

How an internet intervention works to achieve benefit for patients with coronary heart disease

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PhD Thesis

Declaration

I Cicely Elizabeth Philippa Kerr confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Internet interventions have the potential to support patient self-management of long term conditions. However, their mechanisms of action are unclear. There is also a concern that lack of equity of internet access may limit their benefits. The aim of this thesis was to develop a greater understanding of the potential of internet interventions for patients with a long term condition, in this case coronary heart disease (CHD), and their mechanisms for supporting patient self-management.

Mechanisms of action were explored using constructs from psychological theories. Literature reviews of internet and CHD self-management interventions identified illness perceptions, self-efficacy and social support as psychological constructs that may explain mechanisms of action of internet interventions for patients with CHD. These constructs were evaluated in a prospective study with 168 patients with CHD.

Participants, with or without home internet access or prior internet experience, had unlimited access to a CHD internet intervention over 9 months. Use of the intervention and changes in psychological constructs, behavioural, emotional and quality of life outcomes were evaluated using a mixed quantitative and qualitative design.

Only a small proportion of eligible patients with CHD participated. Participants were predominantly male, highly educated and had better internet access and/or internet experience than was likely in the wider CHD population. Few had experienced recent problems with their condition. Overall use of the intervention was low compared to other internet interventions. Participants who were older, had more recently experienced a cardiac event or diagnosis, had home internet access and prior internet experience made greater use of the intervention. Most participants were positive about the

intervention but no significant changes in psychological constructs or health outcomes were found.

This implementation of an internet intervention to support CHD self-management appears to have limited potential, particularly for those without home internet access or confidence using computers.

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Chapter 1 : Introduction

1.1 Long term conditions

Long term or chronic conditions are a major and increasing area of concern for patients and health care providers. Government figures estimate that 1 in 3 people in the UK are currently suffering from a long term condition (1). Advances in medical treatment have resulted in more people surviving and managing conditions that were once potentially fatal. Together with an overall increase in life expectancy, this means that increasing proportions of people are living with a long term condition for many years.

1.2 Self-management

Self-management has been defined as *“the individual’s ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”* (2). While medical intervention plays an essential role in managing long term conditions, healthcare professionals are only present for a fraction of the disease experience, so responsibility for day-to-day care over the course of an illness falls to patients themselves (3;4). The rising prevalence of long term conditions has been accompanied by a greater focus on optimal patient self-management. Optimal self-management has been defined as *“the means to achieve the highest degree of functioning and lowest level of symptoms given the severity of the condition”* (5) with the goal being *“maintenance of pleasurable and independent living”* (6).

In healthcare policy, optimal self-management has become a central tenet of strategies to cope with the increased demands on services and the rising cost of treating greater numbers of patients with long term conditions. In the UK, the Wanless report into NHS resource requirements viewed optimal self-management as essential for achieving the ‘fully engaged’ scenario likely to bring about the greatest public health benefits (7). The

subsequent NHS improvement plan views self-management support as the appropriate (and the only affordable) disease management strategy for low risk patients with long-term conditions, a group which make up 70-80% of the population of patients with long term conditions (8).

The rising importance of self-management is also partly due to cultural changes in roles of doctors and patients. In recent decades attitudes towards healthcare delivery have shifted away from the traditionally paternalistic model of healthcare towards one of more active patient involvement (9). With this comes recognition of patients as experts in their own illness and increased demand for information and support to enable patients to actively engage in healthcare decisions and their own treatment (10).

1.3 Coronary heart disease (CHD)

This thesis focuses on Coronary Heart Disease (CHD) as an example of a highly prevalent long term condition. It is the leading cause of death in the UK, responsible for over 110,000 deaths per annum (11). In England, over 2 million people have CHD (12), and are at increased risk of subsequent vascular events (e.g. heart attack). A major focus of treatment is secondary prevention, which aims to prevent or postpone premature death among patients who have been diagnosed with CHD. This means preventing disease progression and vascular events by reducing modifiable risk factors such as cholesterol levels, blood pressure, obesity, physical inactivity and smoking. In the main this is achieved through a combination of prescribed medications and healthy lifestyle behaviours. As a consequence, the effectiveness of CHD secondary prevention is highly dependent on the self-management activities of patients to adhere to medical regimens and implement long term lifestyle change.

1.4 Self-management information and support needs

For self-management support to achieve the desired individual and public health benefits, it needs to address patients' needs. The information and support needs of patients with long term conditions have been found to be extensive, complex, occur over the course of years and change over time (13;14). Needs increase and decrease according to symptoms, the course of the illness and shifting perspectives patients have of their condition (14). In an in-depth qualitative study, Corbin and Strauss identified common concerns related to three types of work required for people to adapt to and manage long term conditions. These concerns and types of work are common across different conditions:

- (i) medical work (e.g. taking medications, symptom management)
- (ii) biographical work (maintaining, changing and creating new life roles)
- (iii) everyday work (performing daily tasks to maintain households and relationships) (13).

More recently, Lorig and Holman highlighted the importance of the work of managing the emotional impact of having a long term condition (14). The different types of work are interrelated and their relative importance varies according to different phases of an individual's illness trajectory (13). The implication for interventions which aim to support or optimise self-management is that they must address all of the different types of work if they are to meet the complex needs of patients with chronic disease (14). It also follows that interventions must address needs in the long-term, with the flexibility to address different concerns as and when required.

In addition to common concerns and needs, specific information and support needs are related to individual conditions. CHD is a condition that can be experienced very differently by patients depending on whether or not they experience a heart attack,

cardiac surgery or symptoms such as shortness of breath or angina. For many patients it is characterised by asymptomatic phases, punctuated by acute dramatic events such as heart attack or cardiac surgery.

Most work assessing needs of patients with CHD has been carried out in relation to cardiac events, most notably after heart attacks (15). Emotional problems are more common during recovery from a heart attack than from scheduled heart surgery (16). At this time patients commonly struggle to make sense of what has happened to them, particularly if their heart attack was the first sign of disease (17). They prioritise information that relates to symptom management, immediate survival and recovery over information relating to long-term management (15;18). Later, patients report the need for long-term monitoring and support, including help in following lifestyle advice, sharing with people with similar experiences, getting answers to medical questions and gaining reassurance over their current state of health (19). Six months after hospital discharge heart surgery patients report information needs similar to the later needs of heart attack patients, relating to harmful side-effects of treatment, physical condition, risk factors, convalescence and knowledge of CHD (16).

Patients with CHD may be in particular need of help in developing an accurate understanding of their condition. Studies suggest that patients commonly view their heart attack as an acute event rather than a symptom of a chronic condition (17). This perception gives little motivation for the long-term self-management efforts required for effective secondary prevention. By contrast patients with angina commonly understand episodes of angina to be overly severe, viewing them as 'mini heart attacks' resulting in irreversible damage to the heart muscle (20). As a result patients can become extremely fearful of imminent death and of doing anything that might trigger an episode of angina.

This response can have a direct negative impact on patients' quality of life (20) and exacerbate the condition through increased anxiety and avoidance of activity (21).

As well as increased anxiety experienced in relation to angina, depression is common among patients with CHD, particularly after a heart attack. It is estimated that up to 65% of patients experience symptoms of depression after a heart attack and up to a third of patients develop clinical depression over the following year (22). Significant incidence of depression has also been found in newly diagnosed patients with CHD, patients awaiting coronary artery bypass surgery and 6 months after surgery (22).

1.5 Self-management outcomes

There are a number of potentially relevant outcomes for evaluating self-management. Much of the self-management literature focuses on patient quality of life as the main outcome (2;5;6) with patients' behaviour as the important mediator of nearly all self-management outcomes (3). Identification of the different types of work carried out by patients with long term conditions suggests important behaviours (e.g. managing symptoms, taking medicines and everyday life activities) and cognitive and emotional self-management activities (e.g. day-to-day decision making in response to changes in condition, learning to manage stress and anxiety) as outcomes (13;14).

In the context of CHD, secondary prevention is an important additional aim of self-management. This extends relevant outcomes to include physiological measures of risk factors such as cholesterol levels and blood pressure as well as clinical outcomes such as recurrent cardiac events and mortality. It also extends relevant behavioural outcomes to include health-promoting behaviour such as aerobic physical activity, smoking cessation, and eating a heart-healthy diet. Health-related quality of life and emotional outcomes such as depression and anxiety gain additional importance in relation to

secondary prevention of CHD as both have been found to predict recurrent cardiac events and CHD mortality (23-25).

It is unclear which out of improving quality of life and achieving effective secondary prevention is considered to be the primary or most achievable aim of self-management support. This may depend on whether self-management is viewed from the perspectives of individual patients or public health. However, in general there seems to be an assumption in the literature that self-management and secondary prevention aims are aligned and essentially the same.

1.6 Self-management support

Given the complex needs of patients with long term conditions and the broad aims of self-management, it is not surprising that interventions designed to support self-management vary greatly in terms of content, duration and mode of delivery and most comprise multiple components (2). In the UK, since 2001, the provision of self-management support for low-risk patients with long term conditions has centred on the Expert Patient Programme (EPP), a lay-led 6-week group intervention aimed at developing generic self-management skills, common to all patients with long term conditions (10). Other disease-specific interventions also aim to support self-management and for patients with CHD the most common of these are cardiac rehabilitation programmes (26).

Self-management interventions for patients with long term conditions have been found to improve patients' knowledge, self-management behaviours, self-reported health status (2), physiological measures of risk factors, symptoms and clinical markers of disease control (27;28). However, it is not clear what characteristics or components are responsible for their effects (2;5;27). The EPP and similar lay-led interventions have been found to improve outcomes such as self-rated health and distress in the short term,

although there is less evidence for any meaningful effect on longer term, clinical or emotional outcomes (29).

Cardiac rehabilitation and other CHD secondary prevention interventions for patients have demonstrated reductions in recurrent coronary events, hospitalisation and mortality (overall and cardiovascular), and improvements in clinical markers of disease (30). Interventions which include psychosocial components (e.g. health education, stress management and risk factor counselling) have been found particularly to improve risk-reducing behaviours (31), emotional distress (32;33), physiological measures of risk factors, recurrence of coronary events (31-33), mortality (31-34) and quality of life (34).

Despite these positive effects, existing self-management interventions for patients with long term conditions and disease-specific interventions for patients with CHD suffer from important shortcomings. Typically interventions are delivered over only a few weeks or months and evaluated over a follow-up period of no more than 6 months, both of which are inadequate time-frames given the duration of most long term conditions (2;5). Instead self-management support needs to be delivered and evaluated in the long term (3) and more support is required after completion of cardiac rehabilitation to extend positive effects (34).

Self-management interventions have also been criticised for relying on motivated volunteers to participate, with the likelihood that these participants may not be representative of the wider population of patients with long term conditions (35). The EPP and similar lay-led programmes have come under particular criticism regarding their ability to engage all types of patients with long term conditions. The EPP, for example, has had low uptake, and a predominance of female, white, highly educated participants (29;36;37). Barriers to accessing self-management support include difficulties in attending face-to-face or group programmes run at specific locations due

to transportation problems and physical limitations affecting mobility and causing fatigue (38). However, these types of barriers do not properly account for the predominance of female, white, highly educated participants.

Similar concerns over equality of access and engagement have been levelled at cardiac rehabilitation programmes. Firstly, provision of cardiac rehabilitation is inadequate (39) and varies greatly across different areas in the UK. Overall only around 30% of eligible patients enrol in cardiac rehabilitation programmes (39). Secondly, a disproportionately high number of cardiac rehabilitation participants are male, relatively young, highly educated and have a relatively high income (40). The risk is that although intended to be equally available to all patients, existing self-management support for patients with CHD may contribute to health inequalities through the ‘inverse care law’ (41) whereby those most in need receive least care.

1.7 Internet interventions

The term ‘internet intervention’ was first applied to online versions of effective face-to-face psychotherapeutic interventions (42;43). However it has also been used as a more accessible term for online examples of interactive health communication interventions (IHCAs) (44). These interventions combine health information with interactive components, such as self-assessment tools, support for behaviour change, communication with other patients (peer support) or everyday and health-care decision support (45). As a result they are complex information and support systems which can address multiple needs (46). Particular advantages of IHCAs include the potential to convey information more meaningfully by tailoring content to individual patients. IHCAs also have the potential to overcome educational barriers by presenting complex information accessibly, for example through animation or video. As a result they may be particularly useful for supporting self-management among less educated patients.

The ever-increasing reach of the internet provides an opportunity to deliver support for self-management in the form of internet interventions. Recent figures show 70% of UK households now have home internet access (47) and the internet is also available to those without home access through free public internet provision (48). For many patients the convenience of being able to access support for self-management in their own homes at any time may overcome some of the practical barriers to accessing support by other means (38). The networked nature of the internet allows interventions to include online communication among patients and between patients and experts. It also allows interventions to be easily updated and expanded over time giving them enduring relevance and appeal.

As a permanently available resource, the internet has the potential to provide interventions over much longer time-frames than is usually feasible with more traditional modes of delivery. Internet interventions have the potential to provide support for self-management over years rather than merely weeks and months, addressing patients' needs in the long-term. Although internet interventions can be costly to design initially, once set up, their ongoing costs are much less than those associated with more traditional modes of intervention delivery. In contrast to more conventional modes of intervention delivery (e.g. face-to-face), internet interventions are largely unaffected by the number of people making use of them at any one time, so it is not necessary for patients to end their use of an intervention to allow others to begin.

Initial research on internet interventions supports their promise for patients with long term conditions and with CHD in particular. Systematic reviews of computer-based interventions, including those delivered via the internet, found they improved health promotion and risk reduction behaviours among general population and long term

condition samples (49;50) and improved clinical outcomes for patients with long term conditions (49). Qualitative research with people with long term conditions, including patients with CHD, found they saw the potential of internet interventions in meeting their information and support needs (44;51). Finally a survey of patients with CHD found high and increasing use of the internet for health information and a strong interest in online communication for specialist CHD advice (52).

However, there are also some concerns over the potential of internet interventions.

While access to the internet grows year by year, it is not equally spread (47;53). Home internet access is lowest among those with lower educational qualifications and lower incomes. Internet use is relatively low among women and those who are older (in particular those aged over 65), although use by both women and older age-groups is increasing (47). Relatively low use has also been found among people with health problems or disability (53). Internet use for seeking health information shows a somewhat different pattern from overall use. Surveys suggest that this kind of internet use is relatively high among women and people with long term conditions, and that people in older age-groups make at least as much use of the internet for health information as younger age-groups (54;55). However, the lack of equity of internet access and use has raised concerns that a 'digital divide' may mean that internet interventions could exacerbate rather than reduce health inequalities (56;57).

It is also unclear what the key components of internet interventions are for effectively supporting self-management of long term conditions. Like other self-management interventions, internet interventions comprise multiple components and these vary greatly between individual interventions (49;50). There is considerable heterogeneity in the effects of internet interventions but it is not clear why some are more effective than others (49). Moreover, qualitative data suggests that not all examples of internet

interventions are likely to meet patients' needs (44). In order to be able to design effective internet interventions it is important to identify what their key components are and how they work to achieve benefit for patient self-management.

1.8 Evaluating complex interventions

Identifying key intervention components or 'active ingredients' is a problem that is common to internet, self-management and other complex interventions (58). It is widely accepted that randomised controlled trials (RCTs) are the 'gold standard' approach to evaluating effectiveness. However, complex interventions, which are made up of various interconnecting components, pose additional problems for evaluation over the single-component, pharmaceutical interventions that RCTs were originally designed to evaluate (59). Complex interventions found effective by RCT evaluation can be difficult to reproduce if their key components and mechanisms of action have not been clearly identified. Mechanisms of action are the means by which intervention components work independently or interdependently with other components to achieve benefits. When complex interventions are developed without clearly defined key components and mechanisms of action they risk failing to achieve their goals. In this situation costly evaluation by RCT will not only result in null findings, but also provide little guidance for future intervention development.

In order to address these problems and reduce the risk of costly RCT evaluations yielding null findings, the UK Medical Research Council (MRC) has developed a framework for evaluating complex interventions (58;59). This framework specifies a 5-phase approach to evaluation:

- Preclinical phase – exploring relevant theory to hypothesise how and why the intervention should work
- Phase 1 – modelling how the intervention should work

- Phase 2 – pilot testing the intervention in an exploratory trial
- Phase 3 - definitive RCT
- Phase 4 – evaluating long-term implementation in uncontrolled settings

The key novel aspect of the framework is the emphasis on the early developmental work advocated in the first 3 phases. Further development of the framework recommends considering these early phases as part of one larger iterative activity to develop an understanding of the problem the intervention aims to address, and optimise the intervention, and evaluation methods, before definitive RCT (60).

The MRC framework has recently been used to guide developmental work on a secondary prevention intervention for CHD (61). Before conducting an RCT, phase 0-2 evaluation of the SPHERE (Secondary Prevention of Heart Disease in General Practice) intervention involved a literature review exploring relevant theory, patient and staff focus groups at four participating GP practices and a pilot test of the resulting intervention. The authors concluded that application of the MRC framework helped to determine the feasibility of the intervention and deepen understanding of how it would perform (61). However at the time when work was conducted for this thesis, the MRC framework had not previously been applied in internet intervention research.

1.9 Thesis aim and structure

The aim of this thesis is to develop a greater understanding of the potential of internet interventions for supporting self-management for patients with CHD, by conducting work advocated in the first 3 phases of the MRC framework for evaluating complex interventions (58;60;62). Chapters 2 and 3 represent ‘preclinical phase’ work exploring relevant theoretical frameworks and existing evidence. Based on this evidence, Chapter 4 presents a model of how an internet intervention for patients with CHD is likely to work, and discusses design issues for exploratory evaluation of such an intervention.

Chapter 5 then describes work carried out to develop a suitable internet intervention for exploratory evaluation. Chapter 6 presents methods used for the evaluation of the intervention. Results from the evaluation are presented in Chapters 7 and 8. Chapter 9 concludes with a discussion of results from this study and their implications.

Chapter 2 : Use of psychological theory in the design and evaluation of internet interventions for patients with CHD: A review of relevant literature.

2.1 Introduction

This chapter is the first of two literature reviews, which together aim to identify the likely mechanisms by which an internet intervention might achieve change in key outcomes for patients with CHD. This chapter reviews available evidence from internet intervention literature and Chapter 3 reviews relevant CHD intervention literature. The overall purpose of identifying likely mechanisms of intervention action was to guide the design of an empirical study investigating how an internet intervention works to achieve benefit for patients with CHD. The mechanisms of action evaluated in the empirical study are discussed in Chapter 4.

This thesis aims to make use of psychological theory to predict and evaluate how an internet intervention works to achieve benefit for patients with CHD. The aim of this chapter is to review the use of psychological theory in the design and evaluation of internet interventions for patients with CHD and other relevant internet-based or computer-based interventions, and what this reveals about their likely mechanisms of action.

To provide the context for this review, the chapter starts with two background sections on psychological theories (Section 2.1.1) and relevant internet-based or computer-based interventions (Section 2.1.2). These are followed by a summary of the literature on the use of psychological theory in internet-based or computer-based interventions (Section 2.1.3). The methods used to identify relevant evaluation studies are then described before evidence from these evaluations is presented and discussed.

2.1.1 Psychological theories

Psychological theories identify key psychological factors that determine health behaviours and other health outcomes, and explain how changes in these outcomes occur. Many psychological theories have been developed and applied to explain and predict health behaviours and subsequent health outcomes. However they share a common focus on factors intrinsic to the individual. These factors are mainly cognitive (relating to beliefs and perceptions), on the basis that cognitive determinants are assumed: (i) to be important causes of behaviour through which other extrinsic factors may also operate and (ii) to be more open to change than other factors (63). Some psychological theories also contain other non-cognitive determinants of behaviour, for example emotional determinants or past behavioural habits.

It is the focus on individual change which makes psychological theories so useful in identifying constructs on which an intervention should impact in order to achieve change in health outcomes. With knowledge of health risks frequently found to be already adequate or even high in individuals targeted for behavioural change, these theories tend to regard knowledge as a precondition for change. According to psychological theories, additional cognitive and other influences are needed to overcome barriers to adopting new lifestyle or self-management habits (64).

There are several advantages of using psychological theories to investigate the mechanism of action of an internet intervention in patients with CHD. Firstly, the use of common theories and constructs across different samples and interventions allows comparison between studies. Together these studies build a body of knowledge that is likely to be generalisable to other interventions and samples. Using constructs from psychological theory to understand and evaluate how an internet intervention is likely to work should in turn increase the generalisability of the findings of the subsequent

empirical study. Evaluation should also be facilitated by the measures that previous researchers have developed to capture theoretical constructs that make up hypothesised mechanisms of intervention action.

Psychological theories and constructs can be applied in different ways in intervention research. Firstly, they can guide intervention design and secondly they can guide evaluation of intervention effects. Empirical studies of interventions provide different levels of evidence for psychological theories and constructs as mechanisms of action depending on whether these theories and constructs have been used in intervention design and/or evaluation.

Using theory to guide intervention design aims to increase the effectiveness of an intervention in changing health behaviours and other health outcomes. Theory-based interventions focus on achieving change in the key constructs predicted to determine health outcomes. Reviews of interventions designed to change health behaviours have found theory-based interventions to be more effective than interventions not guided by an explicit theory (65;66). One review calculated effect sizes of behavioural health promotion interventions for adolescents with type 1 diabetes on psychosocial, self-management or physiological outcomes (65). The review found interventions with an explicit theoretical basis (stated in publications reporting evaluations of the interventions) produced significantly larger effects than interventions with no explicit theoretical basis. In a narrative review of 76 healthy eating interventions, use of an intervention model incorporating behavioural theories and goals rather than based on the provision of information was identified as one of the characteristics of effective interventions (66). The theory used to guide intervention design provides an explanation of how the intervention is likely to work (i.e. its mechanism of action). When a theory-based intervention is found to be effective in achieving positive change in health

outcomes this suggests that the intervention has worked by mechanisms specified by the relevant theory.

Studies which use theory to guide evaluation of intervention effects provide stronger evidence for psychological theories and constructs as mechanisms of action than those which only use theory to guide intervention design. In these studies the key constructs that are predicted by a theory to form part of the mechanism of action are then measured as intermediate outcomes. When change is found in these psychological constructs and in health outcomes, this provides evidence that the intervention has worked in the way expected. For example, a review of interventions to reduce HIV-risk amongst adolescents found interventions that resulted in larger changes in intermediate cognitive outcomes (e.g. knowledge, beliefs, intention or self-efficacy), had larger effects on health behaviours than interventions that achieved smaller cognitive changes (67). This supports the utility of the cognitive theories used (68). Where theory has guided evaluation, lack of change in either psychological constructs or health outcomes indicates that the intervention has not worked in the way predicted by the theory. The strongest test for an intervention working according to a predicted mechanism of action involves conducting mediator analysis on psychological constructs and health outcomes (69). If mediator analysis of intervention effects demonstrates changes in psychological constructs mediate (i.e. account for) changes in health outcomes, then this provides strong evidence that the intervention has worked according to the mechanism predicted by the theory used.

2.1.2 Internet interventions for people with long term conditions

The potential benefits of internet interventions and the information and support needs of people with CHD or other long term condition have been discussed in Chapter 1.

However, health-focused interventions that are delivered through the internet vary in

terms of aims, content and availability. The focus here is on interventions to support self-management by people with long term conditions. Internet-based interventions which do not focus on self-management are excluded from this review (for example interventions to facilitate communication between patients and their healthcare professionals, telecare interventions which enable remote-monitoring of patient symptoms, and interventions for use by health professionals).

In Chapter 1, internet interventions were defined as combining health information with interactive components, such as self-assessment tools, behaviour change support, peer support or decision support (45). An important feature of these interventions for people with long term conditions is their complexity. Instead of providing only one type of information or a single supportive tool, they combine components into systems which can meet multiple needs (46). In addition, internet interventions can be available in the long term for users to return to as and when they want, offering patients with long term conditions information and support according to their ongoing and changing needs. In particular the networked capability of the internet enables interventions to be dynamic and responsive, with content that is changed and updated over time and allows flexibility over time and place of use.

To fully capitalise on the advantages offered by the internet as a mode of intervention delivery, internet interventions for patients with long term conditions should:

- (i) be complex systems with multiple information and support components
- (ii) provide unrestricted access and changing content.

Use of psychological theory in the design and/or evaluation of interventions that share these characteristics will provide the most useful evidence for likely mechanisms of action of an internet intervention for people with CHD.

2.1.3 Background literature on use of psychological theory in internet-based or computer-based interventions

The value of psychological theory for computer or internet-based interventions has been argued from an early stage in the field (45;70;71). This included extensive guidance published in 1999 by the Science Panel on Interactive Communication and Health (45), a collaboration of US researchers, convened by the US Office of Disease Prevention and Health Promotion to assess and direct the emerging field. The panel argued for the use of psychological theory to strengthen intervention design and identified common constructs from theories for this purpose (45;70;71). These were outcome expectations (or perceived benefits and costs), self-efficacy (or perceived behavioural control), intentions (stage of change or motivation), attitudes, causal beliefs (or attributions), normative influences and social support. It was suggested that choice of constructs would depend on the intervention, sample or targeted health behaviour (71). By comparison, guidance for theory-based evaluation has been less widespread and, where given, is less detailed (45;70).

When the current review was conducted, several previous literature reviews of computer-based or internet-based interventions had discussed use of psychological theories in intervention design (72-77). Although most of these reviews identified the theories that were used, none tested whether theory-based interventions resulted in greater change in outcomes or which theory-based interventions were most successful.

Two previous reviews had considered theory-based mechanisms of action of computer-based or internet-based interventions. These reviewed Interactive Health Communication Applications (IHCAs) for people with long term conditions (49), and computer-delivered interventions for health promotion and behavioural risk reduction (50). Both reviews included analyses of change in psychological constructs (49;50). The

first drew on psychological and IHCA literature to identify a hypothesised pathway by which IHCA for people with long term conditions were expected to change health behaviours and clinical outcomes. The pathway included changes in knowledge, self-efficacy, social support, motivation, affect (e.g. anxiety), health behaviours, and clinical outcomes. Meta-analysis was used to test for change along this pathway and found significant positive intervention effects for knowledge, social support, behavioural and clinical outcomes, and a non-significant trend for improved self-efficacy. However, the authors concluded that too few studies measured psychological constructs for the hypothesised pathway of action to be fully tested (49).

The second review selected theoretically meaningful antecedents of health behaviour change (knowledge, attitudes, intentions, social norms and self-efficacy) and conducted meta-analysis of the effects of computer-delivered interventions on each of these psychological constructs and on various health promotion and risk reduction behaviour outcomes. The review found significant small to medium positive effects for knowledge, attitudes, intentions and several types of health behaviours (nutrition, tobacco use, substance use, safer sexual behaviour, binge/purge behaviours, general health maintenance) (50). However, despite coding use of theory in intervention design, it was not tested as a potential moderator of intervention effects. Nor was magnitude of change in psychological constructs investigated as potential moderator of behavioural outcomes.

So, when the current review was conducted, previous reviews had provided little evidence for which psychological theories or constructs explained mechanisms by which reviewed interventions worked. Moreover, while complex and networked interventions were included in these reviews, no distinction was made between them and other computer-based or internet-based interventions or interventions where access

was restricted to single occasions or locations. As a result, findings from previous reviews revealed little about theory-based mechanisms by which complex, networked and freely accessible internet interventions might work for patients with CHD.

More recently, a meta-analytical review has been conducted, which specifically aimed to identify the characteristics of effective internet-delivered interventions for behaviour change (78). This meta-analysis capitalised on the recent development of a taxonomy of theory-linked behaviour change techniques (79) and related coding scheme (80), to categorise interventions according to their use of psychological theory. The meta-analysis found that more extensive use of theory-linked behaviour change techniques by interventions was associated with greater effects on behavioural outcomes (e.g. physical activity, dietary behaviour, alcohol consumption and smoking abstinence). Largest effects were found with interventions based on the theory of planned behaviour (TPB) (78). This meta-analysis focused purely on interventions that were delivered via the internet. However, it is notable that most interventions included in the review targeted a single behaviour, predominantly for health promotion in disease-free samples. Although interventions for people with long term conditions were included, they were not evaluated separately. This limits direct generalisation of the findings of the meta-analysis to the context of an internet intervention for CHD self-management.

2.2 Methods

2.2.1 Relevant literature

The aim of this review (to evaluate the use of psychological theory in the design and evaluation of relevant internet-based or computer-based interventions, and consider evidence for their mechanisms of action) was broad. This meant that useful evidence might come from a wide range of studies. Studies evaluating complex and freely accessible internet-based interventions for people with CHD would provide the most

relevant evidence. However, internet intervention research is a relatively young field and this was likely to limit available evidence. Research which has identified common self-management challenges faced by people managing various long term conditions (13) suggests that interventions used by samples with other long term conditions may also provide relevant evidence. In common with other long term conditions, self-management of CHD also involves managing the impact on mental health (e.g. anxiety or depression) and performing health promoting behaviour (e.g. concerning nutrition, physical activity, smoking cessation, weight management, and reduction of alcohol intake). So the use of psychological theories in the design and/or evaluation of similar mental health or health promotion interventions might also be relevant.

In terms of the interventions themselves, earlier technological platforms (e.g. CD-ROMs or local computer networks) which offered interactivity (e.g. automated information tailoring, feedback or communication between users) might provide additional evidence about mechanisms of action. The same may be true of evaluations of less complex internet-based interventions providing relevant individual components (e.g. tailored information to promote behaviour change, peer support or self-help therapy). Findings from evaluations of these additional types of computer-based or internet-based interventions were also considered in this review for any additional evidence they provide.

The wide range of potentially relevant studies meant that a systematic review approach was not appropriate. Specifying fixed a priori search parameters and applying methodological filters common to systematic review searches might have ruled out types of studies or interventions with relevant evidence. Instead a search strategy was devised which approached the literature in a number of different ways and used intentionally broad terms.

2.2.2 Search strategy

The aim of the search strategy was to identify literature which provided evidence for individual psychological theories and constructs as likely mechanisms of action of internet interventions.

The search strategy included hand searches of literature that had been identified during earlier work in this field (49;81). Hand searches were followed by electronic searches of three large online databases, Medline, PsychINFO and Web of Science. These databases were selected to provide good coverage of both medical and psychological literature.

Both strategies aimed to identify:

- Reviews of relevant interventions to identify relevant primary studies from those cited
- Primary studies describing development or evaluation of relevant interventions.

Relevant publications identified by the hand search were used to generate a list of general and specific terms for use in the electronic searches. The general terms aimed to identify the field of research and included internet, ehealth or e-health, interactiv* (interactive, interactivity), computer* (computerised, computerized, computer-based, computer-delivered), online or on-line, and electronic. The more specific terms aimed to identify types of relevant interventions and included CBT, therap* (therapy, therapeutic), decision and aid or support, support, discussion and group or board.

Where possible search terms were mapped to relevant subject headings used in each database. The terms electronic and discussion (combined with group or board) were abandoned as they did not map onto available subject headings and identified too many irrelevant studies.

Searches were conducted in August 2008. To identify relevant reviews, general terms were combined with each other using the 'OR' operator and limits were applied to restrict search results to English Language reviews (systematic, literature or meta-analysis) published in the last 10 years (1998-2008). To identify relevant primary studies specific terms were also combined with each other using the 'OR' operator and with the same combination of general search terms used to identify reviews using the 'AND' operator. The only limit applied to searches for primary studies was English Language. The Web of Science database did not use subject heading terms so an additional search combination of AND (health OR illness OR disease) was added to focus the search on more relevant papers and reduce the total number of search results to a manageable number. Exact search terms and combinations used in each database are listed in Appendix A.

For the review of the most relevant interventions, interventions were considered relevant if they were:

- internet delivered self-help interventions
- contained multiple information and support components
- provided unrestricted access and changing content

These relevant interventions (and all papers describing them) were included for review if:

- they had been quantitatively evaluated on psychological constructs, health behaviours relevant to CHD and/or other health outcomes relevant to CHD
- psychological theories or constructs were used in their design and/or evaluation

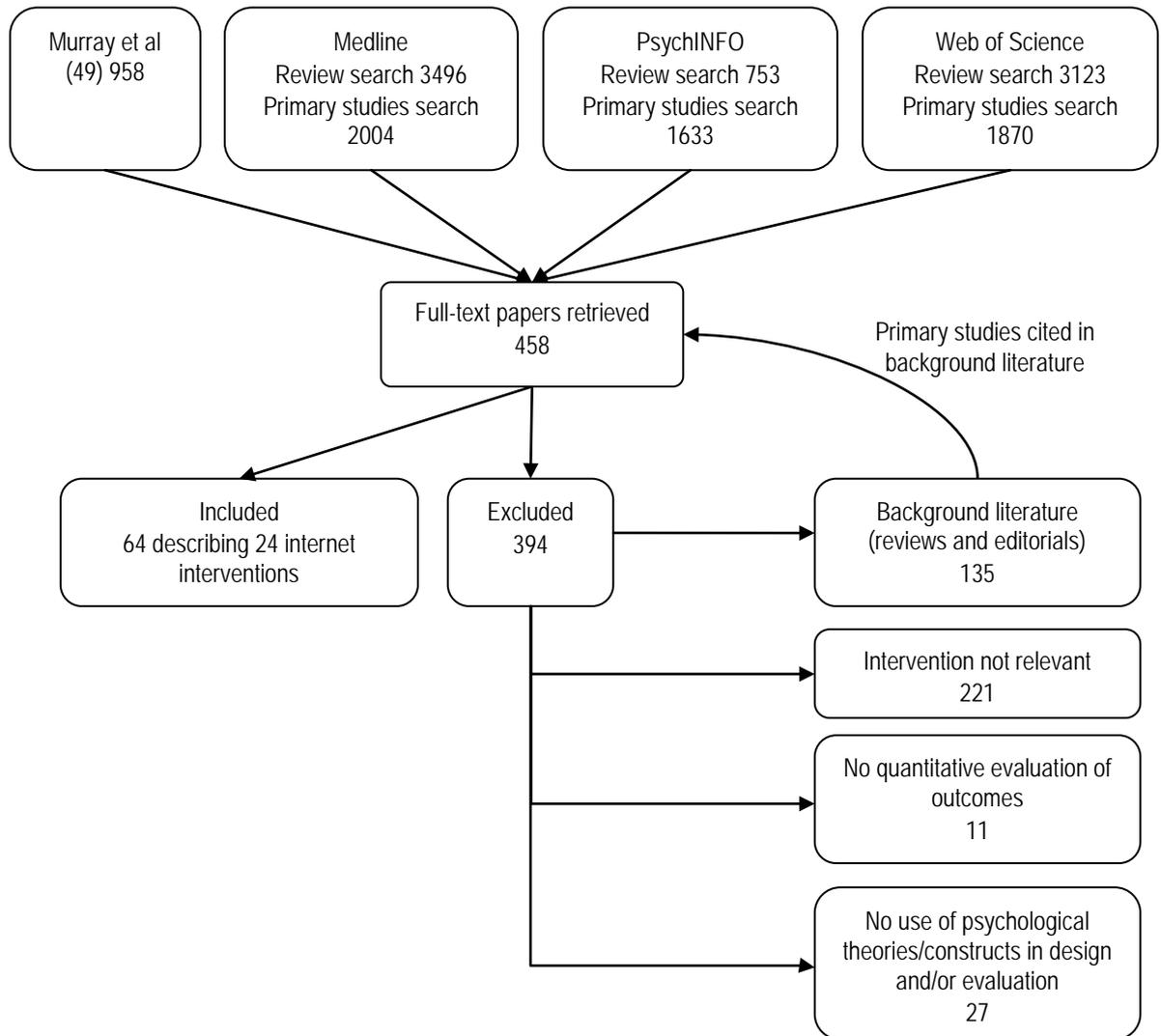
Papers were excluded from the review of the most relevant interventions if they:

- were background literature (reviews and editorials) rather than describing an intervention
- described an intervention that was not relevant because it:
 - was not internet delivered (included interventions with off-line components)
 - was not self-help, e.g. relied heavily on communication with health-care professionals or therapists to deliver intervention content
 - did not contain multiple information and support components
 - did not provide unrestricted access, e.g. interventions designed to be accessed only once or only accessible at a specific time or place
 - targeted outcomes that were not relevant to patients with CHD e.g. mental health problems other than depression or anxiety, health promotion behaviours not relevant to CHD, such as behaviours to prevent skin cancer
 - targeted carers rather than patients or healthy individuals for their own self-management or health promotion
- described an intervention that had not been quantitatively evaluated on psychological constructs, health behaviours and/or other health outcomes
- described an intervention where there was no suggestion that psychological theories or constructs were used in its design and/or evaluation

The process of paper/intervention selection is summarised in Figure 2.1. Titles and abstracts of all papers identified by the electronic searches were screened for relevance (a total of 12879, including duplicates). Judgements over whether an intervention was relevant and whether design of a relevant intervention was guided by psychological

theory or constructs relied on explicit statements made by the authors in their publications. In most cases it was possible to screen the full text of publications to make this judgement as most publications were published in electronically available journals. The number of full-text papers retrieved shown in Figure 2.1 refers to the number of potentially relevant articles that were downloaded and saved for further consideration or as background literature. As the aim was to include evidence from as many relevant interventions as possible, papers cited as providing further information about design and intervention development were also retrieved. For the same reason, studies which evaluated a relevant intervention's effect on psychological constructs were included regardless of whether a theory was explicitly mentioned. The development of a theory-linked taxonomy of behaviour change techniques (79) and related coding scheme (80) means that in future reviews can take a more systematic approach to classifying interventions which relies less on authors report. However, the taxonomy and coding scheme were not available when the current review was conducted. Many of the papers that were excluded because they described interventions that were not relevant contributed to the review of additional evidence from other computer-based or internet-based interventions.

Figure 2.1 Review selection process.



2.3 Results

2.3.1 Relevant interventions

The literature searches identified 24 complex and networked computer-based or internet-based interventions where psychological theories or constructs had been used in intervention design and/or evaluation. Table 2.1 provides details of the interventions and design of the studies evaluating them. In the following sections individual interventions are referred to by the names listed in Table 2.1.

The earliest complex and networked computer-based or internet-based interventions were developed in the early 1990s for people with HIV or AIDS by the American

Computer Link and CHESS (Comprehensive Health Enhancement and Support System) research teams. The field has continued to be dominated by interventions developed in the USA, accounting for 20 of the interventions identified. Publications describing interventions developed by European research teams did not appear until 10 years later. Most interventions were designed to provide information and support for managing a specific long term condition, including HIV/AIDS (Computer Link, CHESS HIV/AIDS), breast cancer (CHESS Breast Cancer, Bosom Buddies), diabetes (D-NET, Women to Women Diabetes, Take Charge), heart disease (CHESS Heart Disease, Heartnet) and COPD (eDSMP). However, from 2002 onwards a number of interventions were designed to meet common needs of people managing various long term conditions (STARBRIGHT, Women to Women Chronic Disease, Internet CDSMP). Other interventions targeted a single area of lifestyle change for health promotion, in all cases either diet or exercise. While some of these interventions were aimed at secondary prevention among people with long term conditions or physical disability (D-NET Active Lives, Heart-Web, Physical Activity Program, E-CHANGE), most were aimed at primary prevention among relatively healthy samples (Dietary Skill-Building, WIN, HIP-Teens, Tailored Physical Activity Advice, Mediterranean Eating, Get Active, Family Eats). These included all of the interventions designed by European research teams.

Table 2.1 Details of interventions using psychological theory in their design and/or evaluation.

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
Computer Link (82;83)	AIDS	USA	1994 – 1998	Specialised computer network Information + Peer support + Ask an expert + Decision support	6 months	Randomised trial of intervention vs control (printed brochures and monthly telephone call)	51 immunology outpatients with AIDS (25 intervention, 26 control)	Baseline and 6 months
CHES HIV/AIDS (84-88)	HIV/AIDS	USA	1994 – 1999	Information + Peer support + Ask an expert + Decision support + Behaviour change support	6 months (Cohort 1) 3 months (Cohorts 2 + 3)	Randomised trial of intervention vs control conducted in 3 cohorts	204 HIV+ patients (107 intervention, 97 control) 58 in Cohort 1 (30 intervention, 28 control) 146 in Cohorts 2+3 sample (77 intervention, 69 control)	Baseline, 2, 5 months and 9 months (Cohort 1) Baseline, 2 and 5 months only (Cohorts 2+3)
CHES Breast Cancer (87-93)	Breast cancer	USA	1995 – 2005	Information + Peer support + Ask an expert + Decision support + Behaviour change support	6 months	Randomised trial of intervention vs control (relevant book)	246 women aged <60 years, newly diagnosed women with breast cancer and receiving hospital treatment. (125 intervention, 121 control)	Baseline, 2 and 5 months

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
D-NET (94-99)	Type 2 Diabetes	USA	1998 – 2003	4 versions: Information only Information + Tailored self-management training Information + Peer support Information+ Tailored self-management training + Peer support	10 months	Randomised trial comparing the 4 intervention versions	320 primary care patients diagnosed with Type 2 diabetes ≥ 1 year, with little or no previous internet experience (80 in each intervention group)	Baseline, 3 months and 10 months
CHES Heart Disease (100)	Heart disease	USA	2000	Information + Peer support + Ask an expert + Behaviour change support	6 months	Randomised trial of intervention vs control (usual care)	52 patients who recently had a heart attack or heart surgery (25 intervention, 27 control)	Baseline and 6 months
Women to Women Diabetes (101;102)	Diabetes	USA	2000	Information + Peer support	5 months	Randomised trial of intervention vs control	30 women (35-60 years old) with diabetes living in rural areas (15 intervention, 15 control)	Baseline, 2.5, 5, 7.5 and 10 months
D-NET Active Lives (103)	Type 2 diabetes	USA	2001	Information + Peer support + Online coach providing tailored information and ask an expert) + Behaviour assessment, planning and tracking tools	8 weeks	Randomised trial intervention vs control (diabetes information articles and glucose-tracking)	78 internet-users aged ≥ 40 years with Type 2 diabetes and low levels of physical activity. (38 intervention, 40 control)	Baseline and 8 weeks
STARBRIGHT (104;105)	Children with long term conditions	USA	2002	Private hospital-based computer network Information + Peer support + Interactive educational games + Health activities	Depended on length of hospitalisation (mean hospitalisation 4 to 5 days)	Non-random comparison of intervention vs control	110 children aged 8-18 years, hospitalised with sickle-cell disease or asthma (50 intervention, 60 control)	Baseline and before discharge from hospital (depended on length of hospitalisation).

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
Bosom Buddies (106)	Breast cancer	USA	2003	Information about peer experiences + Professionally moderated educational peer discussion + Journal	12 weeks	Randomised trial of intervention vs control (waiting list)	72 women diagnosed with breast cancer in the preceding 32 months (36 intervention, 36 control)	Baseline and 12 weeks
Women to Women Chronic Disease (107-109)	Long term conditions (including heart disease)	USA	2003 – 2006	Information + Peer support	5 months	Randomised trial of intervention vs control	100 women (aged 35-65 years) with diabetes, rheumatoid arthritis, heart disease, cancer or multiple sclerosis and living in rural areas (43 intervention, 57 control)	Baseline and 3 months
Dietary Skill-Building (110)	Health promotion for poor diet	USA	2004	Information + Ask an expert + Weekly peer/expert support + Twice monthly educational e-mail, voicemail or letter	6 months	Randomised trial of internet intervention vs weekly face-to-face intervention vs control (usual care)	98 healthy men and women who were in precontemplation, contemplation or preparation stages for dietary goals (33 internet intervention, 33 face-to-face intervention, 32 control)	Baseline and 6 months
Heartnet (111)	Heart transplant	USA	2004	Information + Peer support + Ask an expert + Skills workshops	4 months	Non-random, historic comparison between intervention and control (usual care enrolled in previous studies)	64 recipients of heart transplants within the preceding 6-36 months and 60 caregivers (24 patients + 20 caregivers intervention, 40 patients + 40 caregivers)	Baseline and 4 months

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
Heart-Web (112)	Health promotion for increased cardiovascular risk	Canada	2004	Tailored nutritional counselling + Peer support	8 months	Randomised trial of intervention vs control (usual care)	146 primary care patients aged ≥ 40 years with hypertension, diabetes and/or high cholesterol (73 intervention, 73 control)	Baseline, 4 and 8 months
WIN (113)	Health promotion for poor nutrition	USA	2004	Information resources + Tailored information (online and weekly e-mails) + Peer support	12 weeks	Non-random before and after comparison	84 employees at a corporate work-site	Baseline and 12 weeks
HIP-Teens (114-116)	Health promotion for overweight adolescents	USA	2004 – 2006	Information lessons + 4 face to face sessions in first 12 weeks + Online counselling (weekly contact with therapist) + Daily diet monitoring with automated and nutritional expert feedback + Peer support + Knowledge quizzes	2 years	Randomised trial of intervention vs control (information-only website)	55 family pairs of overweight African American adolescent girls and obese parents (28 intervention, 27 control)	Baseline, 6 12, 18 and 24 months
Tailored Physical Activity Advice (117-120)	Health promotion for low levels of physical activity	Belgium	2004 – 2007	2 versions: Information + Tailored feedback + Behaviour change support + Peer support Information + Tailored feedback + Behaviour change support + Peer support + reminder e-mails + 2 nd assessment and tailored feedback after 3 months	6 months	Cluster randomised trial of versions of intervention vs control (waiting-list)	434 healthy parents and staff aged 20-55 years from primary and secondary schools in three geographical areas (3 clusters). (129 intervention group 1, 173 intervention group 2, 132 control)	Baseline and 6 months (intervention 1 and control) Baseline, 3 and 6 months (Intervention 2)

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
Physical Activity Program (121;122)	Physical disabilities	USA	2005	2 versions: Sequential information available weekly Sequential information available weekly + Peer support	4 weeks	Randomised trial of the two intervention versions vs control (sent thought of the week and encouraging messages by e-mail)	151 patients with physical disabilities in precontemplation, contemplation or preparation stages for physical activity. (50 intervention group 1, 51 intervention group 2, 50 control - intervention groups combined for analysis)	Baseline, 4 weeks and 6 months
Mediterranean Eating (123;124)	Health promotion for poor diet	UK	2005 – 2006	Information + Behaviour assessment and change support to set and meet a series of 6-week dietary goals + Tailored email feedback	6 months	Non-random comparison between intervention and control (minimally tailored dietary feedback to baseline questionnaire + healthy eating booklets)	72 healthy female university employees aged 25-55 years. (53 intervention, 19 control)	Baseline and 6 months
eDSMP - internet dyspnoea self-management program (125;126)	Chronic obstructive pulmonary disease (COPD)	USA	2005 – 2008	Information + Peer support + Behaviour change monitoring supported by personal digital assistant (PDA) + 6 weekly nurse-led live chat educational sessions	6-months	Randomised trial of eDSMP intervention vs face-to-face group DSMP intervention	50 internet users with COPD. (26 internet intervention, 24 face-to-face intervention)	Baseline, 3 and 6 months

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
Internet CDSMP - chronic disease self-management program (127)	Long term conditions (including heart disease, lung disease or type 2 diabetes)	USA	2006	Information + Peer support	6 weeks	Randomised trial of intervention vs control (usual care) Non-random comparison between subsample of internet CDSMP intervention and face-to-face group CDSMP intervention	Randomised comparison: 958 internet users with heart disease, chronic lung disease or type 2 diabetes (457 intervention, 501 control) Non-random comparison: 189 patients with heart or lung disease (136 internet intervention, 153 face-to-face intervention)	Baseline, 6 and 12 months
Get Active (128;129)	Health promotion for low levels of physical activity	UK	2006 – 2007	Information + Behaviour-change assessment, monitoring, tailored and charted feedback supported by accelerometer and email or phone reminders + Peer support	9 weeks	Randomised trial of intervention vs control	77 healthy men and women aged 30-55 years not vigorously physically active (47 intervention, 30 control)	Baseline and 9 weeks
E-CHANGE (130)	Recovery from heart bypass surgery	USA	2007	Nurse-led WebTV intervention Sequential information modules + Structured exercise tracking and graphing tools + Nurse support	3 months	Non-random comparison between intervention and matched control	25 participants in a cardiac rehabilitation programme who had experienced a cardiac event. (7 intervention, 18 control)	Continuous from baseline for 6 months (portable heart rate monitors and diaries)
Take Charge (131)	Diabetes	USA	2007	Information + Behaviour monitoring tools + Nurse feedback and support + Weekly nurse-led educational discussion	6 months	Randomised trial of intervention vs control (usual care)	62 patients aged ≥ 60 years diagnosed with diabetes (type 1 or 2) ≥ 1 year (31 intervention, 31 control)	Baseline and 6 months

Intervention name	Health problem	Country	Year(s) of publication(s)	Intervention content	Intervention access	Evaluation design	Sample	Measurement time-points
Family Eats (132)	Health promotion for African American families	USA	2008	Information + Weekly cartoons depicting family situations around healthy eating + Activities, goals and problem – solving	8 weeks	Non-random before and after comparison	67 African American families (parent and 9-12yr old daughter) with home internet access	Unclear, most likely baseline and after 8 weeks

2.3.2 Psychological theories and constructs used

A number of psychological theories or constructs were used in the design or evaluation of the relevant interventions. Brief descriptions of these psychological theories and their main constructs are given in Table 2.2. Their use in the design and/or evaluation of the relevant interventions is summarised in Table 2.3.

Use of psychological theory in intervention design

Nine interventions were guided by a single psychological theory (CHESS Heart Disease, D-NET Active Lives, Family Eats, Heartnet, Internet CDSMP, Physical Activity Program, WIN, Women to Women Chronic Disease, Women to Women Diabetes). However, more often, interventions were guided by a number of constructs drawn from multiple psychological theories (12 interventions: CHESS Breast Cancer, CHESS HIV/AIDS, Dietary Skill-Building, D-NET, E-CHANGE, eDSMP, Get Active, Heart-web, Mediterranean Eating, STARBRIGHT, Tailored Physical Activity Advice, Take Charge).

Table 2.3 shows that social cognitive theory (SCT, in particular self-efficacy) was the psychological theory most frequently used to guide intervention design (12 interventions), followed by social support theory (8 interventions). Four psychological theories (or their constructs) have only been used to guide the design of interventions that were also guided by constructs drawn from other psychological theories (theory of reasoned action/theory of planned behaviour (TRA/TPB), health belief model (HBM), transactional model of stress and coping, goal setting theory). The precaution adoption process model (PAPM) has only guided the design of interventions aimed at primary prevention among relatively healthy samples.

Use of psychological theory in intervention evaluation

Psychological theories or constructs were used less frequently to evaluate interventions. Although 17 interventions were evaluated on change in at least one psychological construct, only 10 interventions were evaluated on change in psychological constructs from theories used to guide their design. This included 7 of the interventions with design guided by a single psychological theory (CHESS Heart Disease, Family Eats, Internet CDSMP, Physical Activity Program, WIN, Women to Women Chronic Disease, Women to Women Diabetes), but only 3 of the interventions with design guided by constructs from multiple theories (eDSMP, Heart-web, STARBRIGHT). Seven interventions were evaluated on change in psychological constructs from theories that were not used in their design (Computer Link, CHESS Breast Cancer, CHESS Heart Disease, Bosom Buddies, Women to Women Chronic Disease, HIP-Teens, eDSMP).

Table 2.3 shows that social support (9 interventions) was the most frequently evaluated psychological construct, followed by self-efficacy (7 interventions). Intervention effects on constructs from four psychological theories were rarely or never evaluated (HBM, transactional model of stress and coping, PAPM, Goal setting theory).

Table 2.2 Psychological theories and constructs used in the design and/or evaluation of relevant interventions.

Brief descriptions of psychology theories – based on overviews given in (133;134)

Psychology theories	Key constructs	Details of theory
Social Cognitive Theory (SCT)	<ul style="list-style-type: none"> • Self-efficacy - an individual's confidence in his or her own ability to carry out a particular behaviour • Outcome expectations - an individual's beliefs about the outcomes that are likely to result from a particular behaviour or situation 	<ul style="list-style-type: none"> • People are motivated to perform behaviours they are confident they can carry out (self-efficacy) and that they believe will produce desired outcomes (outcome expectation). • Self-efficacy is an important predictor of choice of behaviour, the effort an individual is prepared to expend and their level of persistence in performing a behaviour as well as their thought patterns and emotional reactions. Outcome expectations are highly dependent on self-efficacy. • A number of learning strategies increase self-efficacy including modelling (learning through the observation of other's actions and resulting outcomes).
Social Support	<ul style="list-style-type: none"> • Social support - the functional content of social relationships • Emotional support - the provision of empathy, love, trust and caring • Informational support - the provision of advice, suggestions, and information that a person can use to address problems • Instrumental support - the provision of tangible aid and services that directly assist a person in need 	<ul style="list-style-type: none"> • Social support has been conceptualised as having various dimensions, most commonly emotional support, information support and instrumental support • Perceived social support is more strongly linked to recipients' health and well-being than other social support measures (e.g. behaviours involved in social interactions or social network size). • Perceived social support is thought to influence health outcomes both directly and indirectly through influencing individual coping resources and buffering the effect of stress on health.

Psychology theories	Key constructs	Details of theory
Transtheoretical Model (TTM)	<ul style="list-style-type: none"> • Stages of change: <ul style="list-style-type: none"> ○ Precontemplation - not intending to change behaviour in the next 6 months ○ Contemplation - thinking about making a change in the next six months but not committed to taking action ○ Preparation – planning to change behaviour in the next month ○ Action - engaged in making a change in behaviour ○ Maintenance – change initiated (action) at least 6 months ago ○ Decisional balance – relative weighing of pros (perceived benefits) and cons (perceived barriers and costs) of changing • Processes of change – activities for progression through the stages of change 	<ul style="list-style-type: none"> • Change process is conceived as 5 distinct and sequential stages of change: precontemplation, contemplation, preparation, action, and maintenance. • The specific processes of change that will assist progression through the stages of change differ according to an individual's current stage. • The model uses constructs specified in other social cognition models (e.g. self-efficacy, perceived benefits, perceived barriers) for the process of adoption and maintenance of behaviour laid out in the stages of change. • Processes of change which facilitate decisional balance are more important for transition through earlier stages of change, whereas increasing self-efficacy is more important for transition from contemplation through preparation and action stages. • Examples of processes of change include seeking and using social support.
Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)	<ul style="list-style-type: none"> • Intentions - motivation required to perform a particular behaviour • Attitudes – beliefs about the behaviour combined with an evaluation of outcomes of the behaviour • Subjective norms - perception of social pressure, beliefs about social norms combined with individual's motivation to comply with these norms • Perceived behavioural control - perceived ease or difficulty of performing behaviour from a combination of perceived control and perceived power 	<ul style="list-style-type: none"> • Based on the assumption that individuals are conscious of and consider the consequences of specific actions before acting. • Behaviours are mainly determined by intentions. The more one intends to perform a behaviour, the more likely one is to carry out the behaviour. • Intention is determined by attitudes towards the behaviour and subjective norms. The relative importance of subjective norms and own attitude towards a behaviour varies from person to person. • The additional construct of perceived behavioural control was proposed in the TPB to predict both intentions and behaviour, extends the TRA to apply to behaviours not completely under an individual's volitional control.

Psychology theories	Key constructs	Details of theory
Health Belief Model (HBM)	<ul style="list-style-type: none"> • Perceived susceptibility - belief about the chance of experiencing a particular health problem • Perceived severity – belief about seriousness of the health problem and its potential consequences • Perceived benefits – beliefs about the efficacy of a particular behaviour in reducing the risk or seriousness of the impact of a health problem • Perceived barriers – beliefs about the costs or difficulties attached to performing the behaviour 	<ul style="list-style-type: none"> • Uses two aspects of an individual's representations of health behaviour to predict response to an illness threat: (i) perceptions of illness threat and (ii) evaluation of behaviours to counteract that threat. • Perceived susceptibility combines with perceived severity to produce perceived threat, and perceived benefits combines with perceived barriers to produce an evaluation of the behaviour or course of action to be taken. • People are more likely to engage in a health action if they believe: (i) they are at risk of a condition or problem they consider to be severe (ii) the health action can protect them against the threat and (iii) the barriers to doing so do not outweigh the potential benefits. • The construct of self-efficacy was added in later conceptualisations of the HBM to make the model more applicable to sustained behaviour change such as lifestyle change rather than one-off preventive actions.
Transactional Model of Stress and Coping	<ul style="list-style-type: none"> • Appraisals: <ul style="list-style-type: none"> ○ Primary – evaluation of the potential threat ○ Secondary – self-evaluation of ability to alter the situation and manage negative emotional reactions • Coping strategies: Responses aimed at altering the situation and regulating emotional reactions. These can include: <ul style="list-style-type: none"> ○ Problem-focused coping – coping strategies aimed at changing a stressful situation ○ Emotion-focused coping – coping strategies aimed at changing the way one thinks or feels about a stressful situation ○ Avoidance – coping strategies aimed at avoiding thoughts and feelings about the stressful situation. 	<ul style="list-style-type: none"> • Stressful situations are seen as person-environment transactions where the effect is mediated by appraisal of both the stressor and available resources and abilities. • Choice of coping strategies depends on the outcomes of primary and secondary appraisals. • Problem-focused coping is considered more adaptive for managing stressors that are changeable • Emotion-focused coping is considered most adaptive for stressors which are not controllable or where all available problem-focused strategies have already been tried. • Avoidant coping may be adaptive in the short-term to reduce initial distress but is considered a maladaptive response to long-term stressors with negative psychological well-being and health behaviour outcomes. • Social support is a coping resource which influences both secondary appraisal and coping strategies.

Psychology theories	Key constructs	Details of theory
Precaution Adoption Process Model (PAPM)	<ul style="list-style-type: none"> • Stages of change: <ul style="list-style-type: none"> ○ Unaware of issue ○ Unengaged by issue – no longer unaware but not engaging with decision-making ○ Deciding about acting – engaged by the issue and considering response ○ Decided not to act – one possible end to the precaution adoption process ○ Decided to act – planning initiated but not acting ○ Acting – initiating behaviour ○ Maintenance – maintaining behaviour over time 	<ul style="list-style-type: none"> • Aims to explain how an individual comes to a decision to act and how decision translates into action • Stage-based model which recommends intervention should be tailored to individuals' stage of change • Emphasis on awareness and decision-making for deliberate action to distinguish stages rather than intended and actual time of action.
Goal-Setting Theory	<ul style="list-style-type: none"> • Implementation intentions – plans as to when, where and how an intended goal will be translated into action 	<ul style="list-style-type: none"> • Example of a behavioural enaction model which specify processes by which intentions to perform behaviours become actions. • Goal-setting strategies include making implementation intentions where an individual makes a commitment to a specific course of action that relates to specific environmental conditions so that when the specific environmental conditions are met the behaviour is more likely to be performed.

Table 2.3 Summary of use of constructs from psychological theories in design/evaluation of relevant interventions and change found in constructs/health outcomes.

Psychological theory	Construct(s) used	Intervention name (alphabetical by construct)	Use of psychological theory		Any significant change (compared to control where applicable)	
			Intervention design	Evaluation	Construct	Health Outcome(s)
Social Cognitive Theory (SCT)	Self-efficacy	Bosom Buddies	✘	✓	✘	✓
		CHESS Breast Cancer	✓	✘	-	✘
		CHESS Heart Disease	✓	✓	?	-
		CHESS HIV/AIDS	✓	✘	-	✓
		Dietary Skill-Building	✓	✘	-	✘
		D-NET (versions with SCT-based component)	✓	✘	-	✓
		E-CHANGE	✓	✘	-	?
		eDSMP	✓	✓	✓	✓
		Family Eats	✓	✓	✓	-
		HIP-Teens	✘	✓	?	✓
		Internet CDSMP	✓	✓	✘	✓
		Tailored Physical Activity Advice	✓	✘	-	✓
		Take Charge	✓	✘	-	✓
		Mediterranean Eating	✓	✘	-	✓
	Women to Women Chronic Disease	✘	✓	✘	✘	
	Outcome expectancies	Dietary Skill-Building	✓	✘	-	✘
		E-CHANGE	✓	✘	-	?
	Skills modelling	Family Eats	✓	✓	✓	-

Psychological theory	Construct(s) used	Intervention name (alphabetical by construct)	Use of psychological theory		Any significant change (compared to control where applicable)	
			Intervention design	Evaluation	Construct	Health Outcome(s)
Social support	Perceived social support	CHESS Breast Cancer	✗	✓	✓	✗
		CHESS HIV/AIDS	✗	✓	✓	✓
		Computer Link	✗	✓	✓	✗
		D-NET (versions with social support-based component)	✓	✓	✓	✗
		eDSMP	✓	✓	✗	✓
		Heartnet	✓	✗	-	✓
		Heart-web	✓	✓	✗	✗
		STARBRIGHT	✓	✓	✓	-
		Tailored Physical Activity Advice	✓	✗	-	✓
		Women to Women Chronic Disease	✓	✓	✓	✗
		Women to Women Diabetes	✓	✓	✗	✗
Transtheoretical model (TTM)	Stages of change	Dietary Skill-Building	✓	✗	-	✗
		eDSMP	✗	✓	?	✓
		Heart-Web	✓	✓	✗	✗
		Mediterranean Eating	✓	✗	-	✓
		Physical Activity Program	✓	✓	✗	✓
		Tailored Physical Activity Advice	✓	✗	-	✓
	Perceived benefits and barriers/decisional balance	Dietary Skill-Building	✓	✗	-	✗
		Get Active	✓	✗	-	✓
		Tailored Physical Activity Advice	✓	✗	-	✓
	Processes of change	CHESS Heart Disease	✗	✓	?	-
Physical Activity Program		✓	✗	-	✓	

Psychological theory	Construct(s) used	Intervention name (alphabetical by construct)	Use of psychological theory		Any significant change (compared to control where applicable)	
			Intervention design	Evaluation	Construct	Health Outcome(s)
Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)	Attitudes	CHES Breast Cancer	✓	✗	-	✗
		CHES HIV/AIDS	✓	✓	?	✓
		Get Active	✓	✗	-	✓
		Mediterranean Eating	✓	✗	-	✓
		Tailored Physical Activity Advice	✓	✗	-	✓
	Normative beliefs	CHES Breast Cancer	✓	✗	-	✗
		CHES HIV/AIDS	✓	✗	-	✓
	Intentions	Get Active	✓	✓	✓	✓
		Tailored Physical Activity Advice	✓	✗	-	✓
	Perceived behavioural control	Get Active	✓	✓	✓	✓
		Mediterranean Eating	✓	✗	-	✓
	Social norms	Mediterranean Eating	✓	✗	-	✓
	Health Belief Model (HBM)	Perceived barriers	CHES HIV/AIDS	✓	✗	-
D-NET			✗	✓	✗	✓
D-NET Active Lives			✓	✗	-	✗
E-CHANGE			✓	✗	-	?
Mediterranean Eating			✓	✗	-	✓
Take Charge		✓	✗	-	✓	
Perceived benefits	D-NET Active Lives	✓	✗	-	✗	
Transactional model of stress and coping	Emotion-focused coping	CHES Breast Cancer	✓	✗	-	✗
		CHES HIV/AIDS	✓	✗	-	✓
	Problem-focused coping	CHES Breast Cancer	✓	✗	-	✗
		CHES HIV/AIDS	✓	✗	-	✓
	Positive coping	STARBRIGHT	✓	✓	✓	-
Negative coping	STARBRIGHT	✓	✓	✓	-	

Psychological theory	Construct(s) used	Intervention name (alphabetical by construct)	Use of psychological theory		Any significant change (compared to control where applicable)	
			Intervention design	Evaluation	Construct	Health Outcome(s)
Precaution Adoption Process Model (PAPM)	Awareness	Mediterranean Eating	✓	✗	-	✓
	Stage of change	WIN	✓	✓	✓	✓
Goal setting theory	Goal setting	Get Active	✓	✗	-	✓
		Take Charge	✓	✗	-	✓

Key: ✓ = yes ✗ = no - = not measured ? = unclear whether change was significant

2.3.3 Evaluation of psychological theories and constructs as mechanisms of intervention action

Table 2.3 also summarises change in psychological constructs and health outcomes found by evaluations of the relevant interventions identified. The most informative evaluations were those of interventions that:

- achieved positive change in psychological constructs and health outcomes (CHESS HIV/AIDS, eDSMP, Get Active, WIN)
- achieved positive change in psychological constructs but not health outcomes (D-NET (versions with social support-based components), Women to Women Chronic Disease, CHESS Breast Cancer, Computer Link)
- achieved positive change in health outcomes without significantly changing psychological constructs (Bosom Buddies, Internet CDSMP, Physical Activity Program)

Interventions that were guided by a single psychological theory and achieved positive change in health outcomes were also informative to some extent, even if relevant psychological constructs were not evaluated (D-NET (versions with SCT-based components)).

Evaluations of intervention effects on psychological constructs only, or where the effect on psychological constructs or health outcomes was unclear, were less informative (CHESS Heart Disease, Family Eats, HIP-Teens, STARBRIGHT); as were interventions that achieved no significant change in either psychological constructs or health outcomes (Heart-web, Woman to Woman Diabetes). Least informative were interventions designed using multiple theories or constructs, where change in relevant psychological constructs was not evaluated. Lack of theory-based evaluation meant that

for five interventions which achieved positive change in health outcomes, it was unclear which out of the multiple theories used in design provided the mechanism by which the intervention worked (E-CHANGE, Heartnet, Mediterranean Eating, Take Charge, Tailored Physical Activity Advice). Two other interventions using multiple psychological theories did not achieve positive change in health outcomes, and were not evaluated on change in psychological constructs (D-NET Active Lives, Dietary Skill Building).

The following sections consider findings for evidence of mechanisms of intervention action. Firstly, evidence from evaluations of the few interventions used by people with CHD is reviewed, as this is the most directly relevant. Then evidence from all of the interventions is considered by taking each theory in turn, starting with the most frequently used.

Interventions used by people with CHD

Only three relevant interventions were designed specifically for people with heart disease (CHESS Heart Disease, Heartnet and E-CHANGE). Unfortunately evaluations of interventions revealed little, if anything about their mechanisms of action. Only one evaluated psychological constructs (CHESS Heart Disease). This did report positive change in self-efficacy and processes of change, however, this small pilot evaluation did not measure any other outcomes and was only briefly reported without details of measures, analysis or magnitude of change. So it is unclear how change in psychological constructs was tested, what change was found and what effect this change might have had on any health outcomes.

Two more informative evaluations were conducted on interventions used by people managing various long term conditions, which included people with heart disease (Women to Women Chronic Disease, Internet CDSMP). Both were evaluated on

relevant theory-based intermediate outcomes in randomised controlled comparisons with control groups who received no intervention. Despite this, the evidence they provided for mechanisms of action of these interventions was not strong. Women to Women Chronic Disease was based on social support theory and was found to significantly improve social support but not self-efficacy compared to the control group. However, the intervention did not achieve positive change in depression, so the evaluation provided no evidence that improvements in social support resulting from the intervention in turn resulted in any improvement in health outcomes.

Internet CDSMP was based on SCT and developed from an earlier face-to-face version of the intervention. It was found to achieve improvements in certain exercise behaviour (stretching and strengthening) and quality of life outcomes (health distress, fatigue, pain, shortness of breath) compared to the control group. Correlational analysis found that change in self-efficacy from baseline to 6 months was significantly related to quality of life improvements at 12 months. This seems to provide some evidence for self-efficacy as the mechanism by which this intervention worked. However, two important limitations of the evaluation undermine this conclusion. Firstly, despite a large sample size (nearly 1000 participants), the intervention did not significantly improve self-efficacy compared to control, although there was a non-significant positive trend in this direction at 12 months. Secondly the reliability and validity of measures used in the evaluation were unclear. The construct of self-efficacy was measured with a single item, validated only by its previous use in studies evaluating the face-to-face version of the intervention and not against any previously validated measure of the construct. This was also true of the health behaviour and most of the quality of life outcomes on which the Internet CDSMP was found to have positive effects. As a result the reliability of these measures and their validity in measuring the construct of self-efficacy, health behaviour or domains of quality of life is unclear.

All relevant interventions

Social Cognitive Theory (SCT)

Significant positive effects on self-efficacy were found for only 2 of the 7 interventions where it was evaluated (eDSMP, Family Eats). One of these (eDSMP) also achieved positive effects on exercise health behaviour and quality of life equivalent to or better than those achieved by the comparator face-to-face intervention. Moreover, no positive intervention effect was found on social support, making self-efficacy appear the more likely mechanism by which eDSMP achieved positive effects in health outcomes.

However, this conclusion is undermined by several limitations to the evaluation. Firstly, eDSMP may not have been responsible for the positive effects found in the intervention group. All eDSMP participants first received an intensive nurse assessment to develop an individualized exercise plan based on baseline exercise performance and exercise stage of change. This may have had more of an effect than the eDSMP because participants made low use of the interactive components of the internet intervention and positive change was also found in exercise stage of change. Other limitations include the small sample (n=50), technical problems with eDSMP (which resulted in the evaluation being stopped early), and significant differences found on a number of baseline characteristics between the completing participants and those who dropped out. Finally, the construct of self-efficacy was measured with a single item, validated only by its previous use in studies evaluating the face-to-face version of the intervention and not against any other measure of self-efficacy.

The other intervention which achieved positive effects on parental self-efficacy for diet behaviours, also achieved positive effects on daughters modelling their parent eating fruit (Family Eats). This was the only study to evaluate an SCT construct other than self-efficacy. However, this was a small pilot evaluation with no control group and no health outcomes were measured.

The effect on self-efficacy was unclear in evaluations of two interventions where it was measured (CHESS Heart Disease, HIP-Teens). Although positive effects on self-efficacy were reported for CHESS Heart Disease, the limitations of this briefly reported pilot study with no evaluated health outcomes have already been discussed. HIP-Teens achieved positive effects in health behaviour and physical markers of health behaviour, and was the only evaluation which included statistical analysis of mediators of intervention effects. However, self-efficacy was not found to qualify as a mediator. This means that 6-month change in self-efficacy either did not differ between groups, or did not correlate with change in body fat, although it is not clear which from the study report. Despite the more complex analysis of intervention effects, this evaluation only involved a small sample (55 family pairs). This means that it was unlikely to have had sufficient power to detect mediator effects and the evidence it provided against self-efficacy as a mediator of intervention effects is weak.

Although the SCT-based Internet CDSMP did not significantly improve self-efficacy, the authors proposed self-efficacy as the likely mechanism by which it improved certain exercise behaviour and quality of life outcomes compared to control groups. This was based on a non-significant positive trend in self-efficacy at 12 months and correlational analysis which associated change in self-efficacy from baseline to 6 months to quality of life improvements at 12 months. However, doubts introduced by the lack of significant improvement in self-efficacy, given the large sample size and the measures (lacking established validity and reliability), undermine this conclusion. Neither of the other two interventions that did not achieve significant improvement in self-efficacy was based on SCT (Bosom Buddies, Women to Women Chronic Disease, HIP-Teens). Both resulted in positive effects on emotional outcomes, which suggest these were achieved through mechanisms other than self-efficacy.

Two interventions guided by SCT measured psychological constructs from other theories (but not SCT) and achieved positive change in health outcomes (CHESS HIV/AIDS, D-NET (versions with SCT-based components)). As CHESS HIV/AIDS also achieved improvements in social support and attitudes, social support theory or TRA/TPB may more likely explain the mechanism by which positive change in affect was achieved than SCT. For the versions of D-NET with SCT-based components, marginally significant improvements in quality of life were found at 3 months, although these were only short-term and were not sustained to 10 months. These short-term positive effects on quality of life were not found for the control group or those with the purely social support-based component. Social support was found only to increase in groups with versions of the intervention that contained the social support component, so positive effects of SCT-based versions of the intervention on quality of life were unlikely to be explained by social support. As the theory on which the effective components were based, SCT may provide the mechanism by which they worked, although this would have been clearer if constructs from SCT had also been measured.

Social Support

Positive effects on social support were found for 6 of the 9 interventions where it was evaluated (ComputerLink, CHESS HIV/AIDS, CHESS Breast Cancer, D-NET (versions with social support-based components), STARBRIGHT, Women to Women Chronic Disease). However, only one intervention that improved social support also found positive effects on any health outcomes (CHESS HIV/AIDS). So while relevant interventions may have improved social support, there was little evidence that this in turn resulted in improvements in health outcomes.

The exception, CHESS HIV/AIDS, improved social support, negative affect and quality of life (cognitive functioning and active life) at 2 months compared to the control group.

However, changes in both social support and negative emotion were sustained to 5 months only when participants were given longer access to the intervention. For participants who were only given 3 months' access to the intervention, one quality of life measure (cognitive functioning) was significantly worse than the control group at 5 months. This suggests that prolonged access to the intervention was a factor in improving quality of life. However, the longer intervention access also had a positive effect on attitudes, so the positive intervention effects on health outcomes may equally be explained by the TRA/TPB. Unfortunately, the authors did not specify any of the outcome measures that were used in this evaluation, nor any information about their reliability or validity. This undermines any conclusions that can be drawn.

One of the three interventions that did not improve social support (eDSMP) did improve some exercise health behaviour (endurance and strengthening physical activity) compared to a face-to-face intervention. This intervention also improved other exercise health behaviour (exercise performance) and physical quality of life equivalent to the face-to-face intervention group. This is a positive effect of the internet intervention in this type of comparison. As for Internet CDSMP, eDSMP was based on a similar face-to-face intervention and the evaluation suffered from similar limitations introduced by measures validated only by previous use in studies evaluating the face-to-face version. However, despite these limitations, the findings still suggested that something other than social support was the mechanism of the positive intervention effects, as the measures used for social support (which did not improve), exercise performance and physical quality of life (both of which did improve) in this evaluation had been previously validated.

The other two interventions that did not improve social support had no effect on physical markers of health behaviour (Women to Women Diabetes, Heart-Web) or

quality of life outcomes (Women to Women Diabetes) compared to control groups. Lack of intervention effects on health outcomes may have been due to lack of intervention effects on social support, however these were not sufficiently rigorous evaluations to justify such a clear conclusion. One randomised comparison (Women to Women Diabetes) only involved 30 participants and the other (Heart-Web) reported that the intervention was only used by 33% of the 73 participants randomised to the intervention group.

Transtheoretical Model (TTM)

Of the three interventions that were evaluated on the TTM stage of change construct, none clearly achieved significant change in the construct. Nevertheless, two reported positive effects on stage of change and other health outcomes (eDSMP, Physical Activity Program). The eDSMP achieved increases in the proportion of the sample in action or maintenance stage of change equivalent to the face-to-face intervention to which it was compared. However, it was not clear whether this increase was significant. Improvements in exercise health behaviour may equally be explained by the significant improvements achieved in self-efficacy. Alternatively both improvements in stage of change and exercise health behaviour may have resulted from the intensive face-to-face baseline assessment with a nurse to develop an individualised exercise plan that was itself based on TTM, rather than the eDSMP that followed.

The Physical Activity Program found a near-significant positive movement in stage of change at 4 weeks along with positive change in exercise health behaviour. However, the high rate of attrition in this study cast doubts over the validity of either finding. The positive intervention effect on behaviour at 4 weeks was only found significant in analysis of the participants who responded at 6 months (<33% of the baseline sample). Moreover the significant effect was only found at 4 weeks and not at 6 months.

Equivalent analysis on the larger sample of responders at 4 weeks (<50% of the baseline sample) only found a non-significant trend in improved behaviour of small to medium effect size. Although the authors found no difference between responders and non-responders at 4 weeks, the fact that the effect was magnified in the smaller sample that responded again at 6 months suggests that continuing participants may have been a select group.

The only other psychological construct from TTM that was measured was processes of change but only in an evaluation that was too limited to provide any evidence of mechanisms of action (CHESS Heart Disease).

Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)

The only two interventions which were evaluated on psychological constructs from TRA/TPB both achieved change in psychological constructs and health outcomes (CHESS HIV/AIDS, Get Active). However any positive conclusions about TRA/TPB explaining mechanisms of action were undermined by limitations of these evaluations. Although longer access to CHESS HIV/AIDS was reported to achieve positive effects on attitudes toward risk behaviour and disclosure of HIV status to potential partners and on negative affect and quality of life, the positive intervention effects on attitudes were only reported in summary text, without any specific data or details of comparisons made. So it is unclear whether attitude improvements among the cohort with more than 3 months intervention access were found by comparing them to the control group, to participants with less than 3 months intervention access or to baseline scores. Social support may also have been a mechanism by which CHESS HIV/AIDS achieved improvements in health outcomes. However, the greatest limitation is the lack of information about measures used in that evaluation, which applies to measurement of attitude outcomes as much as it does to all the others. The evaluation of Get Active was

also limited by the measures used. Although positive intervention effects were reported for behavioural intention, perceived behavioural control and health behaviour outcomes, the cognitive measures used were designed specifically for the study. Tests of the internal consistency of these measures showed the two items used to measure perceived behavioural control had a comparatively low internal consistency (Cronbach's alpha of 0.63). No other tests of reliability or validity were performed.

Health Belief Model (HBM)

Only one intervention was evaluated on any psychological constructs from the HBM (D-NET). Although perceived barriers were significantly reduced at 10 months, there was no significant difference in change between the control group and the different versions of the D-NET intervention. Moreover, no details of the measure used to evaluate perceived barriers were given.

Transactional Model of Stress and Coping

The only intervention evaluated on any psychological constructs from the transactional model of stress and coping (STARBRIGHT), increased positive coping and decreased negative coping compared to the control group in sickle cell patients but not asthma patients. However no health outcomes were measured, so it is not clear whether these positive changes in coping were the mechanism for any health benefits.

Precaution Adoption Process Model (PAPM)

The only intervention where the PAPM stage of change construct was measured (WIN) was found to improve both stage of change and diet health behaviour. However, this was only a before-and-after comparison without a control group so the extent to which these changes resulted from the intervention is unclear.

Goal-Setting Theory

The effect of goal-setting theory was not evaluated for any interventions.

2.3.4 Additional evidence from other computer-based or internet-based interventions

Other interventions (either early computer-based health communication interventions or less complex internet-based interventions) provided little additional evidence. Most of these provided either peer support, tailored information, decision-aid or cognitive behavioural therapy (CBT).

Of these, psychological theories were most frequently used in the design of tailored information interventions. These interventions used computer algorithms to personalise information content, based on individual assessments, although they varied in how this information was delivered. Tailored information interventions that allowed repeated computer-based and user-directed access were uncommon (135). Of those identified (136-144), design was often based on constructs from multiple psychological theories (136;137;139;140;142;143) with only few evaluated on psychological constructs (136;138-140). No evaluations tested whether change in theory-based outcomes mediated change in health outcomes.

Online peer-support interventions included publicly available listservs, mailing lists, discussion forums and chat-rooms for a specific health topic, or private networks set up for specific patient groups to communicate with each other. These types of interventions were networked, and offered self-directed and repeated access to users. Despite widespread discussion of the proposed benefits of online peer-support interventions for increasing social support (145) research evaluating effects of online peer support interventions was lacking (146;147). The rare evaluations of online peer support

interventions did not measure social support or any other psychological constructs (148;149).

Interactive computer-based or internet-based CBT interventions have been extensively developed for mental health problems (150-163) and to a lesser extent for coping with physical health problems (164) or for health promotion (165-170). However, strict modelling of these interventions on face-to-face versions meant that most offered restricted, highly structured, short-term use and primarily relied on online communication between patients and individual therapists. Positive effects of computer or internet-based CBT interventions on mental and physical health outcomes have been found (157;164) but psychological constructs were not commonly measured.

Computer or internet-based decision-aids for patients were almost universally designed around specific one-off decisions about screening or treatment (171-179) rather than designed for ongoing use. Only one intervention made reference to psychological theory, but no evaluation has been published (180).

2.4 Discussion

2.4.1 Use of psychological theory in the design and evaluation of computer-based or internet-based interventions

A number of psychological theories have been applied in studies of computer-based or internet-based interventions. The theories most widely applied in the design of relevant interventions were SCT, in particular the construct of self-efficacy, and social support theory. The way psychological theories have been applied, and the specific psychological constructs used, may have been influenced by published guidance (45;70;71). Although direct reference to this guidance literature was rarely made, the more common use of psychological theories to guide intervention design than

evaluation, and use of psychological constructs drawn from multiple theories to guide the design of a single intervention were both consistent with its recommendations.

2.4.2 Evidence for mechanisms of action of internet interventions

Despite use of psychological theory in the design of interventions, limitations in the evaluations of these interventions meant they revealed little about mechanisms of action. The largest limitation was the infrequent measurement of psychological constructs. This meant that where several theories had guided intervention design, it was not possible to establish which one had explained the mechanism by which an effective intervention had worked. For other interventions, it ruled out the possibility of conducting mediator analysis to test mechanisms of action. Only two of the evaluations of interventions which measured psychological constructs conducted analysis of relationships between changes in psychological constructs and health outcomes, and only one conducted mediator analysis. Clearly, establishing the mechanisms by which interventions work has not been a strong focus of evaluation work in this field to date.

Evidence was further limited by use of outcome measures for which validity and reliability had not been established. In some cases, studies did not even specify the outcome measures used, in others, measures were untested apart from use in previous evaluations of similar interventions or basic checks of internal consistency. Where studies used questionnaires that were not clearly validated, it was not certain that they had actually measured the outcomes that they claimed to; hence it was unclear how findings compared to other studies, apparently measuring the same constructs, but using different measures. Where studies used questionnaires without established reliability, it was not clear whether change found over time reflected meaningful change rather than measurement error.

It was also notable that many evaluations used small samples. In several cases this was because they were designed as pilot or feasibility studies. This is perhaps unsurprising given the relative youth of this field of research. For those that measured both psychological constructs and health outcomes it meant that lack of positive effects in either may have been due to lack of power in statistical analysis to detect them, rather than a failure of the intervention or predicted mechanisms.

Together these limitations mean that there was scant evidence on which to base any conclusions about mechanisms of action of relevant interventions. Evaluations of interventions for people with heart disease were particularly limited. Even when these were considered alongside other interventions (for other long term conditions, mental health or health behaviour), there was still little evidence on which to base conclusions.

The constructs of self-efficacy and social support were the most widely used in the design and evaluation of interventions. Where these constructs were measured, positive intervention effects were more often found in social support than in self-efficacy.

However, most studies which found positive intervention effects on social support did not find similar effects on main health outcomes, and no evaluation tested change in social support as a mediator of change in main health outcomes.

Positive change in self-efficacy was related to improved health outcomes in one study but did not mediate change in health outcomes in the only study to carry out statistical analysis of psychological constructs as potential mediators. However, the conclusions of both of these evaluations were undermined either by the measures used or sample size.

Evaluations of other computer-based or internet-based interventions added little evidence. Although some of these interventions were clearly theory-based, evaluations

were just as limited by failure to measure psychological constructs or test mediating effects.

In contrast to a recent meta-analysis of internet-delivered interventions (78), constructs from the TPB did not emerge as likely mechanisms of intervention action. The theory was not used in the design and/or evaluation of many complex and networked interventions. Limitations in studies evaluating these interventions in turn limited evidence for the theory explaining any intervention effects.

Compared to recent systematic reviews (50;78), this chapter identified relatively few interventions as relevant to include. This is likely to be due to the very specific definition of relevant interventions used in this chapter to focus on evidence most generalisable to an internet intervention for CHD self-management. However, in order to include all relevant interventions, the current review was relatively non-specific about the types of health outcomes on which relevant interventions were evaluated. Here health behaviours, emotional status, quality of life and clinical outcomes were all grouped together as health outcomes without systematically considering the different types of outcomes when reviewing the evidence for intervention effects.

Arguably one would expect interventions to have a greater impact on more proximal outcomes (e.g. health behaviours), with impact on more distal outcomes (e.g. clinical outcomes) harder to achieve and more open to influences other than the intervention. Grouping distal health outcomes with proximal health outcomes might have resulted in a lack of clarity in the overall picture of effectiveness of these types of interventions. It might also have undermined the evidence for psychological constructs by treating interventions found effective on psychological constructs but not distal health outcomes the same as those found effective on psychological constructs but not proximal outcomes.

2.5 Conclusion

This chapter has reviewed the use of psychological theories in the design and evaluation of computer-based or internet-based interventions as a first step towards identifying mechanisms likely to explain how an internet intervention works for people with CHD. While psychological theories and constructs have been used to guide intervention design, there was insufficient evidence to support any one theory or construct as a mechanism of intervention action. As a result, no firm conclusions can be drawn based on internet intervention literature alone. This underlines the importance of also considering evidence from other CHD interventions, which is the focus of the next chapter.

Chapter 3 : Review of evidence for psychological mechanisms of action of CHD self-management interventions

3.1 Introduction

Following on from the previous chapter's review of internet intervention literature for likely psychological mechanisms of action, this chapter focuses on self-management interventions for people with CHD. Conclusions drawn from reviewing these two bodies of literature were used to guide the design of an empirical study, which is described in Chapter 4.

The aim of this chapter is to review the evidence for psychological mechanisms by which self-management interventions have been found to improve outcomes for people with CHD. Discussion in Chapter 1 of self-management and secondary prevention outcomes for people with CHD identified emotional, behavioural, clinical and quality of life outcomes as relevant. Evaluations of self-management interventions on these types of outcomes are considered here. It is important to note that the focus here is on behavioural and psycho-educational interventions targeting patient self-management of CHD. Other surgical (e.g. coronary angioplasty) or pharmacological (e.g. statins) interventions for people with CHD are also important for improving clinical and quality of life outcomes. However these work predominantly through physiological rather than psychological or behavioural mechanisms, with the patient essentially a more passive recipient of the effects of an intervention. This compares with behavioural and psycho-educational interventions that influence an individual's response to their condition and require more active participation from patients. This is not to say there is no overlap between the different types of interventions and their mechanisms. For example, although statins achieve their effect by lowering cholesterol levels in the blood, they rely on patients taking the medications as directed. The adherence of patients to these

directions is itself a self-management behaviour and so likely to be determined by psychological factors. However, it is very unlikely that internet interventions for people with CHD share mechanisms of action with interventions that are purely surgical or pharmacological without any additional behavioural or psycho-educational components. As a result evaluations of purely surgical or pharmacological interventions are not reviewed in this chapter.

Behavioural and psycho-educational interventions share the same aims as internet interventions for people with CHD as well as relying on patient self-management for their effects. Although the internet provides a different mode of intervention delivery, one could argue that what works off-line is likely to work online, so these interventions are likely to share mechanisms of action. Moreover it is clear that the relatively new field of internet interventions has been guided by what has been found to work in earlier off-line interventions. The International Society for Research on Internet Interventions (ISRII) describes internet interventions as usually based on effective face-to-face interventions (43) and this is clearly the case for several of the relevant interventions reviewed in chapter 2 (125-127).

Unlike Chapter 2, this chapter focuses purely on interventions for CHD and not on interventions for other long term conditions. This is due to the fact that CHD self-management and secondary prevention is a much larger body of literature, developed over decades rather than only recent years. As a result, it is reasonable to expect this literature to contain both more and more complex evaluations of CHD self-management interventions and hence less need to turn to interventions for other long term conditions for additional evidence. However, as noted before, one of the strengths of using theory is the generalisability it allows between samples.

3.2 Methods

Search and review methods for this chapter were informed by background reading of health psychology and long term condition self-management literature (2;14;28;63;133;134;181;182) and an initial, general literature search, conducted in March 2005. In this electronic search, names of common psychological theories and constructs identified from background literature were combined with search terms relating either to key outcomes, CHD or other long term condition samples. It was clear from the results of this search that:

- (i) The literature in which psychological theories and their constructs have been applied to CHD is extensive
- (ii) Within this literature, psychological theories and constructs have been applied in many different ways. The majority of studies have explored relationships between psychological constructs and outcomes in CHD samples or examined psychological constructs as predictors of health outcomes.
- (iii) Only a sub-set of studies in which psychological theories and constructs have been applied to CHD are relevant to review for evidence of mechanisms of action of self-management interventions (i.e. behavioural or psycho-educational CHD interventions evaluated on change in both psychological constructs and health outcomes).
- (iv) There were no common search terms which would distinguish relevant studies from those applying psychological theories or their constructs in CHD samples in other ways.

It was also clear that the strength of evidence from studies evaluating relevant CHD interventions on change in both psychological constructs and health outcomes varied depending on aspects of design or analysis. For example, randomised evaluations

provided stronger evidence that any change found could be attributed to the intervention than cohort studies evaluating change from baseline in intervention samples only. However, if these cohort studies tested relationships between change in psychological constructs and change in health outcomes, they provided a stronger test of an intervention's mechanism of action than randomised evaluations comparing change between intervention and control groups only. Randomised evaluations in which relationships between changes in psychological constructs and desired outcomes were tested provided the strongest evidence. However, these were rare, and in some cases results from different analyses were published separately, making them harder to identify.

As a result, a systematic, but broad, search strategy was combined with a critical narrative review approach. Rather than using systematic review methods which would require *a priori* inclusion criteria and search filters, the selection of studies from search results relied on personal judgement of relevance based on study design and analysis conducted. Relevance of interventions for samples that included, but were not limited to, people with CHD was also judged on the design and analysis of these studies.

3.2.1 Search strategy

Systematic electronic searches were conducted in March 2009 on three large databases which cover both medical and psychological literature (Medline, PsychINFO and Web of Science). The search strategy used in each database combined three sets of terms which related to CHD, psychological theories and relevant interventions respectively. The search strategy included key words and common terms used by relevant studies identified in the initial, general search. Terms for identifying use of common psychological theories and constructs were based on those used in background health psychology literature (133;134;182).

Where possible, subject headings that mapped onto the search terms were used. Terms were first combined separately for CHD, psychological theory and interventions using the 'OR' operator, before the three groups of terms were combined using 'AND'.

Specific search terms and combinations used in each database are listed in Appendix B.

3.3 Results

Evidence was drawn from self-management interventions that were evaluated on change in psychological constructs and other relevant outcomes, where evaluations were randomised control trials (RCT) and/or tested relationships between changes in constructs and outcomes. Firstly, a brief overview of the types of interventions evaluated is given. The evidence for psychological theories as mechanisms of action of these interventions is then discussed.

3.3.1 Types of interventions

Most of the relevant interventions targeted CHD patients who had recently been hospitalised for CHD treatment (e.g. heart attack (myocardial infarction (MI), heart failure, coronary angioplasty, coronary artery bypass graft (CABG) surgery) (183-198) or who had been referred for cardiac rehabilitation soon after hospitalisation (199-211). Most of these were cardiac rehabilitation interventions, focused on increasing levels of physical activity (193;199-211). Two other main types of interventions were individual coaching, counselling or psychotherapy (183;188;189;196;198) and supported home-monitoring after hospital discharge, predominantly for heart failure patients (184;185;187;190;192). The remainder were brief interventions delivered at hospital discharge or soon after (191;195;197), a small-group lifestyle skills intervention (186) and peer support provided during hospitalisation and short-term recovery (194).

Fewer interventions were for CHD patients who had not recently experienced hospitalisation (212-225). People who received these interventions were either

identified from outpatient or primary care records, or volunteered in response to adverts. Most of these were evaluations of two small-group interventions: The Chronic Disease Self-management Program (CDSMP; UK version known as the Expert Patient Programme, EPP) (212;213;218;220;221) and Women Take PRIDE (215;219). An intensive, part-residential lifestyle intervention was also evaluated in more than one sample (214;224). Other interventions focused specifically on exercise training and could be conceived of as later phase cardiac rehabilitation (216;217;223). The remainder were a brief individually tailored intervention (225) and extensive individual and group-based psychotherapy (222).

3.3.2 Evidence for psychological theories or constructs as mechanisms of action of interventions

The following sections review evidence from evaluations of the CHD self-management interventions. Evidence for each theory or construct is reviewed in turn, starting with the most widely evaluated. The final section considers evidence from interventions which have been evaluated on change in psychological constructs from more than one theory as these allow direct comparison between potential mechanisms of action. Discussion of evidence is supported by Table 3.1, which summarises findings from RCT evaluations of CHD self-management interventions.

Table 3.1 Findings from RCTs evaluating effects of CHD self-management interventions on psychological constructs and health outcomes.

Study reference	Significant change in psychological constructs compared to control	Significant change (or difference) in health outcomes compared to control	Significant relationship between changes in psychological constructs and outcomes
Beniamini et al (1997) (201)	Self-efficacy ✓	Exercise ✓	Self-efficacy and exercise ✓
Ewart et al (1986) (217)	Self-efficacy ✓	Exercise ✓	Self-efficacy and exercise ✓
Rejeski et al (2003) (223)	Self-efficacy ✓	Exercise ✓	Self-efficacy and exercise ✓
Carlson et al (2001) (203)	Self-efficacy ✓ Social support ✗	Exercise ✓	
Izawa et al (2005) (207)	Self-efficacy ✓	Exercise ✓	
Senuzun et al (2006) (210)	Self-efficacy ✓	Exercise ✓	
Gortner & Jenkins (1990) (190)	Self-efficacy ✓	Physical activity ✓	
Barnason et al (2003) (184)	Self-efficacy ✓	Salt intake ✓ Exercise ✓ Stress management ✓ Quality of life ✓	
Benatar et al (2003) (185); Bondmass (2007) (187)	Self-efficacy ✓ (only when limited to African Americans)	Heart failure readmissions ✓ Length of hospital stay ✓ Anxiety ✓ Depression ✓ Symptom distress ✓ (only when limited to African Americans) Quality of life ✓ (only when limited to African Americans)	
Toobert et al (1998) (224)	Self-efficacy ✓ Social support ✓	Healthy diet ✓ Exercise ✓ Stress management ✓	
Wiggers et al (2005) (225)	Self-efficacy ✓ (only higher-educated participants)	Smoking cessation/intention to quit ✓ (only higher-educated participants)	
Lorig et al (2003) (221)	Self-efficacy ✓	Quality of life ✓ Exercise ✓ Stress management ✓ Communication with physician ✓	
Mendes de Leon (1991) (222)	Self-efficacy ✓ Social support ✗	Anger ✓ Depression ✓ Type A behaviour ✓	
Griffiths et al (2005) (218)	Self-efficacy ✓	Symptom management ✓ Depression ✓ Anxiety ✗ Quality of life ✗ Communication with physician ✗	

Study reference	Significant change in psychological constructs compared to control	Significant change (or difference) in health outcomes compared to control	Significant relationship between changes in psychological constructs and outcomes
Kennedy et al (2007) (213)	Self-efficacy ✓	Quality of life ✓ Exercise ✓ Stress management ✓ Diet ✗ Communication with physician ✗	
LaFramboise et al (2003) (192)	Self-efficacy ✓	Quality of life ✗ Depression ✗	
Oldridge & Rogowski (1990) (193)	Self-efficacy ✓	Returned to work ✗ Participation in rehabilitation ✗ Exercise ✗	
Aish & Isenberg (1996) (183)	Self-efficacy ✗	Healthy diet ✓	
Collins et al (2004) (216)	Self-efficacy ✗	Exercise ✓	
Parent & Fortin (2000) (194)	Self-efficacy ✗	Anxiety ✓ Exercise ✓	
Elzen et al (2007) (212)	Self-efficacy ✗	Exercise ✗ Symptom management ✗ Quality of life ✗ Communication with physician ✗	
Allison & Keller (2004) (199)	Self-efficacy ✗	Exercise ✗	
Schmitz et al (1999) (196)	Self-efficacy ✗	Smoking cessation ✗	
Bishop et al (2005) (186)	Social support ✓	Heart rate ✓ Blood pressure ✓ Perceived stress ✓ Anger ✓ Depression ✓ Life satisfaction ✓	
Arthur et al (2002) (200)	Social support ✓	Quality of life ✓ Waist-hip ratio ✓ Exercise capacity ✗ Blood pressure ✗ Heart rate ✗	
Writing Committee for the ENRICHD Investigators (2003)(198); Burg et al (2005) (189)	Social support ✓	Recurrence of MI ✗ Death ✗	Social support and death ✗
Clark et al (2000) (215); Janevic et al (2004) (219)	Social support ✗	Symptom impact ✓ Exercise capacity ✓ Weight ✓	Social support and functional status, symptom impact and depression ✓
Pischke et al (2008) (214)	Social support ✗	Diet ✓ Exercise ✓ Self-management ✓ Weight ✓ Cholesterol ✓ Artery stenosis ✓ Clinical events ✓ Psychological distress ✓ Hostility ✓	

Study reference	Significant change in psychological constructs compared to control	Significant change (or difference) in health outcomes compared to control	Significant relationship between changes in psychological constructs and outcomes
Petrie et al (2002) (195)	Illness perceptions ✓	Angina symptoms ✓ Delay in return to work ✓	
Sethares & Elliot (197)	Perceived barriers? Perceived benefits?	Quality of life ✗ Heart failure readmission ✗	
Brodie et al (2008) (188)	Readiness to change?	Quality of life ✓	

Key: ✓ = yes ✗ = no ? = unclear whether change was significant

Self-efficacy

Self-efficacy (Chapter 2, Table 2.2) was by far the most widely evaluated psychological construct. Several studies compared the effect of self-management interventions to randomised control or other intervention groups on both self-efficacy and health outcomes. These include exercise-focused cardiac rehabilitation (193;199;201;203;207;210;216;217;223), remote telecare-enabled home-monitoring (184;185;187;192), small-group (212;213;218;221), individual coaching (183;190), extensive counselling or psychotherapy (196;222), intensive lifestyle change (224), brief individually tailored (225) and peer support interventions (194). More often than not these interventions were found to improve both self-efficacy and health outcomes.

The majority of randomised evaluations of exercise-focused cardiac rehabilitation interventions increased both self-efficacy and measures of fitness, exercise tolerance or exercise behaviour compared to control groups (201;203;207;210;217;223). One other study found the intervention significantly increased self-efficacy but no significant difference in numbers of patients who returned to work, participated in outpatient rehabilitation or reported to exercise regularly (193). However, these outcomes were yes/no answers only measured at follow-up and so are unlikely to be very sensitive and do not reflect change. Evaluations of the two remaining exercise-focused cardiac rehabilitation interventions found that they increased self-efficacy but not significantly

more than control groups (199;203). In both cases, the studies did not achieve their target sample size for sufficient power to detect expected differences.

Two randomised evaluations of remote telecare-enabled home-monitoring interventions for people with heart failure also found positive intervention effects on both self-efficacy and other outcomes compared to controls, including health behaviours (salt intake, exercise adherence, stress management), symptom distress and quality of life measures (184;187). One study found the intervention achieved significantly fewer heart failure readmissions and shorter length of hospital stay without significantly greater increases in self-efficacy compared to the comparison group (185). However, self-efficacy did significantly increase from baseline in the intervention group, and a secondary analysis found self-efficacy increased significantly more in the intervention group than the control group when analysis was limited to African-American participants (who made up 86% of the sample) (187). In another study self-efficacy increased significantly more in the two groups with a home-monitoring intervention than one usual care control group (telephone case-management) but not a second, more intensive usual care control group (nurse home visits) (192). There was no significant difference in improvement in quality of life between groups but all improved significantly from baseline. In this small feasibility study intervention effects were likely to have been reduced by the fact that 30% of patients assigned to the home-monitoring intervention could not use it.

The randomised evaluations of small-group interventions which have measured both self-efficacy and other outcomes have all been conducted on versions of the CDSMP (212;213;218;221). The CDSMP is an intervention designed specifically to increase self-efficacy for self-management among people with long term conditions. Participants included people with CHD, although they made up no more than 20% of the sample in

any of these evaluations and no more than 6% in two of them (212;218). Three of these evaluations found CDSMP (or EPP) significantly increased both self-efficacy and other outcomes (self-management behaviour, depression, quality of life) compared to control groups (213;218;221). One of these studies also found a reduction in depression along with significantly greater increases in self-efficacy among those who attended over half of the CDSMP sessions compared to control groups (218). However, in another study the Dutch version of CDSMP did not achieve change in self-efficacy or other outcomes (exercise, symptom management, communication with physicians, quality of life) (212). This study differed from the other three by having group leaders who were trained study investigators rather than trained patients with long term conditions. It also used different measures, specifically well-validated measures of self-efficacy and quality of life. It is not clear whether lack of intervention effects were due to differences in the intervention or the use of more rigorous measures.

Three of the other types of interventions also achieved significant change in both self-efficacy and health outcomes compared to randomised control: an in-patient education and post-discharge telephone coaching intervention for physical activity (190), a lengthy counselling and psychotherapeutic intervention for coronary-prone Type A behaviours (222) and an intensive lifestyle intervention (224). In addition, a brief counselling intervention for smoking cessation, tailored to each individual's stage of change, found a small positive intervention effect on both self-efficacy and intention to quit but only in the minority of participants with relatively high levels of education (225). Self-efficacy increased significantly in intervention groups of all three of the remaining interventions, although not significantly more than in control or other intervention comparison groups (183;194;196). One of these studies did not achieve their target sample size for sufficient power to detect expected differences (194). In another, treatment fidelity ratings carried out on recordings of counselling sessions from

a cognitive behavioural smoking relapse prevention intervention to increase coping self-efficacy, failed to distinguish it from the comparison educational/supportive intervention, suggesting the intervention had not been delivered as intended (196).

Analysis testing the relationship between changes in self-efficacy and health outcomes was conducted in seven studies evaluating exercise- and/or diet-focused cardiac rehabilitation (201;204;205;209;211;217;223) and one study evaluating the CDSMP intervention (220). Three of the cardiac rehabilitation interventions were among those found to have increased both self-efficacy and measures of fitness, exercise tolerance or exercise behaviour in randomised evaluations (201;217;223). Of these, two found change in self-efficacy was significantly related to improved upper body strength, lower body strength and maximum treadmill time (201), gains in arm strength and exercise endurance (217). It is not clear why increases in self-efficacy were not significantly correlated to change in physical activity or fitness in the other study (223). This study took a different approach to calculating change which took into account the correlation between baseline and follow-up scores (residualised change) rather than simply calculating the difference between scores at the two time-points (absolute change).

Three other studies also found significant relationships between absolute changes in self-efficacy and diet behaviour (211), exercise tolerance (204) or healthcare utilisation (220). The first compared the effect of a diet-focused cardiac rehabilitation intervention with a non-random control group and found significantly greater increases in self-efficacy and diet behaviour in the intervention than the control group, along with a significant relationship between changes in self-efficacy and diet behaviour in the intervention but not the control group (211). The other two were cohort studies evaluating change from baseline in intervention samples only (204;220). One was an evaluation of the CDSMP (220). Randomised evaluations of other versions of the

CDSMP have already been discussed (212;213;218;221). This evaluation was a longer-term follow-up of an originally randomised evaluation, although the original waiting-list control group had now also participated in CDSMP. In this case it was not clear whether CDSMP had significantly increased self-efficacy compared to control groups in the original randomised study, as intervention effects on self-efficacy were not reported (226). However in the follow-up study change in self-efficacy from baseline to 6 months was significantly correlated with reduced healthcare utilisation at 1 year (220).

Residualised change scores were used in two cohort studies evaluating change during cardiac rehabilitation (205;209). In the first, self-efficacy, diet, anxiety, depression and quality of life were all found to significantly increase in the first 8 weeks of cardiac rehabilitation. However, residualised change in self-efficacy in the first 8 weeks did not significantly predict diet, anxiety, depression or quality of life at 8 weeks (209).

Although the authors concluded that self-efficacy was not the mechanism by which the cardiac rehabilitation worked, the self-efficacy measure used in this study undermines the certainty of this conclusion. While the three individual self-efficacy items (for diet, exercise and stress management) were based on guidelines for measuring the construct, their reliability and validity were not established. This was in contrast to the well-validated questionnaires that were used to measure other outcomes in the study. In the second study, self-efficacy, physical activity and weight were all found to significantly improve in both the first 6 weeks and between 6 and 12 weeks of cardiac rehabilitation. Diet behaviour only significantly improved in the first 6 weeks and depression only between weeks 6 and 12. Cross-lagged analysis testing relationships between residualised early to mid and mid to late changes found early to mid change in self-efficacy significantly predicted mid to late changes in depression and physical activity. As early to mid changes in depression and level of physical activity did not significantly predict mid to late change in self-efficacy this suggested that increased self-efficacy was

the mechanism by which cardiac rehabilitation improved depression and physical activity (205).

Social Support

Several studies compared the effect of self-management interventions to randomised control or other intervention groups on both social support (Chapter 2, Table 2.2) and health outcomes. These include counselling or psychotherapy (189;198;222), small-group or lifestyle skills interventions (186;215;219), intensive lifestyle (214;224), cardiac rehabilitation (200;203) and brief tailored interventions (225). Together these studies provide mixed evidence for interventions achieving change in both social support and health outcomes.

Only three studies found significantly greater improvements in both social support and health outcomes as a result of the intervention compared to control groups (186;200;224). A home-based cardiac rehabilitation intervention for patients after CABG significantly improved social support, exercise behaviour, quality of life and waist to hip ratios at 3 and 6 months compared to traditional hospital-based cardiac rehabilitation (200). A small-group lifestyle skills intervention, also for patients after CABG, significantly improved social support, resting heart rate, blood pressure and heart rate variability, perceived stress, anger, depression and life satisfaction at 3 months compared to an information-only control group (186). The third study was one of two which evaluated versions of the same intensive lifestyle intervention. The version of the intervention evaluated in this study was for post-menopausal women with heart disease. Although the intervention significantly increased social support, it was only found to do so at the later 12-month follow-up, whereas significant improvements in diet, exercise and self-management behaviours were found in the intervention compared to the control group from four months (224). This would suggest that

significant change in social support as a result of the intervention occurred later than change in health outcomes. Moreover, the study evaluating the original version of the intervention in a sample of men and women found significant improvements in health behaviours (diet, exercise and self-management), CHD risk factors (weight, total and LDL cholesterol), markers of disease (artery stenosis) and clinical events, hostility and psychological distress as a result of the intervention, but no significant change in social support (214). Sample sizes in both of these studies were notably small with total samples of 28 (16 in intervention group) and 48 (28 in intervention group) respectively. They may not have had sufficient power to detect differences in change in social support, although clearly the changes in health outcomes were of sufficient magnitude to be detected even in such small numbers.

Three other interventions achieved significant change in health outcomes compared to control groups without achieving significant change in social support (203;215;222). One found a non-significant trend for increased social support in the group that received a lengthy counselling and psychotherapeutic intervention for coronary-prone Type A behaviours compared to a group that received only counselling (222). As this study involved over 1000 participants it was unlikely to have been underpowered, although the fact that the comparison group also received a lengthy intervention may have made improvements as a result of the main intervention harder to demonstrate. This was also true of a modified cardiac rehabilitation intervention that was compared with traditional cardiac rehabilitation. However, in this study social support in both the modified and the traditional cardiac rehabilitation groups was found to significantly decrease rather than improve over 6 months (203). The third study compared their small-group intervention with a control group in a large sample of women with CHD. Although significantly greater improvements in symptom impact, exercise capacity and weight were found in the intervention compared to control group, there was no significant difference in

change in social support between groups (215). Despite this lack of intervention effect on social support, analysis of longer-term follow-up data from this evaluation tested the relationship between changes in social support and health outcomes (219). This sophisticated analysis using multi-level modelling found different patterns of relationships between changes in social support and health outcomes in the intervention compared to the control group: greater increases in total, tangible and affectionate social support and social interaction were associated with improved depression in the intervention group only; greater increases in tangible social support were also associated with improved symptom impact and functional status in the intervention group only. Other changes in social support and health outcomes were also significantly associated but did not differ between groups.

Of the remaining randomised evaluations, the large-scale Enhancing Recovery in Coronary Heart Disease (ENRICHED) trial found an intensive 6-month cognitive psychotherapy intervention significantly improved social support in patients after MI (selected for participation on the basis of their low levels of social support) but did not reduce recurrence of MI or death by 18 month follow-up (198). A secondary analysis also found that change in social support at 6 or 12 months did not predict subsequent death (189). Although the intervention did significantly improve social support compared to controls at 6 months, the difference was not sustained at 30 months, largely due to improvements in social support in the control group. This may also explain the lack of intervention effects on recurrence of MI or death. However, these are obviously 'harder', objective clinical outcomes compared to the more subjective outcomes evaluated in other studies. The final study evaluating brief tailored counselling found no significant intervention effect on either social support or smoking behaviour (225).

Illness perceptions

Illness perceptions (also known as illness representations) is a multidimensional construct from self-regulation theory (also known as the 'common sense model' (227;228). This theory views the individual as a problem solver, dealing with (i) the perceived reality of the health threat and (ii) emotional reactions to this threat. The central cognitive construct of the theory is the set of illness perceptions held by an individual. These are the individual's common-sense definitions of health threats and have five dimensions: identity, timeline, cause, controllability and consequences.

Identity refers to the disease or health threat label (e.g. heart attack) and associated ideas about symptoms of the disease (e.g. chest pain, shortness of breath, fatigue etc). Timeline refers to ideas about how long a disease develops or lasts and includes beliefs about the chronic, acute or cyclical nature of diseases or health threats. Cause relates to ideas about why the disease or health threat has occurred (e.g. stress, infection, genetics, diet etc). Controllability is the degree to which an individual believes the disease or health threat can be prevented, cured or managed as a result of their own or professional intervention. Consequences are the anticipated personal, emotional, economic or other consequences of the disease or health threat for the individual. Illness perceptions, along with emotional reactions elicited by the illness threat, guide coping (behavioural and emotional) and appraisal of the outcomes of coping.

One randomised evaluation of the effect of a self-management intervention on both illness perceptions and health outcomes has been conducted (195). The relationship between changes in illness perceptions and health outcomes has been explored in a cardiac rehabilitation cohort (209). A brief hospital intervention designed to alter patients' negative illness perceptions about their MI significantly changed illness perceptions, reduced angina symptoms and reduced delay in returning to work compared to controls (195). Specifically the intervention was found to change illness

perceptions of consequences, timeline and control. Significant changes in illness perceptions of control and cause were found between baseline and 8 weeks of cardiac rehabilitation, along with significant changes in anxiety, depression, diet behaviour and quality of life (209). Increase in illness perception of control between baseline and 8 weeks (residualised change) significantly predicted lower depression at 8 weeks, with a positive trend towards significance for predicting anxiety at 8 weeks. Changes in illness perception of cause did not significantly predict health outcomes, and other dimensions of illness perceptions (identity, timeline and consequences) did not significantly change.

Multidimensional health locus of control (MHLC)

Multidimensional health locus of control (MHLC) is a construct which distinguishes between internal and external locus of control orientations (229). An individual holding an internal locus of control sees events as the consequence of their own actions. An external locus of control means the individual sees events as unrelated to their actions and therefore beyond their control. The external orientation is further split into powerful others and chance to distinguish between health events which are seen as under the control of health professionals and those which are seen as due to fate. According to MHLC people who have an internal locus of control orientation will be more likely to engage in health behaviours as they will believe health events to be under their control and take responsibility for their health.

One study evaluated the difference in changes in health locus of control and health outcomes between a self-management intervention and a control group (191). In this small study (n=30), it is not clear whether allocation to intervention or control groups was random, although there were no significant differences in demographic characteristics between the groups at baseline. It is also not clear when intervention group participants received the audio-taped progressive muscle relaxation training

(before or after discharge from hospital after MI). However, significant differences in change in one dimension of health locus of control and improvements in anxiety, reported pain, physical activity and psychological distress were found between the intervention and control groups. While internal health locus of control was unchanged in the intervention group, external health locus of control increased in the control group.

The relationship between changes in health locus of control and health outcomes was also explored in a cardiac rehabilitation cohort (202). This study found a small but significant increase in internal health locus of control during the 6-weeks of cardiac rehabilitation along with small but significant reductions in anxiety and depression. Neither internal health locus of control nor anxiety or depression changed significantly in the 12 weeks after cardiac rehabilitation, although beliefs in chance health locus of control significantly reduced during this time. Significant correlations were found between absolute changes in internal health locus of control and anxiety but not depression during and after cardiac rehabilitation.

Perceived benefits and barriers and susceptibility

Perceived benefits, barriers and susceptibility are constructs from the Health Belief Model (HBM; Chapter 2, Table 2.2). Two randomised studies have evaluated the effect of self-management interventions on HBM constructs and health outcomes (197;208). These were both brief health education interventions, one for people hospitalised with heart failure (197) and the other for patients entering cardiac rehabilitation (208). The design of both of these studies meant that neither could compare changes in HBM constructs between intervention and control groups, which limits the extent to which change in these constructs can be attributed to either intervention. The first found perceived barriers significantly reduced and perceived benefits significantly increased in the intervention group (they were not measured in the control group) but no significant

differences in change in quality of life and heart failure readmission rates between groups (197). The second compared two versions of the intervention (gain-framed and loss-framed) with a control group, but only measured HBM constructs post-intervention. This study found significantly lower perceived susceptibility in the control group than in either intervention group, significantly greater perceived barriers in the loss-framed intervention group than in the other groups and significantly better attendance at cardiac rehabilitation exercise sessions over 3 months in the gain-framed intervention group. However, as perceived susceptibility and perceived barriers post-intervention did not significantly predict attendance at cardiac rehabilitation exercise sessions over 3 months, the authors concluded they did not mediate the effect of the gain-framed intervention (208).

Readiness to change

Readiness to change is a measure of the stage of change construct from the Transtheoretical model (TTM; Chapter 2, Table 2.2). One RCT of an intervention which achieved significantly greater change in quality of life than the control group, also reported improvement in readiness to change but did not test whether this improvement was statistically significant (188). A cohort study found significant improvements in readiness to change cardiac self-management behaviours, positive and negative mood, fitness, activity level, diet and weight during cardiac rehabilitation (206). Greatest improvement in readiness to change cardiac self-management was found in the first 3 weeks of the 12-week rehabilitation. Increases in readiness to change cardiac self-management in the first 3 weeks (residualised change) significantly predicted positive mood, activity level, diet and weight after 3, 6, 9 and 12 weeks of cardiac rehabilitation.

Studies evaluating change in constructs from more than one theory

Four RCTs evaluated the effects of interventions on both self-efficacy and social support. These were a 6-month exercise-focused cardiac rehabilitation intervention (203), a 4.5 year counselling and psychotherapeutic intervention for coronary-prone Type A behaviours (222), an intensive 16-month lifestyle intervention for post-menopausal women (224) and a brief tailored intervention for smoking cessation (225). Although very different interventions, all four gave stronger support to self-efficacy than social support as the mechanism by which they achieved improvements in health outcomes. The first achieved significant increases in both self-efficacy and exercise behaviour compared to the control group, but no significant difference in change in social support, which decreased in both groups (203). The second achieved significant improvements in self-efficacy, anger, depression and coronary-prone Type A behaviours compared to the control group, with only a trend towards improved social support (222). The third achieved significant increases in self-efficacy at 4 months and diet, exercise and stress-management behaviour at 4 and 12 months compared to the control group. In this study, social support significantly increased in the intervention group compared to the control group, but only at 12 months, i.e. after change in health outcomes had started (224). The final intervention did not achieve any significant change in either self-efficacy, social support or intention to quit compared to the control group. Self-efficacy and intention to quit did significantly increase in the minority of participants with relatively high levels of education but social support did not (225).

The relationships between changes in self-efficacy, illness perceptions and health outcomes have been tested in one cardiac rehabilitation cohort (209). The study found significant increases in both self-efficacy and illness perceptions (control and cause) in the first 8 weeks of rehabilitation along with significant improvements in diet behaviour, anxiety, depression and quality of life. However, only change in the illness

perception of control was found to predict depression at 8 weeks. Although this seems to favour illness perceptions over self-efficacy as the mechanism by which cardiac rehabilitation worked, the self-efficacy measures used undermine confidence in this conclusion. In contrast to the standard, well-validated questionnaires that were used to measure illness perceptions, anxiety, depression and quality of life, the self-efficacy items were developed for the study and not piloted for reliability or validity.

3.4 Discussion

3.4.1 Types of CHD self-management interventions

This review included CHD self-management interventions which had been evaluated on both psychological constructs and health outcomes either by RCT or by analysis testing relationships between changes in constructs and outcomes. The majority of included interventions were for CHD patients who were or had recently been hospitalised for CHD treatment and most were cardiac rehabilitation interventions. Evidence from interventions delivered in primary care or those which aimed to support CHD patients in the longer term was lacking.

As a group, the interventions included in this review varied greatly in terms of content, delivery, intensity and target group of CHD patients. Nevertheless they all aimed to improve patient self-management. Without the use of common theoretical constructs it would be impossible to draw conclusions about mechanisms of action that might be common to such diverse interventions. Although different intervention characteristics introduce complexities that hamper comparisons between them, any overall patterns of evidence are strengthened by their consistency across such diverse interventions.

3.4.2 Evidence for mechanisms of action of CHD self-management interventions

Overall, self-efficacy has been the most widely evaluated psychological construct, and it has the strongest evidence as a mechanism by which CHD self-management interventions have worked. In the majority of RCT evaluations in which self-efficacy was measured, interventions successfully increased self-efficacy along with achieving improvements in health outcomes. In addition several intervention studies found a significant relationship between increases in self-efficacy and improvements in health outcomes. In studies which allowed comparison with the effect of interventions on other psychological constructs, self-efficacy emerged as a more likely mechanism than social support.

Although intervention effects on social support were also evaluated in a number of RCTs, the role social support played in achieving effects on health outcomes was not clear. While some achieved change in social support and health outcomes, others achieved change in health outcomes without changing social support, or only changed social support but not health outcomes. The relationship between change in social support and change in health outcomes was found to be significant in one study but not in another, although the health outcomes predicted in these two studies were very different. Finally, studies which allowed comparison between the effect of interventions on both social support and self-efficacy did not favour social support as the mechanism by which these interventions worked.

None of the other psychological constructs reviewed were as widely evaluated. Of these, illness perceptions, particularly the perception of illness control, looked the most promising as a mechanism of action. The evaluation in which changes in both illness perceptions and self-efficacy were used to predict health outcomes favoured the

perception of illness control as the likely mechanism. However, the findings of this study are undermined by the comparatively weak measure of self-efficacy used.

3.5 Conclusion

This chapter has reviewed evidence for psychological mechanisms by which self-management interventions improve outcomes for people with CHD from studies which have evaluated self-management interventions on change in psychological constructs and health outcomes either by RCT, analysis testing relationships between changes or both. Despite including quite diverse interventions, the review found evidence for self-efficacy as a common mechanism of intervention effects. Based on the few evaluations in which it has been measured, the psychological construct of illness perceptions may also be a mechanism of intervention action. The evidence for social support was less clear.

In the next chapter, conclusions drawn here about likely mechanisms of action of self-management interventions for patients with CHD are combined with those from the previous review chapter to guide the design of an empirical study.

Chapter 4 : Aims and design of the empirical study

4.1 Introduction

This chapter discusses the aims and design of an empirical study evaluating an internet intervention for CHD. The intervention evaluated in this study is described in Chapter 5 and details of the study methods are given in Chapter 6.

The chapter starts with a summary of conclusions drawn from reviewing internet and CHD self-management intervention literature (Chapters 2 and 3). These conclusions guided the aims of the study and the identification of likely mechanisms of action of internet intervention for patients with CHD, which follow. The chapter continues with a series of sections discussing relevant study design issues. These sections provide the rationale for design decisions made.

4.2 Conclusions from reviewing internet and CHD self-management literature

Not all of the literature reviewed in Chapters 2 and 3 was available in 2005, when this study was designed. More recent evaluations of relevant internet interventions (107;116-119;124;126-132) and CHD self-management interventions (187;188;206;210;212-214) have added further evidence. However, they have not significantly changed the overall conclusions drawn from reviewing the two bodies of literature. No study had previously tested psychological mechanisms of an internet intervention in a sample of patients with CHD. However, taken together the reviews suggested psychological mechanisms by which an internet intervention might have its effects.

In both bodies of literature, self-efficacy and social support were the most widely evaluated psychological constructs. However, in internet intervention literature,

evidence for either construct as a mechanism of action was very limited. More evaluations of CHD self-management interventions had measured effects on psychological constructs. These provided support for self-efficacy as a likely mechanism of action. However, the evidence for social support was less clear. The review of CHD secondary prevention literature also identified illness perceptions as a potential mechanism of action of these types of interventions. Although evidence came from only two studies, both provided support for the construct as a likely mechanism by which interventions achieved positive effects. Illness perceptions or self-regulation theory (also known as the ‘common sense model’ (227;228)) from which the construct is drawn, had not previously been applied in internet intervention research.

4.3 Study aims and objectives

The main aim of the study was to evaluate how an internet intervention has its effects for patients with CHD by means of changing psychological constructs. As so little research had been conducted on internet interventions for CHD, an additional aim was to explore use of such an intervention by patients with CHD. In order to achieve these aims, the objectives of the study were to:

- (i) track changes in psychological constructs and health outcomes in a sample of patients with CHD using an internet intervention
- (ii) relate change in psychological constructs and health outcomes in this sample to use of the intervention
- (iii) identify factors which are associated with use of the intervention, with a particular focus on the role of home internet access and prior internet experience

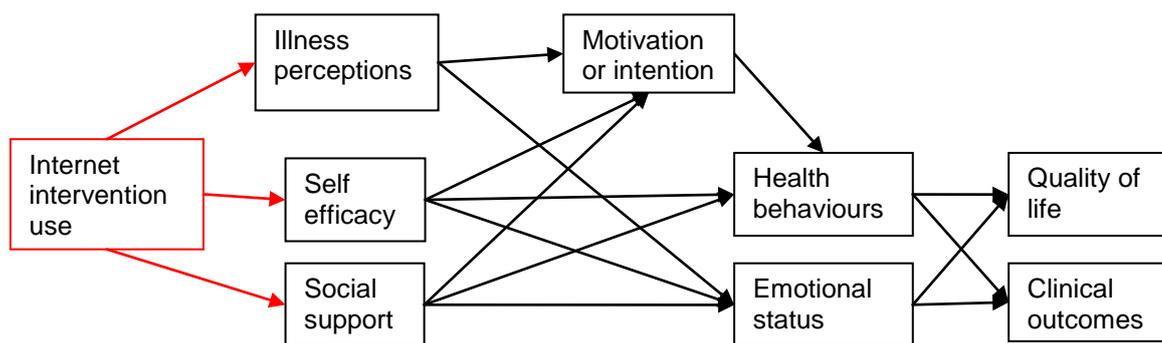
The rationale for these objectives is laid out in the following sections.

4.4 Likely psychological mechanisms of action of an internet intervention for CHD

The findings of the two literature reviews were used to develop a conceptual model (Figure 4.1) of how an internet intervention might work for patients with CHD. In this model the intervention was conceived as likely to impact on illness perceptions, self-efficacy and perceptions of social support. Intervention effects on one or more of these psychological constructs in turn would affect an individual's motivation for health behaviour, the health behaviour they engaged in and their emotional status. Quality of life and clinical outcomes would then be impacted as a result of the indirect effects of the intervention on health behaviour and emotional status.

The model was not intended to be comprehensive. Arguably many other arrows could have been added to the model based on additional evidence and theory. For example, the three psychological constructs may be linked (230-232). The model also implies linear causality from left to right when in fact many relationships may be bidirectional, for example health behaviour, emotional status, quality of life and clinical outcomes are all likely to influence and be influenced by each other. Other factors that are likely to impact on health behaviour, emotional status, quality of life and clinical outcomes such as clinical factors (e.g. CHD diagnosis and severity, time since diagnosis, time since last cardiac event, concurrent health problems) were not included. However, the model was developed as a starting point for evaluation and as such it was intentionally kept simple.

Figure 4.1 Conceptual model of likely mechanisms of action of an internet intervention for patients with CHD.



4.5 Issues in study design

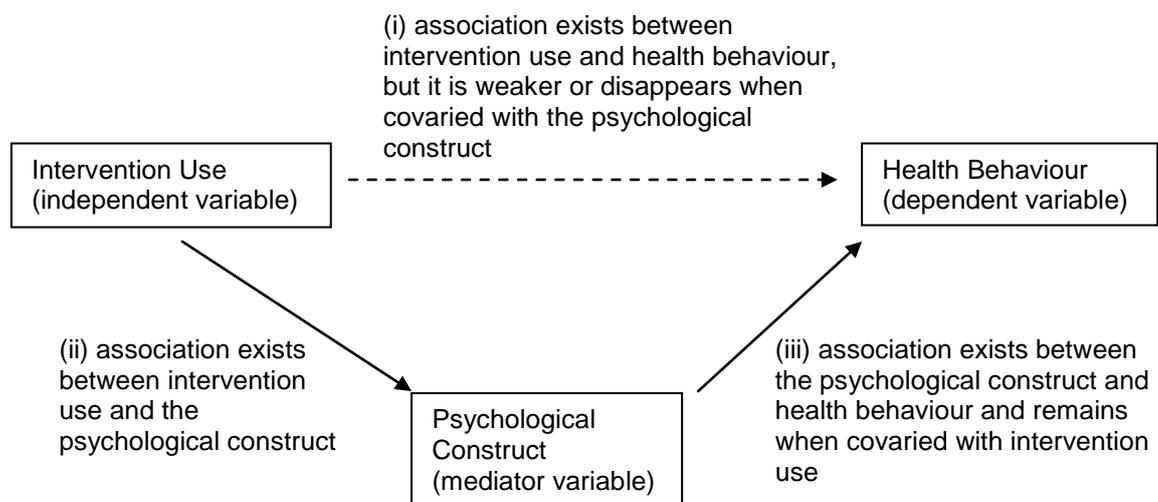
Two bodies of methodological literature were particularly influential in deciding how best to design a study to address the aims. The first was the MRC framework for evaluating complex interventions (59) that was introduced in Chapter 1. In particular, recommendations for simultaneous research on the early evaluation phases of the framework (phase 0 - preclinical or theoretical, phase 1 – modelling and phase 3 - exploratory or pilot trial) (60). The combination of early phases fitted well with the dual aims of this study to test mechanisms of action of the intervention and evaluate use of the intervention.

The second body of literature related to methods of evaluating statistical mediation and additional requirements for evaluating mechanisms of action of interventions (also known as mechanisms of change). A statistical mediator is a variable which has been found to statistically explain the relationship between an independent and a dependent variable. The procedure for testing statistical mediation is well established and set out by Baron and Kenny (69). In order to show a variable is a statistical mediator of the relationship between an independent and a dependent variable it is necessary to demonstrate:

- (i) That the independent variable is associated with the dependent variable (path (i) in Figure 4.2)
- (ii) That the independent variable is associated with the mediator variable (path (ii) in Figure 4.2)
- (iii) That the mediator variable is associated with the dependent variable (path (iii) in Figure 4.2)
- (iv) That when the independent variable and the mediator variable are covaried with the dependent variable, the mediator continues to be associated with the dependent variable (relationship (iii) in Figure 4.2) but the relationship between the independent and the dependent variables (path (i) in Figure 4.2) is reduced.

If this pattern of relationships is found, then one can conclude that the independent variable is related to the dependent variable through its relationship with the mediator variable. Figure 4.2 shows this pattern of relations in a path diagram using intervention use as an example of an independent variable, a psychological construct as an example of a mediator variable and health behaviour as an example of a dependent variable.

Figure 4.2 Path diagram of a mediator of the relationship between intervention use and health behaviour.



While demonstrating the pattern of relationships required for statistical mediation is essential for demonstrating mechanisms of change, it is not sufficient. In a recent paper, Nock (233) summarised the existing body of knowledge on study design for testing mechanisms of change and made the following recommendations:

- Ground investigations of mechanisms in theory and be guided by broader scientific knowledge
- Measure multiple potential mechanisms in order to demonstrate specificity of any one
- Assess all measures of mechanisms and outcomes at multiple time-points, ensuring that measurement is timed to best capture change
- Include reliable and valid measures of mechanisms and other constructs that are objective and sensitive to change
- Assess mechanisms by which outcomes may change outside of the intervention

It was also clear from methodological internet and CHD intervention literature that a number of other issues needed to be considered in the design of this study. These are discussed in the sections below, to provide the rationale for resulting design decisions.

4.5.1 Quantitative and qualitative methods

Methodological literature on evaluating mechanisms of action of interventions suggested that the main study aim required a quantitative design to test for causal effects (69;233). The conceptual model shown in Figure 4.1 specified three psychological constructs as likely mechanisms of action which could be tested using quantitative methods. However, the rationale behind the additional aim of exploring intervention use was the lack of previous research on internet interventions among patients with CHD. This aim might be better met by a qualitative design, which would allow issues to emerge from the data rather than require testable hypotheses to be

specified in advance. A qualitative design might also aid evaluation of the mechanisms of action of the intervention. Given the speculative nature of the conceptual model, due to the scarce and equivocal evidence on which it was based, it was possible that the intervention might work through mechanisms not previously identified. Qualitative methods could identify these mechanisms and provide a richer and more complex picture of how the intervention works for individuals than could be gained from quantitative measures.

In recognition of the advantages of qualitative methods for increasing understanding, the MRC framework for evaluating complex interventions encourages their use, particularly in the modelling phase of evaluation to contribute to:

- developing an understanding of why something happens (e.g. change in an outcome)
- evaluation of how an intervention works
- identification ‘active ingredients’ of a complex intervention and elements that are not related to change
- finding potential barriers to change
- testing underlying assumptions in relation to an intervention or a hypothesis (59)

The ideal would be to combine the strengths of both quantitative and qualitative methods. Both patient education (234), and sociological literature (235) have argued the benefits of mixed qualitative and quantitative methods for valid and comprehensive evaluation. However, there are pitfalls in attempting to integrate qualitative and quantitative methods as they are based on different research paradigms (236).

A particular challenge is the integration of findings from the two approaches. To be able to integrate findings it is important to have clear aims for each method both in relation

to the study aims and to each other. Theory-based quantitative methods were given priority in this study in order to maximise the generalisability of findings. The main aim of the qualitative component was to validate and aid interpretation of quantitative data evaluating intervention use and effects. For the qualitative component to achieve this aim it was important for the qualitative analysis approach to be mindful of the conceptual model driving the quantitative evaluation. One way of achieving this was to take an induction-abduction approach in qualitative analysis (237). In this analytical approach, themes are identified both by topics and issues emerging directly from the data (inductive inference) and by applying prior knowledge (abductive inference). This enabled the analysis to remain firmly grounded in the data, without ignoring the conceptual basis of quantitative data collection and statistical analysis.

The inclusion of a qualitative component required a further decision over when and how qualitative data should be collected. The conceptual model (Figure 4.1) focused on individual change resulting from the intervention. For the purpose of integration it made sense to capture the same individual change process in both quantitative and qualitative data, hence individual interviews were more suitable than focus groups. The main quantitative methods already involved significant measurement burden for participants, so the additional interviews were conducted at a single time-point. This was after the final quantitative follow-up in order to capture the full change process recorded by quantitative measures.

4.5.2 Study design to test mechanisms of intervention action

Methodological literature suggested that in order to fully evaluate mechanisms of action of an intervention:

- multiple psychological constructs should be measured to be able to demonstrate that any one is a mechanism by which an intervention has its effects (specificity)

- the amount of the intervention should be varied in order to demonstrate a dose-response relationship with change in measures of both psychological constructs and outcomes (gradient)
- psychological constructs and outcomes should be measured repeatedly in order to demonstrate that change in psychological constructs precedes change in outcomes (temporal relation)
- an experimental design with random assignment should be used to demonstrate that changes in both psychological constructs and outcomes result from the intervention (causality)
- observed results should be replicated across studies, samples and conditions (consistency) (233).

However, frequent assessment of a wide range of constructs in RCTs is '*an ambitious agenda and one that will require enormous time and resources*'(233). One of the aims of the MRC framework for evaluating complex interventions is to encourage phase 1 and 2 work before embarking on large, costly RCTs, so that researchers are in a better position to conduct worthwhile, rigorous and feasible trials (60). While the framework emphasises the importance of identifying mechanisms of intervention action at an early stage, the phased approach allows the task of evaluating the full list of criteria for mechanisms of change to be spread across early pilot studies and the later definitive RCT.

Capturing change requires data from a later time-point to be compared with data from an earlier time-point, making a prospective design essential. A prospective study in which multiple psychological constructs are measured and intervention use (and hence dose) varies across participants, allows criteria of specificity, gradient and temporal relation to be evaluated. Although this does not test all of the criteria, the next phase of

evaluation (phase 3 randomised trial) (59) can build on the findings to test the remaining causality and consistency criteria for psychological constructs for which early evaluation finds evidence of gradient and temporal relation. The findings can also be used to inform further intervention development to maximise its effect on psychological constructs that have evidence as mechanisms of intervention action. If a particular psychological construct does not meet gradient and temporal relation criteria in the early evaluation, then it can be ruled out as a mechanism of intervention action to measure in phase 3 evaluation.

4.5.3 Target population

Treatment and review of CHD patients in the UK takes place in both primary and secondary care. Clinical characteristics of CHD patients identified in primary compared to secondary care are likely to differ in important ways. CHD patients treated in secondary care settings are likely to have experienced a recent cardiac event (e.g. heart attack, cardiac surgery). Because of their recent experiences, secondary care CHD patients may have significant information and support needs. However, by its very nature secondary care treatment is a time of increased intervention. This would make it difficult to distinguish the effects of an internet intervention from other interventions (e.g. acute treatment, surgery or rehabilitation) being delivered at the same time.

There are many more patients with on-going CHD than those currently treated in secondary care. The population of CHD patients treated in primary care also includes those who have been diagnosed less recently and those who have not experienced a cardiac event. One of the benefits of internet interventions is their potential to reach large numbers of patients, so it made sense to try to reach the wider population of CHD patients in this evaluation. A further benefit of internet interventions is their availability as a resource for patients to use and return to according to information and support

needs that change over time. Their potential suitability for patients managing CHD in the long-term means it was particularly important for the sample to include patients who may not have been diagnosed with CHD particularly recently.

Once the decision was made to recruit CHD patients in primary care, it became important to anticipate some of the difficulties reported by other research conducted in primary care settings (238;239). As a result recruitment and data collection procedures were designed to place minimum burden on practice staff. Also primary care practice recruitment was targeted to approach practices that would most likely participate but also served diverse communities of patients.

4.5.4 Inclusion and exclusion criteria

The inclusion and exclusion criteria used in a study affect the validity of its findings. Stricter inclusion and exclusion criteria reduce variation in a study sample to increase the ability to attribute effects to an intervention (internal validity), rather than to differences between individuals. However, reducing variation in the sample by excluding segments of the target population also reduces the relevance and generalisability of the study findings to the target population (external validity). The decision to recruit in primary care was driven by a wish to reach as large and as diverse a sample of CHD patients as possible. With external validity the greater priority, it was important to design the study to be as inclusive as possible. The ideal was to keep inclusion criteria as wide as possible and exclusion criteria to a minimum.

One of the main inclusion decisions to be made in evaluations of internet interventions is over internet access and experience (56). While CHD is more prevalent in older age-groups, internet access and use is lowest among older age-groups and among people with long-term conditions (47;53). It was likely that a significant proportion of CHD patients registered at participating GP practices would not have home access to the

internet or experience in using the internet. Excluding people without home access to the internet or prior internet experience would most likely result in excluding a large number of patients with CHD. However, inclusion of participants without home internet access or prior experience requires additional resources and an awareness of these users in intervention design (56).

Some previous evaluations of internet interventions have overcome problems of internet access by providing participants with laptops and home internet access for the duration of the study (97;240). However, this limits wider implementation of internet interventions as this provision would not be sustainable outside research evaluations. It would also have been prohibitively expensive in this study.

Another solution for CHD patients without home internet access would be to take advantage of facilities which provide public internet access. Since 2002 a network of online centres has been set up to provide free internet access, support and training for internet use in convenient community locations in the UK (48). Use of the intervention at these facilities might be encouraged by tailored training and provision of information about local public internet access and training courses. However, not having home access to the internet intervention might still restrict use, and initial training might not be sufficient to make an internet intervention accessible to individuals without previous internet experience. As a result, exploration of the relationship between home internet access, level of internet experience and use of the intervention was made a specific focus of the relevant study objective.

As well as including those without home internet access or prior internet experience, a representative sample of UK patients with CHD should include a significant proportion of people of South Asian origin and other ethnic groups. Prevalence of CHD is higher in certain ethnic groups. In particular people of South Asian origin living in the UK have a

50% higher risk of dying prematurely (before 75yrs) of heart disease or stroke than the general UK population (241). In order to include CHD patients from these ethnic groups both interventions and study materials need to be designed with awareness of relevant cultural norms. As English is not the first language of many older adults from these ethnic groups who live in the UK, ideally interventions and materials should also be translated into other relevant languages.

In this study, while efforts were made to include culturally relevant content, available resources did not permit any translation into other languages. Efforts to increase the accessibility of the intervention for patients whose first language was not English were limited to ensuring that content was written in plain English. The study could only include patients whose first language was not English if they had a relatively good grasp of the language. This has implications for the representativeness of the study sample and limits the generalisability of its findings.

4.5.5 Selecting outcomes

As discussed in Chapter 1, there are a number of important outcomes for people with CHD, which include emotional status, health behaviours, quality of life and clinical outcomes. These four types of outcomes were included in the conceptual model (Figure 4.1). Ideally all four types of outcomes would be measured in a study evaluating the effects of an internet intervention for these patients.

Some of these outcomes were particularly important to measure to evaluate relationships shown in the conceptual model (Figure 4.1). The effects of the intervention on clinical and quality of life outcomes were expected to be mediated by its effects on health behaviours and emotional status. As more proximal outcomes on which further change depends, health behaviours and emotional status were particularly important outcomes to evaluate.

Quality of life and clinical outcomes may have been relatively less important for testing the mechanisms of action specified in the conceptual model, but were arguably more important outcomes to improve for people with CHD. Of these, clinical outcomes were particularly hard to evaluate in this study. The results of recent clinical tests could have been made available by participants' consent (e.g. blood cholesterol levels). However, routine tests would not have been frequent enough to evaluate change within the study time-scales and with no control over the timing of tests, they would not have matched baseline and follow-up completion of other measures.

Selection of health behaviours and emotional status as outcomes for evaluation required further decisions about the specific health behaviours and emotional outcomes to measure. CHD self-management involves a number of different types of health behaviours (e.g. exercise, diet, smoking cessation, moderation of alcohol consumption, taking medications as prescribed, stress management). Ideally relevant health behaviours would be evaluated by a single, comprehensive CHD self-management measure. However, no such measure was identified. Measures of multiple health behaviours that were identified only minimally covered behaviours of interest and included some irrelevant behaviours (242;243), confounded measuring health behaviours with quality of life measures (244), or required clinical data not available in this study (245-248). So, diet, exercise and medication adherence behaviours were selected for measurement primarily based on their relevance to all patients with CHD, but also on the availability of measures of self-efficacy for equivalent behaviours. This was based on guidance that self-efficacy is more likely to predict a particular health behaviour if it is measured specific to that health behaviour (249).

For emotional status outcomes, depression was selected for evaluation because of its noted prevalence in CHD samples and importance as a predictor of relevant clinical

outcomes (250;251). Anxiety was selected because of the importance of relieving anxiety reported by CHD patients (252) and to capture possible negative intervention effects in terms of raised levels of anxiety.

4.5.6 Selecting measures

Psychological constructs and outcomes

For this study, most potential measures were identified through their previous use in internet intervention and CHD studies, although specific literature and online searches were also conducted to identify suitable and available measures. Selection of measures of psychological constructs and outcomes aimed to use the following criteria:

- Relevance to the target population and the intervention (content validity)
- Reliability (including acceptable internal consistency (Cronbach's alpha) and test-retest reliability)
- Construct, convergent and discriminant validity (expected relationships with other validated or clinical measures and ability to discriminate between groups expected to differ on the construct/outcome)
- Sensitivity to change
- Brevity (minimise measurement burden given multiple outcomes to be measured and maximise response rates as a result)
- Likelihood of yielding normally distributed scores (to allow use of parametric statistical analysis)

Unfortunately measures that met all or even most of the criteria did not necessarily exist. In some cases there was a wide choice and many of the criteria could be applied. For example, numerous generic and disease-specific measures of health-related quality of life (HRQL) have been used in research with CHD samples. Generic measures provide a broad assessment of the health status of an individual and allow comparisons

of HRQL between groups of patients with different conditions whereas disease-specific HRQL instruments measure those areas of life which may be affected by a specific condition or illness (253-255). Disease-specific instruments tend to be more clinically sensitive and more responsive to change over time due to intervention than generic measures (253;255), so a disease-specific measure was selected for use in this study.

The MacNew Quality of Life was selected over other disease-specific measures including the Cardiovascular Limitations and Symptoms Profile (CLASP (256)); the Quality of Life Index – Cardiac version (QLI (257)); the Seattle Angina Questionnaire (SAQ (258)); and the Myocardial Infarction Dimensional Assessment Scale (MIDAS (259)) for the following reasons:

- It had been used in both angina and MI samples (255) and validated in a UK sample (260) with reference data available (261)
- It had good internal reliability (Cronbach’s alpha 0.92 for global score (254)).
- Researchers have reported a low risk of ceiling effects (262)
- It had been found to predict clinical outcome after adjusting for other risk factors (24).

The MacNew did not perform so well on other criteria. Negative skew had been reported for distributions of some MacNew scores (261;263) and there had been mixed results over its responsiveness and sensitivity to change (254;262). However, score distributions for other scales were no more normally distributed, or not reported, and no other measure was clearly more sensitive to change.

For other outcomes, once available measures were restricted to those that were relevant to the target population and intervention there was little choice to be made. For example, self-efficacy measures had to be relevant to the health behaviour outcomes

selected and not refer to activities contra-indicated for CHD patients. This meant that self-efficacy measures that were specifically designed for use with cardiac samples were most relevant. However some of these were ruled out because they were not suitable for use in a primary care sample who had not necessarily recently experienced a cardiac event or in-patient stay e.g. the Jenkins Self-efficacy Expectation Scales (190). In the end one item in the Cardiac Exercise Self-efficacy Instrument (264), one of the three self-efficacy measures selected to cover relevant health behaviours, was omitted because it referred to pre-hospital levels of exercise. Equally, selection of a social support measure ruled out those which focused on support delivered face to face or by partners and family members, e.g. the ENRICHD Social Support Inventory (265). Although this measure was specifically designed for CHD patients, very few of its items were open to change by an internet intervention. Instead, the MOS Social Support Survey was selected because it had an 8-item perceived emotional and informational support subscale which did not require face to face delivery of support (266).

In addition to other measurement criteria, Nock (233) recommended that researchers use objective measures. However, these are only relevant in the measurement of outcomes that can be observed objectively. In this study this only applied to the measurement of health behaviours. Exercise, for example, could be measured objectively by ambulatory monitoring. Although potentially more accurate and reliable than self-report measures, objective methods of measuring health behaviour are intrusive and time-consuming, especially if repeated measurement of several behaviours is planned. Self-completion questionnaires seemed more suitable as they would be less time-consuming and intrusive. However, the potential for inaccuracy in self-reports of health behaviour was a concern, particularly as suitable self-report measures of diet and medical adherence were not easy to find. Most dietary assessments identified involved lengthy assessment of frequency of intake of extensive lists of foods. While previous studies with CHD

samples had devised briefer self-completion measures out of necessity, their validity and reliability were not clear. As a result two of these measures, the Healthy Diet Habits Score (267) and 6 food frequency items (268) were selected with the intention of using scores from whichever measure proved to be the most internally reliable and normally distributed in this study. Mindful of repetition and response burden, the measures selected asked about different aspects of diet relevant to healthy eating recommendations for people with heart disease. The only medical adherence behaviour measure identified was the Medical Adherence Report Scale (MARS (269)). Although not a published measure, it has been widely used (270-274) and some unpublished pilot data was available on which to assess reliability and validity, but not sensitivity to change (269).

No directly suitable measures of motivation or intention to carry out or change the selected health behaviours were identified, so items were devised for use in this study. Convention among studies measuring behavioural intentions in CHD samples was to use single-item measures for each behaviour. Some evaluated strength of agreement to a statement about intention to carry out a behaviour (275), others evaluated strength of intention to engage in a behaviour over a certain time period (276). No tests of reliability or validity of any of these measurement methods were reported. Some guidelines recommend use of 3 items to measure intention for each behaviour (asking participants whether they expect to, want to and intend to carry out the behaviour (277)). However, the use of such repetitive items in the context of the multiple measures required in this study seemed unwise. A single intention item for each health behaviour was used, based on items used in a previous study (275).

Concerns over measurement burden meant that brief versions of selected measures were used where available. So the 9-item Brief Illness Perceptions Questionnaire (Brief IPQ

(278)) was used instead of the longer Illness Perceptions Questionnaire (IPQ (279)) or the 80-item revised Illness Perception Questionnaire (IPQ-R (280)). Also the short 7-item version of the International Physical Activity Questionnaire (IPAQ (281)) was used instead of the 27-item version.

Because of restricted choice and the frequent absence of desired information, the set of measures selected for this study (listed in full in Chapter 6, Table 6.1) was pragmatic rather than ideal. Even after taking care to select brief measures, baseline questionnaire completion took participants between 30 and 60 minutes.

Measures of intervention use

Standard website programming enables any use made of internet interventions to be automatically recorded. This means it is possible to collect highly detailed intervention use data which includes all pages viewed, time and date of access, search terms used and any text entered during a particular period of time. If users are required to log in with a specific username, the detailed data recorded can be used to summarise each participant's use or 'dose' of intervention.

Many different variables could be calculated from this wealth of detailed data. For example, overall use of the intervention could be calculated by frequency of use (number of log-ins), duration of use (time spent using the intervention), or amount of intervention content accessed (pages requested). The most common measure of intervention use used in previous evaluations of internet interventions was the number of logins (or uses) made either overall (82;84), by time of day (82;84), on average per month (97), or per type of intervention service (84). Studies have also reported total minutes of use (84) and mean minutes logged on per month (102).

In all of these studies, the data was used primarily for describing intervention use.

While this was also important for the current study, intervention use data would also be used in analysis as a measure of the 'dose' of the intervention received. There was little guidance in the literature at the time over which measure or combination of measures would meaningfully capture intervention use for this purpose. A conference presentation reported correlating various measures of intervention use with weight loss (the outcome targeted by the intervention). This presentation suggested that their attempts to develop an index score of intervention use, which incorporated use of key intervention components, yielded little advantage over a simple count of logins (282).

However, number of logins is purely a measure of frequency of intervention use and does not necessarily capture the amount of intervention use. It does not distinguish between those who made little and those who made extensive use of the intervention in a single login. Duration of intervention use or number of intervention pages accessed would seem to be better measures in this regard. These were not considered in the conference presentation (282). Duration of each login can be calculated from recorded time of access for each page, however this is likely to be subject to error introduced by variation in download times for pages (dependent on connection bandwidth) and the likelihood that pages may remain on screen when they were not actually being viewed (e.g. while participants were viewing other websites in other browser windows or tabs, or if they left the computer). Number of intervention pages accessed does not suffer from the same error problems and can also be split down by different types of intervention pages to reflect type as well as amount of use. Whether or not number of intervention pages accessed is a better measure of intervention use than frequency of logins has yet to be established. It seemed reasonable to measure both and examine distributions of use and inter-correlation between the measures to decide on the most suitable measure of intervention use for analysis.

4.5.7 Collecting other participant information

The secondary aim of the study was to explore use of the intervention by the target population. This required collection of other types of information to describe the sample, compare participants to the target population and identify factors influencing intervention use. Demographic and clinical information was recorded for this purpose, along with participants' level of internet access and experience. Collection of clinical information could also be used to assess mechanisms by which outcomes might change outside of the intervention. For example:

- Recent cardiac events are likely to influence participants health behaviours, emotional status and quality of life
- Participants with concurrent cardiovascular problems may be more motivated to change health behaviours because self-management guidelines are similar for these conditions and having them may increase the importance of self-management for participants
- Other concurrent health problems may restrict participants' ability to change health behaviours, either directly by physical disability or through treatment and conflicting self-management. These conditions are also likely to have their own effect on participants' emotional status and quality of life
- Cardiac events (e.g. heart attack) or hospital treatment for heart disease which occur during the intervention period may influence participants' use of the intervention. Surgery or cardiac events may be particularly likely to increase patients' need for information and support, and hence use of the intervention. They are also likely to have their own effect on participants' capacity for healthy behaviours, their emotional status and quality of life.

Clinical information could either be collected from participants by self-report or from electronic summaries in their GP notes. Available literature gave little guidance on the relative accuracy of GP notes and patient recall. Previous studies have concluded both that angina is under-reported in UK primary care records compared to patient recall (283) and that MI is over-reported by patient recall compared to UK primary care records (284). The situation is complicated by the treatment of CHD in both primary and secondary care settings and the relatively recent introduction of electronic primary care records. Details of cardiac events treated in secondary care may not be accurately recorded in primary care notes. Cardiac events and diagnoses which took place a number of years ago may not feature in electronic summaries of GP notes.

To maximise the accuracy of clinical information, both methods of data collection were used in this study. Questions and response options for self-completed clinical information were designed to gather sufficient information for:

- classifying participants by CHD diagnosis and concurrent long term conditions
- calculating variables of time since earliest CHD diagnosis and time since most recent cardiac event
- calculating the total number of medicines participants were taking
- monitoring cardiac events and treatment during intervention period

Because of concerns about the completeness of GP notes, information from the electronic summaries was used to add to and correct clinical information reported by participants who consented to this, rather than to replace it.

Coding of clinical information from the two data sources was guided by identification of clinical characteristics commonly used to describe samples and hypotheses about how clinical factors might influence intervention use or change in outcomes

independent of the intervention. Coding decisions frequently required clinical knowledge and so were guided by discussion with Elizabeth Murray (primary supervisor and GP).

4.5.8 Paper-based or electronic data collection

Data collection in this study relied heavily on measures self-completed by participants. The measures selected for this study were traditionally printed, given or posted to participants to be completed and returned to researchers. However, the development of new technologies means that electronic data collection was also possible. Electronic questionnaires can either be made available online or emailed between participants and researchers. They have several advantages over their traditional paper and pen counterparts. People often find them more convenient to complete, they are less costly and potentially less error-prone. For example, electronic questionnaires can be programmed to require users to provide valid answers to questions on each screen and responses can be downloaded directly into statistical databases without the cost and potential error associated with manual data entry. There is also some evidence that they require fewer reminders and might increase follow-up rates (285).

However, there are also some potential drawbacks to electronic data collection. In the small amount of literature available at the time, one study of experienced internet users with chronic conditions found good agreement between paper and online health-related questionnaires (285), while another found that online questionnaires could not be assumed to share the psychometric properties of their paper-based counterparts (286). Also people with little or no computer or internet experience would be likely to find them more difficult to complete than paper-based questionnaires. Online questionnaires or those sent by e-mail would also be hard to access and complete for those with limited access to the internet. Because most free public internet access is time-limited, this

might impact intervention use by participants without home internet access as they would have to choose between accessing the intervention and completing questionnaires in the time available.

As a result of concerns about equivalent validity of different versions of measures it seemed important to use the same method of data collection with all participants at all measurement time-points. Because of the potential difficulties for participants without home internet access, computer or internet experience, printed questionnaire booklets were used to collect data from participants throughout the study.

4.5.9 Statistical analysis approach

Investigating predictors of intervention use

This study differed from previous internet intervention studies in ways that might well influence the use made of the intervention. No previous study had evaluated an internet intervention in a UK primary care long term condition sample or included participants with different levels of internet access and experience. Although patterns and predictors of intervention use have been reported in previous internet intervention studies (84;85;92;97;102), because of the differences in samples and settings these did not provide strong evidence for selecting predictors of use in this study. As a result, it seemed appropriate for statistical analysis of predictors of intervention use to be exploratory rather than driven by specific hypotheses.

However, it was still necessary to have some grounds for selection to reduce the predictors from the large number of variables measured at baseline to a number that analysis had sufficient power to test. Selection was based on factors that have generally been found important in patterns of internet use, in particular for health information (53;287). Selection of other predictors was based on statistical grounds. Variables which did not vary greatly among participants would be unlikely to significantly predict

intervention use and so were ruled out in favour of other variables with wider variation in scores and higher correlation with intervention use. Similarly, where high inter-correlations between variables were observed, the variable with the widest variation in scores and the highest correlation with intervention use was selected. Given the exploratory aim of this analysis, overall selection aimed for a balance across demographic, internet, clinical and baseline scores on psychological constructs and outcomes.

Investigating mechanisms of action of the intervention

Various methods of statistical analysis could be used to evaluate the potential mechanisms of intervention action shown in Figure 4.1. The suitability of different methods depends on whether analysis aims to test the model as a whole or test parts of the model separately. Baron and Kenny's (69) procedure for testing statistical mediation, can test the relationships between the intervention, a single psychological construct and one type of outcome. The relationships are tested using a series of regression analyses. This procedure could be applied to each of the potential mechanisms of action specified in the conceptual model, testing different parts of the model separately.

Alternatively more sophisticated analysis, such as structural equation modelling, could be used to test the whole conceptual model. The advantage of this approach would be to capture the full complexity of possible relationships between all the psychological constructs and outcomes included in the model. However, the evidence on which the conceptual model was based was not particularly strong and the model was intended as a starting point for evaluation rather than an attempt at a comprehensive representation. As a result, evaluation of the model as a whole did not seem a useful first step, particularly as this kind of analysis typically requires a much larger sample. Sample size

requirements were an important consideration in this study because of the resource constraints of a single study researcher and because the likely response rate of primary care patients with CHD to an internet intervention study was unknown.

Regression analysis conducted in this study needed to take into account the prospective design of the study and test the effects of the intervention on change in psychological constructs and outcomes rather than simply test relationships between scores at a single time-point. Scores at follow-up time-points needed to take into account baseline scores in order to reflect change. This could be achieved either by calculating the difference between scores at baseline and follow-up (absolute change) or by controlling for baseline scores in analyses predicting follow-up scores (regressed change). Of the two, the latter method has been advocated as the more powerful test of change as it takes into account the correlation between baseline and follow-up scores (288). Mechanisms by which outcomes might change outside of the intervention can then be addressed by controlling for demographic and clinical characteristics that were likely to independently influence outcomes when testing for intervention effects. Selection of characteristics to be controlled for in analyses could either be guided by a priori hypotheses about how clinical factors might influence change in outcomes independent of the intervention (Section 4.5.7). They could also be guided by the findings of preliminary analyses. These might include baseline characteristics found to significantly predict intervention use or found to differ significantly between responders and non-responders at follow-up.

Approach to managing missing data

The completeness of data collected has implications for the statistical power of analysis to detect significant relationships between variables. Maximising the number of cases in analysis serves to maximise the statistical power. There is also the ethical consideration

of making best use of data that participants provide. Participants were encouraged to answer all questions but did not have to answer any question they objected to. It seemed reasonable to assume that where participants completed most, but not all items on a scale, they still expected their responses to count.

There are various approaches to imputing data for cases where data is missing to maximise the number of cases that can be included in analysis. These include imputation from an earlier score for the same participant, an average score for that participant on other completed items in a scale and an average score from similar participants or from the sample as a whole. However, measurement validity is weakened by imputing large amounts of data, particularly where individual data is imputed from means calculated from scores of others. Last score carried forward did not seem a suitable approach in a study which had such a focus on individual change over time. A conservative approach to imputation, which still increased the cases of included data, was to only impute data for near complete cases from mean scores of the same individual participant on other completed items of a particular scale, unless the scoring instructions for a particular measure states otherwise. The robustness of findings of analyses conducted on outcomes with imputed data could then be checked by repeating analyses for complete cases only.

Management of skewed data

The score distributions of data influence the analysis that can be conducted. Univariable linear regression analysis requires the dependent variable to be normally distributed. For multivariable linear regression analysis it is the residuals of the dependent variable that must be normally distributed. However, this is unlikely to be achieved if the scores on the dependent variable deviate significantly from a normal distribution.

Although one of the selection criteria for measures was yielding normally distributed scores, this criterion could rarely be given priority most commonly because this information was not available or because choice was so restricted. Decisions about how to manage skewed data needed to be based on meeting the statistical assumptions of the methods of analyses used, as violation of these assumptions was likely to invalidate findings. Options include transforming data to achieve more normally distributed scores, although this is only likely to work for certain types of skewed distributions and can make results of analyses difficult to interpret. Alternatively skewed data can be re-coded into categories and analysed using non-parametric tests, although this reduces analytical power to detect significant effects.

4.5.10 Target sample size

The target sample size was guided by the requirement for sufficient power to detect relationships in multiple regression analysis. By one calculation an analysis including up to 15 predictors would require 138 subjects to detect medium effect sizes (typically involving $R^2 = 0.13$ (289)) as statistically significant at the 5% level, with 80% power (290). A standard rule of thumb holds that samples should aim for 10 participants per predictor (291). This would allow up to 13 predictors to be used in analysis with the same sample size.

With any prospective design, target sample sizes should take into account the likelihood of participants dropping out of the study over time (attrition). For design purposes rate of attrition can be estimated from previous studies of similar interventions and similar samples. In this case secondary prevention in CHD primary care samples (292) and previous studies of internet interventions in chronic disease samples (86;97) suggested that it would be wise to allow for 20% attrition during the study, i.e. recruit 173 participants for an end sample of 138.

4.5.11 Follow-up methods

Achieving a high follow-up rate is important both to achieve sufficient statistical power in analysis and to minimise response bias in the data collected. With high rates of attrition, participants who provide data at follow-up may not be representative of the full study sample. If those who do not complete follow-up are different in important ways from those who do, then there is a possibility that study findings might have been different if data from the full sample were included. Those who are successfully followed up can be compared to those who are not on characteristics measured at baseline. The effects of any characteristics found significantly different among responders can then be controlled for in analysis. However, this assumes that all of the important characteristics on which participants could differ were measured at baseline. Moreover, the analysis still does not include data from those not followed up.

The best way to minimise response bias is to maximise follow-up rates. However, overly intrusive and persistent follow-up methods may deter participants from taking part, or cause them to withdraw from the study. So it is important to strike a balance.

Methods in this study were designed to maximise follow-up in three ways. Firstly, by making response at follow-up as easy as possible for participants. Questionnaire length (measurement burden) was kept to a minimum and reply-paid envelopes were provided for questionnaire return. Secondly, by a system of reminders for those who did not respond immediately. This started with minimally intrusive letters and emails, so only those who had not responded to several postal/email reminders were then contacted by phone. Thirdly, by methods to increase commitment to study participation. These included providing information about study progress in regular newsletters and highlighting the importance of receiving follow-up data from all participants in follow-up reminders.

4.5.12 Study time scale

Internet interventions need to be made available for a sufficient amount of time for changes in outcomes to occur. Completion of follow-up measures needs to be timed to capture change at the time it occurs, and should aim to capture change in mechanisms that occurs before change in outcomes. Ideally the intervention period and measurement time scale should be guided by theories from which the proposed mechanisms of action are drawn. However, no guidance over time scales for expected change (also known as causal lag (293)) was found in the theoretical literature. Instead time-scales were based on evidence from previous studies evaluating similar interventions and change in relevant CHD outcomes.

Selection of the intervention and measurement time scale for this study took place in 2005 so guidance came from evaluations of similar interventions included in a relevant systematic review published at the time (49). Intervention exposure in these evaluations varied greatly, from 20 minutes access on a single scheduled occasion to many hours during repeated self-directed home-access over 12 months. Only seven of the 24 studies included in the review were complex and networked computer-based or internet-based interventions which allowed repeated, self-directed access to adult samples of patients with a long term condition (49). Table 4.1 summarises the intervention periods used in these studies.

Table 4.1 Intervention periods of internet intervention studies.

Intervention period	Long term condition
3 months	AIDS/HIV (86)
5 months	Diabetes (102)
6 months	AIDs/HIV (83)
	AIDs/HIV (86)
	Breast Cancer (91)
	Diabetes (294)
10 months	Diabetes (97)
12 months	Obesity (295)

One study used more than one intervention period and found that when the intervention was removed after 3 months its positive effects had mostly disappeared by 5-month follow-up. However, after 6 months access positive effects on social support and participation in healthcare were still evident 3 months after the intervention was removed (86). This would seem to recommend an intervention period of at least 6 months.

In addition, it made sense to give access to the internet intervention for as long as participating patients would use it within a feasible time frame. One of the particular benefits that internet interventions offer to patients with long-term conditions is that they are a resource for patients to return to time and again with different needs and questions. Studies which reported patterns of use of internet interventions over 5 or 6 months indicated that while use dropped off over time, on average participants were still using the intervention for 37 minutes in the final month access (month 5) in one study (102) and an hour a week in the final month of access (month 6) in another (84). In both cases use in the final month was at a similar level to use in the preceding month, a level of use that Boberg and colleagues (84) named 'steady-state'. This raised the possibility that regular use of an internet intervention may continue after 6 months. In order to allow participants maximum amount of use and potential for change in psychological constructs and health outcomes in this study, participants were given access to the internet intervention for 9 months.

Patterns of use of relevant interventions also guided selection of the measurement time-point for early change. According to previous research, 3 months marked a point where users of internet interventions settled into the longer-term 'steady-state' pattern of use (84). Use was heaviest in the first month in particular, then declined gradually over the next two months, with median use of an internet intervention in the first 13 weeks once

a day among a sample of people with HIV/AIDs (84). Similarly mean minutes of use of an internet intervention among a sample of women with diabetes was 129 minutes in the first month, had declined to 78 minutes by the third month and settled at around 40 minutes per month for months 4 and 5 (102). Given this likely change in patterns of use, a 3-month follow-up point would be likely to capture effects of early intervention use.

In addition, 3 months is a common measurement point in cardiac rehabilitation, self-management and lifestyle change intervention studies. At this point studies have found change in relevant CHD outcomes including:

- quality of life (296-298)
- health behaviours – diet, exercise and stress management (298), self-care behaviours (299)
- motivation for health behaviour (300)
- depression (301;302)
- anxiety (302)

So a first follow-up point was set for after 3 months of access to the intervention to capture change after early intervention use. A further follow-up was also required to give some indication of longer-term change and allow evaluation of the temporal relation of changes in mechanisms to outcomes. Outcomes such as health behaviour may well change by 3 months, however, to have a meaningful impact on clinical outcomes health behaviour change needs to be sustained over time. Typical outcome timescales in studies evaluating similar interventions ranged from 5-10 months for measures of social support, 3 weeks to 8 months for self-efficacy and 5-12 months for health behaviour (49), with measurement time-points related to length of intervention exposure. In line with the intervention period in this study, participants were followed up at 9 months, at the end of their access to the intervention.

Without any clear direction from theories over causal lag, the measurement time points in this study were based on available evidence from previous internet and CHD intervention studies. The systematic review of similar interventions (49) brought together the evidence from literature available at the time, but unfortunately none of the studies included in the review were with CHD samples. As a result the adequacy of the intervention period for achieving change and of the measurement time scale to capture change was a concern. However, any change captured in this study at the 3 and 9-month time points would contribute to the literature and be available to guide future studies.

4.6 Summary

The purpose of this chapter was to present the study aims and to consider how best to design a study that would meet them. Consideration of methodological literature and previous evaluations of similar interventions suggested that an appropriate design would:

- be a prospective study of primary care patients with CHD
- be as inclusive as possible
- use mixed quantitative and qualitative measures
- give access to the internet intervention for a period of 9 months
- measure psychological constructs and health outcomes at 3 time points (baseline, 3 and 9 months)

Chapter 5 : The internet intervention

5.1 Introduction

This chapter describes the process by which a CHD-focused internet intervention was selected and developed for use in this study, as well as the intervention maintenance required throughout the study. A brief account of the process of applying user-generated quality criteria to develop this intervention has been published in a peer-reviewed journal (303).

It was unrealistic to expect to design a high quality internet intervention within the limited time and resources of a PhD, particularly when the thesis aims also required prospective evaluation. Given the constraints of limited time, funds and technical expertise, this study required an existing CHD-focused internet intervention. It was also important that the designers were prepared not only to permit the use of their intervention in this study, but also to provide data on intervention use by study participants.

5.1.1 Intervention selection

A systematic approach to selecting an internet intervention would involve searching for a number of CHD-focused internet interventions, and choosing the best one according to a set of criteria. However, this assumes that a number of CHD-focused internet interventions exist and that the developers of any intervention selected would support its use in this study. Previous experience conducting a study, which involved identifying and selecting available internet interventions for CHD and other long term conditions (44), suggested these assumptions may not hold true. In the previous study, three strategies were taken to identify different examples of internet interventions that patients and carers could use before discussing them in a focus group. The first strategy was to contact authors of studies included in the systematic review of IHCA for long

term conditions (49). The second strategy was to conduct Google internet searches on each long term condition. The third strategy was to ask researchers, academics and consumer representatives for details of any relevant internet interventions they knew of.

The first strategy was largely unsuccessful, as researchers who had developed or evaluated interventions reported in the literature were hard to track down (contact information from published papers was largely out of date and many had moved institutions). The majority of those who could be contacted were unable to provide access to online interventions because they no longer existed in any usable form. This approach was particularly unsuccessful for identifying CHD-focused interventions as so few had been evaluated by published studies, none were included in the systematic review (49). Google internet searches identified a large number of relevant websites. However, once those that were not interactive or did not offer any additional support components were excluded, there were few to choose from. These were largely commercially sponsored US websites with no evidence of previous user or academic evaluation. Researchers, academics and consumer representatives approached as part of the third strategy only identified a few additional interventions. The only additional CHD-focused intervention identified by the third strategy was a minimally interactive CD-ROM.

The process of identifying interventions for the previous study only took place a year before selection of the intervention for this study. There seemed little value repeating the search strategy as it would be unlikely to identify additional suitable and available interventions. Instead a more targeted approach was taken, which built on an existing collaboration between colleagues in the E-Health Unit at UCL and the CHES (Comprehensive Health Enhancement Support System) Team at the University of Wisconsin-Madison. The CHES team have extensive experience in developing

internet interventions for patients and carers managing long term conditions (240). They have developed internet interventions for patients and/or carers managing HIV/AIDS, CHD, breast cancer, prostate cancer, terminal care and asthma.

5.2 CHESS Living with Heart Disease

The *CHESS Living with Heart Disease* internet intervention had been developed by a multi-disciplinary team at the University of Wisconsin-Madison, comprising clinicians, health psychologists, health educators, health journalists, information scientists, researchers and IT programmers following a needs assessment of US patients with CHD. A small randomised pilot study found positive effects of *CHESS Living with Heart Disease* (100), but no further evaluation had been undertaken. Other CHESS internet interventions developed using the same needs assessment and design process have been evaluated by RCTs and found to be highly acceptable to users and their clinicians, to enhance patient involvement in their health care, to improve social support, emotional and quality of life outcomes (85;86;89;91;240).

CHESS Living with Heart Disease offered users the following services:

- Information – in the form of basic information about heart disease, frequently asked questions, a library of articles on heart disease from medical, voluntary and lay organisations, and an ‘ask an expert’ service.
- Emotional and social support – through personal stories, information about likely emotional reactions to heart disease, and a moderated on-line discussion group.
- Self-assessment questionnaires and a monitoring tool - to help users identify areas for improvement, whether in behaviours (diet, exercise, smoking), personal relationships (friends, spouse, family), or medical interventions (lipids, blood pressure, medications).

- Behaviour change support - with formal exercises to aid the user in prioritising areas for change, setting goals for change, identifying barriers and facilitators to change, and providing encouragement and feedback.

5.3 Quality criteria for internet interventions

Although *CHESS Living with Heart Disease* had been developed by an experienced team, it was important that users in this study would judge it to be of sufficient quality for them to want to use it. At the time of intervention selection for this study, quality criteria for evaluating health information for consumers on the internet had been largely developed by professionals in response to widespread concern about patient misinformation as a result of accessing poor quality information on the internet (304;305). This was a large body of research. A systematic review of relevant empirical research identified 79 studies evaluating 5941 health websites (306). However the quality criteria tended to reflect professional concerns such as accuracy, completeness, readability, disclosures and references. Despite the proliferation of such evaluation tools their use to consumers is debateable (307). Users may have different criteria for information quality, depending on their needs (308). Also, research which sought patient perspectives on more traditional information sources, such as leaflets or videos, suggested that patients use a wider range of criteria for rating patient information materials. These included the extent to which their questions are answered, ease of finding information, the tone of the information, and whether the information appears to be commercially funded or driven (309).

At the time, only a small number of studies had sought users views of online health information, from samples of general public internet users (310-312), or from patients managing long term conditions (313;314). More studies have been published describing user's perspectives of online health information since the time when the intervention

was selected for this study. However, quality criteria from studies available at the time had limited relevance to an internet intervention for patients with CHD. Firstly, because people with a long-term condition, such as CHD, have different information and health needs to healthy volunteers and hence may use different quality criteria. Secondly, even where views of patients managing long term conditions had been sought, studies only considered online health information, rather than interactive websites which combine information with interactive support tools.

Our previous study aimed to address this gap in the literature at the time (44). In this qualitative study, disease-specific groups of patients (managing diabetes, heart disease or hepatitis C), carers of people with Alzheimer's disease or parents of children with diabetes, used three internet interventions relevant to their condition. Each group then discussed the strengths and weaknesses of the different internet interventions.

Transcripts of the focus groups were thematically analysed to identify quality criteria generated in the discussions. The quality criteria were fed back to patients and carers who validated them by rating and ranking criteria for importance. Participants generated detailed and specific quality criteria relating to information content, presentation, interactivity, and trustworthiness. Details of these overarching and more specific criteria are summarised in Table 5.1.

Table 5.1 Patients' and carers' quality criteria for internet interventions.

Taken from (44).

Main criteria	Detail of criteria	Related criteria
Information content	<ol style="list-style-type: none"> 1. Needs to be detailed, specific and of practical use. 2. Long-term use requires increasing depth of information as self-management experience grows as well as new and up to date information. <p>A good internet intervention will provide UK-focused information about:</p> <ul style="list-style-type: none"> • What to expect of the condition and treatment, e.g. usual course of the condition, possible complications, tests and treatments that may be offered • Medication, e.g. indications for use and potential side effects • Available treatments, in the UK and treatments available elsewhere • In-depth scientific information, about the condition and treatments • The practicalities of day-to-day living, e.g. going on holiday, travelling, planning what food to buy and eat • Practical information, e.g. guidance on what relevant books and gadgets are available and where to buy them, information about legal issues and benefits available, including completed examples of relevant forms, letters and templates • Local services and resources, e.g. local health services, voluntary organisations and self-help groups • New research and areas of scientific or medical uncertainty, e.g. new research presented with an evaluation of the available evidence-base and current practice; conflicting expert or scientific views, with an explanation of what this uncertainty means for users e.g. over minimally tested research developments and complimentary therapies or treatments • Other people's experiences, e.g. personal stories from other people with similar health problems, other people's questions and answers, facility to interact with other people • Information for family members, addressing the concerns and roles of those around them 	<p>Manage the quantity and depth of information available.</p> <p>Allowing the user to control how much information, and on what topic, they access at any one time. Users need to easily access understandable information on the correct topic and to easily find the correct level for them.</p> <hr/> <p>Ensure all information is accurate and up-to-date.</p> <p>This means dating entries, providing information about the frequency and means of updating, referring to recent media stories and developments.</p>

Main criteria	Detail of criteria	Related criteria
Presentation	<ol style="list-style-type: none"> 1. Needs to facilitate easy and speedy access to relevant information content. 2. Needs to be attractive, engaging, understandable and visually varied. <p>A good internet intervention will have excellent web-design, including:</p> <ul style="list-style-type: none"> • Easy navigation, including rapid and easy return to the home page; easy to locate search engines which run intelligent searches confined to the site and respond meaningfully to simple search terms; use of hyperlinks to link up sections of information within a site and for easy navigation by novice users; site maps for easy navigation by more experienced users • An attractive appearance, using colours, graphics, videos, animations, photos and text broken up into small sections • Use of plain English, with a straightforward, but non-patronising tone. Medical terms and jargon should be explained, but not avoided 	<p>Logging-in Not unnecessarily requiring users to log in or enter personal details before allowing access information.</p> <hr/> <p>Links to other sites Only for additional information and resources, with clear warnings about being taken off-site and summaries of information content and other relevant details of other sites.</p>
Interactivity	<ol style="list-style-type: none"> 1. Contributes to the tone of internet interventions. 2. Need to provide multiple, optional, interactive components and allow users to choose which, if any, to use. <p>A good internet intervention will include a range of interactive components, such as:</p> <ul style="list-style-type: none"> • personalised on-line assessments, advice and monitoring of the condition • on-line facility for asking an expert questions about the condition or treatment • a question and answer facility or on-line chat room for on-line questioning and discussion with other people with similar health problems 	
Trustworthiness	<ol style="list-style-type: none"> 1. Needs to be deemed trustworthy, both immediately and on subsequent or return visits. 2. Trust has to be maintained, and can be lost if the site is not updated regularly. <p>A good internet intervention will establish its trustworthiness by:</p> <ul style="list-style-type: none"> • being accurate • having no commercial links • not displaying advertisements. • being authored or sponsored by a known trustworthy organisation (e.g. the NHS, a local hospital, well-known university, charity or patient organisation) • being regularly updated 	

5.4 Assessment of CHESS Living with Heart Disease with user generated criteria

A comparison of the services offered by *CHESS Living with Heart Disease* against the main user criteria detailed in Table 5.1 suggested that the intervention should appeal to users because it provides:

- Different types of information content including treatment information, practical information, details of local services and resources, and other people's experiences. It also had the potential for expansion of the content within each type of information to cover more topics and provide more depth of information (Table 5.1 - information content)
- Multiple, optional, interactive components including assessments and monitoring of the condition, a facility for asking questions of experts and an on-line facility for discussions with other people with similar health problems (Table 5.1 - interactivity)
- Independent information authored by a known trustworthy organisation (in this case a university) free from commercial advertising or sponsorship (Table 5.1 - trustworthiness)

However, an in-depth assessment applying the detailed user criteria (Table 5.1) identified elements of *CHESS Living with Heart Disease* that would be less appealing. These are summarised in Table 5.2.

Table 5.2 Problems with CHESS Living with Heart Disease according to user quality criteria.

Main criteria	Detailed criteria	Problems with <i>CHESS Living with Heart Disease</i>
Information content	UK focused information	Originally designed for US patients, so: <ul style="list-style-type: none"> • Used US terms • Linked and referred to US resources • Contained information that is not relevant to or not correct for UK patients • Lacked information important for UK patients • Featured experiences of patients operating in a different culture and healthcare system
	Sufficiently comprehensive and wide-ranging information	Lack of certain types of information including: <ul style="list-style-type: none"> • Detailed scientific information • Depth and breadth of information on surgery and other interventions, rehabilitation and recovery
Presentation	Easy navigation and use of hyperlinks	Navigation limited to using information topic structure, keyword searches or searches on the titles of information. No hyperlinks meant: <ul style="list-style-type: none"> • Users could not move from one piece of information to another without going back to a menu page • The dictionary was stand-alone so could not be referred to while reading information
Related to Information content and Trustworthiness	Up to date and accurate information	In general information did not display dates making it unclear when information was last updated. Also, the intervention was originally designed in 1997 and was last updated in 2001. As a result: <ul style="list-style-type: none"> • Certain content was out of date • Information did not refer to recent research studies • Many links to other sites were dead or no longer connected to relevant information
Related to Information content and Presentation	Manage the quantity and depth of information available.	<ul style="list-style-type: none"> • Much of the information presentation was rather flat and lacked the desired structure of a simpler piece of information leading on other more in-depth pieces of information • Topics varied as to the depth of the information within them • Information within a topic was presented in alphabetical order rather than from simple to more in-depth
Related to Presentation and Trustworthiness	Links to other sites	<ul style="list-style-type: none"> • In several topics no information was provided except through links to external websites • It was not very clear when users were being directed to an external website for information • Little information was provided about the external resource and website that hosted it • Many external links were to US websites, organisations and resources which are not relevant to UK users • Many external links were to commercial websites or websites that featured advertising from sponsors

5.5 Development work

Assessment with the user-generated criteria suggested that *CHESS Living with Heart Disease* required development work before it was likely to be suitable for participants in this study. This development work required advanced clinical knowledge and technical skills. Consequently it was not something a PhD researcher could do alone, nor would it be wise to try (56). A multi-disciplinary working group was set up to assist with the necessary development work to anglicise, update and improve the *CHESS Living with Heart Disease* internet intervention to better meet patient quality criteria. The working group was led by the PhD researcher and additionally made up of two GPs (Elizabeth Murray and Irwin Nazareth), a consultant cardiologist (David Patterson), researchers specialising in health services and cardiac nursing (Jo Burns and Gretta Woods) and a user representative recruited from a local hospital (Indra Turner). The working group was further supported by two cardiology specialist registrars (Mark Westwood and Catherine MacAdam) and the senior IT programmer with the CHESS team at the University of Wisconsin-Madison (Haile Berhe).

Within the working group, development work was carried out by:

- Group discussion
 - to review and decide the main principles for development
 - to agree the extent of restructuring
 - to agree the extent and type of information to be included
 - to allocate individual tasks according to expertise and available time
 - to review progress
- Individual tasks
 - to review and develop information topics
 - to review and develop interactive and other services

- to review each other's individual work
 - clinicians reviewed and edited researchers' and each other's work for accuracy
 - researchers reviewed and edited clinicians' work for readability and use of plain English

In addition technical work was required to make changes within *CHES Living with Heart Disease* programme files. Much of this work was done using the CHES in-house database software. The software was installed by the senior CHES IT programmer who then trained two researchers in adding, editing, formatting, linking and restructuring text, documents and topics. This technical work emerged as a significant task, so a further researcher and additional administrative staff were trained in using the software. Once changes were made using the CHES in-house software, database files were sent electronically to the senior CHES IT Programmer with which to update those on the host CHES server. Where changes required more complicated programming materials, algorithms and instructions were sent to the senior CHES IT Programmer for programmers in the CHES team to implement.

The main tasks of the development work were:

- Reviewing and re-structuring the menu of information
- Checking, updating, anglicising and expanding existing content
- Replacing personal stories from US patients with those from UK patients
- Updating and anglicising interactive support tools
- Organising, structuring and linking information

Further details of the work involved in each task and who carried it out are given in Appendix C with supporting information in Appendices D and E.

Once the development tasks were complete, the new *UK CHES Living with Heart Disease* files were loaded onto a test server where three members of the working group (a cardiologist, a GP and the user representative) performed a global check for gaps, errors and inconsistencies. Following this initial check, the test version of *UK CHES Living with Heart Disease* was evaluated by a panel of patients.

5.6 Formative evaluation of UK CHES Living with Heart Disease

User evaluation is strongly advocated in the development and implementation of information systems (315), at the prototyping stage of developing user interfaces (316) and to test usability of eHealth interventions (56). The value of user evaluation is that it provides an initial test of an intervention in its intended operational context. In this case UK patients with CHD, accessing *UK CHES Living with Heart Disease* in their own homes. Formative user evaluation also provides the opportunity for user contribution to the development of an intervention intended for their use and benefit. Their contribution, along with the user-generated criteria (44) and the participation of a user representative in the working group increased the likelihood of developing an internet intervention that would be relevant to user needs and hence would be used.

5.6.1 Methods

The user evaluation panel was drawn from the sample of volunteers who were recruited to provide UK personal stories. When they volunteered to provide their story they were asked if they were interested in further involvement through participating in an evaluation panel (Appendix E). To participate in the user evaluation panel, volunteers needed to have home access to the internet. Interested volunteers were provided with information about what would be involved (Appendix F).

The user panel was made up of 5 volunteers (4 men and 1 woman, age range 41 – 84 years). They had been recruited and interviewed individually for their personal stories, so were not previously known to each other. Each member of the user evaluation panel was visited in their own home to set up access to the test version of *UK CHESS Living with Heart Disease* and provide brief guidance in the various services it offered. During the 3 weeks in which they accessed the intervention they were asked to:

- Look for information that interested them
- Use the other services in *UK CHESS Living with Heart Disease*
- Record any comments and suggestions they had in diaries designed for this purpose

The diaries were largely unstructured, allowing users to make as many comments and/or suggestions as they wanted.

The panel provided further evaluation and feedback through 2 focus group discussions, which were held after 1 and 3 weeks of home access of the test version of *UK CHESS Living with Heart Disease*. This time scale was designed to encourage feedback of initial impressions and after repeated use. The fortnight between discussions also allowed patients to comment on content changes made in response to suggestions they made during the first focus group.

After the first and third week of intervention access panel members were asked for their diaries plus any other comments and suggestions they wanted to make. Focus group topic guides were then developed from the content of the diaries and any other individual feedback (Appendix G). The aim of the focus-groups was to clarify comments and suggestions from individuals, and seek consensus for any further development work. The process was aided by having the test version of *UK CHESS*

Living with Heart Disease projected onto a screen to refer to during focus group discussions. This helped panel members explain their comments using concrete examples and helped others understand comments and suggestions. Groups were facilitated by the PhD researcher and another researcher (Jo Burns) who was already known to the user panel members through interviewing and drafting their personal stories. Following each focus-group a list of further development tasks was drawn up. As for the personal stories, members of the user evaluation panel were reimbursed for their time according to INVOLVE guidelines (317).

5.6.2 Results

Overall panel members made generally positive comments about the information content provided by the test version of *UK CHES Living with Heart Disease*.

PP01: "... you can choose your level of depth of information, so that you can go from [a] two-liner definition, to a news item, to a scientific journal ...on the same topic, and I thought that was excellent, because you could just pitch at your level of the kind of information that you're particularly seeking"

However they were critical of its presentation, ease of navigation through the content, understanding what was offered in the different services and finding the information they were after.

PP05: "... although it was really interesting, just how it was set out... it just didn't do it"

PP04: "...what you've got there is a good tool for somebody suffering with cardiac problems to find out what they want, it just needs to be reorganised and tidied up so that it's easier..."

While these general comments give an idea of how users responded overall to the test version of *UK CHESS Living with Heart disease*, the majority of comments and both focus group discussions concentrated on specific problems and suggestions for improvements. The user evaluation and discussions identified the following further development tasks that were carried out by the working group (Appendix H):

- Additional information content to fill information gaps identified by users
- Renaming services and redesigning the ‘services menu’ (home-page)
- Showing all the main topics in the topic menu at a glance to make information easier to find
- Listing only the most relevant documents under any one topic or sub-topic to make information easier to find and less overwhelming
- Improving the search function to make information easier to find
- Improving the book-marking service to make previously viewed information easier to find again
- Displaying relevant dictionary definitions after a topic name before listing content to give a better idea of topic content at a glance
- Expanding the scope and information in the ‘CHESS guide’ (introductory and help pages) to make services clearer from the start
- Making clearer visual distinction between the keyword and dictionary search pages
- Improving the use and presentation of the ‘CHESS update’ (an area of the home-page which lists what has been recently added to the site) to make it easier to see when CHESS was last updated, what has been added and how new information fits in with existing information
- Adding relevant graphics and images to make presentation more appealing, engaging and less text-based

- Making it clearer when to expect a response from the ‘ask an expert’ service to clarify expectations of the service
- Making links to external websites open in a new window to make it easier to return to CHESS and more obvious when information is from an external website
- Providing an option not to show disclaimer information after the first log-in, reducing the need to re-read less interesting information and speed access to the main site

Most of the additional development tasks identified by the users required technical and structural changes to improve presentation and ease of navigation. Many of these required significant programming work that could not be carried out using the CHESS in-house database software. Given time and resource restrictions at this point, not all changes suggested by users could be carried out. Specifically, the following changes were suggested but not carried out:

- Further simplify presentation by listing services in drop-down menus from headings
- Replace search with a Google-style text (rather than keyword) search
- Re-order items in the exercise behavioural self-assessment tool to start with more common types of physical activity

Screen-grabs of the ‘services menu’ (home-page) before and after development work are shown in Appendix I.

5.7 UK CHESS Living with Heart Disease

The components and services offered by the *UK CHESS Living with Heart Disease* internet intervention that was used in the empirical study are summarised in Table 5.3.

Table 5.3 UK CHES Living with Heart Disease - components and services.

Component	Services within component	Description of services
Information	Questions and Answers	Answers to hundreds of questions commonly asked by people with heart disease.
	Instant Library	Articles, leaflets, booklets, fact sheets and research summaries hosted by other websites.
	Web Tools and Resources	A collection of areas of web sites that contain relevant online tools and resources for people with heart disease (e.g. quizzes, calculators, lists of resources, topic focused information to explore).
	Directory of Organisations	Descriptions and contact details of relevant organisations offering information, help, support and resources for dealing with heart disease and associated issues.
	Useful information sites	Descriptions and links to recommended websites to search for research findings, information about evidence-based treatments, patient information and UK healthcare.
	Overview	Section to help those who are just starting with CHES or living with heart disease. Three overview sections (Heart Disease Basics, Risk Factors and Heart Treatments) group together some of the most relevant CHES information and give a taster of the kinds of information to be found in other information services
	Dictionary	Searchable dictionary of definitions of heart and other terms used in CHES information. Individual definitions hyperlinked from CHES information text.
Behaviour change	Health Tracking	Consists of Health Tracking Survey (15 questions) and Health Tracking Feedback to track heart health and lifestyle behaviours. The Health Tracking Survey comes up automatically on first login with reminders at login every two weeks. Health Tracking Feedback is personalised to Health Tracking Survey answers. It provides a tip of the day, relevant suggestions and information graphs of progress over time, and links to related CHES information.
	Assessments	Tools to assess current levels of health behaviour (diet and exercise) and mood. Provides feedback on score and tailored pointers on reducing risks.
	Action Plan	Two step-by-step guides to help plan and carry out change in diet or levels of exercise and other physical activity. Each Action Plan helps set realistic goals and plan how to achieve goals. Plans are then evaluated to identify barriers to success and provide advice on how to overcome them.
Support	Personal Stories	Real-life accounts of people living and coping with heart disease in the UK.
	Ask an Expert	A confidential service to ask a question, and get a personal answer from the team of cardiologists, GP, health psychology researcher and healthcare librarian. Features Open Expert Messages, which are edited and anonymised versions of questions answered through this service.
	Discussion Group	Moderated, on-line support group allowing anonymous communication among CHES users for sharing information, experiences, giving and receiving support.
	Personal Journal	Private and confidential place to record personal thoughts, feelings and experiences. Contains writing tips and exercises to help get started.

5.8 Maintenance of UK CHESS Living with Heart Disease

Unlike most other interventions, internet interventions cannot remain unchanged from beginning to end of intervention delivery. Instead content must change to respond to users of interactive services and to maintain the quality of the intervention, particularly in terms of offering up to date and accurate information (56).

5.8.1 Monthly updates

Updates were prepared each month containing:

- Relevant online news articles and resources
- Additional personal stories
- Additional information topics

Relevant online news articles were identified primarily by a healthcare librarian (Richard Peacock), but also by other members of the working group. Articles and resources were discussed with Elizabeth Murray (GP and primary supervisor), who also checked their accuracy, before they were added. Criteria for relevant news articles were guided by the user-generated criteria (44) and discussed with the working group.

Relevant articles included new research findings, UK guidelines and policy relevant to heart disease treatment, diagnosis and management through lifestyle change. They included research findings that were widely reported in the media but based on minimal evidence, in which case the update in *UK CHESS Living with Heart Disease* contained critical comment on the lack of evidence. News articles on primary prevention, primary risk of heart disease, UK healthcare delivery or performance indicators e.g. mortality rates of UK hospitals, were considered less widely relevant and useful to users.

Additional information topics were either sub-topics which would complete information planned in the menu of topics set during development work (Appendix D), topics raised

by users in questions to the ‘ask an expert’ service, or topics raised by recent news articles.

These documents and topics were added to the relevant service (‘questions and answers’, ‘instant library’, ‘directory of organisations’, ‘web tools and resources’, ‘personal stories’) and keyword search terms. They were also listed as hyperlinks under the ‘CHESS update’ section on the ‘services menu’ (home-page). Functionality of all links to documents, resources and organisation home-pages on external websites were checked and corrected as part of the monthly update (administrative support provided by Orla O’Donnell). All updated electronic files were sent to the senior IT programmer with the CHESS team who loaded them onto the training server to be checked and tested before they were made available on the intervention website for participants to access.

5.8.2 Interactive services

Throughout the study the ‘ask an expert’ and ‘discussion group’ services were checked several times a week for new messages from users. Messages posted in the ‘ask an expert’ service were emailed by the PhD researcher to an expert team made up of a GP (Elizabeth Murray), two cardiologists (David Patterson and Mark Westwood) and a healthcare librarian (Richard Peacock). Members of this expert team drafted responses, edited and commented on each other’s responses until consensus was reached over the response to give. Responses were then formatted with links to additional relevant information in other services on *UK CHESS Living with Heart Disease* before being posted for the individual user to access when they next logged in. The team aimed to respond to questions asked via the ‘ask an expert’ service within a week. At a later date, questions and answers were edited to remove any unnecessary detail or identifying

information and posted as ‘open expert messages’, linked to relevant topics and available for all users to access.

The ‘discussion group’ service required moderation of information posted by users for other users to read. New messages were discussed with Elizabeth Murray to decide whether any moderation was required. Messages from the moderator were only very occasionally posted in the ‘discussion group’. These were either:

- To correct information posted by users. This was the main reason for moderating the ‘discussion group’. The intention was to post corrections or additions to any erroneous or potentially misleading information posted by users. If necessary messages posted by users could be removed. However, this was not a situation which arose.
- In response to messages where users asked a question for which other services offered relevant information or where the question may be better answered by the CHESSE expert team.
- To suggest discussion topics where more than one research participant had expressed similar experiences or concerns during contact with the researcher (e.g. during CHESSE training, baseline data collection or contact about a technical query).

5.9 Discussion

In order to provide participants in this study with a high-quality CHD-focused internet intervention, an existing intervention, *CHESSE Living with Heart Disease*, was developed according to users’ criteria and feedback. Given available skills, time and resources, the decision to use an existing intervention was pragmatic and made possible by a pre-existing collaboration with the experienced CHESSE research team.

Despite the advantage of starting with an existing intervention, *CHESS Living with Heart Disease* in its original form was unlikely to appeal to participants in this study without being developed to better meet their needs. The most obvious problems included its US focus and out of date information. The development work required to address these and other short-comings proved significant, involved a large multi-disciplinary working group, took a full year to complete and would not have been possible without the availability of additional grant-funding. In the end the extent of the development process was still limited by the amount of available time and technical expertise.

Arguably efforts could have been limited to correcting inaccuracies introduced by the US focus and out of date information. Identifying these obvious inaccuracy problems did not require user-generated criteria or formative evaluation by a user panel, and addressing them might have been a quicker and easier job. However, in order to evaluate an internet intervention for CHD it was important that patients would use the intervention. It made sense that the intervention would only appeal to users if it met their needs. The user-generated quality criteria make it clear that these needs extend well beyond accurate information to other criteria for information content, presentation, trustworthiness and interactivity. The comments and suggestions made by members of the user panel supported this approach by echoing the user-generated quality criteria. The formative user evaluation also contributed by providing a pilot-test of the usability of *UK CHESS Living with Heart Disease* in its operational context, and by guiding further refinement of the intervention to better meet users' needs.

Chapter 6 : Methods

6.1 Introduction

This chapter describes the methods of the empirical study evaluating an internet intervention for CHD. The aims and rationale for the study design were discussed in Chapter 4. The *CHESS Living with Heart Disease* internet intervention evaluated in this study was described in Chapter 5.

Study methods described in this chapter are:

- Ethics and research governance
- Steering group
- Recruitment
- Consent
- Measures
- Data collection
- Intervention management
- Analysis

6.2 Ethics and research governance

Ethics and research governance approval for the study design, materials and procedures were obtained from Camden and Islington Local Research Ethics Committee (Ref: 06/Q0511/3) and local Primary Care Trusts (Camden, Islington, Barnet, Enfield and Haringey). Honorary contracts were issued by each PCT for the research to be conducted with primary care staff and patients at practices in their trust. University College London was the study sponsor.

6.3 Steering group

Ongoing conduct of the study was monitored and guided by a multidisciplinary project steering group made up of two GPs (Elizabeth Murray and Irwin Nazareth), a consultant cardiologist (David Patterson), a Chartered Clinical Psychologist (Lorraine Noble), two statisticians (Richard Morris, Christian Bottomley (later replaced by Louise Marston)), a medical sociologist (Fiona Stevenson), a healthcare librarian (Richard Peacock) and two user representatives recruited from a local hospital and the British Cardiac Patient Association (Indra Turner and Keith Jackson). The steering group met quarterly to review progress, advise on issues relating to recruitment and data collection and to discuss results.

6.4 Recruitment

6.4.1 Primary care practice recruitment

Participating primary care practices were part of the North and Central London Research Consortium (NoCLoR), a partnership between Camden, Islington, Barnet, Enfield and Haringey Primary Care Trusts, Camden and Islington Mental Health and Social Care Trust, and Barnet Enfield and Haringey Mental Health Trust. As a result NoCLoR covers a large ethnically and socio-economically diverse area of London. Selection of practices to approach was guided by Elizabeth Murray (primary supervisor and GP) and other colleagues in the Department of Primary Care at the sponsor institution, based on their knowledge of research interests of GPs at the practices and the diversity of communities they served. Practices were sent information about the study and what participating would involve for practices and patients (Appendix J). Interested practices were then offered a visit to discuss the study and demonstrate the intervention. Primary care practices were approached until the target sample size of 173 participants was reached.

6.4.2 Participant recruitment

Participating practices were asked to generate a list of all patients on their CHD register. This register of patients with coronary heart disease is remunerated as part of the 2004 GP contract. One or more GPs at each practice screened the list using the inclusion and exclusion criteria listed below. Once ineligible patients had been excluded, all other patients on the CHD register were invited to participate in the study. Potential participants were sent a letter from their GP surgery explaining the purpose of the study (Appendix K), which included:

- A patient information leaflet about the study (Appendix L)
- A form for interested patients to complete with their contact details
- A postage paid envelope addressed to the researcher

All responders were contacted to answer any initial queries and arrange an appointment to discuss the study before completion of consent procedures.

The study inclusion and exclusion criteria were as follows:

- Inclusion criteria, patients:
 - Registered with a participating North London general practice with a diagnosis of coronary heart disease
 - Willing to visit local public internet services to use the intervention or able to access it at home
 - With or without experience of using the internet
- Exclusion criteria, patients who:
 - Were terminally ill (less than 9 months life expectancy)
 - Were not able to give informed consent, due to mental incapacity (e.g. psychotic illness, learning difficulties, cognitive impairment)

- Did not speak English well enough to consult without an interpreter (routinely flagged in patients' electronic records)
- Were not able to use a computer independently due to visual, hearing or motor impairment; housebound patients with home internet access were included but housebound patients without home internet access were excluded (eligibility of any housebound CHD patient interested in participating was usually established during discussion of the study information with the researcher rather than by GP screening)

6.5 Consent

Participants were invited to ask any questions they had about the study both when contacted initially and at their research appointment. The appointment started with a discussion of the study information leaflet. Those interested in participating were then asked to read a consent form (Appendix M), agree to 8 points (including their right to withdraw without giving any reason) listed on the form and sign to participate.

Participants could also agree to a 9th point to allow a member of the research team to check information about their heart disease and treatment in their GP medical notes but they did not need to agree to this to take part. Participants were given a copy of the signed consent form to keep for their own records.

A second consent procedure was carried out with the sub-sample of participants who were interviewed. These participants were sent an interview information leaflet and consent form to read before their interview appointment (Appendices N and O). The leaflet included information about likely interview topics, data storage and data protection. The content of the information leaflet was discussed with each participant before they were asked to sign the consent form. Interview participants were given a copy of the signed consent form to keep for their own records.

6.6 Measures

6.6.1 Self-completed measures

Details of self-completed measures of participant information, psychological constructs and health outcomes are given in Table 6.1. Measurement time points for all self-completed data are given in Table 6.2.

6.6.2 Intervention use

The following intervention use variables were calculated:

- Frequency of intervention use (number of logins)
- Amount of intervention use (total number of pages viewed)
- Amount of different types of services used (page requests for each of):
 - Information component, which included ‘question and answer’, ‘instant library’, ‘directory of organisations’ and ‘web tools and resources’ services (number of information services pages viewed)
 - Behaviour change component, which included ‘health tracking’, ‘assessments’ and ‘action plan’ services (number of behaviour change services pages viewed)
 - Support component, which included ‘ask an expert’, ‘discussion group’, ‘personal stories’ and ‘personal journal’ services (number of support services pages viewed)

Table 6.1 Quantitative measures used (self-completed by participants).

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
Participant information	Demographic details	Age	Single item, participant Date of Birth (Day, Month, Year)	Age = Date of baseline data collection – Date of Birth	Checked against date of birth in GP medical records
		Sex	Single item, select male or female		Checked by researcher observation
		Current employment (item used in previous study (44))	Single item, select one out of 6 options: <ul style="list-style-type: none"> • Employed (part or full-time) • Self-employed • Full-time carer • Retired • Not working but looking for work • Not working and not looking for work 		
		Highest Educational qualification (item used in previous study (44))	Single item, select one out of 3 options: <ul style="list-style-type: none"> • School leaver; • 'A' levels or vocational equivalent; • Degree, HND or similar 		

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		Ethnic background (item used by the Office of National Statistics (318))	<p>Single item, select one category:</p> <ul style="list-style-type: none"> • White – British, Irish, or other white background (free-text details requested) • Black or Black British – Caribbean, African, or other black background (free-text details requested) • Asian or Asian British – Indian, Pakistani, Bangladeshi, or other Asian background (free-text details requested) • Mixed Race – White and Black Caribbean, White and Black African, White and Asian, or other mixed race background (free-text details requested) • Other ethnic background – Chinese, or other ethnic background (free-text details requested) 		
	Internet access and experience	Level of experience of using the internet (item used in previous study (44)).	<p>Single item, select one out of 4 options:</p> <ul style="list-style-type: none"> • Novice (e.g. never used the internet) • Basic (e.g. used the internet a few times but not often) • Experienced (e.g. used or currently use the internet regularly) • Expert (e.g. work is to do with the internet) 		Checked by researcher observation
		Home access to the internet	Single item, select Yes or No to having a computer linked to the internet that they can use in their home		Checked by researcher observation
		Use of other heart disease websites in the last month	<p>2 items, select Yes or No for each of:</p> <ul style="list-style-type: none"> • Health information (relevant to heart disease) • On-line health advice, chat-rooms, discussion or support groups (relevant to heart disease) 		

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
	Clinical information	CHD diagnosis	<p>3 initial items, select Yes or No for each of:</p> <ul style="list-style-type: none"> • Angina • Heart Attack • Other heart condition <p>2 additional items if Yes selected to relevant initial item:</p> <ul style="list-style-type: none"> • Heart Attack – Yes or No to more than one heart attack • Other heart condition – free text details 	<p>Free text responses to other heart condition were coded as:</p> <ul style="list-style-type: none"> • other CHD diagnoses (e.g. CHD diagnoses in participants who had not experienced angina or heart attack, or further CHD diagnoses in participants who had experienced angina or heart attack such as arrhythmia cardiomyopathy or heart failure) • heart conditions which were not CHD (not caused by the same disease process e.g. congenital heart problems, rheumatic fever in childhood) 	Checked against GP medical records

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		Time since earliest CHD diagnosis and since most recent cardiac event	<p>4 Items completed if Yes selected to relevant items in CHD diagnosis:</p> <ul style="list-style-type: none"> • Age first developed angina • Age first had a heart attack • Most recent heart attack (month and year) • Age first developed other heart condition <p>Additional item, select Yes or No to Hospital visit or stay for heart tests or treatment if Yes completed Month and Year of most recent visit or stay in hospital for non-routine heart tests or treatment and asked for free-text detail</p>	<p>Time since earliest CHD diagnosis = Maximum out of the difference between current age and:</p> <ul style="list-style-type: none"> • Age first developed angina • Age first had heart attack • Age first developed other heart condition <p>The age participants with heart conditions other than CHD developed their condition may not relate to onset of CHD, so the variable of time since earliest CHD diagnosis was not calculated for participants if it was not clear they had made this distinction</p> <p>Time since most recent cardiac event = Minimum out of:</p> <ul style="list-style-type: none"> • Difference between current age and age first developed angina, age first had heart attack or age first developed other heart condition • Difference between baseline date and date of most recent heart attack or most recent visit or stay in hospital for non-routine heart tests or treatment 	Checked against GP medical records

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		Concurrent long term conditions	Select whichever apply out of: <ul style="list-style-type: none"> • Diabetes • Stroke • Other health problem (completed free text detail) 	Initially coded into one of three different types of concurrent long term condition: <ul style="list-style-type: none"> • Diabetes • Other cardiovascular condition (including stroke, hypertension and peripheral artery disease) • Other condition (including asthma, arthritis and many other conditions) Any new conditions mentioned at 3 or 9 month follow-ups were added to the coding for 0-3 types of concurrent long term conditions	Checked against GP medical records
		Current medications	List of prescribed and other medicines currently taken	Total number of medications was calculated from those listed Prescribed topical creams or ointments and medical testing equipment (e.g. lancets and testing strips) detailed in participants' GP notes were excluded from the list Medications prescribed at more than one dosage counted only once	Checked against GP medical records

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		Cardiac care or event during intervention use	<p>2 items, select Yes or No to:</p> <ul style="list-style-type: none"> • Heart attack in the last 3 months (or 6 months if 9-month follow-up) • Hospital visit or stay in the last 3 months (or 6 months if 9-month follow-up) for heart tests or treatment <p>If Yes, asked to provide detail</p>	<p>Hospital tests or treatment were coded as either routine (e.g. stress or treadmill test, outpatient echocardiogram) or a cardiac event (e.g. invasive procedures such as angiogram or surgery, unscheduled visits to hospital as a result of worsening symptoms)</p> <p>Heart attacks reported during the intervention period, at 3 or 9-month follow-up, were also coded as cardiac events</p>	Checked against GP medical records

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
Psychological constructs	Self-efficacy	Cardiac self-efficacy (319)	13 items with 5 response options from 0 – ‘Not at all confident’ to 4 – ‘Completely confident’ or option to select ‘not applicable’	<p>Scored in two subscales excluding any items rated ‘not applicable’:</p> <p>Control symptoms</p> <ul style="list-style-type: none"> Sum of items 1-8 divided by number of control symptom items rated for a mean control symptoms score ranging from 0-4 Higher scores mean higher self-efficacy to control cardiac symptoms such as chest pain and breathlessness with physical activity, medication and seeking help from doctor <p>Maintain functioning</p> <ul style="list-style-type: none"> Sum of items 9 to 13 divided by number of maintain functioning items rated for a mean maintain functioning score ranging from 0-4 Higher scores mean higher self-efficacy to maintain functioning in usual social, family, work, sexual and physical activities 	Cronbach’s alpha: Control symptoms 0.88 to 0.89 maintain functioning 0.92
		Cardiac diet self-efficacy (264)	16 items, rated on a 5-point scale from 1 – ‘Very little confidence’ to 5 ‘Quite a lot of confidence’	<p>Scored by summing ratings for all 16 items and dividing by the number of items rated for a mean cardiac diet self-efficacy score ranging from 1-5</p> <p>Higher scores mean high self-efficacy to adopt and stick to a heart- healthy diet as well as achieve and maintain ideal weight through healthy diet</p>	Cronbach’s alpha 0.93 to 0.95

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		Cardiac exercise self-efficacy (264)	15 items, rated on a 5-point scale from 1 – 'Very little confidence' to 5 'Quite a lot of confidence'	<p>Scored by summing ratings for all 15 items and dividing by the number of items rated for a mean cardiac exercise self-efficacy score ranging from 1-5</p> <p>Higher scores mean high self-efficacy to endure, fit in, safely and regularly carry out appropriate levels of exercise without chest pain</p>	Cronbach's alpha 0.93 to 0.95

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
	Illness Perceptions	Brief Illness Perceptions Questionnaire (278)	<p>9 items, 8 items rated on an 11-point scale from 0 – 10 for dimensions of:</p> <ul style="list-style-type: none"> • Consequences (effect of heart disease on life: no effect at all – severely affects life) • Timeline (how long heart disease will continue: very short time – forever) • Personal control (feeling of control over heart disease: absolutely no control – extreme amount of control) • Treatment control (how much treatment can help their heart disease: not at all – extremely helpful) • Identity (symptoms of heart disease currently experienced: no symptoms at all – severely affects life) • Concern (concern over heart disease: not at all concerned – extremely concerned) • Illness coherence (understanding of heart disease: don't understand at all – understand very clearly) • Emotional response (emotional effect of heart disease: not affected emotionally – extremely affected emotionally) <p>9th item – Cause dimension - free-text response to list up to 3 important causes of their heart disease in order of importance</p>	<p>Cause dimension initially coded as either:</p> <p>0 – no idea of cause (stated as no idea, does not include cause left blank)</p> <p>1 – most important cause is lifestyle/health behaviour</p> <p>2 – lifestyle/health behaviour one cause but not most important</p> <p>3 – important causes listed but lifestyle/health behaviour not among them</p>	

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
	Social Support	Medical Outcomes Study (MOS) Social Support Survey, emotional and information subscale (266)	8 items, rated on a 5-point scale from 1 – 'None of the time' to 5 'All of the time'	Scored by summing ratings for all 8 items and dividing by the number of items rated to give a mean social support score of ranging from 1-5 Higher scores mean perceived higher availability of emotional and information support to call on in different circumstances	Cronbach's alpha 0.96 to 0.97
	Behavioural intentions	Items designed for this study	3 single-item measures rated on a 5-point scale from 1 – 'Strongly disagree' to 5 – 'Strongly agree' for intention to: <ul style="list-style-type: none"> • take their medicines regularly • eat a heart healthy diet • exercise regularly 		
Health outcomes	Emotional status	Hospital Anxiety and Depression Scale (HADS (320))	14 items each with 4 separate response options	Responses to each item scored 0-3 Anxiety subscale scored by summing 7 items (after 5 items reverse-scored) for a maximum score of 21 Depression subscale scored by summing 7 items (after 3 items reverse-scored) for maximum score of 21 Higher scores on each subscale mean higher levels of anxiety or depression, scores ≥ 8 on a subscale indicate possible clinical levels of anxiety or depression	Cronbach's Alpha: Anxiety 0.75 to 0.86 Depression 0.79 to 0.85

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
	Health behaviours	Medical Adherence Report Scale (MARS (269))	5 items with 5 response options from 1 – ‘Always’ to 5 – ‘Never’	<p>Scored by summing all 5 items for a maximum score of 25</p> <p>Higher scores indicate better adherence to taking medications as instructed</p>	Cronbach's Alpha 0.55 to 0.68
		Health Diet Habits Score (267)	<p>4 items on types of routine dietary choices:</p> <ul style="list-style-type: none"> • Bread: White, Brown, Wholemeal, Other (asked to supply detail) • Milk: Whole milk, Semi-skimmed, Skimmed, Other (asked to supply detail) • Spread: Butter, Low-fat spread (e.g. polyunsaturated margarine), Other (asked to supply detail) • Salt: Salt before tasting food, salt only after tasting food, do not use salt at all 	<p>Scores for responses given in brackets:</p> <ul style="list-style-type: none"> • Bread: White (1), Brown (2), Wholemeal (3), Other bread (1), No bread eaten (0) • Milk: Whole milk (0), Semi-skimmed (2), Skimmed (3), Other milk (1) • Spread: Butter (0), Low-fat spread (2), Other spread (1), No spread used (3) • Salt: Before tasting food (0), Only after tasting food (1), No salt used (3) <p>Scored by summing all 4 items for a maximum score of 12</p> <p>Higher scores mean healthier diet habits</p>	Cronbach's Alpha 0.22 to 0.31

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		Food Frequency items (268)	<p>6 items measuring frequency of consumption in the last 4 weeks of:</p> <ul style="list-style-type: none"> • Fresh or frozen fruit, salad and vegetables • Fish (excluding fried fish) • Fried food • Chicken or turkey • Beef, pork or lamb (red meat) • Chocolate, crisps or biscuits (unhealthy snacks) <p>7 response options for portions of each of:</p> <ul style="list-style-type: none"> • Less than once a week • 1-3 days a week • 4-6 days a week • 1-2 times a day • 3-4 times a day • 5 or more times a day 	<p>Scores for each response given in brackets:</p> <ul style="list-style-type: none"> • never (0) • Less than once a week (1) • 1-3 days a week (2) • 4-6 days a week (3) • 1-2 times a day (4) • 3-4 times a day (5) • 5 or more times a day (6) <p>Healthy food frequency score calculated by reverse-scoring fried food, red meat and unhealthy snacks and summing with other scores apart from frequency of eating chicken or turkey for overall score of 30 - higher scores mean higher frequency of healthy foods to unhealthy foods in the last 4 weeks</p>	Cronbach's Alpha 0.30 to 0.46

Type		Measure/variable	Details	Scoring	Validity/reliability check in study sample
		International Physical Activity Questionnaire (IPAQ (281))	<p>6 items measuring number of days in the last 7 days and time (hours and/or minutes) per day of vigorous, moderate and walking exercise</p> <p>Responders instructed to include only activities they sustained for at least 10 minutes at a time. Examples provided of types of exercise which count at each level, moderate exercise excludes walking</p> <p>7th item measures time per day spent sitting on weekdays in the last 7 days (hours and/or minutes)</p> <p>Response options include tick box for no physical activity at each level in the last week (allows responder to skip to the next type of activity without completing days or time) and 'Don't know/not sure' option for time at each exercise level and for time spent sitting on weekdays</p>	<p>Total score of week's MET value calculated by summing:</p> <ul style="list-style-type: none"> vigorous MET minutes per week (8 x number of vigorous activity days x minutes of vigorous activity per day) moderate MET minutes per week (4 x number of moderate activity days x minutes of moderate activity per day) walking MET minutes per week (3.3 x number of walking activity days x minutes of walking activity per day) <p>Higher week's MET value means higher levels of physical activity in the last 7 days</p>	
	Health-related quality of life	MacNew heart disease health related quality of life (MacNew (24))	<p>27 items with 7 response options scored 1 to 7 about how responder has felt in the last 2 weeks</p> <p>Item 27 (effect of heart problem on sexual intercourse) has additional 'Not Applicable' option</p>	<p>Global score calculated by summing scores from all 27 items and dividing by number of items scored (not applicable on item 27 is not scored) for a mean score ranging from 1 to 7</p> <p>Higher scores indicate better emotional, physical and social heart disease health related quality of life in the last 2 weeks</p>	Cronbach's Alpha 0.95 to 0.96

Table 6.2 Measurement time-points for participant information and outcome measures.

Type of measure			Measurement time-point			
			Baseline	3 months	9 months	
Participant information	Demographic details	Age	✓	✗	✗	
		Sex	✓	✗	✗	
		Current employment status	✓	✗	✗	
		Highest educational qualification	✓	✗	✗	
		Ethnic background	✓	✗	✗	
	Internet access and experience	Level of experience of using the internet	✓	✗	✗	
		Home access to the internet	✓	✗	✗	
		Use of websites other than UK <i>CHESS Living with heart disease</i>	✗	✓	✓	
	Clinical information	CHD diagnosis	✓	✗	✗	
		Time since earliest CHD diagnosis and since most recent cardiac event	✓	✗	✗	
		Concurrent long term conditions	✓	✓	✓	
		Current medications	✓	✓	✓	
		Cardiac care or event during intervention use	✗	✓	✓	
	Psychological constructs	Self-efficacy	Cardiac self-efficacy	✓	✓	✓
			Cardiac diet self-efficacy	✓	✓	✓
Cardiac exercise self-efficacy			✓	✓	✓	
Illness perceptions		Brief Illness Perceptions Questionnaire	✓	✓	✓	
Social support		Social Support Survey (emotional and information)	✓	✓	✓	
Behavioural intentions		Medicines, diet, exercise	✓	✓	✓	
Health outcomes	Emotional status	Hospital Anxiety and Depression Scale	✓	✓	✓	
	Health behaviours	Medical Adherence Report Scale	✓	✓	✓	
		Healthy diet habits score	✓	✓	✓	
		Food frequency items	✓	✓	✓	
		International Physical Activity Questionnaire	✓	✓	✓	
	Health-related quality of life	MacNew heart disease health-related quality of life	✓	✓	✓	

6.7 Data collection

6.7.1 Self-completed measures

Procedure at baseline

Participants completed a questionnaire, containing all relevant measures, immediately after consenting to participate. Participants were encouraged to select answers themselves rather than seek guidance, apart from clinical information, where participants could seek help from family members if they had difficulty in remembering dates.

Procedure at follow-up

Follow-up questionnaires were posted to participants 3 and 9 months after completion of baseline questionnaires along with a reply-paid envelope in which to return them to the researcher. Participants received a reminder letter and a second copy of the relevant questionnaire if their completed booklet was not received back within a fortnight. If after another fortnight a questionnaire had not been received, participants received a further written reminder, either by post or e-mail. Participants without email addresses who had not responded after another fortnight then received up to 2 phone calls a fortnight apart, while others received a further email reminder and a phone call a fortnight later if necessary.

6.7.2 Checking against GP medical notes

Ninety-five percent of participants (n=160) consented to a member of the research team checking clinical information in their GP medical notes. Participating primary care practices provided standard summary printouts from notes of consenting patients at the end of the months in which these participants completed baseline, 3-month and 9-month follow-up. The practices were contacted monthly with details of patients who had consented to participate in the preceding month and provided with copies of consent

forms from all participants who had consented to give access to their GP medical records.

6.7.3 Intervention use data

Full details of all logins, pages viewed, text entered and time accessed, were automatically recorded on the CHESS server at the University of Wisconsin. The CHESS Team generated and sent databases for each calendar month of use of the intervention. All monthly databases were imported into a single database using STATA software (321). The number of total and failed logins and different types of page requests identified by specific file paths of intervention services were then counted by participant codename. Monthly totals for these variables were calculated for each codename, summarising individual use throughout their 9-month intervention period. The 30-day months were calculated individually for each participant starting on the date when their codename was first used to login to the internet intervention. The first training login and all pages requested during training were discounted from the totals for each participant codename. This work was conducted by a statistician (Christian Bottomley) in collaboration with the PhD researcher. Extracted counts for the login and page request variables were checked against raw use data in the original monthly databases by the PhD researcher.

Data were then imported into SPSS software (322) where summary intervention use variables were calculated and could be analysed along with the other questionnaire data.

6.7.4 Qualitative data

At the end of the 9-month follow-up questionnaire, participants were asked to indicate their interest in being interviewed about their experiences over the last 9 months.

Interviews were conducted in small batches of 3-4 interviews. Before each batch of

interviews was arranged, the available sample of volunteers was considered to select individuals who varied in their use of the intervention over the 9 months, and/or their change in psychological constructs in the first 3 months of use.

The sub-sample was purposively selected to include participants who made a range of use (frequency and duration) of the different intervention components, and demonstrated a range of change in psychological constructs. Specifically, the interview sub-sample aimed to include participants who varied in terms of:

- Demographics:
 - Sex: male and female participants
 - Ethnicity: white and non-white participants
 - Levels of education: school leavers, participants with A-level educational qualifications, participants with degree level educational qualifications
- Computer experience and access:
 - Participants with home internet access and those without
 - Levels of experience with computers: novice, basic and more experienced
- Intervention use:
 - Total intervention use - participants who had made:
 - no use
 - low use (used only in first/early months, infrequently across several months)
 - high use (used frequently across several months)
 - Use of different intervention services - participants who made higher than average use of certain types of services (information services, behaviour change services or support services)

- Change in psychological constructs baseline to 3 months. The size of an individual's change was compared with the mean change for all participants with available 3-month follow-up data at the time, to class individuals as showing no change (within 1 standard deviation of the group mean) or some change (more than 1 standard deviation above or below the group mean) in the following psychological construct variables:
 - Social support (emotional and information)
 - Self-efficacy (cardiac – control symptoms, cardiac – maintain function, diet, exercise)
 - Illness beliefs (consequences, timeline, personal control, treatment control, concern, identity, coherence, emotional response, cause)

Sampling for early batches of interview participants was based on variation in demographics, computer access and experience, and total intervention use. As quantitative data collection and analysis progressed in the whole study sample, comparative data on use of different intervention services and baseline to 3-month change data became available and were used to select participants for later interview batches. Sampling continued to the point of saturation, when no new themes emerged from interviews.

A list of general and follow-up questions was developed to guide discussion of relevant topics in the interviews (Appendix P). This interview schedule was refined after discussion with the multidisciplinary project steering group.

Interviews were digitally recorded and transcribed verbatim. Transcripts were checked against original interview recordings for accuracy and anonymised by removing names of people and places.

6.7.5 Other data

Participating GP practices provided limited demographic summary data (age and gender) from their CHD registers to allow some comparison of the study sample with the wider CHD population from which it was drawn. It is not ethically permissible to access clinical data from primary care records without patients' consent, so it was not possible to compare clinical characteristics of the sample with those of other CHD patients registered at participating practices.

UK general population data-sets were used as the basis for comparison of other sample characteristics. Comparative data for highest education qualification were generated from the 2005 Health Survey for England (HSE) dataset, downloaded from the UK Data Archive (323). As the HSE also collects data on experience of heart attack and angina, proportions of people with the various levels of educational qualifications could be calculated for those with CHD (n=805). Comparative data for levels of home internet access and internet use were taken from published reports of two national surveys of internet access and use that were conducted in 2007 (53;287). Comparative data for baseline scores on psychological constructs and health outcomes were taken from published normative data for the relevant measures and from published results of studies which used the same measures in general public and CHD samples (231;261;267;268;278;324;325).

6.8 Intervention management

6.8.1 Initial intervention training

Each participant chose their own codename and password for accessing the intervention. All participants received training in how to log in and use the intervention. Training was tailored to participants' levels of computer and internet experience and took between 15 minutes and an hour. Training was supported by a printed booklet containing the *UK*

CHESS Living with Heart Disease website address, the individual participant's login details, a guide to all the different services on the intervention and details of local places offering free and low-cost public internet access and training courses (Appendix Q). Participants received the version of the booklet that contained local information about the area in which their GP practice was located.

Intervention training took place after informed consent and baseline data collection, either:

- immediately after baseline data collection, for participants:
 - with home internet access who had been visited at home for baseline data collection
 - without home internet access who knew where they wanted to use the intervention from the start, so the initial research appointment was held at the chosen public internet service
 - with internet experience who elected to attend research appointments at the researcher's office
- or at a second training appointment, usually within the following week, for participants:
 - with home internet access who had technical problems with their home computer or internet access at the time of baseline data collection
 - without home internet access after discussing local options for internet use at baseline data collection. Participants chose where they would prefer to use the intervention and the researcher made arrangements to meet them there and carry out the training

Participants were withdrawn from the study if intervention training was not completed before 3-month follow-up data collection was due.

6.8.2 Technical support

The PhD researcher's telephone and email contact details were included in both the training booklet and the help pages on the intervention (accessible both before and after login). Participants were encouraged to use these to report any technical problems with the intervention and if they wanted further training in how to access or use the services offered by the intervention. Where possible, technical support and further training was delivered by telephone or email. If necessary participants were visited to resolve problems. Details of any programming errors or error messages were passed on to Haile Berhe (senior IT programmer with the CHESS team).

6.8.3 Reminders

Monthly intervention use data received from the CHESS team were used to identify participants who had not used the intervention within a month of initial training. These participants were sent a reminder of the intervention website address and their login details, and offered further intervention training.

Newsletters which gave information about study progress, new content added in the monthly updates to the intervention and the topics of new discussion group and open expert messages were sent to participants every 2-3 months. The newsletters also reminded participants of the intervention website address and their login details.

Participants were also reminded of the intervention website address and their login details in the letter which accompanied 3-month follow-up questionnaire booklets.

6.9 Analysis

6.9.1 Statistical analysis of quantitative data

All analysis was conducted using SPSS software (322).

Management of missing data

Intervention use

Data was missing for one participant's final month of intervention use due to delayed CHES training, which meant that his 9-month intervention period extended after the last monthly database was received. Intervention use data for the final month of access was imputed from the mean number of pages requested by the participant in months 4-8, after the typically higher use in earlier months to avoid overestimation.

Outcomes

For all but one total score measure, data were imputed for near-complete cases (missing a single item of data on a scale or subscale). Missing data were imputed by substituting an individual's mean score across valid scale or sub-scale items for the missing item before summing the valid and imputed items. This applied to HADS (320), Healthy Diet Habits Score (267), diet score calculated from food frequency items (268), and MARS (269). The exception was the IPAQ measure of exercise behaviour for which only complete cases were scored, in line with scoring instructions (326). This resulted in a large number of cases with missing IPAQ scores (15-23% at any one time-point). Alternative methods of calculating exercise scores from the IPAQ items that might make use of near-complete data were considered, however the validity of any alternative scoring approaches could not be tested. As a result of this concern, and following previous researchers faced with the same dilemma (327), no attempt to re-score or impute data missing on IPAQ items was made.

All but one of the mean score measures were calculated for complete or near-complete cases, only: those with <2 missing item of data for scales with <17 items (CDSEI, CESEI (264), MOS Social Support Survey (266)); those with up to 3 missing items for a scale with 27 items (MacNew (24), item 27 counted as missing if answered 'not applicable'). The exception was the Cardiac self-efficacy questionnaire (319) where mean scores were calculated for all cases with any valid responses. In this questionnaire each of the 13 items in the two subscales allowed a 'not applicable' response. The questionnaire was designed for calculating two mean subscale scores across any relevant items with valid (scored rather than not applicable) responses. Thus 'not applicable' responses were not the same as missing data even though they did not contribute to scores.

No attempt was made to impute data missing on single item measures or subscales (BIPQ (278), behavioural intentions).

Analysis of predictors of intervention use

Total number of pages requested by individual participants were similarly distributed and highly correlated with their total number of logins ($r=0.95$). Page request data contained a greater range and variation in scores and so was selected as the measure of intervention use for analysis. Both login and page request data were highly positively skewed, with a floor effect that meant attempts to transform the data would be unlikely to achieve normally distributed data. As a result the intervention use data were not suitable for use as a dependent variable in linear regression analysis.

Instead, ordinal categories of intervention use were coded from page request data and ordinal regression analysis was conducted. Ordinal regression was chosen over simpler logistic regression to retain more information on level of intervention use. Due to the

relatively reduced power of ordinal compared to linear regression analysis the number of predictors was limited to 10. Results of this analysis are presented in Chapter 7.

Dependent variable: Level of intervention use

As there was no clear rationale for what an effective ‘dose’ of the intervention might be, participants who had used the intervention were divided into ‘low’ and ‘high’ use categories based on a median split of total page requests. This was the statistically strongest way to divide the sample into use categories as it resulted in groups of relatively equal size.

Categories of intervention use were coded from page request data as follows: Those who made 0 page requests were categorised as having made no use of the intervention; page request data for those who made ≥ 1 page request were median split into low and high use categories. No, low and high intervention use categories were coded for:

- (i) early intervention use (from number of page requests in months 1-3)
- (ii) overall intervention use (from number of page requests in months 1-9)
- (iii) use of information component (from number of pages requested in ‘question and answers’, ‘dictionary’, ‘instant library’, ‘web tools and resources’ and ‘directory of organisations’ services in months 1-9)
- (iv) use of behaviour change component (from number of pages requested in ‘health tracking’, ‘assessments’ and ‘action plan’ services in months 1-9)
- (v) use of support component (from number of pages requested in ‘ask an expert’, ‘discussion group’, ‘personal stories’ and ‘personal journal’ services in months 1-9)

Predictor variables

As discussed in Chapter 4 (Section 4.5.9), with no strong evidence for selecting predictors of intervention use in this study, this analysis was exploratory rather than driven by specific hypotheses. Predictors of intervention use were selected from patient characteristics and baseline outcome score variables. The predictors selected for inclusion in analyses predicting intervention use were:

- age (years)
- sex (male/female)
- educational qualifications (school leaver with no further educational qualifications/A levels or equivalent/degree level of equivalent)
- internet experience and access (basic or no internet experience without home internet access/basic or no internet experience with home internet access/internet experienced or expert, most with home internet access)
- time since most recent cardiac event or diagnosis (years)
- perception of illness identity
- depression
- perceived social support

The rationale for selecting these predictors was as follows. Age, sex, educational qualifications, internet experience and access were all selected as factors that have generally been found important in patterns of internet use, in particular for health information (53;287). Selection of other predictors aimed for a balance across clinical factors and baseline scores on psychological constructs and health outcomes.

Several clinical factors measured at baseline might be plausibly associated with use of the intervention. For example, recent diagnosis with CHD or a recent cardiac event may increase patients' need for and interest in self-management information and support

offered by the intervention. Participants who have had a heart attack may view their condition as more serious and hence be more motivated to access information and support to effectively self-manage their condition than those who have CHD but who have not had a heart attack. Equally, those with angina may have greater need for information and support than those with CHD who do not experience symptoms. Participants with other concurrent cardiovascular problems may also be more motivated to access information and support to effectively self-manage because the importance of effective self-management may be higher for these individuals and self-management guidelines are similar across their different cardiovascular conditions. Participants with other concurrent conditions may be less motivated to access information and support for CHD specifically because of the potential conflict between self-management guidelines for different conditions. Similarly, baseline scores on several psychological constructs and health outcomes might be plausibly associated with use of the intervention. In particular, social support, anxiety and depression were highlighted by internet intervention, long term condition and/or CHD literature as factors which may play an important part in support-seeking.

In all, 35 plausible predictors of intervention use were identified among variables measured at baseline. With more plausible predictors of intervention use than could be entered into an analysis if it was to have sufficient power to find any effects, the final decision over which clinical factors and baseline scores on psychological constructs and health outcomes was based on observed statistical grounds. The variation in scores observed across the potential range was considered first, and any without a good spread of scores at baseline were ruled out. Next inter-correlations between scores on remaining potential predictors and those selected a priori as important factors in patterns of internet use for health information were examined. High intercorrelations between predictors would be likely to result in multicollinearity in multivariate analysis and

distort analysis findings as a result. So where groups of potential predictors were highly inter-correlated (e.g. dimensions of illness perceptions), one predictor variable was selected based on levels of variation in scores and correlation with total intervention use in the first 3 months of access. In the case of illness perceptions this was illness identity. Time since most recent cardiac event was selected over time since earliest CHD diagnosis in this way, as was depression over anxiety. Selection of variables to test as predictors of intervention use was conducted in consultation with a sub-group of the project steering group which included two statisticians, Elizabeth Murray and Lorraine Noble (primary and secondary supervisors for this thesis).

Analyses conducted

Separate univariate and multivariate ordinal regression analyses were conducted predicting the 5 intervention use variables (early intervention use, overall intervention use, use of information services, use of behaviour change support services and use of other support services). Correlations between the three baseline score predictor variables (perception of illness identity, depression and social support) exceeded $r=0.4$, raising concerns that the intercorrelations between these variables might distort analysis findings. So multivariate analyses were repeated excluding each of these variables in turn to establish whether this affected independent effects of the other predictor variables.

Testing changes in outcomes

Related t-tests, Wilcoxon signed ranks and McNemar tests were used to test for change in outcomes depending on whether data were normally distributed or categorical. Results of this analysis are presented in Chapter 8.

Selection of tests

Score distributions for each outcome variable at baseline, 3- and 9-month follow-up were checked by producing frequency histograms. Related t-tests were used to test change in outcomes for variables with frequency distributions which did not clearly deviate from the normal curve at any of the data collection time-points. Wilcoxon signed ranks test were used for variables with skewed data.

For the illness perception of cause variable (BIPQ cause (278)), free text lists of the 3 most important factors participants believed caused their heart disease were coded into one of two categories: either heart disease caused by lifestyle factors or not. Participants giving 'don't know' responses were excluded from tests of change in this variable. Change in illness perception of cause category was tested with the McNemar test for related categorical data.

Analyses conducted

Tests of change were conducted for change between baseline and 3-month follow-up and change between baseline and 9-month follow-up. Change was tested in the whole sample and among participants who had made some use of the intervention (those who made ≥ 1 page request in the first 3 months for tests of change from baseline to 3 months; those who made ≥ 1 page request in months 1-9 for tests of change from baseline to 9 months. A conservative threshold for significance was set ($p < 0.01$) due to the large number of tests.

Analysis predicting changes in outcomes from intervention use

Significantly skewed psychological constructs and outcomes were not suitable for use as a dependent variable in linear regression analysis. Variables with skewed data were either median-split into binary categories on which logistic regression analysis was performed, or they were excluded from analysis. The illness perception dimension of

timeline (BIPQ timeline (278)), all three behavioural intentions and medical adherence behaviour (MARS (269)) were excluded from analysis because of near complete ceiling effects of scores. Exercise behaviour (IPAQ (281)) was excluded from analysis because of concerns over validity of data in addition to problems introduced by skewed data. In addition to the large numbers of cases excluded from analysis due to missing data as a result of the instruments' scoring instructions, re-scoring IPAQ data to categorise people as inactive, minimally/sufficiently active or HEPA active (highly active) (326) resulted in only 16% of cases categorised as inactive at baseline. This was lower than expected and raised the concern that people with lower levels of physical activity may have been less likely to give valid answers to all required items, inflating the proportions of participants reporting moderate or high levels of physical activity among the cases that could be scored.

Results of linear and logistic multiple regression analyses used to predict changes in outcomes from intervention use are presented in Chapter 8.

Dependent variables: Outcome scores at 3 and 9 months

Dependent variables used in linear regression analyses were:

- Cardiac diet self-efficacy
- Cardiac exercise self-efficacy
- Illness perception of consequences
- Illness perception of personal control
- Illness perception of treatment control
- Illness perception of identity
- Illness perception of concern
- Illness perception of coherence
- Illness perception of emotional effects

- Perceived information and emotional social support
- Healthy diet behaviour
- Anxiety
- Depression
- Health-related quality of life

Dependent variables used in logistic regression analyses were:

- Cardiac self-efficacy to control symptoms (median split into low/high)
- Cardiac self-efficacy to maintain function (median split into low/high)
- Illness perception of cause (heart disease caused by lifestyle factors/not cause by lifestyle factors - participants giving 'don't know' responses were excluded).

Independent variables: Intervention use

Independent intervention use variables used in linear and logistic regression analyses were:

- Analyses of change from total intervention use:
 - Total number of pages requested in the first three months of access (for analyses predicting 3-month follow-up scores)
 - Overall intervention use - total number of pages requested in all 9 months (for analyses predicting 9-month follow-up scores)
- Analyses of change from use of intervention components:
 - Use of information component ('question and answers', 'dictionary', 'instant library', 'web tools and resources' and 'directory of organisations' services)

- Total number of information component pages requested in the first three months of access (for analyses predicting 3-month follow-up scores)
 - Overall information component use - total number of information component pages requested in all 9 months (for analyses predicting 9-month follow-up scores)
- Use of behaviour change component ('health tracking', 'assessments' and 'action plan' services):
 - Total number of behaviour change component pages requested in the first three months of access (for analyses predicting 3-month follow-up scores)
 - Overall behaviour change component use - total number of information component pages requested in all 9 months (for analyses predicting 9-month follow-up scores)
- Use of support component ('ask an expert', 'discussion group', 'personal stories' and 'personal journal' services):
 - Total number of support component pages requested in the first three months of access (for analyses predicting 3-month follow-up scores)
 - Overall support component use - total number of information component pages requested in all 9 months (for analyses predicting 9-month follow-up scores)

Covariates

These were demographic or clinical characteristics that were likely to independently influence outcomes or had been found to significantly predict intervention use:

- MI (yes/no)
- Angina (yes/no)
- Concurrent cardiovascular condition (yes/no)
- Other concurrent condition (yes/no)
- Age (years)
- Time since most recent cardiac event (years)
- Level of internet access and experience (coded as 2 dummy variables, as for predictors of intervention use analysis)

No baseline demographic or clinical participant characteristics were found to significantly differ between responders (n=140) and non-responders at 3 and/or 9 months (n=28).

Analyses conducted

Analyses were conducted for each psychological construct and health outcome and for each change period (baseline to 3 months, baseline to 9 months). A conservative threshold for significance was set ($p < 0.01$) due to the large number of tests. Analyses were repeated for complete cases only to test for the robustness of findings using variables with imputed data.

6.9.2 Qualitative analysis

Thematic analysis and data collection were conducted concurrently, with analysis starting as soon as early interviews were transcribed. Corrected transcripts were loaded into Atlas.ti software (328) where they were coded using an induction-abduction approach (237) to identify themes relating to hypothesised mechanisms of intervention action, intervention use and effects. Themes identified in initial analysis were discussed with Elizabeth Murray (primary supervisor and GP) and Fiona Stevenson (medical

sociologist) who had read all 19 corrected interview transcripts. Emerging findings from the qualitative analysis were then discussed with the multidisciplinary steering group.

Themes identified by the qualitative analysis were compared to comments made by participants in a free-text section at the end of their 9-month follow-up questionnaire. This served to check whether themes identified from the interview sub-sample broadly represented the views of the wider study sample.

Qualitative analysis results are presented in Chapters 7 and 8.

Chapter 7 : Results – Sample characteristics and use of the intervention by patients with CHD

7.1 Introduction

This is the first of two chapters presenting the results of the study. This chapter presents details of the sample (recruitment and participant characteristics) and results relating to the use participants made of the intervention. Results relating to the effects and mechanisms of action of the intervention are presented in Chapter 8.

Results in this chapter are presented in three sections to address the following questions:

- Who wanted to participate?
- What use was made of the intervention?
- Which factors were associated with intervention use?

7.2 Who wanted to participate?

7.2.1 Sample recruitment

175 patients with CHD were recruited from 10 North London primary care practices between November 2006 and October 2007. Details of the participating practices are shown in Table 7.1 along with response rates for each. For descriptive purposes Carstairs deprivation scores for each practice are also given in Table 7.1. These scores are a summary measure of relative material deprivation within small populations (329). They are based on four indicators from Census data: no car, overcrowding, male unemployment and social class IV & V. Positive scores reflect more deprivation. Carstairs scores have been calculated across the UK, ranked and divided into quintiles – Quintile 1 contains the fifth of the UK population living in the least deprived areas, Quintile 5 contains the fifth living in the most deprived. Nine of the participating

practices had positive Carstairs deprivation scores, eight of which fell within the most deprived quintile of the UK population.

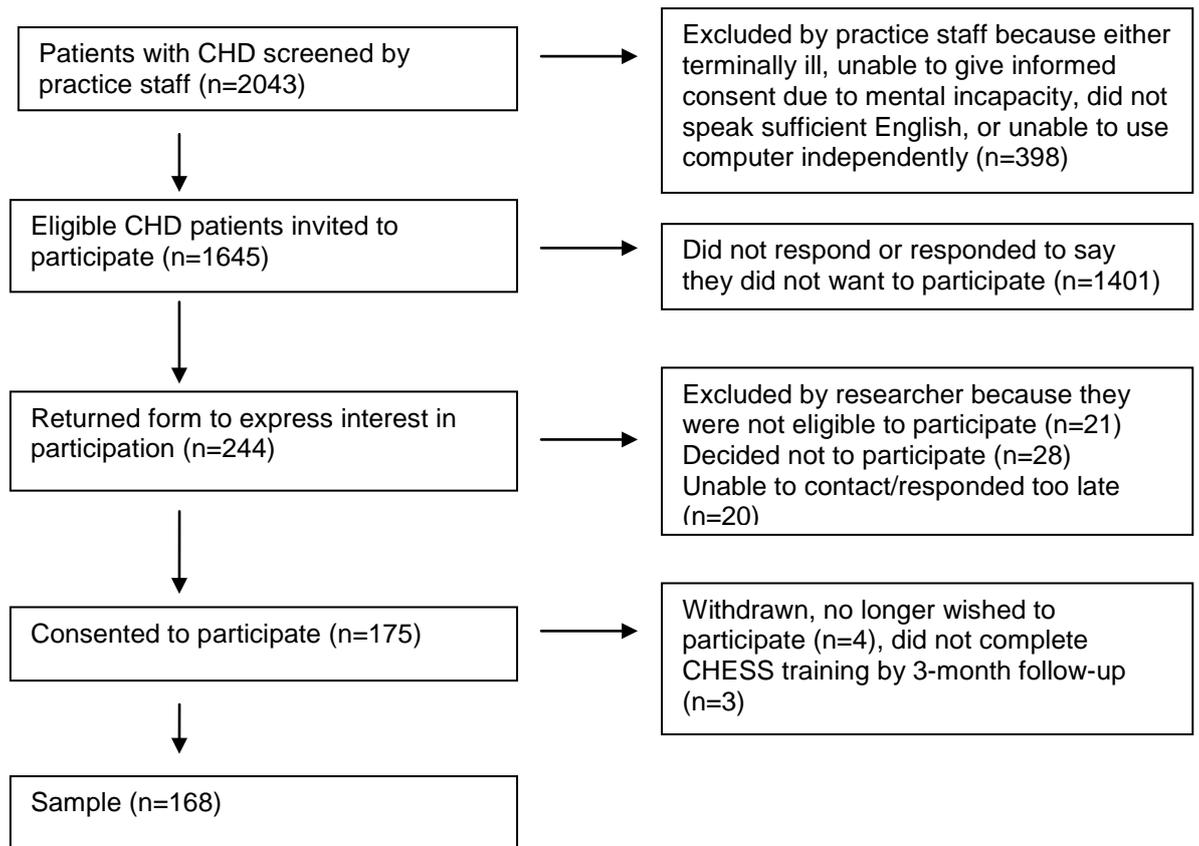
Details of sample recruitment are given in Figure 7.1. Overall, over 80% (1645/2043) of patients with CHD registered at participating practices were screened by practice staff as eligible and invited to participate. Just under 15% (244/1645) of CHD patients invited to participate expressed an interest in the study and just over 10% (175/1645) consented to participate. Sixty-nine CHD patients who had expressed an interest in the study did not participate. Some were found ineligible at this point, most of these because they were housebound and without home internet access so unable to use a computer independently (an exclusion criteria that screening GPs could leave for the researcher to establish later). The final study sample was made up of 168 of the 175 patients with CHD who originally consented to participate (see Figure 7.1 for further details).

Table 7.1 Participating practices and response rates.

Primary Care Practice	Postal area	Carstairs UK Deprivation ^a		List size	Patients with CHD screened	Eligible patients with CHD	Interested patients	Participants (% of eligible)
		Score	Quintile					
1	HA8	7.00	5	12,200	379	326	48	38 (11.7)
2	NW3	-0.07	3	8,800	209	168	30	22 (13.1)
3	NW3	6.70	5	10,300	241	178	32	19 (10.7)
4	NW3	0.69	4	2,500	62	57	6	4 (7.0)
5	NW5	2.97	5	4,700	92	58	11	11 (19.0)
6	NW5	8.26	5	7,500	224	181	23	17 (9.4)
7	N7	8.19	5	10,000	225	161	24	19 (11.8)
8	NW1	6.65	5	15,700	221	177	30	21 (11.9)
9	NW1	13.50	5	6,000	159	148	23	14 (9.5)
10	N1	6.00	5	10,900	231	191	17	10 (8.9)
Total					2043	1645	244	175 (10.6)

^aScores and quintiles for each practice taken from a national database developed by the National Primary Care Research and Development Centre, University of Manchester, May 2006.

Figure 7.1 Sample recruitment.



7.2.2 Sample characteristics

Baseline demographic and clinical characteristics of the study sample, along with their internet access and level of internet experience are shown in Table 7.2. The sample was predominantly male, well educated and white but contained a wide spread of ages and employment status.

Table 7.2 Sample baseline characteristics.

		Sample (n=168)	Interview sub- sample (n=19, 11%)
Age (years)	Range	38 - 87	53 - 82
	Mean (standard deviation)	66.8 (10.1)	71.0 (8.8)
Sex	Male	137 (81.5%)	13
	Female	31 (18.5%)	6
Employment	Employed (full or part-time)	31 (18.5%)	1
	Self-employed	34 (20.2%)	1
	Full-time carer	6 (3.6%)	2
	Retired	80 (47.6%)	12
	Other economically inactive (unemployed or not working for other reasons)	16 (9.5%)	3
	Not disclosed	1 (0.6%)	0
Educational qualifications	School leaver (no further/higher qualifications)	57 (33.9%)	9
	A levels or vocational equivalent	32 (19.0%)	4
	Degree, HND or similar	76 (45.2%)	6
	Not disclosed	3 (1.8%)	0
Ethnic group	White (British, Irish, other)	141 (83.9%)	14
	Black (British Caribbean, African, other)	9 (5.4%)	2
	Asian (British Indian, Pakistani, Bangladeshi, other)	14 (8.3%)	3
	Other (Chinese, other)	4 (2.4%)	0
Heart disease	Angina	103 (61.3%)	13
	MI	86 (51.2%)	8
	Both	46 (27.4%)	4
Concurrent long term conditions	Cardiovascular (including diabetes, stroke)	68 (40.5%)	10
	Other	91 (54.2%)	11
	Both	42 (25.0%)	8
Time since earliest CHD diagnosis (years)	Range	0 - 35	1 - 22
	Mean (standard deviation)	10.6 (7.3)	9.8 (6.5)
	Diagnosed in the last year	2 (1.2%)	0
	Diagnosed 1-2 years ago	22 (13.1%)	4
	Diagnosed 3-5 years ago	28 (16.7%)	2
	Diagnosed 6-10 years ago	37 (22.0%)	3
	Diagnosed >10 years ago	77 (45.8%)	9
	Earliest CHD diagnosis given as rheumatic fever in childhood	2 (1.2%)	1
Time since most recent cardiac event (years)	Range	0 - 21	0 - 15
	Mean (standard deviation)	5.4 (4.9)	3.7 (3.6)
	Cardiac event in the last year	21 (12.5%)	1
	Most recent cardiac event 1-2 years ago	44 (26.2%)	8
	Most recent cardiac event 3-5 years ago	42 (25.0%)	7
	Most recent cardiac event 6-10 years ago	32 (19.0%)	2
	Most recent cardiac event >10 years ago	29 (17.3%)	1
Home internet access	Yes	134 (79.8%)	13
	No	34 (20.2%)	6
Level of internet experience	None or basic	67 (39.9%)	11
	Experienced or expert	101 (60.1%)	8

Just over half of the sample had been diagnosed with angina, around half of the sample had experienced at least one myocardial infarction (MI or heart attack) and just over a quarter of the sample had experienced both angina and MI. However, this was not necessarily a recent experience. Nearly half of participants had been first diagnosed with CHD over 10 years ago, with very few diagnosed with CHD for the first time in the preceding 2 years. A greater proportion had experienced a cardiac event (MI, surgical intervention or emergency hospitalisation) or CHD diagnosis (angina, MI or heart failure) in the preceding 2 years, however, nearly 40% of participants had not experienced either in the last 5 years. Just under half of the sample also had at least one other cardiovascular condition (e.g. diabetes) and over half of the sample also had at least one non-cardiovascular long term condition (e.g. arthritis), with a quarter of the sample reporting both types of conditions at baseline as well as CHD.

Most participants were experienced in using the internet and had home internet access. However, 40% had no (novice) or only basic internet experience (used the internet once or twice but not regularly) and a fifth of the sample did not have home internet access. Although the study was successful in including some patients without prior internet experience or home access, 80% of those who chose to participate had home internet access and/or some prior experience of using the internet.

Comparison of the sample's baseline distributions of age (Figure 7.2) and sex (Figure 7.3) with available data from the CHD registers of the 10 participating GP practices suggests that the sample may not have been representative of the wider CHD population from which it was drawn. Despite the wide range of participant ages in the sample, Figure 7.2 shows that CHD patients who chose to participate in the study were relatively young, with patients aged 35-74 years over-represented in the sample and patients aged >75 years under-represented in the sample. Figure 7.3 shows that the

wider CHD population was also predominantly male. However this imbalance was exaggerated in the study sample. A greater proportion of men chose to take part in the study with less than 20% of the study sample made up of female participants.

Figure 7.2 Age distributions of the sample and CHD patients registered at participating practices.

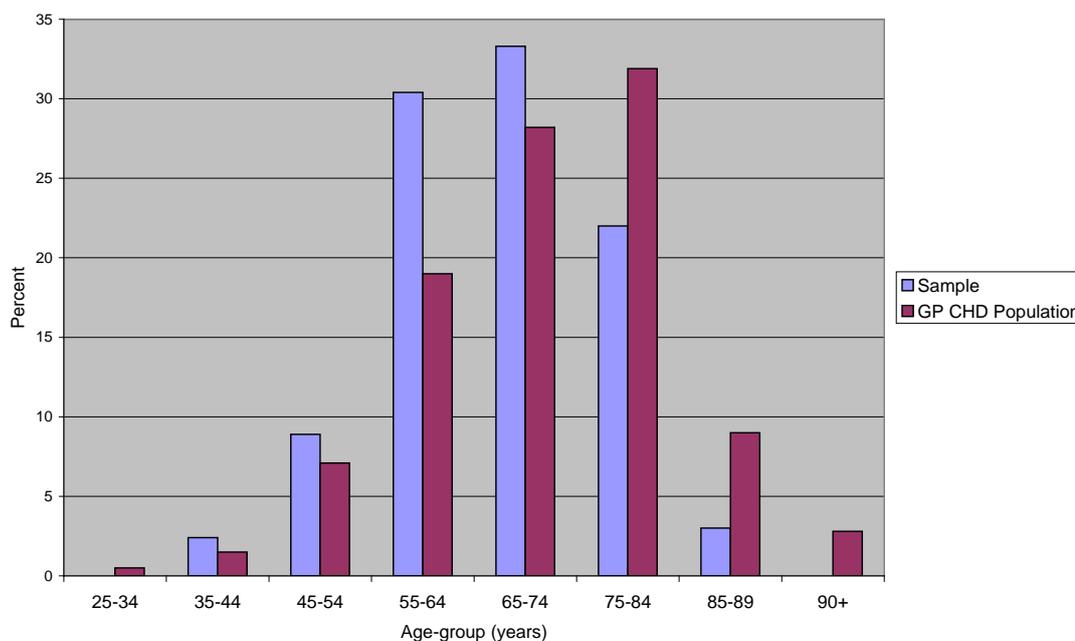
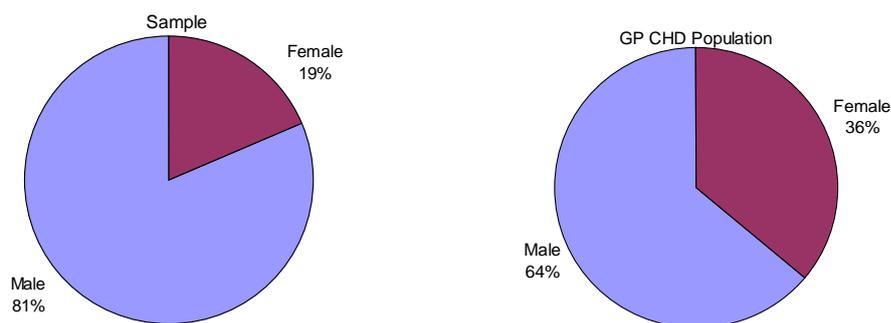


Figure 7.3 Proportion of men and women in the sample and of CHD patients registered at participating practices.



When compared to UK population surveys, the proportion of participants in this study with degree level educational qualifications (45%) was high. In the 2005 Health Survey for England less than 8% of respondents with heart attack or angina had a degree level qualification (323). The proportion of participants with home internet access and/or

some prior internet use (80%) was also high. National surveys conducted in 2007 found only 30% of adults aged over 65 years reported having ever used the internet (287) and only 36% of patients with a health problem or disability reported internet use (53).

Participants' mean baseline scores on psychological constructs and health outcomes are shown in Table 7.3. The pattern of mean scores across the different dimensions of illness perceptions suggest that, on average, the sample perceived little consequence of CHD on their life but expected their CHD to continue for a long time, they felt they had a moderate amount of personal control over their CHD, with more control achieved by their treatment. They experienced few symptoms from their CHD but were moderately concerned about it. They felt they had reasonably good understanding of their condition and it did not affect them emotionally to any great extent. Brief IPQ scores in a sample of 103 patients at discharge from hospital post-MI showed a similar pattern of illness perceptions (278), although compared to the post-MI sample, participants in the current study perceived slightly less consequences of their condition (3.3 vs 4.1), a longer timeline (8.2 vs 7.2), less personal control over it (6.1 vs 7.7), less concern about it (5.1 vs 6.2), less understanding of their condition (6.7 vs 8.0) and less emotional effects (3.3 vs 4.2). In terms of the IPQ cause variable, patients who believe lifestyle factors contributed to their CHD might be more receptive to health promotion information and support relating to lifestyle change. In the current sample, 28% of participants believed a lifestyle factor was the most important cause of their CHD, a further 29% believed one or more lifestyle factors were important causes of their CHD but were not the most important cause, 37% did not list any lifestyle factors as important causes of their CHD but identified other important causes and 6% did not know what had caused their CHD.

Table 7.3 Baseline scores on psychological constructs and health outcomes.

Psychological constructs and health outcomes		Scale maximum	Mean baseline scores	Standard deviation
Illness perceptions	Consequences	10	3.3	2.9
	Timeline	10	8.2	3.2
	Personal control	10	6.1	3.1
	Treatment control	10	8.0	3.1
	Identity	10	2.9	2.8
	Concern	10	5.1	3.4
	Coherence	10	6.7	9.0
	Emotional effects	10	3.3	3.2
Self-efficacy	Control symptoms	4	2.8	1.0
	Maintain function	4	2.7	1.2
	Diet	5	3.7	0.8
	Exercise	5	3.2	1.0
Social support	Emotional and information	5	3.6	1.1
Behavioural intentions	Medicine adherence	5	4.8	0.6
	Diet	5	4.4	0.9
	Exercise	5	4.0	1.2
Health behaviours	Medicine adherence	25	23.9	1.5
	Healthy diet habits	12	7.8	2.1
	Diet from food frequency	30	19.8	2.7
	Exercise MET minutes per week	No maximum	3014.3	3896.6
Emotional status	Anxiety	21	5.9	4.0
	Depression	21	4.4	3.3
Health-related quality of life		7	5.7	0.9

The mean self-efficacy scores for diet, exercise, controlling symptoms and maintaining function in the sample shown in Table 7.3 were above scale mid-points. This may indicate that on average, participants felt relatively confident in their ability to manage their condition and engage in healthy lifestyle behaviours. However, a UK sample of patients hospitalised following a heart attack or with angina showed only slightly lower self-efficacy for diet (3.5 vs 3.7) and exercise (2.9 vs 3.2) (231). Relevant comparative data were not available for the emotional and information subscale of social support, but the average score in the study sample was also above the mid-point for the sub-scale. This may indicate that at baseline participants had good levels of emotional and information support.

Table 7.3 shows that on average participants in the sample had close to ceiling intentions to adhere to medical guidelines for taking medication, to eat a healthy diet and exercise regularly. As a result, it would appear that the sample was made up of highly motivated patients. This motivation was matched by high levels of reported adherence in medication taking behaviour, healthy diet behaviour and regular exercise behaviour.

The average medicine adherence score was close to ceiling, however a similarly high level of reported medicine adherence (23.8) has been found before in a much larger primary care sample of CHD patients (324) . On average, study participants scored higher than a general public sample on healthy diet habits (7.8 vs 5.6) (267). When study participants' reported baseline levels of physical activity (MET minutes per week) were rescored according to established categorical levels of exercise (326), only 18% of the study sample were categorised as engaging in a low level or no physical activity (inactive), compared to 67% who were categorised as engaging in levels of physical activity that either met current public health recommendations (minimally active) or exceeded them (health enhancing physical activity, HEPA). A further 15% could not be categorised due to missing data.

Study participants' mean level of anxiety at baseline (Table 7.3) as measured by the HADS (320) was much lower than a UK samples of patients who had experienced a coronary event in the previous 3 months (5.9 vs 7.9 and 7.2) (268) and even slightly lower than a large UK general population sample of adults (6.1) (325). In the study sample 30% of participants met the score threshold for possible clinical levels of anxiety (HADS anxiety scores ≥ 8 , (320)) and 16% met the score threshold for probable clinical levels of anxiety (HADS anxiety scores ≥ 10 , (320)). This is similar to the level of possible clinical anxiety found in a UK general population sample of adults (33%)

and lower than levels of probable clinical anxiety found in UK samples of patients who had experienced a coronary event in the previous 3 months (23 – 26%) (268).

Participants' mean HADS depression score of 4.4 was more as might be expected, falling around half-way between that of the general population sample (3.7) (325) and samples of CHD patients who had experienced a recent cardiac event (4.8 – 4.9) (268). Prevalence of possible (HADS depression scores ≥ 8 , (320)) and probable clinical levels of depression (HADS depression scores ≥ 10 , (320)) in the study sample were 18% and 8% respectively. These levels are higher than those found in the UK general population sample of adults (11% possible clinical depression) (325) and similar to those found in samples of CHD patients who had experienced a recent cardiac event (5 - 7% probable clinical depression) (268).

Finally, study participants' mean baseline MacNew health-related quality of life score of 5.7 was higher than the mid-score point for the scale. Their health-related quality of life was also relatively higher than other CHD samples (261), although this is perhaps not surprising given the reference data was collected from various CHD patient groups 4 months after discharge from hospital. MacNew global scores in these CHD patient groups varied according to age-group and sex, ranging from

- 4.8 (females aged 75-85 years) to 5.3 (males aged less than 65 years) among patients discharged post-MI
- 4.1 (females aged 65-74 years) to 5.0 (females aged less than 65 years) among heart failure patients
- 4.6 (females aged 75-85 years) to 5.1 (females aged less than 65 years) among CHD patients discharged after being admitted to hospital by emergency

- 4.8 (females aged less than 65 years and 75-85 years) to 5.5 (males aged 65-74) among CHD patients discharged after being admitted to hospital for elective procedures

In summary, despite an inclusive recruitment strategy, participants in this study appear to have been a select group. They are likely to have been better educated and have had better access to and/or experience of the internet than the wider CHD population. Few had experienced a recent cardiac event or complications, overall levels of anxiety were low and health-related quality of life high, which may indicate that they were in relatively good health with relatively few CHD-related problems.

7.3 What use was made of the intervention?

Overall participants made 1278 separate logins to the intervention. However, use varied greatly across the sample. Figure 7.4 shows the percentage of the sample who logged in to the intervention per month of intervention access. Overall the intervention was used at least once by 77% of the sample (Figure 7.5). There was a clear drop off in use over time: falling from use by over 60% of participants in their first month of access to a maximum 15% of participants using the intervention in any one month from month 5 onwards. Over 50% of participants that used the intervention did so only in their first 3 months of access.

Figure 7.4 Proportion of the sample that used the intervention per month of access.

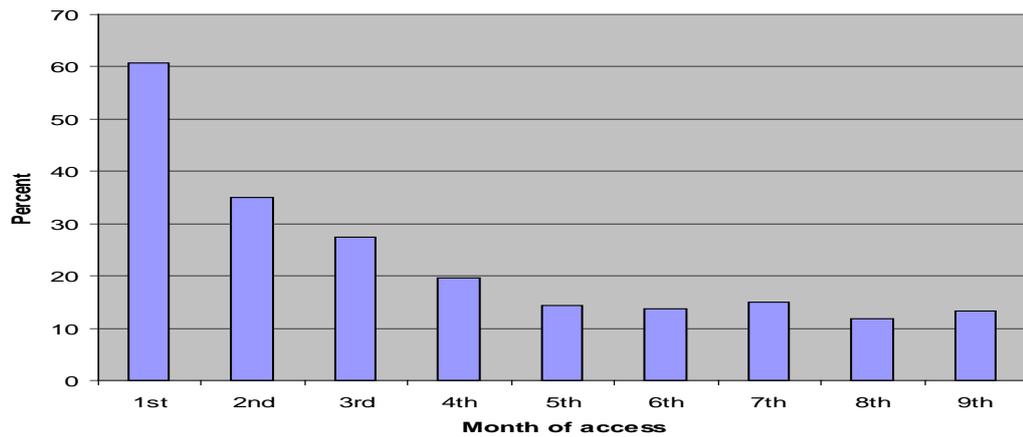


Figure 7.5 Proportion of the sample that used the intervention in earlier, later and overall periods of intervention access.

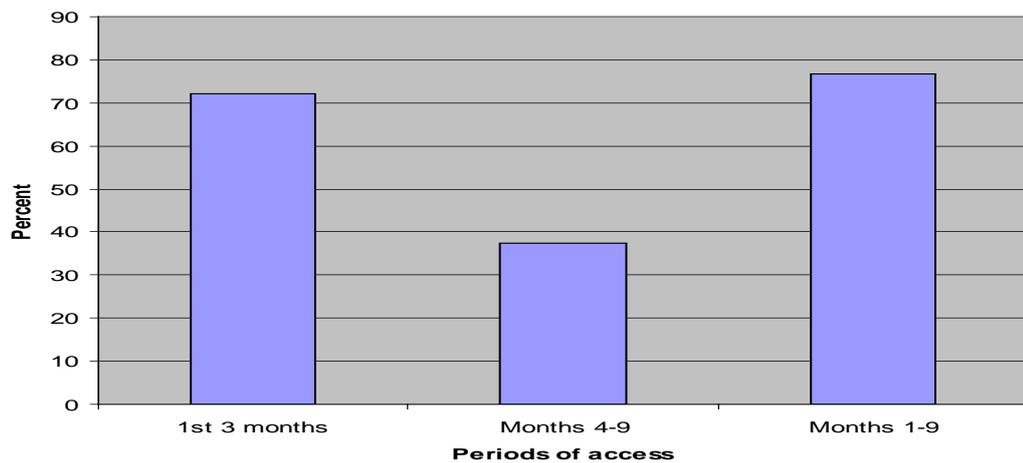
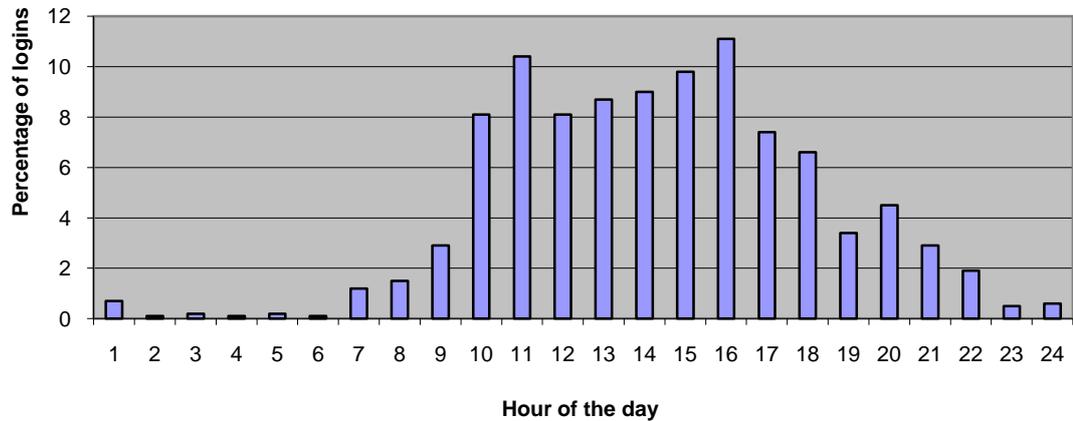


Figure 7.6 shows intervention use by hour of the day. Most intervention use occurred during the day with the highest percentage of logins made around 4pm and over 80% of logins made between 9am and 6pm.

Figure 7.6 Time of day of intervention use - percentage of logins by hour of the day.



Amount of use among participants who used the intervention varied greatly. Figure 7.7 shows the frequency of intervention use per month (number of logins) among participants who used the intervention. Participants logged in on average (median) 3 times in the first month and between 1 and 2 times in other months of access. However, this average masks a wide variation in use between individual participants (range 0-149 logins, 10-90 percentile 0-23). Even after excluding the extreme outliers, 10-90 percentiles of logins show an increase in frequency of use in later months for some participants.

Figure 7.7 Median and range (10-90 percentiles) of logins per month among participants that used the intervention.

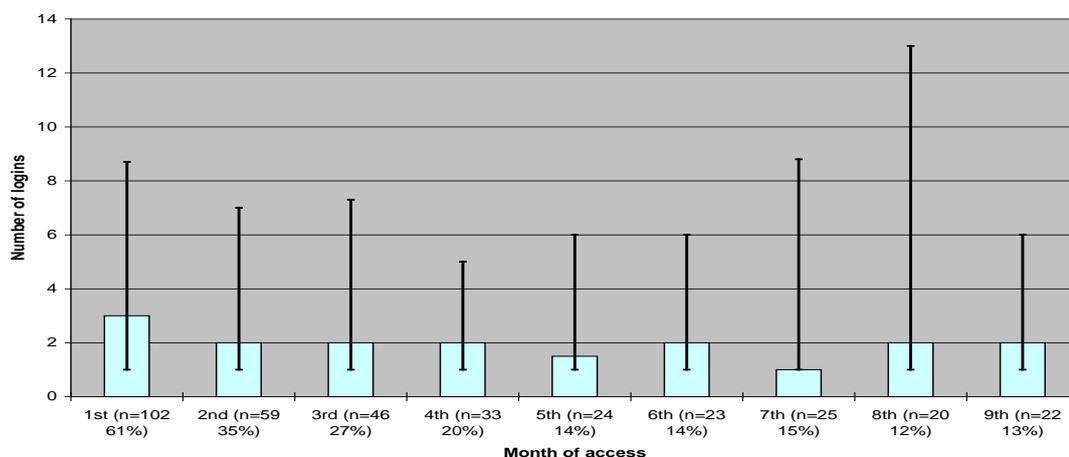
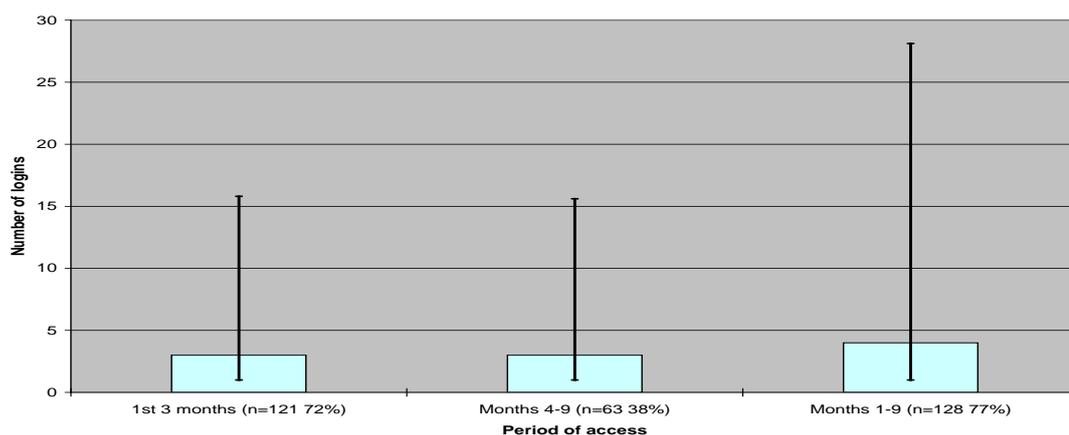


Figure 7.8 Median and range (10-90 percentiles) of logins per intervention period among participants that used the intervention.



The total number of pages viewed on the intervention gives a different measure of intervention use (volume rather than frequency) but shows a very similar pattern of both median and range of use among users over the 9 months of their access to the intervention. These two measures of intervention use were highly correlated for total use over the 9 months ($r=0.95$).

Use of different types of intervention components (information, behaviour change, support) fluctuated over the 9 months of intervention access (Figure 7.9 and Figure 7.10). Overall, least use was made of the support component. This was due to low use

of the ‘discussion group’ and ‘personal journal’ support services. However those who continued to use the intervention in later months made greater use of the support component than other components. Use of the behaviour change component appears to have been higher than use of other components, however this was inflated by pages in the ‘health tracking’ behaviour change service which were programmed to automatically appear immediately after log-in (rather than by user request) to remind users to complete or update their ‘health tracking’ answers.

Figure 7.9 Use of different intervention components - median page requests per month among participants that used the intervention.

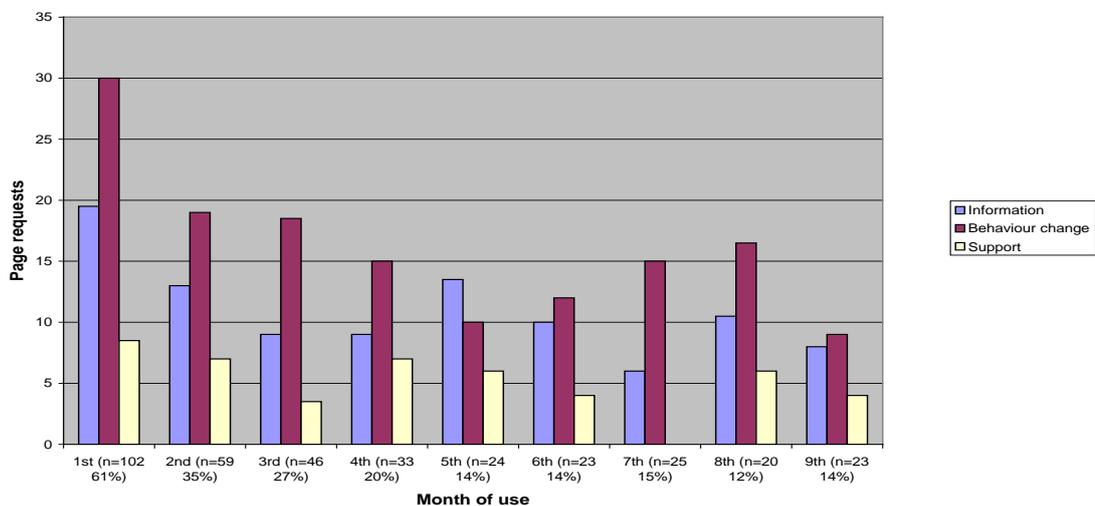
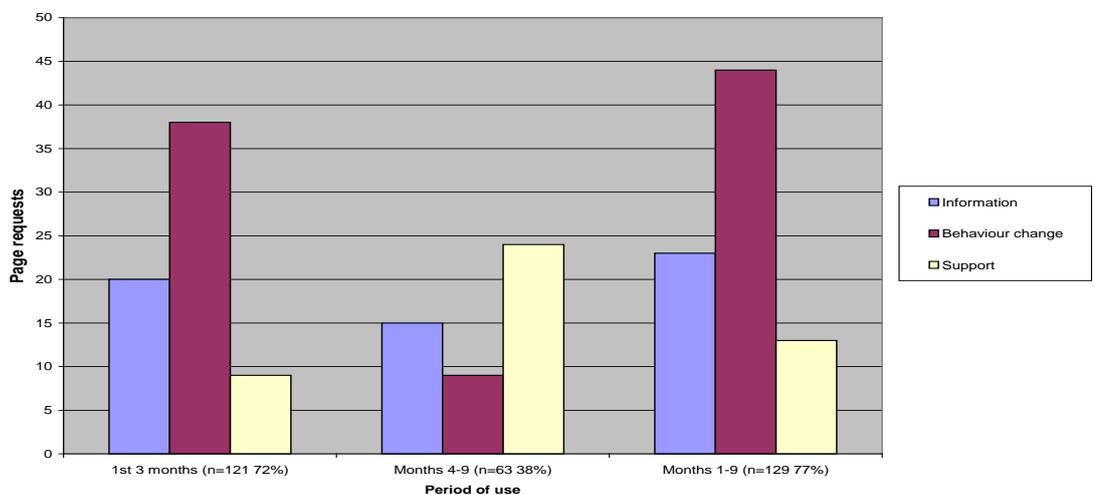


Figure 7.10 Use of different intervention components - median page requests per intervention period among participants that used the intervention.



7.4 Which factors were associated with intervention use?

This question was addressed by analyses of both quantitative and qualitative data.

Results from statistical analysis of baseline and intervention use data from the whole sample are described first. Then findings from qualitative analysis of discussions relating to intervention use with the sub-sample of interview participants are presented, before findings from the two methods are integrated.

7.4.1 Predictors of intervention use: Results of quantitative analysis

Univariable and multivariable ordinal regression analyses predicting overall intervention use were carried out on all complete cases of data (n=161). Incomplete cases (n=7) were excluded due to missing educational qualification (n=3), baseline perception of illness identity (n=3) and baseline perceived social support data (n=1). Methods for these analyses were reported in Chapter 6 (Section 6.9.1).

Full results are presented from the univariable and multivariable analyses predicting overall intervention use (months 1-9). Then significant results from other univariable and multivariable analyses (use in first 3 months, use of information, behaviour change and support components) are presented for comparison.

Table 7.4 and Table 7.5 provide descriptive statistics for the analysed sample for each of the predictor variables by level of overall intervention use. Level of overall intervention use were categorised from median split of pages requested as follows:

- No overall use = 0 page requests
- Low use = between 1 and 148 page requests (up to and including the median page requests among participants who made ≥ 1 page request)
- High use = more than 149 page requests (greater than median number of page requests among participants who made ≥ 1 page request)

Table 7.4 Frequencies for categorical predictors by level of overall intervention use.

Predictors (categorical variables)		Frequency (percent) by level of overall intervention use		
		No use (n=35)	Low use (n=64)	High use (n=62)
Sex	Male (n=130)	27 (21%)	53 (40%)	50 (39%)
	Female (n=30)	8 (27%)	11 (36.5%)	11 (36.5%)
Educational qualifications	School leaver (n=55)	10 (18%)	21 (38%)	24 (44%)
	A levels or equivalent (n=29)	3 (10%)	16 (53%)	11 (37%)
	Degree or equivalent (n=76)	22 (29%)	27 (35.5%)	27 (35.5%)
Level of internet experience and home access	Basic or no experience without home access (n=30)	10 (33%)	11 (37%)	9 (30%)
	Basic or no experience with home access (n=32)	4 (12%)	16 (49%)	13 (39%)
	Experienced or expert, most with home access (n=98)	21 (21%)	37 (38%)	40 (41%)

Table 7.5 Mean scores for continuous predictors by level of overall intervention use.

Predictors (continuous variables)	Mean (SD) predictor score by level of overall intervention use		
	No use (n=35)	Low use (n=64)	High use (n=62)
Age (years)	65.9 (9.3)	64.9 (9.7)	69.0 (10.7)
Time since most recent cardiac event or diagnosis (years)	5.7 (4.7)	6.2 (4.9)	4.3 (5.0)
Perception of illness identity (symptoms experienced)	2.4 (2.6)	2.5 (2.4)	3.6 (3.1)
Depression	3.6 (3.1)	4.2 (3.2)	4.9 (3.5)
Perceived social support (information and emotional)	4.0 (1.0)	3.5 (1.2)	3.5 (1.1)

Multivariable ordinal regression analysis found significant predictors of level of overall intervention use to be age, time since most recent cardiac event or diagnosis, internet experience and home internet access: Participants who were older, had more recently experienced a cardiac event or diagnosis, had home internet access and experience of using the internet were more likely to make some or high use of the intervention (Table 7.6). Perception of illness identity was also a significant predictor level of overall intervention use in multivariable analysis if depression was excluded from the analysis (perception of illness identity OR=1.16, 95% CI (1.02, 1.31) p=0.027). So participants

who perceived they experienced more symptoms from CHD were also more likely to make some or high overall use of the intervention.

Despite being a significant predictor in univariable analysis, depression did not significantly predict level of overall intervention use in multivariable analysis, whether other correlated predictors were excluded from analysis or not. Sex, educational qualifications and perceived social support did not significantly predict level of overall intervention use in any univariable or multivariable analyses.

Table 7.6 Results of univariable and multivariable ordinal regression analyses predicting overall level of intervention use (no use, low use or high use).

Baseline predictors		Univariable analysis		Multivariable analysis	
		Odds ratio (95% confidence interval)	p	Odds ratio (95% confidence interval)	p
Age		1.14 ^a (0.99,1.32)	0.064	1.25 ^a (1.06,1.47)	0.009 ^d
Time since most recent cardiac event or diagnosis		0.77 ^a (0.58,1.04)	0.086	0.69 ^a (0.50,0.95)	0.025 ^c
Internet experience and home access	Basic or no experience without home access	1.00 ^b	0.266	1.00 ^b	0.014 ^c
	Basic or no experience with home access	2.03 (0.81,5.12)		2.85 (1.02,7.93)	
	Experienced or expert, most with home access	1.76 (0.82,3.76)		3.74 (1.52,9.22)	
Perception of illness identity (symptoms experienced)		1.14 (1.03,1.27)	0.015 ^c	1.13 (0.99,1.29)	0.073
Depression		1.09 (1.00,1.20)	0.048 ^c	1.06 (0.94,1.19)	0.314
Educational qualifications	School leaver	1.00 ^b	0.316	1.00 ^b	0.102
	A levels	0.97 (0.42,2.22)		1.40 (0.55,3.56)	
	Degree	0.63 (0.33,1.21)		0.61 (0.29,1.28)	
Sex	Female	1.00 ^b	0.606	1.00 ^b	0.361
	Male	1.21 (0.58,2.53)		1.44 (0.66,3.15)	
Perceived social support (information and emotional)		0.79 (0.61,1.03)	0.086	0.85 (0.62,1.18)	0.332
Model Fit (compared to intercept only)				0.002 ^d	

^a Odds ratio calculated for 5 year increase, ^b Reference category, ^cp<0.05, ^dp<0.01

Table 7.7 Significant predictors of intervention use in the first 3 months of access and use of intervention components.

Baseline predictors		Intervention use (no use, low use, high use):															
		First 3 months of access				Information component				Behaviour change component				Support component			
		Univariable		Multivariable		Univariable		Multivariable		Univariable		Multivariable		Univariable		Multivariable	
		OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p
Age		1.22 ^a (1.05, 1.42)	0.008	1.32 ^a (1.11, 1.57)	0.001			1.22 ^a (1.05, 1.42)	0.013	1.19 ^a (1.05, 1.35)	0.021	1.28 ^a (1.11, 1.49)	0.003	1.20 ^a (1.05, 1.42)	0.015	1.25 ^a (1.05, 1.49)	0.007
Time since most recent cardiac event or diagnosis		0.74 ^a (0.55, 1.00)	0.048	0.63 ^a (0.45, 0.86)	0.005	0.72 ^a (0.55, 0.95)	0.031	0.63 ^a (0.61, 0.86)	0.006							0.72 ^a (0.52, 1.00)	0.045
Internet experience and home access (compared to basic or no experience without home access)	Basic or no experience with home access			3.63 (1.28, 10.28)	0.015			1.77 (0.65, 4.81)	0.009			2.09 (0.76, 5.70)	0.015			3.16 (1.13, 8.85)	0.029
	Experienced or expert, most with home access			3.34 (1.36, 8.17)				3.77 (1.55, 9.21)				3.64 (1.49, 8.94)				3.01 (1.25, 7.32)	
Perception of illness identity		1.14 (1.03, 1.27)	0.015	1.14 ^b (1.01, 1.30)	0.038									1.16 (1.04, 1.28)	0.007	1.15 (1.01, 1.31)	0.039
Depression		1.10 (1.01, 1.21)	0.030											1.10 (1.01, 1.21)	0.030	1.16 ^c (1.40, 1.30)	0.011

Baseline predictors		Intervention use (no use, low use, high use):															
		First 3 months of access				Information component				Behaviour change component				Support component			
		Univariable		Multivariable		Univariable		Multivariable		Univariable		Multivariable		Univariable		Multivariable	
		OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p	OR 95% CI	p
Educational qualifications (compared to school leavers)	A levels or equivalent						1.72 (0.68, 4.35)	0.041									
	Degree or equivalent						0.62 (0.30, 1.28)										

^a Odds ratio calculated for 5 year increase; ^b Only significant predictor in multivariable analysis without depression entered as a predictor; ^c Only significant predictor in multivariable analysis without perception of illness identity entered as a predictor;

 Non-significant predictor in analysis

Univariable and multivariable analyses predicting early intervention use, use of information, behaviour change and support components found a similar pattern of univariable and multivariable predictors (Table 7.7).

Due to the potential for inflating Type 1 error through the multiple tests performed, findings were interpreted with caution. Conclusions over the predictive value of a variable were based on the consistency of levels of significance over all of the analyses and in combination with qualitative analysis findings. After seeking advice from statisticians in the multidisciplinary steering group, this approach was preferred over more arbitrary reductions in the threshold for significance (e.g. $p < 0.01$ or Bonferroni correction (330), p50) for this exploratory analysis. The concern was that a more arbitrary approach might have been overly conservative, and hence increased the potential for making Type 2 errors.

The most consistent predictors in multivariable analyses of level of intervention use were age, internet experience and home internet access. Participants who were older, had home access to the internet and experience of using the internet were more likely to make some or high early and overall intervention use and use of information, behaviour change and support components. Time since most recent cardiac event or diagnosis was also a significant predictor in all analyses predicting level of intervention use apart from use of behaviour change components. Participants who had more recently experienced a cardiac event or diagnosis were more likely to make some or high early and overall intervention use and use of information and support components.

Perception of illness identity and depression were both significant univariable predictors of levels of early and overall intervention use and use of support components.

Participants with a greater perception of illness identity (i.e. participants who perceived they experienced more symptoms from CHD) or a higher depression score were more

likely to make some or high use of the intervention. However in multivariable analyses their effects tended not to be significant unless one or the other was excluded. This means that some of the variance in level of intervention use that each explained when they were the only predictor analysed was accounted for by the other predictors in multivariable analyses, weakening their individual effects. This was anticipated due to the relatively high correlation between the two predictors and was the reason why the repeated multivariable analyses were planned. Of the two, odds ratios were higher and more consistently significant in multivariable analyses for the effect of perception of illness identity on level of intervention use.

Educational qualification significantly predicted level of intervention use in one analysis. In this multivariable analysis predicting level of use of the information component, the confidence intervals for both of the odds ratios comparing the effect of having either A levels or degree level education with school leavers crossed 1. Also the odds ratios suggest the two levels of educational qualification had opposite effects on level of use of the information component, with increased likelihood of information component use among those with A level qualifications but decreased likelihood among those with degree level qualifications. As educational qualification was not a significant predictor of level of intervention use in any other univariate or multivariate analyses and its effect on level of use of the information component was not consistent as educational qualifications increased this single significant finding seemed likely to be an artefact, found significant by chance due to multiple tests.

The test of parallel lines was significant for two ordinal regression analyses:

- multivariable analysis predicting levels of use of the intervention behaviour change component ($\chi^2(10)=30.27, p=0.001$)

- univariable analysis predicting levels of use of the intervention support component from educational qualifications ($\chi^2 (2)=15.50, p<0.001$)

This suggests that the parallel model used in these analyses, which assumes that predictors exert the same effect across all three levels of intervention use (i.e. slope coefficients are the same), may not be accurate. In these analyses the odds ratios, confidence intervals and levels of significance are more likely to reflect an average of the effect of predictors across the three levels of use of behaviour change support services rather than accurately indicate the effect of a predictor on any one of the levels of use. For all other analyses the test of parallel lines was not significant.

7.4.2 Post hoc analysis of intervention use among participants who experienced a cardiac event during study participation

Time since most recent cardiac event or diagnosis at baseline was found to be a significant predictor in most analyses predicting levels of intervention use. As a result post hoc analysis was conducted to investigate intervention use among participants who reported experiencing a cardiac event (heart attack, invasive procedures such as angiogram or surgery, or unscheduled visits to hospital as a result of worsening symptoms) while they had access to the intervention.

A total of 26 participants (15.5%) reported experiencing a cardiac event during study participation: 6 between baseline and 3-month follow-up, 16 between 3- and 9-month follow-up and 4 experienced a cardiac event in both time periods. Due to the small numbers, these participants were grouped together and their use of the intervention was compared with participants who did not experience a cardiac event during the study (n=139). Data for cardiac events experienced during study participation was missing for 3 participants.

Figure 7.11 shows apparently higher intervention use (mean page requests per month) among those who experienced a cardiac event during study participation. However, between-group t-tests found their use of the intervention was not significantly different to participants who had not experienced a cardiac event during study participation (Table 7.8).

Figure 7.11 Intervention use by participants who did or did not experience a cardiac event during their 9-months of intervention access.

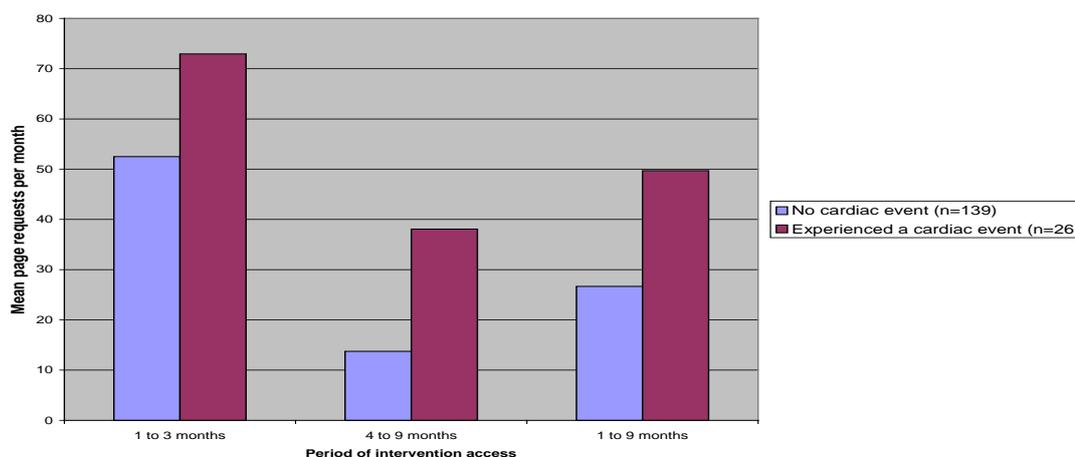


Table 7.8 Results of post-hoc statistical analysis of difference in intervention use by participants who did or did not experience a cardiac event during their 9-months of intervention access.

Intervention use (page requests)	Cardiac event during intervention access		Between-group t-test	
	Mean use (sd)		t value (df=163)	p value (2-tailed)
	No (n=139)	Yes (n=26)		
Months 1-3	52.49 (78.71)	72.95 (82.05)	-1.208	0.229
Months 4-9	13.75 (35.75)	38.06 (138.42)	-0.890 ^a	0.382 ^a
Overall (months 1-9)	26.66 (44.92)	49.69 (93.29)	-1.232 ^a	0.228 ^a

^aLevene's test for equality of variances significant p<0.05, results do not assume equal variances

7.4.3 Interview discussion of intervention use

Interviews were conducted with individuals at the end of their 9 months of intervention access. Discussions of intervention use often occurred naturally in interviews in response to initial general questions about what participants thought of the intervention and what they expected to get from it when they started. Discussion of intervention use

was also initiated by more focused questions about whether they had used the intervention as much as they expected to, when they were most likely to use it and when they had found it useful or unhelpful. Some participants were selected for interview based on their relatively high use of particular intervention components. If these participants did not discuss these components in response to questions about intervention use, their use of these components was mentioned and followed up with further questions (Appendix P).

The earliest interviews were conducted in November 2007 and the iterative process of interviewing and analysis continued until August 2008, when the final participants reached their 9-month follow-up. This meant that qualitative analysis of discussions of intervention use was largely carried out before quantitative analysis of intervention use. However, as the main aim of the qualitative component was to validate and aid interpretation of quantitative data, further qualitative analysis was conducted to address issues raised by quantitative findings.

Interview sub-sample and sampling validity check

The baseline characteristics of the 19 participants who were interviewed are shown in Table 7.2 alongside the characteristics of the study sample from which the interview sub-sample was drawn. Interviews were conducted with men and women with a range of ages, ethnicity, educational qualifications, CHD diagnosis and experience, concurrent conditions, level of internet access and experience. Free text comments made by participants in the wider study sample at 9-month follow-up were consistent with themes identified by the qualitative analysis and raised no additional themes relevant to use made of the intervention.

Results of qualitative analysis: Themes relating to use of the intervention

The following sections summarise the content of interview discussions relating to intervention use. They include themes relating to intervention use raised generally by participants and themes that relate to predictors of use identified by quantitative analysis. Each section is supported by illustrative quotes from interview transcripts. These quotes have been edited for the purpose of brief and clear presentation, although the original qualitative analysis was conducted on un-edited interview transcripts. Where quotes also contain questions or responses from the researcher who conducted the interviews, these are identified as 'R'. To aid interpretation, each quote is presented with the ID number, age, sex and level of internet experience of the participant who made it.

Overall need for CHD information, advice and support

There was a strong connection between participants' perceived need for help with their CHD and their intervention use. Many participants felt they were not currently in need of help. They had few questions or concerns about their CHD because they were not currently experiencing problems and generally felt well and able to carry on with their normal lives.

P0110: "I'm glad that you are doing this because it possibly could have helped me but I suppose I'm fortunate that I haven't got a problem and therefore I didn't need any."

(79 year old male, basic internet experience)

Participants' levels of need were also connected to views about their CHD, the length of time since they had been diagnosed with CHD or experienced a cardiac event and the adequacy of their existing sources of information and support.

Views about their CHD

Many felt their CHD was not as severe as others. This view was often based on whether or not they had experienced a heart attack.

P0110: “Well very fortunately none of the problems that other people have with heart problems. I haven’t, I didn’t have a heart attack, I had a bypass.”

(79 year old male, basic internet experience)

Others judged the severity of their condition by whether they were currently experiencing any symptoms from their CHD.

P0802: “... symptoms wise I do not have any heart problem... I had [a] heart attack... and so there’s obviously, its effect is there within me in some way, but it does not affect my daily life and I do not have any pain”

(79 year old male, experienced internet user)

In addition, symptoms that were experienced were often not considered problematic because they resolved after a short time or were attributed to other causes (e.g. other health condition, the weather, age).

Length of time since CHD diagnosis or cardiac event

Many felt they already knew a lot about their CHD and this reduced their current need for help.

P0110: “I felt that I’d gone well past that stage because I’ve had my heart problem for 17 years. And as I said before, before CHESS came

along I was already reasonably informed about most of the problems that would help me in my problem, how to deal with it.

(79 year old male, basic internet experience)

Some participants felt that they would have made more use of the intervention soon after they were first diagnosed with CHD. However, a more recently diagnosed participant felt it had taken time to accept having CHD and only felt ready to start using the intervention at the end of the study.

P0308: "... you're going through all these other things as well, you know, sort of understanding your pains and... I'm still puzzled by the whole thing ... I think I've more accepted that I've got this illness. Now I'm getting used to it... the whole things finished"

(53 year old male, no previous internet experience)

However, more recent CHD complications did increase need and intervention use.

P0112: "... it's been very useful to tell me what was going on after my situation changed about 2003"

(64 year old male, experienced internet user)

Adequacy of existing sources of information and support

Views on this differed greatly between participants, commonly focusing on level of access to health professionals with sufficient time and expertise. Several felt they had good access to trusted health professionals and no need to seek additional information.

P0608: "I'm not shy in coming forward... I ask him you know ... always go to the specialist and that's it. If I don't get the right answer I go and ask another one..."

(66 year old male, experienced internet user)

Others had no wish to question the advice they received from health professionals.

P0110: "... why sort of double check something that somebody tells you... whom you trust... if your website or your answers would have been the same as ours well that confirms it, but I didn't feel I was in need of confirmation."

(79 year old male, basic internet experience)

However, some felt that their health professionals had insufficient time to address their queries and concerns. For them the intervention played an important role in meeting this shortfall.

P0101: "... the cardiologist and GP, I only get very limited information from them. Mainly from the cardiologist but the amount of information he can give me in the time that he can devote to me is very limited and just... highlights points... which often I want to know more about"

(82 year old male, experienced internet user)

Competing priorities

Intervention use was greatly affected by events in other areas of participants' lives. For those who felt little need of heart disease information and support, other areas of life

took priority. Participants who were busy with other priorities had little time to use the intervention.

P0110: “My wife and I fortunately lead a very busy life and we travel quite a lot still and so there’s rarely a time when I sort of sit at my desk and say now what can I do ...when I prioritise things I have to do, there isn’t a great deal of time left...”

(79 year old male, basic internet experience)

For others, concurrent health problems were currently more of a concern than their heart disease so these took priority. This was particularly true if participants experienced frequent symptoms from concurrent conditions or these conditions required daily management.

Computer skills and internet access

Home internet access

The convenience of using the intervention at home was highly valued.

P0121: “Well yes I could go up and have a look at it, you see, it was great, great just to press a couple of buttons and you’re there... I could go upstairs any time and look to see if I could find the answer up there.”

(79 year old female, experienced internet user)

With a couple of notable exceptions, those without home internet access saw it as a barrier to intervention use.

P0320: “... just the effort of getting out, going to the library and doing it, I know I would have done better with one [at home] because often I

felt like doing that sort of in the evening... I didn't like the forward planning, I'd have liked of just sort of get out the old computer, put it down and do it when I felt like it"

(81 year old female, no previous internet experience)

Participants who did make high use of the intervention at local public internet services had unlimited, free access to the internet there, and in one case, extensive technical support from staff (P0905, 76 year old female, basic internet experience). These participants perceived additional benefits to using the intervention at local public internet services such as taking exercise to get there (P0317, 63 year old male, no previous internet experience) or getting away from a busy home environment (P0905, 76 year old female, basic internet experience).

Confidence using computers

Lack of confidence with using computers hampered use of the intervention for many participants with little or no internet experience. Consistent with this, one participant with no prior internet but extensive computer experience had no difficulties in using the intervention (P0705, 58 year old female).

Participants with little internet experience were also likely to forget how to use the intervention, particularly if other priorities included travel away from home.

P0129: "I have used it so little that I have forgotten what to do... the thing is I've been away quite a lot... that is why I think... and each time I come back I kind of got, well I didn't think of it too much."

(61 year old female, basic internet experience)

Moreover, those lacking confidence using computers felt uncomfortable asking for help.

P0308: “You did volunteer to help me and I was embarrassed”

(53 year old male, no previous internet experience)

Attitudes towards computers and the internet

Some participants’ lack of previous internet experience appeared to be due to preference. They did not enjoy using computers so an internet intervention was not particularly appealing.

P0906: “I had to feel like going on the computer to start with, which I don’t always”

(72 year old male, no previous internet experience)

There was also the view that sitting at a computer was not a good use of time and so some participants kept intervention use to a minimum.

P0601: “How people can sit at computer hours on end I don’t know, I just go into it for what I need and then I switch off”

(69 year old male, basic internet experience)

Perceptions of the intervention

Views of the intervention varied greatly between participants. In general participants who held positive views of the intervention used it, although some participants with low need for information and support, or low confidence in using computers made little use of the intervention despite viewing it positively. Perceptions of the intervention were generally formed through comparison with other sources of information, advice and support; judgements of intervention components; and participants’ personality traits and personal philosophies.

Comparison with other sources of information, advice and support

In general the intervention was compared favourably to other websites because it provided quicker access to relevant information.

P0101: "It was a quick source for the information whereas previously I had to go over other websites or publications to get the information. This helped to centralise that I can go to the CHESS site, it would lead me to other links."

(82 year old male, experienced internet user)

The intervention was also compared favourably to newspapers because it provided more information that was easier to understand.

P0121: "...it was giving me information that I wouldn't have had otherwise... you wouldn't read those sort of things in the paper... probably the information wouldn't be there... you get maybe a page of it in the paper, but just little bits..."

(79 year old female, experienced internet user)

However, newspapers and books were preferred by participants who only wanted brief information or who had little confidence with using computers.

P0320: "I suppose I just didn't get the facility in using a computer that I would have liked, the way I could using books... which I'm very familiar with of course."

R: So by comparison it was

P0320: It was hard work..."

(81 year old female, no previous internet experience)

Some participants compared the intervention favourably to contacts with health professionals because it was easier to access and without time pressures.

P0121: "... it's very difficult because if I want to ask my doctor a question... I have to go through the receptionist ...and I might not speak to my own doctor, so the doctor I speak to doesn't really know me, and I think that's very off-putting. Whereas if I can go get what I want from upstairs with no problem at all... just switching the computer on, then that's great... I'd much rather do that"

(79 year old female, no previous internet experience)

However, participants were most critical of the intervention when they compared it to seeking or receiving information and support by face-to-face discussion. By comparison, the intervention was seen as more difficult, less personal and less effective as a means of communication.

P0906: "I would rather go out and meet somebody and talk to them like this because I think... you can't convey a lot of that over a forum"

(72 year old male, no previous internet experience)

Judgements of intervention components

Appeal and experience of different intervention components varied. Views of the information component (in particular the monthly updates) and the 'ask an expert' support services were generally positive and encouraged ongoing use.

P0137: "I was keen to get information yes, I was very happy to sign on the site and get all the information I wanted... I liked best was the news really, the updating... and also referring to other websites"

(63 year old male, no previous internet experience)

P1010: "Well I like that you can get in touch with an expert and, and when you get the answers you realise it is an expert because it's so detailed and it's really good and you know, you can ask them anything and the answer's fairly quick in coming back"

(63 year old male, experienced internet user)

By comparison the 'discussion group' support component was less appealing. Some participants expected it to be difficult to use, particularly if they had low confidence in using computers or written English.

P0217: "It's the written word that I don't like I suppose... maybe I'm afraid I'll make blunders with my grammar or something like that"

(80 year old male, no previous internet experience)

P0111: "... although I try to be very fluent in English I am not that fluent really, I am not an English person really and when you talk with an English person you find that you are at a drawback all the time..."

(70 year old male, experienced internet user)

Others judged it not to be relevant to them, either because they viewed their CHD as relatively less severe or because they felt they had little in common with other patients

featured in the 'personal stories' support service. This was particularly true for participants who had not had a heart attack.

The resulting low activity in the 'discussion group' meant it was disappointing to those to whom it did appeal.

P1010: "I thought that would be one of the, the big things of it... I thought that would be one where everybody, 'oh yeah well I've tried doing this, how about you try doing this', and nothing"

(63 year old male, experienced internet user)

Personality traits and personal philosophies

Participants recognised general preferences for information, advice and support that influenced their view and use of the intervention. It appealed particularly to people who saw themselves as information seekers or who enjoyed learning.

P0101: "... I'm always open to getting or finding out things that would help me in my problems in a positive way as to why it was happening, what was being done to help counteract it, improve it"

(82 year old male, experienced internet user)

It also appealed to those who felt the need to seek confirmation from more than one source or check alternatives.

P0112: "I'm the sort of person, if anyone tells me something I automatically tend to double check it, I'm built that way and can't do much about it"

(64 year old male, experienced internet user)

Patterns of intervention use among those who used it

These differed between participants but two patterns emerged: use when needed and repeated or regular use.

Use when needed

P0112: “When is when I feel I needed help. I didn’t sort of surf it, as it were...”

(64 year old male, experienced internet user)

Need and use occurred most often in relation to participants’ healthcare treatment, either to supplement information from health professionals, to make sense of letters from health professionals, to increase understanding of an issue before discussing it with a health professional, to check interpretation of test results, or to understand medication changes and any implications.

P0316: “I was curious about one of the drugs I was taking because ... the practice had changed it into a cheaper drug and maybe coincidental but things seemed to change... I had tests... prior to... the change and then twice afterwards to see if there was a change and I felt there was, they say there was but it didn’t matter. So I just got another look at it.”

(78 year old male, experienced internet user)

Some participants were aware of decline in their use over time and linked this to:

- Having a greater number of questions or concerns at the start. Once they had received answers or read relevant information they had no further need to use the intervention.
- Increased importance of other priorities.

- Greater amounts of advice and support from health professionals.

P0111: "I think I got a bit busy with other things as well, so lately I didn't do as much using. In the beginning I used it quite a lot then I tapered off... I was inquisitive in the beginning... but now that I am getting all this help I am less inquisitive"

(70 year old male, experienced internet user)

Repeated or regular use

Some participants were clearly aware of the intervention throughout the time they had access to it.

These participants used it frequently, in one or more of the following ways:

- In response to anything CHD-related that they read, heard or thought of, or just to see what was new.

P0101: "Usually every couple of weeks it would suddenly come into my mind I'll have a look at the CHESS, there'd be some problem that would be on my mind"

(82 year old male, experienced internet user)

- Triggered by the intervention itself, monthly when the information component was updated or in response to regular automatic messages at login to update information in the 'health tracking' behaviour change service.

P0121: "... I went up 'specially after about a week at the beginning of each month because that's when all the new stuff was coming through."

(79 year old female, experienced internet user)

P0601: "... I forget how often it comes up but it's about once every two or three weeks, it suddenly tells me that it's time to fill out the questions again... then I would do it straight away"

(69 year old male, basic internet experience)

- To ask questions they felt their health professional might see as less relevant or not have time for.

P1010: "... you could be waiting for an appointment and you don't really want to go in to the doctor, say, listen how much saturated fat should I be having... whereas if you can just get on and see and say well am I doing this right, am I doing that right... it's a quick reference to get an answer"

(63 year old male, experienced internet user)

- Because they enjoyed it.

P0905: "I made it as a routine thing... because I was learning things and I'll be honest, I do love reading... I enjoyed it."

(76 year old female, basic internet experience)

- Because they felt they should due to research participation.

P0121: “Yes because I felt I should look anyway. I mean what’s the good taking part in research if you don’t look at what’s going on...”

(79 year old female, experienced internet user)

P0601: “I was very aware that I was under this programme and that I ought to click on that particular website quite frequently...”

(69 year old male, basic internet experience)

Continued or future use

Many participants expressed a desire for continued access to the intervention for future use. For some this was to continue making similar use of it.

P0101: “I’d be happy to have the facility to go onto the CHESS site at any future date to get information”

(82 year old male, experienced internet user)

For others, including those who had made no use of the intervention, this was because they felt they had not used it as much as they would have liked.

P0137: “I haven’t got around to it as much as I would like to, but I would definitely carry on... there’s still a lot of things I’ve got to go through”

(63 year old male, no previous internet experience)

P0308: "It's a shame it's not... sort of like a permanent experience... that's the only thing I regret, it's finishing while I'm getting ready to start"

(53 year old male, no previous internet experience)

A few participants wanted the intervention to continue to be available for the benefit of other patients with CHD.

P0111: "It's a very useful website and I would like you to carry on with it, for future people... my son or somebody else's son... it could be useful to them."

(70 year old male, experienced internet user)

7.4.4 Summary of factors influencing intervention use

Together the quantitative and qualitative analyses suggest that participants were more likely to make some or high use of the intervention if they had recently experienced a cardiac event or diagnosis, had home internet access and experience of using the internet. Participants were less likely to make some or high use of the intervention if their original CHD diagnosis or event was a long time ago with no recent cardiac event or diagnosis, if they were not confident in using computers and if they currently experienced no symptoms from CHD, particularly if they had not had a heart attack. These factors appeared to influence both overall use of the intervention and use of the different intervention components (information, behaviour change and support).

The length of time since most recent cardiac event or diagnosis and lack of current CHD symptoms appeared to influence intervention use because of their effect on participants' need for the information, support or advice. Patients who were diagnosed a number of

years ago, who experienced no symptoms that they attributed to CHD and had no recent cardiac event or heart-related complications expressed little need for the intervention. Most felt their existing knowledge, self-management or lifestyle behaviours and sources of information and support were sufficient and/or that their CHD was not currently much of a problem. Participants without any symptoms they attributed to CHD and who viewed their CHD as relatively less severe (e.g. they had not had a heart attack), not only perceived lower need for information and support, but judged intervention content as more relevant to others than themselves.

Home internet access appeared a clear facilitator of use of the intervention. Qualitative data from a few participants who made high use of the intervention at public internet services, revealed that these participants could access the internet as much as they wanted at convenient community centres and felt that accessing the intervention away from home had additional benefits. By contrast, most of the qualitative data from those without home internet access suggested that they perceived drawbacks to having to use the intervention elsewhere and that this was a barrier to use.

As well as validating and aiding interpretation of quantitative results, the qualitative analysis identified additional factors influencing use. The relationship between participants' experience of healthcare and intervention use emerged purely from the qualitative analysis as it was not covered by quantitative measures. This experience was related to intervention use in two ways. Firstly, participants' general satisfaction with their level of access to healthcare professionals affected their overall need for and use of the intervention. Those who felt they had good access to trusted health professionals had few unmet needs. By contrast those who were not satisfied with their access to health professionals valued the intervention highly and made greater use of it. Secondly, healthcare contacts and experiences that occurred while participants had access to the

intervention were triggers for specific intervention use due to questions or concerns they raised. There was evidence that participants used the intervention to supplement and interpret information from their health professionals, and to prepare for discussion with their health professionals. The qualitative analysis also highlighted the effect of individual participants' personality traits and personal philosophies on participants' motivation to use the intervention, as well as the effect of research participation itself.

Finally, the qualitative analysis identified intervention components that held more or less appeal than others and those that encouraged ongoing use. Services that held most appeal were the 'ask an expert' service, regular information and news updates and the 'health tracking' service. In contrast, many participants found the 'discussion group' service was unappealing.

Chapter 8 : Results – Effects of the internet intervention for patients with CHD

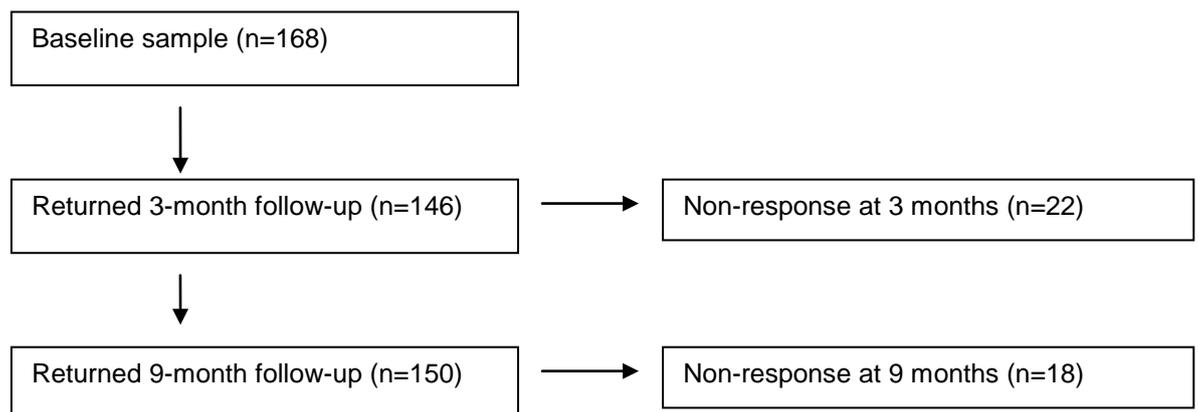
8.1 Introduction

This second results chapter presents study results relating to the effects and mechanisms of action of the intervention. As these could only be evaluated in participants who provided follow-up data, the chapter starts by reporting follow-up rates and results of analysis testing for differences between participants who did and did not respond at follow-up. Then results of quantitative analyses of overall change in outcomes and change from intervention use are presented, followed by results of qualitative analysis of interview discussions of intervention effects.

8.2 Sample retention

The rate of follow-up in the study was high: 87% and 89% of participants returned follow-up questionnaires after 3 and 9 months respectively. Figure 8.1 shows the retention of the sample throughout the study.

Figure 8.1 Sample retention.



In all, 83% responded at all 3 time-points. These responders (n=140) did not significantly differ from non-responders (n=28, participants who did not return 3 and/or 9 month follow-up questionnaires) on any demographic or baseline clinical characteristics.

8.3 Overall change in psychological constructs and health outcomes

Table 8.1 and Table 8.2 summarise levels of change in psychological constructs and health outcomes for continuous variables, firstly in the sample as a whole and secondly, among participants who used the intervention at least once. Table 8.3 and Table 8.4 show levels of change in the illness perception of cause (a categorical variable), in the sample as a whole and among participants who used the intervention at least once.

Table 8.1 Change in psychological constructs and health outcomes in the full sample (continuous variables).

Psychological constructs and health outcomes		Mean/median scores (sd)			Change at 3 months				Change at 9 months			
		Baseline	3 months	9 months	Mean change (sd)	t/z score (df/n) ^a	Sig. p	Effect size r	Mean change (sd)	t/z score (df/n) ^a	Sig. p	Effect size r
Illness perceptions	Consequences	3.3 (2.9)	3.3 (2.8)	3.1 (2.6)	0.01 (2.5)	t=0.03 (n=140)	0.97	<0.01	-0.13 (2.6)	t=-0.60 (n=147)	0.55	0.05
	Timeline	10.0	10.0	10.0		z=-2.16 (df=128)	0.03 ^b	0.14		z=-1.70 (df=137)	0.09	0.10
	Personal control	6.1 (3.0)	6.2 (2.7)	6.4 (2.6)	0.12 (2.6)	t=0.53 (n=136)	0.60	0.05	0.27 (3.0)	t=1.08 (n=143)	0.28	0.09
	Treatment control	8.1 (2.6)	7.8 (2.3)	7.7 (2.6)	-0.25 (2.5)	t=-1.17 (n=136)	0.24	0.01	-0.30 (2.5)	t=-1.48 (n=146)	0.14	0.12
	Identity	2.8 (2.7)	2.9 (2.7)	2.9 (2.6)	0.07 (2.0)	t=0.43 (n=136)	0.67	0.04	0.12 (2.1)	t=0.66 (n=147)	0.51	0.05
	Concern	5.1 (3.3)	5.2 (3.2)	4.6 (3.2)	0.15 (2.9)	t=0.61 (n=136)	0.54	0.05	-0.36 (3.0)	t=-1.46 (n=148)	0.45	0.12
	Coherence	6.7 (3.0)	7.5 (2.5)	7.7 (2.3)	0.71 (2.9)	t=2.86 (n=138)	<0.01 ^c	0.24	0.97 (2.9)	t=4.12 (n=148)	<0.01 ^c	0.32
Self-efficacy	Emotional effects	3.1 (3.0)	2.9 (2.9)	2.8 (2.8)	-0.21 (2.1)	t=-1.20 (n=139)	0.23	0.10	-0.35 (2.3)	t=-1.84 (n=146)	0.07	0.15
	Control symptoms	3.0	2.9	3.0		z=-2.16 (df=142)	0.01 ^b	0.13		z=-0.35 (df=146)	0.73	0.02
	Maintain function	3.0	2.8	3.0		z=-3.27 (df=142)	<0.01 ^c	0.19		z=-1.05 (df=145)	0.29	0.06
	Diet	3.7 (0.8)	3.6 (0.9)	3.6 (0.9)	-0.07 (0.5)	t=-1.61 (n=123)	0.11	0.14	-0.06 (0.6)	t=-1.24 (n=123)	0.22	0.11
Social support	Exercise	3.3 (1.0)	3.2 (1.1)	3.3 (1.0)	-0.04 (0.7)	t=-0.62 (n=115)	0.54	0.06	-0.03 (0.7)	t=-0.49 (n=118)	0.63	0.05
	Emotional and information	3.6 (1.1)	3.5 (1.2)	3.5 (1.1)	-0.11 (0.8)	t=-1.79 (n=140)	0.08	0.15	-0.11 (0.9)	t=-1.48 (n=145)	0.14	0.12
Intentions	Medicine adherence	5.0	5.0	5.0		z=-0.58 (df=134)	0.56	0.04		z= -1.14 (df=148)	0.89	0.07
	Diet	5.0	5.0	4.0		z=-1.67 (df=140)	0.10	0.10		z=-1.16 (df=140)	0.11	0.07
	Exercise	4.0	4.0	4.0		z=-0.99 (df=143)	0.32	0.06		z=-1.12 (df=146)	0.26	0.07
Behaviours	Medicine adherence	24.0	24.0	24.0		z=-0.58 (df=126)	0.56	0.04		z=-2.03 (df=136)	0.04 ^b	0.12
	Healthy diet habits	7.9 (2.0)	7.9 (2.1)	7.9 (2.1)	0.01 (1.4)	t=0.12 (n=141)	0.91	0.01	0.12 (1.7)	t=0.87 (n=144)	0.39	0.07
	Diet from food frequency	19.8 (2.6)	19.9 (2.9)	20.0 (2.7)	0.10 (2.6)	t=0.44 (n=139)	0.66	0.04	0.29 (2.7)	t=1.28 (n=139)	0.20	0.10
	Exercise	1605.0	1386.0	1770.0		z=-1.24 (df=97)	0.22	0.09		z=-0.29 (df=96)	0.77	0.02
Affect	Anxiety	5.8 (4.0)	5.5 (4.1)	5.5 (3.8)	-0.27 (2.7)	t=-1.18 (n=140)	0.24	0.10	-0.19 (2.8)	t=-0.82 (n=146)	0.41	0.07
	Depression	4.4 (3.4)	4.5 (3.5)	4.5 (3.5)	0.07 (2.7)	t=0.30 (n=140)	0.77	0.03	0.19 (2.7)	t=0.84 (n=145)	0.40	0.07
Health-related quality of life		5.7 (0.9)	5.6 (1.0)	5.6 (1.0)	-0.09 (0.5)	t=-2.09 (n=136)	0.04 ^b	0.18	-0.10 (0.6)	t=-2.01 (n=141)	0.05	0.17

^aMedian scores presented and Wilcoxon's signed ranks test used to test change where data were not normally distributed at one or more time-point; ^bp<0.05; ^cp<0.01

Table 8.2 Change in psychological constructs and health outcomes in those who used the intervention at least once (continuous variables).

Psychological constructs		Mean scores (sd)			Change at 3 months				Change at 9 months			
		Baseline	3 months	9 months	Mean change (sd)	t/z score (df/n) ^a	Sig. p	Effect size r	Mean change (sd)	t/z score (df/n) ^a	Sig. p	Effect size r
Illness perceptions	Consequences	3.2 (2.8)	3.4 (2.8)	3.1 (2.6)	0.21 (2.7)	t=0.79 (n=106)	0.43	0.08	-0.19 (2.8)	t=-0.74 (n=115)	0.46	0.07
	Timeline	10.0	10.0	10.0		z=-1.66 (df=97)	0.10	0.12		z=-1.40 (df=106)	0.16	0.10
	Personal control	5.9 (3.0)	6.0 (2.8)	6.5 (2.7)	0.17 (2.5)	t=0.71 (n=103)	0.48	0.07	0.61 (3.1)	t=2.07 (n=111)	0.04 ^b	0.19
	Treatment control	7.8 (2.7)	7.7 (2.3)	7.7 (2.7)	-0.09 (2.6)	t=-0.34 (n=103)	0.74	0.03	-0.17 (2.6)	t=-0.71 (n=115)	0.48	0.07
	Identity	2.9 (2.7)	3.0 (2.7)	3.0 (2.7)	0.16 (2.1)	t=0.78 (n=104)	0.44	0.07	0.07 (2.2)	t=0.34 (n=116)	0.73	0.03
	Concern	5.0 (3.1)	5.4 (3.1)	4.6 (3.2)	0.39 (3.1)	t=1.28 (n=102)	0.20	0.13	-0.34 (2.9)	t=-1.28 (n=116)	0.20	0.12
	Coherence	6.8 (3.0)	7.4 (2.5)	7.7 (2.2)	0.64 (2.5)	t=2.60 (n=104)	<0.01 ^c	0.25	0.84 (2.6)	t=3.44 (n=116)	<0.01 ^c	0.30
	Emotional effects	2.9 (2.8)	2.8 (2.8)	2.7 (2.7)	-0.17 (2.3)	t=-0.76 (n=105)	0.45	0.07	-0.41 (2.4)	t=-1.80 (n=114)	0.08	0.17
Self-efficacy	Control symptoms	2.8	2.8	3.0		z=-1.68 (df=108)	0.09	0.11		z=-0.06 (df=116)	0.95	<0.01
	Maintain function	3.0	2.7	3.0		z=-2.51 (df=108)	0.01 ^b	0.17		z=-0.54 (df=115)	0.59	0.04
	Diet	3.6 (0.8)	3.6 (0.8)	3.6 (0.8)	-0.06 (0.5)	t=-1.15 (n=92)	0.25	0.12	-0.03 (0.6)	t=-0.44 (n=101)	0.66	0.04
	Exercise	3.2 (1.0)	3.2 (1.1)	3.3 (1.0)	-0.04 (0.7)	t=-0.49 (n=87)	0.62	0.05	0.02 (0.8)	t=0.21 (n=92)	0.84	0.02
Social support	Emotional and information	3.5 (1.1)	3.5 (1.2)	3.5 (1.2)	-0.04 (0.7)	t=-0.66 (n=108)	0.51	0.06	-0.05 (0.90)	t=-0.58 (n=114)	0.57	0.05
Intentions	Medicine adherence	5.0	5.0	5.0		z=0.00 (df=101)	1.00	0.00		z=-0.71 (df=117)	0.48	0.05
	Diet	5.0	4.5	4.0		z=-1.58 (df=108)	0.11	0.11		z=-1.82 (df=114)	0.07	0.12
	Exercise	4.0	4.0	4.0		z=-1.32 (df=109)	0.88	0.09		z=-1.26 (df=114)	0.21	0.08
Behaviours	Medicine adherence	24.0	24.0	24.0		z=-0.97 (df=95)	0.33	0.07		z=-0.24 (df=109)	0.03 ^b	0.16
	Healthy diet habits	7.9 (2.1)	7.9 (2.1)	8.0 (2.2)	-0.02 (1.5)	t=-0.11 (n=108)	0.92	0.01	0.11 (1.7)	t=0.69 (n=114)	0.49	0.06
	Diet from food frequency	19.7 (2.7)	19.6 (2.9)	20.0 (2.7)	-0.04 (2.6)	t=-0.18 (n=106)	0.86	0.02	0.36 (2.8)	t=1.37 (n=108)	0.17	0.13
	Exercise	1507.0	1413.0	1386.0		z=-0.76 (df=76)	0.45	0.06		z=-0.38 (df=79)	0.70	0.03
Affect	Anxiety	5.7 (3.8)	5.4 (3.8)	5.2 (3.6)	-0.33 (2.8)	t=-1.24 (n=108)	0.22	0.11	-0.41 (2.6)	t=-1.7 (n=116)	0.09	0.16
	Depression	4.6 (3.8)	4.7 (3.5)	4.5 (3.5)	0.05 (2.9)	t=0.18 (n=108)	0.86	0.02	-0.25 (2.7)	t=-0.10 (n=115)	0.92	0.01
Health-related quality of life		5.7 (0.9)	5.6 (1.0)	5.7 (0.8)	-0.10 (0.5)	t=-1.88 (n=106)	0.06	0.18	-0.07 (0.6)	t=-1.34 (n=111)	0.18	0.13

^aMedian scores presented and Wilcoxon's signed ranks test used to test change where data were not normally distributed at one or more time-point; ^bp<0.05; ^cp<0.01

Table 8.3 Change in illness perception of cause (BIPQ cause) in the full sample (categorical variable).

Illness perception of cause category (cross-tabulated frequencies)					Change			
Baseline	3 months		9 months		At 3 months		At 9 months	
	Lifestyle	Other factors	Lifestyle	Other factors	n	McNemar test sig. p	N	McNemar test sig. p
Lifestyle	70	9	71	7	126	0.52	127	0.13
Other factors	13	34	15	34				

Table 8.4 Change in illness perception of cause (BIPQ cause) in participants who used the intervention at least once (categorical variable).

Illness perception of cause category (cross-tabulated frequencies)					Change			
Baseline	3 months		9 months		At 3 months		At 9 months	
	Lifestyle	Other factors	Lifestyle	Other factors	n	McNemar test sig. p	N	McNemar test sig. p
Lifestyle	57	7	58	6	96	0.80	100	0.17
Other factors	9	23	13	23				

Overall there was little change in psychological constructs and health outcomes either in the sample as a whole or among participants who used the intervention at least once. Perception of illness coherence did significantly increase from baseline at 3 and 9 months. The size of this effect was small at 3 months ($r < 0.30$ (289)) and bordered on a medium sized effect at 9 months. However, the effect was no larger among those who had used the intervention at least once. The only other change that was significant at the $p < 0.01$ level was a small decrease in cardiac self-efficacy to maintain function in the full sample from baseline to 3 month follow-up. Again, this effect was of a similar magnitude when change was tested among the smaller sample of participants who made some use of the intervention. There was no significant change in any other psychological constructs and no significant change in any health outcomes at either follow-up point among those who used the intervention or in the full study sample.

8.4 Change from intervention use

8.4.1 Change from total intervention use

Table 8.5 gives the results of the multivariable linear regression analyses testing intervention use as a predictor of change at 3 months after controlling for baseline participant characteristics. Table 8.6 gives the results of equivalent analyses testing for change from intervention use at 9 months. Table 8.7 and Table 8.8 give results of the logistic regression analyses predicting change in categorical outcomes from intervention use at 3 and 9 months. Methods for these analyses were reported in Chapter 6 (Section 6.9.1). Descriptive statistics from cases included in these analyses are given in Appendix R. Together these results show that intervention use did not significantly predict change in any intermediate or main outcomes at 3 or 9 months.

The relationship between overall intervention use and an improvement in diet score at 9 months neared significance. However, the validity of this scoring of food-frequency items is unclear and the measure showed poor internal consistency in this sample at each data collection time-point (Cronbach's Alpha 0.30 to 0.45). Moreover, when the analysis was restricted to complete cases, rather than including any imputed data for the diet score, the significance of overall intervention use was reduced (unstandardised coefficient for 100 page increase in intervention use = 0.08, 95% CI (0.01, 0.15), $p=0.023$).

Restricting other analyses to complete cases, rather than including any imputed data, made little difference to the results. In all analyses p-values for the intervention use predictor remained greater than 0.01.

Table 8.5 Results of multivariable linear regression analyses of baseline to 3 month change from first 3 months of intervention use.

3-month follow-up scores			Predictors			
			Baseline score and patient characteristics ^a	Intervention use		
				R ²	Unstandardised coefficients (95% CIs) for 100 page increase in intervention use ^b	p
Psychological constructs	Illness perceptions (BIPQ)	Consequences	0.43	0.08 (-0.09, 0.25)	0.36	0.004
		Personal control	0.45	-0.10 (-0.26, 0.06)	0.23	0.007
		Treatment control	0.28	-0.02 (-0.17, 0.13)	0.81	<0.001
		Identity	0.57	0.03 (-0.12, 0.17)	0.72	<0.001
		Concern	0.40	0.06 (-0.14, 0.26)	0.55	0.002
		Illness coherence	0.30	-0.15 (-0.30, 0.01)	0.06	0.019
		Emotions	0.58	-0.05 (-0.20, 0.09)	0.48	0.002
	Self-efficacy	Diet (CDSEI)	0.69	-0.00006 (-0.04, 0.04)	1.00	<0.001
		Exercise (CESEI)	0.65	-0.003 (-0.05, 0.05)	0.91	<0.001
	Perceived social support	Emotional and info subscale (MOS SSS)	0.69	-0.02 (-0.07, 0.04)	0.57	0.001
Health outcomes	Health behaviour	Healthy diet habits	0.59	0.05 (-0.05, 0.15)	0.33	0.003
		Diet score	0.37	0.03 (-0.15, 0.21)	0.72	0.001
	Emotional status (HADS)	Anxiety	0.64	-0.06 (-0.24, 0.13)	0.54	0.001
		Depression	0.55	0.11 (-0.08, 0.30)	0.25	0.005
	Health-related QoL	MacNew Heart Disease	0.76	-0.01 (-0.05, 0.03)	0.48	0.001

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

^b100 pages represents a significant increase in intervention use among this sample, median page requests among participants who made any use of the intervention was 148 pages.

Table 8.6 Results of multivariable linear regression analyses of baseline to 9 month change from overall intervention use.

9-month follow-up scores			Predictors			
			Baseline score and patient characteristics ^a	Intervention use		
				R ²	Unstandardised coefficients (95% CIs) for 100 page increase in intervention use ^b	p
Psychological constructs	Illness perceptions (BIPQ)	Consequences	0.39	0.01 (-0.06,0.08)	0.73	0.001
		Personal control	0.23	0.01 (-0.07,0.09)	0.78	<0.001
		Treatment control	0.31	-0.02 (-0.09,0.06)	0.66	0.001
		Identity	0.57	0.04 (-0.02,0.10)	0.21	0.005
		Concern	0.41	-0.05 (-0.13,0.04)	0.25	0.006
		Illness coherence	0.19	-0.05 (-0.12,0.02)	0.12	0.014
		Emotions	0.72	-0.05 (-0.12,0.01)	0.12	0.009
	Self-efficacy	Diet (CDSEI)	0.61	0.01 (-0.02,0.02)	0.89	<0.001
		Exercise (CESEI)	0.55	0.003 (-0.03,0.02)	0.82	<0.001
	Perceived social support (MOS SSS)	Emotional and info subscale	0.50	0.02 (-0.01,0.05)	0.25	0.005
Health outcomes	Health behaviour	Healthy diet habits	0.49	-0.01 (-0.06,0.04)	0.71	0.001
		Diet score	0.58	0.10 (0.02,0.18)	0.01	0.032
	Emotional status (HADS)	Anxiety	0.61	0.04 (-0.04,0.12)	0.34	0.003
		Depression	0.48	0.02 (-0.07,0.11)	0.60	0.001
	Health-related QoL	MacNew Heart Disease	0.65	0.004 (-0.02,0.02)	0.70	<0.001

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

^b100 pages represents a significant increase in intervention use among this sample, median page requests among participants who made any use of the intervention was 148 pages.

Table 8.7 Results of logistic regression analyses of baseline to 3 month change from first 3 months of intervention use.

3-month follow-up categories		Predictors					
		Baseline score and patient characteristics ^a		Intervention use			
		Cox & Snell R ²	Nagelkerke R ²	Odds ratio (95% CIs) for 100 page increase in intervention use ^b	p	Cox & Snell R ² change	Nagelkerke R ² change
Illness perception (BIPQ)	Cause	0.40	0.56	1.04 (0.82,1.31)	0.76	<0.001	<0.001
Self-efficacy (Cardiac self-efficacy)	Control symptoms	0.28	0.37	1.02 (0.85,1.22)	0.85	<0.001	<0.001
	Maintain functioning	0.32	0.42	1.01 (0.83,1.23)	0.93	<0.001	<0.001

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

^b100 pages represents a significant increase in intervention use among this sample, median page requests among participants who made any use of the intervention was 148 pages.

Table 8.8 Results of logistic regression analyses of baseline to 9 month change from overall intervention use.

9-month follow-up categories		Predictors					
		Baseline score and patient characteristics ^a		Intervention use			
		Cox & Snell R ²	Nagelkerke R ²	Odds ratio (95% CIs) for 100 page increase in intervention use ^b	p	Cox & Snell R ² change	Nagelkerke R ² change
Illness perception (BIPQ)	Cause	0.36	0.51	0.97 (0.87,1.15)	0.55	0.002	0.003
Self-efficacy (Cardiac self-efficacy)	Control symptoms	0.20	0.26	0.99 (0.92,1.07)	0.86	<0.001	<0.001
	Maintain functioning	0.24	0.32	1.05 (0.97,1.13)	0.25	0.006	0.008

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

^b100 pages represents a significant increase in intervention use among this sample, median page requests among participants who made any use of the intervention was 148 pages.

8.4.2 Change from use of intervention components

Results from multivariable linear regression analyses testing use of specific components

of the intervention as predictors of change at 3 months and 9 months after controlling

for baseline participant characteristics are summarised in Table 8.9 and Table 8.10.

Table 8.11 and Table 8.12 summarise results of the logistic regression analyses

predicting change in categorical outcomes from use of specific intervention components at 3 and 9 months.

Overall use of the information component was found to significantly predict a reduction in the extent to which participants reported their illness to affect them emotionally (IPQ emotions) at 9 months. However, use of the information component did not significantly predict any wider emotional change (HADS anxiety or depression), nor change in any other psychological constructs or health outcomes at the same time point.

Use of a specific intervention component approached significance as a predictor of change in one other psychological construct at 9 months (overall use of the behaviour change component and increased perceived emotional and informational social support) but none at 3 months. There were also near-significant relationships between behaviour change component use and improved healthy diet habits at 3 months, and between information component use and improved diet score at 9 months. However, the large number of statistical tests conducted for these analyses raise concern over Type 1 errors and it seems likely that these predictors may only have approached significance by chance rather than represent true effects.

When analyses were restricted to complete cases, rather than including any imputed data, p-values for all intervention component use predictors remained greater than 0.01.

Table 8.9 Results of multivariable linear regression analyses of baseline to 3 month change from first 3 months' use of components of the intervention.

3-month follow-up scores			Predictors									
			Baseline score and patient characteristics ^a	Information component use months 1-3			Behaviour change component use months 1-3			Support component use months 1-3		
			R ²	Unstandardised coefficients (95% CIs) for 100 page increase in information component use ^b	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in behaviour change component use ^c	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in support component use ^d	p	R ² change
Psychological constructs	Illness perceptions (BIPQ)	Consequences	0.43	0.24 (-0.39, 0.88)	0.45	0.003	-0.06 (-0.84, 0.72)	0.89	<0.001	0.42 (-0.28, 1.12)	0.24	0.006
		Personal control	0.43	-0.43 (-1.03, 0.17)	0.16	0.009	0.32 (-0.44, 1.07)	0.41	0.003	-0.56 (-0.14, 0.12)	0.11	0.012
		Treatment control	0.28	-0.31 (-0.87, 0.26)	0.29	0.007	0.27 (-0.45, 0.98)	0.46	0.003	-0.30 (-0.94, 0.35)	0.36	0.005
		Identity	0.57	0.21 (-0.34, 0.76)	0.46	0.002	-0.15 (-0.81, 0.50)	0.64	0.001	0.30 (-0.29, 0.89)	0.32	0.003
		Concern	0.40	0.38 (-0.35, 1.10)	0.30	0.005	0.59 (-0.33, 1.51)	0.21	0.008	0.19 (-0.62, 1.01)	0.64	0.001
		Illness coherence	0.29	-0.45 (-1.08, 0.09)	0.09	0.015	-0.38 (-1.12, 0.36)	0.31	0.006	-0.50 (-1.15, 0.16)	0.14	0.012
		Emotions	0.58	-0.30 (-0.84, 0.24)	0.28	0.004	-0.29 (-0.97, 0.39)	0.40	0.002	0.04 (-0.57, 0.64)	0.90	<0.001
	Self-efficacy	Diet (CDSEI)	0.69	-0.005 (-0.15, 0.14)	0.95	<0.001	0.09 (-0.10, 0.28)	0.33	0.003	-0.002 (-0.17, 0.16)	0.98	<0.001
		Exercise (CESEI)	0.65	-0.04 (-0.24, 0.16)	0.70	0.005	0.15 (-0.10, 0.39)	0.23	0.005	-0.10 (-0.31, 0.12)	0.38	0.003

3-month follow-up scores			Predictors									
			Baseline score and patient characteristics ^a	Information component use months 1-3			Behaviour change component use months 1-3			Support component use months 1-3		
			R ²	Unstandardised coefficients (95% CIs) for 100 page increase in information component use ^b	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in behaviour change component use ^c	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in support component use ^d	p	R ² change
Perceived social support	Emotional and info subscale (MOS SSS)	0.69	-0.03 (-0.23, 0.16)	0.73	<0.001	0.07 (-0.17, 0.31)	0.56	0.001	-0.14 (-0.35, 0.07)	0.20	0.004	
Health outcomes	Health behaviour	Healthy diet habits	0.04 (-0.34, 0.43)	0.82	<0.001	0.47 (0.00, 0.94)	0.05	0.012	0.12 (-0.31, 0.55)	0.58	0.001	
		Diet score	0.002 (-0.67, 0.68)	1.00	<0.001	0.18 (-0.66, 1.03)	0.67	0.001	-0.07 (-0.84, 0.70)	0.85	<0.001	
	Emotional status (HADS)	Anxiety	-0.08 (-0.79, 0.62)	0.82	<0.001	-0.79 (-1.67, 0.09)	0.08	0.009	-0.04 (-0.84, 0.75)	0.91	<0.001	
		Depression	0.55 (-0.14, 1.24)	0.12	0.009	-0.01 (-0.89, 0.86)	0.98	<0.001	0.52 (-0.26, 1.31)	0.19	0.006	
	Health-related QoL	MacNew Heart Disease	-0.10 (-0.24, 0.04)	0.17	0.004	0.009 (-0.17, 0.19)	0.92	<0.001	-0.14 (-0.30, 0.02)	0.09	0.005	

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

^b100 pages represents a large increase in information component use among this sample, median information component page requests among participants who made any use of the intervention was 34 pages.

^c100 pages represents a large increase in behaviour change component use among this sample, median behaviour change page requests among participants who made any use of the intervention was 44 pages.

^d100 pages represents a large increase in support component use among this sample, median support page requests among participants who made any use of the intervention was 23 pages.

Table 8.10 Results of multivariable linear regression analyses of baseline to 9 month change from overall use of components of the intervention.

9-month follow-up scores			Predictors									
			Baseline score and patient characteristics ^a	Overall information component use			Overall behaviour change component use			Overall support component use		
			R ²	Unstandardised coefficients (95% CIs) for 100 page increase in information component use ^b	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in behaviour change component use ^c	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in support component use ^d	p	R ² change
Psychological constructs	Illness perceptions (BIPO)	Consequences	0.39	0.10 (-0.42, 0.22)	0.55	0.002	-0.10 (-0.54, 0.34)	0.66	0.001	0.05 (-0.37, 0.48)	0.81	<0.001
		Personal control	0.23	-0.02 (-0.38, 0.33)	0.90	<0.001	0.44 (-0.07, 0.95)	0.09	0.017	0.01 (-0.48, 0.46)	0.97	<0.001
		Treatment control	0.31	0.02 (-0.31, 0.34)	0.93	<0.001	0.07 (-0.39, 0.42)	0.78	<0.001	-0.20 (-0.63, 0.23)	0.35	0.004
		Identity	0.57	0.21 (-0.06, 0.48)	0.12	0.008	0.05 (-0.33, 0.43)	0.80	<0.001	0.20 (-0.46, 0.56)	0.26	0.004
		Concern	0.41	-0.14 (-0.51, 0.23)	0.45	0.002	-0.24 (-0.77, 0.29)	0.38	0.003	-0.28 (-0.78, 0.21)	0.26	0.005
		Illness coherence	0.19	-0.11 (-0.41, 0.19)	0.47	0.003	-0.15 (-0.58, 0.28)	0.50	0.003	-0.07 (-0.47, 0.33)	0.74	0.001
		Emotions	0.51	-0.42 (-0.71, -0.12)	<0.01	0.027	-0.27 (-0.70, 0.15)	0.20	0.006	-0.11 (-0.51, 0.29)	0.58	0.001
	Self-efficacy	Diet (CDSEI)	0.61	0.007 (-0.08, 0.09)	0.87	<0.001	0.09 (-0.03, 0.21)	0.15	0.007	0.03 (-0.08, 0.15)	0.59	0.001
		Exercise (CESEI)	0.55	0.01 (-0.11, 0.14)	0.82	<0.001	0.06 (-0.10, 0.22)	0.44	0.003	0.04 (-0.10, 0.18)	0.60	0.001

9-month follow-up scores			Predictors										
			Baseline score and patient characteristics ^a		Overall information component use			Overall behaviour change component use			Overall support component use		
			R ²	Unstandardised coefficients (95% CIs) for 100 page increase in information component use ^b	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in behaviour change component use ^c	p	R ² change	Unstandardised coefficients (95% CIs) for 100 page increase in support component use ^d	p	R ² change	
Perceived social support (MOS SSS)	Emotional and info subscale	0.71	0.12 (-0.01, 0.25)	0.07	0.012	0.21 (0.02, 0.39)	0.03	0.018	0.10 (-0.07, 0.28)	0.24	0.005		
Health outcomes	Health behaviour	Healthy diet habits	-0.01 (-0.24, 0.22)	0.93	<0.001	0.05 (-0.28, 0.39)	0.75	<0.001	-0.10 (-0.41, 0.21)	0.53	0.002		
		Diet score	0.43 (0.03, 0.83)	0.03	0.023	0.43 (-0.05, 0.91)	0.08	0.016	0.39 (-0.06, 0.84)	0.09	0.015		
	Emotional status (HADS)	Anxiety	-0.21 (-0.57, 0.16)	0.26	0.004	-0.19 (-0.71, 0.33)	0.47	0.002	-0.07 (-0.56, 0.42)	0.77	<0.001		
		Depression	0.11 (-0.28, 0.50)	0.58	0.001	-0.24 (-0.80, 0.32)	0.40	0.003	-0.12 (-0.65, 0.40)	0.64	0.001		
	Health-related QoL	MacNew Heart Disease	0.07 (-0.03, 0.16)	0.16	0.006	0.06 (-0.08, 0.19)	0.41	0.002	0.005 (-0.12, 0.13)	0.94	<0.001		

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

^b100 pages represents a large increase in information component use among this sample, median information component page requests among participants who made any use of the intervention was 34 pages.

^c100 pages represents a large increase in behaviour change component use among this sample, median behaviour change page requests among participants who made any use of the intervention was 44 pages.

^d100 pages represents a large increase in support component use among this sample, median support page requests among participants who made any use of the intervention was 23 pages.

Table 8.11 Results of logistic regression analyses of baseline to 3 month change from first 3 months' use of components of the intervention.

3-month follow-up categories		Predictors													
		Baseline score and patient characteristics ^a		Information component use months 1-3				Behaviour change component use months 1-3				Support component use months 1-3			
		Cox & Snell R ²	Nagelkerke R ²	Odds ratio (95% CIs)	p	Cox & Snell R ² change	Nagelkerke R ² change	Odds ratio (95% CIs)	p	Cox & Snell R ² change	Nagelkerke R ² change	Odds ratio (95% CIs)	p	Cox & Snell R ² change	Nagelkerke R ² change
Illness perception (BIPO)	Cause	0.40	0.56	1.00 (0.99, 1.01)	0.88	<0.001	0.001	1.00 (0.99, 1.02)	0.97	<0.001	0.001	1.00 (0.99, 1.01)	0.65	0.001	0.001
Self-efficacy (Cardiac self-efficacy)	Control symptoms	0.28	0.37	1.00 (0.99, 1.01)	1.00	<0.001	<0.001	1.00 (0.99, 1.01)	0.66	<0.001	<0.001	1.00 (0.99, 1.01)	0.92	<0.001	<0.001
	Maintain function	0.32	0.42	1.00 (0.99, 1.01)	0.98	<0.001	<0.001	1.00 (0.99, 1.01)	0.98	<0.001	<0.001	1.00 (0.99, 1.01)	0.67	<0.001	0.001

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

Table 8.12 Results of logistic regression analyses of baseline to 9 month change from overall use of components of the intervention.

9-month follow-up categories		Predictors													
		Baseline score and patient characteristics ^a		Overall information component use				Overall behaviour change component use				Overall support component use			
		Cox & Snell R ²	Nagelkerke R ²	Odds ratio (95% CIs)	p	Cox & Snell R ² change	Nagelkerke R ² change	Odds ratio (95% CIs)	p	Cox & Snell R ² change	Nagelkerke R ² change	Odds ratio (95% CIs)	p	Cox & Snell R ² change	Nagelkerke R ² change
Illness perception (BIPO)	Cause	0.36	0.51	1.00 (0.99, 1.01)	0.77	<0.001	<0.001	1.00 (0.99, 1.00)	0.16	0.010	0.014	1.00 (1.00, 1.01)	0.62	0.002	0.002
Self-efficacy (Cardiac self-efficacy)	Control symptoms	0.20	0.26	1.00 (1.00, 1.00)	0.85	<0.001	<0.001	1.00 (1.00, 1.01)	0.95	<0.001	<0.001	1.00 (1.00, 1.01)	0.38	0.004	0.006
	Maintain function	0.24	0.32	1.00 (1.00, 1.01)	0.07	0.017	0.023	1.00 (1.00, 1.01)	0.84	<0.001	<0.001	1.00 (1.00, 1.01)	0.20	0.009	0.012

^aParticipant characteristics: MI, angina, concurrent cardiovascular condition, other concurrent condition, age, time since most recent cardiac event, level of internet access and experience

8.4.3 Further mediator analysis

Analyses reported in the preceding sections found only low levels of change in psychological constructs and health outcomes overall, no significant relationship between total intervention use and any change in outcomes. A single, possibly chance, significant relationship between use of one of intervention components and change in a psychological construct at 9 months, but no significant relationship between use of any specific intervention component and change in any health outcome. As a result, further statistical analysis testing mediating effects of change in intermediate outcomes on main outcomes as a result of overall intervention use, or of use of intervention components, was not conducted.

8.5 Qualitative analysis of intervention effects

The following sections summarise themes from interview discussions relating to the effects of the internet intervention. Discussion of intervention effects either occurred naturally in response to general questions about what participants thought of the intervention or it was initiated by questions about whether the intervention had made a difference to them. Some participants were selected for interview based on their relatively high use of particular intervention components. If these participants did not discuss effects of these components in response to questions about any difference the intervention had made for them, their use of these services was mentioned and followed up with further questions. Others were selected for interview based on their individual change in quantitative measures of psychological constructs from baseline to 3 months. If these participants did not discuss this change in response to questions about intervention effects, they were asked further questions to establish reasons for changes. (Appendix P).

As for the qualitative results reported in Chapter 7, the following sections present themes relating to the effects of the intervention that were identified during the iterative process of data collection and analysis, and themes identified as a result of further analysis seeking answers to questions raised by quantitative findings. Each section is supported by illustrative quotes from interview transcripts. Again, free-text comments made at 9 months by participants in the wider study sample raised no additional themes relevant to intervention effects.

Lack of intervention effects

Many interview participants reported no or only limited intervention effects. Some participants, particularly those with little or no internet experience, attributed this purely to the low use they had made of the intervention.

P0320: "... I think it is a facility that is useful, but I didn't use it enough to make it really useful for me"

(81 year old female, no previous internet experience)

Several of the participants who used the intervention reported that its effects had been limited by living with CHD for many years already and effects of ill-health and other medical conditions.

Living with CHD for many years already

These participants felt they had already gained extensive knowledge from earlier sources and treatment experiences.

P0316: "Well I've got a good idea about what my condition is... you learn a lot if you are alert, before and after the operation. You know what they've done, you know what the risks are and you know what they

are trying to correct and you know really, from the medicines and talking to the doctor, how you should proceed in order to get the best out of it”

(78 year old male, experienced internet user)

They also felt they had already made extensive changes to their lifestyle as a result of their heart disease.

P0101: “Oh I was already doing that. It was part of my lifestyle for some years already.”

(82 year old male, experienced internet user)

However, some participants found the intervention useful as a more recent source of information, in particular for more recent heart disease complications.

P0112: “... it’s actually made a big difference to me... at that time, 2003 the trouble started, I had, I had been living with this for thirteen years and it gets to you after time...”

(66 year old male, experienced internet user)

Several participants felt that the intervention would have greater beneficial effects if available shortly after first diagnosis or cardiac event.

P0137: “... if... I was with the website 12 years ago it wouldn’t have taken me that long to really sift out what was useful... I could have got that straight away and after I had my angioplasty I would have got onto the correct road for dieting and all this a lot sooner.

(63 year old male, no previous internet experience)

However, there was no evidence of this from more recently diagnosed participants.

Effects of ill-health and other medical conditions

These limited the amount of possible change in health behaviours and independently affected participants' quality of life. Some participants' felt their health had deteriorated during participation due to worsening medical conditions.

P0121: "I don't say it's affected my lifestyle because the other things have taken over, the arthritis and things like that."

(79 year old female, experienced internet user)

Intervention effects

Where participants reported effects of the intervention these were in the areas of knowledge and understanding, confidence, emotions, lifestyle, feelings of isolation and relationships with healthcare professionals.

Knowledge and understanding

Several participants reported gains in knowledge or understanding of their treatment and of their heart condition as a result of the intervention.

P0111: "... all these I didn't have the idea and then I went on to this website and I got the idea of what is happening, you know, what is happening to me."

(70 year old male, experienced internet user)

This was reported particularly in connection with the 'ask an expert' support services and information services.

P0137: "... a lot of information you get from the questions and answers, from ask the expert, it helps you really to learn a lot about the problems you get and what's happening..."

(63 year old male, no previous internet experience)

Confidence

Several participants reported increased confidence as a result of feeling they had greater or easier access to information because of the intervention.

P0112: "... it gives you a sort of confidence that I didn't have before... knowing that there is someone out there who is going to tell you what your problem is and knowing that there is one central source of information where you can find things out"

(66 year old male, experienced internet user)

Participants could experience this benefit even if they had made little or no use of the intervention.

P0316: "...it's handy if I need it...makes you feel a bit more comfortable... even though I haven't used it I just know that it's there if I need to go to it"

(61 year old female, basic internet experience)

Others felt they had gained confidence from increased knowledge and understanding as a result of the intervention.

P0137: “Yeah you get more, more confidence of course, through the knowledge...”

(63 year old male, no previous internet experience)

Emotions

Several participants reported that they felt better as a result of the intervention through reduced anxiety or increased confidence.

P0905: “I feel, I’ll be honest, the last few weeks I’ve felt on top of the world... I suppose I feel a bit more confident... what I’ve got, maybe that’s why I feel like this... I really feel much, much better and I don’t think of it all the time, it’s gone, you know, I don’t class myself as being ill or unwell”

(76 year old female, basic internet experience)

This was either through increased knowledge and understanding, increased access to information, or reassurance over managing their CHD correctly.

P0121: “And something might be nagging away and worrying you when you can get the answer on the computer.”

(79 year old female, experienced internet user)

P1010: “I think it’s just reassuring more than anything of what I’m doing is the way to go... it just stops me worrying completely.”

(63 year old male, experienced internet user)

Emotional effects were reported in relation to information and some support services ('ask an expert', 'personal stories').

P0217: "... when you see people overcoming things like that, it gives you a boost... especially people who are at an advanced age like meself"

(80 year old male, no previous internet experience)

Lifestyle

No major lifestyle change was reported as a result of intervention use. However, some participants had made small refinements to changes already made.

P0601: "Well it's made me eat more fruit than I have done in the past and it made me sort of, be very conscious of that fact... and when I buy food, meat in particular, I don't go for the fatty stuff, I try and get lean things and if I get a steak I always cut the fat off before I cook it and so it's positive in that way."

(69 year old male, basic internet experience)

For some the intervention served to confirm participants' existing behaviours and helped maintain motivation to continue.

P0112: "... it's made me realise that, again, weight wise and exercise wise I'm going in the right direction and really ought to continue doing it."

(66 year old male, experienced internet user)

Regular reminders from the 'health tracking' behaviour change service helped with this.

P1010: “Well where they say it’s about time you had another test, what’s your blood, what’s your cholesterol level, how many times are you going down the gym... and sometimes... if you’ve not been going down the gym... I think it pushes you a bit in that respect”

(63 year old male, experienced internet user)

Others felt that the intervention had raised their awareness of lifestyle issues or given them suggestions for later change.

P0121: “... it was good because it gave me an insight, really of what I should be doing as well.”

(79 year old female, experienced internet user)

Feelings of isolation

Female participants reported feeling less isolated as a result of intervention use or that intervention use helped occupy time alone.

P0129: “If I say not suffering alone, is that right?... I have, people there with me, not knowing friends, but friends in that way... going through the same thing”

(61 year old female, basic internet experience)

P0705: “... I’ve enjoyed having that there, it’s something else to occupy my mind, because, you know I do get so fed up, especially when I’m on me own”

(58 year old female, no previous internet experience)

However these benefits were not consistently drawn from the same intervention components and were discussed in relation to use of the behaviour change component and some support services ('personal stories', 'personal journal').

Relationships with healthcare professionals

A few participants reported intervention use had resulted in either better communication with or greater trust in their health professionals.

P0111: "Yes, bit of knowledge and then I could, you know, talk with them."

(70 year old male, experienced internet user)

P0112: "Another thing this proves was that my cardiologist's treatment was absolutely correct, I have no need to query it... it did convince me that the treatment was absolutely correct and he couldn't do anything else because... what it suggested was exactly what was being done for me, so that helped... stopped me trying to second guess my cardiologist..."

(64 year old male, experienced internet user)

However, one participant was considering changing his GP as a result of news read in an information service (although he felt access to this information was positive).

P0137: "... I've been trying since then to get the [drug], to find the GP who prescribes it, so I'm going to change my GP if necessary, because I asked them, they wouldn't prescribe it"

(63 year old male, no previous internet experience)

Negative effects

Although participants were asked about negative effects of the intervention, virtually none were reported. Most commonly, if the intervention or any components did not appeal, they simply did not use it.

Only two participants reported any negative experiences of the intervention. The first (P0101, 82 year old male, experienced internet user) became worried when he read some information on the intervention that contradicted advice he had been given by his healthcare professional. However, he was able to relieve this worry by querying the information in a question to the ‘ask an expert’ service. As he was satisfied with the subsequent response, overall he was not concerned by this experience. The second participant (P0906, 72 year old male, no previous internet experience) found the experiences of other heart disease patients he read in the ‘personal stories’ support service somewhat depressing. This caused him to avoid using the ‘discussion group’ support service as he felt it would be used by similar sorts of people and he didn’t *‘really want to go down that line of making myself depressed on purpose’*. He also found that the level of detail in library and news articles in the ‘instant library’ information service *‘frankly frightens you sometimes’*, and so stuck to reading about health news in daily newspapers, which he preferred.

8.6 Summary of effects of the internet intervention

The quantitative analysis found little evidence of significant change in psychological constructs that were hypothesised as mechanisms of action of the intervention (illness representations, levels of self-efficacy, perceived social support) or in health outcomes (health behaviour, emotional status or quality of life) overall and little evidence that any change was related to intervention use. The significant but small increase in the illness coherence dimension at 3 and 9 months and decrease in cardiac self-efficacy at 3

months in the sample overall were no greater in those who used the intervention and were not significantly predicted by intervention use. This meant that the first two requirements for statistical mediation (69) were not met and further analysis to test the remaining two requirements was not justified.

The qualitative analysis also found that for many participants the intervention had no or only limited effects. However, qualitative data did reveal some intervention effects which were almost universally positive. Participants who reported an effect of the intervention felt it had increased their knowledge and understanding, which in turn increased their feelings of confidence and reduced their levels of anxiety. Confidence was also gained through the feeling that participants now had easier access to information and advice should they need it, a positive effect of the intervention even when it had not been used. As a result of increased confidence, increased knowledge and understanding or both, participants felt better and were able to stop worrying about their heart disease, something that those who experienced it valued highly. This qualitative finding supports the validity of the relationship between use of the information component and reduced emotional effect of the illness, which was the sole significant quantitative finding from analyses predicting change in outcomes from intervention use.

By comparison, fewer and more minor effects on lifestyle change were reported. These were generally limited to small refinements to an already healthy diet or reinforcing and maintaining changes already made. The reassurance drawn from confirmation that what participants were already doing was correct was another positive effect of the intervention.

Other intervention effects were reported by fewer participants. Feelings of reduced isolation were reported only by female participants. For some of these participants this

was the main effect of the intervention for them. A few participants also reported positive effects of the intervention on communication with and trust in their healthcare professionals.

Qualitative analysis identified certain intervention components that were more frequently linked to perceived positive effects than others. The regular information and news updates, 'ask an expert' support service and 'health tracking' behaviour change service were most frequently noted. However, even perceived effects of the lesser used 'personal stories' and 'personal journal' support services were mentioned. Reports of how the intervention reduced feelings of isolation highlighted the fact that similar effects experienced by participants may have resulted from the use of different intervention components.

Neither quantitative nor qualitative analyses found any significant negative effects of the intervention.

Chapter 9 : Discussion and Conclusions

9.1 Introduction

This chapter discusses the results presented in Chapters 7 and 8. The discussion considers strengths and limitations of the study and implications for future development and evaluation of internet interventions. At the end of the chapter conclusions are drawn in relation to the study aims and the wider aims of the thesis.

9.2 Who wanted to participate?

10% of eligible patients with CHD chose to participate in the study. No previous study has offered an internet intervention to primary care patients with CHD so it was not clear what participation rate to expect. However, given that one of the potential benefits of internet interventions is their ability to reach large numbers of patients this rate of participation seems low. It compares to participation rates of 48 – 71% for other types of CHD secondary prevention interventions delivered in primary care settings (62;331;332). These interventions were quite different from internet interventions. All were delivered in person by nurses or health visitors, two involved reviewing patients and providing personalised health education every few months over a year or more (62;331), and the other involved a one-off educational group session (332). The comparatively low level of participation in this study may indicate that internet interventions are relatively less appealing to patients with CHD than other types of primary care interventions.

It is unclear how the participation rate in this study compares with those of other internet intervention studies. For many studies the size of the populations from which samples were drawn is not clear, for example, where recruitment relies on response to community or online adverts (99;102;107;114;118;121;123;126-128;131;132). Previous studies which have also sought to involve participants without existing internet access

or previous internet experience have provided participants with lap-top computers and home internet service. This added incentive is likely to have contributed to their higher participation rates of 61-93% (91;97). Possibly the most equivalent internet intervention study to the current one was conducted in a Canadian primary care setting (112). The Canadian study offered an 8-month tailored nutritional counselling and peer-support intervention to patients identified at risk of heart disease. The main differences were that participants had to already be internet users and the study had a randomised design so only half of participants would receive the intervention. Participation rate in that study was 17%, only slightly higher than in the current study.

The demographic characteristics of participants in this study suggest that the small proportion of CHD patients who chose to participate were unlikely to be a representative sample of the wider population of CHD patients. In particular, participants were predominantly white, male and well-educated. Although there was a wide age range in the sample, comparison with figures from CHD registers at participating GP practices showed that older patients with CHD were still under-represented. While the CHD registers showed more men than women among eligible patients, of these proportionally more men than women chose to participate. When compared to UK population surveys, the sample appeared highly educated with a disproportionately high number of participants with degree level educational qualifications (323). In addition, a much higher proportion had home internet access and/or prior experience of using the internet than would be expected of people in the UK with a long term health problem or aged over 65 years (53;287).

In terms of clinical characteristics the sample appeared diverse in CHD diagnosis and concurrent health problems. As it is not ethically permissible to access clinical data from primary care records without patients' consent, these clinical characteristics could

not be compared with general clinical characteristics of CHD patients registered at participating practices. However, it was notable that most participants had been diagnosed with CHD a number of years ago with relatively few who were newly diagnosed. This is perhaps surprising given that comparison with CHD registers indicated that younger patients with CHD were over-represented in the sample. In addition, nearly 40% of the sample had not experienced a cardiac event (heart attack, routine or emergency surgery) or new CHD diagnosis in the last 5 years. So the sample included many participants whose CHD had been stable in recent years. This may indicate that participants in this study were managing their condition well or that their CHD was relatively unproblematic.

Comparison of baseline scores on health outcomes with reference data from CHD and general public samples also seem to indicate the study sample might be a select group. Participants in this study appeared highly motivated and reported relatively good levels of medical adherence, diet and exercise behaviours and health-related quality of life as well as a relatively low level of anxiety.

Taken together the recruitment rate and sample characteristics in this study suggest that providing facilitated access to an internet intervention is unlikely to overcome health inequalities noted in traditional self-management programmes. In common with other self-management and cardiac rehabilitation interventions and in line with patterns of internet use, participants in this study were younger and relatively highly educated. Traditionally the EPP and similar self-management interventions have appealed more to women (29;36), as has use of the internet for health information (55). So greater numbers of male participants in this study may suggest internet interventions are a more successful way to engage with male patients with long term conditions. However, the overall low response rate in this study and the similarly high proportion of men who

participate in cardiac rehabilitation (40) undermines this interpretation. Instead the sample may reflect a low level of appeal of an internet intervention to women with heart disease. Alternatively it may indicate that among women there are particular barriers to accessing internet interventions, as have been noted for accessing cardiac rehabilitation (40).

9.3 What use was made of the intervention?

Overall use of *UK CHESS Living with Heart Disease* was low compared to use of internet interventions for other types of long term conditions (82;84;97) and nearly a quarter of participants in the current study made no use of the intervention. Lack of use by a significant proportion of participants has not been reported as a common problem in internet intervention research. However, it did occur in the evaluation of the Heart-Web intervention for Canadian primary care patients at risk of heart disease. Heart-Web was used by only 33% of patients randomly assigned to the intervention group and most of these only used it once (112). The authors attributed the lack of effectiveness of Heart-Web to low intervention exposure (due to low use made of it by participants) and the relatively high levels of motivation, support, health and medical treatment noted among participants at baseline compared to those who chose not to participate (112). This seems to reflect a situation similar to the current study.

Although efforts were made to encourage ongoing use of the *UK CHESS Living with Heart Disease* intervention, use was greatest in the earliest months of access and declined over time. This declining pattern of use is one commonly reported with internet interventions (84;97;99;102;124;132). However, in the current study use of the intervention varied greatly between individual participants and was not well-represented by graphs of average use. Some participants made high and regular use of the

intervention throughout the 9 months and others made more rather than less use of it over time.

Although a potential advantage of internet interventions for supporting self-management is their availability for use at any time of day or night, it was notable that the majority of intervention use in this study occurred during the day. By comparison, use of internet interventions by patients with AIDS was found to be greatest in the evening or at night (82;84). Predominant day-time use may be related to the fact that a large proportion of participants in this study were retired. This is not surprising given the mean age of the sample and the increased prevalence of CHD with age. However, it does mean that 'out of hours' access to information and support via an internet intervention may not have been as important to these participants as perhaps it would be to others with greater barriers to accessing healthcare services or the intervention itself during normal working hours.

Interestingly, despite the relatively low use made of the intervention during the study, at the end several participants expressed their wish for continued access to the intervention. This included not only those who had made regular and repeated use of the intervention but also others who had made little or no use of it. For some of these participants it appeared that 9 months had been too short for them to make sufficient use of the intervention and others valued the intervention as a long-term resource which they wanted to retain for use to address future information and support needs.

In summary, overall use of the intervention was low, although not for all participants. Despite low use during the study, participants were positive about the intervention and many wanted access for anticipated future use.

9.4 What were the main factors which were associated with intervention use?

9.4.1 Need for information and support

It is not surprising that participants with greater perceived need made greater use of the intervention. What appears striking, in light of previous research with CHD samples (15;16;18;19), is the low need for information, advice and support among many participants in this study. However, much of the previous research identifying patients' needs was carried out with samples shortly after a cardiac event, and most often after a heart attack (15;18). In addition, the studies reporting patients' longer term needs were conducted with patients only 6 months after a heart attack or surgery (16;19). By comparison, a significant proportion of participants in this study had not experienced a heart attack or hospitalisation for their CHD in recent years. As the long-term needs of CHD patients have not been a focus of research it is not clear whether the low level of need reported by many in this study is typical of patients who have had CHD for some years. Alternatively it may be that the needs of many CHD patients in the long-term are already met by existing services and resources. However, the likelihood that this sample was not representative of the wider population of patients with CHD raises doubts about the generalisability of either explanation to CHD patients in general.

Participants' expressed opinion of their CHD as relatively mild may reflect a misunderstanding of CHD as an acute cardiac event, now treated and in the past, rather than a long term condition. This is a misunderstanding that has been identified as a problem for CHD self-management by previous research (17). However, participants' median score on the timeline illness perception item, which is intended to measure patients' beliefs about the long term nature of their condition, was the maximum at all 3 time-points. This suggests that most participants believed that their CHD was a long

term condition. By comparison their scores for perceptions of illness consequences were much lower, as were their scores on the perception of illness identity, which relates to the extent to which patients experience symptoms from their condition. In the qualitative data participants often referred to their absence of symptoms when expressing the view that their CHD was not severe. The absence of symptoms over long periods of time appears to be an important characteristic of CHD which distinguishes it from other types of long term conditions. Qualitative research with patients managing various long term conditions at different stages of their illness suggested that symptom management was a major focus of patients' self-management work (13). However, if patients do not experience symptoms from their condition then this element of self-management is not necessary.

9.4.2 Home internet access and confidence with computers

Home internet access appeared a clear facilitator of use of the intervention. Qualitative data from a few participants who made high use of the intervention at public internet services, revealed that these participants could access the internet as much as they wanted at convenient community centres. They also felt that accessing the intervention away from home had additional benefits. By contrast, most of the qualitative data from those without home internet access suggested that they perceived drawbacks to having to use the intervention elsewhere and that this was a barrier to use.

Experience of using the internet and of computers in general was also important for intervention use, even among those with home internet access. Qualitative data revealed that for most participants without previous internet experience, lack of confidence in using computers and feeling uncomfortable asking for help limited their use of the intervention. Lack of confidence in using computers affected both overall use of the intervention and use of the more interactive services offered by the intervention (e.g.

'discussion group', 'health tracking'). Although participants were aware of people who could help, many preferred not to use the intervention than to ask for any help.

It is important to note that these effects were found in a sample in which only 20% of participants did not have home internet access and/or some prior experience of using the internet. It is likely that the majority of patients with CHD who did not have home internet access or internet experience chose not to participate in the study at all. Those who did participate who did not have home internet access or prior internet experience may not have been particularly representative of this group. It seems reasonable to assume that they were the most willing and interested in using the intervention, yet they still made less use of the intervention than patients with home internet access and who were confident using computers and the internet.

These findings have implications for the potential of internet interventions to engage disadvantaged groups who are less likely to have home internet access or experience (53). They suggest that public internet provision and current training initiatives are insufficient for facilitating use of internet interventions by these groups. This poses a real challenge as to how to provide sufficient internet access along with accessible training and support.

A previous internet intervention study was more successful in encouraging intervention use by novice internet users (97). The study sample was limited to diabetes patients without either home internet access or any previous experience of using the internet. High use among novice internet users was achieved by providing home installation of networked computers for the duration of the study, using simplified computer and intervention software and providing extensive training. Although successful, there are some obvious drawbacks to adopting this approach more widely. Firstly, it is unlikely to be feasible outside of funded and time-limited research projects. Secondly, the

simplified software and design are likely to limit the kinds of information and support the intervention can provide. This may mean it is unlikely to appeal to more experienced patients (44). It may also lose its appeal in the long-term as patients become more experienced. Whether it is possible to develop interventions that both facilitate use among novice internet users and appeal to experienced internet users is unclear.

9.4.3 Healthcare contacts, treatment and experiences

Qualitative analysis identified a relationship between participants' experience of healthcare and intervention use. Use of an internet intervention in this integrated and supportive way echoes previous qualitative findings (44). In common with the current study, discussion of intervention use in relation to healthcare treatment occurred naturally without being a direct focus of interview questions. The repeated emergence of this topic of discussion in relation to internet interventions underlines the importance to patients with long term conditions of integrating use of this kind of resource with their existing healthcare treatment.

However, in the current study there were also examples of use of the intervention to check or challenge information patients had received from healthcare professionals. Concerns have been raised over the effect of use of internet health information in this way on the doctor-patient relationship (333;334). Little can be concluded from these few examples, given this topic was not systematically explored in this study. However, they underline the importance of the relationship between internet interventions and healthcare treatment for consideration in intervention design and future research.

9.5 Who used and benefited from the intervention most?

There was some indication that those with recent complications from long-standing heart disease made greater use of the intervention. Qualitative data suggested use by

these patients related to new information and support needs. Mean use of the intervention by the small group of participants who experienced a cardiac event or additional CHD diagnosis during the study did appear to be higher. However, post-hoc statistical analysis found their intervention use was not significantly greater than use made by other participants.

Some participants suggested that the intervention would be of greater use to patients recently diagnosed with heart disease because of the greater need for information and support at that time. However, the data does not support this proposition. Firstly, less than 15% of the main study sample was made up of patients diagnosed within the previous 2 years. The implication is that seeking information and support from an internet intervention may not appeal at this early stage. Secondly, the only recently diagnosed participant to give insight on this indicated that he had felt too emotionally overwhelmed to make use of the intervention from the start. An alternative explanation is that the period shortly after diagnosis or cardiac event is likely to be a time of relatively intense medical management and other interventions such as cardiac rehabilitation. It may be that the patients' needs at this time are better met through other types of interventions, particularly if they are more likely to be focused on immediate survival and recovery rather than long-term management (15;18).

9.6 Which components were responsible for intervention use and effects?

Statistical analyses planned and conducted to answer this question were limited by the overall low use of the intervention and lack of significant change in outcomes found in this sample. Statistical mediator analysis was not justified.

Those who made continued use of the intervention made greater use of support components than of other components. Qualitative data suggest that it was the ‘ask an expert’ support service, where participants could ask a question and get a personal answer from a team of experts or read expert answers to questions posed by other participants, that was responsible for this ongoing use. Other services responsible for the ongoing appeal and use of the intervention according to the qualitative data was the regular information and news updates and the ‘health tracking’ behaviour change service, where participants entered information about their heart health and lifestyle behaviours and could view tailored information and graphs of their responses over time.

According to the qualitative data participants valued the information available on the intervention, in particular the regular information and news updates. Overall use of the information component of the intervention was the sole significant predictor of any change in a psychological construct. Although use of the support and behaviour change components of the intervention did not significantly predict change in psychological constructs or health outcomes, qualitative findings suggested that the ‘ask an expert’ support service and ‘health tracking’ behaviour change service were also more frequently linked to perceived positive effects than were use of other services.

Although, some lesser used support services, for example ‘personal stories’ and ‘personal journal’, were also mentioned by individual participants for having positive effects. Reports of how the intervention reduced feelings of isolation highlighted the fact that similar effects experienced by participants may have resulted from the use of different intervention components.

Of particular note in this study was the low use of the ‘discussion group’ peer support service. This is in contrast to internet interventions for other long term conditions, where similar online peer support groups accounted for most of the use patients made of

interventions (82;84;97). The low use of the online peer support in this study may well explain the low overall use of the intervention compared to these other interventions. It may also explain the relatively low use of the intervention during the evening and overnight. In previous qualitative research, patients with long term conditions valued seeking emotional support through online peer support groups and emphasised the importance of being able to access them for this purpose at any time, day or night (44). Qualitative data from the current study suggest that the 'discussion group' service was unappealing to most participants. The lack of appeal appeared to apply to online peer support groups in general rather than specifically to the 'discussion group' service offered by this intervention. The general lack of appeal of support groups (online or other) for patients with CHD compared to other long term conditions patients has been noted before (335), although it is not clear why patients with CHD might differ from other patient groups in this respect. In the current study, those who wished to interact with other patients expressed a preference for doing so through face-to-face rather than online interaction.

9.7 Why were the hypothesised effects of the intervention not found by quantitative analysis?

In answering this question it is relevant to consider the extent to which the following might have been responsible for the largely null quantitative findings:

- lack of use of the intervention
- the study sample
- psychological constructs and health outcomes measured
- quantitative measures used
- the intervention
- the intervention period
- study design

9.7.1 Lack of use of the intervention

Given the comparatively low use made of the intervention this would seem the most obvious explanation for the largely null findings. This explanation is supported by some interview participants who clearly felt that the reason why nothing had changed for them as a result of the intervention was because they had not used it. However, low or no intervention use was not the only reason for lack or limited intervention effects identified by qualitative analysis. This suggests that other factors may also have contributed to the largely null quantitative findings.

9.7.2 The study sample

To what extent was the lack of change in psychological constructs and health outcomes a result of the characteristics of the patients who chose to participate? There are a number of grounds on which it is reasonable to conclude that study participants were not a representative sample of patients with CHD. In particular, most had been

diagnosed a number of years ago and had not experienced any recent cardiac event.

Time since most recent cardiac event or CHD diagnosis significantly predicted intervention use and appeared highly influential in qualitative analysis of both use made of the intervention and effect experienced. As a result it seems likely that this clinical characteristic may have been a major contributor to the null quantitative findings.

Qualitative analysis revealed that patients who were diagnosed a number of years ago, and who had no recent cardiac event or heart-related complications expressed little need for the information and support provided by the intervention and as a result many made little use of it. Effects of the intervention were limited for patients who had been living with CHD for a number of years because of knowledge they had already gained and changes they had already made to their lifestyle. Although the effect of time since most recent cardiac event or CHD diagnosis was controlled for in regression analyses testing change in psychological constructs and health outcomes from intervention use, this can only control for the effect of this characteristic among those who participated. It cannot address the lack of data from patients who are not well-represented within this sample, i.e. those with more recent cardiac events or more recently diagnosed.

9.7.3 Psychological constructs and health outcomes measured

Is it possible that the intervention had significant effects but these were through mechanisms and on outcomes that were not measured in the study? This seems unlikely given the relatively low level of use of the intervention overall and the fact that qualitative analysis also found that for many participants the intervention had little or no effects. Also, the few intervention effects reported in the interviews were conceptually similar to the psychological constructs and health outcomes measured. The illness coherence dimension of illness perceptions includes knowledge and understanding of the condition; self-efficacy includes confidence; perceived information and emotional

social support includes perceived access to information and feelings of isolation; health behaviours includes lifestyle change and maintenance of lifestyle change; effects on anxiety and worry could fall within either the emotional dimension of illness perceptions, emotional status or quality of life depending on whether they relate to disease-specific worry or general anxiety. Quality of life includes generally feeling better as a result of ceasing to worry. The only intervention effects that were not conceptually similar to psychological constructs and health outcomes measured (communication with and trust in health professionals) were reported by just a few participants.

9.7.4 Quantitative measures used

Given the qualitative analysis found intervention effects conceptually similar to the psychological constructs and health outcomes measured, is it possible that significant intervention effects were not captured by the measures used? At the point of study design, considerable effort was made to identify measures that were valid, reliable and sensitive to change through intervention. However, selection was limited by the paucity of measures from which to choose and by lack of information about identified measures on which to base selection decisions.

Statistical analysis was then hampered by the data produced by some of the measures. Significant skew caused problems for parametric statistical analysis and data from some measures were unusable due to substantial amounts of missing data which were unlikely to be missing at random, or ceiling effects which resulted in little variability across the sample and an insensitivity to change. The inadequacies of the diet (poor internal consistency and unestablished validity), exercise (significant skew and data unlikely to be missing at random) and medical adherence measures (near-complete ceiling effect) meant that behavioural outcomes in particular were poorly measured in this study.

Questionnaires used to capture cardiac self-efficacy, illness perceptions and behavioural intentions also produced some skewed data, which meant that some of these variables had to be analysed non-parametrically and/or excluded from analysis. These failings may have introduced measurement error or resulted in reduced power in analysis sufficient to increase the likelihood of Type II errors, where significant intervention effects would be missed.

However, again the relatively low level of use of the intervention overall and the qualitative finding that for many participants the intervention had little or no effects suggests that this is an unlikely explanation. While some of the intervention effects reported in individual interviews seem quite powerful, taken together it seems more likely that most effects that were conceptually similar to psychological constructs and outcomes measured were either too small (e.g. effects on lifestyle too small for change in health behaviour outcomes) or not sufficiently widespread (e.g. reduced isolation only reported by a few female participants) to have been found significant across the full study sample.

Content of the discussion of some of the intervention effects found by qualitative analysis also suggest that some effects, which seem conceptually similar to psychological constructs and health outcomes measured, may in fact differ in important ways. For example, participants' discussions of intervention effects on confidence were notably of a general feeling rather than specific to a particular self-management or health behaviour. The measures of self-efficacy used in this study were selected to be specific to behaviours measured. This was guided by literature that recommended self-efficacy to be more likely to predict a particular health behaviour if measured specific to that behaviour (249). It may be that the self-efficacy measures used were too specific to capture the more general feeling of confidence reported by participants in the qualitative

analysis. Similarly effects of the intervention on ceasing to worry about heart disease and generally feeling better that were identified by the qualitative analysis can be conceived as effects on participants' quality of life. However, they seem very different from the conceptualisation of quality of life on which the MacNew heart disease quality of life measure was based (24).

9.7.5 The intervention

To what extent do the null quantitative findings reflect a failure of the internet intervention evaluated? At the time of study design, the *CHESS Living with Heart Disease* intervention appeared to be the best available. Extensive work was conducted on the intervention to develop it to better meet the needs of UK patients with CHD. This was based on previously identified user-generated criteria (44) and guided by formative evaluation by a panel of patients with CHD. However, most of the development work was restricted to changes that could be made using the database software that the CHESS team had designed to organise the information content of the intervention. Time and resources prevented other significant technical and structural changes identified by the formative evaluation that could not be achieved using the database software alone. This meant that although the best available at the time, *CHESS Living with Heart Disease* was not an optimal internet intervention for meeting patients' needs.

Equally, although other CHESS-designed internet interventions had been found to achieve positive change for patients with other types of long term conditions (86;91;240), *CHESS Living with Heart Disease* may not have been optimally designed for achieving change in self-management outcomes for patients with CHD. The minimal prior evaluation that had been conducted on the intervention was only briefly reported, with little detail of methods used and effects found (100). Use of psychological theory to guide internet intervention design has been recommended to

increase effectiveness (45;70;71). The minimal information available suggests that the design of *CHESS Living with Heart Disease* was guided by SCT to increase self-efficacy and the TTM. However, it is not clear how theory was used and to what extent intervention components were based on a theoretical framework. Lack of clarity over whether and to what extent interventions are theory-based is a problem in behavioural intervention research in general. Recently a theory-linked taxonomy of behaviour change techniques used in interventions has been developed to help address this issue (79). This taxonomy has been used to categorise theory-linked behaviour techniques used by internet interventions and identify techniques common to effective interventions by meta-regression analysis (78). In future this should aid both theory-based intervention development for increased effectiveness and assessment of the potential of existing interventions.

As an intervention, *CHESS Living with Heart Disease* was information heavy. This was partly due to the way the intervention was originally designed, partly because the majority of the user-generated criteria which guided development of the intervention relate to information content (44), and partly because it was this component of the intervention that could be directly altered using the database software provided by the CHESS team. Participants in this study clearly valued having access to information and the significant relationship between use of the information component of the intervention and perceived emotional impact of CHD for participants is in line with previous qualitative research which emphasised the importance of information for meeting emotional needs (51). However, previous research has also found that information alone is insufficient for achieving change in self-management behaviour and outcomes (35). It is possible that had *CHESS Living with Heart Disease* offered stronger, support and behaviour change components in addition to information, it might have been more effective.

From the participants' perspective, negative perceptions of the intervention and some of the support components were expressed. However, many were based on general opinions rather than specific to this intervention or based on participants' experience of use of it. Negative comments that were based on use of the intervention related to lack of personal relevance of individual accounts in the 'personal stories' support service and lack of activity in the 'discussion group' support service. However, low need for information and support in general was more widely expressed than dissatisfaction with the intervention itself.

9.7.6 The intervention period

Was 9 months of access to the internet intervention long enough for it to achieve hypothesised effects? Although lengthy compared to most conventional self-management interventions, in the context of a long term condition 9 months is still a relatively short time. Comments made by some interview participants suggested they wanted to have continued access to the intervention or that 9 months had not been enough for them to make sufficient use of the intervention.

However, it was not clear that given more time participants would necessarily have made greater use of the intervention or derived more benefit. Had significant change in psychological constructs been found by the end of the study but not change in health outcomes then it could have been argued that there had been insufficient time for psychological changes to influence health outcomes. Although a single significant relationship was found between use of a specific component of the intervention and change in one of the psychological constructs at 9 months, this result may represent a Type 1 error, found significant only by chance as a result of the large number of statistical tests. In terms of the qualitative data, participants valued feeling they had access to information via the intervention should they need it. However, there was no

guarantee that any need would arise. There was some suggestion that their need might increase if they experienced CHD-related complications or a cardiac event, but in 9 months this only happened to around 15% of the sample. In any time period, if only a small proportion of participants are benefiting from the intervention it would be unlikely that significant change would be found in the sample as a whole.

9.7.7 Study design

The use of a prospective cohort design in this study was based on an assumption that the action of the intervention would be captured as change in outcomes. Is it possible that the lack of change found in psychological constructs and health outcomes was not a null finding but actually represented a positive effect of the intervention in maintaining, rather than changing, health behaviour, emotional status and quality of life? This would be particularly relevant if the sample characteristics were an indication that participants were already managing their condition well or that their CHD was not particularly problematic. For these kinds of patients, maintaining the status quo might be a more appropriate intervention goal.

Some interview participants reported that the intervention played a role in maintaining their existing healthy lifestyle and self-management activities. This is not something that can be tested by the prospective cohort design used in this study. The fact that effect sizes of change were no different among participants who used the intervention than they were in the full study sample, which included the 23% of participants who made no use of the intervention, argues against the possibility that lack of deterioration was related to intervention use. However, without a control group of participants who did not have access to the intervention, the possibility that no significant change was a positive effect of the intervention cannot be evaluated.

9.7.8 Summary

Overall, it seems unlikely that psychological constructs and health outcomes selected on the questionnaires used to measure them were responsible for the null quantitative findings. Weaknesses in the design of the intervention may have contributed and it is possible that some positive intervention effects were not detected as a result of the study design. However, it is likely that the characteristics of the CHD patients who participated in the study were largely responsible for the lack of use made of the intervention and the general lack of significant change as a result.

9.8 Other explanations

In this section two additional possibilities are proposed which may explain study findings. These are post hoc explanations that have arisen through reflection on the study findings as a whole and on additional insights gained during the study.

Consequently, these explanations are not the result of systematic data collection and analysis. However, they are included here because of their potential to offer greater understanding of the study findings.

9.8.1 The shifting perspectives model of chronic illness

The shifting perspectives model of chronic illness offers an interesting interpretation of a number of this study's findings. According to this model, patients cope with the experience of long term conditions by shifting between illness and wellness perspectives (336). These perspectives and the model itself were derived from a metasynthesis of 292 qualitative studies of patients' experiences with long term conditions. In the illness perspective patients attend to their condition, focusing on sickness and the associated burden. By contrast, in the wellness perspective patients can distance themselves from the disease and focus on other aspects of their life. Whether patients hold an illness or a wellness perspective at any particular time affects how they

relate to their disease, to others and to life. Their perspective also reflects their needs at a particular time.

The model offers an explanation for the effect of time since diagnosis or coronary event. Having a long term condition for many years is one of the facilitators of a shift to a wellness perspective (336). Holding a wellness perspective is a reflection of having relatively few needs relating to a long term condition. Moreover, patients with a wellness perspective may not wish to use something that requires them to focus on their illness e.g. an internet intervention, as it might make it harder to maintain this perspective. Although intentions for intervention use at baseline were not systematically explored or recorded, several participants mentioned they felt they were unlikely to use the intervention much as their CHD was not currently causing them problems and they did not want to think, worry or be reminded about it.

The indication that those with recent complications from long-standing heart disease may have used and benefitted most from the intervention is also consistent with the shifting perspectives model of chronic illness. Signs of disease progression would be likely to cause a shift from a wellness to an illness perspective, requiring patients to once again focus on their condition and heightening their needs (336). For those who experienced them, the model may also explain the importance of the effects of the intervention on ceasing to worry about heart disease and generally feeling better. These intervention effects seemed particularly valuable to participants as they allowed them to put their heart disease to the back of their minds. This appears to be consistent with a shift to a wellness perspective. Patients gain this perspective in many ways, including learning as much as they can about the disease, reframing their disease situation so it appears less daunting and locating resources to help them deal with it (336). For some participants the intervention may have helped them achieve a wellness perspective. For

others who already held a wellness perspective, the existence of the intervention as a resource to help them deal with their CHD should their situation change, may have increased their confidence in their ability to maintain this perspective. This offers an explanation for the apparent paradox of people wanting continued access to the intervention despite never having used it.

The model presents the two perspectives as adaptive, reflecting people's needs and situations at a particular time, and does not consider any one perspective to be right or better. However, the findings here suggest that being able to take a wellness perspective is highly valued by patients. Holding a wellness perspective reflects a reduction in attention a patient pays to their condition. This would seem to conflict with the aims of secondary prevention, which requires active patient self-management. The effect of maintaining a wellness perspective for disease management and secondary prevention seems worthy of further investigation.

9.8.2 Altruism

Another paradox in this study was the participation of people who did not think they would use an internet intervention or who reported a general lack of appeal of using computers. Comments made by participants at the time they were recruited suggest that for some, taking part in a research project held more appeal than the intervention itself. These patients viewed the study as an opportunity to give something back for the treatment they had received, or to pass on the benefit of their experience to future patients. It must be acknowledged that these were comments spontaneously made by a few participants and it is not clear how widely this altruistic motivation for participation was held. Although this is only anecdotal evidence, its plausibility is strengthened by the importance of contributing to research apparent from some interview participants' comments about intervention use. Repeated and regular use of the intervention by some

participants appeared to be motivated by their research participation more than any particular personal need.

Altruism as a motivator for research participation has been reported before, most commonly in the context of clinical trial participation (337;338) but also in other health-related research including cancer screening (339) and qualitative studies (340). Being motivated by altruism has been found to relate to adherence in a clinical trial (341). It seems it may also have been related to some intervention use in the current study.

Although there was no direct evidence that altruism was responsible for any other kind of adherence in this study, if it was a widely held motivation for participation then it may account for the high follow-up rates. Participants who did not make great use of the intervention continued to contribute to the research by completing follow-up questionnaires. Altruistic motivation may be another characteristic of this particular sample of patients with CHD. Again, this underlines the likelihood that those who participated in this study were a select group of patients.

9.9 Strengths and limitations

In exploring explanations for the null quantitative findings, discussion so far has focused on limitations of the sample, design, measures, and intervention. However, the study also had many strengths.

Firstly, the focus on psychological theory in the selection of mechanisms of action to test meant the study was able to build on the findings of previous research. It also followed guidelines for the evaluation of complex interventions (58-60) and for testing mechanisms of change through intervention (233).

Despite the study sample that resulted, sample criteria and recruitment were designed to be inclusive. The targeted approach to recruitment of GP practices included

consideration of the socio-economic and ethnic diversity of areas they served. Carstairs's deprivation scores for the participating practices suggest that the majority were located in relatively deprived areas of the UK, although the use of lack of car ownership and overcrowding to generate these scores may reduce their validity as markers of deprivation in areas of London. Here lack of car ownership and high population density may not distinguish materially deprived from more affluent areas particularly well.

However, due to the inclusive criteria adopted in this study, over 80% of CHD patients registered at participating practices were eligible to participate. Patients without home internet access or prior internet experience were included in the study and their inclusion was supported by identification of local free and low-cost public internet access and training in how to use the intervention. Intervention training was tailored to patients' level of experience with computers or the internet. For patients without home internet access training was delivered at local services providing public internet access.

Despite its short-comings, the intervention was selected as the best available at the time and developed according to the needs and quality criteria of UK patients with long term conditions. Furthermore it was supported and updated throughout the study by a team of UK cardiologists, a GP, a healthcare librarian and a health psychology researcher.

A strength of study design was the use of integrated quantitative and qualitative methods. While quantitative data aimed to capture intervention use and effects in the wider sample, qualitative data aimed to extend understanding of quantitative results.

The two methods worked well together in this study precisely because they were designed to address the same research questions. The interview sub-sample was carefully selected to capture the diversity of experiences within the sample as a whole.

The effectiveness of this selection process was checked against comments made by participants in the wider study sample at the end of their intervention period. As a result

of this methodological integration and rigour, the qualitative component of the study has proved invaluable in checking the validity of quantitative findings and evaluating explanations for the null quantitative findings. This was balanced by the quantitative component providing the appropriate context for interpreting and generalising qualitative findings from the interview sub-sample.

Follow-up rates in this study were high, exceeding 86% at 3 months and nearing 90% at 9 months. This reduces the chance of response bias influencing results and means that although the quantitative analysis resulted in null findings, there can be little doubt that these findings were robust.

However, the limitations of this study and their likely contribution to the null quantitative findings cannot be ignored. The lack of use of theory in the design and development of the intervention is a serious failing. Had the intervention been based on a clear theoretical framework then selection of the appropriate mechanisms to evaluate would have been determined by this. Also a more theory-based design may have increased the effectiveness of the intervention and so allowed the mechanisms of action to be tested.

At the time of study design, inclusion of a control group without access to an internet intervention was not considered essential for this initial study evaluating mechanisms of intervention action. However, given the lack of change that resulted from intervention use and the characteristics of the study sample, it became a limitation. The lack of any control group has meant that questions remain over the effect of the intervention.

Although the limitations of several quantitative measures used in the study are likely to have had little impact on the study findings because little use was made of the intervention, their failings are a concern for future research. Self-completion measures

of health behaviour were particularly weak, yielding skewed and, in the case of the IPAQ (281), large amounts of missing data which were likely to bias findings. As a result all but one measure of health behaviour was excluded from analysis. Even the single dietary measure that was retained had no established reliability or validity, unsatisfactory internal consistency in this sample and was only used because no better measure was identified. Objective behavioural measures could have been used but these tend to be intrusive and place a high measurement burden on participants. Moreover, the complexity of self-management of a long term condition means that measuring a single type of behaviour is unlikely to comprehensively capture self-management activities. Objective measurement of multiple health behaviours is likely to place an unacceptable measurement burden on participants.

Since this study was designed the lack of suitable measures to evaluate self-management interventions has been recognised and extensive work has been carried out to develop a generic measure for capturing meaningful outcomes of such interventions, the Health Education Impact Questionnaire (heiQ), (342). Interestingly the heiQ appears to cover two important issues highlighted in this study which were not captured by the quantitative measures used here: items within the constructive attitudes and approaches dimension relate to the ability to adopt a wellness perspective; items within the health services navigation dimension relate to the integration of an intervention with healthcare. However, the heiQ only contains four items in the health directed behaviour dimension, with physical activity the only behaviour clearly measured. Its social integration and support dimension may also be of limited use in evaluating internet interventions as items rely on spoken interaction and tangible support provided by friends, family and carers.

9.10 Implications

The findings of this study have implications for future development and evaluation of internet interventions and their potential for supporting self-management of CHD and other long term conditions.

9.10.1 Implications for development of internet interventions

Regular information updates, expert answers to user questions and tools with tailored feedback for monitoring health and self-management activities were the components which most encouraged ongoing use of the intervention in this study. These findings provide some guidance for the design of interventions with ongoing appeal for patients with CHD. It is important to note that while monitoring tools require little, if any, maintenance or development after their initial design, information updates and ask an expert services require significant ongoing maintenance and resources which need to be planned and funded. Contrary to internet interventions for other patient groups, online peer-support groups were unappealing to this sample of CHD patients. Patients with long term conditions may share common needs and user criteria for internet interventions. However, needs assessment and formative evaluation with patients from the target group are important for intervention design to meet their specific needs and preferences.

The study has identified two specific challenges for the design of future internet interventions. One is to design internet interventions which allow greater integration with patients' treatment and contacts with health-care professionals. A second is to design interventions which both facilitate use among novice users and appeal to experienced internet users.

Effectiveness of the intervention in this study might have been increased by stronger theory-based support and behaviour change components. Previous internet intervention

and CHD literature identified self-efficacy, illness perceptions and perceived social support as likely mechanisms of intervention action. So, incorporating techniques aimed at increasing self-efficacy, improving illness perceptions and perceived social support into the design of support and behaviour change intervention components may increase effectiveness. Future theory-based design of intervention components may be facilitated by the recently developed taxonomy of behaviour change techniques for use in behavioural interventions (79).

9.10.2 Implications for evaluation of internet interventions

Future evaluations of internet interventions can learn from strengths and limitations of this study. The integrated quantitative and qualitative methodology used in this study was a strength worth noting for future evaluation. However, evaluations may need to be conducted over time-scales longer than 9 months to meaningfully capture changing needs and associated intervention use. The addition of a control group, without access to an internet intervention would allow studies to evaluate whether maintenance of self-management behaviours, emotional status and quality of life may be positive effects of internet interventions. Systematically collecting data on or from non-participants, including reasons for declining participation and, if possible, their clinical and socio-demographic characteristics, would facilitate assessment of the representativeness of participants and extend understanding of barriers to uptake of these kinds of interventions.

The lack of reliable and valid self-report measures of relevant psychological constructs and health outcomes is a major issue for the evaluation of internet interventions. In particular, better measures are needed to capture self-management behaviours and the impact of internet interventions on psychological constructs and outcomes. The ability to adopt a wellness perspective and the integration of an internet intervention with

healthcare may be important outcomes from the patient perspective. A recently developed outcome measure for evaluating self-management interventions may prove useful for capturing these outcomes in future evaluations (342).

9.10.3 Implications for the potential of internet interventions

Findings from this implementation of an internet intervention question the potential of internet interventions for secondary prevention of CHD through improved patient self-management. In the context of this study, the potential of the intervention appeared to be limited by both patient need and lack of home internet access and experience.

Patient satisfaction with the intervention, despite lack of meaningful change on health outcomes in this study may suggest a tension exists between patients' own self-management priorities and the public health priorities for secondary prevention. This may have limited the potential of the intervention to improve health outcomes, although this study provides no firm evidence of this. Investigation of the relationship between secondary prevention aims and patients' self-management priorities and implications for the potential of internet interventions for patients managing long-term conditions may be a useful area for future research.

This study would seem to cast doubt over the likelihood of achieving significant health benefits for patients with long term conditions who do not have home internet access or experience of using computers by providing facilitated access to an internet intervention. UK government policy of providing free public internet access may not be sufficient to overcome the digital divide for these patients. However, this needs further exploration with other internet interventions and patient groups before any firm conclusions can be drawn.

9.11 Conclusions

This study aimed to explore use of an internet intervention by patients with CHD and evaluate the mechanisms of action of this intervention. Only a small proportion of patients with CHD participated in the study and overall use of the intervention was low. Little change in psychological constructs or health outcomes meant that it was not possible to statistically test mechanisms of intervention action. It appears that the characteristics of CHD patients who participated in the study were largely responsible for low use of the intervention and lack of change as a result.

This thesis aimed to develop a greater understanding of the potential of internet interventions for supporting self-management for patients with CHD. Findings from this implementation of an internet intervention cast doubt over the potential of internet interventions to overcome health inequalities noted in traditional self-management interventions for patients with CHD. Further research is needed to understand barriers to uptake and use of internet interventions and to establish the generalisability of these findings to other internet interventions and other patient groups.

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List of Abbreviations

BIPQ	Brief Illness Perceptions Questionnaire
CABG	Coronary Artery Bypass Graft
CDSMP	Chronic Disease Self-management Plan
CDSEI	Cardiac Diet Self-Efficacy Inventory
CESEI	Cardiac Exercise Self-Efficacy Inventory
CHD	Coronary Heart Disease
CHESS	Comprehensive Health Enhancement and Support System
CI	Confidence Interval
df	Degrees of Freedom
EPP	Expert Patient Programme
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HBM	Health Belief Model
HRQL	Health Related Quality of Life
HSE	Health Survey for England
IHCA	Interactive Health Communication Application
IPAQ	International Physical Activity Questionnaire
MARS	Medical Adherence Report Scale
MHLC	Multidimensional Health Locus of Control
MI	Myocardial Infarction
MRC	Medical Research Council
n	Sample Size
OR	Odds Ratio
PAPM	Precaution Adoption Process Model
RCT	Randomised Controlled Trial
SCT	Social Cognitive Theory
sd	Standard Deviation
TRA/TPB	Theory of Reasoned Action/Theory of Planned Behaviour
TTM	Transtheoretical Model

Appendices

Appendix A – Internet intervention literature review search terms and combinations

Database: ISI Web of Knowledge – Web of Science

Topic search terms and combinations:

1. For review literature: (internet OR ehealth OR e-health OR online OR interactive*)

Limits: English Language, Reviews, years 1998 – 2008

2. For primary studies: (internet OR ehealth OR e-health OR online OR interactive*) AND (((decision AND (aid OR tool)) OR (behavior* AND change) OR support OR CBT) AND (health OR illness OR disease))

Limits: English Language

Database: Medline (accessed via WebSpirs)

“MeSH” and other search terms and combinations:

1. For review literature: (“Internet” OR “Online-Systems” OR “Computer-Systems” OR interactiv* OR ehealth OR e-health)

Limits: English Language, Reviews, years 1998 – 2008

2. For primary studies: (“Internet” OR “Online-systems” OR “Computer-systems” OR interactiv* OR ehealth OR e-health) AND (“Cognitive-Therapy” OR “Decision-Making-Computer-Assisted” OR “Decision-Support-Techniques” OR “Decision-Support-Systems-Clinical” OR “Behavior-And-Behavior-

Mechanisms” OR “Health-Behavior” OR “Social-Support” OR “Self-Help-Groups”)

Limits: English Language

Database: PSYCHInfo (accessed via WebSpirs)

“Thesaurus” and other search terms and combinations:

1. For review literature: (“Internet” OR “Electronic-Communication” OR “Online-Social-Networks” OR “Online-Therapy” OR “Computer-Applications” OR “Computer-Assisted-Therapy” OR ehealth OR e-health OR interactiv* OR online)

Limits: English Language, Literature-Review OR Meta-Analysis OR

Systematic-Review, years 1998 – 2008

2. For primary studies: (“Internet” OR “Electronic-Communication” OR “Online-Social-Networks” OR “Online-Therapy” OR “Computer-Applications” OR “Computer-Assisted-Therapy” OR ehealth OR e-health OR interactiv* OR online) AND (“Social-Support” OR “Support-Groups” OR “Behavior-Change” OR “Coping-Behavior” OR “Health-Behavior” OR “Illness-Behavior” OR “Descision-Support-Systems” OR “Cognitive-Behavior-Therapy” OR “Cognitive-Therapy”

Limits: English Language

Appendix B – CHD intervention literature review search terms and combinations

Database: Web of Science (accessed via ISI Web of Knowledge)

Topic search terms and combinations: (coronary OR heart disease OR cardiac OR angina OR heart attack OR myocardial infarction OR cardio* OR ischemi* OR iscaemi*) AND (psycholog* theor* OR psycholog* model OR self efficacy OR social cognit* theory OR outcome expecta* OR health belief model OR perceived susceptibility OR perceived severity OR perceived benefit OR perceived barrier OR theory of reasoned action OR theory of planned behavior* OR attitude* OR social norm* OR subjective norm* OR motivation OR perceived behavior* control OR stage* of change OR transtheoretical model OR decisional balance OR process* of change OR social support OR transactional model of stress OR cognitive appraisal OR threat appraisal OR coping OR self regulation theory OR common sense model OR common sense theory OR illness belief* OR illness perception* OR illness representation*) AND (secondary prevention OR rehabilitation OR disease management OR self management OR self care OR health education OR lifestyle)

Refined by: (Document Type=Article) AND (Languages=English)

Database: Medline (accessed via OvidSP)

“MeSH” and other search terms and combinations:

(“Heart Diseases” OR “Angina Pectoris” OR “Coronary Artery Disease” OR “Myocardial Ischemia” OR “Myocardial Infarction”) AND (“Psychological Theory” OR “Cognition” OR “Models, Psychological” OR “Self Efficacy” OR social cognit* theory OR outcome expecta* OR health belief model OR perceived susceptibility OR

perceived severity OR theory of reasoned action OR theory of planned behavior* OR
“Intention” OR “Attitude to Health” OR perceived benefit OR perceived barrier OR
subjective norm OR social norm OR social influence OR perceived behavior* control
OR transtheoretical model OR stage* of change OR decisional balance OR process* of
change OR “social support” OR transactional model of stress OR threat appraisal OR
coping OR self regulation theory OR theory of self regulation OR common sense model
OR illness perception* OR illness representation* OR illness belief*) AND
 (“Secondary Prevention” OR “Rehabilitation” OR “disease management” OR “Self
Care” OR “Health Education” OR “Life Style”)

Database: PSYCHInfo (accessed via OvidSP)

“Subject Heading” and other search terms and combinations:

(“ischemia” OR “heart” OR “Cardiovascular disorders” OR “angina pectoris” OR
“cardiology” OR “heart disorders” OR “Myocardial Infarctions”) AND (“psychology”
OR “cognition” OR “theories” OR “models” OR “psychosocial factors” OR
“psychological theories” OR “health care psychology” OR “Self Efficacy” OR “Social
Cognition” OR “Expectations” OR outcome expecta* OR social cognit* theory OR
health belief model OR perceived susceptibility OR perceived severity OR perceived
benefit* OR perceived barrier* OR “Reasoned Action” OR theory of reasoned action
OR theory of planned behavior* OR “Intention” OR “Attitudes” OR “Health Attitudes”
OR “Physical Illness (Attitudes Toward)” OR “Social Norms” OR “Planned Behavior
OR “Motivation” OR “Social Influences” OR subjective norm* OR perceived behavior*
control OR “Stages of Change” OR transtheoretical model OR stage* of change OR
decisional balance OR process* of change OR “Social Support” OR transactional model

of stress OR “Cognitive Appraisal” OR threat appraisal OR “Coping Behavior” OR
“Self Regulation” OR self regulation theory OR common sense model OR common
sense theory OR illness belief* OR illness perception* OR illness representation*)
AND (“Rehabilitation” OR “Rehabilitation Education” OR “Psychosocial
Rehabilitation” OR “Self Management” OR “Self Care Skills” OR “Prevention” OR
“Disease Management” OR “Health Education” OR “Lifestyle Changes” OR
“Lifestyle”).

Appendix C – Details of intervention development work tasks and members of the working group that carried them out

Tasks	Methods	Detail of work
<p>Reviewing and re-structuring the menu of information.</p> <p>See Appendix D for the updated topic menu.</p>	<ul style="list-style-type: none"> Individual members of the working group reviewed the menu of main topics of information Main information topics and sub-topics relevant for UK users were then agreed through group discussion. Most of the technical changes to the topic menu were made before anglicising and updating the information content to guide the process and development work The menu of topics was further refined and expanded during the task of anglicising and updating the information content and following input from the user representative. 	<p>Changes to the topic menu as a result included:</p> <ul style="list-style-type: none"> Anglicisation of treatment names and medical terms (e.g. EKG to ECG, Edema to Oedema or swelling) Replacing topics less relevant to UK users (e.g. Health Insurance Coverage) with those more relevant (e.g. NHS services, NHS standards and Patient Choice in the NHS) Expansion of the main and sub-topics to include more comprehensive, wide-ranging, basic and in-depth information as demanded by user criteria (e.g. adding overview sub-topics within main topics that link on to more detailed sub-topics, adding sub-topics about preparation and what to expect to surgery topics, adding rehabilitation and recovery topics) Reordering the topics menu more intuitively to reflect an illness journey and increasing in complexity (e.g. placing risk factors and heart-healthy lifestyle topics before treatment topics, placing medication treatment topics before surgical treatment topics).
<p>Checking, updating anglicising and expanding existing content.</p>	<ul style="list-style-type: none"> Researchers carried out most of the work reviewing existing and writing additional content (to increase use of plain English) before being checked for accuracy by GPs and cardiologists More clinical topics were reviewed and additional content written by a GP (e.g. symptoms, diagnostic tests and investigations) and the cardiologists (e.g. medicines, surgery, other procedures and devices) before being checked and edited for plain English by researchers CHESS-trained researchers then did the technical work to add and format new documents and text, and delete out of date or irrelevant documents 	<p>This was the major task of the development work. In order to meet user criteria:</p> <ul style="list-style-type: none"> Content was expanded to provide both basic and more scientific and technical information and resources, with each piece of information presented in a short 'bite-sized' section as part of the Question and Answer information service. An information service (Consumer Guide) that provided lengthier, highly US-focused information on certain topics was removed Content was added for topics which only previously contained links to information or resources provided by other web-sites (e.g. most diagnostic tests and investigations topics) Information was made more evidence-based and more clearly up-to date by referring to specific research findings.

		<ul style="list-style-type: none"> • Dictionary terms and definitions were similarly anglicised and expanded to include additional scientific and technical terms. • Links to information and resources provided by other websites were replaced with links to information and resources mainly from (but not limited to) UK non-commercial websites • Descriptions of providers of information and resources on these external websites and of the information and resources themselves were added to give a better idea of where users were choosing to go • Review dates were added to each article provided by an external website. <p><i>CHES Living with Heart disease</i> originally:</p> <ul style="list-style-type: none"> • Contained just over 400 documents of information in the Question and Answer service. This development work increased the number to nearly 800. • Linked to approximately 350 articles, resources and details of organisations provided by external websites. This development work increased the number to over 700.
<p>Replacing personal stories from US patients with personal stories from UK patients.</p> <p>See Appendix E for personal stories volunteer information sheet.</p>	<ul style="list-style-type: none"> • UK patients with heart disease were recruited by a cardiac research nurse and a health services researcher by placing adverts and flyers in the local press, patient groups and patient group publications and by visiting cardiac rehabilitation exercise classes. • The two researchers then interviewed volunteers about their experience of heart disease (including impact on life and relationships, treatment, recovery, help and support). • The health services researcher then drafted a "Personal Story" for each volunteer based on transcripts of these tape-recorded interviews and guided by DIPEX (now healthtalkonline) training and methodology, provided by the Health Experiences Research Group, Department of Primary Health Care, University of Oxford. • Each "Personal Story" was checked and edited by the individual volunteer until they were happy for it to appear on <i>CHES Living with Heart Disease</i>. • Volunteers' names were replaced with pseudonyms to protect 	<ul style="list-style-type: none"> • The 20 US personal stories were removed • 13 UK patients volunteered, of these 7 were interviewed. The remaining volunteers were not interviewed either because they had similar characteristics to others who were interviewed, or because travel time and costs made arranging interviews unfeasible • 2 UK personal stories were completed and ready for the test version of <i>UK CHES Living with Heart Disease</i> • Remaining UK personal stories were added when ready at a later date

	<p>their anonymity.</p> <ul style="list-style-type: none"> • Volunteers were reimbursed for their time according to Involve guidelines (317). • The PhD researcher and trained administrative staff carried out the technical work to remove the original personal stories from US patients from <i>CHESS Living with Heart disease</i> and add, structure, format and link the UK stories to relevant topics. 	
Updating and anglicising interactive services	<ul style="list-style-type: none"> • One of the GPs searched for suitable UK English versions of assessments, adapted existing and wrote additional material • Replacement assessments were then programmed by the CHESS Team • The PhD researcher checked all the other interactive services and where possible made simple content and technical changes in files supplied by the senior CHESS IT Programmer. • The CHESS team carried out more complex programming changes. 	<ul style="list-style-type: none"> • Diet, exercise and mood self-assessment tools were replaced by UK English versions based on questionnaires designed for or used with UK samples, including scoring algorithms and written feedback for all levels of scores • Language, information and instructions in other interactive services (e.g. Health Tracking, Action Plans, Personal Journal, Discussion Group, Ask an Expert) were anglicised and updated to reflect UK guidelines.
Organising, structuring and linking information	<ul style="list-style-type: none"> • Where researchers checked and updated information topics they also determined the order of documents and identified where documents, topics and dictionary definitions should link • As part of reviewing topics checked and updated by clinicians the PhD researcher determined the order of documents and identified places for links. • CHESS-trained researchers and administrative staff then carried out the technical work to order and link documents and add hyperlinks. 	<ul style="list-style-type: none"> • Information documents within each topic were ordered intuitively from simple or introductory to more in-depth and specific. • Hyperlinks were embedded within sections of information linking on to more in-depth and specific information, relevant information in another topic or service and to dictionary terms, allowing more in-depth information to use more technical terms and still be relatively brief and understandable.

Appendix D – CHES Living with Heart Disease updated and anglicised Topic Menu

1 - Heart Disease		
11 - Introduction	111 - Structure and function of the heart and blood vessels	
	112 - Disease process	
	113 - Facts and Figures	
12 - Cardiovascular Disease (CVD)	121 - Coronary Heart Disease (CHD)	1211 - Heart Attack (MI)
		1212 - Angina
		1213 - Heart failure
	122 - Stroke	
	123 - Aneurysm	
	124 - Cardiomyopathy	
13 - Valvular Heart Disease		
14 - Arrhythmias	141 - Types of Arrhythmias	
	142 - Sudden Cardiac death	
15 - Symptoms	151 - Chest pain (angina)	
	152 - Difficulty in breathing	
	153 - Palpitations	
	154 - Swelling	
2 – Risk Factors		
21 – Risk factors overview		
22 – Cholesterol and other blood lipids / fats.	221 – Cholesterol	
	222– Triglycerides	
23 – High Blood Pressure (Hypertension)		
24 – Obesity and being overweight		
25 – Genetics	251 – Genetics overview	
	252 – Family history	
	253 – Ethnicity	
26 – Diabetes		
27 – Smoking		
28 – Drugs and Alcohol		
29 – Other risk factors		
3 – Diagnostic tests and Investigation		
31 – Blood and Urine tests		
32 – Chest X-Ray		
33 – ECG (Electrocardiogram)		
34 – Stress/Exercise Test		
35 – Heart Monitors		
36 – Catheterisation		
37 – Echo (Echocardiogram)		
4 – Heart-healthy lifestyle		
41 – Overview of heart-healthy lifestyle		
42 – Diet		

		421 – Healthy diet and heart-healthy foods	
		422 – Diets	
		423 – Sticking to a diet	
		43 – Exercise and physical activity	
		44 – Achieving a healthy weight	
		45 – Stopping smoking	
		46 – Alcohol	
		47 – Recreational drugs	
		48 – Support from others	
		49 – Spiritual well-being	
5 – Emotional and relationship issues	51 - Emotions and heart disease overview		
	52 – Anxiety and fear		
	53 – Anger, hostility and frustration		
	54 – Stress management		
	55 – Sadness and depression		
	56 – Staying optimistic		
	57 – Sex		
	58 – Partner or spouse		
	59 – Family and friends		
6 – Treatments	61 – Medicines	611 - overview of treatments for different coronary heart disease conditions	6111 – Angina treatment
			6112 – Heart attack treatment
			6113 – Heart failure treatment
		612 – Lowering Blood Pressure	6121 – Overview of treatments to lower blood pressure
			6122 – ACE inhibitors
			6123 – Alpha-blockers
			6124 – Angiotensin II inhibitors
			6125 – Beta-Blockers
			6126 – Calcium channel blockers
		613 – Lowering your cholesterol	6131 – Overview of treatments to lower cholesterol
			6132 – Fibrates
			6133 – Statins
		614 – Preventing blood clots	6141 – Overview of treatments to prevent blood clots
			6142 – Aspirin
			6143 – Clopidogrel
			6144 – Dipyridamole
			6145 – Warfarin

	615 – Improving blood flow to your heart and controlling heart rhythm	6151 – Overview of treatments to improve blood flow and control heart rhythm
		6152 – Digoxin
		6153 – Nitrates
	616 – Getting rid of excess fluid (diuretics)	6161 – Overview of treatments to get rid of excess fluid (diuretics)
		6162 – Thiazides
		6163 – Furosemide
		6164 – Spironolactone
	617 – Controlling pain	6171 Overview of treatments to control pain
		6172 Paracetamol
		6173 NSAIDS
		6174 Codeine and Opiates
	618 – Drug interactions	
	619 – Getting the best from your medicines	
62 – Procedures to widen arteries – Percutaneous Coronary Interventions (PCI)	621 – Overview of Percutaneous Coronary Interventions (PCI)	
	622 – Angioplasty	
	623 – Stents	
	624 – Brachytherapy	
63 – Surgery	631 – Coronary Artery Bypass Graft Surgery (CABG/CABS)	6311 – Bypass surgery
		6312 – Preparing for bypass surgery
	632 – Heart Transplant	6321 – Heart Transplant Surgery
		6322 – Preparing for heart transplant
	633 – Heart valve repair and replacement	6331 – Heart valve surgery
		6332 – Preparing for heart valve surgery
64 – Other procedures and devices	641 – Pacemaker	
	642 – Defibrillators	
	643 – Left Ventricular Assist Device	
	644 – Ablation	
	645 – Balloon Valvuloplasty	
65 - Alternative/Complementary Treatments	651 – Food supplements and vitamins	
	652 – Therapies	

7 – Rehabilitation and recovery	71 – What to expect after ...	711 – Heart attack	7111 – Making sense of your heart attack	
			7112 – Heart attack recovery	
			7112 – Helping heart attack recovery	
		712 – Hospital based procedures	7121 – Procedures to widen arteries – Percutaneous Coronary Interventions (PCI)	
			7122 – Other procedures and devices	
		713 – Surgery	7131 - Coronary Artery Bypass Graft Surgery (CABG/CABS)	
			7132 - Heart Transplant	
			7133 - Heart valve surgery	
		72 – Cardiac rehabilitation	721 – Cardiac rehabilitation programmes	
			722 – Accessing cardiac rehabilitation	
73 – Resuming activities	531 - Everyday activities			
	532 – Going back to work			
8 – Your healthcare systems	81 – NHS Services			
	82 –Doctors, other healthcare professionals and communication			
	83 – NHS standards	831 – National Service Framework (NSF)		
		832 – National Institute of Health and Clinical Excellence (NICE)		
		833 – Patient rights		
		834 – If things go wrong		
		84 – Patient choice in the NHS		
	85 – Private healthcare			
86 – Research				
9 – Benefits and Social Services	91 Benefits			
	92 Prescription Charges			
	93 Social Services			

Appendix E – Personal stories volunteer information sheet

[UCL Departmental headed paper]

Personal Stories for an interactive website to help people with coronary heart disease – the Comprehensive Health Enhancement and Social Support (CHESS) system for patients with Coronary Heart Disease

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask us if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

The Comprehensive Health Enhancement and Support System (CHESS) for patients with coronary heart disease is an interactive website developed in Wisconsin, USA. Its aim is to provide comprehensive help for people with heart disease by giving information about the condition and treatment, emotional and social support, self-assessment questionnaires and help to improve people's diet and exercise. We are adapting the website to make it suitable for people living in Britain.

One of the parts of the website that people have found helpful in the past is a collection of "personal stories" from people living with heart disease. These are reports from people with heart disease, describing in their own words what the illness has meant for them and their families.

At the moment, all the "personal stories" are from the United States and we would like to replace these with stories from British people with heart disease.

Once the CHESS website has been adapted for use in Britain, we will investigate:

- Which parts of the website are the most helpful for patients
- The best way for patients to use the website in order to improve their health

2. Who can take part?

We hope to interview people with different experiences of heart disease, from as many different backgrounds as possible.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. If you decide that you do not want us to use your interview, we will respect your wishes and dispose of the tape securely.

4. What will happen to me if I take part?

A researcher from UCL will interview you before the end of March 2006. The interview should take about an hour and there should only be one visit. This will be in a mutually agreed place, which could be your home, or wherever you are most comfortable.

We will ask you to tell us your experiences of heart disease and how you felt about them. The interviewer will tape-record what you say and use this to write a description of your experience in your own words. This written “story” will be returned to you to check and change as you wish.

Once you are happy with the “story” to be placed on the website, we will ask you to sign a Release Form allowing this. If you are not happy with the “story” going on the website, you do not have to give your consent at this point, and your interview will not be used.

Although the “story” will be in your own words, we will edit it so that the general reader cannot identify you.

5 What are the possible disadvantages of taking part?

There should be no disadvantages to taking part in the interview. If, however, you change your mind about taking part, for example if you were to find it upsetting, you would be able to stop immediately.

Your travel expenses will be reimbursed and you will be reimbursed £45 for your time. This reimbursement will cover the time taken in the interview, and in checking and changing your ‘story’. Reimbursement at this level will not disadvantage volunteers in receipt of benefits.

6. What are the possible benefits of taking part?

Being interviewed for our study will not help you. However, hearing about your experiences and feelings might give some insight and support to others with heart problems.

7. What if there is a problem?

We think it is very unlikely that something could go wrong, as we are only conducting interviews, but we need to tell you what procedures will be in place, should you have any complaints. If you have any concerns about the study, please contact the Project

Researcher Jo Burns, on 020 7288 3027. If they do not answer your questions satisfactorily, you can contact Dr Elizabeth Murray (please see contact details at the end of the information sheet) who has overall responsibility for the study. She can also advise you who else to contact, if she is unable to answer your concerns or questions.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital or through these contact numbers: NHS Direct: 0845 4647 The Independent Complaints Advisory Service: 0845 120 3784

8. Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept strictly confidential.

Our procedures for handling, processing, storage and destruction of your data are compliant with the Data Protection Act 1998. Any information about you that leaves the University will have your name and address removed so that you cannot be recognised from it.

The procedure will be as follows:

- The interview will be recorded on audio tape
- The tape will be numbered and kept in a locked cabinet in a room that is kept locked when no one is there
- When we type the interview we will remove details that might identify you. The typed version of the interview will also be given to you to check so that you are happy that you should not be identified by the readers of the website

- Identifiable data about you will only be seen by authorised persons such as the research team
- Tape recordings of discussions will be stored securely and destroyed at the end of the study

As a participant, you have the right to check the accuracy of data held about you and correct any errors.

9. Anonymity

The interview will be put on the website without your name attached and every attempt will be made to ensure your anonymity. However, complete anonymity cannot be guaranteed. It is possible that somebody somewhere – perhaps, for example, somebody who looked after you in hospital or a relative – may identify you.

The personal stories will initially only be seen by the research staff and people who are invited to use the website for our research. However, if the website is found to be helpful to people with heart disease, there is the possibility that your “personal story” could be made available, in an anonymous form, on the internet at some time in the future.

A picture of someone else, obtained from a photographic agency, may be attached to the text of your “personal story”.

10. What will happen to the results of the research study?

The results of the research on CHESS will be published in academic journals. You will not be identified in any report or publication arising from this research.

11. Who is organising and funding the research?

The research is organised by the E-health Unit in the Department of Primary Care and Public Health Sciences, Royal Free and University College Medical School. The BUPA Foundation Medical Research Charity is funding the research.

12. Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the Camden and Islington Local Research Ethics Committee.

13. Contact Details

If you have any queries or require any further information, please contact:

Dr Elizabeth Murray – Project Leader	Address:
Jo Burns – Project Researcher	E-Health Unit
Tel: Jo Burns 020 7288 3365	Primary Care and Population Sciences
Project office 020 7288 3475	University College London
	Level 2 Holborn Union Building,
Fax: 020 7281 8004	Archway Campus
E-mail: jo.burns@pcps.ucl.ac.uk	Highgate Hill, London N19 5LW

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for considering taking part in our study and taking the time to read this sheet.

Appendix F – Patient panel information sheet

[UCL Departmental headed paper]

Who are we?

The e-health unit is part of the department of Primary Care and Populations Sciences at University College London. The unit was established in 2002 by Dr Elizabeth Murray, who holds a Department of Health Career Scientist Award.

What do we do?

The unit focuses its research on the role of new technologies in enabling patients to take better care of their health. For more information about the e-health unit, please see our website: <http://www.ucl.ac.uk/pcps/research/ehealth/index.htm>

One of the main focuses of research within the unit is the role of “internet interventions” in the self-management of chronic illness.

What do we want?

We are seeking to recruit a maximum of 8 people to help us assess a specific internet intervention for people with heart disease called CHESS (see below). We have revised CHESS for use in the UK but before we begin formally testing its impact within a funded research study we would like to get feedback on the changes we have made. We want to do this by forming a patients panel consisting of 6 –8 people with heart disease who are willing to use the programme over a period of 3 weeks. During this time members of the patients panel will come together up to 3 times so that our researchers can identify any barriers to using the programme that they might have come up against.

What is CHESS for Coronary Heart Disease

The Comprehensive Health Enhancement and Support System (CHESS) for patients with Coronary Heart Disease is a multi-faceted interactive computer programme.

Unlike standard health websites the CHESS system contains more than information alone. Its main components are:

- Information Functions

Health information about heart disease in the form of questions and answers, an electronic library of evidence based articles on heart disease, a CHESS address book listing medical, voluntary and lay organizations, collated web based tools and resources, and an “ask the Expert” e-mail service

- Information PLUS Functions

- **Emotional and social support:** through personal stories, information about likely emotional reactions to heart disease, and a moderated on-line discussion group
- **Self-assessment questionnaires:** to help the patient identify areas for improvement, whether in behaviours (diet, exercise, smoking), personal relationships (friends, spouse, family), or medical interventions (lipids, blood pressure, medications)
- **Behaviour change support:** formal exercises to aid the patient in prioritizing areas for change, setting goals for change, identifying barriers and facilitators to change, and providing encouragement and feedback as the patient moves through the cycle of change

CHESS is developed by a multi-disciplinary team in Wisconsin, USA, which combines computer expertise with input from clinicians, health psychologists, health educators,

health journalists, information scientists and researchers. This team has nearly 15 years experience of developing CHES modules and have published extensively.

Why anglicised and update CHES CHD?

Although CHES in its American form is likely to meet the needs of patients with CHD - data from a previous E-Health Unit study suggests that patients welcomed access to such internet interventions **that were tailored to the UK situation, and contained local health service information.** The unit has therefore spent the last few months updating and amending the US version of CHES (which has only been piloted with a US audience). The CHES UK version now includes more recent research evidence, complies with British guidelines and provides measurements in British units. The language of the programme reflects British English usage rather than American English. Information about local hospitals, voluntary groups, and services is also included.

Who are the UK team?

The updating process has been undertaken by a multi-disciplinary team comprising of clinicians (both general practitioners and cardiology specialists), a health psychologist, an educationalist, an information scientist, a health services researcher, and a cardiac research nurse. The team also receives technical support from CHES US-based personnel, such as computer programmers.

What will be expected of Patient Panel members?

The UK CHESS heart disease module is in a draft form. In order to ensure that it will be suitable for use in future research trials we would like to trial it with a panel of users. Patients are people who already have heart disease and who are willing to use the programme and give us their feedback on it so that we can improve it, as necessary. As a member of our patient panel you will be:

- Trained in the use of CHESS for CHD
- Have access to the draft version in your home
- Fully involved in discussions about the content and presentation of the updated programme

The trialling will take place over a 3-week period. It will be up to you how long you spend using the programme each day – what we will ask is that during this period of home access you keep a diary recording your use of the programme and detailing any problems or concerns you encounter during use. Patients will travel to Archway in North London to participate in up to 3 focus group meetings. At these meetings you and other members of the patients panel will be asked by researchers to clarify problems encountered. You will also be asked to help generate or give feedback on potential solutions. After each focus group meeting alterations will be made to the programme in the light of agreed solutions and you will be asked to monitor and report back how useful these have been.

Do I need to have a home computer?

Yes - this is essential

Do I need to be connected to the internet already?

Yes. You will need to have a home computer that is already connected to the internet either via a dial-up or a broadband connection.

Do I need a special type of computer?

No. The computer you are currently using should be fine. If you do experience any problems with your computer when viewing the website you should record that in the diary given to you.

Do I need computer skills ?

No. No specific computer skills are needed. At the start of the panel we will show you around the CHESS website and answer any queries you might have.

When will I need to be available?

We hope to trial CHESS for 3 weeks commencing in the month of July 2006. You will need to set aside some time during this period both to use the programme at home and to attend up to 3 focus group meetings to be held in North London. **The dates of the focus groups are still to be confirmed but 2 are likely to take place on the afternoons of 14th and 28th of July respectively.**

Will I be reimbursed for my time and or travel?

Yes. You will receive £40 pounds a week for 3 weeks. This is to cover time spent recording your use of the programme in a diary provided by the research team. You will also receive £35 each time you attend a focus group meeting. In addition, you will be able to reclaim your travel to and from focus group meetings (up to a maximum of

£10.00 per meeting). Please note that this level of payment may affect eligibility for state benefits.¹

What will happen to the programme after its trialling by the patients panel?

We have already secured funding for a research study investigating how CHESS can help patients with Coronary Heart Disease achieve better health. The updated programme when finalised by the patient panel will be used in this study

What should I do if I want to be a member of the patient panel?

Please read through this information carefully and contact a member of our research team at the number given below if you have any questions you would like to ask. If having done this, you decide that you would like to take part please return the attached form to the E-Health Unit at UCL as soon as possible. We will be recruiting a maximum of 8 people to sit on the patient panel and want to select a mix of people that are representative of the UK population so we may not be able to involve everyone who wants to help us.

What if I change my mind?

You are free to withdraw from your involvement with us at any time and you do not have to give a reason for this.

¹ If you are interested in taking part but do not want your involvement to any affect state benefits claimed - a lower reimbursement level of £10 per week to record your use of the programme and £20 per focus group attended can be arranged. You may need to inform your local benefits office that you will be receiving these payments.

If you have any queries or require any further information, please contact:

Dr Elizabeth Murray – Project Leader

Address:

Jo Burns – Project Researcher

E-Health Unit

Tel: Jo Burns 020 7288 3365

Primary Care and Population Sciences

Project office 020 7288 3027/3474

University College London

Fax: 020 7281 8004

Level 2 Holborn Union Building,

E-mail: jo.burns@pcps.ucl.ac.uk

Archway Campus

Highgate Hill, London N19 5LW

Appendix G – Patient panel focus group topic guides

G.1 Topic guide for first patient panel focus group 18.07.06

General Impression: Overall what did you think about the CHESS for heart disease website, best bits and bits you liked least?

Questions on specific topics:

Q1. From the diaries I have a number of questions or topics which we currently don't have answers to or information on. These include:

- More in managing your medicines - When to take different medicines (what time of day) or how to seek advice about this, what do you do if you are away and running low on medicines (how can you get more?)
- Information on new weight loss drug that is being trialled and said to reduce relevant risk factors (Acomplia)
- Advice for people who have had a heart attack and find they need to take NSAIDs for chronic pain control (article useful but not specifically focused on heart disease patients)
- Strong interest on having information on financial implications of chronic disease, available support, assessment and benefits (benefits section planned but not there yet)

Was there anything else you looked for on the website which you couldn't find? If so what?

Q2. Emphasis on lifestyle changes to reduce risk and manage condition. There were various comments on this:

- That it repeatedly emphasizes this (which is good/which is bad?)

- That it can be a bit guilt-inducing (you've brought this on yourself)
- That it is overly rosy, if all this is true then how come fit and healthy people get ill too. Progression of heart disease might not be prevented even with lifestyle changes.

Is this something that needs changing? If so how?

Q3. Who is the website aimed at. A couple of people commented about who would or would not find this website useful:

- Too confusing and overwhelming for the average person with heart disease
- Good for someone who is already motivated but would it motivate someone who isn't
- Too comprehensive for the people who need the advice the most

How can we get the balance right between providing enough but not too much?

Q4. Look and feel of the site. Comments:

- Links to pictures and diagrams off-site but does not use them in Q&A
- Doesn't look engaging, instead looks a bit flat, a bit doom and gloom

What can we do about this?

Q5. New in CHESS section. Various comments:

- Library articles on recent news stories good
- Confusing to have questions there because not clear that they lead to info in the form of an answer (e.g. could be a quiz, could be questions they want you to answer)

- If link to one question out of a topic then you assume that's the only info CHESS has on the topic (whereas if you looked in the topic you'd see there were lots of questions on that topic)
- Confusing to have personal stories there as well as listing them in the personal stories section

What is it most useful to link to in the new in CHESS section?

Q6. Where to put Beginners guide. Various comments:

- About CHESS should be more obvious, you'll want to read it at the start e.g. in new in CHESS
- Basic web skills is something you might want to be taken to the first time you log in at the start, not really relevant after

Should we try and take people to Beginners guide when they log in for the first time?

Does it need moving to another area of the services menu?

Q7. Exercise assessment. Various criticisms:

- Annoying to go through a list of activities you don't do, or couldn't do even if you wanted to
- Confusing to answer, not clear if it is total time or per session
- Should discriminate between daily exercise rather than a long sessions of exercise less often, so that it reflects guidelines

How can we change this so it is clearer and better to complete?

Q8. Contradictory responses - bits some people liked but others disliked:

- Discussion group
- Journaling
- Action plans

Do we need to change these at all or just keep them as they are for people to take or leave them as they prefer?

Q9. Other comments. There are lots of more specific and technical comments made in the diaries that either we need to discuss with the IT people or didn't seem to need group discussion for us to make changes. However do any of you have any other comments or suggestions for the website that you would like to discuss with the others here?

G.2 Topic guide for second patient panel focus group 31.07.06

Feedback

- Changes made following last discussion
- Further changes planned following last discussion
- More suggestions for missing content from diaries (Q1 last time) These include:
 - How often to have cholesterol levels checked (although there is general info on how often blood tests should be done)
 - Convalescence after heart attack (what to expect in a convalescent home, info for carers of someone convalescing, odd symptoms e.g. muscle spasms and how to deal with them)
 - Troponin test
 - Drinking water as part of healthy lifestyle

Will add more info but no need to discuss further here

- Think we discussed questions 2-6 pretty well at last meeting so not planning to discuss them further here. Instead discuss a couple of things we were planning to change but individual members have now said they like, some new suggestions people have made and the remaining questions from last time

Questions

Q1. Things we planned to change but some people have now said they like

- Health tracking appearing when you log in to give you the option of updating it
- News items – links to BHF news (in CHESS update?)

Q2. New suggestions

- Structure instant library and address book (directory of organizations), rather than alphabetical list - can also structure web-tools
- Showing dictionary definitions after keywords

How can we get the balance right between providing enough but not too much?

Q3. (Q7 from last time) Exercise assessment. Various criticisms:

- Annoying to go through a list of activities you don't do, or couldn't do even if you wanted to
- Confusing to answer, not clear if it is total time or per session
- Should discriminate between daily exercise rather than a long sessions of exercise less often, so that it reflects guidelines

How can we change this so it is clearer and better to complete?

Q4. (Q8 from last time) Contradictory responses - bits some people liked but others disliked:

- Discussion group
- Journaling
- Action plans

Do we need to change these at all or just keep them as they are for people to take or leave them as they prefer?

Q5. (Q9 from last time) Other comments. There are lots of more specific and technical comments made in the diaries that either we need to discuss with the IT people or didn't seem to need group discussion for us to make changes. However do any of you

have any other comments or suggestions for the website that you would like to discuss with the others here?

Appendix H – Further development work carried out following user evaluation

Task	Aim	Details	Who did the work
Additional information content	To fill information gaps identified by users	<ul style="list-style-type: none"> • More content about managing medicines (when to take certain medicines, getting more medicines when away from home) • Other specific information requested by users 	<ul style="list-style-type: none"> • Content mainly written the lead GP in the working group • The PhD researcher then carried out the technical work using the CHESS in-house database software.
Renaming services and re-designing the home-page	To make services more obvious from the start, simplify layout and make presentation more appealing	<ul style="list-style-type: none"> • Used more intuitive names for services • Grouped services under fewer, clearer headings (names and headings suggested by users). • Moved the renamed CHESS update to the right of the screen • Enlarged the most appealing heart-focused image. See Appendix I for screen grabs of the home-page before and after further development. • Restructured, re-named and changed graphics throughout to be consistent with new names and grouping. 	<ul style="list-style-type: none"> • Significant amount of design and programming carried out by the CHESS team • The PhD researcher then tested out changes and identified further programming refinements and corrections • Further programming carried out by the CHESS team
Show all the main topics in the topics menu at a glance	To make information easier to find	<ul style="list-style-type: none"> • Topics menu changed to an expanding list of topics and sub-topics (like a file-store). Initially shows only the 9 main topics. Users then click on the main topic they are interested in to see sub-topics and access the information they want to find. 	<ul style="list-style-type: none"> • Programming work carried out by the CHESS team
Listing only the most relevant documents under any one topic or sub-topic	To make information easier to find and less overwhelming	<ul style="list-style-type: none"> • Number of documents of information linked to any one topic or sub-topic limited to no more than approximately 15 so that when viewed the list fills no more than a screen. • Where necessary more sub-topics were added to the topics menu to enable this. Repetition of the same information items in several topics was reduced so information in any one topic became more focused. 	<ul style="list-style-type: none"> • The PhD researcher carried out the technical work using the CHESS in-house database software.

Improving the search function	To make information easier to find	<ul style="list-style-type: none"> Improved the sensitivity of the keyword search by increasing number of keywords to make them more specific and each linked to smaller amounts of information. The original 280 CHESS keywords eventually increased to over 700 by the earlier development work expanding the topic menu, and this further development work 	<ul style="list-style-type: none"> The PhD researcher carried out the technical work using the CHESS in-house database software.
Improving the book-marking service	To make previously read information easier to find again	<ul style="list-style-type: none"> Adding the option to bookmark to the end of each information document in all of the "finding information" services. Included instructions on book-marking in the re-named CHESS Guide 	<ul style="list-style-type: none"> Programming work carried out by the CHESS team The PhD researcher wrote instructions for the book-marking service and added it to the re-named CHESS Guide
Displaying a dictionary definition when user clicks on a topic name before listing relevant information	To make topic content clearer from the start	<ul style="list-style-type: none"> Topic keywords linked to relevant definitions in the dictionary service 	<ul style="list-style-type: none"> The PhD researcher carried out the technical work using the CHESS in-house database software Minor programming to display linked definitions carried out by CHESS Team
Expanding the scope and information in the re-named CHESS Guide (formerly Beginner's Guide)	Making services clearer from the start	<ul style="list-style-type: none"> CHESS Guide re-written to provided better descriptions of available services and for use in training users in how to get the best out of <i>UK CHESS Living with Heart Disease</i> 	<ul style="list-style-type: none"> The PhD researcher re-wrote the CHESS Guide and carried out the technical work using the CHESS in-house database software Programming work carried out by the CHESS team to add relevant graphics for the additional services described
Clearer visual distinction between keyword search and dictionary search	Making different services clearer and reducing confusion	<ul style="list-style-type: none"> Altered the layout of the dictionary search to differ from the keyword search 	<ul style="list-style-type: none"> Programming work carried out by the CHESS team
Improving the use and presentation of the renamed CHESS Update (formerly New in CHESS)	To make it easier to see when CHESS was last updated, what has been added and how new information fits with existing information	<ul style="list-style-type: none"> Feature the month and year when new information is added Added facility to go to topics of information to which new information has been added rather than just to the single new/updated information item 	<ul style="list-style-type: none"> The PhD researcher carried out the technical work through remote access to this specific area of the files on the CHESS server Some minor programming work carried out by the CHESS team

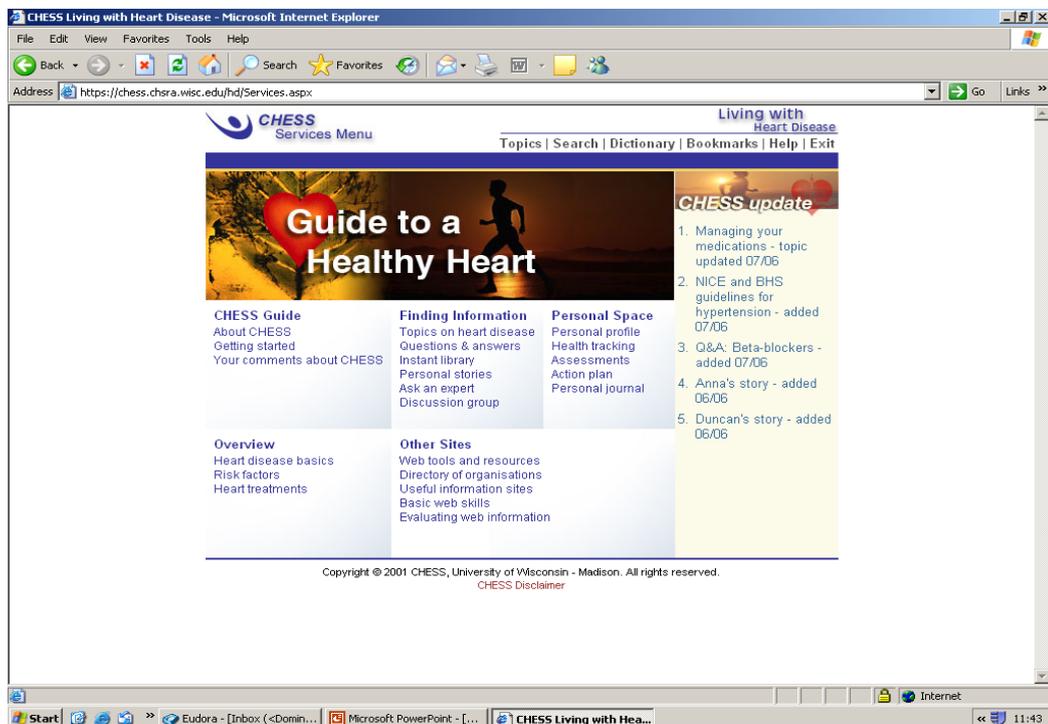
Adding relevant images	To make presentation more appealing, engaging and less text-based	<ul style="list-style-type: none"> • Relevant copy-right free images identified and purchased • Images resized, made web-ready and stored for easy access on a local server • Links to relevant images embedded in question and answer documents so images would appear when information in the question and answer pages were viewed by users 	<ul style="list-style-type: none"> • The PhD researcher was supported in identifying, purchasing, storing and linking images by local IT and administrative support staff • Some guidance provided by the senior CHESS IT programmer
Making it clear when to expect a response from the Ask an Expert service	To clarify expectations of the service	<ul style="list-style-type: none"> • Text was added to the Ask an Expert service to indicate users could expect a response in a week • This was judged feasible based on the pilot Ask an Expert questions posted by members of the user evaluation panel and users were happy with this response time 	<ul style="list-style-type: none"> • The PhD researcher wrote the changes and the CHESS team made did the minor technical work to add the text to relevant files
Making links to external websites open in a new window (rather than within the CHESS window)	To make it easier to return to CHESS after visiting an external website and more obvious when information is from an external website.		<ul style="list-style-type: none"> • Programming work carried out by the CHESS team
Option not to show disclaimer information after first log-in	To reduce the likelihood of re-reading less interesting information		<ul style="list-style-type: none"> • Programming work carried out by the CHESS team

Appendix I – Screen grabs of CHES Living with Heart Disease

I.1 Screen grab of Services Menu (home page) before development work



I.2 Screen grab of Services Menu (home page) after development work



Appendix J – Information for primary care practices

[UCL Departmental headed paper]

Study title: How does a web-based intervention benefit people with heart disease?

Why are we doing the study?

A systematic review has shown that web-based interventions that combine high quality health information with interactive services such as decision support, behaviour change support and peer support can benefit people with long-term conditions such as heart disease. However, we do not know how these interventions work, nor which components of these interventions are needed to help people. This study is designed to answer these two questions.

What is the web-based intervention?

The intervention we are using is called CHESS (Comprehensive Health Enhancement and Support System). It was originally designed by a team in the US, who have 15 years experience of designing and evaluating similar interventions. We have updated it, and adapted it for use in British General Practice. The team updating it included Dr David Patterson, Consultant Cardiologist at the Whittington Hospital, Cardiology Specialist Registrars, a Cardiology research nurse, academic GPs at UCL (Professor Irwin Nazareth and Dr Elizabeth Murray), health psychology and health services researchers. It has been thoroughly reviewed by a user panel of people with heart disease.

CHESS for Heart Disease now contains high quality, evidence-based information, presented in an accessible and interactive format. Most of the information is presented in a 'question and answer' format, with additional back up from a library of more detailed articles covering all aspects of heart disease and its treatment. An 'ask the

expert' service (with responses provided by the GPs, cardiologists and a librarian) allows users to ask for information they cannot find. This service does not provide individual clinical advice, it only provides generalised evidence-based information.

Additional services include “personal stories” – narratives by people with heart disease about how they responded to the diagnosis, and how they have changed their lives.

These “personal stories” are popular with other patients, and have been chosen to reflect the ethnic and social diversity in London, as well as a range of illness experiences.

There will be a moderated on-line discussion group, where participants can exchange information and support. Users have access to self-assessment quizzes, to help monitor diet, exercise and mood. Tailored information and support is provided in response to the results of these quizzes. Users are encouraged to complete ‘action plans’ to help them improve a specific health behaviour – e.g. diet or exercise.

What are the implications for the practice?

If you agree to participate, you will need to:

- Print out a list of all the people on your coronary heart disease register
- Review the list to see if any patients should not be approached. These are people who:
 - Are terminally ill (less than 9 months life expectancy);
 - Are not able to give informed consent, due to mental incapacity (e.g. psychotic illness, learning difficulties, cognitive impairment);
 - Do not speak English well enough to consult without an interpreter;
 - Are not able to use a computer independently due to visual, hearing or motor impairment.

- Send a letter to the remaining patients on the list, enclosing a study information sheet, and a consent form allowing the researchers to contact the patient.

Patients do not have to have any previous computer experience to participate, nor do they need to have home access to a computer. Training in use of CHESS will be provided, along with information on local free or low-cost public Internet access points.

Agreeing to participate in this study will not commit you to any work apart from these three tasks. However, patients may want to discuss the study with you before returning a consent form.

What are the implications for your patients?

Your patients will receive a letter, information sheet and consent form from the practice. Patients who opt-in to the study, by returning the consent form, will be contacted by Cicely Kerr, the research fellow on this study. She will explain the study over the phone, and if the patient is happy to proceed, will arrange to meet them at a mutually convenient place (either the patient's home if they have home Internet access or a public Internet access point). She will obtain informed consent, ask the patient to complete some baseline questionnaires, and provide training in the use of CHESS. Follow up training and support will be available, either by phone, or if necessary, face-to-face.

The patient will then have unlimited access to CHESS for nine months. There will be no compulsion on the patient to use CHESS if they do not find it helpful, but our experience is that most people enjoy using it. All participants will be asked to complete two further sets of questionnaires (at 3 and 9 months). Patients may leave the study at any time, without giving a reason.

CHES will not be available for use after the end of the study, but the long-term aim of our research is to make programmes like this freely available to everyone, e.g. via NHS Direct On-Line.

What are the expected benefits for participants?

Our previous research predicts that patients who use CHES are likely to:

- Become more knowledgeable about heart disease;
- Have a better understanding of what they can do to stay healthy (e.g. diet, exercise, stop smoking, take medication regularly);
- Feel more able to follow a healthy lifestyle;
- Feel better supported socially;
- Adopt a healthier lifestyle;
- And as a result of these changes, have an improved quality of life.

Who is doing the study?

The study is being run from the E-health unit in the Department of Primary Care and Population Sciences at UCL. The Director of the Unit, and PI on this study, is Dr Elizabeth Murray. She is a GP principal in Kilburn as well as being an academic. The research fellow is Cicely Kerr. Cicely is a health psychology researcher, and has a doctoral award from the Department of Health for this study. The study receives additional funding from the BUPA Foundation for Medical Research, a charity that is independent of the parent BUPA organisation.

The steering group for this study includes Professor Irwin Nazareth. Irwin is Professor of Primary Care at UCL, Director of the MRC GPRF, and a GP principal in Hampstead. Dr David Patterson, Consultant Cardiologist at the Whittington is on the steering group,

and plays an active role in updating and checking the CHES content. In addition the steering group contains Dr Lorraine Noble (Clinical Psychologist at UCL), Dr Richard Morris (Reader in Statistics and Epidemiology at UCL), and two user representatives.

If you would like to know more about the work of the E-health unit, please visit:

<http://www.ucl.ac.uk/pcph/research/ehealth/index.htm>

Appendix K - Letter from primary care practices to potential participants

[Practice headed paper]

[Date]

[Patient's name and address]

Dear *[Patient's name]*

Re: Taking part in a research study

Can you help?

Our practice is working with researchers at University College London to find out how patients can benefit from using a website specially designed for people with heart disease.

The study looks at how an interactive website helps patients with heart disease take care of their health. The website provides high quality information about heart disease, the different treatments available for heart disease, and how patients can help themselves to take better care of their health. Patients who take part in this study will have access to this special website, which is not publicly available, for nine months. In return, the researchers will ask you to fill in various questionnaires.

We think that you might be interested in taking part in this study. You do not need to have used the internet before and you do not need to have a computer at home to take part. Please take time to read the enclosed information leaflet, which gives details of the study and what it involves.

If you think you might like to take part, please fill in the expression of interest form (enclosed) and return it to Cicely Kerr (the main project researcher) in the pre-paid envelope provided. If you are unsure whether this study is suitable for you or you have any questions about the study, please ring the researchers on 020 7288 3027/3475.

It is up to you to decide whether or not to take part. Deciding not to take part will not affect the standard of care that you receive from your GP.

Thank you for taking the time to read this letter,

Yours sincerely

[GP's or practice name]

Appendix L – Study information for potential participants

[UCL Departmental headed paper]

Patient Information Sheet:

Study Title: How does an interactive website help patients with Coronary Heart Disease? The Comprehensive Health Enhancement Support System (CHESS) for patients with Coronary Heart Disease

You are being invited to take part in this research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve for you. Please read the following information carefully, and take time to decide whether or not you wish to take part.

What is the purpose of the study?

We know that most people with heart disease want more information about their heart problem and treatment options. People with heart disease often need help and support to help them take the best care of themselves. Unfortunately, not everyone gets the information and support they need.

We think one way of helping people with heart disease get the information and support they need is through a website. Websites like the one we are using in this study have been shown to benefit people with long-term health problems like diabetes and asthma, so we think that people with heart disease are also likely to benefit. But we don't know how these websites work. In other words, we don't know why people who use these sort of websites find them helpful, and why people who use these sites often end up with better health than people who don't.

This study aims to find out the answer to this question by following people with heart disease as they use this website, and examining what happens to their thoughts, beliefs, feelings and health-related behaviours.

This will help us design better websites in the future.

Why have I been approached?

We are looking for people with heart disease to use this website. Your General Practice has agreed to send this information to everyone with heart disease registered at your practice to give you the opportunity to participate. We are looking for about 170 people with heart disease to take part in the study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given a consent form and asked to sign it. You are still free to withdraw at any time and can do so without giving a reason. A decision not to take part, or a decision to withdraw at any time, will not affect the standard of care that you receive from your GP.

What will happen to me if I take part?

If you decide to take part, we will show you how to use the website we are studying. You will then be able to access the website as often (or as seldom) as you wish for next nine months. We will ask you to complete a questionnaire before you start using the website, and after three and nine months of using it. A few participants will also be asked if they would like to be interviewed about their experiences of using the website.

What is the website I will be using if I take part?

The interactive website that we are using in this study is called the Comprehensive Health Enhancement and Support System (CHESS). It has been specially designed for people with heart disease by researchers at University College London and heart specialists working in the NHS. There are many different components to the programme, including high quality information about heart disease, treatments for heart disease, lifestyle changes people can make to improve their health, and practical tips about day-to-day living that other people with heart disease have found helpful. There is the opportunity to read about other people with heart disease, and how they dealt with their illness. There will be an on-line chat room, where you can discuss things with other people participating in the project. This chat room will be confidential, and you don't need to give your name or any other identifying information unless you chose to. There is no need to use the chat-room at all if you would rather not – it is there for people who find it helpful and want to use it. There are also quizzes, and self-assessment tools, to help you decide whether you are leading a heart-healthy lifestyle, or whether there are things you would like to change. If you do decide to change something about your life, the website provides tips and tools to help you make these changes.

Only people participating in this research study can access this website. All the participants will be people with heart disease registered with one of the General Practices that is helping us with the study. We will teach you how to use the website, and answer any questions or difficulties that you have with it during the study. If you have internet access at home, you can use the website at home. If you do not have internet access at home, we will tell you about public Internet access points, such as local libraries and internet cafes. You will have a password which protects your access

to the website, so that only you can read the information that you put onto the website.

You are free to use the website as much (or as little) as you want.

What else will I have to do?

If you decide to take part in this study, you need to return the enclosed form giving your details to the research team. Once we receive this, we will contact you, and arrange a time to meet with you that is convenient for you. At this meeting we will explain the study, and answer any questions you may have. Once you are sure you would like to take part, we will give you a consent form to sign – but remember, even after you've signed the consent form you can withdraw at any time without giving a reason and without affecting the care you receive from your GP. The researcher will give you a questionnaire to complete and will then show you how to use the website either at the same meeting or at another convenient time. Filling in the questionnaires and being shown how to use the website will probably take about an hour each. If you need more help with using the website, you can phone the researcher and she will help you over the phone.

After three months we will send you another questionnaire to complete, and again after nine months. A few people will also be asked if they would like to be interviewed about their experience of using the website. You do not have to agree to be interviewed if you don't want to.

What are the possible benefits of taking part?

Previous research has shown that people using websites like this tend to become more knowledgeable about their illness, feel better supported, adopt healthier behaviours and improve their health. However, not everyone who uses these websites benefits, and we

do not know whether this website will help you personally. Your participation will help design better websites for you and other patients in the future.

What are the possible disadvantages or risks of taking part?

We do not think that there are any risks to your health from taking part. If there are certain parts of the website you do not like, or things you would rather not know, you do not have to look at these parts. If you do not like using any part of the website, you do not have to use it.

You will be giving up some of your time, both to use the website (if you find it helpful) and to fill in our questionnaires. We cannot reimburse you for this time. However, we can reimburse you for any travel expenses you have, for example travelling to meet the researcher. You will also have to meet the cost of internet access – either through your existing home Internet arrangements, or at public internet access points. We will let you know about local places that usually provide free internet access, such as libraries.

You may find some of the questions in the questionnaire rather personal. You do not have to complete any individual questions that you would rather not answer.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. Our procedures for handling, processing and storing any information you give us are in accordance with the Data Protection Act 1998.

What if there is a problem?

We think it very unlikely that something could go wrong, but we need to tell you what procedures will be in place should you have any complaints. If you have a concern

about any aspect of this study, you should speak with the main study researcher, Cicely Kerr (see contact details below) who will do her best to answer your questions.

If she does not answer your questions satisfactorily, you can contact Dr Elizabeth Murray who has overall responsibility for the study (see contact details below). She can also advise you on who else to contact if she is unable to answer your concerns or questions. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from: NHS Direct: 0845 4647

The Independent Complaints Advisory Services: 0845 120 3784

Who are the research team?

The research team are doctors (GPs and cardiologists), psychologists and researchers based at University College London. The study is funded by the BUPA Foundation medical research charity and has been approved by Camden and Islington local research ethics committee. If you have any queries or require any further information please contact us on: 020 7288 3027/3365.

Contact details.

Dr Elizabeth Murray – Project E-Health Unit, PCPS,

Leader

University College London, Archway Campus

Cicely Kerr – Project

Highgate Hill, London N19 5LW

Researcher

Tel: 020 7288 3027/3365

Fax: 020 7281 8004

<http://www.ucl.ac.uk/pcps/research/ehealth/index.htm>

E-mail: c.kerr@pcps.ucl.ac.uk



Appendix M – Participant consent form

[UCL Departmental headed paper and PCT logos]

CONSENT FORM: Patient Identity Code:

CHESS Codename:

Study Title: How does an interactive website help patients with Coronary Heart Disease? The Comprehensive Health Enhancement and Support System (CHESS)
for patients with Coronary Heart Disease

Please initial box

1. I confirm that I have read and understand the patient information sheet dated 06.07.2006 (version 5) 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 participating in the above study involves providing researchers with information by completing questionnaires.
3. I understand that participating in the above study involves having access to the CHESS interactive website to use whenever I want over a period of 9 months.
4. I understand that my use of the CHESS interactive website over the 9 months will be recorded.
5. I understand that all information that I provide while taking part of this study will be kept confidential and stored securely in accordance with the Data Protection Act 1998.
6. 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.

7. I agree to my GP being informed of my participation in the study.

8. I agree to take part in the above study.

9. I agree to a member of the research team checking information about
my heart disease and treatment in my GP medical notes

Signature of Participant: _____ Date:

Name of researcher taking consent

Signature:

Date:

You will be given a copy of your signed consent form to keep for your records

Appendix N – Interview information

[UCL Departmental headed paper]

Interview Information Sheet:

Study Title: How does an interactive website help patients with Coronary Heart Disease? The Comprehensive Health Enhancement and Support System (CHESS) for patients with Coronary Heart Disease

As part of the above study you have had access to the CHESS interactive website for at least 9 months. We would now like to interview you about your experience. Before you decide whether to participate in an interview it is important for you to understand what it will involve. Please take time to read the following information carefully and to decide whether or not you wish to be interviewed.

What is the purpose of the interview?

In this study we want to find out how the CHESS interactive website helps patients with CHD. The interviews are part of the same study, however we are only interviewing some of the patients who have participated in the study. The interviews will give us more in-depth information about whether the CHESS interactive website has helped you (if so how, if not why not?).

We will use this more detailed and in-depth information to inform the results from the questionnaires you completed during the study and to make sure that the results take into account individual experiences of patients who took part.

Why have I been approached?

We are only going to interview a small group of the patients who took in the study. Within this group we hope to interview people with different experiences of using the CHESS interactive website. We have used the information recorded by the website to make sure the group of patients we interview vary in how much use they have made of it. We want to interview both people who have used the website rarely and people who used it a lot.

Do I have to take part in the interview?

No. It is up to you whether or not you want to take part in an interview. If you do, you will be given an interview consent form and asked to sign it. You are still free to withdraw at any time and can do so without giving a reason. A decision not to take part, or a decision to withdraw at any time, will not affect the standard of care that you receive from your GP.

What will taking part in the interview involve?

A researcher will contact you to arrange a convenient time and place for the interview, which could be your home, or wherever you are most comfortable. The interview should take about 40 minutes.

The researcher will answer any questions you have about the interview and ask you to sign the interview consent form. In the interview you will be asked about your experience with the CHESS interactive website over the last 9 months: what you thought of it, what it was like to use, when you did or did not use it, when it did or did not help you, how it helped if it did. With your permission, the researcher will audio-record what you say.

What are the possible benefits of taking part in the interview?

Being interviewed as part of this study will not help you. However, sharing your experience in an interview will make the results of this study stronger and more useful in helping design better websites for you and other patients in the future

What are the possible disadvantages or risks of taking part in the interview?

You will be giving up 40 minutes of your time for this interview. We cannot reimburse you for this time. However, we can reimburse you for any expenses you incur if you travel to meet the researcher for this interview.

There should be no risks to taking part in the interview. We will only ask you about your experience using the CHESS website and will not ask you to discuss anything personal or upsetting. However, if you find you are discussing something you would rather not talk about or not have recorded on tape you will be able to stop the recording or the interview at any time.

What will happen to the information I provide in the interview?

The information that you provide in the interview will be kept confidential. Our procedures for handling, processing and storing any information you give us are in accordance with the Data Protection Act 1998.

The procedure will be as follows:

- The audio-recording of your interview will be labelled with the identity code that you were given when you originally consented to participate in the study, not your name, and kept in a secure locked cabinet or secure electronic file.

- We will write down the content of the audio-recording of your interview word for word and remove any names of people or places so that you cannot be identified by them. This transcript will be linked to your identity code, not your name, will be kept securely in a locked cabinet and in a secure electronic database, separate from your name and contact details.
- The audio-recording and your name and contact details will be destroyed at the end of the study which will make the transcript of your interview anonymous.

What if there is a problem?

We think it very unlikely that something could go wrong, but we need to tell you what procedures will be in place should you have any complaints. If you have a concern about any aspect of this study, you should speak with the main study researcher, Cicely Kerr (see contact details below) who will do her best to answer your questions.

If she does not answer your questions satisfactorily, you can contact Dr Elizabeth Murray who has overall responsibility for the study (see contact details below). She can also advise you on who else to contact if she is unable to answer your concerns or questions. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from:

NHS Direct: 0845 4647

The Independent Complaints Advisory Services: 0845 120 3784

Contact details.

If you have any queries or require any further information please contact the E-Health Unit on: 020 7288 3027/3365

Dr Elizabeth Murray – Unit Director

Address:

Cicely Kerr – Project Researcher

E-Health Unit

Tel: 020 7288 3027/3475

Primary Care and Population Sciences

Fax: 020 7281 8004

University College London

E-mail: c.kerr@pcps.ucl.ac.uk

Level 2 Holborn Union Building,

Archway Campus

Highgate Hill, London N19 5LW

Thank you for taking the time to read this information.

Appendix O – Interview consent form

[UCL Departmental headed paper]

INTERVIEW CONSENT FORM:

Study Title: How does an interactive website help patients with Coronary Heart Disease? The Comprehensive Health Enhancement and Support System (CHESS) for patients with Coronary Heart Disease

Patient Identity Code:

Please initial box

1. I confirm that I have read and understand the interview information sheet dated 05.09.07 (version 2) for an interview as part of the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that in the interview I will be asked about my experience of the CHESS interactive website in the above study.
3. I understand that the interview will be audio-recorded.
4. I understand that all information that I provide in this interview will be kept confidential and stored securely in accordance with the Data Protection Act 1998.
5. I understand that my participation is voluntary and that I am free to withdraw at any time, and can do so without giving any reason, without my medical care or legal rights being affected.
6. I agree to take part in an interview as part of the above study.

Signature of Participant: _____ Date: _____

Name of researcher taking consent

Signature:

Date:

You will be given a copy of your signed interview consent form to keep for your records

Appendix P – Interview schedule

Introduction:

Check participant has no further questions before the interview begins. Remind them they can stop the recorder at any time if they want. Let them know when the recorder is being started.

Main questions and possible follow-up questions (order may vary or questions may be omitted depending on responses to early questions or level of CHESS use):

Q. Overall, what did you think of CHESS?

What did you find most useful about it and why?

What did you like least about it and why?

Q. What did you think you might get from the CHESS website when you started?

How did it match up to your expectations?

Q. Did you use the website as much as you expected to?

If not why not?

Was there anything that affected how much you used CHESS? If so what?

Q. When were you most likely to use CHESS?

Why then?

Q. On what kinds of occasions did you find CHESS useful?

How did CHESS help you then?

Q. Were there any occasions when you found CHESS did not help you?

What help were you looking for then?

Q. Were there any occasions when you thought to use CHESS but did not?

Why did you not use CHESS then?

Q. Has CHESS made a difference to you?

If so what difference has it made? How has it achieved this?

Has it affected what you know about your heart disease? If so how?

Has it affected the way you see your heart disease? If so how?

Has it affected how you feel about your heart disease? If so how?

Has it affected your confidence about anything to do with your heart disease? If so how?

Has it affected anything you have done? If so how?

Has it affected your lifestyle, for example your diet or how much exercise you take? If so how?

If invited for interview in the basis of overall CHESS use, use of a particular CHESS service or their change on a key variable but there has not been relevant discussion of this so far in the interview:

- Feed-back the main reason we were particularly interested in interviewing them
- Explore:
 - For CHESS use/use of a particular service
 - What affected their use (e.g. prompted or discouraged - probe for examples)
 - What did they get from their use
 - What effect did use have for them
 - For change on a key variable
 - What do they put any change down to
 - What was CHESS's role in this change

Q. Is there anything else you would like to say about your experience of CHESS?

Conclusions and thanks:

Remind participant that if there is any information in the interview they do not want used they can say so. Thank participant for giving up their time to help us. Reimburse travel expenses where applicable.

Appendix Q – Example intervention training booklet

This example training booklet was for use with patients recruited from a primary care practice in the NW1 area of North London. Separate local public internet access and training information was prepared for each area in which participating primary care practices were located. Participants received the version of the booklet that contained local information for the area in which their GP was located.

This booklet has been reformatted for presentation in this appendix. It was originally formatted to be duplex printed and centre-stapled to produce an A5 size booklet. The content remains the same.



CHES for Heart Disease User Booklet

Thank you for participating in this research project using an interactive website designed to help patients with Coronary Heart Disease.

This booklet contains:

- Page 1 - Your user details
- Page 2 - Where to get help if you are having difficulties with the CHES for heart disease website
- Page 3 - Information to help you get the most out of the CHES for heart disease website
- Page 17 - Details of local places to access the Internet

YOUR USER DETAILS TO ACCESS THE CHES WEBSITE:

Website address (URL): <http://chess.chsra.wisc.edu/hd>

Codename:

Password:

Need Help?

Computer Problems?

If you experience any problems with using CHES for heart disease on your computer, give the E-health Unit a call on 020 7288 3027. If you are using CHES at a public access internet service (e.g. a library) and are having problems, then staff nearby may be able to help you. Otherwise give us a call.

Cicely Kerr is the main project researcher and is usually available Monday to Friday from 9am to 5pm. She may not be able to solve your problem herself but she can call on technical support from experienced IT staff both locally and in the CHES team in Wisconsin, US.

If you have problems after hours, or if Cicely is out of the office visiting participants, you can leave a voice mail message and she will get back to you as quickly as possible on her return or the following working day.

Other Questions

If you have other questions/observations/concerns about CHES, again, give Cicely a call on 020 7288 3027 or e-mail her at c.kerr@pcps.ucl.ac.uk

She, or any other member of the CHES team at the E-health Unit would be happy to help, or to direct you to the appropriate place.

If for any reason there is no answer on Cicely's number, call 020 7288 3474 (the phone number for the Department of Primary Care and Population Sciences, University College London, where we are based) and ask for the E-Health Unit.

Getting the Most Out of CHESS

This information is here to help you get the most out of CHESS. You can find a copy of this information in **CHESS Guide** and in **Help** on the CHESS for Heart Disease website.

In the following pages it describes each service in CHESS. You can get to any of the services from the **Services Menu**.

Page	Service	
4	Services Menu	
5	CHESS Guide:	About CHESS, Getting Started, Your Comments About CHESS
6	Overview of Heart Disease:	Heart Disease Basics, Risk Factors, Heart Treatments
7	Finding Information:	Topics on Heart Disease, Questions & Answers
8	Finding Information:	Instant Library, Personal Stories, Ask an Expert
9	Finding Information:	Discussion Group
10	Other Sites:	Web Tools and Resources, Directory of Organisations
11	Other Sites:	Useful Information sites, Basic Web Skills, Evaluating Web Information
12	Personal Space:	Personal Profile, Health Tracking
13	Personal Space:	Assessments, Action Plan, Personal Journal
14	CHESS Update, Other Services:	Topics, Keyword Search
15	Other Services:	Dictionary, Bookmarks
16	Other Services:	Help

Services Menu

The Services Menu contains links to all parts of the CHES website. The information in CHES is divided into different sections, which contain specific services. If you click on the title of a section, you will come to a page with an explanation of and links to the services in that section, as well as links to the different categories.



You can get to the Services Menu from anywhere in CHES by clicking on the Services Menu link at the top left-hand side of the page.



Do you want to know more about CHES, why it was developed and who developed it? The CHES Guide gives you all the background as well as information about the different CHES services and how to use them. Read about CHES and let us know what you think of it.

About CHES

About CHES provides information about how CHES was first developed, who the developers are, and its research activities and findings. The service has information sections on What is CHES? Why was CHES developed? How is CHES used? Why is CHES information credible? Who develops and funds CHES? CHES's Security Policy.

Getting Started

Getting Started can help you work out where to start if you are using CHES for the first time, and understand how to move around CHES. Getting Started also tells you where you can get help, and contains the information you are reading now to help you get the most out of the information in CHES.

Your comments about CHES

This service allows you to tell us about your experiences of using CHES for heart disease. There is an evaluation survey to complete, or you can simply send us your opinion of CHES.



Overview of Heart Disease

Overview is in CHESS to help those of you who are just starting with CHESS or just starting to live with heart disease. You may have recently been hospitalised with a heart problem or are just beginning to try a more heart healthy lifestyle.

The three overview sections group together some of the most relevant CHESS questions and answers, instant library articles and personal stories for you. They also give you a taster of the kinds of information you will find if you start looking in the more extensive content of the **Finding Information Services** (described on p 7 - 9)

Heart Disease Basics

Here you can find information about what heart disease is, how it progresses, and some of the different types of heart disease.

Risk Factors

Here you can find information that can help you better understand and manage your risk factors. There are a number of risk factors associated with heart disease. Some of these risk factors are affected by your lifestyle, such as cholesterol and other lipids in your blood, high blood pressure, smoking, alcohol and drugs, being overweight or obese, or developing diabetes. Other risk factors, such as your genes and family history, cannot be changed.

Heart Treatments

Here you'll find information about what treatments are available, why they are used and which are used with different types of heart disease.



In Finding Information you can find answers to the questions you have, read articles about various aspects of heart disease and read about other people's experiences with heart disease. For more specific information you can ask the CHESSE expert team or join a discussion with other CHESSE users living with heart disease.

Topics on Heart Disease

Here you will find the extensive information available in all the **Finding Information** services (Questions & Answers, Instant Library, Personal Stories, Ask an Expert and Discussion Group) as well as information on **Other Sites** (Web Tools and Resources, Directory of Organisations, described on p 10-11) all organised into a menu of topics. Click on any of the topic links to see all the different types of information CHESSE has on that topic.

Questions & Answers

Here you will find answers to hundreds of questions commonly asked by people with heart disease. The answers were put together by a multi-disciplinary UK team made up of clinicians (both general practitioners and cardiology specialists), a health psychologist, a health services researcher and a cardiac research nurse. Like the Topics on Heart Disease service, Questions & Answers are organised into the same menu of topics. However, here you can also view a full list of questions and search within the titles of the questions.

Instant Library

Instant Library contains articles, leaflets, booklets, fact sheets and research summaries. Articles cover a broad range of topics, and come from scientific journals', NHS, public health, patient organisations', charitable organisations' and other internet sites. You can view a full list of library articles or search within the titles of the articles. If you want to see what Instant Library articles CHES has on a particular topic use the Topics in Heart Disease Finding Information service and click on the topic or use the Keyword Search in Other Services (described on p 14).

Instant Library articles are hosted by other websites so when you look at one you will be going outside of the CHES website. However, CHES will provide a description of where the link takes you before you decide whether you want to go to the website that hosts the article. The other website will open in a new window, so to get back to the CHES site you can either close the new window (click on the red x at the top right of the window), or click on the chess tab in the bar at the bottom of your screen.

Personal Stories

Real-life accounts of people living and coping with heart disease in the UK. Many of these stories have information that can help you deal with your own situation. Here you can see a brief description of each person's circumstances and choose who's story you want to read. If you want to see which personal stories or parts of personal stories relate to a specific topic, use the Topics in Heart Disease Finding Information service or the Keyword Search in **Other Services** (described on p 10)

Ask an Expert

This is a confidential and anonymous service that allows you to ask a question, and get a personal answer from our team of experts. The team is made up of cardiologists, a GP, a health psychologist and a healthcare librarian.

Use this service to send us your health questions and ask for any information you cannot find in the other CHES Finding Information services. We aim to answer all questions within a week.

If you have completed your Personal Profile in **Personal Space** (described on p 12), the CHES expert team have access to this information along with your question. You can see and make changes to your Personal Profile either in the Personal Space service or by clicking on 'About You' in this service. In Ask an Expert you can also read open expert messages. These are questions that other CHES users have asked, and answers provided by the CHES expert team.

DISCLAIMER: The CHES Ask an Expert Service can only offer general evidence-based and clinical information and cannot offer individual clinical advice or a second opinion. Information provided here should not replace medical consultation with a qualified health or medical professional.

Discussion Group

This is an on-line support group which allows anonymous communication among CHES users living with heart disease. You can share information, experiences, hopes and fears, give and receive support, and offer different perspectives on common issues. A trained facilitator monitors groups to keep discussion flowing smoothly. Use this service to ask other CHES users about information you have been unable to find in the other CHES Finding Information services. In Discussion Group you can also look in Discussion Group Archives. Here you can read previous group discussions of topics.

DISCLAIMER: The content of discussions here should not be considered medical advice nor be used as such.



The Internet is part of the CHESS package. This means that you can access not only the information within CHESS, but anything else on the Internet as well. In this section you will find links to other websites, including help in evaluating information you find on the Internet.

Web Tools and Resources

This is a collection of areas of web sites that contain relevant online tools and resources for people with heart disease (e.g. quizzes, calculators, lists of resources, topic focused information to explore). When you look at or use one of these web tools or resources you will be going outside of the CHESS website. However, CHESS will provide a description of where the link takes you before you decide whether you want to go to the website that hosts the tool or resource. The other website will open in a new window, so to get back to the CHESS site you can either close the new window (click on the red x at the top right of the window), or click on the chess tab in the bar at the bottom of your screen.

If you want to see what Web Tools and Resources relate to a specific topic, use the Topics in Heart Disease **Finding Information** service (described on p 7) or the Keyword Search in **Other Services** (described on p 14).

Directory of Organisations

This Directory lists relevant organisations offering information, help, support and resources for dealing with heart disease and associated issues. CHESS provides information about the organisations' services, how to contact them and a link to organisations' web sites (if they have one).

If you click on a link to look at an organisation's website, it will open in a new window. To get back to the CHESS site you can either close the new window (click on the red x at the top right of the window), or click on the chess tab in the bar at the bottom of your screen.

If you want to see what Organisations in the Directory relate to a specific topic, use the Topics in Heart Disease **Finding Information** service (described on p 7) or the Keyword Search in **Other services** (described on p 14)

Useful Information Sites

This section describes and links you to a number of good, reliable websites that have been recommended by CHESS. You can search the sites for research findings, information about evidence-based treatments, patient information and UK healthcare.

Basic Web Skills

Basic Web Skills describes what the World Wide Web (or Internet) is, how the Web works, what it offers and how you can get the most out of it. The information provided here is designed for people who are new to the Internet and perhaps even new to personal computers. Here, you will learn the basic skills and information you need to get started on the Web and how to search for information.

Evaluating Web Information

This guide helps you evaluate the quality of online health information, gives you helpful questions and things to keep in mind as you do research on the web, as well as links to useful websites that will help you achieve this. The guide was originally written for cancer patients in the North London Cancer Network and focuses particularly on evaluating the quality of health information.



Personal Space is your own place in CHES to keep track of your health and health-related activities, assess how you are doing, set goals, and write about your thoughts and feelings.

Personal Profile

Personal Profile asks 5 questions to form brief summary of your heart disease. You will be asked to complete your Personal Profile at the start of the Health Tracking Survey which comes up automatically the first time you log in. If you complete your Personal Profile the CHES Expert team will be able to view it alongside any Ask an Expert questions you send. Because of this you can also view and complete your Personal Profile by clicking on 'About You' in the Ask an Expert **Finding Information** service (described on p 8).

Health Tracking

Health Tracking allows you to track your heart health and lifestyle behaviours and is in two parts: Health Tracking Survey (15 questions) and Health Tracking Feedback. You can get to both parts by clicking on Health Tracking in Personal Space on the Services Menu. However, the Health Tracking Survey also comes up automatically the first time you login and then every two weeks to help you keep track of your health and risk reduction activities, such as diet and exercise.

The first time, the survey begins by asking you to fill in your personal profile before asking you to complete the health tracking survey. There are 15 questions in the full health tracking survey. You only answer the questions you want to. When you complete or update the survey you choose which activities you wish to answer questions about or the activities where you want to change your earlier answer.

Once you have completed all or some of the survey you can get Health Tracking Feedback. The Feedback is personalised to your Health Tracking Survey answers. It provides a tip of the day, suggestions and information related to your situation, graphs of your progress over time, and links to related information in CHES. The idea is to return regularly to Health Tracking to keep your survey answers up to date and track your feedback over time.

Assessments

The Assessments section contains tools to assess your current levels of health behaviour (Diet and exercise) or mood. When you fill in an assessment you receive feedback on your score and pointers on what you can do to better reduce your risks.

Action Plan

The Action Plan provides two step-by-step guides to help you plan and carry out change in your diet or levels of exercise and other physical activity. Each Action Plan helps you set realistic goals and plan how to achieve those goals. The plan is then evaluated to identify any barriers to your success and provide advice on how to overcome them.

Personal Journal

Personal Journal provides a private and confidential place for you to record your personal thoughts, feelings and experiences. The journal contains writing tips and exercises to help you get started.



CHESS Update is the way we keep you up to date with new heart disease information added to CHESS. When we have added new Topics in Heart Disease, Instant Library articles, Personal Stories, Useful Organisations, or Web Tools and Resources we will list them here. Click on the link to be taken directly to the new information.



Topics, Keyword Search, Dictionary, Bookmarks, Help

The Other Services in CHESS that are described in this section are lined up at the top of the screen on the right hand side. You can see and access these services not just from the Services Menu (described p 4), but also from wherever you are in CHESS.

Topics

If you click on 'Topics' you will be taken to the Topics in Heart Disease **Finding Information** service (described on p 7). Topics in Heart Disease is one of the quickest and easiest ways to find all sorts of relevant information in CHESS. It is like the contents page of a book. This link makes sure you can easily look for Topic information without having to go to the Services Menu first.

Keyword Search

Like the Topics in Heart Disease Finding Information service (described on p 7), the Keyword search groups together information in all the Finding Information services (Questions & Answers, Instant Library, Personal Stories, Ask an Expert and Discussion Group, described on p 7-9) as well as information on Other sites (Web Tools and Resources, Directory of Organisations, described p10-11).

The difference is that the Keyword Search allows you search for more specific information beyond the main topics in heart disease. If Topics is like the contents page of a book, Keyword Search is like the index.

You can search for a specific keyword in two ways. One way is to type in what you are looking for and CHESS will search all its keywords for a match. It is often better to type in a single word rather than a phrase as CHESS will bring up all keywords that contain your search word. The other way is to click on the first letter of what you are looking for and CHESS will list all the keywords that start with that letter. Either way, when you spot the keyword you are after, click on it to see all the different types of information CHESS has on that subject.

Dictionary

Click on Dictionary to find definitions of heart and other terms used in CHESS information. You can search for dictionary terms in one of two ways. One way is to type in the term you are looking for and CHESS will search the dictionary terms for a match. The other way is to click on the first letter of the term you are looking for and CHESS will list all the dictionary terms that start with that letter. Either way, when you spot the word you are after, click on it for a definition. If CHESS has further information to follow on from the definition you will see a link at the bottom you can click to see all the different types of information CHESS has on that subject.

Bookmarks

Bookmarking is there to help you mark and store useful information in CHESS. You will see the option to 'Save to Bookmark' at the bottom of each page of information in CHESS Questions & Answers, Instant Library, Personal Series, Web Tools and Resources and Directory of Organisations. If you click on 'Save to Bookmark', CHESS will store the relevant page in your Bookmarks.

Then at any later time you can find it again by simply clicking on 'Bookmarks' at the top of your screen. This will show the title of all the pages you bookmarked and the date on which you bookmarked them.

You can order your bookmarked pages by date or by service to make it easier to find the one you are after. Click on the title of one of your bookmarked pages to go straight to it. Click 'remove' by any of your bookmarked pages to remove it from the Bookmarks store.

Help

Click on 'Help' at the top right of your screen if you are having trouble using CHESS or finding the type of information you are after. The Help pages include information to help you move around CHESS, details of how to get in touch with someone who can help you use CHESS, and the information you are reading now to help you get the most out of CHESS.

Free Local Public Internet Access Services in Camden

Camden Town Library	Opening hours
Crowndale Centre 218 Eversholt Street London NW1 1BD Tel: 020 7974 1563	Mon: 10am – 7pm Tues: 10am – 6pm Weds: 10am – 6pm Thurs: 10am – 7pm Fri: 10am – 6pm Sat: 10am – 5pm Sun: Closed
Additional information	
<ul style="list-style-type: none">• Internet access free for up to 1 hour per day. You can use the Internet there as a guest, without being a library member, however you must be a library member to book time on the Internet in advance. Non-members just have to turn up and wait until a computer becomes free.• After the first hour you can pay 50p per half hour (25p concessionary rate) for further Internet access the same day.• Printing costs: Black and white 10p per sheet• To become member of this or any other library in Camden bring with you proof of your name and address (e.g. a household bill from within the last 3 months). Once you have become a member of one library in Camden you can use the Internet at any of the other Camden libraries.• Library staff can help you get started with accessing the Internet from the library computers.• The library also contains a Camden Learning Centre which offers free computer courses. If you wish to learn more about how to use a computer or the Internet, enrol with the learning centre where staff will find out what you want to know or what help you need before tailoring informal training to suit you.• Free 10-week over 50s computing course Thurs 10.30am – 12 run by Age Concern with lots of volunteer instructors for beginners, call their Computer Training Officer 020 7837 3777	

<p>Regents Park Library</p> <p>Compton Close Off Robert Street London NW1 3QT</p> <p>Tel: 020 7974 1530</p>	<p>Opening hours</p> <p>Mon: closed Tues: 10am – 6pm Weds: 10am – 6pm Thurs: 10am – 7pm Fri: closed Sat: 10am – 5pm Sun: closed</p>
<p>Additional information</p> <ul style="list-style-type: none"> • Internet access free for up to 1 hour per day. You can use the Internet there as a guest, without being a library member, however you must be a library member to book time on the Internet in advance. Non-members just have to turn up and wait until a computer becomes free. • After the first hour you can pay 50p per half hour (25p concessionary rate) for further Internet access the same day. • Printing costs: Black and white 10p per sheet • To become member of this or any other library in Camden bring with you proof of your name and address (e.g. a household bill from within the last 3 months). Once you have become a member of one library in Camden you can use the Internet at any of the other Camden libraries. • Library staff can help you get started with accessing the Internet from the library computers. • The library also contains a Camden Learning Centre which offers free computer courses. If you wish to learn more about how to use a computer or the Internet, enrol with the learning centre where staff will find out what you want to know or what help you need before tailoring informal training to suit you. 	

<p>St Pancras Library</p> <p>Camden Town Hall Extension Argyle Street London WC1H 8NN</p> <p>Tel: 020 7974 5833</p>	<p>Opening hours</p> <p>Mon: 10am – 7pm Tues: 10am – 6pm Weds: 10am – 6pm Thurs: 10am – 7pm Fri: 10am – 6pm Sat: 10am – 5pm Sun: closed</p>
<p>Additional information</p> <ul style="list-style-type: none"> • Internet access free for up to 1 hour per day. You can use the Internet there as a guest, without being a library member, however you must be a library member to book time on the Internet in advance. Non-members just have to turn up and wait until a computer becomes free. • After the first hour you can pay 50p per half hour (25p concessionary rate) for further Internet access the same day. • Printing costs: Black and white 10p per sheet • To become member of this or any other library in Camden bring with you proof of your name and address (e.g. a household bill from within the last 3 months). Once you have become a member of one library in Camden you can use the Internet at any of the other Camden libraries. • Library staff can help you get started with accessing the Internet from the library computers. • Free 10-week over 50s computing course run by Age Concern with lots of volunteer instructors for beginners, call their Computer Training Officer 020 7837 3777 	

<p>Hillwood Resource Centre</p> <p>1 Polygon Road London NW1 1QH</p> <p>Tel: 020 7387 7628</p>	<p>Opening hours</p> <p>Mon: 10am – 4pm Tues: 10am – 4pm Weds: 10am – 4pm Thurs: 10am – 4pm Fri: 10am – 4pm Sat: closed Sun: closed</p>
<p>Additional information</p> <ul style="list-style-type: none"> • Free drop-in access to use computers and the Internet • Free 10-week over 50s computing course run by Age Concern on Friday mornings, with lots of volunteer instructors for beginners, call their Computer Training Officer 020 7837 3777 • To register with the centre simply call and talk to a member of staff who will ask for some address and contact details. No proof of address or identity required. 	

<p>Training Link</p> <p>54-56 Phoenix Road London NW1 1ES</p> <p>Tel: 020 7383 5405</p>	<p>Opening hours</p> <p>For drop-in use of the Internet: Wednesday 12.30-2.30pm and 3-6pm</p>
<p>Additional information</p> <ul style="list-style-type: none"> • Offer drop-in access to use computers and the Internet on Wednesday afternoons. • Run a 6-week course called Computers for Beginners throughout the year with a break in the summer. Course restarts from 2nd week in September • Both the drop-in computer access and the course are free to Camden residents. To register for either simply call in with proof of your address and complete their registration form. 	

<p>Maiden Lane Community Centre</p> <p>156 St Paul's Crescent London NW1 9XZ</p> <p>Tel: 020 7267 9586</p>	<p>Opening hours for computers</p> <p>Mon: 10.30am – 1pm and 7-9pm Tues: Closed Weds: 7-9pm Thurs-Sun: Closed</p> <p>Although the rest of the centre is open 9am –4.30pm weekdays</p>
<p>Additional information</p> <ul style="list-style-type: none"> • Free drop-in access to use computers and the Internet, Mondays and Wednesdays 7-9pm • Over 50s silver surfer computer training sessions Mondays 10.30am – 1pm, not running over the summer but restarts from 10th September • The centre is in the process of increasing computer access and organising more computer courses so more will be available soon 	

Other free local computer courses and help

Age Concern

- Runs courses for over 50s at various venues across Camden (e.g. Camden Town Library, St Pancras Library, Hillwood Resource Centre)
- Courses usually run for 10 weeks in small groups with lots of volunteer instructors to help beginners
- Can also visit you at home 1 hour a week for up to 10 weeks to train you in using your own computer. You need to be a Camden resident and have your own computer or laptop for this home training
- Contact Age Concern Camden's Computer Training Officer on 020 7837 3777

IT Can Help (ITCH) network

- Provide free computer support and training at home to disabled people
- Can provide advice on buying computer equipment, hardware and software upgrades
- Can help you install new equipment and software, get connected to the Internet and e-mail, get you started and solve technical problems that may arise
- Call via AbilityNet freephone (and Minicom): 0800 269545

Other Local Public Internet Access Services

<p>Cyber Money Transfer</p> <p>46 Eversholt St, London NW1 1DA</p> <p>Tel: 020 7388 6164</p> <p>Opening hours: Mon – Sun: 9am – 9pm</p>	<p>Cost:</p> <ul style="list-style-type: none"> • £1 an hour • Minimum access is 1 hour • Printing: Black and white 15p per sheet, colour 80p per sheet
<p>Bel Phoori Cyber Cafe</p> <p>98 Drummond St London NW1 2HN</p> <p>Tel: 020 7383 0022</p> <p>Opening hours: Mon – Sun: 12-6pm</p>	<p>Cost:</p> <ul style="list-style-type: none"> • £1 an hour • Minimum access is 1 hour • Printing: Black and white 20p per sheet
<p>Easy Internet Café</p> <p>Inside the Post Office 114 – 120 Camden High Street London NW1 ORR</p> <p>Opening hours: Mon – Fri: 8.30am – 6pm Sat: 8.30am – 5.30pm Sun: closed</p>	<p>Cost:</p> <ul style="list-style-type: none"> • £1 an hour pay as you go • Costs can be lowered by buying a pass e.g. £3.50 for using it as much as you like in 24-hour period, £7 for use in 5-day period, £20 for use in 25-day period <p>Additional information: Self-service, you pay at a machine, no staff on hand to help.</p>

<p>Ellisa Star Restaurant and café</p> <p>154A Camden High Street London NW1</p> <p>Tel: 020 7168 4055</p> <p>Opening hours: Mon – Sun: 7am – 11pm</p>	<p>Cost:</p> <ul style="list-style-type: none"> • £1 an hour • Minimum access is 15 mins which costs 50p, 30 mins for 70p <p>Additional information: Internet access is provided in a small room at the back of the restaurant/café, beyond the counter</p>
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<p>Net Stop Internet Café</p> <p>Channel Films 20 Kentish Town Road London NW1 9NX</p> <p>Tel: 020 7267 1081</p> <p>Opening hours: Mon-Sun: 10am – 10pm</p>	<p>Cost:</p> <ul style="list-style-type: none"> • £1 an hour • Minimum access is 15 minutes which costs 50p • Printing: 20p per sheet <p>Additional information Internet café inside Channel Films film rental shop</p>
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<p>Solo Tech</p> <p>174, Royal College Street London NW1 0SP</p> <p>Tel: 020 7482 4545</p> <p>Opening hours: Mon – Sun: 10am – 10pm</p>	<p>Cost:</p> <ul style="list-style-type: none"> • £1 an hour • Minimum access is 30 mins which costs 50p • Costs can be lowered if you open an account, then you can less for longer periods of time to use up as and when you want. Minimum £4 for 5 hours to open an account • Printing: black and white 10p per sheet
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<p>IFKA Telecom Centre</p> <p>126 Camden Road London NW1 9EE</p> <p>Opening hours: Mon – Fri: 9.30am – 9.30pm Sat - Sun: 10am – 9.30pm</p>	<p>Cost:</p> <ul style="list-style-type: none"> • 50p per hour • Printing: black and white 10p per sheet
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Appendix R – Descriptive statistics from cases included in analyses of change from intervention use

Mean baseline, 3 and 9 month outcome scores for variables and cases included in linear multivariable regression analyses

Outcomes			T0 – T3			T0 – T9		
			n	T0 Mean (SD)	T3 Mean (SD)	n	T0 Mean (SD)	T9 Mean (SD)
Intermediate outcomes	Illness perceptions (BIPQ)	Consequences	140	3.3 (2.9)	3.3 (2.8)	146	3.3 (2.8)	3.2 (2.6)
		Personal control	137	6.1 (3.0)	6.2 (2.7)	142	6.2 (3.0)	6.5 (2.5)
		Treatment control	136	8.1 (2.6)	7.8 (2.3)	145	8.0 (2.5)	7.7 (2.5)
		Identity	136	2.8 (2.7)	2.9 (2.7)	146	2.8 (2.7)	2.9 (2.6)
		Concern	136	5.0 (3.3)	5.2 (3.2)	147	4.9 (3.3)	4.6 (3.2)
		Illness coherence	138	6.7 (3.0)	7.5 (2.4)	147	6.7 (3.0)	7.7 (2.2)
		Emotions	139	3.1 (3.0)	2.9 (2.9)	145	3.1 (3.0)	2.8 (2.8)
	Self-efficacy	Diet (CDSEI)	123	3.7 (0.8)	3.6 (0.9)	124	3.7 (0.8)	3.6 (0.9)
		Exercise (CESEI)	116	3.3 (1.0)	3.2 (1.1)	119	3.3 (1.0)	3.3 (1.0)
	Perceived social support (MOS SSS)	Emotional and info subscale	141	3.6 (1.1)	3.5 (1.2)	145	3.7 (1.1)	3.5 (1.2)
Main outcomes	Health behaviour	Healthy diet habits	142	7.9 (2.0)	7.9 (2.1)	145	7.8 (2.1)	7.9 (2.1)
		Diet score from food frequency items	140	19.8 (2.6)	19.9 (2.9)	139	19.7 (2.8)	20.0 (2.7)
	Emotional status (HADS)	Anxiety	141	5.7 (4.0)	5.5 (4.1)	146	5.7 (3.8)	5.5 (3.8)
		Depression	141	4.4 (3.4)	4.5 (3.5)	145	4.3 (3.3)	4.5 (3.5)
	Health-related QoL	MacNew Heart Disease	136	5.7 (0.9)	5.6 (1.0)	140	5.7 (0.9)	5.6 (1.0)

Baseline, 3 and 9 month frequencies of outcomes for cases and variables included in logistic multivariable regression analyses

Intermediate outcome		Category	T0 – T3			T0 – T9		
			n	T0 frequency	T3 frequency	n	T0 frequency	T9 frequency
Illness perception (BIPQ)	Cause	Not lifestyle	125	46	42	125	47	39
		Lifestyle		79	83		78	86
Self-efficacy (Cardiac self-efficacy)	Control symptoms	Low	141	69	72	145	72	69
		High		72	69		73	76
	Maintain functioning	Low	141	57	72	144	61	67
		High		84	69		83	77