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## DOCTOR OF HEALTH (DHEALTH)

### Continuity of care and its effect on patients' motivation to initiate and maintain cardiac rehabilitation

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‘Continuity of care’ and its effect on patients’  
motivation  
to initiate and maintain cardiac rehabilitation

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A thesis submitted for the degree of Doctorate in Health  
University of Bath  
Department for Health

April 2015

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## **Abstract**

*Background:* Despite national guidance and empirical support for its clinical and cost-effectiveness, cardiac rehabilitation (CR) is underused. Only 44% of patients go to CR, with angioplasty (Percutaneous Coronary Intervention; PCI) patients being least likely to attend (31% of 87,000).

*Aim:* To investigate the relationship between 'continuity of care' and patients' motivation towards CR, through the lens of self-determination theory, and develop a model to inform service design to increase CR uptake and adherence.

*Methods:* A mixed methods approach was used. In Study 1, a theoretical model of continuity of care and motivational antecedents was tested with a cross-sectional sample of 107 PCI patients. To further explore interactions between continuity of care and motivation towards cardiac rehabilitation, a Critical Interpretive Synthesis of the extant literature was used in Study 2, and focus groups were carried out with patients and service providers in Study 3.

*Results:* In Study 1, continuity of care positively predicted patients' autonomous motivation towards CR, and this was partially mediated by autonomy support. Autonomy support was associated with CR attendance. In Studies 2 and 3, aspects of continuity of care with positive effects on attendance were identified. These included timely, appropriate information provision, relationships bridging CR phases and settings, and continuing management strategies incorporating trusting, warm staff-patient relationships, and positive encouragement and feedback about progress. The SDT constructs of autonomy support, need satisfaction, internalisation and quality of motivation helped to explain positive and negative influences of continuity on attendance.

*Conclusion:* Continuity of care has a positive effect on patients' motivation towards CR. The most enduring motivation comes from delivering continuity of care in an autonomy-supportive and competence-supportive way. Longitudinal research is needed to compare how need-supportive and need-thwarting aspects of continuity of care affect CR attendance and adherence, and whether these relationships are influenced by need satisfaction and need frustration.



## Abbreviations

AMI	Acute myocardial infarction
BACR	British Association for Cardiac Rehabilitation
BHF	British Heart Foundation
CABG	Coronary Artery Bypass Graft
CHD	Coronary Heart Disease
CIS	Critical Interpretive Synthesis
CofC	Continuity of care
CR	Cardiac rehabilitation
CSM	Common Sense Model
HAPA	Health Action Process Approach
HLOC	Health locus of control
LOC	Locus of control
MI	Myocardial infarction
NACR	National Audit of Cardiac Rehabilitation
NCCSDO	National Co-ordinating Centre for NHS Service Delivery and Organisation
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
PCI	Percutaneous Coronary Intervention
SDT	Self-determination theory (Deci and Ryan)
SIGN	Scottish Intercollegiate Guidelines Network
SCT	Social Cognitive Theory
SET	Self-efficacy
SLT	Social Learning Theory
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TTM	Transtheoretical Model (Stages of change)

## Statistical abbreviations

$\alpha$	Cronbach's alpha
AVE	Average Variance Extracted
$\beta$	Path coefficient
CB-SEM	Covariance-based Structural Equation Modelling
CR	Composite reliability
CI	Confidence interval
$f^2$	Cohen's $f^2$ (effect size of an endogenous latent variable)
OR	Odds ratio
p	P-value; Probability value
PLS-SEM	Partial Least Squares Structural Equation Modelling
$q^2$	Effect size of an endogenous latent variable
$Q^2$	Stone-Geisser's $Q^2$ (predictive relevance)
RR	Relative Risk
$R^2$	Coefficient of determination (predictive accuracy)
SD	Standard deviation
$\chi^2$	Chi-square(d)

# Chapter 1: Introduction

Cardiac rehabilitation (CR) has been shown to be an effective intervention for patients recovering from heart attacks or heart surgery (NHS Centre for Reviews and Dissemination, 1998), reducing secondary events and death rates (Clark, Hartling, Vandermeer, & McAlister, 2005; Heran et al., 2011; O'Connor et al., 1989; Oldridge, Guyatt, Fletcher, & Rimm, 1988; Taylor et al., 2004), and improving quality of life (McAlister, Lawson, Teo, & Armstrong, 2001; Shepherd & While, 2012). Uptake of CR is now increasing each year in England, Northern Ireland and Wales, after remaining at around 30% of eligible patients for most of the 2000's. During 2010-2011, 44% of patients with acute myocardial infarction (AMI), bypass surgery (CABG) and percutaneous coronary intervention angioplasty (PCI) took part, up from 38% in 2007-2008. The highest attenders are CABG patients (74%), while those undergoing a PCI have the lowest attendance (31%) (BHF Care and Education Research Group, 2012). This is well below the target of 85% set by the National Service Framework on coronary heart disease (Department of Health, 2000). In order to improve uptake, particularly among PCI patients, there is a need to understand why patients do not attend.

Reasons for low uptake and adherence have been investigated in three main strands of research: patient characteristics, service/practitioner characteristics, and interactions between them (Beswick et al., 2004). Continuity of care is one aspect of service delivery with a potentially positive effect on CR participation (Riley, Stewart, & Grace, 2007), though it is uncertain how continuity of care interacts with patient characteristics. The present study addresses this uncertainty in order to clarify the role of continuity of care in CR attendance.

The idea that patient and organisational characteristics interact, resulting in differential CR uptake, may be supported by self-determination theory (SDT) (Deci & Ryan, 2008). This theory has been used as a framework for understanding people's motivation to follow healthy behaviour recommendations (eg. Edmunds, Ntoumanis, & Duda, 2007; Williams et al., 2006; Williams, Gagne, Mushlin, & Deci, 2005). Consequently, SDT may help to explain the relationship between continuity of care and patients' motivation to attend cardiac rehabilitation.

This will be achieved by testing a model of continuity of care and motivational antecedents of CR attendance in PCI patients (because PCI patients have the lowest CR uptake), based on previous literature and theory. Specific elements of continuity of care that affect patient motivation for CR attendance will then be explored by reviewing the literature using Critical Interpretive Synthesis (CIS) methodology. The model from the first

study will be amended to illustrate the relationships identified in the CIS. The validity and applicability of the model will be evaluated through focus groups with PCI patients and health professionals. The amended model will be refined as necessary and recommendations for practice and further research will be made.

## ***1.1 Organisation of the thesis***

Chapter two summarises current knowledge and practice relating to the topic under investigation. This includes: epidemiology and costs of heart disease, treatment and secondary prevention, and the role of cardiac rehabilitation in preventing further cardiac events. Patient motivation for uptake and adherence to cardiac rehabilitation, 'continuity of care' and the role of theory-based frameworks in guiding research are discussed. Self-determination Theory is introduced, and its role in framing the present project is described. The aims and objectives of the present studies conclude the chapter.

The present thesis consists of three empirical studies. The purpose was to conduct a series of logically ordered investigations, starting with a foundation of measurement and hypothesis testing of the interaction between continuity of care and patient motivation for cardiac rehabilitation. Once evidence of such a relationship was established, and further uncertainties were identified from Study 1, critical interpretive synthesis was used in Study 2 as a means of exploring the associations between constituents of continuity of care and motivation in cardiac rehabilitation in greater depth and breadth. This allowed the nuances of interactions between factors from Study 1 to be considered, additional putative factors contributing to the model to be identified, and a more expansive theory about the overall relationships between service delivery (specifically continuity of care) and patient motivation to be developed. In Study 3, understanding gained from Studies 1 and 2 is built on by exploring the experiences of current patients and staff in the UK, to ensure that the overall findings are derived from, and relevant to current NHS practice.

Chapter three reports on a cross-sectional quantitative survey (Study 1) to test a theoretical model developed from previous research, in 107 patients who had a percutaneous coronary intervention in the previous 2-6 months. This approach was used because although causal links cannot be made, the results can be used to design testable interventions to encourage CR attendance, and indicate directions for future research. The hypothesised relationships between continuity of care, autonomy support and quality of motivation in PCI patients are assessed using Partial Least Squares Structural Equation Modelling (PLS-SEM). PLS-SEM gives sufficient power for smaller samples, allows prediction and theory-development and does not require normal distributions or multivariate normality, so is appropriate for the present study. This was considered appropriate as an initial parsimonious stage in exploring the relationship

between continuity of care and patient motivation in CR, which has not previously been examined.

Chapter four presents the methodology and results of a Critical Interpretive Synthesis (CIS, Study 2), culminating in proposed amendments to the model tested in chapter three. The aim was to identify evidence for, and elucidate the relationship between 'continuity of care' and patients' motivation to engage with cardiac rehabilitation (CR) from existing literature. CIS was chosen because it is an interpretive approach, incorporating diverse literature, and resulting in a critical overview of evidence. The outcome is insightful theory which can inform practice and research. This is considered appropriate as a means of exploring the understanding of specific elements of continuity and motivation, and their interaction, from multiple settings and interpretations.

Chapter five presents a focus group study (Study 3) with patients who have undergone a percutaneous coronary intervention (PCI), and health professionals who work in cardiac rehabilitation. The aim was to explore the experiences of current patients and staff in UK settings, to improve the understanding gained from the CIS. Focus groups were chosen to encourage participants to express their individual and shared experiences. The results from four focus groups are triangulated and analysed using thematic analysis (Braun & Clarke, 2006). The model developed from the survey and CIS is amended with respect to PCI patients, to provide insights that can inform future research and practice, to encourage greater attendance among PCI patients.

Chapter six brings together the overall conclusions of the three studies. Their contribution to knowledge about continuity of care and patient motivation in cardiac rehabilitation is outlined. Limitations of the present studies are highlighted, and a model and recommendations are made regarding future practice and research directions.

## **Chapter 2: Literature Review**

The purpose of this chapter is to introduce current knowledge and practice, and the conceptual and theoretical underpinnings that inform the research objectives of the present work. First, the role of cardiac rehabilitation (CR) in preventing cardiac events, the need for CR attendance and adherence to healthy behaviour recommendations, current trends in CR participation, the many barriers to attendance and adherence, and research that has aimed to explain and overcome these barriers is discussed. In particular, the use of behaviour change theories to guide investigations is presented, as behaviour change within CR is the specific practical aim of this project. As the focus of this research is the interaction between continuity of care and patient motivation, these concepts are introduced, and Freeman's continuity of care matrix (Freeman et al, 2007) and Self-determination theory (SDT; Deci & Ryan, 2000, 2008), the theoretical frameworks that guides the present work, are discussed.

### ***2.1 Heart disease and cardiac rehabilitation***

#### **2.1.1 Epidemiology and costs of coronary heart disease**

Death rates from coronary heart disease (CHD) have fallen steadily since the 1970's, but have fallen more slowly in younger people and fastest among over 55s (Townsend et al., 2012). Fifty-eight percent of the decrease during the 1980's and 1990's was attributable to reducing major risk factors, particularly smoking, and 42% due to treatment, including secondary prevention (Unal, Critchley, & Capewell, 2004). However, CHD still causes 80,000 deaths a year in the UK, including 25,000 premature deaths (death before age 75), and results in 500,000 hospital inpatient episodes (Townsend et al., 2012).

CHD increases the risk of heart attack (acute myocardial infarction - AMI), when the heart suddenly loses its blood flow, usually due to a blood clot. Clots can form if fatty patches or plaques in the linings of the arteries (atheroma) rupture and interact with the blood. An estimated 103,000 people experience AMIs each year in the UK (Townsend et al., 2012). About 1.5 million UK citizens have had a heart attack, 851,000 of them under 75, and 1.6 million men and one million women have CHD (Townsend et al., 2012).

The annual estimated cost of CHD is £6.7 billion, comprising 27% for healthcare, 47% from productivity losses, and 26% for informal care (Townsend et al., 2012).

Efforts to reduce the incidence and cost of cardiac events in CHD patients include initial drug treatment or surgery, and risk reduction strategies.

## **2.1.2 Treatment and secondary prevention for coronary heart disease**

Treatment of coronary heart disease involves managing the risks and/or consequences of an acute event. There are established effective first line treatments for acute events, which are followed by secondary prevention interventions.

### **First line treatment of acute events or high risk of acute events**

Acute myocardial infarction is treated by thrombolysis<sup>1</sup>, coronary artery bypass grafting (CABG)<sup>2</sup>, or percutaneous coronary intervention (PCI)<sup>3</sup>. CABG or PCI are also increasingly used in patients at high risk of AMI. Around 18,000 CABG operations and 87,000 PCIs were performed in the UK in 2010 (Townsend et al., 2012).

### **Secondary prevention by cardiac rehabilitation**

Cardiac rehabilitation (CR) is a set of secondary prevention strategies that enhances the effectiveness of first line treatments by helping to prevent further cardiac events, including death (Clark et al., 2005; Hammill, Curtis, Schulman, & Whellan, 2010; Heran et al., 2011; Taylor et al., 2004). CR is also a set of services to help people with coronary heart disease to preserve or resume their optimal functioning (NICE, 2011). In the UK, CR is organised in four phases. Phase one, during hospitalisation, consists of advice about the event, future diet, activity and smoking, and prescription of drugs such as aspirin, beta-blockers and statins. Phase two, during the first few weeks convalescing at home, includes lifestyle advice and encouragement to increase physical activity. Phase three, 2-6 weeks after AMI or surgery, includes an outpatient programme of supervised exercise, advice about diet, stress management, alcohol and smoking, and may include psychological support and behaviour change methods. Home-based programmes with support materials, such as The Heart Manual (The Heart Manual Management Group, 2008), are available in some areas. Phase four involves ongoing self-care, and may include individualised exercise programmes, and patients are followed up in primary care (Bethell, Lewin, & Dalal, 2009). Most countries have similar models to those in the UK, although phase names vary. For example, in the USA, the Home program, Phase two and Phase three are similar to Phase two, three and four respectively in the UK (Healthwise, 2013). In the present thesis, the UK naming system will be used.

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<sup>1</sup> Thrombolysis uses drugs to dissolve the blockage

<sup>2</sup> CABG is heart surgery in which the blockage is bypassed using a section of vein or artery from the patient's arm or leg

<sup>3</sup> PCI involves feeding a tiny wire with a balloon into a large artery in the groin or arm. It is guided into the blocked section of the artery. The balloon is inflated inside the blocked part of the artery to widen it. A stent (mesh tube) may be left in to help keep the artery widened

Cardiac rehabilitation is considered clinically effective and cost-effective for patients recovering from AMI, PCI or CABG, and is recommended by NICE<sup>4</sup> (NHS Centre for Reviews and Dissemination, 1998; NICE, 2011; NICE, 2013)<sup>5</sup>. However, some researchers dispute the effectiveness of CR. For example, West et al (2012) contend that effectiveness data comes from systematic reviews that pre-date improvements to AMI management (Joliffe et al., 2001; O'Connor et al., 1989; Oldridge et al., 1988). West and colleagues suggest that drug developments (aspirin for secondary prevention, beta-blockers, ACE-inhibitors, statins), thrombolysis and angioplasty have nullified the benefits of CR. Their trial in 1800 patients found no significant difference in mortality (after 2 or 7-9 years), cardiac events, quality of life or wellbeing between patients attending CR versus usual care (West, Jones, & Henderson, 2012). However, West et al's study has been criticised (summarised by Sheppard & Furze, 2012). Specifically, it was carried out before improvements to CR encouraged by the NACR<sup>6</sup> audit initiative (eg. BHF Care and Education Research Group, 2012) and the publication of BACR<sup>7</sup> standards (BACR, 2007), and the sample size was too small to assess the primary outcome of two year mortality. Heran et al's (2011) update of Joliffe et al's Cochrane review provides evidence to contradict West et al's conclusion about mortality. Seventeen studies published from 1999-2008 were identified in addition to the 30 included by Joliffe et al. After meta-analysis, Heran et al concluded that CR programmes including exercise reduce death from cardiac events (12 studies: RR 0.87; 95% CI) or other causes (16 studies: RR 0.74; 95% CI). This applies to studies with greater than 12 month follow-up, and median follow-up was 24 months (range six to 120 months). The number of studies analysed and assessment of study quality, bias and heterogeneity suggests that the findings of the Cochrane review may be more reliable than West et al's study, though future research may alter these conclusions.

Taylor et al (2006) concluded that half of reductions in death result from reducing risk factors by attending exercise-based CR. Rehabilitation programmes without an exercise component reduce death rates by about 13% (National Collaborating Centre for Primary Care, 2007). There is also some evidence of a dose-response relationship between CR attendance and long-term outcomes, including mortality and AMI, emphasising the importance of adherence (eg. Hammill et al., 2010). However, Heran et al (2011) concluded that there was no dose-response relationship, based on their calculations from exercise components of 47 studies. The Cochrane review also highlights the heterogeneity of the evidence base, variable quality of studies and predominance of

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<sup>4</sup> NICE - National Institute for Health and Care Excellence

<sup>5</sup> NICE clinical guideline 48: Secondary prevention in primary and secondary care for patients following a myocardial infarction, last updated 2013

<sup>6</sup> NACR – National Audit of Cardiac Rehabilitation

<sup>7</sup> BACR – British Association for Cardiac Rehabilitation

younger male participants. Sample sizes, contents and duration of the CR programmes tested vary. Thirty of the studies reviewed by Heran and colleagues included only AMI patients, and there were too few PCI and CABG patients to allow results to be stratified by patient group. There is also a lack of published studies with negative results, so the results of reviews may be biased in favour of CR (Heran et al., 2011). These limitations mean that it remains difficult to judge the effectiveness of CR, though current best evidence suggests that it is effective.

Although every UK hospital treating acute heart problems has a CR centre to which to refer patients, few centres meet BACR or SIGN<sup>8</sup> standards for staffing or funding (Bethell et al., 2009). The 2008 NICE Commissioning guide stated that cardiac rehabilitation cost between £17 and £2186 per patient, and was highly cost effective at £550 per patient (NICE, 2008). However, some services have no core funding, but rely on donations and time 'borrowed' from hospital departments (NICE, 2011). The introduction of mandatory post-discharge tariffs to incentivise integration of acute and community services, including cardiac rehabilitation, from April 2013 (Department of Health Payment by Results team, 2012), and guidance on developing high-quality cardiac rehabilitation services (Department of Health, 2010b) are expected to improve access, uptake and service quality (NHS Improvement: Heart, 2010).

The organisation of CR services varies in terms of who provides different phases, and the elements included. Phase one CR may be provided by cardiac care staff, Phase two by primary care or CR teams, Phase three by specialist CR services and Phase four by fitness instructors, private or council-run gyms, though there are many variations on this model (Lane & Smith, 2010). Some Phase three programmes are run by multi-disciplinary teams, most are run by nurses and 64% have a physiotherapist (BHF Care and Education Research Group, 2012). Payments for nurse-led clinics in primary care are now included in the GP contract as part of the Quality and Outcomes Framework (QOF) (NICE, 2011), and this may encourage a greater preponderance of primary care-based CR.

In summary, CR is clinically effective and cost-effective, but there is variation in the organisation and funding of services, though newly introduced guidance and incentives may improve CR provision. Before discussing the role of continuity of care in service provision, the following section provides an overview of evidence supporting the study of heart patients' attendance at CR and adherence to healthy behaviour.

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<sup>8</sup> SIGN - Scottish Intercollegiate Guidelines Network



## **2.2 Attendance and adherence in cardiac rehabilitation**

### **2.2.1 Cardiac rehabilitation attendance and adherence rates in the UK**

Despite the effectiveness of CR, only 44% of patients with acute myocardial infarction (AMI), coronary artery bypass graft (CABG) or percutaneous coronary intervention (PCI) attended Phase three CR in England, Northern Ireland and Wales in 2010-2011 (BHF Care and Education Research Group, 2012). This has improved from the estimated average of 30% from 2000-2004 (Bethell, Evans, Turner, & Lewin, 2007), but remains well below the 85% target set by the National Service Framework (Department of Health, 2000). Twenty-one percent of patients referred to CR do not participate (BHF Care and Education Research Group, 2012), and varying numbers drop out without completing a programme. Accurate recent UK figures are not currently available, though this is being addressed (Department of Health, 2012). Adherence among patients with chronic conditions drops dramatically after the first six months of therapy (Van Dulmen et al., 2007). High dropout rates are usual in clinical exercise settings, and approach or exceed 50% within six months (Dishman, 1982), a similar rate to that observed in non-medical populations attending gyms (Partington, 2005).

Type of intervention after a cardiac event is one differential between those who do and do not engage with phase three CR. The highest attenders are CABG (74%) and AMI patients (44%) while those undergoing an angioplasty or PCI have the lowest attendance (31%). Reasons for these discrepancies are uncertain, but possibly CABG patients are motivated by their more serious intervention, or patients who appear more motivated, younger or fitter are more likely to be offered a CABG (Bethell et al., 2007). The number of attenders after PCI in different Health Authorities ranges from 12% in North Wales to 46% in North East England (BHF Care and Education Research Group, 2012).

### **2.2.2 Adherence to cardiac rehabilitation recommendations**

The effects of cardiac rehabilitation on outcomes have been discussed above. It is also important to adhere to drug and lifestyle recommendations after a cardiac event, because adherence improves outcomes, particularly over the long term (Horwitz & Horwitz, 1993). Some contend that increasing the effectiveness of adherence interventions may have a greater impact on health than improvements in medical treatments (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008). However, the magnitude of the relationship between adherence and outcomes remains uncertain.

Most studies have examined adherence to medication rather than lifestyle change. In a meta-analysis of 44 prospective studies of patients taking cardiovascular medications, Chowdhury et al (2013) found that 9.1% of all cardiovascular events were attributable to

poor medication adherence, and this was not related to socioeconomic status, polypharmacy or co-morbidity. They estimated that good adherence could be associated with 20% lower cardiovascular risk and 35% reduced risk of all-cause mortality. Another meta-analysis compared drug adherence in various conditions, including eight studies in patients with myocardial infarction (Simpson et al., 2006). Good adherence was associated with lower mortality in all patients, though it varied between conditions. The pooled odds ratio for mortality in participants with good compared with poor adherence was 0.55 (0.49 to 0.62), and 0.52 (0.41 to 0.66) in AMI patients. Both authors note limitations in primary studies, including varying definitions of adherence, insufficient data on individual drugs and doses, and differences in how outcomes are measured. This may lead to attributing outcomes to adherence rather than confounders such as sub-optimal drug doses. Some of these limitations were addressed by Rasmussen et al (2007), who carried out a longitudinal population-based cohort study in older people after AMI, and found that adherence to statins and beta-blockers correlated positively with survival, and this association increased over time. Calcium channel blockers showed no such association with survival.

The relative effectiveness of medication adherence or behavioural adherence is debated (Chowdhury et al., 2013). Simpson et al (2006) concluded that adherence to placebo was associated with reduced mortality, with a pooled odds ratio of 0.45 (0.38 to 0.54) in AMI patients. They speculate that the effects of healthy behaviour might be hidden by the apparent drug effects. One meta-analysis investigated adherence and outcomes in various conditions and concluded that 26% more patients had a better treatment outcome when adherence rates were high (DiMatteo, Giorani, & Lepper, 2002). The risk difference was similar for patients with hypercholesterolemia and hypertension, but non-significant in heart disease patients. However, adherence and outcomes were most closely related in non-drug interventions. The authors suggest that this may be because diet and exercise changes have a powerful effect on health, or because medication effects are variable. Significant benefits in event and mortality outcomes of following healthy lifestyles have been demonstrated in cohort studies in healthy populations (eg. Van Dam, Li, Spiegelman, Franco, & Hu, 2008). Van Dam et al concluded that never smoking, regular exercise, healthy diet and not becoming overweight were significantly related to lower mortality over 24 years. They estimated that 72% of cardiovascular mortality could have been avoided by adherence to these activities. However, studies of cardiac patients have included data from intervention studies rather than general cardiac populations, making it difficult to judge the effect of adherence to healthy lifestyle after a cardiac event.

In summary, current evidence supports the role of adherence to drugs and healthy lifestyle in avoiding adverse events and mortality. Some patients achieve this, but for many it involves lifestyle changes that they find difficult to sustain.

### **2.2.3 Definitions of attendance and adherence**

There is no standard definition of attendance and adherence in previous CR research. Some researchers differentiate between attendance at the first Phase three class (described as uptake, initiation, assessment or enrolment), and other sessions attended, while others use different cut-off points to define attendance or attrition. For example, Clark et al (2004) compared individuals with high attendance (>60% attendance), high attrition (<60% attendance) and non-attendance (0% attendance), while Grace et al (2002) asked whether participants attended no sessions, a few sessions, almost half, most or all sessions. Some researchers also refer to adherence to attendance at phase three or phase four classes, meaning attending most or all sessions. For example, Jackson et al (2005) defined patients' adherence as the percentage of phase three sessions attended, regardless of the length of time required to complete the programme. However, the term 'adherence' is also widely used to mean the longer-term practice of healthy behaviours recommended during the CR timeline. Attendance, adherence to attendance (i.e. the proportion of sessions attended compared to overall possible sessions) or medication adherence may be easier to measure than behavioural adherence, and this perhaps explains the predominance of attendance studies in the extant literature.

In the present work, the focus in Study 1 is on attendance, and is defined as attending one or more Phase three sessions. In Study 2, both attendance and adherence are explored, reflecting variations in a sample of the extant literature. In Study 3, the focus is on attendance and sustained attendance (adherence to attendance) at Phase three classes, but longer-term adherence to healthy behaviour will be included as it arises in discussions.

### 2.2.3 Barriers to attendance and adherence

Many patient and organisational characteristics affecting CR attendance and adherence have been identified (Table 1). Each of these characteristics might be expected to contribute to patients' desire to take action, that is, to be motivated to participate in CR.

**Table 1: Examples of patient and organisational barriers to attendance and adherence**

Patient barriers	Organisational barriers
<p><b>Psychological factors</b>, eg. psychological functioning (Glazer, Emery, Frid, &amp; Banyasz, 2002), perceived control (Barry, Kasl, Lichtman, Vaccarino, &amp; Krumholz, 2006), intentions (Brady, Thomas, Nolan, &amp; Brooks, 2005), self-efficacy (Woodgate &amp; Brawley, 2008), mood (Blanchard, Rodgers, Courneya, Daub, &amp; Black, 2002), perceived severity (Shanks, Moore, &amp; Zeller, 2007), illness perceptions (French, Cooper, &amp; Weinman, 2006), powerlessness to stop disease (Gulanick, Bliley, Peirno, &amp; Keough, 1998), controlled motivation (Mildestvedt, Meland, &amp; Eide, 2008)</p>	<p><b>Non-referral</b> due to eg. physician knowledge (Kemps et al., 2011), referral norms (Grace, Evindar, Abramson, &amp; Stewart, 2004), uncertainty about which provider is responsible for referral (Grace et al, 2004), time constraints (Scott, Lindsay, &amp; Harden, 2003), professionals' beliefs about efficacy of CR (Grace et al., 2004), perceived quality of CR programmes (Grace et al., 2008)</p>
<p><b>Health factors</b>, eg. physical functioning (Brezinka, Dusseldorp, &amp; Maes, 1998), medical complications (Ratchford et al., 2004), multi-morbidity (Evenson, Johnson, &amp; Aytur, 2006), history of heart events (Cooper, Jackson, &amp; Weinman, 2002), sedentary lifestyle (Farley, Wade, &amp; Birchmore, 2003), higher risk factors (Dorn, Naughton, Imamura, &amp; Trevisan, 2001)</p>	<p><b>Communication</b>, eg. with patients speaking different languages (Chauhan, Baker, Lester, &amp; Edwards, 2010)</p>
<p><b>Social needs and roles</b>, eg. marital status (Jackson, Leclerc, Erskine, &amp; Linden, 2005), lack of social support (Van Horn, Fleury, &amp; Moore, 2002), work (Evenson et al., 2006)</p>	<p><b>Access</b>, eg. programme capacity (Gurewich, Prottas, Bhalotra, Suaya, &amp; Shepard, 2008), location of classes (Harrison &amp; Wardle, 2005)</p>
<p><b>Understanding</b>, eg. educational background (Brady et al., 2005), understanding of causes of CHD (Murphy et al., 2005), misperceptions about CR or role of exercise (Cooper, Jackson, Weinman, &amp; Horne, 2005), lack of perceived benefit (McKee et al., 2013)</p>	<p><b>Fragmented care</b>, eg. communication between primary and secondary care (Cupples, Tully, &amp; Dempster, 2010), inconsistent clinical data sharing (Riley et al., 2009), lack of invitation (Melville, Packham, Brown, &amp; Gray, 1999)</p>
<p><b>Quality of life</b>, eg. wellbeing (Komorovsky et al., 2008)</p>	<p><b>Prejudice</b>, eg. age, race, gender (Beswick et al., 2004)</p>
<p><b>Socio-demographic</b>, eg. gender (Bjarnason-Wehrens, Grande, Loewel, Voller, &amp; Mittag, 2007), age (Sundararajan, Bunker, Begg, Marshall, &amp; McBurney, 2004)</p>	<p><b>Design of CR</b>, eg. group format (Farley et al., 2003)</p>
<p><b>Logistics</b>, eg. transport (Doolan-Noble, Broad, Riddell, &amp; North, 2004), distance (Grace et al., 2008), travel time (Bruhal et al., 2010), parking (Tod, Lacey, &amp; McNeill, 2002)</p>	

### ***Patient barriers***

Numerous reasons for CR non-attendance have been reported by patients (Farley et al., 2003), and captured through questionnaires (eg. Whitmarsh, Koutantji, & Sidell, 2003), including demographic, practical, physical and psychological barriers. Research evaluating individual factors has focused on sociodemographic barriers to CR attendance, such as age (Sundararajan et al., 2004). However, this approach does not allow confounding or mediating factors to be taken into account. Focusing on individual factors may also overlook patients' ambivalence when considering whether CR is worthwhile and achievable (Everett, Salamonsen, Zecchin, & Davidson, 2009). Jolly et al (2007) found that diverse multiple factors affect individuals, and other researchers have considered how multiple barriers interact to affect patients' decisions about attending CR. For example, women have sometimes been identified as less motivated to attend than men (Tardivel, 1998). However, several factors may combine to affect this decision. Women may be less inclined to attend as they tend to be older than men when they have a cardiac event, less used to exercise, have more multi-morbidity, greater psychological distress and lower self-esteem (Bjarnason-Wehrens et al., 2007).

It is also difficult to assess the impact of barriers due to conflicting results, from heterogeneous studies. For example, travel time to CR classes is a barrier identified in some, but not all studies (Brual et al., 2010). Brual and colleagues addressed this uncertainty by carrying out a retrospective medical record study using Geographic Information Systems (GIS) to judge distances. They tested the impact of drive-time on referral, enrolment and participation. Results showed that drive-time affected referral and enrolment, concurring with studies using self-report. The study established that 60 minutes or less drive-time predicted enrolment. However, drive-time was unrelated to subsequent participation, suggesting that other factors affected patients' motivation for attendance.

Health factors have also been implicated in CR attendance, but research results are not easy to interpret. A systematic review concluded that patients undergoing angioplasty (PCI) were significantly more likely to attend CR than AMI or CABG patients when assessed with multivariate testing (Cooper et al., 2002). However, this significance was lost on regression analysis, demonstrating that some analysis methods may over-estimate effects. In contrast, Ratchford et al (2004) examined an administrative database and ascertained that surgery or two or more cardiac events within four weeks of the index event were the strongest predictors of attendance. Different research methodologies, patient groups and CR programmes may have influenced the different results in these investigations, and the accuracy and generalisability of the conclusions is unclear.

Social needs and roles have also been shown to act as barriers to attendance. Molloy et al (2008) investigated the influence of stressful marital relationships and social network size on medication adherence and CR attendance. Drug non-adherence was significantly associated with partner stress in the six months before hospitalisation (OR 2.89, 1.21 to 6.95). CR attendance was significantly related to medium and large social network (OR for large network 3.42, 1.42 to 8.25). A further study found that practical rather than emotional support was associated with CR attendance (Molloy, Perkins-Porras, Bhattacharyya, Strike, & Steptoe, 2008). The authors speculate that patients' social environment also influences their beliefs, which in turn affects the likelihood of attending CR. In a later study, Molloy et al confirm the influence of interpersonal processes in the social environment on the cognition and planning that determines physical activity (Molloy, Dixon, Hamer, & Sniehotta, 2010).

Patients' understanding of their condition, or of what CR entails, may also be a barrier to attendance. Cooper et al (2005) conducted a semi-structured interview study with AMI patients after discharge but before CR attendance. Patients who considered CR unnecessary or inappropriate were unaware of the content of CR, did not understand the causes of heart attack or the role of aerobic exercise in recovery, despite having discussed CR with staff. Cooper et al also report that patients who did not expect CR to be helpful were more likely to cite logistical barriers to attendance, implying that these may mask motivational barriers. The authors suggest that misperceptions may relate to illness beliefs. A meta-analysis concluded that illness perceptions (positive identity, controllability or curability, positive consequences and coherence beliefs) predicted CR attendance (French et al., 2006). However, only cure/control remained statistically significant after confounders (small effect sizes, measurement unreliability, unequal numbers of attenders and non-attenders, and wide confidence intervals) were taken into account.

### ***Organisational barriers***

Organisational barriers to CR attendance can be at the level of service provision or policy, or how these are delivered by organisations, or individuals within organisations. Variable service provision is frequently cited in the literature. For example, despite national guidance, 6% of CR programmes did not accept PCI patients in 2010-11 (BHF Care and Education Research Group, 2012). Programme capacity also may not allow all eligible patients to participate. Jennings and Carey (2004) documented a shortfall in CR provision in Ireland, where four hospitals met 90% of their identified need for CR places, while four others met between 35 and 51% of need.

In addition to capacity, Gurewich et al (2008) identified referral systems, the degree of integration of CR services with hospitals, and relationships between CR services as potentially enabling attendance. CR services that networked with each other facilitated referrals for patients living outside their locality, and those located within hospitals were more able to develop links with referring doctors. Gurewich and colleagues also found that staff efforts to invite patients varied as availability of places fluctuated, meaning that some patients were excluded.

Referral has received much attention, with non-referral related to local processes and practice. Doctors' endorsement of CR has frequently been identified as positively affecting uptake (eg. Grace et al., 2008), but non-referral can also be influenced by doctors' beliefs about poor quality of CR services (ibid), or that CR is ineffective (Grace et al., 2004). Doctors' lack of knowledge about CR or adherence to guidelines has also been shown to be an issue (Fernandez, Davidson, Griffiths, & Salamonson, 2010). Clinicians' beliefs about their patients, and communication difficulties, may also affect the decision to refer, and influence patients' perceptions about the service, affecting uptake. For example, patients speaking different languages to the clinician may have difficulty understanding discussions about CR, or feel excluded from a consultation if doctors talk only to their family members (Chauhan et al., 2010). Prejudice may also create barriers to attendance. For example, Allen et al (2004) found disparities in referral and enrolment for African-American women, and women on low incomes, compared to white women on higher incomes.

A recent line of enquiry addressing the issue that CR services are delivered in multiple settings over the long term, shows that fragmented care is associated with non-attendance and discourages adherence to CR recommendations, while continuity of care is associated with attendance (Cupples et al, 2010; Grace et al, 2008; Riley et al, 2007; Riley et al, 2009). For example, Riley et al (2009) found that, out of 50 primary care physicians, only 42% received discharge summaries from CR. Provision of attendance data, clinical information, medication data and recommendations for appropriate behaviour modification was variable in quality. It was also sometimes slow to arrive, reducing practitioners' ability to advise their patients appropriately.

### ***Interaction of organisational and personal barriers***

The interaction between personal and organisational barriers has been explored in few papers. Grace et al (2008) assessed contributions of physician and patient factors, and demonstrated their interaction in relation to suboptimal referral to CR. This was achieved through a nested study of doctors and a sample of their patients. Grace and colleagues concluded that patients may identify barriers during the referral discussion, which then

affects doctors' referral behaviour. Mitoff et al (2005) also examined patient-provider communication in CR referral in a grounded theory study. The authors concluded that patients' perceptions of their illness severity, causal attribution and controllability affected how they interpreted physicians' comments about the need for CR. For example, non-attenders were more likely to not consider their condition serious, and perceived that their doctor felt the same.

#### **2.2.4 Service delivery interventions addressing barriers to attendance and adherence**

Novel ways to deliver CR which meet the needs of patients who do not attend classes have been developed and tested in the UK. The Heart Manual is a comprehensive self-help CR package based on cognitive behavioural techniques, facilitated by a health professional, but used by patients at home (Lewin, Robertson, Cay, Irving, & Campbell, 1992). M. Clark et al (2011) evaluated the effectiveness of the Heart Manual compared with centre-based CR in seven studies, including two RCTs. No significant differences in psychological, social, medical or service delivery issues were identified in the RCTs, though two comparison studies found that Heart Manual patients had significantly more confidence in their recovery, perception of physical progress or believed their illness was controllable. One comparison study found a significant reduction in smoking in Heart Manual patients, while another found that Heart Manual patients reported longer and more frequent exercise. Only one of the RCTs measured adherence, and found that exercise frequency was significantly higher in Heart Manual patients (Jolly et al., 2007).

Other home-based programmes are varied, mostly individually tailored, and some include an initial centre-based session (Dalal, Zawada, Jolly, Moxham, & Taylor, 2010). In Dalal et al's (2010) Cochrane review comparing home-based with centre-based CR, nine RCTs reported adherence data. Adherence was significantly greater in home-based patients in four studies, showed a trend towards higher adherence in two studies, while two studies found no difference between home and centre-based adherence. However, adherence was measured differently in each study, and drop-out rates were inconsistently reported, reducing certainty about these results.

Internet-based programmes mimicking centre-based CR are being developed, though adherence data is not yet available. A Canadian programme aimed at patients in rural areas resulted in similar risk factor improvements to centre-based historical controls in a pilot study (Zutz, Ignaszewski, Bates, & Lear, 2007), and is undergoing further evaluation. In the UK, the 'Activate your heart' programme, managed in primary care, is also being evaluated (Devi, Singh, & Evans, 2012).



Interventions to address fragmented care include nurse-led follow-up in primary care to improve secondary prevention, though few aim to encourage CR attendance. Murchie et al's (2003) RCT tested an intervention in which patients were invited to attend secondary prevention clinics where symptoms, medication and lifestyle were assessed and behaviour change negotiated. Suggested follow-up was two-six monthly over one year. Drug adherence, diet, exercise, blood pressure and lipids significantly improved in the intervention group compared to controls at one year, and were sustained at four years. Jolly et al's (1998) RCT aimed to improve communication between primary and secondary care, and provide structured follow-up. Significantly more intervention than control group participants attended CR, though this study included angina, as well as AMI patients. A recent randomised pilot study evaluated the feasibility of a transition programme after hospital discharge for patients moving to nursing homes or receiving home care (Dolansky, Zullo, Boxer, & Moore, 2011). This used self-management education and low-intensity walking to facilitate recovery, and led to significantly greater CR attendance in the intervention group. However, the feasibility of running the programme in nursing homes was in doubt, as residents were afraid of falling, and staff discouraged them from walking.

### **2.2.5 Interventions to address patients' motivational barriers**

While some barriers to CR attendance (e.g. distance, dislike of groups, multi-morbidity) may be addressed by innovative service delivery, patient barriers have been targeted with interventions, particularly with the aim of engaging patients' motivational resources. These include cognitive, social and emotional prerequisites for action, such as beliefs, perceptions, norms, expectations, intentions or self-regulation (planning and goal-setting), and are based on behavioural and motivational theories, as discussed below. While a few have been effective, many more have resulted in no significant improvement in attendance, so additional approaches need to be evaluated.

Additional studies have aimed to enhance long-term adherence to secondary prevention recommendations, particularly exercise adherence, in patients completing a phase three CR programme. Much of this research is limited by self-reported psychosocial data from moderate-sized convenience samples, meaning that the conclusions may not be reliable (Beckie & Beckstead, 2010). Interventions are often complex, so it is not possible to ascertain which components affect the outcomes, though components may work synergistically (Beckie & Beckstead, 2010)

### **Summary**

In summary, CR attendance is improving in the UK, aided by National guidelines, audits and policies, though provision is still variable. Numerous patient and organisational

barriers to attendance and adherence have been identified, and alternative service delivery approaches have been developed to address these barriers. CR services are delivered in multiple settings over the long term, and fragmented care is associated with non-attendance and discourages adherence to healthy behaviour, while continuity of care is associated with attendance and adherence. However, there is a lack of research investigating the mechanisms by which fragmented care deters attendance, and whether continuity of care can make a difference despite a patient's context and motivational characteristics.

The present project aims to address this knowledge gap by investigating the interaction of continuity of care and patient motivation in encouraging CR attendance, adherence to attendance (sustained attendance), and adherence to heart-healthy behaviour recommendations in the longer term. The rationale for focusing on continuity of care is that CR consists of multiple services provided by different providers over time, and continuity of care within each service, and between them, is considered necessary in order to provide seamless and cohesive care, as outlined in the following section.

## **2.3 Continuity of care**

### **2.3.1 The Continuity of Care model used in the present study**

Concern for continuity in medical specialties has emerged since the 1980s, reflecting increased complexity in managing long term conditions, and delivery of services by different providers (Haggerty et al., 2003). The notion that intermittent or fragmented care for patients is poor practice underpins service evaluation, yet continuity of care (CofC) has proved difficult to define (Reid, Haggerty, & McKendry, 2002). This led the NHS Service Delivery and Organisation (NCCSDO) to commission a scoping exercise to identify definitions and conceptual boundaries, and propose a working definition (Freeman, Shepperd, Robinson, Ehrich, & Richards, 2001). The exercise included a systematic overview of existing literature, a survey of voluntary organisations, communications with researchers, and a conceptual analysis. The authors identified 10 distinct definitions of CofC, of which three were most prevalent (Appendix 1). They recommended a six element definition of CofC: experienced continuity (the patient's experience), continuity of information, cross-boundary and team continuity, flexible continuity, longitudinal continuity, and relationship or personal continuity (Freeman et al., 2001). Meanwhile, a Canadian team carried out a systematic survey of how 'continuity of care' was used in the literature, and discussed the resulting paper at a workshop with researchers and decision-makers (Reid et al., 2002). The Canadians concluded that continuity of care is achieved by bridging elements in the care pathway (different episodes, interventions by different providers, changes in disease status). It includes three key areas: information to support care, therapeutic relationships, and management (structures and care plans) (Haggerty et al., 2003).

In the UK, six primary studies were then commissioned, from which a continuity of care matrix was proposed, amalgamating and rationalising existing models (Freeman et al., 2007). The project team worked closely with Canadian colleagues working on a programme of primary studies for the Canadian Health Services Research Foundation, resulting from Reid et al's (2002) review.

Freeman et al's Continuity of care matrix (Figure 1) was adopted as a framework for the present study for the following purposes: 1) as a benchmark, against which to judge whether care elements constitute continuity; 2) to help identify relevant studies for, and themes from, the Critical Interpretive Synthesis, 3) to aid development of questions for, and themes from, the focus groups. Freeman et al's matrix was selected because it represents the accumulated evidence on continuity of care, which has been scrutinised, evaluated and extended through further empirical research. The matrix has been further

validated (Parker, Corden, & Heaton, 2010). It was developed for use in the UK but resembles the Canadian CofC definition, as the two teams have influenced each other, but come to similar conclusions from different empirical studies and methods. This gives greater confidence in its validity.

**Figure 1: Continuity of care matrix proposed by Freeman et al 2007, and validated by Parker et al 2010**

	<b>Person-focused care</b>	<b>Disease-focused care</b>
<b>Relationship continuity (longitudinal, personal, continuous caring)</b>	<ul style="list-style-type: none"> <li>• Patient provider relationship that spans various episodes and often different care settings or care given by a core group of providers (e.g. home care)</li> <li>• Identified main coordinator of health care (e.g. family physician)</li> </ul>	<ul style="list-style-type: none"> <li>• Consistent with group of providers with clearly defined role (e.g. mental health care team)</li> <li>• Organisational culture responsive to personal needs of patients (e.g. patient care)</li> <li>• Identified main care manager for specific disease (e.g. diabetes nurse, mental health key worker)</li> </ul>
<b>Management continuity (cross-boundary, team care, flexible, seamless service)</b>	<ul style="list-style-type: none"> <li>• Identified main care manager for specific disease (e.g. diabetes nurse)</li> <li>• Co-ordination of care directly affecting patients (e.g. members of individual primary care team or ward based team)</li> <li>• Detection of significant changes in functional status (e.g. severe mental health care)</li> </ul>	<ul style="list-style-type: none"> <li>• Common care plan between providers (shared goals and agreed-on means)</li> <li>• Negotiation of ongoing access to needed services (e.g. long-term community mental health care)</li> <li>• Inclusion of patients as partner in the management plan (e.g. diabetes care)</li> </ul>
<b>Informational continuity</b>	<ul style="list-style-type: none"> <li>• Accumulated knowledge – often tacit – of values and personal circumstances of the patient (e.g. palliative care or psychosocial problems)</li> <li>• Up-to-date record of care and test results available at point of service (primary health care)</li> <li>• Patient and family included in information loop (e.g. follow-up cancer care)</li> </ul>	<ul style="list-style-type: none"> <li>• Information transfer between different providers (hospital discharge to community care)</li> <li>• Up-to-date record of past service and results available at point of service (e.g. maternity care)</li> <li>• Consistency of messages communicated to patient (e.g. self-management of diabetes)</li> </ul>

Note: this figure is reproduced from: Parker et al, Synthesis and conceptual analysis of the SDO Programme's research on continuity of care: Executive summary for the National Institute for Health Research Service Delivery and Organisation programme, 2010, p.12.

### 2.3.2 Continuity of care in cardiac rehabilitation

CR services can be delivered by different providers at each of the four phases (2.1.2), and continuity of care within each service, and between them, is considered necessary in order to deliver the recommended services effectively (Department of Health, 2010a; NICE, 2011). Continuity may also encourage patients to see CR as an essential part of recovery (Arena et al., 2012).

Patient perceptions of continuity, and their relation to cardiac rehabilitation participation, have been investigated. A two-stage survey of 506 acute coronary syndrome patients in Canada, using the Heart Continuity of Care Questionnaire (Hadjistavropoulos, Biem, & Kowalyk, 2004) identified discontinuity regarding outpatient visits and prescriptions (Riley et al., 2007). Correlates of perceptions of continuity of care after nine months were CR participation, greater tangible support, and less serious perceptions of illness consequences at the time of acute coronary syndrome. However, there is limited existing research that is explicit about the constituents of continuity of care in cardiac rehabilitation. The present project aims to address this by identifying CofC elements in existing literature (Chapter 4) and through focus groups (Chapter 5), and mapping them to Freeman et al's Matrix (Figure 1).

The aim of mapping is to ensure that the present project uses and builds on previous understandings of continuity, by identifying elements that fit this model. Elements that are considered to be part of continuity which do not fit the model will be proposed as additions to the model. Elements will be mapped to the Matrix by considering where they fit best. For example, Jolly et al's (1998) nurse-led intervention aims to bridge a gap between two services using a liaison nurse. Although this paper does not explicitly refer to continuity of care, the liaison nurse role could be considered relationship continuity (mapping to 'patient provider relationship that spans various episodes' in Figure 1). In terms of management continuity, the aim of the intervention could be considered to be about 'Co-ordination of care directly affecting patients' in Figure 1. Informational continuity may be one of the liaison nurse's roles ('Information transfer between different providers' in Figure 1). The effect of these elements on patient motivation for cardiac rehabilitation will then be explored. In the cross-sectional study (Chapter 3), the Heart Continuity of Care questionnaire (Hadjistavropoulos et al., 2004) will be used to measure perceived continuity and Freeman's Matrix will be referred to in interpreting the results.

The previous sections have outlined the evidence and knowledge gaps around barriers to CR attendance and adherence to healthy behaviours, and particularly the relevance of fragmented service provision and continuity of care. A number of patient characteristics, including intentions, self-efficacy and illness perceptions have also been outlined, which

can be considered motivational barriers to attendance. The present work focuses on patient motivation because this is expected to drive the decisions and action required to ensure CR attendance, continued attendance, and adherence to heart-healthy behaviours after phase three. The following section introduces the rationale for using a theoretical framework to guide the present work, and introduces behaviour change theories that have contributed to understanding patient motivation for CR attendance and adherence.

## ***2.4 Understanding motivation for attendance and adherence in cardiac rehabilitation: the contribution of behaviour change theories***

According to Michie and Prestwich (2010), the development of effective interventions to encourage healthy behaviours needs a reliable theoretical foundation, because this enables a systematic approach to identifying and testing hypothesised constructs and processes. It also allows evidence to be compared across different contexts and aids understanding of change mechanisms. Interventions using theory more explicitly have been shown to be more effective (Taylor, Connor, & Lawton, 2012). While standalone interventions may be effective, without a theoretical foundation it may be difficult to ascertain why they are effective, how they work, or to justify their application. Theoretical frameworks provide a way of using existing theories to organise and communicate observations in new research, showing how new findings fit into existing knowledge and clarifying future research directions (Dunn & Elliott, 2008).

Patients who do not engage with cardiac rehabilitation have often been perceived as 'unmotivated', though the definition of motivation is debated (Maclean & Pound, 2000). Resnick (2002) summarises the critical attributes of motivation as internal desires followed by action to achieve a goal. This broad definition is reflected by many theorists, though they vary in how far motivation is considered to derive from individuals' personalities, social influences or a mixture of the two (Maclean & Pound 2000). Patients offered cardiac rehabilitation sometimes respond that they are 'not interested' (eg. Kerins, McKee, & Bennett, 2011), and health professionals may interpret this as a lack of motivation. However, lack of interest may mask various motivations, such as not perceiving that CR will meet their needs, fear of failure or triggering another cardiac event, but these are not well explored.

More than 80 behaviour change theories exist (Michie et al., 2014), and have been enlisted to try to understand and influence patients' perceptions and motivation. Of these, the most prevalent in CR uptake and adherence intervention research are cognitive, self-

regulatory and stages of change theories (Karmali et al., 2014). Many theories do not explicitly measure motivation, but can contribute to better understanding of the psychological antecedents and expected outcomes of motivation (Dixon, 2008). For example, Social Cognitive Theory (SCT) considers that goal attainment requires positive self-regulation, commitment, self-evaluations of progress, evaluation of goal difficulty, beliefs about the expected outcomes of actions, values and comparisons with other people. Together these elements are considered to sustain motivation (Schunk & Usher, 2012).

The evolution of multiple theories has resulted in the development of different models with many similarities but a lack of standardised terminology and this may result in confusion about the processes and mechanisms of behaviour change, and difficulty in designing effective interventions (Michie et al, 2013). For example, Self-efficacy (SET; Bandura, 1977a), a sub-set of SCT, derives from Social Learning Theory (SLT; Bandura, 1977b), and has been incorporated into other models, including the Transtheoretical Model (TTM; DiClemente, Prochaska, Velicer, Rossi, & Velasquez, 1991) and the Health Action Process Approach (HAPA; Schwarzer, 1992). SET proposes that adoption of an activity is determined by the perceived ability to execute specific tasks (eg. walk or jog) and the perceived consequences of engaging in the activity (eg. enjoyment, improved fitness). Expectations of self-efficacy come from how well one performs a task, vicarious experience, verbal encouragement and emotional responses. Behavioural control, one aspect of the Theory of Planned Behaviour (TPB; Ajzen, 1991) also resembles self-efficacy, as it is the perceived ease of performing an activity (Munro et al., 2007). TPB is a social cognitive extension of the Theory of Reasoned Action (TRA; Fishbein & Ajzen, 1975). Some commentators also consider self-efficacy to be similar to sense of competence within self-determination theory (SDT; Deci & Ryan, 2000), which refers to the perceived ability to carry out activities, and can be encouraged by positive feedback from others. The relevance of self-efficacy or behavioural control for CR lies in the notion that CR patients anticipate the skill required (e.g. to exercise), and how much they will benefit from participation, though Rothman's behaviour change model suggests that self-efficacy becomes less able to predict behaviour as people try to maintain the behaviour, or it becomes more difficult (D'Angelo & Reid 2007).

More than one theory includes the concept of intention as an antecedent to action. TRA considers that intentions are the main determinant of behaviour, and that intentions are influenced by attitudes and beliefs about an activity and its outcome, while HAPA incorporates elements of TPB, including outcome expectancies and perceived self-efficacy, which are considered to combine to predict intentions. While intention to attend CR or adhere to healthy behaviours might be considered a prerequisite for attendance

and adherence, other cognitive, emotional or practical demands might be expected to prevent its translation to action. For this reason, HAPA incorporates volition theory (Heckhausen, 1991), in which people use processes to achieve their goals, including planning, envisaging the desired future situation and actions needed to attain it, self-efficacy to judge the required effort, then self-regulation (or action control) which consists of self-monitoring, social comparison and effort.

Although TTM differs from other theories as it is a heuristic model of the whole change process, it is also, like HAPA and volition theory, concerned with people's intentions and behaviour and includes cognitive strategies including conscious learning to support new behaviours. TTM proposes that people are at different stages of change, and that they use 10 processes of change to help themselves progress through these five stages: pre-contemplation, contemplation, preparation, action and maintenance, though they may also relapse to earlier stages. TTM resembles cognitive theories in its focus on reflective self-evaluation, which includes seeing personal change as an important part of one's identity, and this is also reminiscent of SDT, which posits that humans have a natural tendency towards personal growth. TTM also reflects the idea in SDT that non-controlling support helps people to achieve their goals, as one strategy for change in TTM is to seek non-controlling support. The concepts of self-evaluation and natural motivation for self-improvement are pertinent to CR in that patients might be expected to want to recover from their cardiac event or intervention and reduce the likelihood of further events (Thow et al, 2008).

HAPA, similarly to the Common Sense Model (CSM; Leventhal, Meyer, & Nerenz, 1980), a self-regulation theory, considers that, as well as weighing up their ability and anticipated outcomes of activities, people consider the risks and benefits of health behaviour change. CSM differs from cognitive models in incorporating emotional illness perceptions, though it posits that these interact with coping mechanisms which are essentially cognitive. In CSM, cognitive representations include identity (symptoms or information), cause (attribution), timeline (how long the illness will last), consequences and controllability /curability. CSM is relevant to CR in that patients may assess their symptoms, information they receive from health professionals and other sources, the causes of their cardiac event and the long-term effects and possible solutions, and these rationalisations are coloured by emotional responses to the illness and its impact. In addition to personal cognitive or emotional responses, some theories incorporate social dimensions. For example, TRA includes people's perceived expectations of others in the social group (subjective norms), and the degree of motivation to meet those expectations. Social norms may not include mixed-gender exercise, or exercise for older women for example, and this might be expected to influence patients' motivation for CR attendance.



## **Motivational mediators of CR attendance and adherence to recommended healthy behaviours**

Social cognitive theories in particular contribute to understanding behaviour change processes in cardiac rehabilitation, either by comparing characteristics of attenders and non-attenders, or as a basis for interventions and outcome measures. SET is frequently measured in studies of CR attendance and adherence and different types of self-efficacy have been shown to be related to different outcomes. For example, Maddison and Prapavessis (2004) found that barrier efficacy (ability to overcome barriers) at the start of a CR programme was associated with attendance, while task efficacy (ability to perform a task) was not. However, although SET might affect initiation of CR, it appears to fluctuate over time and is not necessarily predictive of adherence, as suggested by Rothman (2000). In Butler and colleagues' intervention study of post-CR exercise adherence, for example, intervention patients spent significantly more time exercising and had more walking sessions at six weeks and six months, but their exercise self-efficacy was not significantly greater at six weeks or six months compared to controls (Butler, Furber, Phongsavan, Mark, & Bauman, 2009). Such a finding suggests that adherence was encouraged by factors other than self-efficacy.

Constructs from TPB, specifically subjective norm, attitude and perceived behavioural control have also been shown to predict CR attendance (Johnston, Earll, Pollard, Giles, & Johnston, 1999) but also to predict exercise adherence in CR attenders (Blanchard et al., 2003). Blanchard and colleagues found that together these constructs explained 30% of the variance in exercise intention. Intention explained 12-23% of the variance in exercise compliance. Intention to exercise for a specific number of times per week over a number of weeks also contributed to predicting CR attendance in Maddison and Prapavessis' (2004) study, perhaps suggesting that participants used CR attendance as a strategy to help them to achieve their exercise goals, as well as a goal in itself. Also, McKee (2013) found that 80% of patients intending to attend CR did so, but 44% of those with no intention also attended. This may indicate that intention changes over time or just that cognitive theories predict active behaviour, but are less adequate to explain inactive behaviour (Sorensen, 1997).

Characteristics of attenders and non-attenders have been compared using CSM in several studies, and face-to-face nursing interventions to encourage attendance based on CSM have been evaluated. Broadbent and Petrie's (2009) RCT tested a tailored illness perception intervention during hospitalisation. Intention to attend CR was higher in the intervention group than controls, but attendance was not significantly different between groups. Nevertheless, intervention patients gained a greater understanding of

their condition, did significantly more exercise and had a healthier diet at three and six months follow-up. In a similar study, Cossette et al (2012) found significantly greater attendance in intervention patients, but no significant difference in exercise or diet between groups. These conflicting results suggest that patients' perceptions may fluctuate over time, making it difficult to draw conclusions based on these measures.

TTM has shown promise in explaining CR and exercise adherence. Being in later stages (preparation, action and maintenance) has been associated with completing Phase three CR (O'Brien, Thow, & Rafferty, 2009) and with maintaining exercise post-CR (Hellman, 1997). Interventions based on TTM have shown some promise both during Phase three (Beckie & Beckstead, 2010), and Phase four (Moore et al., 2006; Pinto et al., 2011). Beckie and Beckstead's RCT compared a gender-tailored intervention delivered with a motivational interviewing counselling style, with standard CR. The intervention group attended significantly more CR exercise and education sessions. However, these interventions were complex, so it is not possible to ascertain which components affected the outcome, though the authors suggest that the components synergistically improved adherence to attendance.

Dohnke et al (2010) measured HAPA constructs six months after the end of Phase two (T1), which consisted of short-term inpatient rehabilitation. They found that Phase three attenders (T2) had higher self-efficacy for regular attendance, positive outcome expectations and decreasing negative outcome expectations. Patients with low intention and maintenance self-efficacy at T1 were more likely to drop out by T2. Several intervention studies have operationalised HAPA. For example, Sniehotta, Scholz and Schwarzer (2006) compared action planning (when, where and how patients intended to exercise) with combined planning (action planning plus three coping strategies to overcome anticipated barriers). Facilitators were trained to guide planning in a non-directive way. Only the combined planning group did significantly more exercise, and adhered to exercise recommendations two months after CR. The intervention explained 9% of the variance in exercise. Sniehotta et al (2010) also found that action planning and intention predicted Phase four CR attendance, but only perceived behavioural control predicted exercise. The authors suggest that the cyclical nature of cardiac symptoms reduces exercise adherence despite planning and intention.

As outlined above, disadvantages of social cognitive models include their focus on proximal factors affecting behaviour, with limited consideration of social, cultural and personality factors (Sutton 2002), and this may be particularly pertinent when behaviour needs to be maintained (Rothman 2000). The impact of staff patient relationships, which are fundamental to the delivery and acceptance of behaviour prescriptions in healthcare

(Thom, 2001), and in cardiac rehabilitation, is not considered in these models. Cognitive models also focus on only some aspects of change processes, so that their contribution to behaviour change in applied situations may be modest (Noar & Zimmerman, 2005).

### **Summary**

In summary, research based on behaviour change theories has identified some motivational mediators (self-efficacy, intention, subjective norm, perceived controllability/curability, action planning, coping strategies) that predict which patients are more likely to attend CR or adhere to recommendations, and interventions based on these models have improved attendance and adherence somewhat. However, it is uncertain how mediators change over time, whether additional elements contribute to patient motivation and how mediators are affected by social context. Theoretical concepts may also be hard to operationalise, so that interventions may not enhance the behavioural mechanism that is intended, and interventions are often complex so it is difficult to ascertain which component affect outcomes, and whether components synergistically improve attendance or adherence. Additional approaches therefore need to be evaluated to inform the development of interventions with the potential to promote patient motivation for attendance and adherence. The next section introduces the central tenets within SDT, the theoretical framework that guides the study of patient motivation in the present work.

## **2.5 Self-determination Theory**

### **2.5.1 Self-determination theory as the theoretical framework in the present study**

In the present study, Self-determination Theory (SDT) will be used as the theoretical framework to fulfil the roles that Michie and Prestwich (2010), and Dunn and Elliott (2008) outlined (2.4). SDT guides the selection and testing of motivational elements, and aids the discussion about their interaction with continuity of care, in a cross-sectional survey (Chapter 3). It also aids the interpretation of observations in a Critical Interpretive Synthesis (Chapter 4) and Focus groups (Chapter 5).

Self-determination theory is particularly applicable as a framework for the present studies. Unlike other motivation theories, which predict the amount of motivation, SDT predicts the quality of motivation (Deci & Ryan, 2012). This allows nuances of motivation for behaviour to be explored. SDT is also more complex than other motivation theories, and considers interactions between personal attributes, external influences and social contexts (Deci & Ryan, 2012). Therefore it is relevant to cardiac rehabilitation, a social

context in which patient motivation is not fully understood, and where there is limited existing research on the interaction between patient and organisational factors. SDT is empirically derived, and widely tested in health behaviour change (Fortier, Williams, Sweet, & Patrick, 2009), exercise (Teixeira, Carraca, Markland, Silva, & Ryan, 2012) and other settings (eg. Deci, Connell, & Ryan, 1989; Deci, Vallerand, & Pelletier, 1991), giving it credibility as an explanatory and predictive theory. In a meta-analysis, Ng et al (2012) concluded that SDT is a viable conceptual framework for the study of antecedents and outcomes of motivation for health behaviours. SDT has also previously been applied in cardiac rehabilitation, where it is starting to contribute to an understanding of patient motivation (D'Angelo, Reid, & Pelletier, 2007; Mildestvedt & Meland, 2007; Mildestvedt, Meland, & Eide, 2007; Mildestvedt et al., 2008; Russell & Bray, 2009; Russell & Bray, 2010; Sweet, Tulloch, Fortier, Pipe, & Reid, 2011; Thow, Rafferty, & Kelly, 2008).

### **2.5.2 Outline of Self-determination theory**

SDT is a meta-theory of motivation and personality that has evolved as a set of five mini-theories, and considers interactions between personal attributes, external influences and the social context (Ryan & Deci, 2002). SDT accepts that humans have an innate tendency for growth (personal and social), but also suggests that specific social factors support or thwart this tendency (ibid).

#### ***The five mini-theories***

**Cognitive evaluation theory (CET)** addresses the effects of social contexts on intrinsic motivation. CET assumes that people need to feel autonomous and competent, and factors within the social context promote these feelings (eg. optimal challenges, positive feedback), enhancing intrinsic motivation. Factors that undermine these needs (eg. rewards contingent on success) leave people feeling externally motivated or amotivated (Gagne & Deci, 2005).

**Organismic integration theory (OIT)** addresses the concept of internalisation. This refers to the extent to which people integrate social norms and rules into personal values and self-regulations in order to develop their sense of self within their social context. People show different degrees of internalisation of behaviours on a continuum from the least autonomous (external regulation), through partially internalised (introjected regulation), understanding and endorsing the value of a behaviour (identified regulation), assimilation of values and goals (integrated regulation) to the most autonomous (intrinsic regulation) (Vansteenkiste, Niemiec, & Soenens, 2010).

External regulation occurs when a person acts to get a reward, avoid punishment or comply with social pressures. In health care this includes professionals suggesting

incentives or using authority to motivate. Introjection, where patients act to receive praise or avoid disapproval or guilt, may also be encouraged by health professionals. These controlled behaviours are unrelated to long-term adherence (Ryan, Patrick, Deci, & Williams, 2008). However, in the short term they can be motivating, so may be important for patients initiating CR.

Autonomous motivation includes identified regulation, when patients identify with the value of a behaviour, and integrated regulation, when patients include it among their own values and lifestyle choices. Practitioners encourage identified regulation by providing information and rationales for behaviour change, without pressurising. They help patients to integrate change by supporting them as they work out how to overcome barriers to change (Ryan et al., 2008).

Autonomous engagement in an activity, and the maintenance of the behaviour, is a function of patients internalising both values and skills relating to it. This results in a sense of self-determination. Autonomous behaviours are those in which people have a sense of choice and intention and act because the behaviour is important to them (Williams, Ryan, Rodin, Grolnick, & Deci, 1998). An understanding of internalisation processes is therefore relevant when investigating patients' motivation to participate in CR, and to adhere to recommended healthy behaviours.

**Causality orientations theory** (COT) describes people's tendency to consider their actions to be controlled (i.e. regulated) by themselves or by external events. This affects how people respond to their environment to support their own self-determination. People who consider that actions come from themselves are likely to be intrinsically motivated, while those who experience action as contingent on external control are likely to act when external regulations are in place (Hagger & Chatzisarantis, 2011).

**Basic needs theory** (BNT) conceptualises needs in relation to psychological health and well-being. SDT suggests people have three innate psychological needs: autonomy, competence, and relatedness to others (Ryan & Deci, 2002). Greater need satisfaction leads to better quality, or autonomous, motivation.

Sense of competence is important in enabling internalisation of change, and is supported by sense of autonomy. Practitioners encourage this by helping patients to learn, and giving feedback about their progress.

Internalisation of behaviour change is enhanced by developing a trusting relationship in which there is mutual respect, care and understanding (Ryan et al., 2008). It creates an

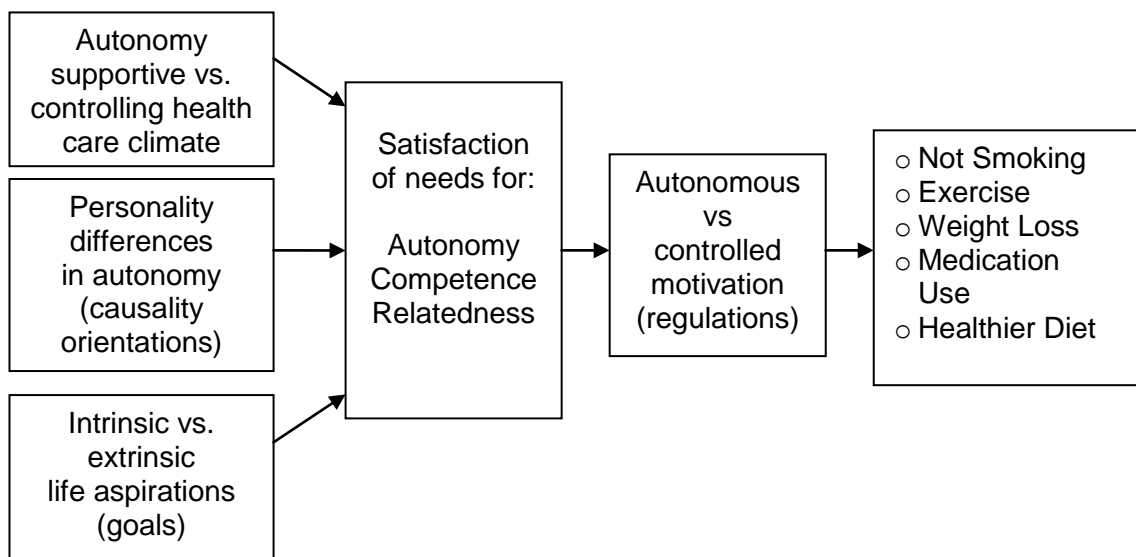
environment in which patients are more open to information, and practitioners offer guidance. Patients' knowledge and understanding of their health status, CHD and CR affects their initiation of CR. The quality of practitioner-patient relationships seems likely to impact on this.

**Goal content theory (GCT)** considers the degree to which goals are intrinsic or extrinsic. Intrinsic goals promote personal growth through satisfaction of basic needs, and extrinsic goals aim to promote status but without need satisfaction. Intrinsic goals are more closely related to wellbeing and positive health outcomes (Sebire, Standage, & Vansteenkiste, 2011).

***How SDT has been applied in previous health behaviour studies***

In existing healthcare studies, SDT has been applied to explain and predict differences in behaviour change, adherence, and the processes that precede change (Figure 2).

**Figure 2: Self-determination Theory Model of Health Behaviour Change**



Note: Aadapted from Ryan et al (2008) and Teixeira et al (2012). Five groups of variables involved in SDT health process models. Some of the direct and indirect steps in this simplified model have been tested, and a few examples are given below.

Previous research includes cross-sectional and longitudinal surveys examining relations between SDT constructs and health outcomes (Ng et al., 2012). Some have investigated interactions between SDT and constructs from other behavioural theories, particularly self-efficacy (eg. Markland & Tobin, 2010). Also, SDT-based interventions have been tested in clinical trials, in particular examining the effects of encouraging practitioners to support patients' psychological needs (Ng et al., 2012).

## **Understanding motivation for healthy behaviour: the contribution of Self-determination theory**

A body of research in clinical settings supports the theory that autonomous regulation predicts healthy behaviour, while controlled regulation may only predict short-term adherence. For example, autonomous regulation predicted attendance at an obesity programme (Williams, Crow, Freedman, Ryan, & Deci, 1996), medication adherence (Williams et al., 1998) and improved glucose control (Hb1ac) among diabetic patients (Williams, Freedman, & Deci, 1998). Williams et al (2004) then found that increasing autonomous regulation over time predicts improving glycaemic control. Increasing personal autonomy also predicted healthier diet and exercise over three years in patients tested for CAD (Williams et al., 2005), and smoking cessation in intervention research (Williams et al., 2006). These findings are important because they suggest that delivering health services in a way that supports autonomous regulation may encourage patients to internalise the values pertinent to adopting healthy behaviours.

Satisfaction of the three basic psychological needs, autonomy, competence and relatedness, has been positively associated with self-determined (autonomous) motivation and healthy behaviour, particularly in relation to exercise adherence. For example, need satisfaction predicted self-determined regulation among obese patients prescribed exercise (Edmunds et al., 2007), and female exercise referral participants (Markland & Tobin, 2010), and need satisfaction and autonomous motivation were associated with exercise in these studies. Research has also established that an autonomy-supportive interpersonal style from health professionals is positively related to autonomous self-regulation, for example in a study with diabetic patients (Williams et al., 2009), and in a physical activity intervention study (Fortier, Sweet, O'Sullivan, & Williams, 2007). In both these studies autonomous regulation predicted perceived competence, which predicted medication adherence and exercise respectively. Edmunds et al (2007) also found that relatedness need satisfaction increased in participants with greater exercise adherence, though Markland and Tobin (2010) found that personal relatedness was associated with greater introjected regulation.

Autonomous causality orientations have also been found to be associated with autonomous behaviours, including weight loss in obesity (Williams et al., 1996) and lifestyle change in chest pain (Williams et al., 2005). However, there is a lack of intervention studies, perhaps because it is easier to change practitioners' interpersonal style than patients' personality traits (Sheldon, 2003).

The relationship between intrinsic goals, behavioural regulation and exercise adherence has been studied in young people (Gillison, Standage, & Skevington, 2006) and healthy populations (Ingledew & Markland, 2008; Sebire et al., 2011). For example, Gillison and colleagues found that intrinsic goals, such as health and enjoyment predicted self-determined motivation, which positively predicted exercise, while extrinsic goals such as weight control and attractiveness negatively predicted self-determined motivation. SDT interventions may help to perpetuate intrinsic health aspirations, encouraging, for example, long-term tobacco abstinence (Niemic, Ryan, Deci, & Williams, 2009). This approach may be applicable to other health-promoting settings, though further research is needed.

### **Studies examining SDT constructs in cardiac rehabilitation**

CR studies using SDT have investigated some aspects of the process model (Figure 2), though further interactions remain to be examined. D'Angelo et al (2007) investigated interactions between heart patients' general tendency to be more or less autonomous (degree of internal or external regulation), tendency to be more or less autonomously motivated in exercise, and their self-efficacy around intentions and planning to exercise. Patients were recruited from a tertiary-care cardiac centre, but it is unclear whether they had started attending an exercise-based CR programme. The authors concluded that greater self-efficacy gives patients sufficient competence to initiate exercise behaviour, while more self-determined motivation drives exercise maintenance. Nevertheless, exercise was not measured, limiting the clinical application of the results.

Russell et al (2009) examined interactions between need satisfaction (autonomy, competence and relatedness), degree of autonomous or controlled regulation, and exercise. Sixty-eight patients were recruited after completing a CR programme, and followed a six week continuation programme. This consisted of either 12 exercise sessions, or 9 exercise and 3 group cognitive-behaviour for exercise sessions. Autonomous motivation for exercise was measured after the last session, and was related to amount of exercise three and six weeks after completing the continuation programme. Need satisfaction for autonomy and competence were related to autonomous motivation, although after multiple regression only competence independently predicted self-determined motivation. Russell and colleagues point out that autonomy and competence are highly correlated, and conclude that greater feelings of competence may have encouraged a sense of autonomy.

Sweet et al (2011) used latent class growth modelling to classify CR attenders according to their exercise and motivational patterns. Participants were 251 patients enrolled in the Tracking Exercise After Cardiac Hospitalization study (Reid et al., 2006). Patients



categorised as having more self-determined motivation were more likely to increase and maintain exercise over two years, while those with less self-determined motivation were unlikely to increase and maintain exercise levels. Outcome expectations also contributed to exercise maintenance, with those with low expectations and those with moderate expectations that decreased over six months having no probability of maintaining exercise.

### **SDT studies examining organisational and patient interactions in cardiac rehabilitation**

SDT research has also addressed the interaction of patient and organisational factors (specifically autonomy support). Williams et al (2005) examined the relevance of SDT in predicting health behaviour change in 390 patients undergoing diagnostic testing for heart disease. Patients' perceptions of doctors' autonomy support at three year follow-up was related to increasingly autonomous motivation over time, and this predicted improving diet and exercise. Although patients became less autonomously motivated three years after their initial chest pain, those with test results suggesting a higher likelihood of heart disease maintained greater autonomous motivation for healthy lifestyle. Russell and Bray (2010) also found that perceived autonomy support correlated with self-determined motivation for exercise among 53 male CR participants. Self-determined motivation predicted exercise volume and duration 10 weeks later but was not related to CR attendance. The authors attribute this to high attendance among participants, though research is needed to explore this further.

Mildestvedt et al's (2007; 2008) RCT compared standard CR with CR plus individual lifestyle counselling, based on SDT and Social Cognitive theory (Bandura, 1997) in 176 inpatient CR attenders. The intervention aimed to increase patients' self-efficacy and autonomous motivation through autonomy-supportive counselling. Significant improvements in exercise resulted after two years, but no significant differences in diet maintenance, smoking status, exercise capacity, intensity or amount were found between the groups after six or 24 months. Autonomous motivation predicted increased exercise and low saturated fat diet, but autonomy support had no additional effect on outcomes. The authors suggest this may be due to participants already being motivated for long-term adherence or to intervention and control groups attending the same group-based programme. Further studies are needed to better understand the role of autonomy support in CR.

## ***Summary***

Self-determination theory is a meta-theory with empirical foundations which has the capacity to identify and predict relationships between peoples' psychological characteristics and social contexts. There is a strong foundation of cross-relational, longitudinal and intervention studies using SDT in secondary prevention in healthcare and exercise settings, giving it credibility as a theoretical framework. In the present study SDT will allow a consideration of whether continuity of care can make a difference to attendance and adherence despite a patient's characteristics.

## ***2.6 Conclusion***

In this chapter, the theoretical background and justification for the investigation of continuity of care and patient motivation for cardiac rehabilitation attendance, and adherence to healthy behaviour recommendations has been outlined. The context of the project, specifically the rationale for cardiac rehabilitation and its structure and constituents within the NHS were introduced. The concepts of attendance, sustained attendance, and adherence to healthy behaviours were defined, and the mismatch between national attendance targets and actual attendance outlined. Evidence was presented for specific patient and organisational barriers to attendance and adherence, and the focus on the interaction between patient and organisational barriers in the present work was justified based on the limited existing research assessing their interaction. The rationale for the focus on continuity of care in the present project derives from the line of enquiry demonstrating the effects of fragmented care on non-attendance and continuity of care on attendance, but raising questions about how this affects patients' behaviour. The rationale for the focus on motivation in the present project derives from the idea that patients require drive to actively engage with CR and do so for a multitude of reasons. Therefore, behaviour change theories were outlined and antecedents to patient motivation from these theories were considered. SDT, a human motivation theory, was introduced as the guiding framework for this work, given its empirical support and explanatory power in the health and exercise domains. Research investigating the interaction between continuity of care and patient motivation is lacking, and establishing such a link may indicate potential directions for interventions to encourage attendance and adherence.

## **2.7 The research question**

The three empirical studies reported in the present thesis contribute to the body of research seeking to explain why cardiac rehabilitation is underused, despite evidence that it is clinically and cost-effective, and despite National guidance (BACR, 2007; Department of Health, 2000; NICE, 2013; Scottish Intercollegiate Guidelines Network, 2002). The study also aims to provide a practical outcome, through the development of a model to inform service design to increase uptake and adherence to cardiac rehabilitation, for the benefit of patients. Many studies have identified elements that affect patients' decisions to participate in cardiac rehabilitation, but few have explored 'continuity of care', and none has explored whether lack of continuity has a negative effect on patient motivation to follow cardiac rehabilitation recommendations in the UK.

### **2.6.1 Aims and objectives**

This project aims to examine how 'continuity of care' in cardiac rehabilitation affects patients' motivation to initiate and maintain cardiac rehabilitation recommendations.

The objectives are:

- To empirically test a theoretical model of continuity of care, autonomy support and self-determined motivation in patients who have undergone a percutaneous coronary intervention and are eligible for cardiac rehabilitation;
- To carry out a Critical Interpretive Synthesis (CIS) of existing literature to identify factors that clarify the relationship between 'continuity of care' and patients' motivation to engage with cardiac rehabilitation, interpreted using self-determination theory;
- To carry out focus groups with cardiac rehabilitation patients to explore factors affecting perceived continuity of care and motivation;
- To carry out focus groups with cardiac rehabilitation professionals to explore barriers to providing continuity of care, and perceived results of continuity of care;
- To develop a model of the relationship between continuity of care and patient motivation to uptake and adhere to cardiac rehabilitation, based on the results from the three studies, to be tested in future research.

## **Chapter 3: Test of a model of continuity of care and motivation for cardiac rehabilitation using Partial Least Squares Structural Equation Modelling (PLS-SEM)**

Study 1, reported in this chapter, addresses the first objective of the present project. This study sought to establish whether the hypothesised relationship between continuity of care, an autonomy supportive healthcare context, and patient motivation for cardiac rehabilitation exists. This hypothesis is based on the previous research and theory outlined in Chapter 2.

### ***3.1 Introduction***

Cardiac rehabilitation (CR) is effective in preventing further cardiac events and mortality after treatment for an acute coronary event (Clark et al., 2005; Heran et al., 2011; O'Connor et al., 1989; Taylor et al., 2004), and is recommended by NICE for patients recovering from acute myocardial Infarction (AMI), coronary artery bypass graft (CABG) or percutaneous coronary intervention (PCI), (NICE, 2011; NICE, 2013). However, many people do not attend, particularly patients who undergo a percutaneous coronary intervention (PCI). In the UK, only about 31% of those with a PCI attend cardiac rehabilitation programmes (BHF Care and Education Research Group, 2012).

Although patient and organisational barriers to CR attendance have been identified (Beswick et al., 2004), few previous studies have investigated the interaction of patient and organisational factors, and how they affect attendance. Continuity of care is one aspect of service delivery with a potentially positive effect on CR participation (Riley et al., 2007), though it is uncertain how continuity of care interacts with patient characteristics. The present study addresses this knowledge gap. Motivation research can contribute to this by clarifying the mechanisms underlying patients' behaviour (Patrick & Williams, 2012), and providing a reliable theoretical foundation on which effective policies and interventions can be based (Michie & Prestwich, 2010). Motivation is frequently referred to in the literature as a requirement for patient engagement with CR, and many theory-based psychological antecedents of motivation have been measured or used to design interventions to increase attendance (eg. self-efficacy, planned behaviour).

In the present work, a contemporary meta-theory of human motivation that takes into account the social context and its effects on psychological antecedents of motivation was considered particularly relevant as CR is a social (healthcare) context which aims to influence patients' motivation to adopt and adhere to healthy behaviours. Therefore, tenets and phenomena from self-determination theory (SDT; Deci & Ryan, 1985; Deci & Ryan, 2000) were used as a basis for the present study. A SDT approach has been used

in many contexts, including healthcare (eg. Williams et al., 2006), heart disease (eg. D'Angelo et al., 2007) and more recently in CR (Mildestvedt et al., 2007; Mildestvedt et al., 2008; Russell & Bray, 2010; Sweet et al., 2011). In the latter examples, SDT has been used to help explain and understand service-patient interactions. Taking the collective contribution of previous studies into account, SDT was considered an appropriate framework for the present study. SDT was used to inform the development of a process model which examines whether service delivery (perceived continuity of care during the rehabilitation timeline after a PCI) and quality of staff interaction with patients (autonomy support) are implicated in the quality of patients' motivation for CR.

Continuity of Care (CofC) is a model that describes three facets of service delivery that give patients a sense of coherence about their treatment over time (Parker et al., 2010). Freeman et al's (2007) model of CofC consists of several person-focused and disease-focused characteristics within the three facets. Management continuity is cross-boundary team care that is flexible and seamless, informational continuity consists of both staff-patient communication and information transfer between providers, and relationship continuity refers to consistent long-term roles for staff involved in a person's care. Most continuity research has measured only provider continuity rather than the three facets of continuity outlined by Freeman et al (2007), and has focused on health service resource use or patient satisfaction as outcomes (Van Walraven, Oake, Jennings, & Forster, 2010). Few continuity studies have investigated attendance or adherence to health prescriptions, though the relationship between continuity and medication adherence has been investigated (eg. Brookhart et al., 2007; Kerse et al., 2004; Uijen et al., 2012). Kerse et al (2004) found no consistent or independent relationship between continuity and medication adherence. However, Brookhart et al (2007) found that statin use was dynamic over seven years, with patients stopping and resuming medication over time. Resuming adherence was related to events including re-visiting the prescribing doctor, visiting another doctor, cholesterol tests, AMI and cardiovascular-related hospitalisations. Uijen and colleagues (2012) also identified non-linear relationships between continuity and medication adherence. Heart failure patients seeing three or more care providers in general practice were less likely to adhere to medications than those who saw fewer, and those who saw no providers had high levels of adherence. They also found that both high and low levels of team continuity (collaboration between providers in general practice) were significantly associated with maximum adherence. The variations and dynamic nature of patient behaviour may suggest that unidentified patient factors interact with continuity to affect adherence. This is supported by qualitative research which found that quality of relationships with health professionals as well as their continuity affects patient satisfaction (Frederiksen, Kragstrup, & Dehlholm-Lambertsen, 2009).

There has been very little continuity research in cardiac rehabilitation, though patients have expressed a desire for better continuity following discharge after a cardiac event (Paquet, Bolduc, Xhignesse, & Vanasse, 2005). However, Riley et al (2007) showed CofC to be positively related to CR attendance in a survey study with 506 patients recruited when hospitalised for an acute coronary syndrome. Nine months later participants completed the validated Heart Continuity of Care Questionnaire (Hadjistavropoulos et al., 2004), answered open questions about continuity perceptions and reported CR participation. CR attendance was significantly related to perceived continuity. In a General Linear Model, CR participation, tangible social support and perceived illness consequences were significant correlates of perceived continuity after controlling for gender, age, body mass index, condition / procedure, systolic blood pressure, marital status, ethnocultural background, family income and smoking status. Riley et al suggest that relationship continuity allowed the development of a staff-patient relationship that met patients' needs. The authors also concluded that informational continuity is likely to have a positive effect on patients' care needs, as information about the patient is transferred between settings, leading to patient satisfaction. However, it remains uncertain how continuity of care interacts with patients' characteristics to result in attendance.

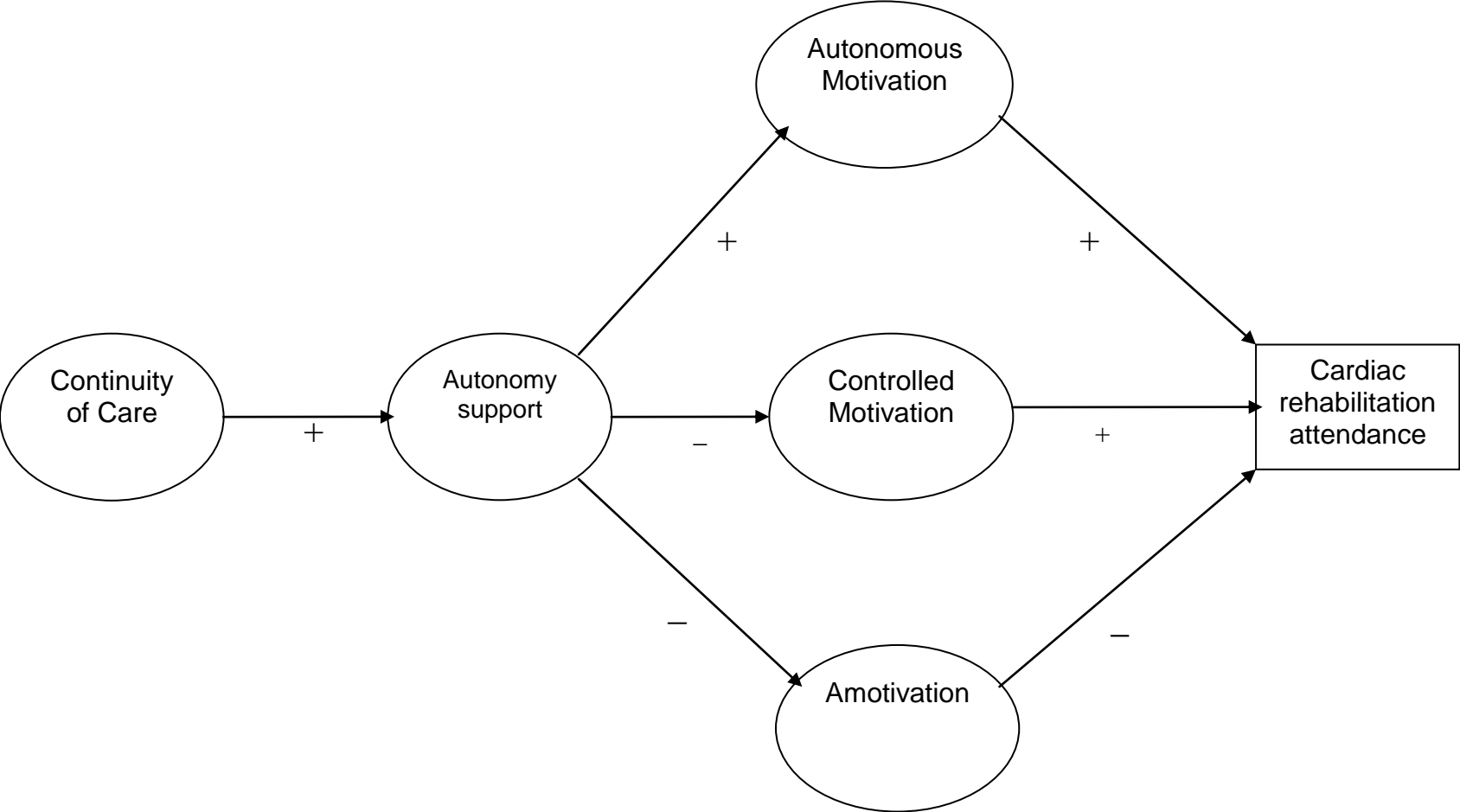
SDT is an empirically-derived theory of human motivation within which it is considered that a person's quality of motivation varies towards particular activities and is influenced by social contexts. People experience motivation along a continuum from extrinsic to intrinsic (Ryan & Connell, 1989). Intrinsic motivation means doing something for the enjoyment of it, while extrinsic motivation is doing something through a sense of duty or coercion. In line with this continuum, people regulate their actions through more or less autonomous motivation. Autonomous motivation has greatest 'quality' for the individual, because it is experienced as coming from the self, with minimal conflict. In healthcare, autonomous motivation has been associated with patients adopting healthy behaviours, for example by predicting improved diet, exercise and smoking cessation in patients with chest pain (Williams et al., 2005), and adhering to a low saturated fat diet throughout the two years after a CR programme (Mildestvedt et al., 2007). Controlled motivation is experienced as coming from coercive others, or the coercive self, and is associated with acting through duty, to avoid punishment or gain prizes. Although it has been associated with engagement in healthy behaviour (eg. Peddle, Plotnikoff, Wild, Au, & Courneya, 2008), controlled motivation is also associated with negative psychological outcomes such as depression and anxiety (Ng et al., 2012). It has also been shown to be negatively associated with adherence to a low saturated fat diet (Mildestvedt et al., 2007), and exercise (Mildestvedt et al., 2008) in the two years following a CR programme, and less sustained exercise over one year in weight management programmes (Teixeira et al.,

2006). Amotivation is a state in which people lack intention to act, resulting in either a lack of action or acting without a sense of intention, and has been associated with a lack of adherence to healthy self-care, for example following diet recommendations in diabetes (Julien, Senecal, & Guay, 2009).

SDT research has demonstrated that the quality of the social environment can influence the quality of people's motivation, by nurturing or undermining their psychological needs (autonomy, competence and relatedness) (Ryan et al., 2008), and this has valuable applications in healthcare settings, where the aim is to encourage the practice of healthy behaviours (Ryan et al., 2008). Much cross-sectional and intervention research has shown that an autonomy supportive climate encourages patients' engagement with exercise (eg. Fortier et al., 2012) and other healthy behaviours (eg. Williams et al., 2009) by offering guidance, discussion, choice and encouragement through mutually respectful staff-patient relationships (Sheldon, 2003). In cardiac rehabilitation, a cross-sectional study of 53 male participants found that perceived autonomy support correlated with self-determined motivation (Russell & Bray, 2010). Self-determined motivation predicted total exercise volume and length of exercise session 10 weeks later, though self-determined motivation was not correlated with CR attendance. The authors suggest that this may be due to the high level of attendance (over 75%) in their study. The present study builds on Russell and Bray's work by investigating whether continuity of care affects patients' perceptions of autonomy support and whether this influences patients' self-determined motivation for CR.

The aim of the present study was to examine whether patients have better quality motivation for CR when they experience continuity of care, and when this care is perceived as autonomy supportive. SDT was expected to clarify the psychological mechanisms underlying patients' differing quality of motivation for CR. Based on the theoretical assumptions and previous research described above, it was hypothesised that perceived continuity of care would be positively associated with autonomous motivation and CR attendance (Figure 3). It was also hypothesised that autonomy support would be positively associated with better quality motivation (i.e. autonomous regulation). Autonomous motivation, as opposed to controlled motivation or amotivation, was hypothesised to be more closely related to attendance at CR. In summary, the aim of the present study was to examine whether autonomy support is related to continuity of care, and whether this in turn affects PCI patients' motivation to attend CR. To our knowledge, there has been no previous research examining the effect of continuity of care on patients' motivation for CR.

Figure 3: Hypothesised model of motivational processes





## **3.2 Methods**

### **3.2.1 Participants**

A cross-sectional survey was carried out with 107 patients (85 male; aged 40-89 years) who had undergone a percutaneous coronary intervention (PCI) for an acute coronary event, or risk of a cardiac event, 2-6 months previously. The patients had their intervention at nine hospitals in the South of England. All patients were eligible for cardiac rehabilitation and 61 were currently attending Phase three classes. Twenty-two had previously attended, 18 of which had attended six or more sessions. Twenty-four had not attended. Three patients reported not being invited to attend, one of whom attended. Seven did not know if they had been invited, one of which attended. Seventy-five patients stated how many CR sessions they had attended (Range 0-15 sessions,  $M = 5.7$ ,  $SD = 3.04$ ).

### **3.2.2 Procedures**

Ethical approval was gained from University of Bath School for Health Research Ethics Approval Panel and the National Research Ethics Service (NRES). Approval from the relevant NHS Trust departments, and Research and Development approval for each of them, was sought and requirements for practice were followed. Patients meeting inclusion criteria were identified by cardiac nurse specialists from seven hospitals, who distributed packs containing invitations, information and questionnaires. Participants returned signed consent forms and completed surveys to the researcher.

### **3.2.3 Measures**

A survey pack can be seen in Appendix 10.

*Continuity of care.* The Heart Continuity of Care Questionnaire (Hadjistavropoulos et al., 2004) is a 33 item self-report questionnaire developed for patients with congestive heart failure or atrial fibrillation. It is used to assess three types of perceived continuity, from informational, relational and management subscales, which correspond to continuity of care models, such as that of Reid et al (2002) and Freeman et al (2007). Example items are "My heart condition was clearly explained to me" from the informational subscale, "My family physician (GP) was continually involved in or aware of my care" from the relational subscale, and "Within two months of discharge from hospital, I reviewed my overall treatment plan with a doctor" from the management subscale. Items were rated on a 5-point Likert scale from 'strongly agree' to 'strongly disagree', with an additional item for 'not applicable'. The original 37-item scale had excellent internal consistency, with a Cronbach alpha of 0.95, and evidence of validity including strong correlations with the Continuity of Care Index (Kowalyk, Hadjistavropoulos, & Biem, 2004). Hadjistavropoulos

et al (2004) amended the scale and confirmed its reliability and validity through factor analysis and correlations. The sub-scales had Cronbach alpha coefficients of 0.93 (informational continuity), 0.86 (relational continuity) and 0.84 (management continuity) (Hadjistavropoulos et al., 2004). Riley et al (2007) used the scale in patients with acute coronary syndrome, and the equivalence test statistics were 0.50, 0.48 and 0.50 for informational, relational and management continuity respectively.

*Autonomy support.* The short-form 6-item Health Care Climate Questionnaire (HCCQ; Williams, McGregor, King, Nelson, & Glasgow, 2005) was modified to assess how well patients thought staff gave them choices, understood them, listened and encouraged them when discussing cardiac rehabilitation. Participants select a score between 1 (not true at all) and 7 (very true), to questions such as “My healthcare practitioners encourage me to ask questions about my attendance at Phase three cardiac rehabilitation classes”. Williams et al (2005) developed the 6-item HCCQ from the 15-item HCCQ scale (Williams et al., 1996) based on a factor analysis of data across previous studies (n = 638). The 15-item HCCQ was adapted for healthcare settings from Climate questionnaires for non-healthcare settings (Deci et al., 1989; Grolnick, Ryan, & Deci, 1991). The 6-item HCCQ had similar internal consistency (0.93), to the 15-item scale (0.91) (Williams et al., 2005), and the version adapted for exercise had a Cronbach’s alpha of 0.91 to 0.95 (Edmunds et al., 2007).

*Regulation for cardiac rehabilitation attendance.* A modified version of the Treatment Self-Regulation Questionnaire (TSRQ; Williams et al., 1996) was used to assess the degree to which participants’ motivation for attendance at Phase three classes was autonomous versus controlled or amotivated. The TSRQ is based on a general scale assessing autonomous self-regulation (Ryan & Connell, 1989) and has been adapted and modified for different health behaviours, using between 9 and 19 items (Levesque et al., 2007). The 15 item TSRQ was adapted for the current study from the version that is part of the Healthcare SDT Questionnaire Packet ([www.selfdeterminationtheory.org](http://www.selfdeterminationtheory.org)). Items consist of a stem: “The reason I would attend Phase three cardiac rehabilitation classes is.....” followed by items reflecting quality of motivation. For example: “Because I feel that I want to take responsibility for my own health”. Items are scored between 1 (not true at all) and 7 (very true). Previous research supports the construct validity of the 15 item TSRQ and their equivalence in tobacco, diet and exercise across four research sites (Levesque et al., 2007). Internal consistency ranged from 0.85 to 0.93 for autonomous motivation, 0.74 to 0.86 for introjection and 0.73 to 0.91 for external regulation (together introjection and external regulation comprise controlled regulation). One value for amotivation was unacceptable (0.41), but the remainder were acceptable, ranging from 0.73 to 0.79 (Levesque et al., 2007).

*Attendance.* The following questions were asked: Have you received an invitation to attend Phase three cardiac rehabilitation classes? Are you currently attending Phase three cardiac rehabilitation classes? How many sessions have you attended so far? Do you intend to join a Phase three cardiac rehabilitation class? An attendance variable was created, which consisted of current attenders and people who stated the number of sessions attended (n=83), leaving 24 non-attenders.

### **3.2.4 Data analysis**

Partial Least Squares Structural Equation Modelling (PLS-SEM) was used to model the hypothesised relationships between continuity of care, autonomy support, quality of motivation (i.e. autonomous vs controlled), and amotivation in patients eligible for cardiac rehabilitation (Figure 3). PLS-SEM was chosen to ensure a robust approach to analysing the data from this PCI population, which by its nature is without normal distribution and multivariate normality. Conventional covariance-based (CB) SEM would be inappropriate given the sample size, non-normal distribution and multivariate non-normality. Using PLS-SEM, adequate statistical power and reduced possibility of type-II error was ensured by recruiting sufficient participants for each parameter in the hypothesised model<sup>9</sup>. This is a variance-based modelling approach developed by Wold (1975). Models consist of three aspects: the measurement (outer) model, structural (inner) model and relationships between loadings when the indicators are reflective, or weightings when the indicators are formative (Haenlein & Kaplan, 2004). In the present study the indicators of each latent construct were considered reflective. This is because the indicators are highly correlated and are dependent on their own latent construct. Also, the removal of one indicator would not change the relevant latent construct (ibid). Indicators are measures representing the effects of an underlying construct (Hair, Hult, Ringle, & Sarstedt, 2014). For example, the latent construct 'Autonomous motivation' is measured through six indicators in the TSRQ. Autonomous motivation is considered to be the cause of all of the indicator items, such as "The reason I would attend Phase three classes is because I feel that I want to take responsibility for my own health". Because each of the six indicators is a reflection of the same construct, the indicators are considered similar and interchangeable, and removing one of them would not alter the construct 'Autonomous motivation'. This theoretical judgement was tested in the measurement model.

Iterative calculations are carried out on separate (partial) sections of the model at a time, using Ordinary Least Squares regression models, as follows: Weight relations of indicators to their latent variable are estimated; these weight relation estimates are used

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<sup>9</sup> With 4 paths to be estimated in the model, 65 observations are needed to detect R<sup>2</sup> values of around 0.25, assuming a significance level of 5% and a power of 80% (Cohen, 1992, in Hair et al., 2014).

to calculate values of latent variables from the weighted averages of their indicators; and these values are used to calculate coefficients and  $R^2$  in the structural model (Haenlein & Kaplan, 2004). This minimises residual variances and maximises the explained variance of the exogenous (dependent) latent constructs (Hair, Ringle, & Sarstedt, 2011).

Based on the following reasons (ie. as outlined by Hair et al., 2014), PLS-SEM was chosen, rather than Covariance-based SEM (CB-SEM), because:

- PLS-SEM is preferred for prediction and theory-development, while CB-SEM is preferred for theory testing;
- The partial approach of PLS-SEM gives greater statistical power than CB-SEM, which makes it suitable for smaller sample sizes;
- The data do not meet CB-SEM assumptions exactly, while PLS-SEM does not require normal distributions or multivariate normality

### ***Model evaluation***

#### *Testing the measurement model*

Prerequisites for appropriate measurement models were assessed as follows (Hair et al., 2014 p.97). Indicator reliability was assumed when standardised loadings on latent variables were higher than 0.70. Internal consistency was assessed as composite reliability higher than 0.70. Composite reliability is considered more appropriate than Cronbach's alpha, because it does not assume equal weightings of indicators (Hair et al., 2011). However, Cronbach's alpha was also calculated to allow comparisons with previous studies that have used this to assess measure reliability. Convergent validity was met if the average variance extracted (AVE) was higher than 0.50. Discriminant validity consisted of the AVE of each latent construct being higher than construct's highest squared correlation with other latent constructs (Fornell-Larcker criterion), and the indicator's loadings being higher than all its cross-loadings.

#### *Testing the structural model*

The structural model was evaluated as follows. Collinearity was assumed if the variance inflation factor (VIF) was less than 5 (Hair et al., 2014). Goodness of fit indices are not appropriate for PLS-SEM, but assessment is based on criteria determined by the model's predictive ability (Hair et al., 2014). Bootstrapping (n=999; re-sampling with replacement) was used to assess the significance of the path coefficients. The number of bootstraps must be at least equal to the number of valid observations in the original dataset (n=103 in the present study) (Hair et al., 2014). Although Kock recommends using 100 bootstraps because higher numbers of re-samples leads to little improvement in p-value reliability (Kock, 2013), using more is deemed to reduce the effect of random sampling errors in the bootstrap procedure (Peng & Lai, 2012). Although 5000 bootstraps are often

recommended (eg. Hair et al., 2014; Preacher & Hayes, 2008a), the maximum allowed in WarpPLS is 999.  $R^2$  values for latent variables were measured to assess the model's predictive accuracy (Hair et al., 2011). The  $f^2$  effect size was calculated. Predictive relevance was assessed using Stone-Geisser's  $Q^2$  (Geisser, 1974; Stone, 1974). Values larger than 0 indicate that exogenous constructs predict endogenous constructs (Hair et al., 2011). The  $q^2$  effect size was calculated.

WarpPLS version 3 was used to carry out the modelling (Kock, 2013). The Warp3 PLS regression algorithm was used because it includes transformations to take account of non-linear (S-curve and U-curve), as well as linear relationships between latent variables. This was considered appropriate in the present study because it consists of behavioural phenomena, which are generally non-linear (Kock et al., 2011).

#### *Testing for mediation*

As recommended by Preacher and Hayes (2008b), bootstrapping with re-sampling was used to test for significance of direct and indirect paths between variables with two segments. Two models were built, Model 1 with only direct paths from continuity of care to the other latent variables, and Model 2, with direct and indirect paths included. Baron and Kenny's criteria were used to assess mediation (Baron & Kenny, 1986):

- In Model 1 the paths between variables are significant ( $p < 0.05$ )
- In Model 2 the path between the exogenous variable and the mediator (continuity of care and autonomy support in the present study) is significant
- In Model 2 the paths between the mediator and the endogenous variables (autonomy support and the regulation variables in the present study) are significant

The variance accounted for (VAF) was assessed to determine the amount of variance in the endogenous variables (the regulation variables in the present study) explained by the direct and indirect relationships with the other variables, that is, whether the effect of continuity of care on the regulation variables is partially or fully mediated by autonomous regulation. A VAF less than 20% denotes no mediation, 20% to 80% partial mediation, and greater than 80% full mediation (Hair et al., 2014).

#### ***Comparison of CR attenders and non-attenders: perceived continuity and motivation***

T-tests were used to compare continuity of care, autonomy support and quality of motivation (autonomous, controlled) and amotivation scores of attenders ( $n=83$ ) and non-attenders ( $n=24$ ). The unbiased form (corrected for small sample size) of Hedges'  $g$  effect sizes (Hedges & Olkin, 1985) are given, as this is appropriate for uneven sample sizes.

This is a conservative version of the standardized mean difference, or the difference between the means of the groups divided by the pooled within-group standard deviation (Grissom & Kim, 2005). Effect sizes of 0.20, 0.50 and 0.80 are considered small, moderate and large respectively, at a probability of 0.05 (Cohen, 1988).

### **3.3 Results**

PLS-SEM was used to test a theory-based model of the process by which continuity of care and autonomy-support predict quality of motivation for cardiac rehabilitation.

#### **3.3.1 Measurement Model evaluation**

Indicator reliability was assessed, and most indicator loadings were higher than 0.70. Continuity of care had loadings between 0.87 and 0.92 ( $p < 0.001$ ), autonomy support had loadings between 0.84 and 0.93 ( $p < 0.001$ ), autonomous motivation had loadings between 0.73 and 0.90 ( $p < 0.001$ ), controlled motivation had loadings between 0.53 and 0.81 ( $p < 0.001$ ), and amotivation had loadings between 0.62 and 0.80 ( $p < 0.01$ ). Two indicator loadings were lower than 0.69, but were retained because they were above 0.40 and composite reliability was very good for both variables (Hair et al., 2011). One was an indicator of amotivation (0.62), and the other was an indicator of controlled motivation (0.53).

The AVE of each latent construct was higher than the construct's highest squared correlation with any other latent construct (Fornell-Larcker criterion), and all indicators' loadings were significantly higher than their cross-loadings. This indicates discriminant validity, and supports the theory that these are reflective indicators.

Table 2 shows that all latent constructs had satisfactory internal consistency reliability (0.70-0.90; Nunnally & Bernstein, 1994), and acceptable convergent validity (AVE above 0.50; Hair et al., 2014). Cronbach's alphas were deemed acceptable for all scales (Nunnally & Bernstein 1994), except the amotivation sub-scale of the TSRQ. However, this measure was theoretically important, so was retained. Continuity of care had a significant positive correlation with autonomy support, autonomy support correlated significantly with autonomous regulation, and significantly negatively with amotivation. Autonomous regulation correlated significantly with controlled motivation, and controlled motivation correlated significantly with amotivation. Attendance significantly correlated with autonomy support, but not with continuity of care or the other motivational constructs.

**Table 2: Composite reliability (CR), average variance extracted (AVE), Cronbach's alpha, correlations of latent constructs**

Latent construct	CR	AVE	$\alpha$	Correlations					
				1	2	3	4	5	
1. Continuity of care	0.92	0.80	0.88	-					
2. Autonomy support	0.96	0.78	0.94	0.48***	-				
3. Autonomous	0.92	0.66	0.90	0.16	0.32***	-			
4. Controlled	0.87	0.53	0.82	0.12	0.16	0.21*	-		
5. Amotivation	0.75	0.50	0.50	-0.11	-0.27**	-0.11	0.30**	-	
6. Attendance\$				0.13	0.26**	0.03	-0.01	0.00	

Note: N=107, correlations (Pearson 2-tailed) \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001, \$attenders n=83, non-attenders n=24

### 3.3.2 Testing the hypothesised model

Figure 4 shows the structural model, with path coefficients ( $\beta$ ), bootstrapped standard errors (SE) and the amount of variance in the endogenous (dependent) latent constructs that is explained by the exogenous (independent) latent constructs ( $R^2$ ). Latent constructs were developed that captured the key elements of the hypothesised model. Seven variables were measured, but for parsimony, and because they were quite highly correlated ( $r = 0.63-0.77$ ), the three aspects of continuity (management, informational and relationship continuity) were combined in a single latent variable. These three aspects were used as indicators of 'Continuity', combining the 32 items from the continuity of care instrument.

As hypothesised, greater perceived continuity of care positively predicted perceived autonomy support. Greater autonomy support positively predicted autonomous motivation toward CR, and negatively predicted amotivation for CR. The paths from continuity of care directly to motivational regulation constructs were non-significant in the full model. This indicates that continuity of care had no direct effect on quality of motivational regulation, but continuity of care contributed to motivation indirectly through autonomy support. The model explained 3%, 14% and 9% of the variance in controlled and autonomous motivation and amotivation, respectively.

The predictive relevance of the model was assessed using the Stone-Geisser  $Q^2$  test. The  $Q^2$  scores were: autonomy support 0.26, autonomous motivation 0.13, controlled motivation 0.04 and amotivation 0.09. All  $Q^2$  scores were above zero, providing support for the model's predictive relevance for the four endogenous constructs (Hair et al., 2014). The  $Q^2$  results closely resembled the  $R^2$  results, indicating that the path model accurately predicted the original observed values (Hair et al., 2014).

Table 3 shows the effect sizes of the path coefficients (Cohen's  $f^2$ ) (Cohen, 1988) and the relative impact of the predictive relevance ( $q^2$ ). Values of 0.02, 0.15 and 0.35 represent small, medium and large effects of the exogenous latent variable ( $f^2$ ), and indicate that an exogenous construct has a small, medium or large predictive relevance ( $q^2$ ) for an endogenous construct (Hair et al., 2014). Thus, the effect size of autonomy support on autonomous motivation was medium, and the effect size of autonomy support on controlled motivation and amotivation was small. Autonomy support had a small-medium predictive relevance for autonomous motivation and a small predictive relevance for controlled motivation and amotivation.

**Table 3: Effect sizes**

Exogenous Variable	Endogenous Variable	$f^2$	$q^2$
Continuity of care	Autonomous	0.03	
Continuity of care	Controlled	0.00	
Continuity of care	Amotivation	0.01	
Continuity of care	Autonomy support	0.25	
Autonomy support	Autonomous	0.13	0.09
Autonomy support	Controlled	0.02	0.02
Autonomy support	Amotivation	0.09	0.08

Note:  $f^2$  = Cohen's  $f^2$  (Cohen 1988)

Table 4 shows indirect, direct and total effects used to test for mediation in the structural model. The direct relationships between continuity of care and controlled motivation, and continuity of care and amotivation were non-significant. Therefore, these relationships are not assumed to be mediated by autonomy support. For autonomous motivation toward CR, the VAF was 46%, indicating that the effect of continuity of care was partially mediated by autonomy support.

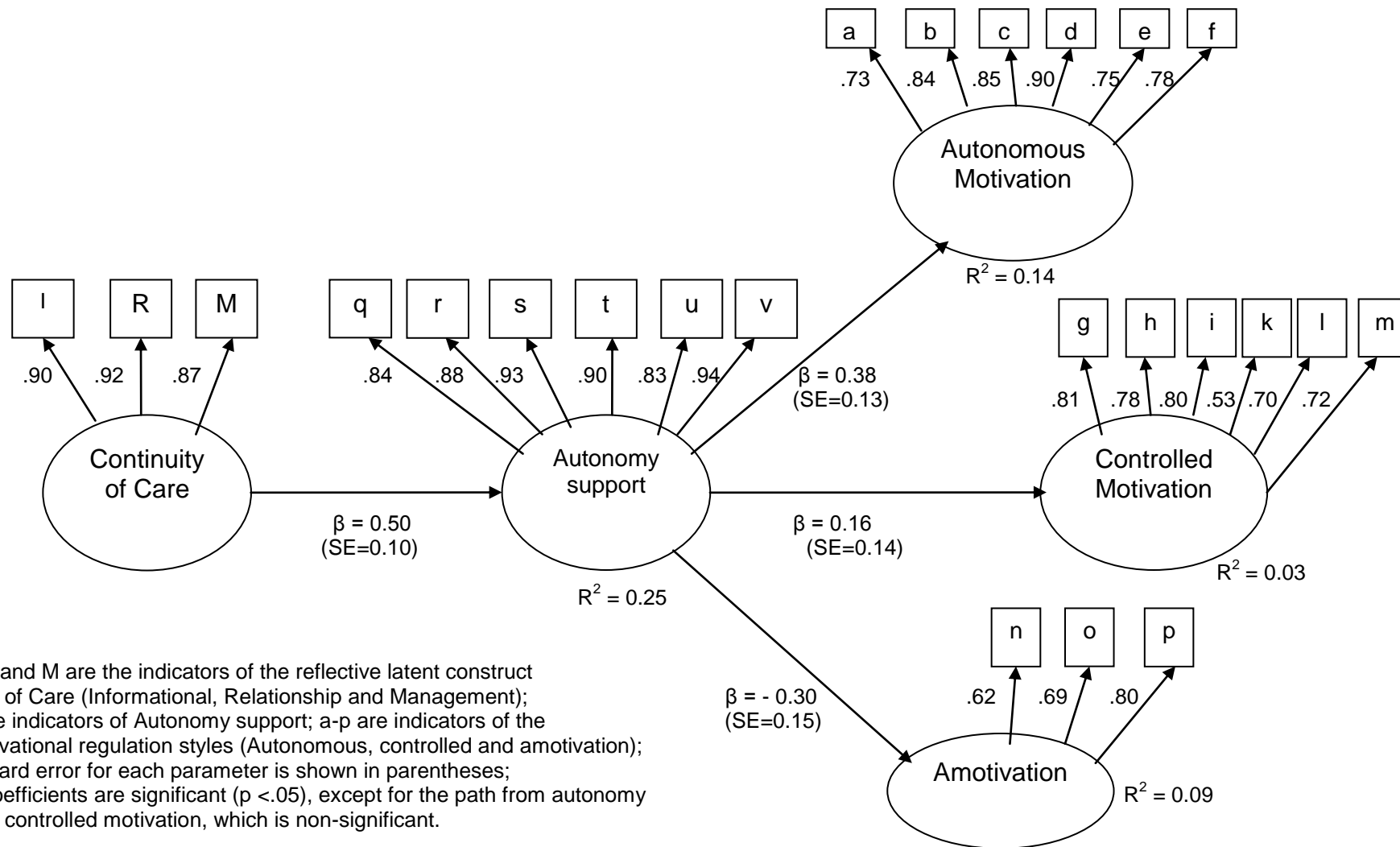
**Table 4: Tests of mediation in the structural model**

Relationship		Total Effect (SE)	Indirect Effect via Autonomy support	Direct Effect	VAF
From	To				
Continuity of care	Autonomy support	0.50			
Continuity of care	Autonomous	0.19** (0.17)	0.19**	0.22*	0.46#
Continuity of care	Controlled	0.13 (0.17)	0.08	0.10	n/a
Continuity of care	Amotivation	-0.15* (0.10)	-0.15*	-0.12	n/a

Note: estimates represent 999 bootstraps. \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ , # = partial mediation



**Figure 4: Path diagram of final Partial Least Squares Structural Equation Model**



Note: I, R and M are the indicators of the reflective latent construct Continuity of Care (Informational, Relationship and Management); q-v are the indicators of Autonomy support; a-p are indicators of the three motivational regulation styles (Autonomous, controlled and amotivation); The standard error for each parameter is shown in parentheses; All path coefficients are significant ( $p < .05$ ), except for the path from autonomy support to controlled motivation, which is non-significant.

### 3.3.3 Comparison of continuity perceptions and motivation between attenders and non-attenders

Independent samples t-tests were carried out to compare quality of motivation between those who attended (n=83) or did not attend (n=24) CR. Contrary to expectations, no significant difference was found between the two sub-groups. There was no significant difference between the groups with respect to the continuity of care latent variable, but autonomy support was significantly higher in attenders than non-attenders (t=2.268, p=0.03, Hedges' g=0.64). Post-hoc t-tests compared variables among those who intended to attend CR (n=13) or not attend (n=7). Those who intended to attend scored significantly higher on controlled regulation with a large effect size (t=2.225, p=0.04, Hedges' g=1.00). Among those currently attending CR (n=61) compared with not currently attending (n=46), autonomy support (t=2.370, p=0.02, Hedges' g=0.49) was significantly higher, with a moderate effect size. Effect sizes of 0.20, 0.50 and 0.80 are considered small, moderate and large respectively, at a probability of 0.05 (Cohen, 1988). Differences on all variables are shown in table 5.

**Table 5: T-tests comparing attenders and non-attenders**

Groups (n)	Variables	T-test	Sig. 2-tailed	Effect size (Hedges' g)
Attenders (83) vs non-attenders (24)	Continuity of care	1.325	0.19	0.31
	Autonomy support	2.268	0.03*	0.64
	Autonomous motivation	0.312	0.76	0.07
	Controlled motivation	0.145	0.89	0.03
	Amotivation	0.002	1.00	0.00
Current attenders (61) vs not currently attending (46)	Continuity of care	1.829	0.07	0.42
	Autonomy support	2.370	0.02*	0.49
	Autonomous motivation	0.625	0.53	0.15
	Controlled motivation	0.306	0.76	0.07
	Amotivation	0.702	0.48	0.16
Intend to attend (13) vs no intention (7)	Continuity of care	0.106	0.92	0.03
	Autonomy support	1.142	0.28	0.26
	Autonomous motivation	1.398	0.20	0.32
	Controlled motivation	2.225	0.04*	1.00
	Amotivation	0.138	0.89	0.03

Note: \* p < .05

### **3.4 Discussion**

The purpose of the present study was to investigate whether continuity of care is related to autonomy support, and whether autonomy support affects PCI patients' motivation to attend cardiac rehabilitation. A significant relationship between patients' perceptions of continuity of care and autonomy support was identified, which then predicted greater autonomous motivation for cardiac rehabilitation. This was established by testing a model which accounted for a moderate proportion of the variance in autonomy support ( $R^2=0.25$ ) and a small proportion of the variance in autonomous motivation ( $R^2=0.14$ ). The present work adds to the extant literature by empirically documenting support for a model of motivation encompassing relationships among continuity of care, autonomy support, quality of motivation and amotivation. In this model, continuity of care had a small direct effect on autonomous motivation, but no direct effect on controlled motivation or amotivation. However, when autonomy support was included in the model, the effect of continuity of care on autonomous motivation was partially mediated by autonomy support. This finding adds to previous research by demonstrating that these psychological mechanisms are affected by continuity of care in CR. This result also concurs with much previous SDT research showing that autonomy support predicts more autonomous motivation. For example, Russell and Bray (2010) found that autonomy support was associated with autonomous motivation in CR. The results of the present study show the importance of continuity of care for patient motivation, but also identify a mechanism through which it works. The significant effect of continuity of care in predicting autonomy support builds on previous research which suggested that continuity of care in CR encouraged positive patient-staff relationships, supported patients' individual care needs, and indirectly affected patient satisfaction when details about their history, diagnosis and treatment were shared between settings (Riley et al., 2007). This aligns with SDT, which posits that autonomy-supportive staff-patient relationships developed over time are supportive of a person's basic psychological needs (Ryan et al., 2008).

Consistent with past work (eg. Williams et al., 2006) and tenets within SDT, autonomy support significantly and positively predicted autonomous motivation toward CR. The effect size of autonomy support on autonomous motivation in the present study was moderate, and at the higher end of the magnitude of effect calculated in previous healthcare studies based on SDT (Ng et al., 2012). That is, within their meta-analysis, Ng and colleagues reported small to moderate effect sizes (Spearman's rho) between autonomy support and autonomous regulation in previous studies. In the present study, patients had a mean age of 65 and reported on a treatment setting that included physical activity. This concurs with Ng and colleagues, who reported effect sizes in studies of physical activity to be higher with older compared with younger participants, and in treatment compared with non-treatment settings. It is also possible that including

continuity of care in the model contributed to the greater effect size, though further research is needed to confirm this. It would also be valuable to test the contribution of other service delivery variables that have been associated with patients' decisions to attend CR, such as travel time (e.g. Bruhal et al., 2010), location of CR centres (e.g. Harrison & Wardle, 2005) or programme content (e.g. Moore, 1996).

In the present study, greater autonomy support also significantly negatively predicted amotivation. This is in line with Ng et al's (2012) meta-analysis, which found a small to moderate negative effect on amotivation from autonomy support. However, the effect on controlled motivation differs from the results of Ng et al's analysis. These authors calculated very small effects of autonomy support on controlled motivation, whereas in the present study autonomy support predicted a small amount of controlled motivation. This may reflect participants partially internalising the values of CR but also attending in order to please the staff or avoid disapproval. This aspect of controlled motivation, called introjection regulation within SDT, was not measured separately in the present work, but has previously been positively associated with need satisfaction in exercise intervention research (eg. Markland & Tobin, 2010; Silva et al., 2010).

Contrary to our hypothesis, in the present work there was no significant difference between CR attenders and non-attenders in terms of quality of motivation or perceived continuity of care. However, in Riley et al's 9-month survey after patients were discharged from hospital (n=506), correlates of continuity of care included CR attendance ( $p<0.05$ ) (Riley et al., 2007). It may be that the measure of attendance in the present study did not differentiate sufficiently between attendance and non-attendance. In the present study, experiencing greater continuity of care may also have encouraged some patients to feel competent to carry out self-rehabilitation at home, rather than joining a CR programme. Ng et al (2012) point out that autonomy does not always result in an outcome that practitioners want, and this may be reflected in the results from the present sample. Similar to results reported in the present study, Russell and Bray (2010) found that self-determined motivation did not correlate with CR attendance, in a group of patients surveyed 10 weeks after attending a CR session. However, in that study, patients' autonomous motivation correlated with exercise duration and volume, suggesting that they adhered to CR advice even if they did not attend. Autonomous motivation has been associated with increased adherence to healthy behaviour in patients with chronic conditions (eg. Shigaki et al., 2010), including in CR (eg. Sweet et al., 2011). However, Ng et al's (2012) meta-analysis showed that effect sizes of paths from autonomous motivation to health outcomes are generally small.

Ng and colleagues (2012) also concluded that competence explained more of the variance in health outcomes than did autonomous motivation, and it would be useful to measure competence in future CR research. In the present study, need satisfaction measures (autonomy, competence and relatedness) were not included in the model tested, although they have been included in some previous SDT healthcare studies. For example, Williams et al (2006) found that autonomy support and perceived competence had independent effects on smoking cessation, and Russell et al (2009) found that competence need satisfaction predicted self-determined motivation for exercise after CR. However, the aim of the present study was to determine whether there was an interaction between continuity of care and self-determined motivation, and whether this was affected by an autonomy supportive healthcare context. It was theoretically unclear where in the model need satisfaction would be placed, as need satisfaction might be expected to be proximal to continuity, to mediate the relationship between autonomy support and self-regulation, or to have an independent influence as in Williams et al's (2006) study. It was also considered that the inclusion of need satisfaction would make the results more difficult to interpret, and require a greater sample size. Once a clear relationship between continuity and motivation was established, further hypotheses about the potential role of need satisfaction could be developed.

Notably, in the present study autonomy support was significantly greater in patients who had ever attended than non-attenders ( $g=0.64$ ), and post-hoc t-tests identified significantly greater autonomy support among current attenders ( $n=61$ ) compared with those who were not currently attending ( $n=46$ ). Current non-attenders included 24 non-attenders and 22 previous attenders, 18 of whom had attended six or more CR sessions. This may suggest that autonomy support encourages CR attendance through mechanisms other than autonomous motivation. Previous research has identified a relationship between autonomy support, perceived competence and adherence to smoking cessation (Williams et al., 2006), and to diet, exercise and glucose testing in diabetes (Williams, McGregor, Zeldman, Freedman, & Deci, 2004) and to medication adherence in diabetes (Williams et al., 2009), and further research to test the interaction between autonomy support, competence and attendance in CR would be useful. Alternatively, in the present study Phase three attendance may have been necessary in order to experience significant autonomy support. This may suggest a deficit of autonomy-support during Phase one and two, though further research is needed to test such an assertion.

### **3.4.1 Limitations, future research and implications for practice**

A limitation of the present study is that it is cross-sectional. Thus, any changes in patients' perceived continuity of care, autonomy support or quality of motivation over time could not be considered. The study was powered to detect  $R^2$  results of around 0.25, indicating a sample size of 65. The lower  $R^2$  results mean that the study is slightly underpowered ( $n=107$ , rather than the recommended  $n=137$ ), reducing the confidence of the present results, though combining the three components of continuity of care attenuated the effect of this, by reducing the number of variables in the model from seven to five. Including patients at different stages of the CR timeline may also have reduced the ability to differentiate between attenders and non-attenders in terms of quality of motivation. Future research would do well to include measures that distinguish between motivation for attending CR classes and motivation for self-rehabilitation, include greater numbers of participants to increase power and reliability (and thus our confidence in the estimated parameters), and be longitudinal in design. Investigating the three components of continuity of care (informational, management and relationship) separately, rather than a composite, is also recommended as this would allow differential or cancelling effects of continuity on motivation to be identified.

Nevertheless, the present study contributes to the motivation-related literature pertaining to CR by documenting a role of continuity of care in positively predicting autonomous motivation towards CR. Post-hoc findings also suggest that an autonomy-supportive approach from clinicians is associated with CR attendance in current attenders, which suggests that it encourages adherence once patients start to attend. These results imply that practice developments would do well to include improved continuity of care throughout the CR timeline, for example by developing methods to encourage inter- and intra-institutional relationships, ongoing staff-patient relationships, and referral and discharge processes. This suggestion is further supported by previous research which found that key informants perceived that improved continuity was likely to improve CR uptake (Grace et al., 2006), and that patients' perceived continuity of care was related to CR attendance (Riley et al., 2007). The results of the present study also imply that beneficial practice developments would include staff training to deliver autonomy support in CR, in order to encourage greater CR attendance and adherence. This recommendation is supported by previous research demonstrating the role of autonomy support in encouraging patient adherence to healthcare prescriptions, including glycaemic control (Williams et al., 2005), medication adherence in diabetes (Williams et al., 2009) and exercise referral (Duda et al., 2014). Staff training to encourage autonomy support has also previously been shown to improve participation in exercise classes (Edmunds et al., 2008), and sports education (Tessier et al., 2010).

### **3.5 Conclusion**

The present work provides support for the notion that continuity of care enhances PCI patients' autonomous motivation for cardiac rehabilitation through an interpersonal social context characterised as being autonomy supportive. These findings suggest that improving continuity of care is likely to have beneficial effects on patients' acceptance of the values of cardiac rehabilitation, and may contribute to their willingness to attend or adhere to CR classes or to practice heart-healthy behaviours. Further research is needed to investigate whether improved continuity for all PCI patients from Phase one onwards can enhance perceived autonomy support sufficiently to improve uptake of Phase three classes. In order to achieve these aims, research is first needed to identify which aspects of continuity of care affect patients' experiences of CR, and influence their motivation to attend. Future research to test the mediating role of other motivational antecedents, particularly need satisfaction, in encouraging CR attendance and adherence would also be valuable.

## Chapter 4: Critical Interpretive Synthesis

The study reported in Chapter 3 tested a hypothesised model of the relationship between continuity of care, autonomy support and self-determined motivation for cardiac rehabilitation attendance among patients who had undergone a percutaneous coronary intervention, and established the existence of a predictive relationship between these three latent variables. Additional questions were identified, specifically whether the different domains of continuity of care (informational, management and relationship) outlined in Freeman et al's matrix (Figure 1) differentially affect patient motivation, and how continuity manifests itself in everyday practice in cardiac rehabilitation. It was also suggested from other research contexts that additional motivational factors, specifically need satisfaction (autonomy, competence and relatedness) may play a part in encouraging cardiac rehabilitation attendance. Chapter 4 presents a study which investigates the research needs identified in Study 3. Specifically, the relationships between continuity of care and patient motivation are considered in greater breadth and depth, the investigation is expanded to consider adherence to cardiac rehabilitation attendance and adherence to heart-healthy recommendations, and the nuances of interactions between factors are explored. The patient group is broadened to include those undergoing a coronary artery bypass graft (CABG) or receiving medical interventions for acute myocardial infarction (AMI), as well as percutaneous coronary intervention (PCI) patients, in order to consider whether differences in attendance between these groups are related to differences in continuity and motivation.

The aim of the present study is to carry out a Critical Interpretive Synthesis (CIS) of existing literature to identify factors that clarify the relationship between 'continuity of care' and patients' motivation to engage with cardiac rehabilitation, interpreted using self-determination theory. Additional putative factors contributing to the model tested in Study 1 are identified and a coherent overarching theory about interactions between factors is developed. This aim is achieved by identifying relevant patient and organisational factors within existing literature and examining their interactions. Freeman et al's Continuity of Care matrix (Figure 1) is used to aid identification and analysis of factors. Self-determination theory is used to aid interpretation.



#### ***4.1 Critical Interpretive Synthesis: Methodology***

A number of methodological options are available for systematically reviewing literature (Table 6). Each has different purposes, philosophical underpinnings and methods. Systematic reviewing is the most established methodology for synthesising quantitative research in a rigorous, transparent and reproducible way (Khan, ter Riet, Glanville, Sowden, & Kleijnen, 2001). However, it is not designed for synthesising mixed study designs, research from different contexts, or exploratory questions (Hammersley, 2005). Several approaches have been developed to address this limitation, building on systematic reviewing and qualitative methodologies such as meta-ethnography (Noblit & Hare, 1988). The most well-known are Bayesian synthesis (Roberts, Dixon-Woods, Fitzpatrick, Abrams, & Jones, 2002), Meta-narrative review (Greenhalgh et al., 2005), Mixed methods synthesis (Thomas et al., 2004) and Realist synthesis (Pawson, Greenhalgh, Harvey, & Walshe, 2005). Each of these methodologies was considered for the present study.

**Table 6: Overview of review methodologies that include both qualitative and quantitative primary studies**

Methodology	Developed from / influences	Purpose	Research question	Study types included	Searches	Quality assessment	Sampling	Analysis	Output
Bayesian synthesis (Roberts et al., 2002)	Bayes' theorem (Berger, 1985)	Includes qualitative and quantitative data in formal synthesis, to avoid omitting factors that are potentially important for addressing policy issues	Pre-specified	Qualitative and quantitative studies	Databases, relevant major journals, and article reference lists for studies published in peer-reviewed journals	Study quality not used as an inclusion criterion	All papers meeting inclusion criteria	Factors from reviewer's views and qualitative papers → content analysis. Factors ranked → prior probability. Combined with quantitative data → posterior probability. Bayesian meta-regression models	Model expressing the probability of each factor being a determinant of the phenomenon of interest
Critical Interpretive Synthesis (Dixon-Woods et al., 2006)	Meta-ethnography (Noblit & Hare, 1988)  Grounded theory synthesis (Eaves, 2001)  Notions of orders of constructs in meta-ethnography (Britten et al., 2002)	Produces a theoretical account of evidence and existing theory that balances empirical applicability and explanation	Starts with a fuzzy and tentatively defined phenomenon; questions develop from the included literature	All types of study and non-study literature included	Extensive though not exhaustive searching	'Fatally flawed' papers excluded; quality critiqued and reported within analysis	Strategic samples from the literature	Appraisal and critique of included papers, thematic analysis similar to primary qualitative research	Theoretical output in the form of synthesising argument

<b>Methodology</b>	<b>Developed from / influences</b>	<b>Purpose</b>	<b>Research question</b>	<b>Study types included</b>	<b>Searches</b>	<b>Quality assessment</b>	<b>Sampling</b>	<b>Analysis</b>	<b>Output</b>
Meta-narrative review (Greenhalgh et al., 2005)	Meta-ethnography (Noblit & Hare, 1988)  Kuhn's notion of scientific paradigms: diffusion of innovations (Kuhn, 1962)	Maps 'storylines' to trace influence of seminal theory and empirical studies on subsequent research in various traditions	Initial research question broad and open-ended	Qualitative and quantitative	'Browsing' for diverse perspectives, reference tracking for seminal papers in all research traditions, searching key databases, hand searching and snowballing	Generic criteria of scholarship, Comprehensiveness and contribution to subsequent work within each tradition	Identifies key meta-narratives from disparate schools of study, eg. sociology, epidemiology marketing	Identifies key dimensions of problem, narrative account of contribution from each research tradition, conflicting findings explained	Summary of overall messages from research literature plus other relevant evidence (eg. budget, policy-making priorities)
Mixed methods synthesis (Thomas et al., 2004)	Systematic review  Meta-analysis  Primary thematic analysis	Integration of quantitative estimates of benefit and harm with qualitative understanding of people's lives	Pre-specified	Controlled trials and views studies, often qualitative	Sensitive searching	Formal quality assessment; systematic screening against pre-set inclusion criteria	Include all papers meeting inclusion and quality criteria	Qualitative and quantitative research analysed by meta-analysis (quant) and thematic analysis (qual)	Results of qualitative and quantitative strands synthesised via a matrix
Realist synthesis (Pawson et al., 2005)	Realism (the generative model of causality) (Bhaskar, 1978)  Realist evaluation of organisations	Explanation of how, why and for whom intervention works in context, to meet policy	Pre-specified but iterative throughout the review	Empirical evidence to populate theoretical framework: complex epistemology	Exploratory background search; progressive focusing to identify key programme	Uses judgement to supplement formal critical appraisal checklists, and consider	Purposive sampling to test theories; additional 'snowball' sampling to explore new	Synthesis of data to achieve refinement of programme theory	How, why and for whom complex interventions work in particular settings

	(Pawson & Tilley, 1997) Systematic review	objectives		and diverse methodology	theories	'fitness for purpose': relevance and rigour	hypotheses		
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The strength of Bayesian synthesis, a formal way of combining qualitative and quantitative data, lies in identified factors being ranked by the probability of their relative importance (Roberts et al., 2002). However, it does not include non-research material, and the aim is to summarise existing research findings, rather than to develop theory, so it would not fulfil the purpose of the current study. Mixed methods synthesis also uses an aggregative (assembling and pooling data), rather than an interpretive (theory grounded in the concepts in the data) approach. It involves separate quantitative and qualitative reviews, then further synthesis of the results using a matrix (Shepherd et al., 2006). However, the quantitative review requires a manageable body of good quality controlled trials that meet pre-specified criteria. The present study was expected to consist of an amorphous, large body of evidence, with few controlled trials. It was possible that all relevant papers would be excluded if systematic review-type quality and exclusion criteria were used.

Realist synthesis is not limited to study evidence, uses judgement and formal quality appraisal, and combines aggregation and interpretation (Pawson et al., 2005). Unlike Bayesian synthesis and Mixed methods synthesis, the research question goes through many iterations during the review process, leading to repeated sampling to test new hypotheses. The end result is a refined theory about how complex healthcare programmes work or why they fail (Pawson et al., 2005). Realist synthesis may have been suitable for the present study, though it was uncertain whether it would allow consideration of the nuances of relationships between motivation and continuity of care. Realist synthesis may be more useful when evaluating the structure of a policy or programme, rather than patient willingness or motivation (Clark, Macintyre, & Cruickshank, 2007). For example, a realist review of intimate partner violence screening programmes considered structural mechanisms related to successful programme outcomes (Kirst & O'Campo, 2012).

Meta-narrative review is a way of capturing how interest and endeavour in a research topic develops over time (Greenhalgh et al., 2005). This follows a parabolic pattern, peaking and then becoming less prominent. The overlapping patterns of peaks and troughs in different academic traditions, and their different approaches, methods and theories about a topic are also explored. The strength of this approach is that it draws from multiple schools of thought, and seeks to explain contradictory findings. However, the focus of the present study is to explore relationships between motivation and continuity of care, which are not thought to have been investigated in any tradition. A methodology which, while rigorous, allows a broad exploration of the literature without such constraints, is needed.

Critical Interpretive Synthesis (CIS) is a review methodology piloted and developed by Dixon-Woods et al (2005b) for a review of access to health care by vulnerable groups, commissioned by the National Co-ordinating Centre for NHS Service Delivery and Organisation. This was a pragmatic approach to reviewing a large, methodologically diverse and complex literature. Dixon-Woods et al (2006) intended to use meta-ethnography (Noblit & Hare, 1988), because Noblit and Hare's strategies allow synthesis of papers that are similar, that refute each other, or contribute to building lines of argument. However, Dixon-Woods et al (2006) found one strategy of meta-ethnography, reciprocal translational analysis (RTA), to be methodologically and practically problematic. RTA involves interpreting the metaphors (themes) identified by authors of each paper according to the metaphors of other papers. Noblit and Hare (1988 p.38) describe RTA as a strategy for synthesising similar papers, and meta-ethnography was designed for synthesising qualitative studies. However, Dixon-Woods and colleagues aimed to give an interpretive account of methodologically and thematically diverse papers, which might not be similar, refuting or build on each other. Although Noblit and Hare refer to dissimilar papers, they do not suggest a method of incorporating such studies. Drawing on the work of Britten and others (Britten et al., 2002), and combining the RTA and lines-of-argument stages of meta-ethnography, Dixon-Woods et al developed CIS. This has one analytical stage, the synthesising argument, which combines thematic analysis, critical appraisal of the included papers, and an argument about the meaning of the data. It includes 'synthetic constructs', ideas identified by the reviewer but not identified by authors of the included papers. It also takes into account first, second and third level constructs, that is, patient level, researcher level and reviewer level data (Dixon-Woods et al., 2006).

When the present study was conceived, there were no published examples of CIS other than Dixon-Woods et al's (2005b) access study. However, CIS derives from an established methodology (meta-ethnography), is sensitive to methodological issues identified by conventional systematic reviews, and draws on its developers' experience in different approaches to reviewing (eg. Dixon-Woods, Agarwal, Young, Jones, & Sutton, 2004; Roberts et al., 2002; Sutton & Abrams, 2001). Also, although Dixon-Woods et al found the volume of data and search methods challenging, they achieved the aim of summarising and interpreting information from diverse literature. For example, in a synthesis of socioeconomic disadvantage and access to healthcare, Dixon-Woods et al (2005a) summarised previous conceptualisations of access and reinterpreted the definition of access, using metaphors to aid understanding. Rather than accepting previous conceptualisations of access as service utilisation, they differentiated between negotiation, presentation (appearance or invitation), judgements and acceptance, and observed that access was jointly accomplished by people and health services. The

reviewers clarified people's experience of health problems in deprived circumstances, and showed how this affected people's use of health services. They also identified service issues, such as local operating conditions, and less 'porous' services, which made access more difficult. These characteristics (service delivery, the patient's perspective, interpreting existing literature from a different viewpoint) also apply to the aims of the present study.

More recent studies have also applied CIS to questions about the interactions between health services and patients' experiences. For example, Kazimierczak et al (2013) adapted and developed an existing conceptualisation of cancer information as "support for navigating the knowledge landscape". This encompassed information within clinical interactions, links between patient information and patient engagement in healthcare, and relationships between patient-oriented information and cancer care pathways. The study incorporated a diverse literature, including non-cancer publications, and explored the complexity and dynamic nature of the relationship between information and patients. The results give a rich description of the identified levels of patients' agency, autonomy, preferences and understanding of information and its place in their care. This gives confidence that the CIS methodology is useable and also appropriate to answer the present research question.

In summary, Critical Interpretive Synthesis was chosen for the present study because it: i) is exploratory and interpretive; ii) develops theory from concepts grounded in empirical evidence; iii) synthesises evidence from the broadest range of sources: qualitative and quantitative research, theory, editorials, audits, case studies and so on; and iv) need not start with a clearly defined question or pre-determined inclusion criteria. These characteristics are ideal for this review to explore the relationships between 'continuity of care' and motivation to engage with cardiac rehabilitation (CR), because these are currently speculative. A model of continuity and quality of motivation for CR based on previous research and theoretical assumptions has been tested in a cross-sectional study (Chapter 3). The aim of the CIS is to interpret information from the broad literature on service provision and motivation to uptake and adhere to CR, in order to further develop the model, which can then be tested. The inclusion of relevant sources, rather than sources using particular methods, supports the exploratory aim of the present study. Including papers with varied analytical approaches elicits a wider range of factors, allows factors to gain credence through triangulation, and sheds light on different aspects of a problem (Dixon-Woods et al., 2004). The synthesis of a range of data, and the thinking applied to it by researchers with different approaches, is expected to enhance the model by reflecting the breadth of understanding about the phenomena.

The aim is to explore the diverse literature on cardiac rehabilitation in a rigorous, coherent manner in order to understand the connections and interactions between continuity of care and patients' motivation to adhere to cardiac rehabilitation recommendations. The focus is on the development of concepts and theory grounded in empirical evidence, rather than on producing summaries of data.

## **4.2 Critical Interpretive Synthesis: Methods**

### **4.2.1 Summary of methods**

The methods of Critical Interpretive Synthesis (CIS) listed in Dixon-Woods et al's (2005b p.16) report were followed (Appendix 2). Dixon-Woods et al reviewed the broad phenomenon of access to care by vulnerable groups. However, in the present study, the question is more precise, focusing on relationships between specific patient (motivation) and service (continuity) characteristics, and how they affect adherence for a specific group of patients (AMI, PCI or CABG patients eligible for cardiac rehabilitation).

#### ***Key steps in CIS in the present study, developed from Box 1.1 of Dixon-Woods et al's (2005b) report*** (Appendix 2)

1. The CIS started with a precise question, and took an exploratory approach by incorporating relevant data of all types. The aim of the review was to develop a synthesising argument – a coherent and integrated set of synthesising concepts elucidating relationships between concepts within the research topic (4.2.1).
2. Inclusion criteria based on populations of interest were developed (4.2.2)
3. Papers representing the populations and concepts of interest were identified through search strategies to identify a purposive and a theoretical sample (4.2.3).
4. An initial purposive (maximum variation) sample was used (4.2.4).
5. Papers were screened, and those not meeting the inclusion criteria discarded (see 4.2.5).
6. Papers selected for inclusion in the review were re-read to confirm relevance and quality assessed using five simple criteria (4.2.6).
7. Data were extracted using a pro-forma (4.2.7).
8. Detailed analysis of data was undertaken to identify concepts and generate themes, aided by NVIVO8 (4.2.8).
9. Theoretical sampling of the literature was undertaken to extend, confirm, and challenge the analysis (4.2.4).



10. The synthesising argument was generated through explicit integration of themes, and is therefore grounded in the evidence but produces a distinct interpretation (4.2.9).

#### **4.2.2 Inclusion criteria**

Papers that include:

- patients with a myocardial infarction (AMI) or cardiac surgery (CABG, PCI)
- any designs that discuss, test, evaluate, elicit, interpret or explore: patient experiences, family experiences, health professional experiences, patient or health professional practice or behaviour, causes, risk factors, models and theories, or interventions to improve uptake and maintenance of cardiac rehabilitation
- available in English

And within these criteria also capture elements of:

- continuity of care
- patient motivation

#### **4.2.3 Searches**

Medline, PsycInfo, CINAHL, BNI and Google Scholar were searched. Strategies included subject headings, textwords, exploded terms and truncation appropriate to each database. Search terms were developed iteratively using terminology from the literature and brain-storming (complete strategies in Appendix 3):

1. 'continuity of care' (29 terms, including: continuity, seamless, liaison, fragmented)
2. patients' motivation (46 terms, including: motivation, autonomy, intention, drive)
3. cardiac rehabilitation (18 rehabilitation and 15 cardiac terms, adapted from Beswick et al (2004);
4. adherence (14 terms, including compliance, concordance, participation).

The results of 'Medline Strategy A', which combined all four groups of search terms, formed the purposive sample. Additional combinations of terms were used to create a pool of references within which to carry out theoretical sampling. This was supplemented with reference chaining, journal contents page scanning and expert recommendations<sup>10</sup>.

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<sup>10</sup> Experts included: 1 Health Psychologist, 1 Exercise Psychologist, 1 Professor working in Health Technology Assessment, 2 Information Scientists working in academic evidence-based health care

#### **4.2.4 Sampling strategy**

##### ***Purposive (maximum variation) sampling***

The purposive sample consisted of the range of patient groups and characteristics of interest. Purposive sampling is used to allow the topic to be studied in depth, and its nuances to be explored. It focuses on few participants (in this case papers), who are 'information-rich', and who provide information that may not be available from other sources (Maxwell, 1997). This is ideal for theory-building, because it allows the identification of potentially pertinent concepts, themes and links to contribute to an overview.

##### ***Theoretical sampling***

Theoretical sampling followed during data analysis and synthesis. The purpose was to identify additional papers that would provide data to extend, confirm, and challenge the emerging synthesis (Dixon-Woods et al, 2006). The focus moved from identifying papers incorporating all aspects of the patient population of interest (maximum variation), to finding papers addressing the concepts under discussion. The aim was to add further depth or breadth to concepts to reflect patients' average responses to continuity.

Incorporation of additional papers stopped once the reviewer was satisfied that sufficient data existed for each category, in line with the sampling techniques of primary qualitative research (Dixon-Woods et al., 2005b p.29). This was judged to have been achieved when new papers were contributing nothing new to the synthesis, or when no new papers relevant to a category could be identified.

#### **4.2.5 Screening**

Titles and abstracts of search results from 'Medline Strategy A' (See 4.2.3) were screened within a Reference Manager database. There were no exclusions based on methodology because in theory-development it is appropriate to include items at the level of 'relevance' of concepts, not only those at the top of a 'hierarchy of evidence' (Dixon-Woods et al., 2006). Also, there is no agreed 'hierarchy of evidence' for qualitative studies, which form a key part of the review. In CIS quality is explicitly discussed within the synthesis, so that the reader can see why particular conclusions are made.

Potentially relevant concepts in abstracts were noted, and full papers obtained for these references. Papers were excluded if they were not about CR, continuity of care, motivation, or adherence; there was no available English translation; or they contained too little detail to explain the topics under investigation (excluded papers listed in Appendix 6).

#### **4.2.6 Quality assessment**

Papers were assessed using criteria adapted by Dixon-Woods et al (2005b), from those proposed by the National Electronic Library for Health (now NICE Evidence Services) for the evaluation of qualitative research<sup>11</sup>. Quality assessment was a starting point for critically appraising the papers within the synthesising argument (4.3.4). No papers were excluded at this point.

The criteria are:

- Are the aims and objectives of the research clearly stated?
- Is the research design clearly specified and appropriate for the aims and objectives of the research?
- Do the researchers provide a clear account of the process by which their findings were produced?
- Do the researchers display enough data to support their interpretations and conclusions?
- Is the method of analysis appropriate and adequately explicated?

#### **4.2.7 Data extraction and coding**

A data extraction pro-forma, based on that developed by Dixon-Woods et al (2005b), was used to summarise participant demographics, intervention (if any), setting, methods of data collection and analysis, major findings and source of papers. Excerpts relating to motivation, continuity of care and CR attendance or adherence from each included paper were copied into data extraction forms (example in Appendix 3).

Coding was used to categorise key concepts within data extracts, aid identification of relationships between concepts, and develop themes. Inductive codes were developed from the content of papers included in the review. This was supplemented with theory-based codes generated by the researcher, based on existing models of continuity of care and Self-determination theory. These theories aided the identification of relevant excerpts and the choice of codes (details in 2.3 and 2.4). However, excerpts and codes reflecting other perspectives were also used to allow a more rounded synthesising argument, and improve the explanatory power of the present study.

Coding evolved as more concepts were developed, and similar codes were merged. Papers were revisited during data analysis to check details and contexts of excerpts. Dixon-Woods et al (2005b) 'summarised informally' large documents. However, in the present study, data was extracted in the same way for large as for small papers.

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<sup>11</sup> Despite an extensive search this source could not be identified

A random selection of five papers was quality assessed and data extracted by an additional reviewer, experienced in systematic reviewing. Similarities and differences in interpretation and coding were discussed and this contributed to the analysis by allowing the reviewer to reflect on possible alternative interpretations.

#### **4.2.8 Data analysis and development of overarching themes**

NVIVO8 software was used to help manage the data. Completed data extraction forms were imported into a database. Attributes of included papers were tabulated (Appendix 5). The database was interrogated to retrieve data by codes or text-words during construct and theme development.

#### **4.2.9 Data synthesis**

The development of themes was aided by grouping and re-grouping data extracts with reference to attribute and coding lists. A 'synthesising argument' was made. This is a critical discussion that integrates ideas and evidence from across included papers, giving a coherent theoretical framework, consisting of networks of factors (constructs) and relationships between them. New concepts ('synthetic constructs') are developed where patterns emerge that were not identified in the original research (Dixon-Woods et al, 2006). For example, 'communication uncertain', 'cues' and 'perceived susceptibility' were some of the codes categorised under the concept 'Message transmission, understanding and acceptance' in Theme 2: Using and sharing information.

Each construct within the synthesising argument was further interpreted in terms of Self-determination theory. This ensured that the argument was grounded in existing understanding of motivation, and enabled the synthesis to inform the further development of the model developed in Chapter 3.

## **4.3 Critical Interpretive Synthesis: Results**

### **4.3.1 Search results**

The search results are outlined in Figure 5. Of 252 papers identified by Medline strategy A, 85 were included in the purposive sample in the synthesis. Nineteen papers were excluded: six were not about CR; four were not about continuity of care; one was not about adherence; one was not about motivation or continuity; one was opinion and theory based on limited evidence; three were not available in English; in two the results were too sparse to be useful; and one listed previous research findings with no additional interpretation (Appendix 6).

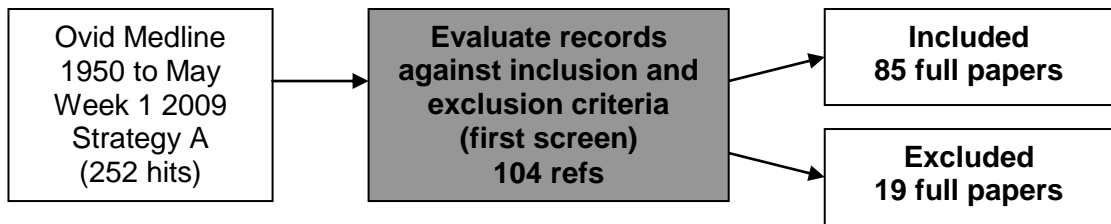
The pool within which theoretical sampling took place was populated with results from multiple searches (4.2.3). The numbers of references captured from sources other than Medline and PsycInfo were not documented (Figure 5). Theoretical searches within this pool of references resulted in 22 additional papers contributing to the synthesis (attributes in Appendix 5).

### **4.3.2 Quality assessment**

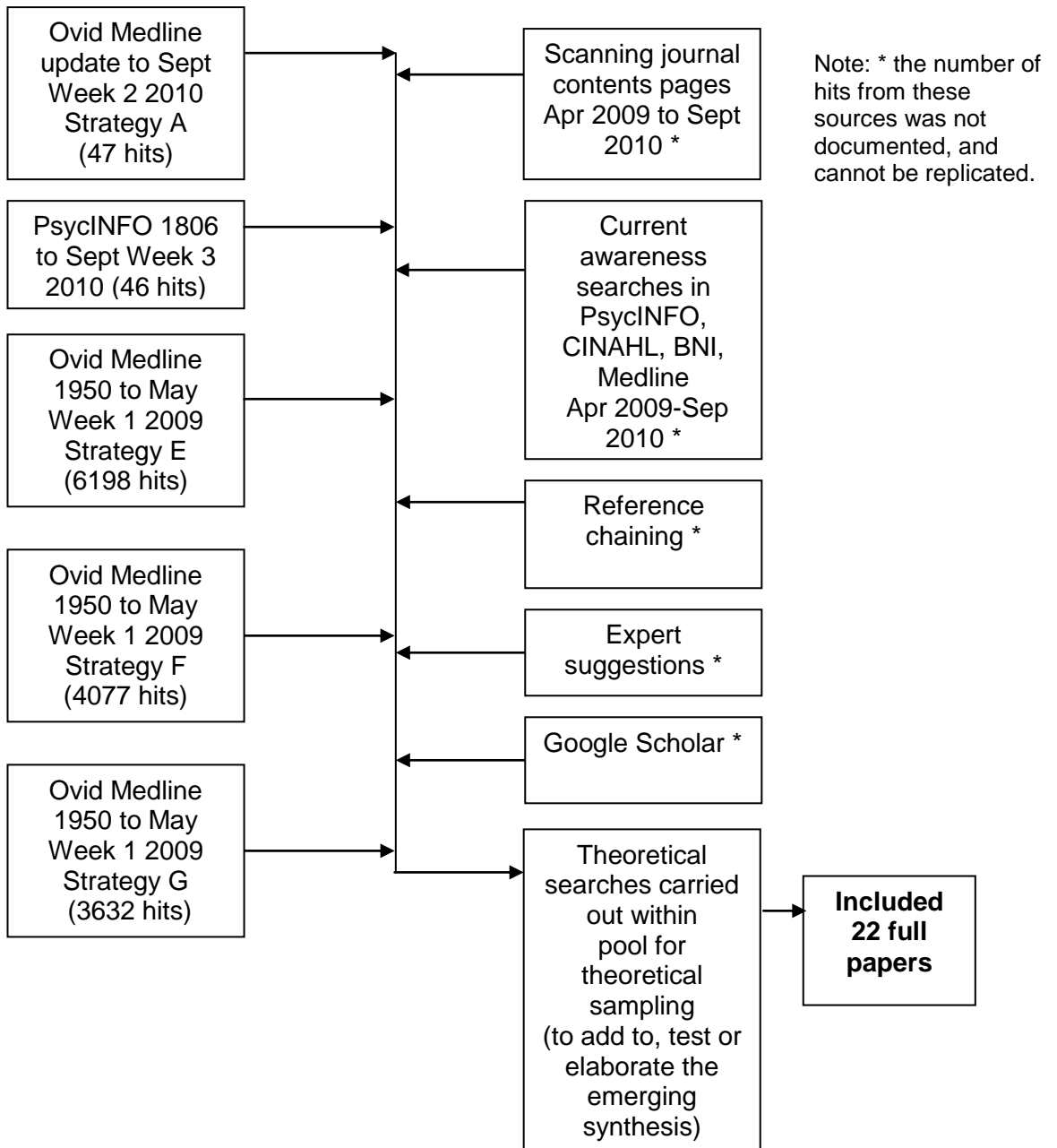
In the purposive sample, all papers met two or more quality criteria, of which 58 met all five quality criteria. All papers were included, because they were relevant and would potentially contribute to the synthesis.

**Figure 5: Flow chart of search steps and results**

**Purposive sample**



**Theoretical sample**



### 4.3.3 Introduction to the synthesising argument: attributes of the purposive sample

In this section the attributes of papers included in the purposive sample are outlined (details in Appendix 5). A summary of the research designs, countries of origin, theoretical frameworks, data analysis and interventions of included papers is given, to describe the context in which the synthesising argument is based (Table 7). The sample achieved maximum variation in that each characteristic of interest was represented in included papers. All heart conditions and treatments of interest, a range of demographics, patients, health-professionals and partners, and attenders and non-attenders were represented.

**Table 7: Characteristics of papers from the purposive sample included in the synthesis**

Research design	Country of origin [number of papers]	Theoretical frameworks*	Data analysis [number of papers **]	Interventions
<ul style="list-style-type: none"> <li>• Audits</li> <li>• Case studies</li> <li>• Chart studies</li> <li>• Controlled studies</li> <li>• Cohort studies</li> <li>• Discussion papers</li> <li>• Focus groups</li> <li>• Instrument development</li> <li>• Literature reviews</li> <li>• Longitudinal surveys</li> <li>• Mail surveys</li> <li>• Phone surveys and interviews</li> <li>• Pre-post studies</li> <li>• Randomised studies</li> <li>• Structured and semi-structured interviews</li> <li>• Systematic reviews</li> <li>• Theory</li> </ul>	<ul style="list-style-type: none"> <li>• Australia [6]</li> <li>• Brazil [1]</li> <li>• Canada [16]</li> <li>• Europe [1]</li> <li>• Germany [2]</li> <li>• Ireland [2]</li> <li>• Jordan [2]</li> <li>• New Zealand [1]</li> <li>• Norway [2]</li> <li>• Scotland [4]</li> <li>• Sweden [4]</li> <li>• UK [12]</li> <li>• USA [32]</li> </ul>	<ul style="list-style-type: none"> <li>• Acute Somatic Disease Framework</li> <li>• Andersen's Health Service Utilisation Model</li> <li>• Continuity of Care</li> <li>• Decisional Conflict Model</li> <li>• Ecological Model</li> <li>• Health Belief Model</li> <li>• Orem's Model of Nursing</li> <li>• Protection Motivation Theory</li> <li>• Self-determination Theory</li> <li>• Self-efficacy</li> <li>• Sense-making</li> <li>• Social Cognitive Theory</li> <li>• Social Learning Theory</li> <li>• Stages of Change</li> <li>• Theory of Goal</li> </ul>	<p><i>Quantitative data</i></p> <ul style="list-style-type: none"> <li>• Inferential statistics [63]</li> <li>• Factor analysis [2]</li> <li>• Content analysis [2]</li> </ul> <p><i>Qualitative data</i></p> <ul style="list-style-type: none"> <li>• Charting [1]</li> <li>• Content analysis [1]</li> <li>• Framework analysis [1]</li> <li>• Phenomenography [1]</li> <li>• Phenomenology [1]</li> <li>• Statistical analysis [2]</li> <li>• Thematic analysis [7]</li> </ul> <p><i>Systematic reviews</i></p> <ul style="list-style-type: none"> <li>• Meta-analysis [1]</li> <li>• Narrative [5]</li> <li>• Quantitative box score (matrix) [1]</li> </ul>	<ul style="list-style-type: none"> <li>• Brief eg. nurse-initiated telephone</li> <li>• Interventions focused on teaching patients eg. CHANGE programme</li> <li>• Intensive interventions eg. Ornish-type</li> <li>• Improving coordination of care eg. liaison nurses</li> </ul>

papers • Validation studies		Attainment • Theory of Planned Behaviour • Transtheoretical Model	Case studies • Inductive thinking [1] • Not stated [1] • Descriptive [2]	
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Notes: \* Theoretical frameworks include those used to guide studies, and those on which instruments used to measure patient characteristics are based (i.e. a study can be designed from a theoretical perspective, or theory-based instruments can be used to measure or compare patient characteristics)

\*\* number of analytic methods is greater than 85, because some papers used more than one method

### ***Theoretical frameworks***

In many included papers, motivation and continuity of care are undefined. Motivation is often presented in a simplistic way, as in Evenson et al's (2006) study, where health professionals considered 'lack of patient motivation' to be a barrier to referred patients attending rehabilitation. Papers with a more complex understanding of motivation were more recent, and had a theoretical basis. For example, Reid et al (2007) aimed to ascertain which theoretical constructs of Protection Motivation Theory, Theory of Planned Behaviour, Social Cognitive Theory, and the Ecological Model could distinguish between active patients who regress and those who remain active. Only one included paper (Riley et al, 2007) refers to the continuity models of Haggerty, Freeman and colleagues (Haggerty et al., 2003). Usually, an understanding of the concept of continuity of care is assumed. For example, "The main point is that it illustrates poor continuity of care in the control of modifiable CAD risk factors by the programmes currently in use" (Lindsay, Hanlon, Smith, & Belcher, 2003). Nevertheless, elements of motivation and continuity were found in all included papers, and these are drawn out in the synthesising argument.

### ***Data analysis***

Most papers in the sample used inferential statistics to identify or clarify associations between patient characteristics and factors affecting engagement with secondary prevention recommendations in CR. The 13 qualitative studies used various analytical methods, ranging from quantitative to qualitative. One included systematic review was a meta-analysis, while the rest were narrative. Rather than pre-judging the relative value of each type of data, the contribution of each paper was evaluated within the synthesis.

### ***Interventions***

Nineteen of the 85 studies evaluated interventions to encourage adherence, improve continuity of care or motivate patients. This included brief interventions such as nurse-initiated telephone calls to enhance attendance at CR intake appointments (Harkness et al., 2005). Other interventions focused on teaching patients. For example, CHANGE aimed to increase exercise maintenance in the year following a cardiac rehabilitation programme by teaching self-efficacy enhancement, problem-solving, and relapse



prevention strategies (Moore et al., 2006). Intensive interventions tended to be based on an approach pioneered by Dr David Ornish, consisting of comprehensive lifestyle change and regular meetings over the long-term. This includes a very low-fat diet, moderate exercise such as walking, stress management including yoga-based stretching, breathing, meditation and imagery, and support groups (eg. Toobert, Glasgow, Nettekoven, & Brown, 1998). Interventions were also designed to improve care coordination. For example, Jolly et al (1998) used liaison nurses to improve communication between secondary and primary care and encourage general practice nurses to provide structured follow-up.

### ***Perspectives, associations and factors***

Papers with patient participants investigated variables associated with referral, enrolment, participation, short and long-term adherence or healthy behaviour (eg. Allen, Scott, Stewart, & Young, 2004; Conn, Taylor, & Abele, 1991; Hagan, Botti, & Watts, 2007). This included initiation of and adherence to drugs or smoking cessation (eg. Attebring et al., 2004; Ye et al., 2007). Other papers assessed factors affecting beliefs, attitudes, coping, decision-making, intentions or motivation in relation to CR advice (eg. Al-Hassan & Wierenga, 2000; Fleury, 1991; Maeland & Havik, 1989). Papers with health professional participants included those about guideline compliance (eg. Heidrich, Behrens, Raspe, & Keil, 2005; LaBresh, Ellrodt, Gliklich, Liljestrand, & Peto, 2004) and CR service provision or design (eg. Doolan-Noble et al., 2004).

### ***Publication dates***

The range of publication dates is 1985 to 2008 in the purposive sample, and 1988 to 2014 in the theoretical sample. Most were published in 2003-2007, with a peak of 14 in 2005. CR programmes have evolved since 1985, begging the question of whether reviewing papers from the last 30 years gives too much weight to the effects of out-of-date practice. However, exploring practice developments can clarify their impact (or lack of impact) on attendance and behaviour.

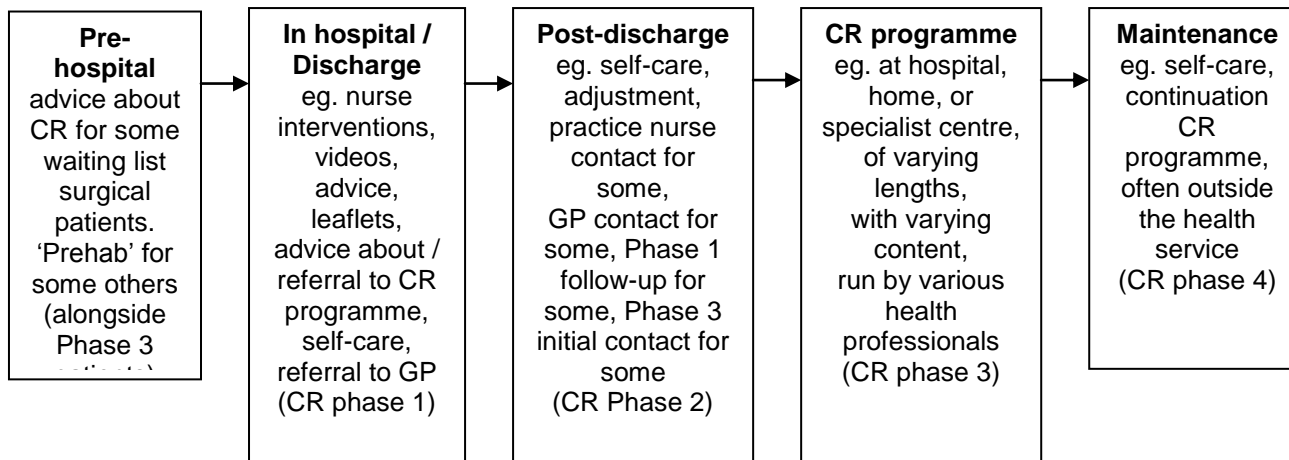
### ***Participants***

Sixty-five studies from the purposive sample had only patient participants. Health professionals were studied in five, both patients and health professionals in six, lay volunteers in one, patients' partners in two, patients and partners in three, and patients' records in three studies.

### **Linear sequence**

Based on this sample of papers, cardiac rehabilitation can be represented by the following sequence (Figure 6). In some countries, such as the USA, Phase two is the point at which a CR programme is followed, and Phase three is the maintenance phase. Some home-based programmes, such as the Heart Manual in the UK, also start their CR programme immediately after discharge.

**Figure 6: Linear sequence of cardiac rehabilitation as identified in the included papers**



#### **4.3.4 Critical Interpretive Synthesis: Synthesising argument.**

##### **Continuity of care and patient motivation for cardiac rehabilitation**

A Critical Interpretive Synthesis is presented here, using a 'synthesising argument' to explore and evaluate data from the papers summarised in the previous section. These are supplemented by reference to papers within the theoretical sample (4.2.4). The synthesis focuses on the relationship between 'continuity of care' and patient motivation to take up and adhere to cardiac rehabilitation. This consists of a critical discussion developed from rigorous qualitative analysis of the sample of published papers summarised in 4.3.3, presented thematically. The aim is to produce a coherent analytical interpretation of the topic, grounded in data from the included papers, which is insightful and useful to those designing cardiac rehabilitation services. The purpose of the CIS approach to reviewing is interpretive, rather than aggregative, that is to develop new and cohesive theory about the interaction of factors, rather than to formally summarise what previous researchers have found or concluded. In the present study, previous conceptions of continuity of care, particularly Freeman's matrix, are used to aid the identification of relevant constructs, though not to the exclusion of other concepts in the data. By being explicit about using an established model of continuity, it is possible to use it to organise and illustrate findings from the study, but also to both build on and challenge assumptions in Freeman's model through an inductive approach to data analysis, thereby developing a novel interpretation. The use of SDT as a lens through which to interpret the findings also allows a coherent overview despite the multiplicity of theories and approaches that exist in the data. This framework contributes to further development of the novel theory about the interaction of continuity and patient motivation established in Study 1, while the findings remain rooted in the data. The synthesis clarifies relationships between continuity of care and motivation, in order to inform the further development of a model tested in a patient survey (Chapter 3). The synthesis is arranged around three overarching themes that sum up how continuity of care affects patient motivation:

- Theme 1: Optimising care;
- Theme 2: Using and sharing information;
- Theme 3: Maintaining supportive relationships.

The three domains of Freeman's Continuity of Care Matrix (Management continuity, Informational continuity and Relationship continuity) are used to aid identification and discussion of 'continuity of care'.

## Theme 1: Optimising care

This theme includes the constructs: negotiating access, monitoring and feedback; and patients as partners in management. Together they capture some elements of management continuity of care that affect patient motivation in relation to cardiac rehabilitation in this sample. Management continuity of care is one of three domains in Freeman et al's Continuity of Care Matrix (Figure 1). The elements of continuity of care identified in the included sample, the related constructs from the management domain of Freeman et al's matrix, and their effect on CR attendance are summarised in Figure 7. Table 8 lists papers informing the constructs within theme one.

**Figure 7: Continuity of care constructs identified in Theme 1: Optimising care**

Continuity of care construct	Related domain and element from Freeman et al's Continuity of Care Matrix (Figure 1)	Suggested impact	CR Phase
Negotiating access	Management: negotiating ongoing access to needed services	+/- Attendance	P1
Monitoring and feedback	Management: detection of significant changes in functional status	+/- Attendance +/- Adherence	P3
Patients as partners in management	Management: inclusion of patients as partners in the management plan	+/- Attendance +/- Adherence	P1-P4

Note: P1 = Phase one cardiac rehabilitation (in hospital), Phase 2 = Phase two (after discharge, convalescing at home), P3 = Phase three cardiac rehabilitation programmes, P4 = after completion of CR classes, possible further classes or referral to exercise classes, or ongoing self-care

+ denotes a positive, and – denotes a negative impact on attendance or adherence

### ***Negotiating access***

#### *Overview*

The concept of 'negotiation of ongoing access to needed services' was exemplified in the present sample in referral to Phase three classes. Evidence suggests that, rather than a transaction whereby the clinician negotiates access to CR on behalf of patients, referral is a process in which access is based on clinicians' and patients' beliefs and perceptions and their interaction. The resulting negotiation is partly based on clinical judgement, but also involves preconceptions by both parties about the capabilities and motivation of the patient, and the appropriateness of CR. These preconceptions may not be overt, but potentially influence decisions about participation.

#### *Health professionals' perceptions of patient motivation*

There is some evidence in the present sample that health professionals' judgements of patients' motivation for CR affects referral decisions, and this may be influenced by preconceptions about demographic characteristics, such as age, gender and socio-economic status, rather than ability and need (Beswick et al., 2004), though clinicians may be unaware of their bias (Beckstead et al., 2014). For example, Corrigan et al (2006)

carried out focus groups and semi-structured interviews with general practice staff during the development of an intervention to improve provision and uptake of secondary prevention of CHD. Staff attributed poor motivation to socio-economically deprived patients, while non-attendance by working people was not considered 'unmotivated' behaviour. Clark, Barbour, & McIntyre (2002) suggest that professionals also consider patients to be motivated if they concur with what staff consider important. In focus groups with secondary and primary care staff, Clark et al found that both groups of staff dichotomised patients into those who were or were not motivated. However, secondary care staff thought motivated people were likely to attend CR, and maintain long-term exercise while primary care staff thought motivated patients would take medications and respond to general health promotion. Thus patients favouring exercise rather than medications for example, might be considered motivated by one professional and unmotivated by another. As Munro et al (2007) point out, using demographics to judge likely adherence is problematic as patients may be seen as 'lost causes' and excluded.

#### *Patient perceptions in referral*

Patients may also see themselves as 'lost causes' and their motivation for CR may be masked or undermined by misperceptions about eligibility and capability. For example, in Heid and Schmelzer's (2004) study of women's participation in CR, all 10 non-attenders interviewed showed an interest in CR, but misconceptions about payment, CR exercise or transport influenced their decision not to enrol. A lack of invitation at the expected time can also undermine patient motivation for CR. Tod et al (2002) explored barriers to CR in semi-structured interviews with 20 patients, nine of whom were still waiting to be invited to CR up to eight months after their AMI. Patients were told they would be sent an appointment six weeks after surgery and assumed that CR would now be pointless. Grace et al (2005) also identified perceptions that prevented women from discussing CR with a health professional. Some patients thought they did not need CR (13/38 patients) suggesting that they may have been unaware of the rationale for CR.

#### *Reciprocal relationship between staff and patients' motivation*

There is some evidence suggesting a reciprocal relationship between the perceptions and motivation of clinicians and patients that affects referral. This can involve clinicians expecting a demonstration of motivation from patients, and being less inclined to refer them if this is not evident, while patients remain passive because they expect staff to direct them. For example, in Grace et al's (2005) controlled intervention study with 69 women PCI patients, 16 stated that they did not discuss CR with a professional because the clinician did not mention it. The intervention, using gender-tailored psycho-educational brochures and motivational interviewing, aimed to encourage women to initiate discussions about CR. This resulted in significantly more intervention patients than controls discussing CR with a clinician (43.8% vs 16.7%;  $\chi^2(1) = 5.99, p = .01$ ).

However, there was a non-significant trend for intervention group patients to be referred (34.4% vs 16.7%;  $\chi^2(1) = 2.83, p = .09$ ). The authors suggest this could be due to ineligibility for CR, physician attitudes or knowledge about CR, distance to CR sites or failure in patient-provider communication. It is also possible that intervention patients overstated how much they had initiated discussions, doctors disliked patients' attempts to be assertive, or patients remained unconvinced about CR, though further research would be needed to ascertain this.

Another aspect of reciprocal motivation occurs when patients and staff agree in their positive or negative perceptions of CR, thereby ratifying each others' views about the need for attendance. For example, Gallagher et al (2003) investigated the influence of patient-related factors on CR attendance among 196 female patients at 4 hospitals in Sydney, in a semi-structured telephone survey. The authors postulated that non-attendance is associated with a combination of health professionals' and women's perceptions about CR being unnecessary or unsuitable. A multilevel design study of 97 cardiologists and 1490 outpatients with CAD supports this idea (Grace et al, 2008). This study found that CR non-enrolment is influenced by professionals' perceptions of poor quality and negative experiences of CR, and patients' scepticism about exercise benefits and the controllability of their disease. Doctors can also agree with patients' feelings about exercise, and their attitudes and confidence in counselling patients may be associated with doctors' own enjoyment of physical activity, self-efficacy and perceived success for ongoing regular exercise (Rogers et al., 2006). Only 41% of doctors in Rogers et al's fitness study met activity guidelines, implying that the remainder might be less keen to encourage patients to exercise.

Grace et al (2008) suggest that doctors are also influenced by patients conveying their perceptions of barriers to CR, and this is supported by a qualitative study in primary care, in which GPs reported abandoning encouragement of secondary prevention after seeing patients' bewilderment or fear about it (Summerskill & Pope, 2002).

### *Motivational referral*

In the present sample, there is some evidence that automatic referral encourages CR attendance. For example, in a cluster RCT, Grace et al (2007) compared automatic referral via a computerised prompt and information pack with referral at the doctor's discretion, in 506 acute coronary syndrome patients. Automatically referred participants were significantly more likely to enrol than controls (OR = 2.28, 95% CI 1.59–3.38). Although more control patients were referred by family doctors (35.0% vs 15.9%;  $\chi^2 = 28.03, p < 0.001$ ), automatically referred participants were significantly more likely to report participation (n = 109, 55.3%) than controls (n = 90, 34.0%;  $\chi^2 = 21.04, p < 0.001$ ).

Automatic referral may have overcome some clinicians' or patients' negative pre-judgements. However, some automatically referred patients were also referred by family doctors, and some control patients may not have been referred, but the contribution of these factors to attendance or non-attendance is unclear. Also, all studies in the present sample found that although automatic referral increased CR enrolment and attendance, many patients still did not attend.

Whether automatic referral deters some patients from enrolling requires further research, but studies in this sample suggest that while a non-judgemental systematic process is effective, better quality discussion may be needed to encourage patient motivation. For example, in a qualitative study, Grewal et al (2010) interviewed four patients referred by each method, either at the doctor's discretion, or by automatic or liaison referral. Patients liked liaison referral because it involved discussions, which started while in hospital, and improved understanding of CR. These results from a small study in South Asian patients reflect preferences, but further research is needed to ascertain whether liaison referral encourages CR attendance. Some patients in this sample gained access to CR by acting on their own initiative, overcoming fragmented care. For example, Tod et al (2002) found that some patients sought advice, paid for private care, took action if communication systems failed, used leisure clubs for exercise and asked friends and family for advice. The authors suggest that more affluent or professional people, used to being 'in control', were more able and had more opportunity to self-refer. However, it may be that other patients would also attend CR if they knew they could self-refer. In a before and after study of factors affecting enrolment of 78 CABG patients, all patients received information about the benefits of CR on discharge, and referral was initiated if wanted by patients (Brady et al, 2005). Fifty-four percent of those referred enrolled in CR, a comparable rate to Grace et al's 2007 study of automatic referral. Although this difference may be due to CABG patients having greater CR uptake than PCI or AMI patients, it is possible that explaining the benefits of CR and leaving patients to make their own decision is more effective than telling patients they are referred.

#### *Summary: Negotiation of ongoing access*

Negotiation of ongoing access to needed services is one aspect of management continuity in Freeman et al's Continuity of Care matrix (Figure 1). While this implies that negotiation of access is a service-provider role, in the present study negotiation of access is seen to encompass negotiation between provider and patient, with the staff role being to encourage participation.

## ***Monitoring and feedback***

### *Overview*

Detection of significant changes in functional status is another aspect of management continuity in Freeman et al's Continuity of Care matrix (Figure 1), and for staff in the included sample this is the purpose of monitoring patients in CR. For patients, ongoing positive feedback encourages lifestyle change. This was embodied in patients comparing themselves to other patients, feedback on achievements from staff and other patients, monitoring, personal record-keeping, experiencing improvements, and feedback from the body. These experiences enable patients to discover their boundaries, particularly in terms of physical activity, so that they can participate confidently. However, there is also evidence that some ongoing monitoring undermines patients' ability to judge their limitations, making them more reliant on staff. Also, for some patients the benefits of monitoring and feedback do not continue after their CR programme.

### *Comparison with others, personal record-keeping and self-monitoring*

Over time, CR participants can be motivated by seeing other patients make progress, or comparing themselves to the relative sickness of others. These effects were described in focus groups with 47 people in Scotland, who had attended a CR programme three years earlier (Clark, Whelan, Barbour, & Macintyre, 2005). This could be explained by Social Comparison theory (Festinger, 1954), which suggests that people compare their own performance with others who are less competent, in order to maintain a positive self-image (downward comparisons) (Corcoran, Crusius, & Mussweiler, 2011). People also compare themselves with others who are more competent, in order to self-improve (upward comparisons) (ibid). In Clark et al's (2005) study, the main positive effects of participation were greater knowledge of personal physical boundaries, and sense of collective identity. Some patients were able to use this as a foundation from which to initiate long-term behaviour change, but for others it was an insufficient basis from which to be confident in their ability to progress. This source of feedback was lost at the end of the programme, particularly if they lived alone.

Personal record-keeping was a potentially more enduring form of feedback identified in this sample, and was enhanced by discussion with staff. For example, home-based patients recorded the exercise they had completed during a RCT comparing hospital with home CR (Jolly et al, 2007). Participants who adhered to home-based CR and took part in focus groups explained that they were motivated in two ways. They could see the progress they had made but they also knew that nurses would check up on them. It is possible that using record-keeping to self-monitor progress may be sustainable after completing CR, particularly if patients discuss it with someone, though research is needed to test this notion. The value of self-monitoring in encouraging adherence was



also highlighted in a study of the theory-based CHANGE programme (Change Habits by Applying New Goals and Experiences). This intervention aimed to encourage exercise maintenance after completion of Phase two (USA)<sup>12</sup> by teaching self-efficacy, problem-solving and relapse prevention in five group counselling sessions (Moore et al, 2006). Two hundred and seventy-three patients were randomised to the intervention plus usual care, or usual care alone. Motivation was measured using the Index of Self-Regulation (Fleury, 1998). The intervention group continued exercising longer than the usual-care group (Log Rank Test = 4.81,  $p = .02$ ), and the usual care group was 76% more likely to discontinue exercise in the year following a cardiac event. However, motivation changed little over the year, and the groups' results did not differ, so the authors did not know what influenced the longer-term exercise adherence in the intervention group. They speculate that self-monitoring skills (diary-keeping, reflection) may have encouraged adherence. It is also possible that continuity provided by the group discussions, rather than their behavioural content, affected adherence.

#### *External recognition and staff feedback*

External recognition of achievements was also important according to results of a questionnaire survey of 52 men involved in CR, where it explained 52% ( $R^2 = .52$ ,  $p < 0.05$ ) of the variance in wellness motivation (Fleury, 1991). External recognition is also evident in some of the more intensive CR regimes in the sample. An observational study of 10 volunteers for an Ornish-type (4.3.3) programme (HeartWorks Plus) found that participants could follow a near vegetarian diet with less than 20% of energy from fat (Franklin, Kolasa, Griffin, Mayo, & Badenhop, 1995). However, it was difficult to sustain this without weekly support and encouragement, particularly as appropriate food choices were limited at work, in restaurants and when visiting friends. Jackson et al (2005) carried out a quantitative review to identify predictors of success for referral and adherence to CR programmes. The authors refer to a survey of 65 CR participants which found that men and women wanted feedback and encouragement from health professionals (Moore & Kramer, 1996). The study found that men and women had similar views about the relative importance of programme features. Positive encouragement from staff and discussions about their progress were rated most highly by both groups. However, men and women thought that although staff were encouraging, discussion about progress was insufficient. Whether feedback about progress influences attendance and adherence would be a useful direction for further investigation.

#### *Physical experience and somatic feedback*

There is evidence from included papers that some patients do not accept that lifestyle change affects recovery, but that this belief can be altered through experience while

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<sup>12</sup> Phase two in the USA is similar to Phase three in the UK, and Phase three is similar to Phase four in the UK

attending CR classes. In Visram et al's (2007) focus group with nine South Asian women members of a CR project in the UK, some participants did not recognise the health benefits of walking until learning about it from health professionals, and experiencing it. The idea that experience plus encouragement allows acceptance to develop also emerged in a phenomenographic study using semi-structured interviews with 113 patients in Sweden between six weeks and one year after a cardiac event (Karner, Tingstrom, Brandt-Dahlgren, & Bergdahl, 2005). Among four categories summing up patients' experiences, somatic incentives, in terms of wanting to reduce pain and increase wellbeing, were important in encouraging lifestyle change. However, positive and negative signals from the body encouraged some patients, but discouraged others. A lack of signals led patients to believe that lifestyle change was unimportant. These findings suggest that CR provides continuity of experience, allowing patients to learn to interpret their body's signals appropriately, and to attribute improvements in wellbeing to their actions. Brady et al's (2005) before and after study of 68 CABG patients referred to CR supports this idea. The study examined exercise tolerance, functional status, exercise behaviour and enrolment. Self-efficacy did not differ between those who enrolled or did not enrol for CR, but improved over time among attenders. This suggests that experience of the behaviour or activity provides feedback to allow patients to judge their capability, while a judgement made prior to participation may be based on inexperience or misconceptions.

#### *Tests and measurements*

Karner et al (2005) also found that indirect signals, in the form of tests and measurements, could encourage or discourage different patients. This is supported by the results of a RCT comparing a highly supervised CR protocol, including ECG monitoring, with a modified protocol that used an educational intervention to promote the adoption of independent exercise, without ECG monitoring (Carlson et al., 2001). Exercising off-site, without ECG monitoring, 63% of less-supervised patients (20/32) and 33% supervised exercisers (11/33) were 'very comfortable'. Exercising on-site, without ECG monitoring, 56% of less-supervised patients (18/32) and 30% of supervised patients (10/33) were 'very comfortable'. Because this was a post-hoc analysis and because the effects of the educational intervention and lack of ECG monitoring could not be differentiated, the authors downplay the suggestion that ECG monitoring could have reduced participants' self-efficacy for unsupervised exercise. Further research comparing supervised monitoring and self-monitoring, and their relation to adherence, identifying functional changes, and clinical outcomes, seems warranted.

#### *Summary: Monitoring and feedback*

Detection of significant changes in functional status is one aspect of management continuity in Freeman et al's Continuity of Care matrix (Figure 1), and for staff this is the

purpose of monitoring patients in CR. However, ongoing positive feedback about changes in status has motivational benefits for patients. Patients comparing themselves to each other, and feedback on achievements from staff and other patients provide useful motivation in the short-term during CR. Learning to self-monitor during CR may provide longer-term motivation for adherence, though this remains to be tested. Patients benefit from health professionals' help in interpreting somatic signals, allowing them to feel confident during exercise. There is also evidence that ongoing ECG monitoring may undermine patients' ability to judge their limitations, making them more reliant on management continuity.

### ***Patients as partners in management***

#### *Overview*

'Inclusion of patients as partners in management planning' is one facet of management continuity in Freeman et al's Continuity of Care matrix (Figure 1). However, in this sample there were examples of staff-controlled and self-management, but little evidence of patients as partners. Patients responded differently to these types of care, depending on whether they had a more internal or external locus of control. Patients also varied in the extent to which they preferred, or tolerated, internal and external motivation, and these preferences interacted with the way in which care was delivered. The interaction of management style with patients' regulation style and beliefs is discussed here in relation to attendance and adherence to CR.

#### *Locus of control*

Several papers in the sample used locus of control (LOC) or health locus of control to ascertain whether patients perceive themselves or external forces as controlling their health, and how this affects their motivation for CR or healthy behaviour. For example, in a study of medical, psychological and social consequences of AMI for 252 women, patients with more internal health locus of control had greater cardiac knowledge, while those with an external LOC had more physician consultations and readmissions at the 3-5 year follow-up (Maeland & Havik, 1989). This implies that patients with an internal locus of control might seek information to help themselves, while those with an external LOC expect experts to direct them (eg. Bailis, Segall, & Chipperfield, 2010). Perhaps differences in patients' LOC need to be considered in CR, with some patients needing support for self-management while others need staff-led care.

However, internal and external LOC may not be mutually exclusive. In a questionnaire survey of 52 men in CR classes with an AMI six months to three years previously, there

were significant positive correlations between both internal and external health LOC and wellness motivation (Fleury, 1991). Although belief in self-control over health outcomes correlated highest, a belief in provider control over health outcomes and chance was also evident. Fleury concluded that this highlights the importance of joint care, and that patient and provider characteristics may interact to increase motivation in cardiac health behaviour. Equally, LOC may not predict attendance. In a semi-structured telephone interview study of 196 women with AMI, CABG, PCI or stable angina in Australia, 12 weeks after their event, perceptions of control did not influence CR attendance as expected (Gallagher, McKinley, & Dracup, 2003). Using the Control Attitudes Scale (Moser & Dracup, 1995), which measures personal control versus personal helplessness, the authors found that personal events, rather than control perceptions, affected attendance.

The conflicting evidence on the effects of control perceptions may be due to LOC changing with age. In a four-year longitudinal study of 124 patients in a health-promotion facility, Bailis et al (2010) found that patients' internal health locus of control (HLOC) increased until middle age, then declined, while external HLOC increased with age. Bailis and colleagues also found that pursuing health goals with more relative autonomy significantly offset the growth of external HLOC, and this has implications for continuity of care. Autonomy support may be particularly needed to enable younger patients to internalise adaptive behaviours, before external HLOC increases. Autonomy support may also help older patients to retain a greater internal HLOC, with the aim of prolonging their ability to self-manage after Phase three CR, though further research is needed to test this.

#### *Staff-controlled vs partnership management*

There was some evidence in this sample that patients' attendance and adherence to rehabilitation advice result from a combination of external and internal motivation. In a semi-structured interview study with 113 patients six weeks or one year after their event, Karner et al (2005) found that patients were motivated externally by advice from staff and internally by patients' reflections on their personal responsibility for health and knowledge. However, studies also found that patients' perceptions of staff-controlled management that did not consider their own perspectives adversely affected attendance. For example, in a focus group study with 44 CR high-attenders, non-attenders and drop-outs in Scotland, high attenders saw health professionals as experts, sources of knowledge, who were interested in their wellbeing and safety (Clark, Barbour, White, & Macintyre, 2004). Non-attenders thought staff were coercive, negative and intense. Drop-outs and non-attenders thought services did not meet their expectations and were poorly organised. Participants' responses suggest that patients had different expectations about

how the service should be delivered. It is possible that high-attenders' expectations of being directed by staff or being involved in their own care were met. However, non-attenders' view of staff as coercive suggests that care was directive, rather than involving them as they wanted. This idea concurs with a survey of 65 CR participants in which men and women stated that they were unable to set their own goals or choose exercises during CR, though they would prefer to do so (Moore & Kramer, 1996). For men, setting their own goals was their greatest unmet preference in CR. These unmet needs had not prevented these patients from attending, but it is credible that this might deter others from participation. This is supported by Clark et al's (2004) study in which non-attenders and drop-outs criticised the exercise programme for being too easy.

However, Visram et al's (2007) focus group study suggests that most women attending a South Asian dance class had self-referred, giving patients a sense that they were doing 'good work'. It is unclear why women had self-referred though the authors report that the women were involved in developing and improving the service, which was designed to be culturally appropriate. Possibly their inclusion as partners, and their values being taken into account, motivated them to participate.

#### *Service barriers to partnerships*

In this sample time constraints and staff attitudes undermined the likelihood of including patients as partners in their management. For example, Arnetz et al (2008) measured staff perceptions and behaviour regarding patient involvement in post-AMI care in a cross-sectional survey of 488 cardiology staff in Sweden. Doctors and nurses considered that priority tasks and lack of time hindered patient involvement in care planning. Some staff also preferred patients to do as they were instructed, rather than being involved. Post-hoc analysis showed that 30% of participants thought that involved patients took time from other patients and might make improper medical decisions. This tension between patient involvement and professional responsibility has previously been highlighted as a barrier to staff-patient partnerships (Kennedy, 2007). Parker et al (2010) also found little evidence of professionals' wanting to encourage patients' agency. However, further research investigating how patient and staff roles can be incorporated to support CR effectiveness would be useful.

#### *Developing self-management skills*

Some patients develop self-management strategies to meet behaviour change targets, such as amending daily activities to incorporate exercise (eg. Jones, Jolly, Raftery, Lip, & Greenfield, 2007). Participants in Jones et al's RCT comparing hospital with home-based CR became bored with prescribed exercise, but started swimming, incorporating exercise with social events or chores. However, some papers suggest that continuity of care is needed to develop self-management skills. For example, an RCT of an Ornish-type

intervention (4.3.3) with 28 post-menopausal women with CHD found that over 12 months participants learned stress-reducing strategies (Toobert et al, 1998). After four months stress-coping scores were non-significant ( $p = 0.07$ ), but by 12 months they were significant ( $p = 0.01$ ). The authors attribute these changes to participants developing strategies to adhere to lifestyle choices, including seeking healthy food providers, persuading children to share participants' diets, and learning to breathe deeply. However, this was achieved after 12 months of twice-weekly four hour stress-reduction meetings, suggesting that long-term, regular, frequent support was needed to develop self-management skills. Further research evaluating supported self-care, and its effects on motivation and adherence, is warranted.

*Summary: patients as partners in management*

'Including patients as partners in management planning' is one aspect of Freeman et al's continuity of care matrix. However, in the present sample patients appear to vary in how much they prefer to be managed by staff, self-manage or a combination of these. This may depend on their locus of control, and their preference for internal or external motivation for behaviour change. Staff also vary in how much they wish to include patients as partners. However, including patients as partners, and using continuity to support the development of patients' self-management skills may encourage long-term adherence to healthy behaviours.

**Table 8: Thematic map of concepts explored in included papers. Theme 1: Optimising care**

<b><i>Negotiating access</i></b>	<b><i>Monitoring and feedback</i></b>	<b><i>Patients as partners in management</i></b>
<p><i>Health professionals' perceptions of patient motivation</i></p> <p>Beckstead et al 2014 (TS) Beswick et al 2004 (PS) Brady et al 2005 (PS) Clark et al 2002 (TS) Corrigan et al 2006 (PS) Munro et al 2007 (TS)</p>	<p><i>Comparison with others, personal record-keeping and learning to self-monitor</i></p> <p>Clark et al 2005b (PS) Corcoran et al 2011 (TS) Fleury 1998 (TS) Jolly et al 2007 (PS) Moore et al 2006 (PS)</p>	<p><i>Locus of control</i></p> <p>Bailis et al 2010 (TS) Fleury 1991 (PS) Gallagher et al 2003 (PS) Maeland and Havik 1898 (PS)</p>
<p><i>Patient perceptions in referral</i></p> <p>Grace et al 2005 (PS) Heid and Schmelzer 2004 (PS) Lindsay et al 2003 (PS) Tod et al 2002 (PS)</p>	<p><i>External recognition and staff feedback</i></p> <p>Fleury 1991 (PS) Franklin et al 1995 (PS) Jackson et al 2005 (PS) Moore and Kramer 1996 (TS)</p>	<p><i>Staff-controlled vs partnership management</i></p> <p>Clark et al 2004 (PS) Karner et al 2005 (PS) Moore and Kramer 1996 (TS)</p>
<p><i>Reciprocal relationship between staff and patients' motivation</i></p> <p>Gallagher et al 2003 (PS) Grace et al 2008 (TS) Rogers et al 2006 (PS) Summerskill and Pope 2002 (TS)</p>	<p><i>Physical experience and somatic feedback</i></p> <p>Brady et al 2005 (PS) Karner et al 2005 (PS) Visram et al 2007 (PS)</p>	<p><i>Service barriers to partnerships</i></p> <p>Arnetz et al 2008 (PS) Kennedy 2007 (TS)</p>
<p><i>Motivational referral</i></p> <p>Brady et al 2005 (PS) Grace et al 2007 (PS) Grewal et al 2010 (TS) Tod 2002 (PS)</p>	<p><i>Tests and measurements</i></p> <p>Carlson et al 2001 (PS) Karner et al 2005 (PS)</p>	<p><i>Developing self-management skills</i></p> <p>Jones et al 2007 (PS) Toobert et al 1998 (PS)</p>

Note: Papers in table were included in discussion, other papers contributed to analysis but are not specifically discussed within synthesis.

PS = purposive sample, TS = theoretical sample (4.2.4)

## **Summary of Theme 1: Optimising Care**

### **Key points**

- **Negotiating access** to cardiac rehabilitation is influenced by health professionals' perceptions of patient motivation and patients' needs for advice, support and encouragement. There seems to be a reciprocal relationship between staff and patients' motivation, which can affect referral. Automatic referral overcomes pre-judgements about appropriateness of cardiac rehabilitation, but also reduces informed choice, which is autonomy supportive and may increase attendance
- **Monitoring and feedback** in cardiac rehabilitation includes comparison with others, acknowledgement of achievements from staff and other patients, experiencing change, and tests or measurements. These can encourage motivation and adherence, though some forms of measurement can encourage patients to rely on staff, while others encourage adherence outside the jurisdiction of staff
- **Patients as partners in management planning** is an ideal of management continuity, but in practice CR is often staff-led and there are constraints on staff encouraging partnerships. Patients' motivation is influenced by their locus of control perceptions, and how they respond to controlling or autonomy supportive staff. Patients desire choice and personal goals and this enhances motivation. Patients are able to adapt behaviour recommendations to fit their lifestyle, but continuity may be needed to support optimal long-term self-management skills



## Theme 2: Using and sharing information

This theme includes the constructs: service use of knowledge about patients; consistency of messages; and information available when needed. The first two constructs relate to aspects of informational continuity of care from Freeman et al's Continuity of Care Matrix (Figure 1). The third construct is an additional aspect capturing patients' need for information and guidance, which is not currently included in the Matrix. In this sample, there is evidence that all three constructs affect patient motivation in relation to cardiac rehabilitation. The elements of continuity of care identified in the included sample, the related constructs from the informational domain of Freeman et al's matrix, and their effect on CR attendance are summarised in Figure 8. Table 9 lists papers informing the constructs within theme two.

**Figure 8: Continuity of care constructs identified in Theme 2: Using and sharing information**

Continuity of care construct	Related domain and element from Freeman et al's Continuity of Care Matrix (Figure 1)	Suggested impact	CR Phase
Service use of knowledge about patients	Informational: accumulated knowledge of patients' values and personal circumstances	+ Attendance	P1-P4
Information available when needed	Not applicable	+ Attendance + Adherence	P1-P4
Message transmission, understanding and acceptance	Informational: consistency of messages communicated to patient	+ Attendance	P1-P4

Note: P1 = Phase one cardiac rehabilitation (in hospital), Phase 2 = Phase two (after discharge, convalescing at home), P3 = Phase three cardiac rehabilitation programmes, P4 = after completion of CR classes, possible further classes or referral to exercise classes, or ongoing self-care

+ denotes a positive, and – denotes a negative impact on attendance or adherence

### ***Service use of knowledge about patients***

#### *Overview*

This sample includes research exploring the impact of patients' fluctuating readiness to change on attendance and adherence to CR, particularly in relation to the Transtheoretical model. Non-cardiac life events also lead patients to prioritise other activities above CR. The linear structure of the CR timeline does not necessarily fit well with patients' readiness or the ups and downs of people's lives. One facet of informational continuity in Freeman et al's continuity of care matrix refers to services' accumulated knowledge of patients' values and circumstances. It is suggested that using knowledge of patients' readiness and life events to decide when to offer services, or to encourage readiness, may encourage more patients to participate.

### *Readiness to change*

The linear conceptualisation of four phases of cardiac rehabilitation (Figure 6) underpins service design, and represents the ideal patient journey (Department of Health, 2000). However, this is contingent on patients being ready for each phase when services are available. In this sample, there is variation in patient readiness to use services when they are offered, and unready patients can be labelled 'unmotivated' (Brady et al, 2005; Evenson et al, 2006) or not referred (Grace et al., 2005). This suggests that staff may be aware of patients' lack of readiness, but this may result in their access to CR being curtailed, rather than their readiness being encouraged, or flexible access being suggested. Nevertheless, there is evidence in the present sample that knowledge of patient readiness can be used to encourage adherence to healthy behaviours.

Most studies in the present sample use the Transtheoretical model to measure readiness (DiClemente et al., 1991; Prochaska & Velicer, 1997). This posits that people move through stages of pre-contemplation, contemplation, preparation, action and maintenance of a behaviour, using various experiential and behavioural processes to do so (2.4). Cardiac rehabilitation attendance and adherence has been associated with a higher stage of change (eg. O'Brien et al., 2009), and Reid et al ( 2007) demonstrated that patients whose stage of change progressed believed that regular exercise could reduce future heart problems, had home exercise equipment and were more likely to attend CR. This data came from a survey of 782 adults hospitalised with CAD (Reid et al., 2006). However, there is also evidence from papers not discussing Stages of Change that non-attenders may progress towards wanting to attend. For example, all 10 non-enrollers interviewed in Heid and Schmelzer's ( 2004) study expressed an interest in a CR programme, but the authors speculate that they may not have been emotionally and physically ready to choose CR when offered during hospitalisation. Interventions to support patients' progress through stages of change have demonstrated effectiveness, for example in relation to diet adherence in CR attenders (eg. Frame, Green, Herr, & Taylor, 2003). However, research into interventions to support progress through stages of change to encourage CR attendance would also be useful.

The Transtheoretical model emphasises that people can regress as well as progress between stages of change, suggesting that they may need continued support to stay in the maintenance or action stages of adherence to healthy behaviours. Hellman (1997) carried out telephone interviews with 349 over-65s post-Phase three with people at all stages of change, to determine predictors of exercise adherence and validate the Stages of Change in Exercise Adherence (STAGES) measure. Participants' self-efficacy, perceived exercise benefits and barriers, and interpersonal support for exercise were significant predictors of exercise adherence, accounting for 50% of the variance in stage

of exercise adherence. This may suggest that, rather than continuing naturally from Phase three, starting Phase four needs a new sense of competence, understanding of exercise benefits, and interpersonal support. Interventions to support self-efficacy and prevent regression have been somewhat effective in patients already in the action/maintenance stage during Phase four (eg. Pinto et al., 2011). However, even among these high adherers there was a 26% attrition rate, perhaps suggesting that people need breaks from progress and adherence, though further research would be needed to confirm this.

### *Life events*

In this sample there was evidence that the timing of personal circumstances also impacts on motivation to participate in CR. Significant life events including comorbidity, bereavement, moving house or losing jobs, feature in the demographic and qualitative data. A semi-structured telephone questionnaire of 196 female inpatients in Australia found that 26% of respondents had a major stressful event within 12 weeks of hospitalisation (Gallagher et al., 2003). This included life-threatening illness or death of a spouse, severe illness, forced residential change or loss of income. Gallagher et al found that the odds of CR attendance decreased almost five times with stressful events during follow-up, unemployment or retirement. It is not surprising that people experiencing these events consider CR participation a low priority. This does not necessarily mean that people are unmotivated to participate, but may be currently more motivated towards other activities. Whether continuity of care has a role in making CR available for patients once they become ready for it, and offering rehabilitation advice that they can incorporate within their current circumstances, requires further research.

### *Summary: service use of knowledge about patients*

Patients' readiness for CR or adherence to healthy behaviours varies over time, and may be influenced by life events other than their heart condition. Stages of change interventions help some patients to progress to, or not regress from action stages, implying that health professionals' knowledge of patients might be used to encourage patients' readiness. However, intervention studies are needed in the early stages of CR, to test whether encouraging readiness encourages enrolment. There is also a lack of research investigating flexible CR provision based on knowledge of patients' circumstances.

## ***Information available when needed***

### *Overview*

While many patients are happy with the information and guidance they receive throughout the CR timeline, there is evidence that some receive too much or too little guidance, or they consider it inappropriate. Patients may find it hard to take in information during hospitalisation or at discharge, and continue to have questions about healthy behaviours throughout the timeline. Phase two is the time that patients may feel most in need of guidance, but this need may not be met. The concept of 'information available when needed by patients' does not exist in Freeman et al's matrix (Figure 1). However, based on the present analysis it is suggested this may be a useful addition to the Matrix.

### *Timely, appropriate guidance*

Several papers in the sample explored patients' needs for specific, appropriately timed guidance. According to the included papers, guidance is provided at certain points in the CR timeline, depending on local practice, and whether care is part of a trial. Usually this is at convenient points for the service, during hospitalisation or Phase three programmes. However, even during contact with services, patients can experience uncertainty about healthy behaviour. A survey of 35 patients and 29 spouses during Phase two CR (USA)<sup>13</sup> investigated how patients coped with a cardiac diet, using Dervin's sense-making approach (Montgomery & Amos, 1991). Attendees were somewhat uncertain about their diet (mean score  $2.86 \pm 0.18$  on a 5 point scale in which 2 = seldom and 3 = somewhat) and thought that having answers to their questions would make them more motivated (mean score  $3.71 \pm 0.18$ , on a scale of 1 = not at all to 5 = a lot). This implies that not having answers to questions may undermine patients' motivation. Even experienced patients had recurring questions about which brands to buy, interpreting labels, quantities of food allowed and which foods were high in sodium and fat, suggesting that ongoing guidance was needed. When patients' expectations of appropriate guidance are not met, attendance may also be affected. For example, Clark et al (2004) carried out focus groups with 50 people purposively selected to cover a wide range of ages, CHD diagnoses and attendance levels in Scotland. Drop-outs in this study had misconceptions about heart disease, and disagreed with staff about their current exercise capacity. This suggests that misconceptions may need to be addressed before Phase three, though further research is needed to investigate how this can be achieved.

Some included papers showed that patients can be overwhelmed by too much information during Phase one, but that informational continuity provided by Phase three attendance or the Heart Manual is helpful. In the BRUM study, which compared home-

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<sup>13</sup> Phase two in the USA is similar to Phase three in the UK, and Phase three is similar to Phase four in the UK

based with hospital-based CR, while most of the 525 participants were satisfied with the support and information they received, 40 people (20 from each arm) thought they were given too much information post-event (Jolly et al, 2007). Hospital-based Phase three attendees considered the quality of education sessions variable, but helpful. Home-based patients liked the content, relevance, scope and positive tone of the Heart Manual. The ability to read it or refer to it in their own time was useful, particularly for those who had difficulty absorbing information given in hospital. This suggests that the Heart Manual allowed patients to access guidance whenever they needed it. Nevertheless, some patients who found the Heart Manual useful were not motivated to exercise, suggesting that guidance alone is insufficient to promote healthy behaviour. Tailoring guidance to individuals' risks might encourage healthy behaviour, as suggested by previous studies (eg. Newens, McColl, & Bond, 1997). Individualised guidance was certainly strongly desired by 17 patients participating in a randomised trial comparing home-based with hospital-based CR (Dalal et al., 2005), interviewed by Wingham, Dalal, Sweeney & Evans (2006) up to 10 days before their CR programme started. Future research to test whether individualised guidance affects attendance and adherence would be useful.

#### *The Phase two gap*

Phase two care is provided in some locations, in primary or secondary care. For example, Lavin et al (2005) found that 82% of Irish hospitals admitting cardiac patients had Phase two provision. However, in the present sample, patients' experience of guidance during Phase two was variable. For example, Riley et al (2007) investigated perceptions of guidance among 506 patients with acute coronary syndrome. Experiences ranged from one patient whose family doctor explained everything he needed to know and was very supportive, to another who "received absolutely nothing". Other studies identified a need for guidance early in the CR timeline. In a semi-structured interview study with 20 AMI patients up to 8 months post-event (Tod et al, 2002) found an unmet desire for a phone helpline during the first two weeks post-discharge. A structured interview study of 130 CABG patients comparing home with hospital CR programmes also identified a decrease in patients' ability to control stress between 2 weeks and 6 months after discharge among those not attending structured programmes (Schuster, Wright, & Tomich, 1995). This suggests that Phase two is a period in which patients are motivated to gain advice and support, without which they are uncertain about optimum self-care. This may be particularly important in areas where Phase three classes are not offered for some patients (eg. Tod et al., 2002), there is a long wait for CR because service capacity is limited (eg. Corrigan et al., 2006) or there are time constraints on health professionals (eg. Arnetz, Winblad, Arnetz, & Hoglund, 2008). A lack of guidance in Phase two may also reduce patients' motivation to attend Phase three classes. For example, a qualitative

study with staff and patients in South Yorkshire found that patients waited 12 months for CR, by which time attendance seemed pointless (Tod et al, 2002).

*Summary: information available when needed*

Patients' need for ongoing information and guidance was evident throughout the CR timeline, even among Phase three attendees receiving regular education sessions. Home-based patients valued the Health Manual as a constantly available source of information, but may need individualised guidance to encourage motivation for healthy behaviour. Some patients experienced a guidance gap during Phase two, when they were most uncertain about optimal self-care. This was exacerbated by variable GP support and insufficient Phase three capacity.

***Message transmission, understanding and acceptance***

*Overview*

'Consistency of messages communicated to the patient' is an aspect of informational continuity in Freeman et al's Continuity of Care Matrix. In the included sample, there was some evidence that consistent messages from health professionals may have encouraged CR attendance or healthy behaviour. However, patients' decisions about CR may also be affected by the way that they interpret, and whether they accept, the messages that they receive. Individual motivational written information may also have a small positive effect on attendance.

*Consistent messages from health professionals*

There is limited evidence from included studies to suggest that consistent messages promote healthy behaviour. For example, Attebring et al ( 2004) conducted structured interviews with 348 hospitalised CAD patients in Sweden to identify factors linked to continued smoking. Three months after discharge, 94% had thought of quitting and 72% had tried. Half had ceased smoking, but there was no difference between quitters and non-quitters in terms of motivation to quit (stage of change) or health beliefs about smoking. However, smoking cessation was related to CR attendance as 56% of attenders vs 34% of non-attenders quit ( $p < 0.0001$ ). The CR programme consisted of five group lectures by different health professionals, each followed by an exercise session. The authors suggest that consistent messages about heart risks at these lectures may have encouraged smoking cessation, though it is possible that patients may have attended CR to gain support for stopping smoking.

In an interview study with 20 AMI patients Tod et al ( 2002) found that inconsistent messages could cause confusion about healthy behaviour, and Riley et al ( 2007) found

that inconsistency could be generated when health professionals do not share information about patients. This led to less appropriate advice and support, duplication or contradictory advice. Riley et al concluded that patients who attended CR perceived better continuity of care partly because CR staff received referral forms from acute care outlining patient-specific information, and primary care physicians received a discharge summary from CR. Staff were therefore able to offer more consistent advice for CR attenders than non-attenders.

### *Interaction of patients' beliefs and perceptions with health messages*

The interaction of health messages and people's beliefs was evident in this sample, with patients' understanding and interpretation of information affecting acceptance and CR attendance. In an interview study with 20 AMI patients, Tod et al (2002) found examples of information being misunderstood by patients. This was worst in group situations, for deaf people and for those whose first language was not English. However, some patients may decide they do not need CR before discussing this with health professionals. In a prospective case-control study of 69 female PCI patients, 38 stated they did not discuss CR with a health professional, of which 13 stated they did not need it (Grace et al, 2005). Referral information may also be unconvincing. For example, in a cluster randomised study comparing automatic and usual referral, 18.5% (n=36) of referred patients did not attend an assessment because they perceived it was unnecessary (Grace et al, 2007). Encouraging acceptance of the rationale for CR and lifestyle change may be hard to achieve, particularly as non-attenders have fewer opportunities to discuss this with staff. For example, in focus groups with 44 full, partial and non-attenders at CR, all groups listed smoking, family history, diet and stress as causes of CHD (Clark et al, 2004). However, most considered themselves not at risk, because they were young, or lacked one risk factor, such as sedentary lifestyle, suggesting that patients may not understand the contribution of multiple factors. Attenders accepted that sedentary behaviour, high alcohol levels, and high blood pressure could lead to CHD, while non-attending and high attrition groups were sceptical that smoking caused CHD, blaming stress, work and busy lives. Patients who attend may already agree with health messages received during their care, but may also develop an understanding of risks by receiving ongoing health messages.

There was evidence in the present sample that perceived illness severity could affect motivation for CR positively or negatively. A study of 41 patients completing Phase two (USA)<sup>14</sup>, using the Health Belief Model (Rosenstock, 1974), found a weak but significant positive correlation between greater perceived severity and general health motivation

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<sup>14</sup> Phase two in the USA is similar to Phase three, and Phase three is similar to Phase four in the UK

(Holm, Fink, Christman, Reitz, & Ashley, 1985). However, a survey of 782 people with CAD using the Stages of Change Model (Reid et al, 2007) showed that some patients regressed from an active stage of change between baseline and six months, which was associated with increasing perceived susceptibility to future coronary events. Such patients were less likely to participate in CR. The authors suggest that fear may increase if patients have a coronary event despite exercising regularly, but it is also possible that patients become more fearful once they learn about risk factors or experience heart symptoms. Interestingly, in a survey of 506 mostly PCI patients, Riley et al (2007) found that perceived consequences and controllability of heart disease were unrelated to severity assessed by clinicians using New York Heart Association classification, or by self-report on the Duke Activity Status Index. However, less grave perceived consequences and greater perceived controllability were related to CR attendance and positive continuity perceptions. This may suggest that continuity encourages some patients to underestimate the severity of their condition, but allows them to overcome their fear. Whether this makes them more or less inclined to engage in healthy behaviour, requires further research.

#### *Motivational messages*

Written information contributed to motivating patients for CR in this sample, particularly if it was theory-based. In a systematic review (Beswick et al, 2004), motivational letters based on the Theory of Planned Behaviour (2.4) (Wyer et al., 2001) and pamphlets (Krasemann & Busch, 1988), were identified as effective in increasing CR attendance. In the study by Wyer et al, motivational letters were sent to patients three days and three weeks after a cardiac event. The aim was to enhance intention to attend CR, by influencing attitudes, subjective norm and perceived control over the behaviour. Eighty-six percent of the intervention group and 57% of the control group patients attended CR ( $p < 0.0025$ ). Krasemann and Busch's study involved post-phase three patients receiving details of local heart groups with or without a pamphlet containing motivational information. Those receiving the pamphlet were more likely to attend the heart group, but Beswick et al point out that no comparison of baseline characteristics was reported, so it is unclear whether the results were biased.

#### *Summary: message transmission, understanding and acceptance*

Consistent messages across the CR timeline can influence patients' motivation for CR and healthy behaviour. However, patients' beliefs and understandings about heart disease risk factors may make it difficult for them to accept the rationale for CR, particularly without the continuity provided by CR attendance.



**Table 9: Thematic map of concepts explored in included papers. Theme 2: Using and sharing information**

<b><i>Service knowledge of patients' circumstances</i></b>	<b><i>Information available when needed</i></b>	<b><i>Message transmission, understanding and acceptance</i></b>
<p><i>Readiness to change</i></p> <p>Brady et al 2005 (PS)            Evenson et al 2006 (PS)            Frame et al 2003 (TS)            Grace et al 2005 (PS)            Heid and Schmelzer 2004 (PS)            Hellman 1997 (PS)            O'Brien et al 2009 (TS)            Pinto et al 2011 (TS)            Reid et al 2007 (PS)</p>	<p><i>Timely, appropriate guidance</i></p> <p>Clark et al 2004 (PS)            Dalal et al 2005 (PS)            Jolly et al 2007 (PS)            Montgomery and Amos 1991 (PS)            Riley et al 2007 (PS)            Wingham et al 2006 (PS)</p>	<p><i>Consistent messages</i></p> <p>Al-Ali and Haddad 2004 (PS)            Attebring et al 2004 (PS)            Riley et al 2007 (PS)            Tod et al 2002 (PS)</p>
<p><i>Life events</i></p> <p>Gallagher et al 2003 (PS)</p>	<p><i>The Phase 2 gap</i></p> <p>Arnetz et al 2008 (PS)            Corrigan et al 2006 (PS)            Johnson et al 2004 (PS)            Lavin et al 2005 (TS)            Riley et al 2007 (PS)            Schuster et al 1995 (PS)            Tod et al 2002 (PS)</p>	<p><i>Interaction of patients' beliefs and perceptions with health messages</i></p> <p>Clark et al 2004 (PS)            Corrigan et al 2006 (PS)            Grace et al 2005 (PS)            Grace et al 2007 (PS)            Holm et al 1985 (PS)            Reid et al 2007 (PS)            Riley et al 2007 (PS)            Tod et al 2002 (PS)</p>
		<p><i>Motivational messages</i></p> <p>Beswick et al 2004 (PS)            Krasemann and Busch 1988 (TS)            Wyer et al 2001 (TS)</p>

Note: Papers in table were included in discussion, other papers contributed to analysis but are not specifically discussed within synthesis.

PS = purposive sample, TS = theoretical sample (4.2.4)

## ***Summary of Theme 2: Using and sharing information***

### ***Key points***

- **Service knowledge of patients' circumstances** is needed to allow cardiac rehabilitation services to be flexible enough to respond to variations and fluctuations in individual patients' readiness to change and life events. The linear conceptualisation of the CR timeline does not easily fit with this.
- **Information available when needed** refers to patients' desire for information and guidance when they need it, without which their motivation for CR may diminish. Phase two has been identified as a time when patients need much guidance, yet this may be where there are most gaps in service provision.
- **Message transmission, understanding and acceptance** suggests that consistent messages from health professionals may help patients to understand the rationale for CR and healthy behaviour. However, patients' views of the need for CR may be coloured by prior beliefs. Delivering messages in a non-controlling way may encourage greater acceptance of the value of CR.

### Theme 3: Maintaining supportive relationships

This theme describes patterns of contact and contexts that engender the development of ongoing relationships which encourage CR attendance and adherence. This includes the constructs: relationships bridging rehabilitation phases; and social environment in Phase three. The ongoing staff-patient relationships and the social situation created in Phase three classes appear to affect patient motivation for cardiac rehabilitation in this sample. Figure 9 shows the elements of Freeman et al's Matrix that aided identification of these constructs. Table 10 lists papers informing the constructs within theme three.

**Figure 9: Continuity of care constructs in Theme 3: Maintaining supportive relationships**

Continuity of care construct	Related domain and element from Freeman et al's Continuity of Care Matrix (Figure 1)	Suggested impact	CR Phase
Relationships bridging rehabilitation phases	Relationship: patient provider relationship that spans episodes and care settings	+ Attendance	P1-P4
Social environment in Phase three	Relationship: organisational culture responsive to personal needs of patients	+ Attendance	P3

Note: P1 = Phase one cardiac rehabilitation (in hospital), Phase 2 = Phase two (after discharge, convalescing at home), P3 = Phase three cardiac rehabilitation programmes, P4 = after completion of CR classes, possible further classes or referral to exercise classes, or ongoing self-care

+ denotes a positive, and – denotes a negative impact on attendance or adherence

#### ***Relationships bridging rehabilitation phases***

##### *Overview*

'Patient-provider relationship that spans episodes and care settings' is one aspect of Freeman et al's Continuity matrix. Within this sample, staff-patient contact bridging the gap in CR between Phases one and three had a positive effect on attendance, and continuing follow-up after Phase three encouraged maintenance during Phase four.

##### *Phone follow-up to encourage CR attendance*

Phone follow-up to encourage CR attendance had a positive impact on attendance, and the benefits of telephone follow-up were serendipitous outcomes in some phone survey studies. For example, one study used phone interviews to determine the effects of exercise on mood and severity perceptions in 65 people referred to CR (McGirr, Rukholm, Salmoni, O'Sullivan, & Koren, 1990). Some CR drop-outs expressed an interest in returning to the programme, one person was referred for psychological counselling, and participants welcomed the emotional support provided by the call, leading the authors to speculate about the potential motivational benefits of such methods. Patients'

motivation for guidance or CR can be hidden, but may be unearthed by contact from a health professional. This may be particularly important for patients who do not make their needs known, perhaps because they are afraid of being a burden. For example, in semi-structured interviews exploring factors influencing CR attendance, one patient avoided asking friends or family for help to attend because she did not want to be a nuisance (Hagan et al, 2007).

Harkness et al (2005) investigated the effect of a nurse-initiated phone call two weeks before scheduled CR appointments, on CR intake attendance, in 1251 CABG patients compared with 2285 retrospective controls. The intervention involved determining the appropriate timing of CR appointments in relation to health status, rescheduling appointments, referral, explaining why CR was important and helping patients develop strategies to overcome barriers. Despite all patients being automatically referred at discharge, 50.1% of controls attended CR intake, compared with 78.1% of the intervention group ( $P < .0001$ ). The nursing phone call was the strongest independent predictor of attendance (unique variance 56.9%, odds ratio 3.429 (95% CI = 2.919-4.028;  $P < .0001$ )). This suggests that nurse follow-up can encourage motivation, particularly if it involves a supportive discussion and is sensitive to patients' needs. However, this does not explain why 22% of patients did not attend. No papers were found that investigated whether too much follow-up may reduce patients' attendance. Negative effects of continuity have been identified in primary care, though they focus on patients seeing the same GP regularly over time. Gray et al (2003) summarised the few studies, concluding that relationship continuity had no significant positive effect on outcomes, and resulted in poorer blood glucose control in diabetic patients. It may be that 'too much' contact also has a negative impact on CR attendance, though further research would be needed to test this.

The possibility that phone calls from staff from different professions have different effects on patients' motivation was raised in some papers. For example, Gallagher et al (2003) investigated the influence of patient-related factors on attendance at CR in 196 female patients at 4 hospitals in Sydney in a semi-structured telephone survey. The odds of attending CR were seven times greater for women undergoing CABG rather than medical treatment for AMI. CABG patients were more consistently referred, but also received more telephone reminders and calls from a range of health professionals, including cardiac surgeons. Gallagher et al suggest that reminders may have influenced attendance, but whether surgeons, or the combination of professions making calls had a greater effect could be investigated in further research. Research evaluating whether

relationship continuity with specific individuals or with the service in general is most effective would also be helpful.

### *Liaison nursing*

Some success of liaison nursing interventions in bridging gaps between secondary and primary services, and enhancing CR attendance was also demonstrated in this sample. For example, the SHIP RCT evaluated liaison nurse-led follow-up of acute heart disease patients in 67 general practices (Jolly et al, 1998). The intervention involved fortnightly patient visits from practice nurses between discharge and Phase three, then three monthly follow-up, using patient-held records to encourage discussion about heart health. CR uptake was greater in the intervention than the control group (37% vs 22%,  $P < 0.001$ ), and intervention patients attended 5/6 vs 3/6 sessions, though most of this difference was accounted for by angina rather than AMI patients. Another approach involved liaison nurses who assessed AMI patients in hospital, offered home or hospital-based CR, passed discharge details to practices and linked with specialist CHD primary care nurses (Dalal & Evans, 2003). An audit of this service found that 87% of patients choosing to follow the Heart Manual at home completed the programme, 49% of those choosing hospital-based CR attended four or more sessions, and the percentage of those achieving risk factor targets increased over one year. However, although the authors state that CR participants adhered to preventive drugs at one year, this was only significant for statins. One strength of the intervention was that practice nurses were alerted to the needs of the 25% of included patients who required individualised support because standard programmes were inappropriate due to comorbidity. It is possible that the liaison role enabled ongoing staff-patient and staff-staff relationship continuity across Phase one to three, ensuring more seamless management and informational continuity. Liaison nursing may allow cross-border staff relationships to develop, leading to improved coordination of care. However, identifying AMI patients in hospital was challenging, highlighting one reason for gaps in care. More robust research is needed to assess how the liaison role affects continuity of care and CR participation.

### *Post-phase three follow up to encourage maintenance*

Many studies suggest that patients completing Phase three CR do not sustain sufficient physical activity, which declines over the next year (eg. O'Connor et al., 1989). In this sample, one RCT evaluated a post-Phase three intervention to encourage exercise adherence among 70 patients (Hughes, Mutrie, & Macintyre, 2007). The intervention group received exercise information and consultations at baseline and six months, and phone calls at three and nine months. Controls received all but the exercise consultation.

Exercise was maintained in the intervention group but declined in the control group over 12 months. As both groups had regular contact with staff, relationship continuity with staff may not have influenced adherence. However, the exercise consultations included assessment of stage of change, discussion about exercise benefits, strategies, relapse prevention and goal setting. Thus, possibly the quality of the ongoing relationship may have been effective. Nevertheless, the authors struggled to explain why the intervention group appeared to overestimate, and the control group underestimated their exercise compared to accelerometer readings. This suggests that intervention design needs to consider the effect on people's perceptions. Continuity provided by longer-term Phase three or Phase four programmes may encourage adherence to exercise (Bock, Carmona-Barros, Esler, & Tilkemeier, 2003), but for those who do not attend Phase four, it remains uncertain whether follow-up helps.

*Summary: relationships bridging rehabilitation phases*

Telephone follow-up after hospital discharge seems to encourage CR attendance, particularly among people who were previously unsure about CR. Involving the patient in a discussion about their wellbeing, the benefits of CR, and ways of overcoming barriers to attendance are also effective. There is some evidence that nurse-led follow-up or liaison between CR settings may encourage CR attendance, though the notion that relationship continuity underpins the success of these interventions requires further research, and interventions need to be tested further before the optimum service is defined.

***Social environment in Phase three***

*Overview*

According to Freeman et al's continuity matrix (Figure 1), one aspect of relationship continuity is an 'organisational culture responsive to personal needs of patients'. In Phase three classes, this might involve the creation of a social environment which encourages patients to participate. In this sample, some patients found group CR daunting, reducing the likelihood of attendance. Others enjoyed the social interaction, the sense of being 'in the same boat', and the emotional support of peers and staff, encouraging them to participate.

*Social benefits of CR attendance*

The social benefits of CR were discussed in several papers, particularly in terms of the interaction between patients in classes, and the gradual realisation that others had similar fears and needs. For example, a focus group study with 47 people who had completed a

CR programme in Scotland found that initial fears turned into enjoyment of each others' company, which motivated them to keep attending (Clark et al., 2005). Some described their loneliness, and the importance of ongoing social contact in their motivation for behaviour change, and losing this contact meant they did not continue to exercise after completing the programme. This suggests that motivation for participation may stem from social goals, not just fitness or cardiac event prevention. However, for others the social element was enjoyable, but graduating with new heart-healthy behaviours was more important. There is also evidence of gender differences in patients' preferences for programme content. For example, in a focus group study women desired more social interaction during CR (Moore, 1996).

Quality of life may also explain some of the motivation for CR attendance. In a survey of 209 CABG patients, CR attenders had significantly higher social function scores than non-attenders (74% vs 62%,  $p=0.04$ ) on the SF-36 quality of life measure 16 months post-operatively (Lindsay et al, 2003). However, attenders also started with a higher social function score preoperatively (50 vs 44%). This may indicate that greater perceived physical or emotional problems which interfere with social activities may deter attendance. The greater increase in social function score in attenders than non-attenders may reflect greater physical and emotional improvement. Alternatively, it may suggest that attenders need social interaction within the CR programme, while non-attenders do not. Thus for some patients, social interaction may motivate attendance, and provide an element of continuity that allows them to adhere to classes, despite being less motivated by class content. Further research is indicated to confirm or refute these suggestions.

#### *Groups as a disincentive for CR*

While many CR attendees found camaraderie and peer support within the group (eg. Clark et al., 2005; Toobert et al., 1998; Visram, Crosland, Unsworth, & Long, 2007), and patients in Clark's focus groups stated that the group was a major factor in their increasing confidence and motivation, several included papers discussed patients' dislike of groups as a disincentive to attend CR. For example, in a longitudinal Canadian survey of 304 CABG patients, 96 of whom attended CR, 15% of attendees left before completion, and one reason was dislike of classroom or group events (King, Humen, Smith, Phan, & Teo, 2001). A semi-structured interview study with patients and staff exploring barriers to access to CR in South Yorkshire found that some patients found group CR inappropriate and unappealing (Tod et al, 2002). This was particularly because patients found this situation socially stressful, lacking privacy, disliked domination by some group members, or felt they would be the odd one out. Some felt that they might be

made more unwell through contact with other patients. Another semi-structured interview study embedded in a randomised controlled trial with patient preference arms, explored 17 patients' choice of hospital or home-based CR after AMI (Wingham et al, 2006). Some expressed a very strong dislike of groups, and would not have participated if home-based CR had not been available. One patient's view that "You get around and share each others' you know, scratch each others' nits....." suggests that CR was expected to be a group therapy session, perhaps with a stigma akin to that attached to drug-use or mental health rehabilitation.

*Summary: social environment in Phase three*

Patients' adherence to CR may be encouraged by staff encouraging social interaction among patients. This can meet patients' needs for social contact, improve social functioning and create a sense of camaraderie and confidence. However, a dislike of groups may deter some people from attending.



**Table 10: Thematic map of concepts explored in included papers. Theme 3: Maintaining supportive relationships**

<b><i>Relationships bridging rehabilitation phases</i></b>	<b><i>Social environment in Phase three</i></b>
<p><i>Phone follow-up to encourage CR attendance</i></p> <p>Gallagher et al 2003 (PS)            Gray et al 2003 (TS)            Hagan et al 2007 (PS)            Harkness et al 2005 (PS)            McGirr et al 1990 (PS)</p>	<p><i>Social benefits of CR</i></p> <p>Clark et al 2005 (PS)            Moore 1996 (TS)            Lindsay et al 2003 (PS)</p>
<p><i>Liaison nursing</i></p> <p>Dalal et al 2003 (TS)            Jolly et al 1998 (PS)</p>	<p><i>Groups as a disincentive for CR</i></p> <p>Clark et al 2005 (PS)            King et al 2001 (PS)            Tod et al 2002 (PS)            Toobert et al 1998 (PS)            Visram et al 2007 (PS)            Wingham et al 2006 (PS)</p>
<p><i>Post-phase three follow-up to encourage maintenance</i></p> <p>Bock et al 2003 (TS)            Hughes et al 2007 (PS)            O'Connor et al 1989 (TS)</p>	

Note: Papers in table were included in discussion, other papers contributed to analysis but are not specifically discussed within synthesis.

PS = purposive sample, TS = theoretical sample (4.2.4)

### **Summary of Theme 3: Maintaining caring relationships**

#### **Key points**

- **Relationships bridging rehabilitation phases** includes phone follow-up after hospital discharge to offer support, answer questions and encourage patients to attend Phase three classes; nurse-led follow-up to encourage patients to adhere to medications and advice; post-phase three follow-up to encourage patients to maintain adherence to exercise and other healthy behaviours; and liaison roles to coordinate care across Phases one to three. These interventions overcome some of the gaps between different CR phases, and between providers, which may allow patients' motivation for cardiac rehabilitation to wane. Such interventions use the staff-patient relationship to act as a human arc between phases.
- **Social environment in Phase three** involves staff encouragement of a welcoming social environment in Phase three classes, so that patients are motivated to attend. Patients who enjoy the camaraderie or social interaction, or are lonely, may be motivated to keep attending for the social involvement, as much as for the content of classes. A lack of social interaction, or a dislike of the group situation, may deter others from attending.

### **4.3.5 Interpretation of the synthesising argument through the lens of Self-determination Theory**

One aim of the present study was to explore whether additional insight could be gained by interpreting the findings through the lens of Self-determination Theory. This may help to explain how and why aspects of continuity of care affect patients' attendance and adherence in CR. In particular, the SDT constructs of internalisation, autonomy support, psychological need satisfaction (autonomy, competence and relatedness) and autonomous vs controlled regulation are discussed in relation to elements of continuity of care identified in the synthesising argument.

Elements in themes one and two suggest that continuity of care may influence CR attendance and adherence by supporting internalisation of values relating to CR and heart-healthy behaviours. In SDT, encouragement of internalisation requires provision of information and a meaningful rationale for the recommended behaviour, without pressurising, while acknowledging the patients' feelings and conveying choice (Deci, Eghrari, Patrick, & Leone, 1994). This approach is described as autonomy-supportive (Ryan et al., 2008). In the present study, theory-based letters and invitations, consistent messages, telephone or nurse-led follow-up, and liaison nursing were identified as somewhat effective in encouraging attendance. In terms of SDT, these elements might be expected to support internalisation by providing a consistent, meaningful rationale and allowing discussion of ways in which barriers may be overcome. However, there was evidence that some messages or follow-up strategies were less effective, and this may reflect the idea from SDT that health professionals can give messages in ways that are difficult to internalise (Sheldon, 2003). Communication perceived as controlling could reduce the likelihood of acceptance, while messages conveyed in an autonomy-supportive way might be expected to encourage attendance. Autonomy support has been associated with self-determined motivation in a number of clinical settings (eg. Williams et al., 2009), including CR, where it also related to exercise duration and volume (Russell & Bray, 2010). Whether autonomy support encourages CR attendance and adherence requires further research.

Elements identified within all three themes resemble the SDT construct of competence, suggesting that continuity may impact on competence need satisfaction. As discussed in theme one, not being referred may lead patients to believe they are considered incapable, or reinforce patients' belief that they are incompetent to attend CR. Staff may alternatively ratify patients' autonomous choice not to attend, by concurring with their negative views about CR. The Phase two gap discussed in theme two may similarly allow

patients to make autonomous decisions about self-care, but may limit patients' ability to understand the rationale for CR and make health-promoting choices. In terms of SDT, patients' sense of competence may be undermined by these examples of discontinuity. Exercise testing in CR, as discussed in theme one, may also undermine patients' competence and intrinsic motivation if they think they may 'fail', or be compared to others (eg. Ntoumanis, 2001). This may apply particularly to patients who dislike exercise or consider themselves less capable, undermining their competence and perhaps leading to avoidance (Patrick & Williams, 2012). Examples where continuity seemed to support patients' competence were also identified. In theme one, positive feedback from staff, self-monitoring and personal record-keeping appeared to be enduring forms of feedback which encouraged adherence. SDT research has shown that positive feedback about someone's improvement in relation to themselves, rather than in comparison to others improves perceptions of competence and intrinsic motivation in physical activity settings (Mouratidis, Vansteenkiste, Lens, & Sideridis, 2008), and self-monitoring enhanced competence and autonomous motivation in weight loss research (Webber, Tate, Ward, & Bowling, 2010). In theme two, it was suggested that individualised guidance or guidance given when needed might enhance patients' ability to understand and follow CR recommendations, and in theme three nurse-led follow-up allowed staff to reassure patients about their competence to participate, and help patients to understand the benefits of CR. These findings evoke SDT in that competence satisfaction supports the internalisation of values and skills relating to a behaviour, enhancing behaviour change (Deci & Ryan, 2008). The role of competence in encouraging autonomous motivation and adherence to prescribed behaviour has been demonstrated in several healthcare settings (eg. Munster Halvari & Halvari, 2006; Williams et al., 2006). Whether continuity in CR supports patients' need for competence and enhances autonomous motivation for attendance and adherence requires further research.

The SDT construct of autonomous vs controlled motivation is suggested by several elements identified in the synthesis, particularly in themes one and two. People experience a combination of external and internal motivation in social contexts (Deci & Ryan, 2000). However, autonomous motivation plays an important role in adherence because action that is contingent on external control only lasts until that control stops (Hagger & Chatzisarantis, 2011). In theme one, it was suggested that patients may be less adherent if CR is staff-managed without patient involvement, and this is reminiscent of controlled motivation in SDT. Monitoring for clinical purposes, as discussed in theme one, could also be interpreted as controlling. Some patients appeared to accept staff control, believing it supported safety, and controlled regulation may be needed while patients learn to self-monitor. However, elements reminiscent of autonomous motivation seemed to encourage attendance and adherence. In theme one, explaining the benefits

of CR and leaving patients to decide whether to attend appeared more effective than telling patients they were referred. Patient involvement in care planning and choice of activities also appeared to encourage attendance. Offering choice and involvement in goal-setting are supported by SDT because they satisfy psychological needs and increase participation in the chosen activity (Hagger & Chatzisarantis, 2008). Choice is also effective in enhancing attendance in clinical settings (eg. Vandereycken & Vansteenkiste, 2009), and further research is needed to confirm whether this applies in CR referral and during Phase three. In theme two, being in the action and maintenance stages of change, and progression towards these stages, were linked to CR attendance and adherence. This may indicate increasingly autonomous motivation, as identified in research with diabetic patients (Fortier et al., 2012) and in exercise programmes (Milne, 2008), though research would be needed to test this in CR. However, Fortier et al (2012) suggest that supervised exercise may prevent self-determination in some patients, while autonomy supportive exercise counselling supporting choice may be more effective. This may also be applicable in CR, and further research exploring this would be useful.

Elements reminiscent of the SDT construct of relatedness were identified in theme three. There was some evidence that ongoing contact by phone or in person encouraged CR attendance, and this may have been supported by the development of trusting relationships between nurses and patients meeting some patients' need for relatedness. Staff encouragement of a supportive social environment also seemed to make CR more welcoming and enjoyable. This could reflect the SDT construct of relatedness support, which has been shown to encourage a sense of belonging in experimental situations (Sheldon & Filak, 2008), though further research is needed to test this in CR. In theme three, social interaction in Phase three encouraged some patients to attend, perhaps suggesting relatedness satisfaction among participants, as has been shown to encourage attendance in exercise programmes (eg. Edmunds et al., 2007; Wilson, Rodgers, Blanchard, & Gessell, 2003). However, examples were also outlined in theme three of group-based CR discouraging some patients from attending. In terms of SDT this may reflect the idea that some people avoid situations where their need for relatedness might be met, perhaps to avoid the pain of potential rejection (Moller, Deci, & Elliot, 2010). Alternatively, patients may not participate due to social pressure or disapproval engendered within the group, but the decision to rely on themselves, rather than be dependent on the group or the health service, may also be autonomous (Chirkov, Ryan, Kim, & Kaplan, 2003). Further research is needed to examine whether and how relatedness need satisfaction affects CR participation.

Previous research has considered how CR attendance, healthy behaviours and adherence relate to continuity of care or psychology and motivation. However, using SDT

as a lens through which to observe the findings of the CIS has allowed a focus on what works best at the congruence between patients' psychological needs and how the service is delivered. It appears that the quality of staff-patient interactions when applying elements of continuity, in addition to continuity per se, affects motivation for attendance and adherence.

#### **4.3.6 Conclusions**

The present study employed a Critical Interpretive Synthesis to identify and characterise evidence for a relationship between continuity of care and patients' motivation to attend and adhere to cardiac rehabilitation programmes and healthy-heart advice in a sample of the diverse literature on cardiac rehabilitation. The analysis suggests that continuity of care can affect patient motivation for joining CR programmes, and following healthy behaviours. This varies depending on individual patients' characteristics and contexts, and different aspects of continuity (relationship continuity; management continuity; and informational continuity) may affect motivation in different ways.

Under the theme of 'Optimising care', the analysis suggests that patients' access to cardiac rehabilitation is negotiated between patient and health professional(s). Discussions and referral initiate a continuum of care, and this is a crucial point at which motivation can be enhanced but there is some evidence that reciprocal motivation between patients and staff may reduce the likelihood of CR attendance. Automatic referral can enhance uptake rates, because it is not biased by value judgements, but the most effective method may be provision of information followed by self-referral, because this supports patients' needs for competence and autonomy.

Monitoring and feedback seem to have varying effects on attendance and the likelihood of patients continuing to practice healthy behaviours after completion of Phase three. Extensive monitoring allows management continuity, as staff identify functional changes in patients, and make appropriate clinical judgements. However, there is some evidence that such monitoring undermines patients' confidence in deciding for themselves how much to exercise, while learning to self-monitor, keeping diaries, and receiving feedback from staff supports their sense of competence in physical activity.

Patient reliance on staff seems to be partly a result of patients having an external locus of control, partly related to whether management is controlling or autonomy supportive, and partly influenced by how autonomous patients feel. Further research is needed to tease out these interactions and the balance between service-led care, staff-patient

partnerships and self-management, in encouraging short and long-term behaviour change.

In the 'Using and sharing information' theme, it was argued that the linear design of the CR timeline did not fit well with patients' fluctuating motivation in terms of readiness to change over time. This affected uptake of Phase three or four programmes and learning new behaviours. Also, for some patients CR timing conflicted with other significant life events. Patients needed timely, appropriate guidance at different points, suggesting that flexible continuity of care may be needed to ensure access to services and support. Phase two was identified as the time when patients desired most support and information, while continuity could be missing, leading to a lack of confidence in the service and themselves.

The role of consistent messages given to patients throughout cardiac rehabilitation was discussed. Evidence was found that patients' prior beliefs affect how they perceive and understand health messages, but also that consistent messages from different staff may help to encourage patients to accept the role of CR and healthy behaviour in secondary prevention. Information from health professionals may be more effective when backed up by public health messages, theory-based motivational letters and pamphlets, and reference sources such as the 'Heart Manual'. The quality of message design and delivery, not just consistency, is also important.

The theme of 'Maintaining supportive relationships' outlined interventions, such as nurse-led and phone follow-up bridging gaps between care settings and groups of providers. These increased CR attendance and referral to other needed services, possibly through increasing patient motivation, or allowing latent motivation to be expressed. Participation in Phase three had a motivating role due to ongoing staff-patient, and patient-group relationships, which seemed to support the patient's need for relatedness and competence, and encourage adherence. Staff-patient interactions characterised by discussion, encouragement, and patient-led exercise choices and goal setting seemed to be most motivating.

The analysis highlights that management, informational and relationship continuity are intimately co-related, suggesting that all three aspects of continuity are needed to encourage CR attendance and adherence. However, the quality of staff-patient interactions when applying elements of continuity, rather than continuity per se, appears to have the greatest impact on motivation for attendance and adherence.

In the present study, elements of Freeman et al's continuity of care matrix were considered from a patient-centred position, furthering work by other researchers in mental health and cancer (Parker et al., 2010). Some amendments to the matrix are recommended, particularly where it is unclear how staff should apply some continuity elements. For example, one element of informational continuity is 'accumulated knowledge – often tacit – of values and personal circumstances of the patient'. The present study identified knowledge of patients' readiness and life events as relevant to this element. However, how staff use this knowledge to help patients to progress, rather than the knowledge itself, is what allows continuity of care. The analysis of this continuity element also identified the mismatch between the linear CR timeline and fluctuations in patients' journeys. This adds to previous work highlighting the difference between ideal care pathways and patients' complex journeys in stroke and learning disabilities (Parker et al., 2010).

An element of informational continuity missing from the matrix, but identified in the present sample, is 'Information and guidance available when needed'. Currently, the matrix includes 'Patient and family included in information loop', which implies that patients will receive information when it is generated for clinical purposes or as part of a process, rather than in response to patients' needs for advice and understanding.

The present approach takes a coherent overview of the whole CR timeline, overcoming the limitations of previous research which focused on individual phases of the CR timeline, or specific aspects of treatment, such as diet or exercise. The present study also adds to previous knowledge by contributing to the understanding of the variable and fluctuating nature of patient motivation and how service delivery interacts with this in increasing or reducing the likelihood of CR attendance, and adherence to healthy behaviours.

The findings of the present study are now presented in a proposed model of the relationship between continuity of care and patient motivation. The constituents of the model are theoretical, and open to further iteration and validation, which could include further exploration of existing evidence, or primary research, both qualitative and quantitative.



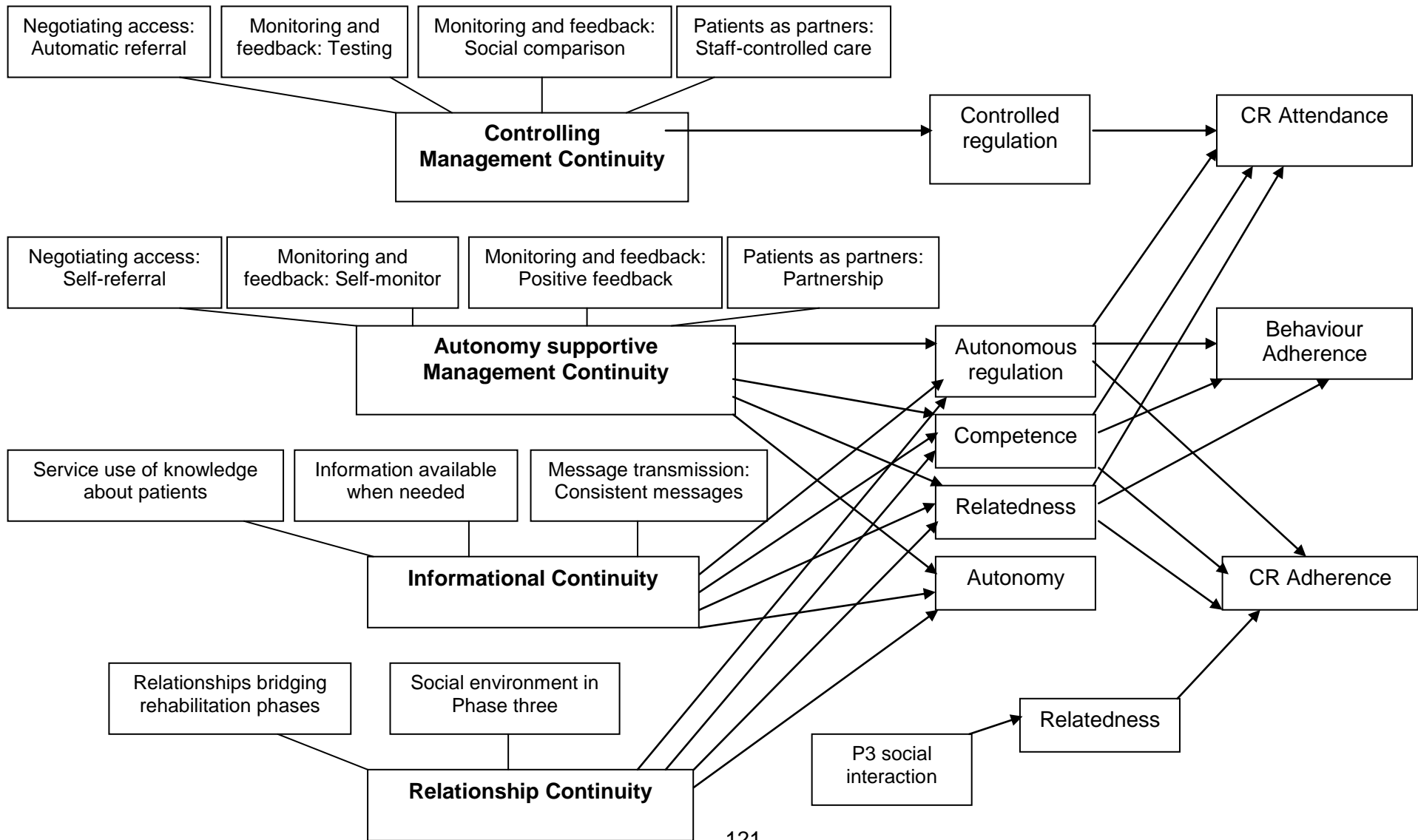
#### **4.3.7 Model developed from the Critical Interpretive Synthesis: The elements of continuity of care that affect motivation to adhere to cardiac rehabilitation**

The proposed model developed from the results of the CIS is shown below (Figure 10). This presents elements of continuity of care identified from the reviewed literature sample that are relevant to cardiac rehabilitation. Each element is mapped to the relevant domain(s) of Freeman's Continuity of Care matrix (Figure 1), that is, relationship, management or informational continuity. Two aspects of management continuity have been differentiated, representing controlling and autonomy supportive styles, as the synthesis suggests that both aspects may encourage CR attendance, through different mechanisms. Controlling management continuity may work through controlled regulation, while autonomy supportive management continuity may work through autonomous regulation and need satisfaction. Satisfaction of the needs for autonomy, competence and relatedness, and autonomous regulation are anticipated to predict adherence to CR and healthy behaviours. The encouragement of social interaction during Phase three classes is expected to encourage a sense of relatedness, which may contribute to CR adherence.

The proposed model resembles the model tested in Study 1 in that continuity of care is predicted to influence motivation for CR attendance, but it also differs from that model. In Study 1, continuity of care predicted autonomy support, which predicted the degree of self-determined motivation for CR attendance. However, the results of the present study suggest that the three aspects of continuity of care (management, informational and relationship) interact differentially with motivation, so are presented separately in the proposed model, along with practices and processes in which they appear to be characterised. In Study 1, autonomy support was predicted by continuity of care, but in the present model, both autonomy supportive and controlling aspects of management continuity are presented, as their differential effects were identified in the present study.

Primary research is needed to investigate aspects of the proposed model. The first study to address this need is a focus group study with CR patients and staff (Chapter 5).

**Figure 10: Proposed model of continuity of care and motivation to adhere to cardiac rehabilitation**



Note: P1 = Phase one cardiac rehabilitation (in hospital), Phase 2 = Phase two (after discharge, convalescing at home), P3 = Phase three cardiac rehabilitation programmes, P4 = after completion of CR classes, possible further classes or referral to exercise classes, or ongoing self-care. The figure includes: 1) elements of Continuity of Care that affect motivation for cardiac rehabilitation in specific phases of rehabilitation, eg. Monitoring and feedback is evident in Phase three; 2) The number of the Theme from which that element is taken (eg. Theme 1: Optimising care); 3) The antecedent(s) of motivation that is/are affected by that element of Continuity of Care and whether the effect is positive or negative; 4) Whether uptake and/or adherence to cardiac rehabilitation is positively affected.

#### **4.3.8 Limitations of the synthesis and implications for research**

Several caveats must be made when considering the findings and conclusions of the present study. This is an exploratory study, using a small sample of primary papers. Although efforts were made to include papers representing all aspects of the population of interest, the sample may not be representative of all research on continuity of care and motivation for cardiac rehabilitation. Therefore the results may not reflect the average case. The number of papers identified from some sources was not documented, reducing transparency in the reporting of methods. The search strategies used may have missed papers that might have contributed to or refuted the synthesising argument. This means that it is uncertain whether data saturation was achieved within each construct. However, this modest study did not aim to capture every element of continuity within cardiac rehabilitation, and further research is recommended to investigate additional aspects of this topic. Using Freeman et al's continuity of care matrix and Self-determination theory may have biased the results though this aided interpretation of the data. Limitations of the included papers may have contributed to limitations in the synthesis, particularly where there was unclear reporting.

##### **Limitations of the dataset**

Many included studies do not specify at what point in the timeline patients participated in CR, making it difficult to judge how motivation varies over time. Neither do authors often define Phase two or Phase three. In the USA, for example, cardiac rehabilitation providers' descriptions of Phase two are similar to Phase three in the UK (Ascension Health, 2007), but this was not overt in the papers. Neither are specific contents, duration, intensity and frequency of elements of CR programmes, such as exercise, diet advice or stress management, always described. Studies that describe programmes tend to be those that focus on one element, such as exercise, diet, drugs or smoking cessation.

In some papers it is unclear which patient groups are being discussed, or whether they are at low, moderate or high risk of cardiac events. Others analyse AMI, CABG or PCI patients together, so one cannot tell whether continuity affects motivation of sub-groups differently (eg. Allen et al, 2004; Corrigan et al, 2006; Reid et al, 2007). Some papers include patients outside the focus of the present study, particularly people with angina (eg. Harrison & Wardle, 2005; Ramsay et al., 2005). However, some papers explicitly compare outcomes for different patient groups. For example, Brophy, Bourgault and Brassard (2003) compare prescription-filling by CABG and PCI patients and Gallagher et al (2003) compare CR attendance in women with CABG or AMI.

The age of patients eligible for inclusion is sometimes described, as is the actual age range or mean age of participants, but it is unusual to find all three elements in a paper. Comparison of study results is difficult due to widely differing age ranges of participants. For example: 18-50, 20-85, 30-52, over 30, over 67. Most papers include both men and women, though women tend to be in the minority. Four papers included men only, and seven only women.

Attendance or adherence thresholds vary considerably, making it difficult to compare the results of studies. For example, a focus group study compared individuals with high attendance (>60% attendance), high rates of attrition (<60% attendance) and non-attendance (0% attendance) (Clark et al, 2004), whereas a retrospective observational study measured those who completed a CR programme, did not attend any programme, or partially completed (less than 50% of time) (Lindsay et al, 2003).

In summary, the present study is exploratory, the results, conclusions and model are theoretical, and further testing is recommended. Specifically, confirmation of findings about the relationship between continuity of care and patient motivation in CR from the present study is required. For example, do staff misperceptions about patient motivation result in less referral, affect motivation, or influence CR uptake and adherence; is 'too much' continuity perceived as controlling, creating an aversion towards behaviour change; and are patients who avoid CR participation exhibiting autonomous behaviour? Additional research needs identified during the synthesis are summarised in Appendix 11.

## **Chapter 5: Continuity of care and patient motivation for cardiac rehabilitation: thematic analysis of patient and staff focus group discussions**

Study 1, reported in Chapter 3, tested a hypothesised model of the relationship between continuity of care, autonomy support and self-determined motivation for cardiac rehabilitation attendance, and established the existence of a predictive relationship between the three latent variables. Chapter 4 presented a Critical Interpretive Synthesis (Study 2) which explored questions developed from the results of Study 1, considered the relationships between continuity of care and patient motivation in greater breadth and depth, expanded the investigation to consider adherence to cardiac rehabilitation attendance, and adherence to heart-healthy recommendations, identified additional putative factors contributing to the model and developed a coherent overarching theory about interactions between factors, guided by self-determination theory. In the CIS it was concluded that different continuity of care domains (informational, management, relationship), and different elements of cardiac rehabilitation practice may affect patient motivation in different ways, and that there is some evidence that need satisfaction may be implicated in CR attendance, adherence to CR and adherence to healthy behaviours. In Chapter 5, a focus group study (Study 3) of patients and staff in the UK is reported, which investigated the relevance and applicability of these findings in the context of current NHS practice, and explored the cardiac rehabilitation experiences of patients and staff in greater depth in order to inform future NHS practice.

### **5.1 Introduction**

Cardiac rehabilitation (CR) is an effective secondary prevention intervention for people who have been treated for cardiac events (Clark et al., 2005; Heran et al., 2011; Taylor et al., 2004). However, although National targets aim for 85% of eligible patients to attend Phase three CR classes, only 44% participate (BHF Care and Education Research Group, 2012). Previous research has identified many reasons for patients not attending CR, whether health related (e.g. Ratchford et al, 2004), sociodemographic (e.g. Sundararajan et al, 2004), logistical (e.g. Doolan-Noble et al, 2004), social (e.g. Van Horn et al, 2002) or psychological. Psychological barriers are of particular interest in explaining and encouraging attendance, as they are perceived to be amenable to change (Sutton, 2002). Service delivery barriers, particularly non-referral (e.g. Kemps et al, 2011), staff-patient communication (e.g. Chauhan et al, 2010), access (e.g. Harrison & Wardle, 2005), and fragmented care (e.g. Cupples et al, 2010) have also been explored. Service changes and interventions have been tested, and those with a theoretical psychological basis have had some positive effects on attendance and adherence (eg. Beckie &

Beckstead, 2010; Carroll, Rankin, & Cooper, 2007; Sniehotta, Scholz, & Schwarzer, 2006). However, improvements are still needed if more patients are to benefit from this effective treatment. One direction with potential to address this need is the interaction between how the service is delivered and the effect of this on patients' motivation for cardiac rehabilitation. Few previous studies have investigated this interaction, but Riley et al (2007) identified continuity of care as an aspect of service delivery with a positive effect on cardiac rehabilitation participation, and recommended further research to explain how continuity interacts with patient characteristics. In the present study, aspects of continuity of care were discussed in focus groups with cardiac rehabilitation patients and staff, to explore how they affected attendance. Self-determination theory has provided a basis for clarifying mechanisms underlying patients' behaviour, while taking the social context into consideration, in an extensive body of healthcare research (Patrick & Williams, 2012). Therefore, SDT was considered an appropriate framework with which to interpret the findings of the focus group study.

The overall aim of the present project is to investigate the interaction between service delivery (specifically continuity of care) and patients' motivation for CR. In study 1, a Critical Interpretive Synthesis (Chapter 4), previous research was examined for evidence of a relationship between continuity of care (CofC) and motivation to attend CR. Several examples suggesting links between CofC and patient motivation or attendance were found. However, no studies were identified that specifically aimed to investigate the interaction between CofC and motivation. Thus the conclusions of the Critical Interpretive Synthesis (CIS) were somewhat tentative, and needed to be confirmed or refuted by primary research. Therefore, the present study was designed to explore patient and staff experiences of CofC in CR, and how they considered this affected patient motivation to attend.

One limitation of the studies included in the CIS, and of the CIS itself, was that it was not possible to differentiate between sub-groups of patients who received medical treatment, CABG or angioplasty (PCI) after a cardiac event. However, sub-groups may have different experiences and motivating factors. For example, PCI patients may be more likely to believe that they do not have heart disease, or that they are completely cured (Campbell, 2005; Fernandez, Griffiths, Juergens, Davidson, & Salamonson, 2006). In the present study, the experiences of PCI patients are explored, because these are the lowest attenders at CR (31%), and a great number of people (87,000) undergo a PCI each year (Townsend et al., 2012). An insight into their experiences was expected to clarify some of their reasons for deciding whether to attend. The present study was designed to identify key elements of CofC and their effect on motivation, whether or not these were found in the CIS.

In summary, the aims of the present study were to:

- Explore patients' experiences of cardiac rehabilitation, particularly in relation to continuity of care and motivation to attend;
- Explore staff experiences of delivering cardiac rehabilitation, particularly relating to continuity of care and its effect on patients' motivation to attend;
- Compare and contrast patient and staff experiences of CR;
- Compare and contrast experiences of participants at two sites with different ways of delivering the service;
- Discuss these findings in relation to the results of the CIS;
- Amend the model of continuity of care in CR developed from the CIS;
- Make suggestions for further research.

## **5.2 Methods**

### **5.2.1 Research design**

A qualitative approach was chosen because this can reveal patients' priorities in healthcare (Sofaer, 2002). It allows an insight into patient and staff experiences of cardiac rehabilitation, and enables participants to talk about what is important to them, rather than focusing solely on the researcher's perspective (Creswell, 2008). The aim was to improve the understanding gained from the CIS, and identify new questions for future research.

Different methodological approaches were considered for the present study, particularly interpretive phenomenological analysis (IPA; Smith, 2004) and grounded theory (Glaser & Strauss, 1967). Both of these methodologies look for patterns across data, which meets the aims of the present study. However, they also require analysis of meanings for particular individuals in depth (Charmaz, 1990; Smith, 2004), while the present study aims to identify generalities across groups. In grounded theory, data collection is also iterative, and is shaped by emerging theory (Charmaz, 1990), which was not feasible in the present modest study. Both also rely on specific epistemological assumptions, which were not wholly compatible with the position of the researcher, or the research question in the present study (Braun & Clarke, 2006). The overall position taken is one of pragmatism, which means that a range of methods and strategies is used to address the research question (Creswell, 2008). For example, purposive sampling was used to maximise the similarities and differences of information, as in grounded theory (Creswell, 2008).



Focus groups were used rather than interviews as attitudes, feelings and beliefs are more likely to be revealed through social interaction (Gibbs, 2008), and participants feel supported in expressing feelings outside assumed norms, or the researcher's culture (Pope & Mays, 2006 p.23).

### **5.2.2 Sample**

Both patient and staff focus groups were carried out to explore the topic of interest in greater depth, and allow different perspectives to be taken into account. This triangulation approach aims to collect diverse data resulting in a more comprehensive understanding of the situation (Tobin & Begley, 2004). Patients could express their individual and shared experiences of the service, while staff could provide a broader overview of the CR system and processes. This 'person triangulation' was expected to provide a richer picture, and highlight differences and similarities between patient and staff views.

Patients and staff from two CR sites were included in focus groups. This was because practice is known to vary, so experiences may be different in different locations. It was anticipated that this might highlight ways of delivering the services which could enhance or undermine patient motivation. The aim of using this completeness approach to triangulation was to deepen the analysis, make the study more holistic and allow cross-checking (Knalf and Breitmeyer, 1991, Guba and Lincoln, 1989, cited in Grbich, 1999).

Sampling was purposive, to involve participants with the potential to provide rich, relevant and diverse data relevant to the research question (Barbour, 2007). Patients whose PCI took place in the previous 2-6 months were included as they were eligible to have been invited, be attending, or completed CR, and to have current or recent experience of care. The aim was to include attenders and non-attenders, living in areas with more and less integrated CR services. In practice, no non-attenders accepted the invitation to participate, and there was no objective way to judge the degree of service integration. Therefore the aim was adjusted to explore the experience of CR attenders, related to differences in service provision. The aim of staff focus groups was to include those working in a range of roles and phases, so as to explore continuity of care throughout the four CR phases.

### **5.2.3 Recruitment**

Patients and staff were recruited with the help of cardiac rehabilitation specialist nurses, after agreement from their cardiology departments in two hospitals (A and B). Contacts were identified from the Cardiac Rehabilitation Programme Finder (2010), and asked to support the study. Both hospitals were approached because they were easily accessible, and the researcher had visited their CR centres while scoping the present project, so had

developed contacts with them. The researcher visited contacts at the hospitals that agreed to help, to explain the study and the assistance that would be needed. Once governance requirements at each hospital were met, the researcher visited contacts to discuss the recruitment process.

The researcher prepared packs consisting of invitation letters, an information sheet and consent form. CR nurses identified patients meeting inclusion criteria from patient records, and distributed packs. Patients who were willing to participate returned a signed slip to the researcher. The researcher phoned participants to confirm details of the date, time and location of the focus groups, explain how the group would work, and answer any questions.

Potential staff participants meeting inclusion criteria were discussed with contacts. The researcher sent packs including invitation letters, information sheet and consent forms by email. Staff agreeing to take part replied either to the researcher or the contact.

#### **5.2.4 Number and size of focus groups**

The aim was to include between four and eight participants in each group. This was to allow a variety of opinions to be expressed, enable everyone to contribute (Cote-Arsenault & Morrison-Beedy, 2005), while allowing the researcher to facilitate the groups effectively (Barbour, 2007).

Five focus groups were planned. The first, with two patients, piloted the interview schedule. Two further focus groups took place at each site, one with patients and one with staff. This was to allow comparisons to be made between services at different sites, and between patient and staff views (Barbour, 2007).

#### **5.2.5 Ethics**

Ethical approval was gained from the School Research Ethics Approval Panel (SREAP) of the University of Bath, and the National Research Ethics Service (NRES) Nottingham Research Ethics Proportionate Review Sub-Committee. Standard good practice was followed with respect to provision of written information, Participant Information Sheets, consent forms, health and safety, execution of focus group meetings and data protection.

#### **5.2.6 Topics of discussion**

Interview guides were developed to introduce the study, set ground rules, ensure that the topics of interest were addressed and that focus groups were asked the same broad questions. Broad questions allowed participants to describe their experiences in their own language, enhancing the researcher's understanding of participants' own meanings about

CR (Wilkinson, 1998). Example probing questions were also prepared, to steer the discussion towards answering the research question, and encourage responses from several people (Ryan, Gandha, Culbertson, & Carlson, 2013). These were based on previous literature, including the CIS (Chapter 4), but also aimed to extend previous findings by encouraging participants to express their own experiences, rather than providing corroboration for themes identified previously. Interview guides were reviewed by an experienced focus group researcher (Appendices 7 and 8).

Patient groups were asked to discuss their experience of CR, from the time of diagnosis to the present. Four broad questions encouraged patients to reflect on their reasons and motivation for participating in CR, and their experience of service organisation and delivery. For example: "What has been your experience of cardiac rehabilitation?" Probing questions aimed to encourage participants to recall aspects of continuity. For example "What were you told about CR by healthcare staff?" was included because the quality and consistency of messages from staff was identified in the CIS as an aspect of informational continuity that appeared to affect patient motivation. In order to encourage reflection on motivation, questions focused on aspects that had been identified as important in the CIS, such as whether patients felt in control of their decision to attend CR, for example "Did you feel free to choose whether or not you took part?" However, other questions aimed to encourage participants to think more broadly, for example "What would have encouraged you to attend more CR sessions?"

Staff were asked to discuss their experience of working with patients eligible for cardiac rehabilitation. Four broad questions aided participants' reflections about patient motivation, and continuity of care in delivering CR, for example: "In your experience, what motivates patients to take part / not take part in cardiac rehabilitation classes?" Probing questions included aspects of continuity such as "How does information about patients travel between hospitals, cardiac rehab and primary care?" because there is some evidence from the findings of the CIS that sharing information may make care more seamless resulting in improved patient motivation for CR attendance and adherence to recommended behaviours. Other more open questions were designed to give staff freedom to express views without constraining them to consider findings from previous research, for example "How do staff motivate patients to do CR?"

### **5.2.7 Data collection**

The researcher facilitated the focus groups. Discussions lasted between 50 minutes and 1¼ hours. A technical error meant that only the first 25 minutes of the staff focus group at hospital B was recorded. However, the researcher's experience of this group aided

interpretation of discussions from other groups. Discussions were recorded and transcribed verbatim. The facilitator made field notes directly after each session.

### **5.2.8 Data analysis**

Thematic analysis was chosen because it allows a rich, detailed, complex account of the data while remaining flexible (Braun & Clarke 2006). It also acknowledges the researcher's interpretive role, and encompasses critical realism. This allows an acceptance of participants' meanings as a reflection of their thoughts and actions, the impact of social context and a notion of material reality, all of which fit with aspects of the research question. Thematic analysis has been used in research in cardiac, rehabilitation and exercise settings (eg. Beck, Gillison, & Standage, 2010; Mclean & Timmins, 2007; Sutton, Rolfe, Landry, Sternberg, & Price, 2012).

The content of the focus groups, through audio recordings, transcripts and facilitator's notes, was analysed using thematic analysis, as described by Braun and Clarke (2006), aided by NVIVO9 software. Each transcript was read, and potential concepts and ideas arising from this reading were noted. These were influenced by findings from the CIS and the facilitator's notes. Each transcript was re-read and initial codes assigned to sections of the discussion (eg. phrases, sentences, speeches), relating to motivation, continuity of care, CR attendance, and their interaction. Codes summarised both explicit and latent features of the data. Related codes were sorted into categories, from which potential themes were developed (Appendix 9). Data relating to each theme within transcripts were re-read, and themes amended. A thematic map was developed, showing how themes were related. The entire data-set was then re-read to check whether codes, themes and map accurately reflected the data, and further amended.

## ***5.3 Results of the focus group study***

### **5.3.1 Patient participants**

There were three patient focus groups, at two participating hospitals (Table 11). In the first, the interview schedule was piloted. Although the pilot group at hospital A was small (two women participants), this may be beneficial for discussing sensitive topics, particularly when participants are more used to expressing an opinion in small groups (Bloor, Frankland, Thomas, & Robson, 2001). It was considered important to include the women's discussion because only men participated in the other patient group at hospital A. Also, the areas for discussion were alike in the pilot and other groups, so this data was included in the analysis. All of those who agreed to take part were currently attending or had recently completed CR classes.

**Table 11: Characteristics of participants in patient focus groups**

Hospital	Number and gender of participants	Number of Phase 3 sessions attended	How patient found out about CR
A (pilot)	2 women	2 x 8	1 letter from CR 1 during hospitalisation
A	5 men	1 x 3 2 x 6 1 x 6, now in P4 1 unclear	3 during hospitalisation 1 referred by department 1 letter from CR
B	6 men 2 women	2 x 10 3 x 12 1 x 15 1 x 18 1 x 12 in P3, 2 in P4	5 during hospitalisation 2 letter from CR 1 at hospital appointment before PCI

### 5.3.2 Staff participants

There were two staff focus groups, one at each participating hospital. Group A included three participants, and there were eight in Group B. The aim was to include staff from all CR phases, but no GPs accepted the invitation to participate. No practice nurses, and no nurses currently working in Phase one agreed to participate from location A. Some participants worked in more than one role or CR phase (Table 12).

**Table 12: Characteristics of participants in staff focus groups**

Hospital	Phase one	Phase two	Phase three	Phase four
A	1 nurse \$		2 nurses 1 fitness instructor *	1 fitness instructor *
B	1 cardiology associate specialist * 1 CCU sister 1 CR sister*	1 practice nurse / CR nurse *	1 cardiology associate specialist * 1 CR sister* 1 physiotherapist 1 practice nurse / CR nurse * 1 fitness student 1 CCU sister \$	1 cardiology associate specialist* 1 fitness instructor

Notes: \*indicates that this is the same person, who works in more than one phase

\$ indicates that a participant worked in this phase previously

CCU = Coronary Care Unit

### 5.3.3 Findings

Three overarching themes were developed, capturing the essence of participants' descriptions of how cardiac rehabilitation services support or impede motivation for initiation of, attendance at, and adherence to Phase three and four cardiac rehabilitation classes, in two locations in southern England. The themes are: *Relationships; Co-ordination of care across phases and settings; and Patient management.*

Quotes from staff are prefixed 'H...', patients 'P...' and the facilitator 'F...'

## Relationships

A strong theme from the focus groups was the positive relationships between Phase three (P3) patients and staff, which developed as they met over several weeks, and the effect this had on motivating attendance and behaviour. Patients first attended because they reasoned they would get expert help, while being relatively safe, and anticipated a care-giving relationship from staff:

*P225 and that's why I went – cos it was at the hospital – looked after by professionals*

Although patients were apprehensive at first, they found staff encouraging and attentive, and the patient-professional relationship developed over time:

*P226 ... I thoroughly enjoy it, I really do, honestly. And the girls are so nice in there – they put you through, and they ... treat you like you're a human being, you know what I mean? They can see if you're panting or puffing or whatever, one of 'em'll say 'oh sit down, [P226]'. Thank you very much! [chuckles]*

This was also reflected by staff expressing real pleasure at working with patients and seeing them progress:

*H131 .....they often come in with 'a stick' and finish the course without using 'the stick' – which is fantastic. They come in again that's their confidence. They sit in a chair – that's where I'm safe – and then you can see them - 'oh I wanna get up and have a go'*

Most P3 and P4 staff also thought that if staff did not empathise with patients' situations, and relate well to them, patients' attendance and adherence would be adversely affected:

*H132 ...but [H131] and I have worked in rehab for years and both of us can think of nurses that perhaps should never have been rehab nurses....didn't have that personality  
H131 ...and it showed...now – looking back – on the uptake and the staying power and what they [the patients] went on to do or didn't do*

All the focus groups discussed the role of P3 in allowing patients to gain or regain confidence in themselves and their bodies. Staff-patient relationships developed during the few weeks of classes provided continuity, which supported participants' increasing confidence and competence for physical activity, and for coping with their condition, making them want to continue to attend:

*P3210 .....it's been quite an experience actually – it's been quite - builds your confidence. That's one thing I've found. Before I came here I didn't know my limitations. This has*

*helped me find...the limitations..... it was quite quick, cos the girls give reassurance as well*

Patients thought that without P3 classes they would be at home wondering what they could do safely, because after their cardiac event they were afraid to test their limitations. It seems plausible that patients who do not overcome their apprehension, and do not attend P3 classes, may continue to feel physically uncertain.

Attendees tended to have been exercisers at some time, and expressed fitness as both an indicator of wellness and a means to recover from injury, so had an underlying rationale for overcoming their apprehension:

*P323 For some of us who play sport - I used to play a lot of sport, you expect to stay – you're quite used to [aches and pains]..... So...to actually have it done, and then get back into training again, was nothing that – to me – wouldn't expect to do. Erm, because the mental thing is, you know, that you've got to get moving again*

For less confident exercisers, friendly familiar staff, and staff participation in exercise at one centre, made attendance and joining in easier. The environment created by ongoing staff-patient relationships appeared to have a positive effect on patients' sense of competence:

*P131 I like to stand beside [Hx] because if I'm beside her I can see but if I'm across the room I've got the wrong arm and the wrong leg [laugh]*

*P132 yeah, what she says 'now heel' and then you know it's a heel [taps heel on floor] but I do erm yeah it's definitely the people – the other people, and the trainers*

*P131 mmm, they're all great*

*P132 they're very approa – approachable, the girls are, which is easy – aren't they?*

Different CR phases are provided by secondary, primary or freelance services, and several examples were found in both locations of staff working for more than one provider, and therefore in more than one phase (see Table 12). Patients and staff thought that meeting P3 staff at Phase one (P1) or two (P2) encouraged them to take up P3 classes:

*P336 ...and then when I had it done [H233, who worked in hospital (P1) and CR (P3)] came and saw me...*

*H232 [a P2 practice nurse and P3 CR nurse].....I try and follow them up shortly after their event, because they often they come out of hospital and they're 'aaahh' – you know.....*

*H233 ...and that's quite good ..... because by the time they come to Phase three they've already met [H232].....*

For some patients who met different staff in different services, relationship continuity was facilitated when there was an 'official' handover. In one service the exercise instructor worked in P3, but also ran Phase four (P4) classes, so patients already knew her when transferring to P4. In the other service the P4 instructor led one P3 class, to introduce herself to those patients ready to graduate. Both instructors stated they had a high uptake at P4, and staff in both focus groups thought that knowing the instructor, and some of the other participants, had a bearing on attendance, though patients did not mention this.

*H233 .....the continuity of care was there right at Phase three where [H237] used to visit the Phase three, and say 'hi, I'm going to take you today cos I'm hopefully if you leave Phase three, you'll be coming to me afterwards'..... and therefore once they graduated we'd say 'right, ok, you're off to [H237] then', and they would be so happy at that, cos they already knew her*

Adherers at P3 benefited from relationship continuity with their patient group. For some, the people were the main motivation for attendance:

*P327 ...the actual rehab for me, doing the exercises, it just makes you feel better, even if it's just, you know, just being with friends.....*

For most, over time, the shared experience of their cardiac intervention and recovery encouraged a sense of belonging to the group, sharing humour, and experiencing mutual respect and admiration:

*F: What has been your experience of cardiac rehab?'*

*P132: I'd say that really erm good as in like for like people – we're all in the same boat - and we can spur one another on.*

Seeing others improve physically and emotionally demonstrated that improvement was possible. Over time the shared awareness of, and pride in, their growing sense of competence also increased patients' respect for each other:

*P223 I mean he wasn't an athlete, but the change! He could hardly move!*

*P226 I'd stand there – like, he'd normally get behind me – dum dum dum, he'd be pumping on the thing, he done well, I thought. First couple of weeks he was like me, he was run down, but he started to pick up*



Staff also thought that socialising was a motivation for patients attending P4 classes:

*H131 ..... the friendship is, is solid as well – and then they...again they talk, as well – that doesn't change, and then we have little social evenings, so it's friends – they've made friends from what they've been through – um, and that's - for many that's as important as exercising*

However, staff at one location suggested that the quality of relationships varied from group to group:

*H133 ..... sometimes it can depend on the dynamics of the group – doesn't it, if you've got a good group, like this morning's group, it was a brilliant group – they have a lot of fun and then they're encouraged to come back. But other groups, they're a bit drier – you might lose some of the...the people on the outskirts maybe...*

Staff and patients stated that partners were important in helping some patients keep appointments, attend P3 classes and adhere to healthy behaviour recommendations. Some partners drove patients to classes or took part themselves, and a few patients found this helped overcome their apprehension or reluctance to attend:

*P327 .....my partner ..... she came with me to the [classes], probably a good thing – it made me come – once I was here, I met all the people, you know, ..... you just talk to people ..... did the exercise ..... I'm a workaholic, so I was keen to get back to work*

However, partners varied in the degree of encouragement or pressure they put on patients to attend:

*H131 well ....only in the sense not 'forced', but the enthusiasm – you can speak to someone on the phone and they want to come, and others are erm....finding an excuse, and often it is the partner, the other half that will come with them, and once they've been there a few weeks, as the girls said, you know 3 or 4 sessions down the line they're happy they have, but it's not always willingly – because it's just information.... but the partners are sort of protecting them aren't they? They want the best so they encourage them, go with them – almost hold their hand.*

Partners could also be over-protective, fearing that exertion might cause another event. CR attendance tempered such negative aspects of partner support by presenting a

balanced view of safe healthy behaviour, and enhancing patients' competence to interpret symptoms and counteract their partners' fears.

*P324 ...my missus'll tell you, out in the garden, I mean I'll be moving concrete flippin' pots, you know, one side of the pond to other side of the pond. She goes mad.....er, but if I hadn't of had this place, I'd have thought well, if I do that am I going to collapse....*

### **Co-ordination of care across phases and settings**

Cardiac rehabilitation in the UK is organised in four phases (see 2.1.2). Patients and staff described deficits in coordination of care across the CR timeline in both locations. Staff thought that this resulted in inconsistent delivery of rehabilitation advice, and that promoting Phase three (P3) classes at Phase one (P1) and two (P2) was important in motivating patients to participate. They described local barriers to care, and the effect this had on patients' behaviour or attendance at P3.

At location A, staff identified gaps at P1:

*H133 .....I think they [P1 staff] have a rough idea of ..... what happens, up there [in P3], but with patients moving through faster now – I mean when I started up on the wards 8 years ago they could come in with a heart attack and they could be on the ward 2, 3 or 4 weeks waiting to go to [another hospital] for an angio, whereas now they sometimes they come in one night, they have the angio the next day, and they're out the next day, and trying to fit in all the advice and all the stuff that you have to do in that period of time is just – gets harder and harder. Erm, so I think that's a problem for Phase one certainly that erm so patients get a phone call from us as Phase 2 and they've never heard anything about it - maybe read something in a book but that's – you know, that's as much as they've got – erm, so it's not really sold I suppose*

However, most focus group patients at location A received information about P3 during hospitalisation (Table 11). Thus there was a contrast between staff views and focus group patients' experiences. It is possible that non-attenders at Phase three are those who do not receive information during Phase one, but non-attenders and Phase one staff were not included in the focus groups, so this could not be explored.

At location B, many patients believed that P3 was standard treatment, or that staff expected them to participate. Although not compulsory, P1 staff made strong arguments for P3. Some patients accepted it without fully understanding why it was recommended. Others believed health professionals knew best:

*P328 well I thought it was an order.....I thought it was all part of it.....if you didn't come.....what was the point? at least you had to come...and see what it was all about*  
*P329 yeah, they said to me that, although it wasn't compulsory, they made a very good argument for doing it.....and...they put it in such a way that having gone to the trouble of sticking stents in you and....and... all the money that costs and all the rest of it, it was rather stupid if you didn't. But they didn't put it like that, you know, they made you feel like ....erm, it was part of the treatment – it was essential part of the treatment, so.....*

Many attendees responded positively to this approach, accepted the expert's recommendation, and were scathing about patients who 'thought they knew better':

*P3210 ... there was a guy in the bed across from me that had this stent in – and the er nurses would have a chat to him about him doing rehabilitation. 'I'm not bloody doing that. I'm not going up with those fogeys' – that's what he said! [with incredulity]*

However, being pressurised and told you'd be "silly not to do it" may have encouraged some patients to refuse CR. Attendees and staff had examples of patients who rejected CR recommendations during hospitalisation. At location A, staff thought that pressurising patients during P1 would deter some from attending, or following advice, because they did not want to be dictated to:

*H132 ..... if you're the sort of person who's got a smoker who's coming in, and every time they're coming in you're preaching at them, it isn't gonna work – it's not gonna work. That's why we say to them – we're not here to preach, we're here to help, you know – and don't hide the fact you're smoking, we're not gonna judge you – that's not what we're here to do. We're here to ...sort of support you. If you choose, or when you choose that's up to you*

Some patients also favoured sharing information and discussing the rationale for CR, to enhance people's competence to make their own decision:

*P132 well I suppose everybody's different, but I feel if you know what you're up against you can act accordingly...if you're kept in the dark you can't.*

Staff and patients commented on coordination of care during phase two. This related to variation in primary care provision and deficits in coordination between hospitals and primary care. Staff at location B suggested that where continuity was ensured by contact during P2, patients were reassured, given advice about being active, and reminded about

P3 classes. However, phase two was only delivered by some GP practices, so not all patients were contacted. This had led to consideration of P1 or P3 staff providing a P2 service, though this had not materialised:

*H232 you were going to do Phase two years ago, weren't you?.....you were going to push that forward – telephone contact, just a couple of days after discharge*

*H233 yeah*

*H232 I mean our GPs are pretty good – they often will, erm, make telephone contact, erm, but I think it's quite nice if from a nursing perspective to say 'hi' you know 'I'm here. Ring me if you've got any problems. Have you got any problems? You're coming to cardiac rehab aren't you? So, see you again!' [laughs]*

Patients had varied experiences of P2. Some described ongoing care from their GPs, characterised by regular follow-up, discussion and treatment reviews. Even patients who did not like their GPs valued their continuing concern and reassurance:

*P324 our doctor's alright – in small doses, but er.....since I've had this, and nearly every time I go, and he always asks me back at least once a fortnight ..... He always checks me blood pressure – always.....*

However, others were surprised and unimpressed at the lack of follow-up from their GP:

*P329 I haven't had contact with my GP. I...the, the only time my GP wanted to see me was when I rang up I said 'look I've just had a stent put in, would you like to see me?' And he said 'what did the hospital say?' And they said 'you've got to go to rehab' and he said 'you'll be alright'. And that was that.*

While discontinuity caused by a change in GP could have a negative impact, it could also be beneficial if the new GP had more cardiac knowledge, a connection with the hospital, or a fresh view of the patient's needs:

*P131 ..... I had erm a very good doctor ..... she is connected to the cardiac unit here .....and she put me in for this...all these different tests, whereas before I was complaining of being out of breath and getting pains in my chest, and nothing seemed to get done*

Some patients described how GPs provided a second opinion about the value of P3 classes recommended by hospital staff. At location A, one patient had not been offered P3 classes until he had had several problems and interventions, most recently a PCI, but

would not have attended without being asked, and having his invitation endorsed by his GP:

*P226 ..... one of the girls phoned me up and said um 'we've got a thing from one of the wards', or one of the doctors saying that he'd like me to go up there and try it*

*P225 yeah*

*P226 so I took it to my doctor and seen what he said about it, and he said 'yeah, it'd be good [P226], I'll give you a note to take up to 'em'*

However, another patient had had to push her GP to refer her, after not being invited to CR. She speculated that the GP may have been reluctant to refer her due to cost, or because the GP was not aware of P3:

*P132 ... she was a bit draggy heels - coming here – mm.....she was trying to send me to our local leisure centre – er but I mean you don't - it doesn't – I wanted the security of the hospital*

Patients at both locations described inconsistencies between advice from hospital and GPs about the value of P3:

*P225 ..... there's a slight disconnect between the hospital and the GP. The story from the hospital and the story from the GP is slightly different. My GP – my GP's are great – but – they're not marching to the same beat as the hospital, and they were a bit 'oh, you know – you should keep fit – if you wanna go – sounds kind of good.*

Gaps in information sharing were described by participants in all the focus groups. Information transfer between different providers was by various means, including letter, fax, electronic and patient-held records. Records at each phase consisted of referral notes and repeated history-taking. Information was not always passed to all interested parties: for example, in location A GPs were not sent information about patients who enrolled in CR.

Patients were not always given information about CR while in hospital, some received unexpected invitations for Phase three, or invitations several weeks after discharge rather than after two weeks as expected.

However, the inconsistencies and fragmented care that patients described had not prevented them from attending CR. Their own curiosity and a strong message from P1

enabled them to overcome these problems, but they did think that these issues could demotivate others:

*P225..... so I think people could easily slip between the cracks in the pavement*

It is possible that some patients' motivation may have been undermined by this, and non-attendees would be a source of further information about this.

### **Patient management**

There was some debate among staff about ongoing monitoring of patients' functional status, and its effect on motivation for exercise. All staff monitored patients in some way during P3 exercise, and considered this an important part of management. Some favoured technical assessment, such as ECG to measure the heart's rhythm or VO<sub>2</sub> max to identify how intensely people could exercise, to support optimal management decisions, and demonstrate the effectiveness of CR:

*H224... we were trying to encourage, um, the team at York [home of the National Audit of Cardiac Rehabilitation (NACR)] to actually get some outcome measures – for protection of the cardiac rehab – to show that you were improving outcome..... what we were very keen on from the outset was to try and have some outcome measurement of ...of fitness of patients, depending on both psychological and physical fitness.*

Others thought simpler methods were valuable, such as counting the pulse, checking for dizziness or using the Borg scale to measure perceived exertion. These allowed patients learned to self-monitor, so they could exercise effectively and safely on their own:

*H237 .... encouraging people to exercise within their own limits – not necessarily using heart-rate monitors and things like that, because again that's putting an extra set of equipment in..... but getting them used to monitoring...but then they can use their own personal monitoring, to then go out for a walk or when they go out to do some [exercise].....*

*H232 I think that's what it teaches them, cos you use the Borg scale don't you, so you know, so you're teaching them where to...where their limits are, so they can recognize themselves....what their limits are*

Staff knew some patients were deterred from attending P3 because they feared being assessed:

*H235...but the fear!... that's in some of them, that they must do this exercise and they're gonna be assessed, and sometimes that's a really hard one to get through*

However, some thought patients would find technical assessment reassuring:

*H237 in a way it's a bit more reassuring, isn't it, that actually you're all wired up and you're looking at your heart rate and you're seeing there are no ECG changes, and you can reassure people, but actually you can exercise to this level, and.....you're fine, ok.....*

Others considered that feedback from experiencing physical achievement during classes was more motivating:

*H232 but they know themselves, how much better they're going*

*H233 yes, yes*

*H232 I'm terrified of doing that – how far can I go with that – how far shall I push my heart-rate up – I can't push my heart-rate up – at the end of it, I feel great, I feel really motivated to continue exercise*

Some patients endorsed staff comments about feeling protected by being monitored, so they could test their limitations and gain a sense of competence, though none reported being technically monitored:

*P328 ..... it made such a big difference. You know, I walked, but I couldn't do it for too long [laughing], because you were puffing and panting all over the place. It was a very very good thing indeed, to have that [P3] as a back up, and cos they said a lot of people was frightened about it. ... and that disappeared, because you come up here, and they put you through your paces and they monitor...monitored you all the time...*

However, staff suggested that patients who did not usually exercise were particularly afraid of raising their heart-rate and getting breathless through exercise, as these signs had accompanied their cardiac event, and monitoring allowed them to overcome this fear:

*H131.....And you can see fear on them sometimes, can't you?...and their fear that something will happen. It's not...this fear, because as [H132] said they have been risk-assessed, so they're fairly safe, but it's their – their fear about exercising and what it can do and getting breathless, and their heart rate going up*

As staff suggested, some patients discovered through exercising that they were less fit than they thought, motivating them to improve:

*P222.....it certainly erm opens your eyes up and er sort of made you realize er how important things are, and we sometimes take things for granted – exercise, I was fit – until you actually start doing things you don't realize how much you're not fit really*

Whether staff favoured technical or simpler monitoring, they considered that the duration of monitoring and support was important, and should be related to individual patient needs, though the long-term aim was for patients to become less reliant on staff, once they felt confident:

*H131 ....[at Phase four] we're still a patient, you know, and there are still limitations, which of course there are, but it it's them taking responsibility for themselves and understanding what they can and can't do, setting goals, setting targets – erm, they cannot be cotton wool wrapped – not, you know, for an hour or the rest of their lives – they just have to let go, and again it's that confidence and where it comes – whether it...sometimes it hasn't at the end of [Phase] three has it?*

Attendees also varied in how long they wished to be managed. By the end of P3, when they had gained enough confidence to exercise alone, some followed a self-management plan at home:

*P224 ... I don't ... visit the gym to go onto the sort of fourth stage cos I live out in the sticks, and travel in, yeah, I just don't feel it's... it's for me, erm but I bought the [heart] DVD and I use that to... and my wife's Rosemary Conley [diet and exercise products] [laughs]... I use that to sort of erm – make sure I get at least 3 sessions a week – excellent... and er, I feel fine on it*

Those who had been more sedentary, and felt less competent, wished to remain in Phase three, and this could sometimes be accommodated:

*P226 I've got to go up there tomorrow either say yes or no if I'm going to carry on doing the next one [i.e. repeat Phase 3]. I couldn't go on like this gentleman here to Phase four because I couldn't keep up with them. I can't keep up with bloody Phase three let alone four!*

Those who intended to join P4 classes valued the security of an instructor trained in monitoring heart patients:



*P225 now I'm back with the personal trainer, erm, but I'm also going to the Phase four up at the hospital because er, again you know, they're the experts*

While continuity of patient management was considered important by staff in motivating adherence, this was affected by service capacity. The instructor in one service had increased the number of Phase four classes, resulting in improved uptake, as participants had choices of times and class content, and could switch classes to fit around holidays. However, Phase four classes were run by freelance instructors, so there was no process for replacing them when absent. In one service, Phase four took place in a school, which was closed during holidays, and the instructor was going on maternity leave:

*P323 Unfortunately the school is closed down in the summer, and she's having a baby, so I've been told I can come back here till the new year – I don't know how that works really*

Despite this contingency plan, the P3 class was already over-subscribed, with patients sometimes asked not to attend for a week. Although patients were apparently tolerant of this, it is possible that it sent a message that it was not necessary to adhere to CR:

*P328 you have to sign in for next week, you know, if you come on a Monday you have to sign the book to say you're coming, then they know how many's coming. If they're full, those that are a bit late, well they say 'you'll have to come another time'. They try to regulate it as good as they can.*

## 5.4 Discussion of findings

### The role of continuity of care in cardiac rehabilitation

Overall, the focus group results suggest that continuity of care has a role in encouraging attendance at Phase three cardiac rehabilitation classes, and supporting PCI patients in practising healthy behaviours. This emerged from each of the themes outlined:

*relationships; co-ordination of care across phases and settings; and patient management.*

The continuity of care elements identified in the present study, how they map to Freeman et al's matrix, and their proposed impact on attendance is summarised in Figure 11.

**Figure 11: Continuity of care elements identified from the focus group study**

Element of Continuity of Care identified from Focus group study	Related domain in Freeman et al's Continuity of Care Matrix	Attendance / Adherence	CR Phase	Links to which FG theme	Links to which CIS theme
Monitoring and feedback	Management	+/- Attendance	P3	Patient management	Theme 1
Coordination of care	Management / Informational	+ Attendance	P1-P4	Co-ordination of care	Theme 1
Consistency of messages	Informational	+ Attendance + adherence	P1-P4	Co-ordination of care	Theme 2
Ongoing staff patient relationships	Relationship	+ Attendance + Adherence	P3	Relationships	Theme 3
Relationships bridging rehabilitation phases	Relationship	+ Initiation + Attendance + Adherence	P1-P4	Relationships	Theme 3
Social relationships (Belonging to the group in CR)	Relationship	+ Adherence	P3-P4	Relationships	Theme 3
Support from partners	Not applicable	+ Attendance + Adherence	P1-P4	Relationships	Theme 3
Partner needs	Relationship /Informational	+ Attendance + Adherence	P1-P4	Relationships	Not applicable

Note: P1 = Phase one cardiac rehabilitation (in hospital), Phase 2 = Phase two (after discharge, convalescing at home), P3 = Phase three cardiac rehabilitation programmes, P4 = after completion of CR classes, possible further classes or referral to exercise classes, or ongoing self-care

+ denotes a positive impact, and – denotes a negative impact of the CofC element on attendance or adherence

#### *Ongoing staff patient relationships*

The present study adds to Riley et al's (2007) observation that long-term staff-patient relationships in cardiac rehabilitation allowed the establishment of a rapport which was implicated in CR adherence. The present study extends Riley et al's findings by observing that in Phases three and four, the longevity of staff-patient relationships seemed to create an environment in which adherence was encouraged, even (or particularly) for patients who felt least able or confident. These elements are consistent with relationship continuity in Freeman's Continuity of care matrix (Figure 1). There is some evidence from primary care that long-term relationship continuity supports adherence, though the evidence is

inconsistent. For example, Brookhart et al (2007) investigated re-initiation of statins for secondary prevention after periods of non-adherence using case-crossover analysis. Although cardiac event was the greatest predictor of re-initiation, repeat visits to the prescribing physician also encouraged adherence, while seeing a different doctor was less effective. O'Connor et al (1998) also reported that diabetic patients with a regular primary care doctor were more likely to follow diabetic diet, self-monitor blood glucose, and have regular health checks than those without a regular doctor. Nevertheless, seeing a GP intermittently is different to seeing CR staff frequently over weeks or months, and further research is needed to investigate whether frequent ongoing contact is more supportive of CR adherence.

The present study is the first to find that the quality of ongoing relationships in CR, not just their continuity, seemed to be valued by patients and staff. Similarly, Safran et al (2001) found that relationship quality was more important than continuity for patients in primary care, though deficits in both quality and continuity led to patients changing GP. In the present study, relationships between CR staff and patients were described as positive and supportive during Phase three and four, but relationships with GPs could be good, variable or non-existent. While attenders could gain support within Phase three, non-attenders relying on primary care might not find a staff relationship to support their rehabilitation needs, though further research is needed to confirm this. It is also possible that supportive GPs can overcome care deficits for non-attenders, though this needs to be tested. Seeing familiar staff regularly over time may allow understanding and trust to develop, creating an environment in which healthy behaviour can be considered. Previous research has explored the development of trusting relationships between staff and patients in primary care, and identified a need for continuity to achieve this (eg. Baker, Mainous, Gray, & Love, 2003; Eriksson, 2008). However, aspects of relationship quality, for example respect and remembrance (Frederiksen et al., 2009), being caring, encouraging and asking questions (Thom, 2001), have been shown to be necessary in addition to continuity to sustain trust. Future research investigating the interrelation of trust and continuity in CR may help to explain non-attendance.

The present study adds to previous literature in finding that attendance may have been motivated by a combination of relationship continuity and patients agreeing with staff about the need for CR. Reciprocal motivation between patients and doctors, in which their respective perceptions about CR and the patients' competence for CR interact, was found to influence referral in the CIS (4.3.4, Negotiating access). In the CIS, it was argued that the negative outcome of reciprocal motivation was non-referral. In the present study among attenders, patients and staff agreed that Phase three was important, though research with non-attenders is needed to explore whether reciprocal motivation adversely

affects attendance. Previous CR research identified the role of a 'working alliance' between staff and patients in encouraging exercise, diet changes and self-efficacy (Burns & Evon, 2007). The combination of trust and concordance resulted in staff-patient agreement over rehabilitation goals and tasks, which increased over time. Patients reporting improved agreement in the first six weeks of CR improved most in fitness while poor alliance undermined improvements. Research investigating relationship continuity, concordance, trust and attendance is needed to clarify the role of these interactions.

#### *Relationships bridging rehabilitation phases*

This is the first study to find that seeing the same staff at different points in the timeline, for example in Phase one and three, appeared to promote attendance, as did transferring patients to another provider in a different CR phase while the patient was present. Previous research investigating patient involvement in handover has focused on transferring knowledge about patient care needs between health professionals, rather than encouraging attendance (eg. McMurray, Chaboyer, Wallis, & Fetherston, 2010). Flink et al (2012) identified patients who wished to participate in handovers to overcome deficits in continuity of care between secondary and primary care, and there were examples in the present study of patients initiating connections with primary care and Phase three. Future research comparing methods of handover to encourage attendance and adherence would be useful.

Evidence for phone and nurse-led follow-up in encouraging attendance by bridging gaps between CR phases was found in the CIS (4.3.4, Relationships bridging rehabilitation phases). This was also evident in the present study, where staff used phone follow-up or follow-up in general practice to overcome shortfalls in pre-discharge rehabilitation information caused by short hospital stays, and variability in Phase two provision. The effectiveness of nurse-led phone interventions after cardiac events has previously been evaluated (Stolic, Mitchell, & Wollin, 2010). Stolic and colleagues concluded that seven of 24 reviewed studies were rigorous enough to demonstrate effectiveness of nurse-led phone interventions. The authors suggest that effective interventions were carried out by advanced practitioners and included a greater number of phone calls, implying that continuity was important. However, it is possible that some patients may have found repeated calls too controlling, and it is not clear whether knowing the nurse who bridges gaps is important, as was found in the present study. Further research comparing phone follow-up by known and unknown staff on different grades with different protocols would help to clarify this.

### *Social relationships (Belonging to the group in CR)*

In the present study, Phase three adherers benefited from relationship continuity with their patient group, as patients connected to each other through shared experiences of coping with their condition. This was particularly evident in location A, and may have been characteristic of this specific group of patients, although some patients at location B stated that seeing friends, rather than potential health benefits, motivated them to attend Phase three. The role of belonging to a group in encouraging attendance was also identified in the CIS (4.3.4 Relationships – social environment), and has been identified in other research, such as a phenomenological study of pulmonary rehabilitation patients (Halding, Wahl, & Heggdal, 2010). However, Halding et al imply that motivation for social participation is needed to ensure further attendance, and the CIS concluded that groups are a disincentive for attendance for some patients. Research measuring the differential and combined effects of motivation for social participation and motivation for CR on attendance would be useful.

### *Support from partners, and partner needs*

The present study found that many patients had supportive partners who encouraged them to participate, provided instrumental support such as driving them to classes, or participated in classes, and this seemed to have a positive effect on attendance. This agrees with previous research identifying the role of partners in encouraging adherence to lifestyle change (eg. Karner, Dahlgren, & Bergdahl, 2004). The present study also found that some partners were anxious and over-protective, but benefited from attending CR. This agrees with previous qualitative and quantitative studies which found that partners need health professional support (eg. Kettunen, Solovieva, Laamanen, & Santavirta, 1999; Theobald, 1997). Without support and information, partners' anxiety or distress can result in their disengagement from lifestyle change needed by the patient, or over-protection (Mclean & Timmins, 2007). Partner stress has also been shown to predict patients' medication non-adherence (Molloy, Perkins-Porras, Strike, & Steptoe, 2008). Thus, including partners in CR may influence patients' attendance and adherence to a healthy lifestyle by reducing partners' anxiety about heart disease, and by ensuring that patients and partners have the same information and support.

### *Coordination of care*

The present study agrees with previous research identifying deficits in care coordination across the CR timeline. Staff in the present study described gaps in provision leading to some patients missing out on information or invitations to Phase three, and limited sharing of information between CR and primary care. Negative outcomes of informational discontinuity between secondary and primary care have previously been described (Riley et al., 2009; Yee et al., 2011). These studies found that doctors believed that shared

patient records helped them to deliver shared care, affected the number of times they saw patients and improved their management of patients' cardiac risk. Yet fewer than half of primary care providers received transition records from CR, and most found out about CR attendance from patients. Some patients in the present study lost trust in their GP when GPs had no knowledge of their PCI, agreeing with Crooks and Agarwal's (2008) finding that information discontinuity undermines the development of a trusting doctor-patient relationship. Nevertheless, Yee et al (2011) found that fewer than half of primary care doctors read transition records, suggesting that even if systems and processes are good, barriers to sharing information remain. Further research to identify and test processes and practices to optimise care coordination in CR is warranted.

The finding in the present study that information gaps did not deter all patients from attending contributes to sparse evidence from other studies that some patients can overcome fragmented care. All participants in the present study were attending Phase three, despite receiving invitations and information from different sources and at different points in the CR timeline, and having variable experiences in primary care and during Phase one. The ability of patients to overcome gaps was also identified in the CIS (4.3.4, Negotiating access – motivational referral), where self-referral, or an ability to navigate the system and seek information resulted in CR attendance. The view of staff in the present study, that discontinuity adversely affects attendance, probably reflects their broader awareness of different patients and how rehabilitation is delivered, though it is also possible that they misjudge services in which they do not work. Future research investigating why and how patients seek to participate in CR when they experience fragmented care would be valuable.

#### *Consistency of messages*

The present study adds to limited previous evidence that inconsistent messages are unhelpful for patients making decisions about attending CR and healthy behaviour. In the present study staff and patients commented that views of different hospital staff and GPs about the value of CR varied, and they felt this could deter attendance. The impact of consistent messages on CR attendance was examined in the CIS (4.3.4, Service patient communications – consist messages from health professionals). For example, Tod et al (2002) identified patients who reported receiving inconsistent, and therefore confusing, messages from staff, which undermined their trust in CR. A recent meta-summary of continuity studies agreed that inconsistent messages confuse patients and undermine patients' confidence in staff competence (Haggerty, Roberge, Freeman, & Beaulieu, 2013), and Yee et al (2011) conclude that informational discontinuity makes it impossible for staff to be consistent in patient recommendations and care plans. However, the present study is the first to identify some patients who triangulated opinions from different

staff to help them decide whether to attend. For example, one asked his GPs' view after receiving a phone invitation from Phase three. Another described how his GP was ambivalent about CR but CR staff made a good case for CR. Possibly having contrasting messages helps patients to feel they are making their own choices, though this may not be the healthiest choice. Further research is needed to investigate whether contrasting or consistent messages encourage more CR attendance.

### *Monitoring and feedback*

Findings from the present study extend our understanding of the impact of monitoring on patients' motivation for CR and exercise. Some patients felt protected by being monitored, as identified in the CIS (4.3.4, Monitoring and feedback). A new finding in the present study was that feeling protected led some to want to repeat Phase three or attend Phase four. This complements the suggestion in the CIS that ongoing monitoring may undermine patients' ability to judge their limitations. Together these findings may indicate that ongoing monitoring encourages some attenders to be confident to exercise during CR but less confident to exercise outside CR. The notion that different monitoring methods can motivate or deter different patients from attending CR or exercising was identified in the CIS (4.3.4, Monitoring and feedback), but staff in the present study described patients' fear of assessment in general acting as a deterrent to attendance. A new finding from the present study was that staff hold conflicting views about which type of monitoring encourages patients to exercise. Some thought that technical monitoring motivated patients by making them feel safe, while others believed that simple monitoring enabled patients to learn to exercise safely alone. However, patients thought that all monitoring, including the Borg scale, was for staff to assess them, rather than for their own use, agreeing with previous research which found that patients can learn to use the Borg scale (Ilaraza, Myers, Kottman, Rickli, & Dubach, 2004), but most do not use it when exercising at home (Scotto, Waechter, & Rosneck, 2009). The optimum monitoring methods to support patient management and adherence to healthy behaviours remain to be ascertained.

### **Understanding the motivational mechanisms behind the positive effects of continuity**

In this section, an interpretation of the results of the present study is suggested based on Self-determination theory (SDT). SDT is a general motivation theory that has previously been used to explain behaviour, and design and test interventions, in health and physical activity settings (eg. Edmunds et al., 2007; Silva et al., 2010; Williams et al., 2006).

## Relationships

In the present study, relationship continuity during CR appeared to allow trusting relationships to develop between staff and patients which encouraged attendance. This seemed to have developed over time as patients found staff encouraging and attentive. Patients referred to staff as '*nice*', '*approachable*', '*friendly*', and '*reassuring*'. One patient welcomed being treated '*like you're a human being*', as though this was unexpected in a healthcare context. Staff expressed pleasure and seemed to genuinely care about patients' progress and enjoyment of classes. Patients and staff also referred to patients liking to see familiar staff at Phases one, three and four. This is reminiscent of the concept of relatedness, one of three basic psychological needs in SDT (Ryan & Deci, 2002), which is characterised by the development of trusting relationships with mutual respect, care and understanding (Ryan et al., 2008). It seems credible that relatedness support from staff-patient relationships may be one explanation for ongoing attendance among patients in the present study. This is consistent with previous research findings in physical activity contexts, where relatedness satisfaction predicted wellbeing in the general population (Gunnell, Crocker, Mack, Wilson, & Zumbo, 2014), intrinsic motivation in exercise referral (Rahman, Thogersen-Ntoumani, Thatcher, & Doust, 2011), and adherence (Edmunds et al., 2007). However, research using validated measures is needed to investigate the role of relatedness satisfaction in CR attendance.

Patients in the present study also described a sense of belonging to their patient group as they were '*in the same boat*', and discussed shared experiences, humour and their respect for others' achievements. Some stated that seeing friends was a factor in continuing to attend. Staff thought that patients' wish to continue to socialise with friends made during Phase three was a factor in Phase four attendance (*they've made friends from what they've been through – um, and that's - for many that's as important as exercising*). This suggests that patients may experience relatedness need satisfaction from ongoing relationships among the patient group which encourages attendance. Previous research has shown mixed results regarding the role of relatedness need satisfaction among peers in encouraging healthy behaviours, but relatedness has been associated with more self-determined regulations (eg. Gurlan, Trouilloud, & Sarrazin, 2013) and attendance (eg. Lloyd, 2010) in exercise prescription settings. Gurlan and colleagues suggested that strong social relationships may allow self-determined motivation to thrive among obese teenagers, and Lloyd et al concluded that attendance was encouraged partly due to the sense of wellbeing created by relational needs being met. In the present study less confident exercisers in particular talked about the value of belonging to the group, and it is possible that meeting the need for relatedness in these contexts may compensate for a lack of competence need satisfaction, though further research would be needed to explore this in CR. As non-attenders were not included in



the present study, it is not possible to tell whether a lack of relationship continuity undermines the need for relatedness in this context, and whether this affects attendance.

### **Rationale, pressure and choice**

Most patients in the present study had experienced management and informational continuity that was initiated when staff provided information or discussed CR with patients during Phase one and continued with discussions with GPs, written or phone invitations to Phase three. Within this continuity of care, patients described varying degrees of pressure or encouragement from staff to participate in CR. Some patients, particularly at location B, believed that CR was a standard part of treatment, making comments such as *'I thought it was an order'*, and that they would be *'stupid if you didn't'* take part. This suggests that staff gave a rationale for attendance, explaining that CR after a PCI was more effective in preventing future cardiac events, but may not have offered patients a choice about attendance. This is reminiscent of controlled motivation in SDT, which includes external regulation, where people act in response to rewards, punishment or social pressure, and introjection, where people respond to praise or act to avoid disapproval or guilt (Ryan et al., 2008). However, patients in the present study who described a controlling approach still attended CR. In terms of SDT, some may have internalised the rationale for CR and made an autonomous decision to participate because this rationale chimed with their existing values, despite the controlling message. This might apply to previous exercisers, for whom rehabilitation was normal after injury, and to *'get back into training again, was nothing that – to me – wouldn't expect to do'*, and to people who wanted to test their limitations in a safe environment. Some may have complied with social pressure to attend, either from clinicians or partners (*my partner ..... she came with me to the [classes], probably a good thing – it made me come*). In SDT this type of pressure can result in partially internalised or introjected motivation. Although it would not be expected to result in long-term adherence, some studies in clinical populations have shown it to be associated with exercise in the short-term (eg. Silva et al., 2010), and this may be the case in the present study.

Some patients in the present study expressed a preference for staff providing information and a rationale for CR (*'if you know what you're up against you can act accordingly'*). This is consistent with SDT, which posits that people need to feel autonomous, and health professionals can support this need through encouragement, explaining the rationale for behaviours and supporting choice rather than being coercive (Ryan et al., 2008). Some staff-patient interactions that could be interpreted as autonomy-supportive were evident. For example, staff at location A believed that pressurising patients may be counter-productive, and differentiated between preaching to patients and helping or supporting them to make choices. Autonomy support has been shown to predict autonomous

motivation which predicts adherence to healthy behaviour (eg. Fortier et al., 2007; Williams et al., 2009), including exercise in CR (Russell & Bray, 2010). However, Russell and Bray did not find that autonomous motivation correlated with CR attendance, perhaps because they measured exercise motivation rather than attendance motivation.

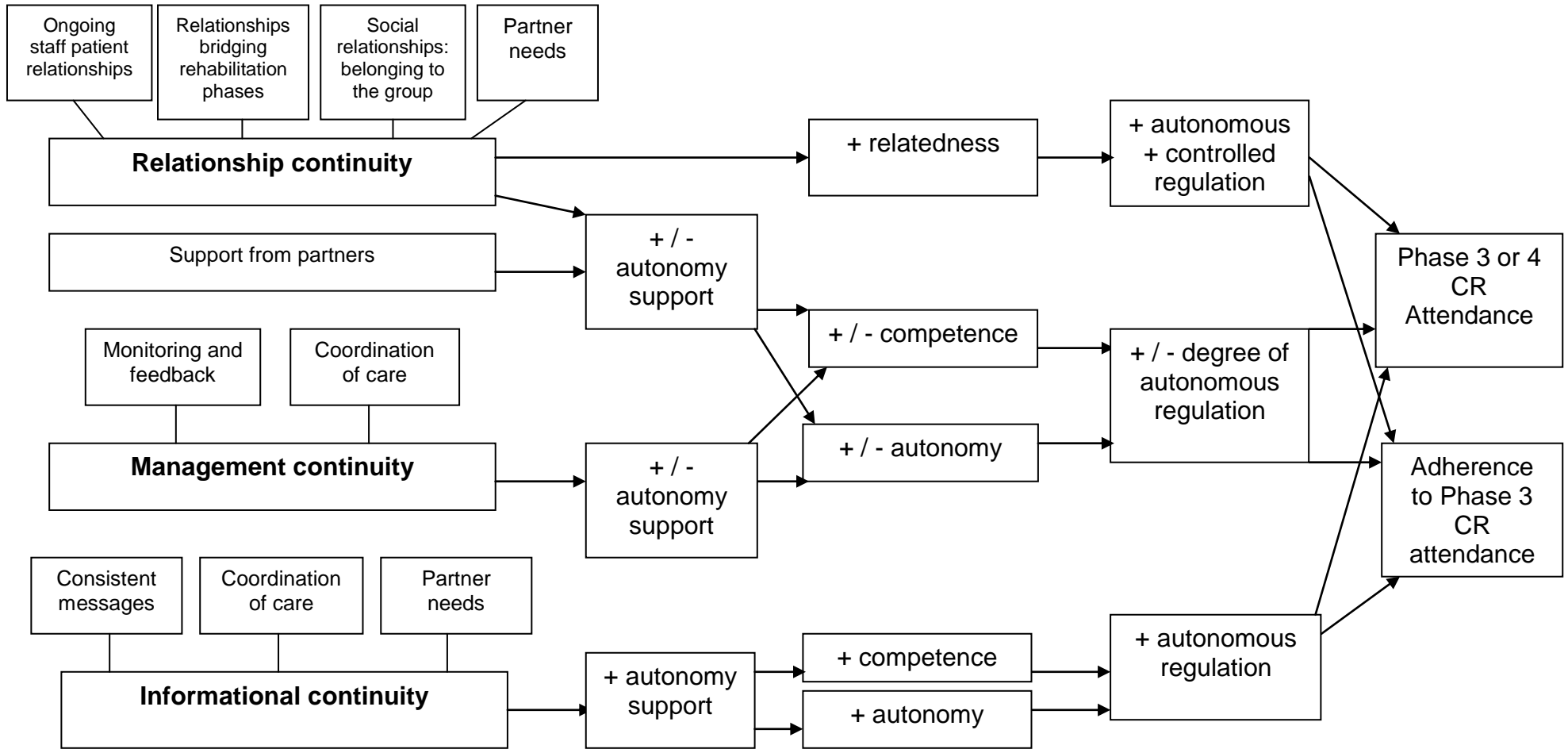
### **Confidence and competence**

Patients and staff commented that inconsistent messages could make patients less confident about the importance of CR and deter attendance (*'The story from the hospital and the story from the GP is slightly different'*). Patients and staff also commented that attenders' confidence increased over time during CR. This was related to feeling safe while testing their physical limitations in an environment where experts monitored them (*a lot of people was frightened about it.. ... and that disappeared, because you come up here, and they put you through your paces and they monitor...monitored you all the time...*), and to receiving positive feedback from staff about their progress (*This has helped me find...the limitations..... it was quite quick, cos the girls give reassurance as well*). These comments could be interpreted in terms of SDT, in which competence is one of three basic psychological needs (Ryan & Deci, 2002). Competence satisfaction is characterised by feeling effective while carrying out optimally challenging tasks, and has been shown to increase when adhering to exercise in clinical settings (Edmunds, Ntoumanis, & Duda, 2008). Nevertheless, for some patients confidence to exercise alone was not achieved during CR (*it's that confidence and where it comes – whether it...sometimes it hasn't at the end of [Phase] three has it?*). This could relate to tasks being too difficult (*I can't keep up with bloody Phase three let alone four!*), or to patients relying on staff rather than learning to self-monitor. Further research would be needed to test these suggestions.

## **5.5 Model from outcomes of focus groups**

The proposed model developed from the results of Study 2, the Critical Interpretive Synthesis (Chapter 4), was amended after Study 3, the focus group study (Figure 12). Suggested positive or negative effects of each continuity of care domain on antecedents of motivation, from Self-determination Theory (autonomy support, autonomy, competence, relatedness, autonomous and controlled regulation), are illustrated by plus and minus symbols. Similarly to the model in Study 2, the elements of continuity of care identified from the focus group study as relevant to cardiac rehabilitation were mapped to the relevant domain(s) of Freeman's Continuity of Care matrix, (relationship, management or informational continuity; Figure 11). Some elements were identified in both Studies 2 and 3, so for example consistency of messages is an aspect of informational continuity that appears in both models. Other elements, for example partner needs, are aspects of informational continuity identified in Study 3, but not Study 2. In Study 2, examples of controlling and autonomy supportive management continuity were differentiated in the model. However, in the present study, elements of continuity with apparent positive effects were identified, and it appeared that the delivery of these elements may or may not be autonomy supportive, depending on patient preferences. For example, different approaches to patient monitoring might encourage or discourage different patients to attend. For this reason, autonomy support is separated from continuity in the model. The model in Study 2 is extended in Study 3 because findings from the focus groups suggest that relationship continuity, as well as management continuity, may be autonomy supportive or controlling. Nevertheless, informational continuity appeared to be positively related to autonomy support. According to the findings of Study 3, relationship continuity may have a direct effect on relatedness need satisfaction, in addition to an indirect effect via autonomy support, perhaps through different mechanisms, though this requires further investigation. In Study 2, there was insufficient evidence to inform the appropriate positioning of need satisfaction or regulation in the model. In the present study, this was clarified, though the model produced from Study 3 needs to be tested. The impact on attendance or adherence to CR, if the assumptions underlying the model are correct, is also presented.

**Figure 12: Proposed model of continuity of care and motivation to adhere to cardiac rehabilitation from focus groups with patients attending Phase three, and cardiac rehabilitation staff**



## **5.6 Limitations**

The present study has several limitations. All patients taking part in the focus groups were attendees at Phase three, or were moving on to or had started Phase four. The aim had been to include non-attendees, so that their experiences of continuity of care and motivation for CR could be compared with those of attendees. They may have been deterred because the invitation to participate came from the service that they declined to attend. Also, the type of NHS permission gained for the study, where hospitals acted as Participant Identification Centres, meant that the researcher could not see patient details until consent had been given. Thus the researcher had no knowledge of which patients were invited.

The representation of staff experiences is also limited by having no GPs in either focus group, and no Phase one staff in one of the focus groups. The part of the CR timeline in which the greatest discontinuity was detected, Phase two, is where GPs may have shed a different light.

As is usual in qualitative research, the results of the present study are not generalisable to all CR populations. The focus groups were carried out in only two CR services in southern England, four out of fifteen patient participants were women, and staff participants at location A were only representative of Phase three.

## **5.7 Conclusion**

Overall, continuity of care appeared to have a positive effect on patients' attendance at cardiac rehabilitation, by providing recommendations, invitations, information and advice over time, and creating an environment in which patients felt safe and motivated to take part. Relationship continuity, through patients seeing the same staff during Phase three or across different phases, or being personally introduced to new staff, seemed to have a positive effect on attendance and adherence. This appeared to allow the development of mutual trust and respect, which supported patients' need for relatedness, and could positively affect autonomous motivation for attendance. This suggests that staff-patient relationships were autonomy supportive, although some patients also experienced pressure to participate in CR, suggesting that some attendance was due to controlled motivation.

Participants' experiences of informational continuity in the present study were individual and varied, but gaps in continuity had not prevented patients from attending Phase three. Gaps in cross-boundary coordination were overcome by some patients, who attended cardiac rehabilitation despite inconsistent messages and lack of referral, partly through support from one part of the service, such as a GP, or through their own autonomous motivation. It may be that supportive GPs mitigate the potentially negative effects of gaps in continuity. Inconsistent information from health professionals was a problem identified by staff and patients, which appeared to undermine patients' need for competence, and could reduce their autonomous choice for cardiac rehabilitation.

A tension was identified between staff-controlled monitoring for patient management, and patients learning to self-monitor for safety and effectiveness, particularly in relation to exercise. Staff-controlled monitoring allowed staff to tailor treatment, measure outcomes and made some patients feel safe, while self-monitoring could encourage patients' competence and confidence to exercise alone, and was autonomy-supportive.

CR attendance may be improved by addressing the issues identified. Improving coordination across the CR timeline, adopting an autonomy-supportive approach to encouraging CR attendance and healthy behaviours, and discussing the role of monitoring and self-monitoring with patients may support attendance and adherence. Nevertheless, these conclusions are based on a qualitative assessment of previous literature, and discussions among few patients and staff in CR, and the resulting model (Figure 12) needs to be tested in a larger group of patients before firm conclusions can be made.

## Chapter 6: Overall discussion

The aim of the interrelated studies within this thesis was to examine how 'continuity of care' in cardiac rehabilitation affects patients' motivation to initiate and maintain cardiac rehabilitation recommendations. Each study contributed to a detailed analysis of the impact of continuity of care on patients' motivation to attend CR classes, sustain attendance and adhere to heart-healthy behaviour recommendations, as reported in the present thesis. The focus of the studies was on the mediating effects of motivational factors between continuity of care and attendance, in line with the theories of continuity of care (CofC; particularly Freeman et al., 2007) and the self-determination theory (SDT; Deci & Ryan, 2000). Continuity of care identifies three domains (management, informational and relationship) that are important in delivering good quality health services (eg. Brookhart et al., 2007; Van Servellen, Fongwa, & D'Errico, 2006). Within SDT it is suggested that autonomy-supportive healthcare encourages autonomous motivation for healthy behaviour (eg. Williams et al., 2006; Williams et al., 1998; Williams et al., 2005), that greater perceived competence enables patients to act more autonomously in relation to healthy behaviours (eg. Williams et al., 2005b; Wilson et al., 2003), and that greater relatedness need satisfaction develops over time in patients who adhere to healthy behaviours (eg. Edmunds et al., 2007). The aim of the current project was to examine whether these theories can aid the identification of factors that encourage attendance in Phase three CR, in order to inform future practice.

To the best of the author's knowledge, these are the first studies to identify a relationship between continuity of care and patients' motivation for cardiac rehabilitation, and to investigate the characteristics and processes involved in that relationship. In Study 1, it was hypothesised that CofC would positively predict autonomous motivation for CR and attendance, and that perceived autonomy support would encourage attendance by positively affecting self-determined motivation. The results showed that continuity had a small positive effect on autonomous motivation for CR, but a greater effect when continuity was perceived as autonomy supportive. Autonomy support was also directly associated with CR attendance. This was the first study to identify the impact of continuity on patient motivation for CR, and to provide statistical evidence for autonomy support as one motivational antecedent mediating the effect of continuity on autonomous motivation toward CR. However, continuity of care was not directly associated with attendance, and none of the regulation variables (autonomous motivation, controlled motivation and amotivation) were associated with attendance. This may have been due to limited

variation in the sample, with far fewer non-attenders than attenders, or because the attendance measure was insufficiently sensitive. The finding that continuity was not associated with CR attendance was unexpected, and it was concluded that positive (eg. ongoing guidance when needed) and negative (eg. inconsistent guidance) effects of continuity on attendance may have cancelled each other out. It was also concluded that additional motivational factors may be implicated in the relationship between continuity and CR attendance.

In Study 2, a Critical Interpretive Synthesis (CIS), the aim was to identify underlying continuity and motivational factors that might interact to positively or negatively influence CR attendance over the four phases of the CR timeline. These candidate factors could then inform the design of future research. Both a purposive and a theoretical sample of literature contributed to the synthesis. Evidence was found to suggest that the three aspects of continuity of care (informational, management and relationship) identified by Freeman et al (2007), are pertinent to CR, and continuity policies, processes and practices appear to enhance or deter CR attendance. Specifically, access to, and ongoing engagement with CR appears to be more likely when it involves discussion, choice, ongoing supportive staff-patient relationships that bridge the four phases of CR, and information sharing among providers and with patients. Continuity appeared most likely to encourage attendance and adherence to healthy behaviours when it involved flexibility in response to patients' personal situations, and provision of consistent messages and appropriate guidance when patients needed it.

Interpreting the CIS findings in terms of SDT, it was suggested that where continuity was most effective in encouraging attendance, adherence and healthy behaviour, it was delivered in an autonomy supportive way. This concurs with the findings of Study 1. However, additional potential motivational antecedents of CR attendance were also identified through the SDT interpretation. The role of patients' sense of competence appeared to be related to their decision to participate, both during referral and after initiating Phase three. This involved competence to participate, exercise and cope with the social interaction involved in Phase three classes. The findings of Study 3, a focus group study with CR patients and staff, similarly suggested that sense of competence had a role in encouraging attendance. Attenders tended to be previous exercisers, and staff and patients talked about encouragement and reassurance from staff supporting them in regaining their sense of competence after this was undermined by their cardiac event or intervention. A sense of competence has also been shown to be important in developing health-promoting self-care practices in previous studies with patients with chronic



diseases, for example diabetes (Williams et al., 2009; Williams et al., 2004, etc.), and in adherence to exercise prescription (Rahman et al., 2011). It would be valuable to measure competence support and competence need satisfaction in future CR research.

In Studies 2 and 3, patients' sense of relatedness was also identified as a potential factor influencing CR attendance. Continuity of care, through relationship continuity appeared to have a positive effect on attendance because patients encountered the same staff at different points in the CR timeline, perhaps during hospitalisation or at the GP surgery, and then again during Phase three classes. When this relationship continuity was characterised by trust, mutual respect and warmth, this also appeared to meet patients' need for relatedness, enhancing motivation for CR participation. Patients' relatedness needs also seemed to be met when staff fostered a positive social environment in Phase three classes, for example by joining in with exercises, encouraging a sense of fun and giving reassurance. Future research incorporating the measurement of relatedness support and relatedness need satisfaction is recommended.

## ***6.1 Strengths, limitations and future research***

The strength of the present project lies in the use of mixed research methods to address a novel research question which is of practical importance to the NHS, and to the numerous patients who experience a cardiac event or undergo a cardiac intervention. The novelty of the project lies in the hypothesised interaction between the way services are delivered and the way patients respond to service recommendations. The choice of methodologies (partial least squares structural equation modelling of survey data, Critical Interpretive Synthesis, thematic analysis of focus group data) allowed the hypothesised relationship between continuity of care and patient motivation for cardiac rehabilitation to be established, the nuances of this relationship to be explored within the extant literature, and these nuances to be explored further in groups of staff and patients in current NHS settings. The findings of each empirical study informed the conduct of the subsequent study(ies), and the respective findings were triangulated to give a richer, deeper, broader, more coherent view of the topic under investigation, and to produce a proposed model to guide future research. The findings are also of relevance to practice in cardiac rehabilitation, and contribute to theory development, for both continuity of care and self-determination theory in cardiac rehabilitation. Specifically, there was evidence in study 2 of a need for a more patient-focused characterisation of informational continuity, and in study 3 evidence of the role of partner support in enhancing continuity of care. Findings around relatedness need satisfaction in Studies 2 and 3 contribute to SDT by providing

evidence of differential effects of individual relatedness support and support of belonging within the patient group.

The cross-sectional design of Study 1 did not allow the sequence of motivational effects of continuity of care to be ascertained, and this may have contributed to the apparent lack of effect of continuity or motivation on CR attendance. The findings of Study 2 suggest that the motivational effects of continuity fluctuate over the CR timeline. For example, studies demonstrate that patients' readiness to attend CR and practice healthy behaviours varies greatly over time, but can be influenced by the way that services are delivered. This suggests that future research needs to be longitudinal, with repeated measures of continuity and motivation, ideally across all four CR phases.

Since the three studies in the present thesis were carried out, there have been developments in SDT research which could contribute to future research investigating the impact of continuity of care on CR attendance and healthy behaviours. Developments include empirical research investigating the differential impact of need supporting and need thwarting social contexts (Vansteenkiste & Ryan, 2013), and need satisfaction and need frustration (Sheldon, Abad, & Hinsch, 2011; Verstuyf, Vansteenkiste, & Soenens, 2012). For example, Bartholomew et al (2011) examined the impact of controlling and autonomy-supportive contexts on need satisfaction and need thwarting, and their effects on ill-being, including eating disorders and biological functioning in athletes. The study demonstrated a difference between low levels of need satisfaction and need thwarting, with need thwarting having more profound negative effects on outcomes. It is possible that continuity during CR may include need-thwarting elements which may deter attendance and adherence, for example relationship continuity that consists of controlling strategies such as guilt-induction, shaming and conditional regard, and management continuity that is characterised by coercion or pressure. In Study 1, autonomy support was measured, giving an indication of the extent to which autonomy support predicted patients' quality of motivation. However, some service characteristics could actively thwart patients' autonomy (eg. automatic or non-referral, ongoing staff-controlled monitoring). The inclusion of need satisfaction measures has already been recommended for inclusion in future studies. Including need thwarting measures in future investigation would allow a more comprehensive understanding of the effects of continuity of care on CR attendance. This could contribute to more robust future practice recommendations.

Another limitation of the present project is that the sample size in Study 1 was relatively small. A larger sample size would be needed to incorporate the recommendations

detailed above, and sufficient non-attenders would be needed to allow between-group comparisons. Study 1 was also limited by CR attendance being by self-report. Future research should use an objective measure of CR attendance, including the number of sessions attended. Context-specific continuity and SDT measures also need to be further developed and undergo testing for reliability, convergent and nomological validity, and different ways of measuring constructs should be used to avoid problems with common method variance (Podsakoff, MacKenzie, & Podsakoff, 2012).

The findings of Study 3 suggest that some patients may be motivated to attend CR or to continue to Phase four after completing Phase three because their need for relatedness is met there. This may be because they feel socially isolated in their daily lives, while in CR classes they experience a sense of belonging among others who have experienced a heart event, which they cannot get even from supportive friends and family at home. To explore this further, it would be useful to measure additional psychological outcomes, specifically wellbeing and quality of life, in future research.

In future research, the model described below (Figure 13) would be tested. Specifically, patients' perceptions of need-satisfaction/frustration and degree of autonomous motivation towards CR would be measured at the start of the CR timeline, at the end of Phase two, during Phase three and after 12 months. Patients' perceptions of need-support / thwarting during CR, CR attendance / adherence, quality of life and wellbeing would be measured during Phase three and at 12 month follow-up. This approach would provide more robust information about the interaction of continuity of care and patients' motivation towards CR, with the aim of informing future service developments.

## **6.2 Implications for practice**

Based on the results of the present studies, some recommendations for practice can be made. In line with self-determination theory research in healthcare (e.g. Fortier et al., 2007; Russell & Bray, 2010; Williams et al., 2009), referral processes that include discussion of the rationale for CR without pressurising, and reassurance about the patient's competence to participate are likely to encourage participation. Sharing patient information between providers seems likely to help staff to give consistent advice, enhancing patients' competence to decide whether to attend CR, as suggested by previous continuity of care research (Riley et al., 2009; Yee et al., 2011). Involving patients in planning and goal-setting, while developing trusting, warm staff-patient relationships in which the rationale for CR and healthy behaviour is discussed without pressurising, is

likely to enhance patients' autonomous motivation for attendance and adherence. This is supported by previous research in cardiac rehabilitation (e.g. Burns & Evon, 2007; Moore & Kramer, 1996), continuity of care (e.g. Baker et al., 2008) and self-determination theory (Ryan et al., 2008). Providing timely, appropriate information when needed by the patient is likely to support patient competence around healthy behaviour, and autonomy-supportive staff-patient relationships, such as nurse-led services that bridge CR phases and settings, are likely to support patients' psychological needs, enhancing their motivation for CR. This is supported by the findings of a review of nurse-led phone interventions by Stolic and colleagues (2010), who concluded that positive effects included enhanced CR attendance, risk factor behaviours, self-efficacy and quality of life. More extensive interventions with an educational purpose, provided by expert cardiovascular nurses during more than six phone calls over at least three months were most effective. Providing positive encouragement and feedback about patients' progress is likely to support patients' competence, as suggested by previous research in physical education and sport (e.g. Mouratidis et al., 2008). Encouraging competence through monitoring and feedback, in tandem with developing staff-patient partnerships and communication strategies, is likely to encourage the development of self-management skills around healthy behaviours, as identified in a study testing a transitional (post-acute care) cardiac rehabilitation intervention (Dolansky et al., 2011).

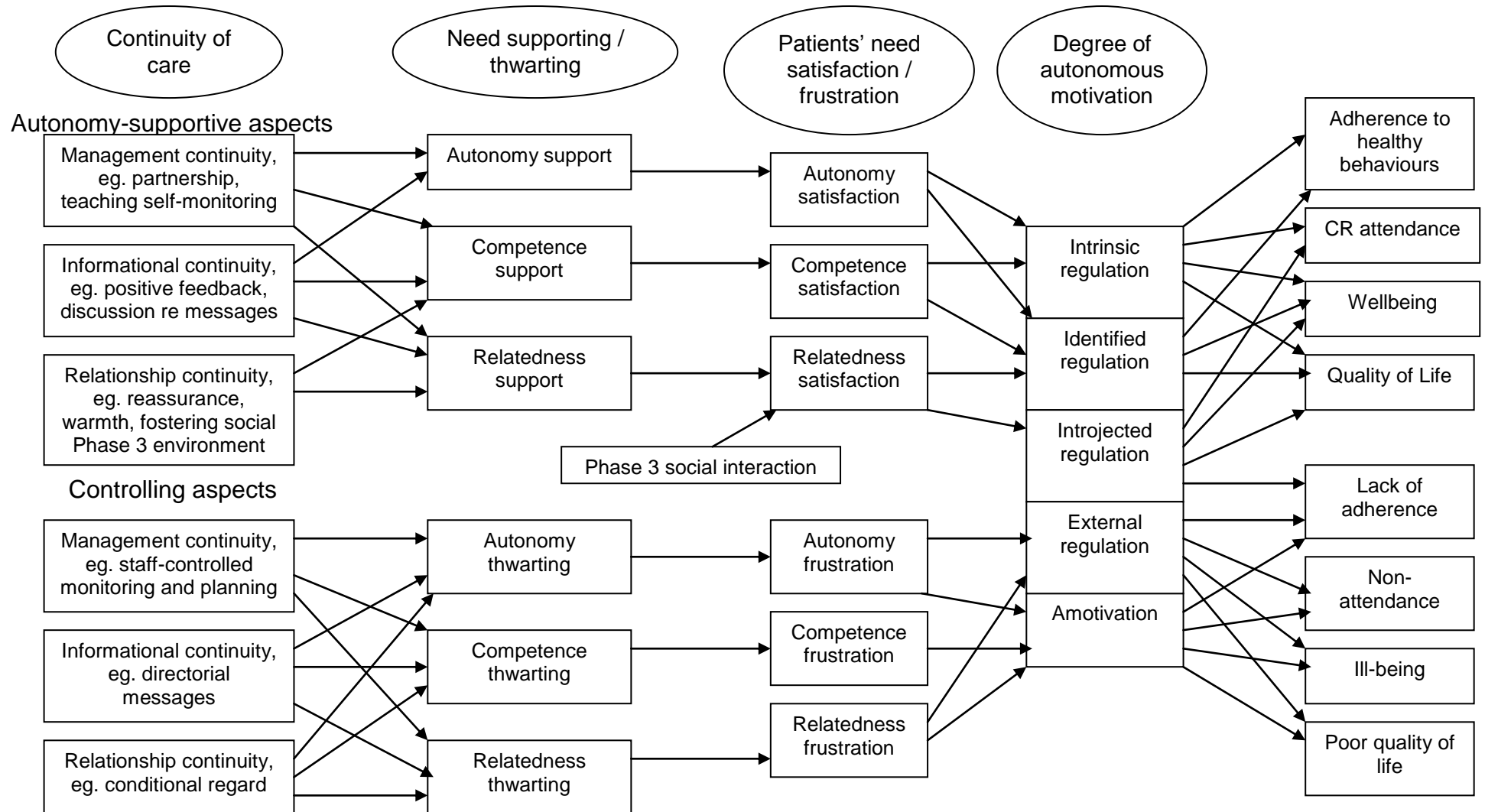
### **6.3 Conclusion**

The findings of the three studies in the present project are the first to provide evidence of a relationship between continuity of care and patients' motivation for attendance at Phase three cardiac rehabilitation classes, and adherence to heart-healthy behaviour recommendations. An original finding in Study 1 was the mediating role of autonomy support between continuity of care and patients' autonomous motivation for CR. Several elements of continuity that appear to positively or negatively affect CR attendance were identified and explored in Studies 2 and 3. After interpreting the results through the lens of self-determination theory, a testable model was developed, which was enhanced after consideration of recent theoretical developments in SDT (Figure 13). Further research is needed to continue to investigate the relationship between continuity of care and patient motivation for CR, in order to contribute to future practice.

## **6.4 Proposed model of continuity of care and patient motivation for cardiac rehabilitation**

The proposed model below incorporates the above suggestions for future research (Figure 13). As shown, the model builds on the motivational sequence from SDT (Figure 2), and on the 3 empirical studies in the present thesis. Thus, the three domains of continuity of care (management, informational and relationship) are presented separately, as they may have different effects on need satisfaction (Studies 2 and 3). The model also aligns with recent research to include need-supporting and need-thwarting contexts, in a similar way to the model suggested by Standage and Vallerand (2014). Specifically, autonomy-supportive and controlling aspects of continuity of care in CR, as identified in Studies 2 and 3, are proposed to have need supporting and need thwarting effects respectively. In line with the motivational sequence from SDT (Figure 2), need support is proposed to enhance need satisfaction, while need thwarting is proposed to have need frustrating effects. Need satisfaction is proposed to enhance self-determined motivation for CR attendance, adherence to healthy behaviours, wellbeing and quality of life, while need frustration is proposed to enhance external regulation and amotivation and increase the likelihood of non-attendance, lack of adherence, ill-being and poor quality of life. As discussed in Studies 2 and 3, relatedness need satisfaction is proposed to enhance identified or introjected regulation for CR attendance and adherence, and thus enhance CR attendance, but be less likely to enhance adherence to healthy behaviours.

**Figure 13: Proposed model to be tested in future research**



Note: arrows depict expected direction of positive relationships. For clarity, expected negative relationships (eg. between intrinsic regulation and ill-being) are not shown

## Appendices

### ***Appendix 1: Definitions and conceptual boundaries of continuity of care***

From: Freeman, G. et al, Continuity of Care: Report of a scoping exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO), 2001, p.14 and p.6

The following ten definitions have been used:

1. *Longitudinal*. How much or for how long the patient has seen the same provider. No assessment of relationship or of quality of interaction.
2. *Relationship/Personal*. The relationship with the provider is assessed in some way.
3. *Team*. As Longitudinal, but with a group or team of care providers either in primary or secondary care.
4. *Geographic*. Care is given/received in person on one site.
5. *Cross-boundary*. Typically hospital/specialist outreach to primary care. Only one instance so far of tertiary to secondary outreach from ICU (Russell, 1999)
6. *Regimen/Comprehensive*. Reference to a common and usually 'comprehensive' treatment programme indicating a multi-skilled team or teams (Bachrach, 1981).
7. *Flexible*. Care adjusts seamlessly and interactively as the individual patient's needs evolve over time.
8. *Information/Records*. Includes computer links and shared records and where outreach is not interactive.
9. *Interactive remote* care including consultation by telephone, realtime computer, email.
10. *Experienced* continuity from the patient's viewpoint.

Of the definitions that were made, the three most common were:

- longitudinal or provider continuity – seeing the same professional
- continuity across the secondary/primary care interface – concerning discharge from specialist to generalist care
- continuity of information through records – either written or electronic.

## **Appendix 2: Summary of Critical Interpretive Synthesis methods**

From: Dixon-Woods, M., Kirk, D., Agarwal, S., Arthur, T., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Sutton, A., & Riley, R. 2005, Vulnerable groups and access to health care: a critical interpretive review, NHS SDO R&D Programme, London.

### **Box 1.1 Methods for critical interpretive review of access to health care by vulnerable groups**

1. Our interpretive synthesis did not start with a precisely formulated question, but with a set of guided topics. The principal aim of the review was deemed to be the development of a synthesising argument – a coherent and integrated set of synthesising concepts.
2. Sets of papers were identified through a range of searching strategies, yielding a sample of potentially relevant papers that were screened for relevance.
3. Relevant papers formed the sampling frame. Sampling aimed to produce a representative sample of the literature.
4. Papers selected to form the sample for inclusion in the review were further screened to confirm relevance and to ensure that they were not fatally flawed, using five simple criteria.
5. Data were extracted using a pro-forma (with some exceptions).
6. Detailed analysis of data was undertaken to identify themes and generate categories.
7. Categories, with explicit specifications, were programmed into QSR N5. Data indexed using these categories, but categories modified iteratively in response to data.
8. Further theoretical sampling of the literature was undertaken to extend, confirm, and challenge the analysis.
9. The synthesising argument was generated through explicit integration of themes, and is therefore grounded in the evidence but produces a distinct interpretation.



## **Appendix 3: Search Strategies**

### **[Rehabilitation terms]**

- 1 exp Rehabilitation/
- 2 exp Rehabilitation centers/
- 3 exp Rehabilitation nursing/
- 4 Aftercare/
- 5 Convalescence/
- 6 exp Exercise therapy/
- 7 Exercise/
- 8 rehabil\$.ti,ab.
- 9 aftercare.ti,ab.
- 10 convalescen\$.ti,ab.
- 11 recuperat\$.ti,ab.
- 12 ((lifestyle or life-style) adj2 intervent\$.ti,ab.
- 13 ((exercise\$ or fitness) adj5 (treatment or intervent\$ or program\$)).ti,ab.
- 14 ((lifestyle or life-style) adj5 (intervent\$ or program\$ or treatment\$)).ti,ab.
- 15 secondary prevention.ti,ab.
- 16 **1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15**

### **[AMI, PCI and CABG terms]**

- 17 exp Heart diseases/
- 18 coronary.ti,ab.
- 19 cardiac.ti,ab.
- 20 CABG.ti,ab.
- 21 Angioplasty.ti,ab.
- 22 Stent\*.ti,ab.
- 23 myocardial.ti,ab.
- 24 angina.ti,ab.
- 25 heart disease\*.ti,ab.
- 26 heart failure.ti,ab.
- 27 Heart attack\*.ti,ab.
- 28 cardiol\*.ti,ab.
- 29 cardiovasc\*.ti,ab.
- 30 exp Angioplasty/
- 31 exp Coronary Artery Bypass/
- 32 **17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31**

### **[Cardiac and rehabilitation terms]**

- 33 **16 and 21**

### **[Additional cardiac rehabilitation terms]**

- 34 exp Heart diseases/rh
- 35 exp Coronary Artery Bypass/rh
- 36 exp angioplasty/rh

### **[All cardiac rehabilitation terms]**

- 37 **33 or 33 or 34 or 35 or 36**

### **[Adherence terms]**

- 38 Patient compliance/
- 39 Patient participation/
- 40 Choice behavior/
- 41 adher\*.ti,ab.
- 42 non-compliance.ti,ab.
- 43 compliance.ti,ab.
- 44 comply\*.ti,ab.
- 45 concordance.ti,ab.

46 uptake.ti,ab.  
47 continuation.ti,ab.  
48 participation.ti,ab.  
49 drop out\*.ti,ab.  
50 sporadic.ti,ab.  
51 utilisation.ti,ab.  
52 **38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51**

**[Continuity of care terms]**

53 "Referral and Consultation"/  
54 Attitude of Health Personnel/  
55 Physician's Practice Patterns/  
56 "Continuity of Patient Care"/  
57 Health Services Accessibility/  
58 (continuity adj2 care).ti,ab.  
59 continuity.ti,ab.  
60 "Delivery of Health Care, Integrated"/  
61 (continuum adj2 care).ti,ab.  
62 Seamless\*.ti,ab.  
63 Joined-up.ti,ab.  
64 Information.ti,ab.  
65 Therapeutic relationship\*.ti,ab.  
66 Support\*.ti,ab.  
67 Organisation\*.ti,ab.  
68 Structure\*.ti,ab.  
69 Provider\*.ti,ab.  
70 Care plan\*.ti,ab.  
71 Care path\*.ti,ab.  
72 Episode\*.ti,ab.  
73 Trajectory\*.ti,ab.  
74 Timeline\*.ti,ab.  
75 Referral.ti,ab.  
76 Referred.ti,ab.  
77 Liaison.ti,ab.  
78 Outreach.ti,ab.  
79 Discontinuity.ti,ab.  
80 Dis continuity.ti,ab.  
81 Fragment\*.ti,ab.  
82 **53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68  
or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81**

**[Motivation terms]**

83 personal autonomy/  
84 self determination.ti,ab.  
85 Motive\*.ti,ab.  
86 Motivation\*.ti,ab.  
87 Motivating.ti,ab.  
88 Amotiv\*.ti,ab.  
89 Demotivat\*.ti,ab.  
90 De motivate\*.ti,ab.  
91 Values.ti,ab.  
92 External influence\*.ti,ab.  
93 Internalis\*.ti,ab.  
94 Intention\*.ti,ab.  
95 Autonomy.ti,ab.  
96 (Autonom\* adj1 support\*).ti,ab.  
97 (Autonomous adj1 behav\*).ti,ab.  
98 (Autonomous adj1 motiv\*).ti,ab.  
99 Controlling.ti,ab.

- 100 Controlled behav\*.ti,ab.
- 101 Controlled motivation\*.ti,ab.
- 102 (Controlled adj1 motivation\*).ti,ab.
- 103 Competenc\*.ti,ab.
- 104 Paternal\*.ti,ab.
- 105 Competent.ti,ab.
- 106 Confidence.ti,ab.
- 107 External regulation.ti,ab.
- 108 Identified regulation.ti,ab.
- 109 Integrated regulation.ti,ab.
- 110 (Integrate\* adj1 change\*).ti,ab.
- 111 Introjection.ti,ab.
- 112 Relatedness.ti,ab.
- 113 Trust\* relationship\*.ti,ab.
- 114 Lifestyle choice\*.ti,ab.
- 115 Need\* satisfaction.ti,ab.
- 116 Willing\*.ti,ab.
- 117 Unwilling\*.ti,ab.
- 118 motivation/
- 119 self concept/
- 120 paternalism/
- 121 intention/
- 122 drive/
- 123 "aspirations (psychology)"/
- 124 "conflict (psychology)"/
- 125 Goals/
- 126 self efficacy/
- 127 Self efficacy.ti,ab.
- 128 Social norm\*.ti,ab.
- 129 **83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98  
or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107 or 108 or 109 or 110 or  
111 or 112 or 113 or 114 or 115 or 116 or 117 or 118 or 119 or 120 or 121 or 122 or 123  
or 124 or 125 or 126 or 127 or 128**

**[Search Strategy A]**

130 **37 and 52 and 82 and 129**

**[Search Strategy B]**

131 **(37 and 52 and 129) not 130**

**[Search Strategy C]**

132 **(37 and 82 and 129) not (130 or 131)**

**[Search Strategy D]**

133 **(37 and 52 and 82) not (130 or 131 or 132)**

**[Search Strategy E]**

134 **37 and 82**

**[Search Strategy F]**

135 **37 and 129**

**[Search Strategy G]**

136 **37 and 52**

**Numbers of hits for each search strategy executed in Medline**

<b>Strategy A</b>	<b>Strategy B</b>	<b>Strategy C</b>	<b>Strategy D</b>	<b>Strategy E</b>	<b>Strategy F</b>	<b>Strategy G</b>
1+2+3+4	2+3+4 not A	1+2+3 not A or B	1+3+4 not A or B or C	1+3	2+3	4+3
252 hits in Medline 1950 to May Week 1 2009 <b>Update search</b> 47 hits Sept Week 2 2010	507 hits in Medline 1950 to May Week 1 2009	815 hits in Medline 1950 to May Week 1 2009	746 hits in Medline 1950 to May Week 1 2009	6198 hits in Medline 1950 to May Week 1 2009	4077 hits in Medline 1950 to May Week 1 2009	3632 hits in Medline 1950 to May Week 1 2009

Notes: Search terms: 1 = continuity of care terms; 2 = patients' motivation terms; 3 = cardiac rehabilitation terms; 4 = terms about patients' concordance with rehabilitation. Each search strategy uses different combinations of these terms, eg. Strategy E retrieved 6198 references, each of which contained continuity AND cardiac rehabilitation terms.

**Journal contents pages scanned  
(For theoretical sample)**

April 2009-Sep 2010

- BMC Cardiovascular Disorders
- BMC Health Services Research
- Clinical Nursing Research
- European Journal of Cardiovascular Nursing
- Health Education & Behavior
- Journal of Health Psychology
- Journal of Research in Nursing
- Nursing Science Quarterly
- Qualitative Health Research
- Scandinavian Journal of Public Health

Additional contribution:

- Identifying key papers not indexed in Medline or PsycINFO, or not identified by the search terms used

## **Appendix 4: Data extraction example**

### **Data extraction form**

**Date extracted:** 15/9/09

**Time taken:** 1 ½ hours

**Initials of data extractor:** LP

**Source of paper:** Medline  
(eg. database, expert suggestion, citation search, etc.)

**First two authors:** Tod, A., Lacey, E.  
(in the following format: Surname, initial, Surname, initial)

**Title of article:** 'I'm still waiting...': barriers to accessing cardiac rehabilitation services

(in the following format: title in full)

**Date of publication:** 2002  
(in the following format: yyyy)

**Country of study:** UK  
(i.e. country where study was conducted, not country of authors)

**Patient group:** AMI  
(categories are: AMI, cabg, pci, other (specify))

**Intervention:**  
(details if there is an intervention)

**Point in timeline:** after hospitalisation for AMI, after previous AMIs or cardiac events (some recruited in hospital, some recruited from records retrospectively – eg. 8 months after event)

**Relevant to motivation and continuity of care:** YES / NO  
If NO, put to one side

#### **Quality:**

1. Are the aims and objectives clearly stated? YES / NO
2. Is the design clearly specified and appropriate? YES / NO
3. Do the researchers provide a clear account of the process through which findings were produced? YES / NO
4. Do the researchers display enough data to support their interpretations and conclusions? YES / NO
5. Is the method of analysis appropriate and adequately explicated? YES / NO

**Acceptable quality?** Excellent / Acceptable / Unacceptable  
(judge overall quality, informed but not guided exclusively by questions above)

If unacceptable, state the reasons below, and put to one side

**Stated aim of the study:** To explore what barriers exist for patients in accessing cardiac rehabilitation services within the South Yorkshire Coalfield locality. P.421, abs

The study presented here was conducted to provide local information to identify what currently prevents people accessing cardiac rehabilitation in the South Yorkshire Coalfields. The intention was to include the views and experiences of populations who are often excluded from cardiac rehabilitation evaluation, for example the elderly, women and those from lower socio-economic groups. The data gathered is likely to be of interest to other health communities with similar levels of deprivation. P.423, para -3

(i.e. aims and objectives)

**Sample / participants:** Purposive sampling was used to select participants. Individual interviews of 15 staff (cardiac rehabilitation staff, nurses, dieticians and physiotherapists, health promotion officers, a public health doctor, health visitor, community exercise worker, hospital and community nursing managers) and 20 post myocardial infarction patients. A range in terms of age, gender, employment, postcode, cardiac history and cardiac rehabilitation attendance (some had and some had not attended CR) was obtained. One group interview with seven health visitors and two with lay members of heart support groups.

(i.e. studied population)

**Study design / Data type:** Qualitative methods, including semi-structured interviews. Also guided workshop groups to test emerging findings from interviews (eg. case-control study, focus group study, etc.)

**Analytic approach:** Framework Analysis

(eg. descriptive statistics, grounded theory analysis, etc.)

**Relationship of concepts:**

	CR	Concordance	Continuity of care	Motivation
Themes	√	√	√	√
Aspects	Phase I Phase II Phase III	Non-attendance Attendance	Underfunding Understaffing Promised contact never fulfilled Targeting one type of not very able patient Inconsistency of message Staff enthusiasm Lack of process	What's the point now? It would be a waste of their time Affluent pts seeking alternatives

(i.e. tick boxes if themes included in paper, and if these are related by the authors)

**Themes:**

(give each theme a title in BLOCK CAPITALS, eg. [STIGMA], then summarise relevant data in ordinary text, eg. '69 percent reported feeling stigmatised')

1 [SERVICE CAPACITY; PATIENTS SLIP THROUGH] "This study revealed a limited service capacity. Big gaps exist between patches of service activity that most patients appear to slip through." P.421, abs

- 2 [ABSENCE; WAITING; COMMUNICATION; UNDERSTANDING; APPROPRIATENESS] "Problems in accessing the service were categorized into five themes: absence, waiting, communication, understanding, and appropriateness." P.421, abs
- 3 [GENDER; AGE; CLASS; ADVICE SEEKING] "Some groups fared worse in terms of access to services, for example women, the elderly and those in traditional working class coalfields communities. Professional and more affluent participants appeared better able to negotiate their way around the system by seeking out advice or 'going private'." P.421, abs
- 4 [LIMITATIONS OF SERVICES] "Staff participants reported an awareness of the limitations of existing cardiac rehabilitation services." P.426, para 2
- 5 [MINORITY OF NEEDS MET; SERVICE GAPS; SLIPPING THROUGH THE NET] "The patient data revealed the extent of these limitations and confirmed that existing services met only the minority of patient's needs. Gaps were seen to exist between patches of service activity, with most patients slipping through the net." P.426, para 2
- 6 [ABSENCE; INADEQUATE COMMITMENT; LACK OF STRATEGY; LACK OF PLANNING; LACK OF STAFF; LACK OF PROCESSES] "Absence was a theme interwoven in the responses of both patients and staff. Staff admitted that there had been a lack of commitment and investment in services in the past. Services were therefore limited and the resultant absence created a fundamental barrier to the many people accessing cardiac rehabilitation after a heart attack. The reported consequence of inadequate past commitment was the absence a clear strategy, funding, planning, enough adequately trained staff and agreed processes to support service delivery." P.426, para 3
- 7 [WORKLOAD; LACK OF RESOURCES; FOCUSING ON ONE ASPECT OF PATHWAY] "Clinical staff felt overwhelmed by the existing workload. There was serious concern at the prospect of having to try and expand the service to other groups of cardiac patients without additional resources, as required by the National Service Framework. Lack of time meant they were unable to think strategically and focused their attention on the one aspect and phase of the service they were trying to deliver, rather than the overall pathway. 'I think when you haven't even got the basic stuff, it's hard to like visualize what you could go on and see' (Staff)." P.426, para 4
- 8 [CR ABSENT WHEN NEEDED; ABANDONMENT; ISOLATION; VULNERABILITY] "The patients accounts of their heart attack and its effects on their lives revealed cardiac rehabilitation services were often absent when needed. People spoke quite powerfully of the abandonment, isolation and vulnerability experienced as a consequence of inadequate services." P.426, para 5
- 9 [TRANSFER TO WARD; 2 WEEKS POST-DISCHARGE; CR ABSENT WHEN NEEDED] "Three time points were identified when the absence of cardiac rehabilitation services were most acutely felt:
- On transfer from the coronary care unit to the medical ward when people began to feel lost to the system.
  - During the first 2 weeks post-discharge when participants thought help was needed to prevent fear and vulnerability developing.
  - At 6–8 weeks post-MI, when, having relied on the written information given in hospital, people were left wondering what to do next (Box 2)." P.426, 427 para 6, -2, 1
- 10 [TRANSFER TO WARD; VULNERABLE; NOBODY CARES] "Transfer from CCU: 'I felt very, very vulnerable in there and they didn't know what was wrong with me'. 'you're thrown upstairs into a ward and it's totally different and you're on a ward and nobody seems to what shall I say? to care really!'" P.426, box 2, para 1
- 11 [2 WEEKS POST-DISCHARGE; NEED FOR GUIDANCE] "First 2 weeks post-discharge: 'I think as soon as you come out of hospital, you need some sort of guidance because that is the critical time not 6 months afterwards'." P.426, box 2, para 2

12 [6-8 WEEKS POST-DISCHARGE; NO APPOINTMENT; WAITING] “6–8 weeks post-discharge: ‘Sister told me that “We’re sending for you in about 6 weeks, Mr X, and we’ll make an appointment for you to come back.” I’ve never heard nothing from them!’ ‘I’d done as much exercise as I could and I was waiting for the next bit to kick in and obviously not hearing anything’.” P.426, box 2, para 3

13 [ADVICE; REASSURANCE; NEED FOR SUPPORT] “Advice and reassurance: ‘If I could have picked a phone up and said, “Look, you know, I’m feeling a bit ropy” that would have been good. Not necessarily visited by anyone, or visiting anyone’.” P.426, box 2, para 4

14 [PSYCHOLOGICAL SUPPORT; GIVING TIMES] “Psychological support: ‘...although you actually suffer the pain when you have the heart attack, I think the mental side of it is worse’. ‘A lot of it is in your head, isn’t it, the recovery and that. I was surprised how much it affected me, you know? But nobody actually came and sat with me’.” P.426, box 2, para 5

15 [GP SUPPORT; PATIENT EXPECTATIONS] “GP support: ‘He never came near us. Never came near us. Well, we sorted it out ourselves ... Yeah, but he never come near us. He’s never been anywhere near us’.” P.426, box 2, para 6

16 [DESIRE FOR PERSONALISED INFORMATION; STANDARD CARE] “Personalized information: ‘I think that was a general description that they give to everybody. Nothing really was aimed at me sort of thing, specifically at my personal case’.” P.426, box 2, para 6

17 [SUPPORT FOR FAMILY; DESIRE FOR HELP] “Support for the partner and family: ‘There’s just nobody. There’s just nothing. There’s no back up at all, is there, or there hasn’t been for me anyway. And sometimes I think, “who the hell is going to help me?”’” p.426, box 2, para 7

18 [DESIRE FOR ADVICE; DESIRE FOR REASSURANCE; DESIRE FOR PSYCHOLOGICAL SUPPORT; DESIRE FOR PERSONALIZED INFORMATION; DESIRE FOR SUPPORT FOR FAMILY] “Participants singled out some specific components of cardiac rehabilitation as particularly important and the absence of these was emphasized. These included, advice and reassurance, psychological support, GP support, personalized information and support for the partner and family (Box 2).” P.427, para 1

19 [WAITING LISTS; SERVICE CAPACITY; WASTING THEIR TIME] “Long waiting lists appeared to be the inevitable consequence of the limited cardiac rehabilitation service capacity. Waiting lists of up to 12 months created a delay and prevented people accessing services at a time when they needed them. He hasn’t been called for it yet because there’s a long waiting list. I mean it’s useless now, isn’t it? (Patient’s wife) He says, ‘Have you been to rehab yet?’ I says, ‘no’ and he says, ‘They’ll be in touch.’ But that’s six months ago since my heart attack and the time’s passed. I think really it’ll be a waste of their time. (Patient)” p.427, para 2

20 [EXCLUSION CRITERIA FOR CR; AGE; EXERCISE TOLERANCE; ANGINA; HEART FAILURE; AWAITING REVASCULARISATION; WAITING CREATED INABILITY TO MOVE ON] “Exclusion criteria for the hospital cardiac rehabilitation group also created a barrier. Exclusions were on the basis of age, a positive exercise tolerance test, post infarct angina or heart failure, despite the fact they may have benefited the most from exercise cardiac rehabilitation. Some participants were temporarily excluded until they had had an interventional cardiology or revascularization procedure. This created two waiting periods, first for the procedure, then for cardiac rehabilitation. In some instances it was the waiting, not just the illness, which impacted upon life satisfaction and well-being and created an inability to move on.” P.427, para 3, 4

21 [COMMUNICATION SYSTEM FAILURES; INFORMATION BETWEEN SYSTEMS; LACK OF PROCESS; DELAYED TEST RESULTS; NO INFORMATION ABOUT EXERCISE SCHEMES] “Barriers because of poor communication fell into two categories; communication systems and the standard of information giving. Examples of failing communication systems included:



- Patients and community nurses unable to extract information about the availability of the hospital cardiac rehabilitation service.
- Inability to pass information regarding patients across health care settings creating delays of months in referral.
- Lack of clarity of how, when and who refers to the hospital cardiac rehabilitation classes and patients.
- Delays in receiving test results, e.g. exercise tolerance tests, which held up patients progress.
- No system to circulate information about the range of exercise and activity schemes available to patients in the community.

Big time gaps occurred between contact, allowing confusion about their recovery and services availability to grow. Staff reported that additional resources, especially Information technology, would help to improve the current deficits in referral." P.427, para 5, -6 [but you can have a system without IT]

22 [COMMUNICATION SYSTEM FAILURES] "Sister told me that 'We're sending for you in about six weeks, and we'll make an appointment for you to come back.' I've never heard nothing from them!...So it's gone haywire in the hospital somewhere I think. and I still haven't heard 'owt, so whether it's their end or what or in between us I don't know. (Patient)" p.427, para -5

23 [INCONSISTENCY OF ADVICE; NON-ENGLISH SPEAKERS; PATIENTS NOT INVOLVED IN DECISION-MAKING; LACK OF COMMUNICATION AIDS] "Inconsistency of advice giving and occasions the information didn't make sense to the patient also constituted barriers to accessing cardiac rehabilitation. Problems with communication were highlighted with those patients who could not speak English. This included people whose first language was sign, as well as another spoken language. Examples included the inadequate availability and use of interpreters, difficulty in accessing information in a group situation, the tendency for staff to make decisions regarding care without consulting the patient and the lack of availability and use of communication aids, for example, computer assisted learning." P.427, para -4

24 [LACK OF CONTINUITY; EPISODIC CARE] "Staff understanding and definitions were dominated by reference to the phases of cardiac rehabilitation. This meant a focus on patches of activity rather than pathways, processes and content of care." P.427, para -3

25 [UNDERSTANDING OF CR; INFLUENCE ON PARTICIPATION; UNMET EXPECTATIONS; LOSS OF CONFIDENCE IN SERVICE] "Patients and carers expressed a lack of understanding of what cardiac rehabilitation is, which influenced their decision of whether to access the service or not. For example, some people had unmet expectations as a result of misunderstanding. If expectations were not met this could lead to a loss of confidence in the service. 'Probably I was expecting too much...I probably read it wrong. It probably wasn't for that, but there again if there's a help line, why have a help line if they're not going to help you?' (Patient)" P.427, para -2

26 [CR AS EXERCISE; NOT FOR ME; EXERCISE IS FOR FIT PEOPLE] "Some patients interpreted cardiac rehabilitation as exercise only. This was a barrier when people did not see exercise for them. 'I mean I don't want to do anything too strenuous. I'm getting lazy in my old age!' (Patient). There was still perception amongst some that exercise is for fit people only and isn't good for you after a heart attack. 'I wasn't looking forward to it. I can tell you that. I'd have gone as it happens, but I didn't know what it entailed. You know? I can't see me jumping up and down on the bars and all this, could you? After an heart attack, I don't know.' (Patient)" P.427,428 para -1, 1

27 [UNDERSTANDING OF CHD; SINGLE ISSUE SINGLE APPROACH] "Patients understanding of coronary heart disease and their heart attack appeared to influence whether they accessed cardiac rehabilitation. Patients attributing the heart attack to one factor instinctively focused on resolving that one issue. Where raised cholesterol was blamed, diet was changed, cholesterol-lowering drugs taken and blood levels improved. There was then little motivation to access cardiac rehabilitation or look at overall heart health." P.428, para 2

28 [MINIMISING SEVERITY OF ILLNESS; NOT ADMITTING WEAKNESS] “Patient’s heart attack experience sometimes differed from their expectations. When the symptoms were not as severe or enduring the instinct was to minimize the severity of the illness. The patient then perceived they did not need cardiac rehabilitation. This inclination was also identified by staff who linked it to a cultural tendency in the South Yorkshire Coalfields, not to admit to weakness. ‘A lot of people don’t appreciate exactly what’s gone off, that they turn round and say ‘Well I’ve had a heart attack and I’m all right now...’ Certainly in this area there’s an ego image with the fellows.’ (Staff).” P.428, para 3

29 [GROUP EXERCISE; SOCIALLY STRESSFUL; PRIVACY; DOMINANT MEMBERS; ODD ONE OUT] “Some participants advocated the delivery of education and exercise in a group setting. Others found it inappropriate and unappealing. People were deterred from attending groups because they found them stressful socially, lacked privacy or were put off by dominant members in the group. There also appeared to be an expectation that they would be the odd one out, with other group members being older, younger, more or less ill than them. I mean there might have been people there who’d had really bad heart attacks and it could have made me worse, you know, by talking to them. (Patient)” P.428, para 5

30 [FEAR OF HOSPITALS; TRAVEL; PARKING; AVOIDANCE OF HOSPITAL] “Those who considered hospital-based services inappropriate valued the choice of a local service. Reasons given for this preference included not wanting to travel, problems with transport, parking at the hospital and also a reluctance to revisit the hospital. The latter was explained by a fear or intense dislike of hospitals and also its association with what had been a terrifying event, the heart attack. ‘Actually I mean I detest hospitals to be quite honest’(Patient). ‘It were quite stressful going [to cardiac rehabilitation] anyway. Like re-visiting the scene of the crime!’ (Patient).” P.428, para 6, -6

31 [GENDER; FAMILY COMMITMENTS; WORK; CULTURE] “Both patient and staff participants reported that women were precluded from attending a cardiac rehabilitation by other commitments. These included childcare, paid employment, housework and family responsibilities. Delay in service availability places an additional barrier upon women because of the speed with which they resume responsibilities in the home and family. The commitments were more acutely felt in areas of high male unemployment and traditional Coalfields communities because, ‘It’s the women that sort of bear the brunt of the caring role’. (Staff)” p.428, para -5

32 [AGE; STAFF PERCEPTIONS; DISRUPTED ROUTINE] “The elderly also experienced specific barriers in accessing cardiac rehabilitation. Staff and patient participants thought existing services inappropriate for the elderly, often because of the hospital base. Frailty because of age or comorbidity may exacerbate problems with travel, transport and distance to services. Elderly participants also emphasized the importance of routine in their lives and the security this offered. If cardiac rehabilitation attendance disrupted their routine, they would not attend. ‘I refused help from the hospital...I said, ‘Well, what’s the times?’ He said, ‘Mornings.’ I said, ‘That’s out’. (Patient)” p.428, para -4

33 [GOING PRIVATE; LOTS OF QUESTIONS; WAITING TIME] “Facilitators in accessing services were also identified. ‘Going private’ or paying for private health care, was considered the only option by some who found NHS services deficient. ‘I have got a lot of questions...I need to sort myself out. and I couldn’t see me waiting that length of time. So I said, ‘Well, I’ll go private’. (Patient)” p.428, para -3

34 [ALTERNATIVE SOURCES OF SUPPORT; LEISURE CLUBS; FRIENDS AND FAMILY; BEING IN CONTROL] “‘Finding alternatives’ was the only option open to some when faced with delay in accessing NHS facilities. These alternatives included accessing leisure clubs for exercise and friends and family who have had a heart attack for information and advice. ‘Being in control’ over aspects of their lives provided patients with more opportunity to access services. For example, having control over their own time and their own transport enabled them to access services whatever the time and location. ‘It’s fortunate that I’m a company director so, you know, to a great extent I can suit myself, but not everybody is as fortunate’. (Patient)” P.428, para -2

35 [KNOWLEDGE; SKILLS; ASSERTIVENESS; TAKING CONTROL] “Having the knowledge, skills and assertiveness to take control when communication systems fell down also marked some patients out as being able to access services when others couldn’t. ‘Things that happened have all been in my favour...I’m not an average national health patient. You see?’ (Patient)” p.428, 429, para -1, 1

36 [VARIED SERVICE LEVEL NEEDS; LIMITED CAPACITY; INFLEXIBILITY] “The level of service required by patients and families in this study varied but limited capacity and inflexibility prevented staff offering an appropriate range of services to ensure access. As a qualitative study these experiences can only claim to relate to the study population.” P.429, para 2

37 [LACK OF INVESTMENT; RELIANT ON ENTHUSIASM; RESTRAINED SERVICE] “Staff participants echoed the view of Bethall (2000) and Fearnside et al. (1999) that lack of investment and omitting cardiac rehabilitation from services commissioned in the past has contributed to the problem. As reported by staff in this study, services can then become reliant on the enthusiasm of dedicated individual practitioners, often nurses, who provide a programme restrained by the limitations of their individual resources and skills (Bethell 2000).” P.429, para 3

38 [AFFLUENT; NEGOTIATING SYSTEM; SEEKING ADVICE; GOING PRIVATE] “The indication was, however, that the professional and more affluent participants appeared better able to negotiate their way around the system by seeking out advice or ‘going private’. This patient group were also in more control over their time and workload and so could access hospital-based programmes regardless of distance to travel or time of day.” P.429, para 4, -8

39 [ROLE RELATED BEHAVIOUR; COMFORT IN PREVIOUS ROUTINES; STOICISM] “Reasons for returning to role related behaviour, and not attending cardiac rehabilitation, were revealed by the South Yorkshire Coalfields participants. Women were under pressure to return to their house, work and family responsibilities. Men living in traditional ex-mining communities were sometimes reticent about the impact of their illness. The prevailing ‘macho’ culture reduced the perceived necessity for cardiac rehabilitation or support. Some of the more elderly participants sought comfort in their previous routines, which they did not want disturbed by attendance at cardiac rehabilitation in the hospital.” P.429, para -6

**Comments:** see box 1 for ‘standard’ content of UK cardiac rehabilitation (i.e. interesting aspects of the methodology and results)

**Memos:** (i.e. implications for developing concepts and theories)

**Meta-narratives:** (i.e. assumed concepts and theories)

## Appendix 5: Attributes of included studies

### Purposive sample

First author and date	AMI, CABG, PCI	Country	Guiding Model	Study type	Analysis	Participants	CR phase	CR element	Compares interventions	Purpose of study	Gender
Al Ali 2004	AMI	Jordan	Health Belief Model	structured interview	stepwise regression	patient	not clear	exercise	no	Identify associations between health belief variables and exercise participation	both
Al Hassan 2000	AMI	Jordan	Decisional Conflict Model	structured interview	forced regression	patient	not clear	exercise	no	Stress as indicator of decisional conflict to interaction of perceived benefits and barriers to exercise; ability to predict decisions to exercise regularly	both
Allen 2004	AMI and CABG and PCI	USA	Not Applicable	phone interview	multivariate logistic regression	patient	Phase 3 (phase 2 USA)	Not specified	no	Predictors of referral and enrollment in CR programmes, comparing white and African American women	women
Altenhoener 2005	AMI	Germany	Self-efficacy	questionnaire survey	logistic regression	patient	phase 3	Not specified	no	Social class and CR participation	not clear
Arnetz 2008	AMI	Sweden	Not Applicable	questionnaire survey	MANOVA	health profs	phase 1	Not specified	no	Measure perceptions and behaviour regarding patient involvement	N/A

Attebring 2004	AMI	Sweden	Not Applicable	structured interview	stepwise logistic regression	patient	phase 1	smoking	no	Identify characteristics of those who will resume smoking after hospitalisation	not clear
Barth 2008	AMI and CABG and PCI	Europe	Not Applicable	systematic review	meta-analysis	patient	not clear	smoking	yes	Evaluate psychosocial intervention strategies for smoking cessation	both
Bellg 2003	Not clear	USA	Self-determination Theory	case study	inductive thinking	patient	phase 2	Not specified	no	[Discussion of theoretical approach to health behaviour change] not stated in paper	women
Beswick 2004	AMI and CABG and PCI	UK	Not Applicable	systematic review	narrative review	patient partner and health prof	phase 3	Not specified	no	Estimate UK need for outpatient CR; methods to improve uptake and adherence to CR; estimate costs of increasing CR uptake	both
Beswick 2005	CABG and PCI	UK	Not Applicable	systematic review	qualitative overview	patient	not clear	Not specified	yes	Identify studies of interventions to improve uptake, adherence and professional compliance in CR	both
Blanchard 2003	Not clear	Canada	Theory of Planned Behaviour	mail survey	hierarchic regression	patient	phase 3 (phase 2 Canada)	exercise	no	Utility of the Theory of Planned Behaviour in explaining exercise intentions and CR adherence	not clear
Brady 2005	CABG	Canada	Not Applicable	before and after study	binary logistic	patient	phase 2	exercise	no	Relationship between exercise	both

					regression					tolerance, functional status, exercise behaviour and CR enrolment	
Brophy 2003	CABG and PCI	Canada	Not Applicable	database study	multivariate logistic regression	patient	not clear	drugs	no	Rate and predictors of filling cholesterol-lowering prescriptions for elderly pts	both
Carlson 2001	Not clear	USA	Not Applicable	rct	multiple regression	patient	phase 2	Not specified	yes	Effect of low-cost modified vs traditional CR protocol on psychosocial predictors of exercise	both
Charlton 1993	CABG	USA	Not Applicable	tool development	inductive thinking	patient partner and health prof	phase 2	Not specified	no	Development of a CR compliance tool to screen new CR participants for drop-out and compliance risk factors	men
Clark 2004	AMI and CABG	Scotland	Not Applicable	focus group	thematic analysis	patient	phase 3	Not specified	no	Decision-making in users, non-users and pts with high attrition rate	both
Clark 2005	AMI and CABG	Scotland	Not Applicable	focus group	thematic analysis	patient	phase 4	Not specified	no	Patient experiences of CR and perceptions of mechanisms and contexts influencing long-term adherence	both
Conn 1991	AMI	USA	Not Applicable	interview (unspecified)	descriptive stats	patient	not clear	Not specified	no	Gender differences in health state,	both

										psychosocial state and adherence; relationship between age and health state, psychosocial state and adherence	
Corrigan 2006	AMI and CABG and PCI	Ireland	Not Applicable	focus groups and semi-structured interview	thematic analysis	patient and health prof	phase 3	Not specified	yes	Explore how complex intervention to encourage provision and uptake of CR could be integrated with current practice in two healthcare systems; acceptability and feasibility of intervention	both
Dalal 2007	AMI	UK	Not Applicable	Rct with preference arms	ANCOVA	patient	phase 3	Not specified	yes	Effectiveness of home-based vs hospital-based CR	both
Doolan-Noble 2004	AMI and CABG and PCI	New Zealand	Not Applicable	audit	logistic regression	patient records	phase 2	Not specified	no	Factors associated with referral and utilization of CR	both
Evenson 2000	Not Applicable	USA	Not Applicable	mail survey	content analysis	health prof	phase 2	Not specified	no	Barriers to participation and adherence to CR according to program staff	both
Evenson 2006	AMI and CABG	USA	Not Applicable	mail survey	content analysis	health prof	Phase 3 (phase 2 USA)	Not specified	no	Describe CR programming; barriers to participation, reasons for drop-out according to	both

										program directors; compare results with similar 5 year old survey	
Ewart 1986	AMI and CABG	USA	Self-efficacy	randomised study	multiple regression	patient	phase 2	exercise	no	Test of self-efficacy assumptions through relationships between self-rated abilities and performance gains in arm and leg training	men
Fernandez 2007	PCI	Australia	Not Applicable	mail survey	principal component factor analysis	patient	phase 3	Not specified	no	Psychometric properties of Revised Cardiac Rehabilitation Preference Form; determine pt preferences in relation to CR	both
Fleury 1991	AMI	USA	Not Applicable	questionnaire survey	multiple regression	patient	phase 4	Not specified	no	Relationships between social support, health locus of control, health value orientation and wellness motivation and influence on patient motivation in CR	men
Franklin 1995	AMI	USA	Not Applicable	observational study (unspecified)	t tests	patient	phase 3	diet	no	Adherence to and acceptance of very low-fat diet	not clear
Gallagher 2003	AMI and CABG	Australia	Not Applicable	semi- structured	logistic regression	patient	phase 3	Not specified	no	Women's attendance at CR;	women



	and PCI			phone questionnaire						influence of patient-related factors	
Grace 2002a	AMI	Canada	Not Applicable	longitudinal questionnaire study	logistic regression	patient	phase 3	Not specified	no	Gender differences and barriers in CR referral and participation; psychosocial variables in CR participation	both
Grace 2002b	Not clear	Canada	Not Applicable	literature review	critical gap analysis	patient	phase 3	Not specified	no	Gender differences in CR participation, focusing on psychosocial factors	both
Grace 2005	PCI	Canada	Not Applicable	case-control, prospective	chi square tests	patient	phase 1	Not specified	yes	Gender-tailored psycho-educational brochure plus motivational interview to facilitate patient initiation of discussion about referral to CR vs usual care	women
Grace 2007	AMI and CABG and PCI	Canada	Not Applicable	cluster controlled study	hierarchic logistic regression	patient	phase 3	Not specified	yes	Automatic referral vs usual referral and enrollment	both
Hagan 2007	AMI and PCI	Australia	Not Applicable	semi-structured interview	thematic analysis	patient	phase 2	Not specified	no	Demographic factors that influence decisions to attend CR	both
Hamm 1986	AMI	USA	Not Applicable	narrative review	narrative review	patient	phase 1	exercise	no	History, safety, types, cardiovascular responses and clinical uses of	not clear

										exercise testing early after MI	
Harkness 2005	CABG	Canada	Not Applicable	controlled cohort, retrospective	hierarchic logistic regression	patient	phase 1	Not specified	yes	Effect of nurse phone call on attendance at CR intake appointment	both
Harrison 2005	AMI and CABG and PCI	UK	Not Applicable	mail survey	logistic regression	patient	phase 2 and 3	Not specified	no	Extent of service provision in locality	both
Heid 2004	Not clear	USA	Transtheoretic al Model	Chart review, semi-structured phone interview	t-test, chi-square (age and gender diffs in enrolment), content analysis of interviews	patient	phase 2 and 3 (USA)	Not specified	no	Compare CR referral rates of men and women; what women learned during hospitalization; how they used information to decide whether to participate	both
Heidrich 2005	Not clear	Germany	Not Applicable	mail survey	multivariate logistic regression	health prof	not clear	Not specified	no	Knowledge and perception of clinical guidelines; secondary prevention treatment practices; impact of guideline knowledge on treatment practice	both
Hellman 1997	Not clear	USA	Stages of Change	phone interview	discriminant function analysis	patient	phase 3	exercise	no	Predictors of exercise adherence and validity of STAGES model	both
Ho 2008	AMI and CABG and PCI	USA	Not Applicable	registry data study	multiple regression	patient records	phase 3	drugs	no	Association between antihypertensive	both

										non-adherence and therapy intensification with blood pressure control	
Holm 1985	AMI and CABG	USA	Health Belief Model	questionnaire survey	correlation matrix	patient	phase 3 (phase 2 USA)	Not specified	no	Health beliefs of pts completing CR programme, and factors that influence or modify beliefs	both
Hughes 2007	AMI and CABG and PCI	Scotland	Stages of Change	rct	Wilcoxon signed rank test, Mann-Whitney, chi-square ANOVA	patient	phase 4	exercise	yes	Long-term effects of exercise consultation vs standard exercise information on maintenance of physical activity and fitness	both
Husak 2004	CABG	USA	Not Applicable	structured interview	sequential logistic regression	patient	phase 3	Not specified	no	Role of social support as predictor of CR participation	both
Jackson 2005	AMI and CABG and PCI	Canada	Not Applicable	quantitative review	correlation matrix	patient	more than one phase	Not specified	no	Predictors of successful referral; predictors of programme adherence; predictors of adherence after CR programme	both
Johnson 2004	AMI and CABG and PCI	Australia	Not Applicable	questionnaire survey	multivariate logistic regression	patient	phase 1	Not specified	no	Factors associated with referral to CR	both
Jolly 1998	AMI	UK	Stages of Change	rct	logistic regression	patient	Phase 2 and 3	Not specified	yes	Effectiveness of nurse-led programme to	both

										ensure follow-up care provision in general practice	
Jolly 2007	AMI and CABG and PCI	UK	Not Applicable	rct	univariate analysis	patient	phase 3	exercise relaxation education and lifestyle counselling	yes	Effectiveness and cost-effectiveness of home-based CR using the Heart Manual vs centre-based programme; explore reasons for non-adherence	both
Jones 2007	AMI and CABG and PCI	UK	Not Applicable	semi-structured interview	charting	patient	phase 3	Not specified	no	Pts reasons for non-participation or non-adherence to home or hospital-based CR	both
Karner 2005	AMI and CABG and PCI	Sweden	Not Applicable	semi-structured interview	phenomenographic framework	patient	phase 3	Not specified	no	How pts experience facilitating and constraining factors related to lifestyle changes	both
King 2001a	AMI and CABG	Canada	Not Applicable	cohort study	MANOVA	patient	phase 3	Not specified	no	Factors that influence pts attendance at CR and their subsequent behaviour change	both
King 2001b	AMI and CABG and PCI	Canada	Self-efficacy	phone survey	hierarchical logistic regression	patient	phase 2	Not specified	no	Factors that influence pts attendance at CR and their subsequent behaviour change	both
Koertge 2003	AMI	USA	Not Applicable	cohort study	ANOVA	patient and partner	phase 3	diet exercise stress	yes	Medical and psychosocial characteristics of	both

								managem ent social support		pts eligible for PCI or CABG vs patients with previous PCI or CABG enrolled in Multicenter Lifestyle Demonstration Project	
Kristeller 1992	AMI	USA	Stages of Change	controlled cohort, retrospective	MANOVA	patient	not clear	smoking	no	Processes and stages of change in smoking pts with cardiac disease vs non-medical smokers	not clear
LaBresh 2004	AMI and CABG and PCI	USA	Not Applicable	audit	t-test	patient records	phase 1	Not specified	no	Evaluation of 'Get with the guidelines' quality improvement programme for secondary prevention	both
Ladeia 2003	AMI and CABG and PCI	Brazil	Not Applicable	interview (unspecified)	t-tests, Mann- Whitney, chi- square	patient and health prof	not clear	Not specified	no	Patient knowledge and attitudes about secondary prevention	both
Liebermann 1998	AMI and CABG	Canada	Not Applicable	questionnaire survey	Chi-square, t-tests	patient	phase 3	Not specified	no	Barriers and incentives most influential in decision to participate in CR; suggests strategies to overcome barriers	both
Lindsay 2003	CABG	Scotland	Not Applicable	observational study (unspecified)	Fisher exact, chi-square, t-test, Mann-	patient	phase 3	Not specified	no	Relation of variables (angina, breathlessness,	both

					Whitney						health and well-being, modifiable risk factors) to attendance at CR programme	
Maeland 1989	AMI	Norway	Acute somatic disease framework	questionnaire survey	multiple regression	patient and partner	more than one phase	Not specified	no		Medical, psychological and social consequences of MI, especially role of cognitive factors in coping and readjustment	both
Mahler 1999	CABG	USA	Self-efficacy	randomised study	multiple regression	patient	phase 2	diet and exercise	yes		Effect on compliance of two experimental videos preparing pts for post-discharge recovery	both
McGirr 1990	Not clear	Canada	Theory of Goal Attainment	phone survey	Chi-square	patient	phase 3	Not specified	no		Perceptions of mood, illness severity, exercise behaviours, quality of life of pts referred to CR	both
Meagher 1987	CABG	Canada	Social Learning Theory	discussion paper	discussion paper	lay volunteer	phase 1	Not specified	no		Description of dyadic support intervention; comparison with similar programmes	N/A
Montgomery 1991	Not clear	USA	Sense-making	questionnaire survey	multiple regression	patient and partner	phase 2	diet	no		Pt perceptions of coping with cardiac diet	both
Moore 2003	AMI and CABG	USA	Not Applicable	descriptive study	hierarchic regression	patient	phase 3 (phase	exercise	no		Factors that predict exercise after completion of CR	women

							2 USA)			programme	
Moore 2006	AMI and CABG and PCI	USA	Self-efficacy	rct	Cox proportional hazards regression	patient	phase 3	exercise	yes	Effectiveness of lifestyle modification programme designed to increase exercise maintenance	both
Ornish 1998	Not clear	USA	Not Applicable	rct	linear regression	patient	phase 2	Not specified	yes	Feasibility of patients to sustain intensive lifestyle change intervention over 5 years; effects of changes on CHD	both
Ramsay 2005	AMI	UK	Not Applicable	questionnaire survey	logistic regression	patient	more than one phase	drugs	no	Medication use for secondary prevention since introduction of NSF; influence of age, class, region and time since diagnosis	men
Redfern 2006	AMI	Australia	Not Applicable	intervention development and testing	descriptive stats	patient	more than one phase	Not specified	no	Develop and test risk factor modules and corresponding information leaflets for secondary prevention	both
Reid 2007	AMI and CABG and PCI	Canada	Stages of Change	questionnaire survey	multiple regression	patient	phase 3	Not specified	no	Transitions in exercise stage of change; relationship between constructs of Protection Motivation Theory, Theory of Planned	both

										Behaviour, Social Cognitive Theory, Ecological Model and Stages of Change	
Riley 2007	PCI	Canada	Not Applicable	questionnaire survey	linear regression	patient	phase 3	Not specified	no	Patient continuity perceptions; compare to another province; correlations of positive perceptions	both
Rogers 2006	Not Applicable	USA	Stages of Change	questionnaire survey	multiple regression	health prof	Not Applicable	exercise	no	Physician physical activity, fitness, physical activity knowledge, use of behaviour modification techniques, attitudes to physical activity, and self-efficacy	both
Schuster 1995	CABG	USA	Self-efficacy	questionnaire survey	t-tests	patient	phase 3	Not specified	yes	Structured hospital-based vs home-based CR	both
Sinclair 2005	AMI	UK	Not Applicable	rct	descriptive stats	patient	phase 3	Not specified	yes	Home-based nursing intervention vs usual care	not clear
Stafford 2005	AMI	USA	Not Applicable	registry data study	multivariate logistic regression	patient	not clear	drugs	no	National trends in aspirin vs statin use in high-risk pts	both
Stafford 2008	AMI and CABG and PCI	Australia	Not Applicable	structured interview	hierarchic logistic regression	patient	more than one phase	Not specified	no	Illness beliefs 6 weeks after hospitalisation	both
Stegman	AMI	USA	Not Applicable	cohort study	Cox	patient	phase	Not	no	Relationship	both



1987					proportional hazards regression		4	Applicable		between repeat MI and attitudes to adherence to CR	
Stenstrom 2005	AMI	Sweden	Not Applicable	semi-structured interview	t-test, chi-square, ANOVA, eta-squared, Tukey HSD	patient	phase 1	Not specified	no	Extent of denial after AMI; compares CR participation in pts with denial or no denial	both
Stillman 1995	AMI	USA	Stages of Change	journal article	overview	patient	more than one phase	smoking	no	Factors influencing smoking cessation in CHD; overview of smoking cessation model	N/A
Timmins 2006	AMI	Ireland	Orem's Model of Nursing	discussion paper	discussion paper	patient	not clear	Not specified	no	Appropriateness of traditional nursing models for modern coronary care nursing	N/A
Tod 2002	AMI	UK	Not Applicable	semi-structured interview	framework analysis	patient and health prof	more than one phase	Not specified	no	Barriers for patients in accessing CR	both
Toobert 1998	AMI and CABG and PCI	USA	Not Applicable	rct	MANCOVA	patient	more than one phase	diet	yes	Effect of comprehensive lifestyle intervention on behavioural risk factors and psychosocial outcomes	women
Tzou 2004	AMI	USA	Not Applicable	questionnaire survey	multiple regression	patient	more than one phase	smoking	no	Smoking correlates and predictors	both
Vestfold 2003	AMI and CABG	Norway	Not Applicable	rct	T test, Mann-Whitney U,	patient	more than	Not specified	yes	Long-term effect of comprehensive	both

	and PCI				Pearson's chi-square		one phase				lifestyle intervention	
Visram 2007	Unassigned	UK	Not Applicable	focus groups and semi-structured interviews	thematic content approach	patient and health prof	phase 3	Not specified	no	South Asian patients experience of CR; factors influencing participation	women	
Wingham 2006	AMI and PCI	UK	Not Applicable	semi-structured interview	interpretive phenomenological analysis	patient	phase 1	Not specified	no	Patients' experience of MI; factors influencing choice of home or hospital CR	both	
Ye 2007	AMI	USA	Andersen's Health Service Utilisation Model	registry data study	Univariate logistic regression, multivariate logistic regression	patient	phase 3	drugs	no	Receive statins vs no statins; factors affecting initiation	both	

### *Theoretical sample*

First author and date	AMI, CABG, PCI or other	Country	Guiding Model	Study type	Analysis	Participants	CR phase	CR or other element	Interventions	Purpose of study	Gender
Bailis 2010	Health-promotion facility members	Canada	Health locus of control and Self-determination theory	interview survey	multiple regression analysis	Health-promotion facility members	N/A	N/A	no	Relationship of age and relative autonomy to development of health locus of control beliefs over four years	both
Beckstead 2014	AMI, CABG, PCI	Canada	N/A	online survey	correlation and regression	health profs	phase 1	referral	no	Determine CR referral policies, degree of insight	both

										into own policies, extent to which judgments related to attitudes to CR	
Bock 2003	AMI, CABG, PCI, angina	USA	N/A	survey and patient records	Chi-squared, ANOVA, correlations	patients	phase 4 (phase 3 USA)	exercise	no	Examine exercise maintenance among patients 12 months after completing CR	both
Clark 2002	AMI, CABG, PCI	Scotland	N/A	focus groups	thematic analysis	health profs	phase 1, 2, 3	Not specified	no	Examine perceived provision of secondary prevention services	both
Corcoran 2011	People	N/A	Festinger's Social Comparison Theory	discussion paper	discussion paper	N/A	N/A	social comparison	no	Why people engage in social comparison, to whom do they compare themselves, how do social comparisons influence the self	both
Dalal 2003	AMI	UK	N/A	audit	descriptive statistics	patients	phase 1,2,3,4	secondary prevention	yes	Audit of an integrated seamless system for CR	both
Fleury 1998	Not stated	USA	Wellness Motivation Theory	Instrument development and evaluation	item analysis, factor analysis, reliability and validity	patients	phase 3 (phase 2 USA)	self-regulation	no	Development and initial psychometric evaluation of a measure of individual self-regulation in the	both

										maintenance of health behaviour change	
Frame 2003	AMI, CABG, PCI	USA	Stages of change	survey	Chi-squared, ANOVA	patients	phase 3	diet	no	Evaluate 2-year movement through stages of change for dietary fat, fruit and vegetable intake	both
Grace 2008	CAD, CABG, PCI	Canada	N/A	survey	mixed logistic regression	health profs and patients	phase 1	referral	no	Investigate physician and patient factors that affect verified CR referral	both
Gray 2003	General	N/A	Continuity of care	Review	Review	health profs and patients	N/A	continuity	no	Examine the published evidence for and against continuity in primary care	both
Grewal 2010	Acute coronary syndrome	Canada	N/A	semi-structured telephone interview	Thematic analysis	patients	phase 1	referral	no	CR referral knowledge and access among South Asian patients	both
Kennedy 2007	Long-term conditions	UK	N/A	discussion paper	discussion paper	N/A	N/A	self-care	no	Why current initiatives fail to deliver support for self-care	N/A
Krasemann 1988	AMI	Germany	N/A	before and after controlled study	descriptive statistics	patients	phase 4	adherence	yes	Does a motivational pamphlet motivate patients to join outpatient heart group	both

Lavin 2005	Not stated	Eire	N/A	survey	descriptive statistics	hospitals	phase 1,2,3,4	service provision	no	Establish levels of service provision, service formats and geographic distribution of services	N/A
Moore 1996	Not stated	Canada	N/A	focus groups	content analysis	patients	phase 4	perceptions and experience	no	Examine perceptions and experience of women attending CR	women
Moore & Kramer 1996	AMI, CABG	USA	N/A	survey	means, ranking and t-tests	patients	phase 3	programme features	no	Identify and compare men and women's preferences for CR programme features	both
Munro 2007	TB, HIV/AIDS	N/A	N/A	review	review	patients	N/A	drugs	no	Assess effectiveness of behaviour change theories to develop strategies for medication adherence	both
O'Brien 2009	AMI, CABG, PCI, angina, valve replacement	UK	Stages of change	survey	means, ROC curve	patients	phase 3	adherence	no	Dispositional optimism and stages of change as predictors of adherence to CR	both
O'Connor 1989	AMI	N/A	N/A	review of rcts	odds ratios	patients	phase 3	mortality, reinfarction	yes	Determine whether rcts in aggregate show a significant benefit of CR	both
Pinto 2011	Not stated	USA	Trans-	rct	linear	patients	phase	exercise	yes	Efficacy of home-	both

			theoretical model and Social Cognitive Theory		mixed effects models, generalised estimating equation		3 (phase 2 USA)			based intervention to support exercise maintenance after CR programme	
Summerskill 2002	CAD	UK	N/A	semi-structured interviews and focus groups	thematic analysis	health profs	phase 1,2,3,4	secondary prevention	no	Why GPs do not follow guidelines about prevention of CHD	both
Wyer 2001	AMI	UK	Theory of Planned Behaviour	rct	chi-squared, t-tests	patients	phase 1	attendance	yes	Develop and implement a psychological intervention to influence patients' beliefs about recovery and CR, in order to increase attendance	both

## Appendix 6: Excluded papers

Paper	Reason for exclusion
Annesi, J.J. 2002. Relationship between changes in acute exercise-induced feeling states, self-motivation, and adults' adherence to moderate aerobic exercise. <i>Perceptual &amp; Motor Skills</i> , 94, (2) 425-439	Not about CR
Bragelmann, F., et al. 1990. [A survey of the medical and psychosocial status of 140 workers 32 months following myocardial infarct]. [German]. <i>Zeitschrift fur Kardiologie</i> , 79, (4) 268-272	No English translation available
Daly, J., et al. 2002. Barriers to participation in and adherence to cardiac rehabilitation programs: a critical literature review. [Review] [95 refs]. <i>Progress in Cardiovascular Nursing</i> , 17, (1) 8-17	Review lists findings of previous research – no additional interpretation
Danilov, I., et al. 2003. [Learning of patients with ischemic heart disease after operations on the coronary arteries at the "School-Club for Coronary Patients"]. [Russian]. <i>Klinicheskaja Meditsina</i> , 81, (3) 47-50	No English translation available
Davidson, P.M., et al. 2003. Australian women and heart disease: trends, epidemiological perspectives and the need for a culturally competent research agenda. [Review] [80 refs]. <i>Contemporary Nurse</i> , 16, (1-2) 62-73	Review lists findings of previous research on heart disease – no additional interpretation
Fridlund, B., et al. 1993. Social support and social network after acute myocardial infarction; the critically ill male patient's needs, choice and motives. <i>Intensive &amp; Critical Care Nursing</i> , 9, (2) 88-94	Not about CofC
Goble, A.J. & Worcester, M.C. 1992. Maintenance of behaviour change in patients with coronary artery disease. [Review] [33 refs]. <i>Annals of the Academy of Medicine, Singapore</i> , 21, (1) 97-100	Review but not systematic, opinion plus theory development based on limited selection of evidence
Gori, P., et al. 1984. Compliance with cardiac rehabilitation in the elderly. <i>European Heart Journal</i> , 5 Suppl E, 109-111	Results too sparse to use, not possible to tell what constitutes 'lack of motivation' or other details
Grant, A.M., et al. 1998. Cardiovascular disease. Physician attitudes toward prevention and treatment. <i>Canadian Family Physician</i> , 44, 780-787	Not about CR
Hotta, S.S. 1991. Cardiac rehabilitation programs. [Review] [40 refs]. <i>Health Technology Assessment Reports</i> (3) 1-10	Not about motivation or CofC
Irvine, J., et al. 1999. Depression and risk of sudden cardiac death after acute myocardial infarction: testing for the confounding effects of fatigue. <i>Psychosomatic Medicine</i> , 61, (6) 729-737	Not about adherence or CR
Kennedy, J.E., et al. 2002. Changes in spirituality and well-being in a retreat program for cardiac patients. <i>Alternative Therapies in Health &amp; Medicine</i> , 8, (4) 64-66	Not about adherence to CR
Kingsbury, K. 1998. Taking AIM: how to teach primary and secondary prevention effectively. [Review] [21 refs]. <i>Canadian Journal of Cardiology</i> , 14 Suppl A, 22A-26A	Not about CofC
Koelewijn-van Loon, M.S., et al. 2008. Improving patient adherence to lifestyle advice (IMPALA): a cluster-randomised controlled trial on the implementation of a nurse-led intervention for cardiovascular risk management in primary care (protocol). <i>BMC Health Services Research</i> , 8,	Not about CR - primary prevention

9	
Krannich, J.H., et al. 2008. [The short- and long-term motivational effects of a patient education programme for patients with coronary artery bypass grafting]. [German]. <i>Rehabilitation</i> , 47, (4) 219-225	No English translation available
Lemanski, K.M. 1990. The use of self-efficacy in cardiac rehabilitation. <i>Progress in Cardiovascular Nursing</i> , 5, (4) 114-117	Not about CofC
Mahler, H.I. & Kulik, J.A. 1998. Effects of preparatory videotapes on self-efficacy beliefs and recovery from coronary bypass surgery. <i>Annals of Behavioral Medicine</i> , 20, (1) 39-46	Not about CR
Metzger, L.K. 2004. Assessment of use of music by patients participating in cardiac rehabilitation. <i>Journal of Music Therapy</i> , 41, (1) 55-69	Results too sparse to use
Segar, M.L., et al. 2008. Type of physical activity goal influences participation in healthy midlife women. <i>Womens Health Issues</i> , 18, (4) 281-291	Not about CR



## Appendix 7: Focus group schedule (patients)

**Date:**

**Location:**

**Facilitator:** Liz Payne

### Welcome

Participants will be greeted by the facilitator and note-taker, and offered tea or coffee. Participants will be encouraged to chat informally among themselves, and with the facilitator and note-taker. The note-taker will reimburse participants for their travel expenses, and ask them to sign a receipt to show that they have received this.

### Introduction for participants

The group will convene, then the facilitator will:

- Thank participants for coming
- Introduce facilitator and note-taker
- Briefly outline goals of the study
- Explain reasons for recording the session
- Outline the format of the focus group
- Outline ethics: confidentiality, anonymisation of data, no compulsion to take part, participation not affecting care
- Outline conventions: conversation between group members; only one person to talk at once; everyone's views are important
- Give the expected duration of focus group session

### Ice-breaker

- Participants write their name on card to put in front of them
- Participants introduce themselves

### Questions

Main questions	Possible probing questions
1. What has been your experience of cardiac rehabilitation?	
2. Why did you decide to take part / not take part in cardiac rehabilitation classes?	<ul style="list-style-type: none"> <li>• How well did CR fit in with the rest of your commitments?</li> <li>• What were you told about CR by health care staff?</li> <li>• Did the reasons given for doing CR make sense to you?</li> <li>• Did the reasons given for lifestyle changes make sense to you?</li> </ul>
3. What motivated you to take part in cardiac rehabilitation classes?	<ul style="list-style-type: none"> <li>• What were your main reasons for taking part in CR classes?</li> <li>• Did you feel free to choose whether or not you took part?</li> <li>• Did anything put you off going to CR classes?</li> <li>• What would have encouraged you to attend more CR sessions?</li> <li>• Did your reasons for attending change over the course of the CR sessions? If so why?</li> <li>• Did you receive any reminders to attend from doctors or your family? If so, were these helpful?</li> </ul>
4. How well have your services organised	<ul style="list-style-type: none"> <li>• How could the organisation of your</li> </ul>

your care from the time you were in hospital until now? (hospital / CR clinic / GP)	care been improved? <ul style="list-style-type: none"><li>• Did the staff at CR and your GP practice know about your PCI (surgery) and your rehabilitation needs (care plan / medication / CR)?</li></ul>
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**Closing the focus group**

- Facilitator will thank participants and briefly explain what will happen to the data they have supplied
- Facilitator will give participants a M&S voucher as a token of thanks

## Appendix 8: Focus group schedule (health professionals)

**Date:**

**Location:**

**Facilitator:** Liz Payne

### Welcome

Participants will be greeted by the facilitator and note-taker, and offered tea or coffee. Participants will be encouraged to chat informally among themselves, and with the facilitator and note-taker. The note-taker will reimburse participants for their travel expenses, and ask them to sign a receipt to show that they have received this.

### Introduction for participants

The group will convene, then the facilitator will:

- Thank participants for coming
- Introduce facilitator and note-taker
- Briefly outline goals of the study
- Explain reasons for recording the session
- Outline the format of the focus group
- Outline ethics: confidentiality, anonymisation of data, no compulsion to take part, participation not affecting care
- Outline conventions: conversation between group members; only one person to talk at once; everyone's views are important; if sensitive issues are raised, not to discuss them outside
- Give the expected duration of focus group session

### Ice-breaker

- Participants write their name on card to put in front of them
- Participants introduce themselves

### Questions

Main questions	Possible probing questions
1. What is your experience of working with patients who are eligible for cardiac rehab?	
2. How well are services able to provide continuity of care from the time patients are in hospital, through cardiac rehabilitation and beyond? (hospital / CR clinic / GP)	<ul style="list-style-type: none"> <li>• How are patients referred to CR?</li> <li>• How does patient management work in the transition between hospitals, cardiac rehab and primary care?</li> <li>• How does information about patients travel between hospitals, cardiac rehab and primary care?</li> <li>• Do patient care plans pass between hospital, cardiac rehab and primary care?</li> <li>• How do patients find out what they need to know about CR?</li> <li>• Who encourages PCI patients to attend CR classes and how is this done?</li> <li>• How consistent are the rehab messages communicated to patients?</li> </ul>
3. In your experience, what motivates patients to take part / not take part in cardiac rehabilitation classes?	<ul style="list-style-type: none"> <li>• How do patients vary in how they are motivated?</li> <li>• Do patients follow exercise / diet</li> </ul>

	<p>recommendations on their own if they don't go to CR?</p> <ul style="list-style-type: none"> <li>• What helps PCI patients to maintain their motivation?</li> <li>• What reduces patients' motivation for CR?</li> <li>• How do staff motivate patients to do CR?</li> <li>• How do staff motivate patients to stick to CR recommendations after they finish classes?</li> </ul>
4. Is patient motivation affected by continuity of care?	

**Closing the focus group**

- Facilitator will thank participants and briefly explain what will happen to the data they have supplied

**Appendix 9:  
Categories of  
initial codes from  
Focus Group data**

**Externally controlled (re CR, medication)**

Monitoring as protection  
Chivvying  
They've pushed me  
Security of hospital  
Security of chair  
Security of stick  
Looked after in exercise  
Looking after you  
Wanting to be told what to do  
Wanting to continue CR  
How to achieve it outside class  
Stagnating at home  
Feeling lucky  
Expertise of staff  
They won't take you off it  
It was expected

**External control (general)**

Being a nuisance  
Controlled by others  
Blaming husband for symptoms

**Introjection / Identified regulation**

Overcoming not wanting to  
Pushing yourself

**Autonomous behaviour**

Doing it themselves  
P3 as a backup

**Mix of internal and external control**

Wanting to do their best  
Pride in attendance  
Wanting to get well  
Wanting to be able to do things  
Wanting to be fit

Wanting to lose weight  
Wanting to be sorted out  
Needing to act  
Dislike of incapacity  
Wanting to be strong  
Not wanting to go back  
Heart attack as motivator

**Degree of patients' confidence in staff**

Nobody knows  
Practice nurse CR knowledge  
Confidence in GP  
GPs cardiac knowledge  
GP knowledge  
Phase one don't know  
phase three  
Confidence in cardiologist  
Clout of a doctor  
Believing what you tell them  
Believing what they tell you  
No other source of information

**Competence needs (Developing in class, starts before class)**

Monitoring as feedback  
Others as a source of inspiration and comparison  
Making a difference to me  
Feeling better than before  
Confidence  
Competence  
Staff encouragement  
Individual attention  
Understanding → interest  
Learning by doing  
Guiding in the right direction  
Patience  
Life isn't over  
Reassurance

**Competence needs (Lacking)**

Apprehension about class  
Embarrassment in class  
Contrast with daughter

Unsure of limitations  
Fear of exercising  
Fear of type of exercise  
Monitoring as fear  
Exercising correctly  
Competence

**Relational needs (not met)**

Not knowing who staff are

**Relational needs (staff and group) (Developing in class)**

Affecting Mood  
Pick them up  
Joining in  
Enjoyment  
Looking forward to class  
Emotionally strengthened  
Feeling comfortable  
Happy group  
Nobody laughs at me  
Friendliness of group  
Company  
Being involved  
In the same boat  
Mutual encouragement  
Joining in  
Nice staff  
Cheery staff  
The Smile factor  
Personalities of staff  
People person sensitive  
Relaxed approach  
Patients talk  
Solid friendship  
Characters  
Humour  
Treated like a human being  
Know each other

**Elements of discontinuity**

Gap between discharge and follow-up  
One shot at information  
Inconsistent information

Gaps in information transfer  
GP lack of time  
GP reluctant for CR  
Money  
Regularity of GP follow-up  
Changing GPs  
Pushing GP to gain access  
GPs and prehab  
Speed of treatment  
Lack of info at Phase one  
Lack of capacity  
Low priority CR  
Lost patients  
Limited timeframe  
Referred to gym  
Communication time-lag

#### **Elements of Continuity**

GP/hospital interaction  
HPs working across boundaries  
Practice nurse follow-up  
HP support  
Hospital follow-up  
GP support  
GP pushing for action  
Phone follow-up  
Waiting for results  
Referral from different sources  
Consistency of message  
4 week plan  
Capacity  
Bridging P3 and P4  
Making links  
P4 for life  
Solid friendship  
Repeat p3  
Staff motivated to get you going  
Completeness of p3  
They've got a hook in you

#### **Invitation to CR:**

CR details during hospitalization P1  
Letter from CR  
Leaflets, booklets and DVDs  
Phone follow-up  
GP recommendation  
Joined up process  
P1 strong recommendation

#### **Making sense of it**

Understanding the stent  
Making sense of what's happening  
Questioning need for medication  
Problems with medication  
Understanding medication  
Lack of understanding  
Reliant on what you're told  
Knowing what you're up against  
Hurdle of understanding  
Gradual realization  
Realizing you're not fit  
Opened your eyes  
Getting a second chance  
Denial  
Doctors' understanding  
Understanding symptoms  
Friends' experiences  
Misunderstanding and myth  
Patient knowledge of P3  
Patient knowledge of health service organisation

#### **Motivated patients**

Big commitment  
Obsessive exercising  
Not good enough  
Distance  
Work  
Fitting it in  
Determination  
Pushing to change medication  
Pushing for answers  
Motivation for action  
Most are keen  
Liking new challenges  
Being an exercise person  
Fear of being told off  
Money  
Choosing alternatives  
Friends dying  
Failure of first intervention  
Pain on exercise  
Don't want to die  
Off-putting knowledge of consequences  
Confidence in effectiveness

#### **Patients expectations**

Wanting action from GPs  
Gaining more than expected  
Definite 'no'

#### **Patients losing motivation (during P3 or afterwards)**

Out of the routine  
Life takes over  
Doing things in fits and starts  
Ok to miss sessions  
Getting back to normal  
Going back to bad habits  
It's not for me

#### **Elements of continuity from group**

Comparing notes  
Model patients  
[Links to relational needs being met within the group]

#### **Family support (Autonomy supportive or controlling / Instrumental support)**

Family close-by keeping a distance  
Family continuity  
Freedom to do anything  
Forced or unforced  
Holding their hand  
Partners as protectors  
Partners as encouragers

#### **Conflicting commitments**

Worry about others  
Work  
Other motivators  
Holiday  
Hospitalisation

#### **Maladaptive behaviour**

Ignoring as a way of coping  
Avoidance excuses

**Selling CR**

Enthusiastic about CR  
Not really sold  
Staff confidence in effectiveness of CR  
Cardiologist pushing it  
Wording on phone  
Discussion of content  
P3 pushing P4  
P4 pushing P4  
Term rehab  
Dependency  
CR as an essential part of the treatment

**Elements of staff motivation**

Dedicated staff  
Determined staff  
Attitude of staff  
Team of staff  
Professionalism of staff

## **Appendix 10: Survey pack sent to participants**

### **Questionnaires pack**

Please complete the following questionnaires, and return to Liz Payne along with the completed and signed consent form, in the enclosed envelope to:

Liz Payne, c/o Fiona Gillison, Bath University Department for Health, Bath, BA2 7AY

### **Background questions**

Please put a tick (✓) by the relevant answers to each question

1. What is your age?

30-39

40-49

50-59

60-69

70-79

80-89

other

2. What is your gender?

Female

Male

3. What is your marital status?

Single

Cohabiting

Married

Other

4. What is your highest level of education?

Secondary school or equivalent

Certificate or training programme

Degree

Masters

Doctorate

Other

5. Do you have any of the following common health problems?

Anxiety

Arthritis

Asthma

Cancer

Depression

Diabetes

High cholesterol

High blood pressure (hypertension)

Hip or knee replacement

Irritable bowel syndrome

Kidney disease

Pain



6. Have you received an invitation to attend Phase three cardiac rehabilitation classes?

- Yes
- No
- Don't know

7. Are you currently attending Phase three cardiac rehabilitation classes?

- Yes
- No

8. If you answered 'yes' to question 7, how many sessions have you attended so far?

.....  
9. If you answered 'no' to question 7, do you intend to join a Phase three cardiac rehabilitation class?

.....

10. When did you have your heart intervention (PCI, percutaneous coronary intervention or angioplasty)?

- Which month.....
- Which year.....

11. At which hospital did you have your heart intervention (PCI, percutaneous coronary intervention or angioplasty)?

.....

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### Quality of life - SF-12 (Short Form)

Question 1. In general, would you say your health is excellent, very good, good, fair, or poor?

- Excellent
- Very Good
- Good
- Fair
- Poor

Question 2. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

First, moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf. Does your health now limit you a lot, limit you a little, or not limit you at all?

- Limited a lot
- Limited a little
- Not limited at all

Question 3. Climbing several flights of stairs. Does your health now limit you a lot, limit you a little, or not limit you at all?

- Limited a lot
- Limited a little
- Not limited at all

Question 4. During the past four weeks, have you accomplished less than you would like as a result of your physical health?

No  
Yes

Question 5. During the past four weeks, were you limited in the kind of work or other regular activities you do as a result of your physical health?

No  
Yes

Question 6. During the past four weeks, have you accomplished less than you would like to as a result of any emotional problems, such as feeling depressed or anxious?

No  
Yes

Question 7. During the past four weeks, did you not do work or other regular activities as carefully as usual as a result of any emotional problems such as feeling depressed or anxious?

No  
Yes

Question 8. During the past four weeks, how much did pain interfere with your normal work, including both work outside the home and housework? Did it interfere not at all, slightly, moderately, quite a bit, or extremely?

Not at all

Slightly  
Moderately  
Quite a bit  
Extremely

Question 9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much time during the past 4 weeks have you felt calm and peaceful? All of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?

All of the time  
Most of the time  
A good bit of the time  
Some of the time  
A little of the time  
None of the time

Question 10. How much of the time during the past 4 weeks did you have a lot of energy? All of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?

All of the time  
Most of the time  
A good bit of the time  
Some of the time  
A little of the time  
None of the time

Question 11. How much time during the past 4 weeks have you felt down? All of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?

All of the time  
Most of the time  
A good bit of the time  
Some of the time  
A little of the time  
None of the time

Question 12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends, relatives etc? All of the time, most of the time, some of the time, a little of the time, or none of the time?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

### Heart Continuity of Care

Please read the following statements and then circle the number that shows how strongly you agree or disagree with them.

How strongly do you agree or disagree with this statement?	Strongly Disagree	Somewhat Disagree	Hard to Decide	Somewhat Agree	Strongly Agree	Not Applicable
I feel I was provided with all the information I needed to know about my heart condition.	1	2	3	4	5	N/A
My heart condition was clearly explained to me.	1	2	3	4	5	N/A
I was told what symptoms I should expect to have as a result of my heart condition.	1	2	3	4	5	N/A
In hospital, I was given the opportunity to ask my health care providers questions about my health.	1	2	3	4	5	N/A
The importance of my heart medication was explained to me.	1	2	3	4	5	N/A
I was informed of when and how much heart medication to take.	1	2	3	4	5	N/A
I was informed of the potential side effects that could occur as a result of taking my heart medications.	1	2	3	4	5	N/A
I was told what to do if I experienced any side effects as a result of taking my heart medications.	1	2	3	4	5	N/A
I was given the same information about my heart medications by all my health care providers.	1	2	3	4	5	N/A
I was told about what changes I should make to my diet.	1	2	3	4	5	N/A
I was given enough instruction about my dietary needs to plan my own healthy daily meals.	1	2	3	4	5	N/A

How strongly do you agree or disagree with this statement?	Strongly Disagree	Somewhat Disagree	Hard to Decide	Somewhat Agree	Strongly Agree	Not Applicable
The influence my heart condition would have on my lifestyle was explained to me.	1	2	3	4	5	N/A
The type of physical activity in which I should or should not participate was explained to me.	1	2	3	4	5	N/A
I feel that my health care providers communicated well with one another while I was in hospital.	1	2	3	4	5	N/A
I feel that my health care providers communicated well with each other in planning my move from hospital to my current residence.	1	2	3	4	5	N/A
I feel that my health care providers both in and outside of the hospital maintained an open line of communication with one another regarding my care even after I had been discharged from the hospital.	1	2	3	4	5	N/A
My health care providers were able to obtain the information they needed from the other health care providers involved in my care.	1	2	3	4	5	N/A
My family physician (GP) was continually involved in or aware of my care.	1	2	3	4	5	N/A
I felt well prepared for my discharge from hospital because I was provided with all the information I needed to deal with my heart condition.	1	2	3	4	5	N/A
I was informed of the symptoms I might experience because of my heart condition that should lead me to call my doctor.	1	2	3	4	5	N/A
I was given consistent information about the symptoms that should lead me to seek help from my health care providers.	1	2	3	4	5	N/A
I knew which health care provider to contact if I had any problems following my discharge.	1	2	3	4	5	N/A
I was satisfied with the level of care provided to me by my	1	2	3	4	5	N/A

How strongly do you agree or disagree with this statement?	Strongly Disagree	Somewhat Disagree	Hard to Decide	Somewhat Agree	Strongly Agree	Not Applicable
health care providers after my discharge from hospital.						
After my discharge from hospital, I was able to access health services for my heart condition when I needed them.	1	2	3	4	5	N/A
Within 2 months of my discharge from hospital, I reviewed my overall treatment plan with a doctor.	1	2	3	4	5	N/A
I had regularly scheduled appointments with a doctor following my discharge from hospital.	1	2	3	4	5	N/A
I believe my doctor is aware of the results of my blood tests.	1	2	3	4	5	N/A
Within 2 months of my discharge from hospital, I reviewed the heart medications I was taking with a doctor.	1	2	3	4	5	N/A
Within 2 months of my discharge from hospital, either a doctor or pharmacist reviewed when and how my heart medications were to be taken.	1	2	3	4	5	N/A
Within 2 months of my discharge, either a doctor or pharmacist reviewed the potential side effects of each of my heart medications with me.	1	2	3	4	5	N/A
Within 2 months of my discharge from hospital, either a doctor or pharmacist reviewed with me what I should do if I experienced side effects from my heart medications.	1	2	3	4	5	N/A
In general, the instructions my doctor gave me agreed with the instructions from my other doctor(s).	1	2	3	4	5	N/A
In general, the information given to me by my various health care providers was consistent (e.g., the information given to me by my doctor and nurse/dietician was the same).	1	2	3	4	5	N/A

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**TSRQ (attendance at Phase three cardiac rehabilitation classes)**

The following question relates to the reasons why you would either start to attend Phase three cardiac rehabilitation classes or continue to do so. Different people have different reasons for doing that, and we want to know how true each of the following reasons is for you. All 15 responses are to the one question.

Please indicate the extent to which each reason is true for you, using the following 7-point scale:

1	2	3	4	5	6	7
not at all			somewhat			very
true			true			true

**The reason I would *attend Phase three cardiac rehabilitation classes* is:**

1. Because I feel that I want to take responsibility for my own health.
2. Because I would feel guilty or ashamed of myself if I did not attend cardiac rehabilitation classes.
3. Because I personally believe it is the best thing for my health.
4. Because others would be upset with me if I did not.
5. I really don't think about it.
6. Because I have carefully thought about it and believe it is very important for many aspects of my life.
7. Because I would feel bad about myself if I did not attend cardiac rehabilitation classes.
8. Because it is an important choice I really want to make.
9. Because I feel pressure from others to do so.
10. Because it is easier to do what I am told than think about it.
11. Because it is consistent with my life goals.
12. Because I want others to approve of me.
13. Because it is very important for being as healthy as possible.
14. Because I want others to see I can do it.
15. I don't really know why.

### **PCS (Attendance at Phase three cardiac rehabilitation classes)**

Please indicate the extent to which each statement is true for you, assuming that you were intending either to begin now attending Phase three cardiac rehabilitation classes, or to maintain your current attendance at Phase three cardiac rehabilitation classes.

Please use the following scale in answering the questions:

1	2	3	4	5	6	7
not at all			somewhat			very
true			true			true

1. I feel confident in my ability to attend Phase three cardiac rehabilitation classes.
2. I now feel capable of attending Phase three cardiac rehabilitation classes.
3. I am able to carry on doing what I learn at Phase three cardiac rehabilitation classes over the long term.
4. I am able to meet the challenge of attending Phase three cardiac rehabilitation classes.

### **HCCQ (Attendance at Phase three cardiac rehabilitation classes)**

This questionnaire contains items that are related to your visits with a health-care practitioner (or group of practitioners) in which your attendance at Phase three cardiac rehabilitation classes was discussed in any way. Health-care practitioners (doctors, nurses, counsellors, etc.) have different styles in dealing with patients, and we would like to know very specifically about your experience of your health-care practitioners in any encounters when your attendance at Phase three cardiac rehabilitation classes was discussed. Your responses will be kept confidential, so none of your practitioners will know about your responses. Please be honest and candid. In some cases, you may have met with only your doctor; in other cases you may have discussed your attendance at Phase three cardiac rehabilitation classes with several people. If you have met only with your doctor, please respond with respect to him or her; if you have met with several practitioners concerning this issue, please answer in terms of your experience of all these practitioners together.

In answering the questions, please use the following scale:

1	2	3	4	5	6	7
not at all			somewhat			very
true			true			true

1. I feel that my health-care practitioners have provided me with choices and options about my attendance at Phase three cardiac rehabilitation classes (including not attending).
2. I feel my health-care providers understand how I see things with respect to my attendance at Phase three cardiac rehabilitation classes.

3. My health-care providers convey confidence in my ability to make changes regarding my attendance at Phase three cardiac rehabilitation classes.
4. My health care practitioners listen to how I would like to do things regarding my attendance at Phase three cardiac rehabilitation classes.
5. My health-care practitioners encourage me to ask questions about my attendance at Phase three cardiac rehabilitation classes.
6. My health-care practitioners try to understand how I see my attendance at Phase three cardiac rehabilitation classes before suggesting any changes.

### **BNS-R 1**

#### ***(Discussions about cardiac rehabilitation with healthcare staff)***

The following questions concern your feelings about your health care since you had your cardiac procedure. Please indicate how true each of the following statements is for you given your experiences with health care since your cardiac intervention. Remember that your healthcare staff will never know how you responded to the questions.

Please use the following scale in responding to the items.

1	2	3	4	5	6	7
not at all			somewhat			very
true			true			true

1. I really liked the healthcare staff who talked to me about my attendance at cardiac rehabilitation after I had my cardiac procedure.
2. I got along with the healthcare staff who talked to me about my attendance at cardiac rehabilitation after I had my cardiac procedure.
3. I pretty much kept to myself after I had my cardiac procedure.
4. I considered the healthcare staff who talked to me about my attendance at cardiac rehabilitation after I had my cardiac procedure to be my friends.
5. The healthcare staff who talked to me about my attendance at cardiac rehabilitation after I had my cardiac procedure cared about me.
6. There were not many healthcare staff that I was close to after I had my cardiac procedure.
7. The healthcare staff who talked to me about my attendance at cardiac rehabilitation after I had my cardiac procedure did not seem to like me much.
8. The healthcare staff who talked to me about my attendance at cardiac rehabilitation after I had my cardiac procedure were pretty friendly towards me.



**BNS – R 2**  
***(Attending Phase 3 cardiac rehabilitation classes)***

The following questions concern your feelings about your health care since you had your cardiac procedure. Please indicate how true each of the following statements is for you given your experiences with health care since your cardiac intervention. Remember that your healthcare staff will never know how you responded to the questions.

Please use the following scale in responding to the items.

1	2	3	4	5	6	7
not at all			somewhat			very
true			true			true

1. I really like the staff at cardiac rehabilitation classes.
2. I get along with the staff at cardiac rehabilitation classes.
3. I pretty much keep to myself when I visit the cardiac rehabilitation class.
4. I consider the staff at cardiac rehabilitation classes to be my friends.
5. The staff at cardiac rehabilitation classes care about me.
6. There are not many cardiac rehabilitation staff that I am close to.
7. The staff at cardiac rehabilitation classes do not seem to like me much.
8. The staff at cardiac rehabilitation classes are pretty friendly towards me.

That's the end of the questionnaire. Many thanks for completing it. Your contribution to this study is very much appreciated.

## ***Appendix 11: Suggested further research***

### ***Suggested further research from the Critical Interpretive Synthesis***

- Do staff misperceptions about patient motivation result in less referral, affect motivation, or influence less uptake and adherence?
- What constitutes being 'properly' invited to cardiac rehabilitation? How does this affect the patient's sense of relatedness, competence and autonomy? Does being 'properly' invited affect uptake and attendance?
- Are patients who avoid CR participation exhibiting autonomous behaviour?
- Why do patients self-refer to cardiac rehabilitation?
- Why do some patients not attend cardiac rehabilitation once referred? Does this depend on how they are referred?
- How do supervised monitoring and self-monitoring affect adherence and clinical outcomes?
- Does shared care increase motivation in cardiac health behaviour?
- Is autonomy support particularly needed to enable patients with internal versus external locus of control disposition to internalise adaptive behaviours?
- How does the quality of health professional recommendation for cardiac rehabilitation affect uptake and attendance?
- How effective is supported self-care, and what effect does it have on motivation and adherence?
- Is Stage of Change a useful screening tool to identify those who are ready to stop smoking, start exercising or join a cardiac rehabilitation programme? Can patients be encouraged to move from pre-contemplation to action? And if so, at what point(s) in time this would be most beneficial?
- Does continuity of care encourage patients to underestimate the severity of their condition, making them less inclined to engage in healthy behaviour?
- Does facilitating internalisation of the values of cardiac rehabilitation encourage attendance?
- Does competence supportiveness help smokers to quit?
- How does message consistency across primary and secondary care and public health affect motivation for cardiac rehabilitation?
- By returning to their normal activities after a heart event, do people feel more autonomous in contrast to being managed by the health care system?
- Does work-based cardiac rehabilitation increase attendance?
- Does a continuity gap during Phase two reduce the likelihood of participation?
- Is 'too much' continuity perceived as controlling, creating an aversion towards behaviour change?
- Does long-term follow-up with non-attenders result in late cardiac rehabilitation take-up and healthy lifestyle?
- Does quality of social support affect take-up, attendance and adherence at cardiac rehabilitation?

### ***Suggested further research from focus group study***

- Is a close staff-patient relationship over weeks and months supportive of adherence in cardiac rehabilitation?
- Does lack of staff-patient relationship continuity reduce the ability of cardiac rehabilitation non-attenders to discuss and enact healthy behaviours?
- Does staff-patient concordance and trust influence cardiac rehabilitation attendance?

- Is adherence enhanced when patients are personally introduced to providers of different cardiac rehabilitation phases?
- Can patients' partners be considered to provide 'continuity of care' by having a clearly defined role and contributing to decision-making about their partner's care?
- What is the optimum balance between monitoring and self-monitoring to enhance adherence to healthy behaviours?
- Does discussion of the options and the rationale for Phase three cardiac rehabilitation, to which the patient contributes, lead to greater management continuity and an autonomous decision to attend?
- Do inconsistent messages from professionals undermine patients' competence needs by leaving them uncertain about the benefits of cardiac rehabilitation and healthy behaviour?

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