

**Exploring everyday functioning in older adults with  
chronic pain:  
New insights with new technology**

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# **Exploring everyday functioning in older adults with chronic pain: New insights with new technology**

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**DECLARATION**

I declare that this thesis is entirely my own work and represents the results of my own research carried out at Teesside University. I declare that no material within this thesis has been used in any other submission for an academic award.

**EDITORIAL STYLE**

This thesis employs the editorial style of the American Psychological Association (APA). This editorial style, including all referencing, is detailed in 5<sup>th</sup> edition of the Publication Manual of the American Psychological Association (2001). British spelling is used throughout this thesis, except when using a direct quote.

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## ABSTRACT

Chronic pain is a widespread problem, especially in the older population, and can affect various aspects of daily living. At a time when it has been acknowledged that the population is increasingly ageing, research regarding the effects of chronic pain on the daily living of older adults is essential. Furthermore, the development of innovative technology is changing the way that much research is being conducted, and can lead to the retrieval of novel information, using a fresh approach. The adoption of this technology in the field of chronic pain research has the potential to examine various aspects of the daily living of older adults living with chronic pain using a different approach to previous research.

This study is underpinned by a Critical Realist ontology and Hermeneutic epistemology and follows a Generic Qualitative Research methodology (Caelli, *et al.*, 2003). The aim of the study was not to generalise the findings but to gather a deep theoretical description of the outcomes and offer an explanation of these findings based on an analysis of the multiple research methods used within the study.

This study had two main aims and was split into two sections according to the aims. Firstly, Part A of this study aimed to explore a range of day-to-day patterns and experiences of functioning in older adults suffering from chronic pain. Part B aimed to explore the usability, acceptance and experience of the technology used to measure functioning as part of the first aim of this study. Part B also aimed to look at the practicalities the participants were faced with when using the technology.

A mixed methods design was used for Part A in which 15 older adults (65+) living with chronic pain (pain >3 months) took part in an in-depth study lasting seven days. As well as the 15 core participants that took part in the study, two older adults (65+) without chronic pain and two younger adults (<65) with chronic pain took part in the study in order to provide some insight into the effects of either pain, or age, on functioning. Part A used four data collection techniques to gather data upon the daily functioning of older adults with chronic pain; the Daily Reconstruction Method diary (Kahneman, Krueger, Schkade, Schwarz, Stone, 2004), the Sensecam (also known as the Vicon Revue, Vicon©), the LifeShirt (Vivometrics Inc) and a semi-structured interview. However, although the LifeShirt was validated, as part of this PhD, and used throughout the study, the gathered data was not analysed due to multiple problems with the data.

The Daily Reconstruction Method, Sensecam and the semi-structured interview were each analysed separately before the results of the Daily Reconstruction Method and Sensecam were integrated into the themes derived from the semi-structured interviews. The integrated results led to the development of two themes, each with sub-themes; '*effect on daily living*' and '*managing pain and functioning*'.

The themes from Part A highlighted the way in which pain affected functioning and the modifications to daily functioning as a result of chronic pain. The way in which individuals perceived the management of their own pain and functioning, as well as strategies and assistive devices to manage pain and functioning were also discussed. This study has furthered current knowledge due to the idiographic nature of the study,

as well as multiple, novel, data collection tools used, adding additional details to how tasks have been modified, reduced, or terminated.

Part B of this study used the *Unified Theory of Acceptance and Use of Technology* (UTAUT, Venkatesh, *et al.*, 2003), the *Flow-State Scale* (Jackson & Marsh, 1996) and semi-structured interviews to explore participants' use of both the Sensecam and LifeShirt. The questionnaires and interviews were carried out with all of the individuals that carried out Part A of this research. From the semi-structured interviews two main themes were reported, each with sub-themes; '*expectations and experiences*' and '*awareness of equipment*'.

Two concepts developed from the themes within Part B that were specific to the participants' experiences of wearing wearable technology in this study, as opposed to '*typical*' non-wearable technology; specifically, the importance of design and the importance of others. Both of these overarching concepts affected the expectations of the technology, the experiences of using the technology, as well as the awareness of the technology during use. Furthermore, both concepts will remain and are long-lasting, despite the development of the technology in this field, but there are specific details that are contemporary and are specific to either the Sensecam or the LifeShirt as used in this study.

## **ABBREVIATIONS**

<b>ADL</b>	Activities of Daily living
<b>DH</b>	Department of Health
<b>DRM</b>	Daily Reconstruction Method
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>ICIDH</b>	International Classification of Impairments, Disabilities and Handicaps
<b>NHS</b>	National Health Service
<b>PC</b>	Personal Computer
<b>TAM</b>	Technology Acceptance Model
<b>UTAUT</b>	Unified Theory of Acceptance and Use of Technology
<b>WHO</b>	World Health Organisation



## **GLOSSARY OF TERMINOLOGY**

### **ACTIVITIES OF DAILY LIVING (ADL)**

Daily, routine tasks.

### **DAILY RECONSTRUCTION METHOD**

A structured diary developed by Kahneman, Krueger, Schkade, Schwarz and Stone (2004).

### **FLOW-STATE SCALE**

A questionnaire designed to assess immersion within a task (Jackson & Marsh, 1996).

### **LIFE-LOGGING**

The use of technology to automatically capture several aspects of daily living.

### **LIFESHIRT**

A wearable jacket developed by Vivometrics Inc. The LifeShirt records various types of data including cardio respiratory data and acceleration data.

### **SENSECAM**

A wearable camera (also known as ViconRevue, Vicon©) that records at least one image every 30 seconds and acts as a visual diary.

### **UNIFIED THEORY OF TECHNOLOGY ACCEPTANCE (UTAUT)**

A questionnaire designed to assess behavioural intention for future use of computer-based systems (Venkatesh, Morris, Davis & Davis, 2003).

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# **CHAPTER 1: INTRODUCTION**

## **1.1 OVERVIEW**

This chapter will initially introduce and explain the context of this PhD. The four main components of the study will be introduced; ageing, chronic pain, functioning and life-logging, and the rationale of the study will be outlined. The contributions of this PhD will also be presented. Finally, the chapter summarises the format of this PhD and will explain the content of each chapter.

## **1.2 SETTING THE SCENE**

### **1.2.1 OUR AGEING SOCIETY**

Ageing is one of the major challenges for health-care in the 21<sup>st</sup> Century (Medical Research Council, 2010). We are living in a continuously ageing population with statistics showing that the number of people over 65 years old in Britain has increased by 16% in the last 25 years (8.5 million to 9.8 million) and this trend is not slowing (Dunnell, 2008). Our ageing population reflects decreased fertility rates in addition to increased longevity and estimates predict that 4% of Britons will be classed as 'oldest-old' (over 85 years old) by 2032 (Office for National Statistics, 2008). The impact of our ageing society is already being witnessed within governmental policy due to changes such as removing the set retirement age, and increasing the working age of entitlement to state pension (Government Digital Service, 2013). Additionally, corporate strategies such as the '*Global Coalition on Ageing*' have brought together stakeholders to explore and develop novel solutions and policies which address the issue of ageing (Global Coalition on Ageing, n.d.). However, an adaptation to policies within healthcare and the outlook we have on healthcare is also needed as a result of the increasing levels of ageing (Killoran, Howse & Dalley, 1997). It is central to recognise the various challenges of ageing, and healthcare should aim to reduce morbidity, maintain independence and well-being, and providing cost-effective care (Medical Research Council, 2010).

One issue with the concept of ageing, and ageing research, is the lack of standardisation of old age, with no exact agreement being made upon the definition of old age (World Health Organisation, WHO, n.d.). Despite the differences between the definition of ageing, and the variance across research, this study specifically refers to older adults as adults aged 65+ due to the cut-off point of old age given by the WHO. The WHO proposed that the age of 60 or 65 is the most widely recognised cut-off point for the definition of older adults in developed countries (WHO, n.d.). The chosen age of 65+, as opposed to 60+, also signifies that all participants that took part in the study were retired, therefore, the functioning of the participants in this study did not differ between one another as a result of working. Furthermore, the definition of older adults as being 65+ also concurs with the definition of ageing used within the guidance on the assessment of pain in older adults (British Pain Society and British Geriatric Society, 2007) and also the definition used within the latest guidelines for the management of chronic pain in older adults (Abdulla et al., 2013).

## 1.2.2 CHRONIC PAIN

Chronic pain, also known as persistent pain, is long-lasting pain that continues after the period of expected healing (British Pain Society, 2007; Merskey & Bogduk 1992). There are numerous types of chronic pain conditions including osteoarthritis, rheumatoid arthritis and lower back, shoulder and neck pain among many others (European Federation of IASP Chapters, EFIC, n.d.). Chronic pain is a widespread problem in the U.K. with 7.8 million reported cases of long-term pain lasting more than six months (Department of Health, DH, 2009). Furthermore, cases of chronic pain are rising with three-times more cases reported now than 40 years ago (DH, 2009).

Chronic pain is especially widespread within the older population with more than half of over 65 year olds reporting feelings of pain in the U.K. (Royal College of Physicians, British Geriatrics Society and British Pain Society, 2007) and studies report the prevalence of chronic pain as ranging from 25-76% in older people living in the community (Abdulla et al., 2013). However, despite the high prevalence of chronic pain in the older generation it is certainly not to say that chronic pain is part of the 'normal' ageing process, despite this view being broadly accepted (Kumar and Allcock, 2008). Furthermore, pain is both under-recognised and under-treated in the older population (Royal College of Physicians, British Geriatrics Society and British Pain Society, 2007).

There are great economic costs to both employers and health services due to the level of chronic pain in society, for example, an estimated £584 million is spent annually on pain prescriptions (Chief Medical Officer, 2009). However, chronic pain also has many individual consequences, due to its persistence. Chronic pain interferes with various aspects of daily functioning and this interference increases with age (Thomas, Peat, Harris, Wilkie & Croft, 2004). The presence of chronic pain can affect various aspects of daily living for older adults, for example, Activities of Daily Living (ADL), such as self-care, domestic tasks, and leisure tasks are often modified, reduced or terminated as a result of chronic pain (Duong, Kerns, Towle & Reid, 2005). Chronic pain can also have a psychological impact and a reciprocal link between depression and chronic pain has been established (Karp & Reynolds, 2009). Finally, the presence of chronic pain can have a negative social impact for older adults as social exclusion and isolation are often experienced (Sofaer, et al., 2005).

Like the issues surrounding the definition of the term 'older adult', issues arise when defining chronic pain. Whereas 'chronic pain' is formally termed as pain lasting for more than 3 months (British Pain Society, n.d.; Merskey & Bogduk 1992) this is not consistent throughout the literature. Chronic pain is also often referred to as pain lasting over 6 months. In addition to the standardisation of chronic pain differing between studies, some studies that have been reviewed within this thesis have included participants with pain but do not specify whether this pain was acute pain or chronic pain and simply discuss 'daily pain' (e.g. Onder et al., 2006; Thomas et al., 2004). Again, this leads to issues when interpreting the results as the differences between acute and chronic pain are vast. The conceptual nature of 'pain' and 'chronic pain' is also an issue in that the research tends to assess the intensity of their chronic pain using a one-off measure during the procedure. The intensity of participants' long-term pain is then often labelled more generally as the intensity of pain experienced at that one specific time, despite chronic pain patients' pain intensity often fluctuating

(Hutchings et al., 2007). This leads to problems with data, as the level of pain experienced, or reported, at that one time becomes discussed as the level of pain experienced more generally for that participant, potentially leading to biased conclusions of daily living based upon ratings of pain intensity.

This thesis refers to chronic pain as *pain lasting for more than 3 months*, as defined by Merskey & Bogduk (1992) as the most convenient period to distinguish between acute and chronic pain. Furthermore, the participants' intensity of pain was not formally measured within this study, although individuals did discuss the varying intensities of their pain, and how this fluctuating intensity of pain could have an effect on functioning.

### 1.2.3 WHAT IS FUNCTIONING?

A specific classification of functioning has been developed within the International Classification of Function, Disability and Health framework (ICF, WHO, 2001) which was first established as there was no classification system for post-diagnosis that looked at function or service needs. The major aim of the ICF is *'to provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants'* (WHO, 2001, pg. 5). The ICF specifically aimed to create a dynamic interaction between these health conditions and both environmental and personal factors (Badley, 2008).

The ICF provides a systematic coding system and is comprised of two major elements; *'functioning and disability'* and *'contextual factors'*. The section of *'functioning and disability'* is made up of three components; *'body functions'* and *'body structures'* which focuses on anatomy, physiological functioning and some psychological functioning, and also *'activities and participation'* which looks at the capability of carrying out ADL. The ICF distinguishes between *'activity'*, the completion of a task or action, such as movement, and *'participation'*, an individual's involvement in society, such as taking part in a social role (see table 1 for list of activities and participation).

<b>Activities and Participation</b>	Learning and applying knowledge
	General tasks and demands
	Communication
	Mobility
	Self-care
	Domestic life
	Interpersonal interactions and relationships
	Major life areas
	Community, social and civic life

**Table 1: The components within the *'Activities and Participation'* list of the International Classification of Functioning, Disability and Health (ICF, World Health Organisation, WHO, 2001).**

Specifically, activities are explained as *'the execution of a task or action by an individual'* in the ICF (ICF, WHO, 2001, pg. 213). Activities signify individual

functioning in the ICF, i.e. the movement required as a part of functioning. Furthermore, activity limitations are expressed as:

*'difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition'* (ICF, WHO, 2001, pg. 213).

Participation is described as *'the involvement in a life situation'* in the ICF (WHO, 2001, pg. 213). Participation signifies societal functioning. Furthermore, participation restrictions are:

*'problems an individual may experience in involvement in life situations. The presence of a participation restriction is determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society'* (WHO, 2001, pg. 213).

One concern regarding the ICF is that despite making the distinction between the definitions of *'activity'* and *'participation'*, the framework does not separate the categories into *'activity'* and *'participation'*, instead providing one linked coding scheme (Badley, 2008). Many of the tasks within the ICF can overlap between *'activity'*, individual functioning, and *'participation'*, societal functioning. For example, an individual's inability to walk or move (activity) may affect their involvement in social tasks, or shopping activities (participation). Alternatively, if an individual is cooking, or carrying out household chores, the actual process of completing the tasks would be classed within the *'activity'* category of the ICF, whereas if they were carrying out these tasks as part of a familial or work-related role the tasks would also be within the *'participation'* category of the ICF. Finally, exercise also provides an example of overlap within the ICF as although the actual body movements involved in exercising are classed as *'activity'* within the ICF, the involvement within exercise, such as playing football, would be classed as *'participation'*. This overlap will be acknowledged throughout this study.

The second category within the ICF is *'contextual factors'* and is made up of *'environment'*, which describes the impact of both immediate and general environmental factors on an individual's functioning and *'personal factors'* which describes how personal characteristics, such as age, race and coping style can affect functioning (see table 2, below, for a full list of ICF components).

<b>Environment</b>	Products and technology
	Natural environment and human-made changes to the environment
	Support and relationships
	Attitudes
	Services, systems and policies
<b>Personal factors</b>	Gender
	Race
	Age
	Other health conditions
	Fitness
	Lifestyle
	Habits
	Upbringing
	Coping styles
	Social background
	Education
	Profession
	Past and current experiences (past life events and concurrent experiences)
	Overall behaviour pattern
	Character style

**Table 2: The components within the ‘environment’ and ‘personal factors’ lists of the International Classification of Functioning, Disability and Health (ICF, World Health Organisation, WHO, 2001)**

As seen in Table 2, the individuals’ contextual factors are very much a focus of the ICF, unlike previous frameworks. From these components the ICF distinguishes functioning as an ‘*umbrella term*’ comprising of the positive factors of body functions and structures, activities and participation and it is with these components that environmental factors interact (Badley, 2008; Bornman, 2004).

There was a shift in the way that the ICF defined functioning compared to older models. The ICF views disability as a continuum of health, as opposed to health and disability being separate entities, therefore acknowledging that all individuals can experience disability, rather than a minority of the population. The ICF is biopsychosocial in nature and was derived from a previous classification of functioning that was more inclined towards the biomedical model (International Classification of Impairments, Disabilities and Handicaps, ICIDH, WHO, 1980). The ICF gives much focus to health, function and the long-term rehabilitation of individuals rather than focusing on disability, like the ICIDH. Unlike the *biomedical model*, the *biopsychosocial model*, proposed by Engel (1977), acknowledges the importance of psychological and social aspects of health, illness and functioning, in addition to biological factors. Furthermore, Engel (1977) recognized the interactions that occur between each of

these components in relation to health related behaviours and outcomes. Like the *biopsychosocial model*, the ICF is greatly advantageous due to the comprehension of not only the importance of physiological aspects of functioning but also the impact of contextual factors and their interaction (Bornman, 2004). Despite the acknowledgement of biopsychosocial aspects of functioning, as well as the ICF being rooted in the *biopsychosocial model*, it remains to be primarily focused upon biological aspects of functioning, with this being the most discussed and explained part of functioning throughout the handbook. The importance of both psychological and social factors of functioning are apparent within the ICF, but are discussed in less depth than biological aspects of functioning, especially psychological functioning, which is described in part within '*biological structures*', and is also listed as '*personal factors*', however, is not comprehensively discussed in either section of the ICF.

Despite the flaws of the ICF, there are multiple benefits to using the ICF as a framework of functioning, as, rather than focusing upon the individual's diagnosis, the ICF framework allows the integration of the biological, psychological and social aspects of the individual's overall health and functioning. Furthermore, the ICF benefits from being standardised therefore can be used at both national and international levels, along with the potential use in areas other than health (WHO, 2002). The ICF framework has been adopted in many research areas, including that of chronic pain (Coenen et al., 2006).

The definitions of functioning given within the ICF are the definitions of functioning used in this thesis, i.e. the acknowledgement of both activities and participation within functioning. As well as the importance of activities and participation on functioning, this study recognises the significance of contextual factors as having an impact upon functioning.

#### **1.2.4 LIFE-LOGGING**

Technological advancements have led to the development of ubiquitous technology such as smart phones, hand-held computer tablets and wearable technology. These technologies, which are both small and mobile, have changed the way many individuals live their lives, such as enhancing modes of communication as well as changing the way individuals search for, and store, information. Further to this, the current development within computing is the move to a '*post-PC world*'; a paradigm shift from the storage of information on the PC to the '*cloud*' system (a networked storage system which can be accessed from a multitude of locations and devices). Both of these advancements, as well as developments within software, higher memory storage and higher battery life, are leading to the rise within popularity of '*life-logging*' (Achilleos, 2003; Gemmell, 2013).

Life-logging is the automatic capture and storage of multiple components of an individual's life (Allen, 2008; Caprani, Gurrin & O'Connor, 2010) and has been described as '*the digital experience of a person*' (Gemmell, 2013). One main form of life-logging is the use of wearable computing on which tasks are automatically recorded and digitally stored. Wearable computers, such as automatic cameras and *Google Glass* provide ways of capturing and storing multiple forms of information without much

effort from the user. Life-logging can be used for a variety of reasons, including both personal use and as a mode of collecting data within research.

### **1.3 RATIONALE FOR THIS STUDY**

The ageing population is steadily increasing and this population shift is not slowing down. Furthermore, chronic pain affects many older adults and can affect daily functioning in various ways as chronic pain can result in physical, psychological and social consequences. This study intends to focus upon the impact of ageing on health and independence in accordance with one of the LLHW (Life-Long Health and Wellbeing initiative) initiative aims for ageing research (Medical Research Council, 2010).

The rise of innovative pieces of technology allow the user's world to be understood from a different perspective and the use of these technological advancements within the research field can potentially lead to the identification of information that could not previously be gathered due to research method limitations. There have been no studies that have used life-logging devices to look at the daily functioning in individuals with chronic pain.

With this in mind there were two main aims of this research. The study is separated into two parts (Part A and Part B) to reflect the two aims. The first aim, for Part A of this study, was to explore a range of day-to-day patterns and experiences of functioning in older adults suffering from chronic pain. The first aim used four separate data collection tools in order to simultaneously to gather multiple forms of data looking at the impact of chronic pain on the daily lives of older adults. A structured diary (the Daily Reconstruction Method, Kahneman, *et al.*, 2004), which has not previously been used in this area, captured information regarding time allocation and feelings toward various tasks whereas a piece of life-logging technology (the Sensecam) gathered innovative visual data of the tasks carried out by participants. A semi-structured interview was also used to gather subjective, personal data from the individuals. One further piece of equipment was used; the LifeShirt. The LifeShirt gathered accelerometer data but was not analysed within this study due to problems with the data.

The second aim, for Part B of this study, was to explore the usability, acceptance and experience of the technology used to measure levels of functioning, as well as looking at the practicalities of this equipment. There were two new pieces of equipment used within this study and neither the Sensecam nor the LifeShirt had previously been used in this area. Furthermore, the usability, acceptance, experiences or practicalities of using either the Sensecam or LifeShirt had not previously been acknowledged in the literature. Therefore, it was important to explore the individuals' experiences of using both pieces of technology, and look at any technical or practical issues the individuals may have experienced.

### **1.4 CONTRIBUTIONS**

Numerous oral and poster presentations, as well as two guest lectures, based on the results of this research, have been given throughout the duration of this PhD, with two

of the abstracts being published (see appendix R and S for a full copy of the published abstracts). Below is a list of titles for the presentations of which I have given relating to this PhD work, in chronological order.

**Exploring chronic pain in older adults; New insights with new technology** (Teesside University's post-graduate conference, May, 2010, oral presentation).

**Exploring chronic pain in older adults; New insights with new technology** (2<sup>nd</sup> annual Sensecam symposium, September, 2010, poster presentation).

**Biopsychological perspectives of health behaviour: Chronic pain** (MSc Health Psychology, Teesside University, November, 2011, Guest lecture).

**Approaches to improving lives of the older population: An exploration of attitudes, technology and experiences toward chronic pain and its management**(Lifelong Health and Well-Being [LLHW] student retreat, November, 2011, oral presentation).

**The experiences, acceptance and usability of the Sensecam: Preliminary findings** (3<sup>rd</sup> annual Sensecam symposium, April, 2012, oral presentation).

**Exploring everyday functioning in older adults with chronic pain: New insights with new technology. The methodology behind the PhD** (Qualitative Health Research group, Durham University, May, 2012, oral presentation).

Wilson, G., Martin, D., Jones, D., & Schofield, P. (2012). Exploring chronic pain in older adults; New insights with new technology. *Journal of Aging and Physical Activity*, 20, S295.

**Daily functioning in older adults with chronic pain: Preliminary findings** (XCAR early career researcher conference, November, 2012, oral presentation).

**Biopsychological perspectives of health behaviour: Chronic pain** (MSc Health Psychology, Teesside University, November, 2012, Guest lecture).

**Daily functioning in older adults with chronic pain: a case study**(Lifelong Health and Wellbeing Showcase Meeting, December, 2012, poster presentation).

Wilson, G., Jones, D., Schofield, P. & Martin, D. (2013). The Use of the Sensecam to Explore Daily Functioning of Older Adults



## **1.5 OUTLINE OF THIS THESIS**

Chapter 1 of this PhD explains the setting of the research and introduces the current context of the area being studied. Chapter 1 also gives the rationale for carrying out the study and an outline of the thesis.

Chapter 2 provides a literature review of the main components of the PhD. Initially, the research surrounding ageing is discussed, before looking at general chronic pain literature. The concept of functioning is explored in relation to chronic pain and older adults. The chapter then explores the measurement of functioning in research. It is here that a systematic search is set out which looks at the use of diary studies in the area of chronic pain and older adults. Finally, research within the fields of life-logging, models of technology use and older adults' use of technology are drawn upon.

Chapter 3 focuses on the methodological considerations of the research project including the aims of the research, the chosen research paradigm, methodological approach, philosophical underpinnings and considerations of rigour. All of these components were central to the way that the study was conducted and the analysis techniques used in the PhD.

Chapter 4 sets out the method of both Part A and Part B of this thesis. All parts of the data collection process are discussed, including a description of the design, sample, instrumentation and procedure. The theoretical background of each data collection tool, and its analysis as well as giving a justification for its use is also given in this chapter.

Chapter 5 discusses the integrated findings and discussion for Part A of the study. The chapter is segmented into the themes developed from the semi-structured interviews. Findings from the Daily Reconstruction Method diary and the Sensecam are integrated into these themes in order to provide additional details to the interview discussions. The individual analyses of both the Daily Reconstruction Method diaries and the Sensecam can be found in Appendices J and L. The integrated findings are related to other literature in the area.

Chapter 6 provides the findings and discussion for Part B. Data from the UTAUT questionnaires, and the Flow-State Scale are described. Themes from the semi-structured interviews are also explored in-depth and the findings are related to literature in the area. Data from the questionnaires is integrated into the themes, when appropriate

Chapter 7 sets out the overall conclusions and the implications of this thesis. The chapter initially concludes the results from Part A and Part B of the study, as well as discussing the limitations of both parts of the study and the future directions for research. My personal reflections regarding the thesis are also explained, as well as

discussing my position as researcher throughout the journey of the thesis. The final conclusions of the study are also set out.

## **1.6 SUMMARY**

It is evident that our population is ageing and chronic pain is highly prevalent within the older population. Chronic pain not only has economic costs, but also individual consequences, as the presence and intensity of chronic pain can affect many aspects of daily living, including functioning. Functioning has been extensively defined within the '*activities*' and '*participation*' component of the ICF (WHO, 2001). The ICF also acknowledges the importance of contextual factors on functioning. Finally, life-logging is an innovative way to capture information of one's life, and has the potential to be used to record functioning.

This chapter has introduced the setting of this PhD in the research field, as well as introducing the four core components of the research; ageing, chronic pain, functioning and life-logging. The rationale for the study has also been provided and the contributions of this thesis have been presented. Finally, an overview of the format of the PhD has been given.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 OVERVIEW**

Chapter one outlined the four main components within this PhD. The aim of this chapter is to provide a deeper account of the concepts and introduce the background literature. Ageing and chronic pain will first be explored and the literature in these areas will be examined before analysing the effects that chronic pain can have on daily functioning. The use of diaries as a measure of functioning, and pain presence, will also be highlighted. Finally, the use of life-logging as a research tool used to measure functioning will be introduced.

### **2.2 AGEING**

Research exploring the area of ageing is important due to our increasingly ageing population, combined with the increased health and social costs as a result of the ageing population (Bowling & Dieppe, 2005). Research in this area has been conducted for some time and there is much theory focusing on the process of ageing and the changes that occur during the '*pensionable age*' (Reed, Stanley, & Clarke, 2004, pg. 15). Both biological and psychosocial theories have attempted to define and explore '*successful*' ageing. Biological ageing is explained as progressive damage to cells. One of the most influential biological theories of ageing is the *Free Radical theory* which states that the mitochondrial region of the cells are the initial sites for cell damage and this damage subsequently leads to the ageing process (Harman, 1992). Of course, in addition to biological theories and explanations of ageing are psychosocial theories of ageing. There are three dominant psychosocial theories, all of which view ageing differently; *Activity theory* (Havinghurst, 1961), *Disengagement theory* (Cumming and Henry, 1961) and *Continuity theory* (Atchley, 1989).

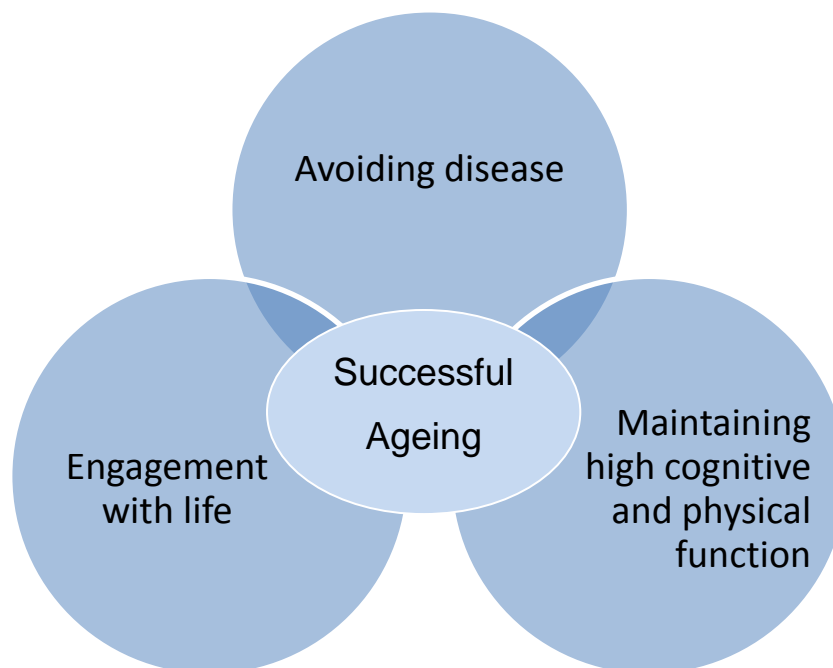
*Activity theory* addressed ageing by implying that individuals' well-being and happiness were directly linked to physical and social participation within society (Marcoen, Coleman & O'Hanlon, 2007). The authors propose that older adults need to remain highly active within society in order to lessen the negative effects that are a part of ageing (Burbank, 1986). Furthermore, the theory suggests that within the pursuit to stay active, older adults are challenged with setbacks as they suffer losses due to ageing, such as retiring, or becoming widowed. The individuals need to therefore replace these social roles and tasks with new tasks in order to seek fulfilment. Despite focusing on the positive interaction of older adults within society, the theory does also highlight numerous losses within the ageing process, bringing a negative light to ageing. Contrastingly, *Disengagement theory* promoted older adults' withdrawal from society, rather than participation, due to their forthcoming death. The authors propose that disengagement from societal roles leads to higher levels of overall satisfaction (Cumming & Henry, 1961). Although this mutual disengagement can be instigated by either the individual or society, society makes this process easier by policies such as retirement. Of course this theory does not support the active roles of older adults within society, and focuses on the negative loss that old age brings, as opposed to positive aspects of ageing (Reed, *et al.*, 2004).

One strength to both theories is their focus upon functioning, despite their contradictory viewpoints, as functioning is still considered as highly important within ageing and well-being. *Disengagement theory* contrasts to *Activity theory* and contradicts recent theoretical constituents of what is deemed 'successful ageing' taken from one systematic search; life satisfaction and well-being, mental and psychological health and functioning, social, community, leisure activities, integration and participation, amongst others (Bowling & Dieppe, 2005). One similarity between both theories, and a criticism for both, is the proposition that the ageing process is not a continuum, with both theories highlighting the differences between younger and older adults. *Activity theory* sees the main difference for ageing adults as their loss of former social roles and responsibilities whereas *Disengagement theory* sees ageing adults as wanting different things and changing their interest in levels of participation. One further similarity between both theories is the lack of individual variation, and lack of understanding of the differences that exist as a result of different societies and cultures. Both theories suggest ageing as a universal phenomenon, with no variability between individuals, or cultures whereas in actuality the ageing population is extremely diverse and consists of a wide range of ages, as well as varying socioeconomic and cultural backgrounds (Medical Research Council, 2010). The context in which we age, including socioeconomic background and culture, differs greatly depending on *micro*, *macro* and *meso* systems around us but is not reflected within these ageing theories (Marcoen, *et al.*, 2007). Both of these theories, despite their contrasting views, highlight the desire for older adults to age 'successfully'.

One additional psychosocial theory of ageing is *Continuity theory* (Maddox, 1968; Atchley, 1989). *Continuity theory* used both *Activity theory* and *Disengagement theory* to maintain direction within the functionalist paradigm. However, rather than highlighting changes during ageing, *Continuity theory* acknowledges the steadiness of the ageing process, as well as acknowledging the influence of both social and cultural context for ageing (Atchley, 1999). *Continuity theory* proposes that middle-aged and older adults endeavour to uphold their internal and external structures by using strategies that they have used in the past, i.e. continuity (Atchley, 1989). These adults strive for internal continuity (psychological) and outer continuity (social) as a way of achieving 'normal ageing' (Atchley, 1989, pg. 183).

Successful ageing has been much further debated within this field since the construction of these theories, however successful ageing is both difficult to define and measure due to individual variability that leads to differences in the outlook of ageing. It is however believed that both objective and subjective factors need to be considered (Baltes & Baltes, 1990). Furthermore, a distinction between usual ageing (i.e. non-pathologic but with high risk) and successful ageing (high function and low risk) has been made within some of the literature (Rowe & Kahn, 1987; 1997). Rowe and Kahn (1997) define successful ageing as three main components: low probability of disease and disease-related disability, high cognitive and physical functional capacity and an active engagement in life (see figure 1, below). It is proposed that this combination of these components within the model that interact to embody successful ageing.

**Figure 1: A model of 'successful ageing' (Rowe & Kahn, 1997)**



Despite the differences between the psychosocial theories of ageing and the construct of successful ageing, a constant similarity is their setting within the functionalist paradigm. The theories, and the definition of successful ageing, recognise the importance of day-to-day functioning, including participation.

### **2.3 CHRONIC PAIN**

Pain is both subjective and personal and may only ever be completely understood on an individual level, by the sufferer (Clarke, & Iphofen, 2007). It is a multi-faceted experience comprising of three main elements; a sensory dimension, which refers to the physical feelings of pain, an affective dimension, which refers to emotions and the perceptions of the pain, and finally the impact of pain, for example, the disabling effects that pain can have on the individual physically, psychologically and socially (Royal College of Physicians, British Geriatrics Society and British Pain Society, 2007).

Chronic pain is a widespread issue, specifically within the older population, with studies reporting the prevalence of chronic pain ranging from 25-76% in older people living in the community (Abdulla et al., 2013). Chronic pain is something experienced by individuals of all ages, however, despite its prevalence in old age, research focusing on the specific elements of the chronic pain experiences of older adults has only developed over the past two decades (Gagliese & Melzack, 1997). The assessment and management of chronic pain in older adults can also differ to that of younger adults as pain is often inadequately managed in older adults (Gibson & Lussier, 2012). The experiences of older adults with chronic pain and younger adults with chronic pain tend to differ for a variety of reasons, including '*vulnerability*' related to age (Gagliese, 2009, pg. 344). The term '*geriatric pain*' (Melding, 1991) was coined as a way of specifically highlighting the chronic pain experiences of older adults as it has been suggested that all components of the pain experience may all be affected by increased age, such as

daily functioning (Thomas, *et al.*, 2004). There are a number of specific differences between the chronic pain experiences of older and younger adults, including perceptions of pain in the elderly, assessment of pain, as well as the heightened likelihood of the presence of co-morbidities (Gagliese, 2009).

Pain is typically '*under-recognised and under-treated in older people*' (Royal College of Physicians, British Geriatrics Society and British Pain Society, 2007, pg. 2) often due to the perception of pain being a part of '*normal*' ageing and something that is to be expected in later life (Gagliese, 2009; Kumar & Allcock, 2008). Pain can also be difficult to assess with the older population due to age-related issues such as sensory impairments including visual and hearing problems (Herr & Mobily, 1991) as well as age-related effects relating to cognition (Abdulla *et al.*, 2013). Stoicism can also affect assessment and it is commonly believed that older adults are more stoic in reporting pain than younger adults, although empirical reports are yet to provide evidence for this (Helme & Gibson, 2001). Furthermore, the presence of co-morbidities not only makes it more difficult for the assessment of pain, but also the management of pain, for example, some age-related health conditions, including dementia and stroke, may make it more difficult for older adults to articulate the presence and intensity of pain (British Pain Society & British Geriatric Society, 2007). Older adults also differ from younger adults in their societal role. Older adults are, typically, no longer working therefore their societal role and daily functioning will have been impacted as a result of this, as well as potential changes to familial roles, due to the adult-status of their children (Glascock & Feinman, 1980).

The pain experiences of older adults and younger adults can differ due to the variations in both societal roles and physical differences, as discussed above. For this reason it is important that research surrounding the chronic pain experiences of older adults, including research looking at the assessment, management and the impact that chronic pain has upon functioning, is researched independently to that of younger adults.

## **2.4 ACTIVITIES AND PARTICIPATION**

Functioning, including activities and participation, as described within the ICF (WHO, 2001, see chapter 1, section 1.2.3), can be affected by the presence or intensity of chronic pain in various ways.

Research looking at the general interference of pain identified an association between age and the amount that pain interferes with daily living (Thomas, *et al.*, 2004). Participants of a large postal survey were asked '*during the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home or housework)*' and the interference of pain upon daily life was seen to continually increase for both males and females from the ages of 50-59 years old (33.4%; 32.1%) to 80+ years old (40.8%; 50.2%). However, it is unknown if individuals within the study were living with chronic pain as pain was defined as '*pain lasting one day or longer over the past 4 weeks*'. Therefore it is unknown whether these individuals suffered from chronic or acute pain, or whether there are differences between the levels of interference between those with chronic or acute pain. Furthermore, pain interference is not expanded upon any more than this, and it is therefore unknown how pain interferes with daily living from this study alone.

Additional studies have gone into more depth about the effect of chronic pain on the specific activities or areas of participation that can be affected as a result of the presence or intensity of chronic pain. The remainder of this literature review that concerns the effects that chronic pain has upon daily living is split into four sections; mobility, Activities of Daily Living (ADL), social factors and psychological functioning. The approach to this literature review encompassed the view of functioning explained in the ICF (WHO, 2001) and the four sections of this literature review categorise daily functioning in a way that is consistent with the activities and participation, and the personal factors, components of the ICF (WHO, 2001).

The search strategy for this literature review was established at the beginning of the PhD process in which I searched various databases (Psycinfo, CINAHL, Medline, web of knowledge, Scopus, science direct, Cochrane central; ASSIA) for studies looking at functioning and chronic pain, with a focus on, but not restricted to, the subject headings used in this literature review. This search was not restricted to research with older adults (>65) as it limited much knowledge regarding the effect that chronic pain had on daily functioning to a wider age range, and I felt that this information was important to consider. Furthermore, the inclusion of these studies enabled me to see what methods had been used for past research in this area. This search was re-ran on various occasions throughout the four years that I carried out this study in order to keep up-to-date with new research in the field. Furthermore, I made sure to keep up-to-date with new research using other resources such as RSS feeds and social networking sites, such as twitter.

#### **2.4.1 MOBILITY**

The ICF encapsulates various aspects of movement within the '*mobility*' section of the activities and participation list, including changing and maintaining body positions, and walking and moving. General movement can be affected as a result of the presence and intensity of chronic pain. This is usually explored using quantitative, controlled, studies but some qualitative reports have also given an insight into the effects that chronic pain can have on movement.

Comparative studies between individuals with chronic pain and healthy controls have been used in this area to explore differences in movement patterns. Research using objective measures, such as accelerometers, has specified that both body position and movement patterns of chronic pain sufferers tend to differ to those of non-chronic pain sufferers. For example, Spenkeliink, Hutten, Hermens & Greitemann (2002) compared the movement patterns of chronic lower back pain sufferers and matched healthy controls in their natural environment. Participants were matched by age, sex and occupation however little information was given regarding the matched working status of participants, which may have affected results, as working patterns are believed to affect levels of physical activity (Sallis et al., 1985). Patterns of body position of chronic lower back pain sufferers differed to healthy controls as individuals with chronic lower back pain spent more time lying down during both the day and the evening, and also spent less time standing in the evening. Furthermore, chronic lower back pain sufferers also walked at a slower speed than healthy controls. This study displays the various patterns and differences of both body positions and movement patterns

between chronic lower back pain sufferers and healthy matched controls. The study benefitted from also collecting self-report data regarding the typicality of the recorded day and excluded data that was not typical. However, individuals were only measured over a 24-hour period, therefore limiting variability of movement patterns over an individual's week, and specifically removing the patterns of movement between working and non-working days.

Similar research has been conducted by Ryan et al. (2009). Using accelerometers, the researchers discovered a similar pattern in chronic lower back pain sufferers. However they monitored participants over a 7-day period in their natural environment in order to observe any individual day-to-day variability. Ryan et al. (2009) also used matched chronic lower back pain sufferers and controls, however, matched the participants more successfully than Spenkeliink *et al.* (2002), specifically regarding work status in that information about working status was given for each participant. Ryan et al. (2009) discovered that chronic lower back pain sufferers spent 0.7 less hours walking and took 29% fewer steps than their matched controls over an average 24-hour period. Additionally, chronic lower back pain sufferers took fewer steps and spent less time walking during the day-time and evening of an average working day than healthy controls. Ryan et al. (2009) found no differences between the two groups for average time standing, unlike Spenkeliink *et al.* (2002).

Both pedometers and accelerometers are often used to detect movement patterns, like in the studies above, however, they are not always successful when used on the older population. Pedometers often fail to count steps of those walking at slower walking speeds. Cyarto, Myers and Tudor-Locke (2004) conducted a study to assess the validity of a waist-worn pedometer for older adults (68+ years). Pedometers continuously underestimated the observed steps of community-dwelling older adults and older adults living in a nursing home whilst walking at a slow (25%; 46%), medium (13%; 55%) and fast (57%; 74%) pace respectively, with the underestimation being highest whilst walking at a slow pace. Additionally, the error was higher for older adults living in a nursing home as the pedometer underestimated the walking speed of these older adults more than community-dwelling older adults, at all speeds, as they walked slower than community-dwelling older adults at each walking speed. However, it is important to note that participants were only observed during purposeful walking durations (i.e. slow, medium and fast paces), rather than during ADL, therefore the accuracy of the pedometer was not analysed in a 'real life' setting, and additional inaccuracies may occur when carrying out ADL. Despite the drawbacks of the study, a systematic search of the literature, conducted by de Bruin et al. (2008), surrounding the use of pedometers by older adults (65+ years old) also strengthens the findings presented by Cyarto *et al.* (2004) in that pedometers often underestimate the number of steps taken at slower walking speeds.

Additionally, accelerometers are not always accurate during use within the older population. Like the issues concerning the use of pedometers in this population, accelerometers can also be problematic due to the slow walking speed of many older adults. One major disadvantage to the use of accelerometers in the older population is the issue of picking up slow walking gait or 'shuffling'. Storti et al. (2008) validated three activity monitors for community-dwelling older adults (65+ years old). Two accelerometers were used in this validation study; the ActiGraph (AG) accelerometer



which was placed on the hip, and the Stepwatch Activity Monitor (SAM) which is an accelerometer specifically designed for slow gait speeds, and was placed on the ankle. A pedometer was also validated (Yamax DigiWalker pedometer, worn on the hip). Overall, the Yamax Digiwalker pedometer had the greatest error and overestimated steps by 13% of all participants, however, both accelerometers also encountered errors with the AG overestimating by 7.1% and the SAM overestimating by 6.9%. These errors were heightened when categorising the participants into three gait speeds; slow, medium and fast. The Yamax Digiwalker pedometer underestimated steps by 31.2%, the ActiGraph underestimated 19.1% and the Stepwatch Activity Monitor overestimated steps by 6.5% for individuals walking at the slowest gait speed. Both accelerometers measured steps with error, specifically for the slowest walking gait within this study. Although the speed of each individual's walking was not controlled, and individuals walked at a 'self-selected' pace, the activity monitors were not validated for step frequency during ADL therefore, additional errors may occur when in a free-living setting.

Pedometers and accelerometers offer important information regarding the physical functioning of older adults; specifically step count, intensity of movement and patterns of movement, which are all important aspects of health status and quality of life. However, accelerometers can be problematic due to the difficulty of detecting slower walking speeds.

Due to issues with the objective measures of movement in the older population, qualitative methods are another useful way to look at this area and there are some qualitative studies which have looked at posture and mobility, often as a small part of overall chronic pain experience. From this research it is possible to see, not the amount of time spent in certain positions, or patterns of movement, but individuals' thoughts upon their own posture and movement patterns, unlike studies using objective measures of movement. Qualitative research has exposed additional insights into the issues surrounding movement patterns, for example, one male with chronic lower back pain found sitting down to be '*a killer*' which often led to pins and needles (Ashby, Fitzgerald & Raine, 2012, pg. 506) whereas walking with fibromyalgia was described by a female sufferer; '*my feet were aching, it was impossible to walk*' (Hallberg & Carlsson, 2000, pg. 32). One other individual described the problems that he faced with mobility that subsequently affected his daily living; '*I will try to get involved with something that's going to take my mind off the pain. But then when I start to move around, there's the pain again*' (Thomas & Johnson, 2000, pg. 690). These studies do not provide an objective measurement of body postures or movement patterns, nor can they compare movement patterns with a controlled group, however, they do allow a different understanding of the participants' movement patterns from a personal perspective that is not captured using objective measures of movement, however all involved younger individuals living with chronic pain.

One study has explored the movement patterns of older adults living with chronic pain qualitatively (Sofaer et al., 2005). The researchers used unstructured interviews to explore the limitations of multiple areas of daily living, and although not looking at movement patterns specifically, the researchers unearthed feelings upon the importance of movement. A Grounded Theoretical analysis (Glaser & Strauss, 1967) highlighted the older adults' lack of movement, such as the inability to walk, and its

effect upon independence, as well as highlighting the reliance upon assistive devices, such as a mobility scooter or walking stick, in order to improve both mobility and independence. The authors specify that '*a plethora of practical aids were used*' (pg. 464) to help the individuals move, but did not identify those other than a walking stick and electric scooter. The sample of 63 participants were mainly females (n=42) and the age of the participants was stated briefly (60-87 years) however there was no other demographic information given for these individuals. Furthermore, there was no definition of chronic pain given, and no indication as to how long the participants had lived with chronic pain. Additionally, information on the pain sites, or number of pain sites was not included. The findings highlight the importance of movement of older adults with chronic pain, however, there are some methodological flaws with the research, as stated above.

Objective measures show that the movement patterns of chronic pain sufferers typically differ from non-chronic pain sufferers. Although objective measures of movement are a useful way of measuring movement, they can be problematic within the older population. Qualitative research has also been used in this area to explore the movement patterns of individuals with chronic pain, often explore movement as part of a larger study. Qualitative studies can unearth other aspects of movement, such as their personal views of moving including how the individual feels when moving, and what helps them when moving. Little qualitative research has focused on the movement of older adults with chronic pain.

#### **2.4.2 ACTIVITIES OF DAILY LIVING (ADL)**

In this section ADL refers to more than one section of the activities and participation list in the ICF; general tasks and demands, self-care and domestic life. These lists have been combined into ADL within this literature review as the studies usually examine multiple areas of daily living at once, as opposed to segregating specific areas of daily living, especially segregating them based upon the areas outlined in the ICF.

Self-report surveys used to explore ADL are widespread in this area of research. One study used a self-report survey to explore self-care tasks that were affected by chronic pain (Duong, *et al.*, 2005). Duong *et al.* (2005) found that only 6% of participants claimed that pain did not result in the modification, reduction or termination of any of their daily tasks; 71% modified, 69% reduced and 22% of the sample terminated at least one task. From the self-care tasks only 3% of participants reported modifying, reducing or terminating basic self-care tasks such as eating, dressing, toileting and bathing. Contrastingly, '*high-order*' tasks were mostly modified, reduced or terminated with 83% of the individuals' high-order tasks being affected by pain; these tasks included walking long distances and gardening. Additionally, 74% of participants' social and recreational tasks were modified, reduced or terminated including travelling, sports, hobbies and going out, and 57% of participants' '*instrumental*' tasks were modified, reduced or terminated, which included driving, cooking and household chores. A lower functional self-efficacy score and higher number of pain sites were predictors of the task being terminated, as opposed to reduced or modified. From this self-report study it is possible to see that chronic pain affects many areas of the individuals' daily lives, and many ADL are either modified, reduced or terminated as a result of chronic pain. The researchers also provide a list of modifications that

participants made to each task, which range from resting during tasks, to the use of assistive devices to aid completion of tasks. There were however numerous issues with this research in terms of the sample and procedure, the definitions of functioning used throughout the study, and the level of detail within the study.

The sample consisted of mainly white (96%) males (84%) and all were veterans, i.e. individuals who had served in the American military, therefore limiting the generalisability of the results.

Additionally, the level of detail in the study inhibits the conclusions that can be made from the study. Firstly, the researchers do not make the distinction between whether tasks differ as a result of pain itself, or if the completion of the task differs depending on the intensity of pain. Levels of pain can often fluctuate and these exacerbations of pain may influence the way in which tasks are carried out, compared to when individuals are experiencing 'usual' levels of pain. It is unknown if the problems with the daily functioning of the participants in Duong *et al's* (2005) study have arisen as a result of experiencing chronic pain itself, or may have occurred when pain worsened and was more difficult to manage. The researchers asked participants '*are there physical activities that you no longer do, do less frequently, or have modified because of your pain/discomfort?*' Therefore, neither the researchers nor the reader know whether or not the participants are discussing changes to their functioning as a result of the presence of pain, or as a result of the intensity of the pain becoming worse. The only conclusions that can be made, as a result of the questioning in the study, is that '*chronic pain*' results in the modification, reduction or termination of specific tasks.

The level of detail regarding the tasks also hindered the researchers' conclusions. Little information regarding the '*reduction*' of tasks was given, other than they are tasks '*performed less frequently*'. Whilst discussing the reduction of tasks the researchers did not specify how much individuals actually reduced each task, i.e. whether the individual's reduction of the task was minimal or severe. Additionally, the original level of frequency of the task is unknown. Results from the study show that 44% of the participants reduced high-order tasks, compared to 0% of the individuals reducing basic ADL. The researchers give no qualitative description regarding these findings, and do not disclose any information regarding the reason why higher-order tasks are reduced more frequently than basic ADL. The difficulty that individuals have in performing these tasks has not been measured. It may not be that '*basic*' tasks are less painful for the individuals, but that they are necessary, whereas '*high-order*' tasks are less necessary for the individuals.

Finally, details of the enjoyment of each task were not gathered, and it is therefore unknown which tasks gave the individuals satisfaction. Details regarding satisfaction are of high importance due to the effect that modification, reduction or termination of tasks has on each individual's quality of life. This study gives information upon many areas of daily functioning, but because of this, the finer details of changes to functioning were not gathered. The details regarding changes to daily functioning are important to explore in order for researchers and health professionals to gain knowledge upon the chronic pain experience, however, Duong *et al.* (2005) took a broad approach towards data collection without exploring the rich detail involved in changes of functioning.

Further self-report studies have demonstrated a significant association between the presence of chronic pain and disability in older adults, again, with numerous ADL being affected, including housework and self-care tasks (Scudds & Robertson, 1998). Scudds and Robertson (1998) use self-report questionnaires to gauge the functioning of the participants. The researchers classified participants as having a disability if they responded '*some difficulty*' in carrying out three or more tasks, from four options; '*no difficulty*', '*some difficulty*', '*much difficulty or aid needed*' and '*unable to do*'. Similar to Duong *et al.* (2005), the study looks at numerous areas of functioning, but does not gather information on the details of these changes in daily functioning, for example, it is unknown if the occurrence of that task has been reduced, whether the task has been modified, and how, or whether the individuals need help from others when completing the task. It is therefore difficult to deem the level of individuals' '*disabilities*' from this study. Finally, like other studies discussed throughout this literature review, the individuals were not specifically living with chronic pain as individuals with pain were classed if they had experienced pain over the two weeks before taking part in the study.

Research looking specifically at the relationship between self-care and pain with old-old participants, i.e. over 80 year olds, looked at the level of disability in ADL, specifically, eating, dressing, transferring, mobility in bed, personal hygiene and toileting (Landi, et al., 2009). The researchers found an association between pain and impaired physical performance, specifically dressing and using the toilet. The researchers concluded that daily pain, as opposed to less frequent pain, or no pain, leads to higher risk of developing disability. Moreover, this disability increases with increased pain severity and increased number of pain sites. However, this pain was not specifically chronic pain, as this research was part of a larger study (Onder et al., 2006, as discussed above) which defined the experienced pain as '*pain manifesting over the last seven days preceding assessment*' (Landi, et al., 2009, pg. 352). Following on from the problems associated with the definition of pain, one further issue with the studies in this area is the different classifications of '*disability*'. Whereas this study classed disability as the '*need of assistance in one or more of the ADL examined in the study*', Scudds and Robertson (1998) classed disability as have '*some difficulties*' with carrying out three or more ADL, with '*much difficulty or aid needed*' being a higher level of disability. It is clear that more synchronicity is needed within classification of '*disability*' in this area, as the inconsistencies in word definition may lead to misinterpretations of research findings.

As well as the consistency of terminology, another general problem with this research is the manner in which participants' disability and their ADL are measured. Like assessment of pain intensity, self-reported ability to complete ADL, is based on one occasion, which is then generalised. Measures such as self-report questions or performance-based tasks measure ADL based on one occasion, or ask participants to report participation of ADL over a specific time period. However, it is important to note that intensity of chronic pain fluctuates, and, there are factors which may affect movement patterns or participation in ADL.

However, not all research reports a relationship between chronic pain and ADL of older adults. Kauppila, Pesonan, Tarkkila & Rosenberg (2007) looked at self-reported

functioning within a small (n=41) sample of mostly male (90%) American veterans (individuals that had served in the military service). Self-report questionnaires were used and the researchers concluded that cognitive dysfunction and depression were better predictors of carrying out ADL, such as bathing and dressing, as opposed to the intensity of pain. Despite the results suggesting that intensity of pain is a lesser indicator of ADL than cognitive dysfunction and depression, the researchers claim that this may be due to the low intensity of pain within their sample of participants. There is currently some variation regarding the effect that presence and intensity of chronic pain has upon impact of ADL, and a more in-depth exploration of the effects of chronic pain on ADL is needed.

### **2.4.3 SOCIAL FACTORS**

Two sections of the ICF make up '*social factors*'; interpersonal interactions and relationships, and community, social and civic life. Once more, multiple social factors are often examined at once and research exploring social factors often does so as one part of a research project. A number of social factors can be affected as a result of chronic pain, specifically, isolation and loss of freedom can often be a consequence of living with long-term pain, and chronic pain can also lead to problems with familial relationships.

Long-term pain can result in social isolation (Clarke & Iphofen, 2008). Isolation can be experienced in two ways; firstly individuals can feel isolated within themselves as the pain itself is unseen by others, and isolation can also be experienced due to the consequences of physical functioning associated with chronic pain.

Isolation can be heightened as a result of chronic pain as individuals can feel '*like a fraud*' due to its invisibility (Clarke & Iphofen, 2008, pg. 660). One participant who specifically experienced feeling like a fraud within Clarke and Iphofen's (2008) qualitative, phenomenological study, ceased attending church as she felt as though she was lying about the severity of her pain as no-one else could physically see it. The problem of isolation has also been highlighted in other qualitative studies. Thomas and Johnson (2000) conducted a study with 13 chronic pain sufferers (27-79 years old) and also highlighted prevalent feelings of isolation. Within the analysis of the phenomenological interviews, the authors identify feelings of isolation from all participants, with the individuals describing feeling '*locked off*', '*caged off*' and '*absolutely alone*' (Thomas & Johnson, 2000, pg. 692). Isolation was discussed by all participants and some felt that their pain had created an obstacle that disconnected them from others. This social isolation developed from individual feelings about their own chronic pain condition and was often due to perceived lack of understanding from others.

Mackrodt (2005) also conducted a qualitative study which involved interviews with chronic pain sufferers of undisclosed ages. One of the themes within this study encapsulated the social isolation experienced by some chronic pain sufferers. This social isolation was not only experienced due to problems with physical functioning, but also loneliness of experiencing chronic pain. One participant stated that '*I didn't want anyone to know how much pain I was in. I thought I had become a pain in the bum to other people. People don't want to know how much pain you are in, so you lie to them,*

*you hide the truth*' (Mackrodt, 2005, pg. 81-82). Isolation arose from not telling others about her pain for fear of misunderstanding and being a '*pain*' herself. Furthermore, Smith and Osborn (2007) accentuated the reluctance of chronic pain sufferers to socialise with others, with one participant describing his preference of spending time alone as he had less pressure upon himself to be happy and sociable than when with others. The researchers highlight the '*socialness*' (Smith & Osborn, 2007, pg. 528) of chronic pain and that the self-identity of the participants had been greatly threatened as a result of living with chronic pain. The qualitative research in this area allowed the individuals' experiences to be discussed in much depth, from their own perspective. However, one issue with this research is the lack of focus upon older adults, with all studies including participants of a wide age range and more research needs to be conducted looking at feelings of isolation, due to the presence of chronic pain, in older adults. As well as feelings of isolation being apparent due the invisibility of chronic pain, restricted discussion of chronic pain, and lack of understanding from others, isolation is also experienced as a result of problems with physical functioning and can be felt due to practical reasons. Older adults with chronic pain can feel socially excluded, often due to a lack of knowledge regarding on-going social activities and requiring transport in order to attend any social events (Sofaer et al., 2005).

Loss of freedom is one consequence of chronic pain, usually seen in the older population (Thomas, *et al.*, 2004). Loss of freedom does not only result from a loss of mobility but can arise due to other reasons, such as a loss of financial support (Sofaer, et al., 2005). Sofaer et al. (2005, as discussed in section 2.4.1, above) conducted unstructured interviews with older adults (60-87 years old) and demonstrated older individuals' desire for control and independence, despite adapting to their chronic illness. Furthermore, one qualitative study found that older women felt it hard to go out with friends or family if they were experiencing pain, or alternatively, they found it hard to plan days out as they were unsure whether their pain may have been bad that day (Roberto & Reynolds, 2002).

An additional social factor that is often apparent within experiences of chronic pain is increased strain on familial relationships. Chronic pain is something that is not experienced in solitude but can affect other individuals. Roberto and Reynolds (2002) conducted a qualitative study involving both interview and focus groups with women experiencing chronic pain (48-86 years old). The women discussed various issues that had been affected since developing chronic pain including problems with family. For example, some of the women felt that family can often become frustrated as they do not understand chronic pain and its effects. Furthermore, relationships were strained as, whereas some women were happy with the physical and emotional support that they received from their husband, others felt that their husbands were helping them more than needed, and this assistance was causing heightened unhappiness for the chronic pain sufferer. As well as partners, the participants experienced a lack of understanding of chronic pain, and a lack of empathy, from their older children and this was discussed within a qualitative interview by older women suffering from osteoarthritis (Roberto, 2001). As well as lack of understanding and empathy the participants discussed the effect of physical restrictions affecting the relationship between chronic pain sufferers and their children. One participant expressed that she '*can't do things for my [children] that I always enjoyed doing*' (Roberto, 2001, pg. 67) because of her pain. Once more the chronic pain sufferer experienced changes in their

family roles as a result of the physical consequences of chronic pain. This can be for many reasons such as the inability to wear heeled shoes which can restrict attendance of more formal outings (Roberto & Reynolds, 2002).

It is evident that chronic pain sufferers can often suffer socially due to the presence of chronic pain. Individuals can feel isolated, due to the invisibility of pain and others' lack of understanding, as well as feeling isolated, and experiencing loss of freedom, due to the physical restrictions that can affect chronic pain sufferers. Finally, it is evident that chronic pain is not experienced in solitude but can also affect other family members and friends, as well as relationships sometimes being affected by chronic pain.

One issue with this research is the lack of focus upon older adults, as much research has so far been conducted with individuals over a wide age range. Therefore, the specific social issues of older adults have not been thoroughly discussed as older adults' social situations are different, for example, due to retirement. Furthermore, it is clear that the literature concerning social impact of chronic pain is dominated by qualitative research, with researchers discussing social consequences of living with chronic pain, predominantly as part of an interview. This qualitative approach allows an in-depth look at individuals' social situations from their own perspective. It also allows participants to discuss the social impact of isolation over a long period of time, as opposed to a one-off period, as the questionnaires, and performance based measures, discussed throughout this literature review tended to do. However, although qualitative research is an important method to use whilst discussing the social impact of chronic pain, upcoming observation technologies, may also be beneficial in exploring some social factors as they allow a look at the individuals' daily lives in a completely different way to the measures already used in this area.

## **2.5 PSYCHOLOGICAL FUNCTIONING**

Within the ICF, psychological factors are discussed in much less depth than physical functioning and social functioning. Parts of psychological functioning are described within the '*mental functions*' category in the '*body functions*' section, whereas other parts of psychological functioning are described as personal factors. Although the ICF recognises that personal factors '*may play a role in disability levels*' (ICF, WHO, 2001, pg. 17) it does not classify them within the ICF due to vast cultural and social variations. Neither section of the ICF provides a comprehensive classification of all psychological determinants of health and health-related functioning, therefore, like previous sections of this PhD, this section will discuss '*psychological functioning*' as one topic, combining the elements described in both '*mental functions*' and various aspects of the '*personal factors*' list of the ICF.

One recent publication has acknowledged the importance and effect that various aspects of psychological struggle can have on the experience of living with chronic pain. A systematic synthesis of qualitative research looking at the experiences of chronic pain sufferers living with non-malignant, musculoskeletal, pain was conducted using meta-ethnography (Toye et al. 2013). The synthesis considered 77 qualitative papers and it was clear that individual struggle was highly important and apparent within experiences of living with long-term pain. The researchers deemed the principal

theme '*adversarial struggle*' (pg. e82) with five of the six synthesised sub-themes being negative (see table 3, below for explanation of six sub-themes).

1. Affirm self	<ul style="list-style-type: none"> <li>• My body is now against me</li> <li>• The old me is my real self</li> <li>• I am becoming isolated from others</li> </ul>
2. Reconstruct self in time	<ul style="list-style-type: none"> <li>• My days are unpredictable</li> <li>• My future will not be what I thought</li> </ul>
3. Construct an explanation of suffering	<ul style="list-style-type: none"> <li>• It doesn't make sense, there is no medical reason</li> <li>• No one believes me because I have nothing to show for it</li> <li>• There must be some other reason</li> </ul>
4. Negotiate the healthcare system	<ul style="list-style-type: none"> <li>• I can't see the point of going to the doctor again but I must</li> <li>• I need someone to listen to me and understand what pain has done to me</li> </ul>
5. Prove legitimacy	<ul style="list-style-type: none"> <li>• Should I hide or show my pain?</li> <li>• I need to show that I am not like other people with pain</li> </ul>
6. Moving forward alongside pain	<ul style="list-style-type: none"> <li>• I now cooperate with my body and work with it</li> <li>• I am still me and can enjoy my life</li> <li>• There are other people like me that believe and value my experience</li> <li>• I don't have to hide my pain and can let people know my limitations</li> <li>• I realise that I have changed but don't need to continue searching for a medical answer</li> <li>• I am confident to give things a go and make changes</li> </ul>

**Table 3: The sub-themes of '*adversarial struggle*' and the thematic sentences used to explain them (Toye et al. 2013, pg. e832-e833)**

It was evident that the struggles participants experienced centred on their own feelings towards their chronic pain. It was also apparent that these internal struggles affected participation within ADL, with the inconsistencies and unpredictability of pain affecting the planning of tasks. Social relationships were also affected when discussing the credibility and legitimacy of pain, as well as feeling a loss of role due to the restrictions that pain placed on them.

As well as the components highlighted within this qualitative synthesis, other psychological issues have been highlighted in past literature. Specifically, there are



three specific psychological factors that are often a part of the chronic pain experience; depression, fear-avoidance and lowered self-efficacy.

A reciprocal link has been found between depression and chronic pain (Karp & Reynolds, 2009). Individuals often struggle to cope with chronic pain and both happiness and well-being can decrease, and depression can increase, within chronic pain sufferers compared to non-chronic pain sufferers (Bridges, 2012). Figures have shown that 49% of individuals living in the UK with chronic pain suffer depression (DH, 2009). Additionally, those with depression are also more likely to suffer from chronic pain.

This reciprocal link between pain interference and depression has been demonstrated within a prospective study in adults over 50 years old, with self-report measures at baseline and a 3-year follow up showing that depression can lead to pain interference, and pain interference can lead to depression over a three year period (Arola, Nicholls, Mallen & Thomas, 2010). Depressive symptoms have also been associated with lowering and discontinuing tasks in self-report data (Duong, *et al.*, 2005). Lin *et al.* (2003) conducted a Randomised Control Trial (RCT) which aimed to examine whether improving management for depression, using medication and/or an intervention, reduced pain, and improved functioning, in depressed older adults (60+ years old) with arthritis. Measures of depression, pain intensity, interference of ADL, general health status and quality of life were all measured at 3, 6 and 12 months. The RCT confirmed that improved management of depression lowered levels of pain intensity and lowered daily interference due to both the presence pain itself, as well as finding that the management of depression lowered levels of pain. This RCT facilitates the notion that depression affects levels of pain, as well as daily interference of pain and arthritis, on ADL. However, due to the study being quantitative, it does not go into detail regarding the way in which depression affects interference of ADL.

In addition to the relationship between chronic pain and depression, fear-avoidance can be one psychological component related to living with chronic pain. The presence and intensity of chronic pain can lead to changing patterns of movement and can affect ADL, however, the psychological aspects of chronic pain can also impact these aspects of daily living. Avoidance behaviours can often occur as a result of fear and are seen to be maladaptive responses to pain (Samwel, Evers, Crul, & Kraaimaat, 2006). The *Fear-Avoidance Model* is a cognitive-behavioural model developed by Vlaeyen and Linton (2000) and explores the development of chronicity stating that an individual may avoid tasks such as movement, leisure tasks and social interactions due to fear as they do not want to increase their levels of pain (Leeuw *et al.*, 2007). This fear leads to a cycle of pain and re-injury which can lead to disuse; a reduced level of physical activity (Basler, Luckmann, Wolf & Quint, 2008). The relationship between the Fear-Avoidance Model and levels of disability has been studied within younger populations with higher levels of pain being related to decreased disability (Denison, Asenlof, & Lindberg, 2004; Lamé, Peters, Vlaeyen, Kleef & Patjin, 2005).

As well as in younger adults, the *Fear-Avoidance Model* (Vlaeyen & Linton, 2000) has been explored within the older population and results are generally consistent to those reported for younger adults in that fear and anxiety may negatively influence the pain experience for older adults (Bishop, Ferraro & Borowiak, 2001). Bishop *et al.* (2001)

used self-report questionnaires to explore the relationship between fear/anxiety and pain, coping, depression and health status of older adults (55-97 years old). Pain-related anxiety was related to self-rated health status, cognitive coping and depression of older adults living with chronic pain. This research suggests that the *Fear-Avoidance Model* is also relevant within older adults, as it is for younger adults. However, again, based on the methods used in the research, little detail is given regarding the details of fear-avoidance and how it affects health status, cognitive coping and depression of these individuals. The study is based upon single-instance reporting, and there are no further details given. Furthermore, the effect of pain-related anxiety on daily functioning was not examined within this study.

Research specifically looking at the daily functioning of older adults has also found fear-avoidance to be one predictor of functional capacity but not a predictor of physical activity (Basler, *et al.*, 2008). Basler *et al.* (2008) looked at the validity of the Fear-Avoidance Model in older adults (65+ years) with chronic lower back pain and included healthy age-matched controls. The researchers used both self-report information and performance based measures to conclude that the functional capacity of individuals with chronic lower back pain was predicted by fear-avoidance, pain intensity and age. Furthermore, differences were seen between chronic lower back pain sufferers and age matched controls as chronic lower back pain sufferers were more fear-avoidant, as well as being less functionally capable and less able to flex their trunk than matched controls. However, there were no differences in levels of self-reported physical activity between the two groups.

Both measures of physical activity were self-reported by participants, and one objective measure of physical activity, such as an accelerometer, would have been a useful indicator of physical activity. Additionally, the self-reported physical activity is flawed in that the period of its measurement was different to other self-report measures. From the measures, fear-avoidance beliefs, functional capacity and physical activity were all self-reported, however, only physical activity measures were reported for a specific duration (i.e. the previous week) whereas both fear-avoidance and functional capacity self-reports were reported more generally. Therefore, the physical activity conducted in the last two weeks is proposed to affect self-reported functional capacity over an unspecified time. The inconsistencies over the timing of the information gathered may have led to inconsistencies in the data and may have affected results regarding the predictors of functional capacity.

As well as the reciprocal relationship between depression and chronic pain, and the effect that fear-avoidance can have upon ADL, self-efficacy is also important. Self-efficacy is the confidence in one's own ability, and has been related to the chronic pain experience in two ways; self-efficacy affecting pain management, and functional self-efficacy affecting ADL. Turner, Ersek and Kemp (2005) looked at the role of self-efficacy in pain experiences of older adults (66-99 years old). The study used numerous self-report measures and demonstrated that higher self-efficacy for managing pain was associated with lowered levels of disability, and lower levels of depression and better coping with pain. One methodological issue with the study was that the sample was made up of 88% female participants, however, significance remained when gender was adjusted. Functional self-efficacy i.e. the confidence in one's own ability to carry out tasks, has been associated to physical disability in older

adults suffering from chronic pain, with lowered functional self-efficacy relating to heightened disability (Barry, Guo, Kerns, Duong & Reid, 2003). However, participants consisted solely of Veterans and there was little information provided regarding disability levels of the participants, other than the number of days affected by pain over the previous months, therefore failing to give details regarding functioning.

The locus of control is also an important part of self-efficacy. The locus of control refers to the amount of control individuals perceive they have with regards to what happens to them (Phares, 1976). Whereas an individual with an internal locus of control believes that they are in control of themselves and what happens to them, an individual with an external locus of control believes that they cannot affect what happens to them, and control is taken away from them. An external locus of control has been related to higher self-reported psychological distress, anxiety, depression and feeling of helplessness for the pain management of working adults, compared to those with an internal locus of control (Crisson & Keefe, 1988). Furthermore, research with older adults has also found a similar relationship between locus of control and aspects of the pain experience. Gibson & Helme (2000) found that an internal locus of control was related to a more overall positive pain experience with an internal locus of control being associated with the use of self-directed coping strategies, higher feelings of pain control and lowered levels of interference. Furthermore, an external locus of control was associated with heightened levels of catastrophising pain. Gibson and Helme (2000) also established a significant increase in an external locus of control with increased age, with adults over 81 years old experiencing higher levels of external locus of control than the adults less than 81 years old. Despite associations between self-efficacy, locus of control, the management of chronic pain and functioning of chronic pain sufferers, research looking at the influences of locus of control on the pain experience in older adults is limited and further research is needed in this area (Abdulla et al., 2013).

There are multiple psychological factors that are often present within the pain experience, and can affect levels of daily functioning for older adults living with chronic pain, namely, depression, fear-avoidance and self-efficacy.

## **2.6 MEASURING FUNCTIONING**

As seen in the research above, mobility, ADL, social factors and psychological factors related to functioning are generally measured using either self-report measures such as questionnaires, diaries, interviews or focus groups, or objective, performance-based measures such as observation, pedometers and accelerometers. The critique of both pedometers and accelerometers within this population is given above. This section will specifically discuss the use of diaries as a data collection tool used in pain research and functioning. This section will also introduce the use of life-logging technology as an upcoming measure of functioning, as well as the theoretical components of technology use and the use of technology in the older population.

### **2.6.1 USE OF DIARIES**

One technique used within chronic pain research is the use of diaries. Diary methods have long been adopted as a method within health research, including being used to

identify factors relating to daily functioning. Diaries not only allow a deep description of daily experiences and functioning from a personal perspective (Day & Thatcher, 2009) but also provide an insight of the individual's interpretation of their own daily living (Alaszewski, 2006).

Diary methods can be useful in the area of chronic pain and functioning due to their subjective nature. Diaries have been used in chronic pain to identify pain symptoms as they enable participants to rate levels of pain over a prolonged period of time, in a natural setting (Lewis, Lewis & Cumming, 1995). Diary studies are also beneficial in this area as they can identify tasks that may worsen or alleviate levels of pain (Liszka-Hackzell & Martin, 2004) and can also explore the meaning of individuals' pain (Dickson & Kim, 2003). Diary methods in the area of chronic pain tend to focus on assessing daily levels, and perceptions, of pain however some studies explore functioning in addition to pain severity (e.g. Huijnen, Verbunt, Roelofs, Goossens, & Peters, 2009).

Generally the use of diaries as a research method is beneficial in that they allow the exploration of experiences in the participants' natural environment (Reis, 1994) and allow a distinctive look at human experiences (Bolgar, Davis & Rafaeli, 2003). Although, of course, diaries can be disadvantageous in their ease of use as they can contain repeated questions which are onerous for participants (Bolgar, *et al.*, 2003). Recall biases are also a well-cited problem with diaries, as some diaries ask individuals to recall information from in the past (McGlynn, Damberg, Kerr & Brook, 1998).

There are numerous types of diaries that are used in research, such as structured and unstructured diaries, generic and study-specific diaries as well as pen and paper and electronic diaries. Some research diaries are typical of a traditional diary in that they are free-flow and allow the individual to write various points about their daily living, with the content of the diaries being driven by the participant. These diary methods achieve a great understanding into the complexity of experiences in the individual's own words, such as the chronic pain experience (Clarke, & Iphofen, 2007). Whereas some diaries are structured, with individuals being asked specific questions either in the form of closed questions, open questions, and often likert scales. Non-qualitative diaries, in the form of likert scales or Visual Analogue Scales (VAS), may be beneficial in measuring concepts such as pain ratings on a continuous scale, and allows comparisons between ratings over the course of the measurement period, along with the chance to compare ratings between participants. Research diaries also differ in style and tend to be either generic, standardised diaries such as the Daily Reconstruction Method (Kahneman, *et al.*, 2004) or diaries which have been specifically designed for the use in one particular study in order to best explore their aim, and are known as 'researcher-driven diaries' (Elliott, 1997). The final distinction in diary type is between pen-and-paper diaries and electronic diaries. Electronic diaries are becoming increasingly used as opposed to traditional pen and paper diaries (Broderick, 2008). Electronic diaries are advantageous as they record compliance rates by documenting the time that each diary entry was completed, as well reducing problems associated with legibility of hand-writing and missing data (Hufford & Shields, 2002). Furthermore, a systematic search of electronic diaries conducted with chronic pain patients found that compliance was higher than when using pen-and-paper,

enjoyment of electronic diaries was higher, and data was more reliable when using an electronic diary (Dale & Hagen, 2007).

### **2.6.1.1 SYSTEMATIC SEARCH**

As part of this thesis a systematic search was initially carried out in order to establish what diary methods have previously been used in research involving older adults with chronic pain.

One specific area which needed addressing in more depth was the use of diary methods with older adults, specifically those suffering from chronic pain, along with exploring the benefits and weaknesses of diaries within this population. Much past and current research utilises a large age range, with few participants over the age of 65. As there are multiple methods of collecting diary data, including structured and unstructured diaries, generic and study-specific diaries and the distinction between pen and paper diaries and electronic diaries, it was beneficial to explore the use of these with an older population suffering from chronic pain in order to determine whether any diary method that has been used in research within this area is more advantageous than other methods. For example, the acceptance of new diary methods, including electronic diaries, may not be directly dependent upon age, as suggested in previous literature (Tiplady et al., 1997), however, older adults may have secondary health problems which can hinder the use of diary methods in general, for example, having poor eyesight (Palmlad & Tiplady, 2004).

The overall aim of the systematic search was to identify the use of diary methods for exploring the impact of chronic pain in older adults ( $\geq 65$ ). In particular this search aimed to:

1. Clarify which specific diary methods had been used within an older population of chronic pain sufferers.
2. Explore the advantages and disadvantages of diary methods within an older population of chronic pain sufferers.

### **2.6.1.2 METHOD**

*Inclusion and exclusion criteria:*

Studies were included in this search if the following inclusion criteria were met:

1. All participants were over 65 years old.
2. Participants were sufferers of chronic pain.
3. A diary method was used as the only method, or as part of the method.

Studies were excluded from this search based on the following exclusion criteria:

1. Participants were sufferers of cancer related pain.
2. Participants were awaiting surgery or had recently undergone surgery (within 6 months).

### Search strategy

In April 2010 an electronic database search was performed using the following databases; PsycInfo, CINAHL, Medline, Web of Knowledge (ISI), Scopus, Science Direct, Cochrane (central) and ASSIA. There were no language restrictions. Reference and citation lists were searched in all relevant articles. An author search was also carried out on all relevant articles. An additional electronic database search was carried out in February 2012 in order to look for any missed articles, or articles that had been published since April 2010. The same databases were explored in this search as the search performed in April 2010, however there were additional search terms added to the search carried out in 2012 in order to ensure that all relevant articles were found (see table 4, below).

<b>SEARCH TERM</b>	<b>2010</b>	<b>2012</b>
<b>Pain</b>	Pain	Pain
	Chronic pain	Chronic pain
	Persistent pain	Persistent pain
	Long-term pain	Long-term pain
<b>Diary</b>	Diary	Diary
	Diaries	Diaries
	Daily reconstruction method	Daily reconstruction method
		Retrospective report(s)
		Open-ended self-report(s)
		Journal
<b>Older adult</b>	Older adult(s)	Older adult(s)
	Geriatric(s)	Geriatric(s)
	Elderly	Elderly
	Aged	Aged
		Retired

**Table 4: The search terms used in the systematic search in both 2010 and 2012**

Two reviewers evaluated each article based on the title, abstract and keywords. If the reviewer was unsure of inclusion in the search, a full-text search was carried out.

### 2.6.1.3 RESULTS

In April 2010 a total of 1,540 articles were found after the exclusion of 90 duplicates (see figure 2). After a further exclusion (n=1,435) of clearly irrelevant research 105 studies remained, and were considered further. After a full-text analysis of each remaining study, a further 100 articles were rejected as they did not fully satisfy inclusion criteria (67 studies did not include all participants over 65 years old, 16 studies did not include participants suffering from chronic pain, 10 studies did not use a diary method, 4 studies focused on cancer patients, 2 studies were reviews, and 1 study was using a cost diary). There were 5 articles remaining. Two further articles were added after searching relevant reference, citation and author lists, therefore 7 articles were used within the final search.

The search was carried out again in February 2012, with four additional search terms, and a total of 7,730 articles were found after the exclusion of 1,519 duplicates (see figure 3, below). The vast difference between the totals from the 2010 and 2012

searches is likely to be the inclusion of four additional search terms, as well as the two-year gap. After excluding further irrelevant studies (n=7,447) 283 studies remained. After a full-text analysis of each remaining study they were all excluded as they did not fully satisfy the inclusion criteria. Other than the studies that were found in April 2010 there were no studies found in the search that were relevant.

Figure 2: A flow chart to demonstrate the selection process of the systematic search carried out in 2010

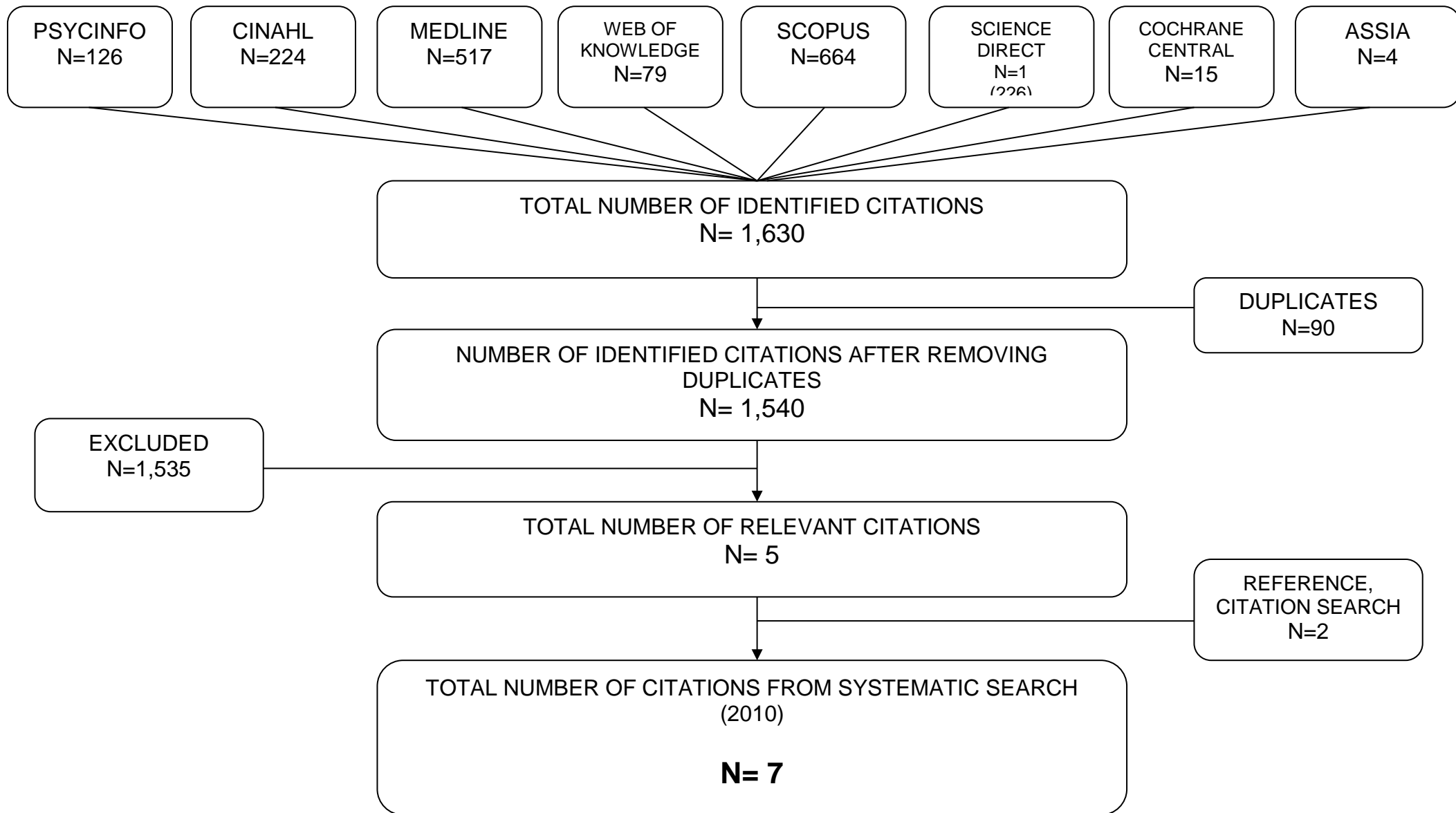
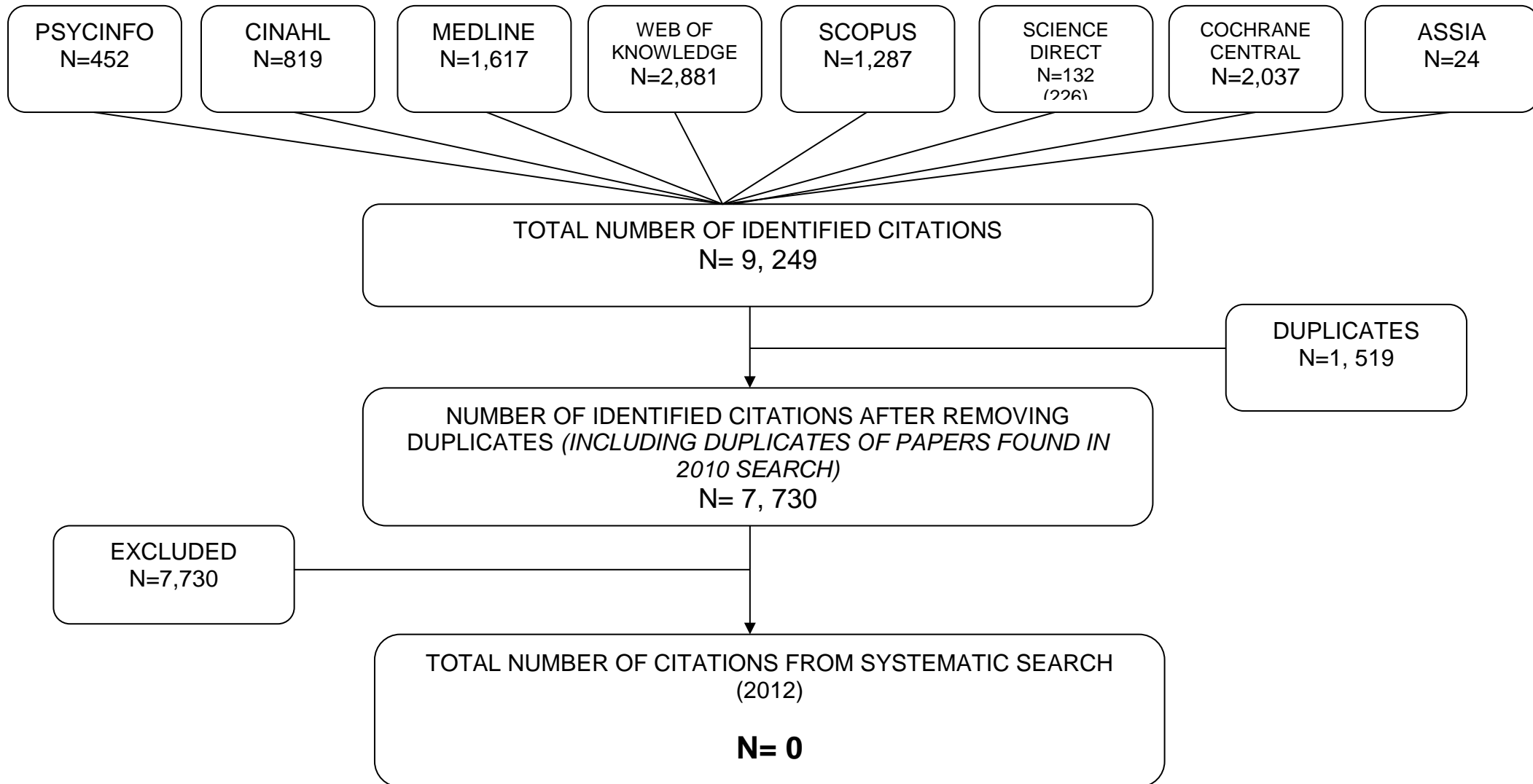




Figure 3: A flow chart to demonstrate the selection process of the systematic search carried out in 2012



### *Research designs*

From the seven articles examined, there were three pilot studies (one Randomised Control Trial [RCT], one pre-experimental design and one descriptive design). Of the other articles, there was one descriptive design, one prospective RCT, one cross-sectional design and one qualitative study.

### *Population Characteristics*

The number of participants within each study varied greatly with numbers ranging from 21 participants to 170 participants (see Appendix A for a table containing descriptions of all studies). Participants within all of the included studies were 65 years old and older, and all participants suffered from chronic pain, with the exception of experimental studies which used a control sample in addition to sufferers of chronic pain.

### *Diary characteristics and outcome measures*

The way in which diary methods were used within each article varied considerably, with only three studies using diary entries as the sole method of measurement (see Appendix A). Further to the inconsistent use of diaries, there were other differences in diary administration throughout the studies, including the length of measurement, how often diaries were completed by participants, the way in which diaries were completed and the way in which the diaries were analysed.

The measurement period of each study also varied (see Appendix A). Two studies included a 1 week diary (one of these was completed retrospectively, and one did not give information regarding completion of the diary), one study included a quarterly diary which was completed retrospectively, two studies included a 2 week diary which was completed daily and two studies included an eight week diary (one of which had a weekly hand in, and the other one did not state when diaries were handed in).

Throughout the articles, the objectives of the diaries also differed considerably, for example, diaries were used to record levels of tasks (Basler, Bertalanffy, Quint, Wilke & Wolf, 2007; Basler, *et al.*, 2008), record levels of pain (Gibson, Woodbury, Hay & Bol, 2005; Hager & Brockopp, 2007; Hager & Brockopp, 2009) and record the compliance and experiences of an intervention (Morone, Greco & Weiner, 2008a; Morone, Lynch, Tindle & Weiner, 2008b). It is clear that although the diaries were used in the same population, the objectives of the diaries varied and diaries were not used for one sole purpose in this area (see Appendix A).

The structure and outcome measures of the diaries also differed, as each study using diaries aimed to explore different objectives (see Appendix A). One study was a free-flow, qualitative diary, and analysed qualitatively (Morone *et al.*, 2008b). This study used the diary as the sole measurement, in order to explore the duration and experiences of an intervention to relieve pain. Six themes were produced which found the intervention to have beneficial effects for individuals, including, reduced levels of pain and increased well-being. Two further studies used a diary as the only measurement, and explored related areas, using a similar diary method, however analysed the data quantitatively (Hager & Brockopp, 2007; Hager & Brockopp, 2009). Hager and Brockopp (2007) aimed to develop the pain diary and discovered an increase of pain entries throughout the measurement period, and furthermore, found an increased use of as-needed medication whereas the outcome measures of Hager and

Brockopp (2009) focused more upon pain experiences, and acquired information regarding levels of pain at rest, levels of pain whilst moving, levels of pain whilst awake, pain descriptors and pain location.

There were four further studies which used diaries, however, the diaries were used as a small part of an overall measurement. Basler *et al.* (2007) used diaries with fixed categories to measure daily activity levels, therefore presenting the diary entries as activity duration. Basler *et al.* (2008) used categorical physical diaries, which were used to categorise activities that individuals participated in, and were converted into MET scores showing the energy expenditure of the experimental and control groups. Gibson *et al.* (2003) used diaries to explore numerous aspects of pain experience, including pain type and pain exposure, which resulted in the presentation of a descriptive report of pain. Finally, Morone *et al.* (2008a) used a diary to record the duration and experiences of an intervention, and although concluded that diaries seemed to give realistic information regarding compliance of the intervention, and richer data than the quantitative measures, there was no further exploration of the outcomes of the diary. All diaries were pen and paper diaries, and there were no electronic diaries used within any of the articles. There was also no use of generic diaries.

There were missing pieces of information within some of the studies regarding both the method and analysis. For example, one study did not give information regarding the structure of the diary (Basler *et al.*, 2007), two studies did not explain how often the diaries were completed (Basler *et al.*, 2008; Hager & Brockopp, 2009) and diary compliance rates were not explored within the analysis of some studies (Basler *et al.*, 2007; Basler *et al.*, 2008; Gibson *et al.*, 2003; Hager and Brockopp, 2007; Hager & Brockopp, 2009; Morone *et al.*, 2008).

#### **2.6.1.4 DISCUSSION**

The aim of this systematic search was to explore the use of diary methods within an older population suffering from chronic pain, and to investigate any advantages or disadvantages of diary methods administered in this sample. Within this search, seven articles have been identified which meet these criteria. This search has demonstrated that there is not a great amount of research using diary methods exploring chronic pain in adults. From the available research in this area, there were numerous methods of diary collection, including varying lengths of measurement, varying diary structures, varying analyses of the diaries and outcome measures.

The outcome measures of the diaries differed, as diaries were not only used to describe levels of pain, but were also used to record levels of activity and to record levels of compliance and experiences of an intervention. Therefore, with regards to exploring the type of diary methods currently being used in this area, it is clear that there are numerous methods being undertaken. Although diary studies are often assumed to be a qualitative method, only one study within this sample captured the data in a qualitative manner, with the majority of diaries comprising of numerical rating scales and multiple choice pain descriptors, and being analysed quantitatively. Furthermore, this makes it difficult to draw conclusions regarding the advantages or

disadvantages of using a diary method with adults over 65, suffering from chronic pain, due to the variance within the administration, structure and analysis of the diaries.

One further issue between these studies is that only one study recorded the compliance of the diary entries, therefore, compliance rates cannot be evaluated within this sample. Compliance is an important aspect of the diary method, and is often viewed as a major weakness of diary methods and a high level of compliance is essential for diaries to produce effective results (Morren, van Dulmen, Ouwerkerk & Bensing, 2009). The compliance of the diary entries was only measured in one of the studies, which reported a decline of diary entries throughout the duration of the study (Morone *et al.*, 2008b). The problems with concluding a low compliance of diary entries in an older population is emphasized by Milligan, Bingley and Gatrell (2005) who previously explored the use of diaries to record health and well-being in a population of over 65 year olds. The researchers discovered that the participants within the sample seemed to increasingly comply throughout the measurement period, writing more information as they became familiar with the writing process. Although Morone *et al.* (2008b) found continually decreasing levels of compliance within the study, this is certainly not sufficient to make a general conclusion regarding diary compliance of all older adults suffering from chronic pain, and further research needs to be conducted to explore the issue of compliance further. One further problem with the rate of compliance reported within this study is that it is based on the weekly hand-in of each diary throughout the 8 week measurement period, and does not explore day to day compliance of the diary entries. This highlights the potential benefits of electronic diaries as they are able to automatically record the date and time of each entry, therefore ensuring more accurate measures of compliance. Improvements in technology are also changing the way in which diary methods are being conducted and the use of electronic diaries, such as web-based diaries, or hand-held computers make it possible to measure additional elements to the traditional pen and paper diary. For example, compliance can be monitored automatically by recording the time and date of each entry therefore eliminating forward-filling and backward-filling (Broderick, Schwartz, Shiffman, Hufford & Stone., 2003; Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003). Furthermore, electronic diaries also have the advantage of automatic prompts in order to remind the individual to make a diary entry, therefore enabling more reliable data (Heiberg, et al., 2007). Despite the generally low reporting of compliance within the studies included in this search, two of the studies were completed retrospectively therefore compliance was not an issue (Basler *et al.*, 2007; Gibson *et al.*, 2003). Furthermore, it would have been disadvantageous for one further study to report upon compliance as completion of the diaries was assisted by health professionals (Hager & Brockopp, 2007). This is one area which may benefit from further research, as in-depth research exploring the compliance of diary entries in this population would be advantageous in order to assess the effectiveness of this measurement. For example, it would be beneficial to explore which diary method is preferable in this population, such as a free-flow diary, a diary made up of numerical scales and descriptors or using electronic diaries, which have, so far, not been used within this population. This could be explored using levels of compliance to each method, along with other measures including questionnaires exploring acceptance and enjoyment of each method.

Acceptance and enjoyment of the diary methods is one further issue which has not been explored in these studies, potentially due to the diaries being a small part of the measurement within some studies. However, it is important to explore the acceptance and enjoyment of these methods in the aim of developing the most effective diary methods to explore the area of chronic pain in older adults.

One problem with this systematic search may be the included age range, as the vast amount of studies that included adults over 65 years old also included adults younger than 65 years old and were therefore excluded. The systematic search was used to inform the main study within this thesis, and as this study excluded individuals under 65 years old, it was also important to exclude them from the systematic search. This is due to the particular focus on the use of diary methods with older adults, and therefore by including studies with younger adults the effectiveness of the method may have been skewed. However, by solely focusing on studies with only adults over 65 years old may have affected the results, as additional diary methods may have been captured by lowering the age range. One further limitation with the sample was the exclusion of individuals with cancer related pain. Cancer related pain was also excluded from this systematic search, as it was excluded from the main study. Cancer related pain was excluded from the main study as there are a number of differences between non-cancer related chronic pain and cancer related chronic pain, such as the origin of the pain itself, its effect on daily living, and the often rapid progression of the intensity of cancer-related pain (American Society of Regional Anaesthesia and Pain Medicine, 2010; British Pain Society, 2010; Cancer Research UK, 2013).

#### **2.6.1.5 CONCLUSION**

This systematic search has highlighted that, despite the small amount of literature in this area, there are varying diary methods currently being used to explore chronic pain within a sample of older adults. Of these studies, no generic diary methods were used, and all of the diaries were conducted using pen and paper, without the use of electronic diaries. Currently, there is not a great amount of knowledge regarding compliance, acceptance or enjoyment of these methods within this population, and research would benefit from exploring this in the future.

### **2.6.2 USE OF TECHNOLOGY**

#### **2.6.2.1 EVOLUTION OF LIFE-LOGGING TECHNOLOGY**

We live in a society in which technology is ubiquitous and use of this technology can also be valuable within healthcare. One strand of technological innovation which is slowly emerging into some areas of health research is life-logging. Life-logging is the idea of automatically capturing several aspects of an individual's life using technology (Caprani *et al.*, 2010). Life-logging arose from the initial idea of Busch's (1945) 'MEMEX' (MEMory EXtender). Busch's (1945) concept was made up of an office desk containing built-in screens, keyboards and other equipment allowing the storage of books, records and other communication strategies which aim to supplement human memory.

Since Busch's (1945) initial notions of future technology, there have been numerous innovative ways in which individuals have tried to capture multiple aspects of their lives.

'Blogging' was the beginning of life-logging and greatly developed with the increasing accessibility of the internet, including social networking sites. However, with continuing technological advancements, blogging is just one small way of recording life experiences, and one which has numerous burdens, such as the need to manually upload information and it being time consuming. Additionally, the content of the blog is only what is written by the user, as opposed to a collection of numerous sources of data, as Busch (1945) initially proposed.

The development of life-logging has now moved away from blogging as the sole method of capturing individual information and there are an increasing number of life-logging tools which aim to capture and store multiple aspects of the user's life. The process of using digital life-logging tools as a way of recording data is also described as '*the quantified self*'; i.e. quantifying and storing multiple aspects of behaviour using life-logging technology (Lupton, 2013). '*MyLifeBits*' (Bell & Gemmell, 2009) is one example of a life-logging database on which a user adds information from various sources therefore being able to store, organise, pattern and annotate information, whereas '*Slife*' is a web-based programme which aims to streamline all computer-based activities by automatically observing and recording all computer interactions allowing individuals to keep track of what activities are carried out on their computer and the amount of time taken to carry out these tasks. These life-logging devices allow a multitude of information to be automatically captured from the user, which they can store, archive and delete.

One of the benefits to life-logging is storing information on a '*digital memory*' that is particularly more accurate and objective than human memory which can be '*subjective, patchy, emotion-tinged, ego-filtered, impressionistic, and mutable*' (Bell & Gemmell, 2009, pg. 56). This digital memory allows the user to store a multitude of information from a variety of sources. Unlike blogging, or other forms of diary keeping, upcoming life-logging technologies tend not to rely on human memory but use alternative ways in which to keep track of and store information without the influence of individual.

As well as general life-logging devices, life-logging is becoming increasingly used to explore individuals' health, including health improvement, rehabilitation and prevention of illness. Individuals can be given life-logging technology by health professionals, or voluntarily take up life-logging in order to engage with, and increase awareness of, their own health (Lupton, 2013). Life-logging health behaviours can take many forms, for example, there are numerous '*apps*' on which users can log all manner of health behaviours automatically, as long as they are carrying their mobile phone or tablet with them. One example of these '*apps*' is '*Endomondo*', a mobile application which can track the time and speed of the user's run or cycle journey as well as locating it on a map, and again, allowing the user to upload the information to a social networking site if required.

The development of life-logging technology is continuously progressing at a rapid rate and life-logging is becoming increasingly wearable with body worn wireless transmitters being incorporated into wearable smart garments, such as the *LifeShirt* (Vivometrics Inc), the *ProeTEX* (Curone et al., 2010), and the *SmartShirt* (Park & Jayaraman, 2003) as well as wearable jewellery (Miner, Chan & Campbell, 2001). Very recently, SONY launched their newest wearable product at the 2014 Consumer Electronics Association

(CES) conference, as part of the Consumer Electronics Showcase. SONY's *Smartband* is a waterproof wearable band that works in addition to a smartphone. The wearable band is worn continuously and acts like an accelerometer as well as monitoring sleep quality, tracking and alerting the user on daily weather, and vibrating when they receive a text message. One further example of a piece of recently developed wearable technology, which has received much media attention, is '*Google Glass*'. *Google Glass* is a piece of augmented eyewear which is hands-free and voice controlled. *Google Glass* can record photographs, videos and give the user various pieces of information, including travel advice, whilst being worn. The information captured on *Google Glass*, and many other pieces of wearable life-logging devices can then be wirelessly transmitted, and stored, on external devices (Lupton, 2013). Wearable cameras are an increasingly recognised form of life-logging. This type of life-logging was first developed by Steve Mann in the 1980's but has more recently developed due to technological advancements allowing use of small cameras with large memories and high battery life. Cameras, such as the *Sensecam* (ViconRevue, Vicon, see chapter 3, section 3.7.2 for more information on the Sensecam), the *Autographer* (Autographer©) and the *Get Narrative* camera (previously known as Memoto) are current life-logging cameras and are worn on the user's body to capture continuous automatic images allowing a '*film*' of the user's day to be played back when they wish. This type of life-logging allows a continuous, automatic recording of the individual's day without much effort from the user.

Life-logging is a relatively new concept, however, it is not only the availability of the technology itself that generates usage, but there are multiple factors that affect the intention to use technology. For example, general technology use is proposed to be affected by the amount of support the user has when using the technology, its ease of use, the attitudes of others toward use and any perceived benefits of using the technology (Venkatesh, Morris, Davis & Davis, 2003). Recent discussion in the area has acknowledged the lack of research looking into the experience of using these technologies as a part of daily life, and the general user experience whilst using these types of technology (Chan, Estève, Fourniols, Escriba, & Campo, 2012; Lupton, 2013). Currently, research mainly focusing on life-logging and the use of wearable technology in the field of health mostly looks at the potential applications of wearable technology, and how it can be used (e.g. Ananthanarayan & Seik, 2012) as opposed to looking at the user experience, and how the individual feels about using the technology.

The comfort and wearability of wearable technology have been the focus of research in this area. The *SmartShirt* is one piece of wearable technology that was originally designed for use with the military but had other uses when designed, including use within healthcare (Park & Jayaraman, 2003). Upon designing the *SmartShirt* the researchers considered multiple components of use, including aspects that would make the technology functional (performance metrics, usability in the field, durability, maintainability and functionality) as well as considering the '*wearability*' of the system, which includes the comfort, weight, maintenance of motion and irritation when wearing the system, among others. However, the description of the *SmartShirt's* user requirements, which includes wearability, was a small part of the research, and these components were not described in any detail. Gemperle, Stivoric, Bauer & Martin (1998) also looked at the use of wearable technology and designed a set of guidelines which promote the importance of full maintenance of movement, comfort and

unobtrusiveness when wearing technology. Although both studies acknowledge the importance of comfort and wearability as well as highlighting aspects of technology use specific to wearable technology, there is no evaluation of these guidelines from users, or any discussions with participants in order to provide feedback on the wearability of these pieces of technology.

Finally, Knight, Baber, Schwirtz, & Bristow (2002) presented a *comfort rating scale* which is intended to be used by designers when manufacturing wearable computers and acknowledges multiple dimensions involved within 'comfort'. The *comfort rating scale* encapsulates six aspects of comfort including *emotion*, which includes feelings on the appearance of the technology, *attachment*, which involves how the technology feels, *harm*, any damage caused to the body, *perceived change*, feeling physically different whilst wearing the technology, *movement*, the technology affects the movement of the user and *anxiety*, worrying about the safety of the device. The scale was initially developed from 92 terms used to define 'comfort', and was further developed by eight participants who grouped these terms to eventually develop the six components of comfort. However, the scale was not developed from experiences of wearable technology. Although, Knight *et al.* (2002) demonstrated the use of the *comfort rating scale* for two pieces of wearable technology, this was in a pre-defined quantitative format, with no feedback from participants providing additional information to be used as part of the scale.

There is currently a lack of research looking into the user experience of wearable technology, and although some research has looked into issues of comfort and wearability, there remains to be a lack of discussion from participants themselves. Regardless of limited research in this area, the importance of looking at the user experience of wearable technology has been acknowledged (Chan *et al.*, 2012; Lupton, 2013). Despite the lack of research into the usability of wearable technology, there are multiple models which provide an explanation of user experience and intentions for use of general, non-wearable, technology.

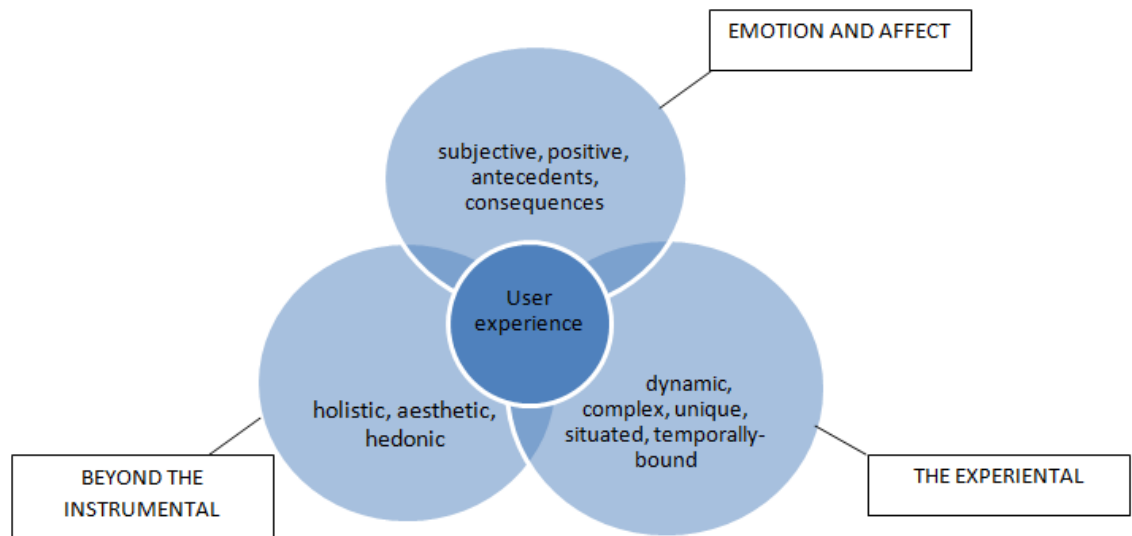
#### **2.6.2.2 MODELS OF TECHNOLOGY USE**

As previously acknowledged, the use of technology is ubiquitous in our society and the application of technology is constantly increasing. The experience of using technology within the research environment is of utmost importance as our interactions with technology is an experience within itself and '*can involve emotion, values, ideals, intentions and strong feelings*' (McCarthy & Wright, 2004, pg. 2) no matter what the purpose of using the technology is.

'*User experience*' is a term widely used in the field and is connected with a variety of meanings from the usability of the technology to emotional aspects of use, with its definition varying in the literature (Hassenzahl & Tractinsky, 2006, see figure 4).



**Figure 4: The model of User Experience proposed by Hassenzahl & Tractinsky (2006)**



Hassenzahl & Tractinsky believe that engagement with technology goes beyond usability itself and they have proposed three important components of the user's experiences of technology use. Firstly, the individual's internal state can determine whether or not they use a piece of technology (*'emotion and affect'*), as well as affecting their experience whilst using the technology. The individual's mood, motivation, requirements and expectations can all affect their experience. Additionally, the product design can affect user experience (*'beyond the instrumental'*). For example, the complexity of the product, as well as the design and functionality of the product are all of utmost importance. Finally, the environment in which technology is used can affect the individual's experience (*'the experiential'*). The authors specifically focus on the setting of the product's use, its meaningfulness as well as the voluntariness of use (Hassenzahl & Tractinsky, 2006). The authors state that it is the interaction between these three components that determine the acceptance of technology and the user's experience.

As well as focusing upon the *'user experience'* itself, research has specifically looked at the acceptance and use of technology by exploring behavioural intentions of taking up a new technology. Much of the work focusing upon exploring behavioural intention of technology use, and the user experience, has been done within the field of information technology (I.T.), specifically work-based I.T., in order to establish what affects individuals' intentions of using technology in the workplace (Venkatesh, *et al.*, 2003). The basis of these models of acceptance and use of technology is shown below in figure 5.

**Figure 5: Basic concept underlying User Acceptance Models (Venkatesh, Davis, Morris & Morris, 2003).**

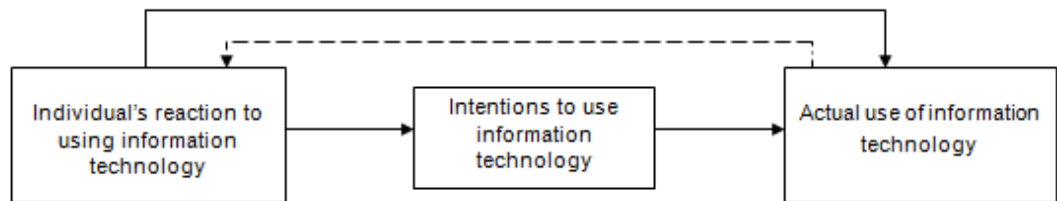


Figure 5 shows that the initial reactions to using the technology play a major role in uptake and can directly affect *actual* use of the technology. Moreover, *actual* use of the technology affects the individuals' initial reactions of the technology. Finally, intentions of using the technology are highly important; behavioural intention is directly affected by individuals' initial reactions, which subsequently affects *actual* use of the technology.

The *Technology Acceptance Model* (TAM, Davis, 1989) was the first model to explore use of technology with intention or usage as the intended outcomes. The TAM located perceived usefulness and perceived ease of use as direct determinants of behavioural intention and therefore use of technology. The TAM has since developed into the TAM2 (Venkatesh & Davis, 2000) and finally the TAM3 (Venkatesh & Bala, 2008) to include additional dimensions, and moderators of behavioural intention and use. One important addition to the TAM2 and TAM3 models is the addition of social influences and rather than intention and use of technology being solely down to individual factors, the models acknowledge the importance of others' views upon use. Finally, the most comprehensive model of behavioural intention and use of technology and I.T. is the *Unified Theory of Acceptance and Use of Technology* (UTAUT, Venkatesh, *et al.*, 2003). The UTAUT integrates eight fragmented models in the aim of creating one unified theory of behavioural intention and usage behaviour (please see chapter 4, section 4.3.6.1 for more information about the constructs within the UTAUT).

Models of behavioural intention have been used in a variety of settings. For example, the UTAUT has been used to investigate factors affecting use of mobile e-books (Gao & Deng, 2012), students' acceptance of tablet PCs (El-Gayar & Moran, 2006) and also the use of 3G mobile communication by users in Taiwan (Wu, Tao & Yang, 2008). Due to the sudden rise in the development of life-logging technologies, including wearable cameras, there is a lack of research exploring the acceptance, use and experiences of using life-logging technologies. Due to this lack of research, there are no models looking at the intention of using life-logging technology, or wearable systems. Therefore the models looking into use of I.T. systems, such as the TAM and UTAUT, are the most appropriate models to explore the acceptance, use and experiences of using life-logging technology until future development of additional models in the specific field of life-logging. Furthermore, these models are primarily based upon work-related I.T. therefore the primary focus of the models were principally of a working age. Although the research surrounding these models has expanded their focus they continue to exclude older adults from their research.

### 2.6.2.3 OLDER ADULTS' USE OF TECHNOLOGY

Older adults' use of technology is important to consider within models of technology use as interaction with technology, such as assistive devices and mobile phones, can be a daily occurrence for some of the older population (Joyce & Loe, 2010). However, contradicting messages about the technology use of older adults prevail within popular culture. On one hand the term '*silver surfer*' (Selwyn, 2004) brings about images of older adults who are '*technologically savvy*' and computer literate, whereas contrastingly, older adults are often portrayed as luddites who '*prefer to do things the old-fashioned way*' (Rogers, Mayhorn & Fisk, 2004, pg.4).

One study has shown that home computer use declines with age from 90% of 25-29 year olds using their home computer, compared to 63% of 70-74 year olds and 39% of 85-89 year olds using their home computer, independent of compositional factors such as gender and education (Cutler, Hendricks & Guyer, 2003). The UTAUT states that age affects all dimensions leading to the intentions to use, and actual use of, technology. However, despite Cutler *et al.* (2003) taking into account the influence of compositional factors such as age, gender, employment status, education and family income, upon use of technology, the research fails to take into account the direct effect of dimensions, and moderators, within technology acceptance models such as those described in the UTAUT. Furthermore, rather than age being a sole determinant of technology use, research has found psychological traits to be more predictive of technology use than demographic details such as age and gender (Park *et al.*, 2006).

Selwyn (2004) carried out a qualitative study involving adults over 60 years old, looking at intention of using I.T. and the internet. Selwyn (2004) found that computer and internet users tended to use them for specific applications, rather than using computers, or the internet, in a dynamic way. There were various reasons for the uptake of internet use, including thoughts of perceived usefulness, such as keeping up-to-date with technological advancements, as well as the internet allowing them to remain independent, despite reductions in mobility. Furthermore, Selwyn (2004) identified the importance of others in I.T. adoption; not only did the participants' children often coerce them into originally using I.T. systems and the internet, they also often showed them how to use the systems which was of great importance to the usage behaviour. Users tended to use the computer in their home where they had support from family and friends. There were also non-computer users within the sample, of whom the vast majority were simply uninterested in using a computer. Within this qualitative study a number of factors within technology acceptance models have been identified, and strengthens the use of these models within an older population, using I.T. systems in a non-workplace environment. This study also benefits from gaining knowledge of the intentions and use of technology without confining responses to the questionnaire items of the various technology acceptance models, and allows the individuals to give in-depth answers about their technology uptake and use. However, this study did not use the UTAUT, or any other technology acceptance model, as a framework for participants' interviews, or the analysis of the findings.

Finally, one review of the literature looked at the application of the TAM, and its related models, towards technology use in older adults (Chen & Chan, 2011). Only 19 studies

were retrieved in this search and of these three related to use of the internet (Ryu, Kim & Lee, 2009; Pan & Jordan-Marsh, 2010; Nayak, Priest & White, 2010), two related to mobile communication (Conci, Pianesi & Zancanaro, 2009; Renuad & van Biljon, 2008) and two related to assistive or health technologies (McCreadie & Tinker, 2005; Yu, Li and Gagnon, 2009). The review suggests that older adults showed positive attitudes toward technology, but were less likely to use technology than younger adults. Furthermore, technology use in this population was predominantly within the home. Over the studies, perceived importance, and perceived ease of use were the most important dimensions of technology use for older adults. There were also multiple aspects of technology use that were specifically important to the use of technology in older adults, including, problems with 'biophysical characteristics' such as vision and hearing problems. This highlights an important aspect of technology use in older adults is to make sure that it is suitable for use in this population, and the term '*Gerontechnology*' is now coined for technology designed for older adults (Joyce & Loe, 2010, pg. 175).

The design of both hardware and software must be suitable for the use of older adults, for example, the sensory, motor and cognitive functioning of older adults must be acknowledged whilst designing the products (Demiris, Finkelstein & Speedie, 2001 and Rogers & Mynatt, 2003). Older adults may use technology in a different way to younger adults due to visual impairments, such as the slower processing of visual information, hearing impairments, lower speech recognition, and slower motor functions, such as the movement of a mouse on a computer (Hawthorn, 2000). As shown in this study I.T. and internet use is only one small part of technology use. '*Technology*' not only encompasses use of computers, but also assistive devices, mobile communication systems and, as previously discussed, life-logging tools. There is currently no research looking at the use of life-logging tools by older adults.

## **2.7 SUMMARY**

Our population is increasingly ageing and ageing is a topic much debated in the literature, with various psychosocial theories describing processes of ageing. The literature within chronic pain research has also provided knowledge around the experiences of chronic pain in older adults and the differences of the chronic pain experience within the older population suggest that the assessment, management and function of chronic pain in the older population should be looked at separately, as in this thesis.

The functioning of older adults can be greatly impacted as a result of living with chronic pain, including restricting general movement and Activities of Daily Living (ADL), as well as having both a personal and social impact. The functioning of individuals living with chronic pain has been measured using a variety of tools, including ambulatory measures, however, the use of pedometers and accelerometers can be problematic in the older population due to slower walking gait. Self-report measures are also used in this area but a systematic search has shown that diaries have not been greatly used in studies solely looking at older adults living with chronic pain. One innovative method of exploring functioning is life logging, a way of using technology to capture multiple aspects of daily life. Using models of technology use may help to explore the use of life logging tools in the older population, as this has not been previously looked at.

The literature review in chapter 2 has set out the backdrop of research focusing on the effect of chronic pain on daily functioning. It is clear from the studies within this literature review that studies focusing on the effect that chronic pain has on the daily functioning of older adults is lacking, with much research currently focusing on younger adults, or encompassing a wide age range. This lack of research therefore highlights the importance of focusing on older adults in this area. Furthermore, the literature review has also acknowledged the small amount of qualitative research focusing upon functioning. Much of the qualitative data highlighted in this literature review has been taken from studies that have explored the general experiences of individuals living with chronic pain, of which some of that information has crossed over into the area of functioning. Of the research specifically focusing upon the functioning of individuals with chronic pain, it is evident that chronic pain does affect daily living, with some studies specifying what specific tasks are affected by pain. However, this research does not go into any further information, such as, how the tasks have been affected, why tasks have been affected, or how individuals feel about these tasks being affected. From this literature review it is evident that research looking specifically at the daily functioning of older adults living with chronic pain is lacking, and the information available in this area lacks details about the changes made to functioning. Therefore, based upon the available research, this study specifically aims to explore the daily functioning of older adults with chronic pain using a mixed method, in-depth, design.

This literature review has also highlighted the infancy of the research into the acceptance and use of wearable technology. Due to the recent developments of wearable technology, current research is in its initial stages with much of it focusing on potential areas that the technology could be used in and benefit. Due to the early stages of this research the use of technology in other areas has been drawn upon in this chapter, such as technology use of older adults, as well as the theoretical models of non-wearable technology adoption and use. It is clear that research into the use, acceptance, experiences and practicalities of using wearable technology is in its infancy and it is therefore useful to explore this area in an in-depth way. The literature review conducted in this chapter has therefore provided a rationale for the qualitative, in-depth analysis of Part B of this study.

Chapter 2 initially reviewed the literature surrounding ageing and chronic pain before going on to explore daily functioning and explain its relationship to older adults with chronic pain. The second part of this chapter discussed the use of diaries as a measurement tool in this area of research before introducing life-logging technology and their potential use in health research. In addition to the general use of life-logging, models of technology use and older adults' use of technology was discussed due to its prominence within this thesis.

## **CHAPTER 3: METHODOLOGICAL CONSIDERATIONS**

### **3.1 OVERVIEW**

In this chapter the aims, chosen research paradigm, philosophical underpinnings, methodological approach and considerations of rigour of the study will be explained and justified.

### **3.2 AIMS**

#### **3.2.1 PART A**

The daily functioning of older adults living with chronic pain can be affected on a daily basis. Part A of this PhD explored a range of day-to-day patterns of functioning and experiences of older adults living with chronic pain. Specifically, Part A explored the areas of functioning outlined in the International Classification of Functioning, Disability and Health (ICF, WHO, 2001, see section 1.2.3). The first objective of Part A looked at the '*activities*' and '*participation*' of older adults with chronic pain based upon the components described within the ICF. The second objective of Part A investigated the impact of '*personal factors*' upon '*activities*' and '*participation*' of older adults living with chronic pain, as described in the ICF. Finally, the third objective of Part A looked at the impact of '*environmental factors*' upon '*activities*' and '*participation*', as described in the ICF.

#### **3.2.2 PART B**

Advancements in technology and research methods have provided new ways to measure daily living. There were two aims within Part B of this study. This first aim was to explore the *usability*, *acceptance* and *experiences* of the Sensecam and the LifeShirt. The second aim of Part B was to investigate the *practical issues* that the participants faced whilst using the technology.

### **3.3 RESEARCH PARADIGM**

This study followed a mixed methods design in which both qualitative and quantitative approaches were used to explore one broad research aim. Mixed method designs are becoming increasingly used within healthcare research (Hadi, Alldred, Closs & Briggs, 2013). Mixed methods can be particularly beneficial, and looked upon favourably, within applied health care research as mixed method approaches can allow a deeper insight into issues and can facilitate the understanding of complex experiences in new ways (Dures, Rumsey, Morris, & Gleeson, 2010; Mason, 2006a; Sandelowski, 2000).

Due to these advantages, mixed methods has been referred to as a '*third paradigm*' that '*will provide the most informative, complete, balanced, and useful research results*' (Johnson, Onwuegbuzie, & Turner, 2007, p.129). The use of various methods, and data analyses in mixed methods allows an exploration of the research question from multiple standpoints, and it is the use of these multiple standpoints that permit the researcher to understand a phenomenon in an enhanced way, building a richer account of the issue being studied (Dures *et al.*, 2010; Gray & Malins, 2004).

Moreover, using a mixed methods approach can merge the advantages of both quantitative and qualitative research, whilst overcoming the weaknesses of using each approach on its own (Hadi, *et al.*, 2013).

This study utilised a *'fixed design'* within its mixed method approach, in that the use of mixed methods was in the original design of the study, and did not emerge during the research process (Creswell & Plano, 2011). This fixed design was implemented *'concurrently'* in that all of the study's components were designed to be implemented at same time, at the beginning of the research process rather than one set of quantitative data influencing another set of qualitative data, or vice versa (Hadi, Alldred, Closs & Briggs, 2014). Furthermore, a *'QUAL+quant'* approach was taken in that both qualitative and quantitative analyses were carried out simultaneously, investigating the same research question, however the qualitative aspects of this study are more dominant as the aim is inductive in nature (Morse & Niehaus, 2009). This *'QUAL+quant'* approach has also been termed as an *'embedded design'* (Greene & Caracelli, 2003). Despite the importance of daily functioning and experiences within this study it is not to say that this was the only thing the study aimed to investigate, and any other significant aspects relating to chronic pain were also of utmost importance. This study (both Part A and Part B) was explorative and did not begin with a hypothesis, unlike studies following a quantitative method. This is certainly not to say that the quantitative aspects of the study were analysed less rigorously, or have less importance, than the qualitative parts, however the emphasis is on a *'qualitative approach'* due to the nature of the research aims. The purpose of the study was not only to look at *'what'*, in terms of the patterns and experiences of functioning, but also *'why'* and *'how'*. Furthermore, the sampling approach used, i.e. a small, purposive sample, replicated that of a qualitative study in that the study was idiographic in nature, and therefore the data from each participant was explored in great depth (see section 4.2.2).

The definition of a *'mixed method approach'* is very broad due to it being a reasonably new approach (Hadi *et al.*, 2013), and researchers utilise a mixed methods design for various reasons. Mason (2006) articulated six strategies for using mixed methods; mixing methods for depth to the analysis, mixing methods due to having more than one research question, mixing methods to answer the connected parts of one research question, using mixed methods as a form of methodological triangulation, using mixed methods to ask different, but intersecting, questions and, finally, mixing methods *'opportunistically'* (Mason, 2006, pg. 11). This study, according to the definitions provided by Mason (2006), used mixed methods in order to answer the connected parts of one research question. Mason (2006) describes this type of mixed methods design as:

*'a way in which different methods may be deployed because each is felt to be the best suited to its own specific part of the problem being researched, and because in combination they give a better sense of the whole' (pg. 6)*

Part A of this study aimed to *'explore a range of day-to-day patterns of functioning and experiences of older adults living with chronic pain'*. Due to the aim, using a mixed-method approach in the way explained by Mason (2006) was beneficial for this study as it allowed numerous factors of *'daily functioning'* to be explored from numerous

perspectives, using different data collection methods, and therefore different data analysis techniques, before all of the data was brought together and analysed using '*interpretative integration*' (Dures, *et al.*, 2010). By analysing all of the methods separately, and as all methods were of equal importance, this type of mixed methods analysis allowed the weaknesses of each method to be compensated by the strengths of the other methods allowing a stronger analysis to be undertaken (Rohner, 1977).

However, the definition that Mason (2006) provides is not consistent throughout the literature, for example, Hadi, *et al.* (2014) defined this type of mixed-method design as '*expansion*' whereas other mixed-method researchers define '*methodological triangulation*' in this same way. Mason (2006) highlighted the way in which the definition of triangulation has become '*limp*' (pg. 8) and specifically described the use of triangulation as being '*different forms of data and method...used to corroborate what they are measuring, and sometimes to corroborate each other*' (pg. 8). However, this is not the only definition of methodological triangulation with some researchers stating that this method of triangulation should be used cautiously (Morse, 1991). Contrary to Mason's (2006) definition of methodological triangulation it has also been described more generally as aiming to ensure that the research problem is viewed in an extensive fashion whilst acknowledging that objective reality can never be fully depicted (Flick, 1992). This study did not use triangulation as a way of validating any of the methods used, or the data retrieved from that method (as described by Mason, 2006); the methods were not used to contradict each other, or validate one another, instead, using multiple methods allowed information to be explained, and more depth gained.

In combining the methods in this integrative way using either Mason's definition, or definitions used by other researchers, it ensured that information from numerous areas of functioning was captured, and was done so in a way most suitable to each aspect of the aim. However, if this integration is done ineffectively, the value of carrying out mixed methods research in this way can be low (Mason, 2006).

### **3.4 PHILOSOPHICAL ROOTS**

The philosophical underpinnings of this research are based on its research design being that of mixed methods, however, there are some limitations to the use of mixed methods. Historically within Social Sciences, and other research areas, quantitative and qualitative methods have been distinct from one another and many academics and philosophers believe that both quantitative and qualitative research are incompatible due to their contradictory paradigms (Cresswell, 2004; Greene, 2006) and philosophical differences (Depoy & Gitlin, 2011). Therefore, one limitation of mixed methods research is that its philosophical roots are heavily fragmented due to combining contradictory ontologies and epistemologies. With this in mind, this study is underpinned by Critical Realism (Bhaskar, 1975); an ontology which accepts that reality is constructed but that it is also objectively experienced and can be explored in that context. Critical Realism is therefore an overarching methodology which is open to be used for research involving both quantitative and qualitative data.

In this mixed methods study the concepts of '*realism*' and '*relativism*' both played a major part and it is naive to suggest that either pure realism or pure relativism was a suitable fit as the ontological positioning of this research. Furthermore, the Critical



Realist perspective that underpins this study articulates that different methods, and sources of data, will represent different aspects of the individual, and the individual's perceived reality, but this is not to say that it is inaccurate, or incorrect. All of the methods used in this study were used to complement each other, and provide more information about that individual from a different perspective.

As an ontology, *Critical Realism* is 'post-positivist' and is situated in an anti-positivist movement in the social sciences (Denzin & Lincoln, 2011). *Critical Realism*, primarily developed by Bhaskar (1975), distinguishes between objective reality, and socially developed knowledge, essentially making an argument that the objective reality that we live in is socially constructed by individuals (Denzin & Lincoln, 2011). Whereas positivism claims that a reality exists which can be studied and comprehended, post-positivists believe that although this reality exists and we can gain access to this reality, reality itself can never be fully understood (Guba, 1990; Baert, 2005). According to *Critical Realism*, an objective reality exists without the interference of human beings, and without human beings this reality would still exist; Bhaskar labels this '*intransitive objects of knowledge*' (Bhaskar, 1975). It is within this objective reality that socially constructed knowledge is located and is based upon personal input, subjective experiences and interpretations. Bhaskar (1975) refers to this knowledge which individuals produce within their own social situation as '*transitive objects of knowledge*' (Bhaskar, 1975).

This study further fits in with the framework of *Critical Realism*, as *Critical Realism* is based on the assumption that observations from different sources will result in different representations of the individual and the individual's experiences. As reality cannot be fully understood it suggests that the use of several methods allow a critical examination of the problem from multiple perspectives and is needed in order to enhance understanding of reality as much as possible. Furthermore, *Critical Realism* is 'fallibilist' in that it can be proven wrong upon further inspection of the situation, using different modes of enquiry (Benton & Craib, 2011).

*Critical Realism* was the most appropriate ontological perspective for this PhD as the views regarding the basis of reality and knowledge were very much congruent with my own views and those of the study; reality exists independently to humans and reality cannot be fully understood. However, using multiple data collection methods allows a deeper look at the individual's experiences of living with pain and their day-to-day functioning as much as possible. Furthermore, this study is also interpretive and *Critical Realism* (post-positivism) falls into one of the major interpretive paradigms (Denzin & Lincoln, 2011).

This study is based upon an *interpretivist* (hermeneutics) epistemology. The study is interpretive due to the ontology that underlies it (*Critical Realism*) and its emphasis upon *transitive objects of knowledge* (Bhaskar, 1975). Of course this transitive knowledge, or individual perceptions, that I am discussing in regards to this study are those of the participants that took part in the study; older adults living with chronic pain. The exploration of this subjective knowledge is accomplished when interpreting the data retrieved from the study, and analysing it in much detail.

*Hermeneutics* is the philosophical underpinning of interpretation, within the epistemology *interpretivism*, and originates from Greek meaning 'to interpret' or 'to understand' (Crotty, 1998). *Hermeneutics* 'is defined accordingly as a method for deciphering indirect meaning, a reflective practice of unmasking hidden meanings beneath apparent ones' (Kearney, 1991, p. 277). *Hermeneutics* aims to allow an understanding of the text in a deeper way than the participants' own understanding of it (Crotty, 1998). There are two concepts of *hermeneutics* that are very much evident within this study; the *hermeneutic circle* and *double hermeneutics*. The *hermeneutic circle*, or 'the circle of understanding' (Heidegger, 1962, p.195) refers to interpreting data both wholly and individually; the dynamic association between the individual of the data and the whole data at numerous levels (Smith, Flowers, & Larkin, 2009). In order to understand, and interpret, the data it is important to look at the data in individual parts, and then look at the data as a whole, continuously moving between both concepts of the data (Crotty, 1998). This process is ongoing, therefore circular, and enables the researcher to understand the data better. Additionally, hermeneutic philosophers explore *double hermeneutics* which involves the researcher interpreting the participants' interpretations of their own world. This double hermeneutical analysis comes around as I, as the researcher, use my own subjective 'transitive' knowledge to interpret the subjective 'transitive' knowledge of the participant. I was mindful of both the hermeneutic circle and double hermeneutics within this study.

Rather than simply describing the information collected within this study, the information was also interpreted. This was due to two main reasons. Firstly, *interpretivism* is an appropriate epistemology for the ontology that underpins this study in that individuals hold transitive, subjective knowledge, and interpretation is beneficial to look at this. Secondly, there were three different types of data collected within this PhD (without the LifeShirt data) and it was my task to integrate these findings after separate analysis was undertaken in order to develop one narrative. Therefore I used interpretation, as well as the *hermeneutic circle*, to pull together the different findings to gain one synchronised narrative.

### **3.5 METHODOLOGICAL APPROACH**

Each perspective, quantitative and qualitative, bring with them their own philosophical assumptions and it is important to combine these perspectives in order to develop a methodology that is appropriate for a mixed methods study, whilst at the same time recognising the philosophical domain from which it was developed (Bowling, 2002). Of course the use of a mixed methods approach uprooted a whole host of philosophical debates around the epistemology, ontology and methodology of the study due to the duelling philosophical assumptions of both paradigms, as discussed above. Quantitative research is deductive, objective, and follows a 'positivist' underpinning whilst aiming to systematically analyse data in numerical form. Contrastingly, qualitative methods are inductive, subjective, and are often interpretive. Rather than data being analysed in numerical form the data is often dealt with as written text, and explored in much depth.

To distinguish a single traditional methodology such as *Phenomenology*, *Grounded Theory* or *Ethnography* which accurately fit with the research paradigm and method that the study used was difficult, due not only to the use of a mixed methods approach,

and the conflicting assumptions of a mixed qualitative and quantitative enquiry, but also methodological triangulation, as each of the assumptions of the three methods and therefore the three techniques of the data analysis in Part A, are contradictory. The research project shares similarities with multiple methodologies but does not specifically fit into one accurately. For example, this study could be seen as somewhat ethnographic due to the use of observation strategies in multiple forms, as well as the use of a semi-structured interview. However, there is no direct observation involved, and the researcher was not physically present within the social setting of the project. Similarly, the project resembles phenomenology in that it is focused on the individuals' experiences, specifically, this project is reminiscent of hermeneutic phenomenology, and Interpretative Phenomenological Analysis (IPA), in that it is very much interpretive. However, this study is not entirely phenomenological due to the use of mixed methods. Phenomenological analysis involves gathering '*rich*' data using techniques such as interviews, free-flow diaries, and in some instances, focus groups, however some of the methods used in this study do not reflect this.

Finally, *Grounded Theory* as a methodology could have been useful within this project as it follows a rather realist ontology, however the aim of the study was explorative, and did not aim to generate theory. As well as the problems listed, *Ethnography*, *Phenomenology*, and *Grounded Theory* reject the concept of positivism, and the reduction of human behaviour to numerical outputs. Although this research aims to study behaviour in an explorative manner, and does not follow a positivist position, some of the data collection tools are quantitative, therefore the study does not completely fit any of the methodologies. Therefore, this research is not based on a '*purist*' methodology but is based upon the Generic Qualitative Research method defined by Caelli, Ray and Mill (2003).

Caelli *et al.* (2003) proposed generic qualitative research which focuses on understanding experience and either combines numerous methodologies or approaches, or alternatively does not follow any methodological perspectives. This research adopted the first stance, in that numerous methodological viewpoints were examined and followed, allowing an analysis of phenomena that was unrestricted by the methodology it followed. This was due to there being three distinct methods and data analysis procedures within Part A. Within Part A one of the methods was entirely quantitative (Daily Reconstruction Method), whereas one method was mixed in itself (Sensecam), and one of the methods was entirely qualitative (semi-structured interview). Part B was solely qualitative and based upon a semi-structured interview, although this interview is semi-structured around a quantitative questionnaire. Due to there being dissimilar analyses used between the components in Part A and Part B of this research it was necessary to adopt a generic philosophical position ensuring the outcomes of the research were not restricted by the methodological philosophies adopted.

Due to the heightening use of qualitative research that does not follow an established philosophical basis, or does not state the philosophical background of the research, Caelli *et al.* (2003) set out four guiding principles which, if followed, ensure that the researcher fully explores the philosophical underpinnings of the study. These guiding principles are requirements proposed by the authors to ensure rigorous and reliable qualitative research; '*the theoretical positioning of the researcher*', '*the congruence*

between methodology and methods', 'the strategies to establish rigour' and 'the analytic lens through which the data are examined'. All of these issues have been discussed in detail throughout this study (see table 5, below, for an explanation of each guiding principle, and the section in which it is discussed within this study).

<u>Key area</u>	<u>Description</u>	<u>Chapter in thesis</u>
1. The theoretical positioning of the researcher	This refers to the 'researcher's motives, presuppositions, and personal history' that leads him or her toward, and subsequently shapes, a particular inquiry' (Caelli, et al., 2003, pg. 10).	This is discussed within a reflective piece based on the reflective diary written throughout the project.  <b>Section 7.4</b>
2. The congruence between methodology and method	The methodology and method must be clearly distinguished from one another and both should be distinctively explained and clarified.	The research paradigm and the methodology is fully explained, as well as the justification of their use in this thesis.  <b>Chapter 3-4</b>
3. The strategies to establish rigour	The approaches needed to establish rigour need to be discussed thoroughly.	Rigour for each of the four methods are explained.  <b>Section 3.6</b>
4. The analytic lens through which the data are examined	'The methodologic and interpretive presuppositions that a researcher brings to bear on his or her data' (Caelli et al., 2003, pg. 17).	The epistemology and ontology, and all of the issues related to this is fully explored in relation to the thesis.  <b>Section 3.3</b>

**Table 5: Four key requirements of Generic Qualitative Research produced by Caelli, Ray and Mill (2003)**

### **3.6 RIGOUR**

Rigour is an important aspect of qualitative research, and is even more so important within interpretive research. Rigour can be described as the 'resulting completeness of the data collection and analysis' (Yardley, 2000, pg. 221). However, rigour is much debated within qualitative research with much criticism being on researchers forcing quantitative, positivist rules to qualitative research to justify their work (Angen, 2000). Rigour is difficult to establish within interpretive, qualitative work as this data will be analysed differently when more than one researcher examines it as 'reality is assumed to be multiple and constructed rather than singular and tangible' (Sandelowski, 1993, pg. 3). One way of ensuring that qualitative data is rigorous is to

explicitly set out the analytic process, and allow the researcher to reflect on their thought processes throughout the entire research process including data collection and analysis. However, whilst it is important to ensure that the research is rigorous, it is essential to remain aware that qualitative research will always be subjective, with alternative interpretations always being achievable (Willig, 2008).

One technique that is often used to improve rigour in analysis and interpretation of research findings is to set-aside their own subjective knowledge during the analysis process, this is known as '*bracketing*'. Bracketing is a technique originally discussed by Husserl (1927) within Phenomenology in which researchers extract, and put to one side, their own subjective knowledge in order to be able to look at the perceptions of others more accurately (Smith, *et al.*, 2009). Some academics believe that a researcher can bracket their own judgements of the researched by writing down all of their preconceptions of, experiences with, and past knowledge of, the research area. However, this is a method much debated by qualitative researchers as many, including myself, believes that one can never completely take away the knowledge and biases of the researcher themselves. Similar to Heidegger's thoughts on bracketing it is seen within this study as a recurring process which can never be fully achieved by the researcher (Smith, *et al.*, 2009).

Rather than bracketing, a '*reflexive*' piece has been conducted within this study in order to show my thoughts throughout the research process, as well as describing the research and analytic process in much depth. This is also known as '*thick description*' or an '*audit trail*' (Ballinger, 2006). However, this reflexive process has been conducted in order to show the reader my thought-processes, and to describe the analytic processes within the study, it has not been carried out to initiate the researcher's objectivity from the research akin to bracketing (Gadamer, 1994). Rather than trying to separate my own subjective knowledge, reflexivity allowed me to bring to light any aspects of my own knowledge around the subject area, as well as changes throughout the project (Bergum, 1991). For example, I was reflexive regarding past education and experiences that may have affected knowledge of life-logging, older adults, and/or chronic pain, preconceptions of the field, method, and/or expected outcomes, and personal experiences of life-logging, chronic pain, and/or older adults. Throughout the study any thoughts that I had regarding the project, and about the way in which it was heading was logged and reflected upon in a reflexive journal. The reflexive piece also includes information regarding any thoughts on the methodology, method, and experiences throughout data collection and data analysis (see section 7.4).

Reflexivity is an important process within qualitative research, specifically interpretive research, as evidence of the thoroughness of the interpretations and analysis helps the reader to understand the interpretive analytic process therefore establishing some rigour within the research (Madison, 1988). Whilst writing this reflexive piece does not rid me from subjective biases, and subjective interpretations, the process allowed me to become mindful of my own thoughts throughout the process of the study. Rigour was a concept that I was mindful of throughout the research process, and developing a reflexive diary allowed me to explore my own thought processes, explore any changes in my thoughts, and also allowed me to log each step of the analysis process. This was then reflected upon, and written explicitly for the reader to see.

### **3.7 SUMMARY**

This study has two parts (Part A and Part B) which reflect the aims of the study. Part A aims to explore the day-to-day patterns of functioning and experiences of the older adults with chronic pain. Part B aims to explore the usability, acceptance and experiences of using the two pieces of technology used to measure functioning in Part A (i.e. the Sensecam and the LifeShirt).

This study is based upon Critical Realism ontology and Hermeneutic epistemology. Both Critical Realism and Hermeneutics underpin this study and provide the theoretical backdrop for which this study is placed. Furthermore, this study used mixed methods, although it is based on a predominantly qualitative approach due to the explorative aims of the research. Finally, the methodology of Generic Qualitative Research is being used as this acknowledges the combination of numerous methodologies and approaches, therefore fitting this research. Rigour is important within qualitative, interpretative methodologies and I have prepared a reflective piece within this study to acknowledge my own views and my importance as a researcher within the study.

The design and methods used in this study are comprehensively informed by its philosophical underpinnings. The assumptions from the Critical Realist ontology allow multiple methods to be used, from numerous perspectives, therefore allowing the adoption of a mixed-methods design. This heavily influenced the methods that were chosen as part of this study, as it meant that the methods were not restricted by the type of data that was collected or the way that they were analysed (quantitative or qualitative). This allows the aims of the study to be answered using more than one tool, from more than one perspective. A hermeneutic epistemology influences the use of multiple methods further by allowing these methods to be integrated into one narrative, using interpretation to do this. Finally, using a generic qualitative methodology (Caelli, *et al.* 2003) allows the theoretical freedom to use various methods, and analyses, whilst remaining rigorous, and reflecting the ontology and epistemology. Overall, both the ontology and the methodology led towards the use of a mixed methods design that was not restricted philosophically, whereas the epistemology allows all of these analyses to be integrated together as one. The philosophical underpinnings of this study influenced the choice of methods in this study by allowing a broad range of tools to be used, from various perspectives, without restriction. This allows the aims to be analysed broadly, from multiple perspectives.

This chapter has discussed the aims, objectives and methodological considerations of this study. Specifically, the Mixed Methods paradigm was discussed. Furthermore, the rationale for using Generic Qualitative Research methodology was explored, as well as an exploration, and justification of the philosophical roots that guided this study (i.e. Critical Realism and hermeneutics). Finally, the concepts of rigour and reflexivity in qualitative research were discussed and an explanation of how they were incorporated in this study was provided.

## **Chapter 4: Method**

### **4.1 OVERVIEW**

This chapter presents the method of Part A and Part B of this study. The design, sampling method, ethical approval, instrumentation and procedure for both part A and part B are explained within this chapter. Additionally, this chapter sets out the justification for using each of the methods in Part A and Part B, as well as explaining the processes to each of these analyses.

### **4.2 PART A**

Part A of the study aimed to explore a range of day-to-day patterns and experiences of functioning in older adults suffering from chronic pain.

#### **4.2.1 DESIGN**

A mixed method design was used for part A. Part A was made up of three data collection methods; the Daily Reconstruction Method, the Sensecam and a semi-structured interview. The LifeShirt was also used in the design. Although the LifeShirt data was not analysed, participants were asked to wear it as part of the method.

#### **4.2.2 SAMPLING METHOD**

A purposive sample was used in which I chose the most suitable participants from those that volunteered. Purposive sampling was used in order to involve individuals with a range of experiences including individuals who suffered pain in various pain regions and for various lengths of time, individuals with different living circumstances, different ages and genders. Snowball sampling was also used in order to reach individuals who may not have otherwise been recruited from the community groups that I approached, therefore it was a practical sampling strategy used to enhance the number of people who were informed about the study. For this, individuals from the social groups acted as an initial contact to communicate information about the study to others, and these participants were then able to contact me if they wished to hear more about the study.

Individuals were excluded if they were awaiting surgery or had recently undergone surgery (<6 months). Individuals with cancer-related pain were also excluded. Individuals with cancer-related pain were excluded for a number of reasons. Pain related to cancer can differ in its origin, for example, pain can sometimes arise from the presence of a tumour, or because of the treatments being received to treat cancer (American Society of Regional Anaesthesia and Pain Medicine, 2010). Furthermore, the daily effects of cancer pain can be more severe due to the presence of cancer, or its treatment, such as fatigue (Cancer Research UK, 2013). Finally, the intensity of cancer-related chronic pain can increase at a much more rapid pace than non-cancer related pain (American Society of Regional Anaesthesia and Pain Medicine, 2010; British Pain Society, 2010; Cancer Research UK, 2013). Individuals were also excluded if they self-reported a diagnosis of dementia, had an allergy to adhesives

and/or the gel used to attach the electrodes (for the LifeShirt that had been used in the procedure), or did not have the ability to press the buttons to use the equipment. All participants needed to be able to give full consent, and also needed to be able to understand all of the instructions and therefore needed to speak English.

A core sample of 15 older adults with chronic pain was gathered of which the results were primarily based upon. All of these individuals must have been over 65 years old, living with chronic pain for three or more months, retired and living in the community. In order to gain some insight into the effect of pain, as opposed to age, upon functioning, two younger adults with chronic pain were recruited. Both participants must have been younger than 65 years old, living with chronic pain, working, and living in the community. Finally, in order to gain some insight into the effect of age, as opposed to chronic pain, upon functioning, two older adults without chronic pain were also recruited. Both participants must have been over 65 years old, with no pain, retired and living in the community.

Participants were recruited from various organisations; the University of 3<sup>rd</sup> Age, Age UK, and other local groups including local lunch and dancing groups. The organisations were approached and those that wished to take part allowed me to talk to the group about the study. Individuals that were interested were then able to approach me and were given further information about the study, i.e. the Participant Information Sheet (see section 4.2.3.2, below). Participants were then able to contact me if they wished to take part using the contact details on the Participant Information Sheet.

Participants that were recruited using the snowball sampling strategy were given the information (either verbal or written) by a correspondent that had attended one of the groups. That individual then contacted me with their wishes to take part. I then sent them the Participant Information Sheet, unless they already had hold of one. The individual then had the opportunity to consider taking part in the study and contact me again once they were fully happy to take part.

### **4.2.3 ETHICAL APPROVAL**

Ethical approval was granted for this study by the School of Health and Social Care Research Governance and Ethics Committee at Teesside University (see Appendix B). Before agreeing to take part in the study individuals were asked to read the Participant Information Sheet (see section 4.2.3.2, below). The individual was encouraged to ask me any questions they had about the study. Once individuals were happy to take part in the study both verbal and written consent were obtained for all participants who met the inclusion criteria (see section 4.2.3.3, below).

#### **4.2.3.1 ETHICAL CONSIDERATIONS OF THE SENSECAM**

There is an ongoing ethical debate surrounding the use of the Sensecam in research, and something that requires much acknowledgement. I was mindful of the ethical considerations of the Sensecam from the offset and there were many considerations that I made before applying for ethical approval and using the Sensecam. In order to ensure that I was aware of the various ethical issues when using the Sensecam I questioned various academics, from various institutions, when I attended the second Sensecam symposium, held in September, 2010. The academics had previous



experiences of using the Sensecam and were able to advise me of the various ethical considerations that they had considered.

There were a number of considerations that were made in this study and steps that were put into place to minimise the ethical concerns of using the Sensecam. Whereas most of these concerns centred around the images and intrusiveness of the Sensecam, there was also some apprehension in the event that the Sensecam was forcibly removed from any of the participants during use. This was dealt with by ensuring that the Sensecam had two clips, one on either side of the lanyard, that would snap open and release the Sensecam if pulled.

In terms of the intrusiveness of the images, the privacy of the participants, and any of the others in the images, was of upmost concern and there were a number of steps were taken to ensure that the participants had control of the images that were recorded, and shown to the research team.

Firstly, individuals were informed that they were able to delete any images that they did not wish to be seen by anyone. If they had recorded any images that they did wish for anyone else to see, the participants were able to view these on the laptop at the end of the study week, and delete any unwanted images that they did not wish to be seen, or analysed, by any member of the research team. Furthermore, individuals were notified at the beginning of the study, both orally and on the Participant Information Sheet, that they should either press the privacy button, or remove the Sensecam, during periods in which they did not want to take any photographs. All participants were also shown how to use the privacy button at the beginning of the study. Participants were constantly reminded that they should only use the Sensecam at times when they felt comfortable doing so, and were encouraged to either use the privacy button, or remove the Sensecam, at any time. Finally, the participants were given a number of note cards, and one of these note cards was attached to the back of the Sensecam. The note cards were used if any member of the public questioned the Sensecam. Rather than the participants themselves having to explain the Sensecam, the note cards gave a brief description of its purpose and also gave the contact information of Professor Denis Martin, if these individuals wanted to receive any further information.

As well as the privacy of the participants themselves, the privacy of other people in the images, known as '*secondary participants*', was of great importance. Once more, there were a number of steps that were taken in order to minimise the intrusion of these individuals. Firstly, the participants were informed in the Participant Information Sheet, and verbally, that they must remove the Sensecam in specific places; GPs office, schools or swimming pools. Participants were also told to inform others of the Sensecam if others entered their home, or the participants entered the homes of others and if the other individuals did not want them to remain the Sensecam, they would remove it. The behaviour of other individuals was not analysed within this study.

#### **4.2.3.2 PARTICIPANT INFORMATION SHEET**

The Participant Information Sheet was given to participants and provided an in-depth explanation of the purpose of the study, set out the inclusion/exclusion criteria for participation and explained all of the equipment that participants would be asked to

use, including the privacy settings in place whilst using the camera (see Appendix C). The Participant Information Sheet also explained the procedure and any potential advantages and disadvantages of the study. Confidentiality of the data was fully explained and contact information for myself and the main researcher's supervisor was also provided.

A similar version of the Participant Information Sheet was given to over 65 year olds without chronic pain and participants younger than 65 years old with pain. The Participant Information Sheets were identical to the one described above other than the inclusion and exclusion criteria slightly differed depending upon the participant being recruited.

#### **4.2.3.3 CONSENT FORM**

The consent form asked participants to initial several boxes; to confirm that they had read the Participant Information Sheet, had agreed to take part, they fitted the inclusion criteria and did not meet the exclusion criteria, that the interview would be verbally recorded using a Dictaphone and they had the right to withdraw up to two weeks after participation (see Appendix D). The consent form asked participants to initial and confirm that they were aware of the privacy issues surrounding the Sensecam including; the safety of themselves and others, when to use the camera and when not to use the camera, and when to inform others about wearing the camera. The consent form also included a section in which both the participant and I were asked to print their name, date and sign the form to confirm their participation and understanding of the study.

#### **4.2.4 INSTRUMENTATION**

##### **4.2.4.1 DAILY RECONSTRUCTION METHOD**

The Daily Reconstruction Method is a quantitative diary comprising of four sections (see Appendix E for a full, incomplete, example of the DRM). The diary was required to be completed the day after the events took place. Section one required the day of the week of which the diary was written to be recorded (see figure 6, below).

**Figure 6: Section one of the Daily Reconstruction Method (Kahneman, Krueger, Schkade, Schwarz & Stone, 2004)**

To begin, please circle the day of the week that YESTERDAY was:

Monday   Tuesday   Wednesday   Thursday   Friday   Saturday   Sunday

The second section required the time that the person woke up and the time that they went to sleep to be documented. This section also required the entrant to record a list of events that they had carried out that day, as well as the time that each event began

and ended (see figure 7, below). The list of events did not need to be given back, and the entrant was able to keep this list if they wished.

**Figure 7: Section two of the Daily Reconstruction Method (Kahneman, Krueger, Schkade, Schwarz & Stone, 2004)**

Diary of events			
Episode Name	Time it Began	Time it Ended	What happened? What did you feel?
1 _____	_____	_____	_____
2 _____	_____	_____	_____
3 _____	_____	_____	_____
4 _____	_____	_____	_____
5 _____	_____	_____	_____
6 _____	_____	_____	_____
7 _____	_____	_____	_____
8 _____	_____	_____	_____
9 _____	_____	_____	_____
10 _____	_____	_____	_____

For each event recorded in section two, a two-page form was completed in section three which expanded the information given about the events (see figure 8, below). Section three provided a list of 16 tasks of which the entrant must tick the ones that had occurred during that event. There was also an 'other' section if a task was carried out which was not on the list. Participants also had to make note of their location during this episode by ticking 'at home', 'at work' or 'somewhere else'. Finally, participants had to make note of their interaction by indicating that they were either alone, or indicating one or more of the interactions from a list of nine possible interactions. Section three also required the entrant to state who they were with during the event, or if they were alone, once again by ticking the corresponding category.

**Figure 8: Section three of the Daily Reconstruction Method (Kahneman, Krueger, Schkade, Schwarz & Stone, 2004)**

**Next Episode**

**Now look at your Diary and select the episode that immediately followed the one you just rated.**

This is episode number \_\_\_\_\_, which began at \_\_\_\_\_ and ended at \_\_\_\_\_.  
 What were you doing? (please check all that apply)

<input type="checkbox"/> commuting	<input type="checkbox"/> working
<input type="checkbox"/> shopping	<input type="checkbox"/> preparing food
<input type="checkbox"/> doing housework	<input type="checkbox"/> taking care of your children
<input type="checkbox"/> eating	<input type="checkbox"/> praying/worshipping/meditating
<input type="checkbox"/> socializing	<input type="checkbox"/> watching TV
<input type="checkbox"/> nap/resting	<input type="checkbox"/> computer/internet/email
<input type="checkbox"/> relaxing	<input type="checkbox"/> on the phone
<input type="checkbox"/> intimate relations	<input type="checkbox"/> exercising
<input type="checkbox"/> other	(please specify _____)

Where were you?  
 At home       At work       Somewhere else

Were you interacting with anyone (including on the phone, via email, in person etc)?  
 no one (skip next question)

If you were interacting with someone (please check all that apply). *Please note that names should **NOT** be mentioned. Just tick the classification of the person you interacted with. If names are written this will be deleted and **NOT** used in the study.*

<input type="checkbox"/> spouse/significant other	<input type="checkbox"/> my children
<input type="checkbox"/> friends	<input type="checkbox"/> parents/relatives
<input type="checkbox"/> co-workers	<input type="checkbox"/> boss
<input type="checkbox"/> clients/customers	<input type="checkbox"/> other people not listed
<input type="checkbox"/> students/patients	

The final part of section three required entrants to complete 12 likert scales which represented emotions that they had experienced during the event; ‘*impatient for it to end*’, ‘*happy*’, ‘*frustrated/annoyed*’, ‘*depressed/blue*’, ‘*competent/capable*’, ‘*hassled/pushed around*’, ‘*warm/friendly*’, ‘*angry/hostile*’, ‘*worried/anxious*’, ‘*enjoying myself*’, ‘*criticised/putdown*’ and ‘*tired*’ (see figure 9, below). The entrant identified the extent to which the adjectives matched their emotions during the event ranging from 0 (not at all) to 6 (very much). Section three was repeated for each of the events that entrants recorded for that day.

**Figure 9: The second part of section three of the Daily Reconstruction Method (Kahneman, Krueger, Schkade, Schwarz & Stone, 2004)**

How did you feel during this episode?

Please rate each feeling on the scale given. A rating of 0 means that you did not experience that feeling at all. A rating of 6 means that this feeling was a very important part of the experience. Please circle the number between 0 and 6 that best describes how you felt.

	Not at all						Very much							
Impatient for it to end . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Happy . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Frustrated/annoyed . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Depressed/blue . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Competent/capable . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Hassled/pushed around . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Warm/friendly . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Angry/hostile . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Worried/anxious . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Enjoying myself . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Criticized/put down . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Tired . . . . .	0	1	2	3	4	5	6	0	1	2	3	4	5	6

The final section required the entrant to state how much they felt ‘in a bad mood’, ‘a little low or irritable’, ‘in a mildly pleasant mood’, or ‘in a very good mood’. Entrants were asked to score these moods with a percentage which totalled 100%. The final part of section four within the DRM required respondents to state the typicality of their day (see figure 10, below). Entrants were asked to circle one option from; ‘much worse’, ‘somewhat worse’, ‘pretty typical’, ‘somewhat better’, ‘much better’.

**Figure 10: Section four of the Daily Reconstruction Method (Kahneman, Krueger, Schkade, Schwarz & Stone, 2004)**

**A Few More Questions about Yesterday- Section 4**

Now that you have told us about your day in detail, we have a few more general questions.

**Now we would like to know overall how you felt and what your mood was like yesterday. Thinking only about yesterday, what percentage of the time were you:**

a bad mood \_\_\_\_\_%  
 a little low or irritable \_\_\_\_\_%  
 a mildly pleasant mood \_\_\_\_\_%  
 a very good mood \_\_\_\_\_%

Sum 100%

Now we'd like to know how typical yesterday was for that day of the week (i.e., for a Monday, for a Tuesday, or so on). Compared to what that day of the week usually is like, yesterday was (please circle one)

Much	Somewhat	Pretty	Somewhat	Much
Worse	Worse	Typical	Better	Better

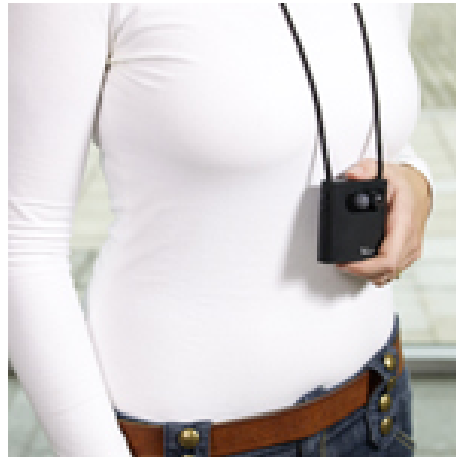
**You have now completed today's diary. Please review each question to be sure you have answered them all. Thank you very much for participating.**

The participants were given 7 blank copies of the Daily Reconstruction Method, as well as additional sheets if they were needed. The participants were also given one completed version of the Daily Reconstruction Method in order to refer to if they needed assistance filling in the diary.

#### **4.2.4.2 SENSECAM**

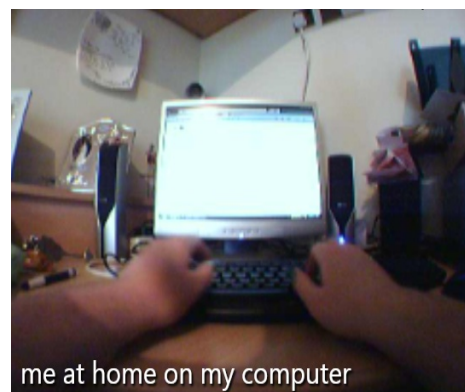
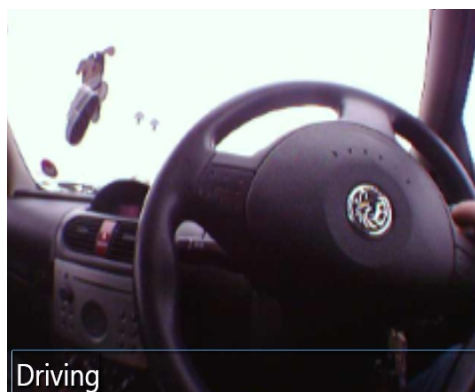
The Sensecam (Vicon©, also known as the ViconRevue) is a small camera (the size of a pack of cards) which is light (93g) and was worn on a lanyard around the neck, resting on the person's chest (see figure 11, below).

**Figure 11: The Sensecam**



The camera automatically took photographs every 30 seconds, and included a light sensor and an infrared thermal sensor. When one of these sensors were triggered an additional photograph was taken, for example, if the individual moved (detected by the light sensor) or the person came into contact with someone else (detected through body heat by the infrared thermal sensor) the camera automatically took additional photographs (Berry, et al., 2007). The Sensecam contained a colour VGA resolution sensor (640 x 480 pixels). It was fitted with a fish-eye lens to provide a full 130 degree field of view (see figures 12-15, below, of sample Sensecam images).

**Figures 12 -15: Sample images from the Sensecam**



Participants were given a Sensecam pack including the camera itself, which was on a lanyard, and a charging wire and plug in order to charge the Sensecam each evening. Participants were also given a number of note cards to give to individuals who asked about the study, or the nature of the camera. The note cards explained the purpose of the research, and contained contact details for my supervisor. As well as the Sensecam pack and the note cards, participants were also given two sets of written instructions; '*how to use the Sensecam*' which contained both text and images showing the individuals how to set up, use, and charge the camera (see Appendix F), and '*how to upload/browse/delete Sensecam images*' which used text and images to show participants how they would look at their Sensecam images, and delete any unwanted images before I could look at them (see Appendix G).

The images recorded on the Sensecam were uploaded onto a Windows PC. The images were stored on to the DCU Sensecam application software which allowed the participant, and me, to browse the images, and delete the images if necessary (<http://sensecambrowser.codeplex.com>). The software was downloaded from the internet and was private therefore it could not be viewed on any other user.

#### **4.2.4.3 LIFESHIRT**

The LifeShirt (Vivometrics®) is a wearable monitoring system which enables the recording of respiration, electrocardiograph (ECG) and body position (posture and posture transition) data (see figure 16, below). The jacket was a light-weight (8 oz.) item of clothing worn underneath normal clothes, on top of underwear in which sensors were woven around the ribcage and abdomen allowing the measurement of respiratory function. Accelerometer data was collected on the anterior surface of the abdomen using a three-axis accelerometer recorded the individual's posture and activity level. Accelerometer data was sampled at 10 Hz. A portable computer (worn in a bag around the waist) and a memory card were used to store all of the physiological and physical information during use. The portable computer was operated via touch-screen.

**Figure 16: The LifeShirt**



The LifeShirt was made up of 10 components which participants were given at the beginning of the study; a wearable jacket, three electrodes (2 placed on the chest, and 1 placed on the left side of the abdomen), one set of wires, a portable computer, a



memory card, a battery, a battery charger, a bag worn around the waist (which kept the portable computer in place) and a calibration bag and nose clip (which were used during calibration of breathing). Participants were given seven memory cards (1 per day), and they were given 24 electrodes (3 per day, and 3 extra). Along with the LifeShirt and its components, individuals also received a set of instructions which included both written information and illustrations showing participants how to set up and remove the LifeShirt and all of its components, as well as how to change the memory card on a daily basis (see Appendix H).

#### **4.2.4.4 SEMI-STRUCTURED INTERVIEW SCHEDULE**

The intention of the semi-structured interview was to explore the individual's functioning in more depth. Fundamentally the interview contextualised the data already captured by the Daily Reconstruction Method and Sensecam and provided additional, more in-depth information about their chronic pain and/or functioning.

An interview schedule was prepared before any of the interviews were carried out, however, as it was a semi-structured interview this schedule was only a guide (see appendix I for the initial interview schedule). I also asked additional questions, based on the responses of the participants, which allowed the participant to discuss aspects of their pain and/or functioning that were important to them. The main areas covered by the interview schedule were; pain history, treatment of chronic pain, description of daily functioning, perceived daily changes since developing chronic pain and anything else that the individual wished to discuss. However, the interview schedule itself was also flexible, and developed between each interview, based on the discussions within the previous interviews. Furthermore, I looked at each participant's Daily Reconstruction Method and Sensecam data before the interviews took place which allowed me to explore certain aspects of the measurement period in more depth. For example, I could question extracts in the Daily Reconstruction Method or images captured using the Sensecam.

All interviews were recorded on a Dictaphone with interviews lasting between 12 and 74 minutes, with one exception which lasted 5 minutes as the participant did not have much time to partake in the interview due to personal responsibilities.

#### **4.2.5 PROCEDURE**

After individuals were given verbal and written information about the study, and agreed to participate, I arranged a time to meet them in their home. On the first day of the study I arrived at each participant's house. Participants were initially shown how to put on the LifeShirt and were also given an instruction manual, including text and images, showing them how to set up and take off the LifeShirt. I then showed the participants how to attach 3 electrodes to their torso (2 on the chest and 1 on the stomach). In order to minimise embarrassment the participants were informed of this beforehand and were advised to wear loose-fitting clothing. Participants were also previously made aware that it may be necessary to shave the areas on which the electrodes were attached (i.e. the chest and abdomen). I gave the participant as much privacy as possible whilst putting on the LifeShirt by leaving the room whilst they were changing, but were there if needed at any point. The participants were verbally instructed to set

up the LifeShirt themselves, and help was given if needed. The participants turned on the recorder and carried out the calibration process which asked them to place a nose clip on their nose and asked them to sit down and breathe rapidly 7 times. They were then asked to wait 30 seconds, before standing up and breathing rapidly 7 times. This calibration process was repeated three times before the set up was complete.

Participants did not need to interact any further with the LifeShirt until they needed to take it off and they were advised to carry on with their day as normal. Participants were asked to charge up the battery for the LifeShirt every evening and were shown how to do this. They were also asked to change the memory card in the recorder each night, and were also shown how to do this.

Participants were asked to wear a Sensecam at the same time as the LifeShirt (i.e. all day, each day for 7 days). The participants were shown how to use the Sensecam on day one of the study and were also given written instructions (including illustrations) explaining how to use it. The participants were shown how to wear the camera, how to turn it on and turn it off, and how to charge it up at the end of each day. Participants were also shown how to use the '*privacy*' button on the Sensecam which is pressed once to turn the privacy setting on, and is pressed again to turn privacy off and resume recording. I explained the information cards to the participants, and informed them to give them to anyone that asked them about the study, or the Sensecam.

Participants were asked to complete a daily diary in the form of the Daily Reconstruction Method. The diary was completed daily, for 7 days. Participants were also given an example of a completed diary which I went through with them.

At the end of the 7 day measurement period I returned to collect the equipment, diaries and upload the images from the Sensecam onto the DCU Sensecam application software which was used to upload and store the Sensecam images (<http://sensecambrowser.codeplex.com>). I showed the participant how to upload the Sensecam images onto the laptop using written instructions (including illustrations), verbal instructions and a demonstration (if needed). The written instructions explained how to upload the photos, and how to browse and delete the photos which they did not want me to see before the data was saved and analysed. I also deleted any images that the participants had failed to delete which I did not feel appropriate to store and analyse.

A period of 1 to 2 days break was given before an in-depth semi-structured interview was carried out at a time of the participants' convenience. Semi-structured interviews took place at the participants' homes or a quiet location of their choice. The interviews were recorded on a Dictaphone.

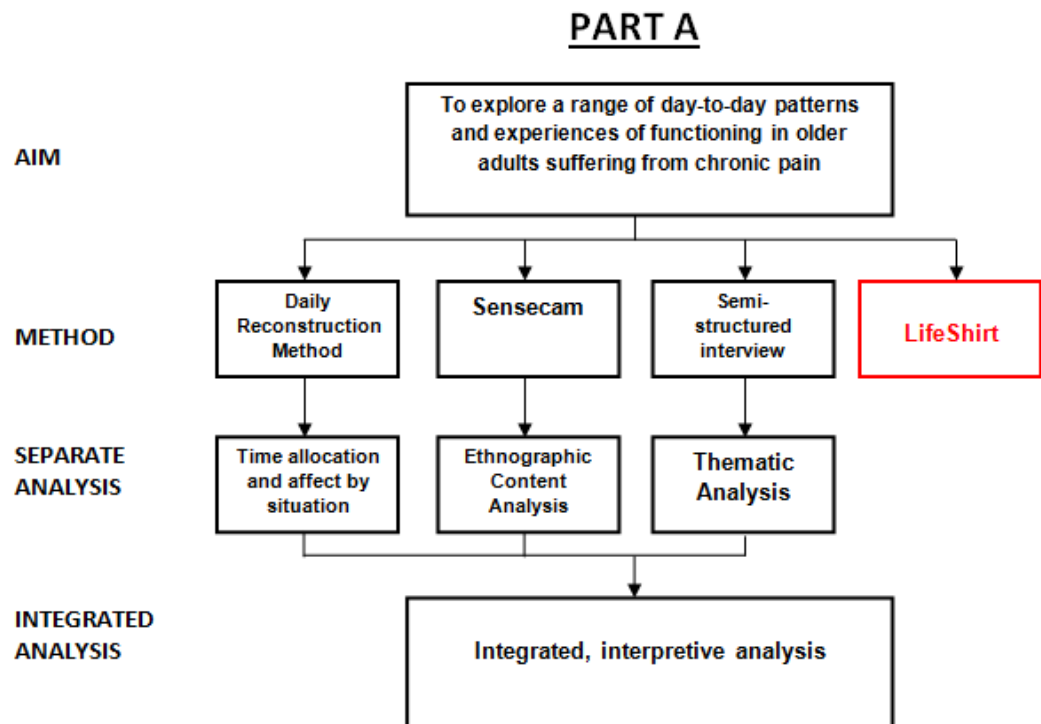
#### **4.2.6 OUTLINE AND JUSTIFICATION OF ANALYSIS**

This section outlines each analysis used in Part A of this study, and provides a justification of use within this study.

There were four separate data collection tools used in Part A of this study, as described above; the Daily Reconstruction Method diary, the Sensecam, the LifeShirt

and the semi-structured interview (please see figure 17, below, for an outline of Part A). However, the data from the LifeShirt was not analysed due to various problems with the data (see Appendix M), therefore information collected from three of the data collection tools were analysed as part of this study. Furthermore, due to the differences in the methods used in Part A of this study, all of the methods were first analysed separately before being integrated into one narrative. This narrative was based around the themes developed from the Thematic Analysis of the semi-structured interviews.

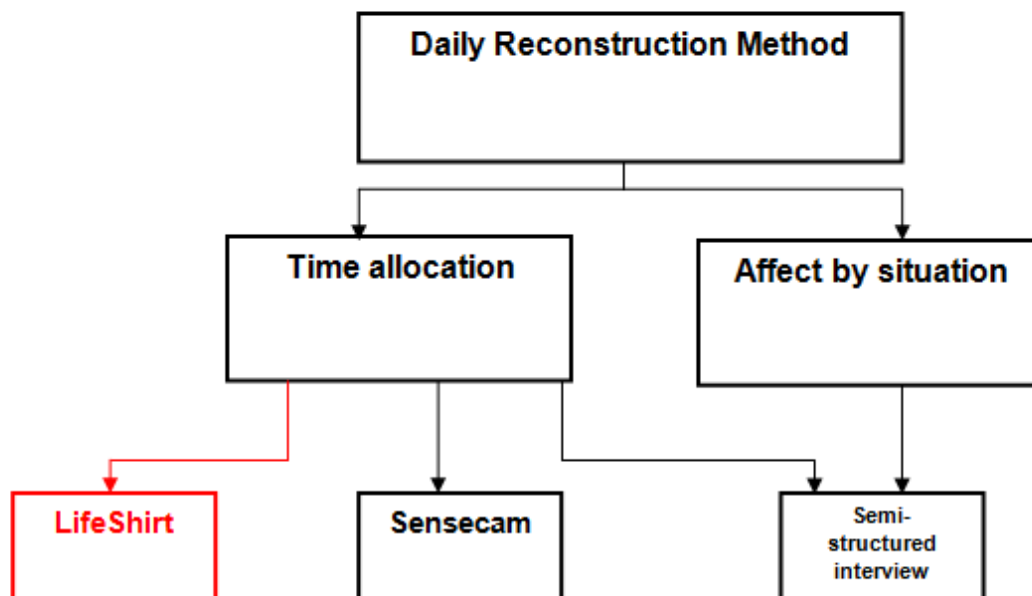
**Figure 17: A graphical representation of the outline of Part A**



However, despite the differences between the data collection tools and the analyses, as seen above, all of the analyses were based on the underlying foundation of gathering data regarding ‘*time allocation*’ and ‘*affect by situation*’. ‘*Time allocation*’ and ‘*affect by situation*’ are both core concepts of the theoretical foundations of the Daily Reconstruction Method; *Time allocation* is the analysis of time spent performing a task, time spent at a location or time spent with other individuals and *affect by situation* refers to the individuals’ perceptions of the time spent partaking in these tasks, at these locations and with these other individuals. It is the concept of *time allocation* and *affect by situation* that is the basis of the analysis, and runs through all of the methods, despite all methods being analysed differently.

The Daily Reconstruction Method explores both *time allocation* and *affect by situation* from the perspective of the participant. The Sensecam collected additional information regarding *time allocation* and the semi-structured interview provided additional information regarding both *time allocation* and *affect by situation* (see figure 18, below).

Figure 18: The framework of analysis (Part A)



The subsequent part of this section provides an in-depth explanation of the framework for analysis of each method used within Part A of this study.

#### 4.2.6.1 DAILY RECONSTRUCTION METHOD

Diaries are traditionally completed in a free-flow, unstructured manner, however the use of structured diaries is increasing. One structured diary that is being increasingly used in health research is the *Experience Sampling Method* (Csikszentmihalyi, & Larson, 1987). '*Experience sampling*' refers to a method which aims to record individuals' feelings and events occurring in everyday life, when the individuals are taking part in the '*experiences*' themselves (Christensen, Barrett, Bliss-Moreau, Lebo & Kaschub, 2003). The *Experience Sampling Method* is carried out electronically and comprises of a number of electronic prompts throughout the day which ask participants to fill in the diary at the time of the prompt. The *Experience Sampling Method* captures data in '*real-time*' with the aim of removing recall biases of which retrospective diaries are persistently criticised (McColl, 2004). The Daily Reconstruction Method (Kahneman, et al., 2004) further developed the concept of the *Experience Sampling Method* by maintaining the framework of a structured diary but changing the time of diary completion, as rather than completing the diary during activities at the time of a prompt, the Daily Reconstruction Method is completed the next day.

The Daily Reconstruction Method is as advantageous as the *Experience Sampling Method* in minimising recall biases and continues capturing episodic memories due to its timely completion. However the Daily Reconstruction Method also eliminates the two major disadvantages that have continuously been observed with the *Experience*

*Sampling Method.* The *Experience Sampling Method* has been criticised for its inconvenience to participants due to individuals being interrupted at numerous points throughout the day, leading to participant burden (Parisi, 2010). Whereas the Daily Reconstruction Method still captures daily fluctuations of feelings, as it is completed soon after the event (i.e. the next day), but does so without interrupting daily living. Furthermore, the Daily Reconstruction Method is more advantageous than the *Experience Sampling Method* in that it allows information to be captured over an entire day as opposed to small portions of data scattered throughout the day (Schwartz, et al., 2009).

The Daily Reconstruction Method was developed by economists as a ‘*hybrid approach*’ to gather both time-use data and affect by situation as a way of measuring subjective well-being (Kahneman *et al.*, 2004). The Daily Reconstruction Method requires individuals to initially complete demographic information and general questions before reconstructing the events of their previous day. Specifically the individual is asked to reconstruct a number of ‘*episodes*’ that can include one or more tasks. The individual is asked to highlight the tasks that took place during the episode, the time that the episode took place, the location in which the episode took place, any interactions that occurred during the episode, and finally their feelings toward the episode which is recorded by 12 different affect dimensions (Schwartz *et al.*, 2009). This process is repeated for each episode that occurred during the individual’s day, for the duration of the study period. Using this approach the Daily Reconstruction Method is beneficial in that it does not rely upon global reports of happiness, but allows the measurement of feelings that occurred during recent events (Belli, Stafford, & Alwin, 2009). This is advantageous as individuals answering questions about their feelings towards general events often respond with a general answer of how they usually feel completing that task, rather than stating the feelings experienced whilst completing that task on that particular instance (e.g. Juster, 1985). Within the Daily Reconstruction Method the individuals’ responses are driven by their actual experiences that occurred at that time, therefore gaining a more accurate reflection of that experience, rather than how they feel about the task in general.

The Daily Reconstruction Method has been used as a tool in a range of research areas to examine concepts such as subjective well-being (Kahneman, *et al.* 2004), diurnal patterns of emotions (Stone, et al., 2006) and also the relationship between daily lifestyle and happiness of older adults (Oerlemans, Bakker & Veenhoven, 2011). However, it has never been used to explore daily functioning and experiences associated with chronic pain.

The Daily Reconstruction Method is typically analysed using either one of two methods; *time allocation* and *affect by situation* (Kahneman *et al.*, 2004) or using *National Time accounting* (Krueger et al., 2009). The developers of the Daily Reconstruction Method primarily used the analysis of two main domains; *time allocation* and *affect by situation* (Kahneman *et al.*, 2004). Both *time allocation* and *affect by situation* benefit from assessing well-being from the perspective of how individuals actually spend their time (Loewenstein, 2009). *Time allocation* and *affect by situation* is the analysis that was carried out as part of this study as they allow a more in-depth, descriptive analysis of the data of the Daily Reconstruction Method components than the *National Time Accounting* analysis which is typically more suited to larger sample sizes.

In the same fashion as *time allocation* and *affect by situation* analysis *National Time Accounting* is a set of methods used for measuring, comparing and analysing how people spend their time and this approach aims to compare individual experiences over time, countries, and other groups of individuals (Kruegar et al., 2009). The major component of *National Time Accounting* developed by the researchers is the '*U-index*' (the 'Unpleasant/undesirable index'). The *U-index* is an ordinal measure of feelings, and shows how much of an individual's day is spent in an undesirable state. Once the individual's day has been categorised into either pleasant states, or unpleasant states it is possible to look at how much of an individual's day is positive, and how much of that day is negative. Although the *U-index* is beneficial to analyse data from large samples, it is a reductionist technique, eliminating all of the in-depth, perhaps useful, detail within the Daily Reconstruction Method (Loewenstein, 2009). It takes away the detail from each likert scale, and only considers '*pleasant*' or '*unpleasant*' factors whereas a task can include both positive and negative emotions, which is an important aspect of affect by situation. Due to the idiographic nature of this study, and the small sample size of 19 participants, the emphasis is on gathering as much in-depth information as possible from the data. Therefore, although *National Time Accounting* is a useful technique, this PhD utilised the original method of analysis for the Daily Reconstruction Method; *time allocation* and *affect by situation* analysis.

The researchers suggest that '*many variations of the method are possible*' (Kahneman et al., 2004, pg. 1780). The Daily Reconstruction Method was adapted to suit this study, and after initial analysis of *time allocation* and *affect by situation*, the data from the diaries were integrated into the overall analysis. *Time allocation* is important in terms of functioning as it is possible to distinguish in what events individuals partook, as well as the frequency of these events over the study period. *Time allocation* also highlights frequency of time spent at home, work or elsewhere as well as the frequency of time spent alone or with others. Using this information it is possible to determine the number of episodes at each location, and the number of episodes spent interacting with others over the study period. *Time allocation* is also analysed by the proportion of sample reporting each task, location and interaction type. By doing this it is possible to distinguish how many participants reported each task, location and interaction type at least once throughout the study week.

The Daily Reconstruction Method also allows an analysis of the *affect by situation* allowing me to gain an insight into the individuals' feelings toward completed tasks using the 12 likert scales which reflect various feelings for each episode that the participants record. Three of these likert scales are grouped into '*positive affect*' (happy, warm/friendly, and enjoying myself) and six likert scales are grouped into '*negative affect*' (frustrated/annoyed, depressed/blue, hassled/pushed around, angry hostile, worried/anxious and criticized/put down). *Positive affect* and *negative affect* show the positive emotions the individual associated with each episode, and also the negative emotions associated with each episode. There are three additional scales; '*competent/capable*', '*tired*' and '*impatient for it to end*' which can also be used to explore the individuals' feelings about tasks they carried out. The *affect by situation* analysis is beneficial as it allows an insight into how the individual feels about their daily life including the tasks they carry out, their location and their interaction.

As the emphasis was on daily functioning, not all of the diary sections were needed. Three sections were removed before giving the Daily Reconstruction Method to participants; 'general questions', 'your job' and 'how do others see you'. 'Your job' was removed as it was irrelevant for participants, as all participants from the core sample were retired. The removal of the other two sections was primarily to reduce the amount of time individuals needed to spend filling in the diary, as this was time-consuming, and neither was necessary for this study. Furthermore, the use of a semi-structured interview at the end of the study period also ensured that additional aspects of daily living were discussed, and daily living and the experiences of chronic pain were discussed on a broader basis. Therefore individuals completed general questions about their previous day (i.e. its typicality, overall mood and reported waking hours), as well as the diary section which required information on time allocation and affect by situation of each activity undertaken the previous day.

The Daily Reconstruction Method is a useful tool which allows well-being to be examined within this research. However, there are of course negative aspects to the use of the Daily Reconstruction Method, and strengthen the rationale for using multiple methods. Firstly, the Daily Reconstruction Method explores well-being, however, well-being recorded by the Daily Reconstruction Method is very much restricted to the emotions within the Daily Reconstruction Method (Loewenstein, 2009). Furthermore, the Daily Reconstruction Method assumes that well-being is based solely on feelings of happiness, as opposed to others factors such as intelligence or health (Loewenstein, 2009). Using other data collection techniques allowed the strengths of the Daily Reconstruction Method as a measurement tool contribute to the study, whilst some of its disadvantages were reduced using additional methods.

#### **4.2.6.1.1 PROCESS OF ANALYSIS – DAILY RECONSTRUCTION METHOD**

The Daily Reconstruction Method was analysed using *time allocation and affect by situation* data analysis, as outlined above. To analyse *time allocation* I calculated the number of episodes participants reported for each task, location and interaction. An overall weekly average (median; minimum, maximum) of the number of times each task, location and interaction was then calculated and presented. Frequency was calculated, as opposed to length, as individuals were able to record more than one task per episode, therefore the data gathered on the length of tasks was inaccurate.

To analyse *affect by situation*, like Kahneman *et al.* (2004), I initially split some of the likert scales into two groups; 'positive affect' and 'negative affect' by taking their average (mean) for each episode. Positive affect was made up of 'happy', 'warm/friendly' and 'enjoying myself' and negative affect was made up of 'frustrated/annoyed', 'depressed/blue', 'hassled/pushed around', 'angry/hostile', 'worried/anxious' and 'criticised/put down'. I was then able to calculate the average (median; minimum, maximum) positive and negative affect for each activity, location and interaction over the week. A weekly average (median; minimum, maximum) was also calculated for impatience for the task to end, competence/capability, and tiredness for each activity, location and interaction over the week. All of this data is shown in Appendix I.

After completing the data tables, and all other analyses, I then integrated the findings from the table describing the time allocation and affect by situation data into the themes developed from the semi-structured interviews (see section 5.3). The Daily Reconstruction Method data and the Sensecam data, acted as information to add more depth to the themes and sub-themes developed from the interview analysis.

#### **4.2.6.2 SENSECAM**

The Sensecam is one piece of technology that allows an individual to capture automatic images which generates a '*visual diary*' of their daily routine. The Sensecam is advantageous in that the photographs not only capture the tasks being carried out but also records contextual information (Kerr, et al., 2013). The Sensecam, and other wearable cameras, offer a close equivalent of the '*gold standard*' measure of observation within the assessment of health behaviours (Doherty, Kelly & Foster, 2013).

The Sensecam was originally used in research as a visual diary to help improve the memory of individuals suffering from cognitive deficits (e.g. Berry, et al., 2007; 2009) and research in this area has shown Sensecam images to improve people's memory for events (Sellen, Fogg, Aitken, Hodges, Rother & Wood, 2007). However, since the early use of the Sensecam, its application has greatly widened with the Sensecam being used to explore areas such as sedentary behaviour (Kerr et al., 2013), travel (Kelly, et al., 2012) and nutrition (O'Loughlin, et al., 2013).

The Sensecam is more advantageous than other cameras due to the constant capturing of images without user interaction, its long battery life, the ease of putting the camera on and taking the camera off, the ability to capture a large amount of images daily and the environmental sensors on the Sensecam (a motion sensor and a heat sensor) which capture additional images when triggered. Although there are numerous pieces of technology which have the ability to capture pictures of an individual's day, such as digital cameras or mobile phones, they have a large participant burden as the individual would need to continuously interrupt their tasks in order to take the photographs.

In addition to the low user burden of the Sensecam, there are further advantages over other life-logging techniques. For example, the Sensecam is reliable in that everything is in real-time, and ensures that individuals cannot forget about certain aspects of their day which may not have been remembered without the use of the camera. Sensecam users have often discovered aspects of their behaviour on the Sensecam that they would ordinarily neglect (Harper et al., 2007; Harper, et al., 2008). Furthermore, research has demonstrated that the automatic capture of photographs make it easier for an individual to recall a situation than the photos manually taken by participants (Sellen et al., 2007).

*Ethnographic Content Analysis* was the method used to analyse the Sensecam data. There have been a small number of studies that have been carried out using the Sensecam as the method of data capture, and have used quantitative statistics to analyse the frequency of details within the images (e.g. Thomaz, Parnami, Essa & Abowd, 2013; Chen et al., 2013; Marinac, et al., 2013). However, there have not been



any published Sensecam studies which have extracted similar elements of the images to that which are being extracted as part of this study, therefore numerous possible analysis techniques needed to be considered. *Ethnographic Content Analysis*, also known as, qualitative content analysis, was deemed the most suitable method for analysing the Sensecam images. *Ethnographic Content Analysis* is a method based on traditional *Content Analysis*.

Altheide (1987) proposed *Ethnographic Content Analysis* which is a reflective, iterative form of *Content Analysis* that brings in components of ethnographic research therefore differing from traditional *Content Analysis* (O'Reilly, 2005). Traditional *Content Analysis* is an objective, systematic technique which uses distinct categories to quantify verbal, written or visual data (Bell, 2001). *Content Analysis* is a numerical method which begins with a specific set of numerical categories which are used to code each image, or appropriate data set (Rose, 2011). This contrasts to the method of *Ethnographic Content Analysis* in that although *Ethnographic Content Analysis* also produces numerical outcomes, *Ethnographic Content Analysis* additionally provides descriptive, thematic information about the data (Altheide, 1987). Furthermore, *Ethnographic Content Analysis* emphasises the exploration of context, meaning and patterns from the data, rather than numerical significance (Altheide, 1996). *Ethnographic Content Analysis* remains to be systematic and reliable therefore the central concept of *Content Analysis* remains, without *Content Analysis*' rigidity, with the addition of written description regarding the data set, as well as an extra level of depth to the data (Smith, Sells, & Clevenge, 1994).

Altheide (1987) aimed to combine a qualitative, ethnographical methodology with the quantitative *Content Analysis* method (Smith, *et al.*, 1994). Altheide's (1987) qualitatively influenced *Ethnographic Content Analysis* is not theoretically bound, but it does have *Grounded Theoretical* overtones (Sandelowski, 2000) in that its aims are of 'constant discovery' and 'constant comparison', and this is reflected in the continuing reflection that occurs throughout the data analysis procedure. Altheide (1987) proposes the importance of both numerical output (complying to *Content Analysis*) as well as textual, descriptive output as being necessary to provide enhanced interpretation. This is an important aspect of the analysis as numerical occurrence does not signify importance, and just because one code may occur most often throughout the data set does not mean that it is of more significance than something that does not occur as frequently (Rose, 2011). *Ethnographic Content Analysis* is more interpretative than *Content Analysis* in that it is not just the numerical frequencies that are important, but also the meaning and content of the data (Sandelowski, 2000). Altheide (1987) distinguishes three main differences between *Content Analysis* and *Ethnographic Content Analysis*; data collection, data analysis and interpretation (see table 6, below).

	<u>Content Analysis</u>	<u>Ethnographic Content Analysis</u>
<b>Research goal</b>	Verification	Discovery; verification
<b>Reflexive research goal</b>	Seldom	Always
<b>Emphasis</b>	Reliability	Validity
<b>Progressions from data collection, analysis and interpretation</b>	Serial	Reflexive; Circular
<b>Primary researcher involvement</b>	Data analysis and interpretation	All phases
<b>Sample</b>	Random or stratified	Purposive and theoretical
<b>Pre-structured categories</b>	All	Some
<b>Training required to collect data</b>	Little	Substantial
<b>Type of data</b>	Numbers	Numbers; Narrative
<b>Data entry points</b>	Once	Multiple
<b>Narrative description and comments</b>	Seldom	Always
<b>Concepts emerge during research</b>	Seldom	Always
<b>Data analysis</b>	Statistical	Textual; Statistical
<b>Data presentation</b>	Tables	Tables and text

**Table 6: Differences between Content Analysis and Ethnographic Content Analysis (Altheide, 1987).**

From the beginning of data collection *Content Analysis* differs from *Ethnographic Content Analysis* and it was clear that the design of my study 'fit' within the frame of *Ethnographic Content Analysis*, as opposed to traditional *Content Analysis*. This was evident from the research goal of discovery and the purposive sampling strategy that was used, to the narrative discovery that I thought was imperative. One of the main differences between *Content Analysis* and *Ethnographic Content Analysis* is data analysis and the role of the 'coder'. Within *Content Analysis* there is a great emphasis that the coder must have no influence over the data set, however, *Ethnographic Content Analysis* is, as previously stated, is a reflective method and puts the coder central to the analysis procedure allowing a more reflective account to be developed (Altheide, 1987). As the research was primarily qualitative, I felt that I was central to the data, and as I had spent much time with each participant, as part of the study, I was

able to analyse the images subjectively, based on my own knowledge of that individual. For example, as I had been in each participant’s home, and in many cases I had met their family, I was able to view the images from a perspective that others would not be able to. Although this does not lead to ‘reliable’ data that multiple coders could agree upon, it led to more ‘reliable’ data in that I had greater knowledge of each participant’s environment, and was able to use this knowledge when analysing the data.

Finally, *Content Analysis* begins with a set of codes which are maintained throughout the data analysis, and no interpretation occurs, whereas *Ethnographic Content Analysis* is data-driven (Sandelowski, 2000). *Ethnographic Content Analysis* follows a more qualitative approach in that there is a set of codes that are theoretically developed before data analysis begins, and these codes are used to direct the analysis, however, additional codes can subsequently emerge during analysis of the data (Grinnell & Unrau, 2011). The analysis of the images in this study began with numerous pre-defined categories, and sub-categories at the beginning of the analysis stage which were based on relevant sources (see Appendix J for description of each Sensecam code). Tasks were developed using the codes in the Daily Reconstruction Method (Kahneman, *et al.*, 2004; see table 7, below) and all other codes were taken from a coding strategy developed for analysing Sensecam images (Chen et al., 2012; see table 8, below).

<b>Task</b>	
Other	0
Commuting	1
Shopping	2
Doing housework	3
Eating	4
Socialising	5
Nap/resting	6
Relaxing	7
Intimate relations	8
Working	9
Preparing food	10
Taking care of children	11
Praying/worshipping/meditating	12
Watching TV	13
Computer/internet/email	14
On the phone	15
Exercising	16

**Table 7: The list of codes used to categorise ‘tasks’ as part of the Ethnographic Content Analysis.**

<u>Body position</u>		<u>Social context/interaction</u>		<u>Indoor/outdoor</u>		<u>Unusable</u>	
Lying down	0	Social/no interaction	0	Indoors (general)	0	Uncodable	0
Sitting	1	Social/interaction	1	Outdoor	1	Not sure	1
Standing	2	Not social	2	In vehicle	2		
Standing moving	3			Mixed	3		
Walking	4						
Changing position	5						

**Table 8: The list of codes used to categorise ‘body position’, ‘social context/interaction’, ‘indoor/outdoor’, and ‘unusable’ data in the Ethnographic Content Analysis**

However, it soon became clear during the analysis of P001 that much detail seen in the images, and details that were important to this study, were not being recorded due to the codes that had been pre-defined. It therefore seemed necessary to be reflective, adding additional codes in order to get the most information out of the Sensecam images, and in order to improve accuracy of the findings and to increase the relevance of the results for the aim of the study (see table 9 and 10 for the codes that developed during analysis of P001; codes in red are those that developed during analysis). The account therefore became iterative in nature as I began thinking about the data, in order to make sure that the codes were relevant and sufficient. At any time an additional code was added, all of the information was re-analysed.

<u>Task</u>	
Other	0
Commuting	1
Shopping	2
Doing housework	3
Eating	4
Socialising	5
Nap/resting	6
Relaxing	7
Intimate relations	8
Working	9
Preparing food	10
Taking care of children	11
Praying/worshipping/meditating	12
Watching TV	13
Computer/internet/email	14
On the phone	15
Exercising	16
Preparing drink	17
Drinking	18
Reading	19
Using assistive device	20
Self-care	21

**Table 9: The list of codes used to categorise ‘tasks’ in the Ethnographic Content Analysis, as developed during the analysis.**

<u>Body position</u>		<u>Social context/interaction</u>		<u>Indoor/outdoor</u>		<u>Unusable</u>	
Lying down	0	Social/no interaction	0	Indoors (general)	0	Uncodable	0
Sitting	1	Social/interaction	1	Outdoor	1	Not sure	1
Standing	2	Not social	2	In vehicle	2		
Standing moving	3			Mixed	3		
Walking	4						
Changing position	5						
In wheelchair	6	Pet	3	Kitchen	4	Taken off	3
Walking with aid	7	Social/not in image	4	Living room	5		
Bending down	8			Bedroom	6		
Stretching up	9			Bathroom	7		
				Other room	8		
				Other person's home	9		

**Table 10: The list of codes used to categorise ‘body position’, ‘social context/interaction’, ‘indoor/outdoor’, and ‘unusable’ data in the Ethnographic Content Analysis, as developed during the analysis**

Similar to the Daily Reconstruction Method, the Sensecam also has its downfalls. One highly important issue relating to the Sensecam is the privacy of both the participant and those who they come into contact with (known as ‘secondary participants’). One method which has been discussed to overcome this is to allow the participant to review the images before giving them to myself in order to remove any images in which they do not want to share (Byrne, Lavelle, Doherty, Jones, & Smeaton, 2007). This has been undertaken within this study, and participants did not need to share any photos which they did not wish to share. Furthermore, individuals were encouraged to remove, or pause recording on, the Sensecam at any time which they did not want recording.

A further issue in this area is that although the Sensecam is user friendly in that once turned on individuals do not need to interact a great deal with the technology, there are user problems with the transferral and uploading of photos onto a computer, and also browsing these photos. Research involving older adults that had used the Sensecam demonstrated that the participants struggled to use the browsing system on the computer for reasons such as feeling that they required previous experience of using a computer, there was no help option available and the images were too small to recognise (Caprani, et al., 2010). Within this study participants were given written instructions of how to upload, browse and delete the images on a laptop. I was nearby at this time if the participant needed any help.

Finally, one further problem that has been found with the Sensecam is the volume of pictures captured, as the Sensecam captures approximately 3,000 images daily and manual browsing of the pictures can therefore be impractical, especially if recording over a long period of time (Byrne & Jones, 2008; Byrne, Doherty, Snoek, Jones & Smeaton, 2009). One way in which research has aimed to solve this impracticality is by breaking the images down into sections, for example, travelling to work and eating lunch, in order to make it easier to browse images (Byrne, Lavelle, Doherty, Jone, & Smeaton, 2007). One image per minute was analysed in this study due to time restraints.

Despite some of the flaws relating to the Sensecam it was an important method within this study. The Sensecam provides a novel method to gather *time allocation* data of daily tasks and by using the Sensecam I was able to explore details of the tasks that the individuals took part in, where they took part in them, and with whom they took part without solely relying on memory, like in the Daily Reconstruction Method. There were many details of these tasks that were able to be captured using the Sensecam, and would not have been picked up using any other data collection technique, for example, the use of assistive devices during certain tasks, and the resting periods taken in between some tasks. Numerous measures were taken to reduce the flaws of the Sensecam, and of course, there were three additional methods which were carried out simultaneously that closed some of the gaps in knowledge. Furthermore, *Ethnographic Content Analysis* was the most appropriate technique used to analyse the Sensecam images in this study as it allowed a reflexive, qualitative analysis of the images.

#### **4.2.6.2.1 PROCESS OF ANALYSIS – SENSECAM**

The Sensecam images were analysed using *Ethnographic Content Analysis*, as outlined above, and formed part of the *time allocation* element of the analysis framework. One image per minute (the first image of each minute) was coded using a set of codes under five main headings; ‘*task*’, ‘*body position*’, ‘*location*’, ‘*interaction*’ and ‘*unusable*’.

I took each image and assigned codes to it depending upon the task, body position, location and interaction in the image. The image was coded as ‘*unusable*’ if it was covered, blurred, I was unsure of the contents or if the Sensecam had been taken off. Tasks were the only coding category that could be coded with more than one code per image. This was due to the individual often taking part in more than one task as a time. Please see Appendix J for the classification criteria for each code.

The process was iterative and once I had looked over the first two participants it was apparent that there were common tasks which were recorded, but not listed in the coding categories. These tasks were therefore given codes, and were analysed as such. All previous data were reanalysed in order to code them with the correct codes. This iterative process was continued throughout all participants. All other, non-common tasks were still classed as ‘*other*’.

After the initial coding process took place, and all images for all participants had been coded, an average (median; minimum, maximum) of each code, within each coding category, for each participant, was presented. This showed overall information of time allocation for tasks, body position, social interactions, location, and usability of the images for each participant (see Appendix K for table of findings).

After completing the data tables I then integrated the findings from the table describing the Sensecam images into the themes from the semi-structured interviews of this study (see section 5.3). The Sensecam data added to the Daily Reconstruction Method data and the themes and sub-themes developed from the interview analysis.

#### **4.2.6.3 LIFESHIRT**

The LifeShirt (Vivometrics®) is another piece of technology that acts as a life-logging device. The LifeShirt is a jacket for 'streaming body sensor data' (Cardenas, Pon & Cameron, 2003, pg. 186). The LifeShirt uses a multi-functional approach as it gathers Electrocardiogram readings and the respiratory rate of the individual in addition to having an optional diary which can be completed by the individual (Grossmann, 2004). Furthermore, the LifeShirt acted as an accelerometer as it monitors the movements of the individual, for example, whether the individual is sitting up or lying down. There were numerous benefits of the LifeShirt, as opposed to other physiological data devices, specifically the ability to capture on-going data from the individual, as opposed to capturing 'snapshots' of data whilst the participant is in a laboratory setting (Cardenas, *et al.*, 2003). Additional advantages included it being mobile and being able to simultaneously gather other data (Heilman & Porges, 2007).

The LifeShirt has been used in a diverse range of research areas, for example, the LifeShirt has been used as a tool for patient monitoring in an operation room (Halin, Junnila, Loula & Aarnio, 2005), to gather ECG data from ambulatory swine (Kyle *et al.*, 2009) and to assess anxiety (Myers & Derchak, 2006). Although the cardiorespiratory components of the LifeShirt have been validated (Clarenbach, Senn, Brack, Kohler, & Bloch, 2005; Witt *et al.*, 2006; Heilmann & Porges, 2007; Kent *et al.*, 2009), the accelerometer component of the LifeShirt had not previously been evaluated. Only the accelerometer component of the LifeShirt was supposed to be used within this study, and the other data recorded by the LifeShirt were not to be considered. The justification for the use of only the accelerometer data retrieved from the LifeShirt was due to the aim of Part A of this study. Although the cardiorespiratory information would have been beneficial when looking at certain aspects of functioning, it would not be useful to analyse this data when exploring the day-to-day patterns and experiences of functioning of older adults living with chronic pain.

The accelerometer component of the LifeShirt had not been used in research before this study, and therefore it was necessary to conduct a validation study in order to make sure that the accelerometer was valid and reliable (see appendix L). Despite the results from this validation study justifying the use of the LifeShirt, and LifeShirt data being collected as part of the main study, it was not possible to analyse this data. Some data had not recorded, and other data was not suitable for analysis, therefore the information collected from the LifeShirt in this study was not analysed (see appendix M for a full explanation for not using the LifeShirt data).

#### **4.2.6.4 SEMI-STRUCTURED INTERVIEWS**

The aim of the semi-structured interview in Part A was to build on the data gathered from the Daily Reconstruction Method and Sensecam as well as contextualising this information and adding a description of the individuals' experiences and patterns of daily functioning.

Semi-structured interviews are a common technique used in qualitative research and benefit from flexibility for both the researcher and the participant (Coolican, 2004). As this study was not bound to one particular methodology the semi-structured interviews in both Part A and Part B were analysed using the method of *Thematic Analysis* as it is

flexible in its use due to its '*theoretical freedom*' (Braun & Clarke, 2006, p.78). The aim of *Thematic Analysis* is to extract themes and sub-themes based on the written transcripts of the verbal accounts by participants essentially highlighting patterns within the dataset (Braun & Clarke, 2006). *Thematic Analysis* describes the data in much detail and allows the researcher to interpret this data (Boyatzis, 1998).

An inductive, '*bottom up*', approach to *Thematic Analysis* was taken within this study and the analysis follows that of inductive *Thematic Analysis* (Boyatzis, 1998). Although the interviews were based on questions relating to the aim of the study, as well as expanding on the data gathered by the Daily Reconstruction Method and the Sensecam, the data was not coded with any previous perceptions or coding framework in mind. The interviews were very much explored on their own, and I kept an open mind whilst reading and analysing the transcripts. I was reflexive throughout the whole process of the study, including the analysis of the interviews, with a reflexive diary being kept throughout. An interpretative approach to the data analysis was also taken, rather than a solely descriptive approach in accordance with the epistemology.

One of the questions Braun and Clarke (2006) discuss in their paper outlining *Thematic Analysis* is '*what counts as a theme?*' (Braun & Clarke, pg.82). Within this study themes and sub-themes were extracted from the data. A '*sub-theme*' was classed as an aspect of information regarding daily functioning or experiences. A sub-theme was established if one or more individuals discussed a point that was important, and central, to the research aim. A sub-theme did not specifically have to be discussed by the majority of participants, it may have only been discussed by one participant, and it did not need to be discussed a lot over the interviews but it was an aspect of data that the researcher (or 'coder') felt was important to the individual(s) and their experiences of living with pain, or their patterns of daily functioning. '*Themes*' were later established by bringing one or more related '*sub-themes*' together. This theme therefore referenced a larger aspect of experiences and daily living, whilst the sub-themes described smaller aspects of experiences and daily living lying within the theme. The classification of both sub-themes and themes was kept flexible, with no rigid rules of how themes were classified by the researcher, as suggested in *Thematic Analysis* literature (Braun & Clarke, 2006).

Semi-structured interviews were used as part of this study as they allowed an in-depth exploration from the individuals' perspective. It allowed both me and the participant to delve into depth whilst discussing their experiences, and keeping the format semi-structured allows the enquiry to be flexible. Furthermore, *Thematic Analysis* was used as the method to analyse the semi-structured interviews as it is also flexible, and is not led by any specific philosophical assumptions.

#### **4.2.6.4.1 PROCESS OF ANALYSIS – SEMI STRUCTURED INTERVIEWS**

The semi-structured interviews were analysed using thematic analysis, as outlined above, and formed part of the *affect by situation* element of the analysis framework. Braun and Clarke (2006) outline six steps to completing a thematic analysis; familiarising yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (please see table 11 below).



1. Familiarising yourself with the data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract example, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

**Table 11: The six steps of conducting Thematic Analysis (Braun & Clarke, 2006)**

Firstly I '*familiarised [myself] with the data*' by transcribing the data from verbal data recorded on a Dictaphone into written data. The written datasets were then read, and re-read until I felt comfortable with the data. At this time the data was highlighted and I took initial notes to aid with the analysis of the data. This familiarisation process was repeated for all of the interviews conducted in both Part A and Part B of the study.

Stage two of the thematic analysis process involved '*generating initial codes*'. Initial codes were very specific words or phrases which described what was being said in the transcripts and one piece of transcript may be coded using multiple codes if necessary. There was no data that was ignored within the initial coding process, no matter how relevant, or irrelevant, it seemed at that time. It was the initial codes that I used to eventually develop sub-themes and themes. Alternatively, some of the initial codes did not develop further, depending on their perceived importance in regards to the research aims. The process of generating initial codes was repeated for all of the interviews conducted in both Part A and Part B of the study.

The third stage of the process involved '*searching for themes*'. The initial codes were investigated for relevance and importance to the main research question and were explored more broadly, over all of the participants in the dataset. Relevant codes were developed into themes and sub-themes. Sub-themes are situated within the overarching themes, and give structure to overarching themes (Braun & Clarke, 2006). Any irrelevant codes or codes which I thought of as less important were not developed into either a theme, or sub-theme, however they were not discarded at this point. This process was conducted in both Part A and Part B of the study.

'*Reviewing themes*' was stage four of the thematic analysis process. This stage involved the themes and sub-themes being reviewed, and potentially revised. The restructuring of the themes involved themes and, or, sub-themes being discarded,

adapted or added to the findings and it was important to make sure that the themes and sub-themes accurately fit with the codes. This stage also involved reviewing the data in its entirety, and ensuring that the themes and sub-themes accurately reflected the original transcripts. This is also known as '*sense checking*' and ensures that the themes generated are in line with the information gathered from the interviews themselves. At this stage I also discussed the themes with my supervisors in order to check that the developed themes reflected the information gathered in the interviews. This process was conducted in both Part A and Part B of the study.

The fifth stage of the process involved '*defining and naming themes*' in which I organised the themes into an account of the data, and used the themes and sub-themes to produce a narrative. The themes and sub-themes were defined, and given depth using initial quotes and codes. This process was conducted in both Part A and Part B of the study.

Finally, stage six of the thematic analysis process involved '*producing the report*'. The narrative of the individuals' stories were defined and explored in stage five, however, stage six allowed me to write up this narrative. The interpretation of the analysis also emerged here.

Once the themes were constructed the information from both the Daily Reconstruction Method and the Sensecam were integrated into the themes, and added further details to the themes that were not gathered in the interview.

### **4.3 PART B**

Part B aimed to explore the usability, acceptance, experiences and practicalities of the technology used to measure levels of functioning in Part A of this study.

#### **4.3.1 DESIGN**

Part B used a mixed method design. The *Unified Theory of Technology Acceptance* (UTAUT, Venkatesh, *et al.*, 2003), *Flow State Scale* (Jackson & Marsh, 1996) and qualitative semi-structured interviews were used to assess the usability, acceptance and experiences of the technology used within Part A of this study. The framework of the semi-structured interview was based on the two questionnaires.

#### **4.3.2 SAMPLING METHOD**

As Part B of the study was to examine the use of the technology and diaries used in Part A, data was gathered from the same participants and was gathered simultaneously. A detailed description of participants and how they were recruited is given above (see section 4.2.2).

#### **4.3.3 ETHICAL APPROVAL**

Ethical approval was granted for this study by the School of Health and Social Care Research Governance and Ethics Committee at Teesside University. The participant

information sheet and the consent form used in part B of this study was that used in Part A (see section 4.2.3.2 and 4.2.3.3 for full details regarding this information).

#### **4.3.4 INSTRUMENTATION**

##### **4.3.4.1 UTAUT QUESTIONNAIRE**

A modified version of the UTAUT questionnaire was used in this study (see Appendix O). The original questionnaire is made up of 32 likert scales, based on 8 constructs within the 5 dimensions of the UTAUT (please see section 4.3.6.1 for an explanation of all 5 dimensions); performance expectancy, effort expectancy, attitudes toward using technology, social influences, facilitation conditions, self-efficacy, anxiety and behavioural intention. The modified version of the questionnaire is made up of 17 scales, as some were irrelevant to the technology being used in this study. All likert scales ranged from 1 (strongly disagree) to 7 (strongly agree).

Participants were given two identical copies of the questionnaire at the beginning of the study; one referring to the Sensecam, and one referring to the LifeShirt. Participants were asked to complete these questionnaires referring to their perceptions of both pieces of technology, before use. Once the participant had taken part in the 7-day study period in which they had used the two pieces of technology, they were once again given, and asked to complete, two identical questionnaires, one referring to the Sensecam and one referring to the LifeShirt. Participants were asked to complete these questionnaires referring to their experiences of using both pieces of technology. Both pre and post questionnaires were identical. Some of the questions within this questionnaire were also used during the interviews.

##### **4.3.4.2 FLOW-STATE SCALE QUESTIONNAIRE**

A modified version of the *Flow-State Scale* was also given to participants to complete, and were discussed in the interviews (see Appendix P). The original *Flow-State Scale* was made up of 36 likert scales, ranging from 1 (strongly disagree) to 5 (strongly agree) whereas the modified questionnaire, used in this study, is made up of 9 scales as many were irrelevant. Participants were given two copies of the *Flow-State Scale* to complete at the end of the 7-day study period.

Both copies of the questionnaire were identical but one referred to the Sensecam and one referred to the LifeShirt. Participants were asked to complete these questionnaires referring to their experiences of using both pieces of technology. Some of the questions within this questionnaire were also used during the interviews.

##### **4.3.4.3 SEMI-STRUCTURED INTERVIEW SCHEDULE**

A semi-structured interview was conducted between me and the participant. The purpose of the interview was to gather in-depth information about participants' experiences of using the Sensecam and the LifeShirt.

As the interview was semi-structured, there was an interview schedule, but individuals were also free to discuss what was important to them whilst using the technology. Two questionnaires were used as a framework for the semi-structured interview schedule;

the *Unified Theory of Acceptance and Use of Technology* (UTAUT, Venkatesh *et al.*, 2003) and the *Flow-States scale* (Jackson & Marsh, 1996). Participants were asked to complete the questionnaires in order to begin thinking about their opinion of their own technology use, and become aware of the questions that would be involved in the interview.

The main areas covered by the interview schedule were; previous experiences of using either the LifeShirt or Sensecam (if any), the expectations of using the technology, ease of use, any technical or practical problems that occurred, issues with wearing the technology e.g. issues of self-consciousness, others' reactions and any other issues that the individual wished to raise. The interview was recorded using a Dictaphone.

#### **4.3.5 PROCEDURE**

Part B was carried out at the same time as Part A, as data was gathered from the same participants at the same time. However in order to gather data for Part B there were some additions to this procedure.

On day 1 I helped the individual to put on the equipment as part of Part A, I asked participants to complete two versions of the UTAUT. The study then took place as stated above (see section 4.2.5). Upon returning to the participant's house to remove the equipment, I gave the participant four additional questionnaires. The participant was asked to complete the final two versions of the UTAUT. The participant was also asked to complete two versions of the *Flow-State Scale*.

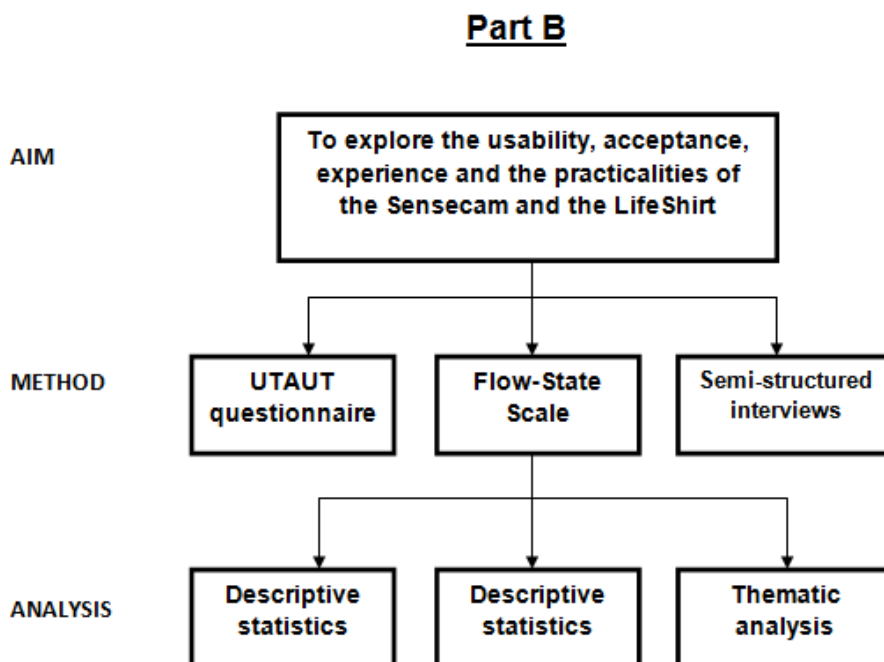
I then returned to the participant's house 1-2 days later. After conducting the interview for Part A, the individual took part in a second interview. Participants were given the option for a break between the interviews for Part A and Part B however all individuals decided to carry on with the second interview and no formal breaks were taken. The semi-structured interviews were carried out in the same setting as the interviews for Part A. Interviews for Part B lasted between five and 61 minutes, with one exception which lasted only three minutes.

#### **4.3.6 OUTLINE AND JUSTIFICATION OF ANALYSIS**

This section outlines the analysis used in Part B of this study, and provides a justification of use within this study.

Part B of this study used three different data collection tools to gather information (see Figure 19, below, for an outline of Part B).

**Figure 19: A graphical representation of the outline of Part B of the study**



Both the *Unified Theory of Acceptance and Use of Technology* (UTAUT, Venkatesh *et al.*, 2003) the *Flow-State Scale* (Jackson & Marsh, 1996) were analysed with descriptive statistics. The questionnaires also informed the semi-structured interviews, and formed the basis of the interview schedule.

#### **4.3.6.1 UTAUT**

The UTAUT questionnaires were filled in both before and after the study to initiate thinking about their perceptions of use of both the Sensecam and LifeShirt.

The UTAUT is a questionnaire designed to explore the intentions for future use of technology. The primary goal of the UTAUT is to understand reasons why individuals take up using new technology and why they continue to use this technology.

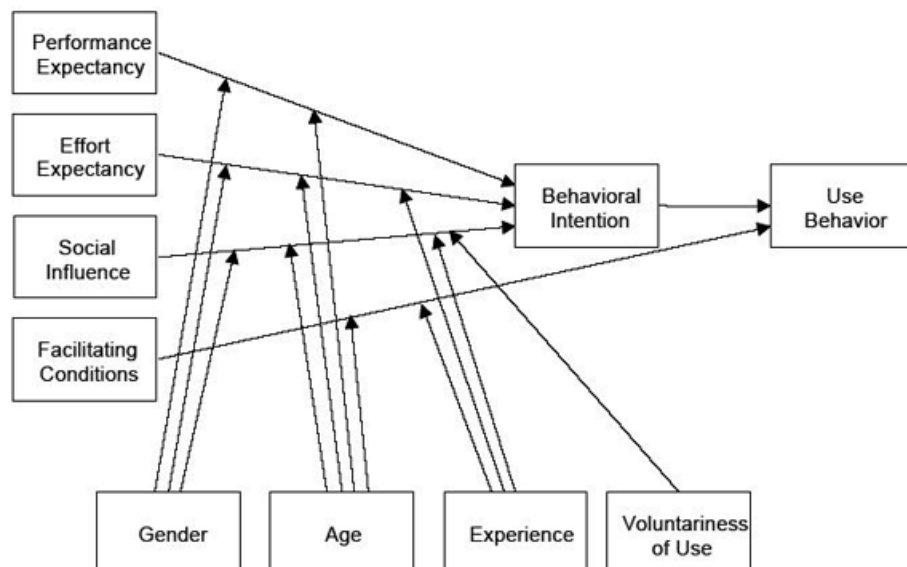
The UTAUT has built upon eight existing models that have previously been used within technology adoption, in the aim of creating a unified theory from eight fragmented models; the *Theory of Reasoned Action* (TRA, Fishbein & Ajzen, 1975), the *Theory of Planned Behaviour* (TPB, Ajzen, 1991), the *Technology Acceptance Model* (TAM, Davis, 1989), the *Motivational Model* (MM, Davis, Bagozzi, & Warshaw, 1992), a model combining both the TAM and TPB (C-TAM-TPB, Taylor & Todd, 1995a), the *Innovation Diffusion Theory* (IDT, Tornatzky & Klein, 1982; Moore & Benbasat, 1991; 1996) and finally, *Social Cognitive Theory* (SCT, Bandura, 1989; Compeau & Higgins, 1995).

From the existing models within the UTAUT it is not only possible to see theories looking directly at the use of technology, but also the inclusion of models of behaviour change such as the TRA and TPB. The importance of social influences is also highlighted within multiple technology acceptance models, as well as models of behaviour change, and the SCT directly explores the influences of others upon

behaviour. The integration of all of these models is evident within the various dimensions of the UTAUT.

The UTAUT itself is made up of five dimensions which all affect usage behaviour; *Performance Expectancy*, *Effort Expectancy*, *Social Influence*, *Facilitating Conditions* and *Behavioural Intention* (see figure 20, below). The UTAUT positions *Behavioural Intention* as the central component of determining technology use in a consistent way to underlying theory (Venkatesh *et al.*, 2003). *Behavioural Intention* and *Facilitating Conditions* are the only two dimensions which directly affect use of technology. *Performance Expectancy*, *Effort Expectancy* and *Social Influence* all directly influence *Behavioural Intention*, therefore affecting technology use. Finally, the influence of age, gender, experience and voluntariness are also evident within the UTAUT and are placed as essential moderators within the model. Although Self-Efficacy and anxiety are acknowledged within the model they were not included as direct determinants of behaviour intention or use of technology.

**Figure 20: The Unified Theory of Acceptance and Use of Technology (UTAUT, Venkatesh, Morris, Davis & Davis, 2003).**



Of the five dimensions in the UTAUT, *Performance Expectancy* is the strongest predictor of behavioural intention and refers to the extent to which an individual believes that using a piece of technology, or I.T. system, will benefit their job performance. *Performance Expectancy* is the most significant dimension of each individual model, and also remains significant whether the setting of using the technology is either voluntary or mandatory (Venkatesh *et al.*, 2003). As seen in the UTAUT, performance expectancy is also suggested to be modified by both gender and age. The UTAUT specifically states that the influence of *Performance Expectancy* is stronger for men, and younger individuals, based on previous research looking at the implementation of technology (Morris and Venkatesh 2000; Venkatesh and Morris, 2000).

*Effort Expectancy* refers to the amount of ease which is associated with a piece of technology, or I.T. system. *Effort Expectancy* was both significant when the use of the technology was voluntary or mandatory, but only for the first time of use (Venkatesh *et al.*, 2003). *Effort Expectancy* then became insignificantly influential toward *Behavioural Intention* after first use. As well as the significance of experience, gender and age also moderate the influence that *Effort Expectancy* has upon *Behavioural Intention*. The influence of *Effort Expectancy* was higher for both women and older adults (Venkatesh & Morris, 2000; Venkatesh *et al.*, 2003).

*Social Influence* refers to the level in which other individuals, that are important to the user, believe the user should use the technology or I.T. system. The effect of *Social Influences* upon behavioural intention is complex, and is moderated by gender, age, experience and voluntariness of use. Within the dimension of *Social Influences* there are three factors; subjective norm, social factors and image. Whereas all three of these factors are significant when discussing usage behaviour in a mandatory setting, all of the three factors lose significance when use of the technology is voluntary. As well as use of technology in mandatory settings affecting the impact of *Social Influences* than voluntary use, Venkatesh *et al.* (2003) proposes the *Behavioural Intention* of older women with little experience of using the technology will be most affected by *Social Influences*, based on past theory and literature (Rhodes, 1983; Venkatesh *et al.*, 2003; Venkatesh & Morris, 2000).

*Facilitating Conditions* directly effects use behaviour, and is the level of support the user believes they are receiving from the organisation and technical infrastructure to use the technology or I.T. system. Venkatesh *et al.* (2003) propose that *Facilitating Conditions* do not affect *Behavioural Intention*, but it does affect usage behaviour. The UTAUT poses that *Facilitating Conditions* do not affect *Behavioural Intention* due to the presence of both *Performance Expectancy* and *Effort Expectancy* and their full facilitation on *Behavioural Intention* (Venkatesh *et al.*, 2003). Furthermore, the influence of *Facilitating Conditions* on usage behaviour is moderated by both age and experience, with the influence being stronger for older adults, and those with more experience of using the technology (Hall and Mansfield, 1975; Morris & Venkatesh, 2000).

The reliability and validity of the UTAUT has been examined and the UTAUT was able to account for over 70% of variance (adjusted  $R^2$ ) for intention to use an information system (Venkatesh *et al.*, 2003). The UTAUT was able to explain a much greater variance of usage intention to each of the eight preceding models on which it is based. This questionnaire was also used as the framework for the second semi-structured interview which aims to explore the usability and acceptance of the method in a more in-depth manner.

Not all of the questions within the UTAUT were relevant within this study, therefore a modified version of the questionnaire was used and analysed. Furthermore, the interview allowed the individuals to discuss their experiences and opinions of both the Sensecam and the LifeShirt, without being confined to the questions posed in the UTAUT questionnaire. However, the UTAUT was beneficial to use as a questionnaire, and as a framework of the interview, as it was an established model of behavioural

intention and use of technology, despite it not being developed in the area of life-logging.

#### **4.3.6.1.1 PROCESS OF ANALYSIS- UTAUT**

The likert scales of the UTAUT questionnaire ranged from 1 (strongly disagree) to 7 (strongly agree). Each likert scale was analysed using descriptive statistics, and the average response (mean; min, maximum) for each question, over the entire sample, was calculated. The UTAUT responses were calculated separately for the Sensecam and the LifeShirt. The UTAUT questionnaires were also separately analysed for the perception of both the Sensecam and LifeShirt before and after use. These findings were also integrated into the interview data when appropriate.

#### **4.3.6.2 Flow-State Scale**

The *Flow-State Scale* (Jackson & Marsh, 1996) was one of the two questionnaires used as a framework to the semi-structured interviews for Part B of the study. The *Flow-State Scale* was filled in after the study to initiate thinking about perceptions of use of both the Sensecam and LifeShirt. Like the UTAUT, not all of the questions within the *Flow-State Scale* were relevant within this study, therefore a modified version of the questionnaire was used and analysed. The *Flow-State Scale* questions used within this study focused on the enjoyment of wearing the experience, awareness of their '*performance*' whilst wearing the technology, their perceptions of control of the technology and their own body, and also their concern over the attitudes of others.

The *Flow-State Scale* is a questionnaire which measures '*flow*'. Flow is a physical and psychological state that is experienced when a person is completely immersed within a performance (Csikszentmihalyi, 1975). The key to experiencing flow is the autotelic experience, i.e. the task is intrinsically satisfying, and it was the desire to understand motivation for autotelic experiences that drove the development of the Flow State theory (Nakamura & Csikszentmihalyi, 2002). It is this flow experience that many developers hope that individuals will experience when initiating new computer products. The flow state has been measured in a variety of areas since, including human-computer interactions (Webster, Trevino & Ryan, 1994), online consumer behaviour (Koufaris, 2002) and online gaming (Wan & Chiou, 2006; Hoffman & Novack, 2009). However, this theoretical concept is not limited to use within technology, and it is said to also occur within areas such as sport (Jackson, 1995) and advertising (Csikszentmihalyi, 1988). Being in this flow state can induce positive experiential characteristics and it has been suggested that being in repeated Flow States will lead to positive outcomes such as improving quality of life (Csikszentmihalyi, 1988 and Jackson & Marsh, 1996). Furthermore, the Flow State is understood to be universal and representative across cultures, age and gender.

The *Flow-State Scale* questionnaire aims to quantify the experience of flow. There are nine main components which are needed to be present in order for the individual to be in a flow state; a challenge-skill balance, action-awareness emerging, clear goals, unambiguous feedback, concentration of task at hand, paradox of control, loss of self-consciousness, transformation of time and an autotelic experience (Jackson & Marsh, 1996). The challenge-skill balance is the most important component of the flow state



and flow is best experienced when the challenge is neither too difficult, nor too easy, for the user.

Despite the psychological advantages of being in a Flow State, experiencing flow is not always the intended outcome for technology use, specifically the life-logging tools that were used within this study. The life-logging devices used in this study are observation tools, therefore experiencing a complete immersion within the technology whilst wearing the life-logging devices is not sought after, as it would be best if the individuals were not aware of the life-logging technologies in the hope that behaviour would not change due to the awareness of being '*observed*'.

#### **4.3.6.2.1 PROCESS OF ANALYSIS - FLOW-STATE SCALE**

The likert scales of the *Flow-State Scale* ranged from 1 (strongly disagree) to 5 (strongly agree). Each likert scale was analysed using descriptive statistics, and the average response (mean; min, maximum) for each question, over the entire sample, was calculated. The Flow-State Scale responses were calculated separately for the Sensecam and the LifeShirt. These findings were also integrated into the interview data when appropriate.

#### **4.3.6.3 SEMI-STRUCTURED INTERVIEWS**

As in Part A, a thematic analysis was used to explore the use of the Sensecam and LifeShirt (see section 4.2.6.4). Semi-structured interviews have been used in Part B as the interviews allowed the individuals' experiences, and perceptions, of the Sensecam and the LifeShirt to be discussed.

Despite the LifeShirt data not being used in Part A of the study, some participants still wore the LifeShirt, and the discussions surrounding its use was still relevant in this study and were important to report in order to explore the experiences of the individuals within this study, as well as being beneficial for future research due to the importance of user experience within use of this technology.

#### **4.3.6.3.1 PROCESS OF ANALYSIS – SEMISTRUCTURED INTERVIEWS**

An identical analysis procedure was carried out for the data retrieved from the interviews in Part B to that in Part A (please see 4.2.6.4.1 for step-by-step guidelines of thematic analysis). Themes and sub-themes were defined in the same way as those in Part A, and were also constructed in an identical way.

### **4.4 SUMMARY**

Part A of this study followed a mixed methods design, for which purposive sampling was used to recruit 19 participants. A core sample of 15 participants was gathered, and all were over 65 years old, living with chronic pain, retired and living in the community. Four additional participants were also recruited in order to gain further insight into the effect of pain and age on functioning.

There were three data collection methods used in Part A; the Daily Reconstruction diary, the Sensecam and semi-structured interviews. Although the LifeShirt was used by participants the data was not analysed due to problems with the output.

All analyses in Part A were based on the concept of time allocation and affect by situation as proposed by the authors of the Daily Reconstruction Method. However, all methods were analysed separately before being integrated together using the themes from the semi-structured interviews as a basis for this integration. The diaries were analysed using quantitative time allocation and affect by situation analysis, the Sensecam was analysed using Ethnographic Content Analysis and the semi-structured interviews were analysed using Thematic Analysis.

Part B of this study was conducted alongside Part A, therefore the same sampling strategy was used, and the same participants took part in both parts. Both the UTAUT and the Flow-State Scale data were analysed using descriptive statistics, and were also used as a basis for the interview schedule. The semi-structured interviews were analysed using thematic analysis.

This chapter has outlined the design, sample, instrumentation and procedure for both Part A and Part B. A detailed description of the analysis process has been given for all data collection methods in this study.

## **CHAPTER 5: PART A- FINDINGS AND DISCUSSION**

### **5.1 OVERVIEW**

The Daily Reconstruction Method data, Sensecam images and semi-structured interviews were all analysed separately using separate analysis techniques. This chapter presents the analysis of the semi-structured interviews in the form of themes and sub-themes, with findings from the diaries and Sensecam integrated into the themes in order to add subsequent details and either strengthen or contradict interview findings (please see Appendix I for the Daily Reconstruction Method table, and K for the Sensecam table).

All discussion of the Daily Reconstruction Method data within these integrated findings is taken from the time-allocation and affect by situation analysis of the Daily Reconstruction Method, in which descriptive statistics were computed for all tasks, locations and interactions recorded in the Daily Reconstruction Method (please see Appendix I for table). Relevant details from the results within the Daily Reconstruction Method table are integrated throughout, and add additional details to the analysis. The Ethnographic Content Analysis conducted for the Sensecam also provided descriptive statistics quantifying details within each analysed image, before these details were explored qualitatively within the integrations of the results (please see Appendix K for table). Findings from other studies will also be discussed within this chapter and related to the current findings.

### **5.2 PARTICIPANT DETAILS**

The details for all core participants that took part in this study are given in table 12, below. Table 12 shows that participants within the core sample were between 65-94 years old. There were 11 females and four males all with various living situations and marital status. All participants were British. Participants also had a range of pain areas and pain durations as well as various co-morbidities. Demographic details of the younger adults with pain and the older adults without pain are also given below.

Fourteen of the participants were recruited from community groups throughout the North East of England, three individuals were recruited from a newsletter that was circulated over the area and two individuals were recruited from the '*snowball sampling*' approach used in the study, in that two of the other participants discussed the study with them and passed on the information.

Table 12 also shows that compliance ratings were high for the completion of the DRM with only one individual failing to complete one day within the diary. Twelve days of the Sensecam data were not recorded over the sample. Other than P003 purposefully removing the Sensecam for one day, the reason for the missing data is unknown. Although not all participants used the Daily Reconstruction Method or Sensecam, all participants took part in the semi-structured interviews. Neither P007 nor P012 completed the diary or used the Sensecam. In the case of P007 she did not feel that she would be able to use them before beginning the study, whereas P012 stopped using the equipment on day 2 as she struggled to do so, but both still wanted to take part in the study. Despite the non-use of the diary and the Sensecam the information

gathered in the interviews were of importance and added insight into this study. Table 13 provides details of the two younger adults with chronic pain that took part in the study and table 14 provides details of the two older adults without chronic pain that took part in the study. All of the details given are identical to those provided for the core participants.

<u>Participant</u>	<u>Age</u>	<u>Gender</u>	<u>Ethnic origin</u>	<u>Marital/ working status</u>	<u>Pain site(s)</u>	<u>Pain duration</u>	<u>Co-morbidities</u>	<u>Retrieved data</u>
P001	75	F	British, white	Widow Lives alone Retired	Cervical spondylosis  Arthritis: ankles, knees, hips, hands	30+ years	Partially sighted  Asthma  Chronic Obstructive Pulmonary Disease (COPD)  Hypertension  Heart problems	Daily Reconstruction Method  Sensecam  Interview  LifeShirt
P002	76	F	British, white	Widow Lives alone with two dogs Retired	Lower back pain  Sciatica: leg	46 years	None	Daily Reconstruction Method  Sensecam  Interview  LifeShirt
P003	74	M	British, white	Married Lives with wife Retired	Cervical spondylosis  Pain: right foot	Cervical spondylosis - 30-40 years  Right foot-12 months	Heart problems	Daily Reconstruction Method (1 day missing)  Sensecam (1 day missing)  Interview  LifeShirt
P004	78	F	British, white	Widow	Arthritis: both wrists, one finger,	Left wrist-7 years	None	Daily Reconstruction Method

				Lives alone Retired	back, right knee	Right wrist – 13 years Other- Unknown number of years		Sensecam (3 missing days) Interview LifeShirt
P005	72	F	British, white	Widow Lives alone Retired	Pain: Left knee, lower back	Approximately 10 years	None	Daily Reconstruction Method Sensecam (2 days missing) Interview LifeShirt
P006	74	M	British, white	Married Lives with wife Retired	Pain: neck, arms, hands, back and legs	Arms and hands – 5-6 years Other – undisclosed number of years	None	Daily Reconstruction Method Sensecam (6 days missing) Interview LifeShirt
P007	94	F	British, white	Widow Lives alone Retired	Pain: back, shoulders, hips	8/9 years	Thyroid problems High blood pressure Previously no sight in one eye	Interview
P008	65	F	British, white	Widow Lives alone	Pain: knee, legs, multiple fingers, lower back	Undisclosed number of years	None	Daily Reconstruction Method

				Retired				Sensecam Interview
P009	66	M	British, white	Married Lives with wife Retired	Lower back pain Pain: shoulders Osteoarthritis: ribs	Approximately 25 years	None	Daily Reconstruction Method Sensecam Interview LifeShirt
P010	65	F	British, white	Single Lives alone with 2 dogs Retired	Osteoarthritis: hips Fibromyalgia: mainly in arms but also elsewhere	Hips – 17 years Fibromyalgia – 12 years	None	Daily Reconstruction Method Sensecam Interview LifeShirt
P011	74	F	British, white	Single Lives alone Retired	Arthritis: Knees	Undisclosed number of years	Previously had breast cancer	Daily Reconstruction Method Sensecam Interview

P012	81	F	British, white	Married  Lives with husband  Retired	Pain: back  Osteoarthritis: Leg	Undisclosed number of years	High blood- pressure  Angina  Sleep apnoea  Knee replacement  Fitted pace maker	Interview
P013	65	F	British, white	Married  Lives with husband (P014)  Retired	Pain: right leg, hip	5 months	Recent heart attack	Daily Reconstruction Method  Sensecam  Interview
P014	65	M	British, white	Married  Lives with wife (P013)  Retired	Pain in: feet  Arthritis: ankles, elbow	60 years	Removed cancer from ear  Recent gout in foot	Daily Reconstruction Method  Sensecam  Interview
P015	65	F	British, white	Married  Lives with husband (P019)  Retired	Back pain  Arthritis: Knees	4 years	Kidney transplant	Daily Reconstruction Method  Sensecam  Interview

**Table 12: Details of the core participants who took part in the study**



P016	56	M	British, white	Married Lives with wife	Pain in: wrists, knee	10-15 years	Diabetes Kidney stones	Daily Reconstruction Method Sensecam Interview
P017	52	F	British, white	Married Lives with husband	Pain in: hip, knees, feet	20 years	Peripheral vascular disease Bypass in leg	Daily Reconstruction Method Sensecam Interview

**Table 13: Details of the two younger adults with chronic pain who took part in the study**

P018	67	M	British, white	Married Lives with wife (P015) Retired	NO PAIN	N/a	Mild heart attack (3 years ago) Repetitive strain injury (whilst working) Bowel cancer (7 years ago) Asthma	Daily Reconstruction Method Sensecam Interview
P019	66	F	British, white	Single Lives alone Retired	NO PAIN	N/a	Diabetes	Daily Reconstruction Method Sensecam Interview

**Table 14: Details of the two older adults without chronic pain who took part in the study**

### 5.3 THEMES

Throughout the interview data two major themes were recognised; '*effect on daily living*' and '*managing pain and functioning*'. The themes capture numerous aspects of the individuals' experiences and daily functioning centring on chronic pain. Whereas '*effect on daily living*' shows the changes to daily living as a result of chronic pain, '*managing pain and functioning*' demonstrates the ways in which individuals try to cope and adjust to these changes. Sub-themes of both themes were also established and will be discussed.

### 5.4 EFFECT ON DAILY LIVING

It became evident from the transcripts that chronic pain affected the daily living for all individuals. This theme encapsulates task-specific aspects of daily living which made up the majority of the discussion between the participants and myself. This theme is segregated into task-specific sub-themes in order to highlight the effect that pain has had upon multiple Activities of Daily Living (ADL). Specifically, there are two overarching concepts that occur throughout the sub-themes; the relationship between pain and functioning and the modifications individuals have made to the frequency of the ADL.

Participants described ADL that they were previously able to do with relative ease, but now have problems doing so due to pain, and in some cases the participants now carry out these tasks at a reduced level, or have changed the way in which they do them. On the other hand there were tasks that individuals completely terminated due to the interference of pain. Tasks that were either adapted, reduced or terminated differed between participants, and often differed due to the affected pain site. Interestingly, three of the participants believed that chronic pain did not generally affect their lives.

*no [there are no changes since developing chronic pain] I just get on with it, I, I don't really stop me doing anything I just, just get around it [004]*

*it hasn't really stopped me doing what I normally do [013]*

*We wouldn't let [chronic pain] stop us from doing anything [016]*

Despite these individuals believing that chronic pain had not generally affected their daily living, the individuals all reported the effect that chronic pain had on specific aspects of daily living at numerous points throughout the interviews. If this study had solely relied upon global questions of the effect on chronic pain upon daily living no further information would have been gathered and the details of actual changes to daily living would have been lost. For example, Thomas *et al.* (2004) asked one global question to determine the degree to which participants' daily living had been affected by chronic pain (during the past 4 weeks, how much did pain interfere with your normal work, including both work outside the home or housework). However, in this study, without probing P004, P013 and P016 about specific tasks in their daily life, the participants would not have gone into the effects of chronic pain further, and the conclusions of the study would have been compromised.

There were some common activities and participatory events discussed in the interviews that were affected by chronic pain, and make up the sub-themes of this

theme; 'movement', 'household tasks', 'travel', 'sleep' and 'recreational tasks'. Not only were the ADL discussed within the interviews, but the Daily Reconstruction Method and the Sensecam allowed details of many of these tasks to be further highlighted; whereas the Daily Reconstruction Method provided additional information regarding both time and affect of some ADL, the Sensecam provided additional visual details of some ADL which aided understanding of participants' daily living. This information could not be gathered using the interviews alone.

#### 5.4.1 MOVEMENT

This theme will begin with the sub-theme 'movement' as it was often the pain associated with body movements that affected the individuals' involvement within activities or participatory events. This sub-theme explores the pain associated with specific movement itself (activities) as well as movement based tasks (participation, ICF, WHO, 2001). The relationship between pain and movement was evident, as well as the modification of participatory tasks as a result of the effect pain had upon functioning. This information in this sub-theme describes the participants' feelings toward their own movement patterns, and how they feel that pain has affected movement, as well as providing data on their actual movement patterns, as recorded in the Daily Reconstruction Method and seen on the Sensecam during the study week.

For one older adult living with chronic pain, as well as one of the younger participants living with chronic pain, moving was beneficial; P012 found that moving made her 'ease up' whereas P016 describes moving as being beneficial as '*it is just a case of limbering them up, you know use, making you use them they get better, if they cease up*'. However, similar to other qualitative studies in the area (Ashby *et al.*, 2012; Hallberg & Carlsson, 2000; Thomas & Johnson, 2000) participants discussed specific body movements that worsened their pain.

*See when you have got arthritis as well, and you stretch up a lot it makes you dizzy when you have got it in your neck, it makes you dizzy, the room starts spinning so you stop doing it [001]*

*bending your knees up and down [hurts] [001]*

*[Back pain] usually happens when I'm standing a lot [005]*

*if I sit with my knees at like 45 degrees...If I sit like that for too long oh, when I straighten it and stand up [it hurts] [005]*

*kneeling down or climbing up ladders that is a no no doing it like that and you're going to be bad you know, you know you're going to be bad [014]*

*Bending, a lot of bending [worsens my pain] erm and I have got arthritic knees so I can't sort of bob down and get back up as well you know which would help erm so I can't do that because my knees are worse than my back [015]*

Pain was often affected by actual body movements, which depended on the pain sites that the individual lived with, with two of the participants speaking of pain in more than one site, as a result of movement. However, this issue was not isolated for older adults

living with chronic pain and movement was also something that increased pain for the younger adults in the sample.

*When I kneel on my knees I get a burning sensation in my right knee so that does hurt quite a bit even now [016]*

*I can't kneel anymore since the knee replacements [as it worsens the pain] [017]*

Unlike quantitative research in this area, which focus' on time spent in body position, and speed of movement (Ryan et al., 2009; Spenkeliink, *et al.*, 2002), this study has been able to explore the details of movement from the participants' perspective, and show how various movements affect pain, and the differences in how movement affects the individuals, depending upon pain location.

As well as the interviews describing differences of how movements affected pain over the sample, the Sensecam highlighted the various differences in body postures and movements seen during the study week. Standing varied over the sample with P001 spending the least amount of time standing (1%), compared to P003 and P013 who spent most time standing (24%). There was also variance for other body positions, including time spent walking which varied between 3-25% over the sample. The Sensecam also showed a high frequency of time spent sitting down by older adults living with chronic pain (ranging from 41-78%) with all participants spending most time sat down, than in any other body position, over the study week. Unlike the accelerometers used in past research, the Sensecam also contextualised the time spent sitting, showing that most time spent sitting down was done so in the living room, often when relaxing, watching TV and socialising. There were no clear differences between the sitting, or standing, time of the older adults with chronic pain, younger adults with chronic pain or the older adults without chronic pain, from the descriptive statistics produced as part of the Sensecam data.

Despite Spenkeliink *et al.* (2002) finding that individuals with chronic lower back pain spent more time lying during both the day and evening than matched healthy controls, it was evident from the Sensecam data that only three of the 13 older adults living with chronic pain that wore the Sensecam lay down at any time (22%). P014 spent much time lying down whilst watching TV, in his bedroom. Neither older adult living without chronic pain lay down during the study week. Of course the results gained in this study may have differed to Spenkeliink *et al.* (2002) with only a small number of participants lying down, as not all of the participants were living with chronic lower back pain, and the participants in this study had pain in various sites. Additionally, the differences may be because participants removed the Sensecam during this time, as opposed to not lying down at all.

As well as general movement affecting pain, movement was affected by a fear of falling for two of the participants.

*I'm scared of falling, whereas I never was, never, but again...I think that your confidence in that does go [002]*

*[I] won't risk now anything where I might fall again, if I think there is a risk well I won't do it, I won't do it [007]*

The fear of falling affected individuals' movements in that they were 'scared' to fall again. Fear avoidance behaviours, a maladaptive response to pain, are something that have been discussed throughout previous literature in both younger and older participants (Bishop *et al.*, 2001; Samwel *et al.*, 2006). The Fear-Avoidance Model proposed that avoidance behaviours may lead to decreased movement, leisure tasks and social interactions, as a result of fear of worsening pain (Vlaeyen & Linton, 2000). This has been reflected in the statements made by both P002 and P007, in that both are fearful of falling, and P007 explicitly states that she adapts her behaviours as a result of this fear.

Older adults living with chronic pain and younger adults with chronic pain were dissimilar in their fear of falling in that neither younger adult with chronic pain discussed the fear of falling. However, like some older adults living with chronic pain, both younger adults with chronic pain were aware of specific body movements that increased pain. Of course, this greatly contrasted to the older adults without chronic pain who did not feel pain upon movement and did not discuss issues with movement as either an 'activity' or within 'participation'.

Restriction in movement, due to the amount of pain experienced when moving, also affected the individuals' exercise levels. There were numerous exercises that individuals felt that they could not take part in due to restricted movement including Pilates [P004, P010], yoga [P004] and tai chi [P008], despite research showing that these movements can often be helpful for individuals living with chronic pain in either reducing the intensity of pain, or increasing levels of functioning (Hall *et al.*, 2009; Rydeard, Leger & Smith, 2006; Williams *et al.*, 2006).

However, not all individuals ceased exercising as a result of chronic pain. According to the Sensecam, four older adults living with chronic pain exercised over the study week with different frequencies (3%-13%) though only P010 exercised daily. Despite only four of the core sample exercising on the Sensecam, nine of these participants reported exercising in the Daily Reconstruction Method with positive affect varying between the participants that reported exercising (2.7-6), although negative affect was low throughout ( $\leq 1$ ). This may be due to the participants' definition of exercise which may differ to my own definition, or alternatively, to the removal of the Sensecam during exercise. For example, there were two different occasions when participants told me that they had removed the Sensecam; both P004 and P008 specifically stated that they had removed the Sensecam when swimming, due to it being a water-based task, and P009 discussed removing the Sensecam on some occasions when 'exergaming' (as described below) due to the excessive movement of the camera.

P009 was one of the four individuals that were evidently exercising on the Sensecam. P009 took part in two different types of exercises over the study week. The participant took one long purposeful walk up the coast, into the town centre, and back home with his wife. The participant walked for the whole duration, other than a short rest on which he leaned on railings. Other than walking, the participant exercised using 'exergaming' (a combination between exercising and computer gaming) equipment, namely the Nintendo® Wii™. The Nintendo® Wii™ is a games console which requires the individual to physically move in order to advance game play. It was apparent on the Sensecam that the participant specifically played on 'Wii fit™', a fitness game

manufactured for the Nintendo® Wii™. *Wii fit™* is made up of numerous short games which promote movement and improve balance, and P009 discussed his use of these exergames within the interview.

*[The Wii™ is] very good it is very good you can do it at your own pace and erm most of it is like running which I like anyway and there is yoga which is good for the posture no it is a very good machine, I think anyway and it save us money [laughs] [009]*

Despite P009 acknowledging the usefulness of the *Wii™*, he was also aware of his restrictions whilst using the game, and acknowledged which exercises he could, and could not carry out.

*[On the Wii™] there is an exercise when you're heading the ball and you are doing a side-to-side movement and that has given me quite a bit of pain erm...and, and the golf exercise when you're twisting from your spine erm, but it is it is worth it and afterwards you do feel pretty good I think the pain is just a consequence of pleasure, well I think that it is pleasure anyway [009]*

Both P003 and P005 also discussed the use of exergames although both participants did not use the exergames as much as they would have liked to, despite having access to them in their home.

*I mean I have got the Kinect [Microsoft®] box but I have only used it twice, I mean it is over a week since you were here and it would be wrong for me to say that I haven't had the opportunity to use it of course I have, I just haven't got the routine I guess [003]*

*I have the Wii™ there and I sometimes do that but erm...I would say I don't do as much as I used to, and maybe I should [005]*

The lack of exergaming was not due to pain for these two individuals, but due to lack of intention. Exergaming is known for its benefits, and is something that is increasingly being used with older adults, especially in the area of balance (Agmon, Perry, Phelan, Demiris, & Nguyen, 2001; van Diest, Lamoth, Stegenga, Verkerke, & Postema, 2013). Whereas P009 used the exergames regularly, both P002 and P005 did not use it as regularly as they would like, and it is clear that motivation is an important factor within use. There is much literature in the area of motivation to use technology, such as flow (Csikszentmihalyi, 1975) and the UTAUT (Venkatesh *et al.*, 2003) however, there is currently limited research with regards to exergaming.

Other than exergaming, participants discussed exercise as being vastly made up of walking. This was also reflected on the Sensecam as walking was the most common form of exercise recorded on the camera. Walking was mentioned as it benefited some of the individuals, either by improving fitness or being beneficial to levels of pain. For example, P010 believes that walking keeps her 'fitter' whereas P009 believes that walking 'probably does [the pain] good'. P009 remained a member of a walking club and walked 'once a month' with them, whereas although P011 enjoyed walking 'despite not being an exercise person', she had to give up being part of a walking club as a result of her knee pain.

*the knees started to give out so I used to go out with [the walking club] on a morning and then we stopped for lunch, I used to leave them and I used to hop on a bus and come back home...until I had to pack it in all [P011]*

In addition to P011, other individuals needed to reduce walking due to their pain. P006 felt that walking was a 'no-no' whereas P007 felt pain in her shoulders as a result of walking. P005 'dreaded' going for long walks due to the pain as she often suffered back pain when she would 'walk a long way'. These responses reflect other qualitative research within this area in which adults of all ages have discussed issues with walking, in which one participant described how it was 'impossible to walk' as a result of pain in their feet (Hallberg & Carlsson, 2000, pg. 32) and one individual felt pain when they tried to move around (Thomas & Johnson, 2000). Both of the younger adults with chronic pain also had problems walking, and it was not restricted to the older adults living with chronic pain.

*I don't think that I could run very far now, sometimes it hurts a bit when I walk [016]*

*there are times when it goes off and I just can't walk on it for the pain then I just have to tolerate that and it tends it put itself right [017]*

Walking affected the younger adults' pain intermittently, and P017's pain affected how much she walked at that time. Again, like specific movements, younger adults with chronic pain are also aware of exercise which affects pain, and walking has also been affected by chronic pain. However, one of the older adults without chronic pain also felt that he did not walk as much.

*I used to erm I used to walk a lot, I used to cycle and I always reckon that that has probably did you know kept the old lungs working and help keep it at bay I reckon [taps his heart] yeah [018]*

*[I don't do] a lot [of exercise] I'm afraid [laughs] walking up and down the stairs... I did have a couple of days at Whitby folk week where I did more walking than normal [laughs]... But that's it but erm yeah [018]*

The individual recognised that he did not walk as far as he used to, however, rather than the lack of walking being due to the presence of pain, it was simply as a result of a change of lifestyle, and different priorities. One further reason as to why his walking levels have decreased may be due to his wife. P018, an older adult without chronic pain, was married to P015, an older adult living with chronic pain. P015 discussed her problems with walking.

*Erm there are certain things that make it worse like erm walking I can't walk very far without intense pain but it is always in the same place yeah [015]*

*Well [walking] is what starts it really off these days [015]*

*...well [I haven't] particularly substituted [activities] but I just don't do you know, we used to do a lot of walking and that and I can't do that now so erm [my husband] just goes off and does*

*his own thing so yes it has affected what we do but I haven't substituted much else because basically I haven't got the energy to do it, or at least nothing active so you know [015]*

P015 discussed how she used to go walking with her husband, but now he is able to 'go off and do his own thing'. However, when speaking to P018 he felt that things were more restricted due to his wife's long-term pain.

*I don't think [there have been any changes in routine/activities] but I think we are a wee bit, because of [my wife's, 015's] health problems perhaps we are more restricted than we were, we have got to be careful sometimes erm but erm you know otherwise we just chug along [018]*

Despite P015 not trying to hold him back, P018 discussed the restrictions placed on him because of his wife's long-term pain, in which a spouse's life can be completely transformed as the result of a long-term health condition (Cutrona, 1996). This shows that pain does therefore not just affect the individuals themselves, but also family, as has been discussed in previous literature (Roberto & Reynolds, 2002). This may be one reason for P018's reduction in walking. There are many instances throughout the remainder of this chapter in which others have been important within daily living for the older adults living with chronic pain. Once more, others are seen to be important and the consequences of living with pain did not just affect the older adults living with chronic pain but also her husband.

One interesting finding regarding individuals' movement was the importance of pets for some of the individuals that walked. Two of the older adults living with chronic pain (P002; P010) each owned a dog along with one of the younger adults with chronic pain (P017). Both P002 and P010 both lived alone and owned dogs that they walked, at least once, on a daily basis. The Sensecam highlighted the frequency of dog walking for both P002 and P010. P002 walked her dogs at least once every day, other than one day recorded on the Sensecam, although the participant had not put on the Sensecam during the morning on this day. From the Sensecam it was evident to see that the participant walked her dogs on a morning, at the beach, marina or the pier. The participant drove to and from the location of the walk, and walks were alone, other than one occasion in which she was joined by a friend.

The Sensecam also showed that P010 walked with her dog at least twice daily, and these walks usually occurred in the park. Like P002, P010 drove to and from the destination of each walk, unless the walk took place late on an evening in which case she walked around her housing estate. Discussions within the interviews also showed the importance of the participants' dogs.

*but [life] would be much worse if I didn't have those dogs [002]*

*walking the dog is essential to my health, physical and mental [010]*

*I love walking the dog even when he pulls and hurts my arms, it gets me out, I live in a very beautiful place there are lots of easy walks[010]*



*having the operations has changed, now I can go now and walk around Herrington park with the dogs for an hour and a half [017]*

However, pain had affected this for P002 as she has recognised that the length that she walks is now shorter than she previously walked.

*I've always have had dogs, and my walking was getting shorter and shorter, I still do probably a couple of miles a day, but not, I mean I would go out for an hour and a half, two hours in the morning, and an hour in the afternoon and I would go across the piers, and love it, and down to the beach, and before that I lived in North Yorkshire and I always walked there [002]*

Walking has reduced due to long-term pain however still occurs on a daily basis despite the change in duration. The dogs are not only important for getting the women to walk, but are also an important companion for their psychological well-being. Social elements were also an important part of walking the dog for both of the participants. P002 states that she would feel 'isolated' if it was not for walking the dogs and walking a dog leads to more social occurrences than walking without a dog.

*there would be some days when I wouldn't go out and that is one thing that I don't like, I don't want to become isolated, I don't mind my own company, I like my own space, but I don't want to become...isolated [002]*

*people speak to you when you have got a dog, so it is a social thing, and that is important when you, when you are on your own, when you are elderly, that you have, even if it is a 'good morning', or 'have a lovely day', erm...and also when I am down and particularly when I first came to live here, I had an old dog with me then, and then I got a lovely little Norfolk, if I felt down in the afternoon and thought 'oh I haven't spoken to anybody all day', I would put his leader on and off I'd go, and I would come back happier, you know...so I found it therapy really [002]*

The social aspect of walking a dog was also important for P010 and it seems that the social aspect is as important for the individuals than the walking itself.

*you get to talk to people [when walking the dog], I mean I live now, as a retired person a fairly solitary existence [010]*

P002 enjoyed the socialising that she took part in during the study week, with high positive affect (4.7) and low negative affect (0.2) being reported. However, the Sensecam showed that P010 spent much time alone (75%) and she did not report any socialising in the Daily Reconstruction Method. Of the time spent with others in the Daily Reconstruction Method, P010 listed them as 'others not listed'. On the Sensecam, time of socialising occurred when visiting places such as a local office block, or talking to a taxi driver. Most of P010's time spent with others on the Sensecam was during chance encounters when walking the dog.

Although P002 and P010 were the only two dog owners two other participants discussed the importance of dogs on their walking.

*Erm...I don't, I don't go out walking for the sake of it, unless I have got a dog, I quite like walking a dog, I'm in 2 walking*

*groups and I go walking with them, but we only do up to three miles, we don't do long walks... [004]*

*I erm...lead a boring life [laughs] the only time I get a bit of fun is when I take [my daughter's] dog for a walk [laughs]... [I find it ok to walk with the dog] because I can pace myself at it, it certainly doesn't affect my neck, sometimes it affects my breathing, especially if it is a hot day, but fortunately or unfortunately the dog is getting old like me so she doesn't bound around as much as she used to [003]*

P004 discusses the necessity of having a dog for a walk, unless walking with a walking group and she will often '*borrow dogs [laughs] from my friends, and walk their dogs*'.

For many of the participants, specifically P002 and P010, the importance of walking the dog was profound. Not only did it promote exercise, but also psychological well-being from socialising.

#### **5.4.1.1 SUMMARY**

The concept of movement as an *activity* and movement as *participation* was discussed by participants. The Sensecam showed variance in the time spent sitting, standing and lying down over the sample, but time spent sitting down was the most common position for all of the older adults with chronic pain. As well as looking at movement in an objective way, this study, unlike other quantitative studies in this area (Ryan et al., 2009; Spenkeliink, *et al.*, 2002), gained information about movement from the individuals' own feelings of their movement. It was clear that many of the older adults living with chronic pain were mindful of specific movements that affected their pain and that movement directly affected pain, depending upon the pain site. There was much variance between the movement of the individuals, with some of the individuals finding movement beneficial, and others feeling as though movement worsened pain.

The variances in movement over the sample were also evident when discussing exercise, as some individuals remained exercising, whilst others had ceased exercise or were mindful of the adaptations they had made to exercising. These individuals acknowledged their body's restrictions, as a result of pain, reflecting past qualitative research which sums up participants' feelings of their bodies as '*a barrier or obstacle rather than an enabler*' (Thomas & Johnson, 2000, pg. 689).

Of those that took part in exercise, walking was the most common form of exercising seen on the Sensecam. However, swimming was one other form of exercising that was carried out by some of the sample, but was not seen on the Sensecam due to the necessity of it being removed. The removal of the Sensecam during exercise is one explanation as to why more individuals reported exercising in the Daily Reconstruction Method diary than were seen on the Sensecam.

The importance of walking a dog was also highlighted for some participants, especially for two of the participants. The dogs not only kept the participants exercising daily but also helped psychological well-being and lessened social isolation due to chance social interactions whilst dog walking. These chance social encounters were not recorded in the Daily Reconstruction Method, nor were they spoke of in the interviews, therefore

the Sensecam enabled this information to be recorded that would have otherwise not been highlighted. Despite the frequency of walking for some individuals, others often felt that they struggled to walk, and there were many exercises that other individuals felt that they could no longer do due to their pain.

#### 5.4.2 HOUSEHOLD TASKS

The discussion of household tasks incorporates food preparation, household chores and gardening. There were many similarities between the three household tasks that were apparent throughout the interviews, on the Sensecam, as well recorded in the DRM. The relationship between pain and functioning is highlighted within this sub-theme, as well as highlighting the modifications made to household tasks.

The way in which pain affected participatory tasks was evident throughout the interviews. Within the interviews P013 was the only participant that specifically stated cooking did not affect her pain; *'[my leg] never bothers me when I'm cooking'*. P013 prepared food more than any other participant over the study week, according to the Sensecam (9%). It was also evident from the Sensecam that P013 cooked for both herself and her husband (P014) and spent most time cooking in the afternoon. The Sensecam also showed that P013 cooked multiple meals for a friend that she visited twice during the week.

The amount of cooking varied between the participants, with the number of Sensecam images spent cooking being between 0-9% over the sample. Participants tended to enjoy cooking as they self-reported cooking with high positive affect ( $3>$ ) and no, or little, negative affect ( $\leq 1.2$ ) despite the problems with pain that they often faced when cooking. The exception to this was P010 who reported cooking with least positive emotion and most negative emotion over the sample (3.2; 1.2).

Despite the general enjoyment of cooking, it tended to affect individuals' pain. Cooking mainly affected pain in the legs as some participants struggled to stand when cooking for a long period of time, as well as affecting pain in the hands as some participants struggled with tasks such as opening jars. P004 found that *'opening jars and things like that...it hurts my hands'*, which supports the experiences of other individuals, within previous studies. Scudds and Robertson (1998) asked older adults living with chronic pain to complete the Stanford Health Assessment Questionnaire (Fries et al., 1980) which provided 20 statements of which individuals highlighted their ability to complete a number of ADL. Within this study it was obvious that some of the participants had problems with cooking related tasks as a result of pain, as 19.9% of participants had at least *'some difficulty'* opening *'jars previously opened'*, of which 1.2% were completely unable to do this. Furthermore, 23.3% of older adults in the study had at least some difficulty opening a new carton of milk. Although Scudds and Robertson's (1998) self-report data shows the effects that chronic pain has had on some of the cooking tasks of many participants, it does not go into detail as to how, or why, the individuals have *'difficulty'* completing these tasks, whereas it is clear that from this interview opening jars directly causes pain in P004's hands.

As well as struggling to open jars, P004 found that she had difficulty picking up items in the kitchen which affected cooking.

*I mean I can do things with this hand but I certainly can't hold a kettle or hold a sauce...a heavy saucepan or anything like that... it is anytime, I can't [pick them up]...[004]*

P004 also has difficulty picking up some kitchen equipment, due to the pain in her hands, and this was apparent in the interviews. P004 did not report preparing food within the diaries despite images of cooking being recorded on the Sensecam, therefore her feelings when cooking during the study week are unknown.

It is evident from the discussions with individuals, that taking part in cooking affected pain. However, what was also interesting was that the relationship between cooking and pain was two-fold; not only did cooking affect the presence and intensity of pain, but the presence and intensity of pain also resulted in changes to cooking. Although participants spoke of how cooking directly affected their levels of pain, such as pain in the hands from opening jars, pain also affected their cooking habits. P001 suffered from arthritis in her hand and the level of pain experienced at any point affected her experiences of cooking. P001 often found herself '*dropping a lot of stuff*' which resulted in '*mess on the floor*', as well as scalding herself whilst cooking, due to the arthritis in her hands. The individual's arthritis has caused her to feel scared about the potential of scalding herself, and has lessened her cooking as a result of this. It was evident from the Sensecam that P001 tended to spend little time in the kitchen on each occasion and most often prepared smaller meals such as sandwiches and ready-made desserts despite cooking and preparing hot drinks for both herself and visitors. The worry of spilling food and scalding herself also changed the food that she ate; '*I am getting terrible with not eating hot dinners...I am frightened in case I scald myself*'.

Highlighted within this two-fold relationship between pain and cooking, pain also changed the way in which other participants prepared food. Other individuals also often turned to ready meals, or easier methods of cooking, to either stop pain occurring as a result of cooking, or to ease, or not increase, pain already being experienced.

*I'm using sort of jars of pasta sauce and you know I mean I don't buy sort of ready meals as such but I buy ready prepared veg to put in the microwave because I can't stand and peel you know veg erm...and that grieves me really because it was something I enjoyed doing but I can't do it so, and like I say I hate cutting corners like you know I would never have bought well I mean I still don't buy the pies and cakes and stuff but you know I am having to buy the things that are ready prepared and you know it is frustrating yeah, yeah [008]*

P008 discussed cooking '*easier*' meals, rather than preparing meals from scratch, as well as buying prepared vegetables, and also cooked two portions of food at once when cooking (see section 5.5.2).

As well as cooking, there were also modifications made to household chores as a result of pain as some individuals reduced the frequency of household chores and some specific household chores were terminated. Like cooking, there was also much variation between participants' time spent doing housework (1-9%). All individuals other than P004 reported more positive affect (>3) than negative affect (<2) for household chores. P004 states that she does not often carry out housework and she rated household chores as least positive affect (1.9) and most negative affect (1.5) in

the Daily Reconstruction Method over the sample. Furthermore, from the Sensecam it was possible to see the type of housework completed, and this ranged between each participant including washing dishes, washing clothes, ironing and hanging clothes out to dry. Washing dishes was the most frequent task as all older adults living with chronic pain, other than P014 and P015, washed dishes at least once over the study week. Uncommon household chores that were carried out were cleaning the oven (P009), changing the bed sheets (P002, P011) as well as cleaning the car and DIY (P003). The number of occasions spent doing housework were often reduced as a result of chronic pain.

*I don't do housework. I only do it about once every three months. Erm, I find that it makes my arm ache if I Hoover for very long, but I never Hoover for very long [laughs] [004]*

*I clean the house and I like it to look nice but I suppose I look at it like it gets a lick and a promise every week, erm and erm I do the downstairs which is where I am mostly I keep the lounge looking nice, do the bathroom, I normally clean the office once a flood, because it is such hard work, there are so many things that need to be moved erm I mean it is hard work erm [010]*

P004 states that she does not often carry out housework and she rated household chores as having least positive affect (1.9) and most negative affect (1.5) in the Daily Reconstruction Method over the sample. Whereas those affected by pain when preparing food often reduced or modified cooking, housework was also terminated in some cases. For example, P002 found that she struggled with 'housework, ironing, I can't do anymore, you know I can't stand to iron and I have never been able to sit and iron, hoovering...erm'. Furthermore other participants also discussed some of the household tasks they could no longer complete due to chronic pain.

*Ooh I'm an expert at vacuuming [laughs] no well I just potter around the house, do a bit of dust, do a bit of vacuuming... I know that I can't do ceilings, decorating, I can't work with my hands above my head for any period of time, I can change a light bulb but, erm, but if you said to hold that while I change a wire I wouldn't be able to do that for any length of time [003]*

*I mean I can't do much in the way of housework [008]*

*I can't iron a week's washing or anything [008]*

*Oh I don't do housework [laughs] it is a good excuse, don't mention it, no I mean I can't I can't do the cleaning and things like that, only a little bit it is just general tidying so [015]*

The individuals tended to reduce their housework in terms of the number of occasions housework was completed, whereas, those that terminated housework tended to terminate specific household tasks that they could no longer accomplish rather than terminating housework as a whole.

Finally, gardening was also affected by pain and the frequency of gardening seen on the Sensecam varied greatly between participants (0-22%). Gardening was categorised within the 'other' section of the Daily Reconstruction Method, and four of the individuals that were seen gardening on the Sensecam did not report gardening in the diary. P013's Sensecam images showed the greatest time spent gardening, and

took part in the task distinctively more than other participants. Whereas 6 of the 13 older adults with chronic pain, who wore the Sensecam, did not take part in gardening, all of the older adults with chronic pain spent time preparing food and doing housework, despite the differences in frequency. Of the older adults living with chronic pain that reported gardening, enjoyment was high ( $\geq 4$ ) for all but one participant (P004; 2.2), in addition to negative affect also being rated low ( $\leq 0.1$ ) for all but P004 (1.3). As well as data being recorded in the Daily Reconstruction Method and on the Sensecam, individuals spoke of the effects of gardening within the interviews.

*[my back] aches after I've mowed the lawn but you know, I still manage to be able to do it you know [004]*

*doing the garden [affects my leg] because it is on two levels... Carrying heavy bags and when I do the garden, it is not a flat garden; I have got to go up steps and that... 3 hours in the garden and I start to feel it coming on, I feel it coming on and then I so now where it wouldn't have bothered me even a year ago spending the day in the garden I only do it 2 or 3 hours at a time because it does affect me [013]*

*Carrying heavy stuff as well, carrying heavy bags... Like cutting the grass and stuff like that [affects my pain]... Where I use shears and that all day where now if I do it my wrists and my kills [014]*

Despite the participants' enjoyment for gardening two of the participants discussed ceasing their gardening activities.

*I can't do anymore...gardening, I have to do on my hands and knees, and I had a very big garden and spent hours and hours in the garden, and I found that it was very therapeutic you know [002]*

*12 months ago, no it is about 2 years ago since we gave up the allotment?...**No, it is about 3 or 4...** I did give up the allotment, I was managing quite well and another disc went in my back and erm...that affected my legs immediately [006, **006's wife**]*

Both P002 and P006 gave up gardening and this cessation was supported by the Sensecam as P006 did not take part in any gardening during the study week, however, whilst P002 did not report gardening in the Daily Reconstruction Method, the Sensecam showed that a small proportion of the Sensecam images was spent gardening (1%). P002s' gardening was specifically made up of watering the plants, and no other gardening tasks were completed.

#### **5.4.2.1 SUMMARY**

All of the data collection tools provided multiple viewpoints for participation in household tasks. Whereas the Sensecam and Daily Reconstruction Method provided information about the frequency of these tasks during the study week, in the interviews participants tended to focus on more general changes that had occurred with their daily tasks.

Similar to findings from previous research, participants in this study either modified, reduced or terminated some household tasks as a result of chronic pain. Duong *et al.* (2005) claim that '*higher-order physical activities*', which included gardening, were modified by 40% of participants, reduced by 44% of participants and terminated by 50% of participants as a result of pain. Additionally, '*instrumental activities of daily living*', which included both cooking and household chores, were modified by 24% of participants, reduced by 25% of participants and terminated by 17% of participants. However, unlike Duong *et al.* (2005) who failed to give specific details about various aspects of the tasks, this study was able to give specific details about the reduction, modification and termination of household tasks.

A two-fold relationship was also evident when discussing cooking. Participants discussed how cooking resulted in pain, but also discussed how these experiences of knowing cooking resulted in pain affected cooking. Therefore, as well as functioning affecting pain, pain also affected functioning. The awareness that cooking affected pain led to the modification of cooking habits with P001 being more nervous when cooking due to the potential of scalding herself, whereas others began preparing '*easier*' meals, including ready meals.

#### **5.4.3 TRAVEL**

Participants used various modes of travel and it was clear that travelling affected pain. Furthermore, as seen in the previous sub-theme, there was a two-way relationship between chronic pain and travel; travel was discussed as both a task which affected pain, and a task which pain affected.

The Sensecam was an invaluable tool in exploring transport issues as it showed that all older adults living with chronic pain commuted at some point during the recorded week, although only six of these participants commuted every day, meaning that seven of the participants did not leave the house for at least one day during the study week. Older adults living with chronic pain typically travelled to either take part in practical tasks, such as going to the supermarket, the post office or to walk dogs, or alternatively to take part in leisure tasks, such as shopping in the town centre, attending social groups and visiting friends. Despite frequently travelling, recorded '*commuting*' within the Daily Reconstruction Method was low, with only four of the 13 older adults living with chronic pain recording any commuting over the study week, and those that did reported low levels of commuting. This may be due to the interpretation of '*commuting*'; whereas I interpreted commuting as any time which involves travelling to and from a destination, some may perceive commuting as travelling to and from work which may have led to reduced reporting of commuting. Alternatively, commuting may not have been reported for other reasons, including its lack of importance for some participants. Of the only participants to report '*commuting*' in the Daily Reconstruction Method P005 was the only participant that did not enjoy commuting, reporting low positive affect (1) for this task, although negative affect was also rated low (0.2).

From the Sensecam it was evident that most of the participants drove a car in order to commute (n=9), whilst walking as a form of commuting was low with only three of the participants doing so over the study week. The Sensecam images showed that car journeys varied in length and there did not seem to be any adaptations or problems

with driving recorded on the Sensecam, however, individuals spoke of problems when travelling within the interviews. Driving was also most often discussed in the interviews as a source of transport, however not all individuals were drivers and some individuals also felt pain when using buses.

*to come from Newcastle [on the bus], it takes about an hour and 35, 45 minutes...I don't actually go and use the bus very much, I love to, and I intended to, but it was just too long of sitting and being rocked [002]*

*Yes, yes [the buses are ok to use]...[when walking to the bus stop] I can walk so long you know, really it is more my legs are stiff but I am more breathless, it stops me from walking further again you know but the legs are stiff like [012]*

There were two separate issues for the individuals whose bus journeys were affected by chronic pain. One individual's pain arose as a result of sitting for too long and 'rocking' on the bus, whereas the other individual felt stiffness as a result of the walking distance to the bus stop; despite the differences, both participants are affected by bus travel. Bukhave and Huniche (2013) conducted a qualitative study which also brought up issues related to travelling, including issues with transport. The participants within the sample specifically suffered from osteoarthritis in their hands, and they avoided using public transport as they were worried that if they could not get a seat, they would struggle to hold the bars when standing. It is apparent that experiences of using public transport, and the issues that individuals consider are related to the pain site, as P002 and P012 suffered from pain in their legs and lower back therefore their issues with public transport were different to individuals suffering from osteoarthritis in their fingers.

Bukhave and Huniche (2013) also highlighted issues that participants had when driving, such as holding the gear stick and steering wheel, opening the car door, as well as retrieving petrol from the petrol pump. Most of the older adults living with chronic pain within this study drove and driving also caused pain for some of these drivers.

*if I go on a long journey now I do get erm cramp in the tendons in my right leg, my hips tends to ache a little bit, but that's because I have got an automatic, the foot is in the same position all of the time, all I am doing is with the right leg and it is this side which is the problem. [003]*

*[The pain in my knee] affects me sometimes when I'm driving, using the clutch you see, I'm alright in the motor home because that's automatic so I can stretch my leg out while I'm driving, but when I'm driving in the other car my knee is at a right angle you see and that is the problem [005]*

*[Driving] affects as I said it affects my erm, sometimes it gives me a lot of pain in my right rib, or the ribcage itself erm, but that it just the car seat and the length of journey but if I drive it now down to Oxford, we generally stop off after about 2 hours and we have to get myself out of the car because I am in a lot of pain so I get up out of the driving seat but it does go off when I walk and wander around the car park or whatever but it does go off... And then I carry on [009]*



Driving caused pain for some drivers, however, similar to the findings from Bukhave and Huniche (2013), it was not just the actual driving that affects pain; P004 discussed the issues she has whilst getting petrol as it hurts her hands; *'I use both hands, getting petrol too, I have to use both hands to get petrol now'*. Scudds and Robertson (1998) also exposed issues with commuting using cars that were not related to the actual task of driving. When older adults living with pain were asked if they had any difficulties getting in and out of the car 44.3% of them had at least *'some difficulty'* doing this. Furthermore, 15.3% of the respondents had at least *'some difficulty'* opening car doors. It is therefore evident that it is not only the task of driving itself, but other tasks surrounding the driving experience, such as getting in and out of cars, and filling the car with petrol, that affects pain as a result of commuting by car.

It was not only driving that affected chronic pain, but like the relationship between household chores and chronic pain, the relationship between pain and driving is not only one-way. Although driving affects pain levels, pain has also affected driving levels. Two individuals discussed their driving being affected as a result of chronic pain in two very different ways.

*the fact is that I am much more reliant on the car than I ever was, I would deliberately walk the other thing is that I cannot carry things, I cannot carry things, I need a handbag that I have strapped across me, I cannot bear the weight, no carrying anything is erm...is awful...anywhere where I push a trolley, I do not park right on the doorstep, I think come on walk to it, so yeah, yes, I have become more reliant on the car, and I was hoping that when I moved here, well I wasn't, I walked everywhere, I would walk to the doctors, I would walk into town for a newspaper, or a bit of shopping, I would walk to the the library, I don't and that has certainly changed, so yes, I suppose...life has changed because of my back [002]*

*I mean driving with arthritic hips and knees is very, very painful, so much so that if I had been out and had to drive down to York, or up to Berwick, or somewhere in the wilds of Northumberland or Durham or erm the Yorkshire dales, I could control the pain with my head until it was time to come home and I would drive home in absolute agony and I quite often, erm I mean it was stupid, I would get as far as the services at Washington and knew that I had to get off the road and I would drive into the car park, put up I have got a little sort of soft quilt, put my chair back and wait until I woke up but that was simply that I had gotten through a lot of work, I had done a lot of walking, I had done a lot of writing, I had seen a lot of people, I had driven a long way well, not necessarily a long way but if you are driving up near Swaledale, or around the wilds of Durham it is not easy driving, erm and I have been able to concentrate, keep my mind on the job and as soon as I had turned for home, my brain would say 'right I have had it' and cut out and then I would be on the A1 thinking, it is still 50 miles, so it I mean I could, I used to, I used to have to decide whether I'd have to rest at Whetherby and could I make it to Bowburn or Washington but Washington is all of 12 miles from here and yet I could not have driven those 12 miles, not at all [010]*

One individual discussed feeling more reliant on the car since developing chronic pain whereas the other individual discussed her problems related to driving, specifically the problems she has driving long distances. Therefore, in a way similar to other ADL, it is

not just chronic pain that affects driving but driving also affects the pain for these participants.

The frequency of travelling did not much differ between older adults living with chronic pain, younger adults with chronic pain and older adults without chronic pain according to the Sensecam images and all but P019 (older adult without chronic pain) commuted every day. Both younger adults with chronic pain and P019 (older adult without chronic pain) drove whereas P018 used public transport as her sole mode of transport. P018 used the bus at least twice each day. Despite the frequent use of transport seen on the Sensecam, only one younger adult with chronic pain (P017) and one older adult without chronic pain (P019) reported commuting in the Daily Reconstruction Method. Neither younger adult with chronic pain nor older adult without chronic pain discussed issues with transport during the interviews and did not need assistance whilst travelling.

#### **5.4.3.1 SUMMARY**

It was clear from this sub-theme that there were various modes of transport that affected participants' pain. Walking was rarely used as a method of transportation, with driving being the most common mode of transport over the older adults living with chronic pain. The use of buses and taxis were also apparent. Most individuals drove when commuting, and once more, variances in the effect that functioning had on pain was demonstrated. Whereas some drivers did not experience worsened pain due to driving, others experienced increased pain due to a number of factors. As well as participants experiencing pain in their legs when driving, like Bukhave and Huniche (2013) one participant also experienced pain when using the petrol pump.

Furthermore, the reciprocal relationship between pain and functioning was once again evident, as not only did participants discuss the effect that travel had upon their pain, but also the effect that pain has upon travelling.

#### **5.4.4 SLEEP**

Sleep disturbances have been described as one of the most common symptoms of chronic pain (Smith & Haythornthwaite, 2004) and some of the participants within this study discussed the effect that pain had on their sleeping habits. Within this study there were three separate issues that arose from individuals having a problem with sleep; pain caused due to lying down, strategies used to try and overcome this pain, and the lack of energy individuals had due to lack of sleep. Neither one of the older adults without chronic pain discussed any problems whilst sleeping.

Sleeping was also not an issue for P016 (younger adult with chronic pain).

*I used to [get pain while I slept] but I don't anymore I haven't had that for ages [016]*

Other than P016, most other participants living with chronic pain discussed the issues between sleep and chronic pain. Lying down affected individuals' pain in numerous ways; for some, pain affected them whilst they were in bed trying to get to sleep.

*[The pain in my foot] does cause quite a few problems especially trying to get to sleep [003]*

*on a night, I can be, it can be very, you know it can keep me awake at night but fortunately it is only the one leg you know [013]*

*I mean that's you do get sleep deprivation with the arthritis if it is bad... You just can't sleep you know because you bear the blankets on you or anything you know so you do get sleep deprivation [014]*

Whereas P001's sleep was 'disturbed' when 'turning over', and moving in general, caused pain whilst she was lying down in bed 'because every time you move the pain sets away'. One other issue with sleep was the action of lying down which resulted in pain when some older adults living with chronic pain arose from bed the next morning.

*[Back pain occurs] usually when I'm flat on you know, when I'm trying to get up and ohh it just catches me, but on the whole you know it doesn't really bother me [004]*

*The thing is I can't sleep on my side because of my hips have been painful, sleeping on my back all night, when it comes to getting up in the morning it takes a while to get gently out of bed but I can do it [laughs] [007]*

*I am stiff when I get up in the morning but that is not pain that is just the fact that I don't move in the night erm, and even when I am not encased in hot water bottles I don't move in the night anymore, I don't have the, turning over is an act of will, I need to, I have now have at the moment, I have a card bed and it has wood sides and I have found that makes it easier because I can get one foot on that ledge to push me over [010]*

Lying down caused pain in various sites and affected sleeping patterns. This may go some way in helping to explain the low occurrence of lying down during the day. The Sensecam showed that despite the high frequency of some sedentary tasks, only 5 older adults living with chronic pain lay down during the week, and frequency was low for all older adults living with chronic pain ( $\leq 6\%$ ) other than P014 who lay for 22% of his week. P014 tended to lie down to watch TV for long periods and this most often occurred on an afternoon for 5 of the 7 days recorded. However, the low amount of time spent lying down may also have been due to individuals removing the Sensecam during these periods as only P001 took a nap, whilst lying down, whilst wearing the Sensecam, whereas 9 of the older adults living with chronic pain reported 'napping/resting' in the Daily Reconstruction Method (although of course napping/resting does not always involve lying down). As well as pain affecting the individuals during the night, or whilst trying to get to sleep, pain also wakes some of the individuals.

*Sometimes I wake up and [my wrists] are aching yes but on the whole not, no... I kind of massage them myself so I don't really take anything on, it is not that bad, but I often wear a thing around to support my wrist [004]*

*Yeah sometimes [pain affects my sleeping], erm a couple of months ago when I turned over in the night it woke me up but that is the first time that has happened for ages [009]*

Three of the participants that discussed problems with sleeping also discussed strategies which they used to try to overcome their issues, as well as one of the younger adults with chronic pain.

*I can't lie on my back whatsoever account of my neck, I also have to have a flat pillow, very very flat to put on my shoulder, to lie my head on, I can't use a normal pillow [001]*

*I have tried a system of pillows when I've been in bed, trying 1 pillow, 2 pillows, 3 pillows, I have came down to 2 but it still doesn't do a lot, you know, after a while your limbs go tingly and I think it is all down to this [points at his neck] [003]*

*I can't sleep on my right side and only with a lot of planning can I sleep on my left side because I have got to wedge my right arm into a position where it does not hurt so normally I sleep on my back with my right arm on a hot water bottle summer and winter alike, that...stops the pain well I don't suppose it stops the pain but it reduces it to a point where I can sleep now, I did have a point where I wouldn't sleep very well erm but on the whole I think [010]*

The individuals used pillows, hot water bottles, or their own body position in order to try and reduce the pain they experience whilst lying down. One younger adult with chronic pain also used strategies whilst trying to sleep.

*sometimes I used to use a wedge in the bed erm just a foam wedge and lay with my feet up and I found that eased it and it took some of the swelling down [017]*

Furthermore, P012's strategy for sleeping better involved sleeping alone, with her husband sleeping in another room.

*I am very restless, I always was in bed I have always been twisting and turning but when you are aching, I daren't put my legs down, you know when you want to put your legs down and get on your back, oh they are painful then mind... that is why I'm sleeping by myself really... well when I had that knee done you know I was frightened that [my husband] would knock it well he is very quiet, he sleeps and he doesn't snore or anything, and he gets into bed and he lies and that is it he does not move and me I am this way, that way and t'other way so I went I there because it was painful, ee I mean getting that done was painful and erm he erm, I went in the other room I said ee I will have to get out of the way, I was frightened that he would knock me even though he is a very good sleeper you know that is why I have been ever since really, but I think he enjoys being by himself now, well we both do you know, it is nice having the bed to yourself [012]*

The participant explained the pain that she experienced in her leg, and that she was also scared of her husband knocking her leg whilst sleeping, therefore the couple began sleeping separate. Lack of sleep due to the presence of pain was not the only issue for individuals. Some individuals believed that their pain resulted in being 'drained' and lacking energy.

*the pain I have got drains me so badly that I could sleep most of the day in fact, and I do, I am much better for a siesta, and only I*

*only need half an hour, I am like Winston Churchill, I like getting into bed, putting my alarm on, draw the curtains and get up whether I give myself half an hour, ¾ of an hour or an hour I am better for that because it then means I have got energy to address the evening [010]*

*Erm I haven't as much energy as I had, I sleep a lot more [015]*

The individuals are aware that their pain reduces their energy levels, and they need more sleep than they did previously. Previous research has suggested a reciprocal link between chronic pain and sleeping, as pain negatively affects sleeping, but on the other hand, poor sleep worsens pain (Tang et al., 2012). Although the participants within this study describe the impact that pain had upon sleep, and acknowledge the consequences of this as lack of energy, the participants do not discuss worsened pain as a result of not sleeping.

#### **5.4.4.1 SUMMARY**

Smith & Haythornthwaite (2004) have described sleep disturbances as one of the most common issues related to chronic pain and within this study participants described issues with sleep. Firstly, pain interrupted sleep due to its presence whilst lying down and this caused individuals to use strategies to overcome this pain whilst trying to sleep. Finally, two older adults living with chronic pain discussed their need for increased levels of sleep due to persistent pain draining the individuals' energy.

#### **5.4.5 RECREATIONAL TASKS**

A range of recreational tasks, which includes both social interactions and leisure tasks were affected due to the presence of chronic pain. Often, leisure tasks were terminated due to the movement involved in the task, such as walking or long periods of sitting. Individuals also discussed socialising and the importance of spending time with both friends and family was apparent throughout the interviews. Information regarding recreational tasks was apparent within both the Daily Reconstruction Method and the Sensecam.

Every older adult living with chronic pain reported spending at least one episode alone and one episode with others in the Daily Reconstruction Method during the study week, therefore all individuals spent time with others at some point during the study week, although this varied throughout the sample. Seven of the 13 older adults living with chronic pain spent more time with others than alone (P003; P005; P006; P009; P013; P014; P015), compared to the six older adults living with chronic pain that reported spending more time alone over the study week.

As well as time spent socialising, leisure tasks were also recorded in the Daily Reconstruction Method, and occurred both alone and with other individuals. Most of the recorded leisure tasks tended to be sedentary. Although some leisure tasks were listed in the Daily Reconstruction Method, specifically, 'computer/internet/email', 'watching TV', 'shopping' and 'relaxing', other leisure tasks were recorded within the 'other' section of the Daily Reconstruction Method, for example, visiting the library (P003), practising the piano (P004), knitting (P005; P015) and baking (P010). Watching TV was one hobby reported frequently in the Daily Reconstruction Method

with all but three participants reporting watching TV during the study week. Frequency of listed leisure tasks was high, other than being on the computer, internet or email, with only six of the 13 older adults living with chronic pain reporting spending time doing this task. Otherwise, watching TV, shopping and relaxing were carried out by much of the sample according to both the Daily Reconstruction Method and also the Sensecam, and the enjoyment of these leisure tasks was also apparent.

The Sensecam also showed some tasks that were not listed, or reported, in the Daily Reconstruction Method. The Sensecam showed that all participants read at some point during the study week and it was a frequent leisure task for many older adults living with chronic pain over the sample (ranging from 2-35%). Reading most often consisted of newspapers and magazines, rather than books. Reading was always carried out whilst relaxing, and sometimes occurred at the same time as watching TV. As well as reading, many of the participants completed daily puzzles, most often the crossword in the newspaper (P002; P008; P010). Participants spent much time doing the crosswords in newspapers, often intermittently in-between reading the newspaper, and doing other tasks. One other method of relaxation was playing games on the PC. Some of the PC users specifically played games such as solitaire during periods of down-time (P003; P015). However, not all hobbies were either recorded on the Daily Reconstruction Method or seen on the Sensecam, either because individuals did not take part in a particular hobby during the study week, or individuals did not record that hobby in the Daily Reconstruction Method or on the Sensecam, therefore, the interviews provided additional information regarding hobbies.

Interestingly, the hobbies recorded in the Daily Reconstruction Method, and viewed on the Sensecam, were not those discussed in the interviews as individuals tended to discuss the hobbies that they have terminated as a result of chronic pain, as opposed to those that they have maintained. Within the interviews both P001 and P015 describe two hobbies which have been ceased as a result of chronic pain.

*I can't get up and dance obviously, but I can listen to the entertainment [001]*

*[The pain] has interfered with hobbies, because I do a lot of, I did a lot of quilting, I can't bend over to cut the fabric, most of the time I have to have somebody to cut the fabric for me, I have to have somebody to lift my sewing machine up onto the table all of those sorts of things you just do without thinking so it is really affected that, yeah [015]*

For both older adults living with chronic pain, it was problems they had with movement (i.e. dancing and bending) that resulted in the termination of hobbies. However, P001 also described the changes to hobbies as a result of her co-morbidities, namely restricted eyesight. As well as chronic pain affecting dancing, her restricted eyesight resulted in the cessation of both embroidery and reading. P001 stated that there was nothing else that she 'could take up' and instead tended to 'just watch the television'.

P002 also terminated various hobbies as a result of chronic pain and there were a number of movements that affected the individual's pain.

*last Saturday Warkworth had put on a foreign film in the memorial hall, and I like going to the playhouse in Alnwick, but I*

*stopped going because I, if I sit there for a couple of hours I can't move and it is painful until I get going [002]*

*I belonged to a birding club and I loved it, and it always made me feel better since you know after my husband died...and I don't do that, and that I regret, but I have got to be sensible, I can't, I can't do it, but you know the memories are wonderful [002]*

*I hate now shopping, if someone said come to Newcastle, years ago I would have said 'yeah, ok' and I would have had a stroll around the shops, gone and had coffee or lunch, now I avoid it like the plague, because it is just so painful and you're doing things so slowly and you're standing about, taking a lot of weight, so I'm not too bothered about missing the shopping but life has changed [002]*

P002 ceased going to the playhouse and also birding club due to sitting in one position for a long time, but also terminated shopping due to walking and standing around. It is therefore clear that P002 has terminated more than one hobby as a result of chronic pain, and these tasks have not only been terminated for only one reason, but issues with various movements have resulted in changes to multiple leisure tasks.

Although some leisure tasks has terminated, some individuals remained socially active, usually as part of various organisations over the region, such as local social groups and the University of the third-age (U3A), and this seemed to affect their functioning greatly.

*I don't [think I'd be as active without the U3A]...getting involved with the U3A gets you thinking, gets you meeting other people and doing other things and finding out what is available out there [003]*

*Monday's I do folk dancing one week, the next week it is a poetry class, a lot of them are alternative weeks, on a Tuesday I do one week of water colour painting and the next week it is reading, erm...Wednesday I go walking, erm...I go to music group in the morning sometimes but that isn't with the U3A, Thursday...erm, I can't remember what I do do now, Friday I go to philosophy and once a month it is gardening on a Friday but then on Friday afternoon I also belong to a band and a choir and we have practise in the afternoon, and on a Monday night I go to the Cobweb orchestra and erm...erm, the community choir, once a month I go to a ceilidh band practice [004]*

*On Saturday nights from 7 o'clock until half past 8 we play bingo for chocolate bars and it is just like a, a home party you know getting all of your family together, and what else did we do, we do something on Thursday's but I can't remember...we only play scrabble on Tuesday...hmm, I can't remember, I know that it didn't interest me so I don't bother with that, no...and if you, if you get fed up of being in your own flat [007]*

*[My social life] has got well since we joined the U3A, we know more people up here, you know I suppose because I'm retired fully than I did when I was in Abingdon, in Oxford [009]*

*This afternoon [in the lounge downstairs] they have got, some of them come to do exercise because we have got the wii machine a few weeks ago and they have the coffee morning on a*

*Wednesday and they have the bingo Tuesdays, Thursdays and Saturdays and we have an art class on a Monday night and a Friday morning [011]*

*[I] have been secretary of the U3A so that has kept me occupied and bits and bats like that so sedentary things [015]*

The organisations provide many tasks for the individuals, including groups, meetings and social outings. It was apparent from the Sensecam that the formal social groups led the participants to spend time with others in various groups, such as lunch groups, bingo, knitting club, folk group, art class and play reading class. Of the participants attending the formal social groups much of their socialising was made up of this type of interaction. These groups usually took place in external settings, such as community centres and local pubs, and individuals travelled in order to attend the groups. However, for P011 the groups took place downstairs in her apartment block, which was home only to individuals over 55 years old. During the study week the participant visited a coffee morning, which also involved bingo, and an art class. Although not a formal social group, P014 visited the pub for a long period of time one afternoon. The participant was not at the pub with his wife, and walked to and from the pub alone, but socialised with a small group of men whilst there. However the attendance of the social groups did not always mean that these individuals socialised more than non-attendees. P001 did not attend formal social groups, but socialised a lot throughout the week. Furthermore, P006, P011, P013 and P014 did not attend social groups but socialised more than some of the attendees. Some of the participants were also involved in the organisation of some of the clubs, which also increased participation in events. There were some social tasks other than formal social groups that were unaffected by chronic pain.

*This Thursday I am going out with the girls we go out for a meal and erm about once a month and then another set of friends I meet on a lunchtime at Penshaw garden centre because they have got a nice café there [008]*

*usually I meet my sister in law on a Tuesday and we tend to go up to the coastline, Tynemouth, Whitely bay if it is a fine day we walk around and have something to eat [011]*

*Not really [pain] doesn't [affect the way I socialise], the type of socialising we do is eating and drinking [laughs], and eating gets me fat, and the drink gets rid of the pain [laughs] no no, I don't mean that [laughs] yeah...I mean we go [to drawing class] at 1.30 and finish at 3.30, 4 o'clock, just socialise with those people at those times, with erm...[the group leader] and her husband, and another couple, we have gone out for a meal occasionally with them but that is about as much socialising with the U3A we do with the them outside of meetings and activities [003]*

Some of the individuals' social lives were active however, despite P003 feeling that his social life had not been affected by pain, he left work as a result of his pain, which affected him socially as he missed his workmates; *'the only thing that I miss about erm, leaving work is all of the people, you know the staff that I worked with were fantastic'*.

For some participants, they recognised changes to social interactions. P002 recognised that her social life was changing, and discussed the necessity of making



'more of an effort' to remain socially active and P001 also felt that her social life had been affected by chronic pain. P001's social life had been affected in a different way P002. Rather than her social life being affected by physical restrictions such as problems sitting in another chair, or lack of effort to go out, the participant recognised the emotional aspect of pain which restricted her.

*if your pain is really bad you are not going to go out socialising, because you don't want to make them miserable do you [001]*

*Well if you are miserable, if you have an awful pain and they are sitting, laughing, talking, carrying on, it is not fair to them, you need to go out and, it doesn't matter if you're in a little pain, you wouldn't think about it, but if you're really really bad, the pain, you just don't go nowhere [001]*

*I don't want to make everybody else feel unhappy, or uncomfortable really, I don't want to make other people uncomfortable [001]*

The participant felt that she did not want to socialise with others when she was in a lot of pain as she did not want her unhappiness to be projected onto others. This has also been observed within past literature. Osborn and Smith (1998) conducted a qualitative study with females living with chronic pain. Three of the participants within Osborn and Smith's study reflected this view and also acknowledge their reluctance to socialise with others as '*the last thing people want to hear is what your misery is*' (Osborn & Smith, 1998, pg. 74) and they also feared that they might '*spoil their fun*' (Osborn & Smith, 1998, pg. 74). These participants, like P001, became more socially isolated as they did not want to tell others about their pain for fear of making them unhappy too. However, contrastingly, Roberto (2001) found that the older women with chronic pain taking part in the study tended to confide in their friends about their pain experience, and these relationships helped the women to cope successfully and lessened isolation. Roberto (2001) proposes that the '*women and their friends often shared strategies for managing pain*' (pg.68). One explanation for the differences between the chronic pain sufferers over this study, Osborn and Smith (1998) and Roberto (2001) may be the social setting in which they are partaking, and the individuals in which they are talking to. Whereas it may be beneficial to talk to other individuals with chronic pain, as a way to discuss strategies of managing pain, or discuss the pain experience with another person that understands that experience, other individuals may socialise with non-pain sufferers which may make a difference in the information that they discuss with regards to pain. It was apparent from the interviews that socialising was very important for P001 and it was apparent that she was lonely living by herself.

*well I cope, I mean I hate being by myself, believe me it is terrible [001]*

*I get company as I like to talk, you will see that on here, erm, that is because I'm on my own, and when anyone comes I can't shut up, the nurse can't get out with me talking [001]*

*Focusing on the holiday is just going away to be with people really, because I'm on my own, I'm lonely, and I like my holidays [001]*

The individual suffers from issues of loneliness despite frequent social interactions. The individual finds the company of others extremely important, and relies on the company of not only her friends, but also her family, to provide this happiness. P001 continuously discussed how happy her family made her, and the importance of family was clear.

*they are my life, they are my life my children...my grandchildren, my great-grandchildren [001]*

*we had a lovely mother's day together and we went, erm my friend pushes me around in the wheelchair so she came and pushed me about and we went to the park and we came back to my daughters and we had a lovely rest of the day there and I thoroughly enjoyed it [001, 2]*

*be thankful for small mercies really I have got my family, my grandbairns, my great-grandbairns and I love them all anyway [001, 2]*

This participant enjoyed social interaction and also clearly enjoys the company of her family.

P010 was the participant with the least amount of social interactions during the study week and stated leading 'a fairly solitary existence'. Like P001, P010 also lived alone and did not seem to be involved in many social interactions. This individual tended to be socially isolated, and got all of her social interactions whilst walking the dog, as discussed in 'effects on daily living'. P010 reported the least variation of interactions as she only reported spending time with 'others not listed', with an average of 2 episodes a day spent with these individuals. P010 did not report spending time with anyone else. Furthermore, although P010 reported spending time with others, she did not report socialising in the Daily Reconstruction Method during the study week. When seen socialising on the Sensecam, P010 took part in chance socialising, specifically when walking the dog. Social interactions were not always planned and there were some chance meetings seen on Sensecam images. Chance meetings were most common during times of commuting and whilst walking dogs. For example, P008, although not often, did speak to passers-by whilst commuting on her electronic scooter, and P015 pulled over on the road whilst driving to chat to a passer-by. Both P002 and P010 often spoke to passers-by whilst walking their dogs. These chance interactions led to a small amount of interaction between individuals. However, not all commuters, even those using transport, interacted with others on their journeys. One individual (P012) also met a friend whilst shopping street in town.

The Sensecam showed nine of the older adults living with chronic pain visiting others' houses throughout the study week with P011 spending much of her time at others' houses, but did not have others visit her. Furthermore, as previously discussed P013 visited her friend and helped him with household tasks as well as socialising with him. P012 also mentioned the enjoyment of speaking to other individuals, at encounters such as whilst shopping.

*I like Wilkinson's I like to look around, go on the bus, go there, come back and get the bus, there is no walking or anything then back home you know and I did that the other week, I wasn't out long but I enjoyed it... It is just you meet*

*people and you have a bit natter you know, because [my husband] doesn't talk much you know so that is it but when the weather is, how I stopped going out not as much [012]*

Many of the participants cherish social interaction, and it is a clearly important part of their daily living. The importance of others was apparent for many of the participants within the Daily Reconstruction Method. As well as retrieving time allocation information of time spent alone or with others from the Daily Reconstruction Method, the feelings of the participants whilst alone or with others were also retrieved. The Daily Reconstruction Method showed that the vast majority of older adults living with chronic pain (n=11) preferred spending time with others than alone. The exception to this is P006 who reported higher positive affect when alone (6) than with others (5.8) although both were high. However, interestingly, although negative feelings when spending time with others was low over the sample ( $\leq 1.3$ ), five of the participants (P001, P003, P004, P005, P006) reported more negative affect when with others than alone, despite all five of these older adults living with chronic pain also reporting more positive affect when with others than when alone. P013 and P014 reported equal negative affect when alone and with others.

Despite socialising, time spent alone was also frequent and eight of the 13 older adults living with chronic pain spent more time alone than with others. Time spent alone was generally frequent over the sample, specifically for those living alone. Only one participant living by herself (P001) spent more time with others than alone, despite living on her own. The participant was continuously visited by friends and family, as well as other individuals such as her cleaner, and the nurse, but she did not attend any formal social groups. The participant also spent all of her time with others outside of the house, due to the dependency that she had with others pushing her wheelchair. Of the three other adults that spent more time with others than alone two of the participants had a very low number of images alone; P006 and P015. Both participants lived with their partners, and P015 also lived with her daughter, and both spent most time with them. However, P015 spent some time socialising with others at a formal knitting group and at a group meeting. Contrasting to the high amount of time that these four individuals spent with others, P004 spent the most amount of time alone. P004 was single and lived alone. The Sensecam showed that P004 did not attend any social groups throughout the study week. Of the small time socialising P004 interacted with friends. There were three specific social encounters captured on the Sensecam, the first being when the participant was visited by another individual to play their musical instruments, on one occasion the participant visited a friend's house and finally, the participant interacted with two individuals that visited her home.

Episodes spent alone or with others did not differ much between older adults living with chronic pain, younger adult with chronic pain and older adult without chronic pain with similar patterns being seen over the groups. Both younger adult with chronic pain spent more time with others than alone, and both were married and living with their partners (P016 also lived with his son). Despite being married, P018 spent more time alone than with others, however, P018 spent more time alone during the study week as his wife and daughter were on holiday with their daughter, therefore, he spent more time alone despite being married and living with others. P019 was single and recorded spending more time alone than with others. One difference was the type of interaction and as well as spending time with co-workers, P017 also spent time with their 'boss'

and 'clients/customers'. Furthermore, like some of the older adults living with chronic pain, P018 who was retired, also reported spending time with 'students/patients'.

#### **5.4.5.1 SUMMARY**

Socialising and leisure tasks were much discussed by individuals, and it is clear that there are many differences between the participation in social and leisure tasks throughout the sample. Whereas some participants remained socially active, and involved with hobbies, others reduced or terminated these tasks.

Many participants in this study terminated leisure tasks due to the movement involved in the tasks. Previous research has also highlighted the termination, reduction and modification of recreational tasks. Duong *et al.* (2005) found that 'social/recreational' tasks was one of the categories most affected by pain, which included going out, dancing and hobbies, along with social tasks. Overall, 11% of the individuals modified, 39% of the individuals reduced and 52% of individuals terminated social/recreational tasks completely. This study adds further detail to this information, as it is not only evident that those participants both modified and terminated their recreational tasks, but the reasons behind the changes are explored. Leisure tasks were predominantly terminated due to the movement involved in the tasks. However, not all recreational tasks were terminated as there were a variety of recreational tasks recorded in the Daily Reconstruction Method and on the Sensecam, specifically socialising. These tasks tended to be sedentary and included knitting, watching TV and reading, among others.

Whereas many individuals ceased taking part in recreational tasks, including social tasks, due to the movement involved in the tasks, for P001, it was the psychological aspects of socialising when feeling pain that hindered socialising, as the individual did not want her own unhappiness to affect others, once more, these findings support previous research (Osborn & Smtih, 1998).

#### **5.4.6 SUMMARY OF EFFECT OF DAILY LIVING**

There were numerous sub-themes that made up the theme '*effect of daily living*'; movement, household tasks, travel, sleep and recreational tasks.

This theme has captured the importance of numerous ADL and the effects that chronic pain has had upon them. Each ADL was affected for some individuals, but not others, and were also affected in different ways for different people. Details of why and how these tasks were affected have also been captured within the Daily Reconstruction Method, Sensecam and interviews.

Rather than solely being able to state that certain ADL have been '*reduced*', '*terminated*' or '*modified*' by participants, this theme has demonstrated the various reasons as to why individuals have changed these ADL.

The main reason as to why individuals modified ADL was due to the relationship between pain and functioning. This relationship was also described as reciprocal for some tasks in that the presence or intensity of pain affected involvement in the task, or

involvement in the task affected the presence or intensity of pain. This two-way relationship between pain and functioning was apparent throughout many of the ADL.

## 5.5 MANAGING PAIN AND FUNCTIONING

In addition to speaking of the effects that pain had upon daily living, participants also spoke of the various ways in which they managed their pain and functioning. There are four sub-themes that contribute towards this theme; *'biopsychosocial perceptions of coping'*, *'use of strategies'* and *'use of assistive devices'* and *'reliance on others'*.

Managing pain and functioning was focused on *'coping'*. Coping has been given various definitions, but the most widely cited definition within health literature (e.g. Adams, Poole, & Richardson, 2006; Richardson & Poole, 2001) is that provided by Lazarus and Folkman (1984) within the *transactional model of stress and coping*:

*...constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (p. 141, Lazarus & Folkman, 1984)*

The discussions in this study, as well as the data gathered by the Daily Reconstruction Method and Sensecam, highlight both *'cognitive efforts'* (i.e. biopsychosocial perceptions of coping) as well as the *'behavioural efforts'* (i.e. the use of strategies and use of assistive devices) as described by Lazarus and Folkman (1984).

### 5.5.1 BIOPSYCHOSOCIAL PERCEPTIONS OF COPING

Over the sample it became apparent that participants inadvertently discussed the various aspects of coping as a biopsychosocial experience. Some individuals spoke of *'biological'* coping; such as having a higher pain threshold, or taking medication to reduce pain as well as age being a biological barrier. Other participants discussed their *'psychological'* coping beliefs and strategies whereas others talked about their *'social'* situation and how other individuals affected their coping. However, participants tended to think of their coping strategies as being made up of some biological, psychological or social aspects, as opposed to being a holistic biopsychosocial experience. Although some individuals managed their pain as a result of these coping strategies, coping constantly changed, as also described by Lazarus and Folkman (1984), and participants also discussed their feelings when they felt they were not coping with their pain. Participants used descriptive words such as *'frustrating'* [P002, P006, P008], *'annoyed'* [P012] *'aggressive'* [P006], *'irritable'* [002, 009, 013] *'short tempered'* [P010, P015] and *'snappy'* [P002, P009, P017] to demonstrate how they sometimes felt as a result of their pain. The psychological impact of pain was obvious by the feelings that individuals expressed, and was even more so shown by P015 who discussed being in an extremely negative state as a result of chronic pain.

*I was ready to just erm overdose and that was it, it got so bad and within a fortnight, well it is not just the pain because when I get the pain it affects my bowel function [015]*

The participant's pain, as well as the side-effects that it caused, made her *'ready to overdose'*.

Perceptions of coping were sometimes discussed in '*biological*' terms by some participants. Individuals denoted two ways in which they felt that their coping was affected physiologically; due to their high pain tolerance and due to the use of medication to reduce pain sensation. Although both of these strategies are '*cognitive*' in that they are the outcome of a cognitive strategy of dealing with pain (Keefe, Salley & Lefebvre, 1992) it is the source of this cognitive strategy that is perceived to be biological by the individuals.

P004 believes that she copes with pain due to her '*high [pain] threshold*', as does P006; '*I can tolerate pain very well actually*'. However, P006 states that he relies on medication if the pain becomes too much. Other individuals also stated that they relied on medication to '*handle*' pain.

*I'll take anything that is going to help me...I will [001]*

*[We can cope] well as long as we have got the proper medication [014]*

*I will tolerate [the pain] as long as I can then I will take the tramadol or a couple of tramadol and that will last me the best part of the day so [017]*

Participants specifically discussed the ways in which they can manage their pain due to biological processes, however, contrastingly, the body was viewed negatively within the qualitative synthesis of papers looking at experiences of living with chronic pain (Toye, et al. 2013). From the review of 77 qualitative papers, the sub-theme '*affirm self*' emerged which described the participants' struggles with their own bodies as they felt their own bodies became '*alienated*' (pg. e831) to themselves. Furthermore, one of the sentences used to describe this sub-theme was '*my body is now against me*' (pg. e832). It is evident that the individuals in this study articulated the positive aspects of how their own body allowed them to manage their pain, rather than discussing the ways in which their bodies had changed negatively as a result of chronic pain.

However, although the participants within this study viewed their biological coping in positive ways, some individuals also viewed their age as being a hindrance when trying to cope with pain. The individuals' perceptions of their own age not only altered the way in which they viewed their pain, and options for pain management, but it also led to some adaptations in their daily living. All of the issues surrounding age were negative, with no positive aspects of age being discussed. Only older adults with chronic pain discussed the negative aspects of age, whereas neither younger adults suffering from pain nor older adults without pain discussed their age in any way.

One aspect of age that repeatedly emerged was that individuals felt as though they did not want another operation for their chronic pain as they were '*too old*'.

*My feet, they want to operate on my feet because they are twisted, but I won't let them, I don't want them to put no plates in my feet, not at my age [P001]*

*4 years ago and that hip has been lovely, it is just the other one, but I'm frightened to get it done. I think I'm too old [P001]*

*I don't think [I'd get any operations now] I think I've put up with it for so long, how many years I have got left, 20, 15, 10, 3, 1, I don't know [laughs] [003]*

*The orthopaedic surgeon at the Freeman as well and he wants to replace both of my ankles but I'm not keen on getting that done at my age... you know I am 65 now and do I need it you know [014]*

Individuals felt as though they were 'too old' to have another operation and would rather manage the pain in other ways. Other than P001 who stated that she was 'frightened' to receive treatment, the participants do not explain why being 'too old' affects their opinions toward receiving treatment. Contrary to this, Rashmi, Schofield & Shovana (2013) conducted a review of the literature and found that older adults with chronic pain in previous studies had stated their reluctance to accept treatment was due to their worries of losing independence in the short-term, rather than feeling 'too old' (Lansbury, 2000; Blomqvist & Edberg, 2002). Participants also felt that they coped less with their pain as the intensity of pain has risen with age.

*[The pain] started and gradually from [a young age] until I was older and then it has come with a force [001]*

*so [my back] really has deteriorated, and people say that it is your age but I really don't want it to be [002]*

*Just old age, just getting on [made my pain worse] [011]*

Individuals stated that they felt as though the intensity of their pain had gotten worse due to their age, however, individuals also acknowledged numerous changes to physical movement, and functioning, which they believe their age has contributed to, rather than only affecting their long-term pain.

*there are times when you are doing something and you have got to stop and say 'whoah', at the end of the day I'm 74, I've got to go and sit down for 10 minutes and then start again but you have just got to be sensible with the way you manage it [003]*

*I have trouble getting up, but then I put that down to an age thing, I notice now that I can't, if, I can't jump like I used to be able to [005]*

*Well I have slowed down a bit since I'm getting older, I tire more easy [011]*

*I am 81, going to 82 but lately I think I am a little bit funny on my legs, unsteady, so whether it is just my age or the weather [012] just doing what you used to do and you don't do anymore because you are getting older [014]*

It is clear from the discussion that many participants felt less in control of pain management, the intensity of pain and also their own functioning as a result of their age. It was stated that the individuals in this study did not look at their own bodies in the same way as the studies within the qualitative review discussed by Toye et al. (2013), in that they did not discuss their body as being 'against' them as a result of chronic pain, but highlighted how their body helped them manage that pain. However, here, the similarities of the statements in the review, and the feelings of the participants

toward their age, as opposed to their pain, are highlighted. Rather than blaming their bodies generally, the participants highlight the role that age has played, and how it is specifically biological ageing that has affected their pain experiences. Once more, the participants in this study do not articulate their feelings in the same manner as those discussed in the review, however, they believe that their body has changed the way in which pain affects them, and view their body negatively as a result of ageing.

Participants acknowledged the biological aspects of coping, as well as age being a barrier, within their pain experiences and functioning. These individuals seemed to remove the control from themselves, and place it on other mediators; either their own physiology, or medication. This relates to a 'passive' style of coping, coined and defined by Brown and Nicassio (1987). Brown and Nicassio (1987) proposed coping strategies were either active or passive. Whereas active coping strategies included efforts to function despite living with pain, for example, using coping techniques such as distraction, passive coping strategies were determined by surrendering control, and depending upon others. It is evident that the way in which these participants cope with the pain is passive, as they removed control from themselves and place this control upon physiological outcomes.

In congruence with the passive coping style, an external locus of control is seen within these perceptions of coping. A health Locus of Control is related to self-efficacy and is the extent to which an individual feels in control of their own health (Abdulla et al., 2013). Whereas someone with an internal locus of control feels in control of their own health, someone with an external locus of control often believes that their health is a result of external forces, and therefore sees themselves as having little control. It therefore seems that the individuals who consider the control of their own pain in biological terms are showing a passive coping style, with an external locus of control. The relationship between external locus of control and the pain experience has been specifically explored in terms of age and research has suggested that increased age leads to an increased external locus of control (Gibson & Helme, 2000). Crisson and Keefe (1988) found individuals with an external locus of control relied on maladaptive coping strategies and experienced greater psychological distress, among other things whereas research has shown that individuals with an internal locus of control report decreased pain intensity and less mood disturbance (Jordan et al., 1998).

Psychological perceptions of coping were the most discussed way of coping with pain, and were discussed in various ways. Individuals once more displayed external loci of control and considered themselves as 'lucky', with one participant making comparisons with others. However, psychological determination was also displayed by some participants.

Participants continuously used the words 'lucky' and 'fortunate'.

*You see I'm lucky because I have learnt to control it over the years [001]*

*I'm lucky because my friend, 2 of them that used to come away with us take me away now [001]*

*I was lucky, our doctor did, he sent me to the physio [001]*



*I suppose that I am fortunate you know [002]*

*I mean I just count myself lucky, because a lot of people my age are in chronic pain aren't they [004]*

*I am lucky really [012]*

*fortunately it is only the one leg you know [013]*

Participants found themselves as both 'lucky' and 'fortunate' for various reasons. Individuals tended to 'cope' with their chronic pain by acknowledging that they could be in a worse situation. Again, like the coping displayed within physiological coping, this coping highlights external loci of control over the sample. The notion of a 'chance locus of control' was explored by Crisson & Keefe (1988). The researchers used self-report methods within a sample of 62 individuals, of all ages, experiencing chronic pain. The researchers concluded that individuals who thought of their own control of their own health behaviours as being external, and due to either 'fate' or 'luck', could end up experiencing both heightened psychological distress and maladaptive coping strategies. It is clear that many of the participants in this sample also displayed these characteristics and spoke of their pain in that way, specifically P001 who discussed her 'luck' on more than one occasion.

As well as specifically stating that she felt 'lucky' P001 described an 'it could be worse' attitude.

*I wish I didn't have it, believe me, it is awful when it bad, but, I always think there is people worse off than me, you have only go to see them, god love them [001]*

*Well there is a lot of people worse off than me isn't there so I am coping, I am coping I have got my family and I have got my friends [001]*

The participant referred to other people, and how they were worse off than her and used the situation of others to display how fortunate she was. Festinger (1954) originally proposed *Social Comparison Theory* in which individuals evaluate themselves based upon their own comparison towards others. Furthermore, it was from *Social Comparison Theory* that 'downward comparisons' (Willis, 1981) and 'upward comparisons' (Gruder, 1971) were developed. Whereas P001 made *downward comparisons* within this study, no other individuals within this study directly compared their pain or functioning to others.

Wood et al. (1985) proposes that downwards comparisons can lead to negative affect when the person of comparison suffers the same chronic illness as the individual, but are worse off. This reinforces the point that the individual can become worse than they currently are which might result in negative emotions (Buunk, Collins, Taylor, van Yperen & Dakof, 1990). This was also seen with individuals living with Rheumatoid Arthritis in which the researchers proposed that downward comparisons were related to negative affect, specifically more frequent depressive symptoms and lower self-esteem (DeVellis et al., 1990). Once more, these individuals specifically compared themselves to others with Rheumatoid Arthritis, as opposed to other health conditions. Osborn and Smith (1998) also conducted a qualitative study, analysed using Interpretative Phenomenological Analysis (IPA, Smith, Jarman & Osborn, 1999) and put forward the

theme 'comparing this self with other selves', among others. Some of the individuals, like P001, compared themselves to others worse off than themselves. However, Osborn and Smith (1998) believe that this is not specifically positive and rather than 'enhancing self-efficacy' they are 'reinforcements of despair' (Osborn & Smith, 1998, pg. 70).

Unlike P001, two participants within Osborn and Smith's (1998) study compared themselves to individuals of the same age as themselves that are able to function more (i.e. upward comparison). Both individuals within Osborn and Smith's (1998) study discussed feeling that they should be able to do more tasks, like other people of their own age. This was not seen throughout the interviews within this study, as P001 was the only participant to compare herself to others, and she made downward comparisons. All participants in Osborn and Smith's study were younger females (25-55 years) and this may have been the reason as to why they viewed their own health and functioning as seemingly worse than others of the same age. Neither younger adult with chronic pain, in this study, discussed comparisons between themselves or others, nor did they discuss feeling 'lucky' or 'fortunate'.

Not all psychological coping demonstrated participants' external loci of control. Determination was also one psychological coping strategy used by participants, with the outcomes of this determination being both psychological and physical.

*Well it changes your life, but you adjust to it...it is something that can be lived with, you have got to, you have got no choice [001]*

*[when things have been bad] I have always found that you must get on, you must get on [002]*

*I think [my personality has helped me cope with my pain] erm, I don't like to let things get me down, I see no point in worrying about something and letting myself get uptight about something it is the just deal with it, live with it [003]*

*you know you can make yourself an invalid you know I just think well I have got pain you know, try and put your mind on sometimes else [008]*

*there are things that help me but the main thing that helps me is my own brain and erm...as somebody explained it, that vicious will-power that makes everything happen [010]*

*you just have the attitude you have just got to get on with things [017]*

But psychological determination was also involved in physical functioning.

*[The pain] doesn't stop me doing, from sitting on a chair doing exercise [001]*

*[A GP I met whilst on a cruise] said to me 'I don't know how you do it', he said 'you don't seem to be that bad', he said 'you were dancing all of last night', and I said 'yeah well I do, because you just get on with it', I just take a couple of tablets and...get on with it, I don't let it stop me you know, but that's the main thing [005]*

*I suppose that the best you can say about my pain is that I am not having it, it is there, I live with it, I curse it but I don't let it stop me doing anything that I want to do [010]*

One participant tells of his 'euphoric' feelings due to 'pushing' himself physically.

*you must push, push, even if it hurts... But everything you do if you push yourself for it is painful... I keep going, believe it or not if I push myself really hard, they say 'don't do too much', but how do I know if you have done too much...I am almost euphoric the next day, it has done so much for me, I mean I might have been bad that day but the next day you see I'm almost euphoric with the feeling of well-being, I get up feeling better, I feel brighter because I've done, I haven't remembered that I have done something, I genuinely feel better for pushing [006]*

There is almost a conflict of feelings between P006's physical and psychological state. On the one hand the individual needs to 'push' through his physical pain during tasks, however, the individual is quite clearly satisfied, and it seems as though this psychological satisfaction is more important than the physical consequences.

One other aspect that affected individuals' coping, and was also often seen as externally controlled was their *social* situation, and more specifically, the importance of others as some individuals felt that they could not cope alone. Coping was affected by the individuals' social circumstances, and participants often discussed both loneliness and their reliance on others in both a physical and psychological manner. The reliance on others is discussed within this analysis (see section 5.5.4). This was also reflected in terms of 'coping' as some participants stated that they could not cope without help from others in a physical sense.

*I wouldn't [be able to cope without friends], I wouldn't, I would have to, I would have to get everything brought in, I would have to get a delivery, because I won't go in a home or anything, no matter how bad my arthritis is with me, there is no way you'd get me in a home, I'm too independent, I want to live my life not...[001]*

Participants tended not to only discuss the importance friends and family play on coping physically, but also emotionally. The 'importance' of others highlights the role other individuals play in the participants' lives as being a source to talk to.

***We talk it through it... We have been away and... If we didn't talk it through we would be in bad way... Me and my wife do talk now [006 and 006's wife]***

The couple discussed how talking to each other allowed them both to cope with the participant's long-term pain. Interestingly, despite both P001 and P006 discussing the importance of others to cope with their pain, both describing this in a different manner; whereas P001 relies upon her friends physically to cope, P006 coped better psychologically by talking to his wife. However, the reliance on others as a way of coping was not reflected by all individuals as one participant believed that they coped better with their pain due to living alone.

*Compared with most people I think I cope with it very well, I think that the majority of people who, certainly the people that I*

*have met going back to post-operation erm hospital visits, erm...I have no choice but to get over my incapacity...because there is nobody else to do it, I can't, I would starve in a dirty house if I gave in and it was too much nowadays you can't as you come out of hospital you can't have meals on wheels it doesn't matter how fragile you are, unless you are very elderly you can't have meals on wheels, you can't have a carer so somebody comes to supervise you for a couple of weeks so that you don't fall when you are having a bath which for me was a waste of time because all I have to do is step up 8 inches into the shower but you know it was nice to have them for a couple of days, I usually got discharged on a Tuesday so having them until the following Sunday was fine because that was the worst of it in terms of erm the brain not fully engaging what you are trying to do but erm...I just have to get on, I usually, if I come out of hospital on Tuesday, the dog comes home on Friday, and when I had my knees done, because I had both of them done together I had somebody to give him his long walk on the afternoon but I gave him his morning walk and his bedtime walk and if my walker couldn't come on an afternoon I had to give him his afternoon walk as well and that was around the village because I wasn't allowed to drive for 4 weeks, so I was actually taking longer no, harder walks in the village because I couldn't drive and I mean I remember going back to the third clinic after I had my knees done, met all of the ladies who had been in my erm little ward and you know, you say 'how are you getting on' and things like that and basically...4 of them were saying oh well they don't know whether it had been a good idea to have it done or not because they were still in pain and I mean by then I just said to them, I said 'oh how has your husband helped you?', 'oh he is fantastic, I haven't cleaned, I haven't cooked, I haven't done anything, for the last', by then I think it was 7 or 8 months and I said 'well there is your problem, you aren't using your knees enough' [010]*

P010 compares herself to others, and believes she is able to physically cope better as a result of living alone.

#### **5.5.1.1 SUMMARY**

There are numerous aspects to individual coping highlighted throughout the data. The overall sample express their coping in an inadvertently biopsychosocial manner, with some individuals expressing their coping strategies from multiple aspects. Participants described '*biological*' coping as coping due to a higher pain threshold, or because of medication, as well as the drawbacks of biological issues, namely that of their own age. '*Psychological*' coping was discussed when thinking of themselves as '*lucky*', comparing themselves to others, as well as showing psychological determination. Participants' coping was also helped by '*social*' encounters, namely due to talking to each other.

The differences in the way each individual views coping restores the notion that not all individuals suffering from chronic pain should be treated in the same way, as '*a homogenous group*' (Adams, *et al.*, 2006, pg. 294) when considering treatment, as it is clear from this study that individuals perceive their own management of pain and functioning in varying ways.

This sub-theme has highlighted the importance of two components within the '*personal factors*' section of the ICF (WHO, 2001). The ICF highlights '*coping styles*' and '*age*' as two components that can affect both '*activities*' and '*participation*'. The information gathered from the interviews in this study have shown that in fact, age can affect coping styles, and both have an effect on the control that individuals believe that they have over the management of pain and functioning. What was evident from this sub-theme was the internal and external loci of control shown by the participants, which reflected participants' active and passive coping strategies (Brown and Nicassio, 1987). Most coping strategies were evidently passive, with individuals exerting little control over their pain or functioning. Coping based on physiological pain thresholds, use of medication and age, as well as considering themselves as '*lucky*' and comparing themselves to others, as well as the reliance upon others, all showed an external locus of control, of which the individuals did not feel as though they had much control over themselves. Whereas, some of the individuals showed active coping strategies, as they were '*determined*' to function both psychologically and physically. In the same way that some participants described coping from multiple viewpoints, some participants also discussed both active and passive coping strategies, showing both internal and external loci of control.

This sub-theme has demonstrated the differences between individuals' coping strategies, and has shown the effect that coping strategies can have on perceptions of coping.

### **5.5.2 USE OF STRATEGIES**

A number of strategies were used within various ADL over the sample. These strategies were principally used to maintain, or to improve, functioning. Primarily, pacing strategies were used, however, participants also used other strategies which lessened either time or movement in order to improve functioning. As well as discussions of these strategies occurring within the interviews, the Sensecam also enabled these strategies to be recorded during the study week.

'*Pacing*' is a term often used within research concerning chronic pain and daily living but problems with the consistency of its definition are apparent (Birkholtz, Aylwin & Harman, 2004). *Time-based activity pacing* was first described as a strategy used to lessen the symptoms of health conditions by breaking up tasks with periods of rest (Fordyce, 1976; Gatchel & Turk, 1996) but other definitions have also been introduced such as reducing the length of tasks, speeding up or slowing down the pace of tasks or keeping at a steady pace (Kindermans et al., 2011). Pacing described in this study refers to pacing as its initial definition, i.e., resting in-between periods of task completion.

Many participants used pacing strategies, especially when completing household tasks such as cooking, doing housework and also gardening.

*'There are lots of things that I can manage, and if I can't manage them I will leave them, and go back to them again later maybe'*  
[001]

*I love [cooking], well I do most of the cooking... It gets a bit achy when you are doing loads of vegetables which I tend to do, you know chopping after a while, you have got to walk away from it and sit down for 5 minutes then go back to it [003]*

*I just potter around, do a bit of gardening, and I just stop when I feel that it is going to happen... I don't do a lot in [the garden] [003]*

*Aw well erm I just I do my washing and ironing myself but I only wash in you know halves I do a bit at the beginning of the week, maybe a white or light load, and at the end of the week I will do a darker load...[008]*

*I Hoover through for [my wife] because she has got back problems as well, neck and shoulders, and erm I do it in 2 stages upstairs maybe upstairs one day and downstairs the next because I don't think that I could do it in one shot but at the end of that point my neck, shoulders and back are really painful [009]*

*Yes my pain level gets in my spine [bends over and points to the part which hurts] yes it does get worse [if I do the garden]... I try and work through it to a degree but if it gets too bad I have got to stop and I sit down and wait until it goes and finish the task [009]*

*[Cleaning] is the only erm activity that I do where I wish I had erm...a video player in each room, and a tele, I don't mind doing the cleaning of the lounge, it is a big room, dusting lots of ornaments and books erm, because I can put a film on and when I think, when it gets to a nice interesting bit I go down and watch it, ok it adds an hour to cleaning the lounge but I've enjoyed it erm...I mean I can clean the kitchen, dining room, bedroom and the hall in an hour and a half if I put my mind to it but I do have a tendency to stop [sighs]... For a rest and I will go back to a crossword that I hadn't finished, or a book that I was reading, it is more interesting than just cleaning [010]*

It is evident that many of the participants used pacing strategies for various household tasks with some of the participants using pacing strategies for more than one task. Furthermore, it is also evident that pacing was not only over a short period of time, but some participants paced their household tasks over days. Not all of the individuals discussed carrying out pacing strategies during the interviews, despite using them. Furthermore, pacing was not often recorded in the DRM as participants did not tend to record multiple episodes of household tasks within one day.

The Sensecam gave some insight into the use of pacing strategies when completing household tasks. P001 continuously carried out a small amount of household chores throughout the day rather than all at once. She interrupted household chores to watch TV throughout the day. As well as watching TV, relaxing and reading were also common tasks carried out in-between household chores and P002 often read the newspaper, completed crosswords and on one occasion read her book. Furthermore, although P013 did not discuss using pacing strategies in the interviews she carried out gardening tasks intermittently each day, according to the Sensecam. P013 spent most time out of all older adults living with chronic pain in the garden and carried out all of the tasks listed above, including kneeling in the garden, as well as cutting down plants

with long-handled trimmers. P013 took long periods of time in between gardening tasks to read, watch TV, or have a cup of tea, before carrying on with gardening.

Pacing was not just a task carried out by the older adults with chronic pain. P016, a younger adult with chronic pain, also used pacing strategies whilst cooking as, according to the Sensecam, he intermittently watched TV, but spent more time in the kitchen during these periods than the older adults living with chronic pain. P016 did not discuss any issues with cooking, nor did he discuss pacing tasks during cooking.

Although pacing was often used by participants when cooking, both P002 and P008 each discussed one occasion in which they did not pace their food preparation when cooking for family members and this prolonged cooking affected their pain. P002 described an occasion on which she wanted to cook specific food for her grandchildren, therefore was in the kitchen for much of the day, which worsened her pain.

*well...Thursday because my grandchildren were coming, and one of them loves fish, anything with fish, so I thought oh I'll make him a fish pie, because I like fish, but it is a lot of standing you know and my other granddaughter loves home-made soup so I thought right I will do all of this preparation on Friday, and then, erm, you know I have got everything for the weekend, and that you know I found that I was in a lot of pain by the end of it because I was standing all of the time and I was not moving very much and I was very tired that night, erm...so I, I do try not to prepare too much at the same time, it was wrong to do the soup and the fish pie at the same time [002]*

P002's chronic pain worsened due to one prolonged period of cooking for her family. However, despite not using pacing strategies when cooking for her family on this occasion, the Sensecam images were able to show that P002 did in fact use pacing strategies when cooking for herself during the study week as she often intermittently sat down and read the newspaper in between periods of cooking.

Similar to P002, P008 cooked 'date crunch' for her family at Christmas, something she had always done. However, she stood for a long period of time which led to increased pain in her leg, and this pain was still affecting the participant at the time of the interview, over a month later.

*I have had a really nice good spell just before Christmas and then on Christmas eve I stood stirring some dates and stuff in the pan to make this date crunch that I make at Christmas and standing too long it sort of kicked my leg off again so I am still struggling with it a bit [over a month later]... yes [I'm still suffering from Christmas eve] I stood for about 5 or 6 minutes it would take but you see I can't do, I cannot but you see it is Christmas and I always make this tray of well we call it date crunchy... well I have made it for I don't know how long I have made it for, it is just a Christmas tradition, but I was determined to do it, you see it is things like that are frustrating, I want to do things and I cannot and I can't accept that I can't, it is hard to say no, but I did say to them well that is your last lot of data crunchy I will not make it next year but it is so frustrating [008]*

*Aw yeah [it has changed the way I live], yeah I can't, I used to have my family Christmas, I used to bake, I used to love you know baking cakes and scones and stocking the freezer up, and I can't stand [up] to do that now [008]*

The participant did not use a pacing strategy when cooking for her family on this occasion, therefore increasing her pain. For P008 it is not only the act of cooking in order to eat, but in this case the participant wished to keep up family tradition, and keep her role within the family at Christmas. P008 said that she struggles to 'accept' that she can no longer carry out some tasks, and is frustrated that long-term pain has affected what she can and cannot do.

It is evident that various participants in this study carry out pacing strategies for various tasks. Past research has shown mixed results regarding the benefits of pacing, with some research suggesting that pacing lessens disability (Nielson & Jenson, 2004) whereas other research suggests that it actually heightens disability (Kindermans *et al.*, 2011; McCracken & Sanuel, 2007). Pacing within this study was viewed as a positive task by participants, and led to lessened pain, such as that experienced by P002 and P008 when pacing tasks failed to be used. It is evident that participants used pacing within various ADL in order to improve levels of functioning.

As well as using pacing strategies, participants also often used various strategies to reduce their movement, or reduce the time needed to complete household tasks. P001 described the way in which she moved less when doing her housework.

*If you get a pinny [apron] with a big pocket on, and put your dusters in, and all of your bits in, and your glasses and carry that around with you when you go for different rooms, rather than going backwards and forwards, backwards and forwards [P001]*

Sitting was most often the strategy used to reduce movement, and this was done to reduce movement whilst both preparing food and completing housework. P002 adopted the way in which she cooked for herself to reduce the effect that cooking would have upon pain. When cooking for herself P002 discussed sitting to do as much preparation as she can, for example on another occasion she sat down to prepare the vegetables '*I sat and did [the vegetables], and I was sitting to do everything erm*'. Whereas P017 said that she '*sits on my bum and shuffy along*' to clean the skirting boards.

However, once more, these strategies were sometimes discussed in the interviews, although not all participants discussed them, therefore, the Sensecam highlighted these strategies when they were not discussed by participants. Although P001 stood up whilst washing the dishes, cleaning the benches and was seen continuously bending down whilst unloading the washing machine, she sat down to do other household tasks, specifically sorting through objects and reaching down to the cupboard on one occasion. Sitting down was also used by both P011 and P010. P011 also sat down whilst changing her bed sheets. Although she stood up and moved around the bed when was necessary, she sat down when possible to complete parts of this task, such as changing pillow cases. Finally, sitting down was also a strategy used by P010 who sat down whilst completing her ironing, despite standing up during other household tasks. The individuals all sat down during completion of some household chores.



As well as strategies to reduce movement, P008 used a strategy to reduce the amount of time that she spent cooking, although this was not discussed in the interview, and the Sensecam enabled this strategy to be recorded. P008 ate a hot meal each night, at home alone, but when cooking the participant would prepare enough food for two meals and she would then heat the second portion of food up for herself the following evening, therefore reducing time spent preparing food in the kitchen. P008 did not discuss this strategy during the interview, and it is unknown as to the reason why she did this, but the strategy was seen on numerous occasions in the Sensecam images over the study week.

### **5.5.2.1 SUMMARY**

Participants used various strategies in order to remain functional, with the most common strategy being pacing. Participants used pacing strategies between various ADL, specifically when cooking, doing household chores and gardening. As well as pacing, other strategies were used, primarily to reduce the amount of movement involved in the task, or the amount of time doing the task.

The use of strategies was not only discussed within the interviews, but were also highlighted on the Sensecam, which made it possible to see that individuals always rested in between these tasks. Furthermore, some of the strategies were not discussed by participants within the interviews, although they were seen on the Sensecam.

### **5.5.3 USE OF ASSISTIVE DEVICES**

As well as strategies to improve functioning, there were also various assistive devices used throughout the sample, however, as well as being used to improve mobility and lessen movement, assistive devices were also used to reduce, or maintain, levels of pain. Assistive devices, including assistive technologies, can reduce some limitations caused by long-term health conditions, such as chronic pain (Pape, Kim & Weiner, 2002). The assistive devices used by participants within this study were discussed as part of the interviews and were also seen on the Sensecam images over the study week.

'Using assistive devices' was one Sensecam code that was added during the process of *Ethnographic Content Analysis* as part of the process of analysis. From the Sensecam it was evident that 10 of the 13 older adults living with chronic pain used assistive devices of some description over the study week, and use of assistive devices ranged from 0-7%, although most participants spent little time (0%) using assistive devices. Assistive devices on the Sensecam were not solely used as a result of chronic pain, for example P001 used a magnifying glass in order to read as she is partially sighted. It was difficult to distinguish the exact purpose of some assistive devices from the Sensecam images without interacting with the participants themselves. Furthermore, participants were unable to record whether they had used assistive devices during episodes within the Daily Reconstruction Method, therefore much of the information within this theme was gathered directly from the interviews.

Assistive devices ranged from devices that participants had adopted themselves to those provided by health professionals and were most often used to improve mobility, lessen the need for movement and lessen pain. Although most of the individuals discussed their need for the use of adaptations, neither older adult without chronic pain discussed using adaptations at all throughout the interviews. Additionally, one of the younger adults with chronic pain also stated that she did not use assistive devices [P017], however, although the participant did not use assistive devices on a long-term basis, she did use assistive devices immediately after coming out of hospital after having an operation due to the condition that caused chronic pain.

*when I had my knees done I had the grab sticks and everything but no they're just tucked away in a cupboard [017]*

*[my husband] built me a frame around the toilet so that I could get up and down off the loo [laughs] [017]*

Four older adults with chronic pain did not believe that they needed assistive devices [P002; P003; P009; P015], however, despite claiming not to use assistive devices, all of these individuals, other than P009, spoke about using assistive devices in some way. This may be that they did not believe that the objects they used were classed as assistive devices.

Assistive devices were often used to improve individuals' mobility and these devices were most often used outside of the home. These devices consisted of a wheelchair [P001; P007], crutches [P010], walking stick [P001; P002; P006], Zimmer frame [P006] and a mobility scooter [P008]. P006 specifically acknowledged his increasing need for devices as he was gradually more reliant on walking aids; '*now I cannot walk anywhere without an aid, I have got to use aids and walls and doors and anything I can get hold of*' [P006]. All of these assistive devices were discussed during the interviews, but not all of these devices were seen on the Sensecam images. This may have been either because they were not used during the study week, or that they were not seen on the Sensecam. Due to the position of the Sensecam some assistive devices were difficult to see, specifically assistive devices such as walking sticks or crutches.

Studies reporting the prevalence of assistive devices used within the general older population, with various health and functional limitations, vary. The National Health Interview survey, conducted in 1990, found that 13% of older adults used assistive devices (Watts, Erickson, Houde, Wilson & Maynard, 1996). Contrastingly, research conducted with a sample of 1405 individuals over 65 years old recorded 74% of participants used assistive devices, with one of the most commonly used assistive devices being a walking stick. Previous research specifically involving older adults with chronic pain also highlighted similar devices used to enhance mobility. Within a study conducted by Duong *et al.* (2005) participants highlighted using wheelchairs when shopping or travelling over long distances in one study. Furthermore, Sofaer *et al.* (2005) conducted a qualitative study with older adults living with chronic pain, in which one of the themes was '*desire for independence and control*'. It was here that the authors discussed the use of mobility aids, in that they gave participants some independence. Like the participants in this study some participants used assistive devices in order to become more physically independent and mobile, specifically mobility scooters and most commonly, walking sticks.

Despite the benefits of the assistive devices in aiding mobility, P008 described her initial reluctance to accept the need for a mobility scooter.

*[my daughter] kept saying you should get one of those scooters and I kept saying I'm not, I'm not using one of them I am not disabled, it is a difficult thing, I still find that hard to accept but erm once I got the scooter why I was away, brilliant, you know, and like I say I realised how restricted I had been before you know [008]*

This participant describes the difficulty in accepting being 'disabled' and needing help to remain mobile. As well as looking at the use of adaptive devices to increase mobility, Sofaer et al. (2005) discussed acceptance, but this acceptance was the acceptance of the pain itself, as opposed to accepting the reliance upon assistive devices.

Mobility aids were primarily used outside of the home, however, there were some mobility aids that were used inside of the home; a grab rail [001, 004], a stair lift [014], which is used if the participant is in a 'difficult situation', and also a mobile trolley [001, 007] which the individuals used to move around her apartment, and used to lean on to provide support. P010 also had a trolley within her home, but this was not seen in use on the SC, and the participant did not describe using it in during the interview. P006 also used a 'walker' which he leant on, and had wheels allowing easier walking. However, the 'walker' was also used to sit on and allowed the individual to sit down during tasks which required standing up, such as cooking.

*...I can peel potatoes, I can do the ironing, I can sit down and...I love ironing...I can sit down and do the ironing and...erm...I keep myself going as much as I can [P006]*

As well as aiding mobility, devices were also often used to lessen movement so that the individuals could accomplish day-to-day tasks such as housework and self-care. P001 used devices in order to improve different aspects of functioning such as housework and personal care.

*I find that an electronic carpet sweeper is easier when I'm really bad I can't use my hoover, so I use my carpet sweeper, and I have got dusters, like big tickly stick things, just, where I can't lift my arms up [P001]*

*[My husband] used to wash my back in the bath, but now I have got to use one of those long pleated, you know, loofers [P001]*

*I have had to get a shower in, because I couldn't get in, I had an electric thing to take me up and down in the bath but this hip is so bad that I couldn't even swing my legs onto that so I had to get a walk in shower, a wet room put in [P001]*

P001 also described using a stool as she cannot bend down to the bottom of the cupboard and sitting on a stool allows her to do that. This was also seen on the Sensecam images, in that the participant used the stool to reach the bottom shelf on the cupboard. However, this aid also provides a problem as she sometimes struggles to get up off the stool; 'I can't get up off the stool but grab hold of the bench and pull myself'. P001 discussed using multiple physical adaptations in order to lessen movement and maintain functioning for both self-care and household tasks.

Other participants also used adaptive devices to reduce movement whilst doing the housework [002] and ease movement whilst cooking, specifically when opening tins [004]. P010 also used various assistive devices on a daily basis.

*Well I have got a grabber, I have got a raised toilet seat, erm which is a new one and it doesn't fit terribly well, I need to keep reminding myself that I need to get in touch with the city, I have had things like shower stools and things like that but my bathroom is extremely small and my shower is the smallest you can get them so actually a shower stool in there is more trouble than it is worth so that has gone back but I have kept my grabber and a erm I have kept my trolley, erm, that is more because it is convenient and useful, I have got 2 grabbers I have got one upstairs and I have got one downstairs and it is very useful but nothing else that no [P010]*

The individuals, specifically P001 and P010, used objects which result in lowered movement in order to accomplish tasks, primarily self-care and household tasks.

Assistive devices were not solely used for functioning, but were also used in order to reduce or maintain, pain presence or pain intensity, these included items specific for pain management as well as less specific devices. Participants used items given to them by Health Professionals which supported their pain areas, and also one device which eased their pain such as *little soft balls to squeeze...just for my hands*[001], *the cervical collar* [003] and also P001 and P014 had specially adapted shoes which aimed to lessen pain whilst walking. However, not all of the devices were specific to chronic pain, or had the specific intention of reducing pain.

*I had to have supervisors chairs as they were padded because I couldn't sit on the others because my back used to go crazy, I couldn't stand the pain [P001]*

*No [the pain does not affect driving] because I have a top of the range car which has a heated seat and the seats in a Vauxhall suit my back they are very supportive of my back so I choose my car carefully [P015]*

*No [I don't find it hard to sleep] particularly because I bought a bed, we bought beds which raise electrically at the back and the foot raise [P015]*

The Sensecam also showed P008 using a cushion under her wrists whilst on the computer on numerous occasions over the study week, although this was not discussed within the interview. There were numerous assistive devices that were used in order to reduce pain, depending upon the individual's pain location.

### **5.5.3.1 SUMMARY**

The interviews and the Sensecam were beneficial in exploring the use of assistive devices throughout the sample, and it was evident that they were used by a variety of participants, for a variety of reasons. Primarily, the physical adaptations were used to increase mobility, reduce movement and reduce, or maintain, levels of pain. This information has supported past studies that have also seen assistive devices used in this way by individuals living with chronic pain. However, this study has furthered this

knowledge by the use of the Sensecam, as it was possible to see how and when individuals were using these devices, as well as viewing devices not discussed within the interviews, for example, the cushion used by P008 when on the computer.

Interestingly, not all of the participants believed that they were using assistive devices in any way, when asked in the interviews, however, when questioned further, all but one of these individuals used these devices in one way.

#### **5.5.4 RELIANCE UPON OTHERS**

Despite individuals using adaptive strategies and assistive devices in order to try and manage both pain and functioning, some individuals relied on others for various physical reasons, and became less independent as a result of this. This reliance on others therefore adapted the way in which they managed their own functioning. Individuals relied on others when cooking, completing household chores, and travelling which also affected participation in leisure tasks and affected the way in which individuals were able to function.

P007 completely adapted the way in which meals were prepared as she was heavily reliant on others for cooking, as well as shopping. Although she could manage to prepare her own breakfast she relied on 'meals on wheels' to deliver her main meal daily.

*I used to cook my own dinners...it would be such a hassle trying to cook for myself that I'm afraid I should start skipping meals as I say because It is brought to me every day I get a real good meal [007]*

*I don't have to go shopping because I get my dinners from meal at home which is run by Newcastle council and it is exceedingly good, the choices and the fact that it is brought to you, all you have to do is eat it...and it is a very good meal so that when it comes to tea time I am not terrifically hungry [007]*

The reliance on others was not only needed for actually providing the meals, but P007 also needed help whilst shopping for groceries that she did buy in herself as she required a wheelchair and was therefore reliant on others to take her shopping. She lived in 'sheltered' accommodation and one of the residents took it upon herself to order a weekly shop for those that needed it; 'we have here one of our ladies makes herself responsible for taking shopping orders from us'. Shopping in the supermarket was also an issue for other participants.

As well as providing food, some participants relied on others to complete household chores. P001, P002 and P008 needed help from hired cleaners, despite also carrying out household chores themselves. It was evident from the Sensecam that P001 and P008 tended to focus on smaller daily chores such as washing the dishes and loading and unloading the washing machine, whereas P002, despite having a cleaner, took part in other household chores such as changing the bed sheets, and cleaning the kitchen. P001 described her cleaner's job as doing 'the heavy work' and P008 said that her cleaner came in to 'blitz it'. P002 did not discuss the cleaner in the interview, but discussed it informally with me, and images of the cleaner were also recorded on

the Sensecam. Furthermore, despite all three participants needing help with some aspects of cleaning all rated their competence and capability of doing the housework they completed in the study week relatively high ( $\geq 3$ ), however, all three participants rated being quite tired when completing household tasks ( $\geq 3$ ) and both P002 and P008 felt highly impatient for household chores to end compared to other tasks carried out over the study week.

The reliance upon others was also highlighted when travelling, with several of the participants relying on others when travelling, which also affected participation in tasks. Both P001 and P008 used different methods of transport depending who they were travelling with. Specifically in the study week, P001 used a taxi and P008 used a scooter when alone, but when with others they both got in a car, or P001 used a bus. On two occasions, when P001 was alone, she used a taxi and the driver helped her by putting the wheelchair on board, and then took it out of the taxi again. She then met friends in town who pushed her in the wheelchair. However, P001 did not use taxis when with friends, she used the bus. The participant pushed her own wheelchair onto the bus, and then sat in her wheelchair. Her friends then pushed her from the bus stop to their intended location. Other than this P001 also got driven in the car by her family on two separate occasions, and walked to her destination from the car. A walking stick was briefly picked up on when the individual was walking from her family's car into a shop alone. One issue with the Sensecam was its difficulty picking up walking aids due to the position of the Sensecam around the user's neck. Therefore the low frequency of using assistive devices when P001 was walking is low on the Sensecam.

P001 used a wheelchair when outside of the house and therefore did not commute alone as she needed someone to push her. This also affected P006 and P007 who both used manual wheelchairs.

*I have great difficulty getting about, I have this, I have this 4 wheeled walker and I have a wheelchair, I am ok getting around here but I can't go out on my own [006]*

*I am restricted in where I can go, if I go off the premises I must have somebody with me I can't shall I say [007]*

Like P001, P006 and P007 also needed someone to push their wheelchairs which drastically reduced their independence and increased their reliance upon others. P008 also needed help when walking short distances.

*[Book club] is just once a month and my friend comes and picks me up and takes me there and she will link me and take me into the place because I am a bit nervous outside, I mean I can walk a bit in the house, you feel safe, but outside I sometimes link her to get in somewhere in case there are steps or whatever, and then I go to the book club on a, once a month, that was yesterday, the monthly meeting is next Thursday yeah [my friend] comes and picks me up, takes me down, I mean I have known her all of my life, we started school together when we were 5 so I have known her for like...59 years....yeah she's my good friend, we are going to Centre parks in May together [008] I can't walk outside erm very far erm I mean we went to the pictures the other day and erm to get out of the car and to walk to the thing I was sort of linking my friend you know [008]*

P008 used various modes of transport as she did not drive. Although P008 was able to commute alone with the assistance of the electronic scooter, she was unable to make all journeys with the scooter. The individual relied on others as she was driven around in a car by both friends and family at various points throughout the week and acknowledged this in the interview.

*I have got a friend who is retired erm and his wife is still working and he is at a loss and he always says give me a ring and he comes and takes me through to the town and you know he drops me off say at 12 and comes back say at about 4 whatever so you know [008]*

*[my friend] took me up to Dalton park and yes I had a mooch around and went to Starbucks and had a cup of coffee and read the paper...and Sunday I think was when I went to Dalton park again with [my daughter] [008]*

It was clear from the Sensecam, and the interviews, that some participants relied on other people during transportation and mode of transport was dependent upon whether they were with another individual.

Additionally, it was not only help with the commuting itself but both P001 and P008 also needed assistance with lifting the wheelchair in and out of the car. The friend also helped P008 as he put the scooter in and out of the car for the participant. Other than this car travel, P008 used an electronic scooter to travel journeys outside of her home when alone. The participant used an electronic scooter whilst travelling around the local area and she was able to stay on the path. She specifically used it when visiting friends' houses, going to the local shop, and visiting town. The participant was able to stay on the scooter at all times, and only walked when in the local shop, which looked too small for the scooter.

#### **5.5.4.1 SUMMARY**

Despite individuals' efforts to function independently, some of the participants relied on others when carrying out various ADL, including food preparation, household chores, and travelling. Although the reliance on others lessened their independence, it simultaneously improved functioning. It was clear that the reliance on others was higher for some individuals than it was for others.

#### **5.5.5 SUMMARY OF MANAGING PAIN AND FUNCTIONING**

Managing pain and functioning was made up of both '*cognitive efforts*' and '*behavioural efforts*', as described within Lazarus and Folkman's (1984) *transactional model of stress and coping*. Individuals spoke of their own perceptions of coping, which reflected multiple '*biopsychosocial*' components, and also discussed using various strategies and devices to aid their functioning, and reduce pain.

From this theme it is evident that individuals perceive their coping in different ways, as well as using different strategies and devices to manage pain and functioning. The majority of participants demonstrated '*passive*' coping styles (Brown and Nicassio, 1987) showing an external locus of control in that they deemed themselves not to be in

control of their own pain and/or functioning. However, the coping strategies differed, and some individuals used 'active' coping strategies (Brown and Nicassio, 1987) specifically psychological determination.

## **5.6 CHAPTER SUMMARY**

There are two main themes that came out of the Thematic Analysis conducted on the semi-structured interviews within Part A of the study; '*effect on daily living*' and '*managing pain and functioning*'. Data from the Daily Reconstruction Method diaries and the Sensecam images have also added to the themes to give additional insights into the daily functioning and experiences of older adults living with chronic pain.

This chapter has highlighted the two themes, and various sub-themes from the semi-structured interviews, as well integrating the findings from the Daily Reconstruction Method diaries and the Sensecam. Findings have been discussed in much depth, and have also been discussed in relation to past literature.



## **CHAPTER 6: PART B - FINDINGS AND DISCUSSION**

### **6.1 OVERVIEW**

Chapter 6 provides the results from the *Unified Theory of Technology Acceptance* questionnaire (UTAUT, Venkatesh, *et al.*, 2003), the *Flow-State Scale* (Jackson & Marsh, 1996), as well as the semi-structured interviews within Part B of this study. The findings are also related to literature in the area.

### **6.2 PARTICIPANT DETAILS**

The details of participants who wore the Sensecam, and those who wore the LifeShirt, are given in chapter 5 (section 5.2). Eighteen participants wore the Sensecam and eight of these individuals also wore the LifeShirt, therefore some did not have experiences of using both pieces of equipment.

There were no apparent differences in the experiences of using either the Sensecam or LifeShirt between the 'core sample' of participants, and either the younger adults with chronic pain, or the older adults without chronic pain. Due to the similarities in acceptance, usability, experiences and practicalities of using the technology, all participants are discussed as one group, without distinctions between them.

### **6.3 UTAUT QUESTIONNAIRES**

The results from the UTAUT questionnaires are shown below. The results are made up of two tables; table 15 shows participants' perceptions of the Sensecam before and after use whereas table 16 shows participants' perceptions of the LifeShirt before and after use. For each question participants were asked to indicate on a likert scale of 1-7 if they '*strongly agreed*' (7) with the statement, or '*strongly disagreed*' (1) with the statement. The average outcome (mean; min, max) of participants' responses are presented in table 15 and table 16, below.

<u>Section of UTAUT</u>	<u>Question</u>	<u>Before use</u>	<u>After use</u>
		<u>Mean (min, max)</u>	<u>Mean (min, max)</u>
Effort Expectancy	My interaction with the SENSECAM would be clear and understandable	6 (4, 7)	6 (4, 7)
	It would be easy for me to become skilful at using the SENSECAM	6 (4, 7)	6 (4, 7)
	I would find the SENSECAM easy to use	6 (3, 7)	6 (3, 7)
	Learning to operate the SENSECAM is easy for me	6 (3, 7)	6 (3, 7)
Attitude toward using technology	Using the SENSECAM is a good idea	6 (4, 7)	6 (4, 7)
	Working with the SENSECAM is fun	5 (4, 7)	6 (4, 7)
	I like working with the SENSECAM	6 (5, 7)	6 (5, 7)
Social Influences	People who influence my behaviour think that I should use the SENSECAM	4 (1, 7)	4 (1, 7)
	People who are important to me think that I should use the SENSECAM	4 (1, 7)	4 (1, 7)
Self- Efficacy	I have the knowledge necessary to use the SENSECAM	6 (4, 7)	6 (3, 7)
	I could use the SENSECAM if there was no one around to tell me what to do as I go	5 (4, 7)	6 (4, 7)
	I could use the SENSECAM if I could call someone if I got stuck	6 (4, 7)	6 (4, 7)
	I could use the SENSECAM if I just had an built-in help facility for assistance	6 (4, 7)	6 (3, 7)
Anxiety	I feel apprehensive about using the SENSECAM	2 (1, 5)	2 (1, 4)
	It scares me to think that I could lose a lot of information using the SENSECAM by hitting the wrong key	2 (1, 3)	2 (1, 4)
	I hesitate to use the SENSECAM for fear of making mistakes I cannot correct	2 (1, 6)	3 (1, 6)
	The SENSECAM is somewhat intimidating to me	2 (1, 4)	2 (1, 4)

**Table 15: Analysis of the UTAUT findings showing participants' perceptions towards the Sensecam before and after taking part in the study**

<u>Section of UTAUT</u>	<u>Question</u>	<u>Before use</u>	<u>After use</u>
		<u>Mean (min, max)</u>	<u>Mean (min, max)</u>
Effort Expectancy	My interaction with the LIFESHIRT would be clear and understandable	4 (3, 6)	4 (2, 6)
	It would be easy for me to become skilful at using the LIFESHIRT	5 (3, 7)	5 (1, 7)
	I would find the LIFESHIRT easy to use	5 (3, 7)	5 (2, 7)
	Learning to operate the LIFESHIRT is easy for me	5 (3, 7)	4 (1, 7)
Attitude toward using technology	Using the LIFESHIRT is a good idea	4 (3, 7)	4 (1, 5)
	Working with the LIFESHIRT is fun	5 (3, 7)	4 (1, 5)
	I like working with the LIFESHIRT	5 (4, 7)	4 (1, 5)
Social Influences	People who influence my behaviour think that I should use the LIFESHIRT	4 (1, 7)	4 (1, 7)
	People who are important to me think that I should use the LIFESHIRT	4 (1, 7)	4 (1, 7)
Self- Efficacy	I have the knowledge necessary to use the LIFESHIRT	4 (2, 6)	5 (4, 5)
	I could use the LIFESHIRT if there was no one around to tell me what to do as I go	5 (2, 7)	4 (3, 6)
	I could use the LIFESHIRT if I could call someone if I got stuck	5 (2, 7)	5 (2, 7)
	I could use the LIFESHIRT if I just had an built-in help facility for assistance	5 (2, 7)	5 (2, 7)
Anxiety	I feel apprehensive about using the LIFESHIRT	3 (1, 5)	3 (1, 5)
	It scares me to think that I could lose a lot of information using the LIFESHIRT by hitting the wrong key	4 (1, 6)	3 (1, 5)
	I hesitate to use the LIFESHIRT for fear of making mistakes I cannot correct	4 (1, 7)	4 (1, 6)
	The LIFESHIRT is somewhat intimidating to me	3 (1, 5)	3 (1, 5)

**Table 16: Analysis of the UTAUT findings showing participants' perceptions towards the LifeShirt before and after taking part in the study**

From table 15 and table 16 it is apparent that there are virtually no changes between the attitudes of the Sensecam or the LifeShirt before and after use.

It is clear that most participants are positive about the Sensecam, both before and after use, in regards to the ease of use, their attitudes toward the Sensecam, their own self-efficacy, as well as their anxiety towards the Sensecam, which was low for most individuals. Of the slight changes that occurred before and after using the Sensecam individuals believed that the Sensecam was slightly more fun to use after they had used it, and also felt slightly more self-efficacious when using the Sensecam without help after use. However, individuals became slightly more fearful of making mistakes that they could not change, after they had experienced using the Sensecam.

In comparison to the Sensecam, the participants felt slightly less positive about the ease of use of the LifeShirt, the attitudes towards the LifeShirt as well as their own self-efficacy of the LifeShirt, however responses for the LifeShirt were positive both before and after use. From the UTAUT it is possible to see that participants were positive about the LifeShirt being easy to use, but were slightly less positive about the LifeShirt being clear and understandable. Participants' attitudes toward the LifeShirt were positive both before using the LifeShirt, and after using the LifeShirt, but they became slightly more negative after use. Participants felt quite sure that they would be able to use the LifeShirt with assistance, as well as without assistance, however were also quite anxious of making mistakes that they were not able to correct, both before and after using the LifeShirt.

For both the social influences on both the Sensecam and the LifeShirt, participants believed that people that were important to them somewhat influenced their decision to use the technology. However, when speaking to the individuals when they were completing the questionnaires, many of the participants did not tend to understand this question, or alternatively, felt that they had not spoken about their participation within the study, therefore were unsure of how to answer this question.

Many of the components in the UTAUT relating to the Sensecam and the LifeShirt were further expanded upon within the semi-structured interviews, and the results from the tables have also been integrated into this qualitative analysis (see section 6.6 and section 6.7).

#### **6.4 FLOW-STATE SCALE QUESTIONNAIRE**

The results from the Flow-State Scale questionnaire (Jackson & Marsh, 1996) are shown below. Table 17 provides the analysis of perceptions toward the Sensecam after use, and table 18 provides the analysis of the perceptions of the LifeShirt. For each question participants were asked to indicate on a likert scale of 1-5 if they '*strongly agreed*' (5) with the statement, or '*strongly disagreed*' (1) with the statement. The average outcome (mean; min, max) of participants' responses are presented in table 17 and table 18, below.

<u>Question</u>	<u>Mean (min, max)</u>
I really enjoyed the experience	4 (3, 5)
I was not worried about my performance whilst wearing the technology	4 (2, 5)
I felt in total control of what I was doing	4 (2, 5)
I had a feeling of total control	4 (2, 5)
I felt like I could control what I was doing	4 (2, 5)
I felt in total control of my body	4 (3, 5)
I was not concerned with what others may have been thinking of me	4 (3, 5)
I was not concerned with how I was presenting myself	5 (3, 5)
I was not worried about what others may have been thinking of me	5 (4, 5)

**Table 17: Analysis of the Flow-State Scale questionnaire (Sensecam)**

<u>Flow-State Scale question</u>	<u>Mean (min, max)</u>
I really enjoyed the experience	4 (2, 5)
I was not worried about my performance whilst wearing the technology	5 (3, 5)
I felt in total control of what I was doing	4 (3, 5)
I had a feeling of total control	4 (2, 5)
I felt like I could control what I was doing	4 (2, 5)
I felt in total control of my body	4 (2, 5)
I was not concerned with what others may have been thinking of me	4 (1, 5)
I was not concerned with how I was presenting myself	5 (3, 5)
I was not worried about what others may have been thinking of me	4 (3, 5)

**Table 18: Analysis of the Flow-State Scale questionnaire (LifeShirt)**

It is evident from table 17 that all individuals claimed that their experiences of using the Sensecam were enjoyable, which was also reflected in the discussion concerning participants' experiences of using the Sensecam and LifeShirt in the interviews (see section 6.6.1). Whereas most of the eight LifeShirt users indicated that the experience of using the LifeShirt was enjoyable in the *Flow-State Scale*, two of these individuals specified that they did not enjoy the experience of using the LifeShirt (indicating '2' on the likert scale).

Furthermore, there was generally little worry about the individuals' *'performances'* whilst wearing the technology, however, participants tended to worry slightly less when using the LifeShirt. This may be due to the difference of the data recorded on the Sensecam and the LifeShirt, with the Sensecam recording images, however, despite the recording of these images, most of the participants did not worry about their *'performance'* whilst being recorded, as seen in table 17, above.

Control was also one of the areas that the *Flow-State Scale* focused on; control of using the technology, and control of one's own body whilst using the technology. It is again evident that most of the individuals believed that they were both in control of their own body, as well as the technology, during use, however, there is variance over the sample for both the Sensecam and the LifeShirt, with some individuals feeling less in control than others.

Finally, the *Flow-State Scale* questioned individuals about their concern of wearing the technology whilst in the presence of others. Most individuals felt as though they were not concerned with, or worried about, the opinions of others whilst wearing either the Sensecam or the LifeShirt, although, once more, there was variance between the responses. P006 was strongly concerned of what others thought of him whilst wearing the LifeShirt, but was otherwise not concerned about how he was presenting himself, nor worried about other may have thought of him when wearing either the LifeShirt or the Sensecam. Additionally, although P004 had some concern with the way that she presented herself whilst wearing the Sensecam, she was otherwise not concerned, or worried about, what others thought of her whilst wearing either the Sensecam or the LifeShirt.

Overall, the responses from the *Flow-State Scale* are positive for both the Sensecam and the LifeShirt. The responses show that the majority of the participants had an enjoyable experience using both pieces of technology, and tended not to be worried about their *'performance'* whilst using the technology. Furthermore, most individuals felt in control of the technology, and their own body, during use, as well as having little concern, or worry, of what others thought of them whilst wearing the Sensecam or LifeShirt. There were however variances between the responses, and some individuals had more positive experiences than other when using the technology, however, this is further explored in the analysis of the semi-structured interviews, below (see section 6.6 and 6.7). Furthermore, many of the aspects in the *Flow-State Scale* were discussed within the semi-structured interviews therefore adding additional depth to these answers (see section 6.6 and 6.7).

## **6.5 SEMI-STRUCTURED INTERVIEWS**

Individuals discussed the technology generally, talking about both pieces of equipment at once, and also discussed the Sensecam and LifeShirt separately. This will be distinguished in this chapter.

Throughout the interviews two themes were established; *'expectations and experiences'* and *'awareness of equipment'*. Both themes demonstrate different concepts that encapsulate individual experiences of using the Sensecam and the LifeShirt. Furthermore, sub-themes of each theme were determined and will be subsequently discussed. Information from the UTAUT questionnaire and the *Flow-State Scale* will also be integrated throughout this section when appropriate.

## **6.6 EXPECTATIONS AND EXPERIENCE**

The participants' expectations of using both pieces of equipment were often very different to their experiences of using them, and the differences between expectations and experiences were discussed continuously throughout the interviews. Additionally, expected attitudes of friends, family, and the general public, and actual attitudes of these individuals, were discussed throughout and were a prominent part of the experience of using the Sensecam, but were less prominent in the use of the LifeShirt. The theme is made up of two sub-themes; *'attitudes toward use'* and *'attitudes of others'*.

### 6.6.1 ATTITUDES TOWARD USE

Throughout the interviews the participants' experiences of using the equipment were different to their expectations. Not all expectations were negative.

*I did not go into it thinking that I would have a problem, and I did not have, because if I went into it thinking that I would have a problem I would not have done it, but the way that it has been explained to me I didn't think that I would have a problem, I was willing to have a go, and I was pleased that I did, because it wasn't any problem [001]*

*I thought it was going to be a huge laugh [laughs] a bit of a joke [005]*

*[I thought the technology was going to be] absolutely no problem [006]*

These individuals described the technology positively with regards to perceived ease of use. These individuals were positive about the equipment, and its use, even before the study began. P001 also stated that her expectations were not negative as although the technology was 'new' she trusted that I would not be asking her to take part in anything that would 'upset' or 'affect' her and P003 mirrored this as he felt that I 'wouldn't be bringing it if it wasn't safe'. However, these positive expectations were not reflected over the entire sample, and P001 still had some negative expectations of the equipment. Some believed that the equipment in general was going to be intrusive and difficult to use.

*Yeah [I thought it was going to be intrusive], but it wasn't, it wasn't intrusive at all, why no [001]*

*Well my heart sank when I saw them [laughs], erm...but I just thought that I would give it a go...I enjoyed it more than I thought that I would do [002]*

*Erm [I thought]...am I going to be able to use this [laughs] [004]*

P001, P002 and P004 discussed their expectations of the equipment, before they took part in the study, as being intrusive and difficult to use. Furthermore, P002 discussed her apprehension at using the equipment due to her anxiety with computers.

*I do use a computer but I am not computer confident .... so I was apprehensive about that because I am never quite sure if I get anything wrong whether I am wiping everything off or whether I can stop and start again so that, I wasn't confident with, erm... [002]*

*normally when if I'm doing documentation, I usually do it when somebody is here and then I can shout 'I'm stuck, I'm stuck, what do I do' I think the fear is worse than actually, there is not much that you can do wrong but you are not convinced at that, so...erm, that I did find I would have liked...my granddaughter here to show me [laughs]... [002]*

The participant emphasises that she was worried in case she destroyed the data when using either the Sensecam or LifeShirt. As previously discussed in Section 4.3.6.1 the

*Unified Theory of Acceptance and Use of Technology* (UTAUT, Venkatesh *et al.*, 2003) has four dimensions which are believed to affect the intention to use technology. One of these dimensions is '*facilitating conditions*', which refers to the level of support the user believes they are receiving from the organisation and technical infrastructure to use the technology or I.T. system. Like the dimension of *facilitating conditions* within the UTAUT, the participant also stressed that she felt more confident if others, such as her granddaughter, were there to support her use of the equipment, especially on first use. However, those *facilitating conditions* were not met for the participant, and she carried out the study regardless. Therefore, although they were important to the participant they did not affect intentions to use the equipment. No other participant discussed *facilitating conditions* as part of either their expectations or experiences of using either the Sensecam or LifeShirt.

Experiences of using the equipment were generally more positive than expectations of using the equipment. Some participants' experiences of using the equipment as a whole were generally positive.

*but once you get it yourself, not everything is easy is that, but it was easy, I must admit it was easy [001]*

*Yeah it was alright...I think...no I don't think I had any problems [putting them on] [004]*

*The equipment was absolutely fine, it was nothing [006]*

When discussing both pieces of equipment generally, participants felt that their experiences were positive, with some of the participants feeling that their experiences were better than their expectations of using the equipment, although not all expectations were negative. This also reflects the data captured from the *Flow-State Scale* questionnaire (Jackson & Marsh, 1996) with most participants agreeing that they '*really enjoyed the experience*' of using both the Sensecam and the LifeShirt.

However, despite individuals discussing their experiences as being more positive than their expectations, this was not specifically reflected in the UTAUT questionnaires for either then Sensecam or the LifeShirt. There were few differences between the expectations and experiences of the ease of use, attitudes towards the technology, participants' self-efficacy when using the technology, or their anxiety toward the technology, within the questionnaires. Although the difficulty of the technology was reflected in the questionnaires, and differences were not highlighted, the intrusiveness of the technology was not discussed in the UTAUT, therefore participants' expectations and experiences of this could not be noted, despite this being one of the issues that individuals felt worried about at the beginning of the study.

When specifically discussing the Sensecam some participants felt as though the Sensecam itself was going to be intrusive and difficult to use.

*when I read through, I thought 'oh gosh, this is too intrusive', you know going everywhere with a camera around your neck and also the time that it was going to take...erm, so it did put me off and then I said to [the person telling me about the study], I don't think that I am going to do this [002]*



Generally, the actual experience of using the Sensecam was less intrusive and a lot easier to use than initially thought.

*I didn't know what it would be, what to expect, until you got it on and once I got it on, on that first day I was just, ok, it was completely different to what I imagined [001]*

*I can't say that it was enjoyable to that extent, but it was alright, erm...thinking back it probably was more enjoyable than at the time, erm...and I, pleasant is not the right word, I would say, it was alright, it was alright you know [002]*

*I was happy with the camera [004]*

*I thought that it was very unobtrusive, just this little thing around your neck, and that was it [009]*

*[The Sensecam was the] easiest thing on the world [011]*

*the camera was ok, well it just sort of worked itself really [012]*

*I found [the camera] no bother [to use] love [013]*

*No [I didn't have any problems with the camera] not at all [015]*

*Aha simple just the button really to press it, turn it on and off [017]*

*Yes [the Sensecam was] no problem [to use] [018]*

The Sensecam was often described as 'easy' and 'no problem' to use. It is clear that the ease of use was important, and many of the participants spoke of the ease of use of the Sensecam whilst discussing their user experience. All models of technology use highlight the importance of technology complexity and ease of use, including the *Technology Acceptance Model* (TAM, Davis, 1989), TAM2 (Venkatesh & Davis, 2000), TAM3 (Venkatesh & Bala, 2008) and the UTAUT (Venkatesh *et al.*, 2003) as well as models of user experience (Hassenzahl & Tractinsky, 2006). Furthermore, Chen and Chan (2011) composed a review of the literature of technology use in older adults using the TAM which looks at the dimension of 'perceived ease of use'. The review found that perceived ease of use was one of the most important dimensions of technology use for older adults, and strongly affected technology acceptance.

However, one aspect that general models of technology do not address, and something that is specific for wearable technology, is its intrusiveness. The potential intrusiveness of the Sensecam was something that many participants discussed, and those participants believed that the Sensecam was less intrusive than they had expected.

Despite the Sensecam being viewed as easy, and the experiences more positive than expectations, there was negative feedback from the participants concerning the use of the buttons.

*sometimes I couldn't remember which button to press [003]*

*I found the, on the camera it was a bit fiddly, the buttons..erm that was the only thing that I found erm difficult to use [009]*

*[yes] I mean the on, off having no finger nails I tended to use a key for the on off but the the erm controls on the side were fine [010]*

Buttons were difficult to press or unclear for some participants. Research has expressed that the design of technology for use within the older population should be thorough; taking into account age-related changes including motor movement, sensory processing and cognitive functioning (Rogers & Mynatt, 2003). Demiris, Doorenbos and Towle (2009) produced guidelines for web-based programmes for use with older adults. As part of their guidelines, the authors propose that websites have icons which are simple, large symbols, accompanied with text, and are clearly distinguishable from others. Currently, the Sensecam's appearance is smooth, as the buttons are flat to its surface. Whilst this is presumably due to aesthetics, it created problems for the older adults using the Sensecam within this study.

Other than this, P012 had the most negative experience using the Sensecam over the sample. The participant initially chose not to use the LifeShirt and she was worried about it being difficult to use and on day two of the study she also ceased using both the Sensecam and Daily Reconstruction Method. The participant was anxious when using the camera and was also unsure whether the camera had charged or whether the images had recorded.

*[Laughs] I don't know how I worked it, were there any photographs? [012]*

*on the last night I put it on I was going to do it, put it on to charge up and when I put it on I wasn't sure whether I done I properly. Was it charged up when you got it back? [012]*

*I thought I bet that isn't charged up in the morning, but I thought I had done it but I didn't know and I thought well it is probably not even working anyway and there were bits of daft little faults but it was me really you know [012]*

Although P012 stated that the Sensecam 'didn't take any working really' she felt anxious about whether she was using the camera correctly and stopped using it during day two of the study period. P007 also chose not to use the Sensecam, or the LifeShirt, for fear that she would not be able to use the equipment. Despite these issues, most individuals, other than P012, stated that they would use the Sensecam again.

*Oh I'd use [theSensecam] again, no problem [015]*

*It wouldn't bother me [to wear the Sensecam again] [016]*

*I would use [the Sensecam] again yeah [018]*

Similar to the Sensecam, not all expectations of using the LifeShirt were negative.

*I, didn't have any, any perceptions about it at all or any feelings about it, it didn't look difficult to use, erm it was just a vest with a few wires coming off it basically, nothing daunting [009]*

However, generally, expectations of setting up the LifeShirt were more negative than use, and participants also felt that it got easier as they got used to using the LifeShirt.

*It was easy, yeah, yeah, I mean the 1<sup>st</sup> morning that I did it by myself I had to think about it, but the 2<sup>nd</sup> morning, you only had to look at the machine and once you have got all of the wires in the machine tells you what to do, so you are not really using your brain to do it [003]*

*It got easier to thread those wires through [laughs][004]*

*No [setting it up] was not a problem, it wasn't a problem you know, I mean, yeah I did it, no [005]*

*[The jacket was] easy to use, yeah because, I, we have used ECGs you see in the ambulance service so erm it was quite, quite straight forward [009]*

*Once I had done it, well I was very conscious [of setting the LifeShirtup] but from the 2<sup>nd</sup> day onwards it went on very easy but that was after you came up and show me how to put it on [010]*

As well as expectations being more negative than actual experiences, some individuals felt as though they became accustomed to using the LifeShirt after the first day, and it subsequently became easier to use after this. From the participants that wore the LifeShirt as part of the study, some of the individuals found the LifeShirt easy to use. P001 also stated that the LifeShirt was easier to use than she expected.

*Well I thought it was all easier than...I was expecting to be honest, much easier than I was expecting [001]*

However, despite the participant claiming that it was easier to use than expected, she had severe difficulties with her eyesight and she could not use the LifeShirt without my help.

*I just struggled because of my eyes, but once I felt where they went I was no problem [001]*

*the only difficult part that I had was with the zips, because I couldn't see, but later on in the week as it got on I did manage the zips, by putting the white zip, putting it on over my head [001]*

This participant used the LifeShirt for the seven days of the study period with my help. Similar to P001, P002 also had overall positive experiences of using the LifeShirt in that 'the life vest, after the first effort, wasn't a problem at all', however, when asked more details there were issues that she faced with the LifeShirt.

*I did you know sometimes when you get confident, you get over confident and a couple of times I blew into the thing without saying 'done', or 'move onto the next', you know, I stood up blew, sat down blew and then I'd think 'awww I haven't gone through the proper sequence' [002]*

Although the individual initially stated that the LifeShirt was easy to use after first use, she remained having problems when setting up the LifeShirt.

Expectations tended to be better than experiences for most participants using the LifeShirt, in that it was easier to use than initially thought. Once more, the perceived ease of use, also described as 'effort expectancy' in the UTAUT, was an important aspect of user experience, despite the technology not being as difficult as individuals originally thought.

There were however a number of practicalities with the LifeShirt, other than ease, which made use more negative, including issues with visibility, bulkiness and comfort. Many participants discussed concerns with the visibility of the LifeShirt whilst wearing it.

*Trying to find something to put over it and people would look at me in the shops you know and I didn't think...[002]*

*But I didn't look a nice shape [laughs] and it is hard you know, I put stretchy sort of, well not stretchy but big sort of t-shirts on top of it, and erm...and remember not to put something on that is too light as you could see through it...[002]*

*Well [I was self-conscious] form a...both really because if you had a coat on you looked, you weren't even, it was one-sided, I thought 'don't be daft, they don't know what, she's just got a bum bag on', because I didn't take a handbag if I had got that on [002]*

*I'm portly to begin with and all of the wires down the front tend to exacerbate that, and also the main wire from the jacket to the erm unit, that tended to hang down at times, and looked as though you had a catheter in, it was a little disconcerting, if it had been higher up the jacket and came out of the side you would have been able to tuck it in your shirt and down that way, apart from that it wasn't bad [003]*

*I wore a black jumper anyway so rather than wearing a white t-shirt with it [009]*

There were many concerns of how participants looked whilst wearing the LifeShirt and some participants made a conscious effort to hide the LifeShirt as much as possible with their clothing. Furthermore, although P005 felt that the LifeShirt 'didn't look too bad' she also said that she 'couldn't have worn these strappy tops that would have been the only real consideration' because of the visibility of the LifeShirt.

The aesthetics of technology are important, and are considered in general models of technology use, such as Hassenzahl and Tractinsky's (2006) model of user experience. However, the aesthetics of wearable technology are considered in a different light. One example of the development of wearable technology based solely upon design is the innovation of digital jewellery which has been suggested as a way of making wearable technology more subtle, based solely upon the importance of aesthetic design (Miner, *et al.*, 2001). The authors consider the aesthetics of the technology to be extremely important in terms of wearability, and consider the design of the jewellery specifically in terms of its aesthetics. One other example of wearable technology is 'Google Glass'. Despite being a wearable piece of technology, the developers made *Google Glass* unobtrusive and promote its 'strong and light, modular design' (Google, n.d.). Furthermore, *Google Glass* also comes in a variety of colours, once more highlighting the importance of aesthetic design.

The aesthetics of wearable technology are essential, and some individuals described its importance when using the LifeShirt, however, it was not just the aesthetics of the technology itself, but also the aesthetics of the individuals when wearing the LifeShirt, such as looking larger. When looking at other pieces of wearable technology, such as the development of digital jewellery and *Google Glass*, it becomes clear that issues of design are long-lasting, and not specific to the LifeShirt. However, it is also clear that some of the aspects of design that affected use of the LifeShirt, such as its shape, and the presence of the wires, are specific to the LifeShirt, and have already begun to change due to the development of wearable technology.

As well as the design of the technology being important in terms of aesthetics, the design was also important in terms of the LifeShirt's comfort. Some participants also found the LifeShirt uncomfortable due to the weight and bulkiness of the computer, and the size of the bag that the computer is held in.

*it actually, for me it felt quite heavy but I think that may be my tiredness and my back problem, and it had to be one way on, it had to be that way on, and you had to take it in...yes that was at times a bit uncomfortable, but the life vest, the life vest [002]*

*But I did find as I say, the computer bit of it, I was tired by the end of the day and it was hanging on the...and it was bulky because it was nicer weather [002]*

*The jacket was fine, the jacket was fine, it was the box, that to me was, I don't know with a man he could have clipped it to his belt probably, and if it had been, if I could have done that, it was an inconvenience, that box, but...that as the only thing I would say, you know, I mean I still did it, it was just... [005]*

*Yeah [I used my own bag] it was smaller [005]*

As well as size, comfort was an issue for many of the participants, although some found the LifeShirt comfortable to wear due to its temperature.

*I wasn't affected whether it was hot or cold [002]*

*I thought [the temperature control] was brilliant, somebody must have really gone into that, it must have been made of that stuff they use in the forces that is breathable [006]*

Comfort was a problem for other participants. P009 did not enjoy wearing the jacket as it 'was *initially quite scratchy*' before washing, whereas comfort issues for some individuals involved the electrodes which were used to attach the electrical component to the skin. The electrodes caused issues for participants over the study week, with some participants finding the electrodes itchy on their skin, and hurt the individuals.

*I didn't find the blimmin electrode things comfortable, it was horrible taking them off, it really hurt [004]*

*The sticky pads started to irritate my skin, they have just stopped itching ... I'm allergic to Elastoplast anyway so whether that was that rather than the gel itself, and they were very*

*sticky, very, you know you had to be careful pulling them off, I had to hold my skin and then pulled them off [009]*

Although these individuals continued to use the LifeShirt despite the irritation caused by the electrodes, two participants discontinued using the LifeShirt after a few hours' use due, in part, to this problem. The issues surrounding the electrodes is particularly a problem for older adults, as older adults' skin often damages easier than that of younger adults as it is more loose, and can tear more easily (Na, Wang, Kirsner, & Federman, 2012; Gilcrest, 1989). One participant left the study due to the use of the LifeShirt as she became quickly irritated by the electrodes, like other participants. P008 also discontinued using the LifeShirt but continued with the other components of the study. This individual felt that the electrodes were irritating her, and the LifeShirt was too uncomfortable to wear.

*I was uncomfortable with the weight of the computer and the strap around my neck, and the bulk of it, I couldn't fasten my clothes properly you know, with a t-shirt you know I couldn't have managed to use...I had all of the wires sticking out erm, so it was really uncomfortable [008]*

*it was in the way all of the time, no matter what I wanted to do, you know even if I had to sit down and read I had to move the computer round and you know, move the bag around it was just too awkward [008]*

*I took it off about half past 3, I just was demented by then and there was, there was the gel patch thing, the sticky patch was starting to itch on my side, abdomen yeah [008]*

The individual was uncomfortable with the electrodes, the LifeShirt garment itself, and its size, and she did not wish to carry on using it. Like P008, P010 also experienced many issues with the LifeShirt, but unlike P008, she carried on wearing it for the entire study week.

*Erm I thought it would be a lot easier than it turned out to be because it looked, it looked very straight forward but it didn't turn out to be as straight forward as you think and that is simply because I have no experience of being wired up [010]*

This participant found the LifeShirt difficult to use. Despite the individual expecting the LifeShirt to be complex and experiencing the LifeShirt as difficult to use throughout the study, the individual did not cease use. P010 also found the LifeShirt as a whole to be tight and uncomfortable.

*the main thing that bothered me was how tight that vest was [010]*

*a less constricting shirt you wouldn't notice it so much erm so somebody wearing that who is 3 dress sizes smaller than I am will probably think that it is a doddle, but anybody that is a dress size bigger than me won't be able to do it ... [010]*

*as far as I am concerned it was bloody uncomfortable [010]*

This participant was particularly uncomfortable using the LifeShirt and had many problems over the course of the week, however, she wore the LifeShirt every day during the study period.

Once more, like aesthetics, the comfort of the LifeShirt is clearly important to users, and is one component that will continue to be important despite which piece of wearable technology is being worn. There was a limited amount of research that was undertaken before this study that considered the design of wearable technology, however this study has added to that limited research. Two studies had specifically focused upon the comfort of wearable technology. Knight, *et al.*, (2002) present a comfort rating scale which is intended to be used by designers when manufacturing wearable computers. The comfort rating scale was made up of six factors; *emotion, attachment, harm, perceived change, movement and anxiety*. Although not all components of comfort were discussed by all LifeShirt users, all components, other than anxiety, were discussed by some of the individuals within this study.

The comfort of wearable technology has also been acknowledged by the developers of a *Smartshirt*, which is not too dissimilar from the LifeShirt (Park and Jayaraman, 2003). Park and Jayaraman (2003) discussed five user requirements of their technology, one of them being wearability. The wearability captured various aspects of the technology use that were also prominent within the use of the LifeShirt, including, the technology being comfortable, causing no skin irritation, being lightweight and breathable.

It is clear that the issues experienced for the LifeShirt by the participants in this study are not unique, and have been discussed similarly when using other wearable technology. However, some of the precise details of comfort discussed in this study are specific to the LifeShirt itself, and have the potential to be eliminated with improved and innovative technology design. The technology involved in the LifeShirt itself has developed since beginning this PhD and as a result of the developments, has reduced some of the aesthetic and comfort issues of the LifeShirt. Vionoetics Inc. have developed additional products, including the Vivosensor. Like the LifeShirt, the Vivosensor measures ECG, includes a Dual Band Respiratory Inductance Plethysmography, and a tri-axial accelerometer, as well as recording additional data. However, unlike the LifeShirt, it is only made up of two straps, worn around the trunk, and a small computer with a removable SD memory card. The components of the Vivosensor are much less bulky than those involved in the LifeShirt. Additionally, the computer (Vivosense, Vionoetics Inc.) is smaller, and is able to be clipped onto a pocket, or belt, as opposed to being placed inside a waist-worn bag. This would minimise, or eliminate, many of the practicalities discussed by participants.

#### **6.6.1.1 SUMMARY**

The difficulties that participants expected to face with both pieces of technology, and the actual difficulties faced often varied. Whereas the Sensecam's intrusiveness and difficulty of use, as well as the difficulties of using the LifeShirt, were common expectations of the technology over the sample, it was the problems surrounding design that caused most issues during use. That is not to say that all individuals found the Sensecam or the LifeShirt easy to use, however the difficulties using the technology were less than expected, and only experienced by few participants.

Although some participants found the LifeShirt easy to use, 11 of the participants that took part in this study did not wish to use the LifeShirt, mostly as a result of the perceived difficulties of its use.

It is evident from the participants' discussions of both the Sensecam and the LifeShirt that issues with difficulty of use were expected to arise whilst using the technology. The UTAUT discusses '*effort expectancy*', perceived ease of use, as a dimension that influences behavioural intention and ultimately use of technology. Perceived ease of use has been seen as an important concept, and is evident in multiple models of technology acceptance. Although the majority of participants did not experience difficulties when actually using the technology in this study, they did perceive difficulties before using the technology. However, despite the importance of expectations about ease of use discussed in the interviews, this was not captured on the UTAUT questionnaire itself. Most of the participants noted both the Sensecam and the LifeShirt as positive on multiple aspects of the UTAUT and the *Flow-State Scale*, in terms of ease of use, attitudes towards the technology, self-efficacy and low anxiety during use. However, what did not come across in the UTAUT questionnaire, were the differences between the participants' expectations and experiences, as discussed in the interviews. Although the intrusiveness, comfort or design of the technology could not be captured using the UTAUT, it did record ease of use and anxiety, however it did not show the differences between the participants' expectations and experiences that were discussed in the interviews.

The fact that both the Sensecam and the LifeShirt were easy to use was an important part of the user experience, and was greatly discussed, as well as it being a deciding factor for some individuals who chose not to use the technology. Of the participants that took part in the study, two individuals did not wish to wear the Sensecam due to the perceived difficulty of use. Whereas P007 did not wish to use the Sensecam at all due to perceived difficulty, P012 began wearing the Sensecam and ceased use after day two. Additionally, neither of these individuals wished to use the LifeShirt due to the perceived difficulties of use they foresaw with using the LifeShirt. Other than these two individuals, nine other individuals did not wish to wear the LifeShirt as part of the study, and one individual removed it after a few hours of use. All individuals did not wish to use the LifeShirt due to the difficulties they foresaw setting the LifeShirt up and taking it off, as well as its physical intrusiveness.

This study has shown that *effort expectancy* remains to be an issue that may affect the acceptance and use of wearable technology, as it does with general technology. Although perceived difficulty did not affect use for all participants, and most individuals, that chose to wear the technology found the Sensecam and LifeShirt easy to use, perceived difficulty remained to be prominent throughout the discussions of using the technology. As well as difficulty of use, the intrusiveness of the technology was one additional aspect that was assumed to be an issue whilst using the technology. This is one aspect of technology use specific to wearable technology that is not considered within general models of technology use, or user experience.

Rather than difficulty of use or intrusiveness being a negative part of actual use, most participants had issues with the design of the technology. Some individuals had an issue with the design of the small buttons on the Sensecam which made it difficult to



press, as well as not knowing if the Sensecam was charged or working. However, most attitudes of using the Sensecam were positive and participants felt that the Sensecam was less intrusive than expected. The issues concerning the use of the LifeShirt also surrounded the design. There were various components of the LifeShirt's design that were negative; its bulkiness, weight, and comfort, specifically the itchy LifeShirt garment and the irritation of the electrodes placed on the skin. The issues surrounding comfort in this study further confirmed that discussed in other studies of wearable technology (Knight, *et al.*, 2002; Park & Jayaraman, 2003).

The general aspects of wearability that participants discussed in this study are long-lasting and are important to all forms of wearable technology, including the importance of design, aesthetics and comfort, despite the actual specific details of design, aesthetics and comfort for both the Sensecam and the LifeShirt being specific to these devices. These specific aspects within the three important areas of wearability will change, and become less important, with the development of wearable technology which is increasingly smaller, lighter and can also therefore be more aesthetically designed.

## 6.6.2 ATTITUDES OF OTHERS

In addition to expectations and experiences of using the equipment, the individuals' expectations and experiences of other people's attitudes also appeared to be an important part of experiences of using the technology. The opinions of others were the most prevailing topic discussed within the interviews and this was mostly regarding the Sensecam. Many participants expected to receive more comments than they actually received whilst wearing the Sensecam.

*I thought that I would use [one of the notes given to explain the Sensecam] if someone stopped me in the shop, say security, said 'what are you doing with that on? What do you think you're doing?', but nobody anywhere did [001]*

*the only thing about the camera on was what other people would be thinking 'what is she doing with a camera around her neck' but as I say nobody make any remark, one or two people in the paper shop that I go into every morning one of them, you know, but they never asked, they never said anything, no I just didn't, I just let it go, I did go into Sainsbury's, I did go into LIDL with it on, and I did go into the local shop and they said nothing [002]*

*I was waiting for people to ask me what it was and they didn't, nobody did, and I mean I was really quite surprised with the camera because it was flashing regularly, it was obvious that it was a camera and that nobody in any of the supermarkets that I went to said 'are you taking photographs of our shelves?' [010]*

Individuals were expecting others to comment on, or question, the use of the Sensecam whilst they were wearing it and most individuals felt that there would be more comments about the camera than they actually received. Despite the initial expectation that other people would notice the Sensecam it did not affect behavioural intention and all of these participants still volunteered to use the Sensecam as part of the study.

Within the UTAUT one of the factors affecting behavioural intention to use technology is 'social influences'. *Social influences* are discussed within the UTAUT as the amount to which important others feel the user should take up using technology. When completing the UTAUT participants were unsure when answering the questions relating to social influences, as they either did not understand the questions, or felt that they had not discussed their decision to take part in the study, therefore wear the technology, with other individuals. Despite individuals' responses on the UTAUT with regards to others influencing their use of the technology, this seemed to be the case when talking to the individuals.

In addition to the UTAUT, the *Flow-State Scale* also questioned participants about others' opinions of the technology, after they had taken part in the study. Most participants strongly indicated that they were not worried, or concerned, with the perception of others when wearing the Sensecam, nor were worried of how they were presenting themselves when wearing the Sensecam. However, it is evident from the discussions that some individuals' use of the Sensecam was dictated by their concern over others people's responses, therefore were not completely comfortable wearing the Sensecam in public on some occasions. For example, others' opinions of the technology did affect some use during the study week.

*To be honest I wouldn't use it outside my house because you are compromising someone aren't you, you know I would have to ask them, but then you have to ask them, or you should, or they would say 'aw what is that around your neck?', 'it is a camera', 'aw well I didn't want my photo taken, I don't want to be on it' [006]*

*I took it off when I went into Tesco's because I think they're a bit funny about cameras in their shops, they are a bit of a funny shop so just in case they thought I was a snoop wandering around photographing the shops so I took it off when I went in there and when I went to the doctors of course [016]*

P006 and P016 were both worried when they used the camera due to the expectation of others' responses, and this therefore affected their use of the Sensecam. Although *social influences* did not affect overall intention to use the Sensecam for these participants, it did affect some use of the Sensecam during the study week.

P002's use of the Sensecam was also affected by expectations of others on some occasions. The participant discussed her '*self-consciousness*' and that she expected more comments whilst using the Sensecam, but also explained that this changed when she felt that she had '*control*' of the equipment.

*I was self-conscious to start with, I was expecting more comments, but when I realised that I had more control over it, I thought 'I have got control of this', so after the 1<sup>st</sup> day I would think, because I think that I went to French the first day and I did switch it off then, I thought there were going to be lots of comments ... but yes to start with I thought that people were going to ask what I was doing, and actually feeling comfortable with you know, you feel bulky, but after the 1<sup>st</sup> day you know, it was ok [002]*

P002 states that she felt in control of the equipment after first use which changed the way in which she felt about the equipment, and therefore changed the way in which she used it; as the participant felt more control, she used the Sensecam more. Having control of the Sensecam was something that was important to P002, when discussing the perceptions of others, and was something that most of the participants felt, according to the *Flow-State Scale* questionnaire (Jackson & Marsh, 1996, see section 6.4).

In most cases individuals expected to receive more comments about the Sensecam than they actually received and participants were generally surprised as to the little amount of comments they received from others, specifically the general public. When participants felt as though some members of the public had noticed the camera, most did not ask what the camera was or asked the participant details about the Sensecam.

*Some people don't, but some people do, you can tell they have you know they have spotted it like you know [014]*

*[the camera was] no problem and nobody ever questioned me when it was hanging around my neck and everything so if they didn't mention it I didn't mention it so you know [015]*

*Not many asked about it but yes I'd say a lot of people noticed it erm and would look but not many asked [017]*

*No, no, [no member of the public mentioned it] [018]*

*Yeah, yeah they weren't worried about it as I say I just got a sense of wariness from one group of people, one or two people, so they didn't actually say you know don't, please don't [018]*

Although most people felt that there were less comments made about the Sensecam than they originally thought, some people did notice the camera, and asked the participant about the camera, however, these were usually friends and family.

*[Friends from a group I attend] said to me 'what is that?', and I said 'you better smile because I'm taking your photo', you know [005]*

*A couple of people from the U3A wondered about what it was about, and then they said 'ah that is brilliant, good on you' they were saying you know, but erm, no nobody else mentioned, [my daughters] mentioned but no [005]*

*Nobody bothered. No, when I went to the bingo they said what is that and I said I am doing a survey for my friend and they said 'oh' and they ignored it, they didn't even ask what survey I was doing' [011]*

*yeah people asked what it was, you know eventually that asked what is that so I'd tell them and explain what it was for and mostly they were fine, one group were I would say wary, they didn't sort of complain about it but I sort of got the feeling that they were a bit wary of me carrying, you know, wearing this thing, erm monitoring you know but yeah and I thought well if somebody objected then I would just take it off [018]*

The importance of others' attitudes towards the presence of the Sensecam is evident throughout and participants were constantly aware of the reactions of others toward the Sensecam, even if others did not give much reaction. In many cases the expectation of the public's reaction did not influence use of the Sensecam but individuals were aware of their reaction, despite this reaction being less than expected.

The participants continuously discuss their perceptions of the public's responses to the Sensecam, and these were generally more negative than actual public reactions. Although the negative perceptions did not affect their decision of taking part in the study, and wear the technology, perceptions of social reactions did affect the amount of time that some participants wore their camera such as when friends and family did not want to be recorded. It was clear that participants were aware of the ethical issues surrounding the use of the Sensecam whilst with others and in public.

Social influences played a part in who participants told about the camera. P003 told others that he was wearing the camera and '*volunteered the information beforehand*'. He also stated that he '*had a habit of saying to people, you know, it is a camera*' and told others that he would remove the camera if they had a problem with it. Whereas others made their own judgement as to whom they told about the camera.

*Well when I went to choir practise I didn't bother to tell the conductor...erm, when I was visiting someone told them but erm...no I mean on the whole nobody took any notice of it, they didn't notice it [004]*

In most cases participants felt positive about using the camera. There was a positive reaction from friends and family, with friends and family being good-humoured about the study, or alternatively, being pleased that the participant was helping with the research.

*[My friends and family] just said, well for you, when I was doing it, well for you [001]*

*my grandchildren weren't phased by it at all no, I threatened one of them with it [laughs] I said 'this is all on camera you know', but no they were alright after the initial, you know, 'rah rah rah' [pulling faces at the camera], they didn't bother [002]*

*[The mechanic] did look and when I told him what it was I think he dived in front of the camera, the little show off [003]*

*Some [of my friends and family] said that you know 'here comes big brother' [004]*

*Yeah [people gave] positive comments, yeah, yes, saying what a good thing you know that I was doing it, so yes that was alright [005]*

*[My family] thought it was a good thing [006]*

*Friends said what are you wearing around your neck, and I said that I'm doing a study, I'm taking part in a study for pain and that was it really yeah, yeah [009]*

*Yeah I mean we used to joke about it you know 'we are watching you' and this sort of thing and we would laugh you know [laughs] [018]*

However, despite mainly receiving positive feedback from friends and family, this was not always the case, and some individuals received negative feedback about the camera, which affected how much the individuals used the Sensecam.

*I did take it off, I wish that I had left it on then, but it was the family being very rude when we went out, we went out for dinner one evening, and yeah I did switch it off then, because they were being obnoxious but obviously didn't [turn it off] when we went to the lunch I did, I did erm, I went out visiting one night and they were uncomfortable with it so I did switch it off then [002]*

*Yeah, yeah lots of old people don't want their photo taken as they have changed, they think they look awful, erm...the rest of the people at the, the erm...erm...play reading weren't bothered but as I say this lady I think she has had quite a lot of depression and a lot of anxiety, 'oh my god' she said, 'oh my god', you know she just didn't want to be on it and as I said when I went visiting I knew that they wouldn't want it in their home so I just took it off [002]*

*I didn't have a remark, only as I say what close things, close things, you know, 'oh I don't want my photo taken' [002]*

*one person who didn't want to be, want me to use it with her, but we have deleted them now ... and I didn't have it on the next time I went to see her .... I think that it was probably because she didn't want [her daughter] on it, and she doesn't like being photographed herself either so [004]*

The information being recorded on the Sensecam meant that some participants worried about others' reactions to the camera during use. One participant described the reason why they were using the Sensecam differently to their family as they did to strangers.

*Well nobody asked me, there was only one person asked me, and they said 'oh what is that?' and I said 'aw it is monitoring my chest, because I have got a bad chest' and they said 'aw', and that was it [001]*

*I didn't want to go into details with anybody, but there was only the one person that asked, nobody else took a bit of notice with any of it [001]*

*I: Did you feel self-conscious telling your friends and family about the equipment?*

*001: No.*

*I: Did you tell them why you were wearing it, that it was to do with chronic pain?*

*001: Aha, yes*

Although the individual felt comfortable wearing the Sensecam in public and also felt comfortable telling their friends and family the reason for wearing the Sensecam, she felt uncomfortable telling others, and made up another excuse for wearing it. P014's wife also told how P014 had told his friends another story about the nature of the Sensecam.

*[P014] made a joke and told them it was a heart monitor [laughs] he said if it turns to red you have to phone an ambulance [013, 014's wife]*

P014 did not tell his friends the reason as to why he was wearing the Sensecam, or what it was.

Participants did not tend to discuss the public's reaction to the LifeShirt. One participant did not tell anyone about the LifeShirt.

*[My friends and family] didn't know about the jacket [004]*

The jacket was more discreet than the Sensecam, therefore the individual did not discuss this with others. However, one individual mentioned that her friends and family took a light-hearted approach to her wearing the LifeShirt.

*they laughed, my friends, they said 'eee you have got a police jacket on', you know when I had no top on [001]*

Individuals did not tend to discuss the opinions of others regarding their own use of the LifeShirt, and participants tended not to discuss others' opinions of the LifeShirt within the interviews.

#### **6.6.2.1 SUMMARY**

The attitudes of others were highly important to the participants. The expectations of others' reactions were more negative than their actual experiences of wearing the Sensecam in public. There were, however, some individuals who were negative toward the Sensecam and this affected the amount of time the camera was worn. Social influences also affected how individuals explained the Sensecam, and the reason as to why they were wearing it.

The participants were much more concerned about the public's attitude to the Sensecam than the LifeShirt, and the attitudes of others toward the LifeShirt were not often discussed.

#### **6.6.3 SUMMARY OF EXPECTATIONS AND EXPERIENCE**

There are two main components that made up expectations and experiences; the expectations and experiences of the use of the technology, and the expectations and the experiences of the perceptions of others. The expectations and the experiences of both the use of the technology and the perceptions of others differed, and the problems with both pieces of technology were not the issues that individuals believed they would face at the beginning of the study.

For some participants the Sensecam was easier to use, and less intrusive than expected, however, not all expectations of the Sensecam were negative. In fact, it was the difficulty of pressing the Sensecam's buttons and not knowing whether the Sensecam had charged that were the most negative aspects of using the Sensecam.

The expectations and experiences of others toward the Sensecam differed. Participants expected other individuals to notice the Sensecam, and ask about the Sensecam more than they did. These perceptions of other individuals' attitudes toward the Sensecam also affected the amount of time the Sensecam was worn for some individuals. The social influences of wearing the LifeShirt were not greatly discussed, and did not seem to be an issue for the individuals involved in the study.

Despite the social expectations or experiences of the LifeShirt not being widely discussed, its use was discussed in much depth. The majority of participants expected the LifeShirt to be more difficult to use than it actually was. As opposed to issues with difficulty of use, most experienced problems with the wearability of the LifeShirt, specifically its comfort, weight, bulkiness and the irritability of the LifeShirt garment and the electrodes. The design of the technology is something which has been looked at in previous literature relating to both non-wearable, and wearable, technology. This study has further confirmed studies highlighting the importance of wearability, including aesthetics and comfort (e.g. Gemperle *et al.*, 1998; Knight *et al.*, 2002; Park & Jayaraman, 2003; Miner *et al.*, 2001) but has given more depth to this knowledge, and has provided knowledge from the perspective of the users themselves.

There are both contemporary and long-lasting issues discussed as part of expectations and experiences. The specific issues that individuals faced with the design of both the Sensecam and the LifeShirt, such as pressing the buttons on the Sensecam, and the bulkiness of the LifeShirt, were specific to those pieces of technology, however the importance of design for both aesthetics and comfort is something that needs to be considered as a long-term issue. Furthermore, social influences are also a long-term issue, and although the specifics may differ depending on the technology itself, the effect of others is more of a long-term problem.

## **6.7 AWARENESS OF EQUIPMENT**

The theme '*awareness of equipment*' is made up of two sub-themes; '*forgetting equipment*' and '*potential effect on behaviour*'. It became apparent that the awareness of the equipment was inconsistent. This theme initially encapsulates the inconsistencies of forgetting and remembering the equipment and secondly looks at how this awareness of equipment may have affected behaviour.

The extent to which the Sensecam and LifeShirt were remembered during the study week, and whether or not they affected behaviour, were important in two ways. Firstly, the awareness of equipment was important for the outcomes of Part A of the study, as it was important that individuals acted as they would without using the technology so as to avoid the Hawthorne effect. The methodological Hawthorne effect is a phenomenon within field studies that occurs when an individual is aware that they are being observed and adapts their behaviour as a result of this (Adair, 1984). Furthermore, it was clear from the interviews that the awareness of the equipment was an integral part to the individuals' experiences of wearing both pieces of wearable technology.

### 6.7.1 FORGETTING EQUIPMENT

The patterns of forgetting equipment were apparent as participants discussed inconsistencies of forgetting the Sensecam and LifeShirt during use. Forgetting about the equipment was an important aspect of users' experiences of wearing the Sensecam and LifeShirt, but the factors that affected forgetting differed between both pieces of technology. Individuals spoke of the intermittent remembering of the Sensecam based around the awareness of their behaviour being recorded, whereas, with the LifeShirt this was usually because of the discomfort participants felt when wearing the equipment.

Some individuals spoke specifically about forgetting the presence of the Sensecam.

*you just hung it around your neck, erm, and pressed your button...erm yeah and I actually forget, you forgot it was there [002]*

*No [I didn't feel self-conscious] I forgot that [the camera] was there actually [015]*

However, contrary to some individuals feeling as though they forgot the camera there were inconsistencies in forgetting.

*See you get that it doesn't bother you, you forget that you had it on, the first day or so, you just forget that it is there [001]*

*I actually forget, you forgot it was there until occasionally I would be reading the paper and I would see 'blip, blip', you know, the light...and realise how many pictures it was taking [laughs] [002]*

*The first day I put it on I was conscious of it then I forgot all about it by the end of that day and I thought just put it on each morning, take it off at night and forget you've got it on around your neck, and I did [013]*

*you hardly realise I had it on I could go to the toilet and it would do [noise, laughs] it was not intrusive or anything never bothered me [016]*

*occasionally I could forget that I had it on [017]*

*[I didn't feel self-conscious wearing the Sensecam] not really, you sort of forget it after a bit erm, I mean you know that you've got it on at the beginning but erm...after a bit it is just there and you carry on [018]*

Participants discussed remembering the camera occasionally. Some participants felt more aware of the camera at the beginning of the study week, whereas others forgot occasionally, or remembered when seeing the flashing lights on the Sensecam. Other than P002 and P016 who stated that they remembered the presence of the Sensecam due to the flashing light and the noises it makes, the reasons for others remembering the Sensecam on occasion were not openly discussed by participants.

The inconsistencies of forgetting and remembering the Sensecam during use were also apparent as participants did not always remember to remove the camera during the private occasions which they wished not to be recorded, for example, whilst going to



the toilet. This suggests that individuals truly forgot the presence of the camera at some points over the study week.

*you forgot you had it on, as I say I went to the toilet a couple of times, I forgot that it was on [001]*

*[Going to the toilet wearing the Sensecam] didn't bother me...but you know I just did it accidental twice, I didn't do it all the time, because you know, I go to the toilet about half a dozen times a day [001]*

*it caught me out twice I was going to the loo and I forgot, all you'll get is a picture of a tulip on the wall [003]*

*you just tended to forget it, you had it on, that's the thing you just forgot that you had it on and erm, I mean, I turned it around occasionally, when I thought 'oh no, this doesn't need to be photo[graphe]d' but half of the time I forgot about it [005]*

*the camera didn't bother me apart from odd times when my bowel was having a flare up and I kept forgetting to take it off so you might have some rather horrible pictures [laughs] [015]*

When participants spoke about forgetting the Sensecam, they spoke of it in terms of what information the Sensecam had captured, highlighting the importance of the information that the Sensecam was recording. Furthermore, forgetting to pause or remove the camera during sensitive moments demonstrates that, in fact, participants did sometimes forget about the Sensecam. However, forgetting or remembering the equipment seemed to be sporadic for most participants throughout each day and the awareness on occasion suggests that the Sensecam was not fully forgotten by participants at all times, for example, although P001 sometimes forgot to remove her Sensecam whilst going to the toilet, other times she '*just lifted it off and put it on the bench*'. The example of going to the toilet showed this well as, similar to P001, there were times in which most individuals removed their camera whilst entering the bathroom but there were other times that were recorded whilst in the bathroom in which individuals forgot to remove the Sensecam.

As discussed, the Sensecam was not always forgotten. It was also apparent that individuals were aware of the Sensecam at other times as some participants also removed the Sensecam when they felt that the images looked boring, or they were doing repetitive activities.

*I think that I took it off on a night time simply because you don't want to see pictures of the ceiling, depending on what I was doing at the time [003]*

*I tell you when I didn't put it on, only if I knew that I would be sitting watching tele because it was fruitless or I kept it on at work if I knew there was a situation where I was only going to sit for two or three hours and you were going to get the same virtual picture then I turned it off it seemed fruitless having it on at that point... like I say when it was 8 o'clock at night and I was sitting down and I thought I was sitting watching tele for the rest of the night and only getting up to get a cup of tea or whatever I would turn it off then because I thought you really don't want to watch Eastenders twice [laughs] [017]*

Despite the participants finding this information boring, and believing that I would not want to see it, it is this data that would have been important to the study. Therefore, data was lost as a result of individuals being aware of Sensecam and believing that the 'boring' data would have been irrelevant. Although individuals did not specifically state that their behaviour was affected by using the Sensecam, they were aware of their behaviour during use, and aware that the researcher would be reviewing the images. Once more this highlights that individuals were aware of the information that was being recorded on the Sensecam.

Despite times of remembering, many individuals forgot the presence of the Sensecam. One reason that may have heightened the individuals' sense of forgetting the Sensecam in the way that most participants did may be because the participants were made aware that they would be able to review the images and delete those that they wished to delete, before I would see them. Furthermore, individuals were aware that only the research team would view these images. These points were clearly stated verbally and were written in the Participant Information Sheet before participants agreed to take part. Therefore, participants may have felt more comfortable wearing the Sensecam, and may have therefore forgotten its presence on occasion, as they knew that they would be able to edit and delete the images before anyone else looked at them, as well as knowing that only the research team would view the images.

Social influences were also important within the inconsistencies of forgetting and remembering the Sensecam during use. When discussing the awareness of the Sensecam, participants discussed becoming aware of the Sensecam when in the company of others, or when others asked about it.

*I was conscious of wearing it erm...but only on the like the post office when I saw the look on the guy's face, I was conscious of him looking at me but apart from that no [003]*

*I forgot about it you know unless someone said what is that you know because they are a nosey lot around here and they notice things like that straight away you know [014]*

Once more, the notion of *inconsistent forgetting* occurring as a result of behaviour being recorded is reinforced but was also affected by social influences, as discussed in the previous sub-theme '*attitudes of others*'. Various models of technology acceptance recognise the importance of others when using technology, including the *Technology Acceptance Model 2* (TAM2, Venkatesh & Davis, 2000), *Technology Acceptance Model3* (TAM3, Venkatesh & Bala, 2008) and the *UTAUT*. These models view *social influences* as one moderator of intention to use technology. Specifically, the *UTAUT* describes *social influences* as the amount that important others believe the individual should be using the technology. In this case, *social influences* did not affect overall use of the Sensecam, but affected the awareness of its use.

P017 also spoke of *social influences* whilst wearing the Sensecam, but spoke of becoming aware of the ethical implications of wearing the Sensecam when in the presence of others.

*most times I was aware I had it on, more from other peoples' point of view, you were always a bit I was more so wary that I was invading other peoples' privacy with it that made me wary [017]*

One of the biggest issues surrounding life-logging technologies, specifically wearable cameras such as the Sensecam, is the ethics of their use, and this is something that is still being continuously discussed by leading academics in the field (Doherty *et al.*, 2013). Specifically, the ethics of 'secondary participants', i.e. individuals that are recorded on the Sensecam images, but have not given consent to be part of the study, or are unaware that they are being recorded on the Sensecam, is of concern (Chen *et al.*, 2013), and interestingly the participants in this study were also concerned about the ethics of these secondary participants.

Doherty, *et al.*, (2013) highlight three important ethical considerations when using the Sensecam within research, firstly, the Sensecam generated thousands of images whilst the user wears it, and is more intrusive than other techniques, such as traditional technology. Additionally, the users can forget about the Sensecam, as seen within this study, and therefore images can be taken when the user is unaware of the camera. Finally, when individuals wear the Sensecam it is not just their own behaviour that is being recorded, but others are also captured on the Sensecam, including friends, family and other members of the public. Since collecting the data for this PhD, researchers in the field have produced an ethical framework which highlights ethical issues around wearable cameras, such as the Sensecam (Kelly *et al.*, 2013). The guidelines are based upon four areas; informed written consent, privacy and confidentiality, non-maleficence and autonomy of third parties. Although these guidelines were not in effect when this study was being conducted, all rules were accounted for within this study and ethical considerations were of prime importance for the participants, and others who were recorded on the Sensecam.

Despite the ethical guidelines being produced in order to guide researchers, the ethical implications of wearing the Sensecam were clearly not just an issue for the researchers but also the participants taking part in this study specifically the ethical consideration of *secondary participants*. The participants often worried about wearing the Sensecam whilst with friends, family or the public, and this often affected the extent to which they forgot about the Sensecam. Although the participants were happy to wear the Sensecam themselves, they sometimes remembered, or otherwise removed, the Sensecam whilst with others.

There was a mixed response about forgetting the LifeShirt. P006 made an overall statement that he '*just forgot that it was on*' whereas other individuals sometimes became aware of the LifeShirt due to its physicality.

*it got to some stages where you forgot, you more or less forgot that it was there and you weren't aware of it, and so you would do something particularly bending, erm...and sitting at the dining table I would have to remind myself that it was still attached in [002]*

*I felt more uncomfortable sitting with it in the evening rather than doing any activities with it, I think because of my back, that was the, that was the biggest thing, but when I was moving around I*

*wasn't so conscious of it at all but at the end of the day I was tired and not as complacent, I was irritable, I was thinking 'right I'll have this off now' I'll take my corsets off [laughs] yeah... [002]*

*[I wasn't conscious of the LifeShirt] until about 3 o'clock in the afternoon, or on a good day 5, I mean in the morning erm unless I was doing something that was banging the bum bag erm...then it was relatively comfortable and easy to forget that it was there it but once I started getting tired I was very conscious of erm and it became progressively more uncomfortable [010]*

Unlike the Sensecam the individuals did not discuss being aware of the LifeShirt due to the information being recorded, but because of its physical presence and it being uncomfortable. Despite sometimes forgetting about the LifeShirt, individuals often became aware of the LifeShirt during specific movements because of its physical presence.

One fundamental difference between the wearable technology in this study and other pieces of technology, such as smart phones and tablets, is the desire for users to forget about the wearable technology during use. Whereas the aim of some pieces of technology is to have their users be completely engrossed within its use, such as computer games, mobile phones and tablets in which a positive psychological 'flow' state is desired (Csikszentmihalyi, 1975), others aim for the individual to be unaware of the technology, for example life-logging equipment used for the purpose of observation. Therefore its aim is not for immersion or complete focus upon the technology, its aim is for users to forget about the technology during use. Although research looking at the awareness of wearable technology during use is lacking, one study has discussed similar concepts as found in this study, relating to *forgetting non-wearable technology*. The patterns of forgetting the Sensecam and the LifeShirt that were discussed in this study reflect levels of intrusiveness defined in previous literature exploring the adoption of 'smart' technology in the homes of older adults (Melenhorst, Fisk, Mynatt, & Rogers, 2004). The authors proposed three levels of intrusiveness; '*Physical obtrusion*' a physical obtrusiveness based on the technology's location as well as its visual design, '*privacy intrusion*' which is the potential to invade the individual's privacy and '*security risk*' which is the potential for others to misuse the gathered information. The findings relating to the patterns of remembering and forgetting in this study reflect the levels of intrusiveness proposed by Melenhorst *et al.* (2004); '*Physical obtrusion*' reflects the discussions based around the LifeShirt whereas discussions surrounding the Sensecam reflect '*privacy intrusion*'. Although the technology discussed by Melenhorst *et al.*, (2004) was technology to be placed in the home, the concept of intrusion adapts to the wearable technology used in this study, and the discussions surrounding this are evident. As well as these levels of intrusion reflecting the patterns of forgetting, it also reflects the potential to affect individuals' behaviour as the potential effect upon behaviour for both the Sensecam and the LifeShirt arose from concepts surrounding 'physical obstruction' and 'privacy intrusion'.

#### **6.7.1.1 SUMMARY**

*Intermittent forgetting* of both pieces of wearable technology during use was discussed by participants in this study, and was an integral part of their user experience. The concept of forgetting the technology during use has not been previously explored in the

literature, but was a central part to the users' experiences of using both the Sensecam and the LifeShirt.

Interestingly, the concept of *intermittent forgetting* and remembering was apparent with both pieces of wearable technology in this study, however, the details as to why the participants forgot and remembered the technology differed; whereas the importance of what the technology was recording was important with *intermittent forgetting* of the Sensecam, the design affected the *intermittent forgetting* of the LifeShirt. It was also apparent that the recording of behaviour on the Sensecam was not just important for the individual themselves, but the presence of others was also of importance within the user experience and further affected when participants became aware of wearing the Sensecam.

The importance of design upon forgetting further extends the knowledge built in the previous theme ('*expectations and experiences*', section, 6.6). Within the previous theme the design of the technology, specifically the LifeShirt, affected the user experience, and its wearability, especially its aesthetics and comfort, were highly important for use. This supported previous studies that highlighted the importance of the wearability of wearable technology (Gemperle, *et al.*, 1998; Knight *et al.*, 2002; Park & Jayaraman, 2003). However, when also looking at *intermittent forgetting*, it becomes clear that the wearability of wearable technology can also affect other areas of user experience; namely *intermittent forgetting*.

Once more, it is apparent that the overarching concept of *intermittent forgetting* within this sub-theme is long-lasting when using wearable technology, including patterns of forgetting being based on the information that the equipment is recording, as well as the physical presence of the equipment. However, the specific aspects related to both the Sensecam and the LifeShirt are contemporary, and will change upon technological developments.

### **6.7.2 POTENTIAL EFFECT ON BEHAVIOUR**

Due to the inconsistencies in forgetting and remembering, the equipment had the potential to affect behaviour. Reminiscent of the previous sub-theme, participants discussed the Sensecam and LifeShirt in two distinct ways and there were two primarily emerging aspects that came across as having the potential to affect behaviour; the individuals' behaviour being recorded on the Sensecam and the physical components of the LifeShirt. However, interestingly some participants also discussed the physical presence of the Sensecam. It became apparent that the Sensecam had more potential to change behaviour due to the information in which it recorded, rather than the presence of the Sensecam, whereas the LifeShirt had the potential to affect behaviour solely due to its physical presence.

Despite use of the technology having the potential to affect behaviour, generally, most participants felt that their behaviour was unaffected whilst using the equipment.

*No, no, no, no, no, nothing got in my way [of my usual activities]  
no [001]*

*I have only tried to be honest, that is my life, that is the way I live, I don't put airs and graces on for anybody, I am me, me [001]*

*I didn't do anything differently [004]*

*No [I behaved] absolutely the same [006]*

*No [it didn't change my behaviour] no not at all [009]*

Individuals stated that they did not feel self-conscious about wearing either piece of equipment, and they did not feel as though their behaviour was affected during the measurement period. This attitude was also reflected when specifically discussing the Sensecam.

*I don't think [I would have acted any differently], I'm not conscious of acting for the camera, I just got on with my normal life and it didn't bother me [003]*

*No not really no [I didn't feel self-conscious] [011]*

*I just feel as though I acted my normal self, I didn't act anything different no [016]*

The patterns of forgetting the Sensecam, and the potential effect that it has on behaviour, was discussed as the information that was recorded on the Sensecam. Despite this, participants did not believe that their behaviour was affected by using the Sensecam, and changed their use of the Sensecam, i.e. removed it, as opposed to changing their behaviour. The choice to remove the Sensecam reflects the control that most individuals felt when wearing the technology. Most participants indicated in the *Flow-State Scale* questionnaire (Jackson & Marsh, 1996) that they felt that they had control over both their body whilst using the Sensecam, as well as feeling as though they had control of the Sensecam itself during use (see section 6.4).

Observational studies have been criticised on many occasions for potential reactivity, which is also known as the methodological Hawthorne effect (Adair, 1984). Participants can change '*demand characteristics*' depending upon what they believe the researcher wishes to see from the observation. This has previously been seen with research using a manual camera to examine participants' behaviour when testing new technology in field trials with participants using phrases such as wanting to produce 'good data' (Brown, Reeves & Sherwood, 2011), however, this has not previously been looked at with any type of wearable technology.

Although individuals did not discuss being self-conscious of wearing the LifeShirt due to it recording their movements, there was much discussion about the physicality of the LifeShirt, and how it restricted individuals' movement.

*it didn't restrict me too much, bending down, kneeling down, yeah it was a little bit because the unit was fairly weighty, it is not a light unit [003]*

*I found it difficult driving with [the bum bag] around my middle ... I mean I can't reach the peddles, I'm short legged and you know I'm...getting in the way of the steering wheel, apart from that no it was alright [004]*

*No, no [I was not conscious of it] not really...only when I was driving because it got in the way [004]*

*I wouldn't have worn it last week, on my holidays, I wouldn't have worn it then, I would have said please can I do it another week because it would have been a bit of a bind [005]*

*No I don't [I could relax whilst wearing it] erm...no not even when was in the car when I was doing a single, unpainful...not uncomfortable, quite unpleasant thing erm I couldn't I could only really relax when I took it off, having said that I did dose a bit with it erm but I never when I went to bed in the afternoon wearing it I never had that sort of out like a light, dead to the world...erm and I don't think that it is anything that you can put through the night [010]*

*the bum bag got in the way when you were trying to do things, you can't iron with that well I sit down to iron so that bag got absolutely in the way at the height I iron [010]*

As opposed to the awareness of the LifeShirt being due to the recording of behaviour, the awareness including inconsistent forgetting and potential to affect behaviour arose from the design of the equipment, and its physical presence. Some individuals felt that the LifeShirt was uncomfortable and got in the way of tasks such as driving and relaxing, which may have affected their behaviour during the week, and although P003 initially stated that it did not restrict him too much, the weight of the LifeShirt affected him bending and kneeling down.

The importance of design, as outlined in section 6.6 above, is once again shown to be important, and in this case its importance is the potential that design has on affecting behaviour. From the literature that has looked at the use of wearable technology, the design of the technology has often been central to discussion. However, the design of the wearable technology is usually centred on aesthetics and comfort (e.g. Knight, *et al.*, 2002; Miner, *et al.*, 2001), as previously discussed in section 6.6 above. The interviews focusing on the LifeShirt within this study have highlighted that rather than the importance of design being solely focused on aesthetics and comfort, the design was important for the awareness of the technology, and affected the individual forgetting wearing the LifeShirt, as well as having the potential to affect their behaviour.

As well as research looking at the general importance of design, some research exploring the implementation of wearable technology has highlighted the importance of maximising physical movement during use (Gemprle, Kasabach, Stivoric, Bauer, & Martin, 1998; Knight, *et al.*, 2002). Gemprle *et al.* (1998) report a set of guidelines for wearable technology that provides a design which allows the most comfort, and the most movement whilst wearing the technology. The importance of lessening the restriction of movement is also highlighted as part of Knight *et al.*'s (2002) comfort rating scale of wearable technology. However, although both pieces of research benefit from being the first to highlight the importance of technology allowing an individual to maintain full movement whilst wearing technology, neither goes beyond this and explores what effect the restrictions of movement can have upon the users' experiences of wearable technology, which, in this study, affected amount that

individuals forgot about using the LifeShirt, as well as having the potential to affect their behaviour.

Although most of the individuals felt that the presence of the Sensecam around their neck did not affect their behaviour one participant felt it best to remove the camera whilst playing the ukulele due to it the camera itself getting in the way.

*I think I did take it off to play [the ukulele], mainly because it was just where I wanted the ukulele because you nestle it in your arm and play like that...it wasn't badly in the way but it was just easier to take it off [018]*

Furthermore, the physicality of the Sensecam affected two other participants as they referred to their awareness of potentially damaging the camera during some activities, therefore demonstrating their awareness of wearing the Sensecam and the problems of the Sensecam's physical presence.

*I just stuck to my usual routine, I was just conscious that I mean on the first time when I made bread when I was wearing it I took the camera off because I was conscious that when I knead the bread bits goes everywhere but the second time I did it I just raised it up, erm, but more than that no, erm...I mean if it was raining I tried to remember to put it inside of my coat and things like that erm...but no it was part of what I agreed to and I just got on with it [010]*

*it was swinging on my neck I took it off because I was more frightened that I was going to break it [017]*

The physical components of the Sensecam also had the potential to effect behaviour. For one participant this was a result of being in the way, and for the two other participants this was of fear of breaking the Sensecam.

#### **6.7.2.1 SUMMARY**

Reminiscent of the patterns of forgetting, the potential effect on behaviour was experienced over both pieces of wearable technology, however, once more, there were dissimilar explanations as to why the Sensecam and LifeShirt had the potential to change behaviour.

Participants mainly discussed the Sensecam as having the potential to change behaviour due to the information it was recording, although interestingly, participants believed that the recording of behaviour was unaffected by the Sensecam. Whereas, once again, it was the design of the LifeShirt that had the potential to affect behaviour, as it caused restrictions in movement. However, interestingly, some participants also discussed the physicality of the Sensecam, and two individuals were fearful of breaking the camera during use.

#### **6.7.3 SUMMARY OF AWARENESS OF EQUIPMENT**

The awareness of equipment was apparent in two ways; inconsistently forgetting and remembering the equipment and the potential of affecting behaviour by either being



recorded or due to the physicality of the technology. It was interesting in that both components of awareness of the equipment were apparent for both the Sensecam and the LifeShirt, however, there were major differences between how individuals discussed the manner in which they remembered and forgot about the Sensecam and the LifeShirt and the potential they both had on affecting behaviour. Whereas individuals tended to remember the Sensecam based on the information it was recording, individuals remembered the LifeShirt when movement was restricted due to its presence. These views also remained when discussing potential effect on behaviour as individuals mostly discussed the awareness of the Sensecam coming from the information that it recorded, although some considered the physicality of the Sensecam, whereas the potential effect on behaviour for the LifeShirt was solely based on its physical presence.

The information regarding design in this study, including its effect on patterns of forgetting, and its potential effect on behaviour, has reinforced information set out in previous literature and extended this further. Like the previous studies looking at wearable technology, the information gathered from the interviews in this study show that the design is an important component of wearable technology. However, as opposed to design solely being important for aesthetics and comfort, the design of the technology can affect how much the individual forgets about wearing the technology, as well as having the potential to affect behaviour, due to components of the technology affecting movement and fear of breaking the technology.

## **6.8 CHAPTER SUMMARY**

There were two themes highlighted in Part B of this study; '*expectations and experiences*' and '*awareness of equipment*'. From these themes two concepts emerged that were of most importance during the use of this study, both of which were specific to wearable technology; the importance of design and the importance of others. Both of these overarching concepts are long-lasting, and are not dependent upon using the Sensecam or the LifeShirt, however, some of the specific aspects of these concepts were distinctively for the Sensecam or the LifeShirt, and will become less important upon developing technology. The study has reflected findings from past studies of wearable technology, and models of general technology use, and has also added to this previous literature.

Results from the UTAUT questionnaire, as well as the Flow-State Scale were separately reported, as well as being integrated into the interview data. This data shows that individuals felt positive about the Sensecam and the LifeShirt both before and after the study. Although some of the data within the questionnaires expand information within the interviews, some of this data also contradicts information that individuals have discussed. These contradictions specifically reflect the differences between individuals expectations and experiences of using the technology. These contradictions may be due, in part, to the questionnaires not including some of the important aspects of the use of both the Sensecam and LifeShirt, such as intrusiveness, comfort and design.

This chapter has provided the results of Part B of this study in which two themes describing the experiences, usability, acceptance and experience of the technology

used to measure levels of functioning, as well as looking at the practicalities of the Sensecam and the LifeShirt. Conclusions of the study have been made and have been discussed alongside literature in the area.

## **CHAPTER 7: CONCLUSIONS AND IMPLICATIONS**

### **7.1 OVERVIEW**

This final chapter will summarise the main conclusions of both Part A and Part B of this study and relate all of the findings back to the initial aims of the research and will show information on how the results from the study have extended knowledge within this area. The limitations of the study and the recommendations for future research will also be considered. Finally, a reflexive account will be also be given from my own point of view, and I will discuss my experiences throughout the PhD and how they have shaped the methods, analysis and outcomes of the study.

### **7.2 PART A**

#### **7.2.1 CONCLUSIONS AND ORIGINAL CONTRIBUTION TO KNOWLEDGE**

The aim of this study was to explore a range of day-to-day patterns of functioning and experiences of older adults living with chronic pain. As part of this aim, there were three specific objectives; to explore the '*activities*' and '*participation*' of older adults with chronic pain, to investigate the impact of '*personal factors*' upon '*activities*' and '*participation*' of older adults living with chronic pain, and to explore the impact of '*environmental factors*' upon '*activities*' and '*participation*', as described in the ICF. The data captured by the Daily Reconstruction Method, the Sensecam and the semi-structured interview all provided information surrounding these objectives.

The results from the Daily Reconstruction Method, the Sensecam and the interviews within Part A of this study highlight two major points; the effect that chronic pain has on daily living, and the ways in which individuals try to manage both pain and functioning.

It was clear that both '*activities*' and '*participation*' were affected by chronic pain experiences as a result of the impact that pain had upon functioning and the participants discussed many specific tasks that had been affected as a result of chronic pain. The findings surrounding the effect that chronic pain had upon both activities and participation supported previous research that has also suggested that chronic pain interferes with ADL, and led to the modification, reduction and termination of various tasks (e.g. Duong *et al.*, 2005; Sofaer *et al.* 2005). However, this study has also further contributed to this knowledge, as due to the idiographic nature of the study, as well as multiple, novel, data collection tools, this study has given much further detail surrounding the modification of tasks. From this study, it is not only possible to see whether or not individuals have changed their daily functioning, as a result of chronic pain, but it is also possible to see how and why individuals have done so and the vast differences between individuals in the study are apparent. This development of knowledge is important within practice, and the self-management of chronic pain. By understanding how chronic pain affects daily functioning in more detail, health professionals can be in a better situation to help individuals when involved with pain management programmes. One self-management programme that is widely used, both locally and nationally, is the Pain Management Plan (Lewin & Bryson, 2010). This plan is used either in conjunction with a health professional, or can be used by the individual alone, and identifies the importance of goal setting as a way to self-manage

individuals' lives with the presence of pain. This additional knowledge showing the details surrounding functioning, and the difficulties that individuals face with specific tasks, can help the health professionals themselves understand how chronic pain may have affected functioning, and the barriers the individuals face when trying to improve functioning. This information may better prepare the health professionals when setting goals with chronic pain sufferers based on this information. Alternatively, the book could be more explicit about changes that occur in functioning as a result of chronic pain, in order to further inform self-users about this area, and once more may help with setting goals.

There were also many differences between the individuals, and how pain had affected their functioning. There were differences in the tasks that were affected by long-term pain, as well as differences of why the tasks were affected, and how they were affected. Furthermore, many of the participants in this study also lived with co-morbidities, once more highlighting the varying health needs of the individuals. These individual differences highlight the importance of communication between the health professional and chronic pain sufferer, as not everyone's daily functioning is affected in the same way by chronic pain, and individuals' needs vary. The importance of this communication, and the therapeutic relationship, has been acknowledged in recent research. Toye et al. (2013) highlighted the role of the patient as being a '*collaborative partner*' (Toye et al., 2013, pg. e835), and promotes the importance of understanding that the individual's entire lived world has been changed as a result of chronic pain. This current study has further highlighted the importance of this partnership between the patient and health care professional based on the various ways that chronic pain affects individuals.

As well as describing the effects that chronic pain had upon functioning, participants also described various ways in which they tried to manage both pain and functioning and it was evident that both *environmental factors* and *personal factors* influenced the individuals' management of both pain and functioning. *Coping styles*, as discussed within the *Personal factors* section of the ICF, was primarily referred to within the theme '*managing pain and functioning*'. Additionally, the impact of *environmental factors* on both *activities* and *participation* was also evident in that assistive devices were used to aid functioning, as well as the reliance upon other individuals being important within functioning.

Like the findings surrounding the effect on daily living, the differences between participants' management of pain were vast, and supported previous research which suggested that individuals with chronic pain should not be treated in the same way, as '*a homogenous group*' (Adams, et al., 2006, pg. 294). Individuals showed both '*active*' and '*passive*' coping strategies (Brown and Nicassio, 1987) which highlighted both internal and external loci of control, and it was evident that the individuals coped with their chronic pain in different ways.

The differences in coping styles affected the way in which individuals considered their chronic pain in this study. The coping strategies adopted by individuals are important to consider within practice when considering suitable pain management strategies, and health professionals may also need to address other issues, not directly related to pain, that affect the way individuals manage their pain and functioning. For example, age

was a specific factor that affected coping for the participants in this study. Individuals felt too old to have an operation to reduce their pain, felt that they coped less with their pain as a result of age, as well as functioning less. For these individuals it was not only their biological age but also their perceptions of their own age that affected their own pain, pain management and functioning. This would suggest that it is important to consider other factors, such as age, within pain management programmes for some individuals, as these indirect factors can affect their perceptions of their own pain, pain management and functioning.

One further example of the importance of looking at individual coping styles is that some individuals also felt that they coped with their pain as they relied on others. They not only relied on them psychologically, by talking to them, as well as physically. The reliance on others should also be considered by health professionals when advancing pain management programmes, and others could be involved in this. For example, some pain groups in the North East currently use the Pain Management Plan (Lewin & Bryson, 2010) in a group setting, in which a group of chronic pain sufferers complete the programme together and are able to provide support for each other. However, this could be further extended in order to include a member of family, a friend or carer of the chronic pain sufferers, either in group settings or during one-to-one meetings. In doing this, these individuals would be more integrated into the self-management programme and will also gain more information about chronic pain and its self-management, along with the chronic pain sufferer themselves.

Individuals also used numerous strategies to maintain or improve functioning, of which, pacing strategies were most commonly used. Previous research has shown mixed results regarding the benefits of pacing (Nielson & Jenson, 2004; Kindermans *et al.*, 2011; McCracken & Sanuel, 2007), however, participants discussed pacing in a positive way, and discussed how it led to lessened pain, and improved functioning.

Assistive devices were also used as a way to manage both pain and functioning, such as devices used to increase mobility, or either maintain or reduce levels of pain. The findings from this study supported past studies that have also seen assistive devices used in this way (Duong *et al.*, 2005; Sofaer *et al.*, 2005). However, the use of the Sensecam has also furthered this knowledge as it was possible to see how and when individuals were using these devices, as well as viewing devices that were not discussed within the interviews.

Interestingly, individuals did not only use devices provided by health professionals, or only devices to manage their chronic pain, but also used devices that they began using themselves, and also devices to improve their functioning. Information could be compiled and disseminated from the data surrounding the assistive devices used by participants in this study as individuals may use different strategies and devices, or none at all, because they had not considered the options, rather than being because they do not think that they would be useful.

As well as conclusions regarding the functioning of chronic pain, this research has provided original knowledge regarding the use of the Daily Reconstruction Method and the Sensecam within this field of research.

The Daily Reconstruction Method was valuable in gathering data regarding participants' functioning. The Daily Reconstruction Method allowed individuals to give their own perception of their functioning, as well as provide details of how they felt during each episode. The Daily Reconstruction Method was also useful for times when the Sensecam was not used, as individuals were still able to record the events in which they took part. However, due to the diary being structured the diary entries were not detailed as individuals were unable to expand upon the tasks in which they were involved, therefore, detail was not captured using the diaries alone.

The Sensecam enabled the physical aspects of the individuals' study weeks to be explored from the first person point of view, essentially acting as an observation tool. The strengths of using the Sensecam included gathering details regarding daily functioning, that were often not recorded in the Daily Reconstruction Method, or discussed in the interview. For example, participants often discussed 'cooking', but the Sensecam recorded the specific tasks involved within cooking, and showed any strategies used within the cooking process, such as cooking two meals to be eaten over two evenings at once or pacing. The Sensecam also contextualised information recorded in the Daily Reconstruction Method or spoke of in the interview, for example, when participants recorded and spoke of walking, the Sensecam picked up where the participant walked, who with, for how long and also if the participant rested during this time.

The Sensecam allowed the contextualisation of data not picked up on other devices, such as accelerometers, as it allows the view of the context in which movement and body position was set. However, there were various pieces of information that could not be measured on the Sensecam. For example, due to the position of the Sensecam on the individual's chest, walking aids were rarely captured. Furthermore, the Sensecam was removed by participants for various reasons throughout the study week (as discussed in chapter 7) therefore there were various aspects of daily living not captured. Additionally, as *Ethnographic Content Analysis* was used to analyse the Sensecam images in this study it relied upon my interpretation of the Sensecam images, and without interaction with the participants during the study period, these interpretations may have been less accurate. As I had visited participants' houses, and in most cases met, or heard about, family members and friends, it was easier for me to be able to interpret these images, as I felt that I knew more about these participants than if I had not been involved in data collection. Therefore, involving additional data collection methods and also interactions with the participants aided Sensecam analysis.

## **7.2.2 LIMITATIONS OF THE STUDY**

There were of course some limitations to the study, whereas some of the boundaries to the research were embedded within the design, others arose during the study.

One of the limitations of the study is that all of the data gathered regarding the effect of chronic pain on daily functioning were solely based upon the participants' perceptions of how chronic pain had affected their daily living. Therefore, the conclusions of this research are based on perceptions of chronic pain, as opposed to being able to concretely state chronic pain has affected functioning in various ways. Although every

effort was made to focus the conversation specifically on the impact that chronic pain had on functioning, all of the retrieved information is based on the participants' perceptions of their own pain and functioning, and there is no objective evidence to show that this functioning had in fact changed directly as a result of chronic pain. For example, the changes to functioning may have occurred as a result of general ageing, due to other co-morbidities, or other reasons. There were no assumptions of changes to functioning made by the researcher when analysing the interviews, Sensecam images or the Daily Reconstruction Method diaries.

Due to the explorative nature of the study the results from Part A are very specific to the individuals involved in the research, therefore limiting the generalisation of these results to the wider population. Although a limitation to the research, this study never set out to generalise findings to the wider population, as its idiographic design set out to gather a lot of specific information from a small sample. Additionally, there were also problems with uptake for the study as many older adults with chronic pain did not want to take part in the study due to the Sensecam and/or the LifeShirt. This sample is therefore a very specific sample in that they are a small minority of the intended population who were willing and able to take part in the study. Only two participants did not wear the Sensecam (P007 and P012), whereas 12 participants did not wish to use the LifeShirt, but were willing to take part in all other parts of the study. The LifeShirt caused many problems with recruitment, and due to the lessening importance of the LifeShirt in the study these individuals were still used within this study. Although this did not affect the aims of the study being met, caution must be taken when interpreting the results as this study is based around a specific set of individuals, and the results cannot be generalised to the wider population.

There were further limitations to the sample of this study. Firstly, although purposive sampling was used in order to gather a sample with much variance, there is little sociocultural variation between the participants in terms of socioeconomic status and ethnicity. This limits the importance of the findings to a specific group of individuals, and further qualitative work is needed, with the inclusion of individuals of various ethnic backgrounds and socioeconomic status, in order to explore any variances in functioning as a result of chronic pain in these populations. Furthermore, most individuals were recruited from community groups and therefore were relatively highly functioning in comparison with other people with greater problems of disability due to back pain. Once more, this means that the findings may only represent the experiences of relatively highly functioning older adults with chronic pain, and future research should look at other ways of recruiting participants in order to allow the participation of less functioning individuals, for example, from NHS groups or newsletters.

The objectives of this study covered many areas, and one of these many areas was the relationship between psychological functioning and pain. Although this study considered the coping strategies of participants, as well as the role of self-efficacy, fear avoidance was only briefly discussed, and the relationship between depression and chronic pain was not examined. Conclusions regarding the fear-avoidance behaviours and the link between depression and chronic pain cannot be made from this study and further research must be conducted in this area in order to make any conclusions.

One of the main limitations to this study was the exclusion of the LifeShirt data. Part of the aim of Part A was to look at participants' *activities* and *participation* of which the accelerometer data would have added objective information. Although this did not affect the aims being met, the accelerometer would have added an additional dimension regarding movement patterns. Eight of the 20 participants wore the LifeShirt over the study but the data was unable to be used due to multiple problems with the recorded data (please see Appendix M). There was also much data lost by the Sensecam, for unknown reasons, presumably user error. Once more, this did not affect the aims being met, but it does add a limitation to the results. Therefore, the data from the Sensecam may be skewed for some participants as less data, therefore less time, was recorded. However, due to the use of multiple data collection tools, there was still much data gathered from both the Daily Reconstruction Method data and the interview, despite the loss of some data, therefore still allowing an in-depth exploration of daily living.

### **7.2.3 FUTURE RESEARCH**

This study was primarily based around self-reports, opinions, and the interpretation of both the participant and myself. Future research could also incorporate some objective measures of functioning, such as an accelerometer, which was to be initially used within this study. Although the LifeShirt was used as an accelerometer within this study there were issues that prevented the analysis of the data as some of the accelerometer data had not recorded, and other data was not suitable for analysis due to problems with the LifeShirt's output (see Appendix M for more detailed information). The use of an accelerometer would enable an additional level of analysis to be carried out, and would provide an objective measure of functioning in addition to the subjective measures.

Although this study gained information regarding the coping strategies and self-efficacy of the participants, there are components related to the psychological functioning of older adults living with chronic pain that cannot be concluded from the current study, therefore, future research would benefit from exploring these issues further. One way in which future research could do this is to employ methods which have previously been used in this area, such as structured self-report questionnaires. Questionnaires, such as the Fear Avoidance Beliefs Questionnaire (Waddell et al., 1993), the Pain Anxiety Symptoms Scale (McCracken, Zayfert & Gross., 1992) and Geriatric Depression Scale (Yesavage, et al., 1983), are all questionnaires which have been used in the research discussed within the literature review of this PhD (see section 2.5). The questionnaires used in these studies benefit from gaining direct information regarding the areas of psychological functioning linked to chronic pain. Alternatively, psychological functioning can also be explored qualitatively, in a more direct way than it was in this study. For example, like Part B of this study, future research could use the structure of pre-existing questionnaires as a basis for the semi-structured interview. This would allow the researcher to focus more upon psychological functioning, but still looking at this in a qualitative manner, and therefore extract in-depth information from participants.

Wearable cameras may be a useful intervention tool, and this is one area of importance within future research. During the study, I was talking to one participant in



a non-recorded meeting whilst looking through her Sensecam images of the study week and she was surprised at her movements, specifically in the kitchen. She said that she hadn't realised that she had gradually stopped using the top shelves, and bottom shelves, of the cupboards. She noticed from looking at the Sensecam images that she did not bend, or stretch up to the cupboards as she used to, but this had not been a sudden conscious effort and she had not noticed this gradually changing over time. The Sensecam, or other wearable camera, would be a good intervention tool in that the camera can highlight individuals of their own behaviours. If the individual is given the chance to watch the Sensecam images after the recording it will allow them to see their behaviours from an 'outsiders' perspective, and potentially highlight elements of this health behaviour to the individual.

Furthermore, in keeping with this, much information about individuals' opinions of the content of the Sensecam images was lost, as participants' conversations were not recorded whilst they viewed the images. One recommendation for future research could be to interview participants whilst viewing their own Sensecam images (after they had initially gone through and deleted unwanted images). This would allow participants to discuss the contents of the images themselves, and add meaning to the images from their own perspective, as opposed to from the perspective of the researcher themselves. This was not carried out within the current study for two reasons. Firstly, individuals wore the Sensecam for seven days, which resulted in around 13,000+ images per participant. The images took a long time to look through and it was therefore not viable to do this with individuals due to time constraints. Future research should consider this when designing the research, and think about the length of time that the participant will wear the Sensecam, if the intention is to interview individuals whilst viewing the images. Secondly, the interview within Part A of this study not only surrounded the Sensecam images, but also more general areas of their pain experience, as well as the information within the Daily Reconstruction Method. It was therefore important that individuals were not interviewed whilst looking at the Sensecam images, so as not to focus their discussions solely around the information in the images.

## **7.3 PART B**

### **7.3.1 CONCLUSIONS AND ORIGINAL CONTRIBUTION TO KNOWLEDGE**

The aims of Part B of this study were to explore the usability, acceptance and experience of the Sensecam and the LifeShirt, as well as exploring the practicalities the participants were faced with when using the technology.

Previous discussions of life-logging research acknowledged the lack of research focusing on user experience, with most previous life-logging papers highlighting the various developments and potential applications of life-logging technologies (Chan *et al.*, 2012; Lupton, 2013). This study was the first to look at the factors affecting acceptance, usability, experiences and also the practicalities of either the Sensecam or LifeShirt.

Data from the *Unified Theory of Acceptance and Use of Technology* (UTAUT, Venkatesh, *et al.*, 2003) showed that most individuals were positive about both the Sensecam and the LifeShirt, with very little changes in attitude before and after use.

The *Flow-State Scale* (Jackson & Marsh, 1996) also showed overall positive responses toward the Sensecam and the LifeShirt after use. The responses show that the majority of the participants had an enjoyable experience using both pieces of technology.

Two key themes were identified within the findings; '*expectations and experiences*' and '*awareness of equipment*', both of which address the aims within Part B of the study. From these themes two concepts were highlighted; the importance of design and the importance of others. Both concepts encapsulated all of the objectives within the aims of Part B.

The results of Part B have shown the relevance of models of user experience (Hassenzahl & Tractinsky, 2006) and technology acceptance, such as the *Technology Acceptance Model* (Davis, 1989) and the UTAUT, however have also shown areas in which these models need to be extended to be more appropriate for wearable technology. For example, whereas the responses in the UTAUT questionnaires often expanded on what the participants said throughout the interview, in some cases, the discussions contradicted the information in the questionnaires. This was most apparent when discussing the differences between expectations and experiences, as whereas participants spoke about their experiences being more positive than their expectations, this was not seen in the questionnaires, with little differences being recorded both before and after use of the technology. Although difficulty of use is highlighted in the UTAUT, and showed no differences, there were some aspects of wearing the technology that individuals worried about before use, and were not asked in the questionnaires, such as issues on intrusion of the technology. Therefore, as well as the questionnaires, the interviews were important within this study in order to acquire information from individuals that were not captured within the questionnaires.

The results in this study also furthered current research in wearable technology. There are a small number of studies that have acknowledged the usability of wearable technology and highlight the important of its design, either because of aesthetics (Miner *et al.*, 2001), comfort (Knight *et al.*, 2002) or the non-restriction of movement during use (Gemprle *et al.*, 1998). The results in this study reflect those discussed in past studies involving wearable technology, and it is clear that the design of the technology is of importance. However, this study not only reflects the findings of previous studies of wearable technology, but extends this knowledge, as the discussions in this study not only confirmed that the design of the wearable technology was important, but also why it is important. The design of the technology, including its weight, comfort, bulkiness and non-restriction of movement are important for both forgetting the use of the technology during use, and in order to not affect behaviour during use.

Furthermore, none of these studies looking into the use of wearable technology, including the study conducted by Park and Jayaraman (2003) which focused on various aspects of the usability of a '*SmartShirt*', looked at the importance of others. Unlike models of general technology acceptance, and user experience, these studies did not take into account the attitudes of others, or their importance within the use of wearable technology. However, it was evident from this study that the importance of others was apparent, not only for the amount of time the technology was worn, but also in terms of the awareness of the technology. The importance of ethics was also accentuated by

the consideration of '*secondary participants*' by the participants wearing the Sensecam. Participants worried about recording images of others and this both reduced the time spent wearing the Sensecam as well as heightening the awareness of the Sensecam.

This study has also raised both long-standing and contemporary issues with wearable technology. Whereas both of the overarching outcomes of this study, i.e. the importance of design and the importance of others, are all long-lasting, and not specific to the Sensecam or LifeShirt, the detailed areas of these outcomes were specific to the technology used in this study, and will change based on the development of technology.

### **7.3.2 LIMITATIONS OF THE STUDY**

There were also limitations to Part B of this study which were a result of the aims of Part B.

Like Part A, the results from Part B are also very specific to the individuals involved in the research, and this again limits the generalisation of the results to the wider population. There was a lack of differentiation between participants, due to the participants being those recruited for Part A of this study. All participants in the core sample were over 65 years old (and two individuals were 52+ years old). Furthermore, all individuals voluntarily used the LifeShirt and the Sensecam and all had no previous knowledge or experience of using either piece of equipment. Additionally, all participants were using the technology for research and were aware that the use of the technology was for only seven days, and that they were not beginning to use these life-logging tools as an integrated part of their daily living. Due to the similarities of the participants the use of the Sensecam and the LifeShirt cannot be generalised to other individuals, and the perceptions of use are limited to these individuals.

Furthermore, as a result of the aims of Part B, only individuals that agreed to take part in the study were interviewed. However, the perceptions of those who did not take part in the study would also have greatly added to the dataset in exploring perceptions of the equipment, and how this affected use. Therefore, the behavioural intention can only be examined for those who had taken part in the study, biasing the results of use of the technology. Previous studies have not only included technology users, but also non-users, as their perceptions of technology use are equally important when discussing the dimensions affecting behavioural intention and use of technology (e.g. Nägle & Schmidt, 2012; Selwyn, 2004).

Finally, one limitation surrounded the ethics of using life-logging technology, specifically observational technology such as the Sensecam. The ethical implications of wearing technology that visually records others is highly discussed in the research area, and although it has been considered within the design of this study, and discussed in part by participants, it is something that has not been looked at in great detail within this study. Although the aim of Part B of this study did not aim to investigate the ethical issues surrounding observational life-logging technology, it is something that has been important throughout the study. Various ethical issues have been considered in this research but conclusions about the participants' perceptions of ethical issues cannot be

concluded in any detail and there is still a vast argument regarding the use of observational life-logging tools that has not been discussed in great depth.

### 7.3.3 FUTURE RESEARCH

There is much future research that can be carried out, and should be considered, when looking at the acceptance, usability, experiences and practicalities of wearable technology, some of which is based on the limitations of this research.

Before considering future research in this area it is important to reflect upon the long-term application of life-logging. Due to the rapid progression of life-logging technologies it is important to look at the concept of the technology, rather than one specific piece of equipment. The LifeShirt is an out-of-date piece of equipment, therefore further research looking at the user experience of the LifeShirt is not needed as the product is no longer being sold. However, that is not to say that the acceptance, usability and experiences of the wearable technology which measure similar constructs should not be looked at. Some of the information gathered in this study is transferrable to future products based upon the LifeShirt and future research would benefit from using similar methods as in this PhD to explore the use of similar products to the LifeShirt that are currently available, such as the *Vivosensor*. Although a newer version of the Sensecam has also been released since the beginning of this study, (the *Autographer*© and *Get Narrative*) the premise of the product remains and it is likely that participants will still be cautious when using the product around others, as they did with the Sensecam. It is important to consider the constant changes that will be made to the technology due to constant progression, however, this research can also go on to help the development of these products.

From this research it is recommended that further research involves a wider range of participants when looking at the usability, acceptance and experiences of these wearable technologies. Participants within this study were of a similar age, with no experience of using either piece of technology. Furthermore, all individuals used the technology voluntarily, and for a set amount of time as a part of research. By gathering information from a wider range of participants further research could add to the outcomes of this research regarding the important aspects of wearable technology.

As well as looking at a wider age range, future research could address one of the limitations of this study in that non-users should be interviewed in addition to technology users. This study did not interview individuals who did not want to take part in the study due to either the use of the Sensecam or LifeShirt. Future research could benefit from interviewing individuals willing to use the equipment, as well as those who do not want to use the equipment in order to look at what factors affect behavioural intention and use of those not willing to take part in the study, as well as those that do wish to take part in the study. One way of doing this is to look at the perceptions of life-logging technologies, such as the Sensecam, from individuals who have not worn these technologies in the past, and have no experience with them, therefore, gathering perceptions of these technologies before use. Furthermore, the insight of individuals before using the technology can also be used to explore their perceptions of being 'secondary participants' of others were to wear the Sensecam, or other wearable

camera which would explore one dominant topic of interest currently the ethics surrounding wearable cameras which has not been sufficiently explored in this study.

## 7.4 REFLECTIONS

Within this section I wish to explain some of my thinking throughout the study; my beliefs of my own position within the research, as well as reflecting on the methods and analyses used and how they came about.

When I first began the PhD process I had a limited knowledge of functioning, chronic pain or life-logging. I had come from a health psychology background, and straight out of postgraduate education therefore my knowledge was very theoretical, primarily based upon theories of behaviour and qualitative research methods. For those reasons, I was very much an outsider from the participants that were involved in the study. I had no personal experiences, or close family experiences, of chronic pain and before speaking to the participants of the study my knowledge of chronic pain stemmed from the academic literature that I had read. Reflecting upon this, I think it was beneficial for the study as I had no expectations of information that may have been acquired within the study therefore I went into the interviews with a broad range of questions.

However, what was surprising was that I began to feel less like an outsider, despite my age and lack of personal experience with chronic pain. I think this was greatly helped by the amount of time that I spent with participants. I met each participant at least three times after they had initially decided to take part in the study. Each meeting gave me a chance to talk to participants within their own homes and although the meetings were solely to carry out tasks related to the study each meeting allowed the participant and me to become more acquainted with one another. I believe that this facilitated the information retrieved from the study in two main ways. Firstly, it allowed me to become more knowledgeable of the participants' lived worlds, including, environmental aspects such as the layout of their home and their neighbourhood, and the makeup of their family life, including becoming familiar with both names and faces of family members. This aided my analysis of the Sensecam images and although the Sensecam images were still analysed using my own interpretation of the participants' lived worlds, as opposed to their own, my knowledge of their environment helped with this analysis. For example, I was able to distinguish the whereabouts of participants within parts of their own home, as I had visited the house myself. I also believe that the frequent contact with the participants enabled them to be more open with me during the interviews. This was not a '*quick and dry*' interview. The participants had spoken to me on several occasions before the interview itself and I felt that the interviews that I carried out at the end of the study period were of much more detail than if I had interviewed participants at the beginning of the study process, when some of the participants were more closed to discussing their lives.

Although I entered this study with no preconceived ideas of what I would get from the study in regards to information about pain, one preconception that I realised I did have was the participants' use of the LifeShirt. When reflecting on my first encounter with P001, at which I had given her the technology, I had come to realise that I had expected the participants to find the LifeShirt difficult to use. This was for three main

reasons. The first reason was that I had struggled using the LifeShirt myself the first time that I used it, and secondly, one older member of my family had informally set up the LifeShirt themselves, before I began recruiting participants, and also struggled with this set-up. Because of the difficulties of both myself, and an older member of my family, I had assumed that others would have the same problem. My preconceptions of use of the LifeShirt also stemmed from my experiences when recruiting participants for the study. Many individuals would approach me to take part in the study, but after reading the Participant Information Sheet they would often decline. Although a handful of these participants did so due to the intrusiveness of the Sensecam most individuals declined as they felt that the LifeShirt would be too difficult to use. These experiences made me presumptuous as to other peoples' reactions to the LifeShirt, even after agreeing to take part in the study. I had not realised this until after the meeting with P001 to give her the equipment. I had realised in hindsight, when writing my reflective diary, that my language was negative when talking to the participant about the LifeShirt, such as '*please let me know if you can't use it*', and '*I know that it is difficult to set-up but...*'. In fact, the participant did not have any issues setting up or using the LS. This realisation when reflecting on the process of data collection made me completely change the way in which I spoke about the LifeShirt to participants.

As well as reflecting on the actual data collection itself, a great amount of my time throughout the PhD has been spent reflecting on the methodology and method that I have chosen to analyse the data. Over the past three years I have spent much time reading around various ontologies, epistemologies, methodologies and methods. For me, it was difficult as I had the task of interpreting and integrating three different methods and analyses into one account, and ensure that this complied with the philosophical underpinnings of the study. This has been beneficial for both the research and me as a researcher. Considering multiple methods and methodologies not only expanded my knowledge, but the critical thinking needed to integrate strategies of analysis and use them in a different way to fit with one another and the philosophical underpinnings of the research.

My position within the research was important, but I was aware of this from the outset. My interactions with the participants were vast and individual, and the role that I played within the interpretation was of great importance. Any preconceived ideas regarding any aspect of the research outcomes may have affected interpretation, but writing field notes, which included my own reflections, for the entirety of the PhD allowed me to continually consider my own position within the research, and during analysis. The chosen research methods and analyses were also of much importance to the outcomes of the research.

## **7.5 OVERALL CONCLUSIONS**

Part A of this study aimed to explore a range of day-to-day patterns and experiences of functioning in older adults suffering from chronic pain. The Daily Reconstruction Method, Sensecam and the semi-structured interview were each analysed separately, before the results of the Daily Reconstruction Method and Sensecam were integrated into the themes derived from the semi-structured interviews. The integrated results led to the development of two themes, each with sub-themes; '*effect on daily living*' and '*managing pain and functioning*'.

The themes highlighted the way which pain affected functioning, in terms of the relationship between pain and functioning and the modifications to daily functioning as a result of chronic pain and also the reduction of independence. The findings also highlighted the vast differences between participants' daily living, and the relationship between each individual's pain and functioning. This study supported previous research that has also suggested that chronic pain interferes with ADL, and leads to the modification, reduction and termination of these tasks (e.g. Duong *et al.*, 2005; Sofaer *et al.* 2005). However, this study has also furthered this knowledge due to the idiographic nature of the study, as well as multiple, novel, data collection tools, adding additional details to how tasks have been modified, reduced, or terminated. There was also a two-way relationship highlighted between pain and functioning, as not only did pain affect functioning, but functioning also affected pain.

As well as the affects that chronic pain had upon daily living, the individuals discussed how they managed their pain. It was evident that individuals showed both '*active*' and '*passive*' coping strategies (Brown and Nicassio, 1987) highlighting internal and external loci of control. Individuals also used numerous strategies to maintain or improve functioning, of which, pacing strategies were most commonly used. Assistive devices were also used as a way to manage both pain and functioning, such as devices used to increase mobility, or either maintain or reduce levels of pain.

Part A of this study has also shown the benefits and the drawbacks of using both the Sensecam and the Daily Reconstruction Method in this field.

Part B aimed to look at the usability, acceptance, experiences and also the practicalities of using the technology used in Part A of this study (i.e. the Sensecam and the LifeShirt). Little previous research has acknowledged the importance the wearability of technology, instead focusing on discussions of the development and application of life-logging technologies. This was the first study to examine the usability, acceptance, experiences or practicalities of using either the Sensecam or the LifeShirt.

There were two concepts developed from the themes of Part B that were specific to the participants' experiences of wearing wearable technology in this study, as opposed to '*typical*' non-wearable technology; specifically, the importance of design and the importance of others. Both of these overarching concepts affected the expectations of the technology, the experiences of using the technology, as well as the awareness of the technology during use.

It was evident that the design of the technology was important for numerous reasons and participants' perceptions of design both reflected and extended previous research in the area (Gemperle. *et al.*, 1998; Knight *et al.*, 2002; Miner *et al.*, 2001; Park & Jamaraman, 2003). The importance of aesthetics, comfort and non-restriction of movement was clear, but this study extended previous research in finding that the these components of design were also important in the processes of forgetting the presence of the equipment, and therefore affecting behaviour. Practicalities based upon design were also evident, and it is important to consider the usability of wearable technology during the design process.

As well as design, the importance of others was also of high importance, but unlike design, the importance of others had not been considered in previous research. It was evident from this study that the perceptions of others were important, not only for the amount of time the technology was worn, but also in terms of the awareness of the technology. The importance of ethics was also accentuated by the consideration of '*secondary participants*' by the participants wearing the Sensecam. Participants worried about recording images of others and this both reduced the time spent wearing the Sensecam as well as heightening the awareness of the Sensecam.

Both overarching concepts encapsulate long-term issues with life-logging technology despite the continuing development of the technology in this field, but the specific details of each are contemporary, as discussed by the participants in this study, and are specific to either the Sensecam or the LifeShirt as used in this study.



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**APPENDIX A: OVERVIEW OF THE STUDIES INCLUDED IN THE SYSTEMATIC SEARCH**

	<u>Aim</u>	<u>Participants</u>	<u>Measurements</u>	<u>Administration of diary</u>	<u>Analysis of diary data</u>
Basler, H.D., Bertalanffy, H., Quint, S., Wilke, A., & Wolf, U. (2007).	Explore the outcome of counselling in physiotherapy within a sample of older adults suffering from Chronic lower back pain (CLBP) based on the Transtheoretical model.	N=170 Age Range= 65-84 <b>Inclusion:</b> >65 years old Current CLBP due to osteoporosis or a degenerative disorder <b>Exclusion:</b> Red flags (tumours etc.) Diagnosis of dementia Surgery within last 6 months	Physical activity levels: <b>activity diary.</b>  Functional capacity: <b>Hannover Functional Disability Scale (HFAQ)</b>  Range of motion: <b>Ultrasound topometry</b>  Intervention: Physiotherapy	7-day activity diary.  Retrospective diary which was completed within the weekly assessment.  No more information is given regarding the layout of the diary.	Diary entries were converted into quantitative data.  Diary entries were shown in the report as average duration of physical activity (minutes per day).  Duration of physical activity was compared between experimental group and control group.
Basler, H.D., Luckmann, J., Wolf, U., & Quint, S. (2008).	To explore whether the Fear Avoidance Belief Model (FABM) is valid in a sample of older adults with CLBP.	N= 162 (including control group) Age range= 65-86 <b>Inclusion:</b> >65 years old Current CLBP due to osteoporosis or a degenerative disorder <b>Exclusion:</b> Red flags (tumours etc.) Diagnosis of dementia Surgery within last 6 months	Fear avoidance beliefs (FABs): Based on a modified version of the <b>Photograph Series of Daily Activities (PHODA)</b>  Functional capacity: <b>HFAQ</b>  Range of motion: <b>Ultrasound topometry</b>  Physical activity levels: <b>Diary</b> and Short form of <b>Freiburg Activity Questionnaire.</b>	7-day activity diary.  Study does not state when or how often diaries were completed.  Diaries were set out into categories: Homework (e.g. cleaning) Gardening (e.g. planting) Other outdoor activities (e.g. walking) More strenuous activities (e.g. cutting wood).	Diary entries were converted into quantitative data.  All information from the diary entries were converted into Metabolic equivalent (MET) units.  MET units were compared between the experimental and control group.

<p>Gibson, M.C., Woodbury, M.G., Hay, K., &amp; Bol, N. (2005).</p>	<p>Focuses on describing pain in older adults, using self-report measures in an institutional residency.</p>	<p>N= 33 Age range= 66-85</p> <p>Convenience sample from Veteran care program.</p> <p>There were no given inclusion or exclusion criteria.</p>	<p>Cognitive status: <b>Standardised Mini-Mental Status Examination (SMMSE)</b> <b>Geriatric Depression Scale (GDS)</b> <b>Anxiety question (ANX)</b> <b>Pain Beliefs Questionnaire (PBQ)</b> <b>Delighted-Terrible Quality of Life Scale (QoL)</b></p> <p>Pain assessment: <b>Pain diary</b></p>	<p>Retrospective pain reports, completed quarterly.</p> <p>Pain assessment was based on direct questions, open questions, numerical scales and multiple choice pain descriptors.</p>	<p>Diary entries were converted into quantitative data.</p> <p>Numerical scales and multiple choice pain descriptors were presented as percentages to illustrate amount of pain and type of pain.</p>
<p>Hager, K.K., &amp; Brockopp, D., (2007).</p>	<p>Assess the use of self-report diary for assessing chronic pain in nursing home residents.</p>	<p>N=21 Mean age= 74.9 (No age range given)</p> <p><b>Inclusion:</b> Documentation of pain Intact cognition Communicative ability</p>	<p>Cognitive status : <b>Minimum Data Set (MDS)</b></p> <p>Pain assessment : <b>pain diary</b></p> <p>Baseline was collected 2 weeks before and end data was collected 2 weeks after the diary was administered.</p>	<p>2-week diary Diary was completed daily with help of project manager.</p> <p>The diary measured pain descriptions, pain location, pain duration, pain whilst, moving and pain at rest and general comments.</p> <p>The diary comprised of numeric rating scales, multiple choice scales and an open-ended section.</p>	<p>Diary entries were converted into quantitative data.</p> <p>Statistics from the numeric rating scales and multiple choice pain descriptors provided information regarding pain levels, pain location, pain duration and used medication.</p>

<p>Hager, K.K., &amp; Brockopp, D. (2009).</p>	<p>Focuses on the development and use of a chronic pain diary for use with older adults in a nursing home.</p>	<p>N=21 Age mean=74.86 (no age range given)</p> <p><b>Inclusion:</b> Documentation of pain Intact cognition Communicative ability</p>	<p>Pain assessment : <b>Pain diary</b></p>	<p>2-week diary Researcher does not specify how often diary entries are recorded.</p> <p>The diary measured pain descriptions, pain location, pain duration, pain whilst, moving and pain at rest.</p> <p>The diary comprised of numeric rating scales and multiple choice scales.</p>	<p>Diary entries were converted into quantitative data.</p> <p>Statistics from the numeric rating scales and multiple choice pain descriptors provided information regarding pain levels, pain descriptors, pain location and number of hours in pain.</p>
<p>Morone, N.E., Greco, C.M., Weiner, D.K. (2008).</p>	<p>To assess the enrolment and adherence of older adults suffering from CLBP to an eight session meditation program. Initial estimates of treatment effects on pain, physical function and quality of life were also developed.</p>	<p>N= 37 Age range= 65-84</p> <p><b>Inclusion:</b> &gt;65 years old Intact cognition Moderate CLBP occurring everyday/nearly every day Spoke English</p> <p><b>Exclusion:</b> Previously participated in meditation program Red flags suggesting underlying illness</p>	<p>Cognitive status: <b>MMSE</b></p> <p>Experiences of program: <b>diary</b></p> <p>Pain Intensity: <b>McGill Pain Questionnaire Short Form (MPQ-SF) and SF-36 Pain subscale</b></p> <p>Pain acceptance: <b>Chronic Pain Acceptance Questionnaire (CPAQ)</b></p> <p>Quality of life: <b>SF-36 Health Status Inventory</b></p> <p>Physical function: <b>Roland and Morris questionnaire, short physical performance battery and SF-</b></p>	<p>Diary used after taking part in intervention at home for an 8-week duration.</p> <p>Participants were asked to record minutes spent meditating and any further comments about the intervention.</p> <p>Researcher does not specify how often diary entries are handed in.</p>	<p>Diary entries were not analysed in any way.</p> <p>Participants revealed that they were not participating in the advised meditation program.</p> <p>The diaries provided a rich source of data, which could not be captured quantitatively in this study.</p>

			<p><b>36 physical function scale</b></p> <p>Baseline measures and end measures were collected. End measures were taken 3 months after program ended using a short questionnaire.</p> <p>Intervention: Mindfulness-based stress reduction program</p>		
Morone, N.E., Lynch, C.S., Greco, C.M., Tindle, H.A., & Weiner, D.K. (2008).	Explore the effect of mindfulness meditation within an older sample of individuals suffering from CLBP.	<p>N=27 Mean=74.3 (no age range given)</p> <p><b>Inclusion:</b> &gt;65 years old Intact cognition Moderate CLBP occurring everyday/nearly every day Spoke English</p> <p><b>Exclusion:</b> Previously participated in meditation program Red flags suggesting underlying illness</p>	<p>Cognitive status: <b>MMSE</b></p> <p>Experiences of program: <b>Diary</b></p> <p>Intervention: Mindfulness-based stress reduction program</p>	<p>The diary was administered for 8 weeks, participants handed in diaries weekly.</p> <p>Duration of meditation was recorded, along with an open-ended section for participants to describe experiences with the intervention.</p>	<p>Data was qualitative, and analysed using grounded theory.</p> <p>There were 6 themes produced:</p> <ol style="list-style-type: none"> <li>1. Experiencing pain reduction from mindfulness meditation</li> <li>2. Improvement in attention skills resulting from mindfulness meditation</li> <li>3. Improved sleep resulting from mindfulness meditation</li> <li>4. Achieving well-being</li> <li>5. Barriers to meditation</li> <li>6. Processes of meditation</li> </ol> <p>Compliance of diary entries was also noted.</p>

**Table 1: An overview of the studies included in the systematic search**



## APPENDIX B: ETHICAL APPROVAL

Teesside University  
Middlesbrough Tees Valley  
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### PRIVATE AND CONFIDENTIAL

Direct Line: 01642 384124

2 March 2011

**Denis Martin**  
School of Health & Social Care  
Teesside University

Dear Denis

**Study No 262/10: Exploring everyday functioning in older adults with chronic pain: New insights with new technology. Researcher: Gemma Wilson. Supervisor: Denis Martin.**

**Decision: Approved**

Thank you for submitting an amended application pack. I am pleased to confirm that the comments raised by the School of Health & Social Care Research Governance and Ethics Committee have been addressed in your amended application pack and your study has been approved through Chair's Action. Your study may proceed as it was described in your approved application pack.

Please note:

I am happy to be able to confirm approval for the study on the basis of the further revised application pack subject to the caveats below:

I am pleased to say that all of the outstanding comments from the original committee decision letter, listed in my email of 11 February 2011 18:19, have been addressed satisfactorily in the revised documents submitted: the email to myself, the revised copy of the Participant Information Sheet, the revised copy of Appendix F Consent Form, the revised copy of Appendix H (was E), the revised copy of Appendix C, the revised copy of Appendix D and the revised copy of Appendix S.

Unfortunately, Gemma submitted an entire application pack and not the documents requested. As with the first revised pack I have tried to identify, review and give an opinion on all of the documents submitted, however, as was the case with the first revised pack the changes made to the additional documents submitted with the second revised pack were neither listed nor highlighted in any way and so I may not have found them all. If there are any amendments to the original, or first revised application packs, made in the second revised pack submitted, which I have not already commented on here or in my email of 11 February 2011 18:19, those amendments do not fall within the scope of this opinion. If you wish to make those amendments then please submit a separate request for approval for those as amendments and I will be glad to review them.

Thank you also for clarifying the status re manufacturers permissions to reproduce and use their instructions and promotional materials etc in the study documents. For the record may I please clarify (at the risk of pedantry) that you must not use the documents containing the Lifeshirt images until you have received the manufacturer's permission to do so? When you do receive that please submit one hard copy to Tricia for filing.

Where applicable, your study may only proceed when you have also received written approval from any other ethical committee (e.g. NRES) and operational / management structures relevant (e.g. Local NHS R&D). A copy of this approval letter must be attached to applications to any other ethical committee. If applicable please forward to me a copy of the approval letter from NRES before proceeding with the study.



In all cases, should you wish to make any substantial amendment to the protocol detailed, or supporting documentation included, in your approved application pack (other than those required as urgent safety measures) you must obtain written approval for those, from myself and all other relevant bodies, prior to implementing any amendment. Details of any changes made as urgent safety measures must be provided in writing to myself and all other relevant bodies as soon as possible after the relevant event; the study should not continue until written approval for those changes has been obtained from myself and all other relevant bodies. On behalf of the School of Health & Social Care Research Governance and Ethics Committee please accept my best wishes for success in completing your study.

Yours sincerely



**Dr. Alasdair MacSween**

Chair  
Research Governance and Ethics Committee  
School of Health & Social Care

## APPENDIX C: PARTICIPANT INFORMATION SHEET

*Words in bold and underlined were adapted depending whether the form was given to an older adult with chronic pain, younger adult with chronic pain or an older adult without chronic pain.*



Teesside University is sponsoring  
this project for the purposes of  
research governance



Version 1 05-10-10

### Exploring everyday functioning in older adults with chronic pain: New insights with new technology

Main Researcher: Gemma Wilson

Other Researchers: Professor Denis Martin, Dr. Derek Jones and Dr. Patricia Schofield

The research team would like to invite you to take part in a research study. Before deciding you need to understand why the research is being carried out and what it would involve for you. Please take time to read the following information carefully. Before deciding to take part, feel free to discuss it with others including friends and family.

Part 1 of this information sheet will explain the purpose of the study and what will happen if you take part. Part 2 gives you more information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you want to take part.

#### Part 1

##### **What is the purpose of the study?**

The study aims to look at a range of things older adults with chronic pain do on a day to day basis. A second aim is to look at whether technology is successful at measuring the activities that people do, and to see how people feel about using the technology. This study will form part of Gemma Wilson's PhD project.

##### **Why have I been invited?**

You have been chosen as you are **over 65 years of age, are retired and are living in the community.** You have also been chosen as you have suffered from chronic

**pain for more than 3 months, in 2 or more joints.** You must also be able to fully understand all instructions and therefore must be able to speak English. You must also have the ability to see small buttons, and press small buttons on one of the pieces of technology being used.

You will not be able to take part in this study if you have cancer related pain, you are awaiting surgery or have undergone recent surgery. You will not be able to take part in this study if you self-report a diagnosis of dementia or if you have an allergy to the adhesives and/or gel used to attach the electrodes.

There will be a total of 20 participants taking part in the project, from the North East of England, North Yorkshire and throughout Scotland.

### **Do I have to take part?**

No. It is up to you to decide. You can browse this information sheet and we will also describe the study verbally. You are welcome to ask the main researcher any questions which you may have about this study. You can then either accept or decline taking part in the study. If you accept we will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw from the study up until two weeks after you have completed the study without giving any reason. Any data which had been collected up until that point will be destroyed and will not be used in the project.

### **What will happen to me if I take part?**

You will be involved in the research project for 9-10 days. After answering any questions which you may have you will be asked to sign a consent form. You will be given a paper timetable which will explain all of the days you will be involved in the study, what you will be doing on these days and if the researcher will be visiting you.

On day 1 the main researcher will meet you at a location decided by you prior to taking part, e.g. your house. You will firstly be asked to complete two copies of a short questionnaire about your feelings toward the equipment you will be using.

The main researcher will show you how to attach 3 electrodes to your upper body (2 to your chest and 1 on your stomach) therefore it would be advisable to wear loose fitting clothing. It may also be necessary to shave the areas where the electrodes will be placed. The electrodes are sticky pads which will be attached to your skin. You will then be asked to wear a zip up 'LifeShirt' which is a jacket which will be worn on top of your underwear, and underneath your clothes.

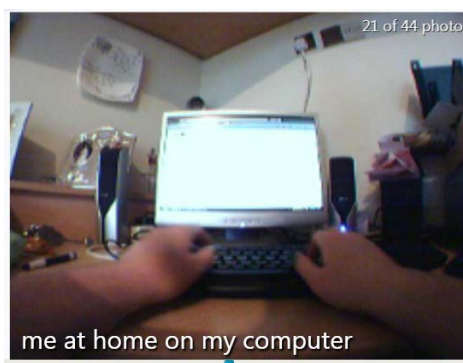
The jacket will record your breathing levels, heart rate and movement and it is both light-weight and breathable. During this time your privacy will be priority and the researcher will leave the room while you put the jacket on, however, if you need help zipping up the jacket the (female) researcher will be there to help you. The researcher will then show you how to attach the electrodes to the LifeShirt. After putting your clothes on you will also be asked to wear a bag worn around your waist which contains a small machine which will be attached to the jacket via wires. You will be shown how to attach all of these to the LifeShirt. All components of the LifeShirt are CE Marked.

As well as the main researcher showing you how to use the LifeShirt, you will also be given written instructions (including illustrations) showing you how to put on, take off and use the LifeShirt.

You will also be asked to wear a small camera around your neck at the same time as wearing the jacket (please see image below).



This camera will take one photo every 30 seconds. The camera also takes photos if another person stands in front of you or you are moving around. **No** audio sound is recorded. The camera has a wide-angle lens which records a large view of what you are seeing in front of you (please see image below for an example photograph).



The camera has a privacy button which must be pressed if you want to pause recording, and this button is pressed again when you want to resume recording. You will be shown how to do this by the researcher, and you will also be given written instructions on how to do this. The Sensecam is CE marked and the strap of the Sensecam, worn around your neck, has a clip on either side, therefore it is easily breakable if the camera gets pulled at any time.

You should only wear the Sensecam when you feel comfortable doing so. If at any time you do not feel comfortable wearing the Sensecam please feel free to either take it off or conceal it underneath your clothes until a time when you do feel comfortable.

As the Sensecam takes photographs you must pause recording in places where photography is not allowed, such as schools, swimming pools or a GP surgery. You must do this by pressing the privacy button whilst in these places and concealing the Sensecam underneath your clothes, or taking it off. If you are in a private area, such as your home, or another person's home you must let any person know that photos are being taken every 30 seconds, but do not contain any audio recording. If at any point

an individual does not want to be recorded, you must press the privacy button (therefore pausing the recording) and/or conceal the Sensecam underneath your clothes.

You will also be given a number of small information cards which explain the nature of the study, and also give them contact details for the researcher's main supervisor. If anyone asks you about the Sensecam, no matter where you are, please give them one of these cards which will explain what you are using it for. There will also be a sticker attached to the back of the Sensecam which will contain the same information as the cards. If someone is not happy being recorded you can press the privacy button, and/or conceal the Sensecam underneath your clothes.

As well as the main researcher showing you how to use the Sensecam, you will also be given written instructions (including illustrations) showing you how to put on, take off and use the Sensecam.

Although both pieces of technology are easy to use and will require little attention whilst you are using them you will be given full guidance to their use on day 1. The main researcher will return at the end of day 1 to check that everything has recorded correctly, and to show you how to take the equipment off, and how to charge them up. The main researcher will also give you written instructions (including illustrations) on how to do this.

The main researcher will not return until after you have completed the 7 days of recording, however, you will have their contact number if you have any queries about using the technology.

You will also be asked to complete a diary each day. The diary will be completed on paper. The format of the diary requires you to write about the previous day and to segment it into events. You will then be asked to answer general questions about your day and rate your feelings of each event on rating scales. The completion of the diary will last up to 45 minutes daily. This process will happen every day for 7 days.

The main researcher will return on day 8 (or a day suitable for you) to put all of the data onto a laptop, and to take the technology away. You will be shown how to put the photos from the Sensecam onto the laptop (via written instructions, verbal instructions and a demonstration) and you will be given plenty of time to look through all of the photos, and delete any photos that you do not want the researcher to see. The researcher will only be able to see the photos that you have not deleted. After you have done this you will be given 4 short questionnaires to complete asking you about both pieces of technology, e.g. how easy it was to use, would you use it again.

After this you will be given 1 to 2 days break from the study. After this time you will be asked to participate in an interview with the researcher, who will ask you about your week and discuss some of the information collected from the LifeShirt, Sensecam and diary. This interview will last approximately 1-2 hours and this can be done face to face, or over the telephone, whichever method you feel most comfortable with. The interview will be recorded using a Dictaphone.

You will be given the option to continue immediately with the study, or you will be given an hour or two break, or alternatively the interview could be conducted the next day. If you decide to have a break, the researcher will leave and return later in the day/the next day, or the researcher will call back later in the day/the next day if the interview is being conducted over the telephone. You will then be asked to participate in another interview to ask you more about the answers you have given on these questionnaires. This interview will last approximately 1 hour. The interview will be recorded using a Dictaphone.

This will be the end of your participation in the study. The main researcher will then write up all of the findings.

### **What will I have to do?**

All participants in the study will be treated the same. On day 1 you will meet with the main researcher to complete 2 short questionnaires. The main researcher will also show you how to put on the equipment and begin recording, and at the end of day 1 you will once again meet with the main researcher to take off the equipment and to make sure all of the data has recorded correctly. You will also be asked to complete 2 questionnaires at the beginning of the study, to put on, record and take off the equipment each day, charge up the equipment daily and fill in a diary daily for 7 days. At the end of the study you will be given the opportunity to browse and delete any unwanted photos and you will be asked to complete 4 additional questionnaires and to take part in 2 in-depth interviews.

Other than this you will simply be asked to carry on with your week as normal, however, the equipment cannot get extremely wet, therefore if you need to go swimming, or shower/bathe whilst using the equipment, it must be removed before the event and put back on after the event.

### **What are the potential risks and disadvantages of taking part?**

As the study uses observation technology (i.e. the Sensecam) and in-depth interviews you may risk disclosing embarrassing and/or private information. However, in order to minimise this, you will be shown the 'privacy' button on the Sensecam which must be pressed at any time when you do not wish to record a situation, and then another button is pressed when you are happy to continue recording. There is no audio information recorded by the Sensecam. All images will be anonymous, as they will not be assigned to your name, but will be assigned to the identity number you will be given at the beginning of the study. Images will be stored on private software, on a password protected computer, and not published in any report. You will also be given a chance to browse and delete any photos that you do not want the research team to see prior to data analysis. During both interviews you do not have to answer any questions that you do not feel comfortable with. Questions will only concern the main aims of the study.

Other individuals may ask questions about the Sensecam while you are wearing it. Only use the Sensecam when you feel comfortable doing so, and if not, you can either

conceal the camera with your clothes or take the camera off until a time when you feel more comfortable. You must stop recording whilst in areas where it is unsuitable to take photos, such as schools, swimming pools and GP surgeries. If anyone asks you about the Sensecam you must explain that it is taking photos every 30 seconds, and it is not recording sound. Also, give them an information card so they can contact the researcher's main supervisor if they have any further queries. If you are in a private area, such as someone's home, always tell them that the Sensecam is recording, and if they object to this you must pause recording, or take the camera off/conceal it underneath your clothes.

Although the equipment will be fine if they get slightly wet (for example in light rain), if any piece of equipment becomes water-logged please stop using it. The researcher will take the equipment away and make sure it is properly tested before any further use.

Please note that you are NOT liable for any damage to, loss of, or theft of any of the equipment used throughout the study.

**Are there any side effects?**

None that we are aware of.

**What are the possible benefits?**

This study will not help you directly but the information we get may assist with treatment given to people like you in the future.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study, or any possible harm you might suffer, will be addressed. The details are included in part 2 of this information sheet.

If the information in part 1 has interested you and you are considering participation, please read the additional information in part 2 before making any decision.

Part 2

**What will happen if I do not want to carry on with the study?**

If you withdraw from the study before the two week period after you take part, the research team will destroy all identifiable data that has already been collected.

**What if there is a problem?**

If you have any complaints during or after taking part in the study please contact the researcher who will try to solve the problem in the first instance.

Gemma Wilson  
PhD Research student  
School of Health and Social care,  
Teesside University,



Phoenix building P2.09,  
Middlesbrough,  
Tees Valley,  
TS1 3BA.  
01642 738306  
[gemma.wilson@tees.ac.uk](mailto:gemma.wilson@tees.ac.uk)

If you remain unhappy and wish to complain formally you can contact the researcher's supervisor.

Professor Denis Martin  
Director Centre for Rehabilitation Sciences,  
Health & Social Care,  
Teesside University,  
Middlesbrough,  
Tees Valley,  
TS1 3BA UK,  
01642 342754  
[d.martin@tees.ac.uk](mailto:d.martin@tees.ac.uk)

or alternatively, another member of Teesside University who is aware of the study.

Alasdair MacSween PhD BSc (hons),  
Principal Lecturer in Research Governance,  
Chair of School of Health and Social Care Research Governance & Ethics  
Committee,  
Health and Social Care Institute,  
P1.18 Parkside West Offices,  
Teesside University,  
Middlesbrough,  
Tees Valley,  
TS1 3BA.  
Tel +44 (0) 1642 342965  
[a.macsween@tees.ac.uk](mailto:a.macsween@tees.ac.uk)

Please note that if any abusive or unprofessional behaviours/actions are disclosed and/or discovered then confidentiality will be breached and the supervisor will be informed (in the first instance) and if deemed appropriate further actions may be taken.

**Will my taking part in the study be kept confidential?**

Your confidentiality will be kept during and after the study with the handling, processing, storage and destruction of data adhering to the Data Protection Act 1998. Any electronic data collected will be encrypted and stored securely on a password protected computer. Any paper documents will be stored in a locked filing cabinet in the School of Health and Social Care, Teesside University, Middlesbrough. Identifiable data including all written documents, physiological information, images and transcribed material will only be viewed by the research team. All of the team will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. The consent forms will be paper documents and will be stored for 10 years in a locked cabinet within the Parkside building of the School of Health and Social Care at

Teesside University, Middlesbrough. When written data is destroyed they will be finely shredded in order to make sure no details can be read.

At the beginning of the study you will be given a numerical code, which will be used throughout the study. All data collected from you will be identified with this code therefore you will not be referred to by name on any documents, including any published materials, therefore remaining anonymous.

You, as the participant, have the right to check the accuracy of data held about you and correct any errors.

### **What will happen to results of the research study?**

The data retrieved from you and the other participants in the study will be used to form the main component of Gemma Wilson's PhD. The data may also be published in academic journals. However, your name will not be used in any article, with all of your data being referred to by the numerical code given to you at the beginning of the project. None of the recorded images will be published in any report, therefore you will not be identified through any images.

If you want to know about your results from the study you are welcome to contact the main researcher who will go through all of your own data with you. The contact details are given at the end of this sheet.

### **Who has reviewed the study?**

This study has been reviewed by the School of Health & Social Care Research Governance and Ethics Committee.

### **Further information and contact details:**

1. For general/specific information about the research project-

Gemma Wilson  
PhD Research student  
School of Health and Social care,  
Teesside University,  
Phoenix building P2.09,  
Middlesbrough,  
Tees Valley,  
TS1 3BA.  
01642 738306  
[gemma.wilson@tees.ac.uk](mailto:gemma.wilson@tees.ac.uk)

2. Who you should contact if you are unhappy about this study, or want to make a complaint-

Professor Denis Martin  
Director Centre for Rehabilitation Sciences,  
Health & Social Care,  
Teesside University,  
Middlesbrough,  
Tees Valley,  
TS1 3BA UK,

01642 342754  
[d.martin@tees.ac.uk](mailto:d.martin@tees.ac.uk)

OR

Alasdair MacSween PhD BSc (hons),  
Principal Lecturer in Research Governance,  
Chair of School of Health and Social Care Research Governance & Ethics  
Committee,  
Health and Social Care Institute,  
P1.18 Parkside West Offices,  
Teesside University,  
Middlesbrough,  
Tees Valley,  
TS1 3BA.  
Tel +44 (0) 1642 342965

[a.macsween@tees.ac.uk](mailto:a.macsween@tees.ac.uk)

**APPENDIX D: PARTICIPANT CONSENT FORM**



Version 1. 05-10-10

**CONSENT FORM**

Title of Project: **Exploring everyday functioning in older adults with chronic pain: New insights with new technology**

Main Researcher: **Gemma Wilson**

Other Researchers: Professor Denis Martin, Dr. Derek Jones and Dr. Patricia Schofield

Please initial  
box

1. I confirm that I have read and understand the participant information sheet dated 05-10-10 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I confirm that I meet the inclusion criteria, and **do not** meet any of the exclusion criteria stated on the information sheet dated 05-10-10 (version 1).

3. I am aware of and understand that my participation is voluntary and that I am free to withdraw up to 2 weeks after taking part without giving any reason.

4. I am aware and understand issues regarding my safety and the safety of others whilst using the Sensecam.

5. I confirm that I will respect the privacy of others when using the Sensecam and I understand when **NOT** to record images on the Sensecam.

6. I am aware of and understand how and when to inform others about the use of the Sensecam.

7. I am aware that the interviews will be audio recorded using a Dictaphone.

8. I agree to take part in the above study.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of Participant

Date

Participant's Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of Researcher

Date

Researcher's Signature

## **APPENDIX E: EXAMPLE DAILY RECONSTRUCTION METHOD DIARY**

### Diary

#### **Yesterday – Section 1**

We would like to learn what you did and how you felt yesterday. Not all days are the same – some are better, some are worse and others are pretty typical. Here we are only asking you about yesterday. Because many people find it difficult to remember what exactly they did and experienced, we will do this in three steps:

1. On the next page, we will ask you when you woke up and when you went to sleep yesterday.

2. We'd like you to reconstruct what your day was like, as if you were writing in your diary. Where were you? What did you do and experience? How did you feel? Answering the questions on the next page will help you to reconstruct your day.

*Section 2 (the written diary) is only for you, to help you remember and describe what happened during the first half of yesterday. It is yours to keep, so your notes are strictly personal and confidential. You do not need to turn it in. Nobody will read what you jot down about your day.*

3. After you have finished reconstructing your day in your diary, we will ask you specific questions about this time. In answering these questions, we'd like you to consult your diary page and the notes you made to remind you of what you did and how you felt.

To begin, please circle the day of the week that YESTERDAY was:

Monday   Tuesday   Wednesday   Thursday   Friday   Saturday   Sunday

## Diary – Section 2

About what time did you wake up yesterday? \_\_\_\_\_

And when did you go to sleep? \_\_\_\_\_

On the next page, please describe your day.

Think of your day as a continuous series of scenes or episodes in a film. Give each episode a brief name that will help you remember it (for example, “commuting to work”, or “at lunch with B”, where B is a person or a group of people). Write down the approximate times at which each episode began and ended. The episodes people identify usually last between 15 minutes and 2 hours. Indications of the end of an episode might be going to a different location, ending one activity and starting another, or a change in the people you are interacting with.

It is not necessary to fill up all of the spaces – use the breakdown of your day that makes the most sense to you and best captures what you did and how you felt. Try to remember each episode in detail, and write a few words that will remind you of exactly what was going on. Also, try to remember how you felt, and what your mood was like during each episode. What you write only has to make sense to you, and to help you remember what happened when you are answering the questions in the next section.

*Remember, what you write in your diary will not be seen by anybody else. The next section is yours to keep if you wish – you don't have to turn it in with the rest of your questionnaire.*

## Diary of events

Episode Name	Time it Began	Time it Ended	What happened? What did you feel?
1 _____	_____	_____	_____
2 _____	_____	_____	_____
3 _____	_____	_____	_____
4 _____	_____	_____	_____
5 _____	_____	_____	_____
6 _____	_____	_____	_____
7 _____	_____	_____	_____
8 _____	_____	_____	_____
9 _____	_____	_____	_____
10 _____	_____	_____	_____

Please look over your diary once more. Are there any other episodes that you'd like to revise or add more notes to? Is there an episode that you would want to break up into two parts? If so, please go back and make the necessary adjustments on your diary pages. If not, you may go on to the next section.

### How Did You Feel Yesterday? - Section 3

Before we proceed, please look back at your diary pages.

How many episodes did you record? \_\_\_\_\_

Now, we would like to learn in more detail about how you felt during those episodes. For each episode, there are several questions about what happened and how you felt. Please use the notes on your diary pages as often as you need to.

Please answer the questions for every episode you recorded, beginning with the first episode in the morning. To make it easier to keep track, we will ask you to write down the number of the episode that is below the line where you wrote about it in your diary. For example, the first episode is '1', the second episode will be named '2' etc. It is very important that we get to hear about all of the episodes you experienced yesterday, so please be sure to answer the questions for each episode you recorded.



## First Episode

**Please look at your Diary and select the earliest episode you noted in the Morning.** When did this first episode begin and end (e.g., 7:30am)? Please try to remember the times as precisely as you can.

This is episode number \_\_\_\_\_, which began at \_\_\_\_\_ and ended at \_\_\_\_\_.

What were you doing? (please check all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> commuting          | <input type="checkbox"/> working                        |
| <input type="checkbox"/> shopping           | <input type="checkbox"/> preparing food                 |
| <input type="checkbox"/> doing housework    | <input type="checkbox"/> taking care of your children   |
| <input type="checkbox"/> eating             | <input type="checkbox"/> praying/worshipping/meditating |
| <input type="checkbox"/> socializing        | <input type="checkbox"/> watching TV                    |
| <input type="checkbox"/> nap/resting        | <input type="checkbox"/> computer/internet/email        |
| <input type="checkbox"/> relaxing           | <input type="checkbox"/> on the phone                   |
| <input type="checkbox"/> intimate relations | <input type="checkbox"/> exercising                     |
| <input type="checkbox"/> other              | (please specify _____)                                  |

Where were you?

- At home             At work             Somewhere else

Were you interacting with anyone (including on the phone, via email, in person etc)?

- no one (*skip next question*)

If you were interacting with someone (please check all that apply). *Please note that names should **NOT** be mentioned. Just tick the classification of the person you interacted with. If names are written this will be deleted and **NOT** used in the study.*

- |   |  |
|---|--|
| <input type="checkbox"/> spouse/significant other | <input type="checkbox"/> my children             |
| <input type="checkbox"/> friends                  | <input type="checkbox"/> parents/relatives       |
| <input type="checkbox"/> co-workers               | <input type="checkbox"/> boss                    |
| <input type="checkbox"/> clients/customers        | <input type="checkbox"/> other people not listed |
| <input type="checkbox"/> students/patients        |  |

How did you feel during this episode?

*Please rate each feeling on the scale given. A rating of 0 means that you did not experience that feeling at all. A rating of 6 means that this feeling was a very important part of the experience. Please circle the number between 0 and 6 that best describes how you felt.*

	<b>Not at all</b>				<b>Very much</b>			
Impatient for it to end . . . . .	0	1	2	3	4	5	6	
Happy . . . . .	0	1	2	3	4	5	6	
Frustrated/annoyed . . . . .	0	1	2	3	4	5	6	
Depressed/blue . . . . .	0	1	2	3	4	5	6	
Competent/capable . . . . .	0	1	2	3	4	5	6	
Hassled/pushed around . . .	0	1	2	3	4	5	6	
Warm/friendly . . . . .	0	1	2	3	4	5	6	
Angry/hostile . . . . .	0	1	2	3	4	5	6	
Worried/anxious . . . . .	0	1	2	3	4	5	6	
Enjoying myself . . . . .	0	1	2	3	4	5	6	
Criticized/put down . . . . .	0	1	2	3	4	5	6	
Tired . . . . .	0	1	2	3	4	5	6	

## Next Episode

**Now look at your Diary and select the episode that immediately followed the one you just rated.**

This is episode number \_\_\_\_\_, which began at \_\_\_\_\_ and ended at \_\_\_\_\_.

What were you doing? (please check all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> commuting          | <input type="checkbox"/> working                        |
| <input type="checkbox"/> shopping           | <input type="checkbox"/> preparing food                 |
| <input type="checkbox"/> doing housework    | <input type="checkbox"/> taking care of your children   |
| <input type="checkbox"/> eating             | <input type="checkbox"/> praying/worshipping/meditating |
| <input type="checkbox"/> socializing        | <input type="checkbox"/> watching TV                    |
| <input type="checkbox"/> nap/resting        | <input type="checkbox"/> computer/internet/email        |
| <input type="checkbox"/> relaxing           | <input type="checkbox"/> on the phone                   |
| <input type="checkbox"/> intimate relations | <input type="checkbox"/> exercising                     |
| <input type="checkbox"/> other              | (please specify _____)                                  |

Where were you?

- At home       At work       Somewhere else

Were you interacting with anyone (including on the phone, via email, in person etc)?

- no one (*skip next question*)

If you were interacting with someone (please check all that apply). *Please note that names should **NOT** be mentioned. Just tick the classification of the person you interacted with. If names are written this will be deleted and **NOT** used in the study.*

- |   |  |
|---|--|
| <input type="checkbox"/> spouse/significant other | <input type="checkbox"/> my children             |
| <input type="checkbox"/> friends                  | <input type="checkbox"/> parents/relatives       |
| <input type="checkbox"/> co-workers               | <input type="checkbox"/> boss                    |
| <input type="checkbox"/> clients/customers        | <input type="checkbox"/> other people not listed |
| <input type="checkbox"/> students/patients        |  |

How did you feel during this episode?

*Please rate each feeling on the scale given. A rating of 0 means that you did not experience that feeling at all. A rating of 6 means that this feeling was a very important part of the experience. Please circle the number between 0 and 6 that best describes how you felt.*

	Not at all						Very much	
Impatient for it to end . . . . .	0	1	2	3	4	5	6	
Happy . . . . .	0	1	2	3	4	5	6	
Frustrated/annoyed . . . . .	0	1	2	3	4	5	6	
Depressed/blue . . . . .	0	1	2	3	4	5	6	
Competent/capable . . . . .	0	1	2	3	4	5	6	
Hassled/pushed around . . .	0	1	2	3	4	5	6	
Warm/friendly . . . . .	0	1	2	3	4	5	6	
Angry/hostile . . . . .	0	1	2	3	4	5	6	
Worried/anxious . . . . .	0	1	2	3	4	5	6	
Enjoying myself . . . . .	0	1	2	3	4	5	6	
Criticized/put down . . . . .	0	1	2	3	4	5	6	
Tired . . . . .	0	1	2	3	4	5	6	

## A Few More Questions about Yesterday- Section 4

Now that you have told us about your day in detail, we have a few more general questions.

**Now we would like to know overall how you felt and what your mood was like yesterday. Thinking only about yesterday, what percentage of the time were you:**

in a bad mood \_\_\_\_\_%

a little low or irritable \_\_\_\_\_%

in a mildly pleasant mood \_\_\_\_\_%

in a very good mood \_\_\_\_\_%

Sum 100%

Now we'd like to know how typical yesterday was for that day of the week (i.e., for a Monday, for a Tuesday, or so on). Compared to what that day of the week usually is like, yesterday was (please circle one)

Much	Somewhat	Pretty	Somewhat	Much
Worse	Worse	Typical	Better	Better

**You have now completed today's diary. Please review each question to be sure you have answered them all. Thank you very much for participating.**

## APPENDIX F: ADVICE SHEET-'HOW TO USE SENSECAM'

- **How to put on/turn on the Sensecam**

1. Put the lanyard over your head and place the camera on your chest with the lens facing outward.



2. To turn on the Sensecam press the button on the top of the camera once. You should hear the camera beep.



3. A flashing yellow light will appear on the top of the camera for 1-2 seconds and then steady green light will appear on the top of the camera when it is ready. You do not have to do anything else with the camera as it will automatically begin recording the images.
4. During recording there will be a steady green light on the top of the camera. Every time the camera takes a photograph a yellow light will flash on the top of the camera.

- **How to turn the privacy setting on**

1. To turn the privacy setting on hold in the top button on the right hand side of the Sensecam (there is **NO** raised circle on this button) for 2-3 seconds until you hear a beep.



2. There will be a red light on the top of the camera whilst the privacy mode is on. As long as this red light is on **NO** photos are being recorded.

- **How to turn the privacy setting off**

1. To turn the privacy setting off press in the bottom button on the right hand side of the Sensecam (there **IS** a raised circle on this button) for 2-3 seconds until you hear a beep.



2. If you can no longer see the red light on the top of the Sensecam the privacy setting will be turned off and the photos will be automatically recording again.

- **To turn off/remove the Sensecam**

1. To turn the Sensecam off press and hold the button on the top for 2-3 seconds.



2. The Sensecam should beep and all of the lights on the top of the camera will turn off.
3. Place the lens cap back onto the lens of the Sensecam by pushing it gently.



4. Remove the lanyard from around your neck.

- **How to charge up the Sensecam**

1. The plug and wire will be in the purple Sensecam box.
2. First of all turn on the Sensecam by pressing the button on the top of the camera for 2-3 seconds. Make sure there is a green light on top of the camera.



3. To charge it up place the end of the wire into the hole on the left hand side of the Sensecam.





4. Then plug the device into a socket. The plug has a small green light on which will light up when it is charging.



5. When the green light turns off the device is fully charged. The device will need at least 3 hours to charge up fully. There will be NO damage to the camera if it is left on charge for longer than 3 hours.
6. When the device is fully charged remove the plug from the socket, and remove the other end of the wire from the Sensecam.
7. Your Sensecam is now ready to use again when needed.

## APPENDIX G: ADVICE SHEET-'HOW TO UPLOAD SENSECAM IMAGES'

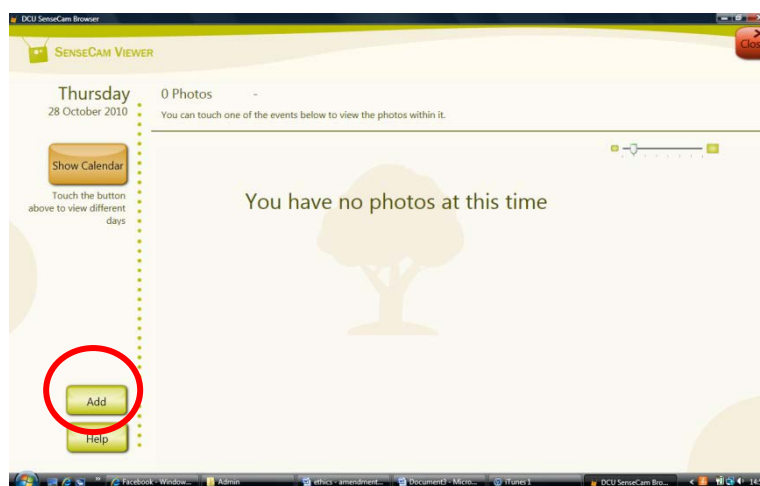
### Written instructions of how to upload/browse/delete Sensecam images

Below are some written instructions showing you how to upload, search and delete images from the Sensecam.

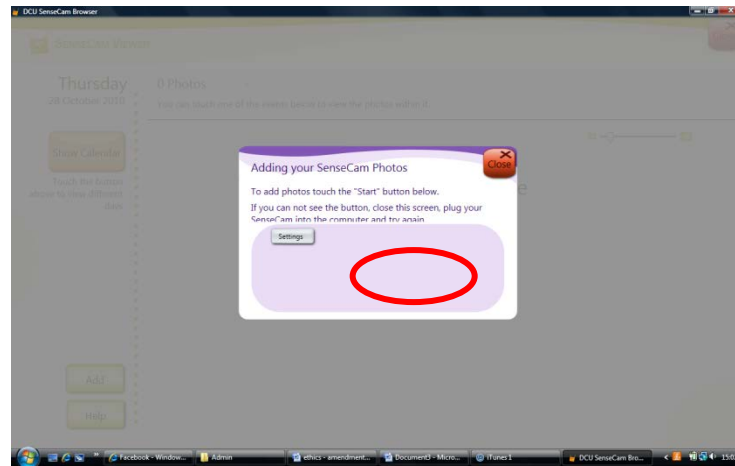
If you have any questions about this process please ask the researcher. The researcher will give you verbal information at any point, without looking at the images.

The researcher will also demonstrate the process with some sample images before you begin the process if you would like this.

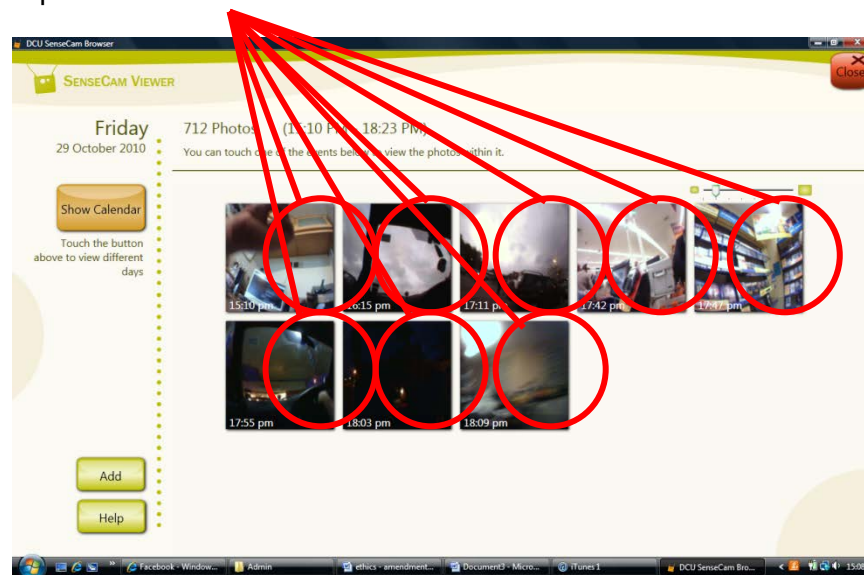
1. The researcher will turn on the laptop and enter the password. The researcher will then access the Sensecam program for you and plug the Sensecam into the laptop.
2. When you are logged in you will see a white screen (see below). This is the homepage. On the bottom, left hand side you will see an 'Add' button. Click on the 'add' button once with the left hand button on the mouse.



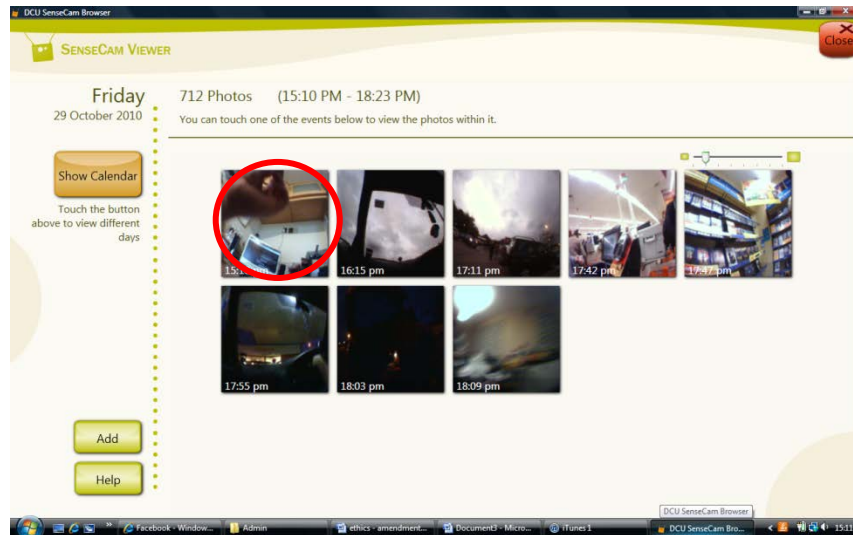
3. The next screen will appear (see below). Click 'start' once using the left button on the mouse.



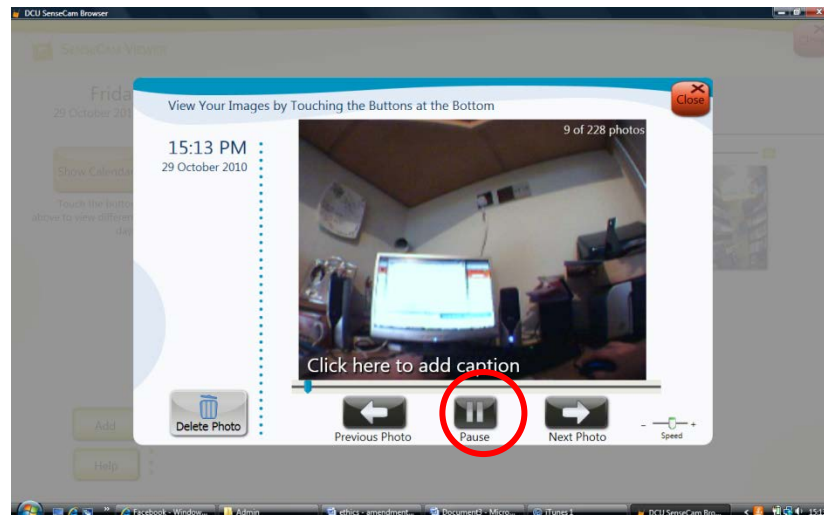
4. Your Sensecam images will then begin to upload onto the computer automatically. This will take 1-2 minutes. When this is finished you will be automatically taken back to the homepage, however, this time your photos will be there.
5. Your photos will be in several sections.



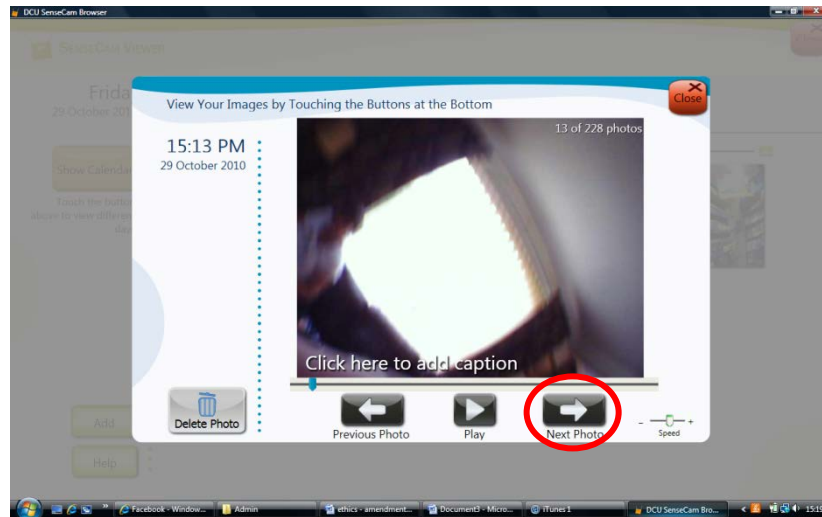
6. To look through the first section double click on it with the left button of the mouse.



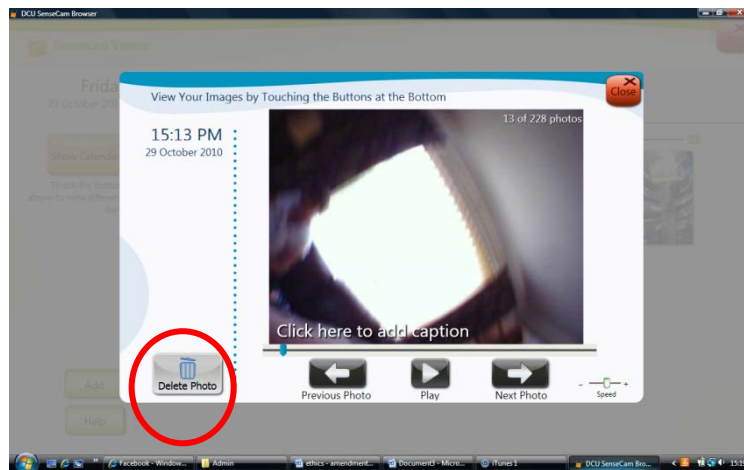
- The photos will automatically start playing through like a slideshow. To pause the slideshow press the pause button at any time.



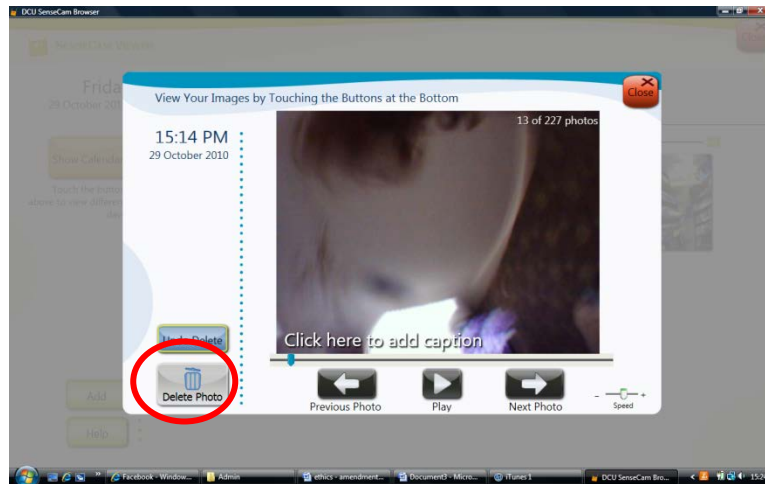
- You can slow down the images, or speed them up (depending which is best for you). To slow down the images click on the 'speed' button (keep the button on the mouse pressed down) and drag it left to the desired speed. To speed up the images click on the 'speed' button and drag it right to the desired speed (keep the button on the mouse pressed down).



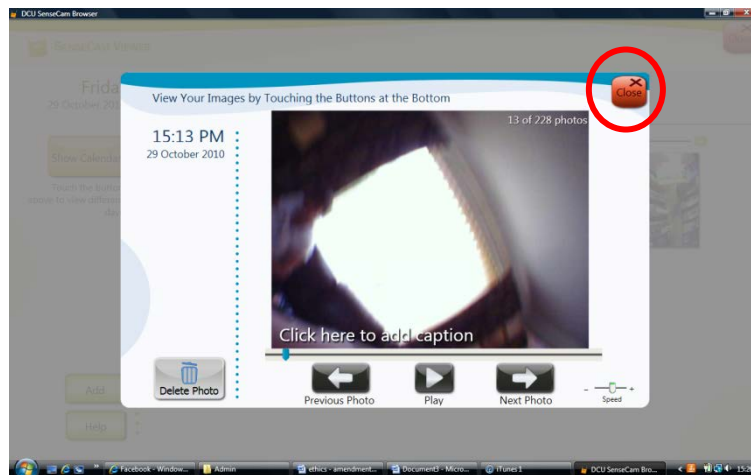
9. To **DELETE** a photo press pause on the photo and click the 'delete button' once.



10. To **UNDO** a deleted photo click 'undo delete' which will appear after you delete a photo.



11. Once you have seen all of the photos in that segment, and deleted all of the photos you do not want the researcher to see click the red 'close' button in the top, right corner. This will take you back to the homepage.



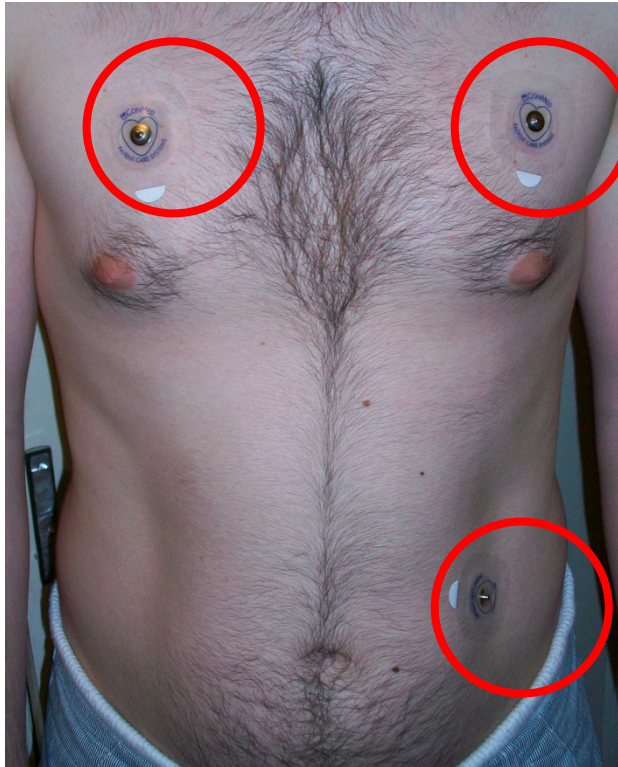
12. Double click on the next section with the left button on the mouse. Then begin the process again from step 7.

When you have looked through all of the sections, the researcher will save the images and log off the laptop.



## APPENDIX H:      **ADVICE SHEET-‘HOW TO SETUP THE LIFESHIRT’**

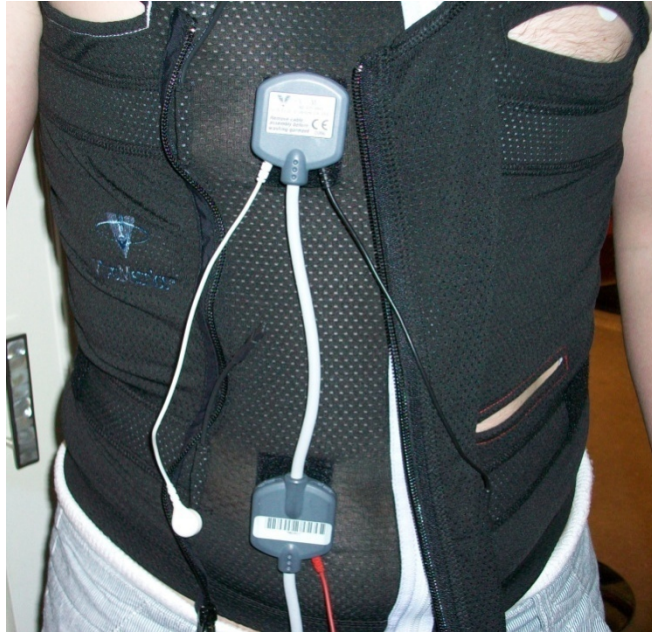
1.      Attach 2 electrodes to your chest, and 1 to the left side of your stomach, see below. (Note: you may need to shave the areas where you are placing the electrodes).



2.      Now put the jacket on and zip up the **white** zip.



3.      Once the white zip is zipped to the top, you can attach the data cable. This attaches to the Velcro in the middle of the jacket, with the long wire hanging toward the floor. See below.



4. Next you need to attach the wires from the jacket to the cable. There are 4 black wires on the jacket, and they slot into the data cable, see below.



5. You can now attach the electrodes to the data cable. This is done via the coloured wires on the data cable. Each wire slots through two holes in the jacket with the matching colour, and then pushes onto the electrode. For example, the red wire



goes through the two red holes in the jacket, and is attached to the electrode on your stomach. There is also a white wire, and a black wire. Please see below.





6. You can now zip up the black zip on the jacket, covering all of the data cable.
7. Make sure you have today's memory card in the hand-held computer (see separate instructions showing you how to change the memory card). After you have entered today's memory card please insert the battery into the back of the hand-held computer.



8. You can then gently push the wire from the data cable into the bottom of the computer, the blue slot underneath the memory card.



9. To turn on the computer flip up the plastic which covers the screen, and press the green button.



10. Follow the instructions on the screen (Note: you are starting a DAY session). The computer will give you instructions to calibrate your breathing. For this you need the calibration bag and the nose clip (given to you by the researcher).

You need to clip the nose clip on your nose, and when instructed to do so you need to follow these instructions.

- Sit down and breathe into the calibration bag 7 times then touch 'continue'.
- Stand up and breathe into the bag 7 times then touch 'continue'.
- Sit down and breathe into the calibration bag 7 times then touch 'continue'.
- Stand up and breathe into the bag 7 times then touch 'continue'.

11. Flip the plastic back over the screen. Clip the black bag around your waist, and put the computer into this.

The equipment is now working, and you do not need to do anything else until you wish to take it off.

## How to take off the LifeShirt

1. To turn off the hand-held computer flip the plastic from the screen. Touch 'quit', 'yes quit', then 'power off'.
2. You can then take the battery out of the machine, and put it into the charging unit so that it is charged for the next day. The light will turn from red to green when the battery is fully charged.

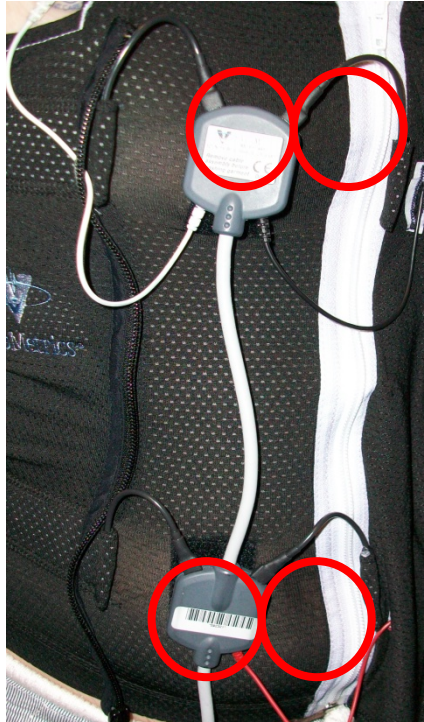


3. You can then remove the data cable from the computer. Push the buttons into the side of the wire whilst pulling it out. See below.



4. Unzip the black zip on the jacket and unclip the 3 wires attached to the electrodes by pulling them. You need to slot the wires back through the coloured slots.
5. You can then gently pull the 4 black wires out of the data cable.





6. Pull the data cable from the Velcro on the jacket, and unzip the white zip to remove the jacket. Remove the electrodes on your chest and stomach by gently pulling them.
7. If you wish, you can hand wash the jackets (however, make sure there are no wires attached to the jacket at this time). The dye may run in the jacket, so be careful when washing it.

### **How to change the memory card**

1. Before putting your LifeShirt on each day you must change the memory card in the hand-held machine.
2. To do this you must remove the previous day's memory card. The memory card is in the slot circled in green.



3. To remove this, press the button on the left hand side of the slot.



4. Now you need to put today's memory card in the machine. The memory card holder will have a sticker on saying which day to use it.
5. Remove the memory card from its holder and insert it into the machine with the arrows pointing toward the machine. Keep the 'recorder side up' on the top, so you can see it.



6. Gently push the memory card into the slot surrounded by green.



7. You are now ready to put on the LifeShirt, please refer to the instructions showing you how to do this.

## APPENDIX I: DAILY RECONSTRUCTION METHOD FINDINGS

		Commuting	Shopping	Doing housework	Eating	Socialising	Nap/ resting	Relaxing	Intimate relations	Working	Preparing food	Taking care of children	Praying/ worshipping/ meditating	Watching TV	Computer/ internet/ email	On the phone	Exercising	Other
P001	Median time allocation (min, max)	0 (0, 2)	0 (0, 1)	2 (1, 2)	3 (2, 4)	2 (1, 3)	1 (0, 2)	3 (1, 3)		0 (0, 1)	3 (1, 4)	0 (0, 3)	0 (0, 1)	2 (1, 4)		2 (0, 3)		3 (1, 9)
	Positive affect; negative affect	5.5; 0	6; 0	4.3; 0	5.1; 0	5.7; 0.1	4; 0.1	4.3; 0.1		4.7; 0	4.7; 0	5.8; 0	4.3; 0	4.3; 0		4.6; 0		5.4; 0
	Impatience to end	0	0	0	0	0.4	0.4	0.5		0	0.4	0.8	0	0.8		0.1		0.4
	Competence/capability	4.5	4.3	3	4.5	5	0.5	0.6		2	4.5	5.6	3	5		5.2		5
	Tiredness	2	1.3	3.1	2.1	1.7	4	3.4		4	2.2	0.8	2	4.4		3.2		1.9
P002	Median time allocation (min, max)	0 (0, 1)	1 (0, 2)	3 (3, 4)	2 (1, 3)	1 (0, 2)		2 (1, 4)		3 (2, 4)	0 (0, 2)		1 (1, 3)	1 (0, 1)	1 (0, 3)	2 (1, 3)	4 (2, 6)	
	Positive affect; negative affect	3; 0.2	3.1; 1.0	3.9; 0.4	4.7; 0.2	4.4; 0.3		4.4; 0.3		3.7; 0.4	5.8; 0		3.7; 0.6	3.3; 1	3.1; 0.7	3.5; 0.4	1.8; 0.1	4.2; 0.1
	Impatience to end	1.7	2.6	1.6	1.1	1.3		1.3		1.6	0.1		1.7	2.3	2.5	1.4	0.8	
	Competence/capability	4	3.6	3.8	4.2	4.3		4.3		3.8	4.8	4	3.5	3.8	3.8	3.9	1.8	1.8
	Tiredness	4	3	3.2	3.7	3.6		3.6		3.3	4.5	3.3	5.7	4	2.9	2.9	1.3	1.3
P003	Median time allocation (min, max)	0 (0, 1)	0 (0, 1)	3 (0, 3)	1 (0, 5)	0 (0, 1)		3 (0, 5)		0 (0, 2)	3 (0, 3)		2 (0, 6)				1 (0, 2)	
	Positive affect; negative affect	5.4; 0	5.5; 0	5.4; 0.3	5.5; 0.1	5.5; 0		5.5; 0.3		4.5; 0	5.4; 0.3		5.6; 0				5.2; 0	
	Impatience to end	1	1	0.1	0.3	0		0.1		4.3	0.1		0				1	
	Competence/capability	5.6	5.5	5.8	5.6	5		5		4.8	5.7		5.7				5	
	Tiredness	2	2.5	2.2	1.9	3.5		2.2		3	2.4		2.4				2.6	
P004	Median time allocation (min, max)	0 (0, 1)	0 (0, 1)		1 (0, 1)	0 (0, 1)							0 (0, 1)	0 (0, 1)		0 (0, 1)	1 (0, 3)	2 (1, 3)
	Positive affect; negative affect	2.1; 1.0	1.9; 1.5		2.7; 1.3	0							3; 1.5	2.4; 1		3; 1	2.7; 1	1.9; 1
	Impatience to end	2.7	2		1	0							3	2		1.7	1.2	
	Competence/capability	2	2		2.3	0							2	2		2.6	1.7	
	Tiredness	1.3	1		1.8	1							1.5	1		1	1.4	
P005	Median time allocation (min, max)	0 (0, 1)	0 (0, 1)	1 (0, 2)	2 (1, 4)	1 (0, 2)	0 (0, 2)	2 (1, 4)		2 (1, 3)	0 (0, 3)		1 (0, 4)	0 (0, 1)	0 (0, 3)		2 (1, 5)	
	Positive affect; negative affect	1; 0.2	4; 0	5.5; 0	3.9; 0.4	4.0; 0.1	4.9; 0.0	3.9; 0.1		4.0; 0	5.0; 0		4.9; 0	2.9; 0.3	5.1; 0.1		5.2; 0.2	
	Impatience to end	6	0.8	1.4	0.6	0	0	0.6		0	0		0.4	2	1.7		1	
	Competence/capability	6	5.5	5.5	5.7	6	5.9	6		6	6		6	6	6		6	
	Tiredness	3	1	2.7	0	0.5	0	0.5		1.9	1.2		1.2	1			1.7	
P006	Median time allocation (min, max)	1 (0, 2)	0 (0, 2)	0 (0, 1)	2 (0, 4)	1 (0, 2)	0 (0, 3)	0 (0, 3)		0 (0, 1)	0 (0, 3)	0 (0, 4)		0 (0, 2)		0 (0, 2)	0 (0, 1)	1 (0, 1)
	Positive affect; negative affect	5.9; 0.7	5.9; 1.2	6; 0	6; 0.4	5.7; 0.6	5.5; 0.5	5.6; 0		6; 0	6; 0.5	6; 0		5.9; 0.7		6; 0.8	6; 0	5.9; 0.9
	Impatience to end	0.9	1.5	0	0.5	0.8	1.2	0		0	0	0		1.2		0.5	1.5	
	Competence/capability	5.7	5.5	6	5.8	5.8	6	6		6	5.3	6		6		6	5.5	
	Tiredness	4.7	3.8	6	4.8	4.8	5	4.6		6	5.7	6		4		5.5	6	
P008	Median time allocation (min, max)	1 (0, 1)	0 (0, 1)	2 (1, 3)	1 (0, 2)	0 (0, 1)	0 (0, 2)	0 (0, 2)		1 (0, 1)			1 (0, 3)	1 (0, 2)	0 (0, 1)	1 (1, 2)	1 (0, 4)	
	Positive affect; negative affect	4.9; 0.1	3.1; 0	3.9; 0.1	5.2; 0.1	2.9; 0.8	4.7; 0			3.7; 0			3.9; 0.1	3.5; 0.1	4.4; 0	3.6; 0.2	4.2; 0.1	
	Impatience to end	0.3	2.3	0.3	0.8	3	0			0			0.3	0.8	1.3	0.3	0.4	
	Competence/capability	4	4	3.6	4.3	4.5	4.3			3.8			3.6	3.8	4	3.4	3.4	
	Tiredness	3.5	4.7	5.1	4.4	5.5	4.8			4			5.1	4.6	5.1	4.8	4.8	
P009	Median time allocation (min, max)	0 (0, 1)	0 (0, 1)	0 (0, 2)	2 (1, 3)	0 (0, 2)	0 (0, 2)	0 (0, 2)		0 (0, 1)	1 (0, 2)			1 (0, 1)	0 (0, 1)	0 (0, 1)	0 (0, 1)	
	Positive affect; negative affect	5.2; 0	5.2; 0	6; 0	6; 0	6; 0	6; 0	6; 0		6; 0	6; 0			5.8; 0	6; 0	5.9; 0.4	6; 0	
	Impatience to end	0.5	0.7	1	0	0	0	0		0	0		0	0	0	0.5	0	
	Competence/capability	6	6	6	6	6	6	6		6	6		6	6	6	5.5	6	
	Tiredness	0	3.3	2.7	2.7	1.5				2	3.5			1.5	6	2.5	1	
P010	Median time allocation (min, max)	1 (0, 2)	2 (1, 3)	3 (2, 4)		0 (0, 1)	3 (1, 4)			0 (0, 1)	2 (1, 3)		1 (0, 1)	1 (0, 4)	0 (0, 2)	2 (0, 4)	3 (2, 6)	
	Positive affect; negative affect	3.7; 0.4	3.9; 0.6	3.8; 0.7		2.7; 0.3	3.8; 0.5			3.6; 1.6	3.2; 1.2		5; 0	3.4; 0.8	3.4; 0.6	3.7; 0.6	1.7; 0.6	
	Impatience to end	2.2	1.9	1.9		0	0			3.3	2		1	2	1.3	2.6	2.9	
	Competence/capability	6	5.9	5.9		0	5.8			6	5.9		6	6	5.7	6	2.9	
	Tiredness	3.6	4.1	3.7		4	3.8			2.7	3.8		2.7	3.8	4	3.8	2	
P011	Median time allocation (min, max)	0 (0, 2)	0 (0, 1)	1 (0, 1)	2 (0, 1)					0 (0, 1)			1 (0, 1)	0 (0, 1)		0 (0, 1)	2 (1, 3)	
	Positive affect; negative affect	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>					N <sup>+</sup>			N <sup>+</sup>	N <sup>+</sup>		N <sup>+</sup>	N <sup>+</sup>	
	Impatience to end	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>					N <sup>+</sup>			N <sup>+</sup>	N <sup>+</sup>		N <sup>+</sup>	N <sup>+</sup>	
	Competence/capability	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>					N <sup>+</sup>			N <sup>+</sup>	N <sup>+</sup>		N <sup>+</sup>	N <sup>+</sup>	
	Tiredness	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>	N <sup>+</sup>					N <sup>+</sup>			N <sup>+</sup>	N <sup>+</sup>		N <sup>+</sup>	N <sup>+</sup>	
P013	Median time allocation (min, max)	1 (0, 1)	1 (0, 1)	1 (0, 2)	0 (0, 3)			1 (1, 2)		0 (0, 1)	0 (0, 2)					0 (0, 1)	0 (0, 1)	
	Positive affect; negative affect	4.9; 0	4.7; 0	5.7; 0	5.8; 0			5.4; 0		4.5; 0	4.8; 0					5; 0	4.7; 0	
	Impatience to end	0	0	0	0			0		0	0					0	0	
	Competence/capability	6	5.3	5	5.4			5.4		6	5.6					6	5	
	Tiredness	1	1.3	2.7	1			2.8		2	2.3					0	3	
P014	Median time allocation (min, max)	1 (0, 1)		0 (0, 1)	0 (0, 2)	0 (0, 1)	1 (0, 4)			0 (0, 1)	0 (0, 1)	0 (0, 2)					0 (0, 1)	
	Positive affect; negative affect	5.3; 0		5.9; 0	6; 0	5; 0	5.8; 0			4; 0	5.7; 0	6; 0					4.9; 0.4	
	Impatience to end	0		0	0	0	0			0	0	0					2.5	
	Competence/capability	5.5		6	6	5	5.8			5.5	6	6					5.5	
	Tiredness	1		1.3	1.2	3	1.8			1	2	1					0	
P015	Median time allocation (min, max)	1 (0, 2)		1 (0, 1)	2 (0, 3)	0 (0, 2)	1 (0, 2)			0 (0, 1)	1 (0, 2)		1 (0, 2)	0 (0, 1)	0 (0, 1)	0 (0, 1)	3 (2, 5)	
	Positive affect; negative affect	4.5; 0.3		3.7; 0.2	4.3; 0.2	3.7; 0.4	4.4; 0.2			4; 0.3	3.6; 0.2		3.9; 0.2	5; 0	2.5; 1.1	4.4; 0	4.4; 0	
	Impatience to end	1.2		0.7	0.5	1	0.6			0	0.7		0.8	1	2	0	0	
	Competence/capability	5.2		4.2	4.7	4	4.8			5	4.3		4.3	5	5	4.3	4.6	
	Tiredness	2.4		3.5	3.3	4.3	3.3			2	3.8		3.9	4	3	3.5	3.5	
P016	Median time allocation (min, max)	1 (0, 1)	1 (0, 1)	2 (0, 2)	0 (0, 1)		1 (0, 1)				1 (0, 3)		2 (1, 3)	1 (0, 1)		0 (0, 1)	0 (0, 1)	
	Positive affect; negative affect	3.7; 0.3	4.8; 0	5.8; 0	5.5; 0		5.7; 0			5.2; 0			5.7; 0	6; 0		5.3; 0	3.7; 0	
	Impatience to end	0.8	0	0	1.5		0			0.1			0.1			0	3	
	Competence/capability	5.5	6	6	5		5.9			5.9			6	6		6	5.7	
	Tiredness	0	2.3	2	0.5		3.3			2.4			2.4	4		1.3		
P017	Median time allocation (min, max)	0 (0, 2)	0 (0, 1)	0 (0, 2)	1 (0, 2)	1 (0, 1)	1 (0, 1)			0 (0, 1)	0 (0, 1)	0 (0, 1)	1 (0, 1)	1 (0, 2)	0 (0, 1)	0 (0, 1)	0 (0, 3)	
	Positive affect; negative affect	3; 0.1	3; 0.1	4.7; 0	4.5; 0	5.5; 0.3	4.8; 0			3.7; 0	3.7; 0	5.7; 0	4.5; 0	4.4; 0	4; 0	6; 0	3.1; 0.2	
	Impatience to end	0	0	1.7	0	0	0			0.3	0	0	0	0	0	0	0.2	
	Competence/capability	5.3	5	6	4.2	4.2	5			5.3	5	6	4.3	4	6	5	3.1	
	Tiredness	1	3	3	3	3	3			0.7	3.7	5	5	4	3	1.7		
P018	Median time allocation (min, max)	0 (0, 1)	0 (0, 1)	3 (3, 4)	1 (0, 2)	1 (0, 2)	1 (0, 2)	5 (4, 7)										



		At home	At work	Somewhere else
P001	Median time allocation (min, max)	5 (3, 7)		1 (0, 1)
	Positive affect; negative affect	4.7; 0		6; 0
	Impatience to end	0.6		0
	Competence/capability	4.7		5.1
	Tiredness	2.7		1.8
P002	Median time allocation (min, max)	6 (5, 8)		3 (2, 4)
	Positive affect; negative affect	3.6; 0.6		4.4; 0.2
	Impatience to end	2.1		0.9
	Competence/capability	3.6		4.3
	Tiredness	3.6		3.0
P003	Median time allocation (min, max)	4 (2, 5)		1 (0, 4)
	Positive affect; negative affect	5.4; 0.2		5.5; 0.1
	Impatience to end	0.4		0.3
	Competence/capability	5.6		5.4
	Tiredness	2.3		2.3
P004	Median time allocation (min, max)	2 (1, 4)		2 (1, 5)
	Positive affect; negative affect	2.1; 1.1		2.7; 1.3
	Impatience to end	1.5		1.9
	Competence/capability	2.2		2.4
	Tiredness	1.5		1.6
P005	Median time allocation (min, max)	7 (3, 7)		1 (0, 7)
	Positive affect; negative affect	4.5; 0.1		4.2; 0.2
	Impatience to end	0.7		1.9
	Competence/capability	5.8		6
	Tiredness	1.7		1.1
P006	Median time allocation (min, max)	3 (0, 4)		1 (1, 2)
	Positive affect; negative affect	5.8; 0.4		5.7; 0.9
	Impatience to end	0.8		1.1
	Competence/capability	6		5.6
	Tiredness	5.1		4.6
P008	Median time allocation (min, max)	5 (4, 7)		1 (0, 2)
	Positive affect; negative affect	3.8; 0.1		4.9; 0.1
	Impatience to end	0.6		0.1
	Competence/capability	3.7		3.8
	Tiredness	4.9		4.7
P009	Median time allocation (min, max)	4 (2, 5)		1 (0, 2)
	Positive affect; negative affect	5.9; 0		5.5; 0
	Impatience to end	0.1		0.5
	Competence/capability	6		6
	Tiredness	2.8		1.7
P010	Median time allocation (min, max)	3 (2, 6)		2 (1, 3)
	Positive affect; negative affect	3.8; 0.8		3.8; 0.3
	Impatience to end	2.2		2.2
	Competence/capability	5.8		5.9
	Tiredness	4		3.8
P011	Median time allocation (min, max)	4 (3, 5)		1 (0, 2)
	Positive affect; negative affect	N*		N*
	Impatience to end	N*		N*
	Competence/capability	N*		N*
	Tiredness	N*		N*
P013	Median time allocation (min, max)	3 (2, 4)		1 (0, 2)
	Positive affect; negative affect	5.1; 0		5.4; 0
	Impatience to end	0		0
	Competence/capability	5.3		5.6
	Tiredness	3.2		0.6
P014	Median time allocation (min, max)	3 (1, 5)		2 (0, 3)
	Positive affect; negative affect	5.6; 0		5.6; 0.1
	Impatience to end	0		0.5
	Competence/capability	5.8		5.8
	Tiredness	1.7		0.9
P015	Median time allocation (min, max)	3 (1, 6)		2 (0, 3)
	Positive affect; negative affect	3.7; 0.3		4.8; 0.1
	Impatience to end	0.7		0.3
	Competence/capability	4.3		4.9
	Tiredness	3.9		2.2
P016	Median time allocation (min, max)	3 (2, 4)		1 (1, 1)
	Positive affect; negative affect	5.5; 0		4.6; 0.1
	Impatience to end	0.3		1.8
	Competence/capability	6		5.3
	Tiredness	2.5		2.5
P017	Median time allocation (min, max)	2 (0, 4)	0 (0, 1)	1 (0, 2)
	Positive affect; negative affect	4.5; 0	3.8; 0	4.6; 0.2
	Impatience to end	0.3	0.2	0
	Competence/capability	4.9	5.7	4.4
	Tiredness	4.1	0.3	2.5
P018	Median time allocation (min, max)	5 (2, 7)		2 (0, 3)
	Positive affect; negative affect	3.7; 0.1		4.4; 0.3
	Impatience to end	0.2		0.3
	Competence/capability	4.4		4.6
	Tiredness	0.6		0.8
P019	Median time allocation (min, max)	4 (2, 5)		2 (1, 2)
	Positive affect; negative affect	5.6; 0		5.9; 0
	Impatience to end	0		0
	Competence/capability	5.5		5.4
	Tiredness	1.2		0.7

**TABLE 3: Analysis of the 'locations' recorded in the Daily Reconstruction Method**

		Alone	With others	Spouse/ significant other	Friends	Co-workers	Clients/ customers	Students/ patients	My children	Parents/ relatives	Boss	Others not listed
P001	Median time allocation (min, max)	4 (2, 6)	2 (1, 3)						1 (0, 2)	0 (0, 1)		0 (0, 1)
	Positive affect; negative affect	4.4; 0	5.6; 0.1		5.3; 0.2				5.9; 0	6; 0		6; 0
	Impatience to end	0.8	0		0				0	0		0
	Competence/capability	4.5	5.1		4.7				5.3	6		6
	Tiredness	3.2	1.8		2.3				0.7	3		3
P002	Median time allocation (min, max)	7 (3, 9)	2 (1, 7)		1 (0, 1)			0 (0, 1)	1 (0, 3)			2 (0, 7)
	Positive affect; negative affect	3.2; 0.6	4.8; 0.2		4.7; 0.4			4.9; 0	5; 0.1			4.7; 0.3
	Impatience to end	2.2	1		0			0	1.6			0.9
	Competence/capability	3.6	4.2		4.1			4.3	4.7			4.2
	Tiredness	3.2	3.7		2.6			3	4.1			3.3
P003	Median time allocation (min, max)	1 (0, 3)	4 (3, 6)		3 (1, 6)	0 (0, 1)		0 (0, 1)		0 (0, 2)		1 (0, 3)
	Positive affect; negative affect	4.9; 0	5.5; 0.2		2; 0.3	6; 0		5; 0		4.7; 0.4		5.7; 0.1
	Impatience to end	0.3	0.4		0.4	0		0		1		0.3
	Competence/capability	5.5	5.5		5.5	6		5		5.5		5.2
	Tiredness	2.7	2.2		2.1	2		1		1.5		2.7
P004	Median time allocation (min, max)	3 (1, 4)	2 (0, 4)		1 (0, 2)							0 (0, 2)
	Positive affect; negative affect	2.3; 1.2	2.7; 1.3		3; 1.1							2.2; 1.9
	Impatience to end	1.7	1.7		1.4							2.2
	Competence/capability	2.2	2.5		2.1							3.2
	Tiredness	1.4	1.7		1.7							1.6
P005	Median time allocation (min, max)	3 (2, 5)	4 (2, 5)		1 (0, 3)			0 (0, 4)	0 (0, 4)			1 (0, 2)
	Positive affect; negative affect	4.1; 0	4.9; 0.3		4; 0.9			5.2; 0.3	5; 0			5.5; 0.1
	Impatience to end	0.3	1.3		2.6			0.6	1.4			0.7
	Competence/capability	5.9	5.8		5			6	6			6
	Tiredness	1.9	1.4		0.8			1.6	1.7			1
P006	Median time allocation (min, max)	0 (0, 1)	3 (1, 4)		2 (1, 4)	2 (1, 2)			0 (0, 3)	0 (0, 1)		0 (0, 2)
	Positive affect; negative affect	6; 0	5.8; 0.5		5.8; 0.6	5.8; 0.7			6; 0	6; 0		5.8; 1.3
	Impatience to end	0	0.7		0.7	1			0	0		2.5
	Competence/capability	6	5.8		5.8	5.7			6	6		6
	Tiredness	6	4.9		4.8	4.8			6	6		3.5
P008	Median time allocation (min, max)	4 (3, 6)	2 (0, 3)		0 (0, 2)				0 (0, 3)			0 (0, 2)
	Positive affect; negative affect	3.7; 0.1	4.7; 0		4.7; 0				5.4; 0			4.4; 0
	Impatience to end	0.6	0.4		0.7				0			0.1
	Competence/capability	3.7	3.8		4.1				3.8			3.6
	Tiredness	4.9	4.7		4.7				4.7			4.6
P009	Median time allocation (min, max)	1 (0, 3)	4 (2, 5)		4 (2, 5)	0 (0, 1)		0 (0, 1)		0 (0, 1)		
	Positive affect; negative affect	5.8; 0.1	5.9; 0		5.9; 0	6; 0		5.3; 0		6; 0		
	Impatience to end	0.4	0.1		0.1	0		0		0		
	Competence/capability	6	6		6	6		6		6		
	Tiredness	1.8	2.9		2.6	0		0		6		
P010	Median time allocation (min, max)	3 (2, 6)	2 (1, 3)									2 (0, 3)
	Positive affect; negative affect	3.6; 0.9	3.8; 0.3									3.8; 0.3
	Impatience to end	2.1	2.2									2.2
	Competence/capability	5.8	5.9									5.9
	Tiredness	3.9	3.8									3.8
P011	Median time allocation (min, max)	4 (4, 5)	1 (0, 1)		1 (0, 1)	0 (0, 1)						
	Positive affect; negative affect	N*	N*		N*	N*						
	Impatience to end	N*	N*		N*	N*						
	Competence/capability	N*	N*		N*	N*						
	Tiredness	N*	N*		N*	N*						
P013	Median time allocation (min, max)	1 (1, 2)	3 (2, 4)		3 (1, 4)	0 (0, 2)				0 (0, 1)		
	Positive affect; negative affect	4.8; 0	5.4; 0		5.4; 0	5.1; 0				6; 0		
	Impatience to end	0	0		0	0				0		
	Competence/capability	5.4	5.4		5.3	5.7				6		
	Tiredness	2.2	2.2		2.5	0.7				1.3		
P014	Median time allocation (min, max)	1 (0, 3)	3 (2, 4)		2 (1, 5)	0 (0, 1)				0 (0, 3)		
	Positive affect; negative affect	5.1; 0	5.7; 0		5.6; 0	6; 0				6; 0		
	Impatience to end	0	0.3		0.4	0				0		
	Competence/capability	5.3	5.9		5.8	6				6		
	Tiredness	1.8	1.3		1.3	2				0.9		
P015	Median time allocation (min, max)	1 (0, 4)	4 (2, 5)		2 (1, 3)	0 (0, 1)	0 (0, 1)		3 (1, 3)			2 (0, 2)
	Positive affect; negative affect	3.6; 0.3	4.1; 0.2		3.7; 0.3	4.2; 0.4	4; 0.3		4.1; 0.2			4.8; 0
	Impatience to end	0.4	0.6		0.9	1.2	0		0.7			0.5
	Competence/capability	4.2	4.6		4.3	5	5		4.5			5.3
	Tiredness	3.7	3.3		3.8	3.5	2		3.7			3.2
P016	Median time allocation (min, max)	1 (0, 1)	3 (2, 4)		3 (1, 3)				1 (0, 3)	0 (0, 1)		
	Positive affect; negative affect	3.8; 0.1	5.5; 0		5.6; 0				5.9; 0	3.9; 0		
	Impatience to end	2.7	0.3		0.2				0.1	3		
	Competence/capability	5.9	6		6				5.8	5.3		
	Tiredness	1	2.5		2.5				3.3	0.3		
P017	Median time allocation (min, max)	0 (0, 1)	3 (2, 5)		2 (0, 4)	0 (0, 1)	0 (0, 1)	0 (0, 1)	0 (0, 1)		0 (0, 1)	1 (0, 2)
	Positive affect; negative affect	3.3; 0	4.5; 0.1		4.6; 0	4.4; 0	3.8; 0	3.9; 0	5.7; 0		3.8; 0	4.5; 0.2
	Impatience to end	0	0.2		0.3	1	0.2	0.2	0		0.2	0
	Competence/capability	4	5		4.8	4.7	5.7	5.8	6		5.7	4.4
	Tiredness	6	3.1		3.6	4	0.3	0.4	5		0.3	2.5
P018	Median time allocation (min, max)	5 (0, 7)	2 (0, 6)		0 (0, 5)			0 (1, 4)				1 (0, 3)
	Positive affect; negative affect	3.7; 0.1	4.3; 0.1		4.0; 0			3.9; 0				4.6; 0.5
	Impatience to end	0.3	0.1		0.1			0				0.2
	Competence/capability	4.4	4.6		4.6			4.6				4.6
	Tiredness	0.6	0.8		0.8			0.9				1
P019	Median time allocation (min, max)	3 (1, 5)	1 (1, 3)		1 (1, 2)					0 (0, 1)		
	Positive affect; negative affect	5.4; 0	6; 0		6; 0					6; 0		
	Impatience to end	0	0		0					0		
	Competence/capability	5.4	5.6		5.6					6		
	Tiredness	1.2	0.9		0.9					3.3		

**TABLE 4: Analysis of the 'interactions' recorded in the Daily Reconstruction Method**

## APPENDIX J: DEFINITION OF SENSECAM CODES

<b>TASK</b>	Commuting	<ul style="list-style-type: none"> <li>• The individual is travelling from one destination to another</li> <li>• Walking to/from the mode of transport to the destination.</li> <li>• Commuting includes walking between destinations and all forms of transport</li> </ul>
	Shopping	<ul style="list-style-type: none"> <li>• The individual is in a shop or supermarket</li> <li>• The individual is walking in town centre/high street between shops</li> <li>• The individual is putting their groceries in the car</li> </ul>
	Doing housework	<ul style="list-style-type: none"> <li>• The individual is holding cleaning equipment such as a sponge or sweeping brush</li> <li>• Cleaning can include cleaning any room of the house and gardening</li> </ul>
	Eating	<ul style="list-style-type: none"> <li>• The individual has a plate of food is in front of them</li> <li>• They are holding a food item</li> </ul>
	Socialising	<ul style="list-style-type: none"> <li>• Talking to an individual for a period of time</li> <li>• In close proximity to a friend/family member for a period of time</li> </ul>
	Nap/resting	<ul style="list-style-type: none"> <li>• Taking a break from a task, such as sitting during a walk</li> <li>• Taking a nap during the day</li> </ul>
	Relaxing	<ul style="list-style-type: none"> <li>• Sitting for a long period of time</li> <li>• Sitting for a long period of time doing a leisure activity</li> </ul>
	Intimate relations	<ul style="list-style-type: none"> <li>• Not applicable</li> </ul>
	Working	<ul style="list-style-type: none"> <li>• Being in a workplace</li> </ul>
	Preparing food	<ul style="list-style-type: none"> <li>• The individual is holding kitchen equipment</li> <li>• There is food being prepared in the image</li> <li>• The individual is looking in the refrigerator</li> <li>• The individual is using a kitchen appliance</li> </ul>
	Taking care of children	<ul style="list-style-type: none"> <li>• The individual is looking after a younger member of the family, for example, washing their hair</li> </ul>
	Praying/worshipping/ meditating	<ul style="list-style-type: none"> <li>• The individual is in a place of worship</li> </ul>
	Watching TV	<ul style="list-style-type: none"> <li>• The TV is turned on and in the image</li> <li>• The TV is turned on and the individual is facing the TV</li> </ul>
	Computer/internet/emai l	<ul style="list-style-type: none"> <li>• The computer is turned on and is in the image</li> <li>• The individual is using a 'tablet'</li> </ul>
	On the phone	<ul style="list-style-type: none"> <li>• A telephone cord can be seen in the image</li> <li>• Images between a wireless telephone being seen the first time and the next time will be</li> </ul>
	Exercising	<ul style="list-style-type: none"> <li>• Walking, Aerobics, exergaming etc</li> </ul>
	Preparing drink	<ul style="list-style-type: none"> <li>• The individual is using the kettle</li> <li>• The individual is pouring a drink</li> </ul>
	Drinking	<ul style="list-style-type: none"> <li>• The individual is holding a cup</li> </ul>

	Reading	<ul style="list-style-type: none"> <li>• Reading material is in the image</li> <li>• E.g. magazine, newspaper, menu, leaflet</li> </ul>
	Using assistive device	<ul style="list-style-type: none"> <li>• These are sometimes difficult to see</li> <li>• The individual is using an item whilst partaking in a task e.g. walking stick, or other walking aid, wheelchair/electronic scooter, grab rail, magnifying glass etc</li> <li>• The individual uses an item to rest on, e.g. leans on bench</li> </ul>
	Self-care	<ul style="list-style-type: none"> <li>• This includes personal hygiene, such as washing hands or brushing teeth, getting dressed, or looking at self in the mirror</li> </ul>
	Other	<ul style="list-style-type: none"> <li>• This is any other task not listed above</li> </ul>
<b>BODY POSITION</b>	Sedentary	<ul style="list-style-type: none"> <li>• The individual is either lying down or sitting down</li> <li>• This can be distinguished by the level of the camera and visual cues such as a table, or a chair</li> </ul>
	Standing	<ul style="list-style-type: none"> <li>• Objects in image remains stationary</li> </ul>
	Standing/moving	<ul style="list-style-type: none"> <li>• The individual walks but remains in the same room</li> </ul>
	Walking	<ul style="list-style-type: none"> <li>• Detectable motion is recorded, i.e. the individual gets closer to an object</li> </ul>
	Changing position	<ul style="list-style-type: none"> <li>• The individual is changing position</li> </ul>
	Walking with aid	<ul style="list-style-type: none"> <li>• The individual is using an assistive device whilst walking, including a walking stick, Zimmer frame, movable trolley, and any other object that helps the individual walk, other than a wheelchair</li> </ul>
	In a wheelchair	<ul style="list-style-type: none"> <li>• The individual is moving whilst being seated</li> <li>• This can either be a manual wheelchair, motorised wheelchair or electronic scooter</li> <li>• This can be detected by the level of the camera and visual cues such as a changing environment whilst being seated</li> </ul>
	Bending down	<ul style="list-style-type: none"> <li>• The individual is bending over, reaching down or is bent down on their knees</li> <li>• This is detected by the level of the camera or by visual cues such as the presence of arms reaching down in the image or the presence of the ground</li> </ul>
	Stretching up	<ul style="list-style-type: none"> <li>• The individual is stretching up</li> <li>• This is detected by the level of the camera or visual cues such as the presence of arms reaching up in the image</li> </ul>
<b>SOCIAL CONTEXT/ INTERACTION</b>	Not social	<ul style="list-style-type: none"> <li>• There are no other individuals in the image</li> <li>• The coder does not believe there to be any other individual in the same room as the participant</li> </ul>
	Social/interaction	<ul style="list-style-type: none"> <li>• There is another person in the image AND an interaction is taking place</li> <li>• Interactions can be distinguished if the person in the</li> </ul>

		image, and the participant, are facing each other, and/or facial gestures/body language suggests an interaction is taking place
	Social/no interaction	<ul style="list-style-type: none"> <li>There is another person BUT no interaction is taking place</li> </ul>
	Social/not in image	<ul style="list-style-type: none"> <li>The coder believes that a social interaction is taking place but other individuals are not in the image</li> <li>Social/not in image can be categorised using images surround the image</li> </ul>
<b>INDOOR/OUTDOOR</b>	Indoor (general)	<ul style="list-style-type: none"> <li>The individual is in a place with at least three walls and a roof</li> <li>The room is not part of the individual's home</li> </ul>
	Outdoor	<ul style="list-style-type: none"> <li>The individual is outdoors</li> </ul>
	In vehicle	<ul style="list-style-type: none"> <li>The individual is in any form of transport</li> </ul>
	Mixed	<ul style="list-style-type: none"> <li>The individual is halfway between an indoor and outdoor environment</li> </ul>
	Kitchen	<ul style="list-style-type: none"> <li>The individual is in a room with at least three walls and a roof</li> <li>The room is in the participant's home AND kitchen units and appliances are present</li> </ul>
	Living room	<ul style="list-style-type: none"> <li>The individual is in a room with at least three walls and a roof</li> <li>The room is in the participant's home AND living room furniture, such as an armchair and/or sofa are present</li> </ul>
	Bedroom	<ul style="list-style-type: none"> <li>The individual is in a room with at least three walls and a roof</li> <li>The room is in the participant's home AND a bed is present</li> </ul>
	Bathroom	<ul style="list-style-type: none"> <li>The individual is in a room with at least three walls and a roof</li> <li>The room is in the participant's home AND a sink, or toilet, or bath/shower is present</li> </ul>
	Other room	<ul style="list-style-type: none"> <li>The individual is in a room with at least three walls and a roof</li> <li>The room is in the participant's home AND is cannot be categorised within another code</li> </ul>
	Other persons home	<ul style="list-style-type: none"> <li>The individual is in a room with at least three walls and a roof</li> <li>The room is part of someone else's home</li> </ul>
<b>UNUSABLE</b>	Camera covered	<ul style="list-style-type: none"> <li>The image is completely covered</li> <li>The image is partially covered, and cannot be identified</li> </ul>
	Not sure	<ul style="list-style-type: none"> <li>The image is blurred</li> <li>The coder cannot identify the image</li> </ul>
	Taken off	<ul style="list-style-type: none"> <li>The camera has been taken off by the participant</li> </ul>

**Table 5: Definition of all Sensecam codes**

## APPENDIX K      SENSECAM FINDINGS

		Commuting	Shopping	Doing housework	Eating	Socialising	Nap/resting	Relaxing	Intimate relations	Working	Preparing food	Taking care of children	Praying/ worshipping/ meditating	Watching TV	Computer/ internet/ email	On the phone	Exercising	Other	Preparing drink	Drinking	Reading	Using assistive device	Self-care	Gardening
P001	Median (min; max)	10 (0, 47)	0 (0, 152)	6 (0, 59)	24 (10, 30)	188 (31, 490)	0 (0, 17)	264 (175, 529)			17 (5, 41)			202 (63, 364)	0 (0, 1)	0 (0, 1)		40 (13, 47)	4 (0, 22)	1 (0, 12)	36 (11, 149)	27 (7, 122)		
	% of images	3%	9%	4%	4%	50%	0%	67%			4%			35%	0%	0%		7%	1%	1%	9%	7%		
P002	Median (min; max)	66 (0, 118)	7 (0, 80)	31 (4, 62)	19 (8, 40)	87 (1, 159)	0 (0, 22)	44 (173, 324)			11 (7, 75)	0 (0, 3)		25 (0, 109)	13 (0, 17)	0 (0, 18)	31 (0, 52)	184 (126, 297)	5 (1, 8)	1 (1, 27)	145 (22, 262)	0 (0, 50)	2 (1, 7)	3 (0, 22)
	% of images	11%	3%	6%	4%	18%	1%	31%			5%	0%		9%	2%	1%	6%	38%	1%	2%	30%	1%	1%	1%
P003	Median (min; max)	69 (19, 68)	6 (0, 100)	13 (0, 19)	2 (0, 28)	97 (37, 285)		96 (0, 265)			12 (1, 56)			57 (11, 152)	0 (0, 39)		0 (0, 65)	17 (5, 216)	2 (0, 13)	1 (0, 16)	7 (0, 17)		3 (0, 17)	7 (0, 68)
	% of images	20%	6%	3%	2%	35%		35%			6%			22%	2%		3%	16%	1%	1%	2%		1%	5%
P004	Median (min; max)	19 (12, 29)	3 (0, 28)	17 (4, 33)	14 (4, 17)	12 (0, 71)	0 (0, 2)	200 (66, 287)			7 (0, 35)			50 (0, 95)		0 (0, 18)		60 (15, 129)	3 (0, 5)	3 (0, 14)	31 (3, 153)	0 (0, 1)	2 (1, 3)	14 (0, 62)
	% of images	5%	2%	5%	3%	6%	0%	49%			3%			13%		1%		17%	1%	1%	14%	0%	0%	6%
P005	Median (min; max)	4 (0, 185)	0 (0, 39)	13 (1, 29)	47 (6, 71)	72 (0, 457)		443 (266, 539)			15 (5, 22)			444 (266, 551)	8 (0, 69)	12 (0, 32)		359 (266, 551)	3 (2, 5)	3 (0, 17)	81 (64, 181)	6 (0, 9)	0 (0, 14)	2 (0, 22)
	% of images	6%	1%	2%	9%	19%		55%			2%			55%	3%	2%		49%	0%	4%	16%	1%	0%	1%
P006	Median (min; max)	17 (17)	16 (16)	11 (11)	18 (18)	166 (166)		191 (191)			1 (1)			95 (95)				172 (172)	6 (6)	4 (4)	106 (106)	12 (12)	1 (1)	
	% of images	3%	3%	2%	3%	28%		32%			0%			16%				29%	1%	1%	18%	2%	0%	
P008	Median (min; max)	31 (0, 90)	42 (0, 103)	25 (10, 47)	6 (1, 14)	28 (0, 178)		263 (331, 417)			10 (3, 21)			188 (94, 404)	13 (0, 68)	6 (0, 46)		41 (18, 80)	5 (1, 6)	2 (0, 9)	24 (13, 155)	19 (1, 63)	2 (0, 19)	
	% of images	6%	6%	4%	1%	14%		53%			2%			38%	3%	2%		8%	1%	0%	13%	4%	1%	
P009	Median (min; max)	0 (0, 92)	0 (0, 75)	11 (0, 83)	0 (0, 2)	52 (12, 254)	0 (0, 3)	105 (9, 228)			4 (0, 33)			19 (0, 138)	25 (5, 191)	0 (0, 17)	5 (0, 61)	34 (14, 76)	7 (0, 10)	2 (0, 4)	70 (42, 149)	0 (0, 2)	1 (0, 4)	6 (0, 69)
	% of images	0%	0%	4%	0%	18%	0%	27%			3%			9%	14%	1%	4%	10%	1%	0%	19%	0%	0%	3%
P010	Median (min; max)	45 (14, 83)	10 (0, 41)	34 (18, 93)	31 (17, 43)	20 (3, 114)		189 (100, 244)			37 (10, 70)				49 (5, 143)	0 (0, 23)	92 (46, 114)	235 (138, 304)	3 (1, 7)	0 (0, 2)	212 (126, 306)	3 (0, 7)	10 (5, 24)	
	% of images	7%	3%	6%	5%	28%		28%			6%				10%	1%	13%	36%	1%	0%	35%	0%	2%	
P011	Median (min; max)	30 (9, 198)	9 (0, 32)	14 (0, 48)	21 (3, 32)	53 (0, 363)		334 (172, 495)			18 (1, 25)			230 (162, 325)		5 (0, 29)		45 (6, 128)	2 (0, 10)	1 (0, 2)	153 (52, 225)	9 (1, 16)	4 (1, 7)	
	% of images	10%	3%	2%	3%	21%		60%			3%			44%		2%		10%	0%	0%	27%	1%	1%	
P013	Median (min; max)	78 (0, 151)	39 (0, 63)	38 (3, 68)	15 (13, 22)	166 (12, 366)	0 (0, 1)	179 (152, 330)			28 (14, 158)	0 (0, 33)		146 (99, 269)		2 (0, 20)		43 (4, 82)	12 (9, 17)	5 (1, 40)	104 (81, 294)	0 (0, 2)	2 (0, 22)	0 (0, 166)
	% of images	11%	5%	5%	3%	26%	0%	32%			9%	1%		29%		1%		7%	2%	1%	21%	0%	1%	7%
P014	Median (min; max)	86 (0, 129)	0 (0, 34)	0 (0, 1)	20 (11, 28)	224 (33, 261)		362 (190, 541)			0 (0, 4)			263 (4, 469)				10 (4, 143)	0 (0, 2)	4 (2, 10)	99 (40, 147)	0 (0, 2)	4 (0, 7)	0 (0, 49)
	% of images	11%	1%	0%	3%	27%		68%			0%			44%				7%	0%	1%	17%	0%	1%	2%
P015	Median (min; max)	83 (36, 193)	20 (0, 92)	0 (0, 12)	13 (0, 26)	252 (217, 625)		476 (193, 578)			12 (3, 26)			234 (100, 343)	114 (39, 123)			169 (94, 323)	0 (0, 3)	0 (0, 1)	65 (40, 151)		0 (0, 1)	
	% of images	14%	4%	0%	2%	54%		61%			1%			30%	12%			25%	0%	0%	12%		0%	
P016	Median (min; max)	42 (18, 159)	1 (0, 6)	23 (12, 32)	8 (1, 29)	199 (134, 411)		318 (234, 493)			23 (6, 67)			327 (52, 486)	0 (0, 21)	1 (0, 4)		20 (4, 267)	4 (0, 7)	2 (0, 7)	82 (47, 113)	0 (0, 2)	3 (0, 13)	0 (0, 43)
	% of images	8%	0%	3%	2%	35%		50%		4%			46%	1%	0%			8%	1%	0%	11%	0%	1%	1%
P017	Median (min; max)	26 (13, 35)	11 (0, 89)	2 (0, 34)		24 (0, 49)		0 (0, 7)		29 (0, 101)	0 (0, 2)		0 (0, 1)	16 (0, 43)	0 (0, 1)		32 (4, 43)	2 (0, 7)		22 (1, 43)		0 (0, 1)	12 (0, 36)	
	% of images	16%	18%	6%		16%		1%		26%	0%		0%	12%	0%		18%	2%		14%		0%	10%	
P018	Median (min; max)	46 (0, 156)	0 (0, 59)	31 (5, 54)	25 (15, 43)	119 (0, 430)		508 (397, 746)			27 (8, 37)			0 (0, 168)	281 (0, 318)	0 (0, 6)		96 (34, 417)	4 (0, 14)	2 (0, 43)	155 (82, 188)		1 (0, 3)	0 (0, 48)
	% of images	8%	1%	4%	3%	20%		63%		3%			4%	24%	1%	0%		19%	1%	0%	16%		0%	1%
P019	Median (min; max)	56 (18, 205)	40 (15, 115)	43 (27, 144)	53 (20, 121)	273 (0, 546)		470 (380, 603)			22 (4, 38)			444 (280, 463)		1 (0, 44)		64 (15, 159)	5 (3, 7)	2 (0, 3)	140 (53, 225)	2 (0, 4)	1 (0, 4)	3 (0, 12)
	% of images	10%	8%	7%	6%	33%		58%		3%			49%		1%			9%	1%	0%	17%	0%	0%	0%

**TABLE 6:** Analysis of the 'tasks' taken from the Sensecam images

		Lying down	Sitting	Standing	Standing moving (in same room)	Walking	Changing position	Walking with aid	In wheelchair	Bending down	Stretching up
P001	Median (min; max)	0 (0, 7)	365 (175, 543)	5 (2, 14)	43 (18, 96)	16 (6, 20)	0 (0, 2)		0 (0, 159)	0 (0, 3)	1 (0, 2)
	% of images	0%	71%	1%	10%	3%	0%		9%	0%	0%
P002	Median (min; max)		390 (89, 415)	77 (28, 118)	7 (0, 16)	88 (31, 184)	3 (0, 7)			10 (1, 16)	3 (0, 10)
	% of images		64%	15%	1%	12%	0%			2%	1%
P003	Median (min; max)		112 (34, 313)	87 (35, 139)	2 (1, 4)	95 (11, 139)	1 (0, 1)			3 (0, 47)	1 (0, 3)
	% of images		42%	24%	1%	25%	0%			3%	0%
P004	Median (min; max)		276 (80, 343)	58 (30, 91)	4 (0, 7)	35 (28, 78)				12 (0, 15)	2 (0, 4)
	% of images		64%	15%	1%	12%	1%			2%	1%
P005	Median (min; max)	0 (0, 0)	662 (283, 800)	78 (8, 130)	10 (2, 14)	22 (1, 64)	2 (0, 4)			31 (0, 54)	5 (0, 6)
	% of images	0%	78%	10%	1%	4%	0%			4%	0%
P006	Median (min; max)		286 (286)	38 (38)	2 (2)	17 (17)				1 (1)	
	% of images		48%	6%	0%	3%				0%	
P008	Median (min; max)		69 (30, 357)	62 (30, 108)	6 (2, 14)	28 (21, 33)	4 (2, 16)		59 (0, 146)	4 (1, 6)	1 (0, 5)
	% of images		61%	11%	1%	5%	1%		10%	1%	0%
P009	Median (min; max)	0 (0, 85)	153 (72, 318)	54 (25, 93)	23 (2, 50)	67 (9, 107)				3 (0, 18)	2 (0, 4)
	% of images	6%	41%	12%	5%	15%				1%	0%
P010	Median (min; max)		289 (183, 487)	85 (63, 161)	24 (18, 72)	137 (88, 152)	7 (2, 12)	3 (0, 7)		10 (3, 14)	4 (0, 8)
	% of images		50%	15%	6%	20%	1%	0%		1%	1%
P011	Median (min; max)		274 (161, 514)	45 (29, 71)	7 (3, 17)	42 (16, 68)	2 (0, 3)			4 (0, 7)	0 (0, 2)
	% of images		55%	9%	2%	8%	0%			1%	0%
P013	Median (min; max)		289 (226, 331)	144 (42, 248)	17 (8, 102)	83 (14, 206)	1 (0, 7)	0 (0, 2)		16 (1, 39)	1 (0, 8)
	% of images		42%	24%	6%	13%	0%	0%		3%	0%
P014	Median (min; max)	190 (0, 223)	344 (184, 478)	30 (16, 48)	12 (7, 63)	46 (18, 67)	1 (0, 3)			0 (0, 3)	
	% of images	22%	56%	5%	3%	7%	0%			0%	
P015	Median (min; max)	0 (0, 77)	466 (274, 753)	17 (5, 42)	6 (0, 18)	32 (17, 77)	1 (0, 6)			1 (0, 3)	1 (0, 5)
	% of images	1%	73%	3%	1%	5%	0%			0%	0%
P016	Median (min; max)	0 (0, 54)	450 (209, 574)	56 (29, 118)	20 (0, 35)	60 (34, 92)	2 (0, 5)			6 (6, 14)	2 (0, 7)
	% of images	1%	59%	9%	3%	8%	0%			1%	0%
P017	Median (min; max)		43 (14, 76)	31 (3, 90)	3 (1, 20)	37 (10, 95)	0 (0, 4)			2 (1, 14)	1 (0, 6)
	% of images		29%	25%	4%	29%	1%			3%	1%
P018	Median (min; max)		590 (508, 819)	82 (27, 158)	30 (10, 49)	37 (16, 159)	0 (0, 4)			6 (0, 13)	3 (0, 6)
	% of images		72%	9%	4%	6%	0%			1%	0%
P019	Median (min; max)		502 (422, 617)	115 (67, 172)	29 (15, 96)	100 (53, 148)	1 (0, 2)			3 (0, 8)	1 (0, 4)
	% of images		64%	14%	5%	12%	0%			0%	0%

TABLE 7: Analysis of the 'body positions' taken from the Sensecam images

		<b>Indoor (general)</b>	<b>Outdoor</b>	<b>In vehicle</b>	<b>Mixed</b>	<b>Kitchen</b>	<b>Living room</b>	<b>Bedroom</b>	<b>Bathroom</b>	<b>Other room</b>	<b>Other person's home</b>	<b>Workplace</b>
<b>P001</b>	Median (min; max)	10 (0, 175)	17 (1, 59)	5 (0, 59)	4 (2, 5)	37 (6, 116)	275 (115, 527)	1 (0, 19)	0(0, 1)	1 (0, 3)	0 (0, 135)	
	% of images	10%	6%	3%	1%	14%	62%	1%	0%	0%	4%	
<b>P002</b>	Median (min; max)	29 (0, 139)	65 (19, 97)	53 (0, 110)	5 (0, 9)	81 (13, 168)	16 (0, 104)	17 (8, 31)	3 (0, 9)	170 (132, 252)	0 (0, 34)	
	% of images	0%	12%	4%	1%	9%	64%	0%	0%	3%	2%	
<b>P003</b>	Median (min; max)	3 (0, 28)	50 (6, 107)	58 (17, 74)	1 (0, 2)	38 (8, 107)	57 (0, 160)	2 (0, 41)	1 (0, 2)	21 (4, 80)	0 (0, 225)	
	% of images	3%	17%	16%	0%	13%	22%	2%	0%	9%	13%	
<b>P004</b>	Median (min; max)	1 (0, 6)	53 (5, 74)	14 (8, 26)	3 (1, 3)	30	274 (71, 351)	0 (0, 1)	1 (0, 4)	14 (3, 17)	0 (0, 28)	
	% of images	0%	12%	4%	1%	9%	64%	0%	0%	3%	2%	
<b>P005</b>	Median (min; max)	0 (0, 215)	17 (0, 73)	1 (0, 170)	2 (0, 5)	37 (7, 85)	453 (269, 585)	1 (0, 1)		111 (15, 317)		
	% of images	7%	3%	6%	0%	5%	57%	0%		18%		
<b>P006</b>	Median (min; max)	10 (10)	8 (8)	11 (11)		68 (68)	236 (236)		1 (1)	9 (9)		
	% of images	2%	1%	2%		11%	39%		0%	2%		
<b>P008</b>	Median (min; max)	59 (0, 138)	33 (0, 101)	0 (0, 26)	0 (0, 3)	104 (41, 184)	243 (147, 432)	2 (0, 4)	0 (0, 2)	29 (13, 64)	0 (0, 25)	
	% of images	10%	6%	2%	0%	17%	46%	0%	0%	6%	1%	
<b>P009</b>	Median (min; max)	0 (0, 126)	52 (2, 210)	1 (0, 34)	1 (0, 2)	32 (6, 67)	85 (0, 168)	4 (0, 7)	1 (0, 1)	140 (29, 301)		
	% of images	5%	17%	2%	0%	8%	13%	1%	0%	32%		
<b>P010</b>	Median (min; max)	18 (3, 115)	118 (70, 135)	23 (2, 61)	6 (0, 12)	190 (102, 201)	158 (97, 210)	20 (6, 47)	0 (0, 1)	83 (16, 166)	0 (0, 2)	
	% of images	5%	17%	4%	1%	28%	25%	3%	0%	13%	0%	
<b>P011</b>	Median (min; max)	63 (6, 225)	18 (0, 53)	0 (0, 85)	1 (0, 2)	28 (8, 49)	236 (177, 361)	5 (0, 16)	0 (0, 3)	2 (0, 8)	42 (0, 152)	
	% of images	14%	4%	3%	0%	5%	46%	1%	0%	1%	12%	
<b>P013</b>	Median (min; max)	40 (0, 58)	38 (0, 209)	74 (0, 133)	1 (0, 5)	66 (43, 214)	14 (6, 98)	6 (1, 59)	1 (0, 7)	218 (159, 346)	0 (0, 169)	
	% of images	4%	11%	9%	0%	12%	6%	2%	0%	35%	7%	
<b>P014</b>	Median (min; max)	4 (0, 136)	44 (0, 154)	143 (0, 169)	2 (0, 4)	5 (0, 23)	14 (6, 69)	225 (0, 363)	2 (0, 3)	187 (11, 335)	0 (0, 24)	
	% of images	5%	10%	15%	0%	1%	4%	31%	0%	27%	1%	
<b>P015</b>	Median (min; max)	48 (12, 134)	11 (2, 38)	81 (34, 187)	1 (0, 2)	12 (1, 26)	435 (168, 551)	1 (0, 79)	0 (0, 1)	3 (0, 21)		
	% of images	9%	2%	14%	0%	2%	55%	2%	0%	1%		
<b>P016</b>	Median (min; max)	4 (0, 12)	18 (3, 289)	37 (1, 132)	0 (0, 3)	59 (32, 110)	336 (71, 508)	7 (1, 17)	0 (0, 2)	42 (26, 89)	0 (0, 43)	
	% of images	1%	9%	7%	0%	9%	47%	1%	0%	7%	1%	
<b>P017</b>	Median (min; max)	5 (0, 87)	30 (1, 78)	23 (10, 30)	0 (0, 5)	7 (1, 23)	3 (0, 6)	0 (0, 2)	0 (0, 4)	3 (0, 17)	0 (0, 9)	29 (0, 103)
	% of images	16%	23%	14%	1%	6%	2%	0%	1%	4%	1%	26%
<b>P018</b>	Median (min; max)	75 (0, 327)	7 (0, 69)	41 (0, 151)	1 (0, 2)	59 (4, 85)	249 (115, 347)	16 (1, 60)	0 (0, 19)	281 (71, 444)	0 (0, 119)	
	% of images	13%	2%	7%	0%	6%	29%	2%	0%	30%	2%	
<b>P019</b>	Median (min; max)	26 (18, 173)	48 (26, 70)	14 (10, 56)	0 (0, 1)	41 (15, 138)	337 (184, 474)	1 (0, 13)	1 (0, 27)	4 (1, 60)	229 (0, 430)	
	% of images	9%	6%	2%	0%	7%	42%	0%	1%	3%	26%	

**TABLE 8:** Analysis of the 'locations' taken from the Sensecam images



		<b>Not social</b>	<b>Social/ interaction in image</b>	<b>Social/ no interaction</b>	<b>Social/ interaction not in image</b>	<b>Pets</b>
<b>P001</b>	Median (min; max)	139 (62, 387)	96 (20, 192)		125 (46, 357)	0 (0, 43)
	% of images	41%	20%		35%	2%
<b>P002</b>	Median (min; max)	383 (199, 442)	58 (1, 136)	5 (0, 69)	37 (0, 105)	6 (1, 44)
	% of images	86%	4%	2%	3%	0%
<b>P003</b>	Median (min; max)	105 (23, 313)	37 (32, 260)	2 (0, 6)	55 (8, 205)	0 (0, 64)
	% of images	46%	23%	1%	23%	3%
<b>P004</b>	Median (min; max)	341 (117, 511)	19 (9, 22)	6 (0, 23)	0 (0, 44)	
	% of images	86%	4%	2%	3%	
<b>P005</b>	Median (min; max)	592 (294, 844)	30 (0, 335)	0 (0, 48)	46 (0, 126)	
	% of images	75%	13%	2%	7%	
<b>P006</b>	Median (min; max)	20 (20)	102 (102)	13 (13)	209 (209)	
	% of images	3%	17%	2%	35%	
<b>P008</b>	Median (min; max)	447 (233, 555)	47 (0, 172)	6 (0, 73)	14 (0, 110)	
	% of images	70%	10%	4%	6%	
<b>P009</b>	Median (min; max)	193 (63, 355)	13 (3, 66)	35 (1, 51)	95 (16, 226)	
	% of images	44%	6%	7%	23%	
<b>P010</b>	Median (min; max)	435 (288, 640)	17 (5, 145)	4 (0, 23)	1 (0, 19)	99 (45, 119)
	% of images	75%	6%	1%	1%	14%
<b>P011</b>	Median (min; max)	267 (0, 443)	85 (8, 287)	18 (1, 224)	6 (0, 183)	0 (0, 4)
	% of images	50%	22%	8%	6%	0%
<b>P013</b>	Median (min; max)	382 (119, 435)	49 (12, 157)	29 (3, 37)	164 (0, 269)	
	% of images	52%	9%	4%	24%	
<b>P014</b>	Median (min; max)	368 (177, 512)	47 (12, 181)	6 (3, 14)	165 (5, 257)	
	% of images	60%	12%	1%	21%	
<b>P015</b>	Median (min; max)	35 (8, 101)	33 (5, 129)	4 (2, 9)	484 (275, 731)	
	% of images	6%	8%	1%	70%	
<b>P016</b>	Median (min; max)	276 (193, 405)	21 (7, 266)	2 (0, 11)	172 (114, 429)	2 (0, 8)
	% of images	42%	8%	0%	31%	0%
<b>P017</b>	Median (min; max)	86 (52, 87)	28 (4, 54)	5 (0, 81)	4 (0, 39)	0 (0, 1)
	% of images	51%	19%	15%	8%	0%
<b>P018</b>	Median (min; max)	541 (349, 837)	115 (1, 334)	0 (0, 39)	4 (0, 373)	
	% of images	66%	15%	1%	11%	
<b>P019</b>	Median (min; max)	499 (226, 713)	264 (0, 400)	19 (4, 65)	58 (0, 147)	0 (0, 84)
	% of images	58%	25%	3%	8%	1%

**TABLE 9:** Analysis of the 'interactions' taken from the Sensecam images

			<b>Uncodable</b>	<b>Not sure</b>	<b>Taken off</b>
<b>P001</b>	Median (min; max)	Average no. of images (median; min, max)	11 (3, 38)	1 (0, 4)	2 (0, 61)
	% of images	% of images	4%	0%	3%
<b>P002</b>	Median (min; max)	Average no. of images (median; min, max)	6 (5, 14)	3 (1, 4)	5 (0, 19)
	% of images	% of images	4%	1%	0%
<b>P003</b>	Median (min; max)	Average no. of images (median; min, max)	7 (1, 15)	2 (0, 3)	0 (0, 19)
	% of images	% of images	3%	0%	1%
<b>P004</b>	Median (min; max)	Page no. of images daily (median; min, max)	13 (7, 21)	2 (0, 5)	1 (0, 5)
	% of images	% of images	4%	1%	0%
<b>P005</b>	Median (min; max)	Average no. of images (median; min, max)	18 (10, 21)	6 (2, 8)	1 (0, 23)
	% of images	% of images	2%	1%	1%
<b>P006</b>	Median (min; max)	Average no. of images (median; min, max)	251 (251)	3 (3)	
	% of images	% of images	42%	1%	
<b>P008</b>	Median (min; max)	Average no. of images (median; min, max)	33 (23, 66)	5 (1, 8)	13 (9, 53)
	% of images	% of images	6%	1%	3%
<b>P009</b>	Median (min; max)	Average no. of images (median; min, max)	61 (14, 240)	2 (0, 4)	1 (0, 11)
	% of images	% of images	19%	0%	1%
<b>P010</b>	Median (min; max)	Average no. of images (median; min, max)	15 (10, 28)	4 (2, 8)	0 (0, 10)
	% of images	% of images	3%	1%	0%
<b>P011</b>	Median (min; max)	Average no. of images (median; min, max)	14 (6, 34)	5 (0, 9)	28 (13, 263)
	% of images	% of images	3%	1%	11%
<b>P013</b>	Median (min; max)	Average no. of images (median; min, max)	31 (14, 88)	24 (8, 32)	7 (0, 52)
	% of images	% of images	7%	3%	2%
<b>P014</b>	Median (min; max)	Average no. of images (median; min, max)	10 (2, 27)	2 (0, 4)	0 (0, 135)
	% of images	% of images	2%	0%	4%
<b>P015</b>	Median (min; max)	Average no. of images (median; min, max)	26 (12, 115)	3 (0, 7)	31 (3, 221)
	% of images	% of images	5%	0%	10%
<b> </b>					
<b>P016</b>	Median (min; max)	Average no. of images (median; min, max)	46 (10, 189)	7 (1, 19)	40 (11, 208)
	% of images	% of images	9%	1%	9%
<b>P017</b>	Median (min; max)	Average no. of images (median; min, max)	1 (0, 7)	6 (1, 10)	0 (0, 15)
	% of images	% of images	1%	4%	2%
<b> </b>					
<b>P018</b>	Median (min; max)	Average no. of images (median; min, max)	7 (2, 11)	5 (2, 10)	24 (5, 191)
	% of images	% of images	1%	1%	5%
<b>P019</b>	Median (min; max)	Average no. of images (median; min, max)	31 (8, 57)	9 (5, 11)	
	% of images	% of images	3%	1%	

**TABLE 10:** Analysis of 'usable' images taken from the Sensecam images

## Validation of posture and posture transition components of LifeShirt during activities of daily living

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**Introduction:** The LifeShirt is a piece of wearable technology which captures both cardiorespiratory and acceleration data. The LifeShirt enables data regarding posture and posture transition to be recorded and analysed in order to measure sedentary behaviour and patterns of movement.

**Aim:** To measure the validity of the posture and posture transition component of the LifeShirt (Vivometrics™) in a controlled setting and whilst performing activities of daily living (ADL).

**Method:** The study design was influenced by the study validating the *activPAL* activity monitor (Grant, Ryan, Tigbe & Granat, 2006). Ten participants wore the LifeShirt whilst holding randomly assigned postures in a controlled setting. The participants then completed six ADL which were randomly allocated. All postures and tasks were recorded using a video camera and the LifeShirt output was compared to this visual recording for analysis.

**Results:** A second-by-second analysis shows that the overall accuracy between the LifeShirt and the observation was 81.4%. The sensitivity and specificity of the LifeShirt for the lying position was 95.2% and 84.4% respectively and the sensitivity and specificity for the non-lying position was 75.1% and 78.8%. The Bland-Altman plot shows overall mean difference for lying between the LifeShirt and the observation was 13.1% (ULOAA43.5%, LLOA -17.3%) and the overall mean difference for non-lying between the LifeShirt and the observation was -8.3% (ULOAA 14.9%, LLOA -31.5%). Posture transition was overestimated by the LifeShirt.

**Conclusion:** The LifeShirt is a valid measurement technique of posture and posture transition in comparison to results from the validation data of similar accelerometers. Although the posture transitions were overestimated and the accuracy, sensitivity, specificity and Bland-Altman are low for some aspects of the LifeShirt data this may be explained by the design of the study. Limitations of the study are discussed.

**Keywords:** LifeShirt, posture, posture transition, observation, validity, accelerometer

Activity patterns are commonly used to predict physical functioning in individuals. Accelerometers are one of the most common measures of physical activity. Accelerometers are advantageous as they allow the measurement of variables such as the intensity, frequency, pattern and duration of activities (Berlin, Storti & Brach, 2006). One piece of technology that acts as an accelerometer is the LifeShirt (Vivometrics™). The LifeShirt is a non-invasive piece of technology which is able to simultaneously gather ECG, respiration and acceleration (body posture and posture transition) data (Heilman & Porges, 2007). The LifeShirt is made up of a lycra® jacket which connects to a portable computer, via electrodes, which is worn around the waist. The LifeShirt allows both physical and physiological data to be gathered in a natural environment. The cardiorespiratory components of the LifeShirt have been validated with success (Heilman & Porges, 2007; Kent et al., 2009) however the accelerometer component of the LifeShirt has not yet been validated. There are two main aims to this report. The first aim is to measure the validity of the LifeShirt as an accelerometer (measuring posture and posture transition) in a controlled setting. The second aim is to measure the validity of the LifeShirt as an accelerometer (measuring posture and posture transition) whilst carrying out Activities of Daily Living (ADL).

## **METHOD**

### **PARTICIPANTS**

A convenience sample of 10 adults took part in the study. Participants were staff and students at Teesside University. All participants were healthy adults and were able to carry out all of the activities involved in the study. Ethical approval was gained from the School of Health and Social Care ethics committee, Teesside University.

### **INSTRUMENT**

The LifeShirt (Vivometrics™) is a Lycra® jacket which gathers both physiological and physical data. The jacket is worn by the individual underneath their clothes, on top of their underwear. The jacket is attached to a small computer, worn in a bag around the individuals' waist. The data from the 3-axis accelerometer is obtained from the anterior surface of the abdomen by the LifeShirt.

The data from the LifeShirt was analysed using Vivometrics' Vivologic system which is compatible with Windows. The Vivologic system gives a second-by-second output of the posture position and also records step count and the time of steps.

## **PROCEDURE**

The study has taken influence from the study used to validate the *activPAL* accelerometer (Grant, Ryan, Tigbe, & Granat, 2006). This study was split into two parts; a controlled section and a section in which ADL were completed. The controlled section consisted of individuals taking 6 positions (supine, prone, right lateral, left lateral, sitting and standing). All positions were carried out in a random order and were held for a random amount of time between 30 seconds and 2 minutes. During the ADL section participants were given 6 everyday tasks chosen randomly from a list of 14 tasks (see figure 1, below, for a list of the ADL).

**Figure 1: List of Activities of Daily Living (ADL).**

<b><u>Activities of Daily Living (ADL)</u></b>
1. Relax whilst lying on bed
2. Wash and dry dishes
3. Sit and watch video
4. Clean mirror
5. Vacuum paper from floor
6. Prepare a sandwich
7. Sit and write a letter/list
8. Lie and read magazine
9. Wash and dry hands
10. Word process document using PC
11. Sit and read newspaper
12. Put on duvet covers and pillow cases
13. Pick clothes up from a pile and hang on a washing line
14. Remove rubbish from swing bin, put rubbish by door and replace bin liner

The individuals wore the LifeShirt throughout each session and were also recorded on a video camera. The LifeShirt output was compared to the video camera observation in order to establish validity.

Both sections of the study were conducted in a lab based at Teesside University. The tools for each activity were placed around the room simulating a natural environment. The participants were instructed verbally by the researcher when they were to move onto the next task and what that task entailed. The tasks involved sitting, standing, stepping and lying down. Whereas some tasks ended naturally, some were given a random time (between 1-4mins). Each session lasted between 20 and 26 minutes in total.

The data from the LifeShirt was uploaded on to the Vivologic system and a second-by-second output of posture position and steps was analysed. The videos were also downloaded onto a PC and were viewed using QuickTime player. A second-by-second analysis of posture was carried out on both the LifeShirt output and the video recording. Posture was classified as supine, prone, right lateral, left lateral, upright (standing or sitting) and stepping (when the participant was upright as well as stepping).

## **DATA ANALYSIS**

The overall time spent in an overall lying position and upright position were determined for the controlled and ADL sections of the study. The lying position is made up of four specific positions; supine, prone, right lateral and left lateral, and the upright position is made up of standing and stepping. The validity of the LifeShirt was verified using one LifeShirt and one observer. There were two methods used to analyse the validity of the LifeShirt; a second by second analysis of the data was carried out using a Bland-Altman plot, and also the accuracy, sensitivity and specificity were calculated.

## **RESULTS**

Ten participants (eight female, two male; age  $31 \pm 12.1$  years; height  $166.3 \pm 9.4$  cm; weight  $73.1 \pm 14.7$ kg) took part in the study. The mean length of time for the controlled section and ADL section was 22 minutes 43 seconds (see table 1 for a breakdown of the information). This data is taken from the observed data. All collected data was used in the analysis.

TIME SPENT	CONTROL	CONTROL	CONTROL	ADL	ADL	ADL
	Lying (min)	Non-lying (min)	Total (min)	Lying (min)	Non-lying (min)	Total (min)
<b>TOTAL</b>	52.32	32.73	85.05	30.23	121.12	151.35
<b>MEAN</b>	5.23	3.27	8.50	3.02	12.11	15.13
<b>SD</b>	1.39	2.20	1.62	1.51	3.02	4.16
<b>RANGE</b>	3.08-7.32	1.05-8.05	5.15-11.33	1.05-5.50	7.38-16.25	9.51-25.26

Table 11: Observed minutes spent in lying/non-lying positions over both control and ADL section

### POSTURE TRANSITION ANALYSIS

There were differences between lying to non-lying transition between the LifeShirt and the observation with the LifeShirt over-calculating the amount of posture transitions compared to the observation. The LifeShirt calculated 66 counts of lying to non-lying transitions whereas the observation calculated 31 lying to non-lying transitions. The LifeShirt also overestimated the non-lying to lying transitions with 60 counts compared to the 24 counts by the observation.

### ACCURACY, SENSITIVITY AND SPECIFICITY

A second-by-second comparison was made between the LifeShirt and the observation. Accuracy refers to the percentage of agreement between the LifeShirt and the observation. Sensitivity is the percentage to which the observation showed the LifeShirt identified the correct posture. Specificity was the percentage to which the observation agreed with the LifeShirt.

The overall level of accuracy in the controlled sections was 91.8% and the overall accuracy for the ADL section was 65.1%. For the lying position sensitivity was 95.2% and the specificity was 84.4%, and for the non-lying position the overall sensitivity was 75.1% and the specificity was 78.8% (see table 2 for more information).

	TOTAL	LYING			NON-LYING		
	Accuracy	Accuracy	Sensitivity	Specificity	Accuracy	Sensitivity	Specificity
<b>CONTROLLED</b>	<b>91.8%</b>	85.1%	98.4%	96.2%	71.8%	81.5%	83.4%
<b>ADL</b>	<b>65.1%</b>	71.9%	92%	72.6%	58.8%	68.6%	74.1%
<b>OVERALL</b>	<b>81.4%</b>	<b>78.5%</b>	<b>95.2%</b>	<b>84.4%</b>	<b>65.3%</b>	<b>75.1%</b>	<b>78.8%</b>

Table 12: The accuracy, sensitivity and specificity of the entire dataset

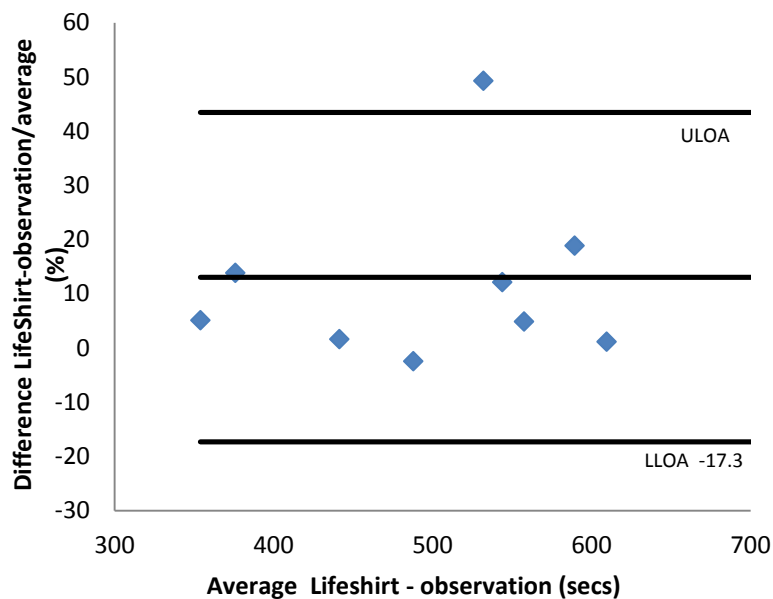
## OVERALL TIME ANALYSIS

Using Bland-Altman analysis the level of agreement of overall time spent in lying and non-lying positions (in both controlled and ADL sections) was calculated in both percentage and minutes (see table 3 and figures 2-5). The overall mean difference for lying between the LifeShirt and the observation was 13.1% (ULOAA43.5%, LLOA -17.3%) and the overall mean difference for non-lying between the LifeShirt and the observation was -8.3% (ULOAA 14.9%, LLOA -31.5%).

	%	%	SECONDS	SECONDS
<b>BLAND-ALTMAN</b>	Lying	Non-lying	Lying	Non-lying
<b>BIAS</b>	13.1	-8.3	72.6	-62.6
<b>ULOAA</b>	43.5	14.9	247.9	114.3
<b>LLOA</b>	-17.3	-31.5	-102.7	-239.5

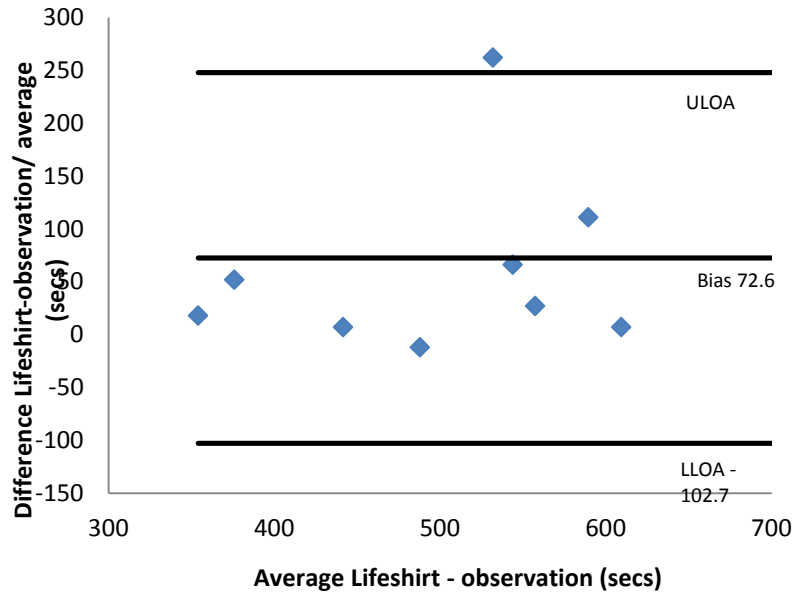
Table 13: Bland-Altman second-by-second analysis

Figure 2: Agreement of LifeShirt and observation in lying position (%)





**Figure 3: Agreement of LifeShirt and observation in lying position (secs)**



**Figure 4: Agreement of LifeShirt and observation in non-lying position (%)**

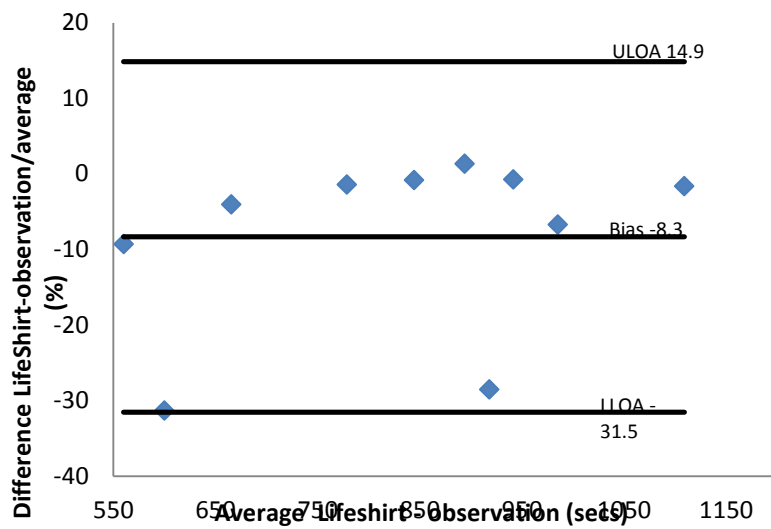
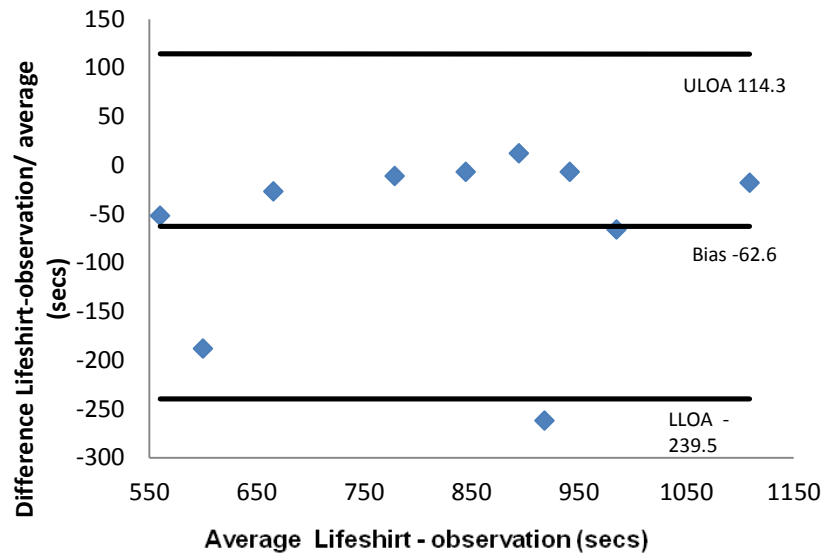


Figure 5: Agreement of LifeShirt and observation in non-lying position (secs)



## DISCUSSION

### POSTURE TRANSITION

The number of posture transitions are overestimated by the LifeShirt for both lying to non-lying and non-lying to lying positions therefore the LifeShirt picked up more transitions than was observed. One reason for this could be due to some of the tasks in the ADL section. Some of the tasks involved a lot of bending over, which was classed as a '*non-lying*' position by the observer however the LifeShirt classed this as the '*prone*' position due to the horizontal position of the chest, therefore increasing posture transition on the LifeShirt. Furthermore, two tasks were completed on a reclined chair. Again, the observation classed this as a '*non-lying*' position, however, the LifeShirt detected the horizontal position of the chest and increased the LifeShirt's postural transition count again.

Although the observation criterion is classed as the 'gold standard' in this study, this may not always be the case. It may not be that the LifeShirt incorrectly scored these postural transitions, but that the observation did not classify these in the correct way. For example, there was no criterion to define the angle in which a non-lying position changes to a lying position; it was simply classed as horizontal or vertical.

### ACCURACY, SENSITIVITY AND SPECIFICITY

The overall accuracy in this study between the LifeShirt and the observation was 81.4%. This result is not too dissimilar to other validation studies which range between 86-99% (Bussmann, Reuvekamp, Veltink, Martens & Stam, 1998; Bussmann, van de Laar, Neeleman & Stam, 1998; Uiterwaal, Glerum, Busser & van Lummel., 1998; Lyons, Culhane, Hilton, Grace & Lyons, 2005; Grant *et al.*, 2006). The sensitivity of the LifeShirt in this study ranges from 75% (for non-lying positions) to 95.2% (for lying positions) whereas specificity of the LifeShirt ranges from 78.8% (for non-lying positions) to 84.4% (for lying positions). Again, this is similar to the validation of other accelerometers which the sensitivity and specificity range from 63.7% to 99.8% (Bussmann *et al.*, 1998; Bussmann *et al.*, 1998; Grant *et al.*, 2006).

The controlled section of the LifeShirt validation was more accurate than the ADL section. Furthermore, both sensitivity and specificity were higher in the controlled section than the ADL section for all postures. This was expected and has been seen in past validation studies (e.g. Grant *et al.*, 2006). However, this result can also be

explained in a similar way to the biases seen in posture transition data. The accuracy, sensitivity and specificity were affected by the misclassification of postures in the LifeShirt and the observation during certain ADL activities, for example, when the individual was reclining or bending over. Although these positions were classed as 'lying' on the LifeShirt they were classed as 'non-lying' by the observation.

The accuracy, sensitivity and specificity may have also been affected due to the overall length of the recorded sessions, which was low. This was due to practicalities of the video camera used as this was the longest length that the camera could record. It may have affected the data in that there were ultimately a lower number of occurrences of different postures than there would have been in a longer session, therefore the data were more sensitive to small differences between the LifeShirt and the observation.

Furthermore, there was a low occurrence of some of the lying positions (i.e. supine, prone, right lateral and left lateral) in the ADL section. This was due to there being fewer activities involving a horizontal position than the combination of standing, walking and sitting activities. Furthermore, when individuals were asked to lie down during the ADL section they were asked to lie in a comfortable position which was usually a supine position. This resulted in a low occurrence of other lying positions during this time and therefore skewed the overall accuracy, sensitivity and specificity data. This is also similar for the accuracy, sensitivity and specificity figures for the non-lying position during the controlled setting. Although individuals were asked to hold a sitting position during the controlled section they were not asked to perform a controlled walk during this time. This also resulted in a low occurrence of 'non-lying' positions during the controlled section and therefore skewed overall accuracy, sensitivity and specificity.

Throughout the entire study (both controlled and ADL sections) there was a low amount of walking. Although individuals walked from activity to activity, and walked whilst participating in some of the activities the sum of this walking was not a great amount. Therefore, the accuracy, sensitivity, and specificity of specifically the 'walking' part of the 'non-lying' position was skewed. The LifeShirt struggled to detect 'stepping' (i.e. shuffling, or shifting weight from one foot to the other) and accuracy dropped due to this. Further studies, should incorporate a higher amount of purposeful walking in both the controlled and ADL section of the study.

## OVERALL TIME ANALYSIS

The agreement between the observation and the LifeShirt is quite poor with wide limits of agreement for both lying and non-lying positions using the Bland-Altman analysis.

The Bland-Altman analysis shows that the LifeShirt detected less non-lying positions than the observation on a second-by-second basis. The Bland-Altman analysis shows better overall results for the non-lying position (ULOA 14.9%, Bias, -8.9%, LLOA -31.5%) compared to lying positions (ULOA 43.5%, Bias 13.1%, LLOA -17.3%). This shows that the LifeShirt and the observation have a higher second-by-second agreement for non-lying positions than lying positions. This may be due to non-lying positions not being misclassified as lying positions by the LifeShirt. Any misclassification of non-lying postures was between the upright and stepping position therefore not affecting the second-by-second analysis of the overall non-lying position. The misclassification of the upright and stepping postures could also be explained by the low sum of purposeful walking in both the controlled and ADL sections and adding more purposeful walking into the method may have improved the stepping data.

Looking specifically at the lying positions the LifeShirt detected more lying positions than the observation on a second-by-second basis. The mean difference was lowest and the limits of agreement were closest for the right lateral position (ULOA 6.6%, Bias -0.8%, LLOA -8.2%). This may have been because there were a low number of occurrences of the right lateral position and no right lateral positions occurred in the ADL section. Contrastingly, the mean difference was greatest and the limits of agreement were widest for detecting the supine position (ULOA 90.9%, Bias 25.6%, LLOA -39.7%). This position was performed the most often of all of the lying positions in the ADL section and was often misclassified by the LifeShirt whilst in the reclined position, similar to the misclassification of some prone postures. This misclassification therefore affected the second-by-second analysis of lying data.

One other study which used Bland-Altman analysis to validate the accelerometer was Grant *et al.* (2006). Grant *et al.* found the mean difference between the accelerometer (*activPAL*, PAL Technologies Ltd, Glasgow, UK) and the observation less than 0.3% for total time sitting and being upright, a mean difference of 1.4% whilst standing and 2% whilst walking. The results differ from the current study as there was an overall mean difference of 13.1% in the lying position and an overall mean difference of -8.3% between the LifeShirt and the observation whilst in the non-lying position. In addition to the misclassification of some of the postures which has skewed the data, one other

reason that the second-by-second analysis may have been that the length of the data sessions were smaller than those in the previous studies. This was due to technological practicalities. The smaller length of the sessions may have accentuated the differences between the LifeShirt and the observation.

There were some limitations to the study. Firstly, the sample size was small which may have affected the results, including the limits of agreement in the Bland-Altman analysis. Another limitation to this study is that the length of the recorded sessions were shorter than those of other validation studies due to practicalities of the equipment. Furthermore, the ADL section should have included more activities which involved lying down, and more activities which involved lying in numerous positions, rather than the majority of lying positions being made up of the supine position. The activities in both the controlled and ADL sections of the study should have been adapted to contain more purposeful walking.

## CONCLUSION

The LifeShirt is a valid tool to measure posture and posture transition when compared to other validated accelerometers (Bussmann *et al.*, 1998; Bussmann, *et al.*, 1998; Grant *et al.*, 2006; Lyons, *et al.*, 2005; Uiterwaal *et al.*, 1998). Although the posture transitions were overestimated and the accuracy, sensitivity, specificity and Bland-Altman are low for some aspects of the LifeShirt data this may be explained by the design of the study such as including more purposeful walking throughout the study, and increasing the number of lying postures within the ADL section. Furthermore, the Bland-Altman results could be improved by increasing the amount of time of the recorded sessions in the study as a low occurrence of postures (which occurred due to the low time) may have led to big differences in the results.

It is also important to acknowledge the disadvantages of the 'gold standard' observation used as the criteria to measure the validity of the LifeShirt. There were numerous postural misclassifications specifically between the upright posture and both supine and prone positions. This was not specifically a fault with the LifeShirt but with the calibration system being used for the observation. One option for further studies is to provide an exact description of what constitutes each posture including the angle of the body. Alternatively, another accelerometer could be worn in addition to the

LifeShirt and the observation in order to look at a comparison of both accelerometer outputs.

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## APPENDIX M: JUSTIFICATION FOR NOT USING LIFESHIRT

Despite the validation study providing justification for using the LifeShirt results, there were numerous problems with the LifeShirt data. There were two main reasons as to why the LifeShirt data was not used within this study; the amount of data that was recorded and the contradictory data produced by the LifeShirt.

There were multiple reasons as to why a lack of LifeShirt data was gathered. Firstly, only eight of the 19 participants used the LifeShirt. Of those that did wear the LifeShirt, the majority of the participants wore the LifeShirt for most hours of most days, with a mean wear time of 626 minutes each day over the sample (see table 4).

	Total	Mean
P001	2246	562
P002	3382	564
P003	4661	777
P004	478	239
P005	5474	782
P006	3328	555
P009	5495	785
P010	4458	743
Overall	<u>29522</u>	<u>626</u>

**Table 14: Amount of time (minutes) the LifeShirt was worn, on days that data was not corrupt**

Table 4 (above) contains information of the days of the LifeShirt which recorded, however, over the study weeks of the eight participants that wore the LifeShirt, a total of 12 days did not record. It is known that on one of these days one participant did not wear the LifeShirt, however, the other files were corrupt. The reason for the corruption of these files is unknown.

### DATA OUTPUT

The LifeShirt produced four main accelerometer outputs; posture indicator, steps taken, activity level and motion indicator. The LifeShirt failed to record steps for many of the participants' days over the study weeks which stopped the use of this data as part of this analysis within the PhD, as was initially planned. Additionally, the LifeShirt produced contradictory results over some of the outputs and in some cases, did not provide enough information, or produced contradictory information, which stopped use of other outputs from the accelerometer.

### POSTURE INDICATOR AND STEPS TAKEN



It was proposed, at the beginning of this PhD, that posture indicator and steps taken were going to be the LifeShirt measures analysed in order to explore movement and non-movement patterns of the participants. However, there were issues with the recording of steps taken which made this analysis problematic. The postural indicator of the LifeShirt distinguishes postural position; upright, supine, prone, left lateral and right lateral. The LifeShirt also counts the timing of steps. As well as the postures distinguished by the LifeShirt 'stepping' was also categorised and was classified when in an 'upright' position and 'stepping' simultaneously. This data would allow an insight into the movement patterns of the older adults with chronic pain taking part in the study.

A validation study was carried out to measure the validation of the accelerometer component of the LifeShirt as this had not previously been reported (see appendix M). Specifically, the validation study aimed to validate the posture indicator and steps measured by the LifeShirt data. However, problems arose when this data was collected with the older adults with chronic pain, as part of the main PhD study as 34 days of the 56 days of data, collected over 8 participants, failed to record any steps. Although posture was recorded on these days, there were no steps recorded. Therefore, without the steps taken it was not possible to distinguish between being movement and non-movement for the majority of days which lessened the usefulness of the data. There were a number of potential reasons as to why the output of steps taken may have failed but the actual reason is unknown.

Firstly, the participants set up the LifeShirt on their own each morning and removed the LifeShirt each evening therefore user error during this process may have led to the data not being recorded. However, this justification of non-recorded data is unlikely as the researcher set up the LifeShirt on the first day of each study and this data did not always record.

Secondly, another reason for the LifeShirt not recording steps is that the participant may have removed the LifeShirt during these periods of recording however, once more this is unlikely as all other measures (to my knowledge) were recorded by the LifeShirt during these periods. Furthermore, when an electrode, or other wire, becomes detached from the user's body the LifeShirt sounds a continuous alarm to alert the user of this. Therefore, it would be unlikely that users would remove the LifeShirt whilst turned on, although, again this is cannot be guaranteed.

Finally, one reason for the failing of steps taken, compared to the data collected in the validation study, may have been to the environment in which they were set and the participants that took part. Whereas the validation study was conducted in a controlled environment with younger, healthy, participants of which each step was purposeful, the LifeShirt was worn in a natural environment during the main PhD study, in which purposeful walking may have been less. Furthermore, the age of the sample varies considerably to those in the validation study. The disadvantages of using an accelerometer within the older population were discussed in the literature review of this study (see section 2.5.3) and the older adults wearing the LifeShirt may have had less defined heel and foot strikes than the younger participants in the validation study. As

older adults often walk with a slower walking gait than younger adults, and can sometimes shuffle, accelerometers can often underestimate walking (Storti et al., 2008). Due to the slower walking gait, and shuffling movements of older adults, an accelerometer with higher sensitivity is more useful as it is more sensitive and can pick up more movement. Some activity monitors, such as the Actigraph, run at up to 100Hz, and is therefore more sensitive to movements, whereas this accelerometer ran at 10Hz, therefore recorded 10 signals per second, and the sensitivity lacked which may have affected the data gathered. Again, the less purposeful movements combined with the low sensitivity of the LifeShirt's accelerometer may have been one of the reasons as to why the steps did not record. The movement of participants in the study may be one reason as to why the steps did not record on the LifeShirt, but again this is unlikely, as full days of steps were missing from the data, rather than a reduced number of expected steps.

The reason as to why steps did not record is unknown and can only be speculated within this study.

### **ACTIVITY LEVEL**

As well as posture indicator and steps taken the LifeShirt produces the output of 'activity level' which separates level of activity into three categories; low (sitting or dormant), medium (walking, light exercise or riding a bike) or high (running, jogging or vigorous exercise). However, other than the classification names of the activity levels (i.e. low, medium and high) and the examples given above, there is no further information given, and the differences between the acceleration of a low, medium or high activity are unknown.

One of the issues that I have experienced throughout this PhD is that the company from which the LifeShirt was produced (Vivometrics) has disbanded. Despite Vivonoetics taking over the LifeShirt, and its software, help has been limited from the company regarding the accelerometer and they are unaware of the calculations on which 'activity level' is based upon. It has therefore been difficult to gather information regarding the cut-off points of the activity level readings of the accelerometer. Therefore, activity level could not be used as an output measure within this study as the levels of activity cannot be explained in any further detail.

### **MOTION INDICATOR**

Additionally, information upon motion indication is limited and also contradictory. Motion indication is said to show the absolute value of motion based upon both of the LifeShirt's motion axes. Motion indication is described in the LifeShirt's handbook as:

*The motion component ranges from 0 for no movement to 50 for running very fast (two extremes). When in the supine resting position, the mean will be below 5. When in the supine position and moving, the signal can reach 10-15 in amplitude. Standing is similar. Walking slowly is approximately 2-5. Walking at a medium pace is 7-10.*

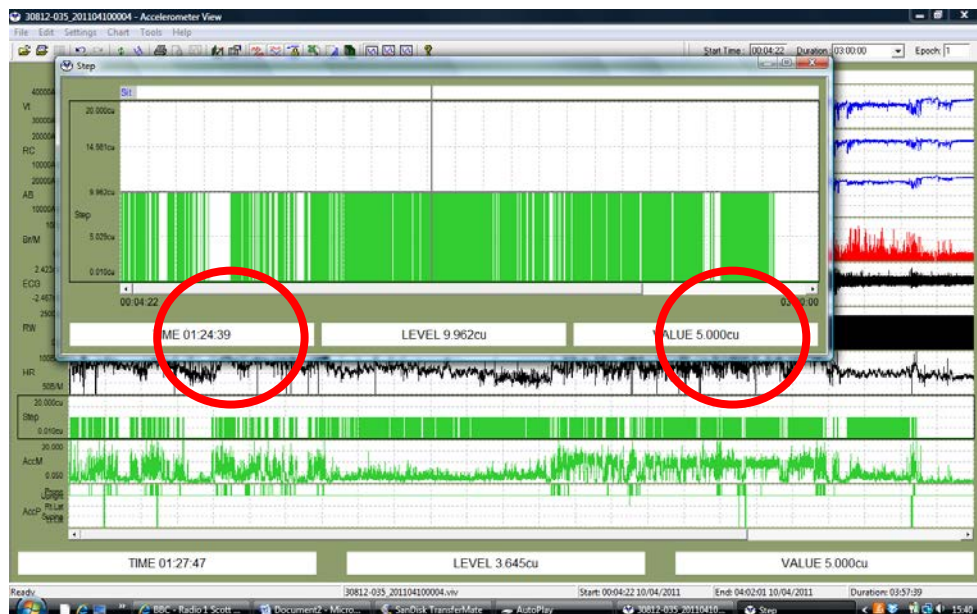
*Walking fast is around 12-18 (Vivologic® Operator's manual, Vivometrics® Inc., pg. 96).*

However, the amplitude numbers are contradictory. When an individual is standing the amplitude would be 10-15, similar to when moving in supine. However, the amplitude of standing is higher than both walking slower (2-5) and moving at a medium pace (7-10) whereas it would be expected that this amplitude would be higher than that of standing without moving. Furthermore, the Vivologic® software handbook states that when in a supine resting position the amplitude will be 5 or below, whereas the handbook also states that walking slowly is between 2-5. It is therefore contradictory in that sitting still and walking slowly are represented by the same amplitude within the software. Therefore, motion indication could not be used as an output measure within this study as the amplitude measures are contradictory.

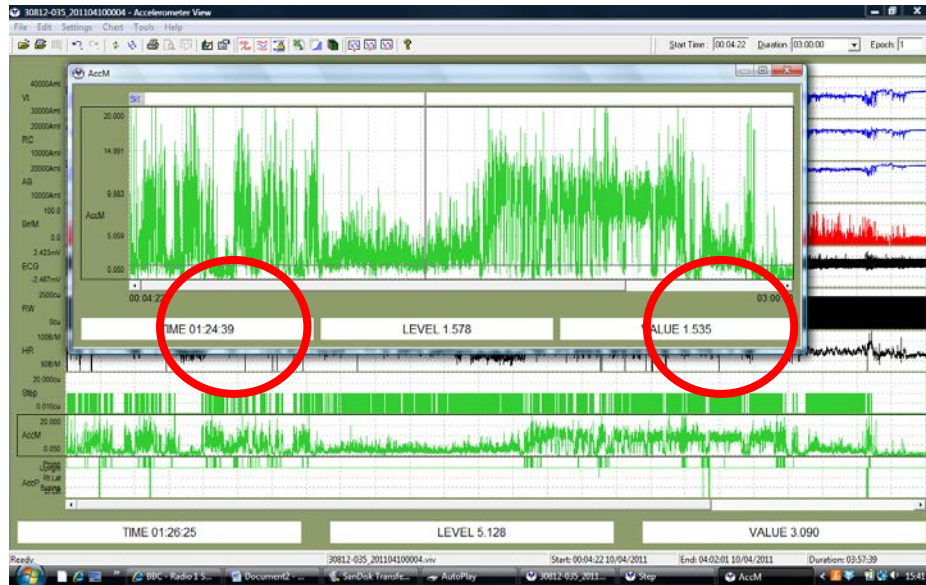
## CONTRADICTIONARY DATA OUTPUTS

As well as some of the data not recording on the LifeShirt, and information in the Vivologic® handbook being sometimes insufficient and contradictory, there were also contradictions in the output itself. It was clear that, on many instances over the sample, the different accelerometer outputs on the LifeShirt contradicted one another. Some examples of these inconsistencies are given below.

Figure 6 below shows a screenshot of the Vivologic® software for P002. At 01.24.39pm the posture indicator on the software shows that the participants is stepping (5.000cu), however, at this same time, the motion indicator shows an amplitude of 1.535. According to the Vivometrics® guidelines this amplitude indicates that P002 is supine and resting, and therefore would not be stepping (see figure 7).



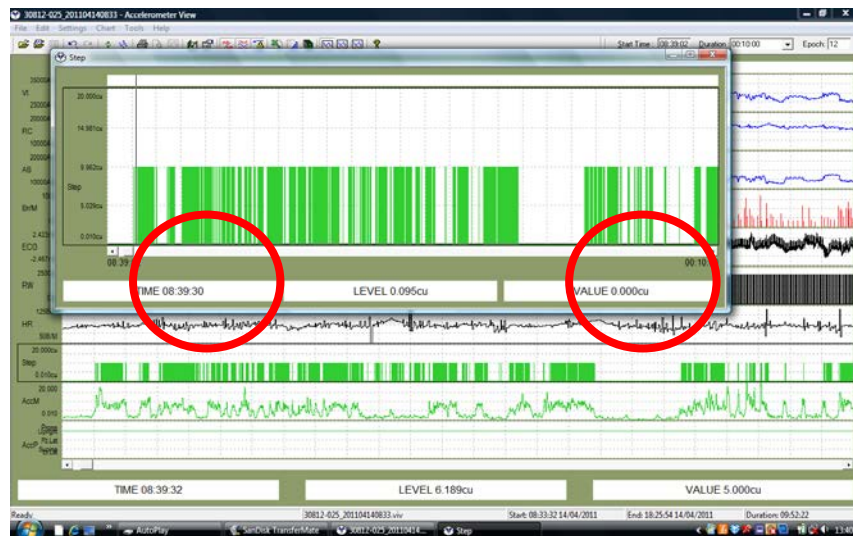
**Figure6: A screen shot of the Vivologic® software showing P002 'stepping' (5.000cu) at 01.24.39 pm**



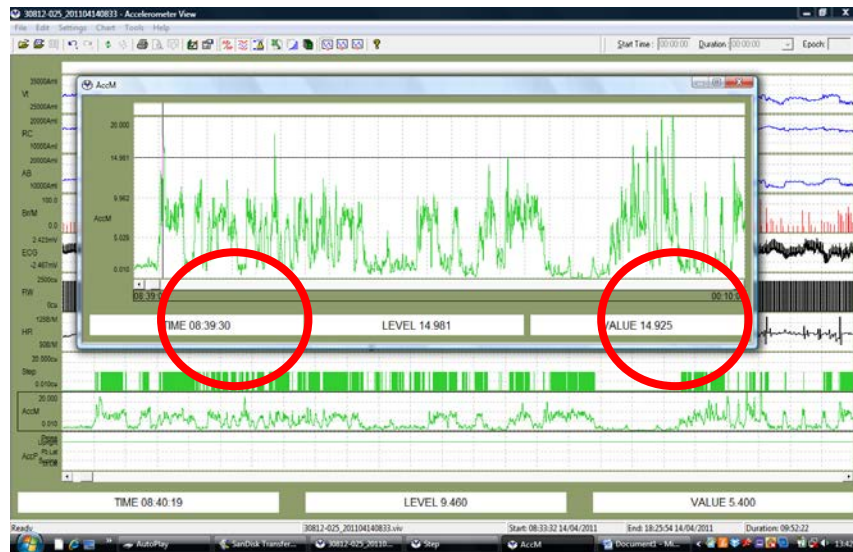
**Figure 7: A screen shot of the Vivologic® software showing P002 in the ‘supine resting position’ (1.535) at 01.24.39 pm**

Vivologic® expresses that slow walking ranges from 2-5 amplitude, and anything lower than this therefore demonstrates a non-upright position and resting, whereas the output states that the individual is also stepping at this time and contradicts the data for P002.

Additional motion indication data and steps taken were contradictory for P002. Whereas the previous example included a step taken with simultaneous low amplitude, the LifeShirt output data also shows high amplitude at the same time as no steps being taken. Figure 8, below, shows P002 not taking a step at 08.39.30am, however, amplitude (as shown in figure 9) at this time suggests that she is ‘walking fast’ (14.925).



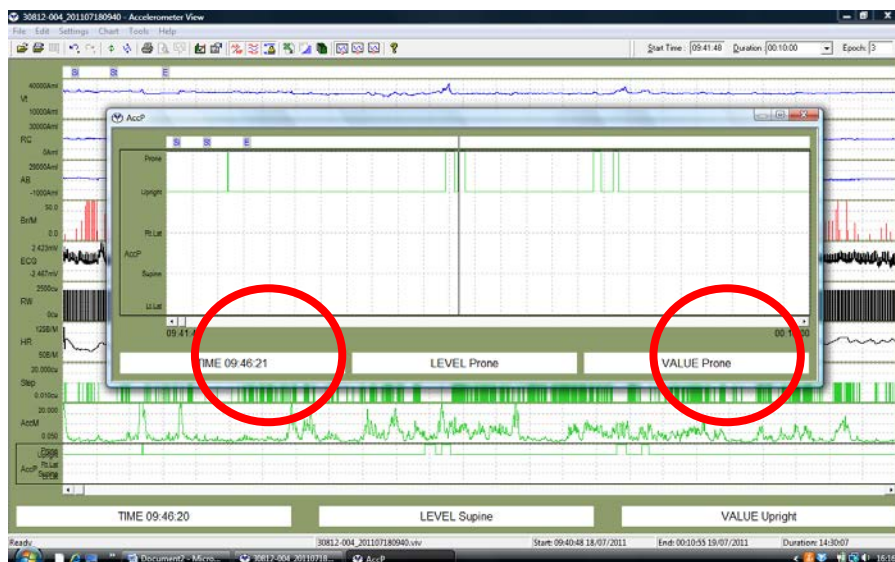
**Figure 8:** A screen shot of the Vivologic® software showing P002 not stepping (0.00cu) at 08.39.30am.



**Figure 9:** A screen shot of the Vivologic® software showing P002 'walking fast' (14.925) at 08.39.30am.

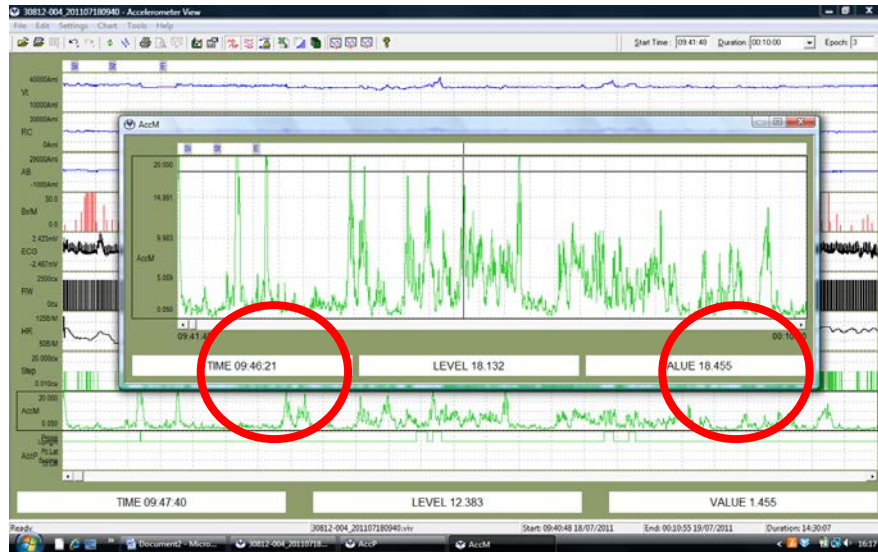
This data is once again contradictory for P002 as although the LifeShirt is not indicating a step is being taken, the amplitude suggests that she was walking at a fast pace.

As well as contradictions between steps taken and acceleration, there are also contradictions in the data between acceleration and posture. P005's data shows that she is in the 'prone' position at 09.46.21am (see figure 10), however, acceleration data also shows that whilst in the prone position her amplitude is 18.455 (see figure 11).



**Figure 10:** A screen shot of the Vivologic® software showing P005 in the 'prone' position 09.46.21am

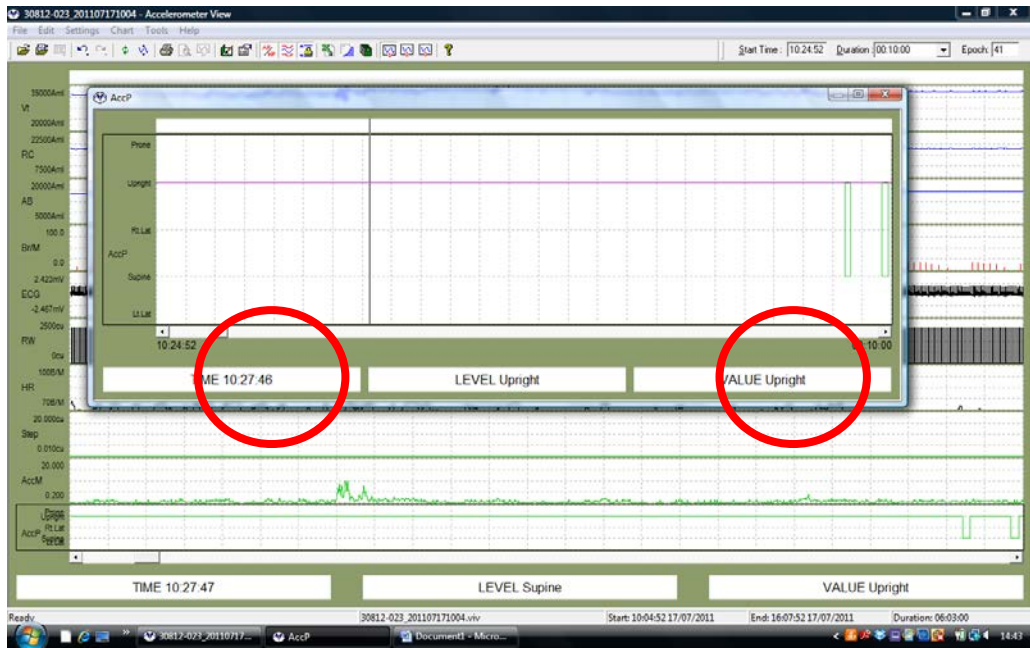




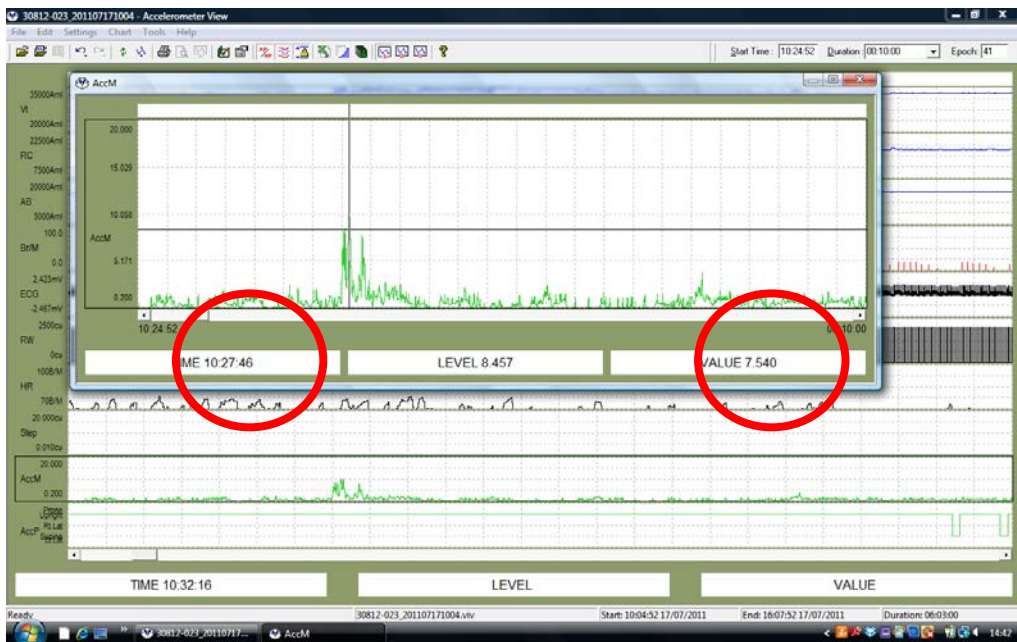
**Figure 11: A screen shot of the Vivologic® software showing P005’s motion indicator as fast walking (18.455) position 09.46.21am**

This data once again contradicts itself. When in a non-upright position and moving the Vivologic® software propose that the amplitude will range from 10-15, however, P005’s amplitude when in the prone position is 18.455, i.e. walking fast.

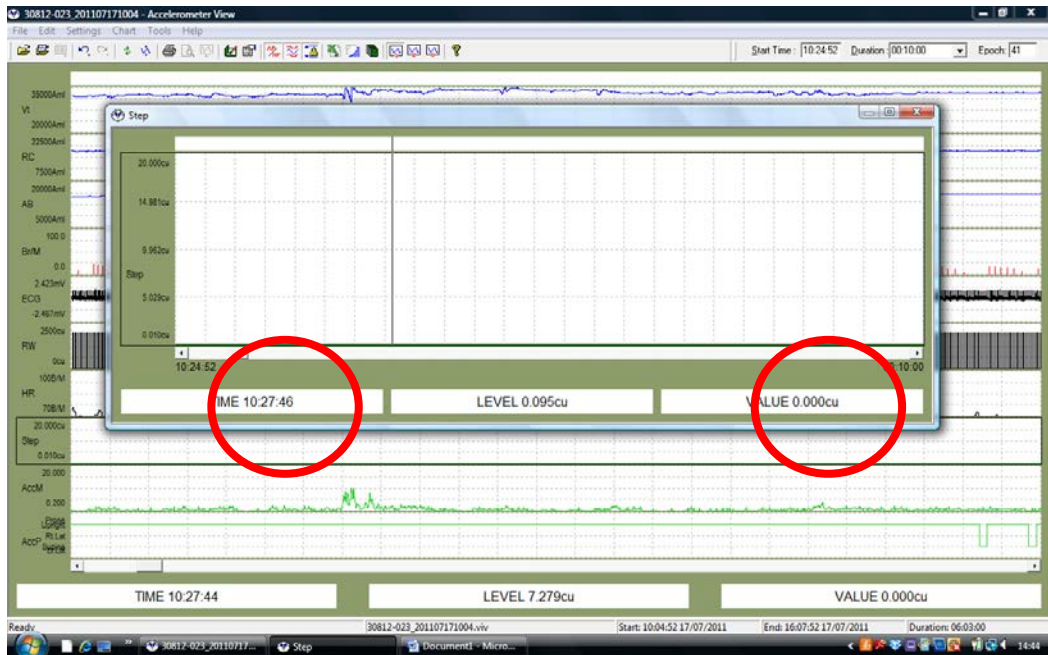
Finally, there were discrepancies between steps taken, acceleration and posture within data from two participants. Data from P005 shows that, when steps were recorded, there were inconsistencies with other data outputs. For example, despite being upright, and showing an amplitude of 7.540 (i.e. walking at a medium pace according to the Vivologic® handbook) no steps were been recorded for this time (see Figure 12 and Figure 13 and Figure 14, below).



**Figure 12:** A screen shot of the Vivologic® software showing P005 ‘upright’ at 10.27.46am.



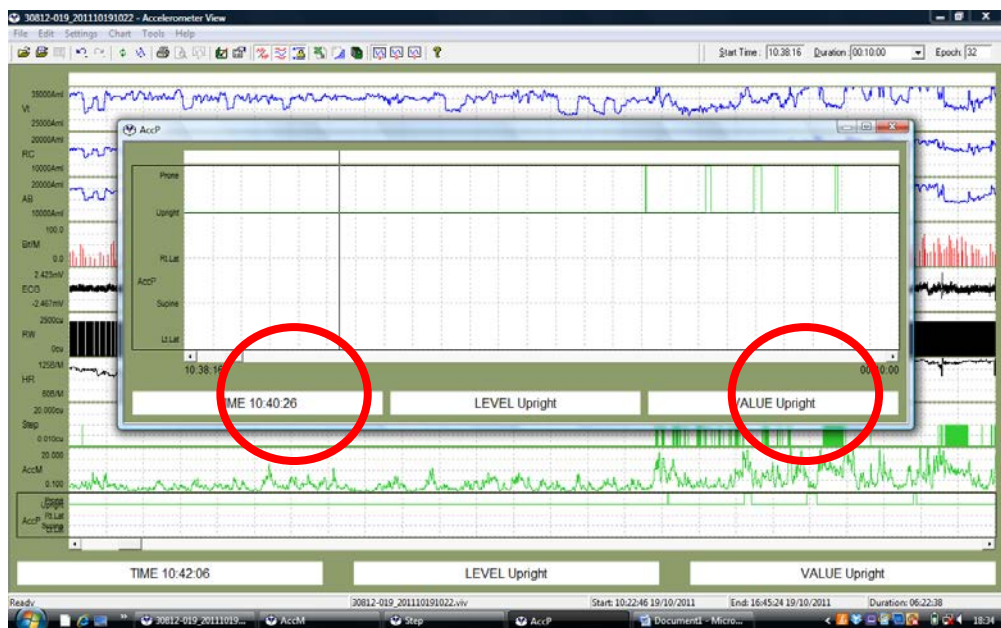
**Figure 13:** A screen shot of the Vivologic® software showing P005 walking at a ‘medium pace’ (7.540) at 10.27.46am.



**Figure 14:** A screen shot of the Vivologic® software showing P005 taking no steps at 10.27.46am.

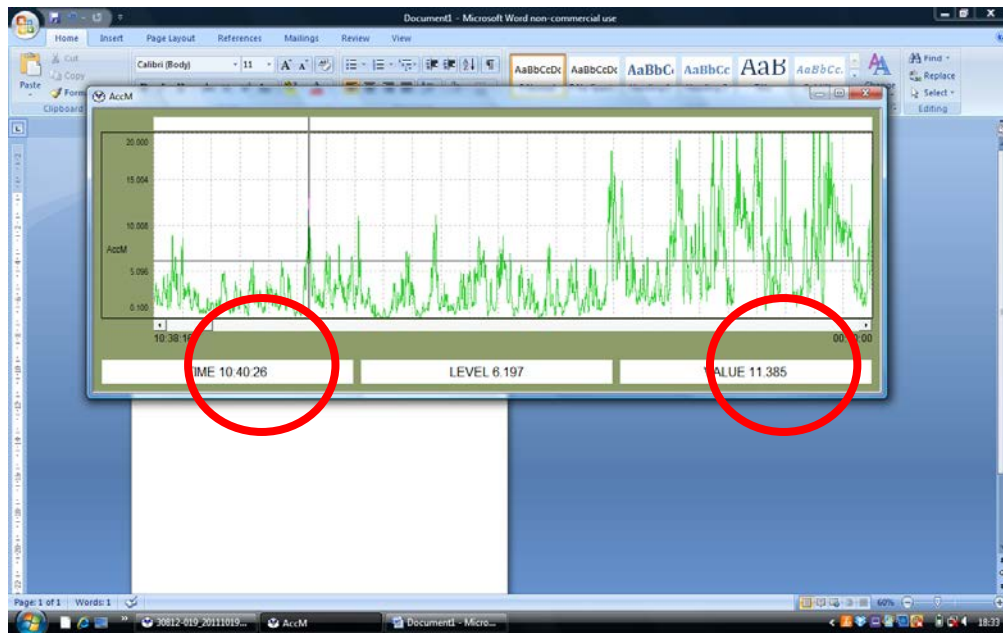
Despite being upright, and displaying an amplitude of 7.540 (i.e. walking at a medium pace), no steps were recorded for the participant at this time, despite steps being recorded at other points during that day. Data from P010 is also similar to this.

Like data from P005, P010's data shows that, despite being upright, and showing an amplitude of 11.385 (i.e. walking at a medium-fast pace) no steps were recorded (see image15, 16 and 17 below).

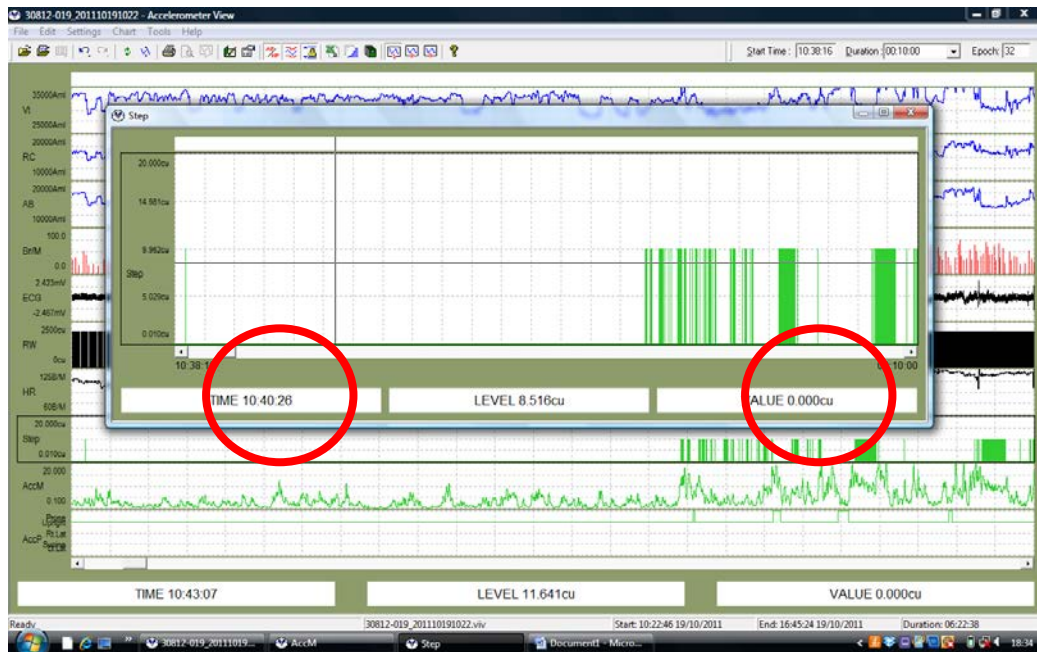




**Figure 15:** A screen shot of the Vivologic® software showing P010 'upright' at 10.40.26am.



**Figure 16:** A screen shot of the Vivologic® software showing P005 walking at a 'medium-fast pace' (11.385) at 10.40.26am.



**Figure 17:** A screen shot of the Vivologic® software showing P010 taking no steps at 10.40.26am.

It is clear that there are inconsistencies for P010 over three data output measures, as despite being in an upright position and walking at a medium-fast pace no steps were recorded at this time, despite steps being recorded at other points throughout that day. There are many inconsistencies between the posture indicator, steps taken and motion indicator of the LifeShirt, and is one of the reasons as to why the data from the LifeShirt is not being used as part of this study.

The LifeShirt data was not used in this study for two main reasons. Firstly, there was only a small amount of data recorded, due to low numbers of participants using the LifeShirt, and more importantly the lack of data due to unknown errors which have meant that a lot of data has not recorded, namely the steps taken. Secondly, data retrieved from the four accelerometer outputs of the LifeShirt were sometimes inconsistent with one another. This led to the removal of this data from the study due to inaccuracies.

## **APPENDIX N: SEMI-STRUCTURED INTERVIEW SCHEDULE (PART A)**

- Hello [insert name here], thank you for taking part in this study and the first interview today. As you know we are going to discuss your experiences with chronic pain in general, and your experiences during this week.
  
- Please could you tell me some information about your pain?
  - How long have you lived with persistent pain?
  - Where do you suffer pain?
  - Have you had any treatment for your pain?
  
- Please could you tell me about your life since developing chronic pain?
  - Has it changed at all?
  - Do you feel like it has improved/become worse?
  
- Have you noticed any physical changes in your life since developing chronic pain?
  - E.g. housework?
  - Exercise?
  - Hobbies?
  - Amount of movement?
  - Has your general daily routine changed?
  - Why do you think these changes have occurred?
  - How do you feel about these changes?
  - What would you like to change about your physical activity levels?
  
- Have you noticed any Personal differences other than the pain itself?
  - How do you feel about yourself since developing chronic pain?
  - Do you feel that you have changed in a positive/negative way since developing chronic pain?
  
- Have you noticed any differences in your social life since developing pain?
  - Do you feel as though your social life has changed since developing chronic pain?
  - Why/why not?
  - If so, how?
  - How do you feel about this?
  - What would you like to change about your social life?
  
- Do you feel as though you have changed your habits to fit in with your pain?
  - E.g. do you use anything to make it easier to move?
  - Do you have any strategies to relieve the pain?

- Please could you describe your experiences whilst taking part in the study?
  - Were there any similarities/differences to your usual routine?
  - Did you have any specifically bad episodes of pain during this week?
  
- What do you feel are the main differences between your daily routine now and before the development of chronic pain?
  - How do you feel about this?
  - How would you change this if you could?
  
- Do you have any other questions or anything else that you would like to discuss today?

Thank you for taking part in the first interview of the study. If you need to ask any more questions, or have any comments please feel free to discuss them in the second interview, or contact me after the interviews have terminated. The second interview will begin shortly, when you are ready.

Thank you.



## APPENDIX O: UTAUT QUESTIONNAIRE

The UTAUT questionnaire (Venkatesh, Morris, Davis & Davis, 2003).

You are asked to indicate your level of agreement or disagreement with each of the statements below by circling one of the numbers on the scale of 1-7, ranging from Strongly Disagree to Strongly Agree.

Underlined statements are those that were omitted from the questionnaire given to participants in this study.

### Performance Expectancy

- |   | Strongly Disagree |   |   |   |   |   | Strongly Agree |
|---|-------------------|---|---|---|---|---|----------------|
| • <u>I would find the system useful in my job</u>                           | 1                 | 2 | 3 | 4 | 5 | 6 | 7              |
| • <u>Using the system enables me to accomplish tasks more quickly</u>       | 1                 | 2 | 3 | 4 | 5 | 6 | 7              |
| • <u>Using the system increases my productivity</u>                         | 1                 | 2 | 3 | 4 | 5 | 6 | 7              |
| • <u>If I use the system, I will increase my chances of getting a raise</u> | 1                 | 2 | 3 | 4 | 5 | 6 | 7              |

### Effort Expectancy

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| • My interaction with the <b>SENSECAM/LIFESHIRT</b> would be clear and understandable | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • It would be easy for me to become skilful at using the <b>SENSECAM/LIFESHIRT</b>    | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • I would find the <b>SENSECAM/LIFESHIRT</b> easy to use                              | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • Learning to operate the <b>SENSECAM/LIFESHIRT</b> is easy for me                    | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

### Attitude toward using technology

- |  |   |   |   |   |   |   |   |
|--|---|---|---|---|---|---|---|
| • Using the <b>SENSECAM/LIFESHIRT</b> is a bad/good idea | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • <u>The system makes work more interesting</u>          | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • Working with the <b>SENSECAM/LIFESHIRT</b> is fun      | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

- |   | <b>Strongly Disagree</b> |   |   |   | <b>Strongly Agree</b> |   |   |
|---|--------------------------|---|---|---|-----------------------|---|---|
|   | 1                        | 2 | 3 | 4 | 5                     | 6 | 7 |
| • I like working with the <b>SENSECAM/LIFESHIRT</b> |                          |   |   |   |                       |   |   |

**Social Influences**

- |  |   |   |   |   |   |   |   |
|--|---|---|---|---|---|---|---|
| • People who influence my behaviour think that I should use the <b>SENSECAM/LIFESHIRT</b>  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • People who are important to me think that I should use the <b>SENSECAM/LIFESHIRT</b>     | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • <u>The senior management of this business has been helpful in the use of this system</u> | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • <u>In general, the organisation has supported the use of the system</u>                  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**Facilitation Conditions**

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| • <u>I have the resources necessary to use the <b>SENSECAM/LIFESHIRT</b></u>                                  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • I have the knowledge necessary to use the <b>SENSECAM/LIFESHIRT</b>   | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • <u>The <b>SENSECAM/LIFESHIRT</b> is not compatible with other systems that I use</u>                        | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • <u>A specific person (or group) is available for assistance with <b>SENSECAM/LIFESHIRT</b> difficulties</u> | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**Self- Efficacy**

I could use the **SENSECAM/LIFESHIRT** if...

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| • If there was no one around to tell me what to do as I go                              | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • If I could call someone if I got stuck  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • <u>If I had a lot of time to complete the job for which the software was provided</u> | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| • If I just had an built-in help facility for assistance                                | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree

Strongly Agree

**Anxiety**

- I feel apprehensive about using the **SENSECAM/LIFESHIRT** 1 2 3 4 5 6 7
- It scares me to think that I could lose a lot of information using the **SENSECAM/LIFESHIRT** by hitting the wrong key 1 2 3 4 5 6 7
- I hesitate to use the **SENSECAM/LIFESHIRT** for fear of making mistakes I cannot correct 1 2 3 4 5 6 7
- The **SENSECAM/LIFESHIRT** is somewhat intimidating to me 1 2 3 4 5 6 7

**Behavioural intention to use the system**

- I would intend to use the system in the next (n) months 1 2 3 4 5 6 7
- I predict I would use the environment I exercised in the next (n) months 1 2 3 4 5 6 7
- I plan to use the system in the next (n) months 1 2 3 4 5 6 7



## APPENDIX P: FLOW-STATE SCALE QUESTIONNAIRE

A Modified version of the Flow State questionnaire (Jackson & Marsh, 1996)

You are asked to indicate your level of agreement or disagreement with each of the statements below by circling one of the numbers on the scale of 1-5, ranging from Strongly Agree to Strongly Disagree. Please base your answers on the **LIFESHIRT/SENSECAM**.

Underlined statements are those that were omitted from the questionnaire given to participants in this study.

	Strongly disagree				Strongly agree
<u>I was challenged, but I believed my skills would allow me to meet the challenge</u>	1	2	3	4	5
<u>I made the correct movements without thinking about trying to do so</u>	1	2	3	4	5
<u>I knew clearly what I wanted to do</u>	1	2	3	4	5
<u>It was really clear to me that I was doing well</u>	1	2	3	4	5
<u>My attention was focused entirely on what I was doing</u>	1	2	3	4	5
I felt in total control of what I was doing	1	2	3	4	5
I was not concerned with what others may have been thinking of me	1	2	3	4	5
<u>Time seemed to alter (either slow down or speed up)</u>	1	2	3	4	5
I really enjoyed the experience	1	2	3	4	5

	Strongly disagree				Strongly agree
<u>My abilities matched the high challenge of the situation</u>	1	2	3	4	5
<u>Things just seemed to be happening automatically</u>	1	2	3	4	5
<u>I had a strong sense of what I wanted to do</u>	1	2	3	4	5
<u>I was aware of how well I was performing</u>	1	2	3	4	5
<u>It was no effort to keep my mind on what was happening</u>	1	2	3	4	5
I felt like I could control what I was doing	1	2	3	4	5
I was not worried about my performance whilst wearing the technology	1	2	3	4	5
<u>The way time passed seemed to be different from normal</u>	1	2	3	4	5
<u>I loved the feeling of the performance and want to capture it again</u>	1	2	3	4	5
<u>I felt I was competent enough to meet the high demands of the situation</u>	1	2	3	4	5
<u>I performed automatically</u>	1	2	3	4	5
<u>I knew what I wanted to achieve</u>	1	2	3	4	5
<u>I had a good idea while I was performing about how well i was doing</u>	1	2	3	4	5

	Strongly disagree				Strongly agree
<u>I had total concentration</u>	1	2	3	4	5
I had a feeling of total control	1	2	3	4	5
I was not concerned with how I was presenting myself	1	2	3	4	5
<u>It felt like time stopped while i was performing</u>	1	2	3	4	5
<u>The experience left me feeling great</u>	1	2	3	4	5
<u>The challenge and my skills were at an equally high level</u>	1	2	3	4	5
<u>I did things spontaneously and automatically without having to think</u>	1	2	3	4	5
<u>My goals were clearly defined</u>	1	2	3	4	5
<u>I could tell by the way I was performing how well I was doing</u>	1	2	3	4	5
<u>I was completely focused on the task at hand</u>	1	2	3	4	5
I felt in total control of my body	1	2	3	4	5
I was not worried about what others may have been thinking of me	1	2	3	4	5
<u>At times, it almost seemed like things were happening in slow motion</u>	1	2	3	4	5
<u>I found the experience extremely rewarding</u>	1	2	3	4	5

## **APPENDIX Q: SEMI-STRUCTURED INTERVIEW SCHEDULE (PART B)**

Hello [insert name here], thank you for taking part in this second interview today. As you know we are going to discuss the questionnaires that you completed before and after the study, as well as your general thoughts on both the Sensecam and LifeShirt (delete as appropriate)

*Thoughts of LifeShirt/Sensecam before beginning the study:*

- Had you ever seen or heard of either piece of equipment before beginning the study?
  - If so, what had you heard and where had you heard it?
  - Why do you think you felt this way?
- Were you completely happy to use the equipment before using it or did you have some reservations? If so what and why?
- Have your views changed, and if so, how have they changed? Why do you think that they have changed?

*Thoughts of LifeShirt/Sensecam during study:*

- Can you tell me how you felt about the LifeShirt/Sensecam?
- Did you find the LifeShirt/Sensecam easy to use?
- Was the LifeShirt/Sensecam clear and understandable?
- Were you worried about making mistakes by pressing buttons on the LifeShirt/Sensecam?
- Was the LifeShirt/Sensecam fun to use?
- Were you apprehensive about using the LifeShirt/Sensecam?
- Did you feel comfortable/self-conscious whilst wearing the LifeShirt/Sensecam? Why/why not?
- Were there any problems with the LifeShirt/Sensecam?
  - Technical?
  - Usability?
  - Practical problems?
- Do you feel as though you would have behaved differently if you were not wearing the LifeShirt/Sensecam throughout the week?
  - If so/not why?

- Were there any activities that you did not want to take part in, or felt that you could not take part in because of the LifeShirt/Sensecam?
- Do you feel that all of your daily activities were captured during the seven days using the LifeShirt, Sensecam and diary?
  - If not, what was not captured?
  - What equipment do you think would be able to do this?
- Did you think that 7 days was an appropriate length to be wearing the equipment?
  - Do you think this time was too short/too long?
  - Why?
- Was it important that the research team were available when using the LifeShirt/Sensecam?
- Would you be happy to use the LifeShirt/Sensecam if there was no-one around?
- Would you be happy to use the LifeShirt/Sensecam if there was only online help?
- Did important others influence you decision to use the LifeShirt/Sensecam? not?
- Did your family and friends make any comments about the equipment?
  - What?
  - Did this affect your thoughts about the equipment?
  - If so, why?

*Future use:*

- Would you use the LifeShirt/Sensecam again?
  - Why/why not?
- Do you have additional thoughts or questions about the LifeShirt, the Sensecam, or the study in general?

Thank you for taking part in the study and the second interview. If you need to ask any more questions, or have any comments you have my contact details. Please feel free to get in touch.

Thank you.

## APPENDIX R: PUBLISHED ABSTRACT (1)

Wilson, G., Martin, D., Jones, D., & Schofield, P. (2012). Exploring chronic pain in older adults; New insights with new technology. *Journal of Aging and Physical Activity*, 20, S295.

**Title:** Exploring Everyday Functioning In Older Adults With Chronic Pain: New Insights With New Technology

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**Introduction:** Chronic pain can affect older individuals in numerous ways, including negatively affecting physical, psychological and social functioning. The importance of functioning is stressed within the International Classification of Functioning Disability and Health (ICF, World Health Organisation, 2001). **Aims:** There were two aims to this study; to explore the day-to-day patterns of functioning and experiences of older adults with chronic pain, and to explore the usability, acceptance and experience of the measurement tools used in the study. **Methods:** All participants were over 65 years old, and all were living in the community with persistent pain (pain for more than 3 months). Individuals took part in the study for a period of 7 days in which they wore 2 pieces of technology; a LifeShirt and a Sensecam. The LifeShirt records physiological and physical information, and the Sensecam acts as a visual diary. The participants also completed a daily diary (DRM). Participants took part in interviews after the study period in order to gather contextual information regarding both pain and daily functioning. Participants also completed questionnaires before and after completing the study, in addition to another interview which aimed to acquire information about their experiences and acceptance of using the equipment throughout the study. **Results:** The data from twenty participants will be looked at in total. Each aspect of the data was analysed separately, using different techniques, due to the contrasting methods used, before being combined and producing an in-depth account of the individual's functioning. **Discussion:** The innovative method allows a deeper understanding of daily functioning of older adults living with chronic pain. As data collection progresses the emerging themes will be explored in more depth.

## APPENDIX S: PUBLISHED ABSTRACT (2)

### The Use of the Sensecam to Explore Daily Functioning of Older Adults with Chronic Pain

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#### ABSTRACT

Chronic pain often interferes with daily living. This study aimed to explore day-to-day patterns of functioning and experiences of older adults living with chronic pain. Thirteen older adults (65+ years) living with chronic pain (pain lasting >3 months) took part in the study. Four data collection techniques were used to gather information on various aspects of daily living. Participants were asked to wear a Sensecam, a LifeShirt, as well as complete a daily diary for seven days. Participants also took part in a semi-structured interview. Themes were developed, based on the images, to explain the effect of chronic pain on the participants' functioning. The Sensecam allowed novel data to be gathered increasing knowledge of the daily functioning of older adults living with chronic pain.

#### AUTHOR KEYWORDS

Sensecam; Older adults; Chronic pain; Functioning

#### ACM Classification Keywords

J.3 Life and Medical Sciences: Health

#### INTRODUCTION

We live in a population that is increasingly ageing. Our ageing society reflects decreased birth rates and increased longevity with predicted estimates claiming that 4% of Britons will be classed as 'oldest-old' (over 85 years old) by 2032[1]. Furthermore, chronic pain is a widespread problem, specifically within the older population, with studies reporting the prevalence of chronic pain as ranging from 25-76% in older people living in the community [2].

Chronic pain interferes with many aspects of daily functioning and this interference increases with age [3]. Mobility can be affected as individuals with chronic pain walk less than those without chronic pain<sup>4</sup> and chronic pain is also associated with greater risk of falls in the older population [5]. Furthermore, activities of daily living, such as self-care, domestic tasks, and leisure tasks are often modified, reduced or terminated as a result of chronic pain [6]. Finally, the presence of chronic pain can have a negative social impact as social exclusion and isolation are often experienced [7,8].

## AIM

The aim of the study was to explore a range of day-to-day patterns of functioning and experiences of functioning in older adults suffering from chronic pain.

## METHOD

A mixed-method design was used. Thirteen participants took part in the study due to the idiographic nature of the study. All participants were over 65 years old and living in the community with chronic pain (9 female, 4 male). This study has been reviewed by Teesside University's School of Health & Social Care Research Governance and Ethics Committee. All participants gave informed consent. All participants wore the Sensecam (Vicon, ViconRevue) for 7 continuous days within their own environment, and were instructed to continue with their daily routine as they usually would. The Sensecam acted as a visual diary collecting data on daily functioning. As well as wearing the Sensecam, data was also collected using three other measures; a LifeShirt (Vivometrics Inc) which is an accelerometer worn as a jacket underneath the individual's clothes, a daily diary (based on the Day Reconstruction Method, DRM) and a semi-structured interview. The four data collection strategies allowed information to be gathered from various perspectives. An initial analysis of the Sensecam findings has been conducted.

## RESULTS

Participants wore the Sensecam for an average of 9.52 hours of each day. Twelve days of data over the sample were not recorded. Ethnographic Content Analysis[9] was used to construct preliminary findings based on the Sensecam images. One image per minute was coded manually by one coder. Four elements of the images were coded; task, body position, location, interaction. The codes were initially developed from codes within the DRM as well as codes developed by other researchers using the Sensecam[10]however, ECA is an iterative process and additional codes were added during the analysis process. Themes were then generated from the tallied codes and the details within the images. Five themes were generated from the images. **Household tasks:** The frequency of cooking, household chores and gardening were low but varied over the sample. One similarity between participants was the use of pacing strategies as individuals often rested in-between household tasks. It was also evident from the Sensecam that many participants used assistive devices whilst completing some tasks, such as devices designed to ease movement or compensate for impaired body movements. It was apparent that some participants relied on others to complete household chores, such as members of the family, or a cleaner. **Down-time:** The participants spent most of their week completing sedentary tasks which mainly consisted of relaxing, watching TV and reading. Participants spent most of their time sitting down but only six participants lay down at any point whilst using the Sensecam. **Travel:** Participants spent most of their time within their own home and most participants did not travel on every day of the study week. However, when travelling most participants travelled by car however both drivers and non-drivers used other methods of transport. Similar to household chores, the Sensecam showed that some participants relied on others whilst travelling, such as for driving, or pushing their wheelchair. **Exercising:** Few participants exercised during the study week, but of those that did, walking was the most common form of exercise. Also, the importance of having a dog for the purpose of walking was prominent for two participants as both participants took a purposeful walk at least once



a day in order to walk their dog. Only four individuals used mobility aids whilst walking; two individuals needed a wheelchair to move around outside of their home, and two participants used walking aids. However, the figure may have been higher as walking aids were often difficult to view on the Sensecam. **Time spent with others:** Socialising was common, however, despite this, the participants generally spent more time alone than with others. Time socialising was carried out in various locations, such as the home, community centres and the pub. Socialising also took many forms from chatting over coffee to opportunity socialising whilst walking.

## CONCLUSION

Functioning can be affected as a result of chronic pain and the Sensecam allowed an in-depth exploration of the daily functioning of older adults living with chronic pain in a novel way. Preliminary themes demonstrate the various ways that chronic pain has affected functioning for the participants within this study. However, the Sensecam does not tell the whole story and some things were not picked up on the Sensecam, such as the use of walking aids. Furthermore, information as to why individuals functioned in the way that in which they did, and the specific effect that chronic pain has had upon functioning, is not gathered from the Sensecam, therefore additional data collection methods are needed. The final analysis of this data will integrate the findings from the three other data collection techniques which will contextualize and expand upon all of the data gathered from the Sensecam. Additionally, to further strengthen the results, data from two younger adults (<65 years) with pain and two older adults (65+ years) without pain will also be analysed in order to compare their daily living to the older adults living with chronic pain.

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