Responses to chest pain. Development and initial evaluation of an evidence-based information resource.

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Declaration

I declare that this thesis is entirely my own work and that it has been submitted only for the degree of PhD.

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Abstract

Coronary heart disease is the leading cause of premature death in the UK. Chest pain, the most common symptoms associated with this disease, accounts for 1% of all primary care consultations, 5% of visits to emergency departments, and up to 40% of emergency admissions to hospital. When people experience acute coronary symptoms such as chest pain, or other symptoms such as pain in the arms, back or shoulder pain and pain in the jaw and neck, we know that prompt diagnosis and treatment of heart disease can significantly reduce mortality. However, we also know that when people experience these symptoms they can wait sometime before seeking medical help. Part of the problem may be that people do not attribute their symptoms to a serious problem such as heart disease. Whilst several campaigns have been aimed at the general population there is no information resource targeted at people who may be at risk of heart disease to help them understand and evaluate their symptoms and take prompt action.

The overall aim of this thesis is to fill this gap by producing a piloted draft information resource which aims to help people to respond effectively to symptoms that might be attributable to heart disease for people at high risk of heart disease. Using focus group discussions and individual interviews with people who had experienced symptoms that might be attributable to heart disease or might be at high risk of heart disease experiential data about their response to symptoms were gathered. Participants were also asked their views on what an information resource should be like and their experiences and views formed the basis of the content of the first draft of the information resource.

In making sense of their symptom the participants drew upon a range of past experiences and the experiences of others to help them; participants who experienced severe symptoms sought help quickly; those whose symptoms were mild or transient waited, in some cases a considerable time, before seeking help. Previous personal experience may be the factor that helped those who acted quickly. Whereas the experience of others, evident in many of the accounts of those who waited, may not be sufficient to help people interpret and make sense of their own symptom experiences.

The information resource incorporated the experiences of people with symptoms that ended up being attributable to heart disease and included examples of the range of symptoms that can be encountered to illustrate the different ways in which heart disease can be manifested as well as information drawn from best practice resources in the management of heart disease. Participants in the original focus group discussions and interviews were asked to be involved in the development of the resource and seventeen agreed. The information resource went through three drafts; at each stage changes were made to incorporate respondent views; at the penultimate draft health professionals' views were also sought and used to inform the final draft which is now ready for further evaluation.

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Chapter 1 Introduction

1.1 Introduction to the chapter

This thesis describes the research-based development of an information resource for people at high risk of heart disease. This introductory chapter sets the scene for the thesis by presenting a review of the coronary heart disease (CHD) and the unexplained or non cardiac chest pain (NCCP) research literature providing a rationale for the research objectives addressed.

The chapter begins by outlining the context and significance of CHD, and in particular the symptoms people may have. Section 1.2 demonstrates that CHD is a worldwide problem, and is of particular concern in the United Kingdom (UK) and Scotland. A discussion on the problem of NCCP is presented in section 1.3. The economic consequences of CHD and NCCP are presented in section 1.4.

The subsequent sections of the chapter review current research on the need to raise awareness of symptoms that may be attributable to heart disease, and the current interventions that have attempted to address this. The chapter concludes with a summary of the CHD and NCCP literature; key messages are discussed, and particular attention is drawn to the need to raise awareness of symptoms that may be attributable to heart disease (section 1.6). Finally, the research questions and study objectives that are addressed in this thesis are presented in section 1.7 whilst section 1.8 describes the content of the subsequent chapters.

1.2 The significance and epidemiology of Coronary Heart Disease

CHD is the leading cause of death world wide; the World Health Organisation (WHO) estimates that globally 3.8 million men and 3.4 million women die from the condition each year (WHO, 2004). In the UK, almost 2.5 million people have CHD, and although the mortality from the disease is falling, death rates in the UK remain amongst the highest in the world – over 117,000 deaths a year, most of which are attributable to acute myocardial infarction (AMI) (Petersen, Peto, Scarborough & Rayner, 2006). This is in comparison to 34,000 deaths a year from lung cancer, 16,000 deaths from colorectal cancer and 13,000 deaths from breast cancer (Petersen et al, 2006).

Primarily a disease of advancing age, CHD also frequently attacks the middle-aged, and in some cases the young. Although CHD has occurred throughout the ages and was well known to doctors in the eighteenth and nineteenth centuries (Eslick, 2005), the rapid advance in diagnostic methods and improved treatment, together with publicity in the media, has raised awareness of CHD. The number of people dying from the disease in the UK as recorded on death certificates during 1942 was 18,591. Twenty years later in 1962 the number of deaths recorded had risen to 102 478, more than a five fold increase. In the UK deaths rates peaked in the late 1970's. Since then they have been falling steadily, and for people under 75 years they have fallen by 40% in the last ten years (Allender, Peto, Scarborough, Kaur, & Rayner, 2008).

1.2.1 Gender differences in the epidemiology of Coronary Heart Disease

Thus CHD is the leading cause of mortality in UK; it accounts for 19% of premature deaths in men and 10% in women. In 2006 in the UK 52,585 men and 41,796 women died as a result of CHD (Allender et al, 2008), but as men and women get older the gap in coronary heart disease mortality narrows. Figures from the British Heart Foundation demonstrate that up to the age of 74 more men will die as a result of coronary heart disease, but over the age of 75 this pattern is reversed (See table 1.1). Gender differences in CHD mortality have been decreasing for some time. Wenger (1996) suggests this is a result of the increasing mortality rates in women. One possible reason for this is the older age at onset of CHD in women which correlates with an increase in comorbid diseases and consequently mortality.

In terms of morbidity, figures provided by the British Heart Foundation suggest that there are just over 2.5 million people living with CHD in the UK, with an estimated 1.5 million men living in the UK who have had CHD (either angina or heart attack) compared to about 1 million women aged over 35 (Allender et al, 2008).

Table 1 Deaths as a result of Coronary Heart Disease by sex and age, 2008

	All ages	**< 35**	**35-44**	**45-54**	**55-64**	**65-75**	**>75**
Men	52,585	114	834	2,809	6,802	11,885	30,141
Women	41,796	34	185	588	1,883	5,494	33,612
Total	**94,381**	**148**	**1,019**	**3,397**	**8,685**	**17,379**	**63,753**

(Source: Allender et al, 2008, p. 20)

In recent years death rates have been falling slowest for both genders in the younger age groups and fastest in those aged 55 years and above. For example between 1997 and 2006 there was a 46% fall in the CHD death rate for men aged 55-64 in the UK, compared to a 22% fall in men aged 35-44 years. In women there was a 53% fall in those aged 55-64 years and a 20% fall in those aged 35-44 years (Allender et al, 2008).

1.2.2 Regional variations in Coronary Heart Disease

Within the UK death rates from CHD are higher in Scotland and the North of England, lowest in the South of England, and intermediate in Wales and Northern Ireland. The premature death rate from CHD for men living in Scotland is 65 % higher than in the South West of England and 112 % higher for women (Allender et al, 2008). Mortality from CHD in Scotland, like the rest of the UK, has fallen in recent years. In 1994 the age standardised mortality rate in Scotland was 223 per 100,000 whilst by 2004 this figure had fallen to 140 per 100,000 (Allender et al, 2008). Yet within Scotland itself there remain variations in mortality rates, with the highest rates being found in the west of the country (Allender et al, 2008).

There are also regional variations in CHD morbidity, although these statistics are much harder to collect than mortality statistics. Data collected from the Key Health Statistics from General Practice on the prevalence of treated CHD (heart attack and angina) suggest that the prevalence of all CHD is higher in the North of England and in Wales than it is in the South of England (Allender et al, 2008). In Scotland the incidence of CHD has been tracked using the Information and Statistics Division (ISD) linked data set. Between 1994 and 2003 incidence fell by 14% in men (from 585 to 501 per 100,000) and by 19% in women (449 to 366 per 100,000). Incidence rates for CHD also show regional variations within Scotland as demonstrated by the different morbidity rates published by health boards. In 2003, the highest incidence for men was in the Western Isles (555 per 100,000), and for women it was in Argyll and Clyde (289 per 100,000). For men the lowest rates were found in Shetland (309 per 100,000), and for women in Dumfries and Galloway (163 per 100,000) (Allender et al, 2008).

1.2.3 Socio-economic variations in Coronary Heart Disease

There are considerable variations in CHD mortality in the different socio-economic groups, with higher prevalence in people in lower socio-economic groups (Petersen et al, 2006).

Although the premature death rate has fallen across all social groups for both men and women in the UK, the decline has been greater in people in higher socio-economic groups. In particular during the 1990's the divide between male manual workers compared to non-manual workers reduced; and fell by 8% to 50% for manual male workers compared to non-manual workers (Allender et al, 2008).

1.2.4 Policy initiatives to reduce the consequences of Coronary Heart Disease

Reducing CHD has been a major public health priority for successive UK governments. In the White Paper, *'Saving Lives: Our Healthier Nation'* (Department of Health, 1999), targets were set to reduce the death rate from heart disease, stroke and all related cardiovascular disease in people under the age of 75 years by at least 40% by 2010. The following year saw the introduction of government health policy aimed at tackling the inequalities in CHD and improving coronary heart disease health and care; this was the National Service Framework (NSF) for CHD in England and Wales (Department of Health, 2000).

This framework outlined an agenda to modernise the way CHD was managed and set a programme to improve the way the disease is diagnosed, treated and prevented. There was a shift in emphasis such that responsibility was placed on a wide range of agencies across the National Health Service (NHS) for both primary and secondary prevention strategies. In the years since the introduction of the NSF there have been significant improvements in the way CHD is treated. There are now more people receiving thrombolysis and prescriptions for the prevention of cardiovascular disease: in excess of 1.8 million people in the UK now receive statins, which equates to over 3% of the population (British Heart Foundation, 2009).

Although improvements in the treatment and prevention of CHD have been made in light of recent government health policy, as we have seen CHD is still a major cause of premature death in the UK (British Heart Foundation, 2009). Reducing CHD morbidity and mortality is of paramount importance to improve the health of men and women in the UK. Research into how primary and secondary CHD prevention interventions can be made more effective is, therefore, likely to result in considerable health and economic benefits for the UK population.

1.3 The significance and epidemiology of Non-Cardiac Chest Pain in the UK

Chest pain is among the most common clinical complaints it accounts for approximately 5% of all presentations to primary care physicians and emergency medical departments (Eslick, Coulshed & Talley, 2002), and in over 50% of these patients CHD is excluded following investigations (Esler & Bock, 2004). Even among those patients referred for coronary angiography, significant proportions show no evidence of ischaemic heart disease (IHD). When heart disease is excluded, the prognosis for patients is usually excellent (Eslick et al, 2002) although many continue to experience symptoms of chest pain, and to seek medical advice and accrue considerable medical costs.

There is surprisingly little known about the large group of people whose chest pain is not attributable to CHD (Mayou, Bryant, Sanders, Bass, Klimes & Fofar, 1997). In a general context, unexplained or NCCP is considered to be chest pain originating from the central chest area that resembles angina yet, after appropriate investigation, appears to be unrelated to the heart (Fox & Forgacs, 2006; Kachintorn, 2005). Part of the problem in definition is the range of terms used to describe it (see table 2), with considerable overlap in terms used by the different medical specialties (Eslick, 2004). The terms unexplained or NCCP can include all chest pain which is not related to cardiac chest pain, but because of the diverse number of possible causes of unexplained or NCCP the actual diagnosis of the cause in many cases can be problematic (Kachintorn, 2005).

Table 2 Terms used to describe unexplained or NCCP

Cardiac syndrome X
Chest pain of undetermined origin
Chest pain of unknown etiology
Chest pain with normal coronary angiograms
Da Costa's syndrome
Efforts syndrome
Functional chest pain
Gorlin-Likoff syndrome
Irritable heart
Neurocirculatory asthenia
Sensitive heart
Soldier's heart

(Adapted from Eslick, 2004)

The epidemiology of unexplained or NCCP is poorly understood, with very few well designed epidemiologic studies investigating this area. Studies that have attempted to address this problem can be divided into two groups; (1) population-based studies; and (2) hospital based studies.

1.3.1 Population based studies

There is a lack of population-based studies which investigate the extent of unexplained or NCCP. In the United States (US), a population-based survey was undertaken to assess the clinical extent of gastroesophageal reflux disease (GERD) in a Minnesota county. The study used a self-report questionnaire designed to highlight the actual symptoms the participants experienced. From the original sample of 2200, 1511 replied (69%); and 23% reported a form of NCCP (which was defined in this case as “those who reported chest pain but did not have a history of cardiac disease”) (Locke, Talley, Fett, Zinmeister & Melton, 1997).

A further population-based study from the UK investigated the prediction of ischaemic heart disease in the general population via a questionnaire and medical examination approach. In this study 7735 randomly selected men aged between 40 and 59 were asked to categorise their symptoms. Part of the selection criteria was based on the Rose Angina questionnaire, examination by a nurse, and previous cardiovascular diagnoses. From the sample the prevalence of “other chest pain” (not cardiac chest pain or angina) was reported to be 24% (Lampe, Whincup, Wannamethee, Ebrahim, Walker & Sharper, 1998).

A more recent Australian study specifically designed to determine the population prevalence of NCCP was undertaken by Eslick and colleagues (Eslick, Jones & Talley, 2003). This population-based study used a specifically designed chest pain questionnaire which was mailed to 1000 (500 male and 500 female) randomly selected adults in a Sydney Suburb. From the 67% (323 males and 349 females) that responded the study reported a prevalence of NCCP of 33%, a somewhat higher rate of NCCP than in the studies described above. This study also found prevalence rates were similar in males and females (32% and 33% respectively), and that it decreased with increasing age (Eslick & Fass, 2003).

Eslick et al (2003) put the population prevalence of NCCP in perspective when they calculate the attributable risk of NCCP based on, what they call, a conservative prevalence estimate of 25% of the US population. Using this figure they estimate that approximately 65 million people in the US have NCCP of some form. Eslick et al (2003) suggest that identifying what causes NCCP is important because a large proportion of these causes will be treatable (Eslick et al, 2003).

1.3.2 Hospital based studies

The focus of hospital based studies has been determining the prevalence of NCCP among patients admitted to an emergency department or out-patient clinic with acute chest pain. A comprehensive Danish study of chest pain patients who did not have acute myocardial infarction (MI) was undertaken to determine the cause of their acute chest pain (Fruergaard, Launbjerg, Hesse, Jorgensen, Petri, Eiken, Aggestrup, Elsborg & Mellemgaard, 1996). The study examined 204 non MI patients (65% male) who undertook a range of diagnostic tests, ranging from: electrocardiogram (n = 204), chest radiograph (n = 204), pulmonary scintigraphy (n = 175), exercise electrocardiogram (n = 148), ultrasonic examination of the abdomen (n = 148), physical examination of the chest wall (n=147), bronchial histamine provocation test (n = 147), echocardiography (n = 146), myocardial scintigraphy (n = 144), Holter monitoring (n = 136), esophagogastroduoendoscopy (n = 133), hyperventilation test (n = 123), pH monitoring of the esophagus (n = 125), and the Bernstein test (n = 87) (Fruergaard et al, 1996).

The main clinical findings reported from the study were that 42% (n = 85) had some form of gastroesophageal disease, IHD was found in 31% (n = 64), and chest wall syndromes accounted for 28% (n = 58). Pericarditis was found in 4% (n = 9), pneumonia in 4% (n = 2), and pulmonary embolism in 4% (n = 2). There were also single cases of; lung cancer, aortic aneurysm, aortic stenosis, and herpes zoster (shingles). The study did have a number of limitations; older patients (those over 70 years) with severe heart disease were excluded, reducing the prevalence of IHD. Further limitations included the lack of routine use of coronary angiography, and a subset of patients (n = 56) received an incomplete diagnostic evaluation, therefore other possible causes of their chest pain way have been missed. No attempt was made in the study to specify which diagnosis was most important in terms of chest pain in patients with more than one diagnosis.

A UK study investigated the cause and outcome of atypical chest pain in 250 patients admitted to hospital in the north east of England in an attempt to determine the cause of each patient's chest pain (Spalding, Reay & Kelly, 2003). Data were collected on each patient on admission to the coronary care unit or medical assessment unit with chest pain initially suspected to be of cardiac origin. The study recorded the investigations performed, discharge diagnosis and follow-up arrangements (via a questionnaire at one year to all patients with atypical chest pain, asking about treatment, and future tests). Initial classification of the patients grouped them into cardiac chest pain (57% n = 142) and 'atypical' chest pain (43%, n = 108). The 108 patients with atypical chest pain were further broken down to a number of different diagnoses: 25% (n = 25) had musculoskeletal pain, 19% (n = 21) had cardiac chest pain; 11% (n = 12) had gastrointestinal pain and 9% (n = 10) had a diagnosis of respiratory pain, and 37% (n = 40) were discharged without a diagnosis.

A major limitation of the Spalding et al (2003) study is the issue of accuracy of the medical records and the potential recall bias associated with using data from a questionnaire one year after the patients' admission to hospital. Spalding et al (2003) themselves report that the patients' perception of the diagnosis differed somewhat from the diagnosis recorded in the medical notes, which could either be due to recall bias or a failure of communication during their consultation with the health professional.

1.4 The costs of Coronary Heart Disease and Non Cardiac Chest Pain

1.4.1 Coronary Heart Disease costs

CHD is not only the single most common cause of death in the UK; it is also very costly, imposing a huge annual burden on the UK economy. The total costs of CHD on the healthcare system alone are over £9 billion a year (British Heart Foundation, 2009). Non-health care cost attributable to CHD also represents a major cost to the UK economy. In 2006, production losses due to mortality and morbidity associated with CHD cost the UK over £3.9 billion, with around 65% of this cost due to death and 35% due to illness in those of working age. The cost of informal care for people with CHD in the UK was estimated to be around £1.8 billion a year in 2006 (British Heart Foundation, 2009).

1.4.2 Non-Cardiac Chest Pain costs

In terms of symptoms that were initially thought to be attributable to heart disease but were later confirmed to be of non-cardiac origin there are also major associated costs. In the US Kahn (2000) has estimated the cost of providing initial care to patients suspected of having CHD, but who are subsequently found not to, to be in the region of approximately $8 billion. Kahn suggests this high figure is due in part to the litigation resulting from a high incidence of missed myocardial infarction and subsequent mortality of those sent home, a problem that may not be so prevalent in the UK where litigation rates are lower (Kahn, 2000). Similarly in Australia non-cardiac chest pain has been shown to be a major contributor to the total public health costs accounting for approximately 2-5% of all emergency presentations **(**Eslick, et al, 2002). Although there is little information on the exact cost of NCCP in the UK, with around 5% of all admissions to accident and emergency departments being due to chest pain, and up to 70% of those due to NCCP, (McGavigan, Begley, Moncrieff, Hogg & Dunn, 2003) the cost in the UK is likely to be high.

For those patients whose chest pain remains unexplained, there remains a significant need. Despite receiving a diagnosis that cardiac disease is not the cause of their chest pain many patients continue to experience distress and disability (Goodacre, Mason, Arnold & Angelini, 2001), and in many cases they return to emergency departments with complaints of chest pain (Jerlock, Gatson-Johansson & Danielson, 2005). This is understandable given the information people are given regarding chest pain. Chest pain is often perceived as a threat to life, and this fear and anxiety can increase the pain (Tueth, 1997). Chambers, Bass & Mayou (1999) suggests that this situation can lead to the patient whose chest pain persists to become confused: having been told their hearts are healthy, even though chest pain persists they are liable to see a new physician, where it is again assumed their chest pain is of a cardiac nature. Continued help-seeking by individuals with NCCP, although understandable, can put pressure on health professionals, resulting in expensive investigations and inappropriate use of medical resources (Robertson, 2006).

It is also important to realise the cost may also be high for the people with NCCP. Studies have shown that the well being and quality of life of people suffering from NCCP can deteriorate (Karlson, Wiklund, Bengston & Herlitz, 1994; Atienza, Velasco, Brown, Ridocci & Kashi, 1999). A study by Karlson et al (1994) showed that people whose chest pain symptoms were not due to a heart attack or MI reported more cardiovascular, psychosomatic and psychological symptoms after one year than people who survived a confirmed MI. Jerlock et al, (2005) undertook a study where people were asked to describe their unexplained chest pain and how it intruded on their everyday life. The nineteen people (11 men) recruited for the study gave descriptions of their pain and how it affected their lives during open ended unstructured interviews. The authors found that unexplained chest intruded into the lives of their participants in a destructive manner. After being given a diagnosis that their chest pain was not cardiac related these participants were left with a range of feelings when their symptoms continued, ranging from fear and anxiety, uncertainty, stress and a loss of strength (Jerlock et al, 2005).

1.5 Raising awareness of symptoms that may be attributable to heart disease

Richards, Reid & Watt (2002) explored socio-economic variations in response to chest pain symptoms in a sample of men and women from Glasgow, Scotland. Part of their study compared qualitative interview responses from men and women from deprived and affluent areas. They found that participants from deprived areas reported a greater perceived vulnerability to heart disease, although this was not associated with an increased presentation to a general practitioner when chest pain was experienced. Richards et al reported that respondents from the deprived group reported greater exposure to ill health which appeared to lead them to confuse their chest pain with other conditions and to ‘normalise’ their chest pain symptoms to more benign causes when compared to those from more affluent areas (Richards et al, 2002).

In 1999, following the publication of the White Paper *Towards a Healthier Scotland* (DoH, 1999), the government announced a total of £15 million was to be made available for a number of health related demonstration projects many of which included increasing knowledge and awareness of CHD including ‘Have a Heart Paisley’ (HaHP). HaHP was established in October 2000 with a £6 million grant from the Scottish Executive. As one of four national demonstration projects it was to be a 'test bed and hot bed' - an attempt to make an unprecedented impact. The long-term aim of HaHP was to reduce the total burden and levels of inequality of coronary heart disease in Paisley through an integrated programme of secondary and primary prevention. HaHP consists of fifteen linked work strands. The intention was to deliver interventions in partnership, engaging the community at all levels of the programme (Scottish Executive, 2005).

Paisley was chosen because it has one of the worst CHD records in Scotland; in some areas within the town CHD incidence is more than 50% higher than the Scottish average (Scottish Executive, 2005). HaHP was a multi-agency, multi-sector, multi-setting project attempting to reduce heart disease at an individual, risk-factor and population level (Blamey, Ayana, Lawson, Mackinnon, & Judge, 2005). The overarching aim of the project however, was to prevent heart disease from developing, to delay progression of existing disease and to ensure people realise the symptoms of heart disease and know how to take appropriate action (Scottish Executive, 2005).

An approach using a wider national strategy was undertaken by the British Heart Foundation in its ‘Doubt Kills’ campaign (http://www.bhf.org.uk/doubtkills). The objective of the campaign was to save lives by reducing the time it takes people experiencing heart attack symptoms to call for medical help by raising awareness of symptoms, and breaking down barriers to calling 999. The campaign was aimed at those most at risk (adults over the age of 45 years) and used a number of different methods to attempt to communicate these messages. These included leaflets, mainstream posters, and radio and television presentations. The campaign was designed to urge people experiencing chest pain, or other heart attack symptoms such as breathlessness, nausea or pain in the jaw, neck, and arm or pain in the back that spreads to the chest, to call 999 immediately (British Heart Foundation, 2008).

For the mainstream UK population the campaign used a patient information leaflet showing an image of a man with a belt around his chest and the words, ‘*A chest pain is your body saying call 999’*. For the South Asian population, adverts depicted a South Asian father who experiences chest pain whilst playing cricket with his son, and the appropriate action to take, i.e. calling 999. The BHF delivered the leaflets to more than 3 million homes across the UK. In addition leaflets were made available through co-op pharmacies prescription bags, general practice surgeries, and BHF shops (British Heart Foundation, 2008).

The BHF estimates it has met the campaign's core objectives. The Foundation web site cites inspiring stories from people who sought help quicker as a direct result of the campaign. In more visible terms the London Ambulance Service estimated it had seen a 25% increase in chest pain calls in the first week of the campaign, with other ambulance services reporting a similar impact (British Heart Foundation, 2008).

The BHF 'Doubt kills' campaign was a national health promotion targeted at people in the general population. What it did not do was target people, or specific groups, identified as being at high risk of developing heart disease. The BHF campaigns strategy to distribute the information was to send information packs to homes throughout the UK. This approach of circulating the information did not target people via primary care settings, an approach recommended by primary care professionals.

This study aims to address these points by creating an information resource for people who are identified as being at high risk of developing heart disease, in order to reduce the time it takes these people who are experiencing symptoms which may be attributable to a heart attack to respond to their symptoms. It is also envisaged that the resource will be distributed in a primary care setting, either during a consultation between the GP and person identified as being at risk, or sent to their home address by their GP when their high risk status is identified.

1.6 The aim and the objectives of this thesis

In this chapter, I have described the significance and epidemiology of CHD in terms of the trends in coronary heart disease over the past few decades and current patterns of CHD in the UK and in Scotland. I have provided evidence of gender, regional and socio-economic variations in CHD in the UK. However, because the majority of people with chest pain seen in accident and emergency departments within in the UK are due to NCCP, I have provided an overview of this subject together with data on NCCP. The costs of both CHD and non-cardiac chest pain were then considered. There then followed a description of the need to raise awareness of the symptoms that may be attributable to heart disease, followed by a description of two recent interventions or campaigns which attempted to highlight the type of symptoms that could be attributable to heart disease.

The overall aim of the research reported in this thesis is to produce a piloted draft information resource which aims to help people to respond effectively to symptoms that might be attributable to heart disease for people at high risk of heart disease.

In order to achieve this aim a number of objectives have been developed, these are:

1. to describe experiences and response amongst a range of people who have had symptoms that might be attributable to heart disease;
2. to select experiential data to include in the content of the resource;
3. to identify the best practice guidelines on the management of a heart attack, MI or acute coronary syndrome (ACS);
4. to combine the experiential data and the guidelines in a draft resource; and
5. to pilot the resource through seeking responses to content and preferred style of presentation from relevant patient groups and health professionals

1.7 Overview of the thesis

Chapter 2 presents a critical review of the literature surrounding the response and interpretation of symptoms attributable to a heart attack, and how the interpretation of such symptoms can affect decisions about whether and when to seek help. This literature review provides the rationale for the research questions addressed in this thesis. At the beginning of the chapter I describe the adaptive function of symptoms and how we respond to and interpret them, with a focus on the symptoms attributable to heart attacks. I consider the substantial contribution the fields of psychology and medical sociology have already made to the study of symptom response and interpretation, illness experience and illness behaviour. I also attempt to cover some of the most influential writings of relevance to this thesis. Subsequent sections of the chapter cover: how people respond to symptoms (including theories of response and research on response to symptoms of cardiac illness); the construction of attributions in response to symptoms; knowledge used in these processes; the role of significant others; the influence of context or situation; and the treatment actions.

Chapter 3 presents an overview of the policy that has driven the development of patient information and outlines research on the principle components essential in production of good written patient information. The chapter begins with an overview of the policy documents that have had a significant influence on the transformation of patient information from a simple handout to an integral component of many health care strategies. I highlight key areas and demonstrate how these policies were integral to the strategy to modernise patient information. I also outline the impact these policies have had in changing the emphasis of patient information from a biomedical perspective to a more patient-centred focus.

Subsequent sections of the chapter present a methodological review of the components important in ensuring the quality of patient information. This is divided into five key areas: readability; recall; the use of pictures and illustrations; technical issues; and the use of patient experiences. The chapter concludes with an overview of patient information in the context of heart disease in the UK.

Chapter 4 (‘Methodology’) provides an account of research methodology used to address the research questions and study objectives. I justify the use of a qualitative approach to obtain the research data and the methods used to achieve this. I discuss the ethical issues of using such an approach and explain the rationale for the initial use of focus groups as a method of data collection, and explain why this method was modified to include the use of individual interviews. I explain the recruitment procedures. I also discuss the strategies for ensuring rigour in qualitative research and managing the data. The chapter concludes with a detailed account of the key stages of the study’s analytical decision trail.

Chapter 5 describes the respondents’ accounts of their initial symptom experiences. It examines the differences in accounts between those who said they reacted by seeking help quickly and those who waited. I describe the respondents’ responses to and their descriptions of their initial symptoms, their initial attributions and whether they had any knowledge or experience of heart attacks, angina, or any other forms of heart disease, the role played by significant others, the situations the respondents were in when their symptoms were experienced and the events which finally led to them seeking help. The chapter presents first the accounts of those who responded quickly and second, those who waited.

The analysis in this chapter is structured in this way in an attempt to distinguish possible differences in those who acted quickly and those who waited across a number of variables. By looking at the two groups separately it may be possible to highlight the factors which facilitate the decision to seek help quickly.

Chapter 6 details the development of the information resource. The chapter describes how the resource was developed and shows how the design process took place from the initial ideas to the production of a working design template. The chapter then describes the development of subsequent drafts of the resource by eliciting and incorporating feedback from a number of patient groups. The chapter considers the factors most relevant during the initial stages in the development of written patient information. I use extracts provided by the respondents during the development stages to accompany these considerations to demonstrate how their input was essential during the early stages when ideas surrounding the direction of the design and the content were not yet agreed.

I demonstrate how the approach taken in the development of this resource drew heavily on that taken by Kennedy, Robinson, Thompson & Wilkin (1999) & Kennedy, Robinson, & Rogers (2003) in their production of guidebooks. I also show how the respondents in this study were involved from the outset in the design and influenced the development process, and their role in evaluating the various drafts. I also demonstrate the key role taken by health professionals in development of the resource.

Finally chapter 7 presents a summary and conclusion for the study. The chapter begins by summarising the main findings from the research (chapters 5 and 6) and considers them in relation to the research literature available. The chapter then considers the production of an information resource. I highlight the benefits of incorporating the accounts of people who have experienced symptoms that have been attributable to a heart attack, and using their experiences and insight in the development process. I also acknowledge the advantage of using health professionals with knowledge of heart disease to provide a professional perspective on the development process. I then discuss the strengths and limitations of the study before discussing recommendations for future research. Finally I discuss the implications for healthcare policy and practice in relation to the findings, before the chapter closes with a number of conclusions.

Chapter 2 Literature review: Illness behaviour: responding to the symptoms attributable to heart disease

2.1 Introduction

In the late 1960's Irving Zola undertook a landmark study of why people arrived at a US emergency room with symptoms of illness. As he wrote:

> *'virtually everyday of our lives we are subject to a vast array of bodily discomforts, and only an infinitesimal amount of these get to a physician'.*

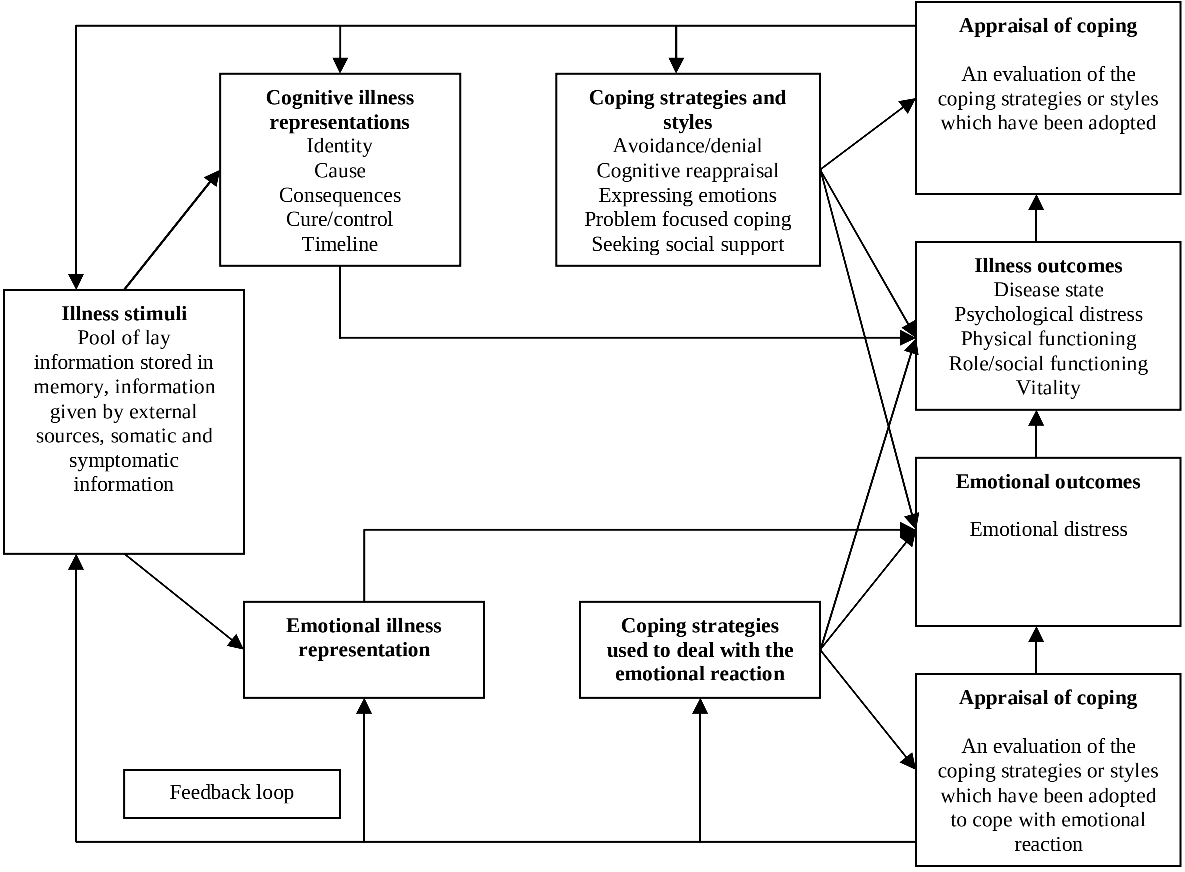
But, he went on:

> *'neither the mere presence nor the obviousness of symptoms, their medical seriousness, or the objective discomfort seems to differentiate between those episodes which do and those which do not get professional treatment'*
>
> (Zola, 1972. pp. 230-231).

Mechanic (1995) defined illness behaviour as: "Illness behaviours arise from complex causes, including biological predispositions, the nature of symptomatology, learned patterns of response, attributional predispositions, situational influences, and the organisation and incentives characteristics of the health care system that affect access, responsiveness and the availability of secondary benefits".

This chapter reviews the literature on illness behaviour in relation to symptoms that end up being diagnosed as attributable to heart disease. It focuses on the interpretation of symptoms, and how this can affect decisions whether and when to seek help. Because it covers the whole process of response to symptoms, from recognition of symptoms, to interpretation, coping/management/response and appraisal of actions, the chapter uses Leventhal, Meyer and Nerenz's (1980) self-regulatory 'Common Sense Model' (CSM) as a framework to describe the literature. The model is summarised in figure 1.

Figure 1 The common sense model of illness representations



The research that would eventually lead to Leventhal's CSM began in the late 1960's with an investigation of whether fear messages could influence people to undertake health behaviours which were beneficial, such as stopping smoking (Leventhal, Brissette & Leventhal, 2003). Leventhal and colleagues found that different types of information were more influential than others in determining the actions people would take to a perceived threat to health. They suggest when people experience symptoms, they form hypotheses about corresponding diagnosis, what the cause could be, how long the problem could last, what the outcome could be and what could be done to control or ease the problem. These hypotheses could be influenced by information from sources such as clinicians consulted by them, other people with similar experiences and broadcast media including the Internet. The CSM is a dynamic model where people can change their hypotheses to accommodate new information and experiences.

In building upon their initial work Leventhal and colleagues proposed a hierarchically organised model featuring the four main stages or steps of response to illness: (1) illness stimuli which includes internal and external stimuli; (2) representations of the illness which could be both cognitive and emotional; and (3) action or coping strategies which include doing nothing or waiting to see what happens as well as self-treatment and consultation with professionals; and, because it is self-regulatory (4) the appraisal of coping strategies and of their outcomes which can require symptoms to be re-interpreted , re-assessed and alternative actions to be taken.

Although these steps, or stages, are overlapping, and indeed, may occur virtually simultaneously, they provide a useful framework for organising the chapter and the sections that follow correspond, as far as possible, to them. Section 2.2 covers research on external and internal illness stimuli; section 2.3 covers research related to cognitive representations of illness; section 2.4 briefly covers emotional influences on interpretations of illness and emotional representations (although much less has been written about this); section 2.5 covers coping strategies (or action taken, response to symptoms); section 2.6 deals with research on contextual or environmental influences on the process of responding to symptoms and finally, section 2.7 summarises the chapter. In each section, where evidence relating to response to symptoms that might be attributable to cardiac disease is available this is given prominence; otherwise, general understanding of response to illness is presented.

Research using the model (Broadbent, Ellis, Tomas, Gamble & Petrie, 2009; Petrie, Cameron Ellis, Buick & Weinman, 2002) has illustrated how influential cognitive representations of symptoms can be in terms of understanding people's response to symptoms. People's cognitions are affected by 'illness stimuli' to which the chapter now turns.

2.2 Illness stimuli

Leventhal et al (1980) have suggested that illness representations, and thus response to them, are informed by three types of information; sensory information, or 'internal stimuli' related to physiological changes and associated symptoms; 'lay' information - what the person already knows about the illness or symptom; and information obtained via the external social environment – that is from significant others, such as family, or from health professionals. The following sections deal with each in turn.

2.2.1 Sensory information – internal stimuli

The first type of information is gained from the actual sensory experience of the symptom itself – whether it is intense, mild, persistent, novel and so on. Symptoms have been described as a change in the physical or mental condition of an individual, often regarded as evidence of disease or illness. The experience of physical symptoms is widespread, and virtually everyone will have to face some form of symptom at some time, although most of the common symptoms we experience are mild, transient and easily explained (Kolk, Hanewald, Schagen & Van Wijk, 2003), as we shall see later. Telles and Pollack (1981) suggest symptoms are important because sickness is a prime human concern, and the way an individual feels is the main criterion of health, illness and recovery. Our ability to use the information provided by our symptoms gives us a higher chance of survival than say an organism which did not have the ability to perceive or interpret symptoms.

Ditto & Hilton (1990) have discussed the problem of identifying which symptoms require medical attention in terms of a 'signal detection theory'. In this respect any given symptom that an individual experiences could reflect the presence of a condition requiring medical attention (i.e., be a signal), or it could simply reflect a common, benign fluctuation in bodily processes (i.e., be noise). They contend that, in general terms, symptoms of a diseased state obviously demand medical attention, while those due to benign fluctuations do not. The problem for the individual is that there is considerable overlap between the distributions of these two classes of symptoms.

Pennebaker (1984) has written about the symptom perception approach to understanding biological, psychological or sociological influences on recognition and response to somatic distress. In this approach, physical symptoms are understood to be the outcome of perceptual-cognitive processes regarding attention, detection and interpretation. Although there is no simple correspondence between physiological changes and the perception of physical symptoms the perception of physical symptoms is generally preceded by physiological changes – what Leventhal calls 'internal illness stimuli'.

Pennebaker has argued that physiological changes can arise from fluctuations in normal bodily processes, from organic disease (acute as well as chronic), from emotions, or they can be induced by environmental conditions. It is suggested that these changes trigger receptors throughout the body, generating information about the state and function of internal organs and the organ systems. However, only a small proportion of this information gives rise to the awareness of bodily changes (Granot, Goldstein-Ferber, & Azzam, 2004).

2.2.2 Lay information

The second type of information is termed 'lay' information - what the person already knows about the illness or symptom. This may be formed through one's own experience, from discussions with others about particular symptoms or illnesses they have had or through general, 'culture' or common-sense knowledge that is generally held in a community. Research within the medical sociological tradition has examined the lay explanations, lay understandings and lay experience of illness – and the ways in which people interpret and read bodily symptoms and react in assessing illness (e.g. Rogers, Hassell & Nicolass, 1999). Rogers and colleagues suggest that lay concepts of health and illness may be 'less expert' but, because they are grounded in subjective experience, these concepts may be better informed, on occasion, than more professional perspectives (Blaxter, 1985).

In medical sociology one way of articulating the information, or knowledge, gained through experience is through the concept of 'lived experience' which provides intimate 'taken for granted' knowledge of the body possessed. Rogers et al (1999) suggest that expert and lay knowledge are mutually dependant in their information content, although 'lay' knowledge cannot be seen as separate from medical knowledge. They suggest that the lay person's views about the cause, prognosis and risk of symptoms are formed in a similar way to the diagnosis made in medical practices (Rogers et al, 1999).

2.2.3 The external social environment – the importance of significant others

The third type of information is obtained via the external social environment – that is from significant others, such as family, or from health professionals. Although Cameron and Leventhal (2003) recognise the role of people's social networks, particularly people close within it, most research on the role of significant others has not used the CSM at all. Because the effect of significant others is often seen to mediate people's response to symptoms in general it is more readily described once these have been covered. Thus sections 2.6, on the effect of the external environment, covers research on the social environment – or the role of significant others - too.

2.3 Cognitive representations of illness

Leventhal and colleagues (1997) suggest that five components of illness representations can be identified. The first of these is *identity*. This is the label or name given to the condition and the symptoms that 'appear' to go with it. Leventhal et al (1980) have argued that people like to label their symptoms in order to legitimise them. The second, and related, component of illness representations concerns the perceived *cause* the person has regarding the origin of their symptoms, which may or may not be medically accurate. As we have seen, the information used to ascertain the cause is based on personal experience, the experiences of significant others, communications with health professionals and information relayed via general cultural resources such as the media. *Time-line,* the third component, concerns the beliefs about duration, how long the person thinks their symptoms/illness will last which are reassessed over time. The fourth component concerns the *consequences* the person feels will result from their symptoms/illness in terms of the physical and social costs. However, it has been suggested that these representations may develop over time (Leventhal et al, 1997). Finally *curability/control* is the construct which relates to how much the person believes their illness is treatable or how much influence they have over their illness.

Research not conducted within the CSM's framework has nevertheless covered very similar ground and the following sections review this research in relation to these CSM-inspired headings.

2. 3.1 Symptom identity or label

Giving symptoms a label or an identity is intimately related to identifying its cause. We have seen that the term 'symptom' can be defined and interpreted in a variety of ways depending on the viewpoint of the individual. Many people view symptoms as subjective indicators of a disease or illness and immediately attempt to understand its cause and to give it a label. McDaniel & Rhodes (1995) suggest that symptoms are indicators of a departure from the normal; they describe symptoms as atypical or disturbing sensations that interfere with our normal activities. According to Rhodes (1987), symptoms are private; they are what the individual experiences and reports as manifestations of their problem.

Mechanic (1992) suggests that most symptoms are normalized, or are evaluated as having little importance in the context of everyday life. He suggests that initially we tend to normalise symptom experiences by applying a common sense rather than a medical label to them – for example a common normalisation process with regards to chest pain as a result of angina is to attribute the pain to 'indigestion' or other minor ailments (Rogers et al, 1999). Tuckett (1976) contends that people generally resist defining themselves as ill and tend to accommodate to their symptoms as they develop. Pennebaker (1982) suggests illness symptoms are differently labelled by individuals in dissimilar social and cultural situations.

Recognising and labelling symptoms involves the consideration of competing cognitions, emotions and perceptions in an attempt to bring meaning to experiences Perceptions have been linked to the social and subjective contexts of people's everyday lives. Pennebaker (Pennebaker1982; Pennebaker, 1984) has suggested what determines the meaning of symptoms is the degree to which perceptual systems can focus accurately on internal bodily sensations in the face of external 'noise'. This refers to the suggestion that symptom recognition is the outcome of a competition for perceptual attention between external (environmental or contextual) stimuli, and internal (bodily or sensory) stimuli. Therefore, while contextual factors are accorded importance by Pennebaker, their role is limited to acting as interference in perceptual functioning. He suggests that these contextual factors cannot play any constructive role or purpose. The more our attention is absorbed by external stimuli (e.g. work, family or daily hassles) the less aware of bodily sensations, unless the external stimuli act as stressors and contribute to a negative emotional state, along with physical sensations. In contrast when external information is relatively low (e.g. life and work are repetitious and boring) attention to and awareness of somatic sensations increase. Other researchers suggest that the interpretation of a sensation as a symptom of disease is guided by illness schemes, cognitive structures that are based upon earlier experiences with, and ideas about illness and disease (Walsh, Lynch, Murphy, & Daly, 2004).

2.3.2 Causal attributions – general

As we have seen, giving a label to a symptom implies an understanding of its causes, together, attributing symptoms to a cause and giving it a label is based on information acquired via various sources which take place over time involving different levels of complexity depending on the nature and familiarity of the symptom / symptoms a person is experiencing. There are a variety of factors which are relevant in shaping our evaluation of the symptoms we encounter. These range from: our own and others' experiences and expectations about health and illness; our roles and responsibilities; our culture and social background; our perception of personal risk and vulnerability; and the use of medication (Rogers et al, 1999).

So, a common reaction to an unexpected negative event, such as the experience of a new symptom, is to attempt to construct a causal explanation or attribution in order to explain it (Weiner, 1985). As Locker (1981) suggests, in the face of symptoms there is 'ubiquitous causal theorizing' (p62) in which one object or event is seen to precede and be responsible for another object or event; symptoms are given a label and through causal theorizing causes are *attributed* to them.

Creating causal attributions is a central part of how we construct cognitive representations to account for our symptom experiences (French, Senior, Weinman & Marteau, 2001). This creation of an explanation helps to make sense of symptoms. In constructing these explanatory attributions we are creating the inferences we draw upon to understand what is happening to us during our symptom experiences.

Theories on how attributions are constructed share four main assumptions (Forsterling, 1988). The first is that attribution theories are essentially cognitive based on the central role played by cognitions in behavior, affect and experience. Second, it is assumed that people are motivated to seek causal explanations for their symptoms. Third, people tend to search for explanations in a similar way to the methods used by scientists. The fourth assumption is that the process of making causal attribution is somehow adaptive. However, only the first two assumptions have been consistently supported by research (Sensky, 1997).

The search for attributions has also been linked with situations of high uncertainty (Turnquist, Harvey & Andersen, 1988) and to the seriousness the person attaches to the event (Weiner, 1985). It is therefore not surprising that Turnquist et al (1988) found that between 75% and 95% of people when faced with a life-threatening illness made a causal attribution to account for their symptoms. Another key feature in the construction of attributions is the conviction with which the attribution is held. Serious illness has been associated with the creation of more attributions (Affleck, Tennen, Croog & Levine, 1987), but interestingly the attributions tend to be held with weaker conviction (French et al, 2001). French et al (2001) suggest that this contradiction can allow the person experiencing the symptoms ready access to alternative causal explanations in the event their first attribution is invalid.

Sensky (1997) suggests causal attributions can be classified along three dimensions: (1) locus of control (internal versus external); (2) stability; and (3) controllability. Perhaps the first question that arises when forming an attribution is whether the symptom originates within the person, or is due to some external or environmental cause. Sensky argues that only when no possible situational attribution is possible do people search for dispositional attributions, within themselves (Sensky, 1997). The importance of this distinction lies in the fact that these dispositional attributions are assumed to be abnormal, and potentially pathological, whereas the situational attributions are commonly thought to be benign, a process described as normalising symptoms (Robbins & Kirmayer, 1991). In a study investigating a community sample of fatigue sufferers, Chandler, Power & Wessely (1996) found that those people attributing their symptoms to social factors, such as stress at work (a normalising attribution), were less handicapped at follow-up than those who made pathological attributions.

When faced with new and unexpected symptoms people have a tendency to interpret these events in the context of prior beliefs and current expectations. Attributions which come to mind most readily at the onset of symptoms tend to be judged more probable (Sensky, 1997). This is even more so if the person has never experienced the symptom / symptoms before. In these circumstances people attempt to construct scenarios to account for their symptoms, and will then judge how probable these are in terms of how plausible the symptoms and the cause are and the ease with which they came to mind (Tversky & Kahneman, 1973).

These processes are however influenced by external factors. Specific media attention concerning certain illness can explain how people can attribute their symptom / symptoms to erroneous causes. If someone is predisposed to make a specific attribution in response to a specific symptom, or a cluster of symptoms, this tends to focus the person’s attention on these cues which are likely to confirm their hypothesis (Cioffi, 1991). Having made an attribution Sensky (1997) suggests the person’s memory for the event is now enhanced in keeping with their developing model of illness, even though it may not be accurate. For example, someone predisposed to associate chest pain with heart disease is likely to recognise the severity of the situation when chest pain is encountered. In contrast people who associate this type of symptom with indigestion are more likely to wait or attempt to self-medicate.

2.3.3 Causal attributions – symptoms that might be cardiac illness

Experiencing a heart attack for the first time is a frightening experience for most people. In a review aimed at describing the patterns of attributions made for the causes of heart disease French et al, (2001) used the results from a number of studies (overall 54 data sets) to determine what attributions were made: chronic stress and specific lifestyle factors were the two most common (both social factors). These two causes were rated as the most important in over two-thirds of the studies investigated (French et al, 2001). A number of other studies have attempted to explore the attributions people have made during a heart attack and how these attributions have affected behaviors such as when to seek medical help, but all elicited attributions some time after the event (Dracup, Moser, Eisenberg, Meischke, Alonzo, & Braslow, 1995; Finnegan, Meischke, Zapka, Leviton, Meschak, Benjamin-Garner, M., et al, 2000). There has been research on the attributions that are made immediately after a heart attack.

One study which has investigated the symptom experiences and attributions made as a result in a group of people immediately following their first myocardial infarction (MI) was undertaken by Cameron, Petrie, Ellis, Buick & Weinman (2005). The authors explored the attributions made by 65 people and found that the majority were related to a heart condition. However, the results showed that the attributions varied by and in relation to the symptom experienced. Symptoms such as chest pain, nausea, and an irregular heart beat were all readily identified as related to a heart condition. In contrast, symptoms thought to be related to a gastrointestinal complaint, irritability or coughing were not thought to be cardiac related. The authors suggest these variations in symptoms attributions may provide some indications regarding the prototypical beliefs people have about heart attacks, as the attribution process involves matching symptom experiences with beliefs about symptoms attributable to a specific disease (Cameron et al, 2005).

Although the results produced by Cameron et al (2005) indicated that many people attributed their symptoms to a heart condition the most common causal attribution was stress, followed by high cholesterol, heredity, fat consumption and hypertension. This pattern was also evident in earlier studies investigating attribution of heart disease (French et al, 2001; Weinman, Petrie, Sharpe & Walker, 2000). For example many people attributed their symptoms to high cholesterol due to their ‘risky’ dietary habits. Others made hereditary attributions based on their family history of heart disease (Weinman et al, 2000). These studies suggest that when people are constructing their attributions they are heavily influenced by specific symptoms (Cameron et al, 2005). However, studies have shown that if symptoms are unfamiliar, a new experience to anything they have experienced before, this has led many people to attribute their symptoms to an unimportant cause and they have ignored them (Pattenden, Watt, Lewin & Stanford, 2002). Incorrect attribution of symptoms has been found to an important factor influencing the decision to seek help (Dracup, McKinley & Moser, 1997; Horne, James, Petrie, Weinman & Vincent, 2000).

Weinman et al (2000) suggest that the causes we attribute to our symptoms help us to make sense of these experiences. Previous studies examining the attributions people have made during the onset of symptoms attributable to a heart attack have found the common attributions people make to account for their symptom is to assign them to poor health habits (Affleck, Tennen, Croog & Levine, 1987; De Vale & Norman, 1992). A common example of this type is the situation in which the person interprets the onset of a heart attack as indigestion, or where they attribute their racing heart rate to their stresses due to their working environment. These attributions of the cause of the symptoms can have fatal consequences, but the person can feel somewhat reassured because they are able to associate their chest pain or increased heart rate to a more benign type of explanation.

In terms of the types of information used to help inform an attribution of symptoms due to heart attacks studies have indicated that people who have had a previous heart attack are no better at responding to their symptoms quickly and to seek help than people who experience their first heart attack (Johansson, Stromberg & Swahn, 2004; Gurwitz, McLaughlin, Willison, 1997). This finding was also reported by Mumford, Warr, Owen & Fraser (1999) in their study investigating the reasons people delay when experiencing acute chest pain in a sample from a Canadian and UK patient population. The authors found that people with a previous diagnosis of angina or myocardial infarction were no better at forming an attribution that their symptoms were related to their heart, and they sought help later than those with no such history. This paradoxical finding was despite those with experience of heart disease having had frequent contact with medical services and therefore direct personal experience of the importance of early admission to hospital (Mumford et al, 1999). This finding was also evident in the findings reported by Leslie, Urie, Hooper & Morrison (2001). But other studies have contradicted this finding and have shown that people with a previous heart attack are more likely to have reduced prehospital delays, as a result of reduced decision times in determining the importance of their symptoms (Ottesen, Dixon, Torp-Pedersen & Kober, 2004). Ottesen et al (2004) also found people who attributed their symptoms to a cardiac cause were more convinced they would die from another heart attack. As a consequence these people were more likely to interpret symptoms as being serious with severe consequences (Ottesen et al, 2004).

2.3.4 Time-line and consequences

In terms of time-line and consequences these are constructs which concern beliefs about how long the person thinks their symptoms/illness will last and what will be the consequences of them in terms of being able to function effectively. Both can impact on the mental representation a person makes in their reaction to symptoms. Although the recommended action on experiencing symptoms attributable to heart disease is prompt help seeking via the emergency medical services in reality many other courses of action take place. Robinson (1971) suggested that there may be difficulty in making the decision to seek help where uncertainty arises in interpreting symptoms as serious and a lack of understanding of the consequences their symptoms may entail. Symptom seriousness is based upon what people are told about the nature of a condition, knowledge through personal experience and other cues and information picked-up informally (Rogers et al, 1999).

A further factor relevant in understanding the decision to seek medical help concerns knowledge of the potential treatment options available for the treatment of heart attacks, MI's or acute coronary syndromes. This is a factor which can directly effect the time it takes a person to make the decision to seek medical help. One of the most important advancements in the treatment of an MI has been the use of reperfusion therapies. Whether thrombolysis or angioplasty the benefits of this type of therapy in improving the outcomes for people are well documented (Luepker, 2005). In an Australian study Dracup et al (1997) found people who had little or no understanding of the benefits of using the Australian emergency medical services. They also had no knowledge of treatment ambulance personnel could offer, and no understanding of the need for timely administration of reperfusion therapies (Dracup et al, 1997).

A United States (US) study investigating the prehospital phase of delay in people with acute myocardial infarction found that 84% knew nothing of the therapies available to treat their condition. The 16% of participants who had some awareness of the existence of the therapies available sought help significantly sooner than those who were unaware of treatment options (Wielgosz & Nolan, 1991). Another study investigated the link between knowledge of treatments available for heart attacks and seeking help. In this case the sample consisted of physicians and non-physicians who were experiencing heart attacks (Schmidt & Borsch, 1990). Their results showed the physicians sought help significantly sooner than the non-physicians (1.8 hours against a delay of 4.9 hours respectively). Schmidt & Borsch (1990) suggest that the faster response to symptoms was a consequence of their knowledge of the benefits of reperfusion therapies and the time dependant nature of their delivery.

2.3.5 Cure or control

In terms of curability/control, the construct relates to how much the person knows about their symptom or illness and how treatable it is or how much influence they have over it (the illness). There is evidence to show that the representation an individual makes in regard to their potential cardiac symptoms can directly influence their help seeking behaviour (Horne et al, 2000). Previous work has shown that people have pre-existing ideas about the symptoms associated with any common illness. In a similar way people identify diseases or illness by comparing the symptoms they experience with those they expect for a given disease (Bishop & Converse, 1986), and evidence has shown this is the case with regards to chest pain attributable to heart disease (Horne et al, 2000).

In terms of the construct cure/controllability, when a person recognises their symptoms to be cardiac in origin, an appropriate evaluation of the urgency of the situation is made more often, and a rapid response is more likely to occur. In these circumstances the person realises they have little control over their situation other than to seek prompt medical attention. Chest pain is a common symptom of a heart attack and there are a number of terms that are typically used to describe the 'crushing' and / or severe pain associated with this symptom. When chest pain is experienced in this form people typically respond to it. That is they know it is serious needing prompt medical attention and realise the only influence they have is to respond quickly. This is in contrast to where people are unsure of the nature of their symptoms, in these circumstances people may think they can control their condition employing strategies such as self-medication or waiting to see if their symptoms develop.

2.4 Emotional influences on symptoms recognition and representations of illness

Whilst Leventhal's CSM is a parallel processing model, the emotional representations of symptoms and illness have been much less researched than the cognitive ones.

This section considers emotional influences on symptoms perception as well as emotional representations in response to symptoms.

We know that symptoms indicate to the individual the possibility of illness but that symptom perception varies between people; Pennebaker suggests this is because we differ in the amount we are able to attend to our internal states. He suggests that those who are internally focused may be more sensitive to symptoms, whereas those who are externally focused may be less sensitive to any internal changes (Pennebaker, 1984). Skelton & Pennebaker (1982) suggest symptom perception is also influenced by mood and cognition. Mood it is suggested can affect our subjective states and cause increases in levels of anxiety. The authors found that increases in anxiety resulted in additional self-reports of pain experience, the expectation about the nature of the symptom can alter the experience of that symptom, and resultant negative mood can influence the attributions made about a symptom. Cognitive states can also influence a person’s perception of their symptoms. Pennebaker suggests that symptom perception is related to a person’s attentional state and that boredom and the absence of environmental stimuli may result in over-reporting, whereas distraction and attention diversion may lead to under-reporting (Pennebaker, 1982).

Pennebaker (1982) has also suggested that a number of other variables have been found to influence the perceptual cognitive processes that are related to the experience of negative mood, and physical as well as psychological symptoms. For example chronic diseases are considered to be a major source of internal, somatic information, the more so when there is more than one chronic disease. Pennebaker (1982) also suggested that negative affectivity (NA) has been repeatedly associated with high reports of physical symptoms, independent of demographic characteristics and health behaviours. The tendency to selectively attend to the body has been defined as the tendency to be aware of or sensitive to, internal bodily processes and states, not typically associated with disease, illness or emotion (Pennebaker, 1982). Selective attention has also been associated with elevated symptom reporting. Other factors may include living alone, social isolation, unemployment, or undemanding, low status jobs on the one hand, and from over demanding work, family, or household responsibilities, as well as conflicts due to multiple roles (e.g. partner, parent, homemaker, and employee). In addition, the association between negative affectivity and physical symptoms was found to be mediated by the tendency to use selective attention (Watson & Pennebaker, 1989).

Emotions are an integral component of the Common-Sense Model. Simultaneous with the development of the cognitive illness representation, an emotional representation develops that is more subjectively experienced by the individual and creates feeling states such as depression, annoyance, anger, and anxiety. Emotion can function in one of two ways. If the emotion is accompanied by an action plan, it can motivate the individual to engage in health care activities. However, if the emotion is overwhelming, less action may be taken; in some cases, no action at all may be the result (Diefenbach & Leventhal, 1996).

2.5 Coping strategies - response to symptoms

The type of response made in response to the onset of symptoms can have major consequences for the person experiencing a heart attack. The previous sections of the chapter have discussed the CSM and the constructs instrumental in creating illness representations, these constructs play a key role in shaping the behavioural response to symptoms. The CSM makes an explicit link between illness representations and actions a person takes in terms of the coping behaviours and strategies they may adopt. The model suggests that interpreting the symptoms guides the action in response to symptom or illness threat (Leventhal et al, 1980). For example, the label or the identity the person uses to describe the condition resulting from their symptoms does play a role in the subsequent response to them. Being able to identify the symptom with a specific condition influences the pathway the person takes from representation to outcome via coping (Hale, Treharne & Kitas, 2007). For example if a person labels their chest pain symptoms as being attributable to a heart attack they are more likely to come to the conclusion their response should be to seek medical help quickly. However, if they are unsure as to identity of their symptoms they may employ another coping strategy which may lead to another response. In these situations people may deny or avoid the presence of their symptoms, they may also use a wait and see approach and re-evaluate their symptoms at a later time or they assign their symptom to another erroneous attribution and attempt to self-medicate.

A UK study investigating the prehospital phase of delay in people experiencing acute coronary syndrome (ACS) found that the people who were able to identify the symptoms they were experiencing were cardiac related were likely to have a shorter pre-hospital delays and sought help sooner than those who were unaware of what their symptoms represented (Perkins-Porras, Whitehead, Strike & Steptoe, 2009). The findings of the Perkins-Porras et al, (2009) study confirmed those of an earlier study by Ottesen et al, (2004) who also investigated pre-hospital delay in acute coronary syndrome. They found that being able to interpret symptoms as resulting from a cardiac cause was a significant factor in responding to them. In this Danish study over half of the sample was able to interpret their symptoms as cardiac and respond quickly (Ottesen et al, 2004).

Ruston, Clayton & Calnan (1998) also found that when people experienced symptoms they knew to be attributable to a heart attack they responded quickly. These people were more likely to see themselves at risk because they knew that their symptoms were serious and what they represented. Additionally the people who responded quickly were less likely to treat themselves or consult others. Leventhal et al (1980) have suggested the response people make to symptoms as in the Ruston et al (1998) study is influenced by how severe the person believes their symptoms are based on the representations they have created. However, when the experience of symptoms is markedly different from what is expected it is perhaps understandable that people are confused and employ coping strategies. Where there is confusion a natural response is indecision and this usually entails a wait-and-see approach. Many people may wait to see if their symptoms disappear or if they evolve into a more recognisable manifestation. The result of either response usually involves a delay before medical treatment is decided upon (Horne et al, 2000).

In a study investigating the complexity of symptom perception and presentation differences between men and women regarding the manifestation of unstable angina pectoris, Granot et al (2004) found some interesting results. They found that women were less likely to complain about pain in the chest and tended to describe their pain as located in the back, stomach, neck and chin. Women also reported higher levels of pain intensity compared to men, and more symptoms, such as dyspnoea, dizziness, palpitations and irritability, that did not characterise the men's chest pain complaints.

In general it seems heart disease is largely seen as a male disease, which may cause women to fail to recognise symptoms attributable to it and consequently fail to undergo medical treatment (Richards et al, 2002).

In a recent US study which investigated the time between symptom onset and the time to seek care the authors identified a range of actions the participants (N=57) took in response to their symptoms (King & McGuire, 2007). For most of the participants in this study their first communication about their symptoms was to a family member or friend, who consequently called the general practitioner (GP) for them (28%). Fewer than 23% called, or had a family member call the emergency medical services. The next most common action in this sample was to self-medicate, which tended to be medication aimed at reducing a gastrointestinal complaint. Finally a small number actually drove themselves to hospital (King et al, 2007).

Leslie et al, (2000) found an initial call for medical help to the ambulance service was made in only 25% of their UK sample of 313 people who had suffered a MI. Of these over a third had suffered a previous heart attack. The reason the majority of these people gave for calling the emergency medical services was that they knew calling a GP would take longer. For the majority of people in this study calling their GP was the first course of action they took. Reasons given for this decision was that people thought their symptoms were not serious enough to trouble the ambulance service. A more drastic course of action was taken in 20% of cases; here both the emergency medical services and the GP were bypassed by people either driving themselves or using a taxi to take them to the nearest hospital emergency department. The reason these people gave for this course of action was that they felt it was the quickest way of getting to the hospital.

Perkins-Porras et al, (2009) found that nearly half of their sample (288) called the emergency medical services when their symptoms began, rather than calling their GP, family or taking any other course of action. The people who called the emergency medical services were also those who responded the quickest to their symptoms. The authors found this decision was related to the experience of intense chest pain symptoms, and the fact they were experienced at the weekend. The authors suggest that the action to call the emergency medical services was prompted in some way because people were unwilling to contact their own GP's out of hours at the weekend. The action taken in this case could be due to fact their options were limited (Perkins-Porras et al, 2009). A similar finding was suggested by the investigators in the GUSTO-1 study (GUSTO, 1993). The authors found that many people had concerns about wasting the time and resources of their GP and this was the reason they gave for delaying contacting them (their GP) when they experienced their symptoms.

A possible explanation for people not using the emergency medical services as their first action could be that many do not realise this is the correct thing to do, they do not realise the consequences their situation entails. It has been suggested that the importance of calling the emergency medical services is often not communicated to people by health professionals. Many health professionals assume their patients already know, and therefore it is unnecessary to inform them that this is the best course of action (Zweifler, Drinkard, Cunningham, Brody & Rothrock, 1997). However, this would appear not to be the case. For many people calling their GP is thought to be the first course of action (Leslie et al, 2000). Although this in itself may lead to the involvement of the emergency medical services there appears to be a reticence among many people to call for an ambulance at the onset of their symptoms. It is also possible that other factors influence the response a person makes and it is to these factors that the chapter now turns.

2.6 Contextual and environmental factors

Although not explicit in the CSM, where symptoms are first experienced can also influence the response to them; as Zola (1974) has suggested symptoms are differently labelled by people in different social and cultural situations. The context in which symptoms are encountered has been argued by some (Zola, 1974; Alonzo, 1979) to be central to the way people make sense of their symptoms. Zola suggests a series of five social and contextual triggers which are central to the symptom evaluation processes, and which differ in their significance between social groups: (1) the occurrence of an interpersonal crisis; (2) the perceived interference with social or personal relations; (3) sanctioning; (4) the perceived interference with vocational or physical activity; and (5) a kind of temporary assignment of symptoms (Zola, 1974).

However Alonzo (1979) argues for a ‘typology of contexts’ in which symptoms become more or less apparent to the individual. He suggests there are several factors which influence the way in which people appraise their symptoms, namely: (a) commitment to and engrossment in situations; (b) tolerance by the person and the credit given by others; (c) power relationships between people; (d) coping resources of the situation; (e) symptom meaning; (f) the presence of normal processes and chronic diseases; and (g) age and sex (Alonzo, 1979).

In a later study Alonzo found the situation where the symptoms of coronary artery disease were experienced certainly played a role in the decision to seek medical help (1986). The findings suggested that if the person was at home during the acute stage they were more likely to self-evaluate their symptoms. He suggests the reasons for this were due to the availability of self-treatment resources and privacy to self-treat and observe the signs and symptoms. These factors, he suggests, would not be available to someone in a non-home setting, for example work or a public venue. This would explain the shorter decision times he observed in people who experienced their symptoms in these settings (Alonzo, 1986). The results produced by Perkin-Porras (2009) supported these findings and showed people who were at home when their ACS symptoms began had longer pre-hospital delays than people in a non-home setting.

In terms of a self-categorization approach, the theory developed by John Turner and his colleagues (Turner, 1982; Turner, 1985; Turner; 1988; Turner Hogg, Oakes, Reicher, & Wetherell, 1987; Turner, Oakes, Haslam & McGarty, 1994) provides an explanation of symptom evaluation which requires a perspective which allows for the influence of context upon perception and understanding. Turner (1988) argues that the theories and the knowledge that a person is able to draw upon to make sense of any given situation vary considerably and are as a result context dependant. Therefore, when applying self-categorisation theory to symptom evaluation, Turner and colleagues do not suppose that every person has a stock of illness representations for each of their social identities (Turner et al, 1987). Rather the theory proposes that different identities imply different criteria for the perception and evaluation of events in general, including those of physical symptoms. Turner also suggests that we assume that those symptoms which threaten some valued dimension of our salient identity will be seen as serious, while those which do not will be dismissed as relatively trivial. Therefore the significance of the symptoms will vary from context to context as a function of which identity is salient (Levine & Reicher, 1996).

Another contextual factor referred to earlier (in section 2.2.3) is the role of significant others. Moser, Kimble & Alberts (2006) suggest that factors such as being married, living with someone, or having another present at the onset of symptoms of a cardiac event can play an important role in the way people recognise and attribute a cause for their symptoms and respond. In this respect significant others can play a serious role in helping to evaluate the symptoms, such as obtaining household or prescription medication, providing support for the individual during the health related crisis, and helping obtain medical treatment (Alonzo, 1986). This last role can have the biggest impact in terms of a positive outcome for the person experiencing a heart attack.

However, the literature concerning the impact of family members or significant others in calling for emergency medical care is mixed. One study, now over forty years old but still relevant today, found that people who were alone at the onset of their symptoms made the decision to seek medical help faster than when the decision was made with their spouse present. They also found the decision to seek care was made faster when friends and colleagues compared to family members were present. The median time taken to seek care in the presence of friends was 2 hours while in the presence of family members it rose to 12 hours (Hackett & Cassem, 1969). The authors suggest the more impersonal and authoritative the interaction with friends the faster the decision was made to seek medical care.

Alonzo (1986) also found people had a significant increase in delay in seeking medical care when they informed their spouse of their symptoms. The findings also suggested that delay was greater when the person experiencing the symptoms was male and the spouse female. Alonzo suggests this is due to females being less capable of influencing their husbands (1986). The findings from this study also showed that when non-family members (workmates or friends) were consulted the delay in seeking help was shorter. Alonzo suggests this is due to lack of negotiation that takes place when friends or workmates are informed. These individuals will usually take control and call for help, a finding similar to that of Hackett & Cassem (1969).

Other studies have produced evidence which also supports the suggestion that the presence of a spouse or family member can increase the delay. Perry, Petrie & Ellis (2001) and Dracup et al (1995) have investigated the time it took people to seek help when experiencing some form of cardiac condition. Both studies found that if the symptoms were experienced in presence of another and they were a relative, particularly a spouse, the person would wait before seeking treatment. The reason suggested for this wait was the treatment strategies often recommended by their spouse in order to deal with the symptoms.

In a more recent UK study investigating patient decision time and home-to-hospital delays with acute coronary syndrome, Perkins-Porras et al (2009) found that people who were married, or who had someone present when they first experienced their symptoms had a shorter home-to-hospital delay. They suggest the reason for short pre-hospital delay was the shortened decision time. It seems in this study the presence of a spouse speeded-up the decision to seek medical care and not delay it.

However, within the literature there is some debate as to how strong this influence is in the decision to seek help. It is clear that once a significant other is informed by someone that they are experiencing symptoms that may be attributable to a heart attack the decision to seek medical care will follow, although the time to reach this decision varies between studies. Informing another that they are experiencing specific symptoms may be a way of seeking confirmation about calling for medical help or it may be a way of legitimising their condition. In either regard the involvement of family or significant others has the potential to provide a corrective evaluation of the symptom or illness experience, it allows another to take control of the situation and either call the emergency services themselves or insist that the patient calls for help.

Another factor which the CSM does not refer to is previous experience of service use can also have an impact on how people evaluate their symptoms. Previous experience of medical services can shape behaviour in a number of ways. How effective the medical services were in the past, the type of service available, changes in the availability of services, and the long-term relationship with the practitioner can all affect service use, as can disillusionment with professionals who were unsympathetic or unresponsive (Telles & Pollack, 1981). Telles & Pollack (1981) suggest that people learned to fit into what was required of them from prior experience of what practitioners considered to be legitimate illness – that is they want to receive sick-role legitimisation.

2. 7 Summary

The chapter has reviewed literature on response to symptoms in general, and symptoms that might be attributable to heart disease in particular. One of the suggestions made by the CSM is the relationship between cognitive representations, coping strategies and the response or outcome. The model proposes that constructs such as identity, cause, timeline and consequences have a direct influence on the coping strategy or actions that a person will employ which influences the response they make. One of the main causes of people waiting before responding and calling the emergency medical services when experiencing a heart attack is they do not recognise that their symptoms are cardiac related and therefore serious. Interpreting the symptom experience has been described as a dynamic process that involves the perception, evaluation and meaning of the response to a symptom. The chapter has shown how a person perceives their symptoms and the attributions they form as a result greatly influence their response to them.

Perceiving symptoms as not important and attributing them to minor illness, when they mark the onset of a heart attack, contributes to the time it takes to contact medical help. Alternatively having a strong illness identity and associated knowledge that the illness had serious consequences may explain why people seek help quickly. People may not be aware of their ability to understand and construct a meaning of illness and how this can determine the action they take in response to their symptoms. By giving people careful explanations of the symptoms of heart disease and guidance as to the action they should take in the form of information this may facilitate in the construction of useful representations and assist in prompt help seeking behaviour.

Chapter 3 Literature review: The development of written patient information, from policy directions to the practicalities

3.1 Introduction

This chapter provides an overview of the policy that has driven the development of patient information and outlines research on the principle components essential in production of good written patient information. The chapter is not a systematic review, but rather, a practical and thematic critique of the literature.

The chapter begins with an overview of the policy documents that have had a significant influence on the transformation of patient information from a simple handout to an integral component of many health care strategies, important in improving quality. In doing so, it highlights key areas and demonstrates how these policies were integral to the strategy to modernise patient information. It also outlines the impact these policies have had in changing the emphasis of patient information from a biomedical perspective to a more patient-centred focus.

The subsequent sections of the chapter present a methodological review of the components important in ensuring the quality of patient information. This is divided into five key areas: readability; recall; the use pictures and illustrations; technical issues; and the use of patient experiences. The chapter concludes with an overview of patient information in the context of heart disease in the UK before ending with a summary.

3.2 The impact of policy on patient information

Changes in the UK National Health Service (NHS) led to a greater emphasis on the patient as someone whose feelings, desires and views are important (England, 1999).

A consequence of these changes was a greater emphasis on patient information. Commitment from the government to improve patient information came in the late 1980's with the publication of the White Paper '*Working for Patients*' (DoH, 1989). This document set forth a recommendation that each hospital should be able to offer the patient clear written information resources detailing what facilities are available and what patients need to know when they come to hospital. This was then set out as a promise to the public in the *'Patient Charter'* (DoH, 1991) under the heading 'Providing Information'. It states:

> *You have the right to have any proposed treatment including any risks involved in the treatment and any alternatives, clearly explained to you before you decide whether to agree to it.*
>
> (The Patient Charter, DoH, 1991, pp5)

This was followed by policy initiatives such as *The Patient Charter* (DoH, 1991) and *The Health of the Nation* (DoH, 1992) represented a continuation of this change in direction from a medical centred approach in providing information to a more patient orientated focus. These policy documents modernised the approach to patient information. These changes meant people were now entitled to be given clear explanations of any proposed treatments, informed of the risks posed, and told of any alternatives. At the time in the late 1980's Dixon-Woods has described the traditional relationship between the health professional and patient as paternalistic in nature, an approach which tended to foster a dependence on health professionals (Dixon-Woods, 2001). The introduction of these new policy directives in relation to information suggested that patients were now being viewed as consumers of health services who had a choice in their own health care (Coulter 1998), and this change demanded that more information needed to be made available.

Subsequent to the publication of these White Papers there was a rapid growth in written patient information. The range of information produced during the 1990's was vast and in relation to a whole range of health concerns served a number of objectives, relating to health promotion, the prevention of diseases, and information concerning self-care (Coulter, Entwistle, Gilbert, 1998). However, a report in 1993 by the Audit Commission found that often patients did not get written information about their condition, treatment options available, and procedures they would undergo and that what was produced was often of poor quality (Audit Commission 1993).

This report represented a 'wake-up' call in terms of patient information. Although there had been an abundance of written patient information produced, patient information was often of poor quality (Audit Commission 1993). What was needed was a clear statement of guidance as to what was suitable and appropriate in producing written patient information.

In response the Centre of Health Information Quality (CHIQ), an organisation concerned with improving patient information, produced the document '*Quality Tools for Consumer Health Information*' (CHIQ. 1997). This identified three key attributes for ensuring high quality patient information materials: (1) the information should be clearly communicated; (2) the information should be evidenced based; and (3) the development of the materials should include members of the intended target audience (Centre for Health Information Quality. 1997).

A similar attempt to offer practical guidance the book '*Informing Patients*' (Coulter et al, 1998), reported a review of the quality of available patient information through patients and the health professionals. The findings mirrored the Audit Commission report (1993). Coulter and colleagues found a great deal of the information intended for patients failed to give a balanced view of the effectiveness of different treatment options, uncertainties were ignored and a patronising tone was used (Coulter et al, 1998).

In a further attempt to address this failing the Department of Health introduced the document *Clinical Governance: Quality in the NHS* (DoH, 1999). NHS organisations would now become accountable for continuously improving the quality of their services and safeguarding high standards through this framework. As a result, the Commission for Health Improvement (CHI) was set up to review local clinical governance arrangements. This review proposed a model in which patients' experiences would be central to its reviews, based on the rationale that they provide one of the key tests of effectiveness of the management arrangements for clinical governance and for health improvement (CHI, 2000). Although the clinical governance and CHI documents were an attempt to raise standards across the board within the NHS, there remained a distinct lack of guidance on how best to produce written patient information.

At around the same time in Scotland, O’Donnell & Entwistle (1999) produced a practical guide on producing information on health and health care. Their guide gave useful ideas and practical advice about how to assess, develop, and revise information materials. The guide was one of a series of initiatives supported by the Scottish Executive Health Department to help improve the quality of information provision within NHS Scotland. It was not until three years later in 2002 that a similar guide, *'Toolkit' for producing patient information* (DoH, 2002), was available in England and Wales.

This provided detailed instruction and guidance for the production of written patient information. The aims of the toolkit were clear. It was to be used to raise the standards of written information for patients, their carers, and people who use the NHS services. It was envisaged that use of the toolkit's detailed guidance would ensure that the material produced would be clear, concise, and relevant. It would also make sure that written patient information used everyday language and conformed to the quality standards of other organisations (DoH, 2002). The 'toolkit' would be the benchmark, which health professionals could use to produce information based on the principles of best practice, which supported and increased the knowledge of patients.

Following the introduction of the 'toolkit', the DoH produced the document *Building on the Best: choice, responsiveness and equity in the NHS* (DoH, 2003). *Building on the Best* was a consultation (in England and Wales) that hoped to establish which changes would do most to improve the experiences of health care for patients and carers. In terms of patient information, nearly 90% of respondents said that in order to make choices about their health and health care they needed the right information at the right time with the support they needed to use it (DoH, 2003).

Building on the Best became a strategy, which attempted to create an information revolution, in terms of the patient information that should be available. The strategy set out its agenda to develop a programme of ensuring the production of high quality patient information. One way suggested to ensure high quality patient information was the introduction of a ‘Kite marking’ system (DoH, 2003). This would guarantee any information produced was of high quality and that patients could rely on it. The strategy also proposed that information should have a stronger patient voice, underpinned by a system of regulation and inspection (DoH, 2003).

One year later the DoH produced *Better information, better choices, better health: putting information at the centre of health* (DoH, 2004). This strategy document aimed to build on the commitments set out the previous year in *Building on the best* (DoH, 2003). It had the intension of making patient information an integral part of healthcare. It states:

> *The future is about sharing – sharing of information, sharing of decisions and sharing responsibility*
> (Better information, better choices, better health. DoH, 2004, pp2).

The strategy was underpinned by a series of principles which highlighted the need for people to have access to high quality understandable patient information delivered in the way they want it. It also wanted to empower the person to ask questions about their healthcare and to be involved, as far as they wished, in making decisions about their care and treatment (DoH, 2004). To support these principles the strategy aimed to embed patient information into the healthcare system as an integral component. It suggested information be given in line with care provision and not as an ‘add-on’. Personalised information given at a specific point in the illness was also seen as essential to help people make choices to improve their health, and also understand what is happening or likely to happen to them. The strategy also proposed the development of a national accreditation scheme for information to give the patient a clear set of quality criteria covering the information available to them, how reliable it is, whether there was any patient involvement in its development, and how accessible the information is (DoH, 2004).

In 2006, the Picker Institute was commissioned by the DoH to determine the current state of health information in England and Wales. The resulting document *'Assessing the quality of information to support people in making decisions about their health and health care'* (Coulter, Ellins, Swain, Clarke, Heron, Rasul, Magee & Sheldon, 2006) was produced. The study reviewed a number of components associated with patient information. It showed that written patient information was effective in improving patients' knowledge and ability to remember medical information, and that the combination of written and verbal information together is more effective than verbal information alone.

The study also produced a number of interesting findings concerning the organisations which produced patient information. Of the 237 organisations that took part in the study 43% were public sector organisations, 30% were commercial concerns and 27% came from the voluntary sector. The majority of the providers (87%) offered information on one topic only. From the telephone survey carried out most respondents were committed to involving patients in developing and evaluating their products, but many lacked any systematic method of doing so. Few had adopted any kind of systematic approach to ensuring issues such as readability or usability of their materials, and although most had made some attempt to ensure their material was evidenced-based there was often no clear systematic approach to do so (Coulter et al, 2006). When asked about the possibility of introducing an information accreditation scheme most respondents reacted favourably. Many could see advantages ranging from: raising quality standards in information provision, greater use of information by patients, and improving the image of information providers. Concerns were raised about how the scheme would operate, who would finance it, how time-consuming it could be, and whether it would flexible enough to encourage creativity (Coulter et al, 2006).

A major conclusion arising from the Picker Institute’s report (Coulter et al, 2006) was that an information accreditation scheme could help raise quality standards in patient information. This led to the development of an accreditation scheme for health and social care information by the DoH (DoH, 2007). The Information Accreditation Scheme (IAS), was seen as a way to improve access to quality information by providing an external ‘seal of quality’ that patients could recognise and trust and was also a way in which the previous systems of improving quality could be updated. The scheme is made up of three main components – the standard, the support, and the testing and certification. The standard is the basis of the scheme, the support is there to ensure the information producer can achieve the quality required, and the testing and certification component ensure that any information meets the required standard. The model proposed can be seen in fig.2.

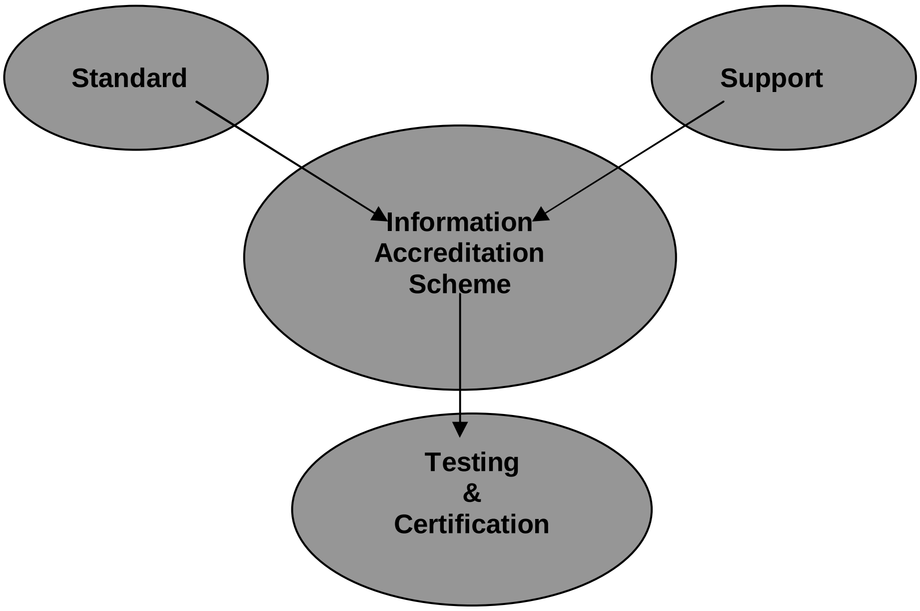


Figure 2 Information Accreditation Scheme model (Adapted from IAS DoH 2007 pp7)

The IAS is a standard for organisations producing written health or social care information to the public. It is hoped the scheme will develop into a nationally recognised standard that will reassure people that the health information they are accessing comes from a reliable and trustworthy source.

Although the policy directives described during the last two decades have seen the standards of patient information rise considerably there still remain a number of fundamental components which must be considered when producing the information. The following sections will describe these including; readability, recall, the use of graphics / illustrations, other technical issues to be considered when developing patient information, and using patient experiences. Finally written patient information in the context of coronary heart disease in the UK will be considered.

In developing any form of patient information, it is important to be clear at the outset for whom and for what reasons it is being produced. There is a wealth of information available on what makes for good quality information. Various checklists have been developed to help the researcher assess the pros and cons of the media options available, evaluate the different types of materials that can be used and help inform the content of health information resources. Perhaps one of the most helpful was developed by The Centre for Health Information Quality.

The Centre for Health Information Quality (CHIQ) in its first newsletter in November 1997 stated that any information developed should present the content clearly. The recommendations they made are as follows:

- Simple and clear presentation;
- Testing of the information for readability;
- Design of the information for legibility;
- Involvement of a range of patients in piloting the information; and
- Evaluation of the information by a range of patients.

(Adapted from Newsletter of the Centre for Health Information Quality, (1997) pp 2)

It is also important during the developmental stage that any information included in a resource matches the target audience's requirements, is understandable and takes into consideration what the intended audience knows about the disease/condition. In attempting to address these issues, the current study recruited patients identified as being at high risk of developing CHD to gauge their knowledge of the subject and ask what their requirements were for a resource aimed at raising awareness of CHD symptoms and appropriate actions.

To make sure the patient information resource was relevant to those at high risk of a heart attack, a review of various forms of information would have to be undertaken during the development phase. This would include evidence on people's experiences; expectations of health and health care interventions; epidemiological research evidence on the causes of particular health conditions and clinical practice guidelines; and health professionals and voluntary organisations.

It was recognised that the information included in the resource needed to be clear and simple (CHIQ, 1997). As a result factors which could maximise readability and recall were taken into account. These included typeface and size; type of words used and the composition of sentence structure to paragraph size; and the use of graphics or illustrations. A balance has to be reached in terms of not overwhelming the person with too much information, but providing them with enough to be helpful.

3.3 Ensuring quality information for People: readability

Written information can only be useful if the recipients are able to read and understand it. Therefore, literacy becomes an important component when producing written information, especially for those with little or no education (Baker, 2000; Gazmararian, Parker & Baker, 1999). Baker (2000) has suggested the literacy demands of written patient information can be modified by careful attention to the content and the design. Based on these recommendations Hoffmann & McKenna (2006) suggest written information should be produced to ensure the content is displayed in language that is written simply and at the lowest level of literacy of those who are likely to read it, whilst ensuring that the information is accurate and understandable. Readability is sometimes viewed as a measure of the quality of the information itself, and a number of scales have been developed to evaluate the reading level of written patient information (Spadero, 1983).

The most common method to determine the reading level of written information has been to apply some form of readability formula to the text to estimate the reading level required for understanding the material. This also has the advantage of giving some idea of the percentage of the population which will also be able to understand it (Ley, 1979). Essentially readability formulae are equations assessing the difficulty of text, using predictors such as word length (the number of syllables in a word), sentence length, and the frequency of the words used in the text compared to their everyday usage. In general terms readability formulae would show that polysyllabic words would be harder to comprehend than monosyllabic words and likewise longer sentences would prove more difficult than shorter ones (Ley, 1982). Medical jargon or phrases, and unusual words, are also harder to understand than words in everyday use (Ley, 1979).

In a review by Klare (1976) identified over 50 readability formulae. In examining the different types of textual information the formulae were intended to measure, Klare was able to identify several factors, which affected the results of these formulae, these included:

1. Standardised reading tests,
2. Speed at which the passage can be read,
3. Judgements on how difficult the text was,
4. Probability that an article in a newspaper will be able to be read and understood, and,
5. Retention of the information.

(Adapted from Ley & Florio, 1996 pp 116)

The higher the readability factor, the faster and easier it is to read. In terms of health-related information a higher the readability factor the better it is for the patient (Ley & Florio, 1996). There have been a number of formulae consistently used to evaluate patient information; these have included the Flesch formula (Flesch 1950); the Dale-Chall formula (Dale & Chall 1948); and the SMOG (simple measure of gobbledygook) grading system (McLaughlin 1969). A review (Ley and Florio, 1996) found the SMOG readability formula to be the most straightforward to use. The Adult Literacy and Basic Skills Unit (ALBSU) suggest that a score of 10 or less on the SMOG indicates that the text will be understood by most people (Adult Literacy and Basic Skills Unit 1994). To use the SMOG it is necessary to select three groups of ten consecutive sentences, normally from the beginning, the middle, and the end of the text. The next step is to count the number of words containing three or more syllables (the polysyllable count). The square root of this value is then added to three to obtain the SMOG grading.

However, many authors caution against relying too heavily on readability formulae (Allensworth, Luther 1986; Meade & Smith, 1991; Walsh & Shaw 2000). Armbruster, Osborn & Davidson (1985) note that readability formulae take no account of other important factors such as the effect the font of layout can have on comprehension. These formulae also fail to take account of how motivated or interested the reader is, or how willing they are to persevere with the subject.

3.4 Ensuring quality information for people: recall

Research has shown that patients tend to forget half of what they are told during discussions with health professionals within five minutes of the consultation ending (Ley, 1981), and retain only 20% of the information conveyed to them (Johnson, Sandford & Tyndall, 2003; Little, Griffin, Kelly, Dickson & Sadler, 1998; Entwistle & Watt, 1998). Research has demonstrated that retention can be increased in some cases by up to 50% by providing the patient with supplemental information (Macfarlane, Holmes, Gard, Thornhill, Macfarlane & Hubbard, 2002; Rogers et al, 1998). Ley suggests possible explanations for this lack of retention of information: (1) factors related to the clinician, such as use of difficult medical terminology; (2) the mode of information (e.g. spoken versus written); and, (3) factors related to the patient, such as low education or specific expectations (Ley, 1979). In trying to improve the amount of information recalled Ley suggests incorporating three steps into written patient information. These are the use of: (1) shorter words and sentences; (2) explicit categorisation; and (3) concrete-specific rather than abstract-general advice (Ley, 1979).

Perhaps the first step is not surprising, when writing for patients the aim should be to keep the text as simple as possible which also increases readability, as we have seen. Hence the text for written patient information should be as clear as possible, logical, and use terms that the patient and their family can understand (Walsh et al, 2000). The use of medical terminology should be avoided and the content should use clear and simple everyday English (Maher, 1996). Maher suggests using words like ‘we’ and ‘you’ rather than ‘the nurse’ or ‘the patient’. Breen (Breen, 1992) advocates a trade-off between the ‘medical elitist terminology’ and everyday language, even though this has the possibility that such clear and simple writing may be seen as unsophisticated. This is a view shared by the ALBSU (Adult Literacy and Basic Skills Unit, 1994) who caution against getting the reading level of the text too low. They suggest that the goal is to get a piece of text below a certain complexity level without it losing all meaning and sounding childish. The longer the sentences and the more complex the vocabulary, the more difficult the text will be to read (Hartley, 1994). Hartley (1994) suggests that longer sentences are also more difficult remember. He states that sentences of less than 20 words will be readily remembered, 20-30 words will be remembered by the majority of people, 30-40 is at the upper limit of what most people can cope with and sentences over 40 words should be re-written.

The second step, explicit categorisation, is the method of presenting the information to the patient in different categories, which are announced in advance. For example, the introduction to a piece of written information would state what was going to be covered. Ley (1974) used explicit categorisation to impart medical information and increased recall. The third step Ley (1979) found that the largest gains in recall were obtained by the use of specific-concrete, rather than general-abstract advice statements. He suggests that by using concrete-specific words the specificity of the word is correlated with perceived importance, which directly leads to greater recall (Ley, 1979). This is consistent with work of Paivio, Yuille & Madigan (1968) who found people were more likely to recall concrete nouns and sentences. Paivio suggested that a mechanism in this greater recall capacity for concrete-specific words was imagery (Paivio et al, 1968). The suggestion is that the person is more likely to follow the advice when they can imagine it, so that advice such as ‘weigh yourself every morning before breakfast’, is more likely to be remembered than the abstract advice of: ‘weigh yourself regularly (Ley, 1979).

Even so, patients with well-developed reading levels can sometimes find it difficult to cope with written medical information. People with poor literacy skills are especially in need of help, and because this group tend to rely more on spoken explanations, they need help remembering what they hear (Houts, Doak, Doak & Loscalzo, 2006). One way to aid the patient in understanding what is written is to combine the information with pictures or illustrations.

3.5 Ensuring quality information for people: the use of pictures / illustrations

A recent review assessing the effectiveness of pictures and illustrations on health communications suggests that adding pictures to written or spoken language can increase patient attention, comprehension, recall and adherence (Houts et al. 2006). The review drew on McGuire's information processing theory (McGuire, 1999) which uses a matrix to explain the communication/persuasion process. The matrix consists of five input variables (source, message characteristics, channel, receiver, and response target) and thirteen output variables (exposure, attention, liking, comprehension, cognitive elaboration, skill acquisition, agreement, memory, retrieval, decision making, acting on the decision, cognitive consolidation, and proselytizing that is converting to another opinion/view point). Pictures fall within one of McGuire's input variables (message characteristics) and four of his output variables (attention, comprehension, memory, and acting on the decision) which all act on increasing attention, aiding comprehensibility, and improving recall and adherence (McGuire, 1999).

The findings from the review resulted in several recommendations. The first was that health professionals should look for ways to include pictures in their health communications. The review also highlighted that pictures can improve the effectiveness of health education materials. Secondly the findings suggest the simplest illustrations or photographs should be used. This finding was also highlighted in an earlier review by Dowse & Ehlers (2001) who recommended that simple realistic pictures with limited content be used so as not to distract the patient with irrelevant details. The third recommendation was that the simplest possible language should be used within the picture to avoid the danger that complicated written material may confuse the picture. Houts et al (2006) suggest pictures are more easily understood when the accompanying text is clear.

The next recommendation concerned how to guide the patient to interpret the picture. Without guidance there is the possibility the patient will develop their own interpretation, which may not be what was intended (Houts et al, 2006). Houts et al suggest the simplest remedy is to situate the text and picture as close together as possible (Houts et al. 2006). Another way to combat this is the use of captions which describe what is happening in the picture. Captions have the added advantage of being able to be presented in a low level of literacy, helping those with limited reading skills understand what is going on.

Houts et al's fifth recommendation that health professionals should be actively involved in the development process is shared with Dowse & Ehlers (2001). Health professionals should ensure any graphic material used effectively conveys the intended message. It is unlikely a graphic artist will have the background to produce effective images that adequately explain the intended message (Houts et al. 2006). The final recommendation concerns the evaluation of the pictures. Houts et al's review showed clearly that pictures provide significant benefits in all four areas investigated (attention, comprehension, recall, and intention/adherence). However, the results were not always consistent, so they recommend systematic evaluation of the use of pictures during the developmental process, and follow-up interviews to assess attention, understanding, and recall (Houts et al. 2006).

In another recent study, Kools, Van De Wiel, Ruiter, Cruts & Kok (2006b) used cognitive psychological theory to help understand how health education information can be made more effective. The study used the premise that pictorial information allows the reader to visualise relations to the text, enabling a mental model of the situation to be formed, thus enhancing understanding of the accompanying text (Meyer 1997). This is explained in terms of a 'mental model theory' which states that, through a variety of different processing routes, text and pictures can produce verbally and visually based mental models (Meyer 1997; Kools, Van De Wiel, Ruiter, Cruts & Kok, 2006a). Meyer (Meyer 1997) suggests these are then combined by the reader into working memory to aid comprehension. The argument is that text and pictures are a better combination than text alone. This comes from the proposition that text in isolation requires more cognitive resources because the idea the information is trying to convey needs to be transformed into a propositional representation and then into a mental model. Pictures, however, are considered to be visual representations that allow the construction of a mental model directly (Ganier 2001).

To test the usefulness of pictures on recall, Kools et al (2006a) used two separate randomised controlled trials. One group of participants received a text only set of medical instructions whereas the other group received a text and picture version. The authors conclude that the presence of pictures in instructions for written medical information does seem to provide some form "*of added value over text alone*" (Kools et al. 2006a). The greater recall with the pictorially enhanced instructions may indicate that the participants were able to form links between their textual and visual mental model, creating two possible cognitive routes to remembering the information, thereby increasing the capacity for recall (Meyer 1997).

The findings from these two reviews (Kools et al. 2006a; Houts et al. 2006) give strength to the argument that pictures/illustrations can enhance written health information. Both papers, however, recommended two areas for consideration. Firstly the type of picture/illustration needs to be as simple as possible in order that it will not detract from the accompanying text. And secondly the use of testing during the developmental stage is vital to ensure the appropriateness of the pictorial information used (Houts et al. 2006; Kools et al. 2006b).

3.6 Ensuring quality information for people: Technical issues

A great deal has been written about the technical aspects of producing written patient information, although as Walsh & Shaw suggest, most of this is anecdotal not based on theory or evidenced based papers (2000). It is most important to be clear about the messages to be communicated bearing in mind that health professionals and people may have different views about what material should be included, so both views are incorporated during the development stage (Hussey 1997; Walsh & Shaw, 2000). A researcher developing written patient information must ensure that content is relevant to the target audience, and presented in a way that is tailored to their needs (Allensworth& Luther, 1986). Tailoring includes both the design and delivery of the information and the reading ability. Research has demonstrated that people are much more comfortable with a resource specifically tailored for them (Walsh 2006), and these tailored messages are more likely to be remembered (Ley 1979).

Other considerations include the design characteristics such as organisation, layout, the typography used, and the size of the page used (Walsh et al. 2004). Hartley (Hartley 1994) argues that the first technical issue to consider is the size of the page; important because it determines all other typographical decisions. When thinking about page size, he suggests the researcher should consider other technical issues, such as type size. The Royal National Institute for the Blind (RNIB) uses a 12 point typeface when producing information for general readers. However, the main point to consider in choosing a type size is the length of line that will be produced. If the type face is too wide (leading to fewer words per line) it can be difficult for the reader to maintain syntactic groupings of words (Hartley 1994).

With over 10,000 typefaces available the researcher is faced with a daunting decision in choosing the right one. The ALBSU (Adult Literacy and Basic Skills Unit 1994) recommend that the typeface used should be clear and distinct, avoiding typefaces where 'm' might be mistaken for 'r n' for example. In trying to determine the effect a typeface can have on comprehension, Lewis & Walker (1989) found that different typefaces do have different connotations for different readers. However, Hartley (Hartley 1994) disputes this and points out that material should be printed using a typeface which does not have any idiosyncratic features.

Other areas relevant to the design and construction of written patient information include line justification, the use of white space and colour (Walsh et al, 2000). The use of justified or unjustified text is dependant on the demands of the resource being produced. Hartley (Hartley 1994) states that experiments have shown there is little to choose from between the two as far as comprehension, reading speed and legibility are concerned. White space, or the space on the page that separates words, phrases, paragraphs, helps the reader clarify the text (Hartley 1994; Walsh et al, 2000). Hartley (Hartley 1994) suggests keeping the spaces within the content consistent, claiming this helps people read faster, assists them in determining which parts of the text are relevant for them, and also helps the reader to see the document as a whole.

Colour is important when a definite contrast between the typeface and paper is required (Walsh et al, 2000). Contrast can be affected by a number of variables such as: paper colour, the colour of ink used, and the size and weight of the typeface. Walsh et al (2000) recommend a black typeface on white or off-white paper. They also recommend the colour of the ink should be as dark as possible, and the use of coloured ink should be avoided where colour paper is used (Walsh et al, 2000). The surface of the paper used is also important. Matt surfaces should be used when ever possible and glossy paper should be avoided as this tends to reflect too much light, making it difficult to read (Walsh et al, 2000).

In trying to produce acceptable written patient information resources the researcher has a great deal of information to consider. In 1993 The Audit Commission report (Audit Commission 1993) stressed the importance of sharing expertise within the organisation which developed patient information. It also important for the researcher to know what work has already been undertaken in the field they are interested in.

3.7 Ensuring quality information for people: incorporating the patient experience

With the development of written patient information there has been the recognition that resources which reflect the requirements and priorities of the patient are more likely to improve their confidence and their ability to deal with their illness (Meredith, Emberton, Wood & Smith, 1995; Kennedy, Robinson & Rogers, 2003). Early research also highlighted that patients needed better information about their conditions (Meredith et al, 1995; Ovretveit, 1996; Kee, 1996). One method of ensuring any form of patient information is patient centred is to include the experiences of those who have lived with the particular disease or condition.

Incorporating the patients' experiences into information designed to promote knowledge and awareness is a recent development in the production of patient information. As Kennedy et al (2003) suggest, before the late 1990's there had been few attempts to incorporate actual patient experiences into official publications within health services. Where written patient information had been produced it tended to convey information which health professionals thought patients should know, not what they themselves wanted to know. Once patients had been asked what type of information they wanted it became clear they were receptive to reading the actual accounts of dealing with disease or illness (Doak, Doak, Gordon, Lorig, 2001).

One example of using patient experiences in the development of patient information resources is a number of guidebooks to promote participation in the management of ulcerative colitis (Kennedy, Robinson, Thompson, Wilkin, 1999) and inflammatory bowel disease (Kennedy, Nelson, Reeves, Richardson, Roberts, Robinson, Rogers, Sculpher, Thompson, 2003). In these examples patients had a central role from the outset in the development of the guidebooks. This ranged from providing patient perspectives about living with the conditions, to views and opinions about the treatment options available, deciding on the content and presentation of the material, reviewing the content throughtout the development process, and providing feedback on the final versions.

The evaluation process involved in the development of the ulcerative colitis guidebook elicited a number of interesting findings. Some patients stated that the guidebooks contained information they had never been given before. Actual patient experiences were viewed as being therapeutic and reassuring, and acknowledged the patient as a highly valued source of information (Kennedy & Rogers, 2002).

A recent study looking at the role of patient information in self-management initiatives indicated that, for information is to be successful, it needed to be specific for a condition and targeted at a particular stage in the illness (Protheroe, Rogers, Kennedy, Macdonald, Lee, 2008). A qualitative meta-synthesis of four published studies concerning self-management was undertaken. This produced a number of new insights into the way people engage with information, the most important in terms of the provision of patient information, concerned the way in which people with different medical conditions responded to information differently. The study concluded that effective patient information must have a solid understanding of what the patient needs to know, be available when it can be most useful, and be presented so that patients are able to engage with it (Protheroe et al, 2008).

These examples represent the embodiment of government policy which advocates increased patient involvement in the provision of health information and the wider strategy to improve the quality of health care provided by the NHS (DoH, 2003). The guidebook for ulcerative colitis represented a practical step in the process of encouraging patients to take a more active role in their care. The study found that when patients were involved in the development process they were easy to work with and enthusiastic about the development of a resource aimed at raising awarness of their condition. Those involved in the development process of patient information also demonstrated a particular insight into the day-to-day management of their condition, how it affected their everday lives and the lives of their families (Kennedy et al, 2002). These patients revealed a depth of knowledge accumulated, in some cases over many years, which would be highly beneficial to patients who had recently developed ulcerative colitis. Those involved in the review process also revealed how important it was to be involved during the developmental stage. Without patient involvement in the early stages of development the resource had the possibility of not addressing important issues.

3.8 Written patient information in the context of coronary heart disease in the UK

In terms of written patient information for heart disease before the Audit Commission (1993) report, Sloan carried out a review of available patient information relating to heart disease (Sloan, 1984). This showed a large range of information products from leaflets to booklets, produced by commercial and voluntary organisations and revealed that the quality and content of the material varied considerably (Sloan, 1984). In a later study, Laidlaw & Harden (1987) reviewed a number of commercially produced cardiac rehabilitation booklets and found that the material was not well designed and was difficult to read.

More recently, Walsh et al (2000) undertook a review of the design of written information for cardiac patients. The majority of the studies identified originated in the United States and were mostly concerned with the application of readability formulae. One of Walsh et al's (2000) conclusions is that material originating from the US should be viewed with caution, because of differences in culture, literacy levels, and patient populations. They also highlight the need for UK based research, suggesting that it should not be limited to identifying only patient opinions, but should also address issues such as increasing patient knowledge, satisfaction, or attempting some form of behaviour change (Walsh et al, 2000).

A number of authors (Timmins 2005; Redfern, Ellis, Briffa & Freedman, 2006) have advocated using an individualised approach to providing patient information. Redfern et al (2006) undertook this approach by developing a patient information resource for the management of CHD. The authors developed and tested a number of patient information leaflets designed to combat CHD, in a manner similar to Kennedy at al (2003; 1999). They used actual experiences of patients and health professionals to guide the development of risk factor information leaflets aimed to encourage shared decision making and empowerment in people with CHD (Redfern et al, 2006).

Using a wider national strategy the British Heart Foundation (BHF) recently undertook its 'Doubt Kills' campaign (http://www.bhf.org.uk/doubtkills). The objective of the campaign was to save lives by reducing the time it takes people experiencing heart attack symptoms to call for medical help by raising awareness of symptoms, and breaking down barriers to calling 999. The campaign was aimed at those most at risk (adults over the age of 45 years) and used a number of different methods to get the message across. The elements the campaign used varied from leaflets, to mainstream posters, to media presentations. The campaign was designed to urge people experiencing chest pain - or other heart attack symptoms such breathlessness, nausea or pain in the jaw, neck, and arm or back that spreads to the chest – to call 999 immediately.

For the mainstream UK population the campaign used a patient information leaflet showing an image of a man with a belt around his chest and the words, *‘A chest pain is your body saying call 999’*. For the South Asian population who are particularly at risk adverts depicted a South Asian father who experiences chest pain whilst playing cricket with his son. The BHF aimed to deliver the leaflets to more than 3 million homes across the UK. In addition leaflets will be made available through pharmacies prescription bags, general practice surgeries, and BHF shops.

The overall results produced by the campaign have been positive and demonstrate how effective patient information can be when targeted at specific groups at a certain point in their illness (BHF, 2008). The BHF estimates it has met the campaign’s core objectives, the foundation cites stories from people who sought help quicker as a direct result of the campaign. In more visible terms the London Ambulance Service estimates it had a 25% increase in chest pain calls in the first week of the campaign, with other ambulance services reporting a similar impact. The Myocardial Infarction National Audit Project (MINAP) also reported four life-saving minutes pain-to-call times (BHF, 2008). However, the campaign omitted one extremely vulnerable group from its focus, women.

The motivation for this study originated from the acknowledgment of a lack of patient information concerning the recognition of the symptoms that may be attributable to a heart attack for people identified at being at risk of such an experience. Furthermore, there appeared to be a lack of information, which was patient-centred, developed using actual patient involvement, and used patient experience in the content of patient information materials.

The background to this study has seen criticisms levelled at the type of patient information available in past, the quality, and the way in which it was developed. There has been recognition in official health policy of short fallings in this area and the need to address them. Research on the provision of patient information has shown that in the past there was a predominance of biomedical concerns during development, depicting patients as passive and open to manipulation (Dixon-Woods, 2001).

In an attempt to address these issues the study endeavours to answer the following research question: *Can experiential evidence of the symptom experience be combined effectively with the best guidelines on how to manage a condition to produce a factual, informed and engaging information resource which will be read by its target audience?* In order to answer this research question, a number of areas will be explored, these are: (1) Generating the data to form the content of the resource. This involved exploring the response and the process of making sense of the symptoms experience and the decision to seek help in people who had encountered symptoms that may have been attributable to a heart attack; (2) Identify the best practice guidelines on the management of a heart attack, MI or ACS; (3) Combine the experiential data with the guidelines to inform the content of the resource; (4) Identify the most effective method of incorporating peoples experience into the content of a resource and to combine this with medical information on the management of the condition; and (5) Incorporate the thoughts and views of people who experienced symptoms with the views of health professionals to guide the development of the resource and provide feedback throughout this process.

In achieving the aim the development of the resource had to achieve certain criteria – these were:

1. To raise the profile of CHD within the “high risk” population so they were aware of dangers it represented.
2. To explain the range of symptoms that are attributable to heart disease within the general population, with particular emphasis on those symptoms more likely to encountered by women, and
3. To explain when, how and from whom they should seek help if they experienced any of these symptoms.

Chapter 4 Methods

4.1 Introduction

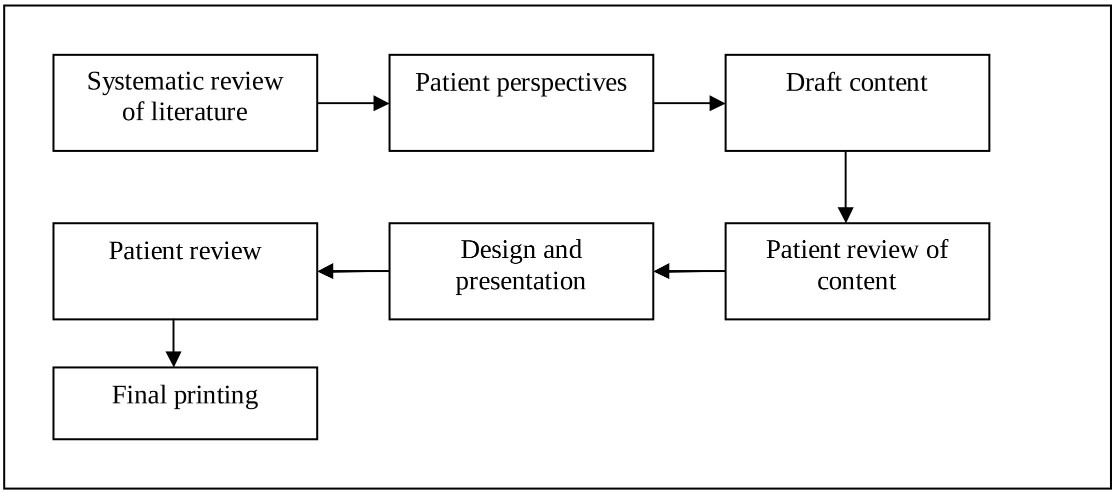
This chapter provides an account of the methods used to produce the findings and the written patient information resource presented in this thesis. It aims to make each stage of the research process explicit, and to provide a clear 'audit trail' of the research and development processes.

The study design outlined in section 4.2 was guided by the work of Kennedy et al (1999; 2003). Section 4.3 describes the sampling for the study together with the groups of participants. Section 4.4 provides an account of the study settings and recruitment procedures. Section 4.5 explains the rationale behind the use of focus group discussions and the decision to use in-depth individual interviews. Section 4.6 then considers the ethical issues of conducting the study with reference to three areas widely recognised as necessary to ensure research is carried out ethically: obtaining consent; reducing the risk of harm; and ensuring confidentiality. Section 4.7 describes the analytical process; it explains how the data was used from the initial recording, to the transcription, and the method used to analyse the data generated from the focus groups and individual interviews. It attempts to explain the study's analytical decision trail, illustrating how the analysis of the focus group discussions and individual interviews evolved from the initial formation of a number of codes to a more in-depth account of how people deal with symptoms that may be attributable to heart disease. Finally this section deals with long term storage of the data. The chapter concludes with a summary.

4.2 The study design

The rationale for the research plan of the development of an information resource was influenced by the work of Kennedy et al (2003; 1999). This work has been described in chapter 3 and the methods they used to create their guidebooks helped form the basis of the approach that was used in this study. The guiding principles of Kennedy et al's (2003; 1999) approach to develop their guidebooks involved using people with experience of a disease or condition to help devise the content and presentation of the material in the guidebooks. They also used these people to provide feedback during the development process. An overview of their development process is shown in figure 3.

Figure 3 Overview of the process of development of an information resource by Kennedy at al (1999)



(Adapted from Kennedy et al 1999, p 180)

The review of the literature, both on how people respond to symptoms, of current heart health education campaigns and of the best practice in the design of information resources has been ongoing over the course of the PhD. Following Kennedy et al (2003) in order to gain the experiential data (patient perspectives) needed to inform and guide the development of the information resource I used focus group discussions to explore the experiences and responses amongst a range of people, both men and women, who have had symptoms that might be attributable to heart disease. I also inquired how they made sense of their symptom experiences, and what their thoughts and actions were when they first realised something problematic had occurred. The focus group discussions also investigated what these people thought of patient information, and what they would require from a resource aimed at improving knowledge of chest pain and other potential symptoms of heart disease. However, due to recruitment problems a number of one-to-one interviews also had to be conducted to generate the data needed to inform and guide the development of the resource (see section 4). One-to-one interviews were also conducted with a number of health professionals to gauge their opinion on the quality, acceptability and accuracy of the information resource.

The literature review section which addressed the question of how people respond to symptoms (see chapter 2) highlighted that a qualitative approach was particularly suited to eliciting a person's understandings and perceptions of illness. Studies by White (1999) and Richards et al (2002) are examples of research that have effectively employed qualitative approaches in exploring people's experiences of dealing with chest pain.

The epistemological assumptions of qualitative methodology were also considered to be appropriate in phase one of the study and in particular the two objectives; (1) to describe the experiences and response amongst a range of people who had symptoms that might be attributable to heart disease; and (2) to select experiential data to be included in the content of the information resource. Epistemology is concerned with beliefs and assumptions about the nature of knowledge and how that knowledge can be made known. Qualitative research is grounded in an epistemological position which is interpretivist. The interpretive approach has its roots in philosophy and the human sciences and centres on the interpretation and creation of meaning by human beings; it is concerned with how the social world is interpreted, understood, and experienced. The approach stems from the constructivist ontology – the assumptions made about the form and the nature of reality – that assumes social reality is produced and reproduced in social relationships and interactions (Guba and Lincoln, 2007).

Denzin and Lincoln define qualitative research as:

> *"… a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible. These practices turn the world into a series of representations including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them".*
>
> (Denzin and Lincoln, 2000: 3)

Qualitative research is, therefore, most appropriately used when the research question is about processes rather than outcomes (Murphy, Dingwall, Greatbatch, Parker & Watson, 1998). Thus because a focus of the study was to describe experiences and responses amongst a range of people who have had symptoms that might be attributable to heart disease a qualitative approach seemed to be appropriate to generate these experiences. The use of the focus group discussions and later the in-depth individual interview technique allowed an in-depth and detailed interpretation of the experience of symptoms that could be attributable to heart disease and the response to them to be obtained.

4.3 Sampling

4.3.1 Sampling strategy and groups of participants

The study had an overall aim to produce a draft information resource to help people who are at risk of heart disease to respond effectively to symptoms that could be attributable to heart disease. We have seen that to do this it was necessary to describe experiences and response amongst a range of people who have had symptoms that might be attributable to heart disease (those who were eventually diagnosed with a cardiac related illness as well as those who were not). In order to gain such insights and produce the information resource, participants were purposively sampled to recruit a range of experiences which would inform and develop the production of the resource.

To this end four distinct participant groups were identified as being central to the study's aim and objectives, these were:

- Group A - people who have previously experienced chest pain which was cardiac in origin;
- Group B - people who have previously experienced chest pain which was not cardiac in origin;
- Group C - spouses of the people with the chest pain or close relatives (such as family or friends); and
- Group D - people who are already identified as high risk patients (those suffering with diabetes, obesity, family history of CHD, or hypertension).

Firstly we identified people who had received a diagnosis of cardiac related chest pain, or who had been referred to the Rapid Access Chest Pain Clinic at the hospital with symptoms of heart disease (group A). These participants were important because my primary interest was in the range of symptoms experienced in people who had had a heart attack. I also wished to investigate the action they had taken when they had first experienced these symptoms, and in particular if they delayed seeking help when first noticing their symptoms. I also wanted to explore what, if any, information might have helped them react quicker.

The second group (group B) consisted of people who had received a diagnosis of non-cardiac related chest pain from the Rapid Access Chest Pain Clinic at the hospital. These people were of interest given the high numbers of patients who are diagnosed with non-cardiac chest pain in the rapid access chest pain clinic (and throughout the UK) and we intended to ensure their experiences were included in the study.

The third group (group C) consisted of the spouse or partner of patients in groups A and B. We know from the literature that many people will confide in their spouse or partner before they decide to seek medical attention, or that it is the spouse or partner who encourages the person to seek help (Perkins-Porras et al, 2009; Pattenden et al, 2002; Leslie et al, 2000). Therefore the circumstances that prompted the person to talk to their spouse or partner and the time between the spouse or partner realising something was wrong was of interest. In sampling from this population it was hoped to gain an insight into the effect these individuals had on their partners when they were dealing with symptoms that could have been attributable to heart disease. It was the intention to cover all types of experiences and outcomes but the need to keep the resource simple overcame this desire. This is explained in a later chapter (see chapter 7)

The fourth group (group D) was composed of people identified as being at high risk of developing coronary heart disease. These individuals were recruited from a general practice in the east of Scotland. They were identified through the register of patients at the practice as those who posed a higher risk of developing coronary heart disease in the near future, as a result of a family history, diabetes, high blood pressure, smoking or obesity. This group was very important to the study as they represent the people the information resource should be eventually targeted at. Therefore their thoughts and ideas on what such a resource should contain and how it should be presented were very important.

Because we know from the literature that the decision to contact medical assistance when faced with chest pain symptoms can be different for women and those from lower socio-economic circumstances (Richards et al, 2002; Moser, McKinley, Dracup & Chung, 2005), the study attempted to obtain a balance of men and women & people from different socio-economic backgrounds. In an attempt to achieve this, the study used a purposive sampling approach (Patton, 2002). That is people were chosen with a ‘purpose’ to represent the variables the study was interested in.

Women and those from lower socio-economic status were targeted specifically to form the participants of groups A and B. Staff at both the rapid access chest pain clinic and the general practice, were informed of this. However, both women and those from lower socio-economic status proved difficult to recruit.

In terms of recruiting women this proved difficult due to the very small numbers attending the Rapid Access Chest Pain Clinic. For those of lower socio-economic status the difficulties in recruiting these people proved to be an inadequate method of identifying them. Deprivation categories, post codes where economic status is defined in a scale from high to low deprivation, were used but these proved to be unsuccessful in identifying households of low socio-economic status again due to the small numbers attending the Rapid Access Chest Pain Clinic.

4.4 Recruitment

4.4.1 Stage 1 study settings and recruitment procedures

In stage 1 of the study two objectives were of particular importance, these were: (1) to describe the experiences and response amongst a range of people who had symptoms that might be attributable to heart disease; and (2) to select experiential data to be included in the content of the information resource. In order to achieve this and generate such data a number of patient groups were to be recruited from a teaching hospital in the central belt of Scotland. This location was chosen because it had a Rapid Access Chest Pain Clinic within the cardiology department and because the consultant cardiologist and the lead clinical specialist nurse were willing to help in the recruitment of subjects. Three groups of participants were recruited here (Groups A, B and C).

I visited the consultant cardiologist with my principle supervisor, Professor Sally Wyke, to explain the study's objectives and the patient groups we were hoping to recruit and to seek permission to undertake the study. Once permission had been granted by the consultant cardiologist the main researcher and another adviser to the study (Patricia Thomson, a lecturer from the Nursing & Midwifery Department of Stirling University and a former clinical nurse specialist), met with the Rapid Access Chest Pain Clinic staff to explain the study and ask for their help in recruiting potential participants. Once permission was obtained from the staff of the Rapid Access Chest Pain Clinic a formal application to undertake the study was submitted to the research department of the hospital's NHS trust.

As I was not a hospital staff member and would be dealing with hospital patients and working in the hospital environment, I obtained an honorary contract (see appendix 5) prior to the commencement of the data collection to allow me to approach patients and to comply with local and national Research Governance guidelines and the Data Protection Act (HMSO, 2001).

Recruitment of people diagnosed with either cardiac or non-cardiac chest pain was carried out by the clinical specialist nurse on duty in Rapid Access Chest Pain Clinic at the time of the persons' appointment. At the end of the appointment the person was to be asked whether they were interested in participating. If so their name and telephone number were to be taken by the nurse and they were to be given the information pack, containing the information sheet, the consent form and a return envelope, and a further pack for their spouse or partner to read and return if they were interested in taking part (see appendices 2-4). Those agreeing to take part were to be told they would receive a phone call from me within a week to discuss their participation. I made an arrangement to contact the clinic twice a week during the recruitment period to obtain the names and contact details of those people interested in participating.

However, recruitment did not progress smoothly at this stage. After several weeks of no recruitment the lead specialist clinical nurse recruiting for the study decided that it was not appropriate to discuss the study with the group of patients who had been diagnosed with cardiac related chest pain because she thought this group of patients had enough information to contend with at that stage, having just been told their chest pain was cardiac related. This posed an important problem as without the participation of this group the study would be completely compromised. A solution was found after discussions with the nurse coordinator of the Rapid Access chest Pain Clinic. She suggested that I should recruit participants for the cardiac chest pain group from other clinics and organisations within the hospital which dealt with the rehabilitation of patients who had received a diagnosis of cardiac related chest pain in the Rapid Access chest Pain Clinic. These were the post myocardial infarction clinic, the cardiac rehabilitation clinic and a local voluntary organisation which helped mentor people following a cardiac related problem.

Contact with the voluntary organisation was made through the organisation's chairperson and the principle administration officer. After a meeting in which I explained the objectives and rationale of the study, permission was obtained to recruit from the voluntary organisation, at the local groups situated throughout Central Scotland. It was agreed that coordinating members at each of the groups would give a description of the study, provided by myself, and then ask for volunteers. Those who agreed were given an information pack and their name and telephone number was forwarded to me. However, this change to the recruitment strategy meant there was an increase in the time taken to recruit people.

Once I had received the names and telephone numbers of potential participants I contacted them by telephone to discuss what their participation in the study would entail, where the focus group discussions would take place, and to confirm they were still willing to take part. Once it was established that the person was willing to participate they were asked to indicate which of several focus groups they could attend and sent a letter confirming the date and time of the focus group together with a plan of the hospital showing the location where the focus group would take place. At the end of the conversation I confirmed that the consent form had been completed and returned using the addressed envelope. I also took the opportunity to ask if the potential participant had discussed the study with their spouse or partner and if they were willing to participate.

The second location where recruitment took place was at a general practice in the east of Scotland. This location was chosen because the general practice was able to identify people who were at high risk of developing coronary heart disease (group D). These people were identified a result of a family history, diabetes, high blood pressure, smoking or obesity. One of general practitioners was interested in the aims of the study and was keen to help with the recruitment. We agreed that the practice would provide me with the name and telephone numbers of potential participants, and also mail these individuals information packs accompanied by a letter from the practice. The location chosen for the group D focus groups was the community education centre because it was situated directly across the road from the general practice, and was familiar to potential participants.

I contacted each of the individuals to discuss the study, their participation and to answer any questions they may have had. If the potential participant was willing to participate confirmation was sought as to their completion of the consent form. The person was then asked to choose which of several dates they preferred to attend a focus group. At the end of the telephone conversation the potential participant was informed they would receive confirmation in writing of the date and time of the focus group together with a map showing the location of the focus group setting.

However, during the early stages of recruitment it became apparent that there was another significant problem with the strategy being used for groups A and B, and as a consequence group C. Once the names and telephone numbers of the potential participants had been obtained from the specialist nurse at the Rapid Access Chest Pain Clinic contacting them was relatively straightforward. However, when attempting to discuss the study and confirm they would attend a focus group discussion it became apparent that a high number of people had changed their minds and were no longer willing to participate. One explanation might be that some individuals were agreeing to give their name and telephone number to the nurse as a thank you for the medical assistance they had just received at the Rapid Access Chest Pain Clinic and were less enthusiastic when I contacted them later. This is demonstrated in the response rates shown in table 3. As a consequence, the number of participants for the focus groups began to diminish rapidly. This had a major impact on the time scale for the study.

A further problem I encountered was non-attendees. I had been aware of this potential problem and had attempted to overcome it by over-allocating for the focus groups. It is generally recommended that focus group discussions should consist of between six and eight participants (Ritchie & Lewis, 2005; Kreuger, 1994) so when arranging the focus groups I attempted to recruit between eight and ten participants to allow for those who would not turn up. However, in the event even this was not enough.

I had estimated that the focus group discussion phase of the study would take around four to six months. However, because of the problems detailed above the time scale had to be re-evaluated. Recruitment began around mid May 2007, with the first focus group conducted at the end of the month. By the end of July six focus groups had been undertaken but the attendance rates were disappointing. Focus groups undertaken with groups A and B varied from as few as 3 participants to a maximum of 6. At this point it became clear that another method of data collection should be considered, and I decided to supplement my focus group data with in-depth interviews. In-depth individual interviews were expected to be easier to arrange because I could go to people’s homes at a time that suited them.

4.4.2 Response rates stage 1.

The overall response rates for stage 1 for both focus group discussions and individual interviews, in each of the groups is illustrated in table 3 and was as follows:

Table 3 Overall response rates for stage 1

	Group A	Group B	Group C	Group D	Overall total
Total approached	25	61	14	16	116
Accepted	16 (64 %)	11 (18 %)	6 (43 %)	11 (69 %)	44 (38 %)
Declined	9 (24 %)	50(82 %)	8 (57 %)	5 (31 %)	72 (62 %)

Table 4 shows the balance of participants achieved through the redesigned sampling strategy. Two focus groups were conducted with 4 and 3 respondents respectively; nine individual interviews were conducted. Four were recruited from the post MI clinic and seven from the voluntary organisation.

Table 4 Characteristics of group A and the data collection method

Pseudonym	*Data collection method*	*Characteristics*	*Recruitment site*
Sarah	Focus group	White female aged 47	Cardiac rehab clinic
Marge	Focus group	White female aged 53	Post MI clinic
Marie	Focus group	White female aged 61	Post MI clinic
Malcolm	Focus group	White male aged 62	Post MI clinic
James	Focus group	White male aged 62	Cardiac rehab clinic
George	Focus group	White male aged 63	Cardiac rehab clinic
Charlie	Focus group	White male aged 76	Cardiac rehab clinic
May	Individual interview	White female aged 61	Post MI clinic
Elly	Individual interview	White female aged 65	Voluntary organisation
Ray	Individual interview	White male aged 57	Voluntary organisation
Danny	Individual interview	White male aged 60	Voluntary organisation
Colin	Individual interview	White male aged 64	Post MI clinic
George	Individual interview	White male aged 64	Post MI clinic
Andy	Individual interview	White male aged 66	Post MI clinic
Bob	Individual interview	White male aged 72	Voluntary organisation
Terry	Individual interview	White male aged 78	Voluntary organisation

The recruitment of patients from group B, those from the Rapid Access Chest Pain Clinic whose chest pain was of a non-cardiac origin, was also not without its problems. Although the Rapid Access Chest Pain Clinic was generating what seemed to be adequate numbers of potential participants, as I have said when I contacted these people a large number had changed their minds, and no longer wished to take part.

From a total of 61 patients who agreed to give their consent and allow their names and telephone numbers to be given to me, 50 later decided against participation. Table 5 shows the characteristics and data collection method used for the 11 patients in group B. Two focus groups were conducted with 6 and 3 respondents respectively, and two individual interviews were conducted. All the respondents in group B were recruited from the Rapid Access Chest Pain Clinic.

Table 5 Characteristics of group B and the data collection method

Pseudonym	*Data collection method*	*Characteristics*	*Recruitment site*
Issy	Focus group	White female aged 56	RACPC
Maureen	Focus group	White female aged 60	RACPC
Ella	Focus group	White female aged 74	RACPC
David	Focus group	White male aged 39	RACPC
Geoff	Focus group	White male aged 49	RACPC
Henry	Focus group	White male aged 51	RACPC
Graham	Focus group	White male aged 78	RACPC
Jonathon	Focus group	White male aged 63	RACPC
Ken	Focus group	White male aged 59	RACPC
Rhona	Individual interview	White female aged 48	RACPC
Katy	Individual interview	White female aged 57	RACPC

Perhaps the most difficult group to recruit during the entire study was Group C, the spouse or partner group. Despite the fact that every patient information pack that was given to patients from groups A & B contained a further pack for their spouse or partner the number of respondents was disappointingly low. It became apparent from an early stage that relying on patients to distribute the spouse or partner packs was not a viable method of recruitment. Thus a further change to the recruitment strategy was needed. Hence, group participants were asked for permission to contact their spouse/partner following completion of either the focus group or individual interview.

Following the completion of the focus group or individual interview I noted down the name and telephone number of the spouse/partner and provided the patient with an information pack for their spouse or partner. I contacted the spouse/partner 24 hours later to discuss the possibility of taking part in the study. However, even with this change in the recruitment procedure it became apparent that there were not going to be sufficient numbers to hold focus groups. Therefore the decision was taken to use only individual interviews as the method of data collection for group C. Table 6 shows the characteristics of participants from group C as well as their spouse/partner's status within the study.

Table 6 Characteristics of group C the data collection method and where they were recruited from

Pseudonym	*Data collection method*	*Characteristics*	*Recruited from*
Bobby	Individual interview	White female aged 57	Husband from Volunteer organisation group A
Marie	Individual interview	White female aged 59	Husband from Volunteer organisation group A
Mary	Individual interview	White female aged 61	Husband from RACPC group B
Marge	Individual interview	White female aged 69	Husband from cardiac rehab group A
Anna	Individual interview	White female aged 70	Husband from Volunteer organisation group A
May	Individual interview	White female aged 72	Husband from RACPC group B
Joan	Individual interview	White female aged 74	Husband from Volunteer organisation group A
Gerald	Individual interview	White male aged 62	Wife from Volunteer organisation group A
Peter	Individual interview	White male aged 73	Wife from post MI clinic group A

The final patient group, those at high risk of developing CHD – group D, were the easiest to recruit. Of a total of 16 patients that were identified by the practice 11 agreed to participate. The reasons for choosing not to participate varied. Three patients misunderstood the aims of the study and refused to participate believing they were not at high risk of developing coronary heart disease. The other two individuals choose not to participate due to home and caring commitments. The details and characteristics of the participants can be seen in table 7. Two focus groups were conducted with 6 and 4 respondents respectively, and one individual interview was conducted. All the respondents in group D were recruited from the general practice.

Table 7 Characteristics of group D and the data collection method

Pseudonym	*Data collection method*	*Characteristics*	*Recruitment site*
Anne	Focus group	White female aged 53	General practice
Frances	Focus group	White female aged 59	General practice
Freda	Focus group	White female aged 61	General practice
Jen	Focus group	White female aged 67	General practice
June	Focus group	White female aged 74	General practice
Monty	Focus group	White male aged 52	General practice
Syd	Focus group	White male aged 68	General practice
Fred	Focus group	White male aged 70	General practice
Mo	Focus group	White male aged 73	General practice
Steve	Focus group	White male aged 77	General practice
Peter	Individual interview	White male aged 57	General practice

4.4.3 Stage 2 study settings and recruitment procedures

In stage 2 of the study three more objectives had to be met, these were: (3) to identify the best practice guidelines on the management of a heart attack, MI or ACS; (4) to combine the experiential data and the guidelines in a draft resource; and (5) to pilot the resource through seeking responses on content and preferred style of presentation from relevant patient groups and health professionals.

Following the combination of data produced by the initial individual interviews and focus groups and the clinical guidelines the first draft of the information resource was developed. This first draft was used as starting point from which to aid the next level of development. Participants from the original focus groups and individual interviews in stage 1 were invited to form the stage 2 focus groups. Three focus groups were conducted with participants from phase 1 to gain an understanding of their views towards the first draft of the information resource.

Following this, a second draft was produced. It is here that a number of health professionals became involved in order to gain their insights on the suitability of the resource. Health professionals from around Scotland, with a special interest in chest pain, were asked to review the contents of the second draft of the information resource. The health professionals were asked to provide their opinion on the appropriateness of the resource in terms of the information presented in it. Following this a further redraft of the resource took place. Table 8 describes the participants in stage 2.

Table 8 Stage 2 participant & health professional interviews and focus groups

	Focus groups	Individual interviews	Total
Group A & B	2 (12 participants)	2	14
Group D	1 (5 participants)		5
Health professionals (4 GP's and 2 Paramedics)		6	6
Overall total participants phase 2			25

Recruitment procedures for stage 2 were relatively straightforward. At the end of each stage 1 focus group or individual interview each participant was asked whether they would consider taking part in the next stage. Every participant that was willing was asked to sign a consent form and their details kept on record. When the time came to recruit for the second stage the focus groups were drawn from these participants. Three focus groups were conducted with 17 respondents during stage 2, two focus groups drawing participants from groups A (5),B (2) & C (5) and one focus group from group D (5). For the focus group using the participants from groups A, B

& C it was decided to attempt to recruit equal numbers from each of the three groups. The final composition of the focus groups for phase 2 is shown in table 9.

Table 9 Participants of stage 2 focus groups and original recruitment source

Focus group No	*Pseudonym*	*Characteristics*	*Recruitment source*
1	Mary	White female aged 61	Spouse – from group B
1	Marge	White female aged 69	Spouse - from group A
1	Gerry	White male aged 62	From group B
1	James	White male aged 69	From group A
1	Chris	White male aged 76	From group A
1	Terry	White male aged 78	From group A
2	Marie	White female aged 58	Spouse – from group A
2	Mary	White female aged 61	Spouse - from group B
2	May	White female aged 67	Group B
2	Danny	White male aged 60	Group A
2	Gerald	White male aged 62	Spouse - from group A
2	Andy	White male aged 66	Group A
3	Agnes	White female aged 53	Group D
3	Frances	White female aged 59	Group D
3	Freda	White female aged 61	Group D
3	Fred	White male aged 70	Group D
3	Steve	White male aged 77	Group D

4.5 Conducting the research

4.5.1 Use of focus groups

In recent times the focus group technique has gained considerable popularity as a means of gathering qualitative data in the study of health, health care, and other social processes (Sim, 1998). It is the ability to produce rich data concerning health care issues which made focus groups the ideal technique for my current study. Focus groups represent a remarkably flexible research tool in that they can be adapted to obtain information about almost any topic in a wide array of settings and from very different types of individuals. Group discussions can be very specific. They may be highly structured or quite unstructured. Visual stimuli, demonstrations, or other activities may be used to provide a basis for discussion (Stewart & Shamdasani, 1990). This flexibility makes the focus group a particularly useful tool and explains its popularity. A straightforward definition of focus groups is given by Krueger (1994, pp. 10-11):

> *The focus group interview….. taps into human tendencies. Attitudes and perceptions relating to concepts, products, services or programs are developed in part by interaction with other people.*

The focus group technique capitalises on the interaction within the group to elicit rich experiential data (Ashbury, Gospodarowicz, Kaegi & O'Sullivan, 1995). It is used to utilise the group processes which can help people explore and clarify the group's own views (Kitzinger, 1995). When group dynamics are working well, when the participants within the group are working well along side each other and the researcher, focus groups have the advantage of helping to move the research in new and often unexpected directions, which would be difficult in one-to-one interviews (Kitzinger, 1995).

Interaction is the key to the focus group method, giving this technique a high level of face validity (Kreuger, 1994) because what participants say can be confirmed (Webb & Kevern, 2001). There are a number of reasons why the technique has become so popular. Firstly, focus groups are a socially oriented research procedure. Ritchie and Lewis (2005) suggest that people interact with and are influenced by others; we all tend to make decisions after listening to the advice and options of those around us. Focus groups are able to exploit these social realities, by placing people in natural, real life situations. The second advantage of focus groups is the format. As Kreuger (1994) writes, focus groups allow the researcher to probe, and this flexible approach means unanticipated issues can be explored if and when they arise. Therefore, focus groups have become an established technique within the social researcher's armoury, where it is widely used and viewed as a valuable research approach.

Within the focus group environment it is important that every effort is made to produce a permissive setting. One way in which this is achieved is through the selection of participants (Krueger, 1994). Although the focus groups in this study were composed of strangers there were a number of characteristics which they had in common (Krueger, 1994). It is this common ground that Jourard (1971) suggests enables people to talk about themselves. Jourard (1971) found that an individual's decision whether to disclose information about themselves to others was based on perceptions they had about them. His studies revealed that subjects who perceived they were similar to others disclosed more to these individuals. Krueger (1994) suggests that focus groups are best conducted with participants who are similar to each other and the rule he puts forward is that participant commonality not diversity is key in determining focus group composition.

In contrast Barbour and Kitzinger (1999) emphasise the importance of having some form of heterogeneity in focus group discussions and suggest that differences between participants often lead to discussions moving in revealing and unexpected directions. It is important to realise that in determining the characteristics of the groups' composition no amount of planning can control for all eventualities. The exact composition of most focus groups will often be a product of circumstance rather than planning, and it is important to accept this situation when recruiting group participants (Barbour and Kitzinger, 1999).

Choosing the setting and location is also important; there was the requirement to balance the needs of the research with that of the participants. Within the literature it is suggested that the location should ideally set the tone of the research as professional and where possible be held on neutral ground. For those people recruited from the general practice the setting was chosen as the community education centre adjacent to the practice. For those recruited from the Rapid Access Chest Pain Clinic or the rehabilitation clinics it was thought that by using the hospital's own conference facilities to hold the focus groups the research would be taking places in a familiar setting, i.e. the hospital where they visited the rapid access chest pain clinic. This location also had the added advantage that it was easy to reach, would be conducive to allow smooth flowing discussions, and it was warm and comfortable (Breakwell, Hammond & Fife-Schaw, 2000). However, the use of this setting was expensive and it could be considered that a setting within the hospital grounds may have disadvantaged some people and may have elicited or suppressed certain types of responses due to the medical surroundings.

The setting for stage 2 was dependant on the groups which were recruited at stage 1. The location for the stage 2 focus groups did not change for the people recruited form the general practice; they continued to be held at the community education centre. For participants from groups A, B & C focus groups were held within a suitable location at the University of Stirling. The decision to change the location from the hospital was purely for financial reasons; by holding the focus groups at the University of Stirling there would no cost. Also a setting within the university could be considered neutral and I was able to obtain the use of these facilities with no cost. Regardless of the setting most group discussions took on average between 1 and 2 hours which is regarded as within the normal range (Breakwell et al, 2000).

4.5.2 Use of individual interviews

Although interviews represent one of the most common methods of data collection in qualitative research they were not the first choice in this study. In any study's choice of methodology it is crucial there is a logical decision process based on epistemological and ontological principles which are tied to the research question and therefore underpin the choice of data collection (Mason, 1996). As I have described, in this case the decision to use in-depth individual interviews was driven by necessity as I was not generating enough participants to form viable focus groups. Therefore I had to adjust the data collection method to gain the experiential evidence needed for the study. Although I debated this decision with my supervisors, I did think this approach might be better in generating accounts of people's experiences.

The use of in-depth interviews allowed me to gain detailed accounts of a small number of topics based upon the topic guide which had been used during the focus group discussions. In addition to the questions I had decided to ask, I also had to consider the use of prompts and probes during the interview to allow me to gain the information I required. This was due in part to the one-to-one nature of the interview. I needed the participants to talk freely about their experiences in order to generate the 'rich' data I required for the study. The use of the in-depth interview allowed me the opportunity to compare the experiences of other participants, who had also participated in an interview, in a way I could not do with the focus group participants. I wanted to compare the experiences of the participants in order to identify similarities and differences between accounts. Therefore although driven by necessity the use of in-depth interviews provided me with a method which would allow me to achieve my goals and generate useful comparable data.

During the early focus groups and to a certain extent the individual interviews I found it difficult to strike the right balance between listening and talking. This was apparent when I and my supervisors listened and read a number of the transcripts. I judged that I was talking too much, perhaps because of a fear of silences and also to get through the questioning schedule. When I encountered a silence during a discussion or interview I would attempt to fill it by either repeating what the individual had just said or quickly moving on to the next question. I realised how inappropriate this behaviour was and attempted to control it in later focus groups and individual interviews. During the later focus groups and individual interviews I also changed the question schedule slightly in order to focus in on specific areas, both the early and later questioning schedule can be seen in appendix 1 and 2.

It is natural to want to fill in gaps in the conversation, and as I was nervous about the success of the focus groups I attempted to curb this behaviour. During the later focus groups and individual interviews I realised that having a pause in the discussion was a very useful technique that allowed the person to think more about the topic being discussed. I realised that some people were shy or reticent about speaking, but found that many people would often speak when there was a break in the discussion. I found in short space of time I was able to use this technique effectively. By using a pause of around five seconds I was able to make eye contact with the person and encourage them to speak.

I also found various types of non-verbal communication were a useful means of prompting a person to talk when a break in the discussion occurred. By raising my eyebrows, nodding, and other gestures I was able to encourage people to talk. This change in technique also encouraged me to attempt to use a more useful form of verbal prompt. Rather than just interrupt and move on to another topic I began to use prompts with more meaning such as “I see, that’s interesting, keep on…” to encourage a person to continue their line of response.

4.6 Ethical issues

Because I initially intended to sample from two distinct participant groups, consent for the study was obtained from a number of sources. Initially contact was made with a hospital in the central belt of Scotland and a general practitioner in the east of Scotland, to negotiate access to the participant groups. Consent was sought from the Stirling University Nursing and Midwifery Departmental Ethics Committee. Consent was then sought from the hospital (to sample patients from their Rapid Access Chest Pain Clinic (RACPC)) and from NHS Board which the GP was associated with (to sample patients from the general practice). Finally because this study was to conducted in a healthcare setting the approval of an appropriate ethics committee was sought to determine that it met with agreed standards, was expected to produced worthwhile findings and ensured that patients were not inconvenienced or harmed (Royal College of Nursing, 2004). The study was approved by the Scottish Central Office of Research Ethics Committees (COREC) on the 27th of November 2006 (project No 06/MRE00/109) (see appendix 3).

There is a debate within the research literature about applying ethical codes originating from the bio-medicine field to qualitative research. I used guidance produced by the Royal College of Nursing which suggest three essential ethical processes in undertaking research these are; ensure you have consent, reduce the risk of harm to your participants, and to guarantee you ensure confidentiality (Royal College of Nursing, 2004). In section 4.6.4 I also describe the issue of offering a small token of gratitude for participation.

4.6.1 Ensuring consent

All participants received details of the study design via one of two sources. Participants received an information pack either by post or by hand from staff at the Rapid Access Chest Pain Clinic at the hospital in the central belt of Scotland. The information packs included a letter introducing the study, an information sheet explaining what participation would mean and a consent form together with a return envelope (see appendix 4 for letter, appendix 5 for information sheets and appendix 6 for consent forms). Once consent forms were received potential participants received a telephone call to ensure they still wished to participate and to answer any questions they had concerning participation in the study.

Prior to the start of each focus group discussion or individual interview I ensured each participant was still happy to continue and that they understood that were free to leave at any time. By its very nature qualitative inquiry may produce issues that arise during the discussion that could not have been anticipated at the time of consent. Participants in this study were therefore informed at the beginning of each group or interview that they could choose not to answer any questions or not to participate if they wished. They could also ask for the recording device to be switched-off, or they could leave the discussion or interview at any time without giving a reason why.

It is also recognised that it can be difficult to gain true voluntary participation if participants feel subject to pressures, such as a sense of duty, or if they thought participation or non-participation may affect their care. For this reason, it was emphasised in the participant information sheet and during the initial telephone conversation that their decision whether or not to take part in the study would have no influence on the care they would receive now or in the future.

4.6.2 Reducing the risk of harm

One area which has the potential to cause anxiety and distress during the qualitative discussion or interview can be the subject matter itself. In this study participants were being asked to discuss their experience of symptoms which could have been attributable to heart disease. Discussing the experiences of their symptoms had the potential to provoke feelings of anxiety about the issues associated with having a serious or potentially life-threatening disease. In an attempt to minimise the distress, all potential participants were provided with a comprehensive account of the nature and purpose of the study so that they could make an informed choice about whether they wished to participate or not. Because the majority of the participants taking part in study had been through some form of traumatic experience, either theirs or their spouse's, I had to be aware of the possible signs of discomfort that reliving these events could cause. In fact two interviews did have to end prematurely because the participant was clearly in some distress.

In trying to reduce the harm to participants a fundamental requirement of any research study is that it is scientifically sound. This means that it is designed correctly and is undertaken by qualified researchers who have sufficient levels of skill to ensure the study will produce results that are of some tangible benefit (Richards & Schwartz, 2002).

4.6.3 Ensuring confidentiality

In order to safeguard the confidentiality of the study participants, all data gathered during focus group discussions and individual interviews were handled in accordance with the Data Protection Act (2001). Participants were assigned a pseudonym as soon as was practical after the focus group discussion or individual interview. Pseudonyms are used throughout the thesis. Focus group discussions and individual interviews were recorded using a digital voice recorder. Digital recordings and transcriptions were secured on the main researcher’s private computer located within a locked office within the University. Hard copies of the recordings (on CD-ROM) and transcriptions were held within a locked cupboard to which only the main researcher had access. Discs are to be destroyed on completion of the project, whereas transcripts will be destroyed fifteen years after the end of the study in accordance with the local and national Research Governance and ethical guidelines.

4.6.4 Compensation for participation

Because the participants were agreeing to take part in a multi stage study which showed a level of commitment it was decided that at each stage the participants were to be offered a £20 Marks & Spencer voucher as a gift to compensate them for their time. Although paying participants to take part in research can be seen as an inducement, it was felt in this instance the vouchers would be seen not as payment but as a gift, and it was hoped this would demonstrate to the participants that their experiences and time were of value.

The use of gifts to compensate people when undertaking focus groups is nothing new. Krueger (1994) suggests these are usually used because participation in a focus group or individual interview requires time and effort. People who are taking part in a focus group give their own time, and for some whose lives are unpredictable and subject to the wishes of others, this can be a considerable commitment. People can also incur expenses when participating in focus groups, this can range from giving their own time, travelling expenses, and even childcare. Finally the level of contribution which the focus groups or individual interview entails exceeds other forms of data gathering, for example mail surveys do not take 1 to 2 hours to complete (Krueger, 1994).

However, the use of such gifts should not be seen as a reward, it is to compensate them for their time and effort. It serves as a stimulus for potential participants to attend the session. The primary function is to get the participants to show up for the focus groups or individual interviews. Another function is to ensure that the time scheduled for the focus group to take place is remembered. Many people may have a number of last minute requests for the same time, so the incentive works to protect that time slot. The use of a gift can also communicate to the participants how important their contribution is.

4.7 Analysis

4.7.1 Managing the data

After each focus group discussion or interview field notes were made concerning four main issues: (1) the initial symptoms the individual could remember; (2) their reasons for either seeking or not seeking help; (3) the role of significant others; and (4) their thoughts on the production of the information resource (i.e. content, layout, format etc). As soon as practical after the discussions or interviews the recordings were downloaded on to the computer and transcribed. They were then listened to and my field notes were amended. It was at this point that pseudonyms were given to each of the participants to ensure anonymity. During this time a further hard copy of the digital recording was made as a safe guard and this was placed in a locked cabinet together with my field notes.

I transcribed the first four recordings, and subsequent recordings were transcribed by a private transcription service. All recordings were transcribed verbatim, and once completed were checked against the original recordings to ensure there were no errors. Once the transcripts had been checked against the original recordings two copies were made; one was stored within a folder in Word and a hard copy was produced, and a second copy was transferred into *NVivo* as soon as possible. All hard copies were numbered and re-checked to ensure all pseudonyms were in place.

4.7.2 The analytical process

A major aspect of establishing rigour and therefore demonstrating the credibility and dependability of the findings of any qualitative study is giving the reader a thorough account of the circumstances of their production (Ritchie & Lewis, 2005). This section presents an account of the key stages of the study's analytical process, with particular attention being given to the development and refinement of the codes, themes and concepts which evolved. The account aims to provide a clear picture of the analytical decision trail to enable the reader of the thesis to judge for themselves the rigour of the findings presented in subsequent chapters.

When looking at the data the research objective of describing the experiences and responses of a range of people who have had symptoms that might have been attributable to heart disease was paramount. Any insights I obtained for the data needed to relate to this objective. By keeping the objective in mind I was able to constantly realise the purpose of the research and thereby keep the focus of the analysis. During this stage all the data was filtered through me, where I had to decide what to use and how to use it. To do this I had to draw upon my own theoretical sensitivity – the combination of my personal and my academic experience, my reading of the literature and my knowledge of theoretical issues – this enabled me to interpret the experiences presented in the data. Here I was looking for evidence of how people interpreted their symptoms, what was their response and how they made sense of their experiences.

At the outset of the study, it was anticipated that I would use a qualitative analysis package to facilitate data management. The analytical process in this case was aided by the computer assisted qualitative data analysis software (CASQDAS) package – *NVivo* (version 7). *NVivo* was used principally as a tool for executing the mechanical task of managing the data and conducting the initial stages of the analysis. *NVivo* is considered a tool which enhances the efficiency with which large amounts of data can be coded. In addition, given the inductive nature of the study’s methodology, *NVivo* also allowed key areas to be located that were relevant to the process of creating conceptual and analytical codes and themes in a more pragmatic way than could have been accomplished entirely by hand.

The analytical process began immediately after each focus group and individual interview; notes were written detailing the group discussion or interview progressed and details of the respondent/respondents. All focus group discussions were recorded using a digital recording device and transcribed verbatim. Initially I transcribed the first focus groups (N = 5) after the recordings were sent to transcribing service. Transcripts were then read by me and corrections made, or gaps filled in where possible (i.e. when the transcribers had difficulty making out what was said).

The data was initially coded into broad categories which reflected the broad topics of interest within the study. The coding began by classifying and making sense of verbatim transcripts obtained from focus group discussions and individual interviews. Codes were attributed to the text following a line-by-line analytical procedure – examining every line and paragraph in order to assign labels to incidents and phenomena described by the participants. These codes were abstract representations of an object or a phenomenon (Strauss & Corbin, 1998), or more prosaically, a mnemonic device used to identify themes in a text. For example codes were used to highlight how people recognised their symptoms, what label they gave them, and how they identified something was wrong. Grouping the respondents' data within these broad codes helped me to see what they were saying about these topics. This was very much like reading all the transcripts together on a single issue.

Initially I worked with both hard and electronic versions of the transcripts, using *NVivo* as a storage facility to aid with the identification and extraction of specific elements of text from both the focus group discussions and individual interviews. I began coding in broad terms using what has been described as a ‘broad-brush’ or ‘bucket’ approach. This method allowed me to ‘chunk’ the text into the broad topic areas, as a first step to identify what was there and to identify those passages which I considered relevant.

Also during this stage I was constantly re-reading the transcripts to compare the accounts of people in both the focus group discussions and individual interviews, identifying similarities and also noting the differences in their accounts. At this stage I tended to read and re-read the transcripts as a whole, in order not to lose the context of the codes I was developing. However, in some ways I could not avoid fragmenting the focus group discussions, due to the focus on the individual account of their experience. The early lack of structure to my analysis pointed, in part at least to my inexperience of working with such large amounts of data.

Following this I then began to question the data, looking at the ways in which the participants talked about their experiences and looking for positive or negative accounts in their descriptions. I was also interested in how the participants suggest significance, what were the symptoms they experienced which indicated something was wrong. The early codes I created were combined with the observations, thoughts and comments I had produced during the early stages of my analyses in a way which I hoped would develop my understanding of their experiences, and develop the analytical process. I hoped this would enable me to understand the persons' own meanings rather than my own perceptions being imposed on the data.

As a result I began to develop broad themes which corresponded to the research aims of the study. Influenced by much of literature on response to symptoms described in chapter two I developed the broad theme of *identity* of symptoms associated with heart disease. The *consequences* of the symptoms (not only for the participants themselves but also their family) and the *significance* they held for them also became themes, as did concerns around *cure, control and coherence.* I was interested in exploring the *decisions* that the people talked about in terms of the reasons they gave for not seeking medical help sooner. An example of how this was achieved can be seen in table 10 below.

Following this the experiences and responses the people made were then introduced into *NVivo.* This was done by entering the text extracts into the software using the free node facility. Nodes were made for the different types of symptoms, experiences the participants talked of and the responses they made as a result of them. By using the free node option no relationships or connections were assumed – the nodes were simply used as a dropping point for the data I was interested in. From this point onwards hard copies of the transcripts were used infrequently, and although only a small number of *NVivo's* facilities were used it still afforded me the perfect tool from which to move between the transcripts for comparison, and helped to ensure rigour was established.

Table 10. An example of using the CSM cognitive representation of illness domains to help analyse the respondent accounts.

The cognitive representations of illness of those who sought help quickly					
Domains Name	**Identity or label**	**Cause or Attribution**	**Timeline**	**Consequences**	**Cure or Control**
Name: Bob Cardiac chest pain	*"I got this pain in my chest. And I knew whenever I got this pain it was … I knew what was going to happen"*	*"I knew right away it was something to do with my heart you know"*	*"I should have sought help. But maybe I felt because it was different pain from the first time I just wasn't sure and maybe that put me off from phoning an ambulance right away".*	*"Then it hit me! I knew there was something but I wasn't sure. But it came to the stage where I thought no there is definitely something wrong here".*	*"My wife was down shopping so I had to phone and she whipped me up to the health centre"*
Name: Marge Cardiac chest pain	*"I woke up in the middle of the night with … really I'd never experienced pain like this in my life"*	*"I had pains down both arms and I knew it was my heart because it felt like it was leaping out of my chest".*	*"And when that (the pain) was not going away I thought I need to go to hospital"*	*"But last time it was coming up my neck, just to reinforce that I must phone the ambulance".*	*"I phoned the help line (999) and explained and they just said we will send an ambulance".*
The cognitive representations of illness of those who waited before seeking medical help					
Name: Andy Cardiac chest pain	*"I knew what it was, it was dam sore. And it was right across my chest … it was like a vice aye!"*	*"I thought it was severe heart burn!"*	*"I'd had it for about six weeks prior and I just, kept putting it off, because I did not think anything of it. I thought it would pass away".*	*"About three o'clock in the morning the sweat was pouring out of me, but as I it'll clear away eventually".*	*"But this one did not clear away, it got worse. And the wife called for our doctor".*
Name: Sarah Cardiac chest pain	*"It was….it was like a burning sensation coming straight up my throat but it was actually a severe pain right along the bottom of my jaw bone".*	*"It was like I had got a severe tooth ache".*	*"And then it happened three times in the space of twenty five minutes".*	*"It was the sensation going up my throat that made me question it….I thought no there is something strange with this pain up the throat and jaw".*	*"So that's when I phoned my G.P."*

I also attempted to make use of another approach to data management analysis known as 'framework analysis' (Ritchie and Spencer, 1994). This approach is particularly useful in applied research where particular questions require to be addressed. I used this tool in later stages when attempting to compare and contrast the experiences and responses of the respondents. There are five stages to the process involved: (1) familiarisation; (2) identifying a thematic framework; (3) indexing; (4) charting; and (5) mapping and interpretation.

The first three stages of this process are similar to, and therefore covered by, the initial coding of the data. The charting process involves creating charts for key subject areas (such as ‘symptom identity’). Then, for each respondent, characteristics related to that subject area can be mapped out (for example identifying symptoms as being cardiac related, knowing their symptoms were serious, and previous experience of symptoms). Charting involves the abstraction and synthesis of the indexed data i.e. the respondent’s view or experience in a particular area is summarised and entered on the chart and the original text is referenced so that the source can be traced for data retrieval or verification purposes. I did not attempt to chart all the data in this study. I saw this method as a way of seeing all the accounts relating to a particular topic area but broken down by thematic areas. This method was a useful tool in the process of constantly checking proposed associations.

4.8 Summary

This chapter has provided an account of the methods used in addressing the aim and objectives in this thesis. The study design, setting, sample, recruitment procedures and ethical considerations have been described in detail. The chapter has discussed how the study’s data collection strategy was developed and the changes that were needed to ensure enough respondent experiences were generated. Finally, a description of the study’s analytical process was presented.

However, it is inevitable that decisions that are taken when conducting research can have consequences that impact on the scope of the work and have implications concerning the findings produced. I have already drawn attention to the limitations of the sample in representing the experiences and views of people recently diagnosed with cardiac related symptoms (those initially proposed as members of group A) and also the spouses and partners of those in groups A & B. There is still further scope for work which can focus more specifically on the experiences of women diagnosed with cardiac related symptoms and men and women from lower socio-economic status groups with the same diagnosis.

5 Chapter 5 Exploring the experience of symptoms that may have been attributable to a heart attack

5.1 Introduction

This chapter describes respondents' accounts of their initial experience of symptoms and their response to them. It considers the nature of the symptoms and response, initial attributions, knowledge or experiences of heart disease and the role of significant others.

Interpreting symptoms and identifying a cause was something all the respondents eventually did regardless of whether their symptoms were eventually diagnosed with cardiac-related (Group A) or non-cardiac related (Group B) conditions. The nature of the sample means that we know they had also sought medical help at some point following the onset of their symptoms. The time taken to realise that medical assistance was required and make the decision to call for help varied both within and between respondents in groups A and B. We have seen that previous research has shown that people can call for help immediately or wait before making this decision following their initial symptom experience (Dracup et al, 1995; Horne et al, 2000; White and Johnson, 2000; and Pattenden et al, 2002). The respondents in this study were no different.

5.2 The distinction between those who responded quickly and those who waited

Making the distinction between respondents in terms of those who responded quickly and waited was influenced by the findings of the GUSTO trial (1993) and information available on the BHF website. The findings of the GUSTO trial suggested that the earlier people responded to their symptoms and sought treatment the faster they would receive reperfusion therapy, and the better their outcomes would be. In the GUSTO trial mortality was found to be twice as high in patients treated 4-6 hours after the onset of symptoms as it was in patients treated within 1-2 hours (GUSTO, 1993). The BHF also suggest that people who respond within 1-2 hours have better outcomes than those who wait before seeking medical help (BHF, 2006).

Therefore in this study the people who said they responded to their symptoms within 1-2 hours were categorised as reacting quickly, subsequently those who sought help after the 1-2 hours were deemed to have waited.

Of the study's respondents, only six reported that they responded quickly when they first experienced their symptoms (as defined above). Twenty one respondents waited before making the decision to seek help for their symptoms. The time they waited varied from under 24 hours in some cases to over three months in others. Some characteristics of the sample are summarised in table 10, which presents first, those who consulted quickly (in the shaded rows) and those who waited.

Table 10 Participant characteristics and type of response

Name	Age	Gender	Social situation	Participant group	Type of response	How the person described the cause of their symptoms	Data gathering method
Bob	72	Male	Married	Cardiac CP	Quick	Heart attack	Interview
Charlie	76	Male	Widowed	Cardiac CP	Quick	Heart disease	Focus group
George	64	Male	Married	Cardiac CP	Quick	Heart disease	Focus group
Marge	53	Female	Single	Cardiac CP	Quick	Heart disease	Focus group
Jonathon	63	Male	Married	Non-cardiac CP	Quick	Heart disease	Focus group
Graham	78	Male	Married	Non-cardiac CP	Quick	Heart disease	Focus group
Andy	66	Male	Married	Cardiac CP	Waited	Indigestion	Interview
Danny	60	Male	Married	Cardiac CP	Waited	Strain / work	Interview
Greg	63	Male	Married	Cardiac CP	Waited	Indigestion	Interview
Terry	78	Male	Married	Cardiac CP	Waited	Breathlessness	Interview
Ray	57	Male	Married	Cardiac CP	Waited	Indigestion	Interview
Elly	65	Female	Married	Cardiac CP	Waited	Medication	Interview
Marie	61	Female	Married	Cardiac CP	Waited	Breathlessness	Interview
James	62	Male	Married	Cardiac CP	Waited	Indigestion	Focus group
Colin	64	Male	Married	Cardiac CP	Waited	Indigestion	Focus group
Malcolm	62	Male	Married	Cardiac CP	Waited	Indigestion	Focus group
May	61	Female	Married	Cardiac CP	Waited	Indigestion	Focus group
Sarah	47	Female	Single	Cardiac CP	Waited	Asthma	Focus group
Katy	50	Female	Married	Non-cardiac CP	Waited	Virus/stress	Interview
Rhona	48	Female	Married	Non-cardiac CP	Waited	Stress	Interview
David	39	Male	Married	Non-cardiac CP	Waited	Not smoking	Focus group
Geoff	49	Male	Married	Non-cardiac CP	Waited	Indigestion	Focus group
Henry	51	Male	Married	Non-cardiac CP	Waited	Strain / work	Focus group
Ken	59	Male	Married	Non-cardiac CP	Waited	Over exertion	Focus group
Ella	54	Female	Married	Non-cardiac CP	Waited	Indigestion	Focus group
Maureen	60	Female	Married	Non-cardiac CP	Waited	Stress	Focus group
Issy	56	Female	Widowed	Non-cardiac CP	Waited	Indigestion	Focus group

5.3 The respondents who made the decision to seek help quickly

5.3.1 Response and the nature of the symptoms

The descriptions these six respondents gave of their symptom/symptoms suggest they interpreted them as serious and requiring immediate medical care. These people said they thought they ‘knew’ what their symptom/symptoms represented when they first experienced them. Bob demonstrates this understanding in the following extracts:

> *“I got this pain in my chest. And I knew whenever I got this pain it was … I knew what was going to happen”*

Later during his interview Bob reiterated again his reaction to his chest pain symptoms:

> *“I knew right away it was something to do with my heart you know”*
> (*Bob cardiac chest pain individual interview)*

Bob felt he ‘knew’ what his chest pain represented as a consequence of a previous heart attack and this led him to seek help immediately, within an hour of his symptoms occurring. In others, the symptoms they experienced were of such intensity and severity that this was enough to ensure they called for medical help quickly as illustrated in the following extracts from Marge.

> *“I woke up in the middle of the night with … really I’d never experienced pain like this in my life, both arms and my chest, and I just knew it was not right….”*

> *“And when that (the pain) was not going away I thought I need to go to hospital”*
> *(Marge cardiac chest pain focus group No 4)*

Marge called for emergency help within 1-2 hours from first experiencing her chest and arm pain. Marge spoke of her earlier diagnosis of angina and of her understanding of the dangers heart disease represented.

George, like Marge, 'knew' something was wrong as soon as he experienced his chest pain and called for medical help within an hour. George said that it was the intensity of the pain he experienced that made him think his symptoms were serious; he describes a "crushing" sensation, as seen in the following extract:

> *"I was sitting in the house and I got a pain in my chest, it was like somebody was crushing me".*
> *(George: cardiac chest pain focus group No 5)*

Of those who called for help immediately only Charlie was in the company of others when he first experienced his symptoms. From the description he gives of his decision to seek help quickly it is evident this was a combination of friends' concern for his welfare together with his own realisation of what his chest pain represented:

> *"I was standing with my pal and I felt a pain across the chest, and my pal says 'you are not looking well you are a terrible colour; you are a right grey colour'.*
> *(Charlie: cardiac chest pain focus group No 5)*

Charlie had reported previous experience of heart disease and was well aware what his symptoms represented. Within minutes of experiencing his symptoms Charlie called for help.

The non-cardiac respondents who acted immediately also said they felt they had a clear understanding of what their symptoms represented at the time. Graham felt a tight sensation in his chest accompanied by a pain in his back. He said his symptoms were enough for him to realise something was wrong, as he explains in the extract below:

> *"My chest pain was like, the first time I got it, it was like a tightening in here (Graham is pointing to his upper chest around his heart) like it was being pushed in. And I had a shooting pain right across my back"*
>
> *AW: "And this is what prompted you to seek help?"*
>
> *"Aye".*
> *(Graham: non-cardiac chest pain focus group No 1)*

Graham called for help immediately after experiencing his chest and back pain symptoms. Jonathon also implied he had a clear understanding of what certain symptoms could represent. He reported how the extension of chest pain to his left arm had a significant impact on him and shaped his decision to consult.

> *"I didn't really do anything about it (his chest pain) until the pain started going down my arm (pointing to his left arm)'.*
> *(Jonathon: non-cardiac chest pain focus group N o 4)*

Jonathon contacted medical help immediately after experiencing the symptom of pain down his left arm. The way he spoke about it implied that he and I had shared knowledge that pain in the arms was indicative of a heart attack. From the descriptions that these respondents gave it seemed they had an understanding of what was happening to them. In the descriptions of how they responded to their symptom / symptoms the intensity of the pain some experienced and the type of symptoms they encountered appeared to shape the course of action they took.

This resulted in them making the decision to seek help quickly possibly because they were confident about the potential cause – and the legitimacy – of their symptoms. There also appeared to be no need for any other explanations perhaps because they were aware how serious their symptoms could be. These factors may have played a role in the time it took them to seek help; all called for some form of help within two hours of first experiencing their symptoms.

5.3.2 Symptom attributions

As we have seen in the previous section these respondents' said they had a good idea what they thought their symptoms represented; they felt that they were able to attribute their symptoms to a cardiac cause or realise that they were serious and they needed to call for medical help quickly. The reasons they gave for 'knowing' their symptoms were serious varied, as did their attributions. For example, Bob said he knew immediately what the cause of his chest pain symptoms was. A number of years previously he had suffered a severe heart attack. He described his symptoms during his first heart attack as follows:

> *"It was if somebody had stuck a knife right into me that's how it felt. It was right…near enough in the middle (pointing to the centre of his chest)".*

During his second heart attack Bob's symptoms were different:

> *"The second time was a funny sensation, it wasn't in the middle at all, but I would have said my shoulders…it went down my arms, I felt I couldn't have done anything with them".*

Despite these different symptoms Bob wondered whether these symptoms were linked perhaps with his heart.

> *"I probably thought it was something to do with my heart but it was just so completely different from the last one (his first heart attack)".*
> *(Bob cardiac chest pain individual interview)*

Marge was in no doubt about the cause of her symptoms. She had a good idea what her symptoms represented having suffered with angina in the past and heard people talk about their heart attacks and the symptoms they experienced. This extract suggests that the intensity of the pain left her in no doubt as to what was happening to her and she attributed it to a heart attack:

> *"But it's the intensity of the pain. You cannot describe it to anybody, because I have heard people talk about it before it happened to me and I could not do anything. I had pains down both arms and I knew it was my heart because it felt like it was leaping out of my chest".*
> *(Marge cardiac chest pain focus group No 5)*

For Charlie it was the intensity of his chest pain and pains down his arm that led him to attribute his symptoms to his heart and take them seriously.

> *"I said 'I have got a pain in my chest' and then I felt a pain in the arm so they phoned a taxi and they helped me out to the taxi…when I got out there they took me down to the doctors".*
> *(Charlie cardiac chest focus group No 5)*

In Charlie's experience, as in many others', more than one type of symptom was present when describing why they 'knew' something was wrong. George, however, reported needing no other symptoms to confirm to him something was wrong. He experienced intense chest pain while at home and immediately said he knew it was serious.

> *"I got a pain in my chest; it was like somebody was crushing me so I phoned the doctor".*
> *(George cardiac chest pain focus group No 5)*

These were the only four respondents whose symptoms were cardiac who said they ‘knew’ immediately that something was wrong. Bob, Charlie and Marge all indicated that they were aware their symptoms were related to their heart. George gave no indication of attributing his symptoms to his heart, in his case it was the intensity of his chest pain that highlighted something was wrong. Amongst the non-cardiac respondents only two formed the attribution that their symptoms were due to their hearts and sought help soon after they first experienced these symptoms. Elsewhere in the interview Jonathon explained that he had knowledge of the specific symptoms attributable to heart disease and implied that this influenced his attribution of symptoms of heart disease:

> *“With me as soon as it went down the arm I thought this is more serious, I had better do something about this”.*
> *(Jonathon: non-cardiac chest pain focus group No 4)*

Graham said it was the combination of his symptoms and the shock of collapsing that caused him to attribute his symptoms to something serious (although he does not actually name the illness, as previous accounts (e.g. Jonathon) the illness attribution is implied.

> *“I was actually doing the hoovering when it first happened. It started and I went and sat down and I just passed out. I just went to sleep”.*
> *(Graham: non-cardiac chest pain focus group No1)*

Similarities between these respondents in terms of attributions focused on the severity and intensity of their chest pain and other symptoms. Experiencing severe chest pain tended to ensure respondents sought help quickly, as demonstrated by the accounts of Bob, George, and Marge. Having knowledge of what specific symptoms represented also helped in forming attributions. For example knowing that pain down the arm is a characteristic of a heart attack led to the realization that things were serious, and to the attribution that their symptoms were cardiac related. The type of knowledge these respondents had and where it originated from is examined in the following section.

5.3.3 The types of knowledge used to help interpret symptoms

For some of these six respondents a personal experience of heart attacks, angina or knowledge of significant others who had suffered such problems meant they could draw on personal experience to make sense of their own symptoms. Bob's personal experience from an earlier heart attack meant he was able to attribute his symptoms to heart disease and as a result contact medical help quickly. Bob described his first heart attack as an abrupt event with symptoms that were incapacitating, an extremely traumatic experience. His second heart attack however, was different. When he initially experienced the symptoms of his second heart attack he was in some doubt as to what was going on.

> *"I wasn't exactly sure what was going on. I knew it was something on that line (cardiac related), but with it being so different from the first time, from what I could remember of the first time. But I was certain there was definitely something wrong"*
> *(Bob: cardiac chest pain individual interview)*

Bob seemed to have been able to construct his own ideas about what a heart attack was like and possibly how it would be in the future. The specific knowledge he had acquired, a consequence of his first attack, was the benchmark he used to assess the symptoms the second time. Being unable to match his previous symptoms to those of his current experience caused Bob to consider them very carefully. Although there were differences in the severity and intensity between the symptoms of his first and second heart attacks, he still reported being certain “there was definitely something was wrong”.

Marge’s knowledge of the symptoms of a heart attack and the need for immediate medical attention were a result of her earlier diagnosis of angina. Living with angina for a number of years had raised Marge’s awareness of the risks she faced. It had also increased her knowledge of the danger signals. When she experienced intense pain in her chest and arms, Marge said she ‘knew’ something was not right and called for help immediately and again her knowledge of heart disease seemed to have contributed to the decision to seek help. Charlie also reports how his knowledge of heart disease because of his history of angina helped him to interpret his own symptoms and realise the gravity of the situation:

> *“For me definitely it is pain in the chest and when it goes down the arm. That is either a heart attack or angina”.*
> *(Charlie: cardiac chest pain focus group No 5)*

Jonathon also said his family history of heart disease resulted in him being more aware of the dangers he faced, as he explains in the following extract:

> *“In my mother’s family there’s some history of heart problems so I was quite tuned into the fact I was dead ringer for you know heart trouble at some stage in my life”.*
> *(Jonathon: non-cardiac chest pain focus group No 4)*

As a consequence of this when Jonathon experienced chest discomfort together with pains down his left arm he called for help immediately.

Other respondents acquired their knowledge of specific symptoms through the experience of colleagues or friends. George is a good example. When he experienced pain going down his left arm he said he ‘knew’ what this symptom represented because of a friend’s experience with angina, as he describes:

> *“Well, well er somebody at work had had er an angina attack that that finished up with them being in hospital. He said that in his case it was the pains down the arm (George is holding his left arm) that the hospital were concerned about, erm from a point of view of a confirmation of a diagnosis of angina. So when I got the same pains in my arm I thought angina straight away.*
> *(George: cardiac chest pain focus group No 5)*

Graham was the only one of the respondents who responded quickly who did not talk of having knowledge or experience of either heart attacks or angina. Through discussion in the interview he reported a series of other unrelated health problems had led him to place a greater emphasis on his general well-being.

> *“Well if you’re a smoker and you have a history of high blood pressure and you realise that what you’ve been doing is against all teachings you have to take notice when things change”.*
> *(Graham: non-cardiac chest pain focus group No 1)*

Therefore, when he experienced his crushing chest pain and collapsed he said he thought he should call his GP immediately.

In attempting to construct an explanation for their symptoms, these respondents were able to utilize knowledge to indicate something was wrong which required prompt medical attention. The knowledge they used to help make sense of their symptoms came from various sources. In terms of the respondents who called for help quickly, all used some form of knowledge to help them make sense of their symptoms and help them to determine what action to take.

5.3.4 The role of significant others

Of those who sought help quickly only Bob, Charlie and Jonathon's accounts suggest that significant others had played any role in this decision. Although Charlie was a widower when he experienced his chest pain, he was in the company of friends at his bookmakers. Though Charlie said he realised what was happening it was the combination of this together with the intervention of his friends which resulted in the decision to call a taxi to take him to his GP. Jonathon said that he had already decided that his symptoms warranted medical assistance but decided to discuss them with his wife, as he explains in the following extract:

> *"Well I think I would have gone anyway but once the women get to grips with it I mean…they are at you aren't they do you know what I mean? You have to go then".*

When asked why he had spoken first to his wife Jonathon replied:

> *"I probably mentioned it to my wife because her family had heart problems, er her father had a bypass operation and her advice was well you know if it's getting down into your arm it looks like it's it might be angina so that was when I went to the doctors"*
> *(Jonathon: non-cardiac chest pain focus group No 4)*

Like Jonathon, Bob appeared to have decided that his symptoms needed medical attention but his decision to discuss them with his wife was due in part to the fact he needed transport to get him to his local medical centre. At the time when he was experiencing his symptoms, his wife had their car, as he explains in the following extract:

> *"I knew when I got the pain it was…I knew what was going to happen. My wife was down shopping so I had to phone and she whipped me up to the health centre"*

When asked why he called his wife first as opposed to calling for an ambulance Bob replied:

> *"Well she has supported me all these years, when I had the last one (heart attack). And you just automatically think well I will call her".*
> *(Bob: cardiac chest pain individual interview)*

The reasons the other respondents did not discuss their symptoms with significant others varied. For Marge, living alone meant there was no one there with whom she could discuss her situation, so she called for an ambulance after waiting a short time to see if her symptoms would subside. George, although married, said he made the decision to call for help on his own. The 'crushing chest pain' he experienced was worrying enough for him to contact his GP directly. When asked if he discussed his symptoms with anybody he replied:

> *"No I just keep that sort of thing to myself. It's only the doctor I'll go to".*
> *(Graham: non-cardiac chest pain focus group No 1)*

Thus, we can see that the reasons for involving a significant other in these decisions was due either to circumstances, as in Charlie's case, or the significant other's input being valued. Valuing their wives' contribution was a possible reason why both Bob and Jonathon informed their wives. Interestingly both stated they would have sought help without their wives' assistance if it had not been available.

5.3.5 Summary

In summary the respondents who responded quickly to their symptoms appeared not to be aware of the advice provided by the BHF in terms of seeking medical help and most sought help from their GP rather than the emergency services. The reason they did this is not evident from their accounts but may be to do with a desire not to 'make a fuss' or been seen to overreact to symptoms. Other studies have shown that many people express reluctance to consult a doctor at all with symptoms (e.g. Rogers et al 1999; Townsend, Wyke and Hunt, 2008).

5.4 The respondents who waited before making the decision to seek help

5.4.1 Response of and the nature of symptoms

Of the twenty one respondents who waited before responding to their symptoms by seeking help the time before they eventually made the decision varied. For some respondents it was a matter of hours for others it was days. In a number of cases the respondents indicated they waited weeks before seeking help. This decision to wait before seeking help could have had serious consequences for the twelve respondents who later received a cardiac diagnosis for their symptoms. As I have said, interpreting symptoms and identifying a cause was something all respondents discussed. However, unlike the accounts of those who responded quickly, many of those who waited were characterised by uncertainty and ambiguity in explaining their symptoms and response to them.

When symptoms were not severe or intense, respondents were not able to respond confidently or were unclear about what was happening to them. Some respondents reported experiencing mild chest discomfort, which lasted for a short time and then receded, as illustrated in the accounts provided by Ray and Danny:

> *"By the time I got back to the room I was experiencing some chest pain. However, I got back into the room, and ten minutes later, it had gone away. It was absolutely fine".*
> *(Ray: cardiac chest pain individual interview)*

> *"I was just sitting in the chair when I had the pain. I sat up and thought I will lie on the couch and it eased away".*
> *(Danny: cardiac chest pain individual interview)*

Pains or symptoms of a short duration are often trivialised or normalised (Mechanic, 1968). It may have been that Ray and Danny had adopted a wait and see approach as a way of responding to their symptoms. This strategy could explain why they waited between two and five days before seeking help. The wait and see attitude was adopted by some others. Sarah reported an unusual symptom during the previous evening, but because of ongoing illness, she remembered deciding to wait.

> *"There had actually been a couple of breathless stages through the night but again I had put that down…I was just assuming that it was my asthma playing up".*
> *(Sarah: cardiac chest pain focus group No 6)*

For some even though their initial symptoms were unusual and out of ordinary, they also said they decided to wait. Marie, for example, talked about how she went as far as monitoring the frequency of her symptoms over a week before she sought help.

> *"It happened on two occasions. On the Monday morning when I got out of bed I had this kind of little sensation in the*

> *chest. In fact for some reason I wrote it down on my calendar and how I felt".*
> *(Marie: cardiac chest pain individual interview)*

If the symptoms did not reappear in the short term, many said they thought the situation had resolved itself, and that further explanations or medical attention were unnecessary. Andy reported experiencing a tightening in the chest over a period of six weeks; his symptoms would appear and then disappear mostly during the night. Andy talked of feeling that his symptoms were simply an inconvenience, and he would attempt to relieve them as he explains in the following extract:

> *"I just thought it was heartburn….it seemed easier to say it was indigestion".*
>
> *"It happened more so at night than during the day. I thought it was the way I was lying in bed. I would get an extra pillow or take one away. I tried all that".*
> *(Andy: cardiac chest pain individual interview)*

Thus initially he remembered his symptoms as intermittent, so Andy said he ignored them.

Malcolm's symptoms were also intermittent in the beginning and this shaped his response to them. He reported waiting a number of weeks before calling for help. Malcolm's symptoms only appeared while he was out walking, as he describes in the following extract:

> *"I didn't think it was anything important. It was so strange that it only happened to me when I was walking up a particular route coming home, it didn't seem to happen any other time".*
> *(Malcolm: cardiac chest pain focus group No 5)*

Terry had also dealt with symptoms that only affected him while walking home. He reported it was a number of months before he called for help. Terry recalled that he had responded to his symptoms by thinking he was just getting old. He describes how the symptom developed in the following extract:

> *"I would find that it got to the stage where I couldn't walk any more than about two to three hundred yards without the tightness coming on".*
> *(Terry: cardiac chest pain individual interview)*

Other respondents described their response to symptoms as 'not being anything to worry about' and they did not see them as being significant. Two women in particular reported that their initial response to their chest pain symptoms was to ignore them. Rhona and May said they had first experienced their chest pain a month before they decided to seek help. They described their first experience of chest pain as follows:

> *"I had been having tight feelings in my chest but you did not think anything about it".*
> *(Rhona: non-cardiac chest pain individual interview)*
>
> *"I had pains in the chest and I just didn't know what they were, I think I had them for a fair time really".*
> *(May: cardiac chest pain focus group No 6).*

A number of male respondents also shared similar experiences. David in particular reported having experienced chest pain a number of months before he took any action. He described his initial symptoms as follows:

> *"It was a tightness across the chest at both sides. I had it for about three or four months before I actually did anything"*
> *(David: non-cardiac chest pain focus group No 4)*

These descriptions contrast with the earlier descriptions provided by those who sought help quickly (presented in section 5.3.1). The respondents who sought help quickly appeared to have a clear idea what was happening to them, whilst the respondents who waited did not. The majority of these respondents described their symptoms as mild or intermittent pain or feelings of tightness or discomfort, rather than as severe or intense pain. These descriptions emphasize the ambiguous nature of the symptoms and highlight how many respondents felt able to dismiss or ignore them at the beginning. Experiencing vague symptoms or symptoms of an uncertain nature can also explain the many attributions these respondents made, as described in the next section.

5.4.2 Symptom attributions

When faced with vague and ambiguous symptoms some respondents found it difficult to identify a cause. Some thought something was wrong, but they were unable to interpret their physical symptoms or they attributed them to other things, whilst appraising and reappraising what was happening to them from time to time.

The attributions made by those who waited varied, but the most common was to attribute chest pain to indigestion. This was the case for the majority of respondents who were later diagnosed with cardiac related symptoms. Ray is a good example. He first experienced his symptoms following a rather large meal. Not seeing himself as being risk of a heart attack, he attributed his chest pain symptoms to indigestion which seemed the most logical explanation, as he describes:

> *"It seemed the logical conclusion at the time, yeah. Not having suffered from indigestion before I wasn't very positive about identifying exactly what indigestion felt like anyway. So just having this pain after a big meal and feeling as if I wanted to break wind which was kind of a symptom as well I suppose".*
> *(Ray: cardiac chest pain individual interview)*

Ray's response was typical of a number of respondents. From Ray's account he remembers how he followed, for him, a logical pathway that there was a cause for his chest pain - a big meal – and thus indigestion was the most likely label he could assign. Although he wasn't sure what indigestion 'felt' like, he could not distinguish between it and anything else.

A similar example is provided by another respondent who experienced his symptoms after drinking with friends. Greg initially attributed his symptoms to indigestion assuming the pain in his chest was a result of alcohol, as he explains:

> *"The first occasion it happened I was going home from the pub and I experienced tightness across the chest and I just thought it was a bout of wind, and besides I'd had a few drinks so I was affected by alcohol".*
> *(Greg: cardiac chest pain individual interview)*

Malcolm also thought his chest pain was a by-product of drinking too much, something he had started to do again after many years. Malcolm had only ever experienced his symptoms when walking home from the pub. The scenario he constructed to account for his symptoms was a build-up of wind. When the symptoms occurred again in the same context Malcolm had confirmed this earlier attribution.

> *"I just thought it was wind".*

> *(Malcolm: cardiac chest pain focus group No5).*

Andy and Colin also thought their chest pain was due to indigestion. Colin's memory of his early experience shows that he was aware of the symptoms that could be related to a heart attack, but when his own experience did not match these expectations he reported attributing his symptoms to the next most likely cause, indigestion.

> *"I just thought it was heartburn. I always thought it would pass away. Something I've eaten which I should not have eaten".*
> *(Andy: cardiac chest pain individual interview)*
>
> *"I really had no idea but I was trying to break wind with burping and so on thinking there is something building up there. But I had no previous pains in the arms to make me think oh yeah that's a heart attack. No chest pains or anything, not even breathlessness".*
> *(Colin: cardiac chest pain focus group No 6)*

Two of the female respondents' (one cardiac) initially attributed their symptoms to indigestion:

> *"I just had pains in the chest and I didn't know what they were, I think I had them for a fair time really and thought it was indigestion".*
> *(May: cardiac chest pain focus group No 6).*
>
> *"Mine was just there you know (holding her upper chest) and you can not swallow or you have got indigestion basically".*
> *(Issy: non-cardiac chest pain focus group No 4)*

Other respondents constructed other explanations. Both cardiac and non-cardiac respondents thought that an ongoing illness was the cause of their symptoms. For example, Sarah initially attributed breathlessness to asthma and not the start of a heart attack:

> *"I took a strange severe tightness in my chest, I wouldn't say it was very painful, it was just a severe tightness and I actually thought it was my asthma playing up because it more or less winded me ".*
> *(Sarah: cardiac chest pain focus group No 6)*

Elly, also diagnosed with cardiac related disease, said she initially thought her symptoms were due to the medication she was taking. Elly's initial symptom was nausea, a symptom she did not know could be a sign she was having a heart attack. Because she was taking medication for another condition, she though nausea could be a side effect of the treatment. It was only after her symptoms worsened the next day and it became clear to her husband that something serious was happening that he called their doctor.

> *"I took a pill the one night and felt quite nauseated, but tablets can do that. In the morning, I took another one. Then I had no pain. It was just like a flat iron lay there (pointing to her chest). I don't know how I looked, but my husband sent for the doctor without even asking me. So rightly or wrongly I didn't think for one minute I had a heart condition".*
> *(Elly: cardiac chest pain individual interview)*

A number of non-cardiac respondents also suggested their symptoms were due to overexertion. Ken and Henry described similar experiences when their chest pain symptoms first occurred. Both were undertaking some form of physical activity. Ken remembered how he viewed his chest pain as a warning that he was just over doing things and he needed to 'slow down'. He offers this as an explanation for dismissing his symptoms for a number of weeks:

> *"I was walking up the stairs with wood and I just had to sit down because of a pain in my chest. I sat on the toilet for half an hour sweating. I said to myself 'this is telling me to*

> *slow down'. And I didn't say anything until three of four weeks later".*
> *(Ken: non-cardiac chest pain focus group No 4)*

Henry described his chest pain as a discomfort. Because he was a physically active man, who encountered pains through his occupation, he initially responded to his symptoms by dismissing them as the onset of flu:

> *"It was probably about ten weeks ago I first started taking a discomfort in my chest. I do a lot of work outside, plus hill walking and that and you get wet a few times so initially you think flu or something like that".*
> *(Henry: non-cardiac chest pain focus group No 4)*

From the extract above, it can be seen that Henry thought that his chest pain might have been a result of flu. His doubts about the origin of his chest pain together with his strong sense of his own masculinity may explain why his attempts to normalize his pain led him to attribute his symptoms to his physically demanding occupation.

> *"But it (the pain) was going on and on and obviously being a man you don't discuss it with anybody. You keep it to yourself. I wasn't in any real great discomfort I just I didn't feel right in my chest. And because I do quite a bit of manual labour you have always got that in the back of your mind, you have maybe strained yourself".*
> *(Henry: non-cardiac chest pain focus group No 4)*

Three of the female respondents attributed their symptoms to stress. All had been under pressure; for Katy and Maureen it was an increased workload at work while for Rhona it was a combination of pressures at home and at work. Katy first perceived her symptoms during a stressful time when she was preoccupied with events at work as did Maureen who experienced her chest pains when she had just completed the flowers for a large wedding party. Rhona was also under pressure at work but she had also recently had to deal with a number of family problems. She was primary carer to her mother who had recently been diagnosed with cancer and around the same time her daughter had miscarried. When she first experienced chest tightness Rhona reported attributing it to her current situation.

> *"Gradually I got these symptoms. I had deadlines to meet that I wasn't going to meet, because other people were not meeting my deadlines. Gradually I began to get these feelings of palpitations, then the chest pain, and then a sort of dizziness. I was pretty sure it was stress".*
> *(Katy: non-cardiac individual interview)*

> *"I was thinking it maybe was stress. When I got them I had been doing wedding flowers and I was under a lot of stress".*
> *(Maureen: non-cardiac chest pain focus group No 1)*

> *"I had been under quite a lot of stress lately, and I just kind of thought well it's just down to that".*
> *(Rhona: non-cardiac chest pain individual interview)*

In summary when the respondents were clear about the nature of their symptoms, they formed attributions that led them to seek help quickly. When symptoms were unusual, vague or caused only a slight or intermittent discomfort the respondents formed various more benign attributions, such as indigestion, or symptoms of an on-going medical condition or the medication they were taking, or stress due to either pressure at work or home. In constructing these attributions the respondents who waited before calling for help utilized a variety of information, including their prior knowledge of heart attacks or cardiac related conditions.

5.4.3 The types of knowledge used to help interpret symptoms

The two previous sections have examined respondents' descriptions of symptoms, response to them and attributions made as a result of their symptoms. Both of these areas are related to the knowledge people had with regard to heart attacks, angina, or other cardiac related conditions. This is of particular interest for the respondents who were in fact having a heart attack or suffering from angina and waited before seeking help.

Of the respondents whose symptoms were eventually diagnosed as cardiac related all the men spoke of having personal experience of family members with some form of heart disease, either heart attack or angina, Greg and Malcolm spoke of friends at work with angina, and Colin spoke of being aware of the symptoms attributable to heart disease. Of the women respondents only Sarah spoke of having personal experience of a family member with heart disease, the other three women did not discuss this.

Of those with experience of family members with heart disease most spoke of parents who had died of a heart attack. Yet even with this knowledge some had not considered the possibility they were at risk. For example Ray had seen both his parents die from heart attacks. When asked to talk about what he knew of heart disease, Ray said that he had some knowledge concerning heart attacks and the dangers of heart disease:

> *"I mean I was always conscious that yeah there was a family history there. But I suppose I am like every generation, I am thinking well I am fitter and healthier, and more knowledgeable than the previous generation so it won't happen to me! I mean I was aware of the chest pains, and the breathlessness, but mine seemed such a mild form that it*

> *never really gave me cause for concern not at all which again with hindsight and all the rest of it is crazy”.*
> *(Ray: cardiac chest pain individual interview)*

Ray’s account shows he did ‘know’ some of the symptoms that are typical of a heart attack but his own experience of the same symptoms did not match the perception he had of what these symptoms should feel like.

Danny had also seen his father suffer a number of heart attacks before he died and said he had considered whether heart disease could be hereditary and as a consequence wondered if he himself could be at risk, as he explains:

> *“My father has had two heart attacks… so I did wonder if you know…if it was in the bloodline you know. But I didn’t give it an awful lot of thought because both my parents are in their eighties so you know…with a wee bit of luck I will be living to a reasonable age as well”.*
> *(Danny: cardiac chest pain individual interview).*

Although Danny did have personal experience of heart attacks, it is difficult to say how much influence this had when he experienced his own symptoms; he waited a few days before calling for help.

Terry also had seen both his parents suffer heart attacks. As a result, Terry said he thought he had a good idea of the dangers he faced and the symptoms he should be aware of although he describes his knowledge as ‘superficial’ and ‘general’. When looking back at his experience Terry remembered about how difficult it was for him to recognise the importance of his own symptoms in spite of his knowledge:

> *“I mean that strikes me as being strange because I am not unintelligent and I remember my father’s experience, I always had. My mother died with coronary heart disease*

> *problems as well. So there was always awareness in the back of my mind that I might go eventually like that. I would have said that like most people my knowledge about coronary heart disease was superficial. You know like most people I had a general kind of idea. And I find that strange in retrospect looking back I did not fully realise what was going on".*
> *(Terry: cardiac chest pain individual interview)*

For others, a personal experience of heart disease provided the knowledge of specific symptoms that were characteristic of a heart attack and consequently they were able to identify the same symptoms in themselves. Sarah remembers how such knowledge allowed her to realise something was seriously wrong:

> *"I knew the pain in the left arm because that's how my mother's was; she took the pain down her arm. My dad had actually got a doctor out to my mother and he told my dad it was a touch of angina, gave her a sleeping tablet, put her to bed and she was dead in the morning!"*
> *(Sarah: cardiac chest pain focus group No 6)*

Sarah had incorporated the symptom of arm pain, particularly left arm pain, into her inventory of potential cardiac symptoms because her mother had the same symptom. Because she 'knew' this specific symptom, her ability to make sense of what was happening to her was increased.

Others said they used knowledge gained through the experience of friends to construct their own ideas about heart disease. In the following extracts, Greg and Malcolm describe how the experiences of a work colleague helped them to make sense of their own symptoms and realise they were at risk. In particular they both remembered pain down the left arm was a particularly serious symptom.

> *"Well somebody at work had an angina attack that that finished up with them being in hospital. He said that in his*

> *case it was the pains down the arm (George is holding his left arm). So when I got the same pains in my arm, I thought angina straight away and I ought to do something about it”.*
> *(Greg cardiac chest pain individual interview)*
>
> *“I remember this guy at work got taken into hospital with an angina attack, and he was telling me about the pain, it was right down his arm, it was the same as mine, the left arm”.*
> *(Malcolm: cardiac chest pain focus group No5)*

Respondents who later received a non-cardiac diagnosis also described having personal experience of heart attacks or angina. Of these the majority of respondents, it was a family history of heart attacks or angina. For Katy it was the experience of their father dying from a heart attack, she took note of her own symptoms when she experienced them, as she explains:

> *“My father died at a relatively young age. He died of heart attack. So I think there is a family history, it’s not something I would want to ignore anyway”.*
> *(Katy: non-cardiac chest pain individual interview)*

Ella, Maureen and David all had a family history of heart problems as they explain in the following extracts:

> *“My husband died of a heart attack, and both sides of the family is rife with heart trouble so I thought I had better get out there (go to the doctor)”.*
> *(Ella: non-cardiac chest pain focus group No 4)*
>
> *“My dad had taken a heart attack”*
> *(David: non-cardiac chest pain focus group No4)*
>
> *“There’s a history in our family of heart problems, my brother’s had a bypass, my father died of a stroke…..maybe there’s something in the genes and my grandmother too she had angina”.*
> *(Maureen: non-cardiac chest pain focus group No 1).*

These accounts show that knowledge gained through personal experience of heart disease is discussed as having an impact on response to symptoms in a variety of ways. Some of those whose symptoms resulted in a diagnosis of heart disease expressed surprise that they had not considered their family history of heart disease in their initial evaluation of symptoms (e.g. Ray, Danny and Terry). Similarly some of those whose symptoms were diagnosed as unrelated to heart disease used their family history to explain their response (e.g. Katy, Ella and Maureen). For others it was knowledge of specific symptoms experienced by others that was said to have contributed to the decision to seek help (e.g. Sarah, George and Malcolm). The role significant others can play in the decision making process has been shown to have an impact for many people. This subject is explored in the following section.

5.4.4 The role of significant others

As we have seen the process of searching for a cause of illness is not limited to the person experiencing the symptoms / symptoms. It is also common for others close to that person to help in the process. In the accounts from the respondents who responded quickly, some symptoms were so obvious or so severe they left the person in no doubt as to what was happening to them – no other input was required. In other circumstances where they were not sure what was happening some tolerated their symptoms until they communicated their experience to another. It was evident in some cases that the respondent experiencing the symptom was aware of a potential problem, but it was only via communication with a significant other, in most cases their spouse, that they finally realised something was wrong.

Andy faced such a situation. He had been suffering with chest pain, sometimes quite severe, for a number of weeks, but had come to the conclusion it was heartburn.

Andy said it was a combination of more intense chest pain and the failure of his attempts at self-medication which led him eventually to talk to his wife about his condition.

> *"Well she was lying beside me she knew, because she could feel the vibrations and all that, but as I said to her, I said' it's only heart burn it'll clear away eventually'. Ah no this one did not clear away. And er…the wife eventually says 'no, docky' (go to the doctor)*
> *(Andy: cardiac chest pain individual interview)*

It was after this exchange with his wife that he sought medical care.

When Ray first experienced his chest pain, the manner in which he described this event implied he was sure it was nothing to worry about and thought it was just a bout of indigestion. Since there were no external indicators that Ray had chest pain a communicative cue was required to alert his wife to the onset of his symptoms, as he explains:

> *"At the time it felt like indigestion that's all you could describe it as. I talked about it to my wife, but ten minutes later it had gone away. The same thing happened again the next day, in fact it happened after breakfast. And my wife immediately said 'see the GP as soon as we get back home. Talk to him about it'."*
>
> *AW: What did she say to prompt you to seek help?*
>
> *"She said 'don't be bloody stupid, you are in your early fifties, you have got a family history of heart attacks let's go and get it checked out'. Those were her words".*
> *(Ray: cardiac chest pain individual interview)*

At his wife's insistence, Ray did contact his GP, but this was two to three days after he had first experienced chest pain. Although Ray did take some form of action it was delayed some time after his initial experience. Ray's account suggests that, at first, his wife went along with the initial attribution, but in a later interview with Ray's wife, Bobby, she explained how she felt when Ray discussed his symptoms with her.

> *"One night he complained about indigestion and the next morning he complained about it again after breakfast. I did not like the sound of this indigestion. So I said 'phone the doctors when we get back and have a word with him'."*
> *(Bobby: spouse individual interview)*

Talking to others also had the function of seeking confirmation that something was wrong. After a few days of mild and intermittent chest pain Danny's symptoms became increasingly painful during the course of an evening. In an attempt to alleviate these painful symptoms, he had gone to bed early. During the early hours the next morning, his symptoms worsened. He said he 'knew' something was wrong but by speaking to his wife he was able to confirm how serious things were and gain her assistance in seeking help.

> *AW: Can you remember what your wife said when you woke her?*
>
> *"Just asked what the matter was, you know where the pain was. Then she just went through and phoned NHS 24. They then asked to speak to me. I explained again how I was feeling, and that my body felt clammy, slightly squeamish. The person from NHS24 decided they would send an ambulance".*
> *(Danny: cardiac chest pain individual interview)*

Often communication helped to establish that symptoms were significant. When someone else says they also ‘think’ something is wrong it can be a confirmation of the respondent’s own perceptions. In the next extract, Colin reports his early symptoms and the interaction with his wife, which he said confirmed for both of them that something was wrong:

> *“When my wife arrived home, I said to her ‘there is something not right here, there is something not right in my chest’. She said ‘I can see that let’s get you up to bed’. She got me lying down and phoned our GP’s number and was then put through to NHS 24…the symptoms were described to the person (NHS 24 operator) at the other end by my wife and they said ‘there will be an ambulance with you within minutes’”.*
> *(Colin: cardiac chest pain focus group No 6)*

Malcolm also said he discussed his symptoms with his wife. In the following extract, Malcolm suggests that he had a good idea about what was causing his symptoms. However, his conversation with his wife may well have been a way of confirming his own thoughts, as he describes:

> *“I must have said to her (his wife) about this (his symptoms) and I thought it was angina. She sort of said ‘well you better go down to the doctor then. It’s quite serious that, it’s not something you can just laugh off’ ”.*
> *(Malcolm: cardiac chest pain focus group No 5)*

The non-cardiac respondents who waited before making the decision to consult medical help were also influenced by significant others. David and Ken both described family as being influential in their decision to seek help. David said he’d been aware of tightness in his chest over a number of months.

> *"It was just tightness across the chest at both sides. I had it for about three or four months before I actually did anything". (David: non-cardiac chest pain focus group No 4)*

David's family persuaded him to make an appointment with his GP after talking about his symptoms. David's father had died from a heart attack, so his family were concerned he was at risk too. Ken also sought help after talking to his wife. His chest pain first occurred while undertaking some home repairs. After flooring a room, Ken said he experienced chest pain and pains down his left arm. After his symptoms had continued over a number of weeks, Ken decided to discuss them with his wife.

> *"I was flooring the loft, so I was walking up the stairs with wood and god knows what, and I just had to sit down because of this pain in the chest and pain down the arm. I did not say anything to the wife for three or four weeks. Then I said 'I think I need to go to the doctor'. I said 'I have got this chest pain and feelings down this arm' (pointing to his left arm)". (Ken: non-cardiac chest pain focus group No 4)*

For Ken talking to his wife may have been his way of justifying his decision to call for help. Ken may well have known that once he had communicated his symptoms to his wife she would take control and call herself. This was in fact what happened. On hearing his symptoms Ken's wife immediately called their GP surgery for an appointment.

Rhona's account of discussing her symptoms with her husband shows another role significant others may play. Rhona's husband seems to have been was the driving force behind her seeking help. Rhona said she had been reluctant to seek help even though she had symptoms for some time. After talking to her husband about how her symptoms had developed, he decided it was time for her to seek help from their doctor, as she explains:

> *"My husband bullied me into going to the doctor because I was convinced there was nothing wrong".*
> *(Rhona: non-cardiac chest pain individual interview)*

By communicating with someone about their symptoms, the person has already acknowledged that there may be something untoward going on. Discussing symptoms with another person can also be a way of seeking an explanation, or a way of confirming a suspicion that something is wrong. Thus accounts of respondents who waited to consult suggest that once a significant other became involved they played a role in explaining symptoms and the decision to seek medical help. However, the role was varied and did not always result in prompt, immediate action.

5.4.5 Summary

For those respondents who waited before responding to their symptoms it is clear they were also unaware of the advice available from the BHF with regards of seeking medical help from the emergency services. The majority of the respondents who waited eventually called their GP, only one respondent called NHS 24, although a second was put through to this helpline after calling their GP. The reasons they took this course of action is not clear from their accounts.

Possible explanations for waiting before calling for help may concern the ambiguous symptoms they initially experienced or the transient nature of their symptoms. It may also have been that these respondents were also reluctant to call the emergency services for the same reasons as those who responded quickly i.e. not wishing to be ‘bother anyone’.

5.5 Comparison between the accounts of those who acted quickly or waited

In terms of the respondents’ response and nature of their symptoms perhaps the most noticeable difference between those who acted quickly and those who waited was the nature of their initial symptoms. Of the six respondents who sought help quickly four (Bob, Marge, George and Graham) described their initial symptoms using terms suggesting severe or intense pain. Their accounts used vivid language to emphasise the severe pain they felt. Terms such as ‘crushing’ or ‘collapsing’ were used to describe chest pain. Other respondents were more straightforward in their accounts describing the severity of their symptoms in terms such as ‘I’d never experienced pain like this’ or ‘it’s the intensity of the pain’. The use of such language was absent in the accounts provided by the respondents who waited, regardless of eventual diagnosis.

As we have seen in section 5.4.1 the respondents who waited their accounts tended to describe their initial symptoms in terms of ‘slight chest pain’, ‘tightness’ ‘heaviness’ or ‘pressure’. The language they used to describe the nature of their symptoms suggests they did not experience severe or intense pain. However, the experience of symptoms is subjective and the accounts provided by the respondents are open to interpretation. But when comparing the nature of the symptoms between the two groups the accounts provided by those who acted quickly suggest their symptoms were more painful. This may be a factor in attempting to explain the reasons why some respondents acted on their initial symptoms while others waited.

In comparing the attributions the respondents made their accounts suggest there was a difference between those who acted quickly and those who waited in response to their symptoms. Those who acted quickly tended to attribute their initial symptoms to a heart related problem regardless of eventual diagnosis. In some cases the respondents discussed the attributions they made initially, as in Bob, Jonathon and Marge's case. They all said they 'knew' their symptoms were heart related. Others implied that their attributions were heart related. Charlie implied that he 'knew' what pain in his left arm represented and George inferred that his 'crushing chest pain' was caused by his heart.

In those who waited none of the twenty one respondents attributed their initial symptom / symptoms to their heart. Although the majority of these respondents did talk of making an attribution for their initial symptoms, these attributions varied. Within the range of attributions provided by these respondents the most common was attributing chest pain to indigestion, this took place in the majority of accounts (ten). In comparing the accounts within this group in terms of eventual diagnosis more respondents with a cardiac cause attributed their initial symptoms to indigestion.

Attributing symptoms to a work or activity related cause was also evident. Although in this case it was more common among the respondents who received a non-cardiac diagnosis. Of the six respondents who spoke of attributing their symptoms in this way only one, Danny, received a cardiac diagnosis. Of the five remaining three attributed their symptoms to stress relating from work (all women), one initially to flu and then to a muscle strain and another to overexertion. Other attributions made varied from symptoms arising due to old age, a previous medical condition, medication or giving up smoking.

The types of knowledge used differed both between those who acted quickly and those who waited. In particular those who acted quickly and reported actual personal experience of heart disease; within this group of six respondents three had experienced some form of heart disease. For Bob it was a previous heart attack and for Marge and Charlie it was angina. Although Bob’s account suggests that his previous heart attack instilled in him a prototype of what a heart attack should be, when the symptoms of his second heart attack failed to match these there was the potential for confusion. Within those who waited no respondents spoke of having experienced heart disease themselves.

Of the other respondents who acted quickly George spoke of ‘knowing’ what certain symptoms represented because of a friends previous diagnosis of angina, whereas Jonathon had a family history of heart disease and this led him to have a greater awareness of his possible predisposition to heart disease. Both these examples of the knowledge used to help interpret symptoms are comparable with the respondents who waited.

In a number of the respondents who waited a knowledge gained as a result of a family history of heart disease was present, but this seemed to make little difference when they were initially interpreting their symptoms. Five of the respondents who later received a cardiac diagnosis spoke of close family members who either had heart disease or who had died as a result of it. In their accounts a number of these respondents commented on the fact that they ‘should’ have remembered their family history and therefore consulted sooner (Danny, Ray and Terry). This type of knowledge was also present in a similar number of respondents who waited and later received a non-cardiac diagnosis. Ella’s husband for example had died as a result of a heart attack, and Katy, Maureen and David all spoke of their fathers dying from heart attacks. Their accounts suggested that this was amongst the prompts for them to seek help.

Examples of knowledge from friends or a colleague with heart disease was also evident in those who waited. However, in this case only two respondents who later received a cardiac diagnosis spoke of knowledge obtained in this way (George and Malcolm). In comparing the accounts provided by the respondents the only difference between those who acted quickly or waited was actual experience of some form of heart disease in the past. Having a knowledge gained through personal experience of heart disease via family history or colleagues did not seem to result in a quicker response in the accounts; it seems this relationship was not straightforward.

As we have seen in sections 5.3.4 and 5.4.4 there appears to be no apparent differences between those who acted quickly in response to their symptoms and those who waited in terms of the role of significant others. In seventeen of the accounts provided by the respondents their spouse or partner was consulted at some point about their symptoms. In the other cases significant others were not consulted because the respondents were either widowed (two), single (two) or the respondents were married but did not discuss talking to their spouses about their symptoms (six).

When the significant other was consulted about their partners symptoms their responses were similar between the two groups. In those who acted quickly only two spoke of discussing their symptoms with their wives (Bob and Jonathon). In both cases it was evident from their accounts that their wives were influential, not in making the decision to seeking help, but in obtaining help. In Bob’s case his wife drove him to their GP’s and in Jonathon’s account he speaks of his wife influencing the speed with which he sought help.

Similar accounts are available in those respondents who waited and later received a cardiac diagnosis. Soon after discussing their symptoms with their wives both Danny and Colin were receiving treatments via an ambulance a result of their wives calling NHS 24. In the non-cardiac respondents the influence of their spouses once they were consulted was also evident. When Rhona and David talked to their spouses about their symptoms Rhona describes her husband ‘bullying’ her to the GP, whereas David described it as ‘nagging’ him to the doctor.

5.6 Chapter summary

The objective of this chapter was to provide descriptions of experiences and response amongst a range of people who have had symptoms that might have been attributable to heart disease in order to select experiential data to be included in the content of an information resource. The data presented in this chapter suggests that interpreting and responding to symptoms that might have been attributable to heart disease can be problematic. Unless the person is aware of what their symptoms signify or the symptoms are of such intensity or severity to leave the person in little doubt that something serious is wrong the response to them is far from straightforward. The data presented in this chapter suggests that when respondents experienced symptoms they ‘knew’ to be due to heart disease or their symptoms were extremely painful they responded quickly. When this was not the case respondents waited. The point to draw here is the fact that symptoms attributable to heart disease may not always be painful they can and do present in a much milder form.

There were similar findings in terms of the attributions the respondents made. Where there was actual experience of a heart attack or angina the attributions made tended to reflect this experience leading to an attribution relating to heart disease and a decision to seek help quickly. In the respondents who waited a range of attributions were described. A possible reason this range was the type of symptoms the respondents experienced. The attribution of indigestion was often a result of mild chest pain or tightness in the chest. The conclusion to draw from the attributions the respondents made would be to increase the knowledge surrounding the types of symptoms attributable to heart disease and the varying ways they can present.

In terms of knowledge relating to heart disease the respondents with actual experience of heart disease, whether it was a heart attack or angina, could draw upon their experiential knowledge to make sense of their current symptoms. However, knowledge gained through the experience of a family member or friend could be problematic. It is debateable how influential this knowledge can be in helping interpret and respond to symptoms. When their current symptoms did not match the ‘illness prototypes’ some had for heart disease respondents may have dismissed or ignored their symptoms assigning to more benign causes. This situation was worrying especially in those respondents who waited before seeking help and later received a cardiac diagnosis. It seems the relationship between knowledge and response is not straightforward. The point to stress concerning knowledge would be to highlight that every heart attack is different and describe the various forms they can take.

Finally the data concerning the role of significant others in determining the response to symptoms and seeking help proved complex. When a respondent did talk to their spouse about their symptoms this interaction did not always lead to speedy consultation. Although in the majority of the respondent accounts where the spouse was informed about their husband's or wife's symptoms their response tended to result in a decision to seek medical help, generally via the GP. Perhaps the conclusion to draw from the role of significant others here is to highlight when the resource is distributed that the spouses' attention is drawn to the information contained within it.

Chapter 6 The production of the patient information resource: incorporating the experiential data with best practice guidelines

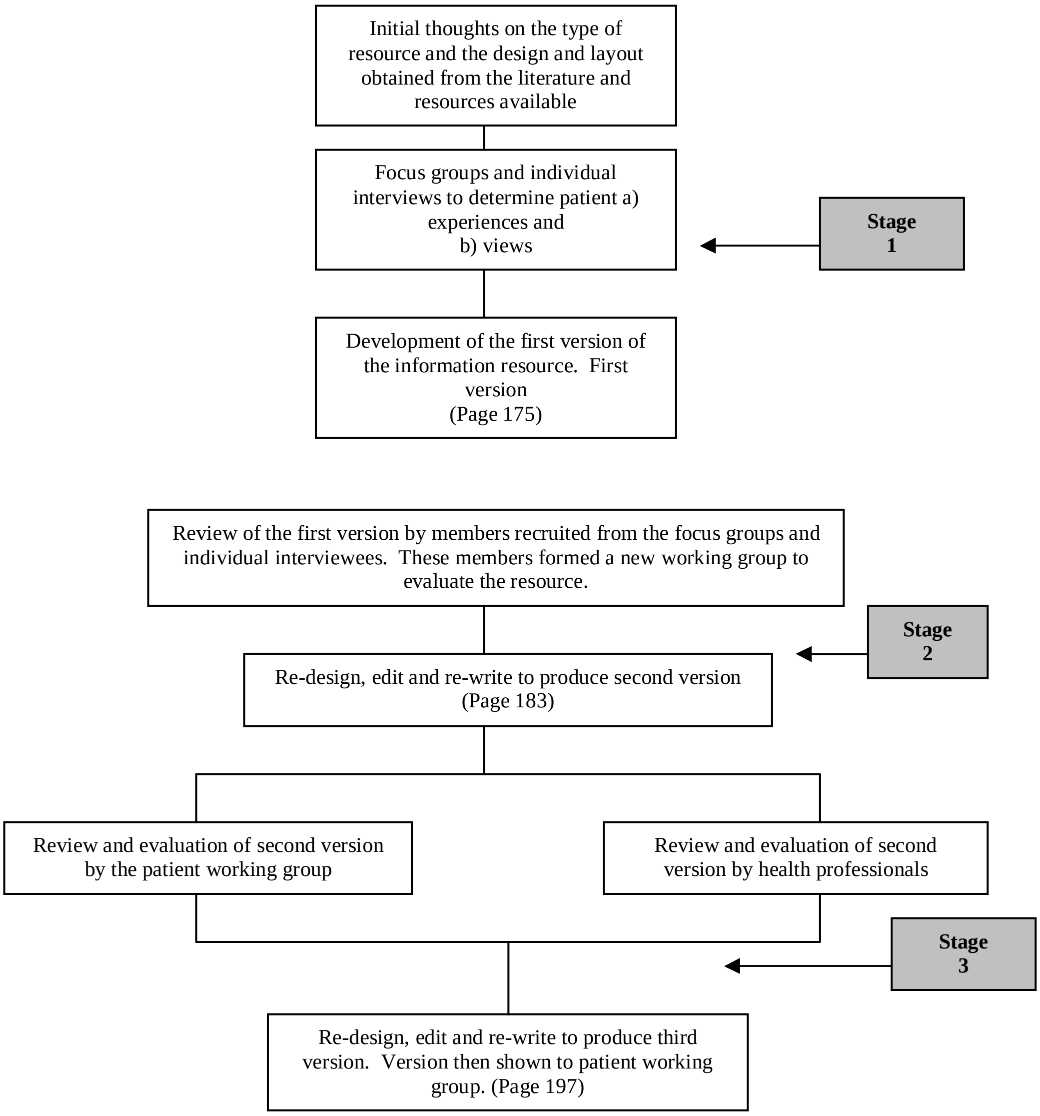
6.1 Introduction

The aim of the study was to produce a piloted draft information resource which aims to help people to respond effectively to symptoms that might be attributable to heart disease for people at high risk of heart disease. In consultation with the study's clinical advisors, and because no other information resource was specifically available for this group in this setting we decided to target the resource for use in primary care, to be given by primary care professionals to people at increased risk of coronary heart disease, such as those with diabetes, smokers, and people with high blood pressure. The resource was intended to:

1. Raise the salience of CHD within the "high risk" population so they were aware of dangers it represented and therefore provide a possible explanation should they encounter symptoms that may be attributable to CHD (that is offer alternative 'illness representations' (Leventhal et al, 1984) than those that might otherwise be available).
2. Raise knowledge and explain the range of symptoms that are attributable to heart disease within the general population, with particular emphasis on those symptoms more likely to be encountered by women, and
3. Explain when, how and from whom they should seek help if they experienced any of these symptoms.

The approach used to develop the resource was based on that of Kennedy et al (1999; 2003) in particular, to ensure that the development of the resource was based on best practice principles, patients were involved in all stages of development. There were 3 phases in the development of the resource and in this chapter I describe them ; in each section providing extracts of recorded discussions with respondents to illustrate how their views were incorporated, I also refer to the guidance on best practice in the production of information discussed previously in chapter 3. Phases of the development are summarised in figure 4.

Figure 4 Flow diagram to demonstrate the process of developing the information resource



(Developed from Kennedy et al, 1999)

6.2 Stage 1: The production of the first version

The type of medium used to present the information is clearly important (Walsh & Shaw, 2000). Walsh & Shaw (2000) suggest that different media have the potential to convey particular types of information more effectively than others. Thus in deciding which medium to use, the target audience needed to be considered, and how the resource would be distributed to them. Three media formats were ruled out immediately because it was felt that they were unsuitable: digital video recordings, CD-ROMs and booklets. Digital recordings and CD-ROMs were ruled out because of their equipment requirements; not all might have access to players and some might not watch them. Whilst booklets are an excellent method when there is a great deal of information about a particular subject that needs to be presented, in this instance it was felt a resource of such length would be unsuitable because it would not be read by the target audience. The danger in using such a format could be that it might exclude, confuse or overwhelm people with information, and in doing so fail to achieve its aim.

A number of factors played a role in reaching the decision to adopt a leaflet format. First, leaflets were attractive because they represented the most cost effective option. Second, they can be read almost anywhere, and people can flick through them quickly to consider the information they feel is important. Thirdly, they can be reused, and be revisited at a later date. Finally, they are small enough to allow sections of information to be found rapidly when required. Leaflets were also supported by the respondents in the first set of focus group discussions undertaken (see chapter 4). Specific questions in these discussions asked respondents to express their views of what they wanted an information resource about heart disease to include. Respondents had very clear ideas about what information they wanted to see and how it could be presented.

> *"It needs to be very simple, the basics. We should be educated, everybody should be educated to the dangers. But you don't need a book on heart attacks, you just want something laid out that you can easily read and inwardly digest".*
> *(Fred: at risk of heart disease)*

> *"I mean if it was something that was sort of leading up to a heart attack if there were mild symptoms contact your GP or whatever. But …if it's these ones (meaning more severe symptoms) then 999 or if you want to err on the side of safety any symptoms at all dial 999".*
> *(Steve: at risk of heart disease).*

> *"Leaflets, as I say, I saw were user friendly, you maybe get the wee ones that you just open up like that. They have got a wee diagram and a few pointers".*
> *(David: non-cardiac chest pain focus group No 4)*

> *"Maybe getting some leaflet saying 'well look you should know this' or 'here's a bit of advice for you' that kind of thing".*
> *(Maureen: non-cardiac chest pain focus group No 1)*

> *"Sometimes you get pages and pages and really you just want something basic to get you in the right direction".*
> *(Issy: non-cardiac chest pain focus group No 4)*

> *"Maybe if it was sort of leaflet that could be issued to everybody at risk".*
> *(Steve: at risk of heart disease)*

Using the leaflet format also meant the information could be taken home to allow family members to become familiar with it. This is particulariy important in cases where the person experiencing symptoms is uncertain about what is happening to them and they consult their spouse/partner. As we know from Alonzo (1986), family members and significant others can be important in prompting health action or indeed, delaying possible action. If their spouse/partner is aware of the signs and symptoms of heart disease and the action to take when they are experienced they may well take that action and call for assistance sooner (Dracup et al, 1995).

It was also felt that primary care professionals could most easily provide and discuss a leaflet in the midst of a consultation. That this was a good way to reach the target audience with the resource was reinforced by the views of the respondents, as illustrated below.

> *"I think you should be able to get it on request when they know you have already got outstanding problems with your heart, or to do with your heart. When you are visiting the doctor they should be able to give you it on request or just offer you it because they have seen the history, you going through it, you know what I mean? ".*
> *(Mo: at risk of developing heart disease).*

> *"I think that if they (GP's) find out you have got something wrong with you information should be given to you. It shouldn't always have to be the patient that is asking for this information because sometimes they don't ask".*
> *(Jen: at risk of deloping heart disease).*

> *"Like your GP he could be specific to what you had and he would just give you that leaflet, that small leaflet for you to read".*
> *(Henry: non-cardiac chest pain focus group No 4)*

The layout and content of the first version was based on a combination of factual content and views of the respondents. This produced a foundation from which subsequent versions would develop. The factual content was based on best clinical guidelines (Fox, 2005) and evidence from the medical literature (Herren & Mackway-Jones, 2001) and other existing resources (BHF, 2008). Information included in the content ranged from the common or 'classic' symptoms as well as more unusual, or less common, symptoms of heart attacks, and the treatment options available after a heart attack. Perhaps the most important information obtained from the literature concerned the action that should be taken on encountering symptoms and the need for such action to be prompt (BHF, 2008).

6.2.1 Presenting the information

Chapter 3 detailed the importance of the text used and the complexity of the layout of the leaflet in determining how legible the resource is (Walsh & Shaw, 2000). These factors were also important to the respondents. When asked what was important in the way information was presented, respondents reinforced their desire for clear messages:

> *"Consise aye. Concise, clear and easy to understand".*
> *(May: non-cardiac chest pain)*
>
> *"Not only do we need more information, but we need information that we understand. Because some information that I have seen is not clear enough for people like me to understand"*
> *(Jen: at risk of heart disease)*
>
> *"The plain facts, no going around the bush to it, hit people with it. Plain and simple".*
> *(Henry: non-cardiac chest pain focus group No 4)*

These extracts are interesting in the words used to describe what they think is important. Expressions such as 'easy to understand', 'not clear enough' and 'plain and simple' highlight a common problem with patient information; it is not easy to understand. Producing information which is both informative and straight forward is a difficult task. The challenge is to present information at a level of complexity that informs without losing all meaning and sounding childish. It was important that the information was presented in the leaflet in a clear and logical manner and written in terms that could be easily understood. It was also evident that medical terminology should be avioded where ever possible. This requirement was raised in focus group discussions:

> *"See reading something that goes into big words to describe…something…you just lose interest or I do anyway".*

> *(David: non-cardiac chest pain)*

> *"Making it more simple. I think the individual person that has heart problems they need to know what to do and what the cause and all the rest of it. And if a message could get across to them, so they would know what to do".*
> *(Anne: at risk of heart disease).*

In the past it seemed many people had been provided with information which they found hard to understand. The attitude towards presentation of the information expressed in the above extracts was based on past experience of reading or having encountered problems with information as a result of other experiences. As a result some respondents believed that sometimes information is targeted at patients who already have a knowledge or an understanding of the problem. Jen provides an example of her past experience of reading patient information resources aimed at people with heart disease.

> *"Probably clearer information, because some information that I have seen on heart disease, not just heart disease other things as well, it's not clear enough for people like us to understand. It's not put down in lay terms you know…..not only do we need more information, but we need information that we understand because we are not medically trained. We are patients".*
> *(Jen: at risk of heart disease).*

Presenting information in a clear and concise manner by using bullet points was a popular form of presentation with respondents. In the next extract May highlights one of the benefits of using bullet points to convey information in a condensed format:

> *May: "Your points, straight to the point telling you rather than have paragraphs".*

> *AW: "You don't want lots of text?".*

> *May: "No. Because people will not take time to read it".*
> *(May: at risk of heart disease)*

Others were also clear as to how the information should be presented, as demonstrated in the following exchange between two respondents dicussing the benefits of bold lettering within a bullet point format:

> *Anne: "Aye the symptoms I would do in bold one after the other. But I would do that in bold because it would really draw your attention to the symptoms".*
>
> *Jen: "I don't think there is any other format that would bring it up better than that. This is clearer".*
>
> *Anne: "It is clearer. Put in bold. And then its really catching your attention every symptom and you can have a quick look at it and you think well OK then fair enough. I will either leave it for a minute or two and see how I feel or I am just going to lift the phone now".*
> *(Focus group with people at risk of heart disease)*

Although the majority of respondents felt comfortable with a bullet point format to present information in the resource, others were more sceptical. Ray had concerns about using a bullet point method to convey all the symptoms potentially attributable to a heart attack. From his experience of cardiac related chest pain, Ray knew that recognising the symptoms was not always a simple task. In the following extract he conveys his doubt about the ability of a list of symptoms to do the job:

> *"And the pain and the symptoms side are very important, but I would find very difficult to put over, very difficult. I am not sure how I would do that, I do not know. And I think it's…to a large extent because the symptoms are so varied, and so many degrees of severity of symptoms if you like, I think it's very difficult to get that across, to get people to recognise it".*
> *(Ray: had cardiac chest pain)*

One way to overcome this difficultly in getting people to recognise the significance of the symptoms attributable to heart disease was to make them seem more germane. The method chosen to achieve this was to utilize some of the patient experiences obtained during the focus groups and interviews.

6.2.2 Selecting the format

Providing the textual information in a manner which helps the reader understand what was being communicated is a prime aim of any patient information resource in order to get its messages across. One way this is achieved is to ensure the information can be read easily. Both the format of the information and the particular way it is used have to be considered. For example, highly compacted text which fills most of a page can look daunting, and will deter many people from reading it.

One suggestion as to how to improve the quality of patient information resources has been the modification of the page layout to highlight significant areas. From the information obtained from the focus groups, interviews and recommendations in the literature I decided that the information resource should be printed on both sides of a single sheet of A4 paper. From this starting point a number of layout designs were considered before the final design was chosen. These can be seen in appendix 8.

Chapter three showed that short sentences, of no more than fifteen to twenty words long, in small blocks of text, with white space between blocks of text to make the information easier to read work best (Walsh & Shaw, 2000). Thus in the initial version generous margins were used together with a reasonably large font size (usually not less than 12 point). The exception to such formats were when pictures or illustrations were used, which a number of respondents said they thought was a good method of presenting the information.

Both portrait and landscape orientations were considered. It was found that the amount of information that could be included by using coloums of text together with pictures or illustrations in a landscape orientation was the most appropriate. This format allowed for a number of columns on both sides of the page, giving the option of allowing the page to be folded in on itself, “concertina” style. The use of columns on both sides of the resource meant there was consistency in the layout. Separation between the columns had to be adequate and the layout had to achieve the objective of linking the textual elements with the pictures and headings.

The use of columns also had the advantage of giving an even textual structure to the leaflet, thus helping the reader by allowing the eye to link words together better by using unjustified text and therefore making it easy to read. The leaflet also used unjustified centrally aligned margins throughout the layout for areas of text. For sequential information however, bullet points were used. The respondents liked the idea of presenting information in this way, as illustrated by Jen’s response:

> *AW: “Would you prefer checklists?”*
>
> *“Yeah I think so. Checklists are great, they are absolutely fantastic because I mean you will sit there and you will read it and you will go aye, aye, aye, and then ….you will look back and you will say ‘oh wait a minute! That’s just not quite right I have got a lot of them (symptoms on the checklist) and I am going to see somebody’.*
> *(Jen: at risk of heart disease).*

6.2.3 Developing the content: using experiential evidence

As I have said the involvement of patients in the development of the resource was central in ensuring the focus was patient-centred. When asked what they thought should be included in the resource the respondents were clear that specific symptoms were a priority. Chest pain was seen, not surprisingly, as the symptom that should be most prominent, as demonstrated in the following extract from respondents who were at risk of developing heart disease:

> *May: "Well that would be chest pain, dreadful pain in the chest".*
>
> *June: "Its chest pain, terrible chest pain".*
>
> *May: "Chest pains of course aye chest pains".*
>
> *Steve: "I think it's everybody's perception that if you get a severe chest pain it's a possible heart attack. It's sort of part of folk lore now isn't it?"*
> *(Focus group with people at risk of heart disease)*

Although the majority of the participants in the high-risk group knew that chest pain was associated with heart disease, when asked if they were aware of any other symptoms attributable to this disease, some respondents were aware of a broader range of symptoms that can be associated with heart disease, as illustrated by Jen:

> *"The pain starts in your chest, radiates down your arms, pins and needles, up into your jaw, sometimes the side of your face.*
>
> *"To me the pain (chest pain) I would say would be enough if this doesn't go away within about half an hour, you're a kind of iffy colour, you are cold but you are clammy to touch then I would just be hitting the panic button".*
> *(Jen: at risk of heart disease)*

Other respondents who had first hand knowledge of heart disease felt it was important to highlight other symptoms that can be encountered. In the following extract David gives a succinct description of the symptoms he felt should be included and how they should be presented:

> *"like pains in your chest, pains down the arm, heaviness in your chest, then maybe that would warn you of the signs".*
> *(David: non-cardiac chest pain focus group No4)*

The use of patients' own words when communicating information is now employed in many contexts. This method has been seen as beneficial in terms of helping others to understand and allow meaning to be constructed around illness. Extracts from patient accounts are able to achieve this because they can be memorable, they are by their nature grounded in personal experience and they can enforce reflection (Kennedy et al, 1999; Swift & Dieppe, 2005). In using patient accounts the information being presented can become personalised, enabling the reader to empathise with the account and in doing so make it seem more realistic. What these accounts can represent are a unique insight into the patient experience of a particular disease, disorder or disability.

Kennedy and Rogers (2002) decided to incorporate patients' own illness experiences in the production of a self care guidebook for people with a chronic condition (ulcerative colitis). Using accounts from patients to guide the development of patient information was in contrast to the normal method of producing such information, as Kennedy et al (2003) explain:

> *"Most medical information … tends to reflect what clinicians want patients to be told or what they think patients may want to know".*
> *(Kennedy at al 2003, pp304)*

They suggest the use of patient involvement in the development of information provides a different perspective that complements medically orientated evidence and reflects people's real life everyday experience of illness. These authors also suggest that, by incorporating patient accounts into an information resource, it reflects the priority this information has and is likely to empower the reader and encourage them to become more active managers of their condition (Kennedy et al, 2003).

A number of respondents thought the use of real patients' accounts could play an important role in conveying information about the symptoms which could potentailly be attributable to a heart attack. In the following extract Katy describes how she thought using a patient's account might help others realise the seriousness of their situation:

> *"Taking them through a case study of someone who had done that, and realised if they hadn't acted quickly they would have been dead before they got to hospital".*
> *(Katy: non-cardiac chest pain individual interview)*

The concept of using an account of someone's experience and converting it into a story is nothing new. In most areas of life we are intrigued when we read about the lives of others. This is most evident in the number of 'human interest' stories which abound in various media sources. As Katy's extract suggests, evidence collected during the focus groups and individual interviews revealed that the respondents had a positive attitude to the use of illness accounts in the information resource. The reasons why the respondents indicated they would like to see more accounts used included the opportunity to highlight their own experience for the benefit of others. One respondent, Sarah, was surprised by the symptoms she experienced during the onset of her heart attack and the lack of information available about them. In the following extract she explains that women should be made aware that they may not experience ‘classic’ symptoms when having a heart attack:

> *Sarah: “Well actually as I say I just did not realise it was a heart attacks. I had no idea. But according to my GP 90% of women get this sensation up their throat rather than their arm”.*
>
> *John: “Is that right?”*
>
> *Sarah: Yeah. Seemingly it was with women, they get this sensation in their throat. And…she went absolutely off her head at me because I phoned the surgery, waited until the surgery opened at half past eight. So…I had no idea, I seriously didn’t realise the severity of it.*
>
> *Mary: “I have never heard of that ever”.*
>
> *Sarah: “Well until the GP said to me, I had always assumed a heart attack was a pain in the arm. She said no 90% of women it’s up the throat and along the jaw”.*
>
> *Mary: “So they must know straightaway”.*
>
> *Jack: “90%.*
>
> *Sarah: “Yeah 90% of women, which is strange I don’t understand why a man gets a pain in the arm and a woman, gets it in her throat. It doesn’t make sense”.*
> *(cardiac chest focus group No 6)*

Ray provides an example of how his own experience of heart disease could be used to convey the seriousness of even the slightest chest pain symptoms. Ray initally attributed his chest pain symptoms to indigestion when really his pains were indicating the onset of a heart attack. As a result Ray suggested the following advice:

> *“If you have got any kind of symptom at all which could in the slightest sense be interpreted as a heart problem check it out immediately”.*
> *(Ray: cardiac chest pain individual interview)*

The use of actual accounts could also be used as a source of information and advice. It is the action that needs to be taken when symptoms are encountered that some respondents considered was the most important advice their experience could provide. Bob's account provides what he thought was sound advice, based on his two previous heart attacks:

> *"It's knowing that the first thing you should do is phone for an ambulance to get you to the nearest hospital. And knowing that only hospitals can deal with problems like this (heart attacks)".*
> *(Bob: cardiac chest pain individual interview)*

Patient accounts could also be used in information resources to identify areas where information is poor. A number of respondents had examples where poor information directly affected their experience and the consequent action they took. They also highlighted the dangers of conflicting information, which can be particulary disconcerting. In these instances the person can be left wondering which one to believe or worse do nothing and ignore them all. The following accounts describe what two respondents who had experienced heart attacks thought in relation to this issue:

> *"Well the first thing is that the traditional…to me anyway, the traditional thoughts in people's heads of what a heart attack is, is a crack! A pain. Well it doesn't seem to be like that. Maybe that is a message that needs to be got across that you know it's far more innocuous and I think that point is excellent".*
> *(Charlie: cardiac chest pain focus group No 5)*
>
> *"I think the traditional ideas are obviously wrong and perhaps something has got to be done to change that".*
> *(Ray: cardiac chest pain individual interview)*

6.2.4 The use of pictures and illustrations in patient information

The use of pictures and illustrations was something a number of respondents considered important. This is in line with evidence within the literature (Houts et al, 2006). As stated in chapter four pictures and illustrations that relate directly to the surrounding text have been found to facilitate learning and are helpful in providing cues and direction, maintaining interest and illustrating important points, providing that any image used adds to the content rather than merely looks attractive (Houts et al, 2006). The following exchange between two respondents demonstrates their thoughts on this:

> *Anne: "I think pictures are a good idea.*
>
> *Jen: (Jen interupts)"I think pictures along with clear information I think is a fantastic idea put into layman's terms".*
> *(Focus group with people at risk of heart disease).*

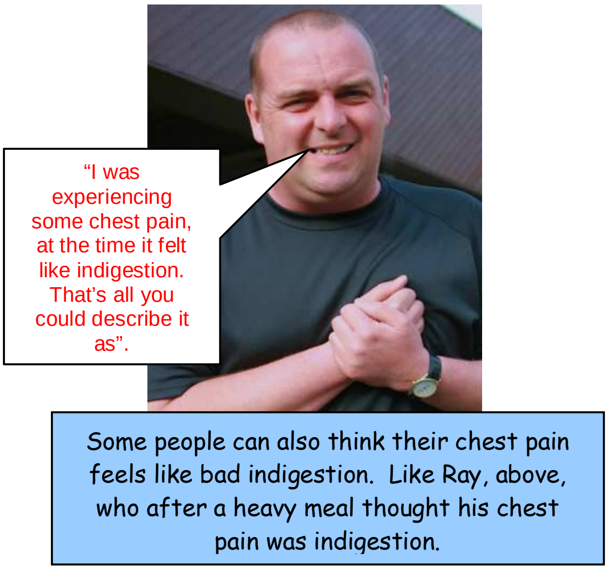
When using pictures and illustrations it is important that the image used is not based on the subjective feelings of the designer but rather the educational needs of the patients. Using the simplest pictures possible is also important, although the pictures should be culturally relevant to the audience. It was decided to use images that most resembled the intended target audience for the resource, and to use actual pictures and not illustrations to reinforce the realistic nature of the respondents' accounts (Houts et al, 2006).

The use of realistic pictures can help viewers, especially those with low literacy skills, to understand the intended message without being distracted by irrelevant details. David, for example, describes his thoughts on the use of images and then goes on to provide an example of how he would use such a combination:

> *"It could actually be a wee picture that gets your attention, and it's got all the wee signs around the side of it (he is talking about the symptoms of heart disease), something like that. Well if you had a picture for instance of a man standing or sitting and mentioning the pain and where it is, the symptoms next to the picture that kind of idea"*
> *(David: non-cardiac chest pain focus group No 4)*

It is important that any image is interpreted correctly by the reader. The use of captions that describe what is going on is one way this can be achieved. The text that accompanies the picture usually guides our interpretation. An example of how captions were used to illustrate actual symptom experience can be seen below in figure 5.

Figure 5 The use of captions to illustrate the symptom experience



It was envisaged that each specific symptom experience included in the resource would be a combination of a textual description, a picture and an actual account within a caption. In the resource, this combination would be used to communicate the different types of symptoms people may encounter when having a heart attack. It was hoped that by providing a range of examples people would be able to understand that many symptoms can be attributable to a heart attack.

Here, extracts of respondents' own experiences were combined with the best practice guidelines on the production of written patient information and the management of chest pain to produce the initial version of the resource which can be seen in figure 6 (full size appendix 9).

Figure 6 First version of the information resourse

Front.

Think about chest pain

The common or classic symptoms of a heart attack include:

- Central chest pain (a pain in the centre of the chest).
- The pain can spread to the arms, neck or jaw.
- Some people can feel sick or sweaty as well as having central chest pain.
- Some people can feel short of breath as well as having central chest pain.

While women can experience the classic symptoms they often experience less common heart attack symptoms than men, such as:

- A dull pain, ache, or 'heavy' feeling in the chest .
- A mild discomfort in the chest that makes you feel generally unwell.
- The pain in the chest can spread to the back or stomach.
- Some people say that the chest pain feels like a bad episode of indigestion.
- Some people can feel a bit light-headed or dizzy as well as having chest pain.

Andy had the classic symptom of central chest pain

Andy: "I knew what the pain was, it was dam sore. And it was right across right across there. A vice aye! Aye aye and I felt as thought this was all going to come in I had visions of it collapsing altogether".

Bob had pains that spread into his shoulders and then his arms

Bob: "The second time was a funny sensation, um… I would have said my shoulders…it went right down my arms, I felt I couldn't have done anything with them".

Sandra had pain in her neck that spread to her jaw

Sandra: "It was. It was…it was like a burning sensation coming straight up my throat but it was actually a severe pain right along the bottom of my jaw bone and it was actually…you know the way when you have got a severe tooth ache?".

Ted had chest pain which was very severe

Ted: "It was as if somebody had stuck a knife right into me that's how I felt. But I definitely remember it was right in the middle as if somebody had stuck a knife in me".

Sarah felt a tightness in her chest

Sarah: "I was just getting ready to go to work and getting the kids ready for school. And I took a strange tight…really severe tightness in my chest, I wouldn't say it was very painful, it was just a severe tightness"

Ella felt a discomfort in her chest

Ella: "Now I had that same sort of thing, it's just not a pain it's just heaviness just here you know, like somebody is weighing a brick or something on top…"

Rear

What to look out for

The symptoms of a heart attack vary slightly from one person to another.

They range from a severe pain in the centre of the chest, to having mild chest discomfort that makes you feel generally unwell.

The pain often feels like a heaviness or tightness which may also spread to the arms, neck, jaw, back or stomach.

Or it may affect only the neck, jaw, arms or stomach. You may also sweat, feel light-headed, feel sick, or be short of breath.

Symptoms can be very mild and produce little discomfort. In some cases people mistake the pain of a heart attack for indigestion and may never report it to their doctor.

If you experience any of these symptoms, don't ignore them. Call 999 immediately.

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Why act immediately?

If you suspect that you are having a heart attack, call 999 immediately.

Your heart needs a constant supply of oxygen-containing blood to keep it healthy and a heart attack happens when a blood clot in an artery interrupts that blood supply.

Calling an ambulance immediately means that, if you need it, you can get a clot-busting drug within minutes of experiencing pain.

In some parts of the country, the paramedics (ambulance staff) may give you the drugs before you reach the hospital, as the sooner you get it the better.

Clot-busting drugs can restore the blood supply to your heart muscle and drastically increase your chances of survival and limit the long term damage to your heart muscle.

There are many reasons why people delay calling - uncertainty about the symptoms, not wishing to make a fuss or refusing to believe that it could be happening to them.

Calling for an ambulance is your only choice.

Marge: "I felt sometimes like it was taking a somersault, I thought it was going to burst through the wall of my chest, it's the strangest thing, it was really"

Craig: "Right er, well I had my first heart attack in 1999 er I was in the bookies! And er standing with my pal and I felt a pain across the chest, and my pal says you are not looking very well you are a terrible colour; you are a right grey colour. I said I have got a pain in my chest and then I felt the pain in the arm".

Marie: "No. It wasn't like a headache that you would get here, or at the side it was a…it was like a kind of pressure. Like a tight feeling going up your head and into you're…up your neck and into your head".

6.3 Stage 2: The production of the second version

Although the production of the first version of the resource was undertaken using best practice guidelines and incorporating the experiences of people who had suffered from heart disease, it was designed by myself. Comments from respondents in stage 2 of the data collection were the impetus for the development of the second draft. This part of the development process was again informed by the recommendations from the Centre for Health Information Quality (1997). Generally the first version of the resource was not well received, although respondents were enthusiastic towards some aspects of the resource there were other aspects the respondents thought required change or a complete re-design.

Some respondents thought the appearance of the leaflet needed to change, because they found the general appearance off-putting and uninteresting. The first version of the leaflet was designed so that the front cover presented two blocks of information relating to the common or ‘classic’ symptoms of heart attacks and the symptoms women may experience. These two blocks of text proved to be unappealing, as did the drab colour scheme. David’s thoughts on the front cover were typical of many respondents:

> *“I think this, the front cover is fairly drab and non descript”.*
> *(David: cardiac chest pain)*

The combination of a front cover composed of just text with a drab colour scheme was seen as unattractive. As Jonathon explains, the front cover of the first version would be the first view people had of the resource:

> *“You see I think people would be unlikely to go and pick out that leaflet”*
> *(Jonathon: non-cardiac chest pain)*

The use of the front cover to convey nothing but information was seen as limiting the appeal of the resource. There was nothing to catch the eye of the potential reader, nothing to engage them or spark their interest. The colour scheme also posed other problems. For Frances the use of a flesh coloured background to the text made reading difficult, as she explains:

> *I have difficulty with the colours and I would have to sort of move around so I could read that”.*
> *(Frances: at risk of heart disease)*

It was clear from these comments that the design of the front cover and the colour scheme used throughout would have to be reconsidered. The front cover needed less information and to have more impact to make it more attractive to the potential reader.

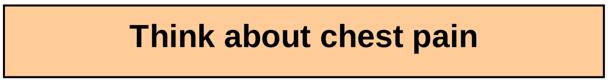
In order to address these issues, information on the types of colour schemes and text combinations that had sucessfully been used in the past was considered. The second version was redesigned using a light blue background and black text to make it easier to read. This combination was used within the same three block layout as the first version, again with each block was separated by a thin white vertical line.

The comments on the cover of the first version also suggested the inclusion of graphic elements would create more impact. A number of options were considered. A range of men and women all experiencing chest pain in different situations was used in various mock-ups. However, one image stood out above all others and seemed to be most suitable. It had the impact needed to attract attention and it would leave the potential reader in no doubt about the purpose of the leaflet. The chosen image was of a man experiencing chest pain (see figure 7).

Figure 7 Man experiencing chest pain

More thought also needed to be given to title on the front cover. In the first version, I did not give sufficient consideration to the influence of the title. The title, ‘think about chest pain’ was placed at the top of the front cover in the format shown in figure 8.

Figure 8 Title banner in the first version



Think about chest pain

I thought that the combination of the image in figure 5 and this title would not be optimal. I thus decided an image would form the major part of the front cover and would be framed, top and bottom, by title banners. These banners were comprised of a block of colour different from the background with contrasting text to stand out. The titles within the banners were used to introduce the leaflet. At the top, the title read ‘Thinking about chest pain?’ and at the bottom ‘To be able to reduce your risk’. An example of the title used at the top is shown in figure 9.

Figure 9 Title banner of the second version

Thinking about
Chest Pain?

A second area that needed to be re-designed was the layout of the leaflet, although the three block format was retained. The double-sided A4 landscape design was retained because it was the only way the concertina format could be used. Despite careful consideration of the number of paragraphs, the length of sentences, sentence structure and the type of words used during the planning stage of the first version the respondents felt that too much information was presented in the first version. Two extracts from the high risk group illustrate how many felt:

> *"I thought there was too much information on it, I think it's too busy"*
> *(Freda: at risk of heart disease)*
>
> *"You could have condensed into a few lines. People will get bored reading it, that's the whole point. I don't want to look at that, it's too much".*
> *(Syd: at risk of heart disease)*

Therefore the amount of information had to be reduced in the second version, and the amount of textual information presented on the two panels on the back of the leaflet needed to be revised. In the next version this information needed to be conveyed in a more concise way. In the second version the layout was changed and the information was broken down into much smaller sections and distributed throughout the leaflet. The respodents responded positively to the changes made as demonstrated in the following discussion:

> *Terry: "I think the balance on this one is probably about right actually. If you…if you have had an impact from this leaflet then I think you would be prepared to digest what's in the leaflet".*
>
> *Charlie: "I think that's right. I don't think that's at all off putting".*
>
> *Terry: "I mean opening it and seeing the case studies I mean I think that's…yeah no I don't think there is too much there"*
> *(Stage two focus group with groups A & B).*

Two examples of how this was achieved concerned the information originally presented on the front cover of the first version. This information described the 'classic' symptoms of a heart attack and the symptoms women may experience. In the second version the layout was changed to incorporate information on the 'classic' symptoms and two personal accounts of chest pain together with a description of how the pain can range in severity. The information about the symptoms women may encounter was similarily presented under two examples of women experiencing these kinds of symptoms.

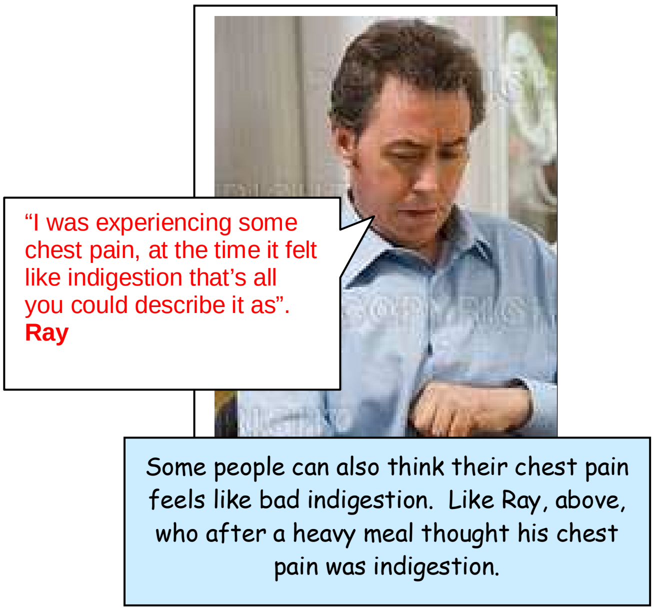
The use of personal accounts or experiences was another area where the layout was changed. In general the respondents liked the idea of using a person's own story to convey information about how they experienced their symptoms. However, a number of respondents comented that the first version had too much of this information, this may have led to a number of respondents feeling overwhelmed.

In the second version the number of personal accounts was reduced from nine to seven. The way the accounts were presented also changed. It was clear that the respondents liked the way the information concerning the patient experience was presented. The combination of an image, a description of the symptom and a personal account appealed to respondents.

> *"I think you have given examples of people and a short description of the different types of symptoms and what can happen and this will hold people's interest".*
> *(Syd: at risk of heart disease)*
>
> *"I like the idea of case histories if you like, I think that's good. I think people will relate to that. It does strike me though looking at that (first version) how effective it is".*
> *(Charlie: cardiac chest pain)*
>
> *"I like the way it's presented. I think it's a good way of doing it. People can see the experiences, that lady has got tightness and that chap has got pains in his shoulders. I think it grabs you. I like it".*
> *(Marge: cardiac chest pain)*

This positive response encouraged me to retain this style of presentation in the second version. However, the reduction to seven examples meant that the combination of image, account and description needed to be re-designed to give the examples more impact. This was achieved by using more illustrative images to accompany the account and description. In the first version a simple picture of an individual accompanied the textual information. In the second version images that conveyed the actual experience were used to highlight the symptom experience. An example of how this was achieved is shown in figure 10 describing how chest pain could be confused with indigestion.

Figure 10 An example of the combination used in the second version



"I was experiencing some chest pain, at the time it felt like indigestion that's all you could describe it as". **Ray**

Some people can also think their chest pain feels like bad indigestion. Like Ray, above, who after a heavy meal thought his chest pain was indigestion.

Another development in the second version was the use of banners to help the reader navigate the resource. In the first version bold headings were used to guide the reader to the different sections or areas of importance. However, the use of bold headings within text boxes that used the same background colour as the rest of the leaflet was not effective; it was felt these did not stand out and clearly indicate where the different information was. In the second version a number of combinations were considered to achieve the right impact, within the design layout and colour scheme. An example of the type of banner used is shown in figure 9.

May gave her thoughts on the second version's new layout in the following extract:

> *"I think that it's balanced between the pictures and text and I think the banners stand out, as I said before I think it's got impact. I think it's good".*
> *(May: non-cardiac chest pain)*

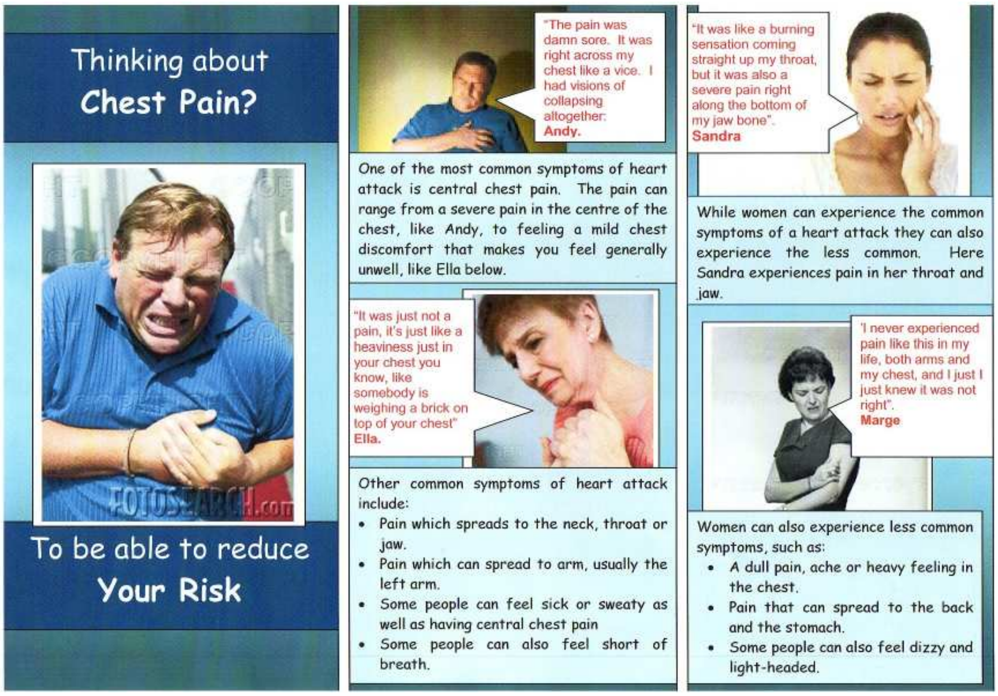
The banners allowed certain information to be highlighted within the leaflet, which respondents found useful. In describing how she found it beneficial, one respondent used a comparison which she had first noticed while shopping.

> *"If you go into a shop and they have have a special offer, it's usually in pretty bold lettering and it catches your attention so you will have a look at it. Well this would be much the same. I mean you need something to catch somebody's attention".*
> *(Frances: at risk of heart disease)*

Changes were also needed in the way in which the information was presented on the rear panel. These resulted in more emphasis on seeking immediate care, which in turn reduced the amount of text. In the second version 50% fewer words were used to communicate the information. The need to call 999 immediately if it is suspected that an individual is having a heart attack had greater emphasis. Although the emphasis in the second version had changed from information on 'clot-busting' drugs to seeking immediate care, a small section on the importance of these drugs was retained. A section highlighting reasons that people have delayed in the past was also included. Finally, the need to call for an ambulance via the 999 system was presented again, this time in a larger font and in bold lettering to give it more impact. The second version of the information leaflet is shown in figure 11 (full size appendix 10). This version was tested in the next stage of the development process.

Figure 11 Second version of the information resourse

Front



Thinking about
Chest Pain?

To be able to reduce
Your Risk

"The pain was damn sore. It was right across my chest like a vice. I had visions of collapsing altogether.
Andy.

One of the most common symptoms of heart attack is central chest pain. The pain can range from a severe pain in the centre of the chest, like Andy, to feeling a mild chest discomfort that makes you feel generally unwell, like Ella below.

"It was just not a pain, it's just like a heaviness just in your chest you know, like somebody is weighing a brick on top of your chest"
Ella.

Other common symptoms of heart attack include:

- Pain which spreads to the neck, throat or jaw.
- Pain which can spread to arm, usually the left arm.
- Some people can feel sick or sweaty as well as having central chest pain
- Some people can also feel short of breath.

"It was like a burning sensation coming straight up my throat, but it was also a severe pain right along the bottom of my jaw bone".
Sandra

While women can experience the common symptoms of a heart attack they can also experience the less common. Here Sandra experiences pain in her throat and jaw.

'I never experienced pain like this in my life, both arms and my chest, and I just I just knew it was not right".
Marge

Women can also experience less common symptoms, such as:

- A dull pain, ache or heavy feeling in the chest.
- Pain that can spread to the back and the stomach.
- Some people can also feel dizzy and light-headed.

Rear

"The pain was like a muscular felling around my shoulder and around my heart".
Katy

Like Katy above it is important to understand that other symptoms or pains can be present along with chest pain.

"I was experiencing some chest pain, at the time it felt like indigestion that's all you could describe it as".
Ray

Some people can also think their chest pain feels like bad indigestion. Like Ray, above, who after a heavy meal thought his chest pain was indigestion.

"I didn't have the tightness then it was just breathlessness. And I was just assuming that it was my asthma that was playing up but it turned out not to be". **Sarah**

It also important to realise that some people can confuse their chest pain with some other cause. Like Sarah, above, who thinks her breathlessness is due to her asthma, when in fact it was a symptom of a heart attack.

What to look out for

The symptoms of heart attack vary slightly from one person to another.

They range from severe pain in the centre of the chest, to mild chest discomfort making you feel unwell.

The pain can often feel like a heaviness or tightness which may spread to the arms, neck, jaw, back or stomach.

If you experience any of these symptoms don't ignore them.
Call 999 immediately

Why act immediately?

If you suspect that you are having a heart attack,
call 999 immediately.

Calling an ambulance immediately means that, if you need it, you can get a clot-busting drug within minutes of experiencing pain.

There are many reasons why people delay calling for help. Uncertainty about their symptoms, not wishing to make a fuss or refusing to believe that it could be something serious.

Calling for an ambulance is your only choice.

If you experience chest pain or any of the symptoms described here
Call 999 immediately

ALLIANCE for SELF CARE RESEARCH
"Enhancing self care"

6.4 Stage 3: The production of the third version

During this stage of the development process comments and views from respondents and health professionals were sought on the second version of the resource (figure 11).

Perhaps the most radical aspect of the re-design between version 1 & 2 concerned the front cover. The new combination of a graphic image with a new colour scheme had a postive impact on a number of the respondents. Two of the most favourable comments came from Frances and Freda, who both had difficulty making out the textual components of the first version.

> *"It maybe just my eyes but the black print on the blue is easier for me to read than the previous one (First version)".*
> *(Frances: at risk of heart disease)*
>
> *"That stands out. I can read that just looking at now".*
> *(Freda: at risk of heart disease)*

However, when asked their opinions of the image used on the front cover of the second version the respondents were divided as to how appropriate it was. Some respondents thought the image was appropriate and gave the resource the impact that it lacked in its previous form. This is demonstrated in the following extract:

> *"To me the immediate thing is the impact, that (the front cover) has far more impact than the first draft for me".*
> *(May: non-cardiac chest pain)*

Other positive comments concerned the impact the image had. A number of respondents described their thoughts on seeing the revised second version.

> *"I think the immediate impact is good. Anybody that's had chest pain or has been concerned about their heart would look at that and think 'I will just have a look at that' and pick it up".*
> *(Jonathon: non-cardiac chest pain)*
>
> *"I think it's got impact. It would certainly make me want to read if I had any thoughts at all about heart problems"*
> *(George: non-cardiac chest pain)*

For one respondent though the use of this image had a negative effect. Maureen's response to this image was one of fear, not a response that I wanted the resource to provoke. Maureen described her reaction on seeing the front cover as follows:

> *"It's a bit too scary. It's the last thing you are wanting to happen. I would start to panic immediately".*
> *(Maureen: non-cardiac chest pain)*

The use of this image was an example of using illustations or images based on the subjective feelings of the designer not the needs of the intended audience. I chose this picture because it portrayed an individual experiencing severe chest pain, and was dramatic and eye catching. Although some respondents liked the image a number of health professionals thought it was inappropriate. One health professional thought the image was wrong because of the reaction it could cause. Brendan, a GP, had similar thoughts to those of Maureen:

> *"Well I wondered about that. I wonder if it's going to cause anxiety."*
> *(Brendan: general practitioner)*

Brendan also felt that the setting and the context of this image was incorrect. He explained that, in his experience, people having a heart attack usually felt their symptoms building up gradually. He described that in the majority of cases he had dealt with there was not sudden or severe chest pain as illustrated on the front cover of the second version. His concerns about the image focused on the confusion the image could cause in the people who may see it.

> *"I would say, he's walking down the street, isn't he, which is not the way most MIs happen. Most MIs come on gradually;*

> *the feelings come on gradually, it builds up and lasts for a long time…*
>
> *There are people who have cardiac arrests in the street but these are less common. And probably that's not the idea that you want to get across".*
> *(Brendan: general practitioner)*

Danny, a paramedic, also thought the image and setting were wrong. Most people he and his colleagues attended to with heart attacks were in their own homes.

> *"I saw that picture I thought that straight away a very stereotypical MI. But ninety nine times out of a hundred they will be in a chair in the living room".*
> *(Danny: paramedic)*

Danny went further in commenting on the cover image used in relation to the leaflet as a whole. He thought the cover image was at odds with the message the leaflet was trying to convey.

> *"To me this is what you are trying to move away from (the front image). You are trying to say well yes everybody knows about that (the 'Hollywood' heart attack). But this is what really happens. That is what I am getting from you here, what you are trying to do. I think that would probably be sending out the wrong message (using that image).*
> *(Danny: paramedic)*

To try to gauge what the health professionals thought would be a good representation of a heart attack victim, I asked them to decsribe a common encounter with someone having a heart attack. Paul, a general practitioner, liked the use of an image depicting someone with chest pain, but also thought the image used in the second version was wrong. He described his thoughts on a possible solution:

> *"He is grasping his chest, I think he looks like someone that there would be no doubt that he would phone. So I wonder if a similar sort of pose and posture but maybe the face wasn't quite so severe. To denote that the symptoms were mild rather than severe*
> *(Paul: general practitioner)*

Danny suggested that the setting should be in someone's home, to better reflect the majority of heart attacks he attends:

> *"I would certainly have them in the home environment, they would probably be inside the house, and they would be sat down"*
> *(Danny; paramedic)*

The following extract from Brendan encapsulates why the image of the man walking down the street suddenly being overcome with severe chest pain was wrong and why it had to be changed:

> *"I think that's maybe the wrong image because of that (the man is walking down the street). I suppose the danger is that if they can't, if they don't have this sudden onset of pain and if they didn't clutch themselves and fall over they wouldn't think it was an MI. If that was the image that was in their head".*
> *(Brendan: general practitioner)*

In developing the leaflet to the next stage, the front cover needed a bold image depicting someone having a heart attack in a more realistic setting to be suitable and effective. An image of an older male in obvious discomfort rather that severe pain was suggested:

> *"I would consider the use of an image from an older male to emphasise the fact that a lot of older people are having heart attacks, because they are living longer. And in these people their symptoms may be less severe".*
> *(Steven: general practitioner)*

Hence, an image which addressed these concerns was chosen for the third version.

Another area of the front cover some health professionals were concerned about was the banners at the top (‘Thinking about chest pain’), and the bottom (‘To be able to reduce your risk’). The top banner of the leaflet expressed a clear message about the subject of the leaflet. However, the bottom message was thought to be less clear. Some health professionals felt this was the wrong message, and it was seen as ambiguous. One GP, Lisa, thought the terminology was wrong.

> *“What is it they are reducing their risk of? Is it having a heart attack, although I’m sure they’re more at risk to more than that”.*
> *(Lisa: general practitioner)*

Brendan also thought the language used was wrong. He thought the message was vague and the emphasis incorrect. He explained why this was the case and suggested an alternative heading to ensure the message was pertinent:

> *“What you maybe haven’t got is an emphasis on the fact that the earlier it’s treated the better the chances and that’s the reason for minimising the delay. You know every minute counts or something”.*
> *(Brendan: general practitioner)*

He then goes on to justify the use of such a message and its relevance for the whole leaflet:

> *“I would think that they can save their life, they can save their own life with earlier contact. Every minute counts. That’s maybe your front page message ‘every minute counts’. Because if you got that message across on the front then the rest becomes important, clinically important”*
> *(Brendan: general practitioner)*

In attempting to ensure that the front of the leaflet achieved a balance between clinical relevance and impact, the banners were changed in accordance with the suggestions of the health professionals. The top banner was changed to ‘Thinking about the symptoms of chest pain’ to emphasise the number of symptoms that may be encountered, not just chest pain. In the bottom banner the message was changed to ‘Because every minute counts’ to highlight the need to to make a decision to seek help quickly and to lay emphasis on the help that can be provided if prompt action is taken.

One area of criticism of the first version was the layout and the inclusion of too much information, and this concern was carefully considered when re-designing the leaflet. When asked their thoughts on the new layout and reduction in the amount of text in the leaflet, two respondents gave the following reactions:

> *“I don’t think you have cut this section down too much. Because sometimes too much information is frightening. I don’t think you have given too much information here”.*
> *(Frances: at risk of heart disease)*
>
> *“I don’t think there is too much information”.*
> *(Maureen: non-cardiac chest pain)*

Brendan also liked the way the second version was organised. He preferred the emphasis on the accounts provided by patients with the combination of description and narrative.

> *“I do like this layout with the people rather than the text”.*
> *(Brendan: general practitioner)*

Opinions on the revised layout of the accounts in the second version were generally positive. Respondents reacted constructively to the reduction in the number of accounts:

> *"I like the way there is space on it, it doesn't feel as if it's smacking you in the face, there is room to move around if you like. I think that comes across better on the second draft".*
> *(David: cardiac chest pain)*
>
> *"I think it's quite a good sort of balance of everything really that you have done with this one (second version) you know".*
> *(Maureen: non-cardiac chest pain)*
>
> *"I think the balance on this one (second version) is probably about right actually.*
> *(Marge: cardiac chest pain)*

The examples used in the second version also produced favourable responses. One positive outcome was the use of the indigestion and breathlessness examples. Although present in the original version they were expanded upon in the second version in which two personal accounts were accompanied by images that were very expressive. These examples appealed to certain respondents because they represented the subtle symptoms that can be experienced and highlighted the sometimes insidious nature of heart disease. This is explained by Freda:

> *"I think it's important to show variety because not everybody starts off bang! Feeling really ill. Some people just think they have eaten too much or I have annoyed my stomach. It does vary and it varies from people to people".*
> *(Freda: at risk of heart disease)*

Other respondents picked up on this theme. Tom, for example, thought the use of such images together with an actual experience emphasised the reality and in doing so gave the information more significance:

> *"To me I think that it makes it even more powerful that these examples are real people with real symptoms".*
> *(Tom: cardiac chest pain)*

Using realistic images in order to make the accounts seem more convincing was highlighted by others. May, for example, thought the use of images from different age groups was important in providing even more realism:

> *"You have got different ages which is quite good. The second draft has got a better range of people than the first".*
> *(May: non-cardiac chest pain)*

The health professionals were also positive about the use of personal accounts together with a realistic image that were used in the second version. Brendan and Paul gave their opinions on presenting the information using this combination:

> *"Well I think it makes people read it and I think it makes them think it could be them. And if you've got the quotes, it makes it real. And I can recognise all these, I've seen them, lots of people talking about it like this, you are getting good examples".*
> *(Brendan: general practitioner)*
>
> *"What I like about this is that you've got a picture and the voice bubble, you know I think that emphasises that this is someone's narrative, and that's great".*
> *(Paul: general practitioner)*

However, there were some mixed views from the health professionals towards the accounts incorporated in the second version. For example, Lisa was clear that certain accounts were beneficial but others were not:

> *"But there are undoubtedly people who think it's indigestion who are having a heart attack. But I wonder about the ones with the muscular feeling around the shoulder. That is a less common symptom, certainly a muscular feeling. I would have thought that would be one you could ditch".*
> *(Lisa: general practitioner)*

The images in the second version were stock pictures from Google Images and were used for demonstration purposes only. It was always envisaged that members of the original focus groups and interviews would be asked to re-enact their symptom experiences for the leaflet. This was undertaken for the third version when a number of respondents were asked to provide accounts of their symptom experiences and visually recreate their response.

As a result I felt there was two messages the leaflet had to communicate, these were to raise the salience of the potential symptoms of a heart attack as an explanation for symptoms; and the need to act quickly and to take appropriate action when they are experienced. The need to seek some form of immediate medical care was contained on the rear panel of the leaflet under the heading ‘Why act immediately?’. The strong emphasis on the role ‘clot-busting’ drugs in the treatment of heart attacks in the first version was thought to detract from the more important message of calling for immediate emergency care. In the second version more emphasis was placed on the need to seek emergency medical care via the 999 system. This was one area which was specifically highlighted, mainly by the high risk respondents. This can be seen in the following discussion below.

> *Syd: “That’s good being specific in saying ‘call an ambulance immediately’.*
>
> *Frances: “I was just going to say the same thing. Doubt starts creeping into your mind doesn’t it? If you have got one choice call the ambulance”.*
>
> *Syd: “That is the only choice”.*
>
> *Frances: “That’s the only choice as you say”.*
> *(Focus group with people at risk of heart disease)*

Perhaps one reason for this positive response was respondents' experiences of calling for a doctor out of hours. In Frances's extract below she explains how her experience of calling for a doctor in the past resulted in what she thought was an ineffective response. She then explains her thoughts on the need to call for an ambulance if someone encounters symptoms which could be attributable to heart disease.

> *"Yes that's right if you tend to call the doctor they tell you to take two paracetamol and to go to bed and get in touch with your own GP in the morning. You phone the ambulance and give them the symptoms (looking at the symptoms on the leaflet) they are going to say right we'll get somebody out".*
> *(Frances: high risk of developing heart disease)*

The connection between the emphasis of the message to call for help immediately and the section containing information on the 'clot-busting' drugs was commented on by Charlie. He provides the best example of this in his description of the overall message conveyed on the rear panel.

> *"Calling an ambulance immediately means that if you need it you can get a clot busting drug within minutes of experiencing pain. I think that's important, that's vital".*
> *(Charlie: cardiac chest pain)*

The use of larger, bold lettering to highlight the need to act immediately at the bottom of the panel, as if to stress this point again, was also seen as a positive step, as can be seen in Freda's comment:

> *"Put it in bold. And then it's really catching your attention every symptom in bold. You can have a quick look at it and you will think 'I am just going to lift the phone now' (and call for help)".*
> *(Freda: high risk of developing heart disease)*

Making the decision to call for emergency help was one area where the input of health professionals was vital to ensuring the leaflet was appropriate in terms of the message it conveyed to people. Giving people who may be at risk of having a heart attack the correct information in terms of what to do if they think they are having such an event was essential. In general the health professionals saw the change as a positive step and the information which was presented was seen as appropriate. This can be seen in following extracts:

> *"And I think what you are advising people to do is absolutely the right thing, and that is to phone an ambulance. You are telling people if they think they are having a heart attack to phone an ambulance and that is entirely appropriate".*
> *(Paul: general practitioner)*
>
> *"I think the weight placed on calling 999 is about right. You have it in bold to emphasise it and that's right. This is action they should be taking".*
> *(Steven: general practitioner)*
>
> *It is 999 and that is it. That is the quickest and best way to do things. So you are saying phone 999 just stick to that. Because if they do contact their GP they'll just order the ambulance".*
> *(Lisa: general practitioner)*

The leaflet continued to include some information about the drugs available in the event of a heart attack. This was linked to information on the need to call for an ambulance. This information also was viewed by health professionals as appropriate. In part, this was due to the changes in the way this form of emergency care is administered by ambulance paramedics and technicians. This is explained in the following extracts provided by Paul:

> *"Because the ambulance crews are now able to deliver thrombolysis, and to be perfectly honest in an acute clinical emergency like that where it is fairly clear cut it's them I'd*

> *want to be seeing me and taking me to hospital. So I think that's entirely appropriate…*
>
> *But I think now with the flying paramedic cars and all the rest of it I think there are certain things which have moved from primary care into the sort of intermediate care. I mean let's face it your heart attack will be managed in the hospital. And the paramedic cars form this relatively new branch of intermediate care, and I think that's what you're looking to trigger off with this leaflet".*
> *(Paul: general practitioner)*

The explanation concerning thrombolytic drugs in the second version was also an improvement. Although considerably shorter in length, the information was seen as relevant and in the correct language. As Danny explains:

> *"That's a nice one that description there. Yeah it's sort of in layman's terms exactly what you're after I would say. And it is accurate.*
> *(Danny: paramedic)*

Another reason to highlight the need to call for an ambulance was suggested by Danny. He knew from experience that even the arrival of an ambulance and the presence of the personnel was enough sometimes to make the situation better, as he explains:

> *"People who are having an MI have this, and this is a really stereotypical thing we have in our like text books, you have this feeling of impending doom, you feel you are going to die. All the symptoms you are talking about here, they are anxious, they are scared, they are not sure what is happening. And you go in there and just turning up you can start to alleviate some of these anxieties you know".*
> *(Danny: paramedic)*

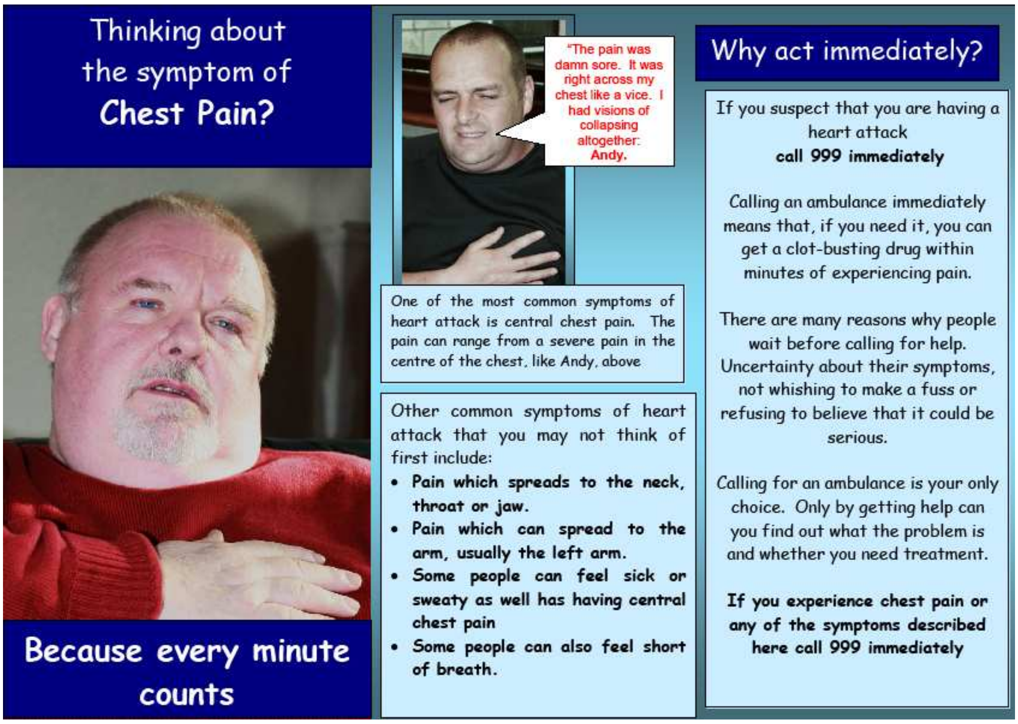
In terms of the information displayed on the rear panel of the leaflet, opinions of both the respondents and health professionals were positive. The information was signposted clearly, so that people could easily find it. The information displayed was relevant, and both respondents and health professionals thought the emphasis on calling an ambulance, was appropriate. The information on the drugs ambulance personnel can provide in the event of a heart attack was endorsed, as was the information on why people have delayed calling for help in the past. This required no modification and went straight into the third version.

To summarise, in general comments on the second version were constructive and gave clear indications as to the areas which would be need to be further developed in constructing the third version. The first area that needed to be revised was the front cover of the leaflet. It was evident from comments that the image on the second version was seen as anxiety provoking, in the wrong setting and communicated the message that having a heart attack would be a severe and debilitating experience. The use of an older male respondent, in the home setting, was integrated into the third version. This image showed an older male in a seated postion experiencing chest discomfort. The messages that accompanied this image also changed. The emphasis was now on chest pain and the need for quick consideration once the symptoms are encountered.

The use of actual experiences in the third version was also revised in accordance with the views of the health professionals. The number and type of examples were reconsidered. In the third version, the number was further reduced to four. These four examples were considered the most relevant in terms of the actual symptoms that could be encountered by people identified as being at high-risk of of having a heart attack. The layout and structure of the third version again were designed in response to the suggestions put forward by the respondents and health professionals. The resulting third version can be seen in figure 12 (full size in appendix 11).

Figure 12 Third version of the information resourse

Front



Thinking about the symptom of **Chest Pain?**

Because every minute counts

"The pain was damn sore. It was right across my chest like a vice. I had visions of collapsing altogether:
Andy.

One of the most common symptoms of heart attack is central chest pain. The pain can range from a severe pain in the centre of the chest, like Andy, above

Other common symptoms of heart attack that you may not think of first include:

- **Pain which spreads to the neck, throat or jaw.**
- **Pain which can spread to the arm, usually the left arm.**
- **Some people can feel sick or sweaty as well has having central chest pain**
- **Some people can also feel short of breath.**

Why act immediately?

If you suspect that you are having a heart attack
call 999 immediately

Calling an ambulance immediately means that, if you need it, you can get a clot-busting drug within minutes of experiencing pain.

There are many reasons why people wait before calling for help. Uncertainty about their symptoms, not whishing to make a fuss or refusing to believe that it could be serious.

Calling for an ambulance is your only choice. Only by getting help can you find out what the problem is and whether you need treatment.

If you experience chest pain or any of the symptoms described here call 999 immediately

Rear

"It was like a burning sensation coming straight up my throat, but it was also a severe pain right along the bottom of my jaw bone".
Sandra

The symptoms of heart attack vary slightly from one person to another. While women can experience the common symptoms of a heart attack they can also experience the less common. Here Sandra experiences pain in her throat and jaw.

Women can also experience less common symptoms, such as:

- **A dull pain, ache or heavy feeling in the chest.**
- **Pain that can spread to the back and the stomach.**
- **Some people can also feel dizzy and light-headed.**

"I didn't have the tightness then it was just breathlessness. And I was just assuming that it was my asthma that was playing up but it turned out not to be".
Sandra

It also important to realise that some people can confuse their chest pain with some other cause. Like Sandra, above, who thinks her breathlessness is due to her asthma, when in fact it was a symptom of a heart attack.

"I was experiencing some chest pain, at the time it felt like indigestion that's all you could describe it as".
Ray

Some people can also think their chest pain feels like bad indigestion. Like Ray, above, who after a heavy meal thought his chest pain was indigestion.

What to look out for

The symptoms of heart attack vary slightly from one person to another.

They range from severe pain in the centre of the chest, to mild chest discomfort making you feel unwell.

The pain can often feel like a heaviness or tightness which may spread to the arms, neck, jaw, back or stomach.

If you experience any of these symptoms don't ignore them.
Call 999 immediately

Once completed the third version was again shown to a number of respondents and health professionals. The feedback from both respondents and health professionals was positive. Below are a number of examples of what these individuals said:

> *"It's one of those leaflets that you want to go around to the back to see what else is there. You are looking at the front and you are going through this and that and then you want to see what else is on the other side. I think its well presented". (Maureen: non-cardiac chest pain)*

> *"I like it because you put this in your pocket, it's not going to clutter up. If you were to hand someone a great big thing, it wouldn't be read. But this leaflet you could just stick that in your pocket".*
> *(George: non-cardiac chest pain)*

> *"You have to grab them (the target group) immediately. If you ask them to perform some task of reading through a brochure or booklet you have lost them. It needs something snappy and that (third version) to me fits the bill I think". (Paul: general practitioner)*

6.5 Chapter summary

In this chapter I have presented an account of how three versions of a patient information leaflet for people at high risk of developing CHD were produced. The resource was intended to act as a decision aid to assist people once they experience symptoms which could be attributable to heart disease. In ensuring that the leaflet was well designed and provided the information that patients wanted and health professionals thought appropriate, the development process incorporated a number of evaluation stages. This ensured that both respondents and health professionals considered the material to be acceptable, appropriate and useful.

During this evaluation a relatively small number of respondents and health professionals were involved. The majority of respondents thought that in its final form the leaflet was easy to read, straightforward to navigate around and they liked the idea of having the patient experiences to emphasise the different symptoms. The respondents also appreciated the presentation of information describing the action to take in response to symptoms and the reasons why this was so important.

It was essential to determine professional acceptability of the leaflet. The majority of health professionals thought the concept of the leaflet worthwhile. The health professionals considered the final draft of the leaflet easy to understand, appropriate to give to patients at high-risk of developing CHD, and most importantly informative.

At the end of the evaluation process the final draft of the leaflet was considered by both patients and health professionals to improve patient knowledge about the symptoms of heart disease, increase the level of preparedness in the event of encountering symptoms and in doing so make them aware of the correct action to take.

Chapter 7 Discussion

7.1 Introduction

The impetus for this thesis was the perceived failure by many people to recognise that their symptoms could be attributable to a heart attack. A failure to recognise the nature of these symptoms can lead a person to wait, sometimes only a short period of time or in other cases considerably longer, before they decide to seek medical assistance.

The overall aim of the research reported in this thesis was to produce an information resource for people at high risk of developing CHD. To achieve this aim the study explored the experiences of people who had had symptoms which could have been attributable to a heart attack. More specifically, it investigated how these people recognised that something was wrong, the responses they made to their symptoms, and how they made sense of their experiences, and the attributions they made to explain their symptoms. At the same time, it also investigated the types of knowledge the respondents drew on to aid their interpretation of their symptoms and to inform the actions which they took as a consequence and the role of significant others in this process.

To achieve its aim the study developed a number of objectives. These were: (1) to describe experiences and response amongst a range of people who have had symptoms that might be attributable to heart disease; (2) to select experiential data to include in an information resource; (3) to identify the best practice guidelines on the management of a heart attack, MI or acute coronary syndrome (ACS); (4) to combine the experiential data and the guidelines in a draft resource; and (5) to pilot the resource through seeking responses to content and preferred style of presentation from relevant patient groups and health professionals.

This chapter begins with a summary of the main findings. It then discusses these in relation to the broader theoretical debates concerning how people respond to symptoms, the attributions they make, the knowledge they use and the role played by significant others in making the decision to seek medical help. The chapter then discusses the relevance of the findings to the development of patient information resources. It ends by highlighting the strengths and limitations of the study, recommendations for future research, and implications for healthcare policy and practice before drawing a number of conclusions.

7.2 Discussion of the findings in relation to the experience of symptoms

7.2.1 Identifying the symptoms as something serious

The nature of symptom presentation and the effect it can have on influencing subsequent illness behaviour is well known. In the present study, when people were confident about the potential cause – and the legitimacy – of their symptoms they sought help sooner. The respondents who acted quickly following their symptom experience were able to identify that their symptoms were ‘serious’ and identify them as being cardiac related (Perkins-Porras et al, 2009; Ottesen et al, 2004; Ruston et al, 1998; Walsh et al, 2004). Other studies also support the current finding that when people were unable to perceive the seriousness of their symptoms or were unable to ascertain their cause they waited before seeking help (Bunde & Martin, 2006). Johansson et al (2004) also found half of the participants in their study were reluctant to seek treatment for their symptoms because they did not recognise them as serious. Respondent accounts used vivid language to emphasise the severe pain they felt. Terms such as 'crushing' or 'collapsing' were used to describe chest pain which suggested they perceived their symptoms as being serious and therefore sought help sooner.

This finding supports that of Walsh et al, (2004) who found that when patients perceived a heart attack as having serious consequences they had shorter delays in seeking medical help and suggested the motivation for seeking help quickly was fear. Although the respondents in the current study did not specifically talk of fear it is possible that such an emotional response was present at the time of encountering their symptoms, but was absent when asked to describe their experiences retrospectively.

When symptoms were not severe or intense, it seemed the respondents were not able to respond confidently or were unclear about what was happening to them. Many of those who waited were characterised by uncertainty and ambiguity in explaining their symptoms and response to them. Perkins-Porras et al, (2009) and Horne et al, (2000) found a similar response. Perkins-Porras et al's (2009) study which investigated pre-hospital delays in people experiencing acute coronary syndrome found that when symptoms were not attributed to a heart attack there was a longer decision time before seeking help. Horne et al's (2000) study investigating the association between expected symptoms of acute myocardial infarction and actual symptoms found that when people experienced symptoms they were not familiar with there was a delay in seeking medical help.

The majority of the respondents who waited described their symptoms as mild or intermittent pain or feelings of tightness or discomfort, rather than as severe or intense pain. These types of descriptions emphasize the ambiguous nature of the symptoms and highlight how many respondents felt able to dismiss or ignore them at the beginning. Other respondents described their response to symptoms as ‘not being anything to worry about’ and they did not see them as being significant. As long ago as the 1960’s Mechanic (1968) suggested that pains or symptoms which are mild in nature and of a short duration are often trivialised or normalised. He argues that in many situations people tend to normalize their symptoms, or evaluate them as having little importance (Mechanic, 1992).

7.2.2 Symptoms attributions

In terms of the attributions the respondents made in response to their symptoms those who made the decision to seek help quickly made the attribution that their symptoms were related to a cardiac cause whereas those who waited made attributions which varied as to the cause. Locker (1981) suggests that when faced with symptoms there follows a ‘ubiquitous causal theorizing’ (p62) in which one object or event is seen to precede and be responsible for another object or event; symptoms are given a label and through causal theorizing causes are *attributed* to them.

In those who acted quickly there were similarities between these respondents in terms of attributions they made. These attributions focused on the severity and intensity of their chest pain and other symptoms. A number of the respondents said they had a good idea what they thought their symptoms represented; they felt that they were able to attribute their symptoms to a cardiac cause or realise that they were serious. Bishop et al (1986) also suggest that people are able to identify the cause of their illness by comparing their symptoms with those they expect for a given disease. When severe or intense chest pain was experienced by the respondents in the current study a number were able to match their symptoms to the mental representation they had for what a heart attack should feel like, suggesting that people in this study made sense of symptoms through implicit matching between symptoms and illness representations as Levine & Riecher (1996) suggest.

However, when people were not able to make such an implicit match between their symptoms and what they thought a disease or condition should feel like they discounted making such an attribution. As Sensky (1997) suggests, when people are faced with new and unexpected symptoms they may have a tendency to interpret these in the context of prior beliefs and current expectations and consequently the attributions which come to mind most readily at the onset of symptoms tend to be judged more probable. This was certainly the case with a number of respondents who waited and were later diagnosed with a cardiac condition. Cameron et al (2005) and White (1999) both suggest that such variations in symptoms attributions may provide some indications regarding the prototypical beliefs people have about heart attacks, as the attribution process involves matching symptom experiences with beliefs about symptoms attributable to a specific disease.

Emslie et al (2005) suggest a number of reasons for a stereotypical ‘coronary candidate’; someone who is overweight, a smoker who leads an unhealthy lifestyle (Emslie et al, 2001; McConnachie, Hunt, Emslie, Hart & Watt, 2001; Ruston et al, 1998). It appears that when some men who view themselves as not conforming to this stereotype encounter symptoms which may be attributable to a heart attack they are confused and may attribute their symptoms to other causes such as indigestion, heartburn or overexertion (Emslie et al 2005; White and Johnson, 2000). These findings are supported in the current study where a number of male respondents who suffered a cardiac event initially did not see themselves at risk and attributed their symptoms to another more benign cause.

Respondents in this study did not attribute their cardiac related symptoms to a heart related cause, because the symptoms did not match what they thought a heart attack should feel like. Turnquist et al (1988) also found in their study investigating attributions made to life threatening illness that between 75% and 95% of people when faced with a life-threatening illness made a causal attribution to account for their symptoms. Attributions made by the respondents who waited varied, although indigestion and stress were cited as a cause by a number of these respondents. Similarly Cameron et al (2005) indicated that many people attributed their cardiac related symptoms to stress or high cholesterol, heredity, fat consumption and hypertension as did French et al (2001) and Weinman et al (2000).

Respondents also spoke of not seeing themselves at risk of heart disease, so when they did experience symptoms such as chest pain which were unusual they attributed them to the most logical cause they could construct. This supports the findings of

Pattenden et al (2002) and Zuzelo et al (2002) which suggest that if symptoms are not the classic symptoms of a heart attack or are unfamiliar, or a new experience to anything they have experienced before, this has led many people to attribute their symptoms to an unimportant cause and they have ignored them.

When faced with vague and ambiguous symptoms some respondents found it difficult to identify a cause. Some thought something was wrong, but they were unable to interpret their physical symptoms or they attributed them to other things, whilst appraising and reappraising what was happening to them from time to time. This supports findings from Rogers et al, (1999) who suggest that in these types of situations people tend to normalize symptoms by applying common sense labels for symptoms.

7.2.3 Knowledge used to help interpret symptoms

For a number of respondents in this study a personal experience of a heart attack, angina or knowledge of significant others who had suffered such problems meant they could draw on personal experience to make sense of their symptoms and react accordingly by seeking medical help quickly. This ‘lay’ information (Rogers et al, 1999) is what the person already knows about the illness or symptom. This knowledge is formed through experience, from discussions with others about particular symptoms or illnesses or common-sense knowledge that is generally held by the person. Ottesen et al (2004) also suggested that people who have had a previous heart attack are more likely to react quickly in seeking medical help. The knowledge acquired through experience meant they could determine the importance of their symptoms (Ottesen et al, 2004). Ottesen et al (2004) also found people who ‘knew’ their symptoms were cardiac related were more convinced their symptoms were serious and could have severe consequences. Walsh et al (2004) also found that people with previous personal experience generally knew what the most serious heart attack symptoms are and reacted accordingly by seeking medical help.

However, some studies have suggested that a previous heart attack is no guarantee that people will respond to their symptoms quickly (Johansson et al, 2004; Gurwitz et al, 1997). Indeed Mumford et al (1999) and Leslie et al, (2001) found that people with a previous diagnosis of angina or myocardial infarction were no better at forming an attribution that their symptoms were related to their heart when compared to people with no such history.

7.2.4 The role of significant others

The role played by significant others in people’s response to symptoms and the decisions to seek help in this study proved hard to measure. Moser et al (2006) have suggested that having a significant other present at the onset of symptoms of a cardiac event can play an important role in the way people recognise and attribute a cause for their symptoms and respond. Perkins-Porras et al (2009) also found that people who were married, or who had someone present when they first experienced their symptoms sought help sooner than people who were alone. However, other studies have produced contrary findings concerning the role of significant others. One study from the late 1960’s found that people who were alone at the onset of their symptoms made the decision to seek medical help faster than when the decision was made with their spouse present (Hackett & Cassem, 1969). In a later study Alonzo (1986) replicated these findings and found people waited before seeking help after they informed their spouse of their symptoms. Others have also produced evidence that the presence of a spouse or family member can increase the time before people seek medical help when having a heart attack. Perry et al (2001) and Dracup et al (1995) found that if the symptoms were experienced in presence of a relative, particularly a spouse, there would be a wait before treatment was sought. The reason suggested for this wait was treatment strategies often recommended by the spouse to deal with the symptoms. The accounts provided by the respondents in the current study suggested that when people inform a significant other that they were experiencing symptoms the decision to seek medical care followed, but there was also variation in the time to reach this decision.

Only one respondent in the present study experienced his symptoms in the presence of friends and at their insistence he sought help quickly. In this respect the involvement of other people can allow them to take control of the situation and either call the emergency services themselves or insist that the patient calls for help. Hackett & Cassem (1969) found the decision to seek care was made faster when friends and colleagues were present. They suggest friends may provide a more impersonal interaction that leads to a decision to seek medical care to be made in a shorter time.

7.3 Discussion of the findings in relation to the production of the information resource

The decision to target the information resource at a specific group, people at high risk of developing heart disease, was made for a number of reasons. Results from campaigns using mass media approaches to target people at risk have been shown to have a negligible impact (Finn, Nick, Shilton, Cunningham & Thompson, 2007). A

Cochrane review (Grilli, Ramsey & Minozzi, 2002) addressed the effect of mass media interventions on health service use (not exclusively in response to chest pain symptoms). This showed that, although the quality of the primary research was poor, there was some evidence to suggest the interventions did have some effect on service use. Nonetheless, evidence to suggest that these campaigns reduce the time taken to seek help in people experiencing a heart attack is unconvincing (Finn et al, 2007).

Another reason to target people at high risk is that they can be identified and approached in a primary care setting (Luepker, 2005). Also a targeted approach for people at high risk of heart disease provides an opportunity to design tailored strategies to initiate prompt help seeking behaviour in the event of a suspected heart attack (Luepker, 2005). Research has demonstrated that people are much more likely to use a resource specifically tailored for them (Protheroe et al, 2008; Walsh, 2006). At risk respondents in the current study were clear that they wanted to receive a patient information resourse targetted at them. They wanted something concise, simple, easy to read and easy to comprehend in a leaflet format.

The information that respondents thought should be included ranged from checklists detailing the different symptoms that may be encountered in plain simple language. Hoffmann et al (2006) suggest that written information should be produced to ensure the content is displayed in language that is written simply and at the lowest level of literacy of those who are likely to read it, whilst ensuring that the information is accurate and understandable.

As expected from earlier research a number of respondents liked the idea of using actual accounts or case studies to highlight what it could be like experiencing a heart attack. Kennedy at al (1999) and Swift & Dieppe (2005) suggest the use of patients' own words when communicating information can be beneficial. They suggest that extracts from patient accounts can be memorable because they are grounded in personal experience and they can enforce reflection (Kennedy et al, 1999; Swift & Dieppe, 2005), although no respondents in this study mentioned this particular reason for their likeing of personal accounts.

The inclusion of participant accounts allowed the resource to portray a number of different symptom scenarios. When someone is having a heart attack, the usual image portrayed is someone grabbing his or her chest in severe pain (Finnegan et al, 2000). This common image is dramatic but may not prepare people for symptoms that are more subtle. Because symptom type and intensity vary widely, it has been suggested public education is needed to heighten awareness of the range of symptoms that can be attributable to a heart attack, including that chest pain is not a universal symptom (Finn et al, 2007). Although many respondents experienced some form of chest pain, many did not initially think that their symptoms could be cardiac related because their pain was not severe and crushing as the popular stereotype suggests. This portrayal of the classic heart attack needs to be balanced by showing the varying ways that a heart attack can manifest itself. Using the experiences of real people to highlight these different symptoms that may be encountered may be an effective way to convey information to people who are at high risk of developing heart disease.

Houts et al (2006) and Kools et al (2006b) have suggested that the presence of pictures and accompanying text in close proximity can add value over text alone. Many respondents in the current study said that they liked the idea of using pictures and illustrations, which they thought would give the information more impact.

However, deciding how relevant or appropriate an image was proved to be an important consideration. Initially a number of images were used which the respondents found to be inappropriate and thought should be changed. Dowse and Ehlers's review (2001) recommended that simple realistic pictures with limited content be used so as not to distract the patient with irrelevant details.

Another finding concerns the use of images. Houts et al (2006) suggest situating text and picture as close together as possible and include the use of captions to describe what is happening in the picture. Certainly respondents in this study found images depicting a symptom experience accompanied by a textual description of the experience to have more impact than just using textual information or images themselves. Captions may have the added advantage of being able to be presented in a low level of literacy, helping those with limited reading skills understand what is going on.

7.4. Strengths and limitations of the study

A particular strength of this study was the inclusion of respondents whose chest pain was later diagnosed as being non-cardiac in origin. Patients arriving at accident and emergency departments with non-cardiac chest pain represent a large percentage of attendees seen by medical staff. Chest pain accounts for approximately 5% of all presentations to emergency staff and in over 50% of these cases heart disease is excluded and the person is diagnosed as having some form of non-cardiac chest pain (Eslick et al, 2004). Although this group represents a large proportion of patients their symptom experience has received modest attention in research literature (Eslick et al 2004; Eslick et al, 2002). This study attempted to address this gap by making the experiences of non-cardiac chest pain patients central to the analysis in order to better understand how these people interpret their symptoms which they perhaps fear may be due to heart disease.

A further strength of the study was the involvement of people who had suffered symptoms that may have been attributable to a heart attack in the development of the information resource (Kennedy et al, 2003; Kennedy et al, 1999). This had the benefit of providing actual accounts of symptom experiences to inform and form part of the information resource. Having the assistance of people who had experienced a range of symptoms in the development of the resource meant valuable insights could be included and the resource was patient-centred.

There were also a number of limitations to the research. As noted earlier, it was only possible to collect data on the symptom experience retrospectively. Therefore the accounts provided by some of the respondents may have been affected by some form of recall bias. The accounts they gave may also have been influenced by information they were given via health professionals during their treatment or information they themselves had read after their experience. The problem of collecting data on the symptom experiences retrospectively was more pronounced in certain respondents due to the considerable time between the experience of their symptoms and discussing them. This was the case with some of the respondents who were recruited from the voluntary organisation who were discussing a symptom experience which had occurred over 18 months previously.

Another limitation of the design of the study was there was no way of establishing how the respondents had acquired their knowledge concerning heart attacks or heart disease. Many respondents talked of ‘knowing’ about what a heart attack would be like, but there was no way to confirm how many of the respondents had explicit knowledge of heart attack or MI through the experience of a relative, friend, or colleague. As a consequence it is difficult to establish whether this influenced their interpretation of their symptoms and their decision to seek help. Although the study attempted to elicit whether such knowledge was used in the interpretation of the symptom experience the questioning schedule used during interviewing did not systematically query this aspect, which I now regret.

Polit and Beck (2004) have suggested that qualitative research should be considered in terms of transferability to individuals in a similar context. The fact that all the respondents in the study were recruited from the central belt of Scotland might limit how transferable the findings are to a wider national and international context. The lack of ethnic diversity in the sample (all the respondents were white from British backgrounds reflecting the lack of ethnic diversity in this part of Scotland) may also restrict how transferable the findings are. In addition, because there is no charge for medical care at point of contact in Scotland, the findings may not be transferable to countries where there is a charge for medical care.

A further limitation concerned the recruitment strategy used by the study. The proposed recruitment strategy was initially seen as a strength. It was planned to recruit (four) participant groups to obtain data on the various aspects of the experience and response to symptoms, the experience of the spouse or partner, and opinions and views on the development of a written patient information resource. To gain experiential data on the symptom experience two groups were targeted; patients who had been diagnosed with cardiac related chest pain (group A) and those with non-cardiac chest pain (group B). Attempts were made to obtain data on the experience of the spouse or partner through recruitment via the respondents. Finally patients at high risk of a heart attack were targeted to provide realistic feedback during the development of the resource. However, as we have seen, it was difficult to operationalise this strategy in practice, leading to what amounted to a convenience sample of respondents.

Initially recruitment took place at only one hospital within the central area of Scotland. The use of only one hospital may have resulted in selection bias. A further issue concerning recruitment occurred when potential respondents who had been diagnosed with cardiac related symptoms could not be recruited from the hospital (see chapter 4). The alternative source of recruitment, the voluntary organisation using the experiences of people who have had heart problems to mentor those who have just experienced such an event or been diagnosed with a similar condition.

In terms of the respondents whose symptoms were cardiac related the sample was inevitably limited to those who had survived their experience. These people may have experienced a different (and more favourable) experience and time to treatment than cardiac patients who did not survive.

Finally, a limitation of the study concerns the resource itself. We know from the literature that providing information alone is not enough. However, the resource developed in this study has been designed for use in primary care, to be recommended by health professionals for people identified as being at high risk of having a heart attack. This may help in raising awareness in these people but it still may have no effect in terms of behavioural responses. What would be desirable in terms of administering the resource would be to incorporate it into a routine review for people at high risk and then develop a trial to establish if it has any impact in helping people to seek help faster when experiencing symptoms that may be attributable to a heart attack.

7.5 Recommendations for future research

Although the study findings can contribute to the way written patient information is developed, planned and evaluated, they principally highlight the need for further research into how people interpret symptoms that could be attributable to a heart attack and the help-seeking decisions they make as a result by trialling this written patient information resource.

The distinct perceptions and patterns of the way the respondents' accessed medical care described in this thesis also highlight a need to explore the representations people have of CHD in wider UK population. Many respondents who later received a cardiac diagnosis said that, when they were first experiencing their symptoms, they did not believe their symptoms could be related to a heart attack. Certain representations of what the experience of a heart attack 'should' feel and look like are still common. The 'Hollywood' image of a middle aged male clutching his chest with a look of intense pain on his face is still common (Emslie et al, 2001; McConnachie et al, 2001; Ruston et al, 1998). Any future strategy to reduce the time taken to seek help once potential symptoms of a heart attack are experienced must address this misrepresentation.

Many previous studies investigating the experience of heart attacks have suffered the limitation of having predominantly male samples. This may have contributed to the widespread notion that heart attacks are mainly a male concern (Emslie et al, 2009; Emsile et al, 2001). Research has attempted to address this stereotype by highlighting that women as well as men are at risk of heart disease but still more needs to be done to raise the salience of heart disease in women. Specifically attention should be paid to women's experiences of a heart attack. Although each person's experience of a heart attack is an individual event it is known that women can experience certain symptoms (Fukuoka, Dracup, Ohno, Kobayashi & Hirayama, 2005; Dracup et al 1997). Future research may specifically target women in order to raise awareness of these gender-specific symptoms and heart disease in general.

7.6 Implications for healthcare policy and practice

As outlined in the literature review, the most important modifiable determinant of the outcome of a heart attack is the speed with which the person seeks appropriate medical care (Perkins-Porras et al, 2009; Dracup et al, 2005). Therefore, opportunities for reducing mortality from a heart attack lie mainly outside the realm of emergency medical care. Evidence from the mid 1990's suggested that survival from a heart attack could be trebled by improvements in a person's response to their symptoms through an understanding that something serious is happening to them and they need to call the emergency services quickly and ensure the deployment of an ambulance (GISSI – Avoidable Delay Study Group, 1995).

Reducing mortality from heart attacks and reducing the time taken for people to seek help for their symptoms as well as raising the profile of such symptoms have been important objectives of the UK government’s health policy (DoH, 2000, pp 8-9). The findings presented in this thesis have shown that understanding that symptoms are serious and represent a real threat to health can play a crucial role in determining when a person makes the decision to call for help. The findings of this research draw attention to the continuing need to raise the salience of the range of symptoms that may be encountered when experiencing a heart attack. When people seriously considered that their symptoms could be attributable to a heart attack the decision to call for help was made quickly. However, where there was uncertainty this decision was put off, in some instances for a considerable time. By highlighting the range of symptoms that may be encountered when experiencing a heart attack it is hoped people will be better prepared to recognise that something serious is happening to them and to take appropriate help seeking behaviour, namely calling the ‘999’ emergency services telephone number.

Previous strategies that have attempted to reduce the delay in seeking help when experiencing heart attacks have tended to adopt a blanket mass media approach, targeted at the general population when conveying their message. This approach has the advantages of being distributed to many individuals but the disadvantage of not being read by or relevant to numerous people. The resource developed in this instance was designed to be targeted specifically at people identified as being at high risk of developing CHD by their GP’s. By targeting individual people and providing them with an information resource highlighting the range of symptoms attributable to a heart attack, the need for prompt helping seeking and the way to contact such help, may be more likely to read, understood and retained for future use.

It is important to have an understanding that the experiences of men and women of a heart attack can be different (Dracup et al, 1995). In order to avoid any assumptions and facilitate the provision of information that is truly gender-sensitive the distinct experiences of men and women must be accommodated. The experiences provided by the respondents in this research have been used to develop an information resource which attempts to address these issues. The resource may be used by others to help them understand the range of symptoms that may be encountered during a heart attack and understand the ways in which others have interpreted their symptoms and sought help.

The study findings have implications for improving the delivery and provision of written patient information. To be effective information has to acknowledge the diversity of a population's attitude, perception and pre-conceived ideas towards a condition. In order to provide useful patient information resources health professionals, or other persons involved in the development of patient information, need to be aware of the differences that influence the interpretation of symptoms and the subsequent help-seeking behaviour of people experiencing a heart attack.

Using patients in the development and review process has also been advocated to ensure that the patient information being produced remains patient centred (Kennedy et al, 1999; Kennedy at al, 2003). The role patients can have in the development process can help decide what the content of the material included should be as well as how it should be presented. Patient involvement can also be highly influential throughout the development process, providing feedback on aspects of the review process. The findings presented in this thesis illustrate that patients have clear ideas about the content of patient information and how it should be presented. These findings could be used in the delivery of primary healthcare services with health professionals using tailored patient information to influence the decision-making process when patients experience symptoms potentially attributable to a heart attack.

Related to this, the study findings also have implications for improving the delivery of effective patient information strategies, targeted specifically at patients who are at high risk of developing CHD in the UK. How the respondents in this study interpreted their symptoms and the help-seeking actions they took as a result had serious implications for the time to receive medical help. Many respondents in the study waited before seeking help, and when they did they were more likely to contact their GP, only one consulted the emergency services as the first course of action. This behaviour of contacting a GP before the emergency services has been identified as a leading to delays in receiving effective treatment (Hitchcock, Rossouuw, McCoubrie & Meek, 2003). Raising awareness of the importance of seeking help quickly when people realise something is wrong may reduce the time it takes people to call the emergency medical services.

7.7 Conclusions

This thesis has described the initial stages of the development of an information resource to help people to respond effectively to symptoms that might be attributable to heart disease for people at high risk of heart disease. It demonstrates the considerable difficulties faced in the initial recruitment of respondents whose experiences were to contribute to the resource but also that once recruited a number who were engaged and enthusiastic about the importance of a well designed resource were involved in the development process. The most important next step is to trial the resource with people identified as being at high risk of heart disease in a primary care setting to examine it's impact on response to symptoms that could be attributable to heart disease.

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Appendix 1

Early questioning schedule for the focus groups.

Focus group question schedule for Group A (individuals who have suffered symptoms attributable to heart disease).

Introduction Give an explanation.
Good morning/afternoon. My name is Alex Woods and this is my colleague (this may/may not happen). Thank you for coming.

Present purpose.
We are here today to find out about your own experience of dealing with your heart problems and the symptoms that were present. The purpose is to find out what you did, what any health providers were like, and what other people said and did. The study aims to produce a draft information resource which will combine experiential evidence with medical facts. I am not here to share information, or give you my opinions. Your experiences and perceptions are what matters. There are no right or wrong answers. You can disagree with each other, and you can change your mind. I would really like you to feel comfortable saying what you really think and how you really feel.

Discuss procedure.
I will be taking notes and recording the discussion so that I do not miss anything you have to say. I explained these procedures to you in the information sheet you received. As you know everything is confidential. No one will know who said what. I want this to be a group discussion, so feel free to respond to me and to other members in the group without waiting to be called on. However, I would appreciate it if only one person did talk at a time. The discussion will last approximately one – two hours. There is a lot I want to discuss, so at times I may move us along a bit.

Introduction/opening question: "This question is here to let me hear your voice so I can tell who you are later on when listening to recordings. Can you tell us your name, what you had for breakfast, and how you got here this morning?"

Introduction question: “We are here are to talk about your experiences of having symptoms and what happened to you. Take a few moments this. Can you tell me about the symptoms, you were experiencing then”.
Symptoms listed by the group will be displayed on a flip chart.

Probes: *“What were the first symptoms you remember?”*
“How did they start?”

Question: “What action did you take having experienced these symptoms?”

Probes: *“Who did you first talk to about your symptoms?”*
“Why did you not seek help with your symptoms?”
“What stopped you seeking help?”

Question: “Take a look at the symptoms we have listed on the flip chart, which is the most important to you in making you take action or which worried you the most?”

Probes: *"or which symptoms worried you the least and why?"*

Question: "What did you do whilst you were having these symptoms?"

Question: "When you were having your symptoms in the beginning who did you talk to about them?"

Probe: *"Tell me why you sought help from this individual?"*

Question: "What sort of things made you want to go to see the doctor?"

Probe: *"What prompted you to do this?"*
"What helped you to decide to see the doctor?"

Question: Using the flip chart. "We know that people who have suffered with a number of symptoms often do not do anything about them, why do you think this is?"

Question: "Did you have any ideas, thoughts, explanations about what your symptoms were? Where did these come from? What sort of information made you think about your symptoms?"

Introduction.
The main aim of the study is to produce an information resource to raise awareness of symptoms that may be attributable to heart disease, the next section will concentrate on your thoughts and feelings on the types of information which could help people become more aware of these types of symptoms. The types of symptoms you have all had are the kinds of symptoms that might suggest a heart problem; therefore I am going to ask a number of questions which will allow me to better understand your views on this subject.

Question: "What other kinds of information do you think it would be useful for someone to have if they were experiencing these symptoms?"

Question: "Do you think knowing more about possible explanations help people?"

Probe: *"Tell me why you think this would be useful?"*

Question: "What types of information would you have found most useful in raising your awareness and understanding of heart disease?" (Using flip chart).

Question: "Of all the information needs we have discussed, which do you think would have been the most useful to you? And could you explain why?"

Probe: *"How would you have liked this information to have been made available?"*

Question: "What do you think should be the contents of such information?"

Probe: *"How should it be displayed?"*

Closing question: “Thinking about your overall experience, do you have any suggestions on how the health service could improve the information they give out about this kind of problem?”

Closing question: “How could your experience be improved or how could patients be better supported when they have symptoms that may be attributable to heart disease?”

End question: “Is this an adequate summary of our meeting?”

Appendix 2

Later questioning schedule for the focus group or individual interviews.

Introduction Give an explanation.
Good morning/afternoon. My name is Alex Woods and this is my colleague (this may/may not happen). Thank you for coming.

Present purpose.
We are here today to find out about your own experience of dealing with your heart problems and the symptoms that were present. The purpose is to find out what you did, what any health providers were like, and what other people said and did. The study aims to produce a draft information resource which will combine experiential evidence with medical facts. I am not here to share information, or give you my opinions. Your experiences and perceptions are what matters. There are no right or wrong answers. You can disagree with each other, and you can change your mind. I would really like you to feel comfortable saying what you really think and how you really feel.

Discuss procedure.
I will be taking notes and recording the discussion so that I do not miss anything you have to say. I explained these procedures to you in the information sheet you received. As you know everything is confidential. No one will know who said what. I want this to be a group discussion, so feel free to respond to me and to other members in the group without waiting to be called on. However, I would appreciate it if only one person did talk at a time. The discussion will last approximately one – two hours. There is a lot I want to discuss, so at times I may move us along a bit.

Introduction/opening question: Tell us your name, where you live and what you enjoy doing the most?

Introduction question: Can you describe the first symptoms you remember experiencing? If so what symptoms were they?

Question: Can you describe how your symptoms felt? Were they painful and sudden or were they mild and intermittent?

Probe: Were your symptom/symptoms easily recognisable?

Question: What did you think was the cause of the symptom/symptoms?

Probe: Did you know what your symptoms were caused by?

Question: How long do you remember experiencing these symptom/symptoms before you made the decision to seek help?

Probe: Did you think your symptoms were serious or an inconvenience?

Question: What was the help you initially sought? And why was this?

Additional question: If you did not call for an ambulance why not?

Introduction.
The main aim of the study is to produce an information resource to raise awareness of symptoms that may be attributable to heart disease, the next section will concentrate on your thoughts and feelings on the types of information which could help people become more aware of these types of symptoms. The types of symptoms you have all had are the kinds of symptoms that might suggest a heart problem; therefore I am going to ask a number of questions which will allow me to better understand your views on this subject.

Question: Do you think information that raises awareness and understanding of heart disease is important?

Probe: Why is it important?

Question: What type of information do you think would be important to know?

Question: Of all the information needs we have discussed, which ones is the most important to you? And would you explain why?

Question: How would you like this information to be made available to you?

Probe: Where would you make this information available to people?

Question: What do you think the contents of such information should be?

Probe: How should it be displayed?

Question: Can you describe to me an information resource you have seen and been impressed by?

Probe: What was it that most impressed you and why?

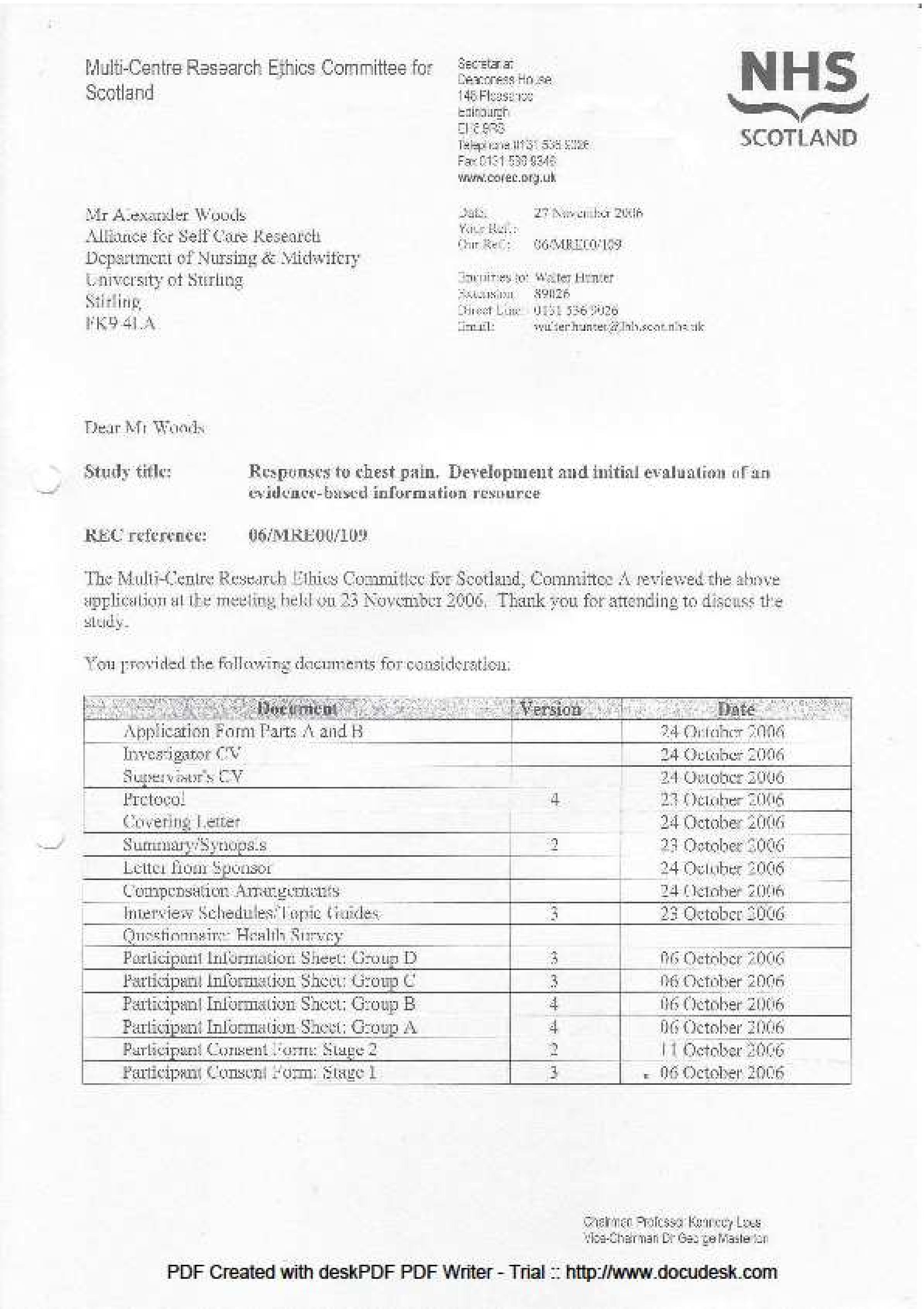
Question: What do you think of including real accounts of someone having experienced a heart attack or other symptoms attributable to a heart attack?

Probe: Would this be beneficial and if so why?

Closing question: Thinking overall do you have any suggestions how the health service can improve the information you could receive.

End question: Is this an adequate summary of the group meeting?

Appendix 3



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SCOTLAND

Mr Alexander Woods
Alliance for Self Care Research
Department of Nursing & Midwifery
University of Stirling
Stirling
FK9 4LA

Date: 27 November 2006
Your Ref.:
Our Ref.: 06/MRE00/109

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

Dear Mr Woods

Study title: **Responses to chest pain. Development and initial evaluation of an evidence-based information resource**

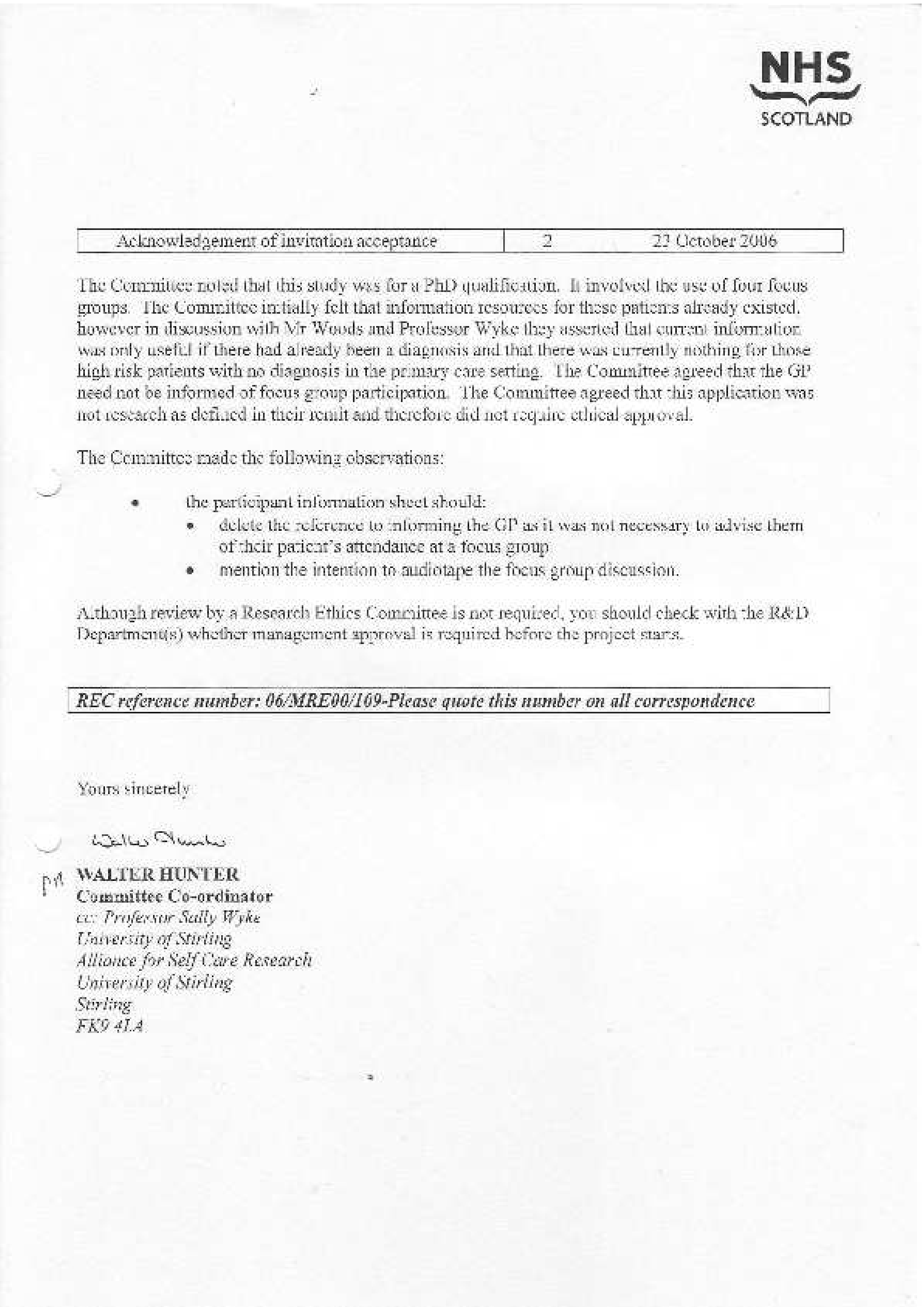
REC reference: **06/MRE00/109**

The Multi-Centre Research Ethics Committee for Scotland, Committee A reviewed the above application at the meeting held on 23 November 2006. Thank you for attending to discuss the study.

You provided the following documents for consideration:

Document	Version	Date
Application Form Parts A and B		24 October 2006
Investigator CV		24 October 2006
Supervisor's CV		24 October 2006
Protocol	4	23 October 2006
Covering Letter		24 October 2006
Summary/Synopsis	2	23 October 2006
Letter from Sponsor		24 October 2006
Compensation Arrangements		24 October 2006
Interview Schedules/Topic Guides	3	23 October 2006
Questionnaire: Health Survey		
Participant Information Sheet: Group D	3	06 October 2006
Participant Information Sheet: Group C	3	06 October 2006
Participant Information Sheet: Group B	4	06 October 2006
Participant Information Sheet: Group A	4	06 October 2006
Participant Consent Form: Stage 2	2	11 October 2006
Participant Consent Form: Stage 1	3	06 October 2006

Chairman Professor Kennedy Lees
Vice-Chairman Dr George Masterton



NHS
SCOTLAND

Acknowledgement of invitation acceptance	2	23 October 2006

The Committee noted that this study was for a PhD qualification. It involved the use of four focus groups. The Committee initially felt that information resources for these patients already existed, however in discussion with Mr Woods and Professor Wyke they asserted that current information was only useful if there had already been a diagnosis and that there was currently nothing for those high risk patients with no diagnosis in the primary care setting. The Committee agreed that the GP need not be informed of focus group participation. The Committee agreed that this application was not research as defined in their remit and therefore did not require ethical approval.

The Committee made the following observations:

- the participant information sheet should:
  - delete the reference to informing the GP as it was not necessary to advise them of their patient's attendance at a focus group
  - mention the intention to audiotape the focus group discussion.

Although review by a Research Ethics Committee is not required, you should check with the R&D Department(s) whether management approval is required before the project starts.

REC reference number: 06/MRE00/109-Please quote this number on all correspondence

Yours sincerely

Walter Hunter

PM **WALTER HUNTER**
Committee Co-ordinator
cc: Professor Sally Wyke
University of Stirling
Alliance for Self Care Research
University of Stirling
Stirling
FK9 4LA

MREC for Scotland, Committee A

Attendance at Committee meeting on 23 November 2006

Committee Members:

Name	Profession	Notes
Professor K Lees	Consultant Physician/Clinical Pharmacologist (Chairman)	
Dr G Masterton	Consultant Psychiatrist	
Mr L Moffat	Consultant Urologist	
Dr A Munro	General Practitioner	
Ms P Peattie	Co-opted Lay	
Mrs A M Peffer	Lay	
Dr R Quigley	General Practitioner	
Professor G Raab	Statistician	
Dr A Richardson	Consultant Clinical Psychologist	
Mrs M Sweetland	Co-opted Statistician	
Dr J Webster	Consultant Physician/Clinical Pharmacologist	
Professor N Webster	Honorary Consultant Anaesthetist	

Apologies

Professor R Anderson	Consultant in Reproductive Medicine
Professor M Donaghy	Allied Health Professions
Ms R McInnes①	Lay
Fr M McManus	Lay
Dr G Masterton②	Consultant Psychiatrist
Mrs M Thomson	Lay
Mr Andrew Walls	Consultant Surgeon

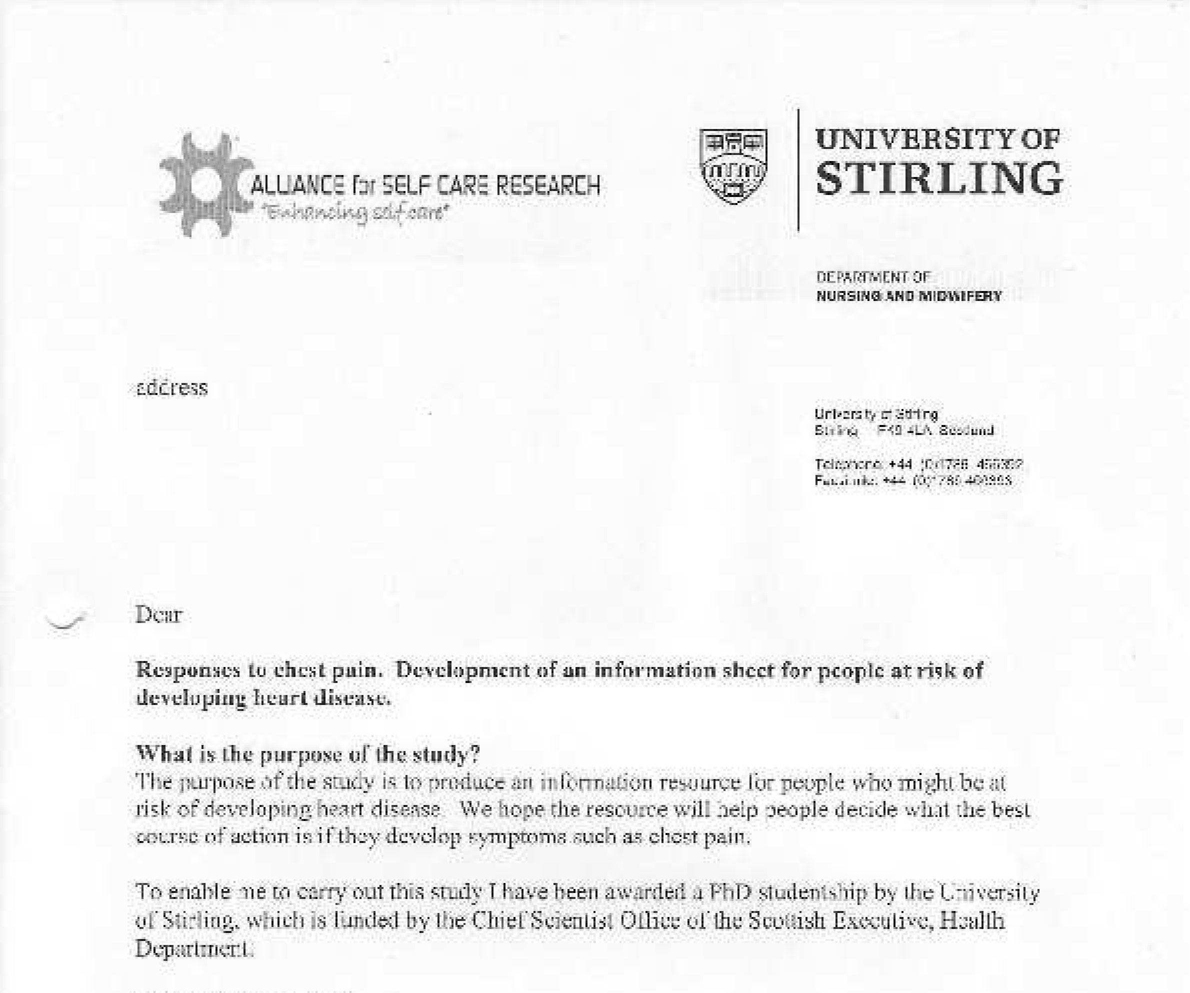
Also in attendance:

Name	Position (or reason for attending)
Mr P Reith	Secretary
Mr W Hunter	Senior Committee Co-ordinator
Mr C Graham	Committee Co-ordinator
Mrs L Roe	Scientific Adviser

① **Provided written comments on 06/MRE00/106 and 06/MRE00/112**

② **Provided written comments on 06/MRE00/80, 06/MRE00/107, 06/MRE00/108, 06/MRE00/109, 06/MRE00/110, 06/MRE00/111 and 06/MRE00/113**

Appendix 4



ALLIANCE for SELF CARE RESEARCH
"Enhancing self care"

UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

University of Stirling
Stirling FK9 4LA Scotland

Telephone +44 (0)1786 466397
Facsimile +44 (0)1786 466333

address

Dear

Responses to chest pain. Development of an information sheet for people at risk of developing heart disease.

What is the purpose of the study?
The purpose of the study is to produce an information resource for people who might be at risk of developing heart disease. We hope the resource will help people decide what the best course of action is if they develop symptoms such as chest pain.

To enable me to carry out this study I have been awarded a PhD studentship by the University of Stirling, which is funded by the Chief Scientist Office of the Scottish Executive, Health Department.

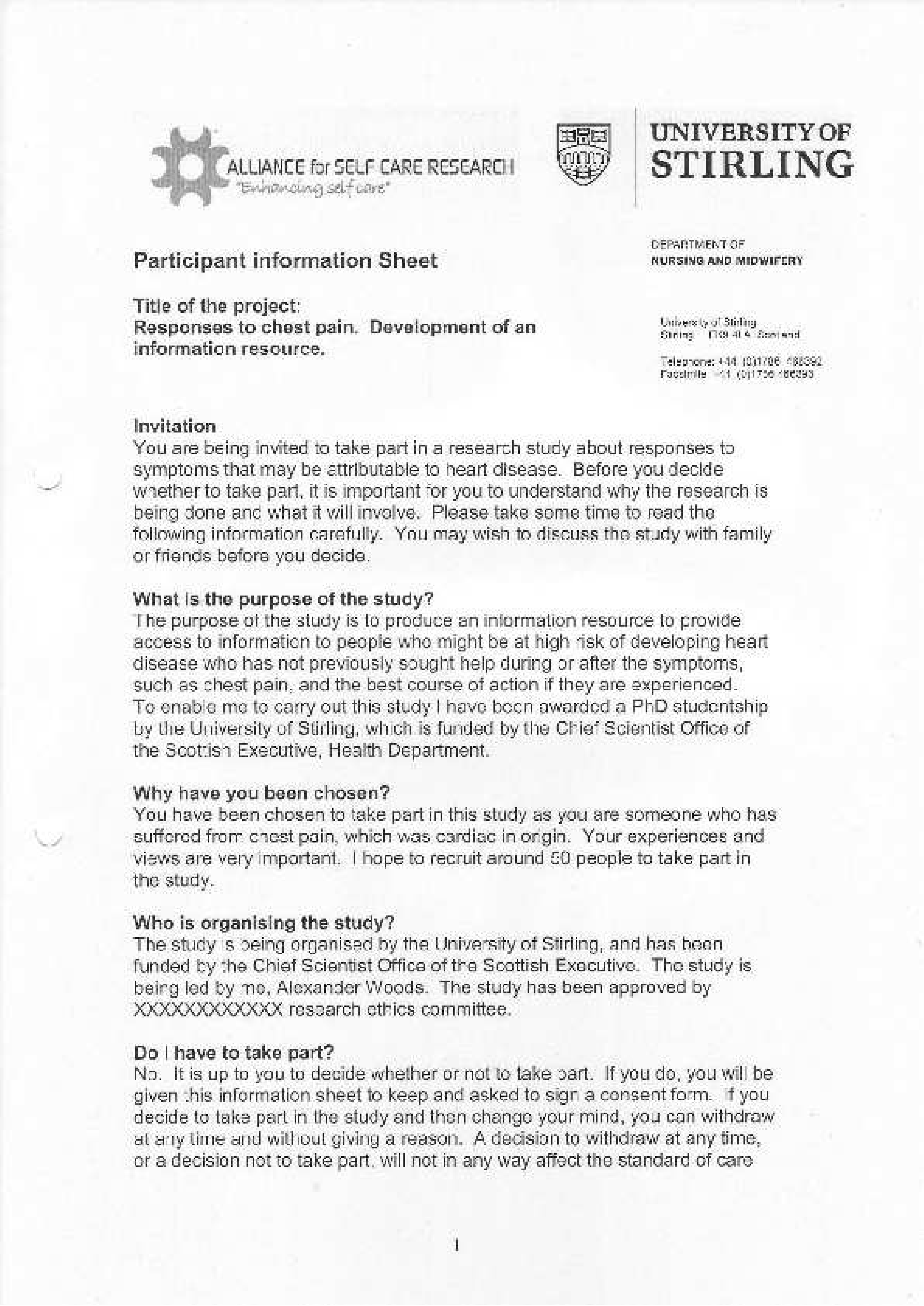
Why is it important?
We believe developing an information resource is important because too few people recognise the symptoms of heart disease and do not seek help for symptoms at an early stage.

How is the information resource being produced?
We are producing the information resource on the basis of what health professionals and people who have experienced symptoms of heart disease tell us is important.

What would be your involvement as team leaders?
Do you think your members would like to hear more about the study? Do you think your members would be interested in becoming involved in helping develop this information resource? If so, would you be happy for me to come and visit your group and talk about the study to you and your members?

What would be the involvement of group members?
Members of your group would be invited to attend a group discussion with around seven other people who have had similar experiences. I will also be there. During the group discussion members will be asked to talk about their experience of their heart problems. Discussions will last an hour or so. All group discussions will be audiotaped and held at a convenient time in a comfortable setting within Falkirk Royal Infirmary or Stirling Royal Infirmary. We hope the discussions will be interesting, and hope the members will feel it was worthwhile participating.

Appendix 5



ALLIANCE for SELF CARE RESEARCH
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NURSING AND MIDWIFERY

University of Stirling
Stirling FK9 4LA Scotland

Telephone: +44 (0)1786 466392
Facsimile +44 (0)1786 466393

Participant information Sheet

Title of the project:
Responses to chest pain. Development of an information resource.

Invitation

You are being invited to take part in a research study about responses to symptoms that may be attributable to heart disease. 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. Please take some time to read the following information carefully. You may wish to discuss the study with family or friends before you decide.

What is the purpose of the study?

The purpose of the study is to produce an information resource to provide access to information to people who might be at high risk of developing heart disease who has not previously sought help during or after the symptoms, such as chest pain, and the best course of action if they are experienced. To enable me to carry out this study I have been awarded a PhD studentship by the University of Stirling, which is funded by the Chief Scientist Office of the Scottish Executive, Health Department.

Why have you been chosen?

You have been chosen to take part in this study as you are someone who has suffered from chest pain, which was cardiac in origin. Your experiences and views are very important. I hope to recruit around 50 people to take part in the study.

Who is organising the study?

The study is being organised by the University of Stirling, and has been funded by the Chief Scientist Office of the Scottish Executive. The study is being led by me, Alexander Woods. The study has been approved by XXXXXXXXXXXX research ethics committee.

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 asked to sign a consent form. If you decide to take part in the study and then change your mind, you can 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 in any way affect the standard of care

1

you receive. **You do not have to make any decisions about the study today.**

What will happen next?
The clinical nurse specialist has given you this information sheet on my behalf. If you decide to take part you should sign the consent form provided, giving the nurse specialist permission for her/him to pass on your details to me. I will then contact you over the next two to three days, which will give you time to consider whether you wish to take part in the study. When I contact you, I will discuss the study with you and answer any questions you may have. If you still wish to take part in the study I will then ask you to attend a group discussion with other people who have had similar experiences to yourself.

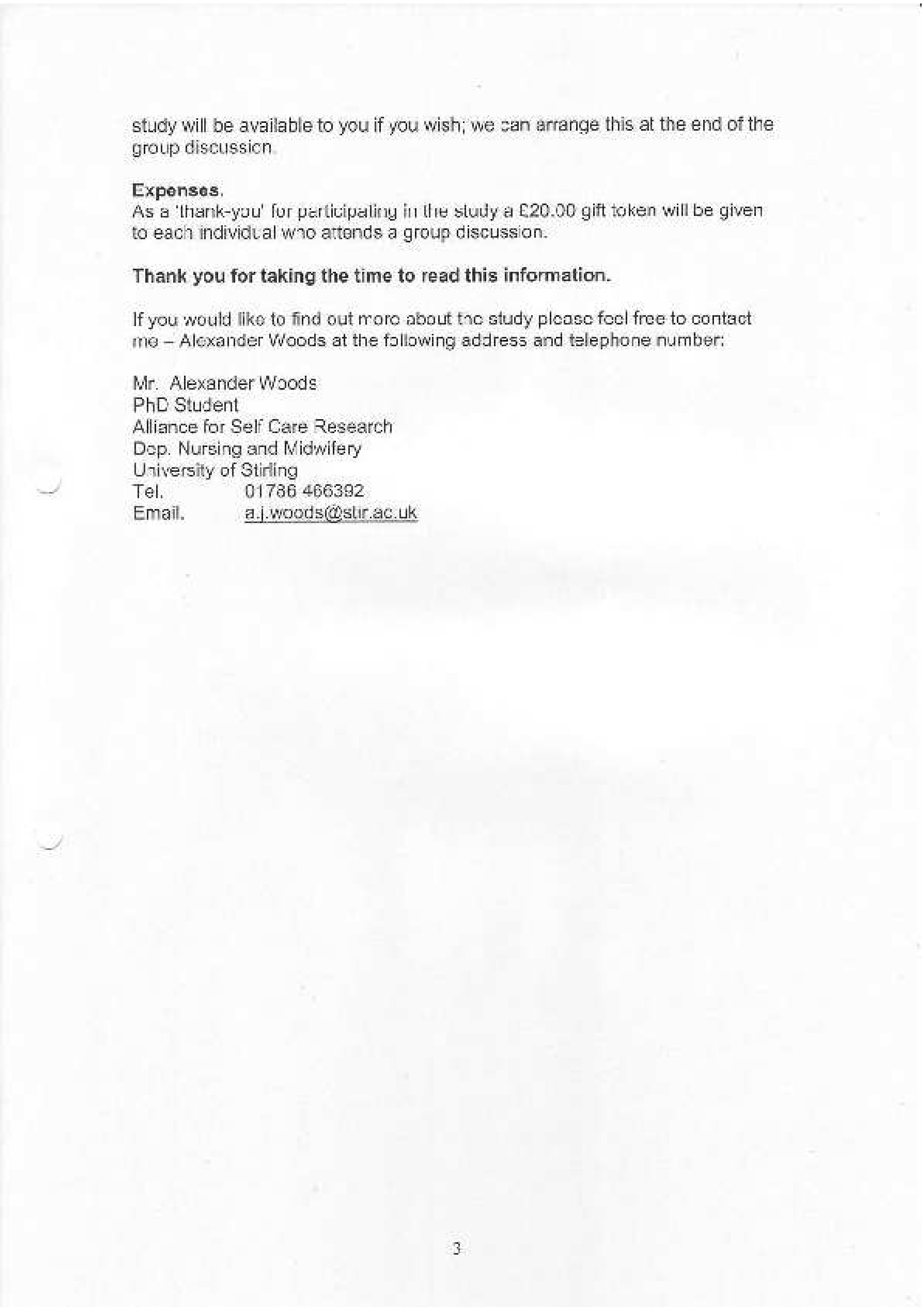
What will taking part in the study mean for me?
Taking part in the study will mean that you will attend a group discussion with around seven other people who have had similar experiences. I will also be there. During the group discussion members will talk about their experience of chest pain. Discussions will last for one to two hours. All group discussions will be held at a convenient time and in a comfortable setting within the hospital.

Will I benefit from taking apart?
I cannot promise that taking part in this study will be of direct benefit to you, but by telling me of your experiences, this will help provide a better understanding of what people, and their families, affected with chest pain go through.

Are their any risks involved in taking part?
It is unlikely that you will come to any harm as a result of taking part in the discussion groups. If you do have any concerns about the way you are approached or treated during the course of the study, please contact either myself or my research supervisor Professor Sally Wyke at Stirling University (01786 466392) or alternatively you can contact the normal National Health Service complaints service which will be made available to you.

Will my taking part be kept confidential?
Any information which is collected about you during the course of the study will be kept strictly confidential. Your personal details will be removed so that you will only be identifiable by a project number and the researcher and his supervisory team will be the only people who have access to your details. All information will be held securely for a period of 10 years, as required by Stirling University. However, any recorded information from you will be destroyed once the project is complete.

What will happen to the results of the study?
When the results of the study have been analysed, a report/thesis will be prepared that I will submit to the University of Stirling. I will also prepare the results for publication and presentations. A summary of the results of the



study will be available to you if you wish; we can arrange this at the end of the group discussion.

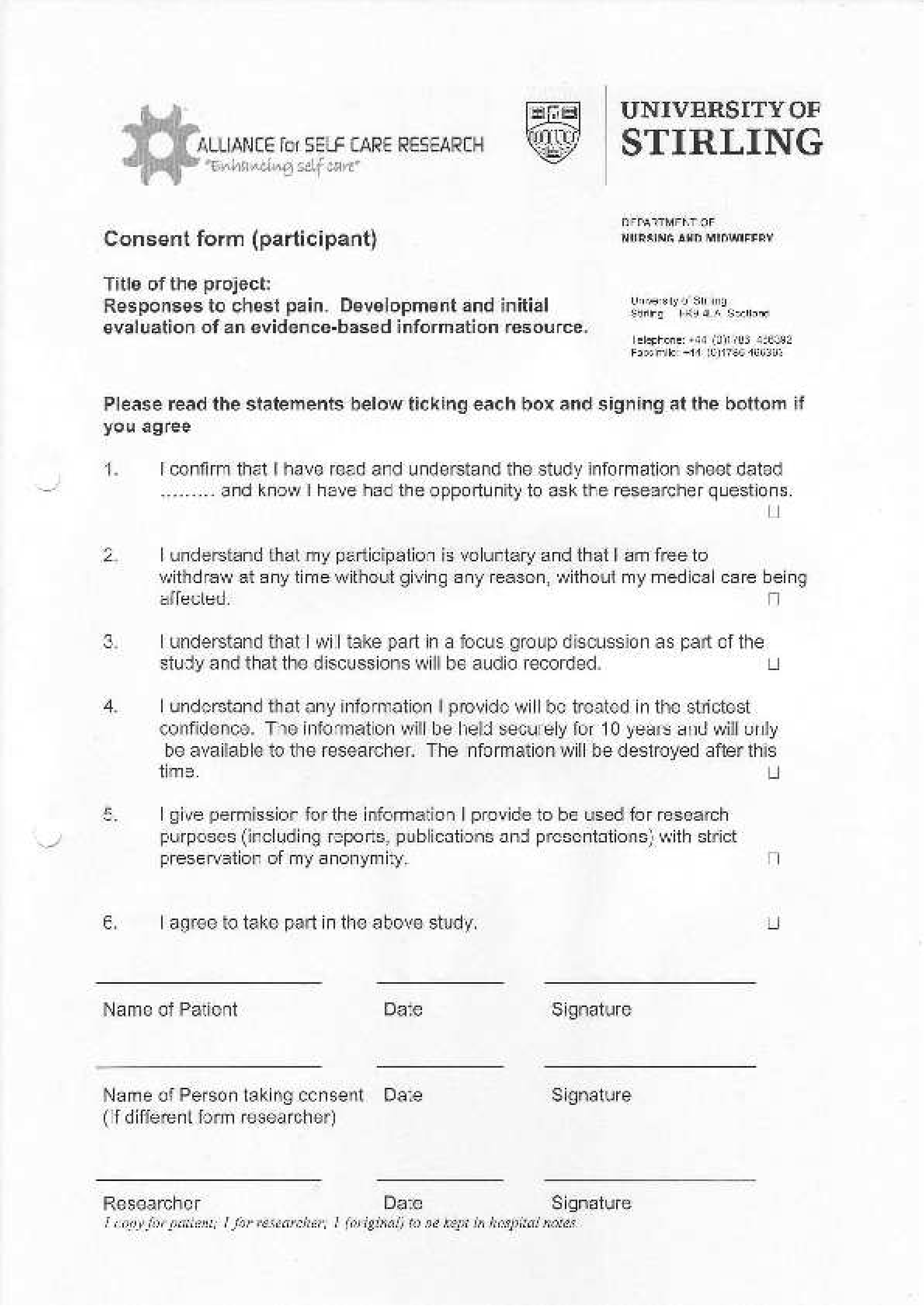
Expenses.
As a 'thank-you' for participating in the study a £20.00 gift token will be given to each individual who attends a group discussion.

Thank you for taking the time to read this information.

If you would like to find out more about the study please feel free to contact me – Alexander Woods at the following address and telephone number:

Mr. Alexander Woods
PhD Student
Alliance for Self Care Research
Dep. Nursing and Midwifery
University of Stirling
Tel. 01786 466392
Email. a.j.woods@stir.ac.uk

Appendix 6



ALLIANCE for SELF CARE RESEARCH
"Enhancing self care"

UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Consent form (participant)

Title of the project:
Responses to chest pain. Development and initial evaluation of an evidence-based information resource.

University of Stirling
Stirling FK9 4LA Scotland

Telephone: +44 (0)1786 466392
Facsimile: +44 (0)1786 466333

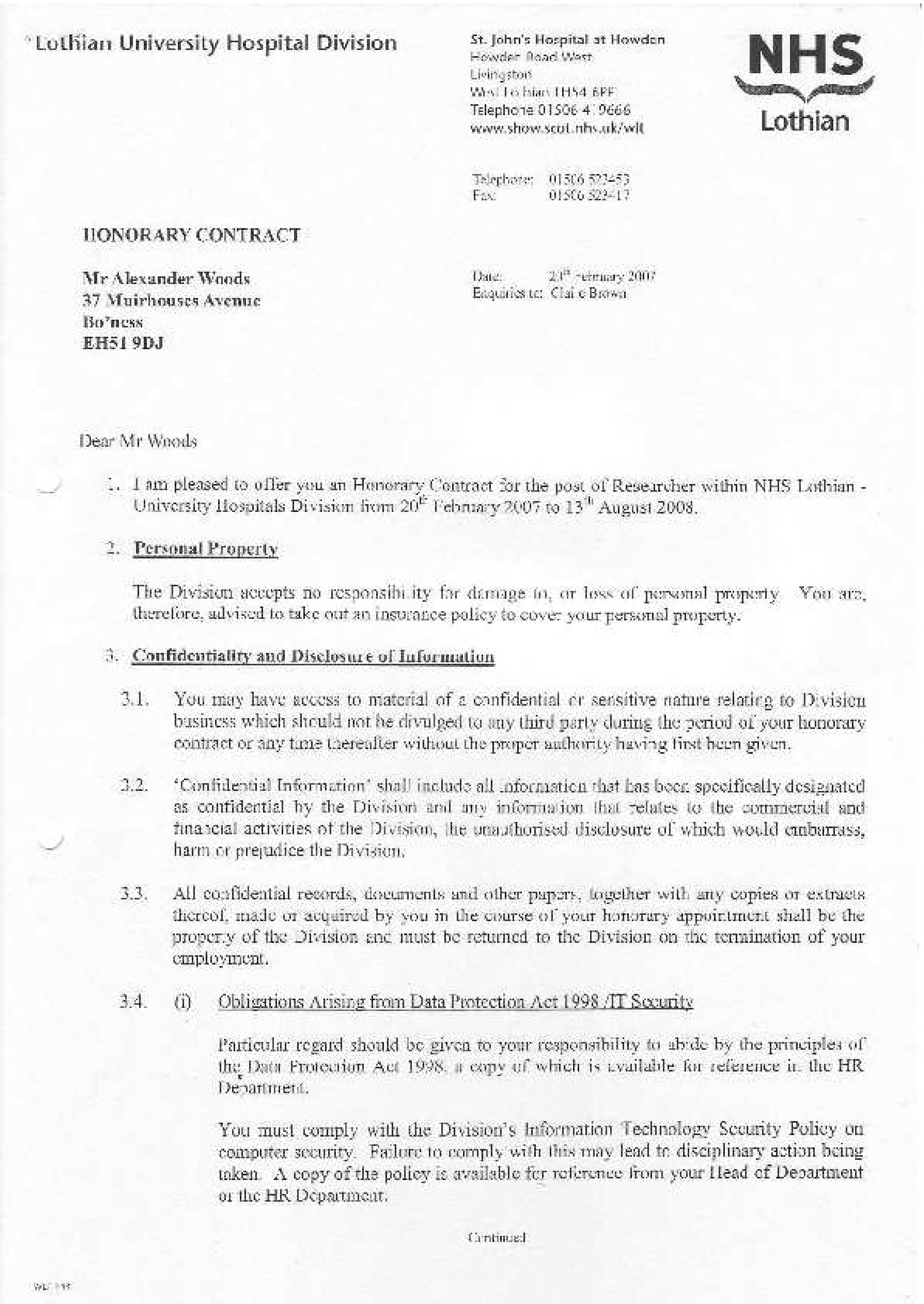
Please read the statements below ticking each box and signing at the bottom if you agree

1. I confirm that I have read and understand the study information sheet dated ……… and know I have had the opportunity to ask the researcher questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care being affected. ☐
3. I understand that I will take part in a focus group discussion as part of the study and that the discussions will be audio recorded. ☐
4. I understand that any information I provide will be treated in the strictest confidence. The information will be held securely for 10 years and will only be available to the researcher. The information will be destroyed after this time. ☐
5. I give permission for the information I provide to be used for research purposes (including reports, publications and presentations) with strict preservation of my anonymity. ☐
6. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Name of Person taking consent (if different form researcher)	Date	Signature
Researcher	Date	Signature

1 copy for patient; 1 for researcher; 1 (original) to be kept in hospital notes

Appendix 7



Lothian University Hospital Division

St. John's Hospital at Howden
Howden Road West
Livingston
West Lothian EH54 6PP
Telephone 01506 419666
www.show.scot.nhs.uk/wlt

NHS
Lothian

Telephone: 01506 523453
Fax: 01506 523417

HONORARY CONTRACT

Mr Alexander Woods
37 Muirhouses Avenue
Bo'ness
EH51 9DJ

Date: 20th February 2007
Enquiries to: Claire Brown

Dear Mr Woods

1. I am pleased to offer you an Honorary Contract for the post of Researcher within NHS Lothian - University Hospitals Division from 20th February 2007 to 13th August 2008.

2. **Personal Property**

   The Division accepts no responsibility for damage to, or loss of personal property. You are, therefore, advised to take out an insurance policy to cover your personal property.

3. **Confidentiality and Disclosure of Information**

   3.1. You may have access to material of a confidential or sensitive nature relating to Division business which should not be divulged to any third party during the period of your honorary contract or any time thereafter without the proper authority having first been given.

   3.2. 'Confidential Information' shall include all information that has been specifically designated as confidential by the Division and any information that relates to the commercial and financial activities of the Division, the unauthorised disclosure of which would embarrass, harm or prejudice the Division.

   3.3. All confidential records, documents and other papers, together with any copies or extracts thereof, made or acquired by you in the course of your honorary appointment shall be the property of the Division and must be returned to the Division on the termination of your employment.

   3.4. (i) Obligations Arising from Data Protection Act 1998 /IT Security

   Particular regard should be given to your responsibility to abide by the principles of the Data Protection Act 1998, a copy of which is available for reference in the HR Department.

   You must comply with the Division's Information Technology Security Policy on computer security. Failure to comply with this may lead to disciplinary action being taken. A copy of the policy is available for reference from your Head of Department or the HR Department.

Continued

(ii) Patients

In the course of your duties you may have access to confidential material about patients. On no account must information relating to patients be divulged to anyone other than authorised persons, for example, medical, nursing or other professional staff as appropriate, who are concerned directly with the care, diagnosis and/or treatment of the patient.

(iii) Staff

Similarly, no information of a personal or confidential nature concerning individual members of staff should be divulged to anyone without the authority of the appropriate Head of Department.

3.5. If you are in any doubt whatsoever as to the authority of a person or body asking for information on patients or staff, or your own authority to divulge information, you must seek advice from your Head of Department.

3.6. If you have any concerns about the quality of service, health and safety, use of NHS money or believe a colleague's conduct, performance or health may be a threat to patient care or to members of staff, you have a responsibility to raise these concerns either directly with your line manager or the HR Department.

3.7. Criminal Convictions

Because of the nature of your honorary appointment, you are required not to withhold information about criminal convictions either previous or subsequent to being employed, including convictions that for other purposes are considered spent. Any information given will be in complete confidence.

These provisions are without prejudice to the NHS's stated commitments in the NHS Code of Openness. Further information is available from the HR Department.

4. Disclosure of Concerns

If you have any concerns about quality of service, health and safety, use of NHS money, or believe a colleague's conduct, performance or health may be a threat to patient care or to members of staff, you have a responsibility to raise these concerns without prejudice directly with your line manager or head of department. If you are unable to, or wish not to raise these concerns directly with your line manager or head of department, you are encouraged to seek the advice of your HR Department or your staff representative.

You are protected against any harassment or victimisation resulting from such a disclosure, therefore in the event that you are subjected to any form of harassment or victimisation, the Division will take formal action against the perpetrators.

5. **Gifts and Hospitality**

You are required to be impartial and strictly independent in your dealings with commercial bodies and individuals. You must not accept gifts or hospitality from any external organisation without the prior permission of the Division. You should contact the HR Department if you are in any doubt. Unauthorised acceptance of gifts and/or hospitality may result in disciplinary action being taken, including dismissal.

6. **Conflict of Interests**

As a general principle, you should not put yourself in a position where your official and private interests conflict, nor must you make use of your official position to further your private interests.

You are required to obtain written permission from the Division Chief Executive (or Director of Human Resources) before undertaking any form of private work which involves the use of confidential NHS information or resources.

7. **Health and Safety**

The Division has a written Health and Safety Policy. The Division has a duty to ensure, so far as is reasonably practicable, the health, safety and welfare at work of all its employees. As an employee, you have a duty to observe safe systems of work at all times, to take reasonable care of yourself and others who may be affected by your activities at work and to co-operate with the Division and others in meeting statutory requirements. Additionally, you are required to report all accidents and "near misses" to your Head of Department and to use any safety equipment provided for your protection.

It is a condition of your appointment that you must attend a Fire Lecture at least once a year.

Failure to comply with the provisions detailed above, without reasonable cause, may result in action being taken against you.

8. **Controls on Hours of Work**

You are expected to co-operate with the Division in protecting your health and safety and that of patients, colleagues and members of the public by abiding by the principles of the Working Time Regulations and NHS Circular MEL(1999)1. Further information is available from your line manager or HR.

9. **Notice Period**

Not applicable

10. **Professional Registration**

Not applicable

11. **Hepatitis B**

If your post is designated an Exposure Prone Procedure (EPP) post, you must produce satisfactory evidence of your Hepatitis B Immunisation status. You are required to maintain Hepatitis B immunity status for the duration of your employment and agree to comply with all requests to monitor and maintain your immune status.

If you agree to accept this appointment on the terms indicated above, please sign the statement of acceptance and return the copy contract to Susan Shepherd. A second copy of this letter is attached and should be retained by you for future reference.

Yours sincerely

Claire Brown

Claire Brown
Recruitment Administrator

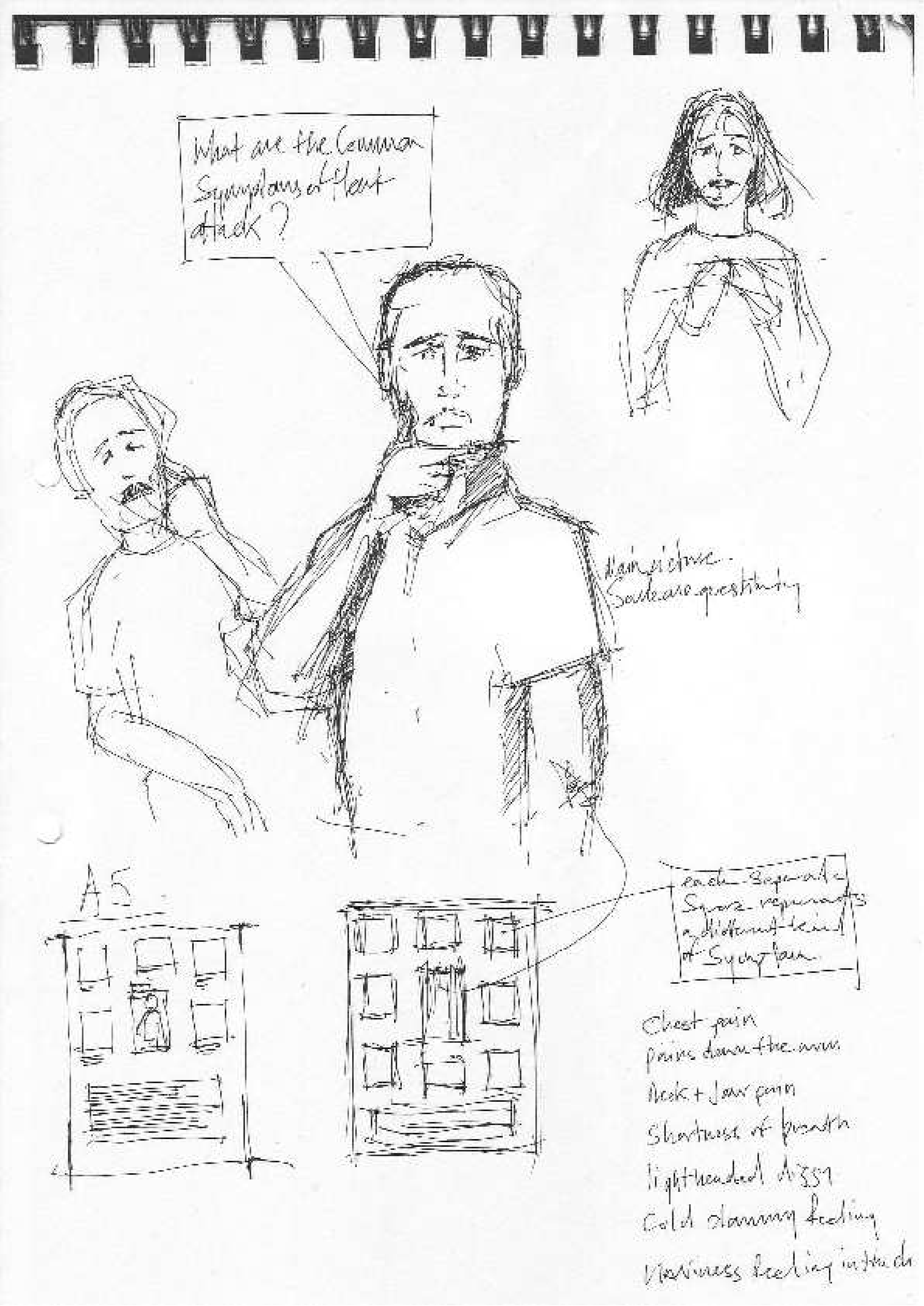
(PLEASE DO NOT DETACH)

Form of Acceptance

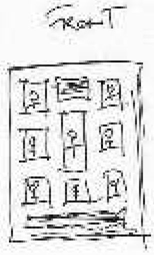
I hereby accept the appointment on the conditions set out in the foregoing contract.

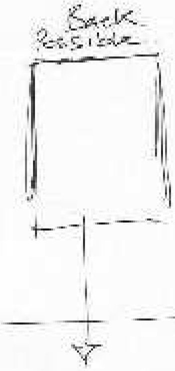
Date ______________________________ Signature ______________________________

Appendix 8


What are the Common Symptoms of Heart attack?
Main picture. Scale are questioning
A5
each Separate Space represents a different kind of Symptom
Chest pain
pains down the arm
Neck + Jaw pain
Shortness of breath
lightheaded dizzy
Cold clammy feeling
Heaviness feeling in the ch


Info about C.H.D
Palpitations.
Breathlessness
Shortness of breath.
Chest pain
Light headed, dizzy with chest pain.
Chest pain in the centre of the chest.
Feeling sick with chest pain
The symptoms can vary
Neck, Jaw pain in women
Pain down the side of the arm
Feeling short of breath with chest pain
Sweating clammy feeling with chest pain
Info on what to do.
With all the images use Positive images
Women – older people
ethnic minority.

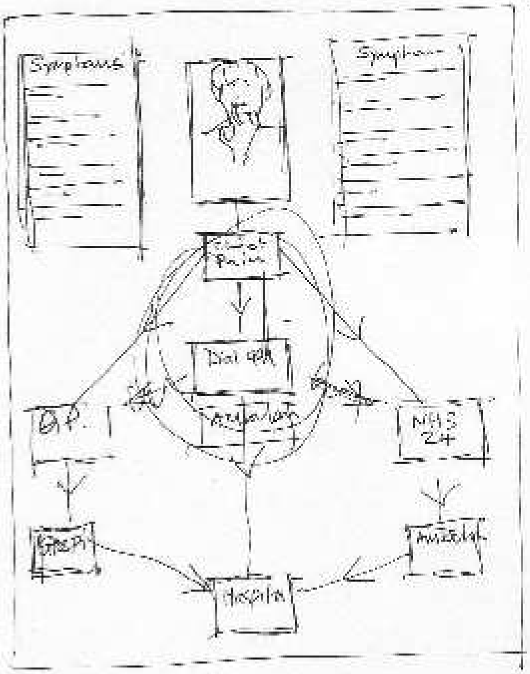




Why? : Sheet As

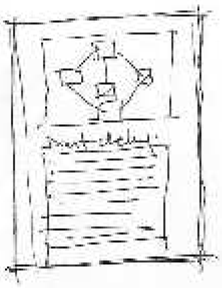
Rational

1) cheap Medium - which will require less expertise to Produce.
2) It can be produced to meet specific needs of the people involved ie. easily tailored for Man [illegible].
3) People will recieve a copy to take with them - to refer to as they want.
4) easy to revise and update
5) Published easily and easily stored
6) Pictures simplify the complex information easy to relate to.
7) The graphics will break up the text making it less daunting.
8) Flow diagrams help people recognise where they are in the process.

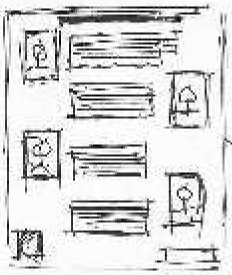


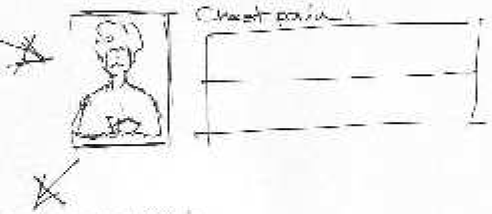
Example.

OR



A.5: Handout – Each picture depicts a different scenario
→ Chest pain – centre of the chest with a description provided by one the individuals interviewed. And how these symptoms can be different ie heavy feeling / discomfort.





chest Pain
Personal account

Then how the symptoms can vary / or where they are.

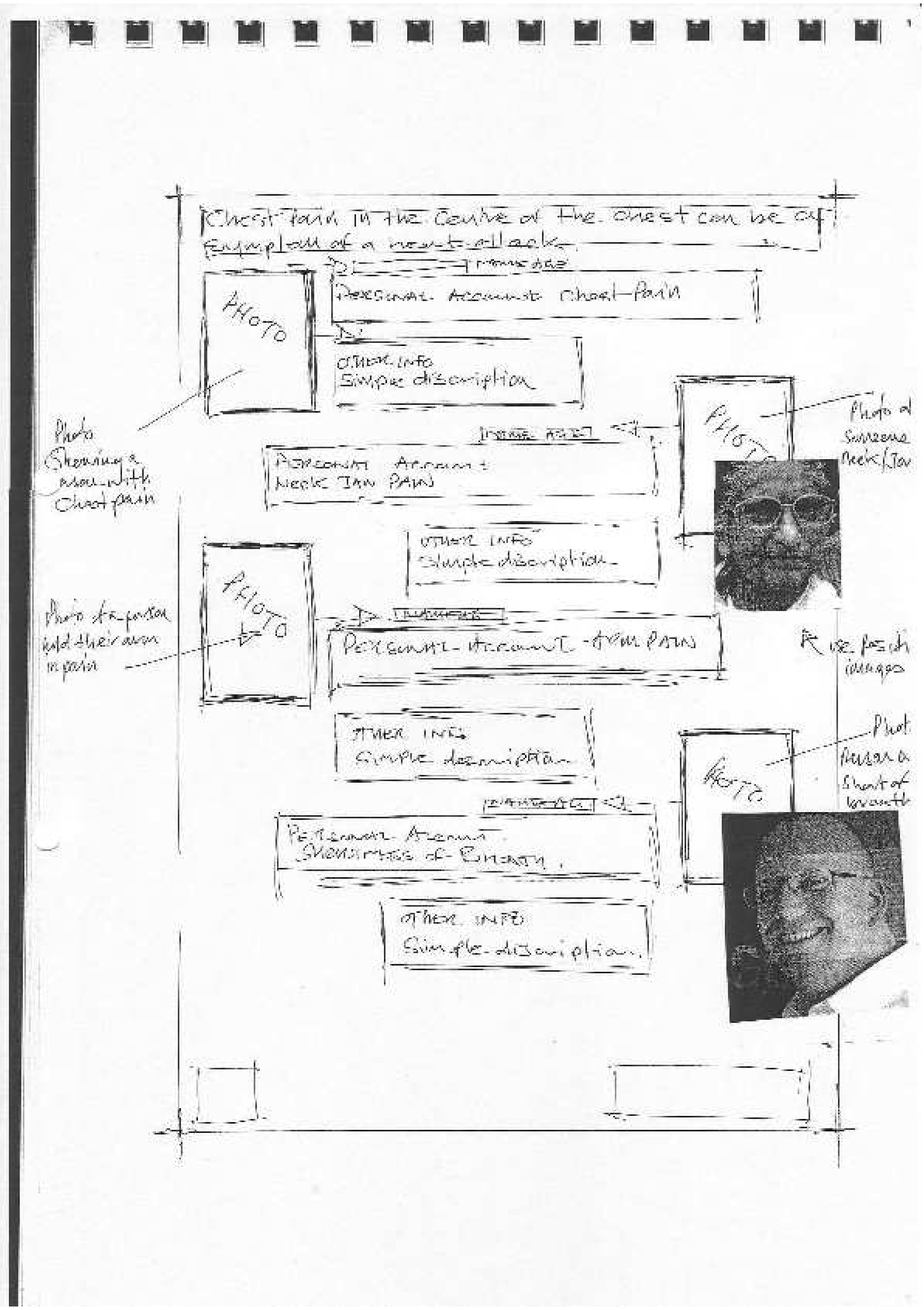
Next comma

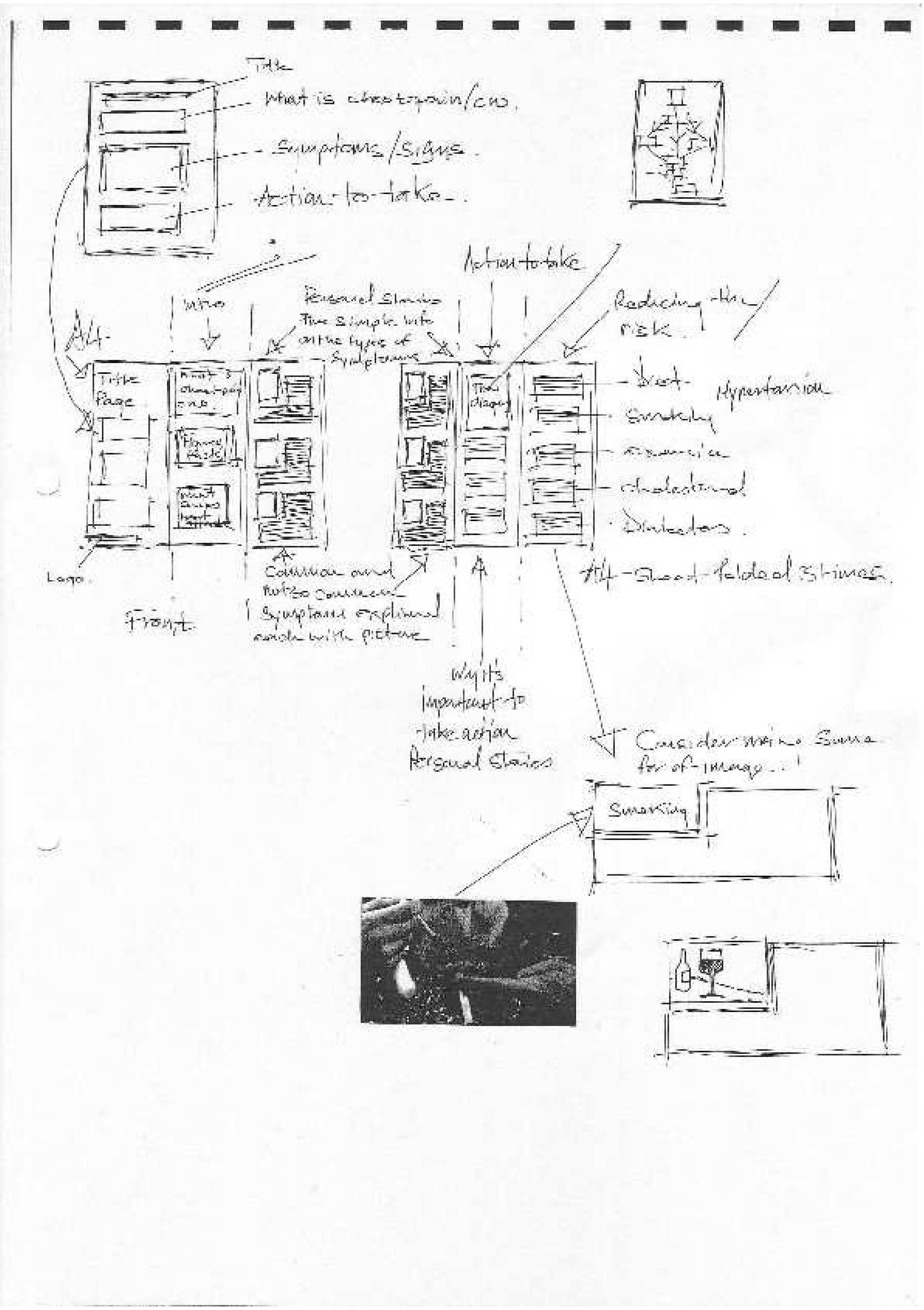
5/4 – Accounts – chest pain. — central chest pain – severe/dull/heavy/discomfo
Neck/Jaw pain,
Pain in the arm
Feeling of nausea/dizzy
Shortness of breath.

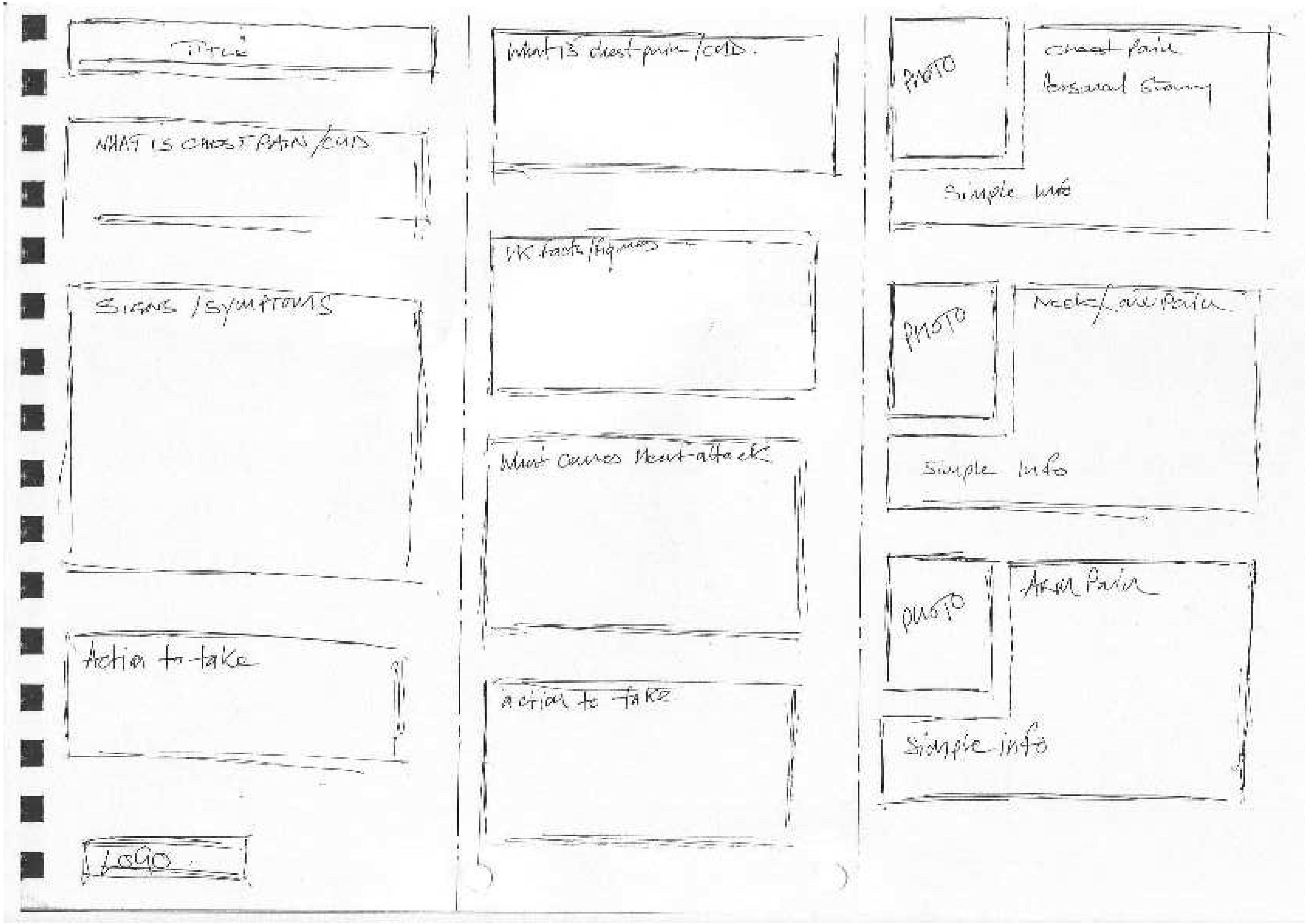
→ Consider the use of positive images – in this case women, older women, women from ethnic minorities → These are the target audience.

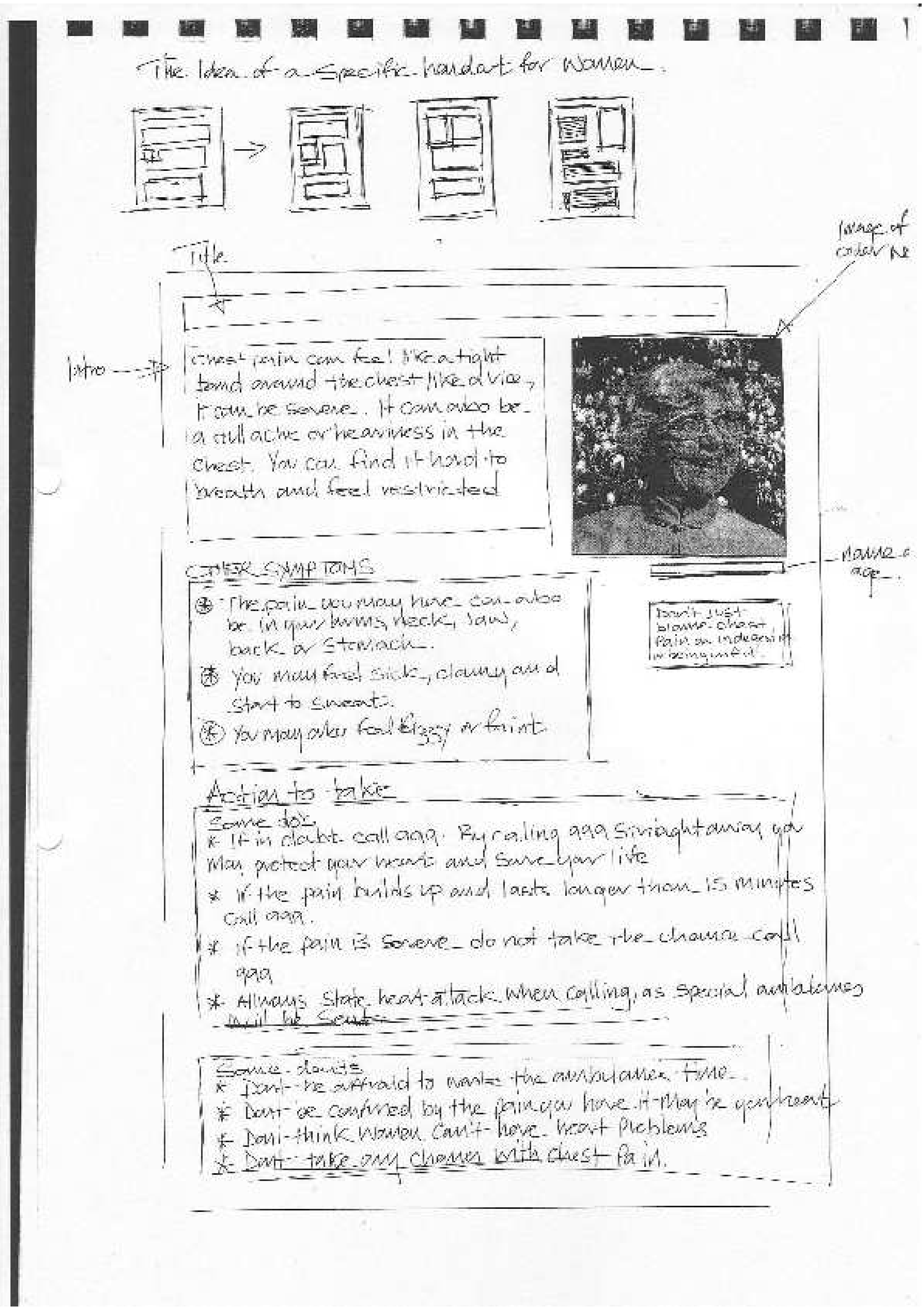
Points.

- * Tightness in the chest, discomfort, squeezing or heavy pressure or a dull ache in the chest
- * A shortness of breath, it becomes harder to breath, you feel restricted
- * The pain may also occur in your arms, the neck and jaw or even in your back and stomach
- * Women may have pains that are difficult to pin down – Don't ignore them.


Chest pain in the centre of the chest can be a symptom of a heart attack.
PHOTO
Personal Account chest pain
Other info
Simple discription
Photo showing a man with chest pain
Photo of someone neck/jaw
PHOTO
Personal Account
Neck Jaw Pain
Other info
Simple discription
PHOTO
Photo of a person hold their arm in pain
Personal Account - arm pain
use posed images
Other info
Simple description
Phot person a short of breath
PHOTO
Personal Account
Shortness of Breath.
Other info
Simple discription.


Title
What is chest pain/CHD.
Symptoms/signs.
Action to take.
Intro
Personal Stories
Two simple info on the types of symptoms
Action to take
Reducing the risk.
A4
Title Page
What is chest pain/CHD.
Figure Facts
What causes heart attacks
Two diagram
Diet
Hypertension
Smoking
Exercise
Cholesterol
Diabetes.
Logo.
Front.
Common and not so common symptoms explained each with picture
A4 - Sheet folded 3 times.
Why it's important to take action
Personal Stories
Consider main scene for of image..!
Smoking


Title
WHAT IS CHEST PAIN / CVD
SIGNS / SYMPTOMS
Action to take
LOGO
What is chest pain / CVD.
UK facts / figures
What causes heart-attack
action to take
PHOTO
Chest pain
Personal Story
Simple info
PHOTO
Neck / Jaw Pain
Simple info
PHOTO
Arm Pain
Simple info



The Idea of a Specific handout for Women.

Chest pain can feel like a tight band around the chest like a vice, it can be severe. It can also be a dull ache or heaviness in the chest. You can find it hard to breath and feel restricted

OTHER SYMPTOMS

- The pain you may have can also be in your arms, neck, jaw, back or stomach.
- You may feel sick, clammy and start to sweat.
- You may also feel dizzy or faint.

Don't just blame chest pain on indigestion or being unfit.

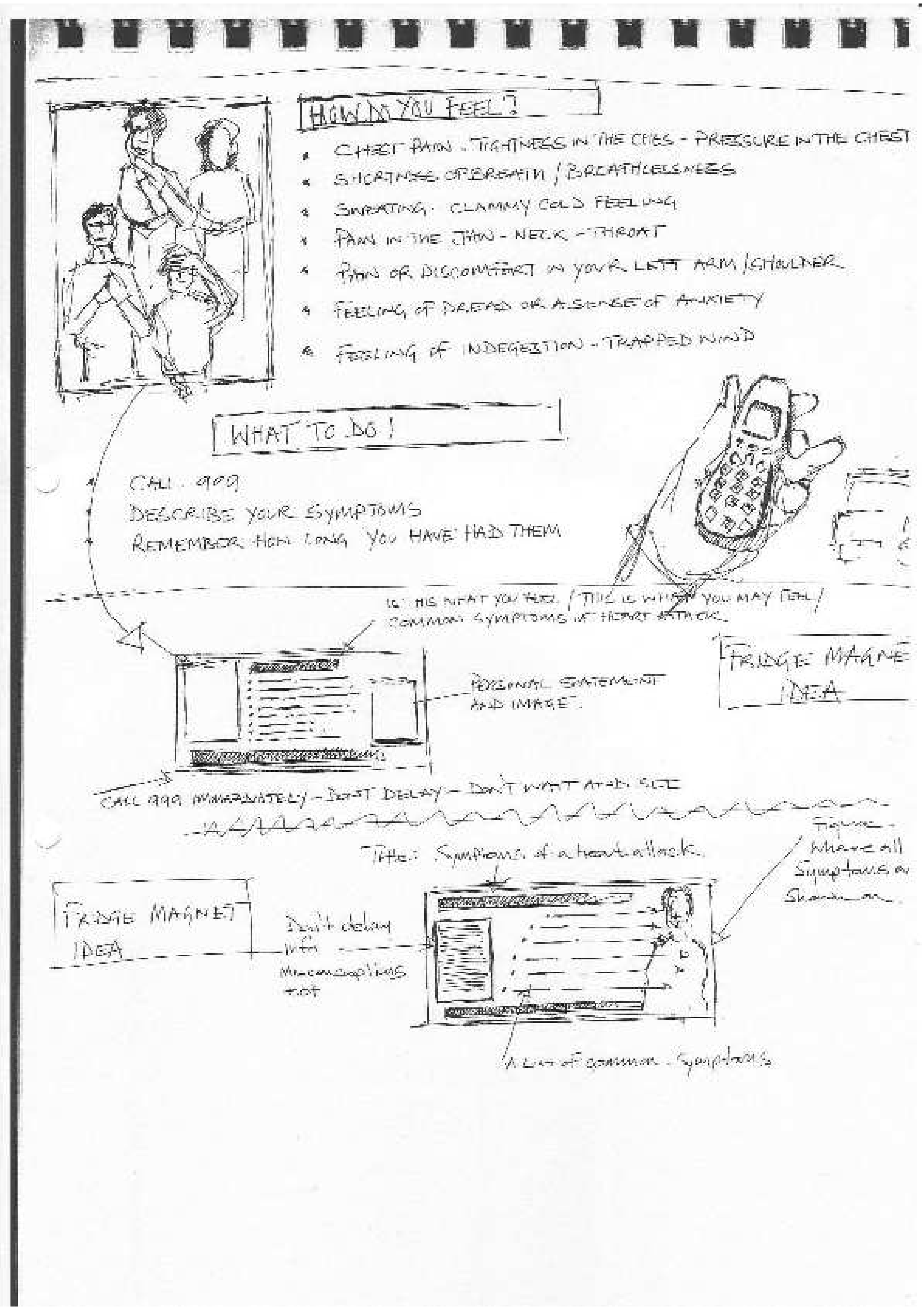
Action to take

Some do's

* If in doubt call 999. By calling 999 straightaway you may protect your heart and save your life
* If the pain builds up and lasts longer than 15 minutes call 999.
* If the pain is severe do not take the chance call 999
* Always state heart attack when calling, as special ambulances will be sent.

Some don'ts

* Don't be afraid to waste the ambulance time.
* Don't be confused by the pain you have it may be your heart
* Don't think women can't have heart problems
* Don't take any chances with chest pain.



HOW DO YOU FEEL?

- CHEST PAIN . TIGHTNESS IN THE CHES - PRESSURE IN THE CHEST
- SHORTNESS OF BREATH / BREATHLESSNESS
- SWEATING . CLAMMY COLD FEELING
- PAIN IN THE JAW - NECK - THROAT
- PAIN OR DISCOMFORT IN YOUR LEFT ARM / SHOULDER
- FEELING OF DREAD OR A SENSE OF ANXIETY
- FEELING OF INDIGESTION - TRAPPED WIND

WHAT TO DO!

CALL . 999
DESCRIBE YOUR SYMPTOMS
REMEMBER HOW LONG YOU HAVE HAD THEM

IS THIS WHAT YOU FEEL / THIS IS WHAT YOU MAY FEEL / COMMON SYMPTOMS OF HEART ATTACK.

PERSONAL STATEMENT AND IMAGE.

FRIDGE MAGNE
IDEA

CALL 999 IMMEDIATELY - DON'T DELAY - DON'T WAIT AND SEE

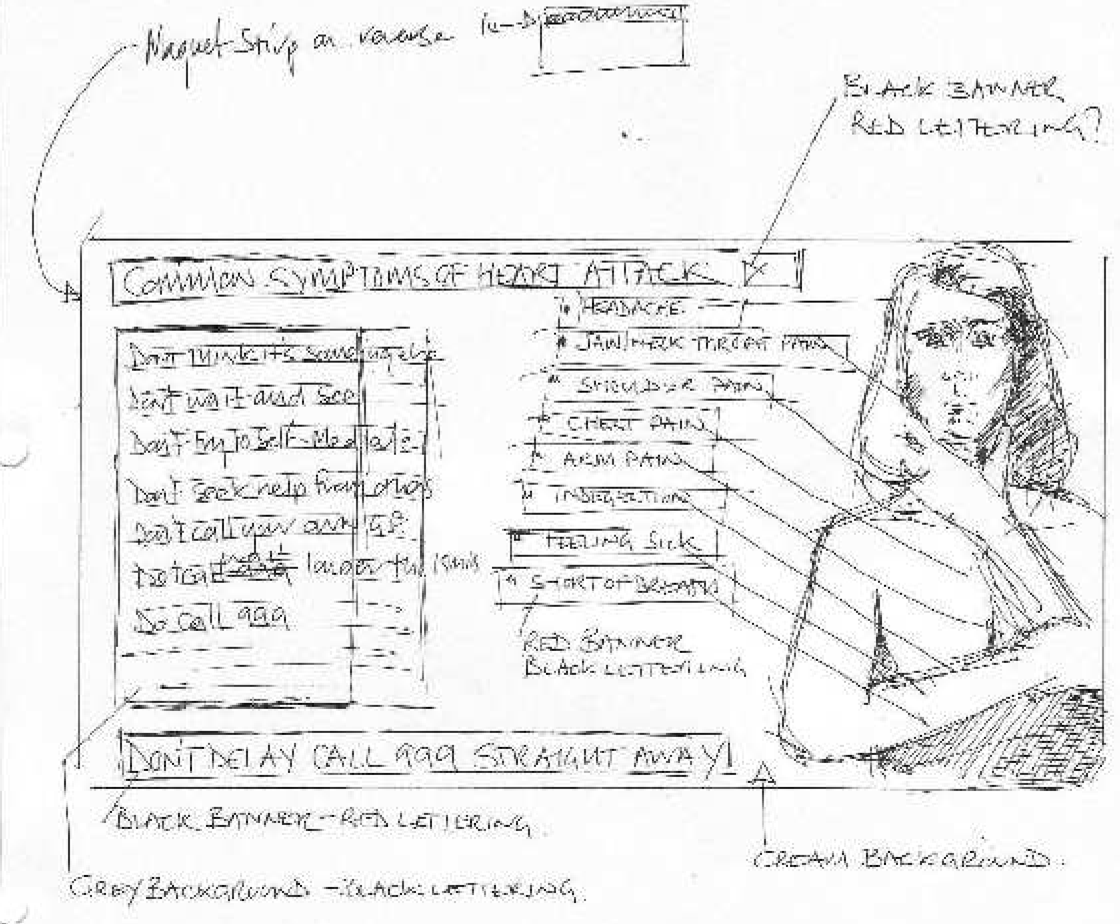
Title: Symptoms of a heart attack.

Figure - where all symptoms are shown on.

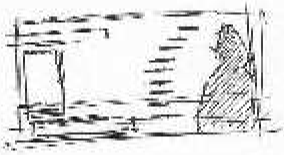
FRIDGE MAGNET
IDEA

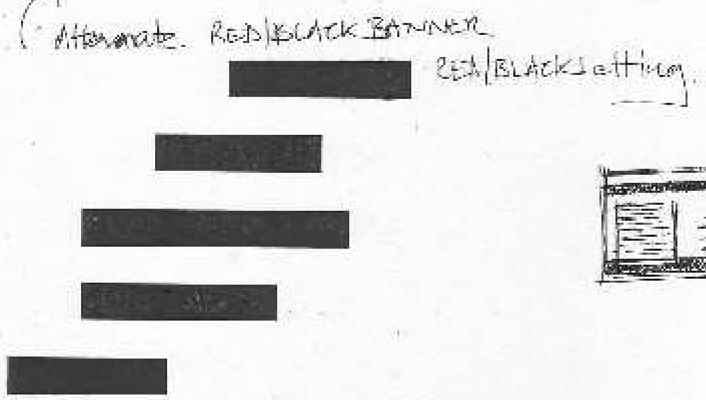
Don't delay
info
misconceptions
etc

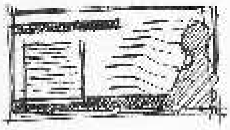
A list of common symptoms

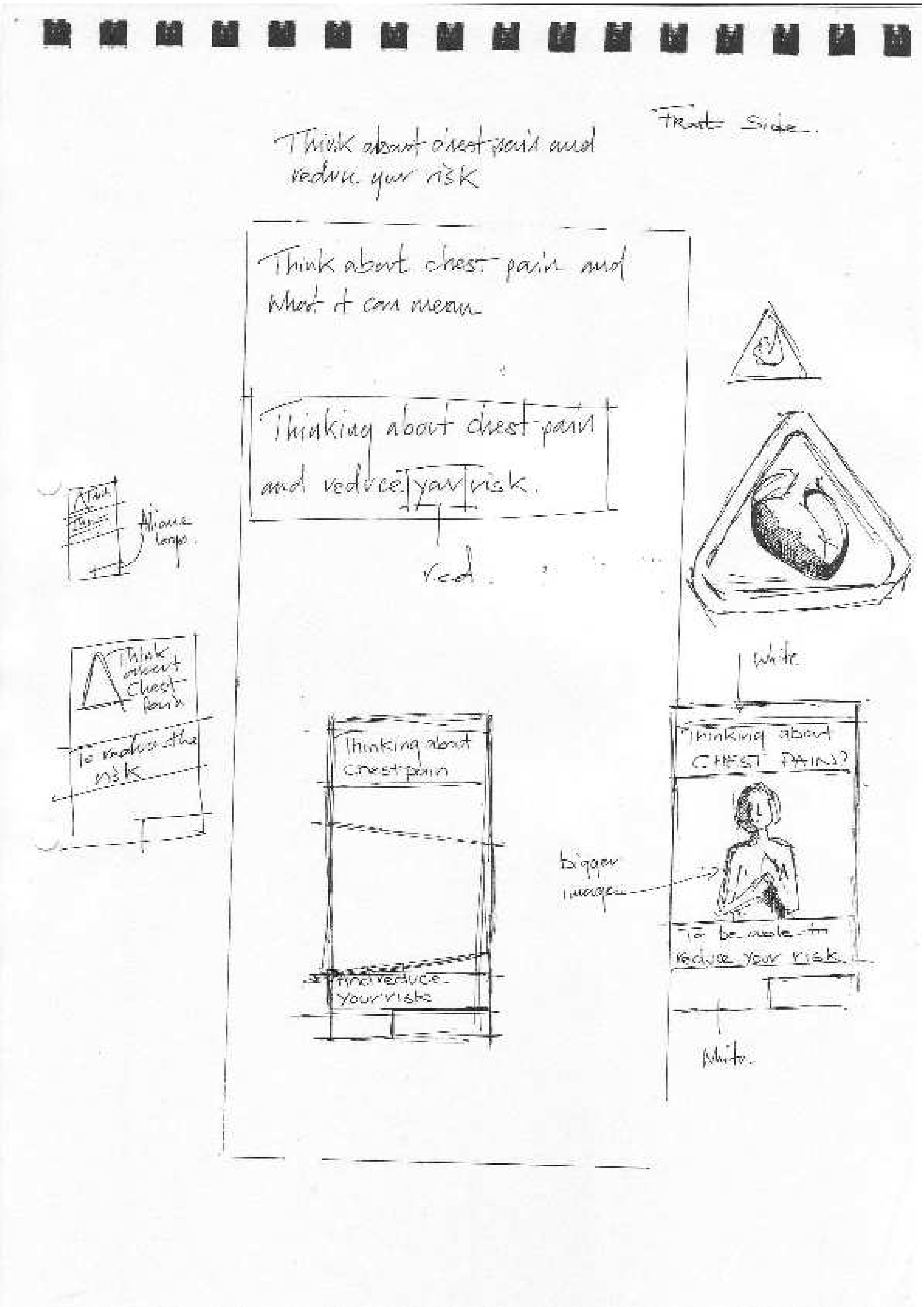

Magnet strip on reverse i.e.
BLACK BANNER
RED LETTERING?
COMMON SYMPTOMS OF HEART ATTACK
Don't think it's something else
Don't wait and see
Don't try to self-medicate
Don't seek help from others
Don't call your own GP
[illegible] the pain
Do call 999
* HEADACHE
* JAW/NECK THROAT PAIN
* SHOULDER PAIN
* CHEST PAIN
* ARM PAIN
* INDIGESTION
* FEELING SICK
* SHORT OF BREATH
RED BANNER
BLACK LETTERING
DON'T DELAY CALL 999 STRAIGHT AWAY!
BLACK BANNER - RED LETTERING
CREAM BACKGROUND
GREY BACKGROUND - BLACK LETTERING

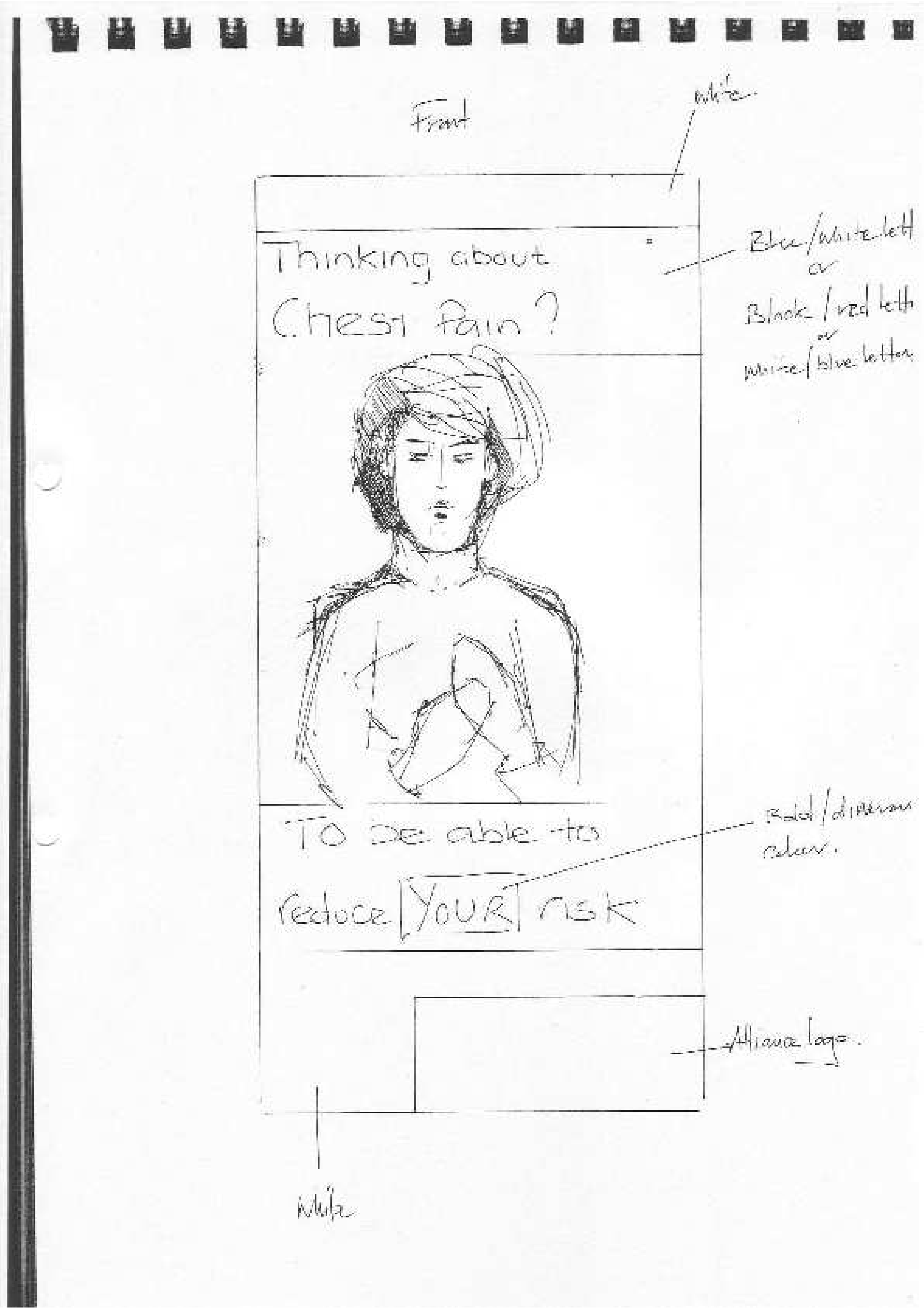

CHEST
ARM



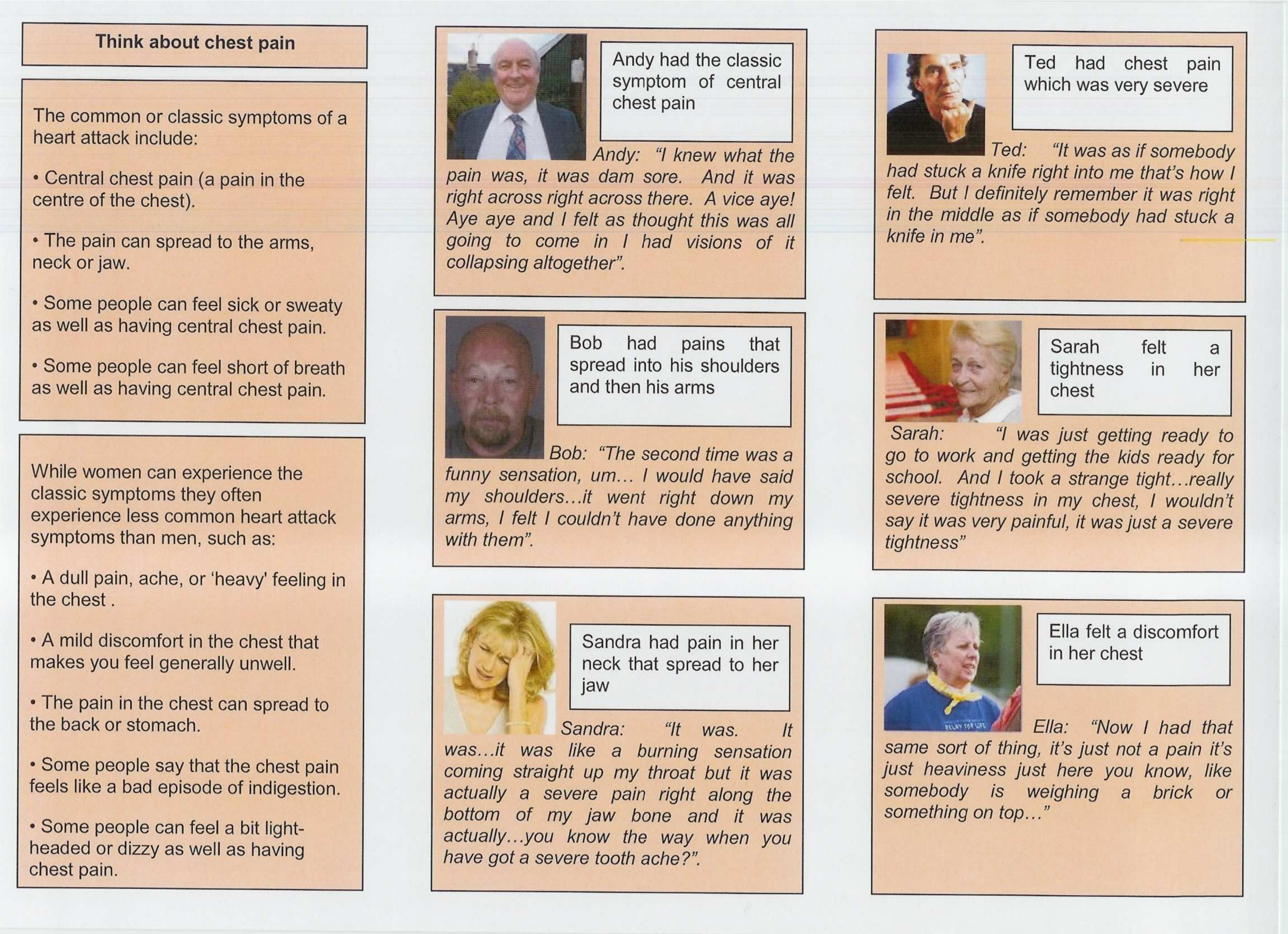

Alternate. RED/BLACK BANNER
RED/BLACK lettering




Treat Side.
Think about chest pain and
reduce your risk
Think about chest pain and
what it can mean
Thinking about chest pain
and reduce your risk.
red.
Alliance logo.
Think about Chest pain
To reduce the risk
Thinking about
chest pain
and reduce
your risk
white
Thinking about
CHEST PAIN?
bigger
image
To be able to
reduce your risk.
White.


Front
white
Thinking about
Chest Pain?
Blue / white lett
or
Black / red lett
or
white / blue letter
To be able to
reduce YOUR risk
Bold / different
colour.
Alliance logo.
white

Appendix 9



Think about chest pain

The common or classic symptoms of a heart attack include:

- Central chest pain (a pain in the centre of the chest).
- The pain can spread to the arms, neck or jaw.
- Some people can feel sick or sweaty as well as having central chest pain.
- Some people can feel short of breath as well as having central chest pain.

While women can experience the classic symptoms they often experience less common heart attack symptoms than men, such as:

- A dull pain, ache, or 'heavy' feeling in the chest .
- A mild discomfort in the chest that makes you feel generally unwell.
- The pain in the chest can spread to the back or stomach.
- Some people say that the chest pain feels like a bad episode of indigestion.
- Some people can feel a bit light-headed or dizzy as well as having chest pain.

Andy had the classic symptom of central chest pain

Andy: "I knew what the pain was, it was dam sore. And it was right across right across there. A vice aye! Aye aye and I felt as thought this was all going to come in I had visions of it collapsing altogether".

Bob had pains that spread into his shoulders and then his arms

Bob: "The second time was a funny sensation, um... I would have said my shoulders...it went right down my arms, I felt I couldn't have done anything with them".

Sandra had pain in her neck that spread to her jaw

Sandra: "It was. It was...it was like a burning sensation coming straight up my throat but it was actually a severe pain right along the bottom of my jaw bone and it was actually...you know the way when you have got a severe tooth ache?".

Ted had chest pain which was very severe

Ted: "It was as if somebody had stuck a knife right into me that's how I felt. But I definitely remember it was right in the middle as if somebody had stuck a knife in me".

Sarah felt a tightness in her chest

Sarah: "I was just getting ready to go to work and getting the kids ready for school. And I took a strange tight...really severe tightness in my chest, I wouldn't say it was very painful, it was just a severe tightness"

Ella felt a discomfort in her chest

Ella: "Now I had that same sort of thing, it's just not a pain it's just heaviness just here you know, like somebody is weighing a brick or something on top…"

What to look out for

The symptoms of a heart attack vary slightly from one person to another.

They range from a severe pain in the centre of the chest, to having mild chest discomfort that makes you feel generally unwell.

The pain often feels like a heaviness or tightness which may also spread to the arms, neck, jaw, back or stomach.

Or it may affect only the neck, jaw, arms or stomach. You may also sweat, feel light-headed, feel sick, or be short of breath.

Symptoms can be very mild and produce little discomfort. In some cases people mistake the pain of a heart attack for indigestion and may never report it to their doctor.

If you experience any of these symptoms, don't ignore them. Call 999 immediately.

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STIRLING

Why act immediately?

If you suspect that you are having a heart attack, call 999 immediately.

Your heart needs a constant supply of oxygen-containing blood to keep it healthy and a heart attack happens when a blood clot in an artery interrupts that blood supply.

Calling an ambulance immediately means that, if you need it, you can get a clot-busting drug within minutes of experiencing pain.

In some parts of the country, the paramedics (ambulance staff) may give you the drugs before you reach the hospital, as the sooner you get it the better.

Clot-busting drugs can restore the blood supply to your heart muscle and drastically increase your chances of survival and limit the long term damage to your heart muscle.

There are many reasons why people delay calling - uncertainty about the symptoms, not wishing to make a fuss or refusing to believe that it could be happening to them.

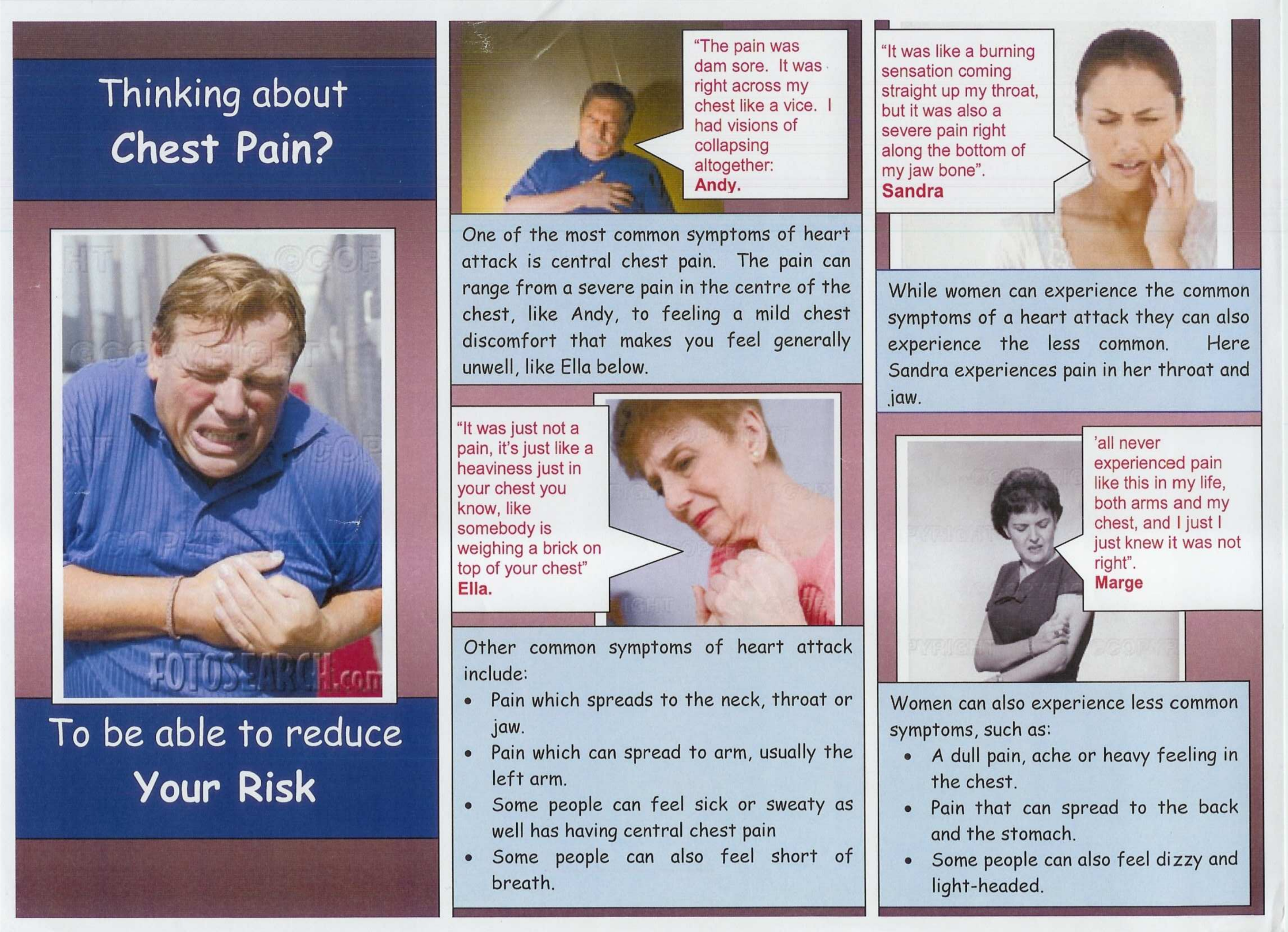
Calling for an ambulance is your only choice.

Marge: "I felt sometimes like it was taking a somersault, I thought it was going to burst through the wall of my chest, it's the strangest thing, it was really"

Craig: "Right er, well I had my first heart attack in 1999 er I was in the bookies! And er standing with my pal and I felt a pain across the chest, and my pal says you are not looking very well you are a terrible colour; you are a right grey colour. I said I have got a pain in my chest and then I felt the pain in the arm".

Marie: "No. It wasn't like a headache that you would get here, or at the side it was a…it was like a kind of pressure. Like a tight feeling going up your head and into you're…up your neck and into your head".

Appendix 10



Thinking about Chest Pain?

To be able to reduce Your Risk

"The pain was dam sore. It was right across my chest like a vice. I had visions of collapsing altogether:
Andy.

One of the most common symptoms of heart attack is central chest pain. The pain can range from a severe pain in the centre of the chest, like Andy, to feeling a mild chest discomfort that makes you feel generally unwell, like Ella below.

"It was just not a pain, it's just like a heaviness just in your chest you know, like somebody is weighing a brick on top of your chest"
Ella.

Other common symptoms of heart attack include:

- Pain which spreads to the neck, throat or jaw.
- Pain which can spread to arm, usually the left arm.
- Some people can feel sick or sweaty as well has having central chest pain
- Some people can also feel short of breath.

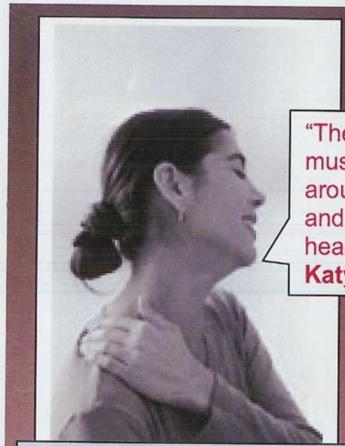
"It was like a burning sensation coming straight up my throat, but it was also a severe pain right along the bottom of my jaw bone".
Sandra

While women can experience the common symptoms of a heart attack they can also experience the less common. Here Sandra experiences pain in her throat and jaw.

'all never experienced pain like this in my life, both arms and my chest, and I just I just knew it was not right".
Marge

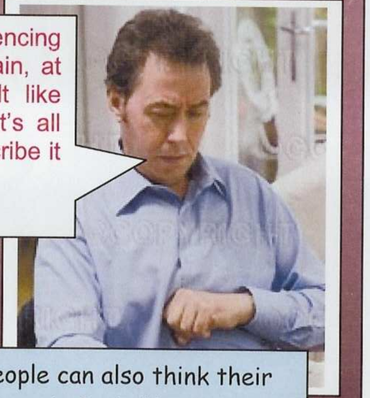
Women can also experience less common symptoms, such as:

- A dull pain, ache or heavy feeling in the chest.
- Pain that can spread to the back and the stomach.
- Some people can also feel dizzy and light-headed.



"The pain was like a muscular felling around my shoulder and around my heart".
Katy

Like Katy above it is important to understand that other symptoms or pains can be present along with chest pain.



"I was experiencing some chest pain, at the time it felt like indigestion that's all you could describe it as".
Ray

Some people can also think their chest pain feels like bad indigestion. Like Ray, above, who after a heavy meal thought his chest pain was indigestion.

"I didn't have the tightness then it was just breathlessness. And I was just assuming that it was my asthma that was playing up but it turned out not to be". **Sarah**

It also important to realise that some people can confuse their chest pain with some other cause. Like Sarah, above, who thinks her breathlessness is due to her asthma, when in fact it was a symptom of a heart attack.

What to look out for

The symptoms of heart attack vary slightly from one person to another.

They range from severe pain in the centre of the chest, to mild chest discomfort making you feel unwell.

The pain can often feel like a heaviness or tightness which may spread to the arms, neck, jaw, back or stomach.

If you experience any of these symptoms don't ignore them.
Call 999 immediately

Why act immediately?

If you suspect that you are having a heart attack,
call 999 immediately.

Calling an ambulance immediately means that, if you need it, you can get a clot-busting drug within minutes of experiencing pain.

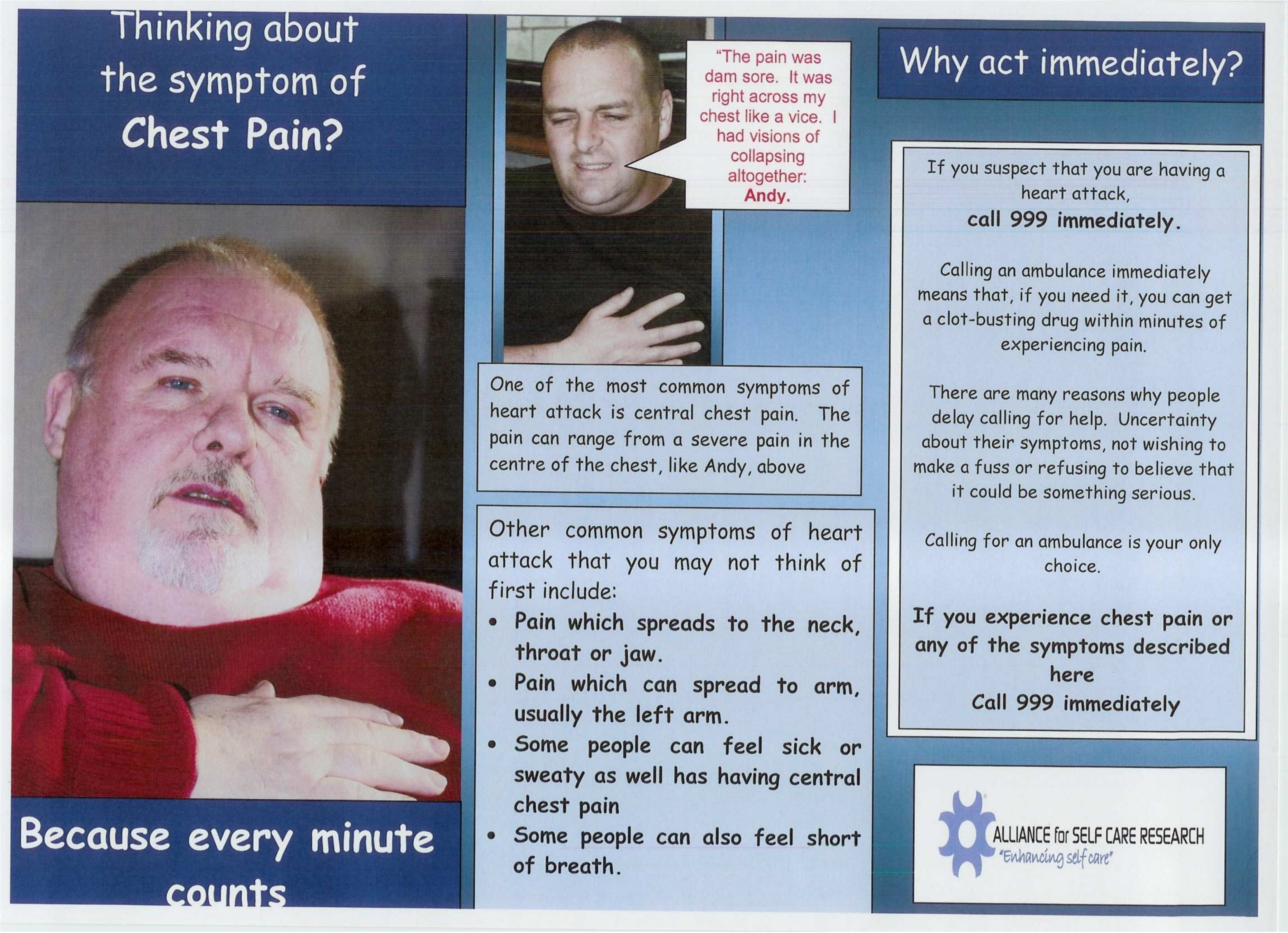
There are many reasons why people delay calling for help. Uncertainty about their symptoms, not wishing to make a fuss or refusing to believe that it could be something serious.

Calling for an ambulance is your only choice.

If you experience chest pain or any of the symptoms described here
Call 999 immediately

ALLIANCE for SELF CARE RESEARCH
"Enhancing self care"

Appendix 11



Thinking about the symptom of Chest Pain?

"The pain was dam sore. It was right across my chest like a vice. I had visions of collapsing altogether:
Andy.

One of the most common symptoms of heart attack is central chest pain. The pain can range from a severe pain in the centre of the chest, like Andy, above

Other common symptoms of heart attack that you may not think of first include:

- **Pain which spreads to the neck, throat or jaw.**
- **Pain which can spread to arm, usually the left arm.**
- **Some people can feel sick or sweaty as well has having central chest pain**
- **Some people can also feel short of breath.**

Why act immediately?

If you suspect that you are having a heart attack,
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Calling an ambulance immediately means that, if you need it, you can get a clot-busting drug within minutes of experiencing pain.

There are many reasons why people delay calling for help. Uncertainty about their symptoms, not wishing to make a fuss or refusing to believe that it could be something serious.

Calling for an ambulance is your only choice.

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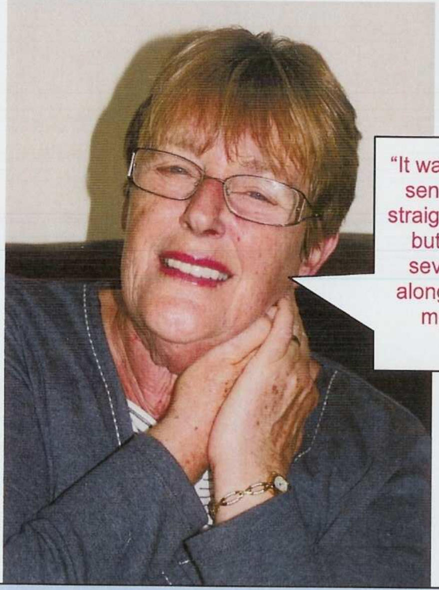
ALLIANCE for SELF CARE RESEARCH
"Enhancing self care"

Because every minute counts



"It was like a burning sensation coming straight up my throat, but it was also a severe pain right along the bottom of my jaw bone".
Sandra

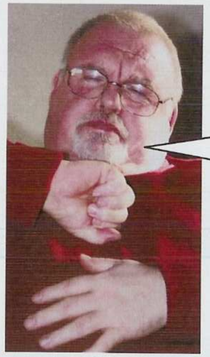
The symptoms of heart attack vary slightly from one person to another. While women can experience the common symptoms of a heart attack they can also experience the less common. Here Sandra experiences pain in her throat and jaw.

Women can also experience less common symptoms, such as:

- **A dull pain, ache or heavy feeling in the chest.**
- **Pain that can spread to the back and the stomach.**
- **Some people can also feel dizzy and light-headed.**

"I didn't have the tightness then it was just breathlessness. And I was just assuming that it was my asthma that was playing up but it turned out not to be".
Sandra

It also important to realise that some people can confuse their chest pain with some other cause. Like Sandra, above, who thinks her breathlessness is due to her asthma, when in fact it was a symptom of a heart attack.



"I was experiencing some chest pain, at the time it felt like indigestion that's all you could describe it as".
Ray

Some people can also think their chest pain feels like bad indigestion. Like Ray, above, who after a heavy meal thought his chest pain was indigestion.

What to look out for

The symptoms of heart attack vary slightly from one person to another.

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