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**An exploration of the help-seeking experiences of men and women referred to a rapid access chest pain clinic (a cardiac physiologist-managed clinic)**

**Stain, Nolan**

A DProf thesis awarded by the University of Westminster.

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**AN EXPLORATION OF THE HELP-SEEKING  
EXPERIENCES OF MEN AND WOMEN REFERRED  
TO A RAPID ACCESS CHEST PAIN CLINIC**

*(A cardiac physiologist-managed clinic)*

Nolan Stain

A thesis submitted in partial fulfilment of the  
requirements of the University of Westminster  
for the Degree of Doctor of Health Sciences

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# **ABSTRACT**

## **Background**

Coronary Heart Disease (CHD) is one of the leading causes of death in both men and women worldwide. It is well documented that early diagnosis and treatment of CHD is associated with better outcomes. This has led to the establishment of targets to ensure prompt access to services for potential CHD (e.g. Rapid Access Chest Pain Clinics). Research has shown that these public health targets have caused decreases in morbidity and mortality rates for CHD in the UK. However, despite these improvements health services are still limited by help-seeking practices of patients as they can only act once a patient has presented for treatment. A number of studies have explored the reasons why patients delay help-seeking for CHD symptoms in an emergency context (i.e. having a heart attack). Many studies have focused on gender and have often suggested that women with emergency CHD symptoms delay help-seeking, although this is controversial. Other studies have suggested help-seeking delay is influenced by multiple intersecting factors (e.g. age, ethnicity and contextual influences) and not just gender. No studies have examined help-seeking for suspected CHD symptoms in the context of accessing Rapid Access Chest Pain Clinics (RACPC). Given the lack of understanding in this area, an explorative qualitative study was undertaken to answer the research question: what are the help-seeking experiences of men and women referred to a rapid access chest pain clinic?

## **Methods**

A total of 30 men and women with a range of ages and ethnicities referred to a RACPC for the investigation of their symptoms were enrolled in this study.

Participants took part in semi-structured interviews that focused on attribution of symptoms and how that, amongst other things, influenced help-seeking decisions for their symptoms. The data was analysed thematically to explore men's and women's experiences and the help-seeking decisions they made. The study findings and relevant literature were used to inform the development of a patient information leaflet to assist with recognition of potential CHD symptoms and to promote help-seeking.

## **Results**

The study found, in general, that: attribution of symptoms was linked to contextual factors; reluctance to seek help and response to symptoms contributed to delay; the influence of others acted as enablers of help-seeking; and barriers were linked to accessibility of GP services and time off work. Additionally, some participants had mixed reactions to a negative diagnosis at the end of RACPC assessment (i.e. symptoms not of CHD origin). Some participants expressed frustration at not having an answer for their symptoms, whereas others said they felt like a 'fraud' for wasting NHS resources. Not all participants had negative reactions and many were delighted that their symptoms were not heart-related. When it came to perceptions of risk of CHD, most believed the 'male lifestyle' was more risky and therefore increased CHD risks in men, but that increasingly women were living 'male-like lifestyles' (e.g. working full time, smoking, drinking and eating a poor diet), thus increasing their risk of CHD.

## **Conclusion**

This novel study based in the RACPC context has produced important findings in this previously unexplored area. Earlier qualitative research based in the emergency

CHD context has highlighted the challenges around symptom attribution, attitudes to help-seeking and response to symptoms, and how these factors contribute to delay. This current study showed that there were many similarities between the two different contexts (emergency and non-emergency). These findings can be used to produce health promotion literature to encourage early help-seeking for non-emergency CHD in the RACPC context in both men and women. The output of the current research makes a contribution to practice in my profession through the development of a lay patient resource to promote help-seeking in the RACPC context.

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## **Glossary**

ACS	Acute coronary event (Heart Attack)
CCM	Constant Comparative Method
CHD	Coronary Heart Disease
DProf.	Professional Doctorate
GP	General Practitioner / Primary Care Physician
MVD	Micro-vascular disease
NHS	National Health Service
NICE	National Institute of Clinical Excellence
NSF CHD	National Service Framework for Coronary Heart Disease
PAS	Patient administration system
RACPC	Rapid Access Chest Pain Clinic
EU	European Union
UK	United Kingdom
WHO	World Health Organisation

## **Dissemination of Findings**

### **Peer Reviewed Publications:**

1. STAIN, N. & UNSWORTH, B. 2013. Gender bias and help-seeking in coronary artery disease. *British Journal of Cardiac Nursing*, 8, 382-387.
2. STAIN, N., RIDGE, D. & CHESHIRE, A. 2014. Gender comparisons in non-acute cardiac symptom recognition and subsequent help-seeking decisions: a mixed methods study protocol. *BMJ Open*, 4.

### **Poster Presentations:**

3. University of Westminster PostGraduate Fair
4. STAIN, N., RIDGE, D. & CHESHIRE, A. 2012-2016. Gender comparisons in symptoms interpretation, understanding of risk factor, subsequent help-seeking practice and the health experience of patients referred to rapid access chest pain clinic.

### **Planned Peer-Reviewed Publications:**

5. STAIN, N., RIDGE, D. & CHESHIRE, A. 2019. The help-seeking practices of men and women referred to Rapid Access Chest Pain Clinic.
6. STAIN, N., RIDGE, D. & CHESHIRE, A. 2019. The Construction of a Lay Patient Resource to improve help-seeking for Coronary Heart Disease.

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## **Author Declaration**

I declare that all the material contained in this thesis is my own work.

## Chapter 1. **Introduction**

Coronary Heart Disease (CHD) remains the leading cause of death for both men and women worldwide and ranks highly in the UK and EU mortality rate indicators, accounting for 45% of all European deaths (Townsend et al., 2015). Despite advances in medical treatments and interventions, the rapid clinical evaluation of chest pain remains crucial to improving patient outcomes (Haasenritter et al., 2012). In light of this, there was a significant health focus from 2000 to improve chest pain evaluation and intervention in the UK. There is evidence that this public health strategy has had a notable benefit, and indeed in recent years CHD mortality incidences have started to fall across Europe (Gyberg et al., 2015, Townsend et al., 2015). However, despite these encouraging statistics, CHD mortality remains high and thus CHD is still a key public health policy issue. To reduce mortality from CHD, health policies have focussed on improving access to rapid CHD evaluation and treatment for both for men and women. In the UK this was achieved and monitored through the establishment of revascularisation therapy<sup>1</sup> rapid targets (90 minutes) for acute myocardial infarction (heart attack), and a 10 day referral target for the rapid chest pain access clinics (RACPC) for stable CHD symptoms (Department of Health, 2000, Fox et al., 2009).

RACPCs are used for rapid management of stable chest pain complaints. i.e. not a heart attack. The creation of the RACPC model by the National Service Framework

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<sup>1</sup> Revascularisation therapy is used for patients experiencing either acute (heart attack) or chronic CHD, and is a process of restoring blood flow to an ischemic area. In the context of cardiology, it relates either to the opening of a blocked or narrowed coronary artery by balloon inflation (widening the artery) or bypassing the blocked arterial area using a vein graft.



for CHD (NSF CHD) in 2000 was a watershed moment in increasing the speed that patients with stable chest pain complaints were evaluated (Department of Health, 2000). In the first few years following their implementation (2002-2006) referral rates for chest pain to RACPCs doubled and deaths from acute CHD events started to fall (Boyle, 2007). However, the effectiveness of these rapid access services is only as good as the help-seeking practices of patients: health services can only act once a patient has taken the decision to actively seek professional help.

The extent to which gender affects help-seeking practices is controversial. Many help-seeking studies covering a broad of range of health complaints including headaches and back pain suggest that women may seek help sooner than men (Hunt et al., 2011, Galdas et al., 2005, Kapur et al., 2005, Oliver et al., 2005, Addis and Mahalik, 2003, Corney, 1990) However, with regards to CHD symptoms, some studies have suggested the roles appear to be reversed and it is women who tend not to seek help, or they delay help-seeking (Benziger et al., 2011, Nguyen et al., 2010, Adamson et al., 2009, Nouredine et al., 2008, Foster and Mallik, 1998, van Tiel et al., 1998). Other studies have criticised this literature for constructing gender in a binary manner (men vs women) or for simply examining sex differences (Galdas et al., 2010, Galdas et al., 2005, Addis and Mahalik, 2003). These studies and others have highlighted that other psycho-social and contextual factors (e.g. age, ethnicity, socio-economic culture, previous experiences) can also interplay with gender to influence help-seeking (Benziger et al., 2011, Adamson et al., 2008, Moser et al., 2005, Zerwic et al., 2003). Indeed, in some cases help-seeking can be independent of gender. Despite this controversy there is some evidence to suggest that in the emergency context women underestimate their own CHD risk, fail to correctly

recognise their symptoms, and may delay seeking help for chest pain, thus increasing their mortality risks (Gyberg et al., 2015, Stain and Unsworth, 2013, Maas et al., 2011).

In view of the emerging qualitative evidence that women, and indeed some men, may delay seeking help in an emergency CHD event, the researcher wanted to explore the intersecting influences (gender and non-gender) on patient's help-seeking practices in the context of accessing a RACPC. This is an important area to explore as delaying help-seeking in the RACPC environment, although not an emergency situation, can also have negative clinical outcomes. It is essential to detect potential heart symptoms early as prodromal symptoms<sup>2</sup> are common up to four weeks preceding acute CHD event, especially in women, but also in some men (Lockyer, 2005). Preventing an acute event is desirable as they can be unpredictable and the outcome is dependent on where you are and your access to treatment. Understanding the experiences of RACPC patients and how these impacted on their help-seeking could lead to improvements in education for both health practitioners and patients to promote early help-seeking. Additionally, patient experiences of help-seeking practices when accessing a RACPC is unexplored in the literature, making this research study novel.

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<sup>2</sup> Early symptoms that indicate the start of a disease before a specific serious diseases event occurs.

## **1.1 Outline of the project**

The thesis is made up of the following chapters. **Chapter 1** is the introduction which provides background to the study and highlights the challenges around chest pain and help-seeking.

**Chapter 2** reviews the literature. This chapter defines what is chest pain, how it is evaluated and explains the role of RACPC. It explores help-seeking behaviour and outlines differences between biological sex and the construction of gender including hegemonic masculinity, manhood acts, inclusive masculinity, as well as 'doing gender' and intersectionality, which were used to interpret the results of the current research. The literature review also examines help-seeking, and gender and help-seeking in the CHD symptoms context. Although contentious, the literature commonly assumes that men are more likely to delay seeking medical treatment for general health complaints than women. Indeed, there is some evidence in the literature to support this gap. However, there is also some evidence to support that the opposite is true for CHD symptoms where it is women that are more likely to delay than men. Lastly, this chapter reviews the limited gender-comparative literature on help-seeking and CHD. The literature in this area is complex, with some studies reporting that women delay longer than men, some rejecting that view, criticising studies for treating a gender in binary fashion and citing other contextual factors intersects with or overrides gender to influence help-seeking delay.

**Chapter 3** sets out the methodological approach employed by the study. The first sections outline the research objectives, the justification for the research design, the sampling framework and recruitment strategy. The section that follows outlines the data gathering, data management and data analysis of patient interviews.

**Chapters 4 – 6** present the participant interview results. Findings were presented under three main themes uncovered in the analysis: symptoms and how they were interpreted and experienced by the participants; help-seeking and what can contribute to delay, as well as the enablers and barriers to help-seeking; and CHD risk factors and behaviours, including participants' perception of risks factors and how to reduce them.

**Chapter 7** presents the lay patient resource and details how it was constructed.

**Chapter 8** is the discussion section. The first part of this chapter provides an overview of the key results in this study, in the context of the known literature. These results are then discussed and analysed in detail by area of interest: attribution of symptoms; response to symptoms contributed to delay; the referrals to RACPC; enablers and barriers to help-seeking; experiences of RACPC, impact of negative diagnosis; and 'male lifestyle' being perceived as high-risk for CHD. The second part of this chapter outlines the implications for clinical practice and makes recommendations. The final part of this chapter presents the conclusions that highlight and summarise the main study findings.

## Chapter 2. Literature Review

### 2.1 Chest Pain

Chest pain, a common health complaint, is the most prevalent symptomatic manifestation of Coronary Heart Disease (CHD) (Haasenritter et al., 2012, Daly et al., 2006). Chest pain refers to pain or a painful sensation in the thorax (chest area) and can be classified by causality e.g. cardiac or non-cardiac origin (NICE, 2015). Non-cardiac origins are numerous and include musculoskeletal pain, respiratory diseases, gastroenterological causes and cancers of the chest region (e.g. lung cancer). However, in some cases it is not possible to identify a cause for chest pain, and it is estimated that about 15% of people presenting with chest pain have a non-specific cause (NICE, 2015).

Whether a chest pain complaint is considered to have a possible cardiac cause on initial evaluation by a general practitioner (GP) warranting an onward referral is a complex issue. A GP would make the clinical decision to refer based on the symptom profile – whether they are CHD-sounding (e.g. squeezing pain, triggered by exertion and relieved by rest), and based on the patient's CHD risk factors (age, gender, smoking, diet, family history, etc). Due to the cost associated with CHD referrals, GPs are likely to filter out many patients based on symptoms, age and CHD risk factors. For example, a patient under thirty years of age with generalised pain in the chest region with no specific risk factor may not be referred. However, a male over fifty-five years of age with chest pain who is a smoker with family history is almost certain to be referred. In line with the National Service Framework for CHD (NSF CHD) (Department of Health, 2000), a patient in primary care who presents with chest pain thought to be of a cardiac nature should be referred for rapid

evaluation in a RACPC. However, despite this initial screening in primary care, it is estimated that nearly two-thirds of patients referred to RACPCs in the UK have non-cardiac chest pain (Chambers et al., 2013).

## **2.2 Help-seeking behaviour**

The effectiveness of these rapid access services is only as good as the help-seeking practices of patients: health services can only act once a patient has taken the decision to actively seek professional help. Help-seeking is a behavioural construct that has gained increasing popularity over the last decade (Cornally and McCarthy, 2011). It is used specifically to understand patient delay, or the motivation required by patients for them to access healthcare services. Defining ‘help-seeking’ or ‘help-seeking behaviour’ is complex, as varying definitions exist depending on the context in which the term is used (Cornally and McCarthy, 2011). However, Rickwood (2005) provides a rather encompassing definition of help-seeking which informed the current study:

*‘Help-seeking is the behaviour of actively seeking help from others. It is about communicating with other people to obtain help in terms of understanding, advice, information, treatment and general support in response to a problem or distressing experience’.*

In other words, help-seeking primarily describes a conscious decision to seek out help in order to address one’s health status, which could be sought from a health professional or a layperson, including family members, friends or colleagues (Rickwood, 2005).

More recently, Cornally & McCarthy (2011) analysed the concept of help-seeking and concluded that it is an intentional-action to solve a health issue. They describe it as an active process which challenges the personal abilities and beliefs of the

person who is not able to help themselves, and therefore in order for a person to seek help they must first acknowledge the existence of the problem and ultimately accept their inability to deal with it on their own (Cornally and McCarthy, 2011). This involves complex decision-making processes which are dependent on many contextual factors including culture, social networks, ethnicity, nationality and gender (Brown and Chen, 2008, Barker, 2007, Wilcox and Birkel, 1983). Additional psychosocial factors which may also impact on help-seeking are the fear of rejection, fear of diagnosis, unwillingness to face reality, and possible sense of repeated rejection should help-seeking in the past have been unsuccessful.

Therefore, help-seeking behaviour in the context of CHD symptoms could be summarised as an intentional behavioural response to a problem (symptom), which a person not only feels they are not able to deal with themselves, but also with which they recognises the need for assistance.

### **2.3 Gender Construction**

Gender and biological sex are often assumed to have the same meaning, but in fact they are different. The World Health Organisation (WHO) defines sex as 'biological and physiological characteristics that define men and women' and gender as 'the socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women' (WHO, 2015). This study will consider biological sex and gender and their influence on symptom interpretation and help-seeking practices. There are different ways to understand gender construction, and therefore this section examines some of these varying approaches including hegemonic masculinity, "doing gender", "manhood acts" and "inclusive masculinity". Lastly, intersectionality and its usefulness for situating this study are considered.

### 2.3.1 Hegemonic masculinity

Hegemonic masculinity is a configuration of gender practice that legitimises men's dominant roles in society, and justifies the subordination of women and marginalised men (e.g. gay, disabled men, men of lower economic power) (Connell and Messerschmidt, 2005, Hearn, 2004). The original formulation of hegemonic masculinity specified the codes of masculinity - or ideals - of what it is to be a real man. Codes associated with hegemony include, for example, physical strength, violence and aggression, stoicism (emotional restraint), courage, toughness, risk-taking, adventure and thrill-seeking, competitiveness, success, and breadwinning (Farrimond, 2012, De Visser and McDonnell, 2013, Courtenay, 2000 ). Hegemony was considered to be “the most honoured way of being a man” in given cultural or historical context, and was always considered an ideal rather than a reality, and meant that men who did not measure up were marginalised (Farrimond, 2012, Connell and Messerschmidt, 2005). Consent is another feature of hegemonic masculinity; for example, in that men and women are encouraged to collude with (and so endorse) hegemonic masculinity (Hearn, 2004). Therefore, according to Connell, masculinity was a society-wide system of power, and positions men and women in a competitive social hierarchy. For example, in the westernised contexts, able-bodied, white, middle-class, heteronormativity are generally been seen as hegemonic, and homophobia has a role in identifying subordinate men and policing gender (by instilling fear in not only gay and bisexual men, but also heterosexual men) (Wetherell and Edley, 1999). However, the idea of what is hegemonic can change over place and time. For example, Lomas and colleagues (2016) found that meditation centres could encourage groups of men to take on an alternative gender



hierarchies where intimacy, abstinence, and spirituality were hegemonic and more traditional masculinities (e.g. stoicism) seen as inferior (Lomas et al., 2016).

Hegemonic masculinity as a theory, however, has been subject to criticisms including the way it centres around heteronormativity, the way scholars tend to use it in practice to signify a collection of “toxic” traits, and arguments it is overly structural and closed in nature, thus neglecting the in-depth subjective worlds of men or the way that issues other than gender influence men and women (Connell and Messerschmidt, 2005). In response to such criticisms, Connell has refined the theory of hegemonic masculinity (e.g. accepting it is possible for a localised hegemonic masculinity that is fully “positive”), but also argued that the focus on multiple masculinities and hierarchies should remain.

Nevertheless, other theorists deny the value of multiple masculinities or hegemony. Schrock and Schwalbe (2009), for example, have argued that the concept of multiple masculinities prevents us from properly considering what masculinity actually is. They developed the alternative concept of manhood acts as *“the identity work males do to claim membership in the dominant gender group, to maintain the social reality of the group, to elicit deference from others, and to maintain privileges vis-à-vis women”* (Schrock and Schwalbe, 2009). They theorise men must demonstrate they possess masculinity through the practice of signifying acts (manhood acts) in order to claim privilege. These signifying acts include demonstrations of physical strength, emotional restraint, risk-taking and even violence (Marcos, 2013, Schrock and Schwalbe, 2009). However, identification of masculinity via manhood acts is fluid. Men - depending on their personal circumstances - are able to use various acts to

claim their privilege associated with the dominant gender (Marcos, 2013, Sumerau, 2012, Schrock and Schwalbe, 2009) For example, some men use occupational status and financial power, while other men use physical strength.

Inclusive masculinity theory challenges the value of hegemony itself, describing *“the emergence of an archetypal masculinity that undermines the principles of orthodox (hegemonic) masculine values – yet that is also esteemed among male peers”* (McCormack and Anderson, 2014). Challenging the focus on heteronormativity, they argue that as the power of homophobia to control men has undergone an unprecedented decline, younger men are now less concerned with actively behaving heterosexual, or of avoiding behaviours that could be interpreted as ‘gay’. Research with young rugby players is useful to illustrate inclusivity. The study elucidated different masculine behaviours between the younger players and their older coaches (Anderson and McGuire, 2010). The younger players when interviewed denied making degrading sexualised remarks about women. They felt such behaviour had no place in a team. Similarly, the players expressed no concerns about gay men. However, they talked about how their older coaches had made degrading comments about women and homophobic remarks about gay people generally. Coaches also used the homophobic comments in attempts to motivate players (Anderson and McGuire, 2010). Rather than being motivated by coaches shouting homophobic slurs, they were angered by them (Anderson and McGuire, 2010). However, it has been argued that the optimistic theory of masculinity is a turn towards conservative sexual politics, involving a kind of postfeminist erasure, when in fact patriarchy remains very much intact (O’Neill, 2015).

### 2.3.2 Doing Gender

'Doing gender' is an alternative theory of gender construction that asserts that gender is not something one is, but rather something one does or performs: '*a routine, methodical, and recurring accomplishment. We contend that the 'doing' of gender is undertaken by men and women whose competence as members of society is hostage to its production*' (West and Zimmerman, 1987). Thus, a choice not to 'do gender' congruent to one's own sex risks harsh judgement and brutal policing. Several studies on gender and its influence on health discuss 'doing health' as a form of 'doing gender' (Noone and Stephens, 2008, O'Brien et al., 2007, Courtenay, 2000, Williams, 2000, Saltonstall, 1993). For example, a man 'doing gender' might be required to appear unconcerned with his health and well-being if such focus might be interpreted as feminine. 'Doing gender' can have positive and negative influences on health. For instance, in one study, as part of doing gender, teenage boys tended to keep their asthma or diabetes a secret, and took steps to be seen as having "normal" health (Williams, 2000); they did this by adhering to the treatment regimes, controlling their diet and exercising regularly. Teenage girls, however, did not feel the need to keep their illness secret nor take specific actions to be seen as normal. Sometimes this had a detrimental effect on the health of girls who frequently did not exercise or control their diet. A study examining coronary heart disease (CHD) found that men often ignore the early warning signs of CHD (O'Brien et al., 2007). Men in the study felt that being the breadwinner in the family was an important part of being masculine, and felt compelled to endure symptoms and work through them. Some of these men went on to have serious CHD events which rendered them unable to work. These men viewed their inability to work as loss of masculinity. Nevertheless, these men were able to re-affirm their masculine gender through being involved in

CHD rehabilitation programmes where strength and endurance could be performed as part of doing gender. In analysing the findings data in the current study, 'doing gender' was considered a more suitable theoretical framework to understand gender construction, while the hierarchical and multiple masculinities focus of Connell's theory proved less useful in interpreting the data.

### 2.3.3 Intersectionality

Intersectionality considers the overlapping or intersecting social or personal identities people occupy simultaneously (e.g. gender, race, nationality, culture, social wealth), and how they interact with each other on multiple levels to create personal traits in a person and social circumstances (Griffith, 2012). Gender needs to be considered together with other social factors and identities to fully understand any differences between people (Griffith, 2012, Hankivsky, 2012). Explained differently, intersectionality therefore purports that gender needs to be viewed with all other social identities, expected social norms, influence of friends and family, politics and power (Hankivsky, 2012). For instance, Bowleg's paper applied an intersectional framework to understand what it is like to be a black man negotiating sex (Bowleg et al., 2013). Traditionally, higher HIV rates in black men were attributed to masculinity and how it is performed specifically. Black men living in socially and economically deprived areas may be prone to certain performances, including aggressive behaviours, violence, thrill-seeking, and promiscuity and, of course, unsafe sexual practices (directly related to increased risk of HIV). However, the study found that race discrimination also had links to HIV infection. Black men were more likely to be out of work, have prison records, and be of low social economic status. Most of the black men interviewed talked about how life was comparatively harder for them than

white people might experience. These intersecting factors (e.g. criminal history, low economics status, unemployment) contributed to poor health options and choices, less access to health services and an increased risk of drug use, which in turn increased risk of HIV infection. Bowleg concluded that improving the overall lives of black men would be likely to improve their overall health and reduce risk of HIV infection; it was not just about masculinity. Other research looked how masculinity intersected, *inter alia*, with other variables including age, social economics, social network, type of illness to influence help-seeking (Farrimond, 2012). The study found multiple variables influenced help-seeking in men. Single young men were more likely to access a wider social network to share their symptoms. Older men who were married for long time formed health alliances with their spouses, and encouraged each other to seek formal help-seeking. The type of illness also intersected with masculinity to impact on help-seeking. For example, illnesses such as testicular cancer or depression were only shared with close friends and family, and often after some delay, whereas a drunken fall or a sport injury was shared widely by men, and often with pride.

Study designs that solely examine gender or sex differences have been criticised for not being well equipped to fully account for men's and women's experiences as they do not consider intersectionality, which is discussed above (Hankivsky, 2012, Galdas et al., 2005, Addis and Mahalik, 2003). Intersectionality (alongside "doing gender") was helpful in understanding the data in this current research as it became clear there were intersecting factors that influenced help-seeking, such as age, ethnicity, belief about own CHD risks (i.e. coronary candidacy), influence of others, and previous of CHD events, not only gender.

## **2.4 Rapid Access Chest Pain Clinic (RACPC)**

RACPC were established early this century by the National Service Framework for Coronary Heart Disease (NSF CHD) (Department of Health, 2000). Their primary focus is the clinical evaluation of chest pain in a non-emergency setting (i.e. not having a heart attack). Although they are termed 'chest pain clinics' (as the symptom of chest pain is the most common early CHD presentation), these clinics investigate all possible chest region pains, aches, niggles or similar discomforts and other symptoms such as arm pain, throat pain, breathlessness and dizziness, since these clinical presentations are strongly linked to potential CHD (Fox et al., 2009). These symptoms can be related to symptomatic stable angina i.e. pain/discomfort caused by a narrowing of the arteries that supply the heart. Stable angina, although uncomfortable or possibly painful, is not considered an immediate threat to life and therefore can be managed conservatively with medications and/or routine angioplasty (widening of arteries with a balloon). The clinics did not see patients with emergency cardiac symptoms as they are considered to be a threat to life and patients are seen in the emergency department. However, RACPCs play an important role in preventing patients from going on to have acute CHD events (heart attack). It is known that prodromal symptoms (stable chest pain complaint) are often present up to a month before the onset of acute CHD events (Gyberg et al., 2015). This is particularly relevant to women who are known to have more prodromal symptoms than men for CHD events (Gyberg et al., 2015).

RACPCs are cardiac physiologist or nurse-led, i.e. staffed by non-medical practitioners, who take on a clinical specialist's role for clinical evaluation of chest pain. This is a role that had been traditionally the purview of medical practitioners.

Duties include clinical history taking, ordering and interpretation of non-invasive diagnostic tests such as electrocardiograms, exercise tests and echocardiograms, the initiation of medical therapy (medications), and referrals for invasive interventional (coronary angiogram) and high radiation imaging procedures (CT angiograms) under the supervision of cardiologists. The RACPC where the study was conducted is managed by the cardiac physiologists who organise the (RACPC) clinics, triage referrals, perform, analyse, and report the relevant cardiac investigations, advise nurses (on interpretation of cardiac investigations) and oversee the onward referrals for complex invasive or high radiation procedures to an acute centre. Additionally, the cardiac physiologists operate virtual RACPC follow-up clinics and screen complex procedure results (e.g. stress echoes or coronary angiograms), directing them appropriately. For example, negative results are sent directly to the GP indicating no further action required and positive results are flagged up to medical consultants for review and further action. The consultation (history taking, giving results, etc) and initiation of medical therapy is primarily carried out by nurse specialists, but on occasion by the cardiac physiologists (under consultant supervision) when required (*see appendix S for the RACPC pathway*). The RACPC runs in tandem with a consultant cardiologist outpatient clinic that provides clinical oversight, much in the same way they would with a junior doctor. This dual model of using both cardiac physiologists and nurses supervised by consultant cardiologists to manage demand is also the pathway in other RACPCs based within inner London hospitals (Mathieson et al., 2017).

This model of nurse and cardiac physiologist-led clinics enables NHS Trusts in England and Wales to better meet the NSF-CHD's 10 working day target for primary

care referrals to be assessed in specialist care centres (Department of Health, 2000). Statistics released by the Department of Health within the first few years of the establishment of RACPCs showed that referral rates for chest pain had doubled between 2002-2006 (Boyle, 2007), suggesting that the NSF-CHD (2000) programme was effective in improving access to services and enhancing public CHD awareness.

## **2.5 Help-seeking for health complaints**

The help-seeking practices of men and women are complex, with multiple differing influences depending on gender including: biological factors in the monitoring of health for gender-specific conditions (e.g. cervical check-ups) and the social influences which make some men prone to 'man out' symptoms, and some women to display stoicism (Galdas et al., 2010, Unruh, 1996). There are also gender independent factors which influence help-seeking including personal attitudes of 'not wanting to bother doctors', 'denial of symptoms' and experiences of the 'severity of symptoms' (Galdas et al., 2010).

### **2.5.1 Friends and Family**

The literature on help-seeking for health complaints, in general, tends to suggest that women are more likely to seek help from friends and family than men (Hunt et al., 2011, Wyke et al., 1998). However, other studies dispute this and have cited that wider factors can interplay with gender and sometimes override gender to influence help-seeking (Farrimond, 2012, Galdas et al., 2010). Galdas found that context was important, if friends and family were present at time of symptoms, they were likely to be consulted and would encourage formal help-seeking irrespective of gender (Galdas et al., 2010). Farrimond found intimacy to be important as older married men who had been married for a long time often form health unions with their wives. They



discuss symptoms, monitor each other's health and motivate each other to seek professional help (Farrimond, 2012). Additionally, the type of health complaint plays a role in help-seeking: drunken falls or sport injuries were openly shared others, whereas illnesses related more sensitive or potentially stigmatising issues (e.g. depression or testicular cancer) were only shared with very close family and friends (Farrimond, 2012).

### 2.5.2 Medical consultations for health complaints

Some studies have reported that medical consultations are more common in women (Galdas et al., 2005, Kapur et al., 2005, Oliver et al., 2005, Addis and Mahalik, 2003, Corney, 1990). Addis's review of the literature in 2003, which explored masculinity and help-seeking decisions, suggested that men were less likely to seek medical help for vulnerable emotions and mental health issues than women (Addis and Mahalik, 2003). Kapur explored the gender differences in GP attendances, reporting that women consulted GPs more than men, and that women on the whole were more likely to seek help for psychological stress than men (Kapur et al., 2005). Corney noted that higher GP attendance in women intersected with age, and low attendance in men was particularly dominant in the age group 20 to 45 years (Corney, 1990). A later review of the literature in 2005 on men's help-seeking behaviour broadly confirmed the work of these early studies suggesting that women's GP consultation rates were nearly three times higher than those of men. Although it was recognised that some of these consultations were related to women's health (family planning, childbirth and child-related issues) however, it still reflects women's greater willingness to access GP services compared with men (Galdas et al., 2005). However, it is not always the case in the literature that medical consultations are

higher in women for all conditions. Hunt's review of 26 papers found medical consultation rates for back pain and headaches were the same for men and women, but more women acknowledged (which the study termed 'reporting') back pain symptoms than men (Hunt et al., 2011). Overall the review confirmed early work by Wyke who also reported GP consultation were similar for both genders (Wyke et al., 1998)

### 2.5.3 Limitations of literature

There were limitations in the literature presented above. Oliver and Kapur were only studying single-centred trials, thus limiting generalizability of their results, and they relied on self-reporting scales which are prone to recall bias (Kapur et al., 2005, Oliver et al., 2005). Additionally, Oliver recognised enrolment issues reporting lower responder rates in the socially deprived parts of the sample as a significant limitation (Oliver et al., 2005). In Hunt's work the inconsistencies in what participants believed constituted a headache or back pain was recognised as a study limitation (Hunt et al., 2011). This study highlights the complexity around classifying symptoms and as different people have different interpretations.

## 2.6 Coronary Candidacy and CHD risk factors

In the past CHD has often been seen as a 'man's disease' and men were viewed as coronary candidates<sup>3</sup>. Women, however, were generally considered to be at lower risk of CHD and therefore not likely coronary candidates (Maas et al., 2011; Mikhail, 2006; Emslie, 2005; Shaw et al., 2004; Schoenberg et al., 2003). Research into

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<sup>3</sup> Coronary candidate is someone perceived by lay person to be high risk for CHD. They are generally male, overweight, red-faced, inactive smokers with a poor diet

gender and CHD has suggested modifiable behavioural CHD risk factors such as smoking, alcohol consumption, illicit drug-taking, and stressful or physically demanding work are more associated with a male lifestyle,<sup>4</sup> putting men at higher risk of CHD (Emslie, 2005, Addis and Mahalik, 2003). Later research also highlighted that men are more likely than women to engage in risky behavioural activities linked to an increase in CHD risk (Emslie and Hunt, 2009). Research into masculinities and manhood found that behaviours known to increase CHD risk, including drug use and binge drinking, are sometimes used to signify being a man (Marcos, 2013). However, Marcos also points out that there are positive behaviours associated with masculinities including sports and exercising to maintain healthy bodies – sports and exercises are known to reduce CHD risk. Further research looking into sex differences for CHD suggested the ‘coronary-prone behaviour’<sup>5</sup> associated with the male lifestyle did not fully explain the increased levels of CHD in men (Barrett-Connor, 1997). The study found that multiple factors aside from behaviours played a role including sex-linked inherited conditions (high cholesterol, high blood pressure), reduced physical activity levels and obesity. Research focussed on women and CHD highlighted that women can be coronary candidates as they also have stressful lifestyles (care-giver and homemaker) (Gyberg et al., 2015, Turris and Finamore, 2008). Indeed, a major European Red Alert study aimed at flagging up risk of CHD in women suggested that social and emotional stresses placed on women increased

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<sup>4</sup> ‘Male lifestyle’ in terms of CHD, relates to risky behaviours known to increase cardiovascular risk factors (e.g. smoking, drinking, illicit drug-taking poor diet, low levels of physical activity, high level of work stress)

<sup>5</sup> ‘Coronary Prone Behaviour’ relates to modifiable CHD risk factors (e.g. smoking, drinking, drug taking, diet, stress, and exercise)

their risk of CHD (Maas et al., 2011). However, research looking at women and coronary candidacy found women did not consider themselves to be 'coronary candidates' and believed they were at a lower risk of CHD than men (Emslie, 2005, Lockyer, 2005).

Other research examined if men or women could identify the modifiable behaviours associated with CHD and whether that led to health improvements (Angus et al., 2005, Green et al., 2003, Roeters van Lennep et al., 2002, van Tiel et al., 1998). A European study found that both men and women were well informed about CHD risk factors including behaviours that could be modified to reduce CHD risk (van Tiel et al., 1998). Another study based in Canada used focus groups to explore what prompted behaviour modifications in men and women (e.g. diet, exercise, smoking cessation etc.) (Angus et al., 2005). The study found acknowledging or accepting one was at risk of CHD prompted behaviour changes to reduce CHD risks in some cases in both men and women. However, in other cases both men and women needed to have a CHD-related event ('a big event') to be convinced of the need to change. The study suggested behaviour modifications a post-CHD event were often not permanent. While men and women initially make behavioural changes, the shock of having a CHD event passed over time and they would lapsed back into previous habits (e.g. drinking, smoking, poor diet, etc.) (Angus et al., 2005).

## **2.7 CHD and help-seeking practices**

Overall, the existing body of evidence for gender, CHD symptoms in the emergency setting and help-seeking is conflicting (Gyberg et al., 2015, Galdas et al., 2010, Nouredine et al., 2008, Moser et al., 2005, Zerwic et al., 2003, Foster and Mallik, 1998, van Tiel et al., 1998). On balance, the current evidence, although

controversial, would lean toward women delaying help-seeking longer than men. Over 400 publications tackle gender, symptoms and help-seeking for CHD from a wide variety of angles e.g. women and CHD symptoms, women, CHD and helping-seeking and men and CHD. Most studies are quantitative in methodological approach, and are framed entirely in the emergency context (i.e. having a heart attack) and there is limited inquiry into help-seeking when accessing RACPCs (i.e. stable CHD symptoms). Additionally, the study quality of these quantitative inquiries have drawn many criticisms (see 2.7.3).

Several studies have found overall that women delayed longer than men for acute CHD symptoms (Ghezeljeh et al., 2015, Benziger et al., 2011, Maas et al., 2011, Nguyen et al., 2010, Adamson et al., 2009, Higginson, 2008, Nouredine et al., 2008, Foster and Mallik, 1998, Meischke et al., 1998, van Tiel et al., 1998). However, some of these studies have used a binary approach, 'men said one thing and women said another', to examine differences between men and women, and did not always account for other influences that may also have had an impact. This approach has been criticised by other studies, which suggest that just comparing men and women or sex differences is inadequate as other factors may intersect with gender to affect help-seeking practices including severity of symptoms, personal beliefs, previous CHD history, age, ethnicity and contextual factors (e.g. influence of others) (Galdas et al., 2010, Galdas et al., 2005, Addis and Mahalik, 2003). In the literature supporting the notion that women delayed longer than men the reasons why remain unclear. However, there is some evidence indicating the different physiological factors and psycho-social beliefs around symptoms to do with gender may play a

role in how these CHD symptoms are interpreted and acted upon (Gyberg et al., 2015, Higginson, 2008, Albarran et al., 2007, Emslie, 2005).

### 2.7.1 Physiological factors

The typical clinical symptomatic manifestation of an acute CHD event is described as central crushing chest pain radiating to left arm and sometimes up into the jaw (Canto et al., 2012a, Maas et al., 2011, Higginson, 2008, Albarran et al., 2007, Emslie, 2005). It is often accompanied by sweating, pallor, and sometimes nausea. These clinical symptoms are widely reported in men, but not so often in women. It is well documented that women can experience less intense and more varied forms of chest pain and associated symptoms. A recent study exploring this phenomenon found that women are more likely to experience a spreading chest pain as opposed to a centrally focused crushing pain (Bruins Slot et al., 2012).

The physiological basis for the sex difference and varied types of chest pain experienced in women is contentious and no definitive causal links have been established, although the evidence does suggest that biological and anatomical differences may play an important role. The three main biological processes are: 1) women more likely to experience plaque erosion whereas men experience plaque eruption<sup>6</sup>; 2) microvascular disease<sup>7</sup> (MVD) is more common in women; 3) and

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<sup>6</sup> Plaque eruption versus plaque erosion refers to different mechanisms whereby fibrous plaque can cause an acute coronary event. In eruption the plaque which is vulnerable to cracking (plaque rupture), exposing lipid plaque to the luminal blood flow, initiating a clotting cascade which ultimately occludes or severely restricts arterial blood flow resulting in myocardial infarction (heart attack) (Ambrose and Srikanth, 2010). In plaque erosion an area of the endothelial cellular covering of the tunica intima layer of an artery wall is absent, exposing blood flow to inner layers of artery wall, initiating the clotting cascade and thrombosis. Erosion is a less aggressive process than eruption.

women have smaller coronary arteries than men (independent of body surface area) (Zuchi et al., 2013, Maas et al., 2011, Banks and Malone, 2005, Ambrose and Srikanth, 2010, Reis et al., 2001, Arbustini et al., 1999). The physical manifestations of these individual biological processes are known to present differently. For example, plaque erosion and MVD both more common in women are generally associated with milder and more varied symptoms than plaque eruption (a more aggressive process). Additionally, women's smaller coronary arteries also thought to contribute to the difference in women's experience of cardiac symptoms when compared with men (Sheifer et al., 2000). According to Zuchi, smaller coronary arteries are prone to abnormal arterial resistance resulting in limited blood flow and can produce CHD symptoms even when there is no coronary obstruction (i.e. artery blockage), and indeed these symptoms are often milder and more varied than is the case where a coronary obstruction is present (Zuchi et al., 2013). This is known as Syndrome X and is more common in women. Overall it is thought the physiological differences described above in anatomical structures, biological processes and disease pathways may account, at least in part, for how women may experience chest pain differently to men.

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<sup>7</sup> MVD is the result of diffuse plaque in coronary arterioles (smaller arteries), as opposed to the wider coronary artery tree. The arterioles are too small to be visualised by angiography (Reis et al., 2001, Arbustini et al., 1999, Lichtlen et al., 1995). The plaque build-up in these arterioles does not lead to obstruction, but causes endothelial damage, resulting in a thickening of the smooth muscle of the arteriole wall. This arterial remodelling results in wall stiffness and consequent loss of ability to dilate in response to emotional and physical stimuli, reducing myocardial blood flow (even though the arteriole lumen remains patent).

### 2.7.2 Psycho-social influences and help-seeking in CHD

Psycho-social factors including age, ethnicity, beliefs and personal experiences, and contextual factors (e.g. the presence of others) and external factors (e.g. media) may intersect gender and play a role in how symptoms are interpreted and acted upon. Some studies that intersected gender with psychosocial and contextual factors reported that women delayed longer than men (Benziger et al., 2011, Adamson et al., 2008, Foster and Mallik, 1998). Adamson concluded that age intersects with gender to influence help-seeking decisions, reporting 'longer delays in older patients compared to younger patients' and that overall older women (especially older than 70 years) delayed the longest (Adamson et al., 2009). Foster and Mallik, on the other hand, found that while women delayed longer than men, there were other factors such as personal beliefs and experiences that intersected with gender to affect delay. For example, the belief that one is having a heart attack encouraged early help-seeking in men, but not in women. For women it was more associated with previous experience of CHD events (Foster and Mallik, 1998). Additionally, the study also found that 'severity of symptoms' was an important moderator in help-seeking in both genders. A more recent study in Lima, Peru which intersected gender, age, education, socio-economics as well as history of CHD symptoms broadly confirmed the results of the early studies, reporting that women are four times less likely to attribute emergency cardiac symptoms correctly than men and act accordingly (Benziger et al., 2011).

A few North American studies (Galdas et al., 2010, Moser et al., 2005, Zerwic et al., 2003) which also compared men and women in the context of CHD did not conclude that women delayed longer than men. The reasons for these more gender-neutral



findings suggested that whilst delays in help-seeking do occur, it is not directly related to gender and can be independent of gender. These studies highlighted that other intersecting social and personal identities or personal choices or circumstances aside from gender, such as age, socio-economic status, self-medication, waiting for symptoms to pass, severity of symptoms and people present at a cardiac event all exerted strong influence over help-seeking decisions.

Both Moser and Zerwic reported that help-seeking delays were independent of gender. Moser found, *inter alia*, that help-seeking was influenced by 'not wanting to bother others with problems/symptoms' and previous experience of cardiac events. Moser also found that older age was associated with longer delay, but that social economics had little impact (Moser et al., 2005). Zerwic, on the other hand, found that older age, ethnic minority and lower socioeconomic status contributed to longer delays (Zerwic et al., 2003). The study reported the longest delay in African Americans compared with Non-Hispanic whites, which were independent of gender. Non-white ethnicity does not always negatively interplay with gender contributing to delay: Gladas et al.'s work on masculinity and help-seeking highlighted that differences can occur between the westernised and non-westernised perspective. While westernised white men sampled tended to view seeking help as weakness, South Asian men did not necessarily see it this way. They considered it a responsible step to getting well (Galdas et al., 2007). Additionally, Zerwic also found that attempting to self-manage CHD symptoms was another contributor to help-seeking delay (Zerwic et al., 2003). Both Gladas (2005) and Nguyen's systemic reviews of literature highlighted that age and socioeconomic status, not just gender, played a role in help-seeking delay. Nguyen additionally suggested that ethnicity was

also associated longer pre-hospital help-seeking delay (Nguyen et al., 2010, Galdas et al., 2005).

Galdas's gender comparative study in 2010 reported that help-seeking for emergency cardiac events was related to complex combination of gender and contextual factors including timing, location of event, severity of symptoms and the people present (Galdas et al., 2010). These results were broadly confirmed by a review of the literature in 2013 which concluded that a patient's help-seeking decision-making was multi-factorial, mentioning severity of symptoms, ability to cope with symptoms, perception of roles and responsibilities (Baxter and Allmark, 2013).

### 2.7.3 Limitations of the literature

One of the main criticisms of the quantitative literature on men, women and help-seeking for CHD is the validity of the instruments used to measure outcomes (Albarran et al., 2007, Ratner et al., 2006). The construction of CHD response-to-symptom instruments were often framed in the expression of typical chest pain often found in men, but not necessarily in women. Thus, it is debatable as to whether these instruments are sensitive to detecting milder and more varied symptoms documented in women. Furthermore, the statistical outcomes in some of these studies failed to meet the thresholds of significance (Mayer, 2014, Gyberg et al., 2015). For example, one of the largest studies to examine help-seeking among men and women for CHD, which enrolled 212 participants, found that women tended to delay longer than men, although it could not achieve statistical significance (Nouredine et al., 2008). The study cited the under-enrollment of women (63 women versus 149 men) as one possible cause for this. Another key limitation is the lack of inquiry into help-seeking decisions in patients within the context of accessing

RACPC for the assessment of symptoms suggestive of CHD. Indeed, only one Dutch study looked at gender differences for patients suspected of CHD in a non-emergency context (van Tiel et al., 1998). The enrolment of patients was done through GP practices and the diagnosis was based solely on the GP assessment (van Tiel et al., 1998). The findings of this study suggested a tendency for women to delay longer than men. However, the study has limited value to the current research as it was conducted outside of the UK and more than 19 years ago. Practice guidelines in the UK have changed since then with the introduction of RACPC and NICE guidelines on management of stable angina (NICE, 2011, Department of Health, 2000). Thus, there is very limited relevant inquiry into the help-seeking practices of men and women accessing RACPC services, leaving this important cohort of patients underexplored in the literature.

#### 2.7.4 Justifying the Research Question

Understanding symptom interpretation and help-seeking decisions is complex. Many European and international studies (Benziger et al., 2011, Nouredine et al., 2008, Adamson et al., 2009, Foster and Mallik, 1998, van Tiel et al., 1998) suggest that women may have difficulty interpreting symptoms and delay help-seeking decisions, a notion that is questioned by a small number of larger North American and UK studies (Galdas et al., 2010, Moser et al., 2005, Zerwic et al., 2003). Research has also highlighted the limitation of the binary gender or sex differences approach taken in many studies and emphasised how contextual factors also influence help-seeking (Galdas et al., 2010, Addis and Mahalik, 2003).

The majority of existing quantitative literature is weak, conflicting, and focused on cardiac events occurring in an emergency situation, while the qualitative literature

often provides a more complete picture. Evidence suggests early presentation and immediate treatment for CHD symptoms are associated with better clinical outcomes (Maas et al., 2011). This is particularly helpful to women who are known to have worse clinical cardiovascular outcomes compared with men (Maas et al., 2011, Mikhail, 2006). Other studies have suggested that prodromal heart symptoms can occur up to four weeks before the onset of an emergency cardiac event, highlighting the importance of early diagnosis and treatment to prevent emergency situations (Noureddine et al., 2008, Albarran et al., 2007). Understanding men's and women's help-seeking experiences and how to improve them will have a significant public health promotion benefit and make a significant contribution to practice for chest pain practitioners. Improved symptom interpretation and promotion of help-seeking may reduce the likelihood of stable cardiac symptoms becoming an emergency situation.

## Chapter 3. **Methodology**

### **3.1 Research question and objectives**

The research question of the thesis is: 'What are the help-seeking experiences of men and women referred to a rapid access chest pain clinic?'

#### **3.1.1 Research objectives**

1. To recruit a varied sample of participants from the RACPC to ensure that a broad range of views relating to chest pain and help-seeking is included.
2. To explore men and women's experience of the RACPC.
3. To conduct semi-structured interviews to understand what participants believe about coronary heart disease (CHD) risk factors, how they consider their own CHD risk and symptoms, and how that impacts on their help-seeking practices.
4. To understand how participants experienced physical chest pain.
5. To examine patterns, commonalities and differences between participants' help-seeking experiences.
6. To examine the personal and social influences that facilitate or create barriers to help-seeking for participants.
7. To understand the participants experience of receiving a diagnosis from the RACPC.
8. To construct a lay patient resource to help patients interpret their chest pain and improve help-seeking through creating awareness.

### **3.2 Design**

The study had two stages. Stage one involved interviewing 30 participants using a semi-structured approach (key topics with probes) to explore participants' symptoms and help-seeking behaviours (Objectives 2-5). Interview data was then triangulated with other sources of data, namely GP referral letters and rapid access chest pain clinic (RACPC) outcome letters, to substantiate patient self-reported 'symptoms' and 'help-seeking delay' (triangulation is discussed further in Sections 3.2 and 3.10).

The second stage of the project was the construction and testing of a new innovative lay patient resource. Interview data and the current literature were used to develop

an evidence-based patient-focussed lay patient resource to help participants better understand and interpret their symptoms, and to promote help-seeking. The leaflet was designed in line with NHS Identity guidelines for producing patient information leaflets (NHS Identity, 2016). The lay patient resource's comprehensibility was tested using two panels of experts: the supervision team and practitioners in the field of cardiology, and a sub-sample of 10 original study participants who were sent the resource to read and provide feedback (see appendix R for the lay patient resource).

### 3.2.1 Qualitative research approach

In this study, an interpretative qualitative inquiry was used since not much is known about this particular area (i.e. help-seeking for chest pain in the RACPC context). Indeed, many quantitative studies in CHD have been criticised in the literature as the instruments of measurement they used have made assumptions which qualitative researchers have questioned (Albarran et al., 2007, Ratner et al., 2006). A qualitative interpretative approach is the best approach to capture participant meaning-making of symptoms, the RACPC experience and the decisions to seek help.

Interpretative research offers insight into how a person makes sense of (i.e. meaning-making) a particular issue (Elliot, 2005). It is about the interpretation of an "area of study" and searching for patterns in what participants said, and drawing out a collective analysis. It also focuses on the processes by which meanings are created and negotiated. Usually the issue being studied relates to a specific life event or experience, for example, having a potentially serious condition. According to Patton and Elliot the key tenets of an interpretative approach include (Patton, 2002, Elliot, 2005): flexible design, purposive sampling, qualitative data collection, inductive

data analysis done in parallel with data collection, and the ability to challenge taken-for-granted assumptions is the cornerstone of good qualitative research.

Additionally, the theoretical framework is not pre-determined, it is derived from the data (i.e. what is the most appropriate framework to understand the data), as much as it is from the literature. Therefore, the theoretical framework is responsive and adaptable as relevant themes from data collection and/ or data analysis emerge. Sampling is generally purposive to provide rich information about the issue being studied. Therefore, cases which offer the most insight, learning points or variations are specifically selected. Often contrasting cases are used to highlight important differences. Data collection in this approach is usually obtained by direct interaction with individuals one-on-one or in a group setting. The data collection focuses on the view of people involved by allowing them to talk on their own terms. Data analysis is frequently inductive and immersive to uncover patterns and interrelationships in data. The researcher must also seek to understand the multiple interrelationships that emerge from the data without make assumptions or specifying a hypothesis. The analysis of data does not occur in a vacuum and must be viewed in the context where it is collected (i.e. context sensitivity).

According to Elliot, qualitative research should include the following to enable adequate critique (Elliot, 2005). Firstly, one's own perspectives need to be described in the methods (reflectivity). Secondly, the sample should be accurately described. Thirdly, credibility checks should be provided by using more than one source of data (e.g. triangulation see 3.2.2). Fourthly, findings should be organised into a coherent structure or framework to enable interpretation of how they fit together. Fifthly, clear

and concise analysis should be used to allow the reader to judge whether it is an accurate representation of the phenomenon.

### 3.2.2 Triangulation

Some participants' ability to recall the original symptoms that led to them seeking help from the GP was not always clear, especially when there were multiple symptoms, or additional symptoms which occurred in the time between being referred by the GP to RACPC and being interviewed. Similarly, some patients could not always recall how long they delayed before seeing their GP for symptoms. Therefore, triangulation<sup>8</sup> was chosen in an attempt to substantiate patient symptoms or patient help-seeking delay with an additional source (e.g. medical records).

### 3.2.3 Lay patient resource

A key feature of the DProf programme is that the student makes a contribution to their profession and organisation (Lee, 2009). This study developed a new lay patient resource, guided by the interviews and literature, as a useful and innovative way of translating the academic research into clinical practice, to improve practice both professionally and organisationally.

## 3.3 Ethics

Before any fieldwork or data collection can be commenced it is necessary to obtain ethics approval. To obtain the NHS research approval required by this study a sponsorship letter was sought from the University of Westminster. On receipt of the

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<sup>8</sup> Triangulation is a qualitative method whereby data is collected from a variety of sources including interviews, focus groups or medical records, which are then cross-referenced in an attempt to find associations, similarities and links between the different sources and substantiate the overall themes in data



sponsorship letter the NHS Research application was submitted. The study underwent proportionate review by the Fulham Research Committee and approval was granted subject to minor amendment (Reference no. 14/LO/0169). Additionally, local Research and Development approval was obtained from St George's Joint Enterprise Research Office to allow the study to be conducted (Reference no. 14.0007). A substantial amendment was obtained on 7 October 2015.

### **3.4 Researcher reflexivity**

When using qualitative research, it is necessary to consider the influence of the researcher on the study. The researcher's background, experience, profession, beliefs, as well as personal and social identity can influence the study, and so researcher reflexivity is required to understand this (Patton, 2002, Richards and Emslie, 2000). Reflexivity can be defined as awareness of self, and awareness of one's influences on the data (Patton, 2002). For example, how the participants view the researcher may influence their engagement and vice versa (Patton, 2002, Richards and Emslie, 2000). Similarly, a researcher's professional expertise may influence how they approach the data analysis (Patton, 2002). It is not possible or desirable to remove the researcher's influence; therefore, the aim is to be as transparent as possible so that readers can reach their own conclusion on researcher influence.

I was born in South Africa to a middle-class family. My father was a senior civil servant and later a business owner, and my mother was an accounts assistant turned graphic designer and chocolate factory business owner. I was diagnosed with dyslexia, dyspraxia, visual perception deficit, and attention deficit hyperactivity disorder (ADHD) when I was eight years old. I was sent to a remedial education

institution for the remainder of junior school years. Later I attended normal stream high school before moving on to higher education in South Africa studying accounting and economics. I moved to the UK when I was 23 years of age, and began my training in a clinical science career in 1999. I have been in a management role since 2009.

I have been practising as a clinical scientist (cardiac physiology) for 17 years and I have a special interest in cardiac physiologist-led rapid access clinics and pathways. Throughout my career, I have overseen the creation of multiple rapid access services (chest pain, heart failure, arrhythmia, cardiac device pre-assessment and cardiac monitor implantations). I was instrumental in redesigning the RACPC pathway where the current research was conducted. I undertook the current research as part of a professional doctorate qualification, which includes research methods training and guidance from my project supervisors. However, my training and work experience has been quantitative and deductive in nature in the past. The practice of clinical science is very quantitative and methods-driven and thus my knowledge of qualitative research techniques was limited. My interviewing experience is largely based on the framework of a clinical consultation, focusing on elucidating the key patient symptomatology to aid clinical decision making in a very limited timeframe. As a result, I initially found it challenging to elicit rich data collection in the interviews. Therefore, I undertook training in qualitative interviewing and sought extra guidance from my supervision team. Additionally, my data analysis experience had been on quantitative data, and I found it equally challenging to organise and code the qualitative data, and thus I undertook qualitative analysis training. Some of this qualitative methods training was part of the professional

doctorate's taught element from my supervision team, and additionally I attended three external courses: an interviewing techniques course at King's College, data analysis techniques course at the University of Surrey, and Nvivo training. The Nvivo training was particularly helpful in translating my data into a more organised format e.g. searchable codes and themes. It took several attempts to understand how to code accurately and identify themes; indeed, I re-coded several interviews before getting it right.

My specific learning difficulties may have impacted on the research processes – difficulty with note taking, transcription, paying attention for long periods of time and consolidating a large volume of written data, but I am aware of these limitations as I live with them daily and consequently I have developed strategies to minimise their impact. In my research this has, for example, required discretely writing keywords spoken by participants during the interviews to keep my mind focussed. When analysing the data, I drew on my scientific skills to overcome my dyslexic challenges. These included the use of spreadsheets and tables to create a 'visual mind-map' of the data's keywords. I found it much easier to handle the data in this format and used it as starting point to form my analysis. To further mitigate unhelpful influences on the research process, I fully utilised university resources for students with specific learning difficulties. I am registered with the university disability service, and I am in receipt of government funding for an array of technical support e.g. high specification digital recorder, transcription service and writing assistance software. I have also had access to a dyslexia tutor as well as two doctoral supervisors to guide me through the doctoral process.

My roles as a researcher, scientist, and department manager within the organisation where the study was undertaken may have impacted on how participants viewed me. The power dynamic created by participants viewing me in a position of authority could affect richness of data collection by limiting responses to certain questions e.g. their experience of the chest pain service or GP experience. Indeed, one participant who had a negative GP experience was hesitant to share it and only did so with the disclaimer, 'I don't want to get anyone in trouble'.

To downplay my managerial role, I always wore more casual dress for interviews, introduced myself as a doctoral researcher, emphasising that I was undertaking the research study for my doctorate, that I was interested in what participants had to say, and that the information would be used for academic purposes only and would not affect their health care in any way. Additionally, I rearranged the seating in my office to promote a more informal interaction e.g. removing the desk or meeting table between myself and the participant. From my perspective, I tended to view participants as 'cardiology patients' and thus I found it challenging to separate my role as a clinical scientist, for example scientifically evaluating patients through symptomatology and physiological testing. As a result, I had to be cautious not to allow the interviews to drift into a clinical consultation or assessment, i.e. short, focused questioning to pinpoint symptomatology, and I tried to focus more on the stories that people were telling me instead.

During the data analysis stage my professional experience in cardiac function testing influenced how I approached the data. As part of my role as a practitioner I focused on matching patient symptoms to test results – patient symptoms that match physiological changes is the desired end point for many cardiac tests (e.g. patient

with chest pain and positive electrocardiogram changes on exercise is a potentially diagnostic result). The ‘matching analysis approach’ was a useful technique in the analysis stage, as it assisted me in linking concepts to confirm patterns: chest pain vs no chest pain and help-seeking; severity of chest pain and help-seeking; other symptoms and help-seeking. I constantly searched for the impact of symptoms on the patient or practitioner decisions e.g. help-seeking, delays, GP referrals, and referrals further cardiac investigations.

One of the challenging influences of my background on the data analysis was that I automatically gravitated towards cardiac symptoms as I understand them and identify them as important. I initially found it hard to relate to non-cardiac symptoms as it is out of my scope of practice and I would not always understand its significance. I was conscious of this, and I often re-read sections of interviews to search for non-cardiac-related symptoms that I may have overlooked in the first analysis, and I consulted with supervisors, medical and nursing colleagues.

### **3.5 Sampling and recruitment**

#### **3.5.1 Sample**

The sample of 30 participants (15 male and 15 female) was selected from participants who were referred to an Inner London rapid access chest pain clinic (RACPC) for the clinical evaluation of their chest pain. Study inclusion and exclusion criteria are shown in Table 1.

**Table 1: Inclusion / Exclusion Criteria**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Males and females over the age of 18 years	Patients presenting with an acute cardiac event.

Have been referred to rapid chest pain clinic RACPC for assessment of chest pain (including associated symptoms i.e. arm pain, throat pain and breathlessness)	Patients not accessing the rapid access chest pain clinic (RACPC). For example, patients referred directly by a cardiologist for the evaluation of chest pain. These patients do not meet the requirements for a RACPC referral because they are co-morbid (heart failure or other unstable cardiac problems).
Only patients who were able to communicate sufficiently in English included	Patients unable to give consent for whatever reason or are deemed unable to give consent, as it would be unethical to do otherwise.
Are able and willing to consent to the study	

It was decided to use the Rapid Access Chest Pain Clinic (RACPC) where the researcher is employed to sample the participant cohort for the study for three reasons: firstly, the ability to recruit participants was within the scope of a work-based practice doctorate, secondly the crucial role of the RACPC in the evaluation of non-emergency chest pain and thirdly the active role that cardiac physiologists undertake in managing the RACPC pathway. As mentioned earlier; 'chest pain' clinics investigate all chest-related discomforts (e.g. chest pain, arm pain, throat pain and breathlessness and sometimes nausea), as these symptoms can be related to stable angina. Unlike an acute cardiac event (i.e. having a heart attack), stable angina is not considered an immediate threat to life and can be evaluated in an outpatient clinic setting (NICE, 2011, Department of Health, 2000). It is important to highlight that not all patients with chest pain or associated symptoms have CHD as there are other possible reasons for these symptoms (e.g. musculoskeletal) and indeed many participants in this current study were deemed to have non-CHD related symptoms by the end of their health evaluation. The role of RACPC is to undertake the initial clinical evaluation of potential CHD symptoms to determine if further intervention is medically appropriate. The GP's decision to refer a patient with symptoms suggestive of CHD to the RACPC would be based on the patient's risk

CHD profile (clinical history, age, gender, smoking, family history, etc). Therefore, using RACPC patients in this study ensured that participants selected had been evaluated by a GP who deemed their symptoms worthy of a referral.

### 3.5.2 Sampling strategy

The study used maximum variation (MV) sampling to recruit a diverse range of participants from the RACPC subject to the inclusion/exclusion criteria (see Table 3). MV is a method of purposeful sampling where the aim is to achieve the maximum variation among study participants (Mirfin-Veitch et al., 2003, Patton, 2002). The researcher sets maximum variation characteristics which they explore such as age, ethnicity, social class and employment status (Coyne, 1997). In terms of this study, variation was sought in gender, age, ethnicity, occupations, and assessment outcome, as detailed in Table 2. Achieving this diversity amongst participants enabled the researcher to reflect the demographics of the Rapid Access Chest Pain Clinic catchment area (see Table 3) and thus identify themes that reflect a cross-section of society from where the sample was drawn (Mirfin-Veitch et al., 2003).

**Table 2 - Recruited Sample**

Participants	Age	Gender	Ethnicity	Occupation	Pathway
PA01	44	Male	White	Senior Manager	Pre
PA02	63	Female	White	Accountant	Pre
PA03	29	Male	White	Manager	Pre
PA04	37	Male	White	Business Manager	Post
PA05	76	Female	Asian	Cake maker	Post
PA06	60	Female	White	Tour Guide	Post
PA07	46	Male	White	Forklift driver	Pre
PA08	54	Male	White	Dog racer / Owner	Pre
PA09	27	Female	White	Lawyer	Pre
PA10	71	Male	Asian	Sales assistant	Pre
PA11	29	Male	White	TV journalist	Post
PA12	47	Male	Asian	Civil Servant	Post
PA13	25	Female	Asian	Beautician	Post
PA14	70	Male	White	Gas fitter/plumber	Post
PA15	80	Male	White	Graphic Artist	Post
PA16	42	Male	Asian	Carpenter	Post

PA17	46	Male	White	Management Consultant	Post
PA18	49	Female	White	Adult Educator	Pre
PA19	77	Female	Asian	Teacher	Post
PA20	48	Female	White	Tailor	Pre
PA21	51	Female	Black	Youth worker manager	Pre
PA22	54	Male	White	Property developer	Post
PA23	76	Female	White	Office worker	Pre
PA24	67	Female	White	Accountant	Pre
PA25	80	Male	White	University Professor	Pre
PA26	72	Female	Asian	Audio-visual worker	Post
PA27	80	Female	White	Catering	Pre
PA28	60	Male	White	Carpenter	Pre
SUBP01	59	Female	White	NHS administrator	Post
SUBP02	61	Female	White	Medical secretary	Post

The dimensions of gender, age, and ethnicity were specifically selected from the start as they are all thought to influence the way that patients experience symptoms and their help-seeking practices (Nguyen et al., 2010, Ratner et al., 2006). The pre- and post-assessment dimension was introduced early on, after the first six interviews. Occupations (or pre-retirement occupations) were used retrospectively as socio-economic status dimension. Each dimension is discussed further in turn below.

Age was an important dimension to include in sampling as age plays a clear role in CHD. For instance, it is well known that women develop heart disease later in life as their risk is reduced by female hormones until menopause (Maas et al., 2011, Mikhail, 2006). Generally speaking, women start developing CHD, which is known to cause chest pain, at age 60 years compared to men who tend to present about 10 years earlier at age 50 (Zuchi et al., 2013).

Ethnic variations are known to have an effect on CHD risks and help-seeking practices (Sheifer et al., 2000). People classified as Asian, for example, are known to have significantly higher risks for CHD than Caucasians. Studies have shown Asian ethnicities to have smaller coronary arteries which are thought to increase CHD risk



as well as having more sedentary lifestyles, and follow unhealthier diets than Caucasians (BHF, 2015, Zaman and Jemni, 2011, Makaryus et al., 2005). Being of Afro-Caribbean origin is associated with higher blood pressure (hypertension) which is linked to CHD risk (BHF, 2015). Delayed help-seeking practices are also more common in some ethnic minorities than in Caucasians (Galdas et al., 2007, Banks and Malone, 2005, Zerwic et al., 2003, Sheifer et al., 2000). In view of these known ethnic variations, the researcher included a variety of ethnicities in the study.

Modern-day socio-economic status is classified by seven categories: 1-higher managerial and professional occupations; 2-lower managerial and professional occupations; 3-intermediate occupations; 4-smaller employers and own account workers; 5-lower supervisory and technical occupations; 6-semi-routine occupations; 7-routine occupations (Langford et al., 2009). It is known that socio-economics can cause social inequalities which impact on morbidity and mortality. Men and women at the lower end of scale classifications (5 - 7) are known to have worse health outcomes, with mortality rates 5.3 times higher than those at the upper end of the scale classifications (1 & 2). More women than men tend to be in the lower end of the scale classifications and thus, on average, experience worse health outcomes and higher rates of mortality due to social inequalities (Langford et al., 2009). Help-seeking and CHD studies have also suggested that the social inequalities created by variations in socioeconomic status may play a role in delayed help-seeking for CHD symptoms (McCartney et al., 2012, Galdas et al., 2005). Whilst the current study did not specifically assign participants to particular socio-economic status or class, it did use occupations (or previous occupations) as an indirect method to postulate where participants were likely to be (e.g. high, mid, lower income ranges).

Pre- or post-assessment status affected the way in which some participants described their symptoms. The researcher noted that if a participant had received their outcome assessment and their symptoms were deemed to be non-CHD chest pain (e.g. musculoskeletal), they were sometimes less forthcoming and downplayed their symptoms. Therefore, an equal number of participants were sampled either pre-assessment outcome or post-assessment to get a variation in the sample.

### 3.5.3 Recruitment

GP referral forms, medical records (paper and electronic) and the hospital's patient administration system (PAS) were all used to identify potential participants who met the inclusion criteria detailed in Table 1. It was necessary to examine these multiple sources to determine patient eligibility for the study as the information required was not necessarily contained in one single source. For example, the GP referrals contained personal details related to gender, age, symptoms, medical history and risk factors, but they rarely contained ethnicity. Therefore, GP referrals were cross-referenced to PAS to confirm ethnicity. A total of 43 patients were identified as meeting the inclusion criteria by this method, and were contacted by phone by the researcher or an assistant and invited to participate in the study. Refusal to participate accounted for only three, but nine were 'lost to follow-up' as they were erroneously sent home by the nurse specialists before the interview and were not willing to return to be interviewed. All participants who gave their written consent were interviewed.

The recruitment process continued until saturation was achieved i.e. no new themes of importance to the study were emerging from the interviews (Strauss, 1998). Although saturation cannot be predicted at the outset, in similar studies in the area of

CHD, researchers had achieved saturation in around 20 interviews (Galdas et al., 2010, Foster and Mallik, 1998). Other researchers have suggested concept density could be achieved with as few as 12-15 participants (Baker S, 2008). It was on that basis that an original sample of 24 interviews was the aim of this study. It was envisaged that this number was likely to achieve saturation and the desired sampling dimensions. At 24 interviews, it was considered that saturation had likely occurred, as no new themes seemed to be emerging. However, the ethnic minority dimensions had not been achieved. In consultation with the supervision team, it was decided that recruitment should continue to 30 interviews.

To achieve greater ethnic minority variation in the sample, I retrospectively searched the RACPC attendance records using the patient administration system (PAS) for the preceding 12 months – February 2013 to February 2014 – in an effort to identify more Afro-Caribbean male and female participants, but none could be found. Due to limited resources the researcher was not able to conduct a wider search. To some degree, ethnicity range in the study reflects the catchment area where the study was conducted, which is a predominately a white, working to middle class area (Office for National Statistics, 2011). Statistics for the catchment area of Wandsworth's borough wards where the study was conducted are detailed in Table 3, and see Appendix A for full demographic breakdown of the study participants.

**Table 3 - Ethnicity breakdown in study centre catchment area**

Queen Mary's catchment Area	Total Percentage %			
	White	Mixed	Asian	Black
East Putney	79.4	4.3	9.9	3.9
Roehampton	65.5	6.5	11.20	3.3
Southfields	75.6	4.3	11.1	7.6

Tooting	47.3	5.1	29	15.6
Wandsworth Common	82.2	4.1	5.8	7.0
West Hill	68.3	5.2	8.8	14.7
West Putney	77.1	5	7.5	7.8
Average	70.77	4.92	11.9	8.5

Source: Wandsworth.gov.uk

Eligible candidates were contacted by telephone by the researcher or a nominated member of the clinical triage team, and invited to participate in the study. If they expressed an interest in participating, the participant information sheet and the consent form were posted to them that day (see Appendices I and J). They were asked to read both and bring these documents to the interview which would be scheduled to coincide with their chest pain clinic (RACPC) appointment. They were provided with the telephone contact details of the researcher should they have any further questions or need clarification. None of the participants contacted the researcher prior to interview. They were also advised that there would be an opportunity to ask questions on the day prior to being asked to consent to the study. Only a few participants asked for further information.

The waiting time after being contacted by the researcher before attending the RACPC appointment was on average ten working days. This gave the participants sufficient time between the first contact and being provided with the information sheet before deciding to provide written consent. This *modus operandi* is deemed good research practice because it gives patients an opportunity to reflect on their desire to participate without feeling pressured into making an immediate decision (Robson, 2011). Written consent was formally taken on the day before the interview commenced and after participants had an opportunity to ask questions. At the point

of entry to the study, each participant was allocated a unique study number to identify them throughout the remainder of the study.

#### **3.5.4 Sample characteristics**

Thirty participants were interviewed over a five-month period of recruitment from February to June 2014 at Queen Mary's Hospital, Roehampton. The study participants' gender was divided equally, 15 males and 15 females, and included a mixture of ages and ethnicities, as detailed in Table 2. The mean age of the participants was 56 years. The mean male participant age was 52.6 years and mean female participant age was 59.4 years. The female mean age is slightly younger than one would expect but this is due to a few outliers i.e. very young participants (less than 30 years of age). The participants came from a range of nationalities including British, Austrian, Russian, Iranian, Philippine, Indian, Hong Kong and Danish. The ethnicity of participants was mostly white but the study did include seven participants of Asian heritage of whom four were women. There was one Afro-Caribbean woman participant in the study. No Afro-Caribbean male participant was referred to the RACPC during the five-month recruitment period. The participants came from a wide range of occupations including traditionally lower income unskilled occupations (e.g. manual worker and sales assistant), to mid-income semi-skilled occupations (e.g. gas fitter, plumber and audio-visual worker) and higher income professional and management occupations (senior managers, accountants and lawyers). It was noted that there were fewer women in higher income professional and management occupations. More than half of the participants had ongoing health concerns aside from their presenting chest pain. The most common conditions were asthma,

hypertension, high cholesterol, a few cases of thyroid complications and an isolated incidence of a rare type of low cortisol disease.

### **3.6 Data gathering**

#### **3.6.1 One-to-one semi-structured interviews**

This study used one-to-one semi-structured face-to-face interview to collect data. By using this approach, not only was the researcher able to keep the interview focused on topics of relevance to the study to ensure data collection met the study objectives, but it also allowed for the potential of rich data collection from areas not initially anticipated in the study (Draper and Swift, 2011, Patton, 2002). Originally it was planned to offer patients a choice of face-to-face or telephone interviews for the sake of participant convenience. Ethics approval was obtained for both methods, but after further debating the merits of both methods with the supervision team it was felt that telephone interviews might not obtain rich data as face-to-face interviews. Therefore, all participants were interviewed face-to-face.

One-to-one semi-structured interviews were chosen over the obvious alternative qualitative data collection methods (namely structured interviews, unstructured interviews and focus groups). Structured, survey-style fixed questions were not used as they assume the researcher knows the areas that are important to participants rather than allowing the participants to tell their own focused account of what is important to them (Draper and Swift, 2011, Patton, 2002). The less focused nature of unstructured interviews was also considered unsuitable, as it was felt that a non-topic based approach interviews would make comparison difficult if participants did not cover the same areas (Stoléru and le Mer, 2007, Patton, 2002). Additionally,

focus groups often run the risk that some participants would simply agree with the views of more dominant participants (Polit, 2009, Patton, 2002, Twinn, 1998).

### 3.6.2 Interview guide construction

The interview guide development was initially informed by reviewing the literature on gender, help-seeking and cardiac complaints, and was further developed through discussions with colleagues and the interviewing process itself. How the interview guide and individual questions evolved throughout the various draft stages is detailed in Appendix B. In outline, the researcher tabled key themes prevalent throughout the body of literature. Using this tabulation approach, it was clear that several overarching key issues (themes raised by multiple studies) existed in the literature, for example: gender variation of symptoms; recognition of symptoms; help-seeking with health professionals and help-seeking with family members; influence of family and friends; personal, professional and social barriers and enablers of help-seeking; and perceptions of CHD risk. These key themes from the literature were used as the foundation to draft the interview guides and probes.

Discussions were also held with the RACPC nurses and cardiac physiologists to obtain insights into the issues they came across in their clinical practice. Elucidating the patient symptoms and determining the differential diagnosis (i.e. if not cardiac, what else it could be) was the main issue raised by the nurses. The RACPC nurses and cardiac physiologists thought it was essential to have probes to elaborate upon symptoms. Clinically, it is common to inquire regarding the location of the chest pain, whether it is static or moving, how long the pain lasts for, what makes it worse or better, and what the patient was doing at the time of the pain. For that reason, key topics with probes were developed to focus on the way participants experience and

understood their symptoms i.e. frequency, duration, activity at time of symptoms were all included in the guide.

A first draft interview guide based on the literature and discussion with nurses and cardiac physiologists was reviewed by my supervisors. Feedback suggested that the first draft was too structured. More open-ended questions were added to bring the interview guide in line with a semi-structured interview approach. In the second draft, multiple closed questions (from the first draft) were grouped together to form open-ended questions. Probes were also included so the researcher could prompt participants to ensure rich but focused data collection. In the second draft, the changes outlined below were made following their recommendations:

- Question 1: 'Symptoms' replaced 'heart symptoms' to encourage a broader response.
- Question 2: 'Health professional' replaced 'doctor' so that participants would talk about their experiences with the chest pain nurses, cardiac physiologists, and not just medical doctors.
- Question 3: Added 'what were you thinking/feeling?' to elicit the participant decision making processes that led to seeking professional help.
- Question 6: The question on CHD risk was expanded to include 'Is there any difference between men and women?' to ensure participants' understanding of gender and CHD risk was better explored.

It was also decided to add questions to the interview guide to extract more data regarding symptoms and help-seeking decisions. Additional questions were:

- What was it like having those symptoms?
- What was the consultation like? What was the doctor like? How did you feel about it?
- How do you feel about asking for help in general? e.g. from doctors, from friends etc.
- What else about your symptoms or experience would you like to say?



The interview guide was then piloted on two participants. Two staff members at the centre had recently attended the RACPC and agreed to take part in the pilot. They signed the consent form and were interviewed by the researcher. These interviews were conducted in the same conditions as the planned study was to be undertaken, e.g. the same questions, the same recording technique and also conducted in the researcher's office. The pilot interviews were transcribed by a professional transcription agency and reviewed by supervisors to assess interview style. The findings prompted, in consultation with supervisors, the inclusion of additional probes, for example to specifically elicit the temporality of help-seeking delay e.g. days, weeks or months.

The final interview guide was used throughout the entire interview stage, but it was continually adapted in consultation with supervisors to include issues raised by participants that had not originally been anticipated e.g. impact of having or not having a diagnosis, accessibility of medical services and the differences between male and female lifestyle (see Appendix A for the final Interview Guide).

### 3.6.3 Interviews

The interviews were held in the researcher's office. The site or 'place' of the interviews can affect interviewee performance and thus influence the data collection process (Sin, 2003). In the context of this study an inconvenient place and time may have reduced participant involvement or affected responses (e.g. time pressures, thus keeping their answers short to finish rapidly), so, therefore, the researcher chose an interview site and time that was convenient for participants. The cardiology office is based in the cardiology department where the RACPC appointments take place. Interviews were also linked to the RACPC appointments before the

assessment or immediately after. Therefore, participants did not need to travel to another part of the hospital nor did they have to wait around to be interviewed nor did they need to return on a different day. However, it is recognised that despite the obvious benefits of basing the interview location around participant convenience that there are downsides to this approach. The formality created by interviewing participants in a hospital setting and using the cardiology office may have some impact, and participants might have responded differently were they in their own homes. The home is a more relaxed and informal environment and this can sometimes encourage participants to speak more freely. The researcher was however restricted by the Trust's policies which discourage visiting patients in their homes other than for delivery of patient clinical care for reasons of personal safety, insurance etc. Additionally, the office can be seen as a place of authority which can, in some cases, affect participant performance (Sin, 2003). The researcher was aware of this potential influence and took steps to mitigate them by reducing the formality of the office and make the environment more comfortable: for example, the seating was changed and the desk removed so that there was nothing between the interviewer and interviewee. Light refreshments (tea, coffee and water) were also available for participants.

Prior to the interviews beginning, pre-interview matters were discussed. The participants were offered an opportunity to ask any further questions about the study. It was reiterated that participation was voluntary and that non-participation would not have any bearing on their care. Once participants were satisfied they were asked to read and sign the consent form. Participants were told to allow one hour for the interview to allow for the pre-interview introduction, questions and paperwork as well

as the interview and any post-interview questions. On average the interview process lasted about 45 minutes.

Once the participant was ready to begin to the interview, the digital recording was initiated and interview questioning began. Participants were initially asked broad questions e.g. 'Tell me about the symptoms that led you to see your GP'. Participants were encouraged to speak freely and they were not interrupted, enabling them to tell their own story in as much detail as possible. During natural breaks in the storytelling, probing was used to zone in on key issues e.g. 'How severe were your symptoms?' This ensured more focused data collection was included without disrupting the flow of the participant's account. Questions were also re-phrased if it was apparent that the participant had misinterpreted what was being asked. Sometimes additional questions or probes were used to either explore an interesting point raised by the participant or to re-direct the interview back to key topics if it had gone particularly off-point e.g. 'So you said your pain wasn't severe, can tell me more about that?'

The first interviews tended to be shorter than the later ones. Despite opening the interviews with open-ended questions, the researcher initially slipped back into clinical consultation questioning, asking focused questions which attracted only short answers. During debriefs with the supervision team the researcher was given guidance on how to keep the interview open-ended e.g. allowing the participant to tell the story and probing to stimulate discussion and obtain richer data collection.

Some participants raised concerns about the symptoms or the implication of their tests results. In these cases, the participant was asked if they would be happy to

discuss these questions at the end of the interview. When the interview had concluded, the researcher addressed any concerns or provided clinical advice to the participant. To bring the interview towards a close, a few general questions were asked about general health, work and family. All interviews were closed asking the participants if they felt there was anything that they did not have a chance to talk about. Before the participant left the researcher's office, the researcher double-checked to see if any outstanding concerns remained and thanked them for participating.

### **3.7 Data management and analysis**

#### **3.7.1 Data management**

Interviews were transcribed verbatim by a professional transcribing agency. The agency was not provided with patient-identifiable information, and all digital recordings were labelled by unique study number only. Additionally, the agency was asked to sign a confidentiality agreement. The researcher removed all names, places or other identifiers from transcripts to fully anonymise them as far as possible. The researcher listened to all recordings and compared them with transcripts to check their accuracy.

#### **3.7.2 Data analysis**

This study used thematic analysis and a constant comparison method (CCM) to analyse and interpret the data. Thematic analysis is a commonly used, generic form of qualitative analysis, whereby data is scrutinised to search for common patterns. Braun and Clarke define thematic analysis as: 'a method for identifying, analysing and reporting patterns within data (Braun and Clarke, 2006). This process involves examining, categorising, tabulating, and recombining data acquired in the

research. This enables the data to be organised into themes to establish underlying patterns and trends (Patton, 2002). CCM originated in the grounded theory approach, but is now widely used in other types of qualitative analysis (Guest, 2012, Patton, 2002). In CCM, the researcher takes a singular segment of collected data (e.g. a single interview, medical record or theme) and compares it with all the other segments of data that are similar. The researcher examines what makes a particular segment of data either similar or somehow different to the other segments of data. CCM was used throughout this study as each interview was reviewed and compared with the others through the interview and analysis process. Thematic analysis and constant comparison method (CCM) data analysis techniques were used in this study as they were considered appropriate for an interpretative approach (described above) and the collected data (e.g. interviews) (Elliot, 2005). The study did not aim to develop an overall “selective” theory as would be the case in grounded theory.

### ***Phase one – preliminary analysis***

Preliminary analysis started during and after first interview, and in subsequent interviews where the researcher reflected on the interview and made observation notes, recording the overall impression of the interview. A more structured approach to analysis started after the first four interviews. Following accuracy checks, all four interviews were read and re-read for data immersion. Initial line-by-line coding was done on paper where the researcher annotated a potential code, interpretations or interesting quote in the MS Word document (e.g. delay or help-seeking). These first four interviews identified an initial 46 codes which were used as a draft coding list. The coding of these four interviews was checked by both supervisors to ensure the researcher was identifying relevant codes consistently (see Appendix E for an

overview of coding development, including changes made to the coding list during the analysis).

As the interviews progressed, digital recordings were checked for accuracy, re-read to fully immerse in the data, and paper coding continued using the draft coding list developed from the first four interviews. That is, transcriptions were checked for these same codes, and any additional codes not included in the first draft. The initial coding list was continually revised and overall 13 codes were added through this process bringing the coding list up to 60 codes (revision stage). The draft coding list was debated with supervisors and some codes were merged with other codes and other codes deleted. A working set of 44 codes was established through this process.

### ***Phase two***

Once paper coding was completed and the code list was finalised, they were entered into Nvivo. The transcript was loaded as an MS Word document in the Nvivo program. Using the paper coded interview transcripts, data segments were assigned to one or more of the relevant codes to enable analysis. After the coding of the interviews in Nvivo was completed, the researcher was able to organise the coded data to search for common themes by running coding enquiries and generating reports. The queries enabled the researcher to explore the relationship between the different codes. For example, codes 'men' and 'delay' were interacted with each other to see what men said about their symptoms. Similar codes 'women' and 'delay' were interacted to get the women's perspective. The researcher was then able to explore what men and women said about delay. The above process was completed for other codes in preliminary stages: 'men and symptoms', 'women and symptoms',

'women and belief', 'men and belief', 'women and behaviours', 'men and behaviours', 'women and CHD risk', 'men and CHD risk'. Similar coding queries were also run on age, ethnicity and occupations: 'age and delay', 'age and help-seeking', and 'ethnicity and delay', 'ethnicity and belief', 'occupations and delay' etc. This coding enabled the researcher to be sensitive and aware of what impact these wider factors had, in addition to gender on symptoms, help-seeking and behaviours.

In order to obtain a broad of overview of potential themes, the researcher constructed a series of tables on a spreadsheet with keywords containing each of the select codes, creating a visual map (see Appendix F for symptomatology, and Appendix G for delay). For example, a table for men and delay and women and delay including reasons for delay, motivations and barriers to help-seeking was created. The tables listed a keyword for how long each participant claimed to have delayed help-seeking e.g. days, weeks or months. The researcher was then able, at a glance, to explore the different reasons for delay. Using these constructed tables, the researcher was able explore links, for example symptoms, thoughts about symptoms, and perception of CHD risks ('men and symptoms' or 'women and CHD risk'). Once potential themes were identified (e.g. gender and severity of symptoms and severity as motivation to help-seeking) the researcher was able to construct short summaries under each potential theme interaction to create an initial interpretation. The researcher was then able to assign relevant quotes from the interviews under each theme and its narrative.

### ***Phase three***

Originally, there were numerous potential themes including types of symptoms, severity of symptoms, frequency of symptoms, duration of symptoms, activity at time

of symptoms, reluctance to seek help from professionals, reluctance to seek help from friends and family, delay, severity as motivation to help-seeking, fear of doctors as a barrier to help-seeking, and CHD risks and health beliefs. Following several debates with supervisors the potential individual themes were merged into two main overarching themes, namely, symptoms and help-seeking for symptoms. The original larger pool of potential individual themes was incorporated into a narrative of the two main themes for this preliminary analysis.

#### ***Phase four***

For the final analysis, all the coding queries run in the preliminary stages were re-run and re-compared with the preliminary analysis to check for accuracy and ensure that important quotes were not missed. Four new quotes were identified as being useful for the study and they were added to the analysis (see Appendix H). A deeper analysis of the codes of beliefs and behaviours was conducted in final stage as this area was only touched on in the preliminary analysis.

Further coding queries were run for the final stage of analysis including 'women and health professional', 'men and health professional', 'women and doctors', 'men and doctors' 'women and diagnosis', 'men and diagnosis', 'women and tests and treatments' and 'men and test and treatments'. These enabled the researcher to extend the areas not explored in the preliminary analysis with a focus on symptoms and help-seeking.

The results section initially had an introduction section and four overarching themes in which to frame the results, namely: Chest Pain and CHD symptoms, Help-seeking practices, CHD risk and behaviours and Test and Treatments. Following further analysis of the interview data and negotiations with the supervisory team it was



decided to make changes to these overarching themes to better reflect data. The introduction section was deleted as it was more appropriate in the discussion section. The CHD symptomatology section was changed to 'Symptoms' to enable a wider inclusion of symptoms. The test and treatments section that underwent several revisions: renamed Chest Pain Clinic and then changed to Health Experience and Outcome. Finally, after further debate with the supervision team it was decided to delete this fourth section, and absorb the relevant sections within the remaining three sections namely: Symptoms, Help-seeking, and CHD risks and behaviours.

### ***Phase five: triangulation***

In order to establish the robustness of the self-reported interview data on symptoms and help-seeking delay, patient reports were triangulated (cross-referenced) to three sources: medical records, the GP referral letter and RACPC outcome letters. To enable analysis, for each participant, data was tabulated under the relevant columns (GP referral letter, RACPC outcome letter and medical records) and matched with the interview data.

## Chapter 4. **Results: symptoms**

This chapter examines the study participants' accounts of the symptoms they experienced that eventually led to seeking professional help from their GP, and in turn gaining a referral to the Rapid Access Chest Pain Clinic (RACPC). Included in this analysis is: what participants interpreted as medical symptoms (e.g. troublesome sensations); what they considered as a potential cause of their symptoms (e.g. potential CHD symptoms or other medical conditions); the different symptoms participants referred for RACPC reported to their GPs (e.g. severity, frequency and triggers); and what symptoms GPs thought were worthy referrals to RACPC. This section also considers the role of coronary candidacy, pre-existing conditions, and the role of media campaigns in whether or not participants viewed symptoms as potential CHD initially.

This chapter has 5 sections: 4.1 Attribution of symptoms; 4.2 Symptoms experienced by participants; 4.3 GP referrals to RACPC; 4.4 Triangulation; 4.5 Summary. These elements will be illustrated with quotations from participants as supporting evidence.

### **4.1 Attribution of symptoms**

Participants referred to the RACPC had similar accounts of what they regarded as potential medical symptoms, and in nearly all cases it was considered an unusually troublesome or unrecognised physical sensation. Participants talked about a wide range of physical discomforts as potentially significant symptoms. Some participants described their symptoms as sensations of 'twinges', 'pressure', 'squeezing'. One participant spoke of feeling 'air bubbles moving' across his chest, while other participants described their symptoms as painful. For some the pain was severe and

frequent, but for others it was milder, occurring infrequently. Indeed, a few participants spoke of a 'dull ache' while others had 'horrific' pain.

*PA14. '...I'd call it air bubbles come across the top in my chest. And then I'd start getting a thumping around the heart area ...' (Male, 70, White, Gas fitter and plumber) (Post)*

*PA06. '... I had a week when I, well every night I woke up, and I thought it was a chest pain and it was quite dull...' (Female, 44, White, Tour guide) (Post)*

*PA22. '... unloaded my car, and I just wasn't feeling brilliant and I felt I was, I just had, just basically chest pains, feeling tired, just suddenly didn't feel brilliant...' (Male, 54, White, Property developer) (Post)*

*PA04. 'I was on the phone, on my mobile, for quite, ten, fifteen minutes and suddenly my arm just didn't lose its sensation of feeling, it was horrifically painful and that's when the first pain started.' (Male, 37, White, Business Manager) (Post)*

A small portion of participants talked about abnormal or unnerving physical sensations or feelings that they did not recognise as symptoms. For them the concern was more about detecting or noticing physiological change in their body (manifesting as a sensation or feeling) that was new and unfamiliar, rather than the degree of physical discomfort or pain.

*PA03. '.... I wouldn't call it pain, no, I would more call it abnormal, un normal...' (Male, 29, White, Manager) (Pre)*

*PA19. 'Basically I had a pain here that went a little bit down my arm, and it was a pain that I didn't recognise...' (Female, 77, Asian, Teacher) (Post)*

Many participants talked about the sensation of physical *pain* as a potential medical symptom, while a few other older female participants spoke of the aches and pains associated with age. However, many other participants talked about their symptoms as the sensation of physical discomfort, but often did not see it as pain... 'it was not pain... It was a heaviness'.

*PA05. '... I had an appointment with him (GP)... I walked fast and I got this pain in my chest. And I said to, he said are you OK? And I said yes I've got this funny pain in my chest ...' (Female, 76, Asian, Retired cake-maker) (Post)*

*Subpo2. 'Because at my age you get aches and pains... you know, it's just an ache and pain' (Female, 61, White, Medical secretary) (Post)*

*PA07. '... like there's some, not like inside, like something from outside, like a pressure from there, why is probably discomfort.' (Male, 46, White Forklift driver) (Pre)*

Coronary candidacy, the belief that one is at risk of CHD, played significant a role in how participants viewed their symptoms. The more participants identified themselves as potential coronary candidates, the more likely they were to consider their symptoms as potentially CHD-related. Many participants, mostly male and a few females, categorised themselves as high risk for CHD as a result of their personal behaviours / lifestyle choices which they believed had the potential to increase their CHD risk. They used this perception as a key reference point for considering whether their symptoms might be potentially CHD. These participants sometimes openly shared some of their more high risk behaviours including excessive drinking 'in excess of 60 units a week', smoking, and previous drug-taking: 'I was addicted to cocaine', and lack of exercise. Other working participants talked about work pressures and stresses and how these factors affected their health. A few female participants who were working mothers also spoke of stress and trying to balance working and family life.

*PA14. 'Men probably ... More stress...You've got to be up five, six days a week going to work, you've got to make sure you do your job proper, otherwise you'll be out of work...' Male, 70, White, Gas fitter and plumber) (Post)*

*PA08. 'Yeah, like I was addicted to cocaine, I don't know up till about six years ago, five years ago. And I give that up like that, and I give up drink like that'. (Male, 54, White, Dog racer/owner) (Pre)*

*PA04. 'I've had a number of stress-related issues in the last two years, my anxiety levels are quite high and the feeling that the pain was to do with my left arm, I've been relatively worried that it's my heart with, I'm a young guy*

*but I'm not very fit... I drink a lot ... in excess of 60 units a week...So that prompted me to connect more dots than were there, probably thinking it is cardiac...' (Male, 37, White, Business Manager) (Post)*

**PA21. And what would cause, in terms of your lifestyle factors, what do you think would contribute to having a heart problem?** *'Well I don't exercise I know that, I have been under a lot of stress lately and probably diet maybe I would imagine...' (Female, 51, Black, Youth Work Manager) (Post)*

A family history of CHD also influenced whether participants viewed themselves as possible coronary candidates. Several participants had a strong family history of CHD and talked about how that played a part in them considering CHD as a possible cause for their symptoms. One young male participant who described having occasional bouts of palpitations talked about his mother's life-long battle with a heart condition that doctors struggled to treat, which made him more vigilant. Another female, older participant who had only mild symptoms while walking, but had strong CHD-related illnesses in her family, talked about how that made her think her symptoms might be CHD related.

*Subpo2. '...Right there's a, I've got a history of angina in my family. My dad had angina and my aunt, obviously, he's died, has still got angina, she's had it for about 30 years.' (Female, 61, White, Medical Secretary) (Post)*

*PA03. '...basically so my mum's got some cramps in the heart that she experienced when she was mid-40s and it was, she was born with that but they couldn't see what it was, so every year I have a heart check....' (Male, 29, White, Manager) (Post)*

A few participants with a history of CHD-related events talked about how they used those experiences as reference points for considering a possible CHD cause for current symptoms 'I've had three or four heart attacks before ... There's something wrong'. They weighed up the similarities and differences between episodes to interpret symptoms. For example, one participant talked about how he knew something was wrong, but the pain was nothing like his previous CHD event (e.g. heart attack). Due to his CHD history he went to the hospital to get himself checked

out. Another participant with a history of cocaine use talked about having three heart attacks in the past, and as a result he was able to recognise the symptoms.

*PA08. 'I've had three or four heart attacks before ... There's something wrong ... I had previous stents fitted..., I've felt a million dollars but since the last time I haven't...' (Male, 54, White, Dog racer/ owner) (Pre)*

A few participants spoke about the role of popular media and media campaigns in considering a possible cause of their symptoms. Participants appeared to have different responses to media campaigns. In some cases participants thought their symptoms were probably not CHD-related as they did not fit the popular depiction in media. For example, one older female participant who had mild symptoms thought it was indigestion initially. She spoke of how she was still able to talk and remain sitting down, and that did not match her impression of what CHD symptoms would be like - an impression that was created from popular media. In other cases participants, especially those who experienced chest pain, spoke of media campaigns, and how these campaigns led to them thinking their symptoms might be CHD-related.

*Subpo1. 'In my head, heart attack or heart problems, you're on the floor, you're writhing about, you can't breathe, you can't, whatever, you see people, on TV, having heart attacks, and that wasn't me. Me, I was able to sit down, I could communicate...'. (Female, 59, White, NHS administrator) (Post)*

*PA14. 'You see it advertised on the TV, if you get chest pains....' (Male, 70, White, Gas-fitter and plumber) (Post)*

A few older participants did not believe that they had CHD. They had consulted their GPs for pre-existing conditions or a general check-up. The GP had assessed their symptoms and medical history, and decided it was appropriate for them to be seen in the RACPC clinic. In many cases these participants talked about having very limited knowledge of CHD. For example, one older participant with a history of advanced lung disease experienced a tightening in her chest as if something was hugging her

to death while walking, was referred by RACPC for further evaluation of CHD (e.g. coronary angiogram<sup>9</sup>). She appeared to be in denial that her symptoms could be CHD and thought they were related to her pre-existing lung complaint. Despite the RACPC outcome that her symptoms needed further testing to confirm this, she did not accept the possibility that there might be CHD requiring treatment. However, she also admitted that she did not really understand what a heart attack was. In another example an older participant who worked as carpenter talked about how he was not sure why he was referred to RACPC as he experienced only mild chest pain which he thought was indigestion. He did not originally consider his symptoms to be potentially CHD-related. He also felt that he lacked an understanding of anatomy, and was not clear where in the body the heart actually was.

*PA27. 'Yes, well I still don't think there's anything wrong with my heart.... I mean I don't know what, a heart attack or what it is really.' (Female, 80, White, Retired Catering worker) (Pre)*

*PA28. 'I don't I don't know.... I really don't know where the heart is...' (Male, 60, Carpenter) (Pre)*

Other participants had pre-existing conditions (e.g. low cortisol disease, mastodynia, lung disease, asthma, high blood pressure, high cholesterol etc). They often linked their symptoms to these other conditions including the side effect of medications they might be taking. It was only when their symptoms did not resolve with self-treatment or worsened that they considered other causes for their symptoms. For example, one participant talked about having a rare low cortisol disease which caused a range of symptoms including pain. She originally believed her symptoms were related to

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<sup>9</sup> An invasive procedure whereby a dye contrast is injected to the coronary arteries to visualise narrowing's or blockages.

this condition and so increased the cortisol medication to reduce her symptoms. It was only when these symptoms continued and then worsened that she considered an alternative cause for her symptoms.

*PA18. 'Yeah, and I just put it down to the cortisol or lack of cortisol... (Female, 49, White, Adult Educator) (Pre)*

*PA10. 'I had a dull ache in my chest, and ... this was about two years ago, I went to the doctor and she said, the GP sorry, and she said it was probably mastodynia so I didn't think about it from then on, I started having little spasms around the chest area, so then, now I'm here...' (Female, 27, Lawyer)(Pre).*

*PA27. '...Well I got COPD or whatever it is POD something ... **Like obstructive airways disease?** Yes ... I just think it's [current symptoms] just something to do with the chest and that's it, sort of thing ...' (Female, 80, White, Retired Catering worker) (Pre)*

*PA16. 'I thought it might have been the asthma because it was exercise induced, maybe it was that ...' (Male, 42, Asian, Carpenter) (Post)*

## **4.2 Symptoms experienced by participants**

Some participants talked about having severe and painful symptoms and in some cases symptoms that were highly suggestive of CHD. These participants used terms like 'sharp pain', 'stabbing pain' and 'severe' to quantify the intensity of their pain. Several other participants talked about how they experienced worsening pain, while a few participants talked about experiencing typical CHD-sounding symptoms such as 'a vice type pain' in her chest and/ or triggered by exertion. For example, one participant talked about how she blacked-out after experiencing pain in the chest: 'everything went black...I just had sharp pain'. In other examples, participants talked about having such 'a lot of pain in my chest' that they went to the emergency department, although it turned out not to be a heart attack, or having such 'horrific' pain in their arm that they almost dropped their phone.



*PA24. 'I had quite a severe, vice type pain in my centre chest...' (Female, 67, White, Accountant) (Pre)*

*PA23. '...everything went black and I just had a sharp pain, a quick sharp pain across her chest...' (Female, 76, White, Retired office worker) (Pre)*

*PA22. '...I was in a lot of pain in my chest... it really was quite bad.... decided that maybe I should go to hospital, this wasn't normal...' (Female, 54, White, Property developer) (Pre)*

*PA04. '...suddenly my arm just didn't lose its sensation of feeling, it was horrifically painful and that's when the first pain started ...' (Male, 37, White, Manager) (Post)*

Other participants only had mild symptoms. Many used milder terms when talking about their symptoms including 'tightness', 'not severe', 'more annoying than painful' or 'unnerving'. A few other participants talked about their mild symptoms in terms of 'chest pressure', 'arm pain' and 'a little bit of nausea' whilst walking. Indeed, many participants in the study specifically talked about their symptoms being not severe

*PA25. 'Well it wasn't, it wasn't severe, it was just unnerving...' (Male, 80, White, Retired University Professor) (Pre)*

*PA03. 'I wouldn't call it severe, no, I would more call it abnormal, un-normal...' (Male, 29, White, Manager) (Pre)*

*PA11. 'No, it wasn't sharp, it was dull and like a pressure and those are the two words that I would say describe it...' (Male, 29, White, TV Journalist) (Post)*

*Subpo2. 'The, it was, that was very mild. The ache down the arm... a little bit sick, but not, not, it was very mild.' (Female, 61, White, Medical Secretary) (Post)*

Participants in this study experienced symptoms of different frequencies and durations. Many often talked about symptoms being regular and recurring or constant. Indeed, some talked about pain happening every day including a participant who experienced symptoms waking her up several times a night in pain over a week. Other participants talked about more episodic symptoms. They often referred to symptoms that were 'on and off' and occurring in short bursts of discomfort.

*PA06. 'Well, I had a week when I, well every night I woke up.... three, four times ... I thought it was a chest pain.' (Female, 60, White, Tour guide) (Post)*

*PA26. 'yes because in, I get pain, last, I think last month, or I get every night I get pain...' (Female, 72, Asian, Retired Audio-visual worker) (Post)*

*PA14. 'It's happened about four or five times... That would be over two months.' (Male, 70, White, Retired Gas-fitter and plumber) (Post)*

*PA15. 'Well, I've been having these pains off and on for about three or four months.' (Male, 80, White, Graphic Artist) (Post)*

Participants also reported experiencing symptoms over a wide range of timescales when it came to duration of symptoms (i.e. how long an individual episode lasted). In some participants, symptoms were constant and in others they lasted only a few minutes. For example, one participant who experienced a sharp pain while “going to the loo” described how her symptoms lasted about an hour. In another example a participant who had a mild chest pain which he thought could be indigestion, described getting daily episodes of the pain that only lasted a minute or so.

*PA23. 'I suppose it must have been about an hour...' (Female, 76, White, Retired Office worker) (Pre)*

*PA28. '...they're just a pain, and they come and go more or less within a minute... I get them, just lately, daily, yeah ...' (Male, 60, White, Carpenter) (Pre)*

Some participants experienced symptoms brought about by exertional triggers (physical activity). This is significant as symptoms triggered by exertion are strongly linked to non-emergency (stable) CHD and would have been instrumental in a GP's decision to refer them to RACPC. A few participants talked about symptoms triggered by highly strenuous physical activity (e.g. running or exercising in a gym).

*PA13. 'When I went to the gym on a treadmill for ten minutes, ... so just a walk for ten minutes, and after that he just put the speed a little bit higher after ten minutes and my blood pressure were high, was higher, and I feel dizzy, I fell...' (Female, 25, Beautician, Asian) (Post)*

*PA08. 'I was at the rehabilitation place here, in the gym, doing general exercise and then I got tightness in my chest ... I was at this, the cardiac*

*rehabilitation place here, I collapsed ...' (Male, 54, Dog Racer / Owner, White) (Pre)*

Other participants experienced symptoms while doing milder activity. One participant talked about getting a sore throat while walking. Another participant had symptoms whilst unloading his car after a weekend trip away.

*PA02. 'Well, I found that when I was walking I was getting a sore throat...' (Female, 63, White, Accountant) (Pre)*

*PA22. 'I'd come back from Canterbury in Kent, unloaded my car...' (Male, 54, White, Property developer) (Post)*

*PA04. 'I was on the phone, on my mobile, for quite, ten, fifteen minutes...' (Male, 37, White, Business Manager) (Post)*

#### **4.3 GPs referrals to the RACPC**

This section explores participants' accounts of what influenced a GP's decision to refer to the RACPC including symptoms, medical history, CHD risk factors and participant concerns. The participants, in this current research, had complex symptoms with varied degrees of severity and aetiology. They often also had a range of co-morbidities (e.g. asthma, obesity, depression etc.). Several participants' accounts gave the impression that GPs tended to look at a variety of factors in combination before deciding to make a referral to RACPC. This included location of symptoms (e.g. chest pain), symptom history, personal risks factors, co-morbidities, family history and personal beliefs of the participants themselves (if they believed symptoms CHD-related). In some cases participants had convincing symptoms with known risk factors and were referred immediately to the RACPC. For example one younger participant with a short but convincing history of chest pain ('bruising pain in chest') who had strong family history of CHD and was a long-term smoker was referred immediately. Indeed, another older participant who had a history of chronic

bronchitis, depression and obesity, with only a single episode of 'very tight' chest pain triggered by walking was also referred immediately.

*PA20. 'Well I went to my GP after having chest pains for about ... it was like a bruising feeling you know sometimes a stabbing sort of poking feeling ... two weeks ... Dr XX who then got quite concerned and she said to me, given your history, your background, your parents, I'm going to refer you to the Chest Pain Clinic at Queen Mary's, so I said, fine OK.' (Female, 48, White, Tailor) (Pre)*

*PA05. '...about a month, three weeks ago I had an appointment with him and I walked fast and I got this pain in my chest. And I said to, he said are you OK? And I said yes I've got this funny pain in my chest and that's when really he started all this about sending me to cardiology really' (Female, 76, Asian, Cakemaker) (Post)*

However, in other cases participants had less clear symptoms were only referred after multiple visits or after symptoms persisted. For example, a younger participant talked about having chest pain linked to a cough and was originally diagnosed with 'mild asthma' by his GP. He talked about symptoms not being severe but rather abnormal. It was only after a long period (6 months) of symptoms and a second GP visit that the decision was made to refer him to the RACPC. Another participant with known hypertension and a long history of non-specific symptoms which the GP thought likely to be muscular was convinced his symptoms were heart related, and the GP felt that because of this, it was worth getting checked out to put his mind at ease.

*PA11. '... Around six months before this appointment ... I started having a cough ... related to a chest pain ... I thought I'd go to the doctors ... really about the cough than it was the chest pain ... he said that I might have mild asthma. The cough was a constant thing over six months ... a couple of weeks ago ... I made second appointment primarily because I'd had the constant pain for a week ... from that the GP referred me to the chest pain clinic ... Sometimes if you're a 29 year old bloke who looks totally fit, I sometimes feel that GPs can be like, oh well he's fine, he's not in the danger bracket here, there's no history of heart disease or whatever. But it was quite nice to have it taken seriously ... felt reassured by him because he wasn't*

*dismissive of it and that's the danger ...' (Male, 29, White, TV journalist) (Post)*

*PA17. '... about six months ago I started to notice.... kind of squeezing in my heart ... **Was it easy to get a referral here? Was it difficult?** .....he said [GP] to me that because of the, this pain I had didn't worsen as I did things, he said he thought it was very unlikely that it was related to my heart. He said it probably was ... something muscular ... but nevertheless he said listen, you see it as an issue and you're identifying it as maybe to do with your heart and this would be a useful thing for you...' (Male, 46, White, Management Consultant) (Post)*

Sometimes these multiple visits to GPs led participants to feel frustrated and distressed as they felt GPs were dismissive even though they were in pain or worried about their symptoms. Participants also talked about the strategies they used to avoid being dismissed or seen as a hypochondriac. For example, one participant explained how it was necessary to present a full picture of your symptoms to the GP in order to be taken seriously and not dismissed. Another participant who visited his GP multiple times because of his chronic pain spoke of his annoyance when he felt his GP suggested he was wasting his time. Other participants spoke of how they felt rushed in GPs consultations to the extent that it felt a bit like a production line and that they often made a quick diagnosis without really taking time to examine them. One participant suggested that GPs derived a sense of satisfaction at being able to get patients out as quickly as possible. Participants also talked about strategies they used to ensure they had the time they did need to explain their health complaint. For example, one participant even booked a double appointment to be sure she was able to present her case to the GP fully. Overall, most participants were appreciative of the time constraints imposed on GPs.

*PA09. 'I was getting mixed reports from the different doctors that I was seeing in my surgery ... I think that it's quite difficult, doctors are under a lot of time constraint and a lot of pressures... when one goes to the doctor one*

*needs to have exactly the symptoms that one can gather together and put them all in front of them, otherwise it's usually going to be dismissed or you might sound like a hypochondriac' (Female, 27, White, Lawyer) (Pre)*

*PA18. '... Did double appointment because I know now with GPs, you can't bother them with too many things at once ...' (Female, 49, White, Adult Educator) (Pre)*

*PA16. '... Because it's just the attitude .... you're here just to waste our time, that sort of thing ... Well, you know what, I'm here, I'm not here to waste your time because I've had the problem for a month or two and I've still got it...' (Male, 42, Asian, Carpenter) (Post)*

*PA17. '... the doctor experience is a bit like a production line... you just feel like, got to get you in there as quick as possible. They get a bit of thrill if they can get you out even quicker... I get a great sense that doctors are extraordinarily busy and they're under pressure, and the system is under pressure as well...' (Male, 46, White, Management Consultant) (Post)*

#### **4.4 Triangulation**

For symptoms there was generally concurrence between medical records and the patient's reports of symptoms. As was expected, there were some minor variations in different health professionals' interpretation of the participant's symptoms and the participant's own recall in the interview; for example, a participant may report 'pains in chest / chest pressure' compared 'chest pain' and 'chest pressure' recorded in the RACPC outcome letter and the GP referral letter, respectively. There were also variations between the lay language used by participants and medical paraphrasing done by health professionals. However, none of the differences in symptoms were especially at odds, nor would they have altered a decision to refer to the RACPC or an acceptance of referral into the RACPC (see Appendix C for full comparison of symptomatology between interviews, GP referral letters and chest pain clinic outcome letters). It was possible to triangulate patient-reported symptoms to at least one health record in all cases. Given general concurrence, it would appear that

quantitative data supports the veracity of the qualitative data, indeed strengthens the analysis.

#### **4.5 Summary**

Participants in the study talked about a range of symptoms with degrees of severity. Some participants talked about very painful symptoms while others had only mild symptoms. Participants also talked about symptoms occurring frequently over many months or in other cases occurring infrequently or episodically. However, overall, many of them considered CHD a cause for their symptoms. Attributing symptoms to a potential cause had multiple influences. The locality of pain, coronary candidacy, previous experience of CHD and media campaigns all influenced these decision-making processes. Coronary candidacy was a particularly strong influence as many of the participants considered themselves to be at risk of CHD, either as result of personal lifestyle choices or family history. Some participants in this study had pre-existing conditions and they linked their symptoms to their underlying illness. It was only when their symptoms did not resolve or worsened that they considered CHD as possible cause. Additionally, participants referred to the RACPC had a complex combination of symptoms, CHD risk factors and family history. These participant accounts suggested that GPs considered all these variable factors when taking the decision to refer to RACPC, including easing participant concerns (if they thought their symptoms were heart related).

## Chapter 5. **Results: help-seeking**

This chapter examines participants' help-seeking practices that led them to see their GPs, resulting in a referral to rapid access chest pain clinic (RACPC) for evaluation of their symptoms for potential CHD. Help-seeking for symptoms can be sought formally through professional help (e.g. doctor) or informally through friends and family who in turn may influence formal help-seeking. While informal help-seeking may facilitate professional help-seeking, it can also contribute to its delay, for example by speaking to relatives first instead of seeing a doctor.

This chapter has 9 sections: 5.1 Seeking help from friends and family; 5.2 Seeking help from Health Professionals; 5.3 Response to Symptoms; 5.4 Enablers of help-seeking; 5.5 Barriers to help-seeking; 5.6 Experiences of RACPC; 5.7 The impact of the diagnosis; 5.8 Triangulation; and 5.9 Summary. These sections are discussed and explored in detail throughout this chapter. Patient quotations are used to evidence the analysis provided.

### **5.1 Seeking help from friends and family**

Many participants in this study were reluctant to seek help from friends and family. Often it was related to not wanting to worry or burden others. Some participants were concerned with not bothering or worrying their children, especially if they were young. In many cases they had not told their children about their symptoms or the RACPC appointment and had no plans to do so unless it turned out to be more serious. For example, one participant who was a widower was cautious not to worry his only daughter unnecessarily, and expressed a preference for speaking to his brother or sister about his symptoms as opposed to his daughter. Other participants



who had also lost their partners talked about not worrying their children as they were the only surviving parent.

*Subp02. 'I don't like to speak to my family because, especially my youngest daughter, because being my youngest and losing her father the way she did, she worries about me.'* (Female, 61, White, Medical Secretary) (Post)

*PA08. '... What I'm saying is I'd rather talk to my brother or a sister rather than like my daughter...'* (Male, 54, White, Dog racer/owner) (Pre)

*PA15. '... I didn't tell my family or anything like that about it.... Yeah, so, because I wouldn't want to worry them. Why should I, if it's nothing...'* (Male, 80, White, Graphic Artist) (Post)

*PA18. '... my daughter is 17... I don't want to worry her...'* (Female, 49, White, Adult Educator) (Pre)

Other participants who had sick partners for whom they were the sole carer talked about how they avoided adding any further pressures that might worsen their ill partner's condition: 'he's got different heart trouble... I didn't want to bring on anything'. Some participants also avoided telling partners and sometimes other close relatives as they were worried about the impact that it might have on them. For example, a young male participant with a history of work-related stress was clearly anxious about his health issues, talked about how his wife was a strong emotional stabiliser for him and how she worried about his 'psychological health'. Because of this he had kept his attendance at the RACPC a secret from her and had no plans to tell her unless he had to.

*PA04. 'I didn't go home and tell my wife. She doesn't know I'm here now.... worries about my psychological state...'* (Male, 37, White, Business Manager) (Post)

*PA23. 'No, because to be honest because since he's got different heart trouble... I didn't tell him because I didn't want to bring on anything with him... No, no, I didn't speak to anybody...'* (Female, 76, White, Retired Office worker) (Post)

Stoicism and self-reliance was also present amongst a few participants who wanted to keep their health issues to themselves. One older Muslim participant of Asian heritage with a history of depression, who had suffered trauma as a child, described her childhood as 'appalling'. Her mother was burned to death when she was four years old and she was also badly burnt. As a result of these experiences she was a 'solitary' person who was self-reliant and private. She was very secretive about her health concerns and rarely discussed them with others. She went on to say she was not a people person and described herself as 'not good with women'. She talked about how she would not chat with other people or say 'I have this or that ache or pain'. She acknowledged that if it was important she would speak about it, but she had a need for self-reliance. Another older participant with long-standing chronic lung disease talked about how she concealed her health concerns from her family to avoid the pressures they placed on her to deal with them. She felt that her children were so focused on ensuring her health needs were met, they did not really listen to what she wanted, which may in some cases be no treatment. One younger male participant who worked as a forklift driver was particularly worried about his self-image and did not want to be viewed as an 'unhealthy man'.

*PA07. '.... think they will think, he's not very healthy man, even if he doesn't smoke, or don't drink, but still not healthy. I don't say anything because I like it when people think I'm healthy and this better way...' (Male, 46, White Forklift driver) (Pre)*

*PA05. '... Not often, I'm really quite a, I was going to say a private person, but probably secretive is more... I think it's me as a person really, I've never been one to. I'm not very good with people as a group, I'm not good with women, I don't sit there chattering away all day about, I'm a slightly solitary person and if I thought I was really in trouble then I would say but... It is self-reliance ... and I don't like saying I've got this or I've got that.' (Female, 76, Asian, Retired cake-maker) (Post)*

*PA27. '... all deciding what we're going to do, never mind what mum wants to do, it's what they all want me to do...' (Female, 80, White, Retired catering worker) (Pre)*

Other participants felt they did not want to be seen as 'moaning' as they were conscious that other people had their own problems

*PA06. 'Because people would worry and, I don't know why I decided not to, no I didn't talk to anyone, Yes, and I didn't want to moan about it because everybody's having their own problems...' (Female, 60, White, Tour guide) (Post)*

Social isolation was also an issue for some participants. A few participants did not have any family and friends to share health concerns with, while other participants of non-Caucasian ethnicity who were born abroad also expressed a degree of isolation. They talked about isolation created by having one's immediate family living far away. Cultural influences and past experiences also played role in social isolation. For example, an older participant of Asian heritage, a widow, talked about herself as being solitary and did not actively seek the company of others as a result of her cultural background and personal experiences.

*PA26. '... Because I don't have any family here because my family's in Philippines. I am, I ... was alone here, so...' (Female, 72, Asian, Retired Audio-visual worker) (Post)*

*PA22. 'I don't really have any family, so I don't have anyone to ask...' (Male, 54, White, Property developer) (Post)*

*PA05. '...I'm not very good with people as a group ... I'm slightly solitary...' (Female, 76, Asian, Retired cake-maker) (Post)*

Many other participants were happy to share and talk about their symptoms. For them, it was often the first step towards formal help-seeking. They spoke to friends and family to validate their symptoms and they were often prompted to seek help immediately after. This process of validating symptoms was strongest in participants

who had close friends or family who were, or had been, health professionals (influence of friends and family is discussed in detail later in 5.4).

*PA20. 'I talked to family and friends and they all said to me, look, xx, for God's sake, go and get it checked out, that's what you ought to do...' (Female, 48, White, Tailor) (Pre)*

*PA24. 'Oh, no, no, I don't mind, I'm happy to share...' (Female, 67, White, Accountant) (Pre)*

However, a few male participants in particular tended to restrict talking about these health concerns to close partners and immediate family (e.g. a son or daughter and siblings). Some of them only shared with their wives. A few male participants talked about sharing their concerns with friends in a jokey manner and they used humour to downplay the potential significance of their health matters. They talked about comparing behaviours with friends and making light of risk factors in a social environment

*PA14. 'Just my daughter... I'd discuss it with my daughter if she was there. But if I forgot about it, nobody would know...' (Male, 70, White, Retired Gas-fitter and plumber) (Post)*

*PA08. 'Yeah, I talked to my brother...' (Male, 54, White, Dog racer/owner) (Pre)*

*PA15. 'Only my wife....' (Male, 80, White, Graphic Artist) (Post)*

*PA04. 'I think I probably had a joke with about it, with one of my friends in the pub, to be honest. Because we're relatively similar age, stressed out guys and we sort of, we joke about who's going to be in the box first...' (Male, 37, White, Business Manager) (Post)*

## **5.2 Seek help from health professionals**

Many participants expressed reluctance for seeking help from health professionals. Not wasting the doctor's time was a particular concern. Participants were aware that there were pressures on the doctor's time and there was a 'queue' of people, often worse off than them, waiting to be seen. Often participants did not want to be seen bothering doctors 'with little things'. It appeared that wasting the doctor's time was

viewed as a *faux pas*. Many participants talked about how they would only go to see the doctor if they felt that something was genuinely ‘wrong, wrong’ and could not be resolved by time or self-medication. They also talked about making the decision to wait to see if their symptoms improved before going see a doctor so that they did ‘not waste the doctor’s time with triviality’. For example, one participant who worked in the NHS and understood the pressures on health services talked about how she did not want to go to A&E and waste their time. Another participant with a long history of chronic health problems and pain following an industrial accident who worked as a carpenter talked of how he had been waiting for three months for his symptoms to subside, and when they did not, he did not ‘feel bad’ going to the doctor because he was clear he needed help.

*PA05. ‘... The only thing is that I don’t want to, it sounds potty but I don’t want to worry them with triviality, because they all seem frightfully busy and I know one should go and I do go if I think there is something desperately, not desperate but wrong, wrong...’ (Female, 76, Asian, Retired cake-maker) (Post)*

*Subpo1. ‘I, I was not going to go and sit in A&E and waste their time. I wasn’t going to ...’ (Female, 59, White, NHS administrator) (Post)*

*PA09. ‘I wouldn’t go to the doctor for every single petty problem that I have...’ (Female, 27, White, Lawyer) (Pre)*

*PA16. ‘... As for asking a doctor, I suppose I don’t feel too bad because I’m that attitude, well, I waited two or three months so I’m not somebody here that’s just to waste your time...’ (Male, 42, Asian, Carpenter) (Post)*

*PA10. ‘I, my personal opinion, I don’t want to unnecessarily make a problem for the doctor because I feel this is very necessary then I go to the GP otherwise not...’ (Male, 71, Asian, Intercom Technician) (Pre)*

*PA23. ‘...I don’t waste no doctor’s time, put it that way. I won’t go round because I’ve got a cold, I go to the chemist and buy some Lemsip, and if it didn’t go away then I would go to the doctor, which I do...’ (Female, 76, White, Retired Office worker) (Pre)*

Other professional participants talked about other time-saving strategies they adopted to make the doctor's job easier as well as to save their own time. This included one participant who worked as an accountant who put off asking her GP about her current CHD symptoms when attending for another (at the time) more severe health complaint as she felt that GPs do not like to be bothered with too many complaints at once. Another participant worked as a lawyer and whose mother was a nurse explained how she waited to be able to collate all her symptoms over a period of time so she could present a clearer picture for the doctor. She did this to avoid having her symptoms dismissed by a time-stretched doctor.

*PA18. 'I know now with GPs, you can't bother them with too many things at once...' (Female, 49, White, Adult Educator) (Pre)*

*PA09. 'I think that it's quite difficult to, doctors are under a lot of time constraint and a lot of pressures, and I think when one goes to the doctor one needs to have exactly the symptoms that one can gather together and put them all in front of them, otherwise it's usually going to be dismissed...' (Female, 27, White, Lawyer) (Pre)*

Some older participants spoke of a fear or a dislike of going to the doctors, or the idea of going to hospital. One older participant, who accepted the need to get medical help if you are not well, talked about how he was terrified of hospitals or any sort of medical environment. Another older participant talked of his dislike of the modern GP surgery which were often quite large with lot of people waiting in them, and of his family motto and personal belief which amounts to 'the fewer doctors the better' for one's health.

*PA19. 'I don't actually like the idea of coming to the hospital.' (Female, 77, Asian, Retired Teacher) (Pre)*

*PA15. 'I don't, I, first of all, I don't like the modern surgeries, that's why I don't go to doctors, because you get all the ill messing around breathing on you and I don't, hate that... We have a saying our family, the less doctors the better...' (Male, 80, White, Graphic Artist) (Post)*

*PA28. 'Well, I've never liked going to the doctors but the thing is if you're not well you go, don't you? And that's it, well, I've never liked going to them. I never like coming into these places. It terrifies me...' (Male, 60, White, Carpenter) (Pre)*

A few participants talked about having negative past experiences with their GPs and how that put them off seeking help. One elderly participant of Asian heritage openly shared her negative experience. She had a history of multiple symptoms ranging from pins and needles in the arm, swelling around the arms, and most recently chest pain. There was a previous incident where a doctor at the GP surgery had appeared frustrated with her because her blood pressure reading had been higher than expected and she talked about how he was 'shouting' at her to relax so that her blood pressure levels would go down. She also talked about how some doctors rushed her in the consultation telling her that they needed to be 'be quick' as other patients were waiting. Similarly, another participant who worked as carpenter and suffered with chronic pain after a work-related accident where a wall fell on him, causing crushing injuries, also talked about one GP's attitude "that there is nothing that can be done and one has to live to with it". He went on to say that he has avoided seeking professional help since this experience.

*PA26. '... I went there, he just told me, OK be quick I have patients waiting, and that's it, and then after a while they do my blood pressure and of course you are sitting like that, well I, as he was shouting, relax, relax, I say, I am relaxing I am sitting, I am relaxing. And then three times he had to tell me, and three times he had to do my until I think my blood pressure go down, and then my blood pressure goes... OK, you're all right now...' (Female, 72, Asian, Retired Audio-visual worker) (Post)*

*PA16. 'Past experience, I suppose. I've moved up this way for the job, back in 2012, and I suppose from past experience of my GP in Peterborough, puts me off going to a GP. There's nothing they could do so you might as just bloody live with it sort of attitude. So that's why, maybe that was why I left the breathlessness for quite a bit of time before' (Male, 42, Asian, Carpenter) Post*

Other participants talked about the positive experiences that they had with GPs and how comfortable they were going to the GP. Several participants used terms like 'very good', 'understanding' and 'receptive', 'marvellous' or 'brilliant' to describe their GPs. They also talked about deliberately maintaining long-term relationships with their GPs. One participant had a long-term GP and said that he 'actually enjoyed seeing him'. Another older participant, who had not been to a doctor in a while talked about how much things had improved and described his experience as 'quite pleasant'.

*P20. 'Oh she was brilliant, very, very good, very good...' (Female, 48, White, Tailor) (Pre)*

*P23. 'Well I thought they was marvellous in ... absolutely marvellous...' (Female, 76, White, Retired Office worker) (Pre)*

*PA22. 'No I do see my doctor because I've managed specifically and deliberately to maintain the same doctor I've had for many, many years. So, it may sound awful, I actually quite enjoy seeing him...' (Male, 54, White, Property developer) (Post)*

*PA14. 'Yes, no, it's fine.... I haven't been for years, until I went the other week, and it's changed a lot, it was quite pleasant...' (Male, 70, White, Retired Gas-fitter and plumber) (Post)*

*PA21. 'I have no qualms of my GP and XX Surgery, they've been, oh gosh, since '95, so I've been with them for a really long time so, yeah, I have no problem...' (Female, 51, Black, Youth worker/manager) (Pre)*

Feeling their symptoms justified seeing a doctor was a factor for some participants, often male, in this study. These participants talked about having 'no problem in booking an appointment', 'if I felt I need treatment, I go straight around see him' or 'If I think need help, then I will do something about it ...'. However, they also often indicated that they had rarely felt the need to go to doctor in the past: 'I might go every couple of years' or 'I haven't been for few years'. They went on to say that if they needed to go, they would happily go, if they felt it was justified. Symptoms



needed to be of sufficient severity in terms of discomfort, frequency and duration to cause them concern.

*PA04. 'I maybe go to the doctors twice a year or I might go once every couple of years, or whatever, but I have no qualms about going to see him.'* (Male, 37, White, Manager) (Post)

*PA25. 'But if I felt I was physically or mentally unwell, I'd be round to the doctor's. If I felt I needed treatment right away, I'd just go straight to the doctor's...'* (Male, 80, White, Retired University professor) (Pre)

*PA16. 'I really try and avoid it, to be honest.... Past experience, I suppose, because it's just the attitude back from, I got for one doctor, about you're here just to waste our time, that sort of thing.'* (Male, 42, Asian, Carpenter) (Post)

*PA05. '... if I think I need help then I go and I do something about it ... don't like wasting their time if you see what I mean, with little things. And I'd go if I, I know me kind of thing and I can tell if I'm really bad as with the bronchitis thing...'* (Female, 76, Asian, Retired cake-maker) (Post)

### **5.3 Response to symptoms**

Most participants in the study talked about a variety of initial responses to symptoms before seeking help from their GPs, which ultimately led to a referral to the RACPC. These responses included dismissing or normalising symptoms or self-managing which sometimes contributed to an initial delay in seeing their GP. Participants reported a range of time delays sometimes for a few days, in other cases it was weeks and even months.

#### **5.3.1 Dismissing and normalising symptoms**

Many participants in this study tended to dismiss or normalise their symptoms in the first instance by not taking them seriously, not attributing them to any pathological process (e.g. age processes or lack of fitness) that would require medical intervention, and in other cases associating symptoms with pre-existing conditions.

Some participants did not consider their symptoms to be important and chose not to attach meaning to their symptoms. This was often the case if symptoms were mild or infrequent. In some cases it was the belief that they were otherwise healthy and therefore symptoms are not likely to be too serious and so they were dismissed. For example, one participant believed that she was 'fit' and 'active' and that in her view going to the doctor implied ill-health and she preferred not to be in that situation and dismissed her symptoms as not being important.

*PA10. 'I not take it very serious this.' (Male, 71, White, Intercom Technician) (Pre)*

*PA24. 'I see myself for my age as being reasonably fit. I do quite a bit of exercise. I am very active. And I suppose psychologically by going to the doctor suggests that you are unwell. And that I've always rather not gone than gone...' (Female, 67, White, Accountant,) (Pre)*

*PA20. 'No, I wouldn't have gone, I wouldn't have, no, I'd just say, oh well it'll pass, it'll be fine...' (Female, 48, White, Tailor) (Pre)*

Other participants dismissed or normalised symptoms to non-pathological processes. In a few cases older participants just accepted their symptoms as part of life: 'just one of those things'. They often held the view that symptoms would resolve on their own and they would wait to see if they might pass and dismissed the need for medical help initially. For example, one older participant linked her symptoms to the natural ageing process - 'the aches and pain that come with age'. Some younger participants normalised their symptoms to lack of fitness, muscular pain, stress-related and diet. As a result of this, they put off seeking help. A few others thought and indeed feared their symptoms were psychosomatic or imagined, and initially dismissed them, waiting to see how they progressed.

*PA17. 'if anything did slow me down it was that psychosomatic thing, so, or at least the sense, my worry if I was just imagining it...' (Male, 46, White, Management consultant) (Post)*

*PA16. 'I thought it may be just my fitness levels at first, again, thinking, you're just probably unfit, you really do need to start exercising...' (Male, 42, White, Carpenter) (Post)*

*PA07. 'I don't know because I usually think, oh maybe this is muscular, or maybe this something...' (Male, 46, White, Forklift driver) (Post)*

*SUBPO2. 'Because at my age you get aches and pains and I don't like to go to the doctor for nothing and just, you know, it's just an ache and pain...' (Female, 61, White, Medical secretary) (Post)*

Some participants with pre-existing conditions dismissed their symptoms as being connected to the condition and thus did not feel the need for additional medical help. However, when their symptoms did not resolve or got worse they made the decision to seek help from their GP. For example, a young female participant had an ache in her chest and was previously told by her GP that it was related to Mastodynia (pain in the breast area more common in younger women) and thus she did not worry about it at first. It was only when she started to have more troublesome spasms in that area that she decided to seek medical attention.

*PA18. 'Yeah, and I just put it down to the cortisone, or lack of cortisone .... I just mentioned it last time at the GP...' (Female, 49, White, Adult Educator) (Post)*

*PA10. 'I had a dull ache in my chest, and ... this was about two years ago, I went to the doctor and she said, the GP sorry, and she said it was probably mastodynia so I didn't think about it from then on, I started having little spasms around the chest area, so then, now I'm here...' (Female, 27, Lawyer)(Pre)*

### 5.3.2 Self-managing symptoms

Some participants in this study took active steps to manage their symptoms in the first instance and this additionally contributed to them delaying seeing their GP initially. Although the majority of participants in this study suspected CHD might be a possible cause of their symptoms, professional help-seeking was often not their first response to resolving them. There were only a few participants with severe

symptoms who talked about their first action being to get professional help. This included a participant with a previous history of CHD who had very severe chest pain whilst driving, to the extent that he had to swerve off the road and use a roadside phone to call for an ambulance.

*P08. 'I just swerved to the hard shoulder, to one of the orange phones. And when they got there, he was a doctor funny enough, the paramedic, and they rushed me into [hospital]...' (Male, 54, White, Dog racer/ owner). (Pre)*

Some participants attempted to self-medicate before professional help-seeking to manage their symptoms. One participant with a long history of unrelated chronic pain following an industrial accident talked about how he had self-managed his current symptoms with prescription painkillers and alcohol. Another participant of Asian heritage talked in detail about using natural and herbal remedy including taking cod oil liver, eating oranges, and having water with a few drops of lemon juice to clear his system and purify his body. One participant with a pre-existing condition (low cortisol disease, which causes pain) experienced a bruising and stabbing pain in her chest and talked about using over-the-counter painkillers for a few days to alleviate her symptoms before going to see her GP.

*PA20. '...took ibuprofen for a couple of days three times a day...' (Female, 48, White, Tailor) (Pre)*

*PA18 '... I take the cortisol if I'm really in a **And that makes it go, reduces the pain?** ...' (Female, 49, White, Adult educator)*

*PA16. 'I've suffered chronic pain ... the pain's always been there, it's never eased up...**And do you take painkillers for it?** ...Tylex, I do take some alcohol as well, I'll admit that...' (Male, 42, Asian, Carpenter)*

*PA12. 'I start taking cod fish oil ... I did try to take some sort of oranges as well, I thought might be some sort of clot or something, blockage, so this is better, orange is something, it's natural ... two few drops of lemon, drink glass of water it will clear all your congestion in the whole body and filter, clean the blood, clean the bladder, clean the stomach and make you fresh blood. That's a purifier basically, lemon is purifier for the blood, natural purifier, very mild warm water as well.' (Male, 42, Asian, Civil servant)*

A small number of participants attempted to self-manage their symptoms by undertaking physical activities or making changes to their diet. They hoped the changes in exercise regime or diet would 'cure' their symptoms and thus avoid the need to see a doctor. Additionally, there was one participant who talked extensively about 'information seeking' as a first approach to symptoms. He would search the medical literature on the internet to make sense of his symptoms and appraise the possible diagnoses before seeking professional help.

*PA03. '... doing, taking a walk or something like that ...' (Male, 29, White, Manager) (Pre)*

*PA09. 'I tried to drink less coffee for a bit but that's quite difficult, and I tried to focus a little bit more on my diet...' (Female, 27, White, Lawyer) (Pre)*

*PA07. 'Just search on internet, if same symptoms... why this can happen...' (Male, 46, White, Forklift driver) (Pre)*

#### **5.4 Enablers of help-seeking**

The influence of others was a strong enabler of help-seeking for participants in this study. Many participants in this study talked about how they shared health concerns with partners, family and friends, and sometimes work colleagues which led them to seek professional help from their GPs (although some did so reluctantly, as outlined above). Some participants talked about being 'nagged' by partners or work colleagues to seek help professionally which led them to go the doctor to appease them. Another participant talked about how his brother reminded him of the fact that he had previously had a CHD event and advised him to get straight to the hospital, which he did. In another case a participant talked about how her husband drew similarities between her symptoms and the symptoms of another relative who ended up having heart problems that required urgent surgical treatment (widening of the coronary artery with balloon and stents) and how that prompted her to go immediately to the doctor.

*PA18. '...So I suppose I went to the doctor, after about a week I went to, I made an appointment with the doctor, basically to appease my husband...' (Female, 49, White, Adult Educator) (Pre)*

*PA24. I mentioned it to my husband, and it was in fact in discussion with a friend who related a similar story that prompted me to quickly go to the GP. That a mutual friend had had stents put in...' (Female, 67, White, Accountant) (Pre)*

*PA20. 'And what made me go was the friends and family nagging...' (Female, 48, White, Tailor) (Pre)*

*PA08. 'Yeah, I talked to my brother... Well he, do you know what I mean? Because it's like, straight to the hospital because you've had one.' (Male, 54, White, Dog racer/ Owner) (Pre)*

The influence of other people in seeking professional help was particularly strong in participants who had friends or family with some kind of medical background. Several participants talked about discussing their symptoms with medical/nurse friends or family members as a way of validating them. This often prompted them to seek help with their GP. They talked about how these friends and family members who were ex-nurses or doctors encouraged, warned and sometimes nagged them to get help to be on the safe side. For example, one participant who worked in a hospital talked about how 'alarm bells started ringing' when she discussed her symptoms with colleagues, especially when one colleague talked about how she had had similar symptoms which turned out to be heart-related. Her colleagues nagged and pressured her into seeking help immediately.

*SubP01. 'It was a colleague. A colleague at work... Alarm bells started ringing. So, colleague 1 said to me, oh my God, this is how they discovered about my heart troubles ... you know you really ought to go and see somebody...' (Female, 59, White, NHS administrator) (Post)*

*PA20. 'And I have friends who are ex-nurses and they said, look just don't mess around with it get it checked out...' (Female, 48, White, Tailor) (Pre)*

*PA01. 'I had a word with my wife who's a doctor... it doesn't sound like my much, but might as well be on the safe side...' (Male, 44, White, Senior Manager) (Pre)*

A few other participants talked about feeling bad about speaking to friends, but nevertheless did. For example, one participant whose mother is a practising nurse regularly consulted her mother about her symptoms before seeking medical advice, and expressed that she felt 'quite bad for harassing' her with all current health concerns. However, she admitted that it was a result of her mother's influence that she ended up seeking help.

*PA09. 'I tell her everything and she says whether I should go to the doctor or not. I usually, I don't know, usually, God I feel quite bad for harassing her with all my problems now...' (Female, 27, White, Lawyer) (Pre)*

Several male participants talked about only sharing health concerns with a select few, confined to partners or close immediate family. However, one male participant of Asian heritage talked about having multiple influencers starting with his partner and his children, and later colleagues. These influencers not only encouraged him to seek professional help, but also to make his employer aware that he was having health issues which may affect his performance. His family feared his employer might think he was lazy.

*PA15. **Did you talk to any friends or family about the symptoms you were having?** ... 'Only my wife.' (Male, 80, White, Graphic Artist) (Post)*

*PA11. "I spoke to my wife ..." (Male, 29, White, TV Journalist) (Post)*

*PA08. 'Yeah, I talked to my brother...' (Male, 54, White, Dog racer/ Owner) (Pre)*

*PA12. '... I told my wife that, oh, I am having this, I told my children basically, .... They just said go to the GP and tell my line manager as well that I am feeling, they said. One time they said, definitely, I told my colleagues that, they said, go to GP, and then might be I'm lazy or something like that...' (Male, 47, Asian, Civil Servant) (Pre)*

The severity of symptoms was also a prominent enabler of help-seeking for participants in this study. It was often the severity and continuation of their symptoms that eventually led to them help-seeking from a GP. One busy participant who

worked part-time as an accountant and was very active in the community, was reluctant to seek help and talked about how she was driven to do so after about 6 months of discomfort which did not relent. She eventually felt that given the continuing symptoms it was time to take action. Another busy participant who also worked as an accountant felt that her 'trigger point' to seek help was the severity of pain she experienced. She described it as a 'vice type' pain in her chest, which was certainly a strong indicator of CHD-related symptoms. Other participants were prompted to seek help when their on-going symptoms started to affect their life (e.g. ability to daily tasks or work effectively) or started to worry them. Some talked about being in a lot of pain lasting for several hours. They felt this was not normal which worried them. They felt it was time to stop burying their heads in the sand and took the decision to seek help.

*PA24. 'But I think probably the trigger point to go to my GP is last Monday I had quite a severe, vice type pain in my centre chest...' (Female, 67, White, Accountant) (Pre)*

*PA02. 'I suppose the fact that I was aware that it was of the discomfort. Because when I first mentioned it, it would be now about six months ago, so I suppose something had made me think, maybe I should do something about this...' (Female, 63, White, Accountant,) (Pre)*

*PA22. 'I didn't have a good night's sleep; I was in a lot of pain in my chest...so decided that maybe I should go to hospital, this wasn't normal...' (Male, 54, White, Property developer) (Post)*

*PA04. 'So it must have kept reoccurring over the course of a couple of months for me to stop burying my head in my sand and go, I'm going to go...' (Male, 37, White, Business Manager) (Post)*

*PA15. 'Because it's been continuing off and on for these three or four months... so they didn't come all that regularly but I was worried enough to go and see the GP...' (Male, 80, White, Graphic Artist,) (Post)*

Other less prominent factors that acted as enablers of help-seeking for participants were family history of CHD events, fear, familial responsibility, and media campaigns. A few participants with a strong family history of CHD talked in detail



about how their relatives had suffered from a heart condition and in some cases died. This family history had worried them when they had symptoms and prompted them to seek help immediately. Sometimes these participants drew similarities between their own symptoms and the symptoms that had been experienced in their family, and that motivated them to seek help.

*PA12. '...my mother died in the heart patient, she was a heart, she had a heart attack, and then my brother ... had a heart attack last year.... make me more panic basically to come to see the GP...' (Male, 47, Asian, Civil Servant) (Post)*

*Subpo2. 'I've got a history of angina in my family. My dad had angina and my aunt... the symptoms I was getting I knew from them were similar, the breathlessness, the pain down the arm...' (Female, 61, White, Medical Secretary) (Post)*

A few participants talked about fear as the enabler that prompted them to get help. The fear was often related to having frightening symptoms (e.g. severe pain, unable to breathe properly, dizziness) especially when alone. These participants had a range of troubling symptoms whilst being alone which enabled help-seeking. For example, a participant who experienced pain who lived alone was afraid that she might have a heart attack. In another case a participant who also lived alone experienced severe breathlessness; he talked about how he did not want to seek help initially, but he feared that he 'might suffocate'.

*PA26. 'I get pain, and I don't know, if I were, because I was alone, and I'm afraid that I will get heart attack...' (Female, 72, Asian, Retired Audio-visual worker) (Post)*

*PA25. 'I didn't want to, well, it was worrying, I thought I might suffocate...' (Male, 80, White, Retired University Professor) (Pre)*

Familial responsibility and the need to maintain health in order provide and care for one's family was another enabler for help-seeking for participants. A few participants were concerned with ensuring they were well enough to care for their partners or not

cause their partners, who themselves were ill, any further stress over their welfare. One male participant talked about being a breadwinner and provider for the family unit which had prompted him to seek help in order to get well (e.g. well enough to work).

*PA23. 'Well I wanted to go to the doctor because of the dizziness, I didn't want my husband going out ... I just crash to the floor; I wouldn't want him to come back and find me on the floor because of his heart problems...'  
(Female, 76, White, Retired Office worker) (Pre)*

*PA07. 'Do you see your responsibility as the breadwinner and the carer of the family, do you make sure you're healthy so that you're in a position to provide? Yeah, yeah. If I'm a good healthy man, why not? I can't look after...'  
(Male, 46, White Forklift driver) (Pre)*

A few participants talked about recent media campaigns on television and how they described the kind of symptoms you need watch out for. The take-home message from these campaigns is always if you get any kind of chest pain you need to seek medical help/advice immediately. Consequently, when they had chest pain they went to the doctor.

*PA14. 'You see it advertised on the TV, if you get chest pains. Yeah, that's why I went to the doctor...'  
(Male, 70, White, Retired Gas-fitter and plumber)  
(Post)*

*PA26. 'I see it on TV or I read in the newspaper, that you know it goes in there...'  
(Female, 72, Asian, Retired Audio-visual worker) (Post)*

## **5.5 Barriers to help-seeking**

Access to GP services was an issue for participants in this study. Several participants talked about the difficulty of being able to get a GP appointment within a reasonable timeframe. Indeed, in some cases, participants talked about waiting as long as two weeks for an emergency appointment and three weeks or more for a routine appointment. For example, a participant who worked as an intercom

installation technician explained that his GP practice was so busy they had temporarily suspended booking non-urgent or routine appointments. He was told in order to book an appointment via the urgent route he would need to call on the day in the early morning. A limited number of appointments were available via this method. They were offered on a first come first served basis. Other participants also raised concerns that their GP only worked part-time making it harder to get appointments quickly. Other participants talked about inconvenient times of GP appointments especially if they were working. For example, a participant who worked as lawyer talked about the 'unhelpful' timing of emergency appointments, which tended to be in the middle of the morning when she needed to be at work (in court).

One older participant with moderate to severe chronic obstructive airways disease (COPD) spoke of the special relationship long-term she had with her GP who only worked one day a week and so she would wait until she could see him. However, she would seek help from other GPs if it was urgent, but always tried to wait if she could. The lack of availability of 'home visits' was another issue. Another participant, who had a sickly partner who was experiencing chest pain with episodes of dizziness and thus was not able to travel to her GP practice, requested a home visit, but was told there were no appointments for home visits for that day. In the end, she had to call emergency services to take her to hospital.

*PA09. '...It was very difficult to get appointments less than three weeks in advance and, although they did have emergency appointments in the mornings, but it wasn't always useful...' (Female, 27, White, Lawyer) (Pre)*

*PA13. 'Yeah, sometimes it's appointment, can't get easily.... Because my GP, my doctor, he just works three days a week...' (Female, 25, Beautician, Asian) (Post)*

*PA23. 'didn't feel well enough to go to them ... So, I rung to see if we could get a doctor's appointment for a home visit, and they said, no way, and there were no appointments...' (Female, 76, White, Retired Office worker) (Pre)*

*PA10. 'No, I found it difficult because ... they tell me at 9 o'clock you get, you can phone us then, no sorry, you haven't got an appointment today because they were busy...' (Male, 71, Asian, Intercom Technician) (Pre)*

*PA12. 'I wanted to see my GP they took two weeks, that was emergency appointment...' (Male, 47, Asian, Civil Servant) (Pre)*

Access to GPs was not always an issue. Indeed, a few participants reported positive experiences when accessing their GP's services. They commented on how good their GP practice was and how easy it was to get an appointment and they were often able to get appointments at the time they wanted. One older participant spoke about her long-term, on-going, positive patient experience with her practice – all she had to do was to ring up and explain her symptoms to get a quick appointment. She mentioned she never had to wait more than a few days to be seen. Another elderly participant talked about being offered a later appointment, but he had insisted on being seen 'now' and his GP practice accommodated him.

*PA05. 'No not at all, no. Our doctor, our surgery, surgery it's called, they're very good and if you think something terrible is happening you ring and they see you, they get you in that day or that morning or whatever or whatever and I've never had to wait three or four days to see them at all...' (Female, 76, Asian, Retired cake-maker) (Post)*

*PA25. 'I said I want to see the doctor, and they said, we can give you an appointment next week, I said I want to see one, and I want to see one now, and I sat there and she saw me...' (Male, 80, White, Retired University professor) (Pre)*

Finding time to go and see the doctor was another issue for participants. It was largely centred on being able to get time off work. A few working participants (especially those who were self-employed) talked about the financial impact of taking time off work when 'you don't get paid'. For example, one participant who had her own business spoke about not being able to afford time off work because her

lifestyle was too busy doing the things she needed to do. In another example a working professional participant talked in detail about the multiple time pressures and challenges created by going to see the doctor. This included finding time to call and book an appointment, trying to organise an appointment time slot that is the least disruptive to work, re-organising his work schedule to accommodate the appointment, and then waiting time in the GP's surgery to be seen, which could be long. All these factors put him off bothering to make an appointment in the first place. A few other participants also talked about the time constraints created by their familial responsibility as a care-giver and other family commitments. For example, one working participant who was also active in the community and her family life spoke about not having 'time to be sick' and she was not able to 'fit it in' to her busy work, familial and social commitments.

*PA12. '...it is the time, waiting time to see GP and particularly finding time as well, either you have to find book appointment in the morning or late evening, then you have to change your work schedule as well. Finding time and getting appointment time from the GP ...' (Male, 47, Asian, Civil Servant) (Post)*

*PA14. '...If you want to see the doctor and you've got work to go to, you have to go to the work, rather than go to the doctors... Well you don't get paid...' (Male, 70, White, Retired Gas-fitter and plumber) (Post)*

*PA02. '...so on work days it's actually quite difficult, I've actually got to be not going there to be able to see the doctor...' (Female, 63, White, Accountant) (Pre)*

*PA20. 'yeah, definitely, you know I can't afford the time off, I can't afford not to do things...' (Female, 48, White, Tailor) (Pre)*

*Subpo1. 'No, I just, I haven't got time to be sick. And that's a really selfish attitude, I know, but I really haven't. I can't fit it in. I just can't allow to, because I'm, I've got things to do. I've got a life outside, I've got a social life, I've got work, I've got a family...' (Female, 59, White, NHS administrator) (Post)*

A few male participants talked about trying to 'man it out' when it came to dealing with their symptoms, while a few others talked about how they feared being seen as a 'weak' person or a man who is unhealthy and not strong.

*PA22. 'Because I, I'm trying to man it out I guess, I don't want, I think there's people worse off than me...' (Male, 54, White, Property developer) (Post)*

*PA07. 'I don't try to be like, you know, like person who weak. I try to be strong...' (Male, 46, White Forklift driver) (Pre)*

A few younger participants talked about having their help-seeking intention rejected by friends or family who dismissed their concerns. For example, one participant was anxious about his heart as his mother had suffered with heart problems all her life. He talked about when he spoke to friends, they joked 'you're not going die'. In another example a participant spoke about how his wife seemed to be worried about his mental health and had on occasion 'told him to calm down' and not be 'stupid'.

*PA03. 'They say, ah don't worry, it's nothing, you're not going to die.' (Male, 29, White, Manager) (Pre)*

*PA04. '...she'll be like, calm down, are you being stupid?' (Male, 37, White, Business Manager) (Post)*

## **5.6 Experience of the RACPC**

Participants talked about their experiences of the health professionals in the RACPC. This included the RACPC nurses and cardiac physiologists who conducted the consultation, gave them advice, and communicated the final outcome and the cardiac physiologists who explained and undertook the various diagnostic heart function tests and procedures. This sometimes also included the doctors who referred them for further procedures and tests.

Many participants spoke highly of the professionals they had seen. They used descriptive words such as "pleasant", "kind", "marvellous", "really nice", "very good" and "professional" to convey their thoughts. For example, one older participant who had never walked on a treadmill talked about how the cardiac physiologist took the time to explain things to her.

PA06. *'I thought that both of the ladies there were very, very nice.'* (Female, 60, White, Tour Guide) (Post)

PA13. *'Yeah, she's very kind ...'* (Female, 25, Asian, Beautician) (Post)

PA01. *'Fine...Just asked the relevant questions and you know, so felt fairly comfortable...'* (Male, 44, White, Senior Manager) (Pre)

PA07. *'Yeah, it's all right. It's good professional people here. Right things.'* (Male, 46, White, Forklift driver) (Pre)

PA05. *'I think they were all very, they've all been extremely good and they bother to explain what's going to happen, they explained about, particularly about the treadmill which I've never been on before...'* (Female, 76, Asian, Retired cake-maker) (Post)

A few other participants talked about the efficiency of the process. They commented on how quickly they were seen, getting all assessments done on the same day, and how overall they felt it was a good experience.

PA11. *'Yeah, very good. Arrived, it was very efficient, no waiting really. I, well it started with a chat with I think the senior nurse, just going through a lot of the background and paperwork questions and stuff, all the sort of general health questions and stuff, measured, weighed and stuff. Quite an efficient system...'* (Male, 29, White, TV Journalist) (Post)

PA14. *'They done an ECG, blood pressure tests, treadmill, it's pretty efficient.'* (Male, 70, White, Gas Fitter/Plumber) (Post)

PA02. *'Reasonably efficient, everybody was very pleasant...'* (Female, 63 White, Accountant) (Pre)

Many participants talked about the tests they had undertaken as part of the RACPC assessment. The most commonly discussed was the treadmill test (cardiac exercise tests). Participants had mixed feelings about this part of the RACPC assessment. A few participants who had heard about it were either excited or nervous about doing it. Other participants had negative feelings. Some asked to stop the cardiac physiologist to test early due to dizziness or fatigue. Indeed, one participant talked about being anxious when he noticed his vital signs rising and another described it as 'torture.' Yet another participant thought he had "failed".

PA04. *'I think I was more disturbed and I think I could see the numbers shooting up when I looked at the numbers. Is this on the treadmill? Yeah...'* (Male, 37, White, Business Manager) (Post)

*PA15. 'Yeah, on the treadmill, which I failed. So I hide my head in shame really, but that's it basically...' (Male, 80, White, Graphic Artist) (Post)*

*PA10. 'But when I walk then I'm dizzy then I told him to stop, please. So you got dizzy on the treadmill? Because I think, I think, I'm back up my blood pressure 129 then 158 then 127 and then going very fast up down. And did you ask them to stop the treadmill, did you say I want it to stop? Yes, because I feel very dizzy...' (Male, 71, Asian, Sales Assistant) (Pre)*

*PA18. 'That was quite a torture. I should get a medal really...' (Female, 49, White, Adult Educator) (Pre)*

## **5.7 The impact of the diagnosis**

Participants in this study had taken a decision to seek help from their GP for their symptoms. Many of the participants had thought their symptoms might potentially be CHD, while a few others did not. However, they were all referred to RACPC as their GPs deemed their symptoms to be potentially CHD based on history and CHD risk profile. At the end of their assessment the vast majority of the participants (but not all) were not diagnosed with CHD symptoms. Many of the participants talked about how they felt about getting this “negative” diagnosis i.e. their symptoms were ultimately determined as not coming from their heart. Overall, participants had mixed feelings about their outcome.

A few participants were happy when they were told that they did not have CHD-related symptoms. They were often ‘happy’ or ‘delighted’ at being given the ‘all clear’. For example, a participant who had been experiencing pain in her chest on the left side was told that her symptoms were most likely to be normal muscular pain; she talked about how ‘really happy’ she was with that outcome. Another participant who had resisted seeking medical help expressed how ‘delighted’ she was with her outcome. Other participants spoke of feeling ‘relieved’ and were keen to put the experience behind them. For example, one participant who had an acute chest pain and thought he might be having a heart attack talked about being pleased to put the



experience behind him and had no plans to give it any more thought. Similarly, another participant who had a thumping feeling in the chest and had been told he did not have CHD-related symptoms, talked about his outcome as 'quite relieving' and that he 'felt a lot better'.

*PA14. 'Yeah, no, that's, it's been quite relieving... Yeah... A lot better...'  
(Male, 70, Gas Fitter/ Plumber) (Post)*

*PA22. 'Fine, I'm now going to, just get on with my life, I didn't really give it another thought to be honest...'  
(Male, 54, property developer) (Post)*

*PA06. '...there is nothing wrong with my heart ... that's good news, yes...'  
(Female, 60, White, Tour guide) (Post)*

*PA13. 'He said, it's just a normal muscular pain really.... Happy, yeah. I'm really happy...'  
(Female, 25, Beautician, Asian) (Post)*

*PA26. '... but that pain is not from my heart, is that, so I say, OK... I feel happy like that...'  
(Female, 72, Asian, Retired Audio-visual worker) (Post)*

A number of male participants, often fairly young, expressed dissatisfaction that the outcome of their assessment determined their symptoms not to be CHD-related. They were also sometimes left with feelings of incompleteness. Although they were happy at not having CHD, they felt they were back to square one and had no solution. They used terms like 'frustrating', 'not resolved' and 'incomplete' to convey thoughts about the outcome of not having CHD. Many of them had a long history of symptoms which had been investigated by other clinical services (e.g. nerve or muscle testing, respiratory, blood pressure etc.). They talked about how they felt that it was a 'good session' and they felt the service was '100%', but that they were 'going away' with no answers and no resolution. They felt that they were still left wondering what their symptoms might be, if not their heart then 'well, what is it then?' One young participant who worked in a high stress environment, with a history of arm pain, talked about his frustration from a previous outcome when the nerve clinic ruled that his symptoms were not neuromuscular-related. However, he was much happier with his RACPC clinic outcome. Another young participant, who also worked

in a high stress environment as a TV journalist and had had a 6-month history of symptoms and numerous visits to GP and referrals for tests, felt that the service was 'brilliant' and '100%'. He talked about how he was happy to have concerns that it might be his heart 'off his mind', but that despite this good news, tomorrow he would 'still have pain'. He was frustrated that he had gone through this assessment but in the end 'nothing had changed' for him. Overall there was a sense of frustration and dissatisfaction amongst these working professionals that they were left uninformed as to what their symptoms might be.

*PA04. '...I was relatively unhappy when the nerve issue got ruled out because it would have been a better answer, he would have gone, yeah you've got a trapped nerve in your arm. But I'm far more pleased from the outcome of today...' (Male, 37, White, Business Manager) (Post)*

*PA08. '... Frustrating...' (Male, 54, White, Dog racer/Owner) (Post)*

*PA11. 'Well that's the problem, I don't, I have nothing wrong with my heart today, but actually, so in a way the problem which I've come, I'm coming away with here with no resolve in a way. All I know is that there's nothing wrong with the heart, which is great, and that's good and that's 100% worthwhile, So, but I do feel, yeah, so I feel good to have that off my mind... nothing has changed for me, I will still have the pain maybe tomorrow... nothing resolved, there's no diagnosis.' (Male, 29, White, TV Journalist,) (Post)*

*PA17. 'Yeah, so it, it's a bit strange. It feels like it's half done, in a sense... So, I don't know where that leaves me really. So, it feels a bit incomplete, I guess.' (Male, 46, White, Management Consultant) (Post)*

A few older female participants talked about being a 'fraud' or 'feeling like fraud' because their symptoms turned out not to be CHD-related. For example, one older female participant with a history of shortness of breath talked about how much 'malingering' there was in the NHS, wasting doctors' and health professionals' time and how cautious she was not to be one of them. She was very concerned that she had started the 'hoo-hah' at the expense of NHS resources for nothing and now felt like a fraud. Another older female participant, who had had a one-off episode of pain

and was also given a non-CHD related diagnosis, talked about feeling 'like a fraud' and she was concerned that she should not be interviewed as a result.

*PA05. 'Yeah absolutely, I feel a bit of a fraud.... Simply because I, I've started a little hoo-hah which is expensive for the National Health Service and all the rest of it and I don't honestly think there's very much wrong with me, other than my possible asthma thing...' (Female, 76, Asian, Retired cake-maker) (Post)*

*PA19. 'You mentioned a little bit about feeling like a fraud earlier on before we started recording? 'Well, just because I haven't had the pain again and obviously, it takes time to work through doesn't it, to get here...' (Female, 77, Asian, Retired Teacher) (Post)*

## 5.8 Triangulation

For help-seeking delay, the medical record sources were not as complete as they were for symptoms. Health records did not always record patient delays or outline a timeline of symptom presentation as definitively as they did in the case of symptoms. Timelines were rarely recorded in the GP referrals, but were often recorded in RACPC outcome letters. There were four cases where the interview data could not be compared with historically-recorded health data, as delay or delay timelines were not specifically recorded in any health records. There was also one incident where triangulation could not be performed as the patient records had been lost. Despite the gaps in the health records it was possible to triangulate the interview data to at least one additional source (and in some cases both), either RACPC outcome letters or GP referral letter for the clear majority of participants. As was the case with symptoms there was general concurrence between medical records and the delays reported by the participants. Again, some minor variations did occur, e.g. 'a few months' compared with '6 months' in another source (see Appendix D for triangulation help-seeking delay). It was possible to triangulate help-seeking delay to one health record in the vast majority of cases. It would appear that, on whole, this

quantitative data supports the qualitative data, strengthening the robustness of the analysis.

## **5.9 Summary**

Many participants did not want to be a burden to others with their worries and were reluctant to seek help from family and friends. However, participants often did seek help in this way and it encouraged them to see their GP. A few male participants said they would only seek help from partners and sometimes close family. Many participants initially dismissed and normalised symptoms. A few other participants dismissed symptoms as age-related pains, while some younger participants normalised symptoms as a lack of fitness. Other participants actively took steps to self-manage their symptoms (e.g. self-medicate or information-seeking). One participant of Asian heritage talked in detail about a range of natural and herbal remedies he used to self-medicate.

Most participants were enabled or influenced to seek professional help by other people. Partners and close family were the strongest motivation although a few participants avoided speaking to partners especially if they were not in good health or speaking to their children if they were still young. Severity of symptoms was another important enabler. Accessibility of GP services acted as barrier to help-seeking for many participants. A complex booking process and long waiting times for appointments were particular issues. Taking time off work was a particular concern for working participants, especially if they had their own businesses.

Additionally, participants generally spoke very positively of their experience of RACPC, commenting on its effectiveness and on the professionalism of health professionals they encountered. However, when it came to receiving their RACPC

diagnosis participants appeared to have a mixture of reactions if it was negative (not potentially CHD-related). Many younger male participants were often frustrated and felt that process was incomplete as they had not received a definitive answer to the cause of their symptoms. A few older female participants said they felt frauds and had wasted NHS resources, whereas other participants were happy to have a non-cardiac cause for their symptoms and were keen just get on with their life.

## Chapter 6. **Results: CHD risk factors**

This chapter examines participants' understanding of the CHD risks, what behaviours they believed increased their risk factors, and what behaviour modifications they had taken to mitigate their risk factors. This chapter has 3 sections: 6.1 Identification of CHD risk factors; 6.2 Male lifestyle vs Female lifestyle; and 6.3 Behaviour Modifications.

### **6.1 Identification of CHD risk factors**

The vast majority of participants in this study correctly identified the various types of behaviours (modifiable risk factors) that increased CHD risks, namely smoking, diet, drinking alcohol, obesity and lack of exercise. Some participants had strong views on diet as a major risk factor and specifically talked about eating habits. For example, one participant compared 'food and the body' to a 'car and fuel' and he said if you do not put the best or right fuel in your car it would likely 'break down'. A few other participants said they did not know what the risk factors of CHD were. One female participant talked about anxiety as a potential CHD risk.

*PA01. 'Smokers, overweight and people who don't exercise...' (Male, 44, White, Commercial Manager) (Pre)*

*PA03. 'Just elderly, very overweight, drinking, smoking people maybe yeah...' (Male, 29, White, Manager) (Pre)*

*PA19. 'Well, I think overweight, probably. Also, lack of exercise. I would have thought anxiety as well...' (Female, 77, Asian, Retired, Teacher) (Post)*

*PA20. '...just I don't know.' (Female, 48, White, Tailor) (Pre)*

*PA22. '... and then food and diet is obviously important. Like a car, if you put lousy fuel into a car it would break down.' (Male, 54, White, Property developer) (Post)*

Some participants also spoke about the non-modifiable risk factors (not related to choices or behaviours) associated with CHD. This included attributes such as age, congenital abnormalities, family history and genetics. For example, one participant talked about her father and aunt, both of whom had CHD. She highlighted that neither of them had smoked nor were they drinkers of alcohol yet still got CHD; she felt that it must 'run in the family'. Overall, most participants mainly believed that lifestyle and personal behaviours were the main risks of CHD.

*PA03. 'Just elderly.' (Male, 29, White, Manager) (Pre)*

*PA16. '.... genetics, family history...' (Male, 42, Asian, Carpenter) (Post)*

*PA17. '... and then probably just inheritance, genetic inheritance...' (Male, 46, White, Management Consultant) (Post)*

*PA18. '...probably inherited factors. Yeah, all the, a birth defect or something' (Female, 49, White, Adult Educator) (Pre)*

*Subpo1. 'My dad wasn't a big drinker or smoker, but obviously, it runs in the family, and my aunt wasn't actually, thinking about it...' (Female, 59, White, NHS administrator) (Post)*

## **6.2 Lifestyle and risk of CHD**

Participants agreed that lifestyle was an important factor in risk of developing CHD. A key area of discussion for participants was whether 'male' vs 'female' lifestyle placed one gender at higher risk than the other. Many participants believed the traditional western male lifestyle (which they defined as work full time, high-stress, smoking, drinking, drug-taking) created the highest risk of developing CHD-related illnesses. As a result these participants believed that men were at higher risk of CHD than women.

*PA08. 'I'd say men [are at more risk]...You know, like a woman is left home with children... 'Yeah, and men socialise more, don't they? Well they did in my day, it's all changing now, isn't it?' (Male, 54, White, Dog racer/ Owner) (Pre)*

*PA23. 'I think men [are at more risk]... I'm going back in, like my generation ... I only did part-time until my daughter... I was at the generation when you had your children you stayed at home.'* (Female, 76, White, Retired Office worker) (Pre)

*PA11. 'In my mind the stereotype is men are at a higher risk...I feel that men are, look after their bodies less than women, they're a bit unhealthier...'* (Male, 29, White, TV Journalist) (Post)

*PA10. '...the stress makes this men's disease.'* (Male, 71, Asian, Intercoms Technician) (Pre)

Several participants in study also talked about men not always being good at personal self-care in terms of physical well-being. For example, one participant who worked as an adult educator raised the issue of men and their penchant for not looking after themselves properly, and went as far to say that men are generally 'rubbish' at self-care. She believed they were less likely to go to the doctors and more likely to drink alcohol and smoke. Another participant described how men were not good at looking after themselves in the 'physical' sense, considered men to be generally 'unhealthier' than women. He talked about this phenomenon as the stereotypical male behaviour which increased CHD risk in men.

*PA18. 'Because they're [men] rubbish looking after themselves, they don't go to doctors, smoke or drink more...'* (Female, 49, White, Adult Educator) (Pre)

*PA11. 'In my mind the stereotype is men are at a higher risk...I feel that men are, look after their bodies less than women, they're a bit unhealthier...'* (Male, 29, White, TV Journalist) (Post)

A few male participants who worked in manual occupations (e.g. gas fitter/plumbers) talked about having to work up to 'six days a week' and 'very hard' to keep themselves from being 'out of work'. Another male participant who also worked in a manual occupation spoke about the hard 'physical' work that men were expected to undertake to earn a living. They believed that as this hard physical work was usually undertaken by men, this placed men at greater risk of CHD.



*PA10. '...men are stressed often because of this very hard life nowadays ... (Male, 71, Asian, Intercoms Technician) (Pre)*

*PA14. 'Men probably ... More stress...You've got to be up five, six days a week going to work, you've got to make sure you do your job proper, otherwise you'll be out of work...' (Male, 70, White, Retired Gas-fitter and plumber) (Post)*

However, there was also an acknowledgment among participants that these views were often based on the 'stereotyped' man and traditional gender roles, which were now changing, thus increasing women's risk too.

*PA18. 'Generally probably men but I think women are catching up perhaps' (Female, 49, White, Adult Educator) (Pre)*

A few male and female participants believed that women or the traditional female lifestyle (which was defined as caregiver, homemaker, and multiple social responsibilities) placed women a higher risk of CHD than men. They talked about the pressures of being a woman. The multifaceted roles that a woman needs to undertake nowadays as a care-giver, raising children, taking care of their spouses, maintaining a household, and shouldering the emotional burdens of the family whilst being expected to work full-time. They felt it was these lifestyle pressures that increased their risk of CHD. They linked these stresses directly to heart disease: 'stress... has a lot do with heart problems'. For example, one participant talked about her stress, and how women had to juggle many more plates than men, making their lives more stressful.

*PA13. 'Women... Because their lifestyle... they have more responsibility for the children and family...' (Female, 25, Beautician, Asian) (Post)*

*PA21. 'Woman because she has much more to deal with than a man does, that might be sexist but... we take a lot on our shoulders emotionally... like a lot of the time we are the caregivers so it's just the lot that we have on our plates... We have more of a stressful life than a man does...' (Female 51, Black, Youth worker/manager) (Pre)*

*PA20. 'I think women actually because we get more stressed out about a lot of things. I think stress has got a lot of, a lot to do with heart problems...'* (Female, 48, White, Tailor) (Pre)

A few male participants (controversially) suggested that women were of higher risk of CHD as they were in some way the weaker sex. For example, one male participant said that although he did not know of any 'statistical figure', he believed women were physically weaker and therefore at higher risk of CHD. He went on to claim that women's lack of strength was because they had fewer opportunities to exercise than men. In his view, women were mainly at home looking after the children and therefore were not able to make themselves physically stronger to handle disease. Another male participant believed that women were 'lazy' and that they 'didn't do a lot'. He also believed that women never exercised enough, thus increasing their risks. He also claimed women were 'lazy' in terms of 'sport and exercises'.

*PA07. 'Yeah, I think for a woman is more often probably because they not strong enough probably, from my opinion...'* (Male, 46, White Forklift driver) (Pre)

*PA12. 'I am thinking the women...The reason, I am not, I have no... Yeah, I have no statistical figure...Because they might be, because they get less opportunity to exercise...'* (Male, 47, Asian, Civil Servant) (Post)

*PA22. 'Women...Because I think they're lazy... I don't think they, they don't do an awful lot....and lazy in terms of sports and exercise and things like that...'* (Male, 54, White, Property developer) (Post)

Some participants believed that CHD risks were related to lifestyle and was independent of gender. Several participants talked about how the modern women now also undertook risky behaviour (e.g. smoking, drinking,) putting them at equal risk of CHD to men. Other participants talked about rising stress levels in women: 'stress has moved over to women these days.' These participants held the view that although historically the male lifestyle was riskier and more unhealthy than the female lifestyle, this was no longer always the case. For example, one participant

talked about how society has changed over the past 30 years and how those 'old school' days of men going out drinking and smoking while 'the wife would be at home' were gone. As a result, they believed that nowadays women and men were at equal risk. Another participant talked about how she believed that women nowadays were behaving more like men (e.g. smoking and drinking). She made reference to her own granddaughter, whose behaviours she described as 'appalling'.

*PA04. '... heart disease was more prevalent in men until maybe in the last 30 years when the lifestyle has changed.... If you think the old school in this country, the attitude of only men went in pubs, smoking and drinking while the wife would be at home.... I would say equally...' (Male, 37, White, Business Manager) (Post)*

*PA16. 'Equal really, I think. It's all about your lifestyle, isn't it.? Diet, exercise, genetics, family history...' (Male, 42, Asian, Carpenter) (Post)*

*PA05. '... I think that was so once, but I think with women smoking themselves into a corner now and drinking and women do drink a lot; my granddaughter is appalling...' (Female) (Post)*

*PA26. 'Men they, either they smoke, they drink, women are like that as well ... they're about the same.' (Female, 76, Asian, Retired cake-maker) (Post)*

*PA10 '... the stress makes this men's disease...stress has moved over to also women...' (Male, 71, Asian, Intercoms Technician) (Pre)*

A few participants also believed CHD risks between men and women were equal and did not link it to lifestyle or behaviours. They had had other beliefs which influenced their views. For example, one participant thought it simply a case of biology; she believed the heart was a heart irrespective of which body it was in. She likened it to breaking an arm. An arm could break regardless of whether you were male or female. Another participant talked about her experience of CHD through the people around her (e.g. family and friends). She spoke about the community club that she regularly attends. It was here that she mostly heard other women talk about what heart procedures they had had done which made her think of women being at

higher risk. She went on to say she also experienced men in her family with heart disease, as a result she felt the risk was equal.

*PA06. '...we've all got hearts and I'd imagine that whatever goes wrong with a heart, goes wrong with a heart regardless of whether you're male or female yeah?' '... like if you break an arm whether you're male or female you've broken your arm...' (Female, 60, White, Tour guide) (Post)*

*PA27. 'I go to a community club and we've got people there, they've had these different things done to them and I hear conversations, mostly women of course, but on the other side I had a brother in law and I had my nephew, and so I equal it up that way...' (Female, 80, White, Retired catering worker) (Pre)*

One participant who was the daughter of medical doctors, showed extensive knowledge of women and heart disease, and the protective role of pre-menopausal hormones. She was the only participant to have such detailed knowledge.

*PA02. '... as I understand it, pre the menopause, men are, post the menopause, women are equally at risk, or maybe not equally but certainly the risk factors go up...' (Female, 63, White, Accountant) (Pre)*

### **6.3 Behaviour modification**

Some participants talked about what steps they had taken to modify their behaviours in the recent past to reduce their risk, as a result of the referral to RACPC. These participants were concerned that they needed to be referred to RACPC by the GP for a potential CHD condition. As a result they implemented a range of strategies to improve their general health including diet changes, exercise, weight loss, and a reduction of alcohol and drug use. For example, one recently widowed participant talked about suffering from a bout of depression after the death of her husband to the extent she no longer cared if she lived or died. She gained a substantial amount of weight during this time which she believed increased her CHD risk. However, she had sought treatment and she was coming out of this depressive experience and

was working hard to bring her weight back under control through her diet. Another participant with a long history of CHD-related problems including palpitations and hypertension, talked about her lack of exercise, previous marijuana smoking, and the stress that she had been under since separating from her partner of 23 years as contributors to her symptoms and possibly increasing her CHD risk factors. However, she had stopped smoking marijuana and taken other steps to be back in control of her life, including looking for a new job.

*PA05. 'Since my husband died I've put on two stone because, but I'm coming out of it now, because the first four years I really didn't care whether I lived or died and, but I'm coming out of that now. So, I'm on this two, four diet or five, two diet or whatever ...' (Female, 76, Asian, Retired cake-maker) (Post)*

*PA09. 'I did try to drink less coffee for a bit, but that's quite difficult, and I tried to focus a little bit more on my diet.' (Female, 27, White, Lawyer) (Pre)*

*PA21. 'Well I don't exercise I know that, I have been under a lot of stress lately ... I was smoking marijuana ... I stopped in January' (Female, 51, Black, Youth worker/manager) (Pre)*

*PA12. '...so what I did I changed, I cut drastically my food habit to go on the safer side...' (Male, 47, Asian, Civil Servant) (Post)*

One participant who had several previous heart attacks talked openly about his cocaine addiction, which had lasted for a number of years, but he had given it up a few years before. He told of how he also drank alcohol excessively, but he had given that up too to improve his health.

*PA08. 'Yeah, like I was addicted to cocaine, I don't know up till about six years ago, five years ago. And I give that up like that, and I give up drink like that...' (Male, 54, White, Dog racer/Owner) (Pre)*

Not all participants had adopted positive behaviour changes. Some talked about being resistant to modifying their behaviours to reduce their CHD risk and found ways to justify it. For example, one participant who admitted to not doing regularly weekly exercise talked about his unwillingness to do so. He shared stories of people

he had known who had led sedentary lifestyles but started exercising because it was meant to be healthy. They ended up having heart attacks and other health problems as a result. He had made the decision not to risk it and not to partake in exercise, regardless of the recommendations. Another participant who smoked regularly felt that regardless of the outcome she would still continue to smoke, but she would be more conscious of the amount she smoked.

*PA15. 'I'm not doing any exercise, I've seen these people that have been sedentary all their life, they do a bit of exercise and drop dead of a heart attack and it's happened more than, I've read about it very often lately... It's a risk which I'm not prepared to take...' (Male, 80, White, Graphic Artist) (Post)*

*PA20. 'I think I'll probably still smoke but I will be careful how many I smoke, OK? I don't consider myself to be a heavy smoker...' (Female, 48, White, Tailor) (Pre)*

One participant talked about how he drank up to 60 units of alcohol a week with his partner and friends and was worried about how that was increasing his CHD risks. He admitted that now he had been given an all-clear diagnosis, he felt licensed to continue drinking at these unsafe levels.

*PA04. 'I drink relatively heavily... I don't think the issues I have come from my heart... Which I was quite pleased about, I'll carry on drinking...' (Male, 37, White, Business Manager) (Post)*

## **6.4 Summary**

Nearly all participants correctly identified the main lifestyle-mediated risk factors for CHD, namely diet, obesity, inactivity, smoking, and alcohol. Most participants believed that the traditional male lifestyle was more high risk for CHD than the female lifestyle. They believed men's work-related stresses, their poor health choices and that fact that men were not good at self-care all increased their chances of

developing CHD. Other participants believed the female lifestyle was more high risk for CHD (e.g. working women, being a caregiver). Some other participants believed it was related to lifestyle in general, therefore the risk was now equal as result of societal changes, which meant more women were engaging in the same high risk behaviour as men, and also had similar work-related stress.

In response to their referral to the RACPC, some participants immediately took steps to reduce their CHD risk while waiting to be seen in the RACPC or in the recent past. They talked about changes to diet, smoking cessation and reducing alcohol intake. This was not always the case. Some participants decided not to improve their health behaviours to reduce their CHD risk and found reasons to justify these decisions (e.g. exercise can be dangerous). Indeed, there were also a few cases where participants believed a non-cardiac chest pain diagnosis was licence to continue living as they had.

## Chapter 7. **Lay patient resource**

This chapter presents the construction of a lay resource. The first part of this chapter outlines the format of the lay resource and the methods used to construct it. The second part demonstrates how the literature and the results from this study informed the choice of questions and answers to be included in the lay resource. The last section deals with feedback on the comprehensibility of the lay resource by two panels of experts and a sub-sample of 10 participants (see Appendix R for the lay patient resource).

### **7.1 The structure of the lay resource**

The format of the lay patient resource was informed by the NHS Identity checklist for patient leaflets and the Royal College of Psychiatrists' (RCP) leaflet for mental health and help-seeking (Ahmed and Hussain, 2014). The NHS Identity Agency has oversight of NHS communications and brand strategy and as such offers best practice advice for the construction of NHS patient information guides. The NHS Identity Agency provides checklists of recommended areas to be covered in information leaflets for different types of patient leaflets, but it does not provide a checklist for a help-seeking leaflet. The most relevant checklist that could be found for this study was the leaflet for 'conditions' (NHS Identity, 2016) (see Table 5 for the full list).

The RCP's leaflet for mental health and help-seeking in Muslims used a question and answer format (e.g. 'what is it like to have mental illness?'). This structure was also chosen for the help-seeking for chest pain (HSCP) leaflet developed by this study because it used simple language and addressed real concerns in the community it was intended for (e.g. 'What if my problem is caused by Jinn



possession or evil eye?') (Ahmed and Hussain, 2014). NHS Identity guidance for a 'Conditions' leaflet suggests that any leaflet should explain what the clinical condition is, what the symptoms are, what to do about them, things patients can do for themselves to improve their condition, and information on where to get help or further information (NHS Identity, 2016). Thus, the first part of the HSCP leaflet (Q1-Q3), informed by relevant literature, addresses the clinical condition (i.e. non-emergency cardiac symptoms). The second part of the HSCP leaflet, Q4 –Q7, is derived from patient interviews supported by literature and focuses on help-seeking promotion. The final question on the leaflet for this study (Q8: What kind of help is available?) was included as it is recommended by NHS Identity guidance for all patient leaflets, to provide information on alternative sources of help and support (NHS Identity, 2016). More information is provided below on the content of each of these sections.

**Table 4 - NHS identity checklist for writing a patient guide**

What is the leaflet about? Who is it for?
What condition is being described?
What causes this condition? If the cause is unknown, say so.
Does anything increase the risk, for example, age, sex, ethnic origin or family history?
What are the signs and symptoms?
Are there any tests or examinations needed to confirm the diagnosis?
What treatments are available? Give brief descriptions.
What are the side effects and risks associated with treatment?
What are the side effects and risks of not receiving treatment?
What are the next steps?
What can patients do for themselves?
Are there other implications, for example, infecting other people?
Who can they contact if they have any more questions?
Patients will need to know where they can find more information – for example, support groups and websites.

## **7.2 Construction of the lay resource**

Data analysed from the interviews and themes that emerged from the literature informed the development of a lay patient resource designed to improve symptom recognition and promote help-seeking practices among lay people. The researcher

used the literature and qualitative analysis to generate key themes relevant to interpretation of symptoms, help-seeking practices and CHD risk factors.

Five key themes emerged and were used to inform the construction of the lay resource and developing its questions:

1. Patients have difficulty understanding the concept of CHD and interpreting its symptoms.
2. CHD symptoms are not what patients expected them to be; they are often milder or different to those depicted in the popular media (Hollywood-style heart attack scenario)
3. Patients are unsure when to go and see a doctor, thus often delay seeking medical assistance for stable CHD symptoms.
4. Patients do not like to be seen to be wasting the doctor's time for potential stable CHD symptoms.
5. Accessibility of GP services can be barrier to help-seeking for potential stable CHD symptoms.

#### 7.2.1 How the questions were constructed

**What are symptoms of heart disease? My symptoms are not what I expected heart symptoms to be like?**

Questions 1 & 3 of the lay patient resource aim to improve symptom recognition and interpretation. These questions incorporate two main themes from the current research: 'Patients having difficulty understanding heart disease and interpreting its symptoms' and 'CHD symptoms are not what patients expected to be, they are often milder than depicted in the popular media (Hollywood-style heart attack scenario)'.

The patient interviews highlighted a lack of understanding of heart disease by some participants:

*PA28 'I don't I don't know.... I really don't know where the heart is...' (Female) and PA27 'Yes, well I still don't think there's anything wrong with my heart.... I mean I don't know what, a heart attack or what it is really'.*

Interviews also showed that participants did not always know how to interpret their symptoms. This was made worse by popular media depictions confusing participants as their symptoms did not match the 'Hollywood heart attack' (Zerwic et al., 2003).

*SubPA01 'my perception of a heart attack is someone flaking out on the floor. So, in my head, if I had flaked out on the floor, clutching my heart, yes I was having a heart attack...but I could sit down ... as far as I'm concerned it's ... not heart problems at all'.*

Interviews confirmed the known literature, which suggests the CHD symptoms can vary, and that understanding symptoms is an issue for patients (Gyberg et al., 2015, Canto et al., 2012b, Galdas et al., 2010, Higginson, 2008, Albarran et al., 2007, Emslie, 2005).

Therefore, the patient resource specifically provides information about heart disease in order to address patients' lack of knowledge in this area. It also highlights that CHD symptoms can be varied and do not always follow the 'Hollywood attack'



**Figure 1 - Hollywood-style heart attack**

Source: <http://resources2.news.com.au/>

scenario (see Figure 1), and highlights the difference between stable and unstable CHD symptoms. This is important because unstable CHD symptoms are an emergency situation known as acute coronary syndrome (ACS), 'heart attack'.

### **What should you do when you have these symptoms?**

Question 2 of the lay resource addresses the current research finding: 'Patients are unsure when to go and see a doctor and thus often delay seeking medical assistance for stable CHD symptoms'. When to go to the GP was an issue for patients in this study. They were often concerned their symptoms were not severe enough to bother the doctor.

*PA23 '...I don't waste no doctor's time, put it that way. I won't go round because I've got a cold, I go to the chemist ...'.*

Whilst it is true that most of the participants' symptoms in this study were determined not to be CHD symptoms at the end of their evaluation, it is still essential that such patients seek help early. Studies have shown that in some cases, patients can have prodromal symptoms (chest discomfort, palpitation, breathlessness, chest pain) starting several weeks before the onset of acute coronary event (ACS), commonly known as a heart attack (Nouredine et al., 2008, Albarran et al., 2007). Early diagnosis may prevent ACS from occurring which has significant health benefits (Sekhri et al., 2007). If the patient goes on to have an ACS it could lead to permanent heart muscle damage, a precursor to heart failure, which is associated with significant physical and psychosocial disability and poor health outcomes (Foster and Mallik, 1998, Albarran et al., 2007, Evangelista et al., 2001).

Therefore, Question 2 aimed to improve help-seeking but ensure patients know what to do when they get symptoms. When selecting the wording of this question the

researcher was cautious not to be prescriptive. The patient resource's role was to educate patients to enable them to make their own informed decisions, and not provide diagnostic criteria which could have a negative effect (i.e. the patient does not seek help because their symptoms fall outside the diagnostic criteria provided in the patient resource, a known problem highlighted in the literature). In view of this, an open question was used 'What should you do when you have these symptoms?'. The answer to this question provides advice on a range of options; for example, going to see your GP, attend a local NHS Walk-in clinic, or attend the emergency department.

### **I cannot get an appointment with my GP. What can I do?**

Question 4 of the lay resource addresses the current research finding that 'Accessibility of GP services can be a barrier to help-seeking'. Participants often spoke of having to wait for long periods of time to see their GP – sometimes several weeks:

*PA12 'I wanted to see my GP; they took two weeks, that was an emergency appointment...'*

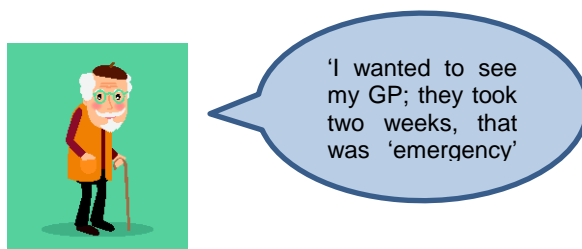
Other participants talked about how appointments were often at inconvenient times:

*PA09 '...It was very difficult to get appointments less than three weeks in advance and, although they did have emergency appointments in the mornings, but it wasn't always useful...'*

Participants talked about GP practices not offering home visits when they were not well enough to travel to the GP's surgery:

*PA23 'didn't feel well enough to go to them ... So, I rung to see if we could get a doctor's appointment for a home visit, and they said, no way, and there were no appointments'*

Research has also found accessibility of medical services as potential barriers to help-seeking for both men and women. Emslie (2005) highlighted that long waiting times and inconvenient surgery times posed barriers for CHD patients (men and women). According to Gyberg (2015), access to medical services presented barriers when patients were unsure how and where to access them (Gyberg et al., 2015, Emslie, 2005). Therefore, this section's focus was aimed at advising patients on how to get an emergency GP appointment and informing patients of other medical services available (e.g. NHS walk-in clinics), when GP services are difficult to access and/or not available in a timely manner.



### **I don't want to bother the doctors.**

Question 5 of the lay resource addresses the current research finding 'Patients do not like to be seen to be wasting the doctor's time'. This study found that many participants were very concerned that they did not waste the doctor's time. Indeed, they saw this as negative behaviour and delayed seeing a professional in order to be sure their health complaint was valid enough to justify seeing a doctor:

*PA05 'I'm nearer a scraping off the ground ...I don't like wasting their time if you see what I mean, with little things'*

*PA10 ‘...Because I know ... so many cases in the queue... if I am not a major problem why do I go there...’.*

Other literature also highlighted not wanting to waste the doctor’s time, fears of embarrassment for falsely raising the alarm and not wanting be seen as a nuisance by the doctor, as common barriers to help-seeking (Power and Wardle, 2015, Higginson, 2008, Turris and Finamore, 2008, Emslie, 2005). Indeed, participants in this study took steps to avoid going to the doctor in the first instance, often resulting in help-seeking delay.



I don't like wasting  
the doctor's time  
with little things

Question 5 therefore aims to encourage patients to see doctors promptly if their symptoms might be heart related. It is very important that patients get symptoms checked out urgently as patients get mild symptoms which act as warning signs (prodromal symptoms) for major emergency CHD events (Noureddine et al., 2008, Albarran et al., 2007).

### **I don't have time to go and see the doctor.**

Question 6 of the lay resource address this theme: finding time to go to the doctor. Some participants were concerned they did not have time to consult a doctor. Some felt their work responsibilities prevented them from seeing a doctor, especially if it had a financial impact (not getting paid):

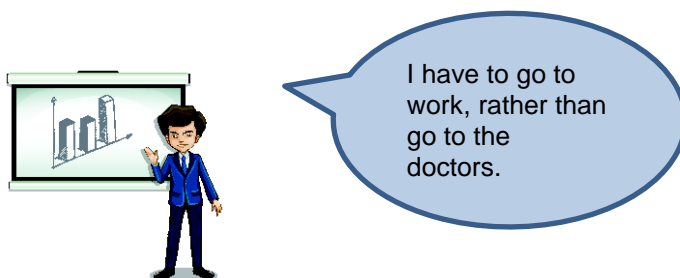
*PA14 ‘...If you want to see the doctor and you’ve got work to go to, you have to go to work, rather than go to the doctors... Well you don’t get paid...’*

Other participants prioritised their family or social commitments before their own health complaints:

*SUBPO1 'No, I just, I haven't got time to be sick. And that's a really selfish attitude, I know, but I really haven't. I can't fit it in. I just can't allow to, because I'm, I've got things to do. I've got a life outside, I've got a social life, I've got work, I've got a family'.*

Other literature found that women tried to preserve their daily routine as a good mother, wife and employee. This could lead to a delay in seeking help as they prioritised those activities first (Gyberg et al., 2015, Turris and Finamore, 2008). A recent study in the cancer field found that over one third of participants (both men and women) cited being too busy and that other priorities took preference, as a reason for delaying help-seeking (Power and Wardle, 2015). Therefore, Question 6 highlights the benefits of getting early treatment for a potentially serious health complaint like CHD and the importance of getting help promptly.

### **I don't like going to the doctor**



Question 7 of the lay resource addresses the theme: fear of going to the doctor. This research found that some men in particular didn't like going to doctors. Some had a dislike of modern surgeries:



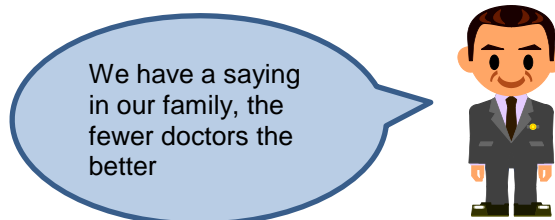
*PA15 'I don't, I, first of all, I don't like the modern surgeries, that's why I don't go to doctors, because you get all the ill messing around breathing on you and I don't, hate that...'*

Other patients had a fear and general dislike of doctors:

*PA15 'We have a saying our family, the less doctors the better...'*

*PA28 'Well, I've never liked going to the doctors but the thing is if you're not well you go, don't you? And that's it, well, I've never liked going to them. I never like coming into these places. It terrifies me'.*

Research also suggests that barriers to help-seeking for men with CHD include the GP surgery being considered 'male-unfriendly' (O'Brien et al., 2007). Another study on barriers to help-seeking in cancer patients found that men and women avoided doctors because they were worried or scared (Power and Wardle, 2015). Therefore, this question aimed to address the fear associated with consulting health professionals by providing information on the benefits of getting help early and attempts to deal with the male issues described above.



### **What kind of help is available?**

Question 8 of the lay resource addresses this and fulfils the guidance by the NHS identity checklist that a leaflet should provide details of other sources of information for patients. Therefore, this leaflet included health information websites, emergency and non-emergency telephone numbers, as well as details on how to contact local

NHS walk-in services if they were having difficulty accessing their GP, as detailed in Table 5.

**Table 5 - Health information and Medical Services**

<b>Your local GP practice</b>
Your local GP practice should provide assistance with any non-emergency medical issues.
<b>NHS Choices</b>
Provides a list of walk-in clinics, online information, and guidance on all aspects of health and healthcare to help you make decisions about your health. <b>Web:</b> ( <a href="http://www.nhs.uk">www.nhs.uk</a> )
<b>NHS 111</b>
You can call NHS 111 when you need medical advice or help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. <b>Telephone: 111</b>
<b>Emergency Services</b>
If you think you are having a heart attack you should contact the emergency services immediately, without delay. <b>Telephone: 999</b>

### 7.3 Testing the lay patient resource

Once the lay patient resource was constructed, it was initially sent to the supervision team for review (Director of Studies and 2nd Supervisor). The supervisory team's background covers psychology, psychotherapy, specialist expertise in men's health, masculinities, patient experience, patient information and devising questionnaires.

They constituted the first panel of experts who provided feedback on the first draft's comprehensibility. The draft resource was sent via email to each supervisor independently and feedback was emailed back. The feedback was tabulated for analysis (see Table 4). The first draft was amended to incorporate the first panel's feedback. It was then sent to a second panel of experts which comprised three consultant cardiologists, a chest pain nurse specialists and a cardiac physiologist. The same approach was followed for the second panel as the first. The second draft was sent independently to the panel members and their feedback was tabulated for analysis and incorporation in the final resource. Both panels were asked to feedback

on concepts and comprehensibility and to ensure wording was appropriate for patients i.e. easily understood. Additionally, the clinical panel was asked to check for clinical accuracy and clinical appropriateness.

Patient involvement commenced once both panels of experts were satisfied. The lay resource was then piloted on a sample of the interview participants (5 men and 5 women) to assess comprehensibility from a patient perspective. The sample randomly selected every third woman and man on the study participant key list, which is recorded in the order of interviews. Participants were sent a covering letter inviting them to participate in the second part of the study (see Appendix M for covering letter). The participants had already been invited to participate and had provided consent for the second phase of the research when they enrolled in the study at the interview stage. However, as this part of the study had been amended, it was necessary to take consent again. To that end, a new ethics approved participant information sheet (PIS) and consent form were sent to each participant in the sample (see Appendix L for second consent form and Appendix K for second patient information sheet). They were asked to read the participant information sheet and sign the consent form, and to return them along with comments on the lay patient resource. Participants were also sent a copy of the lay patient resource and an open box questionnaire to help patients review the lay patient resource and record their answers (see Appendix N for lay resource questionnaires and Appendix R for the lay patient resource). They were asked to read the lay patient resource and comment on it using either the open box questionnaire provided or by writing their comments on the lay patient resource or leaflet. Participants were offered the option of using the

stamped addressed envelopes or emailing the researcher to return their comments and consent form.

Participants were given a three-week response time. At the mid-point, approximately ten days, only one male participant had returned their response sheet. One female participant letter was returned to sender and the participant could not be traced as they had moved out of the area. Therefore, steps were taken to improve the response rate. The researcher called the remaining participants asking them if they would still like to participate and encouraged them to respond. Two women called who had moved and thus they did not receive the leaflet pack, so the researcher immediately re-sent it to them at their new addresses. One man explained that he could not participate. It was decided that in cases where an invited participant was 'return to sender' (and could not be contacted) or they declined to take part in this, to restart the selection process by choosing every fourth man and woman on the patient key, until a minimum of five responses was received. This was in keeping with the original practice of selecting every third participant. Accordingly, an additional two participants were contacted bringing the total mail-out to 12. Following this exercise (calling patients and sending out additional invitations), the participant response rate increased to 5 participants, two female and three male participants.

#### **7.4 Expert and patient feedback on lay patient resource**

Overall, the clinical panel of experts' feedback was very positive. They noted that the lay patient resource achieved a good clinical standard. Indeed, one of cardiologists suggested that he would like to give it to his patients. However, a few changes to terminology and clinical instructions were suggested (see Appendix P: second panel

of experts). The minor suggestions were considered by the researcher and were incorporated into the patient lay resource where appropriate.

The patient feedback was also very positive about the lay patient resource. Most of the patients who responded did not make any specific comments about things that they felt needed changing or addressing. However, two patients provided detailed feedback which was considered and debated with the supervisory team (see Appendix Q for patient feedback). Key points from the patient feedback centred on the Clip Art used (purchased from an icon and clip art website) in the resource to emphasise comments made by participants. One participant thought the clip art was 'very catchy' but others expressed minor concerns, for example, about the image of an old man sitting down which was thought to be irrelevant, and that some of the figurines detracted from the seriousness of the resource. Other concerns centred on the length and the clarity of some of the wording of the text. See summary of changes made from expert and patient feedback, detailed in table 6.

## **7.5 Summary**

The patient lay resource was constructed using a combination of the current literature and interview data collected in this study. In order to ensure the lay resource was clinically accurate and comprehensible to patient it was 'tested' by experts in the field and sub-sample of the participant themselves. Feedback from experts and patients were positive. A few constructive suggestions were made and they were incorporated in the final lay resource.

**Table 6 - Summary of Changes**

Title	Question 2	Question 4	Question 5	Question 6	Question 7	Question 8	General
'Heart artery disease' was replaced with 'Stable Heart disease'	'these symptoms must be a heart attack' was rephrased to 'these symptoms may represent a heart attack'	Added the recommendation that patients do not drive themselves to hospital if they have symptoms.	'Research shows that patients often have mild symptoms in the weeks leading up to heart attack (prodromal symptoms). If you seek help early it may be possible to prevent you from having a heart attack' was deleted	'However, if you don't go to the GP your symptoms could get worse. There is even the possibility that your heart symptoms could turn into heart attack' was deleted	Figure of old man sitting was replaced with another figure with man of middle age.	Clarification was added between 'NHS choices' versus 'NHS walk-in clinics'	Figures used replaced by new 'licence to reproduce' figures
'stable' was deleted and the term 'heart disease symptoms' was used	Waiting time after first spray of GTN reduced from 10 to 5 minutes		Question was re-worded from 'I don't want to bother the doctor' to 'I don't want to waste the doctor's time'	Figure of a smiling man was replaced by a figure with a more serious expression.			Grammatical corrections be made throughout the leaflet
	'It is important to check and see if these symptoms are heart artery disease related so they can be managed' was deleted as it was redundant.			'If you get help early, your recovery time is reduced, and you can get back to your daily activities faster' was replaced with 'The sooner you get help and treatment the sooner you can get back to your daily activities'.			

## Chapter 8. Discussion

This study explored the help-seeking experiences of both men and women referred to a rapid access chest pain clinic (RACPC) for assessment of symptoms thought by GPs to be potentially CHD-related. At the RACPC, participants are evaluated (e.g. clinical history, physical examination, cardiac testing) to see if their symptoms warrant further intervention such as a coronary angiogram<sup>10</sup>. Indeed, the vast majority of participants in this study were found not to have CHD-related symptoms at the end of the RACPC evaluation. However, all were professionally assessed to be at potential risk of CHD by their GP. This novel study of a previously unexplored area makes a contribution to the literature and clinical practice by offering insight into men and women's experiences of help-seeking for concerning symptoms and accessing a RACPC. This includes what influencing factors played a role and led participants to consider CHD as possible cause for their symptoms, how participants responded to their symptoms (e.g. self-medicating), what symptoms participants thought were worthy of going to see their GP, the complex combination of symptoms, risk factors and personal belief that GPs took into account when deciding to refer to the RACPC, how contextual factors influenced them to seek help, and their understanding of their own CHD risks. Most notably:

- Attribution of symptoms had multiple influences (e.g. coronary candidacy, the influence of others, previous own experience of CHD, and sometimes media campaigns)

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<sup>10</sup> Coronary angiogram is invasive technique where contrast dye is injected to image the coronary arteries to look for blockages. It is considered the gold standard for the diagnosis of coronary artery disease. Due to the risk associated with an invasive cardiac procedure it is generally when the patient history, CHD risk factors and other non-invasive test are suggestive of potential CHD.

- Response to symptoms contributed to delay (e.g. dismissing symptoms, self-managing symptoms or self-medicating)
- Contextual factors were important influences on help-seeking (e.g. influence of the others, severity, own beliefs, previous CHD experiences)
- Participants referred to the RACPC had a complex combination of symptoms with varying severity and aetiologies. GPs appeared to consider the totality of these factors when making a referral to the RACPC
- The male-lifestyle was considered to be more risky than the female lifestyle for CHD
- Additionally, many of the challenges in symptom attribution, help-seeking practices, and understanding of CHD risks which are widely reported in emergency situations (e.g. heart attacks), are similar in the RACPC context.

The study also explored the beliefs around the risk of CHD and the extent it impacted on whether or not CHD was considered a possible cause. The key findings of the study are outlined below.

Firstly, attribution of symptoms had multiple influences. The majority of participants ultimately considered CHD as potential cause for the symptoms before consulting their GP. However, it was not always their initial symptom attribution. Depending on their age, some participants thought their symptoms were age-related or fitness-related. While others linked them to pre-existing conditions or other conditions that could be self-managed. Participants did eventually 're-consider' symptoms to be potentially CHD, based on multiple influences including to what extent they believed they were a coronary candidate, the influence of others, previous own experience of CHD, and sometimes media campaigns.

Secondly, response to symptoms sometimes contributed to delay in help-seeking for symptoms. Although most participants eventually did consider CHD as a possible cause for symptoms, their first response to symptoms was rarely help-seeking. Participants often initially dismissed or normalised their symptoms to non-medical



(explainable) events or known pre-existing conditions. They also often opted to attempt to self-manage their symptoms in the first instance (e.g. self-medicate or changes to lifestyle). It was only when their symptoms failed to improve that they decided to seek help from the GPs and were ultimately referred to the RACPC.

Participants referred to the RACPC had a complex combination of symptoms. Participants also gave the impression that their GP took into account the complexity of their symptoms, risk factors and pre-existing conditions, and their own beliefs about the cause of symptoms in totality when make a decision to refer to the RACPC. Indeed, participants with convincing symptoms, multiple risk factors and comorbidities were immediately referred to the RACPC. However, other participants with a less clear presentation had to make multiple visits to their GP to get a referral. Making multiple visits sometimes led participants to feeling frustrated and distressed because they felt dismissed despite being in pain.

Participants also talked about how other people, severity of symptoms and media campaigns acted as enablers of help-seeking for their symptoms. However, participants also talked about how the difficulties in accessing GP services and finding time to go to the doctor (especially if participants were full-time employed), and how these factors acted as barriers to help-seeking. A few male participants additionally talked about not wanting to appear weak to others by acknowledging health problems and wanted to 'man out' symptoms.

The study participants had mixed responses to their negative diagnosis of CHD from the chest pain clinic assessment – most participants did not actually have CHD, as is often the case with patients who visit the clinic. Some younger working male

participants often said they were dissatisfied and frustrated, as they had no clear answer as to what caused their symptoms. A few female participants felt like a 'fraud' for wasting NHS resources. However, other participants expressed delight and relief that their symptoms were not CHD-related.

Most, but not all, participants believed that the 'male lifestyle' was high risk for CHD, and as a result, men were at higher risk than women. Others believed social changes meant that many women were leading a more 'male lifestyle', like smoking, drinking and having to work full-time while raising a family. Therefore, risks in women were considered to be on the increase. Finally, gender was only one of a range of factors that influenced help-seeking by participants in this study. While some participants did appear to be doing gender appropriately to their gender (e.g. "manning out symptoms" and "focusing on housekeeping duties") it was by no means straightforward, and it was not always the case in this study that men and women conformed to expected male and female presentations. For example, some female participants expressed stoicism while a few male participants talked of being afraid of the medical environment. The strongest gender finding in the current research was that the majority of participants believed that men's were at greater risk of CHD than men.

Several findings from this current study were used to inform the development of a lay patient resource to improve symptom interpretation and encourage early help-seeking. The resource makes a contribution to clinical practice by translating research findings from this study into a novel patient information resource to improve the understanding of symptoms, what to do when people get symptoms, and how to

access help. It is planned that the leaflet will be distributed for use in GP practices and cardiology departments.

### **8.1 Attribution of symptoms had multiple influences**

The attribution of symptoms by participants in this study can be broken down into two phases: firstly, whether or not a new physical sensation was regarded as a potentially concerning medical symptom and secondly, whether or not that medical symptom was attributed to CHD. On the whole participants tended to regard 'new' and 'troublesome' physical sensations as warning signs of a potential underlying medical problem. Physical sensations did not necessarily have to be severe or painful to be regarded as a symptom, although they often were. Indeed, in some cases participants described their symptoms as abnormal or unrecognised. Overall, it was possible to group the description of symptoms by participants in this study into four main categories: pain, discomfort, abnormal symptoms and unrecognised symptoms. This is broadly in line with previous research on interpreting symptoms for range of health conditions: patient symptoms could often be categorised as painful, discomfort or unknown (Kolk et al., 2003, van Wijk and Kolk, 1997). These studies also found that patients tended to view new physical sensations as potential medical symptoms. However, participants in this study did not always initially interpreted new physical sensations if they only cause mild discomfort. Often these participants tolerated mild symptoms for long periods of time before attaching any medical meaning to them. Indeed, some participants in this study who had experienced mild symptoms initially normalised new physical sensations as the aches and pains that come with older age, while others normalised new physical sensations as a lack of fitness, or having a psychosomatic component (normalising

symptoms are discussed further in Section 8.4). This is consistent with previous research in the emergency CHD context and other general health conditions which highlight patients' potential to normalise symptoms in the first instance especially if they are not severe. However, believing symptoms might be psychosomatic was not highlighted in these studies (Gyberg et al., 2015, Albarran et al., 2007, Kolk et al., 2003, van Wijk and Kolk, 1997). These studies also found that whether or not a physical sensation is interpreted as a medical symptom depends on the context: previous health experiences and knowledge of health issues, beliefs about own health and risks, location of symptoms, and other social factors including the advice of others. The current research also found that certain 'contexts' could interplay with new physical sensations to cause greater concern for participants than if the new sensations had occurred in isolation. For example, a few participants talked about how 'being alone', 'having no other adult in the house' or 'the worry that if they collapsed or something their ill partner would find them', led them to be more concerned about their symptoms than they otherwise would have been (contextual factors and symptom attribution are discussed further below).

Although some participants initially had difficulty interpreting of symptoms (e.g. mild symptoms, pre-existing conditions), most participants went on to consider CHD as a potential cause before consulting their GP. Participants used a combination of contextual factors to reach this decision. The location of symptoms (chest region), coronary candidacy, previous experience of CHD and sometimes media health campaigns or other portrayals of CHD, all played a role in whether or not participants considered their symptoms to be of a CHD origin or not. In this study, coronary candidacy, in particular, played an important role in how symptoms were attributed.

The more participants believed they were a potential coronary candidate and thus high risk for CHD (through own behaviours or family history), the more they were likely to consider CHD as a cause of their symptoms. It is salient to highlight here the belief that they might be a coronary candidate may have come from information provided to them by others (e.g. GPs, family and friends and media). Other CHD research has also found that 'coronary candidacy' is strongly associated with symptoms being attributed to potential CHD and that it promoted early help-seeking (Emslie, 2005, Lockyer, 2005).

Participants in the study also had a tendency to compare their symptoms to what they believed CHD symptoms should feel like. This was based on what they had heard about CHD symptoms from friends or family who had previous CHD experiences, as well as what they had seen in the media. Indeed, some participants did not initially consider symptoms to be potential CHD because they did not follow their expectations of what CHD might be like. This included a few participants who did ultimately receive a CHD diagnosis. These participants had expected to be in extreme pain and clutching their chest whilst collapsing to the floor in agony when having CHD symptoms, as seen on TV and at the movies. Thus, the milder symptoms which can occur in stable or non-emergency CHD symptoms (i.e. not having a heart attack) were overlooked by these participants. Previous research of CHD in the emergency context has highlighted how men and women can be confused by symptoms when they do not follow the traditional popularised 'Hollywood heart attack' scenario (Kirchberger et al., 2012, Nouredine et al., 2008, Albarran et al., 2007, Zerwic et al., 2003). However, it was not always the case that participants in the current study were confused by the media. Some participants

spoke of how they were motivated to seek help as result of media campaigns. Indeed, some other studies have also found the media to be very helpful in assisting men and women to recognise symptoms for CHD and other conditions (Turris and Finamore, 2008, Foster and Mallik, 1998). This highlights the conflicting opinions and complexity in this area. Despite these diverging opinions, the use of patient information leaflets to improve symptom recognition is widely advocated in health promotion and by NHS Identity organisation which issue guidelines for the creation of leaflets (BHF, 2016, NHS Identity, 2016).

It is important to highlight that there was a lot of complexity around identifying potential causes of chest pain and chest discomforts in this study, not only for the participants, but also for the GPs that refer to the RACPC. This is illustrated by the fact that most participants eventually thought their symptoms were potentially CHD, and they were all judged by their GP to be at sufficient risk of CHD (based on symptoms and CHD risk profile) to warrant specialist investigation. Ultimately, the vast majority of participants were found not to have CHD-related symptoms by the RACPC. However, it is relevant to highlight here that is known that some GPs may refer patients even if they did not feel it is warranted as a means to reassure them (Marks et al., 2014). Despite this, given the potential for these kinds of symptoms (i.e. chest pain, chest discomfort, palpitations, breathlessness with nausea etc.) to progress to a lethal cardiovascular event (e.g. fatal heart attack or cardiac arrest), it is essential that patients recognise them as warning signs of CHD and seek help

urgently. These types of symptoms can sometimes be prodromal<sup>11</sup> symptoms which precede and are associated with a future acute CHD event (i.e. heart attack). It is known for prodromal symptoms to occur up to four weeks before an actual heart attack (Noureddine et al., 2008, Albarran et al., 2007). Other studies have also shown early interpretation, attribution and intervention can reduce or eliminate acute dangerous CHD events (Maas et al., 2011, Mikhail, 2006).

Additionally, some participants in this study reported having underlying conditions ranging from low cortisol disease, thyroid disease, obstructive airway disease and asthma. Many of these conditions could produce symptoms similar to mild non-emergency CHD symptoms such as chest pain, palpitations and breathlessness. This may account, in part, for why some participants in this study initially had difficulty establishing a potential cause of their symptoms. However, as stated earlier, many of these participants did eventually go on to consider CHD as possible cause, if their symptoms persisted or worsened, and sought medical help as a result.

## **8.2 Participants' response to symptoms**

Participants' initial responses to symptoms in this study sometimes contributed to help-seeking delay. Responses included normalising or dismissing symptoms, or attempts to self-manage symptoms. Sometimes a reluctance to seek health professionals' advice also discouraged early help-seeking. Participants reported a range of help-seeking delays, sometimes for a few days, in other cases it was weeks and even months. In this current study, a shorter delay tended to be reported among

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<sup>11</sup> Early symptoms that indicates the start of a disease before a specific serious diseases event occurs.

white, younger male participants, and those in higher income professional occupations (e.g. senior manager). Among female participants, longer delays tended to be reported by older participants of Asian heritage and in lower income occupations. Here, it is recognised that a number of other factors interplay to influence help-seeking including the role of family and friends, previous history of disease and personal beliefs. However, it is salient to highlight this interplay with gender, age, ethnicity and socio-economics and other CHD studies have produced similar findings (Benziger et al., 2011, Adamson et al., 2008).

Participants in this study had a different range of symptoms with different aetiologies and degrees of severity. Participants often initially dismissed or normalised symptoms to explainable events not requiring medical treatment. Some participants (especially if they were younger) normalised troublesome 'physical sensations' as conditions that they could self-manage, for example, lack of fitness, indigestion or psychosomatic issues. Their initial symptoms did not meet their own criteria for them to be considered a medical problem, and thus there was little justification to seek help at that stage. It was only when their 'physical sensations' progressed or continued for a substantial period of time that they re-evaluated their initial interpretation. Other research in men and women and help-seeking for symptoms for a range of conditions had broadly similar findings (mental health and minor ailments) including CHD has had similar finding (Emslie, 2005, Lockyer, 2005, O'Brien et al., 2005). Men and women are motivated to normalise symptoms to indigestion, lack of exercise, or fitness or sometimes stress-related discomfort. Other studies focusing on men suggest that men try to normalise their pain and they often adopt the view that if they are not incapacitated there cannot be anything wrong (White and



Johnson, 2000). Along a similar vein, CHD research suggests that men do not necessarily consider symptoms important if they are not severe enough, and therefore often take no immediate action initially, preferring to see if the symptoms progress or pass (Emslie and Hunt, 2009, O'Brien et al., 2005). Similarly studies focussed on women in the CHD context find that women sometimes self-diagnose, normalise or dismiss symptoms as harmless issues including, sore muscles or stress, which hindered their help-seeking (Gyberg et al., 2015, Schoenberg et al., 2003). However, age also played a role in the normalising or dismissing symptoms by some participants in this study. For example, several older participants associated their symptoms with the aging process and as a result they dismissed or normalised them. Normalising symptoms to non-pathological processes (notably age-related pains) is commonly reported in previous research on many health conditions including CHD. These studies often highlighted how older men and women can initially dismiss symptoms as part of getting older. However, if their symptoms are severe, continue for period time or worsen then they would go on to seek help (Gyberg et al., 2015, Albarran et al., 2007, Lockyer, 2005, O'Brien et al., 2005, White and Johnson, 2000). Indeed, another large UK study which studied over 600 older people and musculoskeletal-related (MSK) symptoms found older people tend to dismiss or normalise MSK-related symptoms as age-related "wear and tear" especially if they considered themselves to be otherwise healthy (Grime et al., 2010). However, the study also reported that this was not always the case, especially if symptoms had new sudden onset that was severe. In these cases older people were likely to seek help early. The studies discussed above highlights the complexity of symptom interpretation among older patients, particularly when they have milder (potentially pathological) symptoms which are difficult to distinguish from normal age-

related pain. Additionally, several other participants in this study who had other long-term non-cardiac health conditions (e.g. low cortisol condition, mastodynia, or asthma), often attributed symptoms to these conditions if they were mild, and thus they did not feel they required medical assistance and delayed seeking help from their GP. Previous research in CHD and the cancer contexts also found that symptoms were often attributed to harmless causes or other less serious or existing health complaints if they were mild and non-specific (Gyberg et al., 2015, de Nooijer et al., 2001).

Most participants attempted to self-manage symptoms on their own in the first instance, which sometimes contributed to delay in help-seeking. Although there was often difficulty attributing symptoms initially, most participants in this study went on to consider CHD as a possible cause. Even after CHD was considered to be a likely cause they did not always seek external help as a first line strategy to manage their symptoms. The four most common responses to symptoms in the current study were waiting for symptoms to pass, ignoring symptoms, self-managing symptoms (e.g. self-medication) and information-seeking. Changes to diet and exercise were another first-line approach used by a few participants in this study, especially if they were younger. Research covering a range of cardiac health conditions including chest pain and heart failure in the emergency context has produced broadly similar findings: women and men prefer to self-manage symptoms which sometimes contributed to help-seeking delay (Baxter and Allmark, 2013, Moser et al., 2005, Zerwic et al., 2003, Bennett et al., 2000). Studies focused on women found that they used a range of self-help strategies, including 'watch and wait' as the first line response as they were afraid of being embarrassed by wrongly raising the alarm

(Nguyen et al., 2010, Moser et al., 2005). Often the use of these strategies in women contributed to a delay in help-seeking (Nguyen et al., 2010). Previous research focused on men found that they often ignored symptoms to avoid accessing health services (Galdas et al., 2005). Men believed that physical symptoms would eventually go away on their own, and seeking professional help was not the obvious first choice. It was also noted in the current study that a few participants of Asian heritage talked at length about the use of natural and herbal remedies to purify their system to improve their general health and self-manage their symptoms before seeking professional help. It is salient to highlight here that there were only a few ethnic minority participants in the study, however, other research into self-treatment in the ethnic elderly found similar results (Najm, 2003). Patients of Asian heritage had a preference for self-treating their conditions with herbal and natural remedies. A later US study looking at complementary therapies in adults across the broad spectrum of American ethnicities also reported preference for alternative therapies in those of Asian of heritage to manage conditions (Barnes et al., 2004).

Another contributor to delay was that many participants claimed to be reluctant to consult with health professionals. Being a burden on medical services by wasting the doctor's time was a concern for participants in general. Many participants in this study said that the doctor's time was a precious resource and it should not be wasted with triviality. As a result, they would often wait to see if their symptoms would pass on their own, in the hope that it would negate the need for medical assistance. These findings are similar to other research on CHD based in the emergency context which found that patients were worried they might be seen as a nuisance, wasting the doctor's time or falsely calling emergency services (Emslie,

2005, Turris and Finamore, 2008). Other strategies used by some participants, especially those in higher professional occupations (e.g. accountants or lawyers), included making the doctor's life easier by storing up health complaints to present to the doctor in one visit, taking time beforehand to prepare for the consultation to give the doctor a clear concise picture or choosing to focus on their primary complaint at the time and not raising any secondary symptoms or concerns they may have. Indeed, one participant talked about not always mentioning all her symptoms to the doctor and remarked 'doctors don't like you to bother them with too many things at once'. Sometimes these strategies contributed to help-seeking amongst these participants in this study. Adopting strategies to avoid wasting doctors time is also found in other research studies covering a range of GP consultations (general, mental health, cancer), although they did not highlight some of the specific strategies used by participants in the current research, for example storing up health complaints to present in one visit (Robb et al., 2009, Pollock, 2002, Cromarty, 1996). These studies suggested that patients would monitor their doctor's behaviours and responses during in a consultation and adjust their own behaviour accordingly. If they formed a view the doctor was busy or dismissive they would self-impose time constraints by truncating their clinical history and/or not consulting for any secondary issues they might have. This impression sometimes affected future consultations where patients would think through their symptoms in advanced to be able to present them concisely to get the best out their consultation or delay seeking help for fear of bothering their busy doctors with unimportant issues.

Other participants, more often male, were happy to seek help as long as they felt justified, especially if they had put with symptoms for a period of time or attempted

self-management strategies first. However, this was not always the case. Some participants did seek treatment immediately if the pain was strong or they had a previous experience of CHD. Other research has found similar results where men and women sought help quickly if symptoms were severe, continued for long period, if they believed they were at risk of CHD or they had had a previous experience of CHD (Galdas et al., 2010, Nguyen et al., 2010, O'Brien et al., 2005, Foster and Mallik, 1998).

Overall, it is plausible that the beliefs about CHD risk, severity of symptoms and previous experience of a CHD event, as well as cultural beliefs all interplayed to produce the variety of responses to symptoms demonstrated by the participants. These responses to symptoms sometimes contributed to participants delaying seeing their GP. Despite most participants considering CHD as possible cause of their symptoms they did not always consult a GP in a timely manner. They either dismissed or normalised symptoms to unexplainable events (fitness or older age) or sometimes to other conditions. They also adopted self-help strategies to manage symptoms on their own. All of these factors contributed to a delay in help-seeking until participants believed they needed medical assistance and would not be seen as wasting the doctor's time.

### **8.3 Referrals to the RACPC arise from a complex combination of symptoms**

There was a complex case mix of referrals to the RACPC included in this study. Participants presented with a wide range of symptoms and degrees of severity, frequency and duration. For example, some participants reported intense and painful symptoms which occurred daily or were constant. Other participants had milder symptoms and reported them as discomfort or unnerving symptoms which tended to

reoccur episodically and at irregular intervals. A few other participants had symptoms triggered by physical activity, which is important as typically stable CHD (non-emergency) presents as episodes of chest pain often triggered by physical activity and relieved by periods of by rest (BHF, 2016). Additionally, some participants also presented with symptoms occurring simultaneously with other long-term health conditions including depression, chronic bronchitis, asthma, and obesity, all adding further complexity. It is salient to highlight at this point that the RACPC where the study was conducted has liberal criteria for accepting/rejecting referrals into the clinic. Another RACPC which applied stricter referral criteria may have rejected some of the referrals seen in this clinic, and therefore would have a less complex case mix of patients. Indeed, most non-medically-led RACPCs do operate stringent triaging referrals to restrict referrals to simple cases of potential CHD symptoms. Patient referrals with a more complex combination of symptoms are re-directed to medical clinics. The RACPC where the study was conducted is a cardiac physiologist-managed service which runs in tandem with a consultant cardiologist medical clinic, allowing them to manage a broader case mix and therefore such stringent triaging is not required – chest pain practitioners have immediate access to a cardiologist for advice.

It is also important to note that several participants gave the impression that their GPs appeared to take into account their complex clinical histories, pre-existing conditions as well as the presenting complaint when making a decision to refer them to the RACPC. They were also sensitive to patients' own beliefs (e.g. if they considered their symptoms to be CHD). However, GPs are known to filter out patients if their clinical history, presenting symptoms and risk factors are not deemed

worthy of a referral to the RACPC. The time taken for GPs to refer a participant to the RACPC appeared to vary. In some cases, participants were referred immediately if their symptoms, risk factors and comorbidities were judged by the GP to warrant it. In other cases where participants presented with milder symptoms and had lower risk factors, multiple visits to the GP were needed before a referral was made. The need to make multiple visits was a source of distress for some participants, as they felt dismissed or had no clear explanation for their pain. These findings are in line with other research in two other RACPCs which also had a complex combination of chest pain-related symptoms in terms of frequency, duration and severity (Marks et al., 2014, Dumville et al., 2007). Both these studies found patients were often managed in primary care for a period of time, if their GPs were not sufficiently convinced their symptoms had a possible CHD cause. These patients would need to make multiple visits before they were referred to the RACPC to 'rule out' CHD and re-assure. The need to make multiple visits to GPs prior to being referred was a source anxiety for these patients. Additionally, Robertson also found that patients experience psychological distress by the mere fact that there was a need to be referred to the RACPC for potential heart problems (Robertson et al., 2008). This distress can persist even after a negative diagnosis (no heart problems detected), especially if the underlying cause is not established, and can negatively affect a patient's help-seeking practices in the future as they feel dismissed (see 8.5 *Participants' mixed responses to negative diagnosis*).

#### **8.4 Contextual factors acted as enablers and barriers to help-seeking**

The influence of others was a strong enabler of help-seeking. There was a link between informal help-seeking (speaking with other people) and formal help-seeking

(consulting a doctor) for participants in this study. Many participants would discuss symptoms with others including friends, colleagues or family, especially a partner in the first instance, and in most cases this input would encourage seeking medical help. Previous research for a range of health conditions including CHD, mental health issues, and minor ailments also highlights the important role of others in encouraging help-seeking practices (Farrimond, 2012, Emslie, 2005, Lockyer, 2005, Moser et al., 2005, Foster and Mallik, 1998, O'Brien et al., 2005). However, speaking to friends and family did not always promote professional help-seeking; there were a few cases where participant help-seeking was hindered by consulting others because their partners thought they were over-reacting. Other research has also suggested that seeking help from others can sometimes encourage delays in help-seeking for potential CHD, as significant others minimise symptoms or re-assure (Emslie, 2005). This highlights that although there was often an association between informal help-seeking and early formal help-seeking found in the current study, as well as in the literature, it is not always straightforward. The relationship dynamics between help-seeker and help-giver can interplay to produce different influences depending on whether either party is inclined to be stoical or view the other party as over-anxious.

Although many participants in the current study claimed to be reluctant to seek help from friends and family, they often did, but they were less likely to seek help from dependent family members. Where participants had ill partners, or they were the only surviving parent or had a dependent child, they were more likely to speak to friends, colleagues or other family members. As with previous help-seeking research including CHD and the cancer context, men and women seek advice from family



members, friends and colleagues, depending on their individual circumstances. However, they avoid being a burden on family members especially if they are ill or dependent (Emslie, 2005, de Nooijer et al., 2001). Another study focused on women illustrated how one woman endured chest pain all night as she did not want to wake her husband, who was also ill (Lockyer, 2005). However, speaking to other people often enabled participants to see the significance of symptoms which led to CHD being considered as a potential cause. This was particularly strong in cases where participants had friends or family members with a medical background. These participants would be made aware by these friends and family of the possible dangers of CHD symptoms and the need to seek immediate professional help (Emslie and Hunt, 2009, Lockyer, 2005).

A few male participants said that they would only talk about health concerns with partners and sometimes close family members. This is consistent with previous research on CHD and other health conditions which suggested that men seek help from their wives who encouraged them to seek medical help and rarely from other friends (Emslie and Hunt, 2009, Emslie, 2005, White and Johnson, 2000, O'Brien et al., 2005). Indeed, a more recent study found that older married men often create health unions with their partners and they encourage each other to seek help (Farrimond, 2012). In a similar vein a few male participants spoke about the steps they took to conceal their health status from their partners, family and friends. One participant expressed concern that other people would think he was a 'weak' and 'unhealthy man'. Another participant talked about how his wife worried about his mental health; he had no plans to speak about his symptoms or visit the RACPC unless he had to. Other research into men and a range of health complaints also

suggested that men conceal health issues so as not to appear weak to colleagues or friends (O'Brien et al., 2007, Courtenay, 2000, White and Johnson, 2000). However, not all male participants in the current research restricted help-seeking to partners: one male participant of Asian heritage talked about his health conditions with his whole family who persuaded him to tell his employer, which he did. This fits with other research which suggests that there is a difference between westernised and non-westernised perspectives when it comes to help-seeking. Some men of Asian heritage in particular view seeking help for health conditions as an essential step to maintain good health and well-being vital to their ability to provide for their families (Galdas et al., 2007). Social isolation was a factor for some male participants, and a few female participants who had been born abroad. These participants frequently did not have friends or locally-based family to talk to about their health issues. The findings for male participants aligns with the literature showing that men are generally more isolated than women (Stephoe et al., 2013, Vandervoort, 2000).

Many participants also described severity of symptoms as enablers for them. Severity of symptoms in this study was defined as the degree of discomfort, including frequency or duration of symptoms. Some participants talked about their symptoms as 'painful', 'severe', and 'worsening' which enabled them to seek help. Other participants talked about milder and 'ongoing' symptoms that persisted for several weeks or months. It was the continuation of symptoms rather than the degree of discomfort that acted as an enabler. In other cases participants were prompted to get help when symptoms started to interfere with their ability to do daily tasks or work effectively. Previous CHD and help-seeking research also highlighted severity of symptoms as an enabler for help-seeking. Some of these studies

suggested severity of symptoms at onset, degree of discomfort and symptom progression (worsening) enables help-seeking (Nguyen et al., 2010, Emslie, 2005, Foster and Mallik, 1998). However, other CHD research has suggested that severity of symptoms is only one factor that can interplay with a range of contextual factors including the location of the patient when symptoms occur and the other people around to enable help-seeking (Galdas et al., 2010). Additionally, Zerwic noted that a similarity (or lack of similarity) between experienced symptoms and the expectation of what symptoms should feel like also impacted on help-seeking (Zerwic et al., 2003). Research focused on men and masculinity for a range of health conditions highlighted the significance of temporality of symptoms as an enabler in men. Such research suggests that there is a need for men to put up with a degree of discomfort before considering the need to take action (Galdas et al., 2010, Noone and Stephens, 2008, O'Brien et al., 2007, Emslie, 2005, Addis and Mahalik, 2003).

A few participants reported being enabled by media campaigns. They had either seen an official health message published or broadcast in the media, or something they had observed in the popular media (TV programmes) that had prompted them to seek help faster. Indeed, this was true of one of the few participants in the study who was diagnosed with CHD. However, in contrast, a few other participants in the study were confused by media depictions and therefore not encouraged to seek help. This inconsistency is also present in the literature where the effectiveness of media campaigns to improve health knowledge and enable help-seeking is disputed. Some studies suggested that media campaigns were often unhelpful and confused patients when their symptoms did not follow a traditional pathway; that is, the symptoms did not represent a 'Hollywood attack' situation (Baxter and Allmark, 2013,

Tullmann and Dracup, 2005, Zerwic et al., 2003). On the other hand other research argued that media campaigns and health information produce real benefits by improving patients' symptom recognition for CHD which enabled help-seeking and reduced delay (Turris and Finamore, 2008, Foster and Mallik, 1998).

Conversely, participants also encountered both internal and external factors that acted as barriers to seeking help. The main barrier for many participants in this study was the limited accessibility of GP services. The ability to get appointments within a reasonable timeframe was a particular issue. Waiting times of several weeks were not uncommon. Even urgent appointments were sometimes difficult to obtain, offered at inconvenient times, or involved cumbersome booking processes: for example, calling on the day, and if no appointments were available, then having to try again the next day or the day after until one was available. These issues were reported as preventing participants from making an appointment in the first place. Some older participants who suffered with comorbidities and who were carers for their ill partners also commented on the lack of availability of home visits. However, accessibility was not always an issue and a few participants spoke of the ease of getting timely appointments. This study confirmed the work of previous researchers in both the CHD emergency context and for other non-CHD health complaints which also found that long waiting times and inconvenient surgery times, and complex appointment procedures to access medical services can act as barriers for both men and women (Gyberg et al., 2015, Emslie, 2005, Schoenberg et al., 2003, Tod et al., 2001). However, these studies did not mentioned barriers created by a lack of home visits, which was found in the current research. More recent research specifically examining barriers in primary care for cancer symptoms also highlighted the difficulty

in making a timely appointment as one of the most important barriers to seeking help (Power and Wardle, 2015). Taking time off work, especially when this had a financial impact, was also an important barrier to help-seeking in this study. Several working participants, especially if they were self-employed, found appointment-making expensive (e.g. loss of earnings or loss of time). They were also concerned with being absent from work, particularly if it was a busy period. These findings are in line with other research with help-seeking for a range of health conditions which also highlighted that taking time off work for illness and indeed loss of earnings due to being ill as an important barrier to help-seeking (Emslie and Hunt, 2009, Nouredine et al., 2008, O'Brien et al., 2007, Courtenay, 2000 ).

A barrier for a few male participants in the current study was the concern that they may appear 'weak' or 'an unhealthy man' to others in their social networks. As a result, these male participants tended to 'man out' symptoms. They tolerated a sufficient level of pain/discomfort for a substantial period of time before feeling justified to seek help. Once these male participants had validated symptoms through pain and endurance they were happier to seek help. It is salient to highlight here that many male participants in this study talked about having mild symptoms e.g. 'It was not pain...it was heaviness', and it is plausible that if these participants had more severe symptoms they may have acted differently. Indeed, the few male participants that did have severe symptoms sought help quickly. However, 'manning out' symptoms are a not uncommon finding in research in men's health for CHD and other health complaints. Several studies have discussed the need for men to put up with an element of pain or discomfort for a substantial period of time, so as not to appear weak or effeminate in their social networks (Galdas et al., 2010, Noone and

Stephens, 2008, O'Brien et al., 2007, Emslie, 2005, Addis and Mahalik, 2003, White and Johnson, 2000).

### **8.5 Participants had mixed responses to their negative diagnosis of CHD from the RACPC**

Many participants were relieved or delighted by the outcome that their symptoms were not CHD-related. They were very glad to put this experience behind them and move on with their life. Indeed, many of them had already made positive changes to lifestyle to improve their health. However, some male and a few female participants had negative feelings when receiving a non-diagnosis of CHD from the chest pain clinic assessment. Some younger working male participants in the study expressed dissatisfaction and were left with feelings of frustration when they were told their symptoms were not CHD-related. Similarly, a few older female participants also admitted to having negative responses stating that they now felt 'like a fraud' and had wasted NHS resources when their symptoms were determined to be not CHD-related; this feeling confirmed the fears that had made them reluctant to seek help in the first place. A few other participants who received the all-clear from CHD, who had been undertaking risky behaviours including excess alcohol consumption and smoking, saw a non-CHD diagnosis as licence to continue as they had been doing and openly declared intent to do so. This has not previously been highlighted in the literature to date to the same extent. The findings in this study were broadly consistent with previous research for general health complaints where it was noted that dissatisfaction often occurs in men and women when they have symptoms that cannot be explained (Røysland et al., 2013, Jerlock et al., 2006, Jerlock et al., 2005, Nezu et al., 2001, Hartz et al., 2000). Studies which specifically looked at chest pain also found that frustration and anger were more common among patients when their

chest pain was unexplained by conventional clinical assessment (i.e. negative results from cardiac testing). Other studies also highlighted that women sometimes felt like frauds for consulting health professionals when their chest pain did not have a known cause (Albarran et al., 2007, Jerlock et al., 2006, Jerlock et al., 2005).

It was also evident from the frustration expressed by some participants in this study that the RACPC did not provide adequate support and reassurance for those receiving a non-cardiac chest pain (NCCP) diagnosis. In many cases these participants had often waited many months to seek help and they had an expectation of leaving the RACPC with a definitive answer. Additionally, some of them also had their symptoms investigated by other clinical pathways (e.g. neuro-muscular testing) and were exasperated that another set of clinical tests had produced no answers; and they felt that they were 'back to square one'. Other research in the RACPC environment highlighted that current protocols do not sufficiently provide adequate support for NCCP patients who often have physical limitations as a result of their symptoms and distress (Marks et al., 2014). However, this RACPC specific study did not uncover the degree of 'frustration' reported by some male participants in the current research at the end of their assessment. Marks and colleagues concluded that a multi-disciplinary approach should be introduced to RACPCs (e.g. access to psychological therapies) to provide a blended mix of biopsychosocial support for these patients. Other research conducted in Norway on chest pain, in a general context, found that patients did not feel reassured at the end of pathway when CHD was not determined to be the cause of chest pain and they were often unclear as to what to do next (Røysland et al., 2013). However, despite the issues around receiving a negative diagnosis raised by some participants, many others highlighted

their satisfaction at the efficiency of the clinic's pathway including timely appointments and having all their tests on the same day (see *appendix S for the RACPC pathway*). Other research into rapid access cardiac physiologist and nurse led-services in both RACPC and other contexts including syncope clinics also noted that the efficient way this model operates improves patient satisfaction (Mathieson et al., 2017, Sampson et al., 2010).

## **8.6 Lifestyle practices and Risk of CHD**

There was much debate amongst participants in this study about whether the male lifestyle or female lifestyle was inherently riskier for CHD. However, most participants believed men were at higher risk than women. Overall, these participants considered men's health to be generally worse than women's. Primarily they believed that the masculine stereotype is not concerned with self-care or looking after themselves in the physical sense to the same extent as women. They talked about men being more likely than women to undertake risky behaviours in terms of smoking, drinking and sometimes drug-taking. They also commented that men are less likely to go to the doctor's. The combination of these factors led them to believe there was an increased risk of CHD in men. Indeed, a few male participants in this study openly admitted to behaviours like excessive alcohol use, illicit drug use, smoking, unhealthy diet and promiscuity. The current study's findings were in line with other research into men and help-seeking for a range of health conditions including CHD which suggested that men are more likely than women to engage in risky activities (Emslie and Hunt, 2009, Addis and Mahalik, 2003). Other help-seeking studies have found that codes of masculinity restrict men's ability to take good care of themselves. 'Real' men are thus less concerned with health matters and do not fuss over



themselves because it is potentially feminising (O'Brien et al., 2007, Courtenay, 2000 ). Courtney argues that men would go to great lengths so as not to look weak in front of other men, including compromising their own health: 'a man with diabetes, unable to manoeuvre both his wheelchair and a cafeteria tray, would skip lunch and risk a diabetic coma' rather than ask for assistance (Courtenay, 2000 ). While a few male participants did express a desire not to look weak in front of their social networks, such behaviours (as outlined above) were not highlighted in the current research. Many participants also believed that work-related stress increased CHD in risk in men. They felt that men, unlike women, who often had part-time jobs, needed to work full-time, often in high pressured or manual jobs. A few male participants in this study, mostly those who worked in manual jobs, sometimes made reference to having to work long hours doing physically demanding work to earn a living and being the breadwinner, and its impact on their health. Previous research also highlighted increased risk of CHD associated with men working in manual jobs and earning lower income, and the pressure and stress of being the breadwinner (Emslie, 2005). Other research looking across the broad spectrum of health and social economic status in the UK has also suggested that men in lower income jobs generally have poorer health than those in professional jobs (Langford et al., 2009).

A few participants felt that the female lifestyle was inherently more stressful given how they had to 'juggle many more plates' than a man, therefore putting them at higher risk of CHD than men. Previous research has also acknowledged that there is stress and pressure associated with the female lifestyle (Gyberg et al., 2015, Turris and Finamore, 2008). Women also work like men and are also under other pressures, such as to maintain the appearance of being a 'good' wife or mother, a

homemaker, and to play an active role in their social networks (Gyberg et al., 2015, Turris and Finamore, 2008). A major European study into women and the risk of heart disease suggested that social and emotional stresses placed on women increased their risk of heart disease (Maas et al., 2011).

Other participants, both male and female, believed that CHD risk was independent of gender and it all came down to lifestyle behaviours. They held the view that although men were historically at higher risk as result of their lifestyles, nowadays women were catching up. They felt that many women these days behave like men and live a 'male lifestyle'. More women nowadays are working mothers, they smoke and drink alcohol, and so on. As a result of women adopting these 'male lifestyle' behaviours the risk of CHD in women was increasing. Therefore, they believed there was no difference in CHD between men and women. Previous research suggests that both men and women perceived their own lifestyles to be stressful. The studies also determined that these lifestyle behaviours were the main cause for their CHD risk (Emslie, 2005, van Tiel et al., 1998). However, other research examining CHD risk associated with the 'male lifestyle' or 'coronary prone behaviours' (smoking, alcohol intake, obesity, inactivity) dismissed the notion that these behaviours completely accounts for the increased risk in men (Barrett-Connor, 1997). The study cited wider factors playing a role in increasing CHD risks in men including family history of CHD, personality traits (affecting behaviours) and sex-linked genetic conditions or predispositions (e.g. high blood pressure and cholesterol). The study also highlighted protective role of female hormones against CHD, which may also account for the higher incidence of CHD in men under 60 years of age when compared with women of a similar age (Townsend et al., 2015, Barrett-Connor, 1997). These studies

demonstrate that while lifestyle and personal behaviours do have the potential to increase CHD risks, there are other non-lifestyle factors that also come into play.

Despite the debate by participants in this study on the riskiness and stressfulness of male lifestyle versus female lifestyle, many of them, regardless of gender, took immediate steps to reduce their own CHD risk in response to a RACPC referral. Some participants stopped undertaking their previous high risk behaviours including smoking, drinking alcohol or drug-taking, while other participants in the current study had started to take steps to improve their exercise regime and modified their diet. However, not all participants took steps to improve health. Some found ways to justify their risky choices. For example, a few participants who had smoked or drunk excessively received the all-clear in the RACPC; they then felt this had given them licence to continue as they had done previously. Other research conducted in Canada has also produced mixed findings on whether or not men and women took steps to change their behaviours when presented with the idea they might be at risk of CHD (Angus et al., 2005). The study held a series of patient focus groups to evaluate 'who' and 'what' led to behaviour modifications to reduce CHD risk in both men and women. In some cases, acknowledging one was at personal risk as a result of one's own risky behaviours (diet, weight, smoking, and alcohol consumption) led to changes in personal habits to reduce risk. In other cases, participants wanted to see evidence of CHD risk, and they waited for the 'big event' (having a heart attack or similar) to be convinced of the need to change. However, even in cases where men or women experienced a 'big event', permanent changes did not always occur. Although the shock of a 'big event' often did prompt initial changes, over time the event was forgotten and participants tended to slip back into old ways. The

participants in the current study did not have a 'big event', but many still made changes to improve their lifestyle often before attending the RACPC, indicating that even a suspected risk of CHD is sufficient to prompt a change in behaviour in the short-term. The long-term monitoring of behavioural changes was outside the scope of this study. It is possible that some participants in this study who planned to continue unhealthy practices were perhaps waiting for their 'big event'. These findings are consistent with other research in so far as the possibility of CHD risk may produce short-term behaviour modifications in both men and women (Angus et al., 2005).

### **8.7 Doing gender**

Within the 'doing gender' framework, gender is thought to be performed, and we are held accountable for gendered performances (Section 2.3). However, West and Zimmerman recognised that 'accountability' can shift and the acceptable performance of gender for a particular sex can evolve over time as social and cultural norms change. Gender performance can also vary depending on circumstances (West and Zimmerman, 2009).

In the current study, hegemonic masculinity was not helpful in interpreting these results as male and female participants sometimes appeared performing gender appropriately for their sex in a given set of circumstances. For example, some men talked about the need to 'man out' symptoms for a period of time before seeking help. However, this was not always the case. Despite any gender performances, some men admitted their inner vulnerability and talked about being in a panic or afraid of their symptoms. Some sought help as a consequence. Female participants in the study also appeared to be doing gender, as they talked about prioritising care-

giving needs above their own. However, other female participants did not perform gender in this way and talked about being stoic and reliant. This highlights the complexity around gender performances and that doing gender is fluid.

It is as argued throughout this thesis that gender intersects with a number of factors including personal attitudes and networks (i.e. intersectionality). Indeed, some participants in the study raised the issue of changing social attitudes to gender. They believed that the historical view of men being unconcerned with health is out-dated, and men being resistant to seeking help was changing. They also believed that socially accepted norms of how women are expected to behave have evolved. They thought that increasingly women were adopting masculinised gender performances e.g. working full time, taking risks, smoking and drinking etc. In summary, they believed that how men and women were doing gender was evolving.

## **8.8 Intersectionality**

Intersectionality argues that people cannot be defined on a single dimension (e.g. gender) and that in order to completely understand participants, it is necessary to consider all the intersecting factors (social status, gender, ethnicity, personal beliefs and personal experiences) that contribute to their identity and social position (Griffith, 2012, Hankivsky, 2012). Intersectionality was a useful framework to understand the results of the current research, as how participants viewed their symptoms (and the need to seek-help) depended on varying intersecting factors including age, health status (fitness), beliefs about CHD risks, previous CHD experiences and pre-existing conditions. Sometimes intersecting factors would produce positive effects and participants would seek help early. For example, a participant who had painful symptoms drew similarities with his previous experience of CHD and that prompted

him to seek help early. In other cases intersecting factors did not necessarily promote help-seeking. For example, some younger participants who did not follow a healthy regime linked their symptoms to a lack of fitness and dismissed them, and therefore did not seek help immediately.

## **8.9 Implications for practice and recommendations**

This section begins by outlining the implications for practice that have emerged from this study. This is then followed by recommendations for future research and clinical practice.

### **8.9.1 Implications for practice**

There are three clinical practice implications emerging from this study's findings: (1) The participant's difficulty in attributing symptoms; (2) the role of media campaigns and information in interpreting symptoms, understanding of CHD risk factors and promoting help-seeking; and (3) the role of the RACPC in supporting patients who have a negative CHD diagnosis.

#### ***Interpreting symptoms and understanding risk***

Many participants who had mild chest pain or discomfort, symptoms which are suggestive of CHD, were initially not sure as to that was potential cause. This was particularly noticeable if they had a pre-existing condition or believe that they were otherwise healthy and a low of risk of illness. As a result they did not always act on their symptoms in the beginning choosing to self-management strategies (e.g. self-medicating or 'wait and see') as a first line approach. It is acknowledged that most patients in this study were found not to have potential CHD. However, it is still important that patients are able to identify the possible warning symptoms of CHD, mostly notably chest pain or discomfort, and seek help urgently. The risk of delaying

help-seeking for chest pain, if it does turn out to be CHD, can have life-threatening consequences. Patients failing to act on potentially lethal symptoms has important implications for primary care and RACPC practitioners.

It was also important that, in the current study, some female participants tended to believe their personal risk of CHD was low. It is acknowledged that this was not the view of all female participants, but it was the majority view. Male participants, on the whole, believed that their personal risk of CHD was high. This has implications for practice, as being aware of the one's personal risk plays an important role in how symptoms are likely to be interpreted and subsequent help-seeking.

Therefore, it is essential that education in primary care and specialist centres continues to highlight how the symptoms of stable CHD might present (e.g. mild chest pain, discomforts and sometimes nausea), and to encourage early help-seeking. Furthermore, it is important that patient information literature moves away from the Hollywood style attack which is known to confuse patients (Emslie, 2005, Lockyer, 2005). Stable CHD symptoms rarely present in this dramatic way (BHF, 2016). This study addresses this clinical practice implication amongst others as its output: the development of a lay patient resource to improve symptom interpretation, awareness of CHD risk as well as prompt help-seeking practices, and awareness of the variety of sources of medical assistance available.

### ***Improving health professionals' diagnostic ability for CHD***

This study also raises the question of whether or not health professionals (nurses, cardiac physiologists, cardiologists and GPs) also need further education on the risks of CHD in men and women. It was clear in this study that even GPs face a challenge when establishing a differential diagnosis of mild chest pain, given the high

number of referrals resulting in non-chest pain outcomes. It is acknowledged that this study was too small to make a definitive conclusion of primary care referrals and only wishes to highlight this anomaly. It would be reasonable to suggest that further exploration this area is undertaken.

### ***Role of the media and patient education***

The use of media campaigns has important implications for practice for health professionals. It was evident in this study that popular media, media health campaigns, and patient health information literature can be helpful, but can also hinder symptom interpretation and help-seeking. Patients are sometimes confused by media depictions of CHD, especially if their own experience does not fit the general depiction. This is particularly problematic in popular media and its portrayal of a dramatic Hollywood style heart attack (Emslie, 2005, Zerwic et al., 2003). Whilst not much can be done to control the popular media, official health campaigns and patient health information literature can be used to educate patients that this scenario is not always that case. Indeed, it is rarely the case in stable CHD. Properly framed media information can be helpful tools to help patients interpret their symptoms and promote early help-seeking. Indeed, some participants in this study were enabled to act on their symptoms as a result of media interventions; one of these participants was deemed to have CHD symptoms and was referred for intervention. Very few health information leaflets on stable CHD specifically address the issues of the 'Hollywood heart attack', and it is often an over-dramatic depiction in these circumstances. The patient lay resource which was produced as part of this professional doctorate addresses this issue by aiming to promote patients' awareness of all potential CHD symptom manifestations.



### ***Responding to a negative diagnosis of CHD***

The impact of a 'negative diagnosis' (symptoms being determined as not likely to be CHD-related) on many participants in this study has implications for practice for RACPCs. Many male participants in this study expressed frustration at not having a resolution or explanation of their symptoms. They had been through a battery of clinical tests and were still at square one. Their only option was to go back to the GP and start the process again down another pathway. It is acknowledged that this is how a public health system operates: if a patient receives a 'negative diagnosis' from a speciality clinic, they are referred back to the GP, who co-ordinates their care for further referral and investigations. However, given the level of patient dissatisfaction this produces, the RACPC could consider providing additional support to these patients. For example, a patient leaflet could outline the next steps, and make some suggestions as to what patients can do to help themselves. The creation of such leaflet would need further inquiry on how best to construct it and that falls outside the scope of this study. Additionally, a few women in the study who also received a negative diagnosis stated they felt a fraud for wasting NHS resources. It is important these women are not discouraged from seeking help in the future and they should be reassured that they made the right decision to seek help. How to feedback to patients in this situation could be included in RACPC protocols to ensure that practitioners approach this correctly and that the patient does not feel dismissed. Further inquiry on how to manage this process is needed but it falls outside of the scope of this study.

### **8.10 Study recommendations**

As a result of the implications for practice discussed above, this study makes the following three recommendations:

- Further work to be undertaken to raise awareness of chest pain in both women and men
- Further work to be undertaken to improve access to CHD health services for ethnic minorities, as there was some evidence in the study that these groups had difficulty accessing help
- RACPCs to provide more support and advice for patients who received a diagnosis of non-cardiac chest pain (negative diagnosis).

### **8.11 Critical reflections**

While every effort was made in this study's methodical approach to ensure its scientific rigour and steps were made to address potential shortcomings throughout the study, a few limitations are present which are important to reflect on critically. Some of these potential limitations are connected to researcher influence, which may impact on the approach of the researcher and thus may have affected the results. In order to ensure that qualitative research is accepted as credible, it is essential to be reflexive (Patton, 2002). Researcher reflexivity is discussed in detail early in Chapter 3, but the specific areas with regard to potential study limitations are outlined below. There are other limitations in this study which are also discussed. Broadly, these limitations can be grouped into two main areas: sampling and data gathering.

#### **8.11.1 Sampling**

The study took care to recruit by purposive sampling to achieve maximum variation in terms of gender, age and ethnic minorities, including over-enrolment. While a range of dimensions was achieved, as a single-centre study there were limitations in the catchment area and therefore some minority groups were poorly represented in the study: only one black woman and no black men were sampled. The catchment

area where the study was conducted includes a largely white working to middle class population (Office for National Statistics, 2011). Including more participants of black ethnicity, especially men, may have produced more varied results. Indeed, Zerwic (2003) found accessing medical services was issue among African Americans (Zerwic et al., 2003).

In addition, the sample comprised a low number of patients who were determined to have possible CHD warranting further intervention, usually an angiogram (an invasive procedure to visualise the heart's arteries): only 4 patients out of 30 patients (12%). Previous research has showed that about 33% of patients seen in the RACPC are determined to have potential CHD needing further invasive investigation (Fox et al., 2009, Tenkorang et al., 2006). These studies were, however, conducted on a much larger sample of over 1,200 participants, and over a 12-month period. In this study, data collection was conducted over 5-month period (February to June). A study with a higher number of patients with a potential CHD at the end of the RACPC assessment may have presented with different accounts of symptom interpretation and help-seeking pathway to treatment.

#### 8.11.2 Data gathering

Prior to starting on this qualitative research project, my interviewing experience was limited to a clinical consultation, and so my interviewing skills had to develop throughout study. Indeed, I took steps to remedy this by undertaking several qualitative interviewing techniques courses both as part of the professional doctorate and external courses. However, I still had challenges, certainly in the early interviews. My lines of questioning had a tendency to drift into a clinical consultation style approach, which can restrict the participants' telling of their own account and

limit rich data collection (Patton, 2002). My interviewing skills certainly improved throughout my interviewing journey. It is possible that some rich information capture may have been lost at the start of the data gathering process, which might not have happened if I had been a more experienced qualitative interviewer.

My lack of personal experience of CHD may have affected my interview style. Although as a clinical scientist specialising in heart function testing with over 17 years of experience I am well versed in the official accounts of what chest pain or related heart symptoms should or may feel like, I have never had personal experience of chest pain or breathlessness that may be attributed to CHD. Being told or reading what something may, or should, feel like is very different from the physical experience. Also, the fears and the thoughts attached to the physical experience cannot easily be recreated in the second person, so to speak. Another interviewer that had had a personal experience of CHD may have been able to identify with participants and extract different explanations. However, it is also acknowledged that lack of personal knowledge may also have been advantageous. Someone with personal CHD experience might inadvertently make assumptions and lead participants based their interpretations on their own experiences.

In the same vein, my professional practice in cardiology may have influenced my interview approach to symptom extraction. What symptoms should or may feel like is entrenched in my thinking and indeed this may influence my line of exploration, and may at times have influenced the response that I received from participants. Another interviewer without such in-depth knowledge of CHD symptomatology and its presentation may have used a different line of exploration. As a result, there may have been subtle differences in the participant accounts. In an effort to mitigate this, I

triangulated two key areas of information, namely symptom presentation and help-seeking delay to medical records. Triangulation strengthens the overall robustness of a qualitative study (Polit, 2009, Patton, 2002). However, this could not be done for every aspect of the interviews.

The role of media campaigns and the benefit of health information to impact CHD symptom interpretation and help-seeking became an important finding of this study. Whilst media campaigns and health information were mentioned by some participants in the study, it was not explored deeply with all participants. The importance and significance of media campaigns and health information developed later in the study. As a result, I did not explore it as deeply as I would have if its significance had become apparent sooner. Indeed, it was only after the interviewing process had been concluded and as a result of the transfer process that it was decided the final output of this study would be a lay patient resource to improve symptom interpretation and help-seeking. Previously, a help-seeking scale to measure a patient's willingness or reluctance to seek help was under consideration. However, the exploration of media campaigns and health information in this study was of a sufficient level to draw useful conclusions. It also supported the development of a lay patient resource as the final output. Despite this, it cannot be denied that further deeper exploration of all the participants may have produced additional meaningful and helpful data for analysis and discussion.

## **8.12 Conclusion**

This study explored the experiences of male and female participants' help-seeking when attending a rapid access chest pain clinic (RACPC). This exploration was novel and produced important findings. The study findings have shown that many of

the challenges experienced by patients and health professionals in symptom attribution, help-seeking practices, and understanding of CHD risks which are widely reported in the emergency CHD context can be translated to the RACPC context; it also reveals the different ways participants respond to symptoms which sometimes contributes to delay, and the strong role other people (e.g. family and friends) play in encouraging help-seeking for symptoms. Additionally, participants had mixed reactions to a negative diagnosis at the end of a Chest Pain Clinic assessment (i.e. symptoms not of CHD origin). Many participants expressed frustration at not having an answer for their symptoms. Overall, this study confirmed that, despite ongoing work to improve symptom attribution and the promotion of early help-seeking in men and women, these still remain an issue and they continue to present an important hurdle to health practitioners, who can only act when the patient has presented for treatment. Therefore, it can be concluded that more work needs to be done around how to improve symptom interpretation and the promotion of help-seeking in both men and women.

The final output of this doctoral inquiry attempts to do just that, by developing a novel lay patient resources based on the participant accounts in this study with the aim of improving symptom interpretation and promoting early help-seeking to be used in clinical practice.

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## Appendix A: The Final Interview Questions

1. Can you tell me something about the symptoms the led you to see a doctor?

Probes:

Feeling / experience?  
Most noticeable symptoms?  
Actions at the time of symptoms  
Action in the symptoms free immediately before?  
Length?  
Recognised symptoms?  
Previous symptoms?

2. What was it like having those symptoms?
3. Tell me what you did about your symptoms

Probes

Family / friends  
Self-medicated  
Waited to pass  
Saw a doctor or other health professional e.g. pharmacist

4. Did you delay seeing the doctor?

Probes

How long?  
Why did you delay?

5. Tell me about when you decided to see a doctor / GP? What were you thinking and feeling?

Probes

Waiting time / delays  
Promoting factors / Barriers  
Influences (friends / family)  
Severity of symptoms  
Previous symptoms

6. What was the GP like?

Probes

Difficulty / Easy to get a referral  
Understanding

7. How did you experience that chest pain clinic consultation?

Probes

Thoughts and feeling  
Advice / medications  
Reassure  
Onwards referrals  
Further tests

Chest pain outcome e.g. thoughts / feelings (appropriate to pre or post assessment)

8. What do you understand about people at risk of having heart disease?

Probes

Are there any differences between woman and men do you think?

Cultural influences? Are any groups more likely to get heart disease?

Personal beliefs

Male vs Female Lifestyle

9. How does your day to day pressures affect your ability to see a doctor?

Probes

Role as mother / father

Primary care giver

Professional life / breadwinner

Domestic duties

Other responsibilities e.g. social club etc.

Accessibility of medical services

10. How do you feel in general about asking for help? From doctors?

11. Can you tell me a bit your background?

Probes: Married/Children/Profession/Live / exercise / diet

12. Can you tell me a little about your health in general?

Probe: Any underlying non-heart related medical conditions?

13. What else about your symptoms or experience would you like to tell me?

14. Anything else we have not covered you would like to say?



## Appendix B: Construction of the Interview Guide

First Draft	Second Draft	Final Draft
<p>Tell me about the symptoms which made you want to come to hospital today? Can you describe them in detail?</p> <p>Which of these symptoms you describe was the most noticeable, the most painful or limiting?</p> <p>What did you think these symptoms were?</p> <p>How often do you get these symptoms?</p> <p>When you get these symptoms? <i>Probes during activity / at rest / when under stress</i></p>	<p>Can you tell me about the heart symptoms? <i>Probes:</i> Feeling; experience; notable symptoms, activity immediately before symptoms, length, recognition of symptoms, previous symptoms</p>	<p>Can you tell me something about the symptoms the led you to see a doctor?</p> <p><i>Probes:</i> Feeling; experience; notable symptoms, activity immediately before symptoms, length, recognition of symptoms, previous symptoms</p>
<p>What do you do to manage your symptoms? E.g. <i>Probe</i> Sit and wait for them to pass, self-medicate or walk more slowly?</p>	<p>Tell me what you did about your symptoms. <i>Probes:</i> Family, friends, self-medicated, waited to pass, saw a doctor</p>	<p>Tell me what you did about your symptoms? <i>Probes:</i> Family / friends, self-medicated, waited to pass, saw a doctor or other health professional e.g. pharmacist, GP or nurse</p>
<p>How long did you have your symptoms before you spoke about them with a family member?</p> <p>How long after your symptoms started did you see your GP or health professional?</p>	<p>Tell me about when you decided to see a doctor? <i>Probes:</i> Waiting times /delay, promoting factors, barriers, influences, severity, previous symptoms</p>	<p>Tell me about when you decided to see the doctor / GP? What were you thinking and feeling? <i>Probes:</i> Waiting time / delays, promoting factors / barriers, Influences (friends / family), severity, previous symptoms</p>
<p>What did the doctor advise?</p>	<p>What did the doctor do?</p> <p><i>Probes:</i> Advise, medications, onward referral, further tests,</p>	<p>What was the GP like?</p> <p><i>Probes:</i> Difficulty / easy to get a referral, understanding</p> <p><i>Added a Probe:</i> accessibility of GP services / getting an appointment</p>
<p>You said you waited xx before consulting your doctor. Was there anything that stopped you from speaking to them sooner?</p>	<p>How do your day-to-day pressures affect your ability to see a doctor?</p> <p><i>Probes:</i> Role of mother / father, primary care giver, domestic duties,</p>	<p>How do your day-to-day pressures affect your ability to see a doctor? <i>Probes:</i> role as mother / father, primary care giver, professional life / breadwinner, domestic duties, other responsibilities e.g. social</p>

<p>You waited XX before speaking to your friends or family members. What made you speak to them? Is there anything you feel prevented or delayed you from talking with them?</p>	<p>other responsibilities</p>	<p>club etc.</p>
	<p>What do you understand about people at risk of heart disease? <i>Probes:</i> Cultural influences, personal beliefs, help-seeking</p>	<p>What do you understand about people at risk of having heart disease? <i>Probes:</i> Are there any differences between women and men, what do you think? Cultural influences? Are any groups more likely to get heart disease? What are your personal beliefs?</p> <p><i>Added a probe "age"</i></p>
<p>Can you tell me about any heart symptoms or other conditions you've had in the past?</p>	<p>Can you tell me a little about your health in general? <i>Probe:</i> Any underlying non-heart related medical conditions</p>	<p>Can you tell me a little about your health in general? <i>Probe:</i> Any underlying non-heart related medical conditions?</p>
<p>What is your age?</p> <p>What is your ethnicity?</p> <p>Are you married / co-habiting / civil partner?</p> <p>Do you have family? How many children do you have? How old are your children?</p> <p>Where are you or your family from originally?</p> <p>What exercise do you undertake? a) how many times a week? b) how long have you been exercising? c) how have your current heart symptoms affected your exercise?</p>	<p>Can you tell me a bit about your background? <i>Probes:</i> Married, Children, Profession, Life experiences, Exercise, Diet.</p>	<p>Can you tell me a bit your background? <i>Probes:</i> Married/Children/Profession/Live / exercise / diet</p>
<p>How many times have you seen your GP in the past for your symptoms?</p> <p>Did you ever talk about your symptoms with a family member or friend? e.g.</p>		<p>How do you feel in general about asking for help? From doctors?</p>

What made you decide to speak to them?		
		<p>Added question: How did you experience your consultation? <i>Probes:</i> Thoughts and feeling, advice /medications, reassure, onwards referrals, further tests</p> <p>Added rewording of questions "How did you experience your chest pain clinic consultation with the nurse practitioners?"</p>
		<p>Added question: How long did you delay from your first symptom to going to see the GPs?</p> <p><i>Probes:</i> hours, weeks, days, months</p>
		<p>Added question: (Post) You have received your outcome/ result from the chest pain clinic. How you feel about these results?</p> <p>(Pre) You have received your outcome / results today. What did you think the outcome might be? How did you feel about that?</p>

## Appendix C: Triangulating Symptoms

Study no.	Gender	Patient self-report symptoms	CPC outcome letter	GP referral forms
PA01	Male	Slight Pain in Chest	Chest tightness	Chest tightness
PA03	Male	Palpitation / LT arm numb	Left arm numbness / discomfort	Odd sensation in LA
PA04	Male	Pain down LF arm / numb	Left arm discomfort	Left arm discomfort
PA28	Male	Chest Pain	chest tightness	On and off chest pain
PA07	Male	Discomfort / heavy	Left side chest pain	Central chest pain
PA08	Male	Chest Tight / Sick / Collapsed	chest pain tightness	Chest pain and collapse
PA10	Male	Arm Pain	Left arm pain	Tightness and arm pain
PA11	Male	Chest Pain related to cough	Retrosternal chest pain	Central chest pain to upper jaw
PA12	Male	Chest Pain / Arm Pain	Left side chest pain	Chest pain down LA
PA14	Male	Air bubbles across chest pain	Left chest bubbling discomfort	Bubbling in left side of chest & pain
PA15	Male	Pains / chest pressure	Retrosternal chest pain	Chest pressure
PA16	Male	Breathlessness	Chest tightness & SOB	Sob on exertion
PA17	Male	Heart squeezing	Left sternal chest pain	Squeezing sensation in chest
PA22	Male	Pain radiating down arm	Arm pain	Pain radiating down RA and LA
PA25	Male	Cough / Out of breath	Out of breath	Cough / out of breath & ECG changes
PA02	Female	Sore throat in cold and exertion	Throat and neck discomfort on walking	Tightness in throat on walking
PA05	Female	Chest Pain fast walking	Chest pain / discomfort with rapid walking	Chest pain with rushing
PA06	Female	Chest Pain	Lower left chest pain	Chest pain
PA09	Female	Dull Ache in chest area	Left side chest pain	Left side chest pain
PA13	Female	Chest Pain / SOB	multifocal chest pain and radiating to LA	Chest pain on exertion
PA18	Female	Chest Area Pains / Ache	Chest pain / arm pain	Chest pain & arm pain
PA19	Female	Arm Pain	Right sided chest pain & arm	Right chest tightness with breathlessness
PA20	Female	Chest Pain	Left sided chest pain radiating to LA	Chest pain affecting LA
PA21	Female	Palpitation / blockage in chest	Localised chest pain radiating to LA	Right chest tightness with breathlessness
PA23	Female	dizziness / arm pain	Retrosternal chest pain	anterior pain
PA24	Female	Chest Pain	chest and arm pain	Pain in Central chest
PA26	Female	Pain / Arm pain	Chest pain radiating to LA	Chest pain radiating to LA

PA27	Female	tight chest pain / (COPD)	Chest pain and breathlessness	Episodic chest pain
SubPo1	Female	Indigestion type pains	Chest Pain	Records lost
SubPo2	Female	Chest Pressure	Exertional chest pain	Chest pain & sob

## Appendix D: Triangulating Patient delays

Study No	Gender	Patient Reported Delay	Delay GP Referral	CPC letter
PA01	Male	1 month	Not recorded	2 months
PA03	Male	3 months	Not recorded	3 months
PA04	Male	6 months	Not recorded	Not recorded
PA28	Male	Not recorded	Few months	3 years' history
PA07	Male	A few months	Not recorded	past few months
PA08	Male	10 days	10 days	10 days
PA10	Male	4 months	Not recorded	4 months
PA11	Male	6 months	5-7 months	6 months
PA12	Male	A few months	2 months	6 months
PA14	Male	two months	a few months	a few months
PA15	Male	3 months	Not recorded	3 to 4 months
PA16	Male	2 months	Not recorded	a few months
PA17	Male	6 months	Not recorded	6 months
PA22	Male	12 hours	Not recorded	Not recorded
PA25	Male	3 weeks	Not recorded	3 months
PA02	Female	6 months	6 months	6 months
PA05	Female	No delay	Not recorded	3 weeks (since appointment)
PA06	Female	1 weeks	one week	one week
PA09	Female	4 weeks	not documented	2-year history
PA13	Female	6 months	a few months	6 months
PA18	Female	4 months	2-3 months	a few months
PA19	Female	1 weeks	not recorded	a few months
PA20	Female	2 weeks	few weeks	2-3 weeks
PA21	Female	Not reported by patient	Not recorded	a month
PA23	Female	A few hours	2 weeks	2 weeks
PA24	Female	A few months	2 months	few months
PA26	Female	1 weeks	2 weeks	one months
PA27	Female	A couple of months	Not Recorded	Not Recorded
SubPo1	Female	A few months	Records lost	Not recorded
SubPo2	Female	A few months	6 weeks	1 month

## Appendix E: Development of the Codes

Initial Codes	Revision of Codes	Current Codes
Cardiac Symptoms Severity of Symptoms Types of Symptoms Thoughts about the Symptoms Approach to symptoms Pain	Approach to symptoms Severity of symptoms Types of Symptoms Interpretation of symptoms	Symptoms
Compartmentalising	Feeling and Emotions	Feeling and Emotions
Age profile for heart disease	Age	Age
Lifestyle factors Risk Factors for	Risk Factors	Risk Factors
Doctor Consultation Nurse Consultation	Doctor Consultation Nurse consultation	Consultations
Procedural complications Procedures	Test and Treatments Procedural complications Procedures	Test and Treatments
Non-Cardiac Conditions	Other conditions Co-morbidity	General Health
Physical Activity Non-physical Activity	Activity	Activity Exercise
Gender Issues	Gender Issues Social Role evolution	Gender
Behaviours Beliefs Denial Culture	Belief and Behaviours Denial Trivialising of symptoms Concealing symptoms Being judged Coping Culture	Behaviours Beliefs
Motivators	Motivators Breadwinners	Motivations

Help-seeking Barriers to help-seeking Facilitators to help-seeking Delay	Help-seeking	Help-seeking Delay
Family	Family	Family
Friends	Friends	Friends
Attitude to self Thoughts	Attitude to self Self-talk Thoughts Misconceptions of heart disease	Thoughts
Avoidance of people when unwell	Avoidance of people when unwell	Behaviours
Timing	Timeliness	Time
Previous medical experience	Health Knowledge	Health Knowledge
Diagnosis	Diagnosis	Diagnosis
Social Activity Profession	Social Profession Activity Professional Disappointments	Occupations
Mental health	Mental health Psychology	Mental health
Media	Media	Media
Partners	Partners	Partners
Referrals Access to medical services	Accessibility	Accessibility
	Physical Limitations Daily living limitations	Limitations
	Incidental findings	Help-seeking
	Diet	Diet
	Anti-help-seeking	Help-seeking
	Deference to doctors Doctor consultation	Doctors
	Nurses Cardiac Physiologists	Health Professionals



	Culture	Culture
	Stress	Stress
		Severity
		Duration
		Frequency
		Barriers
		Women
		Men
		Pre (outcome)
		Post (outcome)
Identity issues	Identity issues	<i>Deleted</i>
Hospitals	Hospital	<i>Deleted</i>
The future	<i>Deleted</i>	
Positive Effect of a cardiac experience	<i>Deleted</i>	
Chest Pain Clinic experience	Chest pain experience	<i>Deleted</i>
Escapism	<i>Deleted</i>	

## Appendix F: Symptoms Profile, Activity, Thoughts and Response

Study No	Gender	Chest Pain Symptoms	Activity	Severity	Frequency	Duration	Thoughts	Response
PA01	Male	Slight Pain in Chest	Waking up at rest post exercise	Intense/Severe	once off	20 min	Potentially heart	Doctor wife
PA03	Male	Palpitation / LT arm numb		abnormal	every 2 weeks	ten seconds	Heart related	Activity to help
PA04	Male	Pain down LF arm / numb	on phone	horrific pain	Happen 2 twice	15 min	Circulation / nerve in arm.	Wait / evaluate
PA28	Male	Chest Pain	Incomplete	Not severe	Come & go in 1 minutes	1 min	Indigestion	Never bothered / nothing
PA07	Male	Discomfort / heavy Chest Tight / Sick / Collapsed	Driving / Seating Exercise/ Rehab gym	Not a sharp pain	A couple of times	10-15min	Muscular	Information seek
PA08	Male			No as painful	a few days	7 days	Might be heart.	Help-seek
PA10	Male	Arm Pain	In the GP surgery	N/A	on and off	Non-specific (at night)	Psychosomatic	Non-specific
PA11	Male	Chest Pain related to cough	Nothing particular	Dull pressure	Recently 7days	Constant 7 day / 5 min	Heart related	Self-medicate
PA12	Male	Chest Pain / Arm Pain	Working	Not severe	On and off....	a while	Maybe heart related / Maybe Indigestion	Self-medicate
PA14	Male	Air bubbles across chest pain	Work / Sit / Drive	Constant /Intense	4-5 times	2-3 minutes	Heart related	Nothing relax
PA15	Male	Pains / chest pressure	Sitting at Computer	Not painful	On and off....	variable min /days	Heart related	Be aware
PA16	Male	Breathlessness	Walking	Worsening	On and off. Worse	5-10 minutes	Fitness related / not heart	Self-medicate
PA17	Male	Heart squeezing	Doing something	Noticeable	15 times	Non-specific (when walking)	Psychosomatic	Wait
PA22	Male	Chest Pain	Unloading the car	lot of pain	once off	Constant	Heart-related	Wait
PA25	Male	Cough / Out of breath	Waking coughing up	Unnerving	Happen 2 twice	Non-specific	None specified	Self-medicate
PA02	Female	Sore throat in cold	Walking	Worsening	Regularly	"not long"	Rhinitis	Husband
PA05	Female	Chest Pain	Walking (fast)	Dull ache	Once off	10 minutes	Asthma	Wait
PA06	Female	Chest Pain	Walking	Enough	Every day 4	Hard to say	Pulled a muscle	Wait

					week	(sleep/wake)		
PA09	Female	Dull Ache in chest area	On train Walking (and at rest)	Dull ache	Sporadically / 3 times	Constant	Mastodynia	Lifestyle Change
PA13	Female	Chest Pain / SOB	Waking up / Sleeping	Can't breathe	one and off	3 days	Heart related	Activity to help
PA18	Female	Chest Area Pains / Ache	Stressed	Not pain - ache	a few occasions	Non-specific	Cortisol related	Self-Medicate
PA19	Female	Arm Pain	Moving / doing a house work	NA	Twice	Couple of hours	Stress / Unrecognised symptoms	Acupuncture
PA20	Female	Chest Pain	Palpitation / blockage in chest	Bruising / Poking	two weeks	two weeks	Don't know	Self-Medicate
PA21	Female		None specific	Not serious	Over years / incidental	Non-specific (incidental)	Indigestion	Wait
PA23	Female	dizziness / arm pain	Going to the loo	Sharp Pain	Once off	About an hour	Heart related	Wait
PA24	Female	Chest Pain	Walking	Vice like pain	two weeks	5-6min	heart related	Ignored
PA26	Female	Pain / Arm pain	In bed	Worsening	3 nights a week/ sometimes nightly	"quiet long"	Don't know	Wait / Self-Medicate
PA27	Female	tight chest pain / breathing (COPD)	None specific	Tightness	Once or twice weekly	10-15 minutes	COPD	Wait
SubPo1	Female	Indigestion type pains	sitting	Waves / Intense	Once off	period of time	Indigestion	Wait / ignore
SubPo2	Female	Chest Pressure	Walking	Dull ache down the arm /mild	Daily walking	a couple of minutes	Age-related weight pain /	Wait

## Appendix G: Help-seeking - Delay, Motivation and Barriers

Study No	Gender	Delay time	Delay reason	Motivation	Barrier
PA01	Male	1 month	None specific	Doctor Wife	None
PA03	Male	None	None	Family History	None
PA04	Male	6 months	Burying in sand	Reoccurring symptoms	None
PA07	Male	A few months	Not severe	Severity	Time off work
PA08	Male	Couple of hours	thought it would ease	Brother / severity / Previous experience	None
PA10	Male	4 months	Not both doctors / psychosomatic	Severity	Access/ Not wanting to bother GP
PA11	Male	6 months	Severity / Constant	Severity & duration / media	Time off work / Access
PA12	Male	A few months	Not severe	Wife and Children	Time work / Access
PA14	Male	Two months	None specific	Worried about symptoms	Time off work / being busy / Access
PA15	Male	3 months	None specific	Reoccurring / frequency symptoms	Don't like doctors
PA16	Male	2 months	? Fitness related	Severity	Bad GP experience
PA17	Male	6 months	Psychosomatic	worsening symptoms	Time off work / not want to waste people time
PA22	Male	12 hours	man's it out	Daughter / ongoing symptoms	People worse off/ delays in A&E and environment & change of GP/ Access
PA25	Male	10 days	Not severe	Symptoms unnerving	Access / Time off work
PA28	Male	3 years	Not severe	Seeing health professional	Don't like doctors
PA02	Female	12 months	Not specific	Severity	Being busy
PA05	Female	None (incidental)	Not specific	On the way to doctor	Not bother doctors
PA06	Female	1 week	Initially not severe	Didn't pass	Self-reliance / time off work
PA09	Female	4 weeks	non-specific	Mother's a nurse	Access / Rejection / doctors are busy
PA13	Female	6 months	Severity / Reoccurrence	Family History	Access
PA18	Female	12 months	thought related to illness	Family and Friends / appease husband	Access / rejection / GP experience
PA19	Female	1 weeks	Delay as it personality	Husband	Preferred Acupuncture
PA20	Female	2 weeks	Self-medicated	Severity/ meds not working / friends and family who are ex nurses	Time off work / avoidance
PA21	Female	Incidental	non-specific	Worried about symptoms	Non-specific

PA23	Female	a few hours	Not bother doctors	Something wasn't right	Access
PA24	Female	a few months	non-specific	Family history / husband	Prefer not to go to doctors
PA26	Female	1 week	bad GP experience	Family and friends' history	GP bad experience / prefers to self-medicate
PA27	Female	None (incidental)	non-specific	Family (daughter forces too)	Access / Being busy / I don't like doctors
SubPo1	Female	a few days	Indigestion thought it weight related pain	Medical colleagues	Don't like doctors
SubPo2	Female	about Months		Got worse	Being busy / Don't like doctors

## Appendix H: Additional quotations from Phase Three Analysis

Study No.	Quotation
Subpo1	"I ignored them because I was too busy" (Female)
Subpo1	"No, I just, I haven't got time to be sick. And that's a really selfish attitude, I know, but I really haven't. I can't fit it in. I just can't allow to, because I'm, I've got things to do. I've got a life outside, I've got a social life, I've got work, I've got a family..." (Female)
PA26	"I went there, he just told me, OK be quick I have patient waiting, and that's it, and then after a while they do my blood pressure and of course you are sitting like that, well I, as he was shouting, relax, relax, I say, I am relaxing I am sitting, I am relaxing. And then three times he had to tell me, and three times he had to do my until I think my blood pressure go down, and then my blood pressure goes ... OK, you're all right now". (Female)
PA17	"...if anything did slow me down it was that psychosomatic thing, so, or at least the sense, my worry if I was just imagining it". (Male)
PA16	"we've all got hearts and I'd imagine that whatever goes wrong with a heart, goes wrong with a heart regardless of whether you're male or female yeah"? "... like if you break an arm whether you're male or female you've broken your arm". (Female)

## Appendix I: Participant Information Sheet 1

St George's Healthcare



NHS Trust

Queen Mary's Hospital

Roehampton Lane  
London  
SW15 8PN

Direct Line: 020 8 487 6008  
e-mail: Nolan.Stain @stgeorges.nhs.uk

22/01/2014

### **PARTICIPATION INFORMATION SHEET (version no. 02)**

#### ***Help-seeking for cardiac symptoms***

Researcher \_\_\_\_\_

Staff Supervisor (if applicable) \_\_\_\_\_

You are being invited to take part in a research study. The study will look at the length of time it takes a patient to seek help from the doctor when they have heart symptoms (chest pain or discomfort and shortness of breath).

#### Why I have been chosen?

You have been selected as you were referred by your GP to the chest pain clinic for assessment of your symptoms, and you meet the gender, age and ethnicity requirements of the study.

#### The study will involve you:

1) being interviewed either in person at the chest clinic or by telephone by a researcher. You will be asked questions about your symptoms and how long it took you to get help. The interview should last about 45-60 minutes and will be digitally recorded (you will be anonymous). The digital recording of your interview will be stored *securely* on the Hospital server for five years, after which time it will be destroyed. Short, direct quotes may be used in a way where you will not be identified.

2) completing a short questionnaire based on the information obtained in the interview. The questionnaire will be posted or emailed to you about 6-9 months after the interview. This part of the study is optional. You can indicate on the consent form whether you wish to take part in the second study.

Please note:

- Participation is entirely voluntary.
- You have the right to withdraw at any time without giving a reason.
- You have the right to ask for your data to be withdrawn (as long as this is practical) and for personal information to be destroyed.
- You do not have to answer particular questions either on the questionnaires or in interviews if you do not wish to.
- Your responses will be confidential. No individuals will be identifiable from any collated data, written report of the research, or any publications arising from it.
- All personal data will be kept in a locked cupboard on Hospital premises
- If you wish you can receive information on the results of the research.
- The researcher can be contacted by email ([Nolan.stain@stgeorges.nhs.uk](mailto:Nolan.stain@stgeorges.nhs.uk)) or by telephone (0208 487 6482).
- Further information, in the first instance; please contact the researcher's supervisor, Professor Damien Ridge ([d.ridge@westminster.ac.uk](mailto:d.ridge@westminster.ac.uk)), at the University of Westminster. For information about the University's research policy contact the Research Degree Manager John Briggs ([j.briggs@westminster.ac.uk](mailto:j.briggs@westminster.ac.uk)) or telephone (0207 911 5000).



## Appendix J: Consent Form 1.

St George's Healthcare



NHS Trust

Queen Mary's Hospital

Roehampton Lane  
London  
SW15 8PN

Direct Line: 020 8 487 6008  
e-mail: Nolan.Stain @stgeorges.nhs.uk

13/01/2014

### CONSENT FORM (Version 02)

**Title of Study:** *Help-seeking decision for cardiac symptoms*

**Lead researcher:**

-----

1. I confirm that I have read and understand the information sheet dated [22/01/2013] (version 02) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the study (interviews)
4. I agree to take part in the second part of the study questionnaires. *This is optional.* Circle as appropriate YES or NO
5. I understand that the interviews will be tape recorded and for the data to be used for the purpose of this study. I understand that direct quotations may be used but in a way where I will not be identified.
6. I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Westminster, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

This consent form will be stored separately from any data you provide so that your responses remain anonymous.

I have provided an appropriate explanation of the study to the participant

Researcher Signature \_\_\_\_\_

## Appendix K: Participant Information Sheet (Substantial Amendment)

Roehampton Lane  
London  
SW15 8PN  
Direct Line: 020 8 487 6008  
e-mail: Nolan.Stain @stgeorges.nhs.uk

Queen Mary's Hospital

07/08/2015

### PARTICIPATION INFORMATION SHEET (version no. 03)

#### ***Help-seeking for cardiac symptoms***

Researcher \_\_\_\_\_  
Staff Supervisor (if applicable) \_\_\_\_\_

You previously took part in an interview for a research study about help seeking for your chest pain symptoms.

As part of the study you also agreed to participate in the second part of the study which involved “completing a short questionnaire based on the information obtained in the interviews”. We have found it necessary to make a change to the second part of the study. Instead of completing questionnaire we would like to you to read and answer some questions on a *patient information resource* about help-seeking for chest pain. We want to see if the *patient information resource* is clear to read and helpful to patients.

As we are making a change in second part of the study we will need to ask for your consent again. If you would still like to take part in the second part of the study, please sign the attached consent form and send it back to the researcher with your feedback forms. Your feedback will be anonymous.

Please note:

- Participation is entirely voluntary.
- You have the right to withdraw at any time without giving a reason.
- You have the right to ask for your data to be withdrawn (as long as this is practical) and for personal information to be destroyed.
- You do not have to answer particular questions either on the questionnaires or in interviews if you do not wish to.
- Your responses will be confidential. No individuals will be identifiable from any collated data, written report of the research, or any publications arising from it.
- All personal data will be kept in a locked cupboard on Hospital premises

- If you wish you can receive information on the results of the research.
- The researcher can be contacted by email ([Nolan.stain@stgeorges.nhs.uk](mailto:Nolan.stain@stgeorges.nhs.uk)) or by telephone (0208 487 6482).
- Further information, in the first instance; please contact the researcher's supervisor, Professor Damien Ridge ([d.ridge@westminster.ac.uk](mailto:d.ridge@westminster.ac.uk)), at the University of Westminster. For information about the University's research policy contact the Research Degree Manager John Briggs ([j.briggs@westminster.ac.uk](mailto:j.briggs@westminster.ac.uk)) or telephone (0207 911 5000).

## Appendix L: Consent Forms (Substantial Amendment)

Roehampton Lane  
London  
SW15 8PN

Direct Line: 020 8 487 6008

e-mail: Nolan.Stain @stgeorges.nhs.uk

07/06/2015

### CONSENT FORM (Version 03)

**Title of Study:** *Help-seeking decision for cardiac symptoms*

**Lead researcher:**

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1. I confirm that I have read and understand the information sheet dated [07/08/2015] (version 03) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the study second part of the study – provide feedback on patient information resource to promote help-seeking.
4. I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Westminster, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

This consent form will be stored separately from any data you provide so that your responses remain anonymous.

I have provided an appropriate explanation of the study to the participant

Researcher Signature \_\_\_\_\_

## Appendix M: Covering letter lay resource



Queen Mary's Hospital

Roehampton Lane  
London  
SW15 8PN

Direct Line: 020 8 487 6008

e-mail: [Nolan.Stain @stgeorges.nhs.uk](mailto:Nolan.Stain@stgeorges.nhs.uk)

Dear

Thank you for very much for agreeing to participate in this part of the study. As explained, in the information sheet we have produced patient lay resource / leaflet based on the interviews you have taken in part it. It is hope that leaflet would help patients understand their symptoms and seek help as early as possible.

We would like to get your feedback on what you think about this patient resource / leaflet. Is the word of the questions and answers clear, is there enough detail, have we left anything out, and how can it be improved? To help us do this please read the patient leaflet enclosed and comment on it.

You may do this by:

- Completing the questionnaire below or;
- Writing your comments on your copy of the leaflet.

You either post your comments together with your completed consent forms using the self-addressed and stamped envelope included or you email to me.

If we don't hear back from you with three weeks we will assumed that you don't wish to get take part.

Many thanks again for your help with the interviews and commenting on patient lay resources / leaflet.

Kind Regards

Nolan Stain

## Appendix N: Patient Lay resource questionnaire

### Title

Please comment on the title of the patient leaflet. Is the wording clear? Are the clinical terms understandable? Do you have concerns about it? Do you have any suggestions for improvement?

Comments \_\_\_\_\_

### Questions

Please comment on the Q1-7. Is the wording of question clear and understandable? Please also, comment in the answer in Q1. Is the clear and understandable? Do you feel it answers the question. Do you feel there is an enough detail? Any suggestions on how it can be improved?

Question 1. \_\_\_\_\_

Question 2. \_\_\_\_\_

Question 3. \_\_\_\_\_

Question 4. \_\_\_\_\_

Question 5. \_\_\_\_\_

Question 6. \_\_\_\_\_

Question 7. \_\_\_\_\_

### Question 8

Please comment on Question 8. Information provided clear and understandable? Do you feel other information should be included?

\_\_\_\_\_

**General Comments** (is there anything else you would like to add)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Appendix O: First Panel of Expert (Academic Supervisors)

	Director of Studies	2 <sup>nd</sup> Supervisor
Title	Do you need to say this term, as it is not very lay friendly? Can you say "heart artery"?	
Q1	No comment	No comment
Q2	No comment	If they are using GTN (nitrates) already, wouldn't they have already seen a heart specialist?
Q3	<p>A word is missing from this thought bubble, and the one below, making them hard to read.</p> <p>Check you are allowed to use the illustrations; you might have to buy them from an online provider.</p>	
Q4	No comment	Keep terms consistent. Use as 'clinic' earlier in this section.
Q5	<p>There is weird formatting throughout that would need to be fixed, in fact you should get professional help to format this.</p> <p><i>"Research shows that patients often have mild symptoms in the weeks</i></p> <p><i>leading up to heart attack (prodromal symptoms). If you seek help early it may be possible to prevent you from having a heart attack"</i> This is repeated, only have it in one place. Delete here?</p>	It's not your results section, so you can change the quote to make it make more sense
Q6	<i>"However, if you don't go to the GP your symptoms could get worse. There is even the possibly that your heart symptoms could turn into heart attack,"</i>	<p>If is not self-employed people, some employed people also don't get paid if they are sick</p> <p>Women, study also had concerns about taking time off work.</p>
Q7	No comment	No comment
Q8	No comment	NHS choices or NHS drop in centre/clinic? As these are 2 different things

General	Grammatical edits were made to all questions.	Grammatical edits were made to all questions
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## Appendix P: Second Panel of Experts (Clinical Opinion)

	Cardiologist 1 <sup>st</sup>	Cardiologist 2 <sup>nd</sup>	Cardiologist 3 <sup>rd</sup>	Chest Pain Nurse Specialist	Clinical Scientist in Cardiac Physiology
Title	Replace “stable heart disease” with “symptoms of heart disease”	No comment	No comment	“stable heart disease” symptoms may confuse patients. This should re-be worded.	Title of ‘worried about your symptoms? Think they might be coming from your heart? Unsure if you should go to the doctor?’  Shorten to:  <b><i>“Worried that your symptoms might be caused by a problem with your heart? Unsure if you should go to the doctor?”</i></b>
Q1	Replace “stable heart disease” with “symptoms of heart disease”	No comment	No comment	Second last sentence insert “without chest pain”.	Subtitle: Regarding purpose of leaflet  <b><i>“This leaflet explains when and where you should seek help if you are worried that you might have a heart problem”</i></b>
Q2	Delete “coronary heart disease” and leave “symptoms”  Delete “or more”. 15 minutes should be maximum people wait before calling for the emergency services.  Replace “These symptoms may be a	No comment	“I often say if pain persists after 5 mins take another spray, if > 15-20 mins dial 999. Not sure If there are formal guidelines”.	Patient will only have GTN if seen a doctor (GP or specialist).  GTN is fast acting “10-20 min is a bit long. Use 5-10 minutes.	<b>Add ‘more than’-</b>  “If your symptoms do not improve and continue for <u>more than</u> 15 mins....”

	heart disease" with "These symptoms may represent a heart attack"				
Q3	No comment	No comment	No comment		No comment
Q4	No comment	No comment	No comment	Insert "Don't wait to see a GP if the pain is severe or last more 15 minutes' call 999. Do not drive yourself to hospital."	No comment
Q5	No comment	No comment	No comment		No comment
Q6	No comment	No comment	No comment		No comment
Q7	No comment	No comment	No comment		The last sentence of this paragraph does not make sense.  Possible to replace with ?  <b>'Any delay in seeing your GP is likely to make you more anxious'</b>
Q8	No comment	No comment	No comment	If you think you have heart attack ... insert "or you have severe chest pain call 999 immediately.	
General Comment	Minor grammatical corrections throughout the document	No specific comments other than to say overall the leaflet lot good and no concerns	Looks v good... I would give it to my Coronary Heart Disease patients		Very good leaflet - Lots of good advice for patients  No too much medical terminology so no risk of patients not understanding the main message.  Minor grammatical errors

					<p>The little sound bites taken from the patients who were interviewed are a nice touch. I think patients will find them funny and familiar.</p>
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## Appendix Q: Third Panel (Patients)

Area	SubPo2 (F)	PA06 (M)	PA01 (M)	PA07 (F)	PA05 (M)
Heading	I think the title is a little long, needs to be more concise	It seems a quite informal but, I think that is fine	No comment	V Good	It very clear
Q1	Very clear and Well explained.	I think it is fine, very descriptive in an amount of words which is needed to be concise.	No comment	No comment	Yes, good
Q2	Answer is too long. Slightly confusing where it says <i>"if your symptoms improve you may have stable heart symptoms"</i>	I'd question that "wait", if I thought I was having a heart attack, I wouldn't sit wait.	No comment	No comment	Yes, good
Q3	Well explained	Good point. Might make people who don't want to be a nuisance save	No comment	No comment	Yes, good
Q4	Well explained	All good	No comment	No comment	Yes, good
Q5	Questions need to be re-phrased i.e. I don't want to waste the GP's time.	I am ambivalent on this, as I do believe there are a lot of people who block up surgeries. But, that heart is a serious thing.	No comment	No comment	Yes, good
Q6	Explanation is long a bit long winded.	Those people are mad and should see the mind doctor after the heart specialist.	No comment	No comment	Yes, good
Q7	Well explained	I don't think picture of the old man is relevant, most Drs are full of old people.	No comment	No comment	Yes, good
Q8	I think all areas covered and clear	All clear and straight forward.	Everything is very clear	No comment	Yes, good
Comment	Diagrams look attractive and	None	The leaflet is very	I think you leaflet is very	Very useful

	catch the eye.		comprehensive.	good and need not changing other than little pics which makes in less than serious than it is.	
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## Appendix R: Lay patient resource

### *Worried about your symptoms? Think they might be coming from your heart? Unsure if you should go to the doctor?*

*This is a leaflet about why and how to seek help for possible symptoms of heart disease*

#### 1. What are symptoms of heart disease?

The most common symptoms of heart disease are sensations of pain, tightness and/or heaviness in your chest area. These sensations can spread from your chest to your jaw, neck, arms, back or stomach, and are usually short-lived (a few minutes). These symptoms can happen with physical activity, eating, stressful events or cold weather, and are relieved by rest (stopping the activity or exposure). Some people experience different heart symptoms, such as shortness of breath or nausea *without chest pain*. Women, those aged over 60, or people with diabetes (type 1 or 2) are more likely to have these less typical types of symptoms.

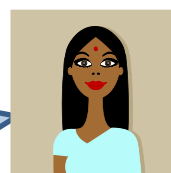
#### 2. What should you do when you have these symptoms?

If you are having these symptoms: *Stop what you are doing; sit down and relax; if you have a GTN (nitrates) spray or tablets you may use them; wait 5 minutes. **If your symptoms do not improve and continue for 15 minutes, or if they start occurring at rest, call 999 immediately. These symptoms may represent a heart attack.*** If your symptoms improve within 5 minutes you do not need call 999 but you may still have heart disease, and this should be investigated. Make an urgent appointment with your GP to explore further evaluation and treatment options. **Do not delay seeking medical assistance** from your doctor. Research has shown that some patients get mild symptoms up to four weeks before having a heart attack (known as prodromal symptoms).

#### 3. My symptoms are not what I expected heart symptoms to be like?

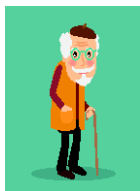
Heart symptoms can be mild and varied (not just a bad pain in the chest). Research suggests people expect to have a “Hollywood attack”, where someone is clutching their chest while collapsing to the floor in pain. This sometimes happens in very severe heart attacks. More often people have milder symptoms, especially with the symptoms described in Section 1 of this leaflet. If you have any heart symptoms even mild ones, go to your GP.

*My perception of a heart attack is clutching my chest in pain and then flaking out on the floor.*



#### 4. I cannot get an appointment with my GP. What can I do?

If you tell your GP that you think you are having heart symptoms, you may get an urgent appointment right away. If you are not able to get a GP appointment, you can attend a local walk-in clinic. NHS Choices ([www.nhs.uk](http://www.nhs.uk)) provides details of your nearest walk-in clinic. They also provide an online medical advice and information to assist you. If you have severe chest pain that lasts more 15 minutes, do not wait to see a GP. Telephone: 999. Do not drive yourself to hospital.



*"I wanted to see my GP;  
they took two weeks, that  
was emergency  
appointment..."*

## 5. I don't want to waste the doctor's time.

Many people feel that they don't want to waste the doctor's time. Others are afraid they may appear foolish for going to the GP with a "small" problem, so wait until their symptoms get worse before going. But heart symptoms can be easily treated if detected early. Waiting for them to get worse can lead to you having more serious health problems.



*I don't like wasting  
the doctor's time  
with little things*

## 6. I don't have time to go and see the doctor.

People with care-giving responsibilities often feel the needs of the family are more important than going to see the doctor. Those with work responsibilities may be concerned with taking time off work, especially if they would then lose income. But, important to see you doctors as soon as possible. If you delay it could lead to symptoms in turning into a heart attack which can have a long recovery time. The sooner you get help and treatment the sooner you can get back to your daily activities.



*I have to go  
to work,  
rather than  
go to the  
doctors.*

## 7. I don't like going to the doctor.

Many people don't like going to the doctor. Very often people are afraid of what the doctor might find. Others don't like medical environments or waiting around in GP surgeries. Whilst it is not unusual for people to feel anxious when consulting for a medical problem, most people feel relieved when they have a diagnosis or get their symptoms treated. Delaying seeing the GP can make you more anxious in the long-term than if you went to see them earlier.

*We have a saying  
in our family, the  
fewer doctors the  
better*



## 8. What kind of help is available?

### Your local GP practice

Your local GP practice should provide assistance with any non-emergency medical issues.

### NHS Choices

Provides a list of walk-in clinics, online information, and guidance on all aspects of health and healthcare to help you make decisions about your health. **Web:** ([www.nhs.uk](http://www.nhs.uk))

### NHS 111

You can call NHS 111 when you need medical advice or help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. **Telephone:** 111

### Emergency Services

If you think you are having a heart attack you should contact the emergency services Immediately, without delay. **Telephone: 999**

## Appendix S: Rapid Access Chest Pain Pathway

