

**Improving the uptake of cardiac rehabilitation in  
invited patients: a multi-method evaluation**

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## Abstract

Cardiac rehabilitation (CR) can reduce mortality and morbidity through assisting patients in regaining physical and psychosocial well-being. CR is effective yet uptake rates are 44%. Of non-attenders, 30% expressed a 'lack of interest'; the focus of this thesis' question '*What strategy would improve uptake of CR in invited patients.*'

A sequential, multi-method approach was used. *Literature reviews*, assessing strategies to increase CR uptake and participation in other health services, found similar intervention designs, such as peers or health behaviour theory-based (HBT). An *e-survey* explored invitation strategies in CR practice and confirmed letters are used and low-cost. An advancement of theory-based letters is valuable but little is known about the operationalisation of HBT. *Telephone interviews* were conducted to explore the latter through patients' viewpoints. A *quasi-experiment* evaluated the amended letters.

One review found six RCTs testing peer support, professional support (or combined) and letters, the latter two increased attendance. Twenty-three reviews on strategies promoting participation support access-enhancing methods, organisational changes, letters and calls. 190 CRPs indicated that multiple invitation strategies including in-hospital (70%), telephone (70%), letters (50%) are used; variations exist. Feasibility considerations supported the development of existing HBT letters. Interviews revealed a preference for less authoritative content outlining positive effects. Of 6 sites, with different organisational structure, 1 increased CR uptake using the new letter.

The amended theory-based letter had limited impact in CR uptake perhaps due to extrinsic factors, the letter itself or methodological issues. CR is a fragmented service and results highlight the importance of context-sensitive policies.

## List of Contents

Acknowledgements.....	12
Author's declaration.....	13
<b>Chapter 1.....</b>	<b>15</b>
Introduction.....	15
1.1 Coronary heart disease.....	15
1.2 Cardiac rehabilitation.....	17
1.3 Cardiac rehabilitation guidelines.....	20
1.4 Who are the attenders and non-attenders in cardiac rehabilitation?.....	22
1.4.1 Non-attenders.....	23
1.4.2 Summary.....	27
1.5 The format of this thesis.....	27
1.5.1 Development of the research aims.....	28
1.5.2 Structure of this thesis.....	29
1.5.3 A note on methodology and methods.....	30
1.6 Conclusion.....	30
<b>Chapter 2.....</b>	<b>33</b>
A systematic review of interventions designed to improve uptake in cardiac rehabilitation with a secondary focus on groups less likely to attend.....	33
2.1 Background.....	33
2.1.1 Objectives.....	34
2.2 Methods.....	35
2.2.1 Definitions.....	35
2.2.2 Procedure.....	35
2.2.3 Electronic searches.....	35
2.2.4 Inclusion and exclusion criteria.....	37
2.2.5 Selection of studies.....	37
2.2.6 Data extraction.....	38
2.2.7 Bias assessment.....	38
2.2.8 Data synthesis and analysis.....	38
2.3 Results.....	38
2.3.1 Search results and study selection.....	39
2.3.2 Excluded studies.....	40
2.3.3 Included studies.....	41
2.3.5 Risk of bias.....	50

2.4 Discussion.....	54
2.4.1 Peer support.....	54
2.4.2 Professional support.....	55
2.4.3 Invitation letters .....	56
2.4.4 Under-represented groups and non-attenders.....	58
2.4.5 Health behaviour theory .....	60
2.4.6 Limitations of the studies .....	61
2.5 Limitations and strengths of my review .....	61
2.6 Methodological considerations.....	62
2.7 Conclusion.....	63
<b>Chapter 3 .....</b>	<b>65</b>
Strategies and interventions used to encourage patients to participate in health services..	65
3.1 Background.....	66
3.1.1 Objectives.....	68
3.2 Methods .....	69
3.2.1 Definitions.....	69
3.2.2 Search strategy .....	70
3.2.3 Databases.....	75
3.2.4 Review eligibility: inclusion and exclusion criteria.....	75
3.2.5 Data extraction and data analysis .....	75
3.3 Results .....	75
3.3.1 Uptake and self-management programmes .....	76
3.3.2 Screening.....	76
3.3.3 Service uptake .....	104
3.3.4 Additional findings .....	109
3.3.5 Towards a typology of intervention strategies .....	115
3.4 Discussion.....	120
3.4.1 Intervention categories .....	120
3.4.2 Results in regards to CR (Chapter 2) .....	121
3.4.3 Self-management programmes.....	123
3.5 Limitations and strengths of the review of reviews.....	124
3.6 Methodological considerations.....	124
3.7 Conclusion .....	125
<b>Chapter 4 .....</b>	<b>127</b>
Strategies used to identify and invite patients to CR in current clinical practice.....	127
4.1 Background.....	128

4.1.1 Objectives .....	129
4.2 Methods.....	130
4.2.1 Material.....	130
4.2.2 Participants .....	131
4.2.3 Procedure .....	132
4.2.4 Analyses.....	132
4.2.5 Ethical considerations.....	133
4.3 Results .....	134
4.3.1 Attendance .....	134
4.3.2 Identification.....	135
4.3.3 Invitation.....	136
4.3.4 Non-responders.....	136
4.3.5 Potentially under-represented groups .....	137
4.3.6 Associations between uptake rates, identification and invitation methods .....	138
4.4 Discussion .....	139
4.4.1 Participating programmes.....	139
4.4.2 Identification and invitation methods .....	140
4.4.3 Groups less likely to attend .....	142
4.5 Limitations and strengths.....	144
4.6 Methodological considerations .....	145
4.7 Conclusion .....	146
<b>Chapter 5.....</b>	<b>149</b>
The patient perspective on letters of invitation to CR as a means of exploring the operationalisation of health behaviour theory.....	149
5.1 Background .....	149
5.1.1 The common-sense model of illness representation (CSM).....	152
5.1.2 A brief overview of the TPB .....	153
5.1.3 Research objectives .....	156
5.2 Methods.....	156
5.2.1 Sampling .....	156
5.2.2 Exclusion and inclusion criteria .....	157
5.2.3 Recruitment methods and participants .....	157
5.2.4 Materials .....	158
5.2.5 Ethical considerations.....	161
5.2.6 Data collection .....	161
5.3 Data analysis .....	162

5.4 Findings .....	165
5.4.1 Participants .....	165
5.4.2 Findings of interviews with 11 male participants .....	166
5.4.3 Findings of the interview with the two female participants .....	174
5.5 Discussion .....	178
5.5.1 Motivating attendance - choice and professional recommendation .....	179
5.5.2 Communicating about cardiac rehabilitation – language and content .....	181
5.5.3 Benefits of CR - emotional support and outcome .....	182
5.5.4 Summary of findings .....	186
5.6 Findings in regards to theoretical concepts as operationalised in letters .....	187
5.6.1 The theory of planned behaviour .....	187
5.6.2 The common sense model of illness representation .....	191
5.6.3 The new letter .....	193
5.7 Limitations and strengths .....	194
5.8 Methodological considerations .....	196
5.9 Conclusion .....	198
<b>Chapter 6 .....</b>	<b>199</b>
Does an amended invitation letter increase uptake of CR? .....	199
6.1 Background .....	199
6.1.1 Objectives .....	202
6.2 Methods .....	202
6.2.1 Recruitment procedure .....	202
6.2.2 Measures and outcomes .....	203
6.2.3 Data collection .....	204
6.2.4 The intervention .....	205
6.2.5 Data analysis .....	206
6.2.6 Ethical considerations .....	207
6.3 Results .....	207
6.3.1 Recruitment of CR centres .....	207
6.3.2 The invitation letters .....	207
6.3.3 The intervention sites .....	209
6.3.4 Summary data .....	223
6.3.5 The NACR uptake rates .....	224
6.4 Discussion .....	225
6.4.1 Why did the letter work in one site? .....	226
6.4.2 Recruitment .....	226

6.4.3 The letter .....	228
6.4.4 Extrinsic factors .....	229
6.4.5 Previous studies .....	231
6.4.6 Methodological problems .....	232
6.4.7 Missing data .....	232
6.5 Limitations and strengths .....	233
6.6 Methodological considerations .....	234
6.6.1 Recruitment methods .....	234
6.6.2 Study design: experimental versus quasi-experimental methods .....	235
6.7 Conclusion .....	236
<b>Chapter 7.....</b>	<b>239</b>
Conclusion and discussion .....	239
7.1 Summary of key findings.....	239
7.2 A comment on methodology.....	246
7.2.1 Reflexivity .....	246
7.2.2 The researcher’s background.....	247
7.2.3 Reflections on methodological approaches chosen .....	247
7.2.4 Reflections on the quantitative methods.....	247
7.2.5 Reflection on the qualitative research piece .....	249
7.2.6 The combination of multiple methods.....	250
7.3 Limitations and strengths .....	252
7.4 Implications and contributions to the field .....	254
7.4.1 The operationalisation of health behaviour theory .....	254
7.4.2 The survey .....	255
7.4.3 A behavioural theory-based intervention letter .....	256
7.4.4 Communicating the importance of CR .....	256
7.4.5. Summary of the contributions and implications.....	259
7.5 Future directions .....	260
7.5.1 Research.....	260
7.5.2 Policy and practice.....	262
7.6 Concluding remarks .....	263
<b>Appendix A .....</b>	<b>265</b>
<b>Appendix B .....</b>	<b>270</b>
<b>Appendix C.....</b>	<b>284</b>
<b>Appendix D .....</b>	<b>291</b>



<b>Appendix E</b> .....	<b>300</b>
<b>References</b> .....	<b>323</b>

## List of Tables

Table 2.1: Inclusion and exclusion criteria .....	37
Table 2.2: Number of results by database (with available time periods) .....	39
Table 2.3: Participant characteristics .....	42
Table 2.4: Study characteristics .....	44
Table 2.5: Assessment of risk of bias per study (rows) and across studies (columns).....	51
Table 3.1: Reviews on interventions to increase screening in under-represented groups .....	78
Table 3.2: Reviews on interventions to increase screening .....	89
Table 3.3: Interventions to increase service access .....	105
Table 3.4: Intervention-specific reviews .....	110
Table 3.5: Towards a typology (all interventions reviewed) .....	115
Table 4.1: Attendance rates per CR phase .....	134
Table 4.2: Methods used to identify patients .....	135
Table 4.3: Methods used to invite patients .....	136
Table 4.4: Patients less likely to attend.....	137
Table 4.5: Average uptake rates per group, test values .....	139
Table 5.1: Determinants from the TPB in invitation letters .....	155
Table 5.2: Side-by-side comparison of invitation letters .....	159
Table 5.3: Key topics from the interview guide .....	162
Table 5.4: Participant characteristics .....	166
Table 5.5: Attitude component of each invitation letter .....	187
Table 5.6: Subjective norm .....	189
Table 5.7: PBC as operationalised in the letters .....	191
Table 5.8: Controllability.....	192
Table 5.9: Perceived consequences .....	193
Table 6.1: Number of letter sent (L), number of patients (P), uptake rate (%) .....	210
Table 6.2: Change in mean uptake rate per intervention site (before & after) .....	213
Table 6.3: Comparing patient, intervention and hospital data across six sites .....	215
Table 6.4: Site 6 compared with each other site on age and co-morbidities .....	222
Table 6.5: Site 6 compared to each other site on gender .....	223
Table 6.6: Summary data (number of patients & letters per months).....	224
Table 6.7: Phase 3 attenders (NACR data for all sites) .....	225

Table 7.1: Results of a systematic review on interventions to increase CR uptake .....	240
Table 7.2: Strategies used to engage under-represented groups in health care .....	241
Table 7.3: Most common invitation methods used by 190 CRPs in survey .....	241
Table 7.4: (Non-) Motivational statements mentioned by participants .....	243
Table 7.5: Reasons for differential impact of amended letter .....	245

## List of Figures

Figure 4.1: Frequency distribution of uptake (% of patient in phase 3).....	135
Figure 5.1: Parallel processing in the common-sense model .....	153
Figure 5.2: Theory of planned behaviour as illustrated by Ajzen .....	154
Figure 6.1: Recruitment process.....	203
Figure 6.2: Number of letters sent and patients attending per month (number of patients adjusted to months letter sent) .....	212
Figure 6.3: Uptake rate .....	223

## List of Boxes

Box 1.1: Policy and practice guidelines in the United Kingdom .....	21
Box 2.1: Search terms (medline).....	36
Box 2.2: Key findings of the systematic review .....	64
Box 3.1: EMBASE search strategy for self- management.....	72
Box 3.2: DARE/HTA search.....	73
Box 3.3: Screening search in EMBASE.....	74
Box 3.4: Service uptake search in Cochrane Library .....	74
Box 3.5: Key findings .....	125
Box 4.1: Phases of cardiac rehabilitation .....	129
Box 4.2: Survey.....	131
Box 4.3: Definition of an audit.....	145
Box 4.4: Key findings .....	146
Box 5.1: Advantages and disadvantages of using health behaviour models.....	150
Box 5.2: Analytical steps.....	164
Box 5.3: Key findings .....	186
Box 5.4: New invitation letter .....	194
Box 6.1: Generic invitation letter .....	206

Box 6.2: Observation from the experimental group (top line) and the control group (bottom line), with a broken line indicating non-randomised groups (Reichardt and Mark, 1998)	236
Box 6.3: Key findings	237
Box 7.1: Concepts from the theory of planned behaviour (changes from previous wording in bold writing)	244

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**Author's declaration**

I declare that this thesis is the product of my own work other than that duly acknowledged to others.

The material contained in this thesis has not been submitted for a degree in this or any other awarding institution.

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# Chapter 1

## Introduction

The purpose of this thesis is to develop and evaluate an intervention that encourages more patients to participate in cardiac rehabilitation (CR). The central question of my doctoral thesis is: *'What strategy would improve uptake of CR in patients who have been invited?'* I am motivated to address this question because cardiac rehabilitation significantly reduces morbidity and mortality. Nevertheless, the National Audit of Cardiac Rehabilitation (NACR) in the United Kingdom reports consistently low attendance rates of 42-44%, while about 85% of patients are expected to be well enough to attend. The most common reasons for non-attendance reported by patients invited to cardiac rehabilitation phase 3 is a lack of interest (30%) (The National Audit of Cardiac Rehabilitation, 2012).

The first Chapter – in two parts – offers context to the research question. The first part of this Chapter introduces coronary heart disease and cardiac rehabilitation as well as policy and practice in the UK to set the scene. A brief outline of attendance and non-attendance in cardiac rehabilitation is given to justify the thesis' research question. The second part of the Chapter describes the development of the research aims and offers an overview of the structure of this thesis before concluding.

## 1.1 Coronary heart disease

Cardiovascular disease is the biggest cause of death worldwide with death rates estimated to reach 23.6 million by 2030 (World Health Organization, 2010b). The UK sees about 150,000 deaths each year due to cardiovascular disease (Capewell et al. as cited in Pearson-Stuttard et al., 2012, p.1573). It is a major source of premature death and disability, and it is predicted to remain the leading cause of death.

Cardiovascular disease is an umbrella term for a number of disorders of the heart and blood vessels (World Health Organization, 2010a). These include cerebro- and peripheral vascular disease, hypertension and coronary heart disease (CHD). CHD is defined as inadequate circulation to the heart muscle and tissue. Coronary artery disease is the result of the accumulation of plaque in the arteries (atherosclerosis) causing insufficient supply of oxygen and blood to the heart and hence CHD (Schoenberg et al., 2009).

Coronary heart/artery disease develops slowly over the course of life (Mendes and Banerjee, 2010; Schoenberg et al., 2009). Risk factors include hypertension, hypercholesterimia, diabetes mellitus as well as smoking, lack of physical activity and unhealthy eating habits (Mendes and Banerjee, 2010). In addition, psychological factors and wider determinants - including low income, illiteracy or employment status - can influence disease development (Mendes and Banerjee, 2010).

A severe and frequent complication of CHD is a myocardial infarction, an interruption of blood flow due to a blood clot, which then causes cell death (A. Cooper et al., 2007). To ensure blood circulation in and around the heart patients presenting with part or full obstruction of their coronary arteries can undergo a variety of procedures such as percutaneous coronary intervention (PCI), which widens narrow arteries or coronary artery bypass graft surgery (CABG), which bypasses them. Over the past years, an increase of 5% per year in PCI and a 6-fold rise in CABG could be observed in England (Allender et al., 2008). Furthermore, pharmacological treatment with, for example, statins to reduce blood cholesterol levels, beta-blockers to slow the heart and reduce blood pressure, or antiplatelet medication to stop blood clotting, are given to coronary artery disease patients to ease the condition.

In 2010, the UK saw over 80,000 acute myocardial infarcts (AMI), of which 1/3 were fatal, 2/3 occurred in men and 3/4 in individuals older than 65 (Smolina et al., 2012a). Re-infarction is somewhat common (one in six AMIs), which calls for better prevention (Smolina et al., 2012a). Thus, a downward trend in mortality, partly due to a decline in AMI rates by around 30% over the past ten years, is being accompanied by an upward trend in morbidity (Heart Stats, 2010; Pearson-Stuttard et al., 2012; Smolina et al., 2012b). Improved technological and pharmacological (cost-effective) interventions have contributed to higher survival rates after experiencing cardiac events and invasive interventions (Davies et al., 2008; O'flaherty, Buchan and Capewell, 2013; Piepoli et al., 2010). In-hospital treatment of coronary heart disease has increased by 13% from 2002 to 2008 (Allender et al., 2008). Yet the impact of lifestyle, including poor diet and tobacco, must not be underestimated (O'flaherty, Buchan and Capewell, 2013). CHD remains the second most widespread long-term condition (Allender et al., 2008) with the highest rates of CHD and high-risk status emerging in (urban) North England (Allender et al., 2008; Dalton et al.,



2013). Between 1994 and 2006, self-reported prevalence rates of CHD in British men rose from 6% to 6.5%, and remained stable at 4% for all women with circa 1,5 million CHD patients living in the community in 2007 (Pearson-Stuttard et al., 2012). Inequalities in CHD are prevalent (Pearson-Stuttard et al., 2012). More people live with chronic heart conditions some of whom will develop heart failure. As a result, an increased personal and overall disease burden can be observed, specifically in the over 65 year olds (Allender et al., 2008; Piepoli et al., 2010; Smolina et al., 2012a). An efficient and cost-effective method to lower this burden is cardiac rehabilitation.

## **1.2 Cardiac rehabilitation**

CR is a comprehensive, multi-disciplinary programme aimed at improving the physical, psychological and the social performance of patients who have suffered an acute cardiac event with the aims of limiting or even reversing CVD risks and enabling patients to return to a healthier life long-term (Day, 2008; Heran Balraj et al., 2011; Piepoli et al., 2010; The National Audit of Cardiac Rehabilitation, 2009).

The World Health Organisation (WHO) defines cardiac rehabilitation as:

[...] the sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible physical, mental and social conditions, so that they may, by their own efforts, preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be regarded as an isolated form of therapy, but must be integrated with the whole treatment, of which it forms only a facet (World Health Organization. Consultations, 1993, p.5)

The WHO first enquired further into the effects of physical activity following a cardiac event in the late 1960s and released first guidelines in 1968. In 1870, Prof. Dr. med. Oertel had been the first to actually prescribe increasing exercise for heart disease patients and subsequently reported a decrease in blood pressure (Nägele, 2007). Despite his findings, absolute rest for patients was commonly believed to be the best method for recuperation following a heart attack (Nägele, 2007). A major change occurred when Levine allowed his cardiac patients to sit in an armchair rather than lie in bed during the recovery period. In the latter half of the 20<sup>th</sup> century, the debate on physical inactivity causing decreased functionality in acute myocardial infarct (AMI) patients was opened, and the first graded exercise programmes were designed (Perk, 2007). Myocardial infarct patients are being cared for as acute

patients within the hospital settings (William, 2008). The ability to monitor vital signs and the development of revascularization techniques made coronary care units a part of every modern hospital (William, 2008). Initially, CR measures were inpatient based programmes but since Hellerstein prescribed outpatient follow-up physical activities in the 1960s, cardiac rehabilitation has also become a structured, supervised, outpatient programme (Certo, 1985).

Today, 'comprehensive' cardiac rehabilitation typically encompasses exercise, health education and lifestyle advice over 6-10 weeks, delivered as an outpatient course. When the patient is stable but still in hospital, advice on lifestyle modification is given and pharmacological interventions are prescribed (traditionally called phase 1) (Ad Beswick et al., 2005; Bethell, Lewin and Dalal, 2009). Then, in the second phase, the patient recuperates at home but should be advised by the CR team or general practitioner (GP) during that time. Educational resources such as the Heart Manual<sup>1</sup> are provided and some form of basic physical activity is suggested (Ad Beswick et al., 2005; Lacey et al., 2004). The third phase of CR starts 2-6 weeks later when a multi-faceted team provides structured support to aid lifestyle modifications and medication adherence (Piepoli et al., 2010). The exercise component is the most important part of CR, but many topics - including risk factors like smoking, alcohol and diet, as well as work and stress, sexual activity and other worries and potential anxieties - are addressed (Bethell, Lewin and Dalal, 2009; Day, 2008; R.S. Taylor et al., 2004). Often, changing more unhealthy habits can be hard, and patients need help with overcoming common misconceptions and understanding their disease and the subsequent impacts (Great Britain. Department of Health, 2000). Furthermore, early readmissions can be due to psychosocial issues (Murphy et al., 2008; Oxlad et al., 2006), hence social support is needed and reduces the burden of disease (Mookadam and Arthur, 2004). These programmes were traditionally more hospital-based group schemes, but a move towards community settings as well as more individually tailored/ menu-based approaches is advocated (Bethell, Lewin and Dalal, 2009; British Association of Cardiac Prevention and Rehabilitation, 2012). However, huge variations in staffing, duration and frequency as well as programme

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<sup>1</sup> The Heart Manual is a home-based cardiac rehabilitation programme for patients with CHD. ([www.theheartmanual.com](http://www.theheartmanual.com))

content and compositions are observed, which lead some to question their effectiveness (Brodie, Bethell and Breen, 2006; Doherty and Lewin, 2012; The National Audit of Cardiac Rehabilitation, 2011). A dose response has been suggested based on longitudinal mortality data in US adults (>25 CR sessions versus < 25 sessions), and benefits of an expanded CR programme have been seen. This may merit further research, since trials have yet to consider such variations (Beauchamp et al., 2013; Plüss et al., 2011; Suaya et al., 2009).

Clinical research trials verify that CR reduces (modifiable) risk factors (Chatziefstratiou, Giakoumidakis and Brokalaki, 2013) as well as cardiac and all-cause mortality (11%), morbidity and results in biomedical benefits (Alter, Oh and Chong, 2009; Dobson et al., 2012; Heran Balraj et al., 2011; Piepoli et al., 2010; R.S. Taylor et al., 2004). Meta-analyses of trials including more than 10,000 patients show a significant reduction in systolic blood pressure, overall cholesterol level, and patient-reported smoking as well as a reduction in all-cause mortality but no effect on recurrent cardiac events in patients who attended CR (Heran Balraj et al., 2011; Jolliffe et al., 2001; R.S. Taylor et al., 2004). Furthermore, CR offers psychological management. Reductions in anxiety and depression scores in those who attend have been found (Eshah and Bond, 2009). CR lowers the overall and personal burden of disease and reduces the chances of future hospitalization (Piepoli et al., 2010). It is also safe; data from more than 140 US-based CR programmes revealed a mortality rate of 1 per 784,000 patient hours (Pasquali, Alexander and Peterson, 2001). Last but not least, cardiac rehabilitation is very cost-effective, especially compared to biomedical interventions such as PCIs (A D. Beswick et al., 2004; Hambrecht et al., 2004; L. Å Levin, Perk and Hedbäck, 1991). For example, tobacco consumption is addressed in order to prevent premature death and disability long-term as compared to biomedical interventions (PCI) that might have to be performed repeatedly (Doherty, P., 2012, personal communication). The financial needs of a 12-months exercise programme were found to be significantly lower than PCI costs (Hambrecht et al., 2004). In addition, secondary prevention and self-management of chronic conditions become increasingly important in a political climate with diminishing resources for patient support facing an aging population.

Controversy has been sparked by West's recent publication of his 1997 trial, where no differences between the CR/non-CR groups were found. Sample composition,

such as too few participants to execute significant power and biases have been critiqued (Doherty and Lewin, 2012). Though scarce resources effecting outcome through cuts in staff and programme components are being debated. West argues, that when considering modern trials only, there is no evidence for improved survival due to better medical treatment (Doherty and Lewin, 2012; Doherty and Rauch, 2013; West, Jones and Henderson, 2013).

The benefits of cardiac rehabilitation attendance are well established, but attendance in the UK remains low (see p. 17). Attendance is equally low in many European countries and the US (Bjarnason-Wehrens, 2008; Dunlay et al., 2009). Of the percentage of patients referred to CR who did not take part (21-25% as recorded in the NACR 2008 -2011) about 30-31% stated a 'lack of interest' (The National Audit of Cardiac Rehabilitation, 2011).

Encouraging more patients to participate in CR is the focus of this thesis and will be discussed further following a short outline of current UK guidelines.

### **1.3 Cardiac rehabilitation guidelines**

It is estimated that about 85% of eligible patients would be well enough to participate in CR (The National Health Service, 2010). Recently the goal of offering CR to patients has been readjusted to 65%, perhaps due to scarce resources (Great Britain. Department of Health. Cardiovascular Disease Team, 2013). Myocardial infarct survivors and coronary revascularization patients are prioritised before services are extended to other heart disease patients (Great Britain. Department of Health, 2000; The National Audit of Cardiac Rehabilitation, 2011). Nevertheless, MI, heart failure (HF), unstable angina, CABG, PCI and ICD are considered within the benchmark for commissioning services (The National Institute for Health and Clinical Excellence, 2012). There are no mandatory standards for hospitals to offer CR or how CR is set-up. The various UK policy and practice guides are outlined in box 1.1

- **The British Association for Cardiac Prevention and Rehabilitation (BACPR)**, a national organisation for professionals involved with cardiac rehabilitation founded in 1993, provides guidelines but membership is not mandatory (British Association of Cardiac Rehabilitation, 2010). The guidelines outline 7 core standards to be delivered by cardiac rehabilitation programmes in order to provide high-quality care (British Association of Cardiac Prevention and Rehabilitation, 2012)
- **The Department of Health** implemented the **National Service Framework for Coronary Heart Disease (NSF-CHD)** in **2000** when CR was set out as one of the 7 standards that local communities were expected to achieve (Great Britain. Department of Health, 2000). Key aspects of the guidance were for local Trusts to develop procedures inviting 85% of eligible patients to CR before they leave the hospital (Great Britain. Department of Health, 2000). Integrated, multi-disciplinary programmes are emphasized, and a list of interventions was included that should be provided taking individual needs into account.
- **Scottish Intercollegiate Guidelines (SIGN)** guidelines from **2002** had been adopted by BACPR. The SIGN guidelines apply in Scotland.
- **National Institute for Health and Clinical Excellence (NICE) guidelines** for secondary prevention in post-MI patients and unstable angina & NSTEMI were issued in **2007** and **2010**, respectively. All MI patient should be offered CR. Education, social and psychological support, as well as needs assessments and patient engagement were emphasised (National Institute for Health and Clinical Excellence, 2007)
- **NICE guidance for heart failure (HF)** state to offer CR to HF patients, which can be integrated with existing CR programmes (National Institute for Clinical Excellence, 2010)
- In **2010**, an NHS **commissioning pack** was developed to guide providers and purchasers about the best way to provide and commission CR (Great Britain. The Department of Health, 2010).
- Since **2013**, the **Cardiovascular Disease Outcome Strategy. Improving outcomes for people with or at risk of cardiovascular disease** outlines outcomes for patients with CVD (risk).

### **Box 1.1: Policy and practice guidelines in the United Kingdom**

From April 2013 cardiac rehabilitation has been added to the GP payment plan. Quality Outcome Framework targets are debated with the aim of moving towards more integrative prevention and CR (P.Doherty, 2012, NHS Improvement Team, presentation). The infrastructure is currently put in place.

The National Audit of Cardiac Rehabilitation (NACR) supports the implementation of the new guidelines and is an ideal tool for quality assurance. The NACR collects data on the number of patients attending CR, types of diagnoses served, as well as clinical, behavioural and health elements data to evaluate CR service provision (Lewin, Thompson and Roebuck, 2004). The NACR was established in 2005 and is now used by 382 cardiac rehabilitation programmes (CRPs). The British Association for Cardiac Prevention and Rehabilitation includes the NACR as a standard to support systematic data collection, audit and evaluation (British Association of Cardiac Prevention and Rehabilitation, 2012).

While cardiac rehabilitation is strongly recommended and supported by policy documents and practice guidelines, there are no mandatory steps in the care process. CR history and research outcomes described above show the benefits of CR, yet different patient communication or hospital pathways perhaps lead to rates of attendance being below desirable. This raises important questions about who attends and who does not attend.

#### **1.4 Who are the attenders and non-attenders in cardiac rehabilitation?**

There are a total of 382 CR programmes in the country, and yet few cardiac patients attend CR (see p.17) (The British Heart Foundation, 2010; The National Audit of Cardiac Rehabilitation, 2012). Alternative programmes including the Heart Manual, a home-based cardiac rehabilitation programme, courses in community settings or for specific types of patients have proven to be as successful as traditional hospital-based programmes (Jolly et al. 1998). Despite these different options, consistently low attendance rates are reported. Investigations into non-attendance of CR and related patient characteristics have been made, yet developments in the area of CR have been slow (Great Britain. Department of Health, 2000).

The following sections offer a brief overview of the literature on attenders and non-attenders in cardiac rehabilitation. This thesis takes a sequential approach to the main

question of how to increase attendance in CR. As a first step, the aim was to explore who the attenders and non-attenders are and whether any evidence for under-represented groups exists. The literature was reviewed, and a non-exhaustive list of relevant publications can be found in appendix A.

#### **1.4.1 Non-attenders**

Older women are the only patient group found to be under-represented based on data from the NACR. About 30-32% of female patients were being referred, yet only 26% attended CR (The National Audit of Cardiac Rehabilitation, 2010, 2012). This may be a result of an underlying gender bias, differences in disease presentation (Daniels et al., 2012), age or a combination of all three. Reviews have shown that women were referred less often (Benz Scott, Ben-Or and Allen, 2002; Grace et al., 2002b) and women as well as older patients were significantly less often invited to CR (Colbert et al., 2013). They also took up the invitation less often (Daniels et al., 2012; Harrison and Wardle, 2005; Lloyd, 2009). Physicians' differential understanding of disease presentation, risk and need in women may contribute to lower referral rates (Beckstead et al., 2013; Daniels et al., 2012), while family or domestic responsibilities were often perceived as barriers to attendance by the women themselves (Daniels et al., 2012; Grace et al., 2009; King and Lichtman, 2009; Tod, Lacey and Mcneill, 2002). Conversely, smaller studies found that CR participation was perceived in terms of regaining independence and improving ones functional status. Women trusted their physician's recommendation and liked classes with a non-competitive environment (Moore, 1996 as cited in Daniels et al., 2012; Heid and Schmelzer, 2004; Rolfe, 2010). Another review highlights those different needs during CR but did not always find gender as a predictor of attendance (Day, 2008) or a difference in uptake once referred (Weingarten et al., 2011). Eshan and Bond cited one study that included only women with an attendance rate of over 90% referring to appropriate motivation methods and, somewhat indirectly, to cultural appropriateness (Eshah and Bond, 2009). However, women-only trials found difficulties with recruitment despite great efforts (as experienced here, see Chapter 5) (Beckie, 2006; Beckie and Beckstead, 2010). As many studies point out, women tend to be older and suffer from more physical and psychosocial impairment, which may explain lower attendance rates (Daniels et al., 2012; Day, 2008; Harlan et al., 1995).

Co-morbidity rates are higher in older patients (Harrison and Wardle, 2005) and likely the reason why many studies, across countries and health care systems, find age to be predictor or determinant of non/attendance or that attenders are likely to be younger (A. Cooper et al., 2002; Cortés and Arthur, 2006; Cupples et al., 2010; Fernandez et al., 2008; French et al., 2005; Harrison and Wardle, 2005; Husak et al., 2004). Co-morbidities may also be a reason for not being invited to CR (Harrison and Wardle, 2005; Melville et al., 1999). From the patients' perspective, a review of qualitative studies highlighted personal and physical barriers in elderly patients in regards to attendance (Neubeck et al., 2012). Socially embarrassing issues like incontinence or other limiting factors like pain or fear of pain are frequently cited in the literature on CR as well as age (Dolansky, Moore and Visovsky, 2006; King and Lichtman, 2009; Neubeck et al., 2012; Tolmie et al., 2009). Elderly patients may experience social isolation, lower functional status, thus the risk for depression, and perhaps lower income.

Few studies focus on deprivation, but most find that attendance is lower in more deprived, lower socio-economic status (SES) or less educated patients (Beauchamp et al., 2010; A. Cooper et al., 2002; Grace et al., 2002b; Harlan et al., 1995; Kerins, Mckee and Bennett, 2011; Melville et al., 1999; Nielsen et al., 2008; Valencia, Savage and Ades, 2011). Others could not confirm this but found sex, age, or marital status to predict attendance (Fernandez et al., 2008; Harrison and Wardle, 2005).

Marital status is used as a proxy for social support; after controlling for other variables, no association with attendance could be found (Grace et al., 2002a; Husak et al., 2004), though some research found partnered patients to have higher odds of attending (Molloy et al., 2008). Other psychosocial variables are less often investigated (A. Cooper et al., 2002). Perceived illness control has been suggested as related to attendance (French, Cooper and Weinman, 2006) but interacts with physician and systems factors (Grace et al., 2008)(further discussed in Chapter 5). Depression and anxiety are higher in women. Anxiety, along with self-efficacy predicts CR participation in all patients (Grace et al., 2002a). The relationship between CR and depression in women is less clear (Grace et al., 2002a). Though other studies found no association between attendance and higher depression scores (Casey and Sydeman, 2013).



Most studies exploring CR experiences or attendance in cultural or ethnic groups concentrate on people of broad South Asian origin in the UK and Canada (Ski and Thompson, 2011). Such debates lack a degree of sophistication and nuance. Issues beyond language and religion -for example, health beliefs or health-seeking behaviour, or the impact of wider determinants - are rarely unpacked (Davidson et al., 2010). Davidson who reviewed cultural competence in light of cardiac rehabilitation, discovered few publications (Davidson et al., 2010). Nevertheless, lower referral and participation rates or poorer recording in ethnic and culturally diverse populations is often discussed (Chauhan et al., 2010a; Grewal et al., 2010; Jolly et al., 2005a; Mochari et al., 2006; Valencia, Savage and Ades, 2011). UK national audit data does not suggest an uptake issue in this (heterogeneous) group (The National Audit of Cardiac Rehabilitation, 2011).

The way that ethnic background is assessed can be challenged because it may introduce bias due to the descriptors chosen for data collection. From most qualitative studies, the need for more culturally appropriate CR becomes apparent (Banerjee et al., 2010; Chauhan et al., 2010b; Darr, Astin and Atkin, 2008; Galdas and Kang, 2010; Sloots et al., 2011; Vishram et al., 2007) to also avoid inequalities in outcome post-CR (Deck, 2008; Sanderson et al., 2007). The Whitehall II study found cardiac care rates to be higher in UK South Asian<sup>2</sup> patients, suggesting this was due to the awareness of increased risk in patients and practitioners (Britton et al., 2004). These findings challenge the common notion of under-representation of South Asian patients in cardiac care services and whether, for example, there is actual evidence for the language barrier. Language and cultural barriers can lead to impoverished communication (Ski and Thompson, 2011) (communicating the importance of CR is discussed in Chapter 7). Providing culturally appropriate services is challenging (Atkin and Astin, 2010), especially with differing dynamics in generations between ethnic origin and cultural surroundings. Further characteristics- for example, low socio-economic status or gender - make for harder-to-reach groups and confound effects (Ski and Thompson, 2011).

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<sup>2</sup> People of South Asian origin are the biggest ethnic minority groups in the UK; though such a category shows considerable heterogeneity in terms of culture, ethnicity, language, religion and history of migration (Darr, Astin and Atkin, 2008)

Professional and system-level factors can be as important as patient characteristics in mediating attendance rates. For example, one review found physician endorsement to be the main predictor of referral and attendance (Jackson et al., 2005). Others found that younger age, English language or admission to a hospital with a CRP increased the odds of being invited or referred to CR (Cortés and Arthur, 2006; Williams, Byles and Inder, 2010). A multi-level study also found physician perception of CR, experience and perceived benefits to be an influential factor in referral (Grace et al., 2002b; Grace et al., 2008), and another review highlighted that physician endorsement, beliefs around CR and their speciality are related to referring patients (Ghisi et al., 2013). Grace had originally found that more than 65% of patients were never invited (Grace et al., 2002b). The combination of automated referral and liaison increases enrolment and uptake (Gravelly-Witte et al., 2010) and automated referral leads to higher referral of under-represented groups (Grace et al., 2012). Other factors that may influence referral and enrolment are related to limited funding and capacity (for example in North Yorkshire; Lindsay, 2008). The NACR indicates waiting times from referral to starting phase 3 CR being around 55 days (The National Audit of Cardiac Rehabilitation, 2011). Hence, some patients may not get referred, and for others it is too late to attend.

Currently, no data links exist connecting hospital data to information from the CR centres. Patients are not tracked along the clinical pathway, many appear to drop out of the system. The NACR calculates uptake rates (42% in 2011) using the Hospital Episode Statistics (HES) data for acute myocardial infarct incidences relative to numbers enrolled as reported by the 382 UK programmes registered with the NACR. Attendance rates are similar in other countries, and it is fair to say that they are below desirable. Furthermore, every AMI-treating hospital has a CR programme, yet considerable regional variations in attendance exist (Bethell et al., 2008).

Finally, a comment on barriers and facilitators; the majority of literature considered in the summary above outlines attenders and non-attenders but also facilitators and barriers simultaneously. It is to note, however, that, while attendance rates are clearly influenced by these, for this research it was decided not to add further literature exploring barriers and facilitators. It would be a suboptimal use of resources and a thesis is unlikely to bring about clearer patterns. Instead, the focus remains on increasing attendance, in a pragmatic yet theory-informed way, which is why the

next Chapter presents a systematic review of interventions to increase uptake that have been tested thus far.

### **1.4.2 Summary**

In the last 10 years, the issues surrounding the uptake of CR have been widely debated and researched. Most studies are small, and they originate mainly from industrialised/western countries. They have mostly focused on psychosocial, demographic or economic patient-related predictors although there is a growing amount of research taking health care professional and system factors into account. Although socio-economic status and deprivation have an influence on heart disease, this has rarely been explored in the cardiac rehabilitation literature. And while many indicators of non-attendance resurface in the literature across regions no easily identifiable patterns emerge and there is no clear evidence for under-represented groups.

Wider determinants, such as waiting times, finances or the lack of transport, prevent patients from attending, but also, on the individual level, a lack of understanding of CHD and CR (De Vos et al., 2013; Neubeck et al., 2012). Of those invited that do not attend, 31% decline due to a lack of interest (The National Audit of Cardiac Rehabilitation, 2011). Efforts to effectively communicate the importance of cardiac rehabilitation are to be made to increase attendance (Bethell, Lewin and Dalal, 2009; Jolliffe et al., 2001). And while the diversity of the CR patient population is of potential importance and the needs of the local patient population should be considered by CRPs, a more generic intervention tapping into patient motivation would be easy-to-implement, low-cost and low-risk (National Institute for Health and Clinical Excellence, 2007; The National Institute of Clinical Excellence, 2010). Despite the complexity of these debates, a key theme remains *'What strategy would improve uptake of CR in patients who have been invited to CR?'*

## **1.5 The format of this thesis**

Having established the context for my work and justification for my research question, this section provides an overview of the research aims and outlines the structure and presentation of the thesis, while briefly commenting on methods and methodology.

### 1.5.1 Development of the research aims

Motivated by the low attendance rates in cardiac rehabilitation and the belief that CR is an important part of the treatment and recovery process, I wanted to find a way of encouraging more people to attend cardiac rehabilitation. The main research questions is: *'What strategy would improve uptake of CR in patients who have been invited?'* My work is of direct relevance to health care (and the NHS)<sup>3</sup>.

The research question is of a practical nature. It is supported by a series of six secondary research aims. To start off with, I wished to understand in more detail 1) *who the patients are who do and do not attend rehabilitation*, as already described above, and 2) *what strategies had been employed so far to encourage attendance*. When moving through the latter literature review, the lack of evidence, especially with regards certain patient groups, led me to explore connections with other health care areas, such as screening. I wanted to gain an understanding of evidence for the strategies found in the cardiac rehabilitation literature and also gain further insight into 3) *the strategies and interventions used to encourage more patients to participate in other health services such as self-management programmes, screening or vaccinations*.

With the knowledge that clinical practice - in terms of referral, identification and invitation methods - and programme design in cardiac rehabilitation are diverse, I first sought to become aware of 4) *which invitation methods are used in current practice*. Based on the evidence and feasibility, the decision was made to work with health behaviour theory-based invitation letters. Now I wanted to involve parties concerned 5) *to investigate the perception of existing invitation letters as a means of exploring how health behaviour theory is operationalised in written materials to further develop previously tested letters*. And finally, I wanted to implement and

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<sup>3</sup> The Collaborations in Leadership for Applied Health Research and Care (CLAHRCs) are NHS and academic partnerships funded by the National Institute of Health Research. This thesis is associated with CLAHRC and its underlying aims to better connect health research with practice and to help in solving problems (Leeds Teaching Hospital NHS Trust, n.y.). The thesis responded to low attendance rates in cardiac rehabilitation, and the work was done in close contact with CR programmes. In searching for potential approaches to increasing uptake rates, a pragmatic stance was taken and solutions were adapted flexibly to local circumstances (Chapter 6). In addition, three papers based on Chapters 2, 3 and 4 have been published, with plans to submit two more in 2014 as well as to present findings at the annual BACPR conference in 2014. Finally, the work presented in this thesis was completed solely by the student.

evaluate the changed invitation letter on a larger scale to see 6) *whether an amended invitation letter encourages more patients who had been invited to attend CR* and to disseminate my findings as well as to develop recommendations.

### **1.5.2 Structure of this thesis**

The structure of this thesis reflects the different design states used to answer my research question.

**Chapter 2** describes a *systematic review* of interventions designed to increase the attendance at cardiac rehabilitation with a secondary focus on groups less likely to attend. The aim of the review was to assess the evidence on interventions aimed at enhancing enrolment in CR to inform and justify the development of an intervention specifically addressing non-attenders.

**Chapter 3** presents a *narrative literature review* on interventions to increase the participation in other health care services. The aim was to find further evidence supporting CR-specific interventions (Chapter 2). The rationale lies within common ideas that underpin interventions, such as generic health behaviour theories or peer support used in a variety of health and social care settings.

**Chapter 4** depicts an *e-survey* of cardiac rehabilitation programmes in the UK enquiring about identification and invitation methods, *among other things*, to see whether invitation letters would be a practicable method to develop and implement in current practice.

**Chapter 5** describes patient *interviews as a means of exploring and developing the operationalisation of health behaviour theory* in written invitation materials. Interviews also elicited key motivational messages to increase attendance at CR.

**Chapter 6** portrays a *quasi-experimental, pragmatic evaluation* of the amended invitation letters implemented across 6 CRPs assessing their impact on attendance rates.

**Chapter 7** is the final Chapter and presents the *key findings* of the overall study, outlining contributions, strengths and limitations as well as implications and future directions. Final concluding comments are offered.

### **1.5.3 A note on methodology and methods**

In response to the sequentially emerging research aims, a multi-method approach was appropriate. In health sciences, research methodological decisions are underpinned by pragmatics, which drives the choices of methods more than the theory (Pope and Mays, 2006a, Silverman, 2009 #1145). Consequently, a multi-methods approach to my emerging research aims is possible choosing strategies that best fit with the research purpose (Morgan, 2007, Patton, 1990 as cited in Creswell, 2009). The view driving my selection of methods has its roots in a more (post) positivist as well as constructionist stance, with pragmatism assisting in the fusion. It allows a focus on the research aims, as outlined above, and for it to drive the selection of methods without the selection of one particular paradigm (Creswell, 2009). History and context, social and political environments remain important and are debated throughout the thesis (Creswell, 2009). In the end, the choice of methods across all research pieces calls for a systematic, rigorous and transparent approach. As Carter and Little (2007) emphasized, an internally consistent approach can be recognised by researchers with differing theory bases and hence reflects credibility (Carter and Little, 2007).

Rather than having one traditional methodological Chapter, each Chapter includes, the description of the methods chosen along with a debate on the ‘methodological considerations’. This is to help the flow of the research story and to help provide a coherent, sequential account, in which the findings from each stage feed into the next. This was felt to present a more succinct and accessible piece of work, since a more traditional methods Chapter would have been unwieldy and unlikely to be helpful in making sense of the approach I chose. Each part of the research, for example, has its own defined method. The final Chapter offers a synthesis of results and comments on the adequacy of the methods utilised.

## **1.6 Conclusion**

Cardiac rehabilitation is a (cost) effective treatment yet uptake rates remain below those advocated in policy documents. This may be due to a lack of resources and system-related barriers, but also due to patients not accepting the invitation. A multi-stage approach was chosen to respond to the research aims to explore, in a focused yet contextualised way, how to increase attendance at CR in patients invited. The

next Chapter will outline what strategies had been tested so far to encourage attendance: *'Is there a way to improve the uptake in patients invited to take part in CR?'*





## Chapter 2

### **A systematic review of interventions designed to improve uptake in cardiac rehabilitation with a secondary focus on groups less likely to attend<sup>4</sup>**

My doctorate is concerned with encouraging more patients to attend cardiac rehabilitation, since uptakes rates are below desirable. As discussed in the previous chapter, low attendance rates exist due to system-related or financial issues but also due to a lack of interest. This chapter describes a systematic review of interventions promoting cardiac rehabilitation, answering the research aim, 2) *what strategies have been employed so far to encourage attendance?* It also enquires whether these strategies targeted or were tailored to any specific groups or issues. As the first chapter showed, there are some indicators that surfaced repeatedly, for example, older women are under-represented. A wealth of literature exists, but the evidence on under-represented groups is inconclusive. Therefore, conducting further primary research on attendance/non-attendance would be an insignificant addition to the large evidence base and a suboptimal use of resources. Instead, this review informs the design of an intervention to encourage attendance and will ideally further developments in the field on theoretical as well as practical grounds.

### **2.1 Background**

Cardiac rehabilitation<sup>5</sup>, as seen, is a therapy that helps patients regain psychosocial, occupational and physical functioning and, as a secondary prevention programme, teaches people to self-manage their condition and aims at modifying common risk factors for chronic diseases (Piepoli et al., 2010). Cardiac rehabilitation is proven to be beneficial, cost-effective, reduces in-hospital stay, and cardiac mortality, and is hence recommended as a standard of care in many industrialized countries (Bethell, Lewin and Dalal, 2009; Gravely-Witte et al., 2010; Heran Balraj et al., 2011; R.S. Taylor et al., 2004).

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<sup>4</sup> Dressler, C., Pattenden, J., Lewin, R.J., Atkin, K. (2012) Interventions to increase the uptake of cardiac rehabilitation: systematic review. *British Journal of Cardiac Nursing* 7(7):338-345

<sup>5</sup> Comprehensive cardiac rehabilitation was described in Chapter 1.

In the UK, there are around 382 cardiac rehabilitation programmes treating 50,000 patients per year, but only 42-44% of patients overall attend (relative to Hospital Episodes Statistics). Around 24-27% of the patients who had been referred to CR did not take part in 2009/10 (The National Audit of Cardiac Rehabilitation, 2010, 2012).

Some studies suggest that older women, ethnic groups or the employed are less likely to attend; however, only the former group is confirmed by the NACR (Cupples et al., 2010; Grewal et al., 2010; The National Audit of Cardiac Rehabilitation, 2011). As discussed in Chapter 1, a variety of demographic and psychosocial factors can predict referral and attendance, yet non-attenders are a heterogeneous group (A. Cooper et al., 2002; Williams, Byles and Inder, 2010). System-related barriers, a lack of understanding of the benefits and setup of CR and a lack of interest prevent patients from attending CR (Neubeck et al., 2012; The National Audit of Cardiac Rehabilitation, 2011).

The research focus needs to turn towards how uptake in cardiac rehabilitation can be increased. Previous reviews found just three strategies, namely a motivational letter, social worker support as well as liaison staff, all of which were successful (A D. Beswick et al., 2004; Davies et al., 2010). The purpose of this chapter is to update the review and look for evidence globally.

### **2.1.1 Objectives**

The aim was to conduct an international systematic review of randomised controlled trials (RCTs) of interventions designed to increase the uptake of CR. The objectives were to:

- systematically assess the evidence on interventions designed to increase enrolment in cardiac rehabilitation;
- explore, as a secondary focus, interventions specifically addressing issues of non-attendance or patient groups less likely to attend.

These objectives are the first step in informing the thesis aim '*improving uptake of CR in patients who have been invited*' through a critical examination of existing evidence on interventions tested thus far.

## **2.2 Methods**

Adopting the systematic review method allowed for a transparent and concise way of identifying and evaluating studies that tested interventions designed to increase the attendance at cardiac rehabilitation (Harden and Thomas, 2010). This systematic review is less subjective than, for example, narrative reviews and uses standardized tools, such as the data extraction sheet, and a protocol planning data analyses and bias assessments (see Appendix B).

### **2.2.1 Definitions**

For the purpose of this thesis, *attendance is defined as participating in at least one phase 3 session/assessment* (definition as used by the NACR). Attendance and uptake are used interchangeably. Note that *adherence* is not addressed here due to time and resource restrictions and because, as Jackson et al. concluded, the factors that affect participation in cardiac rehabilitation differ in each phase (Jackson et al., 2005).

*Under-represented groups* are defined as eligible patients that use or access a service less than expected (Oliver and Mossialos, 2004).

### **2.2.2 Procedure**

A previous systematic review by Beswick and colleagues (2005) was consulted to develop the review protocol outlining and justifying the inclusion and exclusion criteria, the search terms and databases used as well as the selection process (see Appendix B). A short overview of each will be presented next.

### **2.2.3 Electronic searches**

Six electronic databases (displayed in Table 2.2) were searched for randomised controlled trials (RCT). The search strategy combined terms relating to heart disease, CR and a broad selection of terms on potentially under-represented groups (Box 2.1). The criteria were developed from Welch et al., Hawthorne et al. and experts in the field of cardiac rehabilitation in the UK (Hawthorne et al., 2008; Welch et al., 2010). Reference lists of all appropriate trials and previously identified papers were scanned (A D. Beswick et al., 2004; Davies et al., 2010).

1. exp Ethnic Groups/	29. motivation.ti,ab.
2. exp Refugees/	30. exp "Patient Acceptance of Health Care"/
3. exp Cultural characteristics/	31. (non?compli\$ OR non?attend\$).ti,ab.
4. ((underserve\$ or disadvantage\$) adj6 (group\$ or population\$)).tw.	32. or/24-31
5. ethnic\$.tw.	33. exp Heart Diseases/
6. (migrant\$ or immigrant\$).tw.	34. (heart or coronary or myocardial or angina or CABG or PTCA).ti,ab.
7. refugees.tw.	35. or/33-34
8. ((hard to reach or depriv\$ or disadvantage\$ or Under?represented or under-represented or under?served or underserved or low income or poor or low\$ socio?economic? or low socio economic or low\$ socio demographic\$ or low socio?demographic or inequal\$ or inequit\$) adj3 (status or group? or population? or position or disparity or area or region or place?)).ti,ab.	36. exp Coronary Disease/rh [Rehabilitation]
9. ((Gender adj difference) or (female adj patient?) or wom?n).ti,ab.	37. exp Rehabilitation/
10. ((Old or elder\$ or homeless or traveler) adj patient?).tw.	38. exp Rehabilitation Centers/
11. exp Aged/	39. ((rehab\$ or recover\$ or aftercare or Aftercare or convalescen\$ or recuperat\$) adj5 (heart attack or revascular or coronary or cardiac)).tw.
12. Sex factors/	40. exp Self Care/
13. Age factors/	41. (selfmanag\$ or self manag\$).ti,ab.
14. Poverty/	42. (self care or selfcare).ti,ab.
15. Minority Groups/	43. or/36-42
16. Income/	44. randomized controlled trial.pt.
17. Social Class/	45. controlled clinical trial.pt.
18. Co-morbidity/	46. randomized.ab.
19. exp Socio-economic Factors/	47. placebo.ab.
20. (cormorbid\$ or co-morbid\$).ti,ab. ((minority or ethnic) adj3 group\$).ti,ab.	48. drug therapy.fs.
22. exp Homeless Persons/	49. randomly.ab.
23. or/1-22	50. trial.ab.
24. (compliance or complie\$ or comply\$).ti,ab.	51. groups.ab.
25. (take up or promot\$ or utilisation or utilisation).ti,ab.	52. (animals not (humans and animals)).sh.
26. (uptake or attend\$ or accept or particip\$).ti,ab.	53. or/44-51
27. exp Patient Compliance/	54. 53 not 52
28. exp Motivation/	55. 32 and 35 and 43 and 54
	56. 23 and 55

**Box 2.1: Search terms (medline)**

## 2.2.4 Inclusion and exclusion criteria

The inclusion/exclusion criteria are shown in Table 2.1 (a detailed description can be found in the protocol, Appendix B). Language or dates of publication were not restricted.

**Table 2.1: Inclusion and exclusion criteria<sup>6</sup>**

	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Study design	randomised controlled trials including cross-over, parallel, cluster, factorial	observational studies quasi- experimental designs
Participants	adults	minors patients already enrolled in CR
Diagnosis	myocardial infarct revascularization procedure (PCI or CABG) angina	heart failure heart replacement surgery
Intervention	patient, professional and system- level interventions	comparisons of types of CR compulsory CR
Outcome	uptake or enrolment in CR	medication adherence adherence to CR single risk factor trials

## 2.2.5 Selection of studies

Results were retrieved, assessed, and obviously irrelevant titles were excluded by the author (CD). The remaining abstracts were independently evaluated against the criteria by two researchers (CD and JP<sup>7</sup>). Any disagreements were resolved by discussion, which is sufficient to capture all eligible studies (Centre for Reviews and

<sup>6</sup> With permission, Table 2.1 and Table 2.2 from publication

<sup>7</sup> Jill Pattenden, researcher, Department of Health Sciences, University of York, UK

Dissemination, 2009). Excluded abstracts were recorded along with the reasons for their exclusion.

### **2.2.6 Data extraction**

Data that summarized information on the method, country of origin, aim and design of the intervention, sample size, age and gender of participants, outcome measures, type of analysis and results were extracted (extraction sheet, Appendix B). Data was compared by two reviewers (CD and JP) to ensure correctness, because data extraction is prone to human error. Where data was found to be incomplete or ambiguous, the authors were contacted for further information.

### **2.2.7 Bias assessment**

Following data extraction, a risk of bias assessment took place. The criteria were adapted from PRISMA and as recommended by the Cochrane Heart Group (Centre for Reviews and Dissemination, 2009; Higgins, Green and Cochrane, 2008; Moher et al., 2009; The Cochrane Heart Group, 2010). Bias was assessed using six criteria, namely *sequence generation*, *allocation concealment*, *blinding*, *attrition bias*, *selective reporting bias* and *other sources of bias* (described in the protocol, appendix B, box 1). Studies considered to present a high risk of bias were not excluded, because the assessments may help with the decision of how much emphasis to put on each study's results.

### **2.2.8 Data synthesis and analysis**

All references and abstracts identified by the search were imported into EndNote X4, and duplicates were removed. Where more than one publication per study was found, the paper most relevant to the issues of initial uptake of CR was included.

As in previous reviews, it was anticipated that studies would be too heterogeneous to be quantitatively synthesized. Indeed, it was found that there was considerable clinical heterogeneity across studies and the timing of the outcome assessment, which made this review unsuitable for meta-analysis. Therefore, the results were qualitatively synthesized, and studies were critiqued separately.

## **2.3 Results**

The following section presents the literature search results and study selection process followed by an overview of included studies and the results of the bias assessment.

### 2.3.1 Search results and study selection

The electronic search yielded 2,163 results. The results per search engine are displayed in Table 2.2 below. The original search was run in September 2010<sup>8</sup>.

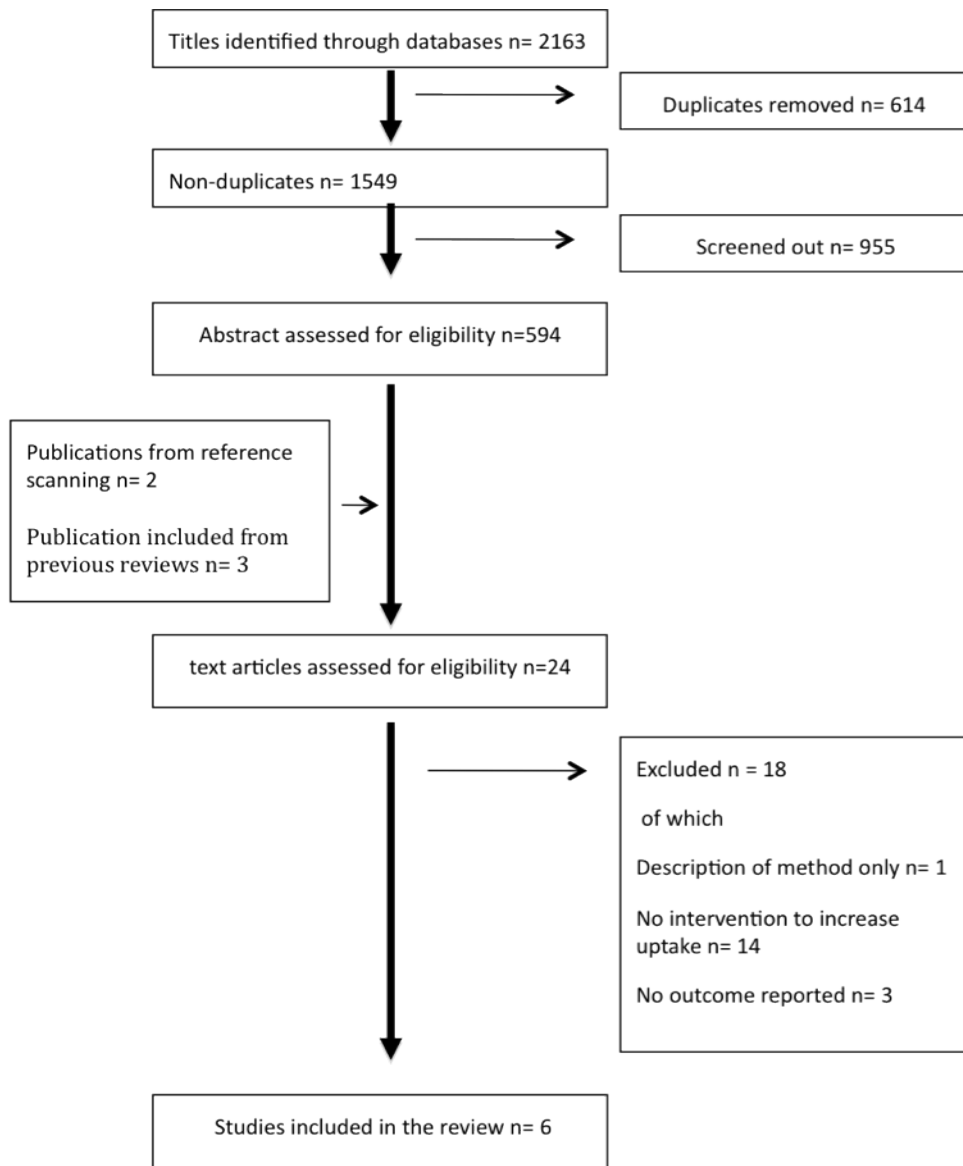
**Table 2.2: Number of results by database (with available time periods)**

Database	Limitations	Results
Medline	1950- August Week 3 2010	908
EMBASE	1980 to 2010 Week 34	426
Psychinfo	1987 to August Week 4 2010	43
CINAHL	none	124
Cochrane	none	267
Web of Science	SCI-EXPANDED, SSCI, CPCI-S, CPCI-SSH 1980- 2010	395
		<b>2163</b>

Of 2163 titles, 614 duplicates were removed and 955 papers excluded due to obvious irrelevance. The remaining 594 abstracts were scanned. Two further potentially important studies were identified through reference scanning and added to the pool as were three publications identified by the previous reviews (Furber et al., 2010; Walters et al., 2010). On the basis of abstract and reference assessment, 24 papers were obtained for further appraisal. A final six studies met the inclusion criteria (one found through its protocol and one through reference scanning). Figure 2.1 illustrates the selection process and the reasons for exclusion.

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<sup>8</sup> The search was re-run in February 2012 and found no additional eligible RCTs. For details, please see: (C Dressler et al., 2012)



**Figure 2.1: Study selection process**

### 2.3.2 Excluded studies

A list of the 18 studies excluded from the review can be found in Appendix B, which lists the reasons for elimination, including: no intervention to increase uptake (14 publications), no outcome measure (3 publications) and description of design only (1 publication).



### 2.3.3 Included studies

Three additional studies have been identified, but only one of those studies targeted under-represented groups. In order to add knowledge in a systematic way, it was decided to review all existing studies. Where available data appeared ambiguous, authors were contacted. Carroll et al. (2007) clarified which figures represent initial uptake of CR, and Mosleh provided additional information on the trial and outcome which has not yet been published (Carroll, Rankin and Cooper, 2007; Mosleh, 2011)<sup>9</sup>. Table 2.3 shows an overview of participant characteristics.

All six studies included in the review were conducted between 1995 and 2009. Five studies were published in English, and one study was published in German. One trial was conducted in Germany, one trial in Canada, one trial in the United States, and three trials came from the United Kingdom.

The studies included a total of 1,489 participants at point of enrolment with a sample size ranging from 549 to 80. Two studies had relatively small sample sizes of under 100 participants and were single- or two-site studies (Grace et al., 2005; Hillebrand et al., 1995; Wyer et al., 2001b), whereas the other four studies had comparatively larger sample sizes, ranging from 121 to more than 500 participants.

Age, sex and primary diagnosis varied greatly across studies. For example, Hillebrand et al. (1995) involved patients up to the age of 60, and Carroll et al. (2007) enrolled only patients older than 65 years of age. All studies included adults with a mean age range of 52.2 ( $SD = 6.2$ ) to 76.4 ( $SD = 6.4$ ). In terms of initiation event, the studies focused on myocardial infarct (MI) only (two trials), MI and coronary artery bypass graft (CABG), CABG only, MI and angina patients, or MI, CABG and percutaneous transluminal coronary angioplasty (PCTA) combined. In terms of the male/female ratio, in five studies, the participants were mainly men (Hillebrand et al., 1995; Jolly et al., 1998; Mosleh, 2011; M. Parry et al., 2009; Wyer et al., 2001b), whereas in one study, the majority of patients were women (Carroll, Rankin and Cooper, 2007).

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<sup>9</sup> Mosleh et al. RCT was published in June 2008: Mosleh, S. M., Bond, C. M., Lee, A. J., Kiger, A., and Campbell, N. C. (2013). Effectiveness of theory-based invitations to improve attendance at cardiac rehabilitation: A randomized controlled trial. *European Journal of Cardiovascular Nursing*

**Table 2.3: Participant characteristics**

Study	Diagnosis	Sample Size <i>N</i>		Mean Age ( <i>SD</i> )		Female <i>N</i> (%)	
		control	intervention	control	intervention	control	intervention
Carroll et al. (2007)	MI, CABG	121	126	76.2 (6.2)	76.4 (6.4)	87 (69)	76 (63)
Hillebrand et al. (1995)	MI	41	46	52.7 (6.3)	52.2 (6.3)	2 (4.3)	8 (19.5)
Jolly et al. (1999)	MI, early-onset angina	320 (start) 255 (4 months)	277 (start) 226 (4 months)	64 (10.30)	63.2(10.1)	83.2(26)	88.64(32)
Mosleh et al. (2009)	MI, CABG and PTCA	96	96; 92; 91	63.00 (10.3)	60.65 (12.53); 63.38 (10.25); 63.18 (11.25)	32 (33)	24 (25); 31 (34) 29 (32)
Parry et al. (2009)	CABG	52 (start) 50(analysed)	69 (start) 45(analysed)	64 (10)	62 (11)	9 (17)	8 (16)
Wyer et al. (2001)	MI, referred to CR	44	43	63.36 (unknown)	62.12 (unknown)	5 (11.4)	6 (14)

Only two studies addressed a patient group that had been mentioned in the literature as under-represented in cardiac rehabilitation (see Chapter 1): Carroll et al. targeted older, unpartnered adults, and Hillebrand et al. recruited only blue-collar workers (Carroll, Rankin and Cooper, 2007; Hillebrand et al., 1995).

In terms of the interventions, two studies used similar invitation letters that addressed the patients' behaviour through operationalising HBT-identified motivational concepts (Mosleh, 2011; Wyer et al., 2001b). Two studies contained an element of peer support (M. Parry et al., 2009), one of which combined peer and advanced practice nurse support (Carroll, Rankin and Cooper, 2007), and one study used a liaison nurse only (Jolly et al., 1998). The latter two cited theoretical underpinnings. One study used a social worker support programme, but the authors did not mention any theory used (Hillebrand et al., 1995).

In six studies, CR participation was stated as a primary outcome. In all but one trial, the outcome was self-reported via questionnaire or interview. Follow-up periods varied from 6 weeks to 12 months. There were no reports of adverse effects except for Wyer et al., who stated that a message in the letter may have been fear-inducing (Wyer et al., 2001b).

Out of the six studies included in this review, four reported significant differences between the intervention and the control group. The average improvement in uptake was an increase in 70.1 percentage points. Detailed descriptions of the studies, including results, can be found in Table 2.4. The results presented are brought together and placed within the broader context in the discussion (Section 2.6) following the risk of bias assessment.

**Table 2.4: Study characteristics**

Study	Methods	Intervention	Specific Group	Outcome Measure	Results
Carroll et al. 2009	Parallel RCT	<p><b>Aim</b></p> <p>To determine if community-based intervention (nurse &amp; peer support) would increase CR participation and reduce hospital readmission</p> <p><b>Design</b></p> <p>- <b>Community-based collaborative peer advisor &amp; advanced practice nurse</b> provided social &amp; self-efficacy support (Social Cognition Theory), (theoretical underpinnings (Carroll and Rankin, 2006)). Intervention started within 48 hours of discharge, adv. practice nurse contacted patient via phone 3 times &amp; made 1 home visit; the peer advisor made weekly calls for 12 weeks; identified key strategies used were verbal encouragement &amp; support, active listening, exercise promotion, teaching about the disease, etc.; peer advisors recruited from CRPs, 45 were trained, 24 of whom remained active; 2 nurses were trained who then assigned peer advisors (by age &amp; gender)</p>	Unpart-nered adults older than 65 years of age	Self-reported measure via telephone on cardiac rehabili-tation attendance	<p>Control group: 4 patients attended CR at 6 weeks</p> <p>Intervention group: 6 patients attended CR at 6 weeks</p> <p>Result: <math>\chi^2=0.206</math> OR 1.36 95% CI [0.35,5.2]</p>

Table 2.4 continued

Study	Methods	Intervention	Specific Group	Outcome Measure	Results
Hillebrand et al. 1995	Parallel RCT	<p><b>Aim</b></p> <p>Does a special outpatient social care support worker increase the participation rate of blue-collar workers in heart groups?</p> <p><b>Design</b></p> <ul style="list-style-type: none"> <li>- <b>Follow-up care by social worker</b>; first contact at the end of inpatient CR via semi-structured interviews in order to reinforce CR content; discussion of potential problem in daily life &amp; possible solutions; social worker made 3 or more contacts: at 1 &amp; 6 month via telephone, home visit at 3 months.;</li> <li>- Patients received information on other health groups or, e.g., counselling services in their locality; support with work-related issues was given.</li> <li>- Ambulatory heart group attendance was encouraged.</li> <li>- Control group did not receive additional support.</li> </ul>	Blue-collar workers 60 years and under	Interview at home, 1 year post-inpatient CR	Control group: 11 (27%) patients attended the heart group Intervention group: 26 (57%) patients attended the heart group Result: chi-square not reported $p = .005^*$
Germany					

Table 2.4 continued

Study	Methods	Intervention	Specific Group	Outcome Measure	Results
Jolly et al. 1998  UK	Cluster RCT	<p><b>Aim</b></p> <p>Connect primary &amp; secondary care, include behavioural change theory and create structures to aid patient follow-up; promote adherence to therapies</p> <p><b>Design</b></p> <ul style="list-style-type: none"> <li>- <b>Cardiac liaison nurses</b> trained in theory of behaviour change (Stages of Change/the 'Helping People Change' programme), and motivational interviewing for 2 days.</li> <li>- Nurses were offered bimonthly support meetings; they were responsible for recruitment, creating the patient-held records to aid follow-up containing information on medication, risk factors, life style; nurses promoted CR, supported the patient &amp; family, coordinated transfer to secondary care; follow-up biweekly visits</li> <li>- Intervention practices also received local guidelines on heart disease care.</li> <li>- It appears that the control group did not have contact to the liaison nurse and there were no patient-held records.</li> </ul>	No other criteria given	At 4 months, survey about health services including CR	Control group 22 % had attended at least 1 CR session at 4 months Intervention group: 37 % had attended at least 1 CR session at 4 months Results: chi-square not reported $p < .001^*$

Table 2.4 continued

Study	Methods	Intervention	Specific Group	Outcome Measure	Results
Mosleh et al. 2009 (protocol) and personal communication (2011)	2x2 factorial design	<p><b>Aim</b></p> <p>The primary outcome of the RCT is attendance of at least one phase 3 CR session</p> <p><b>Design</b></p> <p>- <b>Motivational invitation letter</b> based on the theory of planned behaviour and the common sense model of illness representation.</p> <p>- 2nd intervention was a leaflet also based on TPB and CSM (extensive description of the development (Mosleh, Kiger and Campbell, one phase 3 2009))</p> <p>- Patients eligible for CR received either a standard letter alone or the intervention (motivational) letter alone, or either one in combination with a leaflet. The leaflet was designed to be read the day before the first session to reinforce positive beliefs</p>	All ages included	Attendance status was identified by liaison with the CR secretary, who sent the names of patients who had and had not attended CR; evaluation after 12 months.	<p>CR attenders by group:</p> <p>standard letter 70 (73%)</p> <p>theo.letter 83 (87%)</p> <p>standard letter &amp; leaflet 68 (74%)</p> <p>theo.letter &amp; leaflet 74 (81%)</p> <p>Results:</p> <p><math>p = .07</math></p> <p>standard letter 138 (74%)</p> <p>theoretical letter 157 (84%)</p> <p>Result:</p> <p><math>p = .018^*</math></p>
UK					

Table 2.4 continued

Study	Methods	Intervention	Specific Group	Outcome Measure	Results
Parry et al. 2009	Block RCT	<p><b>Aim</b></p> <p><b>Design</b></p> <p>Testing the effect of peer support after CABG</p> <p><b>Peer support by telephone</b></p> <ul style="list-style-type: none"> <li>- Peer supporters had previously undergone CABG surgery &amp; CR. Of 22 screened, 14 participated in 4 hours of training. Communication was to focus on exercise, pain management and encouragement of CR attendance. Peer activity logs were designed to measure compliance and dose of intervention.</li> <li>Most peer supporters (98%) contacted patients within 72 hours, then provided 8 weeks of telephone support, where a significant difference in number of calls between men and women became apparent (<math>n=8</math> and <math>n=15</math>, respectively). Each volunteer supported 4 patients.</li> <li>- Control group had usual pre- and postoperative education and was visited by the hospital peer volunteer.</li> </ul>	<p>None. The authors mention that peer support may be an effective intervention where large geographic distances present a barrier to CR.</p>	<p>Standardized questionnaire; CR uptake defined as number of patients who had been referred and attended at least 1 session</p>	<p>Control group: 6 (12%) patients attended at least 1 session</p> <p>Intervention group: 11 (25%) patients attended at least 1 session</p> <p>Result: <math>\chi^2 = 2.5</math>, <math>p = .11</math></p>



Table 2.4 continued

Study	Methods	Intervention	Specific Group	Outcome Measure	Results
Wyer et al. 2001  UK	Matched pair RCT	<p><b>Aim</b> Design, implement and theory of planned behaviour were designed to evaluate TPB-based intervention in clinical setting</p> <p><b>Design</b> - Two <b>intervention letters</b> based on the theory of planned behaviour were designed to impact upon attitude, subjective norm and behavioural control, which should influence intention to attend CR. - Patients received a sealed envelope three days post-MI, half of which contained a 'thank you' note (controls). The other half contained the same note with an additional sentence asking to read the enclosed letter (intervention). - A second letter was sent to patients from the intervention group who accepted CR to influence attendance three weeks post-event.</p>	None	<p><b>Acceptance</b> defined as: verbal 'yes' to nurse &amp; allocation of a place in CR; attendance</p> <p>defined as patients who attended the first week of CR</p>	<p><b>Control group:</b> 31 (70%) patients accepted, 26 (59%) patients attended CR</p> <p><b>Intervention group:</b> 37 (86%) patients accepted; 37(86%)patients attended CR</p> <p><b>Results:</b> acceptance <math>\chi^2 = 3.097, p &lt; .04^*</math> attendance <math>\chi^2 = 7.91,</math> <math>p &lt; .003^{**}</math></p>

### **2.3.5 Risk of bias**

A standardized form with six predetermined criteria for the ‘assessment of risk of bias’ was used (Appendix B, Box 2). Information from the studies is provided in Table 2.5 below, where possible. Each row represents the individual study risk assessment and each column, the assessment of bias across studies. Attrition, blinding, sequence generation and allocation concealment were appropriately handled in most studies. There appears to be no selective reporting (for example, Mosleh et al acknowledge a lack of power), and the likelihood of other sources of bias is low. Therefore, the quality of the studies was moderate to good.

**Table 2.5: Assessment of risk of bias per study (rows) and across studies (columns)**

Study author	Sequence generation	Allocation concealment	Blinding	Attrition bias	Selective reporting bias	Other sources of bias
Carroll et al. (2007)	Patients were consented, interviewed and then randomly allocated.	not reported	not reported	During the 12-months study period, 46 patients could not be followed-up on (death or withdrawal). The attrition rate stated was 18.6%.	not reported	Treatment fidelity was addressed by using standardized training
Hillebrand et al. (1995)	At the end of their inpatient CR, patients were randomly assigned to either an intervention group or a control group.	not reported	not reported	53 patients were randomised to interventions & 41 to control. Of these, 7 patients could not/did not participate which resulted in 46 in intervention & 41 in control group. Analysis conducted with final numbers of participants.	not reported	not reported

Table 2.5 continued

Study author	Sequence generation	Allocation concealment	Blinding	Attrition bias	Selective reporting bias	Other sources of bias
Jolly et al. (1998)	not reported	not reported	Follow-up nurse did not know group allocation	At 4 months, 24 patients had died. Crude response rate was 80.6%.	not reported	not reported
Mosleh et al. (2009), personal communication (2011)	Randomisation list was generated by statistician	List sent directly to CR secretary	CR staff, researcher and research advisors were blind to randomisation.	no information given	not reported	not reported
Parry et al. (2009)	Centrally controlled internet-based randomisation service	The research assistant was blinded to group assignment.	The assistant was blinded to group assignment. This took place during the data collection and assessment.	Intention to treat analysis; less than 10 % attrition in both groups (8% intervention; 4% control).	not reported	not reported

Table 2.5 continued

Study author	Sequence generation	Allocation concealment	Blinding	Attrition bias	Selective reporting bias	Other sources of bias
Wyer et al. (2001)	Numbered envelopes with intervention or control group information were assigned by random number assignment.	Only the research assistant knew the allocation. Patients received sealed letters with a random number assignment.	Only the research assistant knew the allocation; CP nurse was unaware of group assignment, all patients were handed an envelope containing either control or intervention group information.	not reported	not reported	There was no procedure in place that stopped the patients from telling nurses what was in the envelope.

## **2.4 Discussion**

The current chapter systematically reviewed the evidence on interventions encouraging the attendance at cardiac rehabilitation. Six RCTs were found, three more than in previous reviews, but only one of those RCTs addressed an under-represented group. To add knowledge systematically, all six papers were reviewed.

The trials employed patient-level interventions addressing patient behaviour through improved communication. The ‘liaison nurse trial’ was a combination of organisational changes and patient intervention, because patient records and communication links were created. (An overview of interventions that address patient participation in health services can be found in Chapter 3, which has the aim of finding further evidence of the strategies found by this systematic review). The following sections discuss peer support, professional support, invitation letters, under-represented groups and the use of health behaviour theory in the CR intervention context, and contextualizes these aspects within a broader perspective. In health care (research), theoretical, but also wider pragmatic considerations are of importance when assessing options for how best to improve access and use<sup>10</sup> of health services.

### **2.4.1 Peer support**

Cardiac rehabilitation programmes are often underfunded, and peers are commonly used to help encourage patients in the class. Two trials tested peer support interventions, but neither increased the number of patients enrolling in CR. In Carroll’s et al. trial an advanced practice nurse phoned or visited patients in addition to the peer support (Carroll, Rankin and Cooper, 2007). The trial had a relatively short assessment period but indicated increasing CR enrolment rates over time. For these older, unpartnered patients, initial recuperation periods may be longer, which would partly explains the results. Female and older cardiac patients often have lower functional abilities and higher co-morbidity rates (Benz Scott, Ben-Or and Allen, 2002) (Chapter 1).

Physical problems may be an additional barrier to access. The most common co-morbidities amongst UK attendees are hypertension (~45%), arthritis (~20%),

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<sup>10</sup> Access and use of services are defined in Chapter 3

diabetes (~20%) and asthma (~10%) (The National Audit of Cardiac Rehabilitation, 2010). These rates are much lower than the rates reported in the trial (perhaps due to more female participants). High co-morbidity rates may explain why older women are under-represented but also partly explain the trial result since professional support, which was deemed successful in two other trials, did not have an impact here. Carroll's et al. study was included in a review of peer phone calls that found evidence of the impact of peer support on some but not other health behaviour changes (Dale et al., 2008).

Parry's et al. sole peer support intervention found no effect either, despite apparent robust trial design and conduct (M. Parry et al., 2009). Noticeably low participation rates were recorded (12% control group; 25% intervention group).

Both studies had a variety of objectives, and peer supporters may have focused on behaviour change rather than CR attendance. The effect of peer support varies due to training, role and support given, causing different outcomes (Andrews et al., 2004). In addition, the interventions may have had different objectives, which made it hard to compare them (Newman, Steed and Mulligan, 2004). Lastly, health care in the United States and Canada is not free but it remains unknown how cost may have impacted on trial outcomes.

#### **2.4.2 Professional support**

While the combination of professional and peer support was deemed unsuccessful, as discussed above, in two trials, professionals alone supported the patients, and both resulted in increased uptake of CR (Hillebrand et al., 1995; Jolly et al., 1998).

Jolly et al. used a liaison nurse who coordinated patient transfer and motivated and supported the patients (Jolly et al., 1998). This trial did not support a specific patient group but was of good quality and increased uptake. It highlights the need for better communication between health care professionals and along the clinical pathway. In the UK automated referrals are typically not used, and the patient is not tracked along his or her care pathway. More research in this area and the consideration of automated referrals are suggested, although this is not a new debate. Grace et al. compared automated with non-automated referral methods, with the latter leading to more equitable access but not participation. This turns the focus to patient communication or wider barriers such as transport (Grace et al., 2012) (further discussion in Chapter 7).

The other trial used a social worker to encourage cardiac group attendance, which had a positive impact. Since the trial targeted blue-collar workers, an under-represented group, further aspects of the study will be discussed in Section 2.4.4 below.

It has been found that patient attendance can be predicted by physician support of CR (Jackson et al., 2005). Johnson et al. found that nurse recommendations increased the chances of CR attendance compared to physician recommendation, yet there is some evidence for selective referring (Johnson et al., 2010; Williams, Byles and Inder, 2010). Communicating the importance of CR to health professionals in the treatment pathway and explaining the goals and setup of CR to patients remains important (Section 2.4.5; the role of professional recommendations is further discussed in Chapter 7).

### **2.4.3 Invitation letters**

Letters were found to be a successful tool for motivating uptake of cardiac rehabilitation in two trials. Both studies were conducted in the UK and had a similar theoretical underpinning. The theory of planned behaviour (TPB) and the common-sense model of illness representation (CSM) were used to tailor the letters (both theories are described in Chapter 5)(Ajzen, 1991; Leventhal et al., 2012). Ten years passed between the trials; the more recent study had a larger sample size, more female participants, and included various ‘initiating events’.

Wyer et al. used an invitation letter based on the theory of planned behaviour operationalising subjective norm (perception of others’ beliefs), control beliefs and attitude. The latter was transformed into ‘research has shown that attendance can reduce the chances of dying from another heart attack’, which the authors felt to have the potential of inducing fear. While it is unclear what measures were used to control for fidelity and contamination, blinding and randomisation were addressed appropriately, but still suggesting a small risk of bias.

Mosleh et al. further developed the above-mentioned research and added the concepts of controllability and consequences from the CSM model (Mosleh, 2011). A separate paper about the design was published that made the development transparent (Mosleh, Kiger and Campbell, 2009). In addition, the bias assessment suggests good-quality trial conduct, albeit the attrition rate being unknown (Mosleh, S., 2011, personal communication).



While both trials were successful, neither explored nor commented upon the operationalisation of health behaviour theory (HBT) into writing. It remains unclear to what degree patients were involved in the design<sup>11</sup> of the letter. While HBT predicts and aids the understanding of behaviour, little is known about its use in intervention designs (as discussed in Chapter 5). Additionally, Wyer et al. compared the letter with no letter<sup>12</sup>, which first and foremost provides evidence regarding a written reminder and not the use of HBT. Furthermore, a second letter was sent only to ‘accepters’, but no separate outcome assessment of the two letters took place. All patients received an assessment and an invitation by a nurse making it hard to evaluate the evidence. Conversely, the other trial compared the theoretical letter with a ‘normal letter’ but since nothing is known about the original content, questions about the impact of health behaviour theory remain (discussed in Chapter 6).

Previous research found that (personalized) invitation letters, signed, for example, by the GP were effective in recruiting patients for screening (Jepson et al., 2000). Written material may have an impact when a personal component is present, in which case more elaborate cognitive processing takes place (Sohl and Moyer, 2007). Neither letter was signed by the GP. GPs are currently not involved in CR care in the UK, but from 2013, CR will be added to their payment plan, and QOFs are being debated (Doherty, P., 2012, NHS improvement team, personal communication). In addition, Noar’s et al. (2007) assessment of tailoring<sup>13</sup> found print magazines and newsletters to work better than letters or booklets. They suggested that this was due to additional graphics and pictures. The leaflet included with the letter in Mosleh’s et al. factorial design trial did not result in a statistically significant difference (Mosleh, Kiger and Campbell, 2009). Graphics were not mentioned (Mosleh, Kiger and Campbell, 2009).

It is self-evident that letters are low-cost and potentially easy to implement (be it with regard to a change in content or as a new invitation method). The advantages of using letters include that they are of low-cost and, with technology an easy

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<sup>11</sup> Mosleh et al. consulted expert patients but gave no details, and Wyer et al. had previously explored barriers to attendance in a qualitative piece with a phenomenological approach (Wyer et al., 2001a).

<sup>12</sup> A ‘thank you’ note was sent to all RCT participants.

<sup>13</sup> Tailoring refers to formulating a message after assessment of individual characteristics such as age, gender, health behaviour theory concepts (Sohl and Moyer, 2007).

distribution via the NACR, the possibility of reaching many patients, are highlighted here (Noar, Benac and Harris, 2007).

In light of under-represented groups, discussed next, the evidence from screening uptake suggests that reminders are less effective and direct contact strategies might be more appropriate for these populations (Bailey et al., 2005). Improved communication strategies are important, as will become clear in the next chapter, which looks at interventions encouraging patients to participate in other health services like cancer screening.

#### **2.4.4 Under-represented groups and non-attenders**

Only two trials targeted potentially under-represented patients. One study specifically recruited blue-collar workers in Germany (skilled and trained labourers under the age of 60) (Hillebrand et al., 1995). Usually, manual labour is classed as a lower socio-economic status, further discussed below (Gilbert, 2002). Although a statistically significant difference was found, the group sizes were under 100 patients and study quality was suboptimal. Furthermore, the paper explicitly stated that only patients with insurance coverage who had *already* undergone inpatient CR were included<sup>14</sup>. I.e., the support focused on reinforcement, not just on CR promotion. The intervention may be less relevant for promoting CR uptake, but it may be of interest in terms of long-term chronic disease self-management.

The same might be true for the study by Parry et al. (2009). The potential relevance of covering large geographic distances or reaching homebound patients was highlighted, even though no under-represented group was specifically targeted. In that respect, a review of telehealth concluded that this method was effective in terms of secondary prevention of CHD and even suggested its relevance in increasing the uptake of prevention programmes including cardiac rehabilitation (Neubeck et al., 2009). In UK practice, the heart manual is given to patients as a home CR guide, and many CRPs contact their patients once they have been discharged from hospital (see survey Chapter 4).

Only the trials from the US and Canada reported the socio-demographic characteristics of their samples. About half of Carroll's et al. participants fell into the

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<sup>14</sup> The paper was included here because two previous systematic reviews classified this trial as 'promoting uptake of CR'.

lowest income bracket (under US \$25,000 annual household income), 19% had less than high school education and 36% finished their education after completing high school (Carroll, Rankin and Cooper, 2007). Parry et al. reported similar figures. This information is not commented on but worth exploring with regards to the appropriateness, access and use of care (defined in Chapter 3). Income or educational level are often used as proxies to determine socio-economic status, which, in terms of explaining CR attendance may play a complex role amongst other predictive factors (as discussed in Chapter 1).

It is often suggested that CR non-attenders are from less well-resourced backgrounds. The percentage of cardiovascular disease in lower socio-economic groups tends to be higher, which one expects to mirror in the frequency of cardiac events, treatment and CR attendance (Mendes and Banerjee, 2010; Van Lenthe et al., 2002). In fact, Perelman et al. (2009) found an obvious social gradient in admission rates of hospitals with cardiac facilities in the US and Canada. Pell et al. (2000) had found deprivation to impact investigation and offer of cardiac surgery in Scotland (Pell et al., 2000; Perelman et al., 2009). This reverse treatment effect<sup>15</sup> does not appear to be mirrored in the populations recruited by either trial<sup>16</sup>. One explanation could be that trial participation meant free service, but no information is available. Alternatively, CR is usually fee-for-service in the US, which may have presented a barrier to access. After all, social gradients in cardiac treatments are a real issue (Adamson et al., 2003).

It remains unclear whether the samples are representative of the patient population or if socio-economic status or co-morbidities modify potential effects of peer support. The role of peer or lay supporters can vary, but assumptions about community membership are made (such as ethnic background or socio-economic status), and matching based on experience took place (Andrews et al., 2004). As discussed above, peer support may have had a limited effect because CR uptake was not the sole objective of the trials.

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<sup>15</sup> The *Inverse Care Law* describes the availability of care as inversely related to the need of the population (in Wales) (Hart, 1971).

<sup>16</sup> Mosleh et al (2013), June 2013, highlighted that their participants had a relatively high socioeconomic status.

Overall, little information on ethnic origin, gender or income precludes further discussion. Although two trials targeted under-represented groups (blue collar workers and older, single adults), there was limited information on specific patient groups or other methods (such as tailoring, other than after health behaviour theories, discussed in the following section).

#### **2.4.5 Health behaviour theory**

*Tailoring* can be based on various characteristics including ethnic background, age, barriers to access or theory (Sohl and Moyer, 2007). Four of the reviewed interventions were based on psychological or behavioural theory, including the theory of planned behaviour (TPB), the stage of change theory and the social cognition theory. Some evidence has been found for illness perception, the TPB and the CSM to predict CR attendance (French, Cooper and Weinman, 2006; Mosleh, Campbell and Kiger, 2009). Using behavioural theory may address some of the obstacles and facilitators of CR on the individual level, such as self-efficacy and perceived benefits of CR as well as normative beliefs and assumptions (Daly et al., 2002). This will be discussed further in Chapter 5.

All interventions contained a motivational element, which appears to be an easily applied technique in various settings. A recent review of qualitative studies found that many patients stated that they had been given little or no information from the hospital physician (M. Clark et al., 2012). On the one hand, this may suggest that currently, health care providers are failing to encourage their patients to partake in cardiac rehabilitation. On the other hand, it may be the result of limited resources (staff hours or capacity) that some CRPs experience (The National Audit of Cardiac Rehabilitation, 2011, 2012). The Quality Outcome Framework (QOF) targets to release patients from hospital as soon as possible, which may not allow the CR staff to visit the patient in time (Doherty, P., 2012, personal communication). Some patients may receive no personal/direct contact, as several CR programmes only send invitation letters (a strategy with less impact on under-represented groups, see Chapter 3 (Bailey et al., 2005)). Currently, QOF targets for CR are being debated (Great Britain. Department of Health. Cardiovascular Disease Team, 2013). Still, the importance of patient engagement is highlighted here.

#### **2.4.6 Limitations of the studies**

Limitations at study level include the fact that three out of six studies had a small sample size. The majority relied on self-reported outcomes. Except for two studies it remains unknown if piloting or some sort of process evaluation, user involvement or local adjustment took place. None of the studies commented on cost-effectiveness or financial implications. Time invested in developing and implementing the interventions was rarely reported.

Several of the interventions contained a combination of features that leave it unclear which components, or combination thereof, were effective (such as peer training). Conversely, several types of available interventions increased the patients' options, which potentially affected the study outcome. In addition, more recent studies have published information on trial design and intervention development, which increases transparency and reproducibility. Hence, the conclusions are limited due to the low number of studies evaluating each intervention, the different countries/health care systems, study quality and varying threat of bias.

#### **2.5 Limitations and strengths of my review**

Methodological advances result in comparable accounts and consistent quality assessments when systematic review techniques are applied, as was the case here. Due to the rigorous structure, however, there is a danger of losing some of the complexities in health care interventions.

A more elaborate discussion of the trials allowed for a better understanding of the challenges involved in evaluating these complex interventions. Additionally, intervention designs and under-represented groups were discussed in detail to highlight the importance of the latter. Systematic reviews are a transparent concise method of evaluating studies. However, especially when it comes to reviewing RCTs, the reductionist nature, in regards to, for example, in regards to study populations and the complexities of operationalising CR uptake interventions in diverse UK practice must be noted (further discussed below).

Due to differences in year of study, location and inclusion criteria it was not possible to judge whether study populations were representative of the general patient population here. It would be incorrect to weight the importance of each study.

Choosing a systematic approach to reviewing the literature allows for a concise way of using explicit methods such as bias assessments (when dealing with the growing amount of literature), which leads to a stronger evidence-base than a narrative review would offer.

## **2.6 Methodological considerations**

The Cochrane review methodology allows for a systematic and coherent account of a literature review under the quantitative research paradigm, which ‘objectively’ tests an assumption. This refers to effect sizes, which can be assessed via meta-analysis techniques. Since research is probabilistic when it tries to predict human behaviour or searches for causality, the distribution of the studies’ results may enhance understanding (Taveggia, 1974 as cited in C.M. Cooper, Patall and Lindsay, 2009). Generalisability of results in meta-analysis is proclaimed too, which fits with the post-positivist side of the theoretical stance (B N. Green, Johnson and Adams, 2006).

In this particular review, only randomised controlled trials (RCTs) were included, because this type of experiment can detect causality. RCTs are said to be the cornerstone of evidence-based medicine (The International Development Research Centre & Swiss Agency of Development and Cooperation, 2000). However, evidence-based medicine is not in all aspects patient-centred due to the disease-specific inclusion criterion (Jozien, 2000). Exclusion criteria are often extensive, and additional information about the participants is not of interest. The narrow focus can become a disadvantage, which was the case here. In cardiac rehabilitation, eligible patients tend to be older and hence experience multi-morbidity as well as having more complex heart conditions and ~50% do not just experience a ‘simple’ acute myocardial infarct (The National Audit of Cardiac Rehabilitation, 2012). Age and co-morbidities are the most frequently used exclusions criteria, which results in an the elimination of people who would typically make up a large proportion of the patient population. A threat to external validity arises (Mckee et al., 1998).

Considering the review studies, only one of the six studies looked at older adults. Tensions arise between patient-centred approaches and trial methodology (such as *a priori* randomisation, inclusion and exclusion criteria, and attrition rate).

Trial methods are not concerned with patient characteristics, which often permits the exploration of diversity in trial samples. Randomised controlled trials usually consent patients individually. As a consequence of only including trials in my systematic

review, the danger of focusing on patients who are not representative of the patient population and the exclusion of hard-to-reach groups need to be noted. Potentially under-represented patient groups were discussed (Chapter 1), and although no clear evidence exist, the decision was made to look for trials that targeted, or were tailored to, groups less likely to attend, with the aim of gaining specific information in response to the actual target population. It is known that ‘retired’ and ‘elderly’ people are two characteristics found in over 50% of people referred to CR (The National Audit of Cardiac Rehabilitation, 2010). Studies are often designed in response to local circumstances, and even though, CR services in the UK differ greatly (Chapter 4, 6 & 7), results could be transferrable to some, albeit not all other sites.

Furthermore, an RCT-based approach is reductionist, as it does not explain why something does or does not work. It also relates to the point that trials or systematic reviews of trials target practitioners’ ways of evidence extraction and interpretation (Jozien, 2000). Patients’ experiences and shared decision-making are not considered. A relevant example would be peer support; here the recognition of reductionism has an impact, in that, it is only possible to speculate why health care professional support resulted in greater enrolment rates in CR, but health care professionals support, in combination with peer support did not.

More recent developments in research include practitioner effects, patient preference, pragmatic trials or the nesting of a qualitative study in trying to gain a better understanding of trial materials and results. However, the political climate influencing the research and clinical practice is still not taken into account. Note that there are no developments in systematic review methods to account for these recent advancements.

## **2.7 Conclusion**

The review found very few trials that evaluated interventions promoting the uptake of cardiac rehabilitation. As a consequence of dissimilarities in terms of patient characteristics, interventions tested and country of origin the comparability across studies as well as the applicability of each intervention to other settings is limited, and few conclusions can be drawn. The key findings are highlighted in Box 2.2.

- Only six eligible trials were found which assessed the impact of motivational letters, peer support, and peer support in combination with nurse support, a social worker and a liaison nurse.
- The effect of peer support is unclear yet worth exploring in more detail
- Support by additional health staff appears promising
- Lack of evidence on under-represented patient groups in cardiac rehabilitation
- Motivational letters appear to be a simple and low-risk intervention

### **Box 2.2: Key findings of the systematic review**

All trials tested patient-level interventions addressing behaviour and one combined this with a system-related component (liaison staff). Improving attendance remains challenging since some organisational or personal barriers will remain non-modifiable (Chapter 7).

Whilst organisational changes or interventions are important in terms of altering health behaviour and address access to and appropriateness of care, the lack of resources unfortunately makes such changes not a viable option for a doctoral thesis. However, invitation letters were found to be effective, low-cost and low-risk, and easy to implement and hence could be a feasible option to explore further (accessibility<sup>17</sup> assumed).

Due to the limited evidence from the cardiac rehabilitation literature review, it would be resource-efficient to look across other health areas for further supporting evidence on interventions designed to increase the participation in care services<sup>18</sup>. As common ideas underpin such designs - for example, the aforementioned health behaviour theory - it is worth inquiring, *what are the strategies and interventions used to encourage more patients to participate in other health services?*

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<sup>17</sup> Access to care is further defined in Chapter 3

<sup>18</sup> Cardiac rehabilitation and CHD are separate from chronic disease management in terms of terminology and health policy.



## Chapter 3

### Strategies and interventions used to encourage patients to participate in health services<sup>19</sup>

The benefits of CR have been well established, yet only a limited number of interventions have been published that aim at increasing low attendance rates, as seen in the previous chapter. This chapter presents a review of interventions encouraging cancer screening, self-management programme participation and service access to answer research aim 3) *strategies and interventions used to encourage more patients to participate in health services*. The areas were chosen because with preventive care having become more important due to diminishing resources in health and an aging population, attention has been paid in the last decade to increasing uptake. Cancer screening rates have already risen, for example, and it is of interest how this was achieved.

While the chosen areas differ from cardiac rehabilitation, the vaster literature offers thematic ideas relevant to the research questions. For example, peer support is common in various health care areas<sup>20</sup>, and health behaviour theories are increasingly utilised to design interventions and influence outcomes (Dennis, 2003; Michie et al., 2008). This review further supports the evidence on interventions in cardiac rehabilitation (Chapter 2) and widens the perspective to other strategies that increase participation in health services not (yet) used in CR. In this way, more evidence-based options than were found by the systematic review can be considered, which assists with the development of an intervention in cardiac rehabilitation.

Given the time and resources available it was impractical to review primary research. Instead exploratory reading guided the identification of the above-mentioned health services and led to a narrative overview of reviews.

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<sup>19</sup> Dressler et al., 2012

<sup>20</sup> Peer support does not originate in a specific school of thought (Carr et al., 2011).

### **3.1 Background**

The World Health Organisation predicts chronic illnesses to be the leading cause of death by 2020 (World Health Organization, 2011). In response to increasing rates of cancer, cardiopulmonary diseases and diabetes, an aging population and diminishing resources in health care, measures such as screening or disease self-management are heavily advocated (World Health Organization, 2011). Such measures avert premature mortality and morbidity through early detection and reduce the burden of disease. Some of these preventive or rehabilitation services experience similar issues with access and uptake, hence interventions to increase patient participation are being developed (Jepson et al., 2000).

Jepson et al. (2000) reviewed interventions to increase screening and revealed that, among other things, telephone calls and invitation letters were successful. These interventions are similar to the ones discovered in cardiac rehabilitation (Chapter 2). Therefore, other strategies used to encourage the uptake of screening might be relevant and of interest here. After all, invitation to breast cancer screening and screening rates themselves have increased by 40-50% in the past decade; mammography and cervical screening rates in England have risen to 75% and 78%, respectively, similar to US insured population groups (Ross, Bradley and Busch, 2006; The National Health Service Information Centre Public Health Indicators and Population Statistics Team, 2010; The National Health Service Information Centre Workforce and Facilities, 2010).

Ross and colleagues found in their large US representative cross-sectional study that not being insured predicts less access to cancer screening and to services for diabetes care in lower- and higher-income populations (Ross, Bradley and Busch, 2006).

They suggest that uninsured adults may not believe in or understand the value of preventive and chronic care (Ross, Bradley and Busch, 2006). Alternatively, the inability to pay for health care is a strong predictor for non-access (Hall et al., 2008).

Concerns exist that those of a lower socio-economic status are not being reached,

along with concerns about increasing health inequalities<sup>21</sup> (Gately and Rogers, 2010; Jordan and Osborne, 2007; Thoolen et al., 2007; Warsi et al., 2004).

Preventive and specialist services have user rates that are positively related to income (Dixon et al., 2007; Van Doorslaer et al., 2000). For some population groups, preventive health care may not be a priority. The use of health care may differ between those with equal access and equal need due to preference but, as Oliver and Mossialos (2004) state, a lack of skills or information are not acceptable reasons for differential use (Oliver and Mossialos, 2004). How to engage harder-to-reach groups<sup>22</sup> leads to a debate about access to care. Access to care is defined as “whether those who need care get into the system” (Aday and Andersen, 1974, p.218), a definition focusing on the systems side.

In the UK, cervical and bowel cancer screening rates are lower in Asian groups even where socio-economic and demographic characteristics are controlled for, but since screening services are free of charge this may be a matter of use (Szczepura, Price and Gumber, 2008). For example, doubts about the acceptability of the procedure involved may deter certain patients. The context, such as costs, illness experiences, tolerability of the nature of treatment, normative beliefs, real or perceived consequences of the care services, influences uptake (Conrad and Barker, 2010; Jepson et al., 2000). Lastly, it is worth noting that the appropriateness of a care service is rarely discussed and neither is patient choice (Chapter 7).

Despite their effectiveness, various health services have experienced issues with access and use (A D. Beswick et al., 2004; Jepson et al., 2000). These services may involve different behaviour, procedures and consequences as compared to cardiac rehabilitation, yet commonalities in motivating self-care behaviour exist (Rothman and Salovey, 1997). For example, due to the basic similarities of CR and self-management programmes (outpatient courses targeting lifestyle and medication management), it is helpful to explore how patients were encouraged to participate in

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<sup>21</sup> *Health inequality* describes the variation in health between different socio-economic groups (Graham, 2007).

<sup>22</sup> *Hard- to-reach* is a term for a heterogeneous groups of patients, differing, for example, in diagnosis or sex, and at each point of contact with the health care system (Kalathil, n.d.). Generally, it is also said that there are no hard-to-reach groups, but only insufficient services. The term hard-to-reach groups, commencing from social marketing, refers to groups in certain institutional-based service who are seen to be inaccessible via traditional methods (Brackertz et al., 2005; Kalathil, n.d.).

self-management programmes (Barlow, Turner and Gilchrist, 2009). In diabetes self-management, as in CR, about 30% of non-participants state a ‘lack of interest’ (The National Audit of Cardiac Rehabilitation, 2010; Thoolen et al., 2007). In addition, reasons for non-participation such as logistic concerns or lack of time appear to be common across health issues (Elzen et al., 2008; The National Audit of Cardiac Rehabilitation, 2010; Thoolen et al., 2007).

Mechanisms underlying interventions may be the same, and perhaps emerging schemas shed further light on the issue of how to encourage participation (Pawson, 2006). Informal theories and more intuitive ways of how to encourage participation may be similar across conditions; for example, peer support is widely used in health care to influence outcomes (Dennis, 2003). Likewise, generic health behaviour theories are increasingly used to explain behaviour and to guide the design of interventions (Michie et al., 2008). The evidence from the CR literature was scarce (Chapter 2). Two trials included in the systematic review (Chapter 2) used health behaviour theory-based invitation letters to encourage CR uptake. Letters are generally used as invitations to cancer screening too. Despite being behaviour-focused interventions, they are of low cost and low risk, an opportunity in a system with scarce resources.

The question is whether exploring interventions to increase uptake across health care disciplines will reveal patterns. If so, is this information valuable for the development of interventions and specifically in light of this thesis’ question, *‘What strategy would improve uptake of CR in patients who have been invited?’*

### **3.1.1 Objectives**

The overall aim was to look for further evidence supporting the three strategies found by the systematic review and to look for additional, new interventions that have not been tested in cardiac rehabilitation. Those may originate from other health care services that experience similar problems with access and use. The two specific objectives were to:

- Explore the literature on interventions used in other health care areas that address, 1) participation in self-management programmes, 2) partaking in cancer screening, and 3) service uptake/access.
- Provide insight into evidence on intervention designs that target specific under-represented/non-attending groups.

## 3.2 Methods

A cross-disciplinary narrative overview of reviews on interventions promoting health services was conducted. It was appropriate to assess reviews rather than single studies considering the limited time frame and the purpose of this Chapter to explore other interventions and additional evidence. With the rise of evidence-based medicine the wealth of reviews available can be overwhelming which supports the conduct of overviews of reviews (Smith et al., 2011).

In contrast to the previous chapter, this is a narrative review discussing the broader issues of interventions published to date, specifically in regards to their relevance for cardiac rehabilitation (Section 3.4.2). The methodologies used by the included studies were not evaluated. Nevertheless, a planned approach to literature reviewing was applied, which increased transparency and credibility (strength & limitations, Section 3.6).

### 3.2.1 Definitions

A number of terms have been defined to focus the search. The meaning of the words *intervention*, *uptake* and *under-represented* groups differ depending on the context.

*Intervention* is defined as ‘any type of treatment, preventive care, or test that a person could take or undergo to improve health or to help with a particular problem’ (Agency of Healthcare Research and Quality, n.y.). For example, when patients have already accessed a health care service, they become subject to a health care intervention designed to modify their current health condition. These interventions have multiple outcomes including health care utilisation, which is mainly the changed need for health care in response to the intervention. The current review focuses solely on interventions that promote uptake (often placed in the care pathway). The patient accesses a new service due to an event or a diagnosis, for example pulmonary rehabilitation, or interventions that promote uptake of an entirely new health care service, such as vaccinations. It is noteworthy that reviews often group studies according to health problem or uptake mechanism, which makes it challenging to judge the efficacy/effectiveness of interventions, as will become clear later.

For the purpose of this scoping review, I define *uptake* as having been invited to a health care service followed by (self-) reported participation. This stands in contrast

to opportunistic partaking, where the invitation to the health care intervention occurs in the setting in which the intervention is immediately available.

Referring to the discussion above (and as examined in Chapter 1), *under-represented groups* is used here as an umbrella term for groups that use or access a service less than expected based on need and eligibility (Oliver and Mossialos, 2004). Depending on the health care area, this may include patients with lower socio-economic status or education, different ethnic backgrounds, or older age.

### **3.2.2 Search strategy**

Consultation with a number of health services researchers identified areas facing similar challenges to cardiac rehabilitation. The areas suggested include 1) self-management, 2) cancer screening programmes and 3) service uptake. Three different search strategies were used to look for reviews on interventions to increase uptake: 1) Cochrane, DARE/HTA and EMBASE were searched for reviews on interventions to increase the participation in self-management programmes

1. self care/ or self administration/ or self medication/
2. (selftreat\$ or self treat\$).ti,ab.
3. (selfmanag\$ or self manage\$).ti,ab.
4. (self care or selfcare).ti,ab.
5. (self help or selfhelp).ti,ab.
6. (selfdeterminat\$ or self determinat\$).ti,ab.
7. (selfcure or self cure).ti,ab.
8. (selfremed\$ or self remed\$).ti,ab.
9. (self administ\* or selfadminist\* or self medicat\* or selfmedicat\*).ti,ab.
10. Self-Help Groups/
11. exp Health Program/
12. exp Self Care/
13. exp secondary prevention/
14. exp rehabilitation/
15. (secondary adj2 prevent\*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer]
16. (((rehab\$ or recover\* or after) adj1 care) or Aftercare or convalescen\$ or recuperat\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer]
17. (self adj3 (manage\* or care or motivate\*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer]
18. or/1-17
19. (uptake or attend\$ or accept\$ or particip\$).ti,ab.
20. (compliance or complie\$ or comply\$).ti,ab.
21. encourag\$.ti,ab.
22. (respon\$ or non-respon\$).ti,ab.
23. (takeup\$ or promot\$ or utilisation or utilisation).ti,ab.
24. (attitude\$ or self select\$).ti,ab.
25. (poor attend\$ or non-attend\$).ti,ab.
26. Patient Compliance/
27. "Patient Acceptance of Health Care"/
28. Motivation/
29. or/19-28
30. exp Meta Analysis/
31. ((meta adj analy\$) or metaanalys\$).tw.
32. (systematic adj (review\$1 or overview\$1)).tw.
33. or/30-32
34. cancerlit.ab.
35. cochrane.ab.
36. embase.ab.
37. (psychlit or psyclit).ab.
38. (psychinfo or psycinfo).ab.
39. (cinahl or cinhal).ab.
40. science citation index.ab.
41. bids.ab.
42. or/34-41
43. reference lists.ab.
44. bibliograph\$.ab.

45. hand-search\$.ab.
46. manual search\$.ab.
47. relevant journals.ab.
48. or/43-47
49. data extraction.ab.
50. selection criteria.ab.
51. 49 or 50
52. review.pt.
53. 51 and 52
54. letter.pt.
55. editorial.pt.
56. animal/
57. human/
58. 56 not (56 and 57)
59. or/54-55,58
60. 33 or 42 or 48 or 53
61. 60 not 59
62. 18 and 29 and 61
63. exp pulmonary rehabilitation/
64. chronic obstructive lung disease/rh [Rehabilitation]
65. 63 or 64
66. 62 and 65
67. exp ARTHRITIS/dm, pc, rh, th [Disease Management, Prevention, Rehabilitation, Therapy]
68. 62 and 67
69. exp OSTEOARTHRITIS/dm, pc, rh, th [Disease Management, Prevention, Rehabilitation, Therapy]
70. 62 and 69
71. exp chronic disease/dm, pc, rh, th [Disease Management, Prevention, Rehabilitation, Therapy]
72. 62 and 71

### **Box 3.1: EMBASE search strategy for self- management**

1) The Cochrane Library and DARE/HTA were searched for reviews on interventions to increase screening uptake (Box 3.2), and EMBASE was searched for reviews on interventions to increase screening uptake in under-represented populations to widen the search (Box. 3.3)

1. exp primary prevention
2. exp secondary prevention
3. exp screening
4. screen\* NEAR /5 program\*
5. test\* NEAR/5 program\*
6. primary NEAR/3 program\*



7. secondary NEAR/3 program\*
8. exp population surveillance
9. 1-8/OR
- 10.(compliance or complie\* or comply\*) NEAR/5 (test\* or screen\*)ti,ab,kw
- 11.(poor attend\*) NEAR/5 (test\* or screen\*):ti,ab,kw
- 12.(non compli\* or non attend\*) NEAR/5 (test\* or screen\*):ti,ab,kw
13. (improv\* NEAR/5 uptak\*):ti,ab,kw
14. (improv\* NEAR/5 non-attend\*):ti,ab,kw
- 15.((interven\*) NEAR/5 (uptak\* or attend\* or accept\* or participat\* or comply\* or compli\* or promot\*)):ti,ab,kw
16. (promot\* NEAR/5 (test\* or screen\*)):ti,ab,kw
- 17.(intervention NEAR/5 (attend\* or accept\* or paticipat\* or comply\* or compli\*)):ti,ab,kw
- 18.(uptak\* or attend\* or accept\* or participat\*) NEAR/5 (test\* or screen\*):ti,ab,kw
19. 10-18/OR

### Box 3.2: DARE/HTA search

1. exp primary prevention/
2. exp secondary prevention/
3. exp SCREENING/
4. ((screen\$ or test\$) adj5 programm?).ti,ab.
5. ((primary or secondary) adj3 programm?).ti,ab.
6. exp population surveillance/
7. or/1-6
8. ((uptake or attend\$ or accept or particip\$ or intervention?) adj5 (screen\$ or test\$)).ti,ab.
9. ((compliance or complie\$ or comply\$) adj5 (screen\$ or test\$)).ti,ab.
10. (improv\$ adj5 (uptake or nonattend\$)).ti,ab.
11. ((poor attend\$ or non-attend\$) adj5 (screen\$ or test\$)).ti,ab.
12. ((take up or promot\$ or utilisation or utilisation or us\$) adj5 (screen\$ or test\$)).ti,ab.
13. or/8-12
14. exp review/
15. (literature adj3 review\$).ti,ab.
16. exp meta analysis/
17. exp "Systematic Review"/
18. or/14-17
19. (medline or medlars or embase or pubmed or cinahl or amed or psychlit or psychlit or psychinfo or psycinfo or scisearch or cochrane).ti,ab.
20. RETRACTED ARTICLE/
21. 19 or 20
22. 18 and 21
23. (systematic\$ adj2 (review\$ or overview)).ti,ab.
24. (meta?anal\$ or meta anal\$ or meta-anal\$ or metaanal\$ or metanal\$).ti,ab.
25. 22 or 23 or 24

26. 7 and 13 and 25
27. exp Minority Groups/
28. exp Ethnic Groups/
29. exp Refugees/
30. exp Cultural characteristics/
31. ((underserve\$ or disadvantage\$) adj6 (group\$ or population\$)).tw.
32. ethnic\$.tw.
33. (migrant\$ or immigrant\$).tw.
34. refugees.tw.
35. ((hard to reach or depriv\$ or disadvantage\$ or Under?represented or under-represented or under?served or underserved or low income or poor or low\$ socio?economic? or low socio economic or low\$ socio demographic\$ or low socio?demographic or inequal\$ or inequit\$) adj3 (status or group? or population? or position or disparity or area or region or place?)).ti,ab.
36. ((Gender adj difference) or (female adj patient?) or wom?n).ti,ab.
37. ((Old or elder\$ or homeless or traveler) adj patient?).tw.
38. aged/
39. exp sex difference/
40. age/
41. exp POVERTY/
42. INCOME/
43. social class/
44. ((ethnic or minority) adj3 group\*).tw.
45. SOCIO-ECONOMICS/
46. exp CO-MORBIDITY/
47. (comorbid\* or co-morbid\*).ti,ab.
48. exp homelessness/
49. or/27-48
50. 26 and 49
51. 50 and 2000:2011.(sa\_year).

### Box 3.3: Screening search in EMBASE

- 1) The Cochrane Library and DARE/HTA were searched for ‘service access’ literature reviews (Box 3.4).

1. promot\* NEAR/3( attend\* or enrol\* or uptak\*):ti,ab,kw.
2. increas\* NEAR/3(access\* or enrol\* or attend\* or uptak\* or recruit\* or participat\* or utili\* or initiat\*)
3. exp Health Services Accessibility
4. exp "Patient Acceptance of Health Care"/
5. or/1-4

### Box 3.4: Service uptake search in Cochrane Library

### **3.2.3 Databases**

The Centre of Reviews and Dissemination's (CRD) database DARE is regularly updated, covering EMBASE, MEDLINE, ASSIA, Health Technology Assessments (HTA), Psycinfo, and the Social Science Citation Index as well as a variety of grey literature (Centre for Reviews and Dissemination, n.y.). Cochrane reviews assess healthcare and health policy. EMBASE covers all Medline content and conference proceedings, has a broad scope and is commonly used for systematic reviews (Embase, 2012). In addition, reference lists of included papers were scanned to avoid missing key reviews (Smith et al., 2011).

### **3.2.4 Review eligibility: inclusion and exclusion criteria**

The inclusion criteria were review papers published in English and after January 2000. Using the PICOS criteria (Smith et al., 2011), the population was limited to adults, the intervention was any intervention promoting service uptake, the outcome was service use or access depending on intervention target, and eligible study designs were reviews and systematic reviews only.

Two exclusion criteria were developed, namely workplace interventions, because these may exclude harder-to-reach or under-represented populations and health care professionals. HCP may have a different understanding of health, illness and access to health care.

### **3.2.5 Data extraction and data analysis**

The author scanned titles and abstracts against the inclusion and exclusion criteria. When reviews matched the criteria, data on review topic, interventions assessed, number of papers included and the review authors' conclusion was extracted. The results were summarised in a qualitative fashion for each literature search separately followed by a synthesis of interventions across topic areas. Quantitative analysis was not appropriate.

## **3.3 Results**

The following sections present the results separately for each search, starting with self-management programmes and followed by screening and service access. Then additional findings of reviews by type of interventions as well as an overview, that synthesising all types of interventions identified are presented.

### **3.3.1 Uptake and self-management programmes**

The search produced 2488 results. All titles were screened, of which 62 abstracts were assessed. Two full papers were read that included studies assessing health care utilisation. However, attendance or uptake of self-management programmes were not assessed. No reviews on interventions to increase uptake of self-management programmes could be found.

### **3.3.2 Screening**

The screening search found 552 titles (287 EMBASE, 25 Cochrane Reviews, 65 CRD - HTA and 175 DARE). A total of 49 abstracts were scanned, leaving 15 systematic reviews on interventions to increase the uptake of screening (one on screening and immunisations). One review was found through reference lists. Six reviews focused on under-represented populations, which are discussed in the following section. Ten other reviews did not focus on a specific population and are discussed thereafter.

#### *3.3.2.1 Under-represented groups*

Six reviews focused on under-represented groups, namely low-income, black/ethnic minority, Latina, and 'traditionally under-represented'. Table 3.1 provides an overview of each review's scope, aim, number of studies included, interventions assessed and the authors conclusion. The interventions as described in the original papers are listed: two papers applied meta-analysis techniques, hence number of studies and reported effect size are stated. Five papers provided qualitative descriptions, hence number of studies finding a statistically significant impact (a) versus total number of studies assessing this intervention (b) is provided (in the following format: (a/b+)). The overlap of included studies was assessed to avoid an overstatement of intervention effects.

Five reviews found that access-enhancing interventions (such as free screening, logistical assistance, vouchers) were successful in promoting screening in under-represented groups (Bailey et al., 2005; Corcoran, Dattalo and Crowley, 2010; Han et al., 2009; Legler et al., 2002; Masi, Blackman and Peek, 2007). Note that the majority of studies (six) included in the Corcoran et al. (2010) meta-analysis had been reviewed by Legler et al. (Legler et al., 2002). The meta-analysis, which found a small effect overall, also concluded that free services increased mammography uptake the most (Corcoran, Dattalo and Crowley, 2010). Han's et al. (2009) meta-

analysis found access-enhancing interventions to have the most, and individually directed interventions<sup>23</sup> to have the second-most impact.

Bailey et al. (2005) claim to extend the Legler et al. (2002) review (11 studies overlap), focusing on RCTs only. Legler et al. (2002) previously suggested that access-enhancing interventions combined with individually directed interventions might have the highest impact on mammography screening though individually directed intervention alone also encourage screening.

Bailey and colleagues (2005) found peer educators to have an impact on mammography screening, but they remarked that a combination of different interventions might be most effective. Furthermore, Bailey et al. (2005), Kupets et al. (2001), and Masi et al. (2007) found patient reminders to have no impact on screening in under-represented groups (there was an overlap of six studies). Conversely, Kupets et al. (2001) discovered a combination of physician and patient reminders to increase cervical and breast cancer screening; however, they only assessed strategies to be used by primary care physicians. Furthermore, provider – targeted interventions and physician reminders also have an impact on under-represented populations (Kupets and Covens, 2001; Masi, Blackman and Peek, 2007).

Studies incorporating peers were found to be effective more often than those who do not (Bailey et al., 2005). Thus, Han's et al. (2009) meta-analysis only found a small effect.

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<sup>23</sup> see table 3.5

**Table 3.1: Reviews on interventions to increase screening in under-represented groups**

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Bailey et al. (2005)	Mammography Medline Cochrane, Cancerlit, ISI WoS; English 1980-2003	To examine effectiveness of community-based educational interventions to increase mammography screening in low-income women	24 (23 RCTs & 1 cohort with control)	was addressed and described	<p>1) mobile unit/van 3/3+; cost voucher 3/3+; 3 of those also used peer educators all +; home visit 3/4 +)</p> <p>2) community education alone (0/1 +)</p> <p>3) referral &amp; education (1/1 +)</p> <p>4) multi-strategy 4/5 + (letter call &amp; visit peer 1/1 +, education &amp; appointment &amp; reminder &amp; cost 0/1; 1 x community screen &amp; appointment (+) vs. media (-); 1 x prof. education &amp; reminder (+) vs community participation (-); counselling (+) vs card (-) 1/1+; pamphlet &amp; call 1/1+)</p> <p>5) phone calls (1/2 +)</p> <p>6) video &amp; print (1 study tried 4 types of messages; all+)</p> <p>7) print (2/5 +)</p> <p>8) overall, 8 studies used peer lead (7/8+); other 16 did not use peers (5/16+)</p>	<p>- Most effective studies use peer educators as primary strategy to encourage screening in low-income women</p> <p>- logistical &amp; financial assistance promoted screening</p> <p>- multi-faceted interventions might be successful because women were exposed to the message more often</p> <p>- letters and phone reminders were not effective, but meta-analysis of interventions to increase screening for all women found different results (Bonfill et al. 2001; Table 3.2);</p> <p>- this review extends Legler et al (2002)</p> <p>- the findings mirror barriers to access in low-income women</p>

Table 3.1 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Kupets et al. (2001)	Cervical and breast cancer screening	To assess strategies for implementing breast and cervical cancer screening and determine their effectiveness by primary care physicians	14 RCTs	not explicitly mentioned	3 categories (note, single studies included in multiple categories where appropriate) 1) physician-based (including reminder, audit, feedback, information sheets) - computer-generated reminders for cervical screening (3/6+); breast cancer screening (4/6+); breast exam (2/3+) - audit & feedback for breast screening and mammography (3/3+), by 10-30% (cervical) and 5-23% (breast) - feedback & reminders (0/1+) - information sheet in chart (0/1+) - manual reminder in chart/flow chart: (1/2+) 2) patient-based strategies - mailed reminders (1/4+) - touch screen (0/1+) 3) combination of physician & patient strategies - physician & patient reminder cards (4/4+)	- computer-generated reminders improved delivery of preventive health care service; cervical screening, mammography and breast examinations improved - patient interventions: increase by 10% cervical and breast screening - physician alone: cervical 9-40%, breast 6-35% - patient & physician: increase by 10-30% (cervical) and 5-23% (breast) - highest success rate in physician reminders - authors suggest highest response rate where letters used (but evidence not clear) - suggestion that patient and physician reminders may have additive effect - dominant reason for non-occurrence in primary practice are physician barriers

Table 3.1 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Legler et al. (2002)	Mammography Medline, EMBASE, Psycinfo, 1984-1997	Which types of mammography-enhancing interventions are most effective for groups of women with historically lower use of mammography	38 (quasi-experimental)	not known	<p>1) Interventions<sup>999</sup> (number of studies; reported OR [95% CI])</p> <p>a) individually directed (health care): 15; 2.5 (1.9,3.4)</p> <p>individually directed (community):13; 1.3[1.0,1.6]</p> <p>b) access- enhancing: 14; 2.3 [1.7,3.1]</p> <p>c)social network: 7; 1.4[1.0,2.0]</p> <p>d)community education: 14; 1.5[1.2,1.9]</p> <p>e) media: 6; 1.3 [1.0-1.8]</p> <p>2) Regression Model</p> <p>- final model only indicated 'access-enhancing' as significant (9%, <math>p = .019</math>)</p> <p>- access-enhancing coupled with individually directed also significant (2.5, 16.7%; 0.8, 14.6%, respectively)</p> <p>3) sensitivity analysis: (no of studies; OR [95% CI])</p> <p>- access-enhancing greatest impact on mammography use, multiple types of interventions used; most included some form of personal contact 14; 18.9% [10.4,27.4]</p> <p>- impact of individually directed interventions in health care was nearly same as access-enhancing strategies: 15; 17.6% [11.6,24]</p> <p>- individually directed community:</p>	<p>- strongest effect in access-enhancing, second strongest in individually directed interventions in health care settings</p> <p>- strong effect when access-enhancing and individually directed are combined, also the combination of access-enhancing and system-directed (small number of studies)</p> <p>-authors' findings support an ecological perspective</p> <p>- strongest interventions targeted access-enhancing (structural, financial, geographic) issues and inter/intrapersonal barriers</p> <p>- access-enhancing (going to the patient (van), appointments that day, vouchers and cues to action increasing exposure to the message, increasing support and opportunities to be screened</p> <p>- multiple strategies appear to</p>



Review	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Legler et al. continued	<p>13; 6.8% [1.8,11,8]</p> <ul style="list-style-type: none"> <li>- community educational: 13; 9.7%</li> <li>- social network: 7; 5.8%</li> <li>- media: 6; 5.9%</li> <li>- all but social network showed estimated significant effect</li> </ul> <p>4) other characteristics ((no. of studies): intervention effect (CI))</p> <ul style="list-style-type: none"> <li>- single intervention group: 29</li> <li>- older women (6); subgroup of older women (5): 11; 7.9% [10.5-25.4]</li> <li>- assessment of low income: 26; 12.7% [7.3,18.2]; only low-income participants (2)</li> <li>- &gt;40% women of colour: 24; 12% [6.7,17.4]</li> <li>- rural area (7)</li> <li>- Health Belief Model (13) and social learning theory (9); no theory (14)</li> <li>- majority used multiple strategy</li> <li>- note that control group rates increased with time</li> </ul>	<p>have more impact than single strategies for mammography uptake</p> <ul style="list-style-type: none"> <li>- individual-directed interventions in health care settings (health care professional recommendation) have a huge motivating effect</li> <li>- individual-directed strategies, e.g.: phone, letter, reminder, voucher/coupon, facilitators or lay advisor: cues facilitate mammography screening</li> <li>- authors suggest that 'hard-to-reach' populations are actually not addressed in appropriate ways that encourage screening</li> <li>- authors discuss previous reviews: Wagner et al. found tailored reminders to be more effective than generic ones (<math>OR = 1/48, p &lt; .001</math>) and Yabroff &amp; Mandelblatt had similar results but labelled categories differently (see Table 3.2)</li> <li>- in conclusion: this analysis shows that interventions can have an impact on uptake of mammography screening in harder-to-reach populations; access-enhancing interventions are recommended as an addition to individual interventions</li> </ul>

Table 3.1 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Masi et al. (2007).	Breast cancer Cochrane, Medline Cinal, 1986-2005, English, US	Review regarding health care organisation-based interventions to improve breast cancer screening, diagnosis and treatment in racial and ethnic minority women	42 RCT (36 breast cancer screening on follow-up, 2 focused on treatment looked at survivorship)	quality score 0-27	<p>1) Patient-only interventions (14): primary intervention types were reminder-based, culturally-tailored, multi-faceted,</p> <ul style="list-style-type: none"> <li>- reminder-based: letter or phone call related to SES/demographics but otherwise only in combination (2/2+ in white but 0/3+ in minority groups)</li> <li>- culturally tailored: nurse w/ cultural training (1/1+), video(1/1+), class room instructions (2/2+), educational video &amp; small group (1/1+)</li> <li>- multi-faceted interventions: logistic/financial barriers (4/8+)</li> </ul> <p>2) Patient and provider interventions (18)</p> <p>2.1) mammography</p> <ul style="list-style-type: none"> <li>- provider intervention more successful than patient intervention (6/7+);</li> <li>- chart-based reminders for provider more effective than patient reminders (3/3+)</li> <li>- combined provider &amp; patient reminder (+) versus patient reminder alone (-)</li> <li>- provider and patient intervention versus</li> </ul>	<ul style="list-style-type: none"> <li>- suggestions that letters and phone counselling does not effectively address women from lower SES/ education backgrounds, connection to SES/background of target population</li> <li>- authors suggest access-enhancing to have more impact than reminders,</li> <li>- interventions largely effective but more so in white, educated women</li> <li>- population-based screening rates are higher than rates in trials, often percentage of uninsured women in trials is higher than in the general population</li> <li>- various strategies used including letters, phone calls, cost and transport, videos etc</li> </ul>

Table 3.1 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Masi et al. (2007) continued	<ul style="list-style-type: none"> <li>usual care (6/unclear+)</li> <li>(of those 3 not effective in minority women)</li> <li>2.2) breast exam               <ul style="list-style-type: none"> <li>- (2/4+) of the above studies</li> </ul> </li> <li>3) Provider-only interventions (3/4+)               <ul style="list-style-type: none"> <li>3.1) mammography                   <ul style="list-style-type: none"> <li>- chart reminder, flow, admin assistance increase (3/3+)</li> </ul> </li> <li>3.2) breast exam                   <ul style="list-style-type: none"> <li>- chart reminder (0/1+)</li> </ul> </li> </ul> </li> </ul> <p>[interventions to expedite testing &amp; improve treatment were omitted here due to the research aim]</p>	<ul style="list-style-type: none"> <li>- reminders were less successful in low-education populations and those with no history of mammography</li> <li>- financial and logistic interventions increased mammography screening in diverse populations</li> <li>- provider-targeted interventions in low-income populations had greater impact than patient target</li> </ul>

Table 3.1 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Han et al. (2009)	Mammography CINAHL, EMBASE, WoS, Medline, 2000-2008	Determine effect of intervention programs on mammography screening amongst ethnic minority women <i>ethnic minority women in the US</i>	23 studies	Quality score 0-4	<ul style="list-style-type: none"> <li>- total participants no: 22,849</li> <li>- Intervention type<sup>99</sup> (number of studies; OR [95%CI])               <ul style="list-style-type: none"> <li>a) individual-directed: 19; 0.099 [0.073, 0.110]</li> <li>b) access-enhancing: 6; 0.155 [0.087, 0.223]</li> <li>c) social network (peers): 6; -0.023 [-0.078, 0.032]</li> <li>d) community education: 4; 0.013 [-0.067, 0.094]</li> <li>e) mass media: 4; 0.065 [-0.007, 0.138]</li> </ul> </li> <li>-theory-based: theory 14; 0.090 [0.042, 0.137] &amp; no theory: 9; 0.062 [0.009, 0.116]</li> <li>- tailoring: tailored 4; 0.101 [0.057, 0.145] not-tailored: 19; 0.076 [0.035, 0.116]</li> <li>- Ethnic group: African American: 9; 0.098 [0.023, 0.174]; Hispanic: 5; 0.036 [-0.034 to 0.106], Asian Pacific Islander: 5; 0.094[0.000, 0.189]</li> </ul>	<ul style="list-style-type: none"> <li>access-enhancing biggest increase (15.5%), then individually-tailored interventions (9.9%)</li> <li>- social networks or peer advisors had small to negative effect size</li> <li>- mass media and community education had no effect</li> <li>- theory-based interventions more effective than non-theory bases ones</li> <li>- tailored interventions greater effect size than non-tailored</li> <li>-targeting community had greater effect size than other cultural strategies (but ns)</li> <li>- intervention effect bigger in health care settings than in community settings</li> <li>- women attending health care settings might have had fewer barriers &amp; more support like letters &amp; counselling</li> </ul>

Table 3.1 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Han et al. (2009) continued	<ul style="list-style-type: none"> <li>- Setting: health care: 4; 0.113 [0.081, 0.114]</li> <li>community: 19; 0.067 [0.027, 0.107]</li> </ul>	<p>comparing groups: African - average of 7.8% increase: American bigger effect size, Asian Pacific only marginally sign., Hispanics not sign.</p> <p>- conclusion: access-enhancing important component; need for increased theory use and tailoring (review comparable to Legler et al. and Yabroff and Mandelblatt)</p>

Table 3.1 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarized in the papers)	Authors' discussion/ conclusion
Corcoran et al. (2010)	Mammography	To increase mammography <i>US Latina, primarily low SES</i>	9 studies	allocation, attrition and other bias was assessed	-the odds ratio (random effects model) was 1.385 (95% CI [0.974,1.970]) - the interventions used were promotoras (5), printed mailings (3), educational groups using culturally tailored interventions (5), television campaigns (2), access-enhancing (1) - several studies used more than one method; in detail: (main intervention & OR [95% CI] per 1 study): lay health workers: 33.000 [9.528,114.297] media & volunteers: 1.692 [1.113,2.571] educational: 1.385 [0.813,2.361] mailing & cost reduction: 1.325 [0.858,2.045] group education: 1.138 [0.564,2.295] lay health workers: 1.120 [0.477,2.628] outreach & printed material: 1.103 [0.928,1.312]; access-enhancing: 0.801 [0.616,1.043] media & volunteers 0.463 [0.0733,2.918] -all interventions had culturally sensitive components, e.g. Spanish	- small effect size was observed - not enough studies to test moderating roles - lower effect sizes found than Bonfill et al. (Table 3.2) - free services resulted in the highest impact

<sup>999</sup> Rimer's Typology

### 3.3.2.2 *General population*

The search found 10 reviews with no focus on a specific population group. Table 3.2 below provides an overview of each review's scope, aim, number of studies included, interventions assessed and the authors' conclusion. The interventions are listed as in the original papers, reporting effect sizes or the number of studies included that found a statistically significant impact.

Several reviews found that patient reminder letters and/or phone calls were successful (Bonfill Cosp et al., 2001; Jepson et al., 2000; Stone et al., 2002; Tseng et al., 2001; Yabroff, Mangan and Mandelblatt, 2003). Black et al. (2002) also found reminder letters to be of use, but emphasise the use of registries. Furthermore, Yabroff et al. (2003) found behavioural interventions (letters and phone calls) targeting patients to often have had an impact on papanicolaou (pap) smear use. Tseng et al. (2001) meta-analysis of patient reminders showed an impact on screening uptake, yet they explicitly concluded that reminder letters had less effect in lower socio-economic groups, as remarked in the previous section.

Furthermore, direct contact strategies also increased screening (Denhaerynck et al. only reviewed calls and visits) (Denhaerynck et al., 2003; Holden et al., 2010). The Denhaerynck et al. (2003) review found no difference in the impact of telephone versus personal contact, and Jepson et al. (2000) found inconsistent results when comparing telephone calls and letters. Bonfill Cosp et al. (2001) also discovered that letters and/or phone calls increased mammography uptake, and home visits did not have an impact in their review. Jepson et al. (2000), by contrast, found some evidence for home visits.

Tailoring telephone, print or in-person interventions, personalisation and physician recommendation had a small effect on mammography uptake (Sohl and Moyer, 2007). However, tailoring after age, gender, ethnic origin, barriers and risk was not more encouraging than not tailoring after these factors (Sohl and Moyer, 2007). The Edwards et al. (2003) meta-analysis assessed the impact of personalized risk information (written, spoken or visual). They saw a significant increase in uptake, concluding that risk information appears beneficial but may not be necessary, and potential harm must be assessed (Edwards et al., 2003).

Stone et al. (2002) discovered that patient reminders had less impact on screening and immunisations, uptake than organisational change or financial assistance. Holden et al. (2010) also found that changes to the system and removal of structural barriers (FOTB test procedures) increased colorectal cancer screening. Jepson et al., who found that simpler procedures increased screening, confirmed the latter (Jepson et al., 2000).

In addition, Jepson et al. (2000) found financial assistance increased uptake but did not find enough information in regards to mass media. Black et al. (2002) found that mass media in combination with education or screening clinics or education with free screening increased cervical cancer screening.

A combination of patient and physician reminders was found to be effective in one review (Jepson et al., 2000). Another review did not find the combination to be more effective than patient reminders alone (Yabroff, Mangan and Mandelblatt, 2003). The reviews suggest mixed results for provider education (Jepson et al., 2000; Yabroff, Mangan and Mandelblatt, 2003), and provider feedback was deemed unsuccessful (Stone et al., 2002).

Audiovisual and educational material and education in general had little impact on screening uptake (Jepson et al., 2000). Stone et al. (2002) confirmed that patient education had a smaller effect on screening uptake. Information brochures alone did not increase colorectal cancer screening (Holden et al., 2010) or the use of papanicolaou smear tests (Yabroff, Mangan and Mandelblatt, 2003).

Yabroff et al. (2003) assessed, among other things, sociologic and sociologic & cognitive patient-targeting interventions (most of which were actually 'lay health workers') and found some impact on uptake (Yabroff, Mangan and Mandelblatt, 2003). The Black et al. (2002) review found that peer support encouraged cervical cancer screening in nine of 13 studies and suggested this intervention for minority women. None of the other reviews discussed peer support explicitly.



**Table 3.2: Reviews on interventions to increase screening**

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Black et al. (2002)	Cervical cancer Medline, CINAHL, EMBASE, psych-info, Cochrane Sociol. Abstracts English French 1989 –1999	Effectiveness of strategies to increase womens' participation in cervical cancer screening <i>women in community-based settings</i>	94 identified - focus only on 1) women in community (42), 10 studies targeted disadvantaged women	Assessment tool used: 19 studies rated moderate to strong	-In all 19 studies the most frequently intervention used included: mass media, alone (1/4+) or combined with screening clinics (2/3+) or education (4/6+); individual education with free screening or letter/reminder (4/4); letter/reminders (5/5+); reminder only (1); of those, 9 studies used peer interventionist (9/13+); (note, numbers are based on number of publications) - studies with non-significant results report several limitations, several e.g. statistical power	- mass media combined with tailored information addressing women or providers appear successful - reminder letters should be considered but require registry -lay health educators suggested for minority women

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Teng et al. (2001)	Cervical cancer Medline, Cancerlit 1966-2000	To assess the efficacy of mailed patient reminder letters on the rate of pap smear screening (particular attention to less responsive groups)	10 RCTs (USA, CAN, AUS, UK)	none	<ul style="list-style-type: none"> <li>- only mailed patient reminders were assessed</li> <li>- pooled OR of 1.64 [95% CI 1.49-1.80] patients receiving mailed reminders were significantly more likely to undergo screening</li> <li>- test for homogeneity: <math>\chi^2 = 31(9)</math> indicating heterogeneity, investigated possible sources but none resolved</li> <li>- most studies used medical records to identify patients</li> <li>- definition of 'due for screening' varied between 1-5 years</li> <li>- studies found association between younger age &amp; higher rates of pap smear (2/4++)</li> </ul>	<ul style="list-style-type: none"> <li>- meta-analysis of 10 studies showed effect of mailed letters in terms of increasing cervical cancer screening</li> <li>- less significant effect in lower SES groups</li> <li>- little information on Hispanics, elderly, less educated populations might be more resistant to letters but unknown if findings extend to other underserved populations</li> <li>- effect of letter reminders appears consistent across countries</li> </ul>

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Bonfill Cosp et al. (2001)	Breast cancer Medline EMBASE - 2000	To assess effectiveness of different strategies for increasing participation rate of women invited to community breast cancer screening activities or mammography programs	16 RCTs	45 studies were removed due quality issues	Interventions to increase community breast cancer screening (5/7+ intervention types found a significant impact) - only studies that compare intervention with usual care were included: (no. of studies, OR, [95%CI]) 1) letters: 5; 1.66[1.43,1.92] 24 months interval:1; OR = 4.1 [2.57,6.45] 2) letters to multiple exams& educational material:1; OR = 0.62[0.32,1.20] 3) mailed educational material:1; OR = 2.81[1.96,4.02] 4)letter& phone call: 3; OR = 2.53[2.02,3.18] 5) phone calls: 2; OR = 1.94[1.70,2.33] 6) training and reminder: 1; OR = 2.46 [1.72,3.50] 7) home visit:2; OR = 1.06[0.80,1.40]	- Five interventions were effective, namely a single letter, mailed educational material, letter combined with a phone call, and training combined with a reminder - home visits and invitations to multiple examinations did not increase screening - combined actions addressed poorer or multi-ethnic women and it seems these had a greater effect - participation rates in the studies varied from 9 to 77% - letters & phone calls are of low cost and present a good alternative

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Denhaerynck et al. (2003)	Mammography Cochrane Medline, Psycinfo 1980s - 2001	Effect of <i>direct contact strategies</i> (phone or personal contact) on breast cancer screening	21 papers describe 25 interventions	Cochrane assessment of bias criteria (5)	<p>- only direct contact strategies were included (no of studies): phone calls (18), visit (7), control group received letter (17), peer support (1)</p> <p>- pooled effect sizes of (no of studies; relative risk [95%CI])</p> <p>1. Good quality studies with similar control group: 6; <math>RR = 1.26[1.11, 1.44]</math></p> <p>2. Pooled with lower-quality studies: 14; <math>RR = 1.32[1.11-1.56]</math></p> <p>3. Pooled with studies including dissimilar control groups: 23; <math>RR = 1.21[1.10, 1.34]</math></p> <p>- subgroup analysis (1/3 statistically significant)</p> <p>non-responders <math>RR = 1.27[1.08, 1.51]</math> compared to primary population <math>RR = 1.19[1.05, 1.33]</math>;</p> <p>telephone compared <math>RR = 1.24[1.11, 1.39]</math> to personal contact <math>RR = 1.14[0.95, 1.36]</math>;</p> <p>under-users <math>RR = 1.05[1.01, 1.08]</math> compared with general population <math>RR = 1.27[1.19, 1.35]</math> was significant,</p> <p>- studies of subpopulations of non-responders (9)</p>	<p>- the analysis showed that direct contact increases participation by 21- 46 % with a smaller effect in under- using groups (note that many compared with mailed reminder)</p> <p>- no difference between phone and personal contact could be found</p> <p>- no difference between primary population and non-responders</p> <p>- findings consistent with Bonfill review (see above)</p> <p>-direct contact strategies could be useful for women with minority &amp; lower SES background</p> <p>- limitations include that frequent decline in women, who were invited multiple times was not taken into account</p>

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Edwards et al. (2003)	Medline, EMBASE, Cancer Lit, CINAHL, ClinPSYC, the Science Citation Index Expanded	To assess effect of providing individual risk estimates in comparisons with more general risk information	13 RCTs (10 mammography, 2 cholesterol, 1 prostate, 1 cervical, 1 colorectal screening)	little info, appear to use Cochrane criteria	<ul style="list-style-type: none"> <li>- 12 studies measured uptake of screening (10 with reliable meta-analysis)</li> <li>- overall: individualized risk communication (written, spoken, visual) increased uptake of screening (<math>OR = 1.5</math>; [1.11,2.03])</li> <li>- statistical heterogeneity was found</li> <li>- differences between types of risk communication (e.g. numerical calculation <math>OR = 1.22</math> [0.56,2.68]; risk categories <math>OR = 1.42</math> [1.7, 1.88]; listing personal factors <math>OR = 1.7</math> [1.17,2.48]) were not significant</li> <li>- studies addressing mammography (<math>OR = 1.33</math> [0.98,1.29]) had a smaller effect than the whole group</li> <li>- studies addressing individuals at higher risk (4) had larger effects <math>OR = 1.99</math> [1.52,2.6]</li> </ul>	<ul style="list-style-type: none"> <li>- there is evidence that personal risk communication increases uptake, but there is no evidence for it to be necessary</li> <li>- limits: few studies, mainly mammography screening</li> <li>- effect seems greater amongst 'high risk' -populations</li> <li>- this intervention may be useful on a public health level</li> <li>- careful to avoid harm</li> <li>- it remains unclear if increased uptake is associated with informed decision</li> </ul>

Table 3.2

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarized in the papers)	Authors' discussion/ conclusion
Holden et al. (2010)	Colorectal cancer (CRC) Medline, Cochrane 1998-2009	Which strategies increase appropriate use and follow-up?	21 on appropriate use (51 studies addressing factors associated with screening were not relevant here)	graded strength of evidence based on Agency for Healthcare Research and Quality, Effective Healthcare Program	21 studies on increasing appropriate use [info in brackets (strength of evidence, no. of studies with a significant impact/no. of studies assessing the intervention)] 1) patient level: 15 studies in 6 categories - all look at under-use 1.1) eliminate structural barrier: FOTB test & instructions (high; 5/5+) ineffective, 1.2) one-to-one interaction: nurse, health educator, phone (high; 3/3+) 1.3) reminders (high; 3/3+) 1.4) small media: e.g. print material mailed (high, 0/4+) 1.5) small media & decision aids: e.g. includes info on risk and benefits through print/web/video (low, 2/3+) 1.6) group education: civic group, church (low, 0/2+) 2) provider level 2.1) physician reminder for overdue patients (low, 1/1+) & clinical reminder (low, 0/1+) 3) system level, such as liaison or referral changes to system (high, 5/5+)	- mailing FOBT cards, 1-on-1 counselling by non-physician, and help to understand CRC appear to be effective strategies in increasing appropriate CRC screening - the use of information pamphlets appeared ineffective, - limited evidence on interactive decision aids, but these may help understanding risks and benefits of colorectal cancer screening - logistics may increase use because of the procedures involved in testing - monitoring and feedback as well as policy support would be needed to implement such interventions - review limitations included potential for selective reporting and publication bias

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Sohl et al. (2007)	Mammography PubMed, Dissertation abstracts, Psycinfo, English and tailored, 1997-2005	review of tailored intervention to promote mammography screening (person, phone and print)	28 studies	unclear	<p>phone, print and in-person interventions were assessed</p> <ul style="list-style-type: none"> <li>- most common methods of tailoring were TTM and barriers to care</li> <li>- phone and print more frequent than in-person</li> <li>- physician recommendation (5)</li> <li>- medical charts &amp; self-report used equally often</li> <li>- clustering: HBM often delivered in person (<math>\varphi = .53, p &lt; .01</math>) and included physician recommendation (<math>\varphi = .67, p &lt; .001</math>); phone intervention tailored by barriers (<math>\varphi = 0.63, p &lt; .01</math>) and prints tailored by age (<math>\varphi = 0.63, p &lt; .01</math>)</li> <li>- intervention characteristics (no. of studies that included the intervention: <math>OR, p</math> values): <ul style="list-style-type: none"> <li>- under-served did not effect impact (9: <math>OR = 1.46, p = .84</math>)</li> <li>- tailoring to ethnicity was less effective (4: <math>OR = 0.96</math>) than not (<math>OR = 1.51, p = .03</math>)</li> </ul> </li> </ul>	<p>- tailoring appears to encourage mammography uptake</p> <ul style="list-style-type: none"> <li>- very small effect size consistent with Tseng et al, 2001</li> <li>- authors suggest that tailored interventions work equally well in populations with lower uptake rates</li> <li>- only interventions that used HBM were found to be more effective; tailoring after the TTM, age, sex, ethnicity, risks or barriers did not have an impact</li> <li>- ethnicity was significantly 'worse' (4 studies)- unclear why</li> <li>- in-person delivery more likely to use HBM, HBM more likely to use physician recommendation, but more personal contact does not increase mammography use</li> </ul>

Table 3.2 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Sohl et al. (2007) continued	<ul style="list-style-type: none"> <li>- tailoring to HBM more effective (6: <math>OR = 2.51</math>) than not (<math>OR = 1.27, p &lt; .001</math>)</li> <li>- TTM-tailored interventions (14: <math>OR = 1.47</math>) not more effective than those who did not (<math>OR = 1.40, p = .7</math>)</li> <li>- age (8: <math>OR = 1.33, OR = 1.47, p = .52</math>)</li> <li>- risk (5: <math>OR = 1.34, OR = 1.45, p = .73</math>)</li> <li>- barriers (23: <math>OR = 1.48, OR = 1.26, p = .32</math>)</li> <li>- no differences in terms of delivery mode was found: in-person (4: <math>OR = 2.18</math> or not <math>OR = 1.35, p = .08</math>); print (14: <math>OR = .31</math> or not <math>OR = 1.57, p = .14</math>); phone (18: <math>OR = 1.39</math> or not <math>OR = 1.54, p = .50</math>)</li> <li>- physician recommendation had an impact (5: <math>OR = 2.46</math> or not <math>OR = 1.29, p &lt; .001</math>)</li> <li>- comparison in-person to phone (0/3+)</li> <li>- comparison tailored print to phone (0/2+)</li> <li>- comparison of print &amp; phone to print (0/3+)</li> <li>- tailoring of print or phone call by age, sex, ethnicity, TTM or HMB or no model used</li> </ul>	<ul style="list-style-type: none"> <li>- physician recommendation increased effect size (as found by Jepson et al. and Legler et al., Table 3.1)</li> <li>- active control group did not lower effect size</li> <li>- findings support reliability of self-report measures</li> </ul>



Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Yabroff et al. (2003)	Cervical cancer, 1980 – 2001, English, US only	Effect of controlled interventions to increase pap smear use	46 studies, unclear of which 31 RCTs	Quality assessment unclear	<p>46 studies with 63 separate interventions targeting: patients (24), physicians (25), both (12), system (2)</p> <ul style="list-style-type: none"> <li>- most included women 50-59 years of age</li> <li>- many had &gt;20% minority women</li> <li>- trend towards active controls and multi-components over time</li> </ul> <p>1) patient-target interventions(24)</p> <p>1.1) behavioural interventions (letter &amp; phone reminders)</p> <ul style="list-style-type: none"> <li>- behavioural intervention: 1; 24.4% increase 95% CI [11.1, 37.7] (1/1+)</li> <li>- compared with active controls(4/5+) (phone reminder had largest increase)</li> </ul> <p>1.2) cognitive interventions (educational letter/pamphlet or telephone counselling)</p> <ul style="list-style-type: none"> <li>- theory-based compared with active controls: letter (0/3+), phone reminder (1/1+)</li> <li>- cognitive &amp; behaviour: mailed info/reminders (1/3+); health educator &amp; phone call (1/1+)</li> <li>1.3) sociological interventions</li> <li>- mostly lay health workers</li> </ul>	<p>many interventions increased pap smears, showing:</p> <ul style="list-style-type: none"> <li>- patient characteristics &amp; potential barriers are of importance when selecting the intervention</li> <li>- most interventions increase uptake, few statistically significant</li> <li>- behavioural interventions for patients, e.g. letters and phone calls, were mostly effective and could be an inexpensive option</li> <li>- cognitive sociological ones were not</li> <li>- overcome forgetting by reminding patients (phone calls effective, 18% increase) and providers (chart sheets)</li> <li>- cognitive educational phone interventions increased uptake, as did provider education</li> </ul>

Table 3.2 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Yabroff et al. (2003) continued	<ul style="list-style-type: none"> <li>- interventions using sociological &amp; sociological and cognitive strategies were similar, most improved uptake 2.7%-9.2% (5/11+), intervention combining sociologic, behavioural &amp; cognitive theory (2/3+), health work/education brochures and financial incentives (1/1+), lay worker &amp; workshop &amp; information (1/1+), media role model (0/1+)</li> <li>2) provider (27) &amp; provider-patient (12) interventions</li> <li>2.1) behavioural (chart reminders/flow charts)               <ul style="list-style-type: none"> <li>- compared to UC (0/9+)</li> <li>- no clear difference between reminders and flow charts</li> </ul> </li> <li>2.2) cognitive               <ul style="list-style-type: none"> <li>- seminar/audit (3/3+)</li> </ul> </li> <li>- combination of cognitive &amp; behavioural strategies (1/3+)</li> <li>2.3) sociological               <ul style="list-style-type: none"> <li>- combination of all 3: general education (0/1+) church liaison, mass media, lay health worker, education, community activities (4/4+ sub studies)</li> </ul> </li> <li>3) system intervention               <ul style="list-style-type: none"> <li>- same-day screening (1/1+) and community health worker (0/1+)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- provider-based interventions were inconclusive</li> <li>- combinations did not seem more effective than one intervention alone</li> <li>- some ineffective interventions here were effective in some populations when applied to a different test, e.g. mammography, suggesting that beliefs about cancer and test differ</li> </ul>

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Stone et al. (2002)	Cancer screening & immunisations EPOC, MEDLIN, EMBASE, HCQIP, previous reviews – 1999	Effect of strategies to promote use of preventive services	108 (95 RCTs and 13 controlled clinical trials)	“in standard fashion”	- a meta-regression was performed, which characterized interventions according to 7 interventions (reminders, feedback, education, financial incentives, regulatory interventions, organisational change, media campaigns) & four targets (patient, provider, organisation, community) 1) organisational change was effective (20 studies) immunisations (adj <i>OR</i> = 1.6, 95% CI [1.2,2.8]); mammography (adj <i>OR</i> = 2.47 [1.97,3.10]); cervical screen (adj <i>OR</i> = 3.03, 95% CI [2.56,3.58]); colon screening (adj <i>OR</i> = 17.6, 95% CI [12.3,25.2]); included diverse components fitting 4 categories, namely separate clinic, use of planned care visits for prevention, techniques like quality improvement, design-specific prevention responsibilities for staff; 2) reduce costs/financial incentives effective	- direct comparison between intervention components of controlled studies - great impact of organisational change - the combination of effective components can increase participation in screening and immunisations - more studies on the combination of patient, provider and organisation are highlighted - provider feedback is ineffective - overall, Stone et al. suggest that a needs assessment should guide the selection of an intervention, inclusion of local teams encouraged - the next step might be patient reminders

Table 3.2 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Stone et al. (2002) continued	<p>immunization (<i>adj OR</i> = 3.42, 95% CI [2.89,4.06])  mammography (<i>adj OR</i> = 2.74, 95% CI [1.78,4.24]), cervical (<i>adj OR</i> = 2.82, 95% CI [2.35,3.38]), colon (<i>adj OR</i>=1.82, 95% CI [1.35,2.46])  3) patient reminders (less effective than 1&amp; 2): immunisation (<i>adj OR</i> = 2.52, 95% CI [2.24,2.82]), mammography (<i>adj OR</i> = 2.31, 95% CI [1.97,2.70]), cervical (<i>adj OR</i> = 1.74, 95% CI [1.58,1.92]), colon (<i>adj OR</i> = 2.75, 95% CI [1.90,3.97]), personalized/signed reminders more effective than generic ones (1/1+)  4) patient education: least effective  immunizations (<i>adj OR</i> = 1.29, 95% CI [1.14,1.45]), mammography (<i>adj OR</i>=1.31, 95% CI [1.12,1.52]), cervical (<i>adj OR</i> = 1.53, 95% CI [1.30,1.81]), colon (<i>adj OR</i> = 1.38, 95% CI [0.84,2.25])  5) provider feedback: ineffective  immunisations (<i>adj OR</i> = 1.23, 95% CI [0.96,1.58]), mammography (<i>adj OR</i>=1.76, 95% CI [1.44,2.15]), cervical (<i>adj OR</i> = 1.10, 95% CI [0.93,1.31]), colon (<i>adj OR</i> = 1.18, 95% CI [0.98,1.43])  6) provider reminder: no patterns  immunisation (<i>adj OR</i> = 3.80, 95% CI [3.31,4.37])  mammography (<i>adj OR</i> = 1.63, 95% CI [1.39,1.92]), cervical (<i>adj OR</i>=1.37, 95% CI [1.25,1.51]), colon (<i>adj OR</i> = 1.46, 95% CI [1.15,1.85])  7) provider education: no patterns  8) provider incentives, media, regulatory strategies not assessed due to lack of information</p>	<p>- patient or provider education, feedback had not/had less impact, and there may be no advantage to adopting those strategies</p>

Table 3.2 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Jepson et al. (2000)	All types of screening		190 65% US 18% UK 12% ANZA	7 quality criteria	<ul style="list-style-type: none"> <li>- 62 took place in health settings, 38 in the community, 17 in HMOs, 29 in clinics, 18 organised programmes, 9 uni/work, 17 other</li> <li>- 37 theory-based (most common HBM 17/38, PRECEDE 6/38, TRA 4/38, TTM 2/38, SL 4/38)</li> <li>- outcomes included: screening, knowledge, intention, anxiety, beliefs</li> <li>1) individually directed interventions (57; 44RCTs):               <ul style="list-style-type: none"> <li>- giving appointment (11/14+); fixed appointment more effective than control or open</li> <li>- intervention letters (28): letter vs. control (13/24+); letter from different authorities (1/3+); personalised letters (0/1+);</li> <li>- phone calls: calls vs. control (4/5+); call from different authorities (0/1+); follow-up (10; 6/8+ RCTs; 1/2+ quasi); prompt/credit cards (2/3+)</li> <li>- comparing interventions (8): letter vs. phone call (two biggest studies opposing results, other 3 non-sign.); appointment vs letter (two studies with opposing yet sign. results); appointment vs. verbal (0/1+)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>1) evidence for appointments, letters and phone calls, some evidence for follow-up; inconsistencies for letter vs calls</li> <li>2) some evidence for effect of reminder on mammography uptake</li> <li>3) evidence of limited effectiveness of printed material, of audiovisual education materials and of group educational sessions</li> <li>- some effectiveness of home visits</li> <li>- evidence of limited effectiveness of individual educational settings</li> <li>4) insufficient evidence in regards to message framing</li> <li>5) risk factor questionnaires have a limited impact</li> </ul>

Table 3.2 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Jepson et al (2000). continued	<p>2) reminders for non-responders (8) including letters, appointments, phone calls: reminder letter vs. control/other (1/3+ RCTs), reminder calls vs. control/other (0/1+), reminder appointments vs. control/other (1/1+)</p> <p>3) educational interventions (42,32 RCTs) : included audiovisual, group &amp; individual teaching, home visits:</p> <p>3.1) print materials vs. control (2/11 RCTs), leaflet shorts vs long (0/1+)</p> <p>3.2) audiovisual education videos(1/2+; 2 method. flawed)</p> <p>3.3) group teaching (5/10+)</p> <p>3.4) educational phone call by nurse(1/1+)</p> <p>3.5) home visits (6/10+)</p> <p>3.6)individual teaching in other settings (1/5+)</p> <p>3.7)combined educational approaches (1/2+)</p> <p>3.8) studies comparing educational interventions (3/6+)</p> <p>4) message framing (0/5+)</p> <p>5) risk factor assessment &amp; management (2/6+)</p> <p>6) counselling (via phone3/4+, face to face 1/3+, stepwise 0/1+)</p> <p>7) procedures/service provision/opportunistic (29), dietary (0/5+), combined test (0/6+), service provision (5/8+), opportunistic screening (5/6+), notification of results (~)</p> <p>8) economic interventions</p> <p>8.1) free test, transport, postage (6/8+),</p> <p>8.2) rewards/incentives (2/5+)</p>	<p>6) evidence for telephone calls, limited impact of face-to-face counselling</p> <p>7) simpler procedures increase uptake and evidence in support of opportunistic screening</p> <p>8) financial assistance facilitates uptake but rewards/incentives do not</p> <p>9) some evidence supports multi-component community interventions; insufficient evidence for media campaigns and community education,</p> <p>10) some evidence for combinations</p> <p>11) physician reminders effective, some evidence for office systems and audit &amp; feedback, not enough evidence for physician education</p> <p>12) evidence for physician &amp; individual combined</p> <p>13) interventions targeting individuals have slightly more impact than physician-targeted interventions</p>

Table 3.2 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Jepson et al (2000) continued	<p>9)community intervention studies(14)</p> <p>9.1) mass media(1/2+)</p> <p>9.2) community participation (2/2+)</p> <p>9.3)community education (1/3+)</p> <p>9.4)combined community intervention (5/9+)</p> <p>10) combined; individually-targeted (15)</p> <p>10.1)letter &amp; education (1/1+)</p> <p>10.2)letter &amp; prompts (1/1+)</p> <p>10.3)letter&amp; counselling (0/1+)</p> <p>10.4) multiple interventions (3/3+)</p> <p>10.5) letter &amp; reminder or prompt vs control (2/2+)</p> <p>10.6)education &amp; counselling (1/1+)</p> <p>10.7) education &amp; economic incentive (1/2+)</p> <p>10.8) education &amp; access (1/1+)</p> <p>11)single interventions for physicians</p> <p>11.1)physician reminders (21): physician reminder vs control (14/19+), varied by type of test; chart reminders (1/1)</p> <p>11.2) physician education (3/4+)</p> <p>11.3) office systems/staff (4/6+)</p> <p>11.4)audit &amp; feedback (4/5+, but varied by test)</p> <p>11.5) interventions aimed at other HCW(1/1+)</p> <p><i>(continued in cell on right)</i></p>	<p><i>(continued from cell on left)</i></p> <p>12) interventions aimed at HCP &amp; individuals(7)</p> <p>12.1) education &amp; reminder (2/3+)</p> <p>12.2)education &amp; support (0/1+)</p> <p>12.3)education &amp; office support (1/1+ varied by test)</p> <p>12.4) economic incentives &amp; reminders (0/1+)</p> <p>12.5)audit or feedback &amp; reminder (0/1+)</p> <p>13) physician vs. individual interventions (13)</p> <p>13.1) physician reminder &amp; invitation to individual (7/9+)</p> <p>13.2) physician reminders &amp; individual education (2/2+)</p> <p>13.3) multiple interventions aimed at physicians (3/4+)</p> <p>14) physician vs. individually targeted interventions (11)</p> <p>14.1) physician reminder vs. invitation (6 studies pooled showed +; 1/3+)</p> <p>14.2) audit &amp; feedback (0/2+)</p>

### **3.3.3 Service uptake**

The search for service uptake/access interventions yielded 325 papers, of which three reviews were relevant (Table 3.3). These reviews assessed interventions to increase vaccinations (Briss et al., 2000; Maglione, Stone and Shekelle, 2002; R Thomas, Russell and Lorenzetti, 2010). Personalised reminders (phone calls or letters) appear to be effective in promoting vaccinations. Home visits may also encourage uptake. Physician reminders were effective overall, but not in the review focusing on the elderly which were also the target population for mass mailings that found little effect (Maglione, Stone and Shekelle, 2002).



**Table 3.3: Interventions to increase service access**

Review	Scope	Aim & Population	Number of studies	Qual. Ass.	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Brisset al. (2000)	Vaccinations	To assess interventions to improve MEDLINE; improve EMBASE; vaccination PsycLIT; CAB Health; and Sociological Abstracts.	183 studies		<p>1. Interventions to increase community demand</p> <p>1) client reminder (42), client reminder/recall only: 8% median percentage point change (MPPC); client reminder/recall as part of multi-component interventions: 16% MPPC</p> <p>2) multi-component interventions including education (17): MPPC in 15 studies -4% - 29%, in clinical setting (16%), in community setting (12%)</p> <p>3) community-wide education only (0)</p> <p>4) clinic-based education (3) insufficient evidence</p> <p>5) client/family incentives (3) with 4% MPPC but not enough evidence</p> <p>6) client-held medical records (3/4 reported 5%-15% percentage point change but not enough evidence) enhancing access to vaccinations</p> <p>7) reducing costs (19) 5 single intervention studies found -1%-29% (10% median) change, 13 median percentage point change of -8%-47% (median 15%), 8 studies with multiple components found -8%-47% (median 16%)</p> <p>8) expanding access in health care settings (16; 12 multi-component) MPPC 10% (range -8%-35%)</p>	<p>interventions to increase community demand</p> <p>- client reminder/recall interventions are strongly recommended</p> <p>- multi-component interventions that included education have a strong impact on vaccination uptake</p> <p>- community-wide, education-only interventions; client or family incentives and client-held medical records showed insufficient evidence</p> <p>- reducing costs is supported by strong evidence</p> <p>- expanding access in health care settings: as part of multi-component interventions, expanding access is strongly recommended due to strong evidence</p>

Table 3.3 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/ conclusion
Briss et al conti- nued	<p><i>(vaccinations for children excluded for the purpose of this chapter)</i></p> <p>2. Provider-based interventions</p> <p>2.1) provide reminder/recall (29); reminder-only studies found 17% MPPC, reminder as part of multi-component had 14% MPPC</p> <p>2.2) assessment &amp; feedback (14) 1%-43% (median, 16%), assessment feedback alone studies 16% MPPC, assessment &amp; feedback as part of multi-component study 17% MPPC</p> <p>2.3) standing orders (11) standing orders alone 51%MPPPC, standing orders as part of multi-component study 16%</p> <p>2.4) provider education alone (4) -30% - 7% MPPC, insufficient evidence</p>	<p>provider-based interventions.</p> <ul style="list-style-type: none"> <li>- provider reminder/recall are strongly recommended</li> <li>- assessment and feedback for vaccination providers are strongly recommended</li> <li>- standing orders to vaccinate adults are strongly recommended</li> <li>- provider education only: insufficient evidence exists</li> </ul>

Table 3.3 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Thomas et al. (2010)	Interventions increasing influenza vaccination rates in 60 years or older	Interventions to increase community demand and enhance access, provider-, system-based and societal interventions	44 RCTs	Cochrane criteria	<p>1. Interventions to increase community demand</p> <p>a) reminders: postcard reminders (5/11+); personalized call, letter, card (9/13+), call by trained senior (1/1+), call (+) vs. drop-in (-) (1/1+), letter and leaflet vs. letter (0/1+), custom vs. formal letter (0/1+)</p> <p>b) educating &amp; vaccinating participants: nurse education &amp; vaccination (+) vs. control (-) (2/2+), risk appraisal (1/1+), (all 3 rated high risk of bias)</p> <p>2. Intervention to increase access</p> <p>a) group visits (1/1+) (high risk of bias)</p> <p>b) home visit: visit (+) vs. letter (-)(1/1+), visits (1/1+), visits &amp; care plan by physician (1/1+), visit&amp; encouragement vs. visit &amp; safety instructions (0/1+), (all 4 low risk of bias)</p> <p>c) free vaccination: free (+) vs. paid (-) (2/2+), free (+) vs. usual care (-) (2/2+), (both high risk of bias)</p> <p>3. Provider/system interventions</p> <p>a) reminders to physicians (1/4+, but high risk of bias), posters &amp; cards to participants (1/1+), posters vs. cards (0/1+),</p> <p>b) facilitators &amp; educators of professionals: facilitator encouragement (3/4+), high risk of bias, chart review &amp; feedback/educational material or outreach(2/3+) (high risk of bias)</p> <p>c) financial incentives to physicians (2/2+), high risk of bias</p>	<p>authors remarks that heterogeneity precluded meta-analysis</p> <p>- the authors do not compare and contrast but leave the information (as displayed in the cell to the left) as conclusion</p> <p>- study quality was often graded as high risk of bias</p> <p>The authors conclude that:</p> <ul style="list-style-type: none"> <li>- personalized postcards or phone calls are effective</li> <li>- home visits and facilitators may be effective;</li> <li>- reminders to physicians were not found to have an impact on vaccinations</li> <li>- insufficient good evidence for other interventions</li> </ul>

Table 3.3 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Maglion et al. (2002)	influenza vaccine HCQIP database – of 1999	Mass mailings' effect on utilisation of influenza vaccine among Medicare users 65 years or older;	5 RCTs	unclear	- 5 RCTs on mass mailing were included, all letters were signed by staff, mailing took place through Medicare records - (1/5+) – 4 studies were unpublished, 2 had a statistically significant, but not a clinically significant outcome - US-based	- the authors review mailing signed letters or postcards to increase influenza vaccinations in Medicare receivers - the card/letter came from Peer Review Organisation rather than from the physician and was therefore said to be different from a reminder. - they do not recommend continuing mass mailing and said publication bias had contributed to this list still being used

### **3.3.4 Additional findings**

While searching the literature and reference lists, four papers were found that compare types of interventions across diseases. The intervention categories were peer phone calls, community health workers, and mass media (Table 3.4). Peer support appears to be successful in some but not other outcomes (Dale et al., 2008), and mass media may support the use of services (Grilli, Ramsay and Minozzi, 2002).

Community health workers are used in a variety of health areas (Andrews et al., 2004; Swider, 2002). Although the reviews had some mixed findings, there appears to be at least a partial effect. This could be due to the variations in type of role, duration and health issues (Andrews et al., 2004). The reviewers grouped interventions by strategy. The effect on multiple outcomes is evaluated. Only reviews that included studies assessing health care access or use as an outcome were included. As mentioned earlier, it is difficult to disentangle the effect on participating in a new service, because patients may already be involved.

**Table 3.4: Intervention-specific reviews**

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Dale et al. (2008)	Peer phone calls Medline, Embase, Cinhal, - 2007, reference scanning, grey lit search	Evidence for peer-support, phone-delivered interventions involving verbal communication aiming to improve health/behavior	7 RCTs	Cochrane guidelines used; overall quality fairly poor	note that the authors included psychological, physical, social and behavioural outcomes - peer phone versus control (5); 3rd arm with professional phone support (2) - theoretical underpinning (4): HBM, self-efficacy model, research base, behaviour change model & decision making (Anderson2000/Rollnick2002); unclear theory base (3) - trained peers (6), additional materials(3), follow-up/ongoing support(3) - number of calls ranged from once a year (mammography) to once a week(MI) peer support interventions aimed at per 1 study: - mammography giving informational support (RR = 1.4, 95% CI [1.2 to 1.7]) (1/1+)	- 7 RCTs, no negative impacts - some evidence for positive impact on: postnatal depression, diet change post-MI, continue to breastfeed, prolong mammography screening - little theoretical basis used, - poor quality - diversity in peer recruitment practice, e.g. number of calls - design of intervention varied too, hence findings should be interpreted with caution - some evidence that combination of informational appraisal and emotional support contribute to impact

Table 3.4 continued

Review	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Dale et al. continued	<ul style="list-style-type: none"> <li>- post-MI self-efficacy (0/1+) health/behaviour (0/2+) via emotional support</li> <li>- post-MI diet (1/1+), QOL(0/1), smoking (0/1+) with informational support</li> <li>- diabetes self-efficacy via emotional support &amp; appraisal (0/1+)</li> <li>- uptake of breastfeeding via emotional, information support &amp; appraisal(56.8% versus 40.3%, <math>p = .01</math>) (1/1+)</li> <li>- postnatal depression reduction via emotional, information support &amp; appraisal (14 week (<math>p=.02</math>) and 8 week (<math>p = 0.01</math>)) (1/1+)</li> <li>- mammography screening via informational support ( 7.5% higher in control group, <math>p = .029</math>) (1/1+)</li> </ul>	<p>where complex behaviours are targeted</p> <ul style="list-style-type: none"> <li>- without information support (diabetes study), no effect, which suggests combination</li> <li>- peer calls always have element of social interaction, even if information only is intended</li> <li>- education and socio-economic background matching might be important</li> </ul> <p>conclusion: some evidence that peer phone calls have a positive impact on changing health outcomes and health behaviours (too limited to recommend practice)</p> <ul style="list-style-type: none"> <li>- from studies reviewed here, those that had information element appear more effective than those without</li> </ul>

Table 3.4 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Swider et al. (2002)	Community health workers (CHW)	Efficacy of community health workers on hard-to-reach populations	20 studies US-based	unclear	<ul style="list-style-type: none"> <li>-ethnic minorities, vulnerable populations (low education, low income, lack of insurance, rural, women)</li> <li>- CHW (15/20+)</li> <li>- CHW role were health education (8), case management (8), assisting service access (8)</li> <li>- outcomes: change in access, e.g. screening (11/15+), behavioural change (5/6+), health status, e.g. child health, diabetes, mental health (3/4+), knowledge on diabetes, HIV (0/2+), costs (0/2)</li> </ul>	<ul style="list-style-type: none"> <li>- authors conclude that CHW do make an impact on hard-to-reach populations</li> <li>- highest impact in 'access to care' category</li> <li>- impact on behaviour change, health status and knowledge was limited, and the authors suggest more research</li> <li>- limited information on CHW role, mode of delivery, etc.</li> <li>- CHW appear to promote health</li> </ul>



Table 3.4 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Andrews et al. (2004)	Community health workers Medline, Cinhal, - 2002	Critical appraisal of use and effectiveness of CHW	24 studies (22 after 1990) US-based		<ul style="list-style-type: none"> <li>- review focused on CHW targeting ethnic minority women in the US- CHW roles were coded as educator(18), data collector(3) or case manager (4), outreach promoting programmes/access(14), - great variability in role, training, supervision, payment, etc</li> <li>- outcome: access (16/16+) many papers concluded CHW could promote access, but high attrition rate); knowledge (5/7+), behaviour (5/6+); albeit not assessed, CHW are a cost-effective intervention</li> </ul>	Authors conclude that studies show positive impact of CHW on ethnic minority women in the US in regards to knowledge, access and behaviour- great variation in CWH role, training, procedures, supervision etc

Table 3.4 continued

Review	Scope	Aim & Population	Number of studies	Quality assessment	Intervention (as summarised in the papers)	Authors' discussion/conclusion
Grilli et al. (2002)	Mass media & uptake of services Cochrane (1996 to 1999), MEDLINE, EMBASE, Eric, PsycLit (to 1999)	Mass media effects on health care utilisation	20 RCTs	Cochrane criteria, quality was very variable	- Mass media studies (19/20+) but re-analysis does not confirm this for all studies - outcomes (re-analysis of 19 studies): immunisation (1/2+), screening (4/8+), HIV testing (1/2+), reduced delay in hospital admission for MI symptoms (1/2+), care utilisation (5/5+)	- studies were of poor quality, but still, mass media may encourage/influence the use of health care interventions

### 3.3.5 Towards a typology of intervention strategies

From the literature reviews, a list of interventions used to promote service uptake was derived synthesising all intervention strategies found across screening, vaccinations and service uptake (Table 3.5). The interventions are grouped into five categories, namely: population-level, community-level, patient-level, system & provider-level and multiple levels. A level is defined as ‘at whom the intervention is aimed so that either directly (where aimed at patients, for example) or indirectly (where aimed at the system to change working processes), the uptake of services increases’.

The interventions are further categorised by Rimer’s typology (for interventions to increase breast cancer screening) (Rimer, 1994). These are, a) mass media, b) community education, c) access enhancing, d) social network, e) system or provider, f) individually-directed. A category for g) multiple level interventions was added. This review extends the typology from breast cancer screening across different health services.

**Table 3.5: Towards a typology (all interventions reviewed)**

Level of intervention target	Intervention category	Intervention as categorised by review author	No. of studies positive impact/no of studies reviewed (where not available other summary provided)	First author of review
population-level	mass media (including television, radio, magazines, leaflets or similar on a population level)			
		mass media	6/ some effect	Legler
		mass media	4/ no effect	Han
		mass media	lack of information	Stone
		mass media	1/4+	Black
		mass media	12/19+	Grilli
		mass media	1/5+	Maglione
		mass media & screening clinics	2/3+	Black
		mass media & education	4/6+	Black
		media & volunteers	0/1+	Corcoran

Table 3.5 continued

community-level			
	community education	14 pooled studies	
	community education	showed some effect	Legler
	community education	4 studies, no effect	Han
	community education	1/3+	Jepson
	community participation	2/2+	Jepson
	combined community interventions	5/9+	Jepson
patient-level	access-enhancing (going to the patient (van), appointment on the same day, vouchers or free screening) from Legler. In the case of vaccinations, home visits are classified as access-enhancing (Thomas)		
	access-enhancing	14 studies pooled show effectiveness	Legler
	access-enhancing	6 studies, 15.5% increase	Han
	access-enhancing	0/1-	Corcoran
	access-expanding	16, 10% increase	Briss
	Same-day screening	1/1+	Yabroff
	mobile van	3/3+	Bailey
	procedural change/service provisions/opportunistic	10/25+	Jepson
	reducing costs	19, 10%-16% increase	Briss
	reducing costs	effectiveness	Stone
	voucher	3/3+	Bailey
	elimination of structural barriers	5/5+	Holden
	removal of logistic/financial barriers	4/8+	Masi
	cost reduction & mail	1/1+	Corcoran
	free test/transport/postage	6/8+	Jepson
	incentives	not enough evidence	Briss
	rewards/incentives	2/5+	Jepson
	social network (peer or lay health advisors (Rimer, 1994))		
	social network	7 studies pooled show small effect	Legler
	social network	6 studies, small negative effect	Han
	Peer-lead (in combination w/ other)	9/13+	Black
	Peer-lead (in combi w/ other)	7/8+	Bailey
	lay health workers (sociological & cognitive)	5/11+	Yabroff
	lay health workers	0/1+	Corcoran
	peer support	5/10+ outcomes in 7 studies	Dale
	community lay health workers	15/20+	Swider
	community lay health workers	16/16+ to increase access	Andrews
	community health worker	0/1+	Yabroff

Table 3.5 continued

direct contact (including telephone calls, visits, staff and peer contact)		
direct contact (call,visit,peer)	14 studies <i>RR</i> =1.32, 95% CI [1.11,1.56]+	Denhaerynck
1-on-1 contact (staff, call,peer)	3/3+	Holden
Individually directed ( includes calls, letters, reminders, facilitators)		
Individually directed	17 effective	Legler
Individually directed	19 studies, 9.9% increase	Han
phone calls	2 studies pooled <i>OR</i> =1.94	
phone reminder	95%CI [1.70,2.33] +	Bonfill
phone calls	1/1+	Yabroff
phone call	1/2+	Bailey
follow-up call	4/6+	Jepson
phone call & health educator	7/10+	Jepson
counselling via phone	1/1+	Yabroff
counselling face to face	3/4+	Jepson
letters/reminders	1/3+	Jepson
individual/patient reminders	5/5+	Black
letters	10 studies pooled <i>OR</i> =1.64, 95%CI[1.49,1.80]+	Teng
letters/reminders	5 studies pooled <i>OR</i> =1.66	
letter (cognitive theory-based)	95%CI[1.43,1.92] +	Bonfill
letter (cognitive behaviour)	3/3+	Holden
reminders	0/3+	Yabroff
print	1/3+	Yabroff
reminders	effectiveness, but less than organisational change or cost reduction	Stone
letters	2/5+	Bailey
reminders	1/4+	Kupets
reminder & other intervention	14/28+	Jepson
postcard reminders	42; 8% increase (of above) 16%	Briss
letter & phone call	5/11+	Thomas
card & call	3 studies pooled <i>OR</i> =2.53,95%CI [2.02,3.18] +	Bonfill
Letter & call & visit	9/13+	Thomas
letter plus other intervention	1/1+	Bailey
letter to multiple exams	7/8+	Jepson
letter or call (behavioural)	1 study, <i>OR</i> =0.62, 95% CI [0.32,1.20]-	Bonfill
letter or call	5/6+	Yabroff
comparing delivery mode (person, print, phone)	2/2+ in white 0/3+ in minority women	Masi
giving appointment	(4,14,18 studies) ns	Sohl
	11/14+	Jepson

Table 3.5 continued

	individual education	least effectiveness	Stone
	education	17; 12-16%	Briss
	individual education, free or letter	4/4+	Black
	education & other intervention	3/4+	Jepson
	individual teaching in various settings	1/5+	Jepson
	group education	0/2+	Holden
	group education	0/1+	Corcoran
	group teaching	5/10+	Jepson
	group education & video	1/1+	Masi
	classroom instruction	2/2+	Masi
		2 studies pooled <i>OR</i> =1.06, 95%CI [0.80,1.4]	
	home visit		Bonfill
	home visit	6/10+	Jepson
	home visit	3/4+	Bailey
	home visit	3/4+	Thomas
	small media, e.g. printed materials	0/4+	Holden
	small media & decision aids, e.g. information on risks and benefits through print/web/video	2/3+	Holden
	video & print	1/1+	Bailey
	touch screen	0/1+	Kupets
	video	1/1+	Masi
	audiovisual	1/2+	Jepson
		1 study, <i>OR</i> =2.81,	
	mailed education	95% CI[1.96,4.02]	Bonfill
	leaflet/print	2/11+	Jepson
system & provider level	provider-directed (including reminders, flow charts, audit, feedback, incentives and education)		
	physician reminder	1/2+	Holden
	provider reminder	no patterns	Stone
	physician reminder	14/19+	Jepson
	physician reminder	1/4+	Thomas
	provider reminder	29, 17% median increase	Briss
	chart reminder/flow chart	0/9+	Yabroff
	chart info/reminder	1/3+	Kupets
	chart reminder	3/4+	Masi
	physician reminder (automated)	9/15+	Kupets

Table 3.5 continued

	provider feedback	ineffectiveness	Stone
	audit & feedback	3/4+	Kupets
	audit & feedback	4/5+	Jepson
	chart review & feedback	2/3+	Thomas
	assessment & feedback	14, 16% median increase	Briss
	incentives	2/2+	Thomas
	provider incentives	lack of information	Stone
	seminar/audit	3/3+	Yabroff
	provider education	insufficient evidence	Briss
	physician education	3/4+	Jepson
	multiple interventions aimed at physicians	3/4+	Jepson
<hr/>			
	system-directed (includes additional staff, change in staff role or office system, working procedures e.g. additional clinics)		
	liaison/referral	5/5+	Holden
	organisational change (e.g. separate clinics, planned visits, quality improvement, prevention responsibilities for staff)	20 studies, adj <i>OR</i> for 4 screening outcomes show effectiveness	Stone
	office system & staff	4/6+	Jepson
	facilitator	3/4+	Thomas
<hr/>			
multi-level intervention	interventions that combine multiple aspects		
	liaison & mass media & lay health worker & community activities	4/4+	Yabroff
	physician & patient reminder cards	4/4+	Kupets
	physician education & patient reminder or support	2/4+	Jepson
	provider intervention more successful than patient interventions	6/7+	Masi
	combined provider & patient reminder more effective than patient reminder alone	1/1+	Masi
<hr/>			

Out of the major categories, individual-targeting interventions are most often used, and there appears to be a tendency towards multi-component interventions.

Methods used within many of the interventions included role models (Black, Yamada and Mann, 2002), motivational elements, personalisation (R Thomas, Russell and Lorenzetti, 2010) and tailoring by theory (theory-based interventions

(14) more effective than interventions not based on theory (9))(Han et al., 2009). Interventions tailored after the Health Belief Model (HBM) were more successful in increasing uptake than those that were (6 studies  $OR = 2.51$ ,  $OR = 1.27$ ,  $p < .001$ ) (Sohl and Moyer, 2007). Interventions tailored after the Transtheoretical Model (TTM) did not differ in impact as compared to interventions not using this model (Sohl and Moyer, 2007). Personal risk/ risk status awareness tailoring had an impact on uptake (12 studies  $OR=1.5$ , 95% CI [1.11,2.03]) (Edwards et al., 2003) as did some studies on risk factor assessment and management (2/6+) (Jepson et al., 2000). Message framing did not appear to be successful (Jepson et al., 2000). Targeting was used when under-represented groups ought to be included too. In addition, a multitude of implementation settings (home, health care, community, church, as well as telehealth) became apparent.

### **3.4 Discussion**

Similar strategies to encourage participation in health services are used across health care areas. A cross-disciplinary review on strategies to increase the participation in 1) self-management programmes, 2) cancer screening and 3) service access, with specific attention to under-represented/non-attending groups, was conducted. The overall aim was to look for further evidence supporting the three strategies found by the systematic review and to look for additional, new interventions that have not been tested in the cardiac rehabilitation context.

A great number of reviews on interventions to increase access to and use of cancer screening were found (16), yet very few studies on how to promote service uptake generally (3) and no studies about increasing uptake of self-management programmes were found. The following sections talk about interventions in regards to cardiac rehabilitation. Consideration is given to under-represented/non-attending groups.

#### **3.4.1 Intervention categories**

The list of interventions towards a typology of strategies used to promote service uptake includes mostly evidence from the screening literature. Nevertheless, the commonalities between intervention designs from cardiac rehabilitation (Chapter 2), immunisation and use of services emerge.



Previously, Rimer's typology listed seven categories of interventions to increase breast cancer screening (Rimer, 1994). Current findings further extend Rimer's typology across health services, and a category for multiple interventions was added.

The focus of this review was on increasing participation and, as will be discussed below, similarities in terms of impact exist.

### **3.4.2 Results in regards to CR (Chapter 2)**

Mass media and community-level interventions were found to have some effect but are not suitable for cardiac rehabilitation due to the nature of the service. These interventions could be appropriate in a preventive rather than a (cardiac) rehabilitation context, since the population or large groups of people in a community are targeted.

In terms of provider-level interventions, provider education alone was not supported by all the literature and may not be considered as a first step when looking for ways of promoting cardiac rehabilitation attendance. In addition, provider or chart reminders, which showed some impact, might be more appropriate at the stage where patients get referred to the cardiac rehabilitation team. Currently, automated referral systems do not exist in the UK.

A change in procedures at the system level might be useful. There is evidence for nurse assistance/liaison or additional staff as well as for combining patient and provider reminders. The former had been successful in one cardiac rehabilitation trial using a liaison nurse (Jolly et al., 1999). Due to the variety of clinical practice in the UK this intervention appears less straightforward and of higher resource need and may be a good choice, but not always a feasible choice one.

Access- enhancing services appear to increase access of services especially in under-represented groups. Contrary to the definition of uptake used here, it appears that opportunistic screening can be an effective way of recruiting patients in the US, where most reviews originated. The introduction briefly discussed health inequalities and pro-rich user rates in preventive services, explaining the success of access-enhancing and opportunistic interventions. As regards cardiac rehabilitation, patients should recuperate at home first, and financial assistance may not be needed in the UK, since screening, vaccination and cardiac rehabilitation are free of charge. However, transportation costs might be relevant, transport being an issue repeatedly

mentioned as a barrier to attendance (for example, in the survey (Chapter 4) and by an interview participant (Chapter 5)).

The Andersen framework on ‘access to care’, which denotes three population characteristics for access - namely, *predisposing factors* such as socio-demographic aspects or individual beliefs, *enabling factors* referring to resources and knowledge, and *need*, which encompasses professional as well as individual evaluation for the necessity of care - is the more commonly used framework (Aday and Andersen, 1981; Hall et al., 2008). As a whole, the interventions found here target these aspects. Nevertheless, political decisions and scarcity of resources, which affect CR in the UK, likely lead to behaviour-focused interventions being used most frequently while tapping into the knowledge aspect of access to care (Great Britain. Department of Health. Cardiovascular Disease Team, 2013).

#### *3.4.2.1 Individually directed interventions*

Peer support had a mixed impact, which mirrors the findings from the cardiac rehabilitation literature. As Andrews et al. (Andrews et al., 2004) remarked, the different findings might be due to variations in trial outcome, duration, task and skills training of peers involved. Since obvious benefits of peer support exists, further research into how to effectively use peer support it is suggested. Peer-led methods remain attractive, despite variable success due to low resource implications (Obrist et al., 2007). In cardiac rehabilitation, peers sometimes help with the exercise, relaxation classes and sometimes recruitment (Lewin, B, 2013, personal communication).

Small media, such as leaflets, had limited effects but tailoring print materials was found to have an effect on some health behaviour in a meta-review by Noar and colleagues (Noar, Benac and Harris, 2007). A variety of interventions used to promote uptake are tailored after behaviour change theory. Sohl and Moyer (2007) found that interventions using the Health Belief Model (HBM) were more effective in promoting screening uptake than those that used the Transtheoretical Model (TTM) and those that tailored for age, gender, and ethnic origin (Sohl and Moyer, 2007). Other reviews, for example, Bridle and colleagues reviewed the TTM and found limited evidence for the effectiveness of interventions based on this model (Bridle et al., 2005). The two trials involving invitation letters to increase uptake in

cardiac rehabilitation used the theory of planned behaviour and the common-sense model of illness representation (Chapters 2 & 5). It is very intriguing to explore how to operationalise health behaviour theory to motivate patients. Currently, no literature on how to operationalise health behaviour theory in written material exists (further discussed in Chapter 5). Of course, individually directed methods do not address system-related barriers (as already discussed), but considering resource limitation, letter are of low cost and low risk, and hence present a interesting and feasible option to explore.

While evidence for individually directed methods, such as patient reminders and phone calls, became apparent, reminders were less effective in lower socio-economic groups. Goldman and Smith (2002) suggest that less educated patients need simpler regimes and more monitoring (Goldman and Smith, 2002), which would hint towards the use of peers but there is insufficient evidence for peer phone calls from the cardiac rehabilitation trials (Carroll, Rankin and Cooper, 2007; M. Parry, 2008).

Conversely, reminders could be less effective either due to either access being a barrier to use or to the appropriateness of a health service in those under-represented groups. This claim is based on ethnic minorities often being targeted or tailored to in the intervention, as found in the screening literature. As discussed in the introduction, health inequalities can explain the differential access in minority groups in the US (Corcoran, Dattalo and Crowley, 2010; Hall et al., 2008). In fact, a review of predictive factors in mammography use found a variety of socio-economic barriers less important than, for example, immigrant status or physician access, which explains why access-enhancing strategies were most successful in US populations (Schueler, Chu and Smith-Bindman, 2008).

### **3.4.3 Self-management programmes**

The lack of evidence around the promotion of self-management programmes appears to be a symptom of a bigger issue, namely, that the development and implementation of chronic disease programmes is inconsistent, and with the changing political environment, it remains in its infancy. A tendency to provide individual rather than group support might exists. Therefore, no further evidence for cardiac rehabilitation strategies could be extrapolated.

### **3.5 Limitations and strengths of the review of reviews**

There was little overlap of included studies between the six reviews looking at under-represented groups and screening. Reference overlap for all remaining studies was not assessed due to time limitations. Furthermore, only reviews, not single studies, were looked at which means that the assessment of what works provides a guideline only. This scoping review is by no means a complete overview of the research literature. Nevertheless, I started to develop a taxonomy of interventions that aiming at increasing the participation in health services across disciplines. This highlights similarities in designs and their effectiveness across different health care services. More cross-discipline work and further investigations into detailed mechanisms are suggested.

The majority of included studies were conducted in the United States, which may limit the relative importance of intervention methods depending on the particular health care system elsewhere. Furthermore, many of the included trials were gender-specific. When targeting women and cardiac rehabilitation, this may be of more use than non-targeting approaches.

The review, in its more narrative fashion, lacks the critiques of reviews included as well as a clear plan for result synthesis (B N. Green, Johnson and Adams, 2006). Thus this structured review was pragmatic in its nature, because its purpose was to explore intervention strategies across health areas to support or find new options in consideration of the systematic review results (Chapter 2) and to draw upon a broader evidence base before deciding on an intervention to work with. Creswell (2009) has described pragmatism today as having moved towards a focus of inquiry on what works and the research aim – a practical take chosen here.

In addition, the review might be subject to selection and reviewer bias (Chapter 7) as no clear data collection and analysis method was used. This makes the overview a weaker piece of evidence than, for example, the systematic review (B N. Green, Johnson and Adams, 2006). However, to make the review more transparent and repeatable, definitions, criteria and literature search strategies were developed.

### **3.6 Methodological considerations**

This overview of reviews included papers that summarised RCTs, controlled clinical trials, cohort studies and quasi-experimental studies as defined by their original

selection criteria. Many of the considerations debated in Section 2.6 apply here too. These include tensions between experimental designs and patient-centred care as well as external validity, or the fact that the reductionist approach of a quantitative design detects causality but does not explain why something works (Jozien, 2000; Mckee et al., 1998).

### **3.7 Conclusion**

Common ideas underpin interventions designed to increase attendance or participation across health care areas, hence cross-disciplinary reviews are useful, and key findings here are displayed in Box 3.5.

- Common ideas underpin interventions to increase uptake across health care areas
- Lack of evidence on how health care providers engage with chronic disease patients to encourage self-management programme participation
- The role and effects of community health workers/ peer support are worth exploring in more detail because some positive impacts have been observed
- Access-enhancing strategies encourage use of services in under-represented groups; targeting and tailoring to characteristics of the group appear to be supporting use of services but the evidence is less clear
- Individually-directed interventions are common and they appear to be low-risk and cost-effective ways for recruiting patients

#### **Box 3.5: Key findings**

While access-enhancing strategies and the reduction of financial barriers were found to be more successful in the targeting of under-represented groups, letters and phone calls appear to be appropriate, low-risk options for further supporting evidence on uptake in cardiac rehabilitation in the UK. Although letters were found to be less effective in under-represented groups - likely due to access barriers, as Sheldon suggests - any well-planned structured health care intervention can have a significant impact on health inequalities (Sheldon, 2011).

The purpose of this chapter was to find further evidence and new interventions. The results inform the design of an intervention to encourage attendance in CR. In realms of the main research question access remains important, but in terms of this thesis, and given the diversity of cardiac rehabilitation services in the UK (as explored in the next chapter), an access or system intervention is not feasible. Nevertheless, it remains important to recognise the limitations of an individual or behaviour-focused intervention (as discussed in Chapter 7).

This overview lends additional support to invitation letters. Previously used letters had been tailored after health behaviour theory, which was originally developed to explain and predict behaviour but now is increasingly used to design interventions. With further interest in CR invitation letters it is important to first inquire into current use of methods in CR, specifically, *‘what are the strategies used to identify and invite patients to CR in current clinical practice?’* - in order to assess the potential value of advancing letters. The next chapter introduces a short survey of UK cardiac rehabilitation programmes on invitation and identification methods.

## Chapter 4

### **Strategies used to identify and invite patients to CR in current clinical practice**

This chapter fuses the results of previous chapters on interventions to encourage participation in health services and cardiac rehabilitation into a survey exploring which of these methods cardiac rehabilitation programmes currently utilise in practice. Specifically, it looks at which methods used to identify and invite eligible patients to cardiac rehabilitation, which patient groups may be less likely to attend, and how this is addressed.

With the knowledge that clinical practice in cardiac rehabilitation, terms of referral and invitation methods as well as programme setup, is very diverse, this chapter answers the research aim 4) *which invitation methods are used in current practice*. It is important to first inquire about current use of invitation strategies in CR to assess practicability of intervention methods. Based on the reviews in the two previous chapters, motivational letters became of interest as an appropriate, low-cost and low-risk intervention for further primary research. The systematic review of interventions to increase uptake of cardiac rehabilitation also found peer support (which merits further enquiry) and professional health care and liaison support (both of which had a positive impact, but are less feasible for doctoral thesis as are broader access-enhancing interventions) successfully used in other health care areas (Chapter 3). Organisational and financial barriers to attendance exist.

Current policy documents recommend the use of letters, calls and direct contact to encourage attendance, but no aggregate information on common practice is currently available (National Institute for Health and Clinical Excellence, 2007). A short electronic survey was utilised as a uniformed, easy method to collect information about practice routines based on the intervention methods discovered in previous chapters. The results further inform the decision on how to proceed with the development of an intervention to encourage attendance and to assess the focus on motivational letters as a feasible option.

## 4.1 Background

Through the National Health Service (NHS), CR is offered to patients at no additional cost in the UK, yet uptake rates remain below desirable (The National Audit of Cardiac Rehabilitation, 2011) (Chapter 1). The National Audit of Cardiac Rehabilitation (NACR) collects data to show how many patients and which diagnoses are catered for. The NACR evaluates service provision and flags up inequalities (Lewin, Thompson and Roebuck, 2004). However, CR attendance rates as shown by the NACR provide an incomplete picture, and the number of patients not referred to CR services remains an estimate (The National Audit of Cardiac Rehabilitation, 2010). Not all programmes provide complete data, and links to the Hospital Episodes Statistics (HES), to track eligible patients along their care pathway, are missing. This may be, because cardiac rehabilitation programmes operate differently in terms of referral and enrolment practices, and in the way the programme elements are organised. Little information is available, which somewhat hinders service improvement activities. An exploration of working practices could encourage knowledge exchange and discussion.

In addition, financial resources are extremely variable, for example, some primary care trusts secured funding through health action zones<sup>24</sup> allowing them to secure more support since then. Other programmes lack funds, which impacts on service provision. In Yorkshire, for example, a qualitative study found staff to be aware of limited service availability (Lindsay, 2008). This may increase waiting times and influence which patients are invited.

While cardiac rehabilitation is divided into four phases (Box 4.1), the British Association of Cardiac Prevention and Rehabilitation (BACPR) advocates a move towards a more menu-based programme. However, due to scarce resources, some programmes had to cut education or relaxation sessions, and they can no longer provide menu-based choices tailored to patients' needs (personal communication with CR coordinators as part of the evaluation, Chapter 6).

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<sup>24</sup> Health Action Zones started in 1997 to work locally across boundaries and improve services, especially focusing on the reduction of health inequalities. (Health Development Agency, 2004)



Phase 1: Post-event in hospital, where patients recuperate and are assessed; education starts

Phase 2: Post-Discharge recuperation at home, when phone support or home visits take place

Phase 3: Approximately six weeks post-event, a multi-disciplinary team assists with exercise, medication and lifestyle change management; typically 6-8 week outpatient programme

Phase 4: Long-term maintenance; can be in form of a cardiac support group.

#### **Box 4.1: Phases of cardiac rehabilitation**

No clear evidence on under-represented groups emerged from the literature (Chapter 1). Assessment categories, geographic variation and diversity in practice can provide a blurred picture, but the NACR only shows that ‘older women’ are missing (Valencia, Savage and Ades, 2011). The composition of the population in different areas may impact on practice in diverse ways, such as tailoring of programme content to better meet needs. It remains important to explore which patient groups are less likely to attend, why or at which stage in the clinical pathway patients drop out or are simply overlooked, to better understand the patients’ and the programme needs. Interestingly, the Commission for Healthcare Audit and Inspection discovered that 60% ( $n = 1124$ ) of non-attenders in the community had never been offered CR (Commission for Healthcare Audit and Inspection, 2004), which could partly explain low uptake rates.

Little is known about how cardiac rehabilitation programmes routinely identify and invite their patients, and whether the development and/or implementation of letters would be worthwhile here.

##### **4.1.1 Objectives**

The overall aim of the survey was to explore which methods are used to identify and invite eligible patients to CR and whether any of those affect attendance rates. Furthermore, patients less likely to attend and methods to address this were explored. The objectives were to:

- investigate methods used to identify and invite eligible patients to cardiac rehabilitation, and to investigate whether these are associated with attendance rates;

- investigate patient groups less likely to attend cardiac rehabilitation as perceived by the individual programme staff, and how this is addressed.

In response to the overall research question, this survey explored current practice to better situate the findings of the reviews on interventions to increase uptake (Chapters 2 and 3) in clinical practice. It is important to consider programme setup, policy and practice (Chapter 1) to be aware of system-related barriers and facilitators to attendance before making a choice of intervention (further discussed in Chapter 6).

## **4.2 Methods**

A cross-sectional 10-item internet-based survey was sent to publically identified cardiac rehabilitation coordinators in the UK. The following section will provide a brief overview of materials, participants and procedures.

### **4.2.1 Material**

The survey items were based on the list of interventions to *invite* patients that was derived from the reviews in Chapters 2 and 3. Since there is no literature on strategies used to *identify* eligible patients, experts on cardiac rehabilitation in the UK (Professors Robert J. Lewin and Patrick Doherty) were consulted on typically used identification and invitation methods. The survey was piloted prior to use. All but two questions were designed in a binary manner calling for yes/no responses. A summary of the 10 items is given in Box 4.2. Uptake is defined here by the survey item: ‘Approximately what proportion (%) of patients who are invited to your programme do you think come to at least one session/assessment?’ - a definition familiar to NACR users.

Which phases of Cardiac Rehabilitation do you offer? Phase 1-4  
Approximately what proportion (%) of patients who are invited to your programme do you think come to at least one session/assessment? Please provide % for all that apply. Phase 1-4

Which of these methods do you use to IDENTIFY patients? Please select all that apply.

- Going around hospital wards on a regular basis
- Nurses/physiotherapists on wards make referral to you
- Nurses/physiotherapists on wards tell patients about the programme
- Cardiologist/hospital physician refers all suitable patients to programme by letter/phone/fax
- Cardiologist / hospital physician tells every suitable patient about programme
- Use troponin list to identify patients
- Other

Which of these methods do you currently use to INVITE patients? Please select all that apply.

- In-hospital invitation by a member of the CR team
- In-hospital recruitment by another health professional
- Patients are told about programme and then contact the CR programme/nurse themselves
- Post-discharge letter with your contact details
- Every patient sent a written invitation /reminder
- Every patient gets a phone call from a professional in your team
- Every patient gets a phone call from peers
- Home visits by a professional in your team
- Home visits by peers
- Other

If a patient does not respond/attend do you have the resources to chase them up?  
Yes/No

If yes, how do you do this?

Have you found anything that helped to recruit more people? Yes/No

If yes, please specify.

Are any of the groups below less likely to come? Please select all that apply.

- Older women
- Older men
- People at work
- People from ethnic minorities
- People from poorer parts of the area
- People from wealthier parts
- Other

Do you use any specific methods to recruit patients from the groups you indicated above?

## **Box 4.2: Survey**

### **4.2.2 Participants**

The sampling frame encompassed the 354 publicly identified ‘coordinators’ of UK cardiac rehabilitation programmes as listed online on the National Register of CR/

National Audit of Cardiac Rehabilitation (NACR)<sup>25</sup>. The list includes programmes from Wales, England, Northern Ireland and Scotland. Note that Scottish programmes do not participate in the NACR, and not all other programmes impute data. All listed coordinators, with the exception of phase 4-only programme coordinators<sup>26</sup>, were contacted via email, and it was asked for the most appropriate member of the CR team to complete the questionnaire.

#### **4.2.3 Procedure**

The website link to a cross-sectional 10-item survey (Box 4.2) was emailed to the 354 publicly listed UK cardiac rehabilitation coordinators. First, the survey was tested with 10 randomly selected cardiac rehabilitation programmes; nine responded within 10 days and one reminder email. The purpose was to ensure clarity of layout. Responders were asked to comment, but no feedback was received. Changes were not made as neither questions nor irregularities arose. This is an audit-based survey of an exploratory nature (validity and reliability are discussed below).

Following this test, the remaining 344 cardiac rehabilitation centres were contacted via email and asked to complete the online survey. Several reminders were sent out via email over a period of 10 weeks. Data collection took place in the summer of 2011 (14<sup>th</sup> June 2011 – 26<sup>th</sup> of August 2011)<sup>27</sup>.

#### **4.2.4 Analyses**

Commonly used descriptive statistical parameters including number of cases, percentages, means or medians, and standard deviations were utilised to explore the data and the question which methods are used in what frequency to identify and invite patients to CR. The outcome variables used for the majority of inferential analyses were uptake rates. These variables were collected in percentages (0-100) and hence treated as ratio scale data. Other variables used were binary, hence differences in mean uptake rates could be explored using independent t-tests

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<sup>25</sup> <http://maps.cardiac-rehabilitation.net/>

<sup>26</sup> At this stage, patients would have been through a phase 3 programme and this no longer stands as a first time contact method.

<sup>27</sup> Seasonal variations are not relevant (Dales, Veronica 2012, the NACR specialist, personal communication).

(assumptions met, see Appendix C). Crude and unadjusted analyses were performed due to the small sample size and the exploratory nature of the survey.

Some outcome variables, such as number of identification/invitation methods, are count data, but were treated as continuous variables. Therefore, Pearson's product moment correlation coefficient was explored to investigate, for example, whether these are associated with attendance rates.

*Hypotheses:* It was hypothesised that there is: 1) a positive association between number of identification methods and uptake rates in phase 1, and 2) a positive association between phase 3 uptake rates and number of methods used to invite and identify eligible patients (assumptions, see Appendix C). Furthermore, it was hypothesised that, 3) a difference in mean uptake rates between CRPs (3a) indicated to have resources to chase-up non-responsive patients and those who do not have resources to chase-up non-responsive patients, and (3b) those who have found strategies that recruit more patients and those who have not found strategies that recruit more patients.

Since invitation letters were identified by the systematic review as increasing uptake (Chapter 2), and results are somewhat supported by the findings of the overview of reviews (Chapter 3), letter use was further explored to see whether uptake rates differ between programmes that use and those that do not use them.

When the dataset was first explored, it became apparent that almost all cases were complete. Therefore, it was decided to treat those cases as having missing data in which more than five of the non-binary data collected were missing. The number five was chosen arbitrarily, because it meant that approximately 50% of the cases' data would be missing. Where this was true, the case was removed for analytical purposes; no case was removed, as all participating programmes provided at least 90% of the data. Pairwise exclusion was chosen.

Data was analysed using STATA 10.

#### **4.2.5 Ethical considerations**

The Chair of the Department of Health Sciences Research Governance Committee at the University of York had confirmed this project to be an audit process (Appendix C; see methodological considerations, Section 4.6). In addition, approval to contact

publically identified ‘coordinators’ of the CR programmes as listed online on the National Register of CR/National Audit of Cardiac Rehabilitation (NACR) website was given by the appropriate data protection personnel (Appendix C).

### 4.3 Results

190 cardiac rehabilitation programmes (CRP) participated, which is a response rate of 53%. The following sections present an overview of the survey results on phases of cardiac rehabilitation, uptakes rates<sup>28</sup>, identification and invitation methods as well as non-attending groups. Attendance rates were compared, and associations between uptake rates and identification and invitation methods were explored.

#### 4.3.1 Attendance

Cardiac rehabilitation in the UK is traditionally divided into four phases (Box.4.1), but not all programmes offer all four phases. Notably, 9 % ( $n = 17$ ) sites offer just one phase, 25.3% ( $n = 48$ ) sites offer two phases of CR, 40.5% ( $n = 77$ ) of CRPs offer three phases of CR, and only 25.3% ( $n = 48$ ) of CRPs offer all four phases of CR. The proportions of referred patients participating in each of the four phases of CR are shown in Table 4.1. The attendance rate in phase 3 of cardiac rehabilitation is averaged at 66.3% of patients invited.

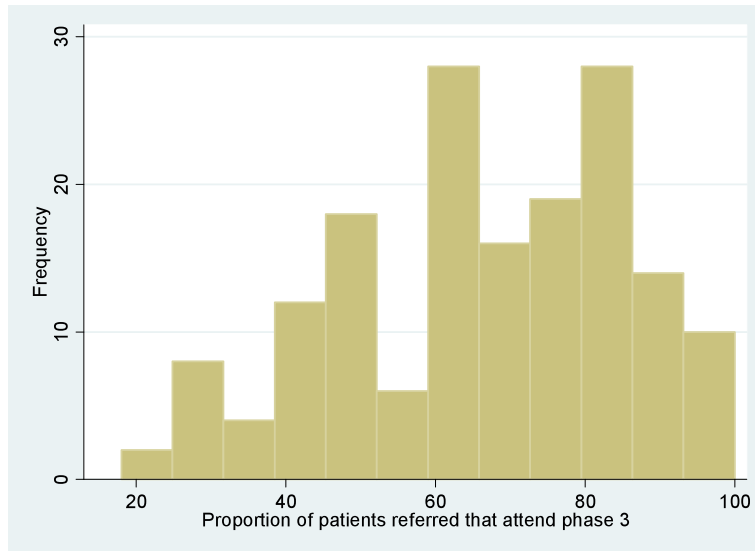
**Table 4.1: Attendance rates per CR phase**

Phase	<i>n</i> of CRPs offering each phase	Uptake <i>M</i> ( <i>SD</i> )	Range	<i>N</i>
Phase 1	136	83.5% (26.0)	0-100	112
Phase 2	157	81.5 % (19.9)	0-100	131
Phase 3	178	66.3% (18.7)	18-100	165
Phase 4	65	43.5% (25.7)	0-99	66

As illustrated by Figure 4.1, uptake rates in phase 3 of cardiac rehabilitation are quite high with an average of 66.3% (range: 18-100%), as compared to the NACR data (~40%), further discussed below.

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<sup>28</sup> *Uptake* is defined here by the survey item: ‘Approximately what proportion (%) of patients who are invited to your programme do you think come to at least one session/assessment?’ This is equivalent to the NACR definition and used interchangeably with *attendance* throughout this thesis.



**Figure 4.1: Frequency distribution of uptake (% of patient in phase 3)**

#### 4.3.2 Identification

The most common methods used to find eligible patients were: ‘CRPs receiving referrals from the wards’ ( $n = 157$ ), or ‘from cardiologist/hospital physician’ ( $n = 102$ ) and ‘going around wards regularly’ ( $n = 112$ ) (Table 4.2). Nine programmes (4.74%) indicated that they use all six methods listed to identify patients, 10.5% ( $n = 20$ ) of programmes use five, 17.9 % ( $n = 34$ ) of the programmes use four, and 26.8 % ( $n = 51$ ) of programmes use three methods.

**Table 4.2: Methods used to identify patients**

Methods used to identify patients	%	<i>n</i>
Nurses/physiotherapists on wards make referral to the CRP	82.63	157
Going around wards regularly	58.95	112
Cardiologist/hospital physician refers all suitable patients to programme by letter/phone/fax	53.68	102
Nurses/physiotherapists on wards tell patients about the programme	39.47	75
Troponin list	29.47	56
Cardiologist/hospital physician tells every suitable patient about programme	23.68	45
Other methods	50.53	96
For example, GP referrals		24
Referral from tertiary centres		20

### 4.3.3 Invitation

The most frequently used methods to invite patients to attend CR indicated here were: ‘in-hospital invitation by CR team’ ( $n = 134$ ), ‘calling every patient’ ( $n = 133$ ) and using a ‘written invitation/reminder’ ( $n = 96$ ). Most programmes ( $n = 127$ ) use at least 3 methods to invite patients (Table 4.3). Specifically, 23.2% ( $n = 44$ ), 22.6 % ( $n = 43$ ) and 18.4 % ( $n = 35$ ) of programmes use 4, 3 and 2 of the methods listed, respectively. Somewhat surprisingly, 12.6 % ( $n = 24$ ) use just 1 method for inviting patients. Of those 24 programmes that used just 1 method to invite patients, the most common method used was ‘every patient gets a phone call from a professional in the team’ ( $n = 10$ ).

**Table 4.3: Methods used to invite patients**

Methods used to invite patients to cardiac rehabilitation	%	<i>n</i>
In-hospital invitation by a member of the CR team	70.53	134
Every patient gets a phone call from a professional in your team	70	133
Every patient sent a written invitation /reminder	50.53	96
Home visits by a professional in your team	40.53	77
Post-discharge letter with your contact details	33.68	64
Patients are told about programme and then contact the CR programme/nurse themselves	27.89	53
In-hospital recruitment by another health professional	21.58	41
Every patient gets a phone call from peers	6.32	12
Home visits by peers	2.63	5
Other methods to invite patients (phone calls, letters and email or a combination thereof was mentioned most frequently)	19.47	37

### 4.3.4 Non-responders

When asked about resources to chase up non-responders, 76.3% ( $n = 145$ ) of CRP staff replied that they have resources to do so, and all provided details on how they do this. The majority of CRPs use telephone calls, often combined with letters, to reach their patients (75.2%,  $n = 112$ ,  $N = 149$ ), while 8.1% ( $n = 12$ ) use letters only. Another 8.7% of CRPs ( $n = 13$ ) stated that in addition, the patients’ general practitioner (GP) is informed – a notably low involvement of primary care, especially at a time when commission is handled by the general practitioner (or clinical commissioning groups), and quality and outcome framework targets are



being debated (Great Britain. Department of Health. Cardiovascular Disease Team, 2013).

When asked if they had found anything that helped recruit more people, 61.2 % ( $n=118$ ) confirmed this, and 130 CRPs provided details on a number of approaches. Telephone calls were mentioned (19.2% ( $n = 25$ )) as well as good communication well with the patients (16.2% ( $n = 21$ )), followed by leaflets (5.4% ( $n = 7$ )) and letters (5.4% ( $n = 7$ )).

#### 4.3.5 Potentially under-represented groups

Altogether, 156 CRPs indicated at least one group to be perceived as less likely to attend (Table 4.4).

**Table 4.4: Patients less likely to attend**

Patient groups less likely to attend	<i>n</i> (CRP)	%
People at work	124	65.26
Older women	79	41.58
People from poorer parts	48	25.26
Ethnic minorities	41	21.58
Older men	26	13.68
People from wealthier parts	8	4.21

When asked which other groups are less likely to attend, 52 responses were provided that varied greatly, yet ‘lack of transport/transportation issues’ was mentioned most frequently (26.9%,  $n = 14$ ).

Notably, 16.8 % ( $n = 34$ ) of the CRPs did not indicate any of the groups as less likely to attend 33.2% ( $n = 63$ ) selected just one group (mostly ‘people at work’ ( $n = 45$ )), 25.3% ( $n = 48$ ) selected two groups, and 15.3% ( $n = 29$ ) selected three patient groups that were less likely to attend CR. Lastly, 9.5% ( $n = 18$ ) indicated four or more groups mentioned that were less likely to attend.

A total of 72.1 % ( $n = 137$ ) of the 190 participating programmes replied when asked about methods to recruit patients less likely to attend. The most common answers were: offering home exercise programmes/Heart Manual ( $n = 19$ ), providing assistance with transportation ( $n = 10$ ) and offering evening/flexible classes ( $n = 19$ ). Many other things were mentioned, including slower-paced classes, contacting the employer or using religious venues, perhaps reflecting local circumstances.

#### **4.3.6 Associations between uptake rates, identification and invitation methods**

The variables used here, namely uptake rates in phase 1 and 3, total number of identification methods and total number of invitation methods, are all on an interval or ratio scale. One outlier was excluded from the Pearson's product-moment correlation coefficient calculation for invitation methods and uptake (for details, see Appendix C).

It was hypothesised that 1) there is a positive association between number of identification methods and uptake rates in phase 1. The overall Pearson's correlation coefficient for uptake and identification methods was found to be  $r(110) = .19$ , ( $p = .5$ ). The null hypothesis was not rejected.

In addition, it was also hypothesised that 2) there is a positive association between phase 3 uptake rates and number of methods used to invite eligible patients. The Pearson's correlation coefficient was found to be  $r(162) = .09$ , ( $p = .23$ ). For both results, the coefficient is almost zero, the p-value is above  $p = .05$  and hence, there is no association between the variables, and the null hypothesis is not rejected. From these analyses, it can be seen that the number of identification/invitation strategies used did not affect uptake rates.

Letters were further explored. Of the 190 CRPs partaking, 50.5% ( $n = 96$ ) use invitation letters. Those CRPs use on average one other invitation method ( $M = 3.89$ ,  $SD = 1.34$ ;  $M = 2.57$ ,  $SD = 1.46$ , respectively). The CRPs that use letters have an average phase 3 uptake rate of 68.85% ( $SD = 18.56$ ,  $n = 86$ ). Those who do not use letters have an average phase 3 uptake rate of 63.58% ( $SD = 18.78$ ,  $n = 79$ ), with no significant difference ( $t = -1.81$ ,  $p = .07$ ).

Lastly, it was hypothesised that 3) there is a significant difference in mean attendance rates between CRPs that (3a) indicated to have resources to chase-up non-responsive patients and those who do not have resources to chase-up non-responsive patients and (3b) those who have found strategies that recruit more patients and those who do not have found strategies that recruit more patients were compared. As mentioned in the introduction, the availability of resources and the knowledge of effective recruitment strategies may affect uptake rates in phase 3. CRPs were sorted into two groups according to the other variable (resources; non-responder strategies).

Results of the t-tests can be seen in Table 4. 5 (assumptions are met, see Appendix C).

**Table 4.5: Average uptake rates per group, test values**

<i>Uptake rates</i>	<i>N</i>	<i>M(SD)</i>	<i>t-test</i>	<i>p-value</i>
(1) no resources	36	64.63 (20.8)		
resources	129	66.80 (18.24)	-0.62	.54
(2) No recruitment	63	64.49 (19.98)		
recruitment	102	67.47(18.03)	-0.99	.32

No significant differences were found in uptake rates.

## **4.4 Discussion**

This was the first survey enquiring about methods used to identify and invite eligible patients to CR in the UK. This survey explored current practice to better situate the findings of the reviews on interventions to increase uptake (Chapters 2 and 3) in clinical practice and to assess the potential use and appropriateness of developing invitation letters.

### **4.4.1 Participating programmes**

The average attendance rate of 66% differs from the figure of 42% provided by the NACR (The National Audit of Cardiac Rehabilitation, 2011). The NACR calculates this figure based on patients discharged alive from hospital following MI, PCI or CABG whereas the percentage given by the programmes is likely based on all patients referred or known to them. It is to be expected that the percentage given by the programmes, here would be somewhat higher here than the NACR figure.

Considering the survey's low response rate of 53% these figures may indicate that primarily better-resourced programmes participated. This is further supported by the fact that the majority of CRP staff indicated the availability of resources to chase up non-responders. Rates of participation in phase 2 were also above 80%, which suggests good support to patients while at home. This could be one explanation as to why, in general, none of the analyses found a statistically significant impact on uptake rates. That said self-selection bias always presents a short-coming in research. Patients unknown to the programmes may not be included in the CRPs.

In regards to the overall aim *to encourage attendance at cardiac rehabilitation in patients invited*, this constitutes an important consideration when planning on how to evaluate the intervention: to ideally avoid self-selection bias and include all eligible patients, while being as pragmatic as possible (Chapter 6).

#### **4.4.2 Identification and invitation methods**

‘Referrals from hospital wards’ or ‘from cardiologist/hospital physician’, ‘going round wards’ and ‘nurses/physiotherapists telling patients about the programme’ are the four most commonly used practices to identify patients eligible for cardiac rehabilitation. The average participation rate in phase one is 83.5%, which, in fact, is close to the estimate for the percentage of patients expected to be well enough to attend CR (Lewin, RJ, 2012, personal communication; Great Britain. Department of Health, 2000).

To invite patients to cardiac rehabilitation, ‘in-hospital invitation by CR team’ via ‘telephone call’ or ‘written invitation/reminder’ were mostly used. Patients are also visited at home, which requires more resources. Visits might be necessary because the target for discharge of patients from hospital is two days; a knock-on effect might be observed here, with a higher likelihood for the CR team to miss patients in hospital (Doherty, P., 2012, personal communication). Some patients could get discharged into the community, and since GP involvement is rare, some may never know they should have gone to CR. As mentioned in the introduction, 66% of non-attenders had never been invited (Commission for Healthcare Audit and Inspection, 2004).

Written invitation/reminder letters were used by 50.5% of the participating programmes. No statistical difference in attendance could be observed between those that use a letter and those that do not (68.85%, 63.58%, respectively; further discussed in the last paragraph). Telephone calls were used by 2/3 of programmes to invite patients generally and - alone or in combination with letters - as the most successful methods for chasing up non-responders. The availability of resources to contact non-responders or having found something that helps to recruit more patients had no impact on uptake. Individual visits and telephone calls can be resource-intensive. The overview of reviews in Chapter 3 suggested that direct contact methods are effective. For example, Yabroff et al. found the combination of

telephone and letter to successfully increase screening uptake (Yabroff, Mangan and Mandelblatt, 2003). If other programmes use these methods too, one wonders why the national uptake rate remains low. (A related discussion on the presentation of CR as treatment versus lifestyle choice can be found in Chapter 7).

Most programmes use at least three methods to both identify and invite patient, but using more methods was not associated with attendance rates in phase 3. It has been suggested that low uptake rates in CR are often caused by the lack of referral (Jackson et al., 2005). Interestingly, automated referral was not mentioned here, and it remains surprising that this has not been implemented. Gravely-Witte and colleagues' review found that automated referral could have a positive effect on enrolment rates (Gravely-Witte et al., 2010; Tiller et al., 2013). Furthermore, Grace et al. investigated the effect of four referral methods at a number of sites in Canada (Grace et al., 2011). Their prospective study found that automated and liaison referral increased the chances of being referred by eight times. In any case, once referral had taken place, uptake was always above 80% in this study, which suggests that more patients are lost at the identification rather than the invitation stage (Grace et al., 2011). Thus, improved access may not always lead to a better outcome, as discussed in Chapter 7. Better data linking and liaison should be considered, thus the need for higher capacity as a result of improved uptake should be kept in mind (Tiller et al., 2013).

Integrated care and the involvement of primary care become increasingly important with the new commissioning services in the UK. At the moment, cardiac rehabilitation is separate from primary care and GP involvement was rarely mentioned here (Note that Quality and Outcome Framework targets for CR are currently being discussed). A Northern Ireland study investigating primary care involvement found that for 23% of patients, no information on CR was available in their primary care records (Cupples et al., 2010). Furthermore, the present study indicates that not all CRPs offer all phases of CR, which further questions the continuity of care. This supports liaison work (Jolly et al., 1998).

The diversity of referral and invitation methods used may be a symptom of a fragmented, hugely varied service, which aggravates service improvement (Chapter 6 & 7). For example, in Chapter 5, which also focuses on improving motivational

letters to encourage attendance, the tensions between organisational setup (barrier being small spaces) and individual motivators (such as partner involvement) are debated. And while diversity in CR practices also suggests tailoring to local circumstances and context-sensitive policy, better linkages appear appropriate as a first step. Due to limited capacity and resources and hence limited ability to provide good services, the provision of CR remains complex (Fernandez et al., 2011).

#### **4.4.3 Groups less likely to attend**

The most frequently reported patient group to be less likely to attend CR was ‘people at work’. Work could be a confounder for socio-economic status through, for example, the lack of sick pay. Some employment groups, such as blue-collar workers or unskilled labourers, may not get paid when not working, or it could be harder for them to get time off work. Socio-economic background can be an underlying explanatory factor for work commitments and links between socio-economic background and heart disease exist (as briefly mentioned in Chapter 1) (Mendes and Banerjee, 2010). Together with other structural barriers like opening hours or appointment times, those wider social determinants are rarely discussed in the CR literature (A. M. Clark, Barbour and McIntyre, 2002; A. M. Clark et al., 2004). The taxonomy of interventions to increase service uptake developed in Chapter 3 suggested that access-enhancing strategies<sup>29</sup> were the most successful intervention to increase uptake of services in under-represented groups.

‘Lack of transport’ was an additional reason for non-attendance. This could, in fact, also mask older women, especially in more rural areas (Regitz-Zagrosek, 2012). The NACR finds older women to be the only under-represented group. By the nature of the disease, women tend to be older and present with more co-morbidities. Another study discovered that older patients are less often invited and less likely to attend in the Northern Ireland sample (Cupples et al., 2010). A recent Black county audit report found older patients to be the only under-represented group (Tipson, 2011).

As suggested by the NACR in 2010, ethnic minorities may not be under-represented, as thus indicated by 20% of CRPs here. Grewal et al. found a variety of issues when interviewing South Asian patients, including communication of information and

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<sup>29</sup> Access-enhancing can refer to bringing the service to the patient assistance with tackling potential financial and structural barriers, or cues to action (Legler *et al.*, 2002)

flexibility (Grewal et al., 2010). Both appear to be important for other patient groups too. Taylor et al. found in their review that a better understanding of heart disease is related to attendance of CR (G H. Taylor, Wilson and Sharp, 2011). Extra encouragement and offering a home-based programme (such as the Heart Manual, Road to Recovery) were mentioned in this survey as ways of getting more patients to attend as were evening classes.

Interestingly, Madden and colleagues' qualitative study found that patients see choice as less obvious than health care professionals, and due to a lack of alternatives, choice was not often a real choice. Restrictions such as area, transport, hours, etc., present barriers to making choices (Madden, Furze and Lewin, 2011). The diverse information on patient groups collected here perhaps reflects in the diverse invitation strategies that CRPs employ to recruit these patients. Local circumstances and the nature of the resident population influence working practices. This suggests, contrary to Madden, that health care professionals do make an effort to communicate and present options well. However, as discussed above, it appears that mainly well-resourced CRPs participated here.

The diversity of CRP services reflects in the different phases of CR offered, various combinations of identification and invitation methods utilised as well as the diversity of under-represented groups and ways to invite them. Considering this context and the initial interest in invitation letters sparked by the previous reviews, the survey revealed that letters are used by 50% of CRPs, but nothing is known about the content or use within local contexts. Letters are a low-risk option for encouraging attendance of CR in a diverse health service with locally different under-represented patient groups. However, tailoring the letters to locally under-represented groups would lead to too many types of letters and perhaps ineffective use. A more generic intervention using health behaviour theory to motivate patients requires low resources and is straightforward to use in clinical practice. Therefore, further exploring and advancing the content could be valuable, since motivational letters had a positive impact in past trials. One trial compared them with no letters (Wyer et al., 2001b) and another one with a standard letter, but no information about standard content or health behaviour theory operationalisation was given (Mosleh, Kiger and Campbell, 2009). If successful, this cost-effective intervention could subsequently be

implemented on a larger scale with the potential of reaching more patients. (The development and evaluation of the letters are described in Chapters 5-6).

#### **4.5 Limitations and strengths**

First, the data collected in this report is anecdotal, and work, age and other factors could be confounders. Secondly, the way services are provided differs in each region and might therefore influence who attends and who gets invited, taking limited resources into account.

A low response rate and self-selection may present limitations. The rather high uptake rates reflected in this sample may indicate that results only represent well-resourced programmes. Although one may assume that methods to identify and invite patients are similar to other (non-participating) programmes, the association with uptake rates could be different, which impacts on external validity. Due to the cross-sectional nature, causality cannot be determined, as temporal directionality remains unknown (Bowling, 1997). And while the anonymity of an online survey encourages honesty, information may be presented in a more favourable light.

However, considering the scarcity of resources in UK cardiac rehabilitation practice, an internet-based, rather than a paper-based, survey was convenient, fast and economical in reaching health care professionals. It could be completed at a time of convenience and likely elicited more responses than a paper-based or telephone surveys would have, albeit only in the first few days (Opperman, 1995 as cited in Jansen, Corley and Jansen, 2007). Traditional drawbacks of web-based surveys, such as a biased sample or technological problems, were less relevant here because all cardiac rehabilitation coordinators work with computers and could contact internal IT or the researcher for assistance (Jansen, Corley and Jansen, 2007).

The survey items were derived from the systematic review (Chapter 2) and the narrative review (Chapter 3), which means that the survey questions were guided by evidence, and systematically assembled. Experts in cardiac rehabilitation were consulted (Professors Robert J Lewin and Patrick Doherty). Content validity was assured (Fink, 2009).

Furthermore, the layout had already been optimised through surveymonkey (<http://www.surveymonkey.com/>) and responses were collected in an account only accessible with a password to ensure confidentiality.



## 4.6 Methodological considerations

The survey took an audit-driven approach, since it explored current practice of identifying and inviting patients to CR to see whether further developing invitation letters would be viable. An audit, defined in Box 4.3, is designed to assess current practice in order to maintain or improve said practice (Bowling, 1997). No change was involved, the project did not include patients and requested minimal staff time in answering the 10 questions online (Wade, 2005).

An audit can be defined as

*'...a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change. Aspects of the structure, processes and outcomes of care are selected and systematically evaluated against explicit criteria. Where indicated, changes are implemented at an individual, team, or service level and further monitoring is used to confirm improvement in healthcare delivery.'*

(Principles for Best Practice in Clinical Audit, NICE, 2002. Available at: [http://www.leedsteachinghospitals.com/sites/research\\_and\\_development/quick.php](http://www.leedsteachinghospitals.com/sites/research_and_development/quick.php) [Accessed 18.10.2011])

### Box 4.3: Definition of an audit

Reliability, the consistency of the results across time, individuals and setting, is less narrow in audits than in surveys (Colorado State University, 1993-2012; The Office of Auditor General Canada, 2007). Cronbach's alpha was not appropriate to compute, because no concepts (for example, traits or skills) were measured using multiple items.

A survey is a quantitative method measuring phenomena in the post-positivist tradition (Bowling, 1997). This means categories are pre-defined and relationships are explored (Creswell, 2007, 2009). Thus, while the categories for non-responders, for example, are derived from previous literature reviews, the collected responses originate from staff reporting their perception of who these patients are, rather than from data they collected. Boundaries between qualitative and quantitative data become less clear, as discussed in Chapter 7.

## 4.7 Conclusion

A number of different methods to identify and invite patients are used, and good uptake rates could be observed. Key findings are listed in Box 4.4.

- ‘Referral from ward’, ‘ward visits’, ‘cardiologist/physician referral’ were the three most frequently indicated identification methods
- ‘In-hospital’, ‘phone call’ and ‘written invite/reminder’ were the three most frequently indicated invitation methods
- A number of methods to identify and invite patients are used simultaneously, differing by programme
- No associations between uptake rates and number of identification/invitation methods found
- Methods used do not predict uptake
- ‘People at work’ was most frequently indicated as patients less likely to attend, followed by ‘older women’
- Resource availability and knowledge of successful methods to recruit ‘patients less likely to attend’ had no impact on uptake rates

### Box 4.4: Key findings

Since the literature suggests that patients are missing at the referral and identification stage, more attention and possibly automated referral is recommended, while noting that improving access may not improve attendance or outcome (Chapter 7).

Due to differences in practice, service audit and improvement activities remain challenging, yet the results here provide useful information towards service development and knowledge exchange activities. With the current NHS developments heart disease rehabilitation is being prioritised, which cardiac rehabilitation programmes should be able to use to their advantage, securing support and resources (Lewin, R.J., 2012, personal communication).

Further advancing the content of invitation letters would be valuable since letters are being used by 50% of CRPs and this cost-effective intervention could subsequently be implemented on a larger scale. Little is known at the moment about how the letters used in practice are written/developed at the moment. Previously, two trials

used letters tailored after health behaviour theory (Chapter 2), but there is no information on whether the results have been implemented. Health behaviour theory is increasingly used for tailoring interventions, but there is a gap in the literature on how exactly this is done. Therefore, it is of interest to explore *the patient perspective on letters of invitation to CR to elicit key motivational messages and as a means of exploring the operationalisation of health behaviour theory.*



## Chapter 5

### **The patient perspective on letters of invitation to CR as a means of exploring the operationalisation of health behaviour theory**

Based on the evidence of the reviews and the survey as well as feasibility considerations, the conclusion was drawn that health behaviour theory-based invitation letters are the most appropriate method for conducting further primary research in the United Kingdom. Since letters have been found to be successful in increasing uptake in two small trials (Chapter 2) and are economical, low-risk and easy to implement (and to potentially distribute via the NACR), it is of interest to investigate invitation letters further. The patients' perspectives become important when developing such letters to avoid inappropriate content and in order to formulate messages that resonates with the patients' experience rather than with clinical or health care professionals' opinions.

I decided to consult patients comparing two existing letters instrumentalising descriptive qualitative research methods, specifically thematic analyses of semi-structured telephone interviews. This allowed me to investigate potential key messages likely to motivate people to attend CR. It enabled me to explore the operationalisation of health behaviour theory into motivational text to help contribute further theoretical knowledge in health communication. This theoretically informed, yet pragmatic approach answers research aim 5) *to investigate the perception of existing invitation letters as a means of exploring how health behaviour theory is operationalised in written materials* to further develop previously tested letters.

#### **5.1 Background**

Health behaviour theories are used to predict and identify determinants of behaviour. They are increasingly used to design interventions in health care that target said determinants and to test their effectiveness (Michie et al., 2008). Such models, often similar in concepts incorporate cognitive processes and stand in contrast to the medical model that looks at physical symptoms only (Diefenbach and Leventhal, 1996; Munro et al., 2007; Redding et al., 2000). The disadvantages and advantages of working with behaviour models are listed in Box 5.1.

<p>The advantages of using behaviour models:</p>	<p>General points of criticism of behaviour models include:</p>
<p>Parsimonious models that help understand and organise the many factors influencing health behaviour, coping or decisions to act (Diefenbach and Leventhal, 1996)</p>	<p>Models do not appear to have evolved in the last decades. Testing those theories on health behaviour rather than just using the theory to inform the research takes place (Painter et al., 2008)</p>
<p>Theories focus on key determinants of behaviour, which are perhaps modifiable (Sutton, 2010)</p>	<p>Theories are designed for the individual and often fail to incorporate wider determinants of behaviour (Crosby and Noar, 2010). There are also questions in terms of socio-cultural context (Munro et al., 2007), and social class could be a moderator (Mceachan et al., 2011);</p>
<p>Many provide clear guidance on how to operationalise the theory to measure behaviour (e.g. theory of planned behaviour (Mceachan et al., 2011))</p>	<p>These models are not dynamic; while aiding our understanding, they are often too rational and have no emotional component</p>
<p>Using models to predict behaviour can be useful in understanding and, in applied research, explaining behaviour, which can help directing the focus of an intervention (Mceachan et al., 2011))</p>	<p>Lack of predictability (weak correlations between determinants) or small effect sizes are found</p>

**Box 5.1: Advantages and disadvantages of using health behaviour models**

In cardiac rehabilitation research, generic health behaviour theories have been used to identify concepts that instigate a behaviour change, for example, to explore or modify attendance rates (Sutton, 2010). As listed in Box 5.1, studies (mentioned below) identify modifiable determinants and aid in the understanding of behaviour but focus on, for example, individual rather than social determinants. In regards to the main research question ‘improving uptake of CR in invited patients’, Cooper et al (1999) confirmed that *intention* in CR attenders was 90%, but it was only 60% in

non-attenders (A. Cooper et al., 1999)<sup>30</sup>. Patients, who *attributed* their heart problem to lifestyle and believed their condition to be *controllable* (commons-sense model of illness representation, Section 5.1.1), were more likely to attend CR (A. Cooper et al., 1999). Attenders were more likely to be employed and younger in this study. Employment was mentioned as a barrier in the CRP survey (Chapter 4), which may suggest that participants in the Cooper et al. study were of higher socio-economic status (wider determinants are neglected; Box 5.1). The NACR does not indicate work to be a major barrier. Only 2% ( $N = 27,381$ ) of non-attenders indicate this to be the reason for not participating in CR phase 3 (The National Audit of Cardiac Rehabilitation, 2011).

Dohnke and colleagues' (Dohnke, Nowossadeck and Muller-Fahrnow, 2010) longitudinal study used the health action process approach (HAPA) measuring *risk perception, outcome expectancy, and self-efficacy*, and found, among other things, that participants had higher self-efficacy and lower negative outcome expectancy scores than intenders. They suggested that higher negative outcome expectancy prevents intenders to become actors and participate in CR phase 3 (Dohnke, Nowossadeck and Muller-Fahrnow, 2010).

*Illness perception*, also a concept from the CSM, is related to outcome in many health areas such as chronic disease (Leventhal et al., 1980, see Figure 5.1). There is some support from a meta-analysis including eight studies that illness perception predicts cardiac rehabilitation attendance (French, Cooper and Weinman, 2006). The effect is small and not all CSM components correlate, yet this review provided evidence for the development of one of the invitation letters explored. Mosleh et al. (2009) operationalised *controllability* and *perceived consequences*, as described in Section 5.1.1 below.

While the identification of modifiable determinants of CR uptake - for example, high intention or controllability - is explored in research, there appears to be a lack of discussion in the literature on how these determinants are subsequently targeted in intervention designs to modify behaviour; written text being of specific interest

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<sup>30</sup> Note that this study was included in the review by French *et al.* 2006, mentioned below.

here<sup>31</sup>. Furthermore, discussions or more formal involvement of the patients' perspectives appears largely absent. The systematic review of interventions to increase attendance at cardiac rehabilitation programmes (Chapter 2) found, among other things, two 'invitation to CR' letters based on the theory of planned behaviour and the common-sense model of illness representation (Table 5.1). Below, both health behaviour models are introduced briefly in light of the concepts operationalised in those letters.

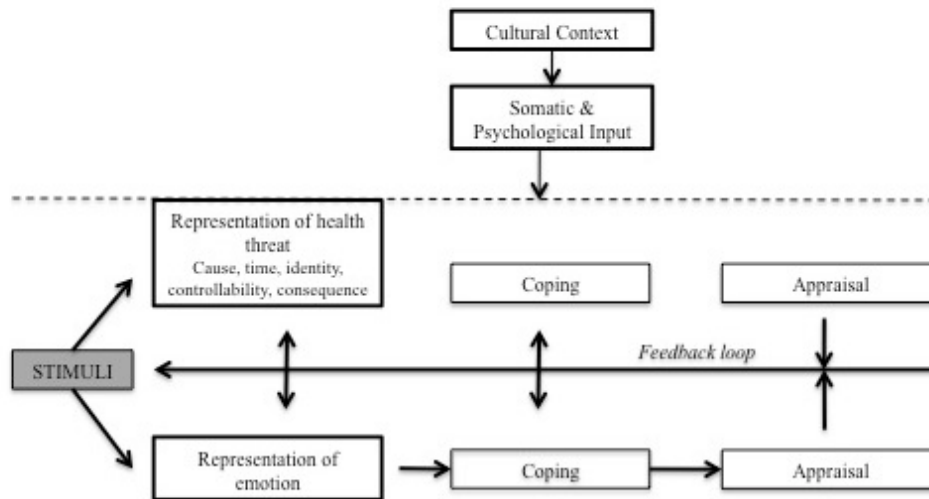
### **5.1.1 The common-sense model of illness representation (CSM)**

The CSM, a cognitive model for illness behaviour, suggests that individuals develop a *cognitive picture* of their illness in response to a health threat (Leventhal et al., 2012). The picture is the result of existing lay views, the person's current experience of the illness as well as information from external sources, such as family members or health professionals, and skills acquired up to that time (Hagger and Orbell, 2003; Leventhal et al., 2012). The *emotional reaction* to the health threat is processed in parallel. Both elicit coping and appraisal and result in the cognitive picture that guides the decision. It is also called the self-regulation theory, because multiple representation-coping-appraisal cycles are run through in reaction to a new stimulus (Martin and Suls, 2003). Illness beliefs influence health behaviour (Diefenbach and Leventhal, 1996; McAndrew et al., 2008) (see Figure 5.1).

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<sup>31</sup> Note that the *Health Communication* literature focuses on health behaviour models too, and *Social Marketing Practice* emphasises getting the message right yet detailed instructions are missing (Mattson and Basu, 2010). This can be observed across specialities in health care. For instance, remember that the review by Tseng et al. (Chapter 3) found reminders to be beneficial, yet a look at the individual studies revealed that details on design were missing (cancer screening uptake (Tseng et al., 2001)). No examples from the cardiac rehabilitation literature could be found with regards to written materials.





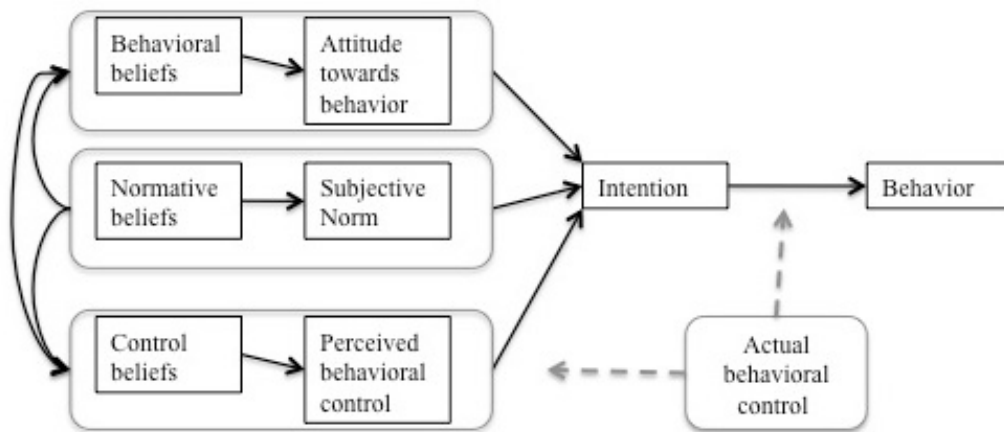
**Figure 5.1:** Parallel processing in the common-sense model

The illness representation is comprised of cause, identity, time, consequence and controllability; the latter two were operationalised in the invitation letter by Mosleh et al. (Hagger and Orbell, 2003). *Controllability*, which describes whether the illness threat is perceived to be responsive to one’s own or professional interventions was operationalised in the letter as “During the programme you will participate in supervised aerobic exercise in a safe environment, followed by relaxation sessions”. *Perceived consequences*, which pertains to the consequences of the illness, was phrased as “After leaving hospital, many patients still have episodes of chest pain and distress, which can stop them returning to normal daily activities quickly” (Diefenbach and Leventhal, 1996). Note that Mosleh et al. also operationalised *attitude*, *subjective norm* and *perceived control* from the theory of planned behaviour described below.

### 5.1.2 A brief overview of the TPB

The theory of planned behaviour is a social cognition model that establishes cognitive determinants of behaviour. Ajzen writes about human behaviour being triggered by three beliefs: 1) considerations about the results of a behaviour and the evaluation of these results, 2) considerations as to what others may expect in terms of behaviour and the importance of compliance with expectations, and 3) barriers, facilitators and control beliefs towards actual performance (Ajzen, 2006a).

Intention (INT), the motivating concept, and perceived behavioural control (PBC), a proxy to actual behavioural control, forecast behaviour (Ajzen, 2006b). Attitude (ATTN), subjective norm (SN) and PBC are the direct predictors and result in INT formation (Mceachan et al., 2011). Ajzen (2006) said: “As a general rule, the more favorable the attitude and subjective norm, and the greater the perceived control, the stronger should be the person’s intention to perform the behavior in question” (Ajzen, 2006b, p.1). Emotional impact, for example, of threat or fear, is not considered in the model, and wider determinants are not discussed.



**Figure 5.2:** Theory of planned behaviour as illustrated by Ajzen<sup>32</sup> (Ajzen, 2006b, p.1)

A review of TPB-based interventions found that the theory was mostly used to predict behaviour rather than design interventions (Hardeman et al., 2002)<sup>33</sup>. There is some predictive value in the TPB, but little indication on how to modify predictors is given (Hobbis and Sutton, 2005). *Attitude, subjective norm* and *perceived control* are the theoretical concepts used in both CR invitation letters of interest here, as shown below (Table 5.1).

<sup>32</sup> With permission for non-commercial use <http://people.umass.edu/aizen/tpb.diag.html>

<sup>33</sup> The review has not been updated since. Only one study used a written intervention (a poster for testicular self-examination), but no detailed description on how the components of the TRA were operationalised was included (Brubaker and Wickersham, 1990).

**Table 5.1: Determinants from the TPB in invitation letters**

<b>Theoretical comments</b>	<b>LETTER A By Wyer et al. (2001)</b>	<b>LETTER B By Mosleh et al. (2011)</b>	<b>Theoretical comments</b>
subjective norm (TPB)	The medical and nursing professions recommend that people who have had a heart attack should attend a cardiac rehabilitation programme.	Your consultant and health team have recommended that you undergo an 8-week cardiac rehabilitation programme, which aims to help you to recover and improve your health and life.	subjective norm (TPB)
perceived control (TPB)	During this programme, you will be offered advice and information about how best to recover after a heart attack. It will be up to you to follow these if you want to recover as well and as quickly as possible.  Experience has shown that the more effort you can put in, the more quickly the results will be achieved.	The programme is multidisciplinary, which means that the doctor, cardiac rehabilitation nurse, and dietician, physiotherapist, and the occupation therapist work together to tailor the programme to meet your individual needs.	perceived control (TPB)
attitude (TPB)	This is because those who attend such a programme are more likely to recover sooner and better than those who do not attend. In addition, research has shown that attendance can reduce the chances of dying from another heart attack.	Research shows, however, that people who attend cardiac rehabilitation are more physically fit, return to work and other activities more quickly, and have lower chances of having chest pain, anxiety, or depression, than those who don't attend.	attitude (TPB)

To summarise, both models assist in the understanding of determinants of health behaviour, and some key concepts in regards to CR attendance have been identified, as outlined in the first section. However, there is no information on how the concepts are operationalised in interventions to modify behaviour (written text being of interest here). Through participant interviews, key messages likely to motivate CR attendance and how these resonate with the theoretical concepts introduced above, will be explored. This exploration might shed light on further theoretical developments in designing intervention materials. Within the thesis, this is a

theoretically informed, yet pragmatic approach to increasing attendance in patients invited to CR.

### **5.1.3 Research objectives**

The main aim of the chapter was to explore the operationalisation of health behaviour theory in motivational text, specifically, two ‘invitation to CR letters’, and to investigate potential key messages likely to motivate people to attend CR. The specific objectives were to:

- explore which of the 12 statements (drawn from existing invitation letters) were perceived as most/least important as well as most/least convincing in terms of participation in cardiac rehabilitation;
- develop an understanding of how participants would arrange and/or rephrase the statements in the letter, and which information was redundant or missing;
- understand the key messages and information necessary to effectively communicate the importance of CR to patients;
- juxtapose the accounts of men and women to highlight similarities and differences;
- utilise interviews as a means to exploring how theoretical concepts are operationalised in writing, specifically in the two existing CR invitation letters.

## **5.2 Methods**

Interviews were conducted with 13 participants who were asked to comment on two previously used invitation letters based on health behaviour theory (as introduced in Sections 5.1.1, 5.1.2). Recruitment took place at three cardiac support groups. The data was concurrently analysed using thematic content analyses and descriptively presented, staying close to the data by - for example - utilising participants’ expressions as category labels (Anderson, 2007; Sandelowski, 2010). Further discussion on the methods chosen can be found in Section 5.8, ‘Methodological considerations’.

### **5.2.1 Sampling**

The aim was to recruit both men and women, ideally older and with a complex history of heart disease, in response to the criticism that research in CR is often based on younger men with a relatively straightforward diagnosis. The aim of *purposive*

*sampling* - addressing people with key experiences to gain insight in regards to the questions about invitation letters - lead to recruitment at community cardiac support groups (J Green and Thorogood, 2009; Mays and Pope, 1995; Teddlie and Yu, 2007). Attenders had a history of heart disease and were likely to be retired elderly people, two characteristics found in over 50% of people referred to CR (The National Audit of Cardiac Rehabilitation, 2010). Despite the use of theoretical considerations, this is *convenience sampling* - a strategy of approaching easy-to-access (potential) volunteers (J Green and Thorogood, 2009; Teddlie and Yu, 2007). In addition, *snowballing* was used through leaving contact details and information with the group. A potential participant had mentioned two other women who might be interested in volunteering.

### **5.2.2 Exclusion and inclusion criteria**

The inclusion criteria were adults with a sufficient knowledge of English who had experienced an acute heart event in the past. Exclusion criteria were hospitalization in the past three months or a coronary incident in the past six months.

### **5.2.3 Recruitment methods and participants**

As a consequence of the difficulties of recruiting both men and women, three consecutive attempts at recruiting participants were made. With permission of the cardiac support group leader, I visited the first community cardiac support group and set up a table with information materials. The group leader introduced my study and gave attendees the option of visiting my table during the break or after the meeting. Several attendees approached the table during the break and expressed interest in participating in the telephone interview. All were given the study pack, which included an information sheet, a consent form and the two invitation letters (Appendix D). Volunteers were asked to return the consent form by postal mail. They were asked to include their telephone number and a time at which they would like to be called.

The first recruitment resulted in a sample consisting of 11 white men, all of whom had had more complex cardiac events. Since it was desirable to have a larger and also less homogenous sample, another recruitment attempt was made at the community heart failure (HF) group. The inclusion of heart failure diagnosis allowed for a broader history of heart disease to be included and hence for the possibility to

include participants with a wider range of experiences. Incidences of heart failure at 65 years of age or above are distributed evenly between the genders (Pilote et al., 2007). Hence, it was thought that attending this group might give access to more women.

Following the HF group meeting, I was introduced by the nurse and proceeded to briefly describe my study. It was emphasised that women are particularly sought after for participation in this research. As this was the end of the session, I was able to hand out the study materials as people were leaving. Only three women participated in the heart failure group, men showed no interest in participating in this study, and no new participants were recruited.

Consequently, a third community cardiac group was visited. This time, a more socially diverse area was chosen (Bradford). Due to the lack of female participants (in the groups and the studies), the decision was made to recruit only women for participation. This was important, because  $\frac{1}{4}$  of cardiac patients are female, and the NACR shows that older women are under-represented in cardiac rehabilitation. The community group leader had approached six women prior to the meeting and had asked them if they would be interested in staying behind and hearing about the research. I was able to briefly describe my study to five women. All women took the information materials, two participated in the research, and one woman recommended friends who the group leader took the information pack for.

#### **5.2.4 Materials**

The materials used were two previously tested, theory-based invitation to CR letters (Table 5.2). Participants received both letters on separate pages with the statements separated as shown below.

A) Invitation letter A as designed by Wyer et al. (2001)

B) Invitation letter B as designed by Mosleh et al. (2011)

**Table 5.2: Side-by-side comparison of invitation letters**

<b>LETTER A</b> <b>By Wyr et al. (2001)</b>	<b>LETTER B</b> <b>By Mosleh et al. (2011)</b>
Like many other patients who have had a heart attack, you will shortly be offered a place on a cardiac rehabilitation programme.	
The medical and nursing professions recommend that people who have had a heart attack should attend a cardiac rehabilitation programme.	Your consultant and health team have recommended that you undergo an 8-week cardiac rehabilitation programme, which aims to help you to recover and improve your health and life.
During this programme, you will be offered advice and information about how best to recover after a heart attack. It will be up to you to follow these if you want to recover as well and as quickly as possible.  Experience has shown that the more effort you can put in, the more quickly the results will be achieved.	The programme is multidisciplinary, which means that the doctor, cardiac rehabilitation nurse, and dietician, physiotherapist, and the occupation therapist work together to tailor the programme to meet your individual needs.  During the programme you will participate in supervised aerobic exercise in a safe environment, followed by relaxation sessions.  In addition, there are education sessions once per week, providing information on anatomy and physiology, healthy eating, long-term exercise, medicines, and stress management.  After leaving hospital, many patients still have episodes of chest pain and distress, which can stop them returning to normal daily activities quickly
This is because those who attend such a programme are more likely to recover sooner and better than those who do not attend. In addition, research has shown that attendance can reduce the chances of dying from another heart attack.	Research shows, however, that people who attend cardiac rehabilitation are more physically fit, return to work and other activities more quickly, and have lower chances of having chest pain, anxiety, or depression, than those who don't attend.

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If you have any questions about cardiac rehabilitation, you will be able to ask the cardiac rehabilitation nurse, when she comes to talk to you about the programme. With best wishes for your recovery.

Your appointment is on ..... You should come to the Westburn Centre on the Foresterhill site, off Westburn Road (see enclosed map).

If for any reasons you are unable, or do not wish to attend please contact us on xxxxx. If we are not in the office please leave a message and we will call you back. You should allow approximately one hour and 15 minutes for this visit.

During this time you will be given information about the programme.

You will be asked to do walking test in a safe supervised environment, so please do not plan a busy day. You should wear comfortable clothing and flat, rubber soled shoes.

Please bring a list of your medication with you and reading glasses if needed.

We look forward to meeting you.

Yours sincerely

Cardiac Rehabilitation Team

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Mosleh et al. used the Medical Research Council (MRC) framework and arrived at their invitation letter through reviews, expert and patient consultation and intervention modelling (Mosleh, Kiger and Campbell, 2009). Theoretical concepts and how these relate to CR were debated, and a letter was designed to motivate, inform and reassure patients. The actual choice of words was not discussed.

The other letter, originally developed by Wyer et al. (2001), aimed at influencing attitude, subjective norm and perceived control (TPB). Patients were originally interviewed about their experience. The CSM and the TPB were used as explanatory frameworks for the patient interviews. No information on the subsequent operationalisation of theoretical concepts into a written format was provided. Wyer et al. (2001) also sent a second letter to patients who had accepted CR (not of interest here).



### **5.2.5 Ethical considerations**

The University of York Research and Governance Committee approved this project (Appendix D). Eligible participants heard the short introduction and were able to ask questions. Those interested were given an information pack.

Interested participants were asked to provide a contact telephone number and their name with the signed consent form and to return it by postal mail. The researcher stored consent forms separately from the audio files and interview transcriptions. Confidentiality, not disclosing any identifiable information to other people, was guaranteed, as only the researcher was aware of the names of the interviewees. Anonymity was maintained through the use of pseudonyms in all notes including the transcripts, and non-disclosure of where the individual participants were recruited. The use of anonymised quotes in publications or study documents was excluded. This was explained in the consent form, using lay terms and basic sentence structure to ease understanding (Britten, 2006).

The support groups meet once a month for discussion of heart health topics and/or for social events. All members attend voluntarily and are likely to have reconciled with their heart disease-related experience.

### **5.2.6 Data collection**

The semi-structured telephone interviews were conducted using open-ended questions to guide the communication, which simultaneously left the option of exploring unexpected topics of interest around CR attendance (Britten, 2006).

Participants were given copies of the two invitation letters ahead of the interview. In order to stimulate a discussion about them, a topic guide was used (key points listed in Table 5.3). There was some variation in the order and use of questions and probes depending on which topics the participants had mentioned themselves. In addition, the phrasing used by the researcher varied to match the interviewees' choice of words, which helped build rapport (Britten, 2006).

**Table 5.3: Key topics from the interview guide**

- Socio-demographic questions and disease history
- Invitation letters: What do you think? Do they encourage attendance?
- Look at the statements separately:
  - Which ones encourage you/which ones put you off
  - How would you rephrase?
  - Should any statement be deleted?
  - Is there information missing?
- Which letter do you prefer?
- Forget about letters, is there a better way to get those people who say they are not interested to attend CR?

The topic guide (Appendix D) for the telephone interviews evolved from the previous publications as well as from the concurrent analysis. For example, the first few volunteers commented on the statement about dying, which had also been discussed as a potential fear message by Wyer and colleagues (Wyer et al., 2001b). Consequently, all participants were prompted on this statement if they had not mentioned it already.

The interviews with the female participants were approached in the same way as the ones with male participants to remain consistent. In response to the lack of women in this study, a couple of additional questions in regards to women and cardiac rehabilitation were asked (1. ‘Very few women participant in your heart group and cardiac rehabilitation – why do you think this is?’ 2. ‘Forget about the letter, what do you think is the best method of inviting WOMEN to CR?’)

Each volunteer was called at a time of his or her convenience. The interviews typically lasted 20-30 minutes. The interviews were audiotaped (which provides more details and allows for the researcher to immerse herself in the data while transcribing) and subsequently written out (Silverman, 2009).

### **5.3 Data analysis**

The outcome measure of the research was a descriptive, qualitative account of participants’ perceptions of invitation letters as a means of exploring the operationalisation of theory and motivational statements that were used to develop

an amended invitation letters. Findings were discussed separately and then related to the health behaviour models used in the discussion Section 5.6.

The transcriptions of the interviews provided the raw data, which needed to be interpreted (Pope, Ziebland and Mays, 2000). The interview topic guide, statements or topics included in the letters themselves were used to guide the analysis. To give an example, every participant was asked ‘Forget about letters, is there a better way to invite those people who say they are not interested to attend CR?’. The reply was then coded into *invitation strategies* and compared across participants.

In this analysis, themes and patterns were searched for in the transcripts of the interviews. In health care research, *a priori* theory undeniably exists (such as health behaviour theory, discusses above) (Creswell, 2007). As a result of the intensive review of literature (Chapters 1-3), awareness of indicators for attendance exist (such as: married men are more likely to attend CR) (Benz Scott, Ben-Or and Allen, 2002), making it unavoidable that my own knowledge directs my attention when reading (Schmidt, 2010). My attention was drawn, e.g., to the statements several men made about having their spouse accompany them, which I immediately coded *partners*. Other statements, for example, ‘as part of the treatment’ remained unnoticed at first until having repeatedly read all interviews at the end of the data collection phase. Applying *concurrent analysis* merits a dynamic interplay between data, interview guides and analysis allowing for an exploratory approach (Hansen, 2006); to give an example, I asked other interviewees what they thought about partner involvement.

An attempt was made to preserve validity by means of paying fair attention to negative case findings and discussing potential reasons (Mays and Pope, 1995). However, concurrent analysis may continue to draw attention to concepts used in the letter or those discussed in the reviews (Chapter 1-3). This made it hard to focus on statements that were unexpected or contrasting. An example was given above. *Constant comparison* of data and codes took place: data was sorted into categories (a collection of similar data) and themes (reoccurring aspects throughout the text) (Morse, 2008; Pope, Ziebland and Mays, 2000). I went back and forth between the transcripts and the codes, juxtaposing them against each other repeatedly to avoid the common limitation of *conventional content analysis*, namely, missing key themes (Hansen, 2006; Hsieh and Shannon, 2005). Attention was paid to negative cases and

exceptions to give a comprehensive picture of the diversity of participant accounts (Pope, Ziebland and Mays, 2000). Similarities and differences between the interviewees' responses were drawn out. In response to the scarcity of female participants, their accounts were described separately, as reference points, and in more detail, to provide a thick description (Yin, 1998). In addition, I took coded sections (quotes) from the transcripts to explore how or if they resonated with the men's accounts, in order to *compare and contrasts* - an exploratory approach to converging and mismatching statements (Guba and Lincoln, 1998).

Generally, the use of quotes shows real data. Quotes that contain similar themes are presented as well as those that show contrasting opinions. In the Findings section (5.4), CAPITAL letter indicate loudness, [ ] square brackets indicate materials added or omitted by the researcher, and unfinished words with a hyphen - indicate an interruption by the next utterance. As much data as possible is presented to aid the reader in re-constructing the setting and in getting a sense of the data's origin (Chenail, 1995).

1. Pre-coding
2. Rereading all transcripts and refining codes
3. Use of final codes to analyse all transcripts
4. Compare first with final analysis
5. Explicit comparisons with theoretical concepts used in the invitation letters

**Box 5.2: Analytical steps**

Data transcription and a first coding, which was not done specifically following the interview guide, took place after the 5<sup>th</sup>, the 8<sup>th</sup> and the 11<sup>th</sup> interview. Appendix D provides a table of the provisional categories or codes and how these were refined over time, to make the analytic process more transparent (Pope and Mays, 2006a).

I reread the transcripts often and immersed myself in the data (see Box 5.2; loosely guided by Schmidt, 2010). I listened to the audio files repeatedly to remind myself of the tone used by participants and interviewer as well as of pauses. In the final stages, I went back to earlier interviews, in case new information from later interviews had not been paid attention to in the first few interviews.

Data was analysed using the ATLAS.ti 5.x software to assist with the coding. No quantification of codes took place in order to avoid the assumption that codes might be of equal importance or indicate analogous viewpoints (Creswell, 2007).

## **5.4 Findings**

The following sections present a socio-demographic summary of the participants' characteristics, followed by a rich description of the comments that participants made based on the letters. The data is presented in a narrative logic, but the focus remains on the topics or content commented on. Key messages likely to motivate CR attendance are explored. To compare and contrast, the accounts of the male participants are presented separately from the female accounts. A descriptive account is given first, followed by a discussion section at the end of the chapter. In the final part of the discussion, an investigation is made into how patients' opinions and the key messages elicited resonate with the health behaviour theory concepts operationalised.

### **5.4.1 Participants**

Eleven men and two women participated. A difficulty in recruiting women from three groups was observed. The percentage of women in the community groups was around 25% (3-10 women). This constitutes a typical group composition (according to the information by the group leaders), a percentage similar to CR trials (systematic review, Chapter 2). In order to somewhat compensate for the lack of female participants, the accounts of Kathryn and Ellen are presented separately, with the purpose of comparing and contrasting them with the male participants' accounts. Descriptions of the data, with some analysis to aid the flow, are juxtaposed with quotes. Quotes were chosen as representative to the themes and to enable the reader to assess transferability (Sloots et al., 2011).

An overview of characteristics, where participants were happy to share this information, is provided in Table 5.4 below. Pseudonyms are used to preserve participants' anonymity. Eleven participants were male, white and had retired. Two participants were female and white, and one of them continues to work. The majority of participants were married and had been to cardiac rehabilitation. Only three non-attenders who had never been given the opportunity to attend took part. Nine participants preferred letter B, three preferred letter A, and one had no preference. In

contrast to most trials, participants were older than 70 years, and most participants had experienced complex heart problems.

**Table 5.4: Participant characteristics**

#	gender	marital status	heart problem	rehabilitation attendance	letter preference	pseudo-nym
1	m	not known	not known	1x	A	Saul
2	m	married	AMI, valve replacements	2x	B	Luke
3	m	married	AMI, bypass	2x	B	James
4	m	married	valve replacements	1x	B	Wesley
5	m	not known	AMI	no	B	Benjamin
6	m	widower	valve replacements	1x	B	Adam
7	m	married	bypass	1x	A	Callum
8	m	not known	heart surgery	1x	B	William
9	m	married	HF - bypass, pacemaker	2x	B	Lee*
10	m	married	AMI	1x	both	Simon
11	m	married	not known	not known	A	Malcom
12	f	widow	AMI	1x	B	Kathryn
13	f	married	heart surgery	no	B	Ellen

\* participant's wife also communicated via the phone because husband is hard of hearing

### 5.4.2 Findings of interviews with 11 male participants

The following section presents the findings of the 11 interviews with male participants in a narrative fashion. The data is organised into three overarching themes 1) Motivating Attendance, 2) Communicating about cardiac rehabilitation and, 3) The benefits of cardiac rehabilitation. These themes respond to the aim of exploring key messages to motivate CR attendance. How participants' comments resonate with the operationalisation of health behaviour theory will be considered in detail in the second part of the discussion section (5.6).

#### Motivating Attendance

The letters are designed to invite patients to attend CR. As mentioned above, the letters seek to convince the patient to attend as well as conveying logistic or organisational information, such as the date of the appointment. There appear to be

four areas that could influence attendance: a pre-scheduled appointment, professional recommendation, partners, and negative consequences.

A set appointment can either be a positive or a negative aspect of the invitation letter. Some participants expressed that a set appointment would tell the recipients of the letter something positive...

Adam: But uh you need uh uh letter two, letter B, it tells you something positive when the thing is on, at what time and so and so forth

Simon: Making a positive appointment[...].

...which may also help with attendance ...

...on letter A, it's a very direct statement, 'you will be offered a place' but here [letter B] it's just a recommendation [...] I like A better in that case [Simon had no preference for either letter].

Malcom: I like paragraph 6 [letter B], actually, they make an appointment for people uh to come [...], yeah, I think I think, I mean our experience is that people say they come and they don't, you know, they half-hearted when they say and they change their minds. I think doing it that way helps them come around and do something.

...and to not give them the choice to opt out easily;

Adam: You've gotta tell them that to really recover they have to follow this programme [...] part of the treatment [...] I wouldn't say 'do not wish' [to attend] uh because they should come

Although the three participants did not prefer the same letter, these statements show that Adam, Simon and Malcom all felt that it was necessary to attend CR and that this could be communicated via a firm invitation message, in this case, including the date and time of the appointment in the invitation letter.

In contrast, other participants did not want to be told what to do but preferred to be invited politely. Telling patients in letter B 'your appointment is on...' might be perceived as authoritarian.

Benjamin: [...] little bit uh mmmm to the point [...] makes it softer. An appointment has been booked for you. You know. uh uh you're not, you're not so disciplinarian sort of thing.

Despite this comment, Benjamin still preferred letter B, while Callum liked letter A better.

Callum: 'Your appointment is on...' bang, you've gotta come. [...] Well, you could [put], you will be offered an appointment, uh, you will be contacted to be offered an appointment, rather than, your appointment is on. It's a bit bland.

Three other participants commented more generally on the wording being politer in letter B.

Lee: [Letter B] was much politer. The other one was more stating facts, wasn't it.

James: [...] I thought uh letter B would have, would have made me want to come more than letter A. cause that was, that was, sort of not, not firm enough, I thought, really.

James's statement fits with the positive subtheme, whereas Saul's statement (below) is in line with the negative subtheme. He referred to letter A, which ...

Saul: [...] sounds just a little bit sort of military to say, 'it will be up to you to follow these if you want to recover' [...] uh, my own feeling would be to say, if you follow this it will help you to, etc., etc.

Seeing the appointment as something positive suggests that CR is perceived as progress in terms of recovery, and that these participants see it as a helpful event for others to attend, too. However, the motivational component is recognized. As said by Malcom and Adam, the wording and setup should make it easier to come, and a set appointment removes the barrier of having to schedule a time. In addition, opt-out options should not be included.

Conversely, Benjamin and Callum preferred to be invited and not to be told what to do. Based on the fact that these two participants also attended the support group, one may assume they are in favour of CR. This shows the dilemma of how to communicate the importance of CR to patients whilst still giving them the choice. What is perceived to be encouraging towards attendance differs amongst participants.

Professional recommendations are often thought to be supportive and help make a decision.

Wesley: Uh rather than just say, you know, like many other patients, uh you will shortly be offered a place. But who is offering you the place [in regards to letter A], if you know what I mean. So you, you have actually told them that your consultant and health team are recommending in letter B.

Benjamin seemed to express a similar opinion.

Benjamin: Yes, no. that's fine. 'The consultant and health team recommend that you undergo an 8-week cardiac programme'[letter B]. Yeah that's fine.

Choice has increasingly become a key word in health care. To make an informed choice, patients need all relevant information from the health care professional.

Simon commented on what he was told by the doctor and how that influences him:

Simon: And the thing that motivated me is, the doctor said to me 'you can't go back to work until you can walk three miles'.

In Simon's case, the doctor actually made a reference to something that is personally relevant to him. Later it will become more apparent that several participants mentioned more tangible, day-to-day activities in regards to CR outcome.

Through health care professionals' recommendations, power dynamics may not only come into play in regards to treatment choices but also in terms of respectful



communication. Of course, patients not only consult professionals but also seek lay opinions when making decisions, such as asking the spouse (or others around them; peers are discussed below).

Partners could be a third motivating factors. They may worry and would be interested to know more about heart disease.

James: We found, we have had quite a few people say, well you know that their partners found it just as, just as interesting or uh as more as uh help to sort of put them, their minds at rest, their husband digging in the garden or whatever and so on.

While James highlighted the partner's need for more information, Luke explicitly mentioned that his wife was attending with him.

Luke: Uh, my wife came with me [...] and there is no mention of that. And I thought you could put a little bit in paragraph seven [...] With say, 'you may bring your spouse/partner with you' for this initial meeting.

Partners may also take the role of carer and provide support, as mentioned by Lee.

Lee: I mean, that is very important to know because they are the ones that are having to do with it and don't ... they are having to keep the patient going and they are having to keep themselves going, and it is very hard.

Therefore, including partners in the communication might be beneficial. An invitation might indirectly lead to partners persuading their spouses to attend CR.

The final category that is related to motivating attendance is the mention of negative experiences, namely chest pain and the chances of death. The information discussed thus far conveys positive statements, but the letters also include some more negative connotations. Letter A contained the statement: 'research has shown that attendance can reduce the chances of dying from another heart attack' (letter A).

Simon: I think the dying bit is a bit emotive

Benjamin : The chances of dying was a little bit severe

Simon and Benjamin appeared to express that it is not appropriate to talk about negative consequences. The statement conveys something emotive. Later on, benefits of CR attendance (in terms of physical health) were addressed, but little in terms of emotional outcomes surfaced.

Wesley: Yea we don't want that, do we [laughs]? Nobody dies

In fact, none of these three participants appeared to be in favour of this statement. Wesley hinted towards the fact that death is rarely discussed; it is often a taboo topic. Other participants would have liked to rephrase the sentence.

James: I think, everybody who has had heart surgery or have had a heart attack or whatever else is aware that they can die from it, therefore if you're saying that doing this reduces the chances of dying from another heart attack, or maybe you could put reduce the chances of having another heart attack.

Although one participant also expressed that patients are aware of death, others felt that referring to it was a bit too much and suggested to changing the wording to 'reduce the chances of another heart problem' or a 'heart attack reoccurring' or 're-admission to hospital' or similar.

Lee: It's a bit hard [...] can reduce chances of dying from another heart attack. Now that is true, but it its kind of a, it it's, it would give me a bit of a shock.[...]I think it's ok to be told that, but in a letter formally that the chances of dying from another heart attack is a bit severe.

It is to note that while many participants commented on the sentence ' [...] attendance can reduce the chances of dying [...] ' independently, all others were asked specifically what they thought about this statement. Only two of 11 participants thought it would encourage people to attend CR.

Adam: To be honest, some people need a bit of a frightening to waken them up.

Saul: [...] that is reasonable, because people that have heart attacks have very much in their mind that they could have died.

Letter B contains a statement about the possibility of chest pain: 'After leaving hospital, many patients still have episodes of chest pain and distress, which can stop them returning to normal daily activities quickly'. While one participant would prefer chest pain not to be mentioned, another suggests that

Wesley: Uh you know, to say that you may still have them [chest pains], I I just wonder if, in fact, you would suggest to them that uh they might be having a chest pain

Another participant felt it might distress the reader.

Callum: I can forward in letter B 'after leaving hospital, many patients still have episodes of chest pain and distress' uh probably a bit frightening to some people.

One person would soften the statement, but the others did not comment.

Malcom: Yeah leave it in. But I think 'many' [patients, rather than, say, 'some'] is, and another uh uh 'not a distressing term', but something that puts people off a little bit, makes them upset, you know.

It appeared that many participants would rather not read about negative or painful side effects of the heart problem (death), but a few others would still like to include the statements. The evidence on the potential motivational impact of negative statements is somewhat conflicting.

## Communicating about cardiac rehabilitation

The second theme discussed is 2) Communicating about CR. Bear in mind that still only the male accounts are discussed here in light of key messages likely to motivate attendance through invitation letters.

In addition to choosing the content *per se*, the letter content must be accessible and understandable to all patients. Patients disliked the use of technical terms but were in favour of including more detailed information about cardiac rehabilitation.

James: [...] interested in anatomy and physiology and what's going on, but I think a lot of people may, might find it a bit uh uh off-putting [...], anatomy and physiology, that are two words that uh that ordinary people might be put off by [...] not helpful to be confronted by big words.

Referring to letter B, several participants (six) mentioned that using words such as anatomy, physiology or multi-disciplinary is complicated, off-putting or a bit much for people.

Callum: [...]too complicated, a bit too intense, I think, in some of the the wording on it. [...] multi-disciplinary, which means that the doctor, cardiac rehab nurse, dietician, physio work together. It seems a little overcomplicated [...] everybody would understand what anatomy and physiology etc mean I don't know.

Malcom: [...] mention anatomy and physiology, I think that is a bit much for a lot of people. [...]I did like the brevity of the first one[...] it is a bit more concise [...] letter B, it's a bit long.

Malcom and Callum also preferred letter A, which was shorter and does not include those or similar words.

Callum: Letter A. It was simpler.

Many participants suggested that it is vital to provide details about the activities at CR.

James: Might be better, uh it would give them an idea of what it actually is they are going to let themselves in for.

Adam: People need to know what's in front of them, and the second letter [B] tells them that Participants liked to include information about what is going to happen to them at CR and, as Wesley highlighted, what to bring along.

Wesley: Yeah well, you see, that is quite, that's quite, it's quite explanatory. What is going to happen [...]Uh number uh number 7 actually tells you uh like everything else what you should wear, it's a good suggestion of what you should wear, uh also bringing medication, reading glasses [laughs], that's a brilliant idea.

Benjamin: gives you a bit more information [...] more about what rehab is.

Not giving people enough information about what is happening at the CR could be off-putting and hence a barrier to attendance. William also expressed it even more clearly saying that

William: an overall sort of strategy in order to help people understand the process that they are going through and and uh and the benefits of the programme.

### **The benefits of attending CR**

In addition to commenting on giving information on what exactly happens at the CR course, all participants commented on the impact or benefits of CR in regards to letter B.

Luke: And uh, to say, 'research shows, and then cross out the however, that people who attend cardiac rehabilitation', and I changed 'are' to 'will become'

Malcom: ..., rehabilitation are more fit, I wouldn't, I would put the word 'become' there, instead of are.

Luke and Malcom recommended a change to the future tense, which suggests a positive outlook. (Adam and Simon, as described in the first paragraph, had expressed that being given an appointment place and time was a positive message). It also conveys a sense of optimism.

Simon: I think you are really saying the important things in the letter by saying it will aid your recovery more quickly and you get back to work or whatever uh I think that must be the best motivation

Adam: Because you've gotta tell them that to really recover they have got to follow this programme.

Both participants talked about including statements on the importance of participating in CR and the outcome.

William: [referring to letter A] Overview of uh sort of the outcomes that, you know, people at the end of the day will probably improve and uh uh and their lifestyle will be a bit better, but I think that the second one [letter B] gives more of an overview point, you know, people that are there to help you.

In addition, the wording 'will become' that several participants mentioned allows for a relative comparison to the participants' own fitness level and make it a relevant, relatable statement independent of the patient's current condition.

All participants emphasised on the impact of CR. The comments refer more generally to health and lifestyle outcomes without going into details. Only Adam actually, had used the word 'treatment', a word choice that presents CR as more crucial to the recovery process as opposed to a mere lifestyle choice. One other participant referred to work. Another one mentioned physical activities, which also

links with the medical recommendations that health care professionals can give (as discussed above) and the help that peers could provide (discussed below).

Lee: And the doctor and the consultant but they can't tell you anything from the personal side of things, you know, sort of, how will you feel after you have had it done and how long before I can whatever and you know, go cut the grass or help my wife with the washing or that kind of thing. The medical staff don't seem to be able to do that.

Through social support, CR attendees can exchange information and experiences with fellow sufferers on the impact of a heart problem and gain insight through more tangible examples on how the recovery may progress. Amongst the more obvious physical benefits CR can provide, the option of dealing with emotions through peers is mentioned.

Wesley: ...sat round after the, after your training, and you just talk amongst yourselves. And it's, it's quite good because people want to talk about what they have been through. [...] and and, you know, to the outside it might be a bit boring, but, but when you get so many people who had a similar, had a similar experience, then it does help. It's part of the healing process.

Few statements about the emotional experiences around heart problems and the after-effects were made. Two participants commented explicitly on anxiety.

James: It's the relieving anxiety, I think it is mentioned in letter A. But uh I thought, in letter B that something like that should be put in because that was the one that uh uh in, when I, after I had my bypass that was the one I think that I had found most sort of helpful [...] talking to people uh, you know, who had actually had the various things uh made it a lot easier to understand and feel more at ease.

Peers helped these participants to understand their condition, and the programme gave them confidence.

Wesley [mentions this again at a later stage during the interview]: Yeah I mean, when you come out, you do, you do, like a little bit of, uh well, you just a little bit afraid of maybe crossing roads and things like that. But this, this rehab programme, it, it sort of gives you confidence

This is one of the very few times where a personal reference (the first-person pronoun) is made and the participants obviously draw on their own experiences. Throughout most of the interviews, participants did not talk about their own past experiences as explicitly or use the first-person pronoun singular. This could be either because the participants had had positive experiences attending CR or, in some way, because they see themselves as advocates of CR.

Earlier on, the negative emotional association connected with the expressions 'chest pain' and 'chances of dying' were discussed. This was seen as potentially off-putting whereas anxiety relief at CR is beneficial.

### **5.4.3 Findings of the interview with the two female participants**

The accounts of Kathryn and Ellen are presented separately with the purpose of comparing and contrasting them with the male participants' accounts (see above) and to understand the extent to which gender mediated experience. The same three main themes are presented: 1) Motivating Attendance, 2) Communicating about CR, and 3) Benefits of attending CR, following a short introduction of both participants.

#### **Kathryn**

Kathryn is a 78-year-old woman who experienced a heart attack. She attended cardiac rehabilitation and joined Keep Fit classes and still continues to attend the socials of the heart support group. Kathryn reported that she returned to work as a bookkeeper once she had recovered from the heart event. Her husband had taken time off work when she was first recuperating at home, but he never joined in any heart groups. Kathryn reported to not have any heart problems now.

#### **Ellen**

Ellen is a 70-year-old woman who was a child heart patient and later had a valve replacement. She was not offered cardiac rehabilitation but was told to walk two miles a day. She joined the heart support group through a friend and takes part in the social meetings. Ellen reported that she was a farmer's wife and continued to work. She said that she did not have any heart problems now but struggled with arthritis.

#### **Motivating Attendance**

Some male participants had said that a set appointment conveyed a positive message. Conversely, others preferred to be invited and not to be told what to do. In addition, polite or friendly wording overall was preferred by some (from Letter B), but not by others, over firmer statements.

Kathryn and Ellen both commented on the wording in terms of friendliness. Kathryn mentioned the ending while male participants debated other sections.

Kathryn: Well I think it is also friendly. Where it says at the end, 'we look forward to meeting you' and 'yours sincerely' [referring to letter A]. [But] I didn't like that as much, no. [...] I didn't think it covered as many things. I didn't feel it was as friendly. It seemed a little bit more formal.

Ellen also referred to letter B as 'friendlier'.

Ellen: I suppose ... the letter B um, sounds a little bit friendlier.

And later on she reinforced that

Ellen: the second one [Letter B] sounds a little more inviting and urm, explains things in a gentler way...probably would persuade people better.

Referring to letter A, she said:

Ellen: Well it gives all the information, but uhm it's a bit more, sort of, you know, telling people they should come rather than inviting them.

This is similar to statements made by two of the men, who also preferred to be invited and not to be told what to do.

Like all other participants, Kathryn was asked how she felt about the statement 'reduce the chances of dying' in letter A.

Kathryn: I think if you got over uh a heart attack or whatever, you don't need it pointing out that there could be chances of another one, and you could die next time. I think that is just a bit much. Do you know what I mean, [interviewer's name]? [...] no, I don't think it is. I think it could also, I know, although it says that it helps you, I think you could think for yourself, oh well, if I start exercising and do things like that, am I going to bring another one on?

She felt pointing out 'dying' was a bit much, as did many male participants (all but two who had thought this would be a 'wake[n]-up'. Ellen mentioned the statement without prompting:

Ellen: I think, I think there was urm, sentence 4 in the first one [letter A]. [...] I thought that was perhaps urm, ...just a little bit sharp. It says, you know, urm, .. I mean people, I suppose, are a bit apprehensive anyways, so, you know, if you sort of gone say to them ...[laughs]: If you don't come, you might die.

When asked what could be written instead, she referred to letter B.

Ellen: Well, I think, I think the sentence, the sentence is in the other letter, isn't there

A point that Kathryn talked about several times but none of the other participants mentioned relates to safety.

Kathryn: uh... also where it tells you that 'you will be asked to do a walking test. It does say in a SAFE SUPERVISED environment'. Which again, I think is very encouraging. Because you are not frightened of doing it if you know that is somebody there who is going to supervise you.

In fact, Kathryn repeatedly talked about anxiety and the safety aspect of being with a doctor or on hospital premises repeatedly. She saw this as encouraging attendance.

This is discussed again in terms of the benefits of attending CR (see below).

Kathryn: I went, uh, rehab in those days was a class within the hospital, which was very comforting because there was always a doctor there. Uhm, so you felt very safe. It wasn't split up into different areas like it seems to be now. Uhm, and then, uh,... I also joined heart support group and went to uh, stresss management classes, which was a great help. Uhm, you know, once I was back on me feet, that was.

This may also convey a sense of trust in health care professionals' knowledge, although not directly stated. Ellen mentioned doctor's advice as a way of inviting patients.

Ellen: So I would think, you know, sending letters out is probably one of the best ways, unless you can encourage them through the doctor's surgery, [...]if the doctors sort of advise it or if you have information on the doctor's surgery. Try and encourage people that way.

Professional recommendations as a motivator, specifically 'doctor' and 'consultant', had also been mentioned by three male interviewees.

Additionally, three men discussed the involvement of partners or spouses. Kathryn also mentioned the family, but related this to the entire care process and not just to CR.

Kathryn: I do feel, I mean, it is nothing to do with rehab really, but I feel very much that when anybody within the family suffers uh ... any sort of heart disease problem, that it does affect the rest of the family, and I think uh, it might help if rather than the patient passing on to the family what has been said, it might help if the family were talked to, because I mean, I know that I mean my husband was at home with me at first, he took time from work, and I would find him, I could feel him looking at me, and he used to watch me an awful lot, making sure that I was alright. And so, you know, it does them very very much. and yet, all they do is watch the patients, what you can pass on to the rest of the family about what you have been told.

### **Communicating about cardiac rehabilitation**

Several of the men had commented on the wording in letter B saying it was 'complicated' or 'a bit much for a lot of people'. Ellen expressed that it was a lot to read.

Ellen: Yeah ... as I say, I just think maybe you could uhm..you know, just cut the other one [letter B] down perhaps a little bit [...] may be a lot for some people to read. I mean that is older people. They get a bit fed up, don't they, reading? [...]I think just a lot of the detail, just sort of to say that uhm, you know, like where it says, 'during the programme you will participate in supervised exercise' I think uhm,..... you could just say, perhaps, 'the medical team', you know, 'tailor the programme to you'. Uhm. Just have to make it a little bit more simple.

As noted in the male accounts, the interviewees used the third person pronoun when talking about the letter's wording.

Keep in mind that many of the men had mentioned it was good or important to tell patients in the letter what happens at cardiac rehabilitation: some said a lack of information could be off-putting. Kathryn expressed similar views in that she saw 'a more comprehensive' letter as 'encouraging'.

Kathryn: [Letter B] I think it's more comprehensive, it's more...uh... encouraging. Uh...I think as well it, it tells you that it's going to cover quite a lot. [...] Not like the other letter [A] does.

Interviewer: What do you mean with covering?

Kathryn: Uh, well, where it says, uh... 'the programme is multidisciplinary, which means that the doctors, cardiac rehabilitation nurse, and dietician, physiotherapist and the occupational therapist work together to tailor the programme to meet your individual needs'. Uh.....I think that comes over very well.



Kathryn and Ellen were the only participants who mentioned the usefulness of being told why CR is important.

Kathryn: [...] I mean, I found it really useful that at rehab that, uh, it was explained to us about the heart being a muscle, and muscle needs working, and, you know, and has to be fit just like every other part of your body; and I found that that helped knowing why I was doing the rehab, what the reason was.

Ellen: [...] you have covered everything ...urm... no, I think...I think it's good. I think it's good that you, have, you know, explain why you want people to come [...] yeah, I just, mmm I think ....as I say, the tone of the first one is perhaps a little bit official...mmmm..but the other one is a little bit long, I thought. In a way, but uhm obviously you got to try and uhm explain why.... imagine people come to this programme.

Ellen talked about the length of the letter versus trying to explain why people should come to CR.

### **The benefits of attending CR**

Overall, many of the men and Kathryn liked the statements outlining the benefits of CR in the letter.

Kathryn: Uh, yes. I think uh,... in the letter where it says uh.... 'that research shows that people who attend cardiac rehabilitation are more physically fit', I think that is encouraging, yeah, uh,[...] uh and also that you have a lower chance of having chest pain, anxiety, or depression', because I do feel that anxiety and depression play a big part after you had uh a heart attack.

Kathryn also referred to fear and the safety aspect again when talking about Keep Fit classes.

Kathryn: And I went to those twice a week. Again, we were on the hospital premises. So the safety aspect was there because I think that is one of the things, after you realize, well, it hits you, you know, oh my goody, I have got heart disease, am I be able to going to get back to normal etcetera, and I think a big part of it is fear. You are so afraid that it could happen again.

In addition, Kathryn wanted the interviewer to know that she did not like being in a mixed ward when she woke up from her heart attack. However, mixed CR was not a problem. None of the men mentioned anything in regards to mixed gender wards or classes.

Kathryn: [laughs] When I was coming around from uh having a heart attack the following day I realized I was in a ward with men as well as women. I didn't like that at all [laughs].

Interviewer: Ok, so urm, you would prefer to be men and women separate?

Kathryn: Yes, very much so.

Interviewer: as part of the rehab programme, it wasn't separated?

Kathryn: The rehab programme was mixed and everybody got on well together, no that was fine. She also said 'everyone got on well together' which could refer to social support.

Kathryn talked about peer support when prompted by the interviewer about what she tells people when recruiting for the community cardiac support group.

Kathryn: And they can spend it with people who know what they have gone through, virtually, and encourage them to sort of get back to doing something socially once they have gone through rehab and they are feeling able to do that.

Peer support was not discussed in regards to CR, and only when eventually asked directly whether this was also a benefit of CR did she concur.

Interviewer: You also mentioned that you tell people um, they get to sort of, be with others that have been through the same experiences?

Kathryn: Yes, yeah.

Interviewer: Do you think uhm that would be something to mention for the cardiac rehabilitation as well?

Kathryn: YES I DO. Everybody is in a very similar state, aren't they. Even if they had bypasses etcetera. It is still all heart-related, isn't it.

Nevertheless, this is similar to the male participants mentioning the benefits of talking to others who have had similar experiences in terms of acute heart problems.

Conversely, Ellen did not talk about peer support or emotional impact and commented little on the benefits of attendance, because she did not get the opportunity to attend. When prompted about why she thought fewer women attend CR and the cardiac support group, she did not know why, but later on said:

Ellen: I don't know because...in our heart group, it's um they are all quite elderly, um, I mean we are trying to sort of recruit new members but um it has got a bit of a 'fuddy duddy' image, our group, I think. It has been going too long. And as I say, I mean, younger people having heart attacks, they just get back to work so quickly, and I don't think they want to be bothered with groups, I think they want to try and sort of carry on with their life as it was. And possibly, if they are interested in sports and such they don't want to be coming to a lunch where the average age is about 80. [...] And I think that is the problem with the ladies [...]. Lots of them are now widowed and they find it difficult to get places [...] A lot of older women don't drive, and if they lose a partner, they tend to be a bit stuck.

She also mentioned timing and transport as barriers to attendance.

Ellen: I mean, that is one of the things that has come out in a survey we have done, at the heart groups, wondering why people are not attending meetings, and a lot of the reasons, well, one of the main reasons that have come up is transport and the fact that our meetings are held in the evening.

In summary, both women talked about preferring a friendly, explanatory and easy-to-read letter that does not include a statement on dying. Professional recommendations or supervision was discussed, as were the benefits of attendance with regards to peers and anxiety. This was similar to the male accounts. Only the women talked about including 'why' CR is important, and Kathryn mentioned the safety aspect. Ellen suggested timing and transport as barriers to attendance.

## **5.5 Discussion**

Findings in regards to potential key messages likely to motivate people to attend CR were outlined above. These will be discussed and situated within the existing

literature next in order to better understand what statements motivate patients and to contextualize this within UK cardiac care services and thus wider determinants of health (further discussed in Chapter 7). How participants' views resonate with the theoretical concepts used in drafting the letters will be examined in the second part of the 'Discussion' section.

Three main themes emerged from the literature: 1) Motivating attendance, 2) Communicating about CR and 3), The benefits of attending CR, the latter two supporting the first.

### **5.5.1 Motivating attendance - choice and professional recommendation**

A few participants mentioned the doctors' or consultants' influence on attendance. In accordance with preceding research, physician recommendations are seen as important or positive by participants (A. M. Clark et al., 2004; Rolfe, 2010). Clark et al. (2004) found that professional recommendation and peer support were seen as positive elements by CR attendees, yet more scepticism was expressed by non-attenders who believed in 'rest is best' rather than exercise (Wyer et al., 2001a) and generally did not trust in the benefits of CR as well as doubting health care professional recommendations (A. M. Clark et al., 2004). It is to be kept in mind that both studies were rather small.

Of course, patients do not accept guidance from professionals unquestioningly, but as their knowledge is limited, they seek advice (Nettleton, 1995). The relationship between the health care professional and the patient is marked by an uneven distribution of knowledge and consequently power. As we have seen, several participants preferred less authoritarian, friendlier language in the letter, which may be important in terms of establishing mutual respect and balancing power. In addition, professional advice guides the patients' decisions, but tension between professional advice and maintaining the option of informed choice exists (debated further in Chapter 7). Madden et al. (2011) interviewed patients and staff about choices given between home, hospital and community-based CR. Patients saw the choices as less clear-cut, and home CR was not seen as a positive option. Madden et al. (2011) commented that current CR services in the UK do not come under the umbrella of informed choice that lay out all options, even though the British Association for Cardiovascular Prevention and Rehabilitation emphasises a module-

based, individually tailored approach for CR (British Association of Cardiac Prevention and Rehabilitation, 2012). Some patients felt pressured to attend CR through a pre-scheduled appointment ('bang you've gotta come'), whereas others thought it conveyed a positive message.

As described in the findings, some male participants mentioned the involvement of the spouse/wife in cardiac rehabilitation. Married men had been found to be more likely to enrol in CR, and more married men than married women do so (Benz Scott, Ben-Or and Allen, 2002). In general, women are found to be a major source of advice (Graham, 1985 as cited in Clarke, 2001). Cooper et al. (2002) had suggested that marriage is a gender-specific barrier, since married women might have conflicts in terms of responsibilities. In that respect, one female participant preferred for the family to be involved more in the entire care process. This could have wider effects in terms of care, well-being and family life and not only in terms of relieving the partners' distress or assisting with disease self-management (O'farrell, Murray and Hotz, 2000). Unfortunately, not many CRPs in the UK will have the capacity to accommodate partners or peers. As with the provision of a pre-scheduled appointment, tensions arise between an individual-level facilitator and organisational barriers to cardiac rehabilitation attendance (further discussed in Chapters 6 & 7). While pre-scheduling an appointment is an easy option for some programmes, others may work differently, and including a booked appointment would require a change in working processes (system- and individual-level intervention, Chapter 3; different design of the intervention, Chapter 6).

In previous qualitative research, especially non-attenders expressed that the body was perceived as vulnerable, whereas attenders recalled realizing that exercise stresses are safe (A. M. Clark et al., 2004). Only one woman (in the present study) commented on the aspect of safety, such as being with a doctor or on hospital premises, which eases anxiety about the possibility of exercise causing another heart attack. The safety aspect was seen in other studies on women and CR, too (Barlow, Turner and Gilchrist, 2009; Moore, 1996). In line with statements made by some male participants, this suggests trust in professional recommendation and medical care.

The final points discussed under the ‘motivating attendance’ theme refer to mentioning the negative aspects of chest pain and dying as a potential consequence of non-attendance. An acute coronary problem suddenly occurs and the survivors are confronted with their own mortality; often, heart attacks are actually perceived as a quick way to die (Emslie, Hunt and Watt, 2001). In that respect, two participants liked the message ‘attendance can reduce the chances of dying from another heart attack’, since it may motivate attendance (loss-frame messages are discussed in the theoretical section). Most other participants perceived these messages as scary or frightening and suggested rewording to ‘prevent another heart problem/hospital readmission’. As seen, one participant even said ‘nobody dies’, perhaps hinting towards the fact that death is not typically dealt with in everyday life in Western societies and may be hard to fathom. Due to the patients’ recent experiences, talk about death may initiate unpleasant memories or thoughts.

Based on current and previous results, professional recommendation merits inclusion in invitation material, as does perhaps a pre-scheduled appointment. More negative aspects were disliked, as was more authoritarian language. The presentation of cardiac rehabilitation as a life improver versus part of the treatment (only mentioned by one man) merits further discussion (Chapter 7).

### **5.5.2 Communicating about cardiac rehabilitation – language and content**

Many participants criticized the use of technical terms such as ‘physiology’ or ‘anatomy’. Complicated language may exclude patients with poor literacy skills and hence present a barrier to accessing health care. In fact, low literacy is an independent predictor of poor health and around 16% of adults in England have limited abilities (Clement et al., 2009). In addition, literacy is very low in the non-English speaking cardiac population of the UK (Jolly et al., 2003). Health literacy is associated with self-confidence, whereas low literacy is linked to higher hospitalisation and death rates in heart failure patients (Dennison et al., 2011; Holmes et al., 2011). While letters were found to be effective across the health areas explored in Chapter 3, various review authors had noted the limited effectiveness in lower socio-economic groups (for example, Tseng et al., 2001). It could encompass, for example, literacy, work conditions, and the elderly. One woman had mentioned that the longer letter using complex terms was a lot to read for older people. The other woman thought it was more comprehensive and encouraging, which highlights

the difficulties of finding a balance between enough information and brevity in presentation.

What information is included in the letters is of importance too. The letter should preferably inform participants about the activities at CR, which prepares them, not only for what to bring along. Not knowing what is ahead can initiate feelings of uncertainty, insecurity or worries. Fear of the unknown was a theme found in non-attenders of community prevention programmes (Murimi and Harpel, 2010). Kathryn liked that it was explained to her why she should exercise in regards to the heart being a muscle, which was not mentioned in the letters. A generalisation based on the one female participant is avoided here. Further exploration of these topics to be included in letters is suggested because, as said, a lack of understanding can lead to feelings of anxiety about the condition or CR itself (Roviaro, Holmes and Holmsten, 1984). Through use of less authoritarian language and explanation of the ‘what’ and ‘why’, the patient may feel more in control or even motivated (controllability is discussed in the theory section). Letter content and language connect to the first theme. Using less technical language and giving information about what happens during the CR session may reduce the power imbalance between the patient and the professional.

Being able to return to work faster as a ‘motivator for attendance’ was mentioned by one participant. Work was indicated as a barrier rather than a facilitator to attendance in the survey of CRPs (Chapter 4; 65% of CRPs had indicated ‘people at work’ to be less likely to attend CR). The NACR states that only 3% of non-attendees reported work to be the reason for non-attendance (The National Audit of Cardiac Rehabilitation, 2010). Here, outlining the benefits of attendance functions as a motivator (overlap of themes).

### **5.5.3 Benefits of CR - emotional support and outcome**

All patients commented on the effect of CR, which suggests that not only do they believe in it (which is likely, since they are members of a cardiac support group), but also that it is an important point to be made in the letter to encourage attendance.

Several participants suggested rewording ‘people in rehabilitation are fit’ to ‘will become more fit’. The changed wording suggests an optimistic look at the future. Rephrasing the text using future tense results in a gain-framed message outlining that

engaging in an activity results in a positive outcome (Bartholomew et al., 2006) (for further discussion, see Section 5.6). Furthermore, participants can relate to this message independently of their current level of fitness. Keeping in mind the target population of elderly patients, health and aging need to be considered, as during middle age, a shift in balance between years lived and years to come occurs. With this, the consideration of time left to enjoy life might be more important than the risk a behaviour presents (Wurm, Tesch-Römer and Tomasik, 2007). Therefore, CR attendance, exercise and lifestyle adjustments may be less desirable. Physical exercise might be hard to imagine, especially when multi-morbidity is faced. In addition, higher attributions to age lead to a lower level of favourable health behaviour (Leventhal and Proshaska, 1986 in Wurm, Tesch-Römer and Tomasik, 2007).

Thus far, only positive and physical outcomes of CR have been discussed. In terms of health and aging, positive beliefs are related to better physical functioning (Levy et al, 2002, as cited in Wurm, Tesch-Römer and Tomasik, 2007). In addition, age-related gains are seen as more controllable than losses, and the impact of control beliefs is important in maintaining optimism (Wurm, Tesch-Römer and Tomasik, 2007). In the beginning, the dislike for statements in the letters about chest pain and death was discussed. Patients may feel less in control and hence may like to avoid the confrontation.

Anxiety and depression are well-known and persistent psychological problems in myocardial infarct patients (Lane et al., 2002). Both issues were mentioned in the letters yet only two male patients mentioned the ‘relieving of anxiety’ and exchange of ‘similar experience... then it does help’. In Western culture, men are not socialized to express emotions (Luck, Bamford and Williamson, 2000), and perhaps this is why they engage in complex renegotiations of gender identity when they become older and less healthy (Robertson, Sheikh and Moore, 2010). This could be why dealing with psychological health is not mentioned as much. Instead, ‘work’ or physical activities like ‘cutting the grass’ came up. In fact, in cardiac rehabilitation, it is difficult to combine the relaxation element with the physical power attached to the male identity (Robertson, Sheikh and Moore, 2010).

The female participants talked about anxiety on several occasions. A variety of the literature also discusses women's different perception of heart disease and symptoms as well as higher rates of anxiety, depression and the need for social support (Davidson et al., 2003). Several studies found that women find it difficult to negotiate their role in the family and as primary care giver with their heart health (Clark et al. 1994, Lisk & Grau 1999). Their experience of a heart attack is much more emotive in comparison with men's (Davidson et al., 2010). One woman talked about involving the whole family in the care process. In regards to CR non-attendance, family responsibilities are frequently discussed in that women may resume domestic responsibilities very early in the recovery process (King and Lichtman, 2009; Tod, Lacey and McNeill, 2002). Absence from such responsibilities might cause stress as there is no counterpart or societal picture to 'men who have experienced a heart attack better rest', and heart attacks are still seen as a men's disease (Kessler et al, 1985 as cited in Martin and Suls, 2003). Conversely, one female-only study found the desire to achieve independence and functioning, and presumably return to daily life a driving force to enrol in CR (Macinnes, 2005). However, gender roles might be less relevant in the future with the change in traditional marriage (Martin and Suls, 2003). This is not to say that family roles should no longer be considered.

The difference in gender-related roles and associated illness experience is illustrated, but must be treated with caution due to the small sample size. Note that Sohl and Moyer had found in their review that tailoring after socio-demographic variables did not have more impact on screening uptake than not doing so (Sohl and Moyer, 2007). The focus here remains on tailoring after HBT so that, in combination with conveying logistic information, one simple tool is created for CRPs. Nevertheless, gender is just one example of how wider experiences can influence the perception of ill health. Overall, there is a lack of consideration of wider determinants in cardiac rehabilitation, perhaps due to the complexities of factors involved that lead to non/participation, as discussed in Chapter 1.

Women's non-attendance at the support groups appears to mirror non-attendance at CR. This was less expected, since reasons for non-attendance at CR (e.g. higher age and more co-morbid conditions) may be less relevant for community support groups due to monthly meetings, transport provision and the absence of exercise (which may



be a concern to women as discussed). One woman had mentioned transport and timing as barriers to attendance. Alternatively, women are more likely to die of a heart attack than men, hence the differential representation (British Heart Foundation, 2012). Longer hospital stays, more pain and co-morbidities are reported in women; one woman mentioned problems with arthritis here (Pilote et al., 2007). Additionally, there is much folk myth about cardiac rehabilitation exists, for example, sweating in front of others. Many patients feel embarrassed about exercising with strangers (A. M. Clark et al., 2004; Lloyd, 2009). Especially women may feel uncomfortable about co-morbid conditions such as arthritis or incontinence (King and Lichtman, 2009; Lloyd, 2009). Only one female participant mentioned disliking the mixed hospital ward, but she also said she did not mind the mixed rehabilitation classes, perhaps due to peer support, as ‘all got on well’.

Participants recalled that talking to peers helped them deal with their experiences and exposed them to more concrete examples of what activities are possible and when, like ‘helping the wife with [the] washing’. Peer support has previously been expressed as a positive side of CR attendance (A. M. Clark et al., 2004; Galdas and Kang, 2010; Rolfe, 2010). Of course, all participants are members of a peer cardiac support group. Interestingly, a review of cardiac support groups could not find statistically significant effects on the assessed outcomes such as quality of life or social support (Song et al., 2011). Nonetheless, the frequent use of health services is connected with wide-ranging kinship networks, and advice-seeking on health care matters has been found to be very common (Scrambler et al, 1981 as cited in Clarke, 2001).

Both review chapters (2& 3) found peer support to be an often-used method in helping patients. Evidence from such reviews is ambiguous, which may be due to the differences in health problems, peer supporter training and health care systems, as concluded in Chapter 3. Because of the effect of support through shared beliefs and value systems as well as the potential relief of the burden on the health care system, further explorations into the mechanisms of peer support would be constructive.

In summary, it can be said that social support, emotional coping and exchange of experiences are positive aspects of cardiac rehabilitation and should be included in invitation materials as well as more relatable, gain-framed messages.

### 5.5.4 Summary of findings

Interviews were conducted to explore key message likely to motivate attendance at CR with a view to amending existing invitation letter and hence increasing uptake in patients invited to CR. Suggested findings are summarized in Box 5.3.

- An invitation letter should be in an accessible format and concise, but at the same time provide enough information.
- Including details on what CR entails was seen as favourable, and the benefits of CR attendance should be highlighted.
- Some participants preferred a more polite, open invitation whereas others saw a set appointment as a facilitator to CR.
- Many participants said that the possibility of bringing partners along should be mentioned
- Individual motivators (bringing partners & a set appointment) might face organisational barriers (capacity & different CRP setup)
- Being able to talk to peers at the CR about their experiences was seen as positive.
- More negative side effects or outcomes were not seen as appropriate to include by most, yet some thought the shock effect would encourage attendance.
- Although the latter touches on emotional coping, emotional experiences such as anxiety were hardly addressed by men; few mentioned physical tasks.
- Anxiety and safety were recurrent subthemes in the female accounts.

### Box 5.3: Key findings

The findings indicate how invitation letters could be amended to better motivate CR attendance. But before this is discussed (in the final part of the discussion) an investigation is made into how the findings on patients' opinions and elicited key messages resonate with the health behaviour theory concepts operationalised.

## **5.6 Findings in regards to theoretical concepts as operationalised in letters**

As we have seen in the introduction, health behaviour theories are used to tailor interventions, specifically invitation letters in cardiac rehabilitation. This section revisits the TBP and CSM concepts used in the invitation letters. Their operationalisation is explored in light of the information and messages likely to motivate attendance at CR that were elicited through interviews based on existing letters (as summarized above). The aim here is to add further theoretical knowledge on intervention design in health communication and, in combination with the interview findings, to arrive at an amended invitation letter. In regards to the overall aim of the thesis of ‘increasing uptake in patients invited to CR’, a theoretically informed yet pragmatic approach is taken with an evaluation of amended letters to follow in Chapter 6.

### **5.6.1 The theory of planned behaviour**

The TBP outlines key determinants of behaviour, namely attitude, subjective norm, and perceived behavioural control, which together impact intention (Figure 5.2). Intention is the motivational component and in combination with perceived behavioural control explains or predicts behaviour (Sutton, 2010).

Ajzen suggests targeting the most often mentioned salient beliefs, but this is problematic when using the TPB for a more general intervention that encompasses all patients eligible for CR (Ajzen, 2006a). To change beliefs, nothing is mentioned explicitly, other than ‘providing information, engaging in the behaviour or observing others do it’ (Sutton, 2010, p.12). The concepts that comprise the TPB need to be complementary in terms of target, action, context and framework when the behaviour is defined (Ajzen, 2006b). The main aim is to target non-intenders and change their key beliefs through modifying the three key concepts. Attitude, subjective norm and perceived behavioural control will be discussed separately next.

#### **Attitude**

Both letters operationalised attitude in similar ways with two components; one about achieving a better state of health and one about avoiding negative consequences (Table 5.5).

#### **Table 5.5: Attitude component of each invitation letter**

Letter A (Wyer, 2001)	Letter B (Mosleh, 2011)
This is because those who attend such a programme are more likely to recover sooner and better than those who do not attend.	Research shows, however, that people who attend cardiac rehabilitation are more physically fit, return to work and other activities more quickly,
In addition, research has shown that attendance can reduce the chances of dying from another heart attack.	and have lower chances of having chest pain, anxiety, or depression, than those who don't attend.

The TPB conceptually includes the perception of a threat/outcome and, as an expectancy value model, regards attitude as an evaluation of the likely outcomes of behaviour as well as the outcome itself (Ajzen, 2006a). Attitude is usually operationalised by providing a statement which is then rated by participants along a scale of degrees of (dis)agreement. A similar approach appears to have been taken in the previous trials (Mosleh, Kiger and Campbell, 2009; Wyer et al., 2001b), yet participants in the current study suggested changing the verb from present to future tense: 'people who attend rehabilitation will become more fit'. Independent of their current fitness status, people can relate to this.

Message framing is a way of tailoring a message to a specific population: the presentation frame is manipulated to instigate behaviour change (Myers, 2010). Rephrasing the first part results in a gain-framed message: *people who attend cardiac rehabilitation **will become**<sup>34</sup> more....* The goal-framing approach uses gain-framed messages to instigate a behaviour based on the gain associated with it whereas loss-framed messages outline a loss when a certain behaviour is not performed and thus both support the same behaviour (I P. Levin, Schneider and Gaeth, 1998).

O'Keefe found more support for gain-framed messages, whereas Levin and colleagues found more support for loss framing (I P. Levin, Schneider and Gaeth, 1998; O'keefe and Jensen, 2008). Other evidence suggests that different personalities react to different types of message. Approach personalities respond to reward messages, and avoidance personality types respond more to threat messages (Carver, Sutton and Scheier, 2000; Myers, 2010). The only CR-related study was conducted

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<sup>34</sup> **Bold** writing in letter statements indicates a change in wording from previous letters.

by McCall et al. (2004), who looked at the effect of message framing on cardiac rehabilitation adherence and found that exposure to gain-framed messages led to higher adherence (Mccall and Ginis, 2004). Since this intervention targets all patients eligible for CR (Chapter 6), including both types of messages in intervention materials would be favourable.

*Research shows that people who attend cardiac rehabilitation **will become** more physically fit, return to work and **social activities** sooner. **Those who do NOT attend** can have **higher** chances of other **heart problems**, anxiety or depression than those who do attend.*

The last sentence is now a loss-framed message. Some health promotion literature supports utilising threat messages, but only, when in combination with some form of self-efficacy enhancement (Protection Motivation Theory, Bartholomew et al., 2006, p. 98). Health messages that are not supported by framing barriers in terms of self-efficacy are suggested to be less successful (Witte, 1995 as cited in Mattson and Basu, 2010). Therefore the phrases ‘chances of dying’ and ‘chest pain’ were removed. Most participants disliked these statements, and some perceived them as potentially anxiety-inducing. A change to ‘chances of other heart problems’ was made.

Furthermore, one female participant talked about ‘social activities’ (in regards to community groups), while many others mentioned the benefits of talking to peers. The goal was to present the benefits of CR attendance in a more holistic way, hence ‘work’ was kept and ‘other activities’ was changed to ‘social activities’. Note that the TPB is based around the idea that demographic factors only influence behaviour through the concepts included in this case ‘attitude’ (Diefenbach and Leventhal, 1996).

### **Subjective norm**

Subjective norm, which encompasses others’ expectations and the motivation to comply with them, was previously operationalised as seen below (Table 5.6).

**Table 5.6: Subjective norm**

<b>Theoretical comments</b>	<b>LETTER A By Wyer <i>et al.</i> (2001)</b>	<b>LETTER B By Mosleh <i>et al.</i> (2011)</b>	<b>Theoretical comments</b>
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subjective norm (TPB)	The medical and nursing professions recommend that people who have had a heart attack should attend a cardiac rehabilitation programme.	Your consultant and health team have recommended that you undergo an 8-week cardiac rehabilitation programme, which aims to help you to recover and improve your health and life.	subjective norm (TPB)
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Although Clark et al. had found that some patients doubted professional recommendations, some participants here liked to know who wanted them to attend cardiac rehabilitation, as debated in the ‘Discussion’ section (A. M. Clark et al., 2004). This statement was combined with framing CR as a treatment rather than a lifestyle choice (further discussed in the conclusion, Chapter 7).

*As part of your treatment, the medical and nursing professions strongly suggest that you attend a cardiac rehabilitation programme, which aims to help you **get better quickly** and improve your health.*

In addition, peer support, mentioned as a positive side effect, may also tap into the ‘subjective norm’ concepts. In fact, Wyer et al. used a similar statement in their introduction but did not utilize this theoretical concept (see Table 5.5) (Wyer et al., 2001b).

*By attending CR, you will have the opportunity to talk to other people with heart problems.*

OR

*At CR, you will meet other people with heart problems, and you will have the opportunity to share your experiences.*

Decision-making in this context is likely to take place in the home environment with ‘medical’ cues to action being removed. Cues to action could be the invitation letter itself (or the phone call used by 70% of CRPs to invite patients, Chapter 4) or discussion with spouse, family or friends, and their involvement was mentioned by participants (lay advice and companions were discussed, but potential tension between individual motivations and organisational barriers could arise).

*Your spouse/partner is welcome to attend the first session with you.*

### Perceived behavioural control

The third concept, *perceived behavioural control* (PBC), encompasses considerations about barriers and facilitators towards performance, similar to self-efficacy (Sutton, 2010). Within the TPB, the connection could be causal (through control-behaviour) or associative (through actual control) (Sutton, 2010). The latter would not be modifiable, as this refers to, for example, extrinsic barriers like opening hours or transport.

Both letters concentrate on intrinsic barriers. Wyer et al. emphasise that patients must make an effort, and Mosleh et al. presumably employed PBC through including the phrase ‘your needs’. When participants compared this to the other letter, B, they preferred that it included more information and was less authoritatively worded.

**Table 5.7: PBC as operationalised in the letters**

<b>Letter A (Wyer, 2001)</b>	<b>Letter B (Mosleh, 2011)</b>
During this programme, you will be offered advice and information about how best to recover after a heart attack. It will be up to you to follow these if you want to recover as well and as quickly as possible.  Experience has shown that the more effort you can put in, the more quickly the results will be achieved.	The programme is multidisciplinary, which means that the doctor, cardiac rehabilitation nurse, and dietician, physiotherapist, and the occupation therapist work together to tailor the programme to meet your individual needs.

This is very similar to the concept of controllability as used in the CSM; they will therefore be discussed together in the next section. The operationalisation was similar too.

#### **5.6.2 The common sense model of illness representation**

Another concept included was controllability, which is “how the individual may help to control or cure illness” (A. Cooper et al., 1999, p.234) or the perception of receptiveness to interventions (Diefenbach and Leventhal, 1996).

As discussed above, providing easy-to-access information – in this case, telling people ahead of time what CR is about - could reduce barriers to attendance.

## Table 5.8: Controllability

### Letter B (Mosleh, 2011)

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During the programme you will participate in supervised aerobic exercise in a safe environment, followed by relaxation sessions.	Controllability
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The *sense of illness control* plays a role in initiating communication with health care professionals about CR as well as in actual participation in and adherence to cardiac rehabilitation (Grace et al., 2008). Control (controllability or perceived behavioural control) in regards to age was also considered. Interestingly, Keib and colleagues debated the evidence on older adults and CR in light of the CSM. Diefenbach and Leventhal (1996) as well as Keib et al. commented, for example, that older adults may attribute an acute cardiac event to chronic CHD or to age as the cause rather than to a certain lifestyle, which can result in low perceived controllability (Diefenbach and Leventhal, 1996; Keib, Reynolds and Ahijevych, 2010). Cooper and colleagues found that patients who attributed heart issues to lifestyle with a high sense of control (CSM), were more likely to attend CR (A. Cooper et al., 1999).

While it is difficult to incorporate a statement addressing age and controllability, the sentence '*the programme will be tailored to your individual needs*' was adopted to reassure older patients with co-morbidities that their abilities and health status would be considered. For the same reason, the word '*gentle*' was added. Note that '*gentle*' may deter younger patients, but since it is the older ones who are missing, the choice was made to include it.

Controllability and perceived behaviour control are now operationalised in more plain language<sup>35</sup>:

*A team of **different health care professionals** including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your **individual** needs.*

*During the programme you will participate in **gentle** exercises and relaxation*

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<sup>35</sup> Mosleh et al. (2013) assessed socioeconomic status and found that the participants were from more affluent backgrounds. They comment that this could have affected the impact of the letter.



sessions in a safe supervised setting. We also cover session on **how the heart works**, *healthy eating, physical activity and stress management*.

Safety aspects were discussed by the female participants and hence adopted from the original letters.

### **Perceived consequences**

The final CSM concept discussed here is ‘perceived consequences’ (Table 5.9), which encompasses the expected outcomes of the health threat (for example, personal experience, financial or emotional struggle (Diefenbach and Leventhal, 1996)). During the interviews, patients expressed their dislike of this statement as it might distress or upset the reader. This statement does not appear to be motivating, but instead could induce an emotional reaction that keeps people away from cardiac rehabilitation or exercise. One woman said people might feel worried that exercise could bring about another heart attack. Consequently, this statement was omitted.

**Table 5.9: Perceived consequences**

#### **Letter B (Mosleh, 2011)**

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After leaving hospital, many patients still have episodes of chest pain and distress, which can stop them returning to normal daily activities quickly	perceived consequences (CSM)
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### **5.6.3 The new letter**

As a result of the interviews, motivational letters tested in 2001 and 2011 were further developed, and the final result can be seen in Box 5.4. Technical terms were removed, and the reading level is now 49% (Flesch Reading Ease)<sup>36</sup>, with only 9% passive sentences, making the letter more accessible. The font size should be 12, since the target population is older, and some may experience visual impairment.

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<sup>36</sup> Score notes: 90.0–100.0 easily understood by an average 11-year-old student, 60.0–70.0 easily understood by 13- to 15-year-old students, 0.0–30.0 best understood by university graduates. Wikipedia [[http://en.wikipedia.org/wiki/Flesch%E2%80%93Kincaid\\_readability\\_tests](http://en.wikipedia.org/wiki/Flesch%E2%80%93Kincaid_readability_tests)]

Dear \_\_\_\_\_

As part of your treatment, the medical and nursing professions strongly suggest that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the programme you will participate in gentle exercises and relaxation sessions in a safe supervised setting. We also cover session on how the heart works, healthy eating, physical activity and stress management.

At CR you will meet other people with heart problems and you will have the opportunity to share your experiences.

Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

Your spouse/partner is welcome to attend the first session with you.

Your appointment is on \_\_\_\_\_ Please come to \_\_\_\_\_

Please wear comfortable clothing and flat, rubber-soled shoes. Please bring a list of your medications with you and reading glasses if needed.

We look forward to meeting you.

Yours sincerely

#### **Box 5.4: New invitation letter**

### **5.7 Limitations and strengths**

The sampling strategy limits access to people who attend support groups and may believe in cardiac rehabilitation. Still, the benefit of including participants who attend CR is that they highlight advantages of attendance unknown to the researcher. As an example, consider how in previous literature peer support was seen as positive, and the question is whether to mention this in the letter (A. M. Clark et al., 2004). Two participants never had the opportunity to participate in CR and could have contributed a different viewpoint (though this did not become apparent in the analysis).

No diversity in terms of ethnic origin was achieved even though recruitment took place in a more diverse setting. As mentioned in Chapter 1, ethnic origin is

frequently discussed in the literature, but few studies have been conducted. Most qualitative studies (from various countries) address the suitability or experience of a specific CR programme (for example: Banerjee et al., 2010; Chauhan et al., 2010b; Darr, Astin and Atkin, 2008; Galdas and Kang, 2010; Sloots et al., 2011). The NACR does not find ethnic background to be an indicator for under-representation in cardiac rehabilitation in the UK (The National Audit of Cardiac Rehabilitation, 2011).

There was a lack of female participants, as in many other studies, as well as in cardiac rehabilitation itself (Davidson et al., 2003; The National Audit of Cardiac Rehabilitation, 2011). Interestingly, the support groups visited also had very few female members. As discussed above, this may be due to women being older and having more co-morbidities. Women may stay away from this more male-dominated area or resume their domestic responsibilities sooner. Women are also still more likely to die after a heart attack (British Heart Foundation, 2012).

Extrapolation of the research findings to other cardiac rehabilitation settings needs to be treated with caution. This is especially relevant in terms of the female accounts being presented as index cases, where a danger of presenting an incomplete account exists (Yin, 1998). As with case studies, only analytical generalisation to the theory/implications but not to the sample or population can be made.

Theoretically, transcription would allow for data analysis by an independent research, however, this being part of a doctoral thesis, an independent analyst was not available. To enhance credibility, the research study is described in great detail, and the coding frame is provided along with much of the data in the form of original quotes (Chenail, 1995).

A danger of participants expressing what they think the researcher wants to hear rather than expressing their actual opinion exists. Power dynamic is a factor, which can make it challenging to conduct interviews and to find the balance between being empowering and empathic while but not being leading. It has been argued that the interview format still contains a power hierarchy because, for example, the participant cannot deflect questions (Kvale, 2006 as cited in Creswell, 2007). Although, some of the participants' comments hinted towards how they perceived

me - namely as a young student they wished to help – their perception influences how they responded to my question.

## **5.8 Methodological considerations**

The potential contribution of the additional qualitative element specific to this thesis was the light it shed on the question why the letters worked in the past, and this might help to improve the accuracy of motivational statements (Popay and Williams, 1998). A qualitative approach fostered the identification of the key messages necessary to motivate CR attendance as well as the exploration of theory in writing, which is a valuable contribution to the development of the theory-based intervention material (Creswell, 2009). The advantage of using a qualitative approach here is that it helps to gain a better or deeper understanding of how the patients perceived existing motivational statements, which also allowed for an examination of how patients' opinions resonated with the theoretical concepts (Flick, 2010). Additionally, an inquiry with open-ended questions aids the capturing of multiple meanings and results in rich descriptions (Creswell, 2009). This approach was instrumental in that it eventually led to the drafting of an amended invitation letters, the basis for the experiment described in Chapter 6.

Methodologically speaking, a descriptive qualitative account analysing transcribed semi-structured interviews based on constructivist epistemology and ontology was presented. This postulates that meaningful realities are created by individuals attempting to make sense of their experiences, here pertaining to the invitation letters (Avis, 2005; Guba and Lincoln, 1998). In this case, choosing semi-structured interviews allowed for a deeper exploration of patients' views (Creswell, 2007; Flick, 2010).

Semi-structured interviews allowed for flexible investigations of the participants' perceptions of the letters, yet depended on the researcher's ability to respond in a constructive way. Data came from the interaction between researcher and interviewee (Avis, 2005). And while telephone interviews are practical and not resource-intensive, one cannot use facial expressions or body language as cues (Creswell, 2007). However, telephone interviews were appropriate here because they can enhance access to harder-to-reach populations and help overcome barriers such as transport or ill health often preventing cardiac rehabilitation attendance,

especially in women (Daniels et al., 2012). One-to-one phone interviews may also encourage shy individuals to express their opinions, as they do not have to face other participants or the researcher directly.

In health research, the research question does not simply drive the choice of methods but instead consists of an iterative process influenced by pragmatic considerations around accessing people with the experiences sought after (Avis, 2005). Despite several attempts it was not easy to recruit participants, women in particular. Due to the difficulties of recruiting women and the resulting dilemma in presenting the material, the interviews with the two female participants were portrayed as separate index cases, with the purpose of comparing and contrasting the experiences of men and women. This was deemed to be the most appropriate and pragmatic approach to what appears to be a more general problem, namely that the recruitment of women to studies in CR is difficult. It also mirrors the difficulties seen in CR attendance itself, where older women are under-represented (as mentioned in the previous section) (The National Audit of Cardiac Rehabilitation, 2011). Consequently, an in-depth description under the umbrella of qualitative research - which is by its nature suited to better understanding the views of women - was chosen (Staker, 1995 as cited in Baxter and Jack, 2008). The goal was to gain broader insight into and appreciation of the opinions of women on cardiac rehabilitation letters (Crowe et al., 2011).

The last methodological consideration discussed here pertains to recruitment and sampling. The purposive sample, in keeping with the nature and purpose of this study, is not a representative sample (Pope and Mays, 2006a). The intention is to understand meaning and not to generalise (Creswell, 2007). The approach was instrumental in improving letters and exploring theoretical concepts, which led to an evaluation of the new letter that includes all patients eligible for CR (Chapter 6). In the context of convenience sampling, a dependence on volunteers and limitations in terms of time and resources for recruitment can reduce transferability and are subject to self-selection bias.

In terms of the sample size, saturation is the point where repetitive data emerges (and is more suitable for phenomenological research) is often mentioned in the literature (J Green and Thorogood, 2009). However, this could mean a lengthy process until all

variations, setting, and connections are explored, which is impractical for this study (and in most research settings).

Appropriate sampling strategies were chosen, although hard-to-reach population groups or people who do not attend a support group were not given the opportunity to participate or people who do not attend the support group, which is a draw back. Still, the interviews were instrumental in exploring key motivational messages as well as the use of theory in text leading to an experiment testing letters which includes all patients eligible for CR (for further discussion, see Chapter 6).

Additionally, only women were approached at the third group, which puts men at a disadvantage. Women are under-represented in cardiac rehabilitation (including research), hence it was desirable to achieve a more proportional representation. Since this a theoretically driven and not a practical decision, no major ethical concerns arise (Lund Research Ltd 2010, 2010). Due to the small number of female participants, the two cases were presented in more detail as index cases. It is to note that the small sample size does not present ethical issues, since no claims to external validity are made (Lund Research Ltd 2010, 2010).

## **5.9 Conclusion**

This study explored participants' perception of two existing invitation letters to understand key messages to motivate attendance at CR (Box 5.3). Findings from this qualitative exploration lead to an adjustment of the motivational letters and simultaneous consideration of the operationalisation of theoretical components. The practical implications point towards the importance of consulting patients and investigating their understanding of health promotion materials. The question is *whether an amended invitation letter encourages more patients who had been invited to attend CR* when implemented on a larger scale in clinical practice?

## Chapter 6

### **Does an amended invitation letter increase uptake of CR?**

The previous chapters described the sequential process of deriving a theoretically informed, yet pragmatic intervention in response to the main research question *‘What is a good way of improving uptake of cardiac rehabilitation in invited patients?’*

Reviews had shown that the majority of evidence evaluating methods to increase patient participation in health services stems from individually directed methods, many of them successful (Chapters 2 and 3). After considering invitation procedures used in current CR practice and the limitations of a doctoral thesis, the decision was made to develop theoretically based invitation letters. Letters are currently being used by 50% of CRPs as one of the ways to invite patients (Chapter 4). If such letters could be rewritten in a motivational manner, this would be a cost-effective way of improving uptake. In the previous chapter, an exploration of the operationalisation of health behaviour theory through patient interviews was described. This led to an amended invitation letter, which specifically targets those patients who have been invited but fail to attend (31% of non-attenders gave their reason as ‘lack of interest’ (The National Audit of Cardiac Rehabilitation, 2011)).

This chapter describes the final step, a quasi-experimental evaluation answering the last research aim 6): *Does an amended invitation letter encourage more patients to attend CR?*

### **6.1 Background**

Cardiac rehabilitation helps patients who have experienced an acute cardiac event to regain their physical strength and psychosocial well-being with the aim of limiting or even reversing CVD risks (Day, 2008; Heran Balraj et al., 2011; Piepoli et al., 2010; The National Audit of Cardiac Rehabilitation, 2009). As described in Chapter 1, comprehensive cardiac rehabilitation includes exercise, relaxation and health education. Risk factors like smoking or stress are addressed (Bethell, Lewin and Dalal, 2009; Day, 2008; Piepoli et al., 2010; R.S. Taylor et al., 2004). Traditionally, this is called phase 3 CR, which ideally starts after 2 to 6 weeks of recuperation at home. The duration of the cardiac rehabilitation programme (CRP), delivered in hospital or community centre settings, varies between 6 to 10 weeks, and most programmes attempt to tailor the CR to their patients’ needs (Bethell, Lewin and

Dalal, 2009; British Association of Cardiac Prevention and Rehabilitation, 2012). Significant variations exist in staffing levels, hours and HCP involvement as well as in programme content and setup (Brodie, Bethell and Breen, 2006; Doherty and Lewin, 2012; The National Audit of Cardiac Rehabilitation, 2011).

Despite proven effectiveness, attendance at cardiac rehabilitation in the UK has remained below desirable (Heran Balraj et al., 2011; The National Audit of Cardiac Rehabilitation, 2012). The NACR, an audit to evaluate service provision in England, Wales and Northern Ireland, provides data exploring patient characteristics and programme information (Lewin, Thompson and Roebuck, 2004). The NACR minimum data set is a standardized audit tool for gathering clinical, health and behavioural data related to cardiac rehabilitation (Lewin, Thompson and Roebuck, 2004). Participating programmes collect anonymised patient information as well as dates at which patients were contacted, waiting times and reasons for non-attendance. A designated person on site enters all data via a web-based or a software platform. Unfortunately, not all CRPs take part in entering individual data, and due to scarce resources, data entry is often incomplete or can be delayed for months. To collect data from programmes that cannot access the online database, the NACR team conducts a yearly survey to inquire about the different health care professionals involved, the staff hours dedicated to (or borrowed for) CR as well as the number of patients receiving phase 3 by gender.

As mentioned in Chapter 1, CR attendance is calculated using HES data as the denominator. Patients are not followed along the care pathway, which makes this number an estimate only. In terms of non-attendance, the Commission for Healthcare Audit and Inspection surveyed almost 4,000 people with coronary heart disease. They found that 60% of non-attenders had not been offered CR and 17% did not think CR was relevant (Commission for Healthcare Audit and Inspection, 2004). Furthermore, the NACR found that the main reasons for non-attendance are 'lack of interest' (30%) and 'physical limitations' (10%), with other things being rarely mentioned ( $N = 31,446$ ) (The National Audit of Cardiac Rehabilitation, 2012)

The brief review (Chapter 1) concluded that non-attenders are a heterogeneous group influenced by geographic location, population composition and system-related issues. The survey in Chapter 4 explored the methods used to identify and invite



patients and uncovered great variations in the use and combination of methods as well as diversity in service provision (CR phases offered). A simple, cost-effective way of recruiting patients is the use of a health behaviour theory-based invitation letter, as suggested by the reviews (Chapters 2 & 3). Guidelines emphasise motivational letters as one of the means of reminding patients to attend cardiac rehabilitation. No examples are easily accessible, even though two trials had investigated this method previously (Chapter 2) (National Institute for Health and Clinical Excellence, 2007).

The evidence from those two trials had shown that letters tailored after health behaviour theory had a positive impact on attendance. While the trials were conducted well they were site-specific and consented patients individually (Mosleh, Kiger and Campbell, 2009; Wyer et al., 2001b). Consenting introduces a number of biases and may in itself affect the outcome. One of the trials compared letters to usual care, which did not involve a letter<sup>37</sup>. It simply showed that a letter significantly increased attendance compared to not using a letter (Wyer et al., 2001b). Only the second trial would have focused on the use of a theoretical letter versus a regular letter. Information on the original letter was not provided (Mosleh, Campbell and Kiger, 2009).

In this study, the invitation letters used in the two previous trials were further developed with patient input, especially in regards to exploring the operationalisation of health behaviour theory in motivational, written materials (Chapter 5). To further advance knowledge, no individual recruitment took place in this evaluation, the aim being a more representative sample. Consideration was given to the content of the original letters compared to the new letter. Note that the current evaluation included multiple centres in various locations. Since working processes and procedures differ between centres, the letter content had to be adjusted, making this a pragmatic quasi-experiment, as further explained in Section 6.2.

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<sup>37</sup> Wyer et al (2001) sent a 'thank you' note to all participants.

### **6.1.1 Objectives**

The main aim of this study was to evaluate the **effectiveness** of an amended invitation letter and thereby increase the uptake rate of cardiac rehabilitation phase 3.

The objective of this study was:

- to evaluate whether the amended invitation letter increases uptake rate at cardiac rehabilitation phase 3 when compared with the original letter in use in that programme.

## **6.2 Methods**

The method used was a pragmatic before-and-after evaluation in which CRPs used their current letter of invitation for a 5-months baseline period before replacing it with the amended letter for a 6-months follow-up period. The data was collected continuously to examine differences in uptake rates.

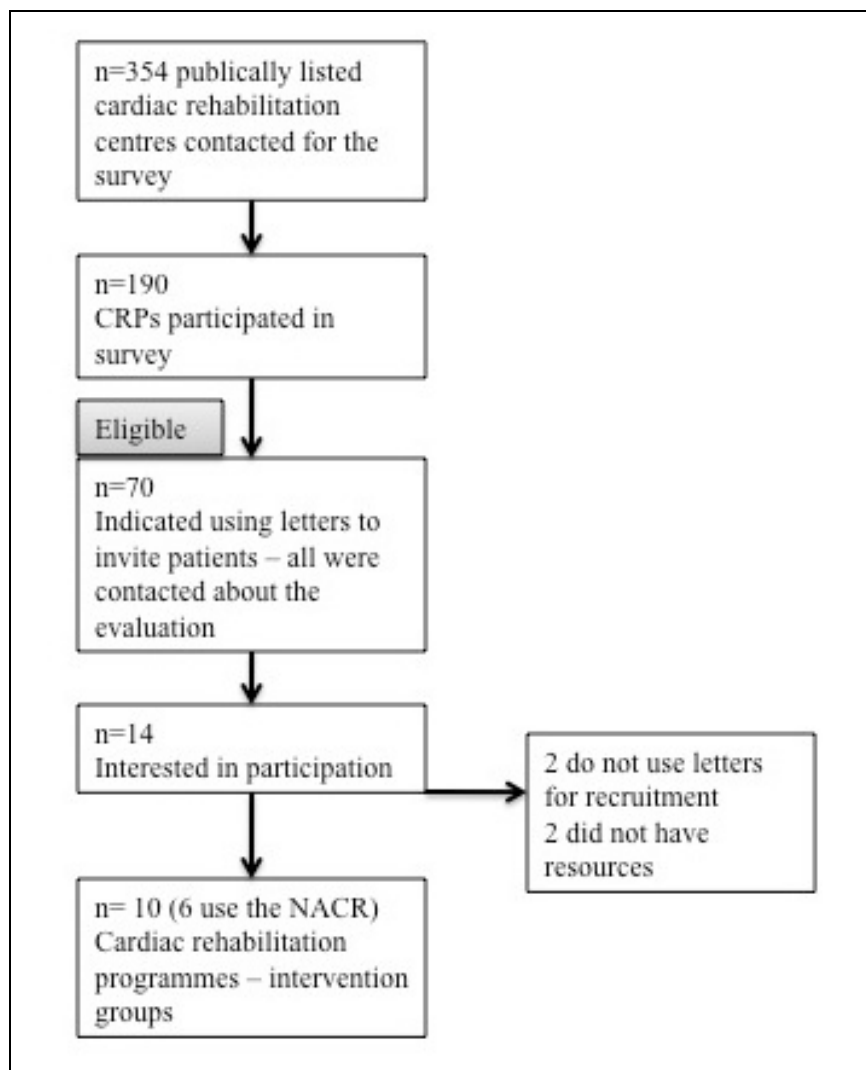
### **6.2.1 Recruitment procedure**

As a first step, all of the “coordinators” of cardiac rehabilitation programmes listed online on the National Register of Cardiac Rehabilitation/the National Audit of Cardiac Rehabilitation (NACR)<sup>38</sup> were contacted and asked to complete a short online survey (Chapter 4). The survey collected data on currently used methods to identify and invite patients to attend CR. Of the 190 programmes participating in the survey, 70 indicated the use of invitation letters and were contacted via email.

An email about the evaluation was sent in Dec 2011/Jan 2012, addressing the 70 CRP coordinators that had participated in the survey and indicated the use of invitation letters. A total of 14 programme coordinators responded with interest in participating in this study and were sent information materials (Appendix E). The researcher had telephone contact with all interested coordinators to discuss the set-up of the CRP and the current use of the invitation letter. The setup of four programmes was not suitable for the evaluation, leaving 10 cardiac rehabilitation programmes that agreed to participate. All centres signed and returned the agreement to participate along with the ‘invitation to CR letters’ they normally use. The recruitment process is illustrated in Figure 6.1.

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<sup>38</sup> <http://maps.cardiac-rehabilitation.net/>



**Figure 6.1: Recruitment process**

### 6.2.2 Measures and outcomes

The *primary outcome measure* was uptake rate. Uptake was defined as participation in at least one phase 3 session/assessment as recognised and noted by CRP staff<sup>39</sup>.

Uptake rate was calculated as the number of new patients who attended at least one phase 3 assessment/session as a percentage of the number of invitation letters sent.

Local CRP staff collected this data and sent it to the investigator each month.

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<sup>39</sup> This definition is equivalent to the NACR definition of attendance and has been used throughout this thesis.

A set of patient characteristics was collected to assess any differences in the patient group attending in the post-intervention period. The researcher received a data set from NACR personnel containing anonymised, individual data on the variables listed below. All data was grouped by CRP. The patient characteristics were:

- *Age M (SD)*
- *Gender N (%)*
- *Ethnic origin N (%)*
- *Marital status N (%)*
- *Co-morbidities N (%) and M (SD)*
- *Initiating event N (%)*

Information about the patient population was extracted in order to compare the cardiac rehabilitation sites that participated with those that did not and to examine any differences to the samples from previous trials of invitation letters. The dataset contained the same information for all non-participating NACR sites<sup>40</sup>. Attendance at CR phase 1 and phase 3 for the same time periods was extracted to compare the sites.

Information on staff hours and the health care professional mix was obtained from the NACR annual survey (2011/2012) and included:

- *Staff hours M (SD)*
- *Health care professionals N*

In addition, the researcher collected data from the participating sites, including

- *other ways of inviting patients to participate in CR*
- *the type of hospital the cardiac rehabilitation site is associated with*
- *waiting times between inviting a patient and his/her appointment or first session.*

### **6.2.3 Data collection**

*Data collection from the intervention sites:* A designated staff member collected data on ‘number of invitation letters sent’ and ‘number of new patients in phase 3’ per month. The investigator contacted this person once a month (if intervention sites did

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<sup>40</sup> Delay in data entry made it impossible to extract complete data, as discussed later.

not provide the data in a timely manner, they were prompted by phone and email to do so). Data was collected over a time period of 11 months (January 2012 – November 2012).

*Data collection from the NACR:* From the NACR, anonymous summary data on patients' age, gender, marital status, co-morbidities, initiating event and ethnic origin were extracted for each participating site (January – November 2012). The number of patients entered into the NACR and registered for phase 1 and phase 3 was extracted for intervention sites and for all other NACR sites.

*Data collection from the annual programme survey:* Data on overall staff hours and number of health care professionals involved in CR was provided by the NACR staff for each intervention site.

Data was extracted in January 2013.

Data collected from the intervention sites, data extracted from the NACR as well as from the survey and the information provided by the coordinators were combined. The information is presented for each intervention site separately as well as in a summary table comparing sites in Section 6.3 'Results'.

#### **6.2.4 The intervention**

The new letters were introduced after five months, and data collection continued for the following six months. A generic version of the invitation letter can be seen in Box 6.1. Due to local circumstances, the letter had to be adjusted to fit each site, details of which are provided in the 'Results' section. This makes this a pragmatic quasi-experiment measuring effectiveness - real-life circumstances (rather than efficacy - ideal conditions) (Roland and Torgerson, 1998).

Dear \_\_\_\_\_

As part of your treatment, the medical and nursing professions strongly suggest that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals, including the doctor, the physiotherapist and nurses, work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the programme, you will participate in gentle exercises and relaxation sessions in a safe supervised setting. We also cover sessions on how the heart works, healthy eating, physical activity and stress management.

By attending cardiac rehabilitation you will have the opportunity to talk to other people with heart problems.

Research shows that people who attend cardiac rehabilitation will become more physically fit, and return to work and social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

Your spouse/partner is welcome to attend the first session with you.

Your appointment is on \_\_\_\_\_ Please come to \_\_\_\_\_

Please wear comfortable clothing and flat, rubber-soled shoes. Please bring a list of your medication with you and reading glasses if needed.

We look forward to meeting you.

Yours sincerely

### **Box 6.1: Generic invitation letter**

#### **6.2.5 Data analysis**

For each intervention site, descriptive statistics were used to explore the data. The variables 'number of letters sent' and 'number of patients attending' were collected as count data but treated as continuous variables. Crude analyses were performed. The number of patients attending was adjusted according to waiting times, as described below.

Other variables were extracted from the NACR (such as age, marital status), and the above-mentioned parameters were used to describe the data. Differences were explored using t-tests, the Mann-Whitney U or chi-square test. Assumptions for the tests were assessed (appendix E) (Field, 2005).

*Hypotheses:* It was hypothesised that a) there are no differences in patient characteristics between the pre- and the post-intervention period, and b) there is a difference between uptake rates comparing the two time periods.

#### 6.2.5.1 Summary analysis

Uptake rates (mean, standard deviation) for all other NACR sites were calculated to compare these with the intervention sites. A t-test was performed to compare differences in uptake rates (limitations discussed). Statistical significance was set at values of  $p < .05$ .

Data was analysed using IBM SPSS, version 21.

#### **6.2.6 Ethical considerations**

The chair of the Northern and Yorkshire Research Ethics Committee deemed this to be a service improvement evaluation that does not require an ethical opinion (Appendix E). Since a population approach was adopted and no individual patient data was collected, it was not considered necessary to obtain individual patient consent. The study guarantees the confidentiality of cardiac rehabilitation centre data. The intervention was applied to all patients, and there was no randomisation.

### **6.3 Results**

Ten cardiac rehabilitation programmes in England agreed to take part in the 11-month prospective study in 2012. The following sections briefly describe the data collected and the data extracted from the NACR for each site individually and then present summary data.

#### **6.3.1 Recruitment of CR centres**

A total of 10 cardiac rehabilitation programmes had agreed to participate in the study; however, four programmes withdrew for reasons such as dislike of the new letter or time restraints (Appendix E).

#### **6.3.2 The invitation letters**

The researcher amended the letter for each site herself and discussed this with each site coordinator via telephone. All practical information from each original letter had to remain unchanged due to working processes and setup, and some information had to be removed (e.g. 'your appointment is on' where no appointment date/time was

provided and the patients were required to contact the CRP instead. The statement ‘spouse can attend’ was removed where space was too limited to allow this. With the exception of these practical changes, the intervention sites were required to include all of the theory-based motivational statements in their new letter. Changes to each site’s letter are summarised below, and each letter can be seen in detail in Appendix E.

- Site 1 used the new version as displayed in Box 6.1. The original version did not contain any theoretical statements. Information on ‘this appointment being an assessment’ and the duration were added to the new letter (from the original).
- Site 2 had previously used a similar letter for their separate invitation to the education sessions that each patient receives. The original version included ‘your partner is also invited to attend the appointment’ (not theory-based) and ‘the programme can be planned for you’ (similar to perceived behavioural control), which were reworded to match the new version. The new version was used as above, with the exception of ‘doctors’ and ‘relaxation sessions’ being removed (as not provided). A pre-scheduled appointment was not provided either because patients are required to contact the CRP. An opt-out option was removed and practical information on pay & display parking was added.
- Site 3 (like site 2) the original invitation to the education sessions, which already included two statements similar to the new letter that each patient receives (attitude and a statement about peers that taps into subjective norm, Chapter 5). Original PCI, MI and HF invitations (3 separate ones) did not include the theoretical statements but all gave a scheduled appointment. The amended invitations included all theoretical statements of the new letter (Box 6.1). The following were added:
  - the assessment is done by a nurse/specialist
  - simple exercise bike assessment involved
  - patients are told to bring the questionnaire
  - information about CR as a teaching facility.
- Site 4’s original letter stated that ‘partner/friends can come’, but it included no theory-based statements. An appointment time was given. The new letter



includes all the theoretical statements, but the invitation is for an assessment. Hence, the statements ‘we will check blood pressure [...] you will not be doing exercise’ had to be included.

- Site 5’s original letter did not include any of the theoretically developed statements but had a second page outlining three options: hospital CR, community CR, home CR. The new version included all theoretical statements and the original second page. However, patients are still required to contact CR (no pre-scheduled appointment was included).
- Site 6’s original letter stated that ‘...programme is designed to meet the special needs of the patients’, similar to the PBC statement in the new letter. Set times for the CR sessions were given. The amended letter included all statements as above (Box 6.1) and the set times for weekly CR sessions. Still, the patients are required to contact the CRP to confirm he/she wants to attend – an opt-out option was removed. All patients also receive an information sheet explaining what happens during the exercise, relaxation and education session (it had a photograph of actual patients stretching).

### **6.3.3 The intervention sites**

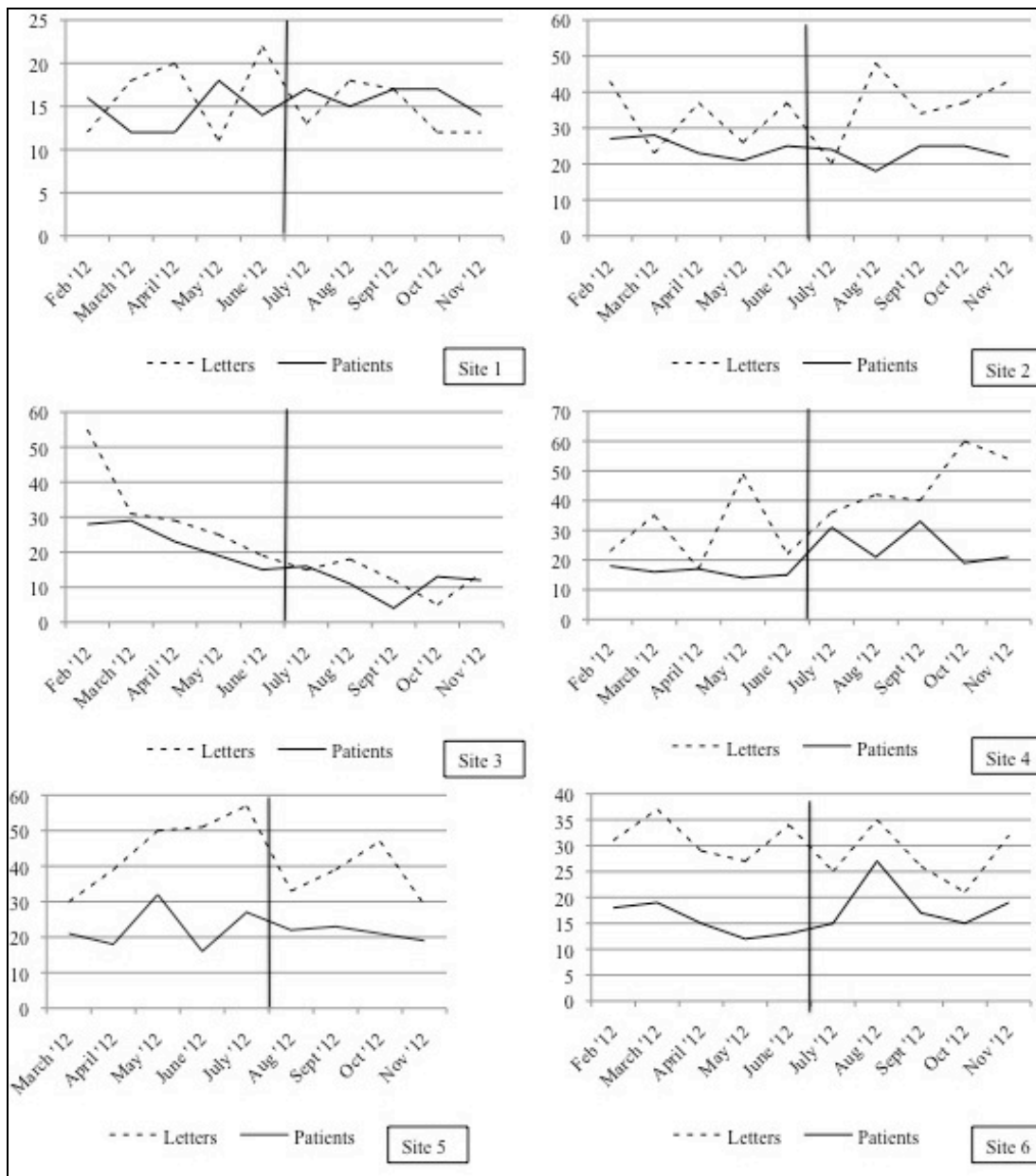
Six sites participated, with 1,997 letters being sent and 1,316 patients enrolling in phase 3 sessions/assessment. A complete table of the data per centre, including comments on data variation, can be found in Table 6.1.

**Table 6.1: Number of letter sent (L), number of patients (P), uptake rate (%)**

	1*		2		3#		4^		5\$		6							
	L	P %	L	P %	L	P %	L	P %	L	P %	L	P %						
February '12	12	16	133	43	27	63	55	28	51	23	18	78	30	21	70	31	18	58
March '12	18	12	67	23	28	122	31	29	94	35	16	46	39	18	46	37	19	51
April '12	20	12	60	37	23	62	29	23	79	17	17	100	50	32	64	29	15	52
May '12	11	18	164	26	21	81	25	19	76	49	14	29	51	16	31	27	12	44
June '12	22	14	64	37	25	68	19	15	79	22	15	68	57	27	47	34	13	38
July '12	13	17	131	20	24	120	15	16	107	36	31	86	33	22	67	25	15	60
August '12	18	15	83	48	18	38	18	11	61	42	21	50	39	23	59	35	27	77
Sept '12	17	17	100	34	25	74	12	4	33	40	33	83	47	21	45	26	17	65
October '12	12	17	142	37	25	68	5	13	260	60	19	32	29	19	66	21	15	71
Nov '12	12	14	117	43	22	51	14	12	86	54	21	39	48			32	19	59
December '12	24			33			13			33			37			33		

\* staff turnover March/April  
# January high: patients from last year; vacation May/June; low June/July data reflects referrals; in Sept. department moved and patients suspended  
^ March/April shift due to annual leave  
\$ April/ June annual leave

Self-evidently, because the letter invited people to attend at a point in the future, the effect of changing the letter could not be reflected until that point was reached. This adjustment period was set at one month for all centres except for site 5, which had a delay of eight weeks (as seen in Table 6.1). Figure 6.2 plots the effect of this changeover by centre. The months correspond to the months in which the patients attended, and the number of letters is adjusted by 1 months. For example, the number of letters sent in January is displayed under February. The new letter was implemented at all sites from June 1<sup>st</sup> affecting the number of patients from July 1<sup>st</sup> at sites 1 to 4 and 6, and from August 1<sup>st</sup> at site 5.



**Figure 6.2: Number of letters sent and patients attending per month (number of patients adjusted to months letter sent)**

A visual inspection suggests that for site 1 and 2, the numbers appear to remain similar over time. Site 3 shows a decline in both numbers. Reasons for this included departmental closure due to holidays and relocation, but also a low number of referrals (Table 6.1). Site 4 showed an increase in letters and patients over the post-intervention period. For site 6 and perhaps site 5, a smaller ‘gap’ between number of letters sent and number of patients attending was seen after the intervention was implemented.

Table 6.2 below shows the mean uptake rates per site for the baseline as well as for the post-intervention period (adjusted). It is noticeable that sites 1, 2 and 3 have fairly high uptake rates (70%+) in the time period before the intervention was implemented. For sites 1 and 3, an increase can be seen that is not statistically significant. Sites 4, 5 and 6 have lower initial uptake rates; only site 6 shows a statistically significant increase in uptake.

**Table 6.2: Change in mean uptake rate per intervention site (before & after)**

Site	Uptake rate % <i>M (SD)</i>	Test-statistics	Mean change in rate %
1	97.60 (47.86)	$t(8) = 0.713$	- 69.74
	114.60 (23.65)	$p = .496$	-47.45
2	79.20 (5.03)	$t(8) = 0.502$	1.22
	70.20 (31.34)	$p = .629$	17.21
3	75.80 (15.54)	$t(8) = -0.835$	7.01
	109.40 (88.61)	$p = .428$	-5.24
4	64.02 (27.64)	Mann Whitney $U = 12.00, z = -0.104$	-10.08
	58.00 (25.05)	$p = .917^{41}$	-15.42
5	51.60 (15.57)	$t(7) = .844$	-5.66
	59.60 (10.14)	$p = .427$	-37.69
6	48.60 (7.60)	$t(8) = 3.733$	- 4.6
	66.40 (7.60)	$p = .006^{**}$	- 0.16

A comparison of patient, hospital and intervention characteristics can be seen in Table 6.3. More detailed comparisons of the NACR variables per site are displayed

<sup>41</sup> The data was not normally distributed (Appendix E).

in Appendix E for each site separately (for statistical test assumptions for uptake, age, and co-morbidities see Appendix E). Site 1 has the highest mean age and the highest percentage of women, and a completely new letter was used. No difference in age or gender but in the number of co-morbidities during the different time periods has been found (only 10 patients were recorded). The teaching hospital recruits patients via letter only, has 184 staff hours available per week, and a nurse, a secretary, and an exercise specialist<sup>42</sup> are involved in CR.

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<sup>42</sup> Data for the following health care professionals is collected by the yearly survey: nurse, physiotherapist, dietitian, psychologist, social worker, counsellor, doctor, HCA, secretarial support, administrative support, exercise specialist, assistant physiotherapist, occupational therapist, pharmacist.

**Table 6.3: Comparing patient, intervention and hospital data across six sites**

Site	Summary of patient population characteristics		Information about the intervention		Hospital characteristics					
	Age <i>M (SD)</i> before after	Gender (female) % before after	Co-morbidities <i>M (SD)</i> before after	Degree of change in letter	Time between letter sent & patient attending	Other Invitation methods	Staff hours per week	HCP	Hospital size (teaching, DGH, or small site)	Other information
1	71.23 (13.29) 70.45 (12.80)	37.5 35.1	1.22 (1.12) 2.7 (2.21)*	- new letter - added info about assessment	2-6 weeks	letter only (very occasional phone call)	184	3	teaching hospital	- NACR data summarises 7 sites (2 participated) -NACR update 1x per year

Table 6.3 continued

Site	Summary of patient population characteristics		Information about the intervention		Hospital characteristics					
	Age <i>M (SD)</i> before after	Gender (female) % before after	Co-morbidities <i>M (SD)</i> before after	Degree of change in letter	Time between letter sent & patient attending	Other Invitation methods	Staff hours per week	HCP	Hospital size (teaching, DGH, or small site)	Other information
2	66.70 (14.77) 62.23 (14.57)	31.8 27.3	0.85 (0.946) 1.38 (1.06)	- perceived behavioural control in original letter - no appointment -added info about assessment -opt-out option removed	4 weeks	letter to all patients, few receive additional phone call in phase 2	64	6	DGH	- low N in NACR



Table 6.3 continued

Site	Summary of patient population characteristics			Information about the intervention		Hospital characteristics				
	Age <i>M (SD)</i> before after	Gender (female) % before after	Co-morbidities <i>M (SD)</i> before after	Degree of change in letter	time between letter sent & patient attending	Other Invitation methods	Staff hours per week	HCP <i>N</i>	Hospital size (teaching, DGH, or small site)	Other information
3	65.84 (11.15) 65.18 (14.04)	20.2 23.2	1.41 (1.59) 1.1 (1.45)	partly new letter (attitude and partly subjective norm was in original letter) -added info about assessment	2+weeks	Phone call followed by letter to arrange the appointment	172	6	DGH	- decline in numbers due to closure & holidays - differences in % of MI & angina
4	67.48 (12.38) 69.92 (11.57)	30 30.5	2.11 (1.48) 2.15 (1.46)	New letter ('partners can come' was already included) -added info about assessment - no exercise	2+weeks	letters are followed-up with a telephone call if patient did not reply	47.5	4	Small Trust	differences in % of angina & aortic valve disease

Table 6.3 continued

Site	Summary of patient population characteristics			Information about the intervention		Hospital characteristics				
	Age <i>M (SD)</i> before after	Gender (female) % before after	Co-morbidities <i>M (SD)</i> before after	Degree of change in letter	Time between letter sent & patient attending	Other Invitation methods	Staff hours per week	HCP <i>N</i>	Hospital size (teaching, DGH, or small site)	Other information
5	n/a	25.7 year 2011/'12	n/a	New letter - no appointment - 3 options outlined	2 months	Letter only	62	4	Small Trust	No capacity to use NACR
6	64.48 (12.42) 63.50 (12.56)	27.1 26.2	2.68 (2.07) 2.73 (2.09)	- original letter contained one theory statement (Perceived Behaviour Control) - CRP has set times for sessions - an opt-out option was outlined	40 days	letter to everyone then call or text message if patient did not get in touch	80	5	Teach- ing hospital	-more ACS & angina compared to NACR data

HCP= health care professionals \**p* < .05

Sites 2 and 3 show a decrease in uptake rate and a lower mean change in rate after the intervention letter was implemented but no significant difference. The other patient variables appear to be similar pre-post intervention, suggesting that changes in the uptake rate are less likely due to a change in patient population. For site 2 the number of patients entered into the NACR is lower than the data collected, and there is much missing data. The original intervention letters differed. They had included perceived behavioural control and attitude (2) and subjective norm (3). Site 2 is a district general hospital that uses only the letter to invite patients to phase 3 CR attendance/assessment, with no pre-scheduled appointment. The site has 64 weekly staff hours available for CR, and six different health care professionals are involved (nurse, physiotherapist, dietician, secretary, occupational therapist, pharmacist). Site 3 contacts all patients via telephone prior to sending a letter to confirm the appointment for phase 3 CR attendance/assessment. They had noticeably fewer female patients. This site is a district general hospital with 172 weekly staff hours available, and six different health care professionals are involved in CR (nurse, dietician, psychologist, secretary, exercise specialist, pharmacist).

Site 4, somewhat similar to site 6 in patient population characteristics and uptake rate, has slightly less staff (weekly hours) available but also contacts non-responders. The original letter 4 had no theoretical statements, hence the intervention letter was new. The statement 'no exercise at this session' was included in letter 4. The variables displayed in Table 6.3 are very similar for both time periods. Only site 6 has set times for the CR, and this information remained in the letters, but the patients still had to contact the CRP. An opt-out option was removed. The original letter only included one motivational statement similar to PBC. Here, a significantly higher uptake rate post intervention was found. They use the letter only to invite patients, but call or send a text message to many non-responders. This is a teaching hospital which has 80 weekly staff hours and five different health care professionals available. Site 4 is also a small trust that uses telephone calls to follow up the letter if patients are not seen at the clinic. The site has 47.5 weekly staff hours available, and four different health care professionals are involved in CR (nurse, dietician, physiotherapist, secretary).

Site 5 has an average delay time of 2 months delay between the letter being sent and the patient attending. This site states to not have enough resources to use the NACR. From the yearly survey, it is known that in 2011/2012, a total of 121 patients attended CR, 31 of whom were women (25.62%). They have four different health care professionals involved in CR and 62 weekly staff hours available. It is a small site that caters for all initiating events (categories in the NACR) and invites patients via letter only. The original did not contain theory-based statements, but the second page outlines three CR options. A high negative mean change in rate and no significant difference in uptake rate were found. Note that sites 5 and 6 had a mean uptake rate of 50% or below prior to the new letter being implemented. Both sites are relatively small, have similar staff involvement, and both require patients to get in touch with the CR.

It appeared that patient population characteristics remained similar over time in all sites. The NACR report 2012 indicated the following data across all sites: about 30% of participants are female, and the initiating events are mainly MI (52%), PCI (15%) or CABG (12%) (The National Audit of Cardiac Rehabilitation, 2012). Most patients are married/partnered (74%), 12% are widowed and 8% are single. In terms of ethnic origin, 82% indicated to be white, and all other categories were indicated as 2% or less. About 50% of patients have one to two co-morbid conditions. Compared to these statistics, three sites were similar (2, 3 & 4). As stated above, site 1 had a higher mean age and higher co-morbidities, whereas site 6 had higher mean co-morbidities<sup>43</sup> and a slightly lower percentage of female participants as well as MI patients, but more ACS and angina events. More 'other ethnic origin' was indicated.

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<sup>43</sup> Note that data for co-morbidities was scarce for all participating sites.

### 6.3.3.1 Site 6 further explored

Only one of the six sites showed a significantly higher uptake rate. This site (6) was compared to the others to explore whether it differed from the others.

The mean baseline uptake rate at site 6 ( $M = 48.6\%$ ,  $SD = 7.73$ ) was statistically significantly lower than at site 3 ( $M = 78.5\%$ ,  $SD = 15.55$ ),  $t(8) = 3.50$ ,  $p = .008$ ) and at site 2 ( $M = 79.2\%$ ,  $SD = 25.09$ ),  $t(8) = 2.61$ ,  $p = .031$ ) (Appendix E). The mean post-intervention uptake rate at site 6 ( $M = 66.4$ ,  $SD = 7.6$ ) was significantly lower than site 1 only ( $M = 114.6$ ,  $SD = 23.65$ ),  $t(8) = 4.34$ ,  $p = .002$ ).

Their original letter contained one theory-based statements (PBC) like the one from site 2 and both had an opt-out option removed. The letter was a 'friendly', yet solely administrative invite similar to three other sites (whose original letters contained no theory-based statements: sites 1, 4, 5). This site was the only site one with set sessions, but patients still had to get in touch with CRP to arrange a starting date (like site 2, 4 and 5). There was a second sheet explaining the content of the sessions. This informal comparison suggests that site 3's original letter was neither 'worse' than all others nor that the changes in the amended version differed greatly.

For more formal analyses, patient characteristics were compared. The NACR data was used to explore mean age, gender and mean number of co-morbidities to see whether site 6 differed from all other sites (Table 6.4). Since there were no differences pre-post intervention for these variables per site (Table 6.3), data from the entire time period was used to increase sample size.

**Table 6.4: Site 6 compared with each other site on age and co-morbidities<sup>44</sup>**

		Site 6	Site 6	
		AGE <sup>1</sup> <i>M</i> = 62.87 ( <i>SD</i> = 12.65) <i>N</i> = 296	CO-MORBIDITIES <i>M</i> = 2.44 ( <i>SD</i> = 2.03) <i>N</i> = 116	
Site 1	AGE <i>M</i> = 71.01 ( <i>SD</i> = 13.13) <i>N</i> = 1025	<i>U</i> = 105646.5 <i>Z</i> = -7.968 <i>p</i> = .000***	<i>U</i> = 2806.5 <i>Z</i> = - 4.673 <i>p</i> =.000***	CO-MORBIDITIES <i>M</i> = 1.50 ( <i>SD</i> = 1.34) <i>N</i> = 79
Site 2	AGE <i>M</i> = 67.32 ( <i>SD</i> = 13.17) <i>N</i> = 109	<i>U</i> = 14439.5 <i>Z</i> = - 1.62 <i>p</i> =.105	<i>U</i> = 1824.0 <i>Z</i> = - 6.306 <i>p</i> =.000***	CO-MORBIDITIES <i>M</i> = 0.87 ( <i>SD</i> = 0.95) <i>N</i> = 69
Site 3	AGE <i>M</i> = 65.75 ( <i>SD</i> = 12.16) <i>N</i> = 188	<i>U</i> = 25944 <i>Z</i> = - 1.254 <i>p</i> =.210	<i>U</i> = 1330.5 <i>Z</i> = - 3.898 <i>p</i> =.000***	CO-MORBIDITIES <i>M</i> = 1.55 ( <i>SD</i> = 1.45) <i>N</i> = 39
Site 4	AGE <i>M</i> = 67.70 ( <i>SD</i> = 12.85) <i>N</i> = 226	<i>U</i> = 26517 <i>Z</i> = - 4.060 <i>p</i> =.000***	<i>U</i> = 2354.5 <i>Z</i> = - 1.382 <i>p</i> =.167	CO-MORBIDITIES <i>M</i> = 2.28 ( <i>SD</i> = 1.60) <i>N</i> = 47

<sup>1</sup> sites 2,3,4,and 6 entered age for 100% of patients imputed into the NACR, site 1 entered age for 31% of patients they entered into the NACR

Mean age was statistically significantly lower for site 6 when compared to two of the four other sites individually. The mean number of co-morbidities was statistically significantly higher for site 6 when compared to sites 1, 2 and 3, but no statistical significant difference was found for site 4. Less patient data was available for co-morbidities, hence results must be treated with caution. There were no statistical significant differences in gender when site 6 was compared to all other sites individually (Table 6.5).

<sup>44</sup> The data was not normally distributed (Appendix E), yet Levene’s Test for Equality of Variances was not statistically significant for all: Mann-Whitney U tests were performed. Due to multiple comparisons the Bonferroni correction led to the alpha level being set at 0.05/4= 0.0125

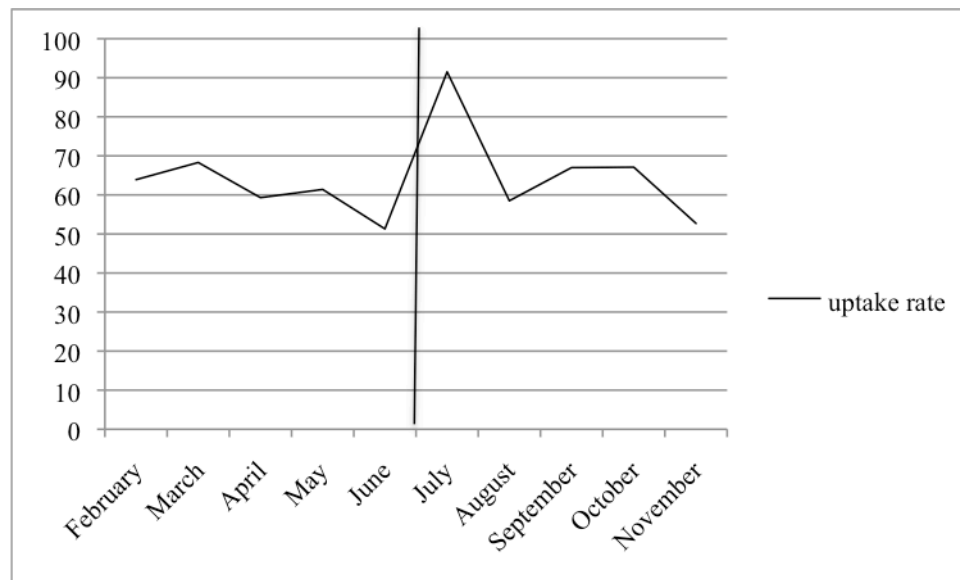
**Table 6.5: Site 6 compared to each other site on gender**

Sites	1	2	3	4
6				
Men				
<i>N</i>	646	2284	322	431
(%)	(73.6)	(64.6)	(70.93)	(74.96)
Women				
<i>N</i>	232	1254	130	144
(%)	(26.4)	(35.4)	(28.63)	(25.04)
chi - squares (compared to Site 6)				
<i>p</i> - values	2.064	0.345	4.695	2.064
	.151	.557	.096	.151

Staff hours available for CR and number of difference health care professionals differed by site (Table 6.3) with means of  $M = 101.58$  ( $SD = 60.2$ ) and  $M = 4.67$  ( $SD = 1.21$ ), respectively. Site 6 lies close to the averages (80 hours and 5 hours), suggesting no differences. Similar to site 4, phone calls are used as a way to recruit non-responders.

### 6.3.4 Summary data

As suggested by the individual data, the overall uptake rate exhibits a spike after the intervention was implemented (Figure 6.4).



**Figure 6.3: Uptake rate**

An average uptake rate of 60.85% ( $SD = 6.29$ ) with a mean change of -19.98% was computed for the baseline period. A total of 393 letters were sent by the six centres and 571 patients were recorded (Table 6.10). During the post-intervention period an uptake rate of 67.38% ( $SD = 14.81$ ) with a mean change of -9.71% was computed (Table 6.6). Altogether, 885 letters were sent, and the data collected for the post-intervention period summarizes to 585 patients. While the overall uptake rate post-intervention was higher and the slope declined less steeply, no significant differences were found between the overall uptake rates ( $t(8) = -0.906, p = .391$ ).

**Table 6.6: Summary data (number of patients & letters per months)**

Months (before)	Letters <i>N</i>	Patients <i>N</i>	Uptake rate %	Rate change %	Months (after)	Letters <i>N</i>	Patients <i>N</i>	Uptake rate %	Rate change %
2	194	124	63.92		7	142	130	91.55	
3	183	125	68.31	4.39	8	200	117	58.50	-33.05
4	182	108	59.34	-8.97	9	176	118	67.05	8.55
5	189	116	61.38	-2.04	10	164	110	67.07	0.02
6	191	98	51.31	-10.1	11	203	107	52.71	-14.36

### 6.3.5 The NACR uptake rates

In order to compare intervention sites with all other NACR sites, data for phase 1 and phase 3 attendance was extracted from the NACR for all sites (Table 6.7).



**Table 6.7: Phase 3 attenders (NACR data for all sites)**

	Intervention sites <sup>1</sup> (N = 5)	Intervention sites (N = 5)	All other NACR sites (N = 129)	All other NACR sites (N = 119)
	before	after	before	after
Phase 3 non-attenders				
N	25	18	6220	3928
(%)	(15.2)	(31.6)	(52.4)	(58.1)
Phase 3 attenders				
N	140(84.9)**	39(68.4)	5648(47.6)***	2837(41.9)
chi-squares	6.058		59.918	
p – values <sup>3</sup>	.014		.000	
Total N	165	57	11868	6765
Total N in NACR	1127	787	39336	30694

1) only 5 intervention sites use NACR, one of which imputes all data from the acute hospital

2) Phase 3 attendance rate: only patients that attended phase 1 are included in the calculation

3) The test compared the pre-post intervention periods.

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

There is a significant difference in the number of phase 3 attenders and non-attenders between intervention and all other NACR sites ( $\chi^2 = 90.949$ ,  $p = .000$ ) prior to the intervention as well as post-intervention ( $\chi^2 = 16.259$ ,  $p = .000$ ). While the higher pre-intervention percentage of attenders supports the assumption that the intervention sites differ from all other NACR sites, the higher post-intervention percentage needs to be treated with caution due to the missing information on phase 3 attendance entries in the NACR (as compared to number of patients entered into the NACR).

Additionally, there is a significant difference within each group between the two times periods with a lower percentage of attenders in the post-intervention period (Table 6.7). These numbers suggest a delay in data entry (see Appendix E), because the data collected in this experiment showed higher percentages post-intervention (Section 6.3.2).

Despite this analysis, these results cannot be considered reliable due to data quality. Consequently, patient variables could not be compared for the other NACR sites to explore differences to the intervention sites.

## 6.4 Discussion

The current chapter employed a pragmatic, quasi-experimental before-and-after evaluation to assess the impact of an amended invitation letter on CR phase 3 uptake

rates. The intervention letter was developed in the previous chapter. The six intervention sites implemented the letter after a 5-month baseline period and continued data collection for another six months. Data on patient population characteristics and programme variables were explored to compare the pre- and post-intervention time periods and to assess any differences between the intervention sites. Though data quality impacts the reliability of results (discussed below).

Attendance rates in the intervention group were 60.85% prior to and 67.38% post intervention. This difference was not statistically significant. However, in one site, a statistically significant difference in uptake rate was found.

#### **6.4.1 Why did the letter work in one site?**

This site had the lowest baseline uptake rate, yet it was only significantly lower than at two of the other five sites. The first question was whether their original letter differed greatly from all others. An informal exploration suggested that their original letter was no ‘worse’ than the other original letters, nor did the change differ. The site (6) had an ‘opt-out option’ removed, similar to site 2, which had much higher initial uptake. Interview participants in Chapter 5 discussed opt-out options as ‘an easy way out’. This could be one reason as to why uptake increased.

When comparing patient characteristics, there were no differences in gender, but mean age was significantly lower in two sites and mean number of co-morbidities was higher when compared to three of four other sites. Due to the low numbers on co-morbidities, this result must be treated with caution.

No clear patterns emerged when comparing site 6 to the other intervention sites, which suggests that the motivational components in the letter may have worked. The uptake rate was low to begin with, and extrinsic factors might not have presented a barrier (discussed below).

Next, a variety of potential factors need to be explored as to why the intervention did not impact uptake at five sites, among them, recruitment, the letter content, extrinsic factors and methodological issues.

#### **6.4.2 Recruitment**

One explanation as to why a theoretical letter had no impact may be that the patient population in previous trials was not representative of the general CR patient

population. Individual patient recruitment took place in both previous trials, whereas in the current experiment, all eligible patients were automatically included. Patients who were not able to or did not plan to attend CR may not have agreed to participate in the previous trials, which led to unusually high (80%) attendance. Physical limitation was the second-most mentioned reasons for non-attendance (10%) recorded in the NACR. Those patients may not consent to take part in trials about CR. One fact indicating that these were different samples may be that mean age was higher at the intervention sites (~68) than in other CR uptake trials ( $\leq 63$ ) (Benz Scott et al., 2013; Jolly et al., 1998; Mosleh, 2011; Wyer et al., 2001b). One of the previous studies included a much lower percentage of women. Although Mosleh and colleagues recruited around 30% female participants, similar to the percentages recorded in the NACR, Wyer et al. only had 14% (Mosleh, 2011, personal communication; Wyer et al., 2001). This may have increased uptake due to lower age and co-morbidities (as discussed below). Furthermore, Wyer et al. excluded people with medical complications from the trial, reducing thus external validity.

Seventy CRPs were asked to take part, and 10 initially agreed to participate. Therefore it could be argued that self-selection bias was operating at the programme level. Self-selection is also a threat to external validity, because the intervention sites may differ from all other sites on (un)known parameters, hence the findings may not be generalisable (Reichardt and Mark, 1998). Very high uptake rates (3 sites) suggest more resources or effective working practices. Since about 85% of patients are expected to be well enough to attend, it could be hard to increase uptake. Comparing the intervention sites with all sites in the NACR showed that they were largely similar in patient characteristics in three sites; in two other sites they differed. Site 1 had a higher mean age and higher co-morbidities, whereas site 6 had higher mean co-morbidities but a slightly lower percentage of female participants (differences between site 6 and all other intervention sites were discussed above). Differences in staff hours or working processes are likely to affect recruitment (extrinsic factors, discussed below).

As seen in Table 6.7, there were statistically significant differences in the percentage of attenders and non-attenders between the intervention sites and the other NACR sites (using NACR data only) as well as between the two time periods.

Unfortunately, due to missing data, this information cannot be seen as reliable, as

explained below. Thus, differences between the intervention sites may help explain the non-significant results in themselves as well as compared to previous trials.

### **6.4.3 The letter**

The intervention letter was not the same as the ones used in the previous studies. Both letters were further developed with patient input (Chapter 5). The participants in the research employed to modify the letters were older, experienced more complex conditions, and not all had had the opportunity to attend CR. Only heart group support attenders took part, and there was a lack of diversity in terms of gender and ethnic origin. Therefore, the letter may have only appealed to certain patients such as those feeling comfortable about joining group events. Furthermore, limitations due to the use of health behaviour theory apply, as outlined in Chapter 5, Box 5.4. There are also reservations about its applicability to diverse socio-cultural contexts (Munro et al., 2007). The letter may not be perceived as motivational by patients with diverse ethnic or cultural backgrounds.

It is possible that the experimental letter was too similar to the existing letter being used by programmes. Three original letters already contained one or two statements that tap into health behaviour theory concepts (attitude, subjective norm and perceived behavioural control, Table 6.3). Technically, there was less change in content.

Of the six participating sites here, only three sites (1, 4 & 5) implemented a completely new invitation letter, neither of which led to an increase in uptake rate. While the new letters were similar in content and included all HBT-conceptualized statements, the degree to which they could be changed was limited. For instance, sites 1,2,3 and 4 added information about the assessment, sites 2 and 5 do not provide a pre-scheduled appointment, and site 6 has set times for CR. This makes it difficult to evaluate whether the HBT statements would motivate more patients to attend. They may have motivational character, but other factors, such as the patients being required to contact the CRP if they wish to attend, could present a barrier, discussed next. Since this was a pragmatic, real-life evaluation, it shows how difficult it can be to evaluate interventions in health services.

#### 6.4.4 Extrinsic factors

There may be a number of reasons related to factors external to the intervention that overwhelmed the effect of the intervention. Several participating programmes used a number of other methods to ensure a high uptake. One site (3) contacted every patient by telephone - a direct contact strategy. Here, the letter may only have functioned as a reminder and the content was not as influential. Two sites (4 & 6) contact non-responders via telephone or text message, and one site (2) called 'some' patients. The review by Yabroff et al. concluded that behavioural interventions (telephone plus letter) have an impact on screening uptake and that more direct methods appeared to be more successful in under-represented groups (Yabroff, Mangan and Mandelblatt, 2003). Therefore, a motivational letter may only be important when no personal contact takes place.

Many cardiac rehabilitation programmes provide their patients with information sheets or leaflets. Depending on their content, these could interfere with the effect of the invitation letter. Site 6, where a significant increase in uptake was found, also uses an additional information sheet explaining the content of CR sessions, but it contained no motivational statements. Mosleh et al. (2009) tested their letter and an additional leaflet which addressed potential concerns about CR but no information about CR session content was provided, and the leaflet had no impact (Mosleh, Kiger and Campbell, 2009). Further exploration may be valuable in the future.

The two sites that did not use other contact strategies implemented a completely new letter. Site 5 had a two-month waiting period between invitation and appointment and only used the letter to invite patients. Since they had no resources to use the NACR, perhaps scarce resources overall present a barrier to more patient contact or better communication.

It is possible that the intervention sites already had very good initial uptake rates and that other barriers (personal or organisational) to raising uptake prevented the intervention having an impact. Site 1 had an initial high uptake rate of 70+% as well as a higher mean age (70+) and a higher number of women (35%+)<sup>45</sup>. This differs

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<sup>45</sup> Note that the NACR collects summary data from the hospital site that links to 7 CRP, hence this data may not be meaningful.

from the NACR data, according to which the percentage of women participating, on average, is 30% (The National Audit of Cardiac Rehabilitation, 2012). As summarised in Chapter 1, women tend to be older and present with more co-morbidities, and advanced age, in turn, can predict non-attendance (A. Cooper et al., 2002; Cortés and Arthur, 2006; Cupples et al., 2010; Fernandez et al., 2008; French et al., 2005; Harrison and Wardle, 2005; Husak et al., 2004). Two other sites had initial uptake rates of around 50% (4 & 6). One site (6) showed a higher mean number of co-morbidities, and both had a slightly different distribution of ‘initiating events’ compared to all other intervention sites as well as to the NACR figures. This may suggest that more patients with physical impairment are invited, which would contribute to an initially lower uptake rate as well as to a new letter having limited impact. The NACR indicates that 10% of non-attenders indicate ‘physical incapacity’ as a reason for not coming (The National Audit of Cardiac Rehabilitation, 2012).

While this was an experiment assessing effectiveness (rather than efficacy as done by previous trials), local circumstances had a high impact. It is possible that differences in staff hours and the number of different professions involved would influence outcome (Doherty and Lewin, 2012). In Chapter 4, the survey found that not all CRPs provide all phases of CR and that identification and invitation methods are used very differently at each site.

The NACR shows an average waiting period of 50 to 60 days with only some programmes meeting the national requirement of performing an assessment within 10 days of the event (The National Audit of Cardiac Rehabilitation, 2012). People may have returned to work or recovered enough to no longer show interest, which would also explain the lack of impact. In fact, four sites had mentioned that ‘people at work’ were less likely to attend, two mentioned ‘people from poorer parts’, and one site mentioned ‘rural’ (Chapter 4). These are wider determinants that remained the same in the pre- and post-intervention time period. As discussed throughout the previous chapters, wider issues around access preventing attendance exist, and a behaviour-targeting intervention, as tested here, cannot overcome those (further discussed in Chapter 7).

#### 6.4.5 Previous studies

Two previous studies claimed to test HBT-based invitation letters and both found a significant increase in uptake. There are differences between this study and the previous trials that may explain the different results.

Wyer and colleagues compared their letter to ‘no letter’ (the control group received a ‘thank you’ note) in a small, one-site trial where the results, in fact, suggested the positive impact of using ‘a’ letter rather than a ‘theoretical’ letter. The letter targeted acceptance, and only those patients who accepted CR received a second letter reinforcing attendance three weeks later. While their trial increased attendance (86% in the intervention group, 59% in the control group), it is difficult to judge which element of the trial lead to attendance of CR or whether the combination was influential. Furthermore, all participants received an assessment and a personal invitation to CR by a nurse. This suggests that the letter perhaps targeted adherence, or that it simply served as a reminder to attend and that theory use has no influence. Therefore, this previous study is not pivotal in discussion the impact of a health behaviour theory-based letter on uptake of CR.

Conversely, Mosleh and colleagues had compared a regular letter with the theoretical letter and achieved higher uptake rates (Mosleh, Kiger and Campbell, 2009). They only collected data from one site in Scotland, where the investigator may have had more personal contacts, possibly resulting in fewer issues with fidelity and more influence on patient recruitment (Mosleh, Kiger and Campbell, 2009). While this trial supports the efficacy of a theoretical letter, effectiveness is more complex, as discussed above, for example, individual self-selection bias. Information about the degree of change in letter content is not available due to the randomised controlled trial methods, nor is it known what other strategies were used to invite patients. This precludes further inference<sup>46</sup>.

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<sup>46</sup> The RCT was published in 2013. The authors suggest that attendance in the control group was also higher because an appointment had been made and telephone calls were made ahead of time (Mosleh et al. 2013).

#### **6.4.6 Methodological problems**

Each intervention site reported average time periods between the letter being sent and the patient attending. Due to data being collected ‘per month’, this was adjusted as closely as possible, but the results might not have been accurate. Data quality was suboptimal. No fidelity measure was in place, meaning that the investigator had no means of checking if correct data was reported or if the intervention was implemented as instructed.

The ‘spike’ in uptake rate just post-implementation (Figure 6.4) could suggest that sites perhaps implemented the letter but did not continue using it the letter or changed it. The initial rise seen in the graph may also be due to inaccurate time adjustments. There was an overall decline in referrals across the time of the study, which may have led to more capacity and time for recruiting patients or to shorter waiting times that in turn allowed for a temporary increase in uptake. Alternatively, the spike could be an artefact due to summarising data across sites or, most likely, is due to unknown factors.

Furthermore, due to the limited data, it was only possible to perform tests to compare means, which neglects time dependency and regression to the mean. An interrupted time series segmented regression analysis would be the most appropriate statistical method to assess the impact of an amended invitation letter. Time series analysis was not used here, because with only 10 data points but three (times series) predictors, such as a regression model would hugely overfit the data (for further discussion on statistical analysis, see Section 6.6.3 ‘Methodological considerations’, as well as Appendix E).

Testing for significant changes in mean uptake rate overall and then in six subgroups can lead to a Type I error (Yusuf et al., 1991). Working with a p-value of 0.05 still means that there is a 5% chance of finding a significant result where there is none, a possibility here.

#### **6.4.7 Missing data**

There were unexpected problems with the NACR data, because data entry is behind by months due to working processes, waiting times or lack of data entry clerks.

There is no way of assessing whether a CRP has completed data entry, and it is to note that some only update the database once per year. Not all programmes



participating in the experiment actually entered data in 2012. While patient characteristics were compared to assess differences between programmes, data quality precluded strong conclusions. This only became apparent when exploring the data.

## **6.5 Limitations and strengths**

Six centers took part in this study and self-selection bias may have been in operation, which would impact on the external validity of the results. The participating programmes may somehow differ from the ones that do not participate and in this manner cause an intervention effect - an example here may be other invitation to CR strategies (Reichardt and Mark, 1998; Thoolen et al., 2007; Torgerson and Torgerson, 2008).

However, recruiting programmes rather than individual patients made it possible to include a more representative sample. Patients were not consented individually and therefore did not receive additional research study materials similar to the intervention letter (discussed below).

There were no inclusion or exclusion criteria, which is how the letter would be implemented 'in real life', making this a pragmatic evaluation. This differed from previous trials that tested efficiency, not efficacy. Both of the above issues meant that there was little room for experimental variables to influence the uptake rate as in previous studies.

Only programmes that participated in the survey (Chapter 4) were approached to take part in the study. It is possible that the intervention sites here may have more resources that enable them to participate in a study, and all sites already had higher attendance rate than the majority of programmes (The National Audit of Cardiac Rehabilitation, 2012). It also appears that not all but some are more up-to-date with NACR entry.

Patients who were not referred to CR were not reached in this evaluation. This is an important drawback to notice, since it has been suggested that it is at the identification or referral stage where many patients get overlooked. However, patient communications, is an important factor that needs to be addressed.

The adjustment of waiting times for statistical assessment may have had an impact on results. Time series models would be suitable for data collected over time and can include a control group. The few data points here did not allow for this, as further discussed below (Yanovitzky and Vanlear, 2008). Instead, independent t-tests were performed to assess statistical significance in the differences in uptake rates.

No fidelity measure was in place, which means that the investigator had no means of checking if correct data was reported or if the intervention was implemented as instructed. There are some concerns regarding the ‘dislike’ of the letter expressed by several CR nurses/coordinators. However, the investigator amended all letters herself and stayed in close contact with the sites.

## **6.6 Methodological considerations**

Before concluding, the following sections briefly discuss options of study design and patient recruitment that were taken into account when designing the quasi-experiment.

The experimental methodology here is congruent with the post-positivist paradigm, in which probabilistic testing takes place (e.g. *p*-values, which encompass the probability of having a result more extreme than by chance; note that *p*-values do not give information about the magnitude or the direction of a relationship/association (Bland, 2000)). This experiment is consistent with the pragmatic stance, which combines reliability based on quantitative methods and insight from the contextualising element (Chapter 5) (O. Parry, Gnich and Platt, 2001). For further discussion, see Chapter 7.

### **6.6.1 Recruitment methods**

Treweek and colleagues investigated interventions that improve trial recruitment (Treweek et al., 2010). The most successful interventions found included telephone contact and reminders, and the use of opt-out procedures and non-blinded designs in which patients were aware of their group assignment (Treweek et al., 2010). These procedures mirror the findings of interventions designed to promote screening and cardiac rehabilitation uptake (Chapters 2 & 3). It would be conceptually bizarre to try and recruit participants to a trial using phone calls and letters to then test the impact of those very same methods (letters) on cardiac rehabilitation uptake. This argument would suggest not consenting participants individually, which may also lead to more

representative participant populations. In reality, participants are volunteers, and it is the patients who are missing who need be considered (Barlow et al., 2002).

The brief discussion on non-attenders in CR (Chapter 1) showed that this is a heterogeneous group, which presents difficulties for the service improvement design. Furthermore, the survey (Chapter 4) revealed that people who are perceived as being less likely to attend comprise different groups depending on the CR site (although all participating sites mentioned ‘people at work’ as less likely to attend). Still, under-represented groups must be given the opportunity to participate in research (World Medical Association, 2008). In order to not disadvantage certain patients, an all-inclusive method to investigate the effects of a new invitation letter was chosen. Those who would decline for various reasons are included here, since all patients in contact with the participating CRPs are counted (Mckee et al., 1998).

Programme variables and patient characteristics were compared for each participating site. A threat to internal validity arises, which includes regression to the mean. Therefore, experimental and quasi-experimental methods were considered, which are discussed next.

### **6.6.2 Study design: experimental versus quasi-experimental methods**

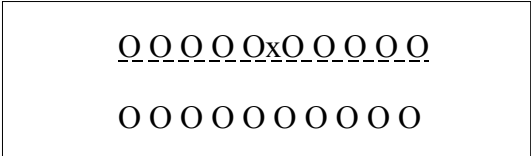
Quasi-experimental methods were adopted. In general, quasi-experimental designs present two problems. Due to the lack of randomisation<sup>47</sup> in the design, causality cannot be assumed *per se*, and an effect could be due to covariates.

An interrupted time series design (Figure 6.1) responds to potential threats of bias in a better way than observational studies do (Owens et al., 2010). If cause precedes effect, as it does here since the researcher introduced the letter, and cause co-varies with effect, which can be controlled for statistically using a segmented regression analysis and a non-equivalent control group (e.g. all other NACR sites), an interrupted time series constitutes the strongest quasi-experimental method (Yanovitzky and Vanlear, 2008). Due to the trend prediction, the regression to the

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<sup>47</sup> A randomised controlled trial (RCT) design was considered, where randomisation takes care of unknown confounders and counterbalances a potential regression to the mean effect, as this is the most robust method to assess causality and counteract such potential threats to validity (Torgerson and Torgerson, 2008).

mean effect is taken care of, and the control group can be used to adjust for variations (Linden and Adams, 2011).



**Box 6.2: Observation from the experimental group (top line) and the control group (bottom line), with a broken line indicating non-randomised groups (Reichardt and Mark, 1998)**

Unfortunately, a non-equivalent control group using the National Audit of Cardiac Rehabilitation could not be created because a great deal of data, especially for the post-intervention period, was missing.

The most appropriate analysis for assessing differences in uptake rates over time would be a segmented regression analysis for time series data (Wagner et al., 2002). To compute a robust model, 10 data points per predictor are necessary, yet it was not possible to collect 30 to 40 data points within the time frame of a doctoral thesis. In Appendix E, an adjusted time series model was computed for exemplification purposes. An over-fitting of the data takes place, as seen in the high value of the adjusted  $R^2$ .

Note that mean uptake rates were compared using t-tests, which assume independence of observations (Field, 2005). This, however, ignored the time component. Future directions for this research are discussed in detail in Chapter 7.

### 6.7 Conclusion

The quasi-experiment found that an amended intervention letter had no impact on the pooled uptake rate across six centres, but it did in one centre. This may have been a statistical artefact, or the amended letter actually motivated more patients to attend, considering the low baseline uptake. The overall lack of impact in the other five sites could be due to 1) initial high uptake rates, 2) letter content, 3) extrinsic factors, 4) methodological issues, or 5) a combination thereof (Box 6.3).

- CR uptake increased at one of six sites
- This site had the lowest baseline uptake rate; no other differences became apparent, suggesting the letter worked
- No impact in five of six sites due to the letter (degree of change, logistic information), methodological issues (missing data), recruitment (self-selection, external validity), or extrinsic factors (invitation methods, population characteristics)

### **Box 6.3: Key findings**

This suggests the need for a pragmatic trial that, through randomisation, takes care of known and unknown confounders while allowing for the letter to be tailored to local circumstances (further discussed in Chapter 7) - again without individual recruitment as done here. Alternatively, a more extensive evaluation over a longer time period may also be appropriate, since patient and programme characteristics could be taken into account. An option could be an A\_B\_A design and the inclusion of a non-equivalent control group.

An individually directed intervention aimed to improve only uptake; access and equity is also called for, and the appropriateness of service has been questioned (Great Britain. Department of Health, 2000; Great Britain. The Department of Health, 2009).

My final chapter answers the question: *What are the implications for cardiac rehabilitation services in the UK in light of the research question: how to encourage attendance in patients invited to CR?*



## Chapter 7

### Conclusion and discussion

Cardiac rehabilitation reduces mortality, morbidity and provides psychosocial support (Alter, Oh and Chong, 2009; Dobson et al., 2012; Heran Balraj et al., 2011; Jolliffe et al., 2001; Piepoli et al., 2010; R.S. Taylor et al., 2004). The literature identified low attendance rates at cardiac rehabilitation in the UK. The purpose of this thesis was to look at low uptake rates and strategies to increase attendance in the UK (C. Dressler, 2012; C Dressler et al., 2012). Results established that one simple, pragmatic intervention might be to develop health behaviour theory-based invitation letters. The aim was to then develop and evaluate letters to encourage more patients to participate in cardiac rehabilitation phase 3.

The main research question was '*What strategy would improve uptake of CR in patients who have been invited to CR?*' The research question was addressed in a sequential manner, choosing the most appropriate (multi-) research methods. In this Chapter, I present a summary and synthesis of the research findings. I offer a discussion that outlines the contributions of the thesis to the fields of health communication and encouraging participation in cardiac rehabilitation in the UK. I discuss the adequacy of methods chosen before outlining limitations, alternative explanations and future directions for research, policy and practice.

### 7.1 Summary of key findings

With the aim of increasing uptake in cardiac rehabilitation (CR) I first explored, using a scoping review, 1) *who the patients are who do and do not attend rehabilitation*. This gave me an idea of the characteristics of non-attenders and the focus of previous studies. The review found that most studies investigate (mainly non-modifiable) individual patient characteristics in regards to CR attendance. Studies were conducted in different geographic locations and the target population varied. While research on system-related factors is growing, no easily identifiable patterns with regard to under-represented groups emerged. Many studies explore non-attenders as well as facilitators and barriers. Instead of adding further literature to this topic, which is unlikely to bring clarity, I decided to take a pragmatic stance by focusing on increasing attendance rather than examining the reasons for non-attendance. Consequently, the second phase of my work explored 2) *what strategies*

had been employed so far to encourage attendance in CR to get an overview of the existing evidence. Only six RCTs were found, with little focus on specific patient groups. The limited evidence precluded larger conclusions. Two trials assessed the impact of motivational letters, simple and low-risk, which were compared to standard care or a standard letter. Four trials compared peer support and peer support in combination with nurse support, a social worker and a liaison nurse to standard care (results in Table 7.1).

**Table 7.1: Results of a systematic review on interventions to increase CR uptake**

Non-UK-based trials		UK-based trials	
Peer support	-	Liaison nurse	+
Peer support & nurse	-	Theory based invitation letter	+
Social Worker	+	Theory based invitation letter	+

-no difference in uptake rates/ + increase in uptake

Two trials targeted an under-represented group, namely older, un-partnered adults and blue-collar (lower socio-economic status) workers. Only the trial utilising the employment of a liaison nurse attempted to target patient behaviour, while also changing working practice by creating records and links between departments.

The small number of trials and the limited evidence base led me to investigate a more general question, as way of context 3) *What are the strategies and interventions used to encourage more patients to participate in other health services.* With a growing focus on preventive health care and, for example, increasing rates of cancer screening, it is resourceful to look across disciplines and explore methods used to recruit patients to other health services. A structured narrative review of reviews confirmed that interventions are based on similar ideas across health care areas in terms of type of intervention - for example, access-enhancing (such as financial assistance) or individually directed interventions targeting behaviour (Table 7.2 shows main strategies for under-represented groups only). Similarities were also found in terms of intervention design such as the use of health behaviour theories or peers.



**Table 7.2: Strategies used to engage under-represented groups in health care**

<b>Strategies to engage under-represented groups</b>	
Access-enhancing	+
Peer support	+
Provider targeted	+
Invitation/reminders	+/-
-no difference in uptake rates/ + increase in uptake	

Cardiac rehabilitation is free at the point of entry in the UK, and since patients need to recuperate at home first, opportunistic recruitment is not possible. Access-enhancing strategies such as fee waivers or outreach, as done for screening, are not appropriate either. The impact of peer support remained unclear, and while additional staff in liaison or support capacity might be effective, this is an organisational intervention. Due to its resource implications it is neither feasible for a doctoral thesis to implement or evaluate nor a realistic option in the current political climate, diverse local circumstances aside. In cardiac rehabilitation, much as with other health care services, scarce resources increase staff workload and limit time available for individual patients.

Before going ahead with exploring an invitation method guided by review evidence, a consideration of feasibility was necessary. Clinical practice in terms of referral, identification and invitation methods is diverse in cardiac rehabilitation as is programme set-up. Consequently an e-survey seemed appropriate to explore 4) *which invitation methods are used in current practice*. Patients are typically invited in-hospital, via telephone calls and letters or a combination thereof (Table 7.3 below). Using these strategies is supported by the literature reviews outlined above.

**Table 7.3: Most common invitation methods used by 190 CRPs in survey**

<b>Invitation to CR methods</b>	<b>%</b>
In-hospital invitation by CR team	70.5
Every patient gets a phone call	70
Every patient gets sent a written Reminder/ invitation	50.5

Narrative review results had shown that direct personalised communication (telephone calls and letters) are more effective, as are tailored invitations, for

example, informed by health behaviour theory (Chapter 3). Peer telephone calls had no impact on uptake although two RCTs suggested that letters based on health behaviour theory made a significant impact on attendance rates in the CR specific trials (Table 7.1; Chapter 2). One trial found that a letter (intervention), when compared with no letter, achieved a higher uptake of cardiac rehabilitation (86% in the intervention group; 59% in the control group), but only patients who accepted CR received a second letter encouraging them three weeks later (Wyer et al., 2001b). The letter could have been a simple reminder, and the use of theory may not have been influential. The exclusion of 13 people who developed medical conditions questions external validity. Another RCT compared a theory-based letter with a standard letter<sup>48</sup> and demonstrated an uptake of 84% in the intervention group and 74% in the control group. Attendance in the control group was higher than the NACR average of 51% (of patients referred to phase 3 CR). Individual patient recruitment, exclusion criteria or methodological issues begin to explain the results (discussed in Chapter 6). Depending on the purpose of the previous (standard) letter, the content could be conveying logistic information only (such as the location of the class and the appointment time). It is unclear whether motivational wording or health information - for example, the benefits of CR - are included. Nonetheless, it seems highly unlikely that a standard letter would have contained wording that explicitly deters patients from attending. This highlights the value of patient input when designing such invitation letters. Hence, I was interested to explore theory-based letters further.

The National Institute for Health and Clinical Excellence recommends the use of letters but there appear to be no easy-to-access examples (National Institute for Health and Clinical Excellence, 2007, p.7). The low-cost, low-risk and potential easy implementation via the NACR launched an interest in developing existing letters further. In previous trials, patients were involved in the intervention design, but the extent of direct input in regards to the motivational wording remains unclear. Additionally, the lack of a more theoretical debate in the literature on how to use behaviour theory in intervention materials led to semi-structured interviews with

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<sup>48</sup> No information about the standard letter is available.

community heart group attendees. Interviewees were shown and asked about two existing health behaviour theory-based invitation letters. Questions targeted the content, such as least or most important statement, missing information participants would think to be motivating others to attend CR, and wording, such as what phrases they liked/disliked and how to rephrase them (box 5.3). The aim was 5) *to investigate the perception of existing invitation letters as a means of exploring how health behaviour theory is operationalised in written materials* and to elicit key messages likely to motivate people to attend CR (Table 7.4).

Most participants disliked the inclusion of medical terms or negative outcomes post-cardiac event. Some felt that friendly wording, the option of bringing the spouse and outlining the positive results of CR attendance would motivate others to come. Information on ‘what CR is and why attendance is important’ is important if provided in an accessible format. Giving patients an appointment was seen as motivating by some, others preferred a more open invite. Getting advice pertaining to daily activities through talking to other patients, such as helping with the dishes, was discussed briefly. Only two women touched upon emotional aspects such as feeling safe. Findings were situated within the existing literature to contextualize this within UK cardiac care services and thus wider determinants of health (Chapter 5).

**Table 7.4: (Non-) Motivational statements mentioned by participants**

<b>Topic</b>	<b>Perception motivational value</b>
Professional recommendations	+/-
Pre-scheduled appointment	+/-
Authoritarian language	-
Medical terms	-
Negative consequences of non-attendance	-
Spouse involvement	+
Friendly wording	+
Outline benefits of CR	+
Peer support at CR	+

+ liked/ -disliked/ -/+ varied by person

When assessing how patients’ comments resonated with the theory-based wording used in previous letters, it became apparent that most concepts were either directly or

indirectly addressed. Subsequently, the attitude statement was changed to a gain-framed message (see box 7.1) that is more relatable, as patients had mentioned explicitly.

- **ATTITUDE:** *Research shows that people who attend cardiac rehabilitation **will become** more physically fit....*
- **SUBJECTIVE NORM:** use '*peers*' in addition to the statement 'health care professionals *strongly suggest* that you attend CR...'
- **PERCEIVED BEHAVIOURAL CONTROL:** *The programme will be tailored to your **individual** needs.*

**Box 7.1: Concepts from the theory of planned behaviour (changes from previous wording in bold writing)**

Behavioural control/controllability was reinforced by emphasising 'individual' needs, and subjective norm was extended from 'professionals' to 'peers' to tap into lay networks (debated in Chapter 5). Findings from the patient interviews led to an adjustment of the motivational letters. This took the operationalisation of theoretical concepts into account; the wording was amended. The language was also simplified and more practical information on CR session content was provided, such as what to bring to the session. Some statements are individual motivators, for example, 'your spouse can accompany you'. The organisation of CRP meant they might not be feasible due to organisational constraints like limited space, as explained in Chapter 6.

The amended invitation letter, as described above, was then evaluated in a before-and - after study. Recruiting multiple sites and including all patients increased external validity and furthered previous trials. Since the letter had to be tailored to local circumstances effectiveness, not efficacy, was tested. All theoretical statements were included but degree of change from each original letter and logistic information differed between the sites. The quasi-experiment assessed 6) *whether the amended invitation letter encourages more patients who had been invited to attend CR*. Only one of the six intervention sites showed a significant increase in attendance rate. This site had the lowest baseline uptake rate and the change from a mainly administrative invitation to a theory-based letter appears to have increased uptake. That the letter

did not increase uptake rate at five of the six sites might be due to including a more representative patient population. It could be due to how much the letter differed from the original version and what logistic information was included (Table 7.5), both of which differed from previous trials.

**Table 7.5: Reasons for differential impact of amended letter**

The letter:
<ul style="list-style-type: none"> <li>• degree of change in content from original letter,</li> <li>• other logistic information (e.g. pre-scheduled appointment)</li> </ul>
Recruitment:
<ul style="list-style-type: none"> <li>• more representative patient population</li> <li>• self-selection bias of programmes (high initial uptake rate<sup>49</sup>)</li> </ul>
Extrinsic factors:
<ul style="list-style-type: none"> <li>• local circumstances (hospital size, CR phases provided, staff hours &amp; health care professionals involved, waiting times)</li> <li>• other invitation methods</li> <li>• patient characteristics (e.g. co-morbidities) &amp; wider determinants</li> </ul>
Methodological issues
<ul style="list-style-type: none"> <li>• suboptimal data quality</li> <li>• statistical testing presents threat to internal validity</li> </ul>
Other unknown confounders

Other extrinsic factors, methodological issues, or a combination thereof also come into play (Chapter 6). A theory-based letter may encourage more patients who had been invited to attend CR. The letter targeted only individual behaviour, but wider determinants such as waiting times or transport were not addressed. Access remained a barrier to using CR. Results highlight the importance of locally tailored solutions in regards to increasing uptake, discussed below.

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<sup>49</sup> Recent policy documents (March 2013) advocate an uptake rate of 65% (Great Britain. Department of Health. Cardiovascular Disease Team, 2013). There is no increase in funding, hence extrinsic factors and wider determinants could be a crucial hurdle.

## **7.2 A comment on methodology**

This section offers an account as to whether the methodology employed was adequate to answer my research question. An exploration of adequacy of methods chosen and limitations is followed by a short commentary on the fusion of multiple methods. Before doing so, an examination of reflexivity sets the scene. These discussions are key to making sense of the findings and assist in shaping final reflections.

### **7.2.1 Reflexivity**

Reflexivity refers not only to how the researcher experiences impact on all aspects of a study chosen but also to the connection between the reality studied and how this is communicated (Alvesson and Sköldbberg, 2000; Knuuttila, 2002; Pope and Mays, 2006b). It is also about transparency; justifications are important. The researcher (CD) created a narrative, the thesis story, and decisions were made about what to include and how the phenomena were placed in context (Flick, 2010). Richer descriptions and the inclusions of ‘methodological considerations’ represent an attempt to enhance transparency. Finally, interaction with and interpretation of data can only come through experience (Alvesson and Sköldbberg, 2000). For example, the effect of methods chosen on the outcome (or findings) are considered, such as who was recruited to participate (for example, participants from heart support groups), what questions were asked, which lead to the (interview) findings being reported within a ‘standard’ framework or paper layout (Pope and Mays, 2006b). The researcher made an effort not to lead participants and paid attention to negative case findings (Chapter 5).

Standardized approaches are an attempt to eliminate such influences, often seen as a resource, but bias of the discourse presented remains. For example, using certain language produces assumptions (Alvesson and Sköldbberg, 2000). But text is subject to re-interpretation and depends on time and socio-political context. This is a commonality of qualitative and quantitative approaches. Reflexivity in quantitative research is, however, rarely discussed due to a fear of questioning validity (Ryan and Golden, 2006).

### **7.2.2 The researcher's background**

CD is a 31 year-old female who gained a Bachelor's degree in Psychosocial Science whilst working in the social care field during her 20s. She proceeded to briefly work in policy research before pursuing a Master's degree in Health Psychology in the Netherlands. Prior to starting the Ph.D., CD worked as a research assistant/coordinator in family medicine and cardiac epidemiology in Canada. CD was not familiar with cardiac rehabilitation, but assumptions were formed through reading the literature and talking to researchers in the field. It is possible that the assumption of favouring cardiac rehabilitation had an impact on the formation of the research aims as well as data collection, analyses and interpretation. CD attempted to remain aware of these assumptions and as neutral as possible throughout the research.

### **7.2.3 Reflections on methodological approaches chosen**

Health service research is multi-disciplinary and utilises multiple methodologies and methods. Theory typically informs health service research rather than being an end in itself (Lohr 2002). The emphasis is on the applied, with practical intent, rather than abstract speculation. Methodological congruence is achieved through a pragmatic approach and transparent reflections on methodological choices, as discussed in each Chapter (Morse and Richards 2002, 2007, as cited in Creswell, 2007). The merits and limitations of each method were contemplated, leading to a multi-method approach.

### **7.2.4 Reflections on the quantitative methods**

I chose to adopt systematic review, survey and quasi-experimental methods that follow the principal underlying assumptions (methodology, epistemology and ontology<sup>50</sup>) of post-positivism. Positivism represents an ontology of a reality independent of the observer, and epistemologically, it is postulated that a single objective truth exists that is observable (Guba and Lincoln, 1998). The independence

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<sup>50</sup> Methodology, the theory of how research proceeds, is a direct base for why a method is chosen. Epistemology, how knowledge comes about, and ontology, about the nature of reality and being, are also part of the greater debate about research paradigms. Kuhn (Gower, 1997) defined paradigms as "constellations of beliefs, values, techniques, and so on shared by members of a given community" (p. 144, Kuhn, 1970a in p.244Gower, 1997). Method is the actual technique of how evidence is collected (Brink, Van Der Walt and Van Rensburg, 2006; Guba and Lincoln, 1998).

of the researcher is assumed, while the purpose of scientific enquiry is to find causal mechanisms (Appleton and King, 2002; Crotty, 1998). Post-positivism today argues that scientists work within a paradigm. Imperfect observation and errors are possible, and theory can be developed and adjusted (Creswell, 2009; Popper 1959, Kuhn, 1970, as cited in Crotty, 1998). The impact of the post-positivism stance resonates not simply within the application of the chosen quantitative methods, but with the interpretation of results claiming objectivity, validity and generalisability (Crotty, 1998).

My thesis falls under post-positivism. Utilising review methods allows for the questioning of methodology and assesses biases, which fits under the post-positivism umbrella. Trials apply methods of randomization that embody reductionism but result in the assumption of causality due to the isolated mechanisms assessed. Yet inclusion/exclusion criteria question the effectiveness of the intervention assessed (relevant here in regards to previous letter trials). Evidence could be evaluated, such as RCTs of theory-based letters using concise review methods, but reductionism leads to a loss of understanding of the complexity of intervention, for example peer support (discussed in Chapters 2 & 3).

This paradigm also sees research as broad and recognises complexity (Ryan and Golden, 2006). Thus post-positivism allows for multiple methods, hence utilising a qualitative piece under the constructionist stance adds different insight (Trochim, 2006). Interpretation around meaning becomes possible and methods are commensurable, as discussed in section 7.2.3 (Trochim, 2006). Epistemologically, the observer is no longer assumed to be independent (Crotty, 1998); reflexivity comes into play.

The survey falls under the same post-positivist paradigm: through quantification, relationships are assessed. As an audit approach, it did not follow scientific criteria as strictly. For example, it is missing reliability or validity measures, and it does not add to the knowledge base to the same extent (Bowling, 1997). Normally the sample is seen as generalisable to the entire population, though this is to be taken with caution due to the huge diversity in CR services (Creswell, 2009; Dobson et al., 2012; The National Audit of Cardiac Rehabilitation, 2012). Still, the primary research here adds specific understanding – what strategies are used to invite patients



in practice. Results are related back to the review findings, as discussed above, to identify starting points for changes or service improvement (research) in CR that can be supported by that evidence. Specifically, invitation strategy use in current CR practice and past CR-specific trial conduct and outcome are evaluated together in pragmatic terms. This led to the consideration of developing theory-based letters and their potential to motivate patients.

The quasi-experiment has further advanced knowledge by recruiting multiple sites and going from an individual to an all-patients inclusive design (no individual selection bias; exclusion criteria), which also falls under the post-positivist stance whereby the researcher sought to manipulate the outcome (uptake rate) via implementing the amended letter at a certain time point (Appleton and King, 2002). Health research is concerned with assessing, among other things, 'effectiveness and efficient use' (Bowling, 1997, p.7). The quasi-experiment responded to the different organisational set-ups and only recruited sites that already used a letter. The amended letter was tailored to include local administrative information and to fit with the organisational circumstances. The intent was pragmatic and effectiveness was tested. However, the before-after quasi-experimental method only partially answers my research question. This is due to the factors discussed above (Table 7.5; Chapter 6), specifically suboptimal data quality, one unforeseen challenge (delayed data entry and variations in time between invitation letter sent and patient attending CR), and not having more extensive data (e.g. over a longer time period or following individual patients). The latter precluded the use of longitudinal statistical methods to assess the outcome (uptake rate) and less control over the manipulation, such as regression to the mean, is executable. Extrinsic factors such as other invitation methods or waiting times, raised new questions in regards to their potential impact on uptake rate and, more generally, service provision. This made it difficult to evaluate the evidence despite the systematic approach. Pragmatic considerations and future directions were outlined in Chapter 6. Nonetheless, the quantitative material gave me valuable information on the importance of real-life circumstances when developing a behaviour-based intervention.

### **7.2.5 Reflection on the qualitative research piece**

This sequential approach, in which results from one research piece feed into the next step, determining methods and aims also included a qualitative piece. This

investigated patients' perceptions of existing invitation letters by taking an explorative, constructionist approach. The purpose was to engage indirectly through patients experience with their heart disease and CR and explore their perception of the invitation letters (Guba and Lincoln, 1998). Social constructionism fuses objectivity and, subjectivity, as it too, recognises the relationship between method and purpose (Crotty, 1998). Dialectic method/ology seeks to explore complexities of views, highlighting similarities and differences, rather than condensing them into a small amount of categories, as quantitative research methods suggest (Creswell, 2007, 2009). This means pre-defining categories and looking for relationships (survey). The addition of a qualitative piece helps with contextualization – why or how specific letter content could motivate CR attendance- and to better understand the consequences of the intervention letter (Pope, Mays and Popay, 2006). The aim was to explore most/least convincing motivational statements in the invitation letters how to arrange them and the extent to which health behaviour theory resonates with these statements. It is possible to juxtapose meanings that are equally valid. Some patients, for example, thought a prescheduled appointment was motivating, whereas others found it to 'pushy'. Each person's social reality arises through interactions (and past experiences) (Avis, 2005; Guba and Lincoln, 1998). Obvious limitations to this research piece include the lack of more female participants and diversity in patients, such as a variety of ethnic backgrounds. The partiality of the account presented was debated in Chapter 5, acknowledging its contingency (Atkin, K., 2011, 'Qualitative Methods in Health Research', Lecture, The University of York, unpublished). The interviews were instrumental in exploring how to operationalise health behaviour theory, but the limited transferability of findings perhaps exceeds the inherent role it usually takes in qualitative approaches. A behaviour-targeting intervention, then, could be a facilitator and barrier simultaneously and may increase health inequalities, as debated in the 'Limitations and strengths' section below. Nonetheless, the qualitative material was valuable in gaining insight into how letters were perceived. It highlights the importance of a systematic assessment of patients' perception of intervention materials.

### **7.2.6 The combination of multiple methods**

Qualitative and quantitative methods are traditionally seen as separate approaches, although current debates emphasise how qualitative research should not be seen as

the opposite of quantitative research (Popay and Williams, 1998). For example, as seen in the analysis of the semi-structured interviews, using words such as ‘*many* participants commented on the sentence ...’, *none* or *some* illustrates that qualitative research also quantifies (Crotty, 1998). In the same way, but less acknowledged in the literature, the survey of CRPs (Chapter 4) collects data on strategies currently used by cardiac rehabilitation programmes to identify and recruit patients as well as information about patient groups less likely to attend CR. Categories for the latter are derived from evidence-based literature, yet the quantification is based on anecdotal reporting by staff - their perception of reality. Consequently, information collected is not always exclusively qualitative or quantitative in nature. This highlights how evaluating evidence can be complex and difficult in terms of the implications. For example, should one present the survey results as hard facts when the answers are based on anecdotal evidence (mentioned above)?

Commonalities of qualitative and quantitative research include, for example, formulating a research aim and developing research objectives, justifying a sampling strategy, having a clear set of questions and topics to explore, and a detailed and transparent plan of analysis (Mayring, 2001). Both approaches draw upon different methods, utilising their strengths, being aware of their weaknesses, leading to a greater insight than one approach alone could have provided (O’cathain and Thomas, 2006). The fusing of qualitative and quantitative methods is assisted by subtle realism, a “[...] sensible pragmatism that assumes reality is filtered through various lenses, but that it is none the less not infinitely malleable, and that it is, to an albeit limited extent, knowable” (J Green, 2003, p.1). Assumptions about an existing empirical reality that can be expressed through human interaction are made, and research itself is assumed to be able to communicate this reality (Draper, 2004).

I used multiple methods to best address different aspects pertaining to the same overarching aim - ‘increasing uptake in CR’ - and to gain more complete insight through combining methods. A multi-method strategy includes using several different methods that stand alone. This differs from traditional mixed-method approaches that address the same objectives with different methods. Mixed-methods tend to ‘add in’ a strategy to increase or broaden insight but, as being part of one project, remain under one dominant paradigm (Tashakkori and Teddlie, 2003). Conversely, as described in each Chapter’s opening paragraph as well as in the

‘Summary of findings section’ above, each piece here stands alone, and the results are synthesised in sequential triangulation feeding into the next step (Morse, 2003). In the present research, using multiple methods led to a more comprehensive understanding of the topic area as well as showing knowledge gaps and limitations in health research.

### **7.3 Limitations and strengths**

Limitations of each method and research piece were discussed per Chapter and briefly outlined above. For the thesis as a whole, several overarching limitations need to be acknowledged.

The intervention developed here is solely an individually directed, behaviour-focused intervention. While this does target the specific patient group of those invited who are not interested in attending (31% of non-attenders due to ‘lack of interest’, the NACR) no system-related barriers such as waiting times or transport costs were tackled. This intervention aimed at increasing use but access and wider determinants of health that may be influential, from waiting times to transport, ill health or employment-related barriers were not addressed (Chapters 4 & 6) (The National Audit of Cardiac Rehabilitation, 2012). It is important to develop effective patient communication/motivation to facilitate informed choice and use of CR services. Thus, targeting use and behaviour alone only addressed one piece of the puzzle leading to greater use and access of CR. Using a health behaviour theory intervention also includes disadvantages in regards to diverse socio-cultural contexts or the lack of an emotive component (Munro et al., 2007) (Chapter 5). Hence the intervention may only appeal to a small group of patients. This could also inflate health inequalities (Chapter 3). Those patients who are better off are more likely to be able to deal with wider determinants such as transport costs or waiting times (by going to a different service or using private care). Outcome, the impact of having attended CR on health and wellbeing, is not addressed here.

In any case, an intervention designed to facilitate use can also be a hurdle. For example, HBT concepts address facilitators of CR on an individual level, such as self-efficacy and perceived benefits of CR, but these could also be perceived as barriers (Daly et al., 2002). For example, patients with significant physical

impairment may be put off by ‘gentle exercise’ or ‘talk to others’ rather than motivated. The impact is limited to a small part of the patient population.

This research is subject to the criticisms outlined in the systematic review. There was no focus on a particular patient group other than ‘non-attenders’. Though issues of non-attendance in CR were explored in Chapter 1 showing a heterogeneous group. In terms of (policy) implications, tailoring to local circumstances becomes important, as discussed below. A one-fits-all approach might not be appropriate in a service so diverse as CR in the UK.

Under the framework of the service evaluation, all patients could be included, and individual selection bias was avoided. Efficacy was perhaps proven in previous trials, but the effectiveness approach taken here showed the complexities of even just a small, individually tailored intervention being entwined with local circumstances. All AMI-treating hospitals in England, Wales and Northern Ireland have a cardiac rehabilitation programme, but the set-up of the programme and the working practices across the patients’ pathway differ substantially and variations exist, as confirmed by the survey (Bethell et al., 2008; The National Audit of Cardiac Rehabilitation, 2012). This includes resource availability and together aggravates service improvement (research), as became clear in Chapter 6. Causal inference is limited due to the quasi-experimental design, and the time period did not make it possible to use statistical methods for trend prediction (Chapter 6, appendix E). As discussed, questions in regards to internal validity arose due to the method chosen. Selection bias at the individual (Chapter 5) and the programme (Chapter 6) level necessarily limit transferability and external validity. Thus recruitment strategies for the interviews about letters were extended to other settings in response to the limited interest. While external validity was enhanced through multiple site inclusion, result interpretation is complex (Weinberger et al., 2001). Results can only be generalised to programmes in the UK that use an invitation letter, as per inclusion criteria however, diversity in circumstances and unknown confounders may limit this further (Weinberger et al., 2001).

The decision to use a quasi-experimental approach to evaluate the letters was influenced by the resource constraints of a three-year doctoral project. Political and financial constraints can have a significant impact on design decisions (Popay and

Williams, 1998). Research ethics and governance procedures can be extensive, and it is impossible to separate research and audit reliably (Wade, 2005). I used this to my advantage employing a service evaluation framework (audit) in which no individual data is collected, but I was still able to evaluate the amended letter in the given time frame. As mentioned above, this can lead to suboptimal data quality and less time for data collection, which can make it difficult to assess the intervention. One must necessarily admit that research in health services needs to balance desirability and feasibility. Resource use and time during the research process are valid considerations in a climate of constant reformation of services (as in the NHS) as are the appropriateness or the cost-effectiveness of the potential research aim (in this case, the letter)(Bowling, 1997).

The potential of researcher bias<sup>51</sup> needs to be recognised, as the research process is not entered naively. Reflexivity acknowledges the influence of assumption on the research process, rather than framing the researcher's influence as introducing systematic error (Hansen, 2006). My own preliminary understanding of the importance of CR, as became clear in Chapter 1, drives the research agenda as well as the choice of methods and maybe introduced bias. This pertains to the overall limitations of the thesis including the choice of methods being limited by external circumstances such as time or resources. Not having a second analyst may enhance bias and is a drawback to reliability. Conversely, including protocols and the discussion of biases is an attempt to enhance transparency and acknowledge boundaries of established methodological approaches as well as personal viewpoints.

## **7.4 Implications and contributions to the field**

The following sections examine the original contribution made by this thesis to the literature around cardiac rehabilitation attendance, while contextualising the work within broader theoretical and empirical debates.

### **7.4.1 The operationalisation of health behaviour theory**

A contribution to the field of health communication and health psychology has been made by exploring the operationalisation of health behaviour theory in relation to intervention materials, specifically, to motivational letters. I discussed how the

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<sup>51</sup> Bias refers to the systematic errors that could be introduced at any point on the research process.

theoretical concepts of the theory of planned behaviour (TPB) and the common sense model of illness representation (CSM) resonated in participant interviews and how, in regards to these concepts, the wording could be optimised to increase its motivational potential (Ajzen, 1991). This differs from the original letters and the way the theoretical concepts tend to be operationalised for research purposes such as questionnaires. It highlights the importance of involving the target population in a more systematic way when designing motivational material.

When using, for example, the TPB, predicting behaviour rather than using the TPB for intervention designs is still at the forefront (Mceachan et al., 2011; Michie and Johnston, 2012). A nuanced understanding of its efficacy in different contexts, referring to its applicability to different health behaviours, is just becoming apparent (Mceachan et al., 2011; Michie and Johnston, 2012). While the field of health communication advocates the importance of getting the message right (Mattson and Basu, 2010) and points towards health behaviour theories, a theoretical debate on use and operationalisation does not yet exist in regards to health communication materials<sup>52</sup>. This research piece opens the debate on how to formulate texts in concordance with theoretical (TPB) concepts in a motivational manner and suggests ways of tapping into the theoretical concepts that determine behaviour in order to instigate behaviour change.

#### **7.4.2 The survey**

The survey of which identification and invitation methods are currently being used was the first of its kind (Chapter 4). While this was an exploratory, unadjusted audit survey, it confirmed variability in service provision including the lack of a consistent approach when engaging patients. The results support knowledge exchange, since CR services in the UK are extremely diverse in local circumstances and patient population. A one-fits-all approach, such as improving invitation letters, is hard to implement. However, using motivational text where letters are in place already could be an option. It has been recognised that some CRP remain isolated, with little connection to other programmes or knowledge exchange opportunities (BACPR conference) (Great Britain. Department of Health. Cardiovascular Disease Team,

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<sup>52</sup> Ajzen (2006b) explicitly discussed questionnaire design but no debate on health promotion or intervention materials exists.

2013). This raises questions on how good practice (such as a letter or other motivational material) is disseminated. There is value in encouraging individual site comparisons and exchange of strategies between programmes to tackle access and use of CR (further discussed below), especially since in practice letter content gets adjusted without formal evaluation.

### **7.4.3 A behavioural theory-based intervention letter**

A contribution to the field of increasing uptake in CR was made by developing a simple tool to motivate individuals. A letter could be changed or implemented easily with little to no cost, which is crucial since there is no additional funding for cardiac services with the new Health and Social Care Act 2013 (Great Britain. Department of Health. Cardiovascular Disease Team, 2013). Why the letter did not work was discussed above: it included reasons such as dis/advantages of HBT and limited patient input (Chapter 5), extrinsic factors or methodological issues (box 7.5). Awareness of these issues raises questions in regards to the efficacy of service improvement intervention (Dobson et al., 2012). Cardiac rehabilitation provision in the UK is still a patchy service with limited resources and, as seen in Chapter 1, a heterogeneous group of non-attenders. Patient communication remains important, and perhaps a more nuanced, locally-tailored letter would increase uptake.

Although evaluating the evidence from the HBT letters is complex, the methods chosen have helped in further understanding some of the processes and effects in CR. Rather than offering a comprehensive understanding of *'What strategy would improve uptake of CR in patients who have been invited?'* in the UK, this synthesis shows tensions, complexities and gaps. The implications here are to advocate for more context-sensitive policies. In fact, these results support more flexible solutions in accordance with local circumstances, some of which have been recognised in recent policy documents - Cardiovascular Disease Outcome Strategy 2013 (Great Britain. Department of Health. Cardiovascular Disease Team, 2013). Still, tensions arise between a behaviour-focused intervention and barriers to accessing a service with limited resources, discussed below.

### **7.4.4 Communicating the importance of CR**

The thesis adds to the debates of how knowledge pertaining to cardiac rehabilitation is created. Fostering effective engagement between the health care system and the



patient results in improved care as well as illness experience and may reduce the burden of disease.

Tensions arise because nurses often present CR as a ‘lifestyle improver’, which may not convey the necessity of CR in terms of treatment (A. M. Clark et al., 2004, p.546). In the interview results (Chapter 5), only one participant used the word treatment, which supports Clark et al.’s statement. Failure to communicate the importance of CR as part of the treatment means patients are missing out on the well-established benefits of CR (Chapter 1). It remains debatable where one draws the line between ‘selling’ CR as part of the treatment and giving a choice. Still, the emphasis on informed choice, decision-making and preference in the health care arena is growing. As mentioned in Chapter 5, Madden et al. (2011) state that current CR services do not come under the umbrella of informed choice that presents the different CR options clearly to patients. They also wonder whether patient perception of choice would differ if CR was prescribed as a treatment (Madden, Furze and Lewin, 2011, p.546). The practitioner –patient dialogue needs to be improved with a discourse that regards CR as part of the treatment and actually phrases/presents CR in this way.

Complex discharge procedures may lead to the patients’ lack of understanding of CR options (Daniels et al., 2012). Short hospital stays may not result in de-conditioning of the patient, but s/he may miss the CR nurse’s visit, and the emphasis on secondary prevention (in terms of medication and cardiologic interventions) remains stronger. Again, a clear emphasis on the importance of cardiac rehabilitation treatment in practice needs to be made. Additionally, the (grey) literature could adopt the discourse of CR as a treatment to support practice (new guidance documents are currently under development) (Great Britain. Department of Health. Cardiovascular Disease Team, 2013).

Tensions arise between limited time per patient, the nurses’ task-centred approach and effective communication (Timmins and Astin, 2009). Health care use may differ because of preference, but insufficient information should not be the reason for differential use (Oliver and Mossialos, 2004). The British Association for Cardiovascular Prevention and Rehabilitation continues to emphasise a module-based, individually tailored approach to CR, which may be where the focus of choice

needs to be - within CR, not on whether or not to take part in CR (British Association of Cardiac Prevention and Rehabilitation, 2012). This is reflected in the choices between home, community or hospital CR that some sites offer, which could be integrated into the practitioners' dialogue.

This also leads to a debate about access, use and appropriateness of services. The intervention (letter) targeted use only. The acceptability of treatment on what this means within a persons' socio-cultural and economic sphere impacts upon using (and accessing) health care. In Chapter 3, I briefly mentioned that even in the case of universal or equal access to a treatment differential use could occur. Kleinman says that patients hold a belief model self-explaining health, illness and treatment, and Sloots elaborates that professional and patient models must be equivalent for successful CR (Kleinman, 1980 as cited in Sloots et al., 2011). A mismatch between letter content and patients perception of their own health status may lead to thinking CR is irrelevant. Remember 17 % of CHD patients in the community had this opinion (Commission for Healthcare Audit and Inspection, 2004). Furthermore, the patients' self-assessed health status may no longer be 'sick' and the 'sick role' may no longer be accepted, leading to a focus on their daily live rather than (clinical) health status (Chapter 5, patients talking about daily activities) (Maddox, 1962, Garritt 1973, as cited in Roviario, Holmes and Holmsten, 1984 p. 64 ). This could have wider implications in terms of how to support the patients' self-management but also in terms of patient communication, referring back to 'treatment versus lifestyle choice'.

Unless a patient's condition is unstable, referral to CR should take place (R J. Thomas et al., 2010). Selective assumptions remain prevalent in HCP, for example, that women have other commitments (in terms of a more traditional family role) and that older patients are too unwell (Tod, Lacey and Mcneill, 2002). While differential referral exists certain patient groups may get invited less often (Chapter 1). These assumptions and exclusions due to medical reasons perhaps hide what is actually limited service capacity (Lindsay, 2008). In the UK, waiting times are 52 days for MI patients, and resources are scarce (The National Audit of Cardiac Rehabilitation, 2012). Service provision is limited, and an increase in uptake of CR would need to be accompanied by CR service expansion (Tiller et al., 2013). Evidently, policy documents used to suggest that 85% of patients would be well enough to attend CR

whereas now the goal is to increase uptake to 65% (Great Britain. Department of Health. Cardiovascular Disease Team, 2013). Previous work suggests that extra liaison or professional support did lead to greater attendance (Chapter 2) (Jolly et al.)). Diversity in how services work and financial constraints limit the applicability of these interventions. Resource scarcity leads to favouring individually targeted interventions, as was the case here, where only knowledge was targeted as an aspect of access to care (Anderson framework Chapter 3) (Aday and Andersen, 1981; Hall et al., 2008)). Hence, access can be a barrier to use as discussed in Chapter 6 (why the invitation letter had no impact).

On another note, CR studies have shown that automated referral, for example, leads to better equity in access but not in use (Grace et al., 2012). In turn, equal use does not necessarily mean equality in outcome post-CR (Deck, 2008; Sanderson et al., 2007). Hence, barriers and inequalities also exist within the cardiac care service (Adamson et al., 2003). There is a gap in the debate linking use, access, appropriateness and outcome in CR. Due to the diversity in services, evaluating interventions across multiple sites is complex, and the discussion on appropriate services remains largely absent. While the definition of appropriateness includes “[...] desired by the individual patient “ (Hopkins, 1993 as cited in Bowling, 1997 p. 11), the stance remains more evidence-based than patient-centred. Providing culturally appropriate services is only one aspect of a larger debate on this challenge (Astin, Atkin and Darr, 2008; Atkin and Astin, 2010). Within such a scarcely funded service, further advocating a menu-based approach (giving the option of tailoring to the patients’ needs while supporting choice) is emphasised here (British Association of Cardiac Prevention and Rehabilitation, 2012).

#### **7.4.5. Summary of the contributions and implications**

The survey illustrated that cardiac rehabilitation care in the UK operates differently from place to place. Considering the limited resources and a heterogeneous group of non-attenders, knowledge exchange and the dissemination of effective invitation strategies is highlighted. The successful implementation of a uniform recruitment strategy across the UK is unlikely, but improving motivational text where invitation letters are in place already could be an option. Considering the low uptake rate of CR in many European countries, the potential use of cost-effective motivational letters is valuable (Bjarnason-Wehrens, 2008).

Questions arise as to whether a more nuanced letter tailored to local circumstances would increase uptake in CR. A contribution was made in regards to operationalising HBT concepts into text, and the importance of patient input when designing intervention materials became clearer - a relevant finding in regards to international research and practice in the field of health promotion and health communication more generally. This also raised questions about bringing health behaviour theory into clinical practice, CR being a complex health service. Concentrating on theory use could possibly neglect the impact of local circumstances and wider determinants. Conversely, in practice, letters get adjusted without former evaluation perhaps neglecting the motivational potential of using theoretical components. Pragmatism in health services research is crucial.

The thesis highlights patient communication, and a more formal evaluation thereof remains important and adds to the debate about framing CR as a treatment in policy and practice. This is relevant in English-speaking countries (where it is primarily nurses who run CR) as well as in Europe, where cardiologists are in charge for phase 3 CR (Bethell, Lewin and Dalal, 2009) (Bjarnason-Wehrens, 2008). Only half the European countries have legislation to support cardiac rehabilitation, and programme type (in- or outpatients), eligibility criteria, legislation and financial support differ (Bjarnason-Wehrens, 2008; Short, 2008). This thesis' discussions help direct research, highlight potential complexities in health services evaluations and the policy discourse.

## **7.5 Future directions**

### **7.5.1 Research**

Well-conceptualised motivational letters remain a good, low-risk option for encouraging attendance of CR. In a fragmented service with different local patient populations, needs and limited resources this is one of the few generic interventions requiring low resources and hence merit further development. Future directions in research would look towards a pragmatic RCT, evaluating invitation letters across multiple sites and acknowledging the difficulties of multi-site health services research (Weinberger et al., 2001). Still, methodological questions arise in regards to, for example, behavioural motivators versus organisational barriers (Chapter 5). Alternatively, a more extensive quasi-experiment with an A\_B\_A design, collecting programme and patient data for a longer time period is appropriate to assess the

impact of letters. The pragmatic, locally-tailored approach and non-individual patient recruitment remain important. Utilising the NACR again could also allow for direct feedback to participating programmes and assist in locally nuanced service development.

There is also value in comparing currently used invitation strategies in CR and their effectiveness. The survey raised further interest in regards to details on the strategies in place (further discussed below). Process and/or outcome evaluations could assess current strategies (such as contents of telephone calls). This could inform local practice and procedure manuals. The evidence from such an assessment could be translated into simple lists to provide frontline staff with easy-to-access guidelines on how to encourage attendance of CR.

Furthermore, the cost implications of the invitation strategies have not been addressed. Resources are scarce in cardiac rehabilitation services, hence the financial implications are important and need to be assessed alongside any other service improvement activities. Increased uptake of CR would necessarily require an increase in service provision (Tiller et al., 2013).

Pertaining to the discussion above on how knowledge is constructed around CR being part of the treatment, this would merit further exploration. The aim would be to gain an understanding of how CR is presented in everyday clinical practice. An observational study with an ethnographic approach might provide insight. Thus far, in most literature, cardiac rehabilitation is ‘recommended’ as a change in lifestyle (rather than ‘strongly advised’), resulting in a different interpretation of ‘treatment’. A discourse analysis of the national and international literature could shed light on this. Results may be of direct interest for policy development and the improvement of patient communication.

There are obvious disadvantages to using health behaviour theories, such as the lack of an emotional component (Chapter 5). Exploring the use of theories as part of intervention designs would further the theoretical debate in health communication to better ‘get the message right’. More specifically, diversifying the patient population and exploring differences in the perception of letters and motivational content may provide further insight into why the letter developed here had little impact or how to improve it. Alternatively, taking a similar approach to Chapter 3 looking across

health care areas, it may be of value to explore existing invitation materials to assess the current use of theoretical concepts, whether done intentionally or not.

### **7.5.2 Policy and practice**

Current policy documents comment on patient engagement in regards to promoting CR with reminders such as calls, direct contact or motivational letters (National Institute for Health and Clinical Excellence, 2007; The National Institute of Clinical Excellence, 2010). A clarification of the difference between a reminder and a motivational letter could be beneficial. In regards to the practical implications, since only around 50% of CRPs currently use a letter (Chapter 4), it might be of value to implement reminder letters - considering the high uptake rates in programmes using a letter that was found here - (Chapters 4 & 6) and to evaluate the routine use of reminders (supported by evidence from Wyer et al., 2001, and other health care areas, Chapter 3).

In addition, national policy guidelines can provide clearer advice on how to construct a motivational letter outlining basic key content to be included, such as ‘why CR is an important part of the treatment’ and ‘what happens at CR’ (Chapters 5 and 6). Local differences in regard to administrative and logistic information need to be included, and presenting case studies could be helpful.

The emergent difference between and hence importance of working practice, procedure and context of CRPs (Chapter 4) advocates that stakeholders and experts need to be involved in developing local working strategies as well as their practical implications in regards to organisational and financial resources. Both of which would be impacted by an evaluation of current invitation methods, as discussed above.

The dissemination of effective and ineffective patient invitation methods could improve practice. More detailed information on which invitation methods are used to encourage which patient population to attend CR would stimulate a discussion and could result in more effective use of resources such as nurse time. A coordinated approach to knowledge exchange beyond a few ‘best practice’ examples in policy documents is desirable.

Meeting the needs of the local population and being attentive to socio-economic and cultural barriers should be taken into account, as highlighted by current policies

(National Institute for Health and Clinical Excellence, 2007; The National Institute of Clinical Excellence, 2010). Both points remain important because non-attenders can differ by CRP (Chapters 1 and 4). Overall quality improvement and better tailoring to the needs of the local patient population can be fundamentally supported through monitoring - the NACR already being in place. More accurate and timely data entry could improve the service assessment and development cycle, though more resources are needed.

## **7.6 Concluding remarks**

To answer the research question - *'how to encourage attendance in patients invited to CR?'* - I developed six research aims and employed a sequential, multi- methods approach.

Evidence strongly suggests that CR reduces mortality, morbidity, systolic blood pressure and cholesterol level alongside psychosocial benefits (Alter, Oh and Chong, 2009; Dobson et al., 2012; Heran Balraj et al., 2011; Jolliffe et al., 2001; Piepoli et al., 2010; R.S. Taylor et al., 2004). Cardiac rehabilitation in the United Kingdom is a fragmented service with limited resources. Non-attenders are a heterogeneous group, perhaps a symptom of the diverse service. Considering the evidence on interventions to increase uptake and feasibility, invitation letters were further developed. The importance of systematic patient input into formulating motivational text became apparent, which contributed to knowledge in health communication in regards to operationalising theoretical concepts.

The evaluation of letters was taken to the next level with increased external validity. The limited impact of the amended letter due to various extrinsic factors, methodological issues, the letter or a combination thereof highlight the complexity of health services research and evaluating the evidence. This intervention addressed 'use' of cardiac rehabilitation only showing that the debate about improving access remains. This thesis supports context-sensitive policy and locally tailored solutions for CR practice.





## Appendices

### Appendix A

#### 1) Relevant studies on attenders and non-attenders in cardiac rehabilitation (non-exhaustive)

Table 1: Studies on CHD/CR and culture and ethnicity

First Author	Country	Research	Reference
Atkin		Commentary	(Atkin and Astin, 2010)
Chauhan	GB	Qualitative; compatibility of CR practice Quantitative; assessing health records in diff. ethnic groups	(Chauhan et al., 2010b) (Chauhan et al., 2010a)
Banerjee	CA	Qualitative; Exploration on what facilitates attendance	(Banerjee et al., 2010)
Beswick	-	Review	(A D. Beswick et al., 2004)
Britton	GB	Quantitative; Whitehall II	(Britton et al., 2004)
Darr	GB	Overview/Qualitative; illness experience	(Darr, Astin and Atkin, 2008)
Davidson		Review on cultural competence in CR	(Davidson et al., 2010)
Deck	DE	Quantitative; inequalities in CR higher at end of CR	(Deck, 2008)
Digiacommo	AU	Qualitative; health information management as barrier for Aboriginals to access CR	(Digiacommo et al., 2010)
Haghshenas	AU	Qualitative; cultural competency	(Haghshenas and Davidson, 2011)
Galdas	CA	Qualitative; Sikh South Asians and CR	(Galdas and Kang, 2010)
Grace		Review; women & CR	(Grace et al., 2010)
Grewal	CA	Qualitative; diff. referral methods	(Grewal et al., 2010)
Jolly	GB	Ethnic Minorities in RCTs	(Jolly et al., 2005a)
Mochari	US	Quantitative; diff. referral rates in white vs. minority women	(Mochari et al., 2006)
Sanderson	US	Quantitative; gender & socio-demographic variables	(Sanderson et al., 2007)

Ski	AU	Editorial	(Ski and Thompson, 2011)
Sloots	NL	Qualitative; Turkish and Moroccan patients' experience of modified CR	(Sloots et al., 2011)
Valencia	-	Review	(Valencia, Savage and Ades, 2011)
Vishram	UK	Qualitative; South Asian women and perception of CR	(Vishram et al., 2007)

Table 2: Studies on CHD/CR and deprivation

First Author	Country	Research	Reference
Beauchamp	-	Review	(Beauchamp et al., 2010)
Cooper	-	Review	(A. Cooper et al., 2002)
Fernandez	AU	Quantitative; lower SES no impact on CR attendance, but age and marital status	(Fernandez et al., 2008)
Grace	CA	Automated referral to CR to increase equitable access	(Grace et al., 2012)
Harlan	US	Quantitative; non-participants were more likely to be women, less education, lower income	(Harlan et al., 1995)
Harrison	GB	Quantitative; gender and age, but not deprivation predict uptake of CR	(Harrison and Wardle, 2005)
Kerins	IR	Quantitative; non-attenders/compliers of CR are	(Kerins, Mckee and Bennett, 2011)
Lacey	GB	Quantitative; higher CHD in more deprived areas	(Lacey et al., 2004)
Melville	GB	Quantitative; higher deprivation related to lower attendance rates	(Melville et al., 1999)
Nielsen	DK	Quantitative; neg, association with CR attendance, if living alone, foreign, low income	(Nielsen et al., 2008)

Table 3: Psychosocial CHD/CR

First Author	Country	Research	Reference
Casey	US	Higher depression scores not related to attendance, but age and distance were related	(Casey and Sydeman, 2013)
French	UK	Quantitative; illness perception not associated with CR uptake	(French et al., 2005)
French	-	Review; four illness perceptions related to CR attendance	(French, Cooper and Weinman, 2006)
Grace	CA	Quantitative; social support not associated with uptake	(Grace et al., 2002b)
Grace	CA	Quantitative; higher illness control related to higher attendance rates, interaction physician & system variables	(Grace et al., 2008)
Husak	US	Quantitative; no independent impact of social support on attendance	(Husak et al., 2004)
Molloy	-	Meta-analysis of marriage/partner found partnered higher odds to attend CR	(Molloy et al., 2008)

Table 4: Gender

First Author	Country	Research	Reference
Beckie	US	RCT; Women-centred CR,	(Beckie, 2006; Beckie and Beckstead, 2010; Beckie et al., 2009)
Beckstead	CA	Qualitative; physicians' perception of patients for CR	(Beckstead et al., 2013)
Benz Scott	US	Review	(Benz Scott, Ben-Or and Allen, 2002)
Colbert	CA	Quantitative; Alberta registry: women less often referred and invited	(Colbert et al., 2013)
Daniels	US	Review	(Daniels et al., 2012)

Day		Review; men & women have different needs; gender not always a predictor of attendance	(Day, 2008)
Dobson		Review	(Dobson et al., 2012)
Grace	CA	Qualitative; women had different barriers to attendance e.g. family	(Grace et al., 2009)
Harrison	GB	Quantitative, gender and age, but not deprivation predict uptake of CR	(Harrison and Wardle, 2005)
Heid	US	Mixed, gender difference not visible in referral, but in enrolment rates	(Heid and Schmelzer, 2004)
King	-	Review	(King and Lichtman, 2009)
McCarthy	-	Review	(Mccarthy, Vaughan Dickson and Chyun, 2011)
McInnes	GB	Qualitative studies about benefits of CR	(Macinnes, 2005)
Sanderson	US	Quantitative	(Sanderson, Shewchuk and Bittner, 2010)
Tod	GB	Qualitative; Childcare etc. as barrier for women	(Tod, Lacey and Mcneill, 2002)
Weingarten	US	Quantitative; similar enrolment rates after diff. referral	(Weingarten et al., 2011)

Table 5: Age

First Author	Country	Research	Reference
Arthur		Review	(Arthur, 2006)
Cupples	NI	Quantitative; non-attenders in N.Ireland	(Cupples et al., 2010)
Dolansky	US	Qualitative; perception of CR	(Dolansky, Moore and Visovsky, 2006)
King		Review	(King and Lichtman, 2009)
Melville	GB	Quantitative, higher deprivation related to lower attendance	(Melville et al., 1999)
Pasquali	-	Review	(Pasquali, Alexander and Peterson, 2001)

Tolmie	UK	Mixed; older patients	(Tolmie et al., 2009)
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Table 6: System-related factors

First Author	Country	Research	Reference
Cortes	-	Review; determinants of referral	(Cortés and Arthur, 2006)
Ghisi	-	Review; physician factors and referral to CR	(Ghisi et al., 2013)
Grace	CA	Automated referral to CR to increase equitable access	(Grace et al., 2012)
Gravely-Witte		Review of referral strategies	(Gravely-Witte et al., 2010)
Jackson	US	Review of CR uptake	(Jackson et al., 2005)
Lindsay	UK	Mixed methods; staff aware of limited places	(Lindsay, 2008; The National Audit of Cardiac Rehabilitation, 2011)
Williams	AUS	Quantitative; system factors and CR attendance	(Williams, Byles and Inder, 2010)

Table 7: Other papers

First Author	Country	Research	Reference
Cooper	-	Review	(A. Cooper et al., 2002)
Cortes	-	Review, Determinants of referral	(Cortés and Arthur, 2006)
Eshan	-	Integrative review	(Eshah and Bond, 2009)
Neubeck	-	Review of qualitative Studies overall	(Neubeck et al., 2012)

## Appendix B

### 1) Systematic review protocol<sup>53</sup>

#### BACKGROUND

Coronary heart disease (CHD), a major cause of premature death and disability, killed 7.2 million people world –wide in 2004 (World Health Organization, 2010a). Through pharmacological and interventional cardiology treatments a reduction in cardiac death rates has been seen, yet the decline is accompanied by a rise in CHD morbidity (Great Britain. The Department of Health, 2009).

Cardiac rehabilitation is a comprehensive multi-disciplinary intervention that can successfully assist the patient in regaining social, physical and psychological functioning following an acute cardiac event. It encompasses an exercise component and education and assists with lifestyle modification and medication adherence (The National Audit of Cardiac Rehabilitation, 2009). A review by Taylor and colleagues confirmed the benefits of exercise-based rehabilitation in terms of all cause and cardiac mortality as well as in terms of risk factor reduction (R.S. Taylor et al., 2004). Furthermore, cardiac rehabilitation is very (cost) effective; however about 40% of patients do not (have) access (The National Audit of Cardiac Rehabilitation, 2009).

The majority of European countries have cardiac rehabilitation programmes, yet only half of these countries have legislations to support cardiac rehabilitation (Short, 2008). Great differences between type of intervention, eligibility criteria and financial support exist (Bjarnason-Wehrens, 2008). As a result of scarce human and fiscal resources in middle and lower income countries, community-based CR presents the only option, and about 90 countries are making an attempt at that (World Health Organization, 2010b).

Over the past 10 years, two reviews have evaluated literature on uptake and cardiac rehabilitation (A D. Beswick et al., 2004; Davies et al., 2010). Three RCTs were identified and all proved successful in increasing uptake. The interventions were a

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<sup>53</sup> This is the original version from June 2010. Addition or changes are indicated by the use of square brackets.

motivational letter, a visit and peer phone calls and nurse coordinators (Davies et al., 2008). However, only one study was found that targeted hard-to-reach groups, namely blue-collar workers in Germany (Hillebrand et al., 1995).

It has been suggested that certain patient groups are underrepresented in cardiac rehabilitation. These are women, elderly patients, ethnic minority groups, patients with co-morbid conditions, angina or heart failure patients (A D. Beswick et al., 2004). In 2004, the review by Beswick et al. could not find any conclusive evidence with regards to African or Asian patients and CR (A D. Beswick et al., 2004). Since then, a number of studies have been conducted that showed South Asians are still very unlikely to access CR (Grewal et al., 2010). Furthermore, women as well as patients over 65 years of age were significantly less often invited to CR and take-up the invitation less often (Harrison and Wardle, 2005). A recent review confirmed that women tend to be older and may have different needs in terms of CR (Day, 2008). A review by Cooper et al. confirmed that non-attenders were older and have higher deprivation scores (A. Cooper et al., 2002). Despite being aware of underrepresented groups, health inequalities in access and uptake of cardiac rehabilitation persist.

This assessment shall update the past reviews by Beswick et al. (2004) and Davies et al. (2010) with a secondary objective of looking at patient groups less likely to attend cardiac rehabilitation. Results inform researchers, practitioners and policy makers of state-of-the-art research evidence on health interventions that promote uptake of CR.

## OBJECTIVES

The primary objective is the assessment of evidence on interventions to increase the uptake of cardiac rehabilitation. The secondary objective is to look at patient groups less likely to attend CR. We will specifically be looking at: 1) Type of Intervention, 2) Target level, which could mean health care professional, patient or system level changes, and 3) Characteristics of the target population in terms of under-represented groups.

The term *cardiac rehabilitation* encompasses formal rehabilitation courses in health care settings or any other type of self-management with the purpose of comprehensive rehabilitation after an acute cardiac event such as the Heart Manual.

## METHODS

The *Centre for Reviews and Dissemination* guidelines for systematic reviews and the Cochrane Handbook were consulted (Centre for Reviews and Dissemination, 2009; Higgins, Green and Cochrane, 2008). The PRISMA statement and two other Cochrane protocols were used as guidance for the development of this protocol (Grant, and Sutton, 2009; Flight, et al. 2008) (Liberati et al., 2009; Moher et al., 2009).

### Criteria for inclusion and exclusion

#### *Type of Studies*

All prospective studies evaluating an intervention to increase uptake of cardiac rehabilitation are eligible for inclusion. We will include randomized controlled trials (RCT) including parallel, cross-over, cluster and factorial design, controlled clinical trials (CCT), controlled before-and-after studies, and interrupted time series. There are no language restrictions. Review articles will be obtained and reference lists will be scanned.

#### *Type of Participants*

All adults who are eligible for cardiac rehabilitation are to be included. According to the NSF-CHD guidelines, patients with a primary diagnosis of acute myocardial infarction and patients who have recently undergone cardiac revascularization will be included (Great Britain. Department of Health, 2000). This includes both, patients who experienced a first or a recurrent event. Patients who underwent heart replacement surgery or those who were diagnosed with heart failure will be excluded. While heart failure patients should attend cardiac rehabilitation, in clinical practice, there are separate heart failure programmes and specialist nurses. A more integrative approach may be desirable, but this is a recent development and highly unlikely to be found in the literature (Jill Pattenden, 2010, personal communication). Information on cardiac rehabilitation and heart failure can be found elsewhere, for example, Davies and colleagues (Davies Ed et al., 2010).

Patients who already registered for CR will be excluded. Furthermore, as interventions to increase uptake of cardiac rehabilitation might be designed to modify processes and procedures, and involve health care professionals, patient



experts, or lay persons (such as family members or community leaders), these will also be included.

In addition, certain patient groups are underrepresented in cardiac rehabilitation programmes. The patterns are not clear. I decided to focus on underrepresented groups including, but not limited to, women, the elderly, or other 'deprived' groups, as discussed below.

#### *Type of Interventions*

Interventions addressing system, patient or professional modifications will be included in the review. The intervention may intend to modify inpatient, outpatient, home-based, community-based, professionally guided or self-management CR uptake. Interventions can be comprised of single or multiple components, but the mechanisms must be clearly specified. Furthermore, interventions that target uptake of single cardiovascular risk factors management programmes, for example smoking cessation, dietary regulation, and medication will be excluded. These are not multidisciplinary.

Comparative studies, such as the comparison of a formal cardiac rehabilitation programme versus a home-based programme will be excluded unless uptake of rehabilitation is a secondary outcome. Compulsory rehabilitation programmes and interventions that were designed to target adherence to cardiac rehabilitation only will be excluded.

#### *Type of Outcome*

The main outcome is uptake/attendance at cardiac rehabilitation as recorded in the papers. Other outcomes include changes in organisational structure and/or process resulting in greater uptake. Studies that addressed other outcomes, yet included attendance of cardiac rehabilitation as one measure will also be included. Studies are only included if actual numbers or statistics are reported.

Studies that only addressed adherence to cardiac rehabilitation will be excluded.

Secondary outcome: changes in health behaviour and health beliefs (about CR and self-management) as well as changes in mortality and cardiac mortality rates, (re)hospitalization, acute cardiac event or intervention will be recorded. *[Note, this was not done as we felt it would distract from the focus of this thesis].*

## Search Methods

Randomised controlled trials that were identified by Beswick et al. and Davies et al. will be included in the review. A number of databases will be searched (including EMBASE and MEDLINE, which are the two most important sources for health care interventions (Centre for Reviews and Dissemination, 2009) PSYCHINFO, CINAHL, Cochrane, Web of Science). Citations will be managed in Endnote X4.

## Search terms

Advice was sought from experts of Cardiac Rehabilitation, a health sciences librarian and an expert from the Center of Research and Dissemination at the University of York. Two existing reviews and an HTA were consulted (A D. Beswick et al., 2004; Davies et al., 2008; Furber et al., 2010; Jepson et al., 2000). Papers by Welch et al. and Hawthorne et al. provided guidance in terms of hard-to-reach groups (Hawthorne et al., 2008; Welch et al., 2009).

## Data collection and analysis

The review will be undertaken by two reviewers, CD and JP. CD will retrieve all titles and abstracts and perform the first screen, where studies that are clearly irrelevant will be discarded. An overly inclusive approach will be applied. The two reviewers will go through the remaining abstracts independently and discuss any differences. This is said to be sufficient to capture all eligible studies (Centre for Reviews and Dissemination, 2009). Consultation of a third expert will be sought where necessary.

The study eligibility form and the standardised data extraction forms (designed based on a previous review and recommendation from the *Center of Research and Dissemination* were taken into account (A D. Beswick et al., 2004; Centre for Reviews and Dissemination, 2009)) will be used and piloted on a sample (additional forms below). CD will perform the data extraction and JP will check the complete data extraction forms. A flow diagram will detail the number of studies identified, included and excluded at each stage (see main Chapter) (Centre for Reviews and Dissemination, 2009; Grant and Sutton, 2006).

## Assessment of risk of bias

Bias refers to systematic differences due to methodological flaws in study design, the data collection, analyses, interpretation, publication and review (Centre for Reviews and Dissemination, 2009). Assessing the risk of bias and potential differences in bias between studies can be helpful when trying to understand and explain diverse results (Centre for Reviews and Dissemination, 2009). During the process of the assessment, Cochrane recommends to take the magnitude and the direction of bias into account as this can provide valuable information on effect size (Higgins, Green and Cochrane, 2008). Hence, studies with a high risk of bias were not excluded; instead bias was taken into account when judging the outcome.

Risk of bias criteria were adapted from the Cochrane Heart Group (Group, 2010), the Cochrane risk of bias tool (Centre for Reviews and Dissemination, 2006; Grant and Sutton, 2006) (See box 2). One researcher will make the assessment of risk of bias, which will then be checked by a second reviewer. It is important to understand the different biases as in some situations bias avoidance measures are not practical, for example not blinding the clinician or patient in a pragmatic trial (Roland and Torgerson, 1998). Nevertheless, impact must be assessed. Detailed information on the assessment of each included trial will be provided in the results section.

*Selection Bias* refers to systematic differences in selection and allocation of participants to the different (treatment/intervention) groups. *Sequence generation*, which describes the methods of allocating study participants to a group by (random) chance (Higgins, Green and Cochrane, 2008), and *Allocation concealment*, which means ensuring that prior to assigning the intervention the assignment remains unknown (Centre for Reviews and Dissemination, 2009), fall into this category. In trials where allocation is not adequately concealed a distorted outcome effect could potentially be observed (Kunz and Oxman, 1998; Torgerson and Torgerson, 2008). *Blinding* of participants and personnel means that they are unaware of the group allocation (Higgins, Green and Cochrane, 2008). This way an influenced treatment and/or (outcome) assessment can be prevented, the latter is labelled *Detection bias*. *Performance Bias* refers to systematic differences in exposure to interventions or treatments between the groups. *Attrition bias* depicts the systematic differences between the groups in terms of withdrawal, drop-out, loss of follow-up and exclusion of participants (Centre for Reviews and Dissemination, 2009). If an attrition rate is not random, this could potentially lead to or indicate selection bias, meaning systematic differences between those that remain in the trial and those who do not (The National Institute of Clinical Excellence, 2010; Torgerson and Torgerson, 2008). *Other sources of bias* can also be present. A variety of causes depending on study design or circumstances need to be assessed according to context. For example, *reporting bias* refers to reports being made more thoroughly for an intervention or group compared to another, or the higher likelihood of reporting significant results over non-significant ones within one study (Higgins, Green and Cochrane, 2008).

## Box 2 Biases

Details on studies excluded will be collected in a separate table listing first author and reason for exclusion.

### Assessment of heterogeneity and Data synthesis

An assessment of homogeneity of outcome data in included studies will be undertaken by CD, and checked by second reviewer. Provided data are homogenous, a meta-analysis will be conducted. Otherwise a narrative summary of findings will

be presented.

Additional Forms

**Study eligibility form**

Study ID:	Date:	Reviewer ID:
First Author:		

1. Is an intervention to increase uptake of rehabilitation evaluated?

Yes \_ (go to 2.)      No\_ (go to 3)      Unsure\_\_

2. The evaluated intervention targeted:

2.1 Patients directly      Yes\_\_ No\_\_ Unsure\_\_

2.2 Health Care Professionals compliance      Yes\_\_ No\_\_ Unsure\_\_

2.3 System-level/procedural modifications      Yes\_\_ No\_\_ Unsure\_\_

3. Was the Method described as randomized?

Yes\_\_      No\_\_      Unsure\_\_      Comments:

4. Did the study report figures on uptake of attending cardiac rehabilitation?

Yes\_\_      No\_\_      Unsure\_\_

Final Decision: If 1, 2, 3 and 4 are yes, include study.

Include \_\_      Exclude \_\_      Unsure (please comment below)

***Data Extraction form***

Study ID:	Reviewer:
Citation	
Type of publication:	

Source:                      published    unpublished

Type of Study: (circle)

RCT

Quasi RCT

Not randomised

Before-after comparison between groups

Before-after comparison within groups

Other, please comment:

Participants (circle)

Patients                      Health care professionals

Lay persons                      Primary role (if not patient)

Intervention:

Definition/Type of CR:

Setting:

Recruitment procedure:

Duration/ time of implementation:

Duration of follow-up:

Outcome:

Primary outcome:

Type of analysis used:

Participants	Before/ control	After/ intervention	Type and unit of measure
Age (mean, SD)			
Sex (male/female %)			
# of participants			
Hard-to-reach characteristic Was this identified as such by the authors? Yes/ No			
Primary diagnosis (AMI, PCTA/CABG, heart failure, angina)			
Other comments:			

Outcome (N, %)	Before/ control	After/ intervention	Type and unit of measure
Attendance of CR Was a self-report measure used? Yes/No			Give criteria used:



Loss of follow-up			
Withdrawal			
Mortality			
Cardiac mortality			
Hospitalisation			
Acute cardiac event or intervention			
Risk factors			
Other (specify):			

Other (e.g. reference to other studies, key finding, economic outcome)

## 2) Excluded studies

Table 9 Excluded studies

First author and year published	Reason for exclusion	Notes
Beckie 2010	No intervention to increase uptake	Usual care was compared to gender-specific cardiac rehabilitation
Beckie 2006	No intervention to increase uptake,	Description of methods used by Beckie 2010
Beckie, 2009	No randomisation of patients to recruitment methods, and no statistical comparison between the groups	Description of recruitment methods in detail
Blom, 2009	No outcome measure for attendance	Stress management intervention versus usual care in women
Clark 2008*(Women take Pride)	No outcome measure for attendance, not only CHD patients	Patient choice arm (group or self-directed) versus no choice arm (group versus control versus self-directed)
Coull, 2004	Patients already participated in CR	Recruited from outpatient programmes, patients with Ischemic heart disease,
Gallagher, 2003	No intervention to increase uptake of CR	Phone call versus usual care to promote psychosocial adjustment in women post cardiac event in Australia
Kummel, 2008	No intervention to increase uptake	Comparison of intervention (counselling & lecture but no exercise) versus usual care, nothing on uptake
Leibowitz 2005	No intervention to increase uptake	Modelling of predictors of (non) attendance only
Lewin, 2002	No intervention to increase uptake	Relaxation tape versus music tape to address psychiatric morbidity and misconceptions

Redfern 2008	No outcome measure of attendance	Intervention was designed for CR non-attenders; secondary prevention programme compared with usual CR attenders
Sangster 2010	No intervention to increase uptake	Physical activity group compared to healthy weight intervention group, recruitment of patients 6 weeks post referral to CR
Sinclair, 2005	No intervention to increase uptake	Home-based CR programme (with some care guidance) compared to usual procedure (= advice & invite to CR)
Sniehotta, 2006	No intervention to increase uptake	Action and coping planning were compared to usual care, during CR
Southard 2003	No intervention to increase uptake	Trial on effect of internet-based risk factors management tool versus usual care; variety of patients, secondary prevention
Furber	No intervention to increase uptake	Targeted people who were referred to but did not attend CR; pedometer & phone support versus control group (who only received info material);
Walters, 2010	No intervention to increase uptake	Mobile phone supported multimedia care model (intervention) versus UC
Pasquali 2001 (from Grace05)	No randomization	Education and referral intervention to increase uptake of CR

## Appendix C

- 1) Audit confirmation by Dr. Stephen Holland, Health Sciences Research Governance Committee, University of York. Correspondence via e-mail from 22.05.2011

Dear Cori,

Just to confirm: the email address you request is a generic programme address, not a personal one, right? If so, yes, I can confirm that this is an audit so doesn't require further scrutiny.

Steve

cd675@york.ac.uk wrote:

> Dear Dr Holland,  
>  
> I, Cori Dressler, am 2nd year phd student in the Department of Health  
> Sciences.  
>  
> I would like to confirm with you that a survey I am about to send out  
> is indeed 'audit- only' and ethics approval is not required. I had  
> spoken to senior faculty in the department who agreed and advised to  
> run this by you.  
>  
> The survey is attached: there are only ten items, including Cardia  
> rehab program name and program contact email, followed by 8 items  
> about how patients are currently identified, recruited and if any  
> patient groups are missing.  
>  
> No patient data or personal data of the staff is collected.  
> I appreciate your time in advance. Many thanks,  
> Ms Corinna Dressler, M.Sc.  
> doctoral student 2nd Floor Postgraduate Area ARRC Building  
> University of York  
> Heslington, York  
> YO10 5DD United Kingdom  
> Tel: +44 1904 321876  
> E-mail: cd675@york.ac.uk

## 2) The NACR Audit Data Protection Protocol Response

THE UNIVERSITY *of York*

BRITISH HEART FOUNDATION  
CARE AND EDUCATION  
RESEARCH GROUP

Supported by



Department of Health Sciences  
Area 4, 2nd Floor, Seebohm Rowntree Building  
University of York  
Heslington, York YO10 5DD

Tel (01904) 321393  
Fax (01904) 321388  
Email bob.lewin@york.ac.uk

Director: Professor Bob Lewin

14 June 2011

To Whom It May Concern:

**Re: Audit Data Protection Protocol**

As the person responsible for the publicly available online cardiac register maintained at the University of York ([www.cardiac-rehabilitation.net](http://www.cardiac-rehabilitation.net)), I am happy for Corinna Dressler to access the database for the purposes of research as long as she works within the spirit of UK Research Governance Framework (1994), in which confidentiality and the anonymity of respondents is respected.

Yours sincerely,

A handwritten signature in black ink that reads "Bob Lewin".

Professor Bob Lewin



**Table 11:** Independent t-test for uptake in group 0 (no resources) versus group 1 (resources) – STATA 10 output

Group	Obs	Mean	Std. Err.	Std. Dev.	[95% Conf. Interval]	
0	36	64.625	3.47476	20.84856	57.57086	71.67914
1	129	66.80543	1.606109	18.24189	63.62747	69.98339
combined	165	66.3297	1.463287	18.79626	63.44039	69.21901
diff			-2.180426	3.549715	-9.189781	4.828928

diff = mean(0) - mean(1) t = -0.6143  
 Ho: diff = 0 degrees of freedom = 163  
  
 Ha: diff < 0 Ha: diff != 0 Ha: diff > 0  
 Pr(T < t) = 0.2700 Pr(|T| > |t|) = 0.5399 Pr(T > t) = 0.7300

**Table 12:** Levene’s test of Equality of Variance for uptake in group 0 (no recruitment strategies found) versus group 1 (recruitment strategies found that work) – STATA 10 output

Variance ratio test

Group	Obs	Mean	Std. Err.	Std. Dev.	[95% Conf. Interval]	
0	63	64.49048	2.517311	19.98054	59.45844	69.52251
1	102	67.46569	1.785548	18.03315	63.92364	71.00773
combined	165	66.3297	1.463287	18.79626	63.44039	69.21901

ratio = sd(0) / sd(1) f = 1.2276  
 Ho: ratio = 1 degrees of freedom = 62, 101  
  
 Ha: ratio < 1 Ha: ratio != 1 Ha: ratio > 1  
 Pr(F < f) = 0.8214 2\*Pr(F > f) = 0.3571 Pr(F > f) = 0.1786

**Table 13:** Independent t-test for uptake in group 0 (no recruitment strategies found) versus group 1 (recruitment strategies found that work)- STATA 10 output

Two-sample t test with equal variances

```

-----+-----
Group |      Obs   Mean  Std. Err.      Std. Dev.  [95% Conf. Interval]
-----+-----
0 |          63   64.49048  2.517311    19.98054   59.45844  69.52251
1 |         102   67.46569  1.785548    18.03315   63.92364  71.00773
-----+-----
combined |      165   66.3297  1.463287    18.79626   63.44039  69.21901
-----+-----
diff |                -2.97521  3.012142          -8.92306  2.972639
diff = mean(0) - mean(1)                t = -0.9877
Ho: diff = 0                degrees of freedom = 163

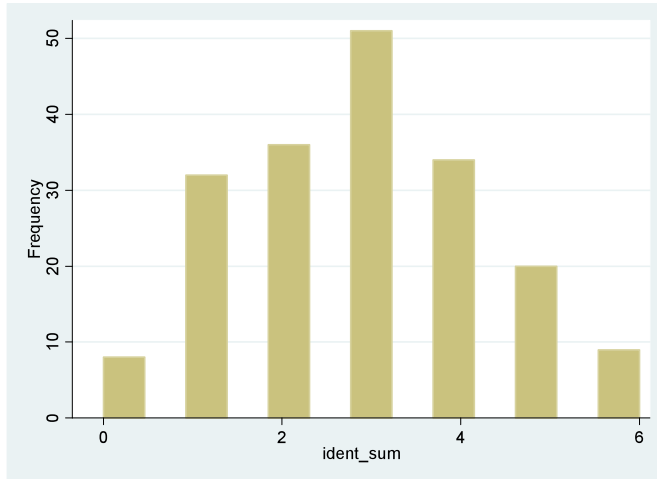
      Ha: diff < 0      Ha: diff != 0      Ha: diff > 0
Pr(T < t) = 0.1624    Pr(|T| > |t|) = 0.3247    Pr(T > t) = 0.8376

```

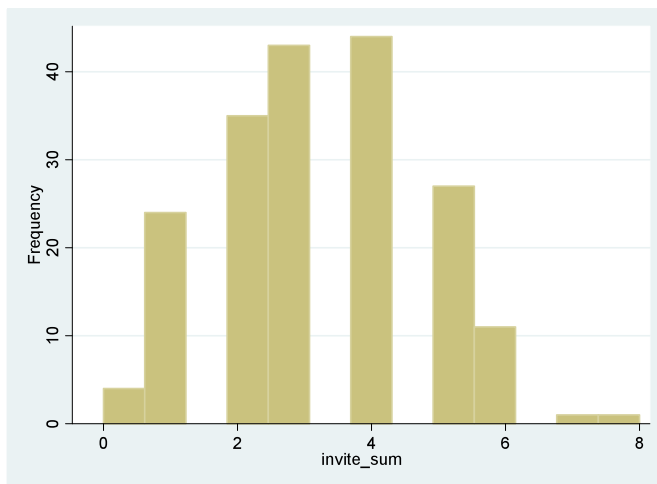


#### 4) Associations between variables

As seen in figure 1, it is reasonable to assume that uptake is normally distributed as are the two other variables (*invite\_sum* and *ident\_sum*), see figure 2 and 3.

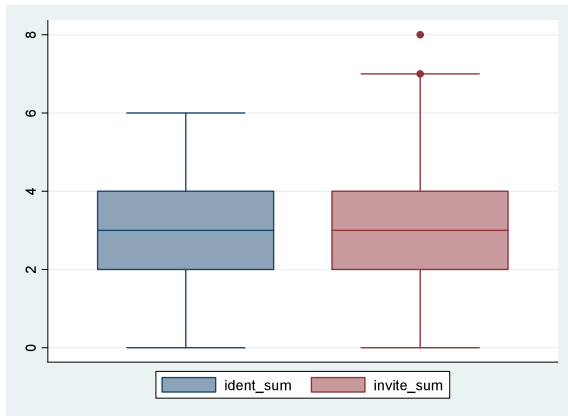


**Figure 2:** Frequency distribution of total number of identification methods



**Figure 3:** Frequency distribution of total number of invitation methods

When exploring the data, it was shown that the variable describing the number of invitation methods used had one outlier (figure 4). This appears to be an influential point, and since there was just one, it was decided to remove it for the analysis.



**Figure 4:** Boxplots of the total number of identification and invitation methods

The two figures below show the STATA 10 output for testing association between uptake and number of methods used.

```

      |   ph3p invite~m
-----+-----
ph3p |  1.0000
      |
      |
invite_sum | -0.0893  1.0000
      |  0.2552

```

**Figure 5:** Pearson's r including p-value for uptake and total number of invitation methods

```

      |   ph3p ident_~m
-----+-----
ph3p |  1.0000
      |
      |
ident_sum |  0.0949  1.0000
      |  0.2251

```

**Figure 6:** Person's r including p-value for uptake and total number of identification methods

## Appendix D

### 1) Information pack

THE UNIVERSITY *of York*

*'Increasing the uptake of cardiac rehabilitation: a multi-method evaluation'*

Investigator: Corinna Dressler

Date: 26.10.2011

#### **Improving the uptake of cardiac rehabilitation**

We would like to invite you to take part in an evaluation study exploring patients' views of invitation letters to cardiac rehabilitation.

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

You have been invited to take part in this study because you have experienced a heart condition.

#### ***What is the study about?***

We know that many people who could go to cardiac rehabilitation choose not to. We would like to ask your advice. We would like to ask your opinion about letters that are used to invite people to come to cardiac rehabilitation.

#### ***Do I have to participate?***

No, you do not have to participate. If you chose not to take part in the study this will NOT affect your usual health and social care or legal rights.

If you decide to take part you will be given a copy of this information sheet to keep and asked to sign a consent form. If you do decide to take part, you are free to withdraw from the study at any time and this includes during the discussion. You do not need to give a reason. Withdrawing from the study will not affect present or future care.

#### ***Why are we doing this study?***

One way researchers have tried to increase the number of people who agree to go to rehabilitation is by using a special letter of invitation. We would like your advice on two of these letters and to hear any ideas you may have as to a better version.

#### ***What happens if I take part?***

If you decide to take part, we will give you a telephone call at a time that works for you. The discussion will be audio-recorded, with your permission, and will take around 15-30 minutes. We will choose people to reflect a range of experiences. You will not be compensated for your participation.

We will ask you whether you were offered cardiac rehabilitation and if so, why. We will also ask you about two invitation letters that you will be given in advance, which one you find more motivating, which paragraphs you find encouraging and also, how paragraphs could be rephrased.

***What happens to the information?***

All the information collected is confidential. No one will be able to identify you from the study. Nor will we share what you tell us with anyone else related to your care, including health professionals involved in your care or family members, including your partner or children. However, if you tell us something, which we believe places you or others at serious risk, we are obliged to tell the relevant authorities.

The audio-files from interviews will be transcribed (listened to and written down in full). The notes taken by researchers, the audio-files and the transcripts will be kept safely in locked offices at the University of York. Only the main researcher can access them. Notes, audio-files and transcripts will be given a code rather than a name, so as to safeguard confidentiality. At the end of the project the audio tapes will be erased and the interview transcripts will be stored for 1.5 years. All data will be treated in accordance with the current Data Protection Act.

***What are the possible advantages of taking part?***

There may be no personal benefit. By taking part you may help to improve the communication between patients and health care professionals.

***What if something goes wrong?***

In the event that something does go wrong and you are harmed during the project there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against University of York (who have indemnity for negligent harm) but you may have to pay your legal costs.

***What if I wish to complain?***

Please raise any difficulties or questions with Corinna Dressler (01904) 321915 (8am to 5pm weekdays) or email [cd675@york.ac.uk](mailto:cd675@york.ac.uk). If you do not receive a satisfactory answer, please contact Professor Karl Atkin (Senior Professor Department of Health Sciences, University of York) via telephone 01904 32(1355) or email [karl.atkin@york.ac.uk](mailto:karl.atkin@york.ac.uk)

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

We will be sharing the results with as many of the UK's rehabilitation programmes as possible so that they can improve uptake. We will do this by giving talks at conferences and publishing papers in medical journals. The results will be made available following the completion of the study in 2013. Publications from the study will also be made available to the patient support group. You can also call the main researcher at any time to discuss the progress of the project.

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

The study is organised by researchers at University of York. The study is part of a doctoral thesis funded by the National Institute of Health Research (NIHR), Collaboration of Leadership in Applied Health Research and Care.

***Who reviewed the study?***

The protocol and procedures have been reviewed by the Human Research Ethics and Governance Committee at the University of York.

If you would like any further information, please contact

Ms Corinna Dressler

2nd Floor Postgraduate Area , ARRC Building

University of York

Heslington, York

YO10 5DD United Kingdom

Tel: 01904 321915

E-mail: [cd675@york.ac.uk](mailto:cd675@york.ac.uk)

**CONSENT FORM: please return by post**

**Title of Project:** Improving the uptake of cardiac rehabilitation

**Name of Chief Investigator:** Ms Corinna Dressler

**Name of Interviewer:** Ms Corinna Dressler

**Please initial box**

1. I confirm that I have read and understood the information sheet dated 26.10.2011 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
  
3. I understand that if I choose to discontinue the phone interview all data collected up to that point will be used.
  
4. I understand that relevant sections of any data collected during the study may be looked at by the investigator's supervisors from the University of York. I give permission for these individuals to have access to my records.
  
5. I agree for my interview to be audio-recorded
  
6. I agree to anonymised direct quotes from this interview being used when reporting the study findings.
  
7. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant      Date      Signature      Telephone number

\_\_\_\_\_  
Name of Person      Date      Signature  
Taking consent (main researcher: Corinna Dressler)

## 2) Ethics

THE UNIVERSITY *of York*

DEPARTMENT OF  
HEALTH SCIENCES

c/o Department of Philosophy  
Heslington  
York YO10 5DD

Telephone (01904) 433253  
Fax (01904) 321383  
E-mail [smh12@york.ac.uk](mailto:smh12@york.ac.uk)

Dr Stephen Holland  
[www.york.ac.uk/healthsciences](http://www.york.ac.uk/healthsciences)

14 Oct 2011

Ms Corinna Dressner  
2<sup>nd</sup> Floor Postgraduate Area  
ARRC Building  
University of York  
York  
YO10 5DD

Dear Corrina

**Study title: Improving the Uptake of Cardiac Rehabilitation**

Thank you for submitting the above research study to the Health Sciences Research Governance Committee for approval, and for attending the meeting on Monday, 10 Oct 2011, to discuss our queries. The committee are happy for the project to proceed but have asked for the following requirements to be met.

1. In Section 9 of the submission, it is stated that data collected from participants who withdraw from the study will be used. This must be made clear to potential recruits on the Information Sheet and Consent Form.
2. Point 3 of the Consent Form should be reworded to clarify who will be allowed to look at data.
3. The committee were concerned as to how the researcher will get the contact details of participants. We advise that telephone numbers can be collected on consent forms.
4. There is no time-frame for consenting to participate. We advise that a time-frame should be added to the consenting process.
5. Consent forms are signed by both the participant and researcher. The participant should receive a copy of the consent form signed by the researcher.
6. The committee suggest that further thought should be given to collecting socio-demographic information in writing as distinct from during the telephone interview. We appreciate that there are pros and cons here, and leave it to the researcher to consider this further in consultation with the supervisor(s).

The committee is happy for you to make these changes to your study in consultation with your supervisor(s) and do not require seeing the submission again. If you make substantial changes to your research study, you may need to resubmit your proposal to the committee. If you have any questions regarding the committee's decision then please contact me.

Yours sincerely

A rectangular box containing a handwritten signature in black ink that reads "S. Holland".

**Stephen Holland (Dr)**  
Chair: HSRGC



### 3) Interview topic guide

1. verbal confirmation of consent and audio taping. Restate confidentiality and thank for participating.

2. Socio- demographic information

Information	Reason for this information to be collected
Sex	Women are less likely to attend CR (The National Audit of Cardiac Rehabilitation, 2010)
Age	Especially in women, risk profile changes with age due to hormonal changes(Lloyd, 2009). In addition, smoking rates for younger women are rising.
Marital status	Has been found to predict CR differently for men and women (A. Cooper et al., 2002)
Education /occupation	Useful as proxy for socio-economic status. Risk profile can differ between those groups.

3. Background

Cardiac rehabilitation –

Were you offered cardiac rehabilitation?

Why were you asked to attend?

Did you attend CR?

4. Invitation letters – I would like to ask you about the invitation letters

Do you have them with you ? / If not, please get them

Did you read them? / If not, please take a few minutes and read them.

If you prefer, I can phone you back?

5. I would like to know what you think about the letters, what other may think.

What do you think about the letters?

Would they encourage you to attend CR?

You just had your [cardiac event] and this letter came to your house.

Yes – why?

No – why not?

Thank you. That is very helpful.

6. Details of the letter – can we look at letter A

Do any of the sentences/ statements catch your eye?

Yes – which ones? (Labelled with numbers)

And why (positive as well as negative comments)

If no, let's have a look at the statements separately. They are labelled with numbers on the right. Can you see that?

Read separately and ask for each statement

- which ones encourage you/ which ones puts you of

- How would you rephrase

(see detailed probes for each statement below)

7. Thank you. We are more than halfway through. Now can we please look at letter B (same as for letter A)

8. Now that we have looked at each letter separately,  
Which one is better?  
Why?

9. Thinking about other people, everyone is different  
What could we put in the letter to encourage other people to attend?

10. Forget about letters, is there a better way to get those people who say they are not interested to attend CR?

11. Thank you very much for your time. It is very helpful to hear your opinion.

#### 4) Provision codes and categories

initial code list	renaming codes/ 2nd round of coding	families (2nd round)	3rd round	families 3rd round	final codes
anxiety/ confidence	anxiety		feelings invitation strategies expected outcome		feelings invitation strategies expected outcome
better way?	invitation strategies				
future effects	expected outcome	attitude	chances of dying	attitude	chances of dying
chances of dying	chances of dying				
chest pain			necessity		necessity
opt out					
follow-up					
inclusivity information needs			inclusivity		inclusivity
big words	over- complicated words	accessibility	over- complicated words		over- complicated words
simplicity	simplicity/co mplicated		degree of complexity		accessibility
letter lengths over- whelming	partner peers	words & simplicity	partner peers		partner peers
partner peers	partner peers				
polite	polite	appointment	polite	wording	polite
commitment	commitment	polite & commitment	commitment		
positive	professional recommen- dation		professional recommen- dation	professional recommen- dation	
professional recommen- dation	necessity				
recovery	shock				
shock			safe environment letter composition		letter composition

## Appendix E

### 1) Confirmation of the research piece being an evaluation not needing an ethical opinion

**Subject:** RE: REC advice on evaluation project, please  
**From:** Peter Heasman <peter.heasman@newcastle.ac.uk>  
**Date:** Thu, 17 Nov 2011 15:35:33 +0000  
**To:** Corinna Dressler <cd675@york.ac.uk>

Dear Corinna,

Thank you for your email. I do get quite a few requests to try to distinguish between research and service evaluation/audit and sometimes it is extremely difficult to come to a decision. In this case, however, there is no such difficulty. Whichever way you look at it, this does not require an ethical opinion.

Hope that helps,

Peter Heasman  
Chair  
Northern and Yorkshire REC  
National Research Ethics Advisor

### 1) Study information materials

#### LETTER OF AGREEMENT

Thank you for agreeing to participate in the evaluation of the invitation letter.

I am Corinna Dressler, currently a doctoral student working in the Department of Health Sciences, University of York along with Professors Bob Lewin and Karl Atkin. My study is looking for practical ways of improving uptake in cardiac rehabilitation programmes.

Research evidence shows that subtle, theoretically informed changes to the letter can improve uptake rates. I am currently developing an invitation letter but prior to publicizing this, a formal evaluation, assessing its impact, is necessary.

To facilitate this evaluation I will contact you about at the end of each months and ask you:

- a) how many invitation letters have been send out by your Department and
- b) how many new patients have attended the rehabilitation programme (phase 3).

After about 8 weeks we will ask you to adjust the content of the letter. I will continue to contact you for about 6 months to collect data on how many letter were send out and how many new patients have attended the rehabilitation programme, offered by your Trust.

All data will be anonymised and treated confidentially. In return, I will share my findings with all rehabilitation programmes in the UK. I will also provide you with your uptake rates regularly.

We really appreciate your help and cooperation. Please sign and return this letter of agreement to Corinna Dressler, 2nd Floor Postgrad Area, ARRC Building, University of York, York, YO10 5DD or via email [cd675@york.ac.uk](mailto:cd675@york.ac.uk). Thank you.  
Corinna Dressler

Hereby, I/we agree to participate in the evaluation of an invitation letter to cardiac rehabilitation conducted by Corinna Dressler, University of York.

PRINT NAME	SIGNATURE	DATE	HOSPITAL/TRUST/PROGRAMME
NAME			

## 2) Data collected for 4 sites that withdrew

Table 14 CRPs were data collection ceased: Number of letter sent (L) and number of patients (P) attending per months

	Site 7		Site 8		Site 9		Site 10	
	L	P	L	P	L	P	L	P
January '12	37	26	53	49	10	3		
February '12	22	20	31	27	8	0	61	38
March '12	24	18	39	34	9	9	78	45
April '12	21	20	25	23	10	10	44	36
May '12	27	27	35	29	7	0	80	39
June '12	17	20			7		62	34
July '12					5	0	60	52
August '12					5	0	50	43
September '12					3	0		
October '12								
November '12								
Reasons for discontinuing the study	They never implemented the new letter due to the lack of administrative support; eventually they dropped out		Cardiologist retired and new nurse in charge disliked the letters and did not want to use them		Letters are sent to non-responders only; due to small numbers and the conceptual differences this site was not included in the analysis		Staff did not have the capacity to continue data collection.	

### 3) Amended invitation letters

The letterheads and all identifiable information have been removed, and the font size has been reduced to 10. Original wording that had to remain in the invitation letter is highlighted in grey (which also shows the difference between the letters), and information that had to be removed (because it was not provided, e.g. relaxation session), has been strike-through. Writing in bold remained identical to the letters used in practice.

Dear

**As part of your treatment**, the medical and nursing professions **strongly suggest** that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the programme you will participate in gentle exercises and relaxation sessions in a safe supervised setting. The session will also include discussion on how the heart works, healthy eating, physical activity and stress management.

This is a letter of invitation to attend an individualised assessment with the cardiac rehabilitation nurse. Your assessment will consist of a brief discussion, recording of blood pressure etc. and a short walk test.

Please allow approximately 45 minutes for the assessment.

By attending cardiac rehabilitation you will have to opportunity to talk to other people with heart problems.

Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and resume their social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

Your spouse/partner is welcome to attend the first session with you.

Your appointment is on \_\_\_\_\_

Please come to \_\_\_\_\_

Please wear comfortable clothing and flat, rubber soled shoes. Please bring a list of your medication with you and reading glasses if needed.

Please would you be kind enough to fill in the enclosed questionnaire and bring with you to the above appointment. If you have any question please telephone

Site 1: the original letter was completely different. Information about this appointment being an assessment was added from the original version (as highlighted above).

Dear \_\_\_\_\_

**As part of your treatment**, the medical and nursing professions **strongly suggest** that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including ~~the doctor~~, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the programme you will participate in gentle exercises and ~~relaxation sessions~~ in a safe supervised setting. The session will also include discussion on how the heart works, healthy eating, physical activity and stress management.

By attending cardiac rehabilitation you will have to opportunity to talk to other people with heart problems.

Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and resume their social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

Your spouse/partner is welcome to attend the first session with you.

To participate in the programme you are required to attend an assessment clinic with a Cardiac Rehab Physio or Nurse. The purpose of the meeting, which last 1 hour, is to monitor your progress, review your risk factors and discuss your current exercise ability. Following this discussion, you will be offered a start date for a medically supervised exercise programme as appropriate.

Please telephone \_\_\_ between 8am and 12pm to book an appointment.

On arrival at the hospital, please report to the Physiotherapy Department in Rehabilitation xxx.

Please wear comfortable clothing and flat, rubber soled shoes. Please bring a list of your medication with you and reading glasses if needed.

Pay and display car parking is now in operation. Please ensure you bring change with you and take note of your bay number before you go to the ticket machine. Car parking facilities for disables drivers are available around the front of the hospital.

We look forward to meeting you.

Yours sincerely

Site 2: The original version included ‘your partner is also invited to attend the appointment’ and ‘the programme can be planned for you’, which were reworded to the new version. An option to decline the invitation was removed.



Dear

**As part of your treatment**, the medical and nursing professions **strongly suggest** that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the programme you will participate in gentle exercises and relaxation sessions in a safe supervised setting. The session will also include discussion on how the heart works, healthy eating, physical activity and stress management. This appointment will involve a very simple exercise bike assessment to determine your current level of fitness. There will be a Cardiac Rehabilitation Nurse and an Exercise Physiologist present at the appointment. You will have the opportunity to discuss any concerns relating to your heart problem.

By attending cardiac rehabilitation you will have the opportunity to talk to other people with heart problems. Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and resume their social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

Your spouse/partner is welcome to attend the first session with you.

Your appointment is on \_\_\_\_\_

Please come to \_\_\_\_\_

Please complete the enclosed questionnaire and bring this with you to your appointment. Please wear comfortable clothing and flat, rubber soled shoes. Please bring a list of your medication with you and reading glasses if needed.

XXX is a teaching centre and there may be a health professional trainee present in the clinic. If you do not wish them to attend your consultation please inform the clinic staff when you arrive. If you have any questions, please telephone the Cardiac Rehabilitation team on \_\_\_\_\_.

We look forward to meeting you.

Yours sincerely

Site 3: Similarly to site 2, the original invitation to the education sessions already included two (theory) statements similar to the new letter. Original PCI, MI and HF invitations (three separate ones) did not include the theoretical statements, but all gave a scheduled appointment. The amended invitations included all theoretical statements of the new letter.

Dear .....

**As part of your treatment**, the medical and nursing professions **strongly suggest** that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the programme you will participate in gentle exercises and relaxation sessions in a safe supervised setting. The session will also include discussion on how the heart works, healthy eating, physical activity and stress management. **The purpose of this appointment is to discuss your recovery and answer any questions you may have. We will check your blood pressure, pulse and weight then arrange a suitable date for you to begin one of the Cardiac Rehabilitation Programmes. (NB You will NOT be doing exercise at this appointment).**

By attending cardiac rehabilitation you will have to opportunity to talk to other people with heart problems. Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and resume their social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend. Your spouse/partner is welcome to attend the first session with you.

You appointment is on: \_\_\_\_\_

Please come to the Physiotherapy Department, which is sign posted from just inside the main entrance of the hospital – turn left and follow the blue line. Please take a seat at the physiotherapy reception on your arrival, you do not need to check in and will be called shortly.

Please wear comfortable clothing and flat, rubber soled shoes. Please bring a list of your medication with you and reading glasses if needed.

We look forward to meeting you. Yours sincerely,

Site 4: The original letter stated that ‘partners can attend’, but no theory statements were included. An appointment time was given. The new letter includes all theoretical statements, but the invitation is for an assessment, hence ‘we will check blood pressure [...] you will not be doing exercise’ had to added from the original versions (as highlighted above).

Dear

**As part of your treatment**, the medical and nursing professions **strongly suggest** that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

We would like to introduce the service that we can provide.

- ❖ If you did not receive any information leaflets whilst in hospital, we can arrange for information to be sent.
- ❖ If you require any information or advice regarding any aspect of your recovery, you can contact us on the above number (a voicemail service is available).
- ❖ If you wish to attend an exercise programme and/or health education day, please contact us to arrange this. *A place will only be allocated once you have contacted us and the appropriate options have been discussed with you.*

We hope that you are making a good recovery and look forward to hearing from you. Yours sincerely

[page 1 of 2]

[page 2 of 2]

Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and resume their social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

During the programme you will participate in gentle exercises and relaxation sessions in a safe supervised setting. The session will also include discussion on how the heart works, healthy eating, physical activity and stress management.

At xxx we can offer you a choice of Cardiac Rehab options.

#### Hospital Based Programme

- Six day programme based at xxx
- Individual Assessments.
- Supervised exercise sessions.
- Health education advice and information including how the heart works, health eating, medicines and stress management.
- Maximum of twelve patients.

#### Community Based Exercise

- Various locations available.
- Individual assessment.
- Independent or group exercise sessions.
- Health Education Day including all aspects of healthy lifestyle.

By attending one of the above cardiac rehabilitation programme you will have to opportunity to talk to other people with heart problems. Please wear comfortable clothing and flat, rubber soled shoes. Please bring a list of your medication with you and reading glasses if needed. Your spouse/partner is welcome to attend the first session with you.

#### Home Based Programme ( Road to Recovery)

- Twelve week programme carried out in your own home.
- Individual assessment at xxx Community Hospital.
- DVD based exercise session.
- Health Education Day including all aspects of healthy lifestyle.

If you would like more information or wish to book a place, please contact the Cardiac

Site 5: The original letter did not include any of the theoretically developed statements but had a second page outlining three options: hospital CR, Community CR, home CR.

Dear

**As part of your treatment**, the medical and nursing professions **strongly suggest** that you attend the cardiac rehabilitation programme. This will help you get better quickly and improve your health.

A team of different health care professionals including the doctor, the physiotherapist and nurses work together to give you advice and information on how best to recover. The programme will be tailored to your individual needs.

During the **8 sessions you** will participate in gentle exercises and relaxation sessions in a safe supervised setting. The session will also include discussion on how the heart works, healthy eating, physical activity and stress management. **The [----] session run Tuesday 10-11.30am and Friday 9.30-11.30am and you will need to attend both sessions.**

By attending cardiac rehabilitation you will have to opportunity to talk to other people with heart problems.

Research shows that people who attend cardiac rehabilitation will become more physically fit, return to work and resume their social activities sooner. Those who do NOT attend can have higher chances of heart problems, anxiety or depression than those who do attend.

Your spouse/partner is welcome to attend the first session with you. Please wear comfortable clothing and flat, rubber soled shoes. Please bring a list of your medication with you and reading glasses if needed.

~~Should you choose to avail of this service, we will first need to carry out an assessment to ensure your safety to do exercise and level of fitness. We will contact you nearer the programme start date to let you know the date and time. more about this.~~

~~If you wish to attend avail of this service please complete and return the enclosed confirmation slip. Alternatively you can email or-call to confirm you wish to attend. Please see the attached sheet for more details about the programme including location.~~

~~If you have any queries, please do not hesitate to contact us on the details above. We look forward to meeting you.~~

Site 6: The original letter stated that ‘programme designed to meet the special needs of the patients’, and set times for the CR session were given. The amended letter included all theoretical statements and the set times for weekly CR sessions. Still, the patients are required to contact the CRP to confirm he/she wants to attend – an opt-out option was removed.

#### 4) Testing Assumptions

The data for age and mean number of co-morbidities comes from different individuals in two times periods, hence the data is considered independent. Below, the Table shows whether the data is normally distributed. If not, a Mann-Whitney U test is conducted.

Table 15 Test for Normality

SITE	Shapiro-Wilk Normality test AGE	Shapiro-Wilk Normality test CO-MORBIDITIES	Shapiro-Wilk Normality test UPTAKE RATE (%)
1	<i>s-w</i> = .986 <i>df</i> = 1025 <i>p</i> = .000*	<i>s-w</i> = .837 <i>df</i> = 79 <i>p</i> = .000*	<i>s-w</i> = .929 <i>df</i> = 10 <i>p</i> = .437
2	<i>s-w</i> = .965 <i>df</i> = 109 <i>p</i> = .005*	<i>s-w</i> = .815 <i>df</i> = 69 <i>p</i> = .000*	<i>s-w</i> = .876 <i>df</i> = 10 <i>p</i> = .188
3	<i>s-w</i> = .976 <i>df</i> = 188 <i>p</i> = .002*	<i>s-w</i> = .817 <i>df</i> = 39 <i>p</i> = .000*	<i>s-w</i> = .697 <i>df</i> = 10 <i>p</i> = .001*
4	<i>s-w</i> = .983 <i>df</i> = 226 <i>p</i> = .007*	<i>s-w</i> = .925 <i>df</i> = 47 <i>p</i> = .005*	<i>s-w</i> = .931 <i>df</i> = 10 <i>p</i> = .457
5	n/a	n/a	<i>s-w</i> = .909 <i>df</i> = 9 <i>p</i> = .310
6	<i>s-w</i> = .995 <i>df</i> = 296 <i>p</i> = .429*	<i>s-w</i> = .925 <i>df</i> = 116 <i>p</i> = .000*	<i>s-w</i> = .984 <i>df</i> = 10 <i>p</i> = .983
all	n/a	n/a	<i>s-w</i> = .347, <i>df</i> = 10 <i>p</i> = .053

\*A significant test statistics indicates that the data is NOT normally distributed.

UPTAKE RATE was normally distributed, but the data is time dependent, and each before-after set comes from one intervention site. Time series analysis is not possible due to too few data points, hence a t-test is conducted with the assumption that the data is from different individuals and hence, independent.

## 5) The NACR data per site

Table 16: Data collected by site 1 and patient characteristics (This site runs two groups, one has two weeks and one has six weeks delay in entry, therefore I adjusted by four weeks, hence strangely high uptake rates).

Data collected Site 1*	Months (before)	Letters	Patients	Uptake rate (%)	Rate change	Months (after)	Letters	Patients	Uptake rate	Rate change	
	2	12	16	133.34		7	13	17	130.78		
	3	18	12	66.67	-66.67	8	18	15	83.34	-47.44	
	4	20	12	60	-6.67	9	17	17	100	16.66	
	5	11	18	163.64	103.6	10	12	17	141.67	-41.67	
	6	22	14	63.64	-100	11	12	14	116.67	25	
<b>The NACR data</b>					<b>Pre-Intervention (February-June)</b>			<b>Post-Intervention (July-November)</b>			
Age <i>M (SD)</i>					71.23 (13.29)			70.45 (12.80)			
					<i>N</i> = 579			<i>N</i> = 446			
Gender											
Female <i>N (%)</i>					231 (37.5)			157 (35.1)			
					<i>N</i> = 647			<i>N</i> = 447			
Co-morbidities <sup>54</sup>											
M (SD)					1.22 (1.12)			2.7 (2.21)			
					<i>N</i> = 69			<i>N</i> = 10			
Initiating Event											
<i>N (%)</i>											
ACS					10 (1.5)			5 (1.1)			
Angina					10 (1.5)			14 (3.1)			
Cardiac Arrest					1 (0.2)			0			
Heart Failure					8 (1.2)			9 (2)			
MI(unknown)					320 (49.5)			238 (53.2)			
Other					295 (45.6)			178 (39.8)			
Unknown					3 (0.5)			3 (0.7)			
Ethnic Origin											
<i>N (%)</i>											
White (all)					269 (41.6)			86 (19.2)			
Bangladeshi					0			1 (0.2)			
Other					0			1 (0.2)			
Not stated/missing					377 (58.4)			359 (80.3)			
Marital status											
<i>N (%)</i>											
Divorced/separated					19 (1.6)			8 (1.8)			
Married/permanent partner					208 (32.1)			130 (29.1)			
Single					27 (4.2)			7 (1.6)			
Widowed					26 (4)			19 (4.3)			
Unknown					73 (11.3)			47 (10.5)			

<sup>54</sup> Data for the following co-morbidities are collected by the NACR: angina, arthritis, asthma, bronchitis, cancer, chronic back pain, claudication, diabetes, emphysema, hypertension, osteoporosis, rheumatism, stroke and other complaint.

Table 17: Data collected by Site 2 and patient characteristics (from the NACR)

Data collected Site 2*	Months (before)	Letters	Patients	Uptake rate	Rate change	Months (after)	Letters	Patients	Uptake rate	Rate change
	2	43	27	62.79		7	20	24	120	
	3	23	28	121.74	59.04	8	48	18	37.50	-82.5
	4	37	23	62.16	-59.58	9	34	25	73.53	36.03
	5	26	21	80.77	18.61	10	37	25	67.57	-5.96
	6	37	25	67.57	-13.2	11	43	22	51.16	-16.41
<b>The NACR data</b>	<b>Pre-Intervention (February-June)</b>					<b>Post-Intervention (July-November)</b>				
Age <i>M(SD)</i>	66.70 (14.77) <i>N</i> = 87					62.23 (14.57) <i>N</i> = 22				
<i>Gender</i>										
Female <i>N (%)</i>	28 (31.8) <i>N</i> = 88					6 (27.3) <i>N</i> = 15				
<i>Co-morbidities</i>										
<i>M (SD)</i>	0.85 (0.946) <i>N</i> = 61					1.38 (1.06) <i>N</i> = 8				
<i>Initiating Event</i>										
<i>N (%)</i>										
Angina	16 (18.2)					2 (9.1)				
Angiogram	1 (1.1)					0				
Aortic valve disease	1 (1.1)					0				
Cardiomyopathy	2 (2.3)					0				
Cardiac Arrest	0					0				
Congl. Heart Disease	2 (2.3)					0				
Heart Failure	0					0				
MI(Nstemi,STEMI, unknown)	48 (54.6)					11 (50)				
Mitral valve disease	1 (1.1)					0				
Other	8 (9.1)					1 (4.5)				
Unknown	9 (10.2)					8 (36.4)				
<i>Ethnic Origin N (%)</i>										
White (all)	71 (80.6)					9 (40.9)				
Mixed white/asian	1 (1.1)					0				
Other asian	1 (1.1)					0				
Bangladeshi	0					0				
Other	0					0				
Not stated/missing	4 (4.5)					13 (59.1)				
<i>Marital status N (%)</i>										
Divorced/separated	1 (1.1)					0				
Married/permanent partner	57 (64.7)					7 (31.8)				
Single	6 (6.8)					1 (4.5)				
Widowed	7 (8)					1 (4.5)				
Unknown	7 (8)					12 (54.5)				

\*number of letters adjusted to months patients attended by 1 months



Table 18: Data collected by site 3 and patient characteristics (from the NACR)

<b>Data collected Site 3*</b>	<b>Months (before)</b>	<b>Letters</b>	<b>Patients</b>	<b>Uptake rate</b>	<b>Rate change</b>	<b>Months (after)</b>	<b>Letters</b>	<b>Patients</b>	<b>Uptake rate</b>	<b>Rate change</b>
	2	55	28	50.91		7	15	16	106.67	
	3	31	29	93.55	42.64	8	18	11	61.11	-45.56
	4	29	23	79.31	-14.24	9	12	4	33.34	-27.77
	5	25	19	76	-3.31	10	5	13	260	226.66
	6	19	15	78.95	2.95	11	14	12	85.71	-174.3
<b>The NACR data</b>	<b>Pre-Intervention (February-June)</b>					<b>Post-Intervention (July-November)</b>				
Age <i>M (SD)</i>	65.84 (11.15) <i>N</i> = 99					65.18 (14.04) <i>N</i> = 82				
<i>Gender</i>										
Female <i>N (%)</i>	20 (20.2) <i>N</i> = 99					19 (23.2) <i>N</i> = 82				
Co-morbidities <i>M (SD)</i>	1.41 (1.59) <i>N</i> = 29					1.1 (1.45) <i>N</i> = 10				
Initiating Event <i>N (%)</i>										
Angina	25 (25.3)					10 (12.2)				
Aortic valve disease	4 (4)					5 (6.1)				
Cardiomyopathy	1 (1)					2 (2.4)				
Heart Failure	15 (15.2)					12 (14.6)				
MI(Nstemi,STEMI, unknown)	49 (49.5)					49 (59.7)				
Mitral valve disease	4 (4)					3 (3.7)				
Other	0					1 (1.2)				
Unknown	0					0				
Ethnic Origin <i>N (%)</i>										
White (all)	72 (72.7)					54 (65.8)				
Other asian	1 (1)					0				
Indian	1 (1)					1 (1.2)				
Black Caribbean	1 (1)					0				
other	0					27				
Not stated/missing	24 (24.2)					0				
Marital status <i>N (%)</i>										
Divorced/separated	2 (2)					1 (1.2)				
Married/permanent partner	69 (69.7)					56 (68.3)				
Single	7 (7.1)					3 (3.7)				
Widowed	6 (6.1)					1 (1.2)				
Unknown	15 (15.1)					21 (25.6)				

\*number of letters adjusted to months patients attended by 1 months

Table 19: Data collected by site 4 and patient characteristics (from the NACR)

<b>Data collected Site 4*</b>	<b>Months (before)</b>	<b>Letters</b>	<b>Patients</b>	<b>Uptake rate</b>	<b>Rate change</b>	<b>Months (after)</b>	<b>Letters</b>	<b>Patients</b>	<b>Uptake rate</b>	<b>Rate change</b>
	2	23	18	78.26		7	36	31	86.11	
	3	35	16	45.71	-32.55	8	42	21	50	-36.11
	4	17	17	100	54.29	9	40	33	82.5	32.5
	5	49	14	28.57	-71.43	10	60	19	31.67	-50.83
	6	22	15	68.18	39.61	11	54	21	38.89	-7.22
<b>The NACR data</b>	<b>Pre-Intervention (February-June)</b>					<b>Post-Intervention (July-November)</b>				
Age <i>M (SD)</i>	67.48 (12.38) <i>N</i> = 130					69.92 (11.57) <i>N</i> = 95				
<i>Gender</i>										
Female <i>N(%)</i>	40 (30) <i>N</i> = 131					29 (30.5) <i>N</i> = 95				
<i>Co-morbidities</i>										
<i>M (SD)</i>	2.11(1.48) <i>N</i> = 27					2.15 (1.46) <i>N</i> = 20				
<i>Initiating Event</i>										
<i>N (%)</i>										
ACS	5 (3.8)					4 (4.2)				
Angina	17 (13.1)					10 (10.5)				
Angiogram	14 (10.8)					3 (3.2)				
Aortic valve disease	8 (6.2)					0				
Cardiac Arrest	0					1 (1.1)				
Heart Failure	0					1 (1.1)				
MI(Nstemi,STEMI, unknown)	79 (60.7)					73 (76.8)				
Mitral valve disease	2 (1.5)					0				
Other	3 (2.3)					2 (2.1)				
Unknown	2 (1.5)					1 (1.1)				
<i>Ethnic Origin N (%)</i>										
White (all)	124 (95.4)					94 (98.9)				
Not stated/missing	6 (4.6)					1 (1.1)				
<i>Marital status N(%)</i>										
Divorced/separated	1 (0.8)					4 (4.3)				
Married/permanent partner	80 (61.5)					57 (60)				
Single	10 (7.7)					6 (6.3)				
Widowed	8 (6.2)					16 (16.8)				
Unknown	31 (23.8)					12 (12.6)				

\*number of letters adjusted to months patients attended by 1 months

Table 20: Uptake rate site 5 (this site does not use the NACR)

	Letters <i>N</i>	Patients <i>N</i>	Uptake Rate %	Rate change %
February '12	30	21	70	
March '12	39	18	46.15	-23.85
April '12	50	32	64	17.85
May '12	51	16	31.37	-32.63
June '12	57	27	47.37	16
July '12	33	22	66.67	
August '12	39	23	58.97	-7.7
September '12	47	21	44.68	-14.29
October '12	29	19	65.51	-20.83

\*number of letters adjusted to months patients attended by 1 months

Table 21: Data collected by site 6 and patient characteristics (from the NACR)

Data collected Site 6*	Months (before)	Letters	Patients	Uptake rate	Rate change	Months (after)	Letters	Patients	Uptake rate	Rate change
		2	31	18	58.06		7	25	15	60
	3	37	19	51.35	-6.71	8	35	27	77.14	17.14
	4	29	15	51.72	0.37	9	26	17	65.38	-11.76
	5	27	12	44.44	-7.28	10	21	15	71.43	6.05
	6	34	13	38.24	-6.2	11	32	19	59.38	-12.05
		<b>Pre-Intervention (February-June)</b>				<b>Post-Intervention (July-November)</b>				
<b>The NACR data</b>										
Age <i>M (SD)</i>		64.48 (12.42) <i>N</i> = 143				63.50 (12.56) <i>N</i> = 141				
Gender										
Female <i>N (%)</i>		42 (27.1) <i>N</i> = 155				37 (26.2) <i>N</i> = 141				
Co-morbidities <sup>55</sup>										
<i>M (SD)</i>		2.68 (2.07) <i>N</i> = 65				2.73 (2.09) <i>N</i> = 51				
Initiating Event										
<i>N (%)</i>										
ACS		31 (21.7)								
Angina		15 (10.5)				42 (29.8)				
Angiogram		21 (14.7)				21 (14.9)				
Aortic valve disease		15 (10.5)				14 (9.9)				
Cardiomyopathy		1 (0.7)				5 (3.5)				
Cardiac Arrest		5 (3.5)				5 (3.5)				
Cong. Heart Disease		0				1 (0.7)				
Heart Failure		18 (12.6)				1 (0.7)				
MI(Nstemi,STEMI, unknown)		27 (18.9)				11 (7.8)				
Mitral valve disease		6 (4.2)				33 (24.5)				
Other		1 (0.7)				4 (2.8)				
Unknown		2 (1.4)				0				
Ethnic Origin <i>N (%)</i>										
White (all)		67 (46.9)				40 (28.4)				
Mixed white/black		0				1 (0.7)				
caribbean		0				1 (0.7)				
Other Asian		1 (0.7)				5 (3.5)				
Indian		0				1 (0.7)				
Pakistani		1 (0.6)				1 (0.7)				
Bangladeshi		0				1 (0.7)				
Other Asian		3 (2.1)				5 (3.5)				
Black Caribbean		2 (1.4)				4 (2.8)				
Black African		2 (1.4)				1 (0.7)				
Black other		2 (1.3)				0				
Other Ethnic group		77 (49.7)				83 (58.8)				
Not stated/missing										
Marital status <i>N (%)</i>										
Divorced/separated		6 (7.1)				6 (4.3)				

<sup>55</sup> Data for the following co-morbidities are collected by the NACR: angina, arthritis, asthma, bronchitis, cancer, chronic back pain, claudication, diabetes, emphysema, hypertension, osteoporosis, rheumatism, stroke and other complaint.

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Married/permanent partner	45 (29)	26 (18.4)
Single	10 (6.5)	17 (12.1)
Widowed	7 (4.5)	4 (2.8)
Unknown	87 (56.1)	88 (62.4)

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\*Number of letters adjusted to months patients attended by 1 months

**5) The NACR data on phase 1 and phase 3 attendance over the intervention time period.**

Table 22: The declining number of patients for whom data was entered into the NACR reflects the delay in data entry or waiting times.

Months in 2012	Intervention sites			all other NACR sites			
	phase1 all <i>N</i>	phase 3 yes <i>N</i>	uptake rate %	phase1 all <i>N</i>	phase 3 yes <i>N</i>	uptake rate %	
February	112	71	54.62	5516	2694	48.84	
March	126	67	59.82	5609	2657	47.73	
April	101	54	42.86	5230	2510	47.99	
May	143	57	56.44	5562	2614	46.99	
June	120	42	29.37	4872	2218	45.53	
July	121	44		4662	2100		
August	68	24		4300	1618		
September	102	23		4129	1222		
October	99	15		3881	906		
November	24	4		3313	544		

## 6) Mean differences between uptake rates

Table 23: Mean differences in uptake (%)

	Site 6	Site 1	Site 2	Site 3	Site 4	Site 5
<b>BEFORE</b>						
<i>M</i>	48.5	97.6	79.2	75.8	64.2	51.6
<i>(SD)</i>	(7.73)	(47.80)	(25.09)	(15.55)	(27.64)	(15.57)
Test statistic		$t(8) = 2.263$	$t(8) = 2.606$	$t(8) = 3.503$	$t(8) = 1.215$	$t(8) = 0.386$
		$p = .54$	$p = .031^{**}$	$p = .008^{**}$	$p = .259$	$p = .710$
<b>AFTER</b>						
<i>M (SD)</i>	66.4 (7.60)	114.6 (23.65)	70.2 (31.24)	109.4 (88.62)	58 (25.05)	59.3 (10.14)
Test statistic		$t(8) = 4.339$	$t(8) = 0.264$	$t(8) = 1.081$	$t(8) = 0.718$	$t(8) = -1.121$
		$p = .002^*$	$p = .798$	$p = .311$	$p = .507$	$p = .264$

\*\* $p < .01$

## 7) Adjusted time series model

The outcome was uptake rate in percent (%) as calculated from the data collected. Data was summarized across centres for each month, and one-month delay between ‘letters sent’ and ‘patients attending’ was taken into account. There was one unit of analysis over 10 time points; more than 100 observations at each data point were made for variability. A linear segmented regression model estimates level and trend pre- and post-intervention, and hence takes the temporal order of observations into account (Eliopoulos et al., 2004; Wagner et al., 2002; Yanovitzky and Vanlear, 2008).

*Hypothesis: The amended invitation letter increases the uptake rate in cardiac rehabilitation phase 3.*

The Durbin–Watson statistic is used to assess autocorrelation and tests for correlated residuals. Values close to zero indicate a strong negative, those close to four a strong positive correlation, and values around two indicate no correlation (University of Texas, n.d.). Assumptions of linearity, normality and independent errors apply. The initial model had a Durbin-Watson of 3.009, therefore a first order autocorrelation. An adjustment for first-order autocorrelation was made using the Prais-Winston rho (GLS) for better estimating the regression resulting in the Durbin-Watson statistic of 2.815 (SPSS AREG command: AREG dv WITH time level slope /METHOD=PW.). The Koenker test (6.29,  $p = .098$ ) for heteroscedasticity can be used for time series and a macro for SPSS was run (Garcia-Granero, 2002). The assumption for homoscedasticity was met.



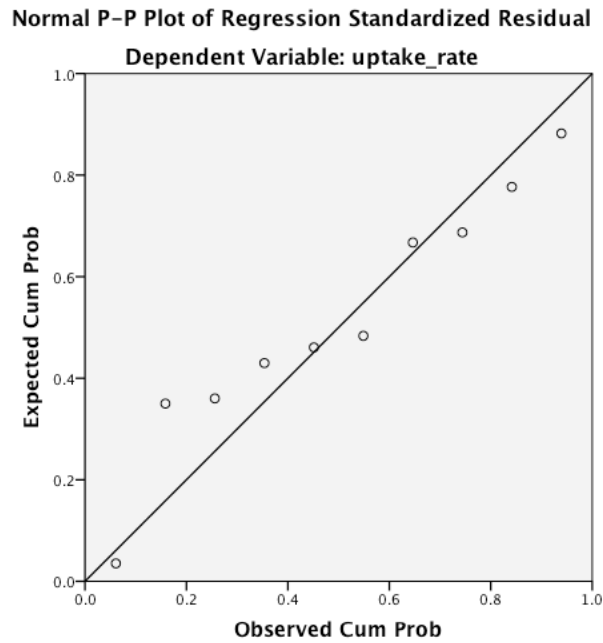


Figure 7 P-P Plot

The p-p plot above questions a normal distribution of the residuals. Unfortunately, data transformation is not possible due to the few data points.

The final model is displayed below with an adjusted  $R^2$  value of 0.472 meaning that 47.2 % of variance in the dependent variable is explained by the predictors. The estimated uptake rate at time zero was 71.63 % with an estimated decrease of minus 2.39 % before the intervention was implemented. There was a significant change in level immediately after the intervention was implemented (24.97 %,  $p < .05$ ), but there was no significant difference in the uptake rate in the post intervention time (-2.80,  $p = .271$ ).

Table 24 Regression Model

	Beta coefficient	Std. Error	t	p-value
time	-2.391	1.727	-1.384	0.225
0-before intervention; 1- after intervention	24.972	7.361	3.393	0.019
Time since intervention	-2.803	2.265	-1.238	0.271
constant	71.626	7.305	9.804	0.000

There was a significant change in level of uptake rate at the time the intervention was implemented. The results must be interpreted with caution, because ten cases per predictors are typically required for a robust regression analysis. Only one third of the required cases were available here, and a danger of over-fitting the data exists. There was no significant change in slope post-implementation suggesting that the letter had no impact overall.

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