fit their personal situation or needs. General service problems may increase likelihood of poor information and thereby non-attendance (Mitoff et al, 2005; Tod et al, 2002; Henriksen, 2003).

Misconceptions about CR and CHD, and failure of professionals to communicate participation benefits and make individuals feel these apply to them may increase likelihood of non-participation. Qualitative researchers (Cooper et al, 2005; Clark et al,

2004) and reviewers (Daly et al, 2002; Oldridge, 1991) have concluded that some people who opted out believing they have 'no need' to attend often hadn't made an informed choice because they hadn't had full and accurate information about CR or their condition. Yet, although improved information has commonly been advocated as vital for improving uptake, it has also generally been acknowledged that like non-referral, lack of information and encouragement are only part of the equation, and other factors are often involved (Cooper et al, 2005; Oldridge, 1991).

Access

Access difficulties have been identified as contributing to non-participation and dropout. Travel-related issues, including lack of transport, distance, cost, and travel anxiety, have been widely reported in quantitative research and reviews (Parkosewich, 2008; Jackson et al, 2005; Daly et al, 2002; Dinnes et al, 1999) and qualitative studies (Jones et al, 2007; Hagan et al, 2007; Clark et al, 2002; Tod et al, 2002; Campbell et al, 1994). Jackson's, Parkosewich's and Tardivel's (1998) reviews suggest these issues may disproportionately affect women and older people, who are less likely to have transport and more likely to have health problems affecting travel; while Parkosewich's review and Campbell et al's qualitative study identify travel distance and anxieties as increasing likelihood of non-participation. Half of Campbell et al's sample identified travel concerns as a deterrent from attending CR. Wingham et al's qualitative study (2006) found participants who perceived specific advantages from attending a centre-based programme were willing to make travel arrangements, whereas people who opted for a home-based programme were not and wanted a programme that minimised inconvenience including travel. This suggests that if people who perceive travel is a problem or inconvenience in relation to their wider life are only offered a centre-based programme (the majority of current CR provision) it may discourage participation.

However, there appear to be caveats to the importance of travel as a barrier. Grimwood et al (2000) had hypothesised that travel problems were the key reason for non-participation in West Lothian, Scotland, but their survey found other factors were more important for many people, particularly health problems. Cooper et al (2005) and Clark et al's (2004) findings also suggest that while travel may be a practical barrier for some people, for others the perceived inconvenience or discomfort compounds wider perceptions that

already disincline them towards attending. Thus Cooper et al (2005) found some people who cited travel costs as a reason for non-participation were nonetheless willing to pay for a taxi to attend clinical appointments, and suggested this showed they perceived the latter more important or valuable. This points to the importance of exploring people's perspectives and underlying beliefs; investigating people's situations in a holistic way to identify the inter-relation between different influences on their non-participation; and considering the possible influence of self-presentation in interview accounts. Moreover, both samples were small (respectively 14 and 8 non-participants). My study expands on these findings and adds further insight on these topics.

Qualitative studies have also reported that inconvenient programme timing may discourage participation, either by conflicting with other life activities or not suiting people's preferences more generally (Jones et al, 2007; Hagan et al, 2007). Language has been identified as a barrier for some people of minority ethnicity in quantitative (Jolly et al, 2004; Cortes et al, 2006 et al, 2000) and qualitative (Vishram et al, 2007; Webster, 1997) studies. Yet the extent this relates to people feeling deterred, or to professionals' assumptions about CR provision or the needs of people of minority ethnicity is unclear and further research is needed (Cooper et al, 2002). Financial issues can also be an obstacle. In the US literature this relates to non-referral of people without insurance and the specific national policy context (Parkosewich, 2008; Jackson et al, 2005). Nonetheless reviews regarding other countries have also found participation and adherence lower amongst people on low incomes or in disadvantaged areas (Beswick et al, 2004; Daly et al, 2002; Dinnes et al, 1999), and qualitative studies have reinforced this. People on low incomes reported they couldn't afford to take time off work (Hagan et al, 2007; Jones et al, 2007; Cooper et al, 2005); and some retired people and people on low incomes said they couldn't afford transport costs (Hagan et al, 2007; Cooper et al, 2005; Clark et al, 2002). Nonetheless, as described above, the latter two studies suggest these issues aren't solely related to practical barriers but are intertwined with people's wider beliefs and attitudes about attending. For example, health professionals in Clark et al's study proposed that people in disadvantaged areas also have alternative day-to-day priorities associated with 'getting by', and low awareness and education about CHD, CR, and rehabilitation.

The need for qualitative exploration to disentangle these issues is illustrated for example by Grimwood et al's quantitative study, which was undertaken in one district of the region in which my study is set. The professional-identified categories of reasons for non-participation are loosely defined and unclear: 'illness'; 'refused'; 'transport'; and 'previous'. The finding that illness was an important factor is important, yet more generally the authors acknowledged the limitations of their results for identifying and explaining the various underlying issues. The authors suggested that the district's socio-economic profile might be influential regarding people's beliefs and possibly also in practical ways, yet this couldn't be ascertained from their findings due to the broad survey categories, and also because quantitative methods identify associations but don't provide an explanation. The authors called for research to elucidate the underlying issues.

Everyday life circumstances

Additional to practical and service-related issues, the literature accords with the wider research on non-use of health resources in finding that factors relating to people's wider life circumstances may also be influential. In particular these include: social support, home life and domestic roles and responsibilities, and employment.

Social support

Some researchers and reviewers have suggested social support may be influential but acknowledge that the current evidence is limited and unclear (Daly et al, 2002). This is partly because the quantitative research that has identified associations with aspects of people's social situations doesn't identify how these may be influential, whereas qualitative findings to elucidate the underlying issues appear scarce. Reviews have reported that having a spouse or partner increases likelihood of participation (Parkosewich, 2008; Jackson et al, 2005; Cooper et al, 2002; Daly et al, 2002), while conversely non-participation has been associated with living alone or not having a partner (Jolly et al, 2004; Farley, 2003; Ramm, 2001; Oldridge, 1991). However, these proxy measures are problematic in the assumption about whether people in such situations have social support. Some quantitative studies have provided clearer indications, for example, Jones et al (2003) found encouragement from friends / family associated with increased attendance, and Johnson (1998) found people with stronger social support networks tended to participate more. Nonetheless, reviewers have concluded overall that the evidence is

equivocal (Parkosewich, 2008; Daly et al, 2002). Some reviews (Jackson et al, 2005; Tardivel, 1998) have suggested that women may have less social support than men and that this may partly explain why women's participation rates are less, however explanations are lacking.

Hagan et al's qualitative findings perhaps offer an explanation for the equivocal nature of the quantitative research, by finding that social support was very influential for some people, but not others. Some CR participants viewed social support from family and friends as important, especially for encouraging them to believe their life was important and worth rehabilitation efforts. Conversely, some non-participants related their lack of social support to their perception that CR wasn't personally relevant or important, and Hagan et al suggested this was because they didn't feel their life was important to others. Yet the findings also indicated that family had little influence over some people's decision-making. Wyer et al's study (2001) found family and friends had little influence on either participants or non-participants because they were perceived to lack CHD knowledge or experience. However, Jones et al's qualitative study (2007) found that social network support could be important in helping people overcome practical barriers such as transport to attend CR. Campbell et al's prospective study (1994) explored people's views about what they wanted from CR and identified that some people's support from their existing networks was limited, and they needed to find social support specific to their post-MI needs. Some viewed group sessions positively because they would enable them to discuss issues they felt unable to talk to family and friends about. Further research to elucidate why and how social support influences people in different ways regarding participation appears necessary.

Home life, domestic roles and responsibilities

Quantitative studies have identified associations between greater likelihood of non-participation and resuming domestic roles and responsibilities, a scheduling conflict between domestic duties and CR, and guilt over family obligations (Parkosewich, 2008; Jackson et al, 2005; Tardivel 1998; Oldridge, 1991). Qualitative studies also have reported that performing caretaking responsibilities and family obligations may be perceived, especially by women, as a priority over CR (Jones et al, 2007; Tod et al, 2002; McSweeney & Crane, 2001). These issues have been found to be most strongly associated

with women, and this has been suggested to be due to women generally undertaking a greater share of domestic roles, and ‘other-focusedness’ – focusing on family members’ needs rather than their own (Parkosewich, 2008; Jackson et al, 2005; Tardivel, 1998). Scott et al’s qualitative study (2004) found some professionals may assume women are less motivated to attend or complete CR due to their home roles and suggested that this may discourage referral. Wingham et al (2006) report that a person who initially opted to attend a hospital course instead changed to a home programme in order to meet their caring responsibilities. This suggests that home responsibilities may temper a person’s participation preference and intentions. Also the individual was male – illustrating that such issues aren’t exclusive to women.

The research has suggested that people’s home lives may also discourage them from attending in the broader sense of seeking to maintain the integrity of their home life. Thus the findings of Tod et al (2002) and Ostergaard-Jensen & Pettersen (2004) suggest some people perceived CR would disrupt their daily lives, particularly due to the way services were provided, for example having to travel, and fit it around other commitments. Tod et al also found elderly people especially valued their normal routine and felt a sense of security from this, and so wouldn’t attend if they believed CR would disrupt this. Wingham et al (2006) report that people were motivated to participate in home-based rather than hospital-based CR particularly because they believed CR should, ‘fit in with their lives rather than their lives fitting with the rehabilitation programme’. Mitoff et al (2005) found non-participants less likely to persevere to overcome obstacles compared to participants. Collectively these findings indicate that a more flexible model of provision that could accommodate people’s circumstances would encourage participation. Gallagher’s survey (2003) found a stressful personal life event in the post-MI period, such as bereavement or divorce, was associated with non-participation, suggesting a further way a person’s home life may be influential. However, further evidence is needed.

Employment

Evidence regarding employment is ostensibly contradictory, in that some research has suggested it may encourage non-participation while other studies have found it may act as a barrier. Yet this may be a function of the quantitative data, which doesn’t explain how associated factors influence a person, and there may actually be different and competing ways that employment can exert an influence. A number of qualitative studies have

provided valuable insights, although the evidence is limited. Some quantitative research has found employment strongly associated with participation (Parkosewich, 2008). Qualitative evidence to support this is sparse, but Hagan et al (2007) did find self-employed people more likely to attend than people working for an employer because they had greater flexibility. Qualitative studies more frequently have found employment to be a barrier, whereby some people view maintaining their income or keeping their job as a higher priority than CR (Jones et al, 2007; Hagan et al, 2007; Cooper et al, 2005; Tod et al, 2002). Quantitative studies have reported that a conflict with working hours and returning to work are associated with non-participation and dropout (Parkosewich, 2008; Oldridge, 1991). Tod et al (2002) suggested that maintaining a working role might be especially significant for people on low incomes and in areas of high unemployment. Cooper et al (2005) found people wrestled with a dilemma between maintaining their health and their job. However, the reason some people gave returning to work higher priority could also relate to health, through a belief that time off and income loss would engender stress, which as a post-MI person, they must avoid.

Health and risk factors

The widely differing aspects of health and the various measurements used make the associations in the quantitative literature between health status and likelihood of attending CR unclear and difficult to compare (Cooper et al, 2002; Daly et al, 2002). Again the quantitative evidence doesn't explain why certain health issues may encourage or discourage participation and consequently the equivocal findings are hard to interpret. Exploratory studies have provided valuable glimpses into the ways a person's health may influence them but the evidence is sparse. The research is inconclusive on whether aspects of poor physical health, such as specific diagnoses, functional capacity and impairment, number of severe CHD events, or treatment type, may make people more or less likely to participate and complete CR (Beswick et al, 2004; Cooper et al, 2002; Daly et al, 2002; Dinnes et al, 1999). However, regarding poor psychological health, depression has more consistently been found to decrease likelihood of participation (Parkosewich, 2008; Cooper et al, 2002; Daly et al, 2002).

Reviews have indicated stronger evidence that poorer health specifically among women and older people may contribute to their lower participation and adherence. The reasons

suggested are that older people experience greater co-morbidity and their condition tends to be more advanced, while women are generally older when diagnosed (Parkosewich, 2007; Jackson et al, 2005; Daly et al, 2002). There is also greater consensus in reviews (Parkosewich, 2008; Beswick et al, 2004; Daly et al, 2002) and qualitative literature (Jones et al, 2007; Tod et al, 2002; McSweeney & Crane, 2001) regarding co-morbidity as a participation deterrent, particularly for people with multiple or serious health problems. Jones et al (2007) report that half their sample had health problems, related to CHD and other conditions, that affected their ability and willingness to exercise, and that this was a leading reason for non-participation and dropout. Their sample were trial participants which limits generalisability, however McSweeney & Crane's exploratory study (2001) also found people with greater co-morbidity generally less likely to participate. Tod et al (2002) found that co-morbidity among elderly people could exacerbate travel difficulties.

Yet, based on the existing evidence, reviewers have concluded that people's beliefs and attitudes about their health may be more influential regarding how they manage their CHD and whether they participate and complete CR or not than people's condition or health status (Cooper et al, 2002; Daly et al, 2002; Dinnes et al, 1999). Similarly, there is evidence that people's beliefs and attitudes about lifestyle 'risk factors' may be important influences (Cooper et al, 2002; Wyer et al, 2001), whereas reviews have found that evidence regarding associations with smoking, physical activity, and being overweight and participation and adherence is equivocal and limited (Cooper et al, 2002; Daly et al, 2002).

Beliefs and attitudes

Paralleling the wider non-use literature, the research has indicated that beliefs and attitudes are powerful influences. The findings appear less equivocal than for many of the influences described above and there is more qualitative evidence. Nevertheless there are some limitations: many studies have been very small and their samples overwhelmingly male; findings from trial participants require further research to ascertain if they apply more generally; and although the qualitative evidence is richer than regarding other factors the findings still relate to a relatively small body of studies.

People's beliefs and attitudes towards their condition have been identified as important and reflect themes from the general non-use literature. A belief that their condition is not

serious, or not sufficiently serious to make attending worthwhile has been linked to non-participation in quantitative reviews (Parkosewich, 2008; French et al 2006) and qualitative studies (DIPEX, 2008; Cooper et al, 2005; Mitoff et al, 2005; Wyer et al, 2001). Commonly people expressed this as perceiving they had 'no need' for CR. Studies have suggested that non-participation may be more common among people who deny or minimise their condition's severity (Parkosewich, 2008; Mitoff et al, 2005; Cooper et al, 2002; Wyer et al 2001). Wyer et al found many people used this as a coping mechanism, and related this to the lack of information people had about their condition to correct their misperceptions. Their study also found that some people who initially believed their condition was serious and accepted a CR invitation because of this then didn't attend if their condition improved after they returned home because they no longer believed CR was necessary. Cooper et al's review (2002) found that a person's belief that their doctor didn't recommend CR was significantly associated with non-participation, while Mitoff et al's qualitative study (2005) identified that a belief that professionals minimised their condition's severity may also encourage people to decide CR wouldn't be personally beneficial.

French et al's meta-analysis (2006) found people who felt they understood their condition were more likely to attend, and Cooper et al's qualitative study (2005) found that if beliefs about their condition created doubts about the value of attending this could discourage participation. For example, people didn't perceive value in CR if they had difficulty identifying a cause for their MI, or didn't see it associated with the risk factors professionals emphasised; while some people viewed their MI as a discrete event rather than a manifestation of an underlying disease that required treatment and rehabilitation efforts such as CR. Other qualitative studies have similarly indicated that people's illness beliefs and models often differ from those of professionals and this incongruence can lead them to view CR as personally irrelevant (Bergman & Bertero, 2003; Gassner et al, 2002). Qualitative studies have suggested that low recovery expectations and low self-efficacy about capacity to recover can deter people about the value of attending CR (Mitoff et al, 2005; Wyer et al 2001) and quantitative reviews have linked these beliefs to increased likelihood of non-participation (Parkosewich, 2008; French et al, 2006; Jackson et al, 2005; Cooper et al, 2002; Daly et al, 2002). Many of these studies found that people who

believed they lacked control over their condition were less likely to consider CR worthwhile.

Beliefs and attitudes about CR are also influential and interact with people's beliefs about their condition. Lack of belief that CR will benefit their condition has been identified in qualitative literature as a key reason people have doubts about participating (Jones et al, 2007; Cooper et al, 2005, Wyer et al, 2001) and widely reported in the quantitative literature as associated with non-participation (Cooper et al, 2002; Daly et al, 2002). Failure by professionals to communicate the value of CR to prospective patients has been identified as an important contributing factor (Clark et al, 2002; Wyer et al, 2001; Daly et al, 2002; Oldridge, 1991). Negative attitudes and erroneous beliefs about the aims, content and format of CR also may engender doubts and discourage people, and poor information has again been reported to fuel this (Cooper et al, 2007, 2005; Tod et al, 2002; Wyer et al, 2001). Exploratory studies have reported that non-participants often had simplistic understandings about CR only being exercise or only talking and couldn't understand how this would benefit them (Tod et al, 2002; Wyer et al, 2001). However researchers have also suggested that some people opt out because they believe CR doesn't address their needs. A belief that CR focused on exercise and lifestyle risk factors while people's felt needs related more to quality of life and / or mental and emotional health issues has been reported among non-participants in several qualitative studies (Paquet, 2004; Henriksen, 2003; Gassner et al, 2002; Wyer et al, 2001; Bergman & Bertero, 2001).

Two recent UK qualitative studies report that while some people actively wished to be based in hospital, have professional supervision, and meet similar others; others believed they could manage well using a home programme themselves and believed their rehabilitation had to fit around their wider life responsibilities and activities. Both studies conclude that not having a choice to suit needs and preferences about the format and location of CR is likely to engender non-participation and dropout (Jones et al, 2007; Wingham et al, 2006). This finding, and the evidence regarding travel and life roles as barriers, suggests that the exclusively hospital-based format of most out-patient programmes in the UK and elsewhere (Bethell et al, 2007; SIGN, 2002; Dinnes et al, 1999) may contribute to non-participation.

Qualitative studies have found negative attitudes towards interacting with groups to be a major deterrent for people who feel uncomfortable in such an environment (Wingham et al, 2006; Cooper et al, 2005; Campbell et al, 1994). Nonetheless, while these studies have suggested this was a common deterrent among their samples, the literature also indicates that some people regard groups very favourably and this actively encourages their participation (Wingham et al, 2006; Campbell et al, 1994). Perceiving oneself different to the typical participant age profile may also discourage some people. Some people believed they were too young to attend what they regarded as an older people's service (Jones et al, 2007; Wyer et al, 2001), while some elderly people believed the service could only benefit younger participants (Cooper et al, 2007; Tod et al, 2002).

Dislike, concerns, fears, and failure to perceive value in the exercise component of CR have been identified in a range of reviews and studies as important reasons for non-participation. These negative perceptions have been suggested to be one contributory factor to explain why participation is particularly low amongst women, older people, and people of minority ethnicity (Vishram et al, 2007; Cooper et al, 2005; Scott et al, 2004). The specific reasons that have been identified include: being insufficiently fit to participate (Jones et al, 2007; Cooper et al, 2005); not believing exercise would benefit their condition (Cooper et al, 2005; Wyer et al, 2001); finding group exercise embarrassing (Parkosewich et al, 2007; Clark et al, 2004; McSweeney & Crane, 2001); believing it could overstrain the heart (Parkosewich et al, 2007; Cooper et al, 2005); being physically incapable of exercise, or the level of exercise they expected CR entailed (Jones et al, 2007; Clark et al, 2004; Tod et al, 2002; Campbell et al, 1994); and believing alternative forms of exercise were more personally appropriate or preferable (Jones et al, 2007). The latter reason was Jones et al's key finding, whereby many non-participants and non-adherers had opted to undertake other forms of exercise independently because they suited their circumstances better. The broad and complex range of beliefs and attitudes suggests that the underlying reasons vary between individuals and cautions against assuming that a particular issue influences people in the same way.

Several qualitative studies have also reported that generally negative beliefs and attitudes towards health care and professionals may also influence non-participation in that people may view their CR invitation through this lens. Dissatisfaction with previous care,

adverse experiences, or lack of confidence in health professionals' knowledge (Cooper, 2005; Clark et al, 2002; Jolly et al, 2004), or fear or dislike of clinical environments (Jones et al, 2007; Tod et al, 2002) may underlie these negative attitudes.

Evidence cited earlier in the chapter that links people's everyday circumstances to non-participation suggests that people's beliefs and attitudes relating to their social support, home life, employment, and socio-economic situation might be important in leading people to prioritise these over CR. Yet, detailed exploration of these has been sparse. Recent studies (Jones et al, 2007; Wingham et al, 2006) have valuably highlighted the intrinsic importance of people's life contexts and the beliefs underpinning these in influencing their participation choices, yet limitations of their study samples mean further research with a wide range of non-participants is needed.

Wyer et al's study (2001) found beliefs about self-reliance could discourage people about CR. Thus some people preferred to apply their usual preference of 'fending for themselves' to their recovery and believed they could manage independently of health services – although the researchers suggest this was based on inadequate information about their condition. Wingham et al's study (2006) found that some people who opted for home-based CR did so because they felt able and wished to manage their rehabilitation themselves as part of their day-to-day life. However others preferred professional support via hospital-based CR, again illustrating the diversity of needs and preferences among post-MI people. Other studies have reported that some people who said they had 'no need' for CR believed they could rehabilitate without professional support (Parkosewich, 2008; Tod et al, 2002; Cooper, 2005). This may ostensibly suggest self-reliance was their preferred option, yet the underlying beliefs regarding self-reliance and attitudes towards 'help-seeking' from different sources have not been examined in detail. It is also possible that some might have accepted CR support if an alternative format had been offered; or that other barriers or issues were more influential for some people but they believed it was more acceptable to present their non-participation in this way. Evidence discussed previously shows that some people were dissuaded by professionals who told them they could recover themselves and so didn't need to attend. This might have influenced some people's beliefs and presentation of their reasons for non-participation. Given the

prominence of self-management in current health policy this appears an important area for further investigation.

The process of CR non-participation

The literature identifies a range of factors that may influence CR non-participation, and a number of reviews and studies have concluded that non-participation is multi-factorial - whereby several factors combine to result in a person not participating (Jones et al, 2007; Daly et al, 2002). However, few studies have shown the relative importance of the factors or explained how they may interact in an individual case; nor have they indicated whether some non-participants perceive advantages in attending and how these balance against the disincentives. Hagan et al's (2007) and McSweeney & Crane's (2001) qualitative studies provide some insight regarding how and when people decide not to attend. Both found a variety of reasons for people declining to participate, although neither indicated the extent that individuals were influenced by multiple or single factors, or the weighting of these. Both reported that some non-participants decided firmly against attending before leaving hospital, believing CR wasn't personally appropriate or preferable in relation to their beliefs about their 'lifeworld' circumstances - such as difficulty attending while maintaining home and work roles, and doubts about the value of rehabilitation if they were elderly, their health was poor, and they lacked family dependents. Hagan et al additionally identified other non-participants who had initially considered attending while in hospital, but changed their mind after returning home based on similar considerations relating to their beliefs about their life situation and circumstances. Wyer et al (2001) also found some people changed their minds about participating when their health improved after they returned home. These findings tentatively suggest that people may decide against participating at different times, and that some non-participants may perceive advantages to participating, whereas others do not. This might be significant in terms of providing appropriate support to address unmet needs. Further investigation is essential - to explore the issue in greater depth, and also because of the limitations of these study samples - for example McSweeney & Crane's sample was all female and comprised six people who had declined CR, while Hagan et al's study included eight non-participants.

Non-participation in CHD and other health-related ‘self-help’ groups

As described in Chapter Two, there has been limited research into CHD Groups and few well-designed studies exist. Moreover, studies specifically examining participation and non-participation have been scarce - limited to a cluster of Swedish studies (Hildingh & Fridlund, 2004, 2001), one US survey of participation (Davison et al, 2000), and one recent Scottish survey of facilitators and participants (Bostock et al, 2007); with a handful of articles providing limited related findings. Until my own study, no qualitative exploratory studies had previously been undertaken with CHD Group non-participants. The Swedish studies are unique in examining non-participation, although in parallel to the CR research, further exploratory investigation is needed to help explain why and how the identified issues resulted in non-participation. Additionally, as Chapter Two describes, there appear to be two main group models – those including exercise, and those focusing on other support functions. The Swedish groups are of the latter category and so further research is needed to ascertain if their findings also pertain to groups that include exercise, and to compare to groups in other countries.

For this reason I also consider evidence relating to other health-related ‘self-help’ groups. However, this must be regarded tentatively, because although evidence on effects and outcomes shows substantial similarity between groups for diverse conditions, it is unknown whether particular features of CHD Groups or CHD may differ in some significant way. Also the wider group literature has limitations in quantity, design, and scope (Barlow et al, 2000; Branckaerts & Richardson, 1992; Lieberman, 1990), while most of these studies reflect the CHD Group and CR literature by focusing on participants rather than non-participants (Davison et al, 2000; Galinsky & Schopler, 1994), and it cannot be assumed that the inverse of factors that encourage participation can explain non-participation. Moreover quantitative studies and descriptive reports have predominated, and qualitative studies to explore non-participation from the perspectives of non-participants have been scarce.

Certainly, researchers and commentators have commonly questioned why, in the context of a proliferation in the number and range of groups and evidence suggesting benefits, more people don't participate and have called for research to elucidate the issue (Davison

et al, 2000; Branckaerts & Richardson, 1992). Although the Scottish guidelines (SIGN, 2002) advocate that CHD Groups should be encouraged as a form of cardiac rehabilitation support, the lack of research evidence relating to these groups and the unexplained issue of why only a minority of people with CHD attend have been highlighted as problematic issues.

There is a consensus in the literature relating to 'self-help' groups for various conditions and health issues that participants are a small minority of the population who experience a condition or issue (Peters et al, 2003; Subramaniam et al, 1999; Lieberman & Snowden, 1993; Levy & Derby, 1992; Gottlieb & Peters, 1991). As Chapter Two reports, Davison et al (2000) found people with CHD were less likely to attend a 'self-help' group compared to other conditions with similar or lower population prevalence, however evidence to reinforce or explain this is lacking. CHD Group studies however have consistently found that a minority of people with CHD participate (Bostock et al, 2007; SIGN, 2002; Hildingh & Fridlund, 2001; Davison et al, 2000). Even when systematically provided with verbal and written information as part of a research study only 32% (64/197) of Swedish post-MI patients attended a CHD Group (Hildingh & Fridlund, 2001). Given that lack of information is identified as a contributory factor in CHD and other 'self-help' group non-participation (described in detail below), this figure is likely to be higher than amongst post-MI people generally.

There are substantial limitations in the available evidence for understanding why people do not participate in CHD Groups. Nonetheless, the literature tentatively suggests three broad areas of influence that may be important and these parallel those in literature on CR and health resource non-use generally. These are: barriers relating to formal service-providers, barriers relating to the interaction of individuals' circumstances and the resource, and people's beliefs.

Non-referral, non-endorsement, and lack of information and encouragement

It seems ironic that while a defining characteristic of 'self-help' groups is their independence of formal, professional-delivered and organised services, issues relating to health professionals and services have been suggested to be an important influence on non-participation in CHD and other health-related 'self-help' groups. Yet, researchers

have shown that high proportions of 'self-help' groups receive some professional input and / or have links to services (Adamsen & Rasmussen, 2001; Lieberman & Snowden, 1993). This relationship appears to be important for understanding the influence health services and professionals appear to exert on whether or not people participate in these groups.

Non-referral, non-provision of information, non-endorsement, and non-encouragement by health professionals have been identified as important participation barriers. Lack of information and awareness about groups as a factor preventing people making an informed choice about whether or not to attend is reported in literature on CHD Groups (Hildingh & Fridlund, 2004; Hildingh et al, 1997, 1994; Morland, 1992), Kurtz's general group review (1990), and other health group studies (Bui et al, 2002; Krizek, 1999; [cancer]). Some studies have reported that a proportion of non-attenders expressed interest in groups when informed about them by researchers (Hildingh et al, 1997 [CHD]; Bui et al, 2002 [cancer]; Trojan, 1989 [various]). The role of health professionals as 'gatekeepers' to information about groups is crucial because information from non-health service sources is limited or fails to reach its target audience (Bostock et al, 2007; Hildingh & Fridlund, 2004; Hildingh et al, 1997, 1994 [CHD]; Damen et al, 2000; Krizek, 1999 [cancer]; Lock, 1986 [various]).

Low awareness and information about groups among professionals is a factor, yet negative attitudes and beliefs among professionals have been suggested to be more influential, resulting in reluctance to endorse, refer, and encourage, and even to make information available (Cardiac Rehabilitation Redesign Steering Group, 2003; Hildingh & Fridlund, 2000 [CHD]; Damen et al, 2000; Bradburn et al, 1992 [cancer]). Hildingh & Fridlund (2000) found a majority of cardiac nurses were aware of groups but did not refer, partly due to lack of knowledge about their function and value, but also because their socialisation as 'expert providers' meant they mistrusted other helping resources. Bradburn et al (1992) found strong scepticism about the value of groups and concerns about their quality among cancer professionals, while the Lothian Cardiac Redesign Report (Cardiac Rehabilitation Redesign Steering Group, 2003) suggests these reasons may similarly impede referral and information about CHD groups. Other studies have identified a clash between health professionals' values and those they believed were embodied in 'self-help' groups (Damen et al, 2000 [cancer]; Kelleher, 1991 [diabetes];

Lock, 1986 [various]). Kelleher suggests the underlying principle of experiential knowledge implicitly challenges the hegemony of health professionals, while Damen et al propose that the anti-professional image of self-help groups in the 1960s and 1970s may continue to deter professionals.

However, echoing the CR and wider non-use literature, 'self-help' group studies have indicated that even when people receive information and encouragement there remain significant factors that may discourage participation. This is illustrated by the sole example of a CHD Group prospective study, in which two-thirds of people didn't attend despite being invited and informed (Hildingh & Fridlund, 2001).

Barriers

Access barriers that have been reported by CHD and other health-related 'self-help' group studies appear highly similar to those in the CR and wider non-use literature. These relate to the interaction of a person's circumstances and the way the resource is provided, thwarting participation among some people who wish to attend, and adding a further deterrent, and possibly also a sense of legitimacy / justification, for people who are disinclined for other reasons. Logistical issues have been most commonly reported: including distance, lack of transport, rurality, and anxiety about travelling alone or due to their condition (Bostock et al, 2007; Hildingh et al, 1997; Klinger, 1985 [CHD]; Bludau-Scordo, 2001 [heart implant patients]; Bui et al, 2002 [cancer]); and inconvenient timing (Krizek, 1999 [cancer]; Levy & Derby, 1992 [bereavement]). Several studies have suggested people from lower socio-economic groups may be less likely to attend (Katz et al 2002; Krizek 1999; Bauman et al, 1992; Deans et al, 1988 [cancer]; Williams, 1989 [ankylosing spondylitis]). However, explanations are lacking and it is unknown whether people in poor socio-economic circumstances are deterred by practical barriers, as some CR studies and the wider non-use literature has suggested, or by beliefs about groups.

Surprisingly and in contrast to the CR evidence, people's life roles and responsibilities have not been explicitly highlighted in CHD Group studies relating to non-participation, and have received limited mention regarding other health groups. Klemm et al's cancer group review (2003) does however suggest caring responsibilities can be a barrier. It is possible that for some reason life roles may be less of an obstacle to participating in 'self-

help' groups than formal health services. Yet it may equally be a function of the limited research on non-participation, the scarcity of CHD Group non-participant studies, and the dearth of qualitative studies that have explored the experiences and perspectives of non-participants in these groups. My study appears to be unique in addressing this gap, and can provide insight into how people's lifeworld may influence CHD Group non-participation.

Health beliefs and attitudes

Evidence in the 'self-help' group literature relating to people's state of health is sparse and equivocal, yet there are indications that people's beliefs and attitudes about their condition may be an important influence on whether people participate or not. Bui et al (2002) found some cancer group non-participants cited poor health as their reason for non-participation, yet the quantitative design fails to explain whether this was because they felt unable, or believed it wouldn't benefit their condition and if so why. Conversely, several studies have reported that a person's perception that their health was relatively good, that they were recovered, or their problems were not serious enough to require additional support from a group, were important reasons for non-participation (Hildingh & Fridlund, 2001; Fridlund, 1993 [CHD]; Bludau-Scordo, 2001 [heart implant patients]; Levy & Derby, 1992 [bereavement]). These contrasting findings tentatively suggest that a perception either of poor health; or alternatively of good / reasonable / recovering health that doesn't require additional support, may discourage a person from attending a 'self-help' group.

Although the evidence is sparse, several studies reflect the CR findings by identifying further beliefs relating to a person's assessment and stance regarding their condition and health status, and have suggested these can be influential regarding whether the person participates or not in a 'self-help' group. Some people adopt an attitude of minimising or denying their symptoms and condition-related problems and have been described as wishing to 'normalise' their lives, trying to 'get on with life', not allowing their condition or their concerns to dominate, or seeking to avoid being 'labelled' as someone with the condition. Researchers have suggested that attending a group focused on their illness and identifying themselves foremost as a person with the condition may be unacceptable or inconceivable for such people (Charlton & Barrow, 2002 [Parkinson's disease]; Damen et

al, 2000; Krizek, 1999 [cancer]; Norton, 1993 [depression]). However, no CHD evidence is available – a gap my study will address.

Wider beliefs and attitudes

Negative beliefs about 'self-help' groups have been reported to be influential deterrents for some people. Personal dislike of, or concerns about group activities have been cited as reasons for non-participation in a number of reviews (Patel et al, 2005; Moeller, 1983) and studies (Jackson, 2000 [CHD]; Levy & Derby, 1992 [bereavement]). Reluctance to discuss personal issues with unknown people can be a significant deterrent for some people (Patel et al, 2005; Levy & Derby, 1992), and Patel et al suggest this may be particularly influential for people from a minority ethnic culture. The semi-formal, non-medical, independent status of groups may also deter people who prefer professional guidance (Hildingh & Fridlund, 2001 [CHD]; Moeller, 1983 [review]). This appears to run counter to evidence indicating the strong professional links of many 'self-help' groups (Adamsen & Rasmussen, 2001; Lieberman & Snowden, 1993), yet if professional involvement and endorsement of groups is not publicised then a person may be unaware of this. Research to ascertain if this is the case is needed. Moreover this issue prompts but doesn't answer the question of whether some of these CHD Group non-participants may be positively inclined towards CR because of the professional, formal status of this resource. This provides a further example of the value of comparing non-participation between the two resources.

A range of qualitative and quantitative studies (Peters et al, 2003 [MS]; Damen et al, 2000 [cancer]; Williams, 1989 [ankylosing spondylitis]; Levy & Derby, 1992 [bereavement]) and reviews (Borkman, 1991; Moeller, 1983) have identified negative images of 'self-help' groups as a deterrent, and have suggested that groups have an 'image problem'. Some studies have found that both participants and non-participants had negative prior images of groups but participants attended either because the image they held was less negative, or because they considered that the intensity of their needs outweighed the stigma they believed was attached to group membership (Levy & Derby, 1992). This again indicates the importance of condition-related beliefs, and the way different beliefs, attitudes and values may be mutually reinforcing or contradictory. Research is needed to better understand why certain beliefs and attitudes take precedence.

Damen et al's qualitative study (2000) found some people viewed groups as (too) radical and alternative, based on their 1960s image. However mostly studies have reported that people are deterred by negative images of other participants, and don't wish to associate themselves, or be associated by others with such people. Negative images of participants included: being 'needy' or lonely (Levy & Derby, 1992), people who only complained and gossiped (Damen et al, 2000); people much older than themselves (Peters et al, 2003; Damen et al, 2000); and being dominated by the opposite sex (Williams, 1989). Damen et al suggest negative images of 'self-help' groups are a cultural stereotype propagated particularly in the media. Perceptions of age and gender dissimilarities with other participants have also been cited in the CR and wider non-use literature as possible deterrents, yet the negative images linked to the nature of the resource which have been identified regarding 'self-help' groups, aren't indicated. Nonetheless some 'self-help' group studies have reported that some non-participants expressed interest in attending (Bui et al, 2002 [cancer]; Hildingh & Fridlund, 2001 [CHD]; Bludau-Scordo, 2001 [heart implant patients]; Trojan, 1989 [various]). These people might possibly have responded to a positive image of groups presented by the researchers; but this finding also points to heterogeneous needs and preferences among 'non-participants' with similarity to the finding in the CR literature. This point is made in the Scottish cardiac guideline (SIGN, 2002), which cites evidence suggesting that while the informal interaction and opportunity to share experiences that are characteristic of groups appeal to some people, others are strongly deterred.

The wider literature suggests that a widespread preference for self-reliance, and informal support as the preferred choice if help is needed, are important reasons for health resource non-use. The 'self-help' group literature provides some evidence to support this. A range of studies have reported that non-participants were more likely to perceive adequate support from their existing networks and so didn't feel they needed additional support from a group (Hildingh & Fridlund, 2001; Fridlund, 1993 [CHD]; Bui et al, 2002; Damen et al, 2000 [cancer]; Levy & Derby, 1992 [bereavement]). This appears to be bolstered by participant research that has shown that although group participants generally have social networks and support, they attend seeking a specific type of empathic and condition-related support that their network cannot provide (Bludau-Scordo, 2001 [heart implant

patients]; Levy & Derby, 1992 [bereavement]; Gottlieb & Peters, 1991 [various]; Jacobs & Goodman, 1989 [mental health).

Williams (1989) suggests that people who interpret the widespread cultural value of 'self-help' to mean individual self-reliance rather than mutual support against common problems may be less likely to participate in 'self-help' groups. Several studies have reported that the moral significance attached to self-reliance and a belief that help-seeking via a group would be seen as a sign of weakness contributed to some people's reluctance to join groups (Bludau-Scordo, 2001; Levy & Derby, 1992; Moeller, 1983). Hildingh & Fridlund (2001) suggest society generally places low value on peer support and that this contributes to reluctance to use CHD 'self-help' groups. Colella & King (2004) reinforce these findings, suggesting peer support is under-recognised and under-valued by health professionals involved in CHD secondary prevention and may possibly compound people's reluctance to seek or use 'self-help' groups. Reflecting a theme in the wider literature (Rogers et al, 1999), Williams argues that health professionals' promotion of independent self-management among patients may also discourage people from seeking group support.

Conclusion

The traditional 'non-compliance' view of non-use of recommended health resources as a negative patient behaviour has been displaced and its successor the 'non-adherence' or 'concordance' perspective acknowledges that there may be obstacles to resource use and people are entitled and possibly justified in not using resources in relation to constraining circumstances. Nonetheless, this perspective - which has been influential regarding health policy and service provision, still presents the following of professional recommendations as the most appropriate option for managing illness. Yet, it is clear that while health professionals and health services may exert an important influence - even regarding non-service-related CHD Groups, people's everyday life circumstances and beliefs are fundamental and sometimes more influential in shaping their actions in relation to health resources.

The literature on non-use of health resources generally and non-participation in CR and CHD Groups has some significant limitations in terms of the scope, quality, and quantity of evidence - issues which are particularly acute regarding CHD Group studies. Nonetheless certain themes have been suggested to be important. There are barriers relating to service provision and organisation and the inter-relation of these with people's circumstances that may impede or deter people from using health resources and specifically CR and CHD Groups. Yet, people may also opt out because the resource doesn't meet their needs and preferences in relation to their wider life and beliefs. Overall the evidence suggests that non-use or non-completion of a treatment or programme is often multi-factorial, whereby several inter-related factors combine to produce this outcome.

However, the weaknesses of the existing evidence mean that the way many of the specific factors influence individuals about whether to participate in CR or CHD Groups has, at best, been partially explained. At present also, although some general non-use studies have provided valuable insights, the interplay between the different factors that may influence individuals regarding CR and CHD Groups is poorly understood. Furthermore, the possible interplay between participation and non-participation in formal and semi-formal resources relating to a particular condition has apparently been little explored, and specifically no previous studies have explored non-participation in relation both to CR and CHD Groups. Whether different factors have greater influence regarding CR compared to CHD Groups, and whether and how people consider these resources in relation to the other in terms of whether they participate or not, have not previously been investigated. My study addresses these important aspects of post-MI recovery. By taking an exploratory approach and considering non-participation in the context of people's wider lives, I build from the existing research that has identified the importance of informal resources for people managing illness, and has suggested that self-reliance may be a factor. This approach offers scope to uncover the relation between use and non-use of formal, semi-formal and informal resources.

Chapter Four - Experiences and perspectives of people with CHD and other chronic conditions and their family members

My study investigates the experiences and perspectives of people who have not participated in either CR and / or a CHD Group. In this chapter I consider research findings on these topics in relation to their significance and implications for my own study population, and identify areas where evidence or understanding is limited. The previous chapter highlighted the sparse and limited evidence on CHD Group non-participants, and although more studies exist regarding CR non-participation, literature exploring their experiences is more limited. Nevertheless, non-participants comprise a substantial part of the post-MI population, and researchers and policy makers have identified strong commonalities in the experiences of people with different chronic conditions (Lawton, 2003; Annandale, 1998; Department of Health, 2001). I therefore draw from the rich body of studies concerning people with CHD and other chronic conditions and their family members to supplement those specifically relating to post-MI non-participants.

Although the limited non-participant literature should be treated as tentative, an overview suggests strong similarities in the major issues and themes regarding CR, CHD Group and other 'self-help' group non-participants, people with CHD generally, and people with other chronic conditions and their family members. In parallel with cross-condition similarities, the literature also emphasises diversity of experiences, needs, preferences, and circumstances among people who share a particular condition, and suggests these variations may be as great as between people with different conditions (Locker, 2003; Bury, 1991). This reflects heterogeneity among people who have a particular chronic condition, in terms of the macro (such as class, gender) and micro level influences (such as relationships, and family / job circumstances) (Lawton, 2003). It also suggests that the experience of illness is subjective to a particular individual and their family, based on the nature of their symptoms, their beliefs, values and attitudes, and their circumstances (Pierret, 2003).

Moreover, the experience of living with chronic illness both for the person and their family changes over time in response to changes in symptoms, circumstances, and their beliefs (Corben & Rosen, 2005; Lawton, 2003; Bury, 1991; Dhooper, 1983). The CHD literature suggests that the experience of many post-MI people evolves in a similar pattern. For many the initial period is most difficult, and resistance and feeling overcome by their illness is widespread. Hildingh & Fridlund (2007) describe this phase as 'succumbing'. People then may progress to a period of adjustment, having found a way of accomodating themselves and their lives to their condition (Gregory et al, 2005; Ostergaard-Jensen & Petersson, 2003; Winters, 1997; Johnson, 1991). However, this transition is not universal - some people experience ongoing disruption and uncertainty (Bergman & Bertero, 2003; Clark, 2003). Nor is it uni-directional, as people's condition, support, and circumstances fluctuate, and mean they may continue to experience periods of difficulty (Hildingh et al, 2007; Clark, 2003).

The impacts of a chronic condition

The type, extent, and duration of impacts that a chronic condition has on a person and their family vary considerably. Nonetheless the experience of coming to terms and learning to live with a condition may be profoundly disruptive, entailing life-changing consequences to some degree - as has been shown in qualitative studies with people with various chronic conditions (Charlton & Barrow, 2002; Bury, 1991; Charmaz, 1991) and specifically post-MI people and their families (Eriksson & Svedlund, 2006; Thompson & Webster, 2004; Clark, 2003). Although physical impacts are of major importance in terms of a person's experience, the consequences and significance of a chronic condition extend far beyond the body and health. Anderson (1992, p. 217) describes having a chronic condition as an, 'assault upon many areas of everyday life', influencing the different spheres of a person's and their family's life, social situations, their autonomy and independence. People with severe problems can find that managing their condition and its consequences 'consumes' their daily life (Locker, 2003).

More fundamentally, the CHD and wider literature indicates that a condition not only transforms a person's way of life but also the person themselves. Thus psychological and emotional health and identity are affected – being an 'assault' on the self as well as the body (James & Hockey, 2006; Wheatley, 2006; Williams & Bendelow, 1998; Anderson, 1992; Charmaz, 1991). The extent of the disruptive influence of CHD for some people has been described as, 'like an explosion in your life' (Clark, 2003, p. 547), while the family can feel like an 'intruder' has entered and begun dictating the terms of their life (Eriksson & Svedlund, 2006). Many studies have described how the illness also may change the future people hitherto envisaged. Svedlund & Danielson (2004) for example, found 'the illness changed the life the women had hoped to live'. Bury (1988) identifies two categories of meaning that a chronic condition can have. 'Meaning as consequence' - the practical consequences the condition has on different aspects of a person's and their family's life, and the actions and responses taken to manage this altered life; and 'meaning as significance' – people's beliefs and attitudes about their condition and the fundamental impact these have on their self-conception. These are discussed below, regarding people with chronic conditions and their family members.

Physical impacts

Physical impacts of chronic illness have been widely reported. Loss of physical capacities, disability, and pain are common experiences, but vary considerably. Some people experience less extensive problems and / or shorter-term or sporadic episodes, whereas others experience irreversible loss of function and deal with major ongoing physical difficulties. Studies report that besides coping with cardiac symptoms, co-morbidity can be an exacerbating issue for people with CHD. Evidence on whether people's experience of their health influences CR and CHD Group participation is limited and equivocal, particularly regarding 'self-help' groups, although the CR evidence does suggest greater co-morbidity may discourage participation. Reviews have found stronger evidence that women and older people with CHD generally experience greater physical impacts (Hildingh et al, 2007; Davidson et al, 2003; Daly et al, 2002), and have suggested that this may contribute to their lower participation and adherence.

Exploratory studies have shown that the significance and consequences for psychological and emotional health, identity, managing everyday life and social situations, and personal autonomy and independence can be at least as important and problematic as physical impacts (James & Hockey, 2006; Charmaz, 1994, 1991; Anderson, 1992). Beyond the experience of symptoms and their effects, people's attitudes and beliefs about their condition and their circumstances can also be influential. Non-participation literature suggests people's perceptions about their physical condition may contribute to a view that CR or a CHD Group is unnecessary, either because they consider themselves well enough to manage without, or believe it would be unfeasible or uncomfortable due to physical limitations. Further research is required regarding CHD Groups.

Psychological and emotional impacts

Exploratory studies have identified psychological and emotional health impacts as a significant feature of the experience of chronic conditions, while WHO survey findings indicate that depression and anxiety exacerbate people's experience of chronic illness and increase likelihood of disability (Moussavi et al, 2007). Psychological and emotional impacts are a major theme in the CHD literature, and it has been widely reported that these needs are poorly met (Sjostrom-Strand & Fridlund, 2007; Paquet et al, 2004; Clark, 2003; Henriksen et al, 2003; Thompson et al, 1995). Reviews have identified depression as reducing the likelihood of CR participation (Cooper et al, 2002; Daly et al, 2002). Research is needed to identify if this may similarly discourage CHD Group participation, or whether the different nature of this resource may prove more accessible or appealing to people experiencing depression. Reviews and qualitative studies have found that women with CHD generally experience poorer psychological and emotional health than men, yet further exploration is needed to uncover reasons for this (Hildingh et al, 2003; Davison et al, 2003).

People's social networks have been identified as an important emotional support resource for people with CHD. Yet research, particularly qualitative explorations of couples' experiences following MI, has shown that such support is neither universally available nor always capable of meeting their needs (Mahrer-Imhof et al,

2007; Kristofferzon et al, 2007; Goldsmith et al, 2006; Thompson et al, 1995). Family members themselves have psychological and emotional needs related to the strain of supporting the person with the chronic condition, but often lack appropriate support (Eriksson & Svedlund, 2006; Tapp, 2004; Van Horn et al, 2002; Svedlund & Axelsson, 2000; Thompson et al, 1995; Moser, 1993 ; Dhooper, 1983). Emotional support has been reported as a key motivation for attending CHD and other 'self-help' groups (page ...), yet participation statistics clearly show few people access this resource. Some people apparently opt out of CR because they perceive it caters primarily for physical rehabilitation and so will not address their psychological and emotional needs (Hildingh et al, 2007; Paquet et al, 2004; Henriksen, 2003; Gassner et al, 2002; Wyer et al, 2001; Bergman & Bertero, 2001). The different nature of CHD Groups, and some limited evidence that non-participants who retrospectively expressed interest perceived they could provide emotional support (Bostock et al, 2007; Gregory et al, 2006a; Hildingh & Fridlund, 2001), suggests that people deterred from CR for this reason might wish to attend a CHD Group. Research is needed to investigate if this is the case.

Widespread experience of uncertainty and existential insecurity amongst people with a condition and family members in terms of the perceived threat to the person's present and future health, and their family's way of life is a major theme in the CHD (Gregory et al, 2006a, 2005; Ostergaard-Jensen & Petersson, 2003; Roebuck et al, 2001; Johnson, 1991) and wider literature (Lawton, 2003; Crossley, 2003; Bury, 1991). People can lose trust in and feel betrayed by their bodies and feel they can no longer take their body, nor daily life and future plans for granted (Mahrer-Imhof et al, 2007; Oakley, 2007; Wheatley, 2006; Charmaz, 1994). Uncertainty and anxiety are especially intense in the early phase of illness when symptoms are unfamiliar and frightening (Lawton, 2003; Bury, 1991) and this may be particularly intense following the acute event of MI when people may fear recurrence (Clark, 2003; Ostergaard-Jensen & Petersson, 2003). Sjostrom-Strand & Fridlund (2007) describe some people being initially 'terrified' of managing at home. For family members an MI has fundamental significance as a 'threat to the integrity of the family' (Kristofferzon et al, 2007; Svedlund & Axelsson, 2000; Dhooper, 1983).

Research has suggested that for many people anxiety gradually lessens as they mentally adjust to their changed situation (Clark, 2003; Winters, 1997; Dhooper, 1983), yet studies also have indicated that residual concerns and uncertainties may remain or re-emerge. Gregory et al (2005) identified that many months after MI people may remain uncertain about their ambivalent status - between being ill and well, and this may limit their confidence regarding certain activities. Persistent worry about their condition combined with lack of guidance about safe activity is an issue for some people (Bergman & Bertero, 2001). Evidence on whether anxiety may encourage or discourage CR and CHD Group participation is limited and equivocal (pages ...) and possibly suggests that anxiety may influence people in different ways. Nonetheless, Clark et al's study (2004) found psychological and emotional needs among CR non-participants and non-adherers remained unmet, suggesting that alternative support was unavailable or inadequate. Evidently further exploratory research is needed to understand how people's mental and emotional health experience and needs relates to CR and CHD Group non-participation.

Yet, while adverse emotional and mental health impacts are most prominent, the diversity of experience is apparent in that some CHD studies have reported that some people perceive positive mental and emotional health effects related to their condition. These people described the threat of their condition as prompting them to reinvigorate their approach to life, and to believe they had a 'second chance' to enjoy life and make positive changes (Hildingh et al, 2007; Paquet et al, 2004; Bergman & Bertero, 2003; Wyer et al, 2001; Winters, 1997). This theme has also been identified regarding other conditions (Seymour, 1998). Dhooper's quantitative study (1983) found 60% of post-MI people and family member interviewees concluded that overall positive emotional benefits of their post-MI experiences outweighed negative aspects. Bergman & Bertero (2003) found it also provided some people with a 'motive power' to undertake lifestyle behaviour changes. Wyer et al (2001) found some people viewed CR as a means to put this new resolve into action, but their motivation ebbed when they saw themselves starting to improve and believed participating was no longer necessary. These two studies suggest that while a 'carpe diem' attitude may encourage some people to use a resource such as CR, it may

equally motivate others to make changes autonomously, while for some people the motivational effect may be short-lived.

Managing the condition

Managing treatment regimes can become a feature of the lives of people with a condition and their family (Oakley, 2007; Locker, 2003; Lawton, 2003; Bergman & Bertero, 2001; Bury, 1991). This can entail attending medical consultations and other treatment and support resources, and seeking information. Waiting for referrals, treatments or results may add to the disruption of ordinary life, meaning other aspects of life have to be put ‘on hold’ (Tod et al, 2002, 2001; DIPEX, 2008; Bury, 1991). Yet, as Chapter Three describes, some people are unable or do not believe it worthwhile to prioritise their condition over wider life issues, such as returning to work or maintaining family and social routines, and so opt not to use resources. However, services and information sources can also engender frustration, confusion, and disappointment if a person cannot find treatment and information that makes sense to them after going on what has been described as a ‘medical merry-go-round’ of searching (Jobling, 1988). For some, treatment can also become part of the problem if it engenders side effects, particularly if these encroach further on everyday capacities and activities (Bergman & Bertero, 2001; Bury, 1991). Herxheimer & Ziebland (2003) highlight the irony that despite the frequency that information about CHD and other chronic conditions features in the media, and the panoply of information resources now available, people often still don’t know how to find information they need regarding their diagnosis and dilemmas about their condition.

Although of considerable significance for many people, health service interactions form a relatively small and infrequent portion of the regime management that people with chronic conditions undertake. The person and / or family members undertake the majority as part of everyday home life (Scambler, 2003). After living with and managing their condition for some time some people have been described as having gained ‘expertise’ regarding their own body, symptoms, and perhaps also treatment options (James & Hockey, 2006; Bury, 1991). Health professionals and policymakers now commonly advocate the concept of the ‘expert patient’

undertaking effective 'self-management' of their condition (Coulter & Redding, 2007; Rogers et al, 1998). While for some this may be empowering, through giving people greater control of their day-to-day lives and reducing medical dependency (James & Hockey, 2006), it is not welcomed by all (Corben & Rosen, 2005; Rogers et al, 1998). Moreover, in order for people and family members to feel confident, motivated, and be effective in managing their condition they require guidance. CHD studies from various countries have identified a deficit in this respect (Gregory, 2005; Ostergaard-Jensen & Petersson, 2003; Davidson et al, 2003; Thompson et al, 1995; Moser, 1993).

Lifestyle behaviour change is recommended as part of self-management for many chronic conditions. For CHD quitting smoking, dietary changes, and exercise are prescribed. People who already followed prescribed measures prior to their condition's onset have been reported as generally needing to make few subsequent lifestyle changes (Wheatley, 2006; Bergman & Bertero, 2001; Johnston, 1999; Sullivan-Smith, 1995). Some people may be motivated to undertake lifestyle changes by the belief they have been given a 'second chance' to improve their life (Wheatley, 2006; Bergman & Bertero, 2003; Seymour, 1998). Bergman & Bertero (2003) found some people were motivated to follow lifestyle recommendations due to gratitude to professionals for care received and resources offered. Benefits have been reported among family members who also undertake lifestyle changes alongside the person with the condition (Wheatley, 2006; Dhooper, 1983).

Nevertheless, reluctance and difficulty undertaking and maintaining changes have been a more common theme in quantitative (Ebrahim & Davey-Smith, 1997; Klein, 2001) and qualitative (Condon, 2005; Gregory et al, 2006b; Webster, 1997; Henriksen, 2003) research among people with CHD. Conflicts with people's wider priorities such as everyday life routines and activities, and avoiding causing tension in relationships have been identified as obstacles (Hildingh et al, 2007; Goldsmith et al, 2006; Condon, 2005; Gregory et al, 2006b), while attempting several changes simultaneously can exacerbate the difficulties experienced (Condon, 2005). Studies have identified dilemmas for family members - balancing between being seen to 'nag' or 'police' their partner and risking damaging their relationship, and their own

anxiety, concern, frustration and desire to care for their partner by encouraging changes (Goldsmith et al, 2006; Tapp et al, 2004). Practical barriers such as poor weather, and lack of transport or neighbourhood safety may deter people (Campbell et al, 1994; Sullivan-Smith, 1995), and lack of support from family or others can reduce likelihood of successful change (Fleury et al, 2004; Ben-Sira, 1990).

Desire to return to their pre-CHD 'normal' life, especially in the context of wider upheavals caused by their condition, may also encourage people to revert to previous lifestyle habits (Hildingh et al, 2007; Svedlund & Axelsson, 2000). Oakley's personal account (2007) describes behaviour change as 'housework of the body', a non-pleasurable 'chore' that is difficult to motivate oneself to perform and maintain in the longer term, especially when professional support often ebbs after initial input in the early post-diagnosis phase. This has been described in qualitative CHD studies (Gregory et al, 2006b; Condon, 2005; Roebuck et al, 2001; Svedlund & Axelsson, 2000).

Beliefs are also significant. Scepticism that lifestyle 'risk factors' are related to their condition, and beliefs in fate, heredity, and stress as CHD's primary cause, have been widely reported as barriers (Condon, 2005; Bergman & Bertero 2001; Webster, 1997; Emslie et al, 2001; Davison et al, 1991). Misperceptions about the nature of CHD: who is at risk, its consequences, and whether successful treatment is possible, may undermine motivation for behaviour change (Condon, 2005; Emslie et al, 2001; Davison et al, 1991). Negative recovery expectations are also a discouraging factor (Macinnes, 2005; Wiles & Kinmonth, 2001; Emslie et al, 2001; Thompson et al, 1995). Wiles & Kinmonth found that if health professionals emphasise likelihood of good post-MI recovery this can inadvertently have a negative effect if people interpret this to mean behaviour change is only needed in the short-term, or become disappointed if they don't recover well and so lose motivation for change.

Ostensibly it appears that similar factors may discourage people from lifestyle change as those suggested to deter participation in CR and CHD Groups. Yet several studies caution against assuming non-participants and non-adherers in these resources do not undertake lifestyle change. Winberg & Fridlund's quantitative

study (2002) found little apparent difference in lifestyle after four years between female CR participants and non-participants - indicating that non-participants also undertook lifestyle modifications, while participants experienced difficulty maintaining changes. Jones et al's qualitative research (2007) found many non-participants and non-adherers used information they received from professionals to undertake their own 'modified programmes' of behaviour change that suited their needs and circumstances better than the structured professionally-set programmes. The authors identify need for programmes to adapt to meet the needs of a broader range of people than the middle-aged men who were the key client group in the early days of CR.

Evidence regarding behaviour change among CHD Group non-participants is sparse. Hildingh et al's longitudinal study (2001) found non-participants undertook fewer lifestyle changes and maintained more risk-factor behaviours. Yet because their sample wasn't randomised and lacked diversity they identified need for further research to corroborate their finding. No previous studies have explored CHD Group non-participants' perspectives, experiences and needs regarding behaviour change - an important gap that my study addresses.

Social consequences

Qualitative research has suggested that the consequences of CHD and other chronic conditions upon a person's 'lifeworld' may be as, if not more, significant than directly condition-related ones (Kristofferzon et al, 2007; Wheatley, 2006; Clark, 2003; Bury, 1988). A chronic condition affects a person's home-life, interactions with their social network, and the lives of their families. Although the extent and duration varies, changes in household roles, responsibilities, relationships, day-to-day practices and routines are commonly experienced. These changes arise from a combination of the effects the person's condition has on their capacities, needs, and perceptions; and also their family's perceptions, which may coincide or conflict with those of the person.

The roles and responsibilities a person undertook prior to their condition's onset may be reduced or undertaken by another person. This practical help can be a vital aid to

a person's rehabilitation, enabling them to rest or avoid over-exertion; or may be necessary to maintain household functioning. Yet it may also entail negative mental and emotional effects if a person feels guilty about being unable to accomplish their usual roles and contribute to the family or frustrated about loss of independence (Hildingh et al, 2007; Helpard & Meagher-Stewart, 1998; Roebuck et al, 2001). Roebuck et al (2001) found people experienced greatest distress not because of symptoms but due to their inability to fulfil daily tasks. Other studies have reported people undertaking 'forbidden' tasks 'on the sly' to attain a feeling of self-mastery while avoiding family censure (Svedlund & Danielsen, 2004; Helpard & Meagher-Stewart, 1998). This has been reported regarding men and women, but reviews have suggested the traditionally greater importance of the domestic sphere to women means their sense of loss and frustration may be greater (Hildingh et al, 2007; Davidson et al, 2004).

There are consequences also for family members who take over roles and tasks. When these additional responsibilities are substantial, and especially when the person also acts as carer for the person with the condition and has limited support or help, the carer's health and quality of life can be adversely affected. This has been reported regarding illness generally (Morgan, 1996) and CHD specifically (Eriksson & Svedlund, 2006; Svedlund & Axelsson, 2000; Dickerson, 1998). My study addresses the dearth of previous research examining the experiences of family members of CR and CHD Group non-participants, and provides insight into whether their needs are similar or different from those reported in the general CHD and wider literature.

On the other hand, the literature indicates that people may experience difficulties trying to maintain usual household obligations, and this can adversely affect their physical and mental health and impede rehabilitation actions. Again qualitative reviews and studies have identified this as particularly likely among women due to their generally greater domestic roles and 'other-focusedness' (Hildingh et al, 2007; Sjostrom-Strand & Fridlund, 2007; Emslie, 2005; Davidson et al, 2004; Sullivan-Smith, 1995). Quantitative findings reinforce this, for example, Hamilton & Seidman (1993) found 75% of women took on household responsibilities within four

weeks of their MI compared to one-third of men (cited in Tardivel, 1998). Moreover, sociological studies on chronic illness and CHD have indicated that although some men undertake substantial caring roles (Svedlund & Danielson, 2004; Arber & Ginn, 1999), men are more likely to receive support of all types from female partners than vice-versa (Kristofferzon et al, 2007; Thompson et al, 1995; Charmaz, 1995). As Chapter Three reports, lack of encouragement and support to attend has been identified as one factor contributing to women not participating in CR and 'self-help' groups. My study will identify if this also applies regarding CHD Groups.

A chronic condition encroaches on people's relationships. In the early phase of coming to terms with CHD or another condition relationships frequently undergo a process whereby both parties adjust to the changed situation, which Wheatley's CHD study describes as 'renegotiation'. This may entail changes in the balance and roles in the relationship and the understandings on which it is based (Wheatley, 2006; Weaks et al, 2005). Some couples experience positive effects after overcoming the threat to the person's health and life, such as increased intimacy or re-evaluating their lives and according their relationship higher priority (Wheatley, 2006; Svedlund & Danielson, 2004; Bergman & Bertero, 2003; Dickerson, 1998). Valued family relationships can be a strong incentive for a person to endeavour to recover or optimise their health, and having people depend on them can impel people to 'keep going' (Wilson, 2007; Doyal & Anderson, 2005; Bilhult & Segesten, 2003). Hagan et al (2007) found this added motivation for some people to attend CR. Conversely however, qualitative CHD studies have suggested that previously problematic relationships are put under further strain and the circumstances created by the condition may trigger the deterioration or breakdown of such relationships (Mahrer-Imhof et al, 2006; Karner et al, 2004; Thompson et al, 1995).

Studies of experiences of chronic illness (Locker, 2003) and CHD (Eriksson & Svedlund, 2006; Wheatley, 2006; Tapp, 2004; Svedlund & Danielson, 2004) have indicated that even in strong relationships tensions and distancing may occur. This is due to difficulties between partners in understanding and communicating their experience and frustrations and difficulties regarding changes in roles, responsibilities, and lifestyle. Ironically, this may occur alongside, despite, and

possibly as a consequence of, family members' efforts to be supportive and caring. Studies have described people and family members undertaking what Hochschild (1979) first described as 'emotion work' – whereby a person tries to conceal negative emotions, such as fears or anger, to present a positive front they believe will protect the other person's emotional and psychological wellbeing. Such 'emotional labour' may however be stressful and damage the person's own emotional and psychological health and the relationship (Eriksson & Svedlund, 2006; Morgan, 1996).

Anxiety about their relative's health and desire to care for and help them has been reported in CHD studies as resulting in family members providing or seeking to provide more support than the person with the condition wants or feels they need (Sjostrom-Strand & Fridlund, 2007; Wheatley, 2006; Goldsmith et al, 2006; Svedlund & Danielson, 2004; Tapp, 2004; Ostergaard-Jensen & Petersson, 2003; Roebuck et al, 2001). Both men and women have commonly been found to perceive their families are 'over-protective' in this way and this can engender frustration and resentment for both parties. Although the person with the condition may appreciate the gesture of caring, nonetheless they may perceive it negatively if it compounds losses of autonomy and independence in their life more generally. Conversely, family members may feel their expression of care has been ignored or rejected, or resent feeling obliged to undertake a 'nagging' role. Goldsmith et al (2006) describe caring as a 'double-edged sword' because this negative aspect often accompanied positive perceptions such as satisfaction from the caring role and affirmation of their relationships. Family members of people most severely affected by a condition may experience sadness and mourning for their previous relationship, life, and envisaged future (Eriksson & Svedlund, 2006; Ohman & Soderberg, 2004; Svedlund & Danielson, 2004).

Inadequate support to help family members cope with and manage their role of supporting relatives is a theme in the CHD and chronic illness literature from various countries. Lack of information and guidance about how to help their family member recover and manage their condition has commonly been reported and it has been suggested that health services focused on the needs of the 'patient' often overlook those of family members (Thompson, 2005). Emotional and psychological support

has been identified as a major deficit. People who perform full-time caring roles may also lack practical support for meeting their relative's day-to-day needs, particularly when help from their social networks is insufficient or inappropriate, or they try to be self-reliant to avoid 'burdening' others or be seen as unable to cope (Tapp, 2004; Svedlund & Axelsson, 2000; Van Horn et al, 2002; Dickerson, 1998; Moser et al, 1993). Initiatives to address information and emotional support needs among post-MI people's family members have been undertaken, including support groups organised by service-providers, although such provision is sparse (Van Horn et al, 2002; Stewart et al, 2001). Some studies of CR participants (Mahrer-Imhof et al, 2007; Wheatley, 2006), CHD Groups (Bostock et al, 2007; Gregory et al, 2006a; Hildingh et al, 1995) and other 'self-help' groups (Williams, 2004) have identified that attending these can benefit some family members. However the studies suggest CR didn't meet some people's needs. Moreover, low participation and awareness of these resources suggests that opportunity and use of such support by family members is a minority experience. My study addresses the need for research into the perceptions and experiences of non-participants' family members regarding these resources in terms of their own and their relatives' needs.

A chronic condition impacts on the social contact and activities of people with the condition and their family members. A condition's physical and social constraints can engender a contraction of their 'lifeworld' and social isolation, particularly for people whose condition entails severe effects and family members providing intense support (Eriksson & Svedlund, 2006; Ohman & Soderberg, 2004; Dickerson, 1998). Dhooper's survey (1983) found generally that families' social lives declined in the initial post-MI months when anxiety and uncertainty were greatest - suggesting that short-term negative impacts may be a widespread experience. However for many people social life was gradually restored. Managing CHD's social consequences has been reported to be as challenging as managing physical aspects (Wheatley, 2006; Gregory, 2005). A condition impacts on people's social identity – the way present themselves to, and are seen by others, and their activities. These may be affected by physical health limitations; uncertainty about safe activity; beliefs about 'appropriate' activities for someone with their condition; and possibly by difficulties reconciling lifestyle recommendations with social activities.

CHD qualitative research has found that being forced to give up or be absent from work is stressful, particularly by creating a financial strain (Sjostrom-Strand & Fridlund, 2007; Emslie, 2005). Several studies have reported that some people opt out of CR because of this (Hagan et al, 2007; Jones et al, 2007; Cooper et al, 2005). My study provides insight into whether a perceived need to return to work may similarly influence CHD Group non-participation – an area which hasn't previously been addressed. Some studies have reported that illness may result in redundancy and thwart promotion (Alaszewski et al, 2007; Hagan et al, 2007; Locker, 2003). Whether a working environment is flexible and a person has social support or not can be influential in helping or impeding return (Alaszewski et al, 2007). Several studies have reported that job loss fears discouraged CR participation (Hagan et al, 2007; Jones et al, 2007; Cooper, 2005). Yet conversely, some CHD studies have found that after reviewing their life priorities some post-MI people sought to reduce their workload, especially if they believed over-work or stress contributed to their MI (Bergman & Bertero, 2003). Being unable to perform employment roles can adversely affect a person's identity. Loss or threat of loss of a working identity can adversely affect self-esteem and confidence and may contribute to depression (Oakley, 2007; Goldsmith et al, 2006). Inability to work may also affect families negatively through reduced household income, and adverse effects that role loss may have upon their relative's emotional and mental wellbeing (Dhooper, 1983).

Men have been reported to minimise their condition's impact on their employment in order to maintain this part of their identity as well as for practical reasons (Charmaz, 1995; Radley 1989). Thus some men develop strategies to enable them to return to work and 'keep up appearances'. The influence of illness on women's employment outside the home however has received scant specific mention. Domestic roles have been accorded far greater emphasis in women-focused research, and wider studies often haven't specified whether an identified employment influence related both to women and men. A few studies, including one on CHD, have reported negative impacts of employment loss for women in terms of income and identity (Alaszewski et al, 2007; Oakley, 2007; Gregory et al, 2005), while Alaszewski et al (2007) found that workplace barriers could impede women returning to work after a stroke. My

study specifically included employed women to explore this issue in relation to CR and CHD Group non-participation.

Impacts on identity

The impact of a chronic condition on a person's identity has been highlighted in the wider literature as one of the most significant and influential aspects of their experience (Lawton, 2003; Seymour, 1998; Charmaz, 1983; Bury, 1982). CHD studies have echoed this theme (Hilding et al, 2007; Wheatley, 2006; Gregory et al, 2005; Goldsmith et al, 2004; Johnson & Morse, 1990). Although traditionally a 'medical model' of health has promoted a view of the body as an entity divorced from the individual who inhabits it, explorations of people's self-concept instead have suggested that a person's body and self are inextricable in that the body is the medium through which people experience the world and by which others perceive them (James & Hockey, 2006; Twigg, 2006). Thus physical changes affect a person's self-conception and the identity others ascribe to them. A condition may be experienced as an 'alien invasion' in that the person feels estranged from the unfamiliar body they are experiencing, and which may not allow them to perform the usual roles and activities that contribute to their sense of self (Oakley, 2007; Charmaz, 1995; Anderson & Bury, 1988).

The impacts of illness on a person and the consequences in their life have commonly been described as having a disruptive effect on their self-conception. Goffman's seminal work in the 1950s and 60s identified how the perceived social stigma of not having socially acceptable 'healthy' status could result in a sense of 'spoiled identity'. A person's self-conception could also be undermined by loss of roles, activities, and capacities that contributed to this (1963). Sociological research in the 1980s and 90s has been important in further developing insight into the adverse impact that chronic illness can have upon identity. Bury described the concept of 'biographical disruption' (1982), whereby a person's understanding of themselves, in the past, present and envisioned future is dramatically disturbed and fundamentally changed by the condition. Charmaz (1983) described how people severely affected by their condition and its effects on their life, and who are unable to find new valued identity attributes to replace those lost or damaged, can experience a 'loss of self'.

Depression and inability to undertake rehabilitation activities or manage their condition and achieve an acceptable quality of life may ensue (Locker, 2003; Anderson, 1992; Charmaz, 1983).

The strategies people adopt to counter or mitigate negative identity impacts have featured prominently in more recent literature. Moreover, it has been suggested that some people's biographical and life circumstances mean they may not experience life with illness as severely disrupted (Lawton, 2003). For example, Pound et al (1992) found elderly people considered a stroke 'not that bad', believing that it was 'to be expected' at their life-stage. Yet other research has shown that despite the inevitability of an illness it may nonetheless be experienced as considerably disruptive (Sanders, 2002). CHD studies have described identity impacts and consequences (Hildingh et al, 2007; Wheatley, 2006; Davidson et al, 2004; Roebuck et al, 2001; Johnson, 1991). Yet while the CR literature implicitly indicates that aspects of identity influenced non-participation, for example a person's age, family responsibilities, and self-reliance; explorations of the underlying importance of these issues for identity have received scant attention. Evidence regarding CHD Groups is lacking. By exploring the perspectives of CR and CHD Group non-participants and their relatives my study provides insight into this neglected and potentially important aspect of understanding the reasons for, and experience of non-participation.

Responses, strategies, and ways of coping with a chronic condition

CHD and other chronic conditions engender major impacts for a person and their family, and although some people may experience some positive effects, the overall experience tends to be unsettling, disruptive and challenging. Yet the other side of the illness experience is the responses and actions people undertake to manage or cope not just with the condition but the impacts on their wider life. Responses may change over time. People may be forced to continually adapt to symptom fluctuations and circumstance changes (Bergman & Bertero, 2003; Clark, 2003; Charmaz, 1995); but also may experiment to find strategies that work best for them – a process of 'trial and error over time' (Bury, 1991).

Managing the social consequences

Use of health services and other condition-related resources may be part of the experience of dealing with a condition and its impacts, and for some people this can be important. Yet, while health professionals may view these as central to condition management, a different story is told by evidence showing the variety of strategies and responses people employ to cope with and manage the condition in their everyday lives – that is, the majority of their time, and the significance of these within their overall experience. People and their families have been shown to be active agents seeking to achieve favourable outcomes in terms of their wider lives as well as the physical condition (Bury, 1991). Moreover, people's varied responses and strategies suggest they often have different priorities to health professionals. Chapter Three describes the medical view of successful adjustment that prioritises adherence with medical treatments, behaviour change recommendations, self-management guidance, and attendance at recommended therapeutic resources. People's experiences however indicate that for them the process Johnson's CHD study described as 'learning to live again' (1991) is uppermost. That is, managing their condition in a way that enables them to maintain important aspects of their life, self-conception, and mental and emotional health (Kristofferzon et al, 2007; Hildingh et al, 2007; Townsend et al, 2006).

The importance of a sense of 'normality'

The importance of the social consequences of CHD and other conditions to the person and their family means that finding ways to handle and negotiate these occupies a major part of people's responses and actions. Attempting to maintain or regain a sense of normality in their everyday life stands out as a widespread and pivotal goal. Seeking normality appears to be interpreted and implemented in two contrasting ways – trying to 'carry on as normal' and 'creating a new normality'. The former strategy has more frequently and explicitly been identified as a way people try to attain a sense of normality, but study findings often appear to implicitly indicate that the latter may also be important.

People may attempt to 'carry on as normal' - whereby they prioritise maintaining or regaining previous or existing roles, routines and activities that form the basis of

their everyday life and identity. This has been identified regarding CHD (Eriksson & Svedlund, 2006; Condon, 2005; Thompson et al, 1995; Johnson & Morse, 1990; Radley, 1989) and other conditions (Townsend et al, 2006; Doyal & Anderson, 2005; Billhult & Segesten, 2003). Practical benefits may be perceived, such as maintaining family income by returning to work, or maintaining domestic harmony and preventing others being overburdened by continuing usual duties.

Moreover, in the context of the uncertainty, anxiety, and disruption experienced by a condition's onset, the emotional and psychological benefits of seeking to protect and maintain familiar aspects of everyday life and minimise disruption are apparent. Svedlund & Axelsson (2000) found some people and their relatives viewed efforts to conduct everyday life as 'normally' as possible as part of 'struggling against it [CHD]', while Alaszewski et al (2007) found some stroke survivors viewed returning to work as an important way to demonstrate their recovery. Regaining usual roles and activities can be a key way people with illness seek to 'preserve their sense of self' (Charmaz, 1995, 1994) and has been shown in studies of people with CHD (Johnson & Morse, 1990; Radley, 1989). As Chapter Three reports, a number of CR studies have found that the perceived importance of regaining work or domestic roles contributed to some people's non-participation. Yet the focus has been upon practical reasons, whereas the possible underlying symbolic and psychological importance of this as an expression of being able to 'carry on as normal' has rarely been explored in depth.

Researchers have identified that although people make 'trade-offs' when they prioritise wider life activities over symptom containment, they experience tensions and dilemmas in doing so (Townsend et al, 2006; Gregory, 2005). Gregory found families adjusting to CHD desired to maintain normal life as far as possible because it maintained their sense of ontological security. Yet this was counter-balanced by a perceived need to follow advice to make changes in order to mitigate the threat of their condition (Gregory et al, 2006b; Gregory, 2005). Wiles & Kinmonth (2001) found that cardiac professionals might encourage people to expect to be able to 'return to normal'. While this could motivate recovery and rehabilitation it could also have the inverse effect on people who found their health and life hadn't returned

to normal in this way. Charmaz (1994) also identifies negative consequences for a person's self-conception and emotional health that may result if their efforts to maintain or regain important aspects of their life are unsuccessful and they don't manage to replace these with other attributes they can value.

Several studies have shown that people may overexert themselves and suffer rehabilitation setbacks due to seeking to maintain roles and activities (Condon, 2005; Goldsmith et al, 2004; Tapp et al, 2004). This strategy may also cause people to downplay, or for others to overlook, their needs (Sanders et al, 2002). Charlton & Barrow (2002) found 'self-help' group non-participants often sought to exclude their condition and continue life as normally as possible. Attending a condition-focused group therefore didn't fit their attitude towards their condition. My study can indicate whether this applies regarding CR and CHD Group non-participation. If invitation and information about CR and CHD Groups is provided it is usually in the early post-MI period. Because this is indicated to be the time when efforts to 'carry on as normal' predominate, it is possible that this timing may increase the likelihood that some people will decline or fail to consider participating.

The extent that 'carrying on as normal' is achievable varies considerably, depending on symptoms, expectations, and available support. It has been suggested that people often start with this goal, but it may subsequently be abandoned or replaced if continuity proves practically unrealistic and unfeasible, or their attitude changes from one of avoiding and resisting their illness to acceptance and 'going with the flow' (Svedlund & Axelsson, 2000; Charmaz, 1995). As Chapter Three describes, CHD and wider studies have suggested that many people gradually move from resisting their condition when initially overwhelmed by their diagnosis and its consequences, to accepting and adapting, although possibly reverting at difficult times. This appears to fit with descriptions of how people may gradually move on from emphasising 'carrying on as normal' as they adapt, accept and make changes in their life and outlook to accommodate the condition. Studies have suggested that 'normalising' the condition and 'creating a new normality' may be part of this process.

Whereas ‘carrying on as normal’ prioritises excluding a condition and limiting interference with usual activities and roles, the literature also indicates an alternative process whereby people seek to ‘normalise’ condition-management actions by integrating these into everyday routines and activities. Changes are accepted as inevitable and necessary but effort is made to make them less central, unsettling, and obtrusive, and so acceptable for the person and their family to live with and in the image presented to the outside world. This has been described in qualitative studies on CHD (Wheatley, 2006; Gregory et al, 2006b, 2005; Bergman & Bertero, 2001; Svedlund & Axelsson, 2000; Johnson, 1991) and other illnesses (Oakley, 2007; Charmaz, 1994, 1995). For example, Gregory (2005) found families often assimilated dietary changes into ‘normal’ family meals to promote a sense of continuity and normality, while Hildingh & Fridlund (2007) report that women recognised they had to redefine less rigorous housework standards as a new normality in order to cope with their changed reality. Studies however have suggested people are selective in creating a ‘new normality’ in that they are unwilling to make changes, especially radical ones, until and unless they perceive health benefits (Hildingh et al, 2007; Brink et al (2006). Some people have been described as ‘normalising’ their view of their condition as a way to come to terms psychologically and emotionally with its profound effects on their health, life and self-conception. Thus some people may rationalise their condition as the ‘norm’ for their community (Davison et al, 1989); age (Pound et al, 1992), or social class (Cornwell, 1984). Williams (2000) argued that such a view of illness as ‘biographical reinforcement’ means some people may not experience illness as severely disruptive.

There are glimpses in the literature that the strategy of normalising a condition within day-to-day life might influence CR and CHD Group non-participation, yet evidence is sparse and the issue hasn’t been examined in depth. Chapter Three reports that difficulty incorporating CR into daily life can deter participation; while some studies have reported that non-participants wished to ‘return to normal’ and ‘get on with life’ and perceived CR would impede this. However, the underlying reasons and beliefs have not been explored in detail. For example, Wingham et al’s study (2006) doesn’t explore the practical and emotional beliefs that underlay the participants’ view that

home-based CR would allowed 'life to go on as normal' whereas hospital-based CR would not. 'Self-help' group studies, including some on CHD Groups, have reported that participants perceive attending, and particularly meeting similar others, can assist the process of 'normalising' their view of their condition (Bostock et al, 2007; Charlton & Barrow, 2002; Lieberman, 1990). The dearth of exploration of non-participants' perceptions means that whether and how the strategy of 'normalising' may relate to CHD Group non-participation and non-participants' experiences of managing their condition has not yet been examined.

'Regaining control' and 'letting go'

Trying to 'regain control'; and in contrast, 'letting go' – acknowledging loss of control, have been reported as important ways people may respond to the impact of their condition on their self and life. People commonly seek to regain and present a sense of mastery over aspects of life disturbed by their condition and to counteract the intense uncertainties it has created. Qualitative research on CHD (Brink et al, 2006; Bergman & Bertero, 2001; Winters, 1997; Johnson, 1991; Johnson & Morse, 1990) and other conditions (Aujolat et al, 2008; Mayor, 2006; Blaxter, 2004) has described different strategies used to try to achieve this. It can be a positive coping device and may encourage practical endeavours such as information-seeking, self-management techniques and rehabilitation activities. It appears that for some people wishing to regain control might encourage them to seek and use helping resources. Johnson (1991), for example, found this underlay some people's motivation to participate in CR; yet wider research has suggested that others may feel greater need to present themselves as independent and in control of themselves and their lives (Aujolat et al, 2008). Brink et al (2006) found that in the early months of post-MI readjustment some people may seek a sense of control by minimising their condition and this may slow and moderate their adoption of condition-management related changes.

As Chapter Three describes, some studies have identified that a person's belief in their capacity to manage their condition independently can be an important reason for non-participation in CR and 'self-help' groups. Yet whether these people managed well or experienced difficulties is unknown. Also, while these findings

might relate to people's different support needs and preferences, some studies have indicated that inadequate information about their condition and the resource can also cause people to opt out and then struggle to manage independently (Wyer et al, 2001). Criticisms of the highly-structured, professionally-guided and hospital-based predominant model of CR (Dalal et al, 2004; Smith, 2004; Henriksen, 2003; Thompson & Lewin, 2000), also implicitly suggest that people wishing to feel in control of their recovery may be deterred. Whether the goal of seeking to regain control after an MI relates to non-participation in CHD Groups, which are less formal and differ in format and functions from CR, remains to be investigated. Also if non-participation is related to people wanting greater control over their recovery it is important to ascertain the consequences this may have for non-participants given that the CHD and wider literature reports that unsuccessful attempts to regain control may damage mental and emotional wellbeing (Aujolat et al, 2008; Wheatley, 2006; Charmaz, 1995; Johnson & Morse, 1990).

CHD and wider explorations of the illness experience have suggested that at least for some people the importance of feeling in control may gradually lessen as they recognise the impossibility of fully controlling their condition (Hildingh et al, 2007; Bury, 1991; Charmaz, 1991). Retaining control may be accompanied and eventually replaced by the contrasting approach of 'letting go' – accepting loss of control and learning to accommodate (Aujolat et al 2008; Brink et al, 2006). This process of 'going with, rather than against the illness' (Charmaz, 1995) has been found to be an important way that people can adapt positively over time in emotional, psychological and practical terms. Aujolat et al found this a crucial way that people may reconcile tensions between accepting their identity as someone with a condition and preserving other personal and social identities, enabling them to see themselves as 'whole'. Also through 'letting go' they found people were able to ask for help rather than trying to manage alone. Brink et al also suggest 'letting go' may enable people to accept lifestyle changes that initially had seemed too radical.

Repairing one's identity

People respond in a number of ways to counter the 'assault on the self' – adverse impacts a chronic condition can have on a person's self-conception. A major theme

in qualitative studies of chronic illness (Williams, 2000; Paterson et al, 1999; Seymour 1998; Charmaz, 1995) and CHD (Hildingh et al, 2007; Goldsmith et al, 2006; Clark, 2003; Thompson et al, 1995) is 'identity reconstruction', whereby people employ techniques to preserve existing elements of their identity, and to replace aspects which no longer fit their altered situation. Frank (1995), describing post-MI recovery, called this 'repair work'. Thus people with a chronic condition enact the process entailed by what Giddens termed the 'self as a reflexive project', whereby an individual constantly re-makes their identity in response to changes in their social world (1991). Charmaz (1995) describes this as an 'odyssey of the self', whereby a person seeks to reconcile their self-conception with their altered body and life. Studies have commonly indicated this process is gradual and, as described above, people may in the early stages of illness prioritise trying to restore their previous sense of self rather than accepting change. Brink et al (2006) found 5 months after MI people commonly engaged simultaneously in 'struggling against' their illness - trying to retain aspects of former identity, and 'struggling with' their illness - 'reorienting the active self' and making changes.

As Chapter Three describes, studies have indicated that beliefs about the self can be an important contributory influence regarding CR and 'self-help' group participation and non-participation. The evidence suggests that both participation and non-participation can be a defensive response in terms of retaining or regaining an aspect of identity damaged by their illness. For example, some people attend CR hoping to restore fitness and health; but others may see participation as a threat to an important aspect of identity such as self-reliance, their employment or domestic role, or their self-conception of their health and age. Findings have also suggested that some people may view participation in these resources as a means to reconstruct their identity as part of learning to live with their condition. Thus some people attend CR and 'self-help' groups to meet similar others and so feel less abnormal about having the condition; while some view CR as a tool to address unhealthy aspects of their lifestyle. Links between non-participation among post-MI people and identity reconstruction are however less clear and understanding this has been hampered by the limited exploration of CR and CHD Group non-participants' perspectives. My

study offers opportunity for further insight into the way people's responses to the identity challenges presented by CHD may influence resource use and non-use.

To understand what has happened to their body and life and what it means for how they see themselves, people undertake a biographical review - seeking meaning from past experience and different aspects of their life to explain their condition (Sangren et al, 2008; Throsby et al, 2007; Cooper et al, 2005; Williams, 2000; Davison et al, 1989). Williams coined the term 'narrative reconstruction' to describe the process whereby people construct a new 'narrative' for life that fits with, and provides a means by which they can explain and justify, their altered body, circumstances and self to themselves and others. This has been described in the wider illness literature as an important process whereby people cope with and find a way to adapt to their condition (Crossley, 2003; Williams, 2000). A person may use this to resist social stigma regarding illness and implication of blame due to lifestyle or personal failings – enabling them to develop a positive self-conception and way of presenting themselves to others (Oakley, 2007; Throsby, 2007; Blaxter, 2004; Frank, 1995).

Qualitative CR and 'self-help' group non-participant research has implicitly suggested that non-participants may use their narratives to legitimate reasons for non-use – to counter negative moral connotations that others may see in their behaviour and explain why they took that course rather than alternatives. Clark et al (2004) allude to the way people may emphasise a reason (access barriers) they believe is more socially acceptable, masking their underlying beliefs and attitudes. Yet, generally it appears that studies have focused more on the literal reasons people have given rather than exploring the way accounts might have been used. The way post-MI people construct their non-participation narratives hasn't received the attention the topic has had in the wider illness literature. In my study analysis I seek to add to understanding of this area by considering the process and implications of the construction of CR and CHD Group non-participants' and family members' accounts.

Use and non-use of helping resources, and self-reliance

A key way that people and families respond to CHD (Paquet, 2004; Radley, 1994; Johnson, 1991) and other conditions (Bury, 1991) is by seeking resources to help them cope with and manage an uncertain situation. Bury (1991) describes this as a way people engage in the 'strategic management' of illness - mobilising what Croog & Levine (1977) called an 'armoury of resources' to optimise outcomes suited to themselves. People may draw on various resources to meet differing needs at particular times, and may seek alternative resources rather than depending on options presented by service providers (Gannik & Dalsted, 2006; Donovan, 1995). However the ability to access resources varies over time and between individuals. Structural factors such as gender, age and socioeconomic factors can promote or hinder access (Locker, 2003) - as Chapter Three illustrates regarding non-referral and non-invitation to CR and CHD Groups. Thus the resources a person assembles may reflect constraints as well as choices.

The primary resource many people draw upon to deal with a chronic condition is informal support from their social network, particularly family members. Also, as Chapter Three describes, although people generally prefer self-reliance, informal support is often chosen if support is required. Pervasive social expectations that family support should be available in times of need also mean that lack of support from the immediate social network may be seen to have particular negative significance (Twigg, 2006; Morgan, 1996). Nonetheless there appear to be some important caveats to the importance of support from one's social network: availability; capacity to meet people's specific needs; and any negative perceived consequences. A number of 'self-help' group studies have reported that some non-participants felt they had sufficient support to meet their post-MI needs from their existing network, whereas attenders felt they needed additional or specific support that family and friends could not provide (Hildingh & Fridlund, 2001; Bludau-Scordo, 2001; Levy & Derby, 1992). CR participant studies echo these findings. Campbell et al's qualitative study (1994) provides an illustration, finding that some people wished to attend CR group sessions because their existing support was limited or they specifically wanted to meet people outwith their network to discuss issues they felt unable to talk to family and friends about.

Riegel (1993) investigated the hypothesis that too much support from ‘over-protective’ family members could foster ‘cardiac invalidism’ - that is, impede post-MI rehabilitation through preventing people re-learning to manage everyday living tasks themselves. The study concluded that, although many people, particularly men, perceived their relatives were over-protective, nonetheless it was people with too little rather than too much support who experienced poorer emotional and psychological health. Reviews have found that women generally report receiving less support from male partners than vice-versa (Hildingh et al, 2007; Jackson et al, 2005; Tardivel, 1998), so it might be assumed they would seek alternative support. Yet, as Chapters Two and Three describe, low CR and CHD Group attendance and qualitative findings suggest these resources may be inaccessible to women or don’t meet their needs.

Studies have shown that CHD-specific resources aren’t the only way people seek to address support needs not met by their social network. Spiritual resources, particularly religious faith, can be important to some people in dealing with chronic illness (Aujolat et al, 2008; Doyal & Anderson, 2005; Loeb et al 2003; Croog & Levine, 1977). Generic community social groups may also be used. For example, Helpard & Meagher-Stewart (1998) describe how some women who found their informal resources lacking ‘branched out’ into the community, groups and events. Yet whether use of generic support was a preference, or they didn’t feel they needed CHD-specific support, or this wasn’t available or accessible wasn’t indicated. By examining non-participation in CR and CHD Groups within the broader context of people’s overall rehabilitation experiences my study offers an opportunity to consider the reasons that people may use alternative resources and the extent to which they meet their needs. This is important given that unmet emotional support needs have been identified, particularly among women (Hildingh et al, 2007; Gregory et al, 2005; Tardivel, 1998; Riegel, 1993). This suggests that if a person’s family doesn’t meet such needs they may not be met by other resources.

Although informal resources play a large part in the day-to-day experience of managing a chronic condition, nonetheless health services feature to some extent in

many people's lives. Yet while people evidently value and want certain types of support from health professionals (Gregory et al, 2005; Ostergaard-Jensen & Petersson, 2003; Bergman & Bertero, 2003; Johnson, 1991), there are substantial limitations on people's ability and / or willingness to use health services. Chapter Three describes how the social value placed on self-reliance as an emblem of moral virtue and social responsibility can contribute to reluctance to seek or accept help from various services and resources. Satisfaction and a sense of achievement from being able to fulfil this in managing their condition have been reported in a number of studies (Bergman & Bertero, 2001; Helpard & Meagher-Stewart, 1998; Billing et al, 1997). Qualitative research has suggested that self-reliance is a common preference among people with CHD, but equally has shown the dilemma many people experience between this and their need to rely on others due to the challenges of their condition (Hildingh et al, 2007; Tapp et al, 2004; Goldsmith et al, 2004). Chapter Three reports that a number of CR, 'self-help' group and CHD Group studies have indicated that self-reliance may be an important contributory reason for some people's non-participation. However, the prevalence and profile of people to whom the issue was important, and the relative importance of this factor in relation to other issues are difficult to ascertain from the limited evidence. Additionally the research has not shown how people who opted to be self-reliant managed in terms of rehabilitating and living with their condition in the absence of these resources.

It appears that a self-management ethos promoted by health professionals may further encourage people to view non reliance on external support as the socially acceptable model of dealing with their condition (Rogers et al, 1998; Williams,1989). The evidence however, is tentative and the increasing importance of this policy means that whether this may apply to post-MI people warrants further exploration. Information from health professionals may still be valued highly (Thompson, 2007; Gregory et al, 2005; Ostergaard-Jensen & Petersson, 2003; Bergman & Bertero, 2003; Johnson, 1991). Nonetheless, various alternative information sources now exist and the general social tendency towards people being less willing to unquestioningly accept information from traditional authorities, means there is less reliance on 'doctor knowing best' (James & Hockey, 2006; Donovan, 1995). Clark et al (2004) found CR attenders placed a high value on professional

knowledge whereas negative perceptions were far more common among non-participants. A number of 'self-help' group studies have reported that some people prefer to be guided by professionals and so can be deterred by lack of professional input and accord low value to lay knowledge and experience (Colella & King, 2004; Hildingh et al, 2001). Yet as Chapter Two reports, 'self-help' group participant research has shown that some people value this highly. My study will investigate whether such perceptions may influence CHD Group non-participation.

Differences between the priorities of professionals and people with chronic conditions might deter people from following professionals' recommendations. An emphasis on clinical issues, risk-factor management, and exercise in CR, together with a perceived low priority on emotional and psychological issues and quality of life can contribute to people not believing attending is worthwhile (Paquet et al, 2004; Gassner et al, 2002; Wyer et al, 2001; Bergman & Bertero, 2001). Frustration, disaffection and scepticism about the lifestyle risk factor emphasis of health services has been reported to apply widely to people with CHD (Karner et al, 2004; Johnston et al, 1999; Billing et al, 1997; Davison et al, 1998) and in the general population (Fitzpatrick, 2001). Yet whether these issues influence people regarding CHD Groups is unknown due to the dearth of research – a gap my study can shed light upon. As semi-formal resources independent of health services these groups might not deter people for this reason, but given that many 'self-help' groups have professional input and service links and people may be referred or informed by professionals this cannot be assumed.

A perception that services tend to focus narrowly on clinical and physical issues, and don't take account of people's wider lives - failing to consider them as 'whole people' and address their needs holistically has been observed regarding CHD and other conditions (Oakley 2007; Bar-On, 1986). This is echoed in criticisms specifically regarding what Seymour (1998) describes as the 'rehabilitation industry', whereby services apply medical goals rigidly which force people to fit this mould rather than addressing issues most relevant to them. Wheatley (2006) suggests the CR ethos embodies Foucault's notion of the 'clinical gaze', using 'confessional, disciplinary, and surveillance techniques' to try to change people's lifestyle

behaviours. Although participants are reported to have perceived benefits and could reconcile themselves to the programme style, the potential for some people to be deterred and opt not to participate or dropout is highlighted. The clinical hospital environment has also been reported as a possible deterrent for some people (Jones et al, 2007; Tod et al, 2002). Yet while for some people the service orientation and organisation of the current predominant CR model may be fundamental deterring factors, studies have also indicated that misperceptions about services and failure to market resources effectively to potential attenders may unnecessarily deter people who might otherwise attend (Clark et al 2004; Cooper et al 2005, 2002; Wyer et al, 2001).

Conclusion

The literature discussed in this section identifies potentially important issues and themes regarding the impacts on, and responses of people and their family members to CHD and other chronic illnesses, including available evidence specifically relating to CR and CHD Group non-participants. It appears there are important common themes, but given that evidence on non-participants is sparse, particularly regarding CHD Groups, the findings must be considered tentative with regard to this section of the post-MI population. Nonetheless it is apparent that living with, and managing CHD and other chronic conditions is challenging, and for some people and their families, life-altering. The impacts extend beyond bodily effects and consequences into the spheres of daily life and can fundamentally change the way people see themselves and are seen by others. In this context understanding the experience of people who aren't supported by the main formal and semi-formal resources specifically for post-MI rehabilitation appears particularly important, especially given evidence that such people constitute a substantial proportion of people with CHD.

The diversity in the ways people and families respond to CHD and its impacts is strongly apparent, but why and how people in different circumstances respond in different ways is not fully understood. Research is also needed to examine the extent that the experiences and perspectives identified amongst the wider CHD population

and people with chronic illness generally are reflected in, and /or dissimilar to people who don't use CR and / or CHD Groups, and how these experiences and perspectives relate to their non-participation. My study seeks to provide insight into some of the important areas and questions that have not been explored or have been insufficiently explained regarding this section of the post-MI population.

People draw upon a range of formal, semi-formal and informal resources to manage illness. Thus besides investigating non-participants' experiences and perspectives in relation to CR and CHD Groups, my study will also explore the broader context, including use and non-use of wider resources and the reasons for this. Regarding the previously unexplored inter-relation between use and non-use of CR and CHD Groups, issues raised in this and previous chapters suggest the possibility that people with different perspectives, experiences and needs might be attracted to one resource but not the other. This is potentially of considerable importance for meeting post-MI needs. One example is the question of whether beliefs about CHD risk-factors may deter people from CHD Groups as has been suggested regarding CR, and how non-participants dealt with these issues without these resources.

A number of other issues are indicated to be of potential importance and require investigation from the perspective of non-participants. First, whether people who emphasise 'carrying on as normal' or 'regaining control' by minimising their condition may be less likely to participate and whether this affects their recovery experience. Another issue is the relative importance of self-reliance compared to other factors, and the experiences of non-participants who perceived themselves able to recover independently. How 'identity reconstruction' may influence non-participation; the way narrative construction may influence non-participant accounts, and what this can tell about non-participants and reasons for resource non-use, also appear to be fruitful avenues for investigation. Finally, my study will explore the neglected area of the perspectives and experiences of non-participants' family members - which may potentially add an alternative and valuable insight into the rehabilitation experiences and needs of their relatives and themselves.

Chapter Five - Methodology

In Section One of this chapter I set out the rationale for my study methodology, design, and methods, explaining the theoretical premises and practical considerations that underpin my research. Initially I describe the issues that prompted the investigation and my personal engagement with them as a PhD, and explain how my key research questions stemmed directly from this base. I then outline the case for selecting a qualitative methodology, informed by the principles of ‘grounded theory’, in terms of its appropriateness to my ontological and epistemological stance on the research topic. I explain my choice of study design and methods in terms of my philosophical standpoint and certain practical considerations relating to recruiting the study population. The principles that guided my sampling strategy are then discussed. Section Two documents the study design, data collection, and analysis. In turn I describe the design and process of the two stages of data collection, and provide tables of the number and profile of participants: firstly for the screening questionnaire; and secondly, the in-depth interviews. In Section Three I outline the methods and process of data analysis. I conclude by briefly summarising the methodology and the outcomes in terms of study participants and data generated, and point to the critical reflections regarding methodological strengths and limitations that I undertake later in the Discussion Chapter.

Section One: Methodological rationale

Study origin and key issues

The research focuses on people recovering following myocardial infarction (MI), who did not use cardiac rehabilitation (CR) - the main formal rehabilitation service, and / or a CHD Group – semi-formal, community-based resources. The literature indicates that CR and CHD Group non-participants comprise a sizeable proportion of the post-MI population in the UK and many other industrialised countries. The local cardiac professionals that I discussed this with during the early planning stages of the study were aware that their CR participants were only a limited proportion of those

deemed eligible for this service, let alone of the overall post-MI population. These issues first came to my attention some years previously while working in the NHS, when I was involved in a multidisciplinary group examining how post-MI support might be improved in a district where CHD rates were among the region's highest. Particularly, a small-scale local study I had undertaken (Jackson, 2000) had suggested that some post-MI people wanted the opportunity to attend a local CHD Group for rehabilitation support. Despite publicity and recruitment efforts over several years, the group that was established attracted few participants and eventually ended.

The working group members and I were frustrated and perplexed as to why more people had not attended, particularly when the idea originated from, and appeared to have been supported by post-MI people. As my literature chapters show, the key issues of why people do not use these groups and also CR, and their experience of rehabilitating without them, have not been fully investigated and consequently remain poorly understood. This PhD presented an opportunity to develop understanding on these questions, which are important both from the perspective of medical sociology and health promotion. The sociological objective being to understand why and how people don't undertake an action that health professionals and researchers identify as beneficial for health; and in terms of health promotion, seeking to identify people's health needs and appropriate strategies to address these.

Study ontology and key research questions

It is advocated that at the outset of planning a study the researcher should consider the ontological and epistemological premises relating to their topic in order to define the key research questions and identify appropriate methods (Mason, 1996). Ontology relates to our views about what constitutes the social world and how we might go about studying it (Barbour, 2008). For the purposes of this study it encompasses the range of phenomena that exist in the world: objects, events, institutions, situations, processes, relations, and structures. These are perceived and interpreted in different ways by individuals and so have multiple meanings attached to them. People's understandings of their world are encompassed within their 'lifeworld' and this was a key concept in conceiving, framing, and analysing my research.

The concept of the 'lifeworld' has been developed by sociologists, stemming from the work of Habermas (1984) to explain the way that people perceive, understand, and explain their social world (Calhoun et al, 2007; Pressler & Dasilva, 1996). It encompasses a person's experience of living *their* life, as constructed from their understandings and interpretations of situations, issues, events, objects, institutions, their own bodies and emotions, and their relation to other people, spanning both the private and public spheres. It is shaped by the various influences upon them both in the past and present, including personal factors such as their family relationships, and broader social and cultural factors such as norms and values. The definition given by Hodge (2008) is a helpful one, and indicates the links between the subjective individual lifeworld and wider society. 'All of us have a lifeworld; it is all that we are and all that we do. It is the sense that we have of ourselves, how we feel emotionally, what our bodies can do physically, the relationships that we have with others, our hopes and ambitions, our perceptions of time past and the future in front of us, the things that we do and all that we value. Although the way that we experience them will be unique for each of us, these aspects of being alive will be shared by all of us.'

The concept of the lifeworld provides an appropriate ontological baseis from which to analyse and so try to understand the experiences of and the influences on the decisions made by the study participants. My study ontology encompasses individuals, who each have a 'lifeworld' as described above. Within the shared social world there are medical conditions or diseases which affect the health and wellbeing of individuals and are experienced by them as illness (Kelly & Field, 1996; Bury, 1991). As Chapter Two describes, Coronary heart disease (CHD) is a prevalent disease and because many more people are surviving the acute event of myocardial infarction or 'heart attack', the importance of understanding their illness experience has increased. Within their 'lifeworld' following the 'heart attack', post-MI people and their 'significant others' will be influenced by the significance of CHD and health in personal, social and cultural terms. For example, by social and cultural views about CHD, and how their condition affects their relationships and roles. Additionally, institutions, systems and processes may impinge upon their experience,

including health services and community resources, and may include cardiac rehabilitation and CHD Groups. How people regard, and whether or not people use the latter two specific resources, and their experience with or without these, in the context of their broader 'lifeworld' forms the focus of my enquiry.

I considered that the non-participants' own perspectives would be the primary source of this information. The key research questions based on this ontology were:

1. *What is the experience of people who do not use CR or CHD Groups of recovering after their MI and managing their CHD?*
2. *What are the reasons for non-participation in CR or CHD Groups?*
3. *If there are unmet needs, how might these be addressed in ways more appropriate to people's circumstances and preferences?*

Initially I hadn't considered using additional or alternative sources. However, as I later explain, the value of also obtaining the perspectives of 'significant others' was identified during piloting. This resulted in my methodology being modified and the fourth research question being added.

4. *What are the perspectives of 'significant others' about non-participation and the experience of post-MI recovery without these?*

Rationale for a qualitative methodology – epistemological and practical considerations

Epistemology relates to theories of knowledge and ideas about the nature of evidence and knowledge, and how one might obtain evidence about the phenomena under consideration (Barbour, 2008). Several important aspects of my topic indicated that a qualitative methodology, using a modified 'grounded theory' approach, would be the most suitable means for gathering evidence in relation to the ontology outlined above. Although the 'target' population was defined by rehabilitation resource non-use, the

literature suggested that reasons for non-use could not be fully understood without examining and placing this in the context of their ‘lifeworld’.

Wanting to learn about non-participants’ rehabilitation experience from their own viewpoint was a key objective in itself. Qualitative methods offered the scope I needed to access non-participants’ own perspectives and interpretations by providing an opportunity for them to give their direct accounts, rather than providing specific but narrow information within the constraints of a set of pre-defined questions (Britten et al, 1995; Mishler, 1991). Qualitative methods also facilitate a wide-ranging exploration by using open-ended questions and so enable people to draw from their beliefs, biography, and day-to-day lives in discussing their experience of a condition (Barbour, 2008; Britten et al, 1995; Lofland & Lofland, 1994).

Owing to limitations of the existing research, little was known about the characteristics and lives of the non-participants; and the reasons for non-participation were, in the case of CR, poorly understood, and for CHD Groups, essentially unknown. For this reason I considered that a quantitative methodology that is driven by pre-existing theories and concepts wouldn’t be appropriate, because it is difficult to design pre-defined questions when little is known about the group. The exploratory capacity of a qualitative method offered a more appropriate alternative, as Britten et al (1995) recommend, ‘...interviewers aim to go below the surface of the topic..., exploring what people say in as much detail as possible, and to uncover new areas or ideas that were not anticipated at the outset of the research’. Specifically, I decided that using an approach informed by the principles of ‘grounded theory’, a research model developed by Glaser & Strauss (1967) and which forms the basis of much qualitative research, would be effective.

‘Grounded theory’ is an ‘open-minded’, ‘open-ended’, iterative approach that allows issues, concepts, and theories to emerge from the data provided by research participants. The knowledge and concepts that form the study findings are ‘grounded’ in the data itself, rather than deriving from and being limited to the parameters of a pre-conceived theory (Charmaz, 2006). Glaser & Strauss, the theory’s originators described the value of this: ‘To generate theory... we suggest as

the best approach an initial systematic discovery of the theory from the data of social research. Then one can be relatively sure that the theory will fit and work' (1967, p.3). I believed this inductive type of analysis would enable my interviewees' perspectives and experiences to emerge from their accounts, and that making these central to developing concepts would provide the insight my study objectives required.

Nonetheless, my approach was pragmatic - selecting strategies to suit my study goals and practicalities. While I believed the inductive emphasis of 'grounded theory' was essential for the above reason, I decided that the combined approach of induction and deduction that some qualitative researchers have advocated, would be the optimal strategy (Pope & Mays, 2001; Seale & Kelly, 1998). Additional to emergent themes I would also actively seek particular themes that, 'reflected the initial aims of the research project' (Seale & Kelly, 1998), for example - reasons for non-participation; and potentially significant themes identified from the existing literature, such as informal resources of support. Melia (1997) suggests that researchers who draw upon 'grounded theory' generally use this to add insights to those that could have been anticipated at the outset. Yet I sought to give an inductive approach greater emphasis within my study, both regarding data collection, as I later explain; and in analysis - prioritising themes arising from my data, and seeking conceptual themes relating to my research questions rather than specific themes arising from the literature.

The case for in-depth interviews

In assessing which of the various qualitative methods would be most appropriate and effective for my study I identified two potential options. Both in-depth interviews and focus groups would suit my retrospective design. Both could generate first-person accounts of people's experiences and perspectives regarding their non-participation and recovery process. Focus groups provide opportunity for interaction between research participants and joint discussion of themes (Kitzinger, 1995), and can give rise to lively debate to uncover why people think the way they do (Barbour, 2008). However, several considerations favoured interviews. I decided that detailed accounts relating to individual experiences and views were my priority – for which in-depth interviews are advocated as particularly effective (Mason, 1996; Silverman,

1993). The appropriateness of in-depth interviews as an exploratory tool is described by Britten et al (1995, p. 106), 'interviewers aim to go below the surface of the topic..., explore what people say in as much detail as possible, and to uncover new areas or ideas that were not anticipated at the outset of the research'.

The philosophical paradigm of 'social constructionism' also influenced my choice, as I will explain after summarising my philosophical stance more generally. The constructionist perspective considers that social reality is not a fixed, factual entity that is 'out there' to be discovered by researchers, but rather is constructed through the understandings and interpretations of individuals when they interact (Robson, 2002; Denzin & Lincoln, 1994; Guba & Lincoln, 1989). I subscribe to Schwandt's view (1994, p. 118) that, 'people give meaning to reality, events, and phenomena through sustained and complex processes of social interaction', and therefore different people may experience a similar phenomenon in very different ways. I consider myself distant from the positivist end of the spectrum of research philosophies and a belief that reality is determined by set structures and social facts that can be ascertained through objective investigation. Yet I do not adhere to the more 'radical relativist' constructionist position that suggests that 'multiple intangible realities exist' that have no relation to natural laws or social structures, as espoused by researchers such as Bhaskar (1975, cited in Appleton & King 2002). My view is that while there are objectively definable phenomena such as illness conditions, and structures such as health services and social security systems, people may perceive and experience these in considerably different ways.

A social constructionist view of research is that it is not only influenced by the researcher, but is co-created through the understandings that result from the interaction between researcher and respondent. This is particularly tangible in an interview scenario where the researcher's presence and input has a 'live' and active influence upon the interviewee. Therefore I acknowledged that a person's account would be 'mutually shaped' - a product of their interaction with myself as interviewer, and inevitably tailored and edited as a result (Lincoln & Guba, 1985). Taking this into account, I sought to maximise opportunity for interviewees to give their perspective. Prior to the interview I could reiterate my aim to hear their

personal perspective and my independence from post-MI support services. By using open questions I could enable interviewees to influence the direction of their accounts. Also, following interviews I could reflexively examine ways in which I, as interviewer, might have influenced the account, either by my active role or through the interviewees' perceptions of the study and myself. This reflexivity forms an important feature of my analysis and discussion chapters. Conversely, I considered that if I used focus groups the interaction between the multiple participants would be the dominant feature and so it might prove harder to access individuals' personal perspectives and experiences. In contrast to the open questions I could use as interviewer, focus group participants would be expressing their views and issues directly, which might deter people from raising contrary or minority opinions (Michell, 1999; Kitzinger, 1995). Also from past personal experience I knew that even with participative facilitation, some participants could dominate and others' experiences would not be heard.

There were also practical reasons that encouraged me to use interviews. The literature suggested that factors that may contribute to some people not using CR and 'self-help' groups included: group environments; access problems related for example to disability and travel; and conflict with life roles. These issues suggested a focus group might potentially deter at least some people from taking part in my study. Besides making recruitment more difficult, this could also restrict my sample to a narrow sub-section of CR and CHD Group non-participants, whose reasons for post-MI resource non-use might differ considerably from people who would be unwilling or unable to attend the study focus group. I had identified this limitation within existing studies and wished to avoid this pitfall. One-to-one interviews, scheduled for a time and venue convenient to the interviewee, offered a more acceptable method. Furthermore, a number of qualitative authors (Hallowell, Lawton & Gregory, 2005; Dyregrov, 2004; Drummond & Mason, 1990) have identified that opportunity to talk about their experiences can be an important incentive for some people to take part in an interview study. I considered that some of my 'target group' might value the opportunity to 'tell their story'. Indeed, owing to their limited contact with formal / semi-formal resources and the opportunities these can provide to talk about their

experiences with someone outwith their social circle, I thought that an interview might even appeal more to some of my target group than to the population generally.

Accessing a 'harder to reach group'

People who had not used CR and / or a CHD Group posed a recruitment challenge as a 'harder to reach' group, who aren't easy to identify and access for a research project. Because CR and CHD Groups only register their users, no records exist based on the criteria that defines the study population as a 'group' – their 'non-participant' status. Additionally, the fact that these people hadn't engaged with services or resources suggested that at least some may have actively chosen to disengage and might thereby be disinclined to participate in a research study. Theoretically one option was a prospective design, whereby post-MI patients could be contacted by staff or the researcher and, with consent, followed up during the subsequent months to identify those who hadn't attended CR and / or a CHD Group. I rejected this for ethical and practical reasons related to contacting people in the very early post-MI period. As my literature section reports, this has consistently been documented as a time when physical and emotional needs are most intensive and information is difficult to assimilate – raising doubts about informed consent, additional to the ethics of whether a study should intrude upon the intensive recovery period. Retrospectively identifying non-participants would avoid contacting people during the most intense initial recovery period, thereby limiting both the potential of causing distress and refusals due to poor physical or emotional health.

Nonetheless, I recognised that later recruitment also entailed challenges. The commonly documented stressful and distressing nature of MI suggested that some people might not wish to be reminded of this. As Chapter Four describes, the literature indicates that after some time people often focus on restoring 'normal' aspects of everyday life and identity instead of thinking of themselves foremost as someone recovering from MI. This might potentially deter some people from taking part in a study that would focus on the issue. Moreover, in practical terms, lack of available records of non-participants would necessitate contacting a cohort of the wider post-MI population, including resource users, (ineligible for the study), and non-users. On balance however, I decided that these issues were outweighed by the

likelihood that this method could successfully identify and recruit people in my 'target group'. I decided that a 'screening' questionnaire would serve two objectives: identify non-participants; and provide data regarding the criteria by which I would select interviewees.

Defining the sampling strategy

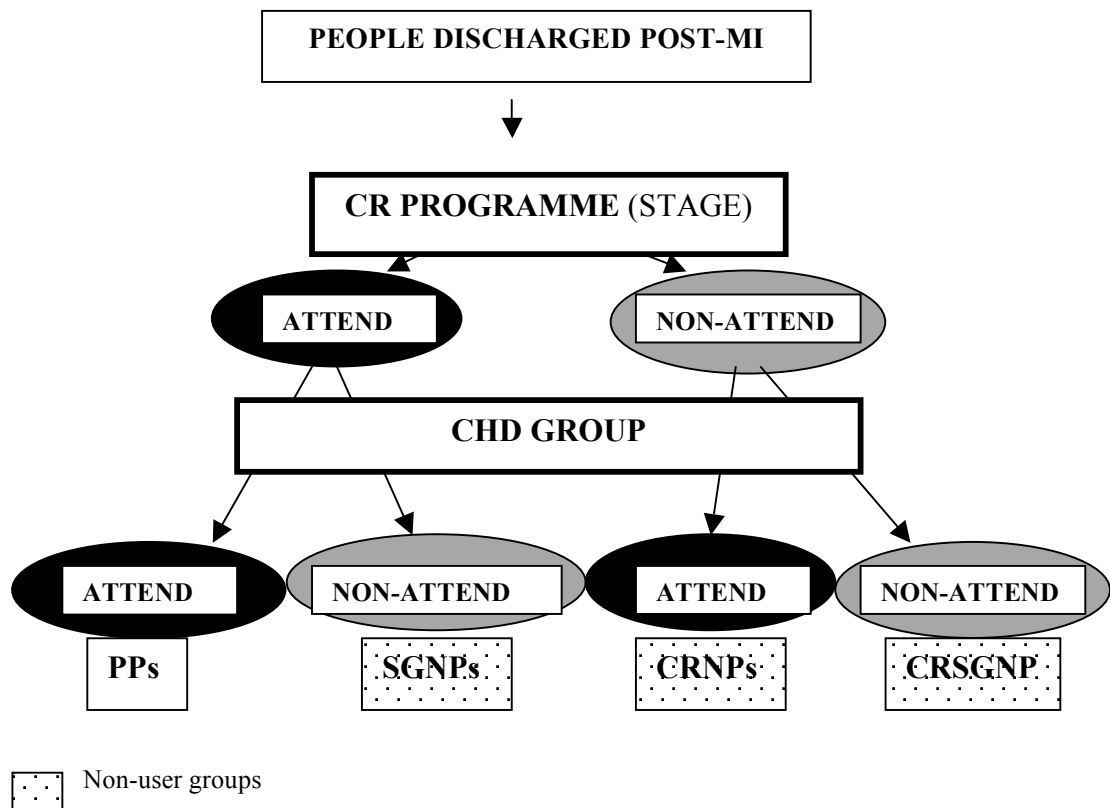
Qualitative research, as the term suggests, prioritises quality of detailed, rich data above the size of study samples, 'collection of rich material and analytic depth means that a relatively small number of cases can generate insights well beyond the confines of the study' (Ziebland & McPherson, 2006, p. 405). Emphasis on data quality within a relatively small sample heightens the importance of selection. Morse (1991) described the fundamental principle of qualitative sampling as selecting people for their appropriateness in terms of what they might provide in terms of the study objectives. It has been advocated that qualitative researchers use judgement to assess their required sample size according to the intended purposes to which the research will be put, the audience, and the method and sample strategy used (Sandelowski, 1995). Nonetheless it has been broadly suggested that between 20 and 50 interviews should allow 'saturation point' to be reached – that is when the data collected can be expected to encompass the range of major issues, themes, and interpretations that one might find among the wider population from which interviewees are drawn (Lofland & Lofland, 1994). I initially set my target interview sample size for between 20-30 post-MI people. This was based also on the pragmatic consideration that this number would be feasible to undertake and analyse within the time available – a necessary 'real world' consideration for people undertaking time-intensive qualitative research (Britten et al, 1995).

Qualitative sampling strategies typically aim to represent a wide range of perspectives and experiences, rather than seeking to replicate their frequency in the wider population (Ziebland & McPherson, 2006). Following this principle I used 'purposive' or 'strategic' sampling to construct a sample of 'maximum variation'. This is the deliberate selection of people of different characteristics with the aim of capturing the widest possible range of experiences and perspectives (Sandelowski, 1995; Patton, 1990). This is important because of the considerable variation in the

way health and illness are experienced and viewed by individuals and different population groups (Annandale, 1998). In using this strategy, the researcher decides the kind of variation that is important in relation to the research questions (Sandelowski, 1995). Nonetheless, I was also aware that recruiting the target number of interviewees within some categories might not be achievable in practice.

Following Morse's (1991) maxim of prioritising the selection criteria most appropriate to the study objectives, my primary criterion was CR and CHD Group non-participation. I anticipated that it would be possible to divide questionnaire respondents into the four groups illustrated in Figure One. I would exclude the first group, who participated in both resources; and aimed to include people from each of the other three groups: people who attended CR but not a CHD Group (SGNPs); people who attended a CHD Group but not CR (CRNPs); and people who attended neither resource (CRSGNPs).

Figure One: Non-participant selection groups



Gender was my second selection criterion. As well as a key variable to reflect general population demography, gender has specific relevance regarding CHD. Although the number of men having MI outweighs the number of women, CHD is nonetheless the leading female cause of mortality and morbidity worldwide (Mackay & Mensah, 2004; Wenger, 2003). Notwithstanding this, CHD continues to be depicted as a ‘male disease’ with the effect that women are frequently rendered ‘invisible’ in terms of their risk and experience. This has been propagated by research, with many studies previously including only men. In turn this has contributed to inequality for women in diagnosis, treatment, and service provision (Hildingh et al, 2007; Emslie et al, 2001). I decided therefore that instead of selecting a male / female ratio to reflect population prevalence (approximately 2:1), I would aim to include equal numbers of men and women in an effort to promote the ‘visibility’ of women’s experiences in my study.

In terms of age I sought to include a diverse age range both among men and women. Geographical area was also important, not only to reflect the diversity of settlements in the study area, but in terms of health systems. I considered the primary division was between West Lothian and the three districts I clustered together as ‘Wider Lothian’. Firstly, West Lothian has its own District General hospital – St John’s, to which the vast majority of the district’s residents are admitted even if subsequently referred to another hospital. The other three districts are served by two hospitals: Edinburgh Royal Infirmary, and the Western General. Secondly, the cardiac care systems, and CR and CHD Group organisation, are organised differently in West and ‘Wider’ Lothian. To reflect and contrast the experiences of people in the two areas I aimed to include approximately equal numbers of interviewees from West and ‘Wider’ Lothian.

I intended if possible to include a small number of people of minority ethnicity as an aspect of wider population diversity. This was reinforced by evidence that people of minority ethnic origin are less likely to attend CR (Beswick et al, 2004; Dalal et al, 2004). I consulted a minority ethnicity research specialist and it was agreed to aim for a maximum of two people, so that the sample would broadly reflect the two

percent non-white minority proportion of the Scottish population (The Scottish Government, 2004). However, I wished to limit the number of questionnaire questions in keeping with systematic review evidence that briefer questionnaires generally reap higher response rates (Edwards et al, 2002). Consequently, I decided that due to the complexity and space required to include ethnicity on the questionnaire, I wouldn't include a specific ethnicity question but instead would use consenting potential interviewees' names. Although a name check cannot accurately identify all people of minority ethnicity, it can identify a substantial proportion of people of minority ethnicity within a dataset (Coldman et al, 1988).

I sought to interview people with different cardiac histories. The literature indicates that beliefs about health and CHD may be influential regarding non-participation. I therefore wanted to reflect the perceptions and experiences both of people who had been aware they had CHD before their MI and people who were first diagnosed after their MI. I also wished to include people whose MI had been clinically categorised as severe and those whose had been less severe, to see whether this appeared to have influenced their non-participation. The basic clinical categorisation is 'STEMI' ('ST Elevation MI' - more severe, implying significant muscle tissue destruction) or 'NSTEMI' ('Non ST Elevation MI' - less severe, implying minimal or no tissue destruction). I decided to obtain this information from hospital records and colour-code questionnaires so that I could identify the clinical category of respondents' MI. First, I considered that few patients would know or recall the clinical category of their MI, also I thought the clinical categorisation could provide an interesting comparison with the way the person self-categorised their MI severity.

Within a sample of 30-50 people it wouldn't be possible, even if desirable, to select people using all available variables. The literature tentatively suggested that socio-economic issues may have some influence regarding resource use and post-MI experience, however the evidence appeared weaker than for the previously described criteria. Moreover, classifying people into social 'classes' has widely been recognised as conceptually and methodologically problematic, and the most robust way of identifying socio-economic groups is generally been considered to be using a combination of multiple indicators (Bolam et al, 2004). I judged this wouldn't be

feasible due to the number of additional questions I would need to add to the questionnaire, which, as discussed previously, wasn't advised in terms of response rates.

A principle of 'grounded theory' is that sample selection is ongoing rather than at one point at the outset of recruitment. This strategic sampling enables the researcher to reflexively shape their study in response to the results of previous recruitment, and also findings from the preliminary analysis of early data, which also takes place 'en route' (Charmaz, 2006). Lincoln & Guba (1985) describe this as an essential facet and strength of qualitative research, whereby the design needs to remain flexible and open enough to allow exploration of whatever aspects arise in the course of studying a topic. This would thereby enable me to fulfil the curiosity that is a distinctive feature and asset of qualitative research (Barbour & Barbour, 2003). Considerations specific to my study also encouraged my use of this reflexive strategy. The major gaps in understanding CR and CHD Group non-participation, described in my literature section, meant I expected that unanticipated issues would arise in interviews. I viewed strategic sampling as a responsive tool that would allow scope to pursue emergent themes. Thus I could select interviewees whose characteristics suggested they might offer valuable data on that specific topic.

This approach resulted in an important study modification. Pilot interviews highlighted the potential value of obtaining the additional perspectives of post-MI interviewees' family members or friends in terms of understanding non-participation and non-participants' experiences. One interviewee explicitly commented that his wife's view about how he had managed since his MI might differ from his own – implying that he might have underemphasised or omitted problematic elements. The other four interviewees referred substantially to the role and views of family, and sometimes also friends, colleagues and neighbours. This initial data was reinforced by the literature, which indicated that the role of family could be important for some people, but that family members' capacity to meet post-MI needs was limited. I decided that additional interviews with 'significant others' would be a fruitful avenue to pursue to shed further light on these topics. And so in line with the iterative process of qualitative research, I added a further research question to my study. This

was: What are the perspectives of ‘significant others’ about non-participation and the experience of post-MI recovery without these resources?

Strategic sampling also offered the capacity to assist me in assembling a robust sample that would reflect important aspects of the diversity that could be expected among the wider population of CR and CHD Group non-participants. To allow for sampling flexibility I decided to send the questionnaires out in a series of ‘waves’ – allowing time for data collection, analysis, and reflection from one ‘wave’ before using these conclusions to then identify and send out invitations to the next sample of potential respondents. I anticipated that recruiting people with certain characteristics might prove more difficult than for others, and viewed ongoing analysis and strategic sampling as a means to identify ‘gaps’ and target my recruitment particularly towards these sub-groups.

Section Two: Study Design and Data Collection

Stage 1: Screening Questionnaire

Questionnaire Design

The questionnaire is provided in Appendix One. To identify non-participants from the wider post-MI population people were asked whether or not they had attended CR and / or a CHD Group. I used descriptive terms that I thought would help people recognise and differentiate between the two resources. Because of the variable terminology used to describe CHD Groups, I combined terms in the phrase ‘Cardiac Self-help / Support Group’, and described CR as a ‘Cardiac Rehabilitation programme’. To serve the questionnaire’s second purpose of generating a data profile of respondent characteristics from which to purposively select interviewees, people were asked for information about their basic demography (gender, age, geographical area); and cardiac history (previous angina, hypertension or surgery).

I additionally included questions on co-morbidity; additional post-MI resources (‘Heart Manual’ and nurse home visit); and whether people had received information

about CHD Groups and other resources. Although not my selection priorities I thought these might highlight whether other aspects of diversity were more important than I anticipated. In any case they would provide useful information about the profile of respondents and the background of interviewees, which might usefully supplement interview data. Questions were brief and closed, (except for an open question allowing respondents to list co-morbidities), to minimise questionnaire complexity and length – factors that have been reported to improve response rates (Sheldon & Rasul, 2006). I piloted the questionnaire informally with a small sample of four, including two people who had previously had an MI and had become lay facilitators of CHD Groups. Feedback indicated the questions were clear, relevant and likely to be straightforward for the target group to answer.

I produced an invitation letter and information sheets to accompany the questionnaire (Appendix Two), to encourage participation and facilitate informed consent about whether or not to participate. These materials were in English, but to make the invitation inclusive and encourage people who had a different first language I included brief translated information in Lothian's four most commonly used minority languages (Urdu, Bengali, Mandarin / Cantonese, and Arabic). Full translation of all information was also offered on request. I had planned to colour-code all questionnaires to indicate the clinical severity of the patient's MI, but this information wasn't available for the 'Wider Lothian' dataset, and so I decided not to use this criterion. I provided a pre-paid return envelope based on evidence that this can enhance response rates especially among 'harder to reach' groups (Sheldon & Rasul, 2006).

Recruitment of questionnaire respondents was indirect. Potentially eligible participants were identified from hospital records and questionnaires and information packs were then sent via patients' General Practitioners (GPs). This was both to 'screen out' and avoid contacting any people who had died or were very unwell (terminal or psychiatric illness or severe morbidity), and to preserve the anonymity of patients whose details had been obtained from hospital records until they decided if they wished to participate. I sent the GPs a letter explaining the study and requesting their assistance to exclude any patients it would be inappropriate to

contact and to forward the materials to eligible patients. I also sent a copy of the documents being sent to the patient; a list of the names and addresses of identified patients believed to be on their practice list; and the corresponding patients' envelopes. A stamped postcard was also provided for GPs to indicate the number of questionnaires forwarded to eligible patients – a technique successfully used in previous studies (Gregory et al, 2006b). This indicated approximately the total number of eligible patients who were sent the study materials out of those identified as potentially eligible from the hospital dataset (Table One). Respondents who were willing to be interviewed were asked to provide a contact telephone number and return two copies of a signed 'consent form' (one I would countersign and return to participants), which confirmed they had read and understood the study information and were willing to be contacted about participating in an interview. This procedure of asking people to actively 'opt-in' was intended to emphasise that the decision to participate or not was voluntary.

Data Collection

I identified the cohort of people discharged from hospital with a diagnosis of MI between 1st July – 31st December, 2005 from patient records at the three acute hospitals in Lothian region (St John's district hospital, West Lothian; and the Royal Infirmary of Edinburgh (RIE) and Western General hospital (WGH), which serve the wider region of Edinburgh, East Lothian, Midlothian, and some referred West Lothian patients). After gaining the Ethics Committee approval that is required for conducting research involving NHS patients I was granted access to on-site records to identify prospective participants and send out the study materials. At St John's I compiled the dataset from handwritten records. At the RIE and WGH data management staff provided me with a patient list from their audit records, which I then matched with individual computer-based records to obtain patient and GP contact details. Prospective participants' details weren't retained, to preserve people's confidentiality until and unless they volunteered to participate in the study by returning the questionnaire and providing their details as prospective interviewees.

The West Lothian tranche of questionnaires for potentially eligible patients (n=140) was disseminated in August 2006 to patients' GPs. Response postcards confirmed that at least 109 were eligible and had been sent the study materials. The encouraging size and profile of the return (n=44) indicated that the method could successfully identify non-participants and a sizeable proportion were willing to volunteer for an interview. Furthermore, because the target size of the interview sample was for between 20-30 post-MI people, I concluded that sending out questionnaires to a proportion of the 'Wider Lothian' cohort of identified eligible patients would generate sufficient responses. This also would minimise the number of 'unused' and possibly disappointed volunteers who wouldn't be able to participate in an interview due to the limited required sample size.

A further change was made for the 'Wider Lothian' sample. According with the 'grounded theory' principle of ongoing strategic sampling, I considered that it would be particularly useful to identify potential participants with characteristics that weren't represented within the sample already gathered. The 'Wider Lothian' questionnaires were thus disseminated in a series of 'waves' between September 2006 and February 2007. The total number of potentially eligible invitees was 94 and GPs confirmed that at least 54 were sent study materials. For the initial 'wave' a random selection of potentially eligible patients for the same period as the West Lothian sample (1st July – 31st December, 2005) were sent study invitations (n=44). The following wave aimed specifically to recruit more women who would consent to be interviewed, and so further invitations were sent to women selected at random from within the same time period. I noted that the majority of consenting interviewees had had their MI between 11-14 months previously and considered it important to recruit some interviewees who were at an earlier post-MI stage. The final recruitment wave therefore focused on people who had their MI later than previous invitees - between May-July 2006 (8-10 months prior to the potential interview).

Table One : Screening questionnaire response-rates

<u>WEST LOTHIAN SAMPLE</u>	n	%	
Total sample - discharged post-MI patients	140		
GP screened patients (confirmed numbers)	109	77.9	(109/140)
Respondents	44	40.4	(44/109)
Consenting to interview	33	30.3	(33/109)
(Proportion of respondents)	/	75	(33/44)
<u>'WIDER LOTHIAN' SAMPLE</u>			
Total sample - discharged post-MI patients	95		
GP screened patients (confirmed numbers)	54	56.8	(54/95)
Respondents	30	55.6	(30/54)
Consenting to interview	20	37.0	(20/54)
(Proportion of respondents)	/	66.7	(20/30)

Table Two : Questionnaire respondent profile

Participation / Non-participation category	Respondents	Consenters
PPs (Participated in <u>both</u> CR & CHD Group)	3	1
SGNPs (Participated in CR but <u>not</u> CHD Group)	37	30
CRSGNPs (Did not participate in CR <u>or</u> CHD Group)	33	21
CRNPs (Participated in CHD Group but <u>not</u> CR)	1	1
Gender		
Male	54	41
Female	20	12
Age		
40-49	7	6
50-59	11	10
60-69	13	11
70-79	15	10
80-89	10	6
Unknown	18	10
District		
West Lothian	44	33
'Wider Lothian':	30	20
-Edinburgh	(15)	(13)
-Midlothian	(9)	(3)
-East Lothian	(6)	(4)
Cardiac history		
-Pre-MI Hypertension	18	12
-Pre-MI Angina	14	8
-Pre-MI Cardiac Surgery	1	0
-None stated	41	33
Co-morbidity		
- One concurrent condition	21	15
- Multiple concurrent conditions	8	4
- None stated	45	34
'Heart Manual'		
-Received	64	48
-Not received / don't know	10	5
Cardiac nurse home visit		
-Received	38	26
-Not received / don't know	36	27
Information about CHD Groups		
-Received	41	33
-Not received / don't know	33	20

Stage 2: In-depth interviews

Preliminary design

I planned to interview each post-MI person on a single occasion at his or her chosen time and location. I anticipated some interviewees might request or assume a partner could be present and contribute to their interview. The literature documents advantages and disadvantages both for interviewing a person alone in private and alongside a partner / spouse. Some studies have suggested interviewees might feel more able to discuss certain issues without family members present (Huby & Dix, 1992 cited in Arksey, 1996), and some have cited the disadvantage of one co-interviewee dominating discussion in a paired interview (Highet, 2003; Arksey, 1996). Some researchers, for example, Radley (1988), have reported that paired interviews might trigger arguments and exacerbate tensions in family relationships, while others have suggested people might be more reluctant to participate in paired research (Pahl, 1989 cited in Arksey, 1996). From a 'constructionist' perspective also I considered that post-MI people's accounts would be constructed to account for their partner's presence, and would need to be analysed with this in mind. Yet, some people might feel more at ease with a familiar person present (Highet, 2003). Other important reported positive features are that the additional person might provide a new perspective, additional insights, and 'fill gaps' forgotten or omitted by their partner (Seymour et al, 1995). Drummond & Mason (1990), for example, decided to view the unexpected presence of partners as a bonus, providing insight into living with a diabetic, as well as the diabetic's own perspective. I opted for a pragmatic approach. If an interviewee wished someone to be present I would accept this to avoid discouraging them from participating or making them uncomfortable; I would treat any co-interviewee input as potentially useful data; and I would reflect on how the person's presence and contribution might have influenced the account.

Although prospective interviewees had declared willingness to be interviewed on their questionnaires, my protocol when telephoning to potentially arrange an interview was firstly to check they were still able to take part. A few did decline at this stage, citing for example being too busy, or being too unwell to be interviewed. This suggested that participation was seen as voluntary. To reinforce the principle of

informed consent, although all interviewees would have received prior written information, I briefly explained the study and provisions for confidentiality, and confirmed permission for audio-recording prior to each interview. All interviews were in English. However, I had obtained funding for an interpreter in case someone whose first language wasn't English wished to be interviewed in their 'mother tongue', to make it easier for them to express themselves more fully.

An in-depth interview is conducted as a 'guided conversation' (Lofland & Lofland, 1994), with the use of a topic guide (Appendix Three) and prompts to encourage participants to speak freely on a range of issues. To ease interviewees into talking about themselves I invited them to introduce themselves, giving some general autobiographical details (for example, age, occupation, family). I then asked interviewees how and when they first became aware of their heart trouble, and used probe questions to explore sub-themes. Topics had been identified with reference to my research objectives and the literature. These included: the perceived impact of CHD on their life and health; theories about possible causes; everyday experience of CHD – including management and coping strategies, medication, treatment and therapies, and perceptions of needs that hadn't been met. Of pivotal importance were their interpretations and perceptions of different types of post-MI support, including availability, accessibility, and reasons for use or non-use.

Sample selection

I used purposive sampling to construct a sample of 'maximum variation' from the data questionnaire respondents provided. Interviewee characteristics from questionnaire data are summarised in Appendix Five. As described in Section One, I anticipated that CHD Group non-participants would outnumber CR non-participants. This was borne out, as Table Three shows, with double the number of respondents not having taken part in a CHD Group (n=70) compared to people who hadn't attended CR (n=34). However a slightly greater number of respondents had attended CR but did not go to a CHD Group (n=37), compared to people who attended neither resource (n=33). Few respondents had participated both in CR and a CHD Group (n=3; 4% of responders), while only one person indicated they had attended a CHD Group but not CR. There wasn't a substantial difference in the likelihood of

respondents consenting to interview between those who had taken part in CR compared to people who had taken part in neither resource.

Table Three: Non-participant groups

	Questionnaire respondents	Consenting potential interviewees
PPs (Participated in <u>both</u> CR & CHD Group) <i>(excluded)</i>	3	1
SGNPs (Participated in CR but <u>not</u> a CHD Group)	37	30
CRSGNPs (Did not participate in CR <u>or</u> CHD Group)	33	21
CRNPs (Participated in CHD Group but <u>not</u> CR)	1	1
TOTAL (n)	74	53

I sought to include a minimum of ten interviewees from each of the two main respondent groups, allowing additional selection criteria to determine the exact ratio beyond this. The resulting sample included 17 people who took part in neither CR nor a CHD Group, and 10 who participated in CR but not a Group. This excluded one man (and his wife) whose interview revealed he had participated in both resources and whose data was excluded from my analysis. I specifically sought to interview the one respondent who said he had attended a CHD Group but not CR, yet the interview revealed he had participated in neither. Nonetheless, his data was a valid non-participant account.

I had aimed to recruit equal numbers of men and women. Yet, the number of potential female interviewees was limited because male questionnaire responders outnumbered women by 2.7 to 1. Also more men consented to interview - 76% (41/54), compared to 60% (12/20) of women. Additionally, some consenting interviewees of both genders were unable or changed their mind about being interviewed. Consequently an equal gender balance wasn't possible. Ten post-MI women and 18 men were interviewed, thus broadly reflecting the gender balance of CHD within the wider population. The additional interviewee attributes I used to maximise variety within my sample were: age; geographical district; ethnicity; co-morbidity; and cardiac history.

After categorising consenting interviewees for non-participation and gender I grouped people into age bands. The age spectrum of questionnaire respondents was substantial, from forty to the mid eighties. I had anticipated a gender difference because the literature indicates a higher average age of MI among women compared to men (Mackay & Mensah, 2004; Wenger, 2003). I was surprised to find that the age range was very similar, and indeed female respondents aged between 40-50 outnumbered men. The mean responder age also was similar but slightly higher for women (68 years) than men (63 years). I sought at least two people of each gender from each decade if possible. Sixteen respondents left the questionnaire age box blank and thus their age data was unavailable, however the majority specified their age and enabled identification and selection of people within the desired age bands. However, some people who hadn't given their age were included if they met other criteria.

The primary geographical division was between West Lothian, and the three 'Wider Lothian' districts. The post-MI interview sample included 14 people from West Lothian and 13 from 'Wider' Lothian. Interviewees from the three 'Wider' Lothian districts were included: 9 from Edinburgh, three from East Lothian, and two from Midlothian. I had sought to include a small number of people of minority ethnicity. Brief review of patient names within the hospital datasets had suggested there were few people of minority ethnicity within the cohort. The number however appeared greater in 'Wider Lothian', which could be expected due to its greater overall

population and established minority communities, compared to only one in 140 names of the West Lothian cohort. I therefore considered it positive that three people of minority ethnicity responded to the questionnaire and consented to interview. In two cases their circumstances impeded participation, but one man of Indian origin and his wife were interviewed.

Not all interviewees completed the cardiac history questions, however the questionnaire and interview data of people who did complete this section generally matched well. Only one respondent had pre-MI cardiac surgery (but didn't consent to interview), but a substantial minority had been diagnosed with angina and / or hypertension before their MI. I included men and women with prior angina or hypertension and people who reported none. The questionnaires indicated that among the potential interviewees were substantial clusters of people with no stated co-morbidity, people with a single additional condition, and some people with multiple co-morbidities. I included people from each category in my interview sample.

In April 2007 I reviewed the interview profile and data to assess whether further interviewees would add value to my study. The richness of the existing data suggested that exploring this fully would be preferable to adding further interviews and sacrificing depth. I was confident that the post-MI interviewees encompassed considerable diversity in terms of the afore-described aspects that I considered were potentially important or interesting for analysis. The profile and diversity of the family / friend interviewees (selected by post-MI interviewees) was a further consideration. I considered the diversity of relationships within the 'significant other' sample valuable. This included a son, daughters, and a close friend, as well as the spousal relationships I had anticipated would predominate and which dominate the CHD literature. Women (fourteen) did outnumber men (four), whereas ideally I had sought a more balanced gender profile. This was partly because male post-MI respondents outnumbered females, hence a greater number of female spouses; while also no co-interviewee was available for some post-MI women. Several factors argued against specifically seeking further post-MI women with a male co-interviewee. Identifying further female potential interviewees, particularly those

who specifically nominated a male co-interviewee and were available for interview, could take several months. More fundamentally, the existing male sample had strength in the quality of interview data; and had several important dimensions of diversity, including: relationship status - two husbands, a son, and a close friend; age span 40s-80s; and the nature and extent of their post-MI involvement. This convinced me to concentrate on the existing data rather than expanding the sample.

'Pilot' interviews – initial data collection and design modification

Piloting my method to assess its acceptability and effectiveness with my 'target group' was important. This enabled me to test my topic guide and identify any ways the guide, format, or process could be improved. I conducted five pilot interviews in September and early October 2006 with a diverse interviewee sample comprising: three women and two men; people from West and 'Wider Lothian'; a wide age range; and people who had participated in neither CR nor a CHD Group, and CR participants who had not attended a CHD Group.

Writing field notes and transcribing the pilot interviews gave me opportunity to reflect on the interview process and data. A number of transcripts were also read by and discussed with the project supervisors. I concluded that people were willing to be interviewed, and the interviews had generated rich accounts of the person's perspectives on their post-MI experiences and use or non-use of support resources. The variety of topics and emphasis of the interviews suggested that my approach of using the topic guide loosely and giving interviewees 'space' to focus on aspects they felt were important, was working. Also, the fact that some interviewees had felt able to discuss sensitive issues, reassured me that my interviewing style was appropriate.

The pilots highlighted some potentially fruitful avenues for further exploration that suggested that certain design modifications could enhance my study. Several themes that interviewees raised spontaneously and hadn't been in my topic guide appeared interesting and possibly important. For example, after the first interviewee discussed their conceptualisation of what 'support' meant, as well as their views on specific types of support, I added this to the guide. Some interviewees mentioned what their prior conceptions about CR and CHD Groups had been either before staff told them

about the resource or before they attended, and it appeared these sometimes differed from their subsequent thoughts. I added this to my guide to pursue with subsequent interviewees.

The initial data collection, transcription, and making field notes, highlighted the issues of dialect and how I would treat 'data' that wasn't part of the actual interviews. All interviewees used certain slang, local, and Scots words, raising the question of whether to 'translate' these into standard English or retain the vernacular. I decided that interviewees' vocabulary was important as part of how they expressed their perspectives. However, to ensure my findings would be widely comprehensible, I decided that while retaining 'non-standard' words in their original form I would add 'translation' in brackets. For example, 'Ye ken?' ['You know?']. Because these words were few I considered this device wouldn't impede dialogue flow. My field notes recorded non-interview 'data' such as comments interviewees made before or after interviews and descriptions of notable features of the interviewee, setting or process. I decided to use this information if it appeared relevant to an issue within the interview, on condition that the person hadn't explicitly indicated it was a private comment and the person's anonymity would be maintained.

Interview literature suggests that retaining certain dialogue features, such as laughter, repetitions, pauses, emphasis, and raised volume, can provide important indications of how an account is framed (Roberts & Sarngi, cited in Ziebland & McPherson, 2006). Close listening to the pilots illustrated the value of this and convinced me particularly that indicating the tone in which certain phrases were said could be useful. Qualitative researchers have advocated this to make the meaning intended by the speaker clear and avoid misrepresenting their views (Barbour, 2008). In several instances this added insight to my analysis of pilot and later interviews. For example, awareness that a participant's dialogue about CR was expressed with anger and irony enhanced understanding of his views about the thwarted nature of his non-participation status.

As described in Section One, the primary issue from the pilots was the potential value that interviewing a ‘significant other’ might add. Prior discussions with experienced researchers during my PhD first year review had suggested that considering either second interviews with the post-MI person or obtaining another person’s perspective might be productive. According with my research approach, informed by ‘grounded theory’, which entails responding to emergent themes and issues, the pivotal question was whether my pilot interviews supported either of these strategies. As described above, the initial data indicated that a family member or friend’s perspective could enhance understanding of non-participation and its consequences. On the other hand, the richness of the post-MI interviewees’ data, and the indication that most changes had occurred between the early months and the time of interview, suggested that follow-on interviews would not be as profitable as talking to a ‘significant other’. The richness of accounts also convinced me to use the pilots within the main analysis.

Post-pilot interviews - Main data collection phase

Between September 2006 and April 2007 I conducted 41 interviews (five paired; thirty-six single). These involved 46 people: 28 who had experienced MI, 17 family members, and one close friend. One paired interview was subsequently excluded (as previously explained). My final dataset comprised forty accounts, involving 44 interviewees. Home was the preferred location, although one interviewee was interviewed in her private work office. An environment that facilitated privacy and avoided distractions was preferable - giving interviewees greater freedom to talk and ensuring the recording was audible. Interviewees facilitated this, for example, tactfully suggesting another person left the room, closing a door, or turning off the TV or music. Because interviews took place in the person’s day-to-day environment some interruptions occurred, such as telephones, restless toddlers, pets, and people entering. Generally this didn’t significantly impede interview flow or the person’s willingness to talk. However, in one case the female interviewee’s negative reactions to her husband’s interruptions into the room appeared to provide a brief snapshot of observational data to illustrate issues from her interview concerning the exacerbating influence of difficulties in their relationship upon her post-MI recovery.

Interview duration ranged from 15 minutes to two hours, but most single interviews lasted approximately an hour and joint interviews an hour and a quarter. Often interviewees continued commenting after recording had finished, sometimes mentioning issues that seemed pertinent - adding to, or even contradicting their interview statements. In several cases this provided important additional insight, which I believed, justified my decision to use this data.

My decision to modify the original design by interviewing a 'significant other' necessitated further ethical approval, which was granted in November 2006. The original invitation process also had to be changed. However, potential interviewees from West Lothian and the first 'wave' of the 'Wider Lothian' cohort had already been recruited based on the original study information. I decided that a pragmatic way to put the amendment into effect for these people would be to telephone and ask if they would consent for a nominated person also to be approached for interview. For the further 'waves' of 'Wider Lothian' recruitment I used new information sheets that requested that willing post-MI interviewees would also invite and pass on an information sheet to a family member or other person (Appendix Four).

In terms of interview format I decided that the rationale for aiming to interview the post-MI person and their family member or friend separately remained, unless interviewees requested otherwise. It appeared that a belief that being interviewed together might be more practical was part of the motivation for three of the five couples that opted for a joint interview. This was based either on a desire to assist a partner's participation, for example to counter deafness; or to economise on the time taken within the couple's daily life schedule. Additionally, in two cases where the spouses were the person's main carers their accounts suggested that the dependency and intimacy of their post-MI relationship made a joint interview seem natural given their involvement in most daily activities and decisions. I decided that if an interviewee didn't wish a family member or other nominated person to be interviewed, but their questionnaire profile suggested they were of potential interest regarding my objectives, then I would interview them alone. In practice most people who had already consented to a single interview were willing to invite a family member, and response rates between the original and modified invitations were little

different. However, in a few cases where the person declined to invite a ‘significant other’ for interview, this decision in itself and their explanation provided data that illustrated themes from their interview.

I wrote up my field notes shortly after each interview, recording ‘non-interview’ data and my immediate reflections on the interview content, process and interviewee. I transcribed the five pilots and undertook extensive editing to improve the accuracy of the remaining interviews that were transcribed by a secretary. This entailed listening to each recording several times and was beneficial in making me very familiar with my data at the time when I was also interviewing and recruiting. In keeping with the ‘grounded theory’ approach of reflecting on existing data to inform ongoing data collection, this familiarity provided me with a better grasp of, for example, what certain resources or clinical experiences might entail, and so I was better able to encourage interviewees to give their own perspectives.

In keeping with data protection requirements; the terms on which ethical approval was granted; and the assurances given to prospective interviewees regarding confidentiality, I took steps to safeguard interview data and interviewees’ identities. Audio-recordings and transcripts were allocated a reference code and pseudonym to anonymise interviewees’ identities, and the audio-recordings will be destroyed after completing the study. The transcripts will be securely stored according to the policies and protocols of the University of Edinburgh for ten years to allow for use in any subsequent publications.

Table Four: Post-MI Interviewee profile

POST-MI INTERVIEWEES	Number (Total n=27)
Non-participation	
Participated in CR but <u>not</u> a CHD Group	10
Did not participate in either CR or a	17
District	
West Lothian	13
Edinburgh	10
East Lothian	2
Midlothian	2
Gender	
Men	17
Women	10
Age groups	
30s	0
40s	4
50s	8
60s	5
70s	7
80s	3
Ethnicity	
'White' Scottish	25
'White' Irish	1
Indian	1
Cardiac history	
No diagnosed pre-MI CHD	17
Pre-MI hypertension	5
Pre-MI angina	5
Pre-MI cardiac surgery	0
Co-morbidity	
No concurrent condition	17
One concurrent condition	5
Multiple concurrent conditions	5

Table Five: 'Significant other' interviewee profile

FAMILY MEMBERS / FRIENDS	Number (Total n=17)
Relationship to post-MI person	
Wife	11
Husband	2
Daughter	2
Son	1
Friend	1
District	
West Lothian	9
Edinburgh	5
East Lothian	1
Midlothian	2
Gender	
Men	4
Women	13
Age groups	
30s	1
40s	2
50s	5
60s	4
70s	4
80s	1
Ethnicity	
'White' Scottish	16
'White' Irish	0
Indian	1

Section Three: Data analysis

Stage 1: Screening Questionnaire

Respondents were each allocated a reference code to anonymise their data. I entered the data into a series of spreadsheet tables using 'Excel' computer software, separating 'Wider' and West Lothian data, and identifying consenting potential interviewees from the respondent sample. I undertook basic statistical calculations using the tabulated data (count, mean, mode, median, and range). This provided a profile of respondents' demography, cardiac history, co-morbidity, and use or non-use of CR and / or CHD Groups (Table Two), and facilitated the purposive selection of interviewees.

Stage 2: Interviews

For a 'grounded theory' based approach analysis begins with the first data collection, allowing indications from preliminary data to guide ongoing sample selection and data collection. I previously described how reflection on the pilot interviews prompted amendment of my design and influenced subsequent interviews. For the initial stage of inductive analysis the literature recommends 'immersing' oneself in the data to identify themes that seem meaningful to the interviewees' narratives (Ziebland & McPherson, 2006; Pope & Mays, 2000). This began with making post-interview field notes, transcribing the pilot interviews, and editing each transcript. Listening intently, reading and re-reading the interviews, engendered data familiarity to the point of the feeling I "knew" the interviewees and about their lives, or at least the versions they had presented. This process of 'getting close to' the data highlighted potential themes and encouraged me to think about these and seek whether they were reflected or contradicted in other interviews.

Producing vignettes - detailed portraits of the forty-four interviewees, using questionnaire and interview data and field notes, furthered this process of familiarisation and conceptualisation. These described key features of interviewees' current lives and biographies, and specifically their views and experiences regarding rehabilitation and post-MI non-participation. Besides providing rich material for my

overall analysis, they constituted the base I used to develop the case studies used as part of my analysis (discussed further below). The vignettes thereby played an important analytical role, but due to the volume of data (over 20 000 words), they are not included directly in the thesis. The vignettes also highlighted wider dimensions of interviewee diversity, showing the considerable range regarding biography, circumstances, and outlook, to add to the heterogeneity already seen in terms of the characteristics used as selection criteria. For example, occupations spanned from manual jobs, such as factory production line operatives, to organisation managers, to retirees. Family circumstances ranged from parents of young children to elderly people dependent on external carers. Relationships included people who felt ‘overprotected’ yet loved and cared for by their close-knit families, and people describing fractured, unhappy home lives, such as the man who had minimal contact with his alcoholic wife, or the interviewee whose partner left them after their MI. Varied biographical experiences included: serving a custodial sentence; being in a wheelchair from childhood; settling in the UK as migrants from another country; and raising a family following MI. The diversity seen in the vignettes indicated that my objective of recruiting a highly diverse sample was achieved.

From gaining considerable familiarity and feeling ‘involved’ with my data during the collection and preliminary analysis I then proceeded to ‘coding’ and developing themes and sub-themes. I broadly followed the approach advocated by Ziebland & McPherson (2006). I initially re-read each transcript to identify themes and issues, noting these to create a master-list of ‘codes’ that I could use to group and retrieve all data relating to that particular topic. In keeping with the inductive emphasis of ‘grounded theory’ I sought to identify themes that emerged from the data. But according with my overall pragmatic approach I also actively looked for particular themes that ‘reflected the initial aims of the research project’, as Seale & Kelly (1998) recommend, for example, reasons for non-participation.

I ‘coded’ each transcript and the related field notes, assigning relevant sections of data to ‘code’ headings. I used ‘Nvivo’ computer software - a specialist programme to facilitate effective storage and retrieval, and enabling links between different sections of coded data. The number of codes was substantial, expanding as my

conceptual ideas developed while coding each account. Thus I had to return and re-code earlier documents with the subsequently-identified codes. This systematic approach enabled me to retrieve all the text coded under each heading from the various interviews and compare and contrast accounts. I produced a summary of each theme and its sub-themes, listing the aspects that appeared in different interviews. From this I could undertake what is generally termed 'axial coding' - considering links between the different issues, and producing broader, overarching themes, and identifying similarities and differences between participants. This provided an overview, what Ziebland & McPherson (2006, p. 409) describe as, 'what is going on in the data'.

My findings are presented in Chapters Six, Seven, and Eight, and discussed in Chapter Nine. I describe and explain the themes I identified and illustrate these using direct quotations from interviewees. To protect participants' identities, each person has been given a pseudonym and biographical details by which they might be identified have been disguised. To provide readers with a snapshot insight into the person quoted I give a brief summary of key characteristics in brackets after quotations. The format for single interview quotations is: (Pseudonym; age; marital status; working status). For paired interviews: (Post-MI person pseudonym; age; working status. Co-interviewee pseudonym; age).

All three analysis chapters and the Discussion draw from my entire dataset. Section two of Chapter Seven differs by focusing on a subset of the data - three specific cases, which I use as case studies. A case study approach entails the intensive exploration of a single case or small number of specific cases, drawing on multiple sources of evidence, to produce a thorough understanding of the phenomena under investigation (Stake, 1995; Eisenhardt, 1989). I compiled each case study using data from two separate interviews - with the post-MI person and their family member; and field notes describing direct observations and contextual evidence. The cases are used as a complementary vehicle to develop and demonstrate my broader finding, presented in section one, regarding the patterning of my data into three non-participation categories. Each case provides a specific example to illustrate the similar process and reasons for post-MI non-participation that I found among other

people within the same category. In this way the case is used to provide illustrative evidence to substantiate a key finding (Yin, 1994).

Summary

I selected a qualitative methodology, using an approach informed by ‘grounded theory’, for its capacity to explore and generate detailed insight into the perspectives and experiences of CR and CHD Group non-participants. In-depth interviews were the specific method I used, based both on appropriateness to my ontological and epistemological stance on my topic, and also for practical advantages in terms of recruiting and gathering data from my ‘target group’. A screening questionnaire enabled me to successfully identify non-participants from the wider post-MI population and provided information to construct a diverse interview sample. My twenty-seven post-MI interviewees encompassed people who hadn’t participated in one or both resources, and of varied demographic characteristics and cardiac and health histories. Therefore my findings may be seen to represent a broad spectrum of the experiences and perspectives of people within the wider post-MI non-participant population.

Application of ‘grounded theory’ principles resulted in an important study design modification, whereby pilot interview data suggesting the value of obtaining the additional perspectives of ‘significant others’ resulted in interviews with seventeen family members / friends. I used established qualitative analytical techniques to translate the substantial volume of rich data into research findings relating to my key research objective of providing insight into the reasons that people do not use CR and CHD Groups and their experience of rehabilitating without these resources. The breadth of my interview sample and the rigour with which I applied my methodology suggest that the findings reported in subsequent chapters are valuable for developing understanding of these issues and strategies to improve rehabilitation support. At the same time however, the reflexivity that was part of my overall approach, suggests there are also certain limitations. I discuss these in relation to my findings in Chapter Nine.

Chapter Six - “Why do people not participate in CR and CHD Groups?” - Part One: The influencing factors

This is the first of two chapters in which I present findings that address the question of why people do not participate in CR and CHD Groups. First, I discuss non-opportunity as a barrier, whereby lack of invitation, information, and endorsement meant that some people didn't have opportunity to decide whether or not to participate in these post-MI resources. I then identify and explain the spectrum of factors, beyond opportunity, that influenced whether or not people would use these resources. These factors related to three aspects of individuals' lives: their 'lifeworld' circumstances; beliefs; and identity; and I show how these could influence people regarding attendance at, and attitudes to participating in CR and CHD Groups. Despite the differences between CR - the formal health service, and the semi-formal, independent CHD Groups, I found the range of factors and the way they could influence people were highly similar. Moreover I found that each factor could exert influence in opposing directions, either to encourage or discourage use of these resources.

Non-opportunity

Many interviewees said they hadn't received information about or an invitation to CR and CHD Groups from service / resource providers. This included almost fifty percent of interviewees who hadn't attended CR (7/17), and more than three-quarters (21/27) of CHD Group non-participants. The table in Appendix Six documents interviewees' self-reported invitation / information status. Regardless of whether these interviewees may have been interested and able to participate, they were denied the opportunity to decide. Dennis, a retired man in his seventies, provides an example. Unlike many interviewees, he had heard informally about CR (via a relative and his tai-chi instructor) and expected to be invited. He was keen to do so, particularly because of his uncertainty and unease about the chest sensations he experienced after hospital discharge. He had thought the monitoring and supervised exercise he had heard were available would provide reassurance. He believed he

wasn't invited because staff thought he could recover independently, and he didn't feel it was acceptable patient conduct for him to challenge health professionals' judgement or imply there had been an oversight.

AJ: "So, you'd heard things about it, but you didn't get the..

D: Opportunity..

AJ: And the nurse who came, presumably she didn't...
It was never mentioned by your GP presumably?

D: No.. no. Well, I've.. I've never heard it mentioned.
No... Maybe I should have asked and said 'I want to do it', but.. I don't know how many places they have..

AJ: I guess people are invited up generally if the professionals involved decide to..?

D: Or, know about it more.. yeah... Or presume someone else has.. That's probably not that difficult nowadays.. [laughs] Having worked in an organisation myself I know that people don't always talk to each other! [laughs]

(Dennis: 77; married; retired pre-MI)

Dennis was among several interviewees who expressed interest in a CHD Group when told about it in the interview but hadn't received information at the time – suggesting one hadn't been locally available or he had missed out on information. Some CR participants also said they would have been interested in attending a CHD Group if opportunity had been available. For example, Colleen, a working woman in her early 60s, was one of several interviewees who believed a follow-on resource

such as a CHD Group would have aided long-term health maintenance and / or addressed an issue unresolved by CR. She had valued the safe exercise environment and company she had at CR, and thought a group might also provide this. Additionally, CR hadn't met her information and emotional support needs specifically related to her experience of CHD as a woman, and she believed a CHD Group might fill this gap. Colleen had assumed a CHD Group wasn't locally available because CR staff hadn't provided information.

C: "See, there was nothing like that. I actually had thought about that, and I thought that would have been actually a good idea, where you could carry on and..

AJ: It wasn't mentioned at rehab or by your doctor or anything?

C: No, nothing, nothing at all. I don't know whether they have anything like that here.."

(Colleen: 63; married; employed)

The wider factors that may encourage or discourage CR and CHD Group participation

Lack of opportunity to attend CR and CHD Groups due to non-invitation and lack of information was a factor in the non-participation of many interviewees. However, accounts of both invited and non-invited interviewees indicated that a wide spectrum of further factors influenced whether the person could, or would wish to use these resources, and contributed to non-participation.

Self-reliance, its power, limitations and compromises

A belief that it was preferable to be as self-reliant as possible in managing ill health was widespread, and beliefs about, and a person's sense of identity relating to self-reliance were powerful influences regarding non-participation. Preference for

managing their condition with minimal help was expressed by interviewees who had retained post-MI independence as well as people who aspired to this but had needed to make compromises. A self-reliant identity appeared to have a two-fold influence deterring CR and CHD Group use – encouraging their belief that they could recover successfully without these; and making independent activities and resource use more attractive. This belief discouraged some from using CR and CHD Groups. Some interviewees who believed their symptoms were minimal were confident that they could manage without these resources. A particular aspect was that conceptions of ‘good patient’ conduct were linked to self-reliance, and could bolster or counteract this tendency. Thus some people believed they should avoid using services and facilities unnecessarily, to ‘free up’ resources for others who needed them more, and avoid being a “burden” or “bother”. For example, because Maisie believed her MI hadn’t entailed significant impacts she reasoned that attending CR would have been unnecessary and wasteful.

M: “I says to her, ‘No, I wouldn’t bother’. I think it was her down there that offered that. Well, I just felt that.. I was alright and.. I just thought well what could they tell me, you know what I mean? So, there was no point in.. taking up someone else’s place... I mean, I’m.. I’m a believer in.. if everything is alright don’t change it.

AJ: Aha.. So, was that.. after that they just said go and see your GP as and when?

M: Well, not really.. not unless there’s something wrong with me. Like, er, I’ve got a repeat prescription so I never see them [coughs], you know what I mean? I mean, you get some people that go to the doctors for anything, don’t they? ...I think you get some that go tae the doctor if they’ve got a headache or.. you know? Unnecessarily, eh?”

(Maisie: 77; widow; retired pre-MI)

A contrasting interpretation of ‘good patient’ conduct however could counterbalance a person’s self-reliance and encourage them to use CR and CHD Groups. Some interviewees believed that being a ‘good patient’ entailed compliance with professionals’ advice and instructions, including use of recommended resources. Gratitude for life-saving treatment during the MI heightened their desire to present themselves as adhering to professionals’ advice. Some interviewees who attended CR indicated this had been a strong motivating factor. For example, although George described several reasons for attending, the first reason he gave was “I comply”, succinctly demonstrating his identity as someone who did what was socially expected. Some West Lothian CR participants indicated that, although there were issues that had deterred them about attending the local CHD Group, the fact that staff recommended it had made them seriously consider the option.

A strong self-reliant identity among others, who had felt they needed some support, led them to supplement their own actions with resources that offered greater autonomy, and so enabled them to maintain their self-reliant identity to a greater extent than they believed would be possible by attending CR or CHD Groups. These could include support from family and friends; the self-directed, home-use 'Heart Manual'; ‘over-the-counter’ smoking cessation products; GP appointments; and local recreational facilities. The perceived advantages of these resources in terms of autonomy included: not attending a structured programme or group; “bothering” service providers less; a setting of their choosing; and ability to conduct activities at their own pace. These features also appeared to be valued because they provided a more tangible outward demonstration of self-reliance.

However, several interviewees indicated that despite uncertainty, difficult symptoms, and problems returning to roles and activities, the importance of self-reliance to their identity deterred them from accepting formal, semi-formal and as far as possible, informal support. Reflecting on their rehabilitation, several interviewees who declined CR and / or CHD Groups believed their recovery might have been more

difficult, slower, or less effective than if they had participated. Nonetheless, they didn't indicate regret about their courses of action – thereby reinforcing the priority they accorded their self-reliant identity. For example, Linda, a 45 year-old woman believed that her smoking cessation attempts had been less successful than if she had accepted specialist support for this either at CR or her local surgery. Yet she stood by her decision.

L: “I said, ‘No, it’s alright. I will not have another cigarette in my mouth... Er, I says there are no problems there, and he says, you know, ‘rehab... smoking cessation.’, and I says, ‘Oh aye, I know, but I won’t.’. And I didn’t.

AJ: So did they offer that as a class?

L: It was a class yeah, just for your ... for some support really.. and I might have listened to it... Er at [District hospital] but you can actually go at Glendale, at the surgery... But I didn’t go, I just went and got the patches from the doctor.. because..by that time I was back at work and it’s.. in the morning. I think it’s twelve ‘til one... But as I say I didn’t take them up because I’d stopped..[ironic laugh] [joke voice] I will.. I will, I’ll stop tomorrow.

AJ: You’ve been sort of on and off since?

L: Yeah, on and off. Yep.”

(Linda: 45; partner; employed)

Several people with long-term health problems spoke of making a ‘trade-off’, sacrificing some independence by declining to use resources, in the belief that this enabled them to preserve aspects of their life that allowed them to view and present

themselves as self-reliant. In this way it appeared that non-participation could be part of a process of reconstructing their identity of self-reliance to accommodate their changed post-MI circumstances. For example, Jean dropped out of CR after attending for some weeks. She said it was physically demanding, but her account suggested that her self-reliance was a stronger influence. Jean judged that other elderly participants were in poorer health, and this encouraged her that, relatively-speaking, she was well enough to be able to regain a form of independence by managing her own recovery at home. Her choice not to attend the follow-on CHD Group she was offered again related more to retaining a sense of independent control over her life than physical comfort – preferring to remain permanently in the house independently rather than relying on others to take her out. Jean thus interpreted independence in a different way to health professionals, who she believed encouraged resource participation to, “get me out of the house”.

J: “It’s goin’ oot an’ meeting everybody that.. I dinna like about it. The idea o’ sittin’ in a wheelchair an’ somebody else, er.. pushing me.. I don’t like the idea o’ t... so I’ve got used wi’ just staying in. I just get a door.. a key.. a.. chair inside the back door and’ sit there... An’ people passing by always shout out to me an’ that... The door’s always open.. An’ there’s always somebody coming out an’ in. They know just tae open the door an’ walk in [laughs.]”

(Jean: 84; widow; retired pre-MI)

On the other hand the importance of self-reliance to some interviewees motivated them to attend CR and / or a CHD Group. For these people, who experienced problematic symptoms and / or were anxious about their future health, accepting support was presented as a short-term compromise to aid recovery. Resource use thereby was seen as a means to regain and retain independence in looking after their health and managing their life thereon. The contrasting interpretations of Ernie, an active retired man, and his best friend Eric provide an example. Both described self-

reliance as a key facet of Ernie's identity. Yet, whereas Eric believed Ernie could have managed well independently, Ernie's fear that his CHD might undermine his capacity for self-reliance encouraged him to attend CR to safeguard this. After attending Ernie felt able to return to independent activity and declined to attend a CHD Group.

Eric: "I think he would have got it anyway, you know? Just from his own.. well, he would have done some research and found out what to... He said some of the exercise routines that he got were very good. He says a lot of them were similar to what.. what he was doing at the gym anyway, so, er, he said it sort o' reinforced what.. what he was going tae be doing at the club.."

(Eric: Ernie's best friend; mid 70s)

Ernie: "I went to the first rehab session.. And the girl there had me walking up and down, er.. increasing speeds.. monitoring the heartbeat all the time.. And then I got to the point.. she says, 'Right, that.', you know? 'That's your level.. that's where you can.. that's as far as you can safely go.. and we want to get that.. *up* [emphasis]'. And they did it by giving me a series of things to do... But I felt I did my thing.. it was ten weeks, and I felt over that ten weeks I gradually became fitter and fitter and fitter, and after the ten weeks of rehab I was able to start, erm.. back on where I'd left off.."

(Ernie: 75; married; retired pre-MI)

A number of interviewees presented themselves as people who, in life generally, proactively sought information and seized opportunities to further their understanding of an issue, and considered this part of their identity. This could

motivate use of CR and CHD Groups as a potential means of enhancing their information about their MI and CHD. Conversely, when self-reliance was an important aspect of their identity, independent information-seeking could also substitute resource use, especially if the person perceived limitations in the resource's information. For example, Kenny, a foreman in his fifties, said CR had been a key information source, and information had been a major incentive for attending. Nonetheless, certain unanswered questions remained and he felt the information originally received in hospital had been incomplete and this encouraged him to seek further information. Having received information and restored his confidence at CR, Kenny's strong sense of independence returned. His pride in his identity as an independent information-seeker then encouraged him to adopt a 'do-it-yourself' approach rather than seeking answers from his GP or a CHD Group.

K: "I prefer to understand what's going on, yeah. I mean, it's.. I suppose it's like food in a way, I mean you're no' just going tae pick something up an' start eating it.. You say, 'What is it?' [laughs and coughs.]

AJ: So where do you get information now if there's something you want to look up, about your medication, or about..?

K: Just go round to ma son's house an' go on the Internet. An' ma wife's got a MIMS book [prescribing manual.]"

(Kenny: 55; married; employed)

Importantly however, I found that some people who wanted and needed support to enable them to restore their faith and capacity to be self-reliant didn't receive opportunities for this. Some interviewees who regarded use of available support resources, including CR and CHD Groups, as a rational and legitimate response to the challenges of their condition, were frustrated and disappointed when such support was unavailable. Some people said they had informally heard about, and would have

wished to attend CR or a CHD Group, yet hadn't made enquiries or asked to attend if staff hadn't mentioned them. Dennis' case, described earlier in the chapter, provides one illustration. They explained this by their belief that as 'good patients' they shouldn't question professional judgement or imply they hadn't received information. Moreover they commonly interpreted the non-recommendation to indicate that staff expected and recommended that they could and should be self-reliant in their rehabilitation.

Informal support

A person's social circumstances could influence them regarding post-MI resource use firstly if they had family, friends, or other acquaintances who provided information to make them aware of the resource. Generally this went beyond neutral information provision and a substantial number of interviewees described active encouragement, or at least indications of support from family and sometimes friends, as an encouraging influence regarding CR and CHD Groups. Often the encouragement appeared to have reinforced the person's own inclinations, but in some cases the family member or friend had worked to change their mind or to persuade them to consider an option they might otherwise have rejected. For example, Teresa, persuaded her husband Ray to reconsider his initial decision not to attend CR, and negotiated with staff to allow time for this.

T: "They said to me initially that they normally introduce this thing as soon as they're discharged, but because erm, they knew that Ray had got problems with his head.. they said that they were going to give us a little bit of time, and erm, it was about two, three weeks.. Because initially Ray had said he didn't want to go.. he told the lady he didn't want to go... He just said, 'I'm not going, I'm not going to that'. So, that was his attitude 'cause he wouldn't have time because he was going back to work."

(Teresa: Ray's wife; 50s)

While a personal relationship could encourage a person to accept their family member or friend's recommendation it appeared that if a person was strongly disinclined for other reasons they would not change their mind even to "keep the peace" in their relationships. A person's social network might provide impetus for CR and CHD Group use also if the person believed their network couldn't provide the kind of support they needed. People who believed they needed CHD-specific advice, information and expertise, and whose social circle couldn't provide this, were particularly inclined towards CR and CHD Groups. For a number of interviewees, limitations of their existing social networks encouraged them to regard CR and / or a CHD Group as a potentially good social activity and opportunity to broaden their social horizons. The nature of their relationships led others to believe either that they couldn't expect emotional support from family and friends, or that they shouldn't 'burden' them with their problems, and this encouraged them towards these resources, believing they might fill the gap. For example, Mike, who was divorced and lived alone, didn't wish to 'burden' his adult children. Instead he turned to CR, where he knew counselling was available and he could talk to other post-MI people. The latter reason also encouraged him regarding a CHD Group, however this hadn't been offered.

M: "I've got two children who are.. adult children.. and you can sort of talk to them, but, you know? You don't really talk about these things to your children too much, or I don't, you know? ..and you don't really want to put.. a burden on them too much... It would have been nice.. If I'd been married or something, it would have been nice to have shared that with somebody who was supportive."

(Mike: 57; divorced; employed)

Conversely however interviewees' relationships could deter resource use. Firstly, when a 'significant other' accepted, supported, or felt unable to challenge a person's

non-participation decision this could encourage the person to feel vindicated in their choice. Accepting the apparent non-availability of a resource as a *fait accompli* could also dissuade someone from challenging the providers or seeking alternative help. For example, Dennis expressed considerable disappointment at not having been invited to CR, particularly because he had heard informally that it was available. He had considered asking staff if he could go, but decided against, siding with his wife Molly's view that if it had been appropriate he would have been invited.

M: "Well, our youngest daughter-in-law, her mother used to go to something.. at the.. the [main regional hospital] I think it was.. But we never were told about anything like that... Whether they thought.. whether she was worse, or.. I just don't know.. 'Cause there must be different.. there are different types of heart attacks.. must be some are worse than others.."

(Molly: Dennis' wife; 70s)

A person's social network could deter CR and CHD Group participation by providing an alternative source of practical and emotional support. Although the common desire of interviewees to be self-reliant led them to minimise this help as far as possible, accounts showed nonetheless that informal help from family and friends was the first 'port of call' for many interviewees and was preferred over 'external' help. This was underpinned by beliefs that mutual support was a normal part of these relationships, with post-MI help often seen as a 'natural' extension of this. Additional advantages were described that strengthened the case for some people to opt for informal support over external help. Support in familiar social settings could be reassuring, convenient, and provide a sense of 'normality' after the disruption of the MI. Being able to undertake a rehabilitation activity with family or friends could add a further incentive.

Social and recreational resources

A person's previous social and recreational resource experiences could encourage them to view CR and CHD Groups as resources that may be beneficial, enjoyable, and an environment in which they would feel safe, comfortable, and motivated. Positive previous experiences of exercise and social groups could motivate a person to anticipate CR and / or a CHD Group would have similar features and benefits. For example, Ernie, a retired man, described how his lifelong experience of the enjoyment and benefits of exercise added encouragement to attend CR.

E: "And she asked me if I'd be prepared to go on the rehab, er.. programme.. And I says, 'By all means, yeah, I want to go on the rehab programme'. I think most of the.. the information I got was from the booklets.. and it became.. patently obvious to me that the worst thing I could do was to mollycoddle.. and.. not.. [pause] become active.. You've got to become active.. within reason.. And this is what the rehab thing did..

AJ: Are.. were you fairly active?

E: Oh, I'd always been.. all my life I've been an exercise.. freak! [laughs]"

(Ernie: 75; married; retired pre-MI)

Conversely, if a person's existing recreational and social resources lacked elements they believed were important this could also be an incentive regarding CR and CHD Groups. Interviewees who found self-motivated exercise difficult and perceived these group resources would help indicated this. Interviewees commonly expressed need for a safe environment for exercise. The incentive of being in a group with others who were aware of, and knew how to respond in emergency to their condition encouraged people regarding CR and CHD groups. In the early post-MI period when

they were most anxious about their condition, the availability of health professionals and resuscitation equipment encouraged a sizeable number of interviewees that CR could be beneficial. Broader concerns about exercising alone, such as fear of attack, could add motivation regarding both resources for women. As group-based resources, CR and CHD Groups could also appeal to people who perceived a deficit in their social network and social contact. This included some interviewees whose network shrank after the MI due to disability and lost independence or redundancy, and some family members with intensive caring responsibilities.

Having an existing social or recreational resource could deter people from seeking or accepting other post-MI resources. The familiarity of a resource that was part of their normal life could be particularly attractive after the upheaval of their MI. Enjoyment of this resource, having friends there, and easy access could also encourage people to return to this rather than attend CR or a CHD Group. Yet this was contingent upon the person not feeling they needed CHD-specific support, and their existing resource meeting their needs regarding social support, and social and physical activities. For example, Maisie opted out of CR and wasn't interested in a CHD Group. Her positive experience of her existing resources was combined with her beliefs that she didn't need specialist help and negative perceptions about CHD Groups.

M: "A group just to talk about your heart doesn't appeal to me.. I think that's a bit.. I think that's a bit.. what could I say? I'd rather go away out wi' somebody and have a good time.. I mean, I wouldn't want to.. I wouldn't want to sit and listen tae.. 'cause to me it's too depressing... No, I go dancing.. I go to the club.. [laughs] I go tae the Masonic, tae the ladies night once a month.. all different dancing, Angela.. old and modern... And then on, er.. the second Tuesday o' the month I go down to the post office club and we have a dance and a cup of tea and that down there, and a game

of bingo and.. I've always went, but.. Oh no.. no, no, I still go up and dance.”

(Maisie: 77; widow; retired pre-MI)

Life roles and responsibilities

People's circumstances, beliefs and identities relating to their roles and responsibilities in the home and family, the workplace, and for some - their status and activities as retired people, could be powerful influences either to encourage or discourage use of CR and CHD Groups. Some interviewees said they were motivated to take advantage of post-MI resources by their desire to regain and maintain roles that made an important practical contribution to their everyday life, their beliefs about their life priorities and appropriate conduct, and their social identities. They perceived CR and / or a CHD Group might help them recover capacities damaged by the MI and enable them to perform their normal roles and duties in the short, medium, and longer term. For example, wanting to maintain their future capacity to fulfil their responsibilities, particularly towards their family, was an incentive to use resources that could potentially help them manage their symptoms and CHD and maintain their health. For some retirees post-MI resources offered a means to return to community and voluntary roles that were important to their identity as a person continuing to lead a productive, active life, despite no longer working.

A strong theme was that for many interviewees their desire to return to their pre-MI roles related as much or even more to reclaiming part of their self-conception as to practical issues and their wider beliefs about their roles. Restrictions on their capacity to perform their usual roles and worries about maintaining these in the future could undermine or threaten the person's sense of who they were and their place in their social world. This was described by a sizeable number of interviewees as a factor that had encouraged them to want to use CR, CHD Groups, and other resources that could potentially aid recovery. Kenny provides an example. Desire to restore his working identity impelled him to attend CR and to re-attend after a relapse.

K: “But I thought, ‘I don’t want tae sit about the house at fifty-five year old’. I knew I was getting fitter. I was feeling better within myself. Life was back to.. yeah, normal. But, I wasnae working. And... I was going stir crazy towards the end. I mean I really was.”

(Kenny: 55; married; employed)

Acknowledging that a valued role and an important aspect of their sense of self had been irrevocably lost as a consequence of their MI might also encourage a person to seek help from a resource they believed could help them adjust and cope. Thus, after being made redundant and experiencing substantial and prolonged difficulties, Ray wished to attend a CHD Group to find out how other people repaired their lives and identities after such a loss.

Supportive circumstances either at work or in the home could encourage people to regard use of post-MI resources as feasible and positive options. For employees, paid ‘sick leave’; Occupational Health support to pursue rehabilitation activities, flexibility regarding working hours, and active encouragement from managers, could all boost motivation to accept rehabilitation opportunities that entailed time off work, particularly CR. A number of accounts suggested that a person’s perception of the need to comply with employment regulations and Occupational Health recommendations could also strengthen the case for attending CR – in a sense acting as a ‘stick as well as a carrot’. Several employees indicated that even if it wasn’t their preference, they had felt it had been in their interest to accept the stipulations that their public sector and company employers had regarding sickness leave and / or rehabilitation after a serious illness. Complying could be seen as necessary to retain their job, favour with their employer, and sickness salary entitlement. For some, having to take a minimum period off work encouraged them about participating as a way to fill their time and alleviate the boredom of not working. Others suggested CR had offered a means to demonstrate their keenness to regain fitness for work.

Confidence that family could successfully ‘hold the fort’ and maintain household functioning without too much difficulty or interference with family members’ usual routines and activities could also persuade a person to take time out or hand over responsibilities. This was a further way that social support could encourage people to participate. For example, George, a retired man, said his faith in his wife Judy’s capability to take over household duties in the early period, enabled him to “err on the safe side” and focus on rehabilitation. His belief that Judy could cope with domestic chores had encouraged him that attending CR and any other resources that might be useful, including a CHD Group, wouldn’t be a problem.

G: “My son... wasn’t here to help my wife. She got the full brunt of it... But, I mean, er, okay, we share activities here.. but it meant for probably six months afterwards she was taking the heavy end of things.. Nobody said don’t, but I think it was an unwritten recommendation.. that you don’t get involved in a too heavy a things.. just take it gradually... I’ve got to be honest.. I would be lazy, but I was erring on the safe side.”

(George: 67; married; retired pre-MI)

Life roles and responsibilities could act as a barrier or deterrent to CR and / or a CHD Group if a person believed that attending would mean they wouldn’t be able to adequately perform obligations they regarded as necessary and important. Regarding employment, it was indicated that concerns that taking time off or requesting flexible working arrangements might be perceived negatively by their employer or colleagues could discourage people about attending CR or a CHD Group. For example, Colleen described how her manager’s resistance would have prevented her attending CR if Occupational Health hadn’t intervened.

C: “It was enough for them [employer] that I was going to these rehab.. because the rehab overlapped in to me going back to work full-time, and that was a problem for them, that I was having to go to that, and it was twice a week on an afternoon. So, they got quite, er..”

(Colleen: female; 63; married; employed)

Not wanting to ‘burden’ or inconvenience others by disrupting home-life routines led some interviewees to opt to try and ‘recover’ independently at home so they could maintain their domestic roles. For example, Freda, Matty’s wife, suggested that his desire to avoid disrupting the childcare arrangements and inconveniencing the family was a major factor in his decision to decline his CR invitation.

F: “Yeah, it was, but he wasn't allowed to drive for, what? Three months, and, erm, and we baby-sit, so I suppose maybe that was what was putting him off.. We baby-sit twice or three times a week... And, erm, ma grandson is just at the nursery so we pick him up just after eleven, so, I suppose this was.. [To M] why you wouldn't go..”

(Freda: Matty’s wife; 60s)

The importance of a work, home, or other productive role for their identity led some interviewees to try to resume this as early as possible. If they believed that attending CR or a CHD Group would have conflicted with this then, even if they believed the resource might assist their recovery, role-resumption took priority. Elspeth illustrates the influence of domestic identity. Even before her MI Elspeth’s restricted mobility limited her capacity to look after her husband Ron in practical terms, yet she maintained a strong identity as a caring wife who monitored Ron’s wellbeing and watched he didn’t over-exert himself. She said that even if invited to CR she

probably would have declined because her first priority after discharge from hospital was to return home and perform her wifely duty by “keeping an eye on” Ron.

E: “Yes, well.. and I wanted tae come home.. [joking tone] Someone's gottae keep an eye on him!”

(Elsbeth: 80; married; retired pre-MI)

Financial issues

Some interviewees said financial support had enabled them to view CR and / or a CHD Group as feasible as well as potentially beneficial options. Paid ‘sick leave’ was an important inducement for some employees who said they knew that taking time off to attend CR wouldn’t prejudice their income. Some interviewees on low incomes who lacked access to a car said transport costs would have impeded CR participation if service transport hadn’t been provided. Public transport would have been problematic due to disability or rurality combined with being unable to afford a taxi. Transport costs could similarly impede CHD Group participation, yet whereas service transport helped some CR participants attend, the absence of such provision for CHD Groups meant this barrier remained in place. One case indicated that financial stress could also indirectly discourage CR and CHD Group participation. Alec, a man in his fifties, and his wife May believed the financial difficulties created when he was unable to claim state benefit for several months after the MI worsened the panic attacks and depression he experienced. These led Alec to restrict his activities and travel from home, and his account suggests that despite believing that meeting other post-MI people would be beneficial these difficulties would likely have deterred him from attending CR and / or a CHD Group even if he had been invited.

Travel and transport

Accessibility and transport availability could encourage use of CR and CHD Groups. Having a family member, friend or neighbour who was willing to provide transport enabled some interviewees to consider CR and CHD Group participation feasible. Some non-drivers without this were nonetheless able to attend CR because they were

invited to use the hospital minibus. Audrey, an older woman who lived some distance from CR and had difficulty walking provides an illustration.

A: "They came for me.. in a wee ambulance. No' an ambulance, but a wee motor thing. They picked up all the patients that was going in for that. And they got me home... Other than that I would hae had tae have went in the bus, and no, therefore I wouldnae have been able to go if I hadnae had that... No, it's, erm.. if Jack is working.. That's him finished his shift now. He starts at six o'clock in the morning and finishes at two."

(Audrey: 74; widow; retired pre-MI)

Availability of an option closer to home, thereby minimising travel, could also facilitate participation. Thus Colleen said she could attend the local outreach CR course whereas the main centre was difficult to reach by bus and too costly by taxi. Yet local options weren't always preferred. For example, despite the inconvenience and greater distance to the main centre Gordon believed their facilities would be better. His wife Aileen also thought Gordon would have preferred the main centre because the outreach course appeared to have more of a group support emphasis.

A: "Erm, I had the feeling that the [main regional CR centre] was more to do with exercise, you know? More like a physiotherapy-type thing, erm, but with other people... Whereas I'm not sure.. I could be wrong, I thought Next-town was more a.. not a self-help group, but.. of that type... It was potentially handier, but I don't know whether he said that the [main regional CR centre] was more the type of.. back-up that he was actually looking for.. Erm, Gordon is not .. you know? This is purely from his point of view.. it might work for other people.. He's not a person who believes in group support, really."

(Aileen: Gordon's wife; 50s)

Travel and transport could be important barriers and deterrents for both CR and CHD Group participation. People prohibited from driving for several weeks and non-drivers faced obstacles if their social network couldn't provide transport and public transport was poor or they couldn't use it due to disability or anxiety about their condition. These issues could only be overcome if appropriate alternatives were identified, and CR provision was better than CHD Groups in this respect. Additionally there were deterrents, which didn't directly impede resource use but made journeys difficult, uncomfortable or entailed other problems. Distance and solo travel either for a post-MI person or their family members, and unwillingness to inconvenience or be dependent upon family or friends could thereby discourage participation.

The resources - CR and CHD Groups

Beliefs about CR and CHD Groups were an important influence. Potential health benefit was foremost, although wider benefits were persuasive for some people. Encouragement from health professionals, people they knew, and other patients, was influential in conveying that CR or a CHD Group could potentially aid recovery. A person's view of their health and condition then influenced whether they believed this benefit could be personally applicable. For example, Jim's unexpected MI aged fifty-three made him anxious about his future health, and he believed he needed help to regain fitness safely and to improve his lifestyle. Encouragement from hospital staff and his friend and his friend's wife convinced him that CR could provide this.

J: "An' there's a boy was actually in ma' class at the school, an' he drinks in the same pub as us, like. Well he had one, oh, it was three or four year ago... An' he actually came intae the hospital tae see me an' telt me, like. He says, 'Whatever ye dae', he says, 'make sure ye go tae the Rehab'. He said, 'Make sure'. An' his wife actually works aside us, an' she telt us an' all. She says,

‘Make sure ye go tae the Rehab. Dae that’, she says,
‘That’s beneficial’.”

(Jim: 53; married; employed)

Some interviewees, whose existing social network was limited, said their belief that CR or a CHD Group might be a good social activity encouraged them to wish to participate. A further perceived benefit described by several interviewees was that these resources would enable them to feel and demonstrate to others that they were productively occupied - engaging with a resource that entailed ‘worthwhile’ activities such as exercise, information, and skills learning. Accounts suggested this stemmed from a belief that being ‘usefully occupied’ was morally and socially-acceptable, whereas inactivity was not. People unable to perform their usual roles could thereby view rehabilitation resource use as a means to maintain an identity and social appearance as good citizens or productive community members. For example, Ray indicated this regarding CR when off work in the early post-MI period, and later regarding a CHD Group, after being made redundant and not having found a meaningful alternative role or activity.

R: “At that point I was still signed off sick from work...
Well, it gave me a time and a place to be.. You know to
drive up there and, erm... Yeah, a focus..”

(Ray: 50; married; redundant post-MI)

Positive attitudes towards group activity could add an incentive regarding CR and CHD Groups. Believing that meeting other post-MI people would aid adjustment, provide practical information and emotional and motivational support, and for some people, help them feel less isolated or ‘different’, were identified as encouraging factors by interviewees who were positively inclined towards CR and CHD Groups. People who lacked other sources of such support were especially likely to seek these from a group resource. Nonetheless, it appeared it wasn’t necessarily a lack of support per se that encouraged a person to attend a post-MI resource, but rather lack of particular types of support related to their needs. Dennis, for example, believed

the group environment at CR and CHD Groups would have provided the extra motivation for exercise he needed.

D: “I think organised exercise is probably better than relying on one’s willpower at times [laughs] Yes, I would have liked that. I would have liked to have done that.”

(Dennis: 77; married; retired pre-MI)

Some interviewees presented their preference for participating in a group environment as part of their identity, believing that they thrived in a collective environment, enjoying the company and sense of solidarity. This encouraged them that they would feel comfortable and get on well with other participants at CR and CHD Groups. A number indicated that a temporary compromise of their identity as people who preferred to undertake activities individually had been necessary in order to use a resource to help them recover. For example, Kenny, a working man in his fifties, said he was “not a group person”, but had believed CR was essential to restore his health and enable return to work. CR restored his confidence for independent activity, after which he reasserted his individualistic identity by declining a CHD Group invitation.

A person’s identity could be an encouraging influence regarding CR and / or CHD Group participation if they believed it would provide opportunity to meet people with similar characteristics who had also experienced MI. Interviewees aged under sixty believed they were ‘too young’ to have had a ‘heart attack’. Their accounts suggested they viewed their CHD as particularly threatening because they potentially had more years to lose than ‘older’ people, and also considered an MI at their age unusual or abnormal. This encouraged some ‘younger’ people to regard CR and / or a CHD Group as potentially useful if they thought similarly-aged people would be there. Desire to meet people of the same sex who also had CHD could also encourage a person about attending a CHD-specific resource. However this issue

was indicated only by a female interviewee, suggesting that male interviewees had taken it for granted that there would be other men at the resources. There were also tentative suggestions that CHD Groups might be perceived as more woman-friendly than CR. Colleen's experience as the sole female at CR made her realise that her experience as a woman was different from that of the men. It also made her feel 'abnormal' because it fostered the impression that CHD was a male disease. She expressed interest in a CHD Group because she thought this might enable her to meet other women who hadn't attended or had previously completed CR.

Some interviewees perceived their MI was minor and so believed they could recover well themselves without a rehabilitation resource. Advice, opinions, or lack of endorsement from health professionals could bolster this. In terms of the relation between CR and CHD Groups, I found that after attending CR some interviewees felt their needs had been met and that they could manage well without support from a CHD Group. Conversely, interviewees who expressed negative recovery expectations often said they didn't think a CHD-specific resource could help them, as did others who were uncertain if their symptoms originated from their CHD or another health problem. A belief that these resources might be health-damaging was less common. However Jean's physical discomfort during CR exercises led her to drop out concluding she would be "better off at home" and this deterred her regarding a CHD Group. Several people said they were disinclined towards CHD Groups because they thought they encouraged people to "dwell on" ill health and this might engender depression.

Negative beliefs about groups deterred some interviewees. A common perception was that group participation might entail sharing personal information. Concerns about privacy, dislike of talking about themselves; or a belief that disclosing personal details was 'hanging one's dirty laundry in public', disinclined some people about attending a group resource. Some interviewees believed group participants were 'needy' or 'resigned' to their condition and didn't wish to associate themselves or be associated by others with such people. On the other hand, some people were discouraged by the prospect that other participants would be dissimilar to themselves

in terms of an important aspect of their identity, particularly age and gender. Although 'younger' interviewees wanted to meet other post-MI people of similar age, at the same time they were deterred by the thought that CR and CHD Groups might not include 'younger' people. Sometimes the encouragement people received and their wider motivation regarding health benefit enabled them to overcome this doubt, but if someone received information that reinforced their doubts they could be discouraged from participating. For example, forty year-old Dave was deterred from CR and a CHD Group after hospital staff told him CR was mainly for older people.

D: "Erm, but as for rehabilitation, it was mentioned but that was it... But they didnae think.. unless it affected me sort o' mentally, er, they didnae think it really would suit me, because, erm, it's sort o' older people kind o' thing..."

(Dave: 40; married; employed)

Age identity wasn't solely an influence upon 'younger' people. Some interviewees in their late sixties, seventies and even eighties viewed CR and CHD Groups negatively because they believed they were dissimilar to, and / or didn't wish to be categorised alongside, the 'older' people they believed such resources were for. This related to their perceptions about the resource, but also suggested a rejection of resource-providers' and possibly also society's definition of what was appropriate for their age. Rena, aged sixty-seven provides an illustration.

AJ: "Would you have gone if they had [invited you]?"

R: Probably not.. probably not, because.. I dinnae want to be classed as an old.. *fuddy-duddy* [emphasis] I dinnae think I'm old.."

(Rena: 67; married; retired pre-MI)

An individualistic identity as a person who preferred to “get on with things themselves” and / or felt uncomfortable in a group environment discouraged some people about group-based post-MI resources. For example, Rena’s self-conception as not being “a mixer” contributed to her disinclination towards attending CR or a CHD Group.

R: “Well.. I’m no’ really a mixer in that way.. Er, I mean, I wouldnae go tae the Church or anything like that..”

(Rena: 67; married; retired pre-MI)

For women, their gender identity and perceptions about the profile of post-MI resource participants could discourage use of these resources. Colleen, for example, found being the sole woman at CR disconcerting and uncomfortable, and felt the course was geared towards men. Anxiety about her physical health and need for support and advice overcame her unease and she completed the course, but her account suggested she might not have attended if she had known about the gender mix beforehand.

C: "Er, look, there was.. mostly I was the only woman there. There were mostly all men, and that sometimes could be a little bit.. At one point there was another lady there but she moved on because she’d gone through the programme... Latterly I was the only woman there, so, that was a little bit.. erm.. off-putting.. in the sense that I don’t think you can compare yourself to the men, if you know what I mean? You could see the men didn’t seem to have the same.. er, pain in the.. My problem was always that I thought if I hadn’t had my boobs I’d have been an awful lot better.. Because my boobs were ohhh, they seemed to be the main

problem, with trying to.. and of course trying to get a bra on was impossible. So, there wasn't like another woman to sort of.. compare that type of thing with, and, erm.. it made you feel a little bit.. Sometimes I felt I would have liked to have had.. that they could have tried and made that a little bit more woman..[oriented] "

(Colleen: 63; married; employed)

Sheila's case also suggests that gender issues could contribute a deterring influence, in that her impression from previously attending with her husband was that it was male-oriented. Additionally, all the examples female interviewees gave of post-MI people they knew were male, implicitly suggesting that a perception that post-MI resources were primarily for men might have discouraged other women. Nonetheless, women interviewees didn't say that this issue deterred them regarding CHD Groups.

Health and CHD

Interviewees' experience, beliefs, and identity relating to their present and past health were powerful influences on whether they were encouraged or discouraged about attending CR and CHD Groups. These considerations were pivotal in determining whether or not a person believed one or both of these resources could be personally beneficial - which was essential for a person to consider attending.

Interviewees universally viewed health in relation to a person's capacity to fulfil functions relating to life roles and activities. Desire to restore lost capacities relating to their work and domestic duties, recreational activities, and manage their life and relationships, was a powerful motivation for some interviewees to use CR and / or a CHD Group, and this could outweigh beliefs and aspects of their identity that might otherwise incline them to manage without. Conversely, interviewees commonly suggested that problematic symptoms or disability might be considered relatively unimportant if they could maintain the most important aspects of day-to-day life. Thus, believing that they had retained or quickly regained their ability to perform their key roles and activities persuaded some interviewees that CHD-specific

resources were unnecessary. For example, eighty year-old Derek's continued ability to independently undertake household tasks and daily walks convinced him that CR or other support wasn't needed.

D: "But you do feel better, and I've been great ever since it. And I've no had any recurrences or anything.. anything at all.

AJ: No.. What advice did they give you.. maybe how you'd feel, or..?

D: Oh! [emphasis] Told me.. tae take care and don't walk too much, and don't do this, and don't do this, and don't Hoover and.. [laughs] and I do everything! I mean, I suppose they were telling me what they tell everybody. But the thing is, is I do all my own housework, I do everything.. I do everything..."

(Derek: 80; widower; retired pre-MI)

Contributing to Derek's positive health assessment and his belief that post-MI support wasn't needed was his conviction that he looked well, which had been reinforced by other people's comments. Others also indicated that a healthy appearance had encouraged them to try to manage independently. Linda expressed frustration that other people said she looked well after her MI, whereas she felt fatigue, weakness, and couldn't conduct her usual activities. The invisibility of her symptoms to others contributed to her view that she should try to manage independently and that taking time off work to attend CR would look fraudulent.

Beliefs in fitness as a sign of, and means to create and maintain health, and way to demonstrate moral virtue as someone pursuing health, were commonly described. A belief that CR and CHD Groups could help them re-attain and maintain fitness and demonstrate their endeavours to regain health, encouraged some interviewees that the

resources could be beneficial. However, interviewees who believed their MI hadn't seriously affected their fitness took this as a sign that a specialist resource was unnecessary.

A person's view of their pre-MI health and health 'career' could be as influential as their post-MI experience. If an interviewee considered their pre-MI health had been good this could significantly boost their confidence of a good recovery, particularly if they were experiencing few symptoms. This frequently discouraged such people from believing that CHD-specific resources were necessary, believing that professionals' assumptions that their health would be impaired applied to others who weren't as 'healthy' as themselves, and that continuing their normal lifestyle was personally sufficient. However, a belief that their pre-MI health had been good intensified the shock and uncertainty some interviewees felt because their previous expectations had been confounded. For example, Jim, a factory worker in his early fifties, hadn't perceived any health problems and was unsettled to think that CHD had been developing undetected. This fuelled his keenness for rehabilitation and preventive help from people who knew about CHD, and underpinned his CR attendance and perception that CHD Groups could be beneficial.

AJ: "Had you been in good health previously?"

J: Well, aye. Aye. I felt as though I was alright like, ken, aye... Obviously, I never had ony idea that it was there and whether this just triggered it off I just don't know.. I mean, er.. they're saying it's.. It was there, just waiting to happen sort of thing.. like. Ken? It could have happened ony time... I mean.. it's definitely worrying, like. Ken? Er, saying that, I kent that I had tae really focus on what they were telling me.. an' what was in the books, like. An' da'en as much o' that as possible like. Tae help myself sort o' thing, like."

(Jim: 53; married; employed)

Some accounts suggested a person might wish to use a rehabilitation resource to ‘repair’ their former identity as a ‘healthy’ person. They sought help to restore their health in practical terms; rebuild their confidence that they could be healthy; and to show others that they were taking steps to restore their health. This is seen for example, in Ernie’s quotation earlier in the chapter. Accounts indicated that a person’s identity and beliefs about their health status - based on their pre-MI experience, might be as influential as practical considerations. People who believed their pre-MI health had been poor or problematic differed considerably in how this influenced their view of CR and CHD Groups. For example, Angus, a 62 year-old man, believed his health had already been ‘spoiled’ before his MI by the disability that had forced retirement, and this discouraged him about the value of CR or a CHD Group. In contrast, Audrey, whose CHD dated back several decades, believed from her past experience that her health would never be good, but that she should nonetheless ‘make the best of’ her situation. This encouraged her to attend CR, and to view CHD Groups positively, believing they might offer new information or advice to ease her symptoms and the restrictions they imposed.

In contrast, surviving previous illness could give a person confidence that they were resilient, and an identity as a ‘survivor’ could deter them from using rehabilitation resources. Jean, an elderly woman, who had previously experienced several life-threatening health illnesses and lived with diabetes for many years, provides an illustration. She initially attended CR because she believed hospital staff expected it and that it would be ungrateful to decline. She found the exercises uncomfortable and her previous experiences of surviving illness without rehabilitation resources persuaded her that she could manage and be more comfortable at home. This was bolstered by the favourable comparisons she made between herself and other elderly attenders. Based on this rationale she ‘dropped out’ of CR and declined a CHD Group invitation.

J: “I’ve really been lucky, I cannae complain.. Really been lucky.. [pauses] I keep saying that an’ folk’ll say... I had a hysterectomy when I was thirty-six.. I’d

had constant bleeding an' that..so.. An' then er.. I had appendix.. a burst appendix so I had tae .. away wi' that. I've had my share o' trouble right enough, but er, I could be worse when you look round about you an' see some poor souls going about..."

(Jean: 84; widow; retired pre-MI)

Interviewees' beliefs about the severity of their MI were based on personal experience, information from professionals, and comparisons with other post-MI people. Perceptions were polarised into 'serious' or 'not serious'. Many interviewees who believed their MI hadn't been serious said this discouraged them from believing that they needed rehabilitation resources. Nevertheless all perceived lifestyle changes or maintenance were needed to prevent their condition worsening – demonstrating that they believed even a mild MI should be taken seriously. Because they believed their MI hadn't been severe they felt that their existing personal, informal and semi-formal resources were adequate for this task. However, some people differentiated between their MI severity and the seriousness of CHD as an underlying condition. The potential threat of CHD to their future health persuaded them that CR and / or a CHD Group could be beneficial.

Viewing their MI as serious added impetus for interviewees to use resources they believed could aid recovery and mitigate risk of recurrence. Yet this didn't automatically mean they wished to attend CR or a CHD Group, in that a strong negative belief about the resource or conflict between their circumstances and the resource could lead them towards alternatives. Some interviewees said their initial belief that their MI hadn't been serious had been confounded by subsequent problematic symptoms. Generally this encouraged people to redouble their recovery efforts, and could motivate someone to reconsider CR and CHD Groups as potentially useful – a theme I expand in Chapter Seven.

Interviewees' beliefs about their symptoms were powerful influences on their perceptions of their post-MI support needs. Beliefs about symptoms related to severity and perceived impacts upon different aspects of their health and life. If a

person considered their symptoms were severe this could incline them positively towards CR and / or a CHD Group. For example, after CABG surgery Colleen experienced severe pain and anxiety about her symptoms and this motivated her to accept her GP's CR recommendation.

C: "Well, I was in quite a lot of pain.. and my, as I've said, my breast bone is still very painful. I've been back three or four times, but they just say, 'It's just one of those things...' Doctor.. my doctor came and she said, 'No, I can get you into this.. [main CR centre] rehab, and she.. she got me going to.. got the contact.."

(Colleen: 63; married; employed)

Interviewees generally appeared to have initially focused on physical symptoms, and only after some time became aware of psychological, emotional and cognitive symptoms. Some non-participants who perceived that CR or a CHD Group might have helped with these kinds of symptoms didn't receive opportunity to attend. Some others however, had passed over the opportunity for such support because at the time of invitation they hadn't experienced the extent of these problems and had believed informal and other existing support would suffice.

A belief that their symptoms weren't serious commonly dissuaded interviewees that they needed rehabilitation support at CR or a CHD Group. Some described physical symptoms including breathlessness, fatigue, chest sensations, and medication side-effects; and a number experienced minor psychological or emotional problems, such as increased irritability. Yet because they had believed these were mild and manageable, and without serious health consequences, they believed they could manage their recovery themselves, with help from family or their GP if necessary, and possibly using general community facilities such as a gym.

The contradiction of people's previous beliefs about CHD risk, and particularly regarding characteristics they had thought made them unlikely MI 'candidates',

appeared to heighten the shock, uncertainty, and anxiety they felt. An MI was seen as particularly shocking in people: below the 'normal' age range; who hadn't previously experienced the kind of symptoms associated with cardiac problems before, during or after the MI; whose prior health had seemed good; and people who were concurrently receiving treatment for another illness. Some people also regarded CHD as a predominantly male condition. The shock of an MI added encouragement for some people who had believed they were 'ineligible' to view CR and / or CHD Groups positively – as Jim's case described earlier in the chapter. However, some interviewees said their MI hadn't surprised them because of prior CHD, family history, an unhealthy lifestyle, or stress. Whereas perceived 'candidacy' encouraged some to view CR or a CHD Group as beneficial, others were disinclined for this reason.

Many interviewees believed family history of illness could increase their likelihood of developing certain conditions. Yet, while some were aware they had a genetic heritage of CHD before their MI, many hadn't considered this until afterwards and awoke to the possibility only through questions or information from hospital staff, or biographical reflections in which relatives' illnesses acquired new significance. Often these interviewees believed they should take preventive action, including lifestyle changes. Some preferred and felt comfortable and able to undertake independent activities, but others viewed resources such as CR and CHD Groups as valuable to learn about and address their condition. People for whom heredity appeared to discourage post-MI resource use were rare. Angus provides an example. His brother's death from MI in his forties made him fatalistic about his own CHD and so sought to forget about the potential threat. Although he perceived CR might have some value, he was deterred from a CHD Group, which he believed only entailed people talking about, and so "dwelling on" their condition.

A: "An' see, like, ma brother who was just older than me, he died o' a heart attack, ma mother died of a stroke..

AJ: Mm-hm.. and had you thought about it.. kind of family.. before that? Before you took the heart trouble..

A: No.. no, no.. I didn't even think about it when I was in the hospital [after his own MI] I'd say... Just put it out of ma mind, 'cause you're sitting here sort o' thinking o' all that sort o' rubbish, I mean, but, you know? Going doo-lally, like, you know? So, I never think about it, like, you know? I just forget it."

(Angus: 62; married; retired pre-MI)

Most interviewees believed mental and emotional health could influence physical health and often believed this had contributed to their CHD. In particular, interviewees highlighted stress due to work, financial or relationship problems, family members' ill-health, insecure housing, or lack of meaningful activity. However, a few, for example, Mike, a manager in his fifties, considered being 'stress-prone' part of their identity.

M: "I think I'm slightly that sort of nature of person, you know? I do sort of, erm, I think it'd be wrong to say I live on my nerves, but I am quite.. I'm a 'Type A' personality, I think, you know? I think I am.. I'm better than I used to be perhaps, but, yes.. I used to be terrible in queues at the bank waiting to be served, or things like that.. 'You know? [mimics impatient tone] 'Hurry up! Come on, come on.' "

(Mike: 57; divorced; employed)

In many cases, although people believed stress was health-damaging, their pre-MI attitude had been either that it wasn't immediately threatening; they couldn't address the cause; or benefits relating to the stressful situation outweighed the risk. Some interviewees, including Mike, who believed stress might have contributed to their

MI, said they were attracted to resources they thought might have helped them cope. People who were aware of the stress management component of CR viewed it in this way, while several expressed a belief that talking to other post-MI people at CR or a CHD Group would also help. Alec's situation was more severe and apparently less common. Alec and his wife's accounts described his identity as having been transformed by his MI to someone who was incapacitated by his anxiety. His fear of going beyond his neighbourhood and avoidance of many ordinary activities for fear of further MI would have been a considerable obstacle to attending CR or a CHD Group even if he had been invited. One other interviewee reported a similar but less severe experience.

An association between lifestyle behaviours and health and illness, and specifically CHD, was made by interviewees of all ages, regardless of whether they felt they had a 'healthy' or 'unhealthy' lifestyle. Beliefs about their lifestyle, and also the fact that many people viewed their lifestyle as an aspect of their identity, could be influential either in encouraging or discouraging people about CR and CHD Group participation. Interviewees gave three different lifestyle identity narratives. Some presented themselves as what I have termed 'hedonists' or 'reformed hedonists'. Before and sometimes also after their MI they continued lifestyle behaviours despite knowing they were 'health-damaging'. They commonly described a 'lifestyle package' of heavy drinking, heavy smoking, eating a diet rich in fat, salt, and sugar, and limited physical activity. Their accounts suggested their lifestyle had been and possibly still was part of their self-conception, symbolising a 'devil may care' attitude, and for some denoted peer group membership. Pride and affection for their lifestyle was often expressed, even among those who had ceased the behaviours – an indication of the powerful influence of identity, even in the face of a potentially life-threatening illness. A number of the 'reformed hedonists' described how this motivated them to use CR and / or a CHD Group as a means to rectify damage their former lifestyle had caused. The shock of their MI, a belief they had a 'second chance', and / or adverse symptoms, had prompted them to accept they should try to make changes.

Alternatively, I found that a 'hedonistic' identity could deter rehabilitation resource use. Some people retained positive feelings about an 'unhealthy' behaviour as an aspect of their life and self and were reluctant to stop, or to stop completely. Believing that change would be too difficult or ineffective to address their health problems could bolster resistance. These issues could deter people from resources that they believed would promote cessation. For example, Rena, didn't perceive smoking was a risk factor for her CHD, or that stopping would improve her health, and cited negatives such as weight gain after previously stopping. She counterbalanced her continued post-MI smoking by emphasising "We don't drink..", and explicitly said she liked smoking and so resented being told repeatedly to stop. She indicated that weariness with health professionals' advice about this and other issues added a further reason to believe post-MI resources wouldn't help but would just entail further nagging.

R: "Well, I had tae go tae see him because they give you a discharge letter every time you come out, and, er, I suppose that's how eventually I was put on all o' the tablets.. and he was still at this, 'Stop smoking', and... Of course I smoked.. I smoked like a chimney... they're always on about smoking, you know? Ma husband.. he stopped about fifteen years ago but what good did it do tae him?"

(Rena: 67; married; retired pre-MI)

There were also people who might be described as 'healthy livers'. Their narratives portrayed endeavours to live in a healthy way as integral to their identity, and belief that certain behaviours could promote or cause ill health had prompted changes prior to their MI. They commonly expressed confusion, frustration and disappointment because they felt their previous efforts had been in vain and their belief that 'healthy' behaviours could protect their health had been undermined. Nevertheless, none abandoned or entirely lost faith in their 'healthy' lifestyle and appeared to adapt their beliefs to incorporate their MI experience and new information. Emphasis was

frequently placed on maintaining or even extending previous lifestyle behaviours against, for example, the threat of hereditary CHD. This inclined some towards CR and CHD Groups, which they believed could offer further ‘healthy lifestyle’ knowledge, safe activity, and new ‘healthy’ activities.

However, some were disinclined to use resources other than those previously used as part of day-to-day life. Their identity as people whose healthy lifestyle was integral to who they were engendered confidence that they could manage well without external, and particularly specialist, help. Information and encouragement from health professionals could enhance a person’s confidence and belief that returning to their former lifestyle was sufficient. Also they commonly perceived affirmation from information that emphasised risk factors behaviours that didn’t apply to them. For example, this was an important contributory reason for Harry, who prided himself on his lifelong non-smoking and teetotalism and was a keen walker, to believe CR and CHD Groups were personally unnecessary.

H: “I’d a couple of nurses, well one came in.. A lady like yourself and she says, ‘Oh’, she says, ‘Oh, I won’t need to come back’. She says, just.. question and answer like, you know?”

AJ: Aha, and why was that.. why did she say she wouldn’t need to come back?

H: Well, the things I was doing.

AJ: Oh, okay, in terms of what you were saying before about exercise and..

H: Yeah, and she says.. well, she says, ‘I won’t need tae come back to see you’, she says.. That was it... She must have trusted me.”

(Harry, 73, married; retired pre-MI)

Some interviewees presented themselves as ‘lapsers’ - people who had at some time undertaken healthy behaviours but had lapsed. Their accounts suggested this wasn’t just viewed as behaviours or actions they had or hadn’t undertaken, but part of their identity in a similar way to the ‘healthy livers’ and ‘hedonists’. Like the ‘reformed hedonists’, ‘lapsers’ indicated that this identity persuaded them to use resources that might address some of the damage they believed their lapses had caused. For example, Martin compared his younger sporty and diet-conscious self with his middle-aged self, who he felt in some respects had ‘let himself go’. He related this to his willingness to use CR, and also perceived value in CHD Groups, particularly for exercise maintenance.

M: “Carol will tell you that all that ever was going through my mind was that I.. I just thought I was unfit, that I needed to lose weight and start exercising again... I just thought that was just the way, erm, that if I had to keep myself.. obviously look after myself’ then I would.. I mean, it doesn’t mean to say that that’s what happen, but I mean.. I used to look after myself just by what we used to eat... I think it was just looking for ways to, if you like, make sure that something like that, like try and pre.. not prevent it, because if it’s something that’s genetic then.. then there’s nothing much you can do about it.. But at least I was gonnae try and make sure that I was healthy, yeah.. yeah..”

(Martin: 54; married; employed)

Conclusion

In this chapter I have reported that many people did not have an opportunity to decide whether or not to attend CR and CHD Groups due to lack of invitation,

information, and endorsement. This is supported by earlier research, but strengthens the previously weak direct evidence from non-participants themselves regarding these barriers, particularly regarding CHD groups. I have presented new evidence showing that some CR participants also would have wished to attend a CHD Group but were thwarted by non-availability of this option. Yet, beyond receiving opportunity, I have demonstrated that a substantial range of further factors could encourage or discourage CR and CHD Group participation. This corroborates the tentative previous evidence regarding the range of factors that may influence CR non-participation, however develops understanding of these by providing a more detailed explanation of their complexity and showing how they operate.

My findings indicate that some factors are more powerful than the body of previous post-MI non-participant evidence suggests. In some respects this accords with, and expands on wider research on CHD and chronic illness, for example, regarding the power and different types of the influence that 'significant others' can have. I have also identified several aspects of factors that have received limited mention or emphasis in previous post-MI non-participation research. These include, for example: financial stress; previous use of social and recreational resources; employment regulations; identity as 'good patients / citizens'; other people's perceptions about a person's health; and the importance of beliefs about pre-MI health. Owing to the dearth of previous exploration, my findings regarding the range of factors that can influence CHD Group non-participation and how they operate are largely new, and are in original in providing the perspectives and experiences of non-participants themselves.

This chapter has demonstrated the complexity of the different factors, showing that each could entail aspects related to a person's 'lifeworld' circumstances, beliefs and identity. I found that identity plays a greater role in non-participation than has hitherto been shown, and provide insight into the breadth of the different aspects of this. Additionally, I have shown that each factor could potentially influence use of both CR and CHD Groups. For example, I report that desire to maintain physical activity could motivate people to attend a CHD Group as well as CR. I have also shown how each factor could operate in opposing directions - either to encourage or

discourage resource use, rather than certain factors acting as facilitators and others as barriers, or some acting on participants and others on non-participants as previous research suggested. In Chapter Seven I go on to demonstrate how the various factors this chapter has identified could inter-relate and combine to produce a non-participation outcome, and shed light on the inter-relation between use and non-use of CR and CHD Groups.

Chapter Seven - “Why do people not participate in CR and CHD Groups?” - Part Two: The reasons for, and process of non-participation

The preceding chapter identified the factors that could influence CR and CHD Group non-participation. This chapter explores the different ways these factors could combine to engender non-participation. I found that non-participation results from a complex and individualised combination of factors that related to an individual’s particular ‘lifeworld’ circumstances, beliefs and identity. Yet notwithstanding the heterogeneity of non-participants’ experiences and perspectives, my data suggests that the reasons for, and process of non-participation may be grouped into three broad categories, based on the way the factors influencing an individual relate to three key issues. In Section One I explain and illustrate these categories, but also show how a person might shift between these during the course of their rehabilitation. In Section Two I employ a case study approach to explore in depth the process and reasons for non-participation in CR and CHD Groups, drawing upon the experiences and perspectives of three post-MI person and their family members to provide an example from each of the categories. The cases additionally provide a vehicle to illustrate the complexity of individual cases, the relation between non-participation in the two different resources, contrasts between the three different patterns of non-participation, and to demonstrate the link between non-participation and rehabilitation difficulties.

Section One: “No need / no point”, “Not worth it”, or “Not possible”: Three categories of non-participation

This section explains how the various competing factors that could encourage or discourage a person regarding CR and CHD Groups inter-related and combined to bring about non-participation. I identify three non-participant categories based on the way the factors influencing an individual related to three key issues. Foremost was the question of what the person believed they needed in terms of post-MI

support, in conjunction with whether they believed a particular resource could potentially help meet their needs. The second issue was whether they believed participation may entail negative consequences, and if these were considered to outweigh the potential benefits, and / or the person was aware of alternative options. The third issue was whether there were barriers that would impede participation and could not be resolved.

The central principle underpinning these categories was the person's attitude towards the resource in relation to their circumstances, beliefs, and identity. The attitude of people in the first category was negative - viewing the resource as personally unnecessary; the second category's attitude was equivocal; while the third were positively inclined towards the resources. This follows from the findings in Chapter Six, which showed that, beyond having opportunity to decide whether or not to use these resources, a range of factors were of major importance in determining whether a person would participate or not. Consequently, although many interviewees said they weren't offered the resources, their accounts of the factors underpinning whether they would have wished and been able to attend if invited are equally important. In discussing the three categories I indicate whether or not the resources were offered (summarised in Appendix Six), and consider whether being invited or informed would have affected their non-participant status.

Among people who participated in neither CR nor a CHD Group (n=17), the categorisation of their non-participation was the same for both resources, with only two exceptions. Most were clustered into either category one or three, at opposite ends of the spectrum – indicating they either didn't perceive value in the resources, or conversely were very positively inclined but impeded by barrier issues. The sample also included post-MI people who participated in CR (n=10), and the categorisation of their CHD Group non-participation also varied. Yet in contrast to the more polarised distribution of those who participated in neither resource, the majority of CR participants came under non-participation categories two and three regarding CHD Groups - indicating that many perceived the groups might be beneficial. CR participants thus appeared more likely to perceive that other post-MI resources might be of personal value compared to CR non-participants – an issue I

later explore. The table in Appendix Six summarises interviewees' non-participant categories.

Non-participation category one: "No need / no point" (Not personally beneficial)

This category encompassed people for whom there were one or more strong negative influences that caused them to believe the resource wouldn't be personally beneficial. These interviewees often identified additional discouraging factors, and for some people these included significant barriers and deterrents, nonetheless the question of personal benefit was indicated to be the pivotal consideration. Regarding CR, almost all of the people who didn't perceive it would be personally beneficial had been invited and declined. The two who were not invited indicated clearly that they wouldn't have attended even if an invitation had been received. The inverse was the case regarding CHD Groups. Only two people were 'formally' invited or informed – that is, given oral or written material by health professionals, the group organiser, or another organisation; and both declined. One other person learnt from a generic CHD information booklet that such groups existed, but received no information or endorsement about local options. The majority said they hadn't received any invitation or information. These people gave clear reasons to explain their belief that the groups wouldn't have been personally relevant or useful.

For example, Rena said she wasn't invited to CR or a CHD Group. Notwithstanding this, she disliked groups and believed such resources were for elderly people and didn't want to be seen or treated as similar to them. Besides these identity conflicts, past health care experiences had made her mistrustful of health professionals' advice. However, the outstanding factor was that after twenty-years of CHD and two previous MIs, and having several current co-morbidities, she believed only a medical or surgical innovation could improve her health and quality of life and so dismissed rehabilitation resources as non-beneficial.

R: "I mean, I know what I can do and I know what I cannae do, and I didnae need them tae tell me.. and *what are they gonnae do* [emphasis]? They can't.. I've had,

erm, stents in ma heart.. twice.. But I've still got.. I don't know, I think it's just one artery that's blocked, and, er, I spoke to.. I read years ago about a wee machine in Australia.. That they could put into your.. artery that's blocked..”

(Rena: 67; married; retired pre-MI)

These interviewees rarely expressed positive perceptions about the resources, and if they did these related to other people, not themselves. Their family members sometimes perceived value for their relative and possibly themselves, and some explicitly said they would have liked their relative to have attended. Yet generally they had been reluctant to voice their concerns. Some seemed to have accepted the apparent non-availability of a resource as a ‘fait accompli’. Some thought it would be unsupportive or unhelpful to undermine the person’s decision, or felt unable to challenge the decision because the power balance in the relationship favoured their partner, or to avoid spoiling their relationship. For example, Julie, Derek’s daughter hadn’t suggested he should accept his CR invitation to avoid losing his trust and damaging their relationship.

J: “Well, if he was happy with that, you know? And it’s not that.. erm, ma Dad’s got a lovely nature, you know? I’ve never ever had words with my Dad in my life, you know? Because he’s so good natured. I just.. as long as he’s happy, and I know that he’s okay, I’m quite happy with that... Mh-hm.. So, that’s it really.”

(Julie: Derek’s daughter; fifties)

Regarding the inter-relation between CR and CHD Groups, only one interviewee who didn’t perceive CR could have been personally beneficial was more positively inclined regarding a CHD Group. The example also illustrates how a wider, non-directly health-related benefit could also be influential and the powerful role a

‘significant other’ could play. Ravi, a man in his seventies of Indian origin, was influenced by his wife Anila’s view that a group might be of value to meet and socialise with other people. Perhaps as influential as perceived benefit for himself, was his awareness that Anila wished to attend to increase her own social contact with others, which had been reduced since Ravi’s MI.

AJ: “If your health was better.. and you didn’t have the dizziness?”

R: Yeah.. yeah, I then, yeah.. to go, yeah..

A: Yeah it will be better to go for the.. in the group.. No, no I would try if I.. you know? Something like that.. if health-wise is okay... I will be [have] more interest.. you will come to know more people, you know?

R: Pass time and .. get some sort of.. social.. you know?

A: Social, yeah.. when it’s like that, you know?

R: Yeah.. some social...”

(Ravi: 75; retired pre-MI. Anila: wife; late 60s)

Two interviewees who believed a CHD Group wouldn’t be personally beneficial related this directly to their CR participation. After completing CR, both Kenny and Ernie had felt restored in fitness and confidence. This had encouraged them that they were able to reclaim their self-reliant identity and return to their preference of managing independently, and so didn’t believe they needed further support from a CHD Group. They considered the groups might benefit others who continued to

experience difficulties and perhaps lacked alternative social or practical resources, but didn't believe this applied to them.

K: "I'm no' backward in coming forward sort o' thing, but I feel that.. [pause] You've had the help, you've had the back-up.. then it's up tae you. I mean, I don't need tae sit in a group an' say, 'Well, I've been doing this, an' I've been doing that.'. It's for me tae get on wi' it. Yeah. It's for tae get on wi' it. I've had the chance of being at [District hospital] an', er, what-have-you, now it's ma turn. I've got-gottae do it... It was for me, but it, but.. maybe it'll be worth for other people. Aye. I've had great support from family and friends.. workmates. Err, maybe other guys don't get that, I don't know."

(Kenny: 55; married; employed)

Non-participation category two: "Not worth it" (Outweighed)

The second non-participant category comprised people who believed CR and / or a CHD Group could potentially be beneficial, but also perceived negative factors that made participation difficult or unappealing. Either powerful individual deterring issues or a combination of several different 'put off' factors led these interviewees to conclude that the negatives outweighed potential benefits. Regarding CR, the two people had declined their invitation, based on their negative evaluation of the 'pros and cons'. Regarding CHD Groups, four of the six people had declined a 'formal' invitation; one had declined an informal invitation from a workmate; and the accounts of one man who hadn't been invited and his wife together indicated that he was unlikely to have attended owing to certain deterring issues.

For example, for Dave the pre-eminent deterrent was his fear that, at forty, he would be the only younger participant at CR or a CHD Group. His age identity appeared to take on greater significance due to his beliefs about the 'normal' age profile of CHD,

and his relatively young age was the main reason he had difficulty accepting his MI. He believed being surrounded again by older people would exacerbate the feelings of abnormality, isolation and anxiety he had felt in hospital. Information from staff that CR was mainly for older people convinced him this would be the case.

D: "I felt as though I.. I just felt as though I shouldnae have been there, erm, especially *'cause it was all old guys that was in the ward, eh?* [emphasis].. seventy.. sixty, seventy, eighty year old are on the ward, and you're only forty year old and thinking, [disbelieving tone] 'I shouldnae be here.. shouldnae be here.'."

(Dave: 40; married; employed)

At the time these interviewees had decided to 'go it alone' they believed their physical symptoms were beginning to abate and had felt sufficiently optimistic about their recovery to believe they could manage without these resources. Retrospectively, the two CR non-participants believed CR might have helped address some of the rehabilitation difficulties they later experienced and expressed some regret that there had been negative aspects that had deterred them. Nonetheless, demonstrating the strength of the deterring factors, they didn't suggest they would act differently if they had their time again and were faced by the same negative factors. Their spouses did regret their non-participation but had accepted their decision, wishing to be supportive and also they had empathised with their reasons.

AJ: "Is there anything that you feel would have been helpful at that point that wasn't there, or not really?"

M: I don't know if he should have maybe went tae a group or something, you know? Just even if you'd heard how other people.. were coping with it, or getting back tae a routine, or... Just.. that you werenae the only forty-something.. who'd had a heart attack

[laughs] But.. I think that was the hardest bit.. that Dave had just turned forty.. that was unusual, and I think maybe the idea o' going tae a group.. 'cause you, you'd be thinking that everybody was older.. So, I suppose that's why you weren't thinking of going tae a group, because you thought it was maybe all going to be seventy and eighty year olds.. at this, erm, heart group.. [laughs] It maybe wouldn't have done it.."

(Maggie: Dave's wife; early 40s)

Gordon perceived a CHD Group might have been beneficial but only if CR hadn't been available or wasn't accessible. This view contrasts with the perception of many non-participants in category three who believed the two resources could be complimentary. His perception that CHD Group benefits would be fewer than for CR appeared to weaken the case for attending a group relative to the negative aspects he also perceived. These findings shed some light onto the relation between CR and CHD Group non-participation. Both Gordon and Dave identified further negative issues relating specifically to CHD Groups as semi-formal resources. For example, after being advised to avoid stress and over-activity after his MI, Dave was discouraged by the thought that he might be pressured to join the group committee and acquire unwanted responsibilities.

Several interviewees who attended CR considered that taking part also in a CHD Group might have been beneficial, yet notwithstanding this all had declined the invitation to continue on to this resource after completing CR. On the one hand they believed there were some significant issues that made participation problematic. For the working men these were travel distance and the inconvenience of fitting it around their work patterns. Whereas Jean, an elderly woman mentioned physical discomfort during exercise and travel, and not wanting to appear dependent by being taken out in a wheelchair. Moreover their accounts suggested that the benefits weren't as compelling as those that had persuaded them to attend CR, particularly in that their CR experiences had encouraged them in contrasting ways to feel able to manage

independently again. For the men, CR had provided information, guidance, and reassurance, and facilitated recovery of their confidence and fitness. In contrast, Jean had compared her health and resilience positively against other participants and concluded she was able and would be more comfortable managing at home. All three returned to relying on non CHD-specific resources. These interviewees all identified obstacles and appeared to believe these strengthened the rationale and legitimacy of their case for non-participation. Nonetheless, their accounts suggested that their non-participation decision related more to their perception that on the whole a CHD Group wasn't appropriate for their needs at that stage of their rehabilitation. Jim's account illustrates both elements but suggests the latter was stronger.

J: "An' it was just basically.. Right.. you could stop at any time, but it was just, er.. You just would be going da'en the same exercises as you were getting.. at [District hospital] in the Rehab like.. just a continuation of that... And.. once I started back [at] ma work, and plus.. the travel fae here tae Iddrington every Monday.. Ten, twelve mile. An' then well, I mean, I didnae drive an' that, like. Ken? So it'd be taking the bus. Er.. I just didnae feel.. that it.. it wouldnae benefit me ony, because I'd be there and then I'd be missing four weeks because I was working. Ken? So, er.. Well, I never even tried it.."

(Jim: 53; married; employed)

Non-participation category three: "Not possible" (Impeded)

The third non-participant group encompassed people who strongly desired to attend CR and / or a CHD Group. These people believed the resource would benefit them, was appropriate to their needs, and had a suitable format, yet were impeded from attending by one or more barrier issues. Not being informed or invited, and in the case of CHD Groups possibly local unavailability, were the primary barriers. However, barriers relating to practical circumstances that were difficult to resolve

could also impede participation. For example, while Mike hadn't been informed a local CHD Group was available and would have liked to attend, he said that after returning to work attending a day-time group would have been impossible. Two CR participants said they wouldn't have been able to attend CR without the transport assistance they received. While this wasn't specifically mentioned when they said they would have liked to attend a CHD Group if it had been offered, their accounts of their circumstances suggested the same barrier would likely have applied. Nonetheless, I observed that practical barriers, including travel, work hours, and physical discomfort due to disability, had greater prominence in the accounts of people in the second category ("Not worth it"). This suggests either that such barriers affected these people more than people in category three, or that non-participants in the second category emphasised their practical barriers to legitimise their non-participation decisions. My evidence suggests the latter was stronger and I explore this further later in the chapter.

Interviewees in category three and some of their family members were thus denied opportunity to use resources they believed would have assisted them after the MI. In Chapter Eight I demonstrate how this was linked to difficulties they experienced. Most of the CR non-participants said they hadn't been invited to attend; while one invitee was told his disability precluded participation (discussed later in more detail); and another appeared to have been referred only to a generic psychological service instead of the CHD-specific support he wanted. All expressed frustration at the lack of rehabilitation support and all except one said they would also have been interested in attending a CHD Group if one had been available, and generally saw this as additional rather than instead of CR. The largest proportion of CR participants were in category three - indicating they would also have wished to attend a CHD Group but were unable to do so. In Ray's case he subsequently reassessed the value of the resource he initially hadn't paid attention to due to lack of endorsement, information, and encouragement. However, most people said they hadn't been informed or invited, and people who had wondered about the possibility of this type of resource had assumed one wasn't locally available because health staff hadn't provided information. This may reflect the general deference towards health staff that was a

common feature of accounts and which I discuss this further in Chapter Eight. Colleen's account provides an example.

AJ: "I know in some areas they've got.. like cardiac groups, some of them do exercise, some of them do..

C: And they still meet even *after* [emphasis] they finish their rehab? See, there was nothing like that. I actually had thought about that, and I thought that would have been actually a good idea, where you could carry on and..

AJ: It wasn't mentioned at rehab or by your doctor or anything?

C: No, nothing, nothing at all. I don't know whether they have anything like that here.."

(Colleen: 63; married; employed)

Shifts between non-participation categories

The complexity of individual cases was a prominent feature of my data. The multi-factorial and often competing influences were one aspect (demonstrated further in Section Two). Additionally, while interviewees' non-participation patterns generally appeared to fit one of the three categories, a further dimension of complexity was that a number of interviewees could be seen to shift between categories in response to changes in their circumstances, beliefs and identity. The study design of interviewing people a considerable period after their MI (between eight and fifteen months) had the benefit of giving interviewees opportunity to reflect on their 'recovery journey' and how their experiences and expectations changed over time. Two accounts showed that, with hindsight, a person who had been invited or informed about CR and / or a CHD Group in their early rehabilitation period, might in the light of their subsequent experiences reconsider their negative assessment that

the resource wouldn't have been beneficial, appealing, or feasible. In this way a person could shift between the non-participation categories.

Firstly, Linda declined to participate in CR and a CHD Group and illustrates a shift from category one – non-beneficial, to two – outweighed, regarding these resources. She initially hadn't believed these resources were personally necessary. She believed she had been "fixed" after angioplasty and was told further surgery wasn't needed; and reinforcing this, people she knew told her she looked well after she had returned home. This had encouraged her that her condition wasn't serious and she could manage herself, which was anyway her preference due to her strong self-reliant identity. With hindsight she believed her recovery might have been more difficult and slower, and her smoking cessation attempts less successful, than if she had accepted this support. Here she describes how support from other post-MI people might have eased her frustrations and worries.

L: "Well I didn't have someone to talk about their experiences, yep. Yep, whereas I think if I'd went maybe four classes or something like that..just to talk and say, 'Well, did you feel like that?', you know. 'Cause I still feel like shite.. Even though it's blah, blah.. You know - 'Do you?', 'Am I doing something wrong?', Whereas you didn't have that... you know... Yeh, nope, in that way I would have liked that support.. er... not even support.. just the comfort maybe.. the closeness of somebody who's went through it." (Linda: 45; partner; employed)

Nevertheless significant deterring factors remained. Her self-reliance made her uncomfortable about accepting more structured support; to overcome travel and transport difficulties she would need to accept dependency on family and was reluctant to do so; and there had been a lengthy delay before she could have attended the resources due to the holiday season. Retrospectively, Linda didn't think these reasons could have been addressed, and said that although the resources might have benefited her, she nonetheless stood by her original decision.

Ray, a CR participant, illustrates a shift regarding a CHD Group, from category one - non-beneficial, to category three – impeded. At CR Ray had seen a poster about a CHD Group, but hadn't considered it of value because staff didn't mention it. At that time Ray had still believed he would be able to return to work and “get on with life” autonomously in the way he felt staff had encouraged people to after CR. However, physical symptoms persisted and resulted in redundancy. He continued to experience anxiety, and contrary to his expectation his depression and mood swings worsened, impeding rehabilitation and straining family relationships. Ray attended his GP but felt they dealt only with his cardiac symptoms.

R: “And, but the GP, she’s going, ‘Well, I don’t really know a lot about this anyway.’. [laughs] ‘Cause that.. that’s what she said. She said, ‘Well, I’ll just keep signing you off, and just keep coming to the CVS clinic.. We’ll just keep checking your blood’. Which.. Great. Yeah, that’s alright... [pause] Well, in so much.. Well.. I don’t really talk to them, they just said, ‘How are you?’ And that’s it. I think they may have seen people and, erm, I mean, I don’t talk to them saying, ‘Well, you know? I get a bit moody, you know? Sometimes I get tired.’. But they just take that as par for the course really..”

Reflecting fourteen months later, Ray and his wife both felt peer support could have helped by showing how others adjusted and coped. Ray regretted not having followed up the CHD Group option earlier and said he would still consider attending if it were possible. However, he lacked information and was unsure if he could attend so long after his MI.

Although not specifically indicated by interviewees, my analysis suggests the possibility that a change in the circumstances of a person in category two might also

remove an important deterring factor and so tip the balance in favour of participating and move them into category three. Ray and Linda weren't the only interviewees whose recovery expectations or circumstances changed over the post-MI months, but other interviewees in this position hadn't been invited or informed about the resources and so hadn't made a decision they might later re-assess. Furthermore, the accounts of people in category three suggested that if barrier issues had been initially identified and addressed their status could also have shifted – to being participants.

Conclusion

The findings in this section take forward understanding of the reasons for, and process of non-participation by addressing the crucial issues of the relative importance, and inter-relation between various competing factors, which hitherto received limited attention and were poorly understood. I have explained how a perception that a resource could potentially benefit them was pivotal to whether a person would consider using CR or a CHD Group. Perceptions about benefits were primarily health-related, but for a few people wider benefits could be important. There are some CR and general resource non-use studies to support my findings by indicating that beliefs about health benefit, and also the capacity of resources to address their needs could be important. My study provides new direct evidence in this respect regarding CHD Groups, and goes beyond the research on post-MI non-participation by showing the more complex nature of perceived benefit. Most significantly, the data indicates that without perceiving that a resource could deliver personal benefits people considered there was “no need / no point” to participation. This was not just one aspect of non-participation that affected some people, as previous findings suggest, but instead was an essential prerequisite for participation, pertaining to all people in considering whether or not to use a resource.

The resources passed this crucial ‘potential benefit’ test among people in category two, yet they also identified barriers and deterrents. These people undertook the ‘weighing up’ process described in the general non-use literature and a number of CR qualitative studies. However, my findings provide new and contrasting evidence by suggesting this process wasn't undertaken by non-participants as a whole but only

by a sub-set of people who perceived both ‘pros and cons’ - which didn’t apply to people in categories one or three. Previous research supports my finding that non-opportunity (non-invitation) and also practical barriers could thwart participation. My study reveals information about the sub-set to whom this applied. It also suggests that practical barriers had greater prominence in category two non-participants’ accounts, and this seemed to relate to their effort to rationalise and legitimate their decision in the context of their equivocal assessment about whether or not to participate. I also highlighted the potential for people to reassess their non-participation stance over time due to a change either in their circumstances and beliefs, or by removal of a barrier, and so come to view a resource as a more positive or viable option. This appears to be significant in terms of the tendency for a one-off, early offer to use these resources (at least among the invited minority). I discuss this further later.

The findings in this section address the hitherto neglected issue of the relation between participation and non-participation in the two different rehabilitation resources. I have reported that a sizeable proportion of post-MI interviewees perceived value in both resources. Also, although many of the people who didn’t perceive value in one resource assessed the other the same way, there were people who perceived value in one, even if disinclined towards the alternative. Additionally, a barrier that applied to one resource didn’t necessarily apply to the other. The significance of this for improving support is discussed in the ensuing chapters.

Section Two: Case Studies of the three non-participant categories

In this section I employ a case study approach to explore in depth some of the themes and issues identified in the preceding section relating to the process and reasons for non-participation and the inter-relation between use and non-use of CR and CHD Groups. The cases demonstrate the complexity of individual cases and illustrate how the factors outlined in Chapter Six, relating to people’s ‘lifeworld’ circumstances, beliefs, and identity, could combine to engender a non-participation outcome. I present three cases, each exploring an example from one of the three categories. In

each I draw upon the accounts of a post-MI interviewee and their family member interviewee. I show how comparing and contrasting the family members' views with those of their relative adds a further dimension to help understand the post-MI person's non-participation and rehabilitation experience, as well as family members' own needs and experiences.

Case study one: "No need / no point" - Sheila and her daughter Sharon

The case of Sheila and her daughter Sharon vividly demonstrates the complex influences that could be involved and the multiple dimensions that could underlie a person's perception of non-benefit from a resource. It powerfully illustrates a female non-participant's experience - according with my aim of promoting the visibility of post-MI women within the study. It shows the important supporting role non-partner family members might play; and how informal support might modify and even transform inter-personal relationships in a positive way, explaining how this might influence and be influenced by CR and CHD Group non-participation. I interviewed Sheila and Sharon separately fourteen months after Sheila's first MI. Sheila was fifty-nine, married, with two adult children and several grandchildren. A former supervisor, she had continued working part-time until shortly after her first MI, combined with looking after her grand-daughter while Sharon, in her early thirties, worked.

The accounts reveal a complex, interwoven web of factors that led Sheila to decline to participate in CR and disinclined her towards a CHD Group. These included some influential deterrents and barriers, yet more fundamentally there were several important factors that caused Sheila to believe CR or a CHD Group wouldn't be personally beneficial, and so there was "no point" participating even had she wanted and been able. Sheila said her initial symptoms were minimal and this, combined with her experience of her husband Iain's post-MI recovery, encouraged her to believe she could manage her rehabilitation herself. Her experience of Iain's rehabilitation was influential in three significant ways. First, it had demonstrated successful post-MI recovery.

S: “I went back to work. I felt great. I felt terrific... I thought I was fine. Yeah, because.. my husband had a heart attack. He flat-lined three times.. but he’d damaged the muscles of his heart.. and they said, ‘Well you can repair the muscles. They can be built back up’. That was six years ago.. Well, ma husband’s terrific. You know? He’s great, and he’s what? Sixty-two now... Went through it with him, you know? ‘I’ll be fine. Back tae work’. I thought that was it... Just back tae normal.”

Sheila viewed herself as having been Iain’s informal rehabilitation coach and instrumental in his recovery. The experience and confidence she had gained was supplemented by knowledge from accompanying Iain to CR sessions and reading his 'Heart Manual'. Sheila therefore believed she already had the knowledge and experience to successfully manage her own rehabilitation and viewed attending CR again as an unnecessary duplication.

S: “After the first heart attack they asked if you want tae go for rehab and all this.. and I says, ‘No’. I’d been through all of it with ma husband.. So I didn’t want tae go through it again... As I say, he flat-lined three times.. and once I got him up and moving he was brilliant..”

Sheila’s prior CR experience with Iain also fostered the impression that although he had benefited, it might be less applicable for herself. Sheila knew Iain had undertaken vigorous exercises at CR and believed these would be personally unfeasible due to her osteoarthritis. It appeared that the possibility of lower-intensity exercise or participating only in non-exercise sessions either hadn’t been offered, or Sheila hadn’t thought this would be useful because she had previously received

information and guidance. In any case Sheila said she felt safe, comfortable and confident gauging appropriate activities herself.

S: "I've got tae watch, erm, once you've had a heart attack they put you on, like a strider.. you're walking uphill.. I can't do that, er, because of the back, because of the knees. It was the same after the operation.. But.. quite happy tae dae it.. dae it my own. You know? At my own pace.."

Sheila's long experience of managing osteoarthritis was a further factor that dissuaded her from believing CR could be beneficial. Sheila presented herself as a successful self-manager, who had learnt to manage and cope with her arthritic symptoms and minimise disruption of everyday activities by experimenting to find a suitable medication regime and developing pain-minimising techniques for activities. Sheila indicated that this had given her confidence that she could also manage her CHD. More generally, Sheila's identity as self-reliant and the person her family relied on – Sharon described her as "the strong one in the family", were significant. Both women suggested this identity had encouraged Sheila to believe she could manage independently and accept minimal help from others. It also deterred her family from trying to change her mind about CR.

Shar: "Erm, but she.. she's the strongest one oot o' it.. Oot o' just sort o' the immediate family. She was the better one. And God forbid that it never happens again, but she was the better one that this happened to, because she's the strongest one out of us all... Erm.. so, she.. she coped with it, and she doesnae like.. I'm a wimp, an' I just lie down tae things.. and no, I'm just terrible, whereas ma Mum's like [mimics no-nonsense voice] 'No. Right. I've been through it.', and carry on.."

Sheila's case succinctly and powerfully illustrates the difficulties non-participants might experience in the absence of appropriate support. She was unique among interviewees in receiving a further CR invitation several months after 'bypass' surgery. After she had initially declined to attend, her confident initial recovery expectations had been confounded by a further MI and surgery, having to quit her job, and ongoing difficulties and distress from problematic symptoms including chest pain, insomnia, appetite loss, depression and 'mood swings'. Additionally Sheila found stopping smoking and undertaking activity considerably more difficult than anticipated. Nevertheless, she again declined and said she didn't regret this, partly because the original reasons for not perceiving benefit remained, but also because she didn't believe CR could address the particular emotional and physical problems she was then experiencing. Her second non-participation decision is significant in demonstrating the strength of her reasons for non-participation; while her continued perception of CR as non-beneficial meant she wasn't one of the people who could be seen to have shifted non-participation categories.

Sheila wasn't invited to a CHD Group, but said she was uninterested; and like her CR stance, there were several deterrents as well as barriers. Yet fundamentally, and again paralleling her attitude towards CR, Sheila didn't believe a CHD Group would have benefited her, again concluding there was "no point" in attending. Confidence in her capacity to self-manage was one reason. Her husband's MI experience and family support also meant she didn't believe meeting other post-MI people would be useful.

S: "Erm, ma own doctor, she done as much as she could.. she was brilliant. Ma family and ma friends, erm, they were great, I could sit and talk tae them if I wanted tae talk tae them.. If I needed help I just had tae lift the phone.. they were there. If I wanted tae do anything, or get anything, they would do it for me, you know? Nothing was a problem that way. I never

missed out on.. help or anything like that... I was well looked after, you know?"

Even if Sheila had perceived CR and / or a CHD Group might be beneficial, both interviewees highlighted several important deterring and barrier issues that would in any case have engendered non-participation. The importance of Sheila's job role to her identity and an activity that enhanced her 'lifeworld' were influential. This encouraged her to return to work as soon as possible, rather than delay for several weeks to attend CR.

Shar: "But she felt.. She kept saying, 'But I like my job'. And she would get upset, and I would say, 'Look, please just stay at home. Just be.'. And she would get upset, saying, 'But I don't want to give up ma job. I like ma job'. And because.. she's always been so independent and strong-willed, erm, she's.. 'Right, okay, I can understand where you're coming from.. You just want tae get out o' the same four walls'."

An additional major deterrent regarding CR was Sheila's fear of hospitals and mistrust of health professionals, stemming from her negative childhood experience of involuntary hospital confinement. Sheila said this had been a key reason for discharging herself from hospital early. An invitation to hospital-based CR was unlikely to appeal, even without other negative factors.

S: "I signed myself out of [District hospital] the last time... I just.. When I was younger I had fluid in the hip and I spent twelve years of ma life in a hospital. And I had tae learn tae walk again. And they would say, 'Oh yes, baby Sheila's getting home tomorrow'... Ma

mum would come for me.. ‘No, baby Sheila’s not getting home’. And I didn’t like that.

AJ: So you *don’t* want to be in a hospital again?

S: So, they had told me, ‘Oh yes, you can go home today’. ‘Thank you’. ‘No, you’re not going home’. ‘Who told you this?’, I says. ‘He told me’. ‘He’s no’ right’. ‘You’re no’ going home’. ‘Oh yes I am’. So..

AJ: You’ve got the power now to.. to make the decisions?

S: Aye. I went home. Nobody was keeping me.”

This provided a further reason that Sheila’s family didn’t try to persuade her to attend. Sharon’s comment below illustrates the family’s awareness of the issue and her empathy with her Mum. Yet, despite Sheila’s resistance they did persevere to persuade and support her to attend her hospital outpatient and GP appointments. Whereas the family perceived these could help, Sharon’s account suggests the family shared Sheila’s opinion that CR wouldn’t benefit her.

Shar: “Getting her into the hospital, you know? That’s basically the hardest part.. It’s like.. she gets there an’.. Even if she’s at the GP, she does the rip on the way, and she.. the sort of feet goes like this [indicates nervous fidgeting with feet] and it’s like, ‘It’s.. I’m no’.’., this.. She gets herself... I didnae know any o’ that until all this illness came out.. and she’s opened up to me an awful lot... She’s always said that she’s had bad hips.. since she was younger. But never said that she was physically kept in. And then the closer we’ve got..

We've got really, really close since.. even the heart attack, erm, she's opened up a lot more of what she's been through when she was younger. And I thought, 'Right, now I really understand'."

Although not being hospital-based might theoretically have made a CHD Group more appealing than CR, my holistic analysis of interviewees' cases indicated that the presence of other deterring issues, as in Sheila's case, could negate an advantage and mean the person participated in neither resource. Although Sheila acknowledged that her husband had valued support from other post-MI people at CR, she felt she didn't need this because her husband provided support and she had met other post-MI people while attending CR with him.

S: "Well, he made friends up at [District hospital] and er, he's still friends with one o' the chaps.. But I just.. I don't need tae discuss everything like that.. [pause] When ma daughter or ma son or ma husband's [there]... Erm, he says, 'You want to go, you go. If you don't, you don't go. If you want tae talk', he says, 'I'm here', he says, 'I'll listen tae you'. I said, 'Well, that'd make a change!' [both laugh] I'm quite happy tae.. go at ma own pace.."

Sheila expressed a negative attitude towards groups, because she preferred independence and had concerns about privacy. This added to her disinclination towards CHD Groups.

S: "And I'm not a person.. I won't sit and discuss anything in front of a lot of people. I refuse tae do it.. Going up and doing that is.. is just no' me."

Sheila's case is notable for the diversity of factors that led her to conclude CR and CHD Groups would neither be beneficial nor appropriate to her needs and circumstances, and weren't appealing. Yet it is also apparent that when Sheila began to experience difficulties and realised she needed help she identified alternative resources that she considered preferable. My consideration of non-participation in the context of people's broader experiences showed in Sheila's case that even without these alternative resources, the combined deterrents and barriers of CR or a CHD Group meant she still wouldn't have participated. Moreover, even though her alternative resources hadn't fully met her needs she remained adamant that she still wouldn't have attended CR or a CHD Group for the reasons given above.

Sheila acknowledged that she couldn't have managed without family support, and considered this preferable to 'external' support such as CR, CHD Groups, and health services. Yet her self-reliance and identity as the family linchpin meant that nonetheless she sought to minimise this support. Initially she resisted household help but gradually relented, especially after her second MI. The family supported rehabilitation activities, in that Sheila could combine family roles and activities, such as swimming with her grandchildren, or walking the dog with her husband. Desire to recover and continue to be with her family also was a strong incentive for recovery endeavours and learning coping techniques. Although her family were Sheila's preferred source of emotional support and were willing, nonetheless she felt uncomfortable accepting rather than giving support.

Sharon's support was particularly significant. She motivated Sheila when she felt low and her symptoms were bad. She sought and applied advice from health professionals; and was pivotal in helping Sheila overcome her reluctance to attend healthcare appointments by accompanying, encouraging, and sometimes distracting her.

Shar: "Erm.. but now, even she's had the operation done, it's like click [fingers click indicating 'easy fix'], 'I should be fine'. An' it's like, [patient tone] 'It's *time*,

Mum.’. An’ it’s like, ‘Ah, but.’. The leg healing sort o’ thing... She says, [mimics stubborn face] ‘Look!’ I says, ‘It’s no’ gonnae take five minutes’, I said, ‘I’ll get you down, get the GP tae look at it.. no harm.’. [mimics stubborn face, shaking head] ‘Uh-uh. I’ll wait’. And I said, ‘Why wait?’ So we ended.. we went down and got that sorted. It was fine, it was just the way it was all knitting together..”

Sharon said this role was new because her Mum had hitherto been self-sufficient and the one who helped others. Also it developed gradually, as the impacts of Sheila’s condition became apparent and Sharon realised her Mum needed help despite her attempted self-reliance. This gave Sharon courage to gradually take a more proactive and involved role and she gained confidence to seek advice from professionals and advise her Mum. Sharon said their mother-daughter relationship developed in emotional closeness and trust after Sheila’s MI, resulting in her new roles as Sheila’s confidante and adviser. Nonetheless she identified challenges: dealing with Sheila’s determined self-reliance, reluctance to use health services, and difficult symptoms such as ‘mood swings’ and depression; while simultaneously managing her own emotions and supporting her Dad. Without the support Sheila received from her GP, and the help Sheila’s doctor gave Sharon, it appeared Sharon may have been less able to support Sheila and cope with her own challenging role.

Shar: “No, she is, such.. such a strong person.. and tae see her sortae.. not being weak, but sort of being like that. It’s hard tae see her like that... That was really, really hard to take..”

Despite not knowing her GP well before her MI, her resistance to health services, and determined self-reliance, Sheila developed a close, supportive, and intensive relationship with her GP. Two other female interviewees similarly described

intensive emotional support from their GP but in contrast they were in the third non-participation category and would have attended a CHD Group and / or CR if opportunity had been available, and their accounts suggested this might have lessened their GP dependence. Sheila's case indicated several reasons she preferred her GP's support. Her previous experience accompanying her husband to CR appeared to have fostered the impression that it wouldn't meet her needs for confidential emotional and condition-related support. She believed it prioritised physical needs and was for people who appreciated talking with other post-MI people. A CHD Group wasn't appropriate either. But besides the deterrents from these two resources, there were some important 'pull' factors towards GP support. Sharon and her GP provided encouragement and support to attend consultations; and the one-to-one situation enabled Sheila to develop trust in her doctor and provided a safe and comfortable environment, which contrasted to her concerns about CHD Groups and CR.

Sheila and Sharon highlighted the value of the regular, unusually lengthy consultations over a prolonged period and suggested these had made Sheila's and the family's difficulties less problematic than they otherwise might have been. Yet Sheila's intensive GP use appeared to have arisen primarily from her disinclination towards other post-MI resources – as indicated below. It is possible that if another professional one-to-one advice and support option had been available and encouragement provided, this might have reduced her GP reliance. Further, the extract reinforces the point that her GP couldn't fully meet Sheila's needs and she continued to struggle with several problems her family and GP couldn't help with. Sheila's case indicates the need for alternative support for people for whom CR and CHD Groups weren't an appropriate option.

AJ: "Is there someone you could ask about.. about more.. how, like, the emotional side effects or the sleep and things?"

S: I suppose you could have done that at rehab. But...
[pause] I could go tae ma own doctor and say tae her,

‘Look, this is really.’ Well.. she’s not one of these... she’s not one o’ these doctors that’d pack you off. She’s always running late... because she spends time.. time with the patients. She doesn’t bump you off and say, ‘Oh, that’s fine, just here, take this’. Talk to her, discuss things with her, she’ll sit and listen tae you, and she’ll do her *best* [emphasis] tae do something... Erm, I’m going tomorrow.. I’m going tae say about this and I want tae know about this bit here [chest tenderness], ‘cause it’s really annoying me.. and see if it’s right or not [laughs]... Though I don’t know if she’ll.. if she’ll know whether it’s right or not..”

Case study two: “Not worth it” - Gordon and his wife Aileen

Gordon and his wife Aileen demonstrate the complex and interwoven combination of influencing factors relating to his 'lifeworld' circumstances, beliefs, and identity, which encouraged him to consider CR and CHD Groups potentially beneficial, yet ironically also provided a stronger case against participating. The couple illustrate the contrasting views between some non-participants and their family members regarding participation and rehabilitation, and the case suggests how this was of significance for post-MI support. Gordon, aged fifty-seven, and Aileen, in her fifties, were interviewed separately nine months after his MI. They lived in a small town in a semi-rural district, where Gordon worked as a building foreman in a small firm.

First, I use Gordon’s case to demonstrate a key element of the second category – that these interviewees said they had perceived value in CR and / or a CHD Group, and initially at least, had been positively inclined to participate. Gordon was invited to CR and several health professionals advised him that it would be beneficial. He gave several reasons for having wished to attend. He said the ‘scare’ of his MI motivated him to take action to regain and improve his health, and his physical weakness and ongoing chest pains reinforced this. His working identity had been an important

incentive to regain fitness, particularly because he undertook heavy manual labour, and was worried about redundancy or career change in his fifties.

G: “But I mean, there’s.. there’s no such thing as light duties. I mean no’ for a working man.. You know? If you’re manual, you’re manual... Well, I thought I was gonnae change ma job.. An’ I’m a bit old an’ long in the tooth for that [sighs]”

Gordon and Aileen both highlighted his fears about MI recurrence and his concern about avoiding over-exertion – shown in the first quotation. The second illustrates Gordon’s belief that CR would provide a safe, supervised environment for exercise to “build up ma strength”, which was a key incentive.

G: “I’ve always had a pain in ma chest all the time. It’s no’ went away.. ever since it happened.. it’s just periodically it comes back.. It’s probably a wee bit exertion and, er, things like that. I mean, it’s not.. painful-painful.. but I was getting a bit worried when they were starting running down ma arm again..”

G: “There’ll be a practising nurse there, or whatever it is.. so if anything does go wrong, you know? You’re under supervision..”

Additionally, Gordon found it difficult to self-motivate to undertake the rehabilitation activities recommended in the 'Heart Manual' alone at home. He had believed company and supervision at CR would be motivating and alleviate the boredom of being off work and having to repeat exercises.

G: “I mean, I got the.. the relaxation tape from.. [pause] the thing.. An’ it just bored me. I just went, ‘No, can’t listen tae that!’ It was *driving me nuts!* [emphasis].. Where.. I think if you got a good practice [at CR], at least you’ve got a wee bit involvement.. and the facilities are there, you know? And you’ve got people that know exactly what they are doing.. Whereupon if I’m sitting listening tae a tape here.. or doing ‘dynamic breathing’, which I cannae do.. erm, doing it by yourself.. You’re sort of going, ‘No.’. [bored tone] I mean, when Aileen would come in, ‘You done your exercises?’ ‘Yes’. ‘What’d you do?’ I said [sarcastic tone] ‘I stood against the wall and pushed myself off it, dear.’. You know? *I am bored!* [with emphasised frustration].. Yeah.. well, it would have given me something to do..”

In common with a number of other female partners across the three categories, Aileen said she had wanted Gordon to attend. Whereas others emphasised their anxieties about safe recovery, Aileen gave preventive health action equal priority - to “kick start” activities to improve his health and particularly his lifestyle. Yet, like many others, at the time she hadn’t pressed the issue, leaving it up to him, especially because he had resisted her own efforts to encourage lifestyle improvements. Nine months on she witnessed his ongoing physical problems, his anxiety about further MI, and no progress with lifestyle changes. She regretted not having been aware at the time of the potential importance of CR, whereby she could have tried to persuade and assist Gordon to attend.

A: “I mean, actually, now that you mention it, it probably would have made sense if somebody had actually said to me, ‘Look, you really need to try to get him to do this.’. You would then know. I mean, I.. I

actually felt.. I didn't feel left out of it, but I felt there was nothing I could do, because I'm not a professional."

Gordon wasn't invited to a CHD Group but said he might have been interested in attending in the early period. Because he hadn't received information specifically about groups he considered it in relation to the information he'd received about CR. He thereby believed it would be useful if it shared CR features, particularly organised exercise, but was more accessible - available outside working hours and if possible at weekends, and easier to travel to.

However, the other crucial feature of the second category was the concurrent perception of one or more important disadvantages, which outweighed the positive reasons and so engendered non-participation. Both Gordon and Aileen said the financial imperative to return to work had been a key deterrent regarding CR. Gordon's employer didn't provide 'sick pay' and the couple said the level of state benefit was inadequate. They perceived that if Gordon had taken time off beyond his initial six weeks it would have adversely affected their income.

G: "I mean, I should have stayed off longer, but.. on sixty-five pound a week it doesn't pay for anything.. you know? I think that's what a lot of people don't understand.. is that.. you've got to live, and you've had a standard o' living, er, an' you just can't afford to.. you know?"

Gordon also linked this to his identity as a 'breadwinner' and belief that it was a husband's duty to 'pull his weight' financially and provide for his wife.

G: "I actually earn a good wage.. a lot of people don't. So, if they're talking a day's wages.. if I lose a day's wages that's my pocket money away, I'm just not going

anywhere. But if some people lose a day's wages that's their money, plus part o' their wife's.. that's the way I look at it, you know? Practical-like..”

Additionally, Gordon felt an obligation to his employer. He believed taking more time off would have been unfair because the firm was small and there wasn't anyone to temporarily take on his foreman role.

G: “And I just told them I was coming back, erm.. Because even though I'm off the now.. There's only a couple of us work there, and the chap that's actually working at the moment, er, is still getting trained..”

A second barrier the couple identified was difficulty travelling to either the main CR centre or the 'outreach' CR course in their district. Gordon didn't drive and his wife worked full-time and couldn't take time off to take him, while public transport within and beyond their district was poor. Also, in the early period Gordon was uncertain whether or not he could walk the extra distance from the bus terminus to the centre, joking, “I mean, why you send heart patients there? I mean, they'll probably not arrive!”.

A: “I was going to say the problem is there's lots of buses from Scotstown.. but if you're actually going, you know? Towards Puggleton, over by Next-town, then there's not a lot.. They're not frequent... They don't come through Midville [their town], you know? Erm, I don't know, maybe a lot of the assumption with these things is that people drive. But then if people.. if people who've had heart attacks can't drive anyway... You do think sometimes think that maybe it's not a

person who's had a heart attack who has all these ideas..”

Nonetheless Gordon and Aileen said it was a change in Gordon's beliefs about his condition that made the non-participation case irreversible. After several weeks Gordon began to perceive his condition was improving and this gave him confidence that he could manage without attending CR. Both said that if he had been able to attend CR earlier rather than waiting six weeks, he could have commenced the course while he still perceived it necessary, as well as avoiding the return to work problem.

A: “And I think he.. you know? He was starting to feel that wee bit better by the end, so he just thought.. so he just thought he'd get on with it himself... I think if it had been, you know? Earlier on.. if he'd started then, I think, you know? Once he had the confidence to.. get back out the house if you like, which only took about a week..”

These deterring influences constituted a strong combined case. Yet while these reasons were explicit and prominent in both accounts, two further factors were indicated to be influential but were treated differently by each partner - which in itself appeared to suggest the factors were significant, albeit ones Gordon preferred not to acknowledge. Aileen identified Gordon's reluctance to renounce his former lifestyle and the identity it entailed as an important contributory factor. She believed he hadn't wanted to confront lifestyle issues that he didn't want to change and didn't think would make a difference to his health. She felt this had deterred him from resources that would focus on this, and implied that the barrier issues and symptom improvement provided him with a legitimate excuse not to go.

A: “I think it scared the living daylights out of him, erm.. and I think to be begin with he would probably have been motivated to.. you know? Try and improve his lifestyle and everything else, you know? His exercise regime.. But now... Erm, with him there’ll always be an excuse.. ‘Why I can’t do it’... It’s.. it’s more hassle than it’s worth, you know? Okay, so I put myself through all this, I give up the things that I enjoy.. an’ I drop dead anyway, so.. you know?”

Certainly the importance of his lifestyle as part of his identity, his enjoyment of this and the associated social life, and the difficulty he perceived making changes, were prominent in Gordon’s own account. He cited various examples demonstrating his resistance to health professionals, family or friends ‘nagging’ him about his lifestyle, and was evidently aware that others saw these changes as the right thing to do. Together with Aileen’s insights, these features suggest that Gordon might have preferred, or believed it was more acceptable, to attribute his non-participation primarily to the work and transport barrier issues than his reluctance to alter his lifestyle.

G: “I live quite a hectic lifestyle, ‘cause I smoke and I drink, you know? Erm, an’ I think it’s called, er.. ‘I work hard and I play hard.’. You know? And when I went there an’ they says tae me, ‘How much dae you drink?’ And I said, ‘A hell of a lot’. Because they actually asked me if I needed alcohol when I was there in the hospital.. an’ I said, ‘No, I can do without alcohol.. I just like the stuff!’ [laughs]”

Aileen believed that a fatalistic attitude underlay Gordon’s approach to his lifestyle. Gordon didn’t mention family history but Aileen revealed that his father died of an

early 'heart attack' and said Gordon avoided discussing this. She believed he was scared to acknowledge the potential threat to his own health, yet equally, a belief that an early death from CHD was inevitable undermined his resolve to take preventive measures.

A: "And.. it's almost that he's got a death wish, you know? This is going to happen to me anyway. I mean, he didn't think that until he had the heart attack, you know? It's happened in the family, erm, chances are I'll be dead before sixty-five... Because I'm sounding like a psychiatrist here, and I don't mean to, but with Gordon it's sort of, like, 'Brick wall I don't think I can do this, so I just won't even bother', you know? And some people are determined they are going to run a marathon, they're determined that they're going to.. you know? Erm, with him there'll always be an excuse.. 'Why I can't do it.'"

Aileen believed the counselling available at CR might have helped address this underlying factor and that without such input Gordon would remain incapable of tackling the issue, while her own efforts would be ineffective. Whereas Gordon presented participation as "not worth it" due to disadvantages, Aileen suggested it was a lost opportunity and serious problem in terms of mitigating the threat of Gordon's CHD.

The immediate barrier regarding a CHD Group was that Gordon hadn't been aware the option existed. While Gordon identified potential benefits he nonetheless suggested that, like CR, several deterring factors would probably have resulted in non-participation. Gordon said similar transport difficulties and conflict with working hours applied, in that it would be difficult to finish work early to wash,

change and negotiate the problematic public transport system to reach the venue on time. However, he suggested a weekend group might have been more feasible.

G: “No, I mean.. if they’d have said, ‘Right, there’s a session Saturday morning.’. Fine. Get the wife tae run me up.. You know? ‘Cause the wife’s got the car.. erm, or.. I don’t work on Saturday so I can get up then..”

Parallel to the CR accounts, Gordon emphasised these practical barriers and his belief he had been starting to recover independently. Aileen similarly highlighted these obstacles, however she also identified additional underlying factors. She suggested the lifestyle and fatalistic issues influenced Gordon’s whole approach - including his attitude to independent rehabilitation activities and attending the different resources. She highlighted a further deterrent regarding CHD Groups that Gordon didn’t mention - suggesting he generally wasn’t a ‘group person’. She therefore thought he would have been more likely to have attended CR if he had perceived a CHD Group was more group discussion than activity. Gordon reinforced this by indicating that his provisional interest depended on exactly what the group entailed. This suggested that if he had received information about a group, the descriptions of the format and functions would have been a crucial influence on whether he would have considered attending.

Gordon attended follow-up hospital consultations and consulted his GP if a problem interfered with day-to-day activities. Some interviewees in this second non-participation category said they had identified and used alternative resources and these had met at least some of the needs they thought CR and / or a CHD Group might have addressed. However, Gordon and Aileen’s accounts indicated that the standard clinical health services weren’t able to fully meet his specific needs and he lacked an appropriate and acceptable alternative resource.

A: “I mean, it’s.. it’s fine getting taken to the hospital and getting told your blood pressure’s fine, erm, check

your medication, or blood pressure.. whatever.. But that's all very clinical, and as I've said before, I don't think that the clinical side is the problem..You know? I think it's what's in the head that's more the problem than what's in the heart, erm, and I think that's the bit that doesn't get addressed at all, as far as I can make out.. you know?"

Both accounts revealed difficulties, particularly Gordon's ongoing problematic symptoms; his fear of recurrence; and his inability to undertake the recommended lifestyle changes. Overall the evidence was that Gordon's rehabilitation had been stalled and was incomplete. Both Gordon and Aileen believed the CHD-specific resources, particularly CR, in the early period could have been beneficial, and both suggested Gordon's choice had been constrained by barriers and deterrents. The accounts together indicate that Gordon considered the disadvantages of attending CR outweighed the possible benefits, and with hindsight wouldn't have acted differently; and perceived the 'cons' also outweighed the 'pros' regarding a CHD Group. Aileen in contrast regretted his CR decision and believed the advantages of rehabilitation support outstripped the disadvantages.

Case study three: "Not possible" - Joe and his wife Moira

The third category comprises interviewees who had perceived CR and / or a CHD Group could have substantial benefits, was appropriate to their needs, and its format was suitable. Yet participation was "not possible" due to one or more barriers. This case presents Joe, a sixty-six year-old man and his wife Moira, in her sixties, who I interviewed separately thirteen months after Joe's MI. The case illustrates several barriers and the adverse influence these could have for rehabilitation and family members. Joe had been wheelchair-bound since childhood and experienced periodic ill health, but had worked until ill health forced retirement. For some years Joe had had a care-worker, providing daily personal care and easing Moira's practical care burden, providing brief breaks from her '24/7' caring role. The couple had long experience of coping with and managing life around Joe's disability and illness, but

said their capacity to cope had been severely strained in the two years before the MI by several serious illnesses alongside their son's health problems. Joe's unexpected MI added to their emotional strain, making them feel "it was one thing after another".

Joe and Moira both said he had difficulty accepting his MI. He had no history of 'heart trouble' and couldn't believe he could be so unlucky as to have this while receiving treatment for other serious illnesses. Joe said he couldn't distinguish MI symptoms from his other illnesses, and the lack of distinct and dramatic symptoms he believed an MI would entail compounded his disbelief.

J: "And I said, 'What's going on?' Because nobody was.. They said, 'You're having a heart attack'. Erm, and I said, 'No, naw, naw. I'm not'. I says, 'Yeah, I'm in with this pain down here.'. And they says, 'No, you're definitely having a heart attack. We have to get you.'. The upshot o' it was.. within about two hours I had angioplasty and two stents put in... Yeah, and to this day I never realised that I'd had a heart attack.."

Difficulty understanding and accepting his MI due to the combination of his beliefs, identity and circumstances described above, was a key reason Joe had considered the information and advice he had been told were available at CR could be helpful. Additionally, both accounts suggested his identity as a 'good patient' had been a further incentive, describing how Joe had felt he should accept the hospital staff's invitation and recommendation.

M: "And he does know his capabilities, and I think he knew even before we went there that it would've been a waste of time, but y'know? You're asked tae do it and you do it, erm.. and that was it.."

The encouragement and information the referring staff provided was crucial in persuading Joe to attend, particularly to overcome a significant barrier that the couple said would otherwise have caused him to decline. The accounts indicate that Joe's self-conception as a disabled person made him keenly aware of his physical capacities and limitations. Consequently, when told that CR included exercise, Joe's immediate reaction was to question whether his restricted mobility would impede participation. The couple said he had raised the issue but had been assured he could attend, and so they assumed he could participate in the non-physical elements if the exercises proved unsuitable.

J: "They just said it would be tae talk about it and tae talk about exercise and that... I already told them all, but they said..."

However, when the couple attended, Joe was told that his disability precluded participation in the exercise programme. They had anticipated this but were disappointed and frustrated when not invited to participate in non-exercise sessions. Joe was thereby thwarted from putting his participation intention into practice, leaving him frustrated, rejected and angry.

J: "But then when I went and spoke to the physio and that, and she saw ma situation and whatnot, she said tae me, 'Really, it's been a waste of your time coming.. An' when I read your notes', she says, 'I thought it'd be a total waste of time as well'. I already told them all, but they said..."

AJ: And did they say anything else that there was going on as part of that? Or they just said the exercise isn't any good..?

J: No, no... just, er.. well, they didn't even say.. just,
"Bye, bye!" [ironic, angry tone]

Nonetheless, the accounts indicate that at the time Joe accepted the decision and hadn't expressed his frustration and disappointment to the CR staff. This represents a different aspect of the desire to adhere to 'good patient' conduct that had initially encouraged them to follow the recommendation to attend. It accords with the widespread reluctance to criticise health services I found among interviewees (discussed further in Chapter Eight). Joe and Moira's accounts both implied the referring staff had invited Joe inappropriately, yet neither had felt it appropriate to challenge the decision, remaining silent when the service failed to meet their needs and expectations. Yet, whereas Joe now expressed the dissatisfaction he hadn't vented at the time, Moira instead appeared to accept the CR standpoint - that Joe didn't 'fit' their service rather than the service being inflexible and having failed to accommodate Joe's circumstances and needs.

M: "Well I was with him and they just said that it wouldn't help... Joe's.. he's had operation to his shoulder, in fact the other one's away now as well, but they thought physio would have helped... But when we got there it was decided that it just.. it wasnae possible for Joe to do.. the things that.. for your heart.. I think it was after the heart attack.. and obviously exercise is good for you and they thought some form of physiotherapy.. But he couldnae even do things y'know? With his arms, so there wasnae really any.. kind of exercise that Joe could do... So, that.. that was it."

Joe and Moira said they hadn't been invited to, or informed about a CHD Group, and so this option hadn't been available. Joe's case illustrates my finding that lack of

information about CHD Groups was prevalent among CR non-participant interviewees. My evidence suggests CR non-participants might be doubly disadvantaged in that they often hadn't had opportunity to attend CR and because of this were less likely to gain opportunity to attend a CHD Group, as CR was the main source of information about this. Joe and Moira said they would have been open to other options, such as a CHD Group, particularly because of the difficulties they experienced in the year after the MI. Moreover, their description of unsatisfactory primary care experiences, additional to the rejection from CR, suggested that a CHD Group might have appealed particularly as an independent, non health service resource.

To accompany the 'Heart Manual' information book Joe received a visited from a local nurse, however he didn't feel the book and visit addressed his needs. He felt the focus had been lifestyle change rather than his priority of understanding his condition and the uncertainties that caused him unease. He was also deterred by what he saw as the nurse's unsympathetic and uncompromising approach to lifestyle issues. He felt she had discounted efforts he had made and hadn't tried to understand his circumstances and perspective, particularly the reasons he had chosen to cut down rather than stop smoking altogether.

J: "I find that when I stop smoking I become very, very stressed. And I've tried everything, I've tried patches, I've tried acupuncture, I've tried.. every bloody thing, and I just cannae do it. Erm, so I've cut doon considerably, but I haven't stopped smoking. But, I'm weighing up.. what I'm saying tae myself, 'What's the worst? Me stressed and.. or..?' Aye, an' I mean, I think I would have more chance of going with a heart attack *being stressed* [emphasis] than having.. er.. You know? Sort of ten fags a day and being fine. So, that's how I look at it."

Joe had approached his GP seeking help with the stress, unease, anxiety, and frustration he experienced for several months. He related this to the combined difficulty of accepting his MI; ongoing pain, discomfort and uncertainty relating to his co-morbidities; and the strain of his son's ill health. Joe readily accepted his GP's suggestion that he could attend the nurse counsellor who held sessions at the surgery. He believed it might ease and help resolve his difficulties, and also thereby ease the emotional burden on Moira, who he knew was under strain from supporting him and their son. However, Joe was then told he was ineligible because he exceeded the service's age threshold. This offer then withdrawal based on Joe's characteristics and circumstances seemed to echo his CR experience. His frustration and disappointment led him to decline his GP's offer to try to find an alternative. Alongside the previous two case studies, Joe and Moira's case further reinforces my finding that needs that CR or a CHD Group might have helped address were often not met by other resources.

M: "The doctor Joe is under.. erm, he's a lovely guy [coughs] and him and Joe have got a great rapport together, and he does listen to what Joe is saying, and Joe was getting quite upset. And I think the doctor thought Joe was a bit depressed, and he *did* [emphasis] offer counselling to *Joe* [emphasis], erm, he said it was a new thing that had started in the practice.. it only lasted a few weeks but would Joe like to try it? And Joe said yes. And then the next thing we heard was that Joe was too old to have this.

AJ: Oh right? [bemused tone] I wonder what on earth.. 'cause Joe is only..

M: [humourless laugh] So.. And then I think he did say do you want me to get somebody else to speak to you, and Joe had.. I think he was just so disgusted.. And he just said no."

Joe's concern for Moira had contributed to the impetus to seek help from his GP. This suggests that besides the opportunity to receive information and support with his own difficulties, if Joe had been aware that Moira could have accompanied him to a CHD Group and met and talked with other family members facing similar challenges, this might have added a further participation incentive. Moira's account, like Joe's, highlighted a deficit in emotional support. She described the strain of dealing with her own anxiety and distress about Joe's condition, while also supporting him to cope with the emotional and bodily impacts of his illnesses; and being her son's main confidante, and coping herself with her feelings about his illness and its impact on the family. Moira said she would have appreciated advice about Joe's condition, and identified information and support relating to her carer role as a key deficit that might have improved her own experience and helped her support Joe. By the time of interview the emotional difficulties Moira described suggested that intensive support such as counselling may be needed - a need she identified herself. The palpable extent of Moira's difficulties, manifested when she broke down in tears several times during her interview, prompted me to cross the boundary from interviewer to informal 'referrer' by providing information about a carer support service I was aware of through my previous work. Nonetheless, the couple's accounts strongly suggested that opportunity to attend a CHD Group earlier might have helped alleviate and possibly mitigate the strains that, without support, had developed into greater problems.

M: "Yeah. Don't get me wrong, I know if I needed.. like, they have a number for the, I don't know what you call them.. the people that see to bath seats, an'.. Occupational therapy. They have a phone number if you have any problems with *these* [emphasis] things... *but*.. [emphasis] But there's like.. nobody... [long pause]

AJ: So, when you said that Joe had been offered the counselling.. I mean, do you think as well it would have been helpful if they'd offered that sort of thing for yourself? Or.. or is it not..?

M: Possibly, it would.. but I just.. I just feel I'm.. I'm the mother, an' I just feel I'm.. It's crazy.. I just.. I should be.. [tearful] I'm the one that's... I should be here for everybody, but... [crying] It's just getting a bit difficult."

Conclusion

The three cases illustrate how different combinations of factors that could engender non-participation. This heterogeneity was also apparent between interviewees within the same non-participation category. Yet, notwithstanding this diversity, the non-participation of the twenty-seven post-MI interviewees followed one of the three broad patterns. The cases demonstrate both the potential and limitations of CR and CHD Groups for people in the three categories, and also the value and limitations of the alternative resources that were available. Sheila's case shows how the resources, at least in their present form, were unsuited to the needs and circumstances of people in the first category. Gordon's case illustrates how people in the second category and their family members believed that CR and or a CHD Group could potentially have helped address post-MI difficulties and aided rehabilitation. It also demonstrates a range of the deterrents and barriers that meant this potential wasn't realised in practice. Joe's case highlights the way people in the third category were thwarted from using resources they considered would have helped their recovery.

The cases illustrate a number of important wider findings that take forward understanding of the reasons for, and experience of non-participation. Sharon's account shows the potential importance of non-partner family members in supporting rehabilitation, an issue not highlighted in existing CHD literature, which is dominated by partner studies. Her case also builds on previous research by

illustrating how informal support might modify and even transform inter-personal relationships in a positive way, and shows how this might relate to CR and CHD Group non-participation. The need for courage by family members in undertaking new roles and dealing with issues that placed them outside their 'comfort zone' adds new insight regarding family support. Sheila's case raised important issues about non-participation. Direct experience of helping a family member's post-MI recovery – the role of informal rehabilitation coach, might encourage a person to try to manage their rehabilitation themselves, and deter CR and CHD Group use. Prior CHD experience within their social network could also mean they didn't perceive the need to participate in a resource to meet other post-MI people. Prior experience of self-management of another condition similarly may encourage CHD self-management and discourage use of structured support. These issues highlight a need to consider and balance between supporting a person's own health needs and their possible role as carer and supporter of a relative, and between encouraging self-management and supporting people to access appropriate help.

The cases provide evidence that lack of family encouragement to attend could be a significant influence regarding both CR and CHD Group non-participation. This is supported by the limited previous research, which suggested this may increase likelihood of non-participation. The three cases show how family members' perspectives add insight regarding non-participation, for example, revealing the different rationales that could underlie lack of family encouragement to attend. Family interviews are relatively common in the CHD literature but not non-participant research. The contrasting views between some non-participants and family members regarding participation and rehabilitation has important implications for supporting post-MI people and their family members, which I later explore.

Regarding the inter-relation between CR and CHD Group non-participation, Joe and Gordon's cases demonstrate the finding that CR non-participants could be doubly disadvantaged, in that CR non-participation meant they were unlikely to be invited to a CHD Group. Each case shows that without these resources or suitable alternatives, substantial rehabilitation needs remained unmet and made the recovery process

difficult for the person and their family. Chapter Eight now examines this important finding in detail.

Chapter Eight - Difficulties in the post-MI experience of non-participants and their family members

In this chapter I focus on an issue that featured prominently in interviewees' accounts - the difficulties that non-participants and their family members experienced following the MI. Interviewees and family members varied considerably in their assessments of the recovery period. There were people who believed successful progress towards recovery had been made, and considered that overall their recovery process had been manageable and without enduring major problems. Yet there were many whose experiences had been, and sometimes continued to be, extremely challenging, and struggled to manage. The cases in Chapter Seven show that post-MI people and family members responded in various ways to deal with the challenges facing them and to try to make the best of their situations, and in some cases they believed these had been effective. Nonetheless my findings indicate that this shouldn't be interpreted to mean that there were non-participants and family members who experienced a 'trouble-free' recovery and whose needs were fully met. Even people who felt recovery was proceeding well had encountered hurdles on their recovery journeys.

It appears that if certain issues had been addressed and certain types of support had been available the post-MI recovery process could have been significantly better for people and their families – what health professionals commonly term 'unmet needs'. Together with the evidence presented in the preceding chapters regarding the non-use of rehabilitation resources, these findings are of major importance from a health promotion perspective. From these, the areas on which non-participants and their family members wanted further support can be identified and suggestions for appropriate ways to meet these needs can be obtained.

In the first section I highlight the way that deference, stoicism, beliefs about self-reliance, and doubts about the capacity of external resources to provide the required

help limited people's expectations of support beyond their informal networks. The main body of the chapter addresses the specific difficulties people experienced. Interviewees commonly identified needs relating to emotional support, monitoring and motivation, information and guidance; while some people required help regarding psychological and 'cognitive' problems, practical difficulties and social isolation. I examine the extent these related to CR and CHD Group non-participation, and the potential and limitations for these resources to address these needs.

Limited expectations and reluctance to request support

In some cases interviewees explicitly linked a problem to a deficiency in service provision or general deficit in post-MI support. Nonetheless this didn't lead them to blame staff and they often thought it was unreasonable or unfeasible for a service to meet all needs and demands. Some people espoused values of self-reliance and stoicism, suggesting people should 'get on with' problems themselves rather than expecting a service to help. For example, Ray and his wife Teresa felt they were "on their own" dealing with Ray's difficulties after completing CR, but felt they had no right to expect a service to provide such help. They suggested a peer support resource may have been an appropriate alternative yet had been unaware of such an option.

T: "I suppose, it's maybe it's just that, you know?
They've not got the resources..

R: It's probably.. they've not got the time and the
resource for that, have they?

T: Do you know what I mean? And perhaps we're just
having a good ole moan and...

R: No.. it's not that..

T: You know? I mean, I know the NHS is stretched, but sometimes it is quite frustrating because you don't know which direction to go in..”

(Ray: 50; redundant post-MI. Teresa: wife; 50s)

Even in a consumer-focused society, interviewees were generally reluctant to criticise health services, particularly hospital care, for service or support deficits. Deference towards medical authority was strong, and a belief that one should be grateful for treatment and care was widespread. For example, Colleen, who underwent CABG surgery after her MI, said intensive care staff had been unsympathetic and unsupportive compared to her pre-operation care. Yet she downplayed the criticism by suggesting they might have had a ‘good reason’, such as being a clinical strategy to motivate patients.

C: “Oh, there were people about, but you basically you had to get up and on with it.. Erm.. they did what they had to do, Angela, don't get me wrong. They did what they had to do..

AJ: But you noticed a big difference between that and the before-care?

C: Ohhh, tremendous, tremendous difference, erm, there was not at all the same.. the nurses were.. whether or not... I don't know whether or not there's a reason for it, because maybe you might feel too sorry for yourself and you might never get yourself up and get better, I don't know..”

(Colleen: 63; married; employed)

Interviewees who viewed CHD Groups unfavourably tended to couch criticisms and negative perceptions in terms of them not being personally appropriate rather than

suggesting the resource had no value. People who declined to attend accepted that this had been their choice. Therefore they believed they should rely on their own resources and accept any consequences instead of expecting or suggesting that a more preferable alternative should be available. The potential significance of this for improving post-MI support is discussed in Chapter Nine.

K: “They just told you it was a group that was.. was there, an’ if you wanted tae go along.. go along. I don’t actually know, erm, I’m assuming that’s what’s involved, but I don’t know for definite. But they certainly made you aware of it.”

(Kenny: 55; married; employed)

Difficulties on the recovery journey

My findings demonstrate a link between CR and CHD Group non-participant status and rehabilitation difficulties among post-MI people and family members. Chapters Six and Seven have shown that many interviewees weren’t offered opportunity, or faced other barriers or deterrents that impeded use of CR and / or a CHD Group, yet perceived that one or both of these resources could have improved their post-MI recovery. Accounts suggested that problems might have been less severe or shorter-lived, and for some, undertaking and maintaining secondary prevention activities might have been easier, if they had been able or encouraged to attend. However, my findings also demonstrate that there were people with similar needs, for whom CR and CHD Groups wouldn’t have been appropriate or acceptable due to their circumstances, and the beliefs and identity, which underlay their outlook and preferences. Alternative support for these people appears to be needed. Additionally, as I discuss later, a number of people reported intensive emotional, psychological, or cognitive problems that appeared to require more specialist support than CR or a CHD Group could have provided, while certain practical difficulties required support from wider sectors such as employers or Social Services.

Reassurance and motivation

Uncertainty was a major theme among post-MI people and family members. Uncertainty about future health, risk of further MI, and the extent they could retain / regain their former way of life was widespread and caused unease and anxiety. These feelings were universally intense in the early post-MI period. For some they diminished over time, but some people remained very uncertain and anxious many months later. My findings suggest that people without support from CR and CHD Groups and lacking alternative resources capable of meeting their need for reassurance and motivation may be especially vulnerable. Some accounts indicated that these unaddressed needs could damage emotional and psychological wellbeing, and undermine confidence and motivation to return to life activities and undertake recommended lifestyle changes. Not knowing what to expect regarding 'follow-up' support could exacerbate their insecurities and make them feel vulnerable and isolated.

In some cases people didn't receive the primary and secondary care 'follow-up' that staff, acquaintances or other patients had advised them to expect. My findings suggest that non-participants could be particularly vulnerable if they didn't receive 'standard' health service 'follow-up', in that they lacked support from other sources, whether CR, a CHD Group, or alternatives. This created anxiety about whether they would receive support and added to concerns about their condition. Some interviewees investigated this themselves, however many accepted lack of 'follow-up' as a fait accompli, meaning their concerns weren't addressed. For some people this impeded their recovery in psychological, emotional and / or practical terms. For example, Angus' promised hospital 'follow-up' appointments didn't occur and despite mentioning this to his GP he received neither invitation nor explanation for why he didn't need to attend.

A: "Well, when I came out of the hospital the last time and they said they'll send me a letter when to come in for a.. you know? Check up how things was.. One.. one was supposed to be from, er, the cardiac place, and the other one's supposed tae be from just down at the

surgery for a check-up.. But I've never heard anything, eh? That's, er.. left...

AJ: And would it have...?

A: Well, it'll sort of put your mind to rest a bit an' that, you know? If you go back and check that wi' the machine..

AJ: Did you say to your GP that they haven't had you back in for..?

A: Well, he asked me, he said, 'Did you get a letter through?', an' I says, 'I got a letter when I come out o' the hospital', an', er, they said they'll send me an appointment for a follow-up thing, an' they never bothered..

AJ: Mm-hm.. and he didn't follow it up for you?

A: No, he didn't follow it either..”

(Angus: 62; married; retired pre-MI)

Angus saw his GP regularly but felt specialist cardiac 'follow-up', using equipment unavailable with his GP, would have reassured him about his condition. He remained uncertain and pessimistic and this appeared to contribute to his depression and limit his activities to avoid exacerbating his condition. Angus wasn't invited to CR or a CHD Group but indicated he might have considered the former, and indeed had previously attended rehabilitation after a stroke. CR might have helped fill the gap he perceived in CHD-specific monitoring and guidance and aided his recovery.

Some interviewees felt their follow-up support had been too brief or hadn't addressed key needs. Although they commonly considered 'follow-up' had been

good in clinical terms and provided some reassurance about their physical condition, they felt mental, emotional, and ‘cognitive’ issues had received less attention. Few people were able to proactively seek and identify alternative support and often these needs remained unaddressed. A small number of interviewees described severe problems evidently requiring specialist treatment. Generally problems appeared less intensive but could still impede rehabilitation and place strain on family members. Some interviewees regretted not attending CR because they believed it might have addressed these issues, or at least helped them cope, while a notable number perceived this regarding CHD Groups. For example, Gayle believed a CHD Group might have helped her deal with her emotional difficulties and depression, and to understand her distressing symptoms such as memory and speech loss that her GP and consultant hadn’t discussed.

G: “Erm, maybe a wee bit more support an’ that, to tell you that.. sit you down an’ tell you how you would feel six months on down the line, or two months on down the line, what changes in you.. Or even.. like a support group, something like that where it’s happened tae other people an’ you can’ go, or, erm... Because it is a culture shock to your system, like, erm.. ‘Why did it happen to me? What did I do wrong? Blah, blah, blah’. An’ to hear how other people.. cope, get on wi’ it. I mean some people.. how can’ I put it? Some people, never recover, they, they are permanently ill, and there’s other people that are back tae their keep fit.. There’s like two sides to it.. ones no’ successful an’ the other one is successful.”

(Gayle: 41; partner; parent; post-MI non-return to work)

Several interviewees said a three month wait for referral to see a consultant about recurring problems had fuelled anxiety and uncertainty. Seeing their GP and having a consultant appointment scheduled had provided only limited reassurance when

their symptoms were frightening or worrying. Besides reduced waiting time, they suggested that support to help cope with and manage their anxiety and uncertainty would have been beneficial. Family support was valued but generally considered insufficient, while family members acknowledged their limitations and highlighted their own support needs. For example, Maggie, Dave's wife, described how her worry and frustration during the waiting period culminated in seeking emergency care.

M: "The only thing I felt was the wait, you know? 'Cause the GP did put a referral through a couple o' times and when we'd went, and it was like.. now what happened? Erm, that was the October.. That was to go back as an outpatient, and, er, the appointment came through for the January.. So, I said that's.. that's far too long.. when he was getting pains, aha.. I thought that was quite bad, and then as I say, erm, and the next week or two after that he was quite bothered wi' the pain and that's when I just took him into A&E.."

(Maggie: Dave's wife; early 40s)

Yet hospital appointments didn't always provide the reassurance interviewees sought if they felt staff were unsupportive. Interviewees spoke of wanting either encouragement about their recovery or advice about how to address problems and assurance about further available help. For example, lack of encouragement from staff led Dave to believe he wasn't recovering well. He said this initially depressed him and undermined his confidence and motivation for the rehabilitation activities he had been pursuing. Although his wife was supportive, Dave, who had declined to attend CR and a CHD Group because of concerns about feeling abnormal because of his young age, lacked other sources of motivational support.

D: "I went back two months later for another sort o' check-up, then a six month check-up, and that's when I was on the treadmill and I'd say that knocked me back.. That then set in a wee bit o' depression I would say.. I think... It was really just.. an' Maggie says, 'Well.', she says, 'What I'll do is I'll phone up the guy', kind o' the consultant guy.. And she phoned them up and the consultant guy says, 'No, Dave's wrong thinking that way. He done really well'... I mean, if the guy had said that at the consultation we had, eh? If he'd said, 'Look Dave, you done tremendous. You done nine minutes', I would have been chuffed [delighted]. I would be chuffed, aye.. instead of being depressed for two or three days, eh?"

(Dave: 40; married; employed)

Insufficient motivational support for lifestyle behaviour changes was identified. Several interviewees said they had been deterred in the early rehabilitation period by what they felt was a judgmental attitude from certain health care staff. This had sometimes made them reluctant to use a resource; others had simply felt unmotivated to follow the advice. This is seen in Joe's case study and regarding Sheila below. Sheila said one consultant's condemnation of herself and her husband as smokers, without having established whether they planned or had tried to stop, was unhelpful and counterproductive. Her experience of others who were supportive and non-judgmental emphasised the contrast.

S: "And, er, he was the first one I seen, and ma husband was sitting and he more or less said [mimics imperious tone], 'No!', tae ma husband. And I says, 'That's ma husband.'. He says, 'No! You smoke. 'This I don't agree with'. And I went, 'Ah-ah-ah!' [angry, assertive

tone], I said, 'Hold on. I didn't come here for a lecture from you'. I said, 'I'm not taking it'."

(Sheila: 59; married; post-MI non-return to work)

Lack of motivational support beyond the early period, into the medium and longer-term, was highlighted by some people and family members who experienced difficulties without this, either in maintaining earlier changes or because they hadn't previously managed to implement changes. For example, as described in Chapter Seven, Aileen felt her attempts to motivate Gordon to accept and undertake lifestyle changes had largely failed and believed his fatalistic attitude was a barrier that required professional attention. Several barriers had deterred Gordon from attending CR, and a CHD Group hadn't been offered. Aileen saw these as missed opportunities to receive motivational support from professionals and other post-MI people. Nonetheless she proposed that a visit in the later period from the cardiac nurse who had visited shortly after Gordon's MI might help kick-start his stalled rehabilitation. She said he had appreciated the nurse's approach but had lost motivation to implement the advice. Aileen believed a later visit might help him review his situation, discuss barriers, and boost motivation.

A: "But now, as you say, it's about nine months.. probably almost ten months, and.. I mean, as the time goes by.. it's his comfort zone I think. He really has slipped back into more or less.. I would have thought more.. maybe after sort of the six months, seven months, you know? It's putting more on the nurses, poor souls, but you know? More of a sort of, 'Well, how are you feeling?' type of... I mean he's been back at the hospital about a month ago, and the doctor there, the specialist, they reviewed his tablets and I think he's probably going to change them, but... I think he very much felt, he thought the heart nurse was really helpful. I do remember him saying once that she was more sort

of.. ‘You know that you’ve got to stop. If you can’t stop, cut down, and if you don’t, well, hell mend you’, sort of thing, you know? She was very matter of fact, rather than, erm, condescending..”

(Aileen: Gordon’s wife; 50s)

Information and guidance

In Chapters Six and Seven I showed that inadequate information meant many interviewees didn’t receive an opportunity to make an informed choice about whether to attend CR or a CHD Group. In the light of their rehabilitation difficulties this represented a ‘missed opportunity’, as many explicitly identified. My findings show that insufficient or inadequate information and guidance in a broader sense was an important deficit that interviewees perceived had impeded rehabilitation. Lack of full, accurate and easy to understand information about their condition, treatment, and how to manage and re-adjust – which interviewees commonly identified as of major importance, could cause misunderstandings, anxiety, misjudgements, and maladjustment. Alec, who experienced severe anxiety that restricted many activities, including returning to work, provides one illustration. Although not the sole factor, his account suggested his GP’s description of risk of a further MI had fuelled Alec’s concerns, which weren’t subsequently allayed by contact with other health professionals. Alec believed that being able to talk to and share experience with other post-MI people might have helped, but said opportunity via CR or a CHD Group hadn’t been offered.

A: “But er, what he did say.. what he did say tae me, because he can be quite blunt like.. There's no guarantees it won't happen again, which puts the fear o' death in anybody's mind, I think. He says there's no guarantees it won't happen, and then again there's no guarantees that it will happen. So, I'm living now wi' that thought. Is it gonnae be the day that I'm going doon the road and I..”

(Alec: 53; married; post-MI non-return to work)

Inadequate information and advice could also fuel family members' uncertainty and anxiety, adversely affecting their mental and emotional health, family relationships, and their ability to provide practical or emotional rehabilitation support. For example, Teresa, Ray's wife, accompanied him to CR, and although useful, it didn't fully meet her advice and information needs. Also when Ray's problems later intensified she didn't know where to seek advice, believing patient confidentiality prevented his GP providing help, while she had been disappointed by the hospital's guidance and support.

T: "Well, I mean, me and my daughter, Jenny, who's still at home.. We do find it quite hard to deal with because we don't know what to do.. But I don't have anybody that I can contact and say, 'Look, this is happening, I think we might need a bit of help, or I think Ray might need a bit of support'. You know? 'Is there anything that I can do?'" And you get to the point where you sit down and you just think, well, this is what life's gonna be like now, so obviously I've just got to deal with. But sometimes it is very difficult to deal with, because what happens is when Ray's down, it drags me down.. After.. after so long of trying to stay up there, you get exhausted.. So you just think, 'I've had enough and I can't cope with this anymore.'"

(Teresa: Ray's wife; early 50s)

Even family members of people who felt they had managed to recover well and didn't experience serious difficulties indicated that information and guidance could have made their experience easier, lessened their anxieties, and enabled them to help their partner more effectively. For example, Judy, George's wife, felt staff had

provided her with less advice and information specifically because her values had encouraged her to manifest an outwardly stoic attitude. She hadn't wanted to present herself as unable to cope and so hadn't raised her anxieties about recurrence and uncertainty about how to support George's recovery safely. The staff response appeared to have reinforced Judy's perception that she should show herself as capable of coping and to have deterred her from seeking advice.

J: "Well, you know? I could have done with more information at times.. If somebody had taken me there and said, 'Look this, this, this.'., but, erm... But there again, perhaps if I had been one of those people.. and they do get them.. you know? Who had gone into the ward and burst into tears because I just found out he was going to have a triple bypass.. Somebody.. somebody might have, erm, done something then.. but the fact that they thought, 'Oh, she's f..[fine]'

AJ: A shame that you have to go that far.. So, you felt that they let you get on with it, sort of 'DIY'?

J: Yes. Oh yes, aha.. but it might have been different if, er.. if I had reacted differently, but.. but I'm not that type..

AJ: So, have you had.. any other sources of information or advice for yourself in the last year?

J: Oh no, no.. no.. No.. no.. I haven't at all."

(Judy: George's wife; late 60s)

Although some interviewees valued the 'Heart Manual' information book and CD, others felt it was insufficient or inappropriate. Some were particularly frustrated because it was the main or only cardiac-specific information they received after

hospital discharge. For example, Dot, a single mother in her forties, found the manual too intense in the early period and was deterred by what she felt was its clinical focus and the judgmental attitude of the 'Heart Manual' facilitator nurse who had visited. Dot believed advice from other post-MI people at a CHD Group could have helped address her information and advice needs; although other interviewees indicated that alternative options would suit them better.

D: "I mean, I looked at that manual, Angela, an' I'll be quite honest wi' ye, I didnae follow it up.. I just feel as though it's too intense. I really feel as though it's too intense. It's six weeks all crammed intae this one book. Everything that you've got tae dae within the next six weeks, an' I just feel it was all too much. I feel as though I could have done wi' a wee bit more support... They just came in, checked your blood pressure, make sure you were living by the heart manual [tone mix sarcasm & frustration.]"

(Dot: 43; single parent; post-MI non-return to work)

Emotional and mental health

Emotional and mental health issues were key areas in which support was needed. Many interviewees identified a need for additional support with the difficult emotions they experienced after the MI, particularly the uncertainty, anxiety, difficulty accepting the MI and its consequences, and for some - sadness and guilt. Depression and 'mood swings' affected a sizeable number of people, while some family members also experienced depression. Although the duration, extent, and impact of difficulties varied considerably, the inadequacy of available support to meet these needs was a common theme. For example, Gayle, a mother in her forties, experienced post-MI depression and said this made her lethargic and "can't be bothered." She was distressed and alarmed by 'mood swings' and felt these damaged her relationships. She couldn't discuss her MI or emotional issues with her

partner, who she believed was ‘in denial’ about her illness, and felt her GP had also dismissed her difficulties.

AJ: “What, what could you say you could have done with that you hadn’t had?”

G: It might have been maybe even about how you would be feeling after it.. after the initial shock’s away an’ the pains away, it happening.. How.. how you would be feeling. The mood swings.. I don’t know if that’s associated wi’ a heart attack or not... Erm, they just put it doon tae.. [concurrent health problem] an’ stress o’.. the heart attack an’, erm, what I came through.. Just.. Aye.

AJ: Right, so you feel you could have done with more..?

G: Mair support... instead o’ just getting flung a book.”

(Gayle: 41; partner; parent; post-MI non-return to work)

Interviewees identified a need for emotional support beyond their informal networks. Thus although some people had support of some type and extent, this could be inadequate to meet their CHD-specific needs, or they could have reasons for wishing to avoid seeking or accepting help from family and friends. For example, Mike had several reasons for wanting emotional support from outwith his social network. A divorcee who lived alone, he felt uncomfortable discussing emotional issues with friends and didn’t want to ‘burden’ his adult children. Additionally, as a working man in his fifties without prior CHD history, Mike wanted to talk to other post-MI people and receive professional support to help him come to terms with the condition. He attended CR and valued the support highly, but lost this when the course finished. He said he would have appreciated a CHD Group but because he received no information about local groups he had assumed none were available.

M: “You know? You've got no support now at all. It's all just suddenly stopped dead.. and I hadn't thought like that until she'd said it, because I thought, 'Oh, it's a clean break, and that means I'm okay', but actually in the weeks since it's finished I went.. I sort of vaguely miss it, you know?”

(Mike: 57; divorced; employed)

Some interviewees said that despite strong support from family and friends they thought that meeting other people who had undergone a similar experience would help them come to terms with their condition. Dot was one of a number of interviewees who hadn't been invited to CR or received information about a CHD Group and said they would have appreciated this opportunity particularly for this reason. Dot had considerable difficulty accepting her MI and its consequences for her health and life activities. She experienced depression for many months and this undermined her motivation to undertake rehabilitation activities.

D: “Most people that I've heard of had a heart attack, Angela, have *died* [emphasis.] I've never known anyone *my age* [emphasis] tae take a heart attack. So there's nobody that I can relate with, no-one that I can speak tae. Ken? ‘What did you do?’ and ‘How did you cope wi' it?’ I don't know anyone my age just took a heart attack.

AJ: Did they suggest anything when you came out?
You said you had the heart manual..

D: You get the six week follow-up and after that all I've had is ma appointments at the hospital. There's no.. groups that you can go tae, or no-one that you can go

and talk tae, apart fae your own GP... I would have liked tae have went tae a group, of people that had been.. You know, I go tae Alcoholics Anonymous. There everybody is the same as me at Alcoholics Anonymous, they've got a bad alcohol problem. Now, we all talk, how we deal wi' our alcohol problem, how our life was before the alcohol.. I would have liked tae have went tae a group. A group o' say people between the ages o'..

AJ: Did they suggest..?

D: Nope. Nothing. Nothing at all."

(Dot: 43; single parent; post-MI non-return to work)

Wider life difficulties such as relationship problems, housing or financial insecurity, family illness, or pre-existing emotional and mental health problems that hadn't been addressed, also could exacerbate the psychological and emotional difficulties people and family members experienced. Moira's case, described in case study three, provides an example. Her experience reflected that of other family members who weren't offered and didn't independently find formal or semi-formal support to address the needs their family and friends couldn't meet. My findings indicated limitations of CR and CHD Groups to provide the intensive support a small number of interviewees appeared to need, and for whom these resources wouldn't be sufficient, feasible or acceptable. Yet for the sizeable number who were open to considering CR and CHD Groups my findings suggest these might have helped alleviate their emotional and mental health difficulties or at least provided support to help them cope. Furthermore, several accounts, including those of Dot and Moira cited above, indicated that such support in the early period might have lessened the duration and severity of their problems. Also, although the severe problems a few people experienced indicated that specialist help was needed, for some at least, access to the counselling and psychology components of CR might have addressed

this need. In Alec's case it appeared that although specialist support was offered via a psychotherapy group and counselling, CHD-specific support was bypassed, leaving certain needs unaddressed.

A: "I went tae one of these, er, oh, was it? Group things.. er, it was.. But I didn't think it was very helpful. And then I got, was getting.. one-tae-ones, like I'm talking tae ye at the moment. Because when I went there most of the people had stress an' things like that, and they were going on about things.. and it was distant fae how I felt... And I just felt ma problem was different fae theirs.. None of them had had heart attacks. It was more, er, they couldn't sleep at night.. stress.. things like that. They were worried about other things.."

(Alec: 53; married; post-MI non-return to work)

Insufficient emotional support was most apparent among female spouses or partners. Yet there were also indications of unmet need in this respect among male relatives. Colleen's husband Norman's description of the shock of her MI suggested that his thwarted attempt to attend a relatives' meeting had been to obtain emotional support as well as practical information.

N: "It was a shock.. a big shock to me when I got a phone call that she had.. she had.. I just thought she'd gone in for.. She'd been in for the test before and it was fine, everything was fine, and she was getting these pills fae the doctor, and I thought just to.. just to calm down and just don't do as much as you're doing, it'll be fine, but, er, it didn't work like that.."

(Norman: Colleen's husband; 67)

His willingness to attend suggested that some male relatives might be interested in support via CR and CHD Groups if invited and it could be fitted around other commitments.

N: “In fact there was a.. there were supposed to be a.. meetings for heart operations.. for the, you know? The husbands and the family.. And I went along to one and it wasn’t on, and I just was told it was cancelled... I went specially for it.. I think it was an hour before.. visiting time.. and.. nothing happened.”

(Norman: Colleen’s husband; 67)

Gayle’s account also indicated unmet intensive emotional needs among male family interviewees. Indeed this was the reason she gave for not wanting her partner to be interviewed. She said Davey had major difficulty accepting her MI and wouldn’t discuss the issue – with the consequence that he couldn’t provide Gayle with the emotional support she needed. Paralleling Gayle’s non-invitation to CHD-specific resources, Davey wasn’t offered formal or semi-formal support.

G: “Davey’s never really spoke about it since the heart attack... Nope. I don’t know if he’s got such a fright that it’s like.. between his mum dying in the June an’ then me in the July, I don’t know if it was just too much, aye. An’ we never really talk about it. I know fae a couple o’ friends an’ that that he was devastated, but its like.. a chapter that’s... I don’t think he wants tae go back tae it, or he doesn’t really speak about it or anything..”

(Gayle: 41; partner; parent; post-MI non-return to work)

'Cognitive' problems

A major issue for a small number of interviewees was the adverse impact upon their rehabilitation and quality of life of difficulties they ascribed to 'brain damage' after they experienced cardiac arrest during their MI. Memory loss was most commonly mentioned and in severe cases rendered people unable to perform basic life functions. Difficulty speaking and understanding speech were also described. The three interviewees had experienced ongoing difficulties many months after their MI, and in two cases these remained considerable, with damaging repercussions for their and their families' mental and emotional health, relationships, and capacity for everyday tasks. These issues hadn't been addressed as part of their health service follow-up, and in only one case was some, albeit insufficient, treatment received and only due to the family member's persistence and use of social contacts in the NHS. The nature and severity of the symptoms described suggests specialist treatment was required. One interviewee and his wife attended CR yet found the 'cognitive' issues weren't addressed. Need for emotional support to help the person and their family member cope with these problems, and information and guidance for the person and their family were equally prominent. The three explicitly said they would have valued support via a CHD Group, while family members indicated openness to whatever support was available.

A common thread between these accounts was difficulty having the problems acknowledged by health professionals. Interviewees suggested that professionals hadn't identified the issues, while the people experiencing the problems hadn't raised the issue – either failing to recognise their problem or fearing they might be disbelieved. If the issues had been raised it was believed that professionals had either regarded them as medically unproblematic or a low priority relative to their cardiac condition. For example, May, Alec's wife, believed her GP hadn't taken her concerns seriously and that hospital staff had overlooked the issue and had concentrated exclusively on Alec's physical condition. She described the substantial and ongoing difficulties she and Alec were experiencing without appropriate support.

M: "Ma brother-in-law.. his brother, says tae me, he says, 'This is the first time I've noticed Davie's slurring

his word a wee bit'. He says, 'He was like an old man at seventy, rather than a man at fifty-three'. I says, 'Do you notice that too?' I says, 'I'm glad you noticed that', I said, '..because I get told that I'm imagining it'. You know? I mean, I've mentioned it tae the doctor and, erm.. 'Cause he's been off balance quite a bit an'.. he slurs his words an'.. He's forgetting things... He's no' getting tae the toilet in time either by the way.. an' I've mentioned that tae the doctor and she's checked him. But he's just went.. phwww! [gesture suggesting decline] downhill.. But with the brain.. I still think wi' him dying for five minutes.. the brain's got tae have suffered from that.. It has. I've no' been wi' him twenty-seven years tae no' know.."

(May: Alec's wife; 57)

Social isolation

Several accounts described how post-MI physical disability could make an interviewee and possibly also the person caring for them socially isolated, adversely affecting their mental and emotional wellbeing and quality of life. The problem could remain unaddressed, firstly if the support offered was inaccessible due to their physical condition, while their family member didn't want or feel able to attend alone; also if professionals didn't identify a person's need, and the people lacked information to independently identify potential support resources. For example, before her latest MI Audrey had maintained independent social activities and had regular contact with people in her locality. However, post-MI mobility difficulties meant she required a wheelchair escort outside the home. Her son worked full-time and couldn't take her out often, and other family members visited infrequently or lived some distance away. Audrey had attended and enjoyed CR but said further support options beyond this hadn't been offered. Her experience contrasted with Jean, another elderly woman who had attended CR but who had been invited to a CHD Group.

A: “Aye, well, Jack is.. As I say, if I didnae have him I’d be.. I’d be gey lost. I would.. because I would never see a soul. I would never see a person.. Aye, he’s.. Well, likes of Stuart [another son].. he phoned last night.. but he’s got his ain family. And Ally, well, he, as I say, I dinnae ken where he is.. I know that he’s doon in England..”

(Audrey: 74; widow; retired)

Practical difficulties in daily life

Interviewees encountered difficulties across a range of aspects of everyday life that could impact negatively upon rehabilitation and readjustment, family life, and their mental, emotional and physical health. These related to financial matters, employment, domestic and carer responsibilities, the home environment, and travel and transport. Some people received support from statutory services, employers, and family and friends that had addressed or eased their problems - entailing practical assistance and / or advice about managing the difficulties. Yet many interviewees had struggled, and in some cases were still struggling to cope without adequate support and experienced further problems as a consequence, such as stress and depression. Although the support required extended beyond the capacities and remit of CHD Groups, accounts indicated that some interviewees would have appreciated advice and support from other people who were coping with similar issues.

A stressful atmosphere after returning to work could exacerbate general readjustment difficulties that a person was trying to cope with. Employers could be unsupportive also by resisting changes to work practices to accommodate the person’s post-MI health. The importance of a job for identity, self-esteem, and income often deterred the person from giving up work, while post-MI status and being middle-aged discouraged them from seeking alternative employment. For example, this combination of reasons meant Colleen felt she had to tolerate the stressful working

conditions created by her unsympathetic manager and accept their refusal to allow time off or flexible hours to attend rehabilitation resources.

C: "I mean, my work is not a problem, what I do.. it's the environment, it's the people that are in charge that are the problem, erm..

AJ: Did you get any advice about.. about that?

C: Well, that was why I was going to go to these stress-management courses, and that was sort of try and see if we could, they could.. I could learn how to handle the stress that would come, but.. I wouldn't.. I couldn't, as I have said to you, gone off through the day to go to these things."

(Colleen: 63; married; employed)

Being unable to reintegrate in an unsupportive working environment could result in redundancy. For example, Ray found himself redundant at fifty from a career that had been pivotal within his life and identity. His family felt unable to help or to cope with the rudderlessness and depression he experienced from feeling unable to rebuild his life. They believed professional support was needed to help him identify a meaningful alternative role suited to his post-MI limitations. However, they also believed peer support, for example at a CHD Group, could be valuable to learn how others adjusted and coped with their changed situation.

R: "I mean, I'm sleeping no problem.. I mean, what I.. what I'm having difficulty with is, erm, I mean, I don't know whether I want to do voluntary work, I don't know.. And I don't feel that.. I've not.. I've not been in a job... I mean, I've been in a highly specialised job

[laughs] Nobody's looking for the skills that I've done..
I've done all these courses, but.. it's like, well..

AJ: Was there any advice, erm, I guess as part of the rehab for people who worked.. finishing work and kind of, like, 'These are places that you can go who might be able to support you when you're looking at other opportunities.'

R: No.. not really.. No, it was just your.. Get the rehab done... Up to you.. Give you a certificate...

T: Sometimes you need perhaps.. somebody who perhaps has advised other people.. And said, 'Look, what if we do this?' And just sort of shunt you down that way so that you're going in some sort of direction.. Whereas like, when you're on your own with it.."

(Ray: 50; redundant post-MI. Teresa: wife; 50s)

Several interviewees described financial problems, which they experienced as a consequence of the MI and detrimentally, affected their rehabilitation. Financial difficulties related to transport costs and the financial imperative of returning to work impeded CR and CHD Group participation for some people. Added to the prospect of salary loss, the perceived inadequacy of state benefits was a key pressure to return, as described in Gordon's case study. Several accounts indicated that inadequate state benefits could also negatively affect rehabilitation by causing stress and possibly contributing to depression. For example, Gayle felt frustrated and guilty that she couldn't return to work and the family income was substantially reduced. This, combined with other difficulties, contributed to her post-MI depression.

G: "That now I couldnae go back to work, nope, nope.
An' it's no' me.. An' I've worked hard all ma days,

an' I think that's what else is frustrating.. is because you've worked hard, an' done different things, an' all of a sudden you've.. you've nae energy... Aye.. even though the money's short.. it's terrible what they gie ye tae live on."

(Gayle: 41; partner; parent; post-MI non-return to work)

Alec described the severe stress he experienced when he couldn't claim state benefit for the first four post-MI months. The Social Security Department wouldn't accept his GP's statement and his GP refused to amend it, meaning Alec's claim was initially rejected and the household income was severely reduced. Although it was subsequently granted Alec remained highly anxious that the annual case review might stop his allowance. He continued to experience panic attacks about the prospect of MI recurrence and this severely curtailed his rehabilitation and ability to perform life activities. Alec and his wife May believed the financial stress had exacerbated this, but at the time had lacked support to deal with their financial problems.

A: "It was putting a lot of stress on me. I mean, I think I could have done without it at the time... I mean, seventeen weeks I was living on handouts... If it wasnae for that, I feel I... Well, it was very stressful, I can assure you... But the thing is I've only got this for a year.. ma DLA, and then I've got tae re-apply again. But, er, I must be honest wi' you, I.. I mean, ma fear is I don't think I could hold a job down at the moment..."

(Alec: 53; married; post-MI non-return to work)

Not receiving information about welfare entitlements was a problem. Audrey, who became disabled after her MI and required substantial support from her son, provides an example. Her case shows that being in contact with health services, and even

attending CR, didn't necessarily mean a person and their family would receive such information.

A: "No.. well, a friend of mine told me I should be getting care allowance. Right, and er.. but I don't know how tae.. I do get mobility allowance, I do.. Well, I still call it mobility allowance, but I believe that the name's changed. But tae me, mobility.. I can remember what that is. And, erm, I do get that. And, erm.. if I didnae get that.. phhhh! [exhales to indicate difficulty].. Ken? Things would be a lot harder.

AJ: So you.. you didn't get, for example, anyone round saying, 'Now that you're not able to do that after this heart attack or whatever.. maybe you'll be entitled to this benefit, or..?'

A: No. Not a soul.. No. But, erm, I do get, as I say.."
(Audrey: 74; widow; retired)

Some family members experienced stress and adverse physical consequences from undertaking additional roles to fill the gap left by their relative's inability to manage former tasks. None had received advice or information about sources of practical or emotional support. For example, May, Alec's wife, described her difficulty coping with his problems additional to undertaking his share of household tasks. This was particularly problematic because of her arthritis, and made her depressed and frustrated. Additionally she felt she had lost the future support she had envisaged for when her own condition would deteriorate and she could no longer look after the household or herself. The prospect that the future support she had hitherto expected had been lost appeared to exacerbate the negative impacts upon her emotional health. Her account suggested that this might also eventually undermine a carer's capacity to support the post-MI person.

M: “Not before, no. No, no, no, no. No way, he was brilliant, he was absolutely fantastic. He was a good worker, an’ he was a great help in the house.. An’ I.. I know him better than anybody [emphasis] an’ he’s no’ the same.. He’s a very selfish man though, an’ he never used tae be...[raised voice] He’s in there all day sleeping! You see, I cannae see him going back tae work. [confiding tone] But.. he does nothing, eh? He.. he’s supposed to be.. Through time he’s gonnae be ma carer.. And I’m afraid he’ll no’ be able to be ma carer, because he’s just, er, he’s useless! I tell him tae dae.. I asked him tae dae the dishes.. an’ about an hour later I’ll say tae him, ‘Alec, dae ye want tae dae the dishes?’ [mimics Alec] ‘Oh aye, that’s right, yeah.. You asked me tae dae the dishes’. I go.. [head in hands] ‘Oh, God’s sake!’ [emphasis]”

(May: Alec’s wife; 57)

Some family members experienced difficulties undertaking an intensive caring role without sufficient support. Accounts indicated that their difficulties might have been mitigated if they and the post-MI person had received condition-related and emotional support from CR and / or a CHD Group, or an alternative resource. Some, like May, weren’t offered formal assistance. Others had declined support because they believed it wasn’t appropriate to their needs and preferences, or had been deterred by a perceived negative issue. For example, Ron and Elspeth, a couple in their eighties, reluctantly acknowledged that Ron couldn’t fully meet Elspeth’s post-MI needs and trying to meet these without further help risked damaging his own health. They described how Elspeth had fallen several times at night and they had waited several hours for family help. Elspeth could only go up and down stairs once daily because of the pain entailed. Ron also spent an hour in the middle of each night helping Elspeth use the bathroom and then settle. Previous negative

experiences meant they distrusted Social Services, and they didn't believe 'personal care' would be provided in a way to respect their autonomy.

E: "Well, we've not had them ever since.. I've never bothered. So, I think this is why Ron says, 'There's no carer coming in'... We'll do it ourselves.. and I've been prepared to pay anybody to do anything like that, but he just says no, he says, erm.. 'You don't know what they're going to be like, and as long as we can work together we'll manage', you know? And he does awfy well.. he does..

R: Mm-hm.."

(Elsbeth: 80; married; retired. Ron; husband; 80s)

Some interviewees experienced post-MI disability and this lessened their ability to manage at home. Some had received advice, information and practical assistance, such as household aids and home care assistance. However, others appeared to have been overlooked and generally weren't capable of proactively seeking such help, leaving them and their family members struggling to cope. For example, Audrey's son Jack, who lived with her and became her carer after her latest MI, wasn't informed about available support to deal with the mobility problems, which made the stairs difficult and dangerous. Without this Audrey continued to put herself at risk, while Jack believed they had to move house, presuming that if help hadn't been offered it wasn't available – again exemplifying low expectations. Despite being Audrey's sole carer Jack hadn't been offered information or advice – possibly because as a young man he didn't fit the carer stereotype. Again he was reticent to proactively seek this.

A: "And as you see, Jack is decorating, because we're gonna be selling, ye see? It's erm.. once we get a house on the flat.. So that I've no' got any stairs... Aye..

phwoo! [exhales for emphasis] Good job I've got banisters, aye..”

(Audrey: 74; widow; retired pre-MI)

Many family members identified travel and transport difficulties when visiting their relative in hospital. This particularly affected non-drivers; people in areas distant from the hospital and with poor public transport; and interviewees, especially women, who worried about solo travel at night. Parking charges were also a problem. Some accounts suggested that family travel difficulties in the early period could contribute to the post-MI person's view of the issue as a barrier to CR or a CHD Group participation. For example, Freda, Matty's wife described these problems, and Matty indicated that unwillingness to further inconvenience his family by requiring them to drive him to CR was an important contributory reason for not attending.

F: “Transport we did.. because from here to Scotsville [main regional hospital] is an absolute nightmare.. a nightmare.. Oh, and the bypass there's never a good time.. to hit that bypass. So, always ma son or ma daughter came with me... And, erm, only twice I think I drove mysel'... Well, one night there was an accident on the bypass and the police took us off it, an' if I'd been on my own, I don't know where I'd have been.. probably north o' England somewhere... And, erm, even the parking in there.. that was about ten pound a day! Ten pound a day, and the travelling was horrendous.. *absolutely horrendous!* [emphasis]

AJ: But at least, I suppose, you had.. partners in crime..

F: Yeah..

(Freda: Matty's wife; early 60s)

Conclusion

This chapter has highlighted a range of difficulties that CR and CHD Group non-participants and their family members experienced during their rehabilitation. These results go beyond previous research by linking non-participation directly to the difficulties people experienced, and showing that often these needs weren't adequately met by wider strategies and resources. Many people considered the two resources complementary to meet different needs or at different stages – an issue not previously identified due to the dearth of comparative CR and CHD Groups research. The general CHD literature supports my findings regarding many of the difficulties, however I have presented evidence of these specifically amongst people known not to have accessed the main formal and semi-formal post-MI rehabilitation support resources.

I have reported how an information deficit had the double negative consequence of making rehabilitation difficult for post-MI people and families while also impeding them from finding sources of help and support. Emotional and psychological problems were widely experienced, including intensive difficulties for some non-participants; while some family members experienced negative emotional and physical effects in the absence of practical support. Financial difficulties, and pressures and problems returning to work were also significant for some people. Several specific difficulties aren't apparent in the general literature on experience of CHD. These included the significance and consequences of 'cognitive' problems; the exacerbating influence that wider life difficulties, particularly insufficient welfare benefits, and pre-existing mental and emotional problems could have on rehabilitation; and the negative psychological impact that loss of a partner's future support could have for family members.

I conclude that for many interviewees CR and CHD Group non-participation represented a 'missed opportunity', not only for the person and their family but also for professionals seeking to promote the rehabilitation and health of people with

CHD. My findings suggest that non-participants and family members were disproportionately affected by gaps and problems regarding wider support from health and other statutory services, which appeared to have made them more vulnerable to rehabilitation difficulties than people who had received support from CR or a CHD Group or found suitable alternatives. Need for improved access to CR and CHD Groups and provision of alternatives for people for whom these are inappropriate are indicated. The general low expectations and reluctance to make demands for support I found among people and their families emphasises the need for health professionals and policymakers to be aware of these issues and improve the offer and provision of appropriate support.

Chapter Nine - Discussion

My study addresses a fundamental gap in understanding non-participation in post-MI support resources and its significance by providing insight into the process by which CR and CHD Group non-use occurs and the impacts upon non-participants and their family members. In this final chapter I draw together the key elements of the study methodology, literature, and analysis to discuss the significance, limitations, and implications of my research. In Section One, I reflect critically upon my methodology and the impact it may have had upon my findings. I focus particularly on my study sample in relation to the wider non-participant population, and consider the status of my findings in relation to the idea of interview accounts as ‘social constructions’. The thesis spans two disciplines - medical sociology and health promotion, and in Section Two I discuss how my research relates to the two areas. Regarding the former, I expand on the main themes and new findings to show how my study adds to understanding of the reasons, process, and experience of non-participation. From my findings in Section Three I then identify a series of recommendations for ways that policy and practice might better support post-MI rehabilitation and CHD secondary prevention. Foremost are proposals for addressing the ‘missed opportunity’ that exists for many, albeit not all, post-MI people and their families, regarding CR and CHD Groups as resources that could potentially improve their rehabilitation and quality of life. However, the need for alternative provision in certain circumstances is also considered. I discuss these in the context of implementation hurdles and how these might be overcome, including further investigation on several issues.

Section One: Critical reflections

Before proceeding to discuss the significance and potential value of my findings, it is necessary to identify limitations and issues on which there is debate regarding the study methodology. My findings and the implications I draw from these can then be considered in this context.

Study sample

A caveat that applies to all research is that findings relate directly only to study participants. In Chapter Five I explained how my design accounted for the possibility that non-participants might be 'harder to reach' in terms of their willingness or ability to take part in the study. My questionnaire response rates were 40.4% in West Lothian and 55.6% in 'Wider Lothian'. Average response-rates for health-related study questionnaires to patients and members of the public (Asch et al, 1997) have been reported as having a mean response of 60% but with a large standard deviation (+/- 21). This suggests that my target group's response rate may actually be similar to many studies and that not all non-participants are 'hard to reach'. However, while the participant profile may reflect the wider population from which they were drawn in some ways, nonetheless it is possible that their characteristics, perspectives and experiences might differ in certain respects.

A strength of my sample is that the vast majority of responders hadn't participated either in CR or a CHD Group, and so reflected the literature that indicates that a substantial proportion of post-MI people do not use one or both of CR and CHD Groups. I consider the wide-ranging age profile of men and women and the inclusion of people of both sexes within each age bracket an asset in terms of interviewee diversity and in representing a broad spectrum of experiences. The literature had suggested that the average age of female responders would likely be older, yet the mean ages of my male and female respondents were similar, while women aged 40-50 years actually outnumbered men. One possible reason for younger women being more willing to respond could be that their experience of MI at a 'young' age was more shocking than for men due to the cultural stereotype of women's lower CHD vulnerability and the older average age of MI among women, and perhaps this inclined them more to discuss their experiences. However, as my analysis shows, I also found 'younger' men and older women could also be profoundly shocked by their MI.

One consideration regarding when to stop recruiting related to the diversity of the sample of male 'significant other' interviewees. Overall, my analysis supported my

decision to examine the four male co-interviewees' data in depth rather than seeking further recruits, in that there were some important differences and contrasts between these men and their supporting post-MI roles. Nonetheless, I noted that the intensive emotional needs some female family members experienced weren't apparent among the men. My findings in Chapter Eight suggest that rather than male 'significant others' not experiencing or not expressing these needs, the absence of such issues possibly related to the small size of this sub-section of my interviewee sample.

My sample of forty-four (twenty-seven post-MI people and seventeen family members) is large compared to most non-participant qualitative studies. This enabled me to create substantial diversity in the interviewee profile, as shown in Tables Four, Five, and Appendix Five, thereby addressing an important weakness of many previous non-participant studies. The diversity is valuable in that it increases the likelihood that my findings reflect the range of themes and issues amongst non-participants and family members more widely. Further quantitative research with a cross-section of non-participants and family members in other areas is recommended to confirm whether my findings reflect the experience of the wider target population in the UK and other countries.

The social construction of research findings

The 'social constructionist' philosophical standpoint considers that while providing insight into the people and issues that are the research focus, 'findings' nonetheless are also the product of the study design, methods, and the researcher's influence. Reflexivity is a process advocated by qualitative researchers whereby investigators 'turn a critical gaze' upon themselves to examine 'how the researcher and intersubjective elements impact on and transform research'. (Finlay, 2003, p. 3). Finlay and others (for example, Seale, 1999) describe reflexivity as a tool that can test, evaluate, and demonstrate the quality of qualitative research. By making explicit their decisions and dilemmas in a 'methodological log' researchers enable public scrutiny of the integrity of the research, providing readers with the context within which the findings have been framed and being 'up front' about factors that may have influenced findings. Considering study methods, data, and analysis from a reflexive stance can also be seen a practical means to check and show that

explanations and interpretations are convincing (Mason, 1996; Finlay, 2003). However, more fundamentally from the perspective of qualitative research, examining interpersonal dynamics and their impact on the findings can open up a further dimension of understanding to analysis, whereby, ‘subjectivity in research is transformed from a problem to an opportunity’ Finlay (2003). In this way it is important to consider the meanings that underlie the construction of the account – not just taking accounts ‘at face value’, but considering how these may reflect and relate to the person’s experiences.

A benefit of interviewing people between eight and fifteen months after their MI is that interviewees could look back on their ‘recovery journey’ and reflect on how their experiences and expectations changed over time. This does mean some interviewees may have viewed and presented issues, and specifically their resource use or non-use inclinations, differently to the way they had after the MI. As Chapter Three describes, a caveat some researchers have raised regarding health resource non-use (for example, Bury, 1991), is that the act of reflecting in an interview and ‘piecing together’ the events or thoughts that led to a particular outcome may present a person’s non-use as a more logical, considered and conscious process than it was. It is possible also that some interviewees might have felt a need to justify their decisions and actions to themselves as well as to me, as interviewer. In my analysis I considered the retrospective nature of interviewees’ reflections on their post-MI experiences in the light of their non-participation. This may have influenced all interviewees to some extent, but my data suggested that the influence was greater among certain interviewee sub-groups, and may be significant in terms of improving post-MI support to people with similar circumstances and beliefs. I discuss this further later regarding the three non-participation categories.

In terms of interviewer-interviewee interaction, in my analysis I identified instances where I believed a shared characteristic between myself and the person, or the approach I took, seemed to have encouraged an interviewee to disclose difficult or sensitive issues that added insight into their experiences. For example, one female interviewee described how the limited information and guidance she had received had impeded resumption of her sex life for some considerable time until she regained

confidence. I reflected that she might have felt comfortable disclosing this to me as a woman, whereas it might not have emerged had the interviewer been male. Some interviewees appeared to assume that I would agree with their views and this seemed to encourage their frank comments about post-MI support from services or family. Alternatively, several interviewees apparently thought I was linked to health services (despite information to the contrary to try to counteract such perceptions). It is possible that this might have constrained their openness, given the widespread deference and reluctance to criticise health professionals and services. Yet arguing against this, and supporting the insights provided by my findings, there are a number of studies that support my finding of low expectations and deference (for example, Caldwell, 2005; McSweeney & Crane, 2001; Mitoff et al, 2005; Dickerson, 1998). While as Chapter Eight shows, interviewees who identified negative aspects commonly also downplayed connotations of criticism.

The ‘social constructionist’ paradigm argues that the researcher inevitably influences findings through their interpretation of accounts. Although Glaser and Strauss’ ‘grounded theory’ emphasises an iterative approach to discovering findings, nonetheless they acknowledged that the researcher fundamentally shapes their findings: ‘The researcher does not approach reality as a *tabula rasa*. [They] must have a perspective that will help them see relevant data and abstract significant categories for [their] scrutiny of the data’ (1967, p.3). Reflexivity is advocated, whereby the ‘value-laden’ researcher reflects on how their own role may shape the study (Guba & Lincoln, 1989), and provides this information for others to evaluate the findings in this context.

I was aware that my health promotion background could influence my interpretation of what people told me about their health and recovery experiences. I found it a challenge when analysing and writing about the data to avoid ‘translating’ interviewees’ words into what might be described as ‘practitioner speak’ – using technical terminology and considering issues in a distanced way; and to avoid according greater weight to issues of importance to practitioners, such as risk factor behaviours. Given my objective of presenting non-participants’ perspectives, my initial recognition of these ‘practitioner’ tendencies enabled me to refocus on what

interviewees themselves presented as important and on using interviewees' own terminology. Significantly also, this highlighted the way that, despite beneficent intentions and a belief they are acting in their clients' interests and possibly even in a client-centred way, health and social care professionals may still not hear what patients identify as important, with the consequence that these issues remain unaddressed. Valuably, this made me consider post-MI support from this perspective, and reinforced my findings of reticence to seek help and low expectations. This suggested that increased patient and family member involvement may enhance the 'fit' of services to people's rehabilitation needs.

In addition to acknowledging the influence I may have had upon interviews, I also sought to test my interpretation of the findings by seeking the opinions of the three study supervisors. Their involvement - from discussions during the planning and data collection stages through to reading transcripts, meant they could give informed critical comment. Additionally, their different areas of expertise: medical sociology, general practice and primary care, and health promotion, provided opportunity to consider my proposed interpretation from various perspectives. Discussions about my suggested themes and sub-themes and analytical thoughts helped me prioritise themes and explore linkages between themes and interviewees. The supervisors' support for my interpretations was reinforced by findings in the limited research literature and the recurrence of themes in accounts across my broad and diverse interviewee sample.

My stance regarding the 'social construction' of research meant that I anticipated that the interview format and process could influence accounts, particularly through interaction between co-interviewees in paired interviews. Reflecting on the context in which the accounts were produced added a further dimension to my data, as my analysis and further discussion in this chapter show. Here I highlight possible ways that the interview process might have influenced my findings. Firstly, all interviews were conducted in English and no interpretation was requested. One couple, who were native Hindi speakers, declined interpretation and said they were comfortable being interviewed in English. However, while the wife was fluent, her husband spoke haltingly and sometimes I had to clarify the meaning of his statements. This

ostensibly suggests interpretation might have helped, yet this would then also have entailed the alternative debate about the extent the views were his or the interpreter's representation of these. Their account presented a strong belief that public services shouldn't be used, except in urgent necessity, to avoid being a 'burden' on the state and maintain an image as 'good' undemanding citizens. Additionally, the dialogue and interaction suggested that the wife considered herself the couple's spokesperson – not only due to her greater fluency but perhaps more because she had assumed a leading role in the relationship since her husband's post-MI disability. These issues suggested that lack of language interpretation might not have been the only or main constraint on his account, but a solo interview might have enabled fuller self-expression. Whereas Shakespeare (1993) suggests a paired interview with a carer may enable a person who might otherwise be silent to be heard, my interview case suggests limitations of this.

I initially had considered that single interviews could offer greater scope for full and frank accounts of interviewees' perceptions and experiences, without the possible constraints of having a partner present. I had thought important issues might be omitted; or that despite holding a contrary view people might say they agreed with their partner, to present a harmonious public image. Contrasting disclosures in single interviews appeared to support this, as did one woman's negative reactions to her partner's 'intrusions' into her solo interview. A further disadvantage that two paired interviews showed was that one partner, albeit unconsciously, could dominate and curtail their spouse's capacity to express their views. This appeared to occur in relationships where one person was used to playing a leading role due to their partner's disability and seemed to view the interview as a natural extension of this. Yet, in all the paired interviews the co-interviewees did express some contrary views, suggesting that for some couples a joint interview wasn't a disadvantage and facilitated debate between partners. For example, for one couple the visual image of togetherness in being seated together on their sofa contrasted with their determinedly opposed views, suggesting that these issues hadn't previously been openly discussed. I reflected that without the constraints of the study timescale and the greater value of analytical depth over breadth, from a methodological perspective it might have been

interesting to 're-run' some single interviews as pairs to see how contradictory or complementary accounts would compare to a paired account.

A further way that research findings are constructed is through the researcher's identification and selection of the issues from the dataset that they consider important, and which thereby are transformed into 'findings'. There may be questions the researcher chooses not to pursue, and themes or issues they consider less important or peripheral to their study (Finlay, 2003). The richness and volume of my data (approximately sixty hours of interviews) inevitably meant I couldn't pursue all potential analytical avenues within the available timescale. As my methodology chapter describes, my approach was pragmatic. Besides drawing on 'grounded theory' and using an inductive approach; the research design, data collection and analysis were also informed by my knowledge of the issues gained from the literature and my own experience. Nonetheless, because a key objective was to reflect my interviewees' perspectives, my analysis prioritised the seeking of emergent themes. The richness of my data means there are possibilities for further potential lines of investigation, for example, side issues such as use of humour; or regarding minor themes that resonate with the literature, such as 'carrying on as normal', which I identified in a few cases but wasn't a major theme. This thesis presents an in-depth examination of the primary themes to emerge from my investigation.

This section has presented my reflections on the process by which my data was constructed. From one perspective these reflections may be seen to provide information that enable the reader to take a critical perspective regarding my findings and be aware of factors that may have influenced the data. Yet, my epistemological standpoint of social constructionism, suggests this to be a limited view of the production of my qualitative interview data. The constructionist view is that social reality is constructed through the understandings and interpretations of individuals when they interact with each other and society. In this way, 'the relationship between man (sic), the producer, and the social world, his product, is and remains a dialectical one. That is man (sic).. and his social world interact with each other. The product acts back on the producer' (Calhoun et al, 2007). Rather than analysis

enabling an insight into ‘the world beyond the story’ as described, for example, by Melia (1997), the constructionist perspective views the story, in this case the interview account, to be intertwined with the person’s social world. Thus the interview account reflects their world and also has a role in constructing their reality. Recognising this can add a further layer of understanding to qualitative analysis.

In the next section I go on to explore the interrelationship between the main themes and categories I outlined in the earlier chapters.

Section Two: The significance and implications of the study findings

Low expectations, reticence, and reluctance to request support

My analysis highlighted widespread low expectations, reticence about requesting support, and reluctance to criticise health services and resources, and described how this influenced some people to ‘suffer in silence’ with rehabilitation difficulties. Beliefs about correct patient conduct and an identity as a ‘good patient’ - perceived as deferring to professional judgement, could also dissuade people who hadn’t been invited, but knew about or had considered the possibility of such resources, from asking if they could attend. Family acceptance of, or unwillingness to challenge non-availability of support could compound this. These themes are supported by a number of qualitative CR studies that reported low expectations of support (Caldwell, 2005; McSweeney & Crane, 2001) and that reluctance to self-advocate may have contributed to some people’s non-participation (Caldwell, 2005; McSweeney & Crane, 2001; Mitoff et al, 2005). My findings regarding low expectations and reticence appear to be new in relation to CHD Group non-participation, the reinforcing influence that family members could have, and the contribution of identity issues. I found non-invitation was the primary factor that denied people the opportunity to attend post-MI resources. Nonetheless, reticence, low support expectations, and a health service culture that was often described as having failed to encourage patient involvement in decisions about their rehabilitation, appeared to have compounded this.

Further dimensions of specific factors

Despite the limitations of the body of previous research I report in Chapter Three, collectively the literature relating to general resource non-use, CR, 'self-help' groups, and CHD Groups, supports my findings regarding the broad range of factors that could influence non-participation. My study enhances understanding by providing clear evidence regarding factors on which previous research had been equivocal or limited in relation to a specific post-MI resource, particularly CHD Groups. Several aspects of factors discouraging CR and CHD Group use that hadn't previously been highlighted were found, while self-reliance was shown to be more significant and complex in this study than previous research had indicated. These findings about the particular factors that influence non-participation reinforced my broader conclusion that non-participation in both resources was complex, multi-factorial, and related to an individual's particular circumstances, beliefs, and identity. As Chapter Three shows, the former two aspects are well represented in the literature. However, I found identity-related issues also underlay many of the specific factors.

Identity

Identity-related issues played a more influential role among interviewees than previous research had indicated regarding post-MI resource non-use. I identified a broader spectrum of aspects of identity as non-participation influences, and found these to be more distinct from the underlying beliefs and practical circumstances that earlier studies concentrate upon, and more significant in the power they could exert. The importance of identity is well-documented regarding people's responses to chronic illness (for example, James & Hockey, 2006; Williams & Bendelow, 1998; Charmaz, 1991) and specifically CHD (for example, Hildingh & Fridlund, 2007; Wheatley, 2006; Goldsmith, 2006). Yet, regarding general health resource non-use and specifically CR and CHD Group non-participation the profile of this aspect of non-participation factors has been low. Regarding post-MI resources the evidence had been largely limited to working and domestic role identities if mentioned at all. In Chapter Six I showed how aspects of identity underlay various factors, ranging for example, from a person's health and lifestyle, to self-reliance, their social life, and role as a citizen, and could be an important contributor to non-participation.

For example, where previous studies suggested a link with poor health they focused on a person's experience of their condition, practical obstacles due to health problems, and beliefs about their condition (Chapter Three). Additionally and related to these aspects, I found health was often also an important part of a person's self-conception, and a powerful influence regarding resource use and non-use. Interviews provided contrasting illustrations of this, as described in Chapter Six, for example: Angus' view of himself as a person with 'spoiled' health due to previous illness, and Jean's view of herself as a 'survivor' of multiple illnesses. The three case studies (Chapter Seven) demonstrate the potency of identity issues. One example is Sheila's identity as the self-reliant family linchpin, which was pivotal in her decision to decline CR twice and her disinclination towards CHD Groups despite her rehabilitation difficulties. My findings suggest that understanding of the reasons for non-participation, people's needs and appropriate ways to provide support, had hitherto been impeded by the limited investigation into this important aspect of post-MI people's lives.

Self-reliance

Self-reliance was more widespread, multi-faceted, and influential regarding my interviewees' non-participation than the literature had suggested. This theme featured to some degree in the majority of accounts, contrasting with the sparse mention relative to the total body of CR studies and the limited emphasis upon the issue. Some general 'self-help' group studies indicated self-reliance could be an important disincentive (Bui et al, 2002; Damen et al, 2000; Levy & Derby, 1992), yet previous CHD Group evidence was sparse and suggested a preference for informal support more strongly than self-reliance (Hildingh & Fridlund, 2001; Fridlund, 1993). Rather than having a single universal meaning, as had been suggested, I found a range of underlying rationales for self-reliance that related to the differing beliefs, circumstances and identity of different interviewees. This was linked in different ways not only to non-use, but also with use of a variety of post-MI resources.

Most previous studies identified self-reliance solely as a deterring issue. I found that self-reliance could also motivate non-participants to use resources that they perceived might aid the regaining and maintenance of their independence. Options that offered greater autonomy could also have considerable appeal to people who might otherwise try to 'go it alone'. The latter finding accords with evaluations of CR trials that identified increased autonomy as a key reason that alternative CR delivery models, that are more self-directed and individually tailored, could increase uptake and adherence (Wingham et al, 2006; Dalal et al, 2004). This suggests the value of considering ways that post-MI support might be designed to work with rather than against the importance of self-reliance in people's lives.

Further insight on specific factors

The literature identifies informal support from family and friends as an important influence upon non-participation both by its presence and absence (for example, Jones et al, 2007; Daly et al, 2002; Hildingh & Fridlund, 2001; Rogers et al, 1999), even if the form the influence takes and the way it operates isn't always clear. I found lack of encouragement to attend by 'significant others' was a compounding factor in the non-participation of a notable number of interviewees, and sometimes had substantial weight regarding their decisions. Some previous research links encouragement with increased participation, and weak social support more generally has been linked to non-use (Jackson et al, 2005; Johnson, 1998; Roberts, 1988). However, specific evidence that lack of encouragement from 'significant others' to attend a post-MI resource could be a powerful influence has been lacking. Additionally, I identified various forms that lack of encouragement to attend could take.

Distinct from encouragement and support to attend, I found that informal information and recommendations from people they knew had encouraged some interviewees to consider attending a post-MI resource. This influence is well-established in general sociological literature on illness experience, and the term 'lay referral' was coined several decades ago (Freidson, 1970), but hadn't previously been highlighted in relation to CR and CHD Groups. This reinforces my wider findings on the importance of the role of 'significant others' in the post-MI period (discussed further

below) and has implications for improving rehabilitation support. Health beliefs are indicated in the general non-use and post-MI non-participation literature as a significant influence (Horne, 2006; Cooper et al, 2002; Daly et al, 2002; Charlton & Barrow, 2001; Wyer et al, 2001). However, the evidence relates primarily to a person's beliefs about their post-MI condition and health. As Chapter Six shows, among my interviewees it appeared that their health biography and beliefs about their pre-MI health could be as influential, and were intertwined with their perceptions of their current health.

Bidirectional influence of factors

Chapter Three describes how previous studies linked a range of factors with non-participation, and a number indicated that non-participation was multi-factorial and complex, involving a range of factors (for example, Daly et al, 2002). However, limitations in the scope and methodology of many investigations meant that the way factors could result in resource non-use was often unclear, inevitably hampering responses to improve post-MI support. My analysis develops understanding of the process by which the various factors could influence non-participation in a number of ways. First, interviewees' accounts indicated not only that non-participation was complex in the range of factors involved, but also showed that with the exception of non-invitation, specific factors could act in opposing directions. Factors could thereby either encourage or discourage resource use, rather than certain issues facilitating and others impeding resource use, or certain issues applying to participants and others to non-participants, as earlier research had suggested. I demonstrate this in Chapter Six and illustrations can be seen in the discussion above regarding self-reliance and informal advice. The way that factors could potentially encourage as well as discourage non-participants about participating appears potentially significant for identifying strategies to enable people to use these resources, as I later discuss.

Three categories of non-participation – the process by which non-participation occurs

My study addresses an important gap in understanding post-MI non-participation by providing insight into the process by which non-use of CR and CHD Groups occurs.

In Chapter Seven I demonstrate the way that differing combinations of factors engendered the non-participation of different individuals. A number of CR studies (Jones et al, 2007; Hagan et al, 2007; Daly et al, 2002) suggest that several factors may combine to engender non-participation. However, their analyses focused on describing specific factors rather than describing or showing how these might combine in individual cases, and the study samples have some limitations. Previous 'self-help' group and CHD Group literature doesn't show how the influencing factors lead to non-use. Without knowing this, strategies to tackle individual factors may be ineffective or redundant.

Tones' 'Health Action Model' (1979) has been influential within health promotion policy and practice (Thompson & Pickering, 2001; MacDonald, 1998; Tones, 1987). This model provides an overview of various psychosocial and environmental factors that contribute to health-related decision-making. Importantly, Tones' model also suggests how the factors interact and relate to individual intentions to act and a person's capacity to put their intention into practice (Tones & Tilford, 2001; Tones 1987). My findings are supported by Tones' more general model in suggesting there was a hierarchy of factors that influenced a post-MI person's intention to act, and that barrier and facilitating factors then influenced whether or not an intention was carried out. My analysis is further supported by a small cluster of general resource non-use studies which found that perceived benefits for health were balanced against wider negative issues (Horne et al, 2006; Campbell et al, 2001; Cooper, 1998). However, my findings specifically relating to post-MI non-participation differ by suggesting that this process was more complex and didn't apply equally to all non-participants, as I now explain. Notwithstanding the diversity of the combinations of factors that could engender non-participation, seen in the three case studies (Chapter Seven), CR and CHD Group non-participation among my twenty-seven post-MI interviewees followed one of the three broad patterns I have identified as 'categories of non-participation'. These were "No need / no point", "Not worth it", or "Not possible".

Category One: “No need” / “no point”

A perception of potential personal benefit was pivotal. Perceptions about benefits were primarily health-related, but for a few people wider benefits could be important. Earlier post-MI non-use research, primarily regarding CR, supports my analysis, indicating that beliefs about health benefit (for example, Mitoff et al, 2005; Cooper, 1998), and the capacity of resources to address their needs (for example, Jones et al, 2007; Cooper et al, 2002; Clark et al, 2002; Hildingh & Fridlund, 2001) could be influential. Previous evidence relating CHD Groups however was weak, so my findings are significant in this respect. My study additionally suggested that perceived benefit could relate to wider considerations beyond health, something not shown in earlier research. Tones’ model (1979) indicates that beliefs, attitudes, and values regarding a health action form a person’s behavioural intention. My findings specifically indicate that a belief about potential personal benefit was foremost regarding whether a person was inclined to use a post-MI resource or not. This wasn’t just one aspect of non-participation that affected some people, as previous post-MI research had suggested, but was an essential prerequisite for participation. Without this interviewees considered there was “no need / no point” to participation.

The retrospective nature of interviewees’ accounts suggests the possibility that people in the first category may have consciously or unconsciously presented their decision or preference as more clear-cut than it had been at the time, based on their subsequent experience of ‘getting by’ without the resource. However, in analysing this data I found their explanations convincing in that they related to particular issues that were part of their early post-MI experience, in which context their judgement that the resource wouldn’t be beneficial made sense. For example, in Chapter Six I report how several factors contributed to Harry’s decision to decline CR and his disinclination towards a CHD Group. These included his own experience that his health and functionality in conducting usual daily tasks was good, his already ‘healthy’ lifestyle, which corresponded to the information he received, and the reinforcing advice he received from a nurse and his doctor who said he didn’t need to attend.

Some previous studies suggested that better promotion of CR benefits might encourage people who would otherwise opt out to consider attending (for example, Wyer et al, 2001; McSweeney & Crane, 2001). My analysis certainly supports the call for increased and improved information to enable people to make informed choices (an important feature of my recommendations). Yet, as Sheila's case study illustrates, overall my data suggested that, at least in their present form, CR and CHD Groups appeared unsuited to the needs, preferences, and circumstances of many of the interviewees in the first category. Hagan et al's CR study (2007) supports this conclusion, to which my study adds more specific information about the reasons, the subset to which it would apply, and the parallel influence regarding CHD Groups.

Category Two: "Not worth it" and Category Three: "Not possible" - similarities and contrasts

In contrast, people in the second and third non-participant categories believed CR and or a CHD Group could potentially have helped address post-MI difficulties and aided rehabilitation. Some previous studies report that some non-participants said they would have wished to attend (for example, Tod et al, 2002; Hildingh et al, 1997). My findings indicate that for such people the resources passed the crucial 'potential personal benefit' test, which opened the way for wider issues, including encouraging factors and barriers and deterrents, then to be considered. This is supported by Tones' 'Health Action Model' (1979) and general non-use research (Jepson et al, 2007), which indicates that positive health action intentions aren't always fulfilled due to barrier factors. My analysis indicated and explained a differentiation among the people who perceived potential benefit, resulting in non-participation categories two and three. Besides developing understanding of what previous researchers (for example, Sullivan-Smith, 1995) identified as the heterogeneous 'non-participant' population, the categories I identified - which distinguish between different sub-groups, offer the possibility of improving the targeting of strategies to enable attendance or improve support in other ways.

A key difference between people in category two ("*Not worth it*") and those in categories one and three was that the non-participants in category two perceived both 'pros and cons' to participating, identifying barriers and deterrents as well as

benefits; whereas category one were disinclined and category three perceived only advantages. People in the second category appeared to undertake the 'weighing up' process described in the general non-use literature (for example, Campbell et al, 2001; Donovan, 1995). However, at least regarding post-MI non-participation, my data indicates that this process wasn't undertaken by non-participants as a whole but only by the sub-set of people in category two. Hagan et al's study (2007) supports this by showing that after returning home from hospital some non-participants re-evaluated whether or not to attend CR. My analysis demonstrates that this applied within a larger more diverse sample, and that 'weighing up' was also undertaken regarding CHD Groups. This finding suggests the importance of identifying potential barriers early on, while people are evaluating whether or not to attend.

Practical barriers appeared to have greater prominence in category two non-participants' accounts, and this suggests that their accounts might have been 'socially constructed' in relation to their equivocal assessment about whether or not to participate. Acknowledgement that non-participation meant they had missed out on the resource's benefits implied that they possibly felt a need to rationalise and legitimate their decision to themselves as well as to the interviewer. Gordon and Aileen's case (Chapter Seven) provides a tangible example, whereby the different themes revealed by Aileen indicated that Gordon may have emphasised the reasons he considered socially acceptable and omitted those he perceived were not or wished to keep private. By suggesting how narrative reconstruction might apply regarding resource non-use my findings add to the body of sociological research (for example, Peel et al, 2005; Williams, 1984) that identifies the significance of this for interpreting and understanding people's health accounts.

Non-opportunity (non-invitation) and practical barriers contributed to the non-participation of interviewees in category two, yet whereas they also perceived certain disadvantages to attending, people in category three did not. This sizeable group of interviewees perceived CR and / or a CHD Group would have aided their recovery but were prevented from using these resources either by not being invited, or one or more of the barrier issues I have outlined in Chapter Six. Again, the retrospective nature of accounts and 'construction' are likely to have influenced these accounts.

Thus, reflecting on their experience of difficulties some people may have reassessed the resources more positively than they had or would have done earlier in their rehabilitation. Some people may also have believed it more acceptable to present a positive opinion regarding resources to the interviewer. Several factors however suggested that the perspectives presented did reflect their stance regarding the resources. I found corroboration for this in accounts between post-MI people and their 'significant other'; the way that people did identify negative aspects of other issues or resources (albeit usually presenting it in a non-critical way); and the link they made between difficulties they had experienced and the potential for the resource to address these.

Additional to the three categories I highlighted the potential for people to reassess their non-participation stance over time due to a change in their circumstances and beliefs, or by removal of a barrier, thereby coming to view a resource as a more positive or viable option. Evidence that post-MI non-participants or other resource non-users might subsequently change their mind and wish they had participated is not reported in the literature, and is potentially significant in terms of identifying how to improve post-MI support. Lack of previous evidence may relate to the fact that few studies explored non-participants' perspectives and even fewer investigated their experiences, thereby not capturing the potential for re-evaluations.

Secondly, many non-participant studies are undertaken in the early post-MI period. Whereas by interviewing people more than six months later my methodology allowed time for reflection based on subsequent rehabilitation experiences and so detected needs that hadn't been met among some people, which could lead them to re-assess the value of the resources. Rehabilitation difficulties are widely reported in general CHD studies (for example, Wiles & Kinmonth, 2001; Thompson et al, 1995), supporting my evidence relating specifically to non-participants having unmet needs. Wiles & Kinmonth also showed that people's early optimism regarding recovery might be confounded. Whereas they found this could de-motivate people from rehabilitation efforts, my findings suggest confounded expectations might also lead people to re-appraise the value of support resources in a more positive way.

The possibility for re-assessment appears particularly significant in relation to the tendency for a one-off, early offer to use CR and CHD Groups (at least among the invited minority). Accounts indicated, and some interviewees explicitly suggested, that this impeded people from attending later if they subsequently reconsidered the option, and was thereby a ‘missed opportunity’ to support their rehabilitation. While non-invitation and lack of information, encouragement and endorsement have been prominently reported as barriers (for example, Beswick et al, 2005; Cortes et al, 2006; Hildingh & Fridlund, 2004; Kurtz, 1990), the issue of timing has received scant attention. A few CR studies suggest that invitation in hospital can be problematic, especially if a family member does not receive information, in that the person may not retain, or may be confused by the information (Smith & Liles, 2007; Gregory et al, 2005). My study suggests the potential value of offering people a ‘further bite of the cherry’ in terms of rehabilitation support by extending invitation beyond the initial period and providing information in a way that would facilitate this. Thompson (2002) supports my further finding that for some people earlier access to CR may also facilitate participation – as demonstrated in Gordon’s case (Chapter Seven).

Lifestyle identity narratives and the three categories of non-participation

In Chapter Six I described the different types of lifestyle narratives given by interviewees, which I termed, ‘hedonists’, ‘reformed hedonists’, ‘healthy livers’, and ‘lapsers’. Each narrative type was represented in each of the three non-participation categories, thereby not suggesting a clear link between a particular lifestyle narrative and any one non-participation category. However, my evidence suggests more generally that among the interviewees in categories one and two for whom lifestyle identity was an important element of their account, their lifestyle identity could be an important contributory influence to their non-participation in CR and / or a CHD Group. I now consider this in the context of the social construction of accounts.

In category one - ‘no need / no point’, there were ‘healthy livers’ and ‘reformed hedonists’, who said that their view of themselves and their beliefs about their lifestyle had encouraged them to believe they could manage successfully without CR

and / or a CHD Group. This may reflect an element of a ‘moral account’, whereby the person was seeking to justify their actions and present ‘positive’ and socially acceptable reasons for non-participation. For example, self-reliance and healthy lifestyle might have been used to counter any connotation that their resource non-use was irresponsible. Yet, the broader beliefs these interviewees expressed regarding their health and their lifestyle as a contributor to health maintenance suggested that many did indeed regard their long-term or newly healthy lifestyle as an informal resource that negated need to use CR or a CHD Group.

This suggests that rather than giving an ‘excuse account’ for why they hadn’t attended these resources, these interviewees’ narratives operated to assert the moral worth of their own positive actions and resist criticism as ‘non-participants’, in a similar way to that described by Throsby regarding obesity (2007.) Throsby’s interviewees drew on several explanatory frameworks to resist criticism of their fatness as being due to moral failure. Among my interviewees there were also ‘hedonists’ who said their lifestyle had deterred them from CR and CHD Groups because they didn’t wish to be pressurised to change. They appeared also to be resisting the cultural pressure to comply with health service recommendations, but in a different way to the ‘healthy livers’. Their lifestyle identity wasn’t presented as the sole or even the leading explanation for their non-participation, yet it could be powerful, particularly when supplemented by other issues that deterred them from using these resources.

As explained earlier in this Chapter, interviewees in category two were notable in that their accounts identified positive reasons for attending additional to the negative factors that had deterred them. While their different lifestyle identities could serve either to encourage or discourage CR or CHD Group participation, generally they appeared more likely to deter. In parallel to people in category one with similar lifestyle identities, the ‘reformed hedonist’, ‘healthy liver’, and ‘lapsed’ accounts used their lifestyle identity openly to justify their non-participation, claiming they were able to restore and maintain their health through their own lifestyle. Yet this was fractured by acknowledgement among ‘lapsed’ and ‘reformed hedonists’ that they would have appreciated further support to keep them “on the straight and narrow”

with healthy behaviours for CHD secondary prevention. In this context the practical barrier issues that were most prominent among interviewees in category two, such as transport and life role responsibilities, appear either to have been more influential upon their non-participation, or to have been seen to ‘excuse’ them from blame for not taking up support opportunities. The ‘hedonist’ (Gordon – case study two) similarly demonstrated the type of ‘excuse account’ described by medical sociologists in relation to health behaviours more generally (Scott and Lyman, 1968; Monaghan, 2006). Although Gordon was open about, and at times even boasted of his hedonistic lifestyle identity, he appeared to wish to refute this as the explanation for his non-participation by exclusively emphasising practical issues. However, his wife’s account suggested this had been an important factor.

Whereas lifestyle identity was raised as an influential factor in the non-participation accounts of and about people in categories one and two, this wasn’t the case among interviewees in category three. These interviewees didn’t report factors that had deterred them from attending, instead they clearly indicated that they would have sought to attend CR and / or a CHD Group if they had been informed / invited / encouraged to attend. Lifestyle identity was as pertinent to these interviewees’ views of their rehabilitation as for those in categories one and two and a range of lifestyle identities were represented with category three. One might thereby suggest that these interviewees might, with similarity to Gordon in category two, have felt it was more socially acceptable to emphasise the barrier to attending rather than risk blame from presenting it as a choice related to their lifestyle identity. Yet there was no evidence in their own or their partners’ accounts to suggest this.

I also identified the possibility for people to ‘shift’ between non-participation categories, coming later in their rehabilitation to view CR or a CHD Group as a more positive or viable option due to a change over time in their circumstances or beliefs, or the removal of a barrier issue. The two interviewee examples suggest that their lifestyle identity may have played a part in their shift, but this was intertwined with wider factors. The accounts suggested that in the early post-MI period both interviewees believed their own approach to lifestyle could aid their recovery and reduced their need for additional rehabilitation support. Their subsequent experience

of difficulties undermined this belief that they could ‘go it alone’. This was the key reason the ‘reformed hedonist’ and ‘healthy liver’ gave for their shift in viewpoint after several months, to recognise the value of these supportive resources even if other issues prevented them attending. It is again possible that these accounts may to some extent reflect moral narrative reconstruction with similarity to ‘healthy livers’ and ‘reformed hedonists’ in category one who justified their non-use of resources in the early period, and to people in category three who ‘excused’ their non-participation due to barrier issues.

Comparisons, contrasts, and the inter-relation between CR and CHD Groups

CR and CHD Groups are the two main resources specifically intended to aid and support post-MI rehabilitation. Yet, despite their shared client group, overall purpose, and common problem of low participation, the shared features and differences and the inter-relation between participation and non-participation in the two resources had apparently not been investigated prior to my study. The limitations of the literature I describe in Chapter Three impede comparison of studies of the individual resources. As two key elements of the support potentially available for post-MI people I considered that it would be valuable to explore non-participation in each resource, as well as the wider context of resource use and non-use, to gain a holistic understanding of needs and support in the post-MI period. Furthermore, the issues identified in the literature suggested that the differences in the type of resource offered by CR and CHD Groups might be pertinent in terms of features that encouraged use of one possibly deterring use of the other; or conversely the factors that engendered non-participation in one might similarly explain non-use of the other.

As Chapter Six demonstrates, the range of factors and the way they could influence use and non-use in each resource were highly similar. The extent that factors cut across the boundary between formal and semi-formal resource use was striking, particularly in that issues one might have expected to relate more to one resource proved equally influential. For example, while the literature suggested that referral and recommendation would be crucial for both, I hadn’t expected this would relate as much to health professionals regarding CHD Groups as for CR. I additionally had

thought employment and domestic roles might be less influential for CHD Groups, which, unlike the standard CR model, don't require attendance for a set block of time of several full or half days over several weeks; and being community based might possibly be more accessible and so easier to fit around daily life. However, in practice people's roles could encourage or discourage use of both resources equally. The similarity of the influencing factors suggests that they relate more to post-MI people's circumstances, beliefs, and identity than to the particular resources. This is supported by the sociological perspectives on non-use of health resources described in Chapter Three (for example, Oakley, 2007; Gannik, 2002; Donovan, 1995), which suggest the centrality of people, their lives and beliefs in health decision-making, rather than resource provision. Besides providing new comparative evidence on the factors that influence CR and CHD Groups, this finding also offers scope for designing measures that could address the issues in both resources simultaneously.

Regarding the inter-relation between the two resources, many interviewees who attended neither perceived value in, and said they would have wished to have had opportunity to attend both - viewing them as complementary. Reinforcing this, I found some CR participants shared this view, perceiving that CHD Groups could have addressed needs that weren't fully met by CR and supported the continuation of rehabilitation activities after CR ended. The view of CR and CHD Groups as complementary and beneficial resources by many non-participant interviewees is a significant finding, particularly in terms of identifying appropriate strategies to address the unmet needs my analysis identifies.

The limited previous CHD Group non-participant research focused solely on non-exercise groups (Hildingh et al, 2001; 2003). Among my interviewees desire to regain fitness and / or maintain physical activity in a safe, tailored environment motivated some non-participants to wish to attend CHD Groups that incorporated exercise. Previous CHD Group participant research supports this finding (Bostock et al, 2007; Gregory et al, 2006a). This reason similarly encouraged some non-participants about attending CR, thereby suggesting that motivation for attending the resources was more similar than the non-participant literature suggests. Additionally, I found a strong relationship between the resources regarding invitation

and information and this was an important factor in CHD Group non-participation. Although not all CR participants received a CHD Group invitation or information, particularly in the 'Wider Lothian' districts, generally CR was the main source by which people could receive an opportunity to attend. Bostock et al's finding (2007) that three quarters of group participants in a national group survey had participated in CR appears to support this, at least regarding Scottish groups. The corollary of this, indicated by my data, was that CR non-invitees were doubly disadvantaged because their CR non-participation meant they also missed the primary opportunity to receive CHD Group information – thereby compounding their exclusion from rehabilitation resources.

Conversely however, and further demonstrating the diversity of needs among people collectively termed 'non-participants', some interviewees considered single rehabilitation resource use preferable. Some of the CR participating interviewees said the programme had met their needs and provided the confidence, advice, and skills that enabled them to continue independently, and so had concluded that a CHD Group was personally unnecessary. This insight is valuable especially given that previous research doesn't indicate whether CR participation was a contributory issue for some people's CHD Group non-participation. Very few questionnaire returns were from people who attended only a CHD Group (Table Two), which, with my finding that CR was the main source for CHD Group information, suggests that people wishing to attend only a CHD Group would likely be a small minority. Nonetheless, one interviewee's case suggested there might be people who wished to attend a CHD Group, but considered CR unsuitable to their needs or circumstances (Appendix Six). This finding, together with the evidence that some CR participants would also have wished to attend a CHD Group if an opportunity had been available, cautions against assuming that people who opted against attending one resource would not be interested in attending the other, or vice-versa.

Rehabilitation setbacks and obstacles among non-participants and family members

To gain insight into why people did not use CR and CHD Groups and their experiences without them I took a broad exploratory perspective. This encompassed

other resources that people had opted to use instead of, or in the absence of CR and CHD Groups. The spectrum of difficulties I describe in Chapter Eight illustrates a key finding - that although non-participants had access to wider resources to some extent - particularly informal support and wider health services, these didn't fully meet their rehabilitation needs. Many interviewees recounted positive aspects of health care, yet accounts highlighted widespread deficiencies in post-MI primary and secondary care support. The collective evidence of previous studies among the wider population (for example, Bethell et al, 2007; Dalal & Evans, 2003; Clark et al, 2002) supports my finding of the wide range of CHD support deficits among interviewees. In the absence of CR and CHD Groups one might assume that primary and secondary care would gain importance as a rehabilitation support. For a few interviewees this was the case, particularly regarding GP support, as Sheila's case illustrates (Chapter Seven). Overall, however participants recounted important limitations in general post-MI health services, not only in their delivery, but more fundamentally in that they didn't fulfil certain important functions necessary to support rehabilitation. This conclusion is supported by wider research (Gregory et al, 2005). My findings suggest people who lack the additional and specialist support of CR and CHD Groups may be particularly vulnerable to difficulties relating to wider system deficits.

Issues requiring specialist support beyond the remit both of CR and CHD Groups and generic post-MI health service follow-up were also found among interviewees. Clinical literature reports cognitive problems following cardiac arrest, yet this isn't reflected in explorations of people's post-MI experiences or non-participation literature. However, quantitative literature specifically on cardiac arrest does suggest that cognitive symptoms may often go unrecognised and that knowledge about rehabilitation treatment for cardiac arrest survivors is underdeveloped (Moulaert et al, 2007). This may be linked to my finding that these issues weren't addressed as part of interviewees' health service follow-up. The nature, and in some cases the extent of the problems suggest that specialist treatment was required, while one CR attendee's experience suggested cognitive support wasn't available at, or on referral from CR (Chapter Eight). Nonetheless, my findings suggest that even if specialist treatment was available, people dealing with such issues may also value a CHD

Group for emotional support and advice. This reinforces the importance of providing people and family members with information about the range of support available.

Several cases suggested that some people had required but not received specialist vocational rehabilitation support. Those unable to return to work described the negative impacts this could have upon emotional and psychological health, quality of life, family relationships and finances; while some who managed to return struggled to cope, experienced adverse physical effects, and their rehabilitation stalled (Chapters Seven & Eight). Literature on experience of chronic illness and CHD reports similar difficulties and identifies need for vocational rehabilitation support (for example, Alaszewski et al, 2007; Gregory et al, 2005). My findings show these issues specifically among CR and CHD Group non-participants. With similarity to cognitive problems, it appeared that besides specialist help with the specific problem, these people still needed and wanted broader rehabilitation support, their cases emphasising the importance of opportunity to attend CR and CHD Groups.

My study provides evidence that non-participation was considered a 'missed opportunity' by some family members. Firstly, as Chapter Eight demonstrates, non-use of CR and CHD Groups meant some post-MI interviewees struggled to cope with prolonged or unresolved rehabilitation difficulties. This inevitably impacted negatively on their family, intensifying the challenges of post-MI support and possibly adversely affecting relationships, family life, and the emotional, mental, and physical health of the person providing the informal support. Additionally, CR and CHD Groups might have provided support directly to family members to help them manage, be effective, and cope with their role. These needs, particularly advice and information, emotional support, and signposting to wider sources of help, were generally poorly met by other resources. General CHD studies (Tapp, 2004; Svedlund & Axelsson, 2000; Thompson et al, 1995) and broader policy documents (House of Commons Work and Pensions Committee, 2008) identify similar needs. The important difference is that my study directly links these to CR and CHD Group non-participation. My findings indicate that alternative support is needed for some post-MI people for whom CR or CHD Groups are not appropriate. This suggests that some of their family members might opt not to use these resources without their

relative, or due to similar deterring factors, and that access to CHD-specific alternatives, and / or signposting to generic support could be beneficial.

The added perspectives of family members / 'significant others'

Given the limitations of previous investigation into CR, and particularly CHD Groups, from the standpoint of non-participants themselves, it is unsurprising that their family members' perspectives and experiences have been neglected. The seventeen 'significant other' accounts provide new insights regarding non-participation and concur with wider sociological studies, which identify the value of exploring multiple perspectives as a tool for deepening understanding of health-related behaviour (for example, Ribbens-McCarthy et al, 2003). My analysis chapters demonstrate the added value of this further perspective: reinforcing evidence provided by non-participants, and / or adding new and alternative perspectives on the reasons for non-participation and its impacts.

Gordon and Aileen's case study (Chapter Seven) exemplifies both the former and latter. Aileen's account confirmed the significance of the practical barriers Gordon cited as having impeded his CR participation and agreed that the service had failed to accommodate his needs and circumstances - demonstrating these weren't just Gordon's 'narrative reconstruction' to justify non-attendance. Nonetheless, Aileen identified further barriers related to his beliefs and identity, and suggested these were potentially more powerful, albeit issues he was reluctant to disclose – a point corroborated by their absence from Gordon's account. Besides adding new data and providing a revealing 'back stage' insight (Goffman, 1959) or 'private account' (Cornwell, 1984); this information also suggested that Gordon may have constructed his account to emphasise the reasons he considered socially acceptable and omitted those he perceived were not or wished to keep private.

Additionally, the 'significant other' accounts illustrate the differing nature and extent of their own role and experiences of the post-MI person's rehabilitation without support from CR and / or a CHD Group - a situation hitherto uninvestigated. These aspects are important in terms of a more detailed and broader understanding of the rehabilitation experience; and from a health promotion perspective to identify ways

to support family members and enhance their capacity to aid the post-MI people, and the limitations of family support and areas on which formal and semi-formal assistance is needed. My Methodology Chapter describes how the pilot interviews showed that these issues would, at best, only be briefly glimpsed through post-MI people's accounts, and so frustratingly lacked the detail needed to understand them. This encouraged me to alter the study design to include 'significant others'.

The accounts of two daughters, a son, and a friend demonstrated the important role non-partner 'significant others' may play in supporting rehabilitation, and the different experiences, perceptions, and impacts this may entail compared to partners - something rarely shown in the wider CHD literature and a new perspective regarding non-participation. One post-MI man selected a non-family member co-interviewee. Although only one account, this interview highlighted the contribution that non-family 'significant others' may make to post-MI rehabilitation. The man considered that his friend's emotional and motivational support had been a crucial recovery aid, which he had lacked at home due to his wife's alcoholism. This case also warns against assuming that people who live with a partner / family necessarily receive the support they need. This supplements my broader findings and the literature (for example, Tapp, 2004; Van Horn et al, 2002; Svedlund & Axelsson, 2000) in highlighting reasons why family support may be unavailable and emphasising the importance of providing accessible and appropriate formal and semi-formal support. A further assumption staff might make regarding a person's informal support was suggested by the contrasting experiences of the two daughters and the son. The son believed that being a younger male might have contributed to his role as his mother's sole carer being overlooked and explained why he hadn't received information or advice either before or after his mother's hospital discharge (Chapter Eight). In contrast the women received some information and advice, and in one case GP support was particularly important in helping the daughter manage her role of supporting her mother (Case One, Chapter Seven).

Section Three: How can post-MI support be improved?

Recommendations for policy and practice

In this section I make recommendations for ways to develop and improve the support available to help post-MI people rehabilitate and successfully undertake secondary prevention measures. Specific strategies were suggested by the particular issues and unmet needs my analysis identified. However, an important broader point raised by my finding of widespread low expectations and reluctance to request support is that it is essential for health professionals to proactively identify problematic issues and devise strategies to address unmet post-MI needs, because these may otherwise remain hidden and unaddressed. I recommend a range of measures to improve the effectiveness of post-MI support by strengthening or modifying existing resources and practices, and developments needed to address gaps in the system. Yet, beyond these specific improvements, I propose certain actions intended to create a more integrated support system that would be more comprehensive, flexible, and responsive to people's needs than the currently fragmented services and resources. I show how previous studies support my recommendations. The proposals are summarised in Tables Six (policy and practice) and Seven (research). I explain some specific points and discuss the broad implications for policy, practice, and research. Consideration is given to the challenge of implementation in the 'real world' context of opportunities and constraints regarding the health system and wider resources, with particular reference to the UK.

Table Six: Summary of Recommendations for Policy and Practice

<i>Enabling and supporting CR and CHD Group use</i>	
<p><i>Invitation, information</i></p> <p><i>Endorsement, encouragement</i></p>	<ul style="list-style-type: none"> - Universal invitation & information; In-patient, post-discharge, & ‘follow-up’ e.g. 3 and 6 months; various formats to cater for range of needs. - Discussion of perceptions & barriers in hospital & early post-discharge. - All primary / secondary care staff giving strong endorsement & encouragement at ‘follow-up’; Family members informed and encouraged to support attendance.
<i>Availability</i>	<ul style="list-style-type: none"> - Extended ‘window of opportunity’ for attending - early period promoted as optimal, but later & re-attendance possible. - Earlier CR start possible (if participation otherwise impeded). - CHD Group attendance possible from outset whether / not attending CR; Availability / value at different stages promoted.
<i>Format</i>	<ul style="list-style-type: none"> - ‘Menu-based’ CR with guidance to select module options. - Non-exercise & adapted exercise (disability) options.
<i>Focus</i>	<ul style="list-style-type: none"> - CR & CHD Groups developed & promoted as holistic, multi-faceted rehabilitation resources; Complementary use promoted - to draw on different emphasis / strengths of each.
<i>Access</i>	<ul style="list-style-type: none"> - Flexible scheduling: CR - evening / weekend / instalment options; CHD Group - start time / day to encourage working people’s attendance; ‘as and when’ possibility promoted.

	<ul style="list-style-type: none"> - Transport assistance: CR – service transport / private subsidy available; CHD Group - car / taxi share & lift scheme.
<i>General support</i>	<ul style="list-style-type: none"> - Employers encouraged to extend paid leave for CR participation. - CR Attendance Benefit subsidy available to people without ‘sick pay’. - People with financial problems referred to specialist support.
<i>Alternative modes of rehabilitation support</i>	
	<ul style="list-style-type: none"> - Needs assessment (including ‘lifeworld’ aspects) & tailored referral - Local pilots of evaluated alternative models - Research & Trials with identified key groups - people who identify / perceive different needs to those catered by CR / CHD Groups; prefer alternative formats; circumstances require alternative provision.
<i>Developing the wider post-MI support system</i>	
<i>Creating a more integrated support system</i>	<ul style="list-style-type: none"> - Foster a ‘one goal’ partnership culture between different resource providers; Enable cross referral between resources. - Improve communication between different parts of health system. - Service-user information about all resource options – a ‘support map’.
<i>Information and guidance</i>	<ul style="list-style-type: none"> - Universal; Various formats; In-patient, pre-discharge, early post-discharge, medium & longer-term; Topics: condition; treatment; rehabilitation; support resources.
<i>Treatment and support</i>	<ul style="list-style-type: none"> - Active involvement of person & family member.

<i>planning</i>	- Information & encouragement for elective options; Schedule of set 'follow-up'; Designated advice contact person.
<i>'Check-up' monitoring and advice</i>	- Universal scheduled secondary & primary care consultations; Automatic appointment system; Audit of delivery.
<i>Motivational support</i>	- Integral element of all 'follow-up' consultations; Key element of later rehabilitation 'follow-up' visit; Service delivery priority; Staff training.
<i>Professional development and support</i>	- CHD-specific training for non-cardiac staff; Elective specialist skills training e.g. motivational support; care planning involvement.
<i>Culture of active service-user involvement</i>	- Staff training; Service quality standard; Service-users explicitly encouraged & supported to identify difficulties to enable resolution.
<i>Referral to specialist health support</i>	- For example: counselling; cognitive treatment.
<i>Referral & 'signposting' to wider support</i>	- For example: Social Services; 'Citizens Advice Bureau'; Vocational support & re-training; Carer organisations.
<i>Family members support</i>	- Involvement as 'partner' in post-MI support; Information and guidance (condition, treatment, readjustment); advice contact person; Information / referral to wider support organisations. - Opportunity to attend CR & CHD Groups / alternatives; Access to counselling.

Table Seven: Summary of Recommendations for Further Research

<p><i>Research to develop effectiveness of support</i></p>	<ul style="list-style-type: none"> - Quantitative research based on this study’s findings with non-participants and family members in other regions / countries. - Alternative support – research to identify different key groups’ needs; local pilots of existing models. - Pilot of extended ‘window of opportunity’ for CR participation. - Comparative trial of different modes of family member support.
<p><i>Research to aid implementation of policy & practice recommendations</i></p>	<ul style="list-style-type: none"> - Policymakers’ & practitioners’ perspectives on reasons for non-referral to CR / CHD Groups in the study area. - Policymakers’ & practitioners’ perspectives on how to surmount barriers to implementing reforms. - Pilot intervention of supported reform implementation in one area.

Harnessing the potential of existing resources – an efficient and effective strategy

Previous studies have identified important benefits of CR (for example, Clark et al, 2005; Jolliffe et al, 2001) and CHD Groups (Bostock et al, 2007; Gregory et al, 2006b) among participants. Non-participant research identified that many people don’t attend and based on the evidence of participant benefits suggested that non-attenders were thereby missing out (Cooper et al, 2002; Hildingh & Fridlund, 2001). My study demonstrates a direct link between non-participation and rehabilitation difficulties and shows that many interviewees themselves considered the resources potentially beneficial. In this way, for many interviewees non-use represented a

‘missed opportunity’ to aid rehabilitation, assist secondary prevention, and support families. My findings suggest the measures outlined above could address or at least alleviate many of the difficulties interviewees experienced. These recommendations primarily relate to ways that the existing post-MI rehabilitation resources of CR, CHD Groups, and primary and secondary care could better meet the needs of post-MI people and their families. Broadly these entail: improving availability and access to existing resources; modifying resource delivery to address identified problems, increasing flexibility of provision; and developing the integration of the different resources into a more cohesive system. Additionally identified is the need to develop and integrate alternatives within the system to cater for people whose needs and / or ‘lifeworlds’ do not ‘fit’ with CR and CHD Groups.

Promotion

My analysis is supported by previous research (for example, Cooper et al, 2005; Clark et al, 2004; Hildingh & Fridlund, 2001; Damen et al, 2000) in finding that negative perceptions about the nature, functions, and potential benefits of CR and CHD Groups could discourage people from participating. Besides the recommendations for improving information and encouragement given above, my findings specifically suggest that developing and promoting the full range of functions and benefits of each resource both to professionals and potential users is important. The power of lifestyle identity, especially among people who apparently viewed themselves as ‘healthy livers’ and ‘reformed hedonists’, suggests the need to emphasise the breadth of support available via CR and CHD Groups. A narrow conception of the resources contributed to people who didn’t feel they needed lifestyle support to discount them altogether. Previous research supports the recommendation for measures to counter the common impression that CR is solely exercise and lifestyle focused, and to endorse it as a service that also addresses wider needs and provides support (Paquet et al, 2004; Clark et al, 2004; Bergman & Bertero, 2003); and to promote CHD Groups as multi-faceted - offering exercise, information and advice as well as informal support (Bostock et al, 2007). A widespread limited view of both CR and CHD Groups as short-term resources only for the early post-MI rehabilitation period was also apparent. Yet I found that some people who initially felt able and preferred to manage without these might later, after

experiencing problems, reconsider their value. Promoting these resources from the outset as aids for long-term health maintenance might help persuade some people to consider using them in the early period or in future if they perceived need. CHD Groups are designed and set up to provide medium and longer term support as well as reassurance in the early period, yet this message doesn't currently appear to be reaching post-MI people and health professionals.

Chapter Six demonstrates how the factors that influenced whether or not people used CR and CHD Groups could operate in opposing directions – either to encourage or discourage participation. Interviewees who were unable, or decided not to attend for other reasons (non-participation categories two and three), also perceived advantages. Promoting and emphasising these aspects of the resources could potentially encourage participation. Self-reliance provides a prominent example, whereby restoring and maintaining this aspect of identity and their values could be a strong incentive; while people who valued self-reliance were more inclined to consider options that allowed them to feel they retained some autonomy, something previous research supports (for example, Wingham et al, 2006). Developing and making people aware of these may bolster the incentive to attend, and mitigate concerns based on negative images of attenders as needy and dependent. Nonetheless, as the breadth of my recommendations indicates, promotion is only one of a range of actions needed to enable better use of these resources.

A wider 'window of opportunity'

Extending invitation beyond the initial period and providing information in a way that would enable this could be valuable - offering people who are initially unable or disinclined to attend, or decide against using the resource to subsequently reconsider and take advantage of this rehabilitation support. Attending community-based CHD Groups is theoretically not a time-limited opportunity. In practice however, because invitation was only made, if at all in the early period, people who opted not to attend at that time might have forgotten about it, or have the impression that it was only for people who had recently had their MI. Limited information could also mean people weren't aware of the potential value of this resource in the later period or to address

the particular issues they were experiencing. People who were initially discouraged by aspects of their identity, for example self-reliance or their conception of their lifestyle, could be persuaded by persistent problems to reconsider the value of support. Phase III CR is traditionally only offered in the early rehabilitation period, and invitation is generally ‘one-off’ unless the person has further MI or CABG surgery. I found that after some months some non-participants may reconsider and be more inclined to use the resource – something previous research hasn’t shown. Accounts also showed that being able to re-attend after a later relapse was highly valued by attenders. This suggests that an extended ‘window of opportunity’ for CR participation could enable people who would otherwise not use the resource to participate.

Additionally, it appears that enabling earlier attendance among people who for some reason cannot or are reluctant to participate at the standard timescale could facilitate use. Gordon’s case study (Chapter Seven) provided an example. Thompson (2002) supports this as part of encouraging greater flexibility more generally. Enabling earlier or later participation would appear to increase access to the substantial benefits shown to be associated with CR (Chapter Two). Nonetheless, because the existing evidence relates to the standard programme run in the early period, research should also be undertaken to compare the effectiveness of earlier / later attendance. Meanwhile the standard timescale could be recommended as optimal, but with more flexible attendance possible and promoted to people unable to participate earlier.

Alternatives

My findings indicate that even with the implementation of the range of measures outlined above, CR and CHD Groups still fundamentally would not fit the perceived needs and ‘lifeworld’ perspective of some post-MI people – the sub-group I identified as non-participation category one and some people in category two. In particular issues relating to aspects of their identity such as lifestyle and self-reliance could mean they didn’t view CR and / or CHD Groups as offering the kinds of help they needed or wanted. Yet these people had unmet needs, and although addressing the gaps in primary and secondary care will address some issues, others required

more specific rehabilitation support, suggesting that alternative ways to meet these should be devised. There may also be people in the second and third categories whose barrier issues cannot be surmounted notwithstanding the above measures. The CR literature supports development of alternative modes of meeting rehabilitation needs (for example, Jolly et al, 2008; Bethell et al, 2007), while some trials of new models of CR, such as home-based schemes, have received positive evaluations (for example, Jolly et al, 2008; Dalal et al, 2003). Drawing on and building from this existing work and testing such schemes locally would appear valuable. However, my findings suggest that some people might feel an adapted CR model would be inappropriate to their 'lifeworld' priorities, circumstances or outlook. My study adds new evidence that for most of the interviewees in category one who were deterred from CR, CHD Groups weren't perceived to provide a suitable alternative. Appendix Six and Sheila's case (Chapter Seven) illustrate this. Further research to identify the basis from which to design alternative support interventions, tailored to the needs, preferences, and 'lifeworld'-views of people in this group, is essential. Developing a more sophisticated process of assessing people's needs, taking account of wider 'lifeworld' issues, and referral to appropriate support is then needed to ensure the support reaches the target group.

Creating a more integrated system of post-MI support

My findings are supported by previous research in identifying poor connections between different elements of post-MI support as a problem. A sizeable number of interviewees overall considered that both CR and a CHD Group might have benefited their recovery, but many were thwarted through lack of invitation and information. All had been in contact with hospital staff as inpatients, many also as outpatients; all had contact with at least one member of primary care staff in the early post-discharge period and some months later. Some received a home visit from a cardiac-trained nurse; while CR attenders also received input from programme staff. Despite this, referral to CR and CHD Groups was in many cases poor. Additionally, poor communication between primary and secondary care could impede referral for follow-up and cause people to 'slip through the net', causing problems to worsen or remain untreated. Previous European and North American research supports these findings in relation to CR and wider health services, pointing to a fragmented system

(for example, O'Driscoll et al, 2007; Scott et al, 2004; Henriksen et al, 2003; Clark et al, 2002). CHD Group research identifies non-referral from hospital staff as a participation obstacle (Bostock et al, 2007; Hildingh et al, 1995). I additionally found that although CR was the primary source of CHD Group referral, not all CR participants received information. Identification and referral of family members experiencing difficulties to support resources within or outwith the health service were also rare. On the other hand, the role of family members as an important post-MI support resource generally didn't appear to have been acknowledged by service-providers, while opportunities to be involved in planning support from formal and semi-formal resources seemed to have been scant.

Most interviews included examples that indicated that connections between different post-MI support resources were weak - both within the health system and between health services and community resources and patients' families. Table Six outlines various practical measures to improve inter-provider communication and referral, and information to empower informed decision-making by making post-MI people and family members aware of the full range of support options. This would include identification of people requiring alternatives to CR and CHD Groups and referring them to resources more appropriate to their needs and outlook rather than leaving them 'to their own devices' without support. These measures are supported by previous studies (for example, Henriksen et al, 2003; Thompson, 2002; Clark et al, 2002). However, I suggest that for these to be effective initiatives also need to be undertaken to foster a greater partnership culture between the various stakeholders, and a sense of working towards a shared goal. The studies cited above support this, although focus on health services and service-users. My findings are backed by previous CHD Group research (Hildingh et al, 2000) in identifying the importance of acknowledging and integrating CHD Groups within the post-MI support network. I found that wider community resources, such as leisure centres, could be important for some people; while there was unmet need for 'signposting' and referral to non-health service organisations, such as carers support and social services.

My recommendation therefore is that partnership development work should encompass the various formal, semi-formal and informal resource providers,

encouraging them to view themselves as part of a broader post-MI support system rather than a series of weakly associated separate resources. Berwick & Nolan (1995, cited by the Ontario Medical Association, 1997, p. 1) suggested that system integration could be a means to improve service users' experiences, '...the test of the presence or absence of integration lies in the experience of the people served by a system. To us, a system is "integrated" if the people it serves experience it as a responsive whole'. While recognising that different support providers may have different agendas and different methods, the shared goal of helping people rehabilitate and manage their CHD would appear an essential reason for greater co-operation and co-ordination.

Barriers and opportunities

The fact that the recommendations are primarily grounded in the different forms of existing support is significant in relation to the feasibility of implementing the suggested improvements and developments. My own experience of working in the NHS and community-based health promotion means that my approach is pragmatic, based on the premise that for measures to be implemented and effective they need to account for the 'real world' context of opportunities and constraints. Addressing these issues and developing the capacity of these resources in the ways summarised above would seem a logical priority in terms of identifying an effective and efficient way to improve post-MI support.

My study adds important evidence to bolster the case for implementing these measures, enhancing understanding of how and why non-participation occurs – thereby clearly identifying the issues that require to be addressed, and demonstrating unmet needs among non-participants and their families. It is hoped that these added insights will encourage consideration of these measures and dissemination of my findings will be undertaken to encourage this. Nonetheless, it is true that although the comprehensiveness and the span of the resources involved in my recommendations appears new, many individual measures echo those identified by earlier studies that critically examined CR or investigated post-MI non-participation. This is positive in that this strengthens the rationale for implementation, but negative

in suggesting that there are barriers which first need to be surmounted if post-MI support is to improve.

As Chapter Two reports, the literature suggests that within the UK CR hasn't had high priority in health policy, leading to under-resourcing and limiting service development, and calls to address this have recently been gathering pace (British Heart Foundation, 2007; Bethell et al, 2007; Healthcare Commission, 2005). CHD Group research that identifies the benefits of participation also advocates that group development receives further support (Bostock et al, 2007), reinforcing the recommendation in cardiac rehabilitation guidelines (SIGN 57, 2002). The difficulty of resourcing competing health priorities within the NHS is well documented (Kings Fund, 2006; Mossialos & McKee, 2003), while voluntary organisations that support CHD Groups also have a range of concerns claiming upon their attention and funds (for example, Chest, Heart and Stroke Scotland, 2008; British Heart Foundation, 2008).

While this may be an important contributory factor, there are indications that other significant issues require to be tackled. Many of the recommendations are not resource intensive but require impetus and leadership to change protocols, ways of working, and mindsets among resource providers (Clark et al, 2002; Thompson et al, 2002). Moreover, health-related 'self-help' groups (Hedrick, 1993) and specifically CHD Groups (Gregory et al, 2006a) have been found to require relatively few resources compared to health service budgets, and so developing and optimising their role could be a cost-effective measure. It has been suggested that addressing the low awareness and negative attitudes among health service providers and policymakers towards these independent groups is the key challenge (Bostock et al, 2007; Hildingh et al, 2000). The current fragmentation and lack of co-ordination reported above might in itself impede implementation of reforms and efforts to create a more integrated system unless there is a significant external impetus and / or support to undertake this.

Recent UK policy developments potentially offer some scope for addressing these issues. Increased emphasis is being placed upon rehabilitation (Scottish

Government, 2007), condition self-management (Scottish Government, 2007; Department of Health, 2005), supporting the role of family members and carers (House of Commons Work and Pensions Committee, 2008; Scottish Government, 2007), and developing the role of voluntary and community organisations as part of the spectrum of health resources (Scottish Government, 2007). Additionally CHD and secondary prevention remain among the top policy priorities (Scottish Government, 2007). My study adds to previous evidence that suggests that enhancing the existing CHD rehabilitation support resources could be an effective and feasible way to put these goals into practice. Additionally, and to aid this process, my recommendations include a proposal for further research to investigate how to overcome the barriers to implementing reforms. A pilot intervention to support the implementation of reforms in one geographical area, and evaluating the process and outcomes to then use to develop a wider strategy for rolling out reforms could also prove valuable.

Conclusion

When I embarked on this PhD I was seeking to understand what kind of support people who had had MI needed and preferred, in the context of the questions that my own previous experience of witnessing post-MI resource non-participation had raised. The findings I have presented in the analysis and discussion chapters of this thesis, and also the process of gathering the data through interviewing people about their own or their family members' rehabilitation experience, have enhanced my own understanding, but moreover add to the research literature and develop knowledge of the issues. New insights of particular significance are the way the factors that influence non-participation may operate, the process by which they combine and inter-act to engender non-use, and the inter-relation between the two key formal / semi-formal rehabilitation resources. The study provides new insight into the way people's 'lifeworld' perspectives, particularly different aspects of their identity, play an important role in relation to post-MI non-participation. The value of including the perspectives of 'significant others' in investigating non-participation is a further development.

The findings address the important but hitherto neglected question of how non-participants manage in the absence of CR and CHD Groups. Even non-participants who felt they had recovered well had needs that hadn't been addressed and might have been aided in their recovery through support resources of some kind, while many other non-participants experienced considerable difficulties. This provides a strong rationale for implementing the recommendations I have proposed. There are barriers to overcome in this respect but also opportunities. Dissemination to share the findings with policy makers, practitioners, resource providers, and supporting organisations working in the area of CHD and post-MI care and support is the next step.

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Appendix 1 - Screening Questionnaire

Managing coronary heart disease following a 'heart attack': patient experiences and resources of support QUESTIONNAIRE

Please read the letter and Information Sheets enclosed with this questionnaire before completing the questions below. This questionnaire is confidential and should take only approximately 5 minutes to complete. The last section is optional. When you have completed the questionnaire please return it in the enclosed pre-paid envelope (along with the completed Consent form if you are interested in participating in the interview stage of the study).

Please tick the boxes which apply or give a written answer in the dotted gaps

- Male Female Age
- Which area of Lothian do you live in?.....
- Postcode (this is used only so we can compare area responses)

Cardiac and general Health

- Before your 'heart attack' had you been diagnosed with: a. Angina: Yes No
- b. Hypertension: Yes No
- Did you have any surgery for heart problems before your 'heart attack'? Yes No
- Do you have any other long-term chronic conditions (for example diabetes, arthritis, asthma)?
Please state which condition/s

After your discharge from hospital

- Were you given the 'Heart Manual' ? Yes No Don't know
- Were you visited at home by a Cardiac Nurse or Health Visitor? Yes No
- Did you attend a 'Cardiac Rehabilitation' programme or any rehabilitation sessions **after** being discharged from hospital?

Yes No

- Did you receive information about any other rehabilitation groups / activities / resources available in your area?

Yes No

- Have you ever attended a community-based Cardiac Self-Help / Support Group?

Yes No

Thank you for taking the time to complete the questions. As explained in the Information Sheet, a selected number of patients will be interviewed about their experiences and views of managing their condition following their heart attack (representing for example a range of different age groups and areas). Interpretation will be available on request. If you are willing to be contacted to be invited to be interviewed please give your contact details below. These details will be separated from your questionnaire responses and kept confidential, and you will be under no obligation to participate if you are contacted.

Name

I am willing for the researcher to contact me to invite me to be interviewed for the Research Study.

I also enclose the two signed 'Consent' forms.

Appendix 2 – Participant Invitation Letter

Study invitation letter (original study design)



RESEARCH UNIT IN HEALTH, BEHAVIOUR AND CHANGE
School of Clinical Sciences and Community Health
University of Edinburgh Medical School
Teviot Place
Edinburgh
EH8 9AG

‘Managing coronary heart disease following a ‘heart attack’: patient experiences and resources of support’

RESEARCH PARTICIPATION INVITATION

Dear

I am writing to ask for your assistance with a research project being undertaken with people in Lothian who have had a ‘heart attack’ (M.I / myocardial infarction).

A research study is being undertaken to improve understanding about how people who have had a ‘heart attack’ manage their condition within their everyday lives, particularly relating to different types of support; and use or non-use of rehabilitation services and resources. This information can help service planners and health professionals identify how best to meet the needs of cardiac patients.

The study is being undertaken as a PhD within the Research Unit in Health, Behaviour and Change at the University of Edinburgh.

All Lothian residents discharged from hospital after a ‘heart attack’ in the period July-December 2005 are being contacted to request their participation. Hospital discharge records were used by NHS staff to identify potential participants, and these patients’ GPs were asked to forward the questionnaire to eligible patients.

An information sheet giving more details about the study is enclosed with this letter. It would be much appreciated if you would complete and return the brief enclosed questionnaire in the pre-paid envelope. If you are willing to be contacted for an interview for stage two of the study please give your contact details at the end of the questionnaire and also sign and return the two copies of the enclosed consent form (you will be under no obligation to participate if you change your mind or your circumstances change). An interpreter (for languages other than english) will be available if required.

If you have any questions or require further information please contact me on: 0131 651 1157 (office hours).

Yours sincerely

Angela Jackson

Appendix 2.1 – Participant Information Sheet

Participant information sheet (original study design)



Managing coronary heart disease following a ‘heart attack’:

Patient experiences and resources of support

PATIENT INFORMATION SHEET - PART 1

Invitation

You are being invited to participate in a research study. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of the study, why you are being asked to participate, and what will happen if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

If anything about the study is not clear or if you would like more information please contact us (see below). Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This research is seeking to understand how people who have had a ‘heart attack’ manage their condition within their everyday lives, particularly relating to the different types of support they have or use; and in their use or non-use of rehabilitation services and community resources. This information can help service planners and health professionals identify how services and support can better meet the needs of cardiac patients.

The study is being undertaken as a PhD at the Research Unit in Health, Behaviour and Change, within the College of Medicine, The University of Edinburgh. The researcher has previously worked in the NHS, local government and for other organisations in developing patient services and in health promotion.

Why have I been chosen?

All Lothian residents who were discharged from hospital after a 'heart attack' in the period July-Dec 2005-6 are being contacted. Hospital data records were used to identify eligible patients, and the GPs of these patients were then requested to forward the questionnaire, both to avoid contacting patients inappropriately and to enable patients to decide whether or not to participate. Please note that we will not know who you are until you have volunteered to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do you should sign and return the enclosed consent form with your completed questionnaire. The consent form indicates your agreement to participate, based on the information you have received. You will still be free to withdraw at any time and this would in no way affect the standard of care you receive.

What will happen to me if I take part?

The researcher will contact people who indicate that they wish to participate. If the person wishes to proceed then a suitable date, time and place for an interview will be arranged. The detailed interview will be about the participant's own experiences and views about managing their cardiac condition and the types of support available, and will last approximately one hour and take place in the participants' home or another venue if they prefer. Interviews will be tape-recorded (with the permission of participants) and will be confidential (please see Part 2 for the detailed arrangements for maintaining participant confidentiality).

What do I have to do?

Please complete and sign the enclosed consent form and return it in the pre-paid envelope with your completed questionnaire. You will then be contacted by the researcher.

What are the possible benefits of taking part?

Participating in this study is not intended to directly benefit participants, but rather to provide information and insight about the experiences and needs of people recovering from a 'heart attack' that may help NHS and community service providers develop and adapt services and support resources to better meet the needs of such patients in future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. Detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. All information about your participation will be kept confidential. The details are explained in Part 2.

Contact details:

For more information about the study contact Angela Jackson, tel: 0131 651 1157 (office hours).

This completes Part 1 of the Information Sheet.

If you are considering taking part, please continue to read the additional information in Part 2 before making your decision.

PATIENT INFORMATION SHEET - PART 2

Concerns or complaints

If any participant has a concern about any aspect of the study they should contact the researcher who will do their best to answer the questions or resolve the problem. If after this, a participant remains unhappy or wishes to make a complaint formally, this can be done by contacting Dr Susan Gregory, at the University of Edinburgh, who is supervising this study (tel: 0131 650 6199).

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. Questionnaire data will be stored securely on computer file in the care of the researcher for analysis in the study. Originals will be destroyed and the computer file will be deleted when the study is completed. Audio-taped interviews and typed transcripts of the tapes will be referred to and labelled only with an anonymous reference code (participants names / contact details will not be used). Material used in research reports and academic papers will be anonymised so that participants will not be identifiable. Anonymised transcripts will be stored securely after study completion for a period of ten years to allow further research papers and reports to be produced (Procedures for handling, processing, storing and destroying data are compliant with the Data Protection Act 1998).

What will happen to the results of the research study?

It is intended that the study results will be published within the PhD Thesis; a public report (for service-providers and health professionals); and that one or more articles will be submitted for publication in health / medical journals. A summary of the study findings will be produced and circulated to all interviewees and also those who agreed to participate but were not called for interview (due to limited numbers).

Who is organising and funding the research?

This research is sponsored by The University of Edinburgh, which received funding from the UK Medical Research Council.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by Lothian Research Ethics Committee (number 3) in April 2006.

Thank you for taking the time to read this Information Sheet.

You should keep the information sheets for your own information. Participants will also be returned one of their two signed consent forms to keep.

Appendix 2.2 – Participant Consent Form

Participant consent form (original design)

Title of Project: Managing Coronary Heart Disease following a ‘Heart Attack’: Patient Experiences and Resources of Support

Name of Researcher: Angela Jackson

Please initial each box

1. I confirm that I have read and understand the Information Sheets for the above study dated May, 2006. I have had the opportunity to consider the information and ask any questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that data collected during the study may be looked at by responsible individuals within the NHS or University of Edinburgh, where it is relevant to the research study.
4. I give permission for the audio-recording of my interview and possible use of (anonymised) quotes using my exact words.
5. I agree to take part in the above study.

.....
.....
Name of Participant Date Signature

.....
.....
Researcher Date Signature

Please sign and return **both** copies of this form in the pre-paid envelope to the researcher. The researcher will counter-sign both copies and post one back to you for your own record.

Appendix 3 – Topic Guide

Interview Topic Guide

Starter / participant self-introduction

Background details – self description (age, occupation, family etc)

Views, perceptions & understandings of CHD & MI severity, causation, locus control, prognosis, treatment / management

Health

- pre CHD / MI
- CHD history (include family history)
- Current health self-perceptions

Experience of health services

- Pre-MI
- MI / cardiology
- Post-MI – follow up cardiology / Primary Care

Day-to-day experience of living with & managing CHD; & impact of MI on life

- Practicalities daily life - description of typical day
- Successes & difficulties
- Help
- Changes made to accommodate condition / follow post-MI advice
- Work (paid / home) & leisure; homelife; family & social relationships
- Health
- Feelings

What helped recovery / rehabilitation?

- Early period / now
- Things did for self / Things other people did / provided

Did anything hinder / limit recovery / rehabilitation ?

Support

- Kinds of support / help after MI?
 - Early period / Now
 - Range of sources (family-services/facilities)
 - Type of support / help (each source)

- Relative importance sources & types of support
- Concept of ‘support’
- Unmet needs
 - Any type support / help missing / not offered / available
 - Early period / Now
 - Ideas / suggestions of ways to address the need / issue

CR

- Perceptions / attitude / practicalities (invitation, access)
- ‘Non-use’ – rationale & alternatives?

CHD groups

- Perceptions / attitude / practicalities (information, access)
- ‘Non-use’ – rationale & alternatives?

Appendix 4 - Participant invitation letter

Participant invitation letter (modified study design)



RESEARCH UNIT IN HEALTH, BEHAVIOUR AND CHANGE
School of Clinical Sciences and Community Health
University of Edinburgh Medical School
Teviot Place
Edinburgh
EH8 9AG

‘Managing coronary heart disease following a ‘heart attack’: patient experiences and resources of support’

RESEARCH PARTICIPATION INVITATION

Dear

I am writing to ask for your assistance with a research project being undertaken with people in Lothian who have had a ‘heart attack’ (M.I / myocardial infarction).

A research study is being undertaken to improve understanding about how people who have had a ‘heart attack’ manage their condition within their everyday lives, particularly relating to different types of support; and use or non-use of rehabilitation services and resources. This information can help service planners and health professionals identify how best to meet the needs of cardiac patients.

The study is being undertaken as a PhD within the Research Unit in Health, Behaviour and Change at the University of Edinburgh.

Lothian residents discharged from hospital after a ‘heart attack’ in the period April-Jun, 2006 are being contacted to request their participation. Hospital discharge records were used by NHS staff to identify potential participants, and these patients’ GPs were asked to forward the questionnaire to eligible patients.

Information sheets giving more details about the study are enclosed with this letter: one for yourself, and also one for a family member (or other person you may wish to

nominate) who would also participate. It would be much appreciated if you would complete and return the brief enclosed questionnaire in the pre-paid envelope, and if you and a family member / other person are willing to be contacted for an interview for stage two of the study please give your contact details at the end of the questionnaire and each of you sign and return the enclosed consent forms. You will be under no obligation to participate if you change your mind or your circumstances change. An interpreter (for languages other than english) will be available if required.

If you have any questions or require further information please contact me on: 0131 651 1157 (office hours).

Yours sincerely

Angela Jackson

Appendix 4.1 - Participant information sheet

Participant information sheet (modified study design)



Managing coronary heart disease following a 'heart attack':

Patient experiences and resources of support

INFORMATION SHEET – FAMILY MEMBERS / NOMINATED CO-PARTICIPANTS

Invitation

You are being invited to participate in a research study. Please take time yourself to read the following information and talk to others about the study if you wish before you decide whether or not to take part.

What is the purpose of the study?

The study is seeking to understand how people who have had a 'heart attack' manage their condition within their everyday lives, and about the different types of support they have had or used following the 'heart attack'. To do this we are interviewing people who have had a 'heart attack' and members of their family or other people who have been involved in helping manage / recover.

What does taking part involve?

We would like you to participate in an interview to talk about your own views and experiences about the 'heart attack' of your family member / the person who nominated you. The interview will last one hour or less and take place at a time and venue suitable to you, and will be tape-recorded (with your permission).

Why have you been chosen?

Lothian residents who were discharged from hospital after a 'heart attack' in the period July-May 2006 have been contacted. Hospital data records were used to identify eligible patients, and the GPs of these patients were asked to forward the questionnaire and information to enable patients to decide whether or not to participate. Your family member (or the person you know who passed this information to you) intends to participate and wishes to nominate you to be interviewed also.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will still be free to withdraw at any time. This would in no way affect the standard of care you receive.

Will my taking part in the study be kept confidential?

All information collected during the course of this study will be kept strictly confidential. Transcripts of interviews will be anonymised so that in reports and academic papers participants will not be identifiable

Who is organising and funding the research?

The study is being undertaken as a PhD at the Research Unit in Health, Behaviour and Change, within the School of Clinical Sciences and Community Health, The University of Edinburgh, which received funding from the UK Medical Research Council.

Who has reviewed the study?

The study was given a favourable ethical opinion for conduct in the NHS by Lothian Research Ethics Committee.

What are the possible benefits?

The study is not intended to directly benefit participants, but will provide information and insight that may help NHS and community service providers develop and adapt services and support resources to better meet the needs of people recovering from a 'heart attack' in future.

What will happen to the results of the research study?

It is intended that the study results will be published within the PhD Thesis; in a report (for service-providers and health professionals); and that one or more articles will be submitted for publication in health / medical journals. A summary of the study findings will be produced and circulated to all interviewees and also those who agree to participate but are not called for interview (due to limited numbers).

Questions and further information

If anything about the study is not clear or if you want more information please contact Angela Jackson (tel: 0131 651 1157).

The next step

If you are willing to participate in the study please sign the enclosed consent form, which indicates that you agree to participate based on the information you have received. Keep one copy for your own record, and return the other copy in the pre-paid envelope along with the consent form and questionnaire completed by your family member / the person who invited you to take part. You will then be contacted by the researcher.

Thankyou for taking the time to read this information sheet.

Appendix 4.2 - 'Significant Other' information sheet

'Significant Other' information sheet (modified study design)



Managing coronary heart disease following a 'heart attack':

Patient experiences and resources of support

INFORMATION SHEET – FAMILY MEMBERS / NOMINATED CO-PARTICIPANTS

Invitation

You are being invited to participate in a research study. Please take time yourself to read the following information and talk to others about the study if you wish before you decide whether or not to take part.

What is the purpose of the study?

The study is seeking to understand how people who have had a 'heart attack' manage their condition within their everyday lives, and about the different types of support they have had or used following the 'heart attack'. To do this we are interviewing people who have had a 'heart attack' and members of their family or other people who have been involved in helping manage / recover.

What does taking part involve?

We would like you to participate in an interview to talk about your own views and experiences about the 'heart attack' of your family member / the person who nominated you. The interview will last one hour or less and take place at a time and venue suitable to you, and will be tape-recorded (with your permission).

Why have you been chosen?

Lothian residents who were discharged from hospital after a 'heart attack' in the period July-May 2006 have been contacted. Hospital data records were used to identify eligible patients, and the GPs of these patients were asked to forward the questionnaire and information to

enable patients to decide whether or not to participate. Your family member (or the person you know who passed this information to you) intends to participate and wishes to nominate you to be interviewed also.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will still be free to withdraw at any time. This would in no way affect the standard of care you receive.

Will my taking part in the study be kept confidential?

All information collected during the course of this study will be kept strictly confidential. Transcripts of interviews will be anonymised so that in reports and academic papers participants will not be identifiable.

Who is organising and funding the research?

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The study is not intended to directly benefit participants, but will provide information and insight that may help NHS and community service providers develop and adapt services and support resources to better meet the needs of people recovering from a 'heart attack' in future.

What will happen to the results of the research study?

It is intended that the study results will be published within the PhD Thesis; in a report (for service-providers and health professionals); and that one or more articles will be submitted for publication in health / medical journals. A summary of the study findings will be produced and circulated to all interviewees and also those who agree to participate but are not called for interview (due to limited numbers).

Questions and further information

If anything about the study is not clear or if you want more information please contact Angela Jackson (tel: 0131 651 1157).

The next step

If you are willing to participate in the study please sign the enclosed consent form, which indicates that you agree to participate based on the information you have received. Keep one copy for your own record, and return the other copy in the pre-paid envelope along with the consent form and questionnaire completed by your family member / the person who invited you to take part. You will then be contacted by the researcher.

Thankyou for taking the time to read this information sheet.

Appendix 5 - Summary characteristics of Post-MI interviewees

	Pseudonym	Single /	Co-	Age	Gender	Ethnicity	Non-	Marital	Cardiac	Co-morbidity	Socio-economic group
1	Linda	Single	n/a	45	Female	White (Scot)	CRSGNP	Partner		n/a	WC
2	Jean	Single	n/a	84	Female	White (Scot)	SGNP	Widow	HTN	Diabetes, arthritis	WC
3	Jim	Single	n/a	53	Male	White (Scot)	SGNP	Married	n/a	n/a	WC
4	Kenny	Single	n/a	55	Male	White (Scot)	SGNP	Married	HTN	Diabetes, COPD	I
5	Dot	Single	n/a	43	Female	White (Scot)	CRSGNP	Partner	n/a	Depression	WC
6	Gayle	Single	n/a	41	Female	White (Scot)	CRSGNP	Partner	n/a	n/a	WC
7	Harry	Single	Sally	73	Male	White (Scot)	CRSGNP	Married	n/a	n/a	MP
8	Joe	Single	Moirra	66	Male	White (Scot)	CRSGNP	Married	n/a	Paraplegic; Renal	WC
9	Alec	Single	May	53	Male	White (Scot)	CRSGNP	Married	n/a	n/a	WC
10	Ray	Paired	Teresa	50	Male	White (Scot)	SGNP	Married	HTN	n/a	MP
11	Audrey	Single	Jack	74	Female	White (Scot)	SGNP	Widow	MI (2)	Arthritis	WC
12	Sheila	Single	Sharon	59	Female	White (Scot)	CRSGNP	Married	n/a	Osteoarthritis	I
13	Derek	Single	Julie	80	Male	White (Scot)	CRSGNP	Widower	n/a	Balance problems	I
14	Martin	Single	Carol	54	Male	White (Scot)	SGNP	Married	Angina	n/a	I
15	George	Single	Judy	67	Male	White (Scot)	SGNP	Married	Angina	n/a	MP
16	Colleen	Single	Norman	63	Female	White (Irish)	SGNP	Married	Angina	n/a	I
17	Elspeth	Paired	Ron	80	Female	White (Scot)	CRSGNP	Married	HTN	Diabetes; Arthritis	WC
18	Dennis	Single	Molly	77	Male	White (Scot)	CRSGNP	Married	n/a	n/a	MP
19	Gordon	Single	Aileen	57	Male	White (Scot)	CRSGNP	Married	n/a	COPD	WC
20	Matty	Paired	Freda	67	Male	White (Scot)	CRSGNP	Married	Angina	n/a	WC
21	Ravi	Paired	Anila	75	Male	Indian	CRSGNP	Married	n/a	Fibrosis	I
22	Maisie	Single	n/a	77	Female	White (Scot)	CRSGNP	Widow	n/a	Arthritis	WC
23	Ernie	Single	Eric	75	Male	White (Scot)	SGNP	Married	n/a	n/a	I
24	Mike	Single	n/a	57	Male	White (Scot)	SGNP	Divorcee	n/a	n/a	MP
25	Dave	Single	Maggie	40	Male	White (Scot)	CRSGNP	Married	n/a	n/a	I
26	Angus	Single	n/a	62	Male	White (Scot)	CRSGNP	Married	n/a	Lower limb disability	WC
27	Rena	Single	n/a	62	Female	White (Scot)	CRSGNP	Married	MI	Diabetes; Arthritis	I

**Appendix 5.1 - Summary characteristics of
'Significant other' Interviewees**

(overleaf)

	Pseudonym	Single / Paired	Post-MI Co-interviewee	Relationship to post-MI person	Age	Ethnicity
1	Sally	Single	Harry	Wife	70s	White (Scot)
2	Moirra	Single	Joe	Wife	60s	White (Scot)
3	May	Single	Alec	Wife	50s	White (Scot)
4	Teresa	Paired	Ray	Wife	50s	White (Scot)
5	Jack	Single	Audrey	Son	40s	White (Scot)
6	Sharon	Single	Sheila	Daughter	30s	White (Scot)
7	Julie	Single	Derek	Daughter	50s	White (Irish)
8	Carol	Single	Martin	Wife	50s	White (Scot)
9	Judy	Single	George	Wife	70s	White (Scot)
10	Norman	Single	Colleen	Husband	60s	White (Scot)
11	Ron	Paired	Elspeth	Husband	80s	White (Scot)
12	Molly	Single	Dennis	Wife	70s	Indian
13	Aileen	Single	Gordon	Wife	50s	White (Scot)
14	Freda	Paired	Matty	Wife	60s	White (Scot)
15	Anila	Paired	Ravi	Wife	60s	White (Scot)
16	Eric	Single	Ernie	Best Friend	70s	White (Scot)
17	Maggie	Single	Dave	Wife	40s	White (Scot)

Appendix 6 - Categories of non-participation

Categories of non-participation - Post-MI interviewees

<u>CR</u>	<u>Invitation / Information status</u>	<u>CHD Group</u>	<u>Invitation / Information status</u>
<i>Category One- “No need” / “no point” (non-beneficial)</i>			
Sheila (Case study)	Invited / Info	Linda	Invited / Info
Derek	Invited / Info	Kenny (P)	Invited / Info
Harry	Invited / Info	Ernie (P)	Informal Only
Matty	Invited / Info	Sheila (Case study)	No invitation / info
Linda	Invited / Info	Derek	No invitation / info
Maisie	Invited / Info	Harry	No invitation / info
Ravi	Invited / Info	Elspeth	No invitation / info
Elspeth	No invitation / info	Matty	No invitation / info
Rena	No invitation / info	Maisie	No invitation / info
		Rena	No invitation / info
		Angus	No invitation / info
<i>Category Two - “Not worth it” (outweighed)</i>			
Gordon (Case study)	Invited / Info	Jean (P)	Invited / Info
Dave	Invited / Info	Jim (P)	Invited / Info
		Martin (P)	Invited / Info
		Dave	Informal Only
		Gordon (Case study)	No invitation / info
		Ravi	Uncertain / unclear
<i>Category Three – “Not possible” / (impeded)</i>			
Joe (Case study)	Invited / Info	Mike (P)	Informal Only
Dennis	No invitation / info	Ray (P)	Informal Only
Dot	No invitation / info	Joe (Case study)	No invitation / info
Gayle	No invitation / info	Dennis	No invitation / info

Alec	No invitation / info	Dot	No invitation / info
Angus	No invitation / info	Gayle	No invitation / info
		Alec	No invitation / info
		Audrey (P)	No invitation / info
		Colleen (P)	No invitation / info
		George (P)	No invitation / info
<u>“Category Shifters”</u>			
Linda (1 to 2)		Linda (1 to 2)	
		Ray (1 to 3)	

Key: CR participant = (P)

Invitation / information status:

-*Invited / Info* = given information by health staff

-*Informal Only* = information from informal sources only

-*No invitation / info*

-*Uncertain / unclear* - Ravi was invited to a group, but it was unclear if it was a CHD Group or generic Social Services Support Group