# How people present symptoms of Acute Coronary Syndrome to health services: An analysis using the Commonsense Model of Self-Regulation.

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by

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# Abstract

Acute Coronary Syndrome (ACS) is common and associated with high mortality. Effective treatments are available but require prompt administration. Studies have consistently demonstrated that delays to treatment are common, with patient decision time accounting for most delay. Interventions aimed at reducing delay have had little success.

Evidence suggests that psychological factors, in particular illness representations (Leventhal's Commonsense Model of Self-Regulation (CS-SRM)) might be important in relation to patient decision time. This thesis describes a two-stage investigation, undertaken within NHS 24, exploring the content and timing of people's initial presentations with possible symptoms of ACS.

The first stage comprised a CS-SRM-guided content analysis of peoples' initial symptom presentations. The second stage utilised the Illness Perception Questionnaire-revised (IPQ-R) to explore how illness representations relate to patient decision time.

Results show that the components of illness representations accounted for 95% of participants' initial presentations. The components most related to behaviour and outcome were volunteered least (cause, consequences, cure/control and coherence). Decision time for most participants (89%) was out-with the ideal and appraisal time accounted for most of the delay.

Appraisal delay was shorter for those with fewer symptoms and high emotion.

Illness delay was longer where the person making the call reported high treatment control.

Interventions may need to raise awareness of the range of possible presentations and of the consequences associated with delay. Interventions should also provide guidance as to an appropriate time-limit for self-care. Individuals may benefit from being informed about how to respond to strong emotional responses. Interventions aimed at bystanders may need to differ from those for patients. People at high risk of ACS should be informed about how and when to access healthcare out-of-hours.

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# List of Abbreviations

| | |
|---|---|
| A&E | Accident & Emergency |
| ACS | Acute Coronary Syndrome |
| CABG | Coronary Artery Bypass Graft |
| CHD | Coronary Heart Disease |
| CIPQ-R | Caller Illness Perception Questionnaire-revised |
| CS-SRM | Commonsense Model of Self-Regulation |
| ECG | Electrocardiograph |
| ED | Emergency Department |
| GISSI | Gruppo Italiano per lo Studio della Sopravvivenza nell'Infarto |
| GP | General Practitioner |
| GRACE | Global Registry of Acute Coronary Events |
| GUSTO | Global Utilization of Streptokinase and Tissue Plasminogen Activator for Occluded Coronary Arteries |
| HR | Human Resources |
| IPQ | Illness Perception Questionnaire |
| IPQ-R | Illness Perception Questionnaire - revised |
| IQR | Inter-quartile range |
| K-W | Kruskal-Wallis test |
| LHC | Local Health Council |
| LREC | Local Research Ethics Committee |
| Mdn | Median |
| MI | Myocardial Infarction |
| Mins. | Minutes |
| MONICA | Multinational Monitoring of Trends and Determinants in Cardiovascular Disease |
| MREC | Main Research Ethics Committee |
| NRMI | National Registry of Myocardial Infarction |
| ns | Non significant |
| NSTEMI | Non-ST elevation Myocardial Infarction |
| PRM | Patient Relationship Management |
| PTCA | Percutaneous Transluminal Coronary Angioplasty |
| PWMC | Person Who Made Call |
| RCT | Randomised Controlled Trial |
| SAS | Scottish Ambulance Service |
| SD | Standard Deviation |
| SE | Standard Error |
| SPSS | Statistical Package for the Social Sciences |
| TAMI | Thrombolysis and Angioplasty in Myocardial Infarction |
| UA | Unstable Angina |
| UK | United Kingdom |
| USA | United States of America |

# Chapter 1. Introduction

Coronary heart disease (CHD) is the leading cause of death worldwide (World Health Organization, 2007). Most CHD-related deaths are due to Acute Coronary Syndrome (ACS) and most occur before the patient even reaches hospital (World Health Organization, 2007). Early access to advanced life support and to treatments for ACS can significantly reduce mortality and morbidity. However, there is evidence that delay to receipt of treatment is common (Dracup and Moser, 1997; Dracup and Moser, 1997; Canto et al. 2000; Goldberg et al. 2002b). It has been demonstrated that the interval which contributes most to pre-hospital time is *patient decision time* (Gruppo Italiano per lo Studio della Sopravvivenza nell'Infarto (GISSI), 1995). Reductions in patient decision time could lead to a reduction in mortality for ACS. However, to date interventions aimed at reducing patient delay have met with little success (Meischke et al. 1997; Luepker et al. 2000; Kainth et al. 2004). The aim of the thesis is to contribute to the body of knowledge regarding patient decision time in order to inform future, more successful, interventions.

## *1.1 Plan of thesis*

In the following chapter of the thesis, the existing evidence relating to patient decision time and ACS is reviewed. Critical analysis of the literature reveals a number of important limitations and gaps in knowledge and highlights the likely importance of psychological factors in relation to patient decision time. In particular, the likely utility of Leventhal's Commonsense Model of Self-Regulation (CS-SRM) as a theoretical framework for the

study is explored.

Chapter 3 describes the aims of a two-stage investigation which was undertaken to explore both the presentation of symptoms, and patient decision time, in relation to ACS, using the CS-SRM. The study was conducted within NHS 24, a telephone-based health advice service in Scotland. A rationale for the choice of setting is provided.

The first stage of the investigation explored how the CS-SRM related to peoples' initial symptom presentations to health services and comprised a theory-guided content analysis of transcriptions of calls to NHS 24. The methodology, including the preliminary pilot work which was undertaken is described in detail in Chapter 4. Results are presented and discussed in Chapter 5.

The second stage of the investigation explored whether components of the CS-SRM were useful in explaining patient decision time. A cross-sectional survey of people who called NHS 24 with possible symptoms of ACS was conducted using a specifically adapted Illness Perception Questionnaire (IPQ-R). Details of the methodology and of further pilot work are described in Chapter 6. The results are presented and discussed in Chapter 7.

Finally, the overall conclusions from both stages of the investigation are discussed in Chapter 8. Implications for practice, theory and future research are identified.

# Chapter 2. Literature review

## *2.1 Background*

### 2.1.1 Coronary Heart Disease

Worldwide, Coronary Heart Disease (CHD) is the single most common cause of death (World Health Organization, 2007). Within the UK, death rates are highest in Scotland (Petersen et al. 2005). CHD refers to narrowing of the coronary arteries, usually due to *atheroma*. The term atheroma is used to describe a build up of 'fatty plaques' which develop within the inner lining of the artery. A number of factors (e.g. smoking, high blood pressure, high blood cholesterol and diabetes mellitus) are associated with an increased risk of developing atheroma and therefore CHD (Anderson et al. 1991). CHD usually develops over many years before symptoms emerge and is characterised by phases of stability and instability (Bertrand et al. 2002). The onset of an acute coronary syndrome (ACS) is frequently the first presentation of CHD.

#### *Acute coronary syndromes*

Atheromatous plaques can rupture, releasing the thrombogenic material they contain into the lumen of the coronary artery. The term 'acute coronary syndromes' (ACS) is used to refer to the spectrum of clinical manifestations of CHD which share this common underlying pathology (Davies, 1995; Davies, 1997). The term ACS encompasses *myocardial infarction* (MI), *non-ST elevation MI* (NSTEMI) and *unstable angina* (UA)

which are described in more detail below[1].

***Myocardial Infarction***

Rupture of atheromatous plaque may result in complete occlusion of the coronary artery by thrombus or other aggregates. This leads to necrosis[2] of the area of myocardium subtended by the affected artery and is labelled as myocardial infarction (MI). MI is typically associated with ST segment elevation on the electrocardiograph (ECG) and the release of biochemical markers of necrosis (Fox, 2000).

***Unstable angina***

Where less obstructive thrombi exist or, where spontaneous dissolution of the thrombus occurs and flow within the artery is restored within 20 minutes, persistent changes on the ECG or release of biochemical markers do not usually occur. Clinically, this is described as unstable angina.

***Non- ST elevation MI***

Episodes of occlusion may occur where release of biochemical markers of necrosis occurs but where ST elevation is not evident on the ECG. This is termed non-ST elevation MI (NSTEMI) (Fox, 2000).

Mortality risks vary between the syndromes and the treatment indicated for each is different. In particular, emergency reperfusion treatment is indicated for acute MI but not for the remainder of the syndromes (Van de Werf et al. 2003). Early management of ACS is discussed further on page 8.

[1] ST-elevation refers to a particular abnormality of a waveform observed on the Electrocardiograph (ECG)
[2] necrosis refers to death of cells or tissue.

However, the symptoms associated with each ACS are similar and these are discussed below.

### *Symptoms associated with acute coronary syndromes*

Chest pain is the classic symptom associated with ACS (Lee and Cannon, 2005). The particular type of chest pain associated with ACS is known as *angina pectoris.* The nature of angina pectoris is particular in terms of quality, location and duration.

#### *Quality*

Angina pectoris is typically described as a ‘tightening’ sensation by patients and often not described as a pain at all. Words commonly used by patients to describe the discomfort include “pressing”, “squeezing” or “burning”. The sensation of a heavy weight on the chest or of a tight band around the chest are also frequently described (Lee and Cannon, 2005).

#### *Location*

Angina is typically experienced below the sternum or across the chest. Often the discomfort is restricted to the left of the chest and less commonly to the right. It is ‘visceral’ in nature and therefore diffuse and difficult to localise (Lee and Cannon, 2005).

#### *Duration*

Stable angina is usually of brief duration (lasting less than a few minutes) and predictably associated with exertion (Gibbons et al. 2003). However, the symptoms of unstable angina tend to be of longer duration (>10 mins.). Pain which is prolonged (>30 mins.) and associated with other symptoms,

such as sweating or nausea and vomiting, is commonly associated with MI. The pain of a myocardial infarction may last for several hours. Onset of discomfort whilst resting is also highly suggestive of ACS (Braunwald et al. 2002).

### *Identifying symptoms of ACS*

The symptoms of ACS share many common features and are therefore very difficult to distinguish from each other. The features of ACS, described above, could be considered 'typical'. However, there is evidence to suggest that a substantial proportion of patients with ACS experience atypical chest pain (e.g. sharp pain or pain induced by palpation) (Bertrand et al. 2002) or indeed other 'atypical' symptoms such as dyspnoea, nausea and vomiting or palpitations (Canto et al. 2000; Gupta et al. 2002). Furthermore, there is evidence that in patients with objective pathological evidence of MI, a proportion are unable to recall *any* symptom episode they could associate with MI (Kannel and Abbott, 1984).

Particular groups appear to be most likely to present with atypical symptoms or silent ischaemia. These include women, the elderly and people with diabetes (Gupta et al. 2002; Bertrand et al. 2002). The implications of this in relation to help-seeking are discussed in more detail on page 28.

However, it is important to note that the symptoms described above as typical of ACS may also be present in a range of other conditions. These conditions may be related to the cardio-vascular system (e.g. pericarditis; pulmonary embolism; tachyarrhythmia) or to other body systems (e.g.

gastro-oesophageal reflux disorder, musculoskeletal pain or panic disorder) (Goldberg et al. 2002b). The proportion of patients presenting with chest pain who receive a cardiac-related diagnosis varies between clinical settings (Erhardt et al. 2002). A Canadian study of family doctors found that 18% of patients consulting about chest pain received a cardiac diagnosis with the largest proportion (49%) being diagnosed as musculoskeletal in origin (Svavarsdóttir et al. 1996). However, a Swedish study of people transported by ambulance found that for 69% of patients with chest pain a cardiac cause was considered most likely (Herlitz et al. 1995).

Furthermore, symptoms of ACS can also be misdiagnosed. A large study of participants who presented to emergency departments with symptoms suggestive of ischaemia in the USA found that 2.1% of patients with MI and 2.3% of patients with UA were mistakenly discharged (Pope et al. 2000).

Therefore a significant challenge exists for healthcare providers in the evaluation of the complex symptoms of ACS. Large numbers of people present with chest symptoms, most of which are benign (Erhardt et al. 2002). Conversely, a proportion of patients who *do* have ACS will present with atypical or absent symptoms. Acute hospital care for people with ACS is specialised, intensive and costly whilst the consequences of not providing such care, due to a missed diagnosis, are potentially fatal (Lee et al. 1987).

Thus a number of strategies, additional to clinical history and examination,

have been developed to improve the triage of patients with ACS. These include ECG, biochemical assays, and decision algorithms (Selker et al. 1997). Until recently the focus has been on either making or excluding the diagnosis of MI. However, research over the last two decades has improved understanding of the underlying pathological processes and their importance in the evolution of ACS. It is now recognised that a continuum of risk exists in ACS and therefore evaluation now includes assessment of this risk and treatment is tailored accordingly. The treatment of ACS is described below, highlighting in particular the time-dependent nature of the most effective therapies.

## *2.2 Early management of the acute coronary syndromes*

### 2.2.1 Myocardial Infarction

MI is associated with a very high mortality rate. The Multinational Monitoring of Trends and Determinants in Cardiovascular Disease (MONICA) project found that approximately a third of all cases are fatal before hospitalisation, most of these within an hour of symptom onset (Chambless et al. 1997). The project was a large epidemiological study conducted on behalf of the World Health Organisation to monitor trends in CHD over 10 years across 37 populations in 21 countries. Median 28-day mortality rates of 49% for men and 51% for women were documented. Importantly, two-thirds of these deaths (most due to cardiac arrest) occurred before reaching hospital. Survival following cardiac arrest is more likely if the event occurs in the presence of paramedical staff equipped with

defibrillators (Norris, 1998).

Furthermore, a number of medical interventions, particularly thrombolysis (Fibrinolytic Therapy Trialists' (FTT) Collaborative Group, 1994; GISSI, 1995) and percutaneous transluminal coronary angioplasty (PTCA) (Zijlstra et al. 1999; De Luca et al. 2004) have been demonstrated as effective in reducing mortality. However the benefits of such reperfusion treatments are dependent upon prompt administration (Boersma et al. 1996). Greatest benefit is achieved if treatment is administered within an hour of the onset of symptoms. With each minute that passes benefit is reduced, until ultimately a time point is reached where the risks associated with treatment are judged to outweigh any likely benefit. Thrombolysis is usually not given where the onset of symptoms occurred more than 12 hours previously (Van de Werf et al. 2003).

In 1996 Boersma and colleagues conducted a meta-analysis of 22 trials of thrombolytic therapy with data from a total of 50,246 patients being included. They estimated that treatment with thrombolysis saved 65 lives per thousand treated if given within 1 hour of the onset of symptoms; 37 lives per thousand if given 1-2 hours after the onset of symptoms; reducing to 26 and 29 lives per thousand if given 2-3 hours and 3-6 hours respectively after the onset of symptoms. They found evidence of benefit until at least 12 hours after the onset of symptoms, although this was of significantly lower magnitude. They found insufficient evidence to assess benefit after this time point. This meta-analysis was well-conducted and included data from over 50,000 patients. Additionally, recent authors have

suggested that, due to an issue relating to how times were measured in certain trials included within the meta-analysis, results from this analysis might even *underestimate* the favourable effects of early thrombolysis (Terkelsen et al. 2003).

In summary, there are compelling reasons why patients who are experiencing MI should come under the care of appropriately equipped medical or paramedical staff as soon as possible: Firstly to allow the prompt identification and treatment of arrhythmias including cardiac arrest and secondly to facilitate the early administration of beneficial treatments such as thrombolysis or PTCA.

### 2.2.2 Unstable angina / Non-ST elevation MI

Patients with UA/NSTEMI are at a lower, but still significant, risk of death. The large, multinational, observational Global Registry of Acute Coronary Events (GRACE) has been used to derive regression models to predict death from an unbiased population of patients with ACS. Data were collected from 26,267 patients with the full spectrum of ACS. A 30-day mortality rate of 3% was documented for patients with UA, almost 6% for patients with NSTEMI and 9% for patients with ST elevation MI (Fox et al. 2006).

However, data also demonstrate that risks for individual patients are not equal. Patients with high risk features such as pulmonary oedema or ongoing rest pain are at higher risk of death and MI (Braunwald et al. 2002). Methods for stratifying patients into high, intermediate and low risk

categories and tailoring their management accordingly have been proposed in recent practice guidelines jointly published by the American College of Cardiology and the American Heart Association (Braunwald et al. 2002). These guidelines suggest that all except the lowest risk group (who comprise approx 6% of patients with UA or NSTEMI) require urgent hospital care.

A number of treatments including aspirin (Antiplatelet Trialists' Collaboration, 1994), other anti-platelet drugs (Balsano et al. 1990; Yusuf et al. 2001) and anti-thrombin treatments (Eikelboom et al. 2000; Direct Thrombin Inhibitor Trialists' Collaborative Group, 2002) have been shown to be effective in reducing the risk of death and myocardial infarction in this group of patients. Thus prompt medical assessment is warranted for all patients with symptoms suggestive of an acute coronary syndrome, to identify both those with MI *and* those with other ACS, associated with high risk features, requiring hospital care.

## *2.3 Time from onset of symptoms to treatment*

Despite the clear benefits of prompt medical care, studies have consistently demonstrated that the time between the onset of symptoms and hospital treatment (pre-hospital time) is longer than optimal for many patients with ACS. Table 1, below contains a summary of studies where pre-hospital time has been investigated amongst patients with MI[3]. Reports of median pre-hospital time vary between 30 mins (Bleeker et al. 1995) and 474 minutes (Canto et al. 2000). Direct comparisons between studies are

[3] 1987-2007, median pre-hospital time reported

difficult due to important differences in methodology which are likely to influence the results obtained. Firstly, there are differences in the population being studied. Some studies have been conducted amongst participants in randomised controlled trials (RCTs) of thrombolytic drugs (GISSI, 1995; Gibler et al. 2002), a group that is likely to represent a highly selected sample of the overall population of patients with MI. Some investigators have selected patients on the basis of age, either excluding those aged >75 years (Bleeker et al. 1995) or only studying those aged >65 years (Sheifer et al. 2000). Others report less restrictive inclusion criteria (Horne et al. 2000; O'Carroll et al. 2001; Goldberg et al. 2002b).

Secondly, studies have differed with regards to the method of data collection. Some have abstracted data from medical notes or patient registries whilst others have used patient interviews. Previous work in relation to pre-hospital time has demonstrated that data obtained by interview can differ significantly from that recorded within medical notes with people tending to report longer pre-hospital times during interview than those recorded in their medical notes (Goldberg et al. 1998; Goldberg et al. 2002a).

Finally, there are differences in how pre-hospital time is defined. For example, whether the onset of prodromal symptoms is included in the definition of the onset of symptoms is likely to affect calculations of pre-hospital time.

**Table 1: Summary of studies examining pre-hospital delay - MI**

| | *n* | *Country* | *Data source* | *Median time symptom onset - hospital presentation (mins)* | *Notes* |
|---|---|---|---|---|---|
| Rawles, J & Haites, N (1988) | 450 | U.K | Medical records | 120 | |
| Rawles, J et al (1990) | 250 | U.K | Patient interview | 90 | |
| Goldberg, R et al (1992) | 800 | USA | Medical records | 120 | |
| Yarzebski, J et al (1994) | 1279 | USA | Medical records | 120 | |
| Bleeker, J et al (1995) | 300 | Netherlands | Patient interview | 30 | |
| GISSI group (1995) | 5301 | Italy | Patient interview | 230 | |
| Dracup et al (1997) | 317 | Australia | Patient interview | 384 | |
| Rawles, J et al (1998) | 1046 | UK | Medical records | 45 | GP |
| | | | Medical records | 150 | Hospital |
| Goldberg, R et al (2000) | 3837 | USA | Medical records | 132 | 1986 |
| | | | Medical records | 120 | 1997 |
| Canto et al, (2000) | 434877 | USA | Registry | 474 | no chest pain |
| | | | Registry | 318 | chest pain |
| Horne, R et al (2000) | 88 | UK | Patient interview | 132 | |
| O'Carroll, R et al (2001) | 72 | UK | Patient interview | 167 | |
| Gibler, W et al (2002) | 27849 | USA | Thrombolytic trial | 84 | GUSTO I |
| | | | Thrombolytic trial | 84 | GUSTO II |
| Goldberg, R et al (2002) | 3693 | International | Registry | 138 | |
| Dracup, K et al (2003) | 192 | USA | Patient interview | 198 | |
| | 127 | S. Korea | Patient interview | 264 | |
| | 136 | Japan | Patient interview | 270 | |
| | 141 | England | Patient interview | 150 | |
| | 317 | Australia | Patient interview | 384 | |

Despite these problems, it is clear that most studies suggest median pre-hospital times of >2 hours. The consequence of this is that many patients with MI may not receive maximal benefit from the treatments available (described on page 8).

Fewer studies have been conducted amongst patients with ACS other than MI. Table 2, below, summarises those identified which reported median pre-hospital times. The same issues with comparison apply to these studies. In fact, the issue regarding different populations is even more evident. Participants might include those with chest pain (Goff et al. 1999), those with possible symptoms of ACS (Grossman et al. 2003) or those with a final diagnosis of UA or NSTEMI (Goldberg et al. 2002b). However, consistent with the studies of patients with MI, most report pre-hospital times >2 hours.

The GRACE project provides useful data comparing pre-hospital times amongst a large group of patients with ACS (Goldberg et al. 2002b). Eighteen countries participated in the GRACE project, collecting demographic and detailed clinical data on patients hospitalised with ACS. Data from 10,582 patients was used to explore the extent of, and factors associated with, delay to hospital presentation. This sample included 3693 patients with ST elevation MI; 2935 with NSTEMI and 3954 with unstable angina. Delay time was defined as the time interval between the onset of symptoms suggestive of ACS and arrival in the Emergency Department (ED). Average delay times were highest in patients with NSTEMI (mean 6.1 hours, median 3.0 hours) followed by patients with unstable angina (mean

5.6 hours, median 3.0 hours) and were shortest in those with ST elevation MI (mean 4.7, median 2.3 hours). A significant proportion (23% – 32%) of all patient groups arrived in the emergency department more than 6 hours after symptom onset. These data confirm that prolonged times from symptom onset to hospital arrival remain an issue for patients with MI and are also associated with the other ACS, possibly to an even greater degree.

In summary, ACS is common and potentially life-threatening. Interventions are most effective when administered early. However, there is substantial evidence that delays occur between the onset of symptom and receipt of treatment and thus this period of delay is an important focus for research.

**Table 2: Summary of studies examining pre-hospital delay - ACS**

| | *n* | *Country* | *Median time symptom onset - hospital presentation (mins)* | *Data source* | *Participants* |
|---|---|---|---|---|---|
| Goff, D et al (1999) | 3783 | USA | 120 | Medical records | Chest pain or discomfort at ED |
| Goldberg, R et al (2002) | 2935 | International | 180 | Registry | NSTEMI |
| | 3954 | International | 180 | Registry | UA |
| Rasmussen, C et al (2003) | 337 | Denmark | 233 | Interviews | Chest pain, suspicion of ACS |
| Grossman, S et al (2003) | 374 | USA | 240 | Questionnaire | Symptoms suggestive of ACS |
| Ottesen, M et al (2004) | 250 | Denmark | 107 | Interviews | Admitted with ACS |

## *2.4 Factors associated with longer pre-hospital times*

Many studies have been conducted with the aim of identifying factors associated with longer pre-hospital times in patients with ACS. Although there have been some conflicting results, a number of factors have been identified as being associated with longer pre-hospital delay, these are described below.

### 2.4.1 Demographic factors

#### *Age*

A number of studies have found a relationship between age and pre-hospital time. The Worcester Heart Attack Study group in the USA conducted a retrospective chart review of 3837 patients who had been hospitalised and received a discharge diagnosis of MI in seven, one-year periods between 1986 and 1997 (Goldberg et al. 2000). They found that when those who arrived <2 hours after symptom onset were compared with those who arrived >2hours, there were significantly more patients aged over 75 years in the latter group. Multiple regression analysis confirmed age was associated with an increased risk of delay. Similarly, in a study of patients with ACS the GRACE investigators found that 32% of patients aged under 55 years presented within 2 hours whereas only 17% of those aged over 75 years did so (Goldberg et al. 2002b). Similar patterns have been identified in other studies although different time points and age ranges have been used (GISSI, 1995; Gurwitz et al. 1997; Goff et al. 1999).

Dracup et al (1997) compared mean pre-hospital times between patients of different age ranges. The authors found that patients aged 61-86 years had significantly longer pre-hospital times (mean=122 mins.) than those aged 41-60 years (105 mins) or 29-40 years (66 mins.). Investigators using data from Global Utilization of Streptokinase and Tissue Plasminogen Activator for Occluded Coronary Arteries (GUSTO)-I and GUSTO-III found that patients with a pre-hospital time of less than 2 hours tended to be younger (median age = 60 years) than those who arrived at hospital later than 2 hours after symptom onset (64 years, $p$=0.001) (Gibler et al. 2002).

However, a few studies have failed to find an association between age and pre-hospital time. Burnett and colleagues (1995) studied 501 patients who formed a subgroup of participants in the Thrombolysis and Angioplasty in Myocardial Infarction (TAMI) trials (Burnett et al. 1995). Those who requested medical assistance within 60 minutes of the onset of symptoms (early responders) were compared with those who requested assistance later than 60 minutes (late responders). No significant differences in age or other demographic characteristics were found between the two groups. The mean age of the early responders was 57.6 years vs. 57.7 years in the late responder group (*ns*). Similarly, in a study of 88 patients with MI conducted in the UK, Horne et al (2000) found no relationship between age and pre-hospital time.

Possible reasons for the conflicting findings are difficult to identify. Patients aged over 76 years were excluded from participation in the TAMI trial; the absence of this much older group might have reduced the potential for this

study to identify an association. This study also used patient decision time as an outcome measure rather than total pre-hospital time. It is possible that whilst patients take similar times to request medical attention that their subsequent management differs systematically, on the basis of their age, so that older patients ultimately arrive later at hospital.

The different components of pre-hospital time were examined in a Danish study of 250 patients with ACS and thus provide an opportunity to address this hypothesis (Ottesen et al. 2004). However, in this study too, age was not found to be associated with any of the components of pre-hospital delay (time from onset of symptoms until hospital presentation; time from the onset of symptoms until seeking medical attention; time from seeking medical attention until arrival and time from arrival of ambulance to hospital). However, the authors did conclude that the different components of pre-hospital delay were not influenced by identical factors. Further research which differentiates the pre-hospital components of delay would be helpful.

A number of possible reasons for longer delays amongst older people have been suggested. There is evidence to suggest that as people get older, they are more likely to attribute many symptoms to 'normal' ageing (Leventhal and Prochaska, 1986). Older people are more likely to have existing co-morbid conditions, and this may complicate recognition of cardiac symptoms (Ryan and Zerwic, 2003). They are also likely to experience a greater number of symptoms in general, and thus have established patterns of coping which may not be desirable in the context of ACS (Stoller and Forster, 1994). Additionally, older people are more likely to live alone - this may

influence how and when they seek help (Gibler et al. 2002). The importance of the context of the event is discussed further on page 32.

***Female gender***

It is widely reported that women are likely to have longer pre-hospital times than men. Several very large investigations provide evidence of this. Data from 364,131 patients included in the US National Registry of Myocardial Infarction (NRMI-2) between 1994 and 1997 showed median pre-hospital times to be longer for women (Mdn=2.4 hours) than for men (2.0 hours) (Goldberg et al. 1999). Analysis of data from the GUSTO trials by Gibler et al (2002) also demonstrated that 35% women versus 27% men arrived more than 4 hours after the onset of symptoms ($p$=0.001).

In relation to ACS, data from The GRACE project have been reported. This project was described earlier (page 14). Data from 3693 patients with STEMI, 2935 patients with NSTEMI and 3954 with UA were used to explore factors associated with delay to hospital presentation (Goldberg et al. 2002b). Multivariate analysis demonstrated that, for each of the ACS, men were significantly more likely to present within 2 hours of symptoms onset than women. Other studies have found similar results (Gurwitz et al. 1997; Sheifer et al. 2000). However, the evidence is not consistent. Some investigators have found that relationships identified between female gender and pre-hospital time lose their significance when other factors (e.g. age) are controlled for in multivariate analysis (GISSI, 1995; Goff et al. 1999; Goldberg et al. 2000). Furthermore, a Danish study which analysed the various components of pre-hospital time (previously described on page 19)

found that total pre-hospital time was longer for women but, importantly, this was accounted for by physician and transport delays. Patient decision time was not related to gender. Other studies have not found gender differences in pre-hospital time amongst patients with MI (Burnett et al. 1995; Bleeker et al. 1995; Dracup et al. 1997; Dracup and Moser, 1997; Mumford et al. 1999; Horne et al. 2000; Schoenberg et al. 2003; Dracup et al. 2003; Zerwic et al. 2003) or other ACS (Grossman et al. 2003; Rasmussen et al. 2003).

A number of reasons why pre-hospital times might be longer for women than for men are suggested in the literature. There is evidence to suggest that women may be more likely to present with atypical symptoms (Meischke et al. 1998; Canto et al. 2000). This is a factor which has also been associated with increased pre-hospital delay (Dracup et al. 1997; Canto et al. 2000; Grossman et al. 2003).

Women tend to be older than men when they receive a diagnosis of CHD (Lerner and Kannel, 1986). The association between increased age and delayed presentation has already been discussed (see page 17). In each of the studies where the relationship between gender and pre-hospital time did not remain significant in multivariate analysis, age was identified as a significant factor.

It has been suggested that women may perceive their personal risk of CHD to be low and that this might influence what they do in the event of experiencing symptoms (van Tiel et al. 1998; Wilcox and Stefanick, 1999). Martin and colleagues have provided evidence that there are gender biases

in the attribution of cardiac symptoms. In one study, undergraduate participants were presented with vignettes where gender, symptoms and life events were manipulated (Martin et al. 1998). Participants were significantly less likely to attribute symptoms to possible cardiac causes for female victims reporting stressful life events than for females without such stressors or for male victims with or without concurrent stressors. Similarly, in a subsequent study of 157 patients who had experienced MI, women were found to be significantly less likely than men to attribute their pre-hospital symptoms to MI (Martin et al. 2004).

***Ethnicity***

Evidence regarding an association between ethnicity and time to presentation is mixed. The NRMI-2 investigators in a study of 346,131 patients with MI found that African Americans , Hispanics, Asians and American Indians (NRMI-2 authors' terminology) all had significantly longer pre-hospital times (Mdn=2.4 hours, 2.3 hours, 2.2 hours, 3.0 hours respectively) than white people (2.1 hours). Even within this very large registry the proportion of patients of non-white ethnic origin was small, an issue common to all the studies identified.

The GUSTO investigations also found that longer times from symptom onset to hospital arrival were associated with those of non-white race (6% >4 hrs) than those of white race (4% >4 hrs; $p$= 0.02) (Gibler et al. 2002).

Similarly, in a study of time to presentation in elderly patients with MI, Sheifer et al (2000) found that individuals arriving more than 6 hours after the onset of symptoms were significantly more likely to be non-white ($p$=0.001) .

A study which specifically compared the presentation and management of African American and white patients presenting to the ED found similar results (Johnson et al. 1993). After adjustment for presenting symptoms, African Americans were found to be significantly more likely to present at the ED more than 6 hours after the onset of symptoms (OR 1.3; 95% CI 1.1-1.5). The REACT group also found longer pre-hospital times amongst non-Hispanic blacks (Mdn = 3.26 hours) than non-Hispanic whites (2.0 hours) (Goff et al. 1999).

Conversely, a study conducted in the USA amongst 215 patients admitted to a Chest Pain Unit did not find any significant association between race and the timing of symptoms (Klinger et al. 2002). Studies of patients awaiting PTCA (Conigliaro et al. 2002), patients who have died from CHD (Frayne et al. 2002) and of Bangladeshi patients with MI in the UK (Barakat et al. 2003) have also failed to find an association between race and time to presentation.

The weight of available evidence, particularly in the context of MI would appear to suggest an association. The reasons why this would be the case are unclear. In a vignette study conducted in the UK, black respondents were at least as likely as white respondents to seek immediate health care in response to 2 scenarios, one of which was ‘chest pain’ (Adamson et al. 2003). The authors concluded that any barriers to care related to ethnicity must occur at the level of healthcare provision. Other studies have found differences in the management of patients with ACS and chest pain to be related to ethnicity (Johnson et al. 1993; Pope et al. 2000). Future research relating to pre-hospital time and ACS should consider the role of ethnicity and

more actively seek participation of people from various ethnic backgrounds. Evidence about how ethnicity relates to the various stages of pre-hospital time would be particularly useful in order to identify any patient or provider-related issues which might be amenable to intervention.

***Socio-economic factors***

Fewer studies have examined the impact of socio-economic factors in relation to time to treatment in patients with MI. Variations in how socio-economic status was assessed further hampers comparisons between the studies that have been conducted.

Gurwitz et al (1997) studied 2409 people in Minnesota with confirmed MI. Socioeconomic status was determined on the basis of zip code and was not found to be associated with delayed presentation (i.e. time from symptom onset to hospital arrival > 6 hours). Two smaller studies (<100 participants) conducted in the UK amongst patients with MI also found no association between socio-economic status and pre-hospital delay (assessed using the Registrar General's classification of occupation as a measure of socio-economic status) (Mumford et al. 1999; Horne et al. 2000).

However, Dracup et al (1997) studied a subset of 277 patients enrolled in a thrombolytic trial (GUSTO-I) and found that people with an income of more than $20,000 had significantly lower mean time from symptom onset to hospital admission than those with a yearly income of less than $20,000 (103 minutes vs. 136 minutes; $p$=0.01).

Sheifer et al (2000) in their study of over 100,000 older adults with MI also

found an association between residence in an impoverished area and time to presentation. Impoverished areas were identified by zip code. Sixteen percent of those who presented more than 12 hours after onset of symptoms lived in an impoverished area versus 14% of those who presented less than 6 hours after the onset of symptoms (p=0.001). It has previously been suggested that the effect of race might be confounded by socioeconomic factors. Interestingly, in this study, poverty and race were demonstrated to be *independently* associated with time to presentation. However, significant interaction effects were also identified, suggesting that individuals with multiple racial, economic and gender characteristics are at particular risk of delayed presentation.

The GUSTO investigators (2002) evaluated occupation, years of education, type of insurance and living alone as socioeconomic measures. People with higher educational levels (30% vs. 26%; *p*=0.001), management or professional occupations (28% vs. 21%; *p*=0.001), private health insurance (64% vs. 56%; *p*=0.003) or who did not live alone (23% vs. 18%; *p*=0.006) were found to present more quickly to hospital. Again, this sample was selected for a thrombolytic trial and was again conducted in the US so there are limits to the generalisability of the findings.

As mentioned previously, a number of measures of socio-economic status were used in this context. Each has its own advantages and limitations. The use of zip code data as a measure of socioeconomic status can be criticised– all residents of impoverished regions are not poor (Piantadosi et al. 1988). However such data are often used as a proxy when individual data are not

available and has the advantage of being easily replicated, facilitating comparison between studies.

The use of income level alone as a measure of socio-economic status can also be problematic, particularly amongst older people. Older persons' income may be low but they may be wealthy or of high social status. Income may also come from a number of different and possibly indirect sources e.g. tax exemption (Grundy and Holt, 2001).

Classifications based on occupation also have inherent difficulties. No adequate way has been found to classify those who are not in paid employment such as retired people or those caring for young children at home. Furthermore there may be wide differences in income, prestige and education within classes of one occupational group.

A recent qualitative study conducted in Glasgow provides insights into possible reasons why pre-hospital time might be related to socio-economic status (Richards et al. 2002). Data from interviews with 30 participants (15 affluent; 15 deprived) suggested that people from socio-economically deprived areas report higher perceived vulnerability to CHD, probably deriving from their increased exposure to affected family or friends and identification with a high risk stereotype. However, the authors suggested that increased awareness led to normalisation of symptoms such as chest pain. This, coupled with confusion with other conditions and concerns about over-using services, led to a tendency *not* to present to healthcare providers with chest pain.

The relationship between social deprivation and delayed presentation with

ACS is clearly an area which requires further investigation. Future research should aim to include standard measures of socio-economic status and to better represent people from poorer social backgrounds.

### 2.4.2 Clinical characteristics

A number of clinical characteristics, such as symptoms and past medical history have been evaluated in relation to time to presentation in ACS. These factors are discussed in more detail below.

#### *Symptoms*

Many of the largest studies of pre-hospital time in ACS have not examined the influence of the symptoms experienced by patients (Goldberg et al. 1999; Goldberg et al. 2000; Sheifer et al. 2000; Gibler et al. 2002). This is probably due to the reliance of these larger studies on registries and database data. However, other studies have explored the severity, type and number of symptoms in relation to pre-hospital time, these are described below.

##### *Severity*

An association between the severity of presenting symptoms and the time to hospital arrival was reported by the GISSI group (1995). They found that compared with patients who reported strong pain; those with mild / moderate pain were significantly more likely to present more than 6 hours after symptom onset (OR: 1.86, 95% CI: 1.28-2.72).

Similarly, Horne and colleagues (2000) examined symptom severity in

relation to pre-hospital time. A visual analogue scale was used to assess symptom severity. They reported a weak negative correlation between symptom severity and pre-hospital time ($r$= -0.24; $p$<0.05). A qualitative investigation has also suggested that the presence of less severe symptoms may influence decision making processes, leading individuals to doubt that their symptoms could be those of a heart attack (Pattenden et al. 2002).

However, other studies have found no association between pain scores (Walsh J C et al. 2004) or other assessments of pain severity (Dracup and Moser, 1997) suggesting that factors other than the severity of symptoms are important (Dracup et al. 1997; Mumford et al. 1999).

***Type***

The type of symptoms associated with extended pre-hospital time has also been examined in some studies. Following their examination of the NRMI-2 database, Canto and colleagues (2000) concluded that the presence or absence of chest pain was an important factor. They found that patients *without* chest pain had significantly longer pre-hospital time (mean = 7.9 hours) than those with chest pain (5.3 hours). Similar results were found in the UK where the mean delay of patients who did not experience chest pain was 11.5 hours compared with 4.8 hours amongst those who did (Horne et al. 2000). Gurwitz et al (1997) found the presence of chest discomfort to significantly reduce the risk of delay.

The presence of diaphoresis or extreme sweating has been associated with reduced pre-hospital time (Dracup et al. 1997; Bunde and Martin, 2006) whereas the presence of heartburn or other gastro-intestinal symptoms has

been associated with longer delay (Dracup et al. 1997; Dracup and Moser, 1997; Bunde and Martin, 2006).

Amongst patients with ACS, the GRACE investigators found that a higher proportion of those who arrived at hospital within 2 hours had diaphoresis (28%) than did those who arrived > 6hours after symptom onset (20%; *p*<.001) (The GRACE Investigators, 2001).

***Number of symptoms***

The influence of the number of symptoms experienced by patients on pre-hospital time has been explored by a number of authors but no association has been found (Mumford et al. 1999; Horne et al. 2000; Walsh J C et al. 2004).

***Diabetes mellitus***

People with a history of diabetes mellitus are a group who have consistently been shown to have longer pre-hospital times. The studies of patients with MI already described above by the GISSI (1995), NRMI-2 (Goldberg et al. 1999) and Worcester groups (Goldberg et al. 2000) have all found a history of diabetes to be associated with longer pre-hospital times in multivariate analysis (OR (95% CI) = 1.36 (1.09-1.70); 1.20 (1.18-1.22); 1.27 (1.09-1.48) respectively). Similarly, Shiefer et al (2000) found that the presence of diabetes was a significant predictor of hospital arrival >6 hours after symptom onset in their study of patients aged >65 (OR: 1.11, 95% CI: 1.07-1.14).

With regard to ACS, data from the GRACE registry showed that patients with diabetes were significantly less likely to present within 2 hours of symptom

onset than those without (OR: 1.84, 95% CI: 1.14 - 2.95) (The GRACE Investigators, 2001).

Reasons why patients with diabetes might experience longer pre-hospital times have been suggested. Research has demonstrated that people with diabetes who are experiencing MI are significantly more likely to present *without* chest pain (Canto et al. 2000). The absence of this 'classic' symptom may lead to difficulties in symptom interpretation both for patients and bystanders, as well as for clinicians. Diabetes is often associated with neuropathy and it is hypothesised that this results in altered symptom perception in this patient group (Ambepityia et al. 1990; Umachandran et al. 1991), with the result that symptoms are more difficult to interpret. The pathology of CHD in diabetics is also different and associated with extensive and diffuse disease (Morgan et al. 2004). This may influence how individuals experience acute events.

Diabetes is an established risk factor for coronary disease (Garcia et al. 1974), thus people with diabetes are at higher risk of experiencing ACS. Furthermore, outcomes for diabetic patients who experience ACS are poorer than those for patients without diabetes (Franklin et al. 2004). Thus the reduction of pre-hospital times for this group is a particularly important goal for future research.

***Previous history of CHD***

The evidence regarding the importance of patients' previous cardiac history in relation to pre-hospital times is conflicting and difficult to interpret.

The Worcester Heart Attack study group (Goldberg et al. 2000) and Sheifer et al (2000) found that longer pre-hospital times were associated with patients who had a past medical history of angina. However, two studies by Dracup et al found no association (Dracup et al. 1997; Dracup and Moser, 1997). Furthermore, neither of the these studies identified a relationship between a previous history of MI and pre-hospital time, a finding consistent with those of the GISSI investigators (1995). However, studies of elderly patients post- MI (Sheifer et al. 2000) and patients with ACS (Ottesen et al. 2004) have found that a history of MI is associated with reduced delay. More consistently, investigators have found patients with a history of coronary intervention (i.e. PTCA or coronary artery bypass graft surgery (CABG)) to be less likely to have prolonged pre-hospital times with subsequent MI (Gurwitz et al. 1997; Sheifer et al. 2000) or ACS episodes (Goldberg et al. 2002b). However, Ottesen et al (2004) found a history of PTCA to be associated with longer pre-hospital delay in patients with ACS.

Data from qualitative studies provide insights into possible mechanisms. In a study of patients with confirmed second, third or fourth MI, 20 of the 22 patients studied reported that the symptoms of their recent event were not similar to those of any previous MI. This was found to have led to confusion and slow the decision-making process (Pattenden et al. 2002).

Another study suggests that people may find it hard to distinguish the symptoms of MI from those of other pre-existing conditions such as stomach ulcers (Scherk, 1997). This might be especially true for people with an existing diagnosis of angina where the nature of the symptoms may be very

similar. Given that people with existing angina have established CHD and are therefore at increased risk for MI this is of particular importance.

### 2.4.3 Context

The context in which the acute coronary event takes place has also been the subject of investigation. The time of day, location and presence or absence of others have been examined and are discussed below.

***Time of day***

Conflicting results regarding the significance of time of day have been reported. Gurwitz et al (1997) found that patients with symptom onset between midnight and 5:59 hrs were more likely than those with symptom onset between 06:00 and 11:59 hrs to have a pre-hospital time >6 hrs. Similarly the GRACE investigators found that daytime symptom onset (noon-17:59 hrs) was associated with shortest pre-hospital times (Goldberg et al. 2002b).

The GISSI group found that those experiencing symptoms at night or when asleep were significantly more likely to have increased times from symptom onset to admission than those who experienced symptoms at other times. Seventy-one percent of patients who presented in less than 6 hours did so during the day, whereas only 29% did so at night (GISSI, 1995). However the Worcester group found the occurrence of symptoms between noon and midnight to be significantly associated with pre-hospital times of >2 hours and > 6 hours (Goldberg et al. 2000).

Reasons for these conflicting results are not clear. Evidence from a

qualitative study suggests that people might be reluctant to seek help during the night and weekends (Pattenden et al. 2002). The findings of the first three studies are consistent with this hypothesis.

***Location and presence of others***

A number of studies have found that people tend to delay longer if they are at home when symptoms arise (GISSI, 1995; Dracup and Moser, 1997) whilst others have not (Dracup et al. 1997; Mumford et al. 1999). The GISSI investigators (1995) found that the presence of others at the time of onset of symptoms was associated with reduced delay but that the relationship of a bystander to the person with symptoms was an important moderator. Spouses and relatives were less successful in reducing delay than friends or strangers (GISSI, 1995). Living alone was also found to be an independent predictor of pre-hospital delay (OR: 2.11 95% CI: 1.57-2.83), possibly highlighting the importance of others in facilitating help-seeking. Others have not found a relationship between pre-hospital times and the presence of others in the context of MI (Dracup and Moser, 1997; Mumford et al. 1999). Horne et al (2000) found that others were influential in the decision to call for help but only if the patient's experience of their symptoms did not match their prior expectations of a heart attack. This highlights the possible importance of psychological factors in the context of ACS, these are discussed further below.

## *2.5 Patient decision time*

The pre-hospital phase of MI can be conceptualised in 3 phases: *appraisal*

*delay* – the time someone takes to identify a symptom as an indication that they are ill; *illness delay*- the time between someone recognising that they are ill and deciding to seek medical attention; and *utilisation delay*- the time taken between seeking medical care and actually receiving it (Safer et al. 1979).

There are data to suggest that the interval which contributes most to pre-hospital time is the *patients' decision time*, defined as the interval between the onset of symptoms and the decision to seek help (or appraisal and illness delay combined, using Safer et al's definition above). The GISSI group (1995) calculated that patient decision time accounted for approximately 80% of the overall delay in those who delayed over 12 hours and for 23% among those who presented earliest (i.e. within 2 hours).

Data from the Worcester Heart Attack Study (1986 -1997) (Goldberg et al. 2000) and from a pair of thrombolytic trials conducted 1990-1997 (Gibler et al. 2002) suggest that patient decision time has remained unchanged during the respective study periods. The second study (Gibler et al. 2002) found that time from arrival at hospital to administration of treatment had improved significantly due to the introduction of new procedures aimed at facilitating rapid assessment and treatment of this group of patients. However during the same period, the time from onset of symptoms to arrival at hospital had remained unchanged.

Interventions aimed at reducing pre-hospital delay have met with little success. Two RCTs, including the large scale Rapid Early Action for Coronary Treatment (REACT) trial, reported no statistical effect of the

intervention (Meischke et al. 1997; Luepker et al. 2000).

A systematic review of interventions to reduce delay in patients with suspected heart attack identified one controlled trial and three 'before and after' studies which specifically examined patient delay (Kainth et al. 2004). A Swiss before and after study reported a significant reduction in median delay during a 12 month multimedia public campaign (180 mins. vs. 155 mins., $p<.001$) (Gaspoz et al. 1996). The multi-media campaign was intensive and data regarding the long term effect of the campaign could not be identified within the literature.

However, the other before and after studies reported no differences in delay (Ho et al. 1989; Bett et al. 1993). The controlled trial reported an increase in the percentage of patients in the intervention group calling their GP after the intervention (compared with before) but this was not compared with the control group (Rowley et al. 1982).

The content of interventions has varied but most include information about the importance of prompt action when symptoms occur. Given the substantial complexities involved in recognising and attending to symptoms, identifying the likely cause and identifying the appropriate avenue for healthcare such messages may be over-simplistic. Psychological factors are likely to be of key importance in this context. These are discussed in further detail in the following section.

### 2.5.1 Psychological factors

#### *Attributions*

Whether or not an individual attributes the symptoms they are experiencing to the heart has consistently been shown to relate to pre-hospital times in ACS. Data from 501 patients enrolled in a clinical trial of revascularisation procedures showed that patients who arrived at hospital <60 mins after the onset of symptoms were more likely to believe their symptoms were cardiac in nature than those who arrived later (Burnett et al. 1995). A large number of demographic, contextual and clinical factors were considered in this study but attribution of symptoms to the heart emerged as one of the two most significant predictors of pre-hospital time. The authors calculate that attributing symptoms to the heart resulted in patients reaching hospital 26 minutes earlier than if symptoms were attributed to any other body system.

Other studies of patients with MI have found similar results (Dracup and Moser, 1997; O'Carroll et al. 2001; Carney et al. 2002; Bunde and Martin, 2006). However, a number of these studies also demonstrate that the majority of patients do *not* usually attribute their symptoms to the heart and are more likely to attribute symptoms to indigestion (Burnett et al. 1995; O'Carroll et al. 2001; Carney et al. 2002). O'Carroll and colleagues found that 42% of patients with MI attributed their initial symptoms to heartburn or indigestion whilst only 17% believed it was a heart attack. Thus the data provide evidence that patients' cognitions about their symptoms and the meanings they ascribe to them influence when they seek medical help in the context of ACS.

### *Expectations*

Whether or not people perceive their symptoms as related to their heart may be influenced by their expectations of what the symptoms of MI might be. It has been reported that many people share an expectation that a heart attack will be a sudden and dramatic event – the so-called 'Hollywood' portrayal (Finnegan et al. 2000). However, evidence suggests that many patients do not experience sudden or dramatic symptoms. Following interviews with hundreds of patients with MI, Dracup et al (1995) reported that approximately a third did not report abrupt onset of symptoms and consequently found it difficult to specify the time of onset. Similarly, after conducting 34 focus groups amongst people who had experienced or witnessed an MI, Finnegan et al (2000) reported that even classic symptoms were often of gradual onset or preceded by vague or mild symptoms which made them difficult to interpret.

Johnson and King (1995) first highlighted the importance of expectations in relation to help-seeking in their study of 65 patients with MI. They found that only 26% of patients experienced symptoms that matched their expectations. Furthermore, they found that patients, whose experience of MI did not match their expectations, were likely to delay significantly longer than those whose expectations matched their symptoms. A similar pattern was reported by Horne et al (2000) in a study of 88 patients with MI. These authors found that 58% of patients reported a mismatch between the symptoms they expected and those they experienced as part of the MI. They reported an association between patients' expectations and help-seeking too. The decision to call for help was more likely to be made by a third party if the patients' experience of

symptoms did not match their prior expectations ($p$<0.05). Waiting for symptoms to match expectations may explain why many patients, despite realising that something is wrong, describe a 'wait and see' approach (Finnegan et al. 2000). Certainly, in the qualitative study involving patients who had experienced their second, third or fourth MI, many reported waiting until their symptoms resembled those of the previous MI before seeking help (Pattenden et al. 2002). Alternatively, it may be that people choose to 'wait and see' as they expect the symptoms to go away (Leslie et al. 2000). Deciding *not* to 'wait and see' was identified as a predictor of early help-seeking by Dracup et al (1997).

Together, these studies highlight the importance of expectations about symptoms in relation to help-seeking and time to treatment. This is an essential focus for future research as the potential may exist to modify expectations about the symptoms of MI amongst the general population and thus impact on help-seeking and pre-hospital time.

***Influence of others***

The study by Horne et al also highlights that people other than the patient may be important in the decision to seek medical help. It is common for people experiencing possible symptoms of ACS to discuss their symptoms with others e.g. spouse, family member, friend (Brink et al. 2002; Rasmussen et al. 2003; Johansson et al. 2004; Bunde and Martin, 2006). It has been identified within the literature that the responses of others may be either instrumental in facilitating prompt medical help or otherwise (Burnett et al. 1995; Dracup and Moser, 1997). The GISSI investigators found that

patients who experienced symptoms in the presence of others were more likely to have shorter pre-hospital times than those who were alone (GISSI, 1995). Similarly 'seeking social support' was found to be associated with reduced pre-hospital time in patients with MI in a Dutch study by Bleeker et al (1995). An American study of 2316 survivors of MI found that, of those who had contacted '911', only 21% did so themselves. In 40% of cases the call was made by a spouse or significant other; 16% by another family member; 23% by other people (Meischke et al. 1995)

However, in studies where the nature of the responses provided by bystanders has been examined, no differences have been found in the pre-hospital times of patients who received advice to seek medical help and those who did not (Burnett et al. 1995; Dracup and Moser, 1997). Furthermore, results where patients who informed a relative were more likely to have pre-hospital time >2 hours have been reported (Rasmussen et al. 2003). Similarly, qualitative work has identified the positive influence of others in the decision to seek medical help (Brink et al. 2002; Lockyer, 2005) but also highlighted important examples where this was not the case (Lockyer, 2005).

There is evidence to suggest that the decision to seek medical help may be more likely to be made by a bystander if the patient is older (Schoenberg et al. 2003) or male (Martin and Lemos, 2002) Others have found that a third party is more likely to intervene if the symptoms the patient is experiencing do not match their expectations of MI (Horne et al. 2000).

Understanding of the role of others in facilitating patients with possible

symptoms of ACS towards prompt medical attention is incomplete and an important area for future research.

### *Perceptions of symptoms*

Individuals' perceptions of the symptoms they experience have also been found to be related to pre-hospital times. The perceived seriousness of the symptoms has been investigated most often. Consistently, studies have found that those who perceive their symptoms to be serious have shorter pre-hospital times than those who do not (Burnett et al. 1995; Dracup and Moser, 1997; Rasmussen et al. 2003; McKinley et al. 2004; Bunde and Martin, 2006). Indeed in the relatively large (n=501) study by Burnett and colleagues (1995) the most significant predictor of pre-hospital time was the perceived seriousness of symptoms.

A study conducted in Scotland amongst survivors of MI reported that '*not thinking it was serious'* was the second most common reason offered by participants who called for help more than 1 hour after the onset of symptoms ('*thinking the problem would go away'* being the most common) (Leslie et al. 2000). The same study found that thinking that symptoms were '*not important enough for 999'* was the most common reason for choosing the GP as the first point of contact.

Perceptions of control have also been explored. Burnett et al (1995) found that early responders (pre-hospital time <60 mins.) reported less perceived control over their symptoms than late responders (pre-hospital time >60 mins.).

In an international comparison of data on delay in presentation in the context of MI, McKinley et al (2004) report that those with high perceived ability to control symptoms have significantly higher median delay times than those with low perceived ability to control ($p<0.05$) .

O'Carroll et al (2001) used the validated Multidimensional Health Locus of Control scale (Norman and Bennett, 1995), amongst 72 patients 3-5 days post-MI. They found that the belief '*health is largely due to chance factors'* was the best predictor of extended time to presentation. This suggests that those who believe there is little they can do to control their health are most likely to delay and is therefore consistent with the findings of the previous studies.

Thus there is evidence that the beliefs people have about the likely cause and seriousness of their symptoms, and the degree to which they believe they have control over symptoms, may influence how quickly they seek medical help in the context of MI.

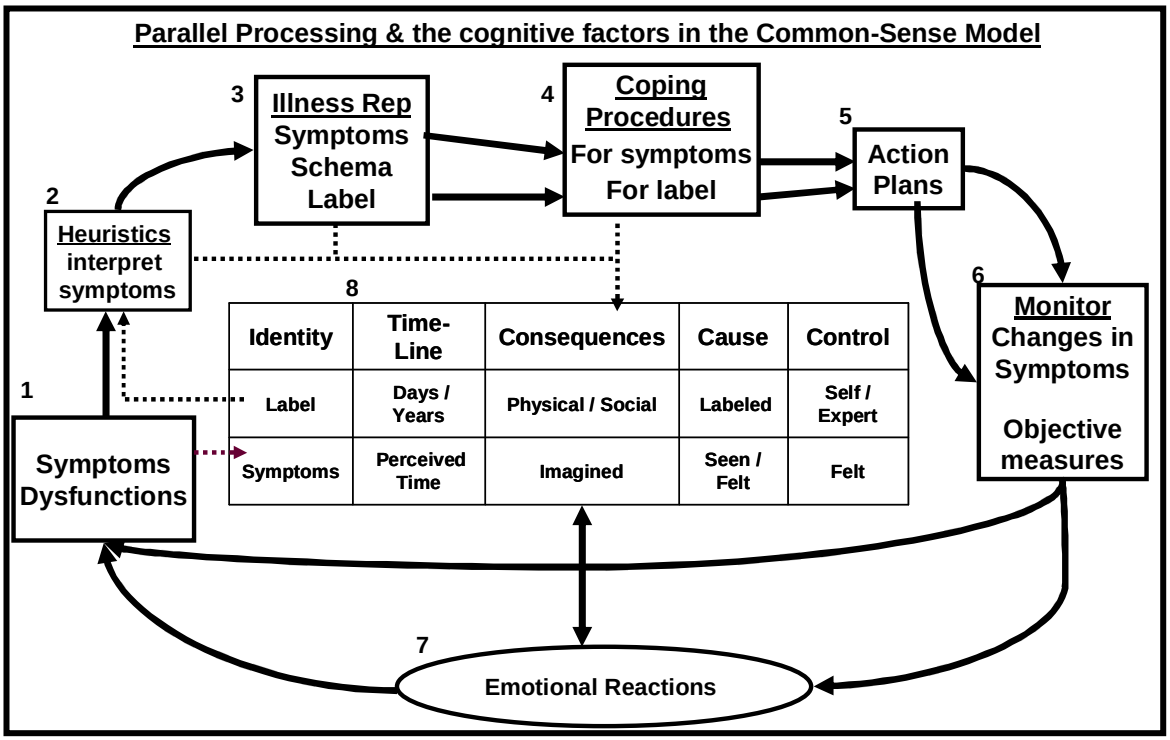
The premise that people hold beliefs about illness which guide their coping is a key component of Leventhal's commonsense model of self-regulation (CS-SRM). The CS-SRM has been selected to provide the theoretical framework for the study. The model and the empirical evidence for it's application in this context are described in detail in the following section.

## *2.6 Leventhal's commonsense model of self-regulation*

### 2.6.1 General overview

The CS-SRM posits that individuals actively develop representations of illness based upon (1) a general pool of knowledge of illness current in culture, (2) social communication with individuals such as health professionals or family and (3) personal experience of illness. It is hypothesised that a change in somatic activity, such as a symptom, stimulates a self-regulatory process whereby individuals integrate such pre-existing ideas about illness with current bodily experiences. The processing system can be viewed as consisting of 2 parallel pathways. One involves the creation of a cognitive representation or 'mental picture' of a health threat and the development of a coping plan. The other pathway involves the creation of an emotional representation of the health threat and an associated plan for coping with the emotional response. The 2 pathways are proposed to interact, as the threat develops, via feedback loops and appraisal of coping strategies. Therefore, failure of coping mechanisms to control emotion may result in a change in the cognitive representation (e.g. intensify or diminish symptoms). Similarly, failure of coping mechanisms to ameliorate symptoms may result in alteration to emotional representations e.g. causing distress (Leventhal et al. 1984).

**Figure 1: Leventhal's commonsense model of self-regulation (CS-SRM).**




*Reproduced with permission from Leventhal et al (2007).*

Thus, the processing system can be conceptualised as operating in three stages. The first involves the creation of cognitive and emotional representations and thus goals for coping; the second stage refers to the development and execution of plans for coping directed towards those goals; the third stage of appraisal involves evaluating whether the coping response has moved the individual closer to, or further from, the goals specified by the representation. Each stage involves both concrete (e.g. chest pains) and abstract features (the idea that one is having a heart attack). It is suggested by Leventhal et al (1984) that cognitive representations might be influenced most by abstract information, whilst emotional representations might depend to a greater degree on concrete processing.

### 2.6.2 Illness representations

Early work by Leventhal and colleagues involved using open-ended interviews to elicit the illness representations of patients with hypertension and cancer (Leventhal et al. 1980). They identified that the content of representations was elaborated around 4 main components, namely *identity, timeline, cause and consequences.* Identity refers to the label a person uses or to the symptoms that they view as being part of their illness. Timeline refers to an individual's beliefs about how long the illness will last. Cause describes an individual's personal ideas about the cause of the health problem. Consequences relate to an individual's beliefs about the likely impact of the illness on quality of life or functional ability. Both abstract and concrete information might contribute to an individual's illness representation.

In studies where undergraduate students were asked to describe the last time they were sick, Lau and Hartman (1983) provided evidence that people also have ideas about how one might recover from a disease and the fifth component of *cure/control* was added to the model. However, in Lau and Hartman's study, the questions were framed in terms of the model, e.g. '*why do you think you got sick?*' (cause), '*why do you think you got better?*' (cure/control) which would clearly have influenced the type of response obtained. However, evidence of the five components of illness perception was confirmed in subsequent studies using different methodologies. Bishop et al (1987) provided participants (undergraduate students) with scenarios of symptoms which varied in their seriousness and typicality . Participants were asked to describe other details that might be associated with the symptoms. The responses were coded according to the components of illness

perception or to a residual ‘other’ category (identity was split into symptoms and labels due to the nature of the study). Results showed that 91% of responses were coded to the 5 components of illness perception.

Similarly, in a later study of students and their parents, Lau and colleagues (1989) asked participants to describe everything they remembered about a recent illness. Responses were divided into distinct thoughts and then coded according to the same categories as Bishop and colleagues (1987). Almost all respondents (99.5%) identified symptoms or labels (identity); 72% gave responses relating to timeline; 51.8% to cause; 45% to consequences; 53.1% to cure/control. Just over 40% of responses were coded as other. These were reported as being idiosyncratic and that they could not be placed in categories that included more than 2% of the population.

Acknowledging that the main limitation of this study was that the coding was performed by the authors, a validation study was also conducted. A random sample of example statements from the original study were selected and given to 20 naïve participants who were asked to sort them into groups that made sense to them. The authors reported high correspondence between the observed groupings of the naïve participants and the a priori, theory-driven categorisations. Together, the results of these studies provide strong support for the existence of the components of illness representations.

The CS-SRM proposes that as an illness unfolds, coping procedures are executed and appraised, and illness representations become increasingly elaborated. It is suggested that the more complex the representations, the more likely that active coping mechanisms will be adopted (Cameron et al.

1993). When this process results in a judgement by an individual that a symptom(s) is (are) serious, disruptive of ongoing activities and difficult to control, it is hypothesised that a person is more likely to seek help.

The Illness Perception Questionnaire (IPQ) was designed to provide a quantitative method of assessing the components of illness representation present in Leventhal's CS-SRM (Weinman et al. 1996). This was revised (IPQ-R) to improve internal consistency of some subscales and to include assessment of emotional representations which were not assessed in the original IPQ (Moss-Morris et al. 2002). In addition, the revised measure includes an assessment of the degree to which a person's representation of illness provides a coherent understanding. Subsequent empirical work by Hall et al (2004) has confirmed *coherence* to be an important factor in predicting health behaviour.

The CS-SRM has been used in a large number of studies amongst different populations including diabetes (Griva et al. 2000), chronic fatigue syndrome (Heijmans, 1998) and coronary heart disease (Petrie et al. 1996). A meta-analysis of 45 studies found evidence of theoretically predictable relationships between illness cognitions, coping and outcome but also highlighted the need for further longitudinal data (Hagger and Orbell, 2003).

### 2.6.3 Illness representations and seeking medical help

The hypothesis that illness representations guide help-seeking, as described above, is supported by empirical evidence. In a longitudinal field study, Cameron et al conducted 111 interviews amongst people spontaneously

seeking medical care from their physician (Cameron et al. 1993). They compared the illness representations of care-seekers with 111 matched controls. The authors found that care seekers were more likely than controls to have identified their symptom problems with a disease label ($p<0.02$). Symptoms were rated as more serious by care-seekers than by controls ($p<0.001$) and ratings of symptom disruption of daily activities were higher for care-seekers compared to controls ($p<0.01$). The data from this study support the hypothesis that symptoms play a key role in the initiation of help-seeking. In addition, they suggest that the presence of symptoms *alone* is not sufficient to motivate a decision to seek care. Controls who experienced comparable symptoms (but who did not seek help) gave their symptoms significantly lower seriousness ratings and were less likely to identify possible consequences. The study reinforces the importance of interpretive processes in prompting care-seeking. However, it should be borne in mind that these data were obtained retrospectively. This introduces the possibility that people who sought care might represent their symptoms in a way which justifies their decision to attend a physician. The authors assert that this is unlikely, as the use of healthcare services as a focus for the study was not apparent to the participants.

### 2.6.4 Illness representations and pre-hospital time

The usefulness of the model as a framework for explaining pre-hospital delay, amongst people with MI, was recently examined by Walsh et al (2004). Sixty-one consecutive patients admitted to a coronary care unit (CCU) were interviewed by a health psychologist 2-4 days post MI. The IPQ (Weinman et

al. 1996) was used to assess illness representations. Data from measures such as the McGill Pain Questionnaire (Melzack, 1975) and the Coping Response Inventory (Billings and Moos, 1981) were also analysed, as were demographic, clinical and social variables. The consequences scale of the IPQ was found to be significantly related to delay ($r$=-.50, $p$<0.01). Those who perceived their MI to have serious consequences had shorter delay times. Coping style was also found to be significantly associated with delay. Those with strong active-cognitive coping style or strong problem-focused coping style had shorter delay times ($r$=-.46, $p$<0.01; $r$=-.43; $p$<0.01). Hierarchical multiple regression was then used to evaluate the components of CS-SRM. Demographic variables were controlled for in step1; symptom identity and pain index were entered next; step 3 comprised cognitive and emotional representations; coping response was entered in step 4 and appraisal in step 5. Cognitive and emotional representations explained an additional 13% of variance to that explained by demographic, symptom and pain variables. Coping explained a further 16% of variance in stage 4. The overall model was significant, explaining 37% of the variance in patient delay.

These data suggest that self-regulation theory is a useful guiding framework for research, and possibly intervention, related to time to treatment for possible symptoms of ACS. However, the sample of patients in this study was relatively small (n=61) and composed only of those who received a diagnosis of MI. The participants were not randomly selected and may not be representative of all patients with MI. The methodology relied upon patients' recall of their thoughts and emotions a number of days after the event, and it may be that their scores were affected by their subsequent experience of MI

and hospital care. It would be useful to further evaluate the explanatory power of the model in the context of a larger, randomly selected group of patients. Ideally this would be conducted at the onset of symptoms. However, given the significant practical difficulties involved in identifying individuals at this time, an alternative would be to identify people at the time they seek help. This would allow the CS-SRM to be evaluated without reliance on recall. This would also allow the opportunity to study the components of illness representation amongst a group of people who have not yet received a diagnosis. Such a study could explore whether the model accounts for how people represent their symptoms to health professionals before diagnostic labels are applied, whether components of the model help to differentiate those who seek help soonest from those who present later and whether the model adds to the medical model in identifying those at highest risk of a poor outcome. Exploration of such questions has the potential to both inform future interventions aimed at reducing treatment delay for people with symptoms of ACS and to contribute to the body of evidence around self-regulation theory and help-seeking.

## *2.7 Conclusion*

ACS is a common cause of death and morbidity. Pre-hospital delay in the context of ACS is an important issue. Further reductions in pre-hospital delay could reduce the high mortality associated with ACS.

The evidence regarding time to presentation to healthcare services with symptoms of ACS is inconsistent. Variations in definitions of time periods

being measured and of the patient groups being studied make it difficult to compare and contrast studies. As a consequence, conflicting results are difficult to interpret. Much of the evidence derives from studies which were conducted amongst those with MI, with its application to those with other ACS unknown. Most studies have identified and studied patients retrospectively. Thus, the experiences of those who die very soon after the onset of symptoms, or are too ill to participate, are excluded. Sample bias, problems with recall or with inaccurate and incomplete medical records may also hamper retrospective methods.

Despite these limitations, the studies discussed above highlight a number of factors which appear to be associated with longer pre-hospital times. Older people, women and those with a history of diabetes seem likely to present later. Non-white ethnic group; socio-economic disadvantage; previous history of angina; or living alone may also be associated with longer times from symptom onset to treatment. This provides useful information about particular groups at risk of late presentation who might be targeted in an intervention. However, this type of knowledge does not inform how an intervention should be developed. The factors identified are generally not amenable to change and much of the evidence is atheoretical.

Psychological factors have been identified as areas of key importance: how people come to recognise that symptoms may be related to their heart and of a serious nature, peoples' expectations about what a heart attack might be like and the influence of others have been demonstrated as important factors in pre-hospital time for people with confirmed ACS. In particular, research

suggests that individuals' representations of illness are likely to influence how and when people seek help with symptoms. In contrast to demographic, clinical and socio-economic factors; psychological factors may be amenable to change and thus offer a possible route for intervention.

Evidence has also been presented which suggests that Leventhal's CS-SRM could be a useful theoretical framework in which to explore these issues and guide intervention. To date the CS-SRM has not been evaluated in the context of people experiencing *possible* symptoms of ACS. Studies have identified participants after diagnosis and evaluated factors retrospectively. Narrowing the focus of research only to those who ultimately receive a diagnosis has not allowed comparison with the larger group of people who may have experienced similar symptoms but not been found to have ACS. It would be extremely useful to study a representative sample of this larger group in order to evaluate the predictive abilities of the model in relation to patient decision time and outcome.

# Chapter 3. Aims and rationale

The overall aim of the investigation is to explore how illness representations relate to presentation to health services amongst patients with possible symptoms of ACS and thus to inform future interventions aimed at reducing delay. As described in Chapter 1, the relationship between the CS-SRM constructs and both (a) the content, and (b) the timing, of initial presentation to health services are of particular interest and thus a two-stage research design was adopted. NHS 24 (a national service in Scotland which provides health related advice and information via the telephone) was selected as the setting for the research. The rationale for this decision is discussed below. There then follows a description of NHS 24, an outline of the aims of the study and finally a brief recap of the rationale for the choice of theoretical framework.

## *3.1 Setting - NHS 24*

NHS 24 was selected as the setting for the research for a number of reasons. Firstly, all calls to Scottish General Practitioners (GPs) in the out-of-hours period[4] were dealt with by NHS 24. Thus, during the out-of-hours period a sample could be obtained from the entire population of people seeking help from their GP in Scotland. Such a sample could be considered more representative than one obtained in a particular region.

Secondly, a dialogue about the nature of the patient's symptoms occurred between the caller and the member of staff at NHS 24. This would not have

[4] Out-of-hours period usually 6pm-8am weekdays, all day and night weekends and public holidays. Varies slightly in different localities.

been possible within the alternative setting of the Scottish Ambulance Service (SAS) where the focus on the immediate need to despatch an ambulance limits the dialogue.

Furthermore, all calls to NHS 24 are automatically recorded and stored in a format where they can be retrieved electronically. Thus there was a rare opportunity to study what people said at the time of seeking help with no impact on the delivery of care. Rather than having to interrupt a consultation to request consent (which would clearly be impossible in such an emergency situation), consent to use the existing recording for the purposes of research was sought at a later date. It would have been very difficult to achieve this in other potential settings (e.g. Accident & Emergency Departments (A&E)) due to the unpredictability of patient presentations and the need to obtain consent before data collection could take place.

Detailed electronic records for each call were stored within a central database. This made it possible to identify all individuals presenting with particular symptoms and then to select a random sample to invite to participate. The ability to identify people before diagnostic labels were applied was important in two ways.

Firstly, it allowed people's accounts of their symptoms at the time of seeking help to be studied without reliance on recall. In contrast to retrospective reports, people's experiences subsequent to the call (such as hospitalisation or receipt of a diagnosis) could not influence this data – a criticism that could be made of previous work in this area. However, the method was not without its own limitations. It was possible that there were important elements of the

patient's experience that they did not share with NHS 24 staff and which would therefore not be identified using this method alone. However, comparison of call-data with subsequent retrospective report (IPQ-R) was possible in a small number of cases (n=35) which allowed the possible impact of this issue to be explored (see page 124).

It was also possible that the degree to which an individual communicated their illness representations was influenced by the consulting style of the NHS 24 staff member, a factor difficult to control for in an organisation with hundreds of staff. Analysis was restricted to only participants' responses to an initial open question from NHS 24 staff in an attempt to limit the impact of this issue.

Secondly, the method allowed a sample to be identified from a population which was more representative of those experiencing possible symptoms of ACS than a sample comprised only of those with a diagnosis of ACS. As a diagnosis of ACS cannot be made solely on the basis of symptoms all those with *possible* symptoms are advised to seek urgent medical help. Thus the research which informs interventions aimed at facilitating prompt help-seeking should be conducted amongst this wider group. Restriction of research to only those who receive an ACS diagnosis excludes from consideration the experiences of people who may have experienced identical symptoms as those with ACS but did not receive a diagnosis. Furthermore, research restricted to only those with ACS would be unable to identify features which might help to distinguish those with ACS from those with other problems. This is an important issue as this is a task which remains

challenging for clinicians.

In summary NHS 24 offered a number of unique opportunities. However the unique context of the clinical and research environment meant that specific methods of identifying, approaching and obtaining consent from participants needed to be developed. A substantial level of detail about the setting is necessary in order to justify the choice of these methods. This detail is provided below and summarised in a diagram within Appendix 1.

### 3.1.1 NHS 24

NHS 24 was established in 2003 and provides telephone health advice and information for people in Scotland. It receives on average 30,000 calls each week. Calls are received about an enormous variety of symptoms in both adults and children e.g. fever; headache; backache; depression; chest pain. The process of how calls are dealt with by the service will be described below. However, it should be noted that whilst this was the process at the time the study was planned and conducted, some processes have since changed.

#### *Call process*

At times when GP surgeries were closed, if someone called their GP's number, their call was automatically re-routed to NHS 24. In addition, at any time, people could reach the service by dialling a dedicated 0845 number.

The call was answered by a call-handler who would briefly establish the reason for the call and record demographic details in a computerised patient record. The call-handler summarised in less than 10 words, within this

record, the reason the caller has given for contacting the service, where possible using the patients own words (this is known as the *call reason*).

In all circumstances where the patient had symptoms (except if they were unconscious or not breathing, in which case an ambulance would be requested immediately), the call (and the associated electronic record) were then passed to a nurse advisor. The nurse advisor assessed the patient's symptoms in order to advise the most appropriate course of action.

The consultation consisted of an initial assessment which allowed the nurse to assess the needs of the patient, followed by further detailed questioning supported by specially designed, decision-making software. The software provided a selection of symptom-related algorithms from which the nurse could choose the most appropriate. The algorithms prompt the nurse to consider a series of relevant questions. These were designed to guide nurses' assessments and ensure the most high-risk clinical scenarios were quickly identified. Where there were multiple symptoms the nurse would choose the algorithm relating to the most serious symptom. Where no algorithm exactly matched the symptom the patient described (e.g. facial drooping) the nurse would either select one which was similar (e.g. weakness) or proceed without one, documenting why an algorithm had not been used.

Where a nurse suspected that symptoms may be related to ACS it was usual practice to select a 'chest pain' algorithm. However, occasionally it was expected that an algorithm might not be used. This would occur where the nurse became aware after their initial questioning that the situation was

immediately life-threatening and would take appropriate action without delay. The use of a specific algorithm was recorded on the electronic record, as were any reasons for not doing so.

After completing an assessment of the patient's symptoms, either with or without an algorithm, the nurse would decide on an appropriate course of action and advise the patient what to do next. The nurse would record this outcome within the record along with an appropriate time-frame (e.g. as soon as possible; within 4 hours). This is known as the 'disposition' and examples include 999 ambulance; a GP home visit; a Primary Care Emergency Centre (PCEC) appointment or self-care.

In summary, the procedures described above meant that NHS 24 could facilitate the identification of a large, representative sample of people with possible symptoms of ACS and provide a recording of their initial symptom presentation. Data relating to a number of demographic and clinical variables (including contact details) were also readily available. It was therefore considered an appropriate and feasible setting for the planned investigation, the aims of which are described in detail, below.

## *3.2 Aims*

### 3.2.1 The content of initial presentations

The aim of the first stage of the investigation was to explore how the CS-SRM relates to peoples' initial symptom presentations to health services. The

study comprised a CS-SRM-guided content analysis of the initial presentations of NHS 24 callers (including a proportion with possible symptoms of ACS). This allowed the utility of the model as a theoretical framework for the overall study to be explored. It also provided an opportunity to develop and pilot a specifically adapted version of the IPQ-R to be used in the second stage of the investigation. Furthermore, it allowed methods of identifying and approaching participants to be piloted. This was important for a number of reasons

1. There were no precedents for using the NHS 24 database to identify a particular clinical group as a population for research and thus new methods had to be developed.

2. The target group were, by their very nature, a challenging group to approach. The definition of 'possible symptoms of ACS' was broad and potentially ambiguous. People with these types of symptoms might have been in circumstances that would make contact very difficult (e.g. still in hospital) and there was also the possibility that some may even have died soon after their call. Thus there were significant ethical issues related to contacting people with these types of symptoms.

3. NHS 24 is a large, national service based in a number of contact centre environments. As such the nature of the relationship between users of this service and those providing care might be expected to differ from other clinical settings. It was not clear how this might affect participation.

### 3.2.2 The timing of initial presentations

The aim of the second stage of the investigation was to explore how illness representations relate to patient decision time amongst patients with possible symptoms of ACS. This study comprised a larger-scale survey of people with possible symptoms of ACS. The IPQ-R was utilised to explore how illness representations related to a number of measures of patient decision time.

## *3.3 Rationale for theoretical framework*

As was discussed in Chapter 2, a common problem with much of the literature with regard to ACS and delay is that much research has been conducted in the absence of an explicit theoretical framework. The consequence being that relationships between empirically derived factors, causal mechanisms and targets for intervention have been poorly defined and do not readily inform an intervention.

The CS-SRM was selected as the theoretical framework for this study for the following reasons:

1. The theory provided a plausible explanation for the patterns of behaviour observed in previous studies. The link between symptoms and help-seeking was made but not assumed to be inevitable.

2. The model conceptualises individuals as rational, problem-solving individuals but does not exclude the influence of other social factors. The role of emotion in affecting health behaviour is acknowledged, an area

neglected by other social cognition models (Fishbein and Azjen, 1974; Becker, 1974).

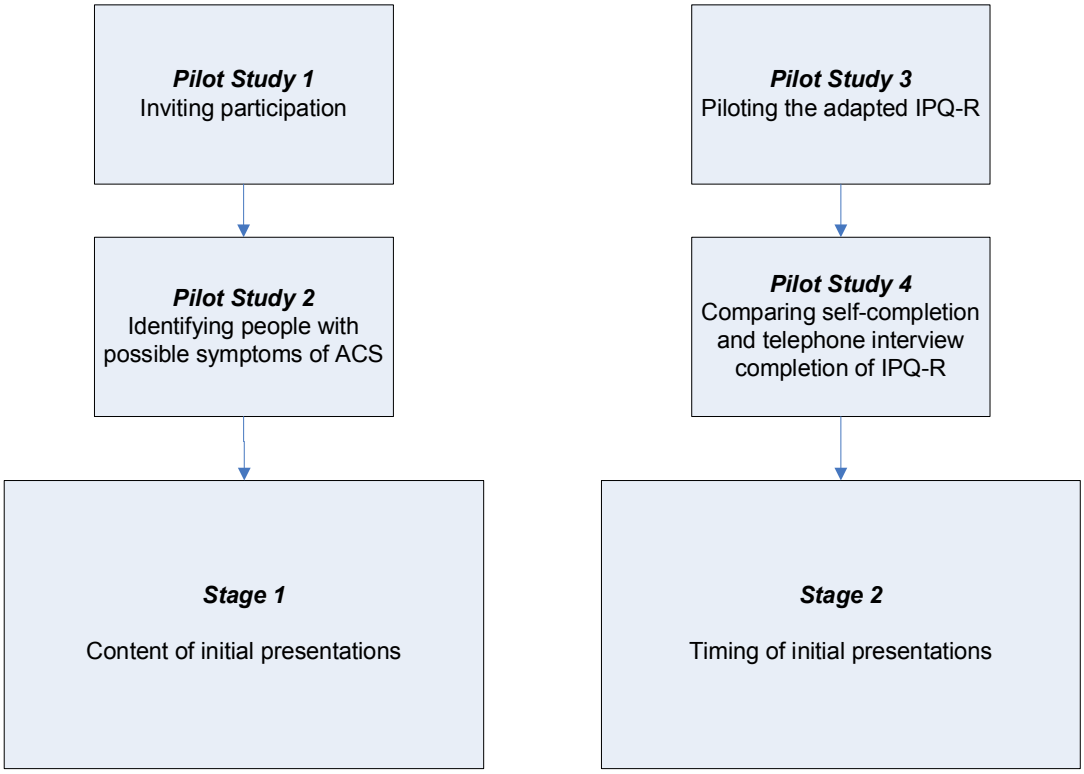
3. A large body of evidence exists to support the illness representation dimensions and their relationships with coping behaviours and clinical outcomes (Hagger and Orbell, 2003).

4. The framework had been used successfully with people with CHD and found to be predictive of outcome (Petrie et al. 1996). The model was found to explain variance in pre-hospital time additional to that explained by demographic and clinical factors, amongst patients with MI, (Walsh J C et al. 2004).

5. The IPQ-R was a tool which could easily be adapted for use with patients with possible symptoms of ACS. (Moss-Morris et al. 2002).

The overall design of the study is summarised in Figure 2, below and described in the following chapters.

**Figure 2: Overall study design**



# Chapter 4. Content of initial presentations: Methods

## *4.1 Introduction*

The following chapter describes the methods used in the first stage of the investigation, exploring the content of participants' initial presentations to NHS 24. The two pilot studies which were undertaken prior to the main investigation are described first. Methods of identifying patients with possible symptoms of ACS and inviting their participation in research were the focus of these pilot studies and informed the methods ultimately employed in this stage of the investigation. These methods are then described in detail.

## *4.2 Pilot work*

### 4.2.1 Background

As has already been discussed in Chapter 3, NHS 24 was chosen as the setting for the research. Previous Scottish research indicated that people with possible symptoms of ACS seek help via 3 main routes –via their GP, the SAS or Accident & Emergency (A&E) departments (Leslie et al. 2000). Any one of these settings could potentially have provided access to the population of interest. However, the recently conceived NHS 24 possessed a number of key advantages which led to it being selected as the setting for this research (these were described earlier on page 52). However, the unique nature of the setting meant that appropriate methods of identifying, approaching and achieving the participation of patients required to be developed. Pilot work around the invitation of patients; the identification of the

clinical population and the administration of the IPQ-R was therefore conducted. This work is described below and served to define the methods used in the main study, exploring the content of initial presentations which are subsequently described on page 90.

### 4.2.2 Pilot study 1: Inviting patients of NHS 24 to participate in research[5]

#### *Background*

Due to the urgent and remote nature of patients' contact with NHS 24, the usual methods of recruitment employed in general practice or a hospital/clinic environment were not feasible (e.g. invitation by clinician, approach in person by researcher). Furthermore, there were no precedents for using the NHS 24 database to identify a particular clinical group as a population for research and the target group were, by their very nature, a challenging group to approach. It was therefore necessary to develop sensitive, but effective, ways to approach patients and achieve their participation in the research.

As it was neither practical, nor ethical, to approach people at the time of their call about research it was, instead, necessary to make contact with people at a later time. Contact could potentially have been achieved in person, by letter or by telephone. However, the geographical spread of potential participants and the ethical difficulties involved in finding out their whereabouts, before they had given consent, meant that direct personal contact was not considered feasible.

[5] This was not originally designed as pilot work but as a result of the issues encountered, ultimately acted as such.

The choice of approach between telephone and letter was driven by both methodological and pragmatic considerations. Methodologically, in order to be able to generalise results it was important to achieve as high a participation rate as possible (Buckingham and Saunders, 2004b). In addition, as patients were being asked to recall their thoughts about their symptoms, it was necessary for this to be done as soon as possible after the call to minimise any problems with recall (Bowling, 2002).

However, a number of pragmatic issues also had to be considered. Given the nature of the symptoms they contacted NHS 24 with, it was possible that some potential participants might be unwell, in hospital or may even have died at the time of contact. The ethical issues regarding the approach to patients were therefore of primary importance. It was essential that the wording of invitation letters was sensitive to the possible circumstances of recipients (who might even be very recently bereaved relatives). It was considered very important that those invited to participate in the research (simply as a result of accessing their GP via the only route available to them at that time) should not feel coerced into taking part. Furthermore the research was being conducted at a time when NHS 24 was subject to high levels of critical media attention (Harper, 2005; Rodrick and Bruce, 2005; Musson, 2005a; Musson, 2005b) also see Appendix 2. It was considered important that the approach to patients did not stimulate any additional negative feedback for the organisation.

In view of these issues the decision was made to invite people to take part in the research by letter rather than by telephone. This allowed potential

participants the freedom to read the information if, and when, it was convenient. The decision about whether or not to take part could be made in their own time and the information could be discussed with others. Furthermore, as returned written consent was a requirement of inclusion, a decision not to take part required no effort on the part of the participant. The approach was also consistent with NHS 24 policy whereby, in order to avoid the negative connotations associated with some contact-centre environments, the organisation did not make unsolicited calls to individuals.

The approach also allowed large numbers of participants to be contacted relatively easily. In addition it provided an opportunity to make contact with those who made calls on behalf of identified patients by asking patients to pass on the relevant information to the appropriate third party.

However it was recognised at the time that the method had a number of limitations. Firstly, the requirement to be able to read written English may have limited certain individuals from participating. It was considered that this could reduce response rates and possibly bias the sample, limiting the generalisability of findings. Low response rate is a well recognised and common problem associated with postal surveys (Buckingham and Saunders, 2004b). However, it was considered that given the nature of the symptoms and the recentness of patients' experiences, that potential participants might be more positively disposed to taking part. In any case, given the lack of previous work with this group; the patients' clinical circumstances and the sensitivities around approaching them at this time it was considered that results from this study would nevertheless be valuable

and worthwhile pursuing despite this limitation. NHS 24 records contained numerous data regarding the characteristics of individual patients and consultations. This allowed checks for non-responder bias in a number of key areas to be made. These included age, gender, social deprivation, whether or not someone made the call themselves, nurse outcome and whether the patient had a recorded history of CHD. It was considered that, in the event of a low response rate, this would allow any potential bias in the sample to be identified and taken into account during the interpretation of results.

Staff members involved in the calls of participating patients were also approached and invited to participate by letter. The same standards of informed consent applied to patients were applied to the staff members. It was not anticipated that staff would be unduly concerned about their calls being utilised for research. All calls to NHS 24 are recorded and regular reviews conducted in order to monitor performance, thus staff were accustomed to this type of surveillance. The decision was therefore made to approach patients and callers in the first instance and then only the staff involved in the calls of participating patients were approached. This avoided the need to approach and inconvenience all 500 staff at NHS 24, when the participation of only a very small number was required.

The approach was piloted in May 2005 and is described below.

***Aim***

To pilot an opt-in, postal invitation to participate in research amongst people who had been in contact with NHS 24.

### *Research Questions*

1. How acceptable is an opt-in postal invitation to participate in research to people who have contacted NHS 24?
2. What participation rate can be achieved by this method of approach?

### *Method*

#### *Design*

A postal survey of people who had sought medical help from the national telephone out-of-hours service (NHS 24), within 10 days of their call.

#### *Setting and participants*

NHS 24 was the setting for the research.

A random sample of 75 calls were identified where either the chest pain algorithm had been used or no algorithm was used as the call was deemed 'immediately life-threatening' and possible symptoms of ACS were identified within the call reason or clinical summary (see Appendix 1 for details of NHS 24 call process).

A further 75 calls where either an algorithm other than 'chest pain' had been used or an algorithm was not used for reasons other than that the symptoms were immediately life-threatening were identified.

The patients involved in these calls (and if applicable anyone who called on their behalf) were invited to take part. Where patients agreed to participate the NHS 24 staff members involved were also asked to participate.

***Inclusion Criteria***

A call had been received and recorded by NHS 24 within the previous 3 days.

***Exclusion Criteria***

It was planned that any patients who stated or documented that they did not wish their data to be used for research were not to be approached. However, this assumed that a recorded message informing callers that their data may be used for research would be active at the time of recruitment. However, for organisational reasons this was not implemented as planned and no mechanism existed for patients to record their wishes.

Any calls involving children aged 16 or under were excluded as ACS in someone of this age would be exceptionally rare (Petersen et al. 2005).

***Procedures***

Ethical and NHS management approval were obtained (see page 96 for details). The sample was identified as described above. The corresponding 150 patient records were then accessed in May 2005. It was identified from the record whether the patient called themselves or if someone else called on their behalf.

***The patient called about themselves***

Where the patient called about themselves (63 cases) a letter and information leaflet was sent to the patient explaining the purpose and nature of the study and inviting their participation in it (Appendix 3 and Appendix 4). They were asked to sign and return a consent form (Appendix 5) if they

wished to take part.

On receipt of the patient's written consent, letters were then sent to the call-handler and nurse who handled the call explaining the purpose of the study and requesting their consent to use their voice recordings (Appendix 6, Appendix 7 and Appendix 8).

***Someone else called on behalf of the patient***

Where someone else called on behalf of the patient (87 cases) an alternative letter (Appendix 9) and information leaflet (Appendix 4) was sent to the patient which included a request to pass 'caller information' to the person who called on their behalf. A second set of information directed towards the person who called, (Appendix 10, Appendix 11 and Appendix 13) was enclosed and the patient requested to pass it to them. Again, staff members were contacted following receipt of the patient's written consent.

Where *any* party declined to give their consent the call was excluded from the study.

Voice recordings of calls exclusively involving consenting patients, staff (and where appropriate callers) were then retrieved and transcribed verbatim.

Patients and callers were also asked to complete and return the adapted IPQ-R and Caller Illness Perception Questionnaire (CIPQ-R) respectively, (see Appendix 12 and Appendix 13) as part of the piloting process for the questionnaire (this is described in more detail in on page 157). The questionnaire also included items (PF1-4) designed to obtain feedback on the acceptability and timing of the approach and on the ease of completion of

the questionnaire.

***Analysis***

Patient and staff response and participation rates were explored.

Feedback from participants regarding the acceptability of the approach was examined.

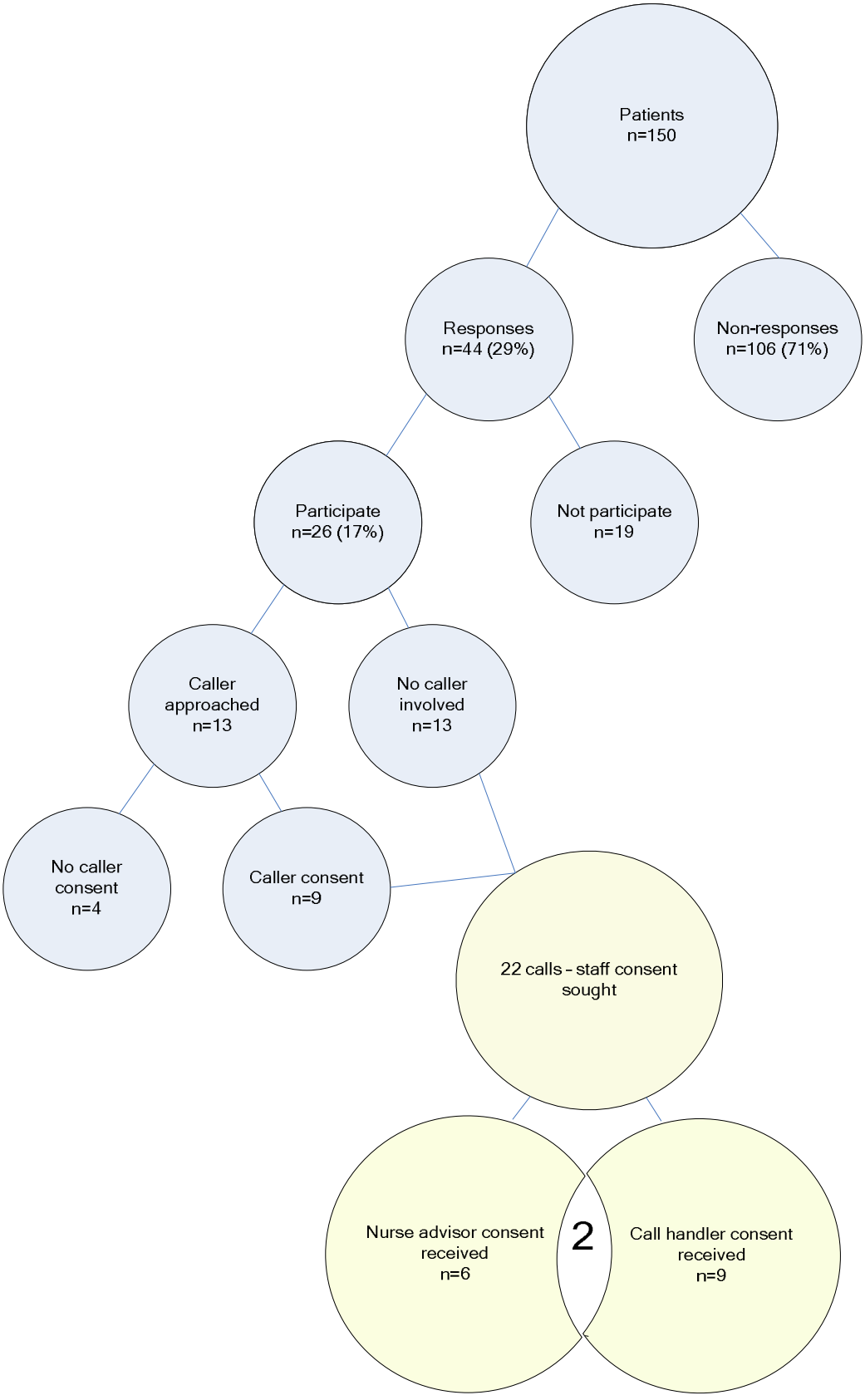
***Results***

Of the 150 calls identified, 63 were made by the patient themselves and 87 were made by a caller on behalf of the patient. Forty-four of the 150 patients contacted (29%) responded to the letter of invitation. A total of 26 (17%) patients agreed to take part in the study. Eighteen of the 87 callers approached responded, 12 agreed to take part.

Nineteen call-handlers and 20 nurse advisers involved in consenting patients calls were approached (some were involved in more than one of the identified calls). Consent was received from 9 call handlers and 6 nurse advisors to access their calls.

Overall the consent of all parties to access the recording of calls was only available for a total of 2 calls (see Figure 3 on page 71).

**Figure 3. Effect of patient, caller and staff response on access to calls.**



## *Discussion*

### *Low response rate from patients*

The response rate of 29% and participation rate of 17% were low. However, given the challenging population being targeted it was difficult to estimate what could realistically be achieved. Higher rates would have been preferable from a methodological point of view. If the majority of people invited to participate did not respond, the generalisability of the results obtained from those who did, was questionable. It was possible that those who chose to respond differed from those who did not in important ways e.g. in age, clinical condition and level of literacy (unfortunately there were insufficient data to assess whether or not this was the case at this time). There were also practical implications of a low response rate. Higher numbers of invitations would be required to achieve the necessary sample and therefore be more costly, take longer and risk causing distress to the increased number of individuals being contacted. These issues were likely to be most significant in the second stage of the project, during which it was planned to recruit larger numbers of patients.

The opportunity for patients to 'opt-out' by simply returning the information was provided and, if patients did not respond to the letter, no further action was taken and it was assumed they had declined. Importantly, this meant that information about why people did not respond was not available. This was problematic. Potential reasons were numerous – the patient may have died, be too unwell, not interested in research, not like the questionnaire, have trouble reading etc. Clearly, non-participation for one reason may have had very different implications for the study than for other reasons.

It was possible that the reasons for non-response were amenable to change and that such change would allow more people to participate and improve the acceptability of the approach for them. It was considered unethical to continue to recruit patients without trying to identify any areas for improvement. The method ultimately adopted for the main study included the opportunity to elicit reasons for non-participation from patients. The results are reported on page 107.

More encouragingly, the experience of approaching these first 150 patients did not produce any particularly negative feedback regarding the appropriateness of the approach to participants. Feedback was only available from those who did agree to participate, but suggested that most considered the approach soon after their call to be appropriate.

It was also considered necessary to take steps to establish if improvement to response rates could be achieved. It was recognised that the relatively impersonal contact of a letter might have been less engaging than other methods of approach and may have contributed to the poor response rate. When people are busy and, perhaps, in the midst of a serious illness episode, such a letter might be easily overlooked. Also, even where people were motivated to take part, difficulties encountered in understanding the information or in completing a questionnaire may have led to non-response or to incomplete responses. Whilst a sincere offer was made to answer any questions or queries, people may have felt reluctant to ask. It was considered that it would be easier to detect and discuss such difficulties in a conversation or one to one situation. Such an approach had the added

advantage of being less likely to result in incomplete data being gathered (Bryman, 2004).

***Low response rate from staff***

The staff participation rate of 38% was also much lower than anticipated. All staff at NHS 24 were aware that all their consultations were recorded and each staff member had at least 2 calls reviewed each month by their team leader. Calls were also reviewed whenever negative feedback was received from patients or from colleagues in partner organisations. Given this level of ongoing surveillance it was not expected that access to calls for the purposes of this research would be problematic.

However, as seen in Figure 3, low staff participation further compounded the problem of the low response from patients. It meant that even larger numbers of potential participants would require to be contacted in order to ultimately achieve the planned number of calls for transcription. Therefore the methodological limitations associated with a postal survey were likely to be further magnified.

It was considered that the response rates achieved might not be a true reflection of NHS 24 staffs' inclination to be part of research. A member of staff, who declined to participate, stated that she was disappointed as she was delighted to hear that a nurse colleague was undertaking research and would have liked to be a part of it. It appeared that concern over potential negative implications had deterred staff who might otherwise have been keen to participate. It was considered essential that steps were taken to ensure that staff felt safe and free to participate in research.

Feedback was received from 2 members of staff indicating that they had concerns about potential negative consequences for them, as a result of taking part. In particular, the information provided in the staff information sheet which stated that

> *" in the unlikely event that serious misconduct was identified during the course of the study, the researcher would be professionally obliged to take action and would bring the matter to the attention of your Team Leader."*

seems likely to have caused particular concern. The statement was included in an attempt to delineate and clarify the boundaries of the chief investigator's role as a clinician whilst functioning as a researcher. It was intended to communicate honestly that there were limits to the confidentiality that could be assured and that in extreme circumstances action might need to be taken.

However, it became clear that the term 'serious misconduct' was open to a number of interpretations. It was extremely difficult to define exactly what it referred to. Thus, the mere suggestion that there may be circumstances whereby staff members participation in this research could have negative consequences for them, may have led to a significant number choosing not to participate. This had a number of implications. Firstly, it unintentionally caused anxiety and worry for NHS 24 staff which was regrettable. Secondly, it resulted in a lower than anticipated level of participation. This seriously impacted on the conduct of the research. There were 18 circumstances where the patients (and caller if applicable) had agreed to participate in the research and given their consent for their call to be analysed. However, their data could not be accessed as at least one member of staff involved in the

call did not give their consent (the consent of both the call handler and the nurse advisor were required). To request data from patients, at such a sensitive time, but not actually use it was considered unacceptable.

As a result the method was adapted to avoid this situation. NHS 24 staff were contacted in the first instance and asked to give their consent for their consultations to be used in the research. Subsequently, potential participants were identified only from calls involving staff who had agreed to participate. The information leaflet for staff was also revised to assure participating staff of absolute confidentiality.

This element of the pilot work also informed the scale of the remainder of the project. Challenges were encountered with obtaining consent to access calls as discussed above. However, unanticipated problems with retrieval of calls were also encountered. This was because there was a time lapse (often a few weeks) before all the relevant consents were obtained. This meant that the call recordings could no longer be accessed from the easily accessible web-based application as planned. Instead they were stored on back-up tapes. Consequently, the team responsible within NHS 24 for these tapes were required to individually retrieve each call. This was inconvenient and extremely time-consuming. Furthermore, as approximately half of the calls were essentially a random selection, many were not urgent and as such tended to be longer in length than those identified as possibly cardiac (some up to 20 minutes long). Thus transcription also took much longer than had been estimated (based on an average 6 minute call). In view of these issues a decision was made to reduce the scale of the main study from a planned

sample of 100, to a quota sample of 60 patients, 30 from each group. It was considered that this would remain sufficient to address the research questions whilst avoiding additional delay to the remainder of the project.

***Conclusions***

1. The opt-in, postal invitation to participate in research did not result in adequate participation rates by patients. This was compounded by inadequate participation amongst staff. An alternative method of achieving participation was required.

2. The lack of information about peoples' reasons for non-participation was problematic, particularly in view of the low response rates achieved. A method of obtaining this information was required.

3. The approach to potential participants was considered acceptable by those who participated. However, additional efforts to improve response rate were required.

4. The situation during the pilot where consenting patients' data could not be used as one of the staff involved in their call had not provided consent was considered unacceptable. All staff of NHS 24 should be approached in the first instance and asked to participate in the study. Then only

potential participants who had consulted with *consenting* staff be approached for consent.

5. In view of the practical difficulties encountered in accessing and transcribing the calls the planned quota sample was reduced from 100 to 60 calls.

### 4.2.3 Pilot study 2: Identifying people with possible symptoms of ACS

***Background***

The population of interest for the study as a whole were people seeking help with possible symptoms of ACS. As was discussed earlier in the literature review, the identification of the symptoms of a cardiac event is generally problematic. There is considerable variation in presentation. 'Typical' symptoms have been described as chest pain; radiating pain or numbness in the arm, neck, jaw or shoulder and collapse (Horne et al. 2000). However, other presentations might include shortness of breath; nausea and/or vomiting; feeling faint and sweating. None of these symptoms are specific to cardiac events and may be associated with a large number of other conditions (e.g. viral illness) making the identification of the symptoms of ACS exclusively and reliably extremely challenging.

It has also been demonstrated that patients without chest pain tend to present later than those who experience this symptom (Canto et al. 2000). Therefore it was considered inappropriate to exclude patients with 'atypical'

presentations from the investigation. A sampling strategy which reliably identified patients with possible symptoms of ACS with as high a degree of sensitivity and specificity as possible was the best that could be achieved.

Two possible methods were identified. The first based upon the nurses use of algorithms (algorithm strategy) and the second based upon the call reason provided by the patient and documented by the call handler (call reason strategy), these are described below.

***Algorithm strategy***

Calls where the nurse's assessment included the use of the chest pain algorithm could be identified from the electronic database. In addition calls where the nurse did not use an algorithm but where the symptoms were considered immediately life threatening could also be easily identified (although given that there could be many reasons a call was considered immediately life threatening, aside from ACS, each call identified by this method required to be screened for other symptoms).

***Call reason strategy***

The initial call reasons given by callers and recorded by the call handlers could be examined and those which included specified symptoms identified for inclusion.

A pilot study compared the 2 possible methods and is described in further detail below.

### *Aim*

To evaluate the relative merits of 2 possible sampling strategies in identifying potential participants at NHS 24.

### *Research Question*

How effective are the algorithm and call-reason sampling methods in reliably identifying patients with possible cardiac symptoms?

### *Method*

#### *Design*

A comparison of the effectiveness of 2 sampling strategies in identifying patients with possible symptoms of ACS from NHS 24 records, utilising a panel of 3 clinical experts.

#### *Setting and participants*

A random sample of 75 calls to NHS 24 were identified where either the chest pain algorithm had been used or no algorithm was used as the call was deemed 'immediately life-threatening' and possible symptoms of ACS were identified within the call reason or clinical summary.

A further 75 calls where either an algorithm other than 'chest pain' had been used or an algorithm was not used for reasons other than that the symptoms were immediately life-threatening were identified.

The patients involved in these calls (and if applicable anyone who called on their behalf) were invited to take part. This was designed to achieve a quota sample of 30 patients in each group.

***Inclusion Criteria***

A call had been received and recorded by NHS 24

The patient (and if applicable anyone who called on their behalf) and NHS 24 staff members had given consent for their voice recording to be used for the purposes of this study. (If the patient had died, the next of kin had given their consent to the recording being used).

Group 1: The nurse used a chest pain algorithm or did not use an algorithm as the call was deemed 'immediately life-threatening' and possible symptoms of ACS were identified within the call reason or clinical summary.

Group 2: The nurse used an algorithm other than 'chest pain' or did not use an algorithm for reasons other than that the symptoms were considered immediately life-threatening.

***Exclusion Criteria***

Any calls involving children aged 16 or under were excluded.

***Procedures***

***Approaching staff***

All call handlers, nurse advisors and team leaders employed by NHS 24 as of 8th November 2005 (total n= 880) were invited by letter (Appendix 14, Appendix 15 and Appendix 16) to give their permission for consultations they were involved in to be used in the project. In order to protect the confidentiality of staff, letters were issued by the Human Resources (HR) department at NHS 24 Headquarters, Glasgow. A list of the names of those invited was provided so that a record could be kept about how many

responses were received and from which staff groups (i.e. call handlers, nurse advisors, team leaders). As the list comprised all current employees, a number of those invited were on maternity leave, long-term sick leave or had already tendered their resignation. HR advised that this was the case for 114 of those invited but were obviously unable to identify which staff this related to, for reasons of confidentiality. It is reasonable to conclude that people in these situations would not be able to participate. Therefore the participation rate has been calculated from the total number invited minus those in identified as absent by HR (n=766). A total of 324 (43%) consented to take part.

On 30th November 2005 the database was searched to identify all calls which fulfilled the inclusion criteria within the previous 3 days. A total of 12 597 were identified. Those handled exclusively by consenting staff was 963. This number is a small proportion because calls were only eligible if *both* the call handler and the nurse advisor involved had given consent. Staff follow a variety of different shift rotas and number of hours per week. Therefore if a high volume of staff who work fewer hours a week have consented to take part then the total number of calls eligible would be reduced. Similarly, staff who work more nightshifts or other less busy times or who are on holiday would be expected to deal with less calls. This may explain the low proportion.

The subset of consultations undertaken only by staff that had consented to participate in the research was identified. This generated a list of unique call identifiers (Patient Relationship Management (PRM) numbers) relating to

eligible calls. The PRM numbers were entered into the Statistical Package for the Social Sciences 14.0 (SPSS) and a random selection of 75 were selected to be approached. The corresponding patient records were then accessed by the investigator. It was identified from the record whether the patient called themselves or if someone called on their behalf. Subsequent to Pilot Study 1 an alternative process of approaching potential participants was developed. This is described below.

***Approaching patients***

The patient called about themselves

Where the patient called about themselves a letter (Appendix 3) and information leaflet (either Appendix 17 or Appendix 18), depending upon randomisation) was sent to the patient explaining the purpose and nature of the study and inviting their participation in it. Permission to telephone them to discuss it further was requested. It was made clear that there was no obligation to receive this call or to take part in the research. If the patient did not wish to be contacted they were asked to notify the researcher, by either returning a postcard (Appendix 19) or by telephoning a dedicated telephone number. Patients who took either of these actions were not contacted further.

Those who did not decline were telephoned and the research discussed further with them as detailed in the schedule for invitation by telephone (Appendix 20). This call was recorded (patients were informed of this at the earliest reasonable opportunity).

It was ascertained whether the patient had received and read the information posted to them. If they had not, they were given the opportunity to do so (if

they wished). Once the investigator was satisfied that the patient had read and understood the nature of the research and had the opportunity to ask questions they then requested the patient's consent to take part. It was made clear that participants were free to withdraw their consent at any time. Arrangements were made for either a telephone interview or for self-completion and return of the questionnaire

The original telephone call of those who consented was accessed, transcribed and analysed at a later date.

Where the patient declined to take part, they were asked sensitively to provide a reason for this which was recorded.

Someone else called on behalf of the patient

Where someone else called on behalf of the patient, an alternative letter (Appendix 9) and the information leaflet (Appendix 17 or Appendix 18) were sent to the patient including a request to pass 'caller information' to the person who called on their behalf. A second set of information directed towards the person who called (Appendix 10 and Appendix 22 or Appendix 23) was enclosed and the patient was requested to pass it to the person who called on their behalf.

Patients who consented to take part, and who had a contact number for the caller, were asked permission to contact that person by telephone (frequently they were a family member).

The caller was invited to give consent and participate in the same manner as the patient (see Appendix 20). Similarly, callers were asked to provide a

reason if they declined to take part.

Where any party declined consent the call was excluded from the study. Where a third party was not available to respond regarding the request for consent, but consent was given by the patient and the NHS 24 staff involved, then the call was included but any personal details regarding the third party omitted from transcripts.

All patients and callers who were invited to participate were also sent the specially adapted IPQ-R (or CIPQ-R) (Appendix 12 and Appendix 13) in order to further pilot the questionnaire – this is described in more detail on page 157. A subgroup of 20 of these participants was asked to take part in a telephone interview in order to share their experiences of completing the questionnaire (see page 162 for more detail).

Voice recordings of calls involving only consenting patients and staff were then retrieved and transcribed verbatim. All personally identifiable information was omitted during transcription. A quota sample of 60 transcriptions was produced, including 30 from the algorithm strategy designed to identify patients with possible symptoms of ACS.

Each transcript was presented to an expert panel of 3 clinical raters (2 registered general nurses and 1 GP). They were each asked independently to assess the degree to which they considered the symptoms described to be ‘possible symptoms of ACS’. After reading each transcript, raters were asked to indicate on a 4 point scale (Appendix 24) how likely the symptoms described were to be possible symptoms of ACS.

In addition the call reason, provided by the patient and stored on the electronic record (see Appendix 1 for more detail) was obtained for both groups. Thus 60 call reasons were available. These call reasons were assessed by the chief investigator and those which included either a 'typical symptom' (as defined in Figure 4, below) or at least 2 'atypical' symptoms (also defined below) were identified and classified as possible cases of ACS.

**Figure 4:** Criteria for possible symptoms of ACS

| |
|---|
| Includes any one of the following 'typical' symptoms: collapse; chest pain; radiating pain in the arm, jaw, back, neck or shoulder<br><br>***Or***<br><br>any two of the following 'atypical' symptoms: shortness of breath; nausea/vomiting; feeling faint or sweating |

Horne R, James D, Petrie K et al. (2000)

***Analysis***

Experts' ratings of 'definitely not' and 'probably not' symptoms of ACS were combined as 'unlikely to be symptoms of ACS'. Likewise ratings of 'definitely' and 'probably' symptoms of ACS were combined as 'likely to be symptoms of ACS'. The 3 ratings for each transcription were compared and the majority opinion accepted as the standard for comparison.

The sensitivity and specificity of the algorithm and call-reason sampling methods for identifying patients with 'possible symptoms of ACS' were then evaluated against the standard generated by the expert panel.

***Results***

Of the 60 transcripts, 35 were rated by the panel as likely to be symptoms of

ACS and 25 were rated unlikely to be symptoms of ACS. The transcriptions rated as likely to contain the symptoms of ACS were compared with those identified by each of the sampling strategies. The results are presented in Table 3 below. The specificity of both methods was identical. Both methods correctly excluded 27 of the 35 transcriptions assessed as unlikely to include symptoms of ACS (although it is important to clarify that the 27 calls excluded by each strategy were not the same calls).

However, the algorithm strategy correctly identified 24 of the 25 calls identified as possibly symptoms of ACS by the expert panel. Only 18 of these were identified by the call reason strategy.

**Table 3. Cases identified by sampling strategies against the opinion of the expert panel**

| | | Expert panel | | Sensitivity | Specificity |
|---|---|---|---|---|---|
| | | yes | no | % correctly identified | % correctly excluded |
| **Algorithm strategy** | Yes | 24 | 8 | 96% | 77% |
| | No | 1 | 27 | | |
| **Call reason strategy** | Yes | 18 | 8 | 77% | 77% |
| | No | 7 | 27 | | |

### *Discussion*

The two sampling strategies performed equally well in excluding cases assessed as unlikely to be symptoms of ACS by the expert panel. However, the algorithm strategy proved more sensitive, identifying a larger proportion of the cases assessed as including possible symptoms of ACS by the expert panel. This informed the second stage of the study where the algorithm strategy was selected to identify the larger number of patients required.

However, two other significant issues related to the selection of eligible

patients were identified during the course of this pilot work. These are discussed below and the subsequent modifications to the protocol required described thereafter.

***Identification of suicidal patients in Group 2***

During the collection of 'general characteristics' data, it became apparent that there were a number of instances (n=2) where the 'call reason' recorded within the clinical record was that the patient was suicidal. This raised the issue of how appropriate it was to contact people in such a critical situation. It was feared that to contact people in this situation and ask them to recall their reasons for seeking help may be, not only insensitive, but could potentially pose a clinical risk. However, as this situation was not anticipated, there were not provisions made within the protocol to deal with it. It was also considered important to ensure that decisions taken to exclude certain groups of callers were clinically justified and would not adversely affect the representativeness of the sample and bias results.

At the time the issue arose, advice was sought from the supervisory team and from a senior clinician within NHS 24. It was decided *not* to approach people in this situation, given the appreciable risk of causing harm balanced against the minimal risk of their exclusion causing bias in the results. Thereafter, people contacting NHS 24 for reasons of this nature were explicitly excluded from the study.

***Identification of patients for whom no algorithm was used as the situation was deemed as immediately life threatening.***

In a substantial proportion of cases where a patient with symptoms of ACS

called NHS 24, an algorithm was not used. This occurred when the nurse quickly recognised that the situation may be immediately life-threatening and thus immediately contacted the SAS to request an ambulance. It was considered essential that patients in this situation were identified for inclusion as they were likely to be a group for whom a diagnosis of ACS was most probable. Thus patients for whom no algorithm was used, and for whom the outcome was a 999 ambulance, were identified for inclusion in the population from which the random sample is drawn.

It was identified in the original protocol that some of the calls which fell into this category would not be related to ACS. Provision was made to exclude those if, after listening to the call, symptoms of ACS were not identified. However, the need to listen to the call necessitated approaching the patient to invite their participation and request consent. It became apparent that most of these exclusions could be made by simply examining the 'call reason' and 'clinical summary' of the electronic record (accessed whilst collecting 'general characteristics' data). If no possible symptoms of ACS were identified within these fields, the call could be excluded. This avoided the need to contact patients (who were possibly extremely ill) to request their consent, only to ultimately have to exclude the call as it did not relate to symptoms which were eligible for inclusion. This approach was adopted in subsequent protocols.

***Conclusions***

1. Given that the specificity of both methods of identifying potential participants was equal and that the algorithm method was more sensitive than the call reason strategy, the algorithm method was adopted for the main study.

2. Call-reasons which suggest that a patient is suicidal should be considered criteria for exclusion during future studies.

3. The call reason and clinical summary should be utilised to exclude calls where no algorithm was used and no possible symptoms of ACS were identified.

## *4.3 Content of initial presentations: Methods for main study*

### 4.3.1 Aim

To explore the utility of Leventhal's model of Self Regulation (CS-SRM) as a theoretical framework for the study.

### 4.3.2 Research questions.

1. How do callers verbal presentations to NHS 24 relate to Leventhal's CS-SRM?

   a. Are the components of illness perception evident in callers' accounts of their symptoms?

   b. Are there further components evident in presentations unaccounted for by the model?

   c. How do illness perceptions expressed at time of seeking help relate to those measured by the IPQ-R up to 14 days later?

### 4.3.3 Method

***Research design***

The study comprised a CS-SRM guided content analysis of recordings of calls to NHS 24 combined with a postal survey designed to further pilot and validate the specially adapted IPQ-R.

***Setting and participants***

As in the pilot work, NHS 24 provided the setting. Participants comprised

- those involved in the 2 calls from Pilot Study 1 where all relevant parties had given their consent (see page 71)

*and*

- those who participated in Pilot Study 2 (see page 80 for details)

Thus a quota sample of 30 calls was achieved where either the ‘chest pain’ algorithm had been used or no algorithm was used as the call was deemed ‘immediately life-threatening’ and possible symptoms of ACS were identified within the call reason or clinical summary

*plus*

another quota sample of 30 calls where either an algorithm *other* than ‘chest pain’ had been used or an algorithm was not used for reasons *other* than that the symptoms were immediately life-threatening were identified.

Thus data obtained from participants recruited during the pilot studies was used in the main study. This has the potential to be problematic as it may not be valid to compare data obtained under differing circumstances. However, the methods for identifying participants and obtaining transcribed data were consistent throughout the respective studies and thus it was considered appropriate to utilise the accumulated call transcriptions in the main study.

***Inclusion Criteria***

A call had been handled and recorded by NHS 24

The patient and NHS 24 staff members had given consent for their voice recording to be used for the purposes of the study. (If the patient had died, the next of kin had given their consent for the recording to be used). Any third party had not declined consent.

***Exclusion Criteria***

Any calls involving children aged 16 or under.

Any calls where the call-reason stated that the patient was suicidal or where the clinical summary revealed that this was the case.

***Procedures***

The transcriptions generated in Pilot Studies 1 and 2 provided the data for this study (see page 81 for details of how the transcriptions were obtained). These were imported into N-VIVO 7©, a software package designed to assist with the management and analysis of qualitative data.

Each transcript began with a call handler's opening statement, usually in the form of an open question. An example from the transcript data being

> *"Hi you are through to [call handler's name], one of the call handlers. Can you tell me briefly why you are calling?".*

Participants' responses to this first open question (and if applicable to any subsequent non-directive prompts e.g. *"yes?"*, "*uh-huh*") were identified for analysis. These responses were considered of particular interest as the content was determined freely by participants and not prompted by NHS 24 staff questions. Thus it was considered that these data reflected how people articulate their reasons for seeking medical help in the context of a real-life health threat without any clinician or researcher contamination (Webb et al. 1999).

The responses identified for analysis were then divided into distinct thoughts

in common with the method described by Lau and colleagues (Lau et al. 1989). Distinct thoughts constituted either whole sentences or portions of sentences where individual thoughts were delimited by pauses, commas, '*but*' or hesitations. These constituted the coding units and each unit was annotated with a unique identifying number to facilitate later inter-rater reliability checks (inter-rater reliability is discussed further on page 112).

Each coding unit was then coded in relation to the components of illness representation by the author. Definitions provided by Howard Leventhal and colleagues in a recent publication were used to code identity, timeline, cause consequences, and cure/control (Leventhal et al. 2007). Definitions of coherence and emotional representations was obtained from the paper describing the IPQ-R (Moss-Morris et al. 2002). A residual '*other*' category was used to code units which did not relate to any of the pre-defined codes relating to CS-SRM. The definitions used are summarised in Figure 5, below.

**Figure 5: Definitions of CS-SRM constructs**

| | |
|---|---|
| Identity | Refers to the category, name or label, and the experience of symptoms, changes in function and visible signs. The combination of abstract and concrete experiential features 'define' or identify the disease. |
| Timeline | The duration that is expected and/or perceived with respect to the onset and duration of an illness both with and without effective treatment.<br>Time-lines are represented abstractly as clock and calendar time and concretely as experienced or felt time. |
| Cause | Reflects the perception of the single or complex set of events that are perceived responsible for disease onset. |
| Consequences | The set of expected and perceived physical/functional, personal and social and economic factors that are impacted by the illness. |
| Cure/control | Refers to the expectation that a specific disease can be cured or controlled by the body's own defences and/or in conjunction with expert intervention, and the actual experience of the effects of these interventions on specific features (symptoms and/or test results) of disease. |
| Coherence | Whether or not people understand or have a clear picture of their illness. |
| Emotion | An emotional representation generated by the illness. |

In order to evaluate the reliability of coding, the responses of a random sample of 30 participants were coded independently by Liz Glidewell, a colleague familiar with CS-SRM from the University of Aberdeen. Thus for each of the coding units generated by these 30 participants, the 2 independent ratings for the presence or absence of each construct were compared.

### *Analysis*

The frequency of occurrence of each component within the coding units was

calculated.

Similarly, the frequency of occurrence of each component within individual participants was calculated.

Krippendorff's alpha was used to assess the degree of inter-rater reliability (Krippendorff, 2004; Hayes and Krippendorff, 2007).

## *4.4 Ethical issues*

The following section outlines the ethical issues relating to the study described. The process of ethical review undertaken in relation to Pilot Study 1 is described first. This is followed by a discussion of the additional ethical issues associated with the revised method of approach and the subsequent additional ethical review required.

### 4.4.1 Process of ethical review – Pilot study 1.

The study was conducted amongst NHS patients and staff in an NHS organisation. The Research Governance Framework for Health and Social Care published in 2001 specified that all research involving patients, service users, care professionals or their data should be reviewed independently to ensure it met ethical standards (Department of Health, 2001).

In line with local guidelines, an application was first made to the Departmental Research Ethics Committee (REC) in the Department of Nursing & Midwifery, University of Stirling on 18th October 2004. This provided an opportunity to receive feedback on the application prior to

submission to the Central Office for Research Ethics Committees (COREC). The submission was approved. In addition the proposal was discussed with patient representatives at a Local Health Council (LHC). They kindly read and discussed the proposal and the patient information. Feedback from the LHC and departmental REC was incorporated into the proposal which was then submitted to COREC. Advice was sought prior to submission about whether it should be considered by a Local (LREC) or Main (MREC) Research Ethics Committee as it was not clear which was most appropriate. Access to records was taking place in one location (NHS 24, South Queensferry). However, the data being accessed was stored electronically on computer servers in 3 separate locations (Aberdeen, South Queensferry and Clydebank). The patients to whom the data pertained could be located anywhere in Scotland. In view of the complexities it was advised that submission to a MREC would be most appropriate and the submission was referred to Fife and Forth Valley MREC. A number of ethical issues associated with the study were highlighted to the committee, along with the proposed measures for addressing them. These are discussed below.

***Potential for distress to patients / relatives at a difficult time***

It was recognised that the sampling strategy risked contacting people who were very ill or who may even have died. The invitation letter and information sheets were carefully worded with these particular groups in mind. However, at the same time it was also considered necessary to avoid causing alarm to the majority of participants, who were likely to have called regarding only minor symptoms.

***Approaching participants who may no longer be alive***

The approach to patients who might no longer be alive was particularly problematic but considered necessary as this group were important. The inclusion of transcripts from people who may have recently died was important for a number of reasons which are discussed below. Although there was the potential to cause distress to some families, it was argued that this was outweighed by the potential gains from improved understanding of this group of patients. However, given the difficulties associated with approaching this group, options to exclude them were considered. This would have necessitated making enquiries as to the status of all potential participants. This raised serious ethical issues around the probity of seeking to acquire such confidential information about patients prior to obtaining their consent. Even if it were possible to obtain this information it was recognised it was only reliable at that time. A letter could be posted to an apparently well individual who might subsequently die before the letter arrives. The practicalities of excluding these patients were therefore problematic.

Furthermore, from a methodological point of view, it was considered important to at least offer the opportunity for relatives of recently deceased patients to participate. Patients who die soon after symptom onset have tended to be excluded from previous research because research has largely relied upon retrospective methodologies which identify people once they have received a diagnosis of MI and asks people to recall events. It was hoped that the approach taken in this study would allow the recordings of peoples' actual words at the time of seeking help to be utilised.

In actual fact, 2 patients were identified in Stage 1 as having died subsequent

to their call. However, next-of-kin were not available to provide consent in either case. Consequently, no data about this group was collected. It is recognised that even if next-of-kin were available it would be extremely difficult to broach such a subject with them so soon after the death of their relative, especially given the lack of any personal relationship. However, knowledge of these poorest outcomes would still be extremely useful. It would appear feasible to design alternative methodologies specifically designed to explore further the experiences of this group. This is considered worthy of further exploration.

***Approach adopted***

Within this study, it was considered that the most appropriate way to proceed was to send letters of invitation to all potential participants and to word this sensitively in the knowledge that perhaps a small number would reach recently bereaved relatives. Within this information it was made very clear that there was no necessity to take part. The acceptability of this was assessed in this relatively small group and informed the larger scale survey undertaken in the study relating to the timing of presentations. It was also identified at the time that it was possible that some relatives might actually take some comfort from participating in research which aimed to better understand the experiences of people in a similar situation to that of the deceased.

***Informed consent***

In recognition of individuals rights to voluntarily participate in research and to freely consent or decline for their information to be used it was essential that

all participants gave their informed consent. However, the context of the study meant there were a number of complexities around this subject. NHS 24 medical records (of which the voice-recording forms a part) pertained to the patient so undoubtedly their consent was required. However the voice and words which were being analysed often belonged to someone else, a third party who called on behalf of the patient. Where possible it was considered desirable to obtain the consent of the third party as well as that of the patient. However, there were specific circumstances where it was clear this would not be possible. Where someone called on behalf of the patient, a record was created for the patient (not the caller). Contact details of the caller were not routinely collected (only the telephone number they were calling from (not necessarily their own number), their name and their relationship to the patient (e.g. spouse/carer). Where a stranger or carer called on behalf of the patient it was not always possible for the patient to contact the relevant person.

It was undesirable to exclude all patients who did not call on their own behalf as it would bias the results. Instead it was proposed that where a decision about consent could not be obtained from the third party, that the callers words would be transcribed and analysed anonymously. However, the difficulties with the implementation of the welcome message discussed earlier (see page 68) meant that this too had to be revisited. As callers were not being automatically informed at the beginning of their call that their data might be used in research, it was not considered ethical to use their data without explicit consent. Therefore, ethical approval was obtained to adjust the protocol such that only calls where all parties had given consent would be

accessed.

***Researcher's role***

Another issue that was identified was the position of the chief investigator as a member of staff within NHS 24. This raised the possibility that misconduct on their behalf might be easily disguised. The following structures were put in place to ensure the protocol was adhered to and that the investigator's conduct was subject to scrutiny.

Prior to receipt of consent, patients' details were accessed in a limited way only, and in the presence of another member of clinical staff. This was to ensure that no personal data about patients were recorded or stored at this stage. (It was necessary to access records at this point in order to obtain the name and address for invitation correspondence and to record anonymous characteristics of all those invited as discussed on page 66.)

Once consent had been obtained from the appropriate parties, records were accessed only for the purposes outlined in the protocol and it was recorded when this took place (all records were electronically 'foot printed' and so it is documented whenever anyone accesses a patient record). No further contact was made with patients after the initial letter.

The process of identifying the sample and selecting a random sample was documented and is available for audit and scrutiny. 10% of transcriptions were randomly selected by Carol Bugge (supervisor) on the 5th April 2006 and the relevant calls accessed to check transcription accuracy and thus confirm authenticity and accuracy.

Furthermore, as a Registered General Nurse with expertise in the area of clinical practice being observed, it was identified that a professional conflict of interest could arise in the unlikely event that serious misconduct by NHS 24 staff was observed during the course of the research. The actions the author would take might be different from those that would normally be taken by a researcher observing practice. The professional guidance issued by the Nursing and Midwifery Council (Nursing & Midwifery Council, 2004) states that

"*As a registered nurse…you must act quickly to protect patients and clients from risk if you have good reason to believe that you or a colleague, from your own or another profession, may not be fit to practise for reasons of conduct, health or competence."*

This was understood to mean that the investigator was duty-bound to take action in circumstances where they observed an act or omission that put a patient at risk. It was therefore documented in the protocol that if such an issue was discovered that the investigator would find and note the name of the member of staff and bring it to the attention of their line manager. This process was agreed with Gill Stillie (Associate Director of Nursing NHS 24) and NHS 24 staff partnership forum (staff representatives). The monitoring of calls was routine practice within NHS 24 and staff were familiar with this type of surveillance therefore it was not anticipated that this would cause a difficulty. However, as discussed on page 74, feedback from staff during the pilot of the recruitment process suggested some may have been uneasy about the potential implications of this additional scrutiny. Revisions were

made to the protocol and it was re-submitted for ethical approval on 16th August 2005. The additional ethical issues associated with the resubmission are discussed on page 104.

### *Data handling*

The research involved access to confidential patient information and it was therefore essential that steps were taken to ensure these data were protected. It was also vital that data from the study were safely stored and made available for external scrutiny (Department of Health, 2001).

Voice recordings remained within secure storage at NHS 24. Calls were only accessed in order to transcribe. Personal identifiable information was stored separately from the transcripts and questionnaires. These were linked by a unique study identification number. Transcripts were stored on a lap-top computer until transferred to a secure hard drive in Stirling University where they were backed-up. All electronic data was password protected. Only the supervisory team (Dr Carol Bugge and Prof Marie Johnston) and the investigator had access.

Voice recordings are routinely stored on tape within NHS 24 for 10 years. Data from the research was stored in a locked filing cabinet for the duration of the study and will be archived within the University. A permanent member of University staff will act as custodian.

### *Outcome of ethical review*

The issues above were considered by Fife and Forth Valley REC at a meeting on 7th December 2004. The written response from the committee

gave a favourable ethical opinion subject to some minor alterations. Formal management approval was granted by NHS 24 on 22nd February 2005 and recruitment commenced for pilot work on 5th May 2004.

### 4.4.2 Additional ethical issues- Pilot Study 2 and main study

The revisions required following Pilot Study 1 meant that resubmission for ethical approval was necessary. Ethical review was again performed by Fife and Forth Valley MREC on 6th September 2005 and approval given on 2nd November 2005. The delay was incurred due the committee having some concerns re the processes for obtaining consent and the action to be taken in the event of staff misconduct which required further discussion at a second meeting. An administrative mix-up resulted in the application not being considered at the meeting planned and instead being delayed until the following meeting.

The ethical issues identified were similar to the initial submission but with the following key differences.

***Opt-out invitation process***

The revised process required that those who did not want to receive a telephone call of invitation were required to take action rather than those who wished to take part. It was made easy for those who did not wish to receive this call to decline by either postcard or telephone. However, the remainder would receive a phone call of invitation which offered them the opportunity to ask questions, discuss the research or highlight difficulties with participation

(e.g. with eyesight). Thus, it was considered this enhanced the informed consent process. It was also emphasised to the committee that it was not assumed that those who did not decline, wished to take part. This would be established during the telephone call once it had been confirmed that the patient had read and understood the information. As before, patients' records would only be accessed with their full and informed consent.

***Informed consent***

The revised process involved inviting potential participants by telephone. Thus consent was obtained verbally rather than in writing. In order to ensure a record of consent was obtained, the phone calls were conducted at NHS 24 where the technology existed to easily record calls and later access them via a secure web-application (patients were informed that the calls were recorded). It was also highlighted that this method had the additional advantage of making the process of obtaining consent available for external scrutiny. This is something which would be unavailable in most situations and was considered to further enhance the rigour of the consent process.

***Researcher's role.***

The role of the chief investigator was explicitly stated to be primarily that of researcher, and not clinician. In order to make staff feel safe to participate, absolute confidentiality for staff was assured and they were reassured that no action would be taken as a result of their taking part in this research. It was emphasised that other mechanisms exist within NHS 24 to ensure the quality of consultations and that it was not within the remit of this study to perform that function.

***Data handling***

Telephone interviews were recorded digitally utilising existing technology for call recording within NHS 24. These were ‘tagged’ to the chief investigator to facilitate easy identification.

# Chapter 5. Content of initial presentations: Results

## *5.1 Introduction*

The following chapter begins by reporting rates of participation and assessment for non-responder bias. The characteristics of the sample are then described.

The results of the CS-SRM guided analysis of all the coding units derived from the transcription excerpts are then reported, in particular describing the content of coding units which could not be coded to a component of illness representation.

Next, the content of illness representations expressed within the initial presentations of individual participants are described. Participant quotations are provided to facilitate scrutiny of how coding was applied.

Then, amongst participants for whom both IPQ-R data and a coded transcription are available, a comparison of the two assessments of illness representation is reported. The coding units of participants scoring above and below the mean for each subscale were compared. Implications of the results are then discussed.

## *5.2 Participation*

Overall, during the two pilot studies already described, 315 patients were invited to participate. Of these, 93 (29.5%) consented to participate in some way with 64 (20%) giving consent for the recording of their call to be transcribed (others participated by completing the IPQ-R but did not wish the

recordings of their call to be accessed). The first 60 to be transcribed constituted the quota sample. For clarity, only those whose calls were transcribed are referred to as participants in the following chapter.

## *5.3 Participants compared with non-participants*

In order to assess if participants differed in significant ways from non-participants, tests for difference across a number of key variables were conducted. The results are reported below and summarised in Table 4, below.

### 5.3.1 Demographics

No significant difference in age was identified between participants (mean age=50 years, SD=17.1) and non-participants (mean=55 years, SD=21.0; $p$=0.107).

More women (n=191) than men (n=124) were identified by random selection, reflecting the pattern observed overall in NHS 24, where approximately 60% of calls received relate to female patients (see Appendix 25). The proportion of women who agreed to participate was 19% (n=37) compared with 18% (n=22) of men. The difference was not statistically significant ($\chi 2$ ($df$=1) = 0.131, $p$ = 0.717).

Participants with higher DEPCAT classification (i.e. living in more deprived areas) were less likely to participate than those with lower DEPCAT classifications ($F$ (6, 306) =2.641, $p$=.008).

**Table 4: Comparison of participants and non-participants**

| | Participants n=59 | Non-participants n=256 | Difference (95% C.I) | *p* - value |
|---|---|---|---|---|
| | *Mean (SD)* | | | |
| Age in years | 50.54 (17.00) | 54.74 (21.05) | (-0.91, 9.30) | 0.107 |
| No of previous calls | 4.00 ( 5.12) | 7.84 (51.20) | (-9.30, 16.99) | 0.566 |
| | *n (%)* | | *df* | |
| Male gender | 22 (37%) | 102 (40%) | 1 | 0.717 |
| Documented history CHD | 11 (18%) | 47 (19%) | 1 | 0.999 |
| Emergency response | 21 (36%) | 88 (34%) | 1 | 0.859 |
| Caller involved | 16 (27%) | 161 (63%) | 1 | <0.001* |
| | | *F* | *df* | *p* |
| DEPCAT score | | 2.978 | 6, 306 | 0.008* |

### 5.3.2 Clinical characteristics

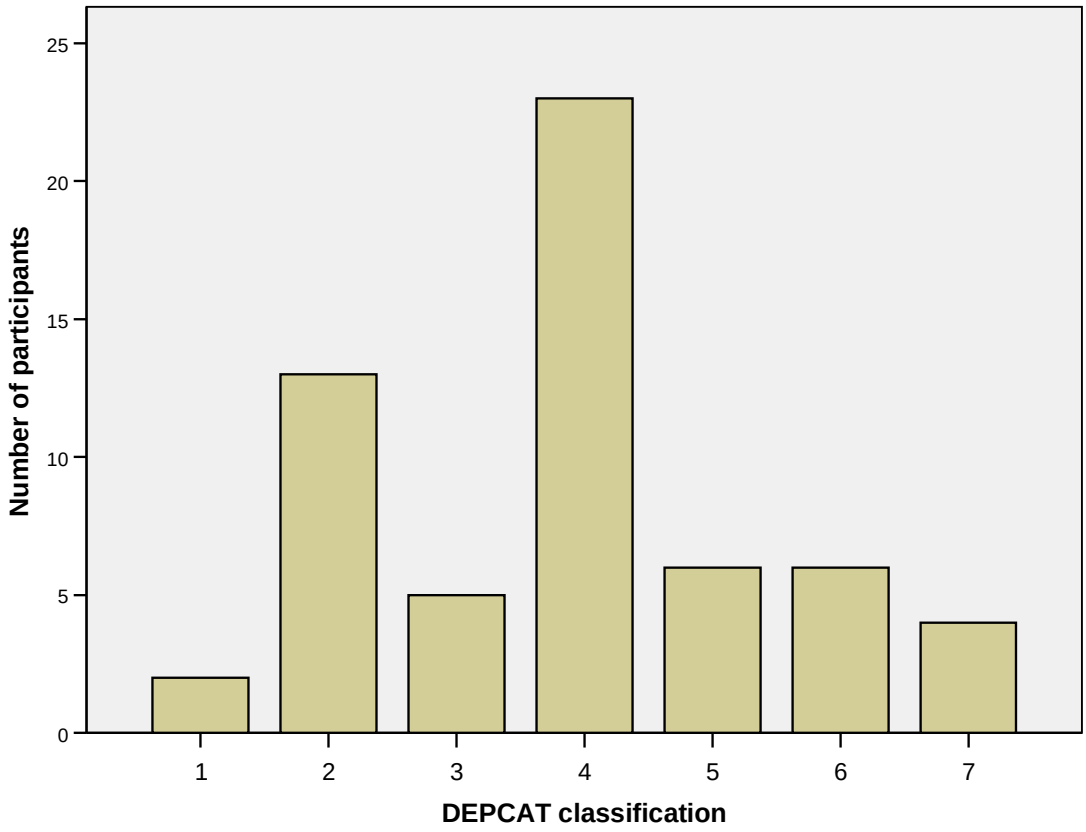
There were no significant differences between participants and non-participants in either their number of previous calls to NHS 24 ($t$=0.575, $p$=0.566); whether or not they had a history of CHD documented within NHS 24 ($\chi$2 (df=1) = 0, $p$ = 0.999) or whether or not the nurse treated them as an emergency ($\chi$2 (df=1) = 0.031, $p$ = 0.859).

However, patients for whom the original call to NHS 24 was made by someone other than themselves were significantly less likely to participate than patients who called themselves ($\chi$2 (df=1) = 25.63, $p$ <0.001).

## *5.4 Characteristics of the sample*

The mean age of participants was 55 years (SD 21.05). People with a range of socio-economic classifications participated in the study (see Figure 6).

**Figure 6: Participants' DEPCAT classification**




In terms of their previous use of the service, 95% (n=61) of participants had called 12 times or less, for 32% (n=19) it was their first call (see Figure 7). Just under a fifth (19%) of participants had a documented previous history of CHD. Calls with a range of outcomes were represented (see Figure 8). In 70% of cases (n=45) the participant called on their own behalf. However, in the remaining 30% of cases (n=19) someone else called NHS 24 on behalf of the patient.

**Figure 7: Number of previous calls to NHS 24**

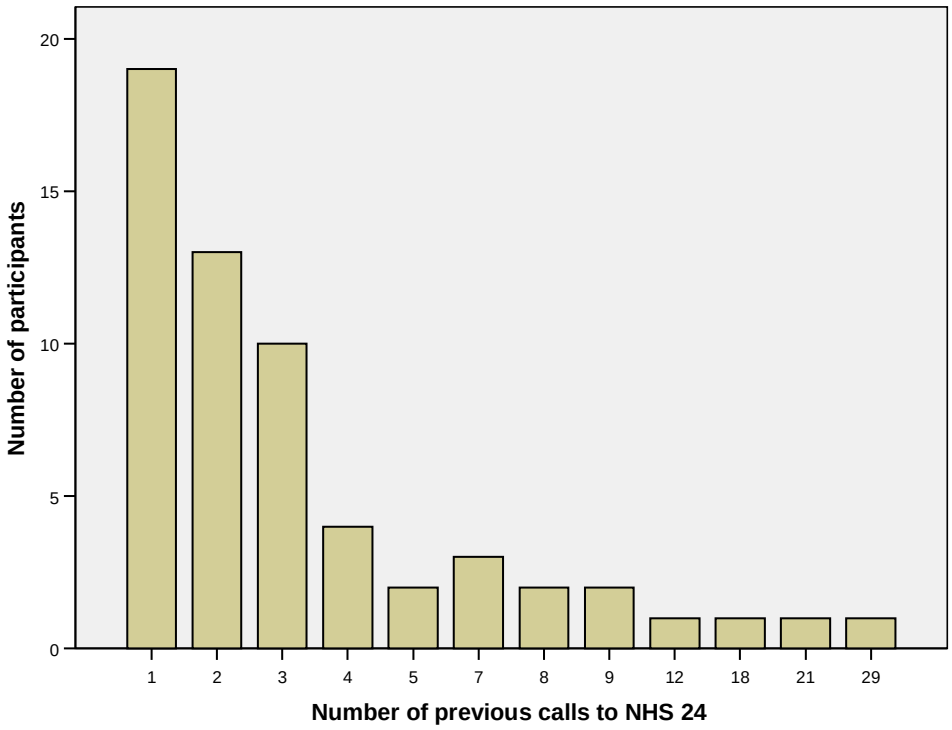
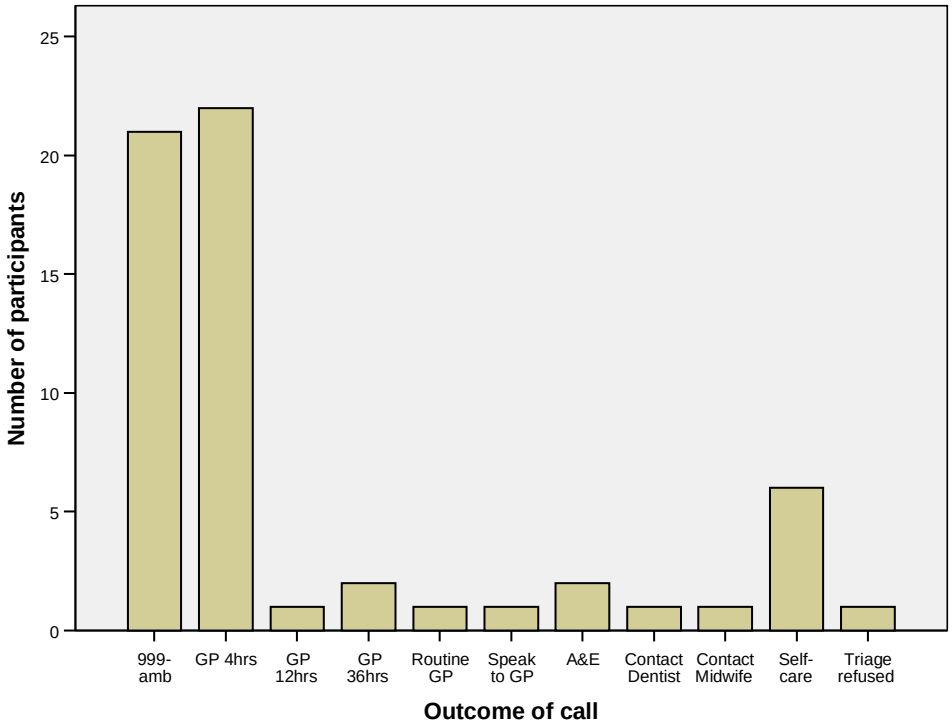



**Figure 8: Outcome of participants' calls**



## *5.5 Illness representations during initial presentation of symptoms*

One transcription was excluded from the analysis as the initial question by the call handler was not an open question. Thus 59 transcriptions were analysed.

The excerpts from the 59 eligible transcriptions contained between 1 and 13 individual coding units, (mean = 3.89, SD=2.78). Thus a total of 230 coding units were available for coding. Overall, 202 (88%) of coding units were coded to at least one component of illness representation.

Analysis of the 230 coding units and of the 59 participants was undertaken and is reported below. However, before presenting these results, data relating to the reliability of coding is provided.

### 5.5.1 Reliability of coding

Coding was performed by the author. Additional coding of 50% (n=30) cases was performed by a colleague who was unconnected with the project but familiar with CS-SRM. The 30 cases yielded 109 coding units which were coded independently by the two coders. Krippendorff's alpha ($\alpha$) was used to assess inter-rater reliability. Results are summarised in Table 5, below. Adequate reliability ($\alpha \geq 0.7$) was achieved for all constructs with the exception of coherence. The results reported are based only on the authors original coding.

**Table 5: Inter-rater reliability**

| | No of units | Krippendorff's alpha | 95% C.I |
|---|---|---|---|
| Identity | 109 | 0.865 | (0.770, 0.962) |
| Timeline | 109 | 0.865 | (0.730, 0.973) |
| Cause | 109 | 0.696 | (0.392, 0.924) |
| Consequences | 109 | 0.791 | (0.478, 1.000) |
| Cure/control | 109 | 0.840 | (0.707, 0.946) |
| Coherence | 109 | 0.593 | (0.186, 0.919) |
| Emotion | 109 | 1.000 | (0.000, 1.000) |
| Other | 109 | 0.809 | (0.555, 1.000) |

### 5.5.2 Components of illness representation within all 230 coding units

Identity was by far the most frequently coded component with 131 (56%) coding units containing references to the experience of symptoms, visible signs or labels. There were 48 (21%) coding units containing reference to timeline. Ten (4%) coding units contained references to possible causes of the symptoms. Participants expressed possible consequences of their symptoms in 9 coding units (4%). References to cure/control were identified within 46 (20%) coding units. Thirteen (6%) coding units contained expressions of the degree of coherence the participant was experiencing. Emotional responses to the symptoms were expressed in 8 (3%) coding units. There were 28 (12%) coding units which could not be allocated to any of the pre-defined codes.

Inductive analysis of the units which could not be allocated to the CS-SRM codes revealed that most (n=16) consisted of a statement in which participants introduced either themselves or the person they were calling about, for example:

*"Good evening, my name is XXXXX XXXXXXXXX"* (Coding unit 4060-1)

*"Hi there. Its em..it's actually my grandfather."* (Coding unit 1050-1)

A further 7 coding units composed of odd words or phrases, usually hesitations within the dialogue, for example:

*"And it was em,.. " (Coding unit 4020-2)*

*"I'll tell you what it is." (Coding unit 5033-1)*

A further 4 coding units appeared to relate to the context in which the symptoms were occurring:

*"I've just come in and my Mum has just phoned me."* (Coding unit 4055-3)

*"She is just sitting beside me just now."* (Coding unit 4068-2)

*"She lives on her own, right."* (Coding unit 5014-4)

*"and its closed* [diabetic unit] *and I can't get in touch with someone."* (Coding unit 5031-2)

One coding unit composed of a statement in which the participant appeared to compare the patient's situation with previous episodes:

*"I've never seen him as bad as this."* (Coding unit 4075-4)

This statement is entirely consistent with the hypothesis of the CS-SRM that people develop representations based upon their previous experience of illness but could not be allocated to any of the definitions of the components

of illness representation.

### 5.5.3 Illness representations expressed by individual participants

The responses relating to individual participants were analysed and reported below. Each participant volunteered between 1 and 6 components of illness representation at least once within their initial response to the open question relating to the reason for their call (mean = 2.24, SD = 1.18) (see Figure 9).

**Figure 9: Number CS-SRM components volunteered at least once by participants**

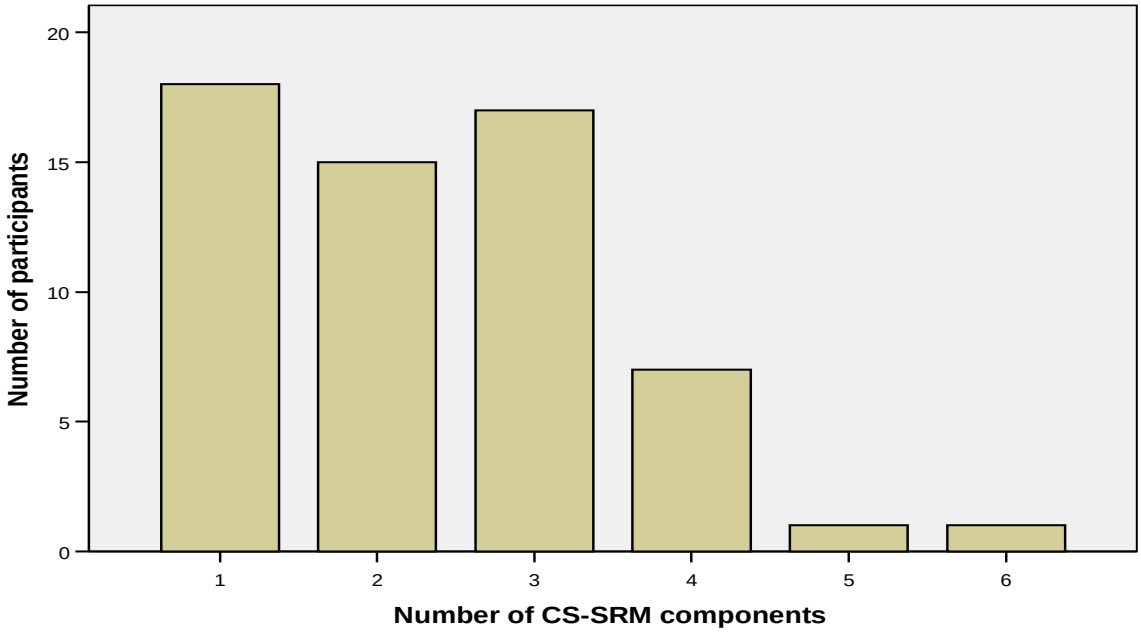
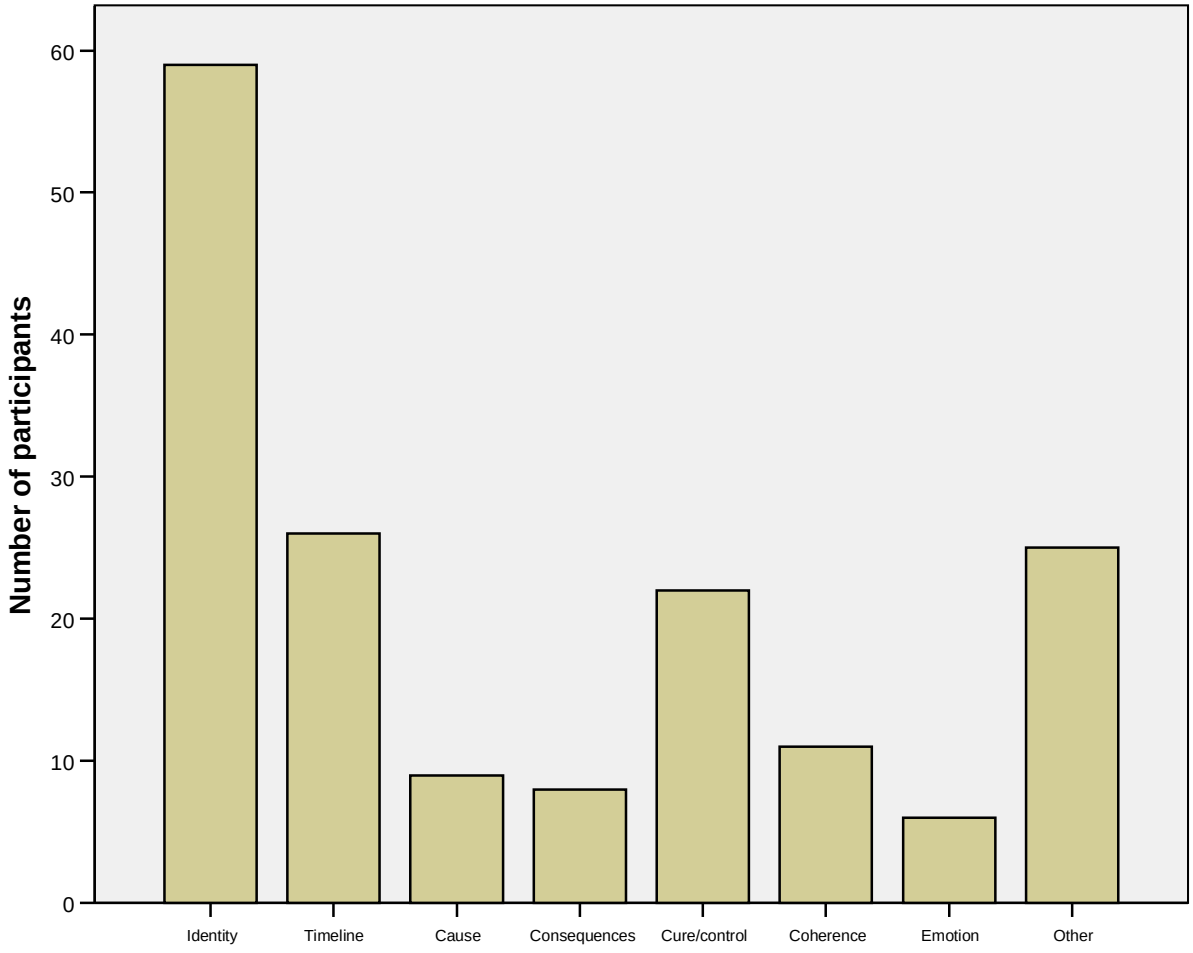



Figure 10, below, illustrates the number of participants who made reference to each component of illness representation. All 59 (100%) participants made reference to identity within their response. The second most commonly identified component was timeline with 26 (44%) participants referring to this.

Cause was referred to by 9 (15%) of participants. Consequences were referred to by 8 (14%) of participants. References to cure/control were made by 22 (37%) participants. References to the degree of coherence were made by 11 (19%) participants and an emotional response to the symptoms was evident for 6 (10%) participants.

**Figure 10: Components of illness representation volunteered by participants**




### *Identity*

All 59 (100%) participants made reference to identity within their response. Most (n=44) described their experience of symptoms. Some examples are:

*"I've been getting pains across my chest". (Participant 4009)*

*"He is having trouble with his breathing something, you know" (*Participant 4019*)*

"*Yeah. I've eh I've got a bad head"* (Participant 4012)

*"..and eh I feel sicky with it but I'm no being sick."* (Participant 5017)

Labels were also mentioned frequently (by n=22 participants), sometimes in relation to the current symptoms and sometimes when referring to previous or ongoing illnesses:

*"Yes, I've got really bad cystitis."* (Participant 4076)

*"..and he's also had a chest infection"* (Participant 5024)

*"I'm asthmatic and I've went doon with this temp"* (Participant 4070)

Visible signs were described by 15 participants (9 of whom were callers), for example:

*"em and to be honest er there's a little bit of blood coming from the tear duct." (Participant 4024)*

*"but she is very pale" (*Participant 5014*)*

***Timeline***

Most of the 26 participants who referred to timeline, referred to the duration of symptoms, for example:

*"He's been up the whole night"* (Participant 4040)

> *"And it's been there since over a week, well over a week now"* (Participant 5017)

Others indicated that the duration of symptoms was longer than they would have expected:

> *"I thought it would go away but eh, this morning it seems to be worse" (*Participant 4027*)*

Some indicated precise times of the onset of symptoms:

> *"It started actually at 8 o'clock this morning I had shooting pains down my left hand"* (Participant 4045)

> *"Maybe it is nothing but she wakened up with a pain down her left arm at 4 o'clock this morning". (*Participant 5014*)*

whilst others indicated the duration of symptoms less precisely:

> *"em, I had a really bad headache all weekend"* (Participant 5027)

> *"Em, it's like the last couple of days I've got like, it's like pins and needles"* (Participant 5033).

One participant volunteered that their symptoms were cyclical in nature:

> *"..and it seems to come maybe every 4 or 5 weeks"* (Participant 5017)

***Cause***

Few participants (n=9) mentioned cause in their responses as to why they were calling. Of those who did, a few clearly articulated possible causes for the symptoms:

> *"I'm phoning up em cos I've got like a bad inner ear infection, I think."* (Participant 5030)

> *"I'm calling because em my husband is experiencing symptoms which almost certainly are from his heart"* (Participant 5010)

> *"I think it is either a muscle spasm or a trapped nerve in her back?" (Participant 5022)*

In some cases it appeared that pre-existing knowledge or experience led participants to suspect a particular cause:

> *"See as soon as I hear about chest pains I think of course about the heart and everything like that, you know."* (Participant 5014).

In another case, the cause the participant suspected was implied through the type of self-care they described having already tried (although clearly this also relates to cure/control):

> *"I've tried to take em stuff for the stomach and I've tried to take em like rennies and things like that but I don't, nothing seems to be helping."* (Participant 5017)

In one case, the participant mentioned a possible contributing factor (regarding his eye problem) but it was not possible to be sure how much he believed this to be the cause of his symptoms:

> "*Um, now I have just been going on and off planes all day*" (Participant 4024)

***Consequences***

Again, few (n=8) participants referred to the likely consequences of their symptoms. Where consequences were mentioned they tended to relate to

physical functioning:

> *"I was in bed and I couldn't get up to open the doors and that"* (Participant 4015)

> *"She just collapsed on the stairs and cant move".* (Participant 4077)

> *"She can't actually walk forwards".* (Participant 5022)

Three references to personal and social consequences were identified but instances relating to economic consequences were not:

> *"Um I've injured my left hand and um unfortunately I am flying out at 3 o'clock in the morning… "* (Participant 4006)

> *"He's been up the whole night." (*Participant 4040*)*

> *"I had a really bad headache all weekend, been in bed"* (Participant 5027)

***Cure / control***

Twenty-two participants made reference to cure/control. Some related to the request for medical assistance, some stating what they thought was required:

> *"Em I was wondering if I could em be seen by a doctor. So I really need to see if..I think what I might need is a hand-brace?"* (Participant 4006)

> *"Hello, eh I am looking for a doctor but obviously eh the doctor is not in at the moment. I'm looking for the doctor eh she is being sick."* (Participant 4037)

Others sought advice as to what would be an appropriate course of action:

*"I just wanted to see if I should go to the hospital or not as I have just been feeling a wee bit sick."* (Participant 4020)

*"and I was just wondering if what we can do about it".* (Participant 4019)

*"..and I think she'd quite like to get it checked out."* (Participant 4068)

A number mentioned attempts they had already made to control the symptoms, either during the acute episode:

*"Yeah, em I've had a constant headache for 2 days and paracetamol is, paracetamol is just not shifting it and my usual migraine tablets that I take aren't shifting it either."* (Participant 5063)

*"And em, she she she got up and made a cup of tea and took two paracetamol."* (Participant 5014)

Or in the past:

*"Well, she has been having blackouts now for oh, about well a year. Just blackouts, we've been back and forward to hospital but she was taken in by ambulance 2 weeks ago and got back. Digoxin was low level and we were on double digoxin she was getting. But she's had, just had 4 or 5 since 7, 5 o'clock this afternoon."* (Participant 5004)

*"I'm on painkillers at the moment for a pain in my lower abdomen and em I've just waiting for a laparoscopy "* (Participant 5060)

Others stated current treatments, possibly by way of introducing relevant past medical history:

*"Eh, I'm asthmatic and on inhalers as well."* (Participant 4009)

> *"Eh I've been taking warfarin for about the past 6 years"* (Participant 4030)

The examples demonstrate patients describing their ideas about what would control symptoms (see Participant 4006), callers describing patients ideas about cure/control (see Participant 5014) and callers describing their attempts to control the patients symptoms (see Participant 4037).

***Coherence***

A number of participants made statements which suggested that they had a clear understanding of their symptoms (the examples have been highlighted before as they include ideas about other constructs):

> *"I'm calling because em my husband is experiencing symptoms which almost certainly are from his heart"* (Participant 5010)

> *"I'm phoning up em cos I've got like a bad inner ear infection, I think."* (Participant 5030)

However, other participants' statements suggested less coherence in relation to their symptoms as in the example of the following 3 statements from a single participant:

> *"But she says she wakened up with chest pains at 6 o'clock but we don't know if she has maybe pulled a muscle or if its flu I don't know...*
>
> *..maybe it is nothing but she wakened up with a pain down her left arm at 4 o'clock this morning...*
>
> *..she says her gums have been bleeding but I don't know if that's anything to do with it."* (Participant 5014)

The examples above demonstrate that patients expressed coherence about their symptoms and that callers expressed their own level of coherence (see Participant 5014). Examples of callers expressing the patient's level of coherence were not identified.

***Emotion***

Emotional responses to symptoms were evident in a small number of participants (n=6) responses to the initial open questions. These ranged from mild concern to high distress. The following examples demonstrate patients expressing emotion about their symptoms and also show that callers expressed both their interpretation of the patients' emotion (see Participant 4052) and their own (see Participant 4075).

> *"I was just a little concerned" (*Participant 4024*)*
>
> *"now what it is, I'm just a wee bit worried" (*Participant 5014*)*
>
> *"She has actually lost a baby before um due to this and obviously she is very concerned" (*Participant 4068*)*
>
> *"Obviously he is very anxious because the symptoms appear to be similar." (*Participant 4052*)*
>
> *"I'm extremely worried about him." (*Participant 4075*)*
>
> *"Em, well he has been in the hospital with em...eh oh dear, oh god ...angina attack" (*Participant 5024*)*

## *5.6 Comparison of IPQ-R data with initial presentation of symptoms*

A total of 46 participants provided IPQ-R during the data collection period described in Pilot studies 1 and 2. A coded transcription and IPQ-R data were available for 35 participants and thus able to be compared. As this further reduced the sample, further tests were conducted to assess whether the 35 participants for whom both types of data were available differed across key variables from the overall population.

The results are reported below and summarised in Table 6, below.

### 5.6.1 Demographics

No significant difference in age was identified between participants (mean age=50 years, SD=15.7) and non-participants (mean=54 years, SD=21.0; p=0.169).

The proportion of women for whom both types of data were available was 10% (n=20) compared with 12% (n=15) of men. The difference was not statistically significant: $\chi 2$ (df=1) = 2.01, $p$ = 0.654.

Participants with higher DEPCAT classification (i.e. living in more deprived areas) were less likely to participate than those with lower DEPCAT classifications ($F$ (6, 306) =3.069, $p$=.006).

**Table 6: Comparison of participants (both IPQ-R and transcription data) and non-participants**

| | Participants n=35 | Non-participants n=280 | Difference (95% C.I) | *p* - value |
|---|---|---|---|---|
| | *Mean (SD)* | | | |
| Age in years | 50.3 (25.7) | 54.4 (20.9) | (-1.79, 9.97) | 0.169 |
| No of previous calls | 4.3 (5.6) | 7.5 (49.0) | (-13.13, 19.5) | 0.701 |
| | *n (%)* | | *df* | |
| Male gender | 15 (42%) | 124 (39%) | 1 | 0.654 |
| Documented history CHD | 8 (23%) | 50 (18%) | 1 | 0.498 |
| Emergency response | 12 (34%) | 97 (35%) | 1 | 0.967 |
| Caller involved | 9 (26%) | 168 (60%) | 1 | <0.001* |
| | | *F* | *df* | *p* |
| DEPCAT score | | 3.069 | 6, 306 | 0.006* |

## 5.6.2 Clinical characteristics

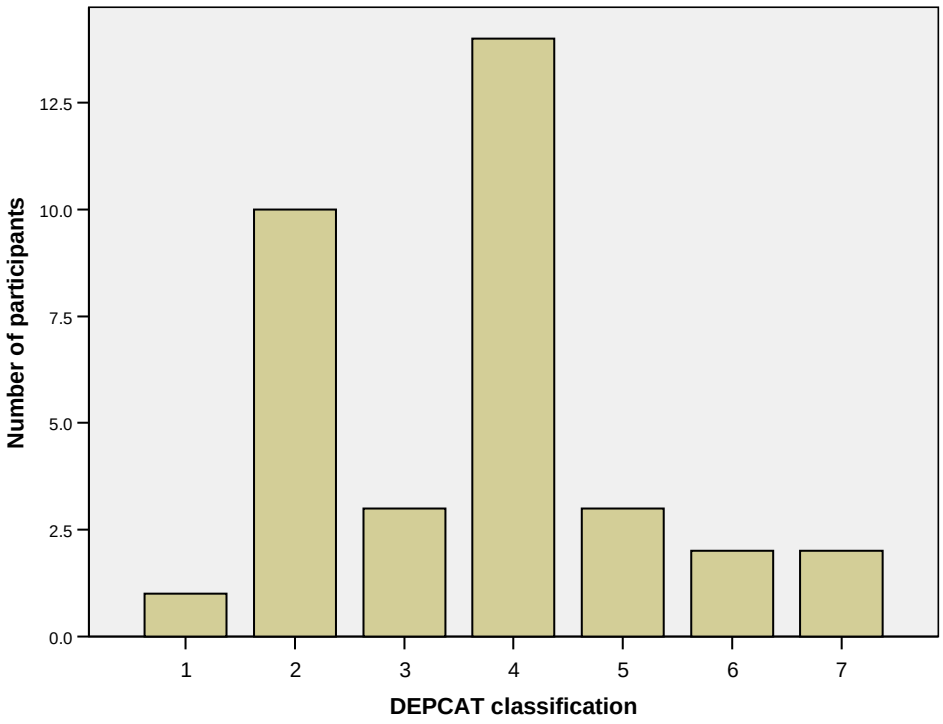
There were no significant differences between participants (for whom both types of data were available) and non-participants in either their number of previous calls to NHS 24 ($t$=0.385, $p$=.701); whether or not they had a history of CHD documented within NHS 24 ($\chi 2$ (df=1) =0.46, $p$ = 0.498) or whether or not the nurse treated them as an emergency ($\chi 2$ (df=1) = 0.002, $p$ = 0.967).

However, patients for whom the original call to NHS 24 was made by someone other than themselves were significantly less likely to provide both types of data than patients who called themselves ($\chi 2$ (df=1) = 15.25, $p$ <0.001).

### 5.6.3 Characteristics of the sample

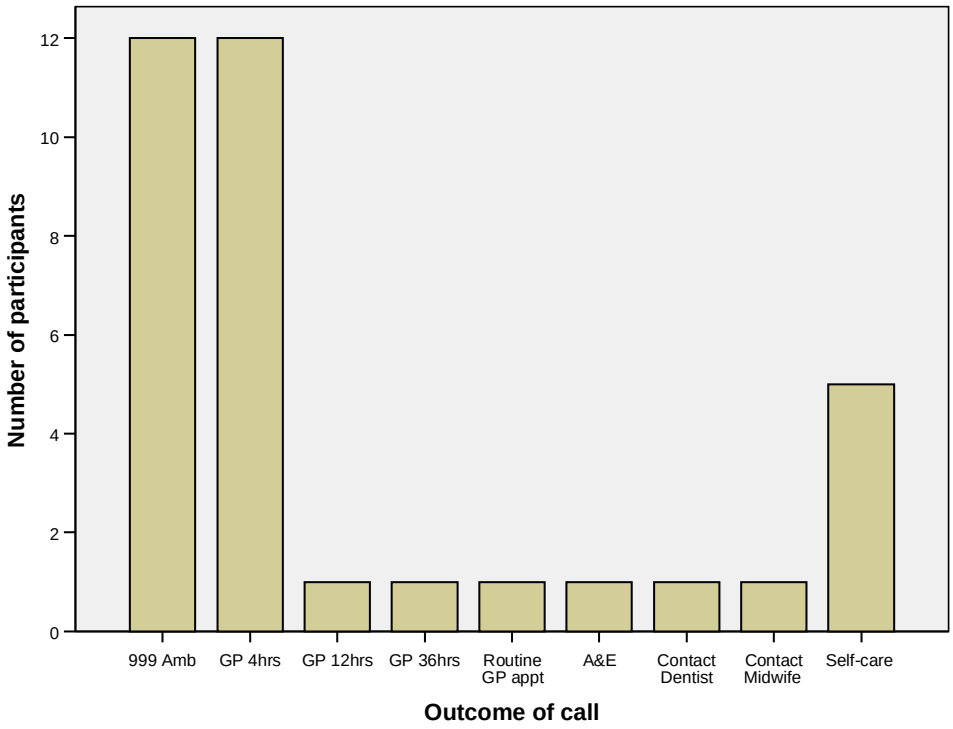
The mean age of participants was 50 years (SD 15.67). People with a range of socio-economic classifications participated in the study (see Figure 11, below).

**Figure 11: Participants' DEPCAT classification**




In terms of their previous use of the service, participants had called on average 4 times, for n=10 (29%) it was their first call. Just under a quarter (n= 8, 23%) of participants had a documented previous history of CHD. Calls with a range of outcomes were represented (see Figure 12, below). In 74% of cases (n=26) the participant called on their own behalf. However, in the remaining 26% of cases (n=9) someone else made the call to NHS 24 on behalf of the patient.

**Figure 12: Outcome of participants' calls**




The two sources of data (coded transcriptions of initial presentations and IPQ-R scores) were compared for each of the components of illness representation and are reported below. Some IPQ-Rs were returned incomplete and thus the number of eligible questionnaires for each construct varied slightly where the number of items completed was inadequate to calculate some subscales.

### 5.6.4 Identity

Symptoms were identified within 44 of the 59 participants' initial presentations. An IPQ-R identity score was available for 23 of these 44 participants.

The 23 participants identified 26 unique symptoms (e.g. 'pain' is a unique

symptom, even if participant refers to it twice) within their initial presentations. Twenty participants reported 1 symptom and 3 participants reported 2 symptoms. Of the 26 symptoms, 17 were captured (65%) by the identity measure of the IPQ-R. Five symptoms were described in a vague way during the initial presentation (e.g. "*not feeling well*" or "*took a turn*") and although participants had checked items on the identity scale it was impossible to be sure about whether the items checked related to their presentations. One symptom (headache) was mentioned by a participant in their presentation but not identified on the IPQ-R despite the symptom being listed. A remaining 3 symptoms were mentioned in presentations but not available on the IPQ-R, namely *palpitations*, *being sick* and a *hurt foot*.

### 5.6.5 Timeline

An IPQ-R timeline score and coded transcription were available for a total of 34 participants. The transcriptions of 17 participants with timeline scores greater than the mean (mean=15) (i.e. those who believed their symptoms were of more chronic duration) were compared with 16 participants with timeline scores lower than the mean (those who believed symptoms were of acute nature). The data of the one participant who scored the mean was excluded from this analysis.

Despite their being approximately equal number in both groups (17 and 16), significantly fewer participants (n=3) with below-average timeline scores made references to timeline within the coded transcripts than participants with above-average timeline scores (n=12) ($\chi^2$ (*df*=1) =10.935, *p*=.001). There were also qualitative differences between the two groups. Eight of the

12 with above-average timeline scores made reference to timeline in terms of durations of days or longer:

> *"yeah well I've got a chest pain and eh I've had it for a few days now and I thought it would go away but eh this morning it seems to be worse." (*Participant 4027*)*

> *"He has a drink problem and he's been drinking since Christmas." (*Participant 4075*)*

> *"Well, she has been having blackouts now for oh, about well a year. Just blackouts, we've been back and forward to hospital but she was taken in by ambulance 2 weeks ago and got back. Digoxin was low level and we were on double digoxin she was getting. But she's had, just had 4 or 5 since 7, 5 o'clock this afternoon. Every day, I've got them all day to you my dear, she just blacks out and within 10 to 15 seconds she's she is all right." (*Participant 5004*).*

Whilst all 3 participants with below-average timeline scores referred to timelines of less than 24 hours (although Participant 4052 also compared the acute episode to one 2 years previous):

> *"Well, I took a turn last night." (*Participant 4015*)*

> *"Eh yes. Em, my partner is em extremely unwell. Has had sickness and diarrhoea since em 5 o'clock this morning. Em, made worse by the fact that em he had this same problem just before a heart attack 2 years, a year and a half ago." (*Participant 4052*)*

> *"And have been in pain for the last 4 hours." (*Participant 5061*)*

However, 3 of those with above-average timelines also referred to symptoms of recent onset although for Participant 5024 this was within the context of an ongoing illness of longer duration:

> *"It's been going on for the last 4 hours." (*Participant 4035*)*

> *"It started actually at 8 o'clock this morning I had shooting pains down my left hand" (*Participant 4045*)*

> *"Eh well I had my wife up at the hospital last night? Em, she's been sick all night. Em, we seen the doctor last night and eh the doctor had said she has got a lung infection. She's got tablets for it …but the thing is...she's no eh holding her food down at all." (*Participant 5024*)*

Unfortunately, IPQ-R data was not available for the one participant who referred to a cyclical pattern in their presentation of symptoms at the time of the call.

### 5.6.6 Cause

The IPQ-R is designed to collect data regarding participants' ideas about the cause of their symptoms differently from other constructs in the IPQ-R. Rather than a scoring responses on a scale, participants are asked to rank in order what they consider to be the 3 most likely causes of their symptoms.

Eight participants suggested possible causes for their symptoms in their original call. IPQ-R data relating to cause were available for 5 of these participants. These were compared with the possible causes subsequently reported on the IPQ-R. In 3 of the 5 cases the most important cause identified by the participant on the IPQ-R was identical to the cause suggested during their initial presentation (heart, ear infection, sinus infection). In one case the participant had suggested the heart as a possible cause during their initial presentation but ranked a "bug" as the most likely cause on the IPQ-R, with heart attack being second. The remaining

participant had mentioned going on and off planes in relation to his symptoms, a statement subsequently coded as ‘cause’. However within the IPQ-R this participant did not mention plane travel as a possible cause and identified being rundown as the most likely cause of his symptoms.

### 5.6.7 Consequences

An IPQ-R consequences score and a coded transcription were available for a total of 33 participants. The transcriptions of the 14 participants with consequences scores greater than the mean (mean=16) were compared with 15 participants with consequences scores lower than the mean (the data of 4 participants who scored the mean were excluded from this analysis). Only 3 of the 31 participants made reference to consequences during their original call. Two participants with above-average consequences scores highlighted potentially serious consequences within their original call:

> *“She has actually lost a baby before um due to this and obviously she is very concerned” (*Participant 4068*)*

> *“My Mum is actually, she just collapsed on the stairs and can’t move.” (*Participant 4077*)*

Whilst the only reference to consequences identified amongst those with below-average consequences scores related to disruption of travel plans:

> *“Um I’ve injured my left hand and um unfortunately I am flying out at 3 o’clock in the morning…” (*Participant 4006*).*

### 5.6.8 Cure / control

The IPQ-R measured 2 aspects of cure/control – personal control and

treatment control. The results for each are reported separately below.

***Personal control***

A personal control score and coded transcription were available for 33 participants. The transcriptions of the 14 participants with personal control scores greater than the mean (mean=18) were compared with 18 participants with personal control scores lower than the mean (the data of 1 participant who scored the mean was excluded from this analysis).

Overall, there were few references (n=2) to personal control within the coded transcripts (most cure/control references related to treatment, see below). One participant with a below-average personal control score made a statement which suggested low personal control:

> *"Yeah, I had an operation on Thursday and em I need cleaning up." (*Participant 5071*)*

Similarly, the transcript of a participant with an above average personal-control score was suggestive of high personal control:

> *"He is struggling and I was just wondering if, what we can do about it." (*Participant 4019*)*

***Treatment control***

A treatment control score and coded transcription were available for 32 participants. The transcriptions of the 19 participants with treatment control scores greater than the mean (mean=17) were compared with 10 participants with treatment control scores lower than the mean (data for 3 participants who scored the mean were excluded from this analysis). One participant with

an above-average treatment control score referred to treatment control by discussing treatment she had recently commenced. In this case, symptoms possibly associated with the treatment appeared to constitute the reason for seeking advice:

> *"Em, actually I've had 2 , 2 different new tablets from my doctor yesterday, right dear, cos you see about 3 weeks ago I had a mini-stroke, right. And a doctor prescribed me tablets, brand new tablets yesterday and I started taking them today. I don't know which ones is giving me a terrible headache and palpitations." (*Participant 4041*)*

Eight participants with below-average treatment control scores made statements relating to treatment control. Most (n=5) related to previous attempts to control symptoms and all suggested that treatment had been inadequate in controlling symptoms (or had led to new symptoms):

> *"Eh, went to the chemist yesterday and got a sort of over the counter prescription em which hasn't done any good" (*Participant 4076*)*

> *"We've been back and forward to hospital but she was taken in by ambulance 2 weeks ago and got back. Digoxin was low level and we were on double digoxin she was getting. But she's had, just had 4 or 5 [blackouts] since 7, 5 o'clock this afternoon." (*Participant 5004*)*

> *"Hi, em I'm on painkillers at the moment for a pain in my lower abdomen and em I've just waiting for a laparoscopy but the painkillers I have are em just aren't helping me" (*Participant 5060*)*

> *"Em, we seen the doctor last night and eh the doctor had said she has got a lung infection…she's got tablets for it …but the thing is...she's no eh holding her food down at all." (*Participant 4059*)*

Other references related to access to expert intervention:

> *"Em I was wondering if I could em be seen by a doctor" (*Participant 4006*).*
>
> *"Hello, eh I am looking for a doctor but obviously eh the doctor is not in at the moment." (*Participant 4037*)*
>
> *"I was told if I took a turn like that to get down to A&E "(*Participant 4015*)*

People with below-average treatment control scores were significantly more likely to mention treatment control during their initial presentation than those with above-average scores ($\chi^2$ (*df*=1) =22.737, *p*<.001).

### 5.6.9 Coherence

An IPQ-R coherence score and coded transcription were available for a total of 35 participants. The transcriptions of the 19 participants with coherence scores greater than the mean (mean=15) were compared with 15 participants with coherence scores less than the mean (data relating to one participant who scored the mean was excluded from this analysis).

None of the participants with above-average coherence scores (i.e. who reported a good understanding of the symptoms) made reference to coherence within the coded transcripts. However, 6 participants with below-average coherence scores referred to coherence. In two cases, the statements were considered to represent a coherent understanding and were therefore inconsistent with the IPQ-R score. However, in both these cases, the participants did also express a suggestion of doubt. This is emphasised by underlining in the following quotations:

*"I'm calling because em my husband is experiencing symptoms which almost certainly are from his heart" (*Participant 5010*)*

*"I'm phoning up em cos I've got like a bad inner ear infection, I think."(*Participant 5030*)*

The remaining 4 participants made statements that suggested a lack of understanding and which were therefore consistent with the IPQ-R score:

*"I don't know whether it was a heart attack or no." (*Participant 4015*)*

*"I don't know which ones is giving me a terrible headache" (*Participant 4041*)*

*"Eh, I'm nae actually sure." (*Participant 4073*)*

*"Em, just ...well I've, I don't know if I've got some kind of infection in the sinuses" (*Participant 5028*)*

Participants with below-average coherence scores were significantly more likely to refer to their level of coherence within their initial consultation than participants with above-average scores ($\chi^2$ (*df*=1) =9.229, *p*=.004)

### 5.6.10 Emotion

An IPQ-R emotion score and coded transcription were available for a total of 33 participants. The transcriptions of the 17 participants with emotion scores greater than the mean[6] (mean=18) were compared with 16 participants with emotion scores less than the mean.

None of the participants with below-average emotion scores (i.e. who

[6] The functionality within N-Vivo that allows participants to be grouped by attributes scores uses actual values within those attributes as filters. As no participants scored the mean for this construct, it was not possible to select scores above and below 19 and therefore 18 was the cut-off instead.

reported lower emotional response to symptoms) made reference to emotion within the coded transcripts. However, 5 participants with above-average emotion scores were found to have made reference to emotion within the coded transcript. References were made to concern, anxiety and worry:

> *"She is 4 and a half months pregnant and she has had a nasty fall and obviously gotten a bit of a scare. She has actually lost a baby before um due to this and obviously she is very concerned" (*Participant 4068*)*

> *"but I was just a little concerned" (*Participant 4024*)*

> *"Obviously he is very anxious because the symptoms appear to be similar" (*Participant 4052*)*

> *"I'm extremely worried about him."(*Participant 4075*)*

> *"Em, well he has been in the hospital with em...eh oh dear, oh god… angina attack …and he's also had a chest infection, now he's taken, I'm a bit concerned just now" (*Participant 5024*)*

Participants with above-average emotion scores were significantly more likely to mention emotion within their initial presentation than participants with below-average emotion scores ($\chi^2$ (*df*=1) =6.261, *p*=.018).

## *5.7 Discussion*

### 5.7.1 Components of illness representation within initial presentations.

The CS-SRM accounted for a large proportion of the content of participants' presentations to NHS 24. A large proportion (88%) of coding units were related to components of illness representation. If coding units where the

participant simply introduced themselves (or the patient) were excluded, the proportion was even higher (95%). Thus the model successfully accounts for the content of participants initial symptom presentations.

Most of the remaining 5% coding units which could not be coded to a component of illness representation tended to relate to the context in which the symptoms occurred (e.g. was the person alone). Within the CS-SRM it is identified that social and environmental factors are an important influence on illness representations and thus coping procedures. Indeed Leventhal states that

*"problem-solving occurs in context" (Leventhal et al. 1998)*

Thus, it may be that people include context as a component when articulating their representation of illness to health services. Another possibility is that people rehearse the context in order to aid their recall of the events surrounding the onset of symptoms (Smith, 1994), i.e. that context is not part of the illness representation but rather a cue to recalling illness representations.

The context of the event emerged as an important theme in a qualitative study where people who had recently experienced an MI recounted their symptoms (Pattenden et al. 2002) confirming 'context' as a key element in illness representations. Furthermore, previous studies have found contextual factors (e.g. whether or not the person was alone [see Participant 5014, page 114]) to be important, both in relation to pre-hospital decision time for people with MI (GISSI, 1995; Dracup and Moser, 1997) and to whether or not an

ambulance was called (Ruston, 2001). The relevance of context in the elaboration and recollection of illness representations is therefore considered worthy of further exploration.

Participants were not comprehensive in their expression of the various components of illness representation within their initial presentations. Eighteen participants (30%) referred only to identity and a further 15 (25%) to only 2 components (one of which was identity as all participants referred to identity). Thus 55% of the sample referred to 1 or 2 components of illness representation. Less than a quarter of participants referred to each of the components: cause, consequences, coherence and emotion.

The results of this study are compared with those of previous work relating to the prevalence of the components of illness representation within peoples' descriptions of illness in Table 7, below. Two studies by Lau and colleagues inspired the methodology for the current investigation (Lau and Hartman, 1983; Lau et al. 1989). The authors asked participants, on a number of occasions, to describe everything they remembered about a recent illness. The results they obtained on first administration are presented for comparison.

**Table 7: Prevalence of components of illness representation. Comparison with Lau, Bernard & Hartman (1989)**

| | Lau et al (1989) | Current study |
|---|---|---|
| Identity | 96% | 100% |
| Timeline | 49% | 44% |
| Cause | 28% | 15% |
| Consequences | 33% | 14% |
| Cure control | 32% | 37% |
| Coherence | ~ | 19% |
| Emotion | ~ | 10% |

It can be seen that similar proportions of participants referred to identity and timeline. However, a much smaller percentage of participants in the current study made reference to both consequences and cause than in the study by Lau and colleagues. Results regarding cure/control were similar in the two studies whilst coherence and emotion were not reported by Lau and colleagues.

The difference in prevalence of consequence and cause statements may be related to the difference in context and methodology. Participants recalling a previous, resolved illness may be more likely to consider aspects such as consequences and cause than those experiencing current symptoms. Alternatively it might be the case that people are particularly reluctant to reveal their ideas about cause or consequence to health services. This could be through fear of appearing ignorant (Weinman and Petrie, 1997) or because they believe that it is the role of health professionals to establish such matters (Participant 4040). It might also be that people present what they consider is expected when they call to seek medical advice (e.g. social and economic consequences were referred to less frequently than physical or functional consequences). Leventhal has suggested that the way healthcare is organised and delivered can influence illness representations (Leventhal et al. 1991). Thus it is plausible that the procedure of presenting symptoms to health services is “socially defined” and that experience (direct or vicarious) of previous consultations with health services influences the illness representations people present on subsequent occasions.

Furthermore, people in the process of seeking medical help may be more

likely to be seeking information about the cause of their symptoms and possible consequences rather than supplying them (Wong and Weiner, 1981).

However, it must also be borne in mind that only participants' responses to the initial open question constituted the subject of this analysis. Whilst this data is particularly valuable as it is largely uncontaminated by either the researcher's or professionals' questions, it represents a small proportion of the overall clinical presentation. It is possible that participants may be more likely to discuss their ideas about cause and consequences later in the consultation. Analysis of the remainder of the transcripts is required (and indeed planned) in order to establish if this is the case.

The transcriptions of participants' initial presentations included 16 where a caller made the call on behalf of the patient. Thus the current study has demonstrated that those calling for medical help on behalf of others also present the same components of illness representation. Interestingly, callers presented either their perception of the patient's illness representation (e.g. "*Obviously he is very anxious because the symptoms appear to be similar*", Participant 4052) or their own representation of the patient's illness (e.g. "*I'm extremely worried about him*" Participant 4075). The relationships between these perspectives are important to investigate further. Previous authors have highlighted the lack of research amongst significant others and their role in medical consultations (Roter, 2003). Specifically, in relation to patient decision time in ACS, the evidence relating to the influence of others is sparse and results are mixed (see page 38). Previous work has identified

that the degree of concordance between spouses illness representations was related to recovery after MI (Figueiras and Weinman, 2003).

Good inter-rater reliability was achieved for all constructs except coherence. It is considered that this may reflect a degree of ambiguity surrounding this construct. The definitions used were obtained from the IPQ-R (Moss-Morris et al. 2002) and measured the degree to which an individual's illness (or symptoms) make(s) sense to them. However, coherence has also been characterised as the degree to which the other components of illness representation 'hang together' to form a logical model of illness (Leventhal et al. 1992; Leventhal et al. 2005). This ambiguity may have been reflected in the raters' coding. Furthermore, there were differences between raters as to whether or not they coded statements suggesting a *lack of* coherence as coherence. It is considered further refinement of coding rules would likely overcome these difficulties and improve inter-rater reliability.

### 5.7.2 Illness representations: Initial presentations compared with IPQ-R

The relationship between illness representations expressed at the time of seeking help and the associated IPQ-R measure differed amongst the components. The patterns observed in relation to each component of illness representation are discussed below.

#### *Identity*

Most (65%) symptoms mentioned by participants during their initial

presentations to NHS 24 were captured accurately by the identity measure of the IPQ-R administered up to 14 days later. However, the measure failed to capture 4 symptoms, relating to 3 participants which is clearly of concern. Two of these symptoms, namely *"being sick"* and *"palpitations"* could be associated with ACS and so are considered important to include in future versions of the IPQ-R (i.e. in the second stage). For 2 participants this meant that the IPQ-R failed to capture any of the symptoms they reported during their call ((i) a hurt foot (ii) headache and palpitations). The symptom of 'headache' in fact appeared as an option on the identity scale. This suggests that occasionally participants may experience difficulty in recalling the symptoms they associated with their call to NHS 24 or that their representations may change in the period between their call and administration of the questionnaire (which was up to 10 days later).

The wide variety of language used by participants to describe symptoms in contrast to the limited options on the IPQ-R meant it was often difficult to compare the two measures of identity. This was particularly problematic where people used vague descriptions of their illness statements such as *"not feeling well*". Such statements could relate to a number of symptoms subsequently identified by participants on the IPQ-R (e.g. *nausea*) but were too ambiguous to be confidently considered consistent. However, that participants who had not identified specific symptoms during their initial presentations to NHS 24 were subsequently able to identify symptoms that they associated with their call on the IPQ-R suggests that for some the list format may be useful in helping them to articulate their illness representations.

### *Timeline*

Participants who reported longer timelines on the IPQ-R were significantly more likely to have made reference to timeline during their initial consultation. This is consistent with the hypothesis that duration is a heuristic used by individuals to evaluate somatic change (Leventhal et al. 2007). Previous work has found that increased duration of symptoms is related to a greater likelihood that older people will seek care for symptoms (Mora et al. 2002). Participants in the current study were more likely to present information about symptoms of longer duration than short during their initial presentations. This provides further evidence that the duration of symptoms is an important factor for individuals which is obviously of particular concern in the context of ACS.

IPQ-R reports of timeline were generally consistent with what people said at the time of their call. The few participants with below-average timeline scores, who made reference to timeline during their presentations, all presented symptoms of less than 24 hour duration. Similarly, most of those with above-average timeline scores reported timelines of days or longer durations. However, there were 2 participants who reported a chronic timeline on the IPQ-R but presented acute symptoms during their initial presentation.

The tendency for people not to present information regarding shorter timelines has important implications. The symptoms of ACS become potentially life-threatening immediately following onset and the aim is for people to seek help within an hour of onset. The current data appear to suggest that the heuristic relating to duration operates over much longer time

periods - people made reference to timelines of > 24 hours early in their presentations to health services but mentioned shorter durations less often. This may be an important element to highlight in interventions aimed at reducing delay. It might be useful to provide precise information about the durations that health professionals consider delay in the context of ACS as these may be at variance with the time frames people would ordinarily consider cause for concern.

The tendency for people not to volunteer information about acute timelines has implications for health professionals involved in evaluating symptoms, particularly the symptoms of ACS. These data emphasise the key importance of questioning regarding the onset of symptoms as this information may not always be volunteered. In addition these results suggest that clinicians should be alert to the tendency for patients to present chronic timelines. Patient emphasis on symptoms of long duration could lead to clinicians failing to identify salient, acute symptoms and thus potentially adversely affect their clinical judgement.

In terms of methodology, the examples where participants reported chronic timeline on the IPQ-R although they had presented acute symptoms demonstrate that some caution is required in interpreting the results of a retrospective report of timeline – patient reports may not accurately describe the content of presentations.

***Cause***

As already discussed, few participants made reference to cause during their initial presentations and thus there were only a small number of cases (n=5)

where IPQ-R reports could be compared. Most participants were consistent between the two reports. The example, where Participant 4024 mentioned "going on and off planes all day" but did not report this as a possible cause on the IPQ-R, illustrated another difficulty in comparing the two sources of data. The example may constitute further evidence that participants find it hard to recall their illness representations or that change over time affects retrospective accounts. However, it is also possible that this participant did not consider his plane travel as a possible cause and referred to it for another reason (possibly providing context as discussed earlier). There are inherent difficulties in trying to interpret what people think from what they say (Halldén et al. 2007). This is particularly true in the context of the current study where there was no opportunity to clarify interpretations with participants. A methodology where participants are given the opportunity to review the recording of their own call might help to overcome this difficulty and provide additional opportunities to elaborate people's representations at the time of seeking help. However, it is recognised there might be a number of practical and ethical difficulties associated with such a method.

***Consequences***

There were few references to consequences within the coded transcriptions and it is therefore difficult to draw firm conclusions about their relationship to participants' IPQ-R scores. However, both participants who identified potential serious consequences during their initial presentations did report above-average consequences scores, providing some support for the validity of the measure.

It is important to observe that a large proportion of participants who later reported that they believed their symptoms to have severe consequences did not share those beliefs with NHS 24 staff when presenting their symptoms (only 2 of 15 participants with above average consequences scores on IPQ-R mentioned possible consequences when presenting their symptoms). This would appear to have important clinical implications, particularly in the context of a telephone triage situation. Information that an individual believes their symptoms to have serious consequences might help the clinician identify urgent clinical situations. Thus it may be important for clinicians to ask questions relating to potential consequences as it appears unlikely to be volunteered. Furthermore, irrespective of the actual urgency of the clinical situation , knowledge that the caller believes their symptoms to have serious consequences would be helpful information for the clinician in their negotiation of an appropriate outcome with the caller and might aid adherence with their advice (Leventhal et al. 1992; Petrie et al. 1996; Horne and Weinman, 2002).

***Cure/control***

There were few references to personal control within the transcripts, with most participants referring to treatment. This is not unexpected. Given that the study involved people who were seeking medical help, it could be anticipated that people would identify the type of help they were seeking. However, it is interesting that when people did make reference to attempts to control symptoms they referred only to treatment and in particular to using medicines. Previous research amongst patients with possible symptoms of MI found that resting and increasing activity were common first responses to

symptoms (Meischke et al. 1995) and yet were not mentioned by any of the participants in this study. This suggests that people might consider non-medical attempts to control symptoms un-important or not valid to discuss in clinical consultations. Again, this has implications for clinicians who need to ensure they ask questions in order to elicit important information about what self-care measures people have tried.

Most references to treatment control related to the failure of medicines to control symptoms or having led to new symptoms. This is a pattern consistent with what the CS-SRM would predict. The model proposes that people implement coping procedures, based upon their illness representations. When an individual appraises the coping procedures as having failed to move them towards the goals specified by their illness representations, help-seeking is more likely to occur (Leventhal et al. 1984; Mora et al. 2002; Martin and Leventhal, 2004). The data presented here illustrate this pattern. Furthermore, most (5/6) of the participants who described the failure of treatment to control symptoms reported below-average scores on the IPQ-R. Other participants who reported below-average scores sought expert advice (e.g. from a doctor). Again, it appears consistent that people who did not believe that treatment (in particular, people referred to medicines) would control their symptoms would look to experts for alternative solutions. Indeed, those with below-average treatment-control scores were significantly more likely to make reference to treatment control than those with high scores.

The IPQ-R scores associated with the 2 references to personal control

identified within the transcripts appeared to reflect the degree of control suggested in the participants' statements. However, clearly additional data would be helpful in drawing firmer conclusions about how accurately the IPQ-R subscale reflects individuals' personal control. The IPQ-R items appear useful in eliciting the personal control component of illness representation, which people tend not to reveal during their initial presentations.

The treatment control subscale appears consistent with representations expressed during initial presentation.

***Coherence***

None of the 20 participants who reported above average coherence scores discussed their understanding of their symptoms at the time of presentation. This suggests that those who had a good understanding of their symptoms did not feel it necessary to discuss their level of understanding and instead talked about other components of illness representation.

Furthermore, most statements made by participants with below-average coherence scores suggested a poor understanding of their symptoms. Together these findings suggest the IPQ-R measure of coherence is consistent with the illness representations expressed during initial presentations and support the validity of the measure.

However, there were 2 exceptions where people presented what appeared to be a good understanding at the time of the call but subsequently reported below-average coherence scores. A number of interpretations are possible.

These exceptions may simply reflect isolated difficulties with recall. Equally,

within the two examples there were indications of uncertainty (see page 135) and so they may actually be consistent with the IPQ-R measure. Alternatively, the two participants may have articulated coherent explanations whilst remaining uncertain about the symptoms. Within an early reference to the CS-SRM, Leventhal and colleagues postulated that what people say is not necessarily always consistent with their underlying beliefs (Leventhal et al. 1980). On the other hand, what was a coherent explanation at the time of the call may have become less so during the interval between the call and completion of the questionnaire, a period during which participants may have received an alternative diagnosis. Subsequently, participants may have reported lower coherence than was apparent at the time of the call.

***Emotion***

None of the 16 participants with below-average emotion scores made statements relating to emotion during their presentation of symptoms. However, 6 of the 17 with higher than average scores did. Participants with above-average emotion scores on the IPQ-R were significantly more likely to express emotion during their initial presentation ($\chi^2$ (df=1) =6.902, $p$=0.018). This suggests that those who express emotion about symptoms at the time of seeking medical help tend to report higher emotion on questionnaire up to 14 days later and those who report below-average emotion scores on IPQ-R were unlikely to have expressed an emotional reaction at the time of presentation. These data provide support for the validity of the IPQ-R measure of emotion.

Overall, the data suggest the IPQ-R is a valid, although possibly incomplete,

retrospective measure of people's illness representations at the time of seeking help. Thus the IPQ-R is considered suitable for use in the second stage of the investigation.

### 5.7.3 Strengths and limitations

The major strength of the methodology was that participants' transcription data were provided at the actual time of seeking help and thus were not reliant on recall. Previous examples of a similar methodology being used amongst people seeking urgent medical help were not identified in the literature.

Further, as responses to an initial open question were isolated, the data could be considered 'uncontaminated' by either the researcher or NHS 24 staff. Furthermore, these data were obtained before diagnostic labels had been applied and thus responses could not have been influenced by whether or not particular diagnoses were made. This has not been possible in prior studies of decision time relating to this patient group and is an important limitation of existing evidence. However, it is recognised that the IPQ-R measure was reliant on recall and may have been influenced by events that occurred between the time of the call and completion of the questionnaire.

The main limitation of the study was the low participation rate (20%) which is likely to have resulted in some bias in the sample. Furthermore, reasons for non-participation were not systematically collected which limits the ability to assess further the likely impact of the low participation rate. However,

patients for whom the call to NHS 24 was made by someone else were significantly less likely to take part. It is possible that patients in this situation are most unwell or less confident communicators and thus that the resultant sample under-represents these groups. However, it is also possible that it was simply the additional burden and complexity of achieving the participation of two people that led to less people in this situation taking part. Secondly people from areas of high social deprivation were significantly less likely to take part than people from low. It is not clear why this was the case although the requirement to complete a questionnaire may have deterred people with literacy problems from taking part, a common issue in areas of deprivation (Organisation for Economic Co-operation and Development, 1997). However, people from socially deprived areas have poorer health outcomes (Townsend et al 1992; Davey Smith et al. 1997) and are at increased risk of CHD (Kaplan and Keil, 1993; Scottish Executive, 2004). It was therefore considered important to achieve the participation of people from these areas and to understand their illness representations. It was considered that the inclusion of telephone interview as an alternative to self-completion (only adopted during Pilot Study 2 of this study) might help to improve the representation of this group in the second stage of the investigation.

The sample is considered representative in other important ways. A variety of information about potential participants was available at NHS 24 which allowed an assessment of non-responder bias to be made. Participants did not differ from non-participants with regard to age, gender, number of previous calls to NHS 24 or previous history of CHD. Importantly, the sample

was selected from the *entire total* of people trying to reach their GP in out-of-hours period and was randomly selected.

Coding was undertaken by the investigator and thus it was possible that the results could be subject to bias in relation to the investigator's interpretation. However, the data were independently coded by a second investigator and coding was found to be highly reliable between the two coders, even after correcting for chance agreement. Furthermore, the use of N-Vivo software ensured that the coding of data is readily available for further scrutiny and independent replication of analysis.

## *5.8 Conclusion*

This study confirmed that the components of CS-SRM were evident within peoples' verbal presentations of their symptoms at the time of seeking medical help. The components of illness representation accounted for a high proportion of the content of people's initial presentations. Illness representations were volunteered spontaneously by participants, without prompting, providing important evidence of the existence of the components. However, a number of participants also made reference to the context in which the symptoms were occurring and these statements could not be assigned to any of the components of illness representation. The relevance of context in the elaboration and recollection of illness representations is therefore considered worthy of further exploration.

Mixed results were obtained when retrospective reports of illness perception

as measured by the modified IPQ-R were compared with those expressed during initial presentation. The identity subscale captured the majority of symptoms identified from participants' initial presentations but importantly not all. The IPQ-R failed to capture any of the symptoms from the initial presentations of 2 participants which was of concern. This finding led to the addition of '*vomiting'* to the next version of the IPQ-R (Appendix 3 and 29) in order to ensure better identification of these particular symptoms. However, it is also recognised that the number of symptoms people might identify as related to their call is without limit and thus that a checklist will always be inadequate. Additional methods of eliciting information about identity might be useful to add to the IPQ-R. In particular, given that all participants made spontaneous reference to identity in their initial presentations, an open question about the reason for their call might be a useful method of eliciting additional information about identity (and possibly other components of illness representation).

Similarly, although most references to timeline within initial presentations were consistent with IPQ-R scores there were 2 instances where the two measures were inconsistent with each other. Furthermore, participants who reported acute timelines on the IPQ-R were significantly less likely to refer to timeline within their initial presentation. Thus high and low timeline scores do not necessarily reflect what people declare during initial presentations.

References to cause, consequences and personal control within initial presentations were rare but the limited examples appeared consistent with the related IPQ-scores. The apparent tendency for these components not to

be discussed has implications for clinical practice and is therefore an important area for further investigation. In particular, it is important to examine the content of consultations beyond only the initial presentation to explore whether further components of illness representation are revealed by patients or indeed elicited by health professionals. However, the comparison between the two types of data also demonstrates the usefulness of a tool like the IPQ-R in eliciting components of illness representation that might otherwise not be expressed. IPQ-R type questions might be usefully incorporated into clinical consultations to improve practitioners' understanding of patients' understanding of their symptoms or illness. This might increase patient satisfaction (Cooper et al. 2007) and adherence with advice (Lang et al. 2002; Horne and Weinman, 2002), lead to improved communication (de Ridder et al. 2007) and possibly improve clinical decisions.

Treatment control scores were generally consistent with illness representations expressed during initial presentations although again, those with above-average treatment-control scores were less likely to refer to treatment control than those with higher scores.

Coherence and emotion scores also appeared consistent with the IPQ-R measure. None of the participants with above-average coherence scores discussed their understanding of their symptoms at the time of presentation whilst most statements made by participants with below-average scores suggested low coherence. Similarly, those reporting high emotional representations tended to express emotion within their presentations

whereas those reporting low emotional representations on IPQ-R did not. This suggests that those with poor understanding of their symptoms and strong emotional representations will tend to reveal this within their initial presentation. These may be useful cues for clinicians who may need to provide more coherent explanations for patients and to take into account patients' emotional representations when providing treatment or advice. The findings support the validity of the coherence and emotion measures within the IPQ-R.

The possibility that subsequent events might distort the subsequent retrospective reporting of illness representations has been a major limitation of prior studies which have used the IPQ-R retrospectively. The results obtained in this study provide additional support for the validity of results previously obtained in such studies although also highlight a number of limitations with the approach.

Overall the CS-SRM is considered a valid and useful theoretical framework for the investigation of patient decision time with possible symptoms of ACS. The IPQ-R appears a valid, although possibly incomplete, retrospective measure of people's illness representations at the time of seeking help and suitable to be utilised within the second stage of the investigation.

# Chapter 6. Timing of initial presentations: Methods

## *6.1 Introduction*

The following chapter describes the methods used in the second stage of the investigation, exploring decision time amongst participants with symptoms of ACS. Firstly, the aims and research questions are described. This is followed by a description of two pilot studies which were undertaken to pilot the content and mode of administration of the IPQ-R, prior to the main investigation. The methods adopted in the main study are then described in detail.

## *6.2 Aim*

The aim was to

1. Learn how the illness perceptions, symptoms and demographic characteristics of patients (who have possible symptoms of ACS) relate to how and when they present to healthcare services and to clinical outcome.

## *6.3 Research Questions*

1. Do patients' or callers'(if applicable) illness perceptions explain variance in decision time additional to that explained by demographic factors (age, gender, social deprivation score, ethnic group) and clinical factors

(presence or absence of pain, previous history of CHD, number of previous calls to NHS 24, presence or absence of diabetes)?

2. How do patients' illness perceptions relate to patient decision time?

3. Do patients' or callers' (if applicable) perceptions of illness predict ACS or other clinical outcomes?

4. What is the relationship between patients' (and callers' if applicable) illness perceptions and outcome at 3 months?

## *6.4 Pilot work*

Before these research questions could be addressed, it was necessary to pilot the adapted IPQ-R and to establish the most appropriate mode of completion for participants recruited from NHS 24. Pilot work relating to both these issues (Pilot Study 3 and Pilot Study 4) was undertaken and is described below. This is followed by a description of the methods ultimately adopted for this study.

### 6.4.1 Pilot study 3: Administering the IPQ-R

#### *Background*

The IPQ-R(Moss-Morris et al. 2002) was developed to assess illness perception and has been used with a wide variety of clinical groups e.g.

asthma (Horne and Weinman, 2002), chronic fatigue syndrome and rheumatoid arthritis (Moss-Morris and Chalder T, 2003) and CHD (Petrie et al. 1996). However, in the context of this study people were identified at the time they sought help with symptoms. They may or may not have received a diagnostic label in relation to those symptoms and in any case it was unknown to the investigator. It was therefore necessary to adapt the questionnaire to assess peoples' perceptions of their symptoms rather than a specific illness. Thus it was necessary to reassess reliability and validity.

In addition, the literature review had not identified any previous examples of the questionnaire being used in a similar context to NHS 24 and so it was considered useful to explore how acceptable it would be to patients. Acceptability was considered especially important given the potential for distress that was identified in relation to contacting this group within the proposed timeframe. The IPQ-R was included within the information sent in Pilot Study 1 (see page 68). However, given the difficulties experienced with recruitment (described on page 72 ) insufficient numbers were completed which meant that validation was not possible at this time. However, feedback from people who *did* complete the IPQ-R, and from a number of enquiries, indicated that there might be ways in which the questionnaire could be made more manageable for participants.

In an attempt to reduce difficulties with the questionnaire semi-structured interviews were conducted with 20 participants. It was planned that feedback from patients could be used to improve the questionnaire prior to further pilot work.

### *Aim*

To explore participants experiences of completing the IPQ-R.

### *Research question*

1. What aspects of IPQ-R completion are problematic?

### *Method*

#### *Design*

Semi-structured interviews designed to elicit participant feedback on the adapted IPQ-R and CIPQ-R.

#### *Setting*

The 24-hour telephone health advice line (NHS 24) provided the setting for the research.

#### *Participants*

A subset (n=20) of the sample identified for Pilot Study 2 (see page 80 for details) participated in this pilot.

#### ***Inclusion Criteria***

A call had been received and recorded by NHS 24.

#### ***Exclusion Criteria***

Any calls involving children aged 16 or under were excluded. Calls where the call-reason stated that the patient was suicidal were also excluded.

***Procedures***

Fifty-nine NHS 24 callers were approached by letter, to ask if they would be willing to participate in a telephone interview. A quota sample of 20 was recruited.

20 telephone interviews were conducted with participants using the interview schedule in Appendix 26. This included additional questions regarding the content and acceptability of the questionnaire. All interviews were recorded and the recording subsequently reviewed.

***Analysis***

Areas of difficulty, confusion or which required clarification were identified (see Appendix 27 for summary).

***Results***

Five symptoms were volunteered by participants which could relate to ACS but which were not included on the questionnaire – vomiting, shaking, pins and needles, sweating and collapse.

Respondents referred to symptoms and time points which did not relate to the NHS 24 call on more than one occasion.

Most participants (17 out of 20) reported the timing of the questionnaire to be acceptable.

Participants consistently found negatively phrased questions such as *"my symptoms would not have much effect on my life"* problematic, requiring clarification and causing frustration.

A number of participants indicated that they would prefer to answer in their own way and disliked too many tick-boxes.

***Discussion***

The symptoms suggested by participants, but which were not listed in the questionnaire, included a number of possible symptoms of ACS (Canto et al. 2000; Gupta et al. 2002). These symptoms were therefore added to the IPQ-R used in the main study (Appendix 28 and Appendix 29).

The interviews highlighted that patients encountered difficulties in identifying which symptoms were being referred to and at which time-point. However, it was difficult to improve the instructions in this regard without priming patients' responses to identity and timeline items. It was considered that such problems might be obscured by self-administration and thus that telephone administration would be preferable.

It was considered that inclusion of an open question might overcome the limiting nature of tick-boxes identified by some participants by providing an opportunity to freely respond.

Minor alterations were made to 17 questions where a number of participants highlighted difficulty (see Appendix 27). The modified questionnaires were resubmitted for ethical review (Appendix 28 and Appendix 29). Data collected in the study exploring the content of initial presentations provided a further opportunity to compare self-completion of the questionnaire with completion via telephone interview. This is discussed below.

***Conclusions.***

The symptom list was changed to include the symptoms noted above and a number of questions were reworded where a number of participants highlighted difficulty.

Completion of the IPQ-R by telephone interview may be preferable to self-completion by providing an opportunity to clarify symptoms and time-points referred to.

An open question was introduced to allow participants the opportunity to freely respond.

### 6.4.2 Pilot study 4: Comparison of self-completion with telephone interview completion of the IPQ-R

***Rationale***

Following the results of Pilot Study 3, the alternative option of administering the questionnaire via telephone interview was considered worthy of exploration. The purpose being to investigate whether this might overcome some of the difficulties identified on page 66 and be perceived as more meaningful by potential participants. Pilot study 4 was also designed to investigate whether interviews might attract a higher response rate and be more likely to obtain complete and timely data. Furthermore interviews offer a more conducive environment for people to ask questions or express concerns and are helpful for people with difficulties in reading or writing.

### *Aim*

To compare self-completion with telephone interview completion of the adapted IPQ-R on response rate, timeliness of response and acceptability to participants.

### *Research questions*

1. What effect does the method of administration (telephone interview or self-completion) of the IPQ-R have on (i) response rate, (ii) response delay, and (iii) acceptability to participants?

### *Method*

#### *Design*

A randomised comparison of the effects of postal self-administration versus telephone interview completion of the IPQ-R on response rate and completeness of questionnaire responses.

#### *Sample*

Participants (n=86) invited to participate in Pilot Study 2 and in the study relating to the content of initial presentations (see pages 80 and 91 for more details) were also asked to complete the second version of the IPQ-R.

#### ***Inclusion Criteria***

A call had been received and recorded by NHS 24

The patient (and if applicable anyone who called on their behalf) and NHS 24 staff members consented to take part.

***Exclusion Criteria***

Any calls involving children aged 16 or under were excluded. Calls where the call-reason stated that the patient was suicidal were also excluded.

***Procedures***

Patients identified as eligible for the study were randomised to either an invitation to take part in a telephone interview or an invitation to self-complete the revised IPQ-R. Letters were sent to potential participants 1-3 days after their call, inviting them to take part in the research using the approach described in Pilot Study 2 (see page 81). The questionnaire (Appendix 28 and Appendix 29) was sent to participants allocated to both groups. This allowed participants who completed the questionnaire via telephone interview to comment on visual aspects such as layout and also acted as a guide for interviews.

Those who were randomised to self-completion were asked to complete the questionnaire within a week and return in the postage-paid envelope provided.

Participants randomised to interview were asked for a convenient time to conduct the interview. All interviews were audio-recorded using NHS 24 technology (participants were informed this would be the case). An interview schedule (Appendix 26) provided the structure for the interview. The duration of interviews was approximately 20 minutes.

Where patients were unable to complete a questionnaire then the alternative of a telephone interview was offered. Similarly, if a telephone interview was not feasible (e.g. the patient was in hospital) then self-completion of the

questionnaire was offered.

***Analysis***

It was planned that the two approaches would be compared in terms of positive responses obtained, completeness of data achieved and in terms of acceptability to participants.

***Reliability***

Analysis of the responses was used to assess internal reliability using Cronbach's Alpha, a method of checking that items within the questionnaire designed to assess specific concepts do so consistently. It would be usual to also assess stability over time using the test-retest method where little variability in responses confirms the reliability of the test. However in the context of this study where patients were experiencing acute and evolving symptoms it was probable that illness perceptions would be changing significantly and it was therefore considered inappropriate to use stability as a criterion of reliability in this context.

***Validity***

The original IPQ-R has been extensively validated and adapted specifically for use with patients with a range of clinical conditions. The adapted questionnaire devised for this study was reviewed by an experienced health psychology researcher familiar with the theoretical and methodological aspects of the IPQ-R (MJ) and considered a logical, balanced and comprehensive measure of the concept of illness perception.

Additionally, the components of illness perception identified in the transcripts

were compared with those assessed by the adapted IPQ-R to establish how the assessment of illness perception compares between the two in this population (convergent validity). The results of this analysis were presented on page 124.

***Acceptability***

Respondents were invited to provide feedback on how acceptable they found both the approach and the questionnaire. These results are presented below and were used to inform the second stage of the study.

***Readability***

The readability of the questionnaire (and indeed of all written material sent to patients) was assessed using the Flesch Reading Ease measure (Flesch, 1948) within Microsoft® Word 2002.

***Results***

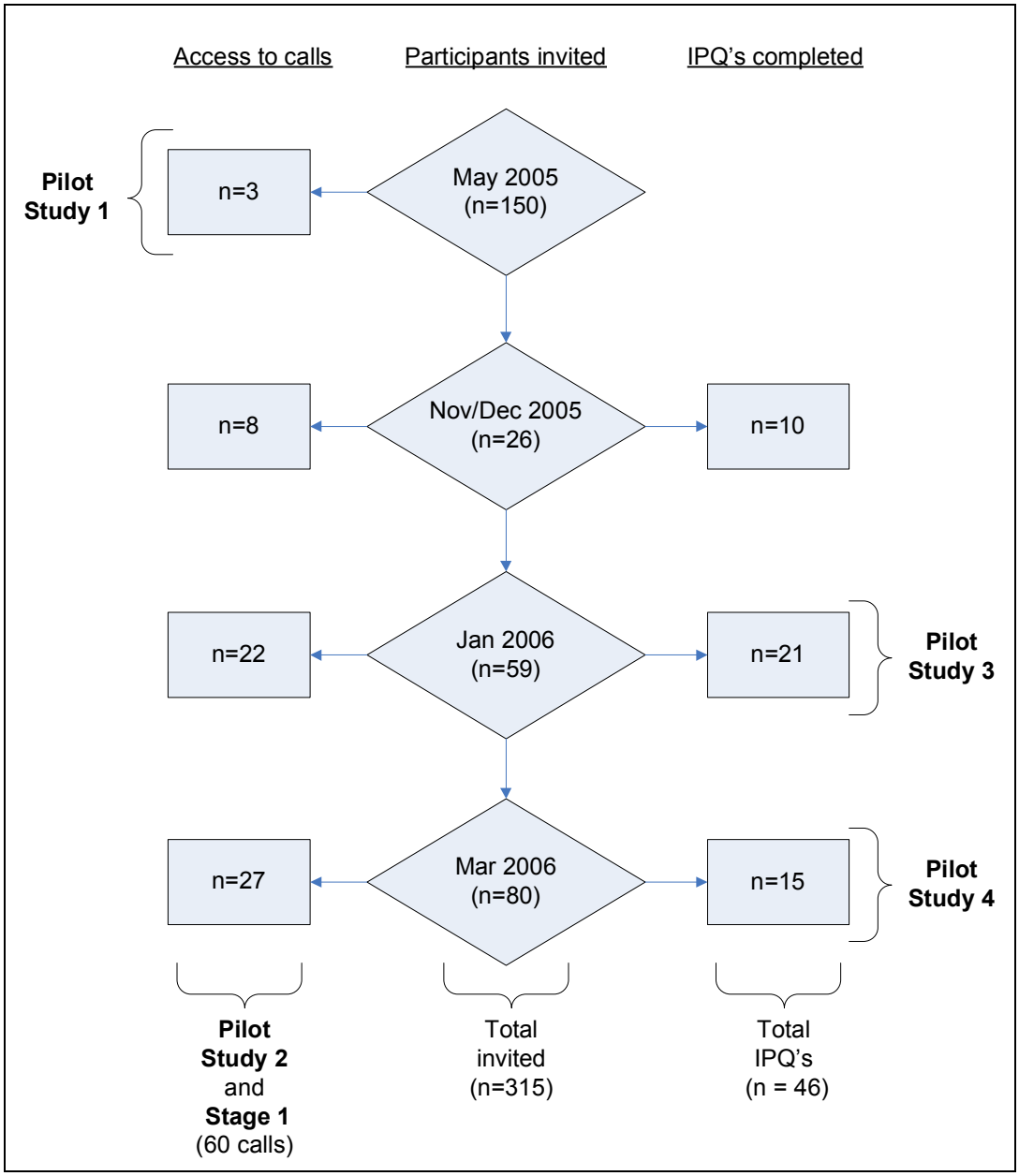
Of 80 participants invited to participate, 15 (19%) provided IPQ-R data (Figure 13 summarises how participation was achieved for each of the pilot studies and the main study exploring the content of initial presentations).

Of the 41 patients allocated to telephone interview, 7 participated (although 5 of these by self-completion). Of the 39 allocated to self-administration, 8 participated.

Therefore there were insufficient data from the telephone interview group to perform a statistical analysis. However data were also available from Pilot study 2. When the two were combined a greater proportion (31%) of those who had been offered telephone interview completed the IPQ-R (although

not necessarily via telephone interview) than those who were invited to self-complete (18%) ($\chi^2$ (df=1) = 2.42, p=0.119).

**Figure 13: Participation achieved for pilot studies and Stage 1**




***Reliability***

Table 8, below shows the Cronbach's alpha scores for the various subscales

of the IPQ-R. All subscales were found to have acceptable internal reliability ($\alpha > 0.7$) with the exception of the treatment control subscale. Due to an administrative error, timeline-cyclic items were omitted from the questionnaire and thus the internal reliability of this subscale could not be assessed.

**Table 8: Internal reliability of modified IPQ-R**

| | N responses | N items | $\alpha$ |
|---|---|---|---|
| Timeline (acute/chronic) | 14 | 6 | 0.717 |
| Timeline (cyclical) | ~ | ~ | |
| Consequences | 13 | 6 | 0.887 |
| Personal control | 12 | 6 | 0.746 |
| Treatment control | 14 | 5 | 0.405 |
| Coherence | 14 | 5 | 0.799 |
| Emotion | 14 | 6 | 0.848 |

***Acceptability***

Fourteen participants provided data on the acceptability of the questionnaire and approach. Responses are summarised in Table 9, below. Most participants reported finding the questionnaire easy to complete, that the timescale was appropriate and that they remembered clearly the reason they contacted NHS 24. However, 2 participants did not find the questions relevant to them.

**Table 9: Participants' responses to acceptability items**

| | *n* | *Strongly disagree* | *Disagree* | *Neither agree or disagree* | *Agree* | *Strongly agree* |
|---|---|---|---|---|---|---|
| The questionnaire was easy to complete | 14 | 0 | 1 | 2 | 9 | 2 |
| I was contacted at an appropriate time | 14 | 0 | 0 | 3 | 9 | 2 |
| The questions were relevant to me | 14 | 0 | 2 | 4 | 6 | 2 |
| I remember reason I contacted NHS 24 | 14 | 0 | 0 | 0 | 10 | 4 |

***Readability***

The readability of the patient information is presented in Table 10 below. Despite substantial effort to limit the complexity of information, the reading ease of patient information ranged between standard and fairly difficult (equivalent to requiring some secondary school education).

**Table 10: Flesch Reading Ease Scores for patient information**

| | *Flesch reading ease* |
|---|---|
| Invitation letter | 52% |
| Information sheet | 61% |
| IPQ-R | 65% |

***Discussion***

The problems encountered with administering the IPQ-R highlighted the challenge of developing a method suitable for all. People with different circumstances had different preferences for the mode of completion. Interviews had the disadvantage of being time-consuming to conduct. Simply achieving contact with potential participants took many attempts and was very time-consuming. Additionally, the requirement for the interviewee and the researcher to be available at the same time to conduct the interview was problematic. The method also has the potential to be susceptible to interviewer bias (Buckingham and Saunders, 2004a).

Telephone interview did have the advantage of ensuring timely data and allowed responses to be clarified. It also allowed participants to ask questions as they occurred. Invitation to take part in a telephone interview tended to be associated with higher participation rates (although participants

did not necessarily take part via the mode offered).

***Conclusion***

On balance, telephone interview was considered the preferable method for the remainder of the study as it offered an opportunity to clarify responses, particularly those relating to the timings of symptoms. However, in view of the difficulties experienced in achieving participation, it was also considered important to continue to offer the alternative of self-completion. This would ensure that all those who wished to take part could do so, even where a telephone interview was not possible.

## *6.5 Timing of initial presentations: Methods for main study*

### 6.5.1 Research design

The study comprised a survey of patients with possible symptoms of ACS who were in contact with NHS 24 (and callers where the call was made by someone other than the patient). Participants were asked to complete the IPQ-R questionnaire, piloted in Pilot Studies 3 and 4, within 2 weeks of contacting NHS 24. Data regarding demographic details, decision time and clinical outcomes at 3 months were also collected.

### 6.5.2 Setting

NHS 24 provided the setting for the research.

The rationale for the choice of NHS 24 as a setting for the earlier part of the

investigation was provided in Chapter 3. Likewise, for this part of the investigation, NHS 24 offered the opportunity to sample from a large population of patients seeking help with symptoms from all over Scotland. Furthermore, pilot work had confirmed that it was possible to reliably identify patients with possible symptoms of ACS from NHS 24 records. Thus it was relatively easy to identify a large, diverse random sample of patients with these types of symptoms.

### 6.5.3 Participants

The aim was to recruit 200 patients who presented to NHS 24 with possible symptoms of ACS. Statistical advice was sought from KH (Statistician, University of Stirling) and the number of participants informed by the following power calculation. Based on testing whether there was a significant correlation between decision time and illness perception then assuming Pearson's product moment correlation was appropriate (i.e. assuming normality), and for a significance level of 5% then using 200 subjects gave an 80% power of finding a correlation of at least 0.2.

During the recruitment period all calls to NHS 24 where either the chest pain algorithm had been used or no algorithm was used as the call was deemed ‘immediately life-threatening’ and possible symptoms of ACS were identified within the call reason or clinical summary were identified.

Twice weekly, a random sample of 60 patients were identified and the patients involved in these calls (and if applicable anyone who called on their

behalf) invited to take part.

***Inclusion Criteria***

A call had been received and recorded by NHS 24.

The nurse had used either the chest pain algorithm ***or*** no algorithm had been used but the outcome was 999 ambulance and possible cardiac symptoms were identified within the 'call reason' or 'clinical summary' (as outlined on page 86.)

The patient had consented to participate.

***Exclusion Criteria***

Any calls involving children aged 16 or under.

Any calls where the call was made by a health professional (as the aim was to investigate lay perceptions of illness)

Any calls where the call-reason stated that the patient was suicidal or where the clinical summary revealed that this was the case.

## 6.5.4 Procedures

***Recruitment and consent***

The recruitment and consent procedures developed in the study relating to the content of initial presentations were used again in this study. Twice weekly, all calls to NHS 24 which fulfilled the inclusion criteria were identified. This generated a list of unique call numbers which were entered into SPSS and a random sample of 60 selected to be approached on each occasion. Based on the levels of non-response experienced in the previous study it was estimated that approximately 600 patients would need to be contacted to yield 200 participants. It was considered that this could realistically be achieved within approximately 7-8 weeks. As before, information about the general characteristics of all patients approached was collected from the

patient record at the time the patient was identified (age, gender, geographic location etc.) in order to assess if the group who responded differed in any significant way from those who did not.

The corresponding records were then accessed by the chief investigator. It was identified from the record whether the patient called themselves or if someone called on their behalf.

***Where the patient called about themselves***

A letter and information leaflet was sent to the patient explaining the purpose and nature of the study and inviting their participation in it (Appendix 30 and Appendix 31). Permission to telephone them to discuss it further was requested. It was made clear that there was no obligation to receive this call or to take part in the research. If the patient did not wish to be contacted they were able to notify the researcher, by either returning a postcard (Appendix 32) or by telephoning a dedicated telephone number. Patients who took either of these actions were not contacted further.

Those who did not decline were telephoned no less than 5 days after the letter was sent, and the research discussed further with them as detailed in the schedule for invitation by telephone (Appendix 33). This call was recorded (patients were informed of this in the patient information leaflet).

It was ascertained whether the patient had received and read the information posted to them. If not, they were given the opportunity to do so (if they wished).

Once the investigator was satisfied that the patient had read and understood

the nature of the research and had the opportunity to ask questions, they requested the patient's consent to take part. It was made clear that participants were free to withdraw this consent at any time. A letter summarising what the participant had consented to was sent to each individual (Appendix 34) providing a further opportunity for participants to change their mind. Arrangements were made for a telephone interview. If it was not possible to conduct a telephone interview participants were offered the opportunity to self-complete and return the questionnaire by post. The interview schedule (Appendix 35) outlined the planned content of the interviews.

The recordings of consenting patients' original telephone calls were accessed and symptoms identified. All participants were also asked if it would be acceptable to approach them again at some time in the future with regard to future projects[7].

If the patient declined to take part, they were asked sensitively if they would be able to provide a reason and this was recorded.

***Someone else called on behalf of the patient***

A letter (Appendix 36) and information leaflet (Appendix 31) were sent to the patient and a request to pass 'caller information' to the person who called on their behalf was included. This comprised a second set of information directed towards the person who called (Appendix 37 and Appendix 38). Patients who consented to take part, and who had a contact number for the

[7] It was considered that particular patients (e.g. those with long decision times but high consequence scores on IPQ-R) might be of particular interest and it was anticipated that data collected in this study could be used in future research.

caller, were asked for permission to contact that person by telephone. The caller was invited to give consent and participate in the same manner as the patient.

All patients and callers who were invited to participate were sent a specifically adapted IPQ-R questionnaire (Appendix 39 and Appendix 40) as an example of the type of questions to be asked in the interview. This also provided an opportunity for self-completion in the event that a telephone interview was not possible.

Interviews were conducted at a mutually convenient time. An interview schedule (Appendix 41) provided the structure for the interview. SPSS Data Entry 4.0, an add-on for SPSS 14.0 was used to produce an electronic version of the IPQ-R with an associated SPSS file. This allowed participants' responses to be entered directly into SPSS, thus minimising the potential for data entry error. All interviews were audio-recorded using NHS 24 technology (participants were informed this would be the case) and are thus available for external scrutiny. The recordings of interviews were also used to transcribe longer responses to the first open question. The average duration of interviews was approximately 20 minutes.

Each patient who agreed to take part was asked permission for their GP to be notified of their participation and contacted in 3 months time to obtain details of their diagnosis. Where participants gave consent, their GP was informed by letter (Appendix 42) of their participation in the study and of the intention to request data regarding the patient's diagnosis at 3 months. The GP was contacted again at 3 months by letter (Appendix 43) to request brief

information regarding each of their patients who had consented to be involved. Where a reply was not received, a telephone approach to the practice manager was undertaken to obtain the required information. Where it was still not possible to obtain the information the researcher contacted the practice again and attempted to negotiate access to the practice to obtain the data in person. To avoid over-burdening practices, the number of cases from each practice was collated and each practice approached only once regarding data for all participating patients.

### *Data collection*

### *Measures*

#### *Patient decision time*

As originally described by Safer and colleagues, the pre-hospital phase of MI can be conceptualised in 3 phases: *appraisal delay* – the time someone takes to identify a symptom as an indication that they are ill; *illness delay*- the time between someone recognising that they are ill and deciding to seek medical attention; and *utilisation delay*- the time taken between seeking medical care and actually receiving it (Safer et al. 1979). Frequently this is collapsed into one measure of pre-hospital delay. However, the time period between seeking medical care and receiving it is largely out with the control of an individual and influenced most by the healthcare staff and systems they encounter. Therefore within this study it was planned to measure appraisal delay (by measuring the time between when participants first began to experience the symptoms that led to them calling and when they began to cause them real concern) and utilisation delay (by measuring the time that

their symptoms began to cause them real concern and when the call was received). This is an area previous research has identified as challenging. The measure obviously relies on patient recall which can be problematic. It also assumes that the time of onset of symptoms of ACS can be readily identified whereas there is evidence to suggest otherwise. Previous research has identified many patients with MI do not report abrupt onset of symptoms (Dracup et al. 1995) and thus may find it difficult to specify a time of onset. However, telephone interview provides the opportunity to ask probing and clarifying questions in order to obtain as accurate timings as possible. In addition, where the patient gave their consent, it was possible to access the voice-recording of the original call and obtain any references to the timing of symptoms. This provided an opportunity to compare these to the data obtained from participants retrospectively.

The IPQ-R contained the following questions about timing. Patients who were interviewed were read the same information.

> *"We are interested in how long you experienced your symptoms before you decided to contact health services. It is really important that this is as accurate as possible, so we ask that you think carefully and double-check your dates and times".*

Questions T1, T2 and T3 from the IPQ-R and CIPQ-R (Appendix 39 and Appendix 40) were used to obtain detailed information about when the participant first noticed the symptoms, when the symptoms began to cause real concern and when they first made contact with medical services. A date and time was recorded for each question.

*T1: When did you first notice the symptoms you spoke to NHS 24 about?*

*T2: When did you your symptoms begin to cause you real concern?*

*T3: Did you contact any other health professional before you spoke to NHS 24? If yes, who and at what time?*

The time the call was received is electronically recorded at NHS 24 providing a reliable measure (T4). Where NHS 24 was not the first point of contact with health services the patient was asked who they first made contact with and at what time.

*Appraisal delay* was calculated as the time elapsed between T1 and T2, *illness delay* between T2 and T3 (if applicable, otherwise T4).

In addition, data re timing were available from the recording of the call. It is common during consultation for clinical staff to enquire about the duration of symptoms. Participants' calls were reviewed by the investigator and all references to timing of symptoms recorded. Where available within the call the duration of symptoms was calculated and is referred to as *decision time from call.*

***Illness perceptions***

The specifically adapted questionnaires (IPQ-R and CIPQ-R) developed following Pilot Studies 3 and 4 were utilised to assess the illness perceptions of the patient and, if relevant those of a caller (Appendix 39 and Appendix 40) within 2 weeks of seeking help.

Scores for each subscale were generated for each participant, as described by the authors of the scale (http://www.uib.no/ipq ).

***Symptoms***

Two measures of symptoms at presentation were obtained. One from the original voice recording of the call received by NHS 24 and the other from the IPQ-R or CIPQ-R.

***Clinical Outcome***

Data about clinical outcome was collected from the patient's GP at 3 months (see Appendix 43). It was established whether the patient was alive or dead, whether or not they received a diagnosis of ACS relating to the symptoms within the call and whether they received any medical diagnosis in the following 3 months. It was also established if the patient was diabetic as this clinical factor is known to be associated with longer pre-hospital time (see page 29).

***Analysis***

The characteristics of patients who responded were compared with those who did not in order to assess non-responder bias. Independent *t*-tests (or, where applicable, non-parametric equivalents) and chi squared tests were used to test for differences in age, gender, known past medical history of CHD, number of calls to NHS 24, NHS 24 nurse outcome and social deprivation scores.

The internal reliability of IPQ-R and CIPQ-R subscales was checked using Cronbach's alpha.

Amongst those participants who gave permission for their call-recording to be accessed, scores for identity and timeline were obtained from the recording. This allowed individual scores on the IPQ-R to be compared with their references to the components of illness perception at the time of the call.

Correlations were used to explore the relationship between (a) illness perceptions, (b) demographic factors and (c) clinical factors and (i) patient decision time (ii) appraisal time (iii) diagnosis of ACS and (iv) outcome at 3 months.

Furthermore, to facilitate comparison with previous studies amongst people with ACS (Goldberg et al. 2000; Goldberg et al. 2002b), two groups were created on the basis of delay time – those who delayed < 2 hours and those who delayed >2 hours. Mann-Whitney tests were used to explore differences between the two groups. In addition, comparisons of illness representations within sub-groups were performed where significant relationships with decision time were identified.

Where relevant, logistic regression analyses were performed to assess whether illness perceptions explained variance in delay category.

It was recognised that in circumstances where a third party makes a call on behalf of a patient that their illness perceptions may differ and that either might relate to decision time. Analyses were performed using the patients IPQ-R and then repeated using the IPQ-R scores and reported decision time of the *person who made the call* (PWMC) (whether this was the patient or caller (CIPQ-R)).

Thus the analytic strategy involved conducting multiple statistical tests. This could potentially increase the likelihood that significant results might be obtained due to chance. Given the exploratory nature of the study, and thus the need to balance the risk of Type I and Type II errors, the conventional significance (*p*) level of <0.05 is applied throughout. However, during the discussion of the results, the pattern of results which would have been obtained using a more cautionary significance level (<0.02) is considered.

## *6.6 Ethical issues*

### 6.6.1 Potential for distress to patients / relatives at a difficult time

As in the previous study, it was recognised that the proposed sampling strategy risked contacting people who were very ill or who may even have died. The invitation letter and information sheets were, again, carefully worded with these particular groups in mind. The opportunity to decline to participate was offered to all and efforts made to ensure this was as easy as possible. Two alternative means of notifying the researcher were offered (postcard and telephone). Participants were not required to speak directly with the investigator and needed only to state their study number.

Where people did not decline, subsequent telephone contact was sensitive to their potential circumstances. It was not assumed that they wished to take part. Rather, the phone call provided an opportunity to answer any questions, discuss the research and establish if they required any further information in order to make a decision about participation.

### 6.6.2 Informed consent

In recognition of individuals' rights to voluntarily participate in research and to freely consent or decline for their information to be used, the consent of all participants was sought. As before, this was requested verbally during the invitation phone call which was recorded at NHS 24. Thus a record that consent had been given was available. A written record of what the patient had consented to was kept by the investigator and a copy sent to the patient (Appendix 34). It was made clear that individuals could withdraw this consent at any time.

### 6.6.3 Researcher's role

The position of the chief investigator as a member of staff within NHS 24 continued to be an important issue, as was the case in the earlier study and the structures put in place at that time were continued, as detailed on page 101.

### 6.6.4 Sensitive topics

By nature of the topic of study some patients were in emergency situations i.e. seeking medical help with possible symptoms of ACS. However, they were not approached at that time, but rather a few days later. This approach was found to be acceptable to the majority of respondents in the study relating to the content of presentations, see page 166.

### 6.6.5 Data handling

Personal identifiable information was stored separately from the

questionnaires. These were linked by a unique study identification number. All electronic data was password protected. Only the chief investigator and supervisory team had access. Voice recordings are routinely stored on tape within NHS 24 for 10 years and will not be removed from their secure storage. Call details were only accessed once the patient had given consent for the researcher to do so. No copies or transcriptions of the call were made. Instead, the call was accessed by the investigator and references to symptoms and the timing of those symptoms documented.

Data from the research was stored in a locked filing cabinet for the duration of the study and will then be archived within the University of Stirling. A permanent member of University staff will act as custodian after the chief investigator has completed the current studentship.

### 6.6.6 Confidentiality

The chief investigator had access to confidential personal and health related data. However they endeavoured to only access this data with the explicit permission of all those involved. Where it was necessary to access records without consent (to send invitation letters and to record anonymous data), this was done in the presence of another member of clinical staff to ensure no personal identifiable data was recorded. As a registered nurse, the chief investigator was bound by their professional code of conduct regarding the disclosure of such information at all times. The minimum data required for the purposes of the investigation was accessed and used only as described in the protocol.

# Chapter 7. Timing of initial presentations: Results

## *7.1 Participation*

A total of 710 eligible patients were invited by letter to take part. However, during telephone follow-up 51 (7%) patients stated that they had not received the information sent about the study. As these individuals did not have an opportunity to make a decision regarding participation, calculations of participation rates have been calculated from the remaining 659 who received the relevant information.

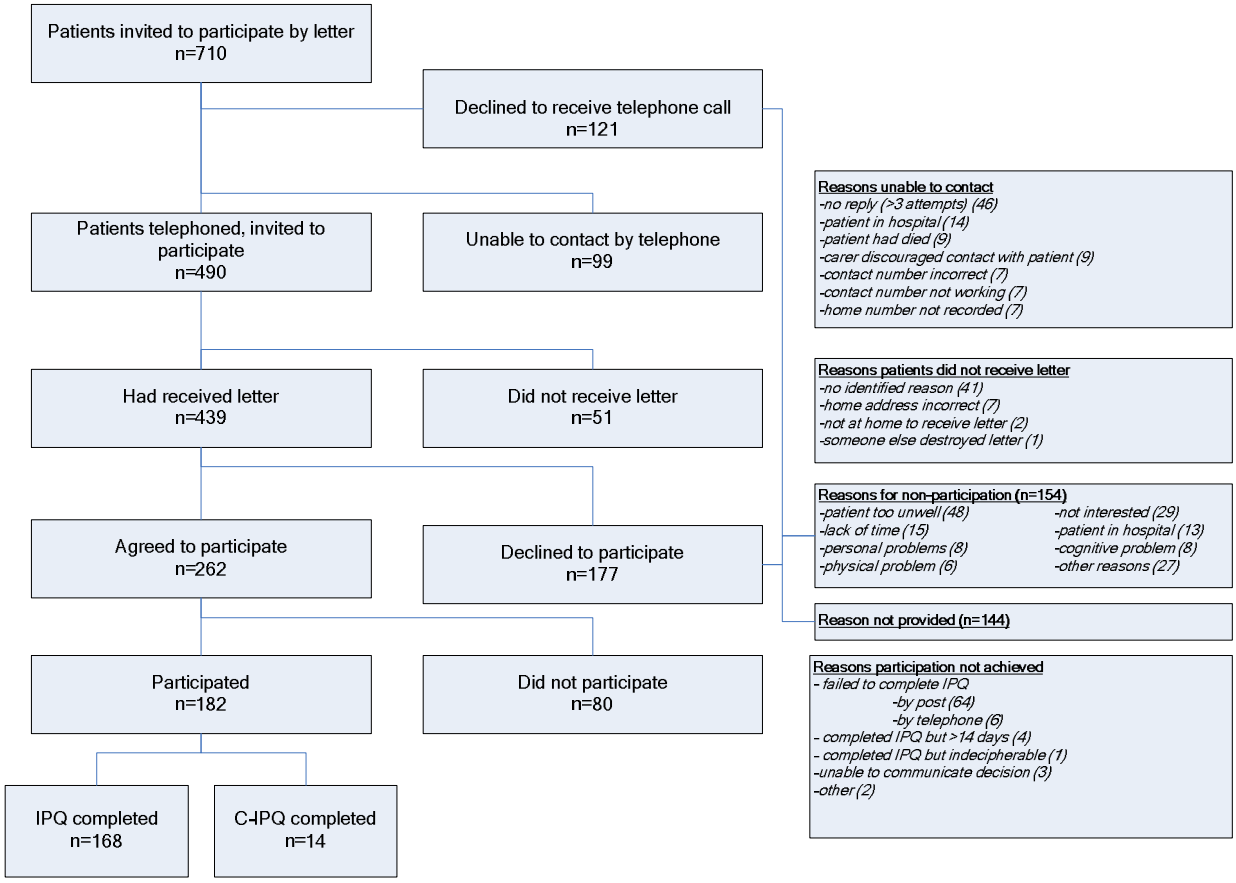
A decline to any further contact was received from 121 (17%) of patients. Follow-up telephone calls were made to the remaining 589.

Overall 262 (40%) patients agreed to participate during the follow-up telephone call. However, actual participation was achieved for 182 (28%). Reasons for non-participation are highlighted in Figure 14 and discussed further on page 281. Those who declined were offered the opportunity to give their reasons. More than half did so and these are also summarised in Figure 14, below.

## *7.2 Participants compared with non-participants*

In order to assess if participants differed in significant ways from non-participants, tests for difference across a number of key variables were conducted. Results are summarised in Table 11.

**Figure 14: Participant invitation process**




## 7.2.1 Demographics

Participants were found to be significantly younger than non-participants (mean age=53 (SD=15.78) versus 57 (SD=20.60), difference 3.5 (95% C.I: 0.6, 6.4), *p*=0.018).

More women (n=386) than men (n=324) were identified by random selection, reflecting the pattern observed overall in NHS 24, where approximately 60%

of calls received relate to female patients (see Appendix 25). The proportion of women who agreed to participate was 24% (n=94) compared with 27% (n=88) of men. The difference was not statistically significant: $\chi^2$ (*df*=1) = 0.729, *p* = 0.393.

There were no significant differences between participants and non-participants in DEPCAT scores *F* (6, 656) =1.394, *p*=.214.

**Table 11: Comparison of participants and non-participants**

| | Participants n=182 | Non-participants n=477 | Difference (95% C.I) | *p* -value |
|---|---|---|---|---|
| | *Mean (SD)* | | | |
| Age in years | 53 (16) | 57 (21) | (0.60, 6.4) | 0.018* |
| No of previous calls | 5 (13) | 5 (12) | (-2.02, 2.1) | 0.970 |
| | *n (%)* | | *df* | |
| Male gender | 88 (48%) | 236 (45%) | 1 | 0.393 |
| Documented history CHD | 47 (26%) | 158 (30%) | 1 | 0.316 |
| Emergency response | 156 (86%) | 458 (87%) | 1 | 0.684 |
| Caller involved | 84 (46%) | 321 (61%) | 1 | 0.001* |
| | | *F* | *df* | *p* |
| DEPCAT score | | 1.394 | 6, 656 | 0.214 |

## 7.2.2 Clinical characteristics

There were no significant differences between participants and non-participants in either their number of previous calls to NHS 24 (*t*=0.037, df=707, *p*=0.97); whether or not they had a history of CHD documented within NHS 24 ($\chi^2$ (*df*=1) = 1.004, *p* = 0.316) or whether or not the nurse treated them as an emergency ($\chi^2$ (*df*=1) = 0.166, *p* = 0.684).

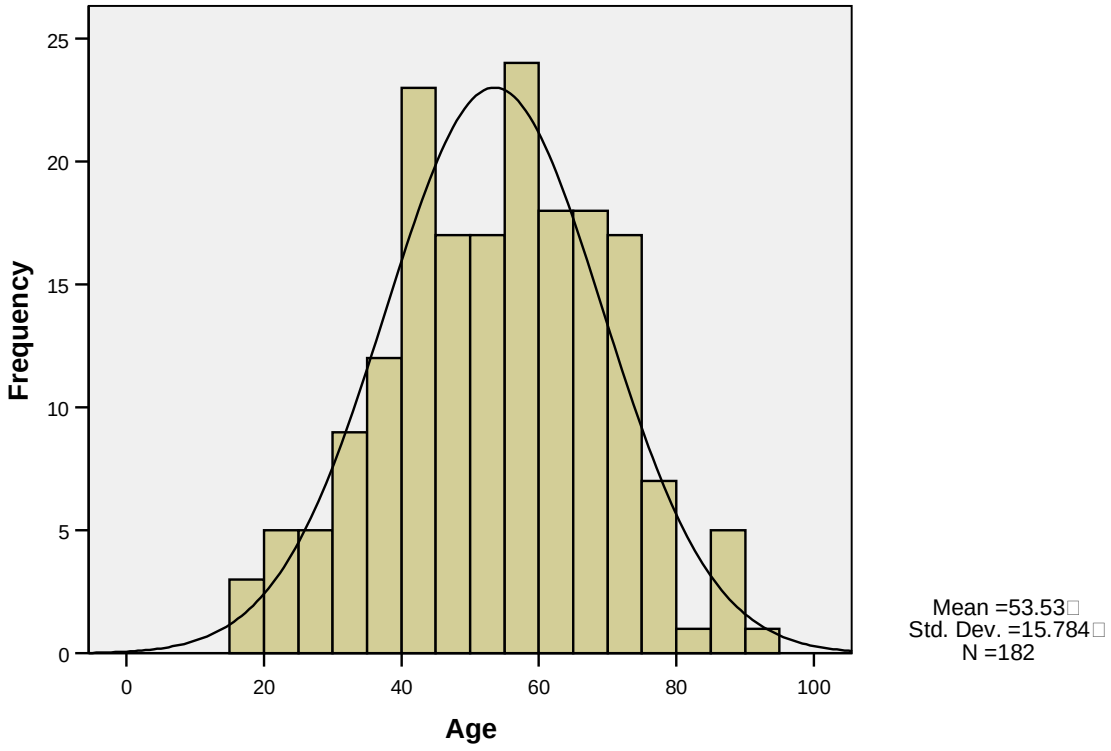
However, patients where someone made a call on their behalf were

significantly less likely to participate than those who called about themselves ($\chi^2$ (*df*=1) = 11.841, *p* = .001).

## *7.3 Characteristics of the sample.*

The mean age of participants was 53 years (SD=15.78). Figure 15, below, illustrates the distribution of participants' ages. As already reported, 94 participants were female and 88 participants were male.

**Figure 15: Age distribution of participants**




People with a range of social deprivation classifications (DEPCAT) participated in the study (see Figure 16, below).

Figure 17 illustrates the geographical location of participants in relation to population density. Rates of participation were considered approximately proportionate to the density of population.

**Figure 16: DEPCAT classifications of participants**

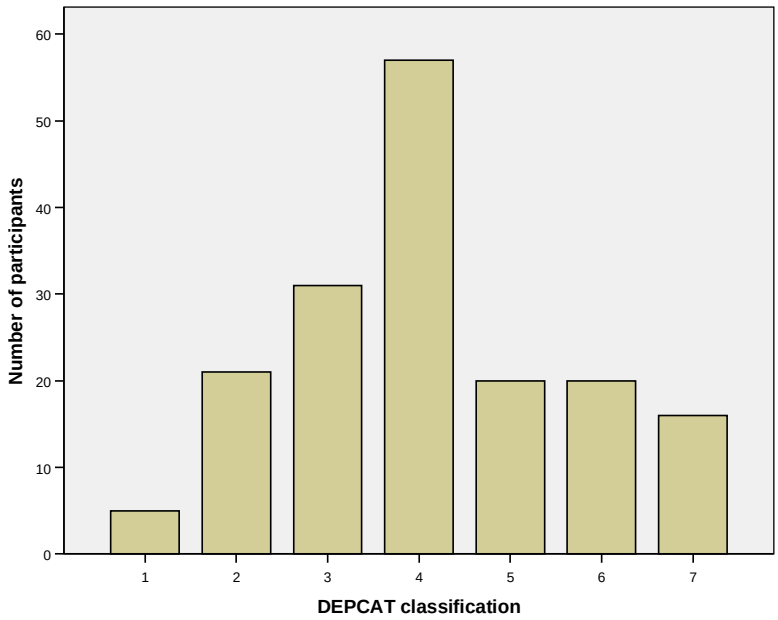
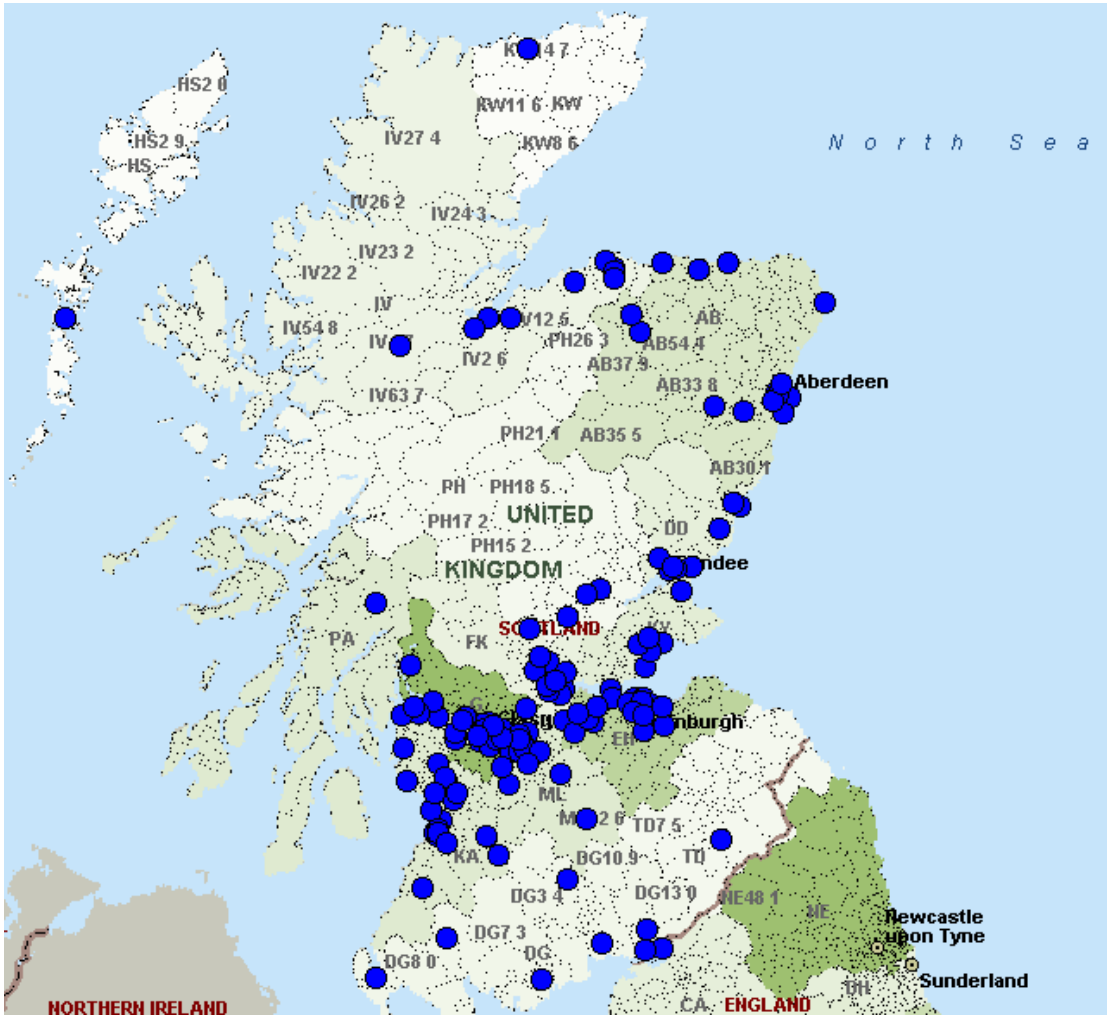
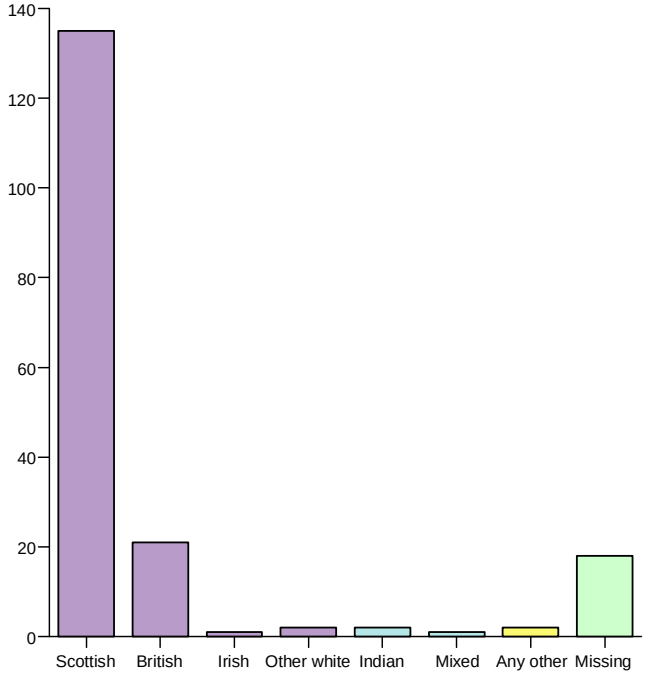



**Figure 17: Geographical spread of participants**



As can be seen in Figure 18, below, 135 (74.2%) participants described their ethnic group as Scottish; 21 (11.5%) British; 1 (0.5%) Irish and 2 (1.1%) other white background. Two participants (1.1%) described their ethnic group as Indian; 1 (0.5%) mixed race and 2 (1.1%) described other ethnic backgrounds. A response to the item was not provided by 18 (9.9%) of participants.

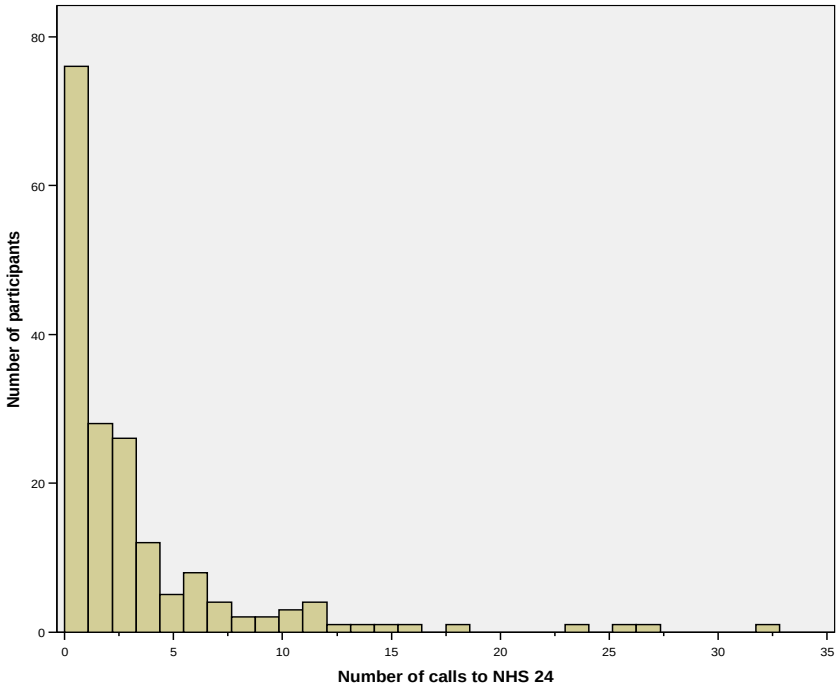
**Figure 18: Ethnic background of participants**




Just over a quarter (26%, n=47) of participants had a previous history of CHD documented at NHS 24 at the time of the call.

In terms of their previous use of NHS 24, 95% (n=173) of participants had called 15 times or less. For 42% (n=76) it was their first call (see Figure 19, below).

**Figure 19: Participants' number of previous calls to NHS 24[8]**

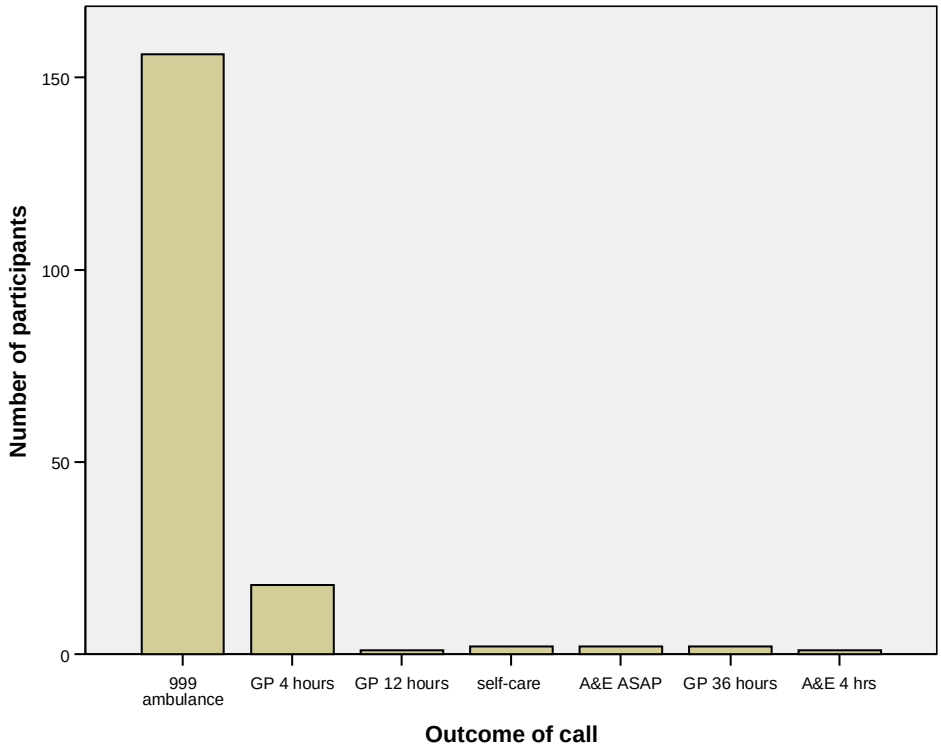



The outcome for most calls (86%) was 999 ambulance with less urgent outcomes being less frequent (see Figure 20, below).

In 54% of cases (n=98) the participant called on their own behalf. However, in the remaining 46% of cases (n=84) someone else called NHS 24 on behalf of the participant.

[8] In order to improve clarity, the data of the 3 participants with the highest number of calls (121, 119 and 42) are not displayed on this graph

**Figure 20: Outcome of patients' calls**




## *7.4 IPQ-R measurement*

### 7.4.1 Administration of IPQ-R

Questionnaires were administered between 2 and 15 days after the patients call to NHS 24 (Mean =8, SD =3). In contrast to what was planned, 70% of patients (n=116) elected to self-complete the IPQ whilst the remaining 30% (n=50) participated in a telephone interview.

In addition, 59 Caller IPQs were completed by people who made calls on behalf of participants. In 45 cases both IPQ and C-IPQ data was collected and in 14 cases, C-IPQ data only. Most callers (n=54) self-completed the

questionnaire whilst 5 took part in a telephone interview.

***Patient IPQ-R***

As is standard procedure (http://www.uib.no/ipq), patient responses to IPQ-R items were scored across the 8 subscales: identity, timeline acute/chronic; timeline cyclical; consequences, personal control; treatment control; coherence and emotion. It is important to note that a minimum number of items are required to be completed for each subscale in order to calculate this score. Therefore, the data of participants who did not complete the required number of items is missing.

Also, as recommended by the authors, participants' beliefs about cause were not measured by a subscale. Instead participants were asked to rank, in order of importance, the 3 most likely causes of their symptoms. These data were used to compare those who identified the heart as the most important likely cause of their symptoms with those who identified other most likely causes.

Cronbach's alpha was used to assess internal reliability of the subscales, with the exception of the identity subscale[9]. In Table 12, below, it can be seen that all subscales were found to have acceptable internal reliability ($\alpha > 0.7$) with the exception of the personal control items ($\alpha = 0.642$). Reliability of the subscales was found to be good regardless of the mode of administration, with the exception of the personal control subscale. This subscale had good internal reliability when the IPQ-R was self-completed

[9] Scores for the identity subscale on both IPQ-R and CIPQ-R compose the sum of a list of disparate symptoms; therefore internal reliability is not relevant.

(n=96; $\alpha = 0.706$) but was poor when telephone administered (n=44; $\alpha = 0.405$).This could not be improved by removal of items.

**Table 12: Distribution of scores and internal reliability of patient IPQ-R.**

| | N responses | N items | $\alpha$ | mean | SD | min | max |
|---|---|---|---|---|---|---|---|
| Timeline (acute/chronic) | 143 | 5 | 0.823 | 13.78 | 4.04 | 5 | 24 |
| Timeline (cyclical) | 147 | 4 | 0.794 | 12.18 | 3.46 | 4 | 20 |
| Consequences | 149 | 6 | 0.753 | 18.67 | 4.43 | 6 | 30 |
| Personal control | 143 | 5 | 0.642 | 13.14 | 3.29 | 5 | 24 |
| Treatment control | 146 | 4 | 0.714 | 15.10 | 2.34 | 5 | 20 |
| Coherence | 153 | 4 | 0.925 | 10.86 | 4.19 | 4 | 20 |
| Emotion | 152 | 6 | 0.716 | 21.52 | 3.77 | 12 | 30 |

### *Caller IPQ-R*

The C-IPQ assessed the caller's perception of the patient's representations across the same 8 subscales. As can be seen in Table 13, all but 2 subscales were found to have acceptable internal reliability. Cronbach's alpha was 0.647 for the treatment control items and 0.627 for the emotion items.

The treatment control subscale alpha could be improved to $0.855$ with the removal of item CIP23 "*There was nothing which could help their condition".* This item was therefore removed. However, there were no items within the emotion subscale where removal improved the internal reliability of the subscale and therefore all items were retained.

It was not possible to assess for the effects of mode of administration amongst C-IPQ items as there were too few callers who participated in telephone interview (n=4).

**Table 13: Distribution of scores and internal reliability of caller IPQ-R.**

| | N responses | N items | α | mean | SD | min | max |
|---|---|---|---|---|---|---|---|
| Timeline (acute/chronic) | 49 | 5 | 0.811 | 14.96 | 4.05 | 5 | 25 |
| Timeline (cyclical) | 48 | 4 | 0.743 | 11.00 | 3.13 | 4 | 19 |
| Consequences | 49 | 6 | 0.822 | 19.24 | 4.57 | 6 | 30 |
| Personal control | 52 | 5 | 0.767 | 12.46 | 3.92 | 5 | 25 |
| Treatment control | 55 | 3 | 0.855 | 11.96 | 1.89 | 5 | 15 |
| Coherence | 53 | 4 | 0.895 | 11.40 | 3.62 | 4 | 19 |
| Emotion | 51 | 6 | 0.627 | 21.96 | 3.32 | 14 | 29 |

Finally, items within the caller IPQ designed to assess callers' perceptions of the patient's illness gave scores on 3 subscales (see Table 14, below). The coherence and emotion subscales had acceptable internal reliability but the personal control items were problematic ($\alpha$=0.526). This was improved slightly to $\alpha$=0.626 when item CIP42, "*There was nothing I could do to affect their symptoms",* was removed but was still lower than 0.7.

**Table 14: Distribution of scores and internal reliability of caller items on caller IPQ-R.**

| | N responses | N items | α | mean | SD | min | max |
|---|---|---|---|---|---|---|---|
| Personal control | 54 | 4 | 0.626 | 12.39 | 3.12 | 4 | 17 |
| Coherence | 54 | 4 | 0.951 | 13.11 | 4.37 | 4 | 20 |
| Emotion | 53 | 6 | 0.729 | 20.73 | 3.84 | 11 | 30 |

## *7.5 Mode of administration*

Patients who participated in a telephone interview were compared with those who self-completed the IPQ-R with regards to demographic and clinical data and IPQ-R scores. Results are summarised in Table 15 and Table 16, below. Those who participated in telephone interview were significantly less likely to have had a caller involved in the original call ($\chi^2$ (*df*=1) = 3.956, *p* = 0.047) and had significantly higher scores for personal control (Mean =13.91,

SD=2.79) than those who self-completed (Mean = 12.67, SD=3.52), difference 1.24 (95% C.I: 0.11 – 2.38), *p*=0.032). This is discussed further on page 289. No other significant differences between the two groups were identified.

**Table 15: Differences relating to mode of IPQ-R administration: *t*-tests**

| | Telephone interview | | | Self-completion | | | | Difference | |
|---|---|---|---|---|---|---|---|---|---|
| | n | mean | SD | n | mean | SD | *t* | (95% C.I) | *p* |
| Age | 50 | 49.02 | 14.25 | 116 | 53.52 | 15.73 | -1.74 | (-9.61, 0.62) | 0.084 |
| Previous calls to NHS 24 | 50 | 7.16 | 17.46 | 116 | 4.53 | 12.12 | 1.11 | (-2.03, 7.28) | 0.267 |
| Identity† | 50 | 5.00 | 5.00 | 107 | 4.00 | 3.00 | 2440.0 | | 0.374 |
| Timeline- acute/chronic | 50 | 13.90 | 3.82 | 101 | 13.77 | 4.17 | 0.18 | (-1.26, 1.52) | 0.856 |
| Timeline - cyclical | 49 | 12.55 | 3.26 | 104 | 12.23 | 3.45 | 0.54 | (-0.84, 1.48) | 0.590 |
| Consequences | 50 | 19.44 | 4.08 | 104 | 18.42 | 4.54 | 1.36 | (-0.47, 2.52) | 0.177 |
| Personal Control | 49 | 13.91 | 2.79 | 103 | 12.67 | 3.52 | 2.17 | (0.11, 2.38) | 0.032* |
| Treatment control† | 49 | 16.00 | 1.00 | 104 | 15.00 | 2.00 | 2113.0 | | 0.080 |
| Coherence | 50 | 10.9 | 3.41 | 106 | 10.83 | 4.47 | 0.06 | (-1.21, 1.35) | 0.918 |
| Emotion | 50 | 21.62 | 3.42 | 107 | 21.55 | 3.97 | 0.1 | (-1.22, 1.35) | 0.919 |

† Mann-Whitney *U*, Median and IQR

**Table 16: Differences relating to mode of IPQ-R administration: $\chi^2$ tests and ANOVA**

| | Telephone interview | Self-completion | $\chi^2$ | *df* | *p* |
|---|---|---|---|---|---|
| Male | 23 (46%) | 59 (51%) | 0.33 | 1 | 0.565 |
| Documented history CHD | 15 (31%) | 27 (23%) | 0.92 | 1 | 0.338 |
| Emergency response | 40 (80%) | 101 (87%) | 1.37 | 1 | 0.243 |
| Caller | 16 (33%) | 56 (50%) | 3.96 | 1 | 0.047* |
| | | | *F* | *df* | *p* |
| DEPCAT classification | | | 0.204 | 6, 148 | 0.975 |

## *7.6 Illness representations*

In order to select appropriate statistical tests, the distributions of scores across each subscale were checked for normality (Appendix 44). All except the identity and treatment control subscales (for both patients and callers) were normally distributed (i.e. absolute value of z-scores for kurtosis and skewness were both <2.58 (Field, 2005) ). The distributions for each subscale for both patients and callers are described below. The scores of patients and callers were also compared; the results of this analysis are reported on page 232.

### 7.6.1 Identity

The range of possible identity scores was 0-17, with the score reflecting the number of symptoms an individual viewed as relating to the reason for their call to NHS 24.

Scores were available for 161 patients and 50 callers and were not normally distributed. Patients reported a median of 5 symptoms (IQR=4) as being *"related to why I was in contact with NHS 24".* The number reported ranged from 0 to 17. Callers reported a median of 4 symptoms (IQR=3) as being *"related to why I contacted NHS 24 on their (*the patients*) behalf".*

### 7.6.2 Timeline-acute/chronic

The range of possible timeline-acute/chronic scores was between 4 and 25,

with higher scores reflecting beliefs that symptoms were of a longer, more chronic duration.

Timeline-acute/chronic scores were available for 154 patients and for 53 callers and were normally distributed. Patients' mean timeline score was 13.78 (SD 4.04) and callers' mean was 14.96 (SD 4.05).

### 7.6.3 Timeline –cyclical

The range of possible timeline-cyclical scores was between 3 and 20, with higher scores reflecting beliefs that symptoms were cyclical in nature.

Scores for cyclical timeline were available for 156 patients and 54 callers and were normally distributed. Patients' mean score was 12.28 (SD=3.42). The callers' mean was 11.38 (SD=3.24).

### 7.6.4 Cause

Participants were asked to identify (in order of importance) what they considered were the 3 most likely causes of their symptoms. 163 participants identified at least one likely cause of their symptoms. These responses were reviewed by the investigator and those causes which related to the heart identified (n=39). The decision times of this group were compared with the remaining participants who had not identified the heart as the most likely cause of their symptoms.

### 7.6.5 Consequences

The range of possible consequences scores was between 4 and 30, with higher scores reflecting beliefs that symptoms had more serious consequences.

A score on the consequences subscale was available for 157 patients and 55 callers and were normally distributed. The mean score for patients was 18.67 (SD 4.43). The callers' mean was 19.57 (SD 4.63).

### 7.6.6 Personal control

The range of possible personal control scores was between 4 and 25, with higher scores reflecting beliefs that individuals had high personal control over their symptoms.

As already discussed, the internal reliability of personal control items was less than optimal ($\alpha$=.642). However, as the reliability could not be improved, the scores available were analysed. Scores were normally distributed. Scores of personal control were available for 155 patients, mean score was 13.11 (SD=3.33). Callers reported their assessment of patients' degree of personal control. A mean score of 12.62 (SD=3.94) was reported by 55 callers. Callers (n=56) also reported *their own* sense of personal control, the mean score was 9.58 (SD=2.97).

### 7.6.7 Treatment control

The range of possible treatment control scores was between 3 and 20, with higher scores reflecting confidence that treatment could control symptoms.

Treatment control scores were available for 156 patients and 56 callers but were not normally distributed. Patients' median score was 16.00 (IQR=2.00). Callers median score was 12.00 (IQR=0.00).

### 7.6.8 Coherence

The range of possible coherence scores was between 3 and 20, with higher scores reflecting a clear understanding of symptoms.

Coherence scores were available for 159 patients and were normally distributed (as were callers' scores). The mean score was 10.86 (SD=4.13). Callers report of patient coherence were available from 54 callers (Mean=11.33, SD=3.62). In addition scores relating to the coherence of the caller were available for 55 callers (Mean=13.02, SD=4.38).

### 7.6.9 Emotion

The range of possible emotion scores was between 4 and 30, with higher scores reflecting stronger emotions in relation to symptoms.

Scores for the emotion subscale were available for 160 patients (mean=21.58, SD=3.77). Callers report of patient emotion were available from 54 callers (mean=22.12, SD=3.30). In addition scores relating to the

emotion of the caller were available for 55 callers (Mean=20.79, SD=3.87). All were normally distributed.

## *7.7 Decision time*

The timings provided by patients (and where relevant callers) in response to questions T1, T2 and T3 were used to calculate total patient (or caller) decision time (T3-T1); appraisal delay (T2-T1) and illness delay (T3-T2). Graphs of the raw distributions are shown in Figure 21, below.

Initial exploratory analysis revealed a number of participants' decision times to be negative (i.e. participants reported symptoms starting after they had sought help for those symptoms). Examination of the individual cases suggested that this was most probably due to errors by participants in recording dates. These cases were therefore excluded from each calculation of decision time. Results of the comparison of questionnaire data with the real-time call data are reported on page 248.

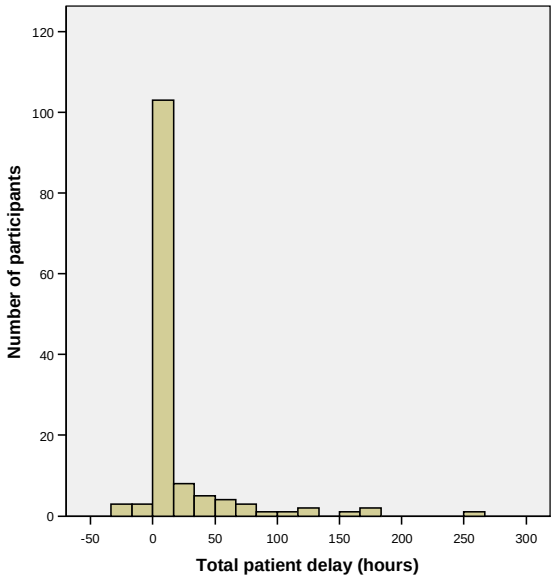
Furthermore initial analysis showed that results for decision time were not normally distributed; being skewed towards shorter times and with a small number of extreme scores affecting the mean (see Figure 21, below). Thus median and Inter-Quartile Range (IQR) have been used to describe central tendency and dispersion of decision times and non-parametric statistics have been used to explore the relationship between the patients' illness representations and decision time.

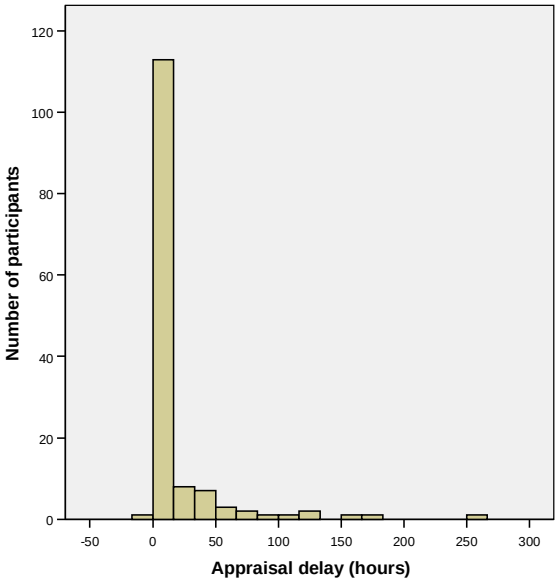
Spearman's correlations ($r_{S)}$ were used to explore relationships between

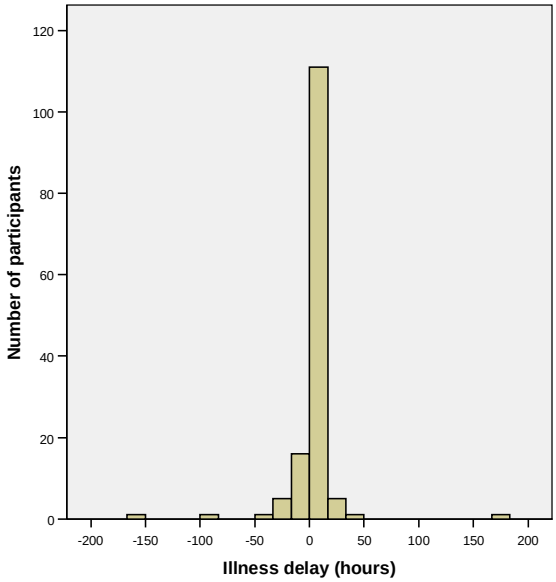
continuous variables. Mann-Whitney tests (*U)* were used to test for differences in binary variables. The Kruskal-Wallis test (K-W, *H* ) was used to explore whether decision times varied in relation to DEPCAT classification. Mann-Whitney was also used to test for differences in illness representations between those who delayed <2 hours with those who delayed >2 hours.

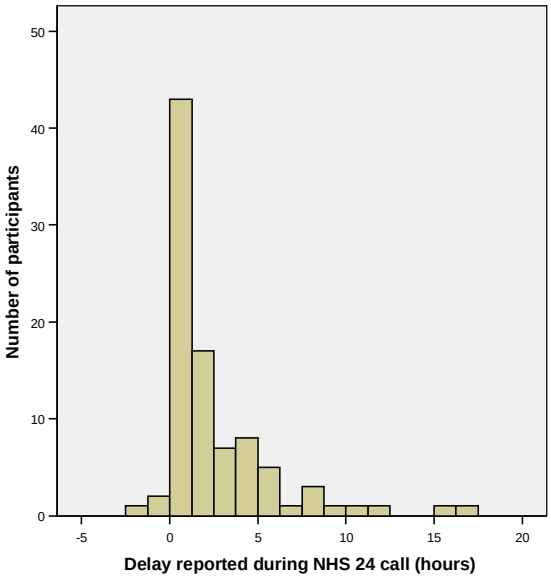
However, as previously discussed, in a number of circumstances calls were not made by the patient, but instead by a caller. The measures of decision time have been calculated using the time the call was made, and therefore were possibly defined most by the person making the call. Therefore, the relationship between the illness representations of the person who made the call (be that the patient or a caller) and each measure of decision time were also explored.

**Figure 21: Distributions of measures of delay**



### 7.7.1 Total delay

Median total delay reported by patients was 4 hours 26 mins., range 0 minutes to 104 weeks , IQR = 13.89 hours. Median total delay reported by callers was 3 hours 48 mins., range 19 mins. – 89 weeks, IQR = 18.58 hours.

Callers' reports of total delay were highly correlated with those of the corresponding patient ($r_S$ =0.736, $p$<.001) and there were no significant differences between the two reports ($z$=-0.805, $p$=.421).

When the total delay time reported by the PWMC (whether that be a caller or patient) was calculated for each call, median total delay was 4 hours 42 minutes, range 0 minutes – 104 weeks, IQR = 18.5 hours.

***Relationship between study variables and total delay time***

***Patients***

***Demographic and clinical factors***

No significant relationships were observed between patient delay time and the patients age ($r_S$ =-.057, $p$=.507). No significant difference was found between men and women ($U$= 2106, $p$= .373) or DEPCAT classifications ($H$ (6) = 6.535, $p$=.366, see Table 17 page 206) or between people of white and non-white ethnic group ($U$= 27, $p$= .315).

Patients who reported pain did not report significantly different total delay times than those who did not ($U$= 512.5, $p$= .831). Total patient delay times for those with a documented history of CHD (Mdn = 4 hours 22 mins.) were not significantly different from those without (Mdn = 4 hours 35 mins.; $U$=

1778.5, *p*= .987). Nor was total delay time significantly different between participants with diabetes and those without (*U*=377.5, *p*=0.783).There was no significant correlation between the number of previous calls to NHS 24 and total patient delay time ($r_S$ =-.017, *p*=.846) nor was a significant difference found between those who were calling for the first time and those who had called before (*U*= 2203, *p*= .831) or between those who received an ambulance as a result of their call and those who did not (*U*= 769, *p*= .197).

**Table 17: DEPCAT classification and patient decision time: Kruskal-Wallis test**

| | *H* | *df* | *p* |
|---|---|---|---|
| Total patient delay | 6.535 | 6 | 0.366 |
| Appraisal delay | 5.515 | 6 | 0.480 |
| Illness delay | 10.604 | 6 | 0.101 |
| Delay reported during call | 8.239 | 6 | 0.221 |

Table 18 shows the results obtained when participants who had total patient delay of < 2 hours were compared with those >2 hours. There were no significant differences between the two groups in terms of age (U=2280, *p*=0.760) or gender. A larger proportion of people with high DEPCAT classifications (i.e. living in more deprived areas) were found in the delay group (42%) than the non-delay group (26%), $\chi^2$ (df=1) = 3.750, *p*=0.053).

There were no significant differences between the two groups regarding experience of pain, previous history of CHD, presence of diabetes, whether or not it was the patient's first call to NHS 24, the frequency of receiving an ambulance response or caller involvement in the call.

**Table 18: Total patient delay: $\chi^2$ test comparing delayers and non-delayers**

| | No delay (< 2 hours) (n=50) | Delay (> 2 hours) (n=92) | $\chi^2$ | *df* | *p* |
|---|---|---|---|---|---|
| Male | 54% | 46% | 0.335 | 1 | 0.563 |
| High deprivation | 26% | 42% | 3.750 | 1 | 0.053 |
| Reported pain | 89% | 88% | 0.034 | 1 | 1.000 |
| Documented history CHD | 22% | 28% | 0.558 | 1 | 0.455 |
| First call | 44% | 40% | 0.191 | 1 | 0.662 |
| Emergency response | 90% | 88% | 0.124 | 1 | 0.789 |
| Caller | 42% | 43% | 0.029 | 1 | 0.865 |
| Diabetes | 9% | 9% | 0.000 | 1 | 1.000 |

***Illness representations***

No significant correlations were found between total patient delay and patients' scores on the identity, timeline- acute/chronic, timeline-cyclical, consequences, personal control, treatment control, coherence or emotion subscales. (see Table 19, below).

**Table 19. Spearman's correlations between IPQ-R subscales and total patient delay (patients)**

| | *N* | *rs* | *p* |
|---|---|---|---|
| Age | 136 | -.057 | 0.507 |
| Identity | 131 | .055 | 0.533 |
| Timeline- acute/chronic | 125 | .050 | 0.582 |
| Timeline - cyclic | 126 | .053 | 0.556 |
| Consequences | 127 | -.029 | 0.749 |
| Personal Control | 126 | -.002 | 0.981 |
| Treatment control | 127 | -.056 | 0.532 |
| Coherence | 129 | .063 | 0.477 |
| Emotion | 129 | -.129 | 0.145 |

Nor were significant differences in scores on these subscales found between delayers and non-delayers (see Table 20, below).

**Table 20: Total patient delay: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| Age | 54.0 | 24.0 | 54.0 | 21.0 | 2228.0 | 0.760 |
| Previous calls to NHS 24 | 2.0 | 3.0 | 2.0 | 2.0 | 2265.0 | 0.877 |
| Identity | 4.0 | 3.0 | 5.0 | 4.0 | 2011.0 | 0.572 |
| Timeline- acute/chronic | 14.00 | 7.13 | 14.00 | 6.50 | 1772.0 | 0.345 |
| Timeline - cyclical | 12.00 | 5.00 | 12.00 | 5.00 | 1597.0 | 0.099 |
| Consequences | 19.25 | 5.35 | 20.00 | 6.00 | 2012.5 | 0.988 |
| Personal Control | 13.37 | 5.00 | 13.00 | 5.00 | 1930.0 | 0.905 |
| Treatment control | 16.00 | 4.00 | 16.00 | 2.00 | 1874.0 | 0.547 |
| Coherence | 8.00 | 5.25 | 10.00 | 6.25 | 1672.0 | 0.064 |
| Emotion | 22.00 | 4.50 | 22.00 | 4.25 | 1754.5 | 0.175 |

Participants who identified the most important likely cause of their symptoms as relating to the heart did not have significantly different total delay time than those who identified other causes as most important (*U*= 1640, *p*= .528, see Table 21).

**Table 21: Differences in delay times between those who identified heart as most likely cause and those who did not (Mann-Whitney tests)**

| | Heart | | Not heart | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| Total patient delay | 3.47 | 9.77 | 3.25 | 4.35 | 1640.0 | 0.528 |
| Appraisal delay | 3.00 | 9.75 | 1.50 | 2.60 | 1740.0 | 0.394 |
| Illness delay | 0.73 | 0.90 | 1.07 | 1.83 | 1103.0 | 0.042* |
| Delay reported during call | 1.50 | 5.30 | 1.80 | 2.95 | 718.0 | 0.876 |

***Person who made call***

***<u>Demographic</u>***

No significant correlations were identified between PWMC report of total delay and the age of the patient ($r_S$ =-0.055, *p*=.561) or the PWMC ($r_S$ =-0.095, *p*=.310). Nor were there significant differences in total delay relating to the gender of the patient (*U*=1536.5, *p*=0.424) or the PWMC (*U*=1598.5, *p*=0.696).

When the people who made the call within 2 hours of the onset of symptoms were compared with those who made the call >2 hours, there were no significant differences relating to either the age of the patient (*U*=1470.5, *p*=0.856) or the PWMC (*U*=1337.5, *p*=0.471), or to the gender of the patient ($\chi^2$ (df=1) = 0.966, *p*=0.326) or PWMC ($\chi^2$ (df=1)=0.104, *p*=0.747).

***Illness representations***

Participants who reported high emotion reported significantly shorter total delay, no other significant correlations relating to illness representations were identified (see Table 22 , below).

**Table 22: Spearman's correlation between IPQ-R subscales and total patient delay – (PWMC)**

| | *N* | *rs* | *p* |
|---|---|---|---|
| PWMC report patient identity | 111 | 0.039 | 0.682 |
| PWMC report patient timeline- acute/chronic | 111 | -0.061 | 0.526 |
| PWMC report patient timeline - cyclical | 109 | 0.032 | 0.740 |
| PWMC report patient consequences | 111 | -0.104 | 0.279 |
| PWMC report patient personal control | 110 | 0.039 | 0.686 |
| PWMC report patient treatment control | 112 | 0.055 | 0.567 |
| PWMC report patient coherence | 112 | 0.028 | 0.773 |
| PWMC report patient emotion | 113 | -0.148 | 0.117 |
| PWMC's personal control | 110 | 0.075 | 0.438 |
| PWMC's coherence | 112 | 0.038 | 0.690 |
| PWMC's emotion | 113 | -0.215 | 0.022* |

When those with a total delay <2 hours were compared with those of >2 hours there were not significant differences in the IPQ subscales (see Table 23, below).

Those who identified the most important likely cause of the patient's symptoms to be relating to the heart did not have significantly different total delay time than those who identified other causes as most important (*U*=1145.5, *p*= .372).

**Table 23: Total patient delay, person who made call: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| PWMC report patient identity | 4.00 | 3.00 | 5.00 | 3.25 | 1241.0 | 0.492 |
| PWMC report patient timeline- acute/chronic | 15.00 | 6.50 | 14.00 | 6.25 | 1342.0 | 0.781 |
| PWMC report patient timeline - cyclical | 11.00 | 6.00 | 12.00 | 5.25 | 1036.5 | 0.072 |
| PWMC report patient consequences | 20.00 | 5.50 | 20.00 | 6.00 | 1380.5 | 0.969 |
| PWMC report patient personal control | 14.00 | 5.50 | 13.00 | 5.00 | 1334.0 | 0.916 |
| PWMC report patient treatment control | 15.00 | 4.00 | 14.33 | 4.00 | 1349.5 | 0.813 |
| PWMC report patient coherence | 12.00 | 8.00 | 10.00 | 7.00 | 1393.5 | 0.939 |
| PWMC report patient emotion | 21.00 | 6.00 | 22.00 | 5.25 | 1253.5 | 0.297 |
| PWMC's personal control | 12.00 | 5.00 | 12.00 | 5.00 | 1306.0 | 0.779 |
| PWMC's coherence | 12.00 | 8.00 | 11.50 | 8.00 | 1279.0 | 0.433 |
| PWMC's emotion | 21.00 | 6.00 | 21.00 | 5.00 | 1172.5 | 0.124 |

### 7.7.2 Appraisal delay

Median appraisal delay reported by patients was  2 hours, range 0 minutes to 90 weeks, IQR = 9.5 hours. Median total delay reported by callers was 2 hours 15 minutes, range 0 minutes to 90 weeks, IQR = 8.5 hours.

Callers' reports of appraisal delay were highly correlated with those of the corresponding patient ($r_S$ =0.634, $p$<.001) and there were no significant differences between the two reports ($z$=-0.769, $p$=.442).

When the total delay time reported by the PWMC (whether that be a caller or patient) was calculated for each call, median appraisal delay was 2 hours 22 minutes, range 0 minutes – 90 weeks, IQR = 9.69 hours.

***Relationship between study variables and appraisal delay***

***Patient***

***Demographic and clinical factors***

No significant relationships were observed between appraisal time and the age of the patient (rs =.002, p=.981). However, appraisal delay was found to be significantly shorter for men (Mdn= 82 mins) than for women (Mdn=180 mins; U= 2077.5, p= .029). As can be seen in Table 42, page 234, men tended to report significantly more serious consequences relating to their symptoms than women ($t$= -2.20, $p$=.029).

Significant differences in appraisal delay were not found between DEPCAT classifications ($H$ (6) = 5.515, $p$=.480, see Table 17, page 206).

Patients who reported pain did not report significantly different appraisal

delay times than those who did not (*U*= 691.5, *p*= .849). Appraisal times for those with a documented history of CHD (Mdn = 150 mins) were not significantly different from those without (135 mins.), (*U*= 2000, *p*= .950). Nor were there significant differences in appraisal time between patients with diabetes and those without (*U*=324.5, *p*=0.885). There was no significant correlation between the number of previous calls to NHS 24 and appraisal time ($r_S$ =-.092, *p*=.273) and those who were calling for the first time did not differ significantly from those who had called before (*U*= 2323, *p*= .362). Patients who received an ambulance as a result of their call had significantly shorter appraisal times (Mdn=2 hours) than those who did not (Mdn=6.5 hours; *U*= 701, *p*= .017), see Table 45, page 239.

Similarly, when those with appraisal time of < 2 hours (non-delayers) were compared with those >2 hours (delayers), there were no significant differences between the two groups in terms of age (*U*=2614.5, *p*=0.848). However, there were a significantly larger proportion of women than men in the delay group (see Table 24, below). There were no significant differences between the two groups as to whether they had high or low DEPCAT classification.

Neither were there differences between the two groups regarding experience of pain, previous history of CHD, presence of diabetes or whether or not it was the patient's first call to NHS 24. A significantly higher proportion of patients with appraisal delay of <2 hours (96%) received an emergency response as a result of their call than those with appraisal delay >2 hours (81%; *p*=0.047) (see Table 24).

No significant differences relating to whether a caller was involved in the call were identified.

**Table 24: Appraisal delay: $\chi^2$ test comparing delayers and non-delayers**

| | No delay (< 2 hours) (n=74) | Delay (> 2 hours) (n=72) | $\chi^2$ | *df* | *p* |
|---|---|---|---|---|---|
| Male | 59% | 43% | 3.93 | 1 | 0.047* |
| High deprivation | 32% | 41% | 1.33 | 1 | 0.248 |
| Reported pain | 87% | 88% | 0.03 | 1 | 0.865 |
| Documented history CHD | 26% | 26% | 0.00 | 1 | 0.961 |
| First call | 42% | 40% | 0.04 | 1 | 0.843 |
| Emergency response | 96% | 81% | 8.40 | 1 | 0.004* |
| Caller | 44% | 46% | 0.10 | 1 | 0.750 |
| Diabetes | 6% | 2% | 2.00 | 1 | 0.270 |

***Illness representations***

No significant correlations were found between appraisal time and patients scores on the identity, timeline- acute/chronic, timeline-cyclical, consequences, personal control, treatment control or coherence subscales. However, a significant negative correlation was found between patients scores on the emotion subscale and appraisal time ($r_S$ =-.205, *p*=.016). Patients with stronger emotional representations tended to report shorter appraisal times (see Table 25, below).

**Table 25. Spearman's correlations between IPQ-R subscales and appraisal time - patients**

| | *N* | *rs* | *p* |
|---|---|---|---|
| Identity | 140 | 0.10 | 0.238 |
| Timeline- acute/chronic | 133 | -0.03 | 0.705 |
| Timeline - cyclical | 134 | 0.06 | 0.507 |
| Consequences | 135 | -0.12 | 0.179 |
| Personal Control | 134 | 0.02 | 0.863 |
| Treatment control | 134 | -0.10 | 0.255 |
| Coherence | 137 | 0.05 | 0.567 |
| Emotion | 137 | -0.21 | 0.016* |

When those with appraisal times of <2hours and >2 hours were compared, no significant differences in scores for identity, timeline–acute/chronic or timeline cyclical were observed. Non-delayers tended to report higher identity and consequences than delayers but both results were just short of statistical significance ($p$=.081, $p$=.068, respectively). Significant differences in personal control, treatment control or coherence scores were not observed between the two delay categories. However, non-delayers reported significantly higher scores on the emotion subscale than those with appraisal delays of >2 hours ($U$=1672, $p$=0.002), see Table 26, below.

Participants who identified the most important likely cause of their symptoms as relating to the heart did not have significantly different appraisal time than those who identified other causes as most important ($U$= 1740, $p$= .394, see Table 21).

**Table 26: Appraisal delay: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| Age | 53.50 | 22.00 | 53.00 | 24.00 | 2614.5 | 0.846 |
| Previous calls to NHS 24 | 2.00 | 3.00 | 2.00 | 2.00 | 2646.5 | 0.944 |
| Identity | 4.00 | 2.00 | 5.00 | 4.00 | 2065.0 | 0.081 |
| Timeline- acute/chronic | 15.00 | 7.50 | 14.00 | 6.00 | 2196.0 | 0.845 |
| Timeline - cyclical | 12.00 | 4.00 | 12.00 | 5.25 | 2215.0 | 0.782 |
| Consequences | 20.00 | 6.00 | 18.00 | 8.00 | 1891.5 | 0.068 |
| Personal Control | 13.00 | 5.00 | 12.50 | 5.00 | 2200.5 | 0.733 |
| Treatment control | 16.00 | 2.00 | 15.00 | 2.00 | 1960.0 | 0.152 |
| Coherence | 10.68 | 6.50 | 9.50 | 6.00 | 2310.5 | 0.770 |
| Emotion | 22.00 | 5.00 | 20.50 | 5.25 | 1672.0 | 0.002* |

A logistic regression analysis was performed with appraisal delay categories (<2 or>2 hours) as the dependent variable and gender, identity score, emotion score and consequences score as predictor variables. A total of 131

cases were analysed and the full model predicted appraisal delay category (omnibus chi-square=19.907, *df*=4, *p*=0.001). The model accounted for between 14% and 19% of variance in delay category, with 68% of non-delayers and 57% of delayers successfully predicted. Overall 62% of predictions were accurate.

Table 27 gives coefficients and the Wald statistic for each of the predictor variables. This shows that identity score and emotion score reliably predicted appraisal delay.

**Table 27: Logistic regression analysis: appraisal delay categories**

| | *B* | *SE* | *Wald* | *df* | *p* |
|---|---|---|---|---|---|
| Identity | 0.215 | 0.077 | 7.747 | 1 | 0.005* |
| Consequences | -0.036 | 0.046 | 0.586 | 1 | 0.444 |
| Emotion | -0.173 | 0.062 | 7.793 | 1 | 0.005* |
| Gender | 0.374 | 0.385 | 0.942 | 1 | 0.332 |
| Constant | 3.121 | 1.348 | 5.361 | 1 | 0.021 |

***Person who made call***

***Demographic***

No significant correlations were identified between appraisal delay and the age of the patient ($r_S$ =0.003, *p*=.975) or the PWMC ($r_S$ =-0.048, *p*=.591*)*. Nor were there significant differences in appraisal times relating to the gender of either the patient (*U*=1739.5, *p*=.147) or the PWMC (*U*=1807, *p*=.276).

When participants with appraisal times < 2 hours were compared with those > 2 hours, there were no significant differences relating to either the age of the patient (*U*=1970.5, *p*=0.721) or the PWMC (*U*=1882, *p*=0.436). Nor were significant differences identified between the 2 groups relating to the gender

of the patient ($\chi^2$ (*df*=1) = 0.755, *p* = .385) or the PWMC ($\chi^2$ (*df*=1) = 0.314, *p* = .576).

***Illness representations***

No significant correlations were identified between appraisal time and any of the subscales of the IPQ-R with the exception of emotion. Appraisal time was significantly shorter where the person who made the call reported high emotional representations themselves or high patient emotion (see Table 28, below).

Those who identified the most important likely cause of the patient's symptoms to be relating to the heart did not have significantly different appraisal delay than those who identified other causes as most important (*U*= 1557, *p*= 971).

**Table 28: Spearman's correlation between IPQ-R subscales and appraisal time – PWMC**

| | *N* | *rs* | *p* |
|---|---|---|---|
| PWMC report patient identity | 120 | 0.138 | 0.132 |
| PWMC report patient timeline- acute/chronic | 119 | -0.080 | 0.385 |
| PWMC report patient timeline - cyclical | 118 | -0.028 | 0.760 |
| PWMC report patient consequences | 120 | -0.149 | 0.105 |
| PWMC report patient personal control | 118 | 0.039 | 0.677 |
| PWMC report patient treatment control | 122 | -0.029 | 0.749 |
| PWMC report patient coherence | 120 | 0.024 | 0.797 |
| PWMC report patient emotion | 121 | -0.216 | 0.017* |
| PWMC's personal control | 119 | -0.023 | 0.804 |
| PWMC's coherence | 121 | 0.020 | 0.827 |
| PWMC's emotion | 121 | -0.267 | 0.003* |

Similarly, when participants with appraisal delay <2 hours were compared with those with appraisal time >2 hours, the only significant difference identified in IPQ subscales was emotion (see Table 29, below). Those reporting appraisal delay of < 2 hours reported higher patient emotion scores

and higher emotion themselves than those with appraisal delay of >2 hours.

**Table 29: Appraisal delay, PWMC: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| PWMC report patient identity | 4.00 | 2.00 | 5.00 | 4.00 | 1499.0 | 0.121 |
| PWMC report patient timeline acute/chronic | 15.00 | 6.00 | 14.00 | 6.00 | 1752.5 | 0.940 |
| PWMC report patient timeline - cyclical | 12.00 | 4.00 | 12.00 | 6.00 | 1685.0 | 0.784 |
| PWMC report patient consequences | 20.00 | 7.00 | 19.00 | 6.00 | 1549.0 | 0.191 |
| PWMC report patient personal control | 13.00 | 5.00 | 12.00 | 5.00 | 1695.0 | 0.826 |
| PWMC report patient treatment control | 15.00 | 4.00 | 14.00 | 4.00 | 1621.0 | 0.217 |
| PWMC report patient coherence | 11.00 | 7.00 | 10.00 | 8.00 | 1676.0 | 0.517 |
| PWMC report patient emotion | 22.00 | 5.00 | 21.00 | 6.00 | 1341.0 | 0.011* |
| PWMC's personal control | 13.00 | 5.00 | 12.00 | 4.00 | 1623.5 | 0.445 |
| PWMC's coherence | 12.00 | 8.00 | 10.00 | 8.00 | 1774.0 | 0.775 |
| PWMC's emotion | 22.00 | 6.00 | 20.00 | 5.00 | 1275.5 | 0.004* |

### 7.7.3 Illness Delay

Median illness delay reported by patients was 75 minutes, Range 0 minutes - 104 weeks, IQR =3.01 hours.

Median total delay reported by callers was 62 minutes, Range 0 – 112 hours, IQR= 1.05 hours.

Callers' reports of illness delay were highly correlated with those of the corresponding patient ($r_S$ =0.660, $p$=.001) and there were no significant differences between the two reports ($z$=-1.452, $p$=.147).

When the total delay time reported by the PWMC (whether that be a caller or patient) was calculated for each call, median illness delay was 75 minutes, Range 0 minutes – 104 weeks, IQR = 2.97 hours.

***Relationship between study variables and illness delay***

***Patient***

***Demographic and clinical factors***

No significant relationships were identified between illness delay and patients' ages ($r_S$ =-.023, $p$=.803). Nor were significant differences identified between male (Mdn = 79 mins.) and female (Mdn = 69 mins.) patients ($U$= 1678, $p$= .431); between DEPCAT classifications ($H$ (6) = 10.604, $p$=.101, see Table 17, page 206).

Patients who reported pain did not report significantly different illness delay times than those who did not ($U$= 394, $p$= .627). No significant differences in

illness delay were identified between patients with a history of CHD (Mdn = 56 mins) and those without (Mdn = 79 mins.; *U*= 1267, *p*= .456). Nor were there significant differences in illness delay between patients with diabetes and those without (*U*=203, *p*=0.098). There was no significant relationship identified between the number of previous calls to NHS 24 and illness delay ($r_S$ =-.161, *p*=.078). However, those who were calling NHS 24 for the first time had significantly longer illness delay (Mdn=93 mins.) than those who had called before (Mdn=57mins.; *U*= 1381.5, *p*= .05). Those who received an ambulance as a result of the call did not differ significantly from those who did not (*U*= 634.5, *p*= .207).

When those with an illness delay <2 hours and >2 hours were compared, there were no significant differences with regards to age (*U*=2072, *p*=0.693), gender ($\chi^2$ (df=1)=0.022, *p*=0.881), DEPCAT classification, ethnic group, presence of pain, history of CHD, presence of diabetes or whether it was their first call to NHS 24. However, a greater proportion of those who delayed <2 hours had a caller involved in the original call ($\chi^2$ (df=1) =3.82, *p*=0.051) and received an emergency response as a result of their call than those who delayed > 2 hours ($\chi^2$ (df=1) =4.42, *p*=0.036), see Table 30, below.

**Table 30: Illness delay: $\chi^2$ test comparing delayers and non-delayers**

| | No delay (< 2 hours) (n=103) | Delay (> 2 hours) (n=42) | $\chi^2$ | *df* | *p* |
|---|---|---|---|---|---|
| Male | 50% | 55% | 0.22 | 1 | 0.640 |
| High deprivation | 37% | 36% | 0.02 | 1 | 0.894 |
| Reported pain | 89% | 89% | 0.01 | 1 | 1.000 |
| Documented history CHD | 26% | 24% | 0.07 | 1 | 0.797 |
| First call | 39% | 50% | 1.53 | 1 | 0.217 |
| Emergency response | 91% | 79% | 4.42 | 1 | 0.036* |
| Caller | 48% | 30% | 3.82 | 1 | 0.051* |
| Diabetes | 6% | 16% | 3.04 | 1 | 0.124 |

***Illness representations***

No significant correlations were identified between illness delay and any of the subscales of the IPQ-R (see Table 31, below). Nor were any significant differences found in subscale scores between those with an illness delay <2 hours and >2 hours (see Table 32, below).

Participants who identified the most important likely cause of their symptoms as relating to the heart had significantly shorter illness delay (Mdn=44 mins.) than those who identified other causes as most important (Mdn=64 mins.; *U*= 1103, *p*= .042, see Table 21, page 208).

**Table 31: Spearman's correlations between IPQ-R subscales and illness delay – patient**

| | *N* | $r_S$ | *p* |
|---|---|---|---|
| Identity | 118 | 0.06 | 0.515 |
| Timeline- acute/chronic | 112 | 0.15 | 0.104 |
| Timeline - cyclical | 112 | 0.06 | 0.567 |
| Consequences | 113 | 0.06 | 0.558 |
| Personal Control | 111 | 0.01 | 0.875 |
| Treatment control | 113 | 0.06 | 0.500 |
| Coherence | 114 | -0.08 | 0.423 |
| Emotion | 115 | 0.05 | 0.577 |

**Table 32: Illness delay: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| Age | 54.00 | 22.00 | 51.50 | 23.00 | 2072.0 | 0.693 |
| Previous calls to NHS 24 | 2.00 | 3.00 | 1.50 | 2.00 | 1925.0 | 0.280 |
| Identity | 4.00 | 3.00 | 5.00 | 4.50 | 1990.0 | 0.688 |
| Timeline- acute/chronic | 14.00 | 7.00 | 14.00 | 6.00 | 1522.0 | 0.135 |
| Timeline - cyclical | 12.00 | 4.00 | 12.00 | 6.50 | 1771.0 | 0.596 |
| Consequences | 20.00 | 6.00 | 19.50 | 7.00 | 1769.0 | 0.618 |
| Personal Control | 13.00 | 5.00 | 13.00 | 5.63 | 1771.5 | 0.692 |
| Treatment control | 16.00 | 2.00 | 16.00 | 2.00 | 1806.5 | 0.644 |
| Coherence | 10.00 | 6.00 | 8.00 | 5.00 | 1790.5 | 0.474 |
| Emotion | 22.00 | 4.00 | 22.00 | 5.50 | 1786.0 | 0.392 |

***Person who made call IPQ-R***

***<u>Demographic</u>***

No significant relationship was identified between the age of the patient ($r_S$ =-0.075, *p*=.454) or the person who made the call and illness delay ($r_S$ =-0.071, *p*=.475). Nor were there significant differences in illness delay relating to the gender of either the patient (*U*=1254, *p*=.637) or person who made the call (*U*=1209.5, *p*=.468).

Similarly, when those with illness delay times of <2 hours were compared to those of >2 hours, no significant differences related to either the age of the patient (*U*=1140, *p*=0.651) or the PWMC (*U*=1161.5, *p*=0.761) or the gender of the patient ($\chi^2$ (*df*=1) =0.005, *p*=0.942) or PWMC ($\chi^2$ (*df*=1) =0.104, *p*=0.748) were identified.

***<u>Illness representations</u>***

A positive correlation was identified between treatment control and the PWMC report of illness delay ($r_S$ =0.234, *p*=.020). No other significant correlations were identified between the illness representations of the person who made the call and illness delay (see Table 33, page below). Similarly, the only significant difference in IPQ subscales when those reporting illness delay of <2 hours were compared with those >2 hours was treatment control (see Table 34, below)

Those who identified the most important likely cause of the patient's symptoms to be relating to the heart did not have significantly different illness delay than those who identified other causes as most important (*U*= 924.5, *p*= .237).

**Table 33: Spearman's correlation between IPQ-R subscales and illness delay – PWMC**

| | *N* | $r_S$ | *p* |
|---|---|---|---|
| PWMC report patient identity | 98 | 0.094 | 0.356 |
| PWMC report patient timeline- acute/chronic | 98 | 0.046 | 0.651 |
| PWMC report patient timeline - cyclical | 96 | 0.133 | 0.195 |
| PWMC report patient consequences | 98 | -0.046 | 0.655 |
| PWMC report patient personal control | 97 | -0.001 | 0.989 |
| PWMC report patient treatment control | 99 | 0.234 | 0.020* |
| PWMC report patient coherence | 99 | -0.023 | 0.818 |
| PWMC report patient emotion | 103 | 0.032 | 0.754 |
| | | | |
| PWMC's personal control | 97 | 0.097 | 0.354 |
| PWMC's coherence | 99 | 0.049 | 0.633 |
| PWMC's emotion | 100 | 0.055 | 0.586 |

**Table 34: Illness delay, PWMC: Comparison of delayers with non-delayers (Mann-Whitney)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| PWMC report patient identity | 4.00 | 3.00 | 4.00 | 3.75 | 1065.5 | 0.784 |
| PWMC report patient timeline- acute/chronic | 14.00 | 5.25 | 14.50 | 6.00 | 933.0 | 0.295 |
| PWMC report patient timeline - cyclical | 12.00 | 6.00 | 12.50 | 5.75 | 812.5 | 0.062 |
| PWMC report patient consequences | 19.50 | 6.00 | 18.60 | 5.75 | 1028.5 | 0.743 |
| PWMC report patient personal control | 13.00 | 4.25 | 13.00 | 4.75 | 1003.5 | 0.691 |
| PWMC report patient treatment control | 14.00 | 4.00 | 15.50 | 2.00 | 815.5 | 0.023* |
| PWMC report patient coherence | 11.50 | 8.00 | 10.50 | 6.25 | 1103.5 | 0.993 |
| PWMC report patient emotion | 21.00 | 5.00 | 22.00 | 5.50 | 1097.5 | 0.774 |
| PWMC's personal control | 12.00 | 4.00 | 13.00 | 5.00 | 824.5 | 0.077 |
| PWMC's coherence | 12.00 | 8.00 | 10.50 | 7.00 | 1055.0 | 0.712 |
| PWMC's emotion | 21.00 | 5.00 | 21.00 | 6.00 | 1091.0 | 0.738 |

### 7.7.4 Decision time reported during the call to NHS 24

Timing of symptoms was referred to in 156 of 162 calls reviewed. However an actual measurable time was only available in 101. The remaining statements (e.g. '*since this morning*') were adequate for the clinician's purposes and not explored further during the call. However, they were not precise enough to be included in the analysis where differences between comparison groups were being measured in minutes. Two negative values were also excluded from the analysis (these occurred when patient reported contacting another health professional earlier than when they stated symptoms started during call).

The median decision time reported during the call to NHS 24 was 90 minutes (IQR= 3 hours 22 minutes), Range 5 mins. -30.87 hours.

The relationship between decision times reported during the call to NHS 24 and the other measures of delay are reported on page 244.

#### *Patient*

##### *Demographic and clinical factors*

No significant relationships were identified between decision time reported during NHS 24 call and patients ages ($r_S$ =-.167, $p$=.115). Nor were significant differences identified between male and female patients ($U$= 979.5, $p$= .696) or between DEPCAT classifications (see Table 17, page 206).

Patients who reported pain did not report significantly different total delay

times than those who did not ($U$= 229, $p$= .209). No difference in call-reported decision time was found between patients with a history of CHD (Mdn = 86 mins) and those without (Mdn = 106 mins.; $U$= 809, $p$=.840). Nor were there significant differences in the decision time reported during the call between patients with diabetes and those without ($U$=177, $p$=0.593). There was no significant relationship between the number of previous calls to NHS 24 and call-reported decision time ($r_S$ =-.144, $p$=.174). No significant difference was found between the call-reported decision times of those calling NHS 24 for the first time and those who had called before ($U$= 838.5, $p$=.194), between those who received an ambulance as a result of the call and those who did not ($U$= 307, $p$=.726) or relating to whether a caller was involved ($U$ =970, $p$ = 0.815).

Those who reported decision times of <2hours during the call to NHS 24 were not significantly different from those who reported decision times >2hours in terms of age ($U$=900.5, $p$=0.235), patient gender, high or low DEPCAT classification ($\chi^2$ ($df$=1) =0.07, $p$=0.791), white / non-white ethnic group, presence of pain, history of CHD or diabetes (see Table 35, below). A significantly larger proportion of those calling NHS 24 for the first time reported a delay of >2 hours (54%) than <2 hours (32%, $\chi^2$ ($df$=1) =4.71, $p$=.030). There were no significant differences between the two groups regarding whether the participant received an ambulance as a result of the call or whether there was a caller involved in the call.

**Table 35: Decision time reported during the call to NHS 24: Comparisons between delayers and non-delayers ($\chi^2$ tests)**

| | Delay < 2 hours (n=57) | Delay > 2 hours (n=37) | $\chi^2$ | *df* | *p* |
|---|---|---|---|---|---|
| Male | 54% | 54% | 0.01 | 1 | 0.975 |
| High deprivation | 35% | 32% | 0.07 | 1 | 0.791 |
| Reported pain | 90% | 85% | 0.36 | 1 | 0.734 |
| Documented history CHD | 34% | 22% | 1.64 | 1 | 0.201 |
| First call | 32% | 54% | 4.71 | 1 | 0.030* |
| Emergency response | 89% | 95% | 0.76 | 1 | 0.385 |
| Caller | 39% | 46% | 0.50 | 1 | 0.480 |
| Diabetes | 10% | 11% | 0.05 | 1 | 1.000 |

### *Illness representations*

No significant correlations were identified between decision time obtained from the call and any of the subscales of the IPQ-R (see Table 36, below).

**Table 36: Spearman's correlations between IPQ-R and decision times obtained from the call – patient**

| | *N* | $R_S$ | *p* |
|---|---|---|---|
| Identity | 87 | -0.055 | 0.614 |
| Timeline- acute/chronic | 80 | 0.077 | 0.497 |
| Timeline - cyclical | 83 | 0.037 | 0.741 |
| Consequences | 82 | 0.096 | 0.393 |
| Personal Control | 83 | 0.148 | 0.182 |
| Treatment control | 84 | 0.008 | 0.940 |
| Coherence | 84 | -0.088 | 0.426 |
| Emotion | 84 | 0.073 | 0.507 |

Similarly, when those who reported a decision time of <2 hours were compared with those reporting decision times >2 hours, no significant differences were identified (see Table 37 below).

Patients who identified the most important likely cause of their symptoms as relating to the heart did not report significantly different delay times during the call to NHS 24 than those who identified other causes as most important (*U*= 718, *p*= .876, see Table 21, page 208).

**Table 37: Decision time obtained during call to NHS 24: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| Identity | 4.00 | 2.75 | 4.00 | 6.00 | 873.0 | 0.458 |
| Timeline- acute/chronic | 14.00 | 6.00 | 14.00 | 4.50 | 748.5 | 0.530 |
| Timeline - cyclical | 12.00 | 5.00 | 12.00 | 4.50 | 810.0 | 0.567 |
| Consequences | 19.00 | 6.85 | 20.00 | 6.25 | 737.0 | 0.363 |
| Personal Control | 12.00 | 4.75 | 14.00 | 4.25 | 676.5 | 0.092 |
| Treatment control | 16.00 | 3.00 | 16.00 | 2.00 | 854.5 | 0.746 |
| Coherence | 10.50 | 6.75 | 8.50 | 5.00 | 766.5 | 0.310 |
| Emotion | 22.00 | 5.00 | 22.00 | 4.25 | 757.5 | 0.243 |

### *Person who made the call*

#### *Demographic*

No relationship was found between the age of the PWMC and the decision time reported during the call ($r_S$ =.130, $p$=.261). Nor were significant differences in call-reported decision time identified in relation to the gender of the PWMC ($U$=701, $p$=0.731).

#### *Illness representations*

No significant correlations were identified between decision time obtained from the call and any of the subscales of the IPQ-R (see Table 38).

Those who identified the most important likely cause of the patient's symptoms to be relating to the heart (on the questionnaire) did not report significantly different decision times during the call to NHS 24 than those who identified other causes as most important ($U$= 512, $p$= .576).

**Table 38: Spearman's correlations between IPQ-R and decision times obtained from call – PWMC**

| | *N* | $r_S$ | *p* |
|---|---|---|---|
| PWMC report patient identity | 74 | -0.02 | 0.872 |
| PWMC report patient timeline- acute/chronic | 71 | 0.12 | 0.305 |
| PWMC report patient timeline - cyclical | 71 | 0.06 | 0.626 |
| PWMC report patient consequences | 71 | 0.12 | 0.335 |
| PWMC report patient personal control | 71 | -0.01 | 0.936 |
| PWMC report patient treatment control | 73 | -0.04 | 0.749 |
| PWMC report patient coherence | 72 | -0.17 | 0.146 |
| PWMC report patient emotion | 73 | -0.01 | 0.913 |
| PWMC's personal control | 71 | -0.06 | 0.596 |
| PWMC's coherence | 72 | -0.18 | 0.123 |
| PWMC's emotion | 72 | -0.01 | 0.899 |

When participants who reported a decision time < 2 hours during the call to NHS 24 were compared to those who reported > 2 hours, there were no

significant differences relating to age ($U$=661, $p$=0.408) or gender ($\chi^2$ ($df$=1) = 0.003, $p$=0.953).

Nor were there significant differences in the IPQ subscales (see Table 39, below).

**Table 39: Decision time reported during call to NHS 24, PWMC: Comparison of delayers with non-delayers (Mann-Whitney tests)**

| | Delay < 2 hours | | Delay > 2 hours | | | |
|---|---|---|---|---|---|---|
| | mdn | IQR | mdn | IQR | *U* | *p* |
| PWMC report patient identity | 4.00 | 3.00 | 4.00 | 5.25 | 657.5 | 0.731 |
| PWMC report patient timeline- acute/chronic | 14.00 | 6.25 | 15.00 | 5.40 | 534.5 | 0.280 |
| PWMC report patient timeline - cyclical | 12.00 | 6.00 | 12.50 | 5.50 | 546.0 | 0.341 |
| PWMC report patient consequences | 19.00 | 8.00 | 20.50 | 5.50 | 547.5 | 0.352 |
| PWMC report patient personal control | 13.00 | 6.00 | 13.50 | 5.25 | 578.0 | 0.557 |
| PWMC report patient treatment control | 14.67 | 4.00 | 14.00 | 4.00 | 573.5 | 0.302 |
| PWMC report patient coherence | 11.00 | 7.00 | 9.00 | 5.25 | 537.0 | 0.227 |
| PWMC report patient emotion | 22.00 | 5.00 | 22.00 | 4.25 | 654.0 | 0.890 |
| PWMC's personal control | 12.00 | 4.00 | 12.00 | 5.00 | 619.0 | 0.903 |
| PWMC's coherence | 12.00 | 8.00 | 9.50 | 6.25 | 530.0 | 0.202 |
| PWMC's emotion | 21.00 | 5.00 | 22.00 | 4.50 | 660.5 | 0.946 |

## *7.8 Other patterns in illness representations*

In order to improve understanding of the results obtained in relation to decision time, additional analyses of the relationship between key demographic factors and illness representations was performed. Differences relating to age, gender, social deprivation, previous history of CHD and to the outcome of the call are reported below.

### 7.8.1 Age

As can be seen in Table 40 below, there were no significant differences in the illness representations of younger and older patients. However, when the illness representations of the person who made the call were examined younger participants reported significantly higher identity scores than older participants (see Table 41, below).

**Table 40: Differences in illness representations relating to age**

| | Younger (age < mean=53yrs) | | | Older (age>mean=53yrs) | | | | |
|---|---|---|---|---|---|---|---|---|
| | n | mean | SD | n | mean | SD | *t* | *p* |
| Identity† | 84 | 5.00 | 4.00 | 77 | 4.00 | 3.00 | 2890 | 0.242 |
| Timeline- acute/chronic | 82 | 14.01 | 4.21 | 72 | 13.51 | 3.83 | 0.763 | 0.446 |
| Timeline - cyclical | 82 | 12.49 | 3.45 | 74 | 12.04 | 3.38 | 0.823 | 0.412 |
| Consequences | 83 | 18.57 | 4.67 | 74 | 18.78 | 4.18 | -0.298 | 0.766 |
| Personal Control | 81 | 13.21 | 3.45 | 74 | 13.00 | 3.21 | 0.408 | 0.684 |
| Treatment control † | 84 | 16.00 | 2.17 | 72 | 16.00 | 2.00 | 2922 | 0.710 |
| Coherence | 84 | 10.53 | 4.21 | 75 | 11.24 | 4.03 | -1.08 | 0.279 |
| Emotion | 86 | 21.79 | 3.73 | 74 | 21.33 | 3.81 | 0.759 | 0.449 |

**Table 41 : Differences in illness representations relating to age of person who made call**

| | Younger (age < mean=53yrs) | | | Older (age>mean=53yrs) | | | | |
|---|---|---|---|---|---|---|---|---|
| | n | mean | SD | n | mean | SD | *t* | *p* |
| PWMC report patient identity[†] | 82 | 5.00 | 3.75 | 63 | 4.00 | 3.00 | 2102.5 | 0.053 |
| PWMC report patient timeline- acute/chronic | 81 | 14.04 | 4.03 | 62 | 14.76 | 3.79 | -1.089 | 0.278 |
| PWMC report patient timeline - cyclical | 81 | 12.35 | 3.73 | 62 | 12.00 | 3.27 | 0.586 | 0.559 |
| PWMC report patient consequences | 82 | 18.58 | 4.78 | 63 | 19.41 | 4.23 | -1.078 | 0.283 |
| PWMC report patient personal control | 80 | 13.07 | 3.66 | 62 | 13.41 | 3.14 | -0.582 | 0.561 |
| PWMC report patient treatment control[†] | 83 | 14.33 | 4.00 | 64 | 14.00 | 4.00 | 2232.0 | 0.092 |
| PWMC report patient coherence | 83 | 10.76 | 4.14 | 62 | 11.18 | 3.80 | -0.617 | 0.538 |
| PWMC report patient emotion | 85 | 21.95 | 3.76 | 62 | 21.51 | 3.62 | 0.714 | 0.477 |
| PWMC's personal control | 80 | 12.35 | 3.42 | 64 | 11.63 | 3.78 | 1.204 | 0.231 |
| PWMC's coherence | 83 | 11.38 | 4.56 | 63 | 11.84 | 4.20 | -0.630 | 0.530 |
| PWMC's emotion | 85 | 21.45 | 4.07 | 63 | 21.03 | 3.68 | 0.639 | 0.524 |

[†] Non-parametric test, Median and IQR reported.

**Table 42: Differences in illness representations by gender (t-tests)**

| | Male | | Female | | | Difference | |
|---|---|---|---|---|---|---|---|
| | mean | SD | mean | SD | *t* | (95% C.I) | *p* |
| Identity † | 4.0 | 3.50 | 5.00 | 4.00 | | | 0.233 |
| Timeline- acute/chronic | 13.99 | 4.38 | 13.58 | 3.68 | -0.64 | (-1.71, 0.88) | 0.525 |
| Timeline - cyclical | 12.17 | 3.26 | 12.38 | 3.57 | 0.39 | (-0.87, 1.30) | 0.695 |
| Consequences | 19.45 | 4.46 | 17.92 | 4.29 | -2.20 | (-2.91, -0.15) | 0.029* |
| Personal Control | 13.48 | 3.40 | 12.75 | 3.24 | -1.38 | (-1.79, 0.32) | 0.171 |
| Treatment control † | 16.00 | 2.00 | 16.00 | 2.00 | | | 0.546 |
| Coherence | 11.15 | 4.26 | 10.58 | 4.01 | -0.87 | (-1.86, 0.72) | 0.387 |
| Emotion | 21.19 | 3.97 | 21.97 | 3.51 | -1.31 | (-1.95, 0.39) | 0.193 |

† Non-parametric test, Median and IQR reported.

### 7.8.2 Gender

As already discussed, there were significant differences in illness representations relating to gender (see Table 42, above). Men reported significantly more serious consequences than women.

### 7.8.3 Social deprivation

The results of analysis exploring the relationship between illness representations and social deprivation are summarised in Table 43, below. Patients from areas of high social deprivation (i.e. DEPCAT classification 5-7) reported significantly higher identity scores than patients from areas of low deprivation (U=2279, p=0.005).

Patients from areas of high deprivation also tended to report a more chronic timeline and more serious consequences in relation to their symptoms than those from areas of low deprivation although this did not reach statistical significance ($p$=0.074, $p$=0.082 respectively). Significant differences in the remaining illness representation subscales were not identified between the two groups.

**Table 43: Differences in illness representations by DEPCAT**

| | Low deprivation (DEPCAT 1-4) | | | High deprivation (DEPCAT 5-7) | | | | |
|---|---|---|---|---|---|---|---|---|
| | n | mean | SD | n | mean | SD | *t* | *p* |
| Identity[†] | 90 | 4.00 | 3.00 | 59 | 5.00 | 3.00 | 2279 | 0.005* |
| Timeline- acute/chronic | 96 | 13.33 | 4.01 | 58 | 14.52 | 4.02 | -1.798 | 0.074 |
| Timeline - cyclical | 97 | 12.20 | 3.42 | 59 | 12.40 | 3.44 | -0.351 | 0.726 |
| Consequences | 99 | 18.20 | 4.54 | 58 | 19.47 | 4.15 | -1.751 | 0.082 |
| Personal Control | 97 | 13.24 | 3.26 | 58 | 12.91 | 3.46 | 0.591 | 0.555 |
| Treatment control [†] | 90 | 16.00 | 2.00 | 59 | 16.00 | 2.00 | 2750.5 | 0.629 |
| Coherence | 100 | 10.86 | 3.94 | 59 | 10.87 | 4.46 | -0.015 | 0.988 |
| Emotion | 100 | 21.58 | 3.88 | 60 | 21.56 | 3.61 | 0.034 | 0.973 |

[†] Non-parametric test, Median and IQR reported.

**Table 44: Illness representations and previous history of CHD**

| | No history CHD | | | History CHD | | | Difference | | |
|---|---|---|---|---|---|---|---|---|---|
| | n | mean | SD | n | mean | SD | *t* | (95% C.I) | *p* |
| Identity † | 118 | 4.00 | 4.00 | 41 | 5.00 | 3.00 | 2419 | | 1.000 |
| Timeline-acute/chronic | 113 | 13.72 | 4.06 | 39 | 14.05 | 4.08 | 0.44 | (-1.16, 1.82) | 0.658 |
| Timeline - cyclical | 114 | 12.05 | 3.48 | 40 | 13.09 | 3.14 | 1.67 | (-1.19, 2.27) | 0.097 |
| Consequences | 114 | 18.18 | 4.70 | 41 | 20.04 | 3.39 | 2.69 | (0.48, 3.22) | 0.008 |
| Personal Control | 112 | 13.03 | 3.19 | 41 | 13.20 | 3.64 | 0.28 | (-1.03, 1.37) | 0.779 |
| Treatment control † | 115 | 16.00 | 2.00 | 39 | 16.00 | 2.00 | 2240 | | 0.991 |
| Coherence | 116 | 10.09 | 3.90 | 41 | 13.01 | 4.16 | 4.04 | (1.49 - 4.33) | <0.001 |
| Emotion | 118 | 21.65 | 3.75 | 40 | 21.53 | 3.82 | -0.19 | (-1.49, 1.23) | 0.852 |

† Non-parametric test, Median and IQR reported.

### 7.8.4 Previous history of CHD

The illness representations of those with a previous history of CHD differed significantly from those without (see Table 44, above). Participants with a history of CHD reported significantly more serious consequences ($p$=.008), greater coherence ($p$<0.001) and also tended to report symptoms of a more cyclical nature ($p$=.097) than those without a previous history of CHD. Patients ($\chi^2$ ($df$=1) = 4.458, $p$=0.035) and the PWMC ($\chi^2$ ($df$=1) = 4.623, $p$=0.032) were also significantly more likely to identify the heart as the most likely cause of the symptoms when the patient had a previous history of CHD.

### 7.8.5 Outcome of call to NHS 24

Significant differences were identified between the illness representations of patients who received an emergency response to their call and those who did not. These are summarised in Table 45, below and show that patients who received an emergency response reported significantly more serious consequences than those who did not ($t$=2.67, $p$=0.008).

**Table 45: Differences in illness representations by outcome of call to NHS 24 (t-tests)**

| | Emergency outcome | | | Non-emergency outcome | | | | Difference | |
|---|---|---|---|---|---|---|---|---|---|
| | n | mean | SD | n | mean | SD | *t* | (95% C.I) | *p* |
| Identity[†] | 136 | 4.00 | 4.00 | 25 | 5.0 | 3.8 | | | 0.783 |
| Timeline- acute/chronic | 131 | 13.77 | 4.13 | 39 | 13.8 | 3.5 | -0.06 | (-1.16, 1.82) | 0.952 |
| Timeline - cyclical | 133 | 12.18 | 3.28 | 40 | 12.9 | 4.1 | -0.90 | (-1.19, 2.27) | 0.370 |
| Consequences | 134 | 19.05 | 4.36 | 41 | 16.4 | 4.3 | 2.67 | (0.48, 3.22) | 0.008* |
| Personal Control | 132 | 13.21 | 3.41 | 41 | 12.6 | 2.8 | 0.87 | (-1.03, 1.37) | 0.384 |
| Treatment control [†] | 133 | 16.00 | 2.00 | 23 | 15.0 | 3.0 | | | 0.188 |
| Coherence | 135 | 10.90 | 4.10 | 41 | 10.7 | 4.4 | 0.24 | (1.49, 4.33) | 0.814 |
| Emotion | 136 | 21.73 | 3.74 | 40 | 20.7 | 3.9 | 1.26 | (-1.49, 1.23) | 0.209 |

[†] Non-parametric test, Median and IQR reported.

## *7.9 Comparison of patients' and callers' illness representations*

Where both the patient and the person who called on their behalf completed the IPQ-R (n=45) there was an opportunity to compare the two representations of the same illness episode. Spearman's correlations were used to explore the relationship between patients' and callers' illness representations. Paired t-tests (and where appropriate the Wilcoxon signed ranks test) were used to explore differences between patient and caller scores for each subscale of the IPQ-R.

Dissimilarity scores were created by subtracting callers' scores from patients' scores and Spearman's correlations used to explore the relationship between dissimilarity scores and the various measures of decision time.

### 7.9.1 Correlations

Callers' reports of patients' illness representations were highly correlated with patients' own on all IPQ-R subscales with the exception of treatment control, (see Table 47, below). Similarly, callers' reports of their own personal control, coherence and emotion relating to the patient's illness were highly correlated with the patients' own.

**Table 46: Spearman correlations between patient and caller IPQ-R scores.**

| | | Patient | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Identity | Timeline-a/c | Timeline-cyc. | Consequences | Personal Ctrl | Treatment Ctrl | Coherence | Emotion | *p* |
| Caller | Identity | 0.845 | | | | | | | | 0.000* |
| | Timeline-acute/chronic | | 0.602 | | | | | | | 0.000* |
| | Timeline - cyclical | | | 0.568 | | | | | | 0.000* |
| | Consequences | | | | 0.660 | | | | | 0.000* |
| | Personal Control | | | | | 0.616 | | | | 0.000* |
| | Treatment control | | | | | | 0.122 | | | 0.430 |
| | Coherence | | | | | | | 0.618 | | 0.000* |
| | Emotion | | | | | | | | 0.560 | 0.000* |
| | Caller's personal control | | | | | 0.508 | | | | 0.000* |
| | Caller's coherence | | | | | | | 0.703 | | 0.000* |
| | Caller's emotion | | | | | | | | 0.319 | 0.037* |

### 7.9.2 Differences

As can be seen in Table 47, below, no significant differences were found between patient and caller reports of the number of symptoms which related to the call (identity score). Caller's timeline-acute/chronic scores were found to be significantly higher (Mean=15.0, SD=4.2) than patients (Mean=13.47, SD= 4.32) (high timeline scores reflect beliefs that symptoms will last a long time and low scores that symptoms will be short-lived). However, no significant differences were found between patient and caller timeline-cyclic scores.

Callers tended to report higher consequence scores (Mean=19.7, SD=4.8) than patients (Mean=18.51, SD=4.7) but this did not reach statistical significance (t (43) =-1.933, *p*=.06).

Callers' reports of patients' level of personal control were not significantly different from the patient's own report. However, callers' treatment control scores were significantly lower (Median=12.0, IQR=1.5) than patients' (Median=15.0, IQR=2.0), t =2, *p*=<.001).

Callers' reports of patients' levels of coherence and emotion were not significantly different from the patient's own report.

However, callers' reports of *their own* level of personal control were significantly lower (Mean=9.61, SD=3.0) than patients' own (Mean=12.54, SD=3.82) (t (43) =-5.618, *p*=<.01). Callers' ratings of *their own* level of coherence were significantly higher (Mean=13.1. SD=4.6) than patients' (Mean=11.23, SD=4.13) (t (42) =-3.5, *p*=<.01). Callers' and patients' reports of their own emotion did not differ significantly.

.

**Table 47: Comparison of patient and caller illness representations: paired *t*-tests**

| | | Patient | | Caller | | | | Difference | |
|---|---|---|---|---|---|---|---|---|---|
| | | mean | SD | mean | SD | *t* | *df* | (95% C.I) | *p* |
| Identity† | n=37 | 4.00 | 3.75 | 4.0 | 3.0 | -1.27 | | | 0.206 |
| Timeline-acute/chronic | n=41 | 13.5 | 4.32 | 15.0 | 4.2 | -2.56 | 40 | (-2.72, -0.32) | 0.014* |
| Timeline - cyclic | n=43 | 11.7 | 3.07 | 11.5 | 3.5 | 0.56 | 42 | (-0.73, 1.17) | 0.647 |
| Consequences | n=44 | 18.5 | 4.70 | 19.7 | 4.8 | -1.93 | 43 | (-2.34, 0.49) | 0.060 |
| Personal Control | n=43 | 12.7 | 3.78 | 12.6 | 4.1 | 0.02 | 42 | (-1.05, 1.07) | 0.982 |
| Treatment control† | n=44 | 15.0 | 2.00 | 12.0 | 0.0 | -5.14 | | | <0.001* |
| Coherence | n=43 | 11.2 | 4.13 | 11.6 | 3.7 | -0.62 | 42 | (-1.38, 0.73) | 0.538 |
| Emotion | n=43 | 21.5 | 3.97 | 22.1 | 3.5 | -1.00 | 42 | (-1.60, 0.55) | 0.328 |
| | | | | | | | | | |
| Callers personal control | n=44 | 12.5 | 3.82 | 9.61 | 3.0 | 5.62 | 43 | (1.88, 3.98) | <0.001* |
| Callers coherence | n=43 | 11.2 | 4.13 | 13.1 | 4.6 | -3.50 | 42 | (-2.88, -0.79) | 0.001* |
| Callers emotion | n=43 | 21.5 | 3.97 | 21.0 | 3.9 | 0.87 | 42 | (-0.87, 1.95) | 0.445 |

† Mann-Whitney *U*, Median and IQR

### 7.9.3 Dissimilarity

A measure of the dissimilarity between callers' and patients' illness representations was created by subtracting callers' scores from patients'. Thus for each construct, positive dissimilarity scores reflected higher scores by the patient and negative dissimilarity scores reflected higher caller scores. Correlations between dissimilarity scores and the various measures of decision time were then performed, results are summarised in the tables below.

**Table 48: Correlations between dissimilarity scores and total patient delay**

| | *N* | *rs* | *p* |
|---|---|---|---|
| Identity | 30 | .125 | .511 |
| Timeline- acute/chronic | 34 | .174 | .324 |
| Timeline - cyclical | 35 | .146 | .403 |
| Consequences | 36 | -.091 | .598 |
| Personal Control | 36 | .110 | .522 |
| Treatment control | 36 | .107 | .535 |
| Coherence | 36 | .039 | .823 |
| Emotion | 36 | -.208 | .224 |
| Caller personal control | 36 | -.032 | .854 |
| Caller coherence | 36 | .183 | .286 |
| Caller emotion | 36 | .008 | .965 |

**Table 49: Correlations between dissimilarity scores and appraisal delay**

| | *N* | *rs* | *p* |
|---|---|---|---|
| Identity | 32 | .251 | .166 |
| Timeline- acute/chronic | 36 | .036 | .836 |
| Timeline - cyclical | 37 | .275 | .099 |
| Consequences | 38 | -.140 | .401 |
| Personal Control | 37 | .155 | .361 |
| Treatment control | 38 | -.014 | .932 |
| Coherence | 37 | .074 | .662 |
| Emotion | 37 | -.300 | .071 |
| Caller personal control | 38 | -.015 | .928 |
| Caller coherence | 37 | .302 | .070 |
| Caller emotion | 37 | -.141 | .406 |

**Table 50: Correlations between dissimilarity scores and illness delay**

| | *N* | *rs* | *p* |
|---|---|---|---|
| Identity | 25 | -.090 | .670 |
| Timeline- acute/chronic | 27 | .061 | .761 |
| Timeline - cyclical | 27 | .142 | .479 |
| Consequences | 28 | .088 | .657 |
| Personal Control | 28 | .119 | .548 |
| Treatment control | 28 | -.073 | .712 |
| Coherence | 28 | -.208 | .289 |
| Emotion | 28 | .223 | .255 |
| Caller personal control | 28 | -.144 | .466 |
| Caller coherence | 28 | .119 | .546 |
| Caller emotion | 28 | .210 | .284 |

**Table 51: Correlations between dissimilarity scores and decision time obtained from call**

| | *N* | *rs* | *p* |
|---|---|---|---|
| Identity | 19 | .199 | .413 |
| Timeline- acute/chronic | 21 | -.124 | .593 |
| Timeline - cyclical | 21 | .123 | .596 |
| Consequences | 22 | -.241 | .280 |
| Personal Control | 22 | .226 | .312 |
| Treatment control | 23 | -.073 | .741 |
| Coherence | 22 | .266 | .231 |
| Emotion | 22 | .141 | .532 |
| Caller personal control | 22 | .441 | .040* |
| Caller coherence | 22 | .166 | .461 |
| Caller emotion | 22 | .068 | .763 |

No significant correlations were identified between dissimilarity scores for any of the subscales of the IPQ-R and either total patient delay or illness delay.

However, a negative correlation approaching significance was identified between dissimilarities in scores relating to the patient's emotion and appraisal time. In other words there tended to be shorter appraisal time where callers reported higher patient emotion than did the patient. There was also a positive correlation approaching significance between dissimilarity scores in relation to patients' and callers' level of coherence. In other words appraisal time was longer where callers reported a higher level of coherence

than patients.

With regard to the delay reported during the call to NHS 24, a significant positive correlation ($p$=.040) was identified between dissimilarity scores in relation to patients' and callers' reported level of personal control. Longer decision times were reported during the call where callers reported more personal control than patients.

## *7.10 Comparison of data derived from call-recording with questionnaire.*

Where the patient gave permission for their original call-recording to be analysed, their was also an opportunity to compare what people presented regarding symptoms and timings at the time of the call with what they later reported on the IPQ.

Overall, 167 patients gave consent for their call to be analysed. Technical difficulties meant that access to 2 calls was not achieved. Thus data regarding the symptoms mentioned during the call was available for 165 patients.

References within the call to the symptoms listed on the IPQ-R were identified and an identity score derived from the call calculated. Hereafter, this is referred to as *call-identity*. Call-identity scores ranged between 1 and 9, Mdn= 3, IQR=3.

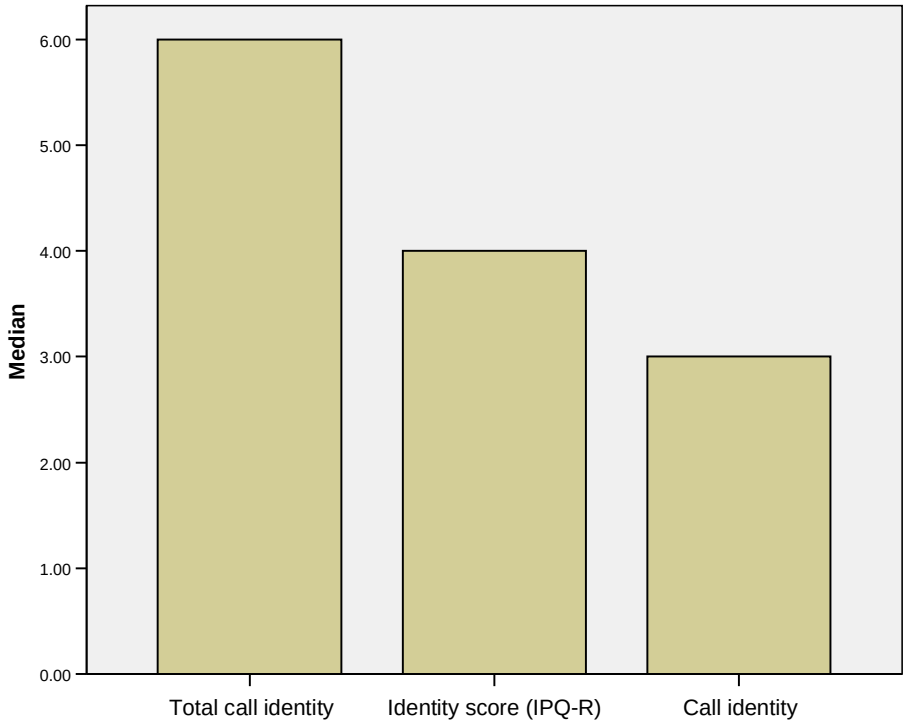
However, participants also mentioned within the call, symptoms which did not relate to those listed on the IPQ-R. Therefore an additional identity score

referring to the total number of symptoms mentioned during the call was calculated and referred to as *total call-identity*. Total call-identity scores ranged between 2 and13, (Mdn=6, IQR=3). Call identity and the number of additional symptoms were significantly correlated ($r_S$=0.205, $p$=0.008).

No significant correlation was found between call-identity and the IPQ-R identity scores of the person who made the call (i.e. the same person who was describing the symptoms during the call) ($r_S$=-0.001, $p$=0.992). However, total call-identity and the IPQ-R identity score of the person who made the call were significantly but weakly correlated ($r_S$=0.173, $p$=0.031).

Wilcoxon's signed ranks test was used compare the various scores of identity for the person who made the call. Call-identity scores were found to be significantly lower (Mdn=3.0) than IPQ-R identity scores (Mdn=4.0) ($z$=-4.530, $p$=<0.001) which in turn were significantly lower than total call-identity scores (Mdn=6.0) ($z$=5.598, $p$=<0.001).

**Figure 22: Comparison of IPQ-R identity with scores obtained from call recording**




As discussed previously, data regarding the timings of symptoms, mentioned during the call were available for 156 patients. However, this was precise enough to be compared with questionnaire data for only 101 patients.

Delay times reported during the call were significantly correlated with questionnaire reports of total patient delay ($r_S$=0.475, $p$=<0.001); appraisal time ($r_S$ =0.608, $p$=<0.001) and illness delay ($r_S$ =0.362, $p$=0.001).

Wilcoxon's signed ranks test was used compare call decision time with total patient delay and illness delay as measured on the questionnaire. Illness delay (Mdn=1.25 hours) was significantly less than call-decision time (Mdn=1.5 hours) ($z$=-2.941, $p$=0.003) which in turn was significantly less than total patient delay (Mdn=4.4 hours) ($z$=-4.854, $p$=<0.001).

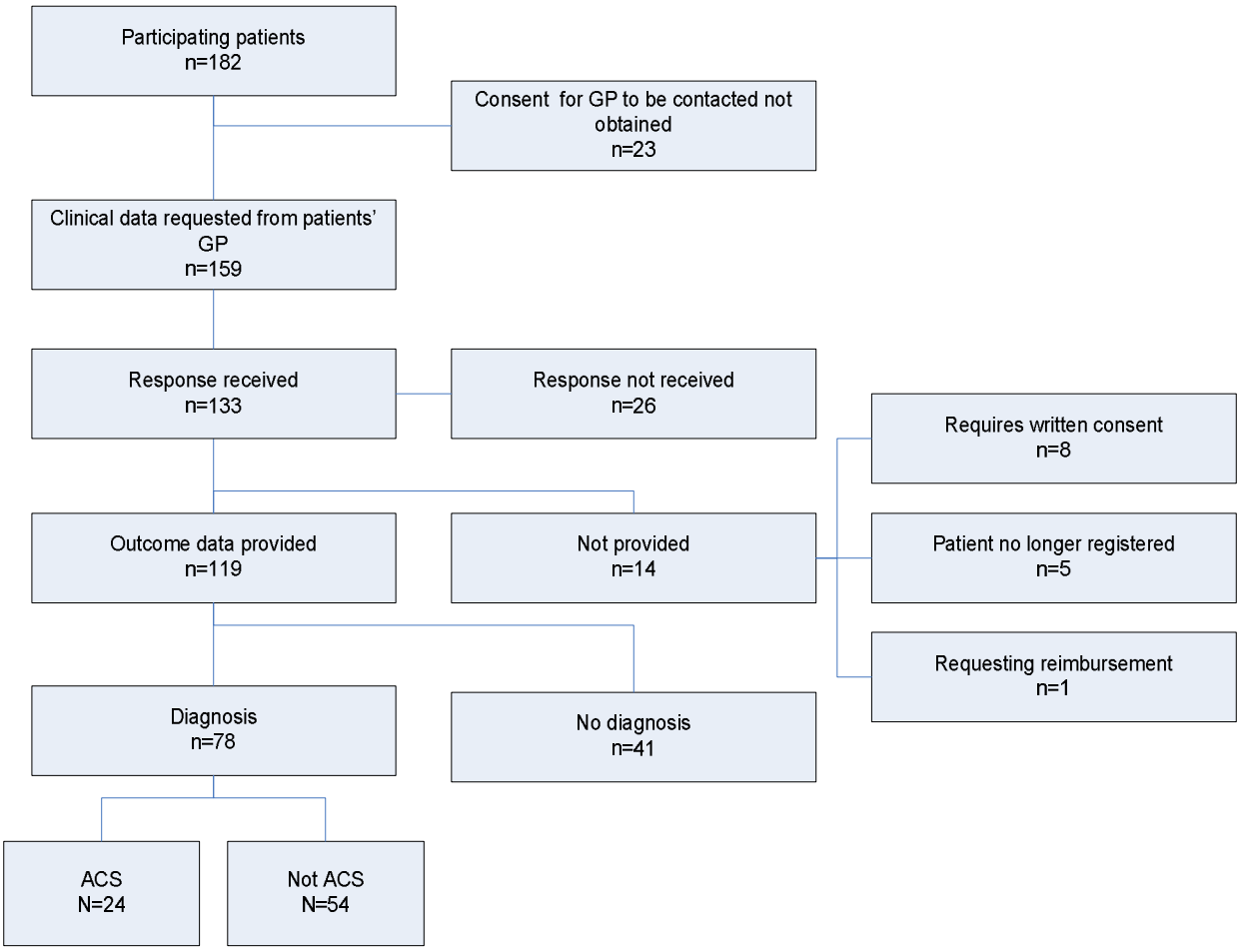
## *7.11 Illness representations and clinical outcome at 3 months.*

Permission to obtain outcome data from GPs, 3 months after the call was provided by 159 of the 182 patients. Figure 23, below provides a summary of the collection of this data.

The GPs of 133 patients responded (73%) and the requested data was available for 119. Thus outcome data was available for 75% of the patients who had consented to it being collected.

Reasons for the data not being available included GPs' requirement for written consent (which was not available as consent was obtained verbally and audio-recorded) prior to release of patient information (n=8); the patient no longer being registered at the practice (n=5) and a requirement for financial reimbursement from 1 practice.

**Figure 23: Collection of outcome data from GPs**




A total of 78 patients received a diagnosis regarding their symptoms. Those who did received a wide variety of diagnoses (e.g. ACS, musculoskeletal, gastro-intestinal, Chronic Obstructive Pulmonary Disease). Those relating to ACS were identified (i.e. a diagnoses of angina, MI or ACS, n=24).

*t*-tests and where appropriate Mann-Whitney tests were used to explore whether the illness representations of patients who received a diagnosis of ACS differed from those who did not (or where appropriate the illness representations of the person who made the call).

### 7.11.1 Patient

#### *Demographic and clinical*

Patients who received a diagnosis of ACS were significantly older (mean age =62 years) than those who did not (mean age =51 years) ($t$=4.149, $p$<.001). There were no significant differences in the proportions of men and women who received a diagnosis of ACS ($\chi 2$ (df=1) =2.125, $p$=0.145) or in those from areas of high and low deprivation ($\chi 2$ (df=1) = 0.059, $p$=0.809).

A greater proportion of those with a previous history of CHD received a diagnosis of ACS than those with no previous history ($\chi 2$ (df=1) =12.054, $p$=0.001). However, there were no significant differences between those with diabetes and those without ($\chi 2$ (df=1) =0.003, $p$=1.00). Those who received a diagnosis of ACS had made significantly fewer previous calls to NHS 24 than those who did not receive a diagnosis of ACS ($U$=815.5, $p$=0.041).

#### *Illness representations*

As can be seen in Table 52 below, there were no significant differences in patients' illness representations between the two groups except for coherence. Patients who received an ACS diagnosis reported significantly higher coherence scores (Mean=13.39, SD=3.23) than those who did not (Mean=10.35, SD=4.17) ($t$=3.24 (95% CI: 1.18, 4.90) $p$=0.002).

**Table 52: Differences in IPQ-R scores by diagnosis of ACS - patients**

| | ACS (n=24) | Not ACS (n=116) | | | |
|---|---|---|---|---|---|
| | mean (SD) | | *t* | Difference (95% C.I) | *p* |
| Identity† | 4.00 (4.00) | 5.00 (4.00) | 887 | | 0.594 |
| Timeline- acute/chronic | 12.71 (4.22) | 14.04 (3.90) | -1.374 | (-3.24, 0.59) | 0.172 |
| Timeline - cyclic | 12.40 (2.83) | 12.26 (3.47) | 0.185 | (-1.39, 1.67) | 0.853 |
| Consequences | 19.76 (4.38) | 18.41 (4.53) | 1.271 | (-0.75, 3.44) | 0.206 |
| Personal Control | 13.68 (2.60) | 13.24 (3.14) | 0.602 | (-0.99, 1.85) | 0.549 |
| Treatment control† | 16.00 (1.50) | 16.00 (2.83) | 868 | | 0.355 |
| Coherence | 13.39 (3.23) | 10.35 (4.17) | 3.239 | (1.18, 4.90) | 0.002* |
| Emotion | 20.79 (3.89) | 21.50 (3.77) | -0.807 | (-2.43, 1.03) | 0.421 |

† Mann-Whitney *U*, Median and IQR

However, patients who reported the heart as the most important likely cause of their symptoms tended to be more likely than those who identified other causes to receive a cardiac diagnosis although this did not quite reach statistical significance ($\chi 2$ (df=1) = 3.469, $p$=0.063).

A logistic regression analysis was performed with ACS diagnosis as the dependent variable and age, history of CHD, number of previous calls to NHS 24, cardiac cause and coherence score as predictor variables. A total of 108 cases were analysed and the full model predicted ACS diagnosis (omnibus chi-square = 30.652, df=5, p<0.001). The model accounted for between 25% and 38% of variance in ACS diagnosis, successfully predicting 95% of patients who did *not* receive a diagnosis and 52% of those who did. Overall, 86% of predictions were accurate. Table 53 gives coefficients and the Wald statistic for each of the predictor variables. This shows that age and coherence score reliably predicted ACS diagnosis.

**Table 53: Logistic regression analysis: ACS diagnosis**

| | *B* | *SE* | *Wald* | *df* | *p* |
|---|---|---|---|---|---|
| Age | 0.055 | 0.028 | 3.889 | 1 | 0.049* |
| Previous history CHD | 0.806 | 0.670 | 1.449 | 1 | 0.229 |
| No. of previous calls NHS 24 | 0.194 | 0.120 | 2.619 | 1 | 0.106 |
| Cardiac cause | 0.762 | 0.626 | 1.481 | 1 | 0.224 |
| Coherence score | 0.167 | 0.074 | 5.048 | 1 | 0.025* |
| Constant | -6.327 | 1.953 | 10.50 | 1 | 0.001* |

### 7.11.2 Person who made call IPQ-R

***Demographics***

***Illness representations***

The PWMC reported significantly higher consequences and coherence (both their own and that of the patient) where the patient received a diagnosis of ACS than where they did not, see Table 54, below. There were no significant differences relating to identity, timeline-acute/chronic or timeline-cyclical scores, and personal or treatment control.

The proportion of patients receiving a cardiac diagnosis for their symptoms was not significantly different where the person who made the call had reported the heart as the most important likely cause of their symptoms and where they had identified other likely causes on the IPQ-R ($\chi 2$ (df=1) = 2.99, $p$=0.083).

**Table 54: Differences in IPQ-R scores by diagnosis of ACS – person who made call**

| | ACS (n=24) | No ACS (n=92) | | | |
|---|---|---|---|---|---|
| | mean (SD) | | *t* | Difference (95% C.I) | *p* |
| PWMC report patient identity† | 5.00 (4.50) | 4.00 (3.00) | 711.0 | | 0.820 |
| PWMC report patient timeline- acu/chr | 14.09 (3.77) | 14.15 (3.86) | -.067 | (-1.96, 1.83) | 0.947 |
| PWMC report patient timeline - cyclical | 12.74 (2.95) | 12.09 (3.69) | 0.769 | (-1.03, 2.34) | 0.444 |
| PWMC report patient consequences | 20.40 (4.00) | 17.99 (4.84) | 2.117 | (0.15, 4.66) | 0.037* |
| PWMC report patient personal control | 13.95 (2.16) | 13.46 (3.40) | 0.630 | (-1.07, 2.06) | 0.531 |
| PWMC report patient treatment control† | 15.00 (4.00) | 14.00 (4.00) | 775.5 | | 0.642 |
| PWMC report patient coherence | 12.86 (3.51) | 10.62 (3.94) | 2.334 | (0.33, 4.13) | 0.022* |
| PWMC report patient emotion | 20.59 (3.81) | 21.41 (3.80) | -0.885 | (-2.66, 1.02) | 0.379 |
| | | | | | |
| PWMC's personal control | 12.09 (3.54) | 12.50 (3.35) | -0.497 | (-2.06, 1.23) | 0.620 |
| PWMC's coherence | 13.62 (3.69) | 11.00 (4.30) | 2.520 | (0.55, 4.67) | 0.014* |
| PWMC's emotion | 20.00 (3.82) | 21.20 (4.01) | -1.242 | (-3.12, 0.72) | 0.452 |

†Mann-Whitney *U*, Median and IQR

## *7.12 Discussion*

The main aim of the study was to explore if illness representations explained variance in decision time additional to that explained by demographic and clinical factors. The relationship between these factors and 4 different measures of decision time was explored. Different factors were identified as significant for various components of decision time. These are summarised in Table 55 and discussed further below.

Firstly, the results regarding the length of decision time are discussed and compared with previous findings in comparable patient groups. The relationship between demographic factors, clinical factors and illness representations and the various measures of decision time are then discussed in turn. Finally the overall strengths and limitations of the study are examined.

**Table 55: Summary of factors associated with delay > 2 hours or diagnosis of ACS**

| | Delay >2hours | | | | Diagnosis |
|---|---|---|---|---|---|
| | *Total* | *Appraisal* | *Illness* | *Call* | *ACS* |
| **Patient** | | | | | |
| Age | ~ | ~ | ~ | ~ | ↑ Age |
| Gender | ~ | Female | ~ | ~ | ~ |
| DEPCAT | ↑ Deprivation | ~ | ~ | ~ | ~ |
| Ethnic group | ~ | ~ | ~ | ~ | ~ |
| History CHD | ~ | ~ | ~ | ~ | Previous CHD |
| Diabetes | ~ | ~ | ~ | ~ | ~ |
| 1st call to NHS 24 | ~ | ~ | 1st call | 1st call | ↓ previous calls |
| Emergency outcome | ~ | Non-emergency | Non-emergency | ~ | ~ |
| Caller | ~ | ~ | ~ | ~ | ~ |
| Identity | ~ | ↑ identity *(p=.061)* | ~ | ~ | ~ |
| Timeline acute/chronic | ~ | ~ | ~ | ~ | ~ |
| Timeline cyclic | ~ | ~ | ~ | ~ | ~ |
| Cause | ~ | ~ | Non-cardiac cause | ~ | Non-cardiac (*p*=.063) |
| Consequences | ~ | ↓ consequences (*p=.076*) | ~ | ~ | ~ |
| Personal control | ~ | ~ | ~ | ~ | ~ |
| Treatment control | ~ | ~ | ~ | ~ | ~ |
| Coherence | ~ | ~ | ~ | ~ | ↑ Coherence |
| Emotion | ~ | ↓ Emotion | ~ | ~ | ~ |

↑ - higher

↓ - lower / less

~ - ns. result

(table continued on next page)

| | Delay >2hours | | | | Diagnosis |
|---|---|---|---|---|---|
| | *Total* | *Appraisal* | *Illness* | *Call* | *ACS* |
| **PWMC** | | | | | |
| Age | ~ | ~ | ~ | ~ | |
| Gender | ~ | ~ | ~ | ~ | |
| Ethnic group | ~ | ~ | ~ | ~ | |
| Identity | ~ | ~ | ~ | ~ | ~ |
| Timeline acute/chronic | ~ | ~ | ~ | ~ | ~ |
| Timeline cyclic | ↑ cyclic ($p$=.07) | ~ | ~ | ~ | ~ |
| Cause | ~ | ~ | ~ | ~ | ~ |
| Consequences | ~ | ~ | ~ | ~ | ↑ Consequences |
| personal control | ~ | ~ | ~ | ~ | ~ |
| Treatment control | ~ | ~ | ↑ treatment control | ~ | ~ |
| Coherence | ~ | ~ | ~ | ~ | ↑ Coherence |
| Emotion | ~ | ↓ Emotion | ~ | ~ | ~ |

↑ - higher

↓ - lower / less

~ - ns. result

### 7.12.1 Decision times

Total patient delay, the time between symptom onset and the first call to a health professional was on average 4 hours. This is similar to the pre-hospital time reported by Grossman et al (2003) amongst patients with possible symptoms of ACS. It is also comparable with previous reports of studies relating to MI (Canto et al. 2000; Dracup et al. 2003) and ACS (Goldberg et al. 2002b; Rasmussen et al. 2003).

Thus this study provides contemporary evidence that average decision times remain significantly out-with what would be considered ideal (<1 hour). Only 11% of participants in this study reported total delay times of less than 60 minutes. That this remains true amongst callers to an apparently low threshold service like NHS 24 is of even more concern. It suggests that the introduction of a 24-hour helpline has done little to reduce delay in this group. Previous research suggests that people feel less concerned about contacting their GP than they would calling an ambulance (Birkhead, 1992; Leslie et al. 2000) and that much delay is related to concern about calling an ambulance (Finnegan et al. 2000; Pattenden et al. 2002).

Appraisal delay, or the time taken by the patient to decide that symptoms are of concern, was on average 2 hours. Illness delay (the time taken from deciding that symptoms were concerning and actually contacting health services) was on average 75 minutes. These results suggest that appraisal time accounts for the majority of delay and should be a priority for intervention.

However, even after people decide that symptoms are a matter of concern the current study demonstrates that there is still significant delay before health services are contacted.

Despite widespread reference to the work of Safer et al (1979), surprisingly few other studies have reported appraisal and illness delay. As discussed earlier in Chapter 2, most have measured total *pre-hospital* time which includes transportation to hospital. The remainder have measured patient decision time but have not differentiated appraisal and illness delay.

Breakdown of the different components of patient decision time is an important area for future research in order to inform interventions aimed at reducing delay. The evidence suggests the key determinants of appraisal and illness delay might be different. Interventions could be developed that aim to reduce one or both aspects of delay. These might address illness representations and beliefs about use of health services as well as the nature of symptoms. Having an impact on both components of decision time could potentially be more effective in reducing delay.

### 7.12.2 Relationship between demographic factors and decision time

#### *Age*

Previous studies have identified a link between patient delay in ACS and age (GISSI, 1995; Goff et al. 1999; Goldberg et al. 2000; Goldberg et al. 2002b). However, several others (Burnett et al. 1995; Horne et al. 2000; Ottesen et al.

2004) have found no such link. In common with these, the current study did not identify a relationship between the age of the patient or PWMC and any of the measures of decision time. Nor did younger and older participants in the current study differ significantly in their illness representations.

***Gender***

Appraisal time was found to differ significantly in relation to the gender of the patient being significantly shorter when the patient was male. These findings are consistent with previous research which has identified longer pre-hospital time for women with MI (Gibler et al. 2002) and other ACS (Goldberg et al. 2002b). However, others have suggested that extended pre-hospital times are accounted for by physician and transport delays and that patient decision time does not differ between men and women (Ottesen et al. 2004). The results of this study do not support this and instead suggest that there are significant differences in how men and women come to be concerned about their symptoms. It has been suggested that the increased delay amongst women may be related to a gender bias regarding perceptions of susceptibility to CHD (van Tiel et al. 1998; McGee et al. 2000). Indeed, illness representation data from the current study support this hypothesis. Men reported significantly more serious consequences in relation to their symptoms than did women. In logistic regression analysis only illness representations emerged as significant predictors of delay category. Thus differences in illness representation appear to underlie the gender difference in decision time.

It may be important for future interventions aimed at reducing delay to have an

element of the campaign specifically targeting the illness representations of women.

***Ethnic group***

Despite achieving representation of people from minority ethnic groups in approximate proportion to the overall population of Scotland, the numbers included in individual analysis were small. It was therefore not possible to perform statistical analysis and draw conclusions about the influence of ethnic group from this data. However, none of the 3 participants of non-white ethnic group reported total delay times of less than 2 hours.

This pattern is consistent with previous studies which have reported longer pre-hospital times amongst patients of non-white ethnic group (Goldberg et al. 1999; Gibler et al. 2002). Others have concluded that delays to treatment for people of non-white ethnic group are due to barriers at the level of healthcare provision (Adamson et al. 2003). The results from the few cases presented here suggest that differences could be evident even before people enter the healthcare system. This is an important area for future research. Further studies, using methodologies which ensure adequate representation of people of non-white ethnic group would be helpful in improving understanding of this issue. This might help to reduce inequalities associated with particular ethnic groups.

***Social deprivation***

When total patient delay was examined, a higher proportion of patients from

deprived areas were found to delay> 2 hours than <2hours. Previous work has identified a similar pattern (i.e. high deprivation associated with longer delay) (Sheifer et al. 2000) although a study using the same measures of socio-economic status and decision time as the current study could not be identified for direct comparison.

The results of the current study show that there are important differences in illness representations between people from areas of high and low social deprivation. Patients from areas of high social deprivation reported significantly higher identity scores than patients from areas of low deprivation and also tended to report a more chronic timeline and more serious consequences in relation to their symptoms than those from areas of low deprivation.

Previous work has suggested that higher prevalence of CHD in more deprived areas may lead to normalisation of symptoms such as chest pain and a tendency not to present to health services (Richards et al. 2002). Leventhal et al (2007) have recently identified both symptom novelty and social comparison amongst 13 *heuristics* or 'rules of thumb' which they suggest people use to translate somatic change into the illness representations which then subsequently guide coping (Leventhal et al. 2007). Thus, the presence of a number of symptoms, expected to be chronic in nature may not be novel enough amongst people in areas of deprivation to prompt people to seek help, despite recognition that they could have serious consequences.

This is an important area for further research. It is important to improve our understanding of the underlying mechanisms that link decision time and social

deprivation. It may be beneficial for an intervention aimed at reducing delay to be targeted specifically toward areas of deprivation. Reducing delay could help improve outcomes for people living in these areas who experience the poorest outcomes from CHD (Scottish Executive, 2004). It is also important to further our understanding of the processes that underlie the development of illness representations as this is likely to be of key importance in the development of interventions aimed at influencing representations or coping.

### 7.12.3 Relationship between clinical factors and decision time

***Past medical history of CHD***

Consistent with the findings of Dracup & Moser (1997) and others (see page 30), patients with a known history of CHD did not differ significantly from patients without such a history on any of the measures of decision time. Data were not available regarding the precise nature of patients' previous CHD diagnosis and so comparisons with the differing results of studies pertaining to particular diagnostic groups were not possible.

Those with a previous history of CHD are at greatest risk of further acute events and should have been informed by healthcare professionals of the need for prompt action in the event of symptoms suggestive of ACS (Lewin, 1997). However, the data in this study confirm the important finding that people with a history of CHD do not seek medical help for symptoms more quickly than others and suggests more effective interventions to reduce delay are required. There are a number of possible explanations.

Despite having a history of CHD the symptoms patients experience may nevertheless be ambiguous and difficult to attribute to the heart (Burnett et al. 1995; O'Carroll et al. 2001; Carney et al. 2002). Indeed, only 36% of the patients with a history of CHD identified the heart as the most important likely cause of the symptoms they were contacting NHS 24 about (symptoms which were subsequently classified as possible symptoms of ACS by the investigator). Patients suspicions tended to be confirmed as a larger proportion of patients who suspected a cardiac cause received a diagnosis of ACS than those who did not although this did not reach statistical significance ($p$=0.063).

Patients with a previous history of CHD may have medications such as glyceryl-trinitrate spray at their disposal. Attempts to self-manage symptoms using such medications may contribute to prolonged decision time (Schoenberg et al. 2004). No significant differences in either treatment control or personal control were identified between those with and without a history of CHD (see Table 44, page 237) in the current study but PWMC with longer illness delay tended to report high treatment control suggesting that attempts to self-manage symptoms may contribute to delay.

In addition, patients with a history of angina may experience heart-related symptoms fairly frequently and it may be difficult to distinguish a new acute event or worsening, unstable symptoms against such a background of chronic symptoms. Indeed, within the current study, patients with a history of CHD did tend to report symptoms of a more cyclical nature than those without such a history ($p$=.097).

A limitation of the current study was that data regarding the history of CHD was obtained from NHS 24 files which obtained the data from the patient. Thus there is a possibility that the data was inaccurate or out-of-date. It is therefore possible that patients who did in fact have CHD were included in the group who did not have a history and vice-versa. However, given the nature of the symptoms the selected sample presented to NHS 24 it is considered highly unlikely that the nurse would not have enquired specifically about a CHD history at the time of the call and thus likely that the data were reliable and current.

This study provides important evidence that the illness representations of those with a previous history of CHD differed significantly from those without (see Table 44, page 237). Participants with a history of CHD reported significantly more serious consequences ($p$=.008), greater coherence ($p$<0.001) whilst tending to report symptoms of a more cyclical nature ($p$=.097). Nevertheless, delay times were not significantly different amongst this group than amongst those with no history of CHD. Thus the relationship between illness representations and the decision to seek medical help requires further exploration. In particular more attention to coping procedures may be warranted.

***Diabetes***

Contrary to much of the published evidence (see page 29), the current study did not identify significant differences in decision time between people with diabetes and those without. It is considered that this is most probably due to

differences in the population being studied. Within the current study, patients seeking help with symptoms which were *possibly* those of ACS were identified. This ensured that the sample was not restricted only to those with chest pain but included those reporting other presentations (e.g. breathlessness). Explanations that have been proposed to explain extended decision times amongst people with diabetes are that they are more likely to experience atypical symptoms (i.e. no chest pain) (Canto et al. 2000) or that due to neuropathy their perception of chest pain, if it occurs, differs from those without diabetes (Ambepityia et al. 1990; Umachandran et al. 1991). Thus, it would follow that when other presentations are considered there are no significant differences between people with diabetes and those without. Within, the current sample the proportion of participants presenting with and without pain were not significantly different between those with diabetes and those without ($\chi^2$ (*df*=1) = 0.815, *p* = 0.685).

People with diabetes are at increased risk of CHD and in regular contact with health services. It might therefore be expected that they would have increased awareness of the need to seek help promptly in the event of possible symptoms of ACS. These results would suggest the behaviour of people with diabetes is no different from the general population and thus would suggest that this group might also benefit from targeted intervention.

***Previous use of NHS 24***

An interesting result was found in relation to people's previous use of NHS 24. Those who were calling NHS 24 for the first time had significantly longer illness

delay (on average >30 minutes greater) than those who had called before. This meant that after deciding that symptoms were of concern, people who had not contacted NHS 24 previously took on average 30 minutes longer to make the call. This significant additional delay could have important implications in the context of symptoms of ACS and other serious conditions. The increased delay may be due to unfamiliarity with the correct telephone number or the appropriate procedure for accessing medical care out of hours. Fear of using services inappropriately or being unfamiliar with correct procedure have previously been cited as reasons for delay (Pattenden et al. 2002). People who have not called NHS 24 before might be concerned about appropriate use of the service and thus hesitate before calling. This may have important implications for how people are informed about how to access the service. Current campaigns emphasise the importance of contacting the service only with symptoms which cannot wait until morning, explaining that this allows the busy service to respond better to people with very serious symptoms (see Appendix 46). This may have the unintended consequence of making even those with serious symptoms hesitate about calling.

These findings suggest it would be beneficial for patients at high risk of CHD (and indeed the public in general) to be informed about how to contact their doctor at times when the surgery is closed. It may also be useful for people, particularly those at increased risk of ACS, to make initial contact with NHS 24 at a time they are not experiencing serious symptoms in order to familiarise themselves with the process and thus reduce delay at a time when their symptoms are urgent. There is evidence that people tend to contact their GP

more readily than they would call for an ambulance (Birkhead, 1992; Leslie et al. 2000) and yet the results of the current study suggest there are still significant delays. It is also possible that adverse publicity about the quality of care delivered by NHS 24 (see Appendix 2) may also have contributed to delay amongst people contacting the service for the first time.

It would be interesting to compare illness delay amongst those contacting the various emergency services available to explore how patients' thresholds for contact differ and to establish more precisely the effect of previous use of emergency services on illness delay. Such an investigation might also usefully inform interventions aimed at reducing delay. If people's thresholds for contacting the ambulance service are higher than for other services and thus contributing to delay, a campaign which encouraged people to seek help via a lower-threshold service (e.g. NHS 24) in the first instance, could result in shorter overall delays (despite the additional time required to assess and transfer the patient).

***Outcome of call to NHS 24***

Patients who received an ambulance in response to their call to NHS 24 reported significantly shorter appraisal times than did those who did not. Similarly, a significantly greater proportion of those with illness delay of <2 hours received an emergency response as a result of their call than those who delayed > 2 hours. A possible explanation is that people experiencing very serious symptoms of the nature that necessitates an emergency response become concerned about their symptoms quickly and then seek help quickly.

Indeed, patients with appraisal times < 2 hours tended to report more serious consequences than those with longer appraisal times although this was not statistically significant. However, if this were universally the case then there would not be a problem with delay in the context of ACS. Another possible explanation is that NHS 24 nurses responded to patients' level of concern, rather than the seriousness of their symptoms and were more likely to provide an emergency response to patients who became concerned very soon after the onset of their symptoms or who sought help quickly. Those who received an emergency response did have higher mean emotion scores than patients who did not although the difference between the two was not statistically significant. This is worthy of further exploration as it is not clear if responding to the emotional response of patients/callers would lead to more or less appropriate clinical decisions. If nurses tend to provide less urgent responses to patients who have already delayed it is possible that they may compound further pre-hospital delay by adding to utilisation delay. In this study, no relationship was found between the emotion scores of patients or callers and whether or not a diagnosis of ACS was made.

***Involvement of a caller***

No difference in any of the measures of decision time was found between patients who made the call themselves and those where someone else made the call on behalf of the patient. Nor was the proportion of calls involving a third party different when delayers and non-delayers were compared. These results would suggest that a third party has little influence on decision time.

This appears inconsistent with the conclusions of other authors who have reported that for many patients (44%) the decision to seek medical help was made by someone else (Horne et al. 2000) and that the presence of a third party is associated with reduced delay (GISSI, 1995; Dracup and Moser, 1997). However, it is important to be clear that whether or not a caller was involved in the original call to NHS 24 is not a comprehensive measure of the influence of others. It is possible that even where the patient made the call themselves that this was actually prompted by a third party. Similarly, the caller making the call on behalf of the patient may have been prompted by an additional individual or by the patient themselves.

Furthermore, it has been suggested in previous studies that spouses or relatives may be less influential in reducing delay than friends or strangers (GISSI, 1995). In the current study only 9 of the 58 callers who provided details of their relationship with the patient were *not* spouses or relatives. This may explain why the presence or absence of a caller was not associated with differences in decision time. Other authors have found no relationship between decision time and the presence of others (Dracup et al. 1997; Mumford et al. 1999).

However, it is considered likely that it is more than the mere presence of a third party which has an influence on delay. Rather, the CS-SRM would hypothesise that the third party also has representations of the patients illness (Leventhal et al. 1980; Leventhal et al. 1984; Figueiras and Weinman, 2003) and that these representations guide their subsequent actions in a similar manner as is

proposed for patients. Within the current study callers' reports of patients' illness representations were highly correlated with patients' own on all IPQ-R subscales with the exception of treatment control .Furthermore, callers' reports of their own personal control, coherence and emotion relating to the patient's illness were highly correlated with the patients' own.

However, some important differences were also identified. Callers reported significantly higher timeline-acute/chronic scores and significantly lower treatment control than patients. They also tended to report higher consequences. Callers' reports of *their own* level of personal control were significantly lower than patients' own and callers' ratings of *their own* level of coherence were significantly higher than patients'.

Previous work had suggested that the degree to which patients and callers differ in their illness representations can be an important factor in adjustment to illness (Heijmans et al. 1999; Figueiras and Weinman, 2003). Thus it was possible that dissimilarities in illness representations might be related to decision time, in particular appraisal time (Leventhal et al. 1984; Figueiras and Weinman, 2003). Results confirmed that appraisal time did tend to be shorter where callers reported higher patient emotion than did the patient and longer where callers reported a higher level of coherence than patients. This suggests that time may be spent negotiating a shared understanding of the situation between patient and caller. Furthermore, in relation to the delay reported during the call to NHS 24, significantly longer decision times were reported during the call where callers reported more personal control than patients. This

suggests that callers with higher personal control than the patient may spend time attempting to control the symptoms, rather than seeking medical help.

These results have important implications for how relatives of patients with CHD and the public in general are informed about what to do in the event of witnessing a person experiencing possible symptoms of ACS. It may be important to emphasise that where a third party has a clear understanding of the situation that they should take action, even in a situation where the patient is unsure. It should also be emphasised that any attempts people make to try to control patients' symptoms should not result in additional delay. For example, it might be helpful to explain that attempts to self-care should be attempted for a maximum of 15 minutes, after which medical help should be sought (Mumford et al. 1999).

Total patient delay and illness delay were not related to dissimilarity in any of the subscales. Thus, once symptoms have been recognised as concerning, dissimilarity in illness representations between patients and others is not related to subsequent delay in obtaining medical help.

This is consistent with the findings related to the direct relationship between patient and caller illness representations and decision times. Significant relationships between illness representations and delay were strongest in relation to appraisal delay. This is important as appraisal delay was found to constitute the largest component of patient decision time. Interventions targeting illness representations might be successful in reducing patient decision time.

These results are also consistent with those of Heijmans et al (1999) who found that the degree to which there was dissimilarity between patients and spouse' illness representations impacted on coping and adaptation to chronic illness (Heijmans et al. 1999). Furthermore, another study demonstrated that the degree of congruence between the illness representations of couples was associated with recovery following MI (Figueiras and Weinman, 2003).

Thus this study suggests that the illness representations of significant others and, in particular, their relationship to those of patients are an important area for future research. Relatives, family members and others may affect a wide variety of factors relating to patient illness e.g. adherence to medication; health behaviours; emotional well-being and quality of life as well as having an important role in seeking medical care (Leventhal et al. 1985).

### 7.12.4 Relationship between illness representations and decision time

The relationship between IPQ-R subscales and decision time varied between the different measures. Illness representations appeared most significant in relation to appraisal time whilst fewer constructs were associated with illness and total delay. Results relating to the constructs of the CS-SRM measured by the IPQ-R are discussed below.

#### *Identity*

Identity scores in those with appraisal times < 2 hours were higher on average than those with appraisal delay > 2 hours and emerged as significant in logistic regression successfully predicting delay category (<2 or >2 hours). It might be

anticipated that people experiencing a large number of symptoms would become concerned more quickly than people experiencing fewer. This might be an important consideration in the development of interventions aimed at reducing delay – the likelihood of ACS is not necessarily associated with the number of symptoms. In the current study those who ultimately received a diagnosis of ACS reported an average of 4 symptoms as being related to the reason for their call and there were no significant differences in identity scores between those who received a diagnosis of ACS and those who did not. Interventions should emphasise that it is important to seek help with any symptoms of ACS and not necessary to wait for a large number of symptoms.

***Timeline***

No relationship was found between timeline-acute/chronic scores and any of the measures of decision time. Nor were there significant differences in timeline-acute/chronic scores between delayers and non-delayers across these measures. However, those with a total delay of more than 2 hours reported symptoms of a significantly more cyclical nature than those who delayed < 2 hours. This is consistent with the findings of previous studies which suggest that symptoms which come and go may be more difficult for people to interpret and thus contribute to longer decision time (Scherk, 1997; Dracup and Moser, 1997). However, the same result was not found in relation to appraisal time or illness delay. Furthermore, the picture may have been complicated by some participants reporting symptoms of a cyclical nature relating to *existing* chronic conditions other than CHD (see page 143).

However, increasing awareness that the symptoms of ACS can come and go might be an important goal of future interventions aimed at reducing delay.

***Cause***

Patients who identified the most important likely cause of their symptoms as relating to the heart delayed seeking medical help on average 20 minutes less than those who identified other causes as most important. This suggests that many people are aware of the need to seek prompt medical attention where a problem with the heart is suspected. This is consistent with the results of previous authors who have highlighted that recognition of symptoms as relating to the heart is a key determinant of pre-hospital delay (Burnett et al. 1995; Dracup and Moser, 1997; O'Carroll et al. 2001; Carney et al. 2002). However, as has been discussed previously, many people do not readily recognise their symptoms as relating to the heart (see page 36). Indeed, in this sample, only 9 out of 24 who received a diagnosis of ACS (37%) reported that they believed the most likely cause of their symptoms to be their heart at the time of the symptoms. Amongst those who received a diagnosis of ACS, those who *did not* consider a cardiac cause as most likely were significantly more likely to identify pins and needles ($\chi 2$ (df=1) =5.00, $p$=0.044) as related to their illness than those who *did* identify the heart as the most likely cause of their symptoms. Otherwise there were no significant differences in symptoms or identity scores ($U$=34, $p$=.210) between patients who did and did not identify the heart as the most likely cause of their symptoms. These results suggest interventions aimed at reducing delay need to communicate the range of

possible symptoms of ACS, particularly pins and needles in order to help people more readily identify a cardiac cause.

***Consequences***

Patients' beliefs about the consequences of their symptoms were not related to any of the measures of decision time. However, patients with shorter appraisal times did tend to have higher consequence scores. Although this was not statistically significant, the trend is in the direction that would be predicted by the CS-SRM and is consistent with the findings of Walsh et al (2004) who, in a study utilising the original IPQ amongst patients with MI found consequences to be significantly related to delay.

Amongst patients who received a diagnosis of ACS, the PWMC reported significantly higher consequences than where the patient did not receive a diagnosis of ACS. This could suggest that the PWMC was frequently able to recognise the serious nature of the symptoms. However, it is important to note that the assessments of consequences were obtained retrospectively. Participants' responses relating to their perception of consequences may have been influenced by the diagnosis of ACS having been made in the intervening period.

***Personal control***

No relationship was found between personal control scores for either the patient or the person who made the call and any of the measures of decision time. Nor were there significant differences in personal control scores between

delayers and non-delayers across the same measures. Thus actual levels of personal control may not be related to decision time. However, due to the poor internal reliability of the personal control measure in the current study it is difficult to draw firm conclusions. Higher personal control amongst callers (where they were involved) than patients contributed to longer delays being reported during the NHS 24 call and suggests that it might be useful to include guidance about how long it is appropriate to try and control symptoms of this nature within interventions aimed at bystanders or relatives of people with CHD.

***Treatment control***

Amongst PWMC, those with appraisal times of < 2 hours tended to report increased patient treatment control than those with longer appraisal times. This suggests that attempts to self-manage symptoms may contribute to delay which is consistent with the findings of previous research (Rasmussen et al. 2003; Schoenberg et al. 2004). It may be important within an intervention aimed at reducing delay to specify a time limit highlight that attempts to self-manage should be time limited.

***Coherence***

No relationship was found between coherence scores for either the patient or the person who made the call and any of the measures of decision time. Nor were there significant differences in coherence scores between delayers and non-delayers across the same measures. It may be that, for some, having a

clear understanding of their symptoms (e.g. that they are having a heart attack) leads them to seek help quickly whereas others may be more inclined to seek help quickly when their symptoms do not make sense to them.

However, coherence was found to be a significant predictor of whether or not participants received a diagnosis of ACS. Patients who received an ACS diagnosis reported significantly higher coherence scores than those who did not. In addition, the person who made the call reported higher coherence amongst patients *and themselves* where the patient received a diagnosis of ACS than where they did not. This suggests that where people have a clear understanding of what is happening, they are more likely to receive a diagnosis of ACS. However it is also possible that people who receive a diagnosis of ACS may be biased in how they subsequently report their coherence, i.e. that they be more likely to report retrospectively that their symptoms made sense because they have since received an explanation that makes sense. However, if this were the case for a diagnosis of ACS, it would also be expected to be true for patients who received other diagnoses. When those who received a diagnosis were compared with those who did not receive any diagnosis relating to their symptoms, there were no significant differences in coherence scores ($t$=-0.186, $p$=.853). This suggests the retrospective reports of coherence are not unduly biased by subsequent diagnoses. The finding that coherence is linked with diagnosis of ACS may be a useful additional clue for clinicians in the difficult position of assessing these types of symptoms.

### *Emotion*

A significant negative correlation was found between appraisal time and patients' level of emotion. Thus patients who had a strong emotional reaction to their symptoms had shorter appraisal time. Furthermore, appraisal time also tended to be shorter where the person who made the call reported strong emotions related to the symptoms. This is consistent with the findings of previous evaluation of the CS-SRM in relation to decision times amongst people with MI (Walsh J C et al. 2004) . These authors found that responses to emotional response items (developed for the study because the original IPQ did not include measures of emotional representations) were significantly associated with patient delay. The only demographic variable they identified as associated with delay was gender, with women having significantly longer delay times than men. Only the consequences subscale of the original IPQ (Weinman et al. 1996) was found to be related to delay.

These are interesting findings and highlight the possible importance of emotion in how people evaluate their symptoms. However it is difficult to envisage how this might usefully contribute to an intervention aimed at reducing delay. It may be beneficial within an intervention to prepare people to cope with the likely emotional response to symptoms. However, this would clearly require careful evaluation as the emotional representation appears to be associated with the desired situation of shorter appraisal time. Interventions which address the appropriate cognitive representations (e.g. beliefs about consequences, discussed above) may offer the most promise in generating the emotional representations associated with prompt help-seeking.

Interestingly the same pattern of results relating to age, emotion and to a lesser degree, consequences were identified in the current study in relation to appraisal time. It is possible that appraisal time constituted the majority of total pre-hospital time in the study by Walsh et al (2004) (as in this study) and thus that variables having most effect on that phase of delay emerged as significant in relation to total delay. However, that was not observed in the current study.

Furthermore, the model that Walsh et al reported, which explained variance additional to that explained by demographic and clinical factors included measures of coping. These were not measured in the current study which may account for why the model was less successful in accounting for decision time.

### 7.12.5 NHS 24 as environment for research

NHS 24 provided the setting for the research described. This clearly provided a number of novel opportunities. The service receives on average 30,000 calls per week from people from all across Scotland. Thus, it was possible to sample from a geographically and demographically diverse population. All calls are recorded and stored within the organisation, which provided the opportunity to study what was said at the time of seeking help without impact on the clinical situation. This would have been especially difficult to achieve amongst patients with serious symptoms such as those of ACS, in other environments. Furthermore, it was possible to identify people early in their illness episode and thus to explore illness representations before diagnostic labels were applied and then subsequent to diagnosis.

These were compelling reasons to choose NHS 24 as a setting for this research but inevitably there also were a number of difficulties associated with the setting.

***Participation***

Most importantly, significant problems in achieving participation were experienced. Response rates via the various methods attempted were low (27% at best), raising concerns about possible bias in the sample. Checks for non-responder bias were carried out across a number of key variables and demonstrated few differences between participants and non-participants but it cannot be exclude that participants differed from non-participants in important ways which could not be assessed. The importance of this issue may vary depending upon the research design and clinical population being approached. The low response rate also has practical implications in that larger numbers of potential participants require to be contacted to achieve the desired sample. This takes longer, increases costs and thus may make larger projects unfeasible.

The nature of the clinical population who were the subject of the current study is likely to have been a factor in the low participation rates. It is possible that people who have experienced possible symptoms of ACS may be very unwell or still in hospital. Indeed, these were common reasons given for non-participation (see Figure 14, page 186). Furthermore, they are a population who tend to be older; this may have reduced participation due to physical and cognitive problems. In addition, the requirement to achieve participation with 14

days is likely to have also limited the potential to achieve high participations rates. It was not considered ethical to contact people any earlier than 5 days after the call and so the window to achieve participations was very narrow. Alternative designs which could rely upon recruitment later after the original call might achieve higher participation.

The lack of personal relationship between patients and either the clinicians at NHS 24 or the researcher may also have been a contributing factor. People may feel less inclined to contribute to research in the relatively anonymous, virtual environment of NHS 24 than they would do in a hospital, clinic or primary care environment. Research designs where recruitment of participants could occur in person, within clinical settings but where access to the original call to NHS 24 was included might overcome this difficulty.

Such designs might also overcome the difficulties encountered in relation to postal invitations to take part. Inaccurate, ambiguous or missing contact details were a problem. As people often call NHS 24 from places other than their home address, the location of the patient is recorded within the record. This ensures that if necessary an ambulance is despatched to the location of the patient, rather than their home. However, inconsistencies in how the various addresses were documented meant it was not always possible to readily identify the current home address. It is recognised that the main purpose of the clinical record is to ensure appropriate clinical care and that research considerations are a secondary consideration. However, if further research is to be conducted using these details, some attention to these issues might be

required. Unexpected issues in relation to the postal service were also encountered. A surprising number of participants reported not receiving their letter of invitation even where details were accurate.

***Ethical issues***

There were also a number of ethical issues associated with the setting of NHS 24. Audio-recordings form part of the clinical record which pertains to the patient at NHS 24 and thus clearly permission from patients was required for their recordings to be used in research. However, callers and NHS 24 staff are also involved in those consultations. Furthermore, calls relating to patients who are no longer alive may also be of particular value in research. In these circumstances the appropriate means of obtaining consent were unclear. The decision was initially made within the current study to obtain the explicit consent of all parties involved in each call. However, this proved impractical and meant that only a tiny proportion of relevant calls would be accessed. Instead an alternative process by which staff were informed about the project and asked to participate in general was undertaken and then only patients involved in calls which had been dealt with by those staff were invited to take part. This was more successful but the response rate from staff was still less than ideal. Furthermore, if such a process were to be repeated for each project it is likely that participation would reduce further. Instead it is suggested that process should be developed where the express position of staff members regarding the use of their consultations in research is recorded. This would negate the need to approach staff regarding each project and increase the

representativeness of the calls identified. Alternatively, the possibility of an opt-out strategy might also be worthy of consideration. This would assume that unless otherwise stated, staff are willing for their consultations to be used in research. However, if they would rather not participate in a particular (or all) projects, easy mechanisms to opt-out would be provided. This might help to ensure increased participation and promote the view of research as 'business as usual' rather than an isolated and separate process from clinical practice.

The same might be suggested in regard to users of the service. All callers to NHS 24 are currently played a message which informs them that call is being recorded. An opportunity to listen to additional information about how data is used within the organisation is provided. As a result of efforts made at the outset of the current project, this now includes reference to research. People are offered the opportunity to decline for their information to be shared with others or used for particular purposes but this is only recorded in relation to particular call. Thus, a readily-available indication of patients' views regarding the use of their data is not available. It is considered that the existing process should be extended, so that the wishes of patients with regard to research (and other uses of their data) are permanently recorded. These could be reviewed each time they call (if clinically appropriate) and would thus provide a contemporaneous record of patient views. This might allow some research to be undertaken without the need for further consent. This would also ensure that people who feel strongly that they do not wish to be involved in research are not inadvertently contacted.

However, this relates to another issue encountered in relation to consent. Within the study relating to decision time, consent (for the original call to be accessed and for information to be obtained from their GP) was provided verbally by patients and audio-recorded. This ensured there was a permanent record of consent for each participant. The process appeared acceptable to patients and where the investigator had any doubt about the validity of the consent, consent was assumed to be absent.

However, when GP's were contacted and the required information requested, many stated they required a copy of written consent. This problem was overcome in the current study by a clinical colleague reviewing the consent of all participants and providing a letter confirming the consent was valid and some GP's contacted patients directly to obtain written consent. Clearly, this was not ideal. It is therefore considered that where clinical information relating to patients is required from other services that written consent be obtained. This would avoid any ambiguity and ensure the data relevant to the project can be collected.

NHS 24 provided a fruitful environment for research. Difficulties relating to achieving the participation of patients were offset by the wealth of data obtained regarding initial presentations. Access to the illness representations of people in the midst of a health threat would have been very difficult to obtain in other settings.

### 7.12.6 Strengths and limitations

The study had a number of important strengths. Participants were randomly selected from the entire overall population of people seeking help from primary care services out-of-hours in Scotland and are thus considered representative. Comparisons between retrospective and real-time reports of decision time and some components of illness representation were performed, strengthening the validity of results. Furthermore, participants were identified early in an illness episode and before diagnostic labels were applied. This ensured that the sample was not solely restricted to patients with confirmed ACS but reflected the larger population experiencing possible symptoms of ACS, the population who are the target of interventions aimed at reducing delay. A strong theoretical framework has enhanced the rigour of the research and ensured results can readily inform intervention.

The main limitation of the study is that despite substantial efforts to achieve high participation, actual participation rates were low (28%). A considerable proportion of non-participation owed to not being able to make contact with eligible individuals due to problems with inaccurate contact details or technical problems e.g. with their telephone. However, a substantial proportion of identified patients were still in hospital or too unwell to take part at the time of contact (6-14 days after the call to NHS 24). Whilst there was little could be done to avoid this problem, given the nature of the symptoms people had experienced, it almost certainly resulted in less participation by the most unwell and is thus likely to have introduced a degree of bias to the sample. This is also likely to be the case for other studies that endeavour to recruit patients

during an acute illness episode and thus probably applies to most studies of pre-hospital delay.

However, the sample is considered representative in other important ways. A variety of information about potential participants was available which allowed an assessment of non-responder bias to be made. Participants did not differ from non-participants with regard to gender, DEPCAT classification, number of previous calls to NHS 24, previous history of CHD or whether or not they made the call to NHS 24 themselves. The only significant difference identified was that participants were slightly younger than non-participants. Nevertheless, participation from a wide distribution of ages was achieved 18-91 years (see page 188). Another strong feature of the sample is that it included people from all regions of Scotland and so is considered more representative of the overall population than a regional sample. Furthermore people from minority ethnic groups were represented in approximately similar proportions (2%) to Census reports of the overall population of Scotland (Office of the Chief Statistician. Scottish Executive, 2004). However, it is recognised that the proportion of people from minority ethnic groups in Scotland is lower than for other parts of the UK and beyond. Therefore, there may be limits to the generalisability of findings to populations outside of Scotland.

Furthermore, although the sample was randomly selected from the *entire total* of people trying to reach their GP in out-of-hours period, people with possible symptoms of ACS who chose to request an ambulance, attend A&E directly or who did not present their symptoms to medical services at all were not

included in this study. The characteristics of these groups may differ in important ways and are important groups to study in the future utilising alternative methodologies.

A second possible limitation of the study is that in contrast to what was planned, most participants elected to self-complete the IPQ-R rather than complete it during telephone interview. The main disadvantage of this was that probing around decision time reports was not possible. However, no significant differences in decision time were identified between the 2 methods. Nor were there are a greater proportion of negative decision times in the self-report group. Whilst not ideal in terms of methodology, the option of two methods of administration was necessary to make participation possible for as many who of those who wished to take part. Some participants found filling in forms off-putting or had difficulty with reading/writing whilst others preferred to complete the questionnaire in their own time. Checks for systematic bias relating to the mode of administration were performed. Those who participated in telephone interview were significantly less likely to have had a caller involved in the original call. It may have been that as the participation of the caller would also have been requested in this context that the additional burden of achieving two 20 minute interviews was a deterring factor. Alternatively, it is possible that patients who did not make the call themselves were in fact more ill and unable to complete an interview. Those who participated in a telephone interview also had significantly higher scores for personal control than those who self-completed. Although unintended it cannot be excluded that explanations provided by the investigator in relation to these items during telephone

interview may have led to different responses. In particular, the issue of whether or not simply making the call to NHS 24 constituted ‘doing something to control the symptoms’ was discussed with more than a few participants. Whether or not such a discussion took place may also have contributed to the poorer internal reliability of personal control items when administered by telephone interview.

It is also possible that there is a cognitive style or trait effect where people who tend to report high personal control in relation to a health threat may also wish to exert control during a telephone interview in preference to passive completion of a questionnaire. No other significant differences between the two groups in relation to demographic, clinical or IPQ-R factors were identified. The differences relating to the presence of a caller and personal control were considered unlikely to significantly affect the overall pattern of results and so it was considered appropriate to combine the analysis of data obtained by both methods.

Thirdly, in common with other studies of this nature, retrospective reports of decision time and illness representation were used. The possibility that people’s experiences subsequent to their call influenced their reporting of decision times and beliefs about their symptoms cannot be excluded. However, realistic alternatives to retrospective reports in the investigation of this phenomenon are not available. Importantly and unusually within this study there was an opportunity to compare retrospective reports of some variables with data obtained from the original call to NHS 24. All measures of decision

times were found to be significantly correlated with what was reported during the call. Furthermore, results from the first stage of the investigation suggested that IPQ-R measures of illness representation collected within 2 weeks of the original call were found to be consistent with the representations presented by participants during their initial presentations.

The modified IPQ-R was found to be a reliable measure of illness perceptions within this group. Internal reliability of subscales was good apart from the telephone-administered personal control items which were discussed above. The strong correlations between patient and caller scores for each subscale except treatment control provide support for the existence of the phenomenon of illness representation shared between the two parties. Furthermore, identity scores were significantly correlated with the total number of symptoms reported during the call. This provided some support for the validity of the construct as measured by the IPQ-R. However, there were a number of issues identified in relation to the IPQ-R.

Firstly, it was apparent that the IPQ-R measure of identity did not capture all the symptoms considered important by patients. Two participants scored 0 for identity, presumably because the reason for their call was not included on the list. Furthermore, when identity scores were compared with the total number of symptoms identified during the call to NHS 24 they were significantly lower ($p<.001$). That participants cannot identify symptoms that they see as related to their illness is considered an important limitation of a measure designed to elicit participants' representations of illness. From a methodological point of

view, this issue may have limited the potential of studies using the IPQ-R to identify important relationships between decision time and identity. In the study relating to the content of presentations, references to identity were made by all participants within their relatively brief responses to an open question about the reason for their call. Thus, the inclusion of a similarly open question within the IPQ-R might be an alternative means of eliciting information relating to identity that is participant-derived rather than suggested by the researcher.

Furthermore, it is not considered that a measure which relies solely upon the number of symptoms adequately represents the relative importance of particular symptoms for participants. Someone may have only one symptom (e.g. chest pain) but believe strongly that it relates to a heart attack.

In hindsight, within the context of ACS, the symptoms listed on the IPQ-R (Appendix 39) were probably too imprecise to meaningfully distinguish particular patterns between participants. For example many patients may have reported ‘pain’ but the location of that pain (e.g. foot or chest) and the nature of the pain (e.g. sharp or heavy) were not differentiated. More detailed descriptions would have been useful. However, it is recognised that such a history would be burdensome to complete and might be difficult include in a self-complete questionnaire. In the context of the current study restricting the mode of completion to only telephone-interview would have resulted in even lower rates of participation. Future studies of this nature are likely to need to balance the depth of detail required regarding symptoms against a possibly lower participation rate.

The burden of the questionnaire was an issue and participants commented that they found it difficult, repetitive or not very meaningful (see Appendix 27). This may have contributed to the low response rate achieved, particularly as the questionnaire had to be presented by post in this context. The questionnaire took approximately 20 minutes to administer by telephone. It would be difficult to include additional measures (e.g. coping measures) without impacting on participation or encountering ethical difficulties relating to the burden placed upon participants (especially those who might be seriously ill). The Brief IPQ recently developed by Broadbent et al (2006) might be a more manageable measure for people completing the questionnaire in this type of situation or where administration of additional measures is required.

Finally, a relatively large number of statistical tests were performed during the analysis of this data, increasing the risk of Type I errors. If a more cautionary significance level of $p<0.02$ were applied fewer factors would emerge as significantly related to the various measures of decision time, these are summarised below.

In relation to total delay, higher emotion scores of the PWMC were associated with reduced delay. Receipt of an emergency response and high patient emotion were associated with reduced appraisal time and identity and emotion scores remained significant in logistic regression of appraisal delay category. Similarly emotion scores of the PWMC remained significantly associated with appraisal delay.The PWMC report of treatment control was significantly associated with illness delay.

### 7.12.7 Summary

Importantly the study has highlighted that delay is a significant problem amongst those with possible symptoms of ACS. Appraisal time constitutes the largest proportion of this time but illness delay is not insignificant. A number of demographic, clinical and IPQ-R factors were found to be associated with different components of patient decision time. This suggests that particular groups, such as those who live in deprived areas or those with a history of CHD or diabetes, might benefit from targeted intervention. Any intervention should address *both* appraisal and illness delay. The factors associated with each component of delay appear to be different. Particular relationships between specific illness representations and both total and appraisal delay were identified which may be useful to consider within a future intervention aimed at reducing patient decision time. This is discussed in detail in the following, concluding chapter.

# Chapter 8. Conclusions and implications

Within this final chapter, the main conclusions of the study are summarised. The implications related to theory and measurement, clinical practice and future research identified.

## *8.1 Theory*

### 8.1.1 Existence of components of illness representations

This study has provided strong additional evidence for the existence of the components of illness representations (Leventhal et al. 1980; Lau and Hartman, 1983; Bishop et al. 1987; Lau et al. 1989). To date, components have been identified from hypothetical patient scenarios or through special interview techniques. The current study has demonstrated that the components of illness representation are spontaneously volunteered during clinical consultations, in the real-time context of significant health threat.

In addition, the study suggests that although there is evidence that patients' models of illness are frequently neglected within clinical encounters (Helman, 1985; Cohen et al. 1994; Heijmans et al. 2001), this is unlikely to occur as a consequence of information not being provided by the patient. Thus, neglect of patients' representations of illness may be more likely due to a lack of awareness or attention on the part of clinician. Increased awareness of the importance of illness representations could have benefits in relation to many areas of clinical practice. These are discussed further under 'Clinical Practice' below.

In common with previous work (Lau et al. 1989), some components of illness representation were mentioned more frequently than others. Importantly, the components least commonly volunteered during initial presentations (i.e. cause, consequences, emotion and coherence) were those found to be most significantly related to decision time or outcome. Thus it is possible that the most influential components of illness representation are those that people are least likely to express. It is possible that where certain components of illness representations tend not to be discussed with others, beliefs related to these components become more deeply held and thus more likely to predict behaviour. These are hypotheses that could not be tested further within the current study but may be useful to explore in future.

### 8.1.2 Context

Many of the statements unaccounted for by the components of illness representation related to the context in which the participants' symptoms occurred. It is considered important to further elaborate the effect of context on illness representation.

### 8.1.3 Description versus prediction

Whilst the components of illness representation successfully explained the content of initial presentations, the results relating to the prediction of decision time were less convincing. Previous investigations have yielded, at best, modest results in predicting various outcome measures (Petrie et al. 1996; Orbell et al. 2006). It is important to consider why this might be the case.

It is possible that too much emphasis has been placed upon illness representations which constitute only one aspect of the model (see Figure 1). Tools such as the IPQ-R may be failing to measure other important aspects of the model such as coping procedures, appraisals and the heuristics that are hypothesised to influence representations. Including measurement of such components may add to the predictive ability of the IPQ-R. However it is recognised that to do so would add to the burden of the questionnaire, possibly limiting its acceptability. Furthermore, the relationships between the numerous constructs may be complex and difficult to disentangle.

Similarly, measurement using the IPQ-R may fail to consider higher level contextual factors such as personality and socio-cultural roles which may influence both representations and coping procedures (Martin and Leventhal, 2004; Leventhal et al. 2005)

Furthermore it may be that research has applied the model to inappropriate outcome measures. Whilst the behaviour of contacting a health professional is of particular interest to health professionals it may only one of a range of coping behaviours undertaken by patients. Thus the model may poorly predict a single pre-defined coping behaviour (such as decision time to call the doctor) but might perform better in relation to a patient-identified behaviour. Future studies might wish to address these issues.

### 8.1.4 Illness representations of significant others

The study also explored the illness representations of significant others who were involved in dealing with a patient's health threat and provided evidence of shared representations of illness.

Results suggest that the degree of concordance or dissimilarity between individuals' illness representations to be significantly related to appraisal time and thus an important issue which is worthy of further investigation. Knowledge of what happens when people with different representations of illness become mutually engaged in a health threat may help us understand how illness representations are shared culturally and of the processes by which they might be changed.

## *8.2 Measurement*

### 8.2.1 Coding

Good reliability was achieved in the coding of transcriptions confirming the components of illness representation can be reliably identified. The method might be usefully applied to other contexts and clinical problems.

Reliability of coding for coherence was less than optimal and thus further elaboration of coding rules is recommended. The level of reliability was achieved between 2 coders familiar with the CS-SRM and additional research is required to establish if similar reliability can be achieved by naïve participants.

### 8.2.2 IPQ-R

The IPQ-R was readily adapted for use with both the patients and callers within the current study. Items with *'my illness'* were replaced with *'my symptoms'.* For example, *'My symptoms will last a long time'* (see Appendix 12). However, for a number of the components of illness representation relating to callers it was less straightforward. It was not clear within personal control, coherence and emotion whether callers' perceptions of the patient's representations or their own representations were most relevant. In the absence of a precedent, the decision was made to assess both (see Appendix 13). Most significant differences were identified between the patients' and callers' own representations. Callers' reports of their own level of personal control were significantly lower than patients' own and their ratings of their own level of coherence were significantly higher than patients'. Appraisal time was shorter where callers reported higher coherence than the patient did. Longer decision times were reported during the call to NHS 24 where callers reported more personal control than patients. However, appraisal time was also shorter where callers perceived higher patient emotion than the patient reported, demonstrating that differences relating to the callers perception of the patient were also important.

These results suggest that examination of the illness representations of significant others *and* their perception of the illness representations of the participant have the potential to provide important insights into behaviour during health threats. It is important to include these in future studies examining the role of significant others. It is also plausible that significant

others might have representations relating to *consequences* for themselves. These were not measured within the current study but might be useful to include in future studies.

Pilot work informed the content of the versions of the IPQ-R used in the second stage of the investigation. The validity and reliability of the measures developed are discussed below.

***Reliability***

The subscales of the IPQ-R were found to have acceptable internal reliability ($\alpha > 0.7$) with the exception of the *personal control* items which had good internal reliability when the IPQ-R was self-completed but was lower when telephone administered. Most subscales of the C-IPQ were also found to be internally reliable with the exception of the emotion subscale. The reliability of the treatment control subscale alpha was improved with the removal of item CIP23 "*There was nothing which could help their condition".*

During pilot work, and subsequent telephone administration, negatively phrased statements were generally problematic for participants (see Appendix 27). This an important issue for future work using the IPQ-R. The psychometric rationale for inclusion of these items may be negated if the complexity of the questionnaire deters people from taking part. The recently developed Brief IPQ might offer a less demanding, alternative method of eliciting the illness representations and might be better suited to postal survey administration (Broadbent et al. 2006).

### *Validity*

The face validity of the adapted IPQ-R was established. However, in addition the research design allowed the relationship between participants' illness representations expressed at the time of seeking help to be compared with those subsequently reported on the IPQ-R and thus to evaluate convergent validity (Bowling, 2002). Conclusions regarding the validity of the IPQ-R measure of each construct are discussed below.

#### *Identity*

Most (65%) symptoms mentioned by participants during their initial presentations to NHS 24 were captured by the IPQ-R. However, the measure failed to capture some symptoms and for 2 participants this meant that the IPQ-R did not capture any of the symptoms these participants reported during their call. This may limit the ability of the IPQ-R to identify significant relationships between identity and other variables. However, there were also instances where participants did not identify specific symptoms during their initial presentations and yet were subsequently able to identify symptoms on the IPQ-R.

Together, these data suggest that the checklist format may be a useful means of helping some individuals to articulate their illness representations but may not reflect precisely the identity expressed previously. Furthermore, components of identity other than symptoms such as labels and visible signs were frequently expressed. These components are specified by the CS-SRM but not assessed by the IPQ-R. Thus additional information relating to identity

may not be captured by the IPQ-R. In particular, visible signs such as pallor, cyanosis and sweating may be important in the context of ACS, particularly amongst significant others (Pattenden et al. 2002).

***Timeline***

IPQ-R reports of timeline-acute/chronic were generally consistent with those expressed by participants during initial consultations although those reporting acute timelines were less likely to refer to time during their presentations. The data available generally supported the validity of the timeline measure but also demonstrated that some caution is required in interpreting the results of a retrospective IPQ-R measure of timeline – retrospective patient reports did not always accurately reflect the content of the original presentation.

***Cause, consequences, personal control and treatment control***

Of the small number of cases available, most participants were consistent between the two reports of cause, consequences, personal control and treatment control providing limited support for the validity of the IPQ-R measure of these constructs.

***Coherence***

The finding that none of the 20 participants with above-average coherence scores discussed their understanding of their symptoms at the time of presentation and that most statements made by participants with below-average coherence scores suggested a poor understanding of their symptoms suggest the IPQ-R measure of coherence is valid measure.

### *Emotion*

None of the 16 participants with below-average emotion scores made statements relating to emotion during their presentation of symptoms. However, 6 of the 17 with higher than average scores did. Participants with above-average emotion scores on the IPQ-R were significantly more likely to express emotion during their initial presentation. This suggests that the IPQ-R is sensitive to emotional representations and provides support for the validity of the IPQ-R measure of emotion.

### *Coping*

A previous study which utilised the IPQ found that the CS-SRM explained a significant amount of variance in pre-hospital delay amongst people with MI (Walsh J C et al. 2004). The current study did not find such convincing results in relation to the continuous measure of decision time although illness representations did emerge as significant in predicting delay category. This may be due to differences in method, context and population. However, another important difference is that Walsh et al (2004) included data related to coping in multivariate analysis. Coping was assessed using the Coping Response Inventory which samples 5 categories of coping styles i.e. problem-focused; emotion-focused; active-cognitive; active-behavioural and avoidant (Billings and Moos, 1981). Coping style was found to explain an additional 16% of variance in pre-hospital time additional to that explained by demographic and IPQ factors. An assessment of coping procedures may have been a useful addition to the IPQ-R in the context of the current study although Leventhal

argues that checklist type measures of coping are too simplistic and inadequate to assess the wide range of procedures in which individuals may engage (Martin and Leventhal, 2004).

### 8.2.3 Decision times

Questions regarding symptom onset were added to the IPQ-R. The questions were based on the stages of patient delay described by Safer et al (1979). Timings were obtained to allow the calculation both of appraisal and illness delay. Previous studies of pre-hospital delay have relied on similar methods. Importantly, within the current study, where the participant gave consent for their original call to be reviewed, there was an opportunity for the timings provided within that call to be compared with those on the questionnaire. Delay times reported during the call were significantly correlated with questionnaire reports of total, appraisal and illness delay suggesting the measures were a satisfactory measure of decision time. Reported illness delay was significantly less than the decision time reported during the call which in turn was significantly less than total patient delay.

This might be expected as people would tend to talk during the call about how long they had been concerned about their symptoms but some may also have referred to when they started. Due to limits of time, data was gathered in a manner which did not easily facilitate the distinction. Thus the measure of decision time obtained from the calls may represent a combination of both total and illness delay. Given that different factors are associated with each of these components of delay; this may explain why fewer relationships were identified

between key variables and call-reported decision time.

## *8.3 Clinical practice*

### 8.3.1 Clinical consultations

Results from the study have a number of important implications for practice within clinical consultations.

Importantly, a large proportion of participants who later reported that they believed their symptoms to have severe consequences did not share those beliefs with NHS 24 staff when presenting their symptoms. This is a significant issue, particularly in the context of a telephone triage situation. Information that an individual believes their symptoms to have serious consequences might be valuable information for clinicians, alerting them to potentially urgent clinical situations. This finding suggests that it may be important for clinicians to ask questions relating to potential consequences as it appears unlikely to be volunteered. Furthermore, irrespective of the actual urgency of the clinical situation, knowledge that an individual believes their symptoms to have serious consequences would be helpful information for clinicians in all settings in their negotiation of an appropriate outcome with an individual. This might help to ensure that any advice and/or treatment provided to patients is adhered to (Leventhal et al. 1992; Petrie et al. 1996; Horne and Weinman, 2002b) and improve patient satisfaction with the consultation (Lang et al. 2002). Failure to attend to patients' concerns about potential consequences could lead to anxiety and repeated presentation (Johnston, 1987; Coia and Morely, 1998).

Where people made reference to attempts to control symptoms they referred only to treatment and in particular to using medicines. Research would suggest that other responses such as resting or increasing activity might be attempted (Meischke et al. 1995) and yet were not mentioned by any of the participants in this study. This suggests that people might consider non-medical attempts to control symptoms un-important or not valid to discuss in these types of clinical consultations. Again, this has implications for clinicians who should ensure they ask appropriate questions in order to elicit important information about the self-care measures people have tried. For example, the information that increased activity was associated with worsening chest pain would be important clinical information. Furthermore, clinicians should be aware of how the content of their communication may perpetuate a medicine-orientated discussion of self-care.

Finally, 1 of the 24 participants, who ultimately received a diagnosis of ACS in relation to their symptoms, did not receive an emergency response as a result of their call to NHS 24. This represents a significant clinical risk and suggests there is potential to improve practice in relation to this area.

### 8.3.2 Reducing patient decision time

#### *Decision time a significant problem*

Within the current study, participants reported an average total patient delay of 4 hours. This is similar to previous findings in relation to similar patient groups (Canto et al. 2000; Goldberg et al. 2002b; Rasmussen et al. 2003; Grossman

et al. 2003; Dracup et al. 2003) and demonstrates that average decision times amongst a representative group of patients with possible symptoms of ACS remain significantly out-with the ideal. Only 11% of participants reported total delay times of less than 60 minutes. Appraisal delay constituted the majority of the delay (average 2 hours) whilst illness delay was on average 75 minutes.

***Appraisal delay***

Appraisal delay was found to be shorter amongst men (who also reported more serious consequences), those with few symptoms and strong emotional representations. Thus interventions aimed at reducing delay may need to emphasise the potential serious consequences of delay in the context of ACS, particularly for women.

It may also be beneficial within a public health or individual patient intervention to prepare people to cope with the likely emotional response to symptoms.

Participants with longer delay times tended to report more symptoms than those with shorter delay suggesting that people experience particular difficulties in evaluating many symptoms. Given that there may be a number of symptoms associated with ACS, it might be useful to highlight this within interventions aimed at reducing appraisal time.

***Illness delay***

Those who identified the most important likely cause of their symptoms as relating to the heart delayed seeking medical help an average of 20 minutes less than those who identified other causes as most important, suggesting that

many people are aware of the need to seek prompt medical attention where a problem with the heart is suspected. However, the symptoms of ACS may be ambiguous and in common with previous work (Burnett et al. 1995), this study demonstrated that many people do not readily recognise their symptoms as being related to the heart. This suggests that interventions aimed at reducing delay should aim to help people recognise a *range* of possible presentations. However, it is recognised that this would likely result in an increase in presentations from people with less urgent symptoms and thus the health economics would require evaluation. The most recent campaign by the British Heart Foundation portrayed a stereotypical image of a middle aged man with a constricting belt around his chest (see Appendix 45). Such images, although well-intended may actually serve to reinforce gender and symptom stereotypes which could actually contribute to longer delays amongst some patients.

Those calling NHS 24 for the first time had significantly longer illness delay than those who had called before. This has important implications for how people are informed about how to access out-of-hours care. Current media campaigns by NHS Scotland (see Appendix 46) emphasise the importance of contacting the service only with symptoms which cannot wait until morning, explaining that this allows busy services to respond better to people with very serious symptoms. This may have the unintended consequence of making even those with serious symptoms hesitate about calling.

It may be useful for people, particularly those at increased risk of ACS, to make initial contact with NHS 24 at a time they are not experiencing serious

symptoms in order to familiarise themselves with the process and thus reduce delay at a time when their symptoms are urgent. At the very least it would be well-advised for people at high risk of ACS to become familiar with the process for seeking medical help, particularly out-of-hours. Advice in this regard could be incorporated into CHD review clinics relatively easily.

Furthermore, it is important that all clinical staff who respond to people seeking help with possible symptoms of ACS reinforce the message that seeking help is appropriate, even where there are 'false alarms'. Fear of embarrassment about wasting resources and false alarms have been associated with longer delay in the context of ACS (Finnegan et al. 2000; Pattenden et al. 2002).

***Role of significant others***

To date, inconsistent results have been reported regarding the role of significant others in relation to decision time in the context of ACS.

Results from the current study suggest that illness representations may be an important mediating factor relating to the impact of significant others on decision time. The degree to which patients and significant others differed in their illness representations was significantly related to decision time.

These results suggest that the content of interventions aimed at potential bystanders may need to be different from those targeting the people experiencing symptoms. Relatives of patients with CHD and the public in general should be informed about what to do in the event of witnessing a person experiencing possible symptoms of ACS. It may be important to

emphasise that where they have a clear understanding of the situation or perceive the patient to be very emotional that they should take action, even in situations where the patient is unsure. Furthermore, it is necessary to make it clear that if attempts to control the patient's symptoms have not been successful within 15 minutes that medical help should be sought.

## *8.4 Research*

### 8.4.1 NHS 24 as an environment for research

NHS 24 provided novel opportunities for research. Access to a geographically and demographically diverse population of people seeking help with possible symptoms of ACS was achieved. All calls are recorded providing an opportunity to study what is said at the time of seeking help without impact on the clinical situation. This might be useful in relation to other clinical conditions.

The significant difficulties encountered achieving participation of patients and staff may have been largely due to the study design and the nature of the particular clinical population. Alternative study designs and clinical populations may prove less problematic. Alterations to some procedures within NHS 24 might help to overcome difficulties relating to participation and thus enhance the potential of the organisation to facilitate further innovative research.

### 8.4.2 Consultations

The study has shown that the CS-SRM accounts for a large proportion of

participants' initial presentations. Whilst this data is particularly valuable as it is largely uncontaminated by either the researcher's or professionals' questions, it represents a small proportion of the overall clinical presentation.

Participants may reveal additional components of illness representation later within the consultation. Staff members at NHS 24, although likely naïve to the CS-SRM may ask questions which elicit further components of illness representation. Examination of the illness representations within the entire consultation would provide additional data about which representations are discussed. Furthermore, the important role of clinicians in either elaborating or restricting the range of representations shared could be explored. The relationship between the number and type of illness representations discussed within consultations and the outcome of the call (e.g. patient satisfaction or clinically appropriate decisions) would be useful to examine. The CS-SRM might usefully inform the pattern of consultations.

Furthermore, the CS-SRM guided content analysis utilised within the current study has been shown to be a feasible and reliable method of eliciting illness representations. However, as already discussed, interpreting what people said during consultations was not unproblematic. It is proposed that a methodology where the participant is involved in reviewing the consultation might be useful both in verifying the interpretation of data but also in elaborating further the relationships between the various components.

### 8.4.3 Pre-hospital delay

The results of this study have demonstrated that different factors are associated with appraisal and illness delay. This has important implications for future research into patient decision time. Breakdown of the different components of patient decision time is important in order to inform interventions aimed at reducing delay. These might address illness representations and beliefs about use of health services as well as the nature of symptoms. Having an impact on both components of decision time could potentially be more effective in reducing delay.

Data from this study and previous research (Johnson and King, 1995; Dracup et al. 2003; Walsh J C et al. 2004) suggest that the CS-SRM is a useful theoretical framework in which to investigate patient decision time. Illness representations emerged as the only significant variables predicting appraisal delay category and may also account for differences relating to demographic factors (e.g. gender). However, it is likely that the relationships between the various components as well as between demographic, clinical and contextual factors are complex. Further detailed exploration of the illness representations revealed during initial presentation of particular participants might be useful in elaborating some of these complexities. For example, the illness representations of those who reported serious consequences but nevertheless delayed may be interesting to examine, perhaps using the cued recall method already described. Similarly, the initial presentations of those who received a diagnosis of ACS might be useful to compare with those who did not. Furthermore, there were participants within the study who had made in excess

of 100 calls to NHS 24 in the preceding 3 years. A detailed analysis of the illness representations of participants who seek help frequently might be useful to contrast with those who delay.

Additionally, the data relating to the initial presentations of participants from the current study could be applied to the issue of utilisation delay (the delay between patients seeking help and actually receiving it). Clinical staff within NHS 24 and in primary care regularly evaluate patients with possible symptoms of ACS. Chest discomfort, and indeed other symptoms of ACS, are common reasons for presentation to healthcare (Fox, 2005) and may be caused by many other conditions ranging from the benign to the immediately life-threatening (Nilsson et al. 2003). A significant challenge exists for clinicians to consistently identify all potential cases of ACS whilst minimising 'false alarms'.

Nurses in the context of NHS 24 face the additional challenge of making these judgements based entirely on patients or relatives verbal accounts of their symptoms. Powerful cues such as pallor, sweating or cyanosis that would be immediately apparent to an experienced clinician in a face to face consultation may be more difficult to assess in this situation. Serious adverse incidents have occurred within NHS 24 where patients with ACS have been inappropriately referred to GP out-of-hours centres.

The exercise within Pilot Study 1, where clinicians were asked to evaluate whether the symptoms presented in transcriptions of consultations represented possible symptoms of ACS, further illustrated the problem. The raters were

rarely unanimous in their assessments and even when the 4-point scale was collapsed into a yes/no dichotomy there remained some disagreements.

A better understanding of how judgements vary in relation to identical cases and of which cues are most powerful in predicting decisions would be helpful in identifying a clear focus for improving clinical decision making. The presentations of participants from the current study, for whom the outcome is known (i.e. ACS or not), could be used as the basis for a study based on signal detection theory. Data from such a study would be useful in identifying the cues most helpful in successfully identifying potential cases of ACS and those factors that lead to less appropriate decisions.

## *8.5 Conclusion*

The CS-SRM provided a useful framework to explore both the content and timing of people's initial presentations with symptoms of ACS. The study has shown that patients and significant others present the components of illness representations within their initial presentations of symptoms. The components of illness representations which most influence behaviour and outcome may be least likely to be volunteered. Clinicians may need to enquire specifically about cause, consequences, cure/control and coherence.

Decision time for most people with possible symptoms of ACS remains well out-with the ideal with appraisal time accounting for the majority of the delay.

Appraisal delay was found to be shorter for men, those with few symptoms and

high emotion. This suggests that interventions aimed at reducing appraisal delay may need to target women and highlight the possibility of a range of symptoms and possible emotional reaction.

Illness delay was shorter where people recognised the heart as the most likely cause of their symptoms. Interventions should aim to help people recognise a range of possible presentations. Illness delay was also longer amongst people calling NHS 24 for the first time suggesting that people at high risk of ACS should be informed about how to access healthcare out-of-hours.

The degree to which patients and significant others differed in their illness representations was significantly related to appraisal time, suggesting that the content of interventions aimed at potential bystanders may need to be different from those targeting the people experiencing symptoms.

NHS 24 provided a fruitful environment for research into patient presentations and there are many other related research questions which could be explored within the setting. Such research could contribute to knowledge in a number of fields including illness representations, clinical presentation and decision-making and thus be of considerable benefit to both staff and patients.

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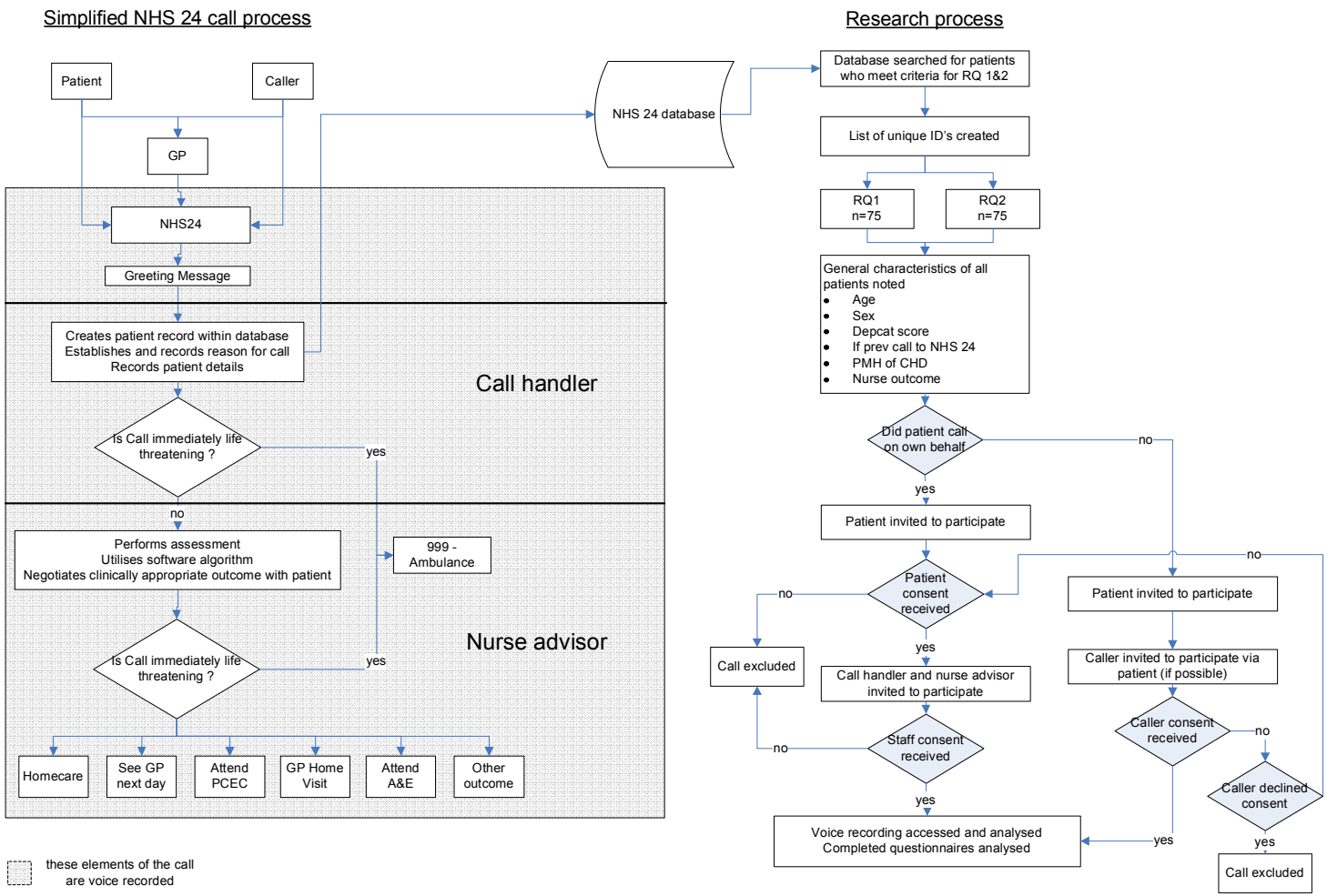
# *Appendix 1*


Simplified NHS 24 call process
Research process
Patient
Caller
GP
NHS24
Greeting Message
Creates patient record within database
Establishes and records reason for call
Records patient details
Call handler
Is Call immediately life threatening ?
yes
no
Performs assessment
Utilises software algorithm
Negotiates clinically appropriate outcome with patient
999 - Ambulance
Nurse advisor
Is Call immediately life threatening ?
yes
Homecare
See GP next day
Attend PCEC
GP Home Visit
Attend A&E
Other outcome
these elements of the call are voice recorded
NHS 24 database
Database searched for patients who meet criteria for RQ 1&2
List of unique ID's created
RQ1 n=75
RQ2 n=75
General characteristics of all patients noted
Age
Sex
Depcat score
If prev call to NHS 24
PMH of CHD
Nurse outcome
Did patient call on own behalf
no
yes
Patient invited to participate
Patient consent received
no
Call excluded
yes
Call handler and nurse advisor invited to participate
Staff consent received
no
yes
Voice recording accessed and analysed
Completed questionnaires analysed
Patient invited to participate
Caller invited to participate via patient (if possible)
Caller consent received
no
Caller declined consent
yes
Call excluded
yes

## *Appendix 2*

Negative NHS 24 publicity

Sunday Post
Section: Main
29 May 2005
Page: 8

Article Size (cm2 ) 122.70
Circulation: 497800
Source: ABC Jun 2004-Jan 2005

# NHS 24 blamed for fatal delays

A JOINT inquiry will be held into two deaths that have been blamed on delays in getting treatment through Scotland's troubled NHS 24 telephone helpline.

The Crown Office said a Fatal Accident Inquiry (FAI) would be held into the deaths of Aberdeen schoolgirl Shomi Miah and 30-year-old Steven Wiseman from Laurencekirk, Aberdeenshire.

The announcement comes just days before a review report into the service is published and less than a week after NHS 24 chair Christine Lenihan announced she was stepping down.

The review was ordered by health minister Andy Kerr in February amid concerns about the service's performance, including delays in callers being phoned back at weekends.

Shomi (17) died from meningitis last October and Mr Wiseman died in December from complications after flu.

Both families have made formal complaints and pressed for an inquiry.

Shomi died on October 26 at Aberdeen Royal Infirmary after suffering from a meningococcal infection.

The schoolgirl was not taken to hospital until 12 hours after her family called G-Docs, the out-of-hours medical service in Grampian run by NHS 24.

Mr Wiseman's fiancee, Kerry Robertson, said the announcement brought back for her the tragic events of the day he died.

She said she had called NHS 24 at about 3am and again about 6am and staff advised her to administer painkillers and wait for her doctor's surgery to open at 8am.

A Crown Office spokesman yesterday confirmed that an FAI was being held into the deaths but said no date had been fixed and he could not comment further.

Daily Mail
Section: Main
26 May 2005
Page: 6

Article Size (cm2 ) 178.64
Circulation: 2409121
Source: ABC January 2005

Healthcare by telephone proposal as ailing NHS struggles to cope

# For a heart scare, press one; cancer, press two...

SCOTLAND faces a future of 'healthcare by phone' as the overloaded NHS struggles to treat growing numbers of patients.

Under a radical plan unveiled yesterday, fewer patients will be treated in large hospitals, which will only be used to carry out the most major surgery or specialist operations.

Instead, people will increasingly be treated by lesser-qualified medical staff – such as GPs, nurses and chemists – in community clinics.

By **Stuart Nicolson**
Scottish Political Reporter

Even patients suffering from serious and long-term illnesses will be kept out of hospital wherever possible.

New technology will also play a much larger part in delivering medical care. As well as extending out-of-hours phone services – such as the much-criticised NHS24 – patients, even those with seri-

Sunday Mirror
Section: Main
1 May 2005
Page: 24

Article Size (cm2 ) 79.76
Circulation: 1652375
Source: ABC January 2005

# DOCS SLAM NEW NHS CALL SYSTEM

**NHS 24 chiefs are set to shell out millions of pounds to replace a computer handling system – just five months after the service was introduced in Scotland.**

By JAMES HARPER

The NHS 24 board will spend £7million updating the complex call-handling system by 2007.

The system has been heavily criticised by doctors and nurses for taking too long to process often-urgent patients' calls.

The system operates "algorithms" which are computer-generated diagnoses and questions. The results help staff offer advice to the patients. But part-time GP Dr Barbara West says the current computer system affects clinical judgments.

"The algorithms are extremely detailed and take a long time to get through," she said.

"Not enough allowance is made for experienced nurses to short-circuit the system to use their clinical judgment. That's why calls take so long."

NHS chief Bryan Robson denied the current system was a risk to patients and said the system was due for an update in 2007.

***Appendix 3***

Dear {patients name},

My name is Barbara Farquharson, I am a nurse working with NHS 24. I am currently undertaking a research project which aims to better understand how people seek medical help with symptoms.

I am writing to invite you to take part in this study. You are one of 150 patients who have been selected after recently being in contact with NHS 24. You have been selected using a method that ensures everyone has an equal chance of being chosen.

I am aware that it is possible that I may be contacting you at a difficult time and I do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider participating please read the enclosed *Patient Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have. If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466287

*Appendix 4*

## Patient Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The aim of this study is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

150 people who have been in contact with NHS 24 recently have been invited to take part. You were selected using a process that ensures everyone who called NHS 24 recently has an equal chance of being chosen.

As some people who call NHS 24 are very unwell, there is a small possibility that you have opened this letter on behalf of someone who has recently died. If this is the case, we apologise for troubling you

and offer you our deepest sympathies. If you wish to simply ignore this request we completely understand. However, if you do feel able to consider taking part we believe you could help us gain a better insight into how people get help for serious symptoms. Whilst, unfortunately, this will not benefit the person we wrote to, it may help us to improve things for others in the future.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you may keep this information sheet and you will be asked to sign the enclosed consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. If you are deciding to take part on behalf of someone who has recently died, please only initial and sign the statements on page 2 of the consent form.

If you decide not to take part please simply return the enclosed material using the stamped addressed envelope included and you will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

**What will happen to me if I take part?**

By agreeing to take part in the study and signing the consent form, you will be giving permission for us to use the recording of the original call you made to NHS 24 for the purposes of this study.

You will also be asked to complete the enclosed questionnaire and return it by post, if possible, within a week. The questionnaire asks about the symptoms you experienced before contacting NHS 24, and your thoughts and feelings about those symptoms. The questionnaire usually takes less than 15 minutes to complete.
This letter is the only contact we will make with you. You will not be contacted in relation to this study again.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

If you decide to take part in this study we would like to inform your GP that you are doing so. If you do not wish your GP to be informed please do not initial that section of the consent form.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be

submitted to healthcare journals for publication. You will not be identified in any report or publication. If you would like the results to be sent to you on completion of the study please initial the appropriate box on the consent form.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact


Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry
Tel: 01786 466287

or

Dr Carol Bugge
Senior Lecturer
Dept of Nursing & Midwifery
University of Stirling
Stirling
Tel: 01786 466109


**Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.**

## *Appendix 5*

**PATIENT CONSENT FORM**

Title: What factors influence patient's behaviour when seeking help with symptoms?

Name of researcher: Barbara Farquharson

Please initial box if you agree with the following statements.

1. I have read and understand the information sheet dated October 2004, version 1 for the above study. ☐

2. I have had the opportunity to ask questions. ☐

3. 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. ☐

4. I understand that the record of my call to NHS 24 will be accessed and listened to by the research team. ☐

5. I would like the results from this study to be sent to me when available. ☐

6. I give permission for my GP to be informed that I am taking part in this research. ☐

7. I agree to take part in the above study. ☐

Name of Patient Date Signature

Researcher Date Signature

1 for patient; 1 for researcher; 1 to be stored at NHS 24

Please only complete this section of the consent form if you are providing consent on behalf of someone who has died.

**CONSENT FORM**

Title: What factors influence patient's behaviour when seeking help with symptoms?

Name of researcher: Barbara Farquharson

Please initial box if you agree with the following statements.

1. I have read and understand the information sheet dated October 2004, version 1 for the above study. ☐

2. I have had the opportunity to ask questions. ☐

3. 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. ☐

4. I understand that the record of the call to NHS 24, about the person named overleaf, will be accessed and listened to by the research team. ☐

Name…… Signature……

Relationship to patient……..Date…….....

_____ _____ _____

Researcher Date Signature

1 for person giving consent; 1 for researcher; 1 to be stored at NHS 24

***Appendix 6***

Dear {staff members name},

My name is Barbara Farquharson, I am a Team Leader with NHS 24 based in the East Contact Centre. I am currently undertaking a research project which aims to better understand how people seek medical help with possible cardiac symptoms.

I am writing to invite your participation in this study. 150 calls to our service have been selected at random. I hope to analyse the voice recordings of these consultations. As you were involved in one or more of these consultations I am writing to request your consent to analyse these calls for the purposes of this study. The patient has given their consent.

I enclose a *Staff Information Sheet* which I ask you to read carefully. It explains clearly what the study involves and should answer any questions you might have. However, if you require any additional information please do not hesitate to contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466287

*Appendix 7*

# Staff Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms which may be cardiac?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. It is important to take time to decide whether or not you wish to take part. Thank you for reading this information.

**What is the purpose of the study?**
A number of treatments are of proven benefit to people having a heart attack if administered soon after the onset of symptoms. However, previous research has shown that many people wait for lengthy periods before seeking help and thus do not receive maximum benefit from treatment. The aim of this study is to learn how people's personal circumstances, symptoms and particularly their *own perceptions* of their symptoms influence how and when they present to healthcare services.

**Why have I been chosen?**
150 patients have been selected randomly after contacting our service seeking help with symptoms. These patients have given permission for their voice-recordings to be used for the purposes of this study. As you were involved in one or more of these calls you are being asked to give your consent for the voice recording to be used.

**Do I have to take part?**
It is up to you to decide whether or not to take part. If you do decide to take part you may keep this information sheet and you will be asked to sign the enclosed consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your employment at NHS 24 in any way.

If you decide not to take part please simply return the enclosed material using the envelope provided and you will not be contacted about this study again.

**What will happen to me if I take part?**
The voice-recording of the consultation between you and the participant identified for the study will be accessed and transcribed. The transcriptions will be analysed to see whether elements of a theoretical model (Leventhal's self-regulation model) are evident within the consultation. It is necessary to include analysis of call-handlers and nurses words to establish which elements were expressed spontaneously by callers and which in response to questions asked.

**What are the possible risks/ disadvantages of taking part?**
The recordings of your consultation will only be accessed for the purposes of this study as outlined in this document. There is no intention to evaluate the performance of staff members. However in the unlikely event that serious misconduct was identified during the course of the study, the researcher would be professionally obliged to take action and would bring the matter to the attention of your Team Leader.

**What are the possible benefits of taking part?**
There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms and may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**
It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, Norseman House or your staff representative.

**Will my taking part in this study be kept confidential?**
All information which is collected about you during the course of the research will be kept strictly confidential. You will not be personally identified within the transcripts or in any publication thereafter.

**What will happen to the results of the research study?**
The results of the study will be reported in a PhD thesis which will be available in Stirling University. The results will also be submitted to healthcare journals for publication. You will not be identified in any report or publication. Reports will also be made available within NHS 24.

**Who is organising and funding the research?**
This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**
The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**
Should you have any questions or require further information please do not hesitate to contact


| | | |
|---|---|---|
| Barbara Farquharson | or | Dr Carol Bugge |
| NHS 24 | | Senior Lecturer |
| Norseman House | | Dept of Nursing & Midwifery |
| 2 Ferrymuir | | University of Stirling |
| South Queensferry | | Stirling |
| | | |
| Tel: 01786 466287 | | Tel: 01786 466109 |


Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.

***Appendix 8***

# STAFF CONSENT FORM

Title: What factors influence patient's behaviour when seeking help with symptoms?

Name of researcher: Barbara Farquharson

Please initial box if you agree with the following statements.

1. I confirm that I have read and understand the information sheet dated October 2004, version 3 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my employment, medical care or legal rights being affected. ☐

3. I understand that sections of medical notes (including voice recordings) relating to patients selected for the study will be examined by responsible individuals from Stirling University or NHS 24 where it is relevant to my taking part in research. I give permission for these individuals to have access to such records. ☐

4. I would like the results from this study to be sent to me when available. ☐

5. I agree to take part in the above study ☐

Name of staff member Date Signature

Researcher Date Signature

1 for staff member; 1 for researcher; 1 to be stored at NHS 24

***Appendix 9***

Dear {patients name},

My name is Barbara Farquharson, I am a nurse working with NHS 24. I am currently undertaking a research project which aims to better understand how people seek medical help with symptoms.

I am writing to invite you to take part in this study. You are one of 150 patients who have been selected after recently being in contact with NHS 24. You have been selected using a method that ensures everyone has an equal chance of being chosen.

I am aware that it is possible that I may be contacting you at a difficult time and I do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider participating please read the enclosed *Patient Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have.

I understand that, in your case, the telephone call to NHS 24 was made by someone other than yourself. Where possible, I would be very interested in hearing their views too. Therefore, if you could pass the '*Caller Information'* on to the person who called on your behalf, it would be very helpful.

If you wish to take part but are unable to pass this information onto the person who made the call, please do not worry. Please

still complete the *'Patient Information'* and return it using the enclosed stamped addressed envelope.

If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466287

***Appendix 10***

Dear {callers name},

My name is Barbara Farquharson; I am a nurse working with NHS 24. I am currently undertaking a research project which aims to better understand how people seek medical help with symptoms.

I am writing to invite you to take part in this study. 150 patients have been selected after recently being in contact with NHS 24. You are being approached as you were involved in making a call on behalf of one of the patients selected. I have asked them to pass this information to you.

I am aware that it is possible that I may be contacting you at a difficult time and do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider taking part please read the enclosed *Caller Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have. If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112

*Appendix 11*

## Caller Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important to take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The aim of this study is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. We are also interested in the views of other people who were present when the telephone call to NHS 24 was made. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

150 telephone calls to NHS 24 have been selected using a process that ensures that everyone who called NHS 24 recently has an equal chance of being chosen. The patients have been invited to participate in this study. Where someone else made the telephone call on their behalf we have asked them to pass this information to that person. You are being approached as you

were involved in making the telephone call to NHS 24 on behalf of one of the patients selected. We are interested in exploring your thoughts about the patient's symptoms.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you may keep this information sheet and you will be asked to sign the enclosed consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or the patient receives.

If you decide not to take part please simply return the enclosed material using the stamped addressed envelope included and you will not be contacted about this study again. If you want to provide the reason why you feel unable to take part that would be very helpful.

**What will happen to me if I take part?**

By agreeing to take part in the study and signing the consent form you will be giving permission for us to use the recording of the call you made to NHS 24, for the purposes of this study.

You will also be asked to complete the enclosed questionnaire and return it in the envelope provided, if possible, within a week. The questionnaire usually takes less than 15 minutes to complete.

This letter is the only contact we will make with you. You will not be contacted in relation to this study again.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**
There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**
It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**
All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

If you decide to take part in this study we would like to inform your GP that you are doing so. If you do not wish your GP to be informed please do not initial that section of the consent form.

**What will happen to the results of the research study?**
The results of the study will be reported in a PhD thesis which will be available in Stirling University. The results will also be submitted to healthcare journals for publication. You will not be identified in any report or publication. If you would like the results to be sent to you on completion of the study please tick the appropriate box on the consent form.

**Who is organising and funding the research?**
This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**
The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact


| | | |
|---|---|---|
| Barbara Farquharson | or | Dr Carol Bugge |
| NHS 24 | | Senior Lecturer |
| Norseman House | | Dept of Nursing & Midwifery |
| 2 Ferrymuir | | University of Stirling |
| South Queensferry | | Stirling |
| | | |
| Tel: 01786 466287 | | Tel: 01786 466109 |


Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.

*Appendix 12*

# ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

**Study ID No……** **Date……**

## YOUR VIEWS ABOUT YOUR ILLNESS

**Listed below are a number of symptoms that you may or may not have experienced when you contacted NHS 24. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms recently and whether these symptoms relate to why you were in contact with NHS 24.**

| | **I have *experienced this symptom* recently (within last 2 weeks)** | | | **This symptom is *related to why I was in contact with NHS 24*** | |
|---|---|---|---|---|---|
| **Pain** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Discomfort** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Sore Throat** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Nausea** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Breathlessness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Weight Loss** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Tiredness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Stiff Joints** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Sore Eyes** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Wheeziness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Headaches** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Upset Stomach** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Sleep Difficulties** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Dizziness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Loss of Strength** | **Yes** | **No** | **_____** | **Yes** | **No** |

**We are interested in your own personal views of how you now see your current illness.**

**Please indicate how much you agree or disagree with the following statements about your symptoms by ticking the appropriate box.**

| | VIEWS ABOUT THEIR ILLNESS | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP1* | My symptoms will last a short time | | | | | |
| IP2 | My symptoms are likely to be permanent rather than temporary | | | | | |
| IP3 | My symptoms will last for a long time | | | | | |
| IP4* | My symptoms will pass quickly | | | | | |
| IP5 | I expect I will have these symptoms for the rest of my life | | | | | |
| IP6 | My illness is a serious condition | | | | | |
| IP7 | My symptoms have major consequences on my life | | | | | |
| IP8* | My symptoms do not have much effect on my life | | | | | |
| IP9 | My symptoms strongly affect the way others see me | | | | | |
| IP10 | My symptoms have serious financial consequences | | | | | |
| IP11 | My symptoms cause difficulties for those who are close to me | | | | | |
| IP12 | There is a lot which I can do to control my symptoms | | | | | |
| IP13 | What I do can determine whether my symptoms get better or worse | | | | | |
| IP14 | The course of my illness depends on me | | | | | |
| IP15* | Nothing i do will affect my symptoms | | | | | |
| IP16 | I have the power to influence my symptoms | | | | | |
| IP17* | My actions will have no affect on the outcome of my illness | | | | | |
| IP18* | My symptoms will improve in time | | | | | |
| IP19* | There is very little that can be done to improve my symptoms | | | | | |
| IP20 | My treatment will be effective in curing my illness | | | | | |
| IP21 | The negative effects of my illness can be prevented (avoided) by my treatment | | | | | |
| IP22 | My treatment can control my symptoms | | | | | |
| IP23* | There is nothing which can help my condition | | | | | |
| IP24 | The symptoms of my condition are puzzling to me | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP25 | My symptoms are a mystery to me | | | | | |
| IP26 | I don't understand my symptoms | | | | | |
| IP27 | My symptoms don't make any sense to me | | | | | |
| IP28* | I have a clear picture or understanding of my condition | | | | | |
| IP29 | My symptoms change a great deal from day to day | | | | | |
| IP30 | My symptoms come and go in cycles | | | | | |
| IP31 | My symptoms are very unpredictable | | | | | |
| IP32 | I go through cycles in which my symptoms get better and worse. | | | | | |
| IP33 | I get depressed when I think about my symptoms | | | | | |
| IP34 | When I think about my symptoms I get upset | | | | | |
| !P35 | My symptoms make me feel angry | | | | | |
| IP36* | My symptoms do not worry me | | | | | |
| IP37 | Having these symptoms makes me feel anxious | | | | | |
| IP38 | My symptoms make me feel afraid | | | | | |

## CAUSES OF MY ILLNESS

**We are interested in what <u>you</u> consider may have been the cause of your symptoms. As people are very different, there is no correct answer for this question. We are most interested in <u>your own views</u> about the factors that caused your symptoms rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your symptoms. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.**

| | POSSIBLE CAUSES | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGRE |
|---|---|---|---|---|---|---|
| C1 | Stress or worry | | | | | |
| C2 | Hereditary - it runs in my family | | | | | |
| C3 | A Germ or virus | | | | | |
| C4 | Diet or eating habits | | | | | |
| C5 | Chance or bad luck | | | | | |
| C6 | Poor medical care in my past | | | | | |
| C7 | Pollution in the environment | | | | | |
| C8 | My own behaviour | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C9 | **My mental attitude e.g. thinking about life negatively** | | | | | |
| C10 | **Family problems or worries caused my illness** | | | | | |
| C11 | **Overwork** | | | | | |
| C12 | **My emotional state e.g. feeling down, lonely, anxious, empty** | | | | | |
| C13 | **Ageing** | | | | | |
| C14 | **Alcohol** | | | | | |
| C15 | **Smoking** | | | | | |
| C16 | **Accident or injury** | | | | | |
| C17 | **My personality** | | | | | |
| C18 | **Being 'rundown'** | | | | | |

**In the table below, please list in rank-order the three most important factors that you believed might be causing <u>YOUR</u> symptoms at the time you called NHS 24. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. _____

2. _____

3. _____

## ADDITIONAL INFORMATION

**In order to help us understand the information you have provided better, it would be very helpful if you could tell us a little about yourself.**

**1. What is your age? _____**

**2. Are you male or female? _____**

**3. What is your ethnic group?** Choose one section from A to E, tick box if appropriate or add your own description.

| | | |
|---|---|---|
| **A. White**<br>Scottish ☐<br>British ☐<br>Irish ☐<br><br>Other White background? | **B. Asian, Asian Scottish or Asian British**<br>Indian ☐<br>Pakistani ☐<br>Bangladeshi ☐<br>Chinese ☐<br>Other Asian background? | **C. Black**<br>Caribbean ☐<br>African ☐<br><br>Other Black background? |
| **D. Mixed** ☐ | E. **Any other ethnic background** | |

## HOW DID YOU FIND THIS QUESTIONNAIRE?

**We are also interested in hearing your views about how reasonable the questionnaire was to complete**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| | **The questionnaire was easy to complete** | | | | | |
| | **I was contacted at an appropriate time** | | | | | |
| | **The questions were relevant to me** | | | | | |
| | **I remember the reason I was in contact with NHS 24** | | | | | |

**Please feel free to make any additional comments below or overleaf:**

**Once completed please put this questionnaire and a signed consent form in the stamped, addressed envelope provided. Please post it within a week if possible. Thank you very much for taking part in this study.**

*Appendix 13*

# CALLER ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

**Study ID No……** **Date……**

## YOUR VIEWS ABOUT THE PATIENTS ILLNESS

**Listed below are a number of symptoms that the patient (the person you called NHS 24 about) may or may not have experienced. Please indicate by circling *Yes* or *No,* whether you believe they have experienced any of these symptoms and whether these symptoms relate to why you were in contact with NHS 24.**

| | **They have *experienced this symptom* recently (within last 2 weeks)** | | | **This symptom is *related to why I contacted NHS 24 on their behalf*** | |
|---|---|---|---|---|---|
| **Pain** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Discomfort** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Sore Throat** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Nausea** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Breathlessness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Weight Loss** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Tiredness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Stiff Joints** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Sore Eyes** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Wheeziness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Headaches** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Upset Stomach** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Sleep Difficulties** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Dizziness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Loss of Strength** | **Yes** | **No** | **Don't know** | **Yes** | **No** |

**We are interested in YOUR own personal views about the patient's symptoms.**

**Please indicate how much you agree or disagree with the following statements about the patients symptoms by ticking the appropriate box.**

| | VIEWS ABOUT THEIR ILLNESS | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP1* | Their symptoms will last a short time | | | | | |
| IP2 | Their symptoms are likely to be permanent rather than temporary | | | | | |
| IP3 | Their symptoms will last for a long time | | | | | |
| IP4* | Their symptoms will pass quickly | | | | | |
| IP5 | I expect they will have these symptoms for the rest of their life | | | | | |
| IP6 | Their illness is a serious condition | | | | | |
| IP7 | Their symptoms have major consequences on their life | | | | | |
| IP8* | Their symptoms do not have much effect on their life | | | | | |
| IP9 | Their symptoms strongly affect the way others see them | | | | | |
| IP10 | Their symptoms have serious financial consequences | | | | | |
| IP11 | Their symptoms cause difficulties for those who are close to them | | | | | |
| IP12 | There is a lot which they can do to control their symptoms | | | | | |
| IP13 | What they do can determine whether their symptoms get better or worse | | | | | |
| IP14 | The course of their illness depends on them | | | | | |
| IP15* | Nothing they do will affect their symptoms | | | | | |
| IP16 | They have the power to influence their symptoms | | | | | |
| IP17* | Their actions will have no affect on the outcome of their illness | | | | | |
| IP18* | Their symptoms will improve in time | | | | | |
| IP19* | There is very little that can be done to improve their symptoms | | | | | |
| IP20 | Their treatment will be effective in curing their illness | | | | | |
| IP21 | The negative effects of their illness can be prevented (avoided) by treatment | | | | | |
| IP22 | Their treatment can control their symptoms | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP23* | There is nothing which can help their condition | | | | | |
| IP24 | The symptoms of their condition are puzzling to them | | | | | |
| IP25 | Their symptoms are a mystery to them | | | | | |
| IP26 | They don't understand their symptoms | | | | | |
| IP27 | Their symptoms don't make any sense to them | | | | | |
| IP28* | They have a clear picture or understanding of their condition | | | | | |
| IP29 | Their symptoms change a great deal from day to day | | | | | |
| IP30 | Their symptoms come and go in cycles | | | | | |
| IP31 | Their symptoms are very unpredictable | | | | | |
| IP32 | They go through cycles in which their symptoms get better and worse. | | | | | |
| IP33 | They get depressed when they think about their symptoms | | | | | |
| IP34 | When they think about their symptoms they get upset | | | | | |
| !P35 | Their symptoms make them feel angry | | | | | |
| IP36* | Their symptoms do not worry them | | | | | |
| IP37 | Having these symptoms makes them feel anxious | | | | | |
| IP38 | Their symptoms make them feel afraid | | | | | |

**We are also interested in exploring how the patient's illness affects <u>you</u>.**
**Please indicate how much you agree or disagree with the following statements about the patients symptoms by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP39 | There is a lot which I can do to control the patient's symptoms | | | | | |
| IP40 | What I do can determine whether their symptoms get better or worse | | | | | |
| IP41 | The course of their illness depends on me | | | | | |
| IP42* | Nothing I do will affect their symptoms | | | | | |
| IP43 | I have the power to influence the patient's symptoms | | | | | |
| IP44* | My actions will have no affect on the outcome of their illness | | | | | |
| IP45 | The symptoms of their condition are puzzling to me | | | | | |
| IP46 | Their symptoms are a mystery to me | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP47 | I don't understand their symptoms | | | | | |
| IP48 | Their symptoms don't make any sense to me | | | | | |
| IP49* | I have a clear picture or understanding of their condition | | | | | |
| IP50 | I get depressed when I think about their symptoms | | | | | |
| IP51 | When I think about their symptoms I get upset | | | | | |
| IP52 | Their symptoms make me feel angry | | | | | |
| IP53* | Their symptoms do not worry me | | | | | |
| IP54 | The patient having these symptoms makes me feel anxious | | | | | |
| IP55 | Their symptoms make me feel afraid | | | | | |

## CAUSES OF THEIR ILLNESS

**We are interested in what <u>you</u> consider may have been the cause of the patient's symptoms. As people are very different, there is no correct answer for this question. We are most interested in <u>your own views</u> about the factors that caused the patient's symptoms rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for their symptoms. Please indicate how much you agree or disagree that they were causes for them by ticking the appropriate box.**

| | POSSIBLE CAUSES | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C1 | Stress or worry | | | | | |
| C2 | Hereditary - it runs in their family | | | | | |
| C3 | A Germ or virus | | | | | |
| C4 | Diet or eating habits | | | | | |
| C5 | Chance or bad luck | | | | | |
| C6 | Poor medical care in the past | | | | | |
| C7 | Pollution in the environment | | | | | |
| C8 | Their own behaviour | | | | | |
| C9 | Their mental attitude e.g. thinking about life negatively | | | | | |
| C10 | Family problems or worries caused their illness | | | | | |
| C11 | Overwork | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C12 | **Their emotional state e.g. feeling down, lonely, anxious, empty** | | | | | |
| C13 | **Ageing** | | | | | |
| C14 | **Alcohol** | | | | | |
| C15 | **Smoking** | | | | | |
| C16 | **Accident or injury** | | | | | |
| C17 | **Their personality** | | | | | |
| C18 | **Being 'rundown'** | | | | | |

**In the table below, please list in rank-order the three most important factors that you believed might be causing <u>the patients</u> symptoms at the time you called NHS 24. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. _____

2. _____

3. _____

## ADDITIONAL INFORMATION

**In order to help us understand the information you have provided better, it would be very helpful if you could tell us a little about yourself.**

**1. What is your age? _____**

**2. Are you male or female? _____**

**3. What is your relationship to the patient? _____**

**4. What is your ethnic group?** Choose one section from A to E, tick box if appropriate or add your own description.

| | | |
|---|---|---|
| **E. White**<br>Scottish ☐<br>British ☐<br>Irish ☐<br><br>Other white background? | **F. Asian, Asian Scottish or Asian British**<br>Indian ☐<br>Pakistani ☐<br>Bangladeshi ☐<br>Chinese ☐<br>Other asian background? | **G. Black**<br>Caribbean ☐<br>African ☐<br><br>Other black background? |
| **H. Mixed** ☐ | E. **Any other ethnic background** | |

## HOW DID YOU FIND THIS QUESTIONNAIRE?

**We are also interested in hearing your views about how reasonable the questionnaire was to complete**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| | **The questionnaire was easy to complete** | | | | | |
| | **I was contacted at an appropriate time** | | | | | |
| | **The questions were relevant to me** | | | | | |
| | **I remember the reason I was in contact with NHS 24** | | | | | |

**Please feel free to make any additional comments below or overleaf:**

**Once completed please put this questionnaire and a signed consent form in the stamped, addressed envelope provided. Please post it within a week if possible. Thank you very much for taking part in this study.**

## *Appendix 14*

Dear Colleague

I am writing to let you know about a research project I am developing within NHS 24 and which you are being asked to get involved in.

The research is funded by a new scheme in Scotland designed to improve the research capacity amongst nurses, midwives and allied health professionals within the NHS. I have been seconded from my post at NHS 24 to one of 6 studentships with the NMAHP training scheme.

The research is concerned with developing a better understanding of how people seek help with possible cardiac symptoms. It will include analysis of calls to NHS 24 from patients with these types of symptoms. The recordings of our consultations provide an ideal opportunity to observe actual behaviour at the time of seeking help without interfering in the patients journey of care. It is planned that permission will be obtained from 100 patients to use the recording of their call for this purpose.

It will be useful to examine what types of information people volunteer and what they provide in response to the questions call handlers and nurses ask. Thus I am writing to request permission from you (and each of your colleagues) to use the recordings of your consultations for the purposes of this research (should you happen to be involved in one of the 100 calls randomly selected). The participation of yourself and your colleagues is vital - without the consent of all parties involved in a call I am unable to access it for analysis.

I'd like to reassure you that my analysis is solely concerned with evaluating a theoretical model about how people interpret illness and NOT with evaluating your performance. Your participation is confidential and no-one will be informed about who is or is not taking part.

A small number of you may have received previous correspondence from me in connection with this study. Thank you to those who have already agreed to take part. I am aware that some information contained within that correspondence has caused some of you concern and prevented you from feeling safe to take part. This was not my intention and I apologise. The protocol has been reviewed in light of this feedback and I now promise you complete confidentiality. I can assure you that there will be

no negative consequences associated with giving your permission for your calls to be used in this way. This also applies to those who have already given their consent.

Please take time to read the enclosed revised information carefully. Contact me on the number provided (or by email) if there is anything which is unclear or if you would like more information. I will also be available in your centre on [specific dates] if you would like to discuss any queries with me in person.

If you decide to take part please ensure you sign and return the consent form in the envelope provided. A reminder will be sent to those who have not responded within 2 weeks. If you do not wish to take part, please feel free to ignore this correspondence although if you could respond, giving your reasons that would be very helpful.

Thank you in anticipation of your help and I look forward to meeting many of you over the next few weeks.

Yours sincerely

Barbara Farquharson
Team Leader / PhD student

Tel: 01786 466112

## *Appendix 15*

**Staff Information Sheet**

**Study Title: What factors influence people's behaviour when seeking help with symptoms which may be cardiac?**

You are being invited to contribute to a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. It is important to take time to decide whether or not you wish to take part. Thank you for reading this information.

**What is the purpose of the study?**

A number of treatments are of proven benefit to people having a heart attack if administered soon after the onset of symptoms. However, previous research has shown that many people wait for lengthy periods before seeking help and thus do not receive maximum benefit from treatment. The aim of this study is to learn how people's personal circumstances, symptoms and particularly their *own perceptions* of their symptoms influence how and when they present to healthcare services.

**Why have I been chosen?**

All NHS 24 nurses and call handlers are being asked to participate. From calls involving staff who consent, 100 calls will be chosen AT RANDOM. The patients involved in these calls will then be approached for their consent. This is to ensure that we only trouble patients for consent when we know that the staff involved are happy to take part.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you may keep this information sheet and you will be asked to sign the enclosed consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your employment at NHS 24 in any way.

If you decide **not** to take part please return the enclosed material using the envelope provided. If you feel able to provide a brief reason that would be helpful. You will not be contacted about this study again.

If we do not receive a reply from you, we will send you a reminder after 2 weeks. If you choose not to respond at this point we will assume you do not wish to take part and will not contact you about the study again.

**What will happen to me if I take part?**

If you agree to participate, **and** a patient you have spoken with is randomly selected and gives their consent, then the voice-recording of the consultation between you and the participant identified for the study will be accessed and transcribed. The transcriptions will be analysed to see whether elements of a theoretical model (Leventhal's self-regulation model) are evident within the consultation. It is necessary to include analysis of call-handlers and nurses words to establish which elements were expressed spontaneously by callers and which in response to questions asked.

**What are the possible risks/ disadvantages of taking part?**

None are anticipated. The recordings of your consultation will only be accessed for the purposes of this study as outlined in this document. There is no intention to evaluate the performance of staff members. The content of the consultation will not be discussed with anyone outside the research team. Your participation is completely confidential. No-one else will be aware of whether or not you took part.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms and may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, Norseman House or your staff representative.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. You will not be personally identified within the transcripts or in any publication thereafter.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in Stirling University. The results will also be submitted to healthcare journals for publication. You will not be identified in any report or publication. Reports will also be made available within NHS 24.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**
The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by Fife & Forth Valley NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry

Tel: 01786 466112

Thank-you for reading this information. Please keep this leaflet and a consent form for your own records.

***Appendix 16***

# STAFF CONSENT FORM

Title: What factors influence patient's behaviour when seeking help with symptoms?

Name of researcher: Barbara Farquharson

Please initial box if you agree with the following statements.

1. I confirm that I have read and understand the information sheet dated August 2005, version 1 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my employment, medical care or legal rights being affected. ☐

3. I understand that sections of medical notes (including voice recordings) relating to patients selected for the study will be examined by responsible individuals from Stirling University or NHS 24 where it is relevant to my taking part in research. I give permission for these individuals to have access to such records. ☐

4. I would like the results from this study to be sent to me when available. ☐

5. I agree to take part in the above study ☐

Name of staff member Date Signature

Researcher Date Signature

(1 for staff member; 1 for researcher)

*Appendix 17*

## Patient Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The aim of this study is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

150 people who have been in contact with NHS 24 recently have been invited to take part. You were selected using a process that ensures everyone who called NHS 24 recently has an equal chance of being chosen.

As some people who call NHS 24 are very unwell, there is a small possibility that you have opened this letter on behalf of someone who has recently died. If this is the case, we apologise for troubling you and offer you our deepest sympathies. . If you wish to simply

ignore this request we completely understand – please just let us know. However, if you do feel able to consider taking part we believe you could help us gain a better insight into how people get help for serious symptoms. Whilst, unfortunately, this will not benefit the person we wrote to, it may help us to improve things for others in the future.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you do not need to take any action. The researcher will contact you over the next few days to confirm that you wish to take part and to make further arrangements with you.

If you do not wish to take part, please respond to the researcher as soon as possible. Please either return the enclosed *'I decline'* card in the pre-paid envelope *or* telephone 01786 466112 and leave a message including this study number -[study number]. You will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

If you do not respond within 3 days the researcher will telephone you. If you receive this call, you are still under no obligation to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

You may keep this information sheet.

**What will happen to me if I take part?**

By agreeing to take part in the study you will be giving permission for us to use the recording of the original call you made to NHS 24 for the purposes of this study.

You will also be asked to complete the enclosed questionnaire and return it by post, if possible, within a week. The questionnaire asks about the symptoms you experienced before contacting NHS 24, and

your thoughts and feelings about those symptoms. The questionnaire usually takes less than 15 minutes to complete.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

If you decide to take part in this study we would like to inform your GP that you are doing so. You will be given the opportunity to advise us if you do not wish for that to happen.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be submitted to healthcare journals for publication. You will not be

identified in any report or publication. You will be given an opportunity to request a summary of the results.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry
Tel: 01786 466112

**Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.**

*Appendix 18*

## Patient Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The aim of this study is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

150 people who have been in contact with NHS 24 recently have been invited to take part. You were selected using a process that ensures everyone who called NHS 24 recently has an equal chance of being chosen.

As some people who call NHS 24 are very unwell, there is a small possibility that you have opened this letter on behalf of someone who has recently died. If this is the case, we apologise for troubling you and offer you our deepest sympathies. If you wish to simply

ignore this request we completely understand – please just let us know. However, if you do feel able to consider taking part we believe you could help us gain a better insight into how people get help for serious symptoms. Whilst, unfortunately, this will not benefit the person we wrote to, it may help us to improve things for others in the future.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you do not need to take any action. The researcher will contact you over the next few days to confirm that you wish to take part and to make further arrangements with you.

If you do not wish to take part, please respond to the researcher as soon as possible. Please either return the enclosed *'I decline'* card in the pre-paid envelope *or* telephone 01786 466112 and leave a message including this study number -[study number]. You will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

If you do not respond within 3 days the researcher will telephone you. If you receive this call, you are still under no obligation to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

You may keep this information sheet.

**What will happen to me if I take part?**

By agreeing to take part in the study you will be giving permission for us to use the recording of the original call you made to NHS 24 for the purposes of this study.

You will also be asked to take part in an interview by telephone. The researcher who contacts you will confirm you wish to take part and make arrangements to interview you at a convenient time. The interview will be carried out by telephone and will last up to 30

minutes. The questions will about the symptoms you experienced before contacting NHS 24, and your thoughts and feelings about those symptoms. The enclosed Illness Perception Questionnaire contains similar questions to those you will be asked.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

If you decide to take part in this study we would like to inform your GP that you are doing so. You will be given the opportunity to advise us if you do not wish for that to happen.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be

submitted to healthcare journals for publication. You will not be identified in any report or publication. You will be given the opportunity to request a summary of the results.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry

Tel: 01786 466112

**Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.**

***Appendix 19***

# I decline

To take part in

Study Title: What factors influence people's behaviour when seeking help with symptoms?

Study Number: 0001

My reasons are:

Please return in enclosed stamped addressed envelope

## *Appendix 20*

**Schedule for invitation by telephone**

Ask for patient, introduce self

Explain call being recorded

Check received and read study information

Check understanding

Request consent – analyse call / take part interview/ questionnaire as appropriate

| NO | YES |
|---|---|
| Consider asking for a reason | Thank you for taking part |
| Thank you for your time | Clarify can withdraw at any time |
| End call | Make arrangements for interview/ completion of questionnaire as appropriate. |
| | If appropriate enquire if they have details of 3rd party |
| | Request consent to contact 3rd party |
| | Request consent to notify GP |

***Appendix 21***

Dear {patients name},

My name is Barbara Farquharson, I am currently undertaking a research project which aims to better understand how people seek medical help with symptoms.

I am writing to invite you to take part in this study. You are one of 150 patients who have been selected after recently being in contact with NHS 24. You have been selected using a method that ensures everyone has an equal chance of being chosen.

I am aware that it is possible that I may be contacting you at a difficult time and I do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider participating please read the enclosed *Patient Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have.

I understand that, in your case, the telephone call to NHS 24 was made by someone other than yourself. Where possible, I would be very interested in hearing their views too. Therefore, if you could pass the '*Caller Information*' on to the person who called on your behalf, it would be very helpful.

If you wish to take part but are unable to pass this information onto the person who made the call, do not worry. Please simply follow the instructions contained in the *'Patient Information Sheet'*.

If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112

*Appendix 22*

## Caller Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The aim of this study is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

150 people who have been in contact with NHS 24 recently have been invited to take part. You were selected using a process that ensures everyone who called NHS 24 recently has an equal chance of being chosen.

As some people who call NHS 24 are very unwell, there is a small possibility that you have opened this letter on behalf of someone who has recently died. If this is the case, we apologise for troubling you and offer you our deepest sympathies. If you wish to simply ignore this request we completely understand. However, if you do feel able to consider taking part we believe you could help us gain a

better insight into how people get help for serious symptoms. Whilst, unfortunately, this will not benefit the person we wrote to, it may help us to improve things for others in the future.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you do not need to take any action. The researcher will contact you over the next few days to confirm that you wish to take part and to make further arrangements with you.

If you do not wish to take part, please respond to the researcher as soon as possible. Please either return the enclosed '*I decline'* card in the pre-paid envelope *or* telephone 01786 466112 and leave a message including this study number -[study number]. You will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

If you do not respond within 3 days the researcher will telephone you. If you receive this call, you are still under no obligation to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

You may keep this information sheet.

**What will happen to me if I take part?**

By agreeing to take part in the study you will be giving permission for us to use the recording of the original call you made to NHS 24 for the purposes of this study.

You will also be asked to complete the enclosed questionnaire and return it by post, if possible, within a week. The questionnaire asks about the symptoms you experienced before contacting NHS 24, and your thoughts and feelings about those symptoms. The questionnaire usually takes less than 15 minutes to complete.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

If you decide to take part in this study we would like to inform your GP that you are doing so. You will be given an opportunity to let us know if you would prefer we did not do this.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be

submitted to healthcare journals for publication. You will not be identified in any report or publication. If you would like the results to be sent to you on completion of the study please initial the appropriate box on the consent form.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry
Tel: 01786 466112

**Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.**

*Appendix 23*

## Caller Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The aim of this study is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. We are also interested in the views of other people who were present when the telephone call to NHS 24 was made. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

150 telephone calls to NHS 24 have been selected using a process that ensures that everyone who called NHS 24 recently has an equal chance of being chosen. The patients have been invited to participate in this study. Where someone else made the telephone call on their behalf we have asked them to pass this information to that person. You are being approached as you were involved in making the telephone call to NHS 24 on behalf

of one of the patients selected. We are interested in exploring your thoughts about the patient's symptoms.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you do not need to take any action. The researcher will contact you over the next few days to confirm that you wish to take part and to make further arrangements with you.

If you do not wish to take part, please respond to the researcher as soon as possible. Please either return the enclosed *'I decline'* card in the pre-paid envelope *or* telephone 01786 466112 and leave a message including this study number -[study number]. You will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

If you do not respond within 3 days the researcher will telephone you. If you receive this call, you are still under no obligation to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

You may keep this information sheet.

**What will happen to me if I take part?**

By agreeing to take part in the study you will be giving permission for us to use the recording of the original call you made to NHS 24 for the purposes of this study.

You will also be asked to take part in an interview by telephone. The researcher who contacts you will confirm you wish to take part and make arrangements to interview you at a convenient time. The interview will be carried out by telephone and will last up to 30 minutes. The questions will about the symptoms the patient experienced prior to you contacting NHS 24, and your thoughts and

feelings about those symptoms. The enclosed Illness Perception Questionnaire contains similar questions to those you will be asked.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be

submitted to healthcare journals for publication. You will not be identified in any report or publication. You will be given the opportunity to request a summary of the results.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by a Main NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry

Tel: 01786 466112

**Thank-you for reading this information. Please keep this leaflet and a signed consent form for your own records.**

## *Appendix 24*

Dear Colleague

Please read the transcripts that you have been given one at a time. Enter the ID number in the column on the left and then tick one box which best describes how likely the symptoms described in the transcript are to be 'possibly cardiac' (i.e. Would you consider the possibility of a cardiac cause for the symptoms described at any point during the call?)

Then, please indicate how confident you feel about your rating on the table on the right.

| **Study Number** | Definitely | Probably | Probably Not | Definitely Not |
|---|---|---|---|---|
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| Very confident | Fairly confident | Not very confident | Not at all confident |
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## *Appendix 25*

**Gender split of calls to NHS 24 on a randomly selected day**

**Adhoc Report**

| | |
|---|---|
| **Requested by** | **Barbara Farquharson** |
| **Information Requested** | **Gender split of previously supplied raw data.** |
| **Period** | ***18th August 2006 – 22nd August 2006** |

**Total records** 14681

**Gender Split**

- Female 8792
- Male 5884
- Blank 4
- Unknown 1

* Same date range as previous raw data sent

## *Appendix 26*

**Interview schedule**

- Introduction and thanks
- Re-check consent
- Explanation of what interview will involve, expected duration
- Opportunity for participant to ask questions
- Instructions read from IPQ-R
- Check understanding
- Read questions from IPQ-R
- Note areas of ambiguity, questions asked, areas of confusion or which cause anxiety in answering. Time how long it takes to complete
- Additional questions
    - How did you find the questionnaire?
    - How could we improve it?
    - Could the instructions be made clearer? If so, how?
    - Could we make it any easier for you? If so, how?
    - How long would be acceptable for it to take?
    - If you received this in the post, would you complete it?
    - If not, why not? Would anything make you more likely to complete it?

## *Appendix 27*

| | Issues | Respondents comments | Modifications |
|---|---|---|---|
| Symptoms | 5 respondents required clarification about which symptoms were being referred to (either which call or which illness)<br><br>3 respondents identified psychological symptoms which were not accounted for in Q<br><br>Other symptoms were identified as reasons for calling but were not listed | <br><br><br><br>Anxiety (2)<br>Hallucinating<br><br><br>Vomiting<br>Shaking<br>Pins and needles (expanded yes to 'discomfort')<br>Diarrhoea<br>Sweating (missing from caller Q)<br>Collapse | Consider adding these to the list |
| IP1 | 2 respondents required clarification about which symptoms were being asked about<br><br>2 respondents issues with the time point of measurement<br><br>2 respondents required reminding about scale | "what symptoms?<br><br>"at the time you cant say how long it is going to last"<br>"do you mean will last or would last" | Reinforce instructions about which symptoms are being asked about<br><br>Make clear within the instructions the time point we are referring to (I'm not clear myself!)<br><br>See section entitled 'scale' |
| IP2 | 2 respondents required clarification before answering | "I'm not understanding where you are leading from. When you say permanent - do you mean is it going to happen again" | Clarity about time point referring to may lessen this confusion |
| IP3 | 4 respondents found it difficult to answer<br>Time point referred to ambiguous. In these two examples one answered about the symptoms at the time, the other 'from now' | "nobody knows how long its going to last."<br><br>"maybe it something i'll have for the rest of my days but how can you tell?" | Clarity about time point referring to may lessen this confusion |
| IP4 | 2 respondents required clarification of the time point being referred to.<br>2 respondents found it difficult to answer as they did not know what was happening at the time | "Is this referring to just this time or in general?"<br><br>"Can't answer because I didn't know what was happening" | Clarity about time point |
| IP7 | 1 respondent identified that this | ip7 - consequences are they positive / negative - he felt | Consider stating 'negative consequences' |

| | | | |
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| | could include positive consequences | positive | |
| IP8 | 2 respondents required to reread question before answering | A respondent answered then realised there was negative within the question, re-read and changed answer | Consider rephrasing without negative |
| IP9 | 4 respondents identified difficulties with this question | People don't know about his symptoms<br><br>I don't know how others see me<br><br>What do you mean by that?<br><br>I don't see many people | |
| IP14 | 2 respondents required the question to be reworded before could answer<br><br>2 responded "I don't know"<br><br>1 respondent qualified their answer with "to an extent" | "i wasnt quite sure about that one. Em, does that mean from a psychological point of view or that I actually wore the hand brace or...or what?" | |
| IP15 | A number of respondents appeared to experience difficulty in making sense of this question –<br>2 respondents hesitated before answering<br>A further 2 required the question to be re-read<br>A further 2 required the question to be rephrased<br><br>2 respondents queried what time period the question related to. | Qualifies answer with 'that night?' | Reword statement. Consider "There is nothing I can do to effect my symptoms" or "there was nothing I could do to effect my symptoms" depending on time point. |
| IP17 | 4 respondents required this question to be reread before answering.<br>1 respondent answered and then immediately changed their mind | | Reword statement. Consider "Any action I take (took) will (would) not effect the outcome of my illness |
| IP20 | 2 respondents required the question to be re-read before answering<br>1 explained they did not receive treatment | | Reword statement. Consider "My treatment is (was) effective in easing my symptoms" |
| IP21 | 1 respondent required | | Reword statement. |

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| | the question to be re-read before answering<br>A further 5 respondents required the question to be re-phrased<br>2 explained they did not receive treatment | | Consider "Treatment reduces the unpleasantness of my symptoms" |
| IP24 | 4 respondents required clarification of the time period being referred to<br>1 respondent explained that the symptoms themselves were not puzzling but why she got them was | "at the time yes, but now less so"<br>"they were…" | Clarify timepoint for coherence items. Consider e.g. "My symptoms were puzzling" |
| IP25 | As above | | See IP24 |
| IP27 | 3 respondents hesitated or were unsure about this question | "some did and some didn't" | |
| IP28 | 3 respondents explained that it required clarification what time period was being referred to | "Are you talking about at the time? Different now." | See IP24 |
| IP29 | 4 respondents identified that this depends on the nature of the illness | "type of thing its not all the time"<br><br>"leave blank because it was a one-off" | Consider excluding calls which relate to accidents.<br><br>Consider removing 'cyclic' items – If all other questions being asked of a particular timepoint i.e. time of call, it does not make sense to ask if change from day-to-day if wasa one-off |
| IP30 | 2 respondents indicated that this question was not relevant if the episode of symptoms were a one-off | "only applicable to something that is ongoing, this was a one-off" | See IP29 |
| IP31 | 2 respondents explained that it required clarification what time period was being referred to | | See IP29 |
| IP35 | 2 respondents indicated that angry was too strong a word | "would say frustrated"<br>"angry too strong a word" | Consider rewording to "My symptoms made me feel annoyed" |
| IP36 | 2 respondents required clarification due to the negative question | "I agree" - I check "They don't worry you?" - "Oh no I disagree, they do worry me"<br>Another respondent checked "do not?" before answering | Consider emboldening "not" and emphasising during telephone administration |
| IP37 | 3 respondents reported | "I'd like to qualify that. I | |

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| | being anxious about issues related to the symptoms e.g. what caused them or the consequences of them, but not about the actual symptom<br><br>3 respondents required clarification what time period was being referred to | was flying out to Milan the following day and that is why I was anxious, not just because of the symptoms. If that hadn't been happening I would not have been anxious"<br><br>"Having them or having had them?"<br><br>"Every now and again or every day?" | Clarify timepoint for emotion items. Consider e.g. "My symptoms did not worry me" |
| IP38 | 2 respondents indicated that afraid might be putting it too strongly | "to a degree"<br>"afraid too strong a word" | Consider rewording to "My symptoms frightened me" |
| IP41 (Caller only) | 2/?? Found this one difficult to answer | "Thats a hard one, can you repeat it?"<br>"Not entirely" | Clarity about time point referring to may lessen this confusion. Consider rewording "There was a lot I could do to control the patients symptoms" |
| IP42 (Caller only) | 1 | "Again its a hard one, tempted to agree but disagree, too direct" | Clarity about time point referring to may lessen this confusion |
| IP44 (Caller only) | 2 | "my actions?"<br>"again its difficult because sometimes yes and sometimes no" | Consider "Any action I take (took) will (did) not effect the outcome of the patients illness |
| IP45 (Caller only) | 1 | "at the time they were, less so now" | Clarity about time point referring to may lessen this confusion. Consider rewording "Their symptoms were puzzling to me" |
| IP46 (Caller only) | 1 | "At the time they were, I thought it was something but it was something totally different" | Clarity about time point referring to may lessen this confusion. Consider rewording "Their symptoms were a mystery to me" |
| IP47 (Caller only) | 3 | "I understood his symptoms but not what was causing them"<br>"I'm not a doctor. If I was getting paid for it well then…"<br>"I understand in a way" | Clarity about time point referring to may lessen this confusion. Consider rewording "I didn't understand their symptoms" |
| IP48 (Caller only) | 2 | "I understand that he is like that but I don't understand why"<br>"I understand in a way" | |
| Cause 1 | 1 participant could not answer<br><br>Another wanted to differentiate between the cause of the | "I haven't got a clue" | |

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| | physical symptoms he had experienced and those of anxiety | | |
| Cause 3 | 2 participants reported what the doctor had said and required prompting to provide their own views. | "Well that's what the doctors thought?"<br>"The doctor never said so". | Adjust instructions to make clear they do not have to be certain / correct cause. |
| Cause 8 | 3 participants described it as "their fault" at least to a degree but were hesitant to agree with this statement | | |
| Cause 9 | 2 participants required clarification | | |
| Cause 10 | 3 participants commented on how past personal worries may have contributed but explained that these were not recent | | |
| The most important causes for me | 6 respondents were able to articulate 3 causes easily<br><br>A further 3 respondents identified 2 causes<br><br>A further 4 respondents identified 1 cause<br><br>4 respondents had difficulty identifying any causes at all | "I havent a clue" | |
| How did you find the questionnaire? | 15 respondents indicated that they found it easy to respond<br><br>6 respondents reported finding it difficult to understand, confusing, too complex | "I found questions straight forward"<br><br>"no problem at all to answer questions"<br><br>"Found it all right. Some of them were easy to answer, some were not. I couldn't understand some of them - the wording "what does it mean". It was alright you know, I hope I was of help"<br><br>I found it complex and have to say if XXXX hadn't been so bad at responding he would have declined. It all looked complex. | Issues with individual questions will be addressed as above<br><br>Consider improving the 'look' of the questionnaire. |

| | | | |
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| | 4 respondents indicated that not all the questions were relevant to that particular call (e.g. accident) although a number also commented that they could see how it would be relevant in different circumstances<br><br>3 respondents found it difficult to answer as requested<br><br>2 respondents commented that repetition of the questions was problematic | I found it total rubbish. What has it got to do with my wife getting ill. I don't think it will help you learn anything. Won't do anything for National Health, they need to get their house in order first" - explains was back in A&E and waited for hours. Explains how he is paying our wages and that is what we should be doing rather than asking stupid questions about illness.<br><br>"When I looked at it I thought a lot of this does not apply to me"<br><br>"Didn't seem that relevant but could see how a lot of it could relate to a previous call when I thought I had bronchitis"<br><br>"Had a read of it and found it hard to just say yes/ no"<br><br>"answering so direct, its very hard to just answer as agree/diasagree"<br><br>"questions repeat themselves, ridiculousy so, you start to question yourself" | Consider excluding those who have had an accident.<br><br>Consider reducing no of options for answering to 3. Would this affect the reliability of the questionnaire and/or limit the ability of the questionnaire to detect differences in IP – advice please |
| Scale | 5 respondents do not use 'strongly' options at all<br><br>2 respondents only use after being prompted<br><br>A number of respondents answer yes/ no even after scale being described<br><br>3 respondents commented that scale was too complex | e.g. you sound very definite do you strongly disagree?<br><br>Makes life complicated<br><br>Might be daunting (5 options for responding)<br><br>Its very hard to answer | Consider reducing no of options for answering to 3. Would this affect the reliability of the questionnaire and/or limit the ability of the questionnaire to detect differences in IP – advice please |

| | | | |
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| | | agree/disagree | |
| Were you contacted at an appropriate time? | 17 agreed they were contacted at an appropriate time<br><br>2 were unsure, feeling taken aback at being called or expressing concern about how would feel if circumstances were different.<br><br>1 participant felt they were contacted too late and it was too late to remember | "2 weeks after the call, if was really ill could not be bothered but 3 weeks might forget important details so I think 2 weeks is perfect"<br><br>Feel timing was right - close to condition<br><br>I was taken aback, not sure. Good to phone back another time. Caught me on the hop. I got agitated thinking about what had happened and how was I going to put it into words. If you'd phoned earlier I wouldn't have been able to answer, still confused<br><br>It was OK but if it had been a heart attack and XXXX was in hospital I would have resented it. And if the person had died that would be almost unbearable. | Timing would seem to be OK. |
| Do you remember the reason you were in contact with NHS 24? | 15 respondents agreed they remembered the reason they were in contact with NHS 24<br><br>2 required prompting as to which call<br><br>1 respondent had trouble remembering | | People appear to remember their call to NHS 24. Consider including the date of the call to invitation letter to assist those with more than one call.<br><br>It is not considered possible to include the call reason for reasons of confidentiality. |
| Were the questions relevant to you? | 8 respondents agree the questions were relevant to them<br><br>4 respondents found some were not relevant<br><br>4 respondents did not find the questions relevant<br><br>2 further respondents | "questions were relevant"<br><br>"some not relevant, because it was never found out what the cause was, no treatment either"<br><br>Didn't seem that relevant but could see how a lot of | Some of this is understandable e.g. Q's about treatment where no treatment was offered.<br><br>People who had experienced accidents found questions relating to 'illness' or 'condition' not relevant – excluding these people may help to improve relevance. |

| | | | |
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| | stated that they did not find the questions particularly relevant to their particular symptoms on this occasion but could see relevance to others | it could relate to a previous call about when she thought she had bronchitis | |
| How long is it acceptable to take? | 4 respondents indicated that they would be happy to take as long as it takes<br><br>9 respondents indicated that up to 30 mins would be acceptable<br><br>9 respondents indicated that up to 20 mins would be acceptable<br><br>1 respondent indicated that 12 mins (actual time taken) was acceptable. | | Most respondents actually completed questionnaire in less than 20 mins. This was considered acceptable by almost all respondents.<br><br>Useful to explain to participants that they can stop at any time. |
| Could the instructions be any clearer? | 19 participants identified that the instructions were clear<br><br>1 commented that they could be clearer | "Instructions perfectly clear, fine."<br><br>"Could possibly be made clearer" (make clearer timepoint being referred to) | |
| If we had posted the questionnaire would you have responded? | 9 respondents indicated it was unlikely<br><br>8 respondents indicated they would definitely have responded<br><br>4 respondents indicated that they had intended to respond but now were unaware of where the documents were!<br><br>8 respondents expressed a preference for doing it over the phone, this included respondents who | "To be honest I forgot all about it, she has been ill too. Questionnaire last thing on your mind."<br><br>Would not have completed questionnaire , was going to write back and say sorry. The way to answer isn't my way of doing it.<br><br>"Would have filled it in"<br><br>"Would have filled it in but good to talk to somebody instead of just writing on the paper"<br><br>"May have got around to it, there is a chance it would've been overlooked. | Telephone approach seems to allow some people to participate who otherwise would not.<br><br>Simplifying and improving the relevance of the questionnaire may improve response by post. |

| | | | |
|---|---|---|---|
| | indicated they would respond to a questionnaire and those who indicated they would not. | Depends on when you catch me, good intentions, more chance over the phone | |
| How might we improve the questionnaire? | Avoid the tick-boxes and let people answer in their own way<br><br>Make sure the questions are relevant to the call<br><br>Reduce the repetition of the questions<br><br>Make it clearer the time frame we are talking about | "Sounds like a recipe, tick boxes, not bring out the emotion of what might be affecting the person"<br><br>"Just ask a question and let people answer in their own way, not degrees etc. Most people don't like answering these sort of questions.<br><br>"A simpler approach may make people more likely to respond"<br><br>"It's very hard to just answer as agree/disagree"<br><br>"Fine tuning actual calls chosen. Lots of questions were fundamental but not in relation to that call"<br><br>"Some questions repeat themselves"<br><br>"Are we speaking past or present –confusing"<br><br>"Main issue is about time frame" | Consider beginning with an open question. E.g. "Please tell us in your own words what led to you being in contact with NHS 24 on (date)"<br><br>Consider excluding calls for which questions may not seem relevant e.g. medicine-related enquiries; accidents<br><br>Clarity about timepoint as discussed elsewhere. |
| Caller IPQ | 1 caller participant checked responses with the patient (his wife).<br><br>The labels are missing from the top of that sheet which makes it difficult to identify the correct column to tick. | | Might be useful to include an instruction not to do this<br><br>Insert the labels |
| Learning points for me in administering over the questionnaire by phone | Addressing people by first name<br><br>Forgetting to explain that call being recorded | Should ask what people would like me to call them<br><br>Useful to explain being recorded so can keep a note of what they have said | Added to interview schedule as a aide-memoir<br><br>Added to interview schedule |

| | | | |
|---|---|---|---|
| | Apologised on a couple of occasions for the questionnaire<br><br>Stated that I had a note of the participants age<br><br>People state 'not relevant' or similar | | Should avoid this<br><br>Might be better to ask their age than to state already know. Might cause anxiety about what other personal information we have recorded.<br><br>Would be helpful to ask 'why not?' |

*Appendix 28*

# ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

**Study ID No……** **Date……**

## YOUR VIEWS ABOUT YOUR ILLNESS

**We are interested in what leads people to seek medical help for their symptoms. Please describe in your own words what led you to be in contact with NHS 24.**

**Listed below are a number of symptoms that you may or may not have experienced recently.**

1) **Please <u>underline</u> any symptoms you have experienced within the last 2 weeks**
2) **Please <u>circle</u> any that relate <u>to why you were in contact with NHS 24.</u>**

**If you experienced additional symptoms that are not on the list please feel free to add them and underline or circle as appropriate.**

| | | | |
|---|---|---|---|
| **Pain** | **Discomfort** | **Numbness** | **Sore throat** |
| **Nausea** | **Breathlessness** | **Weight loss** | **Collapse** |
| **Tiredness** | **Sweating** | **Stiff joints** | **Sore Eyes** |
| **Wheeziness** | **Headache** | **Upset stomach** | **Sleep difficulties** |
| **Vomiting** | **Dizziness** | **Loss of strength** | **Pins and needles** |

**We are interested in your own personal views of how you now see your current illness.**
**Please indicate by ticking the appropriate box how much you agree or disagree with the following statements about your symptoms AT THE TIME YOU CONTACTED NHS 24.**

| | I thought….. | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP1* | My symptoms would last a short time | | | | | |
| IP2 | My symptoms were likely to be permanent rather than temporary | | | | | |
| IP3 | My symptoms would last for a long time | | | | | |
| IP4* | My symptoms would pass quickly | | | | | |
| IP5 | I would have these symptoms for the rest of my life | | | | | |
| IP6 | My illness was a serious condition | | | | | |
| IP7 | My symptoms would have major negative consequences on my life | | | | | |
| IP8* | My symptoms would not have much effect on my life | | | | | |
| IP9 | My symptoms would strongly effect the way others see me | | | | | |
| IP10 | My symptoms would have serious financial consequences | | | | | |
| IP11 | My symptoms would cause difficulties for those who are close to me | | | | | |
| IP12 | There was a lot I could do to control my symptoms | | | | | |
| IP13 | What I did could determine whether my symptoms got better or worse | | | | | |
| IP14 | The course of my illness depended on me | | | | | |
| IP15* | There was nothing I could do to effect my symptoms | | | | | |
| IP16 | I had the power to influence my symptoms | | | | | |
| IP17* | Any action I took would not affect the outcome of my illness | | | | | |
| IP18* | My symptoms would improve in time | | | | | |
| IP19* | There was very little that could be done to improve my symptoms | | | | | |
| IP20 | My treatment would be effective in easing my symptoms | | | | | |
| IP21 | Treatment would reduce the unpleasantness of my symptoms | | | | | |
| IP22 | My treatment could control my symptoms | | | | | |
| IP23* | There was nothing which could help my condition | | | | | |
| IP24 | The symptoms of my condition were puzzling to me | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP25 | My symptoms were a mystery to me | | | | | |
| IP26 | I did not understand my symptoms | | | | | |
| IP27 | My symptoms didn't make any sense to me | | | | | |
| IP28* | I had a clear picture or understanding of my condition | | | | | |
| IP33 | I felt depressed about my symptoms | | | | | |
| IP34 | I was upset about my symptoms | | | | | |
| IP35 | My symptoms made me feel annoyed | | | | | |
| IP36* | My symptoms did NOT worry me | | | | | |
| IP37 | Having these symptoms made me feel anxious | | | | | |
| IP38 | My symptoms frightened me | | | | | |

## CAUSES OF MY ILLNESS

**We are interested in what <u>you</u> considered may have been causing your symptoms at the time you were in contact with NHS 24. As people are very different, there is no correct answer for this question. We are most interested in <u>your own views</u> about the factors that may have caused your symptoms rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your symptoms. Please indicate how much you agree or disagree that they may have been causes for you by ticking the appropriate box.**

| | POSSIBLE CAUSES | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C1 | Stress or worry | | | | | |
| C2 | Hereditary - it runs in my family | | | | | |
| C3 | A Germ or virus | | | | | |
| C4 | Diet or eating habits | | | | | |
| C5 | Chance or bad luck | | | | | |
| C6 | Poor medical care in my past | | | | | |
| C7 | Pollution in the environment | | | | | |
| C8 | My own behaviour | | | | | |
| C9 | My mental attitude e.g. thinking about life negatively | | | | | |
| C10 | Family problems or worries caused my illness | | | | | |
| C11 | Overwork | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C12 | **My emotional state e.g. feeling down, lonely, anxious, empty** | | | | | |
| C13 | **Ageing** | | | | | |
| C14 | **Alcohol** | | | | | |
| C15 | **Smoking** | | | | | |
| C16 | **Accident or injury** | | | | | |
| C17 | **My personality** | | | | | |
| C18 | **Being 'rundown'** | | | | | |

**Below, please list in rank-order the three most important factors that you believed might be causing <u>YOUR</u> symptoms at the time you called NHS 24. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. _____

2. _____

3. _____

## ADDITIONAL INFORMATION

**In order to help us understand the information you have provided better, it would be very helpful if you could tell us a little about yourself.**

**1. What is your age? _____**

**2. Are you male or female? _____**

**3. What is your ethnic group?** Choose one section from A to E, tick box if appropriate or add your own description.

| | | |
|---|---|---|
| **I. White**<br>Scottish ☐<br>British ☐<br>Irish ☐<br><br>Other white background? (please state) | **J. Asian, Asian Scottish or Asian British**<br>Indian ☐<br>Pakistani ☐<br>Bangladeshi ☐<br>Chinese ☐<br><br>Other asian background? (please state) | **K. Black**<br>Caribbean ☐<br>African ☐<br><br>Other black background? (please state) |
| **L. Mixed** ☐ | E. **Any other ethnic background** (please state) | |

## HOW DID YOU FIND THIS QUESTIONNAIRE?

**We are interested in hearing your views about completing the questionnaire. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| | **The questionnaire was easy to complete** | | | | | |
| | **I was contacted at an appropriate time** | | | | | |
| | **The questions were relevant to me** | | | | | |
| | **I remember the reason I was in contact with NHS 24** | | | | | |

**Please feel free to make any additional comments below or overleaf:**

**Once completed please put this questionnaire and a signed consent form in the stamped, addressed envelope provided. Please post it within a week if possible. Thank you very much for taking part in this study.**

*Appendix 29*

# CALLER ILLNESS PERCEPTION QUESTIONNAIRE

**Study ID No……** **Date……**

## YOUR VIEWS ABOUT THE PATIENT'S SYMPTOMS

**We are interested in what leads people to seek medical help for others. Please describe in your own words what led you to be in contact with NHS 24.**

**Listed below are a number of symptoms that the patient may or may not have experienced recently.**

3) **Please <u>underline</u> any symptoms they have experienced within the last 2 weeks**
4) **Please <u>circle</u> any that relate <u>to why you were in contact with NHS 24.</u>**

**If they have experienced additional symptoms that are not on the list please feel free to add them and underline or circle as appropriate. If you do not know about a particular symptom, please just write "don't know" beside it.**

| | | | |
|---|---|---|---|
| **Pain** | **Discomfort** | **Numbness** | **Sore throat** |
| **Nausea** | **Breathlessness** | **Weight loss** | **Collapse** |
| **Tiredness** | **Sweating** | **Stiff joints** | **Sore Eyes** |
| **Wheeziness** | **Headache** | **Upset stomach** | **Sleep difficulties** |
| **Vomiting** | **Dizziness** | **Loss of strength** | **Pins and needles** |

**We are interested in YOUR own personal views about the patient's symptoms. Please indicate how much you agree or disagree with the following statements about the patient's symptoms by ticking the appropriate box.**

| | I thought… | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP1* | Their symptoms would last a short time | | | | | |
| IP2 | Their symptoms were likely to be permanent rather than temporary | | | | | |
| IP3 | Their symptoms would last for a long time | | | | | |
| IP4* | Their symptoms would pass quickly | | | | | |
| IP5 | They would have these symptoms for the rest of their life | | | | | |
| IP6 | Their illness was a serious condition | | | | | |
| IP7 | Their symptoms would have major negative consequences on their life | | | | | |
| IP8* | Their symptoms would not have much effect on their life | | | | | |
| IP9 | Their symptoms would strongly effect the way others see them | | | | | |
| IP10 | Their symptoms would have serious financial consequences | | | | | |
| IP11 | Their symptoms would cause difficulties for those who are close to them | | | | | |
| IP12 | There was a lot they could do to control their symptoms | | | | | |
| IP13 | What they did could determine whether their symptoms got better or worse | | | | | |
| IP14 | The course of their illness depended on them | | | | | |
| IP15* | There was nothing they could do to effect their symptoms | | | | | |
| IP16 | They had the power to influence their symptoms | | | | | |
| IP17* | Any action they took would not effect the outcome of their illness | | | | | |
| IP18* | Their symptoms would improve in time | | | | | |
| IP19* | There was very little that could be done to improve their symptoms | | | | | |
| IP20 | Their treatment would be effective in easing their symptoms | | | | | |
| IP21 | Treatment would reduce the unpleasantness of their symptoms | | | | | |
| IP22 | Their treatment can control their symptoms | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP23* | **There was nothing which could help their condition** | | | | | |
| IP24 | **The symptoms of their condition were puzzling to them** | | | | | |
| IP25 | **Their symptoms were a mystery to them** | | | | | |
| IP26 | **They did not understand their symptoms** | | | | | |
| IP27 | **Their symptoms didn't make any sense to them** | | | | | |
| IP28* | **They had a clear picture or understanding of their condition** | | | | | |
| IP33 | **They felt depressed about their symptoms** | | | | | |
| IP34 | **They were upset about their symptoms** | | | | | |
| IP35 | **Their symptoms made them feel annoyed** | | | | | |
| IP36* | **Their symptoms did NOT worry them** | | | | | |
| IP37 | **Having these symptoms made them feel anxious** | | | | | |
| IP38 | **Their symptoms frightened them** | | | | | |

**We are also interested in exploring how the patient's illness affected <u>you</u>.**
**Please indicate how much you agree or disagree with the following statements about the patient's symptoms by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP39 | **There was a lot that I could do to control the patient's symptoms** | | | | | |
| IP40 | **What I did could determine whether their symptoms got better or worse** | | | | | |
| IP41 | **The course of their illness depended on me** | | | | | |
| IP42* | **There was nothing I could do to effect their symptoms** | | | | | |
| IP43 | **I had the power to influence the patient's symptoms** | | | | | |
| IP44* | **Any action I took would not effect the outcome of their illness** | | | | | |
| IP45 | **The symptoms of their condition were puzzling to me** | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP46 | **Their symptoms were a mystery to me** | | | | | |
| IP47 | **I did not understand their symptoms** | | | | | |
| IP48 | **Their symptoms didn't make any sense to me** | | | | | |
| IP49* | **I had a clear picture or understanding of their condition** | | | | | |
| IP50 | **I felt depressed about their symptoms** | | | | | |
| IP51 | **I was upset about their symptoms** | | | | | |
| IP52 | **Their symptoms made me feel annoyed** | | | | | |
| IP53* | **Their symptoms did NOT worry me** | | | | | |
| IP54 | **The patient having these symptoms made me feel anxious** | | | | | |
| IP55 | **Their symptoms frightened me** | | | | | |

## CAUSES OF THEIR ILLNESS

**We are interested in what <u>you</u> consider may have been the causing the patient's symptoms at the time you were in contact with NHS 24. As people are very different, there is no correct answer for this question. We are most interested in <u>your own views</u> about the factors that may have caused the patient's symptoms rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for their symptoms. Please indicate how much you agree or disagree that they may have been causes for them by ticking the appropriate box.**

| | POSSIBLE CAUSES | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C1 | **Stress or worry** | | | | | |
| C2 | **Hereditary - it runs in their family** | | | | | |
| C3 | **A Germ or virus** | | | | | |
| C4 | **Diet or eating habits** | | | | | |
| C5 | **Chance or bad luck** | | | | | |
| C6 | **Poor medical care in the past** | | | | | |
| C7 | **Pollution in the environment** | | | | | |
| C8 | **Their own behaviour** | | | | | |
| C9 | **Their mental attitude e.g. thinking about life negatively** | | | | | |
| C10 | **Family problems or worries** | | | | | |
| C11 | **Overwork** | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C12 | **Their emotional state e.g. feeling down, lonely, anxious, empty** | | | | | |
| C13 | **Ageing** | | | | | |
| C14 | **Alcohol** | | | | | |
| C15 | **Smoking** | | | | | |
| C16 | **Accident or injury** | | | | | |
| C17 | **Their personality** | | | | | |
| C18 | **Being 'rundown'** | | | | | |

**In the table below, please list in rank-order the three most important factors that you believed might be causing <u>the patients</u> symptoms at the time you called NHS 24. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. _____

2. _____

3. _____

## ADDITIONAL INFORMATION

**In order to help us understand the information you have provided better, it would be very helpful if you could tell us a little about yourself.**

**1. What is your age? _____**

**2. Are you male or female? _____**

**3. What is your relationship to the patient? _____**

**4. What is your ethnic group?** Choose one section from A to E, tick box if appropriate or add your own description.

| | | |
|---|---|---|
| **M. White**<br>Scottish ☐<br>British ☐<br>Irish ☐<br><br>Other white background? (please state) | **N. Asian, Asian Scottish or Asian British**<br>Indian ☐<br>Pakistani ☐<br>Bangladeshi ☐<br>Chinese ☐<br><br>Other asian background? (please state) | **O. Black**<br>Caribbean ☐<br>African ☐<br><br>Other black background? (please state) |
| **P. Mixed** ☐ | E. **Any other ethnic background** (please state) | |

## HOW DID YOU FIND THIS QUESTIONNAIRE?

**We are interested in hearing your views about completing the questionnaire. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| PF1 | **The questionnaire was easy to complete** | | | | | |
| PF2 | **I was contacted at an appropriate time** | | | | | |
| PF3 | **The questions were relevant to me** | | | | | |
| PF4 | **I remember the reason I was in contact with NHS 24** | | | | | |

**Please feel free to make any additional comments below or overleaf:**

**Once completed please put this questionnaire and a signed consent form in the stamped, addressed envelope provided. Please post it within a week if possible. Thank you very much for taking part in this study.**

***Appendix 30***

Dear {patients name},

My name is Barbara Farquharson, I am a nurse working with NHS 24. I am currently undertaking a research project which aims to better understand how people seek medical help with particular medical symptoms.

I am writing to invite you to take part in this study. You have been selected after recently being in contact with NHS 24. You have been selected using a method that ensures everyone with these types of symptoms has an equal chance of being chosen.

I am aware that it is possible that I may be contacting you at a difficult time and I do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider participating please read the enclosed *Patient Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have. If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112

*Appendix 31*

## Participant Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part.

### What is the purpose of the study?

The study is part of a PhD studentship. The aim is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

A number of people who have been in contact with NHS 24 recently have been invited to take part. You were selected using a process that ensures everyone who called NHS 24 recently with particular medical symptoms has an equal chance of being chosen.

As some people who call NHS 24 are very unwell, there is a small possibility that you have opened this letter on behalf of someone who has recently died. If this is the case, we apologise for troubling you and offer you our deepest sympathies. If you wish to simply ignore this request we completely understand – please just return all the

information in the reply paid envelope. However, if you do feel able to consider taking part we believe you could help us gain a better insight into how people get help for serious symptoms. Whilst, unfortunately, this will not benefit the person we wrote to, it may help us to improve things for others in the future.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you do not need to take any action. The researcher will contact you over the next few days to confirm that you wish to take part and to make further arrangements with you.

If you do not wish to take part, please respond to the researcher as soon as possible. Please either return the enclosed *'I decline'* card in the pre-paid envelope *or* telephone [*mobile number]* and leave a message including this study number -[study number]. You will not need to talk to anyone and will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

If you do not respond within 3 days the researcher will telephone you. You should be aware that this call will be recorded. If you receive this call, you are still under no obligation to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

If you do decide to take part we will send you a written record of the consent you have given. You may also keep this information sheet.

**What will happen to me if I take part?**

You will be asked to take part in an interview by telephone. The researcher who contacts you will confirm you wish to take part and make arrangements to interview you at a convenient time. The interview will be carried out by telephone and will last up to 30

minutes. The questions will be about the symptoms you experienced before contacting NHS 24, and your thoughts and feelings about those symptoms. The enclosed Illness Perception Questionnaire contains similar questions to those you will be asked.
You will also be asked to give your permission for the researcher to access your general practice records in approximately 3 months time to obtain additional information –

- what (if any) diagnosis did you receive at the time of your symptoms
- what (if any) diagnoses have you received in the following 3 months
- if you have ever been diagnosed with diabetes

We will ask permission to access the original voice-recording at NHS 24 to obtain details of the symptoms you described at the time you called.
It may be that you could help us with other research in the future. We will check whether you would be happy to be contacted again should this be the case.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the

course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

If you decide to take part in this study we would like to inform your GP that you are doing so. You will be given the opportunity to advise us if you do not wish for that to happen.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be submitted to healthcare journals for publication. You will not be identified in any report or publication. You will be given the opportunity to request a summary of the results.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by Fife and Forth Valley NHS Research Ethics Committee and by the Department of Nursing and Midwifery Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry

Tel: 01786 466112

**Thank-you for reading this information. Please keep this leaflet for your own records.**

***Appendix 32***

# I decline

To take part in

Study Title: What factors influence people's behaviour when seeking help with symptoms?

Study Number: XXXX

If you would like to give a reason please write it here:

Please return in enclosed stamped addressed envelope

## *Appendix 33*

**Invitation schedule**

Ask for patient, introduce self

Explain call being recorded

Check received and read study information

Check understanding

Request consent

- to take part interview/ questionnaire as appropriate
- to access recording of call
- to obtain details of outcome of this call and any diagnosis at 3 months from GP
- to contact you again in the future if necessary

| NO | YES |
|---|---|
| Consider asking for a reason | Thank you for taking part |
| Thank you for your time | Clarify can withdraw at any time |
| End call | Make arrangements for interview/ completion of questionnaire as appropriate.<br>If appropriate enquire if they have details of 3rd party<br>Request consent to contact 3rd party<br>Would you like to receive a summary of the results of the research? |

## *Appendix 34*

[Date}

[Patient Name and Address]

Dear [patient name]

*Re: What factors influence people's behaviour when seeking help with symptoms?*

Thank you very much for agreeing to take part in the above research study. This is to confirm that on [date]

1. you confirmed to me you had read and understood the study information

2. you had the opportunity to ask questions

3. you gave your consent for me to access the recording of your call to NHS 24 made on [date]

4. you gave consent for me to obtain details of the outcome of this call and any diagnosis at 3 months from your GP

5. you agreed it would be acceptable for someone from the research team to contact you again regarding this study if necessary.

I hope this accurately reflects our discussion. If not please let me know as soon as possible. You are free to withdraw from the study at any time - please just call me on the number below and leave a message stating your study number.

If anything is unclear or you would like further information please just call me on the number below.

Thank you once again for your help, your participation is very much appreciated.

Yours sincerely,

Barbara Farquharson
Tel: 01786 466112

## *Appendix 35*

**Interview schedule**

- Introduction and thanks
- Re-check consent
- Explanation of what interview will involve, expected duration
- Opportunity for participant to ask questions
- Instructions read from IPQ-R
- Check understanding
- Read questions from IPQ-R
- Confirm contact details for any future correspondence
- Thank you and goodbye

***Appendix 36***

Dear {patients name},

My name is Barbara Farquharson, I am currently undertaking a research project which aims to better understand how people seek medical help with particular medical symptoms.

I am writing to invite you to take part in this study. You have been selected after recently being in contact with NHS 24. You have been selected using a method that ensures everyone with these types of symptoms has an equal chance of being chosen.

I am aware that it is possible that I may be contacting you at a difficult time and I do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider participating please read the enclosed *Patient Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have.

I understand that, in your case, the telephone call to NHS 24 was made by someone other than yourself. Where possible, I would be very interested in hearing their views too. Therefore, if you could pass the '*Caller Information'* on to the person who called on your behalf, it would be very helpful.

If you wish to take part but are unable to pass this information onto the person who made the call, do not worry. Please simply follow the instructions contained in the *'Patient Information Sheet'*.

If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112

***Appendix 37***

Dear caller

My name is Barbara Farquharson; I am a nurse working with NHS 24. I am currently undertaking a research project which aims to better understand how people seek medical help with particular symptoms.

I am writing to invite you to take part in this study. Patients have been selected after recently being in contact with NHS 24. You are being approached as you were involved in making a call on behalf of one of the patients selected. I have asked them to pass this information to you.

I am aware that it is possible that I may be contacting you at a difficult time and do not wish to cause you any concern. If you feel unable to deal with this request at this time, please simply return all the enclosed information in the envelope provided and accept my apologies for troubling you.

However, if you feel able to consider taking part please read the enclosed *Caller Information Sheet* carefully. It explains clearly what the study involves and should answer any questions you might have. If you require any additional information please contact me on the number below. Thank you for your assistance.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112

*Appendix 38*

## Caller Information Sheet

**Study Title: What factors influence people's behaviour when seeking help with symptoms?**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part. Thank you for reading this information.

### What is the purpose of the study?

The study is part of a PhD studentship. The aim is to learn how people's personal circumstances and thoughts about their symptoms influence how and when they contact health services. We are also interested in the views of other people who were present when the telephone call to NHS 24 was made. It is hoped this information will help us to adapt services to make sure that people get the help they need, as quickly as possible.

### Why have I been chosen?

A number of telephone calls to NHS 24 have been selected using a process that ensures that everyone who called NHS 24 recently with particular medical symptoms has an equal chance of being chosen. The patients have been invited to participate in this study. Where someone else made the telephone call on their behalf we have asked them to pass this information to that person. You are being approached as you were involved in making the telephone call to

NHS 24 on behalf of one of the patients selected. We are interested in exploring your thoughts about the patient's symptoms.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you do not need to take any action. The researcher will contact you over the next few days to confirm that you wish to take part and to make further arrangements with you.

If you do not wish to take part, please respond to the researcher as soon as possible. Please either return the enclosed 'I decline' card in the pre-paid envelope or telephone [*mobile number]* and leave a message including this study number -[study number]. You will not need to talk to anyone and will not be contacted about this study again. If you would like to provide the reason why you feel unable to take part, we would find that very helpful.

If you do not respond within 3 days the researcher will telephone you. You should be aware that this call will be recorded. If you receive this call, you are still under no obligation to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

If you do decide to take part we will send you a written record of the consent you have given. You may also keep this information sheet.

**What will happen to me if I take part?**

You will also be asked to take part in an interview by telephone. The researcher who contacts you will confirm you wish to take part and make arrangements to interview you at a convenient time. The interview will be carried out by telephone and will last up to 30 minutes. The questions will be about the symptoms the patient experienced prior to you contacting NHS 24, and your thoughts and feelings about those symptoms. The enclosed Illness Perception Questionnaire contains similar questions to those you will be asked.

**What are the possible risks/ disadvantages of taking part?**

Some people may find being asked to recall the events which led them to contact health services distressing. Others may find it helpful to do so.

**What are the possible benefits of taking part?**

There is no direct benefit for you in taking part. However, the information gained from this study may help us to better understand how people seek help with symptoms. This may inform how services are developed to better meet the needs of the public.

**What if something goes wrong?**

It is unlikely you will be harmed by taking part in this study. However, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Gill Stillie, Associate Director of Nursing, NHS 24, Norseman House, South Queensferry, EH30 9QZ.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. It will not be possible to identify you from any information which leaves NHS premises.

**What will happen to the results of the research study?**

The results of the study will be reported in a PhD thesis which will be available in the University of Stirling. The results will also be submitted to healthcare journals for publication. You will not be identified in any report or publication. You will be given the opportunity to request a summary of the results.

**Who is organising and funding the research?**

This study is being organised jointly between NHS 24 and the Universities of Stirling and Aberdeen. It has been funded by the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Training Scheme which was developed in association with NHS Education for Scotland (NES), The Scottish Executive and The Health Foundation. No-one will receive payment as a result of your participation.

**Who has reviewed the study?**

The study has been reviewed by the Departmental Research Ethics Committee, University of Stirling and by Fife and Forth Valley NHS Research Ethics Committee.

**Who should I contact for further information?**

Should you have any questions or require further information please do not hesitate to contact

Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry

Tel: 01786 466112

Thank-you for reading this information. Please keep this leaflet for your own records.

*Appendix 39*

# ILLNESS PERCEPTION QUESTIONNAIRE

**Study ID No**……

## *YOUR VIEWS ABOUT YOUR SYMPTOMS*

We are interested in what leads people to seek medical help for their symptoms. Please describe in your own words what led you to be in contact with NHS 24.

## *THE TIMING OF YOUR SYMPTOMS*

We are interested in how long you experienced your symptoms before you decided to contact health services. It is really important that this is as accurate as possible, so we ask that you think carefully and double-check your dates and times.

**T1: When did you first notice the symptoms you spoke to NHS 24 about?**

**Day:** **Month:** **Year:**

**Time:** **am/pm** (please circle as appropriate)

**T1: When did you your symptoms begin to cause you real concern?**

**Day:** **Month:** **Year:**

**Time:** **am/pm** (please circle as appropriate)

**T3: Did you contact any other health professional before you spoke to NHS 24?** (please circle as appropriate)

**No Yes - if yes Who?**
**At what time?**

## *VIEWS ABOUT YOUR ILLNESS*

**Listed below are a number of symptoms that you may or may not have experienced when you contacted NHS 24. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms recently and whether these symptoms relate to why you were in contact with NHS 24.**

| | **I have *experienced this symptom* recently (within last 2 weeks)** | | | **This symptom is *related to why I was in contact with NHS 24*** | |
|---|---|---|---|---|---|
| **Pain** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Discomfort** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Numbness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Sore Throat** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Nausea** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Breathlessness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Weight Loss** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Tiredness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Stiff Joints** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Collapse** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Wheeziness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Headaches** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Upset Stomach** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Sleep Difficulties** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Dizziness** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Loss of Strength** | **Yes** | **No** | **_____** | **Yes** | **No** |
| **Pins and needles** | **Yes** | **No** | **_____** | **Yes** | **No** |

**We are interested in your own personal views of how you now see your current illness.**

**Please indicate by ticking the appropriate box how much you agree or disagree with the following statements about your symptoms AT THE TIME YOU CONTACTED NHS 24.**

| | I thought….. | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP1* | My symptoms would last a short time | | | | | |
| IP2 | My symptoms were likely to be permanent rather than temporary | | | | | |
| IP3 | My symptoms would last for a long time | | | | | |
| IP4* | My symptoms would pass quickly | | | | | |
| IP5 | I would have these symptoms for the rest of my life | | | | | |
| IP6 | My illness was a serious condition | | | | | |
| IP7 | My symptoms would have major negative consequences on my life | | | | | |
| IP8* | My symptoms would not have much effect on my life | | | | | |
| IP9 | My symptoms would strongly effect the way others see me | | | | | |
| IP10 | My symptoms would have serious financial consequences | | | | | |
| IP11 | My symptoms would cause difficulties for those who are close to me | | | | | |
| IP12 | There was a lot I could do to control my symptoms | | | | | |
| IP13 | What I did could determine whether my symptoms got better or worse | | | | | |
| IP14 | The course of my illness depended on me | | | | | |
| IP15* | There was nothing I could do to effect my symptoms | | | | | |
| IP16 | I had the power to influence my symptoms | | | | | |
| IP20 | My treatment would be effective in easing my symptoms | | | | | |
| IP21 | Treatment would reduce the unpleasantness of my symptoms | | | | | |
| IP22 | My treatment could control my symptoms | | | | | |
| IP23* | There was nothing which could help my condition | | | | | |
| IP24 | The symptoms of my condition were puzzling to me | | | | | |
| IP25 | My symptoms were a mystery to me | | | | | |
| IP26 | I did not understand my symptoms | | | | | |
| IP27 | My symptoms didn't make any sense to me | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| IP29 | My symptoms change a great deal from day to day | | | | | |
| IP30 | My symptoms come and go in cycles | | | | | |
| IP31 | My symptoms are very unpredictable | | | | | |
| IP32 | I go through cycles in which my symptoms get better and worse. | | | | | |
| IP33 | I felt depressed about my symptoms | | | | | |
| IP34 | I was upset about my symptoms | | | | | |
| IP35 | My symptoms made me feel annoyed | | | | | |
| IP36* | My symptoms did NOT worry me | | | | | |
| IP37 | Having these symptoms made me feel anxious | | | | | |
| IP38 | My symptoms frightened me | | | | | |

## CAUSES OF MY ILLNESS

**We are interested in what <u>you</u> considered may have been causing your symptoms at the time you were in contact with NHS 24. As people are very different, there is no correct answer for this question. We are most interested in <u>your own views</u> about the factors that may have caused your symptoms rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your symptoms. Please indicate how much you agree or disagree that they may have been causes for you by ticking the appropriate box.**

| | POSSIBLE CAUSES | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C1 | Stress or worry | | | | | |
| C2 | Hereditary - it runs in my family | | | | | |
| C3 | A Germ or virus | | | | | |
| C4 | Diet or eating habits | | | | | |
| C5 | Chance or bad luck | | | | | |
| C6 | Poor medical care in my past | | | | | |
| C7 | Pollution in the environment | | | | | |
| C8 | My own behaviour | | | | | |
| C9 | My mental attitude e.g. thinking about life negatively | | | | | |
| C10 | Family problems or worries caused my illness | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| C11 | **Overwork** | | | | | |
| C12 | **My emotional state e.g. feeling down, lonely, anxious, empty** | | | | | |
| C13 | **Ageing** | | | | | |
| C14 | **Alcohol** | | | | | |
| C15 | **Smoking** | | | | | |
| C16 | **Accident or injury** | | | | | |
| C17 | **My personality** | | | | | |
| C18 | **Being 'rundown'** | | | | | |

**Below, please list in rank-order the three most important factors that you believed might be causing <u>YOUR</u> symptoms at the time you called NHS 24. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. _____

2. _____

3. _____

## ADDITIONAL INFORMATION

**In order to help us understand the information you have provided better, it would be very helpful if you could tell us a little about yourself.**

**1. What is your age? _____**

**2. Are you male or female? _____**

**3. On what date did you complete this questionnaire?_____**

**4. What is your ethnic group?** Choose one section from A to E, tick box if appropriate or add your own description.

| | | |
|---|---|---|
| **Q. White**<br>Scottish ☐<br>British ☐<br>Irish ☐<br><br>Other white background? (please state) | **R. Asian, Asian Scottish or Asian British**<br>Indian ☐<br>Pakistani ☐<br>Bangladeshi ☐<br>Chinese ☐<br><br>Other asian background? (please state) | **S. Black**<br>Caribbean ☐<br>African ☐<br><br>Other black background? (please state) |
| **T. Mixed** ☐ | E. **Any other ethnic background** (please state) | |

## HOW DID YOU FIND THIS QUESTIONNAIRE?

**We are interested in hearing your views about completing the questionnaire. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| | **The questionnaire was easy to complete** | | | | | |
| | **I was contacted at an appropriate time** | | | | | |
| | **The questions were relevant to me** | | | | | |
| | **I remember the reason I was in contact with NHS 24** | | | | | |

**Please feel free to make any additional comments below or on an additional sheet:**

**Once completed please in the stamped, addressed envelope provided. Please post it within a week if possible. Thank you very much for taking part in this study.**

*Appendix 40*

# CALLER ILLNESS PERCEPTION QUESTIONNAIRE

**Study ID No……**

## *YOUR VIEWS ABOUT THE PATIENT'S SYMPTOMS*

We are interested in what leads people to seek medical help for others. Please describe in your own words what led you to be in contact with NHS 24.

## *THE TIMING OF THE PATIENTS SYMPTOMS*

We are interested in how long the patient (the person you spoke to NHS 24 about) experienced symptoms before you decided to contact health services. It is really important that this is as accurate as possible, so we ask that you think carefully and double-check your dates and times.

### T1: When did the patient first notice the symptoms you spoke to NHS 24 about?

**Day:** **Month:** **Year:**

**Time:** **am/pm** (please circle as appropriate)

### T1: When did the patients symptoms begin to cause you real concern?

**Day:** **Month:** **Year:**

**Time:** **am/pm** (please circle as appropriate)

**T3: Did you contact any other health professional before you spoke to NHS 24?** (please circle as appropriate)

**No Yes - if yes Who?**
**At what time?**

## *VIEWS ABOUT THE PATIENT'S ILLNESS*

**Listed below are a number of symptoms that the patient may or may not have experienced when you contacted NHS 24. Please indicate by circling *Yes* or *No*, whether you believe they have experienced any of these symptoms recently (within last 2 weeks) and whether these symptoms relate to why you were in contact with NHS 24.**

| | **They have *experienced this symptom* recently (within last 2 weeks)** | | | **This symptom is *related to why I contacted NHS 24 on their behalf*** | |
|---|---|---|---|---|---|
| **Pain** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Discomfort** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Numbness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Sore Throat** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Nausea** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Breathlessness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Weight Loss** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Tiredness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Stiff Joints** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Collapse** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Wheeziness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Headaches** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Upset Stomach** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Sleep Difficulties** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Dizziness** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Loss of Strength** | **Yes** | **No** | **Don't know** | **Yes** | **No** |
| **Pins and needles** | **Yes** | **No** | **Don't know** | **Yes** | **No** |

**We are interested in YOUR own personal views about the patient's symptoms.**

**Please indicate how much you agree or disagree with the following statements about the patient's symptoms by ticking the appropriate box.**

| | I thought… | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CIP1* | Their symptoms would last a short time | | | | | |
| CIP2 | Their symptoms were likely to be permanent rather than temporary | | | | | |
| CIP3 | Their symptoms would last for a long time | | | | | |
| CIP4* | Their symptoms would pass quickly | | | | | |
| CIP5 | They would have these symptoms for the rest of their life | | | | | |
| CIP6 | Their illness was a serious condition | | | | | |
| CIP7 | Their symptoms would have major negative consequences on their life | | | | | |
| CIP8* | Their symptoms would not have much effect on their life | | | | | |
| CIP9 | Their symptoms would strongly effect the way others see them | | | | | |
| CIP10 | Their symptoms would have serious financial consequences | | | | | |
| CIP11 | Their symptoms would cause difficulties for those who are close to them | | | | | |
| CIP12 | There was a lot they could do to control their symptoms | | | | | |
| CIP13 | What they did could determine whether their symptoms got better or worse | | | | | |
| CIP14 | The course of their illness depended on them | | | | | |
| CIP15* | There was nothing they could do to effect their symptoms | | | | | |
| CIP16 | They had the power to influence their symptoms | | | | | |
| CIP19* | There was very little that could be done to improve their symptoms | | | | | |
| CIP20 | Their treatment would be effective in easing their symptoms | | | | | |
| CIP21 | Treatment would reduce the unpleasantness of their symptoms | | | | | |
| CIP22 | Their treatment would control their symptoms | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CIP23 * | **There was nothing which could help their condition** | | | | | |
| CIP24 | **The symptoms of their condition were puzzling to them** | | | | | |
| CIP25 | **Their symptoms were a mystery to them** | | | | | |
| CIP26 | **They did not understand their symptoms** | | | | | |
| CIP27 | **Their symptoms didn't make any sense to them** | | | | | |
| CIP29 | **Their symptoms changed a great deal from day to day** | | | | | |
| CIP30 | **Their symptoms came and went in cycles** | | | | | |
| CIP31 | **Their symptoms were very unpredictable** | | | | | |
| CIP32 | **They went through cycles in which their symptoms got better and worse.** | | | | | |
| CIP33 | **They felt depressed about their symptoms** | | | | | |
| CIP34 | **They were upset about their symptoms** | | | | | |
| CIP35 | **Their symptoms made them feel annoyed** | | | | | |
| CIP36 * | **Their symptoms did NOT worry them** | | | | | |
| CIP37 | **Having these symptoms made them feel anxious** | | | | | |
| CIP38 | **Their symptoms frightened them** | | | | | |

**We are also interested in exploring how the patient's illness affected <u>you</u>.**
**Please indicate how much you agree or disagree with the following statements about the patient's symptoms by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CIP39 | **There was a lot that I could do to control the patient's symptoms** | | | | | |
| CIP40 | **What I did could determine whether their symptoms got better or worse** | | | | | |
| CIP41 | **The course of their illness depended on me** | | | | | |
| CIP42 * | **There was nothing I could do to effect their symptoms** | | | | | |
| CIP43 | **I had the power to influence the patient's symptoms** | | | | | |
| CIP44 * | **Any action I took would not effect the outcome of their illness** | | | | | |
| CIP45 | **The symptoms of their condition were puzzling to me** | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CIP46 | **Their symptoms were a mystery to me** | | | | | |
| CIP47 | **I did not understand their symptoms** | | | | | |
| CIP48 | **Their symptoms didn't make any sense to me** | | | | | |
| CIP49 * | **I had a clear picture or understanding of their condition** | | | | | |
| CIP50 | **I felt depressed about their symptoms** | | | | | |
| CIP51 | **I was upset about their symptoms** | | | | | |
| CIP52 | **Their symptoms made me feel annoyed** | | | | | |
| CIP53 * | **Their symptoms did NOT worry me** | | | | | |
| CIP54 | **The patient having these symptoms made me feel anxious** | | | | | |
| CIP55 | **Their symptoms frightened me** | | | | | |

## CAUSES OF THEIR ILLNESS

**We are interested in what <u>you</u> consider may have been the causing the patient's symptoms at the time you were in contact with NHS 24. As people are very different, there is no correct answer for this question. We are most interested in <u>your own views</u> about the factors that may have caused the patient's symptoms rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for their symptoms. Please indicate how much you agree or disagree that they may have been causes for them by ticking the appropriate box.**

| | POSSIBLE CAUSES | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CC1 | **Stress or worry** | | | | | |
| CC2 | **Hereditary - it runs in their family** | | | | | |
| CC3 | **A Germ or virus** | | | | | |
| CC4 | **Diet or eating habits** | | | | | |
| CC5 | **Chance or bad luck** | | | | | |
| CC6 | **Poor medical care in the past** | | | | | |
| CC7 | **Pollution in the environment** | | | | | |
| CC8 | **Their own behaviour** | | | | | |
| CC9 | **Their mental attitude e.g. thinking about life negatively** | | | | | |

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CC10 | **Family problems or worries caused their illness** | | | | | |
| CC11 | **Overwork** | | | | | |
| CC12 | **Their emotional state e.g. feeling down, lonely, anxious, empty** | | | | | |
| CC13 | **Ageing** | | | | | |
| CC14 | **Alcohol** | | | | | |
| CC15 | **Smoking** | | | | | |
| CC16 | **Accident or injury** | | | | | |
| CC17 | **Their personality** | | | | | |
| CC18 | **Being 'rundown'** | | | | | |

**In the table below, please list in rank-order the three most important factors that you believed might be causing the patients symptoms at the time you called NHS 24. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. _____

2. _____

3. _____

## ADDITIONAL INFORMATION

**In order to help us understand the information you have provided better, it would be very helpful if you could tell us a little about yourself.**

**1. What is your age? _____**

**2. Are you male or female? _____**

**3. What is your relationship to the patient? _____**

**4. On what date did you complete this questionnaire? _____**

**5. What is your ethnic group?** Choose one section from A to E, tick box if appropriate or add your own description.

| | | |
|---|---|---|
| **A. White**<br>Scottish ☐<br>British ☐<br>Irish ☐<br><br>Other white background? (please state) | **B. Asian, Asian Scottish or Asian British**<br>Indian ☐<br>Pakistani ☐<br>Bangladeshi ☐<br>Chinese ☐<br><br>Other asian background? (please state) | **C. Black**<br>Caribbean ☐<br>African ☐<br><br>Other black background? (please state) |
| **D. Mixed** ☐ | E. **Any other ethnic background** (please state) | |

## HOW DID YOU FIND THIS QUESTIONNAIRE?

**We are interested in hearing your views about completing the questionnaire. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.**

| | | STRONGLY DISAGREE | DISAGREE | NEITHER AGREE NOR DISAGREE | AGREE | STRONGLY AGREE |
|---|---|---|---|---|---|---|
| CPF1 | **The questionnaire was easy to complete** | | | | | |
| CPF2 | **I was contacted at an appropriate time** | | | | | |
| CPF3 | **The questions were relevant to me** | | | | | |
| CPF4 | **I remember the reason I was in contact with NHS 24** | | | | | |

**Please feel free to make any additional comments below or overleaf:**

**Once completed please put this questionnaire in the stamped, addressed envelope provided. Please post it within a week if possible. Thank you very much for taking part in this study.**

## *Appendix 41*

**Interview schedule**

- Introduction and thanks
- Re-check consent
- Explanation of what interview will involve, expected duration
- Opportunity for participant to ask questions
- Instructions read from IPQ-R
- Check understanding
- Read questions from IPQ-R
- Confirm contact details for any future correspondence
- Thank you and goodbye

## *Appendix 42*

Dear Dr {patients GP},

Re: {patient/caller details}

My name is Barbara Farquharson, I am a Team Leader with NHS 24 based in the East Contact Centre. I am currently undertaking a research project which aims to better understand how people seek medical help with symptoms.

I am writing to inform you that the person named above has consented to take part in this study. Their participation involves completing a questionnaire designed to assess illness perception.

They have also given their consent for me to obtain some clinical data from their medical notes in 3 months time. Their consent was obtained verbally and is recorded within NHS 24. Please feel free to confirm this with the patient in the meantime.

I will contact you nearer the time for this very brief information. If you would prefer that I contact someone else in the practice please just let me know. To avoid over-burdening practices, the number of cases from each practice will be collated and each practice approached only once regarding data for all participating patients.

I enclose a copy of the information sheet and questionnaire which have been provided to the patient. If you would like any further detail about the study or have any concerns or questions please do not hesitate to contact me on the number below.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112
email: barbara.farquharson@stir.ac.uk

## *Appendix 43*

Dear Dr {patients GP},

Re: {patient/caller details}

I wrote to you recently to inform you of the above patients participation in the research study I am conducting.

They have given their consent for me to obtain some clinical data from their medical notes. This was given verbally and is recorded within NHS 24. If possible I would be grateful if you could provide the information requested below and return a copy to me using the reply-paid envelope.
Alternatively you may wish to email this to me at the address below.

If, for any reason, I do not receive a reply I will contact your practice in 2 weeks time to discuss how best I might obtain this information with minimal inconvenience to you and your staff.

If you would like any further detail about the study or have any concerns or questions please do not hesitate to contact me on the number below.

Yours sincerely

Barbara Farquharson MSc; BSc; RGN
Tel: 01786 466112
email: barbara.farquharson@stir.ac.uk

GP:

Patient Name
Address

1. What (if any) diagnosis did the patient receive regarding their symptoms of the [date of call].

2. On what date was this diagnosis made?

3. What other diagnoses (if any) has the patient received between [date of call] and [date 3 mths later]?

4. Is the patient alive as of [date 3 mths post-call]? If not on what date did they die?

5. Is the patient diabetic?

Thank you very much for your help.

Please return (SAE enclosed) to:

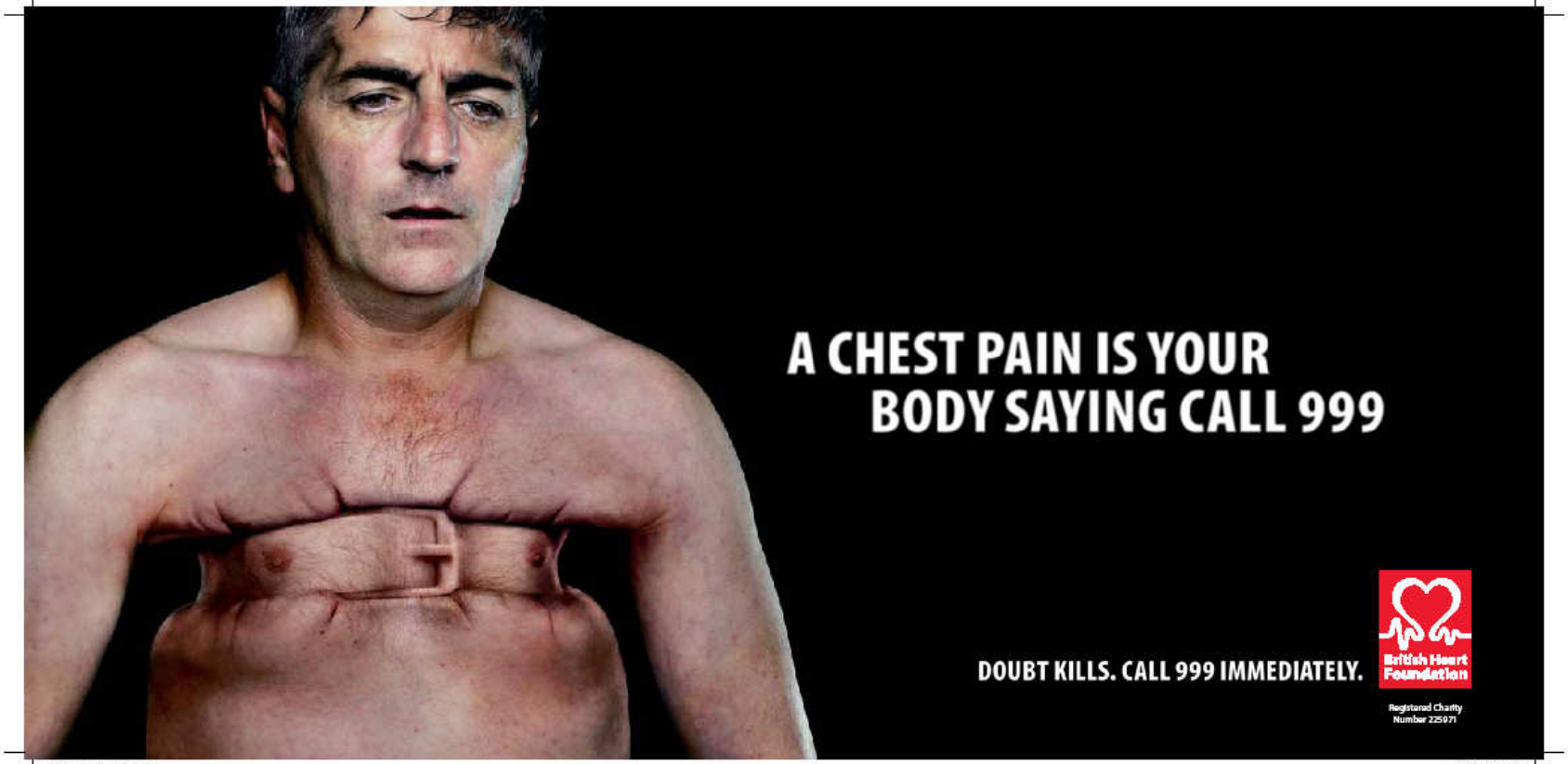
Barbara Farquharson
NHS 24
Norseman House
2 Ferrymuir
South Queensferry
EH30 9QZ

## *Appendix 44*

### *Distribution of subscale scores*

| | Mean | (SD) | Skewness | SE | z-skewness | Kurtosis | SE | z-kurtosis | Normal |
|---|---|---|---|---|---|---|---|---|---|
| Identity | 4.969 | 2.990 | 1.100 | .191 | 5.76 | 1.753 | .380 | 4.61 | no |
| Caller-identity | 4.4800 | 2.476 | .949 | .337 | 2.81 | 1.774 | .662 | 2.67 | no |
| Timeline | 13.779 | 4.035 | .131 | .195 | .067 | -.546 | .389 | -1.4 | yes |
| Caller- timeline | 14.957 | 4.046 | .056 | .327 | .171 | -.224 | .644 | -.34 | yes |
| Timeline-cyclic | 12.278 | 3.415 | -.323 | .194 | -1.66 | -.204 | .386 | -0.52 | yes |
| Caller-timeline cyclic | 11.387 | 3.236 | .048 | .325 | .148 | -.177 | .639 | -.277 | yes |
| Consequences | 18.671 | 4.430 | -.424 | .194 | -2.1 | .107 | .385 | .27 | yes |
| Caller-consequences | 19.578 | 4.634 | -.390 | .322 | -1.21 | .540 | .634 | .851 | yes |
| Personal control | 13.114 | 3.332 | .214 | .195 | 1.09 | .135 | .387 | .34 | yes |
| Caller report patient's personal control | 12.625 | 3.936 | .449 | .325 | 1.38 | .978 | .639 | 1.53 | yes |
| Caller's own personal control | 9.590 | 2.971 | .123 | .319 | .385 | 0 | .628 | 0 | yes |
| Treatment control | 15.077 | 2.403 | -.844 | .194 | 4.32 | 2.198 | .386 | 5.69 | no |
| Caller treatment control | 11.964 | 1.878 | -1.792 | .319 | -5.62 | 8.740 | .628 | 13.91 | no |
| Coherence | 10.864 | 4.131 | .309 | .192 | 1.6 | -.785 | .383 | 2.04 | yes |
| Caller report patient's coherence | 11.333 | 3.619 | .28 | .325 | .86 | -1.130 | .639 | -1.76 | yes |
| Caller's own coherence | 13.018 | 4.382 | -.263 | .322 | -.081 | -.975 | .634 | 1.53 | yes |
| Emotion | 21.576 | 3.765 | -.096 | .192 | -.05 | -.69 | .381 | -1.81 | yes |
| Caller report patient's emotion | 22.118 | 3.298 | -.241 | .325 | .74 | .167 | .639 | 0.26 | yes |
| Caller's own emotion | 20.789 | 3.867 | .051 | .322 | .158 | .169 | .634 | .26 | yes |

*Appendix 45*


A CHEST PAIN IS YOUR
BODY SAYING CALL 999
DOUBT KILLS. CALL 999 IMMEDIATELY.
British Heart Foundation
Registered Charity
Number 225971
4225_Bart_ENG_468hi.indd 1
2/11/05 1:37:25 pm
ARTWORK
THIS IS ARTWORK READY.
THIS IS NOT A PROOF FOR COLOUR
THIS IS CS1 AW!!!

*Appendix 46*


Please remember to check when your GP practice is closed over Easter.
Before Easter weekend:
Find out which days your GP practice is closed between 6th and 9th April 2007
If you take repeat or regular medication, make sure you have enough to cover the Easter holiday period
Over the Easter weekend:
Ask your pharmacist for advice about treatment of any minor illnesses
For self-care advice and pharmacy opening times visit www.nhs24.com or call 0800 22 44 88
Only call NHS out-of-hours services if it can't wait until your GP practice re-opens
NHS
SCOTLAND