

## MASTER OF SCIENCE BY RESEARCH

**Developing feasible CBT-based interventions to manage cardiac misconceptions that are predictive of poor outcomes in people with coronary heart disease in cardiac rehabilitation**

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**DEVELOPING FEASIBLE CBT-BASED  
INTERVENTIONS TO MANAGE CARDIAC  
MISCONCEPTIONS THAT ARE  
PREDICTIVE OF POOR OUTCOMES IN  
PEOPLE WITH CORONARY HEART DISEASE  
IN CARDIAC REHABILITATION**

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**MScR**

**September 2014**



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***A dissertation submitted in partial fulfilment of the University's  
requirements for the Degree of Master of Research***

**Coventry University**

# CHAPTERS

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This dissertation is dedicated to my son, Thomas.

## **DISSEMINATION**

### **Conference Presentations**

- British Association of Cardiovascular Prevention and Rehabilitation Annual Conference, Solihull. October 2013. Oral Presentation - Exploring the acceptability of evidence-based feasible interventions to dispel cardiac misconceptions.
- Postgraduate Conference, Coventry University. March 2013. Poster Presentation - Development of a CBT based intervention to dispel misconceptions about coronary heart disease.
- Midlands Health Psychology Network Annual Conference, University of Birmingham. February 2013. Poster Presentation - Developing an evidence-based feasible intervention to dispel cardiac misconceptions.
- British Association of Cardiovascular Prevention and Rehabilitation Annual Conference, Edinburgh. October 2012. Poster Presentation - Developing an evidence-based feasible intervention to dispel cardiac misconceptions.

## **LIST OF ABBREVIATIONS**

ACS – Acute Coronary Syndrome  
AMI – Acute myocardial infarction  
BACPR - British Association for Cardiovascular Prevention and Rehabilitation  
BCT – Behaviour Change Technique  
BHF - British Heart Foundation  
B-IPQ – Brief illness perception questionnaire  
CABG - Coronary artery bypass graft  
CAD – Coronary artery disease  
CBT – Cognitive behaviour therapy  
CHD – Coronary heart disease  
CONSORT - Consolidated Standards of Reporting Trials  
CR – Cardiac Rehabilitation  
CRP – Cardiac Rehabilitation Programme  
CVD – Cardiovascular disease  
DH – Department of Health  
IPQ – Illness perception questionnaire  
IPQ-R – Illness perception questionnaire – revised  
GAD-7 – Generalised anxiety disorder questionnaire (7-item)  
MI – Myocardial infarction  
NACR – National Audit of Cardiac Rehabilitation  
NHS – National Health Service  
NICE – National Institute for Health and Care Excellence  
NRES – National Research Ethics Service  
NSF – National Service Framework for Coronary Heart Disease  
NSTEMI – Non ST-segment-elevation myocardial infarction  
MI – Myocardial infarction  
PCI – Percutaneous coronary intervention  
PPCI – Primary percutaneous coronary intervention  
PHQ-9 – Patient Health Questionnaire (9-item)

RACPC - Rapid Access Chest Pain Clinic

RCT – Randomised controlled trial

STEMI – ST-segment-elevation myocardial infarction

YCBQ – York Cardiac Beliefs Questionnaire

WHO – World Health Organisation



## ABSTRACT

**Background:** Misconceptions about coronary heart disease (CHD) are correlated with poorer physical functioning and psychological status. Research suggests that cognitive behavioural methods of changing misconceptions are most promising, however, despite guidelines advising cardiac rehabilitation clinicians to dispel cardiac misconceptions, there is a lack of advice regarding how best to go about this.

**Purpose of the study and setting:** To develop interventions to dispel cardiac misconceptions that are acceptable to people with CHD who are attending a Stage 4 cardiac rehabilitation centre.

**Intervention design:** Using Medical Research Council guidelines for developing complex interventions as a guide, an initial design phase identified Leventhal's Common-Sense Model of illness behaviour as a theoretical basis. An individual and group intervention were drafted, and a booklet, with input from an expert panel.

**Study design and methods:** A pragmatic qualitative study using semi-structured interviews and a focus group was used. A convenience sample of people with CHD was recruited from two different Stage 4 cardiac rehabilitation centres. Six people (4 men, 2 women), mean age 61 years, received the individual intervention and completed a semi-structured interview. Eight participants from the second cardiac rehabilitation centre received the group intervention and 5 people (4 men, 1 woman), mean age 54 years, took part in a focus group. One staff member took part in a semi-structured interview about the group intervention.

**Data analysis:** data were analysed thematically using Framework Analysis.

**Findings:** Generally, the study found that both interventions were acceptable and regarded as being of benefit to people with CHD. The process of tailoring the individual intervention was acceptable, however, the findings identified that some people may feel anxious and need reassurance that they are not being 'tested'. The individual intervention was valued for its personal focus and viewed as helpful for enhancing people's understanding of CHD. The group intervention was viewed as useful and well-received by the member of staff and participants valued being with others who had experienced a heart event. The booklet was viewed as being helpful as

an intervention in itself and could be received by patients and/or their family members soon after a heart event. Challenges to the group intervention included some people's experience of poor concentration and memory which should be taken into account when delivering a future intervention. Overall, participants thought the intervention and booklet would be best received soon after a heart event as this is when people would be more motivated and have more time to engage with an intervention to understand their illness.

**Conclusion:** The findings of the study were used to further refine the interventions; changes included making the content of the booklet more acceptable to people with disabilities. While the study found that the interventions were acceptable, it is unknown if the interventions would be experienced differently by people who are not already attending cardiac rehabilitation, therefore, the interventions would benefit from further pilot testing with people who are less motivated to attend or make health behaviour changes. The study did not explore if changing misconceptions led to changes in behaviour, however, focusing on the 'patient's perspective' has enabled interventions to be produced that are more fully developed and acceptable to the people intended to receive them and optimally developed interventions are more likely to be efficacious. A future trial can explore how effective the interventions are at changing behaviour which will also help identify how important a determinant of behaviour change cardiac misconceptions are.

## **CHAPTER 1. INTRODUCTION**

### **1.1 Overview**

This chapter provides an overview of coronary heart disease (CHD) and the importance of secondary prevention measures. The connection between cardiac misconceptions and poor outcomes is explained and current guidelines to manage cardiac beliefs are outlined, providing a rationale for the study. Systematic development of health behaviour interventions is presented and the aims and objectives of the study are outlined. Finally, the structure of the dissertation is explained. All abbreviations are explained on pages 9 and 10.

### **1.2 Coronary heart disease**

Coronary heart disease is the umbrella term for a condition where arteries supplying blood to the heart become hardened and narrowed. CHD is caused by a gradual accumulation of plaque (fatty-deposits) on the inner walls of the blood vessels, a process called atherosclerosis. As a result, the flow of blood is impaired reducing the movement of oxygen and other vital nutrients to the heart muscle and can result in chest pain (angina). A myocardial infarction (MI) usually occurs when a blood clot forms around a fissure in a plaque and suddenly cuts off the blood supply to an area of heart muscle which can cause permanent damage to those muscle cells.

Treatments to restore or improve blood flow to the heart muscle include coronary artery bypass graft surgery (CABG) and percutaneous coronary intervention (PCI). CABG involves taking a blood vessel from another part of the body and grafting it from the aorta to a point in the coronary artery that bypasses the atherosclerotic blockage. One or more grafts may be needed depending on the number of blocked blood vessels. PCI is a procedure that involves inserting a balloon catheter into the coronary artery to widen the narrowed artery. A metal stent is usually placed in the artery to maintain dilation and anti-platelet drugs are used to prevent a clot forming around the stent.

Revascularisation procedures undertaken immediately following MI (termed primary PCI or PPCI) restore adequate blood flow to the heart muscle which can reduce the

potential damage to the heart. Revascularisation can relieve angina and may reduce the risk of MI or further MI. Patients with CHD are also prescribed medication, alongside or instead of surgical interventions, to reduce their risk of further atherosclerosis or MI, for example, aspirin or Clopidogrel, antiplatelet agents to reduce blood clotting. Whilst medical and surgical interventions are important and development of these have contributed to a significant reduction in mortality rates over the years, it is acknowledged that changing unhealthy behaviours, particularly smoking cessation, has had as significant a role.

The British Heart Foundation (BHF) report that CHD is the principle cause of mortality in the UK with over 80,000 deaths a year and is the most common cause of premature death in men and women; the incidence of MI in the UK is high with around 103,000 heart attacks estimated to occur each year (Townsend et al. 2012). Prevalence of CHD is also high; it is the second most prevalent chronic illness in the UK with over 2 million people living with angina and over 1.5 million people who have had an MI (Townsend et al. 2012). Whilst overall CHD mortality rates have decreased significantly since the 1970s due to medical and behavioural interventions, the UK suffers higher death rates than other Western European countries (Townsend et al. 2012). There are also concerns that the decreasing trend in mortality from CHD is slowing due to higher rates, in recent years, of the prevalence of medical risk factors for CHD, for example, obesity and Type 2 diabetes (Townsend et al. 2012). Additionally, the death rate of younger people from CHD is reducing at a slower rate than for older people and socioeconomically disadvantaged people the UK are increasingly more likely to suffer with CHD and die from an MI (Pearson-Stuttard et al. 2012, Townsend et al. 2012).

The cost of CHD to the UK economy is considerable in terms of health care costs, loss of productivity and informal care of people with CHD. Due to high incidence and prevalence, treating CHD is costly to the National Health Service (NHS). Overall, CHD is estimated to cost the economy £6.7 billion a year (Townsend et al. 2012). The increasing prevalence of obesity and Type 2 diabetes in the UK is likely to lead to more CHD and increased burden to the NHS, the individual and society.

### **1.3 Coronary heart disease management**

The World Health Organisation (WHO) report that CHD is related to a number of risk factors relating to lifestyle and is, therefore, a largely preventable disease (WHO 2011). Risk factors contribute to the development of atherosclerosis and are classed as being either modifiable or non-modifiable. Non-modifiable factors include age, sex, ethnicity and genetics; these cannot be addressed by intervention. The impact of ethnicity as a risk factor, however, can be reduced if predisposing health conditions prevalent in certain ethnic backgrounds are better managed, for example, better management of diabetes, which is more prevalent in South Asians.

Modifiable risk factors are those which can be addressed by behaviour change and include high blood pressure, high cholesterol, smoking, high alcohol intake, sedentary lifestyle, poor diet, stress and obesity (Perk et al. 2012). These risk factors can be addressed by adopting health behaviours which may include the following: adhering to a medication regime, consuming a heart healthy diet, increasing physical activity, smoking cessation, alcohol reduction, weight loss and stress management. Behaviour change directly addresses people's risk factors for CHD, therefore, the adoption and maintenance of these changes contributes significantly towards preventing and managing CHD.

Guidelines for the secondary prevention of CHD recommend that patients are supported to make lifestyle changes in order to reduce their identified risk factors (NICE 2007). Cardiac rehabilitation services are tasked with supporting patients with CHD to adopt health behaviour changes, as recommended in the UK by the National Institute for Health and Care Excellence (NICE). Cardiac rehabilitation (CR) has significant benefits for people with CHD, as confirmed by a number of systematic reviews (Clark, Hartling, Vandermeer et al. 2005, Heran et al. 2011, Lawler, Filion and Eisenberg 2011), and includes reduced mortality, reduced disability, improved quality of life and quicker return to work after an acute cardiac event. Despite these benefits, low uptake of CR in the UK led the National Service Framework for Coronary Heart Disease (NSF) for England to set a target to increase the offer of CR from 34% to 85% of patients by 2013 (Department of Health 2000). This target was not achieved, with mean uptake in people following MI only reaching 43% in 2012 (National Audit of Cardiac

Rehabilitation 2013). The NSF has since been superseded by the new 'Cardiovascular Disease Outcomes Strategy for England' which states that uptake of CR (as opposed to the offer of CR) should be at least 65% of eligible patients (Department of Health 2013).

Multiple factors have been found to influence people's attendance of CR, these include medical, psychological and sociodemographic factors (Beswick et al. 2005, Taylor, Wilson and Sharp 2011). Psychological factors that can negatively impact uptake of CR include incorrect beliefs about CHD and about CR (Baigi et al. 2011, Cooper 2004, Cooper et al. 2007, French, Cooper and Weinman 2006). Peoples' thoughts, beliefs and attitudes towards their illness have a strong influence on the adoption and maintenance of health behaviour changes which are important for secondary prevention of CHD (Michie et al. 2005).

#### **1.4 Cardiac misconceptions**

Cardiac misconceptions are inaccurate and maladaptive thoughts, ideas or beliefs about CHD. The negative influence of cardiac misconceptions was identified over 3 decades ago by Wynn (1967) who detected that people with cardiac misconceptions were more likely to have higher levels of anxiety and were more likely to adopt an overly cautious lifestyle, for example, avoiding physical exertion and not returning to work. Maeland and Havik (1987b) and Petrie et al. (1996) similarly found that cardiac misconceptions were predictive of delayed return to work and higher psychological distress.

Misconceptions about CHD are common and come from a variety of sources including the media, family members (Furze et al. 2002, Petrie et al. 1996) and even healthcare workers themselves (Angus et al. 2012). An example of a common cardiac misconception is a belief that stress is a major cause or trigger of MI, to the detriment of more clinically important factors such as smoking or sedentary lifestyle (Clark 2003, Furze and Lewin 2000). People who believe that stress was responsible for their MI are less likely to engage in lifestyle change and reduce their risk factors (Petrie and Weinman 1997, Weinman et al. 2000) and are more likely to engage in maladaptive coping strategies including avoidance of physical activity and delaying return to work (Furze et al. 2005, Petrie et al. 1996). Research shows that cardiac misconceptions are

correlated with levels of functional disability, anxiety and depression in people with CHD, and are more predictive than symptom severity of physical functioning a year later (Furze et al. 2005).

Using the newly developed Illness Perception Questionnaire (IPQ) (Weinman et al. 1996) Petrie and colleagues (1996) demonstrated that people who believed their CHD was amenable to cure or control were more likely to attend CR, and those who perceived their illness as having serious consequences were more likely to delay their return to work (Petrie et al. 1996). Although the Petrie et al. (1996) study was unable to explain the link between illness perceptions and subsequent behaviour, it suggested that people's understanding of MI was resistant to change despite the provision of new, more accurate, information. The study highlighted that education alone is inadequate for changing cardiac beliefs and identified the importance of considering patients' illness perceptions before providing them with health information (Petrie et al. 1996).

As previously mentioned, despite the proven benefits of CR for people with CHD, there is poor uptake and adherence to CR, not just in the UK but worldwide (Bjarnason-Wehrens et al. 2010, Davies et al. 2010). Research has found that negative illness beliefs and misconceptions about CHD are correlated to low uptake of CR (French, Cooper and Weinman 2006), and treatment beliefs, for example, misconceptions about what CR entails also contribute to non-attendance (Cooper et al. 2005, French, Cooper and Weinman 2006, McCorry et al. 2009). Changing negative illness beliefs and dispelling misconceptions may improve uptake of CR (French, Cooper and Weinman 2006) and has been a focus of a number of interventions (Cooper 2004, Cossette et al. 2012, Taylor 2009).

While negative illness perceptions are problematic; cardiac misconceptions that result in an overly optimistic view of CHD are also maladaptive; for example, the belief that one's heart event is not serious is linked to patients viewing risk factor reduction or attendance at CR as unnecessary (French, Cooper and Weinman 2006). Similarly, patients who view themselves as having been cured as a result of hospital treatment may view their illness as an acute episode rather than as a chronic condition and be less likely to make lifestyle changes or attend CR (Astin and Jones 2006). In particular, patients who undergo PCI, a relatively quick and less invasive treatment compared to

CABG, have been found to regard their illness experience as an acute event and their treatment as being a cure (Astin and Jones 2006, Astin et al. 2009, Sampson, O'Cathain and Goodacre 2009).

Levels of depression and anxiety are known to be higher in people with CHD compared to the general population (Leong, Molassiotis and Marsh 2004, Swardfager et al. 2011). Illness perceptions appear to contribute towards the risk of CHD patients suffering depression; Dickens et al. (2008) found that patients with negative illness perceptions in the days after having an MI were more likely to develop subsequent depression. It is important to consider the impact of illness perceptions on psychological outcomes because depression is a known predictor of non-adherence to health behaviours, medication adherence and of worse cardiac outcomes (Bekke-Hansen et al. 2012). Identifying and changing negative illness beliefs and cardiac misconceptions may therefore play an important role in preventing or reducing depression and improving health outcomes in patients with CHD (Stafford, Berk and Jackson 2009).

### **1.5 Rationale for the study**

It has been established that negative illness perceptions and cardiac misconceptions are predictive of poor outcomes for CHD patients. Guidelines for managing CHD and for cardiac rehabilitation state that cardiac misconceptions should be identified and dispelled. The 2013 update of the NICE guideline for the secondary prevention of MI expands on earlier advice for healthcare professionals to “establish people’s health beliefs” (NICE 2007) and states that people's health beliefs and their specific illness perceptions should be established before offering them lifestyle advice and encouraging attendance of CR (NICE 2013). The British Association for Cardiovascular Prevention and Rehabilitation (BACPR) ‘Standards and Core Components for cardiovascular disease prevention and rehabilitation’ advise cardiac rehabilitation staff to “address any cardiac or other misconceptions (including any about cardiac rehabilitation) and illness perceptions that lead to increased disability and distress” (BACPR 2012: 13).

Despite these guidelines there is a lack of advice for health professionals and patients regarding how best to manage negative illness perceptions and cardiac misconceptions. Simply providing information is not an effective strategy as illness beliefs can be



resistant to change (Donovan and Ward 2001). Changing illness perceptions in people with CHD has been successful, for example, a three session intervention delivered by clinical psychologists (Petrie et al. 2002) led to improvements in illness perceptions and return to work, however, the intervention is not practical to deliver as hospital stay has reduced considerably over the decade and clinical psychology is a scarce resource in the NHS. Interventions need developing that can be effectively delivered by cardiac professionals without specialised psychology training. A systematic review by Goulding, Furze and Birks (2010) of 13 randomised controlled trials (RCTs) of psychological interventions aimed at changing maladaptive illness beliefs in people with CHD found that while beliefs could be changed it was unclear if changing illness beliefs had any effect on outcome. The authors did, however, conclude that interventions that used a cognitive behavioural approach were the most promising and advised that further good quality trials were needed (Goulding, Furze and Birks 2010).

Cognitive behaviour therapy (CBT) is a psychological approach that aims to teach people skills to change the way they think, act and feel (Bennett-Levy et al. 2010). Cognitive therapy includes techniques such as cognitive restructuring to help people identify and change their unhelpful thinking. Behaviour therapy applies theory of behaviour to address unhelpful behaviour and includes techniques such as goal setting and pacing to improve activity levels and graded exposure to tackle avoidance behaviour. CBT may have either a cognitive or behavioural focus or may combine both approaches.

## **1.6 Intervention development**

In the context of health research, an intervention is defined as any programme or strategy that intends to influence health or health behaviour in a positive way by promoting healthy behaviour and discouraging unhealthy behaviour (Glanz and Bishop 2010). Complex interventions are defined by the Medical Research Council (MRC) as being “interventions with several interacting components such as occur in health service, public health and social policy” (MRC 2008: 6). The interventions being developed as part of this study are thus classed as being complex interventions.

Increasing evidence shows that health behaviour interventions developed with a theoretical basis are more effective than those without a theoretical basis; theories can improve understanding and explanation of behaviour thus providing insight into factors that may lead to behaviour change (Glanz and Bishop 2010). The MRC framework for designing and evaluating complex interventions to improve health (Craig et al. 2008) emphasises an iterative process of intervention development to help ensure that interventions are optimised to improve the likelihood that the intervention will be successful in an RCT to test its efficacy and cost-effectiveness (Campbell et al. 2007). The MRC framework includes 4 main phases, as illustrated in Figure 1:

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Figure 1: Key elements of the development and evaluation process of the MRC Framework (Craig et al. 2008: 8)

Phase 1, the development phase, includes identifying the evidence-base and appropriate theory on which to base the intervention (Campbell et al. 2000, Campbell et al. 2007). Interventions developed with clearly identifiable components, such as psychological techniques, are also more easily evaluated, replicated and implemented into practice (Michie et al. 2009). Consolidated Standards of Reporting Trials (CONSORT) guidelines for reporting trials emphasise the need for interventions to be reported in sufficient detail so that the components of interventions are clearly identifiable,

providing insight into an intervention's mechanism of action and enabling others to make use of this information in clinical practice or further research (Schulz et al. 2010).

### **1.7 Aims of the research**

This study aims to develop evidence and theory-based interventions to dispel cardiac misconceptions that are acceptable to people with CHD and can be delivered by a non-psychologist. Acceptability refers to the extent to which an intervention is well received and liked by the target population and includes perceptions of the appropriateness of the content, format and delivery (Ayala and Elder 2011). It is important to explore intervention acceptability from the perspectives of the intended recipients because their views are more likely to result in an intervention that will be successful and one that people will engage with (Zauszniewski 2012).

The aim of the research will be achieved through the following objectives:

1. Explore the evidence base to identify an appropriate theoretical basis for the intervention and appropriate cognitive behavioural techniques and components for changing illness perceptions and cardiac misconceptions.
2. Design draft interventions and explore the acceptability of these with CHD patients.
3. Develop final versions of the draft interventions which are suitable for future feasibility and efficacy testing.

These objectives were approached by following guidelines from Phase 1 of the MRC guidelines for designing and evaluating complex interventions to improve health (Craig et al. 2008). The study has two main parts:

Part 1: The initial intervention design phase, which included a review of the literature conducted in a systematic way in order to produce an optimally designed intervention for dispelling cardiac misconceptions.

Part 2: The modelling phase where participants 'tested' the interventions and took part in a qualitative study that explored their experiences and perceptions of the interventions. The qualitative findings were used to further refine the interventions to result in final draft versions.

This study is only applicable to people with heart problems as a result of CHD; other heart problems such as congenital heart disease, cardiac arrest and heart failure have different aetiologies and physiology to CHD and involve different illness perceptions and cardiac misconceptions.

## **1.8 Dissertation structure**

This introductory chapter establishes the context of this Master's research study by providing an overview of the burden of CHD, the benefits of health behaviour change and attendance of CR. The impact of negative illness perceptions and cardiac misconceptions on behaviour change, CR and patient outcomes is discussed and presented as a rationale for the need to develop interventions to change inaccurate beliefs. The importance of structured intervention development is highlighted and the overall aims and objectives of the research presented.

Chapter 2 is concerned with the design of the interventions and provides a systematically undertaken narrative literature review of existing research exploring interventions to change cardiac misconceptions. An overview of the draft interventions are presented at the end of Chapter 2. Chapter 3 describes the modelling phase where participants tried the interventions and fed back their experiences and perspectives of it in a qualitative study. This chapter begins with a discussion of the methodological approach and epistemological assumptions of the study and explanation of the data analysis approach. The method section describes the semi-structured interview and focus group study design that was used to explore the acceptability of the interventions. Chapter 4 presents the qualitative findings; participants' views and experiences of the interventions. Chapter 5 discusses the findings and explains how the findings were used to further refine the interventions and discusses the study's strengths and limitations, implications, future recommendations and conclusion. The References section and Appendices conclude this work.

## **CHAPTER 2. DESIGN OF THE INTERVENTIONS**

### **2.1 Introduction**

As discussed in Chapter 1, cardiac misconceptions are problematic and predict poorer physical, psychological and socioeconomic outcomes for CHD patients. This study aims to develop cognitive-behavioural interventions to dispel these unhelpful cognitions. This chapter provides a review of the literature that informed the development of the draft interventions. The chapter concludes with an overview of the draft individual and group intervention.

### **2.2 Rationale for the literature review**

The importance of systematic intervention development was discussed in Chapter 1 and the rationale to follow guidance from the MRC Framework to develop the study interventions was given (Craig et al. 2008). Phase 1 of the MRC Framework includes: 1) identifying existing evidence and 2) identifying and developing theory; this can only be achieved through a systematic review of the literature. A formal systematic review, however, is beyond the scope of this study and is less crucial because a systematic review of interventions to change maladaptive beliefs in people with CHD has been published (Goulding, Furze and Birks 2010). As non-systematic reviews are criticised for lacking a rigorous scientific methodology, allowing bias to influence findings, this review will manage such methodological limitations by employing a systematic approach including using a comprehensive and transparent search strategy (Bettany-Saltikov 2012).

### **2.3 Review questions**

- 1) On which psychological theories are interventions based and which are the most appropriate?
- 2) What format do interventions take, where do they take place and who are the interventions delivered by?
- 3) What components, strategies or techniques are used in interventions to dispel misconceptions?

## 2.4 Review objectives

The review has three objectives, described below:

### *Objective 1: Identify a relevant theoretical basis*

Identify relevant theory to underpin the interventions to be developed in this study in terms of an overall theoretical framework to provide a rationale for the choice of components and to explain their intended mechanism of action.

### *Objective 2: Identify relevant intervention components*

Intervention components or techniques to change cardiac beliefs are to be identified from the literature. Behaviour change techniques (BCTs) are specific intervention components aimed at increasing a person's healthy behaviour and/or decreasing unhealthy behaviour. Work to standardise definitions of BCTs, for example, Abraham and Michie's (2008) taxonomy of behaviour change techniques, has enabled more thorough and clarified reporting of interventions thus enabling researchers to more easily identify the 'active ingredients' of effective interventions. Improved reporting of interventions, including standardised BCTs, also increases the likelihood that successful interventions are implemented in the manner by which they are intended, optimising their success in clinical practice (Michie et al. 2011). BCTs from the Abraham and Michie (2008) taxonomy may be appropriate for changing cardiac beliefs and a coding manual developed by the authors will be utilised to help identify BCTs in the literature. Although BCTs are focused on behaviour rather than cognitive change, a person's thinking and thought processes can be viewed as a form of covert behaviour (Beck 1987). This view is supported by Gochman's definition of health behaviour which includes beliefs, perceptions and "other cognitive elements" (1997: 3). Thus techniques aimed at changing behaviours may also be appropriate for changing cognitions.

### *Objective 3: Use findings to design interventions*

The review findings are to inform the design of the draft interventions, in addition to input from an expert panel which includes four CR peer support volunteers and professionals from CR, health psychology, psychological therapies and research.

## **2.5 Literature review method**

### **2.5.1 Study inclusion and exclusion criteria**

The search strategy followed the Patient Intervention Comparison Outcome Study (PICOS) framework as this is a structured and evidence-based approach and is recommended by the Cochrane Collaboration in their guidelines for conducting systematic reviews (Higgins and Green 2008).

The criteria for inclusion or exclusion in the review are outlined below:

### **2.5.2 Participants**

Studies were included where participants were over 18 years old with a diagnosis of one of the following: angina, MI, acute MI (AMI), CHD, Acute Coronary Syndrome (ACS), eligible for or recently received revascularisation through PCI or CABG. Participants were included from any setting: in-hospital, home, CR or specialist centres such as a Rapid Access Chest Pain Clinic (RACPC). Studies were excluded if participants were under 18 years old, had a congenital heart defect, heart failure not caused by CHD or other major co-morbid illnesses, for example, terminal illness or dementia.

### **2.5.3 Interventions**

Studies were included if the intervention had a focus or component aimed at changing cardiac misconceptions, incorrect, maladaptive or negative illness beliefs or cognitions or perceptions about angina, MI, CHD or PCI/ CABG. These beliefs could be about the physiology of angina, MI, CHD or PCI/ CABG or include beliefs about living with or managing these conditions and treatments. Studies were excluded if the intervention did not include a component to change cardiac misconceptions or illness beliefs. Interventions could be educational, psychological or a combination.

### **2.5.4 Comparisons**

Studies were included where the intervention was compared with a different intervention or to usual care. Studies were also included if the intervention had no comparison.

#### 2.5.5 Outcomes

Studies were only included where a primary or secondary outcome was a change in cardiac misconceptions, illness perceptions or beliefs measured by any one or more of the following: the Cardiac Misconceptions Scale (Maeland and Havik 1987a), the York Cardiac Beliefs Questionnaire (Furze et al. 2009), the York Angina Beliefs Questionnaire (Furze et al. 2003), the IPQ (Weinman et al. 1996), IPQ-R (Moss-Morris et al. 2002) or Brief IPQ (Broadbent et al. 2006). Studies were excluded if illness perceptions or belief outcomes were measured using the Short Form-36 or the Seattle Angina Scale as these were considered to be measuring perceptions of health-related quality of life rather than beliefs about CHD.

#### 2.5.6 Study design

Due to the nature of this review only intervention studies were included. Quantitative studies with a randomised controlled design are considered the gold standard for intervention studies but as this review is not a systematic review, quasi-experimental studies were included, as were studies employing mixed methods.



## **2.6 Search strategy**

The following databases were searched for relevant literature: AHMED, CINAHL, MED-LINE and PsycINFO. Google Scholar was used to track citations of the Petrie et al. (2002) paper as this is a key study likely to be referenced by relevant studies. Reference list checks of relevant articles were made and additional papers obtained if they provided more detail about an intervention. In order to keep the review manageable the search was limited to articles published between 1996 and March 2013. The year 1996 was chosen because this is when the first recognised questionnaire for measuring illness perceptions, the IPQ, was published (Weinman et al. 1996) and the studies previously identified by Goulding, Furze and Birks (2010) which were published before 1996 predominantly measured knowledge rather than beliefs. Where only an abstract was available an author was contacted to provide further information on the study. The review included grey literature and unpublished PhD theses. Only English language papers were included in the review as translation was beyond the scope of this study. Full details of the literature search can be found in Appendix I.

## **2.7 Search outcome**

The search provided 4021 citations; after review this was reduced to 205. A review of abstracts identified 26 papers to retrieve in full. A further 7 papers were identified from reference checks and one author was contacted to provide further information about an unpublished study which resulted in being provided with a PhD thesis. In total, 11 studies were included in the review. Nine studies were published journal articles and two were part of PhD theses. The researcher alone was responsible for the choice of papers that were included in the review; nobody from the supervisory team or independent researcher checked the citations as this was not deemed necessary for a non-systematic review. The flowchart shown in Figure 2 documents the study selection process.

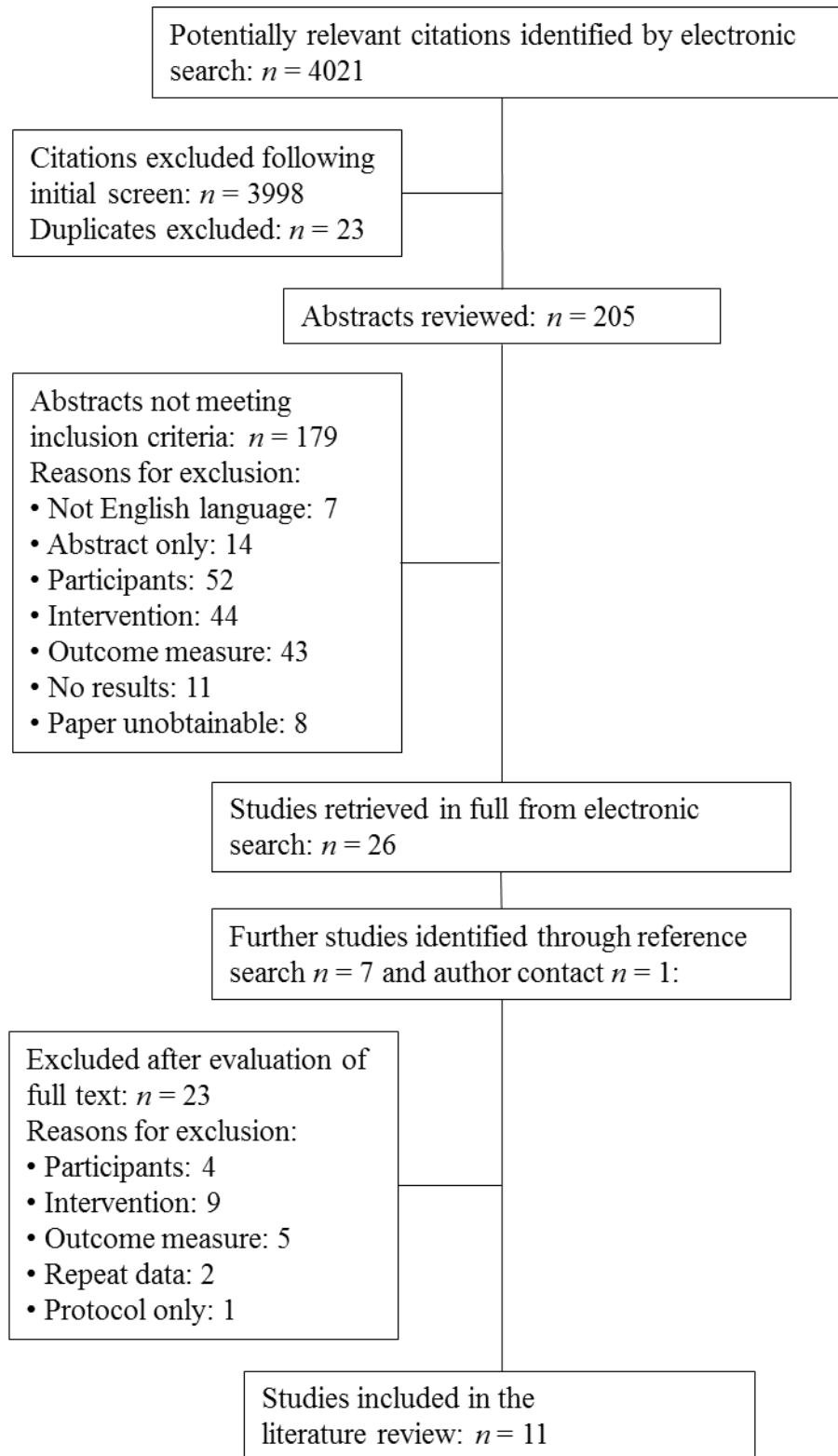


Figure 2: Study selection flow chart

## 2.8 Results

Eleven studies were found which satisfied the inclusion criteria (Broadbent et al. 2009, Broadbent et al. 2013, Cooper 2004, Cossette et al. 2012, Furze et al. 2009, Furze et al. 2012, Gould 2011, Lewin, Thompson and Elton 2002, Petrie et al. 2002, Taylor 2009, Zetta et al. 2011). All of the studies were RCTs which is not surprising as they were all testing the efficacy of an intervention. Table 1 provides a summary of the characteristics of included studies and includes information to put the studies into context in terms of where each study took place (country), the setting (for example, inpatient), number of participants and their diagnosis. An overview of each study intervention is given including its theoretical basis, who administered the intervention, the format, number and length of intervention sessions. Where details were available, an overview of the control condition is given. In the majority of cases this was 'standard care'. Primary and secondary outcome aims and the tools used to measure these are given, along with the follow-up schedule and in the final column a summary of the findings is given.

The components and techniques that were identified from the reviewed studies are presented in a chart in Appendix I. This chart was developed to organise the identified intervention techniques according to the illness representation of the CSM (see below) it was targeting and the intended effect on cardiac beliefs, for example, improve belief in personal control of CHD. Techniques included: cognitive restructuring, action planning, goal setting, and motivational interviewing.

Table 1: Summary of study characteristics

First author (year & country) and study design.	Participant, setting and intervention facilitator	Intervention / Control	Outcomes (primary outcome in bold) Beliefs outcome measure	Follow-up	Findings
Broadbent et al. (2009, New Zealand) RCT.	108 MI inpatients.  Health psychologist facilitated.	Intervention: 4 x 30 minute face-to-face sessions based on CSM (as Petrie et al. 2002) with additional spouse session to address spouses' understanding and illness perceptions. Patients given audio-taping of sessions (n=52).  Control: Standard care – cardiac rehabilitation nurse visit and educational materials (n=51).	<b>Return to work.</b> Illness perceptions, readiness for leaving hospital, intentions to attend CR, attendance at CR, health behaviours, contact with GP / hospital.  Brief IPQ; causal scale from IPQ-R.	Discharge, 3 & 6 months.	At 3 & 6 months the intervention group was more likely to be back in full-time work compared to the control group. Intervention group had greater intention to attend CR but difference in attendance not statistically significant. Intervention group more likely than control group to attribute <i>cause</i> of their MI to high cholesterol and lack of exercise. No changes to illness perceptions for <i>consequences, timeline or control</i> .
Broadbent et al. (2013, New Zealand) RCT.	106 patients hospitalised with ACS.  Nurse facilitated.	Intervention: One 30 minute face-to-face session using computerised risk and decision support tool to communicate risk and risk factor management strategies (n=52).  Control: Standard care cardiac rehabilitation nurse visit and educational materials (n=54).	<b>Risk perceptions and illness perceptions.</b>  Brief IPQ.	Discharge & 3 months.	No difference in risk perception between groups. Intervention group's illness perceptions were significantly higher in areas of perceived <i>control, controllability</i> . At discharge the control group had higher perceptions of <i>consequences</i> . No differences at follow-up.

First author (year & country) and study design.	Participant, setting and intervention facilitator	Intervention / Control	Outcomes (primary outcome in bold) Beliefs outcome measure	Follow-up	Findings
Cooper (2004, United Kingdom) RCT. Unpublished PhD thesis.	81 patients hospitalised with AMI.  Researcher facilitated (Physio- therapist).	Intervention: One hour face-to- face CBT session, based on CSM, to change illness perceptions and encourage CR attendance. Tailored according to answers to IPQ-R (n=40).  Control: Standard care – CR nurse visit (n=41).	<b>Attendance at CR,</b> <b>illness perceptions,</b> symptoms, contact with healthcare services, work status.  IPQ-R.	3 & 6 months.	No difference in CR attendance or significant differences in illness perceptions.
Cossette et al. (2012, Canada) RCT.	242 patients hospitalised with ACS (MI or unstable angina).  Nurse facilitated.	Intervention: 3 face-to-face sessions up to 25 minutes each, based on CSM, to improve illness perceptions and attendance at CR. First session face-to-face pre- discharge. Second session via telephone at 1-3 days post- discharge. Third session via telephone or face-to-face at 8-10 days post- discharge (n=121).  Control: Standard care (n=121).	<b>Enrolment CR</b> <b>program,</b> illness perceptions, family support, anxiety, medication adherence, cardiac risk factors.  IPQ-R.	6 weeks.	Significantly increased enrolment onto CR: 45% (intervention) compared to 24% (control) (p=0.001). Improved perceptions of personal <i>control</i> of heart disease the only significant change in illness perceptions.

First author (year & country) and study design.	Participant, setting and intervention facilitator	Intervention / Control	Outcomes (primary outcome in bold) Beliefs outcome measure	Follow-up	Findings
Furze et al. (2009, United Kingdom) RCT.	204 patients waiting for elective CABG surgery.  Outpatient clinic and home-based.  Nurse facilitated.	Intervention: HeartOp Programme - home-based cognitive- behavioural programme with booklet (HeartOp Plan), CD, goal setting and pacing, telephone follow-up (n=100).  Control: Nurse education and counselling with telephone follow- up (n=104).	<b>Anxiety, length of hospital stay,</b> depression, physical functioning, cardiac misconceptions, cost utility.  YCBQ.	8 weeks post intervention (preop); 6 weeks, 3 and 6 months (postop).	The HeartOp programme significantly reduced misconceptions and reduced preop depression and improved physical functioning. No difference in anxiety, or postop depression, physical functioning or hospital stay.
Furze et al. (2012, United Kingdom) RCT.	142 patients with new onset angina from a RACPC.  Home-based.  Lay person facilitated.	Intervention: The Angina Plan - angina self-management programme including workbook and relaxation CD, delivered by a lay facilitator. Initial 45 minute session then 10-15 minute phone calls or visits up to 3 months (n=70).  Control: Standard care – angina nurse specialist (n=72).	<b>Angina frequency,</b> various including angina misconceptions.  YABQ.	3 & 6 months.	No difference in reports of angina symptoms at 6 months. A cost effective intervention which led to significant improvement in anxiety, misconceptions and exercise levels at 3 months and anxiety, depression and misconceptions and 6 months.

First author (year & country) and study design.	Participant, setting and intervention facilitator	Intervention / Control	Outcomes (primary outcome in bold) Beliefs outcome measure	Follow-up	Findings
Gould. (2011, United States of America) RCT.	129 CVD patients undergoing PCI.  In-hospital.  Nurse facilitated.	Intervention: Discharge nursing intervention, based on CSM, promoting self-regulation of illness at home. Written discharge materials and telephone follow-up within 24 hrs. (n=54)  Control: Standard care – routine discharge materials (n=52).	<b>Utilization of urgent care, illness perceptions.</b>  IPQ-R.	24-72 hours.	Intervention group more likely to have a chronic view of their condition than the control group (p=.006). No other significant finding.
Lewin, Thompson and Elton (2002, United Kingdom) RCT.	243 acute MI inpatients.  In-hospital.  Self-administered.	Intervention: Two 30 minute cassette tapes (one specifically for partner) with advice and relaxation to address misconceptions, concerns and worries (n=114).  Control: Music tape (n=129).	<b>Misconceptions, anxiety,</b> depression, health related quality of life.  CMS.	3 days and 6 months	Significant difference in favour of intervention for changing misconceptions. No differences in anxiety, depression or health related quality of life.
Petrie et al. (2002, New Zealand) RCT.	65 first time MI patients.  In-hospital.  Clinical Psychologist facilitated.	Intervention: Three 30-40 minute tailored cognitive behavioural sessions, based on CSM - targeted at highly negative perceptions and aimed to alter perceptions of <i>timeline</i> and <i>consequences</i> .	<b>Illness perceptions</b> distress, preparation for leaving hospital, return to work, angina symptoms and attendance at CR.	Discharge & 3 months	Intervention led to positive changes to perceptions of illness consequences (p<.05), timeline (p<.001), cure/control (p<.01) at discharge. Intervention group felt more prepared to leave hospital and returned to work quicker (p<.05).

First author (year & country) and study design.	Participant, setting and intervention facilitator	Intervention / Control	Outcomes (primary outcome in bold) Beliefs outcome measure	Follow-up	Findings
Petrie et al. (2002) continued.		Written action plan for patients reviewed in final session (n=31).  Control: Standard care – cardiac rehabilitation in-hospital visit and educational materials (n=34).	IPQ.	Discharge & 3 months	Intervention group experienced fewer angina symptoms than the control group at 3 months ( $p < .03$ ). More people from the intervention group attended rehabilitation at 3 months compared to the control, but not a significant difference.
Taylor (2009, United Kingdom) RCT.	31 patients attending first Phase III CR session.  Researcher (trainee DCLinPsy) facilitated.	Intervention: One 60 minute face- to-face session based on CSM and Motivational Interviewing (n=18).  Control: Standard care (n=13).	<b>Number of CR sessions attended,</b> illness perceptions  IPQ-R.	10 weeks (medical records for CR attendance), 3 months.	Patients in the intervention group were found to attend significantly more CR classes than the control group ( $p < .05$ ). No differences in illness perceptions between groups at three-month follow up.
Zetta et al. (2011, United Kingdom) RCT.	218 in-patients with angina.  Hospital and home-based.  Nurse facilitated.	Intervention: Standard care plus Angina Plan (as Furze et al. 2012) with initial 45 min session in hospital (n=116).  Control: Standard care – identified risk factors, provided advice on angina and risk factor reduction (n=117).	<b>Effectiveness of Angina Plan (multiple outcomes),</b> misconceptions / knowledge.  YABQ.	6 months.	Intervention group had significantly improved knowledge, misconceptions ( $p \leq .000$ ), cardiac risk factors, physical limitation, general health perceptions and social and leisure activities. No reliable effects on anxiety and depression.



## 2.9 Discussion

This section begins with a discussion of the theoretical basis of the reviewed studies and the appropriateness of these theories for underpinning the interventions being developed as part of the current project. The section following on from this will discuss the identified intervention techniques and components and their relevance to the current project.

### 2.9.1 Theoretical basis of interventions

Seven studies (Broadbent et al. 2009, Broadbent et al. 2013, Cooper et al. 2004, Cossette et al. 2012, Gould 2011, Petrie et al. 2002, Taylor, 2009) were based on Leventhal's Common-Sense Model (CSM) of health and illness behaviour (Leventhal, Meyer and Nerenz 1980, Leventhal, Nerenz and Steele 1984). One study did not cite the CSM as the theoretical basis for the intervention but discussed the findings in relation to the constructs of the CSM (Furze et al. 2009). Two studies did not explicitly cite a theoretical basis but described a cognitive behavioural approach as the basis for the intervention (Furze et al. 2012, Zetta et al. 2011); both of these studies were of the Angina Plan, originally developed and tested by Lewin et al. (2002), and which was excluded from the review as it did not measure change in beliefs. The Angina Plan is a multi-faceted angina self-management programme which includes behaviour change techniques to encourage physical activity and has a focus on dispelling misconceptions about angina. The study by Lewin, Thompson and Elton (2002) was an educational intervention of audio-taped information and advice about MI and CHD and instructions for relaxation techniques.

Overall, the CSM was the most widely utilised theoretical basis, however, the degree to which theory was utilised in each study varied; theory provided an overall framework, provided a rationale for the intervention components or was used to explain findings. Studies tended to cite a theoretical basis or framework for the overall intervention rather than link the individual intervention components to psychological theories of cognitive or behaviour change. Lack of detail and rationale for the theoretical basis of interventions prevents researchers and clinicians from understanding and making optimal use of findings thus restricting the progression of health intervention science (Montgomery et al. 2013).

### 2.9.1.1 Leventhal's CSM of health and illness behaviour

The CSM, otherwise known as the self-regulatory model (Leventhal, Meyer and Nerenz 1980, Leventhal, Nerenz and Steele 1984), is a psychological model that examines illness cognitions relating to coping with illness, illustrated below in Figure 3.

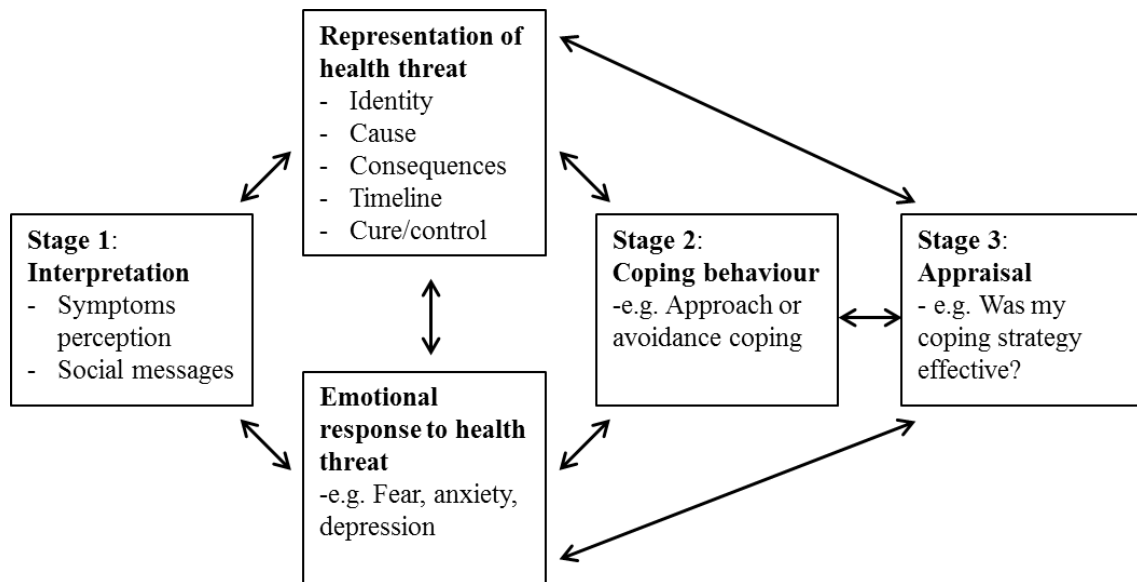


Figure 3: Leventhal's common-sense model of illness behaviour.

The CSM proposes that illness representations provide a framework that helps patients to understand and manage their illness, including responding appropriately to warning signs indicative of an illness or health condition. According to the CSM, when individuals are confronted with a threat to health they build up cognitive representations to make sense of it (which rely on the individual's common-sense and lay beliefs). These cognitive representations inform the individual's coping strategy aimed at managing the health threat and to return to a previous or better state of health. Coping strategies include 'approach coping', such as making required lifestyle changes or 'avoidance coping', such as denial (Leventhal, Meyer and Nerenz 1980, Leventhal, Nerenz and Steele 1984).

The CSM proposes that cognitive representations cover five domains: beliefs about identity, cause, timeline, cure or control and consequences of an illness (Leventhal, Meyer and Nerenz 1980, Leventhal, Nerenz and Steele 1984). An extended CSM

includes dimensions relating to beliefs about treatment and medication (Horne 1997, Horne and Weinman 1999) and illness coherence (Leventhal et al. 1997). Identity representations refers to the label the individual associates with the symptoms of the illness; cause refers to beliefs about what started the illness, timeline relates to beliefs about the illness duration and trajectory; consequences are beliefs about the impact of the illness on the individual's life and cure or control refers to beliefs regarding the illness' potential to be cured or controlled, including beliefs about the degree of personal control over the illness. Treatment representations refer to beliefs about treatment and include perceptions of the benefits and risks of taking medication (Horne 1997). Finally, illness coherence refers to the extent to which the individual understands and can make sense of their illness experience and was added as a subscale to a measure of illness perceptions by Moss-Morris et al. (2002). Research across different cultures and illness types suggests that patients' illness representations do consistently correspond to the five main dimensions of the CSM (Hagger and Orbell 2003).

Another attribute of the CSM is its dynamic nature; illness representations and coping strategies are modifiable through a process of appraisal and feedback. The CSM asserts that individuals appraise their coping strategies in terms of whether or not the expected health benefits were achieved (Leventhal, Meyer and Nerenz 1980, Leventhal, Nerenz and Steele 1984). This appraisal process facilitates the adjustment of inappropriate cognitive representations that will result in a more effective coping strategy and return to health. The CSM demonstrates why it is important for patients to have accurate beliefs about CHD as appropriate coping strategies for managing CHD depend on the beliefs people have about their illness.

A unique aspect of the CSM is that patients' emotional response to an illness threat and emotional coping strategies are taken into account. The CSM proposes that emotional representations, which occur alongside and interact with cognitive representations, guide actions aimed at reducing unwanted emotions, for example, fear, and these actions are similarly appraised for their ability to reduce unwanted emotions (Leventhal, Meyer and Nerenz 1980). Misconceptions about CHD can lead to higher levels of emotional distress which can then result in maladaptive coping strategies, such as

avoidance of exercise (Day, Freedland and Carney 2005, Leong, Molassiotis and Marsh 2004, Ziegelstein et al. 2000).

#### 2.9.1.2 Motivational interviewing

Motivational interviewing was utilised in the CSM-based study by Taylor (2009) to explore its efficacy for improving attendance at CR. Although not based on theory, motivational interviewing is aligned with the transtheoretical model of behaviour change which purports that individuals go through different stages when changing behaviour, from ‘pre-contemplation’ through to ‘maintenance’ of the behaviour; the motivational interviewing approach aims to help individuals move from ambivalence about change to thinking about and making a change (Prochaska and DiClemente 1992). Additionally, motivational interviewing is consistent with the principles of self-determination theory (SDT) (Ryan and Deci 2000) and it has been suggested that SDT can provide a theoretical framework for motivational interviewing (Markland et al. 2005). Miller and Rose (2009) have started to develop a theory to explain motivational interviewing’s mechanism of action and its active ingredients. Their work has identified two main factors; relational and technical components. The relational aspect relates to common factors such as showing empathy and the technical aspect is concerned with the methods used to elicit ‘change talk’ (Miller and Rose 2009).

#### 2.9.1.3 Theoretical framework summary

Leventhal’s CSM provides a theoretical framework on which to base the interventions being developed in this study. Cardiac beliefs and misconceptions correspond to the domains of the CSM, for example, the misconception “it is dangerous for people who have heart disease to argue” (Furze et al. 2003) corresponds with ‘consequence’ representations. The CSM helps to understand the interaction between illness cognitions and behaviour and demonstrates how an appraisal process can lead to changes in both cognitive representations and behaviours. The CSM also considers people’s emotional representations and their attempts to manage unwanted emotions thus providing another explanation for why maladaptive coping occurs. The interventions were developed to provide patients with a simple overview of the CSM, to provide a rationale for engaging in the intervention and for identifying and challenging

cardiac misconceptions.

## 2.9.2 Intervention components and techniques

Strategies used for *identifying* cardiac beliefs and *tailoring interventions* are discussed first and then techniques are examined in relation to which CSM illness representation they were targeted towards changing, as most interventions were based on the CSM.

### 2.9.2.1 Identifying cardiac beliefs and misconceptions

#### *Use of questionnaires*

A number of interventions used patients' responses to a questionnaire to identify their illness representations, beliefs or misconceptions before or at the start of the intervention. Questionnaires included the Illness Perception Questionnaire (IPQ) (Petrie et al. 2002), the Revised Illness Perception Questionnaire (IPQ-R) (Cooper 2004), Brief Illness Perception Questionnaire (Brief IPQ) and the causal scale from the IPQ-R (Broadbent et al. 2009), York Angina Beliefs Questionnaire (YABQ) (Furze et al. 2012, Zetta et al. 2011) and York Cardiac Beliefs Questionnaire (YCBQ) (Furze et al. 2009). For reasons not reported, the Petrie et al. (2002) study did not require patients to complete the causal beliefs section of the IPQ thus these beliefs were not identified or measured at follow-up.

Broadbent et al. (2009) in their further developed version of the Petrie et al. (2002) intervention instead used the shortened version of the 80-item IPQ, the Brief IPQ, developed by Broadbent et al. (2006) to overcome the hindrance of asking unwell patients to complete a lengthy questionnaire such as IPQ-R. Additionally, the brevity of the Brief IPQ makes it more feasible in clinical practice as it is quicker for clinicians to interpret scores. The supposedly robust psychometrics of the Brief IPQ, however, have been questioned by van Oort, Schroder and French (2011) who state that the Brief IPQ has poor content validity and suggest it requires further development. While this has been refuted by Broadbent, Kaptein and Petrie (2011), questions remain about the validity of the Brief IPQ as an outcome measure; however, it may be useful as a clinical tool to promptly identify incorrect or negative cardiac beliefs.

Cossette et al. (2012) administered the IPQ-R as part of the baseline interview but participants' responses do not appear to have been utilised alongside the intervention unlike other studies (Broadbent et al. 2009, Cooper 2004, Petrie et al. 2002). Cossette et al. (2012) only addressed causal beliefs in the third, final, intervention session if patients indicated that they were not planning on attending CR but is unclear from the intervention description how these beliefs were identified.

Furze et al. (2009, 2012) and Zetta et al. (2011) used questionnaires that have been developed specifically to identify common misconceptions about CHD, including physiology and living with heart disease. Items from the YABQ (Furze et al. 2003) and YCBQ (Furze 2011) covered most of the CSM constructs: cause, consequences, cure/control and treatment representations. The YABQ and YCBQ are easy to interpret and reverse scored items are highlighted for ease of identification. The limitation with these questionnaires is that while they have been developed to identify common cardiac misconceptions it cannot be assumed that they will identify every misconception a person holds. The 5-point Likert scale of the research version of the YCBQ allows patients to answer "I don't know" rather than guess a correct response which enables the clinician to identify any areas of insufficient knowledge and potential misconceptions. Furthermore, the Likert scale allows strongly held beliefs to be differentiated from more moderately held beliefs which may allow the clinician to identify where a patient's belief, though correct, may be uncertain due to inadequate knowledge or confusion – or the patient may just require reassurance that they have the correct ideas. Additionally, as strongly held incorrect beliefs can also be identified, it enables the clinician to focus attention where it may be needed most as these beliefs may be more resistant to change.

#### *Use of open questions*

In addition to identifying patients' illness perceptions using the IPQ-R, Cooper (2004) also posed open questions to patients during the intervention, relevant to the constructs of the CSM, for example, "*What do you think caused your heart attack?*" and referred back to the causes the patient had indicated in the questionnaire. Cooper (2004) did not always use open questions; the illness coherence construct was explored with the following closed question, "*Do you understand what has happened to your heart?*" Closed questions invite one word answers that restrict exploration of a topic whereas open questions invite elaboration and promote reflection; asking open questions is a key

aspect of motivational interviewing (Rollnick, Miller and Butler 2008). Unsurprisingly, open questions formed a significant role in the motivational interviewing intervention delivered by Taylor (2009); open questions were used to identify patients' illness beliefs, understanding of their cardiac event and beliefs about treatment, specifically, about attending cardiac rehabilitation.

Other studies appeared to ask open questions as an intervention strategy but in most cases the intervention detail was insufficient to understand what questions were asked. Petrie et al. (2002) and Broadbent et al. (2009) state that patients were asked to identify causal factors other than 'stress' in the first session, but the aim of this was not to identify patients' beliefs but to expand their ideas about causal factors. Illness beliefs were only measured as an outcome of the intervention by Broadbent et al (2013) rather than as part of the intervention.

#### *Tailoring interventions*

Interventions that identified individuals' illness perceptions using questionnaires were more likely to tailor the intervention to the needs of patients. Petrie et al. (2002), Cooper (2004), and Broadbent et al. (2009) tailored the intervention to the individual by eliciting patients' beliefs about their cardiac event prior to the intervention commencing, from patients' responses to the baseline IPQ, IPQ-R or Brief IPQ. This enabled the intervention facilitators to focus on changing problematic illness perceptions. Cooper (2004) also tailored the patient-held intervention booklet according to patients' responses to the IPQ-R; this enabled the written information to be more relevant to each individual, for example, timeline perceptions were recorded in the booklet according to the patient's original response in the IPQ-R and a paragraph followed that either supported their belief, if correct, or, if incorrect, provided an alternative perspective. The disadvantage of tailoring written materials is that this may be burdensome and impractical in the clinical setting.

The manual-based interventions explored by Furze et al. (2009, 2012), and Zetta et al. (2009) did not report an emphasis on tailoring but these interventions focus on changing misconceptions identified by questionnaires and quizzes at the start of and throughout the patient-held workbooks. The HeartOp Plan (Furze et al. 2009) includes a checklist for patients to identify their unhealthy behaviours and where in the manual to find

information relevant to addressing these. Patients are supported to develop individualised goals and plans to achieve these, for example, activity pacing.

Taylor (2009), whilst following a standard intervention structure, tailored his intervention mid-way into the session according to individuals' willingness to change their health behaviours, rated using the readiness ruler (Berg-Smith et al. 1999); the following goal setting component of the intervention used techniques appropriate to the individual's perceived 'stage of change', in keeping with the motivational interviewing approach.

Broadbent et al. (2013) used a computerised cardiovascular risk assessment tool to tailor the intervention according to patients' assessed level of risk. As the study participants had all experienced a cardiac event they were all deemed high risk and, therefore, received identical risk information. The nurse individualised the intervention by emphasising the lifestyle factors relevant for each individual to change. Not enough detail is provided about the intervention to fully understand the interaction between the nurse and patient beyond the exchange of risk information. It appears that the intervention provided information about which behaviour changes were required, for example, increasing exercise, but the intervention description did not expand any further to clarify whether or not information was given on the rationale for making the lifestyle change or *how* to make the required behaviour change. The study outcomes were focused on perception of cardiac risk and illness perception change, not behaviour change and the authors suggest that research is needed to explore if the intervention's effect on risk perception translates into behaviour change (Broadbent et al. 2013). It is unlikely, however, that significant behaviour change will occur as a result of this intervention unless proven behaviour change techniques such as goal setting and action planning are included (or if it is part of a treatment programme which includes such techniques).

The advantage of identifying illness representations, cardiac beliefs and misconceptions before or at the beginning of an intervention is that this allows it to be tailored to the individual's need, namely, their incorrect beliefs and misconceptions. Tailored interventions, as opposed to a one-size-fits-all approach, are advantageous as they have been found to be more successful at facilitating behaviour change and are preferred by



patients (Noar, Benac and Harris 2007, Suhonen, Välimäki and Leino-Kilpi 2008). Tailoring, however, reduces intervention fidelity which may result in biased research findings; this is discussed later on.

#### 2.9.2.2 Changing ‘identity’ beliefs

##### *Strengthen identity beliefs*

The overall aim of interventions appeared to be to strengthen patients’ cognitive representation of the symptoms of MI and CHD. The rationale being that improved identity of symptoms would lead to a more appropriate response, in the case of MI, for example, a quicker response to seek emergency care. It is also important that normal symptoms of recovery or non-cardiac symptoms are interpreted by patients as such so that these sensations do not lead to maladaptive behaviour such as avoidance of physical activity.

##### *Explain CHD/MI, common symptoms and terminology*

Providing information to educate patients about their illness, including an explanation of the commonly used medical terminology and symptoms of CHD and MI was a feature of a number of studies (Broadbent et al. 2009, Furze et al. 2012, Petrie et al. 2002, Taylor 2009, Zetta et al. 2011). Explanations were facilitated by the use of written materials or drawings to provide a concrete image of patients’ heart problem – discussed next. Taylor (2009) did not use these aids but during the discussion about MI with the patient open questions were used to elicit the extent of the patients’ comprehension of the information.

##### *Provide a concrete image of CHD / MI*

Having a concrete image of one’s illness and symptoms is beneficial as it can improve illness comprehension, reduce anxiety, and improve medication adherence (Leventhal). Petrie et al. (2002) used drawings to provide patients with a concrete image of MI, however, details of what these drawings included is not given. The updated intervention by Broadbent et al. (2009) does not describe using drawings but colour diagrams were included in the take-home written materials, again, the content of these is not detailed. A diagram of the heart was used by Cooper (2004) to facilitate the

accurate understanding of the physiology of the heart and coronary arteries and was also included in the intervention booklet. The Heart Op (Furze et al. 2009) and Angina Plan interventions (Zetta et al. 2011, Furze et al. 2012) provided a manual for patients to follow, within these are drawings and pictures explaining the physiology of the heart. The use of pictures can improve patients' understanding and recall of information, especially in patients who have lower literacy levels (Houts et al. 2005).

#### *Distinguish between cardiac and non-cardiac related symptoms*

Patients commonly misattribute physical symptoms to their illness which can impede their recovery and quality of life. Petrie et al. (2006) found that people who associate a larger number of symptoms to their illness are more likely to suffer with sexual dysfunction. Thus, Petrie et al. (2002) and Broadbent et al. (2009) provided patients with information about typical and atypical symptoms of MI with the aim that this would lead to them being less likely to misattribute symptoms to their heart problem. Identity perceptions did not significantly alter as a result of the intervention but patients reported fewer angina symptoms at 3 months compared to the control group (Petrie et al. 2002). Broadbent et al. (2009) did not report the effect of the intervention on identity perceptions; it is assumed there were no significant findings.

A number of interventions were concerned with changing patients' identity perceptions (relating to) in order to improve patients' recognition of future MI symptoms (Broadbent et al. 2009, Cossette et al. 2012, Furze et al. 2009, Furze et al. 2012, Petrie et al. 2002). Petrie et al. (2002) discussed the difference between normal symptoms of recovery and MI symptoms in the third and final session, whereas, Broadbent et al. (2009), discussed symptoms of MI in the third session attended by the patient's spouse; normal symptoms of recovery were discussed in the fourth session. The Angina Plan (Furze et al. 2012 and Zetta et al. 2011) and the Heart Op Plan (Furze et al. 2009) included a section on normal symptoms of angina and of recovery, respectively. Both manuals also include a page with instructions for how to respond to MI symptoms. Cossette et al. (2012) asked patients the following question in the first, pre-discharge, session: "For which symptoms should you go to the emergency department?" so that patients understood when to seek emergency care.

Ideally, people should seek emergency treatment for MI as quickly as possible as this decreases the risk of complications and reduces mortality. One of the factors associated with pre-hospital delay is lack of knowledge about symptoms and mismatch between expected and experienced symptoms; people who recognise the symptoms of MI are more likely to respond quicker (Horne et al. 2000). Even patients who have experienced MI previously have been found to misattribute MI symptoms to other causes, such as indigestion, which highlights the importance of efforts to ensure that patients can distinguish between cardiac and non-cardiac symptoms, symptoms of recovery and MI symptoms.

#### 2.9.2.3 Changing causal attributions

Previous research has shown that patients' perceptions of the cause of their CHD or MI determine subsequent behaviour and outcomes (Furze et al. 2005, Weinman et al. 2000). Incorrect causal attributions can remain despite attendance at CR (Reges et al. 2011) and typically focus on non-modifiable causes and the belief that stress is the main contributing factor (French, Maissi and Marteau 2005).

The identified aims of the interventions, in addition to identifying causal perceptions, were: Expand causal beliefs; Strengthen link between causal factors and health behaviours; Debunk myths about causes and recovery.

##### *Expand causal beliefs*

The following intervention components were utilised to expand patients beliefs about the causes of CHD and MI:

##### *Provide information*

##### *Prompt to consider other causes*

##### *Socratic questioning*

The majority of interventions targeted causal representations by *providing information* regarding the causes of CHD and MI and to address misconceptions that stress is a main cause. This was facilitated through a discussion of causes (Taylor 2009), a combination of discussion and written materials (Broadbent et al. 2009, Cooper 2004, Furze et al. 2009, Furze et al. 2012, Petrie et al. 2002, Zetta et al. 2011) and advice on an audio tape (Lewin, Thompson and Elton 2002). Interventions also encouraged patients to expand

their beliefs about the causes of their MI by *prompting to consider other causes*, for example, being asked to think of other factors that may have contributed to their MI (Broadbent et al. 2009, Petrie et al 2002, Taylor 2009). Cooper (2004) listed and discussed the causes previously given by patients (from the IPQ-R) and added other relevant causes not mentioned. It appears that while Cossette et al. (2012) gave information on risk factors, patients beliefs about what they believed had caused their MI were not discussed. Causal beliefs were only discussed with patients in the final session if they had indicated that they were not planning on attending CR, in which case the nurse focused on *reframing* patients' beliefs towards modifiable causes in effect to persuade patients of the importance of CR, as described by Cossette et al. (2009). *Reframing* is a component of cognitive restructuring from CBT and involves presenting an alternative, often more positive, explanation for an event in order to change a person's beliefs, emotions or behaviour relating to it. It is unknown how often Cossette et al. (2012) utilised reframing to address patients' causal beliefs or its success at doing so. Furthermore, the reframing technique appeared to focus on the didactic giving of information to patients, requiring the nurse to assume an expert stance, known to be less effective and less desired by patients (Britt, Hudson and Blampied 2004).

Cooper (2004) and Taylor (2009) used *Socratic questioning*, for example, "*why do you think these might have caused your heart attack?*" to explore patients' beliefs about why their identified causes had caused their CHD or MI. These questions naturally led on to discussing behaviour change, as discussed further, below. Using the motivational interviewing approach, Taylor (2009), asked patients, "*Do you plan on making any changes in your life as a result?*"

Giving information about important causal factors may have conflicted with the patients' beliefs and together with asking patients to think of which factors, other than stress, may have been responsible for their own illness is likely to have resulted in cognitive dissonance.

Cognitive dissonance is where individuals hold conflicting thoughts or beliefs causing a feeling of discomfort that is alleviated by altering the beliefs and/or changing behaviour. Cognitive dissonance can be induced in psychological interventions to help people make behaviour change by facilitating a change in beliefs and attitudes about the

behaviour, motivating people to make behaviour changes (Miller 2010). Utilising cognitive dissonance is a feature of Motivational Interviewing, an approach that facilitates behaviour change and works through patients' ambivalence to change. Petrie et al. (2002) do not mention Motivational Interviewing as an approach used in their illness perception intervention although it is evidently used.

#### *Strengthen link between causal factors and health behaviours*

After identifying and expanding patients' beliefs about the causes of their illness, a number of interventions aimed to strengthen the link between causal factors and health behaviours, such as smoking or high cholesterol; this is important because patients are less likely to make health behaviour changes and attend CR if they do not believe their illness was caused by factors modifiable through behaviour change (Cooper et al. 1999, French, Cooper and Weinman 2006). Cooper (2004) utilised a *responsibility pie chart*, a cognitive behavioural technique traditionally used to challenge distorted cognitions and emotions about responsibility for events. Cooper (2004) completed a pie chart with each patient to demonstrate how their relevant causes were responsible for their MI, this served as a bridge to discuss behaviour change as patients were then asked to point to which factors they could address.

French, Maissi and Marteau (2005) highlight a number of concerns regarding identifying and changing patients' causal attributions. Firstly, the researchers identified that when patients speak about what caused their MI they tend to think in terms of single causes for what triggered their MI rather than the chronic underlying causes. This finding questions the validity of research into patients' causal attributions as patients may be answering a different question to the one posed by the researcher (French, Maissi and Marteau 2005). Additionally, it highlights that health professionals, when talking to patients about causes of MI and CHD, should acknowledge that patients may be thinking in terms of acute triggers and clarification of this could ensure that patient and health professional are discussing the same issue; this is likely to help focus patients towards behavioural causes such as sedentary behaviour. Secondly, patients' causal attributions may serve an adaptive purpose and it may not be beneficial to address these too early. French, Maissi and Marteau (2005) suggest that

patients focus on attributions that avoid blame and assert control; explaining that stress may be a popular cited cause of MI because 'stress' is a flexible concept and is usually viewed as controllable. Viewing stress as the cause, therefore, may serve as a protective factor against poor emotional adjustment following MI, more commonly associated with blame attributions and reduced sense of control (French, Maissi and Marteau 2005). These findings question the benefit of interventions that focus on changing patients' causal attributions of stress, in particular Broadbent et al. (2009) and Petrie et al. (2002) whose interventions are delivered to patients before discharge from hospital. Indeed, French, Maissi and Marteau (2005) suggest that attempts to change patients' causal attributions of stress may be harmful and further research is required to understand more about the role and purpose of causal attributions.

#### 2.9.2.4 Changing 'timeline' beliefs

##### *Shorten timeline beliefs*

Petrie et al. (2002) and Broadbent et al. (2009) aimed to change patients' perceptions towards viewing their illness as being of short duration. This was as a result of the researchers' earlier findings that longer timeline perceptions were associated with perceptions of more severe consequences and delayed return to work (Petrie et al. 1996). Both interventions *discussed appropriate timelines to normal recovery* with patients and *linked timeline to consequences* by explaining that as recovery progressed patients would be able to return to normal activities. Timeline beliefs were discussed alongside consequences beliefs.

##### *Change timeline beliefs to 'chronic'*

Other interventions (Cooper 2004, Furze et al. 2012, Zetta et al. 2011) focussed on encouraging patients' to view their illness as being chronic in duration. This was achieved by explaining that while MI was an acute event, it is part of CHD, a chronic condition (*emphasising short-term & long-term nature of MI/CHD*). Cossette et al. (2012) found, when developing the intervention, that patients were not aware of the chronic nature of atherosclerosis but report that this belief was not addressed in the first session; it is unclear how the intervention encouraged a more chronic view of CHD.

The benefits to patients of viewing their heart condition as being less serious and less long lasting, as per the interventions by Broadbent et al. (2009) and Petrie et al. (2002), is questionable. Shorter timeline beliefs may help patients feel more optimistic about their illness, helping to prevent depression (Sanjuán, Arranz and Castro 2011) but may mean that patients do not understand the importance of attending CR or of making lifestyle changes (French, Cooper and Weinman 2006). While longer timeline representations have been found to be associated with psychological distress and depression this is where patients also hold negative views about the control and curability of their illness (Dickens et al. 2008, Hagger and Orbell 2003). A chronic timeline representation of CHD is preferable as this predicts greater adherence to medication (Byrne, Walsh and Murphy 2005) and other risk modification behaviours important for secondary prevention of CHD, including attendance at CR (French, Cooper and Weinman 2006).

#### 2.9.2.5 Changing ‘consequence’ beliefs

*Challenge negative belief that activities will need to be reduced long-term*

The second session of the Petrie et al (2002) and Broadbent et al. (2009) intervention focused on reducing negative beliefs patients had about the consequences of MI, particularly relating to activities they believed would have to reduce or cease. Cooper (2004) addressed consequence beliefs by asking patients of their intention to return to work; it is unclear how negative responses were managed or how consequences were addressed for people not in employment.

#### 2.9.2.6 Changing ‘control / cure’ beliefs

While it is known that patients are less likely to attend CR if they have a weak belief in the cure/controllability of their illness (Cooper et al. 1999, Petrie et al. 1996) people who believe they have been cured as a result of treatment (and have an acute model of CHD) are also less likely to attend CR or change their risk factors. Interventions were focused towards strengthening patients’ belief in the potential for their illness to be controlled as opposed to cured. Cossette et al. (2009) interviewed patients as part of a

needs assessment when developing their intervention and found that patients commonly viewed their hospital treatment as having been a cure and lacked understanding about the chronic nature of CHD; the authors report this finding was incorporated into their intervention but insufficient detail about the intervention components means the strategy used cannot be identified (Cossette et al. 2012). Furze et al. (2009) addressed patients' misconceptions that surgery would cure their heart disease by providing information in a 'myths' section in the patient manual that encouraged a chronic but manageable view of heart disease.

*Provide personalised information illustrating how behaviour change can reduce risk*

The computerised decision support tool used in the intervention by Broadbent et al. (2013) gave patients a personalised print out including a graph showing their risk of MI and stroke and how their risk could increasingly reduce if 1, 2 or 3 behaviour changes were made. The nurse facilitator recorded on the sheet which lifestyle changes would be beneficial for the patient; this is not in keeping with a collaborative patient-centred approach and may have resulted in minimal behaviour change although this is unknown as it was not an outcome measure. The intervention led to a short-term improvement in patients' sense of personal control and increased their belief that improving diet and exercise could control their CHD but these changes were not evident at 3 months follow-up showing that further support is required to maintain control beliefs; Broadbent et al. (2013) did not measure attendance at community CR classes so it is unclear what support patients received after discharge.

*Promote idea of a control continuum*

Cooper (2004) showed patients a continuum line with 'no control, down to fate or chance' at one end and 'high personal control – what I do will definitely make a difference' at the other end. Patients were prompted to indicate their belief in personal control by marking this on the continuum line. The rationale for the continuum line was to emphasise that control is not an all or nothing concept and to highlight that control could be increased by managing risk factors and attending CR. The intervention could have been enhanced by using the same method to explore patients' treatment control



perception, their level of belief that treatment, for example, CR, has the potential to cure / control their illness (Horne and Weinman 1999), particularly as the intervention was aimed at encouraging patients to attend CR.

#### *Discuss methods of health behaviour change/ encourage behaviour change*

All interventions emphasised the need to make lifestyle changes in order to manage CHD and to protect from further MI. A smaller number of interventions encouraged patients to increase their sense of personal control over their CHD and supported them to make the relevant behaviour changes. These interventions used methods that are recognised ‘behaviour change techniques’ (BCTs) for behaviours relating to smoking cessation, exercise and physical activity (Abraham and Michie 2008, Michie et al. 2011).

#### *Action planning*

Petrie et al. (2002) and Broadbent et al. (2009) used a written ‘personal action recovery plan’ which included a tailored plan of exercise, dietary change and return to work – this BCT is known as *action planning* (Michie et al. 2011). Action planning involves making a detailed plan of what behaviour is to be carried out, where, when and how many times a day/week or duration (Michie et al. 2011).

The theory of reasoned action (TRA) (Ajzen and Fishbein 1980) and the theory of planned behaviour (TPB) (Ajzen 1991) posit that intentions to perform behaviour predict behaviour. Despite being a relatively strong predictor of behaviour, behavioural intentions do not necessarily translate to behaviour change and there can be a discrepancy between stated intentions and behaviour (Orbell and Sheeran 1998, Sutton 1998). Action planning is believed to ‘bridge the gap’ between intentions and behaviour and has proven its worth across a wide range of behaviour domains (Abraham et al. 1999) and, importantly, is successful at increasing physical activity in cardiac patients (Ferrier et al. 2011).

#### *Goal setting and pacing*

Furze et al. (2009, 2012) and Zetta et al. (2011) discuss the importance of *goal setting*

*and pacing* with patients and explain how this can prevent them getting into an overactivity-underactivity cycle that leads to problems including physical deconditioning. Activity pacing was first developed as a self-management technique for chronic pain patients; it aims to improve activity levels through planned tasks of gradually increasing duration or intensity (Birkholtz, Aylwin and Harman 2004). Lewin et al. (1995) developed the goal setting and pacing method for the Angina Plan intervention (Furze et al. 2012, Zetta et al. 2011) and a similar format is followed in the HeartOp Plan (Furze et al. 2009); it appears that goal setting and pacing is similar to the BCT '*set graded tasks*' (Abraham and Michie 2008).

The goal setting and pacing elements of the Angina Plan and HeartOp Plan supports patients to, firstly, set behavioural goals and, secondly, to plan activities which begin at their baseline level of intensity and gradually increases as tasks are experienced as easy. The manuals included record sheets (Furze et al. 2012 and Zetta et al. 2011) or a diary (Furze et al. 2009) for patients to record progress towards achieving their behavioural goals – a BCT known as '*prompt self-monitoring of behaviour*' and is effective for improving physical activity and healthy eating (Michie et al. 2009). Additionally, follow-ups reviewed patients' progress with their goals and enabled facilitators to give feedback on goals; these techniques are known as: '*prompt review of behavioural goals*' and '*Provide feedback on performance*' and have empirical support (Michie et al. 2009, Michie et al. 2011). Follow-up was conducted by 10-15 minute telephone calls at 3 weekly intervals for about 6 weeks (Furze et al. 2009), 4 weekly intervals for 12 weeks (Zetta et al. 2011) or a negotiable number of follow-ups over 12 weeks by telephone or home visit (Furze et al. 2012). Unfortunately, Furze et al. (2012) did not report on the quantity, duration or nature of follow-ups so the overall 'dose' of received support is unknown.

*Goal setting, self-monitoring of behaviour, review of previously set goals and feedback on performance* are self-management techniques originating from the discrepancy-reducing feedback loop of control theory; the theory posits that goals will be more successfully achieved if people receive feedback on the discrepancy between their behaviour and their goal (Carver 1981, Carver and Scheier 1982). Evidence to support control theory techniques shows that goal setting on its own is insufficient (Michie et al. 2009). The other interventions do not encourage self-monitoring or review goals over a

meaningful timeline, for example, Petrie et al. – goals are reviewed in the final session but as this is only 3 days since the first session and the patient has not yet been discharged performance towards goals has not been possible therefore feedback cannot be given.

While only two interventions mention self-efficacy (Cooper 2004 and Taylor 2009) it is assumed that an illness perception intervention would benefit from addressing cognitions and behaviours associated with self-efficacy. Self-efficacy is “the belief in one’s capabilities to organise and execute the courses of action required to produce given attainments” and is a construct of social cognitive theory (Bandura 1977). Improving self-efficacy is important as it is a key determinant of behaviour and is linked with the adoption and maintenance of physical activity (Sallis et al. 1986). Goal setting and pacing or ‘*set graded tasks*’ are techniques that break a goal into smaller, more achievable, steps which enables people to attain a level of mastery leading to improved self-efficacy for reaching the end goal. Improving patients’ self-efficacy for performing behaviours associated with risk factor reduction can help patients increase their sense of control over their condition. The evidence for ‘*set graded tasks*’, however, is mixed. Recent reviews and meta-analyses by Ashford, Edmonds and French (2010) and Olander et al. (2013) have found that ‘*set graded tasks*’ is associated with significantly lower self-efficacy for physical activity. These findings, however, are for ‘healthy’ people and, therefore, may be less relevant to cardiac patients as their health condition dictates that a gradual increase in activity is followed.

#### *Prompt barrier Identification*

Broadbent et al. (2009) discussed the benefits and problems of changing behaviour but it is unclear whether this was from the patients’ perspective or how perceived problems were addressed or incorporated into the action plan. Cooper (2004) asked patients to identify any difficulties that may prevent them from carrying out behaviour change and ways to overcome them, this is a common strategy termed *prompt barrier identification* by Abraham and Michie (2008). Cossette et al. (2012) similarly discussed patients anticipated difficulties with changing their risk factors but it is unclear if problem solving was involved as the intervention strategy appears to have focused on persuading patients of the benefits of attending CR. Patients who received the intervention by

Cossette et al. (2012) had a significantly greater sense of personal control over their illness ( $p = 0.041$ ) and were more likely to attend CR compared to the control group ( $p = 0.001$ ), whereas, the intervention by Cooper (2004) did not lead to any changes in CR enrolment. The reasons for these, and the other reviewed interventions' successes and failures, however, cannot be attributed to particular intervention components or mechanisms of action as they do not provide adequate detail about the intervention. Cossette et al. (2012) have recognised this limitation and state an intention to analyse additional data concerning the description of the intervention to understand any links between the content of the intervention and changes in illness perceptions.

As an intervention component, *prompt barrier identification* may not be useful; although commonly used in behaviour change interventions it is associated with decreased self-efficacy (Ashford, Edmunds and French 2010). Work by Sniehotta, Scholz and Schwarzer (2006) on improving patients' adherence to physical activity after attending a CR programme suggests that barrier identification is beneficial when it is used to construct a coping plan and only when used in conjunction with an action plan. Taylor (2009) asked patients who were ambivalent about change about their views on the benefits of change and the costs of not changing, whereas patients who indicated a readiness to change were asked to voice their views on what changes are needed and ideas for change; all patients, regardless of readiness for change were encouraged to set goals for the action plan. Ashford, Edmunds and French (2010) suggest that the motivational interviewing (Miller and Rollnick 2002) approach of focusing on reasons to change may be more appropriate than having patients voice their barriers or reasons not to change. Practical barriers to attending CR (Cooper et al. 2005), such as transport, however, may be useful to identify and problem solve.

#### 2.9.2.7 Improve belief in treatment control

##### *Discuss concerns and provide information about taking prescribed medication*

Beliefs about medication were addressed by Petrie et al. (2002) and Broadbent et al. (2009) by discussing the benefits of medication and any concerns patients had about their medication. Petrie et al. (2002) describe explaining to patients the importance of taking medication regularly and not relying on symptoms to guide medication use; it is

unclear if taking medication was added to the action plan or if this discussion also took place in the updated version by Broadbent et al. (2009). Cossette et al. (2012) provided information about medication and inquired about patients' views on adherence to their medication regime. Broadbent et al. (2013) emphasised the importance of taking medication to reduce risk of further MI and Cooper (2004) presents taking medication as one aspect of taking control of CHD.

### *Strengthen belief in CR as a treatment*

In addition to components aimed at changing patients' perceptions about the identity, cause, timeline, consequences and personal control of CHD, a number of interventions addressed treatment control perceptions directly. It appears necessary for interventions to manage any cognitive barriers to attending CR, such as misconceptions about the need for CR or of what CR entails (French, Cooper and Weinman 2006). A number of interventions included enrolment or adherence to CR as a primary (Cooper 2004, Cossette et al. 2012, Taylor 2009) or secondary (Broadbent et al. 2009, Petrie et al. 2002) outcome measure. The Angina Plan intervention (Furze et al. 2012, Zetta et al. 2011) did not encourage enrolment onto a CR programme because CR is not routinely provided to angina patients and the intervention is a home-based CR in its own right. The HeartOp Plan (Furze et al. 2009) did encourage CR participation by providing information about what CR involves but attendance was not included as an outcome measure.

Petrie et al. (2002) and Broadbent et al. (2009) do not mention CR to patients from the intervention description so it is unknown whether this was discussed, a part of patients' action plan or as part of usual care. Patients receiving either intervention had higher intentions to attend CR but although more people did attend CR, attendance was not significantly different compared to the control group. The primary aim of the interventions was quicker return to work, which was achieved; it may be that a bias towards encouraging work meant patients were less likely to attend CR. While return to work has social and economic benefits for patients it may be more detrimental in the long-term for patients to miss CR in favour of work. It is also possible that due to the interventions providing patients with an action plan for reducing risk factors (Broadbent

et al. 2009, Petrie et al. 2002) and having increased patients' perceptions of personal control over their illness (Petrie et al. 2002) that patients believed they had the resources to manage without CR; the long-term effects of this is unknown.

The intervention by Cooper (2004) had no impact on attendance at CR; however, both groups had a higher than average attendance (68%) which was suggested to have been as a result of recent positive changes to improve CR both locally and nationally (Cooper 2004).

The intervention by Taylor (2009) was delivered to patients who were already attending their first CR class so the focus was on encouraging adherence to CR. Taylor (2009) discussed the CR programme with each patient and elicited their perceptions of treatment by asking questions, including, "*What do you think of attending for these sessions?*", "*Do you think this programme is going to help you to recover?*" and corrected any misconceptions about CR using a motivational interviewing style. The intervention group attended significantly more sessions than the control group ( $p=0.043$ ) but, in contrast to Petrie et al. (2002), illness perceptions relating to consequences, control or treatment were not changed. Whilst the study was limited by its small numbers it appears that factors other than illness perceptions led to increased adherence. Taylor (2009) suggests that the goal setting and action planning components of the intervention may have strengthened patients' 'implementation intentions', a construct from the TPB that is related to putting goals into action (Gollwitzer 1999), or that the motivational approach moved patients towards the 'action' and 'maintenance' phases of the TTM (Prochaska and DiClemente 1992). As the intervention was devised to improve patients' self-efficacy this may have contributed to improved CR adherence but as the researcher did not measure self-efficacy the effect of the intervention on this construct is unknown.

#### 2.9.2.8 Emotional representations

Secondary analysis of the data from the Petrie et al. (2002) study found that patients were less likely to benefit from the intervention if they displayed higher trait negative affect, such as low mood or anxiety (Cameron et al. 2005). The authors suggest that the addition of an emotion-focused approach may improve outcomes for patients with low

mood or anxiety (Cameron et al. 2005). The updated intervention (Broadbent et al. 2009) was delivered before these findings could be incorporated as data was collected between 2002 and 2003. However, Broadbent et al. (2009) included an extra session for patients with a participating spouse that could be seen to have explored emotional representations by exploring and normalizing concerns regarding patients' return home. It is not uncommon for the MI patient's spouse to experience psychological distress in response to the patient's MI and this distress can have an adverse effect on patients' recovery (Moser and Dracup 2004). Exploring and correcting illness perceptions and cardiac misconceptions of patients *and* their spouse enables them to have similarly aligned perceptions of MI and CHD which has been found to be beneficial for patients' recovery (Figueiras and Weinman 2003). Cooper (2004) did not include specific stress management techniques but provided information about common mood changes after MI to normalise the experience of low mood and provided brief practical advice.

#### *Stress management/ emotional control training*

Michie et al. (2011) state that the BCT '*stress management /emotional control training*', which includes specific techniques such as progressive relaxation, does not directly target behaviour but may facilitate it as a result of reduced anxiety and stress. Patients' cardiac misconceptions can maintain negative affect and make them less likely to engage in behaviour that will improve their outcomes, including, their emotional and physical wellbeing (Furze et al. 2005).

The Angina Plan and HeartOp Plan have sections dedicated to patients' emotional response to their illness; cognitive behavioural strategies are utilised to manage negative emotions and both interventions include a relaxation CD. The workbooks explain techniques which include: progressive muscular relaxation, positive imagery, breathing techniques, distraction, positive thinking and changing stress related behaviour. The Plans detail how negative thinking is linked to extra production of adrenaline leading to further stress and advice is given on how to deal with negative thoughts; the HeartOp Plan provides more advice on how to change negative automatic thoughts using a brief form of cognitive restructuring. The advice for changing negative thinking, however, does not include writing thoughts down on paper and there is no place in the patients'

Angina Plan weekly record sheet or HeartOp diary to record or challenge unhelpful thinking. The act of writing down thoughts is known to help people identify and make sense of negative thoughts and the use of thought diaries and worksheets is a key part of cognitive restructuring. Interventions aiming to change negative or unhelpful thinking about CHD would benefit from providing a resource to allow and encourage patients to write down and challenge thoughts.

Lewin et al. (2002) aimed to address patients' fears about dying from MI by providing reassurance on the audio tape that this was unlikely as they were now receiving treatment. Cossette et al. (2012) purport to have addressed patients' concerns and worries and state that emotional support was provided depending on patient need and included: normalisation, legitimisation, listening, and reassurance. Details about these aspects of emotional support, however, are not given. Neither of these interventions led to improvements in levels of anxiety or low mood experienced by patients at follow-up which indicates that different or additional methods may be required. Additionally, providing reassurance can be unhelpful for patients who are overly anxious about their health as it increases reassurance seeking behaviour and anxiety (Salkovskis and Warwick 1986).

#### 2.9.2.9 Intervention format

All of the reviewed studies were of interventions that were delivered on an individual basis, either entirely in person (Broadbent et al. 2009, Broadbent et al. 2013, Cooper 2004, Petrie et al. 2002, Taylor 2009) or with an initial session in person followed on by telephone sessions (Cossette et al. 2012, Furze et al. 2002, Furze et al. 2012, Zetta et al. 2011). The tape study intervention was entirely self-administered by the patient (Lewin et al. 2002). No relevant studies were identified that utilised a group format whereas the review by Goulding, Furze and Birks (2010) included a study that had a group-based arm (Barnason and Zimmerman 1995). All but 3 studies (Furze et al. 2009, Furze et al. 2012, Taylor 2009) were delivered to people hospitalised due to their cardiac event and the intervention completed prior to discharge from hospital, apart from the Angina Plan intervention which continued as the patient returned home. Possibly, it is more appropriate to deliver a one-to-one intervention to people who are in hospital due in part



to the practicality and logistics of delivering a group intervention in hospital to patients who are likely to be requiring ongoing machine monitoring. As in-patients may receive an individual session with a CR nurse, to identify risk factors and discuss necessary lifestyle changes, the addition of additional methods to identify and manage cardiac misconceptions is likely to fit within this format.

Group-based interventions do exist in the literature but were not included in this review as outcomes did not include illness perceptions or cardiac misconceptions (for example, Moore et al. 2005) and/or they were multifaceted cardiac rehabilitation (for example, Lidell and Fridlund 1996), psycho-education programme (for example, McGillion et al. 2008) or lifestyle change programmes (for example, Frattaroli et al. 2008) making it difficult to identify which components of these interventions were aimed at changing cardiac beliefs. The social context of group-based interventions has been found to facilitate behaviour change and self-management of chronic illnesses and improves self-efficacy via social support, modelling, social persuasion and social comparison (Gallant 2003, Lorig et al. 2001). Furthermore, patients value the social aspect of group-based CR programmes (Clark, Whelan, Barber et al. 2005). Group-based interventions are also more cost-effective but it is unknown how acceptable a group intervention will be to people because the session cannot be personalised to their individual illness perceptions. Furthermore, as it is not feasible to tailor a group intervention to individuals, this is likely to reduce efficacy.

## 2.10 Quality of reviewed studies

### 2.10.1 Ethical considerations

All studies reported that they received ethical approval before proceeding with the study.

### 2.10.2 Extent of intervention development

As previously discussed, systematic development of an intervention is important for a number of reasons; primarily so that the best components are chosen so to increase the likelihood that an intervention is efficacious and also that the intervention's mechanism of action is understood. Systematic intervention development allows an intervention to

be refined in terms of its content and delivery, optimising its acceptability and feasibility to patients, healthcare staff and services prior to a definitive evaluation of its efficacy and cost effectiveness (Medical Research Council 2008). While the MRC guidelines have been used by researchers worldwide to inform the development of healthcare interventions, other frameworks and guidelines provide more detailed advice for intervention development, these include: Intervention Mapping (Bartholomew, Parcel and Kok 1998, Bartholomew et al. 2011), the PRECEDE-PROCEDE approach (Green and Kreuter 2005) and the Behaviour Change Wheel approach (Michie, van Stralen and West 2011). Intervention mapping is a tool for planning and developing health promotion interventions through a series of iterative steps (Bartholomew et al. 2011).

PRECEDE-PROCEED is a planning model that is also used for developing health promotion interventions that works from an idea of the desired end point and working back to identify objectives that will achieve that goal (Crosby and Noar 2011). The Behaviour Change Wheel is a theory and evidence-based tool that improves understanding of behaviour and enables the design and selection of interventions and policies that consider a range of factors including people's internal motivating factors and external factors such as time (Michie, van Stralen and West 2011). Whilst these models of intervention development could have been chosen for the current project their focus on behavioural outcomes and health promotion made them less relevant for this study which is focused, at this stage of the research, on changing cognitions not behaviour. It was decided that the MRC framework for developing complex interventions are appropriate guidelines to follow because of its focus on modelling and pilot testing to fully develop interventions. A drawback of the MRC framework is that it provides fewer guidelines for developing the content of the intervention than models such as the Behaviour Change Wheel.

Cossette and colleagues followed American guidelines proposed by Whittemore and Grey (2002), similar to the UK's MRC guidelines, to develop their intervention and is detailed in a separate paper (Cossette et al. 2009). However, the use of qualitative methods to develop the intervention was limited to an assessment of 23 patients' illness perceptions and their openness to modify risk factors rather than exploring patients' views regarding potential intervention components, although, it did establish that a

telephone follow-up was preferred. The use of qualitative methods, instead of or in addition to the patient satisfaction questionnaire, to explore intervention acceptability would have enabled a deeper understanding of patients' experiences of the intervention and provided useful data to improve the intervention (Lewin, Glenton and Oxman 2009).

Lewin, Thompson and Elton (2002) briefly explain that the tape intervention was developed as a result of a literature search and interviews with patients. The Angina Plan (Furze et al. 2012, Zetta et al. 2011) reports to be a systematically developed intervention with further details about the Plan provided by Lewin et al. (2002), however, the process of the development is not fully explained. The remaining studies did not report on any attempts to explore the acceptability and feasibility of the interventions prior to their efficacy testing, thus, the degree to which interventions were optimally designed is questionable.

#### 2.10.3 Extent of process evaluation: patient experience and satisfaction

Whilst an RCT can conclude if an intervention appears to be effective or not, its scope is limited in terms of explaining why the intervention worked or didn't work. Process evaluations are one way of exploring the factors which contributed to an intervention's success or failure, including, the intervention's content, its application and the context of the setting in which it was delivered (Medical Research Council 2008). Process evaluations require mixed methods to provide a detailed and more complete understanding of multiple factors impacting the intervention, for example, the extent to which participants received the full 'dose' of the intervention, the extent to which the intervention was delivered as planned and exploration of potential barriers to the intervention's implementation in the clinical setting (Craig et al. 2008). Process evaluation provides a richer understanding of the intervention as a whole, enhancing researchers' ability to further improve and develop similar interventions. Furthermore, process evaluation provides information that allows clinicians to implement interventions outside of the research setting in a way that will optimise success (May et al. 2007).

The reviewed studies reported zero to minimal process evaluation. Broadbent et al. (2009) and Petrie et al. (2002) measured patient satisfaction with the intervention using a brief questionnaire and Zetta et al. (2011) used the treatment satisfaction aspect of the SAQ. The use of brief quantitative methods to explore patient satisfaction and perceptions of an intervention limits the depth of understanding that can be learnt from participants' experiences. Patient satisfaction surveys have been criticised on a number of levels; the lack of consensus regarding the definition of 'satisfaction' and disregard of other factors which influence satisfaction, such as demographics, health status and social-psychological factors which can all hide patient dissatisfaction (Hekkert et al. 2009, Williams, Coyle and Healy 1998). Surveys, in their nature, ask a set of pre-determined questions posed from the researcher's point of view. This inevitably limits patients' responses resulting in findings which may not capture the full picture of peoples' views and experiences (Sitzia and Wood 1997). Furthermore, the timing of a satisfaction survey is important; patients require time to reflect on their experience but over two weeks may increase recall bias (as well as decreasing response rates) (Stevens et al. 2006). Participants in the study by Broadbent et al. (2009) were posted the satisfaction questionnaire at 3 months post-intervention. Consequently, it is quite possible that responses to this questionnaire were affected by recall bias, especially because the intervention was relatively brief and the time lag may have made the intervention harder to separate from other treatment received since.

The only study to use qualitative methods to understand patient experience of the intervention was Furze et al. (2012), who nested a qualitative study alongside their RCT, reported in a separate paper by Nelson et al. (2013). Nelson et al. (2013) found that while patients were accepting of lay-workers' support, their need for information about medication, which cannot be given by a lay-worker, indicated that an entirely lay-supported programme was not practical and an element of nursing support would be needed. Lewin, Glenton and Oxman (2009) report that qualitative methods to help understand the findings of complex interventions are underutilised, as found in this review. Efforts to improve the development, evaluation and reporting of complex interventions will require more researchers to include qualitative methodologies (Craig et al. 2008, Schulz et al. 2010)

#### 2.10.4 Extent of process evaluation: intervention fidelity

The extent to which an intervention was delivered as planned is vital for researchers to measure and report because it informs the reliability and validity of the findings and accuracy by which the findings are interpreted and used for further research or clinical practice (Mars et al. 2013). Fidelity can be monitored and enhanced in a number of ways, for example, by audio-recording sessions and checking a random selection, following a treatment manual or completing a treatment checklist (Spillane et al. 2007). Only a small number of the reviewed studies appeared to make attempts to enhance fidelity, reflecting findings that fidelity is under-evaluated (Craig et al. 2008). Cooper (2004) was the only researcher to audio-record and check intervention sessions, although this appears to have been for supervisory purposes with the emphasis on quality of delivery as opposed to fidelity per se. Taylor (2009) describes following a structured session guide for the purpose of enhancing fidelity to the intervention protocol and provides a detailed copy of this guide. The interventions reported by Furze et al. (2009), Furze et al. (2012) and Zetta et al. (2011) utilised a treatment manual and patient-held treatment booklets so were, therefore, more likely to adhere to the treatment protocol. Other studies described a pre-determined focus for each session but the exact content depended on patients' individual perceived needs (Broadbent et al. 2009, Cossette et al. 2012, Petrie et al. 2002). Cossette et al. (2012), for example, describe flexible use of the intervention components depending on perceived patient need:

*“Based on the nurse’s clinical judgment, interventions included teaching, emotional support (normalization, legitimization, listening, and reassurance), cognitive support (reframing, clinical advice, warnings, and suggestions), reinforcement of internal and external resources/strengths, and referral to external health resources when needed.”*  
(Cossette et al. 2012 p:116)

Flexible delivery of a tailored intervention can enhance the intervention's efficacy as the content can be made more relevant to the individual or the setting and can facilitate the success of an intervention when it is implemented outside of the research setting (Cohen et al. 2008). However, the studies that have utilised a more flexible intervention approach are limited regarding the above benefits as there is a lack of clarity regarding which aspects of the intervention should be used in which circumstances. As Cossette

et al. (2012) relied on the nurses' clinical judgement in deciding which techniques to use during the intervention, rather than following a set protocol, makes it more difficult to distinguish whether the findings were as a result of the intervention components or the personal characteristics of the deliverer.

The studies would have benefited from keeping a record of techniques used in each intervention session; this would provide a measure to report intervention fidelity, clarify which techniques were used in which circumstances and enabled a more complete process evaluation.

#### 2.10.5 Contamination with confounding factors

Two studies considered the influence of intervention contamination and attempted to limit this through the use of an intervention prompt sheet and checklist for nurses (Furze et al. 2009), and instructions to participants not to share the intervention with other patients (Lewin et al. 2002). Other studies did not report attempts to reduce contamination between experimental groups which questions the validity of these studies' findings. Intervention contamination is likely to be more problematic for those studies where the intervention was delivered solely or partially in a hospital setting, due to the close proximity of control group participants and the fact that these studies do not report on attempts to reduce contamination (Broadbent et al. 2009, Cossette et al. 2012, Petrie et al. 2002, Zetta et al. 2011).

### 2.11 Review strengths and Limitations

This review aimed to explore the theoretical basis of illness perception interventions in a CHD population so that relevant theory could be identified and utilised for the intervention being developed in this project. Unfortunately, overall, the theoretical basis of interventions was inadequately explained especially in terms of explaining why intervention components were chosen and explaining interventions' intended mechanism of action. This demonstrates the need for researchers to more adequately detail and explain their use of theory, as identified by Michie and Prestwich (2010).

The review also aimed to explore the components of the identified interventions so that relevant methods and techniques could be identified and utilised in the development of the current intervention. The behaviour change technique taxonomy (Abraham and Michie 2008) was not found to include relevant techniques for changing illness perceptions so this review developed a unique system to identify and class intervention techniques according to the illness representation the technique was said or perceived to be targeting. A number of techniques were identical to BCTs, for example, *goal setting*, but these were able to be grouped according to the illness representation(s) they were likely to affect. Since this review, an updated version of the BCT taxonomy has been published which now includes 93 techniques and may be of more relevance to interventions aimed at changing illness perceptions (Michie et al. 2013). Classifying intervention components according to their illness representation target is a strength of this review as it became clear that the CSM was the most relevant theoretical basis thus linking techniques to illness representations was logical. It is hoped that this will result in a more effective intervention, but this remains unknown until a future trial of the fully developed intervention is completed.

This review only included studies of a CHD population; while this enhances the relevance of the identified theory and intervention techniques, excluding studies from other illness populations, for example, diabetes (Keogh et al. 2011), prevents additional techniques and intervention formats from being identified. It is also important to note that multi-morbidity of long-term conditions is on the increase (Salive 2013) and an intervention aimed at illness perceptions of one illness may be less effective than an intervention that takes into account other illnesses.

Due to time and resource limitations the review was restricted to papers published in the English language, although it is possible that studies were missed, no non-English language studies were identified. Whereas Goulding, Furze and Birks (2010) reviewed only RCTs, this review also included non RCTs which helped to limit publication bias as unpublished work, including one with negative findings, was identified (Cooper 2004). None of the studies were able to explain how or why the intervention led to any changes in illness perception, beliefs or other outcomes and were not able to attribute individual components to the success or failure of the intervention. This is due to the 'black box' nature of complex interventions; this issue is starting to improve with the

publishing of various intervention development guidelines and intervention reporting guidelines.

## **2.12 Conclusion: The draft interventions**

This final section outlines the draft interventions; their theoretical basis and components.

### **2.12.1 Theoretical basis**

- Leventhal's CSM is a relevant theoretical model on which to structure the intervention, therefore, the Representational Approach to patient education which combines the CSM and the Conceptual Change Model is of particular relevance to the aim of changing cardiac misconceptions.
- A motivational interviewing style is appropriate for supporting belief change and also considers what action to take if patients are unwilling to let go of misconceptions, for example, 'rolling with resistance' (Rollnick, Miller and Butler 2008).
- Social cognitive theory – increasing individual's self-efficacy is important for health behaviour change and effective self-management of chronic health conditions (Bandura 1982). Changing cognitions is useful for improving self-efficacy but is inadequate without the addition of experiential challenge, for example, trying a new physical exercise (Lau-Walker 2006).
- Theory of planned behaviour – goal setting and action planning strategies can be employed to improve behaviour change (Taylor et al. 2006). In the case of this intervention, behaviour change may strengthen replaced misconceptions, for example, a goal and action plan to 'have the whole family around for lunch' may strengthen a belief that "busy family time is good for my health" and help manage anxiety that was previously dealt with through avoidance behaviour.

### **2.12.2 Intervention format**

It was decided to develop both an individual and a group-based intervention because ultimately one or both formats may be most effective or appropriate in clinical practice.



- All of the reviewed studies were of individual interventions; one advantage of an individual format is that this enables sessions to be tailored to the individual (Noar, Benac and Harris 2007).
- While no group-based interventions were identified, there is evidence in favour of group-based self-management programmes for people with long-term conditions; including CHD (Lorig et al. 2001, Warsi et al. 2004) and CR classes are usually delivered to groups of patients. Compared to individual-based approaches, group-based approaches typically involve greater interaction and thus provide an environment that is conducive for educational activities, such as social modelling or problem-based learning better than the individual setting (Tang, Funnell and Anderson 2006).
- A standalone group session aimed specifically at changing cardiac misconceptions or illness beliefs has not been reported in the literature but may be an acceptable and potentially cost effective method that is easily integrated into group-based CR programmes. Developing both types of intervention means that the acceptability of both approaches can be explored, from the patients' point of view, which may identify the potential advantages or disadvantages of each approach.

#### 2.12.3 Intervention booklet

- Both draft interventions will include an identical patient booklet that explains the importance of correct cardiac beliefs and the common misconceptions. Providing written materials is necessary to facilitate retention of information and enables patients to refer back to information, this may be especially important to maintain belief change (Donovan and Ward 2001).
- Additionally, the booklet allows for aspects of the intervention to be shared with the patient's spouse or significant others, whom may benefit from identifying and changing their inaccurate beliefs about CHD. This may help towards aligning patients' and their significant other's beliefs, as similarly aligned perspectives of CHD are beneficial (Figueiras and Weinman 2003).

#### 2.12.4 The individual intervention

Below is an overview of the individual intervention, a detailed intervention guide is presented in Appendix II:

Throughout the intervention the addition of simple CBT-based strategies such as checking patients' attitude towards the information or discussion (Furze, Donnison and Lewin 2008) and the 'teach-back' technique, where patients summarise their understanding of the intervention or information will be employed. These techniques could positively impact the acceptability (and success) of the interventions especially for people with sub-optimal health literacy (Bennett-Levy et al. 2010, Schwartzberg et al. 2007).

##### **Step 1) Introduce and explain the rationale for the intervention**

Following patient-centred care principles, the intervention is delivered within a collaborative patient -healthcare professional relationship, rather than the patient being the passive recipient of information. A brief introduction and rationale for the intervention provides the patient with an overview of what is involved and thus enables them to take an active part in engaging with the intervention.

##### **Step 2) Identify the individual's beliefs and cardiac misconceptions**

Patients' cardiac misconceptions will initially be identified using the YCBQ prior to the start of the intervention. Identifying the individual's cardiac misconceptions enables the intervention to be tailored to and thus concentrate on those beliefs that require modification, making the intervention more patient-centred and of relevance to the individual (Morgan and Yoder 2012).

##### **Step 3) Identify the individual's 'control' belief**

Before discussing the individual's misconceptions, their belief in the controllability of their CHD will be elicited because people are more likely to change their views about their illness if they have higher perceived control over their illness (Hagger and Orbell 2003).

A control continuum will be referred to and people will be asked to rate their perceived level of control from 0 per cent to 100 per cent. A motivational interviewing approach will be employed to challenge low perceived control by helping people to identify situations, thoughts or behaviours that could help raise their level of control. People who are satisfied with their level of control will be encouraged and asked what might help them maintain this level of control.

#### **Step 4) Exploring misconceptions**

The individual's answers to the YCBQ are looked at together and a discussion about experiences that have led to these beliefs encouraged. The importance of these beliefs is evaluated, including how strongly the patient believes in them.

#### **Step 5) Creating conditions for conceptual change**

The individual's misconceptions are discussed in terms of how they may negatively impact health and quality of life. Links between misconceptions, confusion or gaps in knowledge will be made to the recovery process, secondary prevention and quality of life.

#### **Step 6) Clarifying misconceptions**

New information is presented to fill in gaps in knowledge, clarify confusions, and replace misconceptions. Individuals will play an active role in coming up with personalised statements that involve the replaced misconception. The benefits of modified beliefs will be explored and individuals will be asked to rate their belief in the replaced misconceptions, out of 10, to identify any barriers that may cast doubt on the replaced misconception, for example, beliefs of other people, mixed information from professionals.

#### **Step 7) Acting on the replaced misconceptions**

This step involves identifying behaviours that will reinforce the replaced misconception, for example, correcting other people's misconceptions, tackling avoidance, continuing

attendance of CR. Individuals will be encouraged to write a brief action plan in the booklet regarding setting a small behavioural goal and how they can go about achieving it, this may be continuing with CR.

### **Step 8) Summary and feedback**

The intervention is briefly summarised and the individual is asked to give brief feedback and ask any questions.

#### **2.12.5 The group-based intervention**

The group-based intervention is to be delivered with the visual aid of a PowerPoint presentation, slide hand-outs and booklet. A detailed description of the group intervention is provided in Appendix II, an overview is provided below:

### **Step 1) Introduce and explain the rationale for the intervention**

Similar to the individual intervention the aim is to maintain a collaborative relationship between the intervention facilitator and patients and promote interaction. A brief introduction and rationale for the intervention provides the group with an overview of what the session is covering and thus enables individuals to take an active part in engaging with the intervention.

### **Step 2) Identify and explore common cardiac misconceptions**

Illness representations of the CSM are explored, beginning with ‘identity’ beliefs. Questions from the B-IPQ are presented, relevant to the illness representation being discussed to encourage participants to reflect and interact with the group, especially in the case of ‘control’ beliefs. Examples of common misconceptions are presented and their negative consequences highlighted. Group members are invited to ask questions, comment and offer their own examples.

### **Step 3) Creating conditions for conceptual change**

General, rather than individual misconceptions are discussed in terms of how they may negatively impact health and quality of life. Links between misconceptions, confusion or gaps in knowledge will be made to the recovery process, secondary prevention and quality of life.

### **Step 4) Clarifying misconceptions**

New information is presented to fill in gaps in knowledge, clarify confusions, and replace general misconceptions. Group participants will play an active role in coming up with example statements that involve the replaced misconception. The benefits of modified beliefs will be explored and the group will be invited to rate their belief in the replaced misconceptions.

### **Step 5) Acting on the replaced misconceptions**

This step involves identifying behaviours that will reinforce the replaced misconception, for example, correcting other people's misconceptions, tackling avoidance, continuing attendance of CR. Participants will be encouraged to write a brief action plan in the booklet regarding setting a small behavioural goal.

### **Step 6) Summary and feedback**

The intervention is briefly summarised and the participants are invited to give brief feedback and ask any final questions.

The following chapter discusses how these interventions were 'tested' by people with CHD and how their views were explored.

## **CHAPTER 3. METHODOLOGY AND METHODS**

### **3.1 Introduction**

This chapter provides an overview of the philosophical underpinnings of this research project and begins with a definition and discussion of the philosophical underpinnings.

This research study uses semi-structured interviews and focus groups as a research method and Framework Analysis as a tool to analyse and interpret the data (Ritchie and Spencer 1994). The literature review presented in Chapter 2 discussed how interventions to change cardiac beliefs have shown some success but these interventions are limited because few have been systematically developed to optimise the acceptability of the interventions to patients. This study thus uses a qualitative methodology to explore the acceptability of the draft interventions from the perspectives of people who have CHD, who are the intended recipient of the intervention. The qualitative study is used to inform the further testing and refinement of the interventions to develop final versions.

### **3.2 Qualitative Approach to Research**

The qualitative research paradigm focuses on gaining a deeper understanding of peoples' lived experience, including their beliefs and opinions, and is concerned with mostly linguistic rather than numerical data in order to explore meaning (Green and Thorogood 2004). Unlike in quantitative research, the eliciting of social realities and meaning enables findings to be put into context. While qualitative research can add to the understanding of a phenomenon or theory, 'applied' qualitative research "strives to improve our understanding of a 'problem', with the intent of contributing to the solution of that problem" (Bickman and Rog 1998: x). Furthermore, Morse (2012) argues that qualitative research that focuses on issues of health and illness should be termed as 'qualitative health research' (QHR), defined as, "an inductive research approach used for exploring health and illness, interested in peoples' experience or perceptions of health and illness" (Morse 2012: 147). Morse (2010) argues that QHR is different to other health research and to qualitative research of other disciplines, for example, sociology, because they have a different focus and methods; methods used by

qualitative health researchers often need adapting to accommodate the needs of unwell patients, the boundaries of the healthcare setting and realities of healthcare services. The aim of QHR, in addition to providing greater understanding, is for the findings to provide practical recommendations which can be applied to real-life health and illness issues (Morse 2010, Thorne 2011). As this study aims to understand CHD patients' experience of the interventions, *and* to apply this knowledge to further refine the interventions for eventual use in cardiac rehabilitation, QHR is an appropriate approach.

### **3.3 Philosophical considerations**

It is considered essential for qualitative researchers to clarify the epistemological and ontological stance taken in their research as this information enables others to understand and determine the validity of findings (Savin-Baden and Major 2013). Ontology refers to the study of what exists; a researcher's ontological beliefs include their perceptions about the nature of reality. Two contrasting views of reality are realism and relativism. Qualitative researchers take a relativist view of reality and are interested in exploring meaning as they believe there are multiple 'truths', that truth is subjective and dependent on multiple factors, on context, and is dynamic in nature. Qualitative researchers' perspectives of reality will lie along an objective-subjective continuum depending on their philosophical beliefs and the nature of the research question. A researcher subscribing to Pragmatism, for example, will view reality as being that which is useful, whereas a social constructivist will have a more subjective view of reality.

Epistemology is the theory of knowledge; a researcher's epistemological viewpoint includes their assumptions about constitutes knowledge, whether something can be known and how it can be known. These assumptions dictate the relationship between the researcher and the people or phenomena being researched. In contrast to quantitative researchers, qualitative researchers do not prioritise objectivity and thus do not distance themselves from participants, however, the degree of 'closeness' depends on the research approach.

Methodology refers to how researchers discover knowledge in a systematic way; methods are the procedures or tools used to achieve the aims of the research. As

different research methods infer varying degrees of objectivity the chosen methodological approach is driven by researchers' epistemological and ontological beliefs. It is important that a study's epistemology, methodology and methods are coherent; Carter and Little (2007) state that coherence is used by others to judge a study's quality. The appropriateness of the choice of methodology and methods in this study will be examined.

### **3.4 Positionality**

The nature of QHR is that the results are expected to provide answers, a 'truth' which can be put to practical use and solve problems; this can imply a post-positivist philosophy. The post-positivist perspective positions the researcher and participant as separate from one another, as objectivity and minimising bias is valued, but it also takes into account that the researcher has an unavoidable influence on the findings (Rehm 2009). Post-positivism, however, is usually confined to the quantitative tradition and has limited use in qualitative research (Savin-Baden and Major 2013). This study could have taken a post-positivist approach by using quantitative methodology, for example, a questionnaire to measure participants' views and opinions of the intervention. The quantitative research approach assumes that findings are objective and 'truth' can be discovered, however, as people construct and interpret their own meanings of an experience this means findings cannot be representative of all people (Silverman 2010). Quantitative data may provide objectivity but qualitative data is able to provide a rich and detailed insight into personal experiences and perceptions of individuals (Silverman 2010). This study aimed to gain more than a superficial understanding of participants' experiences and opinions of the intervention, therefore, a qualitative approach was deemed more adequate and appropriate than a quantitative approach.

As qualitative research aims to gain an understanding of an individual or group's world, a relativist ontology, where reality is viewed as people's interpretation of a socially constructed reality, is a logical stance as opposed to a realist viewpoint (Green and Thorogood 2004). A relativist view of reality, however, is at odds with the aim of this study and the assumption that the findings reflect a certain amount of 'truth' which can be applied to the interventions and result in a more acceptable and feasible methods for



managing cardiac beliefs. To balance the aim of exploring and understanding participants' experiences and views of the interventions with the aim of applying this knowledge to develop the interventions led to the conclusion that the study is best placed within the philosophy of pragmatism.

The philosophy of pragmatism suggests that researchers should use the most appropriate approach as required by the research question and research should take place within the natural context (Savin-Baden and Major 2013). Maxcy (2003) describes pragmatic research as that in which the methods are determined according to 'what works'.

Pragmatism was founded by the American philosopher and scientist Charles Peirce (1839-1914), along with other scholars, to challenge traditional views of science and led them to explore the subjective experience of the social world (Strauss and Corbin 1998, Savin-Baden and Major 2013).

The ontological assumption of pragmatism is an acceptance that there is an external world independent of our minds but we cannot be sure if we can accurately "read the world" (Cherryholmes 1992). Over the years pragmatists have disagreed about the nature of physical reality but generally view 'truth' in terms of its ability to produce a practical consequence (DeForge and Shaw 2012). The epistemological assumptions of pragmatism are an acceptance of both the objective and subjective and that claims of knowledge of an external reality is possible but difficult to "pin down" (Tashakkori and Teddlie 1998). Ergo, causal relationships are accepted but are dependent on context and are liable to change over time. Finally, when it comes to interpreting research findings, pragmatic researchers view bias as inevitable but can be 'managed' through reflexivity as the researcher can make their values known (Tashakkori and Teddlie 1998).

Pragmatists are able to use a range of qualitative approaches to suit the research question; however, the pragmatic qualitative research approach has an eclectic range of methods available for data collection and analysis (Thorne, Kirkham and MacDonald-Emes 1997). Pragmatic qualitative research can "offer a comprehensive summary of an event in everyday terms of those events" (Sandelowski 2000: 336) and is widely used in health research because of its practical focus and ability to provide a close account of the patients' perspective (Neergaard et al. 2009). Pragmatic studies do not aim for thick description, theory development or phenomenological interpretative understanding but

aim instead to describe the event or experience as interpreted by the researcher while staying close to the data – the voice of the participants (Neergaard et al. 2009). Savin-Baden and Major (2013) position pragmatic qualitative research midway between descriptive and interpretative positions, as shown in Figure 4, but point out that a more subjective or objective approach might be taken by researchers, in keeping with the philosophy of doing ‘what works’.

Figure 4: The objective-subjective continuum of pragmatic qualitative research (Savin-Baden and Major 2013:172).

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One view of pragmatic qualitative research is that it is ‘a-paradigmatic’, which is either a positive or a negative depending on one’s philosophical viewpoint (Merriam 1998). Savin-Baden and Major (2013) argue that it is unrealistic for any researcher to operate in a ‘philosophical void’; therefore, ‘a-paradigmatic’ qualitative researchers automatically adopt the philosophical tenets of pragmatism.

Qualitative researchers need to be explicit when stating their theoretical location and methodological orientation otherwise their work can be seen to lack validity (Pope and Mays 2006). Researchers can limit the negative influence of bias on the credibility of their findings by acknowledging how their assumptions and preconceptions have shaped their research choices - this reflexivity can be achieved by keeping a journal throughout the research process (Bradbury-Jones 2007, Pope and Mays 2006).

In order to achieve the aims of this pragmatic qualitative health study, an ontological stance was taken which asserts that reality is to some extent knowable and unknowable - objective and subjective (Silverman 2010). The methods used in the study were viewed as tools which could uncover patient and staff views of the interventions and the analysis and interpretation of these views could be used to improve the interventions and gain a greater understanding of when and where the interventions are best placed. The focus of the study was on optimally developing the interventions in preparation for applying for funds for a future study to test their efficacy.

### **3.5 Reflection**

Although I am a healthcare worker familiar with the pressures of balancing workload and patient care, this is in an NHS primary care mental health setting, therefore I saw myself as an 'outsider' in the cardiac rehabilitation setting, but less so than a researcher without a clinical background (Morse 2010). Trying to retain an objective position was not practical nor desirable as it was considered more useful to the research aim to become familiar with the 'process' of CR and for the staff and patients to become familiar with my presence. As the study progressed it was inevitable that I moved slightly closer towards an 'insider' position; this facilitated a greater understanding of the context in which I would interpret the findings. The nature of the study required that I learnt about the physiology and management of CHD in order to confidently talk to CR staff about the study and to deliver the interventions to participants without inadvertently missing or reinforcing misconceptions. In order to put the patient experience into context and identify the opportunities that CR staff may or may not already take to dispel misconceptions a visit was made to a hospital for a CR nurse-guided tour through the patients' journey. Education sessions at one CR service were attended to get an insight into any attempts by staff to dispel misconceptions, to understand where the interventions might fit into CR programmes.

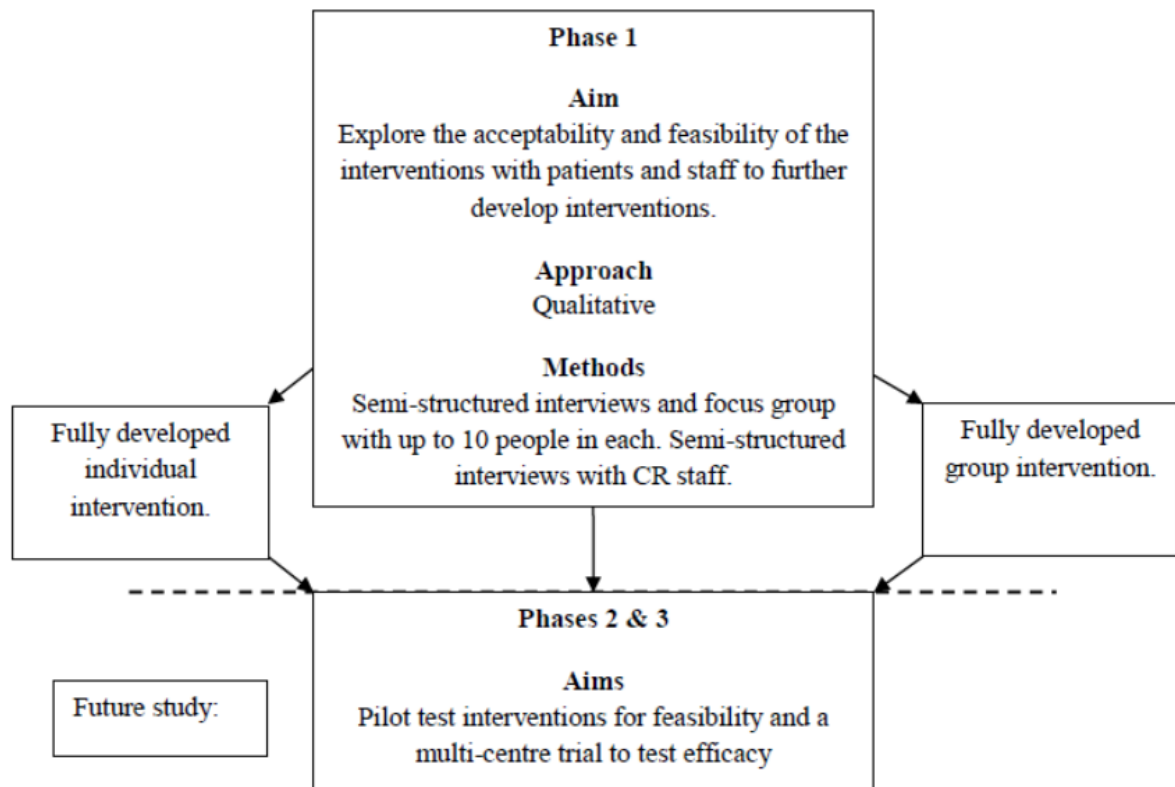
### 3.6 Methods

#### 3.6.1 Overview of methods

This section provides an overview of the methods used for the study, discussion of the research setting, access to participants and approvals.

An overview of the methods and procedures in relation to the aims of the study (Phase 1) is given in Figure 5 and includes an overview of proposed future research (Phases 2 and 3) to show how the current study relates to this.

Figure 5: Overview of methods



#### 3.6.2 Setting

Initially the research took place at one site; however, an additional site was added later on, reasons for this are discussed in the next section. Overall, the research took place at two CR programmes (CRP1 and CRP2) in the West Midlands region. These services were chosen for convenience as they were the nearest geographically to the researcher.

Each setting hosted a different intervention: The site where the individual intervention was delivered served a population of 312,800 people (CRP1) whereas the group intervention site served a population of 250,000 people (CRP2) (ONS website 2012).

The similarities and differences of the CRPs at the two sites are compared in Table 2.

Table 2: Comparison of the two cardiac rehabilitation services

CRP1 (individual intervention)	CRP 2 (group intervention)
Community based	Hospital based
Four exercise classes a week over 2 days	Four exercise classes a week over 4 days
Ongoing bi-weekly education sessions	Education sessions every 8 weeks
Exercise classes led by nurses, exercise physiologists, physiotherapists and peer-support volunteers	Exercise classes led by physiotherapists

The two CRPs differ in terms of setting, provision of education sessions, number and variety of staff. Rather than being a hindrance, differences between the two services were positive as it aided the researcher's understanding of how the interventions might fit within different CR settings; it was considered that this could improve the external validity of the study findings to other CR programmes. While external validity is not an appropriate priority for qualitative research it is a consideration for this study because the findings will be used to inform interventions which may then be delivered in other CR settings.

### 3.6.3 Permissions and access to participants

Prior to seeking ethical approval and permissions, the researcher met with the manager, nursing lead and Clinical Psychologist at CRP1 to discuss the proposed interventions, the research protocol and requirements in terms of recruitment strategy, rooms for delivering the interventions and other logistical matters.

Ethical approval for the study protocol and documents was initially sought from the sponsor, Coventry University, through an online peer review system. Once approval was granted from Coventry University (Appendix III) the researcher sought ethical approval for the study from the National Research Ethics Service (NRES) local committee and approval was granted following a number of clarifications regarding procedures (Appendix III). A Research and Development (R&D) application and research passport form were submitted to the locality's Research Management and Governance (RM&G) office and permission for the research to take place at the cardiac rehabilitation service was duly granted (Appendix III).

Once permissions had been granted the researcher met again with CRP1 to present the study to the wider staff group (and new Clinical Psychologist as the previous Psychologist had left) to introduce myself as the researcher and to provide information about what the study involved and to explain the recruitment process.

Over the course of the study CRP1 underwent a major change; the service moved to a new venue and availability of patient education sessions was increased from two-weekly every six weeks to twice a week, nearly every week. Whilst very positive for the CR service, these changes and a delay in opening at the new venue made recruitment and availability of space to deliver the group intervention more difficult. It was, therefore, decided to recruit patients for the group intervention from an additional CRP. The additional site was chosen due to its convenient location and the fact that as regular educational sessions did not occur this would enable the group intervention to fit into the programme more easily. As the researcher had already met with the Clinical Psychologist at CRP2, from their time at CRP1, it was agreed that they would act as Local Collaborator. The researcher was put in touch with the physiotherapists who run CRP2 to discuss the study protocol. Satisfied that the study was appropriate for CRP2 and that there was a suitable group room available, the researcher gained approval from the sponsor to add an additional site. The RM&G team for the locality of the additional site was contacted to gain permission and the researcher's research passport was updated.

Prior to the start of the study the researcher attended mandatory Good Clinical Practice (GCP) training and attended RM&G and Site File training in order to understand the guidelines and frameworks which govern research with NHS patients.

#### 3.6.4 Sampling and recruitment

All patients with CHD, registered with CRP1 or 2 were the population from which the sample was drawn. A diagnosis of CHD had either been made by the patients' GP or by the hospital consultant. Patients had either experienced an MI and/or had undergone revascularisation procedures (PCI or CABG). Patients with congenital heart problems and valve problems were not included as the physiology of these conditions is very different to CHD. Patients were included irrespective of whether they had previously experienced a cardiac event.

A convenience sampling strategy was used as individuals were selected on the basis that they were attending a CRP that is in close proximity to the researcher. Qualitative research has no set rules for determining sample size and instead a number of different recommendations exist, depending on the research aim and methodology, and take into account time constraints and the concept of data saturation (Green and Thorogood 2004). For this study a sample size of between six and twelve people for each intervention was considered sufficient. Morse (1991) suggests that at least six participants are sufficient for research that aims to understand experience of a phenomena; the phenomena in this study being the experience of the interventions. Furthermore, Guest, Bunce and Johnson (2006) provide an evidence-based guideline, based on their own research, that a sample size of between six and twelve people includes sufficiently different viewpoints. As the sample is relatively homogenous, as all participants had experience of CHD, a sample of at least six people for each intervention was considered adequate. This *a priori* sample size was chosen rather than continuing until data saturation was achieved because the concept of data saturation, common in grounded theory, is a contentious issue and was inconsistent with the philosophical position of the researcher.

Study participants were recruited from people attending a stage 4 CRP rather than from in-hospital for two main reasons. Firstly, it was considered more ethical to involve participants at a stage when they had had some time to process the distress of their cardiac event. Secondly, it was assumed that people attending a CRP, having had some time to reflect on their illness, were best placed to experience the interventions and express their views on them. It was considered that people attending CR may be more open to providing critical feedback about the interventions as their dependence on healthcare professionals was decreasing (Nisbett and Wilson 1977).

Exclusion criteria were applied to those unable to read or speak English as the study could not provide translated materials or for the interventions and interviews to be conducted in other languages. This was unavoidable due to the complexities of providing accurately translated materials and use of an interpreter for interviews within the constraints of student research.

At CRP1 staff gave out the study flyer and participant information leaflet (Appendix IV) to patients attending exercise classes but no response was received using this method. Personal introduction (De Vaus 2002) is useful for improving response rates; a more positive response was gained when the researcher was introduced by a CR nurse to give a brief talk about the study at the beginning of patients' group education sessions. At CRP2 the researcher was introduced by staff to a group of patients attending an exercise class and a brief explanation of the study was given.

### 3.6.5 Measures

The demographics questionnaire (Appendix V) had 7 questions to identify age, gender, marital status, ethnicity, educational background and work status. A final, tick-box, section asked participants to identify their specific heart problem and any treatment received in hospital. This questionnaire was adapted from the baseline questionnaire used in a previous CR study (Furze et al. 2012).

Following the completion of the demographics questionnaire, the 22-item York Cardiac Beliefs Questionnaire (YCBQ) was administered which includes statements about heart attacks, angina and living with heart disease (Appendix V). The YCBQ, developed from patient interviews by researchers at The University of York, has been used to



explore CHD patients' cardiac beliefs (Furze et al. 2009, Furze 2011, Lin et al. 2012) and the beliefs of healthcare workers (Angus et al. 2012). The YCBQ has two versions: the YCBQ-clinprac has a simple 'agree' or 'disagree' tick box and is thus easier to use in clinical practice, whereas the YCBQ-Res has a 5-point Likert-type scale and is a more sensitive tool for research.

The YCBQ-Res version was chosen, not because it is a more sensitive tool for measuring differences in misconceptions, as this was not the aim of this study, but because it was viewed as being more useful for tailoring the intervention and as an intervention tool in its own right. The Likert scale of the YCBQ-Res helps to identify how strongly a belief is held or if people are unsure of an answer and could be a valuable tool to initiate Socratic dialogue with the individual, an approach fundamental to cognitive behavioural therapy, and would allow people's responses to the YCBQ to be explored in more depth. The opportunity to explore people's cardiac beliefs from the responses given by completing the YCBQ would be limited if the YCBQ-clinprac version was used.

Participants' cardiac beliefs were measured once only because the primary reason for using the YCBQ was to assist with tailoring the individual intervention, as an intervention tool and to gain an overall picture of the level of cardiac misconceptions held by participants at the two sites, rather than to test the interventions' efficacy.

### **3.7 Recruitment and intervention procedures**

The individual intervention took place at CRP1 and the group intervention took place at CRP2. A summary of the procedures is given in Figure 6.

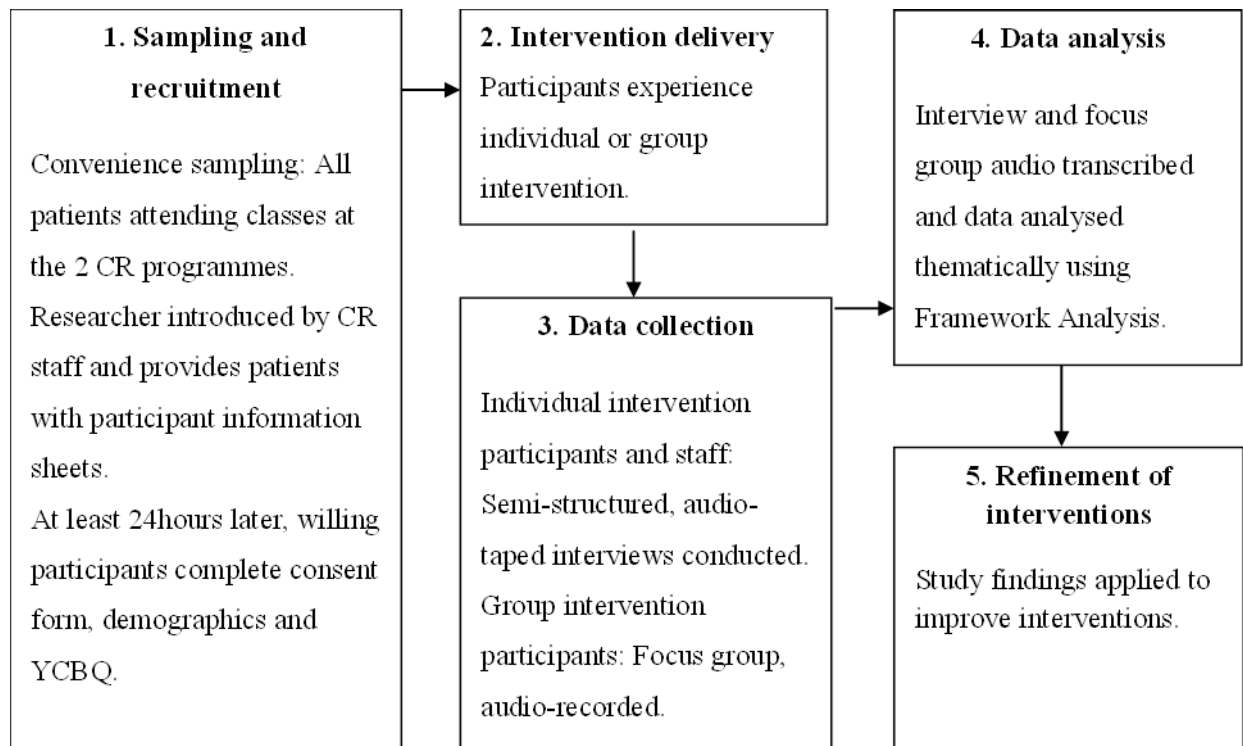


Figure 6: Summary of procedures

### 3.7.1 Individual Intervention – CRP1

People attending CR who were interested in taking part in the research study took a participant information sheet (Appendix V) and were given the option of leaving their contact details with the researcher to be contacted at least 24 hours later. Where contact details were left, the researcher telephoned to check people's understanding of the requirements of the study and answer any questions. A meeting was then arranged, if agreed, to obtain written consent and to complete the demographics questionnaire and YCBQ. This brief meeting took place just before or after participants' scheduled CR education or exercise class in order to reduce extra burden with regards to participants' time and parking costs. Three consent forms (Appendix V) were completed: 1 for the participant, 1 for the researcher and 1 for CR. The demographics questionnaire (Appendix V) was then completed.

A convenient time was arranged with participants for them to receive the individual intervention; either the CR centre or their home. Four participants received the intervention at their home and two people met with the researcher in a room at the CR centre suitable for an individual consultation. The draft individual intervention protocol

was followed (Appendix II); each participant also received the draft intervention booklet (Appendix II) and was encouraged to write in it and ‘test’ their family or friends on their cardiac beliefs. At the end of the intervention an appointment was made at least one week later to complete the interview to discuss the intervention. The researcher audio-recorded and wrote notes about the delivery of the intervention to aid reflection on the process.

### 3.7.2 Group-based intervention – CRP2

The physiotherapist running the exercise class introduced the researcher to give people attending a brief overview of the study and the date of the proposed draft group intervention. The researcher provided participant information leaflets (Appendix V) and attended the following exercise session 2 days later to obtain written consent from people wishing to take part. As participants were seen in a group rather than individual context it was not feasible for them all to complete the demographics questionnaire and YCBQ at the same time, therefore, people were given the option to return these at the start of the group intervention. The physiotherapists running the exercise classes at CRP 2 advised that the best time to deliver the group-based intervention would be before an exercise class. The session took place in the sports hall where exercise classes are held. The group intervention protocol was followed (Appendix II) and began with reminding participants about keeping group discussion confidential, as per the consent form. Participants were given a plastic wallet with a colour hand-out of the PowerPoint presentation (Appendix II) and a copy of the draft intervention booklet. Appropriate group interaction was encouraged but managed so that the session did not run over time. At the end of the session, once any questions were answered, the group was reminded about attending the focus group. The date and time of the focus group was set at exactly one week after the group intervention.

## 3.8 Data Collection Methods

Two methods of data collection were used to explore participants’ experience of the intervention and views on the booklet: individual semi-structured interviews and a focus group. The two methods were utilised to reflect the different formats of the intervention, to get the benefits of both methods, and for practical reasons. All

participants were given a £10 voucher for taking part in the interventions and interview/focus group to reflect their time and additional parking costs.

### 3.8.1 Semi-structured individual interview

One-to-one interviews were considered an appropriate method to explore the experiences and views of participants who had tried the individual intervention, rather than a group interview, for a number of reasons. Firstly, as individual interviews allow in-depth examination of the lived experience of people (Silverman 2010), they enable an in-depth understanding to be gained of participants' personal experience of the intervention, which could not be achieved in a group interview. As confidentiality is more easily maintained, individual interviews allow participants to discuss personal views more openly (Green and Thorogood 2004). Additionally, the time constraints of a focus group would not enable in-depth discussion of each person's experience of the intervention thus limiting the depth of the data.

It was also more practical to collect data via individual interviews rather than a focus group. As recruitment ran over a number of weeks, arranging individual interviews with participants was more practical rather than waiting for a focus group at the end; this meant all participants had a similar time gap between receiving the intervention and being interviewed. Interviews were scheduled one week after the participant received the intervention to allow them enough time to reflect on their experience but not too long that so that they might have difficulty recalling their experience.

A semi-structured interview format was used as it allowed the views and experiences of participants to be explored in-depth while maintaining a focus on answering the research question (Silverman 2010). Participants were given the option of completing the interview either in a room at the CRP or in their own home, depending on what was more convenient or comfortable for them. An interview schedule (Appendix VI) was developed to explore participants' experience and views regarding cardiac beliefs and the intervention, which included the booklet (Appendix II). The interview schedule helped to ensure all relevant areas were addressed with participants to facilitate adequate cross-case analysis. The interview schedule began by reiterating the aim of the interview, to check consent for audio-recording and included a statement to remind participants that their data would be treated confidentially, and recordings destroyed at

the end of the study. Once the researcher had answered any questions and the participant was happy to continue, the audio-recorder (Olympus Digital Voice Recorder DM-450) was turned on and the interview commenced with open questions relating to the participant's experience of their heart event aimed at helping participants become comfortable with talking, being recorded and to enable them to 'tell their story' (Savin-Baden and Major 2013).

Open questions followed an order congruent with participants' 'journey' from experiencing symptoms, getting treatment, attending CR and, finally, to experiencing the intervention. Probing questions were used to expand participants' responses to questions, as advocated by Legard, Keegan and Ward (2003), for example, '*What did you think was going on at that point?*' prompted a participant to expand on their response which enabled a deeper level of meaning to be uncovered. Probing can also be used to seek clarity on a topic, for example, '*And was that in a talk when you learnt about that?*' helped clarify how the participant learnt about cholesterol when they had said '*...I learnt it here*'. Participants' experiences were explored in order to identify if and when their cardiac knowledge and beliefs had been explored by CR staff or how misconceptions had been addressed, for example, '*Did anyone ask you about your ideas or your knowledge about heart attacks?*'

Perceptions of the intervention and the booklet explored areas that the participant viewed to be useful and not useful, for example, '*Was there anything about it that you thought wasn't helpful?*', including the readability and understanding of the written materials, '*Is there anything about the booklet that you would change?*' and views on the potential benefits to other people of receiving the intervention and booklet and timing of the intervention.

The interview schedule was used to help guide the order of topics but deviations from the topic or order was deemed necessary in order to maintain rapport with the participant and keep a conversational style (Silverman 2010). One interview did introduce a new topic to allow the participant to talk more about their experience of physical disability as the researcher felt that not asking more about this could have been perceived by the participant as ignoring the importance of their disability. As it was not directly relevant to answering the research question it was not transcribed but it helped

put the participant's experience into context and enabled a more natural conversational style to continue as opposed to feeling that an experience important to the participant was being ignored.

At the end of the interview participants were thanked for taking part and were reminded that their audio-file would be deleted once the study was finished and that data would be anonymised.

### 3.8.2 Focus group

Participants from the group intervention attended a focus group one week later. For the convenience of participants the focus group was held at the CRP before the start of their exercise class and refreshments were provided.

While a focus group cannot explore participants' views and experiences of the intervention in the same depth, the focus group method has a number of benefits. Firstly, the interaction between the researcher and focus group participants can be viewed as more 'natural' compared to the one-to-one situation of an individual interview and thus participants' accounts can be seen as more 'authentic' (Barbour 2007). Furthermore, the key feature of a focus group is the ability to observe interaction between people in the group; Barbour (2007) suggests that the group environment aids openness to expressing criticism. It is possible, therefore, that the focus group participants may feel less pressure to make positive comments about the intervention, which may not be representative of their private opinions. Group dynamics, however, have the potential to limit openness, for example, a group member voicing strong opinions may lead to other people feeling unable to voice contrasting views, which, unmanaged, can result in an incomplete representation of overall opinions (Krueger 2000).

A focus group was considered appropriate for exploring participants' views of the group intervention because their shared experience could be explored through instigating and observing conversation between group members, something that an individual interview is unable to do. Although the focus group and individual interview participants had experienced a different intervention everyone had received the same intervention

booklet. It was, therefore, viewed that the focus group data would complement data collected from the individual interviews and provide a different perspective on participants' views of the booklet, enhanced by potential interaction between group participants (Kitzinger 2006).

At the beginning of the focus group a brief introduction was given to attune the participants to its intended aims, to re-check consent for audio-recording and to reiterate confidentiality and data protection. The group was given a copy of the group intervention hand-out as an aide memoire, if required. The focus group was audio-recorded (as before) and was transcribed verbatim by a professional transcriber. An initial round-robin, asking people to give their name and favourite piece of gym equipment, aimed to help people feel comfortable about talking and, later, to help identify people on the audio-recording.

The focus group schedule (Appendix VI) served as a guide for the researcher to follow although the aim was to allow people to talk as freely as possible. Where it was felt that one person was dominating the conversation the researcher asked about other people's opinions. For both the individual interviews and focus group, an enthusiastic but neutral stance was taken to avoid influencing people's responses to questions.

A reflexive account of the focus group from the researcher's perspective was written up soon as possible.

### 3.8.3 Use of multiple data sets and multiple methods

This study used multiple data sets and multiple methods. Participants who tested the individual intervention were interviewed on a one-to-one basis as their individual beliefs and experiences were the focus of the research whereas a focus group allowed the collective responses of the group-based participants to be explored. Combining these two qualitative methods was done with the aim of gaining a greater insight into participants' experiences and perceptions of the interventions as well as for practical reasons. Individual interviews and focus groups can be used together as a way of triangulating methods to increase the validity of qualitative research findings (Lambert and Loiselle 2008). The choice of methods in this study, however, was based primarily on what was most practical and appropriate for the participants, the researcher and the

study. It was assumed that the interviews and focus groups would produce parallel data sets (Barbour 2007) and that combining the methods would add value by enabling the views of the individuals to be compared with those of the group. Comparing the data sets was not done to confirm the validity of the findings as this is not in keeping with a qualitative paradigm; rather, they were used to highlight similarities and differences.

### **3.9 Data analysis and interpretation**

Framework Analysis, developed by Ritchie and Spencer (1994), was chosen to analyse the semi-structured interview and focus group data. Ritchie and Spencer (1994) developed the framework approach for use in applied qualitative research where research objectives are to produce outcomes that can be put to practical use.

Framework provides a more deductive approach to analysis because it starts from the aims already set out by the study, for this reason it is an appropriate method of analysis for healthcare research (Pope and Mays 2006). Framework analysis is congruent with a pragmatic position as it is flexible and not aligned with a particular theory or epistemological position.

The framework approach to managing data enables the researcher to analyse the data in a systematic way whilst still exploring the data in depth. Framework produces a transparent audit trail from the construction of charts which describe the themes in a matrix format, enhancing the rigour and credibility of the findings (Ritchie and Spencer 2002)

The key features of Framework are summarised overleaf in Table 3:



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Table 3: The key features of Framework Analysis (Srivastava and Thomson 2009).

The framework approach has five stages of data analysis:

1. Familiarisation
2. Identifying a thematic framework
3. Indexing
4. Charting
5. Mapping and interpretation

Below is a description of each stage and how it was followed:

#### 3.9.1 Familiarisation

This involved reading through the transcripts again and again to become familiar with the range and diversity of responses (Ritchie and Spencer 2002). The audio- recordings were also listened to again to make sure they had been transcribed accurately.

### 3.9.2 Identifying a thematic framework

The transcripts were revisited to identify issues and themes that could be used to examine the data. The initial list was long and the process was repeated and judgements made about meaning and the relevance of issues to make the list more concise. Index categories were assigned numbers.

### 3.9.3 Indexing

The thematic framework was applied to the data and involved making judgements about which concepts in the data were assigned which indices.

### 3.9.4 Charting

Devising charts was the next step and involved ‘lifting’ data from the transcripts, their original context, and arranging them according to the themes they are in reference to (Ritchie and Spencer 2002). The Framework approach facilitates interpreting and synthesizing the data, compared to other methods of qualitative analysis, because rather than ‘cutting and pasting’ chunks of verbatim text, summaries of the data are made and inserted into the chart along with page references (Ritchie and Spencer 1994)

### 3.9.5 Mapping and interpretation

This final stage was influenced by the identified themes and the influence of the original research objectives. The charts were used to map the range and nature of the findings and to find associations between themes and between the participant groups.

The analysis was not checked by another person as it was not deemed necessary for Masters research.

## 3.10 **Summary**

This chapter introduced a qualitative research methodology and presented a discussion and rationale for the pragmatic qualitative research approach. An overview of the methods was given and the rationale for choice of methods presented. The procedures for data collection were explained including issues relating to sampling, research setting and validity. The framework analysis approach was presented and an outline of the

process given. The results of the data collection and analysis are presented in the next chapter.

## **CHAPTER 4. RESULTS**

### **4.1 Introduction**

This chapter has two main objectives: to report on participant recruitment and to report on patient experiences of the interventions. The study recruitment and flow of participants through the study will be described including challenges with the data collection. This is followed by an outline of participant characteristics and baseline measures. The qualitative study findings will then be presented.

### **4.2 Summary of method**

Participants were recruited from two CR services to try either the individual or group intervention, along with the booklet. Participants' views regarding the acceptability of the interventions were examined by conducting semi-structured interviews with the individual intervention participants and a focus group with the group intervention participants. These methods allowed an in-depth examination of participants' experiences of the interventions and booklet, resulting in suggestions to further improve the interventions. The interviews and focus group were analysed using framework analysis (Ritchie and Spencer 1994), as described in Chapter 3, section 3.9.

### **4.3 Participants**

The demographic characteristics of the participants from both research sites are outlined in Table 4. Demographic details, including cardiac diagnosis and treatment, are summarised in Table 5 for participants who took part in the individual intervention and in Table 6 for the group intervention participants. Participants have been assigned a pseudonym to protect anonymity.

<b>Demographic Characteristic</b>	<b>Individual Intervention</b>	<b>Group Intervention</b>
<b>Age (years)<sup>a</sup></b>	61 (43 –76)	54 (36-77)
<b>Male</b>	4	4
<b>Female</b>	2	1
<b>Ethnicity</b>	White British – 5 Black (other) – 1	White British – 5 Black (other) - 0
<b>Marital status</b>	Partner – 1 Single – 0 Married – 1 Divorced – 2 Widowed - 2	Partner – 1 Single – 1 Married – 3 Divorced – 0 Widowed – 0
<b>Employment</b>	Employed – 2 Retired - 4	Employed – 4 Retired - 1
<b>Education</b>	Degree – 2	Degree – 1
<b>Diagnosis</b>	MI – 5 ACS - 1	MI - 5
<b>Treatment</b>	PCI – 5 CABG - 1	PCI – 4 CABG - 1

<sup>a</sup> Values are mean (range)

Table 4: Overview of demographic characteristics of participants

<b>Participant</b>	<b>Age</b>	<b>Sex</b>	<b>Post 16yrs Education</b>	<b>Diagnosis</b>	<b>Treatment</b>
Steve	43	M	No	NSTEMI	PCI
John	70	M	Yes	NSTEMI	PCI
Bob	45	M	No	ACS	PCI
June	71	F	No	STEMI	PPCI
Mandy	62	F	Yes	NSTEMI	PCI
David	76	M	No	STEMI	CABG

Table 5: Individual intervention participant demographics

Participant	Age	Sex	Post 16yrs Education	Diagnosis	Treatment
Sam	36	M	Yes	NSTEMI	PCI
Graeme	47	M	No	STEMI	PPCI
Matthew	77	M	No	NSTEMI	PCI
Alison	55	F	Yes	NSTEMI	PCI
George	73	M	No	STEMI	CABG

Table 6: Group intervention participant demographics

Of 18 patients directly approached at CRP1 to participate in the individual intervention, 6 people consented to take part. All participants who tried the individual intervention completed the individual semi-structured interview. On average the interview duration was 58 minutes (range 40 minutes to 80 minutes).

Of 10 patients approached at CRP2 about taking part in the group intervention, 8 people consented to take part; 2 patients declined due to unavailability. Of the 8 participants who attended the group intervention 5 attended the focus group the following week; 1 person was away on holiday and the other 2 people were unable to attend for unknown reasons. The focus group duration was 30 minutes.

The median scores for the three sections of the YCBQ (heart attack, heart disease and angina) are shown separately in Table 7 to give an overview of participants' cardiac misconceptions before receiving the intervention. Higher scores indicate more misconceptions and a stronger belief towards these misconceptions.

York Cardiac Beliefs Questionnaire	Individual Intervention	Group Intervention
Heart disease score overall (0-48)	26 (11-44)	38 (12-41)
Heart attack score overall (0-20)	10 (7-15)	13 (0-16)
Angina score overall (0-20)	10 (8-17)	13 (3-14)

Table 7: Participants' YCBQ scores, values are median (range)

Individuals at both research sites varied in their responses to the YCBQ items, for example, the heart attack section received scores ranging from 0 ('no' misconceptions)

to 16. The standard deviation of overall mean YCBQ scores was 19 for the individual intervention participants and 23 for the group intervention participants. As the sample is not powered to detect significance differences in scores, these have not been explored further, however, the range of scores shows that some people had a better understanding of their illness than others which lends further support to the need to tailor interventions to individual needs.

The YCBQ required people to respond on a 5-point Likert-type scale; due to factors such as social desirability, people can be reluctant to answer towards the extreme ends (Ogden and Lo 2012). The majority of participants in this study answered 'agree' or 'disagree' and feedback from the individual intervention participants was that were not confident enough in their knowledge and beliefs to admit to strongly agreeing or disagreeing with the statements. This indicates that whilst some participants had mostly correct cardiac beliefs there was still scope to strengthen these beliefs. Strengthening correct beliefs could prevent them from being altered as a result of coming into contact with incorrect information, for example, from family, friends or the media.

In terms of the feasibility of utilising the YCBQ to tailor the intervention, a few practical issues meant that some people required more time and support to complete it. Four participants struggled to answer the questionnaire, one person due to literacy issues and three people due to poor eyesight and not having their reading glasses with them. The researcher therefore read the questions aloud to three of these participants and one participant completed the YCBQ two days after completing the demographics questionnaire (but before the intervention). Reading out the questions to participants may affect their responses and increases the potential for response bias – an important limitation for future efficacy testing of the intervention. Considerations for a future study would be to have a large-print version of the YCBQ readily available to enable those with poorer eyesight to complete the measure more easily. In this study, reading the YCBQ aloud to people was not seen to bias the findings as the measure was not used to explore the efficacy of the intervention on changing cardiac misconceptions because 1) this was not the study's aim and 2) the study was not powered to detect statistical significance.

Unfortunately, it was not possible to interview staff at CRP1 about the interventions due to their lack of availability. At CRP2, a semi-structured interview was carried out with a member of the team who observed the group intervention.

#### 4.4 Qualitative findings

The individual intervention and group intervention data were analysed separately; the analyses regarding the intervention booklet were compared and brought together.

The following sections will describe and illustrate each theme using quotes from the individual interviews and focus groups.

#### 4.5 Individual interview findings

Four main themes were generated from the analysis of the individual interviews:

1. Acceptability of tailoring the intervention
2. Acceptability of intervention components
3. Acceptability of the intervention format and delivery
4. Timing of the intervention

##### 4.5.1 Acceptability of tailoring the intervention

Participants' responses to the YCBQ were utilised to tailor the individual intervention. It was expected that responses would differ, with some participants scoring higher for misconceptions than others, depending on how many weeks they had already attended at the CRP. It was anticipated that people who had attended for longer would have fewer misconceptions than the new starters. Participants who were further along in their CRP reported that they might have answered the YCBQ differently had they been given it at the start, however, one person identified that, despite being at the end of his CRP there were still parts of the questionnaire that he had been unsure of:

John: *"Changed by the fact that I've been to all the lectures at the rehab centre. So it's difficult to say what my thoughts were beforehand. I have been through this [YCBQ] and there were one or two things that I wasn't sure of."*

Steven: *"As they go on, you learn more about it. At the beginning, a lot of them, you would probably 'disagree' but you weren't too sure to 'disagree' but now I*



*think you'd know more about the symptoms or just a lot more about things so you'd probably have different answers to what you had five weeks ago."*

June: *"yeah it was ok, the questions, some of the questions you thought 'yes, people do say that' and I was silly to think that."*

One participant reported to have had less confidence completing the angina section of the YCBQ; this section received the most 'not sure' responses compared to the other sections of the YCBQ. Participants explained that they knew less about angina as it was not discussed in the education sessions at CR:

John: *"I don't remember them saying anything about angina. And that was basically the questions I was unsure of, were regarding angina."*

This participant felt that as he did not experience angina it was not so important for him to understand:

Interviewer: *And do you think it would be important; it would be useful for them to talk about angina?*

John: *"Well, if you suffer from it, absolutely. I don't and, therefore, I'm not so concerned about it. Just that when the questions came, I wasn't sure."*

Another participant found it reassuring to learn that angina did not damage the heart:

Steven: *"you always would have thought angina was damaging...at least that's one good thing."*

Participants conveyed that they sometimes found the YCBQ confusing, including the version in the booklet; however, reviewing their answers in the intervention session helped them gain understanding.

Bob: *"A couple of questions, you know, if you read them quickly you could build something in your mind that gave you a different vision of what the question actually was. But then, when you spoke to me one-to-one about it instead of just reading it from the booklet, you made me understand it more. And definitely, you know, some of the questions I would have put different answers to with not fully understanding the question, rather than explaining to me what the question actually meant."*

One person did not find completing the YCBQ difficult as they were already familiar with the correct responses:

Wendy: *“Well I found, from my point of view there probably wasn’t a lot of things on that questionnaire that I, I didn’t know.”*

For one participant, David, completing the YCBQ was described as a daunting experience. Due to problems with his eyesight, and not having the right glasses with him, he agreed to have the questionnaire read to him. Despite being conscious of making sure that David did not feel pressure to get the ‘right’ answer, it appears that he still felt anxious; this issue was only highlighted afterwards, in the interview. This person also felt that there were too many questions and that they were too personal, however, he went on to explain that after answering a few questions he felt more comfortable with continuing.

David: *“I found it a bit strange to say the least...and she’s asking me these questions that she’s already probably read and understood ‘em better than me...and I found it a bit daunting, to say the least...you asking me questions”*

Interviewer: *“How difficult did you find it answering those questions and those statements?”*

David: *“there was too many – there was questions there and I thought, you know, yeah, I’ll answer them. I’ve got to be honest with myself. If I’m not honest with myself and I’m wasting her time and my time...And I found some of the questions that you asked a bit personal, if you want to put it that way”*

Interviewer: *“So, with the questions, did you find that maybe some of them, well you said, were too personal, were maybe a bit too personal?”*

David: *“But at the same time...they had to be answered...They were questions that you were asking me and I had to answer them to be honest with myself. And to be honest with you, that was it, once I’d got that registered in my brain...it gave me, well, you could ask me twenty-one questions then, once I had that registered, that was it.”*

#### 4.5.2 Acceptability of the individual intervention components

The use of Socratic questioning to explore patients’ beliefs was found to be acceptable and viewed as a helpful way to gain better understanding:

Bob: *“you asked me to explain what I meant by “This condition’s for life and I strongly agree” ...You could relax and talk about it rather than be questioned like, you know, you go to court and you’re being questioned on something that you shouldn’t have done. But it was more about helping you to understand your condition and it was really good...I understood exactly what you were putting over to me. And if I didn’t understand a question, you made sure that not knowing what I was trying to say in that way, you asked me questions to try and understand where I was coming from...it was really good. It was helpful.”*

Of note was this participant’s reflection on their experience of exploring his belief that *“these are the cards I’ve been dealt”*, which indicated a fatalistic view of the cause and control of his heart problem. By exploring this belief further, in the intervention, the participant was able to explain what he meant by *“these are the cards I’ve been dealt”* and this uncovered an adaptive rather than maladaptive attitude towards his heart event.

Bob: *“I’m not saying ‘it’s the cards you’re dealt and it’s going to happen anyway’. Like we said last time, it’s just a case of, “Right, I’ve got it but what I do now to maintain it, or prevent it from happening again is now up to me.”*

John reflected that the misconceptions he had had before experiencing his MI, namely that his exercise and diet was sufficiently healthy, were not identified by staff at his GP surgery and he felt that his MI could have been avoided if he had had more knowledge.

John: *“Before my heart attack...I thought the golfing I was doing was doing me some good, and my varied diet with fruit and vegetables was managing me ok. So that was my misconception. My exercise was not sufficient...Yeah, and although I was eating my five a day, I was ruining it by all the red meat and all the bad stuff. So if you ask me beforehand, I thought, in fact, we used to go for a quarterly check-up at our doctors for blood pressure check and other things...And they said, “Diet?” And I said, “Yeah, definitely have our five a day, if not more. Everything we have is fresh cooked.” So I thought my diet was okay.”*

John’s experience highlights the problem of assuming that someone has full understanding of a topic; if a little more time had been spent, for example, to question

John further about his diet it would have uncovered that he ate high fat foods and red meat every day.

The intervention resonated with participants' attitudes towards the importance of making lifestyle changes and taking responsibility for their own health:

John: *"Because you're saying, "Now I know I need to take care of my heart, I'm less likely to have another heart attack, as long as I change my behaviour." And I've realised that. I've got to change my lifestyle."*

David: *"You can take me to the front door, but I've got to open it and that's the only way to explain it to you. I've got to open that door...Not you, me...I've got to be able to say "no, no, it's me; I've got to open it." You've done enough for me. If you've done 25% for somebody, I'm sure the person does 75% by himself, and if he doesn't, you're wasting your time...I just think it's fair I should pull my own weight"*

The intervention was viewed favourably as it was believed to be grounded in 'fact':

Interviewer: *"Was there anything it that you thought wasn't very helpful?"*

Bob: *"no, not really, because it was all fact, you know it was all sort of factual and there's nothing in there that you could have said, "That's a load of rubbish." It was all just looking at facts"*

The goal setting part of the interventions was not utilised fully as participants were all engaging in CR and had goals already set that they were working towards. The benefits of having goals for exercise were identified as an aid to motivation and to help start doing exercise while waiting to attend CR exercise classes:

Bob: *"and it does make it something you can achieve. But when you don't even think about it, or nobody gives you a target, you probably just think to yourself, "oh well, I'll get around to that." Or, "I'll wait till I start cardio classes and then I'll start doing it." Whereas then, you've just lost four to five weeks."*

Participants reported finding the individual intervention and booklet informative and that they learnt something from taking part and reading the booklet:

Bob: *"But it was, again, really informative, and sometimes made you think a little bit more about your condition rather than, you know, there's stuff in there I*

*didn't even know...it makes you more aware of how to counteract things, and it's really good in that way."*

#### 4.5.3 Acceptability of the intervention format and delivery

The intervention was delivered in a style that was liked and facilitated people to feel relaxed and able to talk:

Bob: *"we were chatting about a serious subject without making it feel serious...you could relax and talk..."*

David: *"I thought it was excellent, the way you put everything...You explained everything in there, what's this and what's that, and the difference in opinions and whatnot"*

The one-to-one approach was liked and participants thought personal input was necessary as opposed to the idea of receiving the booklet alone:

Bob: *"one-to-ones like this is the way it needs to be done. If you have this as a booklet and you didn't have anybody giving you support, it'd be harder to read."*

June: *"I think the personal input is always better, always. Some people haven't got the concentration to sit there very long and take something from paper whereas they will sit and talk...Something will always stop in, something will always stay there. So I think the two, the personal impact and the booklet"*

Participants had views about who they thought would not engage with the intervention:

June: *"The ones who are going to throw it in the bin straight away are the ones - they're going to do that anyway. They're the ones whose attitudes you'll never be able to change."*

David: *"you're wasting your time on them people when there're other people out there that want you, they appreciate you more and know quite well that you're helping them, or you want to help them...I'll take all the help I can to get myself put right – I'm not too proud. I'm not."*

June and David thought that it was not worth trying to help change people who displayed a negative attitude towards accepting help and making change. Whereas my

view is that people with a negative attitude were in greater need of an intervention as they might be more likely to have misconceptions and be engaging in maladaptive behaviour.

#### 4.5.4 Timing of the intervention

Most participants reported that they thought the intervention should be given as early as possible after a heart event. In particular, people thought that the booklet could be given to patients soon after their admission into hospital and the intervention session delivered at some point thereafter.

One participant thought that the booklet could be used as a primary preventative measure:

John *"Before you've had it. I mean, prevention's better than cure"*

To put John's comment into context, he had previously conveyed that he thought his cardiac event could have been avoided had he been made aware that his lifestyle was not as healthy as he had thought, for example, he was unaware that his exercise was of little cardiovascular benefit because it did not raise his heart rate sufficiently.

Some participants thought it would be useful to receive the booklet while still in hospital, before discharge, to help make sense of their heart condition and combat any negative feelings surrounding it:

David: *"The sooner the better...I think what you should do is try to get them in people's hands, especially when they're lying in hospital"*

Bob: *"..whilst you're sat in hospital and grasping everything that's happened to you at that stage, where your mind's got all these things going on that you're unsure of, if I'd have read that and was in a negative way about the condition in hospital, it would have put me on the right track a lot quicker"*

It was also thought that while on the ward, patients had time to read the booklet and would be able to check any uncertainties with staff:

Wendy: *"I think, possibly, when they're still in hospital, really. Because they've got time on their hands...and anything they're not too sure of, they've got people there to ask."*

June also felt that patients should receive the booklet as soon as possible, irrespective of how mild or severe their condition:

June: *“as soon as you can. Whether they’ve gone in there because of severe angina and they’re sort of being monitored for that or even the ones that have the bypasses. I’d say as soon as, as soon as possible after admission.”*

One participant felt that the best time to receive the intervention was at discharge, before attending Stage 4 CR, because people would be motivated to learn more about their condition and they have time at home, whilst recovering, to read:

Interviewer: *“At what point do you think would be the best time?”*

Steven: *“Coming out of hospital.”*

Interviewer: *“Right, okay.”*

Steven: *“Because that’s what you want...Because you’ve had something happen to you, you’re more aware, “hang on I want to know more about it,”...So I wouldn’t do that at the end of doing this [stage 4 CR], you want it at the beginning when they’ve got more time sitting at home to read.”*

#### **4.6 Focus group findings**

Three main themes were generated from analysis of the focus group data:

1. Acceptability of intervention components
2. Acceptability of, format and delivery
3. Timing of the intervention

##### **4.6.1 Acceptability of the group intervention components**

The cognitive behavioural model was acceptable to patients and they were comfortable with the concept that thoughts, feelings and behaviour are connected:

Sam: *“I think it’s very true, I do think if you hear something it goes into your head then your body reacts to what you’re thinking. Yeah, most definitely”*

The intervention highlighted that participants understood more about their experience of other people telling them they should be ‘taking it easy’ – that this was due to people’s misconceptions about heart disease:

Sam: *“I mean talking to people in general their misconception is generally ‘oh should you be doing this’? I get that all the time ‘should you really be doing that?’”*

Matthew: *“Same here, I think people believe I need to be sat at home, but I’ve always been an active person. I’m not happy sitting around and I keep telling people “it’s ok, I’m going to exercise classes, I’m allowed to be active.””*

The youngest participant, Sam, who was 36 years old, found that that the information he received in hospital was tailored to older people, which frustrated him as lead to him feeling confused about the level of activity that was right for him:

Sam: *“Everything was tailor made for an older generation ...they’re forever telling me to ‘turn it down, turn it down, don’t ...’ and I don’t know if I should.”*

Participants from the group intervention reported problems with poor concentration; this was not mentioned by the individual intervention participants. Group participants found it difficult to concentrate on the session and the PowerPoint slides; they thought this might be due in part to their overall poor concentration and memory since having had their heart event, rather than due to the intervention.

Sam: *“since my heart attack I have no concentration. So, although they were there, I just drifted off”*

Despite finding the group intervention difficult to concentrate on, one participant thought that more could be done in the intervention to dispel misconceptions if the ‘reality’ of more misconceptions was uncovered.

Sam: *“But there’s a lot more misconceptions out there to do with heart disease, a lot lot more. I think being able to say a misconception is ‘this’ but the reality is ‘this’ - I think a large piece on that would be more beneficial for people with heart disease because it will get rid of our misconceptions.”*

#### 4.6.2 Acceptability of the group format

The group intervention participants liked the group format and found being with other people who had been through a similar experience reassuring. A group member reported that he did not feel prepared for what to expect after being discharged from



hospital and felt that being told what to do and what not to do was insufficient. This view was supported by other members of the group:

Sam: *“I think it’s quite useful to sit in a group and discuss, because we’ve all got ‘a heart something’, each one of us has had something whether it’s a heart attack or people have had bypasses and stuff. I think, to sit and get rid of any misconceptions that you’ve got would be good because I don’t think anybody really tells you what to expect afterwards, they tell you that you should do this, this, this, and this, and that’s pretty much all you get told. So you do listen to a lot of other people and it fills your head with misconceptions.”*

Matthew: *“People are thinking here the same as yourself, it ain’t like being on your own and thinking ‘Oh God what do I do here?’ but with other people around me it’s better.”*

Alison: *“Group dynamics, you get a lot out of groups.”*

#### **4.7 Intervention booklet**

The focus group and individual interview data were combined, as all participants had been given the booklet. Themes identified were:

1. The benefits of the intervention booklet
2. Barriers to making use of the booklet
3. When to receive the booklet

##### **4.7.1 The benefits of the intervention booklet**

Incorporating the YCBQ in the booklet, along with a page towards the back to explain the myths and truths for each question was viewed favourably by participants.

Interviewer: *“were there any bits you thought were more useful than others?”*

June (Individual): *“I think the myths and the truths and the myths. Yeah because it sort of shortens it a bit... everything that you’ve got here, you come to that, the myths... and the answers, you know, the truth and the myth is there beside it so you can, you can compare straight away, and so that is very useful.”*

Interviewer: *“Is there anything about the booklet that you didn’t like, or would change?”*

Wendy (Individual): *“No. No I don’t honestly think there is. I liked the, sort of like, little quizzes and, and that, you know. And also as well, to be able to go and find out if you were right or wrong, to have that information, I think, is important.”*

Participants found the YCBQ-clinprac version of the YCBQ in the booklet useful and found that being required to choose a definite answer made them think more about the their answer.

Steven (Individual): *“The questionnaire, disagreeing and agreeing sort of thing because I think when you did the one before you had, like, three answers but it can be...you can always go for the middle one, but with two you...you’ve got to make a decision sort of thing.”*

June (Individual): *“...it makes you think before you say you agree or disagree, if that’s the only choice that you’ve got, to agree or disagree, it makes you think.”*

Participants had been encouraged to write in their copy of the booklet during and/or after their intervention; this was seen to be a useful way to engage with reading the booklet, help make sense of the information and as a way to demonstrate their understanding.

Bob (Individual) : *“And how would you know if somebody picked that up, if they didn’t write anything, you wouldn’t know whether they’d read it or not. And I think the text side of it and actually physically writing on it, forces the person to want to read it, and secondly, understand what they’re reading. And give you that information back to know that they understand what they’re reading”*

Having the booklet to keep meant that for one participant he had time to reread it and this helped him absorb the information.

David (Indiviudal): *“I didn’t realise some of them at the time. It’s only now I realise when reading it about it. And that’s being honest again. You know I could’ve said to you, ‘oh well, yeah, it was, I understand everything’ and you don’t, not at the time.”*

Interviewer: *“So do you feel you needed a bit of time to reflect and think about it?”*

David: *“You need time to absorb it all.”*

*“There’s a lot of stuff in there, I’ll read it no end of times now – now I’ve got one I’ll read it more and more and more”*

Participants were accepting of the booklet – one participant highlighted that he saw the content of the booklet to be factual:

Interviewer: *“Was there anything in the booklet you didn’t agree with?”*

Bob: *“No, not really. It’s all factual, so if it’s fact you can’t sort of disagree with it really.”*

#### 4.7.2 Barriers to using the booklet

Group participants’ poor concentration and memory also highlighted problems with engaging with the booklet. Unfortunately only one participant had had a proper look at the booklet as the others said they had forgotten. However, this identified the barriers patients may have with regards to engaging with the booklet, including views that it was too long:

Graeme (Group): *“It’s too large, I think there could be too much information in there, as Sam said, I’ve noticed myself my concentration span is not very good at the moment since I’ve had the heart attack. If all you’re seeing is loads of words, you’ll just end up throwing it away”*

Sam (Group): *“not only that. I don’t know if anyone else is, but my memory’s quite bad as well and I find if it’s a big piece of paperwork that I’ve got to read by the time I’ve got to the bottom of it I’ve generally forgotten some part, then it doesn’t make sense to me anymore because I don’t know what it’s equating itself to”*

Individual intervention participants, in contrast, did not report finding the booklet too long:

Interviewer: *“in terms of the amount of writing and the amount of text, how did you feel about that?”*

Bob (Individual): *“That was okay, because, unless you did do that, how would you interact with it?”*

A possible reason for the apparent non-engagement by group participants with the booklet was given by an individual intervention participant. He thought that a group version of the intervention would not be sufficient to engage people or encourage them to read the booklet:

Bob: *“Or if you were in a class and someone put on a presentation and no-one spoke to you, you’d skip through that and not read it; you’d read it very vaguely.”*

Although Bob had not experienced the group intervention, he could relate the group intervention to his experience of attending the CR education classes.

John identified that parts of the booklet needed to be more inclusive to people with disabilities and that, as a disabled person, he found that much of the advice given at CR excluded the needs of disabled people:

John: *“And I put here, “Still ignoring the disabled”*

John: *“...all the lectures we’ve had, nobody’s ever mentioned disabled people”*

John thought that the booklet could mention disabled people and reinforce that cardiovascular exercise important:

John: *“I think a section on disabled and the importance of people who are disabled still doing exercise, finding some exercise they can do”*

John: *“I mean, in here, you’ve put about walking and I put to the side of it, “But at a pace to increase your heart rate”*

#### 4.7.3 When to receive the booklet

Discussing the best time to give out the booklet in the focus group, the group intervention participants reported to have felt that they were lacking in information either in hospital or after discharge and would have found the booklet useful. The group participants also had to wait longer (between 6 to 10 weeks) to begin stage 4 cardiac rehabilitation and reported to have received little input in the meantime.

Graeme: *“That’s the thing you get no guidance in the meantime... I got another date but got readmitted again, but in those times that I was readmitted and let out there was nothing, nothing whatsoever to get the information.”*

Alison: *“Yeah that would be good because I was completely ignorant to everything; I didn’t physically get diagnosed for 5 days. Absolutely nothing was in my head, so if I’d have had something to read and then you go home for 4 weeks because you can’t drive and do everything it’s an horrendous time, you shouldn’t be left that long, absolutely no way, it just saps your confidence enormously.”*

In the discussion, one person thought that it would be confusing to receive the booklet in hospital due to the amount of other information being given at the same time. However, another participant interjected that the booklet would be beneficial for relatives to read:

Interviewer: *“...at what point do you think would be the best time for them to receive a booklet like this?”*

Sam: *“I wouldn’t say directly afterwards because you’ve got the cardiac rehab team in hospital and they’re telling you so much information then if you whack a load of other information on top of it I think you’re just going to get so confused with all this information that nothing’s going to make sort of a lot of sense to anybody. That’s how I feel anyway”*

Graeme: *“Even if not for you at that precise moment, it could be for relatives, family, kind of thing, so they have a better insight.”*

## **4.8 Staff interview**

### **4.8.1 Benefits to patients**

The intervention was viewed as being useful and well-received by participants, particularly the group aspect:

*“Everyone was interested and interacted well with the session. I think they really value the opportunity to sit down together as a group – the education sessions here only run every 6 weeks, so not everyone is around to attend them.”*

The booklet was viewed as being particularly useful for patients and their family members to have while the patient was waiting to attend the CRP:

*“I think the booklet would be really useful for patients to receive just before they go home from the hospital or soon after they get home. Especially for the patients who are waiting to come here, unfortunately our waiting times are longer than they should be. Working through the booklet, reading it and going through the questions would help them and definitely give their family, or whoever, some help with better understanding.”*

#### 4.8.2 Views of patient beliefs

During the intervention, when people were asked to think about how much control they believe they have over their heart problem one participant voiced that he felt like he had no control. The staff member interjected and told the participant that they did have control. Reflecting on their experience of observing the intervention, the staff member noted some frustration that this participant was unable to accept that he had some control of his heart problem:

*“It was frustrating when that patient said he had no control because, of course, he has control, he should know that. He’s actually changed his diet quite drastically and stopped smoking,”*

#### 4.9 Summary

Overall, the individual intervention participants favoured a one-to-one format whereas the group intervention participants favoured a group format. This could be due to their experiences of the intervention but also due to the differences in the cardiac rehabilitation programmes they attend. Individual intervention participants had already taken part in, or were due to take part in, bi-weekly group education sessions whereas the group participants had less opportunity to attend an education class as one ran only every 6-8 weeks, therefore, the group participants were more likely to appreciate being able to talk in a group.

## CHAPTER 5. DISCUSSION

### 5.1 Introduction

This chapter discusses the findings of the qualitative study and links the findings to the theoretical basis of the intervention and intervention components. Modifications to the draft interventions, as a consequence of the qualitative findings, will be explained. The strengths and weakness of the intervention will be highlighted in addition to the strengths and limitations of the study as a whole. The chapter will end with an overall conclusion and suggestions for further study.

### 5.2 Study findings

#### 5.2.1 Individual intervention

The first theme outlined was ‘acceptability of tailoring the intervention’. This theme reflects that the process used to tailor the intervention was a significant part of the intervention experience. The original aim of completing the YCBQ was to identify if and where people held common cardiac misconceptions which could then be addressed through tailoring the intervention to these areas. Compared to other studies of tailored interventions to change cardiac beliefs (Broadbent et al. 2009, Cooper 2004, Petrie et al. 2002), the current study utilised a questionnaire that asked people to consider direct statements about heart disease, for example, *“Your heart is like a battery, the more you do the faster it runs down”*, whereas the other studies utilised the IPQ, IPQ-R or Brief-IPQ, which include more ambiguous statements than the YCBQ, for example, *“My illness is a serious condition”*.

Participants’ experiences highlighted that completing the YCBQ had benefits beyond its use as a tool for tailoring, in that the process of going through the questionnaire appeared to stimulate people’s thinking about heart disease and an interest in finding out the correct responses, therefore, the YCBQ appears to be a useful intervention tool, in addition to its use as a measure of common cardiac misconceptions. As the other studies did not seek the views of participants’ experiences, through qualitative research, it is unknown how people found completing the IPQ, or its other versions, especially in view of the questionable content validity of these measures and concerns that people

completing the Brief-IPQ can misinterpret questions (van Oort, Schroder and French 2011).

The findings provide evidence that completing the YCBQ was accepted by all participants, but the experience and feedback from interviews identified that people had differing reactions to the questionnaire. Problems with completing the questionnaire related to poor eyesight and being slow at reading which were overcome by the researcher reading the questions aloud to two participants. This experience highlighted that barriers to completing the intervention can arise but also can be managed. One person, who had the questions read aloud, reported to have felt self-conscious about responding to someone who already knew the 'answers', despite being reassured that it was not a test. This finding indicates a need to provide an introduction to the questionnaire and rationale for its use, including reassurance that it is not a test; reduce anxiety and reduce the likelihood of social desirability bias affecting people's responses to the YCBQ that might be contrary to their actual beliefs.

The findings suggest that the intervention could be enhanced by completing the YCBQ as part of the intervention, at the beginning, rather than completing it before the intervention is scheduled, this is feasible as the YCBQ is straightforward to score, particularly for a cardiac nurse. Although this would increase the length of the intervention by 5 or 10 minutes it would reduce the need for the pre-session meeting and may, therefore, be less burdensome to patients and staff if used in clinical practice. Furthermore, participants reported that the version of the YCBQ in the booklet, which restricted responses to 'agree' or 'disagree', triggered them to think more about their answers because they were required to make a more definite choice with no middle ground option. Substituting the research version of the YCBQ with the YCBQ-clinprac is an option but it requires further exploration in terms of outcome measures needed if the intervention is efficacy tested in a future RCT.

The second theme illustrated that the intervention components were perceived to be acceptable to participants. The guided discovery approach using Socratic questioning was perceived by participants to be beneficial for both the person providing the intervention and the person receiving the intervention, to clarify understanding and minimise misunderstandings in communication. Some participants appeared to



interpret the questioning, where the facilitator takes a naïve stance, as being required by the student researcher due to their lack of expertise on the subject. While people willingly responded to the questions it is unknown how they would have responded to similar questioning from an experienced CR professional. Better communication with people about what to expect from the intervention, for example, that they may find the style of questioning different, may help people accept the guided discovery approach more readily. Acceptance of the treatment rationale is important as evidence shows it is linked to better outcomes (Bennett-Levy et al. 2010).

The content of the intervention was perceived to be grounded on factual information and that facts are reliable and speak ‘truth’. While this is a positive view of the intervention, believing that information, presented as fact, is a solid ‘truth’ may be unhelpful if it means that the person is less inclined to change their beliefs in response to the provision of more up-to-date knowledge that may refute the original ‘fact’.

Encouraging an open-minded approach, that knowledge of a topic is based on current evidence and new research evidence may bring alternative perspectives may help people adapt their cardiac beliefs more readily. Also, that seemingly factual information needs to be viewed critically when it is garnered from less reliable sources, for example, on the internet.

The goal setting element was not utilised in the intervention because participants already had goals set at CR. However, goal setting was viewed as a helpful aid to building physical activity if the intervention was being provided to people while they were waiting to begin exercise classes.

The third theme ‘acceptability of intervention format and delivery’ illustrated that people liked the individual approach and the style of delivery. The individual format was liked for providing personal support to go through the booklet. It was felt that people might struggle to complete the booklet without personal support; therefore just giving out the booklet without additional input is unlikely to be satisfactory to people. Participants talked positively about the collaborative and conversational style of the intervention and highlighted that it helped them to feel able to relax and talk openly during the intervention.

The final theme related to participants views on when they thought the intervention was best delivered, the 'timing'. Views on the optimum timing varied but providing the intervention as soon as possible was perceived as being the preferred course. One participant thought that he would have benefited from the intervention prior to his heart event – he thought if he had been aware of his misconceptions this could have prompted him to change his unhealthy behaviour and perhaps prevented his heart attack.

People perceived that the intervention was best delivered when they had 'time' – for some people this was when they were still in hospital and for others this was after discharge. The period between leaving hospital and beginning exercise classes was highlighted as an ideal time to receive the intervention as people reported having time at home to read and were motivated to improve their knowledge and understanding. Circumstances where people need to have a longer hospital stay was identified as a reason to deliver the intervention in-hospital. These findings support the findings of Astin et al. (2008); that individual preferences should be taken into account when planning the optimum timing of the intervention because people spend different lengths of time in hospital and have different reactions in terms of their ability to concentrate on taking in information.

#### 5.2.2 Group intervention

Similar themes were identified from the focus group findings. As the intervention was group-based it was not tailored to individual needs, however, people still completed the YCBQ after consenting to take part and completing the demographics questionnaire. No difficulties with completing the YCBQ were identified by the researcher or participants. The first theme 'acceptability of the group intervention components' found that people accepted the cognitive-behavioural model in terms of viewing that thoughts are connected to feelings and behaviours.

The interactivity of the intervention was well received, as observed in the session by the CR staff member, through questions taken from the Brief-IPQ, for example, to rate from 0 to 10, "*How much control do you feel you have over your heart disease?*" Following on from this, the response that one person had about his feelings of lack of control invited other group members to discuss their views on this. If a guided discovery approach had been used at this point it then the person could have defined what 'control

of my heart problem' meant to them, what actions or situations would constitute 'control', what they could do to improve control and a re-evaluation of their current situation. This may have led the patient to discover that on some level their heart disease is controllable and that they themselves had a role in this control through their adherence to medication, CR and healthy lifestyle. The group situation, however, meant that it was not appropriate to explore this issue further in the session whereas an individual session would have accommodated this.

The group format of the intervention was viewed positively by participants and they thought the opportunity to talk as a group, with people who have had and are having similar experiences, was helpful. Without the group participants experiencing the individual intervention is unknown whether they would have valued the individual intervention as highly as the group version. The frustrations of waiting to start CR classes and feeling bored and isolated were experiences the participants shared whereas the individual participants did not voice these issues as strongly. The fact that the group participants had not yet attended any group education sessions may have influenced their enthusiasm about the intervention. It is unknown how participants would have perceived the intervention if they had had the opportunity to attend education classes.

Similar to the individual participant's views on the timing of the intervention, earlier was perceived to be better. The value of having an early intervention reflects the group participants' frustration about their experience of waiting for CR; compared to the individual participants they waited 4 to 6 weeks longer to start stage 4 CR, despite BACPR guidelines for patients to begin within two weeks of discharge.

The optimum timing of the intervention was viewed to be that which balanced people's information needs and their capacity to take on that information at that time. The optimum time was seen as being when people had returned home as they had a lot of time and a desire to have support and more information. Participants thought that the intervention booklet would be useful to have access to straight away rather than waiting for a group. It was seen as something people could engage with at their own pace during their time at home. It may not be feasible to provide a group or for people to attend a group in the early weeks after discharge at this CR centre; providing people with the booklet first would be a compromise. Although people thought they needed

some time to concentrate on reading, they recognised that their family would have benefitted from reading the booklet. It was perceived that if family members reduced their misconceptions then this would be helpful; it was identified that some family members had concerns about the patient doing too much which frustrated them as they were following the advice of CR professionals.

### 5.2.3 The booklet

The booklet was viewed as an important and necessary part of the intervention, a view held more strongly by the individual intervention participants who valued it as a tool for gaining understanding through repeated reading and interaction. Additionally, the booklet was perceived as being a component that could be separated from the individual or group intervention, to enable people to make use of the booklet as soon as possible. Participants viewed that it would be helpful to receive the booklet in hospital or upon discharge as this was a time when they wanted to read information and had time. People who thought they would not read the booklet until they were settled back home still valued the idea of receiving it as they recognised that family members would benefit from reading it.

Group participants had barriers to reading the booklet which centred on lack of concentration whereas individual participants did not report problems interacting with the material. It may be that the individual nature of the individual intervention motivated people to read through the booklet or it might be that other factors were involved, such as, the group participants' dissatisfaction with their experience of waiting for CR. Despite perceptions that the booklet could be provided separately to the intervention, it was viewed that the intervention was still necessary in order to fully understand the material. Similar to the findings of Astin et al. (2008), people viewed the written information in the booklet as being useful to support the delivery of the intervention and that the booklet enabled people to take on the information at their own pace.

As discussed in Chapter 2, previous studies of interventions aimed at changing cardiac beliefs have been limited in not using a qualitative approach to explore the patients' perspective before testing the intervention in an RCT. Where patient satisfaction with the intervention was sought, this was through a brief patient satisfaction survey

(Cossette et al. 2012, Petrie et al. 2002). The angina plan interventions (Furze et al. Zetta et al. 2011) and tape intervention (Lewin et al. 2002) were developed in conjunction with patient input but the details of this have not been published. Exploring the patients' perspective has been recognised as being a vital part of intervention development rather than confining this to intervention evaluation. Involving patients in the development of interventions ensures that, in addition to the intervention being composed of effective components, patients are willing and able to engage with. This study did not explore patient need for the intervention as the literature already provided information regarding common misconceptions. Input from CR volunteers provided insight into the patient perspective when developing the draft intervention.

Other studies aimed at a cardiac population that have followed MRC guidelines and integrated qualitative research into the design and development of interventions include the SPHERE study, a comprehensive secondary prevention intervention by Corrigan et al. (2006) which included development of an educational booklet (Leathem et al. 2009) and the UPBEAT study, a primary care intervention for managing depression and CHD (Barley et al. 2012). Whilst these studies did not focus on changing cardiac beliefs or illness perceptions, their findings can be compared with this study because factors such as tailoring the intervention are relevant.

### **5.3 Study Limitations**

There are a number of limitations to this study. Firstly, the research setting may not be typical of other settings around the UK. An intervention that works in one clinical setting may not necessarily work in another due to a range of differences including the characteristics of the population, the CR service and the staff (Campbell et al. 2007). It is necessary to understand how the context influences the intervention. This study was able to explore two very different CR settings; one hospital-based and one community-based. Other than all participants receiving the same booklet, only one type of intervention was delivered to participants at each site. With more time, both interventions could have been delivered allowing for the acceptability of both interventions being explored at both sites. The group intervention was not delivered at CRP 1 due to the logistical problem of fitting it around the education sessions already

delivered at the setting. Although the context of this CR meant it was not feasible to deliver the intervention in the time constraints of the study, in practice, outside of the research context, the intervention could be placed into the education class schedule. Another option, taking into account participants' views that there are many more cardiac misconceptions than were covered in the session is to discuss misconceptions at the beginning of each talk to help explain the importance of having correct and adaptive beliefs about the topic in question. In the context of CRP 2, where the provision of education classes is less regular, the group intervention was easily delivered as there was adequate time and space available. The patients at CRP 2 were keen to attend the group intervention, perhaps due to a need for more group sessions; however, staff report that when classes are offered, attendance levels are poor. The reasons for poor attendance are unclear but may be due to the irregular nature of the sessions, hospital setting, and parking charges. It is not known if patients at CRP 2 would be as keen to attend the group intervention if it was outside of a research context, where parking charges are not reimbursed. It was observed that a number of patients at CRP 2 attended exercise classes up to 30 minutes early and waited together in the waiting room. Providing short, 15 minute sessions at the beginning of each exercise class to discuss different misconceptions using the booklet as a guide and facilitated by a physiotherapist may be more acceptable to patients who have poor concentration and concerns about parking costs. This suggestion was acceptable to the physiotherapists at CRP 2.

As these sites only received one of the interventions, due to time constraints, it is not known how well the intervention that was not tried would be viewed by patients at these settings. Ideally, both settings would have received both interventions.

The researcher had multiple roles in study which means that interviewer bias cannot be excluded. The fact that the researcher was involved in recruiting participants, providing the intervention and interviewing could have meant that participants were influenced to provide desired answers. Having multiple roles in this study was unavoidable as it was a student research project, however, attempts to decrease the influence of interviewer bias were made at the beginning of interviews by reassuring participants that negative feedback was welcome and would be as useful for developing the interventions as positive viewpoints. Conversely, having the same person provide the intervention and

conduct the interviews and focus group was positive as rapport had already been established allowing for more in-depth discussion of the intervention and the insight the interviewer had into the delivery of the intervention aided the interpretation of the findings.

The participants were all motivated individuals, were attending CR and having made health behaviour changes as a result of their heart event; they spoke about the importance of having the right attitude to health and illness and some thought that unmotivated individuals would not engage with the intervention. It is unknown how less highly motivated individuals might interact with the intervention, such as people who do not attend CR. This is important because negative illness beliefs and cardiac misconceptions are associated with non-attendance at CR and maladaptive coping behaviour (Furze et al. 2005, Petrie et al. 1996). Piloting the interventions further, with a different sample, could help to understand the experience of people who are not attending a CRP or who may be ambivalent about attending as they may have different needs.

This study did not set out to explore whether dispelling people's cardiac misconceptions actually led to positive health behaviour change or any other positive health outcome. Furthermore, the study focuses on cardiac misconceptions which relates to only one determinant of health behaviour; changing cardiac misconceptions alone may not lead to sufficient behaviour change which is important for effective secondary prevention of CHD. This study, however, by developing the interventions, provides acceptable methods of changing cardiac misconceptions that can go on to be evaluated to determine their effectiveness which will also help identify how important a determinant of behaviour change cardiac beliefs and misconceptions are.

#### **5.4 Conclusion**

This study has followed MRC guidelines (Craig et al. 2008) to develop an individual and group intervention to dispel cardiac misconceptions that are predictive of poor outcomes in people with coronary heart disease. The systematically conducted literature review found that Leventhal's CSM (Leventhal, Meyer and Nerenz 1980) was an appropriate theoretical basis on which to base the interventions. Intervention

components were based on the cognitive-behavioural approach. Exploring the experiences of people who tried the interventions has yielded valuable feedback regarding the acceptability of the interventions. Historically, intervention studies have often not explored the ‘patients’ perspective’; this study has ensured that the interventions have been developed optimally before going to the expense of testing their efficacy in an RCT. A refined version of the intervention booklet, which has taken into account feedback from participants’ and members of the expert panel, can be found in Appendix VIII.



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# **APPENDIX I**

## Literature Review

### Search strategy

S1	Heart disease or exp Heart Diseases/
S2	Coronary heart disease or exp Coronary Disease/
S3	Myocardial infarction or exp Myocardial Infarction/
S4	Exp Microvascular Angina/ or exp Angina Pectoris, Variant/ or exp Angina Pectoris/ or exp Angina, Unstable/ or angina
S5	(revascularization or revascularization)
S6	Exp Angioplasty, Transluminal, Percutaneous Coronary/ or exp Angioplasty, Balloon/ or exp Angioplasty, Laser/ or exp Angioplasty/ or exp Angioplasty, Balloon, Laser-Assisted/ or angioplasty
S7	Percutaneous coronary intervention
S8	Exp Coronary Artery Bypass/ or coronary artery bypass graft. or exp Myocardial Revascularization/
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8
S10	Exp Health Knowledge, Attitudes, Practice/ or misconception*
S11	Belief*
S12	(negative thought\$ or negative thinking)
S13	Illness perception*
S14	Illness cognition*
S15	Exp Attitude to Health/ or exp Perception/ or exp Sick Role/
S16	(maladaptive thoughts or maladaptive thinking)
S17	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
S18	S9 AND S17
S19	Cognitive or exp Cognitive Therapy/
S20	Cogni*
S21	Cognitive behavioural therapy or exp Treatment Outcome/
S22	Exp Behaviour Therapy/ or behavioural therapy
S23	Behavio*
S24	Exp Health Behaviour/
S25	Psychotherapy or exp Psychotherapy, Multiple/ or exp Psychotherapy/ or exp Psychotherapy, Group/ or exp Psychotherapy, Brief/ or exp Psychotherapy, Rational-Emotive/

S26	Exp Adaptation, Psychological/ or psychosocial intervention\$.
S27	Rehabilitation or exp Rehabilitation/
S28	Cardiac rehabilitation.
S29	Exp Self-Help Devices/ or exp Self-Help Groups/ or self-help
S30	Disease management or exp Disease Management/
S31	Health education or exp Health Education/
S32	S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31
S33	RANDOMI?ED CONTROLLED TRIAL*
S34	CONTROLLED CLINICAL TRIAL
S35	SU RANDOMI?ED CONTROLLED TRIAL*
S36	SU RANDOM ALLOCATION
S37	SU DOUBLE BLIND METHOD
S38	SU SINGLE BLIND METHOD
S39	SU QUASI EXPERIMENTAL
S40	S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39
S41	SU (ANIMALS NOT HUMANS)
S42	S40 NOT S41
S43	CLINICAL TRIAL
S44	CLINICAL TRIALS or exp Clinical Trial/
S45	SU PLACEBOS
S46	AB Placebo* OR TI Placebo*
S47	AB ( ((single or double or treble or triple) AND (blind* or mask*)) ) OR TI ( ((single or double or treble or triple) AND (blind* or mask*)) )
S48	AB (clin* trial*) OR TI (clin* trial*)
S49	AB Random* OR TI Random*
S50	SU RESEARCH DESIGN.
S51	S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50
S52	S51 NOT S41
S53	S52 NOT S42
S54	S18 AND S32 AND S53

**Coding chart showing techniques used in selected interventions**

Illness representation	Intervention Focus	Strategy / Techniques	Broadbent 2009	Broadbent 2013	Cooper 2004	Cossette 2012	Furze 2009	Furze 2012	Lewin 2002	Petrie 2002	Taylor 2009	Zetta 2011
Causal	Identify causal beliefs	Questionnaire/ quiz	✓		✓		✓	✓				✓
		Open questions			✓	✓						
	Expand causal beliefs	Provide information					✓	✓	✓			✓
		Prompt to consider other causes	✓		List ✓	Refr ame ✓		✓		✓		✓
	Improve perception of link between causal factors and health behaviours	Goal setting – risk reduction			✓		✓	✓				✓
		Pie chart			✓							
		Readiness ruler									✓	
	Debunk myths about causes and recovery	Action planning (written)	✓				?	✓		✓		✓
Identity	Identify beliefs relating to symptoms	Questionnaire/ quiz	✓				✓			✓		
		Open questions				✓						
	Strengthen identity	Provide information of typical and atypical symptoms & onset						✓	✓			✓
		Provide concrete image of illness	✓					✓		✓		✓
		Explain symptoms and terminology	✓					✓	✓	✓	✓	✓

Illness representation	Intervention Focus	Strategy / Techniques	Broadbent 2009	Broadbent 2013	Cooper 2004	Cossette 2012	Furze 2009	Furze 2012	Lewin 2002	Petrie 2002	Taylor 2009	Zetta 2011
Identity	(continued)	Distinguish between cardiac and non-cardiac cognitions						✓		✓		✓
	Strengthen identity	Discuss normal symptoms of recovery	✓						✓	✓		
Timeline	Identify timeline representations	Questionnaire/ quiz	✓		✓			✓		✓		✓
		Open questions			✓							
	Change timeline to 'short' duration	Appropriate timeline to 'normal' discussed	✓							✓		
		Link to consequences	✓							✓		
	Change timeline to 'chronic' duration	Emphasise short-term & long-term nature of CHD			✓	✓		✓				✓
		Provide personalised risk info – high risk of AMI		✓								
Consequences	Identify timeline representations	Questionnaire/ quiz	✓		✓					✓		
		Open questions			✓							
	Change consequences to 'less severe'	Challenge beliefs related to reducing activities	✓					✓	✓	✓		✓
	Change consequences to 'more severe'	Inform what may happen if behaviour not changed										

Illness representation	Intervention Focus	Strategy / Techniques	Broadbent 2009	Broadbent 2013	Cooper 2004	Cossette 2012	Furze 2009	Furze 2012	Lewin 2002	Petrie 2002	Taylor 2009	Zetta 2011
Cure / control	Identify cure / control beliefs	Questionnaire/ quiz	✓		✓			✓		✓		✓
	Increase belief of cardiac risk factors	Personalised information on how BC can reduce risk		✓								
	Increase belief in personal control of CHD	Likert scale to identify control belief & illustrate idea of control continuum			✓							
		Emphasise importance of health behaviour change			✓	✓		✓	✓		✓	✓
		Discuss methods of health behaviour change	✓	✓				✓				✓
		Pros and cons of change discussed	✓								✓	
		Goal setting Or link to goal setting	✓		✓		✓	✓			✓	✓
		Action plan physical activity	✓					✓		✓		✓
		Self-monitor physical activity					✓	✓				✓
		Review behaviour goals and feedback					✓	✓				✓
	Decrease belief in 'cure'	Emphasise need to manage CHD despite surgery				✓						



Illness representation	Intervention Focus	Strategy / Techniques	Broadbent 2009	Broadbent 2013	Cooper 2004	Cossette 2012	Furze 2009	Furze 2012	Lewin 2002	Petrie 2002	Taylor 2009	Zetta 2011
Treatment	Beliefs about specific medications	Discuss concerns about taking prescribed medication	✓			✓				✓		
		Explain need to take meds as prescribed & not be guided by symptoms								✓		
	Beliefs about CR strengthened	Ask about intentions to attend CR			✓	✓						
		Discuss what CR involves			✓	?					✓	
		Action plan					✓	✓	✓		✓	✓
Emotional	Reduce emotional distress	Relaxation CD					✓	✓	✓			✓
	Worries/concerns discussed	Normalise worries about symptoms							✓			
		Worry about experiencing another MI discussed	✓	✓								
		Concerns about going home discussed	✓	✓		✓			✓	✓		
		Create dissonance to instigate belief change									✓	
	Improve social support	Spouse attends session to discuss their understanding	✓									

<b>Illness representation</b>	<b>Intervention Focus</b>	<b>Strategy / Techniques</b>	<b>Broadbent 2009</b>	<b>Broadbent 2013</b>	<b>Cooper 2004</b>	<b>Cossette 2012</b>	<b>Furze 2009</b>	<b>Furze 2012</b>	<b>Lewin 2002</b>	<b>Petrie 2002</b>	<b>Taylor 2009</b>	<b>Zetta 2011</b>
<b>Emotional (continued)</b>	<b>Improve social support (continued)</b>	Discuss spouses' concerns about going home	✓									
		Explain action plan to spouse	✓									
		Discuss/ inform spouse of role in patients' recovery	✓						✓			

## **APPENDIX II**

Draft Individual Intervention Manual  
Draft Group Intervention Presentation  
Draft Intervention Booklet

## Draft Individual Intervention to Manage Cardiac Misconceptions Manual

### **1. Pre-session**

- Score YCBQ and tick off which areas to address.

### **2. Introduction**

- Introduced yourself to the participant as a reminder
- Inform the participant of the expected length of time needed to go through the intervention and check that the participant still has time.
- Encourage the participant to ask any questions they may have at any time during and after the intervention.

*“Thank you for agreeing to review this session, it will take around 30 minutes – is that okay? Please do feel free to ask any questions as we go along, you don’t have to wait until the end”*

### **3. Explain purpose and aim of the intervention**

- Give out common cardiac misconceptions leaflet (will refer to throughout session)
- Explain what cardiac misconceptions are:  
*“Today we’re looking at your thoughts and beliefs to do with your heart attack and heart disease. Misconceptions are inaccurate or muddled beliefs. There are a number of common misconceptions about heart disease, what we call cardiac misconceptions and lots of people, even health professionals have them.”*
- Explain link between beliefs/thoughts, feelings and behaviour (and cognitive behavioural approach) - illustrate the role of thoughts and beliefs on subsequent behaviour:

Belief - Thought → Action / Behaviour

- Introduce problem of having cardiac misconceptions:  
*“Unfortunately cardiac misconceptions are not very helpful because having the wrong ideas can get in the way of recovery and feeling well.”*
- Aim of session: to help patient identify and change unhelpful thoughts and beliefs about heart disease:

*“The aim of today is to show you how to identify your own cardiac misconceptions, we can look at some of the common misconceptions and look at ways to get rid of any unhelpful misconceptions so that you can make the best of your recovery.”*

Any questions? Ok to carry on?

#### 4. Identifying misconceptions

- The first step is to identify thoughts and beliefs about heart disease.

*“You completed this questionnaire before our session today. This was to help us identify any misconceptions. It’s common for people to have these. It’s useful to check if friends and family have misconceptions too because their thoughts and beliefs about heart problems can affect you too. There’s a copy in the booklet so if you’d like someone else to go through it, you can”*

- Feedback outcome of YCBQ (being careful not to sound negative if participant has many incorrect beliefs). Where a participant has few or no misconceptions (as identified by the YCBQ) then offer to explain the common misconceptions and suggest information in leaflet may be useful for family member, etc.


#### 5. Challenge

- The booklet explains the common misconceptions, “you can keep and write in it”
- In collaboration with participant, pick a misconception to address.
  - E.g. belief that “Stress is the main cause of my heart problem”:
  - Use white board or paper, and refer participant to page in booklet to demonstrate unhelpfulness of worrying about stress being ‘bad’:
    - Picture of person worrying about stress, affect on behaviour, impact on physical well-being - vicious circle.
- Show illustration of person who has adaptive belief “stress isn’t dangerous and I can manage it”. Show stress line (i.e. no such thing as 0% stress)
- Show how to challenge an unhelpful belief by weighing up evidence for and against the belief (use separate piece of paper and show page in leaflet). Use participant’s chosen misconception.

#### 5. Changing misconceptions

- Encourage participant to come up with an alternative belief (which is a correct one) and, if they can, encourage them to write it down.
- Explain importance of believing in the ‘new’ belief – rate out of 10
- Discuss ways they can strengthen new beliefs, e.g. written prompts, reminders, doing things to strengthen belief like challenging any avoidance behaviour.
- Any questions?
- Summarise session.

## Draft Group Intervention Presentation

Helen Fletcher – Masters by Research  
Coventry University



**Managing cardiac misconceptions**

### What are Cardiac Misconceptions?

Thoughts, ideas or beliefs:

- Incorrect
- Muddled

“People who have heart disease should always avoid stress”


### Where our illness beliefs come from?







### Thoughts matter!


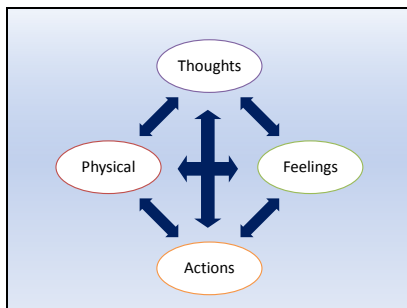
What you **think...**



and what you **do...**




affects how you **feel**


### David

David has chest pain (angina)

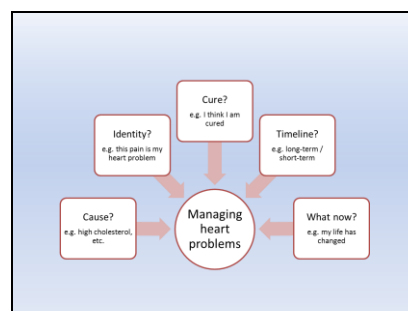
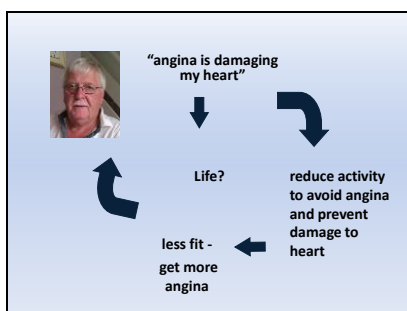


If I take it easy it will stop


12 months later...David is getting more angina. Why?



His tests show nothing has changed?




### Beliefs about symptoms



**David**

"This cannot be heart related – it's heart burn"

Avoid seeking help?



**Jaspreet**

"Oh no! There goes my heart problem again!"

Feels anxious and on edge

How much do you experience symptoms from your heart disease?

0 1 2 3 4 5 6 7 8 9 10

No symptoms at all All of the time

### Beliefs about causes

Please list the three most important factors that you think caused your heart problem.

The most important causes for me:-

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_



**Jaspreet**

- Stress
- Family history
- Smoking



**Mary**

- Family history
- Exercise
- Diet

### Myths

"Stress is very bad for the heart"


"Stress caused my heart attack"

But! smoke to relieve stress... does this mean that if I stop smoking, my stress levels increase, leading to the equivalent heart damage? I think I'll just ignore the survey on second thoughts...

### Facts


- Stress is not a main cause
- Unhealthy behaviours?
- Life with no stress?

### How long will it last?



**Mary**

- "A long time"



**David**




- "A short time"

How long do you think your heart problem will continue?

0 1 2 3 4 5 6 7 8 9 10

a very short time forever


- ✓ A heart attack lasts a short time
- ✓ Heart disease is a long-term condition

How much control do you feel you have over your heart disease?

0 1 2 3 4 5 6 7 8 9 10

absolutely no control extreme amount of control



I'm in the hands of the doctors now

...is David right to think like this?


You can take control of heart disease by:

- Taking medication
- Eating healthily
- Exercising.

How much do you think your treatment can help your heart disease?

0 1 2 3 4 5 6 7 8 9 10

not at all extremely

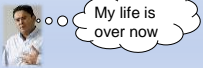


"I don't see how cardiac rehab can help me now. My stent has cured me anyway."

...is Mary right to think like this?

How much does your illness affect your life?


0	1	2	3	4	5	6	7	8	9	10
no affect at all					severely affects my life					




...Is Jaspreet right to think like this?

### Having helpful beliefs

1. Catch unhelpful beliefs
  - What do I think about...?
  - Is it helpful or unhelpful?
2. Challenge
  - Is this belief a myth or a fact?
  - What is the evidence? – check it out



3. Change
  - What is a more helpful way to think about this?
  - Remind yourself (and others)
4. Aware
  - Is that a myth or a fact (or a bit of both)?



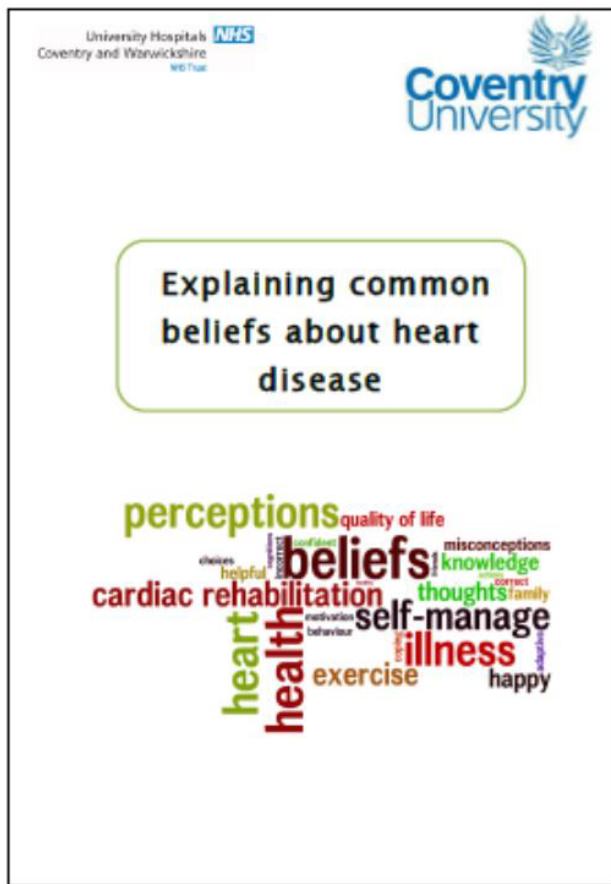
**Booklet** - explains some common misconceptions.

### Summary

- Beliefs about health conditions are important
- It's common to have misconceptions
- Beliefs can be changed
- You need to be on guard to spot myths.



## Draft Intervention Booklet



Introduction	1
Section 1 Illness beliefs	2
Section 2 Common misconceptions	5
Section 3 Changing misconceptions	13
Questionnaire answers	16
Resources	17
Notes	18

### Introduction

Thank you for agreeing to take part in this study. This booklet will help explain the common misconceptions people have about heart disease.

#### *Why have I been given this workbook?*

This workbook is for you and anyone close to you to help make sure that you make the best recovery from your heart problem.

#### *What is this workbook about?*

This workbook is to help you identify any unhelpful beliefs and misconceptions about heart disease. It will show you how to deal with these unhelpful thoughts so that you can make the best of your recovery.

#### *What are cardiac misconceptions?*

Cardiac misconceptions are incorrect or muddled thoughts and beliefs about heart disease.

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Cardiac misconceptions are common and can come from previous experiences, friends and family, and often from the media.

Having correct beliefs about heart disease helps people:

- Manage heart disease better
- Experience fewer angina symptoms
- Return to activities quicker
- Experience less anxiety and depression
- Have a better quality of life.

It's important to get rid of any unhelpful beliefs and misconceptions about heart disease that may be blocking your path to recovery.

This booklet has 3 main sections:

1. What are illness beliefs?
2. Explaining the common misconceptions
3. How to change unhelpful beliefs

As you go through this guide you will be asked to rate how you feel about different aspects of your heart disease. Circle the number which feels right for you. This may help you identify any areas where you could benefit from support. Please do write in this guide, it's yours to keep. There are some blank pages at the end of the booklet to make any extra notes.

You may wish to show this booklet to your cardiac rehabilitation nurse.

2

## SECTION 1: Illness beliefs

People's thoughts and beliefs about illness generally fall into the following categories:

Identity	e.g. Thoughts about your symptoms
Cause	e.g. Beliefs about the causes of heart problems
Timeline	e.g. Thinking about your heart problem as a short-term or long-term
Consequences	e.g. Beliefs about how your heart problem will affect your life
Cure / Control	e.g. Beliefs about how well your heart disease can be controlled and whether or not you can control it
Treatment	e.g. What you think about taking medication

Jane has these misconceptions and incorrect beliefs about her heart disease:



The thoughts and beliefs you have about heart disease are important!

Your thoughts and beliefs about heart disease help you make sense of your illness and help you manage your illness in the short and long-term.

3

Cardiac misconceptions can get in the way of your recovery.

This is because the *things you do to manage your heart problem* depend on your *thoughts and beliefs about it*.



The first step is to identify your own unhelpful beliefs and misconceptions about heart disease. You can do this now by completing the York Cardiac Beliefs Questionnaire below.

Tick whether you agree or disagree with the following statements. You may

Section 1: Questions about living with heart disease	Agree	Disagree
1 People who have heart disease should never get excited or upset	<input type="checkbox"/>	<input type="checkbox"/>
2 People develop heart disease because of worry in their life	<input type="checkbox"/>	<input type="checkbox"/>
3 Rest is the best medicine for heart conditions	<input type="checkbox"/>	<input type="checkbox"/>
4 One of the main causes of heart disease is stress	<input type="checkbox"/>	<input type="checkbox"/>
5 It is dangerous for people who have heart disease to argue	<input type="checkbox"/>	<input type="checkbox"/>
6 Doing exercise can strengthen the heart muscle	<input type="checkbox"/>	<input type="checkbox"/>
7 Heart disease is often caused by people's lifestyle	<input type="checkbox"/>	<input type="checkbox"/>
8 Heart problems are a sign that you have a worn out heart	<input type="checkbox"/>	<input type="checkbox"/>
9 People with heart disease should take life easy	<input type="checkbox"/>	<input type="checkbox"/>
10 Any sort of excitement could be bad if you have heart disease	<input type="checkbox"/>	<input type="checkbox"/>
11 Your heart is like a battery, the more you do the faster it runs down	<input type="checkbox"/>	<input type="checkbox"/>
12 People who have heart disease should always avoid stress	<input type="checkbox"/>	<input type="checkbox"/>

4

Section 2: Questions about heart attack	Agree	Disagree
13 It is dangerous for people who have had a heart attack to exercise	<input type="checkbox"/>	<input type="checkbox"/>
14 People who have had a heart attack must be protected from stress	<input type="checkbox"/>	<input type="checkbox"/>
15 After a heart attack life can sometimes be better than before	<input type="checkbox"/>	<input type="checkbox"/>
16 A heart attack makes a weak area in the heart wall that can easily rupture	<input type="checkbox"/>	<input type="checkbox"/>
17 Once you have had a heart attack you are bound to have another	<input type="checkbox"/>	<input type="checkbox"/>

Section 3: Questions about angina	Agree	Disagree
18 Angina is a kind of small heart attack	<input type="checkbox"/>	<input type="checkbox"/>
19 Any sort of excitement is bad for people with angina	<input type="checkbox"/>	<input type="checkbox"/>
20 People with angina should live life to the full	<input type="checkbox"/>	<input type="checkbox"/>
21 Every bout of angina causes permanent damage to the heart	<input type="checkbox"/>	<input type="checkbox"/>
22 People with angina should avoid being active	<input type="checkbox"/>	<input type="checkbox"/>

You can check your answers on pages 16 & 17

This item has been

How did you do?

Let's now look at these common cardiac misconceptions in more detail.

## SECTION 2: Common misconceptions

This part of the booklet will explain the common misconceptions and beliefs people have about heart disease.

5

**Misconceptions about the causes of heart disease**

Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:-

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

A big part of managing heart problems is to manage the factors which have caused it. It is helpful if your beliefs and thoughts about the causes of your heart disease are accurate. This will help you tackle all of the relevant factors which may have caused your heart disease.

Look at Alan's misconceptions about what caused his heart attack to understand how it affects him.

Alan believes that stress is bad for his heart and thinks it's the main cause of his heart disease.

See what this belief does to the way Alan feels and how he acts.

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The media often portrays stress as being the main trigger for heart attacks.

**FACT:** Stress can contribute to heart disease but it is not a main cause

Researchers think this finding could be due to stressed people doing more unhealthy things like having a poor diet, not exercising, smoking or drinking.

Stress is normal and nothing to be feared. We all have stress in our lives. Would you enjoy life with absolutely no stress whatsoever?

**FACT:** Risk factors like family history, high cholesterol and lifestyle factors, e.g., smoking, cause heart disease.

**FACT:** Some stress is not bad for you. Stress can be managed.

"I know smoking isn't good for me but I worry that stress is bad for my heart. If I try and give up smoking I worry I'll get too stressed..."

**Good to know:** Learning to manage your stress better can help you manage your heart problem. It's easier to make lifestyle changes and stick to them if you feel more relaxed. Going to cardiac rehabilitation classes will give you the skills to relax more easily. If you feel you need more help with this then [www.glasgowsteps.com](http://www.glasgowsteps.com) is a good place to go for help, or speak to your nurse or doctor.

It's safe to get excited or upset. People don't have to treat you any differently.

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**Misconceptions about the consequences of heart disease**

How much does your illness affect your life?

0 1 2 3 4 5 6 7 8 9 10  
no effect at all severely affects my life

Jaspreet thinks that he needs to rest and be careful. He has the misconception that angina is damaging his heart. But resting more makes him feel worse:

"angina is damaging my heart"

REDUCE ACTIVITY TO AVOID ANGINA

INCREASINGLY RESTRICTED LIFE

GET LESS FIT = MORE ANGINA

Jaspreet thinks that if he avoids physical activity then this will be better for his heart. Is he right?

Reducing activity doesn't work well for Jaspreet. He finds he gets angina more often! To cope he reduces his activity even more. Jaspreet now feels fed up and bored. He thinks there's nothing left for him now. What can he do?

**Get more active not less active!**

Trying to avoid angina pain or another heart attack by doing less activity is unhelpful because this reduces fitness levels. This makes angina come on more quickly because unfit muscles are less efficient.

Exercise is also important for many other reasons including lowering your blood pressure and maintaining a healthy weight. It can boost your mood too!

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Jane takes regular exercise. She has the correct belief that angina does no lasting harm to her heart.

"angina doesn't do any lasting harm"

KEEP ACTIVE

LIVING LIFE TO THE FULL

DECREASING FREQUENCY OF ANGINA

DEVELOPMENT OF COLLATERAL BLOOD SUPPLY TO ISCHAEMIC AREA

This is correct!

Jane knows it's better for her heart if she exercises regularly. As Jane has got fit she has found her angina occurs less often.

Jane feels more in control of her heart disease and is living her life to the full.

Jaspreet can feel physically better and happier if he gets more active instead of avoiding activity.

Cardiac rehabilitation exercise classes are ideal for getting back into exercise after having a heart attack or heart surgery. The classes can help you even if you have never exercised much before or been to a gym. Your exercise sessions are guided by trained staff who can help you find alternative exercises if you have any disabilities.

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**Misconceptions about how long heart disease will last**

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

Lucy believes her illness is a short-term problem. She felt dreadful before going into hospital and now feels fine since her treatment. Lucy believes her problem has been 'fixed' by the medical team. Lucy is thinking that she won't bother with cardiac rehabilitation as she already feels better. Is Lucy right to think this?

**FACT:** A heart attack is an acute event but it is due to coronary heart disease - a chronic or long-term condition.

It can be difficult sometimes for people to understand that heart disease is a long-term health condition. Heart disease is a chronic condition. It needs long-term management. This means taking medication and making long-term lifestyle changes for better health.

**Life-style changes need to be for life!**

Lucy decided to go along to a cardiac rehab class anyway and learnt that although she's no longer in pain, she still has heart disease. The good news is that Lucy found out about the different things she can do to help prevent her heart disease from getting worse.

10

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**Misconceptions about symptoms of heart disease**

How much do you experience symptoms from your heart disease?

0	1	2	3	4	5	6	7	8	9	10
No symptoms at all										All of the time

It is common for people to take more notice of their body sensations after having a heart attack. Often, 'normal' body sensations are believed to be a sign of a problem which can cause people to become anxious. Anxiety can cause many of these body symptoms.

Anxiety symptoms can be unpleasant but are not dangerous. Symptoms include increased heart rate and difficulty breathing. You can learn how to manage anxiety symptoms at cardiac rehabilitation. The resources page also has self-help information.

Going to cardiac rehabilitation will help teach you which symptoms are normal and part of recovery, and how to identify when and how you should get help.

**Misconceptions about controlling heart disease**

How much control do you feel you have over your heart disease?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your heart disease?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely

Having a strong sense of control over your illness can help you feel better and more able to get on with life.

11

For some people, a heart attack seems to come out of the blue. However, because you can't see it, heart disease has been lurking unnoticed. It can feel like you have little control over your heart disease and the potential for another heart attack. You might even believe it's up to fate whether or not you have more problems.

There is a lot YOU can do to take control of your health and manage your heart disease.

- Take your medication as prescribed
- Get fitter. Your heart will become more efficient.
- Eat more of these
- ...and maybe you can lose weight
- If you smoke, get help to become a non-smoker

Get help with all of this from your cardiac rehabilitation team

12

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Now you've had a look at some of the most common misconceptions about heart disease. Are thoughts and beliefs about things you can and can't do since your heart problem affecting you? Try filling in the boxes:

Thoughts / beliefs  
e.g. "I mustn't get worked up"

Physical feelings  
e.g. tired, restless...

Emotional feelings  
e.g. angry, sad, anxious...

Actions / behaviours  
What are you doing less of or more of? E.g. resting, worrying.

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The next step is to change these misconceptions and unhelpful beliefs about heart disease!

### SECTION 3: Changing misconceptions into helpful thoughts and beliefs

Sometimes, being given the right information is enough to change cardiac misconceptions. But often beliefs are more difficult to change because you have had them for a long time.

Once you are aware of your cardiac misconceptions you can challenge them and replace them with more helpful thoughts.

Unhelpful belief / Cardiac misconception: Write it here  
e.g. "Stress might set off another heart attack"

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Evidence that this thought or belief is true	Evidence that this thought or belief is false
"My friends and family tell me I work too hard and stress caused my heart attack."	"The information from the cardiac rehab staff has made me realise that stress has led me to live an unhealthy lifestyle. So it's more about making changes to my lifestyle."
"When I feel stressed I can feel my heart beating faster."	"Now I know I need to take care of my heart. I'm less likely to have another heart attack – as long as I change my behaviour."

14

Now weigh up the evidence. Are you right to have this thought? How helpful is it to you?

What is a more helpful thought or belief to have about this? You may want to ask your cardiac rehabilitation team or your family for their ideas.

New and improved thought or belief: write it here  
"Stress is not so bad for my heart, it's the stressful things I do – this I can work on"

How much do you believe this new thought is true?

0 1 2 3 4 5 6 7 8 9 10

Not at all

Completely

This item has been removed due to 3rd Party Copyright. The

How can you test out this new and improved thought? Write it here as an Action Plan:

How/ what?  
e.g. start walking every day for 30 mins

Who with?  
e.g. walking group

Where?  
e.g. the park if it's nice

When? Day:  
Time:

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be

15

On the next pages are the answers to the York Cardiac Beliefs Questionnaire. It will be helpful if you have a read through to understand the myths and truths about heart disease.

	The Myth	The Truth
1	People who have heart disease should never get excited or upset	Life with no excitement? Sorry! Normal excitements won't hurt you. If you often get angry and upset, please talk to your cardiac rehab team or practice nurse – they may be able to help.
2	People develop heart disease because of worry in their life	No, worry doesn't cause heart disease, risk factors do. But, if you are worried or stressed you should do something about it. Ask for advice from the rehab team or practice nurse.
3	Rest is the best medicine for heart problems	No, rest is not a medicine; too much rest makes your heart unfit, leads to a lack of energy and stamina and can cause even more problems.
4	One of the main causes of heart disease is stress	Everyday life stress isn't one of the major causes of heart disease, although it may play a part. But it can make you miserable and lead to bad habits like smoking and not exercising enough which do cause heart disease.
5	It is dangerous for people who have heart disease to argue	No, once again most people should aim to live a normal life. Disagreements are part of everyday life. Settling things up can make them worse.
6	Doing exercise can strengthen the heart muscle	Yes, particularly in the safe way that health professionals can advise you about.
7	Heart disease is often caused by people's lifestyle	Yes, an unhealthy lifestyle is the main cause of heart disease.
8	Heart problems are a sign that you have a worn out heart	Your heart doesn't wear out. You can make it stronger by being more active.
9	People with heart disease should take life easy	No, live as active a life as you can – it will help to prevent more problems
10	Any sort of excitement could be bad if you have heart disease	No, normal levels of fun and excitement help to make life worth living.

16

11	Your heart is like a battery, the more you do, the faster it runs down	No, activity recharges the heart
12	People who have heart disease should always avoid stress	No, avoiding things that may be fun because of a fear of stress can lead to depression. If you need help to cope with everyday stress, talk to your cardiac rehab team or practice nurse.
13	It is dangerous for people who have had a heart attack to exercise	No, providing exercise is built up gradually. The cardiac rehab team or practice nurse can advise about this. Being active reduces the risk of more heart problems.
14	People who have had a heart attack must be protected from stress	This can lead to them being excluded from normal social life and work, and may lead to depression. If stress is a problem, then there are ways to reduce its impact.
15	After heart attack life can sometimes be better than before	Particularly if they have attended cardiac rehabilitation, which reduces the chance of early death.
16	A heart attack makes a weak area in the heart wall that can easily rupture	No, the scar tissue which forms after a heart attack is strong and very unlikely to cause any problems.
17	Once you have had one heart attack you are bound to have another one	No, most people who have had one heart attack never have another.
18	Angina is a kind of small heart attack	No, it is very different; angina doesn't leave any damage. Ask your cardiac rehab team or practice nurse about the difference.
19	Any sort of excitement is bad for people with angina	Excitement makes life worth living. See the answer to question 1.
20	People with angina should live life to the full	Yes, they may have to accept some limitations but should still get the most out of life that they can.
21	Every bout of angina causes permanent damage to the heart	Stable angina does not damage the heart.
22	People with angina should avoid being active	No, people who keep active reduce their risk of more heart problems.

17

On the next pages are the answers to the York Cardiac Beliefs Questionnaire. It will be helpful if you have read through to understand the myths and truths about heart disease.

	The Myth	The Truth
1	People who have heart disease should never get excited or upset	Life with no excitement? Sorry! Normal excitement won't hurt you. If you often get angry and upset, please talk to your cardiac rehab team or practice nurse – they may be able to help.
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3	Rest is the best medicine for heart problems.	No, rest is not a medicine; too much rest makes your heart unfit, leads to a lack of energy and stamina and can cause even more problems.
4	One of the main causes of heart disease is stress.	Everyday life stress isn't one of the major causes of heart disease, although it may play a part. But it can make you miserable and lead to bad habits like smoking and not exercising enough which do cause heart disease.
5	It is dangerous for people who have heart disease to argue.	No, once again most people should aim to live a normal life. Disagreements are part of everyday life. Settling things up can make them worse.
6	Doing exercise can strengthen the heart muscle	Yes, particularly in the safe way that health professionals can advise you about.
7	Heart disease is often caused by people's lifestyle.	Yes, an unhealthy lifestyle is the main cause of heart disease.
8	Heart problems are a sign that you have a worn out heart	Your heart doesn't wear out. You can make it stronger by being more active.
9	People with heart disease should take life easy	No, live as active a life as you can – it will help to prevent more problems.
10	Any sort of excitement could be bad if you have heart disease	No, normal levels of fun and excitement help to make life worth living.

16

11	Your heart is like a battery, the more you do, the faster it runs down	No, activity recharges the heart
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13	It is dangerous for people who have had a heart attack to exercise	No, providing exercise is built up gradually. The cardiac rehab team or practice nurse can advise about this. Being active reduces the risk of more heart problems.
14	People who have had a heart attack must be protected from stress	This can lead to them being excluded from normal social life and work, and may lead to depression. If stress is a problem, then there are ways to reduce its impact.
15	After heart attack life can sometimes be better than before	Particularly if they have attended cardiac rehabilitation, which reduces the chance of early death.
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17	Once you have had one heart attack you are bound to have another one	No, most people who have had one heart attack never have another.
18	Angina is a kind of small heart attack	No, it is very different; angina doesn't leave any damage. Ask your cardiac rehab team or practice nurse about the difference.
19	Any sort of excitement is bad for people with angina	Excitement makes life worth living. See the answer to question 1.
20	People with angina should live life to the full	Yes, they may have to accept some limitations but should still get the most out of life that they can.
21	Every bout of angina causes permanent damage to the heart	Stable angina does not damage the heart.
22	People with angina should avoid being active	No, people who keep active reduce their risk of more heart problems.

17

One last question:

How well do you understand your heart disease?										
0	1	2	3	4	5	6	7	8	9	10
don't understand at all					understand very clearly					

Do you think you understand enough about your heart problem? Perhaps people around you would benefit from knowing more?

If you would like to know more about your illness then ask your cardiac rehabilitation team – they will be happy to answer your questions and give out information.

Below is a list of useful resources.

#### Resources

British Heart Foundation [www.bhf.org.uk](http://www.bhf.org.uk)  
Heart Helpline - 0800 230 3311 Monday – Friday 9am to 5pm.

Managing anxiety and relaxation: [www.glasgowsteps.com](http://www.glasgowsteps.com)

Anxiety and low mood: [www.coventryhhs.uk/last](http://www.coventryhhs.uk/last)  
Improving Access to Psychological Therapies: 0845 521 6100

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This booklet was developed with support and advice from members of Coventry Healthy Hearts group and others attending the Centre for Exercise and Health in Coventry.

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## **APPENDIX III**

Coventry University ethical approval

NRES ethical approval

NHS approval - CRP1

NHS approval - CRP2



## Coventry University ethical approval

**Coventry University**

Priority Street  
Coventry CV1 5FB  
Telephone 024 7688 7688

**Professor Ian M Marshall**  
Pro-Vice-Chancellor (Research)



**TO WHOM IT MAY CONCER**

RRU/Ethics/Sponsorlet

16 November 2012

Dear Sir/Madam

**Researcher's name:** Helen Fletcher  
**Project Title:** Managing misconceptions about heart disease

The above named researcher has successfully completed the Coventry University Ethical Approval process for her project to proceed (ref: 1496).

I should like to confirm that Coventry University is happy to act as the sole sponsor for this researcher and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

**Professor Ian Marshall**

**Deputy Vice-Chancellor, Academic**

Enc

**Pro-Vice-Chancellor's Office**

Direct Line 024 7679 5293  
Fax 024 7688 8030

[www.coventry.ac.uk](http://www.coventry.ac.uk)



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2007

NRES Favourable ethical opinion



**NRES Committee West Midlands - South Birmingham**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839428  
Facsimile: 0115 9123300

22 January 2013

Miss Helen L Fletcher  
Applied Research Centre for Health and Lifestyle Interventions  
Whitefriars Building, Coventry University  
Priory Street  
CV1 5FB

Dear Miss Fletcher

**Study title:** Development of a CBT based intervention to manage cardiac patients' misconceptions about heart disease that are predictive of poor outcomes.  
**REC reference:** 12/WM/0412  
**IRAS project ID:** 89492

Thank you for your letter of 15 January 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Heather Harrison, [nrescommittee.westmidlands-southbirmingham@nhs.net](mailto:nrescommittee.westmidlands-southbirmingham@nhs.net).

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

**NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## Non-NHS sites

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

1. The regulatory paragraph should be added to the consent form: 'I understand that relevant sections of my medical notes and data collected during the study, may be looked at by authorised individuals from the research team, from the Sponsor of the study, from regulatory authorities and from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.'

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Letter from Helen Fletcher	23 November 2012
Evidence of insurance or indemnity	Allianz	01 August 2012
Evidence of insurance or indemnity	AON	01 August 2012

GP/Consultant Information Sheets	Phase 1 letter - v2	15 August 2012
GP/Consultant Information Sheets	Pilot Study - v2	15 August 2012
Interview Schedules/Topic Guides	Focus Group Schedule - v2	10 November 2012
Interview Schedules/Topic Guides	Nurses Interview Schedule - v1	10 November 2012
Interview Schedules/Topic Guides	2 - Individual Interview Schedule	07 January 2013
Investigator CV	Professor Gill Furze	23 November 2012
Investigator CV	Miss Helen L Fletcher	23 November 2012
Letter from Sponsor	Letter from Professor Ian Marshall, Coventry University	16 November 2012
Letter of invitation to participant	Group Intervention Invitation - v1	15 November 2012
Letter of invitation to participant	Focus Group Invitation	15 November 2012
Other: West Midlands CLRN Research Mentorship Programme Letter	Signed by Julie Norris	25 March 2011
Other: Flow Diagram Illustrating Study Design	2	28 August 2012
Other: Patient Reply Slip and Advert	Patient Reply Slip and Advert	27 November 2012
Other: Draft Individual Intervention Manual	5	15 November 2012
Other: Draft Group Intervention Manual	4	12 November 2012
Other: Common Cardiac Misconceptions Explained	6	10 November 2012
Participant Consent Form: Development Phase	1.3	09 January 2013
Participant Consent Form: Pilot Study	2.1	09 January 2013
Participant Information Sheet: Pilot Study	1.5	21 December 2012
Participant Information Sheet: Development Phase	1.7	21 December 2012
Protocol	5	14 January 2013
Questionnaire	Dartmouth Coop Scales	27 November 2012
Questionnaire	Brief Illness Perception Questionnaire	27 November 2012
Questionnaire	GAD-7	27 November 2012
Questionnaire	PHQ-9	27 November 2012
Questionnaire	YCBQ-Res	27 November 2012
Questionnaire: Development Phase Questionnaire	2	20 November 2012
Questionnaire: Pilot Study Baseline Questionnaire	2	12 September 2012
Questionnaire: Satisfaction Questionnaire	2	20 November 2012
REC application	89492/388017/1/665	26 November 2012
Response to Request for Further Information		15 January 2013

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review


**12/WM/0412**

**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

pp   
**Professor Simon Bowman**  
Chair

Email: [nrescommittee.westmidlands-southbirmingham@nhs.net](mailto:nrescommittee.westmidlands-southbirmingham@nhs.net)

**Enclosures:** "After ethical review – guidance for researchers"

**Copy to:** Sponsor - Professor Ian Marshall  
CI - Professor Gill Furze, Coventry University  
Care organisation - Mrs Ceri Jones, Research & Development University Hospitals Coventry & Warwickshire NHS Trust

## NHS Approval – CRP1

# University Hospitals Coventry and Warwickshire NHS Trust

Research, Development and Innovation Department  
Director of R,D&I: Professor Chris Inray - Tel: 02476 96 5222  
Head of R,D&I: Ceri Jones - Tel: 024 7696 6196  
Divisional Finance Manager: Chris Moore - Tel: 024 7696 6196  
Deputy Divisional Finance Manager: Joanne Treadwell - Tel: 02476 966199  
R,D&I Business Manager: Natasha Wileman - Tel: 02476 966197  
Research Associate - Governance: Isabella Pathe - Tel: 02476 966202  
R,D&I Administration Specialist: Joanna Geraghty - Tel 02476 964995  
Research Portfolio Development Manager: Deborah Griggs - Tel: 02476 96 6195

University Hospital  
Clifford Bridge Road  
Walsgrave  
Coventry  
CV2 2DX

Tel: 024 7696 4000  
Fax: 024 7696 6056  
www.uhcv.nhs.uk

8<sup>th</sup> March 2013

Miss Helen Fletcher  
ARC HLI  
Whitefriars Building  
Coventry University  
Priory Street  
Coventry  
CV1 5B

Dear Miss Fletcher,

**Study Title: Development of a CBT based intervention to manage cardiac patient's misconceptions about heart disease that are predictive of poor outcomes**

Thank you for submitting the above study for consideration by the Research & Development Office. I am pleased to inform you that your study has been approved.

The documents approved for use in this study are:

Document	Version	Date
Protocol	5	14.01.13
Participant Consent Form: Pilot Study	2.2	28.01.13
Participant Consent Form: Development Phase	1.4	28.01.13
Participant Information Sheet: Pilot Study	1.5	21.12.12
Participant Information Sheet: Development Phase	1.7	21.12.12
GP/ Consultant Information Sheet – Phase 1 letter	2	15.08.12
GP/ Consultant Information Sheet – Pilot Study	2	15.08.12
Interview Schedules/ Topic Guides – Focus Group	2	10.11.12
Interview Schedules/ Topic Guides – Nurses	1	10.11.12
Interview Schedules/ Topic Guides – Individual	2	07.01.13
Questionnaire	Dartmouth Coop Scales	27.11.12
Questionnaire	Brief Illness Perception	27.11.12

R&D Reference: HF119113  
MREC Number: 12/WM/0412

Version 4, 01.11.2012

Page 1 of 3

Chief Executive: Andrew Hardy

Chairman: Philip Townshend

Questionnaire	GAD-7	27.11.12
Questionnaire	PHQ-9	27.11.12
Questionnaire	YCBQ-Res	27.11.12
Questionnaire: Development Phase Questionnaire	2	20.11.12
Questionnaire: Pilot Study Baseline Questionnaire	2	12.09.12
Questionnaire: Satisfaction Questionnaire	2	20.11.12

- Should you wish to make any changes to the documents listed above, you must obtain R&D approval prior to use.
- An Annual Progress Report (APR) should be submitted to the main research ethics committee (REC) once a year throughout the trial or on request by R&D. The first report is due on 8<sup>th</sup> March 2014. In addition, for CTIMP studies, a Development Safety Update Report (DSUR) should be submitted to the MHRA and the REC once a year. Guidance on the DSUR can be found in SOP 41 'Preparation and Submission of Annual Progress Reports and Development Safety Update Reports'.
- Notification of any serious breaches of GCP or the trial protocol must be reported to the R&D Department and a DATIX Clinical Adverse Event form completed within 24 hours of any suspected breach being identified and confirmed.

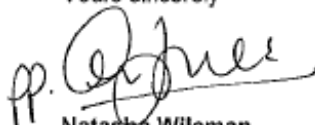
Your research sponsorship & Indemnity is provided by Coventry University.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D Approval assumes that you have read and understand the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

The Trust wishes you every success with your project.

Yours sincerely

  
**Natasha Wileman**  
**R,D&I Business Manager**

R&D Reference: HF119113  
MREC Number: 12/WM/0412

NHS Approval Letter – CRP2



West Midlands (South) Comprehensive Local Research Network  
Fourth Floor, West Wing (ACF40002)  
University Hospitals Coventry & Warwickshire NHS Trust  
University Hospital  
Clifford Bridge Road  
Coventry  
CV2 2DX

31<sup>st</sup> July 2013

Miss H Fletcher  
ARC HLI  
White friars Building  
Priory Street  
Coventry  
CV1 5FB

Dear Miss Fletcher

**Project Title: Managing Misconceptions of Heart Disease**  
**R&D Ref: GEH280613**  
**REC Ref: 12/WM/0412**

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at George Eliot Hospital NHS Trust.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Participant Information Sheet Development Phase	1.8	25.06.2013
Consent Form Development Phase	1.4	28.01.2013
Flyer	4.0	14.01.2013
SSi Form	89482/469387/476/211371/75368	26.06.2013
R and D Form	89482/474398/14/465	05.07.2013

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events and to ensure that they are reported according to the Trust Clinical



Incident policy, where required. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

You will be sent an annual progress report which must be completed in order to ensure that the information we hold on our database remains up to date, in line with RGF requirements.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely



**Natassia Embury**  
**R&D Facilitator**

**Enc:** Pi Agreement

**Cc:** Julie Highfield, Local Collaborator  
Professor Gill Furze, Academic Supervisor, Coventry University  
Ian Marshall, Sponsor Representative, Coventry University

## **APPENDIX IV**

Study Flyer

Participant Information Sheet

## Study Flyer



### **RESEARCH STUDY: Helping people to understand their heart disease**

#### **Have you recently started cardiac rehabilitation?**

You may be eligible to take part in this research study. The purpose of the study is to develop methods for helping people to understand their heart disease better.

The study is being run at Coventry University and the Cardiac Rehabilitation Centre.

For more information about what is involved in taking part in this study please read the Participant Information Leaflet. Please contact me if you would like to know more about the study or if you have any questions.

You may wish to fill out the tear-off slip below for me to contact you.

Thank you for reading this.

**Helen Fletcher**

Applied Research Centre in Health and Lifestyle Interventions  
Whitefriars Building, Coventry University, Priory Street, CV1 5FB.

024 76887175 / 07852 010182

ab1747@coventry.ac.uk



Name:

---

Contact details:

---

---

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## Information about the research

### Helping people to understand their heart disease

We would like to invite you to take part in our research study. It is important that you understand what the study is about and what it will involve. If you wish, one of the research team will go through this information with you and answer any questions you may have. This study is being undertaken as a Masters degree project for Helen Fletcher, and will also help to design a larger study in the future.

The information sheet explains the purpose of the study and what will happen if you take part.

**Ask us if anything is not clear. You may wish to talk to a friend or family member about the study.**

#### What is the purpose of the study?

Cardiac misconceptions are incorrect or muddled beliefs about living with coronary heart disease. There are common cardiac misconceptions that can cause people with heart disease to cope with their condition in a way which results in poor physical and psychological health. Cardiac rehabilitation guidelines recommend that misconceptions are dispelled; however, we do not know the most effective way to do this.

We have developed two methods (called interventions) to tackle misconceptions. These have been developed in collaboration with members of a cardiac support group, the cardiac rehabilitation team and a panel of experts. The interventions are:

- a one-to-one session with a health professional (the researcher)
- a group education session facilitated by a health professional (the researcher)

These are both backed up with a leaflet about common cardiac misconceptions.

We want to find out if people like the interventions before testing them to see how well they work.

Your care with the cardiac rehabilitation team will not be affected.

### **Why have I been chosen?**

The interventions have been developed for use in cardiac rehabilitation programmes. You have been invited because you attend cardiac rehabilitation and have experience of coronary heart disease.

### **Do I have to take part?**

No. It is up to you to decide to take part. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Not taking part or leaving the study will not affect the standard of care you receive.

### **What will happen to me if I take part?**

You will be contacted by the researcher who will check if you can take part by asking you some brief questions.

At this point you can ask more questions you might have about the study. You do not have to take part unless you feel completely happy with the study.

If you are happy to take part then you will be offered either the 30 minute one-to-one session or the group-based session. At one of these sessions the researcher will discuss the common cardiac misconceptions and their effects and provide a booklet for you to keep. You will have time to ask questions. We will arrange a time for you to complete the consent forms and receive the draft intervention.

After you have received either the group-based or the individual intervention I would like to find out more about your experience of it, for example, what you think was helpful or unhelpful about it. People taking part in the group-based intervention will be asked to attend a focus group. . The focus group will be held at Coventry University and will be audio recorded so that the points raised in the group are recorded. Your travel expenses will be reimbursed and refreshments will be available at the focus group.

If you received the individual intervention you will be asked to have an individual interview with the researcher. You can choose to meet face-to-face at a venue of your choice or to complete the interview by telephone. The individual interview will also be audio recorded.

Audio recordings from the focus groups and Individual Interviews will be listened to and transcribed word for word by the research team. This will enable themes to be identified from what has been

said in the interviews and focus groups and will go towards improving the interventions. Audio recordings will be destroyed at the end of the study (September 2013).

**What are the possible disadvantages and risks associated with taking part?**

A risk assessment has been completed which showed there are no significant risks to you in taking part. The only disadvantage will be the taking up of your personal time. At any point during the study you can stop without having to give a reason why.

**What are the benefits to taking part?**

There may be no direct benefits to you by taking part in the study. Your views and opinions will help make sure the intervention is developed to be as patient-friendly as possible.

**What if something goes wrong?**

It is very unlikely that any harm should come to you as result of taking part in this study. However, if you have any concerns about the way you have been approached or treated during this study, in the first instance can contact the study co-ordinator Helen Fletcher (tel: 024 76 887 175) or the principal investigator Gill Furze (tel: 024 76 795804) who will do their best to answer your questions. Alternatively, you can contact the Patient Advice and Liaisons Service (PALS), which is a service providing independent advice, information and support to patients. Telephone numbers can be found at the end of this leaflet.

**Data protection and confidentiality**

All the information you provide will be held securely and in strict confidence. Information that you give about yourself will be kept separate from your name and address to maintain confidentiality. Computer files will be held on secure password protected servers at the Faculty of Health and Life Sciences, Coventry University. Only members of the research team will have access to this information. The research team will not have access to your NHS records. All audio recordings will be destroyed once the project is finished (September 2013). All information that could be used to identify you will be removed in reports of the study. If you do decide to withdraw from the study then all your data will be destroyed and will not be used in the study.

### **Involvement of your GP**

**We will tell your GP that you are taking part in the study. No other results will be given to your GP.**

### **What will happen to the results of the research study?**

Your suggestions for improvement will be used to help make the interventions better and easier to use. The results will also be used to highlight your views and experiences as users of the interventions. The fully developed interventions will then be tried with other participants in order to test how well the interventions work. The results will be written up as part of my Masters by Research final project. The results will also be presented at academic conferences and written up for publication in peer reviewed academic journals. I will provide you with a copy of the written report and an explanation of the findings.

### **Who is organising and funding the research study?**

The research is organised by Helen Fletcher, a Masters student at Coventry University. Helen Fletcher is also a Psychological Well-being Practitioner with the Improving Access to Psychological Therapies service. The research is being funded by the Comprehensive Local Research Network West Midlands (South) [www.crncc.nihr.ac.uk](http://www.crncc.nihr.ac.uk)

### **Who has reviewed this study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Birmingham Research Ethics Committee (Ref: 12/WM/0412).

### **Contact for further information:**

If you would like any further information about this study please get in touch with me at the address below:

#### **Helen Fletcher MSc Research Student**

Applied Research Centre  
in Health and Lifestyle Interventions  
Faculty of Health and Life Sciences  
Whitefriars 105, Whitefriars Street  
Coventry University  
Coventry  
CV1 5FB

Email:  
[helen.fletcher@coventry.ac.uk](mailto:helen.fletcher@coventry.ac.uk)  
Tel: 024 76 887175  
07852 010182

Research supervisor:

Professor Gill Furze  
Faculty of Health and Life Sciences  
Tel: 024 76 795804

Patient Advice and Liaisons Service (PALS):

[www.pals.nhs.uk](http://www.pals.nhs.uk)

You may ring either of these numbers:

University Hospitals Coventry and Warwickshire (UHCW): 02476 966061.

Coventry and Warwickshire Partnership Trust: 0247653 6804.

**Thank you for taking the time to read this information sheet.**



## **APPENDIX V**

Consent form

GP letter

Demographics and baseline questionnaire

Cardiac Misconception Intervention Study  
Helping people to understand their heart disease



Research participant consent form: Phase I

If you wish to take part, **please initial each of the boxes, then sign and date this form.**

Please **INITIAL** box

- |    |  |  |
|----|--|--|
| 1  | I confirm that I have read and understand the Participant Information Leaflet dated 21.12.12 (version 1.7) for the above study. I have had the opportunity to consider the information, ask questions about the study and have had these answered satisfactorily.  | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">1</div>  |
| 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.  | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">2</div>  |
| 3  | I agree to the research team holding my name and contact details to allow for the day to day running of the study.   | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">3</div>  |
| 4  | I give consent for the research team to contact me by telephone.   | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">4</div>  |
| 5  | If I take part in the group-based intervention I understand that people may share personal information. I agree to keep the group discussion confidential.   | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">5</div>  |
| 6  | I understand that I will be asked to take part in a focus group or an individual interview as part of the study. I understand that these will be audio-recorded and transcribed word-for-word and that all recordings will be destroyed at the end of the study (September 2013).  | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">6</div>  |
| 7  | If I take part in the focus group I agree to keep discussions and comments made by other people confidential.  | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">7</div>  |
| 8  | I understand that quotations from the focus groups and interviews may be used in reports and journal articles, but all aspects of these quotations that could be used to identify me will be altered to maintain anonymity. I agree to the use of quotations in this way.  | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">8</div>  |
| 9  | I understand that relevant sections of my medical notes and data collected during the study may be looked at by authorised individuals from the research team, from the Sponsor of the study, from regulatory authorities and from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">9</div>  |
| 10 | I agree to my GP being informed of my participation in the study.  | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">10</div> |
| 11 | I agree to take part in the above study.   | <div style="border: 1px solid black; width: 40px; height: 40px; display: flex; align-items: center; justify-content: center;">11</div> |

\_\_\_\_\_  
Name of participant  
(BLOCK CAPITALS)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(BLOCK CAPITALS)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**PARTICIPANT ID:**

Consent form development phase version 1.4 28.01.13



Helen Fletcher  
**Applied Research Centre for  
Health and Lifestyle Interventions**  
Whitefriars Building, Coventry University  
Priory Street, Coventry, CV1 5FB  
024 76 88 7175 / 07852 010182  
Helen.fletcher@coventry.ac.uk

[DATE]

Dear [GP NAME]

Re: Name - [PARTICIPANT'S NAME]      DOB- [PARTICIPANT'S DATE OF BIRTH]

I am writing to inform you that your patient named above has consented to take part in a research project. The project is aiming to develop interventions to dispel cardiac misconceptions in people with coronary heart disease. Your patient has agreed to review the draft interventions and feedback their views in a focus group. This will lead to further refinement of the interventions to be tested in a pilot feasibility randomised controlled trial.

This study is a student project for fulfilment of a Masters by Research and is being funded through the CLRN West Midlands (South) Research Mentorship programme. Please do not hesitate to get in touch if you have any questions regarding the study.

Kind regards,

Helen Fletcher

CLRN West Midlands (South) Research Mentee

Participant ID: \_\_\_\_\_

Please tell us a little about yourself:

1. What is your age in years?

2. Are you?

Male ☐ 1 Female ☐ 2

3. What is your marital status? (please tick one)

Single ☐ 1Married ☐ 2Permanent partnership ☐ 3Divorced ☐ 4Widowed ☐ 5

4. Which of the following best describes your main activity?

In employment or self-employment

☐ 1

Retired

☐ 2

Housework

☐ 3

Student

☐ 4

Seeking work

☐ 5

Other (Please specify

 6

5. Did your education continue after the minimum school leaving age?

Yes ☐ 1 No ☐ 0

6. Do you have a degree or equivalent professional education?

Yes ☐ 1 No ☐ 0**Please turn the page**

### What is your ethnic group?

<b>1</b>	<b>White</b>	
	British	<input type="checkbox"/> 1
	Irish	<input type="checkbox"/> 2
	Any other White background	<input type="checkbox"/> 3
	.....	
<b>2</b>	<b>Mixed</b>	
	White and Black Caribbean	<input type="checkbox"/> 4
	White and Black African	<input type="checkbox"/> 5
	White and Asian	<input type="checkbox"/> 6
	Any other Mixed background	<input type="checkbox"/> 7
	.....	
<b>3</b>	<b>Asian or Asian British</b>	
	Indian	<input type="checkbox"/> 8
	Pakistani	<input type="checkbox"/> 9
	Bangladeshi	<input type="checkbox"/> 10
	Any other Asian background	<input type="checkbox"/> 11
	.....	
<b>4</b>	<b>Black or Black British</b>	
	Caribbean	<input type="checkbox"/> 12
	African	<input type="checkbox"/> 13
	Any other Black background	<input type="checkbox"/> 14
	.....	
<b>5</b>	<b>Chinese or other ethnic group</b>	
	Chinese	<input type="checkbox"/> 15
<b>6</b>	Any other .....	<input type="checkbox"/> 16

### Your heart problems: (please tick all that apply)

		Please give date(s) (month and year) when you were told by the doctor that you had this problem
Heart Attack (Myocardial Infarction)	<input type="checkbox"/>	_____
Angina	<input type="checkbox"/>	_____
Acute Coronary Syndrome	<input type="checkbox"/>	_____
<b>Treatments that you have had</b>	<b>Dates</b>	
Bypass surgery	<input type="checkbox"/>	_____
Angioplasty and stent	<input type="checkbox"/>	_____
Other heart surgery	<input type="checkbox"/>	_____

**Please can you let me know who your GP is?**

GP Name:

Surgery:

**Would you like to choose your own pseudonym (fake name)? This will be used instead of your real name when I write up the study.**

**Yes** \_\_\_\_\_

**No, choose one for me.**

**Please turn the page**

### YCBQ-Res

We want to know your views and beliefs about why people get heart disease (angina and heart attack) and what they should do about it. It is important that you answer every question.

For each question please **tick one** box. Please don't leave any out.

	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
1 People who have heart disease should never get excited or upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 People develop heart disease because of worry in their life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Rest is the best medicine for heart conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 One of the main causes of heart disease is stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 It is dangerous for people who have heart disease to argue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Doing exercise can strengthen the heart muscle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Heart disease is often caused by people's lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Heart problems are a sign that you have a worn out heart	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 People with heart disease should take life easy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Any sort of excitement could be bad if you have heart disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Your heart is like a battery, the more you do the faster it runs down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 People who have heart disease should always avoid stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 It is dangerous for people who have had a heart attack to exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 People who have had a heart attack must be protected from stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 After a heart attack life can sometimes be better than before	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 A heart attack makes a weak area in the heart wall that can easily rupture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Once you have had a heart attack you are bound to have another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Angina is a kind of small heart attack	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 Any sort of excitement is bad for people with angina	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 People with angina should live life to the full	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21 Every bout of angina causes permanent damage to the heart	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22 People with angina should avoid being active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **APPENDIX VI**

Semi-structured interview guide

Focus group guide



### **Individual Semi-structured Interview Schedule**

**Aim:** to explore participant's experiences of receiving the individual intervention

**Objectives:**

- to explore experiences and perceptions of the intervention and booklet
- to explore changes which could improve the intervention
- to explore how the intervention affected participants including any impact on their cardiac misconceptions / beliefs

**1. Introduction**

Check that there are no objections to the use of the audio recorder; then switch it on. Read out the statement on confidentiality:

**Opinions expressed will be treated in confidence among project staff for the purpose of developing the intervention for managing cardiac misconceptions and in the production of the project report. All responses will remain anonymous.**

Begin by reiterating the purpose of the interview, using the following statement as a guide:

I'm very grateful to you for sparing time to talk about the intervention and the booklet which you have gone through with me. Today I would like to find out about your views on it. There are no right or wrong opinions; I would like you to feel comfortable saying what you really think and how you really feel.

**2. Experience of CHD and misconceptions**

Can I start off by asking you to tell me a little bit about yourself and what brought you to cardiac rehabilitation?

Before you tried the intervention what did you think about the idea that misconceptions about heart problems could affect people?

What experiences have you had of health professionals talking to you about/ correcting misconceptions?

### **3. Experience of intervention and booklet**

Can you tell me about your experience of the intervention?

What was your reaction when you completed the cardiac misconceptions questionnaire?

Can you tell me more about any parts of the intervention which you were unsure about / disagreed with / felt not needed?

Can you tell me more about parts of the intervention which you thought were good / useful?

What are your thoughts on the intervention being 1:1, as you experienced, or being group-based?

What do you think about the booklet?

We can make changes to the intervention and the booklet. Can you tell me about any changes, big or small, which you would think may be helpful? Has the intervention / booklet missed anything out?

### **4. Impact on individual misconceptions**

Has the intervention / booklet had an effect on you or your family and in which ways? (Thoughts, beliefs, feelings and behaviour)

Do you think your awareness of cardiac misconceptions has changed?

Despite the intervention / booklet are there any thoughts or beliefs about heart disease which you are not 100% sure about. Was there anything you find/found hard to believe?

### **5. Ending**

Thank you for your responses to these questions. Is there anything else you would like to add which I may not have covered?

This interview will now be transcribed and analysed to look at things like the different themes people have mentioned. Your personal information will be removed from the transcript and in the write-up of study I will use your chosen pseudonym for any quotes. I will destroy the audio-recording at the end of the study (September 2013). Do you have any questions about this?

## **Focus group interview schedule**

### **Purpose**

To explore participants' perceptions of the intervention (individual or group) they received which aimed to dispel their cardiac misconceptions.

### **Objectives**

To find out:

- Elements of the intervention which are liked or disliked
- Elements of the intervention booklet which are liked or disliked
- If the intervention was useful and in which ways
- If the intervention was sufficient
- Ideas to improve the intervention and booklet

### **Introduction**

Orientate participants to facilities, fire-alarm procedures and offer refreshments. Check that there are no objections to the use of the audio recorder; then switch it on.

Read out the statement on confidentiality:

**Opinions expressed will be treated in confidence among project staff for the purpose of developing the intervention for managing cardiac misconceptions and in the production of the project report. All responses will remain anonymous.**

Begin by reiterating the purpose of the focus group meeting, using the following statement as a guide:

**I'm very grateful to you all for sparing time to talk about the intervention you received. Today I want to concentrate on discussing your experience of receiving the intervention and I'd particularly like to hear from you about what you liked about it and what you didn't like about it. Or, what you found helpful or unhelpful about it. There are no right or wrong opinions; I would like you to feel comfortable saying what you really think and how you really feel.**

Explain ground rules:

**Before we begin I'd like to share some ground rules with you.**

- a. Please feel free to speak.**
- b. It is important to speak up clearly and if only one person could talk at a time. This is so that I don't miss any of your comments when I listen to the tape.**
- c. Please note that all of your contributions will be anonymised and your identity will not be associated with transcriptions. Your chosen pseudonym will be used for any quotes used in the study write-up.**

The meeting will take approximately 1 hour.

**Opening question:**

Focus group schedule v2 10.11.12

All of you here tried the individual / group intervention. I'd like to explore what things you liked and disliked about it.

Were there any elements of the intervention which you found to be unhelpful?

Were there any elements of the intervention which you found to be helpful or useful?

**Key questions:**

What are your thoughts on the length of time the intervention took?

What are your views on receiving the intervention 1:1 / in a group?

The intervention you received included a booklet explaining the common cardiac misconceptions and ways to dispel misconceptions. What do you think about the booklet, for example, was it easy or hard to understand?

Can you put forward any ideas for improving the intervention booklet, for example, the content or way it looks?

**Ending questions:**

The aim of today's meeting was to find out your opinions and perspectives of the individual/group intervention you received which aimed to explain and dispel cardiac misconceptions in people attending cardiac rehabilitation. From the issues discussed is there anything else to add, anything we have forgotten to mention?

**Thank participants for attending and ask if anyone has any questions.**

## **APPENDIX VII**

### Qualitative analysis

### Indexing Chart

<b>1. Beliefs before heart event</b> 1.1 Previous symptoms gone unrecognised 1.2 Awareness of CHD 1.3 Beliefs about MI symptoms 1.4 Carry on with symptoms	<b>2. Heart event experience</b> 2.1 Responding to symptoms 2.12 Seeking help 2.2 Coping mechanisms 2.3 Treatment experience 2.31 Having procedures explained 2.32 Awareness and understanding 2.33 Accepting 2.33 Emotions 2.4 Learning in hospital 2.41 Getting information 2.5 Quick	<b>3. Cardiac rehabilitation</b> 3.1 Invitation to attend 3.2 Deciding to attend CR 3.21 Wake-up call 3.22 View of attending gym 3.23 Away from hospital 3.24 Personal benefits of CR 3.25 Making progress 3.26 Making lifestyle changes 3.3 Support from staff 3.4 Benefits of CR to others 3.5 Tailored programme
<b>4. Illness beliefs</b> 4.1 Beliefs about causes 4.2 Identify of symptoms 4.3 Wanting to learn and understand 4.4 Attitude to life 4.5 Leading a better life 4.6 Feeling lucky 4.7 Taking personal responsibility 4.8 Changing timeline beliefs 4.9 Changing view on consequences 4.91 Changes to emotional regulation	<b>5. Views of intervention</b> 5.1 Easy to understand 5.12 User friendly 5.13 Personal input to discuss and check understanding 5.14 Different viewpoints 5.15 Myth and facts with answers 5.2 Questions asked 5.3 Being honest with yourself 5.4 Give to patients early 5.5 Some people won't change 5.6 Make examples relevant to disabled people 5.7 More on medication 5.8 Accessible language 5.9 Taking time	

Chart 1

1. Beliefs before heart event

Participant	1.1 Identifying MI symptoms	1.2 Responding to symptoms	1.3 Coping mechanisms
John	<p>Confused with indigestion:  <i>"I thought it was trapped wind"</i> 62 <i>"two hours from the start, still thinking its trapped wind"</i> 65</p> <p>Concern increased when pain moved down arms:  <i>"I noticed the pain was going down the top part of my arms, so I was getting a bit concerned then"</i> 66-8</p> <p>Identifies angina and indigestion as separate but occurring together:  <i>"a pain in my chest and indigestion"</i> 61 <i>"at home, two occasions when I've had that tightness in my chest and slight indigestion"</i> 142-3</p> <p>Found out pain experienced a few years ago had been a heart attack:  <i>"This bit down here is from a previous heart attack' - because I had had similar symptoms before - which I had attributed to wind"</i> 134-9</p>	<p>Took blood pressure:  <i>"I took my blood pressure and it was high"</i> 68-9</p> <p>Still thought it was trapped wind but called 111 for advice:  <i>"I still think it's trapped wind, and I called 111"</i> 69-70</p> <p>On being taken to hospital:  <i>"I was happy something was going to happen and, therefore, I'd be told by experts that it was trapped wind"</i> 83-4</p>	
Steven	<p>Confused with indigestion  <i>"I just felt bad pains in my chest and funny pains down my arms and my jaw, just thought I was cold"</i> 23-4</p> <p>Had not been feeling himself for a while, attributed to feeling low  <i>"I hadn't felt right...through the winter I</i></p>	<p>Sought help from neighbour when pains came back  <i>"..I just thought that something's not right, I don't feel right"</i> 31-2</p>	

	<p><i>was so lethargic, no go in me</i>" 38-40</p> <p>Thinks if he had the knowledge he'd have been able to prevent his MI:  <i>"If I'd listened and knew what I know now I would probably have saved myself having a heart attack"</i> 42-4</p>		
Bob	<p>Confused with acid reflux  <i>"I was getting like a burning in my chest, and I thought it was acid"</i> 32-3</p>	<p>Delayed seeking help with symptoms for 3 weeks:  <i>"It was about three weeks before I actually went to A&amp;E"</i> 31-2</p> <p>Not feeling 'right' spurred him on to seek help:  <i>"I thought, 'this doesn't feel right.. We need to go to A&amp;E, I don't feel right"</i> 63-4</p>	Went to see GP for advice. 33
Mandy	<p>Experience of pain not congruent with expectations of heart pain:  <i>"I didn't think the pains that I was experiencing had anything to do with my heart"</i>  <i>"because I hadn't actually got pains going down my arm.. It was just in the centre of my chest."</i> 220-222</p> <p>Now realises had been experiencing angina despite daughter suggesting it at the time:  <i>"my daughter did say to me at the time, 'do you think you've got angina, mum?', and I said oh no, don't be silly."</i> 216-18</p>	<p>Delayed seeking help:  <i>"I suppose I'd had the chest pain on and off for about..four weeks"</i> 7-8  <i>"it may have been six weeks"</i> 13</p> <p>Painful experience one night led to seeking help from GP next day</p>	



June	<p>Had been advised by opticians to get cholesterol checked but didn't</p> <p>Sudden pain but unsure what it was:  <i>"I didn't know whether it was my lungs, my heart, I just didn't know."</i> 76-77</p> <p><i>"I was getting some of the angina pains in my throat previously but that put down to my hay fever"</i> 33-34</p> <p>Had been told by daughter-in-law (a cardiac student nurse) a year ago that she might have angina but June didn't think she knew what she was talking about (session notes)</p>	<p>Family member got help  <i>"I'm so glad my daughter-in-law was there, because I could not have phone myself because I couldn't physically hold the phone"</i></p>	<p>Pain a distraction from fear  <i>"while it's happening the pain is too great for you to have any fear"</i> 41-2</p> <p>Tried to manage pain to see if it would go away  <i>"I sort of tried to relax I couldn't stop the pain and it just got worse and worse"</i> 64-5</p> <p><i>"I thought, ooo if I lie down on my bed I'll be able to relax more"</i> 109-10</p> <p>Believes not knowing what was happening helped:  <i>"I think that if I'd thought 'gosh I'm having a heart attack' – I might have died"</i> 78</p> <p><i>"if I'd have put a name to what was happening to me, if I could have said I'm having a heart attack maybe the fear of having a heart attack would have made it worse"</i> 88-91</p>
David	<p>Felt unwell but didn't attribute to heart attack:  <i>"I didn't know where I was or what I was, or what was going on at first"</i> 115-18</p> <p>Didn't think he was at risk of a heart attack despite having suffered a stroke the previous year.</p>	<p>Delayed seeking help as called brother first to help:  <i>"I rang up my young brother, told him to come get and get me."</i> 72-3</p>	<p>Wanted to get cleaned up before going into hospital:  <i>"stripped me, cleaned me up"</i> 73-4</p>

Chart 3

Participant	3.1 Positive perceptions of intervention 3.2 Negative aspects of intervention	3.3 Impact on beliefs	3.4 Intervention booklet	3.5 Timing / delivery
John	<p>Intervention highlighted his gaps in knowledge <i>"the questions I was unsure of, were regarding angina."</i> 10</p> <p>Agreed with message of self-management of heart disease through lifestyle change: <i>"Because you're saying, 'Now I know I need to take care of my heart...' And I've realised that. I've got to change my lifestyle."</i> 861-63</p>	<p>Had less awareness of angina: <i>"I just didn't know what angina was, relative to a heart attack"</i></p> <p>Previously thought he was living healthily: <i>"Well, I was definitely having 5 a day, but I was also having"</i></p>	<p>Pointed out CR hasn't helped him with relaxation as it says in booklet: <i>"I don't remember any relaxation classes"</i> 686</p> <p>Booklet needs to be inclusive to disabled people: <i>"I can't do...say in here 'walking', I think a section on.. the importance of disabled people still doing exercise"</i> 230-32 <i>"Still ignoring the disabled"</i> 647</p>	<p>Ideally before heart event as a preventative measure:</p> <p><i>"Before you've had it. I mean, prevention's better than cure"</i> 871</p>
Steven	<p>Thought his answers were influenced by attendance at CR – <i>"you'd probably have different answers"</i> 321-8</p> <p>Preferred the agree/disagree version of YCBQ - <i>"you've got to make a decision"</i> 290 - 298</p> <p>Found the reading was useful <i>"Just all the reading...it's like a learning"</i> 264</p>	<p>Learning that angina doesn't damage the heart was reassuring – <i>"you always would have thought angina was damaging...at least that's one good thing.."</i> 343-49</p>	<p>Liked the booklet <i>"it's very good, it's nearly perfect"</i> 266</p> <p>Preferred the true/false YCBQ as it makes you make a decision – <i>"you've got to make a decision..."</i> 291-8</p> <p>As he has some problems reading he felt a few more pictures would help – <i>"probably could do with some more pictures..."</i> 377</p>	<p>Give intervention at discharge, people have time and want to learn: <i>"Coming out of hospital..that's when you want...I wouldn't do that at the end of doing this (CR), you want it at the beginning when they've got more time sitting at home to read..that would be something to start on..you want to know everything"</i> 581-95</p>

Bob	<p>Nothing missing from intervention or booklet: <i>"I think everything's there. And what I've read from I've learnt. But no, it was great "</i> 900-1</p> <p>Agreed with information in booklet as he believes facts cannot be disagreed with: <i>"It's all fact"</i> 590  <i>"it's all factual, so if it's fact you can't sort of disagree with it, really. If you did disagree with it then you're obviously wrong to disagree with it."</i> 906-12</p> <p>Helpful:  <i>"it was really good. It was helpful"</i> 585</p> <p>Helped with understanding and was understandable:  <i>"helping you understand"</i> 575  <i>"I understood exactly..."</i> 577</p> <p>Clarifying what was meant was appreciated:  <i>"you asked me questions to try and understand"</i></p> <p>Interaction enabled understanding:  <i>"When you spoke to me...made me understand more"</i> 608-9</p> <p>Could misread some questions: <i>"if you read them quickly...a different vision of what the question actually was"</i> 605-6</p>	<p>Broadened perspectives</p> <p><i>"there was answers that made me look at it differently"</i> 582-3</p> <p><i>"really informative and made you think a bit more about your condition...there's stuff in there I didn't even know"</i> 620-2</p> <p><i>" it makes you more aware of how to counteract things..."</i> 629-30</p> <p><i>"what I've read from it, I've learnt"</i> 901</p>	<p>Layout good: <i>"it was laid out well"</i> 604</p> <p>Includes enough information: <i>"I think everything's there"</i> 900</p> <p>Thinks writing in the booklet should be encouraged – <i>"if they didn't write anything, you wouldn't know whether they'd read it"</i> 1167-8</p>	<p>In hospital a useful time as you are unsure of what is going on: <i>"...your mind's got all these things that you're unsure of..."</i> 654- 656</p> <p>Thinks 1:1 approach is best <i>"one-to-ones like this is the way it needs to be done"</i> 667-8</p> <p>The intervention made it easy to discuss a serious subject <i>"we were chatting about a serious subject without making it feel serious...you could relax and talk..."</i> 570-2</p> <p>Thinks a group would not engage: <i>"Or if you were in a class and someone put on a presentation and no-one spoke to you, you'd skip through that and not read it; you'd read it very vaguely."</i> 672-674</p>
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Molly	<p>Felt confident answering the YCBQ <i>"there probably wasn't a lot of things...I didn't know"</i> 376-7 but thinks it's harder to put this understanding into practice -379.</p> <p>Liked the 'quiz' and being able to find out the answers – <i>"to have that information is important"</i> 662-4</p>		<p>Positive message from the booklet <i>"after a heart attack, life can sometimes be better"</i> 569</p>	<p>Giving the intervention in hospital <i>"when they're in hospital..because they've got time...they've got people there to ask"</i> 766-71</p> <p><i>"not that you want bombarding with stuff...understanding your condition from the outset is important"</i> 778-81</p>
June	<p>The intervention made sense and found the myths/truths section and having answers to check was useful <i>"...you can compare straight away, and so that is very useful"</i> – 380-1</p>	<p><i>"The questions you were asking made me think. A lot of them are common sense but you can still get them wrong. So the questions were good"</i> 264-5</p>	<p>The intervention made sense and found the myths/truths section and having answers to check was useful <i>"...you can compare straight away, and so that is very useful"</i> – 380-1</p> <p><i>"It makes you think before you say you agree or disagree"</i></p>	<p>Thinks you need personal input not just the booklet – <i>"Follow through with the conversation, you can then talk about it"</i> 335 <i>"I think the two, the personal impact and the booklet"</i> 427-30</p> <p>Thinks people should receive the booklet as soon as possible <i>"as soon as possible after admission"</i> 343</p>
David	<p>Found answering the questions was daunting: <i>"I found it a bit strange..and I found it a bit daunting to say the least...you asking me questions"</i> 592-604</p> <p>Confused about purpose of completing YCBQ - he thought I should know the</p>	<p>Learnt from going through the YCBQ and then having time to read and absorb information from booklet <i>"I didn't realise some of them at the time, it's only now I</i></p>	<p>Positive experience: <i>"I thought it was excellent"</i> 711</p> <p><i>"There's a lot of stuff in there, I'll read it no end of times now – now I've got one I'll read it more and more"</i></p>	<p>Give the booklet to people as soon as possible: <i>"The sooner the better..I think what you should do is try to get them in people's hands, especially when they're lying in hospital"</i> 792-801</p>



David continued	<p>answers "it weren't until I got home..and I thought, that girl's only doing her job and she's learning all the time..." 612-14</p> <p>Too many questions and personal: "There was too many..I found some of the questions a bit personal" 638</p> <p>But thinks the questions were valid "But at the same time – they had to be answered..and I had to answer them to be honest with myself"</p> <p>Needed time to register the questions: "Once I'd got that registered in my brain..you could ask me 21 questions then.." 677-80</p> <p>Intervention well explained: "I thought it was excellent, the way you put everything...You explained everything in there, what's this and what's that, and the difference in opinions and whatnot" 716-9</p>	<p>realise when reading about it..you need time to absorb it all" 690-700</p> <p>The intervention has helped him accept limitations:</p> <p>"I've got to live within my means..you've got to adjust yourself to what you are and not what you've been.." 745-762</p> <p>Living a balanced life to reduce stress: "What's the point of causing myself another heart attack?..Whatever the stress or strain...it doesn't bother me, to that extent. I've changed a lot." 937-49</p>	<p>and more" 780-2</p> <p>"I think everyone who's had a heart problem should get one" 827-8</p> <p>Having the booklet means you can read it over and gain understanding</p> <p>"that part I didn't understand right away. So I read it again and again..now I understand" 734-38</p>	
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## **APPENDIX VIII**

Intervention booklet

## Explaining common beliefs about heart disease



Introduction	1
Section 1 Illness beliefs	2
Section 2 Common misconceptions	5
Section 3 Changing misconceptions	13
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## Introduction

**Thank you for agreeing to take part in this study. This booklet will help explain the common misconceptions people have about heart disease.**

### *Why have I been given this workbook?*

This workbook is for you and anyone close to you to help make sure that you make the best recovery from your heart problem.

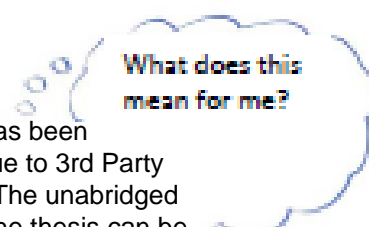
### *What is this workbook about?*

This workbook is to help you identify any unhelpful beliefs and misconceptions about heart disease. It will show you how to deal with these unhelpful thoughts so that you can make the best of your recovery.

### *What are cardiac misconceptions?*

Cardiac misconceptions are incorrect or muddled thoughts and beliefs about heart disease.

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Cardiac misconceptions are *common* and can come from previous experiences, friends and family, and often from the media.

Having correct beliefs about heart disease helps people:

- Manage heart disease better
- Experience fewer angina symptoms
- Return to activities quicker
- Experience less anxiety and depression
- Have a better quality of life.

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It's important to get rid of any unhelpful beliefs and misconceptions about heart disease that may be blocking your path to recovery.

*This booklet has 3 main sections:*

1. What are illness beliefs?
2. Explaining the common misconceptions
3. How to change unhelpful beliefs

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As you go through this guide you will be asked to rate how you feel about different aspects of your heart disease. Circle the number which feels right for you. This may help you identify any areas where you could benefit from support. Please do write in this guide, it's yours to keep. There are some blanks pages at the end of the booklet to make any extra notes.

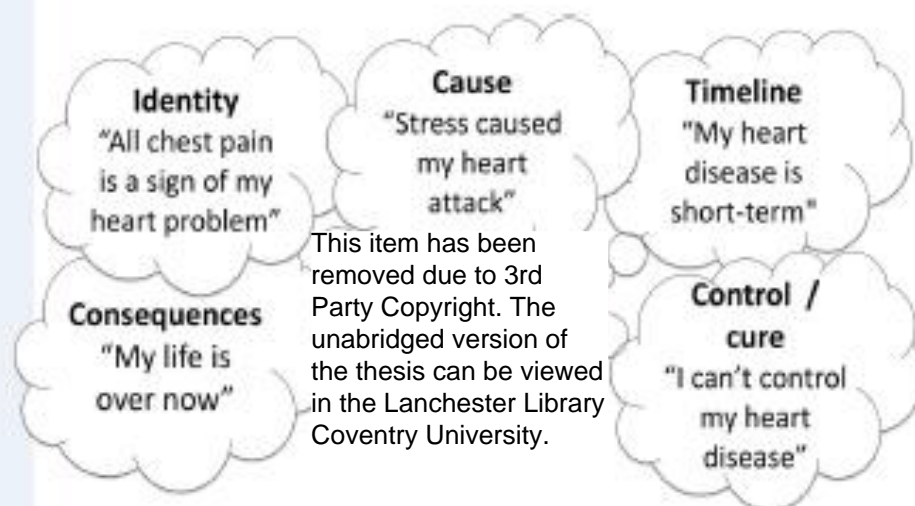
You may wish to show this booklet to your cardiac rehabilitation nurse.

## SECTION 1: Beliefs about having a heart problem

People's thoughts and beliefs about heart problems or any other illness generally fall into the following categories:

Identity	Beliefs you have about your physical symptoms.
Cause	Your beliefs about what caused your heart problem.
Timeline	Your beliefs about how long your heart problem may last.
Consequences	Beliefs you have about how your heart problem will affect your life.
Cure / Control	Your beliefs about how well your heart problem can be cured or controlled and how much you can control it.
Treatment	Beliefs you have about your medical treatment, including cardiac rehabilitation.

Jane, below, has these *misconceptions* and *incorrect beliefs* about her heart disease:

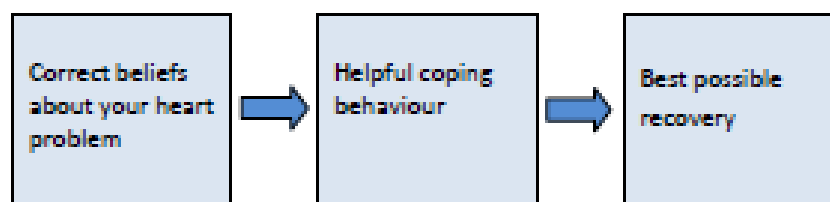


The thoughts and beliefs you have about heart disease are very important.

Your thoughts and beliefs about heart disease help you make sense of your illness and help you manage your illness in the short and long-term.

Cardiac misconceptions can get in the way of your recovery.

This is because the *things you do to manage* your heart problem depend on your *thoughts and beliefs about it*.



The first step is to **identify your own unhelpful beliefs and misconceptions** about heart disease. You can do this now by completing the quiz below - the York Cardiac Beliefs Questionnaire. This questionnaire looks at beliefs about heart attacks and living with heart disease.

It can be really useful for friends and family to have a go too – what they believe about heart problems is important for you too.

**Tick whether you agree or disagree with the following statements.**

**Don't worry if you are not sure if you agree or disagree – just answer what feels right to you.**

Questions about heart attacks	Agree	Disagree
1 It is dangerous for people who have had a heart attack to exercise	<input type="checkbox"/>	<input type="checkbox"/>
2 People who have had a heart attack must be protected from stress	<input type="checkbox"/>	<input type="checkbox"/>
3 After a heart attack life can sometimes be better than before	<input type="checkbox"/>	<input type="checkbox"/>
4 A heart attack makes a weak area in the heart wall that can easily rupture	<input type="checkbox"/>	<input type="checkbox"/>
5 Once you have had a heart attack you are bound to have another	<input type="checkbox"/>	<input type="checkbox"/>

Questions about living with heart disease	Agree	Disagree
6 People who have heart disease should never get excited or upset	<input type="checkbox"/>	<input type="checkbox"/>
7 People develop heart disease because of worry in their life	<input type="checkbox"/>	<input type="checkbox"/>
8 Rest is the best medicine for heart conditions	<input type="checkbox"/>	<input type="checkbox"/>
9 One of the main causes of heart disease is stress	<input type="checkbox"/>	<input type="checkbox"/>
10 It is dangerous for people who have heart disease to argue	<input type="checkbox"/>	<input type="checkbox"/>
11 Doing exercise can strengthen the heart muscle	<input type="checkbox"/>	<input type="checkbox"/>
12 Heart disease is often caused by people's lifestyle	<input type="checkbox"/>	<input type="checkbox"/>
13 Heart problems are a sign that you have a worn out heart	<input type="checkbox"/>	<input type="checkbox"/>
14 People with heart disease should take life easy	<input type="checkbox"/>	<input type="checkbox"/>
15 Any sort of excitement could be bad if you have heart disease	<input type="checkbox"/>	<input type="checkbox"/>
16 Your heart is like a battery, the more you do the faster it runs down	<input type="checkbox"/>	<input type="checkbox"/>
17 People who have heart disease should always avoid stress	<input type="checkbox"/>	<input type="checkbox"/>

You can check your answers on pages 17 & 18

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How did you do?

Let's now look at some of these common cardiac misconceptions in more detail.

## SECTION 2: Common misconceptions

This part of the booklet will explain the common misconceptions and beliefs people have about heart disease.

### Misconceptions about the causes of heart disease

Have a go at writing down the three most important factors that you think caused your heart problem.

*The most important causes for me:-*

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

A big part of managing a heart problem is to manage the factors that may have caused it. These factors are known as your risk factors.

It is helpful if your beliefs and thoughts about the causes of your heart problem, or your risk factors, are accurate. This will help you tackle *all* of the relevant factors that may have caused your heart problem. It's common to have misconceptions about the causes of heart attacks and heart disease.

Look at Alan's misconceptions about what caused his heart attack to see how his thinking affects his life.

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Alan: "I think stress was the main cause of my heart attack; my family say so too. I've heard stress is bad for the heart so I am going to be careful about getting stressed now"

On the next page see how Alan's belief changes how he behaves and how he feels.



Alan has cut down on activities, even seeing his friends, in order to keep his stress levels as low as possible. But he is now feeling bored and low in mood. Alan is also feeling quite anxious about facing situations that may cause him stress. Is it helpful for Alan to avoid stress and reduce his activities?

"I know smoking isn't good for me but I worry that stress is bad for my heart. If I try and give up smoking I worry I'll get too stressed and this won't be good for me..."

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**FACT:** Risk factors like family history, high cholesterol and lifestyle factors, e.g., smoking, cause heart disease.

Newspapers and TV often portray stress as being the main cause of heart attacks.

**FACT:** Stress can contribute to heart disease but it is **not a main cause**. Other risk factors like family history and smoking are more important.

**Too much stress can be bad if it leads to people doing more unhealthy things like having a poor diet, not exercising, smoking or drinking.**

Stress is a normal part of life and can be managed most of the time. We all have stress in our lives. Would you enjoy life with absolutely no stress whatsoever?

Good to know: Learning to manage your stress better can help you manage your heart problem. It's easier to make lifestyle changes and stick to them if you feel more relaxed. Going to cardiac rehabilitation classes can give you the skills to relax more easily. If you feel you need more help with this then [www.glasgowsteps.com](http://www.glasgowsteps.com) is a good place to go for help, or speak to your nurse or doctor.

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It's safe to get excited or upset. People don't have to treat you any differently.

How much do you believe your risk factors caused your heart problem?

0 1 2 3 4 5 6 7 8 9 10  
Not at all Definitely

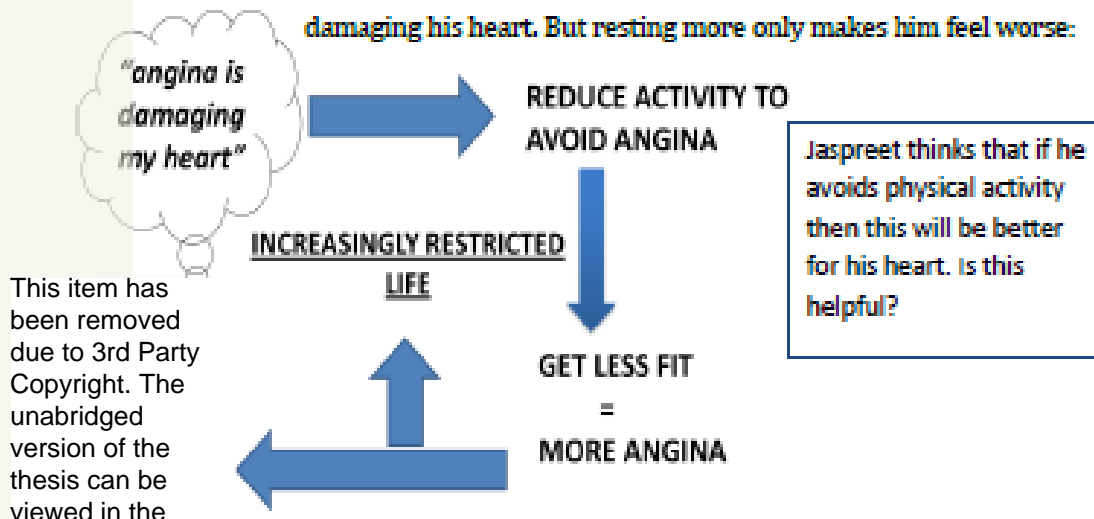
Are there any risk factors you are unsure about?

#### Misconceptions about the consequences of heart disease

How much does your heart problem affect your life?

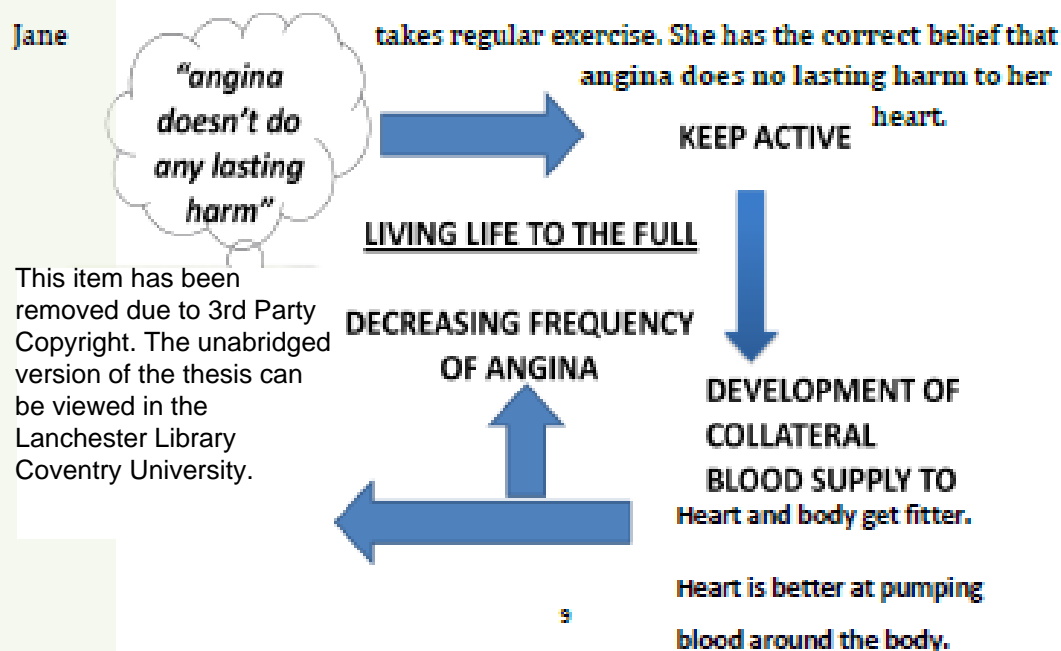
0 1 2 3 4 5 6 7 8 9 10  
no effect severely  
at all affects my life

Jaspreet thinks that he needs to rest and be careful. He has the *misconception* that angina is damaging his heart. But resting more only makes him feel worse:



Reducing activity doesn't work well for Jaspreet. He finds he gets angina more often! To cope he reduces his activity even more. Jaspreet now feels fed up and bored. He thinks there's nothing left for him now. What can he do?

Jane takes regular exercise. She has the correct belief that angina does no lasting harm to her heart.





Increasing physical activity is helpful.

Jane knows it's better for her heart if she exercises regularly. As Jane has got fitter she has found her angina occurs less often. Jane now feels more in control of her heart disease and this is helping her to live life to the full.

### Get more active!

Trying to avoid angina pain or another heart attack by doing less activity is unhelpful because this reduces fitness levels. This makes angina come on more quickly because unfit muscles are less efficient.

Exercise is also important for many other reasons including helping to lower your blood pressure and maintaining a healthy weight. Exercise can boost your mood too!

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Jaspreet can feel physically better and happier if he too gets more active instead of avoiding activity.

Cardiac rehabilitation exercise classes are ideal for getting back into exercise after having a heart attack or heart surgery. The classes can help you even if you have never exercised much before or been to a gym. Your exercise sessions are guided by trained staff.

If you have any disabilities then the team can find alternative exercises for you to do.

### Misconceptions about how long heart disease will last

How long do you think your heart problem will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

Lucy believes her illness is a short-term problem. She felt dreadful before going into hospital and now feels fine since her treatment. Lucy believes her problem has been 'fixed' by the medical team. Lucy is thinking that she won't bother with cardiac rehabilitation as she already feels better. Is Lucy right to think this?

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**FACT: A heart attack is an acute event but it is due to coronary heart disease – a chronic or long-term condition.**

It can be difficult sometimes for people to understand that heart disease is a long-term health condition. Preventing heart disease from getting worse or having another heart attack needs long-term management. This means taking prescribed medication and making lifestyle changes for better health. Cardiac Rehabilitation can teach you the different ways you can self-manage your heart problem.

**Life-style changes need to be for life!**

Lucy decided to go along to a cardiac rehab class anyway and learnt that although she's no longer in pain, she still has heart disease. The good news is that Lucy found out about the different things she can do to help prevent her heart disease from getting worse.

### Misconceptions about symptoms of heart disease

How much do you experience symptoms from your heart disease?

0	1	2	3	4	5	6	7	8	9	10
No symptoms					All of					
at all					the time					

It is common for people to take more notice of their body sensations after having a heart attack. Often, 'normal' body sensations are believed to be a sign of a problem which can cause people to become anxious. Anxiety can cause many of these body symptoms.

Anxiety symptoms can be unpleasant but are not dangerous. Symptoms include increased heart rate and difficulty breathing. You can learn how to manage anxiety symptoms at cardiac rehabilitation. The resources page also has self-help information.

Going to cardiac rehabilitation will help teach you which symptoms are normal and part of recovery, and how to identify when and how you should get help.

### Misconceptions about controlling heart disease

How much control do you feel you have over your heart disease?

0	1	2	3	4	5	6	7	8	9	10
absolutely					extreme amount					
no control					of control					

How much do you think your treatment can help your heart disease?

0	1	2	3	4	5	6	7	8	9	10
not at					extremely					
all										

Having a strong sense of control over your illness can help you feel better and more able to get on with life.

For some people, a heart attack seems to come out of the blue. However, because you can't see it, heart disease has been lurking unnoticed. It can feel like you have little control over your heart disease. You might even believe it's up to fate whether or not you have more heart problems. It is more helpful for managing your heart problem if you have a strong belief that you have control.

**There is a lot YOU can do to take control of your health and manage your heart disease.**

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**Take your medication as prescribed**

It's really important that you take all of your medications. Talk to your nurse, GP or pharmacist if you have any concerns.

**Get fitter!** Your heart will get stronger and a fitter body takes less work.

You can get an exercise plan at Cardiac Rehabilitation classes.

**If you smoke, get help to become a non-smoker**

**Eat 5 fruit and veg a day**

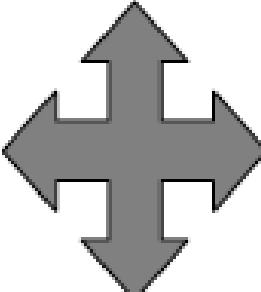
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**Get help with all of this from your cardiac rehabilitation team**

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Now you've had a look at some of the most common misconceptions about heart disease.  
Are thoughts and beliefs about things you can and can't do since your heart problem affecting you? Try filling in the boxes:

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<b>Thoughts / beliefs</b> e.g. "I mustn't get worked up"		
<b>Physical feelings</b> e.g. tired, restless...		<b>Emotional feelings</b> e.g. angry, sad, anxious...
<b>Actions / behaviours</b> What are you doing less of or more of? E.g. resting, worrying.		

The next step is to change these misconceptions and unhelpful beliefs about heart disease!

### SECTION 3: Changing misconceptions into helpful thoughts and beliefs

Sometimes, being given the right information is enough to change cardiac misconceptions. But often beliefs are more difficult to change because you have had them for a long time.

Once you are aware of your cardiac misconceptions you can challenge them and replace them with more helpful thoughts.

**Unhelpful belief / Cardiac misconception:** Write it here  
e.g. "Stress might set off another heart attack"

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Evidence that this thought or belief is true	Evidence that this thought or belief is false
<p><i>"My friends and family tell me I work too hard and stress caused my heart attack.."</i></p> <p><i>"When I feel stressed I can feel my heart beating faster.."</i></p>	<p><i>"The information from the cardiac rehab staff has made me realise that stress has led me to live an unhealthy lifestyle. So it's more about making changes to my lifestyle.."</i></p> <p><i>"Now I know I need to take care of my heart I'm less likely to have another heart attack – as long as I change my behaviour."</i></p>

Now weigh up the evidence. Are you right to have this belief? How helpful is it to you? What is a more helpful thought or belief to have about this? You may want to ask your cardiac rehabilitation team or your family for their ideas.

**New and improved thought or belief: write it here**

*"Stress is not so bad for my heart, it's the stressful things I do – this I can work on"*

**How much do you believe this new thought is true?**

0 1 2 3 4 5 6 7 8 9 10

Not  
at all

Completely

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**How can you test out this new and improved thought? Write it here as an Action Plan:**

**How/ what?**

e.g. start walking  
every day for 30 mins

**Who with?**

e.g. walking group

**Where?**

e.g. the park if it's nice

**When? Day:**

**Time:**

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One last question:

<b>How well do you understand your heart disease?</b>											
0	1	2	3	4	5	6	7	8	9	10	
don't understand at all									understand very clearly		

Do you think you understand enough about your heart problem? Perhaps people around you would benefit from knowing more?

If you would like to know more about your illness then ask your cardiac rehabilitation team – they will be happy to answer your questions and give out information.

On the next pages are the answers to the York Cardiac Beliefs Questionnaire. It will be helpful if you have a read through to understand the myths and truths about heart disease.

	The Myths	The Truth
1	People who have heart disease should never get excited or upset	Life with no excitement? Boring! Normal excitements won't hurt you. If you often get angry and upset, please talk to your cardiac rehab team or practice nurse – they may be able to help.
2	People develop heart disease because of worry in their life	No, worry doesn't cause heart disease, risk factors do. But, if you are worried or stressed you should do something about it. Ask for advice from the rehab team or practice nurse.
3	Rest is the best medicine for heart problems.	No, rest is not a medicine; too much rest makes your heart unfit, leads to a lack of energy and stamina and can cause even more problems.
4	One of the main causes of heart disease is stress.	Everyday life stress isn't one of the major causes of heart disease, although it may play a part. But it can make you miserable and lead to bad habits like smoking and not exercising enough which do cause heart disease.
5	It is dangerous for people who have heart disease to argue.	No, once again most people should aim to live a normal life. Disagreements are part of everyday life. Bottling things up can make them worse.



6	Doing exercise can strengthen the heart muscle	Yes, particularly in the safe way that health professionals can advise you about.
7	Heart disease is often caused by people's lifestyle.	Yes, an unhealthy lifestyle is the main cause of heart disease.
8	Heart problems are a sign that you have a worn out heart	Your heart doesn't wear out. You can make it stronger by being more active.
9	People with heart disease should take life easy	No, live as active a life as you can – it will help to prevent more problems
10	Any sort of excitement could be bad if you have heart disease	No, normal levels of fun and excitement help to make life worth living.
11	Your heart is like a battery, the more you do, the faster it runs down	No, activity recharges the heart
12	People who have heart disease should always avoid stress	No, avoiding things that may be fun because of a fear of stress can lead to depression. If you need help to cope with everyday stress, talk to your cardiac rehab team or practice nurse.
13	It is dangerous for people who have had a heart attack to exercise	No, providing exercise is built up gradually. The cardiac rehab team or practice nurse can advise about this. Being active reduces the risk of more heart problems.
14	People who have had a heart attack must be protected from stress	This can lead to them being excluded from normal social life and work, and may lead to depression. If stress is a problem, then there are ways to reduce its impact.
15	After heart attack life can sometimes be better than before	Particularly if they have attended cardiac rehabilitation, which reduces the chance of early death.
16	A heart attack makes a weak area in the heart wall that can easily rupture	No, the scar tissue which forms after a heart attack is strong and very unlikely to cause any problems.
17	Once you have had one heart attack you are bound to have another one	No, most people who have had one heart attack never have another.

Below is a list of useful resources.

### Resources

British Heart Foundation [www.bhf.org.uk](http://www.bhf.org.uk)

Heart Helpline - 0300 330 3311 Monday – Friday 9am to 5pm.

Managing anxiety and relaxation: [www.glasgowsteps.com](http://www.glasgowsteps.com)

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