

# **A Mixed Methods Exploration of the Relationship between Activities within the Home and Health in Older People with Heart Failure: Implications for Lifestyle Monitoring**

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## Abbreviations

DoH	-	Department of Health
HF	-	Heart Failure
HFSpN	-	Heart Failure Specialist Nurse
LM	-	Lifestyle Monitoring
NHS	-	National Health Service
PIR	-	Passive Infrared Sensor
QoL	-	Quality of Life
QUAN	-	Quantitative
QUAL	-	Qualitative
UK	-	United Kingdom
SCHARR	-	School of Health and Related Research



## **Abstract**

### **Introduction**

Older people and those with long-term conditions are more vulnerable to declining health. One experimental method of detecting early signs of a health decline is lifestyle monitoring (LM) based on the idea that the health state of an individual can be inferred via indirect measurement of home activities. This primarily qualitative research explored activities within the context of heart failure (HF), and range of factors that shape everyday activity. Quantitative analysis tested whether home activities vary according to the health state.

### **Methods**

A mixed methods approach was utilised. Quantitative: analysis of secondary LM data explored associations between proxy activity and self-reported measures of health from 17 participants with HF, aged 60 years and over. Qualitative: twenty older people with HF were interviewed (and 11 partners) to explore whether activities changed during variations in their symptoms; and wider influences on everyday activity. Data was analysed using template analysis. Views of 6 specialist nurses, 27 attendees of a HF support group, and 2 experts on LM, were summarised.

### **Results**

LM data analysis proved that proxy activity levels varied according to self-reported health states, within a significant proportion of the analysis. However results were complex, without any observable patterns in activity according to health. Qualitative enquiry confirmed that health does influence everyday activity but this occurs in a complex way, and is influenced by individual, psychological, contextual, and environmental factors. However during an exacerbation of symptoms common activities were undertaken to ease symptoms.

### **Discussion**

This study adds to the understanding of everyday life lived within the context of HF, and debate about how to improve health monitoring technology. Home activity has many influences, and of these attitudes and psychological factors are key and thus this poses a challenge to LM based on the idea that the health state of an individual can be inferred from home activity. The technology therefore requires further consideration of purpose, methods, and target audience.



## **Chapter 1: Introduction**

### **1.1. Rationale**

Within the general population there are people who are at risk of experiencing serious declines in their health state, either due to the presence of long-term conditions, or the vulnerabilities of advancing age (Goodwin et al 2010, National Institute on Aging et al 2011). There is a growing awareness of the importance of early intervention - prompted by the evidence that if the signs of a decline are noted early enough, a quick intervention may prevent spiralling negative impacts to health and well-being (Barnett et al 2012, Goodwin et al 2010). Left unchecked, symptoms may worsen into an exacerbation potentially requiring a lengthy hospital stay, which is not only disruptive and distressing for the individual concerned (Osman et al 1997), but costly for the National Health Service (NHS) (DoH 2012). For older people at risk of disability, the first sign of difficulties with everyday activities in the home (e.g. bathing difficulties), offers the opportunity to intervene and prevent any escalation of difficulties, that may potentially lead to frailty and disability (Dunlop et al 1997), and the need for residential care (Gill et al 2006).

A growing body of people are living with the risk of experiencing declines in health and well-being. It is estimated that 15 million people live with a long-term condition in England, and the proportion increases with age (DoH 2012). Fifty eight percent of the population aged 60 years and over live with a long-term condition, and over 25 percent of this group have two or more long-term conditions (DoH 2012, Barnett et al 2012). The most prevalent long-term conditions in England are hypertension, depression, asthma, diabetes, and coronary heart disease (top five conditions, DoH 2012). The rise of long-term conditions and the resultant issues around management and healthcare costs has been noted internationally (Christensen et al 2009, WHO 2011).

However, the impact of long-term conditions on the individual varies, from those with stable health conditions requiring little intervention, to others with more complex needs that are more subject to the risk of exacerbations (Department of Health, Social Services and Public Safety 2012).

It is well documented that the population is ageing, with the 2011 census recording the highest ever proportion of people aged 65 and over in England and Wales (16.4% of the total population, 1 in every 6 people) (ONS 2012). There are also increasing numbers of people aged 85 and over, and this age group is more likely to report health problems than younger

age-groups (ONS 2013a). Whilst this increase in life expectancy is to be welcomed, there are also implications for service provision as the number of older people who are expected to require health and social care is forecast to rise over the coming years as healthy life expectancy does not keep up with total life expectancy (Wanless et al 2006). This alteration in the population structure with increasing longevity and a reduction in the younger age-groups is an international phenomenon (Christensen et al 2009, Rechel et al 2013).

A further factor that increases the vulnerability of people at risk of suffering serious decline in their health state relates to whether that individual lives as part of a family, or alone. Older people who live alone are especially vulnerable to a decline in their health due to their isolation (Kharicha et al 2007); and this is a key issue given that older people are more likely to live alone. Just under one third of people aged 65 and over residing in England and Wales live alone; and in the population aged 85 and over, 69 % of women, and 41% of men live alone in private households (ONS 2013, 2013a). A recent report also highlighted the issue of fragmented families, whereby many older parents live a “substantial distance” away from their nearest child (WRVS 2012).

Individuals at risk of a serious decline in health are more likely to live at home (given that most older people continue to live at home) (ONS 2013 & 2013a), and thus this is the environment where the early signs of decline are most likely to occur. This is also a matter of choice, since older people would prefer to stay at home, rather than go into a care home or nursing home when their health declines (Wanless et al 2006). Telecare technologies have been developed to aid those with health needs in the home. Telecare is defined as “...a form of [information and communications technology] ICT –assisted care provision. It involves the use of sensors within people’s homes or worn on their bodies, connected to a monitoring centre and then to a response service. This provides an ‘electronic security blanket’ for those at risk of medical or other physical risk and more continuous monitoring to allow the early detection of changes to an individual’s condition” (Barlow 2006, page 396). Telecare systems have evolved from the first generation systems, which were community alarm systems where the person in distress called for help via a pull-cord which connected the caller to a remote carer; to third generation systems where people are monitored in their homes and alerts are sent to the carer if the system identifies a cause of concern (Brownsell et al 2003). Although the third generation are more at an experimental stage, and older people are far more likely to have first and second generation Telecare products in the home.

The third generation systems use lifestyle monitoring sensor technology to identify when the person is in need of help. “Lifestyle monitoring sensors monitor people’s domestic routines and daily activities such as movement around the house, bed and chair occupancy, the opening of cupboards, doors, fridges and wardrobes, and the use of electrical devices such as kettles, TVs and lamps. The idea of lifestyle monitoring is that by constant passive monitoring of the domestic environment, it will be possible to learn people’s habits and then to recognise significant deviations from the norm. The ultimate aim of lifestyle monitoring is to provide more timely intervention in the event of an emerging crisis” (Hanson et al 2007, page 26). This method of indirectly monitoring daily home activities via Telecare sensors is known as Lifestyle Monitoring (LM), and was devised by Cellar et al (1994, 1995) on the basis that that daily activities can be monitored to provide an indication of changes in the health status of an individual. However despite the fact that Lifestyle Monitoring research projects have been set up all around the world, the evidence base to support the use of activity monitoring for monitoring health needs is weak (Brownsell et al 2011).

## **1.2. Research Questions**

The aim of this research is to explore the underpinning assumption of Lifestyle Monitoring - that there is a relationship between activities within the home, and the health state of the individual undertaking those activities. The two main research questions of this research were as follows:-

- a. Do everyday activities undertaken in the home by older people with Heart Failure, vary according to the health state of the individual carrying them out?
- b. What other factors influence everyday activity in older people?

A sample of older participants with heart failure was chosen in order to examine this assumption in a population more likely to experience serious declines in health. Heart failure is a condition with a high symptom burden (Zambroski et al 2005); with symptoms such as breathlessness, tiredness, and swelling in the limbs or abdomen, arising from the inability of the heart to pump blood round the body as effectively as it should (SIGN 2007). Co-morbidities such as COPD can also complicate the management of the condition (Bayliss et al 2003, Rushton et al 2011). The incidence and prevalence of heart failure increases with age (Davis et al 2006, NHS Information Service 2010), and on average most people receive their initial diagnosis at the age of 76 (Cowie et al 1999). People with heart failure have an uncertain trajectory (Jones et al 2003, Murray et al 2005, NHS Information Service 2010); the

condition is one of the commonest causes of emergency medical admission and readmissions, and the annual risk of death ranges from 10 to 50 percent depending on heart failure severity (NHS Information Service 2010). In common with other long-term conditions (Charmaz 1991) people with heart failure often experience good days where life is lived relatively normally, and bad days where symptoms intrude and activity is potentially restricted (BHF 2010, Clarke et al 2008).

A mixed methods approach was undertaken, with both quantitative and qualitative approaches undertaken to address aspects of each research question. An initial quantitative phase sought to explore the relationship between measures of health and symptoms collected via a user input telemonitoring system, and indirect activity data collected from LM sensors. The quantitative phase addressed the question of whether a relationship between activity and health measures existed, and if so, to describe the nature of this relationship. The subsequent qualitative phases had three purposes: to both validate and illuminate the quantitative findings; to examine everyday activity within varied health states; and finally to explore factors other than health that influence activities. The findings from the qualitative phases were then utilised to identify activities which LM sensors might monitor to detect signs of a decline in health, and to formulate recommendations for future LM systems. This iterative mixed methods approach was chosen to provide a comprehensive understanding of the complex relationship between activity and health, in order that future LM studies may benefit from this improved understanding to both better target participants, and sensor setup. The study also offers insights of value to health specialists working in the field of heart failure, to better understand everyday activity within the context of heart failure, and in particular the influences on everyday activity, and changes in activities undertaken during worsening symptoms.

### **1.3. Overview of the Thesis**

This thesis has ten chapters. The second chapter comprises a literature review examining the purpose and nature of home activity measurement in the fields of health and social care; the relationship between everyday activity within the home and health in older people; and factors other than health that influence activity. This is followed by a short chapter detailing the research questions. Chapter four sets out the research design, with the rationale for a mixed methods approach, and a description of the study design, and epistemological underpinning of the study. The study designs of the quantitative and qualitative elements are also described. Chapter five presents the quantitative findings from the analysis of

longitudinal data collected from LM sensors in the homes of older participants with heart failure, and the association between proxy measures of activity and self-reported health are described. The following three chapters present qualitative findings from studies with participants with heart failure, support group attendees, and Heart failure Specialist Nurses; and by these means interconnections between quantitative and qualitative findings were explored, and understandings drawn from each individual study. The final two chapters discuss the findings and explore the implications for future LM studies, and the contribution to the understanding of everyday activity within the context of heart failure. Strengths and limitations of the study are discussed, and recommendations are made for future research.

## **Chapter 2: Literature Review**

The aim of the literature review was to explore how important the health state is in influencing the undertaking of everyday activities; in order to understand this the influences of activity were examined, as were the meaning of activities within different contexts, and the meaning of specific activities. The literature review did not focus specifically on the role of heart failure symptoms as an influence for behaviour and activity, because a broader understanding of the role of health was required.

In summary, the literature review was devised to explore the following issues pertinent to the relationship between activity and health in older people:-

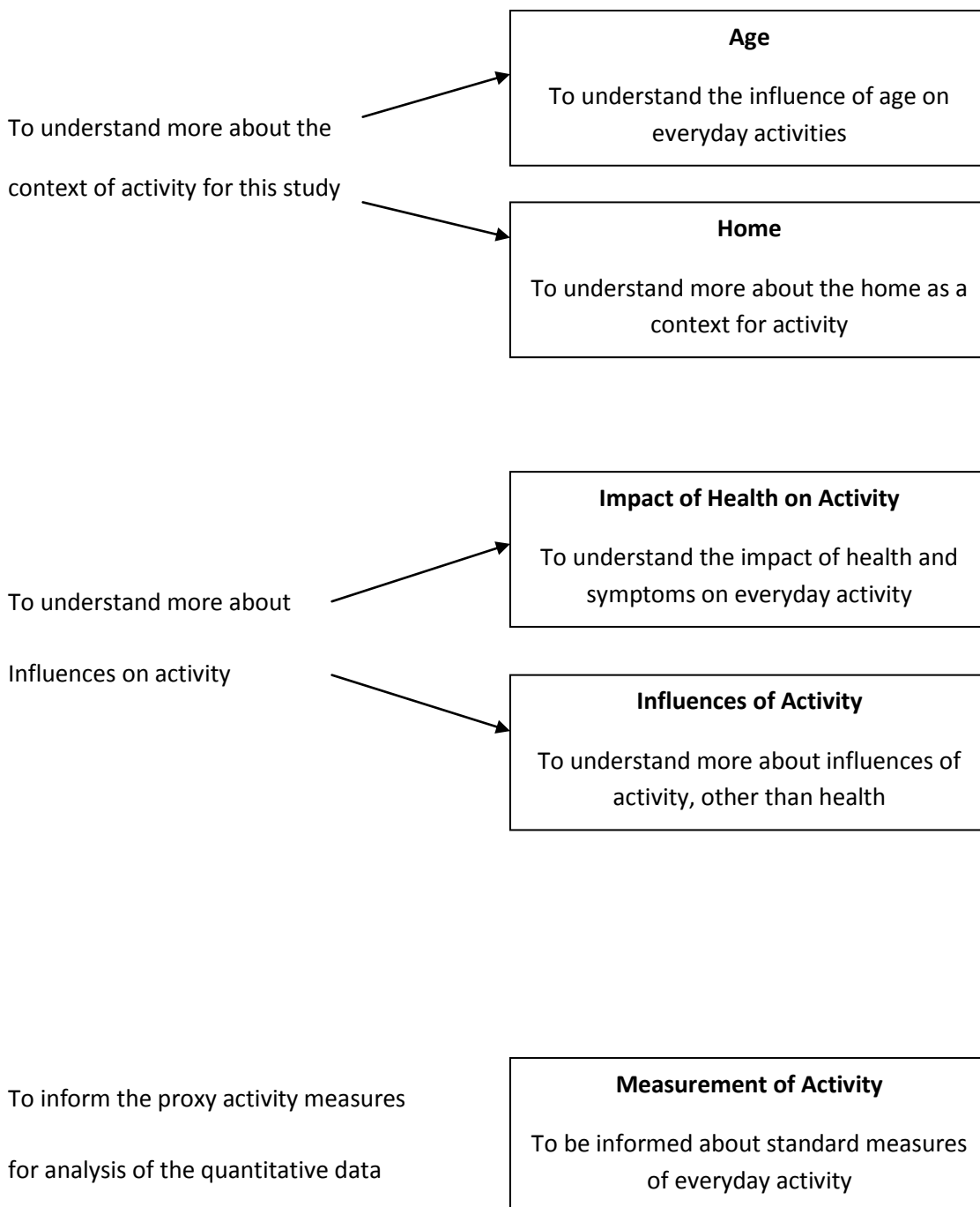
1. What is the relationship between everyday activity and health?
2. What factors other than health influence activity levels?
3. The purpose and nature of activity measurement in health and social care

The purposes of the review are summarised in the following diagram (2.1).



### Figure 2.1: Purposes of the Literature Review

To understand more about the following factors, which may act to encourage or inhibit everyday activity in older people within the home:-



## 2.1 Literature Review Process

The review process followed the steps identified by Aveyard (2010) to develop a rigorous approach to searching for literature. The following search terms were identified from the review questions, and queries were developed using the “building blocks” approach (Booth 2008) described below:-

**Table 2.1: Literature Search Terms**

No.	Concept	Search Terms
1	Older People	Old\$3, eld\$3, aged, senior citizen\$1, pensioner\$1, retire\$4
2	Living at home	Community dwelling, living at home, home living, independent living, living independently
3	Activity	Activit\$3, pastime\$1, pursuit\$1, hobb\$3, interest, leisure activit\$3, behaviour (or behaviour), routine, schedule\$1, habitual activit\$3, customary activit\$3, everyday activit\$3
4	Inactivity	Sedentary, inactive
5	Age	Age, ageing, expectations
6	Location of Activities: indoors	Home, house, dwelling, indoor\$1
7	Location of Activities: outdoors	outdoor\$1, garden, outside, out-of-doors,
8	Health	Health\$1, well-being, wellbeing, well, fit\$4
9	Ill-health	Long term condition\$1, mobid\$3, chronic disease\$1, unhealthy, ill health, ill\$3, unwell, flare up, bad day\$1, exacerbation\$1, poorly, sick, poor health, under the weather, off colour, out of sorts, symptomatic
10	Ill-health: Symptoms	(could have specific symptoms e.g. fatigue, breathlessness, pain, swelling, frailty, etc)
11	Bath and Toilet Activities	Bath\$3, toilet\$3, shower\$3, intimate, wash\$3
12	Food Activities	Cook\$3, bak\$3, food preparation, eat\$3, nutrition, boil, microwave, grill, roast, drink\$3, wash\$3, dine, meal, breakfast, lunch, dinner, snack
13	Sleep	Sleep\$3, nap\$3, rest\$3, snooze, doze, lie down, slumber
14	Television Viewing	Television, telly, TV
15	General Activity	Clean\$3, wash\$3, read\$3, Hoover\$3, vacuum\$3, writ\$3, housekeeping, finances
16	Outdoor Activity	Shop\$4, eat out, eating out, dining out, garden\$3, sport, exercise, golf, cricket, theatre
17	Factors other than health	Bereavement, environment\$2, gender, male, men, man, female, women, woman, lonel\$5, living arrangement\$1, living alone, social ties, participation, education, social class, income, financial, retirement, transport, car, side-effects of medication, personality, outlook, character, demeanour, disposition, positive, optimistic, pessimistic, self-efficacy, attitude\$1, hous\$3

Queries were built up using appropriate sections from table 2.1, for example, the search for food activities combined search terms from sections 1,2, and 12 (1 AND 2 AND 12). Papers were identified by searching the title and abstract field; or using subject headings (such as MESH in Medline) if appropriate. A systematic review was not considered appropriate, as the

review aimed to understand the range of factors influencing everyday activity; rather than seeking to retrieve and assess a complete body of literature within a narrow scope, which is the aim of a systematic review (Cronin, Ryan, & Coughan 2008). For this reason, the number of records gained from the search was not recorded as would be the case in systematic reviews; as the purpose of the search was not to exhaustively search (and record evidence for this systematic information gathering approach), but rather to gain an understanding of the broad range of factors influencing activity.

The following bibliographic databases were searched: ASSIA, Medline, and CINAHL. The British Nursing Index was not searched both because of overlap with CINAHL and the fact that access is no longer provided by the University library. Embase was not searched because of the overlap of sources with Medline. The search was limited to English language publications. Further limits were applied pragmatically. In searches with a small yield of papers no further limits were applied, but in searches resulting in large yields, results were limited to papers from 1990 onwards. The yield of papers varied, from few papers about general everyday activity in older people, to a great many about food preparation and nutrition. The search results were appraised and papers were included in the review if they met with the search criteria, and they added further insights into the understanding of everyday activity in older people. The search process was guided by information skills gained from qualifications in Information Management, and literature searching experience gained whilst working as a Librarian within the health field.

It is acknowledged that searching of on-line bibliographic databases alone is likely to leave important gaps of knowledge (Greenhalgh & Peacock 2005, Ogilvie et al 2005). The processes of snowballing and other informal approaches were undertaken in order to broaden the results. Snowballing refers to checking the references of selected papers to identify further information sources, or using electronic means to link to similar papers to those identified as relevant. In addition to this, information sources were found by chance when searching more broadly, or fortuitous contacts. This element of chance is acknowledged to yield valuable sources (Greenhalgh & Peacock 2005, Ogilvie et al 2005). It is also recommended to hand search through relevant journals, but this was not carried out due to the fact that there are no journals devoted to studies of everyday activity, and this topic tends to be a side issue of papers.

The results of the literature search were summarised using a narrative approach, as this was considered a flexible means of summarising the broad and diverse literature necessary to

understand the subject matter (Dixon-Woods et al 2004). Key to this choice of a descriptive style of review was to provide background knowledge to shape the study, and consider the range of issues at play in everyday activity (Cronin, Ryan, & Coughlan 2008). Narrative reviews have been criticised due to the lack of a systematic searching processes (Dixon-Woods et al 2004), but this was overcome as previously described. The narrative approach is also in keeping with the epistemological stance of this thesis (subtle-realism), since the approach is championed by the leading advocate (Hammersley 2001) (see chapter 4).

The literature search was undertaken in two stages, with an initial search undertaken for the upgrade document in 2010, and a later search to both update and summarise findings more succinctly in 2014. A third aspect of the review was the search on heart failure, which aimed to concisely summarise the impact of the health condition on everyday activities. These two elements of the review (general influences on activity in older people, and health specific influences) informed the study in two ways. Firstly the understanding of the general influences on activity informed the research question on the influence of other factors on everyday activity (question 2a, page 64), and the later analysis of the qualitative data. Secondly, the brief review of the influence of heart failure on activities, informed both the research questions, the interview schedule for heart failure participants, and qualitative analysis. Key to this was the identification of the classification of days according to the degree of intrusion from symptoms (Charmaz 1991), which in part informed the integrative theme (see pages 165,189).

Relatively little is known about everyday activity in older people (Horgas et al 1998, Ver Ploeg et al 2000). Uruh et al (2008) points out the choice of samples often do not match the typical situation of older adults living in the community who are likely to have at least one long term condition, and it is common for people with existing health conditions to be excluded from research. There is a growing body of literature about determinants of physical activity (PA) in old age (Barnett et al 2012, Bauman et al 2012, Brandon et al 2009, Browning et al 2009); these papers were also included in the review where appropriate, on the basis that older people have broad views, and often include domestic activities within their definition of PA (Barnett et al 2012).

## **2.2 Definitions of Activity**

Definitions of activity vary depending on the discipline, for example, within occupational therapy there is the concept of occupation, which is the undertaking of activities necessary for everyday life (Doble & Santha 2008). The term activity is used frequently in gerontology, but

there is no universal definition (Katz 2000). Katz (2000) describes three forms of activity typically described in gerontology: physical movement, social participation, and the pursuit of everyday interests; where the focus is often on where the activity takes place. Concepts of activity however are theorised to move beyond the ability to undertake activities, to ideas about what activity engenders in terms of the sense of self, of meaning, of belonging, of connecting with other people, of participation, fulfilment and well-being (Doble & Santha 2008, Hammell 2004, Law 2002). The meaning of activity is therefore far greater than simply the ability to physically undertake a task.

Activity can also be differentiated in terms of activities undertaken of necessity, and those that are chosen; where the individual has the agency to make choices about what to do, how, when, and with whom (Doble & Santha 2008, Moss & Lawton 1982). Consideration has also been given to whether activities are undertaken passively or actively (Polatajko et al 2007), however this distinction about how involved or engaged an individual is in a given activity is not clear cut (Katz 2000). Definitions may also include judgements about whether an activity is considered to be of value, for example, within the health field exercise is perceived as a beneficial healthy activity, but other activities may be perceived as less worthy, such as gambling or sedentary activities (Katz 2000, Hammell 2004a).

Activity can therefore be perceived as a complex and multifaceted occupation. Another more simple definition is provided by Kelly (1993) who wrote about activity as "...what people do" (page vii). This simple idea was chosen to define the focus of this literature review, which is about what older people do in the home.

### **2.3 Theories of activity within Old Age**

Within normal ageing (in the absence of ill-health) one theory states that older people seek to continue with their familiar patterns of activity unless there is a discontinuity which causes a change in lifestyle (Atchley 1989, Bury 1982). One factor that acts to cement patterns of activity is hypothesised to be purpose in life (PiL), which acts to direct activity in the sense that it is undertaken purposively to achieve goals; and researchers argue that PiL may motivate individuals to continue with activities despite difficulties (McKnight & Kashdan 2009). It is theorised that activity is shaped by values, beliefs, and experiences; which act as a force to motivate activity (as described by social cognitive theory) (Bandura 2001, Cousins 2001). Another motivating force in shaping activity comes from the idea that activity is undertaken with an awareness of limited resources, in terms of time (i.e. that life is short) (e.g. Carstensen et al 1999, Lang & Carstensen 2002), and energy (Baltes & Baltes 1990), and this is a

consideration when choosing which activities to undertake. The same constraints are theorised to influence how activities are undertaken, for example, older people may reduce their activity repertoire and focus on chosen activities (optimization), and use strategies to improve the likelihood that these activities are undertaken satisfactorily (compensation) (explained in Baltes 1997). Theories also suggest that older people may disengage from particular types of activity, such as the disengagement theorists who argue that people withdraw from social situations, with advancing age as end of life nears (Cumming & Henry 1961).

Theories of activity also explore the meaning of activity. According to the activity theory of ageing, quality of life in older people is related to activity (e.g. Havighurst 1961); and satisfaction varies according to differing types of activity undertaken (Lemon et al 1972). This theory is related to the idea of successful ageing, whereby “the person who engages in more than just basic activities, who takes part in the external environment, who turns towards others, and who engages in self-enriching activities is considered more successful” (Horgas et al 1998, page 557). Activity is therefore theorised to be a means of achieving success. Liang and Luo (2012) had criticised this idea with their theory of harmonious ageing. They argue that activity in ageing should be about the meaning of activity for that individual, the spiritual gains that come from activity; rather than the focus on the frequency of activities undertaken. This different focus may reflect cultural differences in the understanding of activity in old age. “Under the successful aging framework, although attention has been placed on the positive impact of physical and social activities on the health status of elders, the mind-body relationship as an explanatory mechanism is often missing” (Liang & Luo 2012, page 331).

There are also models of behaviour change within particular circumstances, such as the Health Belief Model (Strecher & Rosenstock 1997), whereby it is suggested that individuals undertake activities to protect their health when they perceive that the benefits of changing activity outweighs inactivity.

#### **2.4 Measures of activity**

There are a range of measures of activity used commonly to assess medical and social needs in older people (e.g. Katz et al 1963, Lawton & Brody 1969), that use the ability to undertake activities of daily living as a measure of functional ability on the basis that this is more meaningful to older people than biochemical measures (Bowling 1997). For Bowling (1997) these measures test functional status, which is an indirect measure of health via activity, “...it is a measure of the effects of disease [on activities] rather than the disease itself” (page 4).

Measures typically assess the ability to undertake the following home activities: housework, meal preparation and eating, mobility, bathing, dressing, toileting, mobility (such as stair usage, or transferring to a chair), and self-care (such as shaving) (Bowling 1997).

The idea of measuring activity has been criticised by Katz (2000) who questions the validity of collapsing down everyday activity into a list, as there are many other important activities that are not considered by gerontologists or other professionals. In addition, Bowling (1997) argues that the use of activity measures is only appropriate in very specific populations (i.e. the very elderly or severely ill); as in the general population a small proportion report activity limitations due to poor health (in a range of typically assessed activities), and the measure may not be specific enough to report changes due to disease. Most activity measures were developed for elderly people, or those suffering as a result of strokes, arthritis, or musculoskeletal conditions (Bowling 2001); and this may impact on their ability to reflect changes in other conditions. Broad measures of activity may lack sensitivity to detect small changes in function (Graf 2008); or an alteration in methods of undertaking activities, such as, taking longer to perform tasks (Bowling 1997). However a major issue with the use of measures of activity to infer the health-state is that individuals react differently to health challenges (Bowling 1997), this is discussed more in the later health section (2.8.14). In addition, these measures do not take account of the home situation, and other determinants of activity (Bowling 1997), which may act to encourage or inhibit activity.

It is known that activity levels are indicative of the state of heart failure. A study by Walsh et al (1997) found that reduced levels of daily activity are a better indicator of disease prognosis and mortality than cardiopulmonary exercise testing in patients with chronic heart failure. The study used pedometers to monitor daily activity, and the authors' assert that "this type of assessment is valuable in identifying patients at high risk and provides an objective measure of incapacity during normal daily life" (Walsh et al 1997, page 1364).

## **2.5 Benefits of Activity**

People of all ages benefit from increasing activity levels, and for older people this may result in an improvement in health and make it easier to cope with everyday life (BHF NCPAH 2007). The main benefits of physical activity in later life are: disease prevention, greater mobility, improved muscle strength, prevention of falls, and an increased sense of well-being (BNF NCPAH 2007). In addition higher levels of activity are associated with a longer life and independent living (Hirvensalo et al 2000). Activity is also known to be beneficial for those living with some long-term conditions (Naci & Ioannidis 2013).

In 2004 the Chief Medical Officer's report made recommendations on physical activity in later life: older people were advised to take particular care to keep active and to "retain their mobility through daily activity" (BNF NCPAH 2007, page 18). The report states that even low intensity activity can produce a health benefit for older people. This idea is reiterated by a number of reports (BHF NCPAH 2007, Lewin et al 2005). The British Heart Foundation Heart Failure Plan states that any activity is good, even getting out of a chair rather than lying in bed all day (Lewin et al 2005). "Things like going to the shops or walking down the street, or how you move around at home, do the housework or make a cup of tea. Any activity – even just walking round at home – is good for you as long as you do it regularly and every day" (Lewin et al 2005, page 70).

In the past people with chronic heart failure were advised to rest and limit their physical activity (SIGN 2007). However guidelines for the management of heart failure now recommend regular exercise (BHF 2010, Dickstein et al 2008, NICE 2010, Pina et al 2003). The health benefits of exercise training in patients with heart failure occur within a short time of starting the training (Morantz 2003), and benefits include improved symptoms, quality of life, and reduced rates of hospital admission (Corvera-Tindel et al 2004, Davies et al 2010, HFSA 2006, Willenheimer et al 2001).

Individuals with suspected heart failure should receive advice about physical activity (BHF & BCPA 2002), however it is likely that not all heart failure patient receive instructions about remaining active (Moser and Riegel 2001). In addition patients may not have understood or remembered the advice, or they may choose not to act on the advice (Riegel & Carlson 2002, van der Wal et al 2005 & 2010).

## **2.6 Consequences of Inactivity**

Habitual inactivity has a deleterious effect on the body: muscles can weaken and shorten, and changes occur in the metabolic rate, body chemistry, and blood volume (Chipperfield et al 2008a, Hamilton et al 2008); and increase the risk of morbidity and mortality (Chipperfield 2008, Hamilton et al 2007, Lee et al 2012). People who are less active have more trouble undertaking the tasks of everyday living (BHF NCPAH 2007). In addition heart failure patients may find that inactivity exacerbates their symptoms, "Being inactive will make the symptoms of heart failure worse" (NHS Choices 2008).



## **2.7 The Role of the Home as a Context for Activity**

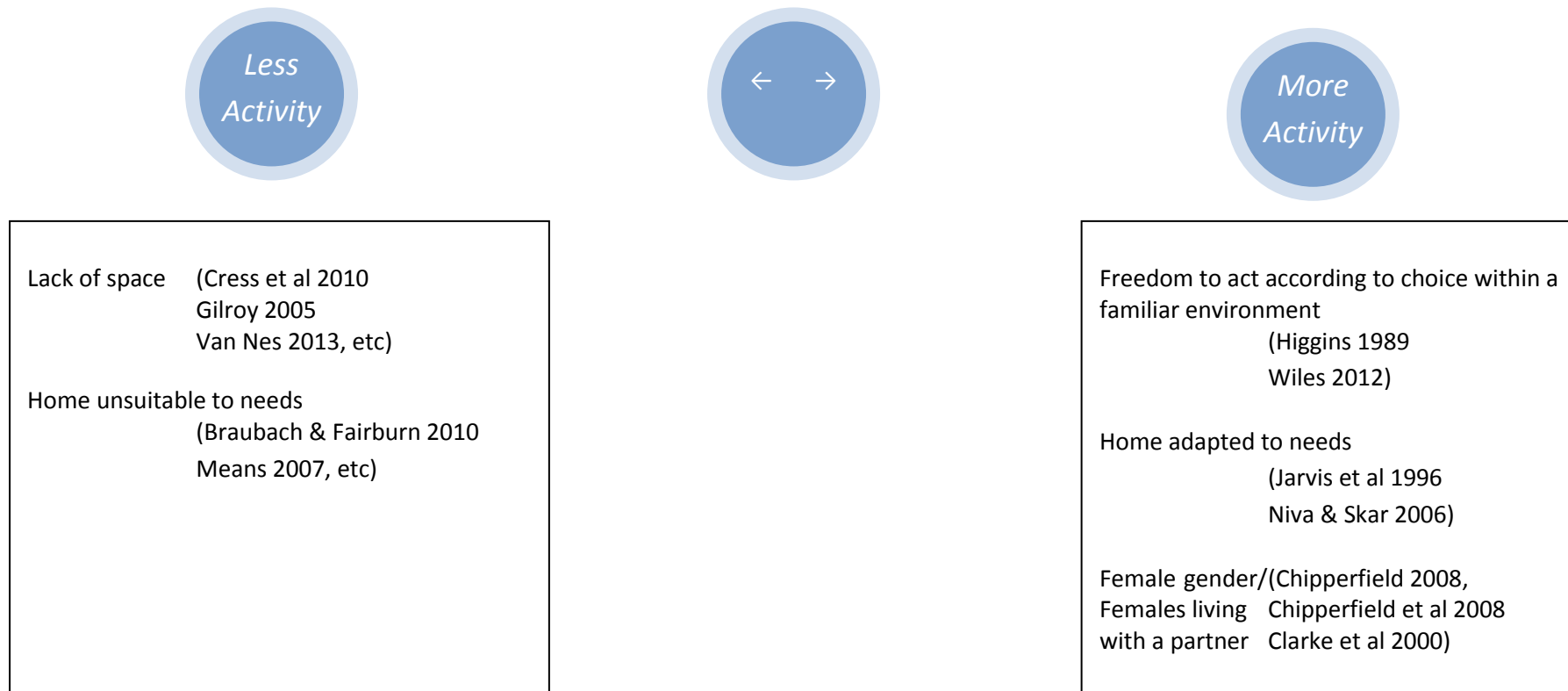
For many older people, the context for the greater part of their activities is within the home, given that older people spend much of their time at home (Baltes et al 1999, Gilroy 2005). The home is therefore of prime importance (Haak et al 2007). For Gilroy (2005) the home is where older people “structure and manage their lives” (page 141), and for Sen (1992) home is a key influence of older peoples’ “doings and being” (page 40).

Within the UK it is the norm for older people to continue to reside in their home for as long as possible, and thus the home is also a context for ageing, which is the idea of ageing in place (Means 2007, Wiles et al 2012). The home has a number of advantages that encourage activity: it is a familiar place, where people are able to exercise their own judgements about both the timing and choice of activities, and to access established social networks (Higgins 1989, Wiles 2012). However, the home can also inhibit activity. For older people living in poorly maintained accommodation, or older housing stock, under-heated homes (Braubach & Fairburn 2010, Cotter et al 2012), activity can become more of a challenge (Means 2007). In addition, older people who move to a smaller home can find the new compact way of living is a barrier to the scope and scale of activity (Cress et al 2010, Gilroy 2005, van Nes 2013, Wiles 2012); and the move may alter others’ perceptions of the capabilities of that older person, and they may no longer be included in activities now thought inappropriate (Gilroy 2005).

Within the home activities can be perceived as an interplay between the home environment and the individual undertaking them (Oswald et al 2006, 2007). It is known that the ability to function and undertake everyday activities within the home is affected by ill-health or frailty, and that the difficulties experienced may be exacerbated by the nature of the home environment, or alleviated by home adaptations, or help from family (Jarvis et al 1996, Niva & Skar 2006). The activities that are typically affected by poor health and frailty are: bathing, cooking, and cleaning, and moving round the home especially going up and down stairs; with difficulties increasing with age (Jarvis 1996).

The influence of the home environment on activity is summarised in figure 2.2, which depicts influences likely to increase or decrease home activity.

Figure 2.2 Schematic Diagram – Home Activity



## **2.8 Factors Potentially Influencing Home Activity**

A complex interplay of factors influence everyday activity in the home and beyond (Desrosiers et al 2009, Haggblom-Kronlof & Sonn 2005, Hinck 2004, Lord et al 2011, Yeom et al 2008), and physical activity (Bauman et al 2012, Browning et al 2009, Lim & Taylor 2005, Moschny et al 2011, Rosenbery et al 2010); and health is just one factor in this mix. It is acknowledged that it is difficult to separate out correlates and determinants of activity (Bauman et al 2012), and in addition support or strategies may mask difficulties in undertaking activities (Kriegsman et al 1997a, Lorenz 2009).

### **2.8.1 Age**

It is known that activity both decreases as people age (Davis et al 2011, Dallosso et al 1988, McMurdo et al 2012), and that the types of activity undertaken also changes over time (Strain et al 2002). Age acts as a influence of activity in two ways. Firstly, individuals may have positive or negative expectations about old age, including stereotypical ideas of physical decline (Andrews 2012, Bennett & Gaines 2010, Brouwer & van Exel 2005, Stewart et al 2011); and this may be a factor in pursuing a sedentary lifestyle (Sarkisian et al 2005, Stewart et al 2011), or act as a motivating force to pursue a more active old age (Barnett et al 2012). In addition older people may have ideas about age-appropriate activities (McMurdo 2000), and give up activities that they perceive as inappropriate for their age, in order to undertake more sedentary activities (Haggblom-Kronlof & Sonn 2005). Secondly, as age increases individuals are more likely to encounter threats to their everyday routine, such as, declines in health, or life events such as bereavement (NHS Inform 2012), and this can lead to a corresponding change in activity (Strain et al 2002). Wright-St Clair et al (2011) describe how age can “announce” itself through activities, for example, by a sudden feeling of weakness that occurs during the undertaking of an activity. During the ageing process individuals may also alter their patterns of activity, for example, alternating activity with sedentary periods, and resting more in the evening (Lord et al 2011a). However activity patterns are very individual; and sedentary behaviour, perhaps undertaken at home, may be followed by intense or more sedate walking (Lord et al 2011a).

### **2.8.2 Past activity**

It is likely that the patterns of activity across the life course have an impact on activity in old age (Kirkwood 2009). A recent review of correlates and determinants of physical activity identified previous physical activity at all ages as one of a small number of variables consistently correlated with physical activity (Bauman et al 2012), and thus this outlines the

importance of this factor. Horgas et al (1998), for example, attributed the homogeneity of lifestyles in older people partially to life-long activity patterns, and Leng & Wang's eleven year longitudinal study in Taiwan (2013) found that participants undertaking gardening and exercise earlier in the study were more likely to maintain their functioning at study end. Wandel & Roos (2006) study exploring men's everyday activity illustrates the potential influence of past activity on future lifestyles, found differing patterns and levels of activity established at middle age, influenced by the life course factors of family, work roles, and life transitions. The influence of past activity thus has the potential to act both as a motivating force for an active or inactive old age (Barnett et al 2012). However it is possible that the influence on encouraging activity is moderated by beliefs about the capability of the body (Jancey et al 2009).

### **2.8.3 Gender**

Levels of daily activity may in part be defined by gender roles. A study looking at the everyday activity levels of older men and women found women to be more active (Chipperfield 2008). The study found that levels of everyday activity declined for men throughout their 80s and 90s, but the decline did not begin for women until the age of 85. The authors speculate about why different factors seem to influence everyday physical activity for men and women; these factors might include "social roles, coping mechanisms, genetic factors, or physiological factors" (Chipperfield et al 2008a, page S215). The health status of women was not a predictor for activity levels, and thus other factors must be at play. The authors speculate that women may have learnt to continue being active despite physical discomfort, through life experiences. There may also be gender roles at play in the choice of activities that older people are motivated to undertake, for example, women were more likely to continue participating in church services/activities, and to attend theatre/cinema/spectator sports, perhaps because of the social nature of these activities (Strain et al 2002), and to be more active in the home (Dallosso et al 1988). Women are also more active when they live with another person, typically a spouse; the same effect was not found in men (Chipperfield et al 2008a). However, in general women live longer than men, and over time women are more likely to experience difficulties with every day activities due to poor health and frailty (Glaser et al 2009, Smith & Baltes 1998).

The social role of men may also influence activity levels. Traditionally men worked away from the home, and those undertaking manual work may also have learnt to work even when not feeling well (Chipperfield et al 2008a). However Chipperfield speculates that this effect may

not have been carried into home life, and therefore men may be more likely to become inactive as a reaction to poor health. In addition, the relationship between activity and health for men in the home may be shaped by traditional roles. A study in the Netherlands looked at the relationship between the ability to carry out the activities of daily living and self-reported health in elderly men (Hoeymans et al 1997). The study found that disabilities in basic activities of daily living and mobility had a negative impact on self-rated health. There was no association between disabilities in instrumental activities of daily living and self-rated health; this may have been because these tasks had perhaps been undertaken by wives or daughters, and thus the inability to undertake these activities had no impact on the elderly men's lives.

A study in Canada looking at the determinants of everyday physical activity in elderly people found that good physical health was a predictor of higher everyday activity for men, but not for women (Chipperfield et al 2008a). The authors point out that there is not a linear relationship between daily activity and health, "physical inactivity should be viewed as both contributing to and being a consequence of poor health" (Chipperfield et al 2008a, page S216).

#### **2.8.4 Environment**

The environment in which a person lives can have a positive or negative effect on levels of activity, especially when activity is limited by ill-health. It is reasonable to suggest that a person coping with advancing age or ill-health would find it easier to remain active in a home adapted to their needs (as previously described), and in a community that is easily accessible (Bird et al 2010, Bowling & Stafford 2007, Carlson et al 2012,

Hand et al 2012, Lord et al 2010, Nettle et al 2012, Rosenberg et al 2012, Rosso et al 2011, Sugiyama & Thompson 2005, Wilkie et al 2007, Zeitler et al 2012). Fristedt et al (2011) describes outdoor activity as an "act of negotiation" in old age, as there are barriers and motivators that encourage or discourage activity outdoors.

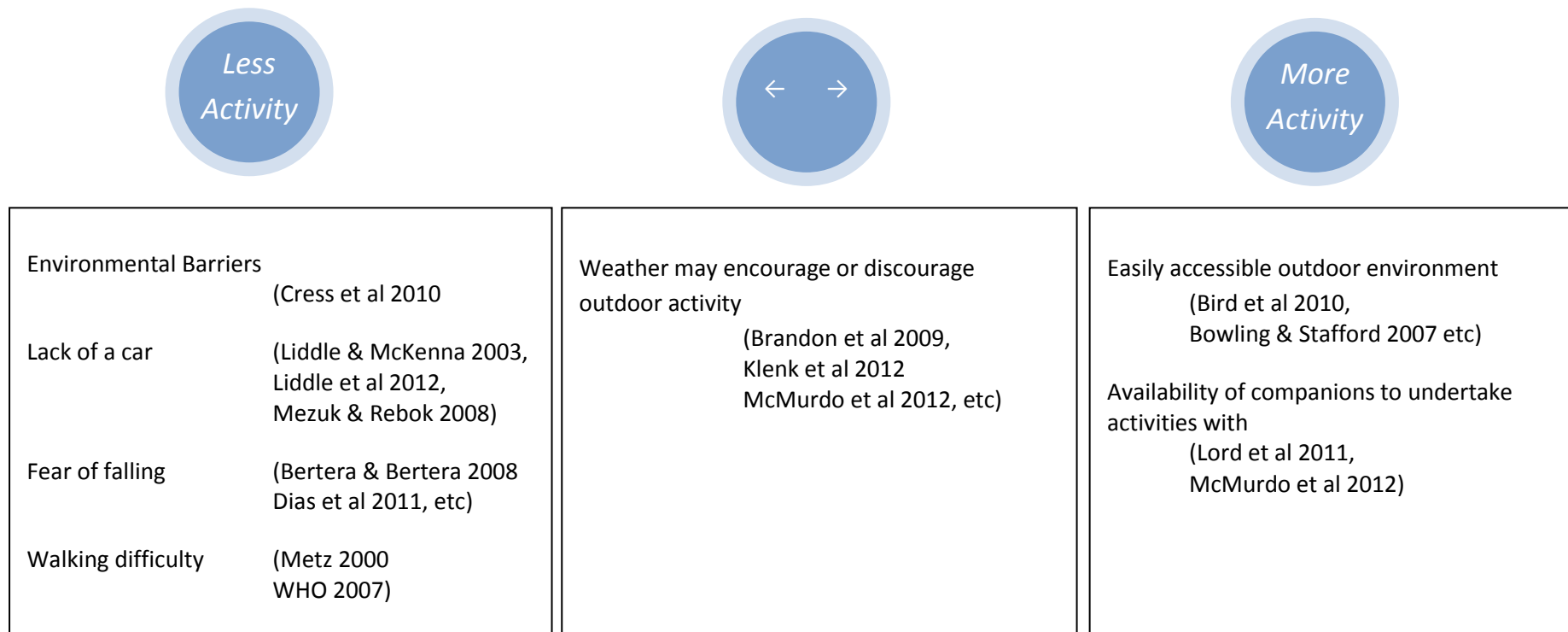
In a study by Levasseur et al (2008) the sample of participants with moderate to severe activity limitations were affected most by the physical environment, and this was associated with reduced levels of participation. "Environments that present more barriers and fewer resources might trigger a pattern of disuse and subsequent reductions in activity level, speeding up the aging process" (Levasseur et al 2008, page 8). Factors other than the built environment are also known to influence outdoor activity, such as, the season and weather (Brandon et al 2009, Jansen 2005, Klenk et al 2012, McMurdo et al 2012, Moschny et al 2011, Rosenberg et al 2012, Sumukadas et al 2009), perceptions of safety (Bird et al 2010, Hand

2012), local topography (Wilson et al 2004), and the availability of companions (Lord et al 2011, McMurdo et al 2012). There is a reciprocal relationship between outdoor activity and health in older people, in the sense that health gains come from outdoor exercise and social contact with others (Day 2008, Jarvis et al 1996, Milligan et al 2004, Sugiyama & Thompson 2005), and on the flip-side that perceptions of health are influenced by views about the surrounding neighbourhood (Bowling et al 2006, Day 2008, Gale et al 2011).

Older people living in areas of deprivation are known to be less physically active than those living in more affluent areas (e.g. Hillsdon et al 2008, Dallosso et al 1988).

The influences on activity that arise from the environment are represented in the following diagram 2.3.

**Figure 2.3 Schematic Diagram – Outdoor Activity**



### **2.8.5 Education**

Educational levels can be considered a proxy for socio-economic position, given the influence of poor educational attainment on poverty in later life (Glaser et al 2009), and the greater likelihood of poor health in old age (Glaser et al 2009).

The education levels of older people may impact on the choice of everyday activities. One longitudinal study looking at the leisure pursuits of older adults found that education levels had some effect on changes in leisure activities (Strain et al 2002). Having more education is associated with continuing more activities through old age, and especially dining out, going to the theatre, cinema, or spectator sports. Education may be serving as a proxy for income level, as these activities require income of a certain level (Burholt & Windle 2006).

### **2.8.6 Living arrangements**

Living arrangements are likely to influence everyday activity levels.

#### **2.8.6.1 Couples**

In a couple, home activity reflects both the nature of the couple's relationship, the individuals within that relationship, and the presence or absence of any challenges to the status-quo (van Nes 2013). van Nes et al's (2013) longitudinal study of everyday activity in older couples, demonstrates the differing norms within couples, with some sharing activities, and others doing things individually. However established patterns of activity changed over time due to changes in health. Broadly, the participants reduced activities outside the home, utilised strategies to maintain the remaining activities, and finally worked together to perform everyday activities. Health impacted both in the range of activities and the way in which they were undertaken. Older people living with a partner have an advantage over their single contemporaries, as the partnership acts as a buffer to protect challenges to activity from ill-health (Dixon 2011). Having a life-partner may also have beneficial effect in reducing the stress of living with a long term condition which in itself can affect activity levels (Clarke et al 2000).

#### **2.8.6.2. Living alone**

Older people in Great Britain are more likely to live alone than any other age-group (Rutherford 2012), and especially older women aged 85 years and over (ONS 2013, 2013a). The home activities of those that live alone are more vulnerable to the impact of ill-health due to the effects of deprivation and lack of support in the home (Haslbeck et al 2012); and older people living alone are considered an 'at risk' group due to their greater burden of morbidity,



and reduced likelihood of seeking medical help (Kharicha et al 2007). Those living alone have to be more self-reliant; and therefore strategies are employed to maintain independence and activities in the home, during ill-health; as activities have perhaps a greater significance for older people living alone as markers of independence (Haslbeck et al 2012). On a more positive note, living alone can give the freedom to engage in activities that build “self growth” and a sense of purpose (Yetter 2010).

### **2.8.7 Social Ties**

Relationships with family and friends are considered a key element in older people’s ideas about quality of life (Bowling 1995, Gabriel & Bowling 2004); and these social ties are an important in shaping older peoples’ activity, because they provide support for home activities (as previously described), and motivation to undertake activities outside the home (McMurdo et al 2012). Those who lack social support may experience loneliness and isolation (Victor et al 2000), however the impact of this on everyday activities depends on the individual (Kirkevold et al 2012).

The amount of contact that people have with friends and family may have an influence on the functional status of people with heart failure. One study in Canada found that social isolation was a significant predictor of risk of experiencing limitations in functional status one year later (Clarke et al 2000). The authors speculate that, “Ongoing involvement with others may help patients to maintain an optimal level of activity, thereby preserving functioning that might otherwise be lost” (Clarke et al 2000, page 297). Friends and family also provide support for people living with long term conditions, and it is possible that those with social ties are more likely to comply with the recommended lifestyle and medication regime (Clarke et al 2000).

### **2.8.8 Life Events**

Life events, such as bereavement, are known to impact on everyday routines (Koeneman et al 2012): with some individuals participating in fewer activities, and experiencing difficulties with everyday activities; but others taking the opportunity to take up new activities (Hardy et al 2002). For some older people that are widowed, there is a reduction in social participation around the time of the spousal death, and an increase in informal social participation afterwards (Donnelly & Hinterlong 2009, Utz et al 2002).

### **2.8.9 Caring for Spouse**

There are 6.5 million carers in the UK, and the number of those over the age of 65 has increased in recent years disproportionately to the general caring population (Carer UK 2012).

Everyday activities are dictated largely by the caring role (e. g. in heart failure: Clarke et al 2000, Imes et al 2010, Luttik et al 2007, Molloy et al 2005, Whittingham 2009), with informal carers describing the impact on routine, a life centred around the home, and difficulty leaving the home (Wiles 2003); resulting in lower levels of physical activity (Hirano et al 2011, Marquez et al 2012), and loss of social activities (Miller & Montgomery 1990). Home activity is also increased as caring demands grow (e.g. Forbes et al 2007). Providing informal care is linked to increased risks of negative impacts on mental health (Marquez et al 2012, Nieboer et al 1998).

#### **2.8.10 Retirement**

Retirement is an important transition point whereby individuals may be motivated to reduce, maintain, or increase activity levels (Barnett et al 2012, 2013). Whilst a retiree may have more time to spend engaged in home activities, participants typically aspire to engage in pursuits outside the home (Barnett et al 2012). However aspirations may differ for individuals who retire early due to ill-health, as their health condition may in part shape activities (e.g. Stamm et al 2010).

#### **2.8.11 Self-efficacy**

Self-efficacy is in essence the belief that the individual has about their own capabilities, and this is part of Bandura's social cognitive theory (Bandura 1986). Self-efficacy may have a positive or negative effect on daily activities, for example, if an individual has pessimistic beliefs or expectations about their physical capabilities they may not undertake any daily activities that they perceive to be too strenuous, and may thus self-limit their life. A study by White et al (2009) found that disability limitations were significantly associated with poor self-efficacy; however the means by which this influences activity could be indirect via the onset of functional limitations (McAuley et al 2009). Self-efficacy has also been investigated as a factor in the undertaking of physical activity, with lower self-efficacy associated with reduced physical activity (Lee et al 2008, Umstattd et al 2008). A strong element of self-efficacy which influences daily activities negatively is fear, which is a much researched factor contributing to activity restriction and its avoidance in older people (e.g. fear of falling as a factor in activity restriction in Bertera & Bertera 2008, Dias et al 2011, Hawley 2009, Nillson et al 2010, Vellas et al 1997).

Fear rather than actual symptoms may limit home activity. A study of patients with moderate heart failure asked why their activity levels were low, and the main reason was a fear of cardiac events (Jehn et al 2009). Recommendations on activity levels for people with heart

failure have changed, and this may provoke fear and apprehension in some people, especially if they have been dealing with the condition over a long period of time, "...the recommendation to become more physically active in the presence of significant heart disease may be frightening and contradictory to previous suggested management.." (SIGN 2007, page 11).

### **2.8.12 Personality/Outlook**

Personality has an impact on everyday activity, since those with an optimistic outlook are more likely to engage in an active lifestyle (Steptoe et al 2006, Terracciano et al 2008), and social activities (Herero & Extremera 2010); this is illustrated by Horder et al's qualitative study (2013) of older people who took a positive approach to life and a key element of this was to keep busy. Personality also has an impact when facing the challenges of ill-health, and those with a positive outlook are more likely adapt in a positive way (Haynes & Watt 2008, Slangen-De Kort et al 2001), with resilience (van Kessel 2013), and motivation (Lawton et al 2002). Those with personality types which are more likely to experience anxiety and negative feelings, face more challenges to remain active during health challenges; as they are more likely to view their health status negatively (Schiffer et al 2008), for example, having an elevated symptom perception (Rachman & Phillips 1975, Melzack 1973).

### **2.8.13 Transport availability**

Many older people do not have access to a car (Davey 2007), and this can lead to a loss of activities in the community and a greater time spent at home (Liddle & McKenna 2003, Liddle et al 2012, Mezuk & Rebok 2008). Older drivers may reduce or cease driving as a response to a decline in health (Campbell et al 1993, Edwards et al 2009, O'Connor et al 2011). However the car may also increase in importance in old age as a means to achieve activities outside the home, when health and functioning declines (Cvitkovich & Wister 2001, Mollenkopf et al 2002)

### **2.8.14 Health**

#### **2.8.14.1 Physical Health**

People do not respond consistently to ill health. Some people remain active, and others reduce activity; and this has been observed in a number of health conditions (Mock et al 2000):-

*"We all know some people whose medical findings suggest that they should be bed-bound and yet live a near-normal life and, in contrast, other people who have little wrong with their bodies yet live like invalids"* (Furze, Donnison, & Lewin 2008, page 28)

In a study on rheumatology, Donovan et al (1989) noted that the sample of patients employed different coping strategies to deal with the painful symptoms; some of the female participants ignored the pain and kept going, while others perceived themselves as seriously ill and lived a restricted life. A study of elderly heart failure patients found that measures of disease severity did not correlate with measured exercise capacity and everyday activity (Witham et al 2006). The authors conclude that the lack of correlation "...suggests that daily activity in heart failure is not simply limited by symptoms. This suggests that a more complex set of factors underlies the variance in daily activity" (Witham et al 2006, page 206). An earlier study investigating the relationship between impairment, disability and handicap in chronic obstructive airways disease found that the relationship between certain measures of lung function and physical disability is not strong (Williams & Bury 1989). The authors speculate that something other than physical ill-health is at play. A study in Canada looking at the determinants of everyday physical activity in elderly people found that good physical health was a predictor of higher everyday activity for men, but not for women (Chipperfield et al 2008a). The authors point out that there is not a linear relationship between daily activity and health, "physical inactivity should be viewed as both contributing to and being a consequence of poor health" (Chipperfield et al 2008a, page S216). However a higher burden of ill-health is more likely to lead to activity limitation (Oldridge & Stump 2004); and specific disease characteristics, such as symptoms which result in decreased endurance capacity (e.g. shortness of breath or fatigue), may impact more on mobility limitations (Avlund et al 2003, Kriegman et al 1997, Wright et al 2011).

#### **2.8.14.2 Mental Health**

People with long term conditions are more likely to be depressed than the general population. It is estimated that one in five heart failure patients is depressed (NHS Choices 2008); and the presence may cause a reduction in daily activities (Alosco et al 2012). One study in Canada found that mood disturbance was a significant predictor of risk of experiencing limitations in functional status after one year (Clarke et al 2000). The authors speculate that, "High anxiety and depression could increase the likelihood that patients prematurely curtail their activities and experience deconditioning in addition to the decline in functioning directly attributable to their cardiac conditions" (Clarke et al 200, page 297). Other studies concur with this finding (Carriere et al 2011, Hybels et al 2009, Machado et al 2008, Norton et al 2012). On the flip side, higher activity levels are associated with better mood in older people (Heesch et al 2011, Stewart et al 2003).

Loss of mobility and the ability to carry out everyday activities may be a trigger for depression. In a study of depression in elderly general practice patients, Iliffe et al (1993) found that depression, especially in its milder forms was associated with a loss of function, particularly a loss of mobility outside the home, or the inability to deal with personal hygiene without help. A study by Copeland found that depression was more likely to be associated with a loss of mobility around the house, rather than outside (Copeland in Iliffe et al 1993).

### **2.8.14.3 Perception of Health**

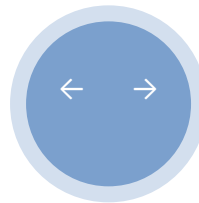
One limiting factor in studies of older people's activity levels is the phenomenon of response shift, whereby people rate their health as good even though they have health conditions that limit their life (Levasseur et al 2008, Schwartz & Sprangers 2000, Sharpe & Curran 2006). This makes it difficult to look at the relationship between measures of activity and health. In addition individuals' perceptions of health are constructed in complex ways; for example, one study found that perceptions were based not on the presence of health conditions, but on an assessment of how capable of activity that person was (Partridge, Johnston, & Morris 1996).

A study in the Netherlands looked at the relationship between the ability to carry out the activities of daily living and self-reported health in elderly men (Hoeymans et al 1997). The study found that disability did not impact on self-rated health for the elderly men, because the authors speculated that disability did not impact on every activities because family members perhaps undertook the activities they found difficult. . In an earlier study, the authors found that the link between disability and self-reported health decreased with ageing, and the authors speculate that as people get older and their ability to undertake activities of daily living declines they accept this as a normal sign of ageing and do not attribute it to a decline in health.

A summary of these influences on activity levels is presented in the following diagram (2.4). The diagram depicts the range of general factors influencing older people's activity levels - with factors known to potentially increase, or decrease activity; or to work either way, depending upon individual responses. These factors have the potential to alter home activity levels in ways that are not clear, since activity decreases may impact more on outdoor activity, for example, a person feeling unwell may choose to stop at home, which may potentially result in an increase in home activity.

Figure 2.4 Schematic Diagram – General Factors Influencing Activity

Part 1: Heart Failure

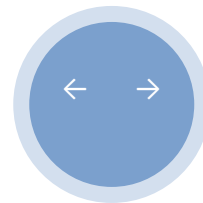
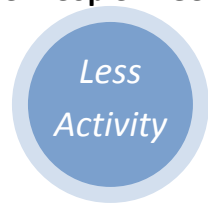


Factors limiting activity in Heart Failure	
Fear	(Jehn et al 2008)
Symptoms	(Ekman & Ehrenberg 2002 Falk et al 2007 Seo et al 2008)
Advanced HF	(Jehn et al 2008 Walsh et al 1997)

Factors potentially increasing activity in Heart Failure	
Activity & Exercise	(Lewin et al 2005 Morantz 2003 Pina et al 2003)

**Figure 2.4 Schematic Diagram – General Factors Influencing Activity**

**Part 2: Older People in General**



Factors potentially limiting activity in older people

Age	(Chipperfield 2008 Davis et al 2011 Dollosso et al 2012 McMurdo et al 2012)
Depression & Anxiety	(Alosco et al 2004 Clarke et al 2000 Illiffe et al 1993)
Loss of car	(Liddle & McKenna 2003, Liddle et al 2012, Mezuk & Rebok 2008)
Poor self-Reported health	(Honeymans et al 1997)
Spousal caring	(e.g. Miller & Montgomery 1990 Wiles 2003)

People do not respond consistently to certain factors, some remain active, others reduce activity

Ill health	(Chipperfield et al 2008 Donovan et al 1989 Lewin 1997 Williams & Bury 1989 Witham et al 2006)
Life Events Bereavement	Hardy et al 2012
Retirement	Barnett et al 2012, 2013

Factors potentially increasing activity in older people

Better self-Reported health	(Chipperfield et al 2008)
Good self efficacy	(White et al 2009)
An active past	(Baumann et al 2012 Kirkwood 2009)
A positive outlook	(Herero & Extremera 2010 Steptoe et al 2006 Terracciano et al 2008)

### **2.8.15 Meaning of Specific Home Activities**

The following section assesses common home activities and their relationship with health, and describes the negative impacts that may arise when disability occurs in these activities. Other factors influencing activity difficulty are also described, in order to understand the relative importance of health as an influence in the onset of difficulty.

#### **2.8.15.1 Food intake**

There is a bidirectional relationship between food intake and health in the sense that people may eat less when they are unwell, and an inadequate diet may cause ill health, “Malnutrition is both a cause and consequence of disease” (ENHA et al 2006, page 7). It is very important to monitor food intake in people with long term conditions since, “It is without doubt that malnutrition is an important influencing factor in the outcome of clinical diseases, and so it is vital that effective treatments and preventative measures are developed” (Hickson 2006, page 7). Disease may cause undernutrition by three means: decreased food intake, impaired gastrointestinal function, and changed metabolism (McLaren 2009). A number of medical conditions are associated with higher rates of malnutrition in older people, and these include, gastrointestinal disorders such as malabsorption, respiratory disorders such as emphysema, neurological disorders such as Parkinson’s disease, infections such as chest infections, physical disabilities such as arthritis, and other disease states such as cancer (Hickson 2006). In addition, reduced food intake may result from depression (Elsner 2002, Huffman 2002), or cognitive changes (Locher et al 2008, McCormack 1997).

Other factors having an adverse effect on appetite in older people, include: loss of taste and smell (Duffy et al 1995, Hickson 2006), reduced physical activity (Gariballa & Sinclair 1998), poor oral health (Help the Aged 2008, Eberhardie 2009, Hickson 2006, WHO 2003), loneliness (Gustafsson & Sidenvall 2002, Locher et al 2005 & 2008, Wylie et al 1999), life events (Elsner 2002, Quandt et al 2000, Rosenbloom & Whittington 1993), and the side effects of medications (Cook & Taren 1990).

#### **2.8.15.2 Food Preparation**

Food preparation can be a barrier to good nutrition for older people, as they may experience tiredness, or other physical or emotional difficulties preventing this. A study of older people in Leeds, for example, highlights the range of problems encountered in food preparation within the sample, “The problems encountered were arthritis causing difficulties in opening jars and bottles, shaking, fatigue, breathlessness, concerns about personal safety due to dropping things, poor mobility leading some subjects having to sit down to prepare food, and back



problems preventing lifting of objects and bending down to ovens” (Wylie et al 1999, page 378). However there may also be a reduction in food preparation due to a loss of motivation (Callen & Wells 2003, Gustafsson & Andersson 2004).

A change in methods of food preparation may occur due to difficulties arising from long-term conditions (Gustafsson & Andersson 2004), or the onset of other illnesses (Kullberg et al 2011); and this may result in people using ready meals rather than cooking from scratch (Eckel et al 2012, McKie 1999, Sidenvall et al 2001). Health may also cause problems travelling to and from the shops (Wylie et al 1999), and shopping (Consumer Council 2007, Sidenvall et al 2001); both of which are demanding physical activities (Consumer Council 2007, Hare 2003, Munoz-Plaza et al 2013, Wylie et al 1999). Food preparation is typically carried out by women (Sidenvall et al 2001), and those experiencing difficulties may be reluctant to acknowledge their problems due to a desire to remain independent (Gustafsson & Andersson 2004).

The influences on food activity are summarised in the following diagram (2.5).

**Figure 2.5 Schematic Diagram –  
Food Activity**

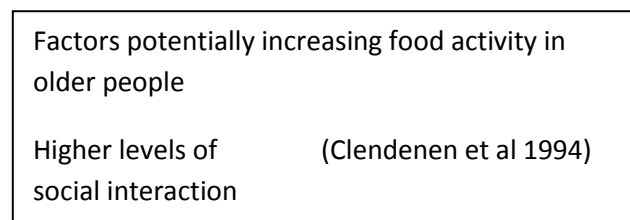
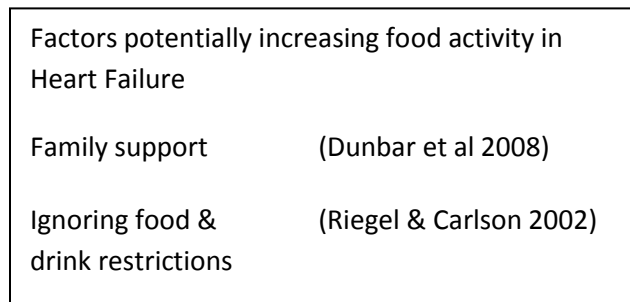


**Part 1**

<p>Factors potentially limiting food activity in older people</p> <p>Alcoholism (Davies 1984)</p> <p>Being housebound (Locher et al 2008)</p> <p>Bereavement (Herne 1995, Elsner 2002 Quant et al 2001 Rosenbloom &amp; Whittington 1993)</p> <p>Continence problems (Eberhardie 2009)</p> <p>Decline in cognitive functioning (Locher et al 2008 McCormack 1997)</p> <p>Dehydration (Elsner 2002)</p> <p>Depression (Elsner 2002 Huffman 2002)</p> <p>Difficulties with shopping &amp; food preparation (Eckel et al 2012 Gustafsson &amp; Andersson 2004, etc)</p> <p>Food less palatable (Busse 1980)</p> <p>Ill health (ENHA 2006 Hickson 2006)</p> <p>Inactivity (Hajjar et al 2004 James et al 1997 Morley 1986)</p> <p>Lack of money (Smithers et al 1998)</p> <p>Loneliness (Clendenen 1994 Wylie et al 1999)</p>	<p>Factors potentially limiting food activity in Heart Failure</p> <p>Loss of appetite (Bennet et al 2000)</p> <p>Fatigue (Anderson &amp; Sidenvall 2001, Haywood 2009 Lennie et al 2006)</p> <p>Illness in the caring partner (Dunbar et al 2008 Locher et al 2008)</p> <p>Nausea (Lennie et al 2006)</p> <p>Side-effects of drugs (Boyd et al 2004)</p> <p>Symptoms (Lennie et al 2006)</p>
	<p>Factors potentially limiting food activity in older people – continued</p> <p>Poor oral health (WHO 2003 Help the Aged 2008)</p> <p>Side-effects of drugs (Cook &amp; Taren 1990)</p> <p>Stress (McIntosh 1989)</p> <p>Swallowing Difficulties (Gariballa et al 1998 Willacy 2010)</p> <p>Symptoms (Telford et al 2006)</p> <p>Transport (Consumer Council 2007)</p> <p>Trigger events (de Castro &amp; Stroebele 2002 ENHA 2006)</p>

## Figure 2.5 Schematic Diagram – Food Activities

### Part 2



### **2.8.15.3 Toileting**

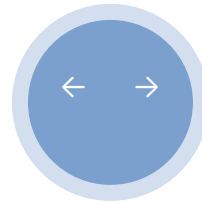
Toileting frequency may provide insights into the health state. A change in bladder habits could be a sign of a number of health conditions, such as, bladder cancer, prostate cancer, kidney disease; and a frequent need to urinate can be a symptom of an overactive bladder (AGDHA 2006), type 2 diabetes (NHS Choices 2009b), or prostate problems (NHS Choices 2009c). Changes in bowel habits can be indicative of health conditions which vary in their severity, these include: diarrhoea, constipation, bowel cancer, Crohn's disease, colitis, diverticulitis, and irritable bowel syndrome (AGDHA 2006). In addition, the toilet can become a sanctuary during episodes of diarrhoea and vomiting, caused by food poisoning (NHS Choices 2009), gastroenteritis (NHS Choices 2010), and norovirus (NHS Choices 2010a), to name a few. Older women are particularly susceptible to urinary tract infections which result in urinary frequency (Baerheim et al 2003, Car 2006, Heath 2009, McMurdo & Gillespie 2000, NHS Choices 2010b, Schulz & Gambert 1991), and if left untreated can lead to greater morbidity, hospital admission, and in frail people, potentially death (Richards 2004). The onset of incontinence may lead to increased toilet visits, and the condition is a risk factor in developing a dependency in activities of daily living (Cigolle et al 2007).

Health conditions may cause toilet visits at unusual times, such as nocturia, which is the need to urinate a number of times during the night (Abrams et al 2002). Older people may not report the condition due to embarrassment (Booth et al 2010), but the condition may be a sign of important health conditions (Kujubu 2009; Mevcha, Gulur, & Gillatt 2003).

Some medications result in increased visits to the toilet, such as the loop diuretics in health failure, which cause episodes of frequent urination (Lewin et al 2005, Healthtalkonline.org 2010, Zambroski et al 2003).

The influences on toileting are presented in the following diagram (2.6).

Figure 2.6 Schematic Diagram – Toileting



Factors potentially decreasing toileting in older people

Dehydration (NHS Choices 2009d)

Factors potentially increasing toileting in older people

Gastroenteritis (NHS Choices 2010)

Incontinence (Cigolle et al 2007)

Overactive bladder (AGDHA 2006)

Prostate problems (NHS Choices 2009c)

Type II diabetes (NHS Choices 2009b)

Urinary Tract Infection (Baerheim et al 2003, Car 2006, etc)

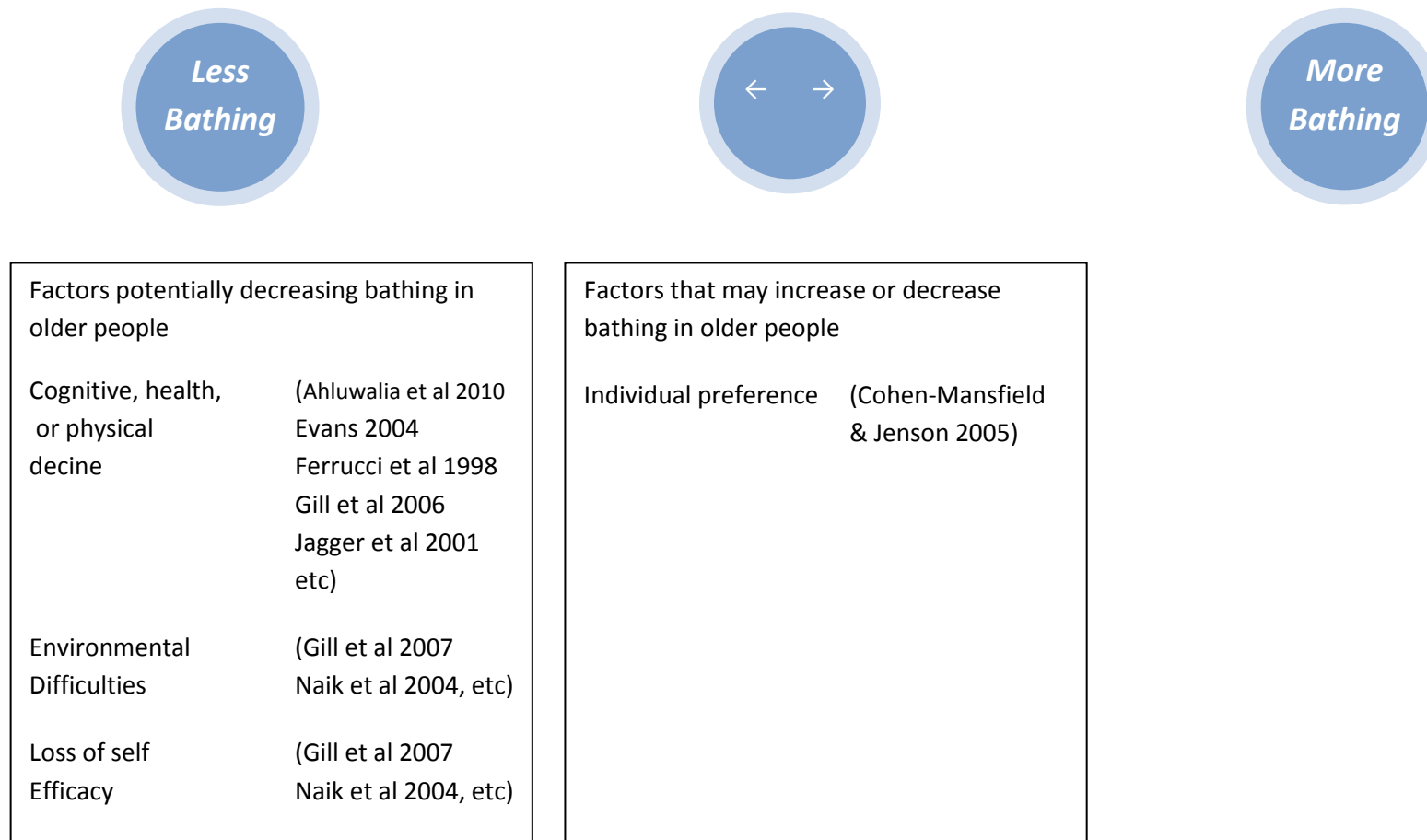
#### **2.8.15.4 Bathing**

There is a paucity of information about the bathing activities of older people (Ahluwalia et al 2010, Cohen-Mansfield & Jensen 2005), and in particular how they respond to functional deficits (Murphy et al 2007). Bathroom activities are subject to individual preferences, and are influenced by varied determinants (Cohen-Mansfield & Jensen 2005). Bathing is a complex activity, and cessation of the activity can be an indicator of cognitive or physical function (Evans 2004) that may require an intervention to prevent further decline (Evans 2004, Gill et al 2006). Bathing may be the first activity of daily living that is effected by declines in health and functioning, in the disablement process (Ferrucci et al 1998, Gill et al 2006, Jagger et al 2001, Katz et al 1963, Spector & Fleishman 1998); and thus bathing disability has been described as “...the first step down a slippery slope ending with death” (Rozzini et al 2007, page 635). It is also a predictor of disabilities in other activities of daily living (Dunlop et al 1997), an increased risk of hospital admission (Reuben et al 2002), and admission to a care home (Gill et al 2006). A more immediate impact for some is becoming stuck in the bath, a traumatic experience which may prompt modifications in bathing (Cadier & Shakespeare 1994, Gooptu & Mulley 1994).

Bathing difficulties are caused by a variety of factors, including environmental issues, self-efficacy; and illness or injuries including heart failure, stroke, arthritis, diabetes, falls, (Gill et al 2007, Naik et al 2004, Reynolds & Silverstein 2003). These issues may manifest in either bathing less frequently, moving from bath to shower, or sponge bathing (Ahluwalia et al 2010).

The influences on bathing frequency are presented in the following diagram (2.7).

**Figure 2.7 Schematic Diagram – Bathing**



#### **2.8.15.5 Television Viewing**

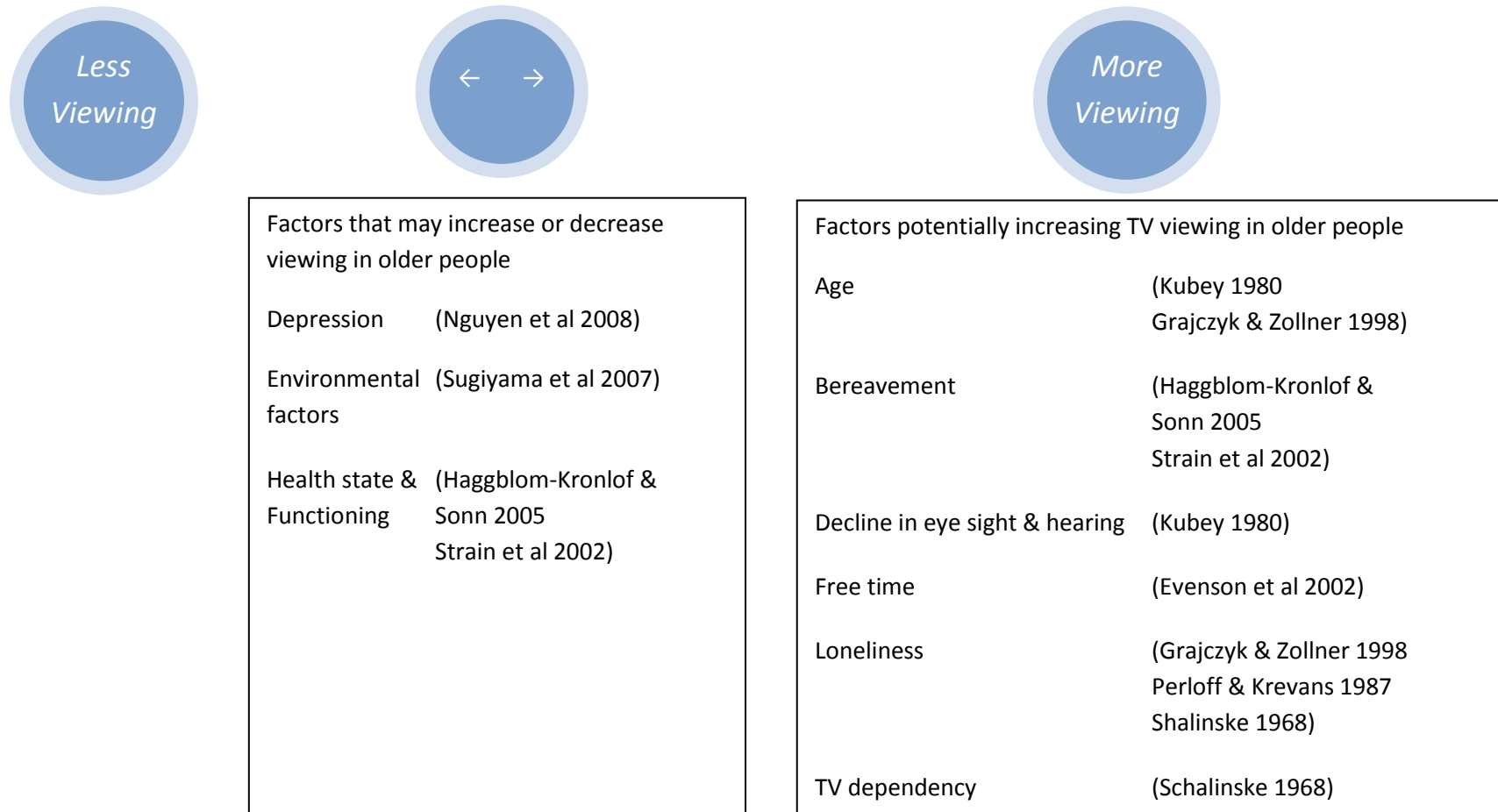
The relationship between television viewing and health is complex. Television viewing has been associated with a number of negative health outcomes (Jakes et al 2003, Johnson et al 2006, Sugiyama et al 2008, Wadsworth & Johnson 2008); although as people age solitary activities such as watching television become increasingly important (Kubey 1980), and viewing may play an important role in maintaining well-being (Chilvers et al 2010, Graney & Graney 1974) and a structure to the day (Grajczyk & Zollner 1998, Schalinske 1968). During periods of depression, older people may increase or reduce television viewing; or change the way viewing is undertaken from engaging in the programmes to watching in a passive way (Nguyen et al 2008). The onset of ill-health may lead to an increase of viewing, and this may become engrained in routine despite improvements in health (Bunzel & Eckersberger 1989). Viewing may also increase as sensory abilities deteriorate, and previous activities (such as reading) become more difficult (Kubey 1980).

A range of other factors are known to increase television viewing, including loneliness (Perloff & Krevans 1987, Schalinske 1968), retirement (Evenson et al 2002), old age (Grajczyk & Zoller 1998), and environmental factors (such as whether the local environment is accessible or inaccessible) (Sugiyama et al 2007). Meyersohn outlined three conditions that make older people more likely to be drawn to television, "First of all, he grows more sedentary; second, he has more leisure time; and third, he has fewer ties with the world" (in Kubey 1980, page 19). Kubey (1980) describes two types of viewing: discriminate and indiscriminate. Schalinske (1968) has described the indiscriminate use of television in the elderly, characterised by passivity and a dependence on television to provide interest and satisfy needs (in Kubey 1980). Television "...may provide an easy opportunity to withdraw from the world of activity into the realm of non-doing" (Kubey 1980, page 26).

The range of factors influencing the duration of television viewing in older people is depicted in the following diagram (2.8).



**Figure 2.8 Schematic Diagram – Television Viewing**



#### **2.8.15.6 General Activity**

General movement around the home would include both walking from A to B, and undertaking activities that require movement around the home, such as cleaning. This ability to move oneself is commonly defined as mobility (Webber et al 2010), and definitions may include both mobility within the home and wider environment (e.g. the World Health Organization's definition includes both indoor and outdoor movement (2001)). Walking difficulties can lead to isolation, and a loss of engagement with the wider world (Metz 2000, World Health Organization 2007). Mobility difficulties are also predictors of disability, loss of independence and a higher rate of mortality (Hirvensalo et al 2000, von Bonsdorff et al 2006). A key test of mobility in the home is the ability to climb the stairs, as described in the following section.

The ability to undertake household chores not only makes the house more pleasant to live in, but the activity is an important form of 'social participation', especially for women (Adamson et al 2004). The World Health Organization defines 'participation restriction' as, the "...problems an individual may experience in involvement in life situations" (Adamson et al 2004, page 294). In a study looking at the relationship between chronic diseases, activity limitations and social participation in older women; the strongest association was between activity limitation and household chores (Adamson et al 2004).

#### **2.8.15.7 Stairs Usage**

Stairs are the means of accessing the rooms on other floors in the home, and for people incapacitated in any way, they can become an impediment to the ease of movement (Hill et al 2000). There is some evidence for the idea that the frequency of stair usage is related to health from a UK qualitative study of stair usage amongst older people (Hill et al 2000) which state that: "As might be expected, individual functional ability affects the frequency of stair use, and those with decreased ability use the stairs less often. Of those who stated that they use the stairs infrequently, the majority pointed out that their condition affect their legs, (e.g. pain in knees or hips), or other medical conditions that make it difficult to exert themselves (e.g. heart problems or breathlessness) was the reason for their stair avoidance" (Hill et al 2000, page 25). Difficulty with climbing the stairs is a predictor for the onset of an activities of daily living disability (Idland et al 2013), and provides a quick means of assessing functional decline (Oh-Park, Wang & Verghese 2011).

Other factors may increase stair usage regardless of health and wellbeing, for example, the use of diuretics may increase stair usage if the only toilet in the house is upstairs (unless the patient remained upstairs during this time of frequent toilet usage, or a bottle or commode

was used downstairs (Davis et al 2006)). In the qualitative study of stair use mentioned previously (Hill et al 2000), for example, some participants mentioned having to go upstairs more often in the morning to visit the toilet because of medications (presumably diuretics).

#### **2.8.15.8 Sleeping**

Sleep is essential to health and well-being (Lan et al 2007). People spend about one third of their lives sleeping, and this plays a vital role in safeguarding mental and physical health (Sutton et al 2001). People of all ages are affected by sleep quality but older people may be more vulnerable to the impact of poor sleep, and thus improving sleep quality may play a vital part in increasing quality of life in elderly people (Yao et al 2008). However there is no definition of normal sleep in older people; how much sleep an individual requires is determined by the perceptions of that individual and the impact on functional status (Kamel & Gammack 2006).

Sleep habits in older people are the result of a complex interaction between a myriad of factors, for example, social, behavioural, psychological, and health factors (McHugh, Casey, & Lawlor 2011; Stranges et al 2008). People sleep less as they get older, and the character of sleep changes becoming less effective and of a poorer quality; and this change occurs in all people regardless of health (Hauser 2006, Klerman & Dilijk 2008). It is common that sleep problems in elderly people are attributed to ageing (Kamel & Gammack 2006), and therefore may not be adequately evaluated by doctors (Lamberty 2003, Lesage & Scharf 2007). However it is likely that many problems could be solved by medical intervention: "Although sleep patterns appear to alter as we age, by far, in elderly people, most sleep problems are not the result of biologic shifts in circadian rhythmicity but rather result from increasing disease burden, medication effects, depression and anxiety, and limited mobility" (Lesage & Scharf 2007 page 53, Foley et al 1999, McCrae et al 2008, Morgan & Clarke 1997, Reid et al 2006, Roberts et al 1999, Sutton et al 2001, Vitiello et al 2002).

Sleep problems left untreated can have negative consequences for the health and well-being of older people, with a possible increased risk of falling, concentration problems, slowed response time, difficulty with memory, daytime sleepiness, poor quality of life, depression and anxiety, unidentified health problems such as sleep apnea and cognitive decline, and finally a higher rate of mortality (Ancoli-Israel 2005, Kamel & Gammack 2006, Latimer Hill et al 2007, Lesage & Scharf 2007, Stone et al 2008, Van Someren 2000). Sleep problems may also be a predictor of nursing home placement in elderly men living in the community (Pollak et al 1990). A number of studies have linked sleep of both long and short duration with increased

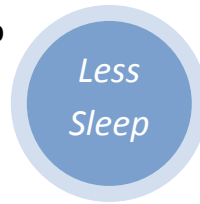
mortality and morbidity (Knutson & Turek 2006, Lan et al 2007, Tamakoshi & Ohno 2004, Van den Berg et al 2008). Poor health can also be a factor in daytime sleepiness and napping in older people (Asplund 1996, Goldman et al 2008, Dautovich et al 2008). However a cross-sectional study in America found that the higher prevalence of long term conditions in older people did not explain changes in sleep, once age and age-sex differences were added to the analysis (Unruh et al 2008). The authors therefore suggest that the sleep problems should be treated by interventions such as behavioural therapy, stress and grief management, and medication; rather than treating underlying medical conditions.

There are issues around the measurement of sleep, whether subjectively by self-reporting, or objectively by mechanical means; as the two measures often do not match (Paudel et al 2008). However, perhaps this may not as important as it initially sounds, as “in many cases, subjective symptoms may be more important to patients than objective impairment” (Paudel et al 2008, page 1234). The majority of sleep studies of older community dwelling adults use subjective measures of sleep, and this has provided evidence of a strong association between self-reported sleep quality and poor health outcomes (Unruh et al 2008). Women are more likely to report poor sleep than men (Foley 1995, McCrae et al 2008, Middelkoop et al 1996); but objective measurement of sleep may show the opposite (Unruh et al 2008, Reuters Health Information 2008).

Sleep recorded by a pressure sensitive mattress pad is valuable because it allows measurement to take place in the subject’s own home, and this is particularly useful for recording the sleep patterns of older people who may be reluctant to sleep in a laboratory (Thoman et al 1993). However there are a number of shortcomings with this method of measuring sleep (Thoman et al 1993). Sleep is only recorded in bed, but people may nap in other places such as a chair; in addition they may have mini-naps, such as when they are watching television, and may be unaware of these. In addition, the bed is not used solely for sleeping, and thus the sensors may be recording other activities, such as, reading, watching television, sewing, or talking on the phone.

The influences on sleep duration are represented in the following diagram (2.9).

**Figure 2.9 Schematic Diagram – Sleep**



Part 1

Factors potentially limiting sleep in older people	
Age	(Hauser 2006 Klerman & Dijk 2008)
Bereavement	(Pasternak et al 1992)
Depression & anxiety	(Lesage & Scharf 2007 Motivala et al 2006 Quan et al 2005 Vitiello 2002)
Decline in cognitive functioning	(Bliwise 1993)
Female gender	(McCrae et al 2008 Middelkoop et al 1996)
Inactivity	(Ohayon et al 2001)
Increased disease burden	(Foley et al 1995 Lamberg 2003 Lesage & Scharf 2007 Vitiello 2002 Zee & Turek 2006)
Lack of Social Interaction	(Dew et al 1994 Ohayon 2004 Yao et al 2008)
Long term Conditions	(Lamberg 2003 Reid et al 2006 Sutton et al 2001)
Loneliness	(Cacioppo et al 2002)
Nocturia	(Asplund & Aberg 1992 B & BF 2008 Lamberg 2003)
Pain	(Gislason et al 1993 Quan & Zee 2004)

Factors potentially limiting sleep in Heart Failure (HF)	
HF	(Redeker & Stein 2006)
Inactivity	(Lewin et al 2005)
Disorders prevalent in HF	(Collop 2007 Hanley & Zuberi-Khokhar 1995, 1996 Ohayon & Roth 2002).
Symptoms	(Brostrom et al 2003 Lewin et al 2005)

Factors potentially limiting sleep in older people (continued)	
Side effects of drugs	(Foley et al 1995 Lesage & Scharf 2007)
Spouse's ill-health	(Bostrom et al 2003 Dzaja et al 2005)
Stress	(Hall et al 2008 Sutton et al 2001)
Symptoms	(Foley et al 1995 Lamond et al 2000)
Widows feeling insecure	(Dzaja et al 2005)

## Schematic Diagram – Sleep

### Part 2



Factors potentially increasing sleep in older people

Activity (Morgan & Clarke 1997)

Higher levels of social interaction (Dew et al 1994  
Ohayon 2004  
Yao et al 2008)

## **2.9 Heart failure**

Heart failure is an unpredictable condition (Wingham et al 2013, Yu et al 2008), which impacts on everyday activity in wide-ranging ways. Activities were modified as a result of heart failure, for example, by altering the timing (Clark et al 2008, Falk et al 2007, Hagglund et al 2008) and speed (Evangelista et al 2000, Falk et al 2007, Hagglund et al 2008, Jeon et al 2010, Rhodes & Bowles 2002) in which they were undertaken. In common with other long-term conditions a pattern of good and bad days occurs, “Most fundamentally, ill people define good and bad days according to their evaluations of the amount of intrusive illness” (Charmaz 1991); and the impact of this fluctuating pattern on everyday life is described in the literature (Aldred et al 2005, Clark et al 2008, Europe & Tyni-Lenne 2004, Evangelista et al 2001, Falk et al 2007, Martensson et al 1997, Pattenden et al 2007, Ryan & Farrelly 2009). As health worsens specific activities may be curtailed (Aldred et al 2005, Bennett et al 2000, Bosworth et al 2004, Europe & Tyni-Lenne 2004, Pattenden et al 2007, Ryan & Farrelly 2009, Zambroski 2003), or undertaken by others instead (Aldred et al 2005, Bennett et al 2000, Clark et al 2008, Falk et al 2007, Hagglund et al 2008, Pattenden et al 2007, Ryan & Farrelly 2009). Common impacts of heart failure are described in a number of reviews of qualitative studies, such as negative impacts on the sense of self (Jeon et al 2010, Welstand et al 2009, Yu et al 2008), uncertainty (Wingham et al 2013), and fear and anxiety (Wingham et al 2013, Yu et al 2008), which have the potential to act as a disincentive to activity.

## **2.10 Summary of Literature Review Findings**

In summary, the literature review identified a range of factors which act to potentially limit activity in the home, such as: homes that are not suited to the needs of older people, or inhibit activity due to lack of space (Cress et al 2010, Gilroy 2005, van Nes 2013, Wiles 2012); or beliefs that old age is about taking things easy (Andrews 2012, Bennett & Gaines 2010, Brouwer & van Exel 2005, Stewart et al 2011). A more positive reason for low levels of home activity comes from older people who are enjoying an active retirement, participating in activities outside the home (Barnett et al 2012). The review identified factors which may increase time spent at home, such as: lack of transport (Liddle & McKenna 2003, Liddle et al 2012, Mezuk & Rebok 2008), poor self-efficacy (such as fear of falling) (Bertera & Bertera 2008, Dias et al 2011, Hawley 2009, Nilsson et al 2010, Vellas et al 1997), caring responsibilities in the home (e.g. Forbes et al 2007), a local environment which is difficult to navigate (Bird et al 2010, Bowling & Stafford 2007, Carlson et al 2012, Hand et al 2012, Lord et al 2010, Nettle et al 2012, Rosenberg et al 2012, Rosso et al 2011, Sugiyama & Thompson 2005, Wilkie et al 2007, Zeitler et al 2012), lack of money to engage in outside activities (Burholt & Windle 2006), or lack of

friends and family to do activities with (McMurdo et al 2012). Within this mix of social, environmental, and individual circumstances and personality types, health is also a factor which may also increase or decrease home activity; but the review demonstrates that the response to poor health is unpredictable, with some decreasing activity and others carrying-on regardless (Donovan et al 1989, Furze et al 2008, Mock et al 2000, Williams & Bury 1989, Witham et al 2006).

The review also looked at the measurement of home activity for assessment of health and social care need, and identified the typical home activities which are surveyed. Strengths of this approach were identified (in the sense that the activities are more meaningful to older people (Bowling 1997), and the measures can be targeted for specific populations (Bowling 1997, 2001)). However critics argue that this indirect measure of health may not capture small changes (Graf 2008), or the strategies that individuals employ when they encounter difficulties (Kriegsman et al 1997a, Lorenz 2009); and such an approach does not take account of the very individual approach to undertaking activities within the context of ill-health (Bowling 1997, Donovan et al 1989, Furze et al 2008, Mock et al 2000, Williams & Bury 1989, Witham et al 2006).

Finally, a range of home activities which are typically measured by health and social care measurement scales were reviewed to establish their value as potential indicators of health in the analysis of the telecare data for this project. All the home activities were found to be valid indicators of a change in need. However changes in these home activities can also arise out of factors other than health.



## Chapter 3: Research Questions

### 3.1 Introduction

A complex picture emerged from the literature of the relationship between activity and health, as people react inconsistently to ill-health, with some remaining active and others' reducing activity. In addition health is just one factor in a complex web of forces which act to inhibit or encourage activity. The premise of lifestyle monitoring is that older peoples' home activities reflect their health state, and yet the evidence from this literature review demonstrates a greater degree of complexity. These findings highlight the need for further research to explore the relationship between activity and health within a sample of participants with a long term condition, both to test the underlying assumption of LM, and to investigate the nature of the potential gap between home activity influenced by health and overall activity. In addition in view of this understanding of the complex nature of everyday activity, further research is needed to assess the utility of the standard LM sensor setup to indirectly measure activities which are subject to change according to the health state, and this research sets out to do this by both examining the sensor setup of a LM study, and by the analysis of participant descriptions of activities undertaken during variations in health

### 3.2 Research Aims

The aim of this research study was to explore the relationship between activities within the home and health amongst older adults with heart failure, living in a South Yorkshire town. The research questions (and sub-questions) were as follows:-

- 1) Do everyday activities undertaken in the home by older people with Heart Failure, vary according to the health state of the individual carrying them out?**
  - a. Do levels of recorded proxy activity captured by lifestyle monitoring sensors vary according to self-reported levels of health?
  - b. Do older people vary their everyday activities according to the three health states of Heart Failure (normal days, bad days, and exacerbations)? And if so, how do these activities differ?
  - c. If these changes in activity according to health occur, are these changes distinctive to the individual or transferable across the whole sample?
  
- 2) What other factors influence everyday activity in older people?**
  - a. Do these factors outweigh the influence of heart failure symptoms, or are they less important?

- b. Do the partners of individuals with heart failure influence the activities undertaken by their spouses with Heart Failure?

The research methods that were employed to address these research questions are described in the following chapters.

## **Chapter 4: Mixed Methods Methodology**

### **4.1 Introduction**

This chapter sets out the mixed methods methodology utilised by this study, with a definition and description of the issues confronting researchers undertaking this approach. The justification for using this method is set out, and details of the research design with consideration of research quality and data integration.

### **4.2 Mixed Methods Approach**

Mixed methods are a relatively recent research method (Creswell 2003), and are defined as “investigations involv[ing] integrating quantitative and qualitative data collection and analysis in a single study or program of inquiry” (Cresswell, Fetters & Ivankova 2004, page 7). The approach which is distinct from multi-method studies which do not ‘mix’ the qualitative and quantitative elements (Bryman 2007, Tashakkori & Creswell 2007), has become more popular in recent times and there are now journals and textbooks dedicated to the subject, and an increasing number of mixed methods studies undertaken within the field of health (O’Cathain et al 2007). Researchers undertaking a mixed methods study face a number of challenges, from epistemological issues around the different traditions of qualitative and quantitative research methods, and the additional work and skill required to collect and analyse both data types (Cresswell 2003, Bergman 2008) and draw the findings together.

### **4.3 Epistemological Issues**

Epistemological issues arise out the differing stances traditionally applied in quantitative and qualitative research: with a positive/postpositive stance applied in quantitative research whereby a theory is developed and tested via data measures in a logical manner; however within qualitative research there is a more complex view of reality with social constructivism stances taking account of individuals’ constructions of their social situation, or advocacy/participatory stances seeking to understand the position of subgroups within the power structure of society (Creswell 2003). However for Bergman (2008a) the positions of the two camps are less distinct and within each there is tremendous heterogeneity; and therefore there is more scope for mixed methods research to move beyond these perceived hurdles.

A solution to this apparent dichotomy is to base the choice of research methods on appropriateness for the research question and the situation in which the research takes place (Devine & Heath 1999, Silverman 2006). In a study of health services researchers, a common motive for utilising a mixed methods approach was for pragmatic reasons - that an approach

utilising a single research method would not capture the complexity of participants and the situation being explored (O’Cathain et al 2007). Such considerations were of greater importance than ideological issues. A pragmatic approach is often utilised by mixed methods researchers because this ontological approach is more concerned with using a variety of methods best suited to the issue under examination, rather than being limited by a single approach (Creswell 2003). Clashes may arise within research teams conducting mixed methods, because of differing methodological expectations (O’Cathain & Thomas 2006); but in a project undertaken by a single researcher these issues would not arise.

#### **4.4 Justification for the Mixed Methods Approach**

A mixed methods approach has a number of advantages, and these are generally stated to be: comprehensiveness, complexity, and confirmation. A mixed methods study is thought to be more comprehensive because the dual methods produce a broader picture of the research topic; and this is the key reason why health services researchers favour this approach (O’Cathain et al 2007). This method is also considered to be suitable for researchers studying complex issues or environments (Moffatt et al 2006), or for researchers seeking to address complex research questions, as is the case typically in the health sphere (O’Cathain et al 2007). Moffatt et al (2006) argue that the use of a mixed methods approach to study complex health issues “...increase[s] the likelihood of arriving at a more thoroughly researched and better understood set of results” (page 10). A third motive for mixed methods is the use of the second method to confirm findings from the first method, and thus to strengthen the evidence; however this idea is problematic since the differing research methods would not necessarily “give” the same answer anyway (Moran-Ellis et al 2006, O’Cathain & Thomas 2006). Although it is argued that by exploring whether the findings from the dual methods converge, diverge, or contradict each other, valuable insights can be gained (Sandelowski 1995). And finally, mixed methods can be used as an emergent methodology when an initial method is found to be inadequate to explore the research question; this is known as an emergent mixed methods design (Cresswell & Plano Clark 2011).

A mixed methods approach was chosen for this study as the best means to answer the different aspects of the research questions, and to garner the strengths and insights from each research method. The study was not initially conceptualised as using a mixed methods approach, but for the reasons explained as follows, the study design altered in an iterative way to meet the changing needs of the study. An initial quantitative approach was undertaken to analyse the relationship between measures of health and proxy measures of activity, in order

to explore this under-researched topic and to test whether there were any statistically significant differences in activity according to gradients of self-reported health. The quantitative findings presented a complex picture, with no observable pattern between the activity and health measures, and thus further methods of explanation were sought. A follow-up qualitative study was undertaken in order to understand more about the experience of living with a long-term condition, and its impact on everyday activity within the complexity of an individual's life. The qualitative study sought to address some of the deficits of the quantitative study, chiefly that the quantitative data did not elucidate what was going on within the home, and it did not explain the lack of uniformity in the findings. The quantitative findings were therefore used to inform the development of the interview questions for the qualitative phase of the study, which was designed to elaborate and explain the initial findings, and to expand the understanding utilising the strengths of qualitative investigation (Pill 1995).

Within the field of research into older people, and more specifically of researching everyday activities, there have been a number of mixed methods studies (e.g. Bowling & Gabriel 2007, Moffatt et al 2006).

The study design was also developed for pragmatic reasons, since the planned second phase of the study focussing on participants with recurrent urinary tract infection, did not come to fruition. Opportunities to further the study were sought, and when the opportunity arose to undertake a qualitative study of activities undertaken whilst living with heart failure; this was considered a better fit than the initial planned second phase study, since it was the same health condition, and enabled further exploration of the quantitative phase. This change in methods was undertaken with an awareness of the importance of the balance between pragmatic and methods-driven research (Kazi 2003).

#### **4.5 Research Paradigm**

One criticism of the pragmatic approach utilised by many mixed methods researchers is that the researchers may not pay sufficient attention to the epistemological ideas that underlie the different research methods that are utilised (Richie & Lewis 2003). In order to counter this, an epistemological stance was taken for this research, and this was understood to be a world view and a set of beliefs that would influence how the research questions are phrased and the undertaking of the research (although it is acknowledged that this is a subject area with many definitions (Morgan 2007)). A subtle realist stance was taken (Hammersley 1992), as this was a

paradigm that is appropriate for both elements of the research process, and also fitted with my own world view. Subtle realists believe that there are multiple non-contradictory versions of reality, and although the accounts differ they may all reflect reality (Murphy & Dingwall 2007). However the approach rejects the possibility of multiple contradictory statements of events representing reality. The role of the researcher is therefore to cast a critical eye over the accounts given by participants to find a version of events that can be reasonably believed to be true, "...whose validity we are reasonably confident" (Hammersley 1992, page 50). However it is essential that researchers should also be aware of their own influence on the research, and through reflexivity seek to identify any erroneous assumptions, attitudes or beliefs; O’Cathain (2009) called this process “situating” yourself within the research.

In the following paragraph I will use the first person to describe my philosophical position, and I will use this approach for periods of reflexivity within the thesis, a method recommended by O’Cathain 2009:-

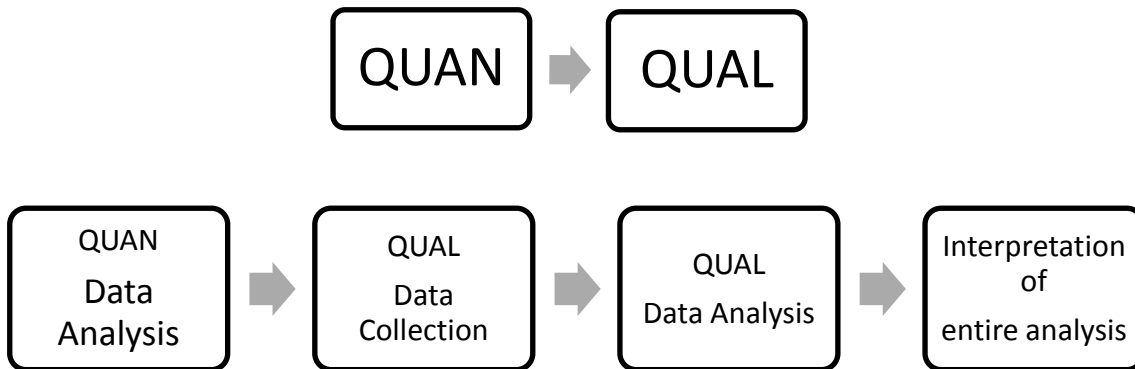
As a subtle realist I believe that there are various versions of events portrayed as the ‘truth’ and it is my role to appraise the most likely version of reality. Within this process I was aware of the influence of myself on the research (of my values, beliefs, attitudes, and past experiences) to impact on both the undertaking of the research and the interpretation of the findings; and this was addressed by a process of reflexivity which will be described later.

#### **4.6 Research Design**

The study was designed to have two stages, quantitative and qualitative, in order to address different aspects of the research question; with both elements acting both as complementary parts of the whole study, and as stand-alone studies in their own right (O’Cathain 2009). The study design also played a part in developing the focus of the study, with the first stage (the quantitative data analysis and findings) informing the design of the interview questions in the qualitative study. This mixed methods approach is defined as a sequential explanatory strategy with a first stage of quantitative data collection and analysis, followed by qualitative stage; such an approach is particularly useful when the initial quantitative findings are unexpected (as was the case in this study) (Creswell 2003, Morse 1991), and works well for researchers working alone as each step is taken sequentially.

Both sections of the study were given equal weighting, which means that both sections of the study were considered of equal importance and given equal priority within the study; as both elements were thought to be of merit in understanding the research topic. However it should be acknowledged that the final study was primarily a qualitative study. The mixed methods research design is represented by the following diagram 4.1:-

**Diagram 4.1: Mixed Methods Design**



(Based on Creswell 2003)

The process of the mixed methods research is illustrated by diagram 4.2, with the quantitative research testing the theoretical assumption that proxy activity levels would vary according to self-reported levels of health. In the event, the statistical tests revealed a complex picture without the expected pattern of lower activity in the worst levels of self-reported health, and thus the qualitative research was designed to explore and explain this finding. The sampling strategy was designed to reflect the original sample, and the interview questions were devised to explore activities within differing health states, and to also seek information about other factors influencing everyday activity.

#### **4.7 Quality Checks**

Quality in mixed methods comes from utilising sound methods in both the quantitative and qualitative elements, and ensuring that the inferences that are drawn out of the mixed methods are also based on sound practice (Teddlie & Tashakkori 2009). The essential ingredients of a quality mixed methods research project have been defined by O’Cathain et al (2008), and this study set out to ensure that attention was paid to each quality criterion:-

- i) Justification of a mixed methods approach for the research question
- ii) Description of mixed methods research design (including purpose, priority, and sequence)

- iii) Description of research design for each method (including sampling, data collection, and analysis)
- iv) Description of data integration (where and how it takes place)
- v) Description of any limitations of methods (as part of the mixed methods approach)
- vi) Discussion of the insights gained from mixed methods or from points of integration

#### **4.8 Data Integration**

Integration is defined as “the interaction or conversation between the qualitative and quantitative components of the study” in order to gain insights greater than the sum of the parts (O’Cathain et al 2010, page 1147). The strength and uniqueness of mixed methods derives from the points of integration, whereby there is interplay between the two methods, either to influence the research design or at the point of data analysis or in later interpretation. In the past integration of qualitative and quantitative findings has been limited (Bryman 2007), but over time, as the literature describing differing methods of integration has grown, so have the studies more fully integrating mixed methods (Bazeley 2009). At the analysis stage mixed methods integration can take place using a variety of methods, such as, a matrix approach drawing together all data sources in order to analyse data (O’Cathain et al 2010); or utilising a technique called following a thread (Moran-Ellis et al 2006) whereby inferences and themes are followed across the project and data sources, moving iteratively between elements of the project (O’Cathain et al 2010). In this study the initial quantitative data analysis informed the qualitative data collection and analysis, with a focus on finding out whether both data sources told the same story of complexity, or whether activity patterns were apparent. The qualitative data collection focused on broader influences of everyday activity than the quantitative, and therefore it was not possible to return to the quantitative data to reanalyse the data.

The second potential point of integration occurs at the data interpretation stage. Farmer et al (2006) described a method of triangulation whereby the data sources are assessed to identify points of convergence and divergence within common themes, and thereby to illuminate and explore the themes in greater depth. This approach was undertaken as a methodology to integrate the differing data sources within this study in order to gain the beneficial insights from integration; although it is acknowledged that whilst this method was followed, the results were limited by the general trend of complex patterns in the quantitative findings. However Farmer et al (2006) acknowledged that there are challenges to integration, since the differing

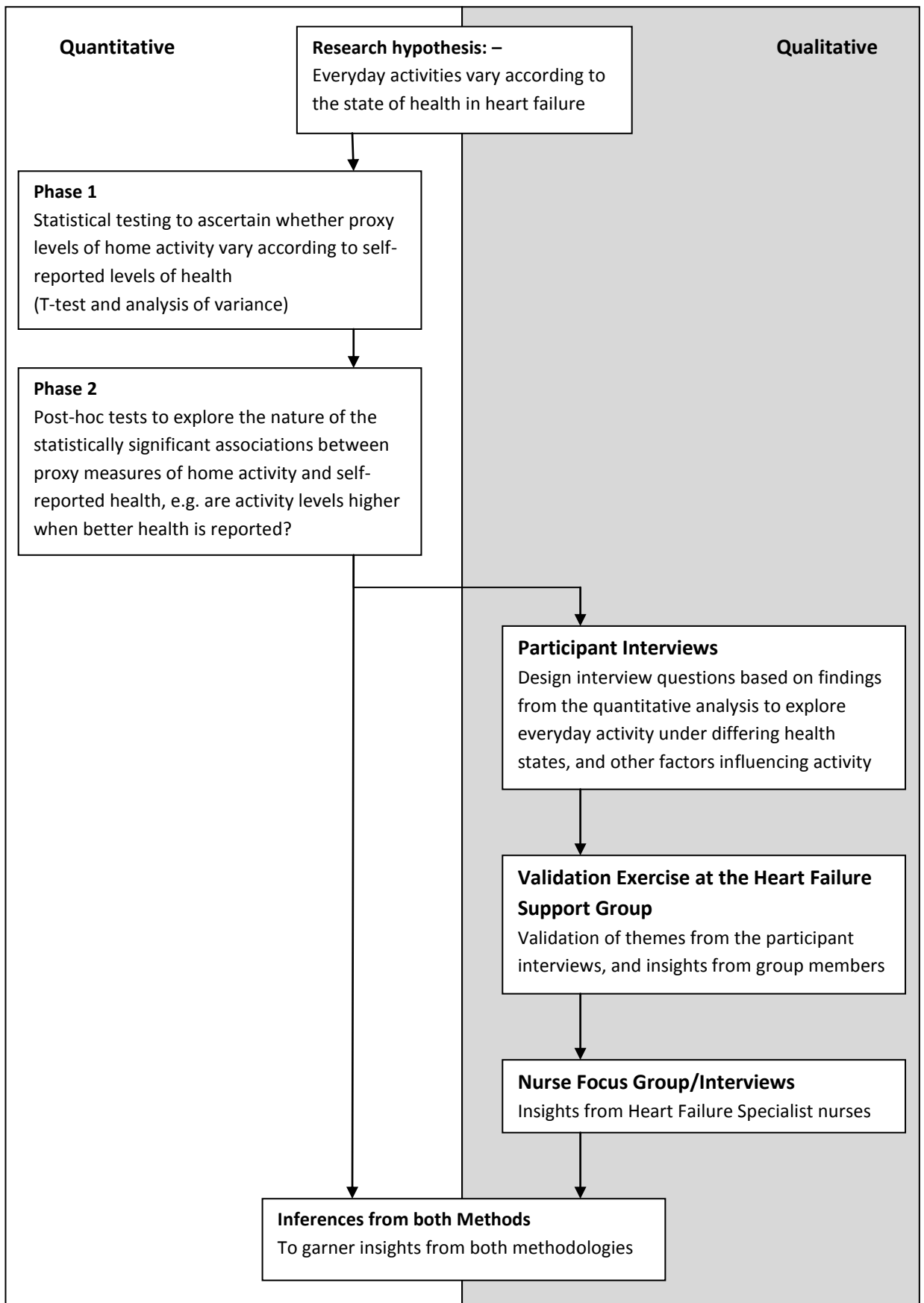


purposes and nature of data sources will mean that some sources are more suited to address particular questions than others, and thus at some points one source will gain more weight than another. In addition, further challenges can arise from participant samples that are not matched in the data sources, since results may arise from the differing participants (Moffatt et al 2006). Therefore taking all these potential impediments to integration into account a pragmatic approach was undertaken, since as Moffatt et al (2006) argue, even where integration is not achieved, valuable insights can be gained from simultaneous interpretation of qualitative and quantitative data sources, “We advocate treating qualitative and quantitative datasets as complementary rather than in competition for identifying the true version of events” (page 9). For this study, where integration was possible this was undertaken, and where this was not possible the varied data sources were used in a complementary way to gain a greater depth in answering the research question.

#### **4.9 Conclusion**

This chapter described the mixed methods approach undertaken for this study, and in keeping with the sequential approach outlined the following chapters detail the quantitative and then qualitative methodologies. Data integration is detailed in chapter 10.

**Diagram 4.2: Schematic Diagram of the Research Design**



## **Chapter 4A: Quantitative Methodology**

### **4A.1 Introduction**

This section presents the rationale for the quantitative element of the study; and a description of the data-set utilised, including sampling, participant recruitment, data collection methods, and ethical considerations of this secondary data. The final section outlines the data analysis undertaken to explore a key research hypothesis of this study, with data preparation and methods of statistical analysis described.

### **4A.2 Rationale**

The key aim of the study was to explore the relationship between everyday activities and the health state in older people, in order to test the assumption that activities change when health deteriorates. The quantitative phase of the study aimed to explore the following research question:-

Do levels of recorded proxy activity captured by lifestyle monitoring sensors vary according to self-reported levels of health?

The quantitative research phase had three key aims. Firstly, to subject measures of activity and health to statistical testing, in order to ascertain whether there were statistically significant variations in the levels of activity according to self-reported levels of health. This first step aimed to find out whether there was a statistical association between the measures of activity and health within this sample; and should this be the case, the further analysis sought to explore the nature of this association. Secondly, to explore the nature of any significant differences in activity according to health (should they occur), to find out whether recorded activity levels were higher or lower according to the self-reported health state; whether recorded activity levels were higher when health was reported as good or poor. Thirdly, to explore whether any variations in activity according to health were present in an observable pattern across the sample, or whether variations were individual in their nature.

In order to answer the research hypothesis a dataset was required that recorded measures of activity and health over-time, in order to explore activity within differing self-reported health-states. Given that both time and financial constraints prevented the commissioning of a Lifestyle Monitoring (LM) project to capture longitudinal data specifically for this project, an existing LM dataset (the Barnsley LM project (BLM)) was identified as the best available source for the following reasons. BLM had sample of older participants with heart failure, and the available dataset had both measures of health and activity captured over-time. The project

had seventeen participants, and therefore this provided the scope to explore analysis both between and within cases. In addition, as the project had been undertaken by the Rehabilitation and Assistive Technology Group, this facilitated both access to the dataset, and expertise from colleagues who had been involved in the both commissioning the project, and data analysis for other projects.

#### **4A.3 Ethical Issues**

Ethical approval for the original study had been gained from NHS Research ethics, and research governance approval was gained from Barnsley hospital (Biddiss et al 2009).

Consideration was given to ethical issues that arise out of the analysis of secondary data (Cresswell 2009). Participant confidentiality was protected as the dataset was anonymised, and participants were referred to in this study by house number only; and when referring to participants any potential identifiers were removed. The dataset was stored safely on a password protected drive on the university network.

The analysis was undertaken with an awareness of the ethical issues around home monitoring of older people (appendix paper 1).

#### **4A.4 Barnsley Lifestyle Monitoring (BLM) Dataset**

This section describes the processes of data collection of the BLM secondary data, as documented by Biddiss et al (2009). Whilst I was not involved in the data collection, I undertook the data preparation and analysis of the raw dataset (as described from section 4A.5 onwards). The wider data collection process is described it was from this broader group of participants that the LM data for this research originated.

The BLM project was undertaken with the primary purpose of exploring the value of health and physiological data collected within the home, to predict key medical events in participants with heart failure. Forty five participants were recruited for the study, after being identified from a review of patient records at Barnsley hospital, according to the following inclusion and exclusion criteria:-

##### **Inclusion Criteria**

1. Age 60 years and over
2. Living at home
3. Heart failure diagnosed by echocardiogram
4. Conventional symptoms of heart failure, including dyspnoea and oedema
5. New York Heart Failure classification of II, III, or IV

### Exclusion criteria

1. Ejection fraction >40%
2. Unstable angina
3. Under the age of 60
4. Severe dementia or another other debilitating psychiatric disorder
5. Inability to read and understand words on an electronic screen
6. Any planned coronary revascularization procedure
7. On a waiting list for heart transplant
8. Participation in any other heart failure research study that would conflict with this project
9. Lack of an operational phone line and electrical socket close by
10. Living in a residential or nursing home

Six participants died, and eight returned their equipment, leaving a total of 31 remaining participants, with the following characteristics (Table 4A.1). :-

**Table 4A.1: Sample Characteristics of BLM Project (n=31)**

Gender	Age	NYHA Scale
Male (83%)	60-69 (35.5%)	II (43%)
Female (17%)	70-79 (50%)	II-III (17%)
	80-89 (14.5%)	III (40%)

These participants were monitored for an average of eighteen months.

The NYHA scale refers the New York Heart Association's grading of the severity of heart failure (The Criteria Committee of the New York Heart Association 1994). Grade II is defined as mild, with ordinary activity likely to result in some heart failure symptoms; and grade III defined as moderate, with symptoms arising from less than ordinary activity

The data analysed for this study came from a subset of 17 participants from this larger sample, who had additional LM sensor data installed into their homes for the study period. The characteristics of this subset were as follows:-

**Table 4A.2: Sample Characteristics of BLM Subset**

Gender	Living Arrangements	Age	NYHA Scale
Male - 14 (82%)	Alone - 7 (41%)	60-69 (41%)	II (59%)
Female - 3 (18%)	Couples - 10 (59%)	70-79 (41%)	II-III (12%)
		80-89 (18%)	III (29%)

#### 4A.4.1 BLM Data Collected

Data were collected from December 2005 to October 2006, from entry to the study to drop out, or study end. The following health and activity data was collected:-

##### 4A.4.1.1 Health Data

Health data was collected by means of a Telehealth health monitor (Docobo 2014) whereby participants input symptom and health scores. The following table shows the symptom data (collected daily) which enabled the participants to record the scale of their self-reported symptoms, ranging from no symptoms, to worse than usual symptoms. The questions were devised from a British Heart Foundation Heart Failure Plan (Lewin et al 2005), and from advice from Heart Failure Specialist nurses involved with the project (SB 2011).

**Table 4A.3: Symptom Questions**

Question	Possible Answers
Do you have a cough?	1) No 2) New cough 3) Same cough 4) Worse cough
1) How many episodes of angina have you had today? 2) Did you sleep well last night? 3) How often did you wake up during the night due to shortness of breath? 4) Have you had any shortness of breath today? 5) Have you felt more tired today? 6) Have your ankles or feet been swollen today? 7) Have you passed less urine than usual today? 8) Have you eaten well today? 9) How anxious have you been today? 10) Have you felt dizzy today?	1) No/None 2) Less than usual 3) As usual 4) More than usual
Did you need extra pillows to sleep with last night?	1) No 2) Yes

Health-related quality of life (HRQoL) was measured using the EQ-5D (Cheung et al 2009) delivered via the Telehealth device. Participants completed the EQ-5D statement questions twice weekly to provide a measure across five dimensions of health: mobility, self-care, usual activity, pain/discomfort, and anxiety/depression (table 4A.4). The responses for each dimension were scored from 1 to 3, with a score of 1 indicating no problems, 2 moderate problems, and a score of 3 indicating extreme problems. The EQ-5D visual analogue scale (VAS) was completed daily to glean a measure of perceived health, from the worst imaginable health-state of zero, to the best of one hundred. EQ-5D was chosen as it is short and easy to

fill out, and had been validated as a measure with similar samples (Ellis et al 2005, Morgan et al 2007, Brazier et al 1996). However, the use was unusual since EQ-5D is generally used as a cross-sectional measure, rather than longitudinally.

#### **4A.4.1.2 Activity Data**

A central tenet of LM is that home activity should be measured unobtrusively, with sensors placed around the home; rather than the alternative more direct approach of requiring participants to wear sensors (Kowalski et al 2012). Activity data was therefore collected via sensors which were devised to record an interaction with participants, in the form of a triggering of the sensor. The sensor data is assumed to represent a home activity based on two attributes: the type of sensor, and the siting of the sensor. Sensors of differing types were developed to detect specific activities within the home, such as mattress sensors that detect when the bed is occupied, or an electrical appliance sensor which detects when a particular electrical appliance has been switched on or off. Other types of sensor have broader purposes, in terms of indicating that home activity is taking place, such as the movement sensors, which are designed to record general movement in a room. The siting of the sensor also offers clues to what type of activity is being undertaken, for example, sensors activated in the kitchen would be assumed to relate to food preparation activity. Thus electronic activations from the sensors formed the raw data collected from BLM.

The Barnsley sensor platform consisted of passive infrared movement sensors (PIR), door contact sensors, electrical appliance sensors, and bed and chair occupancy sensors (table 4A.4). PIR sensors are based on the same technology used in burglar alarm room sensors that are wall mounted. The aim of the PIR is to capture the presence of a person in the room and the sequence of general movement around the home, and potentially to record levels of activity (Tunstall 2012). Door contact sensors capture the activations of opening and closing of doors around the home, with the aim of quantifying usage. Electrical appliance sensors are fitted on the plug socket and record the sequence of on and off activations; the level and duration of appliance usage can therefore be calculated. Kettle, fridge, toaster, and television appliances were monitored (Tunstall 2012a). The bed and chair sensor takes the form of a pressure pad recording when the bed/chair is occupied, and the time when the occupancy comes to an end (Tunstall 2011).

**Table 4A.4: BLM Sensor Platform**

Sensor Type	Room
Bed/Chair	Living room, and master bedroom
Door contact	Food cupboard, and fridge
Electrical appliance	Kettle, microwave, toaster, and TV
PIR	Dining room, downstairs toilet, garage, hall/stairs/landing, kitchen, landing, living room, main bathroom, master bedroom, and second bedroom

#### **4A.5 Development of proxy measures of activity**

Rather than analysing the data captured by individual sensors, a decision was made to combine the sensors into groups to form proxy measures of activity. There were three reasons for this decision. Firstly, the measures were informed by the literature review, which had identified activities which had the potential to provide an indication of the health-state. Secondly, it was decided to treat the sensors as building blocks and build them up as necessary into more concrete proxy measures, that reflected meaningful activity in the home (such as Food Activity). Thirdly, the measures were also informed by the methods utilised by previous LM studies to measure activity. The table 4A.5 summarises the motives for the choice of proxy activity measures, and details the sensors contained within each measure.



**Table 4A.5: Composition and Motives for Proxy Activity Measures**

<b>Proxy Activity Measure</b>	<b>Sensor Type</b>	<b>Room/Object</b>	<b>Justification 1 – Meaningful Activity</b>	<b>Justification 2 – Literature Review – Older People</b>	<b>Justification 3 – Literature Review – Heart Failure</b>	<b>Justification 3 – Previous LM Measure</b>
Bath & Toilet	PIR	Downstairs WC, and main bathroom	Bathing and toileting	Both activities are necessary for health and well-being, and are included in clinical instruments linking activity to health.	A decrease in toileting may indicate that diuretics are not working effectively	Bathroom and toilet visits are commonly monitored by LM projects (e.g. Alwan et al 2006, Bonhomme et al 2008, Chan et al 2005, Glascock & Kutzik 2006, Hsu et al 2007, Suzuki et al 2006, Yamaguchi et al 1998)
Food	Door contact	Food cupboard door, and fridge door	Food preparation and Food intake	Food preparation is known to decrease when health declines. Food intake is essential for health. Both activities are included in clinical	A healthy diet is important in maintaining health	A similar nutrition index was used by Brownsell et al (2008). Food preparation activities are commonly monitored by LM projects, as a proxy
	Electrical appliance	Kettle, microwave, and toaster				
	PIR	Kitchen				

Proxy Activity Measure	Sensor Type	Room/Object	Justification 1 – Meaningful Activity	Justification 2 – Literature Review – Older People	Justification 3 – Literature Review – Heart Failure	Justification 3 – Previous LM Measure
				instruments linking activity to health.		for food intake (e.g. Masuoka 2002, Ogawa et al 2001, Peeters 2000, Sixsmith 2000, Tolstikov et al 2008).
General Activity	Bed/Chair	Living Room	Walking around the house, e.g., going from A to B, cleaning, etc	General mobility is typically measured in order to assess health and social care needs (Bowling 1997).		Gil et al (2006, & 2007) developed the idea of a “busyness” measure of overall activity which they used to establish patterns and levels of activity. The authors moot the idea that it may be possible to develop useful measures of activity without having to identify specific activities, which may
	Door contact	Other door(1)				
	PIR	Dining room, garage, hall/stairs/landing, landing, living room, master bedroom, second bedroom				

Proxy Activity Measure	Sensor Type	Room/Object	Justification 1 – Meaningful Activity	Justification 2 – Literature Review – Older People	Justification 3 – Literature Review – Heart Failure	Justification 3 – Previous LM Measure
						potentially invade the participant’s privacy (Gil et al 2007).
Sleep	Bed/Chair	Master Bedroom	Sleeping	Sleep is essential to health, and is known to become disrupted in response to some health conditions.	Symptoms of heart failure may disrupt sleep	Sleep is commonly measured by sensors in LM studies (for example: Doughty et al 1999, Matsuoka 2002, Ogawa et al 2002, & Peeters 2000)
Television	Electrical appliance	TV	Watching television	Television viewing is a common activity, and viewing patterns are known to alter according to the health state.		Although not as commonly monitored by LM projects, there is precedence for a television viewing measure(e.g. Ogawa et al 2002)

The proxy measures were quantified using counts of the sensor firings, with the exception of the sleep and television measures for which duration of activity was calculated. Measures exploring the timing of activity were also devised to analyse the association between day and night-time activity and self-reported health. It is acknowledged that distinction between night and day was devised arbitrarily, based on my own perception of the hours that form day and night (day between 7am and 9pm). Table 4A.6 shows the justification for the proxy activity measures split by day/night.

**Table 4A.6: Justification for the Day/Night Proxy Activity Measures**

Activity Measure	Justification
Bath & Toilet Night	Health conditions may be a source of sleep disruption, e.g., nocturia (Asplund 1996, Asplund & Agerg 1992, B&BF 2008, Lamberg 2003, Middelkoop et al 1996).
Day Nap	Daytime napping may be linked to ill health (Asplund 1996, Dautovich et al 2008, Goldman et al 2008).
Day/Night Activity	A measure of total day and night activity was devised to provide an overall means of testing any association between day/night activity and self-reported health.

#### **4A.6 Data Preparation**

The raw data output from the sensors was in the form of the following data items: house number, sensor description, type of activation (e.g. on or off), and date and time of activation. The following steps were undertaken to prepare the data for analysis.

##### **4A.6.1 Data Cleaning**

The dataset underwent an initial process of data cleaning via a program devised by Fabien Cardinaux (School of Health and Related Research) in order to remove false readings resulting from technical errors.

A further data cleaning exercise was undertaken on the data analysed by duration, in order to identify and remove false sensor activations that resulting in improbable durations of activity. The data was put into an Excel spreadsheet and an error checking formula was devised in order to identify records where an “off” occurred before an “on”, or the opposite way round. Erroneous records were deleted.

##### **4A.6.2 Preparation of Measures of Health and Well-Being**

All subsequent data analysis was carried out using the statistical package SPSS.

An overall utility score was calculated from the EQ-5D data, in order to convert the health states identified by the BLM sample into a single summary index (Cheung et al 2009). The weighted health state index score has a range of values from 1, perfect health, to -0.402, unconsciousness (Kind et al 1999). The EQ-5D data was converted into an overall utility score using an SPSS program written by Stephen Walters (School of Health and Related Research).

A symptom score was created out of the following most frequently completed symptom questions, with the aim of capturing the fluctuations in symptoms that are characteristic of heart failure (Webel et al 2007).:-

- i Do you have a cough?
- ii Have you eaten well today?
- iii Have you felt dizzy today?
- iv Have you had any shortness of breath today?
- v Have you passed less urine than usual today?
- vi How many episodes of angina have you had today?
- vii Have you felt more tired today?
- viii How anxious have been today?

The questions were scored according to a method used in previous analysis of the dataset (Biddiss et al 2009), with scores ranging from 1 for no, to 4 for more than usual. The food and urine question were scored in the opposite way, as in those cases there would be more of a health risk if intake or output was reduced.

#### **4A.6.3 Outliers**

Outliers are defined as “an observation which deviates so much from other observations as to arouse suspicions that it was generated by different mechanisms” (Hawkins 1986, page 1).

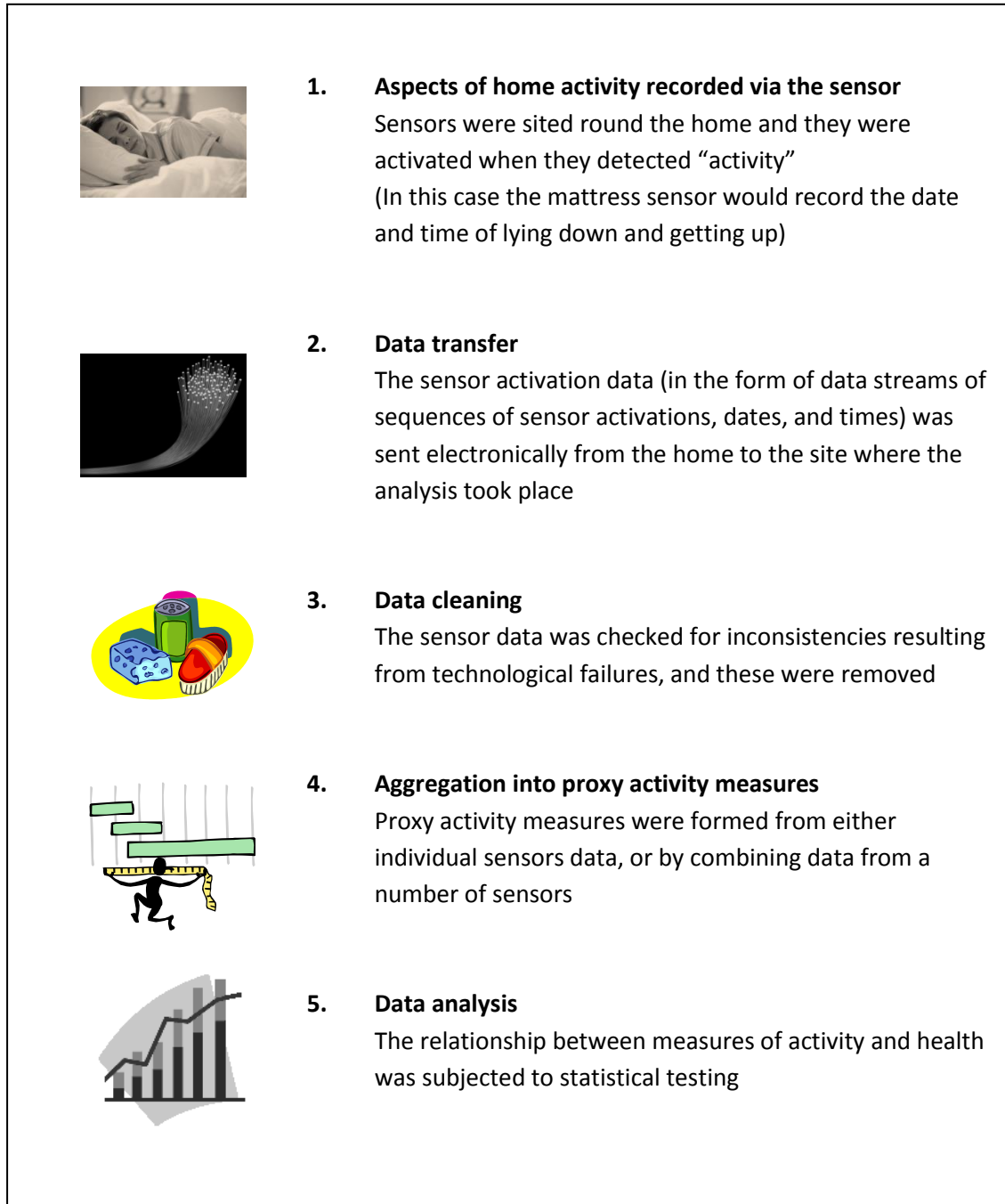
Outliers were removed from the Telecare measures on the basis that extremes in the measures were likely to be the result of technological failures. Statistical advice was sought, and it was recommended to remove extreme values based on anything outside the first quartile minus 1.5 times the inter-quartile range to the third quartile plus 1.5 times the inter-quartile range (Tukey’s ‘hinges’). This method was applied in general with the exception of the sleep data which used the minimum of 5 minutes, and the suggested maximum (based on the inter-quartile range) for the total sleep, and twelve hours maximum for the day sleep. The television duration measure used the minimum of five minutes, and the suggested maximum.

The revised limits were chosen because they seemed more reasonable than the suggested minimums, for example, it would seem reasonable to have a lie down for five minutes.

#### 4A.6.4 Summary of the Process

The process from raw sensor data to data analysis is depicted in diagram 4A.1

**Diagram 4A.1: Processes from Data Collection to Data Analysis**



#### 4A.7 Analysis Strategy

The aim of the quantitative analysis was to explore the relationship between the proxy activity and self-reported health measures.

The level of statistical significance was set at less than 0.05, on the basis that this is a standard cut off point. Due to the very many tests undertaken, there are considerable issues with multiple testing, i.e. we are very likely to observe significant values, even in the absence of an association. In order to counter this, P-values were used as a measure of the strength of the association, and in those with strong associations the trends in values were explored.

I undertook the following steps:-

**a) Visual Checking by House**

Before embarking on statistical analysis, the first stage was to check the data for any apparent associations between activity and health measures within each house.

**i) Trend Charts by House**

The available activity and health measures were plotted on trend charts, by house, in order to look at the measures over the whole study period, and identify whether there were any variations in the activity data that appeared to correspond to fluctuations in self-reported health.

**ii) Locally Weighted Scatter Plot Smoothing (LOESS) Graphs by House**

In order to establish visually whether there were any variations in levels of activity across the study period the data were plotted in LOESS graphs, for each house.

The graph fits a curve to the plots using a window which samples subsets of the data (Wikipedia 2010).

**b) Exploring Relationships between Activity and Health by Living Arrangements**

Consideration was given to the relationship between home activity and health amongst the two types of living arrangement (participants living alone and as a couple), in order to quantify any differences between the two domestic arrangements.

**i) Scatterplots by Living Arrangements**

Average activity and health scores were calculated for each house for the whole study period. The health scores were calculated according to the previously described methodology. The degree of correlation between the two types of variables was tested using Pearson's correlation co-efficient which calculates the degree to which the two variables fit a linear relationship. This association is

represented by the letter  $r$ , with the potential for  $r^2$  to range from 0 to 1 (+ or -). An  $r^2$  of 0 would mean that no linear relationship was present between the two variables; and in contrast an  $r^2$  of 1 would represent a perfect linear relationship (Julious 2009). The strength of the association between measures of activity and health was graded according to the methodology described by Cohen and Halliday (1982), which grades the association from very low to very high (using the value of  $r^2$ ); see table below.

**Table 4A.7: Grading of Scatterplot Associations**

Value of $r^2$	Strength of Association
0 to 0.19	Very Low
0.20 to 0.39	Low
0.40 to 0.69	Modest
0.70 to 0.89	High
0.90 to 1	Very High

(Cohen and Halliday 1982)

**c) Testing for Significant Variations in Proxy Activity Levels across the Increments of Self-Reported Health, by House**

Tests were undertaken to assess whether activity levels varied according to self-reported health.

**i) Analysis of Variance (ANOVA) and t-Tests by House**

Tests were carried out to ascertain whether there was any difference in the level of recorded proxy activity across the increments of self-reported health. ANOVA and t-tests were undertaken (depending on the type of variable) to establish if there were any statistically significant differences in the mean activity levels, between the grades of health (Campbell, Machin, & Walters 2007).

**d) Post-Hoc Tests to Explore the Nature of Significant differences in Activity, by House**

ANOVA and t-tests provide evidence of significant differences; post-hoc tests are utilised in order to describe the nature of these differences, for example, whether activity was observed at higher or lower levels when worse health was reported, and whether patterns of activity were observed across the whole sample (Pallant 2007).



**i) Post-Hoc Tests on Statistically Significant Variations in Activity According to Health, by Single Occupant Houses**

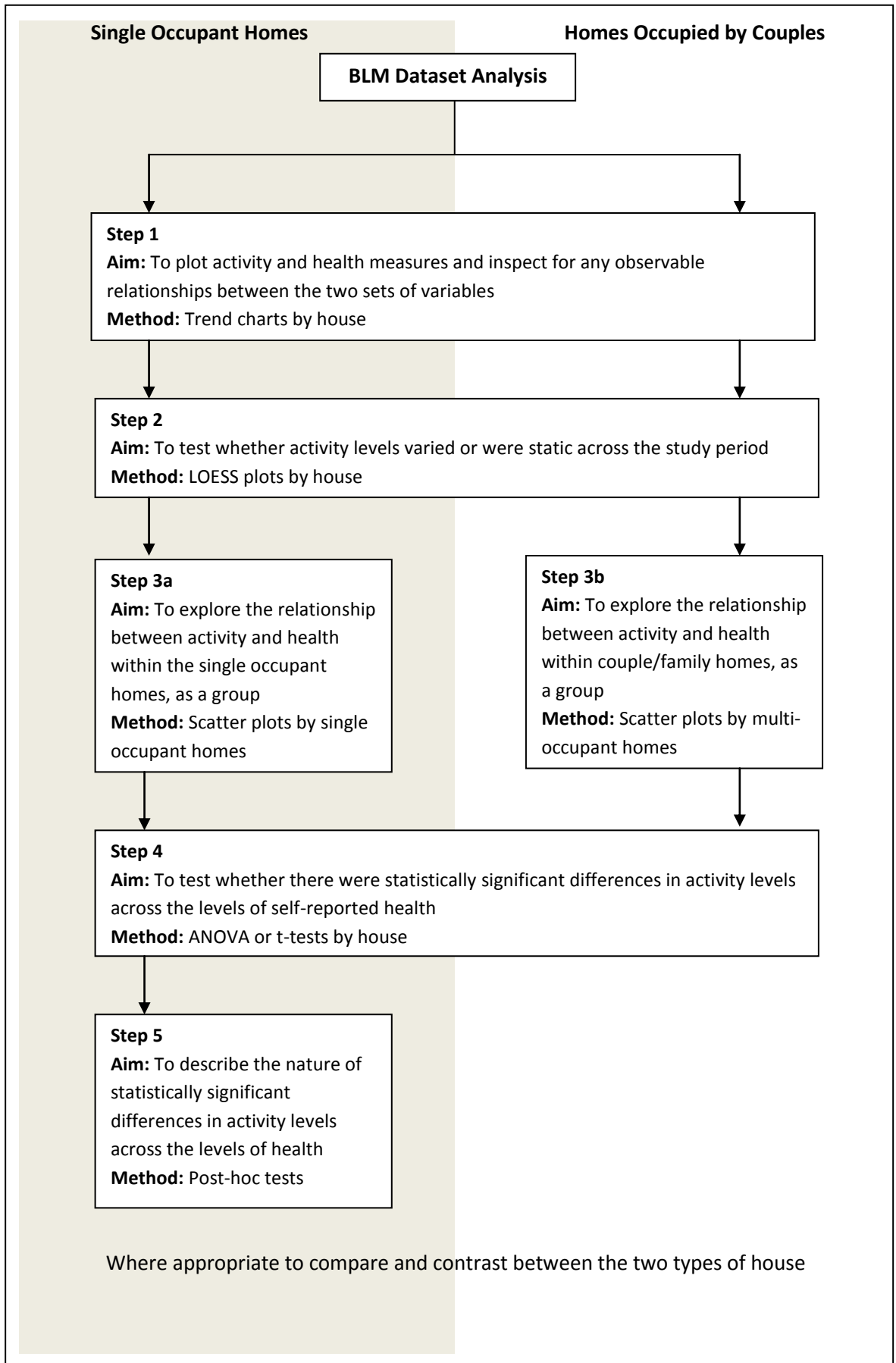
Statistical advice was sought on the most appropriate method of analysis, and the student-Newman-Keuls (SNK) test was recommended as a way of identifying which comparisons with an ANOVA contribute to the significance. This test proved suitable for the majority of associations, however it was not appropriate where the activity levels were unevenly distributed across the health/symptom groupings; in this case the Tukey's Honestly Significant Difference (HSD) test was recommended. In some cases this additional post-hoc test also did not find any significant differences between the health groupings, and further statistical advice was sought. It was recommended that if both tests had proved unsuitable, and the ANOVA level of significance was above the 1% cut off, then these correlations would be considered not to be different. As a result of this fourteen correlations were excluded, and were also removed from the ANOVA analysis.

In addition to this, a further forty two correlations were discarded because of small numbers. Either one group was very small, and the remaining groups were not significantly different; or when the small group was excluded there was only one remaining group. These exclusions were also removed from the ANOVA analysis. A total of 177 associations were examined via post-hoc tests.

Results from post-hoc tests can be very detailed, exploring the relationship between each health increment in greater detail than could be summarised; especially as there were so many associations. It was decided to focus on identifying which levels of health were associated with significantly higher or lower activity, in order to find out whether poorer self-reported health, or better self-reported health, was associated with lower or higher activity levels. In a few cases there was middle range of activity which occurred between high and low activity and was significantly different from the two outer groups; this was recorded as a middle level significant group. In addition the activity levels that were not significantly different were recorded as not different.

The sequence of analysis is represented by the following diagram (4A.2).

**Diagram 4A.2: BLM Dataset Analysis Strategy**



A final stage of analysis was undertaken after a review of the results, in order to explore whether different measures of health would reap more fruitful results in the analysis.

Consideration was given to a narrower symptom index based on the most common symptoms in heart failure (Davis et al 2006), based on the premise that these key symptoms may be more indicative of the health state. An index of daytime breathlessness, night-time breathlessness, tiredness, and swelling was created. The symptom score for each of the separate symptoms were aggregated together using the method previously described, whereby higher scores indicate more troublesome symptoms. In order to carry out the statistical tests the results of the aggregations were divided into three groups: fewest symptoms, middle range symptoms, and worst symptoms. There were 13 different key symptom scores present in the data, ranging from 4 (the level with fewest symptoms) to 16 (the level with worst symptoms). It was decided to split the 13 levels of key symptom scores into two groups of 4, and one of 5, with the worst health group having the greatest number of levels.

In addition, a measure of stair activity was devised. Stairs are the means of accessing the rooms on other floors in the home, and for people incapacitated in any way they can become an impediment to the ease of movement around the house (Hill et al 2000); especially when heart failure symptoms worsen (Clark et al 2005, Hill et al 2000, Ryan and Farrelly 2009). It was acknowledged that a stair measure may also pick up increased traffic to the toilet in response to doses of diuretics (Hill et al 2000), unless participants have access to a downstairs toilet (Davis et al 2006). The efficacy of a stair measure would also depend on the individual circumstances of participants; for example, whether stairs were present in the home and utilised (Barnes et al 2006).

A measure comprising solely of stair use was not available in the BLM data, which necessitated the use of a broader measure of movement in the hall, stairs, and landing areas of the home. It was acknowledged that this grouping of three areas may potentially limit the usefulness of this activity measure, since it would be recording general movement in the hall and landing as well as the more exerting movements up and down the stairs.

The method previously described of testing for significant variations in activity levels across the levels of health was utilised (see section 4A.7c).

#### **4A.8 Issues with the BLM datasets**

The following issues were noted with the BLM dataset, which had the potential to impact both on the data analysis and interpretation of the results:-

**a) Participants joined the study at different times**

The participants in the study did not join and leave at the same time, and thus there is more data for some houses than others.

**b) Gaps in Data Collection**

There were some gaps in data collection when participants went on holiday, or in some cases chose not to fill out the health measures.

**c) Measures collected daily, or twice weekly**

Not all the data was collected daily, some measures were collected twice weekly. A previous study which looked at the health data aggregated the data into weekly measures using the average or median values (Biddiss 2009).

Issues a, b and c were circumvented by the use of average measures.

In addition there were the following issues:-

**d) There was not a uniform set of sensors in every house**

It was not possible to have a uniform set of sensors in each house because the houses were not all the same, and some had rooms and equipment that others did not. The subjects were allowed to choose which sensors they wanted, and the least popular was the bed sensor which was uncomfortable.

**e) Technical issues**

There were technical issues which impacted on data collection and interpretation of the data (for more information on this issue, see chapter 9, technology chapter).

**f) More than one person in the house**

In houses where people live as a couple there is no way of knowing whose activity the sensor is recording. In homes where the person lives alone, there may be other family member, friends, or carers who visit the home, and there is no way of distinguishing this activity from the participant.

#### **g) Indirect Measurement**

There was no way of knowing whether the participant was participating in the activity that was implied by the sensor activation, for example, the television may be on, but the participant may not actually be watching (for more information on this issue, see chapter 9, technology chapter).

#### **4A.9 Conclusion**

This chapter set out to describe and justify the inclusion of quantitative elements in the research. The quantitative analysis set out to explore whether the levels of recorded LM proxy activity data varied according to self-reported levels of health, as the idea that home activity changes with the health state is a central tenet of lifestyle monitoring. The secondary dataset was chosen for the analysis as it had both LM sensor data captured from the homes of participants with heart failure, and self-reported health measures, and thus the relationship between the two types of measure could be explored. The planned data analysis sought to explore this relationship via three means. Firstly, by visually checking trend charts for any observable relationships between the two types of variable for each study participant. Secondly to explore the nature of the relationship between the two types of variable within each housing group (that is single occupant homes, and homes where couples lived) using scatter plots. The final methods of analysis sought to identify any statistically significant differences in proxy activity according to levels of self-reported health, and then to explore the nature of these associations using post-hoc tests.

The following chapter describes the methodology for the qualitative element of the study.

## **Chapter 4B: Qualitative Methodology**

### **4B.1 Introduction**

This chapter presents the rationale for the qualitative elements of the study, the methodologies utilised, and the procedures undertaken. Four qualitative studies were undertaken: participant interviews, a validation exercise to test initial interview findings, both a focus group and interviews with health professionals, and interviews with key informants about telecare technology.

### **4B.2 Rationale**

The key aim of the study was to explore the relationship between everyday activities and the health state in older people, in order to test the hypothesis that activities change when health deteriorates. The qualitative phase of the study aimed to answer the following research questions:-

#### **3) Do everyday activities undertaken in the home by older people with Heart Failure vary according to the health state of the individual carrying them out?**

- a. Do older people vary their everyday activities according to the three health states of Heart Failure (normal days, bad days, and exacerbations)? And if so, how do these activities differ?
- b. If these changes in activity according to health occur, are these changes distinctive to the individual or transferable across the whole sample?

#### **4) What other factors influence everyday activity in older people?**

- c. Do these factors outweigh the influence of heart failure symptoms, or are they less important?
- d. Do the partners of individuals with heart failure influence the activities undertaken by their spouses with Heart Failure?

The qualitative research phase aimed to glean a greater depth of understanding of these issues, and explore the experience of everyday activity whilst living with a long-term condition. A qualitative approach was appropriate to elucidate the potentially wide ranging issues influencing activity, and this additional data was sought because such an exploration was beyond the scope of the Barnsley quantitative data. A further motive for undertaking the qualitative phase was to draw in the insights of a range of participants with an understanding of activity within a long-term illness, and by this to enrich the understanding of the

relationship between activity and health. The views of individuals with heart failure, their partners, and the specialist nurses dealing with this patient group, were sought. The following chapter describes the qualitative research methods for each of these participant groups in turn.

### **4B.3 Eliciting Information from Participants with Heart Failure**

The main research methods within the qualitative field are participant observation, interviewing, and focus groups. Firstly observations, whereby participants are observed in their natural setting, were not chosen - both because of the intrusive nature of observations within the home, and the time consuming nature of observations. Secondly focus groups were rejected, as the group setting was considered inappropriate for understanding individual behaviours and activities. A key issue in considering an appropriate methodology is whether the researcher is seeking naturally occurring data (which can be observed), or generated data (which is interpreted by the participant) (Richie and Lewis 2003). In order to understand the influence of varying health states on activity, it was considered important that participants should be given the opportunity to describe and interpret their behaviours within differing health contexts, the influence of other motivating factors, and the decision making processes involved. A key research method to glean this type of generated data is interviewing, and this was chosen as the most appropriate research method for this phase of the research; both as a means to gain an understanding of a complex phenomenon, and to provide opportunities to explore the experience (Kvale 1996) and seek clarification where explanations were not clear (Ritchie & Lewis 2003). The strength of the interview method is that it gives participants a voice, an opportunity to describe experiences in their own words.

### **4B.4 Interviewing Style**

Two methods of interviewing were employed, with individual interviews where the participant was alone, or chose not to involve their partner; and paired or dyad interviewing when the participant chose to have their partner present. Partners were present in eleven out of the twenty interviews. Joint interviewing can be a concern, since participants may alter their responses to protect their partner's sensitivities (Kendall et al 2009, Reuband 1992), or seek to present themselves in a particular light (Boeije 2004). There is also the risk that spouses may dominate the interview at the expense of their ill partner (Arksey 1996); however it was made clear that the interview was primarily for the participant with heart failure, and partners were invited to "chip in" with opinions, and indeed this is what they tended to do. There are a number of benefits to interviewing dyads, and it was considered that the advantages

outweighed the disadvantages. Paired interviews are a fruitful means of understanding situations where two people interact in a complex situation, such as that of couples dealing with long-term illness (Ritchie and Lewis 2003). The joint explanations can also present a richer picture to the interviewer, due to the insights from differing perspectives (Kendall et al 2009, Ritchie & Lewis 2003), and the participants prompting each other to include or expand upon issues (Kendall et al 2009). In practice, rather than inhibiting participants, the presence of the partners opened up the interview with their vivid descriptions of symptoms, the impact on activities, and the experience of overactivity. The partners provided a counter balance to the instinct of the participants to underplay their symptoms and their impact, as is common in other long term conditions (King et al 2002).

Choices were also made about the style of interview, with an unstructured approach rejected due to the requirement to cover a range of questions pertinent to the research question. A semi-structured interview guide was devised to ensure that all participants were asked the same questions, but within this there was flexibility to explore issues that arose, and to seek clarification when issues were not understood by the interviewer. Open-ended questions were used to enable interviewees to make their own choices about how to reply, and therefore although participants were asked the same questions, there was space for interviewees to explore their own experiences and talk about issues of importance to themselves (Byram 2001). In addition, each interview also ended with a catch-all question asking participants if there was anything else they wanted to say that had not been already covered by the interview, and this gave greater flexibility, and in some cases participants spoke at length when prompted by the catch-all question.

#### **4B.5 Topic Guide**

The interview topic guide was devised to include questions following-up the initial quantitative findings, such as, whether home activities alter according to the health state (Appendix Information Sheet 2). In addition the questions were shaped by reading about heart failure, and including subjects thought to be of importance in shaping activity, such as, the classification of days into good and bad days according to the degree of intrusion from symptoms (e.g. Charmaz 1991). The content of the questions was also informed by the work of Clark et al (2008) who kindly forwarded his interview schedule on the nature of informal caring in the home.

The order of the topic guide is important to ensure a natural flow to the interaction (Ritchie and Lewis 2003), and thus the interview followed a pathway through a description of



symptoms, activities during various health states, other factors influencing activities, and difficulties encountered during indoor and outdoor activities. The order was not followed rigidly, for example if a participant brought up a later topic this would be explored earlier than originally planned; and participants were also free to pursue other issues. The initial question on symptoms acted as a means of opening up the interview, and participants spontaneously talked about the onset of health problems and the impact on their self-perception and everyday life, and gave insights about their attitudes to activity.

The topic guide was found to flow as anticipated and elicit relevant information, and importantly the questions appeared 'true' to the experience of the participant. Two additions were made to the interview guide following the first interview, and this was to ask about difficulties with stairs, and the activity of seeking air.

#### **4B.6 Practical Issues**

The interviews took place in the home of participants which has a number of advantages and disadvantages (Borbasi et al 2002). The home was comfortable and a 'safe' setting for the participants (Legard, Keegan, & Ward 2003), and for those with more advanced heart failure meant that they did not have to exert themselves to leave the house. Also as the home was the scene of much of the experiences recounted it was illuminating to sit within that setting, and to later visualise the scene. The home setting also acted as a prompt to participants when they were describing activities and experiences within that setting. In addition, the experience of visiting the varied domestic setting sparked ideas about the role of the home in facilitating and enabling activity. The disadvantage was occasional distractions from telephones, and on one occasion from the presence of a small grandchild with the television on (Roulston et al 2003). There was also an awareness of potential safety issues for the interviewer, and in order to mitigate this a colleague was texted before going into the home and after leaving. If an issue had arisen the colleague had the addresses of participants in a sealed envelope.

It was anticipated that the interviews would be long enough to cover the topics, but not too long to inconvenience or tire participants. The interviews generally lasted an hour, but in one case where the participant experienced few restrictions from heart failure symptoms, the interview lasted about forty minutes. The longest interview lasted for two hours, and in this case the interview was split into two visits, as it was not convenient to continue.

#### **4B.7 Sample**

The sample included participants selected with a range of characteristics, and living in differing contexts, that were considered relevant to exploring the broad issues pertinent to the relationship between activity and health. This technique of sampling whereby participants are chosen for specific characteristics is known as purposive sampling, and is used by many qualitative researchers as a means to explore the range of factors influencing a phenomenon (Mason 2002; Ritchie, Lewis, & Gillian 2003). The sample for this study was based on the following criteria:-

##### **I. To Reflect the Quantitative Study**

The sample aimed to include participants that reflected the previous quantitative study which recruited participants based on age (aged 60 and over), living circumstances (that they lived at home), and severity of heart failure (that they had heart failure symptoms that would influence everyday activity). In order to explore the complex quantitative findings, the qualitative sample was chosen in part to replicate the original sample in order to explore broader facets of the relationship between activity and health.

##### **II. Home-Living**

A key criterion was that participants should live at home. It was apparent from the initial interviews that the home itself can hinder or enable activity, and therefore the sample included participants living both in bungalows and houses.

##### **III. Age**

The interview sample sought to explore the impact of heart failure on activity at differing stages of life, and to encompass the age-ranges where heart failure is prevalent. The prevalence of heart failure in England increases with age, with fewer than 1% of men and women aged 45 to 64 years recorded with a diagnosis of heart failure on the general practice database; but this rises to 2.7% of men and 1.3% of women in the 65 to 74 age-band; and increases sharply in the 75 and over age-band, up to 13.1% of men and 11.9% of women (2011 estimate, General Practice Research Database 2012). The age breakdown of the sample was not proportioned out to match the prevalence, but to represent the age-groups in numbers sufficient to obtain meaningful data (Mason 2002).

##### **IV. Gender**

The sample sought to explore the impact of gender on activity, since this was identified by the literature review as a factor in defining social roles and influencing everyday activity.

## V. Severity of Heart Failure

It was aimed to balance the sample according to severity of heart failure, since it is known that people with more advanced heart failure are more likely to encounter difficulties with activities (The Criteria Committee of the New York Heart Association 1994). The sample was therefore divided into categories of mild to moderate, and bad to severe heart failure according to descriptions of the symptoms that participants described.

## VI. Circumstances

The sample was chosen to include participants with differing circumstances (for example, those living alone, couples, working, or retired)

## VII. Length of Time Since Diagnosis

It became evident during the initial interviews that the length of time since diagnosis of heart failure had an influence on both attitudes to activity and the degree to which individuals adapted their lives to live with the condition (Schwartz & Sprangers 2000). The sample therefore included both those with a recent diagnosis (within the last few years), and those who had lived with the condition for a long time (for many years).

Table 4B.1 shows the sampling matrix used to construct the interview sample.

**Table 4B.1 Sampling Matrix for Interview Sample**

Selection Criteria	Breakdown	Mild to Moderate Heart Failure	Bad to Severe Heart Failure
Age-group	50-59	≥2	≥2
	60-69	≥2	≥2
	70-79	≥2	≥2
	80-89	≥2	≥2
Gender	Male	≥2	≥2
	Female	≥2	≥2
Length of time since diagnosis	Recently	≥2	≥2
	Long ago	≥2	≥2
Home Circumstances	House	≥2	≥2
	Bungalow	≥2	≥2
	Living Alone	≥2	≥2
	Couple	≥2	≥2
	Working	≥2	
	Retired	≥2	≥2
Total		10	10

#### **4B.8 Recruitment**

Twenty older people with heart failure were recruited for the interviews. In order to both speed up recruitment, and to contribute to another ongoing study, the first ten interview participants were sourced from project assessing the value of a smart phone system to motivate people with heart failure to take a daily walk and build up activity (Brownsell et al 2010a, Haywood et al 2010). These participants were identified from the caseload of Barnsley Heart Failure Specialist nurses, and were initially recruited to the larger study by Annette Haywood (AH). These potential interviewees were then phoned by me to ascertain their willingness to participate in this additional study interview, and arrangements were made.

The focus of the parent study was on motivating a daily walk via technology; and therefore those consenting to the study considered themselves capable of this, and this risked skewing the sample to include only active participants. However in reality the participants were asked to undertake a walk tailored to their own level of fitness, and therefore the level of fitness was not very demanding. Two participants consented to interview, but did not take part in the parent study; one participant because she did not feel capable of walking, and the second because of work commitments.

After thirteen interviews the characteristics of these initial participants were reviewed, and a decision made to seek to purposefully recruit more participants living alone, and of the female gender. Permission was sought to attend a Barnsley heart failure support group in order to both validate the initial theoretical propositions formed from the first round of interviews, and to recruit additional interview participants. The support group was chosen on the basis that members were likely to provide a broader base of potential recruits, and this would balance the sample to include participants who were less fit. The aim of recruiting more participants who lived alone was achieved, as three participants were recruited. The aim of recruiting more female participants was also achieved since two more females were recruited, but it is acknowledged that this was a total of only four female interviewees. A number of factors worked against recruiting more females: firstly heart failure is more prevalent in the male population aged below 75 years (although there are slightly more females in the older age-group) (NHS Information Centre 2010); secondly the recruits identified by the Heart Failure Specialist Nurse's were mainly male; and lastly, the attendees of the support group also predominantly men (often the females were partners of those with heart failure).

I telephoned potential recruits to ensure that they were still happy to be interviewed, and then arrangements were made. At this stage, one participant was lost to the study, due to repeated failure to respond to contact.

In total twenty subjects were recruited and the interviews took place in participants' homes in the period between November 2011 and July 2012. The nine months taken to recruit and interview reflects the delays in initial recruiting to the parent project, and then the difficulties with the walking technology that further delayed recruitment.

The characteristics of the complete interview sample are detailed in table 4B.2, which demonstrates that participants recruited generally matched to the intended sample criteria.

**Table 4B.2 Characteristics of the Interview Participants**

<b>Selection Criteria</b>	<b>Breakdown</b>	<b>Mild to Moderate Heart Failure</b>	<b>Bad to Severe Heart Failure</b>
Age-group	50-59	3	2
	60-69	2	3
	70-79	4	3
	80-89	1	2
Gender	Male	8	8
	Female	2	2
Length of time since diagnosis	Recently	8	2
	Long ago	2	8
Home Circumstances	House	7	5
	Bungalow	3	5
	Living Alone	1	3
	Couple	7	9
	Working	3	
	Retired	7	10
Partner Present		5	6
Total		10	10

#### **4B.9 Ethics**

The study gained ethical approval from NHS Research ethics, and research governance approval was gained from Barnsley hospital (Haywood et al 2011). The potential ethical issues were around interviewing older adults, and the discussion of potentially distressing experiences of living with a long-term condition.

Participants with heart failure may have tired or become symptomatic during the interview, and therefore the participants were told that they could stop the interview at any time. This did not arise in practice, in part because participants chose the timing of the interview, and

those that had limited energy tended to arrange the interview in the morning when energy levels were higher. A key issue with researching older people is around issues of competence to consent (DoH 2001); however this did not arise, since the initial participants were selected as having the capacity to use technology to monitor their walk, and the final tranche of participants recruited at the support group did not demonstrate any sign that they did not understand the processes, or were unable to give informed consent.

#### **4B.9.1 Consent**

Before undertaking the interview participants were asked to consent to take part in the study. Participants are considered to have given informed consent when they understand the following, and are able to make an informed choice:-

- a) The purpose of the study
- b) Who is funding the research
- c) Who will see the data
- d) How the data will be used
- e) What the participants are required to do for the study

(Lewis 2003)

The participants were verbally informed about the purpose of the study in order to give them an opportunity to express interest or decline to participate. An information sheet was sent to the participant's home address prior to the interview, which informed participants more fully about the study (covering points (a) to (e) above) (Appendix information sheet 1). Before undertaking the interview participants were informed about the subject matter that the interview would cover. They were reminded that they could stop the interview at any time, and were free to choose not to answer any of the questions. Participants were informed again that the interview data would be stored safely, and they would not be identified in any reports. Participants were asked if they would be happy for the interview to be recorded. Written consent was taken prior to starting the interview; however this was a fluid agreement, in that participants were free to withdraw consent at any time.

#### **4B.10 Data Recording and Transcription**

The interviews were recorded with a digital recorder which captured the full exchange including tone of voice, pauses, and coughs, which give clues to the interpretation of the data, and could be listened to again to inform the data analysis process (Silverman 2010). Notes

were not taken during the interview in order to focus entirely on the interview. No technical difficulties were experienced.

The audio file was downloaded onto the university network onto password protected disk-space, and the file on the recorder was deleted. Fifteen interviews were transcribed by me, and the remainder by a professional transcriber trusted to undertake regular work for the university. Advice was sought from the postgraduate office on the procedures for sending confidential files, and the audio files were sent to the transcriber in an encrypted file by recorded delivery.

The typed transcriptions were anonymised replacing any names of people or places, or anything else potentially identifiable, with a pseudonym. The transcript was checked for accuracy by comparison with the recorded interview. The transcripts were stored safely on the university network and on a password encrypted laptop, the file names were also coded (from P1 to P20).

#### **4B.11 Conceptual Baggage**

As a subtle realist I needed to situate myself within the research, and have an awareness of my beliefs which may colour perceptions and interpretations during the research process.; I therefore set about considering this so-called 'conceptual baggage' (Horsburgh 2003) before undertaking the research.

My general preconception was that health declines in old age and older people do less, move slower, and eventually end up leading very restricted to lives. I had witnessed this process in my elderly neighbour.

I also had a belief that activity is shaped by outlook, attitudes, and interests; because of witnessing the experiences of my elderly parents. My Mother does have health problems, but generally she focuses on living her life and doing things, regardless of her health state. My Father is still engaged in his lifetime hobby of gardening, and this has kept him fit.

Before the interviews I had a misconception that heart failure would be very debilitating and those with the condition would look unwell, but at first interview this was confounded as the participant was leading a full life and looked well.

#### **4B.12 Contemporaneous Field Notes**

After each interview a reflection was recorded in a field notes book, to record observations about the interview and thoughts about the nature of the relationship between activity and

health. These insights had an immediacy, and by rereading them I was able recapture these thoughts. In addition, the notes provided a sense of perspective, since researchers may give a greater emphasis to events occurring early in their research (Primacy effect), or to events at the end of the time in the field (recency effect) (Suzuki et al 2007).

#### **4B.13 Reflection on the Interview Process**

Another aspect of situating myself in the research, was to consider my place in the interview process (Cresswell 2007). Firstly, to consider my gender as a female, which has the potential to influence both, how comfortable, or forth-coming participants were in the interview situation. It is acknowledged that the male participants may have found it more difficult to talk to a woman about their situation, but on the whole the interviews did not appear to be hindered by this, with participants talking frankly, even about potentially embarrassing issues. Only one male participant was difficult to engage, and answered questions very concisely, and this may have arisen out of his difficulty relating to me. However, it would seem to me that the greatest barrier to a productive interview was a lack of self-awareness on the part of the participants, and in such cases the presence of the partner was invaluable.

During the interviews I became aware that there may be a difference between what people say, and what they actually do. One participant spoke about attending the gym every week, but before the interview I had spoken to his wife who expressed concern that he was not attending the gym regularly. This difference between what people say and actually do was also picked up by partners attending the interviews; and I felt that this exchange of views provided a useful counterbalance, and moved the interviews nearer to reflecting the truth.

#### **4B.14 Data Analysis**

The process of data analysis is one of data management, whereby the interview data is collapsed into a thematic structure, in order to illuminate and explore the research question. Initial ideas for themes were formed during the transcription process (Smith 2008).

##### **4B.14.1 Justification of Chosen Method**

The data analysis method was template analysis (TA) (Crabtree & Miller 1999; King 1998, 2004, 2012, 2013) a form of thematic analysis, and this was chosen for this study for a number of reasons:-

1. **Precedent** – TA is an established method of analysis in the health field (for example: Brooks & King 2012, Dykes et al 2011, Kent 2000, King et al 2002 & 2004a, Rodriguez & King 2009)



2. **Match with Research Method** – TA is most commonly used to analyse interview data (King 2012)
3. **Match with epistemology** - The method is suitable for a range of epistemological stances, including subtle realism (Brooks & King 2012).
4. **Ease of application** – Unlike some approaches like grounded theory, TA is not bound by arduous procedures and therefore the analysis can be tailored to individual needs, and is potentially less time-consuming than some approaches (such as Interpretative Phenomenological Analysis (IPA) Smith, Flowers, & Larkins 2009) (King 2012). The technique is easy to learn for those new to qualitative analysis, and has been successfully applied by both undergraduate and masters' students (King 2004).
5. **Between and Within Case Analysis** - Template analysis provides scope for both cross case and within case analysis, in contrast to IPA where the focus is mainly on detailed case-by-case analysis (Brook & King 2012). The method therefore is appropriate for a study seeking to understand activity within the individual and across the sample.
6. **Sample Size** – TA is suitable for a sample size of 20 (unlike IPA where sample sizes tend to be smaller) (King 2012)
7. **A Priori Themes** –Template analysis allows the use pre-existing themes (based on prior knowledge or theory) to define some of the themes (although the validity is tested during the research process) (Brooks & King 2012); this was important in order to investigate issues raised by the quantitative research, and from the research literature.
8. **The Utility of the Template** -The coding structure within template analysis is flexible, so that the template can be developed to reflect key areas of interest more extensively (Brooks & King 2012). The template also provides a structure for data handling and reporting (King 2004).
9. **Availability of Expertise** – AH who was the qualitative supervisor for this study, had experience both of undertaking and supervising TA, and therefore there was ready source of support and advice. In addition, Nigel King (NK), a leading advocate of the technique (King 1998, 2004, 2012, 2013), provided expert advice on coding and the development of the template.

An earlier criticism of TA is that the lack of a substantial body of literature describing the technique (compared to other more established methods) and could lead to either an overly simplistic or complicated template (King 2004). However the literature on TA has developed over-time with the previously cited works by NK and a website hosted by the University of

Huddersfield (King 2013); and the combination of these information sources in addition to the guidance from the experts prevented this pitfall. NK (2012) also acknowledges that TA is not suited to everyone, but this is true of any method of analysis.

#### **4B.14.2 Analytical Process**

The process of data analysis began with identifying themes within the participant transcripts. In TA themes are defined as “features of participants’ accounts characterising particular perceptions and/or experiences that the researcher sees as relevant to the research question” (King 2013). A minority of themes were identified from pre-existing issues, such as the varying health states; and the remainder emerged from the data. Codes that defined these themes were then applied to the relevant text in the transcript. Themes were coded according to a hierarchy, with higher level codes describing a broad topic, and lower level codes providing levels of detail for this topic; the number of tiers reflecting the depth of data described (King 2012). In cases where interview data reflected more than one theme, the text was parallel coded into as many codes as necessary (King 2012). During the process it became apparent that a particular theme was pertinent to the interpretation of much of the data, and this was identified as an integrative theme (King 2012). King describes integrative themes as “undercurrents running through participants’ accounts” (page 460), and for this study this was the degree of intrusion from symptoms.

Codes were initially applied manually, and then to speed up the process the transcripts were imported into Nvivo for computer aided data analysis (CAQDAS) package. During the initial phase the printed transcripts were read and reread and connections between the codes were identified manually, this provided an immediacy to the coding process which can be lacking in CAQDAS (Bazeley 2007). The CAQDAS software was used primarily as an information retrieval tool, to display all the text coded to a particular theme during the process of developing an understanding of the data, and reporting the findings.

The template displays the coding hierarchy in a visual way, in the form of a tiered list or in a mind map depicting themes relevant to the research question (King 2012). The process of constructing the template began with an initial incarnation based on the first ten transcripts. Later transcripts were coded according to this first draft template, with modifications made as new themes appeared, and code hierarchies or structures altered to reflect new understandings of the data. In some cases codes that no longer appeared relevant were deleted (King 2013). The decision to begin constructing the template at the mid-point was

based on a pragmatic decision to move the process forward whilst decisions were made about further recruitment.

Developments of the template were discussed with the experts, and the template moved from an unwieldy structure describing all the data, to a tighter final version focused on the research questions. Variations of the template were explored using themes listed on post-it notes, at the suggestion of NK. King suggests a pragmatic approach to deciding when the template is complete (King 2012), and within time constraints a template was produced that provided a useful tool to both describe and explore the data.

The data analysis process continued during the write-up of the findings, as quotations were reread and the interview recordings were revisited to recheck the data interpretation (King 2013). During this stage, the participants were in the forefront of my mind, and connections between the data were explored, and ideas formed. This was an important element of the analysis process.

#### **4B.15 Quality Checks**

Steps were undertaken to ensure that the research was of good quality. There are no universally agreed quality standards for qualitative research, since there are different approaches according to methodological and epistemological differences (King & Horrocks 2010, Murphy et al 1998, Seale 1999); and therefore a decision was made to apply the checks recommended by King (2013) as appropriate for TA:-

1. **Scrutiny of the Analysis** –The quality of the coding was independently checked by AH, who coded a sample of transcripts and then comparisons were made with those coded by myself, in order to reach an agreed interpretation. AH had experience both of undertaking previous research with this client group, and interviewing some of the same participants for the parent study; and therefore her insights were considered of particular importance. Coding was also discussed at the monthly supervision meeting, and the input from these experienced researchers was valuable in ensuring that the coding was informed by a range of views, and also reflected the research questions. External scrutiny was sought from NK, who provided advice about the development of the template, both in practical terms and to ensure that template reflected the experience of the participants

A validation exercise was undertaken at a heart failure support group, to gain an overview of the validity of these initial theoretical propositions (see chapter 7). It was

also thought that participants may feel more comfortable voicing their views as part of a group, rather than in a one to one situation, especially if they disagreed with my interpretation (King 2013).

2. **Audit Trails** – Records were kept of the processes involved in shaping the research, such as, the coded transcripts, records of key decisions, and various incarnations of the template (appendix template versions 1 and final version). Notes were taken of meetings about the analysis, and the meetings with NK were recorded. The idea of documenting the processes from interview to reporting of findings is to make explicit the processes, so that it can be open to scrutiny; King (2013) describes this as the “antidote” to the idea of findings emerging from the data.
3. **Reflexivity** – A process of reflexivity was undertaken, in order to create an awareness of myself within the data analysis, with the aim of producing a more objective outcome.

Further steps in ensuring quality were: to ensure that the interviews were transcribed accurately; that sufficient time was given to ensure each research stage was completed adequately; and that the written findings were a product of a thorough approach (Braun & Clarke (2006). Consideration was also given to the use of quotation in the report to ensure that they reflected the views of the participants rather than, for example, picking out striking quotes (White, Woodfield and Richie 2010). In addition by describing the epistemological stance, and methods of data collection and analysis, the reader can make their own judgements about the quality of the study (LeCompte & Goetz 1982, Mason 2002).

#### **4B.16 Methodologies for the Validation Exercise, Heart Failure Specialist Nurses Research, and the Technology Key Informant Interviews**

The following section describes in brief the methodologies used for the support group validation exercise, the research with the HFspNs, and the key informant interviews. The methodologies are not expanded on due to the fact that these were small elements of the whole project, and word constraints prevent full elaboration. The following tables summarise the methodologies:-

**Table 4B.3 Validation Exercise with the Heart Failure Support Group**

1. Justification for this Element of the Project	This element of the research was undertaken to validate and test the initial themes and theoretical propositions developed from the first thirteen interviews with participants with heart failure, before an audience with the same condition; and to gain additional insights. In addition, the group was visited in order to recruit further participants with heart failure for interview
2. Research Method	A focus-group discussion was chosen on the basis that it would be an efficient method of gaining both individual views, and responses emanating from the interplay between group members (Finch & Lewis 2003).
3. Topic Guide	The topic guide (appendix - Participant Interview Topic Guide (Validation Exercise at the Support Group) was based on the initial analysis of the participant interviews, and group members were asked their response to these initial theoretical propositions that were presented to the group in the form of a statement.
4. Practical Issues	The research took place at the hall used regularly for group meetings; and therefore the participants were in a familiar situation, and were not required to travel further to participate.
5. Recruitment	approval was gained, and permission was sought from the Chair of the support group to attend a meeting, and this was readily given.
6. Sample	The sample was based on chance, on which members happened to attend. In the event there were 27 attendees: with a gender split of 19 males and 8 females. There were 7 partners present, and these were mainly female (5). The participants were not asked their age, as this was thought to be too intrusive; but the age-range was estimated to range from 60 to over 80, with the majority in their 70s. It also became apparent that the majority of attendees had been living with the condition for some time, although there were two members who had been recently diagnosed.
7. Ethics	The same ethical issues previously described in section 4B.9 applied to this project. In addition there were potential ethical issues around the disclosure of information in a group situation; in order to mitigate this, participants were assured that they would not be identified in any

	reports, and participants made their own choices about what to disclose.
8. Consent	Consent was sought before commencing the focus-group. In order to ensure informed choice was made, the key issues were explained (see previous section on consent). Consent was also sought to record the session.
9. Data Recording and Transcription	The session was recorded via a digital recorder, and was transcribed by myself, with checks made to ensure that the transcription was accurate. Transcription was a challenge because of the large number of people in the group (Finch & Lewis 2003).
10. Reflection on the Focus Group	The group was larger than the typical focus-group, and this presented challenges in terms of controlling the group (Finch & Lewis 2003). My previous focus group experience was invaluable in ensuring that the participants were given an opportunity to speak. Within large groups there are risks that the discussion may lack depth (Finch & Lewis 2003); however in reality the depth of discussion varied more according to what sparked interest in the group, rather than this being an issue across the discussion.
11. Field Notes	Notes were taken immediately after the validation exercise, and these were invaluable in clarifying and shaping ideas about the relationship between activity and health.
12. Reflexivity	Aware that I was an outsider of the group, I presented myself as seeking help to understand about heart failure, saying this is what I thought but is it true? I think this acknowledgement, helped participants to be more candid.
13. Data Analysis	The data analysis followed the structure of the topic guide (Appendix Information Sheet 3), with responses summarised under each heading. The data was considered more a validation to explore pre-existing themes, and therefore no further thematic analysis was undertaken. Advice had been sought from NK about whether this data should be added to the template, and he recommended keeping the data separate. However during the write-up of the interview findings, any relevant data was incorporated.
14. Quality Checks	The focus group was discussed at the monthly supervision meeting,

	where the interpretation in the summary was checked against the transcript.
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**Table 4B.4 Research with Heart Failure Specialist Nurses (HFspNs)**

1. Justification for this Element of the Project	This element of the research was undertaken to seek an alternative perspective on the relationship between activity and health from health professionals caring for people with heart failure; and the data was also used to validate and check some of the key findings from the participant interviews.
2. Research Method	This section of the research took place as part of a focus-group undertaken for the parent project. The rationale for choice of focus-group was the same as the previous project. For pragmatic reasons two nurses were interviewed individually using the same topic guide.
3. Topic Guide	The topic guide (appendix Information Sheet 4) sought to explore issues arising from the literature, and the quantitative findings.
4. Practical Issues	The initial focus group participants declined to have the interview recorded, and therefore extensive notes were taken. This meant that as it was not possible to record the conversation verbatim, decisions had to be made on the spot about what to record; and the subtleties of the conversation were not captured (such as tone of voice).
5. Recruitment	Five nurses were recruited by AH, and the sixth by myself (after a chance encounter).
6. Sample	The nurse participants were purposively selected to encompass experience of services provided for different case-loads, with the Sheffield service caring for patients with severe heart failure (4 nurses), Barnsley less severe patients (1 nurse), and the Nottingham service focused at the time of the nurse's experience on case management of symptomatic patients (1 nurse).
7. Ethics	The additional ethical issues were around potential breaches of confidentiality which may arise when nurses were discussing individual patients; however this did not arise as no individual identifiers were included in the conversations. Pseudonyms were used in the write-up.
8. Consent	Consent was taken as previously described. Consent was not given to record the Sheffield focus group.
9. Data Recording and Transcription	Extensive notes were taken at the focus group. The interviews were recorded and transcribed verbatim.



10.Reflection on the Focus Group/Interviews	The questions for this project were asked at the end of the focus group, and there was awareness that the participants should not be detained too long. The final interview where the only these questions were asked, felt much more relaxed and there was time to explore the issues.
11.Field Notes	Field notes were taken and these were useful in forming ideas about the range of factors influencing activity levels; and the role of the nurses themselves in either encouraging or discouraging activity.
12.Reflexivity	The Sheffield nurses appeared suspicious of the research, and this seemed to relate to the on-going NHS reorganisation. The nurses were reassured that the research would not compromise their situation.
13.Data Analysis	For the following reasons the HFspN data was summarised, rather than subjecting it to thematic analysis. Firstly, a full transcript of the focus group was not available; secondly, this was a small element of the total research, and thirdly, time constraints prevented full analysis.
14.Quality Checks	The findings were discussed with AH who led the focus group and interviewed the Barnsley nurse, in order to check interpretation.

**Table 4B.5 Lifestyle Monitoring Technology - Key Informant Interviews**

1. Justification for this Element of the Project	This element of the research was undertaken as a quick means to gain an understanding of the key issues around lifestyle monitoring: the purpose of the technology, and the state of the art in terms of the technologies utilised, data analysis, and the strengths and weaknesses of the technology. In addition the interviews were also utilised to gain an understanding of the purpose of the Barnsley lifestyle monitoring project, and the sensor platform utilised; as this data was analysed for this study (chapter 5). The results of the interview data is chiefly reported in chapter 9.
2. Research Method	Two lifestyle monitoring experts were interviewed, as this gave the opportunity to explore a complex subject area in general, and the specifics of the Barnsly LM project.
3. Topic Guide	The topic guide (appendix Information Sheet 5) sought firstly to explore the set-up of the Barnsley lifestyle monitoring project; and secondly to present the interviewees with a list of strategies used by people with heart failure to deal with changes in heart failure symptoms, in order to explore whether LM technology could indirectly capture these changes in home activity. Additional ad-hoc questions were also asked.
4. Practical Issues	The recording device ran out of power during the recording of one of the interviews, and after a failed search to find replacement batteries, notes were taken instead.
5. Recruitment	The experts were colleagues in the same university department where this study took place.
6. Sample	The key informants were purposively selected to encompass knowledge of the set-up of the Barnsley lifestyle monitoring project, and more general knowledge of the subject state of the art.
7. Ethics	Ethical approval was not sought as the participants were university colleagues.
8. Consent	No consent was taken.
9. Data Recording and Transcription	Where possible the interviews were recorded and transcribed verbatim, and in the case where the recording device broke down extensive notes were taken.

10.Reflection on the Interviews	The participants were colleagues, and initially the process felt a bit uncomfortable perhaps for all parties but this soon passed.
11.Field Notes	Field notes were taken in order to reflect on the interviews, both in terms of the understanding of the technology, and insights on ideas about the relationship between activities within the home and health.
12.Reflexivity	I was very aware that I was interviewing colleagues about a subject matter that they are experts in, and thus initially felt some concerns about my relative lack of knowledge. However I took the opportunity to learn, and followed up issues I did not understand; and allowed the interview to develop naturally.
13.Data Analysis	For the following reasons the key informant data was summarised, rather than subjecting it to thematic analysis. Firstly this was a small element of the total research, and secondly, time constraints prevented full analysis.
14.Quality Checks	The findings were discussed with Mark Hawley the supervisor with expertise in technology, in order to check interpretation and understanding of technological issues.

#### **4B.17 Conclusion**

This chapter therefore reflects and justifies the inclusion of qualitative elements in the research, and describes the methodological approaches to each aspect.

## **Chapter 5: Findings from the Analysis of the Barnsley Lifestyle**

### **Monitoring Data**

#### **5.1 Introduction**

This chapter describes the results of the data analysis that was undertaken in order to explore the relationship between measures of activity within the home and measures of health. The participants in the Barnsley study were asked questions about their health and symptoms regularly, and the replies would range from 'no problems' to 'extreme problems' in the EQ-5D, and 'no symptoms' to 'more than usual symptoms' in the symptom questions. This range of answers from no problems/symptoms to extreme problems/more than usual symptoms is used in the Barnsley study as a proxy measure of health, based on the assumption that there is a hierarchy of health within the answers. The analysis therefore set out to find out whether proxy activity levels varied according the self-reported health state.

The plan of analysis was as follows. Firstly, to plot the measures on trend charts to observe any patterns in the variables within the individual study houses. Secondly, to calculate average scores for the health and symptom measures and average sensor counts for the activity measures and plot these on scatterplots for homes where participants lived alone and for homes where participants lived as a couple, and thus to find out whether there were any patterns observable at group level. And finally to investigate within individual houses whether there were statistically significant differences in recorded levels of activity between the self reported levels of health and symptoms, and if so to elucidate the nature of this relationship, for example, is activity higher or lower when participants report better or worse health?

#### **5.2 Trend charts**

Initially all the measures were plotted on trend charts by house in order to look at the data over the whole study period and identify whether there were any obvious variations or patterns in the data. There was evidence of variations in the measures in some houses. In house 3, for example, there was an increase in general activity before a long hospital admission, followed by a clear decrease when the person returned home; however in most houses the trends were less clear (Appendix table 1).

In order to establish whether there were any variations in levels of activity across the study period the data was plotted in LOESS graphs (locally weighted scatter plot smoothing), for each house (Appendix table 1). The LOESS graph fits a curve to the plots using a window which samples subsets of the data (Wikipedia 2010). The method would establish visually whether

activity had changed over the year, because if activity levels remained stable the beginning and end of the plot would match up. The findings from the LOESS plots are summarised in the appendix (table 1). In order to interpret the plots the findings were categorised according to the following structure: no change; slight change; fluctuation; or increase or decrease. No consistent pattern emerged from the LOESS graphs, but there is some evidence of greater variations in activity levels in some houses, than others, for example, in houses 5, 7, 11, and 15. Other houses have more evidence of stable activity levels, i.e., houses 8 and 10.

The LOESS graphs also provided an opportunity to assess which measures of activity appeared to be more subject to variations, or stability. General activity, TV duration, and bath and toilet (night) had a greater number of indications of variations (Appendix, table 1). Greater stability was seen in the following measures: food activity, total sleep, bath and toilet (day), and day nap.

The findings from the LOESS plot showed that there were fluctuations both in the measures of health and in the measures of activity, to a greater or lesser degree, and therefore further investigations were warranted.

### **5.3 Scatter plots**

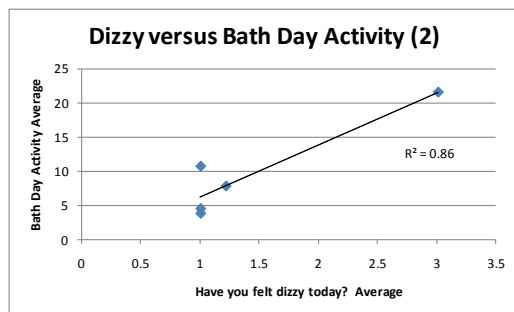
In order to explore the relationship between home activity and health amongst the two types of living arrangement (participants living alone and as a couple), scatter plots were utilised displaying activity variables against health variables scores, averaged across the houses, and across the whole study period. Thus all activity variables were plotted against all health variables, separately for each of the two types of living arrangement (see table 5.6 for the full range of activity and health variables).

The two types of living arrangement were investigated separately because the technology utilised by the Barnsley studies does not make it possible for the individual activity of the study participant to be identified. This shortcoming is acknowledged within lifestyle monitoring community where much of the research has focused on older people living alone (Chan et al 2005, Kaushik et al 2007, Ohta et al 2002, Suzuki et al 2006). It therefore might be supposed that the relationship between home activity and health might be more clearly defined in houses where the participants lived alone, rather than in couples. However there were fewer single occupant homes, than dual occupant houses in the Barnsley study, and in cases where a particular sensor was not chosen by the participant, the available data is further reduced. This is a shortcoming of the research.

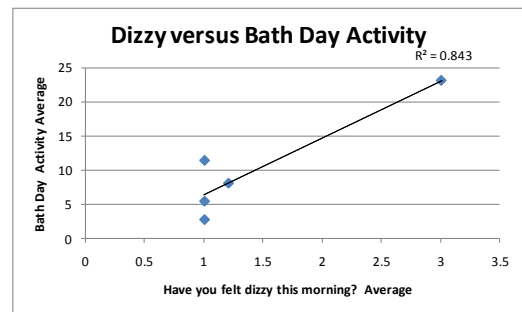
The strength of the associations was tested using the methodology described chapter 4a (page 86). The highest graded associations in the single occupant homes were between health questions on dizziness, food intake, mobility, pain, and tiredness, and bath and toilet activity, especially night-time bath and toilet activity (table 5.1 and charts 5.1 to 5.6). The data on dizziness and bath and toilet activity is limited because two of the single occupant houses did not have a bathroom sensor, and this may have impacted on the results. The high association is the result of one outlier reporting high levels of dizziness and its association with high levels of bath and toilet activity (charts 5.1 and 5.2). In both cases this is the occupant of house 15, a female participant who was very limited in her activities by heart failure. This outlier does not reflect the general pattern between activity and health shown by the other participants, and thus more evidence would be needed before accepting that this is a reliable association. The remaining very high associations showed greater reported problems in mobility, pain, and tiredness associated with lower night-time bath and toilet activities (charts 5.4, 5.5, and 5.6). And in self-reported food intake, lower intake was associated with a greater number of night-time bath and toilet activities (chart 5.2).

**Charts 5.1 to 5.6: Scatterplots of the Mean Activity versus the Mean HRQoL by House, for those with a Strong Association with Health**

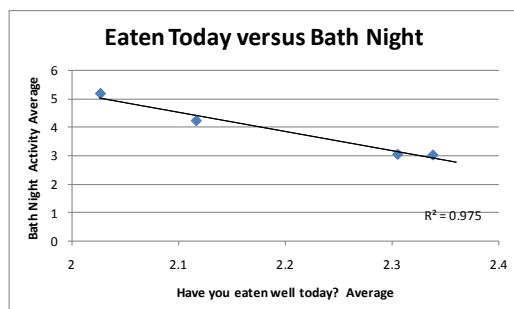
**Chart 5.1**



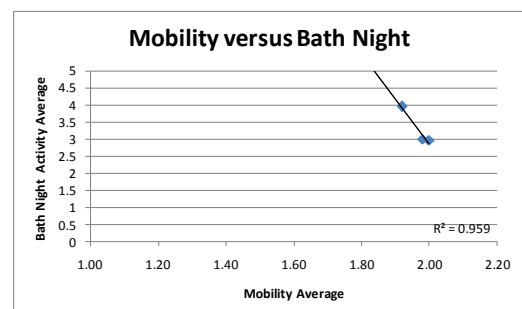
**Chart 5.2**



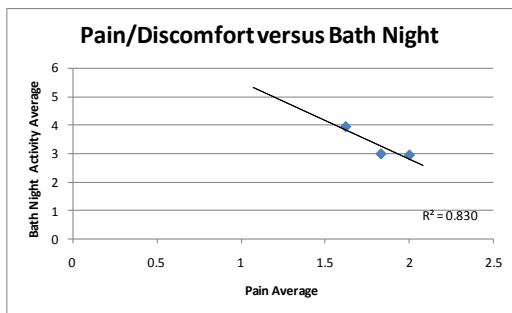
**Chart 5.3**



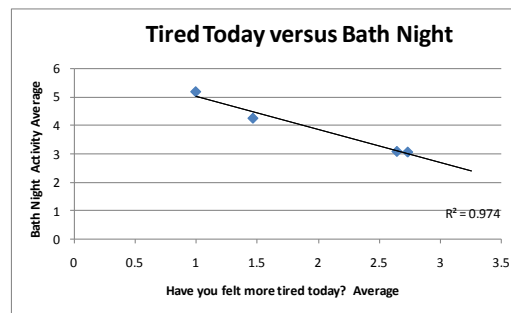
**Chart 5.4**



**Chart 5.5**



**Chart 5.6**



There were eighteen associations between health and activity measures graded as high in the single households. These were between angina and bath and toilet activities; anxiety and bath and toilet activities, television viewing, and sleep; shortness of breath and bath and toilet activities, television viewing, and sleep; cough and bath and toilet activities, and night activity; eaten well and television viewing; EQ-5D total utility score and day nap; EQ-5D pain and day nap; tired today and food, television viewing, and sleep; and finally urine output and bath and toilet activities

In order to quantify the scatter plot associations the results were scored according to the following scheme: very low =0, low = 1, modest = 2, high = 3, and very high = 4. These scores were summed for each health question and activity measure and are shown in table 5.1. The proxy activity measure with the highest association score was night-time bath and toilet activity with a total score of 44, followed by both sleep measures with a score of 28; the lowest score was for food activity, and night activity. The health questions with the highest association score asked about food intake and tiredness, and the health question with the lowest association score asked the participant about sleep and tiredness (table 5.1). The health question asking participants about whether they needed an extra pillow was excluded from the analysis because there was insufficient variation in the pillow score to explore the relationships with activity measures.

Table 5.2 describes the nature of the scatter plot associations, whether there is evidence of a positive or negative association for the charts graded as moderate, high, and very high. This categorisation was complicated by the fact that for some health questions having ‘more than usual’ as a reply implied that symptoms were worse, but for other health questions, such as sleep, food, and urine output this reply would imply a positive outcome rather than negative. In all the charts the predictor of activity was plotted on the X axis, and generally the higher scores represented poorer health. However there were some exceptions to this - for both the EQ-5D visual analogue scale, and the total utility score the higher scores implies a better health

state. In order to avoid confusion in interpreting the results of the scatter plots, the health measures which do not conform to the general scheme are placed at the bottom of table 5.2. The associations were then reversed in order to present the results in a coherent way. The angina versus bathroom activity relationship was excluded from the analysis because there was no evidence of either a positive or negative association, although there was clearly a linear relationship; the interpretation was hindered by the paucity of bathroom data.

As mentioned previously, the health questions with the highest association scores asked about food intake and tiredness. The scatterplots for the food intake question showed a mixed pattern of association, with three charts displaying a positive association, and four a negative (table 5.2). The relationships shown in the tiredness charts were also mixed, with an equal split between positive and negative associations (table 5.2). The two charts with the highest Pearson's correlation coefficient across all the charts for single occupant homes were concerned with food intake and tiredness versus night-time bath and toilet activities (charts 5.3 and 5.6). In the food intake chart not eating as well was associated with more nocturnal visits to the bathroom (chart 5.3). In the case of tiredness, greater reported tiredness was associated with fewer visits to the bathroom (chart 5.6).

A positive association describes a relationship between activity and health where poorer self-reported health is associated with greater recorded activity, and better self-reported health with lower recorded activity. In the single occupant homes the activity measures with the majority of positive associations were: the sleep measure total sleep (88% positive), general activity (86% positive), food activity (80%), and bath and toilet day activity (71%). Some of these positive associations fit in with what might be expected, i.e., if a person is ill they may sleep longer. However other positive associations are a surprise, such as the association between poorer self-reported health and greater food activity, when it might be expected that poorer self-reported health would reduce appetite (as described in the literature review). Further research would be needed to understand the mechanism for this increase in activity, although it is well known that weight gain can be a problem for heart failure patients (BHF 2010); in addition, the activities that are undertaken in the kitchen during periods of ill health may be to do with managing ill-health rather than food intake, such as, taking medications. During periods of poor health, family or friends may visit to offer support, and they may engage in activities within the kitchen. It is interesting to note that bath and toilet day activity is predominantly a positive association, but the night-time activity measure is largely a negative association. It would be reasonable to speculate that during a period of ill-health the



heart failure patient may increase their dose of diuretic and this would result in increased toilet visits during the day (Continuing Medical Implementation 2007).

The negative associations in single households were in the following activity measures: day nap (90%), bath and toilet night-time activity (86%), and TV duration and night activity (both 63%) (Table 5.3). A negative association means that there was higher recorded activity in these proxy measures when better health was reported. The activity measure with the highest association score was night-time bath and toilet, the majority of these associations were negative where poorer self reported health was associated with fewer nocturnal visits to the bathroom. It is interesting that there was apparently more napping during the day when good health was reported, and it might be speculated that the absence of symptoms makes napping easier, although this idea is not in keeping with the positive association for total sleep.

**Table 5.3: Summary Table of Positive and Negative Associations by Activity Measure**

	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity
Single	Positive (86%)	Positive (80%)	Positive (71%)	Negative (86%)	Negative (63%)	Negative (90%)	Positive (88%)	Pos/Neg (50%)	Negative (63%)
Couple	-	Positive (93%)	-	Positive (100%)	Positive (86%)	Positive (89%)	Positive (100%)	Positive (67%)	Positive (78%)

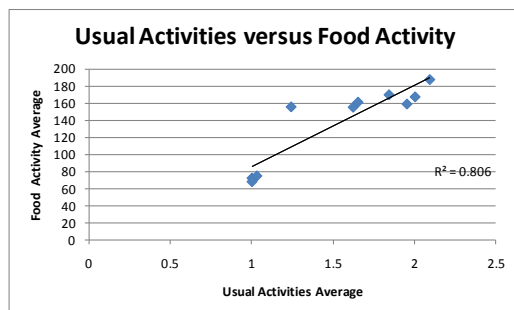
Based on associations graded as moderate, high, and very high.

Because of the different lifestyle and support available to people living as a couple it might be expected that there would be differences in the relationships shown by the average scatterplots. This is indeed the case. Within the households where couples lived there were no associations graded as very high, unlike the single households where there were six (table 5.1 and 5.4). There were 10 associations graded as high in the couples, and 18 in the single occupant households (table 5.1 and 5.4). In the couples these were mainly in the food activity measure (4), and the night-time bath and toilet activity (2); whereas in the single households there were mainly in night-time bath and toilet activity and total sleep (4), and TV duration (3). There were 60 associations graded as modest in the couples, and 50 in the houses where people lived alone. The association score for the couples added up to a total of 219 and for the participants living alone it was 235. The activity measures with the highest association scores in the couples were food activity (36), and night activity (30); in the single households it was night-time bath and toilet activity (44), and both sleep activity measures (28). The health questions with the highest association score in the couples were two EQ-5D questions on mobility and usual activities (17); and in the single occupant homes they were on food intake (18), and tiredness (17).

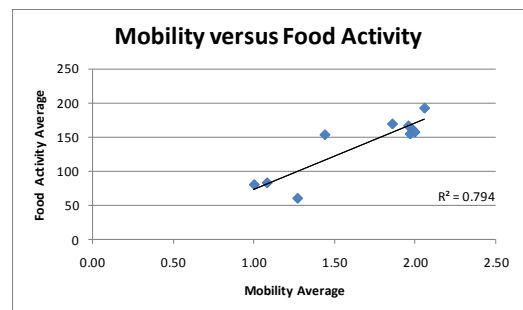
Across all the activity measures in couples, the majority of highly graded associations were positive (table 5.3), whereas in single households there was a mixture of positive and negative associations; this therefore provides further evidence for the role of living arrangements in shaping the relationship between activities within the home and health. In general within the dual occupancy households the response to poorer self-reported health is greater activity, and it would be reasonable to speculate that the additional activity may come from the partner of the heart failure patient. Certainly informal carers of heart failure patients report that they undertake additional activities when they perceive that symptoms prevent the heart failure patient from caring for themselves (Clark et al 2008). It is interesting therefore (as noted previously) that the health questions with the strongest association with activity in couples were reporting problems with mobility and usual activities in the heart failure patient (table 5.4). In the highest graded associations for both these health measures all the relationships with activity measures were positive associations where greater reported health problems were associated with greater activity (table 5.5).

The scatterplot of household averages with the highest Pearson’s correlation co-efficient in the couple households was EQ-5D usual activities versus food activity (chart 5.7), followed by EQ-5D mobility versus food activity (chart 5.8). This association between greater reported health problems and greater food activity is also seen in the single occupant households (table 5.2). However it is likely that in the homes where couples lived the caring partner would also be undertaking activities within the kitchen. Certainly on Internet carer support group websites there is an acknowledgment that carer stress can result in overeating (Economos 2008, US Department of Health and Human Services, Office on Women’s Health 2008).

**Chart 5.7: EQ-5D Usual Activities versus Food Activity**



**Chart 5.8: EQ-5D Mobility versus Food Activity**



**Table 5.1: Average Scatterplot Results Table, Single Households**

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Score
Angina	How many episodes of angina have you had today?	modest	low	high	high	v low	v low	low	v low	v low	10
Anxiety & Depress.	How anxious have you been today?	low	modest	low	high	high	v low	high	low	modest	16
Anxiety & Depress.	EQ-5D Anxiety and Depression	modest	v low	v low	modest	modest	v low	v low	modest	modest	10
Bloating	Does your stomach feel bloated?	modest	low	v low	modest	v low	modest	v low	low	v low	8
Bloating	Has your stomach felt bloated today?	modest	modest	v low	v low	v low	low	modest	modest	low	10
Breathlessness	Have you had any shortness of breath today?	v low	low	low	high	high	v low	high	low	modest	14
Breathlessness	How often did you wake up during the night due...	modest	low	modest	modest	modest	modest	high	modest	v low	16
Cough	Do you have a cough?	low	v low	modest	high	low	v low	v low	low	high	11
Dizzy	Have you felt dizzy this morning?	low	v low	v high	v low	modest	modest	v low	low	v low	10
Dizzy	Have you felt dizzy today?	low	v low	v high	v low	low	low	v low	low	v low	8
Food Intake	Have you eaten well today?	v low	modest	low	v high	high	modest	modest	modest	modest	18
General Health	EQ-5D Visual Analogue Scale	v low	low	low	v low	v low	modest	low	v low	low	6
General Health	EQ-5D Total Utility Score	v low	v low	low	modest	v low	high	low	low	v low	8
Mobility	EQ-5D Mobility	low	v low	modest	v high	modest	modest	low	modest	v low	14
Pain	EQ-5D Pain	v low	modest	v low	v high	low	high	v low	low	modest	13
Pillows	Did you need extra pillows to sleep with last night?										
Self Care	EQ-5D Self Care	v low	low	v low	low	v low	v low	low	low	v low	4
Sleep	Did you sleep well last night?	low	low	v low	v low	v low	low	low	v low	v low	4
Sleep	Have you felt more tired today?	v low	high	v low	v high	high	v low	high	modest	modest	17
Swelling	Are your ankles or feet swollen - 1st 12 hours	modest	low	v low	modest	v low	modest	low	low	v low	9

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Score
Swelling	Are your ankles or feet swollen - 2nd 12 hours	modest	v low	v low	modest	v low	low	v low	low	v low	6
Swelling	Have your ankles or feet been swollen today?	low	v low	v low	low	v low	low	modest	v low	v low	5
Urine	Have you passed less urine than usual today?	v low	v low	high	modest	v low	modest	modest	v low	low	10
Usual Activities	EQ-5D Usual Activities	v low	low	modest	v low	v low	low	low	low	modest	8
	<b>Association Score</b>	21	20	27	44	23	28	28	24	20	

**Table 5.2: Average Scatterplot Results Table, Single Households. Positive or Negative Associations.**

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Positive/Negative
Angina	How many episodes of angina have you...	positive (a)		excluded	excluded						p=1
Anxiety & Depress.	How anxious have you been today?		positive		negative	negative		positive		negative	p=2, n=3
Anxiety & Depress.	EQ-5D Anxiety and Depression	negative (a)			negative	negative (a)			negative (a)	negative (a)	n=5
Bloating	Does your stomach feel bloated?	positive			negative (a)		negative				p=1, n=2
Bloating	Has your stomach felt bloated today?	positive	positive					positive	positive		p=4
Breathlessness	Have you had any shortness of breath today?				negative	negative		positive		negative	p=1, n=3
Breathlessness	How often did you wake up during ...	positive		negative (a)	negative	negative	positive	positive	positive		p=4, n=3
Cough	Do you have a cough?			negative (a)	positive (a)					positive	p=2, n=1
Dizzy	Have you felt dizzy this morning?			positive (a)		positive (a)	negative (a)				p=2, n=1
Dizzy	Have you felt dizzy today?			positive (a)							p=1
Mobility	EQ-5D Mobility				negative (a)	positive	negative		negative		p=1, n=3
Pain	EQ-5D Pain		positive (a)	positive	negative		negative (a)			positive	p=3, n=2
Pillows	Did you need extra pillows to sleep with ...?										
Self Care	EQ-5D Self Care										
Sleep	Have you felt more tired today?		positive		negative	negative		positive	positive	negative	p=3, n=3
Swelling	Are your ankles or feet swollen - 1st 12 hours	positive			negative		negative				p=1, n=2
Swelling	Are your ankles or feet swollen - 2nd 12 hours	positive (a)			negative						p=1, n=1
Swelling	Have your ankles or feet been swollen today?							positive (a)			p=1
Usual Activities	EQ-5D Usual Activities			positive						negative	p=1, n=1
	Positive/Negative Association	p=6, n=1	p=4	p=4, n=2	p=1, n=10	p=2, n=5	p=1, n=5	p=6	p=3, n=2	p=2, n=5	
Food Intake	Have you eaten well today?		positive		negative	negative	positive	positive	positive	negative	p=3, n=4
General Health	EQ-5D Visual Analogue Scale						positive (a)				n=1

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Positive/Negative
General Health	EQ-5D Total Utility Score				positive		positive (a)				n=2
Sleep	Did you sleep well last night?										
Urine	Have you passed less urine than usual today?			negative	positive		positive (a)	negative			p=2, n=2
	Positive/Negative Association		n=1	p=1	p=1, n=2	p=1	n=4	p=1, n=1	n=1	p=1	
	Positive/Negative Association	p=6, n=1	p=4, n=1	p=5, n=2	p=2, n=12	p=3, n=5	p=1, n=9	p=7, n=1	p=3, n=3	p=3, n=5	p=34, n=39

(a) Association the result of one outlier. Colour coding based on the strength of the association: dark blue = v high, mid blue = high, light blue = moderate.

**Table 5.4: Average Scatterplot Results Table, Couples**

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Score
Angina	How many episodes of angina have you had...?	v low	low	v low	v low	low	low	low	v low	low	5
Anxiety & Depress.	How anxious have you been today?	low	modest	low	v low	modest	modest	modest	low	modest	13
Anxiety & Depress.	EQ-5D Anxiety and Depression	low	modest	v low	low	v low	modest	modest	low	modest	11
Bloating	Does your stomach feel bloated?	v low	v low	low	low	modest	low	v low	v low	low	6
Bloating	Has your stomach felt bloated today?	low	v low	v low	low	v low	low	v low	modest	v low	5
Breathlessness	Have you had any shortness of breath today?	low	modest	v low	v low	low	modest	modest	low	low	10
Breathlessness	How often did you wake up during...?	low	modest	v low	v low	v low	v low	v low	modest	low	6
Cough	Do you have a cough?	low	v low	v low	modest	low	modest	low	v low	v low	7
Dizzy	Have you felt dizzy this morning?	low	modest	low	v low	modest	v low	v low	low	modest	9
Dizzy	Have you felt dizzy today?	v low	modest	low	v low	low	high	modest	v low	modest	11
Food Intake	Have you eaten well today?	v low	v low	v low	v low	high	v low	low	v low	v low	4
General Health	EQ-5D Visual Analogue Scale	v low	modest	low	modest	v low	v low	v low	low	low	7
General Health	EQ-5D Total Utility Score	v low	high	v low	modest	low	modest	modest	low	modest	13
Mobility	EQ-5D Mobility	low	high	v low	high	modest	modest	modest	modest	modest	17
Pain	EQ-5D Pain	v low	modest	v low	low	low	modest	modest	v low	v low	8
Pillows	Did you need extra pillows to sleep with last night?	v low	v low	v low	v low	modest	low	v low	v low	low	4
Self Care	EQ-5D Self Care	v low	modest	low	modest	v low	v low	low	low	low	8
Sleep	Did you sleep well last night?	modest	low	v low	low	v low	low	v low	modest	v low	7
Sleep	Have you felt more tired today?	modest	high	v low	low	low	modest	modest	modest	modest	15
Swelling	Are your ankles or feet swollen - 1st 12 hours	modest	low	v low	v low	v low	low	v low	modest	low	7

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Score
Swelling	Are your ankles or feet swollen - 2nd 12 hours	modest	low	v low	v low	low	low	v low	modest	modest	9
Swelling	Have your ankles or feet been swollen today?	low	v low	v low	low	low	low	low	v low	low	6
Urine	Have you passed less urine than usual today?	modest	modest	modest	low	low	v low	low	high	modest	14
Usual Activities	EQ-5D Usual Activities	modest	high	v low	high	modest	low	low	modest	high	17
	<b>Association Score</b>	21	36	8	22	25	28	23	26	30	



**Table 5.5: Average Scatterplot Results Table, Couple Households. Positive or Negative Associations.**

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Positive/Negative
Angina	How many episodes of angina have you...?										
Anxiety & Depress.	How anxious have you been today?		positive			positive	positive	positive		positive	p=5
Anxiety & Depress.	EQ-5D Anxiety and Depression		positive				positive	positive		positive	p=4
Bloating	Does your stomach feel bloated?					positive (a)					p=1
Bloating	Has your stomach felt bloated today?								positive		p=1
Breathlessness	Have you had any shortness of breath today?		positive				positive	positive			p=3
Breathlessness	How often did you wake up during...?		positive						positive		p=2
Cough	Do you have a cough?				positive		negative				p=1, n=1
Dizzy	Have you felt dizzy this morning?		positive			positive				positive	p=3
Dizzy	Have you felt dizzy today?		positive (a)				positive	positive		positive (a)	p=4
Mobility	EQ-5D Mobility		positive		positive	positive	positive	positive	positive	positive	p=7
Pain	EQ-5D Pain		positive				positive	positive			p=3
Pillows	Did you need extra pillows to sleep with...?					negative (a)					n=1
Self Care	EQ-5D Self Care		positive		positive						p=2
Sleep	Have you felt more tired today?		positive				positive	positive	positive	positive	p=5
Swelling	Are your ankles or feet swollen - 1st 12 hours								negative (a)		n=1
Swelling	Are your ankles or feet swollen - 2nd 12 hours								negative (a)	negative (a)	n=2
Swelling	Have your ankles or feet been swollen today?										
Usual Activities	EQ-5D Usual Activities		positive		positive	positive			positive		p=4
	Positive/Negative		p=11		p=4	p=5, n=1	p=7, n=1	p=7	p=5, n=2	p=6, n=1	
Food Intake	Have you eaten well today?					negative					n=1
General Health	EQ-5D Visual Analogue Scale		negative		negative						n=2

Subject	Measures of Health/Wellbeing	General Activity	Food Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Day Nap	Total Sleep	Day Activity	Night Activity	Positive/Negative
General Health	EQ-5D Total Utility Score		negative		negative		negative	negative		negative	n=5
Sleep	Did you sleep well last night?								negative		n=1
Urine	Have you passed less urine than usual today?		positive	positive					positive	positive	p=4
	Positive/Negative		p=2, n=1	n=1	p=2	p=1	p=1	p=1	p=1, n=1	p=1, n=1	
	Positive/Negative		p=13, n=1	n=1	p=6	p=6, n=1	p=8, n=1	p=8	p=6, n=3	p=7, n=2	p=54, n=9

(a) Association the result of one outlier. Colour coding based on the strength of the association: mid blue = high, light blue = moderate.

#### **5.4 Analysis of Variance (ANOVA) and T-Tests.**

The participants in the Barnsley study were asked questions about their health and symptoms regularly, and the replies would range from 'no problems' to 'extreme problems' in the EQ-5D, and 'no symptoms' to 'more than usual symptoms' in the symptom questions. This range of answers from no problems/symptoms to extreme problems/more than usual symptoms is used in the Barnsley study as a proxy measure of health, based on the assumption that there is a hierarchy of health within the answers. The aim of the analysis was to answer the question of whether activity levels were the same across the range of health states, or whether there were differences.

In order to assess whether there were any variations in activity levels between these health states, activity levels for every health question were analysed for each study house (table 5.6) to ascertain whether there were any statistically significant differences. Mean values for the whole study period were analysed. In cases where three or more increments of health were expressed by the answers to the EQ-5D and symptom questions, the data was analysed using analysis of variance (ANOVA); and in cases where only two increments of health were expressed by the answers the data was analysed using a t-test. The analysis could only provide evidence of whether there were any significant variations in activity levels, it could not describe the nature of these variations, i.e., whether low or high levels of activity were associated with any of the increments of health. An initial broad brush, data mining approach was taken with the analysis, in order to ensure that all significant associations were available for interpretation. The possible relationships highlighted by the literature review were investigated later.

The level of statistical significance was set as less than 0.05, on the basis that this is a standard cut off point. There were 177 statistically significant variations in activity levels out of a total of 2033 possible relationships between the proxy measures of health and activity (Table 5.7). This is a significance level of 9%, which is higher than the level that would be expected purely by random variation. The house with the highest number of significant variations was house 3, where a male participant lived with his wife, rarely leaving the home because of his health condition. During the course of the study period he was subject to a long hospital admission, and on his return activity levels decreased (see trend charts previously presented). House 5 had the second highest number of significant variations in activity - the male participant lived with his wife and was not very active. House 11 had the lowest number of associations. The participant living here was a married female, limited in her activities by heart failure. During

the course of the study period one of the adult children came to live in the house for a few weeks, and it is possible that this further reduced any possible associations between activity and reported health of the participant.

**Table 5.6: Data Mining Analysis Plan  
By Houses 1-17**

Symptom and EQ-5D Questions	Bath Day	Bath Night	Day Activity	Day Nap	Food Activity	General Activity	Night Activity	Total Sleep	TV Duration
Are your ankles or feet swollen? - 1st 12 hours	x	x	x	x	x	x	x	x	x
Are your ankles or feet swollen? - 2nd 12 hours	x	x	x	x	x	x	x	x	x
Did you need extra pillows to sleep with last night?	x	x	x	x	x	x	x	x	x
Did you sleep well last night?	x	x	x	x	x	x	x	x	x
Do you have a cough?	x	x	x	x	x	x	x	x	x
Does your stomach feel bloated?	x	x	x	x	x	x	x	x	x
Has your stomach felt bloated today?	x	x	x	x	x	x	x	x	x
Have you eaten well today?	x	x	x	x	x	x	x	x	x
Have you felt dizzy this morning?	x	x	x	x	x	x	x	x	x
Have you felt dizzy today?	x	x	x	x	x	x	x	x	x
Have you felt more tired today?	x	x	x	x	x	x	x	x	x
Have you had any shortness of breath today?	x	x	x	x	x	x	x	x	x
Have you passed less urine than usual today?	x	x	x	x	x	x	x	x	x
Have your ankles or feet been swollen today?	x	x	x	x	x	x	x	x	x
How anxious have you been today?	x	x	x	x	x	x	x	x	x
How many episodes of angina have you had today?	x	x	x	x	x	x	x	x	x
How often did you wake up during the night due to shortness of breath?	x	x	x	x	x	x	x	x	x
EQ-5D visual analogue scale	x	x	x	x	x	x	x	x	x
Which statement best describes your anxiety/depression today?	x	x	x	x	x	x	x	x	x
Which statement best describes your mobility?	x	x	x	x	x	x	x	x	x
Which statement best describes your own usual activities today?	x	x	x	x	x	x	x	x	x
Which statement best describes your pain/discomfort today?	x	x	x	x	x	x	x	x	x
Which statement best describes your self-care today?	x	x	x	x	x	x	x	x	x

The proxy activity measure with the highest number of significant variations was general activity, and this accounted for 16 percent of all of the variations across all of the studies; the proxy measures with the smallest number of variations were total sleep, day nap, and night-time bath and toilet activities (table 5.7). The activity measure with the highest number of significant variations differed between each of the seventeen houses, most frequently it was general activity and night activity (table 5.7).

**Table 5.7: Statistically Significant Variations by Study House and Activity Measure**

House	S/C	General Activity	Day Activity	Night Activity	Food Activity	TV Duration	Bath & Toilet Day	Total Sleep	Day Nap	Bath & Toilet Night	Total	Percentage
3	C	<b>6</b>	2	4	2	3	1	<b>6</b>		3	27	15%
5	C	3	<b>7</b>	1	2	1	3	4	5		26	15%
2	C	<b>5</b>	4	<b>5</b>	2		4		3	2	25	14%
7	C	2	2	<b>3</b>	<b>3</b>	1		1	2		14	8%
10	S	<b>3</b>	1	2	2	1	2			<b>3</b>	14	8%
6	S	2	2	<b>3</b>	2		<b>3</b>			1	13	7%
9	C	3	1		1	<b>6</b>				2	13	7%
13	C				1	<b>4</b>		2		1	8	5%
14	S	1	<b>3</b>	1	2	1					8	5%
15	S			<b>3</b>	1	1				1	6	3%
1	S		1		1			1	<b>2</b>		5	3%
17	S	1		<b>2</b>	1			1			5	3%
8	C		<b>1</b>	<b>1</b>	<b>1</b>				<b>1</b>		4	2%
12	C						<b>1</b>		<b>1</b>	<b>1</b>	3	2%
16	C	<b>1</b>	<b>1</b>				<b>1</b>				3	2%
4	S	<b>1</b>					<b>1</b>				2	1%
11	C	<b>1</b>									1	1%
Total		29	25	25	21	18	16	15	14	14	177	
		16%	14%	14%	12%	10%	9%	8%	8%	8%		

(P-values <0.05). The activity measure with the highest number of significant variations for each house is highlighted in bold type. S/C – living arrangements: S=Single occupant homes, C=Couples.

Table 5.8 shows the breakdown of significant variations by health question and proxy activity measure from the participants living as a couple, and table 5.9 shows the participants living alone. If the significant variations were evenly distributed across the two groups it would be expected that the couples would have 59% of the significant variations, and the group living alone would have the remaining 41%, based on the proportion of the groups within the total sample. However the actual proportions are different, with the couples having a greater share of the significant variations (70%), and the participants living alone a smaller share (30%). On average there were 12 significant variations per house in the couple households, and 8 in the single households (table 5.11). This is a different finding from the average scatterplots, where

as mentioned previously, the association score was higher in the homes where participants lived alone.

Within the couple households, the health questions with the highest number of significant variations in activity asked about dizziness (17, 14 %), anxiety (14, 11%), cough (12, 10%), and passing urine (12, 10%) (table 5.8). In the homes where participants lived alone the health questions with the highest number of significant variations in activity asked about swelling in ankles and feet (6, 11%), and tiredness (6, 11%) (table 5.9). It is possible that the living arrangements of participants have an impact on the relationship between health and home activities. In the couples' homes help would be more readily at hand during periods of poor health. It is therefore possible that living arrangements influence which aspects of health impact on activity levels, and this may be demonstrated by the differing health questions more frequently associated with activity levels in the different houses.

These health questions with high number of significant variations are not necessarily the same as the health questions that had a high association score in the scatterplots, as they analyse different things. The scatterplots were a means of looking between the homes at the same time, with each scatterplot displaying averages of activity and health measures for all the homes at once. The analysis of variance examined the relationships between activity and health measures within each home separately, and thus a different picture emerged.

Questions about shortness of breath do not have as many significant variations in activity as might have been expected. The health question with the fewest significant variations in the couples asked about swelling in ankles and feet, and in the participants living alone it was questions about angina, mobility, and pillows. The health questions with the highest number of significant variations in activity differed between each of the study houses (table 5.10). Most frequently they were questions on ankles and feet swelling, tiredness, and urine output. These were symptom questions, rather than the more general EQ-5D, and are thus perhaps more pertinent to the participants.

It is interesting to note that within the single occupant homes those with the highest number of significant variations were homes in which the male participants were relatively fit and active, leaving the home often to get out and about (house numbers 10, 6, and 14: table 5.11). The single occupant houses with the least significant variations were mainly those with restricted activity (house numbers 1 and 4), although they also included an active male participant (house 17: table 5.11). Within the homes of couples, the houses with the highest

number of significant variations were a mixture of limited activity homes (houses 3 and 5), and an active home (house 2); the three houses with the fewest significant variations were also an assortment of active and inactive participant homes (table 5.11). The top three measures of activity in the single occupant homes were night activity, food activity, and general activity (table 5.9); within the couple homes they were general activity, day activity, and TV duration (table 5.8).

Amongst the seventeen participants of the Barnsley study there was a wide range of lifestyles, from one relatively fit participant who was often out and about (house 6), to others who were very restricted in their activity, rarely leaving the house (houses 1 and 3). In order to examine whether the relationship between home activities and health is stronger in those who were more limited in their lifestyles by heart failure, or in a more active sample, the houses were split into 'active' and 'limited' activity households according to the judgement of the Barnsley Research Nurse. On average there were 9 significant variations in activity per house in the limited activity households, and 11 in the active households (table 5.12), a relatively small difference.

### **5.5 Analysis of Post-hoc Test Results by Health Question**

The following section looks at activity levels in the health and symptom questions with the greatest number of significant P-values, in order to ascertain whether there is any evidence of patterns in the activity levels. The analysis looked at the relationship between proxy activity levels and self-reported measures of health/symptoms, and the sort of patterns in activity levels that would be of interest would be consistently lower or higher activity levels in a particular level of health, for example, higher activity in the self-reported health levels that indicate better health. This section will focus only on the homes of participants that lived alone, because of the difficulty of interpreting activity in homes where couples lived.

As noted earlier, the health questions with the highest number of significant p-values was 'Are your ankles or feet swollen?' (second twelve hours), and 'Have you felt more tired today?' (table 5.9). The following section will explore the swelling question.

Swelling of feet and ankles is one of the main symptoms of heart failure. The swelling occurs due to the build up of fluid that would normally pass out of the body in the form of urine, if the heart were pumping effectively (Lewin et al 2005). If the swelling is new to the heart failure patient, or suddenly gets worse, patients are advised to seek immediate medical attention (Lewin et al 2005).



Swollen ankles and feet were assessed over two twelve hour periods each day, centred at midday. It is interesting to note that there was only one significant variation in activity levels for the first twelve hours question (appendix table 2), the afternoon and evening question provided more significant variations (appendix table 3). Oedema may get worse at the end of the day (Sterns 2012), and thus if the swelling question was going to be asked only once a day, it would be better to target it to later on in the day.

The significant P-values were not distributed evenly across the health questions, activity measures, and houses. There was no health question or proxy activity measure that had significant P-values across all the study houses. The swelling symptom question with the highest number of significant P-values only had significant associations for three houses, and thus the results pertained to individuals, rather than the whole sample. This is also true of all the health questions and activity measures, to a greater or lesser degree.

Appendix table 3 shows the post-hoc test results for the swelling symptom question (second twelve hours). The table is split by proxy activity measure and level of health. The level of health refers to the range of answers to the health questions, from good health – level one, to poorest health – level three, or four (depending on whether the coding scheme has three or four levels). There is evidence of a general pattern of significantly lower activity for level one, and significantly higher activity for level four, which in effect means that significantly higher activity is recorded for poorer health. The activity measures with significant differences in activity levels were bath and toilet activities, and it would therefore be reasonable to speculate that the sensors are recording the increased visits to the toilet resulting from diuretics taken to reduce the swelling (Rose 2010).

Within the average scatterplots for ankles and feet swelling (second twelve hours) there was a negative association for night-time bath and toilet activity (table 5.2), which means that higher activity was associated with better self-reported health. This finding is the opposite of that found in the post-hoc test results.

In one participant there is also a significant association with the total sleep measure (appendix table 3); this is a complex pattern, with significantly higher sleep activity in the best health level. It could be speculated that the longer sleep activity results occurred when congestion symptoms were controlled, however this association is only seen in one participant, and thus is not generalisable to the whole sample.

The tiredness health question had the joint highest number of significant P-values (table 5.9). Tiredness is one of the major symptoms of heart failure (BHF 2010). The majority of the significant associations were found in house 6, a participant who was pretty fit, and often out and about. For this participant the higher levels of self reported tiredness were associated with significantly higher activity, within five measures of activity (appendix table 4). It is difficult to account for this pattern of activity related to tiredness. Activity levels may increase in the home when self-reported health is worse, because the exacerbation of symptoms may make leaving the home difficult. To date, no evidence for this has been found in the research literature, but during the course of a conversation between one heart failure patient and the author, the patient recounted that on bad days it was difficult to leave the house. An increase in home activity during periods of ill health would be observed most clearly in participants who led an active lifestyle, often leaving the house, rather than in housebound participants.

The framework for data interpretation (table 5.13) identifies a possible link between fatigue and reduced food intake. This relationship is not evidenced by the research findings, as a pattern of increased 'food' activity in greater levels of self-reported tiredness is seen in the only participant with a significant association between the tiredness health measure and food activity measure. This association between greater self-reported tiredness and greater food activity is also seen in the average scatterplots (table 5.2).

The health/symptom measures with the next greatest number of significant variations in activity levels concerned anxiety, cough, dizziness, and self-care (table 5.9). The following section will describe the post-hoc test results for each of these measures.

Within the research literature anxiety and depression is associated with reduced home activities, with the exception of television viewing which may either increase or decrease (table 5.13). The post-hoc tests reveal a complex pattern of activity in the two very active participants where significant associations were found (appendix table 5). In the day-time bath and toilet activity measure there was evidence of significantly higher activity in the third level of health, and no significant difference in activity in the fourth level of health. In the night-time bath and toilet activity measure there was significantly higher activity in level two. The Food activity measure does confirm the research literature, with significantly lower activity in level four; however, this is only an association in one participant. There were no significant associations between the television viewing activity measure and the anxiety health measure; in the average scatterplots a negative relationship was found with better health associated with longer periods of the television being switched on.

For the heart failure patient a cough can occur as a result of congestion in the lung or as a side effect of medication (BHF 2010). Most of the significant associations between the cough health measure and activity measures were seen in the house of a participant who took life very slowly, and had a bed downstairs (house 1). The post-hoc tests showed a pattern of lower activity in the best health level and significantly higher activity in the poorest health level used, level three (appendix table 6). This was not a participant that would be leaving the home, and yet the poorer health level was associated with increased day activity, although this could have been due to the activities of the carers who came into the house approximately three times a day. Two of the activity measures that saw higher activity in the poorer levels of health were sleep measures, and in the more active participant in house 10, higher activity was recorded in the television viewing measure in the poorer health level. Both sleep and television viewing are forms of relaxation, and thus it would be reasonable to speculate that the presence of the cough may have made the participants tired.

Dizziness is a common symptom in heart failure caused by an inadequate supply of oxygen to the brain or a side effect of medication (BHF 2010). The significant associations in the dizziness this morning question occurred in houses 14 and 17, both relatively active participants (appendix table 7). The post-hoc tests revealed a mixed pattern of activity levels, with significantly lower activity in the worst level of health (four) in day activity and food activity, and no significant difference in activity levels in general activity. In house 17 there was only one significant association in night-time activity, and in this case activity levels were significantly lower in the best level of health.

One of the EQ-5D questions was in the group of health measures with the most significant associations, and that was the question about self-care (appendix table 8). The significant associations were present only in house 6, the home of a very active participant. A clear pattern of significantly higher activity was recorded when no problems with self-care are reported, and this was seen across four activity measures. The same pattern was seen in the couple households. It is not possible to compare the pattern of activity in the post-hoc tests with the average scatterplots because only very modest associations were found.

## **5.6 Analysis of Post-hoc Test Results by Activity Measures**

The following section examines the post-hoc test results by activity measure. The measures with the greatest number of significant associations were night activity, food activity, general activity, and day activity (table 5.9).

Table 5.15 shows the night-time activity measure by health measure and level of health. The table is sorted by health level, in order to make the association between the health and activity levels clearer. In this table, level one corresponds to participants reporting no problems, and level four to reporting more problems than usual. At level one, the participants with significantly different levels of activity had lower activity. The opposite pattern is seen in the worst health level, with a pattern of significantly higher night-time sensor activity. The patterns of activity are more mixed for the health levels two and three, with mostly high activity at level two, and low activity at level three.

**Table 5.15: Post-Hoc Test Results by Activity Measure - Night Activity**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Are your ankles or feet swollen - 2nd 12 hours	1				low		low	
Have you felt dizzy this morning?								low
Have you felt more tired today?				no diff			no diff	
How anxious have you been today?				no diff				
How often did you wake up during the night due to shortness of breath?					low			
Have you felt dizzy this morning?	2							high
Have you felt more tired today?				low				
How anxious have you been today?				high				
Have you felt more tired today?	3			high			low	
How anxious have you been today?				low				
Are your ankles or feet swollen - 2nd 12 hours	4				high		high	
Have you felt more tired today?				high			high	
How anxious have you been today?				no diff				
How often did you wake up during the night due to shortness of breath?					high			

Table 5.16 shows the significant difference in night-time activity for the food, sleep and visual analogue quarter health measures (this was calculated by splitting the recorded scores into four levels). These health measures are displayed separately because in these measures level four represents participant reporting good health, which is the opposite of the previous table. This table is more difficult to interpret, with no obvious patterns of activity. This is the only significant variation in activity from the EQ-5D VAS, and here the poorer level of health is associated with significantly higher activity. The sleep health measure has data from two participants, and in both of these there was significantly higher night-time activity on average when these participants reported good sleep (levels 4 and 3), and significantly lower night-

time activity in the level of health reporting less than usual sleep. This is the opposite of what would have been expected. However, the night activity measure is a count of all sensor firings during the night including the bed and chair sensors, and this may have made the results difficult to interpret.

**Table 5.16: Post-Hoc Test Results by Activity Measure - Night Activity (Food, Sleep, and VAS Quarter)**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Did you sleep well last night?	4			no diff			high	
Have you eaten well today?						low		
Did you sleep well last night?	3			high			no diff	
Have you eaten well today?						high		
VAS Quarter								low
Did you sleep well last night?	2			low			low	
Have you eaten well today?						low		
VAS Quarter								high
Did you sleep well last night?	1			no diff				

The following tables show the post-hoc test results for the food activity measure by health measure and level of health (table 5.17-19). Within the research literature poorer health is linked with reduced food intake (table 5.13), however, the analysis of activity levels does not show a clear pattern of reduced food activity in the poorer levels of health, the reality is more complex. There were nine significant associations between activity and health measures in the food measure, and analysis of the worst health level for each of these revealed a greater proportion of significantly lower activity (6), than higher activity (3). In the average scatterplots there were mainly positive relationships in the charts with the strongest associations, so that poorer health was associated with higher food activity (table 5.2).

The analysis of the food activity measure provides an opportunity to validate the food intake health question against the Telecare data. The significant relationship between the food health question and food activity measure occurred in only one house (house 10). Where the participant reported 'less than usual' food intake, there was on average significantly higher food activity. This is the opposite of what might be expected. However, the participant living at house ten was relatively fit, going in and out of his home frequently, and thus this would have impacted on the Telecare sensor data leaving gaps in the data collection. In addition, as noted previously, the food activity measure may have picked up activities undertaken in the

kitchen that were not to do with food intake. The average scatterplots also found higher food activity associated with poorer self-reported food intake (table 5.2).

**Table 5.17: Post-Hoc Test Results by Activity Measure - Food Activity**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Has your stomach felt bloated today?	1							low
Have you felt dizzy this morning?						no diff		
Have you felt more tired today?				no diff				
How anxious have you been today?					high			
Has your stomach felt bloated today?	2							high
Have you felt more tired today?				low				
How anxious have you been today?					no diff			
Has your stomach felt bloated today?	3							low
Have you felt dizzy this morning?						high		
Have you felt more tired today?				high				
Have you felt dizzy this morning?	4					low		
Have you felt more tired today?				high				
How anxious have you been today?					low			

**Table 5.18: Post-Hoc Test Results by Activity Measure - Food Activity (EQ-5D)**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Which statement best describes your pain/discomfort today?	1	low						
Which statement best describes your self-care today?				high				
Which statement best describes your pain/discomfort today?	2	high				high		
Which statement best describes your self-care today?				low				
Which statement best describes your pain/discomfort today?	3					low		

**Table 5.19: Post-Hoc Test Results by Activity Measure - Food Activity (Food and Sleep)**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Did you sleep well last night?	4						low	
Have you eaten well today?					no diff			
Did you sleep well last night?	3						high	
Have you eaten well today?					low			
Did you sleep well last night?	2						low	
Have you eaten well today?					high			

Table 5.20 and appendix table 10 shows the post-hoc test results for the general activity measure. It had been expected from the literature review that an exacerbation of symptoms would result in a decrease in home activity (table 5.13). The activity levels across the levels of health were mixed, and no obvious pattern was discernible. In the worst level of health for each of the eight significant associations between activity and health there was an equal split of higher and lower activity general activity. In the two questions on breathlessness there were opposite responses in activity levels, with significantly higher activity associated with the level of health reporting no problems with night-time shortness of breath (house 17); and significantly higher activity associated with more than usual self-reported breathlessness during the day (house 10). As noted earlier, the post-hoc results are very individual, with significant results seen in one home, rather than across the whole sample; and thus it is not possible to compare responses within the participants. The participants with significant general activity p-values were mostly the participants able to lead a relatively active lifestyle.

**Table 5.20: Post-Hoc Test Results by Activity Measure - General Activity**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Does your stomach feel bloated?	1				no diff			
Have you felt dizzy this morning?						low		
Have you felt more tired today?				no diff				
How often did you wake up during the night due to shortness of breath?								high
Does your stomach feel bloated?	2				high			
Have you felt more tired today?				low				
Have you had any shortness of breath today?					low			
How often did you wake up during the night due to shortness of breath?								low
Does your stomach feel bloated?	3				low			
Have you felt dizzy this morning?						high		
Have you felt more tired today?				high				
How often did you wake up during the night due to shortness of breath?								low
Have you felt dizzy this morning?	4					no diff		
Have you felt more tired today?				high				
Have you had any shortness of breath today?					high			
How often did you wake up during the night due to shortness of breath?								no diff

Appendix table 11 and table 5.21 shows the post-hoc test results for the day activity proxy measure, there were a total of seven significant associations between the health questions

and this activity measure. There was no evidence of a pattern in activity levels that varied according to the self-reported levels of health. In the worse level of health there were an equal number of significantly higher and lower levels of day activity. The EQ-5D health question asking about usual activities that day had significantly higher activity in the level of health reporting some problems, however once again this evidence comes from only one participant. The two other EQ-5D health questions with significant associations between health and activity measures had significantly lower activity in the worst health level (table 5.21, self-care and pain). It would not be possible to unpick the different responses to poorer health without talking to the participants, as the data itself does not provide a means of interpreting behaviours.

**Table 5.21: Post-Hoc Test Results by Activity Measure - Day Activity (EQ-5D)**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Which statement best describes your own usual activities today?	1				low			
Which statement best describes your self-care today?				high				
Which statement best describes your own usual activities today?	2				high			
Which statement best describes your pain/discomfort today?						high		
Which statement best describes your self-care today?				low				
Which statement best describes your pain/discomfort today?	3					low		

### 5.7 Post-Hoc Findings by House

It was not possible to discern any patterns of activity across the health and activity measures, and therefore the next step was to examine activity patterns within individual homes. Table 5.22 shows the activity levels for house ten, broken down by health question and activity measure. As stated previously, house ten had the highest number of significant P-values. Within this house there is no one single pattern in activity levels that corresponds to health levels across all the health measures, the pattern is more complex. In general within the best level of health (1) there is mainly significantly lower activity. Within the levels of health expressing health problems (2, 3, and 4) there is mainly significantly higher activity.



**Table 5.22: Post-Hoc Test Results, House 10**

<b>Level of Health</b>	1			2			3			4		
<b>Activity Levels</b>	high	low	no diff	high	low	no diff	high	low	no diff	high	low	no diff
<b>Are your ankles or feet swollen - 1st 12 hours</b>												
Bath Night		x								x		
<b>Are your ankles or feet swollen - 2nd 12 hours</b>												
Bath Day		x								x		
Bath Night		x								x		
Night Activity		x								x		
<b>Do you have a cough?</b>												
TV Duration		x				x	x					
<b>Does your stomach feel bloated?</b>												
General Activity			x	x				x				
<b>Have you eaten well today?</b>												
Food Activity				x				x				x
<b>Have you had any shortness of breath today?</b>												
Bath Day		x								x		
General Activity					x					x		
<b>How anxious have you been today?</b>												
Bath Night		x		x							x	
Food Activity	x					x					x	
<b>How often did you wake up during the night due to shortness of breath?</b>												
Night Activity		x								x		
<b>Which statement best describes your own usual activities today?</b>												
Day Activity		x		x								
General Activity		x		x								
Grand Total	1	10	1	5	1	2	1	2		7	2	1

Table 5.23 shows the post-hoc test results for house six, this house had the second highest number of significant p-values. The pattern of activity levels is different from house ten, with mostly no significant differences in activity levels seen at the best level of health (8), or higher activity (4). The response to poorer health in health levels two, three, and four, was generally lower activity in level two, and higher activity in levels three and four. There is an interesting difference between the EQ-5D activity levels in the two houses. In house ten, better health was associated with significantly lower activity, and in house six better health was associated with significantly higher activity.

**Table 5.23: Post-Hoc Test Results, House 6**

<b>Level of Health</b>	1			2			3			4		
<b>Activity Levels</b>	high	low	no diff	high	low	no diff	high	low	no diff	high	low	no diff
<b>Did you sleep well last night? <sup>a</sup></b>												
Night Activity			x		x		x					x
<b>Have you felt more tired today?</b>												
Bath Day			x		x		x			x		
Day Activity			x		x		x			x		
Food Activity			x		x		x			x		
General Activity			x		x		x			x		
Night Activity			x		x		x			x		
<b>How anxious have you been today?</b>												
Bath Day			x		x		x					x
Night Activity			x	x				x				x
<b>Which statement best describes your anxiety/depression today?</b>												
Bath Night		x		x								
<b>Which statement best describes your self-care today?</b>												
Bath Day	x				x							
Day Activity	x				x							
Food Activity	x				x							
General Activity	x				x							
Grand Total	4	1	8	2	11		7	1		5		3

<sup>a</sup>: In this health measure, level four corresponds to best health, and level one worst health.

## **5.8 Post-hoc Findings Conclusion**

In conclusion, the post-hoc test results reveal a complex relationship between activity levels within the home and self-reported measures of health. There are a number of factors that make it difficult to interpret the findings. Firstly, the significant associations between activity and health are seen sparsely across the possible permutations of the measures and houses, for example, the maximum number of houses with significant associations between the same health and activity measure was two out of seven houses. Mostly the associations occur in only one house. If the significant associations had occurred across all the study houses it would have been possible to discern whether there were patterns in the activity levels that correspond to health states across the whole sample. This is not the case, and therefore it has to be assumed that the relationship between activity levels and health is very individual, occurring mostly in one home within the sample, and at most in two homes.

The second difficulty with interpreting the findings, is trying to understand what the descriptions of activity levels mean on a practical level. Many of the findings raise more questions than they answer, for example, if activity levels increase when poorer health is reported, why is this, and what is happening in the home? The data alone cannot answer these questions, it would therefore be necessary to go back to the participants to ask about what happens during symptom exacerbations. It would not be possible to do that with this sample of participants because the data was collected so long ago, and it is likely that the health state of these participants will have declined since the data collection because of the degenerative nature of heart failure.

The findings also raise questions about the lifestyle monitoring technology, and how accurately the home activities were recorded. There are two factors that make interpreting the sensor data difficult. Firstly, it is not possible to separate out the sensor data for participants, and thus the true relationship between activity levels and health may be masked by the activity of non-participants. Secondly, there were issues to do with the way sensors function that make it difficult to examine activity levels. As mentioned previously, the PIR sensors do not accurately measure activity levels. Both these factors make the interpretation of sensor data difficult, if not impossible.

## **5.9 Key Symptom analysis**

Consideration was given to whether symptoms in combination may be more indicative of the health state, than focusing on individual symptoms. A key symptom index of daytime breathlessness, night-time breathlessness, tiredness, and swelling was created score using the

methodology previously described (chapter 4a), which was split into three health levels according to the degree of symptoms experienced.

The table below (5.24) shows results from the analysis of variations statistical tests for the key symptom index in homes where single participants lived. The test sought to establish whether average proxy activity levels differed across the levels of health. Very few of the associations between activity and health were statistically significant. This does not necessarily mean that there is no relationship between these symptoms and the undertaking of activities in the real world, the results here may reflect shortcomings in the measures employed by the study, or the analysis that was undertaken.

**Table 5.24: Significant Variations in Activity Levels between the Activity Measures and Key Symptoms Measure – Single Homes**

Houses where people lived alone	1	4	6	10	14	15	17	P value <0.05
Bath Day	b	b	.004 <sup>a</sup>	.001 <sup>a</sup>		b		2
Bath Night	b	b	.992	.036 <sup>a</sup>		b		1
Day Nap	.225			.884	.280	b	.386	
Daytime Activity	.895	b	.041 <sup>a</sup>	.817	.226	.343	.423	1
Food Activity	.095	b	.519	.672	.280	.742	.653	
General Activity	.217	b	.112	.288	.513	.272	.128	
Night-time Activity	.018 <sup>a</sup>	b	.030 <sup>a</sup>	.057	.467	.406	.559	2
Stairs	.840	b	.252	.139	.542	.223	.480	
Total Sleep	.145	b		.454	.841	.964	.934	
TV Duration	.489	b	.201	.541	.013 <sup>a</sup>	.504	.912	1
P value <0.05	1	0	3	2	1	0	0	7

<sup>a</sup> statistically significant (P value <0.05)

<sup>b</sup> Only one level of health, or levels of health too small to perform calculations

### 5.10 Significance of stairs in heart failure

Stairs are the means of accessing the rooms on other floors in the home, and for people incapacitated in any way, they can become an impediment to the ease of movement (Hill et al 2000).

The table below shows the number significant variations in stair, hall, and landing activity across the levels of health for single occupant houses. Once again the majority of tests did not yield any significant variations in stair activity, and the few tests that were significantly different were spread inconsistently across the participants and health questions. A more fruitful approach may be to measure stair activity separately, and the duration of the journey upstairs.

**Table 5.25: Significant Variations in Activity Levels between the Hall, Stairs and Landing Activity Measure and Measures of Health/Symptoms – Single Occupant Homes**

Houses where people lived alone	1	4	6	10	14	15	17	P value <0.05
Are your ankles or feet swollen? - 1st 12 hours	b	b	b	.585	b	b	.322	
Are your ankles or feet swollen? - 2nd 12 hours	b	b	b	.173	b	b	.805	
Did you need extra pillows to sleep with last night?	b	b	b	b	b	b	b	
Did you sleep well last night?	.140	.197	.425	.627	.161	.865	.092	
Do you have a cough?	.402	b	b	.325	.233	.758	.049 <sup>a</sup>	1
Does your stomach feel bloated?	b	b	b	.966	b	b	.958	
Has your stomach felt bloated today?	b	.157	b	.500	.161	b	.443	
Have you eaten well today?	.271	b	.661	.131	.436	.000 <sup>a</sup>	.281	1
Have you felt dizzy this morning?	b	b	b	.360	.506	b	.685	
Have you felt dizzy today?	b	b	b	.705	.922	.487	.120	
Have you felt more tired today?	.529	b	.003 <sup>a</sup>	.789	.248	.179	.763	1
Have you had any shortness of breath today?	.370	b	.310	.202	.901	.476	.943	
Have you passed less urine than usual today?	.534	.113	b	.168	.268	.074	b	
Have your ankles or feet been swollen today?	b	b	b	.460	.058	b	.889	
How anxious have you been today?	.127		.129	.663	.209		.863	
How many episodes of angina have you had today?	b	b	b	b	.465	b	.467	
How often did you wake up during the night due to shortness of breath?	.959	b	b	.452	.645	b	.132	
EQ-5D visual analogue scale	.338	b	b	.461	.938	.339	.321	
Which statement best describes your anxiety/depression today?	.403	.180	.705	.513	.296	b	b	
Which statement best describes your mobility?	.874	.315	b	b	b	.852	b	
Which statement best describes your own usual activities today?	.474	.196	b	.638	b	.949	b	
Which statement best describes your pain/discomfort today?	.739	.589	.358	b	.028 <sup>a</sup>	.798	b	1
Which statement best describes your self-care today?	b	.972	.005 <sup>a</sup>	b	b	b	b	1
P value <0.05			2		1	1	1	5

<sup>a</sup> statistically significant (P value <0.05)

<sup>b</sup> Only one level of health, or levels of health too small to perform calculations

### 5.11 General Conclusion

The data analysis did not find any general patterns across the sample, and whilst significant associations between activity and health measures were found, these were very individual and the impact of health on activity levels and health measures was not consistent. The data was difficult to interpret because of this complexity, and it was therefore not possible to gain a clear picture of what happens in the home when health worsens from the data. In addition, the data analysis has therefore not provided any strong evidence for an association between activity levels within the home and health, and therefore explanations for the findings were sought.

**Table 5.8: Couples - Statistically Significant Variations by Health Question (EQ-5D and Symptoms) and Activity Measure (P-values <0.05)**

Health Question	Topic	General Activity	Day Activity	TV Duration	Night Activity	Total Sleep	Food Activity	Day Nap	Bath & Toilet Day	Bath & Toilet Night	Total
Couple - Total		21	18	15	14	13	12	12	10	9	124
Have you felt dizzy today?	Dizziness	4	3	1	1	2	2	2	1	1	17
How anxious have you been today?	Anxiety	3	1	2	2	2	1	1	1	1	14
Do you have a cough?	Cough	5	2	2	1	1			1		12
Have you passed less urine than usual today?	Urine	1	1	3	1	1	3	1	1		12
Have you felt more tired today?	Tiredness	1	2	2	2	1			2		10
Have you had any shortness of breath today?	Breathing	1	2		1	1		1	1	1	8
How many episodes of angina have you had today?	Angina	1	2	2	1			1			7
Did you sleep well last night?	Sleep	1			1		2	2		1	7
How often did you wake up during the night due to shortness of breath?	Breathing	2	1					1		1	5
Which statement best describes your own usual activities today?	Usual activities	1	1		1		1		1		5
Have you eaten well today?	Appetite			1		2				1	4
Are your ankles or feet swollen - 2nd 12 hours	Swelling		1	1				1	1		4
Which statement best describes your anxiety/depression today?	Anx./Depress.				1					2	3
EQ-5D VAS Quarter	Gen. Health				2			1			3
Have you felt dizzy this morning?	Dizziness			1		1					2
Which statement best describes your mobility?	Mobility	1	1								2
Did you need extra pillows to sleep with last night?	Pillows							1	1		2
Which statement best describes your self-care	Self-care		1				1				2

Health Question	Topic	General Activity	Day Activity	TV Duration	Night Activity	Total Sleep	Food Activity	Day Nap	Bath & Toilet Day	Bath & Toilet Night	Total
today?											
Are your ankles or feet swollen - 1st 12 hours	Swelling					1	1				2
Does your stomach feel bloated?	Bloating						1				1
Has your stomach felt bloated today?	Bloating					1					1
Which statement best describes your pain/discomfort today?	Pain									1	1
Have your ankles or feet been swollen today?	Swelling										0



**Table 5.9: Living Alone - Statistically Significant Variations by Health Question (EQ-5D and Symptoms) and Activity Measure (P-values <0.05)**

Health Question	Topic	Night Activity	Food Activity	General Activity	Day Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Total Sleep	Day Nap	Total
Single - Total		11	9	8	7	6	5	3	2	2	53
Are your ankles or feet swollen - 2nd 12 hours	Swelling	2				1	2		1		6
Have you felt more tired today?	Tiredness	2	1	1	1	1					6
How anxious have you been today?	Anxiety	1	1			1	1				4
Do you have a cough?	Cough				1			1	1	1	4
Have you felt dizzy this morning?	Dizziness	1	1	1	1						4
Which statement best describes your self-care today?	Self-care		1	1	1	1					4
Have you eaten well today?	Appetite	1	1							1	3
Which statement best describes your pain/discomfort today?	Pain		2		1						3
Did you sleep well last night?	Sleep	2	1								3
Which statement best describes your own usual activities today?	Usual activities			1	1			1			3
Have you had any shortness of breath today?	Breathing			1		1					2
How often did you wake up during the night due to shortness of breath?	Breathing	1		1							2
Have you passed less urine than usual today?	Urine			1		1					2
Which statement best describes your anxiety/depression today?	Anx./Depress.						1				1
Does your stomach feel bloated?	Bloating			1							1
Has your stomach felt bloated today?	Bloating		1								1
Have you felt dizzy today?	Dizziness							1			1
EQ-5D VAS Quarter	Gen. Health	1									1
Are your ankles or feet swollen - 1st 12 hours	Swelling						1				1

Health Question	Topic	Night Activity	Food Activity	General Activity	Day Activity	Bath & Toilet Day	Bath & Toilet Night	TV Duration	Total Sleep	Day Nap	Total
Have your ankles or feet been swollen today?	Swelling				1						1
How many episodes of angina have you had today?	Angina										0
Which statement best describes your mobility?	Mobility										0
Did you need extra pillows to sleep with last night?	Pillows										0

**Table 5.10: Statistically Significant Variations by House, Living Arrangements, and Health Question (Symptoms and EQ-5D)**

	House	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Total		
	Living Arrangements: Single=S/Couple=C	S	C	C	S	C	S	C	C	C	S	C	C	C	S	S	C	S	S	C	All
Health Question	Are your ankles or feet swollen - 1st 12 hours	0	0	2	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1	2	3
	Are your ankles or feet swollen - 2nd 12 hours	0	1	1	0	2	0	0	0	0	3	0	0	0	0	2	0	1	6	4	10
	Did you need extra pillows to sleep with last night?	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	2	2
	Did you sleep well last night?	0	0	2	0	1	1	1	2	0	0	0	0	1	0	2	0	0	3	7	10
	Do you have a cough?	3	1	2	0	0	0	3	0	2	1	0	0	1	0	0	3	0	4	12	16
	Does your stomach feel bloated?	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	1	1	2
	EQ-5D VAS Quarter	0	0	0	0	1	0	1	1	0	0	0	0	0	0	0	0	1	1	3	4
	Has your stomach felt bloated today?	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	1	2
	Have you eaten well today?	1	0	1	0	0	0	1	0	1	1	0	0	1	1	0	0	0	3	4	7
	Have you felt dizzy this morning?	0	0	0	0	1	0	0	0	0	0	0	0	1	3	0	0	1	4	2	6
	Have you felt dizzy today?	0	6	2	0	5	0	2	0	0	0	0	0	2	1	0	0	0	1	17	18
	Have you felt more tired today?	0	0	4	0	2	5	1	0	3	0	0	0	0	0	1	0	0	6	10	16
	Have you had any shortness of breath today?	0	6	1	0	1	0	0	0	0	2	0	0	0	0	0	0	0	2	8	10
	Have you passed less urine than usual today?	0	0	1	2	8	0	0	0	1	0	0	0	2	0	0	0	0	2	12	14
	Have your ankles or feet been swollen today?	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	1
	How anxious have you been today?	0	6	4	0	1	2	0	0	3	2	0	0	0	0	0	0	0	4	14	18
	How many episodes of angina have you had today?	0	0	3	0	2	0	1	0	1	0	0	0	0	0	0	0	0	0	7	7
	How often did you wake up during the night due to shortness of breath?	0	0	2	0	2	0	1	0	0	1	0	0	0	0	0	0	1	2	5	7
	Which statement best describes your anxiety/depression today?	0	1	1	0	0	1	0	0	1	0	0	0	0	0	0	0	0	1	3	4
	Which statement best describes your mobility?	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	0	0	0	2	2
Which statement best describes your own usual activities today?	0	4	0	0	0	0	1	0	0	2	0	0	0	0	1	0	0	3	5	8	

House	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Total		
Living Arrangements: Single=S/Couple=C	S	C	C	S	C	S	C	C	C	S	C	C	C	S	S	C	S	S	C	All
Which statement best describes your pain/discomfort today?	1	0	0	0	0	0	0	0	0	0	0	1	0	2	0	0	0	3	1	4
Which statement best describes your self-care today?	0	0	0	0	0	4	2	0	0	0	0	0	0	0	0	0	0	4	2	6
Grand Total	5	25	27	2	26	13	14	4	13	14	1	3	8	8	6	3	5	53	124	177

(P-values <0.05). The health question with the highest number of significant variations in activity levels for each house is marked in bold type

**Table 5.11: Statistically Significant Variations by House, Living Arrangements, Activity Indicator, and Health Topic.**

Homes	Activity Indicator	Angina	Anxiety	Anxiety/Depress.	Appetite	Bloating	Breathing	Cough	Dizziness	General Health	Mobility	Pain	Pillows	Self-care	Sleep	Swelling	Tiredness	Urine	Usual activities	Grand Total
<b>Couple</b>		7	<b>14</b>	3	4	2	<b>13</b>	12	19	3	2	<b>1</b>	2	2	7	6	10	12	5	124
3	Limited	3	4	1	1	1	3	2	2	0	0	0	0	0	2	3	4	1	0	27
5	Limited	2	1	0	0	0	3	0	6	1	0	0	0	0	1	2	2	8	0	26
2	Active	0	6	1	0	0	6	1	6	0	0	0	0	0	0	1	0	0	4	25
7	Active	1	0	0	1	0	1	3	2	1	0	0	0	2	1	0	1	0	1	14
9	Active	1	3	1	1	1	0	2	0	0	0	0	0	0	0	0	3	1	0	13
13	Active	0	0	0	1	0	0	1	3	0	0	0	0	0	1	0	0	2	0	8
8	Limited	0	0	0	0	0	0	0	0	1	1	0	0	0	2	0	0	0	0	4
12	Active	0	0	0	0	0	0	0	0	0	0	1	2	0	0	0	0	0	0	3
16	Limited	0	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	3
11	Limited	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1
<b>Single</b>		0	4	1	3	2	4	4	5	1	0	3	0	4	3	<b>8</b>	<b>6</b>	2	3	53
10	Active	0	2	0	1	1	3	1	0	0	0	0	0	0	0	4	0	0	2	14
6	Active	0	2	1	0	0	0	0	0	0	0	0	0	4	1	0	5	0	0	13
14	Active	0	0	0	1	0	0	0	4	0	0	2	0	0	0	1	0	0	0	8
15	Limited	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2	1	0	1	6
1	Limited	0	0	0	1	0	0	3	0	0	0	1	0	0	0	0	0	0	0	5
17	Active	0	0	0	0	1	1	0	1	1	0	0	0	0	0	1	0	0	0	5
4	Limited	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	2
<b>Total</b>		7	18	4	7	4	17	16	24	4	2	4	2	6	10	14	16	14	8	177

Average significant variations per house: Couples – 12.4, Singles – 7.6

**Table 5.12: Significant Variations in Activity Levels by Activity Indicator**

Houses	Significant Variations in Activity	Average
<b>Active</b>	103	11
2	25	
6	13	
7	14	
9	13	
10	14	
12	3	
13	8	
14	8	
17	5	
<b>Limited</b>	74	9
1	5	
3	27	
4	2	
5	26	
8	4	
11	1	
15	6	
16	3	
<b>Grand Total</b>	177	

**Table 5.13: Framework for Data Interpretation**

<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
Activity & Exercise	General Activities			*	Data not collected on self-reported activity Did you sleep well last night? Day activity versus total sleep.
	Sleep			*	
Age	General Activities	*			Data not collected
	Television			*	
	Sleep	*			
Alcoholism	Food	*			Data not collected
Anxiety and Depression	General Activities	*			How anxious have you been today? Which statement best describes your anxiety/depression today?
	Television		*		
	Food	*			
	Sleep	*			
	Bath & Toilet Activities	*			
Balance Problems	Bath & Toilet Activities	*			Data not collected
Bathing Difficulty	Bath & Toilet Activities	*			Data not collected
Being Housebound	Food	*			Categorisation of participants into limited activity households
Bereavement	Television			*	Data not collected
	Food	*			
	Sleep	*			
Continence Problems	Food	*			Data not collected

<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
	Bath & Toilet Activities			*	
Decline in Cognitive Function	Food	*			Data not collected
	Sleep	*			
	Bath & Toilet Activities	*			
<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
Decline in eyesight and hearing	Television			*	Data not collected, although one participant was visually impaired
	Bath & Toilet Activities	*			
Dehydration	Food	*			Data not collected
Diarrhoea or Vomiting	Bath & Toilet Activities			*	Data not collected
Difficulty with Shopping and Food Preparation	Food	*			Data not collected
Disorders Prevalent in Heart Failure	Sleep	*			Data not collected
Environmental Factors	General Activities	*			Data not collected
	Television		*		
	Bath & Toilet Activities		*		
Family Support	Food			*	Data not collected
Fatigue	Food	*			Have you felt more tired today?
Female Gender	General Activities			*	Female participants
	Sleep	*			
Females living with a	General Activities			*	Participants living as couples



<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
partner					
Financial Difficulties	Food	*			Data not collected
Food Less Palatable	Food	*			Data not collected
Getting Stuck in the Bath	Bath & Toilet Activities			*	Data not collected
Good Self Efficacy	General Activities			*	Data not collected
Good Self-Reported Health	General Activities			*	EQ-5D visual analogue scale
Higher Levels of Social Interaction	Food			*	Data not collected
	Sleep			*	
Ignoring Food & Drink Restrictions in HF	Food			*	Data not collected
<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
Illness in the Caring Partner	Food	*			Data not collected
	Sleep	*			
Inactivity	Food	*			Have you eaten well today? Did you sleep well last night?
	Sleep	*			
Loss of Appetite	Food	*			Data not collected
Nausea	Food	*			Data not collected
Nocturia	Sleep	*			Data not collected on self-reported nocturia. Bath and toilet night activities
	Bath & Toilet Activities			*	
Pain	Sleep	*			Which statement best describes your pain/discomfort

<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
					today?
Passing less urine than normal	Bath & Toilet Activities	*			Have you passed less urine than usual today?
Poor Oral Health	Food	*			Data not collected
Poor Self Efficacy	Bath & Toilet Activities	*			Data not collected
Poor Self-Reported Health	General Activities	*	*		EQ-5D visual analogue scale
	Television			*	
	Food	*			
	Sleep	*			
	Bath & Toilet Activities	*			
Prostate Problems	Bath & Toilet Activities			*	Data not collected
Side-Effects of Drugs	Food	*			Data not collected
	Sleep	*			

<b>Factor</b>	<b>Literature Review</b>	<b>Less Activity</b>	<b>More or Less</b>	<b>More Activity</b>	<b>Data Collected</b>
Social Isolation/Loneliness	General Activities	*			Data not collected
	Television			*	
	Food	*			
	Sleep	*			
Swallowing Difficulties	Food	*			Data not collected
Symptoms	General Activities	*			Are your ankles or feet swollen? Did you need extra pillows to sleep with last night? Do you have a cough? Does your stomach feel bloated? Has your stomach felt bloated today? Have you felt dizzy this morning? Have you felt dizzy today? Have you felt more tired today? Have you had any shortness of breath today? Have your ankles or feet been swollen today? How many episodes of angina have you had today? How often did you wake up during the night due to shortness of breath? EQ-5D visual analogue scale Which statement best describes your pain/discomfort today?
	Food	*			
	Sleep	*			
Transfer Difficulties	Bath & Toilet Activities	*			Data not collected
Transport	Food	*			Data not collected
Trigger Events	Food	*			Data not collected
TV Dependency	Television			*	Data not collected
Type II Diabetes	Bath & Toilet Activities			*	Data not collected
Urinary Frequency due to Diuretics	Bath & Toilet Activities			*	Have you passed less urine than usual today?
UTI	Bath & Toilet Activities			*	Data not collected
Widows feeling insecure	Sleep	*			Data not collected

**Table 5.14: Framework for the Validation of the Telecare Activity Measures**

<b>Telecare Activity Measure</b>	<b>Validation Method</b>
Bath and Toilet Day Activity	Have you passed less urine than usual today? Which statement best describes your self-care today?
Bath and Toilet Night Activity	
Day Activity	Which statement best describes your own usual activities today? Which statement best describes your mobility?
Day Nap	Have you felt more tired today?
Food Activity	Have you eaten well today?
General Activity	Which statement best describes your own usual activities today? Which statement best describes your mobility?
Night Activity	Did you sleep well last night? How often did you wake up during the night due to shortness of breath?
TV Duration	
Total Sleep	Did you sleep well last night? How often did you wake up during the night due to shortness of breath?

## **Chapter 6: Interview Findings**

### **6.1 Introduction**

This chapter presents the analysis of the interviews, using the themes as a guide to describe the issues pertinent to activity within the context of heart failure (King 2004). Higher level themes will be explained, along with elements of these thought necessary to elucidate the experience of daily activity with a long-term condition. The Integrative theme will also be described. The integrative theme in template analysis is identified where a theme is found to pervade all the themes, and in order to avoid repetition in the template an integrative theme is described (King 2012). The integrative theme in this analysis was the level of intrusion from symptoms, and this will be explored later in the chapter.

The chapter will focus on key areas that illuminate the research questions, and these are as follows:-

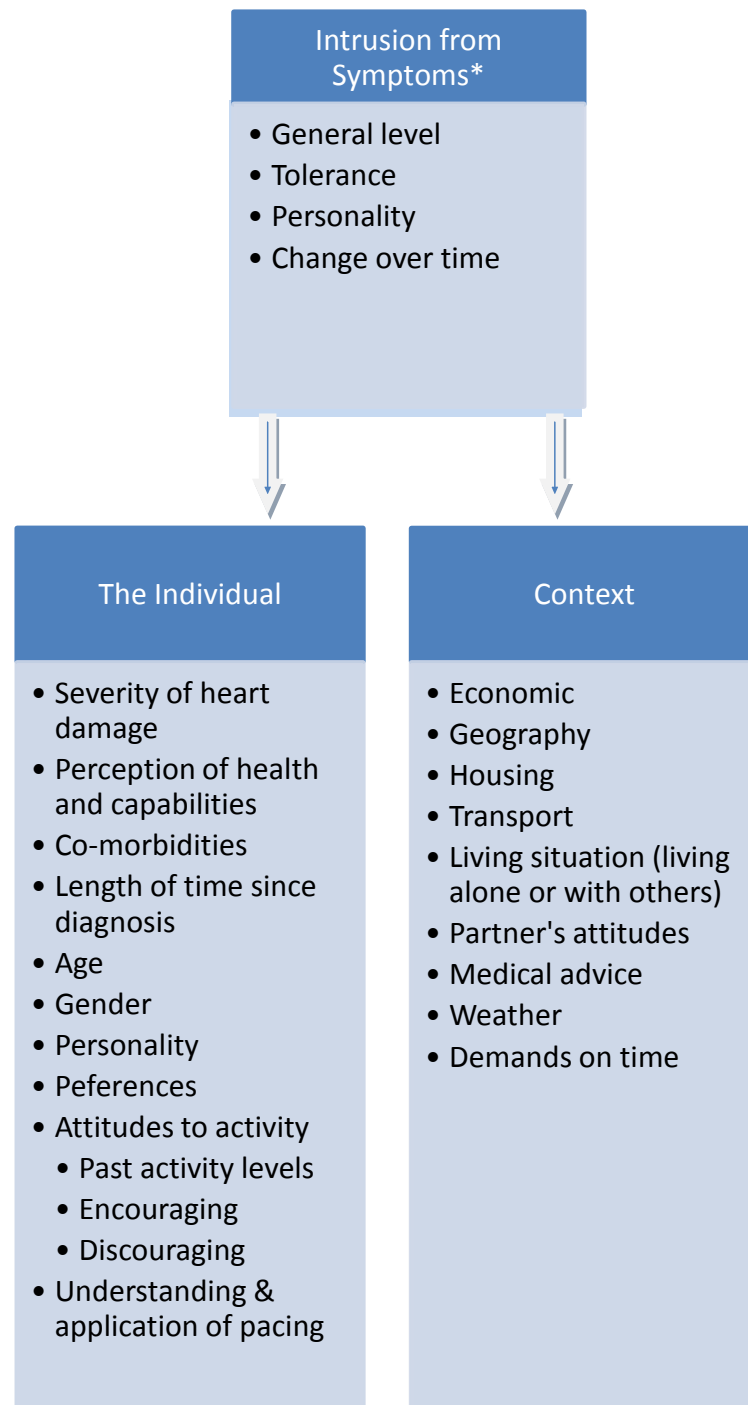
1. The individual situation of participants
2. Changes in activity according to health

Consideration will also be given to the impact of ill health on subsets of the sample, including those relatively young and old, participants experiencing mild or severe heart failure, respondents living alone, and the length of time living with heart failure.

### **6.2 The Individual Situation of Participants**

This section sets out to demonstrate how activity is shaped by the individual circumstances shown on the following diagram (figure 6.1). The implications of this for Lifestyle Monitoring will be discussed in the technology chapter.

**Figure 6.1: Diagram of the Individual Situation of Participants**



\*Integrative theme

### **6.3 The Individual**

The participants in the study were very diverse, with the following factors exemplifying this difference:-

### 6.3.1 Severity of Heart Failure

The degree of heart damage broadly shaped activity levels in participants, with those with little damage able to resume their life and activities; whilst those with significant damage facing a new normality:-

*It cost me my life because you are not living it, you are existing. That is something that I feel every day. You haven't got a life; it is everything that you do (Dawn B/S-L-Y-P-B/S)<sup>1</sup>*

A feature of this new way of living was that health takes a central role in life, which reflects the vulnerable position of those with a damaged heart:-

*And his health is paramount. That is the one thing that we know that he has got this problem and whilst we don't want... what's the word? We don't want to make him an invalid is what I am trying to say. But his health is paramount (Barbara)*

Within the sample, participants had different levels of and types of heart damage, and therefore there was not one single experience of heart failure, as evidenced by a comment by the wife of a participant with severe heart failure:-

*...this heart manual that they like give to you in hospital, but they give it to everybody, so it is just a generalisation. And like everybody is different, or got different kinds of problems... (Nancy)*

Thus it is apparent that heart failure impacts on people in very individual ways. In addition as heart failure is a progressive condition, the functioning the heart declines over time, and with it the capabilities of the individual:-

*... then err as you've done things you've known that a few months ago I could do things that, I can't do now 'cos me heart failure is getting worse (Terry B/S-L-O-A-B/S)*

### 6.3.2 Perception of Health and Capabilities

Participants were asked about their perceptions of health and capability, as these also formed a backdrop to daily activity, with positive views potentially encouraging activity, and negative views discouraging. An individual's perception of their health and capabilities does not

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<sup>1</sup> Participant characteristics were coded as follows (1-2-3-4-5):-

1 = Severity of heart failure, coded as: M/M (mild/moderate), or B/S (bad/severe)

2 = Length of time since diagnosis, coded as : R (recently), or L (long ago)

3 = Age-group, coded as: Y (younger - between 50 and 60 years), or O (older - between 70 and 80 years)

4 = Living arrangements, coded as: A (alone), or P (with partner)

5 = Co-morbidities, coded as: N/M (none/moderate), or B/S (bad/severe)

necessarily match the level of heart functioning, as it could be better or worse. The key measure for health came from the ability to undertake activities, and some of those with heart damage were able to set aside the heart and focus on 'doing.' The following quote demonstrates this mismatch between health and activity vividly, with Alastair looking beyond the heart - much to his wife's frustration:-

*[Silence] Err.. I don't class myself as being bad, poorly (Alastair B/S-L-Y-P-B/S)*

*This is the problem (Alice)*

*Ill. Whatever you want the classification to be. I don't. Well it is just me, I try not to see that part, I think well I am up and running, I am ok (Alistair)*

*But that is your problem, but then you start doing things (Alice)*

The ability to look beyond the heart and define health through activity is only possible where the heart is not too badly damaged. In participants with severe heart failure, the inability to undertake activities reinforced the poor health state, and led to feelings of inadequacy and hopelessness:-

*You get err, you get to the feeling where err the things that you can do get less and less and less. And err what you can do takes more and more effort, you just feel inadequate.*

*You know what I mean, just inadequate that's it, I think that's it (Graham B/S-L-O-P-B/S)*

Feeling of inadequacy can also come from an impression that members of the public are making judgements about the person with heart failure because of their inability to undertake activities, especially as heart problems are not visible from the outside. Participants talked about things like being unable to pick up money that was dropped on the floor, or help older people reach something from a high shelf.

*... she dropped her money out of her purse and it sounded quite a lot of change. Now this is where it feels awful because I can't, I know I wouldn't be able to get up and go and pick it up for her, otherwise. ...And people looking at you, you feel as though people are looking at you like... (Nick B/S-R-Y-P-B/S)*

This inability to do what they had done previously with no thought made participants feel embarrassed and marked out as different, and in turn this also impacted negatively on the sense of self, and perceptions of health and well-being.



In contrast we might expect that participants with mild symptoms would have a positive view of health and capabilities. In general this was true, with participants able to establish their new level of health through activity:-

*...I have started doing this walking group on a Thursday which is five to seven miles but that's great, I just feel great and I realise I can do things. Oh once I could walk Cam Lane from home then I knew I was ok (Janice M/M-R-Y-P-B/S)*

One participant perceived playing in a cricket match as his test of health, and the relief and jubilation was evident from his account of the game, and a renewed feeling of confidence in his physical abilities:-

*A big weight off my mind. Just like all the weight was lifted off. Carry on – there is life after (Ken M/M-R-Y-P-N/M)*  
*It was like a big health boost, it's not here it's off, it's off, oh definitely mm definitely (Karen)*

The need to check the state of health through activity tests was an on-going process, with participants describing how they checked after a period of ill health, or in the case of one participant during a bad day:-

*...I want to prove to myself that I can still do it, so I might still walk down to school and back, even though common sense might tell you that is not the brightest thing to be doing. Because it is just under two miles, but it is up hill going back (Janice M/M-R-Y-P-B/S)*

When participants described their experience of an exacerbation of heart failure, one of the first things they noticed was a difficulty undertaking everyday activities, typically climbing up the stairs:-

*Err well I first noticed it at work when I was climbing some stairs err err I ran out of breath, but I just put that down to my age and being unfit you know, and then gradually it got worse, a little bit worse (Max B/S-R-Y-P-N/M)*

Once the condition has stabilised the same activity may be used as a health check:-

*...and I remember sort of monitoring when I came up these stairs at home (Janice M/M-R-Y-P-B/S)*

Health beliefs also led to a reduction in activity, which from the outside appeared inconsistent with the level of heart damage. Christopher for example had come to believe that he was less capable of activity despite having mild symptoms:-

*Do you feel as confident in your ability to do things as you ever did? (Interviewer)*

*Err no I probably feel. I don't know whether you can smell but we have just had all the ground floor redecorated. At one time I would have done myself, but err we have had professional decorators to do it. You know I have eased off a little bit, you know I am 73 so I am starting to take things a little bit easy, I don't really know why because I have not really had any symptoms (Christopher M/M-R-O-P-N/M)*

### **6.3.3 Co-morbidities**

The majority of the participants had co-morbidities, and the impact of these on their ability to undertake activities varied from no impact, to potentially life threatening conditions worse than heart failure:-

*...and then I started with all these other things. The first one was having a tumour in my bladder that wasn't very pleasant, erm then they kept a close eye on me, on that found silly things in my blood that shouldn't be there, turned out to be completely harmless and no problem. But while they are looking they say, anything else, and you turn out to be anaemic, err we need to find out why. So let's go for more investigations, erm which is when cameras went to everywhere they weren't designed to, then they found a hiatus hernia, they found all these polyps in my bowel, and it has just been a continual battle with health. That and it has depressed me, I don't want to go and see the Doctor because what does he want to have a look at now, yes it gets you like that. Erm to be perfectly honest my heart failure has not been the worst thing, it has been these other things that have cropped up. I think I have learnt to manage my heart failure... (Henry M/M-L-Y-P-B/S)*

Co-morbidities had similar impacts on activities to heart failure, for example, leading participants to give-up activities; causing difficulty undertaking activities, such as, walking on a level and uphill, climbing stairs, sleeping, eating, or in the case of two participants with incontinence difficulty leaving the home. In common with heart failure, some co-morbidities had flare-ups causing participants to be incapacitated. The fluctuating nature of some co-morbidities caused anxiety in some participants, which made everyday life difficult. In addition, co-morbidities can make dealing with heart failure more challenging, with

participants describing the difficulty in separating out where symptoms came from, and sometimes experiencing conflicts of interest between the conditions

#### **6.3.4 Length of Time since Diagnosis**

The duration of time since diagnosis with heart failure varied, with half the sample diagnosed within the last few years, and the remainder for some years. Those recently diagnosed appeared less sure of what activities they are capable of, and a period of trial and error typically followed. For participants who have greater experience of living with heart failure, an adaptation of lifestyle and expectations of activity seem to take place, generally resulting in more of an acceptance of limitations:-

*Because I have adjusted my life over the last seven years, or eleven years all together since the first attack, it has become part of my life anyway. Erm you for instance you wouldn't want to go out and try to beat Linford Christie in the hundred yard dash because you know that you wouldn't do it. And in the same way I know that I can't do things that I used to be able to do, so I never think about them. I have put them out of my mind altogether, and wouldn't think about trying to do them (Brian B/S-L-O-P-B/S)*

#### **6.3.5 Age**

Participants varied in age (see table 4B.2) and this impacted on the way they lived.

Participants commonly identified age as a limitation to activity, with the older participants acknowledging that they could no longer expect to do the things that they had once done:-

*But at 85 what can you expect...? (Terry B/S-L-O-A-B/S)*

For the older participants age was used as means of letting activities go, in the sense that it no longer matters that they cannot do an activity because nobody of their age can. Age was therefore used as a means of feeling comfortable with activity levels, as a justification for not doing things. For younger participants there was a mismatch between age and health, resulting in a feeling of embarrassment that they cannot do activities that someone of their age would be expected to do:-

*...I will see old women and they will go, can you do this for me love? [cough] And I will go, no sorry I can't. You know because they will look at me like you are fit, and they are fitter than me. My mum's 85, and I mean she is fitter than me, for going round doing stuff, you know. I feel embarrassed. I went to rehab and all old ones were walking a lot longer than me and stuff (Dawn B/S-L-Y-P-B/S)*

There is therefore a perceived pressure to conform to age appropriate activities and activity levels.

### **6.3.6 Gender**

Another influence on activities based on societal expectations and traditions are gender roles, which were present in the lives of participants. Some male participants did little in the home:-

*Well I say he don't do nothing domestically (Karen talking about Ken)*

In some homes the male role was about dealing with DIY and gardening, within the limitations of health; but one male participant described how since retirement he now took on the hoovering because his wife was out at work. Traditional roles were also evident in female participants, with cooking and cleaning undertaken sometimes in spite of ill health:-

*Yes, yes because I am not just looking after myself. I wouldn't do anything like as elaborate if I was on my own, and just having a restful day, and I do for you know (William) he is a meat and two veg, type of man [laughter] (Willow M/M-R-O-P-N/M)*

Although another female participant described how she would ask her husband to cook a microwave meal if she was unwell, or make food in advance if she anticipated that she would be too tired to cook. Despite all the variations in the situations of participants it was evident that gender roles did shape activity, and when health disrupted these roles it caused feelings of inadequacy:-

*So then there are a lot of things that Alice does because I shouldn't. And I HATE that (Alistair B/S-L-Y-P-B/S)*

### **6.3.7 Personality**

It was evident that the personality type of participants had an impact on activity, with sociable participants enjoying membership of clubs, a wide social life, and general more opportunities to engage in activity. In contrast more solitary participants were more selective about social activities:-

#### **Sociable**

*I still go to the heart rehab gym in Barnsley, the [name of gym] and because Mark's wife Maria has her hair done regularly at the [name of place] once we have left there, we go there and meet for coffee and a chat (Alistair B/S-L-Y-P-B/S)*

## **Solitary**

*Well I tried mixing, I went down to the [heart failure support group], but I thought it was a bit childish what was going on there, to say we were all pensioners. ...I'm sorry I'm a right misery aren't I? (Ian M/M-R-O-A-N/M)*

The issue of loneliness was mentioned by some participants. This generally happened as a consequence of ill health limiting social opportunities, as life became centred round the home. For some this was a spur to attending a social activity where they felt comfortable, but others seemed more lost and without direction by the loss of friendships, and in the case of one participant the loss of his wife:-

*Well we did everything together you see. I mean I have friends away down the road, ...but when your friends are all married it's not the same you know. ...I don't even go to my daughter's when I think they have got somebody else coming... (Ian M/M-R-O-A-N/M)*

Participants with a positive outlook on life spoke about a drive and determination to undertake activities, and this state of mind was clearly more likely to be linked with action rather than inertia:-

*You have got to be positive and have a go even if you are not a sports person but to say I **am** going to do that (Ken M/M-R-Y-P-N/M)*

A positive 'can-do' outlook enabled some participants to look beyond their health, and get on regardless; and such individuals seemed able to forget the bad days that arose out of overdoing things.

However although clearly outlook was fixed to an extent as part of the essence of self, during health deteriorations a positive outlook can be challenged. Ill health distorted participants' disposition, typically causing a turning inwards and irritation with others; for participants with depression this desire to be alone and not participate was stronger, and the combination of heart failure and depression caused feelings of inadequacy. After a period of poor health, outlook was boosted, and with this the desire to be more active:-

*I have done so much since I recovered, it is like a new lease of life! (Willow M/M-R-O-P-N/M)*

Personality and outlook therefore varied in the sample, and within the individual there was a degree of fluidity in outlook in response to challenges from health and life events. The personality of participants also shaped their attitude to activity, with some more determined than others.

### 6.3.8 Preferences

Participants expressed strong views about choices they made about activities, if, when, and how they were undertaken. Views were expressed typically about television and gardening, but obviously preferences influence the choice of many activities. In terms of television, for example, some participants were selective about what television programmes they would watch, others had the television on all day as background noise, and another participant spoke about stopping activities to watch a favourite programme :-

*I never saw the end one [of World at War]! And then they repeated them during the day at four o'clock. Oh what a series that was, Robert Wagner! (Max B/S-R-Y-P-N/M)*  
*The world stopped for that (Megan)*

Others avoided television, or were indifferent to it.

A similar range of views was expressed about gardening, with some loving it, and others avoiding it:-

*Yeah I do it myself, I don't want to I hate it. Well the lawn should have been cut, but because it rained I clapped my hands, I don't want to do it you see (Ian M/M-R-O-A-N/M)*

Ideas were also expressed about activities that were important to the individual to maintain standards. For one participant personal hygiene was stated as important; and for another a priority was to keep his house clean, and he would ask his friend to tip the chair in order to clean underneath:-

*...yeah, I've always, you know, liked to be clean and tidy (Terry B/S-L-O-A-B/S)*

Irritation was expressed when health prevented the upkeep of standards:-

*So I can't bend over in the garden now cos when I stand up I fall over backwards. It is shown in the garden especially in the surrounding, I mean I have got weeds out here that I would normally never have you know, I would get rid of them but as soon as I start*

*bending down. I generally stop inside because when I go out I see what a state it is and think well I would never have let it get in that state (Eric B/S-L-Y-P-B/S)*

Participants also had preferences about the type of hobbies they engaged in, with some preferring outdoor activities, such as, walking, golf, and cricket, and others indoor hobbies, such as, going on the computer, puzzles, and watching television. These hobbies (shaped by preference, past experience, and physical ability) have an important role in setting customary activity levels. Hobbies were a great source pleasure, a means of stepping away from worries, and a means of self expression. Those with a passion for their hobby, fought hard to maintain their involvement in the activity; but in time some found they were no longer able to undertake more physical hobbies, in spite of preferences for them:-

*Aye, it's not much fun, it isn't cos because you start right at the beginning and they take things off you one bit at a time. All your hobbies go one at a time 'til you are left here with your telly (Graham B/S-L-O-P-B/S)*

### **6.3.9 Attitudes to Activity**

Attitudes to activity in the sample also differed, and these ideas shaped the approach to current activity. This factor is explored in greater detail than other factors, as this reflects the apparent importance of this factor in influencing activity.

#### **a) Past Activity Levels**

The impact of past activity on current activity was acknowledged by the some, especially in male participants who had worked hard, often at strenuous jobs; and others that had played sport all their lives. The influence of this backdrop on attitudes to current activity is summed up by the following quote:-

*If you've been active all your life and then you'll try and stay active when you've got heart trouble (Stuart M/M-L-O-P-N/M)*

#### **b) Attitudes Encouraging Activity**

Participants spoke about the gap between mind and body, whereby the mind forgets the limitation of the body and the urge to be active is still there:-

*...my head isn't compatible with my heart. My head still thinks I can do things. It's like if somebody says you do so and so, oh yes of course I can. It is like my head doesn't want to*

*accept it. It is like they are two different entities; they are not at all in unison (Dawn B/S-L-Y-P-B/S)*

This disconnect between mind and body created the temptation to try and do things which may be beyond the capability of the heart. In addition to this, a desire to try and carry on as normal, also pushed some participants to try and keep up activity levels:-

*And half the time I am trying to pretend I am not ill, not deliberately, but it is like I want to go on as normal (Janice M/M-R-Y-P-B/S)*

Part of this desire to live normally came from a desire not to be defined by the long-term condition, or as one participant said, "I don't want to become Janice [health condition] Smith." This desire to continue as normal led to participants not wanting to acknowledge limitations, and this kept activity levels up. Brian, for example, walked the longer distance from the ordinary car-park rather than apply for a disabled parking permit; and Janice about the reluctance to cancel things:-

*Erm cancel things If I have got any sense, usually I drag myself round doing them. Erm I find it difficult to admit that I need to change what I do (M/M-R-Y-P-B/S)*

The most extreme example of carrying on as normal came from a participant who experienced an exacerbation of heart failure, but still carried on with his routine:-

*I always remember what the doctor said to me that Thursday night when I went to see him, he said you are not working Mr Smith are you? Well I have been to the gym this morning, I have been to work all day, I have just had a shower and I have run down here. He said you could have collapsed and died, this was the cardiologist (Larry M/M-R-Y-P-N/M)*

This desire for normality led to some participants putting on a front in public, as they did not want others notice the 'abnormal' changes in behaviour brought about by heart failure. This need to conform to perceptions of normality was described typically by younger participants:-

*I'm terrible and I hide it from people as well. If I'm say, if I'm out, and I'll see people I will breathe different so they won't see that I'm having trouble. Breathing or I'll go sit or I'll do things so I'll look normal even though I feel like I could collapse at any second, to put on a front, I don't like people seeing me (Dawn B/S-L-Y-P-B/S)*



In a variety of ways, therefore, the need for normality has the potential to increase activity levels in individuals with heart failure; although this is tempered by the degree of damage to the heart.

Some participants recognised the benefits of activity, talking in positive terms about keeping active and exercising, and these ideas encouraged activity. Some had always been active, but the diagnosis of heart failure had increased the desire to be active:-

*...I probably consciously get more exercise (Janice M/M-R-Y-P-B/S)*

Activity was perceived as a means of getting the best out of a damaged body, a means of taking control:-

*...you reach a level [of activity at the gym] and we're now maintaining that level, but you can't cure yourself there is no cure for what we've got, but... you get the best out of your condition you possibly can (Stuart M/M-L-O-P-N/M)*

These advocates of activity spoke passionately about the value of activity, and were also critical of others that they perceived were letting themselves down by being couch potatoes. This idea that inactivity is bad was seen in participants with all levels of heart failure, with inactivity associated with laziness, letting yourself go, and a boring life. The strength of this idea was illustrated by the reluctance of some participants to reduce activity on a bad day:-

*...I suppose I feel quite guilty about not doing stuff on bad days as well. And I know that is completely illogical but I suppose you are trained to get on with things aren't you... (Janice M/M-R-Y-P-B/S)*

The flip side of this idea was that activity was associated with a sense of achievement, of getting things done; and this was acknowledged by participants and was seen as a spur to activity. The scale of activity varied, participants described taking part in a cricket match, and another hanging out the washing; but the sense of achievement was the same.

*A miracle this week I've put some bits on line just outside. I've had trolley like to hold and things, you know, bit scared of falling, but I thought well I think I've achieved something this week (Olivia B/S-L-O-A-B/S)*

Participants generally preferred to be active, to be doing, to be achieving. The contrast between a bad day doing nothing and a day of achieving things was illustrated by a partner's comment:-

*You feel like you have achieved things don't you? (Megan)*

*Err yes (Max B/S-R-Y-P-N/M)*

*Like when you have had a bad day and I come in and you have said I have not done a thing today, I have not; whereas another day it will be, look at what I have done, you know and that. There is that difference there (Megan)*

The impact of activity on feelings of well-being was also spoken about, and activity was also perceived as improving mood:-

*I think the walking gives me a sense of achievement, sense of satisfaction, sense of well-being, sense of returning to a level of health I didn't actually expect to return to (Janice M/M-R-Y-P-B/S)*

### **c) Attitudes Discouraging Activity**

There were also attitudes that discouraged activity.

Some participants talked about altering their attitudes to risk after their health scares, and no longer undertaking activities they perceived as risky. For Stuart, who had a bad fall on some stairs whilst in a remote holiday cottage, stairs were perceived as risky and something to avoid. Other activities were perceived as risky only when health was uncertain, for example, driving was avoided as too risky when participants were feeling unwell. This labelling of some activities as risky was a new thing that happened as a result of a change in health, and is summed up by Janice who used a fair ground ride to illustrate her change in attitude:-

*Things like that, oh those big playground things they had one of those at half-term outside John Lewis when you suddenly drop. I think well, why bother! You know you can do that in intensive care [laughter]. So I think my attitude to risk has changed... (M/M-R-Y-P-B/S)*

Activity levels were also reduced by a loss of will to undertake activities. This loss of will happened not necessarily because of health, as illustrated by the following quote:-

*I get my daily paper from Tesco, which is a ten minute walk away. And I always used to walk on in the morning and back, but I have started using the car for some reason I don't know why (Christopher M/M-R-O-P-N/M)*

Another participant described how after her health scare she reassessed her activities and came to realise that some things she had been doing were no longer enjoyable, and so stopped doing them. Her friend with a life threatening condition had also experienced this reassessment of activities.

The loss of will to undertake activities was linked to health, with participants giving up activities when they caused pain or fear; and thus the pleasure from undertaking the activity was removed, or the consequences in undertaking the activity outweighed the benefit. The heart failure symptoms Eric experienced when undertaking activities round the house and garden led to a loss of will to do things:-

*I try and get something done. I know it is a pun, but my hearts not really in it, if you know what I mean [laughter]. The drives not there anymore, I just think it's got to be done, let's get it done, and I'll do it for ten minutes and then [big exhale of breath which sounds quite despondent]. Then I'll think, I've sat down, I shouldn't have sat down, I've got to sit down (Eric B/S-L-Y-P-B/S)*

For others there was a loss of the will to undertake specific activities, due to unpleasant experiences. Willow suffered an exacerbation of heart failure and despite enjoying a new lease of life after recovery she did not walk as much as she had before the flare-up of symptoms:-

*...err I don't walk very much these days, because of the bad experiences I had when I was just so breathless (Willow M/M-R-O-P-N/M)*

The end result of this loss of will to undertake activities was a state where people with severe heart failure become observers, rather than participants in activity. This was the experience of Nick who had reached a point where he watched others, because trying to do things resulted in a struggle for breath:-

*Err because like I think why should I go, and do someat to knock myself up, when I feel great now [sitting in the chair]. And I know why I am feeling great it is because I am sat here doing nothing. Do you know what I mean so like, I am feeling great, why spoil that?*

*Now I know you might not be doing ... yourself any favours because you need exercise and that, but exercise makes me feel worse anyway (Nick B/S-R-Y-P-B/S)*

This can process of becoming an observer can happen over a period of time as health declines, or suddenly with a catastrophic assault on health.

Attitudes clearly influenced the level of activity in participants. Some attitudes were clearly linked to the severity of heart failure, with those with severe symptoms, for example, more likely to experience of loss of will to undertake activity. However the attitudes were not shaped by just severity, and the process was complex in the sense that the same person may have attitudes which work both for and against activity, and attitudes may change over time.

### **6.3.10 Understanding & Application of Pacing**

Energy limitations varied across the sample, and the ability to manage this resource via pacing also varied. Those who understood and applied pacing used it to facilitate the undertaking of activities:-

*...it is like having a battery that doesn't have as many cells as someone else's battery. You have got a certain amount of energy and that energy will allow you to do so much work erm ...I have sort of trained myself to know what my capabilities are within that energy field... we would have done [tourist attraction] in a day, now we tend to split it up into sections and aim to do that part of it, then we try and do a little bit of it. So we do monitor or limit, I think, what we are going to do... (Brian B/S-L-O-P-B/S)*

Pacing typically involved not being over ambitious in the choice of task; breaking the task into sections; stopping and resting whilst undertaking the activity; and going at a comfortable pace:-

*...the way what I doing sort of fell into little sections and so right ... when I've finished this section I'll just go and sit in the chair for five minutes, then I'll get on with the next section and that seems to work. Took me a long time to realise that (Roland M/M-R-O-P-B/S)*

Another method of conserving energy utilised commonly by those with symptoms impacting on activity, was to sit to undertake the task, "when starting a job adopt the McDonald position, that's sitting, seated. Do everything seated if you can. And then you get a longer day then" (Graham B/S-L-O-P-B/S). In addition, one participant talked about dividing his activity across days:-

*...You can't go to town. We can't say we're going to do spring cleaning and go through whole house and currently we're trying to weed out back ...and I'm going to tackle that gradually perhaps a couple of weeds a day you know... (Stuart M/M-L-O-P-N/M)*

However not all participants applied these methods, either because they had not learnt how to, or because they were tempted to overdo things. Descriptions of overdoing activities typically included the verb 'pushing,' and the idea that nothing would be done if you did not push yourself sometimes. A day of overactivity happened when participants felt more energetic, and carried on going longer than usual:-

*... a good day I can go all day without stopping, you know. Just pottering about in the garden, or go for nine holes in the morning, pottering about in the garden in the afternoon; the days not long enough, you know, I could do with some more day light (Max B/S-R-Y-P-N/M)*

Such overactivity came with a cost, participants talked about suffering for their activity, either later that day, the following day, or even the day after. Participants paid the price for their overactivity with a bad day, or days, where they felt lethargic and generally did nothing:-

*... sometimes I will just think you were really stupid you really shouldn't have done that, whatever it might be and then I will just go and lay down. Sometimes it can take me a few days to get over it, if I have really pushed my luck (Dawn B/S-L-Y-P-B/S)*

Pacing was a difficult art to learn, learnt over time after suffering because of overactivity. However even those that knew the consequences were still tempted, with some more than others.

## **6.4 Context**

The situations in which participants lived were very different, and the factors making up the individual context acted to either encourage or inhibit activity. These factors are described in the following section.

### **6.4.1 Economic**

Whilst not mentioned by all participants money has the potential to impact on activities.

The financial situation of participants varied. Those with a comfortable income were able to choose from a wider range of activities, and were freer to make adaptations to the home which facilitated activity. However affluence can bring its own worries, with one participant

having difficulty sleeping because of investment worries. In contrast, other participants living on smaller incomes had to think carefully about how to spend their money: participants mentioned limiting eating out, delaying household repairs, and difficulties travelling abroad because of the cost of insurance. The cost of paying for household jobs was also mentioned. Participants who had had to give up work due to ill health had to learn to live with a reduced income, and the altered financial state reinforced their sense of loss, both in terms of health and opportunities.

#### **6.4.2 Geography**

Landscape was mentioned commonly as an inhibitor of activity. Barnsley is a hilly place, and due to breathlessness, walking can become a challenge:-

*... anywhere you go from here* (Barbara)

*Is up hill* (Brian B/S-L-O-P-B/S)

*Into town. It is hill, hill, hill* (Barbara)

When participants felt off colour the hilly terrain put them off going out, in a way that may not have happened in a flatter geographical area.

Participants spoke about choosing where to go out based on geography, with flat terrain preferred and hills avoided; the availability of toilets and seats was also a factor in decisions about the location of activity. Those with more severe heart failure had to plan activity around geography, only going to places which did not challenge the heart; whereas those with mild heart failure were freer to go where they chose. The impact of geography on activity varied over time, with participants describing how they were very restricted during flare-ups of symptoms; and more liberated on recovery.

#### **6.4.3 Housing**

The housing of participants acted as a facilitator or inhibitor of activity, with those living in adapted bungalows much freer in their activities than those in a house lacking adaptations. Housing varied across the sample. The impact of the house as a barrier to activity was vividly described by a participant with severe heart failure on a waiting list for a wet room conversion; the current setup of the shower over the bath was incredibly exerting, and thus undertaken only when he felt well enough, and then with great reluctance. The stairs were another key barrier to activity, with those with severe symptoms often circumventing the obstacle by the use of a stair lift, or living downstairs. During exacerbation of symptoms, the relationship with the stairs altered, and this physical barrier became a greater challenge.

#### 6.4.4 Transport

The ability to travel varied in participants, with some able to walk freely and others actively avoiding it because of symptoms. Those forced to walk further than they were comfortable with found it stressful, and thus avoided those situations. Participants with more advanced heart failure relied on the car to facilitate activity, but whilst this enabled them to get around they still had to consider where to park to avoid having to walk distances and uphill.

Participants described having to go back home if they could not find a suitable parking space. A participant with a blue disk allowing him to park in disabled spaces, describing it as “Manna from heaven” (Henry M/M-L-Y-P-B/S), as he no longer had to walk uncomfortable distances.

The means of transportation available to participants varied: many had cars; one used taxis; another had a camper van and would go off for days when he felt well enough; but another’s were more restricted relying on family and friends to take them out. At times participants avoided travel, when symptoms made it difficult or uncomfortable, or it felt too risky, eg, participants did not risk driving if they felt unwell. At other times driving provided a source of freedom, and a means to get away from home and a change of scene, and as such it was highly valued.

#### 6.4.5 Living Alone

The living arrangements of participants varied, with those living with partners enjoying support, care, and company; and greater opportunities for activity from doing things together, and joining in with partners’ interests. Participants living alone lacked this ready source of support, although the degree of being alone varied. One participant spent most days with his partner; another with family support had asked them to step back because she valued her independence; whilst a third felt the loss of his wife keenly and felt very much alone despite having family. Only one participant was truly alone, lacking family and having fewer friends as they died off over the years. For this participant activity was shaped by living alone with a long-term condition, and age added a vulnerability to his position:-

*I walked up there and then I felt terribly dizzy had to go and sit up in the street...  
fortunately there was one [a seat] I sat down there until I felt confident enough to go  
into a cafe and have a coffee and that settled me down a bit. But you’re on your own  
(Terry B/S-L-O-A-B/S)*

Terry acknowledged that nobody generally came to his home, and since the death of his friend who used to check up on him he had to rely on himself. During periods of ill-health his

activities were directed towards keeping himself safe, not using the cooker, sitting quietly until he felt better, and not showering because he once fell in the shower. During these times he was very constrained in his activities, very much aware that one slip and he would be in trouble.

#### **6.4.6 Living with Others**

Three quarters of the sample lived with a partner, but again the situation within these families varied greatly. Some participants still worked, and thus family life was centred round evenings and weekends. Others were retired, but their partners' worked, and thus they were alone during the day. Older couples were both retired, and thus there was more scope for joint activities. The size of families also varied, with some participants having children who varied in age from school children to adults. Those with younger children tended to be still involved in helping their children, but in older participants with severe symptoms the relationship had changed so that the children or extended family supported the participant.

For participants living with partners with a long term condition there were long lasting changes to routine which arose out of a commitment to care and support, as Stuart said:-

*...I run my life by Susan's life, you know, if she's having a bad day I just relax. I don't sort of go off and do things (M/M-L-O-P-N/M)*

Participants talked about the impact on their everyday activities, which ranged from: slowing down to keep pace with their partner; adopting a healthy eating diet; building a bathing and toileting routine around medical requirements; to never going far from their partner. The wives of two participants were wheelchair users and the participants spoke about pushing the wheelchairs, and having to shape where they went because of the chair.

Illness within the family or couple can however alter activities significantly, participants with heart failure talked about changing what they would normally do to respond to the onset of illness in their partner:-

*No we were in Sunday because I was made up with cold (Alice)*

*...while she were in hospital I were doing washing, you know, ... I were taking her clean underwear everyday un-ironed but at least it were clean and it were aired. Taking it next day... (Stuart M/M-L-O-P-N/M)*



#### 6.4.7 Partner's attitudes

The partners of those with heart failure formed ideas about safe levels of activity in their spouse. Such attitudes were shaped most often by witnessing the collapse of their partner, typically in a very dramatic and memorable manner. The fear and worry created by such experiences made the partners feel protective towards their spouse, and they would try to keep their partner safe by limiting their activity. Partners would monitor their spouse's activity levels and intervene if they thought they were overdoing things:-

*I weren't chopping a tree, I was scraping (Ken M/M-R-Y-P-N/M)*

*Well whatever you were doing I could hear it (Karen)*

*Exposing roots (Ken)*

*You know, and I thought what is he doing? So I came out and I could see he were straining and I said have a minute... (Karen)*

In addition to this, partners were also looking for signs of a decline in health, as Nancy explained: "...You see I am thinking is he having another heart attack, what are his symptoms?" They were always on the alert checking the appearance of their partner (especially the face and the eyes), and looked for any changes in activity that might indicate a decline:-

*You get up then don't you? (Alice)*

*And then I get up (Alistair B/S-L-Y-P-B/S)*

*And I am saying, "are you alright, are you alright?" (Alice)*

For Nancy whose partner has severe heart failure, this monitoring of health went on when even when she had left the house, as she would text her husband to check that he was still alright. She was reluctant to leave her partner alone.

This monitoring of activity was seen both in the partners of those newly diagnosed with heart failure, and in those who had lived with the condition for a long time; although clearly during the initial period after diagnosis the monitoring was more intense. In couples where the heart failure was more severe the monitoring was more watchful. Partners gained confidence in the ability of their spouse to undertake activities by watching what happened when they did things; if this happened without incident they gained in confidence, but if health faltered fears re-emerged. One partner, for example, suffered a shock when she tried to encourage her partner to exercise believing that it would improve his health, and then he collapsed and was

rushed into hospital; whilst others were relieved and encouraged to watch their husbands playing sport or at the gym.

A minority of partners were concerned that their partner did not do enough, and Carol, for instance, spoke with irritation about how little her husband did:-

*Well we don't walk like we used to do (Carol)*

*No we don't. No, no (Christopher M/M-R-O-P-N/M)*

*We used to go on long walks, at home and on holiday. And on holiday he hardly moves from the sun-bed now. So we don't go on walks at all (Carol)*

*We do occasionally (Christopher)*

*No we don't. We don't go on walks now. When I take Caitlyn [granddaughter] for a walk you never come. If I go to the shops for a walk you don't come do you? (Carol)*

*Nope it's how I've said, I'm taking things easy. I've got to 73 and I want to keep on going a bit longer hopefully (Christopher)*

#### **6.4.8 Medical Advice**

When the heart is damaged, there is a time when people are fearful of what they should and should not be doing, and thus medical advice plays a key role in determining attitudes to future activity. Medical advice potentially reducing activity included being told to give up activities, such as swimming, driving, lifting. Less specific advice was also given: to avoid stress, to be very careful about what you do, and to take things easier. Others were advised to take a daily rest.

And thus this advice gives the impression that activity is no longer to be undertaken without thought, but must be considered and chosen carefully. Advice about reducing activity was not always followed, especially if it did not fit into routine, or was impractical, as seen by the following quote:-

*They tell you don't do anything at all, relax. But how can you do it? I'd need a cook, I'd need a house cleaner, I'd need everything [laughter] (Terry B/S-L-O-A-B/S)*

Participants referred to the gym for cardiac rehabilitation were given a different message about activity, and whilst they initially felt fear about exercising, many built gym visits into their weekly routine, and gained confidence about being active. The gym leader was spoken of

as an inspirational figure, whose positive attitude to activity was beneficial in enabling participants to reach a new level of fitness and confidence.

Medical advice also had the potential to create uncertainty about what is the right level of activity, as Janice explained:-

*...I think the main thing is a constant fear of over doing it, and that's the question I should ask, what happens if I overdo it? Does it really have an impact on my health? Once the nurse said to me you have to be careful because you could end up with ME. And I think that, I think she mean it seriously (M/M-R-Y-P-B/S)*

#### **6.4.9 Weather**

The weather impacted on the outlook of participants, and choice of activities. For some, hot weather was mood enhancer, and the sun drew participants outside to garden, to do some DIY, or just to sit; or in the case of more able participants to walk or play sport. For these individuals, summer was a season of activity:-

*...and the weather also lifts your spirits as well, a day like today [warm and sunny], I feel more active and raring to go (Willow M/M-R-O-P-N/M)*

However two participants with severe symptoms talked about being limited by heat, one experiencing difficulty breathing, and the other avoiding outdoor activity because he had collapsed on a hot day.

Cold weather was not welcomed by some, with reports of feeling unusually cold in the joints and feet, lips going blue; and the wind taking the breath away. These participants stopped at home more during inclement weather, and this impacted on activity and mood:-

*Well especially in the winter if you are confined to the house you are just, you are not getting out at all and you are not doing anything, and err it tends to play on your mind a bit (Max B/S-R-Y-P-N/M)*

Even for participants not experiencing these adverse symptoms, the winter was seen as dispiriting and an inhibitor of outdoor activity:-

*A grey sky yes, you don't have the same enthusiasm, somehow (Willow M/M-R-O-P-N/M)*

#### 6.4.10 Demands on Time

The activity pattern of the days was also shaped by whether participants were still working or had retired. Participants that had been forced to give up work because of ill health described the shock and range of emotions they experienced when they realised that they would not be going back to work, and this loss of structure to the day impacted on activity:

*Erm when I retired I really got into a cycle of, no I can't be bothered to do that today, I'll do it tomorrow and there was too much time available and I really didn't handle retirement very well (Henry M/M-L-Y-P-B/S)*

Whilst this loss of structure impacted chiefly on those newly retired it was also described by those who had been retired for years:-

*So you know what date is? But since I've retired I haven't a clue (Stuart M/M-L-O-P-N/M)*  
*Each day rolls into next (Susan)*

Many of the participants had a weekly routine of activity, and commitments. For those with caring responsibilities, these commitments shaped activity even when participants felt unwell:

*...erm nobody makes beds properly, they leave the bottom sheet like a furrowed field. So every night I have had to straighten it, and when I was so breathless that really was an effort (Willow M/M-R-O-P-N/M)*

The participant with school-age children faced particular pressures, as she did not want her condition to interfere in her ability to parent, and to impact on the children's activities. On days when she would have preferred to stop and home and rest, she pushed herself to carry on because of a reluctance to cancel things:-

*What I think I should do is put an Agatha Christie on the DVD, have someone bring you afternoon tea and put your feet up... But life's not like that (Janice M/M-R-Y-P-B/S)*

Those that ignored symptoms and carried on with commitments, described dragging themselves through the day, as Graham explained, "I'm in trouble it's a long, long day." The willingness of participants to cancel engagements because of ill-health depended in part on the reaction of their partner, who made an assessment about the capability of their spouse:-

*Barbara's Mum is in a residential home so if we were going to visit your Mum, we would still go and visit, wouldn't we? On that day I would take you to see your Mum? (Brian B/S-L-O-P-B/S)Yes. Unless you were extremely, and I would say, don't bother today (Barbara)*

Those with severe heart failure had few commitments because the unpredictability of symptoms made it impossible to plan activities in advance. The few engagements that remained were especially treasured, with some resting before the Support Group to build up energy levels, and then suffering exhaustion afterwards.

## **6.5 Intrusion from Symptoms**

The integrative theme in the template was intrusion from symptoms, identified because participants described how activities were limited when symptoms intruded and the greater degree of flexibility when symptoms were not troublesome. Heart failure symptoms had the potential to influence and override all of the themes in the template. The degree of intrusion from symptoms varied in participants; and with it the potential for symptoms to impact on activity. The factors that influenced this are explained in the following section.

### **6.5.1 General Level**

Participants with mild heart failure were generally able to carry out everyday activities without the intrusion of symptoms. One participant, for example, said his tiredness came not from heart failure but from stopping up late and having one too many drinks (Ken M/M-R-Y-P-N/M). For those with mild heart damage, symptoms may only intrude when strenuous activities are undertaken.

The most vivid descriptions of everyday symptoms came from those participants with severe heart failure, for instance, here breathlessness is described by one participant whose life had effectively stopped after onset of heart failure:-

*...it varies a lot from time to time, but you get this tightness here [pointing to her chest], even down by your midriff area, and then when you get the fatigue it is all across your shoulders and up your neck (Dawn B/S-L-Y-P-B/S)*

The all encompassing nature of the symptoms is shared by this description of tiredness, as described by an older participant with severe heart failure:-

*... sometimes I'm in the middle of washing up and you have to come and sit down and before I know where I am I'm asleep. It just takes you over, it's terrible (Olivia B/S-L-O-A-B/S)*

Participants with severe heart failure experienced intrusive symptoms in everyday activities, and not just strenuous ones, for example during eating, talking, and light household tasks:-

*I get up err put kettle on, make a drink for her and me, get two yogurts out, get a banana out for her, put morning tablets out for her and me. And when I sit down to have my yogurt and tea I'm short of breath, that's it, that's after a possibly good nights sleep (Graham B/S-L-O-P-B/S)*

Symptoms therefore pervade every aspect of life changing it out of recognition, and the intrusion from symptoms for those with severe heart failure moves from being an irritation (as experienced by those with mild heart damage) to a terrifying feeling that consumes the individual and stops them in their tracks:-

*...you get up to go and do it, to start it, your body tells you, oh hang on. Err now you would be a fool to carry on, you know what I mean so, like you have either got to rest, or slow down. I mean obviously it depends what you are doing err but usually mine's that bad that I have to, you know stop. Err and then, it's like, you lose your breath and it, it it's hard to get it back you know what I mean, and you feel as though you are not going to. Err (Nick B/S-R-Y-P-B/S)*

*And then he panics a bit, you see [laugh] (Nancy)*

Participants were asked which symptom impacted most on everyday activities and typically they said tiredness or breathlessness, although single participants mentioned dizziness, sweating, and a vulnerability to infection. Tiredness was described as more of an issue for those with mild to moderate heart failure, and breathlessness and tiredness in the more severe heart failure sufferers. One participant explained how the two symptoms are interlinked, with breathlessness leading to tiredness (Dawn).

### **6.5.2 Tolerance**

The degree to which symptoms intruded also depended on how conscious participants were of what was going on in their body; or conversely how tolerant of symptoms they were. Typically

recently diagnosed participants were more aware of their heart, actively looking for signs of a health decline:-

*... your always conscious of err what, you're always looking for something. Definitely, definitely you get up on a morning and think oh, you probably go to the bathroom and start getting washed or something, my heart just feels a bit different, what's that?*  
[laughter] (Fred M/M-R-Y-P-N/M)

In addition, living with symptoms was a new experience, which altered the quality of life:-

*So the feeling tired and the feeling ill are all physically quite bad, I have never had to live with any degree of physical disability or discomfort before...* (Janice M/M-R-Y-P-B/S)

Typically participants who had been diagnosed with heart failure for a long time were used to symptoms, and more tolerant and less responsive to discomfort having lived with the condition for a long time. Old hands had learnt to manage symptoms, and were less likely to panic about changes in symptoms, having seen it all before. However, despite this increased tolerance the experience of night-time breathlessness was singled out as a symptom beyond tolerance, as it was so awful:-

*Heart trouble doesn't bother me, only breathing hard at night* (Graham B/S-L-O-P-B/S)

This was also expressed by those recently diagnosed. The experience of being woken gasping for air in the quiet of the night, was particularly terrible:-

*The worst feeling was when you woke up in the night sort of two or three o clock in the morning and you would be laid in bed going [gasping for breath] and you would get up, it was freezing cold last winter, ... and I would have be going to the window and opening the window [gasp] trying to get some air in...* (Larry M/M-R-Y-P-N/M)

### **6.5.3 Stoicism**

Participants often underplayed symptoms, as evidenced by this conversation between Christopher and his wife:-

*I do sometimes get a bit of breathlessness but not a lot* (Christopher M/M-R-O-P-N/M)  
*But you puff and pant a lot when you do things, more than you used to do* (Carol)  
*More than I used to do, yes, yes. But I don't get completely out of breath do I?*  
(Christopher)  
*Not completely, but you are out of breath a lot* (Carol)

*But I think that is more of a habit than anything else... (Christopher)*

This stoicism was evident across the sample, and especially in the older men, many of whom had worked in the harsh environment of the coal mines or steel mills. Participants talked about underplaying their symptoms to friends, and even family:-

*Even like my Mum and my siblings and that, there is really only my husband who knows truly what I am like, I can't for him [put on a front] because he is here all the time. But even with him he will go are you alright and I will go yes, but I'm really not good just now [tiny voice]. But I will go, well I can't hide it from him much, but you do, you just try putting on a front. It is a terrible thing really (Dawn B/S-L-Y-P-B/S)*

Older people with heart failure may not therefore openly acknowledge the degree and impact of symptoms.

#### **6.5.4 Change over time**

During a flare-up of heart failure the degree of intrusion from symptoms alters so that the uncomfortable feelings intrude on everyday life, as the following quotes illustrate:-

*...and the shortness of breath whenever you are going up a hill or up some stairs, and other horrible things I had were when you were wakening up about two, three o'clock in the morning and you felt a though you were drowning (Larry M/M-R-Y-P-N/M)*

*I couldn't move. Well I could move, but I was really struggling to move. You know just getting to the toilet, fortunately I had the wife's chair [stair lift] to get me up the stairs to the toilet. Even then from the top of the stairs into the toilet I was absolutely shattered. From there to the chair I was shattered, from the chair to the end of the settee there [a few steps] and I would have to stand [sound of panting] out of breath completely (Eric B/S-L-Y-P-B/S)*

*My legs were very swollen, if I sat down I needed to get them up and William [husband] used to lift them up because they were so heavy I couldn't lift them up (Willow M/M-R-O-P-N/M)*

The escalation of symptoms can happen suddenly with a collapse, or build-up over time almost imperceptibly:-



*I mean other night erm I was in kitchen ...and I just heard a thud, and I came in and he was just sprawled out here (Nancy)*

*You didn't notice it, you just think you are getting old. I think that thing that happened at Christmas, whatever it was, it was like a catalyst, it was either make him or break him. It was a blessing in disguise 'cos it made him, I think because otherwise it was a slow, slow process (Lauren)*

The sudden dramatic intrusion of symptoms from a collapse alerts the sufferer to a change in health status, but in contrast an exacerbation of symptoms can happen so slowly that participants described being able to live and function with the symptoms until they reached a tipping point and sought medical help.

In summary the degree of intrusion from symptoms varies over time, dependent on the degree of heart damage, how stable the condition is, and the nature of activity undertaken. However within these factors are the individuals with their experience of heart failure symptoms, which are unique to the individual.

## **6.6 Changes in Activity According to Health**

This section describes how health influenced what participants decided to do on a particular day. It should be remembered that this process is very individual, dependent on the circumstances that occur on that day, who is present (whether the participants were alone or with family), and the type of person the participant was (their impulses and attitudes). Health should therefore be perceived as one factor in the decision making process, but the strength of its influence can change as health declines, potentially reaching a point where it becomes the imperative for activity. However this idea is tempered by Larry's story of feeling extremely ill but still going to the gym and work, and then being told by the cardiologist that he should stop doing anything because he risked death. This demonstrates that people do not necessarily behave as you would expect.

The influence of health on activity is described in the following sections.

### **6.6.1 How you feel on the day**

As we all know, you can wake up feeling full of the joys of spring, and this shapes the day, as you plan a walk and maybe some gardening. This idea of waking and checking how you feel was present in the participants, but the process was more complex for those with more severe heart failure, as their health state can alter through the day, sometimes very rapidly:-

*Well you start off good (laughs) then by dinnertime [lunchtime] it's a different story...*  
(Olivia B/S-L-O-A-B/S)

Three health states were identified with accompanying feelings that had the potential to encourage or inhibit activity: normal days, bad days, and exacerbations. Not all participants recognised these states, for example, those with mild heart damage with well controlled symptoms did not necessarily experience bad days; and many of the participants had not experienced a flare-up of symptoms requiring an emergency medical intervention. Sometimes participants said they did not experience the health state but then went on to describe symptoms and feelings that matched the interviewer's perception of these states. The feelings evoked by the three health states are described below, with the accompanying symptoms outlined in the appendix (tables 12).

#### **6.6.1.1 Normal Days**

A good day in heart failure, when symptoms were not intrusive, was described by the participants as a normal day. Participants emphasized that they experienced these days as everybody else does, as the relative freedom from symptoms meant that they were able to live relatively normally:-

*Well on a good day I live like a normal day virtually, don't I? I live a normal life for somebody at 73 years of age, 74 years of age. Erm if I want to go for a walk, we go for a walk. We go out shopping, whatever, visit people...* (Brian B/S-L-O-P-B/S)

When asked how they felt on normal days participants typically described feeling energetic:-

*Erm more energy, more on the ball actually, just more alert – doing tasks isn't so much of a drag, erm particularly household tasks* (Janice M/M-R-Y-P-B/S)

However the reservoir of energy available to participants on a normal day varied, with those with mild heart failure having a greater reserve. For those with more advanced heart failure the degree of normality may alter and shift, until the point where symptoms intrude even on a normal day; and the gap between normal days and bad days narrows:-

*There isn't no days when you are not feeling tired, when you are not feeling breathless. Them days have gone now* (Graham B/S-L-O-P-B/S)

Generally normal days were characterised by the desire to do more, a feeling that now is the time to get on and do things:-

*... you have to make hay whilst the sun shines don't you? No it's err when you are on a good day you just have to you know, if you want owt doing it will be done on that day*  
(Graham B/S-L-O-P-B/S)

There was also a greater freedom to plan more for the day, to pack more in; but with this came the risk of overactivity a feature of heart failure which arose out of the energetic feelings of a normal day:-

*You feel relieved when you wake up in the morning and feel that there's a bit more oomph about you, err, and you sort of plan more in your head about what you are going to do that day... and then of course you pay for it the following day*  
(Willow M/M-R-O-P-N/M)

Normal days are therefore more active days, and this reinforced feeling of well-being in three ways. Firstly, the additional energy enabled participants to undertake activities with less of a struggle, and therefore to derive greater pleasure from activity. Secondly, the greater freedom to live 'normally' allowed participants to step away from their ill-health, to move out of its shadow for a time:-

Janice talked about a bell of ill-health ringing in her head, *"...how well I am determines how far I can push it to the back of my mind, so on an energetic day you can push it away"*

And thirdly, the activity gave participants feelings of satisfaction and achievement, and optimism.

#### **6.6.1.2 Bad Days**

Bad days were in essence the opposite of normal days, characterised by energy loss:-

*You have days when you are tired as well, don't you* (Alice)

*There are days I just seem... bumpf* (Alistair B/S-L-Y-P-B/S)

*His energy goes* (Alice)

*The energy has all gone* (Alistair)

*You are no good on them days (Alice)*

*On them days I just sit back and relax (Alistair)*

The tiredness experienced on bad days went beyond normal tiredness, it was a “*whole systems tiredness*” (Janice M/M-R-Y-P-B/S) described using verbs like: drained, physically shattered, listless, lethargic, fatigued and exhausted. Two participants with severe heart failure felt so weakened by the tiredness that they felt they lacked the strength to even hold their heads up. Such feelings had an emotional impact, with depressed feelings typically described - linked to the inability to do anything:-

*On a bad day you would feel a lot more towards depressed. You can have days when you feel really down and you know it just seems like you are useless you can't do anything and you don't have the energy even to get a meal or anything. I don't even have the energy to eat it sometimes never mind think about cooking it you know*  
(Dawn B/S-L-Y-P-B/S)

There was an irritation with the body and self, and with those around them. Some participants found being with others difficult, either feeling they lacked the strength to join in with conversation, or in a minority of cases wanted to be completely alone.

Such feelings were clearly not conducive to activity, and participants spoke of a lack of enthusiasm for doing anything. Ideally most would have preferred to spend the day at home, but this was not always possible. Bad days were nothing days (or “*nowt'ish days*” as Willow described them), to be endured to reach the better times:-

*A bad day, everything is against you, like treading water, like walking in sand - three paces forward and two back. Nothings right, so what do you do, you go to bed and get rid of that day. Put it down as a bad day, go to bed and hope for a better un next day*  
(Graham B/S-L-O-P-B/S)

The frequency of bad days varied in participants, but it was evident that those with severe heart failure suffered them more frequently.

### **6.6.1.3 Exacerbations**

In exacerbations symptoms build up, and unlike bad days in which the chief symptom is tiredness, there is an interaction of three key symptoms: breathlessness, tiredness, and swelling (see appendix table 12 for descriptions of these symptoms in an exacerbation).

Participants described this experience as awful and terrible, and Willow who had recently suffered an exacerbation illustrated this vividly:-

*It felt absolutely terrible, erm I was putting weight on, erm quite a rapid weight, and my weight and my erm size obviously ballooned. I was so breathless in the end that it was a struggle just to walk about and do things (M/M-R-O-P-N/M)*

Activities that had been possible before became an ordeal, a struggle with breathlessness; and that is the key difference between a bad day and an exacerbation in terms of how the health state felt to the participants, with the body out of control in a “downward spiral” :-

*...just if you were walking up a little incline erm that was something or nowt really you had to stop and you would be going [heavy gasping breaths, followed by big lurching breath] and feel as if you couldn't get enough in (Larry M/M-R-Y-P-N/M)*

Such distressing occurrences led to feelings of terror, bewilderment, and worries about where things were heading:-

*Erm and I presumed it was my heart and I thought well, you know, this is it. I really thought that erm everything was going to stop (Willow M/M-R-O-P-N/M)*

The body preoccupied the mind, and as such, there was a feeling of isolation; which happened both as result of the reduction in outdoor activities, but also the lack of physical resources necessary to engage in conversation:-

*...but I was just sort of sat there quiet erm you just sort of probably withdraw into yourself, you know (Larry M/M-R-Y-P-N/M)*

There was also the feeling that life is moving at a different pace to everybody else's, as life becomes centred round the home, and any activity undertaken is by necessity carried out very slowly:-

*...Erm but just everything was just so slow, so very, very, slow (Willow M/M-R-O-P-N/M)*

The feelings towards activity can be summed up by the expression ‘can't be bothered’:-

*...you were just so lethargic and tired as if everything was too much bother, terrible feeling (Larry M/M-R-Y-P-N/M)*

#### 6.6.1.4 Night-time

Sleep quality was a key element forming participants' views about activity the following day, with a good night encouraging a more positive view about that day's activity, and a bad night discouraging activity:-

*I think the biggest difference is getting up in the morning. If I'm not feeling right and I wake up, I don't really want to get up, but on a good day I can be down here at seven o'clock, half seven, no problem... A couple of cups of coffee, a couple of fags and I'm great on a good day (Henry M/M-L-Y-P-B/S)*

However for a minority with very changeable health states, a good night's sleep does not necessarily lead to a greater propensity for daytime activity:-

*I've had a good night's sleep I can get up feeling err listless, err don't want to join in, I wouldn't take part in this repartee type thing (Brian B/S-L-O-P-B/S)*

Nights during an exacerbation with heart failure typically involve numerous awakenings fighting for breath, and as a result the feeling in the morning is of exhaustion:-

*...you would be wakening up because you couldn't breathe right. Feeling and you were just so lethargic and tired as if everything was too much bother, terrible feeling (Larry M/M-R-Y-P-N/M)*

#### 6.6.1.5 Decision Making on the Day

The process of decision making about what activities are going to be undertaken on a particular day are therefore influenced by a whole range of factors, but at times health comes to the fore. Within heart failure there is an added dimension of uncertainty about undertaking activities because of the limitations of the heart:-

*Erm I think it is like having something in the back of your mind all the time that is going, is that ok, is that ok? (Janice M/M-R-Y-P-B/S)*

During times of greater reserves of energy and breath there is greater freedom to undertake activities, but during days when health comes to the fore the voice of uncertainty gets louder. On bad days participants spoke of trying to avoid activities that were too exerting (such as housework and gardening), and preferring to stop at home. The extent of avoidance of outdoor activities varied, from those that still went out and dragged themselves through the day, to those that felt they had no choice but to stop at home and sit out the bad day:-

*There are days when I just won't attempt to do anything. You know when it is really bad I will just, I am like a rag doll just sat there I don't. I can't even be bothered talking to my husband or owt when he comes in [cough] (Dawn B/S-L-Y-P-B/S)*

In addition, some participants spoke of avoiding activities that required concentration, such as reading letters or emails, or avoiding stressful situations.

In an exacerbation the voice of ill health gets even louder and gradually increases in volume over time. Participants initially tried to carry on with usual activities, but learnt due to frightening experiences with breathlessness that they had to limit what they did and avoid physical activities. In the following quotes Larry and Willow describe a typical day with an exacerbation, and although it sounds like Larry is remarkably active his activities were significantly pared down from his usual athletic routine. Willow similarly scaled down her activities to get the rest that she needed, but she also had to maintain her caring role:-

*Basically eating, I mean I have always eaten well, I don't eat badly, but eating sat down watching the telly, I might just drive down to my mums' in the car or just drive to the library, I mean towards the end to go on bus, I used to catch the bus outside, and the bus stops smack outside here. Erm but that was basically it, **nothing physical at all**, because anywhere at work I had to use the lift to go up and down, I couldn't walk up a flight of stairs. I just felt helpless (Larry M/M-R-Y-P-N/M)*

*Very little. Basically getting up, getting washed and dressed, doing the little bits that I always do for William, cooking his meal which was an effort, I literally flung it at him at some occasions ... And that was basically it, I used to sort of just get on the sofa, you know rest and err... But I did the minimum (Willow M/M-R-O-P-N/M)*

## **6.7 Conclusion**

These findings therefore demonstrate the complex interactions that influence an individual's activities on any given day. For the participants in this study, heart failure was something that they had to live with, but they generally preferred not to let it rule their lives; however it was evident that there were times when health came to the fore in the process of deciding which activities to undertake. However, the study also shows the strong influence of factors other than health in shaping activities, especially attitudes to activity, and that these temper the impact of health on activity. These findings call into question Cellar's hypothesis that the interaction between older people and their home environment can be monitored to assess

changes in health status, and this is of importance because of the amount of TLM studies that have based their research efforts around supposition.

It was evident from descriptions of what happened to participants when they overdid things that the overactivity-rest cycle is present in heart failure; and this is a new finding, since whilst it was supposed that the cycle did influence activity levels in this long-term condition, the lived experience had not been described. This study has also added to the understanding of the everyday life with a long-term condition, since most qualitative studies focus on points where health declines necessitating contact with health services (Sargeant & Gross 2011)

The implications of these findings on the design and development of Lifestyle Monitoring are described in chapter 9.



## **Chapter 7 - Qualitative Findings – The Validation Exercise with the Attendees of the Heart Failure Support Group**

### **7.1 Purpose of the Exercise**

The validation exercise was undertaken with the purpose of checking the validity of the early theoretical propositions formed by myself, a researcher who does not have heart failure; and therefore an opportunity was sought to put these views to the test in front of an audience of people with heart failure, or experience of living with someone with the condition. After undertaking thirteen interviews, and beginning the process of forming the template, it was thought to be a timely stage to validate the emerging assumptions. In addition the insights gained from the attending the group informed the ongoing development of themes and the template.

#### **7.1.1 Method**

Consent was gained to attend a meeting of a Barnsley heart failure support group, and check the theoretical propositions by putting them to the group and asking if they agreed or disagreed, or had alternative views they wanted to express. The following section describes the response of group participants to statements about the impact of heart failure symptoms and other factors on activity, and the role of partners in monitoring activity. After each statement participants were asked whether they agreed or disagreed, and whether the descriptions matched their own actions and experience. Further prompts were given to widen responses, and the researcher sought to ensure that people with views were given the opportunity to speak. Quotations are numbered in Roman numerals to show that different people were speaking.

#### **7.1.2 Participants**

Twenty seven members attended the meeting, a mixture of both genders, although there were more males (19) than females present (8). Although the age of the group members was not asked, it was estimated that those present ranged in age from those in their sixties to eighties, with the majority in their seventies. It also surmised that most of the group had been living with heart failure for some time, although on that day two newly diagnosed people were attending for the first time. The views of partners of those with heart failure were also sought. Seven partners were present, and the majority of partners were female (5).

### 7.1.3 Factors to take into Account

The day of the meeting was exceptionally hot, although the room its self was cool, but it is possible that the weather may have influenced the ideas and opinions of the group, since a later interview confirmed the difficulty of living with heart failure in hot weather.

## 7.2 Findings

The following section reports the findings. The reactions to statements about the nature of activities on bad days and during an exacerbation are reported in chapter 9.

### 7.2.1 Which Symptoms Impact Most on Everyday Activity?

It became apparent from the initial interviews that the heart failure symptom that impacts most on everyday activities is tiredness. This idea was explored to understand more about the aspects of heart failure that change the undertaking of activities, and also in order to follow-up the quantitative finding that the differing states of self-reported breathlessness were not associated with many significant variations in proxy activity measures:-

#### Statement 1: -

**People with heart failure have told me that the heart failure symptom that impacts most on everyday life and the things that people want to do is tiredness, rather than breathlessness**

#### 7.2.1.1 Reaction from the Group

There was general agreement from the majority of the group that tiredness has the biggest impact on everyday activities, with a minority stating that for them a combination of tiredness and breathlessness exerted an influence on their daily activities. It was stated that the response to tiredness was to stop activities and rest:-

*You have got to stop what you are doing (i)*

*Yeah (ii)*

*You have got to sit down, and before you know it you are away [asleep]. It just does it (iii)*

*Yeah that's the only way, just rest (iv)*

### 7.2.2 The Impact of Co-Morbidity on Activity

The interviews revealed that many participants have co-morbidities that impact on activities, and in some cases the impact can be greater than heart failure; and thus there this is an added complexity to the relationship between activity and health. This question explores this idea, as this has implications for LM studies that utilise measures of health that focus on heart failure symptoms exclusively; as this would not reveal the whole picture of the health state.

#### Statement 2: -

**People with heart failure have told me that often they have other health problems as well, and these can interfere more in everyday life than heart failure**

#### 7.2.2.1 Reaction from the Group

There was agreement from the group that co-morbidities do impact on everyday life, but the extent of this depended on individual circumstances. Some already had pre-existing health-conditions before the onset of heart failure, as explained in the following quotation:-

*...what I had was quite nasty before I had heart failure (i)*

Others had conditions that developed after diagnosis:-

*I have started with psoriasis and they have said it's because of the beta-blockers (ii)*

The impact on activities was greater when there was interplay between conditions:-

*I'm affected with arthritis and that's painful as well, I can't walk with that, and I can't breathe when I walk... (iii)*

Various other co-morbidities were mentioned, such as, osteoporosis, and kidney failure. It was evident that the scale of the impact of co-morbidities on everyday activities varied, with an extreme impact summed up by a participant who gave the following statement:-

*Your life's gone hasn't it really? (iv)*

This discussion may have been limited by the group situation, as one participant said that she would not be shouting out her ailments. Later interviews revealed how activity is limited by embarrassing conditions are (e.g. incontinence), and it is unlikely that this would be discussed in a group situation.

### 7.2.3 Other Factors Influencing Activity

One area that was explored by the interviews was the influence of factors other than health that influence activity levels, and this was demonstrated in a number of forms, such as, a desire to help family friends (Alastair), participate in church activities (Brian), and to continue with a life-long interest in cricket (Ken & Larry); and this motivation appeared to override the impact of symptoms. This question aimed to find out how much flexibility individuals with heart failure have when deciding which activities to undertake. This idea is at the core of the relationship between activity and health in heart failure, since if an individual is free to choose what they want to do without paying heed to the scale of symptoms of ill-health, then there would not be a relationship between the two phenomena. During the interviews some participants have described undertaking activities despite ill health, and therefore this question was also a means of understanding whether the chief factor in deciding what activities to undertake is health or the will to undertake activities regardless of ill-health.

The support group were therefore asked about the influence of other factors on everyday activities:-

#### Statement 3: -

**I think that there are lots of things that affect what people do in their everyday life other than heart failure, such as I don't know, your involvement with family and friends, I am just giving examples, hobbies, the weather, or whether they are an outgoing person that sort of thing?**

#### 7.2.3.1 Reaction from the Group

Participants explained that choices of activity were limited by physical capacity, with those with little capacity much more restricted:-

*It is ok if you can exercise if you can't do it, that's it (i)*

*I'll give you an example I went for physio after a knee operation and they were walking round with me with a chair [because the heart failure was so bad]. Only did two or three things and I had to sit down, [after] ten minutes (ii)*

*Well after three heart attacks and bypasses and then still feel rough and apart from that then arthritis both knees, I've had one done but it's vicious circle (iii)*

Those with greater capacity were freer in their choice of activity, and were able to participate in exerting activities:-

*We go to the gym twice a week but we are lucky we can exercise... (i)*

*...and we go dancing, and that's beneficial (ii)*

*The only thing I have found is err the things that I enjoy doing which are physical, gardening, DIY, that sort of thing, it has just slowed me down a bit on that. The other things that I like doing like photography, driving, etcetera etcetera, it has had virtually no effect on (iii)*

Therefore physical capacity has an important influence on activity.

In order to clarify what the most important factor in deciding what to do on a daily basis the participants were asked the following:-

#### **Prompt**

**What is the most important factor in helping you decide what you do in your everyday life, is it your health, or is it other things?**

#### **7.2.3.2 Reaction from the Group**

The majority of the group were in agreement that the health state is the key factor in defining what activities would be undertaken, with comments such as the following:-

*It's your health that restricts you (i)*

*Your health is paramount (ii)*

One exception to this was a participant who had described gardening for five hours the previous day, and he stated that he chose what to do based on how he felt:-

*To keep it simple, it depends on how I feel; it's just as simple as that (iii)*

Those with more severe heart failure still had desires and aspirations about what they wanted to do, but they had to scale these ideas down:-

*Your aspirations come down; I mean the things that you want do... I had a lot of ideas of things that we wanted to do when [my wife] retired and I had that heart attack and it, we just wrote them off, we can't do them anymore. So your aspirations change (iv)*

Other factors influenced the choice of activity were also explored, such as the level of fitness; and one participant put forward the view that attendance at a gym had given him greater flexibility in his choice of activity. The weather was noted as a key influence of activity:-

*I think it depends on weather as well, if it's cold we know not to go out (v)*

*And the wind, the winds the worst (vi)*

*Yes it is (vii)*

*It affects people (viii)*

*There's no oxygen, no oxygen (ix)*

*It does do, doesn't it? (x)*

*Might be age as well [laughter] (xi)*

#### **7.2.4 The Impact of Attitudes on Activity Levels**

During the early interviews participants explained their differing attitudes towards activity, and from listening to their accounts of everyday life it seemed to the interviewer that this had a strong influence on both the scale and range of daily activity. The support group were therefore asked their views about the influence of attitudes on activity levels:-

##### **Statement 4:-**

**Some people with heart failure have told me that they are determined to carry on a normal life and remain active, and others that they are going to be careful and take things easy. Do attitudes shape how active people are?**

##### **7.2.4.1 Reaction from the Group**

The initial response to the statement was to express how unwise it is to overdo things, and then conversation followed with examples of overactivity followed by a slump, characteristic of the overactivity-rest cycle:-

*...It's silly; it is stupid to do that, if you do too much (i)*

*I've done it myself; I've been on the settee for four days, after I've done a bit of gardening or done anything strenuous. It knocks me off my feet for at least two days (ii)*

*I say I've been off my feet, and I only went to Marks and Spencer's. I've had a right week (iii)*

*...We go to a coffee morning at the church and I do all the washing up and you are just out the next day, and sometimes for a couple of days (iv)*

There was acknowledgement of the need to know your own limitations in terms of activity, but that on occasion people pushed too hard:-

*I think sometimes you can push yourself too hard (i)*

*We think we can get out and get on with it, you know (ii)*

*I have been doing that, but I had a really bad do, a really bad do, they had to rush me to hospital (iii)*

Participants spoke of having to gain an understanding of the rules of undertaking activity in this new way of living with a damaged heart:-

*...You have got to learn to pace yourself, it is getting used to that when you have been used to just getting up and doing things, and all of a sudden you can't (i)*

*Education, getting used to doing what when (ii)*

However, this was complicated by the individual nature of the physical challenge of undertaking activity resulting from the extent of damage to the heart (a), any other co-morbidity that potentially limit activity, and the degree of fitness (b), and age at the onset of heart failure (c). This was a complex mix, with the following factors in part determining the available physical capacity for this new way of living:-

**a) Impact of heart damage is very individual:-**

*I think what we have got here is it [the heart] affects everyone in a different way (i)*

*It depends what condition your hearts in love for a start, it's damaged and that's it (ii)*

**b) Fitness:-**

*...We have always danced, we have always exercised. It sets you in good stead even though we have both got heart trouble (iii)*

*It depends on how fit you are, that's another element (iv)*

**c) Age of onset of heart failure impacts on activity levels:-**

*...Age comes into it as well, depending on how old you are when you have your heart attack; I think that comes into it (v)*

In summary participants of the group stated that it is a very well to have an idea of carrying on as normal, but the reality is that the scale of activity is limited by the heart. However, this response demonstrates the limitations of seeking experiences in a group setting, as the participants latched onto the initial statement about trying to remain active and criticised this attitude, which would therefore have made it difficult for participants to acknowledge that they actually took this approach. However, as the discussion developed, a more complex model of activity under the shadow of heart failure developed, with the idea of a combination of: heart damage, fitness, and age - shaping the bodily capacity to undertake activity. The majority view was that damage to the heart fixed the scale of potential activity, with the idea that the capacity for activity could be improved by fitness expressed by a minority. It would therefore seem that there is more scope for attitudes to influence activity levels in people in the less severe stages of heart failure.

**7.2.5 The Potential of the Term Heart Failure to Inhibit Activity**

Some of the interview participants who had been recently diagnosed talked about the shock of a diagnosis of heart failure, because the term implied that at any moment the heart may stop; and thus they had to relearn what the body was capable of. The following statement explores the idea that the term heart failure can be an impediment to activity:-

**Statement 5:-**

**People with heart failure have told me that it is scary being diagnosed with heart failure and being told that your heart is not working as it should, and this can make you fearful of being too active. What do you think of that?**

**7.2.5.1 Reaction from the Group**

There was some agreement from the group about this statement, but it would seem that the impact is limited until the time when an individual learns their own capabilities in terms of activity. There was discussion in the group about how people may have a mismatch between their perception of physical capacity, and the reality:-

*I think sometimes people think they have had a heart attack I can't do anything, but they are capable of doing things... So some people do sit back and think oh I can't do this, I*



*can't do that, and they need that bit of encouragement to say it is alright, you know to do this... (i)*

*...some people feel like it's the end of the world, the end of your life, I suppose if you were told that you had cancer, you had terminal cancer it would be exactly the same thing... And it is this realisation that you life hasn't stopped that you have got to turn down another avenue, you have got to start doing different things (ii)*

The group agreed that the term heart failure can be a disincentive to activity, but with encouragement and after a process of adjustment, over time the term no longer inhibits activity. Activity levels therefore reflect a learning process that starts from the point when the heart is damaged. There was also acknowledgement in the group how difficult this process must be far more difficult in people that live alone:-

*Some people do need that little push, but if you are on your own that must be really hard... (i)*

#### **7.2.6 Measuring Health via Activities**

The interviews revealed the use of activity by participants to gain a perception of the state of their health in two ways: firstly to use a general level of activity to construct ideas about how healthy they perceived themselves to be, e.g., those more capable of activity were reassured that they were still able, in contrast to those severely restricted who found this lack of activity a constant reminder of the loss of health. Secondly, activity was used to check after a decline in health that the level of activity prior to this was still possible, and to use this as an indicator of recovery. The following statement was used to check whether attendees of the support group also used activity for such functions:-

##### **Statement 6:-**

**Some people with heart failure told me that they decide how well they are by what activities they can do, for example, if they can climb the stairs, or walk somewhere, or play a round of golf, they think they are ok, that's sort of how they measure their health by what they can actually do. Does anybody else do that?**

##### **7.2.6.1 Reaction from the Group**

Immediately after this statement a participant agreed that activity was used in this way:-

*I think everybody does, I mean... (i)*

*Your body tells you what you can do (ii)*

*...you have got to find out what your capabilities are, you know not to go beyond that level of activity and I have a routine after that (i)*

Similar assertions were made from other participants of this idea of the body 'telling' people the type and level of activity that was possible:-

*It learns you (iii)*

*You definitely know what not to do (iv) [amusement all round]*

*Well if you have had your heart trouble for a number of years you know what to do (v)*

*It is common sense that's all it is. If you have had a heart attack two or three, you know very well not to do what he has been doing [addressed to a participant who talked about gardening for five hours] (vi)*

The idea that activities would be in proportion to the health state was greeted vigorously by a participant with advanced heart failure, who implied that her activities were very limited by symptoms :-

*If you come to our house love you could see, you'd know (i)*

In summary, there was agreement that activity levels reflect the general level of health, and that if you try to exceed this 'the body' alerted them to the impossibility of going beyond a set level. The idea of a safe environment where this activity level can be challenged was raised; with the gym cited as a place where you can test the body and learn about the body's capabilities, whilst being monitored by staff.

The idea of testing the body after a threat to health was not spoken of, but the respondents were not prompted to consider this.

### **7.2.7 Monitoring Activity by Partners**

During the interviews it became evident that partners are very aware of what their spouse is doing, and have ideas about what is safe both in terms of the type and duration of activities; and will intervene to enforce this if they think their spouse has exceeded safe levels. The following statement checks this idea:-

**Statement 7:-**

**The partners of people with heart failure have told me that they watch what their husband or wife is doing to check that they are not doing too much, and that they may have a different opinion from their husband or wife. What do you think of that idea, do you agree or disagree?**

**7.2.7.1 Reaction from the Group**

The response to this was very enthusiastic, and participants intervened before the statement was completed to shout out agreement; and it seemed to the researcher that it was a welcome opportunity to explore the impact on heart failure on their lives. The wife of a participant who had been talking about his lengthy gardening explained the divergence of views on activity:-

*I'm the wife of the husband that did the five hours gardening, far too much! (i)*

Partners talked about having to learn what level of activity was appropriate after the heart had become damaged, and there was agreement that this varied in the individual:-

*...When you come out of hospital they give you a guide, what you should be doing at certain times, so if you follow that you should be all right. Not everybody can follow it (i)*

*Not everybody's fit (ii)*

*Not everybody's the same (iii)*

*No their not (iv)*

Partners described monitoring their spouse and this took various forms, as listed below:-

**1. Looking for signs of ill-health**

*..I am always checking on him and if he doesn't look right I say, how are you feeling? I mean I can tell he is not right by just looking at him (i)*

*You wake in the middle of the night if they are quiet and you think are they still breathing? You give a sigh of relief; you know they are alright (ii)*

## 2. Monitoring via technology

*...he has a Health Buddy so I say go and check your blood pressure and your heart rate, you know, and sometimes he wants to and sometimes he doesn't, oh it will pass, but I'll keep on at him, oh just do it (iii)*

## 3. Monitoring from afar

*And even if I am out shopping and I hear a siren, I'll start panicking, thinking is he ok, and I'll ring him, oh are you ok? That is constantly on my mind! (iv)*

## 4. Awareness of the impact of overactivity

*He has been here today, he looks ok doesn't he? Tomorrow he will be no good, for that he has to miss gym that Tuesday, and if he does something in particular, you know a bit extra, and then he misses the next one, and this is how it is (v)*

Clarification was sought as to whether activity monitoring occurred only for a time-limited period, or if continued forever:-

### Prompt

**So when someone, say like they have had a heart attack and their heart has been damaged, would the partner be more careful about what the husband or wife does, or does this idea of watching over your husband or wife, does that carry on forever?**

The partners responded very definitely that the monitoring carries on forever:-

*It carries on because they are on a knife edge. Some of them, some aren't as bad as others. Some are (i)*

*And sometimes they are stubborn and do things that they shouldn't do (ii)*

It was evident that monitoring becomes a habit, and after the heart is damaged the lives of partners are also changed irrevocably:-

*And I have tried and tried not to do it [monitoring her partner], and I **cannot**... [bold = emphasis on that word] (i)*

*No, no (ii)*

*...stop doing it, I **cannot** stop doing it! (i)*

*You get into a habit don't you? (iii)*

In summary, partners described a level of monitoring what went beyond the scope of solely focusing on activity, and was more multifaceted both in focus and action. This formed a new role of caring and protecting health of their spouse.

### **7.3 Conclusion**

In conclusion, the validation exercise confirmed that the theoretical propositions were generally true to the lived experience of heart failure, and that activity does indeed take place in a complex milieu. The strongest message from the group was that heart failure dictates activity levels, with those with less damage enjoying a greater degree of choice and flexibility. Participants described a journey starting at the point of heart damage where they learned overtime which activities were suitable for their new state, and those receiving encouragement and support from family, and the gym, more likely to negotiate this process with a new routine of activity in place. The exercise provided a greater understanding of the extent of the monitoring role that partners undertake, and how this is fed by the uncertainty and fear about their partner's situation.

The results are summed up in the table below (table 7.1).

**Table 7.1: Summary of Findings**

Theoretical Proposition	Majority View	Minority View	More Severe Symptoms	Milder Symptoms
1. Tiredness impacts most on everyday activities	Tiredness limits activity	Tiredness and breathlessness limits activity		
2. Co-morbidities may impact more than heart failure on everyday activities	Co-morbidities vary in their impact on everyday activities, and the impact is very individual depending on the nature and severity of the symptoms		Co-morbidities may inhibit activities, for example, due to joint pain	
3. Factors other than health influence the choice of everyday activities	Those with a very damaged heart have a restricted choice of activities, and this is the key factors in the choice of activity		Activities are limited to those which the capacity of the body allows. Factors other than health which do influence activity are the weather, reassessed aspirations, level of fitness, and age.	People with mild heart failure have greater freedom to choose from a wider range of activities, and are more influenced than factors other than health (e.g. what you feel like doing)
4. Attitudes shape the range and level of everyday activities	Participants strongly asserted that people would be foolish to try and ignore symptoms and live a normal life. However they also described the pushing beyond their capacity to undertake activities, and suffering for this.		As above.  People may push beyond their bodily capacity to undertake activities and suffer afterwards. The impact of overactivity is likely to be more severe for those with more advanced heart failure	As above.

Theoretical Proposition	Majority View	Minority View	More Severe Symptoms	Milder Symptoms
5. Fear may limit activity, especially due to the trauma of diagnosis with heart 'failure'	Fear may limit activity in the early days after diagnosis, but overtime people undergo a process whereby they learn what activities the body is capable of.	Some people do restrict activity and take on a sick role.		
6. Activity is used to measure health	Participants agreed that activities do provide an indication of the state of health, in the sense that the body clearly signals which activities it is capable of. This is an on-going process, and overtime people find out what they can or cannot do.		Activities are restricted as the body has less capacity	The body is capable of a wider range of activities
7. Partners monitor their spouse's activities, and differ in their opinion about what is an acceptable level of activity	Partners strongly agreed that they monitor their spouse to check for overactivity and signs of ill-health. This monitoring began at diagnosis and continued onwards, and was most intensely undertaken in partnerships where the spouse was perceived to be "on a knife edge." The monitoring was complex and multifaceted.		Spouses' with severe symptoms were perceived as more vulnerable, and partners sought to care and protect them by monitoring. Partners observed their spouse and formed opinions about their capacity for activity, and monitored to ensure that this was not exceeded.	Spouses' with milder symptoms were still monitored, although their health was less under threat

## **Chapter 8 - Qualitative Findings – Heart Failure Specialist Nurse Focus Group and Interviews**

### **8.1 Purpose of Seeking the Views of Heart Failure Specialist Nurse**

The views of community heart failure specialist nurses (HFspNs) were sought primarily to validate some of the key findings from the initial participant interviews. In addition, by seeking an alternative perspective on living with heart failure, it was hoped to add a depth and richness to the exploration of the relationship between activity and health. The interviews with participants with heart failure demonstrated that medical advice plays a role in shaping participant activity levels, and HFspNs have a key role to play in either encouraging or moderating activity.

#### **8.1.1 Method**

The quickest and most efficient means of seeking the views of HFspNs was considered to be a focus group (see chapter 4b for further details). However the initial four participants were found to have a caseload of patients with very severe heart failure, and thus there was a risk that the findings would not represent the broad experience of the interview participants. Further interviews were therefore undertaken with two other nurses with experience of nursing a less severe caseload, in order to encompass broader experience of living with heart failure.

#### **8.1.2 Participants**

Six nurses took part in the research: four Sheffield nurses attended a focus group, and semi-structured interviews were undertaken with a nurse from Barnsley and a nurse who had formerly worked for the Nottingham service. The nurse participants were purposely selected to encompass experience of differing client groups, with the Sheffield service caring for patients with severe heart failure, Barnsley less severe patients, and the Nottingham service focused at the time of the nurse's experience on case management of symptomatic patients.

#### **8.1.3 Factors to take into Account**

It should also be noted that the nurses were speaking about their perceptions of what they had heard about or witnessed when visiting patients; and the patients themselves may not agree with their insights. In addition HFspNs only home visit or see patients in clinic every so often, and are most likely to see patients when things are going wrong, and thus this may represent a skewed perception of life with heart failure.



The Sheffield nurses declined to be recorded and therefore notes were taken of the dialogue, and although these were as comprehensive as possible this made it difficult to record full quotations.

## **8.2 Findings**

The following chapter reports the findings from four questions which explored the relationship between activity and health in heart failure: the influence of personality, how much everyday activity is directed by health, and the positive and negative impacts of activity.

The nurses will be referred to by the following pseudonyms: Sheffield nurses (Sandra, Sally, Samantha, and Susie), the Barnsley nurse (Bryony), and the former Nottingham nurse (Natalie).

The findings that relate to monitoring in the home are reported in the following technology chapter (9).

### **8.2.1 The Impact of Personality on Activity**

The idea behind this question was to elicit whether some people with heart failure have a elements within their personality that helps them deal with their condition and continue with their lives regardless of heart failure, e.g., a 'get up and go' type of person that will persevere with activities despite the health state. This question was therefore a method of gathering information on whether there are elements other than the health state that impact on levels of activity.

**Question 1: Do some people cope better than others with heart failure? Prompt: Why is that do you think?**

**Follow-up question: Do some people cope better than others at all the stages of heart failure?**

The nurses unanimously agreed that some people do cope better with heart failure than others, and this is seen at all stages of severity. The nurses identified key elements that influence the ability to cope, and the varied nature of these factors and the individual impact illustrates the complexity of factors influencing everyday activity in heart failure patients within the community. This complex picture supports the findings from the interviews with participants with heart failure. The key factors influencing the ability to cope were as follows:-

## I. Positive Outlook

The nurses agreed that a positive outlook on life can improve the likelihood of dealing and living with heart failure.

The Sheffield nurses deal with severe heart failure, and therefore their perspective was about living with very activity-limiting symptoms. However within the confines of this situation, they agreed that the way people deal with heart failure depends on the individual, on their outlook in life, and those with a positive outlook and motivation cope better (Sally).

The Barnsley nurse also agreed that a positive mental attitude is beneficial in coming to terms and living within the confines of the condition:-

*...some people are a bit more positive, and a positive mental attitude goes obviously a long way, and they realise that they can actually live with it, if they live within the limitations... (Bryony)*

The Nottingham nurse gave the example of patients who made the best out of their changed situation by taking an active role in support organisations; and she asserted that this response arose out of a pre-existing positive outlook:-

*...some people will deal with it very well. Become very active with the British Heart Foundation and the voluntary organisations and will, you know, present at conferences and be role models to people and deal with it in that way; but that personality type was probably always there (Natalie)*

Bryony identified a different response from very anxious patients, who make a poor adaptation to their changed circumstances which resulting in a limitation on daily activities:-

*Some people are really, really anxious and like to take on, I am not saying this awfully, like to take on the sick role... (Bryony)*

This contrast between the two reactions appears to mean in practical terms the difference between finding a way to live a life within the boundaries of heart failure, and being so anxious about the health state that this becomes the focus of life.

## II. Attitude to Activity

Some patients are keen to keep active, and this forms part of their weekly routine. Natalie gave the example of a very elderly patient who had been walking to a paper shop some distance away because he was keen to exercise:-

*I saw a ninety two year old the other day who was really fed up because he couldn't get to the paper shop which was actually quite a long walk ..., he wanted to be physically active, but we said well you need to do maybe circuits of your cul-de-sac so you're not far from home rather than looking at an hour and back (Natalie)*

Further examples of this determination and drive to undertake activities regardless of the health state are described in the following section (8.3).

### **III. Previous Activity Levels**

The 'physical ability' of the individual prior to developing heart failure has an impact how capable of activity they will be afterwards (Natalie). This supports the interview finding that past activity shapes attitudes to present activity.

### **IV. The Importance of Cardiac Rehabilitation in Understanding how to be Active**

Attitudes to activity are also formed in part by cardiac rehabilitation, as prior to this, patients can be fearful of overdoing things:-

*...the physio will reassure them that if you are exerting anyway in a normal healthy individual you will get slightly short of breath so, you know, what's normal for them but also what they need to be concerned about, so it's very much looking at their limitations that they don't go off and overdo it, but also to keep themselves physically and psychologically well (Natalie)*

Natalie explained how the rehabilitation can be tailored to individual ability, with most severe patients receiving home visits and a specific exercise programme.

### **V. Management of Medication**

Another aspect of personality that impacts on the ability to cope and live and be active with heart failure is the ability to manage the medication and monitoring regime. For Natalie, those that cope better maintain a routine of medication and monitoring:-

*...some people will, you know, take it on board will be very... organised with their medication um love the self management of it, so if we give them a booklet to fill in, they'll fill that on a daily basis..., and they actually like that organised aspect of it, and feeling in control... (Natalie)*

All the nurses spoke about the importance of patients having their medication optimised, and this has the potential to stabilise heart failure and give patients the best condition in which lead an active lifestyle.

## **VI. Age**

Age was identified as a factor in coping with heart failure (Sandra), as those who are younger and have been recently active have more of an adjustment, and more to give up, than those who are more elderly and most likely living a sedentary life anyway (Sally and Bryony). Bryony described the situation of one younger patient who had previously worked and was finding it difficult to adjust to activity within this changed situation:-

*...he used to go to the gym and erm since now I can't even climb the stairs without getting out of breath and things like you know. So you know you spend a lot of time, you know, trying to make them adjust to what, you know like, what they can and cannot do...*  
(Bryony)

However Natalie pointed out that older people may have added vulnerabilities than younger people do not have, and this may make dealing with heart failure more difficult:-

*...it's predominantly a condition in the very elderly so often they're less resilient to deal with things*

And frailty can lead to difficulty functioning both within and outside the home:-

*... my first assessment was they could get to the front door, because that's half the battle for some patients if they can actually answer the door* (Natalie)

For frail elderly people the vulnerability of their situation means that heart failure has a disproportionate impact on their ability to function, and limits activity:-

*...they're probably more socially isolated, you know, if they haven't got transport and they're used to going into town on the bus..., all of a sudden their life gets closed down quite quickly because of the condition because of its physical implications and ... you're closing down their resources to deal with it...* (Natalie)

## **VII. Support**

Family support was identified as a key factor that aided the individual's ability to cope with heart failure (Samantha). The lack of family support is more likely to impact on the ability to

cope in elderly patients, and those that live alone without support services are most vulnerable since there is nobody to identify signs of a health decline:-

*I think the most at risk people are the frail elderly living alone..., I'm talking about people who haven't got any services going in whereas if you've got patients who've got carers going in or may have um meals on wheels and things obviously those episodes in a day act as a trigger to say 'have you been in that chair all day?' (Natalie)*

It is not surprise that role of the HFspN was also identified as a key source of support, to facilitate coping.

*...they just need that point of contact to help them through the journey (Natalie)*

The interview participants also confirmed the importance of a good relationship with HFspN, and this was especially valued in participants that lived alone.

#### **VIII. Housing**

The type of housing the individual lives in can have implications for their ability to cope and maintain activities. Natalie compared the impact of environment on two elderly ladies, with one living in a modern bungalow and the other in a more deprived situation, in a house with an outside toilet. The combination of frailty, heart failure, and the home environment together made activity within the home more difficult:-

*.... we put them on is beta blockers that can drop their blood pressure and make them dizzy so, you know, so you've got all those other aspects that you as the nurse are worried about thinking how's she going to get to the loo and all that? So you are looking at environment in which someone's living, as well as to how well are they going to actually manage with this condition... (Natalie)*

#### **IX. The Shock of Diagnosis and the Impact of the Term Heart Failure**

At diagnosis with heart failure, patients have to deal with both the shock of learning that their heart is damaged and at the same time need to assimilate key information about living with the condition, and the inability to retain this information impacts negatively on their ability to cope (Sandra). Sandra explained how commonly patients in hospital are given a very positive view of what they will be able to do, but then they have a visit from the Heart Failure nurse and the diagnosis is explained and the limitations of daily life, the contrast between what they have heard in hospital and the reality of the situation makes them "crumble." This shocking jolt into the reality of their new situation forms the backdrop for future activity.

The term 'heart failure' was identified as a negative factor in the ability of individual's to cope as it engenders such terrifying ideas about the heart failing (Susie); and this may make patients fearful of being too active:-

*... they're frightened because if you're told you've got heart failure you think your heart's going to stop so they're quite frightened of actually doing too much (Natalie)*

This inactivity has implications, as it can result in declining physical and mental health:-

*...it's not only the physical side, it's the psychological side un, so yes I do think they [inactive people] just withdraw, and they're the people who sometimes end up getting quite symptomatic as well because they are less mobile, so you're going to get more pooling of your fluids, it's like a revolving door really (Natalie)*

A key role of the nurses is to address these fears and encourage activity (Natalie), and thus information and encouragement from HFspNs may inspire increased activity levels.

#### **X. Co-morbidities**

The Barnsley nurse stated that the extent and impact of co-morbidities can outweigh the effect of the severity of heart failure, on the ability to cope and be active. Bryony argued that the severity of heart failure is not necessarily an indicator of the ability to cope, since other factors can adversely impact on physical capacity (such as co-morbidities), or they may have a positive impact on capacity (such as a positive mental attitude).

For Natalie the presence of co-morbidities may impact on how active an individual may be, and for those with two or more co-morbidities this can become a barrier to activity. However, as with all these factors the impact will be very individual and there is no one size fits all model of how capable of activity a person with heart failure will be, and Natalie described the process whereby the individual learnt their own activity limitations:-

*...if you've got somebody who's got two or more co-morbidities then obviously that's going to impact as well [on activities] but it's really a difficult one to call because they do need to learn **their** limitations (Natalie) [bold = emphasis on that word]*

#### **XI. Side-Effects of Medication**

The side-effects of medication can also make coping and activities difficult. Natalie gave the example of a patient who lived alone and was frail, and she had the added risk of taking medication that caused dizziness:-

*...we put them on beta blockers that can drop their blood pressure and make them dizzy so, you know, so you've got all these aspects that you the nurse are worried about, thinking how's she going to get to the loo and all that? (Natalie)*

This description calls to mind the situation of interviewee Terry, who lived alone and was very affected by dizziness; and this gave him a greater vulnerability (see page183)

## **XII. An Uncertain Trajectory**

The nature of the health condition itself impacts on the ability to cope, and heart failure was identified as a condition especially difficult to live with. Heart failure is a progressive and unpredictable condition:-

*...for other people if it's very unstable and very difficult to get their symptoms managed then that's going to be more difficult for them to come to terms with [the condition] and also I think the very difficult thing with all heart failure is the fact that it is very unpredictable..., because everybody can have exacerbations and that's difficult to deal with, [and this is] really specific to the condition (Natalie)*

## **XIII. The individual Nature of Heart Failure**

Physical capacity is very individual in heart failure:-

*...I think the diagnosis of heart failure is individual, you know the damage to someone's heart or the degree of heart failure is very different for each individual..., it's a bit like COPD, you can't say that because you've got heart failure you will be able to do this, this and this, but you won't be able to [do that], it's very individual... (Natalie)*

In addition to this, patients can have complex medical histories which impact on their physical capacity, for example, cardiac abnormalities, atrial fibrillation, and the presence of implantable cardiac defibrillators; and thus their capacity for activity will vary.

### **8.2.2 Conclusion**

In hindsight this question should have been focused more specifically about dealing with daily activities within the context of heart failure, instead of asking who copes better. However it could be argued that the ability to cope is demonstrated by undertaking everyday activities, and potentially those that are coping better with the condition may be more active. It was noted, that the themes that arose out the responses chime in with the factors that have already been identified from the interviews and validation exercise that encourage or inhibit activity.

In conclusion, the ability to cope is shaped by a complex array of factors, and these are likely to all have an impact on the ability to undertake activities in complex and very individual ways. Personality type appears to pervade a number of these factors, and therefore these findings highlight the key importance of a positive outlook on coping and living with heart failure. These findings support the view from the interviews with participants with heart failure of the individual nature of the relationship between activity and health in the community; where the environment, context, and people with heart failure, all differ in individual ways.

### **8.3 The Power of the Health State to Direct Activity**

The idea behind this question was assess the strength of the health state in shaping activities within the home, and whether this would outweigh other factors in deciding what to do on any given day.

**Question 2: I would like your opinions about how much you think that what people with heart failure do at home is directed by their health?**

**Prompt: Can you give me some examples?**

The nurses were of the opinion that activities within the home are not necessarily directed by the health state, and gave a number of examples of this. The first example is individuals who think that they can go back to normal, even though their health state has altered, and this desire for normality would influence their activities (Sandra). Some people are very driven and will undertake activities despite their heart failure, for example: maintaining an immaculate house (Sandra), going to the allotment (Natalie), taking exerting walks (Natalie), driving when they do not appear capable (Natalie). Susie described visiting a lady with heart failure who was ironing even though she said she felt unwell, and when the nurse told her to leave it to another day; she rejected that idea because she wanted to get the ironing done *that* day. The activities of this individual sounded like they were directed not by the health state, but an overwhelming desire to maintain high standards within the home, the nurse said something along the lines of “*She will keep her house perfect even if she felt unwell*” (Susie). Natalie gave a similar example of patients who push themselves to the limits:-

*...people will push themselves, you know, within their limits, still going, still prepared to go abroad and things like that. You know I've had patients where I thought 'oh God you shouldn't even be driving' but they've still gone anyway* (Natalie)



Natalie described the complex nature of the interaction between symptoms and activity. She asserted that those with troublesome symptoms are more likely to have difficulty functioning in the home:-

*...they are very symptomatic, so very short of breath, very tired and limited mobility and so that is clearly going to impact on how they manage at home... (Natalie)*

However in some a positive outlook may enable them to continue with activities:-

*...it comes back to your attitude because you might get really symptomatic patients but because they have got such a positive attitude they might go for it [go out] anyway (Natalie)*

For her, the most important factor to do with heart failure that shapes activity, is the necessity to be near a toilet because of the diuretics; and this may be of a greater importance than symptoms in limiting outdoor activity:-

*...a lot of people will prioritise what they do despite their symptoms, around can they get to the loo, because they're on diuretics (Natalie)*

She argued that diuretics may prevent patients from venturing far from home out of embarrassment at having to go to the toilet so frequently. Activity may also be limited by embarrassment about the physical presentation of heart failure, 'leaky puffy legs' and 'laboured breathing'; and again this would depend on the type of person the patient is, as some people are likely to limit activity because of this, than others (Natalie).

Activity levels may also vary throughout the day in accordance with levels of tiredness, with people typically doing more in the morning, and then resting in the afternoon because they are "shattered" (Susie). Some people therefore respond to the peaks and troughs of energy availability, rather than challenging their health state like the lady ironing even though she feels unwell.

Bryony highlighted the differences in activity between a normal day, and a 'bad' day. She illustrated the impact of the ability to breathe on how the day is classified, and the resultant activities:-

*... You can guarantee when you go and see a patient, or when you see one in a clinic, I will say how has your breathing been? Oh well I have good days and bad days you know,*

*like some days I can wake up and I can feel like I can run the London marathon, other days I just want to laze about all the time (Bryony)*

In summary it would therefore appear that the activities that individuals with heart failure undertake are not necessarily directed by their health state. Some individuals do follow a pattern of an active morning and inactive afternoon that is in tune with the energy fluctuations of their condition. Other people challenge their health state, driven by other motivations, for example, a desire to live normally, or to maintain high standards within the home. The degree to which activity is directed by the health state is therefore very individual, and personality has strong influence on this.

#### **8.4 The Impact of Activity on Well-being and Capacity in Heart Failure**

The following questions explore the impact of activity to alter the health state in a positive way by improving health through activity.

##### **8.4.1 Beneficial Impacts of Activity**

The nurses were questioned about whether activity through exercise can improve health, as this is a flip side of the relationship between activity and health.

**Question 4: Have you seen any changes in people with heart failure when they have started to become more active, or started exercising? Can you tell me about this?**

**Follow-up question: What happens to heart failure symptoms when people start to exercise?**

From the Sheffield nurses' perspective, improvement due to exercise and activity are more likely to be seen in younger patients, at stages II and III who are able to become more active after their medication is optimised (Sally). The example was given of a man in his early thirties, who was so unwell with heart failure that he was on the heart transplant list, and they sorted out his medication and he was able to regain his life (Sandra). Another example was of a thirty year old man who had his treatment optimised and was able to get out of bed, back to work, and out with his friends (Sally).

When asked about the impact of activity on the health of people with heart failure, Bryony talked about the amazing change that had occurred in one patient:-

*..I got him into clinic, couldn't do anything with his medication erm but he was feeling really, really down and what I did was erm referred him to cardiac rehab and now he has lost three stone and erm his breathing is better, he feels more positive... (Bryony)*

The nurses were then asked whether they have seen any people who start being active of their own volition, and Sally replied that people are afraid to do more in case it exacerbates their symptoms. Natalie also agreed that fear can limit activity, and the combination of suffering a heart attack and being diagnosed with heart failure can make people fearful, she therefore valued the cardiac rehabilitation programme where people learn to exercise in a supportive environment:-

*...the physio will reassure them that if you are exerting anyway in a normal healthy individual you get slightly out of breath so, you know, that's normal for them, but also what they need to be concerned about... it's very much looking at their limitations that they don't go off and overdo it, but also to keep themselves physically and psychologically well (Natalie)*

For Natalie the benefits of increased activity are manifold:-

- I. Positive mood – *“I would always say it is the biggest change”*
  - a) A change in mood, a feeling of well-being
  - b) Feeling more optimistic about the condition
  - c) A follow-on may be a more positive approach to taking medication
- II. Functionality to their heart – *“...difficult to measure but I think that [is] positive wellbeing...”*
- III. Reduced fluid overload – Improved circulation of blood resulting from increased activity, and a reduction of pooled fluid in the ankles
- IV. Improved sleep – *“...if you're doing more during the day you're going to sleep better at night”*

There are cases where activity is not recommended due to cardiac abnormalities, or uncontrolled symptoms, and Natalie explained the importance of an individual assessment that takes account of medical history and therefore activity should be tailored to individual needs.

In summary all the nurses agreed that increased activity can improve feelings of well-being, and in some cases the improvement is almost miraculous. Some of the nurses acknowledged that fear is a barrier to increased activity, and the role of the cardiac rehabilitation programme in aiding people to move beyond this fearful state. The Sheffield nurses stated that the changes in health resulting from activity are more likely to be observed in younger, less severe

patients, where the medication has been optimised; however in contrast Bryony gave the example of a case where activity alone brought about an amazing change in the health state.

## 8.5 Conclusion

The nurses reinforced the previous finding that activity within heart failure is shaped by a complex array of factors; but the common thread that is woven through many of these elements is: the state of the heart and health in general; the impact of personality; and whether patients have the confidence to be active. It would appear that some patients are more in tune with their health state, and live according to fluctuations in symptoms; and others are more directed by other desires and motivations. However, the nurses descriptions of activities undertaken during an exacerbation (described in chapter 9), demonstrate that when symptoms are more extreme, patients have less flexibility in activity. The nurses also described how the choices that patients make about their activity, can have a positive impact on well-being; with patients benefitting from exercise and activity (in some cases showing an incredible improvement). The decisions about activity were shaped by beliefs about the fallibility of the heart, and starting from an initial point of fear and insecurity, nurses and physiotherapists can work towards encouraging activity, and inspiring confidence. Activity levels therefore also reflect the stage that patients have reached in this journey, and the understanding that patients have about how to live within the confines of a damaged heart.

The research also revealed more about the role of HFspNs in influencing activity levels in patients at all stages of the journey through the heart failure trajectory. In cases where patients were perceived to be over-exerting themselves nurses may encourage moderation of activity, and in patients who are inactive, nurses may encourage a more active lifestyle. This can be a complex interaction, taking account of the health state, medical history, and individual circumstance circumstances; but it is up the patient how they choose to respond to this advice:-

*...it's negotiating that with people [about their activity levels] so that they are safe but not putting them off from doing it, but I think the individuals almost need to be to find their way through with what [Natalie]*

## Chapter 9: Implications for Lifestyle Monitoring

### 9.1 Introduction

There are Lifestyle Monitoring (LM) research projects and commercial installations all around the world, and yet the evidence base for their effectiveness in identifying changes in behaviour that are indicative of health or care needs is weak (Brownsell et al 2011a). The following chapter assesses the capability of the sensor platform utilised in the Barnsley LM study to capture changes in home activities that would potentially suggest that participants were experiencing a bad day, or an exacerbation of heart failure. Consideration will be given to strengths and weaknesses of the monitoring technology utilised, and the appropriateness of the proxy measures of activity utilised in this study to explore the relationship between activity and health. Issues around the analysis of LM data will also be described, as this is an essential step in the identification of meaningful changes in activity. And finally suggestions for how to improve monitoring of long term conditions will be made, including ideas about who to monitor, potential input from family members, and issues of patient choice.

The strength and uniqueness of this study comes from the mixed methods approach, which has made it possible to review Cellar's idea that it is possible to infer changes in the health state of participants via the indirect monitoring of home activities. Although this study is focused on heart failure, it has wider implications for LM in general.

This assessment of the LM technology is hampered by the poor quality of the reporting in Telecare research papers, which provide insufficient detail of "... what systems and methods are being deployed and in what context" (Brownsell et al 2011, page 187), and little consideration is given as to whether any changes in activity are linked to changes in health that would require a health intervention. In order to address this deficit, and to understand the processes involved in setting up a LM platform and the analysis of sensor data, two experts were interviewed: Simon Brownsell (SB) an expert in LM, and Fabien Cardinaux (FC) an analyst of LM data (see appendix page 442 for the interview questions asked) . These experts were chosen both for their familiarity with the set up of the Barnsley LM study in particular (which provided the quantitative data for this study), and for their extensive knowledge of LM in general. The interviews were utilised to gain their insights into the sensors deployed in the Barnsley study, to understand more about the strengths and weaknesses of the sensors, the process of data analysis; and their thoughts about how LM can be improved in the future. Insights from the interviews are used throughout this chapter, and can be identified by the reference SB or FC 2011. Broader views were gained from the published literature.

LM stands and falls on the sensor data, since it is through this lens that the health state is assessed. A number of key questions should therefore be asked:-

1. Are the data collection methods reliable and robust?
2. Are the sensors monitoring proxy activity measures that might indicate a significant change in health?
3. Does the data analysis process reveal the activities of the individual being monitored, and any changes that may indicate deterioration in the health state?

The initial sections of this chapter will therefore address those questions, by exploring these issues in relation to the Barnsley study and LM in general. The concluding sections discuss suggestions for improving the monitoring of individuals with long term conditions.

## **9.2 Telecare Data Collection**

LM sensor data is used to create proxy measures of activity, and therefore unless the methods of data collection are reliable, errors will feed into the data analysis process. A summary of the strengths and weaknesses of the LM sensors used to provide data for this study are found in the appendix (appendix tables 13 to 22). The tables show that data collection via such sensors can be problematic, with data quality issues arising out of sensor malfunctioning and breakage, and sensor functioning that may be incompatible with the objective of producing a measure of activity, e.g., the PIR sensor has gaps in data collection. In addition once sensors are placed in the home, issues may arise as participants interact with the technology, on occasion resulting in requests to remove the technology, e.g., the mattress sensor is visible, may move about, and is not comfortable; and some participants may find it intrusive (appendix table 17).

### **9.2.1 Are the sensors monitoring the right things?**

LM systems would only be able to identify signs of a decline in health if the sensors were providing a proxy measure of activities that were potentially indicative of this change in health. The following section uses the Barnsley project as a case study to explore whether the sensors were providing a proxy measure of activities that change when participants experienced changes in the health state. This will be assessed in two ways. Firstly, to find out whether the sensors deployed in the Barnsley study were tailored to pick up activities related to a decline in heart failure. And secondly, to assess the validity of the proxy activity measures developed by this project to explore the relationship between activity and health in the Barnsley LM data, by exploring interview findings describing participants' experiences of these activities under the shadow of differing health states. In addition activities that were not measured indirectly by

sensors in the Barnsley study, but were identified as by the participants with heart failure as subject to change during differing health states, are described at the end of the section.

### **9.2.2 Were the Barnsley Sensors Tailored to Monitor Changes in Heart Failure?**

The sensors in the Barnsley study replicated an existing LM project in Doncaster (for older people in general), and this setup was chosen in order to simplify and speed up the tendering process; and for this reason no consideration was given to matching sensors to the health condition being monitored. The main focus of the Barnsley LM study was to assess the Docobo Telehealth system (the hand-held device which recorded participants' self-reported measures of health and symptoms) (Biddiss et al 2009), and LM was a side issue. The lack of tailoring for heart failure may have reduced the likelihood of the LM system capability to identify changes in the sensor data that would be indicative of an exacerbation of heart failure.

### **9.3 Were the Activities Measured by the Proxy Activity Measures Indicators of Real Change in Health?**

This section draws on data from the interviews with participants with heart failure to examine the validity of the proxy activity measures, used in the quantitative analysis of the LM data, to act as indicators of a change in the health state. As described earlier, the sensors were aggregated into proxy activity measures based on insights from the literature review, and previous measures used in LM studies (page 79). The measures were as follows:-

1. General Activity (general movement around the home using PIRs, and chair activations)
2. Food Activity (kitchen sensor activations, used as a proxy measure of food-related activity)
3. Bath and Toilet Day (daytime bathroom activity derived from count of sensor activations from the bathroom and downstairs toilet)
4. Bath and Toilet Night (night-time bathroom activity derived from count of sensor activations from the bathroom and downstairs toilet)
5. TV Duration (Duration of the time the television was switched on)
6. Day Nap (Duration of time spent in the bed during the data)
7. Total Sleep (Duration of time spent in the bed)
8. Day Activity (count of all sensor firing during the day)
9. Night Activity (count of all sensor firing during the night)

The following section uses interview data from participants with heart failure to describe the impact of health on these activities, by exploring the same activity during the three health states: normal days, bad days, and during an exacerbation. It should be noted that these changes were tempered by the individual situation and context of participants, and the degree of heart failure. Clearly the changes in activity were more marked in participants who lived alone, or were generally more active, than those who were relatively immobile.

### **9.3.1 Bathing and Toileting**

#### **The LM Measure**

The LM proxy measure of bath and toilet activity was composed of counts of PIR sensor firings during the day and night from the bathroom or downstairs toilet.

#### **Evidence from the Interviews**

##### **Bathing**

The impact of ill-health on the bathing routine varied in participants, with some carrying on as normal on bad days, and other's avoiding showering (appendix table 19). Individual factors and circumstances clearly shaped the likelihood of persisting with the normal routine, for example, the medical requirements of Graham's wife guided their bathing routine; Peter's past experience of daily showers after working in a coal mine was still directing his routine even in ill health; and the fact that Eric's most troublesome symptom was sweating made it more likely that he would shower to freshen up even on bad days. Some participants were still bathing during an exacerbation: Willow chose to continue because she thought personal hygiene was important; and Larry also continued even though he found it exhausting and needed the help of his wife. Those with walk-in showers clearly found the process easier.

Other participants stated that they would not bathe on a bad day. Terry, for example, had once collapsed in the shower, and subsequently avoided showering when he felt unwell, and would delay showering until the symptoms had passed. Four participants spoke about missing out a shower if they felt unwell, and this is summed up by Nancy's comment:-

*If you were feeling ill like that you wouldn't dream of getting in a shower*

Olivia also said that she would not shower, but due to the severity of her symptoms she had limited her showers to two or three a week already, and flannel washed the other days.

In conclusion, it could not be assumed that abstinence from bathing indicates a decline in health, since some participants bathed as usual despite feeling unwell, including during an



exacerbation. Bathing could not be used as general health indicator, but selectively in individuals who stop showering when they feel unwell.

### 9.3.1.1 Toileting

Participants reported that the number of visits to the toilet was determined by the diuretics. The number of toilet visits increased in the period after the tablets were taken, and this formed part of the morning routine for many participants:-

*I can go to the toilet ... five or six times [within] half an hour (Dawn B/S-L-Y-P-B/S)*

Most participants noticed no difference in the number of toilet visits when they had a bad day, other than if they had increased the dose of diuretic. Two participants described increased visits, due to stomach problems made worse by a bad day. And one participant said that he would avoid going to the toilet on a bad day because it was too much effort. During an exacerbation toilet visits became a physical challenge, and participants described the slow journey to the bathroom:-

*You know just getting to the toilet; fortunately I use the wife's chair [stair lift] to get me up the stairs to go to the toilet. Even then from the top of the stairs into the toilet I was absolutely shattered. From there to the chair I was shattered, from that chair to the end of the settee there [a few steps] and I would have to stand [sound of panting] out of breath completely (Eric B/S-L-Y-P-B/S)*

In conclusion, toileting was not an indicator of health directly, but indirectly since toilet visits will increase as a result of increased dosages of diuretic taken when participants felt unwell. The number of toilet visits may therefore be a useful indicator of a change in health in individuals who independently manage their diuretic, without consulting a GP. The use of counts of visits to the toilet would not be sensitive enough to pick up the defining characteristic of toileting during an exacerbation, and this was that the journey to the toilet was undertaken very, very slowly.

## 9.3.2 Food Activity – Food Preparation and Eating

### 9.3.2.1 Food Preparation

#### The LM Measure

The LM proxy measure of food preparation activity was composed of counts of: PIR sensor firings in the kitchen; food cupboard and fridge door opening and closing; and kettle, microwave, and toaster switching on and off.

#### Evidence from the Interviews

Few participants were involved in food preparation, and those that did were almost exclusively women. It was evident that on normal days participants had more energy for cooking, whilst on bad days the lack of energy made this difficult (appendix table 20):-

*You can have days when you feel really down and you know it just seems like you are useless you can't do anything and you don't have the energy even to get a meal or anything (Dawn B/S-L-Y-P-B/S)*

Various strategies were employed to reduce the amount of preparation: eating food cooked in bulk on a good day, or simplifying the preparation:-

*...I would try and shortcut a bit. I would love to say I could pull something out to the freezer. I have had a few home-made meals in the freezer recently, which I am very proud, but there are not many left and so I might actually leave it for James when he came home. So I wouldn't prepare food in the same way (Janice M/M-R-Y-P-B/S)*

Others bought ready meals when they felt unwell:-

*...if I'm feeling a bit off I would go across there [to the very close local shop] and get one of those ready cooked meals you just put in the microwave (Terry B/S-L-O-A-B/S)*

This option was not available to participants concerned with limiting salt intake; for example, Janice spoke about avoiding eating out and convenience meals in favour of home cooked meals.

However these strategies to eat without energetic food preparation were not necessarily restricted to periods of ill-health, for example, Dawn would plan to eat a ready meal if she anticipated energy loss later in the day, if she was going to be busier than usual. Olivia, who lived alone, used the bulk cooking strategy all the time, and although she also took advantage of this to simplify eating on bad days:-

*I prepare me potatoes for two or three days and me veg and all that ..., and when I did stewing meat like I did yesterday, that stewing meat will do me for today as well you see*  
(Olivia B/S-L-O-A-B/S)

During an exacerbation food preparation was even more challenging because of the effort required to move around, as Eric described:-

*No I couldn't [cook]. Well occasionally I would go in and manage a sandwich but as I've said I couldn't seem to move anywhere* (Eric B/S-L-Y-P-B/S)

Willow was not able to alter food preparation according to how she felt, as her caring responsibilities meant that she had to carry on regardless of how unwell she felt, even during an exacerbation of heart failure:-

*...I am not just looking after myself. I wouldn't do anything like as elaborate if I was on my own, and just having a restful day, and I do for you know (William) he is a meat and two veg, type of man* [laughter by both] (Willow M/M-R-O-P-N/M)

In conclusion, there was evidence of a change in the style of food preparation during times of ill-health in most of the participants that undertook this activity, but there were exceptions to this. Further detailed information would be required about how food is generally prepared, so that sensors could be focused appropriately to spot changes. The majority of male participants were not involved in food preparation, and therefore this indicator may be of greatest use to females. Partners attending interviews were not asked whether they altered their food preparation in response to their spouse's heart failure, although obviously they would still have to eat. A glimpse into what happens came from this dialogue between Nick and Nancy, where Nick was talking about his loss of appetite on a bad day:-

*At the time when you are feeling [unwell], you know, you are not as hungry* (Nick)

*And he says, and I will say, well you have got to have something. You know what I mean, well probably something light or...* (Nancy)

### **9.3.2.2 Food Intake: Evidence from the Interviews**

The LM food activity measure was also an indirect method of measuring food intake; and this measure was devised to explore the relationship between this proxy measure and measure of self-reported health. The following factors were found to influence food intake generally. Those with heart failure may be encouraged to restrict salt and fluid intake, and thus this may

impact on everyday eating, although it was only mentioned by one participant. Secondly, the severity of heart failure can have an impact on the general ability to eat, with some experiencing breathlessness whilst eating:-

*...sometimes even when he's eating, he's out of breath (Nancy)*

Thirdly, there was evidence of a variation in appetite in general, ranging from one participant who described his enthusiasm for eating, to another who had given up on set meal times and only ate when hungry:-

*I'm terrible with food, I'm on a see food diet [laughter all round] I see food and I want to eat it (Alistair B/S-L-Y-P-B/S)*

*...instead of having a set meal time, you only eat if you are hungry won't you? So he could go right through til tea-time when I come from work, because that's just how you are now... But that doesn't change on your good and bad days, that's just how you are now isn't it? I am not hungry so I am not going to eat  
(Karen, wife of Ken M/M-R-Y-P-N/M)*

Fourthly, factors other than heart failure influence food intake, for example, co-morbidities. Several of the participants had issues with their stomach, and at times this made eating difficult:-

*I do suffer from an upset stomach; always have done ever since I was a child. If there is anything bothering me, my stomach goes (Henry M/M-L-Y-P-B/S)*

Participants were split in their response to variations in heart failure symptoms, with some participants reporting eating less on a bad day, and others eating the same as usual (appendix table 21). Those that ate less described a loss of appetite, and lack of energy to eat:-

*Oh you feel really terrible; you don't feel like eating anything at all. You don't feel like eating. Well I mean you've got to force yourself to eat (Terry B/S-L-O-A-B/S)*

In contrast others did not experience this appetite loss and ate as usual:-

*It's probably a bit more of a struggle to eat purely because I'm tired but I would still eat... Just the same amount I think (Roland M/M-R-O-P-B/S)*

This dichotomy was also seen in the amount eaten when suffering an exacerbation. Larry ate as usual, the only alteration being that he ate in front of the television, which was not usual for

him:-

*Basically eating, I mean I have always eaten well, I didn't eat badly, but eating sat down watching the telly (Larry M/M-R-Y-P-N/M)*

In contrast, others experienced a much reduced appetite, and were unable to eat a full meal:-

*I really lost my appetite when my heart failure was really bad, I couldn't eat large portions, especially when I was really breathless. I was too tired to cook, but I had to for my husband, but I couldn't eat it. I snacked on riveta and ice-cream, it was the only thing that didn't make me feel bloated (Willow M/M-R-O-P-N/M)*

In conclusion, loss of appetite is not necessarily an indicator of ill-health in heart failure, as some will eat regardless of their health state. The indirect monitoring of kitchen activity to imply food intake is not a reliable measure, for a number of reasons. Firstly, on a normal day participants may go out to eat, and thus the absence of kitchen activity comes from feeling well, rather than the opposite:-

*...we like to go out for the day; you know have a meal out... (Graham B/S-L-O-P-B/S)*

Secondly, food may be prepared as usual, but not actually eaten, as seen in the following example:-

*A good example was yesterday, when we were having us tea and just didn't feel good at all (Nick B/S-R-Y-P-B/S)*

*It took you ages, and I said just leave it... (Nancy)*

The kitchen sensors would also not pick up the fact that Nick was eating unusually slowly because of his breathlessness. Another example of this is Willow, who described in the previous quote, preparing food, but not actually eating it. And again, there were subtle differences that were indicative of an altered health state, such as the inability to eat large portions, seen in the change to snacking; but this would not be picked up by the sensors.

### **9.3.3 Television Viewing**

#### **The LM Measure**

The LM proxy measure of the television viewing was a calculation of the duration of television viewing over a twenty four hour period based on the time difference between switches on and off recorded by the socket sensor.

## Evidence from the Interviews

A television viewing proxy measure was analysed on the basis that viewing may alter during periods of ill health. A number of issues would make it difficult to spot any differences in viewing over time. Some participants had the television on during the day as a routine, some as background noise in the home, and others because of activity limitations:-

*...all I do now is sit in that chair and watch television... (Eric B/S-L-Y-P-B/S)*

In homes where participants lived with others, it may not be the participant that is watching television, but there is no way of finding this out from the sensor. In some participants, subtle changes in viewing were reported during periods of ill-health which would also not be picked up by the sensors:-

*It would be on, but I wouldn't really be interested in it. It is just on as a background (Eric B/S-L-Y-P-B/S)*

In addition, in some personal preferences for television impacted on viewing, over and above ill-health, for example, Olivia preferred never to have lengthy viewing sessions, and Janice preferred to listen to the radio rather than watch the television:-

*I would probably watch less, because I would be more likely to lie on my bed and listen to my radio (Janice M/M-R-Y-P-B/S)*

And finally the type of symptoms that participants experienced during ill-health also increased or decreased the likelihood that they would watch television when they felt unwell. Terry who suffered primarily from dizziness, experienced light-headedness on a bad day, and found concentration difficult:-

*...the television [laughs] you see it's ridiculous to say this, but on a good day you can watch telly, but on a bad day it's annoying. You know the noise, and so you switch it off and the quietness is relaxing (Terry B/S-L-O-A-B/S)*

Other participants experienced tiredness, and watched less television because they fell asleep, or went to bed early:-

*... when he's not feeling very good he doesn't watch tele because he falls asleep (Pamela)*

*...on a bad day I'll go to bed early so there will be that few hours in evening where I don't watch (Graham B/S-L-O-P-B/S)*

However despite these caveats, a number of participants did indeed watch more television than usual on bad days with heart failure, as this activity did not require an energy input (appendix table 22):-

*If I'm having an off day, the odds are I'll sit here and watch Jeremy Kyle [laughter]*

(Henry M/M-L-Y-P-B/S)

During an exacerbation, when participants were unusually exhausted, Larry watched more television than usual:-

*I just sort of sat there all day, the only exercise I did was flicking the television remote...*

(Larry M/M-R-Y-P-N/M)

The time of day that the television viewing took place may provide a clue that participants were unwell, since some described watching television during the night when they were unwell with their heart failure. Participants unable to sleep would go downstairs and sit upright on the sofa to ease their breathing, and watch television until the episode passed:-

*And then you just sit up on the side of the bed while it eases off and then if I think I'm going to get back to sleep I get in, or if I'm not I come up have a cuppa, Horlicks or someat, watch telly and then go back after an hour or so* (Graham B/S-L-O-P-B/S)

During an exacerbation, this night-time breathlessness was particularly distressing:-

*...I come down and was watching sport two, three, four o'clock in the morning, and was dozing on the settee. You know awful, awful feeling that, when you waken up in the night-time like that* (Larry M/M-R-Y-P-N/M)

However again, there were exceptions to this link between nocturnal television viewing and ill-health, with a few participants watching television in the early hours for other reason, for example, to escape a partner's snoring, or to watch cricket matches.

In conclusion, additional television viewing may provide an indication of ill-health, especially if it takes place in the middle of the night; but there are clearly numerous other reasons why someone would choose to watch more television than usual.

### 9.3.4 Sleep

#### The LM Measure

The LM proxy measure of sleep was composed of a calculation of the duration of times spent in bed, based on the time interval between on and off bed mattress sensor firings. Measures of daytime naps, and total sleep were calculated.

#### Evidence from the Interviews

It was evident from the interviews that for those living with heart failure, the relationship with sleep changed, especially for those with severe symptoms (appendix table 23). For many of the sample, living with a heart that did not function properly, made them need more sleep generally, as described here by Graham:-

*your days are short, you get up at eight o'clock and by what three four o'clock in the afternoon, you are having a nap or just conserving energy if you want to stop up at night, if you don't get that nap, or just that rest I mean I say, I'm in bed for eight o'clock, that's me day gone (B/S-L-O-P-B/S)*

Some participants would rest or sleep to charge the batteries in order to undertake activities, and to recover afterwards:-

*Charge batteries: If I was going off tomorrow I wouldn't do a thing today  
(Terry B/S-L-O-A-B/S)*

*Recover: ...by time I've washed up, washed meself, prepared me dinner and then I have me dinner sometimes I have to leave I'm in middle of washing up and have to come and sit down and before I know where I am I'm asleep (Olivia B/S-L-O-A-B/S)*

Sleep is therefore used as a means of living with heart failure, to restore the body and recover from energy loss. However there are times of ill-health when more than usual amounts of sleep and rest are needed:-

*... that is how bad a bad day is, I would most likely be on the settee all day  
(Alistair B/S-L-Y-P-B/S)*

Participants described using rest and sleep to combat intrusive heart failure symptoms. The first line of defence on a bad day was to sit, and relax or sleep, on the chair or sofa. Here Terry, Nick, and Dawn describe using relaxation to encourage symptoms to go:-



*...sit down and relax and close your eyes. As soon as dizziness comes on you feel it coming up and if you close your eyes sometimes it goes away (Terry B/S-L-O-A-B/S)*

*... if I feel it coming, you know I put my head back, and like I will close my eyes. Hoping that it might ease it and go away ... (Nick B/S-R-Y-P-B/S)*

*Laying down's my main solution to anything that I find works you know, go to sleep and then it might be better when I wake up and if not I'll be dead... (Dawn B/S-L-Y-P-B/S)*

Graham described his strategy of sleeping away a bad day with heart failure, in the hope of moving on to an improved day:-

*...the only symptoms I get is this tiredness and that's when I'll go to bed...you go to bed and get rid of that day. Put it down as a bad day, go to bed and hope for a better un next day (B/S-L-O-P-B/S)*

Some participants would rest in different ways depending on the degree of intrusion from symptoms; here Dawn describes needing to lie down, rather than sit if symptoms are worse:-

*... only thing I can do really when it's [bad], is just sit down for a while, or if when it is worse... if possible lay down (Dawn B/S-L-Y-P-B/S)*

Participants described resting in different places, either the chair, sofa, in the bed, or on top of the bed. Some had rules about where they would sleep during the day, for example, Olivia said that she only rest in her lounge:-

*I don't go to bed; never go to bed (B/S-L-O-A-B/S)*

Others preferred to go to bed, for example, Janice who suffered from backache found it more comfortable to rest on the bed.

During the night, sleep can also alter according to the degree of intrusion from symptoms. The timing of sleep may alter in response to symptoms, with those that are tired going to bed earlier than usual, or stopping in bed longer:-

*... I am much more likely to go to bed early, and yes, sometimes I go to bed at the same time as Jane and Jake [her children] (Janice M/M-R-Y-P-B/S)*

However, individual circumstances may prevent participants from timing their comings and goings to bed according to their own desires, such as caring responsibilities, and commitments.

In addition, there are many reasons, other than health issues, that would alter timings, such as how active participants have been during the day:-

*...I sleep a lot better when I have been active during the day (Max B/S-R-Y-P-N/M)*

*Yes and you sleep longer, you know you sleep until seven or whatever. Whereas when you have not been active, and you are going to bed at nine o'clock at night you, a lot of the time you were getting up at five in the morning... (Megan)*

The key heart failure symptom that altered sleep was nocturnal breathlessness, although for a minority back pain caused by the build up of fluid, was more intrusive. As previously described, nocturnal breathlessness was shocking, terrifying, and even for long-term sufferers of heart failure, a thing beyond endurance:-

*... [I've] been up fighting for breath and all that malarkey [feeling] scared. Scared. But I don't know you just click in and tell yourself, you know, breathe slow, I don't know, it's scary at first, but err same as I say sometimes my heart feels like it is going to jump out of my flaming chest (Graham B/S-L-O-P-B/S)*

Upon wakening, participants described immediately having to sit up and then sit on the edge of the bed to get their breath back:-

*...when I'd shoot up I'd have to swing my legs round. Get my legs down and sit on the edge of the bed and support myself you know like this [leading forward and breathing heavily] and then I'd get my breath back (Eric B/S-L-Y-P-B/S)*

This technique of rocking to facilitate breathing was seen both in participants experiencing their first exacerbation, and in long term sufferers. Depending on the state of breathlessness, participants would either return to bed, or if it did not settle, go downstairs and sit in the lounge:-

*And then you just sit up on the side of the bed while it eases off and then if I think I'm going to get back to sleep I get in, or if I'm not I come up have a cuppa, Horlicks or someat, watch telly and then go back after an hour or so (Graham B/S-L-O-P-B/S)*

Some participants described being too scared to lie down, as they experienced a feeling of drowning, and thus they slept upright in a chair instead. For some this happened rarely, but for Olivia breathlessness caused long periods of sleeping in the chair:-

*...when water comes I can't breathe at all...I've seen me sit in this chair months at night, not gone to bed, not for weeks, for months (B/S-L-O-A-B/S)*

Again, this need to sit-up during the night was not experienced by all participants when they experienced a flare-up of symptoms, but it happened to a significant proportion of the sample. Willow suffered an exacerbation, and her greatest difficulty was getting settled in the bed, but she was able to sleep once she had done this. However she too sat on the bed-side, but in her case in order to face the challenge of walking whilst experiencing breathlessness:-

*And erm if I got up and went to the toilet, I sat on the edge of the bed for ages, before I could get motivated to go through to the toilet (Willow M/M-R-O-P-N/M)*

Heart failure symptoms also impacted on nocturnal sleep in other more subtle ways, causing restlessness (typically described as tossing and turning), vivid dreams, broken sleep, and wakefulness. For some a bad night with heart failure meant laying in bed worrying, here Nick describes how he fought off his black thoughts by looking and touching a photograph of his grandchildren:-

*...bad experiences, it's always them that seems to come flooding back and not the good ones, err. So like I mean, she will tell you I have got pictures of my grandkids beside of bed, so I can look at them. You know what I mean like, because they are like good things, you know what I mean? They are part of you (Nick B/S-R-Y-P-B/S)*

*Err so when he is feeling down in bed he looks at them (Nancy)*

*And I touch them (Nick)*

In conclusion, changes in sleep may be indicative of a worsening of heart-failure, with participants describing sleeping longer than usual during the day, and potentially waking at night, and having to undertake specific activities in order to reduce the impact of breathlessness. However once again, not all participants experienced all these changes in activity, or the changes could be caused by factors other than health; but these changes were seen in a sufficient proportion of the sample to warrant its use as an indicator of change in health. It is interesting that the place where sleep takes place can alter during a flare-up of heart failure, and thus the use of a LM sleep indicator based on time in the main bed may not be broad enough.

### 9.3.5 Day Activity

#### The LM Measure

The LM proxy measure of day-time activity was composed of counts of all day-time sensor firings (see page 83 for a list of all the sensors that were combined into this indicator).

#### Evidence from the Interviews

Day-time activity was analysed due to the fact that participants may be less active than normal during periods of ill-health. The following elements of day-time activity (dressing, household chores, computer usage, climbing the stairs, outdoor activity, travelling, and social activity), described in the interviews, are used to explore whether there were any differences in activity across the three health states.

##### 9.3.5.1 Dressing

It was commonly reported that dressing was problematic even on a normal day, with some participants sitting rather than standing to dress, and drawing their feet up to put on socks; with these strategies employed to prevent breathlessness and dizziness. During an exacerbation participants noted a greater difficulty in getting dressed, although they continued with to do this as a necessity, with the chief difficulty arising from swelling:-

*I couldn't even get my tights on, my support, no I couldn't bare support, couldn't get them on my legs. I just struggled, you know I had to try and catch my foot. [laughter] And now I can do, you know, things like that absolutely wonderfully, and my shoes, you know I can get into shoes that I couldn't get into before. And the ones with the Velcro fasteners on, I have had to move, you know [make smaller because of the weight loss]. Because my feet were so swollen that they were just about at the limit. You know another ounce or two and I wouldn't have been able to wear them (Willow)*

This change in weight was noted by some in hindsight, with one participant having to have his wedding ring made smaller because he had lost so much weight upon recovery.

It was apparent from the accounts that dressing did become more difficult as heart failure symptoms increased, however the subtleties of this change were not explored in the interviews as part of the interview schedule; and therefore any comments occurred spontaneously. It is possible, although not described, that the partners of people with heart failure helped with dressing more during times of exacerbation of symptoms, as there were accounts of help with similar activities.

In conclusion, dressing could be used as a simple indicator of a change of health, with people with heart failure potentially warned to look out for signs of increased swelling, such as having to loosen shoes or belts.

### 9.3.5.2 Household Chores

The household chores typically described included: cleaning, washing and drying clothes, ironing, washing up, and gardening. Heart failure made undertaking particular aspects of these activities difficult, and typically the issues mentioned were: difficulty bending over (such as bending to weed) and reaching out (which made hoovering a particular problem). Some participants avoided these elements of activity all the time, regardless of their health state. Participants were more likely to describe undertaking chores on a normal day, when the relative freedom from symptoms meant that there was a greater ease in undertaking activities. A typical example of this is the following account by Willow:-

*... hang the washing out, maybe tackle a bit of gardening, err do a bit more cleaning, more thoroughly than I normally do. Erm go out shopping, erm and just generally more active within the house, really, decide to do some clearing up, or something else exciting*  
[laughter from both]

However there was a temptation to do too many chores on a normal day, and this overexertion resulted in exhaustion and ultimately the onset of a bad day. It was apparent from the interviews that participants were well aware of this link between overactivity and bad days, participants typically used the phrase “paying the price” for overdoing things. For some participants there was an acknowledgement of a pattern of overactivity and rest:-

*... I find that if I have two or three days when you have been more active, more physically active, then erm I have what a friend described to me, her mother had angina, and she said her mother said, every now and again, you will get a nowt-ish day. Which is a good Yorkshire expression (Willow)*

On a bad day, participants were more likely to rest, and therefore the amount of chores undertaken would be limited to necessities, and anything requiring exertion would be avoided. There was a decision making process, whereby the physical capacity was matched to a proposed task, and if there was insufficient energy the task may be set aside. Brian described this process:-

*...If I felt that way [listless and lacking in energy], suppose I had got up with the intention of cutting the grass I would say I am not going to cut the grass today, I am going to put that off today*

The phrase 'pottering' was used to describe the type of light home activities undertaken. The scale of activity would depend on individual circumstance, with Henry still committed to carrying out his chores in spite of his health, as they were his contribution to the household, whilst his wife worked:-

*... I will always try to Hoover up before Helen comes home, do the washing up but that's not a problem, make the bed if she hasn't done it when she goes to work. So even on a bad day I'll do that, make myself do that*

During an exacerbation, household chores were not a priority, with attention focussed on conserving energy. In the following account Willow expresses her disquiet about how her house suffered from lack of attention:-

*... the house got [bad], I mean, [it is] not very good now, I never have been house proud [laugh]. Err but I did decide to get a cleaner in, err so she comes once a week. So it really, the only housework that got done really was when [the cleaner] was here, just once a week you know. But erm, yes my whole quality of life was just so poor*

Most participants that experienced a flare-up were male, and therefore may not have undertaken household chores anyway.

In conclusion, the type and amount of chores undertaken therefore varied according to health, although there are exceptions. However the value of this as an indicator of change would be dependent on whether the participant undertook chores anyway. In those that do, there would be the potential to also measure overactivity, in order to avoid the overactivity-rest cycle.

### **9.3.5.3 Computer Usage**

Some participants reported that computer usage was part of their range of usual activities, using it for entertainment, communication, and voluntary work. They would use the computer on a normal day, with the length of use determined by the available time, and the task undertaken. For one participant with severe heart failure, computer use took on a greater significance, as it was one of the few remaining activities that he felt capable of undertaking:-

*I am not exhausted by that, you know what I mean; I am just twiddling my fingers (Nick)*

This lack of physical effort required also made this a suitable activity for a bad day:-

*I'll put the crosswords on the laptop, you know just find something to occupy my time  
(Christopher)*

However other participants used the computer less than usual because of the concentration required:-

*...because my concentration isn't very good, I wouldn't do my email, or anything on my  
computer (Janice)*

This participant talked about having a 'glut' of emails after a bad day, because she had not logged onto the computer. Perhaps for similar reasons, Alistair went on his computer for only a short time on a bad day:-

*Go on laptop for half an hour; mostly watch TV (Alice)*

Only one participant mentioned computer usage during an exacerbation, and this was a brief mention of ordering a book on-line. In good health this person was very active, and thus this day-time computer use may have marked a change of behaviour; but this is speculation.

In conclusion, there is some evidence therefore that computer use changes according to the health state, but the nature of that change would depend very much on the individual. In addition to this there are other reasons why usage may change, such as, the weather outside, or the start of a computer project. Further information is required on what happens to computer usage during an exacerbation.

Participants had individual preferences about what other home entertainments they engaged in, and the way they were undertaken may change according to the health state, for example, participants talked about listening to the radio more in poor health, or reading more.

#### **9.3.5.4 Climbing the Stairs**

The stairs presented the greatest physical challenge in the home for participants, requiring both energy and breath, as described by Willow:-

*I have to take things very easy going upstairs, as I tend to go up one or two at a time, err  
and pause (M/M-R-O-P-N/M)*

As a consequence eight of the participants lived in bungalows, and others avoided climbing the stairs by using stair-lifts or having downstairs toilets fitted; and when out, stairs were avoided unless absolutely necessary (in those with bad heart failure). For those who climbed stairs as part of their normal routine, the onset of difficulty was an indicator to them that something was wrong with their health:-

*...err well I first noticed it at work when I was climbing some stairs err err I ran out of breath (Max B/S-R-Y-P-N/M)*

During a bad day the feeling of exhaustion makes navigating stairs more difficult; but during an exacerbation stairs become a daunting prospect, a challenge to the physical capacity of the body:-

*The breathlessness I mean like when I walk up to work I have three flights of stairs to go up, I had to stop on every level to get my breath back, awful, awful feeling... (Larry M/M-R-Y-P-N/M)*

Participants described avoiding stair usage, either stopping upstairs to use the toilet whilst the diuretic took effect; or in the case of a participant with a downstairs toilet taking everything needed during the day downstairs, and only returning at bedtime. Upon recovery a welcome change was noticed in the ability to cope with stairs:-

*I get breathless on exertion, particularly going upstairs,... nothing like as bad as I did a few months ago when I was so ill, and they have got rid of a lot of the fluid retention, so I can cope a lot better now (Willow M/M-R-O-P-N/M)*

In conclusion, the onset or increase of difficulty in climbing the stairs was an indicator to participants that their health had altered, and this took the form of the activity becoming a greater physical challenge, as a result of this it was undertaken more slowly than usual, and if possible less frequently. This indicator of change would only be of use in homes with stairs that participants utilised routinely.

### **9.3.6 Outdoor Activity**

One key element of a normal day described by participants was outdoor activity, typically: shopping, walking, gardening, sport or exercise, or social activities; or in the case of three participants with very mild symptoms - working. In the following account, for example, Graham describes his typical outdoor activity:-



*Go out with the wife shopping, we like to get out for the day, you know have a meal out, wherever it is we go, owt like that (Graham B/S-L-O-P-B/S)*

For some participants being outdoors in the fresh air took on an extra significance following major threats to health, and they found a greater enjoyment in being outdoors, and sought out opportunities to be outdoors:-

*I like to be outside a lot more now, than I used to be, you know*

*I have been pottering about and had some fresh air, you know. And I think you generally feel better in yourself, you know. Yes you just generally feel better don't you?*

(Max B/S-R-Y-P-N/M)

One participant with severe heart failure perceived fresh air as a key means of improving health:-

*Fresh air is the most important thing there is. It doesn't matter whether you've healthy or not, fresh air helps you to stay healthy, and if you're not healthy, it improves it (Terry B/S-L-O-A-B/S)*

In contrast for many participants a bad day meant not going out. In the following quotation Maria explains the difference between a normal day and a bad day for her partner Max:-

*... if it is one of your off days, you wouldn't go out and do anything would you? Outside. So that's what's different to, you know, you just wouldn't even go out and do anything, would you?*

This preference for being at home during a bad day was shared by many of the participants, who explained that they lacked the energy to contemplate going out, and needed to rest and recharge batteries:-

*When I am bad I won't attempt to go out to be honest, I have times when I wouldn't attempt because I just don't have the energy. When I am fatigued and exhausted, when I am in my exhausted mode, just forget it that is me done (Dawn B/S-L-Y-P-B/S)*

In some cases partners would reinforce this decision to stop at home and relax:-

*..you know if, if Brian says he is not.. not good I just say to him sit there, don't do anything, or read or do whatever he wants to do that is non-strenuous (Barbara)*

For those that were out during a bad day, all pleasure would be gone from the activity, and it would become an ordeal, as Graham explains in the following quotation. In common with other participants, he had a short-hand means of communicating with his wife that his symptoms had worsened, and they would return home:-

*...If I go out and erm if it's a good day [in terms of symptoms] – it's a good day. But if you go out and it's a bad day, I'm in trouble; it's a long, long day (Graham B/S-L-O-P-B/S)*

*So if you were out and you started feeling bad would you come home, or would you persevere? (Interviewer)*

*All I've got to do, if it's getting bad all I've got to say to Grace is I'm struggling here, and then we make our way home (Graham)*

Some participants said that they would still go out if they experienced a bad day, but only in certain circumstances, for example, to fulfil a prior commitment that they were not comfortable to cancel; or to attend the support group, as this was not a physically exerting activity, and also had the potential to boost mood. The participant that lived totally alone recounted that he would only go out to the shop close to his house for a ready meal, in order to cut down on the need for cooking.

During an exacerbation when symptoms are more extreme, there was a similar preference to stop at home, and usual outdoor activities were curtailed:-

*I was just in house and I mean I could still potter in car and go and see Mother but I didn't actually do any [thing else], I used to love going to the gym, I used to love doing exercise, going out in the fresh air, but I couldn't (Larry M/M-R-Y-P-N/M)*

Participants spoke of being unable to plan activities away from the home, such as, holidays, or shopping trips. A good example of this is Willow's account of withdrawing from outdoor activity because of her exhaustion, difficulty moving freely because of her swollen legs, and distressing breathlessness; all of which made outdoor activity too much of an effort:-

*William would say, shall we go to so and so and see so and so, and I would say no, I just can't. I got tickets for the theatre to see [a play] and I just could not, we'd got the taxi booked and everything, because he goes in his wheelchair. And I just couldn't make the effort, and I said I am sorry, I just can't go. And so that was a great disappointment. And he used to say shall we go to see such and such, and I just could not make the effort (Willow M/M-R-O-P-N/M)*

The point at which participants retreated to the home during a flare-up of symptoms depended on individual circumstances, but eventually for all a point was reached whereby normal life was impossible.

In conclusion, changes in the proportion of time spent indoors and outdoors may indicate a change in heart failure, with an increase in time spent indoors potentially signalling a worsening of heart failure symptoms. However before assuming that an increase in time spent at home indicated a worsening of symptoms, it would be necessary to rule out alternative explanations, for example, poor weather, or caring for an ill partner.

### **9.3.6.1 Travelling**

Participants noted changes in their ability to travel that occurred as a result of a worsening heart failure symptoms. The following section describes changes in the ability to walk, and travel by car.

#### **9.3.6.1.1 Walking**

During normal days walking was difficult for participants with severer stages of heart failure, and would be limited according to capacity; and walks of an uncomfortably long distance or up slopes were avoided. For those participants with milder symptoms, walking could be undertaken with less thought, but this activity still had potential to cause exhaustion; but it also could be a rewarding activity that was felt to improve health:-

*I think the walking gives me a sense of achievement, sense of satisfaction, sense of well-being, sense of returning to a level of health I didn't actually expect to return to, because I think when I was first diagnosed by cardiology ... I remember him saying you will be able to do mild slopes, and it just felt like my life was going to be completely incapacitated, so when I go walking it reminds me that it isn't (Janice M/M-R-Y-P-B/S)*

On bad days, as previously described, this exerting activity was avoided. Janice described how she felt not up to her usual walk to drop her daughter off at school:-

*I woke up this morning feeling really tired and I didn't take Jane, I usually take Jane down to school, and usually... I should walk and I'll walk back, which is just under a mile down hill and uphill but erm I asked James if he would do that this morning, I just felt really knocked out*

During an exacerbation of symptoms walking became an ordeal, as the physical effort caused breathlessness. The length of an acceptable walk was scaled down as physical capacity

declined, and the activity was carried out slower than normal, with stops to breathe. This change was observed both in the home and outside:-

*... from the top of the stairs into the toilet I was absolutely shattered. From there to the chair I was shattered, from that chair to the end of the settee there [a few steps] and I would have to stand [sound of panting] out of breath completely (Eric B/S-L-Y-P-B/S)*

*...Just walking to the bottom of the street really slowly and if other people saw me that know me, you should have seen the look on their faces to say what's the matter with you? (Larry M/M-R-Y-P-N/M)*

This extreme difficulty in undertaking an activity that had previously been done without thought alerted one participant to the precarious nature of his health:-

*I could feel my sen [self], I could hardly get out, just walk along front of road here [by the house], and I could feel my sen getting worse and worse all the time, I really were on a downward spiral that needed to be stopped (Larry M/M-R-Y-P-N/M)*

The difference between a walk on a normal day, and during an exacerbation of symptoms was described by Willow:-

*I get breathless on exertion, particularly going upstairs, and walking up slopes, nothing like as bad as I did a few months ago when I was so ill, and they have got rid of a lot of the fluid retention, so I can cope a lot better now (M/M-R-O-P-N/M)*

In conclusion, the ability to walk declined for participants during declines of health, with reduced capability to walk distances, and in common with stair use, this activity became noticeably slower. Walking would therefore be a good indicator of a change in health in heart failure.

#### **9.3.6.1.2 Driving**

During a normal day, driving was a source of freedom and liberation, especially for participants who lacked the physical capacity to walk very far. On a bad day, some participants said that they would not drive, either because they did not feel up to it, or because they considered that it would be unsafe for them to drive:-

*... if I am not feeling right, there is no way I would touch that car. And she knows because there are times when I have said like, you drive (Nick B/S-R-Y-P-B/S)*

During an exacerbation another issue arose that made driving or travelling in a car difficult, and that was the physical effort required to get into the car:-

*...I wasn't going out in the car because it seemed to take so much effort getting into the car and I would have to sit for a few minutes, until my breathing calmed down. So I was becoming quite a recluse. Erm so it was horrible (Willow M/M-R-O-P-N/M)*

Participants that did go out in the car during an exacerbation were very selective about where they would travel to, with long journeys no longer possible, and short journeys restricted to places where only a very short walk was required:-

*Only thing we would possibly do sometimes just for the drive, go to [a farm] you know for the farm shop and a coffee there, or to the farm at [a named place] because you could park literally at the side of the coffee shop so it does impact on your life in a long way (Larry M/M-R-Y-P-N/M)*

In conclusion, journeys by car were restricted as heart failure symptoms intensified, and this has the potential for another source of monitoring.

#### **9.3.6.2 Social activities**

Another outdoor activity that altered according to the health state was the undertaking of social activities. Participants varied in terms of how engaged they were with friendship groups and social activities, but most enjoyed meeting friends on a normal day:-

*We go out shopping, whatever, visit people. Erm and I can't take life seriously, so everything is a big joke to me [laughter] and so especially when I get with people like Herbert it is repartee all the time between us. And there is another chap who lives round the corner from them called David (Brian B/S-L-O-P-B/S)*

However for some participants, talking could bring on breathlessness even on a normal day:-

*...I can be sat here talking to you now and suddenly get breathless...*  
(Stuart M/M-L-O-P-N/M)

During a bad day, participants lacked the energy to participate in conversation, and there was a withdrawal into self:-

*...I can get up feeling err listless, err don't want to join in, I wouldn't take part in the repartee thing (Brian B/S-L-O-P-B/S)*

*I think I withdraw a bit on a bad day, so probably wouldn't take as much interest in the news and stuff, or what the children have to say, or in, yeah I wouldn't bother meeting people on a bad day (Janice M/M-R-Y-P-B/S)*

One participant spoke of wanting to be alone, in order to quietly wait for symptoms to pass; and would actively avoid engaging with visitors, even at home:-

*...you can't really arrange much, to like meet other people, because if he is having an off day he doesn't want to talk to them, and he will like go out of the way if anyone comes (Nancy)*

This avoidance of talking and participation became more extreme during an exacerbation, due to breathlessness:-

*I didn't want to see people, because of breathlessness I couldn't say more than two or three words, I was sort of gulping for breath (Willow M/M-R-O-P-N/M)*

Larry contrasted the difference between his normal exuberant self, and the withdrawal into self he experienced during an exacerbation:-

*I was quieter, I can normally talk the hind legs off a dog I was sat there quiet watching telly, and normally if it is something that I don't watch unless there is somebody watching it, I am jabbering away about someat. I have a very low boredom threshold [laughter] but I was just sort of sat there quiet err you just sort of probably withdraw into yourself... (Larry M/M-R-Y-P-N/M)*

In conclusion, participants generally did describe a reduction in social activities as heart failure symptoms worsened. This follows the pattern previously described of avoiding energetic activities during a decline in health, and although talking may not require the same amount of energy as walking, for example, it does require breath.

### **9.3.7 Night Activity**

#### **The LM Measure**

The LM proxy measure of night-time activity was composed of counts of all sensor firings during the defined night-time period (see chapter 4a).

## Evidence from the Interviews

The following section covers night-time activities that have not already been covered by the sleep and television sections of this chapter.

### 9.3.7.1 Opening Windows

One activity that some participants described undertaking in response to night-time breathlessness was to open a window in order to get more air. However, this would only provide an indication of a change of health, if the window was not normally open. Some participants kept their windows open all the time:-

*I have to have the window open at night to sleep; I think that is to do with breathlessness*  
(Janice M/M-R-Y-P-B/S)

However for others opening a window was not an option, either because they lived in a bungalow and did not feel safe opening the window, or in the case of one participant's because his partner did not like flies to come into the house.

Two participants said that they would go outside into the garden to seek fresh air after getting up because of nocturnal breathlessness:-

*The cooler the air the better, it seemed to you know [help] with your breathing*  
(Nick B/S-R-Y-P-B/S)

However Nick stopped this practice after he could no longer tolerate the cold because of his blood thinning medication, and sound of the door opening woke his dogs up.

Two participants described seeking air during an exacerbation, one using a ceiling fan, and another opening the bedroom window in the middle of the night:-

*...I went to window, opened window, like minus five, minus six [temperature] or whatever it was, getting cold air, and Lauren was like, it is cold in here. I am at window sort of going; I am actually laid with my arms on the window sill going [big gulps of air]. Terrible [said with emphasis]... (Larry M/M-R-Y-P-N/M)*

However other participants said that they did not seek air in response to breathlessness; and therefore, in conclusion, this would only be a useful indicator of a change of health in particular individuals.

### 9.3.7.2 Other Night-Time Activities

Other night-time activities undertaken by participants woken by breathlessness were making hot drinks, moving to another bedroom to avoid waking their partner, and in the case of one participant waking his partner:-

*Now if it is really bad right, I'll wake her up and she comes down with me*  
(Max B/S-R-Y-P-N/M)

However the interviews demonstrated the drink making and bedroom swapping could occur for other reasons, such as, waking early for other reasons, or escaping from a partner's snoring.

### 9.3.8 Subtle Signs of Ill-Health

Whilst not encompassed by sensors utilised in the Barnsley study, one indicator of a change in health commonly spoken of in the interviews, was a change in appearance. Partners of participants with heart failure noted changes in the face, eyes, and general demeanour of their spouse that alerted them to a corresponding change of health:-

*And like I can always tell when he is not feeling [well] by the way he looks and I'll say yes, are you ok?* (Maria)

*He [my partner] can just see it in my eyes and face, and I might think I am doing quite well, I might think I am having a really good day today that's why I haven't been to bed, and he'll come, as soon as he comes to the door and looks at me he knows you have not had your lie down today, have you?* (Dawn B/S-L-Y-P-B/S)

Another partner spoke of being able to tell her partner was exhausted by his appearance.

During an exacerbation participants spoke of a change of facial appearance, with blue lips and face:-

*...and Lauren would say your face has gone blue, your lips have gone blue, what's the matter with you, I don't know* (Larry M/M-R-Y-P-N/M)

Two participants recounted how the consultant they saw told them that he knew immediately what was wrong because of their blue appearance.



There were exceptions to this idea of appearance being an indicator to health, as blue lips also occurred as a response to cold weather. Another participant noted that her appearance did not change even when she felt unwell:-

*People look at your face because I've always looked well it don't matter what. I've been nearly dying and I've still looked like this... (Olivia B/S-L-O-A-B/S)*

In conclusion, facial appearance and demeanour mostly changes during ill-health, and the people most likely to monitor and note this change are close family.

#### **9.4 Signs of an Exacerbation**

The following section focuses on changes in activity that may indicate that an exacerbation of heart failure is occurring, given that this is the health state where an intervention may be necessary to prevent symptoms building up to a dangerous level (BHF 2010, Evangelista et al 2000, Gravely-Witte et al 2010).

##### **9.4.1 Findings from the Heart Failure Support Group Validation Exercise**

Attendees at the support group were asked whether they recognised a statement about the change of activities during an exacerbation of symptoms. There was general agreement that activity during an exacerbation were motivated by the desire to ease symptoms, such as, sitting on the side of the bed, sleeping in a chair, and using sprays and taking extra diuretics to ease breathlessness.

The combination of activities that were undertaken differed depending on the individual, for example, some people described opening windows and other not:-

*My husband used three pillows... Sometimes he will sit at the side of the bed when he is breathless and that but then he gets back in. He doesn't open window (i)*

##### **9.4.2 Findings from the Heart Failure Specialist Nurses**

The HFspNs reported two reactions to an exacerbation of symptoms, with patients either ringing to inform the nurses of a deterioration in symptoms, or more typically sitting the symptoms out in the hope that they will go away. In the second case, nurses reported that by the time this patient group sought help the symptoms had deteriorated to a stage requiring emergency medical help.

When asked what patients do when they experience an exacerbation of heart failure symptoms, the nurses gave a list of activities (table 9.1) that in general terms matches those

reported by the interview participants. The nurses reported patients generally stopping at home watching television; with outings reduced because of the distressing and embarrassing symptoms, for example, difficulty doing up shoes because of swelling, and extreme difficulty in manoeuvring in and out of the car. At night patients were reported to be sleeping in a chair downstairs, either because they were unable to manage the stairs, or breathe in a prone position. Activities to ease breathlessness were also reported, sitting on the edge of the bed, seeking air from fan or window, and as previously mentioned, sitting upright in a chair.

**Table 9.1: Reported Patient Response to an Exacerbation of Symptoms**

Question	Reported Response from Patients
<p>I have been trying to find out what people with heart failure do when they experience an exacerbation of their symptoms, for example, in the days before an emergency admission. Do you have any knowledge about what people do when their heart failure gets really bad?</p>	<p><b>Reaction to a Symptom Exacerbation:-</b></p> <ol style="list-style-type: none"> <li>1. Sitting whilst the fluids build up in the hope that symptoms go away</li> <li>2. Ring to inform the nurse that symptoms have deteriorated</li> <li>3. The onset of social isolation</li> </ol> <p><b>Activities Undertaken by Patients:-</b></p> <ol style="list-style-type: none"> <li>1. Sitting and watching television</li> <li>2. Getting air from a fan or open window</li> <li>3. Sitting on the edge of the bed</li> <li>4. Sitting up at night in a chair</li> <li>5. Avoid climbing the stairs</li> <li>6. Reduced intake of food and drink</li> <li>7. Reduction in going outdoors               <ol style="list-style-type: none"> <li>7.1. An inability to do up shoes</li> <li>7.2. Inability to climb in and out of the car</li> </ol> </li> </ol>

The nurses were asked to make suggestions about what activity should be monitored in the home to provide an indication that symptoms had become worse (table 9.2). Two approaches to monitoring were suggested: monitoring to check for compliance with the self-care regime, and monitoring to detect signs of a decline in health. In terms of monitoring to check for compliance the nurses suggested some means of checking fluid intake, although it was acknowledged that drink could be sourced from outside the home. Monitoring of toilet visits was also suggested in order to check that diuretics had been taken.

The following suggestions were made for monitoring for signs of a decline of health. Nurses suggested monitoring signs of difficulties brought about by fluid build-up: the use of extra pillows, sleeping upright on a chair rather than the bed, monitoring difficulty climbing the stairs, and a reduction in the intake of food and drink. Weight monitoring was also suggested, but this was thought to require either observations from a carer or family member who would notice a change, or nurses to feel the oedema to find out whether it has the spongy texture of severe oedema.

**Table 9.2: Suggestions for Home Monitoring for a Decline in Health**

Question	Suggestions from Nurses
If you were going to monitor home activities to find out whether heart failure symptoms have got worse, where in the home would you monitor, and what home activities would you monitor?	<p><b>Monitoring to check for compliance with self-care regime:-</b></p> <ol style="list-style-type: none"> <li>1. Fluid intake compliance via monitoring the kettle, fridge, and tap</li> <li>2. Diuretic compliance monitored via toilet usage</li> </ol> <p><b>Monitoring for signs of a decline of health:-</b></p> <ol style="list-style-type: none"> <li>1. Use of additional pillows</li> <li>2. Monitoring Weight increase via observations from carers/family/nurses</li> <li>3. Stair monitoring (the number of steps patients can manage before resting. Can patients get upstairs?)</li> <li>4. Bed usage (Are patients sleeping in their bed at night?)</li> <li>5. Chair usage (Are patients moving around during the day, or stopping mainly in the chair? Are patients sleeping in the chair at night?)</li> <li>6. Food and drink intake (Are patients eating and drinking?)</li> </ol>

#### **9.4.3 Summary of Suggestions for Activity Monitoring to Detect Signs of Deterioration in Health that Emerged from the Qualitative Research**

The following table summarised the changes in activity that were gleaned from all aspects of the qualitative research undertaken for this research:

**Table 9.3: Activities that Potentially Change with Health Declines (Identified by the Qualitative Research)**

<b>Home Activity</b>	<b>Does This Change when Health Declines?</b>
Bathing	Depends on the individual
Climbing the stairs	Stairs become more of a physical challenge during a health decline, and may be undertaken more slowly, and less frequently than usual
Computer usage	Depends on the individual (some people use the computer less during poor health)
Dressing	Increased fluid made clothes tighter, such as shoes, belts, and rings. Dressing itself may become more of an effort, especially putting on socks
Food intake	Depends on the individual. There may be subtle signs of change, e.g., eating smaller portions, or snacking
Food preparation	Food preparation is simplified
Going outside	Decreases as health declines
Household and garden chores	As health declines chores may be limited to necessities, and activities requiring physical exertion avoided
Seeking air	Some people seek air during episodes of breathlessness, opening windows or doors, or using a fan
Sitting on the edge of the bed	During episodes of breathlessness people may sit on the edge of the bed in order to recover breath
Sleep	Rest and sleep may increase during periods of ill health, with rest during the day, and nocturnal sleep potentially broken by breathlessness
Sleeping in the Chair	When breathlessness is bad, some people resort to sleeping upright in the chair
Social activities	A withdrawal from social activities occurs as health declines
Subtle signs	People talk less during a decline of health, and withdraw into self. A change of appearance of the face, eyes, and demeanour was noted by partners during a decline of health
Television viewing	Viewing may increase during periods of ill-health, and viewing in the night may be a particular indicator
Toileting	Only if diuretics are increased
Travel by car	Duration of journeys reduced, and destinations limited to those physically easy to access. Travel by car may be curtailed because of difficulty climbing in and out of the car
Walking	Walking become more of a physical challenge during a health decline, and was undertaken more slowly, and walks were less frequently than usual, and of shorter distances.

These findings confirm that activities do indeed change when health declines.

#### **9.4.4 Are Other Studies in Accord with these Indicators of a Decline?**

A literature search was undertaken to identify qualitative studies that focus on the lived experience of heart failure, in order to compare the findings from this study<sup>2</sup>. No other

<sup>2</sup> On-line bibliographic databases, such as, Medline and Cinahl, were searched using the search terms: heart failure and qualitative study. The selected papers were manually searched for information about activities that participants undertake at home to manage symptoms; this was not the main focus of the papers, and therefore small nuggets of information were located amongst the information about other

qualitative study has focused on the changes in activities that occur in the differing health states of heart failure, although studies offer some glimpses into this. The majority of studies explore life with heart failure at different stages, and thus changes in activity recounted relate to an adjustment to this stage of health; although there are some mentions of occasions where health was worse than usual. One rare study identified differing states of breathlessness, exploring everyday good and bad breathlessness, night-time breathlessness, and worsening breathlessness; and there was some description of accompanying activity (Edmonds et al 2005). These studies confirm that the activities identified by this study that change when health declines are commonly described, although they may relate to a more permanent change of behaviour in the later stage of heart failure.

Appendix tables 24 to 26 show the activities related to the differing states of breathlessness identified by Edmonds et al (2005), and the nocturnal breathlessness activities especially chime with the findings of this study. The participants described how they managed the breathlessness by a reduction in physical activity, and therefore it would be expected that home activities would reduce when an episode of breathlessness occurred (unless the reduction in outdoor activities led to an increase in home activities). The strategies employed by the predominantly male sample, were as follows:-

*These including minimising the number and intensity of everyday activities, a reduction of activities outside the home (including hobbies) and in some cases even a need to stop talking, leading to a sense of social isolation. Patients also developed strategies to manage night-time breathlessness, such as altering the time of administration of diuretics or sleeping position (Edmonds et al 2005, page 65).*

Appendix table 27 lists the changes in activity described by the participants of other qualitative studies undertaken to deal with the life-changing symptoms of heart failure. Whilst many of the activity changes relate to permanent changes, the descriptions of activities related to bad days and breathlessness concur with the results from this study. The broader descriptions of activity change may provide an indication of activities that could be monitored to keep track of the progression of heart failure, which would be especially beneficial if medical intervention could delay progression.

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subject matters. A minority of additional papers were found whilst searching for other issues, or from the bibliography of selected papers.

### **9.5 Can this Activity Change be captured by Telecare sensors?**

Appendix tables 24 to 27 details the strategies that participants from the qualitative studies (identified by the literature review) employed to enable them to manage their heart failure symptoms, and describes which sensors might capture these strategies, any potential gaps in sensor provision, and comments about how activity might be recorded, and any issues that may arise. As explained earlier, these strategies are generally employed to deal with the challenges of everyday life, rather than a sudden decline of health; however these strategies tend to be the same as those used for a sudden acute exacerbation of symptoms, and therefore they give provide further clues for what could be usefully monitored.

The table below (9.4) shows the activities that were found by this study to be potential indicators of deterioration in health, and a discussion of how these activities may be monitored by technology. In general current LM technology offers a broad brush approach to monitoring activity, and is unlikely to be able to pick up subtle signs of a decline in health. It is therefore crucial that partners are given the opportunity to feed in their observations of declining health (Brownsell et al 2011b), since they are attuned to monitoring signs of a decline (Clark et al 2008). The study has identified key activities that could potentially be monitored by technology, such as sleeping in a chair rather than the bed, and sitting on the edge of the bed to get breath back.

The more directly that technology can monitor an activity directly, the more likely that a decline in health could be identified. At present levels of sensor activations are often used as a proxy to activity, for example, movement in the kitchen is assumed to signify food preparation, rather than monitoring the tools of food preparation, e.g. a sensor on a pan, the scales, and a wooden spoon. This study has demonstrated that qualitative research can be utilised to identify key activities that change when health declines; and sensors could be developed and fine-tuned to pick up signs of change. The qualitative study also showed the need to personalise monitoring, to take account of circumstances, and individual differences (by identifying activities that are important to that person, that they would be likely to try and maintain unless illness prevented it); and by tuning into the specific health condition (by identifying particular activities that are undertaken to manage worsening symptoms), and individual behaviours, and the unique set-up of the home, has the potential to increase the efficacy of LM. The greater understanding of the health condition being monitored also revealed the potential for a broader use of LM, for example, to identify signs of the overactivity-rest cycle, which could benefit health in the long term.

It is therefore recommended that interviews are undertaken prior to setting up a LM system in the home of an individual with a long-term condition in order to tailor setup. Participants would be asked about their normal routine and activities, and whether there are any activities that they undertake in order to manage symptoms on bad days or exacerbations. There are however additional costs around personalising LM (SB 20111), not only in terms of the greater preparation needed, but in the tailoring of sensors to pick up activities specific to individual circumstances and health conditions. However it is likely that over time as a knowledge-base grows about which sensors are more suited to which circumstances, the costs will fall; although in the short-term there will be increased costs. It is acknowledged that the drive for LM came from industry and not patients or clinicians (Elwyn et al 2011), and this may explain the gap between the existing sensor measurements and those that would be of clinical value to warn of a deterioration in health. For Elwyn et al (2011) this failure to capture data of clinical significance emanates from the choice of data sources, with the focus on data that is easy to collect rather than data that is indicative of a change in health.

**Table 9.4: Potential Methods of using Technology to Monitor Home Activities Identified by This Study**

Home Activity	Issues Around Monitoring Technology
Bathing	An ideal technology would measure i) how often bathing happened ii) how long bathing took, in case the task was carried out more slowly during an exacerbation; and iii) whether a partner was helping, as this may not happen normally. The current method of using a bathroom PIR would not be able to provide this level of detail.
Climbing the stairs	A means of counting both the number and duration of stair ascents and descents should be sought - potentially a device recording the time spent climbing from the first to the last step.
Computer usage	Information would need to be sought about people's habits of computer use, in order to check whether it was worth monitoring. The duration of usage could be monitored via a socket device.
Food intake	Technology could not be used to directly measure subtle signs of change in food intake, but there should be some means of enabling individuals/partners/carers/health care professionals to report observed changes.
Food preparation	Information about normal food preparation methods would need to be sought in order to monitor and measure the duration of these tasks, as during periods of ill-health participants described shorter and less elaborate cooking methods. Microwave usage may potentially increase during periods of ill-health, in order to reheat previously prepared meals, or shop-bought ready meals; this could be measured using an electrical socket device.
Going outside	A key sensor could be used to monitor when the door used to go out is locked from outside (this may differ from the door used to access the garden). However this system could only be used on mortise locks, rather than Yale locks which close automatically.
Household and garden chores	The current method of measuring the undertaking of chores is via room PIRs. A more targeted approach may be more productive, for example, placing a sensor on the door of the cupboard where cleaning equipment is kept, or the garden shed. A sensor on the door going out to the garden may also provide some indication of outdoor activity.
Seeking air	Window monitoring would only be of value if the window was generally closed. Windows and doors opening and closing could be monitored with a door sensor, with openings that occur at night potentially of greater significance.
Sitting on the edge of the bed	A means of monitoring the duration of time spent sitting on the edge of the bed is needed.



<b>Home Activity</b>	<b>Issues Around Monitoring Technology</b>
Sleep	Mattress monitors are currently used to measuring bed occupancy, although they would not be able to pickup subtle signs of ill-health, such as more restless sleep.
Sleeping in the Chair	Information about where people sleep when they feel unwell should be sought in order to monitor use of this alternative sleeping place, as participants commonly mentioned sleeping on the sofa or chair in the lounge during episodes of nocturnal breathlessness. This measure of chair usage would be more reliable if the chair was used exclusively by the participant; and this is not unrealistic, since some participants had an upright chair that they favoured.
Social activities	The key sensor could provide an indirect means of measuring social isolation, as people may cancel social activities. A means of reporting the scale of breathlessness during speech could provide an indicator of worsening breathlessness.
Subtle signs	Some means should be provided for partners/family to report observations about the appearance of their relative with a long-term condition. Partners were very in tune with their partner's health, and thus this valuable information should be fed into the monitoring.
Television viewing	Information about television viewing would need to be sought before monitoring, as people may always have to television on as background noise, or undertake other activities during periods of ill-health, e.g., listening to the radio more. A television electrical socket device could record the duration of time the television is on, but not whether it is actually being watched. A measure of night-time viewing may be an important indicator of a change in health.
Tightening clothes	Some means of reporting that clothes or shoes have become tighter would be a useful indicator of increased fluid build-up. It would be important to find out the order in which parts of the body become swollen, as the fluids build up; and what is the normal pattern in individuals.
Toileting	This activity could be monitored via a toilet counter to check that people are taking their diuretic, in order to prevent flare-ups resulting from lack of compliance with the medication regime.
Travel by car	Car travel could be monitored indirectly via the door key sensor.
Walking	The number of daily steps could be recorded via a pedometer, and speed recorded via an accelerometer (Schimpl et al 2011)

## 9.6 Issues around the Interpretation of LM Data

The method of monitoring health indirectly via proxy measures devised from LM sensor data means that there is a potential gap between the data and what is actually happening in the home (Moretti et al 2013), and during the analysis process there may be an incorrect assumption that an activity has taken place, e.g., just because someone is in the kitchen they are cooking. There are examples in the literature whereby researchers build up a scenario of what they believe has happened in the home and then have to seek confirmation from the participant about what actually did happen (Hanson et al 2009). This suggests that there is a gap between what the data can tell us, and what actually happened; this is what engineers often call 'ground truth,' and it is a well known issue in LM (Hanson et al 2009) . In order for the data to reflect reality more, there needs to be a narrowing of the gap between the actual activity and the data collection.

In addition there are other factors that obscure the interpretation of what is happening in the home. There was no way for the sensors used in the Barnsley project to distinguish between the activity of the participant and other people in the home. This may complicate matters, especially when as demonstrated by the interviews, partners or family may take over activities when participants are unwell. Another factor is weather, with participants more likely to undertake outdoor activity when weather is fine, and stop at home when weather is poor; and this would have to be factored into interpretation of LM data. Once participants leave the home, interpretation of their activity is even more difficult, because of the wide range of activities that participants could engage in, all with a potential different meaning for health. FC (2011) described this as the difference between going out to go dancing, and going out to go to the doctors; and the sensors would not be able to distinguish between these completely different activities. Even when sensors are tailored to specific activities there would still be the potential for misinterpretation, for example, whilst sitting on the edge of the bed may be used for getting the breath back, it may also be used to aid getting dressed.

*Getting dressed you find you sit on the edge of the bed to do it whereas you would have probably stood up to do it before (Henry)*

There is also the potential for older people to subvert the functioning of sensors by activating them deliberately (Milligan et al 2011), for example, participants could potentially open and close the fridge to hide the fact that they are not eating.

Therefore there could always be a potential for misinterpretation of current indirect LM data. Clinicians have also pointed out the difficulty of translating clinical knowledge into algorithms,

and the fact that no system could replace the intuition used by clinicians to spot a decline of health in a patient (Peirce et al 2011). There is also the difficulty inherent in writing algorithms to identify events that happen rarely, although one project aimed to address this by creating synthetic LM data that can be used to test the accuracy of analysis to identify pseudo changes in activity (Cardinaux et al 2010).

### **9.6.1 Bridging the Gap between Activity and Data Capture**

In order to bridge the gap between activity and data there have to be improvements in data collection, in order to reduce the margin of error, and establish what actually happened in the home more accurately. The interview data from this study establishes that there are changes in activities that do signal a decline in the health state, and therefore by improving methods of detecting these changes the LM system would be more effective. The following are examples of means to improve the accuracy of detecting changes in the health state:-

#### **9.6.1.1 Diaries**

A diary could be used both as a means of checking the assumptions made from the LM data (Hanson et al 2007), and as a clinical tool in its own right to identify whether expected activities are being undertaken. Participants could be asked to record a diary of activities undertaken, which could be done simply by selecting from a list of typical activities. Audio diaries have also been used to capture the experience of living with a long-term condition, such as the 'closed diary' approach which the researchers thought would be useful "...to find out more about living with ... chronic conditions while managing ordinary events in daily life" (Sargeant & Gross 2011, page 1368). However there are shortcomings to diaries, as input over time can be arduous for participants, the recording may not be accurate, or incomplete (Cardinaux et al 2010); and the triangulation of data sources can be time-consuming (Hanson et al 2007).

#### **9.6.1.2 Health Monitoring**

Rather than inferring the health state through activity, health can be checked more directly by the daily answering of health questions, for example, the Bosch Health Buddy (Bosch Healthcare n.d.) was spoken of very highly by the participants, who valued the link to Heart Failure Specialist nurses who rang up when issues of concern were highlighted. However, as noted earlier (chapter 5), the scoring of health questions is not necessarily reliable; and the advantage of LM is that this approach does not require any intervention from the older person.

### **9.6.1.3 Input from People**

The gap in understanding might be filled by feeding into the equation, observations from family, friends, carers, and health professionals, “The ability to capture and record observational data from all these sources is likely therefore to be a significant contributor to enhancing the effectiveness of future lifestyle monitoring systems, and hence their levels of acceptance” (SB 2011, Brownsell et al 2011a). It is possible that if this group of family, friends, carers, and health professionals were given the opportunity to report their insights into the health of the participant, this would be a valuable addition to the LM system, since the observations are more direct, and of a greater complexity than the data provided by sensors in the home. A carer in a study talked about the value of routine contact to pick up signs that things are not well via, “little things that can be missed... things you can’t quantify” (Percival & Hanson 2006, page 900). In addition, partners may be better able to assess variations in symptoms and spot important changes in activity than their ill spouse, as the interviews and validation exercise demonstrated a keen awareness and monitoring of changes. This more accurate assessment of symptoms by partners was confirmed by Riegal et al (2010).

In addition this ability to report observations would give partners and family a formal role to play in maintaining the health of their ill relative, and this may potentially empower relatives in this difficult and stressful situation (Imes et al 2010, Pattenden et al 2007, Whittingham 2009). The importance of acknowledging both the needs of family and their role in care is recognised by the Relationship-Centred care model, which although designed primarily for hospital setting has important messages for the community setting (Nolan et al 2004). However this move to formally involve partners would have depend on the consent of the family member with a long-term condition.

### **9.6.1.4 New Technologies and Approaches**

Researchers are experimenting with a range of technologies and approaches to LM, including the following:-

#### **9.6.1.4.1 Video Monitoring**

Researchers are currently working on using obscured images from cameras to monitor home activity, which is a more direct way of viewing activity, but the data will still need to be interpreted (Cardinaux et al 2011). There is the potential to use cameras to make more sophisticated assessments of activity than would be possible from typical LM sensors, for example, typical LM sensors would never be able to pick-up signs that a person is not coping in the home, e.g., a lack of cleanliness (Milligan et al 2011), but video monitoring potentially

could. However there are ethical issues around the use of cameras in the home (Cardinaux et al 2011).

#### **9.6.1.4.2 Radio-Frequency Identification (RFID)**

This technology uses very small sensors that can be placed round the home, for example, on a toothbrush, or in clothing. It may be possible to make monitoring more specific to individual activities, for example, to find out what kitchen implements an individual uses during typical food preparation, and monitor these to obtain a more immediate picture of these activities (Buettner et al 2009).

#### **9.6.1.4.3 Microphones**

Information can be gathered from sound in the house, to provide an indication of need; the analysis of home sound is at an early experimental stage. Such methods are likely to be less controversial than using video cameras (Schroeder et al 2011).

#### **9.6.1.4.4 Emotive Computing**

Researchers are investigating the efficacy of using new technologies to monitor the emotional state of participants, such as, using a webcam to check on facial features and gauge the emotional state (Ball et al 2011). This approach to LM has the potential to tap into the subtle signs of ill-health, such as demeanour, which was noted to alter during bad days with heart failure. The value of appearance as a gauge of ill-health was acknowledged by clinical informants to a study looking for means to improve telecare monitoring of heart failure and COPD (Hardisty et al 2011).

#### **9.6.1.4.5 Monitoring Outdoors**

Technology, such as, Global Positioning Systems (GPS) enabled mobile phones provide an opportunity to monitor activity beyond the home (Boulos et al 2007). Measures of outdoor mobility may prove to be a key indicator of health (Peirce et al 2011), and certainly this study demonstrates that outdoor activity is more likely to be undertaken when participants felt well. The GPS data can provide information about participant's whereabouts, speed, and distance of travel, and monitor for signs of falls (Boulos et al 2007).

#### **9.6.1.5 Focusing Down onto Key Activities**

Another method of narrowing the gap between data collection and home activities is to have a setup with fewer sensors that are targeted at specific activities, and by this means to simplify and reduce the data collected, and the data analysis process. A setup with too many sensors can drown out the important signals so that the analyst cannot see the wood for the trees

(Glascock & Kutzik 2009), for example, within this project the most important sensor may be the downstairs chair sensor, as participants' gave accounts of sleeping in the chair during episodes of breathlessness; however as this sensor was grouped together with others, this data was diluted and thus no strong associations were found. A project in Dundee stripped back the sensors they used, to focus on key rooms (such as the kitchen), and rather than seeking to create proxy measures of activity, used PIR sensors to gain an impression of a general level of activity (busyness) (Stewart 2010). This approach was thought to be less intrusive, and require less data interpretation.

#### **9.6.1.5.1 Making the link to a Health Intervention**

A weakness of current LM research has been the absence of a link between the detection of abnormal patterns in LM data and clinical intervention. "The critical requirement for success would be the identification of a detectable data signature that, if identified, could yield an alert and lead to an effective and timely intervention, in other words, a clear objective that has a clinical benefit" (Elwyn et al 2011). Telecare visionaries conceive of the potential for the technology to not only alert clinicians of important changes in health, but also to identify health and care needs, or the requirement for a reassessment of needs (Amaral et al 2005, Brownsell et al 2011). It is therefore time for this technology to move beyond the focus on methods for data analysis into the 'real' world (Brownsell et al 2011), and to focus on shaping the systems to meet practical needs, especially in these frugal times. Without this link to health, there is little justification for participants to undergo the disruption of having LM systems in their home, and the presence of the systems may raise false expectations (see appendix paper 1 – ethical issues). In addition clinicians involved in telecare studies may become disenchanted (Peirce et al 2011).

This study focussing on heart failure, illustrates the complexity of making this link between an individual with a health condition, to monitoring by LM, and then alerting a healthcare professional of the need for an intervention. The aim of LM in heart failure would be to prevent symptoms deteriorating to a state that would necessitate a lengthy hospital stay. The key, therefore, would be to identify signs of early decline (prodromes) (Hardisty et al 2011), and therefore an additional stage would be required to identify the changes in activity that occur at an early stage in a deterioration. There is little evidence from the literature of what the early signs of deterioration would be, with papers exploring changes in symptoms before a hospital admission demonstrating a lack of clarity (see chapter 8), and as previously mentioned there are sparse published findings about how this would translate into changes into activity.

Whilst the interviews did not specifically ask about the first signs of deterioration, a number of participants spontaneously described the first sign of an exacerbation of heart failure as a new or increased difficulty walking or using the stairs:-

*...I had been having this increasing breathlessness and then the snow, I couldn't go further than five yards with a bag and I had to stop myself and think this is ridiculous*  
(Janice)

*...the first thing I actually noticed was extreme tiredness, just exhausted all the time, and shortness of breath whenever you were going up a hill or up some stairs...* (Larry)

*... I first noticed it at work when I was climbing some stairs err err I ran out of breath*  
(Max)

*It was walking really. I have always been a fast walker and I had to slow down. And I couldn't bend down to clean, like dusting the skirting boards* (Willow)

The idea of monitoring activity to spot the early signs of a deterioration of heart failure was also suggested by participants of a study exploring how to use technology to greater effect for the management of long-term conditions, "Clinical informants raised the possibility that sensors of movement, of activity, rather than physiological variables such as heart rate values, may be helpful indicators of deterioration, anticipating that they may be more responsive" (Elwyn et al 2011, page 5). Another related study suggested that there are other signs that are of less value in detecting the early signs of deterioration, "...if you detect something in someone's voice [e.g. difficulty in breathing] you wouldn't be detecting it early. At that stage it's progressed" (Peirce et al 2011, page 179). Therefore further information is needed to understand if there is an order to which changes in activity occur in response to the symptoms of an early deterioration of heart failure, or any other long-term condition. However it is likely that this may turn out to be a more complex task than it first appears, given the factors impacting on activity already discussed in chapter 6.

Participants with long-term conditions have raised concerns about whether there would be adequate clinical support to react to early signs of a deterioration in health (Hardisty et al 2011); and this chimes in with the experience of participants to this study who experienced difficulty in accessing healthcare despite suffering a decline of health. It would be unethical for a LM system to pinpoint a decline in health, without a timely and appropriate response from clinicians (see appendix paper 1 – ethical issues).

## **9.7 Reflections on the Future Use of Technology to Monitor People with Long-Term Conditions**

Technology has been heralded as part of the solution to the increasing number of people living with long-term conditions in old-age, tight budgets for healthcare, and the desire for individuals to continue living at home (DoH 2013, DoH 2013a). In addition some researchers assert the view that the push for LM has come from industry, rather than older people themselves want (Chan et al 2009, Milligan et al 2011); and therefore within these two forces shaping the future of technology there is a necessity to place peoples' needs and wants at the centre of future developments (Blackburn & Cudd 2012).

### **9.7.1 Facilitating Contact with Health Professionals**

Technology can never replace people, as a participant of a focus group on technology stated, "Yes, it has its part to play but it's not a substitute" (Milligan et al 2011, page 350). Input by people can however make technology more acceptable (Sharvill 2012), such as, the electronic care surveillance system in Sweden which linked to familiar care workers, who attended if issues arose; and thus there was a human face to the monitoring (Essen 2008). Researchers have pointed out the risk of focusing technology based monitoring systems around the medical model of ageing, at the expense of more rounded view of ageing, focusing more on the needs for social contact (Blythe et al 2005, Sinha 2000). Concerns have also recently being raised about the impact of cuts in the community health services (Campbell 2012), and this has implications for the well-being of people living with community with long-term conditions (Audit Commission 2004).

The additional value from contact with a human caregiver comes from not only their ability to pick up on subtle signs that something is wrong (Giordano et al 2011, Percival & Hanson 2006); but also from the relationships formed between older people and health professionals, which benefit and enrich the lives of both parties (Giordano et al 2011). This was emphasized by participants of the interviews who spoke highly of both their Heart Failure Specialist Nurse, and the calls they received from the Health Buddy call centre if concerns were identified:-

*...when there's something they're not satisfied with they (the council call centre) phone me, you know, to ask me questions, so I feel as if I've got help. I think I feel better about me health because I've got that. Somebody to talk to about it, you know, and Karen's good (my Heart Failure Specialist Nurse)... In fact I think she's due next week, they're like friends not nurses - friends (Olivia)*



Technology is therefore valued that facilitates contact with people, and makes living with a distressing long-term condition bearable; and this is a strength that future LM systems should build upon.

### 9.7.2 Addressing Fears

It was apparent from the interviews that during the course of living with a long-term condition, there are times when their symptoms cause fear and distress, and that these episodes have an impact on quality of life (Murray et al 2007). The time when this was more likely to occur was during the night when the feeling of isolation with the illness was most acute, and depressing thoughts fill the mind:-

*And it is scary, when you don't feel well in the night, it is always more scary than daytime isn't it... So that's why he wakes me I think, because he is scared that he is going to die...*

(Nancy)

This is something intensely terrifying about nocturnal breathlessness, and the heightened level of fear, and thoughts of impending death are also described by other studies (Ryan & Farrelly 2009, Shackell et al 2007). Nocturnal breathlessness is difficult both to experience and witness (Brostrom et al 2003, MacCallum & Hughes 2009), and is made worse by anxiety (MacCallum & Hughes 2009). For people living alone a night of breathlessness is particularly gruelling (Ryan & Farrelly 2009).

Other studies have also identified the night-time as a particularly difficult time, with a manager of a community alarm service recounting how a customer called regularly in the night for reassurance, "He's lonely, he's got a catheter and his nights are long" (Blythe et al 2005, page 684). In addition to this, the night-time is also the most difficult time to call for help because of the limited available services during the night hours.

There would therefore be a value in a service that called to check that participants were alright if sensors indicated that people were up in the night, to provide reassurance and to remind people that they are not alone, to provide advice about how to manage symptoms, and if necessary to arrange for a medical intervention. Such a service may also help to counter the depression associated with living with a distressing long-term condition as this may have a far reaching impact (in heart failure this is linked to a poorer prognosis) (Vacarino et al 2001).

### 9.7.3 Interpreting Changes in Symptoms

At the core of preventing an exacerbation of a long-term condition is the recognition that symptoms have worsened, as early recognition can prevent development to a point where hospitalisation is required (see for example the guide to managing COPD exacerbations (NHS Medical Directorate 2012)). In heart failure, as demonstrated by the interviews, there is potential for confusion about assessment of the state of heart failure because of the interaction with symptoms from co-morbidities; and the tendency to attribute symptoms to alternative explanations, such as, the side-effects of medication, age, or everyday health conditions that are not a threat to health:-

*I just thought I had pulled a muscle in my back or something, you know I thought it would just go away, but it didn't go away, it got worse... (Max)*

This tendency to attribute symptoms to a cause other than heart failure was supported by the study by Riegel and colleagues (2010). Such confusions typically lead to delays in seeking medical help, and all the time the exacerbation is building up.

There is a role therefore for technology to provide information and education about the key symptoms participants and their partners should be looking for to spot signs of an exacerbation. Once again, there is the potential for partners to take the initiative, since the interviews demonstrated that they were often advising their spouses to seek medical help earlier than they actually did:-

*Yeah I was just so ill, and Lauren kept saying you should go, you should go to the doctor... (Larry)*

*I had some swelling in my legs also, and then that's when my wife said you ought to go and see the doctor, and I said no [laughter] and then eventually I did, and he said oh we have got to send you to the hospital... (Max)*

Riegel et al's study (2010) corroborated the "vital" role of family caregivers to both "detect and interpret their [family member's] symptoms; caregivers should be targeted for health education" (page 98-99).

It should be acknowledged that there were other factors which delay the decision to seek medical health during an exacerbation (as seen in the interviews), such as, a reluctance to go into hospital, and a feeling of guilt that the parlous health state has been caused by personal weakness. In such cases, the monitoring of activity would assume a greater importance. For

those living alone, the importance of understanding the significance of changes in symptoms is of greater importance, since they may lack others to interpret their state of health.

#### **9.7.4 Creating a Web of Approaches**

By using a combination of approaches: focusing LM on key changes in activity that occur as symptoms decline, and carefully selecting technologies that would most closely monitor and represent these activities; formally enlisting partners and family to record changes in symptoms; and educating and empowering participants and partners about the meaning of changes in symptoms, and how to respond to them – it is anticipated that this would be more likely to be successful at alerting health services to important changes in health.

#### **9.8 Who Would Benefit Most from LM?**

The following section considers who would most benefit from monitoring, as it would be neither possible, nor desirable to monitor everyone with a long-term condition. The first consideration would be to look at who would be most vulnerable to ill-effects from their health? In terms of the participants from the interviews, one participant stood out as most vulnerable, and this was the elderly participant living completely alone (without family and close friends). There is clearly a difference between this state, and the situation of the other participants living alone, but who had frequent visits from family and friends.

Vulnerability also came from instability in symptoms, with one participant in particular describing rapid changes, such as a sudden collapse, and the swift onset of the symptoms of bad days. A number of studies have identified the type of patient who would benefit most from monitoring in terms of clinical need, with those with a high risk of readmission identified as most likely to benefit from monitoring, and stable, the 'worried-well', and end-stage patients identified as unsuitable (Peirce et al 2011). Consideration should also be given to the ease or difficulty of spotting the signs of a decline in health, with those conditions that have easily identifiable symptoms having less need for monitoring, than those conditions with more complex, less perceptible interactions. The nature of the exacerbation may also dictate how beneficial monitoring would be, with conditions with a very rapid onset of exacerbation (Hardisty et al 2011) potentially more difficult to identify via technology and put a solution in place, than those that develop over time. It is likely that vulnerability will change over time, and this complicates any assessment of need for monitoring.

At present there is insufficient evidence about the clinical effectiveness of LM (Brownsell et al 2011), and thus we do not know whether LM can be used to monitor specific health conditions

more efficaciously than traditional means. This therefore is the stumbling block of LM, since without this information the question of who would benefit most from LM cannot be answered.

## **9.9 Conclusion**

This chapter demonstrates the complex nature of the challenges LM faces to identify important change in health and to alert health professionals to these. Complexity is woven through all these processes, and all stages careful consideration of options is necessary. The findings from this study show that there is a relationship between activity and health in heart failure; but within this, there are differences between individuals, and these have to be understood in order to pinpoint suitable activities to monitor. However these activities tend not to be carried out exclusively for health reasons, and firstly these alternative reasons would have to be discounted. The efficacy of LM sensors to identify changes in health is therefore dependent upon a setup which reflects individual circumstances, symptoms specific to a particular health condition, and the appropriateness, reliability and functioning of the technology. The next stage is interpreting the sensor data, and experience has shown the difficulty of relying on data alone to depict what is happening in the home; and therefore future systems should seek to narrow the gap between activity and data, and thereby remove some of the uncertainties. The use of qualitative research methods enabled ideas to develop about how technology could be used to ease some of the difficult aspects of living with a long-term condition: facilitating contact with health professionals, empowering and educating partners, and to remind participants of important signs of decline. Whilst these ideas may be a departure from the purist idea of LM being a technology to identify signs of a decline, the technology could evolve to have multiple roles that reflect both individual needs and wants.

## **Chapter 10: Discussion and Conclusion**

### **10.1 Introduction**

The aim of this research was to explore the relationship between activities within the home and health in older people with heart failure: to find out whether activities alter in accordance with the health state; and if so, whether these changes could be captured by LM sensors. Within this chapter, themes are discussed by following findings across both quantitative and qualitative data sources, and by this means mixed methods integration took place. This chapter presents a discussion of the key finding from all the elements of the research, and outlines any strengths and limitations of these studies; and finally discusses the implications for future research.

### **10.2 The Nature of the Relationship between Activity and Health: Key Findings**

The table below lists the key findings, and identifies whether the findings are present in the quantitative study, the interviews with heart failure participants, or specialist nurses, or the validation exercise at the support group. This method was used as part of the integration of the mixed methods studies, to demonstrate the technique of following themes across studies (Farmer et al 2006, Moran-Ellis et al 2006), and the ticks and crosses indicate where there was convergence (ticks) or divergence (crosses) between findings. The range of issues examined within each study varied, from the wide range of factors influencing activity discussed in the interviews with participants with heart failure, to the very limited exploration of factors influencing activity in the quantitative study (given that this study was set up primarily to explore the use of the Docobo Telehealth device (SB 2011)). This is a limitation of integration, since if all the studies had covered the same subject areas, the results may have been different. However this is a common issue encountered by researchers undertaking an integration of mixed methods, and there is still value in taking a pragmatic approach to integration, and gaining insights from a simultaneous interpretation of data sources (Moffatt et al 2006).

One element that benefitted the integration was the integrative theme of intrusion of symptoms, which was a thread that was interwoven throughout all the strands of the research. The theme was identified as a means of interpreting the qualitative findings from the interviews with participants with heart failure. It was found that participants were subject to ongoing changes in the intrusion of symptoms, which could be characterised as the difference between days defined as: normal days, bad days, or an exacerbation or flare-up of symptoms. This framework was used explore the range of factors influencing daily activity, in order to

understand the relative importance of symptoms in decision making on daily activities. In addition, a range of home activities were explored within the context of these three levels of symptom intrusion, in order to understand the impact on activity. This integrative theme shed light on the understanding of both the relationship between home activities and health in individuals with heart failure, but also informed the understanding of the means by which home sensors could potentially be used to indirectly capture changes in symptomology. The influence of this integrative theme is described in greater detail within this concluding chapter.

**Table 10.1: Key findings on the Relationship between Activity and Health**

A - Quantitative Analysis

B - Interviews with Participants with Heart Failure

C - Validation Exercise with Heart Failure Support Group

D - Focus Group/Interviews with Heart Failure Specialist Nurses

	Key Findings on the Relationship between Activity and Health	Source			
		A	B	C	D
<b>1</b>	<b>The intrusiveness of symptoms influences perceptions of health in complex ways</b>	√	√		√
1a	Symptom recognition is difficult (e.g. an individual may be very unwell, but attribute the change in health to ageing)		√		
1b	Breathlessness is particularly terrible, and influences activity	X	√	√	√
<b>2</b>	<b>The relationship between activity and health is very individual (with the following factors encouraging or inhibiting activity: 2a to 2f)</b>	√	√	√	√
2a	The degree of heart damage determines the scope and scale of activity that the individual is capable of (as a baseline)		√	√	√
2b	Participants described a journey from diagnosis to adaptation to living with a long-term condition; and activity levels reflect where individuals are on this journey, and whether factors are in place to encourage an active lifestyle		√	√	√
2c	Personality (e.g. self-will and determination) is a strong influence on activity (both in terms of choice and level of activity)		√	√	√
2d	Other factors influence activity (e.g. age, family, beliefs, advice, past experiences, the environment)		√	√	√
2e	Factors influencing activity on any given day will vary (commitments, weather, etc.)		√	√	√
2f	Some activities reflect the health state more than others (e.g. use of stairs, speed of walking, TV viewing at night)	X	√	√	√
<b>3</b>	<b>Activities act as complex influences of health and well-being</b>		√	√	
3a	Activities are important expressions of self, individuality, worth, well-being etc.		√	√	√
3b	Activity influences health (e.g. improved fitness, overactivity-rest cycle)		√	√	√

Key: The ticks indicate that this finding is present within this particular study

The crosses indicate that this finding is covered by this study, but this finding was not present

The blank boxes indicate that this issue was not covered by this study

NB: The same system of scoring is used across all the tables in this chapter

### **10.2.1 Key Finding 1: The intrusiveness of symptoms influences perceptions of health in complex ways**

The study aimed to explore whether the health state influences activity within the home. The study however found that perceptions of health are complex constructs (1). It is known that perceptions of health are multifaceted (Bowling 1995, Bowling et al 2006), and individuals may rate their health and quality of life as good despite suffering from ill-health (Carel 2007 & 2008 & 2009, Haynes & Watt 2008, Levasseur et al 2008, Lindsey 1996, Moch 1989, Schwartz & Sprangers 2000, Sharpe & Curran 2006), or impaired functioning (Huber et al 2011, Von Faber et al 2001). Findings from the qualitative elements of this study reflect this complexity, with participants with heart failure describing how they put their health to one side and were able to find happiness and well-being within illness. Further evidence came from the quantitative findings which demonstrated a lack of variation in recording self-reported health, which was unexpected given that heart failure is a variable condition with a high symptom burden (Zambroski et al 2005).

Everyday activity formed an important element of perceptions of health, with those who were most able generally perceiving their health as good, and those who were very incapacitated viewing their health in negative terms (and some participants describes observing their ability to undertake activities in order to check their ongoing health state). However this did not necessarily relate back to perceptions about the well-being of the heart, but was experienced more in terms of the distress felt at the loss of their ability to interact with others and engage in meaningful activities. The importance of the ability to undertake activities in shaping perceptions of health is recognised in the literature, although people may adapt to their medical condition and undertake activities in spite of this (Huber et al 2011, Rodriguez et al 2008).

Heart failure symptoms are known to be particularly distressing (Zambroski et al 2005), and therefore it was thought that participants with heart failure would assess their health state by the intensity of symptoms. However, this was found to be problematic (1b), as participants described varying levels of sensitivity to symptoms, with those newly diagnosed more aware of their body; and in contrast those living with the condition over time became inured to symptoms, and were less responsive to discomfort. In addition participants that had experienced an exacerbation tended to attribute their symptoms to causes other than heart failure, which led to delays in seeking help. Additional evidence from specialist nurses and partners of participants with heart failure, attests to the inaccuracy of symptom perceptions in



people with heart failure. Symptom evaluation is known to be difficult in heart failure (Carlson et al 2001, Gallagher 2010, Giamouzis et al 2011, Horowitz et al 2004, NCCCC 2003, Riegel et al 2010), and the literature also described how this was a factor in delays to seeking medical help during an exacerbation (e.g. Clark et al 2009, Horowitz et al 2004, Riegel et al 2010). This difficulty in both symptom recognition and assessment may also in part explain the lack of variation in the scoring of the self-reported health and symptom measures used in the Barnsley LM study.

The study also explored the influence of differing health states within heart failure on home activity, in order to explore whether there were any variations in activity. Participants with heart failure described tiredness or breathlessness impacting on activities on bad days, with a preference for a restful day at home (however this did not always happen). During an exacerbation symptoms escalated over time, with intrusion from tiredness, breathlessness, and swelling; with breathlessness the most distressing symptom, and thus most likely to be a stimulus to undertake actions to ease the symptom. Research suggests that people living with heart failure may be aware of the worsening of a group of symptoms including swelling and tiredness, but delay reacting until other further incapacitating symptoms, especially breathlessness, occurs (Evangelista et al 2000, Friedman 1997, Friedman & Quinn 2008, Jurgens 2006, Schiff et al 2003). Participants described specific activities that made them feel more breathless during an exacerbation, and strategies undertaken to deal with this (such as activity avoidance, and undertaking specific activities to ease the symptoms). However the degree to which activities changed during an exacerbation varied within individuals, and this finding mirrors the varied responses to worsening breathlessness described in Edmonds et al (2005), and the general body of literature on the differing responses to impairment (as previously cited). In addition, participants did not necessarily relate these changes in symptoms to a worsening of heart failure; and therefore were not necessarily undertaking activities with the conscious thought that their health was declining. This supports the finding of others that people with heart failure do not necessarily understand their condition, and the implications of changes in symptoms (Harding et al 2008).

Whilst these findings emphasise the importance of breathlessness as a key indicator of health in heart failure, there was an apparent divergence in finding from the LM quantitative study. In the study the two measures of shortness of breath did not produce as many statistically significant variations in activity as might be expected given the nature of the symptom. Possible reasons for this are discussed in the limitations section of this chapter.

A key study finding is that perceptions of health within heart failure were complex constructs, which are not necessarily related to the actual health state; and this raises a question about the nature of the relationship. Would an individual need to be able to make an accurate assessment of their health for them to tailor their activities accordingly; or is the relationship more unconscious than this and activity will change spontaneously without the need for conscious knowledge? Certainly LM has been tested on participants with dementia to spot characteristic changes in activity, in a population that is unlikely to be consciously aware that they are behaving in unusual ways; but it is unlikely that all health conditions will bring about changes in activity that relate specifically to that particular condition. It is likely then that the subjects for LM would have to be carefully chosen. There is also some evidence from a telecare study that some participants changed their plans for activities, according to their physiological measure of lung functioning (Pinnock 2012); and this is therefore a rare example of people changing activity based on objectively measured health.

#### **10.2.2 Key Finding 2: The relationship between activity and health is very individual, with factors encouraging or inhibiting activity**

The study provided evidence for a relationship between activity and health which is very individual, with no discernible pattern demonstrated by quantitative study findings, both across the sample, and within participants. The qualitative studies confirmed this finding. The interviews with participants with heart failure illustrated that levels of activity do not necessarily match the health state: with one participant giving up activities even though he was not experiencing symptoms; and others undertaking activities in spite of their health state - pushing themselves to achieve activities, continuing with activities even on bad days, and at an extreme, having an active day whilst suffering an exacerbation. This lack of a linear relationship between activity and health supports the findings from the research literature (Buetow et al 2001, Carel 2008, Donovan et al 1989, Furze, Donnison, & Lewin 2008, Mock et al 2000, Pihl et al 2010, Witham et al 2006). Carel (2008) argues that the medical approach to impairment fails to acknowledge the subjective beliefs about well-being, which may find an expression in activity which does not match the objective measurement of impairment. Given that activity and lifestyles in healthy individuals are very varied, the same diversity is likely to be found in those living with a health condition.

There were potential explanations for this lack of fit between the two factors. Findings suggest that both the scale and scope of activity was to an extent determined by the degree of damage to the heart and the nature of any co-morbidities (2a) (Oldridge & Stump 2004), with both

participants with heart failure and specialist nurses describing how this was very individual; and this fitted in with the idea of the New York Heart Association functional classification, which links severity with activity limitations (NYHA 1994). However, within these bounds there is a degree of flexibility and variation, and this difference between expected capacity for activity and actual activity relates to the range of factors outlined in the following sections.

Participants described a journey from diagnosis to the establishment of a new way of living with heart failure (as described in Wingham et al 2013) (2b), and activity levels may reflect both the stage of this journey and positive or negative experiences, e.g. an individual may move from initial fears about activity at the point of diagnosis, to gaining the confidence to be active from cardiac rehabilitation; or conversely frightening experiences may limit activity. This confirms the importance of rehabilitation and encouragement to move from an initial point of fear (Clark et al 2005, Condon & McCarthy 2006, Tierney et al 2011).

The study identified key internal and external factors that act to encourage or discourage activity. A key factor that seemed to mediate between the physical capacity of the body and the actual activity levels was personality (2c), with both participants with heart failure and specialist nurses describing how greater activity was associated with a positive outlook, a strong will, and determination (2c). Personality is known to be a factor in a good adaptation to an active life within ill-health (Haynes & Watt 2008, Horder et al 2013, Stanton et al 2007, Steptoe et al 2006), and in heart failure in particular (Tierney et al 2011).

A range of other factors were found to influence activity (e.g., age, family, advice, past activity levels, the home and surrounding environment) (2d), as described by participants with heart failure and specialist nurses; and this is in accord with the literature on multifactoral determinants or correlates of physical activity in older people (Bauman et al 2012, Browning et al 2009, Lim & Taylor 2005, Moschny et al 2011, Rosenberg et al 2012), and heart failure in particular (Tierney et al 2011).

The findings gave insights into the factors influencing activity on any given day (2e), which were found to vary according to factors that arose at that time, for example, the weather may encourage or discourage activity, or any plans or commitments may shape the routine for that day; and participants with heart failure described either delaying activities because of these factors, or continuing with activities. Participants also gave examples of changes in response to factors that cropped up, for example, the action of cutting short a trip and returning home may occur as a response to feeling ill, but equally it may happen because a suitable parking

space could not be found, or the weather turned colder. There are examples in the literature of these more immediate factors that influence activity, such as the weather (Brandon et al 2009, Klenk et al 2012, McMurdo et al 2012, Moschny et al 2011, Rosenberg et al 2012, Sumukadas et al 2009, Tierney et al 2011). This highlights the difficulty of separating out health from the many factors influencing activity on any given day.

The qualitative findings suggest that some activities reflect the health state more than others, and these are very specific, relating both to the health condition, individual experience of symptoms and behavioural responses, and the home environment (2f). During an exacerbation of symptoms participants with heart failure, for example, described both changes to existing activities (e.g., reduced speed in walking and climbing the stairs, stopping at home more, and being more sedentary), and undertaking new activities in response to distressing symptoms (e.g., sitting up at night to aid breathing, perhaps watching television). This in itself is not a new finding, since qualitative studies exploring the burden of living with long-term conditions, may describe some of these changes in activity in response to symptoms (e.g. Edmonds et al 2005); but in past studies consideration of activity was a side issue, rather than the main focus of the studies. The need to focus on specific activities that are sensitive to changes in symptoms (specific to a health condition) has not been addressed by the LM literature; where descriptions of systems, methods, and the context in which they are being used, tend to be vague (Brownsell et al 2011).

### **10.2.3 Key Finding 3: Activity is a Problematic Measure of the Health State**

The study confirmed that activity not an ideal measure of the health state, since it was found not to be a neutral instrument that would alter according to the health state. There were two aspects of this, firstly activity was found to have a meaning and significance over and above the undertaking of everyday routines, and secondly activity was found to be a force that could alter the health state.

Participants with heart failure described the meaning of activity within their lives (3a): as a source of achievement and satisfaction; a means of finding normality and constructing an identity within a new situation (see also Charmaz 1995, Christiansen 1999, Johnson 1991, Wingham et al 2013); a means of interacting with the outside world; a way of taking control of circumstances; and fundamentally an expression of self and being. Activity was a means of generating happiness and feelings of well-being. The meaning and value of activity has been described in the literature (e.g. Wright St Claire 2012), with Bury's (1982) idea of a biographical disruption, whereby a decline in health leads to the loss of valued everyday activities, that

gave a structure and meaning to life. However individuals can move from this sense of loss to constructing a new active life within ill-health, and thus achieve a sense of purpose (Hammell 2004a, Thompson et al 2003), meaning (Nolan et al 1996, Vrkljan & Miller-Polgar 2001), control (Lyons et al 2002), and self-worth (Vrkljan & Miller Polgar 2001). In common with other participants with long-term conditions (e.g. stroke patients, as described in Robinson et al 2009), participants in this study spoke of not wanting to centre their lives around their health state (Telford et al 2006), and the undertaking of valued activities provided a more meaningful focus; and at times activities were undertaken in spite of the health state (Thorne et al 2003).

The relationship between activity and health was found to not to be a linear one, with activity influenced by health, but more circular in nature (3b). Activity was perceived in relation to heart failure; with some participants with heart failure believing in the efficacy of activity to improve their situation, and others self-limiting activity in order to protect their health. Thus beliefs about activity were an important mediating factor in influencing activity levels, and these beliefs were confirmed by feeling more capable and experiencing feelings of well-being due to increased fitness; and thus an on-going relationship was formed with activity perceived as a boost to health.

For others activity was feared, as pushing the body too far and risking health, and these ideas may be confirmed when symptoms occurred; and thus a negative relationship between activity and health was established. The importance of beliefs in encouraging or discouraging activity is also described in the literature, both in participants with health conditions (Buttery & Martin 2009, Conraads et al 2012, Lin et al 2012, Sions & Hicks 2011), and in older people in general (Crombie et al 2004, Burton et al 1999, Grant 2008). However within these perceived relationships between activity and health, all participants described on occasion overdoing things, and suffering the following day with a bad day. Thus activity itself had the capacity to alter the health state in heart failure, and this supports similar findings in the literature (BHF 2010, Corvera-Tindel et al 2004, Davies et al 2010, HFSA 2006, Morantz 2003, Willenheimer et al 2001).

#### **10.2.4 Summary of Discussion about the Nature of the Relationship between Activity and Health**

In summary, activity is very individual, relating to both internal and external factors, events within a particular day, and ongoing aspirations to shape a sense of identity, self-worth, and satisfaction. An individual's perceptions of health are complex constructs, do not necessarily

relate to the objective reality of the health state; and thus interactions between these two things are unlikely to be clear cut. However within this complexity, some patterns of activity undertaken at times of stresses from ill-health did emerge when listening to the accounts of activity within differing health states that were described by both participants with heart failure, their partners, and specialist nurses. Those undertaking LM projects need to take into account this complexity, and to make efforts to identify any patterns of activity that emerge in response to ill-health; which may turn out to be very specific relating to a particular health condition, or within individuals. Monitoring would have to take account of this, in both the sensor platform setup and data analysis.

### **10.3 Discussion of the Research Questions**

The previous section addressed findings relating to the top level research question about whether everyday activities undertaken in the home by older people with heart failure vary according to the health state of the individual carrying them out. The table below lists the sub-hypotheses and depicts the data integration between the differing data sources in terms of whether there was agreement or disagreement for each hypothesis. The discussion of each point is presented below the table.

**Table 10.2: Sub-Hypotheses for Hypothesis (1)**

A - Quantitative Analysis

B - Interviews with Participants with Heart Failure

C - Validation Exercise with Heart Failure Support Group

D - Focus Group/Interviews with Heart Failure Specialist Nurses

Sub-Hypotheses	A	B	C	D
a. Individuals with heart failure vary their everyday activities according to the three health states of heart failure (normal days, bad days, and exacerbations)	Not addressed, as there was no measure to record whether participants were experiencing a normal day, bad day, or exacerbation	√	√	√
b. The changes in activity according to the health state are transferable across the sample, rather than distinctive to the individual	X	X√	X√	X√
c. The partners of individuals with heart failure influence the activities undertaken by their spouses with heart failure.	No means of testing this	√	√	
d. Factors other than heart failure influence activities, and in some individuals these other factors outweigh the influence of heart failure	No means of testing this	√	√	√

Key: The ticks indicate that this finding is present within this particular study  
 The crosses indicate that this finding is covered by this study, but this finding was not present  
 The blank boxes indicate that this issue was not covered by this study  
 The cross and tick together indicates that there is evidence, but it is not strong

**1. Older people vary their everyday activities according to the three health states of Heart Failure (normal days, bad days, and exacerbations), and the activities differ accordingly**

**Supporting by the Following Evidence**

All the qualitative studies (B, C, D) provided evidence that people with heart failure do categorise their days as ‘normal’ or ‘bad’ due to the intrusiveness of symptoms they experience, and this makes them more likely to be active during a normal day, and rest during a bad day. Similar patterns of good and bad days are described both in the heart failure literature (Aldred et al 2005, Clark et al 2008, Europe & Tyni-Lenne 2004, Martensson et al 1997, Pattenden et al 2007, Ryan & Farrelly 2009) and in other long-term conditions (Charmaz 1991), and the resultant impact on activities depending on the type of day, “...the types of activity possible, amount of productivity, degree of choice, and amount of control all figure heavily on evaluating the day” (Charmaz 1991, page 49). This study adds greater detail to the

understanding of the impact of bad days on everyday activity within the context of heart failure.

The defining symptom of 'bad' days was tiredness, and this demonstrates the importance of this symptom in influencing activity (Ekman & Ehrenburg 2002, Hagglund 2008, Martensson et al 1997). Both participants with heart failure and the specialist nurses described how a 'bad' day can be brought about by overactivity, and this cycle is described within other long-term conditions (Birkholz et al 2004); and whilst this has a short term impact on health, repeated cycles of activity and rest are indicative of overall poor activity management (BHF 2010, Furze et al 2010).

The qualitative studies (B, C, D) were in agreement that the symptoms of an exacerbation are different from 'bad' days, both in the range and intensity of symptoms; and whether and how activities were undertaken (e.g., slower, or avoiding activities), and the activities that were undertaken specifically to ease symptoms. Studies about the experience of living with heart failure tend to mention impacts on the undertaking of home activities as a side issue, but Edmonds et al's study (2005) describes similar strategies to deal with worsening breathlessness. One key response to worsening symptoms was a delay in seeking medical help, and this reaction is well documented in the literature (Aldred et al 2005, Bosworth et al 2004, Clark et al 2008, Evangelista et al 2000, Friedman 1997, Friedman & Quinn 2008, Jurgens 2006, Schiff et al 2003, Zambroski 2003). Technology could potentially play a role in identifying this change in the health state at an earlier stage, and thus avoid the build up of symptoms to a point where hospital care is required.

Heart failure may be a more suitable focus for LM than other health conditions because participants described a build up in symptoms to a tipping point, in contrast with other conditions, such as COPD, where the build up to an exacerbation is much faster (Hardisty et al 2011). A recent telecare study focussing on COPD attributed a lack of success in identifying the early stage of exacerbations to lack of early predictors, and the authors' speculated that the system may have been identifying signs of bad days rather than exacerbations (Pinnock et al 2013).



**2. The changes in activity according to the health state are transferable across the sample, rather than distinctive to the individual**

**Partly Supporting by the Following Evidence**

Quantitative findings suggested that the relationship between activity and health is very individual. Interview participants with heart failure did describe common adaptations to home activities, and these are also described in the literature (Bennett et al 2000, Bosworth et al 2004, Edmonds et al 2005, Europe & Tyni-Lenne 2004, Evangelista et al 2000, Falk et al 2007, Hagglund et al 2008, Jeon et al 2010, Pattenden et al 2007, Martensson et al 1997, Rhodes & Bowles 2002, Rodriguez et al 2008, Ryan & Farrelly 2009, Zambroski 2003). However, there were also a lot of individual variations in activity during changes in the health state, with some participants avoiding activities, and other carrying on; this varied reaction to stresses from ill-health is well documented in the literature (Buetow et al 2001, Carel 2008). That said, there were a small core of changes in activity that were identified as common to a majority of participants during worsening health, and this was validated both by the specialist nurses and the support group (see chapter 9, table 9.5).

**3. The partners of individuals with heart failure influence the activities undertaken by their spouses with heart failure.**

**Supporting by the Following Evidence**

The partners of individuals with heart failure described the life changing impact of the condition on everyday life; they monitored the health of their partner, discouraged activity at times of concern, and were influential in decisions about seeking medical help. They identified activities that caused difficulties for their partner, and undertook these for them. During an exacerbation they undertook more activities. Partners were more aware of their partners' health state than their partner themselves. The complex nature of informal care has been described by the literature (Aldred et al 2005, Bennett et al 2000, Clark et al 2008, Falk et al 2007, Hagglund et al 2008, Pattenden et al 2007, Ryan & Farrelly 2009). Partners were identified as important forces in shaping their partners' relationship between activity and health, and this was largely guided by their fears and beliefs about the physical capacity of their spouse.

**4. Factors other than heart failure influence activities, and in some individuals these other factors outweigh the influence of heart failure**

**Supporting by the Following Evidence**

Findings from the quantitative study suggested that self-reported health accounts for only some of variation in activity levels, and therefore it was evident that other factors were at play. The qualitative studies described the varied factors influencing home activity and these matched those described in the literature review, and often these factors did outweigh health in influencing everyday activity (as detailed in the earlier sections of this chapter)

**10.4 Lifestyle Monitoring (LM)**

The LM hypothesis was that levels of recorded proxy activity captured by lifestyle monitoring sensors vary according to self-reported levels of health (table 10.3). The quantitative analysis found that there were a greater number of statistically significant associations between indirect activity and health measures than could have occurred purely by chance. As previously described the relationship was complex with no general pattern across the sample; but with some evidence for increased home activity during self-reported ill-health, and this finding was supported by both accounts from the qualitative study and the research literature (Bosworth et al 2004, Edmonds et al 2005, Pattenden et al 2007, Rodriquez et al 2008, Ryan & Farrelly 2009).

**Table 10.3: Lifestyle Monitoring Hypothesis**

A - Quantitative Analysis

B - Interviews with Participants with Heart Failure

C - Validation Exercise with Heart Failure Support Group

D - Focus Group/Interviews with Heart Failure Specialist Nurses

<b>Sub-Hypotheses</b>	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
e. Levels of recorded proxy activity captured by lifestyle monitoring sensors vary according to self-reported levels of health	X			

The findings from the quantitative study were complex and did not reveal any consistent patterns; and thus qualitative studies were undertaken to explore this further. Qualitative studies supported the idea of a complex relationship, with individual internal and external factors influencing the relationship (as described in the earlier section of this chapter).

However the exploration of activities undertaken during changes in the health state revealed that there are specific activities undertaken during stresses from intrusive symptoms, and therefore if this information had informed the setup of the LM sensor platform the results may have more accurately represented the relationship between activity and health in heart failure

(as discussed in chapter 9). This approach may address the criticism that the data captured by LM sensors is not clinically meaningful (Elwyn et al 2011).

The Barnsley LM sensor platform was examined to understand how the sensors function and the strengths and weaknesses of the technology (chapter 9). The measures of activity which were utilised in the quantitative data analysis were explored in the qualitative enquiry, and were found to be flawed as measures of change in health in heart failure. Alternative means of monitoring health were suggested (chapter 9, table 9.5). The study therefore emphasizes the importance of carefully selecting sensors to identify disease specific changes in activity, and to tailor the setup to take account of individual circumstances. This fits in with the idea of personalising technology which has been discussed in other fields (Brownsell et al 2012).

The results of the quantitative analysis are likely to reflect the self-reported measures that were utilised in the study, and thus these were examined to find out whether they reflected the true health state. However there is no available gold standard measure for the assessment of heart failure symptoms (Lee & Moser 2013).

#### **10.4.1 Measurement of Breathlessness**

A key concern was how breathlessness was measured, given the importance of this symptom. Breathlessness was assessed in the study at two time-points: during the day and nocturnal waking; and participants had the choice of four possible answers: No/None, Less than usual, As usual, and More than usual.

There is no approved means of measuring the severity of breathlessness in acute and chronic heart failure, instead a variety of measures are employed in research studies (Johnson et al 2010). The measures can be divided into two types: multi-dimensional and uni-dimensional (Johnson et al 2010). Most measures are multi-dimensional measures that include a measure of the experience of breathlessness, as well as a measure of breathlessness severity, for example, recording which activities caused most breathlessness. Fewer of the measures are uni-dimensional, recording only the severity of breathlessness, by various means. A review of measures of breathlessness used in research studies concluded that "...breathlessness is measured in an incomplete and haphazard way in studies in chronic heart failure" (Johnson et al 2010, page 140). The authors' outlined the constituents of the perfect breathlessness measure:-

"The ideal tool to measure breathlessness should be patient reported, multi-dimensional, and able to detect change (responsive) and have an established minimal clinical importance

difference. There is a need to measure breathlessness severity under clearly described conditions (at rest, on exercise, and patient chosen activities) and timescales (today, yesterday, last 2 weeks), and a need to gain a global sense of improvement or deterioration with an understanding of the broader impact of breathlessness on distress, ability to cope, feeling of control, and caregiver burden” (Johnston et al 2010, page 145). In addition, the authors’ recommend that the use of mixed methods (qualitative and quantitative) would add an additional element to the understanding of the experience of breathlessness.

The measure of breathlessness used in the quantitative study was uni-dimensional with four levels of health (page 77). It would be reasonable to speculate that this may not have been responsive enough to reflect the range of breathlessness experienced by the participants, and this may have made it difficult to examine the relationship with home activities.

Difficulties with symptom recognition have already been described. The Specialist nurses expressed doubts about the accuracy of heart failure patients in monitoring their own symptoms. Other studies have confirmed that the daily assessment of symptoms can be a difficult judgement call for older people with a long-term condition (Ure et al 2012). A study exploring the daily variation of self-reported heart failure symptoms found that two-thirds of their sample reported stable breathlessness over thirty days, and the researchers discussed whether this finding reflected an objective reality, or whether the participants found it difficult to evaluate and detect changes (Webel et al 2007).

The wording of the symptom measures may have impacted on self assessment, since the questions asked for a judgement about whether symptoms were worse or better than usual; and thus this would depend on the individual perception of what was usual. The questions did not anchor this perception to a time period, e.g., did not ask people to compare symptoms with yesterday; and thus there was a potential lack of clarity. The Barnsley specialist nurse also talked about the importance of using local language in symptom measures (what she called “Barnsley terminology”), in order to make the measures clearer and more meaningful to local people.

#### **10.4.2 EQ-5D**

The EQ-5D was used to provide both a more general measure of health-related quality of life. The incorporated visual analogue scale (VAS) provided a measure of self-reported health. The participants in the quantitative study generally reported either having no or moderate health problems, and thus this tendency not to utilise the whole range of answers limited the data

analysis. Similarly, there was little variation in the measurements of self-reported health in the EQ-5D VAS. The EQ-5D has been found to provide validity (i.e. it has been judged to measure what it purports to measure), but there is less evidence for responsiveness (which is whether an instrument is sensitive to changes of importance to the participants) (Mackintosh et al 2009).

There are reports of older people scoring health measures in a rather arbitrary fashion that did not necessarily reflect reality (Hulme et al 2004, Mallinson 1998 & 2002). Indeed some evidence for this came from a Heart Failure Specialist Nurse participant who talked about the stoical nature of Barnsley people, when assessing their health. She gave the example of filling out a general health rating, "...I think the Bosch [home symptom monitoring system] has got something like 'do you feel ok, not too bad, or poorly', half of the Barnsley people will say not too bad, because that means they are ok and in the middle level; and they will always say they feel ok." This tendency to choose the middle option is known as a central tendency bias (Tinsley & Brown 2000).

There is evidence to suggest that scoring of symptoms and general HRQoL may reflect the influence of response shift (Schwartz & Sprangers 2000); and a positive outlook is known to influence EQ-5D scores (Jerant et al 2008). The presence of co-morbid conditions can also make it difficult for individuals to assess their health state (Giamouzis et al 2011, NCCCC 2003); and EQ-5D may not be relevant or sensitive to changes in co-morbid conditions.

Participants may also have grown jaded with filling out daily measures over the course of the longitudinal study, and the lack of variation in recording may reflect this. This issue was highlighted in an evaluation of a COPD telecare project, where one participant recorded the same answer every day to self-reported measures despite having severe and variable symptoms (Ure et al 2012). The log recording communications with the participants in the Barnsley quantitative study recorded incidents where participants were contacted because they had not been filling out the health and symptoms scores. In two cases participants did not input data because they had been feeling unwell; and thus this calls into question whether participants would actually continue to fill out symptom scores during an exacerbation.

#### **10.4.3 The Utility of Lifestyle Monitoring is Limited Because its Focus is Too Narrow**

The quantitative findings supported the view that the focus of LM is too narrow, since the findings were complex and difficult to interpret, and the study left many questions unanswered. It is therefore argued that the scope of LM should be broadened to include the

following elements: firstly, a means of feeding-in intelligence from partners etc; secondly, to broaden the scope of data collection to record activities within more challenging environments, given that outdoor activity may be more indicative of the health state (e.g. Edmonds et al 2005, Rosso et al 2011). Thirdly, LM has been criticised because the activity data has not been used to identify points of significant clinical need (Elwyn et al 2011), and thus attention should be focused on identifying the early signs of an exacerbation of symptoms. Participants in this study recounted that the first sign of an exacerbation they noted was difficulty walking or climbing stairs at their usual pace. Therefore in order to assess this, sensors would need to record speed and duration of walking; and this is a recognised indicator of disease severity in heart failure (Guyatt et al 1985, Jehn 2009, Pollentier et al 2010, Rostagno et al 2008).

## **10.5 Methodological Issues**

This section discusses the methodological issues which arose during the undertaking of this study, and considers the strengths and limitations of the study in answering the research questions.

### **10.5.1 Mixed Methods**

The study evolved into mixed methods project, and this provided a more comprehensive understanding of the factors influencing everyday activities within the context of heart failure, than would have been achieved with only a single method approach. This is a key strength of the study. The decision to add qualitative studies was undertaken in a pragmatic way, in order to understand and validate the quantitative findings, and to add rich descriptions of the experience of living with heart failure from varied perspectives. The addition of these differing perspectives on the research question provided not only a richer, more nuanced picture; but also a means of reassessing the initial quantitative study.

The original hypothesis was that activity changes according to the health state, and it had been expected that patterns would emerge from the quantitative findings, with an expectation that it may show decrease in home activity during poorer self-reported health/symptoms.

However quantitative analysis revealed a far more complex and individual picture, with no discernible relationship between activity and the self-reported health state. Without the qualitative studies it would have been impossible to understand these findings, as the limited quantitative dataset prevented further exploration. Qualitative research revealed the range of factors and mechanisms at play in influencing everyday activities lived within the stresses of heart failure, and thus it was possible to place the influence of health on activity within this

broader context. These findings were then used to cast a critical eye over the setup of the original quantitative LM study and LM as a whole. The two methodological elements of the study therefore acted to build both a more comprehensive understanding and a means of testing ideas across the differing perspectives; and thus this approach led to a unique contribution to current knowledge.

Similarly, initially it had been assumed that individuals would rate their health based on the state of their heart failure, but the qualitative studies revealed that although perceptions of health were shaped in part by the degree of damage to the heart, they were also formed by the ability or inability to undertake everyday activities, and the two aspects did not necessarily match. Thus, this understanding about the complex nature of perceptions of health and symptoms led to a reassessment of the measures of health and symptoms used in the quantitative study. This interplay between the two elements of the study is a key part of a mixed methods approach, and by this method of continually questioning and weighing up the differing aspects of the study, a more sophisticated understanding of the relationship between activity and health was formed.

Mixed methods approaches are known to be challenging given the range of methods used, and the difficulties ensuring that all aspects are conducted to a to a high standard, and the data is integrated. Steps were taken to ensure that quality checks were undertaken in accordance with the recommendations (chapter 3.7), which includes describing limitations of each study (which will be detailed later in this chapter). Thus by following this quality framework, the study was enhanced.

The sequential explanatory mixed methods approach shaped the development of the study, as the later qualitative studies were designed to explain the initial quantitative findings. The qualitative sample of participants with heart failure was designed to explore a range of experience from diverse individuals living with heart failure; and whilst ideally this sample would have been drawn from the quantitative participants this was not possible given the elapse of time, but steps were taken to ensure that participants were recruited from the same geographical location.

The study evolved to include the views and experiences of the partners of participants with heart failure; which came about when some partners wished to be present during the interview and contribute their experiences. This was not anticipated but turned out to be a strength of the study, since partners have an influential role, both in shaping everyday activity

(through either encouraging or discouraging activity), and influencing their partners' perceptions of health (partners' described being hyper-aware of their partner's health state). Similarly when the opportunity arose to collaborate with another researcher undertaking research with specialist nurses, this aspect was incorporated into the research. This additional perspective was beneficial since it was informed by years of nursing experience with a diverse range of patients.

#### **10.6 Quantitative Study - Strengths and Limitations of the Study**

A key strength of the quantitative study came from the secondary data: a longitudinal LM dataset collected from a range of sites using a typical sensor set-up, and also including measures of self-reported health. It would not have been possible to collect these data specifically for this study, given both the prohibitive cost of LM studies, and the length of time needed to collect the data. There was also a source of expertise on the dataset, since the study had been commissioned by the University, and colleagues that were involved in both the commissioning process and data analysis were available to discuss any issues that arose.

A broad range of statistical analysis was utilised, from assessing trends in measure within individual houses, exploration of relationships collectively by type of living arrangement; and finally a comprehensive testing of statistical association between activity and health measures by each study house, with post-hoc tests to explore the nature of any statistical associations. In addition guidance was sought from an expert in statistics to ensure that this was an appropriate approach. This thorough approach was a strength.

There were however some limitations to the study. The data was collected from a small sample from participants living in a town in South Yorkshire living with a specific health condition, and thus it is not possible to know how these findings would relate to larger samples, other geographical areas, and health conditions. It had been hoped to collect more data from another location and health condition, but in the event this was not possible.

The secondary data was collected for another purpose, and thus there was a lack of control and influence on the data collected; which meant that it was not possible to return to the quantitative analysis to explore the findings from the qualitative studies by statistical means. There were also potential difficulties in relying on the measures of health and symptoms (as described earlier in the chapter).

The quantitative findings may have been influenced by the setup of the study, whereby participants' health measures were monitored by health professionals over the study period,



and when danger signs occurred health interventions took place. This is not a typical scenario for community dwelling heart failure patients, and participants may have benefitted from close monitoring and thus symptoms may have been generally controlled. In a sample of heart failure patients within the community in England, for example, a study found a high prevalence of heart failure symptoms and evidence of the burden of this on lifestyle, and most prevalent symptoms were breathlessness and fatigue (Barnes et al 2006).

Heart failure patients may move between NYHA classes, they may improve or deteriorate, although the general trajectory is one of deterioration. The majority of participants in the study were NYHA class II and thus likely to experience only mild symptoms, and therefore they may not have been the ideal participants for this study. In addition, it is possible that some of the participants may have improved, for example, an English study of heart failure patients in the community recruited participants graded as NYHA class II to IV, but by the start of the study some participants had improved to NYHA class I, which is asymptomatic (Barnes et al 2006). It therefore may be expected that a small proportion of the participants would improve to a state where their daily activities were no longer impacted by adverse symptoms.

Another potential limitation to the study was the duration which may not have been long enough to record significant changes in health. Heart failure is progressive, with poor survival rates (The NHS Information Centre 2010), but for patients that survive the first year after diagnosis, the risk of death reduces dramatically (Cowie et al 2000), and these are the typical patients that live within the community (Davis et al 2006). It has not been possible to find statistics on the expected number of exacerbations of heart failure per year in diagnosed patients, but it is likely that this statistic is not calculated as the likelihood would depend on individual patient characteristics (Mosterd & Hoes 2007). The specialist nurses described a subset of patients with difficult to manage heart failure that is more symptomatic; and thus it is likely that such patients would experience a range of health states within a year; however in other patients who are more stable this is less certain. The duration of the quantitative study was chosen not because it was thought to be long enough to witness changes in health, but primarily for pragmatic reasons (SB 2011).

There were also limitations that are common to all LM data analysis: there was no way of knowing who was present in the homes, and thus the sensors may have been recording other people's activity (certainly this was true in the homes where couples live). In addition, there was the information gap between the sensor, and the actual activity that the sensor is supposed to be recording (see previous technology chapter).

The key limitation of the quantitative study was that with hindsight it would have been better to have undertaken the qualitative studies, and used these findings to inform the quantitative data analysis. However at the time the complex nature of the relationship between activity and health was not understood, and thus the study unfolded in unanticipated ways.

There was also a potential weakness to the study from my own lack of technological expertise; but this may also be regarded as a strength since my lack of prior knowledge meant that I was able to start from scratch to understand LM in a questioning and open manner.

#### **10.6.1 Qualitative Study - Strengths and Limitations of the Study**

The qualitative studies had a number of strengths. The interviews with participants with heart failure were guided by a semi-structured interview schedule, which addressed both a priori issues, and gave participants the freedom to explore wider issues and experiences that they considered pertinent; and thus a broader understanding was achieved. The recruitment was undertaken by two methods, firstly as part of partner study evaluating a device encouraging walking, and secondly via the support group. These recruitment methods ensured the selection of a varied sample, since the initial potentially fitter participants were balanced by those who had declined to join in with the walking project, but agreed to be interviewed, and the later more mixed participants from the support group.

The interviews took place in participants' homes and this was found to be advantageous to the study, since participants were in familiar, non-threatening surroundings, and I believe this private environment encouraged them to speak openly about their situation. In addition, I was able to envisage the challenges of everyday activities within the home, in the same environment that participants described; and this was an important step, since prior to this the relationship between activity and health had felt very abstract to me as a researcher. The home also acted as a prompt to participants, as it is the environment where their activities had taken place. If interviews had taken place away from the home, it is likely that participants with the most severe symptoms would have found it difficult, if not impossible, to attend.

In addition my stance as a university researcher was advantageous, since participants were open about their activities in a way that they may not have felt able to be with health professionals. Participants spoke about some activity (especially excessive activity) as a guilty secret, and such an admission may have been difficult without my relative independence; given that people with long-term illnesses are subject to societal definitions of "appropriate" activity levels (Charmaz 1995, page 658).

The experience of interviewing participants was also crucial in the formation of views that LM technology must relate to the lived experience of activity with a long-term condition. This necessity was keenly illustrated by participant descriptions of the activities that had been chosen as proxy measures for the quantitative analysis, which were found to be either not reliable measures of health, or that key alterations to the sensor platform would have been necessary to capture change; and that other unanticipated activities would have been better indicators of changes in health.

The inclusion of specialist nurses in the qualitative research was also beneficial, since they turned out to be a key source of information about activity within the home during periods of declines in health. Although the information they contributed was not as detailed as that provided by the participants with heart failure, it would have been a good starting point to identify which activities to monitor, and where to site the sensors. This demonstrated the value of tapping into information from nurses, as a quick means of gaining valuable information.

There were some limitations in the qualitative research. There may have been some deficits with the interview sample of participants with heart failure. One specialist nurse stated that typical patients with heart failure tend to be older and in poorer health than my sample; and it is certainly true that patients cared for by general practice tend to be elderly (Mosterd & Hoes 2007). However such patients would have been difficult to access, and the aim of the sample was to represent a broad experience of heart failure. There was also a gender imbalance in the sample, as the participants with heart failure were mainly male, and the partners were all female; it had been hoped that this would have been resolved at the second recruitment phase at the support group, but the majority of attendees were also male. There were few participants living alone, and of these only one participant was without support from family and friends; and given that those living alone may be in a more vulnerable position, the research would have benefitted from a greater understanding of life alone with heart failure.

### **10.7 Implications for Future Research**

It is conventional at this stage to address implications for future research, and policy and practice; but given that LM is still at a research stage it was decided to focus solely on the former.

This research project explored the relationship between activities within the home and health in heart failure, and whether health-related changes in activity could be identified by LM

sensors. The study was focused on participants with one particular health condition, living in a Yorkshire town: and thus further research could focus on other health conditions in other geographical areas, using qualitative means to explore whether the same complex relationship is replicated, and whether the findings are transferable. Future research could also explore more broadly the relationship between activity and health in people living alone, since this population is potentially more vulnerable (Haslbeck et al 2012, Kharicha et al 2007); and technology may have a role to play in easing the stress of their isolation.

A key area for future research is to understand more about how activity changes during the early stages of an exacerbation of symptoms, when there would be the potential for a medical intervention to reverse the decline. The current research suggest that within heart failure there was a window of time that was sufficiently long to intervene, since symptoms built up over time; and that the first indication of worsening symptoms that participants experienced was difficulty walking. Further research is needed to explore this key time period, both within heart failure, and other health conditions; both to identify if the time period was long enough to intervene, and to identify if there were distinctive activities that could be used as indicators of need for intervention. This need to focus on clinically meaningful changes in activity is acknowledged by the literature (Brownsell et al 2011, Elwyn et al 2011), and recent findings suggest that there may be some health conditions that are more suitable than others (Hardisty et al 2011, Pinnock et al 2013) for LM.

This study vividly demonstrated the importance of qualitative data, and it is recommended that future LM research should include a preparatory qualitative stage:-

1. To potentially identify the circumstances where LM is likely to work, or not to work (given the tremendous variations which arise from differing health conditions, and individual lifestyles and circumstances). A current evaluation of telehealth has identified that there are particular circumstances where the technology is likely to be of value (Car et al 2012), and this study has shown that it is likely that the same scenario is true of LM.
2. To inform the design of LM sensor platforms; both to identify significant activities to monitor, and to understand more about the complex relationship between activity and health (in order to inform the later LM data analysis). Future research could examine whether this thorough preparation would be more efficacious.

And finally, further research should be undertaken on how partners and family could feed observations into a LM system, since they are able to monitor sophisticated signs of a health decline that technology would be incapable of (Clark et al 2008). Other researchers have also made this suggestion (Brownsell et al 2011a).

## **10.8 Conclusion**

This study challenges a major assumption of lifestyle monitoring, namely that changes in home activity measured indirectly by sensors can be used to infer changes in the health of the individual living in the home (e.g. Celler et al 1994 & 1995, Gil et al 2006, Kaushik et al 2007, Ni Scanail et al 2006). This study challenges this assumption, since participants with heart failure described a much more complex relationship, with activity guided by a whole range of factors and individual circumstances, and of these the study demonstrated the key importance of psychological factors in driving activity (personality, outlook, motivation, self-efficacy).

Whilst to date many LM studies have concentrated on identifying changes in proxy activity data, far fewer have made the leap to link this data to actual changes in health or social care needs (Brownsell et al 2011); and this study suggests that without careful preparation to understand both the individual being studied and the health condition, this link may be difficult to establish. Whilst this study focused on heart failure, it is likely that these findings have a broader application, since the psychological, social, and environmental underpinnings of everyday activity (as described in the literature, e.g. McMurdo et al 2012) are likely to impact on activity in other health conditions, and in addition there are common impacts and patterns of activity that are described in many long-term conditions (e.g. Carel 2008, Charmaz 1991). Recent findings have identified a complex range of factors at play in the success or failure of Telehealth (Car et al 2012), and this study suggests that a similar complex situation would influence the success of LM.

It is thought that this study is the first to utilise a mixed methods approach to explore the findings from LM sensor data analysis, and then to use the qualitative findings to make suggestions for improving the setup of the sensor platform. This iterative use of mixed methods is new, since qualitative data has tended to be utilised to explore the experience of living with telecare technology (Hanson et al 2009, Percival and Hanson 2006, Joint improvement Team et al 2009), rather than to inform sensor setup. In addition, there is lack of clarity around the process of choosing sensors for health purposes, since most studies tend to use a similar range of sensors, but do not explain how these could be used to detect changes in

health (Brownsell et al 2011). In contrast, this study makes explicit the link between worsening symptoms and a range of activity changes in a complex health condition.

This study also contributes to the knowledge of the impacts of heart failure on everyday activity in older people - this very detailed exploration of impacts on activity is unusual, given that most studies either mention home activity as a side issue (e.g. Aldred et al 2005, Bosworth et al 2004, Clark et al 2008, Edmonds et al 2005, Europe & Tyni-Lenne 2004, Evangelista et al 2000, Falk et al 2007, Hagglund et al 2008, Jeon et al 2010, Pattenden et al 2007, Rhodes & Bowles 2002); or describe more broadly the emotional impacts of difficulties undertaking activities, or the way activity is understood (Pihl et al 2011). The detailed description of changes in home activity during an exacerbation is also new; since studies tend to describe a delay in seeking medical help, but do not detail what participants were actually doing (e.g. Aldred et al 2005, Bosworth et al 2004, Clark et al 2008, Zambroski 2003; with the most detailed Edmonds et al 2005).

In conclusion, this study sought to explore the relationship between home activities and health in older people with heart failure. The study found that home activity is influenced by a complex range of factors, with individuals subject to a range of psychological, social, and environmental factors that shape the context of activity; but within each day there are additional factors that are added to the mix, such as, the weather, or commitments. Whilst health was perceived by participants with heart failure as a key element in determining the range of activity that they were capable of - the impact on activity was far more complex; with participants undertaking activities in spite of the intrusion of symptoms, or making a conscious decision to take things easy. However at times distressing symptoms led participants to undertake activities to ease symptoms, such as, feeling too tired to go out, or sitting up at night due to breathlessness; and thus within this complexity, there were activities undertaken because of health. This understanding of the relationship between activity and health in heart failure provides insights which are of value to LM; in terms of the requirement to tailor the platform setup to individual health conditions and circumstances, and to take account of the complex nature of the relationship in the data analysis.

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## **Appendix**

### **Appendix Paper 1**

#### **Ethical Issues of Telecare Lifestyle Monitoring (TLM)**

##### **1.1 Introduction**

The ethical issues that arise from placing telecare lifestyle monitoring technologies in the homes of older people are often not explored (EFORTT 2011), and to date there has been only one paper specifically concerned with the ethical issues of TLM (Bowes et al 2012). A report by the university of Lancaster examining ethical issues in telecare states that, “Telecare and ‘smart home’ technologies raise new ethical and legal problems concerning safety; the reliability of information; new types of provider-patient interaction; new knowledges generated, and ethical implications of increased surveillance (including potential uses and abuses of data). More fundamentally they raise questions about what constitutes good care for home-dwelling older people” (EFORTT 2011, page 4).

##### **1.2 Ethical Framework Pertinent to this Technology**

The ethical issues that arise from TLM technologies arise from two aspects, that of placing a technology within homes, and predominantly the homes of older people; and secondly issues protecting the rights of older people. Issues that arise from research that involves older people, or providing services to this group, are the same as any other age-group, but there is potential of an added dimension of increased vulnerability due to cognitive or physical impairments (Gilhooly 2002). There are four general principles of ethics (Gilhooly 2002), and these should apply to TLM:-

- A) Non-maleficence – that TLM should do no harm
- B) Beneficence – that TLM should do positive good
- C) Justice – that TLM should be provided in a manner that treats people fairly
- D) Autonomy – that TLM should be provided in a manner that demonstrates respect for people

These four elements will therefore be considered in this brief roundup of ethical issues that potentially arise from TLM.

##### **1.3 Non-Maleficence – TLM Should do no Harm**

It would be ethical to continue collecting TLM data from the homes of older people if the data is proven to act as a reliable indicator of declining health (Marx 1998), or if not there is the

potential for harm. To date there is not a strong evidence base for the effectiveness of TLM data in identifying changes in health (Brownsell et al 2011), and Bowes et al (2012) argue that this presents a key ethical issue “It is unethical to ask older people to participate in research where we are unable to justify the intrusions required to collect lifestyle monitoring data” (page 4). The Lancaster University ethical review of telecare asked a similar question about whether it is worth the effort of collecting the data for all parties if the telecare cannot prevent ill health (EFORTT 2011, page 21). It is not yet known who would benefit from TLM, and what health conditions, although the research is ongoing (EFORTT 2011). Despite this there are a ‘significant’ number of commercial TLM services around the world (Brownsell et al 2011), and it is unethical that these products should be sold as benefitting older people when the link between activity and health is not yet proven.

### **1.3.1 Surveillance**

Harm in TLM could arise from the psychological stress of being monitored, which could impact on perceptions of home and self.

A key ethical issue for TLM is the idea that the use of sensors to monitor activities within the home is a form of surveillance, which could be perceived as a ‘Big Brother’ type of invasion of privacy. A participant in a focus group exploring the use of monitoring technologies described the idea of lifestyle monitoring as “... Big Brother is watching you, that’s what it is” (Brownsell and Hawley 2004, page 20). Certain technologies have qualities that inspire suspicions that surveillance is taking place, rather than an effort to use technology to assist people in the home (Hanson et al 2009). TLM using sensor technology is not about watching people, and yet some participants feel as though they are being watched. “Telecare devices can diminish people’s sense of security despite their aims to do the opposite: they can make people feel vulnerable and scrutinised” (EFORTT 2011, page 21). One strand of current TLM research work is focused on using cameras to monitor, and although the image of the person in the home is deliberately obscured, this raises a host of ethical issues at the greater loss of privacy (Bowes et al 2012).

Concern has also been raised about how telecare could potentially be used in the future to monitor people in the home to ensure that they are undertaking the required medical and lifestyle regime to deal with their health condition (Schermer 2009), or to monitor the capability of older people living alone (EFORTT 2011); and this would move monitoring from watching to making a judgement about behaviour (Lyon 2001).

### 1.3.2 Home and Self

Home whilst of great importance to all ages takes on a greater significance to older people because the amount of time spent there, either due to retirement or ill health (Gillsjo et al 2011, Sixsmith 1990). For Fisk home is a symbol of independence where an individual exercises choice and control (1998). Home is also imbued with an emotional significance, a place where key events of the past took place, and of great importance to the sense of self (Lopez and Sanchez-Criado 2009). The key ethical issue for telecare, within the context of home, is what happens to the meaning of home when monitoring sensors are installed? Do feelings change about home? Does it alter the atmosphere of home, and the sense of entering a private space where the individual can relax and be themselves away from the gaze of others? It could be argued that for telecare to be ethically acceptable within the home the sensors should have no impact on the environment, both in terms of how the householder views their home, and in terms of how visible the technology is.

Telecare sensors are not invisible, and therefore their presence in some way changes the home, but it depends on the individual living within that home as to whether the presence of the technology has a good, bad, or neutral impact. For the researchers at the University of Lancaster telecare is perceived as a technology changing home, "Without doubt, telecare changes the meaning of home. Not only physically and spatially..., but telecare itself is an indication that you have changed and you have some care needs. Telecare has an ambiguous connotation: it indicates that you are vulnerable, but at the same time it can give reassurance and a feeling of safety" (EFORTT 2011, page 16). TLM has the potential to remove something of the essence of home, by the act of placing sensors in this private space the home may no longer be ones' castle (Bennet 2011).

The presence of TLM technology could be perceived as a medicalisation of the home (Schermer 2009), a further step in the biomedicalisation of aging (Estes & Binney 1989). It can be a reminder of ill-health, especially if the TLM system includes daily symptom monitoring (EFORTT 2011). Some potential participants of the Whole Systems Demonstrator Trial refused to have telecare technology in their home because it brought to the fore their poor state of health, "I said to the man [who came to do the home visit], 'I appreciate what you're doing... but I'd feel more crippled'" (Sanders et al 2012, page 7-8). The presence of sensors in the home may also signify a potential imbalance of power, between the passive individual being monitored and the organisation controlling the technology (Bennett 2011, Brittain et al 2010).

#### **1.4 Beneficence – TLM Should do Positive Good**

The presence of telecare equipment within the home may have a positive impact, enabling older people to feel safe (EFORTT 2011, SCIE 2010), “Overall, lifestyle monitoring systems potentially offer a new mechanism for ensuring a safe environment for older and vulnerable people to remain at home with the reassurance that, if unforeseen events occur, assistance can be provided in a timely manner” (Brownsell et al 2011, page 185). However to date the value of TLM systems in terms of improved safety for older people living at home is not known, since the systems are largely still at the research stage. The focus of the research has been on identifying changes in activity, rather than working out methods of providing help in a timely manner (Brownsell et al 2011).

#### **1.5 Justice – TLM Should be Provided in a Manner that Treats People Fairly**

Justice in TLM would be about providing the service in an equitable and accessible manner for those that want it, and freedom of choice to reject the service for those that do not.

Current monitoring technologies are not designed to blend in with the home environment, and are obtrusive both in terms of their appearance, and how they function. It is difficult to imagine such designs been considered acceptable for the generations of people drawn to Apple’s iPod and iPad technology, which is renowned for its imaginative design (Turner 2007). It could therefore be argued that the design of the monitoring technologies is in itself unethical, as its focus on practical issues and cost does not consider the impact on the individual when it is placed in the home. The design of home assistive technologies have also tended to focus on practicalities rather than combining good design with aesthetic appeal (Mountain 2011), and this could be perceived as ageist in the sense that older people may not be perceived as worthy of good design. However there may be additional costs associated with improving the design of TLM technologies, and that may raise other ethical issues.

At the heart of the ethics of TLM is the issue of choice since this is fundamental to the principles of fairness and autonomy. Do older people actually want TLM? Much of telecare equipment is installed at the request of family members rather than the older person themselves (EFORTT 2011; Gammon, Christiansen, & Wynn 2012), and thus there is the risk that TLM may be similarly imposed (Gilhooly 2002, Magnusson & Hanson 2003). There is evidence that some older people view telecare as something that would be acceptable only if they became frail and needy (Percival & Hanson 2006), and they would be prepared to make

compromises to stay at home (EFORTT 2011, Townsend et al 2011). For some TLM is the least desirable home monitoring technology (Mihailidis et al 2008), and but others expressed a more positive view (Brownsell et al 2000). Clearly views about TLM differ and thus it is especially important that older people are given the choice of a range of care options (Lewin et al 2010), including care away from the home (EFORTT 2011), and that they should not be fearful of what would happen if they reject the technological solution (New Millennium Research Council 2007). On a more positive note Schermer (2009) argues that Telecare offers the opportunity for a more collaborative approach between older people and health professionals.

For the technology to develop in an ethical way, the sensors would be tailored to the individuals' needs, rather than a one size fits all approach (Hanson et al 2009, Perry et al 2010, Sanders et al 2012). In 2005 the Foundation for Assistive Technology argued that current telecare services provided standardised systems that rather than reflecting the needs of the individual, may reflect the vested interests of others (Down 2005, Percival & Hanson 2006). Others perceive that the technology may be unethical because it being produced to solve the 'aging problem' without contemplating the impact on individuals' lives, "...Telecare implementation can be unethical, even coercive, if it is introduced primarily in order to 'solve the crisis' or save resources" (EFORTT 2011, page 24). It would be an especially contentious issue if resources for carers were diverted to pay for TLM services (EFORTT 2011); or if an unintended consequence of the technology was a reduction in visits from unpaid carers because they believed the technology was looking out for their relative or friend (Bowes et al 2012).

### **1.6 Autonomy - TLM Should be Provided in a Manner that Demonstrates Respect for People**

Autonomy may be about ensuring that TLM is providing in a way that ensures that older people are able to live their lives as they wish, without feeling forced to do things against their will because of the technology.

There is some evidence that telecare technology may alter behaviour in the home (Hensel et al 2006), and this may be an issue of ethical concern since the right to act autonomously within the home is a key issue. Some participants have described watching the PIR sensor trying to work out what it was doing, or feeling like the bed was no longer the haven it was before the pressure mat was fitted and feeling self-conscious about the amount of time spent in bed (Hanson et al 2009). There is a potential for activities in the home and habits to change because of being monitored (EFORTT 2011), and this has already been described in a project



using a wearable monitoring device where participants stopped going out (Doyle, Bailey, & Dromey 2009), and in a telemonitoring project where a participants altered the times she got up in a morning (Essen 2008). Whilst these happenings are unintended consequences of the technology, further research is necessary to identify these potential causes of harm. In cases where the presence of the sensor become a source of stress there is no option to switch off the sensor, and this lack of choice is an ethical issue, "...there are both practical and ethical considerations when deciding if users should be able to turn the equipment off, or whether this would represent an unacceptably high level of risk to the older person" (Poole 2006).

TLM data is only of value if it is shared between people, for example between those professionals involved in planning and reviewing healthcare, and therefore the older person would need to give their permission to do this, and to understand what the data will be used for (EFORTT 2011, Lewin et al 2010, Perry et al 2010). TLM data has the potential to identify a need for changes in healthcare that the older person being monitored may not be happy with, for example the sensor data may show a requirement for a hospital stay, but older person may want to stay at home. Bowes et al (2012) argue that by taking the decision to seek healthcare out of the older person's hands there is a potential loss of autonomy for that individual. However the individual would have the right to reject any changes in care they did not agree with.

### **1.7 Informed Consent**

An older person receiving TLM should be fully informed about how the technology will function, and the implications of having the technology in the home. This is about informed consent. There is evidence that some participants of TLM do not understand how the technology functions and what the service will provide, and thus are left with false expectations (Hanson et al 2006).

A review of Ethical Issues in Telecare by the Social Care Institute for Excellence identified difficulties in conveying information about the technology in a clear and appropriate manner as a barrier to informed consent, especially where participants have cognitive difficulties (Perry et al 2010). This issue is particularly pertinent to TLM since a significant proportion of the research effort has focused on older people with dementia (Perry et al 2009). In cases where individuals are not able to make an informed choice, others may choose for them, and a TLM solution may not necessarily be the best option (EFORTT 2011). Those with the capacity to consent may face pressure to agree to participate in TLM research from others who believe

that the research is beneficial, and thus the participant may not be given the opportunity to weigh up benefit and harm (Bowes et al 2012).

There are also ethical issues around the choice of sensors to place in the home of a participant. Clearly opinions vary, and one ethical route round this issue is to offer people the choice of which sensors they want, as was the case with the Barnsley study; but this risks individuals not accepting the very sensor which may be most indicative of their health state. It would therefore be important for older people to be given a clear explanation of the sensors that would potentially benefit them the most, in order for them to make an informed choice.

TLM is an indirect form of surveillance, as data is created in response to the sensors being triggered, but the level of information this creates is generally very imprecise. Therefore whilst the idea that Big Brother is watching is a long way from the truth, there are large quantities of sensor data created, and this in turn creates ethical issues about ownership and control of the data (Lyon 2001); how reliable the data is to monitor health; and what is the purpose of the data collected?

Because TLM data is created automatically an enormous data stream is created. TLM data should only be collected if it has the potential to be of use in monitoring health, but because it is very easy to collect data there is the temptation to collect as much as possible. The data that does prove useful in TLM is most likely a small fraction of the available data, and therefore ethical issues arise from the collection of data that is never used (EFORTT 2011). However that said, initially a range of data was collected because it was not known which data would be useful, and more recent TLM projects are thinking more about how to reduce the amount of sensors used in monitoring (Stewart 2010). A focus of many TLM papers is the process of analysis of the data without giving any consideration to how to link the process to decision making by health professionals (Brownsell et al 2011). This process of developing algorithms seems to exist in an ethical void (Bowes et al 2012), and in addition there are ethical, social, and clinical implications about the idea of basing care on the analytical findings of a computer program (EFORTT 2011). There are also the more fundamental issues about the security of the data during the processes of data collection, transfer of data, and data storage, and the TLM service provider should ensure that the data is as secure as possible at all stages (SCIE 2010).

Researchers should be aware of all these factors when taking informed consent.

## **1.8 Conclusion**

At present it is difficult to explore ethical issues arising out of TLM since it is chiefly at the research stage, and as the technology develops and is rolled out more issues will arise. The ethical issues may arise out the difference between the potential of TLM and the reality. With the long term monitoring of older people more ethical issues will crop up, for example, the issues arising out of spotting signs of cognitive decline through monitoring, and what to do with this information (McLean 2011). For McLean (2011) technology offers the opportunity for older people to make choices about how they want to live; but before this ideal can become a reality it has to be established whether home activity changes according to health, and this is at the heart of the ethical issues in TLM. In addition in common with general research on assistive technology for older people there is a tendency for a focus on the device rather than the ethical issues that arise (Zwijssen et al 2011), and those involved in TLM need to ask why this is. Reviews of ethical issues in assistive technologies tend to focus on the same issues of surveillance, stigma, etc (Zwijssen et al 2011), but with the reality of placing TLM in the home more issues will arise because of the complex social situations it will encounter; and thus this exploration of ethical issues is not complete.

## **Appendix Information Sheet 1**

### **Consent form for Interviews with Participants with Heart Failure**



#### **Information sheet and consent form**

#### **Home visits (interviewees)**

**Version 1 May 2012**

#### **Understanding the impact of heart failure on activities and everyday life**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The overall aim of this project is to find out about the impact of ill health on everyday life and activities in people with heart failure

#### **What is the purpose of this research?**

We want to find out what happens to everyday activities when health goes up and down due to heart failure, and especially what people do when they suffer ill health. We also want to know about other things that influence what people choose to do, such as hobbies and interests, and family life, for example. We hope that this information will help give us some useful ideas for future health technologies to help people living at home with heart failure.

### **Why have I been chosen?**

You have been asked to take part because you have *heart failure*.

### **Do I have to take part?**

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

### **What if I do not wish to take part?**

You are free not take part and may leave at any time without giving a reason and there will be no negative consequences.

### **What do I have to do?**

A researcher from the University of Sheffield will come and interview you at home. If you wish your husband/wife/partner (if applicable) to join in with the interview, they are welcome to attend and share their experiences.

We are hoping to make audio recordings of participants. If you agree to this, the audio tapes will be of you talking about your experiences.

### **What will happen to the audio recordings?**

All information will be kept strictly confidential. The recordings will be stored securely at the university and only used for the purposes of the research. You may withdraw your consent before, during and after the recording or ask for it to be edited if necessary. You can stop the recording for any reason. You can listen or see the finished recording. After the project ends the recordings will be deleted.

### **How long will the interview last?**

The interview should take about an hour, but may be longer if you have lots to say, or it may be shorter if you do not have much to say.

### **What if I change my mind during the study?**

You are free to withdraw from the study at any time. You will not have to give any reasons for your withdrawal.

### **Are there any risks or disadvantages to taking part in this interview?**

We do not anticipate that there will be any risks or disadvantages to taking part in the interview.

### **What are the possible benefits of taking part?**

The information you give us to understand what happens to the everyday lives of people with heart failure, and what happens when health fluctuates. We hope that will be a future benefit to people with heart failure as the information may be used to inform the development of home health technologies.

### **Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. You will be identified by a code rather than a name.

Any audio tapes will be stored securely. People from regulatory authorities may look at our records to check that the study is being carried out correctly. Your name will not be disclosed.

### **What will happen to the results of the research study?**

We aim to publish results of the study in a health care journal and present our findings at professional conferences. If you would like a summary of the results on completion or details of any publications and presentations please contact Sarah Hargreaves at the address below.

### **Who is organising and paying for the research?**

The early stages of this project were funded by Barnsley Foundation Trust Hospital as part of a PhD studentship. This project is supervised by Professor Mark Hawley from the Rehabilitation and Assistive Technology group at the University of Sheffield (email: [mark.hawley@sheffield.ac.uk](mailto:mark.hawley@sheffield.ac.uk), telephone: 0114 2220682, address: as below)

### **What if I want to know more?**

Please contact Sarah Hargreaves at the address below for more information.

**Sarah Hargreaves**

**Rehabilitation and Assistive Technologies Group**

**School of Health and Related Research**

**30 Regent Court**

**University of Sheffield**

**S1 4DA**

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**Thank you for your time.**

## Appendix Information Sheet 2

### Participant Interview Topic Guide (Participants with Heart Failure)

Thank you for agreeing to talk to me.

#### Introduction

1. Consent
2. Confidentiality
3. Stopping the interview
4. Consent to record

I am very interested to hear how your everyday activities have been affected by heart failure.

Topic	Question	Follow-up Questions
Warm-up question	Apart from your heart failure can you tell me about any other health complaints that affect you?	How does x that affect your everyday life and the things you do?
Heart failure symptoms	What heart failure symptoms do you generally get?	Which of these symptoms impacts most on your everyday activities?  Can you tell me about this?  What sort of things do you do to ease the symptoms?
Good days	Some people with heart failure talk about good days and bad days, do you recognise that description?	How do you feel on a good day?  What sort of things do you typically do on a good day?  How do you feel on a bad day?  What do you do to try and ease the symptoms?  What sort of things do you do on a bad day?  Do you do the same things or different things on a bad day, compared to a good day?
Comparison of good and bad days	I am just going to ask you to compare good and bad days	Do you eat the same things during a bad day, compared to a good day?  Would you prepare food in the same way on a bad day, compared to a good day?  Do you watch the same amount of television on a bad day, compared



Topic	Question	Follow-up Questions
		<p>to a good day?</p> <p>Would you use the loo the same amount on a bad day, compared to a good day?</p> <p>Would you shower or bathe the same amount on a bad day compared to a good day?</p> <p>When your symptoms are troubling you, are there some things you avoid doing at home?</p> <p>What happens about the things you find difficult? Prompt: does someone else do them?</p>
Overactivity- Rest Cycle	<p>Do you ever find that you do too much when you are having a good day?</p> <p>What sort of things do you do?</p>	<p>What happen after you have done too much?</p> <p>How do you feel the day after you have done too much? (What do you do?)</p> <p>How do you feel when you go back to your usual activities?</p>
Good nights/Bad nights	<p>I am interested to know about what happens to you during the night when you are feeling well, and when you are feeling unwell</p>	<p>Can you tell me about a typical night when you are feeling well with your heart failure?</p> <p>Prompt:- How well do you sleep, do you have to get up during the night? What do you do?</p> <p>When you are feeling unwell during the night, what do you do? See prompt above.</p> <p>How do you feel when you are having a bad night?</p> <p>Do you do anything to try and ease your symptoms?</p> <p>Some people with heart failure have described opening windows to get air. Do you do anything like that?</p>

Exacerbations	Have you ever had occasion to ring for emergency help for your heart failure, such as ringing 999, or getting emergency help from your GP or Heart Failure Specialist Nurse?	<p>What made you call for help?</p> <p>How did you feel?</p> <p>What had you been doing in the days before you called for help?</p> <p>(What were you doing during the day/What were you doing during the night?)</p> <p>What did you do to try and ease your symptoms?</p> <p>Do you think anything brought on this episode?</p>
Attitude to life/self efficacy (individual response to ill health)	Compared to your friends, do you think you have good health?	<p>Do you feel as confident in your ability to do things as you ever did?</p> <p>Do you ever ignore your heart failure symptoms and do things anyway?</p>
Home activities	What things you do in the home do you find most difficult?	<p>Can you tell me about that?</p> <p>Have you changed the way you do your every-day activities because of your heart failure?</p> <p>How do you find going up and down stairs?</p> <p>Do you ever sit down to do things that you would have stood up to do before?</p>
Outdoor activities	When you go out, what do you find most difficult?	<p>Can you tell me about this?</p> <p>When your symptoms are troubling you, are there outdoor activities that you would avoid doing?</p>

Is there anything else that you can tell me about to help me understand about the effect of heart failure on the things you do in your everyday life?

Thank you very much

## Appendix Information Sheet 3

### Participant Interview Topic Guide (Validation Exercise at the Support Group)

Thank you for agreeing to talk to me.

#### Introduction

1. Purpose of research
2. Consent
3. Confidentiality
4. Stopping the interview
5. Consent to record

I have been interviewing people with about how their everyday life and activities are affected by heart failure and what people do when symptoms get worse.

I am going to tell you what I think people with heart failure have told me, and I would like you to tell me what you think, whether you agree or disagree with what I have said.

1. I think that the heart failure symptom that impacts most on everyday life and the things that people want to do is tiredness, rather than breathlessness.

What do you think?

2. I want to know what people do when their heart failure gets worse, do they do the same things as usual, or do they change what they do.

I think that when people are having a bad day with heart failure they do different things than normal, like stopping at home more, and doing things that don't require much energy.

What do you think/do?

3. I think that when people with heart failure are suffering from an exacerbation of symptoms they change the things they do. They stop going out, avoid climbing stairs, and other things that require energy. They start to do different things like sitting on the sofa watching television, and people have told me that at night they sit on the side of the bed, open windows to get air, and sometimes sit up all night on the sofa.

What do you think?

What do you do when you have an exacerbation of heart failure?

4. I think that a lot of people with heart failure often have other health problems as well, and these can be worse than heart failure and stop people doing the things they want to do.

What do you think?

5. I think that some people with heart failure decide how well they are by what activities they can do, for example, if they can climb the stairs, or walk somewhere, or play a round of golf, they are ok.

What do you think?

Do you do this, and if so what do you do to check you are ok?

6. I think that there are lots of things that affect what people do in their everyday life other than heart failure, such as family and friends, hobbies, the weather, or whether they are an outgoing person?

What do you think?

What is the most important factor in helping you decide what you do in your everyday life, is it your health or is it other things?

7. I think that the families of people with heart failure watch what their relative is doing to check that they are not doing too much.

What do you think?

8. I think that being diagnosed with heart failure is scary and being told that your heart is not working as well as it should, can make you fearful of being too active.

What do you think?

9. I think that some people with heart failure have been told by health professionals to exercise and others to rest, and this affects how active people are in their everyday life.

What do you think?

10. Some people with heart failure talk about how much they enjoy being outside, since they have had heart problems.

Has this happened to you?

## **Appendix Information Sheet 4**

### **Participant Interview Topic Guide (Heart Failure Specialist Nurses)**

Thank you for agreeing to talk to me.

#### Introduction

6. Purpose of research
7. Consent
8. Confidentiality
9. Stopping the interview
10. Consent to record

#### **Question 1**

I would like your opinions about how much you think that what people with heart failure do at home is directed by their health?

*Prompt: Can you give me some examples?*

#### **Question 2**

At the university we have been looking into the idea that the home activities of people with heart failure could be monitored by technology in order to find out when their symptoms have got worse. For example, you can put sensors in various places in the kitchen to try and monitor whether people are regularly preparing food and drink. If you were going to monitor home activities to find out whether heart failure symptoms have got worse, where in the home would you monitor, and what home activities would you monitor?

#### **Question 3**

I have been trying to find out what people with heart failure do when they experience an exacerbation of their symptoms, for example, in the days before an emergency hospital admission. Do you have any knowledge of what people do when their heart failure gets really bad?

*Prompt: Do they tend to stop at home, or try to carry on as usual? Are there things they do to try and ease their symptoms?*

#### **Question 4**

You will no doubt have heard of the overactivity-rest cycle, where the idea is that when people with heart failure are having a good day they may over do it, and then have to rest, and then when they go back to normal life they have lost some fitness, and overtime they can become

deconditioned. Do you think that this really does happen to people with heart failure? (*Hand out diagram of overactivity-rest cycle that appears in the Heart Failure Plan*)

### **Question 5**

Have you seen any changes in people with heart failure when they have started to become more active, or started exercising? Can you tell me about this?

### **Follow-up question**

What happens to heart failure symptoms when people start to exercise?

### **Question 6**

Do some people cope better than others with heart failure? **Prompt:** Why is that do you think?

### **Follow-up question**

Do some people cope better than others at all the stages of heart failure?

## **Appendix: Template Version 1**

### **Theme One – Co-morbidities**

- 1.1 Arthritis
  - 1.1.1 Walking difficulties
  - 1.1.2 Steps
- 1.2 Gout

### **Theme Two - Heart failure symptoms**

- 2.1 Breathlessness
  - 2.1.1 Difficulty dressing
- 2.2.1 Tiredness
  - 2.2.1 Energy loss

## **1.1**

### **Theme Three - Good days**

- 3.1 Experience
  - 3.1.1 Tiredness
  - 3.1.2 Energy limitations
  - 3.1.3 Slowing down
  - 3.1.4 Pacing
  - 3.1.5 Relying on others
  - 3.1.6 Coming to terms with change
    - 3.1.6.1 Sadness and disappointment
    - 3.1.6.2 The mind hasn't come to terms with the change
    - 3.1.6.3 Finding consolation (friends/support group)
- 3.2 Activities
  - 3.2.1 Sitting
  - 3.2.2 Gardening
  - 3.2.3 Helping friends and family
  - 3.2.4 Helping with the support group
  - 3.2.5 Decorating
    - 3.2.5.1 Taking longer
- 3.3 Difficulties
  - 3.3.1 Getting dressed
    - 3.3.1.1 Find new ways of doing things (new technique, new clothes, help from others)
  - 3.3.2 Walking (going slower)
  - 3.3.3 Steps (assessing where you can go, using lift, partner reconnoitring)
  - 3.3.4 Gardening (sitting down, resting, division of labour, change garden)

- 3.3.5 Distances
- 3.3.6 Going where you feel most comfortable

#### **Theme Four - Bad days**

- 4.1 Experience
  - 4.1.1 Energy loss
- 4.2 Activities
  - 4.2.1 Sitting
  - 4.2.2 Sleeping
  - 4.2.3 Pottering at home
  - 4.2.4 Computer
  - 4.2.4 Television
  - 4.2.5 Stop at home
    - 4.2.5.1 Other reasons for stopping at home, i.e., partner ill
  - 4.2.6 Avoiding steps

#### **Theme five – Comparison between bad days and good days**

- 5.1 Different patterns of activity
  - 5.1.1 Food
    - 5.1.1.1 Eating less
  - 5.1.2 Television
    - 5.1.2.1 Watching more
  - 5.1.3 Toilet usage
    - 5.1.3.1 Avoiding Using
  - 5.1.4 Avoiding activities
    - 5.1.4.1 Other takes over activity

#### **Theme six – Overactivity-rest cycle**

- 6.1 Overdoing it
  - 6.1.1 Helping friends
- 6.2 Paying the price
  - 6.2.1 Payback time (as in when it happens - the following day, or the one after that)
  - 6.2.2 Energy levels
  - 6.2.3 Resting
- 6.3 Going back to normal

#### **Theme seven – good nights**

- 7.1 Experience
  - 7.1.1 Wakening
    - 7.1.1.1 Snoring (from partner)



7.1.2 Feeling tired in the morning

7.2 Activities

7.2.1 Reading

7.2.2 Watching TV

**Theme eight – bad nights**

8.1 Experience

8.1.1 Exhaustion

8.2 Activities

8.2.1 Trying to sleep

8.2.2 Tossing and turning

8.2.3 Propping up pillows

8.2.4 Going down stairs

8.2.5 Listening to music

8.2.6 Windows

8.2.7 Getting fresh air

8.2.8 Sitting

**Theme nine – Exacerbation**

9.1 Stability

9.1.1 Awareness of situation

**Theme ten – Perception of situation and attitude to symptoms**

10.1 Perception of health - being ok

10.1.1 Doing too much

10.1.2 Getting things done

10.2 Perception of capability – some restrictions (some indication of the scale of the change)

10.2.1 Modifying activities

10.3 Ignoring symptoms and doing things anyway

## Appendix: Template Final Version

### First and Second Level Codes

First level Code	Second Level Code
Where I am now	Who I am
	Health
	Attitudes to Activity
Strategies for Undertaking Activities	Adapting
	Controlling Activity Levels
	Planning to Go Out and About
	Reliance on Others
	Sitting and Resting
Deciding what to do Today	Commitments
	Weather
	How you Feel on the Day
	Assessing Activities
	Avoiding Activities
The Changing Nature of Daily Activities	Home
	Outdoors
	Night-time
	Social Activities
	Activities to Control Symptoms

Integrative themes were Integrative theme: level of intrusion from symptoms

### First to Fourth Level Codes

First level Code	Second Level Code	Third Level Code	Fourth Level Code
Expectations of Activity	Who I am	Age	Doing Less with Age
			Feeling Trapped in an Older Person's Life
		Gender	Female Roles
			Male Roles
		Living Arrangements	Alone with Heart Failure
			Living with a Partner
			Family Life
			Where I live
		Disposition	Sociable
			Solitary
			Outlook on Life
			Sleep disposition
		Stage of Life	Working
			Retired
		Preferences	Hobbies
	Health	Threats	A Frightening Event
			The Term Heart Failure
			The Future
			Health Takes Centre Stage
		Co-morbidities	Degree of Intrusion
			Impact on Activities
		Perception of Health and Capabilities	Awareness of Symptoms
			A positive View of Health
			Loss of Health
			Feeling Capable
			Loss of Capability
			Establishing the State of Health Through Activity
	Attitudes to Activity	Pact Activity Levels	Active Jobs
			Active Hobbies
		Medical Advice about Activity	Encouraging Activity
			Reducing Activity
			Not Enough Advice
		Family Concerns	Fear and Worry
			Monitoring Activity
		Attitudes Encouraging Activity	Carrying on as Normal
			Recognising the Benefits of Activity

First level Code	Second Level Code	Third Level Code	Fourth Level Code
			A Sense of Achievement
		Attitudes Discouraging Activity	Attitude to Risk
			Giving-up Activities
			Loss of the Will/Capacity to Undertake Activities
			Monitoring and Limiting Activity
			Learning from Experience
Strategies for Undertaking Activities	Adapting	Activities	Dressing
			Gardening
			Walking
			Using Tools
		Home and Garden	Moving House
			Adapting the Home
			Adapting the Garden
		Life and Expectations	Changing Expectations
			No Adapting Necessary
	Controlling Activity Levels	Pacing	Pacing to Undertake Activities
			A Difficult Art to Learn
		Slowing Down	A New Pace of Life
		Shorter Days	Patterns of Activity
		Building-up Activity Levels	Finding New Activities
			Motivation and Goals
			Improved Fitness
		Overactivity	Pushing Yourself to Get Things Done
			Overdoing It
			Paying the Price
	Planning to Go Out and About	Diuretics	
		Parking	
		Seats	
		Toilet	
	Reliance on Others	Family	Others Being There
			Assisting with Activities
			Taking Over Activities
		Paying for Jobs to be	

First level Code	Second Level Code	Third Level Code	Fourth Level Code
		Done	
		The Car	Becoming Essential
	Sitting and Resting	Charging Batteries	
		Recovering	
		Sitting to Undertake Activities	
Deciding what to do today	Commitments	Routine	Weekly Routine
		Family and Friends	Caring Responsibilities
			Considering Others
	Weather	Cold	Experiencing Cold
			Less Outdoor Activity
		Heat	Experiencing Heat
			More Outdoor Activity
		Wind	Takes your Breath Away
	How you Feel on the Day	Normal Days	Feeling Normal(ish)
			Feeling Energetic
			Feeling Positive
		Bad Days	Energy Loss
		Flare-ups	Feeling Awful
			Can't Be Bothered
	Assessing Activities	Is this Activity OK?	Energy Input
			Breath Input
			Uncertainty
		Prioritising Activities	
		Past Experience	Stress Undertaking Activities
	Avoiding Activities	Bending	
		Carrying	
		Distances	
		Exerting Activities	Slopes
			Stairs
		Laying Flat	
The Changing Nature of Daily Activities	Home	Getting Washed and Dressed	Dressing
			Bathing
		Food	Cooking
			Eating
		Household Chores	Cleaning
		Entertainment	Television
			The Computer
			Reading
		The Stairs	
	Outdoors	In the Garden	Gardening
			Hanging out the

First level Code	Second Level Code	Third Level Code	Fourth Level Code
			Washing
		Out and About	Leaving the Home
			Transport
			Shopping
			Work
			Eating Out
			Days Out
			Holiday
			Sport and Exercise
	Night-time	The Bedtime Routine	Going to Bed
			Getting Up
		Activities in the Bed	Sleep
			Wakening
		Getting up	Seeking Air
			Television
			Drinks
			The Computer
	Social Activities	Participation	
	Activities to Control Symptoms		

### First to Fifth Level Codes

First level Code	Second Level Code	Third Level Code	Fourth Level Code	Fifth Level Code
Where I am Now	Who I am	Age	Doing Less with Age	Attributing Symptoms to the Ageing Process
			Feeling Trapped in an Older Person's Life	Benefits of Being Younger
		Gender	Female Roles	
			Male Roles	
		Living Arrangements	Alone with Heart Failure	Scale of Being Alone
			Living with a Partner	Partner's Ill-Health
			Family Life	
			Where I live	Topography
				Housing
		Disposition	Sociable	
			Solitary (can be forced upon you by health)	Loneliness
			Outlook on Life	
			Sleep disposition	Sleeping like a Log
				Like Maggie Thatcher
		Stage of Life	Working	
			Retired	Loss of Structure
				Money
		Preferences	Hobbies and Interests	Active Hobbies
				Inactive Hobbies
	Health	Threats	A Frightening Event	Vivid Experience
				Emotions (loss of...)
			The Term Heart Failure	
			The Future	A New Normality
				An Interruption
				Health Takes Centre Stage
				Side-Effects of Medication
		Co-morbidities	Degree of Intrusion	No Problem
				Worse than Heart Failure
			Impact on Activities	Difficulties Undertaking Activities
				Giving-up Activities
		Perception of	Awareness of	Length of Time

First level Code	Second Level Code	Third Level Code	Fourth Level Code	Fifth Level Code
		Health and Capabilities	Symptoms	Since Diagnosis
			A positive View of Health	
			Loss of Health	
			Feeling Capable	
			Loss of Capability	
			Establishing the State of Health Through Activity	Proving Yourself
				Feeling Diminished
	Attitudes to Activity	Pact Activity Levels	Jobs	
			Hobbies	
		Medical Advice about Activity	Encouraging Activity	Exercise
			Reducing Activity	Give-up Activities
				Take it Easy (avoid stress & rest)
			Not Enough Advice	
		Family Concerns	Fear and Worry	
			Monitoring Activity	Looking for Signs
		Attitudes Encouraging Activity	Carrying on as Normal	The Mind has Not Come to Terms with Heart Failure
				Not Wanting to Acknowledge Limitations
				Putting on a Front
			Recognising the Benefits of Activity	Perception that Inactivity is Bad
			A Sense of Achievement	Well-Being
		Attitudes Discouraging Activity	Attitude to Risk	
			Giving-up Activities	
			Loss of the Will/Capacity to Undertake Activities	
			Monitoring and Limiting Activity	
			Learning from Experience	
Strategies for Undertaking Activities	Adapting	Activities	Dressing	



First level Code	Second Level Code	Third Level Code	Fourth Level Code	Fifth Level Code
			Gardening	
			Walking	
			Using Tools	
		Home and Garden	Moving House	
			Adapting the Home	Downstairs Toilet
				Walk in Shower
			Adapting the Garden	Less Grass
				Raised Beds
		Life and Expectations	Changing Expectations	
			No Adapting Necessary	
	Controlling Activity Levels	Pacing	Pacing to Undertake Activities	
			A Difficult Art to Learn	
		Slowing Down	A New Pace of Life	
		Shorter Days	Patterns of Activity	
		Building-up Activity Levels	Finding New Activities	
			Motivation and Goals	
			Improved Fitness	
		Overactivity	Pushing Yourself to Get Things Done	
			Overdoing It	Make Hay Whilst the Sun Shines
				We all do it (acknowledge overact)
			Paying the Price	Timescale
				Exhaustion
				Going Back to Normal
				Learning from Experience
	Planning to Go Out and About	Diuretics		
		Parking		
		Seats		
		Toilet		
	Reliance on Others	Family	Others Being There	
			Assisting with Activities	
			Taking Over Activities	

First level Code	Second Level Code	Third Level Code	Fourth Level Code	Fifth Level Code
		Paying for Jobs to be Done		
		The Car	Becoming Essential	
	Sitting and Resting	Charging Batteries		
		Recovering		
		Sitting to Undertake Activities		
Deciding what to do today	Commitments	Routine	Weekly Routine	Seasonal Differences
		Family and Friends	Caring Responsibilities	Shaping Activities
				Pressure to Undertake Activities
			Considering Others	
	Weather	Cold	Experiencing Cold	
			Less Outdoor Activity	
		Heat	Experiencing Heat	
			More Outdoor Activity	
		Wind	Takes your Breath Away	
	How you Feel on the Day	Normal Days	Feeling Normal(ish)	
			Feeling Energetic	
			Feeling Positive	
		Bad Days	Energy Loss	Frequency
				Irritation
				Towards Depressed
				Reinforces the Severity of Illness
				Can't Be Bothered
		Flare-ups	Feeling Awful	Going Downhill
				Bad Tempered
			Can't Be Bothered	
	Assessing Activities	Is this Activity OK?	Energy Input	
			Breath Input	
			Uncertainty	
		Prioritising Activities		
		Past Experience of Undertaking Activities	Stress Undertaking Activities	Learning from Experience (don't walk now because of breathlessness)
	Avoiding Activities	Bending		

First level Code	Second Level Code	Third Level Code	Fourth Level Code	Fifth Level Code
		Carrying		
		Distances		
		Exerting Activities	Slopes	
			Stairs	
		Laying Flat		
The Changing Nature of Daily Activities	Home	Getting Washed and Dressed	Dressing	
			Bathing	
		Food	Cooking	
			Eating	
			Drinking	
		Household Chores	Cleaning	
			Decorating	
		Entertainment	Television	
			The Computer	
			Reading	
		The Stairs		
	Outdoors	In the Garden	Gardening	
			Hanging out the Washing	
		Out and About	Leaving the Home	
			Transport	Driving
				Taxi
			Shopping	
			Work	
			Eating Out	
			Days Out	
			Holiday	
			Sport and Exercise	Walking
				Gym
	Night-time	The Bedtime Routine	Going to Bed	
			Getting Up	
		Activities in the Bed	Sleep	
			Wakening	
		Getting up	Seeking Air	
			Television	
			Drinks	
			The Computer	
	Social Activities	Participation		
	Activities to Control Symptoms			

**Appendix Table 1: Trend Chart and LOESS Plot Summary Table**

House	Hospital Admissions	All Measures Trend Charts	General Activity Loess Plots	Food Activity Loess Plots	Bath & Toilet Day Loess Plots	Bath & Toilet Night Loess Plots	TV Duration Loess Plots	Day Nap Loess Plots	Total Sleep Loess Plots	Increase/Decrease	Slight *crease/fluctuation	Fluctuation		No change
1	3	No clear evidence	No change	Slight increase	No change	Data issues	Slight Fluctuation	No sensor	No sensor	0	0	2	2	2
2		No clear evidence	Decrease	Fluctuation	Clear decrease	Clear decrease	Data Issues	Increase	Increase and stable	4	0	1	5	0
3	1 long	Possible increase in general activity before the hospital admission, and definite decrease in general activity after the admission.	Decrease	Increase	No change	Fluctuation	Fluctuation	No change	Slight increase	2	1	2	5	2
4		No clear evidence	Slight increase	No change	Decrease	Data issues	Slight increase	-	Fluctuation	1	2	1	4	1
5		Decrease in general activity and food activities	Decrease	Decrease	Slight decrease	No change	Slight decrease	Stable and then increase	Stable and then increase	4	2	0	6	1
6		No change	Slight decrease	No change	Slight decrease	Slight fluctuation	Fluctuation	No sensor	No sensor	0	3	1	4	1
7	1	Improvement in symptoms	Slight fluctuation	Slight decrease	Data issue	Fluctuation	Slight Fluctuation	Slight fluctuation	Decrease and then stable	1	4	1	6	0
8		No change	Slight increase	No change	No change	Slight increase	Fluctuation	No change	No change	0	2	1	3	4
9	1	Decrease in general activity	Fluctuation	No change	No change	Fluctuation and slight increase	Decrease	Increase	No change	2	0	2	4	3
10		No clear evidence	Fluctuation	No change	No change	Fluctuation and slight increase	Fluctuation	No change	No change	0	0	3	3	4
11		Decrease in general activity	Decrease	Slight fluctuation	Slight decrease	Fluctuation	No change	Decrease	Slight fluctuation	2	3	1	6	1
12		No clear evidence	Slight decrease	Fluctuation	No change	Slight increase	Decrease	No change	No change	1	2	1	4	3
13		Decrease in general activity	Fluctuation	Fluctuation	Slight decrease	Slight increase	Increase	-	No change	1	2	2	5	1
14	1 other	No clear evidence	Slight fluctuation	Slight decrease	Data issue	Data issues	Slight increase	No change	No change	0	3	0	3	2
15		No clear evidence	Slight decrease	No change	Decrease	Slight fluctuation	Slight Fluctuation	Slight fluctuation	Slight increase	1	5	0	6	1
16		No change	Slight decrease	Slight increase	Slight fluctuation	Slight increase	Data Issues	No sensor	No sensor	0	4	0	4	0
17	1 other	Decrease in EQ-SD VAS	Decrease	Slight decrease	Data issue	Data issues	Slight Fluctuation	Fluctuation	Slight increase	1	3	1	5	0
Increase/Decrease			5	2	3	1	3	4	3					
Slight *crease/fluctuation			8	6	5	6	7	2	4					
Fluctuation			3	3	0	5	4	1	1					
			16	11	8	12	14	7	8					
No change			1	6	6	1	1	5	6					

Other admission = Hospital admission for a complaint other than heart failure

**Appendix Table 2: Post-Hoc Test Results by Health Question - Are your ankles or feet swollen? - 1st 12 hours**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Bath Night	Level 1				low			
Bath Night	Level 2							
Bath Night	Level 3							
Bath Night	Level 4				high			

**Appendix Table 3: Post-Hoc Test Results by Health Question - Are your ankles or feet swollen? - 2nd 12 hours**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Bath Day	Level 1				low			
Bath Day	Level 2							
Bath Day	Level 3							
Bath Day	Level 4				high			
Bath Night	Level 1				low		low	
Bath Night	Level 2							
Bath Night	Level 3							
Bath Night	Level 4				high		high	
Night Activity	Level 1				low		low	
Night Activity	Level 2							
Night Activity	Level 3							
Night Activity	Level 4				high		high	
Total Sleep	Level 1							
Total Sleep	Level 2							high
Total Sleep	Level 3							low
Total Sleep	Level 4							no diff

**Appendix Table 4: Post-Hoc Test Results by Health Question - Have you felt more tired today?**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Bath Day	Level 1			no diff				
Bath Day	Level 2			low				
Bath Day	Level 3			high				
Bath Day	Level 4			high				
Day Activity	Level 1			no diff				
Day Activity	Level 2			low				
Day Activity	Level 3			high				
Day Activity	Level 4			high				
Food Activity	Level 1			no diff				
Food Activity	Level 2			low				
Food Activity	Level 3			high				
Food Activity	Level 4			high				
General Activity	Level 1			no diff				
General Activity	Level 2			low				
General Activity	Level 3			high				
General Activity	Level 4			high				
Night Activity	Level 1			no diff			no diff	
Night Activity	Level 2			low				
Night Activity	Level 3			high			low	
Night Activity	Level 4			high			high	

**Appendix Table 5: Post-Hoc Test Results by Health Question - Have How anxious have you been today?**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Bath Day	Level 1			no diff				
Bath Day	Level 2			low				
Bath Day	Level 3			high				
Bath Day	Level 4			no diff				
Bath Night	Level 1				low			
Bath Night	Level 2				high			
Bath Night	Level 3							
Bath Night	Level 4				low			
Food Activity	Level 1				high			
Food Activity	Level 2				no diff			
Food Activity	Level 3							
Food Activity	Level 4				low			
Night Activity	Level 1			no diff				
Night Activity	Level 2			high				
Night Activity	Level 3			low				
Night Activity	Level 4			no diff				

**Appendix Table 6: Post-Hoc Test Results by Health Question - Do you have a cough?**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Day Activity	Level 1	low						
Day Activity	Level 2	no diff						
Day Activity	Level 3	high						
Day Activity	Level 4							
Day Nap	Level 1	low						
Day Nap	Level 2							
Day Nap	Level 3	high						
Day Nap	Level 4							
Total Sleep	Level 1	low						
Total Sleep	Level 2							
Total Sleep	Level 3	high						
Total Sleep	Level 4							
TV Duration	Level 1				low			
TV Duration	Level 2				no diff			
TV Duration	Level 3				high			
TV Duration	Level 4							



**Appendix Table 7: Post-Hoc Test Results by Health Question - Have you felt dizzy this morning?**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Day Activity	Level 1					no diff		
Day Activity	Level 2							
Day Activity	Level 3					high		
Day Activity	Level 4					low		
Food Activity	Level 1					no diff		
Food Activity	Level 2							
Food Activity	Level 3					high		
Food Activity	Level 4					low		
General Activity	Level 1					low		
General Activity	Level 2							
General Activity	Level 3					high		
General Activity	Level 4					no diff		
Night Activity	Level 1							low
Night Activity	Level 2							high
Night Activity	Level 3							
Night Activity	Level 4							

**Appendix Table 8: Post-Hoc Test Results by Health Question - Which statement best describes your self-care today?**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Bath Day	Level 1			high				
Bath Day	Level 2			low				
Bath Day	Level 3							
Day Activity	Level 1			high				
Day Activity	Level 2			low				
Day Activity	Level 3							
Food Activity	Level 1			high				
Food Activity	Level 2			low				
Food Activity	Level 3							
General Activity	Level 1			high				
General Activity	Level 2			low				
General Activity	Level 3							

**Appendix Table 9: Post-Hoc Test Results by Activity Measure - General Activity (EQ-5D)**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Which statement best describes your own usual activities today? Which statement best describes your self-care today?	1			high	low			
Which statement best describes your own usual activities today? Which statement best describes your self-care today?	2			low	high			

**Appendix Table 10: Post-Hoc Test Results Activity Measure - General Activity (Urine)**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Have you passed less urine than usual today?	3		high					
Have you passed less urine than usual today?	1		low					

**Appendix Table 11: Post-Hoc Test Results by Activity Measure - Day Activity**

Proxy Activity	Level	House						
		1	4	6	10	14	15	17
Do you have a cough?	1	low						
Have you felt dizzy this morning?						no diff		
Have you felt more tired today?				no diff				
Have your ankles or feet been swollen today?						high		
Do you have a cough?	2	no diff						
Have you felt dizzy this morning?								
Have you felt more tired today?				low				
Have your ankles or feet been swollen today?								
Do you have a cough?	3	high						
Have you felt dizzy this morning?						high		
Have you felt more tired today?				high				
Have your ankles or feet been swollen today?						low		
Do you have a cough?	4							
Have you felt dizzy this morning?						low		
Have you felt more tired today?				high				
Have your ankles or feet been swollen today?						no diff		

**Appendix Table 12: Participant Descriptions of the Changing Nature of Symptoms (Normal, Bad, Exacerbation)**

Symptom	Participant	Normal	Bad	Exacerbation
Breathlessness	Christopher	I do sometimes get a little bit breathless but not a lot		
Breathlessness	Willow	I get breathless on exertion, particularly going upstairs, and walking up slopes, nothing like as bad as I did a few months ago when I was so ill, and they have got rid of a lot of the fluid retention, so I can cope a lot better now.		I didn't want to see people, because erm because of breathlessness I couldn't say more than two or three words, I was sort of gulping for breath.  I was so breathless in the end that it was a struggle just to walk about and do things.
Breathlessness	Dawn	Well it sort of feels, it varies a lot from time to time, but it, you get this tightness here [pointing to her chest], even down by your midriff area...	...it is hard to explain, like a fogginess or a like summat could do with clearing out when it comes that thickness	
Breathlessness	Eric			I couldn't move. Well I could move, but I was really struggling to move. You know just getting to the toilet, fortunately I use the wife's chair [stair lift] to get me up the stairs to go to the toilet. Even then from the top of the stairs into the toilet I was absolutely shattered. From there to the chair I was shattered,

Symptom	Participant	Normal	Bad	Exacerbation
				from that chair to the end of the settee there [a few steps] and I would have to stand [sound of panting] out of breath completely.
Breathlessness	Graham	I mean you can't do nowt without some sort of penalty, short of breath, pains, or owt, there's always a price to pay for whatever you do	Oh arr arr, been up fighting for breath and all that malarkey ...sometimes my heart feels like it is going to jump out of my flaming chest.	
Breathlessness	Henry	Shortness of breath if I'm climbing stairs. Err yesterday I went out just to put some rubbish out in the bin, the wind was ferocious, it just took my breath away completely. Erm I can't do things I used to do, can't do anything energetic. That's about it really		
Tiredness	Larry	I mean we're in bed for sort of half ten we are never really late, but it is a nice kind of tiredness an end of day tiredness...		Just absolutely exhausted as if you were wiped out, I mean I have done a bit of running in the past if felt as if you had done a half marathon...
Tiredness	Dawn	You can feel, I can be laughing and joking with my husband and having what we call my giddy half hour, and then	...and then when you get the fatigue it is all across your shoulders and up your neck. It is like you feel like you could do with a	

Symptom	Participant	Normal	Bad	Exacerbation
		two minutes later I can be just fsssss. I don't even want to speak I am just spent	collar on your neck, when it gets bad. You are that tired, like a rag doll. Yes, you are really shot for	
Tiredness	Olivia	Oh tired yeah you could be you could have your dinner by time I've washed up, washed meself, prepared me dinner and then I have me dinner sometimes I have to leave I'm in middle of washing up and have to come and sit down and before I know where I am I'm asleep. It just takes you overtakes you it's terrible	As if you've been punched to death (laughs), tired, listless you know, oh I don't want to do 'owt today.	
Tiredness	Willow	Erm physically I get tired easily, I have to pace myself, erm so it does affect quality of life...	Lethargic, very tired, and just no enthusiasm about anything really [said in a slow, dull sounding voice]	... And that was basically it, I used to sort of just get on the sofa, you know rest and err...
Tiredness	Max		I occasionally get a bit tired in the afternoons, well that is the excuse I tell my wife [laughter]. I couldn't Hoover today love I had to sit down [laughter]	I felt rough [laughter] because I had not had no sleep [laughter]. I felt like a bear with a sore head [laughter]
Tiredness	Eric	Yes I will sit in that chair and start yawning my head	It just seems weary, that's all that I can tell you	Even then from the top of the stairs into the

Symptom	Participant	Normal	Bad	Exacerbation
		off about four o'clock. And yet I can go to bed, normally before this happened I would have a couple of hours sleep a day, and that would be it.		toilet I was absolutely shattered. From there to the chair I was shattered, from that chair to the end of the settee there [a few steps]
Swelling	Willow	No problems reported	No problems reported	<p>My legs were very swollen, if I sat down I needed to get them up and Edward used to have to lift them up because they were just so heavy I couldn't lift them up.</p> <p>Well I presumed it was fluid retention because I was very oedematous, even on my abdomen and my back, the doctor said when I went into hospital</p> <p>and my shoes, you know I can get into shoes that I couldn't get into before. And the ones with the Velcro fasteners on, I have had to move, you know [make smaller because of the weight loss]. Because my feet were so swollen that they were just about at the limit.</p>
Swelling	Larry	No problems reported	No problems reported	When I got married I was fatter probably due to water retention,

Symptom	Participant	Normal	Bad	Exacerbation
				<p>unbeknown to me. So now, me weight's stable now, I have got to go and have my wedding ring made smaller, because if I put it on my wrist , my finger it will just drop off</p> <p>they stabilised me because I had put a heck of a lot of weight on, fluid retention on my legs they were horrible erm and I lost between 10 and 11 kilograms in them ten days I was in just from taking water tablets, could have put my bed in the toilet, you know basically I was just in the toilet all the time.</p>
Swelling	Olivia	...I'll have to sit and put me legs up. Otherwise I can't breathe then because full of water you know what I mean and...?	I'm, I'm different from other people with me legs, I'm told to get in and try [into bed] and by the time I've done that I can't breathe at all and I want to get back out. But you're fighting for breath	I were in a river
Swelling	Max	No problems reported	No problems reported	And err err I used to get swelling in my legs which made it, not difficult to walk but made it awkward
Swelling	Eric	You know when I take my socks and		I had swollen up with fluid



Symptom	Participant	Normal	Bad	Exacerbation
		shoes off I can see my feet, physically it is bigger like Michelin, going that way [the big tyre Michelin man]. That's the only thing I do, put my feet up		And I had built up the fluid.

**Appendix Table 13: Strengths and weaknesses of PIR Sensors**

Evaluation	Strengths	Weaknesses
Sensor functioning in the real world	<ol style="list-style-type: none"> <li>1. The PIR is useful for creating a general measure of activity over a relatively long period of time (where it is functioning in type one operation where the PIR has rest periods to extend battery life, as described more fully in Brownsell et al 2011a) (Brownsell et al 2011a)</li> <li>2. The PIR indicates when participants enter rooms, and therefore a record of movement around the home can be created</li> <li>3. Some participants find the monitoring of movement reassuring (Joint improvement Team et al 2009)</li> </ol>	<ol style="list-style-type: none"> <li>1. If the sensor is incorrectly sited it can pick up activity from a wider area than anticipated, making the measurement of activity inaccurate (Brownsell et al 2011, Porteus &amp; Brownsell 2000).</li> <li>2. The battery saving mode means that there are gaps in data collection, and it is not possible to gain an impression of the level and intensity of activity (in type one operation)(Brownsell et al 2011a)</li> <li>3. PIRs cannot be used to detect participants leaving a room, this can only be inferred by the triggering of sensors in other rooms (Brownsell et al 2011a)</li> <li>4. The red flashing light can be intrusive (although this can be switched off (Hanson et al 2009)</li> <li>5. Participants may not understand how the PIR works, and feel like they are under surveillance (Hanson et al 2009)</li> <li>6. Some participants find movement monitoring intrusive and restrictive (Joint improvement Team et al 2009)</li> <li>7. “Frustration due to low batteries causing false alarms and reducing the confidence of users in the equipment” (Joint Improvement Team et al, page 67)</li> <li>8. Some participants experienced anxiety about causing false alarms and inconveniencing support staff (Hanson et al 2009)</li> </ol>
Issues about the	<ol style="list-style-type: none"> <li>1. “..A good sensor for tracking a general level of movement”</li> </ol>	The sensor goes into battery saving mode, and thus it is not

<b>Evaluation</b>	<b>Strengths</b>	<b>Weaknesses</b>
measurement of activity	(SB 2011, page 8) 2. Good way of knowing where participants are in the home (FC 2011)	possible to get an impression of the finer detail of activity (SB 2011)
Issues about data interpretation	Knowing where participants are in the home may say something about the type of activity that is being undertaken, "...you want to know where people are because it is quite distinctive of their activity (FC 2011, page 1)	The PIR data shows that a participant is in a particular room, but it does not show what they are doing in the room, i.e., it cannot be assumed that just because someone is in the kitchen they are cooking. Additional information is required in order to understand what is actually happening (FC 2011).

**Appendix Table 14: Strengths and Weaknesses of Door Contacts**

Evaluation	Strengths	Weaknesses
Sensor functioning in the real world		<ol style="list-style-type: none"> <li>1. The sensor is bulky, and gets in the way (Hanson 2009, FC 2011)</li> <li>2. It can move or become detached (Hanson 2009, FC 2011)</li> <li>3. The sensor may “upset the balance of the fridge and cupboard doors” (Hanson 2009, page 102)</li> <li>4. Participants may not want these sensors in their home (FC 2011)</li> </ol>
Issues about the measurement of activity	If the door sensor is attached to the fridge this is a good proxy measure of food preparation (FC 2011)	Some versions of the door contact are unreliable, producing spurious open and close sensor firing (Brownsell et al 2011a, SB 2011)
Issues about data interpretation		<ol style="list-style-type: none"> <li>1. Data cleaning can get rid of many of the spurious firings, “However, partial or incomplete closure may not necessarily be detected, resulting in false indicators” (Brownsell et al 2011a, page 270)</li> <li>2. If the sensor is attached to a cupboard door additional information is required about what is in the cupboard in order to interpret the cupboard use (FC 2011)</li> </ol>

**Appendix Table 15: Strengths and Weaknesses of Electrical Appliances TLM Sensors**

Evaluation	Strengths	Weaknesses
Sensor functioning in the real world	The technology works quite well (FC 2011)	<ol style="list-style-type: none"> <li>1. The television sensor may record multiple spurious sensor firings (FC 2011)</li> <li>2. The television sensor does not work with certain makes of television (SB 2011)</li> <li>3. The lamp sensor does not work with energy saving bulbs (FC 2011).</li> <li>4. One participant plugged a double socket into the electrical appliance monitor and plugged a lamp in, creating spurious data (FC 2011)</li> </ol>
Issues about the measurement of activity	The researcher can target appliances that are important to participants, e.g., in England the kettle is important because of the culture of tea and coffee drinking (FC 2011)	Technical issues may mean that the data collected is not meaningful (SB 2011)
Issues about data interpretation		<ol style="list-style-type: none"> <li>1. The electrical appliance sensor works from a particular socket, and therefore if that socket is used for appliances other than the expected appliance, the data would be difficult to interpret (Brownsell et al 2011a)</li> <li>2. In order to understand the sensor data you may need additional information, e.g., if the kettle usage is higher this may mean that the participant has a visitor, but you would need confirmation from other sources (FC 2011)</li> <li>3. Spurious data makes data interpretation more difficult</li> </ol>

**Appendix Table 16: Strengths and Weaknesses of the Barnsley TLM Sensors Chair Sensors**

Evaluation	Strengths	Weaknesses
Sensor functioning in the real world		<ol style="list-style-type: none"> <li>1. The chair sensor cannot be fitted to all types of chair (Brownsell et al 2011a, Hanson et al 2009)</li> <li>2. The sensor may make the chair uncomfortable to use, e.g. causing backache, or pushing the person forward (Hanson et al 2009)</li> <li>3. The visible pressure mat caused annoyance to one participant (Hanson et al 2009)</li> <li>4. Studies tend to put chair sensors on chairs that participants use the most, and hope that they do not start using other chairs (SB 2011)</li> <li>5. The chair sensor is not equipped to deal with finer movements in the chair, i.e., multiple sensor activations can occur when a participants changes their sitting position in the chair (Brownsell et al 2011a)</li> </ol>
Issues about the measurement of activity	People with long term conditions typically experience episodes of tiredness, and therefore the measurement of chair usage should pick up changes over time.	<ol style="list-style-type: none"> <li>1. The chair sensor does not provide any fine detail of chair activity, i.e., it provides information on when the chair is occupied, and when the chair is empty. It does not give information on tremor in the chair, that is, whether participants are struggling to get out of the chair, and this would be a valuable source of information (SB 2011).</li> <li>2. In one study a participant reported in a diary that they were feeling tired in the period leading up to a hospital admission, but this was not picked up by the bed and chair sensor because presumably the participant was resting in a chair</li> </ol>

Evaluation	Strengths	Weaknesses
		without a sensor (Brownsell et al 2011b).
Issues about data interpretation		A narrow view of chair usage is created by wiring up only the chair that the participant tends to use the most. This does not take account of the fact that chair usage may change over time.

**Appendix Table 17: Strengths and Weaknesses of the Bed Sensors**

Evaluation	Strengths	Weaknesses
Sensor functioning in the real world	<ol style="list-style-type: none"> <li>1. Some participants have no objections to the bed sensor, not feeling any inconvenience (Hanson et al 2009)</li> <li>2. Helpful for particular participants, e.g., participants with dementia and learning disabilities (Joint improvement Team et al 2009)</li> </ol>	<ol style="list-style-type: none"> <li>1. The most intrusive sensor. Some participants may experience a negative response to the bed sensor, due to issues about “privacy, dignity and sexuality” (Hanson et al 2009, page 103)</li> <li>2. Some participants asked for bed sensors to be removed (Hanson et al 2009)</li> <li>3. “..Why should I tell somebody on the end of a computer what time I get up, what time I go to bed? That I found distressing” - Mr Heaton, participant (Hanson et al 2009)</li> <li>4. The same sentiment was expressed by a participant of another study using a wrist worn device to monitor sleep (Essen 2008)</li> <li>5. You can see and feel the sensor pad (Hanson et al 2009, SB 2011)</li> <li>6. The sensor pad moves up and down the bed a bit (SB 2011)</li> </ol>
Issues about the measurement of activity	The bed sensor has the potential to provide useful information about activity. If a bed sensor could be devised that recorded when participants went to bed and then got up, this may provide good information (FC 2011)	The current technology is flawed (FC 2011). Numerous sensor firings can be recorded when participants move about in bed (Brownsell et al 2011a).
Issues about data interpretation		The bed sensor is difficult to interpret because it is activated not only when participants get in and out of bed, but also when they move about in bed. In order to process the data you have to make assumptions about the data to “...compensate for the sensor not working exactly like we would like...” (FC 2011).



**Appendix Table 18: Strengths and Weaknesses of the General Telecare Platform**

Evaluation	Strengths	Weaknesses
Sensor functioning in the real world	<ol style="list-style-type: none"> <li>1. Platforms should be tailored to the individual</li> <li>2. Less visible than overt monitoring from devices, such as, a fall detector or flood monitoring, and this gets round issues of denial of need or non-compliance (Blythe et al 2001)</li> <li>3. The sensors are fixed, and therefore they cannot be put to one side like the community alarm pendant (Blythe et al 2005)</li> </ol>	Individual tailored platforms would be of expensive (SB 2011)
Issues about the measurement of activity		<p>There is insufficient validation of the sensor data to ensure that the data that the sensors are producing makes sense, e.g., if a PIR sensor stops sending data, is that because it is broken, or because a participant has stopped using that room?</p> <p>Researchers should put steps in place to ensure that the sensor data is checked and validated (SB 2011)</p>
Issues about data interpretation		<p>"..Not good enough to provide the high level of data that we need for the single assessment process and working out the difference between a change in activity and a clinically important change" (SB 2011, page 8).</p>

**Appendix Table 19: The Impact of Health on Bathing**

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<p>No on a bad day I might miss out on the shower I think, if I felt really knocked out yes. Miss out on the shower. And I don't, I have never really had baths much anyway, I wouldn't now have a bath on my own in the house, err just in case (Janice M/M-R-Y-P-B/S)</p> <p>If you were feeling ill like that you wouldn't dream of getting in a shower (Nancy)</p> <p>No. I just think oh if I am not up to it I don't. I don't push stuff like that anymore (Dawn B/S-L-Y-P-B/S)</p> <p>No. On a good day I would, but on a bad day I would not be bothered sometimes (Henry M/M-L-Y-P-B/S)</p> <p>... I mean if I get up I like a shower in a morning. If I don't feel so well I sit here sometimes it's late when I have a shower or if I don't get well enough I daren't go and stand, get in the hot water 'cos that will raise the temperature (Terry B/S-L-O-A-B/S)</p>	<p>No different from normal days (Max, &amp; Christopher)</p> <p>I still have a shower and also when I get out of bed I always seem to have got a bit of a backache and I think 'right warm water' but this is probably carried on from working at pit obviously, you know, having a shower every day (Peter B/S-L-O-A-B/S)</p> <p>... a bad day never occurs first thing and I get out of bed we get out of bed um I have my breakfast and then I get shaved and showered and dressed um and the bad day never happens till after that period, you know (Roland M/M-R-O-P-B/S)</p> <p>Yes still, because it freshens you up. It gets rid of the sweat and what have you (Eric B/S-L-Y-P-B/S)</p> <p>No, they're all the same. We've got a system, wife's got a stoma bag on, she changes that every second day. So it's shower one day, and we have a bath the second day. Shower bath, show bath, shower bath (Graham B/S-L-O-P-B/S)</p>	<p>...when I wasn't well Lauren sort of had to go in, err just make sure I could get, cos it's in, it's a shower over the bath so I had to just sort of be helped just to climb into bath, and get out of the bath. So on good day I can get in and out myself and dry myself. On a bad day I had to have help showering and getting dried, because it was just exhausting me getting dried (Larry M/M-R-Y-P-N/M)</p> <p>...personal hygiene is important (Willow M/M-R-O-P-N/M)</p>

**Appendix Table 20: The Impact of Health on Food Preparation**

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<p>What I'll sometimes do if I am feeling good is I will make a pan of soup and then I have got that and that will do me for so many days. And then if I have a bad off day as least I have got a nice bowl of soup (Dawn B/S-L-Y-P-B/S)</p> <p>On a really bad day I wouldn't bother cooking the tea (Janice M/M-R-Y-P-B/S)</p> <p>No you do easy, you know, something easy (Olivia B/S-L-O-A-B/S)</p> <p>Well, when you say prepare your own meals err depending if I'm feeling a bit off I would go across there [to the very close local shop] and get one of those ready cooked meals you just put in the microwave (Terry B/S-L-O-A-B/S)</p>	<p>...I am not just looking after myself. I wouldn't do anything like as elaborate if I was on my own, and just having a restful day, and I do for you know (William) he is a meat and two veg, type of man [laughter by both] (Willow M/M-R-O-P-N/M)</p>	<p>...doing the little bits that I always do for William, cooking his meal which was an effort, I literally flung it at him at some occasions because, he tend, his memory is going, and so he tends to just sit around and he will say, is it ready? And then he will come in and help carry things through, you see. Whereas it would have been lovely for him to get on and do vegetables, and things like that, but he is not that sort... (Willow M/M-R-O-P-N/M)</p> <p>No I couldn't [cook]. Well occasionally I would go in and manage a sandwich but as I've said I couldn't seem to move anywhere (Eric B/S-L-Y-P-B/S)</p>

**Appendix Table 21: The Impact of Health on Appetite**

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<p>...on a bad day I don't eat as much. I would eat the same sort of things but less (Alistair B/S-L-Y-P-B/S)</p> <p>I would probably eat more, and I would eat more sweet things, and I think that is about trying to eat to give myself energy (Janice M/M-R-Y-P-B/S)</p> <p>I do tend to lose appetite on a bad day, err so no I tend to eat more savoury things, now more than I used to. But I'll tend to crunch on a riveta, or cereal bar, or something like that, just it seems to boost me a bit (Willow M/M-R-O-P-N/M)</p> <p>A good example was yesterday, when we were having us tea and he just didn't feel good err. It took you ages, and I said just leave it. It was chicken salad, so you know, and he kept having to stop and rest (Megan)</p> <p>Oh you feel really terrible, you don't feel like eating anything at all. You don't feel like eating. Well I mean you've got to force yourself to eat (Terry B/S-L-O-A-B/S)</p> <p>I don't have the energy to eat it sometimes, never mind think about cooking you know (Dawn B/S-L-Y-P-B/S)</p>	<p>...that doesn't change on your good and bad days, that's just how you feel isn't it? I am not hungry so I am not going to eat (Megan)</p> <p>Oh I eat the same things aye (Peter B/S-L-O-A-B/S)</p> <p>It don't affect my appetite no (Christopher M/M-R-O-P-N/M)</p> <p>Usually the same amount [of food], yes (Eric B/S-L-Y-P-B/S)</p> <p>Oh yes, my eating pattern doesn't alter (Graham B/S-L-O-P-B/S)</p> <p>Yes yes it's probably a bit more of a struggle to eat purely because I'm tired but I would still eat... Just the same amount I think (Roland M/M-R-O-P-B/S)</p>	<p>Basically eating, I mean I have always eaten well, I didn't eat badly, but eating sat down watching the telly (Larry M/M-R-Y-P-N/M)</p> <p>I'd have a sandwich and then have a couple of bites and then ouhhhh that's enough, you know, and yet I was still putting on weight (Eric B/S-L-Y-P-B/S)</p> <p>I really lost my appetite when my heart failure was really bad, I couldn't eat large portions, especially when I was really breathless. I was too tired to cook, but I had to for my husband, but I couldn't eat it. I snacked on riveta and ice-cream, it was the only thing that didn't make me feel bloated (Willow M/M-R-O-P-N/M)</p>

**Appendix Table 22: The Impact of Health on Television Viewing**

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<b>Daytime</b>		
<p>I would think on a bad day I would most likely watch a lot more (Alistair B/S-L-Y-P-B/S)</p> <p>So I'll do all those things when I'm feeling ok. If I'm having an off day, the odds are I'll sit here and watch Jeremy Kyle [laughter] (Henry M/M-L-Y-P-B/S)</p> <p>I would probably watch less, because I would be more likely to lie on my bed and listen to my radio (Janice M/M-R-Y-P-B/S)</p> <p>On a bad day you are not interested particularly in anything are you? He just wants to be sat and left alone (Nancy)</p> <p>Well when he's not feeling very good he doesn't watch tele because he falls asleep. I'll find him asleep, he'll be nodding off and that [in front of the television] (Pamela)</p> <p>...on a bad day I'll go to bed early so there will be that few hours in evening where I don't watch (Graham B/S-L-O-P-B/S)</p>	<p>Well I'm not one for watching television all day (Olivia B/S-L-O-A-B/S)</p> <p>I crash out and just don't bother to watch it um so no I probably wouldn't (Roland M/M-R-O-P-B/S)</p>	<p>I would have watched more. I mean I hardly watch any telly now, I might watch an hour or two at night, but I was pretty much sat on my back side [during the exacerbation]...</p> <p>I was quieter, I can normally talk the hind legs off a dog I was sat there quiet watching telly and normally if it is something that I don't watch unless there is somebody watching it I am jabbering away about someat. I have a very low boredom threshold [laughter] but I was just sort of sat there quiet err you just sort of probably withdraw into yourself, you know become</p> <p>I mean me sitting here all day, it is like a cardinal sin, I can't you see, I just don't like doing that, I just sort of sat there all day, the only exercise I did was flicking the television remote... (Larry M/M-R-Y-P-N/M)</p>
<b>Night-time</b>		
<p>Read, watch TV, do a quiz, you know I have got quiz books (Alistair B/S-L-Y-P-B/S)</p> <p>I sit and watch the telly for a bit (Dawn B/S-L-Y-P-B/S)</p> <p>Fortunately I have not had to do that for a long time [get up]. At one it were err, we</p>	<p>So if I do get wakened up in the night, which will be three out of seven on average [by partner snoring]. Sometimes I stay up and read, sometimes watch TV, whatever (Alistair B/S-L-Y-P-B/S)</p> <p>So if you come down at night</p>	<p>So when you say you were getting up, were you coming down stairs? (SH)</p> <p>Yes just for a cup of tea, watching the morning news and whatever (Max B/S-R-Y-P-N/M)</p> <p>and like some nights so I didn't disturb Lauren because</p>

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<p>were going to bed, an hour up watching videos DVDs, and all the [indecipherable] tapes and everything for hours (Graham B/S-L-O-P-B/S)</p> <p>And then you just sit up on the side of the bed while it eases off and then if I think I'm going to get back to sleep I get in, or if I'm not I come up have a cuppa, Horlicks or someat, watch telly and then go back after an hour or so (Graham B/S-L-O-P-B/S)</p> <p>He would definitely get up if there was cricket on from abroad in the early hours. He would think well I might as well watch some cricket. And then I'll go back to sleep. So you did that sometimes, but not regularly (Karen, spouse of Ken M/M-R-Y-P-N/M)</p>	<p>what would you do? Do you switch the television on? (SH) No, no, never (Nick B/S-R-Y-P-B/S)</p> <p>But sometimes you wake up in middle of night and then you can't get back to sleep, three and four o'clock in a morning. And you feel like coming and sitting here and watching that [television]. But I never do (Terry B/S-L-O-A-B/S)</p>	<p>I mean she was running about after me all day I come down and was watching sport two, three, four o'clock in the morning, and was dozing on the settee. You know awful, awful feeling that, when you waken up in the night-time like that (Larry M/M-R-Y-P-N/M)</p>

**Appendix Table 23: The Impact of Health on Sleep**

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<b>Day-time</b>		
<p>...he'll go and lay on bed a lot. When he's not well... (Peter B/S-L-O-A-B/S)</p> <p>If I'm feeling really tired I'll go to sleep. If it is during the day I might have ten minutes up on there [on the sofa], or a nap in my chair (Henry M/M-L-Y-P-B/S)</p> <p>all you do is rest, all you do is rest (Olivia B/S-L-O-A-B/S)</p> <p>Read the papers, relax a bit more, rest a bit more [on the sofa] (Willow M/M-R-O-P-N/M)</p> <p>that's how bad a bad day is [laughter] that is how bad a bad day is, I would most likely be on the settee all day (Alistair B/S-L-Y-P-B/S)</p> <p>Go to sleep most of the time, don't you? (Alice)</p>	<p>So would you do the same things or different things on a bad day compared to a good day? (SH)</p> <p>[breathing sound] It really is more or less the same because I just sit about anyway. Err so I can be sat, feeling good you know what I mean, or I will be sat feeling [pause] bad (Nick B/S-R-Y-P-B/S)</p> <p>Well you start off good (laughs) then by dinner time it's a different story it's very tiring hmm you just want even when you've had a sleep you just (laughs) you just don't want to get up you want to go back to sleep again, you know. You have to force yourself to be awake (Olivia B/S-L-O-A-B/S)</p>	<p>I would just be sat there talking to Lauren and then ten seconds later I would be asleep. Erm about having an hour's kip in the afternoon... (Larry M/M-R-Y-P-N/M)</p> <p>... And that was basically it, I used to sort of just get on the sofa, you know rest and err, he did get on and do tea and things like that, and wash-up, which he always does after tea. But I did the minimum (Willow M/M-R-O-P-N/M)</p> <p>So you were lying on the sofa? (SH)</p> <p>I was like a cabbage really, yes [sleeping] (Willow)</p>
<b>Night-time</b>		
<p><b>Vivid Dreams</b></p> <p>I have never thought about this before, but maybe when I am overtired I dream more, and the dreams can be very intense, and that sort of jades you for the next day as well (Willow M/M-R-O-P-N/M)</p> <p>I seem to get a lot of dreams when I am tossing and turning I don't know, but with my tossing and turning I sort of wake up mid-dream. I am in the middle of a stream trying to get a rope across (Eric B/S-L-Y-P-B/S)</p>	<p>Whether he were having a good day or bad day, it wouldn't make any difference because he goes to bed at night and dies and then wakes up in the morning (Ruth, partner of Roland M/M-R-O-P-B/S)</p> <p>No it was purely needing to go to the toilet usually, that starts me off and I go back to bed and my mind starts working and I can't get back to sleep and that's when I come and sit up (Brian B/S-L-O-P-B/S)</p>	<p>A bad night [exhale of breath] I would be going to bed nine o'clock sometimes, I would be up every sort of, you never slept more than two hours, well either you couldn't breathe right, or you were going to the toilet, and like some nights so I didn't disturb Laura because I mean she was running about after me all day I come down and was watching sport two, three, four o'clock in the morning, and was dozing on the settee</p> <p>Well I found that sitting up what got you better and I sometimes sat on the edge of</p>
<b>Getting to Sleep</b>		

<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<p>Might take you longer to get to sleep but once I am asleep I sleep like a log (Henry M/M-L-Y-P-B/S)</p> <p>Well it takes you a bit to drop off because you go to sleep with a headache and a bit of haziness, dizziness... (Terry B/S-L-O-A-B/S)</p> <p><b>Tossing and Turning</b> ..when I don't feel so well I am always tossing and turning (Alistair B/S-L-Y-P-B/S)</p> <p>...you are uncomfy err so I think, you shall be tossing and turning... (Nick B/S-R-Y-P-B/S)</p> <p><b>Waking breathless</b> ...when water comes I can't breathe at all...I've seen me sit in this chair months at night, not gone to bed, not for weeks, for months. Hmm not been dared to go to bed, you know, even if you're in bed and that you like can't even turn over because you can't breathe</p> <p>...when I can't breathe it's that, you know horrible, you don't want to lay down in fact, I've got habit now... you're just rocking yourself [sitting on the edge of the bed] (Olivia B/S-L-O-A-B/S)</p> <p>Scared. Scared. But I don't know you just click in and tell yourself, you know, breath slow, I don't know, it's scary at first, but err same as I say sometimes my heart feels like it is going to jump out of my</p>		<p>the bed (Larry M/M-R-Y-P-N/M)</p> <p>And err absolutely not sleeping at night Not sleeping just tossing and turning. ...I couldn't sleep because I got this pain in my back</p> <p>Oh I stayed in bed, but then I used to get up at five o clock in the morning, just so I could stand up you know, and whatever (Max B/S-R-Y-P-N/M)</p> <p>But getting into bed and getting settled, I was just so breathless. And erm if I got up and went to the toilet, I sat on the edge of the bed for ages, before I could get motivated to go through to the toilet (Willow M/M-R-O-P-N/M)</p> <p>...the only incident that really frightened me was when it went dark. When I was lying down, because as soon as I was lying down it felt as though this was coming up and I couldn't breathe and then I had to sit up. And if I would nod off to sleep I'd shoot up and I'd be like arhh [sound of breathing and voice sounds loud and excited. Panting sounds]. So I ended up, as I said one night I ended up in the chair, I daren't lie down</p> <p>...when I'd shoot up I'd have to swing my legs round. Get my legs down and sit on the edge of the bed and support myself you know like this</p>



<b>Bad Days</b>		
<b>Different from Normal</b>	<b>No Difference from Normal</b>	<b>Exacerbation</b>
<p>flaming chest. And then you just sit up on the side of the bed while it eases off and then if I think I'm going to get back to sleep I get in, or if I'm not I come up ...(Graham B/S-L-O-P-B/S)</p> <p>...I mean early on there were times when I used to sit in this chair and go to sleep; I never went to bed through the night at all... (Brian B/S-L-O-P-B/S)</p> <p>...I couldn't breathe properly and so I got straight up and come down, and I didn't go back to bed while half past five. (Nick B/S-R-Y-P-B/S)</p> <p><b>Worry</b> On a bad night I will wake in the middle of the night and think oh shit this is, you know, this is what could happen. And it is difficult to escape it (Janice M/M-R-Y-P-B/S)</p> <p>...bad experiences, it's always them that seems to come flooding back and not the good ones... (Nick B/S-R-Y-P-B/S)</p> <p>And it is scary, when you don't feel well in the night, it is always more scary that daytime isn't it? So that's why he wakes me I think, because he is scared that he is going to die basically don't you? (Nancy)</p>		<p>[leading forward and breathing heavily] and then I'd get my breath back (Eric B/S-L-Y-P-B/S)</p>

**Appendix Table 24: Activities Related to Breathlessness and the Implications for Telecare Lifestyle Monitoring – Everyday Breathlessness**

<b>Type of Breathlessness</b>	<b>Strategy</b>	<b>Telecare Sensor</b>	<b>Comments</b>
Everyday	Reduction in the number of activities	All sensors	The impact on monitoring data would depend on the activity that had been curtailed. If outdoor activities are curtailed, there may be an increase in home sensor firings.
Everyday	Reduction in the intensity of activities	All sensors	Unlikely that sensors would be able to pick up this
Everyday	Walking less, or not enjoying walking	External door sensor and the absence of sensor firings in the home	This may mean an increase in home activity, as people may stop at home more and this would be picked up by the Telecare monitoring. Or alternatively people may carry on going out and use a car, rather than walking. This is speculation, and further research is required in order to gain an understanding of what people actually do.
Everyday	Give up gardening	External door sensor and the absence of sensor firings in the home	Participants may potentially go into the garden less, once they give up gardening. Or alternatively, they may go into the garden and just sit. A sensor placed on the external door to the garden would pick up visits to the garden, and any changes over time; but this would not record activities within the garden.
Everyday	Give up cooking	Food activity sensors	The indoor activities that were commonly curtailed included cooking, and this would presumably be undertaken by someone else (a carer or family member), or done another way (i.e., the use of ready meals). A measure sensitive to subtle changes in food activity would be useful.
Everyday	Give up decorating	Room PIR sensors	The decorating would presumably be undertaken by someone else, and thus this would not impact on the Telecare monitoring. Decorating is also an infrequent activity, and the presence or

Type of Breathlessness	Strategy	Telecare Sensor	Comments
			absence of this would most probably not impact on the general picture of activity.
Everyday	Sitting down to rest whilst undertaking activities e.g. whilst washing and shaving	Chair sensor	There was only one chair sensor utilised in the study which was situated in the living room, this would therefore not pick up people resting whilst undertaking activities in other rooms.
Everyday	Breathing exercises, i.e., breathing in through the nose and out through the mouth		Not a suitable activity for monitoring
Everyday	Seeking fresh air	Door sensors	The simplest way to seek fresh air would be to open a window, or door (possibly people would be more likely to use the backdoor to the garden, as it would be more private – but this is speculation). The Barnsley project only had a sensor on the front door, and no window sensors were fitted.
Everyday	Talking less		Not a suitable activity for monitoring
Everyday	Feelings of fatigue and exhaustion	Bed and chair sensors, TV	Telecare monitoring would pick up increased use of these sensors
Everyday - good day	Go out, i.e., shopping, walking, etc	Exterior door sensor	When participants left the house the last sensor would be the exterior and there would be no sensor firings in the home. This reduction in activity would be picked up by the sensors.
Everyday - bad day	Stop at home, and encounter particular difficulties, such as climbing the stairs	All sensors.	Telecare monitoring should pick up increased home activity when the participants stop at home. The combination sensor of hall, stairs and landing is not specific enough to record stair usage.

**Appendix Table 25: Activities Related to Breathlessness and the Implications for Telecare Lifestyle Monitoring – Night-time Breathlessness**

Type of Breathlessness	Strategy	Telecare Sensor	Comments
Night-time	Increase the number of pillows		Participants were asked about the number of pillows they had used the previous night
Night-time	Sleeping in a chair	Bed/Chair sensor	One chair was fitted with a sensor, and this may not be the chair that participants would sleep in when they experienced nocturnal breathing difficulties. The absence of bed usage would be picked up by the bed sensor
Night-time	Ensuring the room had plenty of fresh air		The provision of a bedroom window sensor would enable the analysis of nighttime window openings
Night-time	Altering the time of taking diuretics		Sensor on the medicine cabinet door

**Appendix Table 26: Activities Related to Breathlessness and the Implications for Telecare Lifestyle Monitoring – Worsening Breathlessness**

Type of Breathlessness	Strategy	Telecare Sensor	Comments
Worsening breathlessness	Resting	Bed and chair sensors, TV	Telecare monitoring would pick up increased use of these sensors
Worsening breathlessness	Seeking fresh air		The monitoring of door and window sensors
Worsening breathlessness	Breathing exercises		Not a suitable activity for monitoring
Worsening breathlessness	Seek help or advice from relatives or friends		Not a suitable activity for monitoring
Worsening breathlessness	Prevarication	All sensors.	If people stop at home, the increase in home activity would be captured by the sensors. Further qualitative research is needed in order to gain a clearer picture of what people do when breathing worsens.

Activities based on Edmonds et al 2005

**Appendix Table 27: Signs of Health Decline Identified from Qualitative Papers, and Implications for Telecare Lifestyle Monitoring**

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
Activity modification	<ol style="list-style-type: none"> <li>1. Undertaking activities more slowly/pacing activities (Evangelista et al 2000, Falk et al 2007, Hagglund et al 2008, Jeon et al 2010, Rhodes &amp; Bowles 2002)</li> <li>2. Changing the way activities are undertaken (Falk et al 2007, Jeon et al 2010)</li> <li>3. Resting during activities (Hagglund et al 2008)</li> <li>4. Substituting activities (Bosworth et al 2004, Jeon et al 2010, Rhodes &amp; Bowles 2002)</li> <li>5. The ability to perform activities varies throughout the day (Hagglund et al 2008)</li> <li>6. Not being fastidious about household activities (Hagglund et al 2008)</li> <li>7. Leaving task unfinished (Rhodes &amp; Bowles 2002)</li> <li>8. Sleeping in the afternoon in order to undertake an evening activity (Europe &amp; Tyni-Lenne 2004)</li> </ol>	<p>General activity within the home is recorded by the PIR room sensors, but these do not have the capability of recording the level and duration of activity, and thus they would not be able to record changes in the duration of activities that would be observed in activities undertaken more slowly, or with resting in between spurts of activity.</p> <p>Many of the changes that occur as a result of activity modification would probably be too subtle for PIR sensors to pick up, for example, not completing tasks, or not undertaking them to previous standards.</p> <p>The strategy of sleeping in the afternoon would be picked up by sensors if the participant slept in a bed, or chair, with a sensor.</p> <p>The strategies of activity modification are undertaken as a result of the gradual decline in health that occurs as a result of heart failure, there is no evidence that they pertain to a sudden exacerbation of health. Therefore in order to perceive changes in these strategies, long term monitoring would be required.</p>
Not going out	<ol style="list-style-type: none"> <li>1. Inability to undertake social and recreational activities outside the home (Pattenden et al 2007, Rodriquez et al 2008, Ryan &amp; Farrelly 2009)</li> <li>2. Spending a lot of time alone at home (Ryan &amp; Farrelly 2009)</li> </ol>	<p>As heart failure progresses it becomes more difficult for individuals to leave home as they lack the physical capacity. Telecare sensors should be able to pick up this process of remaining more at home, especially if external doors were wired up to record movements in and out of the house. The process of becoming housebound would occur over time, and therefore long term monitoring would be required.</p>

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
	<ol style="list-style-type: none"> <li>3. Ceasing going outside the house (Martensson et al 1997)</li> <li>4. Fear of going out in case of collapse (Bosworth et al 2004)</li> </ol>	<p>The inability to leave the home is part of the progression of heart failure and not necessarily a sign of a sudden exacerbation of ill health. In order to understand the meaning of remaining at home the context would have to be examined, for example, if the onset of remaining at home was sudden after a previously active life it would be more of a source of worry, than a gradual decline in leaving the home over time.</p>
Not doing things	<ol style="list-style-type: none"> <li>1. Family and carers undertake activities that the heart failure patient would have undertaken previously themselves, such as, dressing, washing, help toileting, and activities that require bending (Aldred et al 2005, Bennett et al 2000, Clark et al 2008, Falk et al 2007, Hagglund et al 2008, Pattenden et al 2007, Ryan &amp; Farrelly 2009,)</li> <li>2. Inability to undertake everyday tasks, such as household chores (Bosworth et al 2004, Europe &amp; Tyni-Lenne 2004, Pattenden et al 2007, Ryan &amp; Farrelly 2009, Zambroski 2003)</li> <li>3. Unable to participate in social activities (Aldred et al 2005, Zambroski 2003)</li> <li>4. Decreasing activities (Bennett et al 2000)</li> <li>5. Difficulty undertaking activities of a long duration (Europe &amp; Tyni-Lenne 2004)</li> <li>6. Inability to participate in family activities, such as Christmas meals, and taking the</li> </ol>	<p>In many cases activities that the participant can no longer perform are undertaken by family, friend, or carers; and thus the sensors would not pickup any changes in activity levels. The inability of people with heart failure to undertake activities can be indicative of a decline in health. In Clark's Scottish study the significance of family undertaking activities was evidenced, "This type of care was not given on a routine basis, but only at times when carers though that worsening symptoms prevented the individual from caring for themselves" (Clark et al 2008, page 378).</p>

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
	grandchildren on holiday (Aldred et al 2005)	
Doing things regardless of symptoms	Continuing to undertake activities to avoid being a burden on family, or friends (Bosworth et al 2004)	<p>This was a scenario described by one participant whereby he undertook mowing the lawn despite feeling unwell, and eventually was found in a collapsed state in the garden. It would not be possible for the Telecare sensors utilised in the Barnsley study to pick up this collapse; a fall monitor could pick this up.</p> <p>This scenario also illustrates the individual responses to the challenges presented by heart failure, as although typically people tend to give up arduous activities, others are more determined to continue.</p>
Stairs (difficulty)	<ol style="list-style-type: none"> <li>1. Difficulty climbing the stairs (Europe &amp; Tyni-Lenne 2004, Ryan &amp; Farrelly 2009)</li> <li>2. Putting a chair between flights of stairs in order to rest (Falk et al 2007)</li> <li>3. Checking before going upstairs that it is really necessary (Martensson et al 1997)</li> <li>4. Fear about lacking the physical capacity to climb the stairs: "I got scared, I didn't know I could manage, if I dared to walk up the stairs" (Europe &amp; Tyni-Lenne 2004)</li> <li>5. "I have got to the stage now that I have to go up the stairs on all fours - hands and legs" (Ryan and Farrelly 2009, page 227)</li> </ol>	<p>The stairs are a challenge for individuals with heart failure, and the monitoring of stair activities may be a useful indicator of physical capacity. However, once again, this decline is to be expected as part of the downward trajectory seen in heart failure, and therefore it would only be of clinical note if there was a sudden decline in stair usage.</p> <p>Technology is available to measure stair usage, and the duration of the climb up and down stairs.</p>
Walking	<ol style="list-style-type: none"> <li>1. Difficulty walking (Pattenden et al 2007, Ryan &amp; Farrelly 2009)</li> <li>2. Giving up walking (Pattenden et al 2007)</li> </ol>	A common theme that emerges from qualitative interviews of heart failure sufferers is a reported difficulty walking, which may result in avoidance of this activity. As described previously, the six minute walk is a commonly

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
	<ol style="list-style-type: none"> <li>3. Avoiding walking because of fear of collapse (Bosworth et al 2004)</li> <li>4. Walking slowly (Europe &amp; Tyni-Lenne 2004)</li> <li>5. Difficulty walking uphill (Europe &amp; Tyni-Lenne 2004)</li> <li>6. Having to rest frequently whilst undertaking a walk due to breathlessness (Pattenden et al 2007)</li> </ol>	<p>used measure of physical capacity. It has been mooted by previous research that this measure could be used as a potential proxy measure of daily activity (Witham et al 2006), a measure of change in health (Jehn et al 2009), and a predictor of long term prognosis (Walsh et al 1997).</p>
Passive pursuits	<ol style="list-style-type: none"> <li>1. Watching television to pass the time (Ryan &amp; Farrelly 2009)</li> <li>2. Spending a lot of time reading (Ekman et al 2001)</li> <li>3. Crosswords, jigsaw puzzles, television in moderation, and listening to the radio (Aldred et al 2005)</li> </ol>	<p>As health declines it is common for heart failure patients to seek solace in passive activities, such as television viewing, and listening to the radio. The undertaking of these activities may happen in tandem with heart failure patients spending more time at home, as they become limited by their health. However what is unclear is the role of these passive activities within the context of a sudden decline in health, for example, would the duration of time undertaking these activities suddenly decrease or increase?</p> <p>It is possible to monitor television usage; however this is just one passive pursuit that may increase as a result of a decline in health. Other passive pursuits would not be suitable for specific monitoring, such as, reading, listening to the radio, jigsaws, and crosswords; although they could be monitored more generally via a room monitor.</p>
Nocturnal breathlessness	<ol style="list-style-type: none"> <li>1. Inability to lie down (Ryan &amp; Farrelly 2009)</li> <li>2. Sitting up all night to avoid nocturnal breathlessness (Ryan &amp; Farrelly 2009)</li> <li>3. Sitting on the side of the bed (Mahoney 2001)</li> <li>4. Using numerous pillows (Ryan &amp; Farrelly 2009,</li> </ol>	<p>A worsening of breathlessness can be indicative of an exacerbation of heart failure that requires medical attention, and therefore any signs of nocturnal breathlessness that could be measured and monitored would potentially offer useful warning signs. The qualitative papers describe various reactions to nocturnal breathlessness and the question is whether these would be</p>



Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
	<p>Mahoney 2001)</p> <ol style="list-style-type: none"> <li>5. Difficulty sleeping (Pattenden et al 2007)</li> <li>6. Changing sleeping position (Mahoney 2001)</li> </ol>	<p>picked up by Telecare sensors?</p> <p>The qualitative participants describe being unable to lie down, and sitting up, either raised by pillows, on the side of the bed, or possibly on a chair (although this was not explicitly stated). The use of pillows was monitored by the health questions in the Barnsley study. Other participants sat up on the side of the bed, and therefore a mattress sensor would need to be targeted on this specific site. If the participant was sitting up in a chair in the bedroom this could be monitored by a chair occupancy sensor; and if the participant had vacated their bed, this would be picked up by the bed sensor.</p> <p>Other responses to nocturnal breathlessness are more subtle and would not be picked up by sensors, such as a change of sleeping position.</p>
Anxiety	<ol style="list-style-type: none"> <li>1. Worry caused by waiting for another exacerbation (Ryan &amp; Farrelly 2009)</li> <li>2. Anxiety provoked by remembering an acute exacerbation (Pattenden et al 2007)</li> <li>3. “The absolute worst is our anxiety and agony” (Falk et al 2007, page 196)</li> <li>4. Anxiety and bad nightmares as a side effect of beta blockers (Pattenden et al 2007)</li> <li>5. A feeling of anxiety that cannot be explained (Martensson et al 1998)</li> </ol>	<p>The participants described feelings of anxiety, which although were not indicative of a health exacerbation, were a blight on their lives. No examples of how the participants reacted to the anxiety in their daily activities were recorded by the qualitative studies, and thus it would not currently be possible to link activity with anxiety levels. In the Barnsley study participants recorded their anxiety levels via the health questions, and the NICE guideline recommends monitoring for anxiety and depression (NCCCC 2003).</p>
Good days/bad	<ol style="list-style-type: none"> <li>1. Unpredictable good and bad days (Clark et al 2008, Europe &amp; Tyni-Lenne 2004, Pattenden</li> </ol>	<p>Unpredictable good days and bad days are described by many of the</p>

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
days	<p>et al 2007, Ryan &amp; Farrelly 2009)</p> <ol style="list-style-type: none"> <li>2. Type and intensity of activities selected according to the daily capability (Clark et al 2008, Falk et al 2007)</li> <li>3. Inability to plan future activities (Aldred et al 2005, Clark et al 2008, Pattenden et al 2007)</li> <li>4. 'Black' days when it is not possible to do anything (Martensson et al 1997)</li> <li>5. Energy required to recover from bad days (Evangelista et al 2001)</li> </ol>	<p>qualitative studies, and this is a feature of many serious, long-term conditions (Lewin et al 2005). Although this pattern of good and bad days is not indicative of a health exacerbation, a greater proportion of bad days may signal a general decline. One of the aims of health care for heart failure patients is to delay progression to more serious disease (Davis et al 2006), and the identification of bad days by Telecare may potentially have a role to play in monitoring the status of the heart failure.</p> <p>There are few clues from the qualitative studies to identify what participants do on a bad day, in order to identify a proxy measure of bad days. One participant mentioned not being able to do anything (Martensson et al 1997), and thus it is likely that this individual would stop at home, and this would be recorded by the Telecare sensors. Further evidence about what individuals do on bad days is required in order to find out whether there are distinct activities that could be measured by Telecare, or whether it would be important to measure the balance between stopping at home, and leaving home.</p>
Fatigue	<ol style="list-style-type: none"> <li>1. Undertaking activities very slowly and then resting, e.g., polishing a shoe takes 15 minutes and then the participant had to sit down and recover (Ryan &amp; Farrelly 2009)</li> <li>2. Sitting down a lot (Ryan &amp; Farrelly 2009)</li> <li>3. Increase in activity, "The more I move around</li> </ol>	<p>The sudden onset, or worsening of fatigue, may be a sign of a health exacerbation and medical advice should be sought immediately (Lewin et al 2005). The participants of the qualitative studies describe a range of responses to fatigue from general fatigue that was mitigated by undertaking activities slower, sitting down, or actually increasing activity; to a more intense fatigue that called for immediate rest and sleep.</p>

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
	<p>the better I feel" (Bennett et al 2000)</p> <ol style="list-style-type: none"> <li>4. Being active despite a feelings of fatigue as "inactivity was seen as dangerous" (Hagglund et al 2008, page 293)</li> <li>5. "...An overwhelming desire to lie down and sleep" (Hagglund et al 2008, page 292)</li> <li>6. Feeling the need to go to bed early and rest in the afternoon (Martensson et al 1997)</li> <li>7. Fatigue varies across the day, i.e., worse in the morning, better in the afternoon (Hagglund et al 2008)</li> <li>8. Limiting bed rest to one hour per day (Hagglund et al 2008)</li> <li>9. A short walk every day (Hagglund et al 2008)</li> </ol>	<p>Telecare sensors would have varied success in picking up this range of activity. The undertaking of slower activities would be too subtle for Telecare sensors to capture, although if the activity was undertaken whilst seated the duration could be recorded by a chair sensor. The ability to record an increase in activity would depend on what activities were undertaken. The use of chairs to rest could be recorded if all the chairs were fitted with sensors; and sleeping could be captured by a mattress sensor.</p>
Loss of hope	<ol style="list-style-type: none"> <li>1. Not doing anything (Aldred et al 2005, Ryan &amp; Farrelly 2009)</li> <li>2. Feeling desperate (Ryan &amp; Farrelly 2009)</li> <li>3. Feeling withdrawn and isolated (Ryan &amp; Farrelly 2009)</li> <li>4. Drinking alcohol (Ryan &amp; Farrelly 2009)</li> <li>5. Loss of zest for life (Falk et al 2007)</li> </ol>	<p>One response to the decline in health experienced by the heart failure sufferers reported by the qualitative studies was a loss of hope. This low mood may be clinically important because of the higher prevalence of depression in heart failure patients compared to the general population (NCCCC 2003).</p> <p>One response to the loss of hope is to do nothing, presumably at home, and this would be captured by the home Telecare sensors. Other symptoms, such as the negative feelings, could only be captured by the use of depression surveys. In the Barnsley study the incidence of depression was measured by the EQ-5D and symptom questions.</p>

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
Adopting a positive attitude	<ol style="list-style-type: none"> <li>1. Finding consolations despite the health state (Bennett et al 2000, Ekman et al 2001, Europe &amp; Tyni-Lenne 2004,, Falk et al 2007, Martensson et al 1998, Pattenden et al 2007)</li> <li>2. Feeling a zest for life despite the health state (Falk et al 2007)</li> <li>3. Focusing on what can be done, rather than what that cannot be done (Hagglund et al 2008, Rhodes &amp; Bowles et al 2002)</li> </ol>	Adopting a positive attitude is a commonly reported response to the rigours of heart failure. It would be important take account of this as part of on-going monitoring of the health state, and as stated above this could be picked up by the use of health questionnaires, rather than Telecare sensors.
Loneliness	<ol style="list-style-type: none"> <li>1. Feeling lonely and isolated (Aldred et al 2005)</li> <li>2. Feelings of “antipathy, boredom and loneliness” (Ryan &amp; Farrelly 2009, page 226)</li> <li>3. A withdrawal from the world (Evangelista et al 2001)</li> <li>4. Loss of friends and social life(Europe &amp; Tyni-Lenne 2004)</li> </ol>	Loneliness is a feeling commonly expressed by the participants of the qualitative studies, and this may impact negatively on quality of life. No measures of loneliness were undertaken in the Barnsley study.

Sign of Decline	Details	Implications for Telecare Lifestyle Monitoring
Negative feelings	<ol style="list-style-type: none"> <li>1. Feelings of guilt, awareness of a dependence on others, and depression (Pattenden et al 2007)</li> <li>2. Feelings of worthlessness (Martensson et al 1998)</li> <li>3. Feeling a nuisance (Martensson et al 1998)</li> <li>4. Feelings of “fear, boredom, frustration, impatience, depression, guilt, and jealousy” (Zambroski 2003)</li> <li>5. Feeling like ‘half a person’ (Hagglund et al 2008)</li> <li>6. “I don’t think I’m as happy as I was” (Rhodes &amp; Bowles 2002, page 445)</li> <li>7. Feelings of emptiness, a lack of strength, and irritation (Europe &amp; Tyni-Lenne 2004)</li> </ol>	<p>The negative feelings commonly expressed by the participants of the qualitative studies are understandable given the change in circumstances that they have had to endure as a result of poor health, if these feeling are last longer than a few weeks they can be a sign of depression (Lewin et al 2005).</p>
Memory (decline of)	<ol style="list-style-type: none"> <li>1. Difficulty managing the drug regime (Pattenden et al 2007)</li> <li>2. Difficulty remembering hospital appointments (Pattenden et al 2007)</li> <li>3. Difficulty remembering lifestyle advice (Pattenden et al 2007)</li> <li>4. Concentration and memory difficulties (Europe &amp; Tyni-Lenne 2004)</li> </ol>	<p>Heart failure patients are advised to seek medical advice if they have new or worsening problems with memory or concentration (Lewin et al 2005). Such declines in memory are unlikely to be picked by Telecare sensors, unless they result in a specific pattern of behaviour. A more fruitful method of measure of memory difficulties would be to utilise a memory survey.</p>

Gardening	<ol style="list-style-type: none"> <li>1. Giving up (Bosworth et al 2004, Pattenden et al 2007)</li> <li>2. Limited in outdoor activities (Europe &amp; Tyni-Lenne 2004)</li> <li>3. Resting on a chair whilst watering and harvesting plants (Falk et al 2007)</li> </ol>	<p>A common response to a decline in health by the qualitative study participants was to reduce, modify, or give-up outdoor activities, such as gardening. These responses show the individual nature of responses to ill health, whilst one person may give up the activity when challenged by ill health, another will find a way to continue with the activity.</p>
Demeanour	<ol style="list-style-type: none"> <li>1. “..Alterations in facial expressions, appearance, complexion and mood” (Pattenden et al 2007, page 377)</li> <li>2. Becoming short tempered due to ill health (Clark et al 2008)</li> <li>3. “It’s just a kind of attitude as well. He is just generally brighter on a better day and less sort of sluggish and more interested in things generally” (Clark et al 2008, page 378)</li> </ol>	<p>Another sign of ill health is a change of demeanour in the heart failure sufferer, with reports from the qualitative studies of altered facial expressions and appearance, and mood, perceived by the relatives of the patient. Such changes are visual, and often only apparent to those that know the individual with heart failure very well, and thus could not be captured by Telecare sensors.</p>
Food preparation	<ol style="list-style-type: none"> <li>1. Preparing lots of meals at once (Falk et al 2007)</li> <li>2. Using frozen meals on occasion (Falk et al 2007)</li> </ol>	<p>One change in behaviour that may occur as a result of a decline in health is a change in food preparation. One participant described preparing lots of meals as once, when energy permits; and another, reheating frozen meals when poor health requires it. This limited evidence from the qualitative papers links food preparation to the health state, although there is no mention of what happens to food preparation and intake during an acute exacerbation of ill health.</p> <p>Telecare can be utilised to monitor the use of various kitchen appliances, such as, kettles, fridge, microwave, and toasters. It depends on what cooking methods are utilised as to whether the food preparation would be recorded by these sensors.</p>

Waiting through symptoms during an exacerbation	<ol style="list-style-type: none"> <li>1. Waiting for symptoms to pass (Bosworth et al 2004, Zambroski 2003)</li> <li>2. Avoiding calling the Doctor (Bosworth et al 2004)</li> <li>3. Delaying seeking medical help, so that by the time the participant acknowledged the need to call 999 he could only indicate this by banging on the table (Aldred et al 2005)</li> <li>4. Only seeking hospital care when home care is no longer possible (Zambroski 2003)</li> <li>5. Waiting for family to pass a judgement about symptoms before seeking medical help (Zambroski 2003, Clark et al 2008)</li> <li>6. Avoiding consulting the GP in case they admit the participant to hospital (Aldred et al 2005)</li> </ol>	The qualitative studies described participants delaying seeking medical help during an exacerbation of ill health, in the hope that the symptoms would pass off. If it would be possible for Telecare monitoring to identify the symptom exacerbation, hospital care could be given at an earlier stage; there is however a lack of evidence about what individuals are doing during such an exacerbation.
Using chairs to facilitate activities	<ol style="list-style-type: none"> <li>1. Arranging chairs around the backyard to enable the participant to empty the rubbish (Bosworth et al 2004)</li> <li>2. Putting a chair between flights of stairs in order to rest (Falk et al 2007)</li> </ol>	The technique of resting during activities, or undertaking activities whilst seated, is a recognised strategy that enables some heart failure sufferers to undertake activities that would too arduous without resting (Lewin et al 2005). The use of chairs may therefore be interpreted within this context as a facilitator to activities, rather than an indication that the individual is resting due to ill health.
Bathing difficulty	<ol style="list-style-type: none"> <li>1. Requiring the installation of a shower with a seat (Aldred et al 2005)</li> <li>2. Loss of breath whilst showering (Europe &amp; Tyni-Lenne 2004)</li> <li>3. Feeling unsafe in the bath, and worrying about being able to get out (Clark et al 2008)</li> </ol>	Three of the qualitative studies highlighted difficulties with bathing that resulted from heart failure. Bathroom activity was measured in the Barnsley study by a room PIR sensor; however this would not have picked up the issues highlighted by the qualitative studies, loss of breath, and feelings of insecurity. The Barnsley study also measured problems with self-care via one question in the EQ-5D; however the utilisation of a specific bathing

		difficulty measure may have been more fruitful.
Avoiding seeking help /Seeking help	<ol style="list-style-type: none"> <li>1. Not feeling comfortable with seeking help from children (Aldred et al 2005)</li> <li>2. Female participants receiving help from their children (Bennett et al 2000)</li> </ol>	Two of the studies highlighted issues about what happens when participants need help, some participants felt comfortable seeking help from their children, but others did not. No measures of unfulfilled requirements for help were undertaken in the Barnsley study.
Activities undertaken to aid breathlessness	<ol style="list-style-type: none"> <li>1. Inhalers (Bennett et al 2000)</li> <li>2. Cough drops (Bennett et al 2000)</li> <li>3. Deep breathing exercises (Bennett et al 2000)</li> <li>4. Cold cloth on the face (Bennett et al 2000)</li> <li>5. Dimming lights (Jeon et al 2010)</li> <li>6. Staying quiet (Jeon et al 2010)</li> <li>7. Sitting upright to aid breathing (Bosworth et al 2004)</li> <li>8. Going outside to aid breathing (Bosworth et al 2004)</li> </ol>	<p>There were some clues from the qualitative studies about what activities were undertaken in an attempt to relieve breathlessness. It was not clear from the studies the degree of breathless that that participants' experienced when they employed these strategies, and therefore it is not possible to make the link between particular activities and an acute exacerbation of breathlessness.</p> <p>The question is whether the strategies that participants employed could be captured by Telecare technologies? It would not be possible to surmise from sensor usage that medication had been administered to relieve symptoms, unless a specific medicine cupboard was wired up with a door sensor. Other strategies are too subtle to be picked up by sensors, such as: sitting up-right, staying quiet, and deep breathing. Other activities are ambiguous, in the sense that unless the context is understood they could be interpreted in a different light, for example, the application of a wet flannel could be understood as part of a bathing routine, rather than a therapeutic application. The application of flannel would result in a bathroom sensor firing.</p> <p>The strategy of dimming the lights would not be picked up by the sensors utilised in the Barnsley study, however this could be rectified by employing a sensor to record when lights are dimmed.</p>



		The link between worsening breathing and seeking fresh air was established by the previously mentioned English study (Edmonds et al 2005). Here once again, the participant one study sought fresh air outside to alleviate breathlessness, and this could be monitored by the use of external door sensors.
Activities undertaken to aid difficulty sleeping	<ol style="list-style-type: none"> <li>1. Reading (Bennett et al 2000)</li> <li>2. Watching television (Bennett et al 2000)</li> <li>3. Drinking herbal tea (Bennett et al 2000)</li> <li>4. Taking sedatives (Bennett et al 2000)</li> <li>5. Taking antidepressants (Bennett et al 2000)</li> </ol>	A number of activities were linked by one qualitative study to difficulty sleeping (Bennett et al 2000), which in its self can be a sign of breathlessness (Lewin et al 2005). There is no indication from the study that the difficulty sleeping was caused by a severe exacerbation of ill-health, and therefore the value of trying to glean difficulty sleeping from Telecare is questionable. In the Barnsley study the participants were asked how they had slept the previous night, and therefore a run of poor sleep could be gleaned from this.

## **Appendix Information Sheet 5: Lifestyle Monitoring Key Informant Interview Questions**

- 1) How did you choose the sensors that were used in the Barnsley heart failure study?

Prompt: Was any research undertaken to find out about home activities that may provide an indication of well-being, or did you get advice from any health professionals?

- 2) I have been thinking that it might be useful to interview participants about the meaning of each room for their condition, in order to target sensors. Have you any thoughts about this idea?

- 3) What were you hoping to find from the sensor data?

- 4) Why was the EQ-5D chosen rather than a specific heart failure measure?

- 5) Was the symptom measure a standard measure?

Prompt: if so, what was it called?

- 6) Was any thought given to the impact of co-morbidities on home activities?

- 7) How was the duration decided? (I assume that the duration of the study was considered long enough to witness changes in health).

- 8) Did you take account of the impact of types of dwelling on living with heart failure, for example, it would obviously be easier to live in a bungalow, rather than a house with steep stairs?

- 9) Why were so many participants living as couples, when this makes it difficult to interpret the sensor data?

- 10) I think that Telecare sensor data is difficult to interpret, and I suspect that my work would have benefitted from meeting the participants, seeing their homes, and interviewing them about their home activities and how they react to worsening health. What is your view on this?

11) People with heart failure use various strategies to deal with their symptoms. Would the Telecare sensors be able to record these strategies, and pick up variations? [Show following sheets]

<b>Strategies for coping with everyday breathlessness</b>
Giving up activities that require too much energy (such as gardening, cooking, and decorating)
Reduce the intensity of activities
Take life slowly
Taking longer to undertake home activities
Undertake breathing exercises
Open the window or door to get fresh air, or maybe going outside
Finding other ways to undertake activities, rather than giving up activities
Resting between activities
Resting during activities, e.g., sitting on the toilet after washing
Reduction in activities outside the home
Avoiding going up and down stairs too often
Walking slowly up and down stairs
Not walking too far
Sleep: changing sleeping position, altering the number of pillows, opening the window to get fresh air, sleeping in a chair, or altering the time of taking diuretics.
Taking naps
Taking life very slowly in the mornings
Getting help from family members with the activities of daily living
Employing cleaners and gardeners
Using mobility aids such as scooters or stair lifts
Doing more on good days (perhaps going out), and less on bad days (stopping at home)
Altering the types and intensity of daily activity according to how they feel
Not talking too much if this causes breathlessness
<b>Coping strategies for worsening breathlessness</b>
Allowing carers to undertake activities, such as, tying shoe laces.
Getting help from carers, i.e., help with toileting

Avoidance of normal or demanding activities

Stopping at house

Resting

Getting fresh air

Breathing exercises

Avoiding walking

Delaying seeking medical help/prevarication

Eventually seek advice from relatives or friends

Going to the GP/hospital

**Signs of worsening symptoms may be subtle**

Family carers of heart failure patients note subtle changes that indicate worsening of symptoms, these include, alterations of facial expression, appearance, complexion and mood (bad mood and loss of interest in things)

