

# **An Exploration of the Health Information Seeking Behaviours of Older People**

**Gillian Hurst**

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Finally, I dedicate this study to my dear Dad, who despite always being there for me, is no longer here to see the completion of my journey.

## **Abstract**

An increasing proportion of people in the United Kingdom are living longer with long-term conditions. The National Health Service is facing the challenge of increased pressure on its service provision. A number of key health policy initiatives encourage individuals to make informed choices and purport to give them rights and control over their own health and healthcare. Within this context, people are actively encouraged to self-care, manage diseases, and make decisions and choices about healthcare in an informed way. To facilitate this, it is important to gain an understanding of the health information seeking behaviours of older people. Health information is available from various sources but little is known about the health information seeking behaviours of older people and what affects this. By exploring this, it helps to reveal how health information is sought regarding on-going health conditions and provides greater depth in understanding the health information seeking process.

The study explores older people's experiences and views on their health information seeking behaviours and endeavours to gain a better understanding of these experiences and views. The study draws on constructivist grounded theory with two phases to data collection: Nine participants completed un-structured diaries over two months with follow up semi-structured interviews, a further twenty participants participated in semi-structured interviews. Major categories were inductively drawn from participant's responses.

Strategies of health information seeking behaviours are not necessarily fixed, but subject to change over time. The analysis suggested three main categories that explained the health information seeking behaviours of older people. Three interrelated conceptual categories were identified: (1) Regulating self (2) Self managing and (3) Self-mobilisation. These categories formed the basis of the emergent substantive theory called 'navigating later life'. There were different patterns of behaviours between participants which captured variations in information seeking; these informed the development of a typology of health information seekers.

Ageing in the 21st century is a complex process; with older people inhabiting a world of more choice, multiple sources of knowledge, changed healthcare roles and increased self-care undertaken within the home. The study provides important insights for healthcare professionals and raises implications for strategies aimed at improving older people's access to appropriate health information. The navigation model provides a potentially valuable tool for policy makers when considering the support older people require to self-care.

# CHAPTER ONE

## INTRODUCTION

### 1.0 Setting the scene

As a result of demographic changes, an increasing proportion of people are living longer with long-term conditions. The healthcare system in the UK is facing a time of transition, from a system predicated on the passive patient to one of working in partnership with active, involved patients. Involving individuals in healthcare decision-making has become a priority for healthcare professionals and policy-makers. Against this altered landscape, this study focuses on the health information seeking behaviours of older people who live independently within their own homes. The research seeks to discover and understand how this particular group maintain their health and manage on-going conditions. Information about health is available from various sources but little is known about the health information seeking behaviours of older people and what influences these behaviours. The purpose of this study is to extend knowledge and understanding of the decisions made by older people regarding health information seeking behaviour, what triggers this and what enables or prevents older people from gaining the information they need.

This chapter firstly outlines the context of the study with an overview of the demographics of ageing and the increasing prevalence of long-term conditions. Secondly, the rationale for the research is introduced. Thirdly, the specific research question and sub-questions are presented and lastly the organisation of the dissertation is described.

### 1.1 Demographic transitions

Population ageing is a result of demographic transition coupled with medical and public health advances which have resulted in increasing life expectancy and numbers of older people in the population (Christensen et al., 2009). Amplified by declining fertility rates, this has resulted in an increase in the proportion of older people within the United Kingdom (UK) (Anderson & Hussey, 2000). On Census day in 2011, 9.22 million people resident in England and Wales were over 65 years old, compared with 8.31 million in 2001 (Office for National Statistics, 2013a). By 2032, it is predicted that the number of those over 65 years will

increase to 16.1 million, 23 per cent of the total population (Dunnell, 2008; Office for National Statistics, 2012). The population of those aged over 85 year is the fastest growing group with numbers rising from 1.01 million in 2001 to 1.25 million in 2011 representing 2.2% of the total UK population (Office for National Statistics, 2013a). Current projections estimate that the number of over 85 year olds living in the UK will reach 3.3 million by 2033 accounting for 5% of the total population (Office for National Statistics, 2011). Additionally, within the ageing population variation exists between men and women, with their experiences of older age being different. Despite a greater percentage increase in the number of men (45%) than women (16%) between 2001 and 2011, women continue to outnumber men by two to one (Office for National Statistics, 2013a). As women tend to have a longer life expectancy than men, they are likely to be widowed, so live later life alone (Select Committee on Public Service and Demographic Change, 2013).

Alongside this increasing longevity comes changing patterns of morbidity and co-morbidities, with older people living with a range of health needs (Dunnell, 2008). This means that causes of death have altered and individuals often live with long term conditions requiring treatment for long periods of time (Crimmins & Beltrán-Sánchez, 2010). The focus of treatment has shifted from curative, to reducing the progression of diseases and to address the functional limitations resulting from long-term conditions (Warshaw, 2006).

## **1.2 Impact of the ageing process**

The natural process of ageing is accompanied by an increased risk of disability (Phillips et al., 2010), with the risk of disability increasing over time (Lin et al., 2012). Evidence suggests that there is a rapid increase in disability with advancing age, with the increase being more pronounced at ages 74 and over, with an increased incidence of disability for those aged 90 and older (Berlau et al., 2009). Generally, the self-reported general health of the age 85 and over group is poorer than that of younger older people (Office for National Statistics, 2013a). Older adults with disabilities may survive longer as a result of advanced medical technology which prolongs the longevity of frail older people (Lakdawalla et al., 2004), thus increasing the proportion of people with disability in older cohorts. However, not all older people have high support needs, and it is important to remember that older people are an extremely heterogeneous group with diverse health needs.

It is unclear whether the extension in life-expectancy has led to improvements in years of good health, with Crimmins and Beltrán-Sánchez (2010) concluding that due to lifestyle choices impacting on health, there is no indication that health is improving for those reaching old age. According to the ‘compression of morbidity’ first described by Fries (1980), the length of healthy old age seems to be increasing with declines in the prevalence of disability in later life. Fries (1980) postulated that the period with disease would be compressed into a briefer period at the end of life, due to shorter and later periods of illness and increases in the length of later life. The net effect being an increase in number of years lived in old age without major health problems (Bloom et al., 2010). This is not a view held by all, for example, Gruenberg (1977) proposed that the decline in mortality from long-term conditions would result in more disease within the population. Midway between these two proposals, Manton (1982) suggests that changes in the progression and severity of long term conditions will keep pace with mortality changes, resulting in more disease but with decreased consequences, for example disability.

### **1.3 Costs**

As an increasing proportion of people in the United Kingdom are living longer with long-term conditions, the National Health Service is facing the challenge of increased pressure on its service provision. Due to the prevalence of diseases that occur in later life, there is a relationship between utilisation of health services and age (Dunnell, 2008). Older people are the major users of healthcare services in the UK (NHS Choices, 2012). Healthcare costs in the UK have increased with spending in 2012 being £144.5 billion, up 1.9% since 2011 (Postins & Payne, 2014). Many reasons exist as to why spending is increasing, but one is as a result of the ageing population. In England, by 2018 compared to 2008, it has been projected that over 50% more people will have three or more long term conditions (Select Committee on Public Service and Demographic Change, 2013). The number of long-term conditions accounts for much of healthcare spending. In 2010, the treatment and care of those with long-term conditions accounted for 70% of health and social care spending in England (Department of Health, 2010c). Health care utilisation and cost of healthcare is significantly increased among patients with multiple morbidities. The mean number of primary care consultations rises significantly with the increasing number of long-term conditions (Glynn et al., 2011). In England, people with long term conditions account for 80% of GP consultations and approximately 15% of people with 3 or more problems account for almost 30% of

inpatient days (Wilson et al., 2005). In order to deal with the increase in demand and cost, it has been suggested that the National Health Service needs to be transformed, as presently the health and social care model is incongruous with changing patterns of diseases (Select Committee on Public Service and Demographic Change, 2013). This transformed system of health and social care would mean that the home becomes the hub of healthcare focusing on the individual, with engaged patients regarding decisions and providing support for disease management and prevention (Select Committee on Public Service and Demographic Change, 2013).

#### **1.4 Rationale**

The current and future cost of caring for people with long-term conditions is one of the key influences driving healthcare reform with the promotion of self-care being a key strand of policy and a core element of chronic care models (Anstiss, 2010). There have been a number of key health policy initiatives (Department of Health, 2006, 2008a) which encourage individuals to make informed choices and purport to give them rights and control over their own health and healthcare. Thus people are actively encouraged to self-care, manage diseases, and make decisions and choices about healthcare in an informed way (Department of Health, 2010a, 2012c). In tandem with this, the shift to consumerism has also resulted in the rise of the informed and active consumer (Wilson, 2001). Self-care is not a new concept, but increasingly it is acknowledged as essential for an effective healthcare system, with the promotion of self-care resulting in more appropriate and cost-effective utilisation of healthcare services (Coulter & Ellins, 2009). To be able to achieve self-care, manage diseases and make choices, information is required and this is becoming increasingly available via multiple sources. Therefore, it is important to gain an understanding of the health information seeking behaviours of older people, to ascertain their current level of involvement in healthcare.

#### **1.5 Personal experiences**

My interest in this subject was initially triggered by a series of events that occurred in my personal life. A friend, who is a nurse, told me that her father had been diagnosed with an aortic aneurysm. Rather than speak to his daughter about this, what it might mean and the implications of this diagnosis, he had sought information from the internet. She was upset about this as she did not feel that he was using her as an information source, but it made me

wonder why he had sought information from the internet rather than any other source and whether this was a normal response to health information seeking. At the same time my father was diagnosed with prostate cancer. I attended appointments with him and the consultant provided information in short consultations that were often forgotten. I picked up a leaflet from the clinic and searched for information on the internet. My brother also did this, but he spoke to a friend whose father had the same diagnosis and relayed this information to us. I used my experience as a nurse with previous experience in urology (quite a few years ago) to try and make sense of the information. The third event that occurred was my sister-in-law being diagnosed with Parkinson's disease; her consultant provided her not only with verbal information but gave her a printed sheet with suggested reading and internet addresses that she could access to help with her understanding. She selected and read a few of the recommended websites and read the autobiography of Michael J Fox, who had been diagnosed with Parkinson's disease at a young age. Her main area of interest was medication, so she used the information gained from the internet in further appointments with her consultant. We did not know anyone else who had been diagnosed with this at her age, and the only professional experience I had was caring for older people with advanced Parkinson's disease, which I chose not to discuss with her.

These three situations puzzled me. What were the reasons for such different responses to health information seeking from the people diagnosed with these conditions?

Reflecting upon my personal experiences of health information seeking behaviour, I wondered how older individuals sought health information and what strategies they used. I thought it was important to understand the meanings expressed by participants to gain an understanding of the process of seeking health information.

## **1.6 Research questions**

While there has been some work on how service-users become informed about healthcare, there has been relatively little previous research specifically on health information seeking behaviours of people as they age, and the studies conducted generally include participants of mixed ages and are disease specific (Lambert & Loiselle, 2007). Of the studies that have included older people there is disagreement within the literature as to whether age affects patterns of information seeking. Shaw et al. (2008) identified that age differences did not have an impact, whilst Mackenzie et al. (2006) found patterns of information seeking did

vary with age. Additionally, Kim (2008) suggested that older people did not seek help as they attributed their medical condition to the ageing process. The challenge for healthcare professionals is to assist older people to understand the nature of their condition, any treatments that they are following, ensure they continue to live as healthily as possible and facilitate a level of individualised information to help the older person make sense of health concerns.

Therefore, the research questions of the study are to explore gaps in the previous research and suggest ways that healthcare professionals could promote strategies that improve older people's access to appropriate information and support its effective use.

### Research questions:

What are the health information seeking behaviours of older people?

What motivates older people to access health information?

What enables older people to access health information?

What barriers to accessing health information exist for older people?

Which sources of information do older people use to gain information about their health?

How can healthcare professional's best facilitate the health information seeking behaviours of older people?

### **1.7 Organisation of the study**

The next chapter provides a review of the literature on health information seeking behaviour, specifically focusing on the experience of illness in later life and help seeking. Included within this chapter is an analysis of the policy surrounding 'greater choice and control'.

Chapter three presents the research methodology and details the study design. Constructivism as a philosophical foundation to the research study is explored, as is the grounded theory design. Chapter four presents the findings of the study and the development of a typology of the older person as health information seeker. Within the discussion (chapter 5), I explore the relevance of a number of theorists in illuminating the health information seeking behaviours of older people. In particular, work surrounding self-regulation, self-reliance, social context

and perceptions are drawn upon. Chapter 6 concludes the dissertation with implications and recommendations for healthcare professionals.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 Introduction**

The aim of this chapter is to review the literature on health information seeking behaviour particularly in relation to older people. A preliminary literature review was undertaken prior to undertaking the study to provide rationale for the study, to inform the research proposal and to identify gaps within the literature. A more extensive literature review and focused reading was conducted after data collection and following the completion of analysis. Firstly, this chapter sets the scene for the study by exploring the concept of health information seeking behaviour and reviewing existing studies. Secondly, some of the key factors influencing health information seeking as a response to illness and an integral part of help-seeking and illness behaviour are explored. Thirdly, changing perspectives of later life and the UK Government's response to demographic changes, long-term conditions and associated resource implications is explored within the agenda to increase levels of self-care. Finally, gaps in the evidence base regarding older people and health information seeking behaviour are highlighted.

#### **2.1 Scope of the literature review**

Within this study, the role of the literature review is to outline the broad parameters of the study and to critique and make comparisons with previous theories and studies (Charmaz, 2006). Only a preliminary literature review was undertaken prior to data collection and analysis. This was used to develop a rationale for the study, to inform my research proposal and to identify gaps within the literature. This proved valuable as it showed a lack of previous work within this area resulting in major gaps in understanding the health information seeking behaviours of older people. The main and more extensive literature review was conducted at a later stage (after data collection and completion of analysis). A structured approach to the literature review was guided by emergent themes from data, rather than a systematic review. This reduced the influence of previous theoretical constructions which could affect the direction of the research followed (McCann & Clark, 2003a).

Prior to the mid-1990's, there was limited research highlighting the concept of health information seeking behaviour (for example Lenz, 1984; Miller, 1987). As there had been some research prior to mid-1990's, it was decided to search literature from 1980 onwards, as it represented a period sufficient to identify any seminal work undertaken on health information seeking behaviour. The following electronic databases were searched: CINAHL, PubMed, British Nursing Index, Medline, ASSIA and Web of Science using the key term "health information". The search was refined by limiting it to literature focusing on over 65 year olds and articles with the major heading of health information. Despite limiting the search to over 65 year olds other adults were also included within research studies.

As illustrated in Figure 1 over three thousand papers were found from an initial search with 254 included.

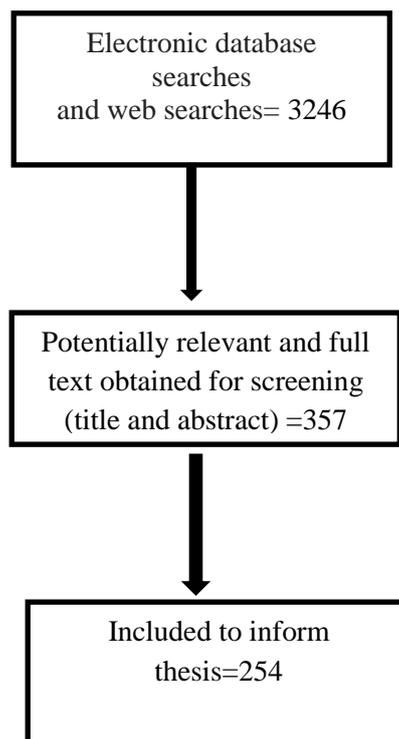


Figure 1: Identification of literature

Combinations of terms, one from each column in table 1 (see below), were searched for. Keywords used in journal articles were also used to assist with accessing further relevant

literature. Pertinent references from the articles were accessed in order to retrieve potentially relevant literature not initially identified. All study types were included and papers were reviewed in terms of their potential contribution to an understanding of health information seeking behaviour in older people.

Term one-search term	Term two-subject major heading	Term three-major headings
Health information	Health information Information seeking behaviour	Internet World wide web Information resources Patient education Health education Health behaviour Access to information Information needs Health literacy Decision making

Table 1: Search terms

## 2.2. Defining health information seeking behaviour

Prior to the mid-1990's, there was limited research highlighting the concept of health information seeking behaviour (for example Lenz, 1984; Miller, 1987). More recently, health information seeking behaviour has become a topic of interest to researchers and clinicians, due to the altered information landscape, the focus on self-care and disease management (Johnson, 2003). Against this back drop, with increased emphasis on individuals as active seekers of information, information seeking research is being undertaken at a growing pace (Rouse & Rouse, 1984).

Currently there appears to be lack of clarity within the literature regarding the definition of health information seeking behaviour. Analysis of the literature revealed a lack of consistent

definition of the concept of health information seeking behaviour, with no unified dominant definition (Lambert & Loiselle, 2007). Health information seeking behaviour is generally viewed as the ways that individuals gain information about health, illness, risks to health and health promotion. Health information serves a variety of needs for example providing practical, psychosocial and decision making support (Smith et al., 2009). Research focuses on health information seeking in response to an illness or disease; although healthy individuals may explore information to maximise health, this is often ignored within the literature (Weaver et al., 2010).

Despite the lack of definition, there are some shared characteristics which include focus on individual skills to obtain, process and understand the health information necessary to make appropriate health decisions (Conley, 1998; Tardy & Hale, 1998). Commonly, definitions suggest that health information seeking is intentional and an overt action, with individuals making a decision to seek health information (Case, 2002; Johnson, 1997). Definitions are often broad and suggest a purposive active search for information, that there is a specific reason for the search and particular actions are used (for example Johnson, 2003; Lambert et al., 2009a; Niederdeppe et al., 2007). However, they do not allude to the method that is used to elicit information and health information can be obtained as the result of a non-purposive search (Longo et al., 2010). Many studies of health information seeking behaviour explore active information seeking, by investigating why and how individuals attempt to gain information that is expected to be suitable for their anticipated needs (Longo et al., 2010). This could be in response to most of the research being disease-focused, for example related to cancer (Davison & Breckon, 2012), arthritis (Tak & Hong, 2005), cardio-vascular disease (Gholami et al., 2014) and diabetes (Longo et al., 2010). However, information can be gained unintentionally via passive exposure from within the environment (Longo, 2005; Longo et al., 2010). Unintentionally gained information happens when an individual does not actively seek information, with knowledge acquisition occurring whilst engaging with daily activities such as watching television or reading newspapers. Indeed, Longo et al. (2010) conclude individuals 'actively weave their own information web' (p337) with a combination of active information seeking and passive receipt of health information.

Commonly, information seeking is undertaken in a variety of contexts, which have been identified within current definitions (Lambert et al., 2009a). However, as much of the research focuses on illnesses, there remains limited understanding regarding patterns of

health information seeking in a range of contexts and at different stages of health and illness. Longo et al. (2010) suggest that the weaving of information occurs over the life course commencing with diagnosis and dependant on the disease trajectory. Furthermore, health information seeking does not take place within a social vacuum with interpersonal communication being a key factor in the information sought and the interpretations of received information (Anker et al., 2011). Tardy and Hale (1998) underscored the importance of interpersonal communications, identifying that information is gained either through active seeking or acquired passively. It is important that both verbal and non-verbal behaviour and communication are considered regarding health information seeking behaviour as this could impact on the message received by the information seeker. Due to the emphasis by Tardy and Hale (1989), these different elements were drawn upon when I defined health information seeking behaviour for this study (see below).

Whilst considering definitions of health information seeking behaviour and the lack of clarity regarding these, for the purposes of this study, health information seeking behaviour is defined in the following way:

Health information seeking behaviour is information gained verbally and non-verbally through everyday interactions, either purposefully or serendipitously, that serves to make judgements and take decisions in everyday life concerning illness, healthcare, being at risk and staying healthy, in order to maintain or improve quality of life throughout the life course.

### ***2.2.1 Rationale for health information seeking in older age***

Health information seeking is undertaken for a number of reasons. Actively searching for health information is recognised as one mechanism for coping with crisis, change, uncertainty and gaining control over health (McIntosh, 1974). One study (Manafó & Wong, 2012) explored older people's experiences of seeking on-line information specific to health and nutrition and concluded that the rationale for undertaking this was to take responsibility for nutritional well-being. Information decreases feelings of anxiety and fear with its significance within the decision-making process highlighted in the literature (Adams et al., 2009; Lenz, 1984). In a systematic review, Gaston and Mitchell (2005) concluded that being informed

reduced anxiety, gave back a sense of control, created realistic expectations and improved compliance. Furthermore, health information potentially empowers individuals by increasing knowledge and participation (Caiata-Zufferey et al., 2010; Manafo & Wong, 2012), theoretically promotes better patient-doctor interaction and efficiency of services (Lewis et al., 2007), reduces preventable health conditions and can lead to improved health outcomes (Denberg et al., 2005).

There tends to be a focus by researchers on the advantages of health information seeking, however information seeking can have negative consequences, resulting in individuals undertaking a limited search for new information. Previous research suggests that some individuals perceive additional information to be confusing, unsafe and exacerbating already challenging situations (Leydon et al., 2000). Some people choose to avoid looking for information altogether as they wish to preserve hope (Barbour et al., 2012; Leydon et al., 2000; Longo, 2005) and information is viewed as threatening, thereby contributing to increased anxiety (Case et al., 2005; S. Miller, 1995). Manafo and Wong (2012) propose that due to the plethora of information, health information seeking can be ‘disabling’ as information can be confusing and create anxiety. Some individuals do not wish to seek further health information or take responsibility for health maintenance and promotion (Henwood et al., 2003; Lupton, 1997), preferring to rely on the health information provided by healthcare professionals (Henwood et al., 2003; Longo, 2005).

### ***2.2.2 Information gathering***

Increasingly, individuals’ desire to have a greater role in healthcare decision making has changed the landscape of the healthcare system (Longo et al., 2001). Healthcare decisions are made within an information environment that is complex and can be challenging, particularly when individuals are faced with difficult decisions. Often choices are made regarding the type, amount and information sources used. Models of consumer-decision-processes, suggest that information search is a key component that impacts on the selection of a product. Within these models an individual gathers all the necessary information and makes a decision based on this (Engel et al., 1968). Parallels can be drawn to health information seeking behaviour, as the search for information is initially based on decisions made regarding whether information should be sought and what should be done with this. However, this process is more complex with Kim et al. (2008) suggesting that trust, perceived benefit, and perceived

risk also impact on decisions. Furthermore, as Longo et al. (2001) suggest there are six phases of information use in healthcare decision making, which range from individuals being unaware that there is relevant available information through to them using the information to make decisions.

Lenz (1984) proposes the information gathering process encompasses six distinctive steps (see table 2) which occur sequentially, but can be terminated at any stage.

Step 1	Trigger
Step 2	Goal setting
Step 3	Decision to act
Step 4	Search behaviour
Step 5	Information acquisition and organisation
Step 6	Decision about adequacy of information gained

Table 2: Steps involved in information seeking process (adapted from Lenz, 1984)

According to this model there are three predictors of variation in search behaviour, which include the individual’s background, personality and context. These factors have all been considered by researchers (for example Longo et al., 2010) and appear to impact on health information seeking behaviour, which will be discussed later in this chapter (see section 2.1.5). This model is beneficial in understanding the decision-making process as it highlights stages undertaken, incorporates sources used and the evaluations made regarding appropriateness.

### **2.2.3 Information behaviour**

Wilson’s models of information behaviour (Wilson, 1981; Wilson, 1999) focus on the work environment, consider all age groups and have undergone many revisions. It considers several elements including contextual, role-related and personal factors (see section 2.2.5). In 1981, Wilson’s model of information behaviour identified that a particular need resulted in the individual undertaking information seeking activities, which could take various forms. The individual seeking information used information systems such as on line sources or alternative information sources such as other people. When information was found it could completely or partially satisfy the perceived need, or it may not, which could result in the

individual seeking further information. Wilson suggested that physiological, affective and cognitive needs drive information seeking behaviour, although the model identifies that needs alone do not necessarily result in information seeking. Indeed, factors such as personal, interpersonal and environmental factors might impact information seeking. A revised general model of behaviour (Wilson, 1997) includes factors that potentially affect information seeking, mechanisms that may support as well as inhibit information seeking. The mechanisms incorporate explicit theories from various disciplines to explain why some needs prompted information seeking more than others. These include stress/coping theory: which may explain why some needs result in information seeking and some do not, risk and reward theory: for example some individuals might be motivated to search for information if the risk of not having it appears high, and social learning theory which includes self-efficacy (Bandura, 1986) or an individual's belief in their ability to undertake a particular task, for example searching the internet. Furthermore, Wilson acknowledges four different types of information seeking; passive attention, passive search, active search and ongoing search. Although Wilson (1997) acknowledges that his model is a simplified representation, in reality information behaviour is a non-sequential process. Despite Wilson's focus on the work environment regarding information behaviour, parallels within the health context can be drawn and will be explored further within this chapter.

#### ***2.2.4 The realities of health information seeking***

Previously, health information seeking behaviour has been conceptualised as either active search or avoidance (Miller, 1995). Within the literature reviewed, this dichotomy is starting to shift as an increasing body of knowledge suggests that individuals vary in their information preferences (Germeni & Schulz, 2014; Steinerova & Susol, 2005). Individuals may differ in their approach to health information seeking behaviour, with some limiting a search to information that is perceived as important for self-care and deliberately avoiding additional information (Friis et al., 2003). To address this, Lambert et al.'s (2009a; 2009b) qualitative study explored the differential health information seeking behaviours among individuals following a cancer diagnosis. The rationale for the study stemmed from the lack of research surrounding potential variations in health information seeking behaviour within the cancer context. Lambert et al.'s (2009a, 2009b) study contributes understanding about the complex nature of health information seeking and highlights why individuals make particular decisions regarding when, where, what and how to seek cancer information. They conducted

thirty individual interviews and eight focus groups with thirty-one further participants. They observed a wide range of information seeking behaviours and showed that participants had five patterns of health information seeking behaviour, ranging from intense seekers to individuals who avoided cancer information. Differences were found regarding the amount, type, sources and information management strategies utilised.

The majority of health information seeking research has focused on information seeking behaviour at one point in time (Anker et al., 2011), therefore not exploring change over time. However, some studies identified that information is sought step by step as the illness develops, to reduce feeling overawed by copious amounts of information (Shaw et al., 1994). More recent research (for example Leydon et al., 2000; Echlin & Rees, 2002; Hawkins et al., 2008; Lambert et al., 2009a; Longo et al., 2010; McCaughan et al., 2011; Davison & Breckon, 2012; Matsuyama et al., 2013; Germen & Schulz, 2014) supports this step-by-step approach in response to individuals changing needs, concluding that information-needs fluctuate across the illness trajectory.

### ***2.2.5 Predisposing characteristics of health information seekers***

In itself, an information need is not enough to prompt health information seeking, as personal, contextual factors impact on this. The degree to which individual's seek information is shaped by cultural, educational and financial background. Socio-economic factors impact on ones capability to access resources, information and support, with culture shaping perceptions of the meaning of health and illness (Harris, 1998). Personal factors influencing health information seeking include age, gender, ethnicity, along with socioeconomic factors like occupation, level of education (Johnson, 1997), and psychosocial factors such as personality, skills, beliefs, values, attitudes and individual expectations (Gholami et al., 2014; Matthews et al., 2002).

Disparities have been found in the access to and utilisation of health information. Studies exploring this suggest that younger people (Ayers & Kronenfeld, 2007), Caucasians (Shim, 2008), those with high health literacy (Chen et al., 2013; Mattson et al., 2014) and higher income levels (Ramanadhan & Viswanath, 2006), are more likely to seek health information. When investigating internet usage, a clear demographic portrait has been identified; those with higher education levels (Cotten & Gupta, 2004), higher incomes (Ayers & Kronenfeld,

2007), and female (Jackson et al., 2013) being more prone to seek health information from this source. A tendency within many studies is that these influences are analysed individually, whereas this demographic portrait emphasises the significance of viewing health information seeking behaviour within a personal and contextual framework. Williams et al. (2012) contend that factors, for example, gender, age or class are not distinct categories, they interact with each other to impact on health. Despite this, it is important to consider the research that has explored some of these factors and the impact they have, in order, to build a picture of the health information seeking behaviours of older people.

#### **2.2.5.1 Influences of ageing on health information seeking**

Although there is a need to access health information, little is known about information seeking undertaken by older people. Of the studies that have included older people, there is some disagreement in the literature as to whether age affects patterns of information seeking. However, the dominant theme appears to be that older people are more likely to be non-information seekers (Mayer et al., 2007). Mackenzie et al. (2006) identified that patterns of information seeking did vary with age, showing differences between the young old and older old. However, Shaw et al. (2008) suggested that age did not have an impact; yet this research included participant's information seeking for urinary incontinence, which potentially impacted on findings as this could be perceived as a stigmatised condition. Despite these findings, a systematic review revealed that older people newly diagnosed with cancer had a high level of unmet information needs (Puts et al., 2012).

Generally, regardless of age, individuals would prefer to receive health information from healthcare professionals, rather than other sources (Friis et al., 2003; Kav et al., 2012; Mayer et al., 2007; Rood et al., 2014). Often this information is supplemented by other sources, such as talking to others with similar conditions (Ohlen et al., 2013), especially in families where there was a history of the medical condition (Longo et al., 2010). In the current information landscape, there are numerous channels for individuals to find information on issues relating to health and illness. The mass media plays an important role in health and illness, highlighting products and services available to help individuals negotiate health and well-being, and performs a key role in education regarding health-related issues (Cotten & Gupta, 2004). Longo (2005) suggests that the use of 'traditional print media' should also be considered when investigating health information seeking behaviours.

More recent studies have focused on the internet as a major health information source (for example Manierre, 2015) with a rapidly increasing body of literature focusing on this specific medium. The internet is utilised to gain health information as it is convenient, accessible and has large amounts of information available (Mayer et al., 2007). Kivits (2009) argues that the internet enables individuals to choose information then retrieve and adapt this to everyday health. Individuals accessing health information in this way can avoid a visit to a healthcare professional, as it empowers them within the medical encounter (Hardey, 1999) and allows for information to be sought unconstrained by place and time. A number of studies identify that older people do use the internet to find information (Flynn et al., 2006; Lee et al., 2014; Leung et al., 2007; Lorence et al., 2006; Robertson-Lang et al., 2011; Ybarra & Suman, 2008). However, others have found that age was a significant factor distinguishing internet information seekers and non-information seekers (Cotten & Gupta, 2004; Xie et al., 2013). One recent study suggested that older adults aged 80-93 did not access the internet when considering what should be done about health concerns (Elias & Lowton, 2014). However, over time these differences may change as older people are becoming the fastest-growing population of online users (Robertson-Lang et al., 2011).

When seeking health information on the internet, searches are usually based on specific health conditions and needs (Nettleton et al., 2005). Relationships between the total number of long-term conditions determine internet usage, with one hypothesis being that as the number of long-term conditions increases, uncertainty about health increases, resulting in a greater need for information regarding each condition (Ayers & Kronenfeld, 2007; Rice, 2006). Other researchers (Lambert et al., 2009b; Nanton et al., 2009) suggest that patients with complex health problems typically rely on healthcare professionals to provide information. As the likelihood of suffering from long-term conditions increases with age, this could potentially impact on health information seeking. Tian and Robinson (2008) found that older people diagnosed with cancer differed from younger people in their information seeking behaviour. There were no differences in use of the media and active seeking on the internet when they were seeking information for themselves, but the differences were with seeking information for others, with younger people tending to do that more than older people. However, Ybarra and Suman (2008) found older people were just as likely as younger people to search for health information about personal concerns as for information regarding others. Older research suggested information needs varied according to age, with younger people

wanting to be better informed and participate in the decision-making process (Blanchard et al., 1988) and the older population traditionally taking a more passive stance (Van Der Molen 1999). Although age is a current predictor for health information seeking, this may not continue to be such an important variable, as younger people age they may bring a new approach to health.

#### *2.2.5.1.1 Beliefs about ageing*

Lawton (2003) and Larsson and Grassman (2012) discuss the importance of age and the impact of ill health in later life. Faircloth et al. (2004) proposed that some are able to incorporate the effects of illness into a continuous life-narrative. It has been proposed that this is why older people rate their health as good and described high levels of well-being, despite experiencing severe symptoms (Sidell, 1995). It also suggests that health is both a biological and social experience that is interpreted in the context of everyday lives. Thus, some older people consider certain conditions, such as osteoarthritis to be part of normal ageing, rather than an illness (Grime et al., 2010). Additionally, the older person may wish to portray an image of health and independence either as a form of denial, or to distance themselves from the stereotype of how older people are viewed. As highlighted in previous research, older people cope with health issues by drawing on ageist stereotypes (Laz, 2003), imagery linked to older people having health problems, along with expectations and beliefs related to health in later life (Roberto and McCann, 2011).

As old age is a time when one might expect to experience long-term conditions, for some, illness and disability is viewed as not unusual. Older people build understandings of illness based on underlying assumptions and knowledge acquired via various sources over a number of years. Additionally, as individuals interact with various stages of the life-course, the meaning of different conditions and surrounding illness alters, which potentially impacts on the perceptions held by the individual (Bury, 1991, Bury, 1988). Therefore, older people may anticipate illness as an inevitable consequence of old age and potentially accept this more readily (Pound et al., 1998). Physical frailty and the associated restrictions to activity are framed as realities of ageing with these often accepted as normal aspects of ageing (Clarke and Bennett, 2013). In later life, long-term conditions are integrated into personal accounts of old age as this is a time when health concerns are anticipated, creating a 'discourse of normality' (Faircloth et al., 2004). Research undertaken with older people with certain

conditions, for example cancer (Hubbard et al., 2010, Sinding and Wiernikowski, 2008), heart disease (Husser and Roberto, 2009), stroke (Faircloth et al., 2004) and arthritis (Gibbs, 2008, Gignac et al., 2006, Sanders et al., 2002) found that rather than being disruptive to personal biography these conditions tended to be viewed as normal aspects of ageing.

Age can influence responses to illness as older people's experiences provide them with skills which facilitate coping with a crisis and successful adaptation to altered circumstances (Pound et al., 1998). Neugarten (1968) identified how experiences which conform to normative age expectations assist adaptation, while those which are out of the ordinary, for example, widowhood at an early age, potentially result in poor health outcomes. One explanation could be that if something occurs at an inappropriate life-stage there are no social comparisons available to the person (Murphy and Bennett, 2004). However, in later life, comparison groups are potentially more common due to the prevalence of long-term conditions and the expectation of illness experience. Furthermore, to cope with adverse negative experiences, individuals compare their own experiences in a more positive way to that of others with this evaluation helping to cognitively restructure their experiences (Murphy and Bennett, 2004). Indeed, Laz (2003) and Clarke and Bennett (2013) found that participants tended to compare physical health concerns, positioning their own health problems as less troubling. Although, comparing with others may have a positive impact and be comforting, it may also act as a source of anxiety. McCaughan et al. (2011) found that 'experiential' information was valued by many, with others attempting to evade contact with cancer sufferers as they believed it would have a negative impact on psychological well-being. Sharing personal experiences is an important source of knowledge as those who have a similar experience understand and offer the right type of support and information (Mazanderani et al., 2013). Other research has suggested that shared understanding and the feeling of affiliation are key elements of peer support (Locock and Brown, 2010, Ussher et al., 2006). This is undertaken alongside information gained via other channels such as healthcare professionals. These sources of information combine and provide the individual with their own medical stock of knowledge in order to conceptualise and give meaning to their altered health.

### **2.2.5.2 Culture and gender influences on health information seeking**

There is a wide breadth of evidence regarding gender and cultural influences on health information seeking behaviour. Research has addressed gender (Manierre, 2015) and cultural-based (Lee et al., 2014) disparities in health information seeking behaviour. It is not the purpose of this section to provide an in-depth analysis on the wealth of literature on culture and gender influences. However, its significance as a factor impacting on health information seeking behaviour must be acknowledged. As the literature review was undertaken post data analysis and these aspects did not resonate with the findings from my sample, only the main points will be highlighted. As previously identified (section 2.2.4), there are various factors which interact with each other and impact on health with age, gender and cultural group.

#### **2.2.5.2.1 Cultural influences**

The cultural background of an individual will impact on health information seeking behaviours. Lay health and illness beliefs are socially embedded in the context of the person's lives, and are structured by an individual's culture with ethnic identity having a strong influence, no matter where they are in the life course (Hodgins et al., 2006b). Despite attempts by participants to empower themselves by using the internet, cultural factors remained dominant within a study undertaken by Yu-Chan (2011). Information seeking behaviours have varied between ethnic groups, with Hispanics less likely to access health information than White or Black individuals (Lorence et al., 2006). Differences were found between Whites, African Americans and Latinos, with those Latinos and African Americans who sought information tending to use the information to adapt approaches to maintain health and increase understanding regarding treatment (Rooks et al., 2012). Not only are there differences within ethnic groups, but the various sources that were preferred and accessed varied between groups (Jackson et al., 2013). Research by Yi et al., (2012) found that the views held about the credibility and reputation of sources, influenced selection and perception of quality, with members of the informal network being heavily relied upon.

Not only might cultural background impact on health information seeking approaches, but ethnic minority groups might experience difficulties in communicating health concerns to healthcare professionals. Key barriers such as the difficulties of cultural understanding and communication both impact on health information seeking behaviour and sources selected for information (Yi et al., 2012). Language barriers have been implicated as the largest problem

for ethnic minority groups when seeking health information as this impacts on understanding (Gholami et al., 2014; Ponce et al., 2006).

#### **2.2.5.2.2 Gender**

A number of papers explicated the particular influence of gender on health information seeking behaviour. Several studies propose information seeking differs between men and women, suggesting each gender has distinct informational needs (Jackson et al., 2013; McCaughan & McKenna, 2007). Health information seeking behaviour is more prevalent among women than men (Manierre, 2015; Weaver et al., 2010) with older women tending to utilise healthcare more than men (Glynn et al., 2011). These gender differences in health information seeking behaviours are not unique within the older population. In a sample of younger people with chronic conditions, women were more likely to use the internet to seek health information than men (Suris et al., 2010). Overall, men tend to play more of a passive role (Yogaparan et al., 2009), avoid information, not ask healthcare professionals questions or talk to people within their social network (Leydon et al., 2000).

#### **2.2.5.3 Health literacy.**

An individual's level of health literacy has been highlighted as a factor influencing health information seeking. Evidence suggests that health literacy is a major determinant of health and possibly explains disparities in health status within populations (Smith et al., 2013). Health literacy is used to describe an individual's capability to seek, understand and use health information (Jordan et al., 2010) and is context and content specific (Smith et al., 2013). Nutbeam's (1998) definition (see below) encompasses the cognitive as well as the social skills essential for social interaction and is commonly cited in research:

*'Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health'.*

*'Health literacy means more than transmitting information, developing skills to be able to read pamphlets and successfully make appointments. By improving people's*

*access to health information and their capacity to use it effectively, health literacy is critical to empowerment’.*

(Nutbeam, 1998 p357)

A model of health literacy was formulated by Nutbeam (2000) which features functional, interactive and critical health literacy:

*Functional health literacy* refers to basic reading and writing skills that facilitate knowledge of health risks and use of healthcare services.

*Interactive or communicative health literacy* refers to the social and personal skills and capacity that enable individuals to derive meaning from different modes of communication and to apply this new information to changing circumstances.

*Critical health literacy* refers to the more advanced cognitive and social skills that enable individuals to critically analyse information and also use it to apply more control over their lives.

Presented as a typology, this is highly relevant to health information seeking behaviour, as it reflects the differences in skills necessary to gain and use information in ways that lead to greater knowledge and understanding of health concerns. There is a relationship between the level of health literacy and knowledge, with those possessing higher levels of health literacy having higher levels of knowledge (Johnson et al., 2010). This is also reflected in the sources that individuals use, those with a basic level of health literacy using limited sources to seek information than those with higher-levels of health literacy (Kutner et al., 2006). This impacts on internet usage as those with limited literacy may be unable to understand and navigate websites, employ unsystematic search strategies (Henwood et al., 2003) and have difficulty deciding which websites to trust (Gutierrez et al., 2014). Inadequate health literacy means individuals may not develop skills that enable them to seek, engage with or use health information to promote health. Individuals with limited health literacy may have less understanding and knowledge of health, potentially reducing their autonomy in decision

making and self-care (Erien, 2004). Those with lower health literacy levels are at risk of reduced health outcomes (Sudore et al., 2006) which has been associated with poor management of long term conditions (Edwards et al., 2012).

However, a paradox exists where individuals are able to access more health information than before, but social disparities impact on the ability to access, use and comprehend this information (Protheroe et al., 2008). Protheroe et al. (2009) recommend that health literacy ought to be more clearly accounted for in policy strategies focused on participation in healthcare. They contend that by reaching a group of patients with higher literacy skills and omitting interventions to deal with low health literacy could result in increased health inequalities. Health literacy skills can be developed over time (Mattson et al., 2014) through educational interventions to increase knowledge (Coulter & Ellins, 2007). Indeed, Cho et al. (2008) suggest improving health literacy is potentially the most effective approach to improve health status and decrease hospital use amongst older people. Increased levels of health literacy result in individuals gaining better understandings of health problems, improved self- management, involvement in decision-making (Edwards et al., 2012; Smith et al., 2013) and enables patients to navigate healthcare services (Nutbeam, 2008). Edwards et al. (2012) explored the development of health literacy for individuals of all health literacy abilities through self-learning and education. They adopted a longitudinal qualitative approach comparing individuals with long term conditions following a health education programme and concluded that over time individuals are able to develop health literacy skills and become more active in healthcare consultations.

### **2.2.6 Contextual factors impacting on health information seeking**

It is apparent that many factors shape health information seeking behaviour. These contextual factors incorporate the information seeking context and source of information. Bungay and Cappello (2009) found wide differences in knowledge and understanding about prostate cancer and treatment within a group of older men, with few interested in seeking additional information. Beyond information provided during consultations with healthcare professionals, no further information seeking was undertaken. They concluded that this was due to beliefs about the normal ageing process, the trust they had in health professionals and overall satisfaction with care. Additionally, Lupton (1997) identified that older people were more deferential than younger people to healthcare professionals, suggesting that age and

social class shaped the way that the medical encounter was approached. Leydon et al. (2000) examined cancer patients information seeking, with three overarching attitudes (faith, hope and charity) impacting on searching. Faith related to a belief that the ‘doctor knows best’, with the healthcare professional perceived as an expert, who provided all the necessary information. Faith and trust have been recognised as a common theme impacting on information seeking, with faith in healthcare professionals resulting in patients being less likely to seek information from alternative sources ( for example Bungay & Cappello, 2009; Lupton, 1997; Nanton et al., 2009). Germini and Schulz (2014) conducted a synthesis of published qualitative research and found that trust and the need to maintain hope were two of the five key motivations for seeking information about cancer. Furthermore, studies have identified that for older people searching for information from sources beyond the medical establishment conflicted with their perception of the ‘good’ patient (Lambert et al., 2009b; Leydon et al., 2000; Nanton et al., 2009).

Having considered some of the individual factors that influence health information seeking, the next section explores help-seeking and illness behaviour and how this impacts on health information seeking behaviour. Health and illness behaviour can be conceptualised as the outcome of a decision-making process with health information seeking behaviour as an integral part of this process.

### **2.3 Health and help seeking**

Access to health information impacts on both health and illness behaviours. It is clear that health information seeking behaviour varies amongst individuals, with seeking information about health not always undertaken as a result of illness. Health seeking behaviour is distinct from help seeking behaviour in that it occurs when a health problem may or may not be present and includes the range from actual to potential health concerns (Cornally & McCarthy, 2011). Therefore, for older people this could be when there is a perceived susceptibility to illness and a risk of developing a health problem as a result of ageing. So, the concept of health seeking behaviour incorporates behaviours that include lifestyle changes, disease prevention and can be undertaken when asymptomatic.

### 2.3.1 *Illness behaviour*

Health information seeking behaviour is often undertaken in response to symptoms and is integral to illness behaviour and help seeking. Information seeking in response to health concerns allows people to assess whether they need to seek medical advice or self-manage the condition. Mechanic and Volkart (1960) coined the term illness behaviour, which has been defined as:

*'the varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilise various sources of formal and informal care'*

(Mechanic, 1995 p1208).

From this perspective, illness behaviour is a social construction and socio-cultural in nature, which offers explanations as to how recognition, presentation and outcome of diseases can be largely influenced by the individual's response to symptoms. Patients understand illness differently from doctors, who adopt a bio-physiological approach which is limited as it ignores the social dimensions of illness (Mechanic, 1995; Young, 2004). Unifying these dichotomies could potentially impact on improving medical outcomes, and to facilitate this healthcare professionals should acknowledge and appraise illness behaviour from the patient's perspective and make appropriate responses (Sirri et al., 2013).

A review by Young (2004) regarding illness behaviour identified that literature from a range of disciplines has strived to understand the factors influencing service utilisation. Within this, two divergent sociological approaches have emerged, the 'dominant' and 'dynamic' approaches. The 'dominant' positivist approach examines variations in the characteristics of users and non-users of healthcare. A profile of service-users is presented which identifies tendencies to help-seek which predicts patterns of healthcare usage (Rosenstock, 1966). Healthcare utilisation is thereby accounted for by broad structural, psychological or demographic factors acting as facilitators or barriers, sometimes presented as a cost-benefit analysis (Pescosolido, 1992). For example, in the socio-behavioural model (Andersen, 1995), individual factors and the societal system impact on decisions regarding help seeking with the underpinning assumption that individuals share beliefs by virtue of socio-demographic variables. From this perspective, seeking help is governed by structural and practical factors,

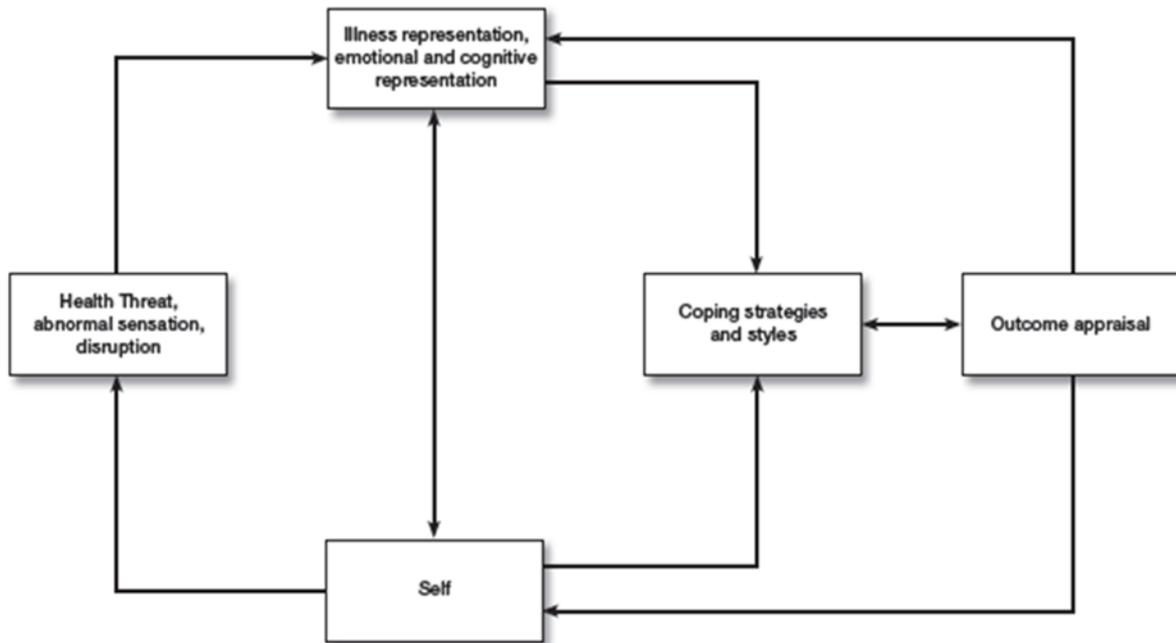
such as cost and access. Critics of this conceptual framework suggest that more consideration should be given regarding the processes via which individuals interpret symptom-meaning and choose treatment options (Leventhal et al., 2004) and the subjective experience of illness (Pescosolido & Kronenfeld, 1995). Critiques of this approach (Dingwall, 2001; Pescosolido, 1992) have resulted in more dynamic conceptualisations, which identify illness behaviour as part of a wider, socially-embedded 'illness career'.

The 'dynamic' models postulate that there are a series of stages the individual must navigate as they cope with illness (Suchman, 1965), however these models have been criticised for being rigid, behaviourist, linear and for giving primacy to medical perspectives (Biddle et al., 2007; Young, 2004). In psychology, these models are represented by the Self-Regulation Model of Health and Illness (Leventhal et al., 1998) and in sociology by Dingwall's interpretivist model of illness action (Dingwall, 2001) and Pescosolido's network-episode model (Pescosolido, 1992), which suggest that illness is understood and dealt with via cultural routines and social interactions. Illness behaviour is conceptualised as an interactive social process that is context-bound and shaped by agency and social networks. Illness behaviour is multi-faceted, a multi-staged process embedded in daily experiences involving a number of strategies including consulting others. Within these conceptualisations, the focus is on the process along with the outcome of decisions (Biddle et al., 2007).

#### **2.3.1.1 Self-regulation model**

The notion of illness representation was conceptualised by Leventhal et al., (1984), in the self-regulation model of illness behaviour (also referred to as the common sense model) with the representation guiding behaviour which is directed at managing the condition. Leventhal et al.'s (1997) self-regulation model (see figure 2) captures and incorporates emotional processes, decisions as dynamic and incorporates feedback methods for appraising progress (Cameron and Leventhal, 2003). Disruptions challenge the integrity of the self, and to manage illness it requires the regulation of aspects of the self, particularly emotional and physical states. The model proposes that illness behaviour depends on the individual's perception or representation of the illness, when activated, an illness representation prompts behavioural and cognitive attempts to reduce health threats (Leventhal et al., 2001). The model examines the factors involved in the processing of information regarding an illness, how the information is integrated and how this directs coping behaviours and outcomes.

There is the assumption that health related behaviours are the product of complex, multi-faceted representations of illness with individuals actively constructing representations of the health threat or illness.



The self-regulation model adapted from Leventhal et al (1997)

Figure 2: The self-regulation model

Illness representations are schemas and share central constructs that form elements of the layperson's disease model: cause, consequences, identity, timeline, cure or control (Leventhal et al., 1984). These illness beliefs not only act as a framework for interpretation of the illness threat, but they direct prospective illness related behaviours, determine coping, appraisal of outcomes and adjustment. These constructs have been explored regarding various illnesses, and appear influential in determining emotional well-being and health behaviours (Sharpe and Curran, 2006). Additionally, the constructs have been associated with disease management behaviours with a clear relationship between illness cognitions, coping behaviour, and illness outcomes being evident (Hagger and Orbell, 2003). Information

provision fosters a sense of understanding, impacts on illness perceptions which is important as positive illness perceptions have been associated with improved health related outcomes (Zoeckler et al., 2014). As the identity of the disease involves both the abstract knowledge (label) and concrete experience (symptoms) this can impact on the illness representation and how the illness is managed. Furthermore, a label is important for the individual as it provides definite ideas on the other elements of the self-regulatory model, for example timeline. However, the utility of the model has been questioned if ‘identity’ is not achieved (Williams and Healy, 2001) and without a distinct label, views on other aspects of the illness can result in uncertainty (Green et al., 2004).

Illness representations direct the choice of actions to eradicate and control possible or on-going threats (Leventhal et al., 2003). At this stage, a choice of action could be to seek further health information, in an attempt to gain further knowledge about the disruption and to make sense of this, as seen in figure 4 (see 4.1). Fundamental to self-regulation theory is the relationship of illness representations to coping responses. Representations guide the formation of coping procedures aimed at problem solving and emotional management, with the appraisal of coping outcomes used to adjust representations and other coping efforts (Cameron, 2003). Problem focused coping prevails when it is perceived that something constructive can be done, whereas emotion focused coping prevails when it is perceived that the situation is one that must be endured (Carver et al., 1989). The final stage is ‘appraisal’ where the individual evaluates their coping strategy and considers whether to continue or to adopt another strategy. Individuals actively appraise the efficacy of the coping strategy and incorporate this information into the representation (Leventhal et al., 2003).

### ***2.3.2 Help seeking behaviour***

Part of illness behaviour is the process of ‘adaptation’ to symptoms (Mechanic, 1968) with help-seeking being a response to illness often used in conjunction with accommodation, coping and self-care (Dingwall, 2001; Mechanic, 1968). Help-seeking is a multi-stage social process where the individual’s pathway is explored. This includes how symptoms are interpreted and managed by individuals and groups, recognising a need for action which normally results in help from a healthcare professional (Horwitz, 1977; Liang et al., 2005). Throughout this process, various sources of health information might be accessed and impact on the decision-making process. The first step within the process of help-seeking is lay

diagnosis which may be affected by denial, delay and normalisation (Dingwall, 2001; Freidson, 1970; Suchman, 1965; Zola, 1973) with the individual's perception of the symptoms being integral (Mechanic, 1978). Symptoms are constructions based on lay explanatory models, experiences and cognitions which help the individual to make sense of illness episodes (Armstrong, 2000). Illness behaviour and responses to symptoms reflect a blending of accumulated understandings with available resources that are similar to a 'bricolage', described as a construction assembled from various available and accessible materials (Stoller et al., 2011). Within research, variations in lay explanatory models are evident, suggesting that individuals with similar symptoms exhibit variations in symptom perceptions and response, with this predicting ensuing behaviour (Corner et al., 2006; Sirri et al., 2013). In later life, due to past experiences, individuals develop and build strategies to manage illness, resulting in someone who might be very knowledgeable about treatment regimens that work well for them (Charmaz, 2000a).

Finally, help seeking behaviour can result in health service utilisation (Thorstensson et al., 2009). Selecting the source of care and timing is shaped by the characteristics of the social and cultural context (Kleinman, 1980; Mechanic, 1995). However, some studies found that for certain conditions, individuals select other forms of help away from formal healthcare (Kleinman, 1980). Currently there are many choices available, although formal healthcare appears to be the preferred option (Coulter, 2011; Henwood et al., 2003; Lambert et al., 2009a). These selections are influenced by past experience of services and practitioners, which shape the service chosen to be accessed (Hunter et al., 2013).

### **2.3.2.1 Factors impacting on help-seeking behaviour in later life**

Many factors influence help-seeking in later life, Sirri et al. (2013) identified three key determinants of illness-behaviour which could potentially impact on health information seeking behaviour. These are 'Doctor-related variables' such as communication skills (Clark et al., 2012), 'illness-related variables' for example characteristics of the illness (Mechanic & Volkart, 1960) and, as discussed previously (section 2.2.4), 'patient related variables' such as gender (Galdas et al., 2005), concerns about being a burdensome patient (Clark et al., 2012) and cognitive representations (Leventhal et al., 2003). Figure 3 provides a general overview of information-seeking in the context of health; highlights predisposing characteristics,

illustrates the factors associated with participating in health information seeking and the associated outcomes.

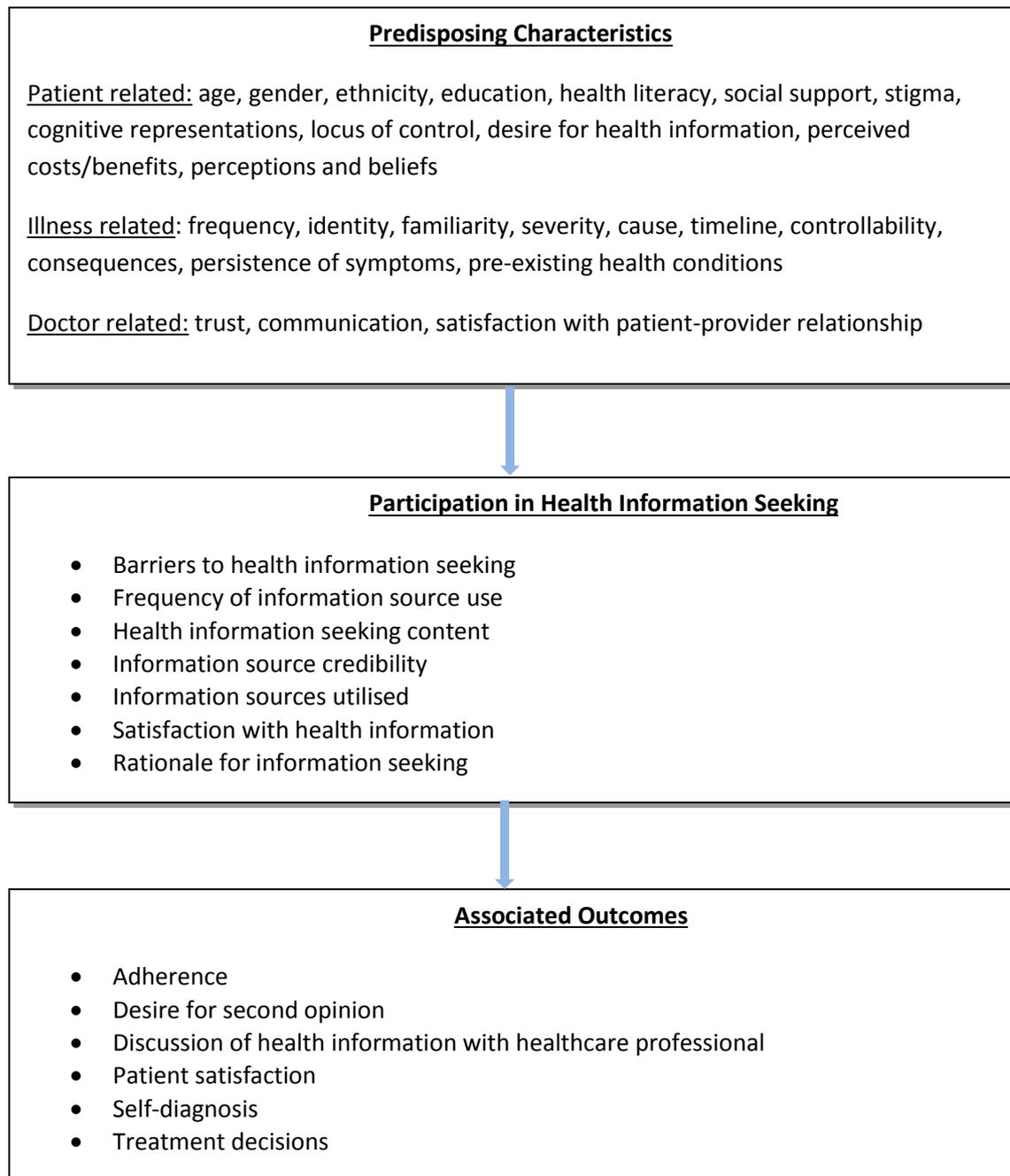


Figure 3: General overview of information seeking in the context of health. Adapted from Anker et al. (2011).

### ***2.3.2.1.1 Informal social support networks***

Included within the ‘patient-related variables’ category influencing help seeking, is the impact of social support. The influence of the individual’s social network is a key component of illness behaviour with help-seeking shaped by the nature and structure of these networks (Horwitz, 1977). Social networks influence virtually all stages of the help-seeking process from symptom perception, illness experience, lay referral system and health service utilisation (Freidson, 1970; Lawton, 2003; Mechanic, 1995; Zola, 1973). Freidson (1970) used the concept of the ‘lay referral’ system to explain help seeking, which has two elements: ‘lay culture’ and ‘lay referral structure’. It is within the context of lay culture that the term illness gains a social meaning with its interpretation potentially impacting on help seeking. In order to make sense of symptoms and decide on actions that need to be taken, it is common to seek advice from informal sources, often from the social network (Clarke, 2010). Support is also provided by the exchange and provision of information which potentially acts as a coping mechanism and impacts on the appraisal of symptoms (Shaw, 1999).

Symptoms can lead to physical and social limitations which are experienced as a source of personal disruption, sometimes leading to individuals’ rearranging their social networks with the absence or presence of a supportive network impacting on disruption (Bury, 1988). Certainly in the field of ageing studies, the importance and significance of social networks, particularly family relations has been highlighted as an area of interest (Phillips et al., 2010). Social network approaches have captured the various family, friends and neighbour relationships available to older people with the importance of family highlighted (Antonucci & Akiyama, 1991). Indeed, spouses play a key part in the process of reconstructing a person’s identity, including minimising or denying failed everyday performances (Corbin & Strauss, 1987).

### ***2.3.2.1.2 Stigma impacting on help seeking***

Along with age and associated beliefs, it appears there is a complex interface with factors other than age impacting on the help seeking process. A key issue that may preclude help seeking behaviour is the stigma associated with certain long-term conditions and potential causes of the condition. The significance and meaning of the illness and different conditions have varying connotations (Bury, 1991), which depend not only on the individual’s culture

and how they regard themselves but also how they perceive others views of them (Bury, 1982). These views potentially impact on whether there is a delay in seeking help. It is widely acknowledged that healthcare professional's should be non-judgemental about patients and their lifestyle choices, however research suggests value judgements are made as to whether the patient is to blame for their condition (Nettleton et al., 2004). Within Western culture, there is an expectation that individuals take responsibility for health, adopt healthy lifestyles and look after their bodies (Lupton, 1995), which impacts on the individual's beliefs about who is to blame for the disease. Awareness of one's vulnerability to ill health is increased by screening programmes and media campaigns, which may result in individuals sensing personal responsibility for preventing illness through control of the body (Lupton, 1995).

An issue highlighted by Scambler (2009) concerned the concept of stigma regarding certain conditions which could impact on help-seeking. When individuals encounter stigma associated with a health concern, they are more inclined to delay seeking medical care (Ahmad et al., 2009). Indeed, Biddle et al., (2007) conclude that normalisation and stigma were key reasons for non-help seeking and were pivotal to illness behaviour. Shaw et al. (2001) suggested that some symptoms frequently experienced by older people were stigmatising and subsequently ignored, for example incontinence and urinary symptoms. Furthermore, if it is perceived that unwise lifestyle choices have been made, it can lead to them being secretive about their medical condition and medical symptoms that are experienced. Chapple et al. (2004) examined how participants with lung cancer experienced and perceived stigma. They suggested that stigma influenced decisions to disclose and fear of this prevented them for seeking support, especially medical support. A further study by Corner et al. (2006) found stigma was an issue with regard to smoking and lung cancer with some participants perceiving themselves as undeserving of medical care if they smoked, impacting on their life expectancy as it led to non-help seeking.

## **2.4 Social construction of old age**

The following section discusses the social construction of old age. When exploring health information seeking behaviours amongst older people it is important to consider how later life alters in character, as this can impact on the lived experience of old age.

### ***2.4.1 Changing perspectives of later life***

Demographic, epidemiological, policy and social changes have impacted upon and transformed the context of ageing, iteratively shaping the contemporary experience of ageing. In tandem with these changes, how old age is perceived can also impact on the lived experience of later life. Notions of what ageing and old age are, have correspondingly been de-established with the experience of later life altering in character from the one experienced by previous cohorts (Rees-Jones & Higgs, 2010). Historically, during the modern period, against a backdrop of population, social and cultural change, frameworks to approach and understand ageing were developed. The functionalist-structuralist paradigm was dominant at this time, with ageing considered as an individual and social problem. This model complemented the biomedical perspective on ageing, with both contributing to the construction of ageing as a social and medical problem (Estes & Binney, 1989) by focusing almost exclusively on the problems of later life and reinforcing a negative portrayal of ageing. The problematisation and medicalisation of old age led to the development of ‘disengagement theory’ (Cumming & William, 1961) which argued that older people withdrew from social roles as they aged, emphasising the mutual benefits that disengagement brought to society and themselves. These theories reinforced the message that older people are a social problem having limited value and declining status. Accompanying these, also based on a functionalist-structuralist paradigm was ‘activity theory’ (Havighurst, 1957) a less negative approach which postulated the importance of keeping older people as active as possible.

Changes such as earlier retirement, meant that old age was reconstructed into a broader category, thus becoming less distinct (Walker, 1999). This resulted in later life becoming a stage in the life-course open to negotiation instead of being controlled by institutions of the state. Additionally, more resources meant that many people were able to shape their retirement facilitating engagement with ‘contemporary lifestyle culture’ (Rees-Jones &

Higgs, 2010 p9). However, this is not available to all as a number of older people lack the resources in social and economic terms to adopt this life choice.

There has been a gradual shift away from an individual-level focus with older people being viewed as a social problem, to ageing being constructed as a global issue and concern (Palacios, 2002). Culturally there is an emphasis on the importance of independence, self-determination and autonomy (Victor, 2010). Havighurst (1961) initially coined the concept of 'successful ageing' which has since evolved to develop multiple theories of successful ageing (Baltes & Smith, 2003; Rowe & Kahn, 1997). 'Successful ageing' signifies a period of potential health and well-being, measured by objective indicators such as absence of disease, high cognitive and physical functioning and active social engagement (Rowe & Kahn, 1997). The subjective dimension is important as older people may define themselves as healthy irrespective of objective indicators (Blaxter, 1983). Also, a disease free older age is unrealistic for most people, with the concept placing an emphasis on responsibility for individual health and well-being and potentially marginalising those without access to resources. The term 'success' is usually associated with material and/or economic achievement (Peel, 2004) with the concept of ageing better situated on a continuum of achievement rather than being dichotomised into failure or success (Bowling, 1993; Bowling & Dieppe, 2005). So, it could be argued that the word 'success' is inappropriate for expressing positive outcomes in later life.

Although there is considerable overlap between concepts such as 'successful', 'productive' and 'active' ageing, it has been suggested that the term 'healthy ageing' proposes an increasingly positive perspective on health and well-being in later life (Cutchin, 2005) and recognises that these are central to quality of life issues (Bryant et al., 2001). However, the term 'healthy ageing' has also been disparaged for the potential of unsuccessful ageing (Li-Wen et al., 2010), producing feelings of inferiority or guilt (Ebrahimi et al., 2013). Against a backdrop of population, social and cultural change, resilient ageing provides a useful framework to approach and understand ageing and facilitates a new perspective on ageing. Instead of viewing the ageing process with a restricted focus on the outcomes of ageing using terms such as productive, healthy and successful, resilient ageing reinforces ageing as a process with resilience being the preferred way to move through the ageing process. Resilient ageing can be applied to older people irrespective of age or medical condition, with adversity a necessary antecedent (Hicks & Conner, 2014). Resilient ageing has the three core attributes

of coping, self-concept and hardiness and is a process that combines all of life's experiences, which considers the role of social resources. There are three protective factors, which are antecedents and reduce vulnerability from the hazards of adversity, and consist of life experiences (Bennett, 2010), social support (Dorfman et al., 2009; Wiles et al., 2012) and activity (Stark-Wroblewski et al., 2008).

## **2.5 Policy context**

The next section goes on to explore key health policies relating to health information with regard to encouraging individuals to be active, self-caring and informed.

### ***2.5.1 An overview of the policies***

Key to UK health policy are the concepts of the informed patient, self-care, self-management and empowerment, which allows individuals to make informed choices and gives rights and control over their health and care (Department of Health, 2006). Darzi (Department of Health, 2008a) emphasized that empowering patients to make care choices increased the likelihood that they would take responsibility for their health with knowledge about health risks providing the opportunity to make better choices. The notion of patient choice in healthcare, healthcare provider and treatment is a key focus and represents a cultural shift in the National Health Service (NHS) with government claiming to be committed to individuals being active participants in care (Department of Health, 2010d). With this largely concerned with patient choice few suggestions were included regarding how shared decision-making would be implemented (Gregory et al., 2012). However, to exercise choice does also depend on the person being an active consumer, able to make informed-decisions (Higgs, 1995). Major structural changes in England within the healthcare setting were implemented in April 2013 (Health and Social Care Act, 2012) with critics claiming the main logic behind these reforms was to intensify the role of competition and choice (Gregory et al., 2012). This is set against a backdrop of providing patient-centred, high-quality care against increasing demand, demographic changes and financial constraints.

### 2.5.1.1 Shared decision making

Policy has led to a consumer-driven healthcare system with a mounting expectation that there is more involvement in active medical decision-making (Department of Health, 2010a). Building knowledge increases ownership of decisions made, focusing more responsibility on individuals to be active participants (Department of Health, 2012c). Shared decision making is anticipated to be the norm with the *White paper Equity and Excellence: Liberating the NHS* (Department of Health, 2010a) promising ‘no decision about me without me’, encapsulating a drive towards a more patient-centred healthcare system that encourages shared decision making.

Policy makers endorse shared decision-making as it potentially expands the use of treatment options, reduces utilisation of treatment choices without clear benefits, diminishes disparities in healthcare delivery and encourages patient-participation in health (Légaré et al., 2010). Patient involvement in decision-making is advocated for various reasons with the failure to provide information and to involve patients’ in their care highlighted in the Francis Inquiry (2013). A recent study by Hunter et al. (2014) within the primary care setting observed that when healthcare professionals provided information regarding behavioural change for patients with long-term conditions, they did not engage in discussion but adopted diffident and deflecting styles. If patients are involved in treatment decisions, they are more likely to start and maintain treatment, which increases adherence and impacts on outcomes of care (Montori et al., 2006). Ethically, as a fundamental right, patients should be involved in their healthcare as they have the right to be informed and give consent for treatment (King & Moulton, 2006).

A critical element of shared-decision making is the establishment of an on-going partnership with the patient-provider relationship being central in the process of sharing decisions (Dy & Purnell, 2012) and agreeing on management decisions (Muller-Engleman et al., 2011). Shared-decision making has been inconsistently accomplished in practice due to a range of structural, preparatory, predisposing and interactional factors (Joseph-Williams et al., 2014). Specifically facilitators and barriers to shared decision-making include patients undervaluing their expertise (Aasen et al., 2012), varying patient preferences for active involvement (Charles et al., 2003; Ekdahl et al., 2010; Henwood et al., 2003) and practitioners attitudes to the implementation of shared decisions (Edwards et al., 2009).

Furthermore, a decision is not always made exclusively in the medical encounter, but against a backdrop of social and cultural contexts that will be inextricably connected to the decisions made. A study by Pinguart and Duberstein (2004) found that participation of older people has not increased over time, with a further study suggesting variation in patients' wishes to participate (Eldh et al., 2006). Some have suggested that older people would prefer to hand over responsibility to their doctors (Pinguart & Duberstein, 2004; Reed et al., 2008), with another study finding that older people wish to participate (Kim et al., 2008). The relationship between healthcare professional and patient seems to be crucial to the process. Partnership working between patients and healthcare professionals is essential (Crisp, 2012), with healthcare professionals being cognisant of patient preferences (Thorne et al., 2013). However, it should not be assumed that all members of society wish to be involved in shared-decision making, some preferring to be managed by healthcare professionals.

#### **2.5.1.2 Utilising unscheduled care**

Current policies are aimed at integrating services for long-term conditions and enabling patient choice in service provision (Department of Health, 2008a). When combined with shared decision-making to maximise self-management this potentially reduces unscheduled admissions (Gregory et al., 2012). Alongside the multiple care choices available, health policy strives to shape and inhibit individual's care decisions to ensure that the service accessed echoes the level of medical need (Hunter et al., 2013). Currently older people use unscheduled care more frequently than younger people (Gruneir et al., 2011). Increases in emergency admissions among those with long-term conditions and emergency bed use in over 65 year olds (Hunter et al., 2013; Simmonds et al., 2014) suggests that the NHS is not doing enough to support people to remain well at home and cared for in the community. Decreasing the number of avoidable hospitalisations offers opportunities for enhancing quality of life and cutting healthcare spending (Freund et al., 2013). Emergency admissions among those with long-term conditions that could be managed in primary care cost the NHS £1.42 billion annually and could be reduced by 8-18% by investing in community-based and primary services (Tian et al., 2012). Hospitalisation for ambulatory care-sensitive conditions are theoretically avoidable through the effective management of long term conditions, prevention of the onset of diseases and by control of an acute episodic illness (Rosano et al., 2013). Specifically, UK policy advocates that unscheduled care should be reduced for those with long-term conditions by establishing alternative care pathways in primary care (NHS

Employers, 2011). Indeed, a systematic review by Huntley et al. (2015) concluded that continuity of care within primary care impacted on Emergency Department (ED) use.

To prevent the use of unscheduled care, healthcare professionals play a key role in the management of people with long-term conditions (Department of Health, 2005c) with the provision of information and care to prevent or manage health crises being integral. Health policies have been guided by the assumption that patients lack knowledge to select services (O'Cathain et al., 2008) or manage health-needs successfully within the community (Gateley et al., 2007). Consequently, policies stress shaping individual's use of appropriate services through education to attend to this alleged gap in knowledge (Department of Health, 2010b). However, the assumption that an individual needs education to make appropriate choices should not be accepted at face-value as other factors impact on decisions and choices when selecting healthcare services. Like every healthcare decision, unscheduled care is selected in a social and cultural context (Huntley et al., 2015; O'Cathain et al., 2008) shaped by perceptions of urgency, access, influenced by prior responses from healthcare professionals and people within the social network (Hunter et al., 2013). From the patient's perspective, unscheduled care is perceived as an appropriate and integral part of the management of long-term conditions and complements routine care (Rees-Jones et al., 2008). Lay ideas about treatment and cause are drawn from the biomedical professional system, but are reinterpreted and integrated into the belief system of lay people in the context of everyday life. A review of qualitative studies of healthcare use with patients with long term conditions identified that patient's use of emergency unscheduled care was shaped by previous experiences of healthcare and reflected values ascribed to the various services (Langer et al., 2013). Additionally, psychological factors may impact on an individual's decision-making as to when to utilise unscheduled care or decrease the ability to cope in emergencies.

### **2.5.1.3 Promoting self-care policy**

It is important that individuals have high quality information due to the increased emphasis on self-management for people with long-term conditions and personal responsibility to maintain health. Older people are living within a society where citizens are encouraged to take greater responsibility for health (Higgs, 1995). Previously, self-care had been viewed as inferior to the care provided by a healthcare professional, however increasingly there has been a shift as individuals attempt to take more control over their health (Nettleton, 2006) and

self-care becoming firmly embedded within the political agenda. The coalition government planned changes which took forward reforms set out by the previous Labour government (Department of Health, 2005a, 2005b, 2007, 2008b) with the promotion of self-care remaining a major strand of health policy. Current policies are layered on top of previous policies that advocated increased use of services for the management of common ailments (Department of Health, 1996) and promoted self-care when self-limiting illness was indicated (Department of Health, 2000a). However, this strategy may also have a detrimental effect on health if individuals delay seeking healthcare for a potentially serious condition or if they are encouraged to self-manage health inappropriately. Critics have proposed that self-care could be a pretext to control costs (Wanless, 2002), as a driver to decrease demand (Poortinga, 2006), but reduces professional care leading to some patients feeling abandoned (Kielmann et al., 2010). It has been proposed that a barrier to self-care is the NHS system itself, as those entitled to free prescriptions may seek help for minor illnesses from a healthcare professional rather than purchasing medication from a pharmacy (Rutter, 2012).

Maximizing an individual's capacity to self-care is a key component of governments endeavour to control the demand for healthcare. By investing resources into health information, the outcomes might lead to an increase in self-management of long-term conditions, and potentially impact on costs and service use. However, self-care is not just an alternative to seeing the healthcare professional, it can also be as a supplement to formal healthcare (MacKichan et al., 2011). It has been suggested that better self-care support could significantly decrease GP consultations, Emergency Department visits, hospital admissions and outpatient visits (Department of Health, 2005b, 2010b). In tandem with the drive for individuals to self-care, there has also been the development of primary care teams and new services (such as nurse-led NHS walk-in centres) resulting in an increase in the range of healthcare professionals available to provide health information.

Despite these policy imperatives, there appears to be little evidence to support the role that health information seeking behaviour can play. The following section outlines limitations of previous studies, focusing on older people and health information seeking behaviour and identifies gaps in knowledge regarding this.

## **2.6 Limitations of previous health information seeking behaviour studies and gaps in knowledge**

Health information seeking is a complex process. With a policy agenda focused on self-care, shared decision-making and reducing the use of unscheduled care it is clear that access to health information can play an important role. Furthermore, despite considerable sociological research on how people live with long-term conditions, the impact of biographical disruption; the role of information seeking within this, particularly for older people, has been neglected. While there has been some work on how older service users become informed about their health, there has been relatively little research on the health information seeking behaviours of people as they age. Studies are mainly with mixed ages and tend to be disease-focused (Lambert & Loisele, 2007) with limited consideration of health information seeking behaviour undertaken in health and when asymptomatic. As a result there is an incomplete understanding of health information seeking behaviour in the different stages of health and illness. Health information seeking appears to cluster into patterns, with information gained from active searching and through passive exposure within the environment, and in order to comprehensively understand this further research is needed.

A limitation of some previous studies (for example Tak & Hong, 2005; Hardt & Hollis-Sawyer, 2007; Wong et al., 2012; Chang & Im, 2014) is their reliance on quantitative evaluations of information seeking using questionnaires, survey or structured interviews (Anker et al., 2011). Whilst these methodologies provide vital information about the characteristics of seekers, they can only provide a 'snapshot' of how information is commonly sought; a qualitative approach provides insights into the process. Longitudinal methodologies follow the health information seeking behaviours of individual's over time and explore the influences of a disease progression on information seeking behaviour. Hawkins et al. (2008) tracked the perceived adequacy of health information for cancer patients pre and post diagnosis, finding that health information was required throughout the cancer journey, with information needs changing. This suggests that health information needs change and a qualitative approach can facilitate the exploration of the older person's unique experience of health information seeking behaviour.

A further limitation of prior studies regarding health information seeking is that samples have been recruited from clinical settings. The recruitment of participants within the healthcare setting, captures a population with access to a healthcare professional as an information

source (Denberg et al., 2005). Far less is understood about individuals outside this environment who might use information sources other than healthcare professionals. Indeed much information seeking is undertaken away from the clinical setting (Longo et al., 2010; Rutten et al., 2005) and by neglecting this it is difficult to view the complete picture of information seeking. Collecting everyday experiences of information seeking can prove challenging as it may be sporadic, changes over time (Hawkins et al., 2008; Longo et al., 2010; Matsuyama et al., 2013) and in various contexts. In order to gain an insight into information seeking behaviours, further research should be undertaken in non-healthcare settings.

## **2.7 Conclusion**

This chapter has explored the literature relating to health information seeking behaviour and considered factors impinging on this process. Health information seeking is integral to help seeking and illness behaviour. Various sociological approaches have been proposed by theorists considering illness behaviour, with dynamic models more appropriate for considering the subjective experience of illness embedded in daily life. Help seeking is a strategy employed in response to illness behaviour and relies on interpretation of symptoms, and based on these may impact on behaviour. Previous studies have identified the importance of considering both social and medical aspects of individual's lives. Health information seeking behaviour is a strategy that can be employed to facilitate coping with changes in health and can help increase knowledge regarding altered health status. The next chapter will present a consideration of the research methodology and methods drawn on to address the aims of the study.

## CHAPTER THREE

### RESEARCH METHODOLOGY AND METHODS

#### 3.0 Introduction

This chapter is divided into two sections. The first section focuses on the methodological approach adopted for this study. Rationale is provided for adopting constructivist grounded theory as the philosophical and methodological framework. This decision is based on the aims of the study, the lack of previous qualitative research undertaken exploring the health information seeking behaviours of older people, my constructivist philosophical stance and the broad research question which is:

*What are the health information seeking behaviours of older people?*

The philosophical underpinnings of constructivism will be discussed and grounded theory methodology will be explored by providing an historical overview and summary of the debates surrounding the use of grounded theory. The second section of this chapter will focus on the methods used for data collection, data analysis, ethics and rigour. To start with, rationale for the research focus will be provided.

#### 3.1 Research focus

As discussed in the previous chapter, there have been a number of key health policy initiatives focusing on the concepts of the informed patient, self-care, self-management and empowerment which encourages individuals to make informed choices and purports to give them rights and control over their own health and healthcare (Department of Health, 2006). Within this context, service users are actively encouraged to make decisions and choices about their healthcare in an informed way. To facilitate this process it is important to gain an understanding of the health information seeking behaviours of older people to ascertain their current level of involvement. This is particularly important as older people are the major users of healthcare services in the UK (NHS Choices, 2012). By exploring this specific population it will help to reveal how health information is sought with regards to on-going health conditions and will provide a greater depth in understanding the health information

seeking process. While there has been some work on how service users become informed in their health care, there has been relatively little previous research specifically on health information seeking behaviours of people as they age, and these studies are mainly with mixed ages and tend to be disease focused (Lambert & Loiselle, 2007). Indeed, no study has been found that explores variations in health information seeking behaviour of older people. This study was designed to address this gap in knowledge.

### **3.2 Philosophical viewpoint**

Demonstrating a clear understanding of philosophical principles helps to increase the robustness of a research study (Appleton & King, 2002). Philosophical foundations are important as they underpin the views that are taken, help shape the nature of the research, identify what is viewed as worthwhile evidence and clarify the conclusions that can (or cannot) be made (Denscombe, 2010). Cresswell (2007) argues that it is important for researchers to make explicit their assumptions and be aware of their impact on the research. The following section will explore the underpinnings of the philosophical approach that I have adopted and identify why this is appropriate for this study.

#### ***3.2.1 The constructivist paradigm***

The constructivist paradigm has shaped the study design and interpretation of findings. The main principles of qualitative research viewed through a constructivist paradigm are highlighted below and will be explored in greater depth:

- Focusing on the phenomena and the building of meanings that follows (Crotty, 1998; Lincoln, Lynham, & Guba, 2013)
- Includes the researchers perceptions and their knowledge of the research area (Charmaz, 2006, 2014)
- Emphasis is on the importance of the unique experience of the individual (Cresswell, 2013; Crotty, 1998)
- Multiple views of reality with regards to what constitutes knowledge (Charmaz, 2013; Corbetta, 2003)
- Emphasis is on how each person makes sense of the world and is as valid as the next persons (Lincoln et al., 2013).

- The data is co-constructed, which means that the participant and researcher produce knowledge together (Charmaz, 2013; Denzin & Lincoln, 2013; Mills et al., 2006b)

### 3.2.1.1 Defining constructivism

Constructivism has its origins in naturalistic inquiry first discussed by Lincoln and Guba (1985) and has evolved since their original discussion of the paradigm. Appleton and King (1997) highlighted that one of the fundamental problems for researchers is the lack of a clear definition for constructivism. However, since then Lincoln (2005 p60) has defined constructivism as ‘an interpretive stance which attends to the meaning-making activities of active agents and cognizing human beings’. Lincoln (2005 p61) expands upon these meaning-making activities by identifying two dimensions to an individual’s social life which include the actual and concrete events and the ‘individual mental stances which impute meaning to those events and situations’ which interact with, for example, the individual’s beliefs, values and attitudes. The focus is on the lived experiences of the participants and constructivists are concerned with the social realities that are constructed by individuals as they try and make some sense of situations, communications, events and other people (Lincoln, 2005). A constructivist studies how the participants construct actions and meanings about a certain situation, with the researcher trying to be as close as possible to this, and from these accounts, the researcher constructs theories and concepts (Charmaz, 2013). Therefore, the focus is on the phenomenon and the building of meanings that follows, it points to each person’s experience as being unique (Crotty, 1998), but at the same time embraces the researcher’s own perceptions of these phenomena (Lincoln et al., 2013).

### 3.2.1.2 Ontology

Within the constructivist paradigm multiple and intangible realities exist (Guba & Lincoln, 1994), the focus is on understanding how the participants construct actions and meanings about a certain situation which is dependent on what they believe to exist (Wainwright, 1997). Ontologically, constructivists believe that reality is constructed through the ‘interaction of the creative and interpretative work of the mind with the physical/temporal world’ (Paul, 2005 p22). There are two realities which exist alongside each other, and they interact and influence each other in ways which are difficult to control, anticipate, or completely understand; the physical/temporal reality which is made up of tangible objects and the constructed reality which relates to activities which create meaningfulness and

order within life (Lincoln, 2005). So it can be seen that these realities are multiple, that they may be conflicting, and are dependent on the individual who holds the construction and the meanings attributed by the individual. Constructivists emphasise the importance of 'verstehen' which involves the understanding of beliefs, opinions and behaviour from the participant's perspective (known as the insider's perspective) which according to Denzin and Lincoln (2013) is one of the reasons why qualitative research is conducted. As each individual's experiences and the context within which they occur are viewed as valid and integrated into the constructions, the researcher aims to acquire a consensus of views, but at the same time explores different or contradictory constructions of reality (Appleton & King, 2002). However Wainwright (1997), a critical realist, argues that constructivism produces only a superficial understanding of individual action because it ignores constraining and enabling structures and mechanisms. The constructivist philosophical viewpoint is different from the critical realist and it states that the multiple realities that exist are not controlled by natural laws or by 'structures that exist independently of us' (Bhaskar, 1975).

### **3.2.1.3 Relativism**

Wainwright (1997) argues that the constructivist ontological position is really what differentiates it from other paradigms as it moves away from realism to relativism. A relativist ontology claims that among individual's meanings and mental constructions vary and even when there are similarities to those held by the individuals within a social group, similar views vary among cultures as these are dependent on individuals (Corbetta, 2003). We construct knowledge through our lived experiences and through interactions with other members of society. This perspective focuses on the unique experience of the individual and how they view and interpret social facts from a variety of different perspectives that are multiple realities. Although, it is important to acknowledge that individuals within and across cultural groups may possess similar views and opinions about the nature of social reality and they can have an impact on the individual's experience (Appleton & King 1997). Within the constructivist paradigm reality is seen as pluralistic that is within a research study there can be a variety of different interpretations, therefore another researcher might view this from another perspective (Denscombe, 2010). This is inevitable, as the constructivist adopts the assumption that what is viewed as real is based on the participant's and researcher's perspectives, and the researcher's interpretation is also a construction.

#### 3.2.1.4 Natural setting

Constructivists believe that research should be carried out in the 'natural setting'. There are multiple-constructed realities that can only be studied holistically and in order to completely understand interactions constructivists believe this should occur in the natural-setting (Lincoln & Guba, 1985). Although undertaking the research in the natural-setting is not unique to constructivism, using this means of inquiry provides researchers with an opportunity to explore in great depth the maze of people's experience as they live and interact within their social worlds. It aims to gain an understanding and explanations of the variety of constructions that people possess, to make some sense of their lived experience, whilst trying to achieve some general agreement of meaning, (Guba & Lincoln, 1994). Although Denscombe (2010) identifies that when participants are the focus of attention they may alter their behaviour, which needs to be considered by the researcher. Guba and Lincoln (1994) suggest that as this process progresses, through gaining more information and experience, both the participant's and researcher's constructions evolve and show deeper understanding, which emphasises the significance of always being alert to new explanations. The importance of listening and building a relationship with participants is vital during the research process as this facilitates openness and allows participants to relay their thoughts and feelings (Charmaz, 2000b).

#### 3.2.1.5 Epistemology

According to Schwandt (1994) the constructivist views that truth and knowledge is not found or discovered, it is constructed as the result of experience. Epistemologically the constructivist researcher takes a transactional and subjective approach (Guba & Lincoln, 1994) and views knowledge as dynamic, that is, created through partnership and interaction between the researcher and participants (Paul, 2005). In order to discover the multiple views of reality that potentially exist for the participant, and to be able to attribute meaning to it, this approach advocates continuous social interactions between the researcher and participants during the research process (Appleton & King, 1997; Appleton & King, 2002). The subjective approach is compatible with the ontological position that social reality for the individual is subjective, created by them and constructed in their minds. This approach of subjectivity is viewed as the only way that constructions held by individuals can be unlocked (Guba, 1990).

Constructivists do not accept that research is value free and they perceive that values are seen as important in knowledge-creation (Guba, 1990; Paul, 2005). Following a constructivist approach requires the researcher to be reflexive, questioning themselves and being self-evaluating throughout every aspect of the research process (reflexivity is discussed later in the chapter, see section 3.17.2).

### **3.3 Methodology**

The appropriateness of using other qualitative inductive approaches such as ethnography and phenomenology were considered. The phenomenological focus on experiences could provide insight into the lived-experiences of health information seeking but could not further its theoretical development. A phenomenological approach would not help to answer the broad research question and aims of the study. As health seeking behaviour is viewed as a social process and the research focuses on a process that has distinct steps that occur over time, the selection of a methodology is based on this. The aim is to develop an inductive theory which would move understanding forward and contribute to the body of knowledge.

An ethnographic approach could help to facilitate understanding of behaviours that affect health information seeking, but having considered the key features of this methodology this approach has not been adopted. The focus is to explain ‘taken-for-granted’ meanings that individuals may have (Barbour, 2008). Although a cultural understanding of health information seeking behaviours may be useful; this is not the focus of the research question. One of the key methods used in the ethnographic approach is observation and although health information seeking may occur in a group such as in a social-support group, health information seeking can be spontaneous and happen in different settings at different times. Therefore, adopting this method would be unlikely to capture the participant’s personal experiences and to observe all types of health information seeking. Hence, an ethnographic approach with its focus on cultural meaning would not be appropriate.

Methodologically the constructivist aims to establish the various constructions that exist and collates them to try and achieve a substantial consensus (Guba, 1990). Within this process there are two dimensions; hermeneutics and dialectics, which aim to create informed and complex constructions (Guba & Lincoln, 1994). Hermeneutics involves gaining an understanding of the importance of the constructions and their meanings

(Appleton & King, 1997). The dialectical process describes how truth is gained through a series of processes, which ends in synthesis (Ransome, 2010) and involves the researcher comparing and contrasting the constructions of the participants and their own constructions (Guba, 1990).

From a constructivist perspective the role of the inquirer is to attempt understanding, within a certain context which is achieved through working in collaboration with the research participants (Paul, 2005). However a constructivist also recognises that it is impossible to gain a single consensus for the phenomena being explored, therefore they try to describe each viewpoint (Appleton & King, 1997). The researcher takes an emic perspective which is closely linked to *verstehen*, and this provides information from the insider's perspective based on their beliefs, perceptions and meaning system (Hennink et al., 2011).

### ***3.3.1 The voice***

Guba and Lincoln (2008) highlight the multiple dimensions to 'voice' and discuss how researchers are becoming more aware of the need to hear the participant's voice and including participant's accounts allows the reader to hear exactly what the participant has said. Within the literature (Koch & Harrington, 1998), it is clearly stated that it is important for the participant's voice to be heard, through verbatim quotations from naturally occurring data, ensuring that the multiple constructed realities are explored through providing rich description of the setting. However this also needs to be considered ethically with regards to issues of confidentiality and anonymity (Lincoln, 1990).

### **3.4 Summary**

I have reflected upon my own values and beliefs and life experiences. In my experience, individuals seek health information in various ways and will use different strategies with regards to this. Due to the lack of previous qualitative research undertaken that explores the health information seeking behaviours of older people, in view of my broad research question and the aims of this study it has become clear that to achieve insight into each older person's experience, a constructivist approach is the most appropriate.

In the following section, rationale for choosing grounded theory is provided as the methodological framework for this study. This includes an overview of grounded theory, exploration of the origins and philosophical underpinnings and a summary of the debates surrounding its use.

### **3.5 Defining grounded theory**

A grounded theory study involves the generation or discovery of a theory, which is ‘grounded’ in the data collected from participants (Glaser & Strauss, 1967). A fundamental principle of grounded theory is that knowledge is increased by the generation of new theories instead of analysing data within existing theories. An inductive research process is used with analysis starting with the individual. This is in contrast to deductive research, which begins with the theory and the researcher attempts to validate this using a top-down approach (Bowers, 1988). The aim of grounded theory research is to explore social processes that occur within human interaction and to move beyond description and to generate a theory about a dominant social process or action (Charmaz, 2013). As the theory is generated from the data, it is solidly linked to the data so the theory cannot be refuted by further data (Glaser & Strauss, 1967) and the theoretical framework is constructed from this (Glaser, 1978). To achieve theory generation, the researcher should not have any preconceived ideas about categories or hypotheses (Glaser & Strauss, 1967). Grounded theory can be used to generate both substantive and formal theory. Substantive theory is developed relating to the specific social phenomenon being researched (Glaser & Strauss, 1967), in this case older people’s health information seeking behaviours. Within this study, the participants have all sought health information during their lives and this does fit with the substantive theory being developed, using a grounded theory approach. By following the strategies outlined within grounded theory and developing theory from the data, this allows for the participant’s multiple-realities to be considered and used to develop the substantive theory. A formal theory goes beyond this, is more general and is applicable across various substantive areas and to the broader environment (Charmaz, 2006, 2014).

#### ***3.5.1 Origins, philosophical roots and overview of grounded theory***

Since grounded theory was first developed there has been much debate about this approach and it has evolved methodologically and philosophically. It is beyond the scope of this thesis

to revisit the historical development of grounded theory, for accounts of this see Glaser and Strauss (1967) and Birks et al. (2006).

### ***3.5.2 Philosophical roots of grounded theory***

Since Glaser and Strauss' (1967) initial description, grounded theory has evolved which has led to the theory undergoing a number of modifications, refinements and diverging into different types. Grounded theory is rooted in symbolic interactionism which originates from pragmatism. To help understand the philosophical basis of grounded theory it is important to provide an explanation of pragmatism and symbolic interactionism.

#### **3.5.2.1 Pragmatism**

Pragmatism's central ideas were developed by Peirce, James, Cooley, Mead and Dewey (Hammersley, 1990). Most pragmatists believe that we cannot know anything beyond our own experiences and experience is a 'world of interrelated phenomena that we take for granted in everyday life' (Hammersley, 1990 p42). The sense of self is a social product and through communication with others we are able to distinguish between the self and non self. By doing this, we are able to adopt others perspectives which is an 'objective' perspective. This perspective is integral to a 'system of co-ordinated action' (Hammersley, 1990 p55). Mead also discussed the role of interaction with others and how this defines the person. In new situations, knowledge is created through action and interaction, is continuously applied and it is assessed for its usefulness (Benzies & Allen, 2001). Cooley (1922) developed the concept of the 'looking glass self' that the person's self grows out of interactions with others and the perceptions of others. So individuals are self-aware, they are able to view themselves from other's perspectives and by doing this adapt their behaviour in accordance with the situation they are in. The interaction with others and adaptation of behaviours in response to this seems relevant to this study, as this can influence health information seeking behaviour.

#### **3.5.2.2 Symbolic interactionism**

Mead from the Chicago sociological tradition laid the foundations of symbolic interactionism in the early 1900's (Bredo, 2014). Blumer (1969) advanced symbolic interactionism as a sociological theory through the Chicago School of Sociology. The goal of this tradition is to understand the world of lived experience from the person's perspective (Schwandt, 1994). It aims to provide explanations about social action by understanding the values, ideas,

meanings, interpretations and the social world of people and offers a way to understand social reality (Charmaz, 2006, 2014). Symbolic interactionism assumes that the self, reality and society are constructed via interaction with the environment and communication with others (Blumer, 1969). It focuses on the way in which people make sense of these social interactions and the interpretations that are attached to social symbols, for example language (McCann & Clark, 2003a). By interacting, there is a process of negotiation where people respond to others, they adjust their behaviours and understanding, which creates a shared sense of reality. The notion of meaning is central to social behaviour and the nature of symbolic interactionism rests on three premises developed by Blumer (1969). Firstly, meanings affect the way that people act. Secondly, the meanings that are attached to this are gained through social interaction with others and thirdly these meanings are handled and adjusted through an interpretive process with the person using them to deal with the phenomena that are encountered. Therefore from this perspective meanings are dynamic and are adjusted on the basis of experience, which can also include the self and who you are. An example of this would be if someone retires from their paid employment, their perception of themselves may change, which changes the meanings of objects, and also changes in behaviour. To understand this process, a person's objects, actions and society needs to be studied from the person's perspective (Gray, 2009).

### **3.6 Summary**

The main influences on grounded theory epistemologically are symbolic interactionism which was influenced by pragmatism (Benzies & Allen, 2001). As Charmaz (2006 p7) highlights the symbolic interactionist perspective assumes that 'interaction is inherently dynamic and interpretive and addresses how people create, enact, and change meanings and actions'. This is relevant to this study, as older people are likely to reinterpret what is important to them when they are faced with a disruption in their lives, such as a chronic condition and change their actions according to this, which can be facilitated by seeking information.

### **3.7 Modifications and comparisons of traditional (Glaserian) and post-modern (Staussian) approach to grounded theory**

Since their seminal work on this approach, both authors have continued to make modifications (Glaser, 1978, 1992; Strauss & Corbin, 1990). Due to the different

backgrounds, opinions and approaches that existed between Strauss and Glaser it is hardly surprising that grounded theory has evolved. However, despite these differences the basic guidelines and fundamental elements which guide the research process still remain. These are theoretical sensitivity, theoretical sampling for developing theory, identification of a core category, memo-writing, comparative methods and the construction of a theory (Glaser, 1998). McCann and Clark (2003b) state that the differences relate to the extent to which an element is adopted. The two main branches of grounded theory that have developed from this original classic version (Glaser & Strauss, 1967) are traditional grounded theory (Glaserian) which is an extension of the original theory (Glaser, 1978, 1992) and the post-modern approach (Straussian) (Strauss & Corbin, 1990). Although the two approaches are informed by positivism, there are differences in their epistemological underpinnings (McCann & Clark, 2003b). The traditional approach is ontologically viewed as post-positivist where the researcher is viewed as independent, a neutral observer from what is being viewed and they discover data in an objective and neutral way (Blaikie, 2007). McCann and Clark (2003b) assert that the post-modern approach has a social constructionist ontology, where there is no such thing as reality, but it can be interpreted (Blaikie, 2007). The researcher within this Straussian approach has a dialectic and active role, meaning that the researcher is viewed as part of the data (McCann & Clark, 2003b).

The traditional approach focuses on the micro context in the field, emphasising the socially constructed world (McCann & Clark, 2003b). However the Straussian approach, not only focuses on the micro, but also the macro context and emphasises how culture shapes how things are perceived, which gives a view of the world (Blaikie, 2007). According to Crotty (1998) this leads to sedimentation, with the cultural meanings acting as a barrier between the participants and the researcher, resulting in this approach being restrictive and affecting the researcher's ability to become close to the individual's realities.

The role of literature, reviewing the literature and the emergence of the research problem differ within each approach. As the researcher's role is to remain independent, the traditional approach advocates the literature review should be undertaken following analysis and should be used to support the emerging theory. Glaser (1992) states that the data should be viewed with as few preconceptions as possible with the problem emerging from the data, which he suggests facilitates the emergence of what is important. This problem emerges through using the techniques of theoretical sampling, open coding and constant comparative analysis

(Glaser, 1992). However, by following this approach it has been argued that it fails to acknowledge implicit theories which can guide work in the early stages (Silverman, 2010). But this would also impact on the emerging theory and would not result in a theory grounded in data as the researcher may be influenced by this literature and issues of importance that emerge from the stories told by the participants, and may be ignored. Additionally, one of the strengths of grounded theory is that it is open-ended and flexible due to the constant comparative analysis, which allows the researcher to 'follow up on ideas' as they develop (Charmaz, 1990). The post-modern approach takes a different view to the role of literature and emergence, Strauss and Corbin (1990) acknowledge the inclusion of the researcher's experiences and views (both personal and professional) and state that the researcher's past experiences and literature are valuable for the development of theory. They acknowledge the characteristics and past experiences of the researcher will influence the data and its interpretation, and the researcher must be aware of their impact when developing grounded theory (Strauss, 1987; Strauss & Corbin, 1998).

As a researcher, I am unable to be as detached as advocated by the Glaserian approach, as I believe that the research will be shaped by my experiences and is co-constructed with the participants. However, this research has been conducted with few pre-conceived ideas about health information seeking and in order to reduce the influence of literature, only a preliminary literature review was undertaken prior to data collection and analysis. This was undertaken to provide rationale for undertaking the study, to inform my research proposal and to identify gaps within the literature. This proved valuable as it identified that this area has not been studied previously and that there are major gaps in understanding the health information seeking behaviours of older people. The main literature review and focused reading was conducted at a later stage (after data collection and analysis), was led by the data and used to support the emerging theory. By doing this, it reduced the influence of previous theoretical constructions which could affect the direction the research followed (McCann & Clark, 2003a).

Procedural differences are also apparent between the two approaches. Glaser (1992) suggests that constant comparative methods are sufficient to develop a grounded theory and argues that Strauss and Corbin (1998) are 'forcing the data' rather than allowing the emergence of what is important (Charmaz, 2000b). Strauss and Corbin (1998) value the use of further procedures such as 'waving the red flag', 'the flip flop technique' and using 'matrices' which

they claim maximises theoretical sensitivity and will lead to a more dense grounded theory. They also impose a Paradigm model (Strauss & Corbin, 1990) which provides a framework for axial coding, to identify links between categories and sub-categories. This can be used to systematically arrange data into an organising scheme and to help make sense of the data. Links are made between categories looking at causal conditions, actions/interactions and consequences.

Both approaches also evaluate grounded theory in different ways. For Glaser (1978, 1992) a grounded theory should be evaluated in terms of its fit, work, relevance and modifiability, so from this perspective emerging categories must fit and explain the data rather than any preconceived concepts forcing the data. However Strauss and Corbin (1990, 1998) use criteria advocated by other researchers such as Kvale (2007) and Chenitz and Swanson (1986).

In the next section, there is a discussion of a further adaptation of grounded theory; constructivist grounded theory and a rationale is provided for choosing this approach.

### **3.8 Constructivist grounded theory**

The constructivist grounded theory approach has been informed by Charmaz (2006) and lies between the positivist and postmodernist paradigms. Constructivist grounded theory shifts from its positivist roots to an 'interpretive portrayal of the studied world' (Charmaz, 2006 p10). This approach highlights the researcher's roles and their actions. It focuses on the place the researcher is in the text, the researcher's relationship with participants with the emphasis that the research is grounded in the data (Charmaz, 2000b, 2006, 2014). Constructivist grounded theory is ontologically relativist and epistemologically subjectivist and places the researcher as author at the centre of the research (Mills et al., 2006a). This approach includes the methodological strategies of Glaser and Strauss, but incorporates reflexivity and relativity throughout the research process (Charmaz, 2013). With its relativist epistemology and its emphasis on reflexivity this means that the relationship between the researcher and participants is re-cast, which leads to more depth and breadth of the research, allowing for a greater understanding of the participants' multiple realities (Charmaz, 2008). Constructivist grounded theory combines Glaser's methodological strategies (i.e. objectivist grounded theory) and builds on the social constructionism inherent in Strauss's symbolic interactionist perspective (Charmaz, 2008). Objectivist grounded theory also emphasises the construction

of emergent concepts, but there is also an emphasis on the neutrality of the researcher (Glaser, 1978). Glaser suggests that the researcher enters the field with an open mind and their position is as an 'outsider', i.e. outside the phenomenon, but from this stance the researcher may include their presuppositions without acknowledging them (Charmaz, 2013). The constructivist approach acknowledges the role of the researcher in the analysis and also in the construction of the emergent concepts and theory (Charmaz, 2006, 2013).

This approach is an 'emergent' technique which allows further exploration and facilitates insight into areas where there is limited research. Charmaz (2013) points out that there is less emphasis on emergence when using Strauss and Corbin's (1998) approach due to the inclusion of preconceived coding ('coding families') and analytic frameworks. It is important when adopting a constructivist grounded theory approach that the researcher acknowledges their own assumptions, knowledge and experience from the beginning. A strength in Charmaz's approach is that the researcher avoids using an imposed framework, with this approach emphasizing an emerging process of theory formation (Cresswell, 2013). Charmaz (2006 p47) claims researchers may believe that the codes 'capture the empirical reality', but ultimately this is influenced by the researcher as they select these words from the data. Charmaz (2013) suggests that adopting a constructivist grounded theory approach takes into account the construction of emergent concepts by the researcher, which emerge because of the questions asked by the researcher. In this study I will not be forcing the participant's views into predefined categories, but there will be emergence from the data from which the codes will be constructed.

A constructivist grounded theory approach includes emphasizing the diverse local worlds, multiple realities and complex worlds, views and actions that exist. There is also a focus on views, values, beliefs, assumptions, feelings and the ideologies of individuals rather than methods of research (Charmaz, 2013). As previously discussed, constructivism assumes there are simultaneously multiple-realities rather than the one 'real reality', which includes the researcher's realities as well as the participants. The researcher and participants hold multiple standpoints on these realities and this approach takes into account how the researcher, the research situation and process affects the construction of knowledge (Charmaz, 2008). Epistemologically, there is a position of subjectivism, a constructivist understands that it is not possible to separate the researcher from the participant, so there is acknowledgement that an interrelationship exists and interaction between the researcher and participant creates the

data (Guba & Lincoln, 1989). In constructivist grounded theory, what is important is that the data is constructed via the on-going interaction between the participant and researcher. Using this approach acknowledges the perspectives and positions of the researcher as well as the participants, with the researcher's perspective being viewed as integral to data collection and the emerging theory (Charmaz, 2008). Therefore the theory is rooted in both the participant's accounts where the researcher is viewed as being part of this approach. Glaser and Strauss's (1967) grounded theory advocates that the theory is discovered which is achieved independently of the researcher's views, a continuing viewpoint of Glaser's later work (Glaser, 1978, 1992).

### **3.9 Summary**

Grounded theory has evolved and continues to do so, with subtleties and differences in its research design that need to be considered when adopting a particular approach. My ontological and epistemological positions have determined the grounded theory approach that has been adopted, with the constructivist approach suiting my philosophical position. The aim of this study has also been considered which is to better understand, through exploration of the process, how older people find out information about their health. Therefore, a methodology was needed that can develop an understanding of health information seeking behaviour which also considers their multiple realities. The importance and acknowledgement of the role of the researcher in the development of theory is important within this approach and it emphasizes an emerging process of theory formation.

This current chapter will now move onto the presentation and consideration of research design and the methods adopted within the study.

### **3.10 Study design**

The guidelines for constructivist grounded theory suggest the adoption of an exploratory qualitative approach which allows the participants to identify issues pertinent to them and to explore their personal accounts (Charmaz, 2006). Diaries and open ended qualitative interview methods are best suited to explore the dynamic nature of health information seeking behaviour as they have the potential to delve into previous events, feelings and perceptions.

The following figure (figure 4) is a visual description of the grounded theory process used in this study. Each stage is explained in further detail in this chapter.

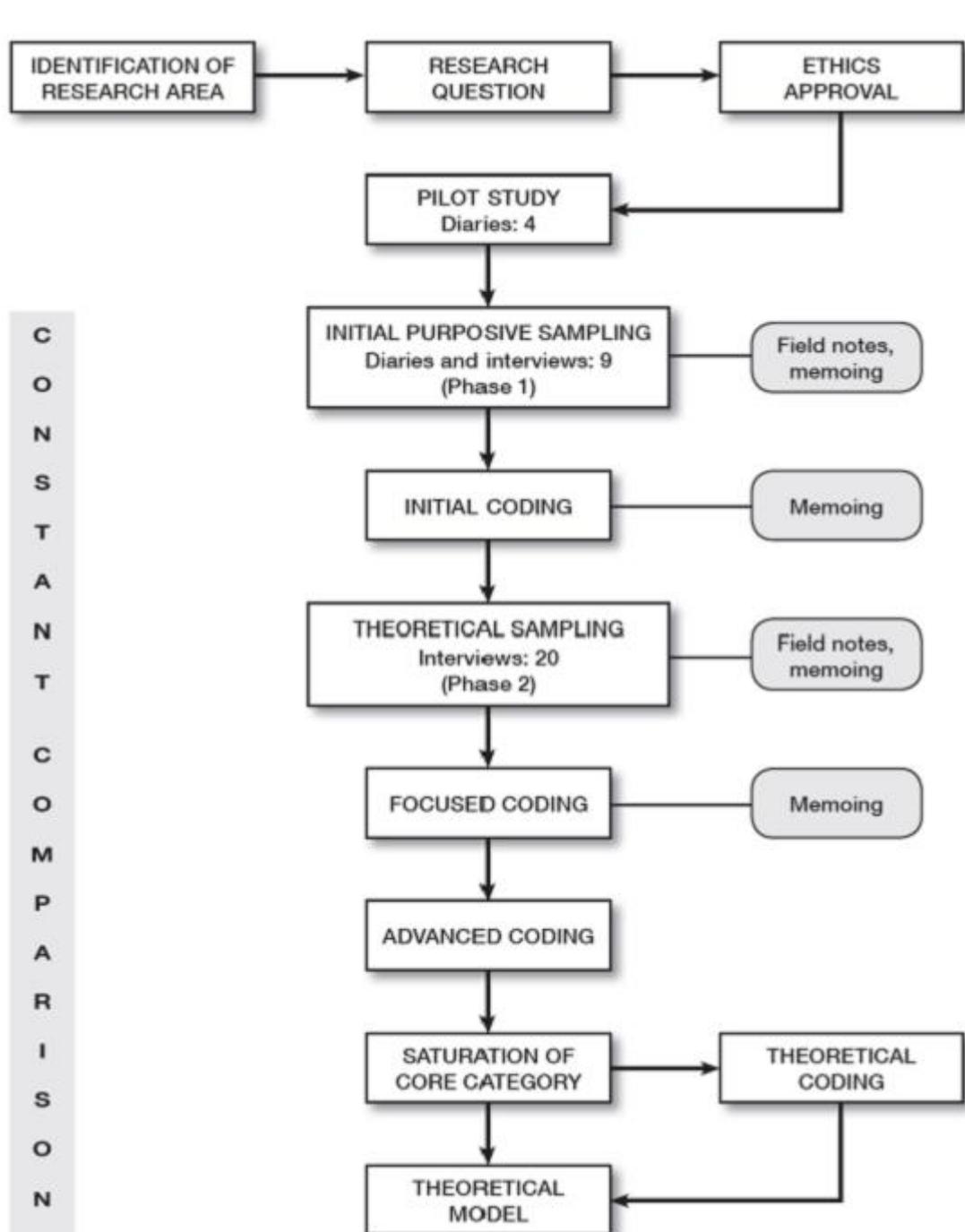


Figure 4: A visual description of the grounded theory process (influenced by Charmaz 2006)

### **3.11 Diaries and the pilot study**

The decision to use diaries was influenced by the research question and sub-questions, the aims of the study and the methodology. A wide range of data collection tools can be used within a grounded theory study and these sources can be used alone or in combination (Corbin & Strauss, 2008).

#### ***3.11.1. Using diaries as a method***

The use of unstructured diaries in qualitative research is uncommon, although in medical research structured diaries where diarists regularly log data have been used for over thirty years (Milligan et al., 2005). Diaries can provide useful insights into different aspects of an older person's life, can aid recall and provide detailed information (Bytheway & Johnson, 2002; Nezlek, 2012). Keeping a diary, allows the participant to actively record and reflect on their behaviours and allows the diarist to identify what is important to them (Milligan et al., 2005). Furthermore, it provides a record of the ever-changing world that the diarist lives in (Plummer, 1983, 2001). Some people are more predisposed to keeping a diary than others, and they will use the opportunity to record and reflect upon events in their lives, whilst others will find the activity onerous (Sheridan, 1993). The use of diaries can be fraught with problems such as non-completion, be prone to individual bias (Kumar, 2005; Walliman, 2005), respondents may alter their behaviour (Oppenheim, 1992) and as with most data gathering tools the influence of social forces such as conformity may affect responses (Dey, 1993). Despite this, the use of diaries can provide an additional and diverse perspective when collecting data and therefore identified as the best approach to obtain rich data for the first phase of this research study.

Milligan et al. (2005) identify that keeping a diary can for some be a positive and therapeutic activity. Valimaki et al. (2007) identified that their diarists found keeping a diary was rewarding and a positive experience for them. Indeed, when one man was recruited he identified that one of the reasons that he had volunteered to participate was for him to gain more insight into his health and what factors may affect his health. After diary completion, he explained that he would continue to keep a diary as it acted as an aide memoir.

### *3.11.2 Pilot study*

The diaries were piloted with 4 older people to check that this method and tool was appropriate, with guidance for diary completion being subsequently further refined. Members from a local Public Involvement in Research Group based at the University of Hertfordshire, also commented on the Participant Information Sheet and their feedback resulted in changes to the language, to make it less technical and easier to understand.

As the study was inductive and sought to identify strategies used by older people to seek health information, initially using diaries followed by a focus group was considered to be the best approach to obtain rich data. However, following the pilot study one of my methods for gathering data was changed, as from a constructivist viewpoint, there is a move away from the collective generation of views and perspectives, with the in-depth interview fitting in more appropriately with this approach. Interviewing each participant individually about their health information seeking behaviours enabled further clarification and exploration of what had been written in the diary. The interview also provides a ‘snapshot’ when used as the only method of collecting data. By analysing diary data entries and interviewing each diarist, this can potentially reveal insights into their lives and identify the significance and importance of entries (Milligan et al., 2005). Additionally, when undertaking qualitative analysis it is important to consider contexts as they can affect the meaning (Dey, 1993) and it is useful to have background information about the participant to allow for a greater understanding of the context of the study (Charmaz, 2006).

Additionally, due to the diversity and geographical spread of the potential participants, it could prove challenging to convene a focus group at a mutually agreeable and convenient venue. Practically, it would also be difficult to facilitate the focus group within a reasonable time of completion of the diary due to the period of time it would take to recruit the diarists and for them to complete the diary. Therefore, slight amendments were made to the original design, an amendment submitted and approved by the ethics committee.

The next sections present the two methods that were used to collect qualitative data; the diary and open-ended interview.

### *3.11.3 Diaries*

The participants were asked to identify where they gained their health information and the triggers for doing so. There was no pre-determined structure to the diary although guidance for completion was given via the diary instructions information sheet (see appendix 3). The Participant Information Sheet (see appendix 4) given to potential participants was carefully composed and the research was described in a way that was clear and understandable. A paper copy of a notebook was given to participants.

Each participant structured their diary in a different way and provided a wide variety of information within it. One woman and one man constructed a table within a word processing document and completed it. One man already kept a detailed diary, focusing on the weather, due to his previous employment as a crop protection salesman. The diaries produced records of the older person's health information seeking behaviours, as well as providing insights both into the diarist's lives and what they considered to be important to their health. Some of the diarists went on holiday during this period and took the diaries with them.

Once the diaries had been returned by the participants, in-depth interviews were organised which were conducted in the participant's home as soon as possible after the diary had been returned, as it was felt this would aid memory of the events recorded within the diary. Usually this was achievable, although one interview with one man was delayed, I noted this when I was analysing the interviews and identified this within my memos (see table 3):

*'Started looking at diary-noticed that he wrote the diary 24<sup>th</sup> October 2010-2<sup>nd</sup> February 2011 (longer than the two months) and then interview was on 28<sup>th</sup> February 2011 which meant that there was a time lapse of over 4 months from when the diary had been started. The interview was quite challenging as I had to keep reminding him of different entries as he had forgotten some of the things that he had written. The delay in interviewing was out of everyone's control-I had contacted him on January 13th and he was still on holiday, he returned the diary to me via email when he had come back from his holiday two weeks later and then arranging a mutually agreeable time also took time with numerous dates being offered and eventually we managed to meet on 28th February.'* (field note memo)

Table 3: Field note memo

### **3.12 Qualitative interviews**

The next section explores the process of conducting the interviews, the setting, the questions and establishing rapport.

#### **3.12.1 Interview setting**

All of the participants elected to be interviewed in their own homes. In adopting a constructivist grounded theory approach the researcher commits to a relationship of reciprocity with participants (Mills et al., 2006a). To facilitate this the researcher needs to consider scheduling interviews at a time and place that are the participant's choice (Mills et al., 2006a). When the participants were contacted, they were asked where they would like to meet and what date and time would be convenient. A range of times were offered during the day, with only one person electing to be interviewed in the evening.

#### **3.12.2 Interview questions**

In the interviews participants were asked to describe their experiences of health information seeking. A guide was used with key questions asked of each participant (see appendix 2). Before the start of each interview, participants were asked if they had any questions, an outline of how the interview would proceed was given and asked if they were happy to continue with the interview. At interview, the participants were asked to explore their health

information seeking behaviour and for those who had completed diaries the focus was on their diaries and to clarify issues that were included within these. The interview was as open as possible, allowing the participant to identify what they felt was important to them, with the diary acting as a signpost and focus for some of the key issues that needed exploring. Following these interviews, one participant had identified that she had found a red patch on her hand and used different sources for seeking information (see table 4):

*'24<sup>th</sup> Dec. I have a red patch on my hand about the size of a five pence piece. It is getting bigger. Apply cream but nothing seems to check it. Tried to match it up to something on the web.*

*26<sup>th</sup> Dec. My daughter looks at my red patch and diagnoses a fungal infection. As it's been there since Mauritius she may well be right. Apply anti-fungicide cream and pray.'*

When she returned the diary a few days later her final comment was:

*'My red patch? It's had everything – antifungal; antibiotic cream; moisturizer.*

*Final thoughts by the Director of Medical Entomology (for whom I provide a media consultancy) probably down to a chemical reaction/allergy to sap from a Lychee tree.'* (Maud, diary)

Table 4: Excerpt from diary

This provided a vignette for the following phase 2 interviews (see appendix 5), which allowed the participants to problem-solve and hypothetically explore where they might seek health information in this scenario.

### ***3.12.3 Developing a rapport***

During data collection, listening and building a relationship with participants is important as this facilitates openness and helps them express their thoughts and feelings (Charmaz, 2000b). To facilitate this, it is important for the researcher to gain rapport with the participants. Rapport is about trying to establish a sense of equality within the relationship (Gray, 2009) which can impact on the quality of information gained at interview. When establishing rapport, it is important to gain trust, provide reassurances of confidentiality

(Miller & Glassner, 2004) and to be familiar with the key issues pertinent to the person being interviewed (Stephens, 2007). With this in mind, when initial contact was made the participants often told me additional information about their lives, which I recorded in field notes and ensured I familiarised myself with prior to meeting them.

The very essence of interviews relies on the ability to maintain and generate conversations with the interviewee (Mills et al., 2006a). Throughout each interview, I felt that a good rapport was maintained as the interview felt a bit like a conversation due to the semi structured format of the interview. Indeed one participant commented at the end of the interview that she felt it was more like a chat than an interview. The interview interaction can be influenced by how the participants perceive the interviewer, and can be affected by the interviewer's looks, actions and the questions that they ask (Seale, 2010). I decided that I wished to create a feeling of informality, so I considered my appearance and what I wore; dressing smart but casually. Also, a big age gap between interviewer and participant could act as a barrier as the interviewee may not take the interviewer seriously (Stephens, 2007). I did not feel that my age was an issue, as I am used to communicating with a wide range of people and I felt that my communication skills were respectful, I acted in a professional manner, and the participants appeared to take me and the research seriously.

The role of the interviewer is to encourage the participant to be open and discuss their experiences of the issue being researched (Ryan et al., 2007). Sometimes the best data collected via interview are when it is unstructured and there are no pre planned questions (Corbin & Strauss, 2008). Mills et al. (2006a) support this and advocate the use of a relatively flexible and unstructured approach to questioning, resulting in the participants having more power over the direction of the conversation. Using the semi-structured technique means that the questions are planned, but that the interviewer is able to explore, probe and seek clarification of the answers given by the participant (May, 2001). Some pre-determined questions (see appendices 2 and 4) were used that acted as prompts, which were open and facilitated the discussion of the participant's experiences of health information seeking.

### **3.13 Recruitment**

A pragmatic approach to recruitment was adopted in order to access older people living in the community, from a range of ages and socio-demographic backgrounds, to allow for an in-depth understanding of a broad range of experiences.

#### ***3.13.1 Sampling***

Within grounded theory, the researcher can shape the information that is gathered (Charmaz, 1990), and if this is completed from the start, it provides the foundations for later coding and categorizing. However, Cutcliffe (2000) cautions that the early participants determine the direction of future sampling, which could potentially affect the direction that the research follows. According to Glaser and Strauss (1967) and Glaser (1978) sampling is theoretical rather than purposeful; their rationale for claiming this is that the sampling is dictated by the emerging theory. This has been debated within the literature and can cause problems for the researcher, as initially, there is no evolving theory to guide theoretical sampling (Cutcliffe, 2000). Therefore, when data collection commences, purposive sampling is used and participants are selected using pre-determined criteria (Burns & Grove, 2001). This is followed by theoretical sampling when the researcher has gathered data, coded and analysed it and highlights the next data that is needed, so that emerging theoretical concepts can be developed (Currie, 2009). New data is used to add, confirm or challenge the emergent patterns in the data. Theoretical sampling continues until no new relevant data emerges and theoretical saturation is reached. For this study, initially purposive sampling was used to explore health information seeking behaviours. A range of strategies were used to recruit the participants for the first phase of the study. Access to participants can cause many challenges for the researcher and the importance of social-networks, gaining access and the difficulties that are involved with this have been highlighted by Silverman (2010). Creswell (2009) also identified that during the data collection process, a further ethical consideration is the gaining of agreement from gatekeepers to provide access to potential participants.

Four strategies outlined by Hennick et al. (2011) were used which included using gatekeepers, informal networks, advertisements and snowball recruitment. These strategies were used to attempt to recruit a wide range of participants. A short summary of the research study was placed on the University of the Third Age (U3A) website and day centres for older people were approached. Contact was also made with the warden of a sheltered housing

complex to gain permission to attend sessions (including a coffee morning) to discuss the research with residents. To increase participation in the study, a poster was designed (see appendix 1) which was displayed at the local indoor bowls club, libraries, and local parish notice boards. For phase one of the study, three older people volunteered to be part of the study from U3A, two were recruited from the coffee morning and four were recruited from the poster displayed at the bowls club and on the parish council noticeboard. For phase one of the study, the aim was to recruit 5 men and 5 women between September 2010 and September 2011, to have an approximately equal sex-distribution. During the process of analysis, no new themes were arising from the 7<sup>th</sup> interview onwards and so data saturation was accomplished and recruitment ceased after the 9<sup>th</sup> respondent. Naively, I thought that the recruitment process would be smooth and would be completed quickly, but it was very time consuming, due to contacting potential groups for recruitment, attending initial meetings, returning to identify potential participants, consenting and preparing each participant, waiting 2 months for the diary to be completed and then arranging and undertaking the interview. However, it is acknowledged that this was a crucial part of the process as this helped with building a relationship with the participant, which, it was hoped would aid retention. Research also suggests that diary studies require more commitment from participants than is required when using other methods (Nezlek, 2012). Due to the commitment required by participants to complete the diary, for example one participant (Victoria) recruited via the coffee morning stated that she did not feel that she could complete a diary but was happy to be interviewed, I commenced recruitment for the second phase of data gathering.

The second phase of recruitment was between June 2012 and September 2012. For phase two of the study, four participants were recruited via poster displayed at bowls club. Following their interview, participants identified potential people from their informal social networks who could be recruited to the study. This snowballed, with these participants suggesting other potential recruits, for example Carol who was recruited via poster at bowls club suggesting Millie who then proposed a further six older people who could be recruited. Two participants were recruited via the poster on the parish council noticeboard. Several themes started to emerge as the data collection and analysis continued and these were included within the interview schedule (see appendix 2 for interview schedule). These emerging themes included the significance of social networks and how they impacted on health information seeking, the sources of knowledge that informed participants and how they were selected, recognising triggers and potential barriers to health information seeking. With these themes and to

explore the emergent patterns, a further 20 interviews were conducted. The table (see table 5) below details the sampling episodes conducted during this study:

<b>Data collection episodes</b>	<b>Analysis stage</b>	<b>Purpose</b>
Purposive sampling Participants: 9 11 hours interview data 9 diaries	Open coding	To look at the data, see patterns and compare. Look for links between patterns in data.
Theoretical sampling Participants: 20 21 hours interview data	Focused and advanced coding	To further explore patterns. To question the emergent relationships. Look to see if there is an emergent concept to explain the phenomena

Table 5: Sampling episodes

Most of the interviews were conducted in private, away from the rest of the household, except for two interviews where the married participants requested that they were interviewed together. These interviews were with Elsie and Anton and Jess and Len.

Individual descriptors of each participant are included in appendix 6. The table (table 6) below provides a demographic profile of each participant, including pseudonym, age, marital status, previous occupation, health status and recruitment strategy:

Phase 1: Diary and interview participants

<b>NAME</b>	<b>AGE</b>	<b>MARITAL STATUS</b>	<b>PREVIOUS OCCUPATION</b>	<b>HEALTH STATUS</b>	<b>RECRUITMENT STRATEGY</b>
Maud	66	Re-married	Newspaper reporter	Hyperthyroidism, hypertension	U3A
Bruce	73	Divorced	Freelance engineer	Enlarged prostate, musculo-skeletal neck aches	U3A
Bob	67	Married	Project management	Asthma, hay fever	U3A
Louise	73	Divorced	Nurse	Irritable bowel syndrome, hypertension, dust mite allergy	coffee morning at independent living with assistance accommodation
Pete	85	Widowed	Car repair panel beating business	Diabetes, macular degeneration, hearing difficulties	coffee morning at independent living with assistance accommodation
Alan	80	Married	Architect	Cardiac problems	poster at bowls club
Tony	66	Married	Salesman	Infected knee joint	poster on parish council noticeboard
Sue	68	Re-married	Receptionist	Plantar fasciitis, hiatus hernia, depression	poster at bowls club
Lorna	80	Widowed	PA insurance company	Osteoporosis	poster on parish council noticeboard

Phase 2: Interview participants

<b>NAME</b>	<b>AGE</b>	<b>MARITAL STATUS</b>	<b>PREVIOUS OCCUPATION</b>	<b>HEALTH STATUS</b>	<b>RECRUITMENT STRATEGY</b>
Pauline	77	Widowed	Secretary	Polymyalgia rheumatica	poster at bowls club
Craig	78	Widowed	Sheet metal worker	Reflux, enlarged prostate, bilateral knee replacements, moles removed for melanoma	poster at bowls club
Erin	77	Widowed	Secretary	Osteoporosis, angina, solar keratosis, hypertension	poster at bowls club
Carol	83	Widowed	Teacher	Osteoarthritis in neck, cataracts	poster at bowls club
James	79	Widowed	Building	Bowel cancer, sciatica	recruited by Craig
Millie	76	Widowed	Office work	Arthritis in knees, indigestion	recruited by Carol
Victoria	84	Widowed	Shop work	Cardiac and chronic chest problems	via coffee morning at Sheltered housing complex
Penny	82	Widowed	Social Services	Pain in shoulder, hypertension	recruited by Millie
Elsie	85	Married	Social services clerical work	Hypertension, hypercholesterolemia, cardiac problems, osteoporosis-fractured spine in 3 places.	recruited by Millie
Anton	87	Married	County Council waste management	Prostate cancer, asthma, curvature of spine	recruited by Millie
Jess	66	Married	PA factory manager	Shoulder pain, bladder infections, sleep problems	recruited by Sue
Len	71	Married	Builder	Collective stress, hypercholesterolemia, stiff shoulder	recruited by Sue
Annie	75	Re-married	Office worker	Hyperthyroid, previous hysterectomy for uterine cancer, hernia, cardiac failure	poster on parish council noticeboard.

Jack	82	Married	Police officer	Arthritis in spine, Carpal tunnel syndrome, prostate cancer, varicose veins	recruited by Pauline
Tom	74	Widowed	Book keeper	Hypertension, hypercholesterolemia, hernia	recruited by Pauline
Fern	75	Married	Parish Clerk assistant	Fall last year-hip replaced, osteoporosis, hypertension	recruited by Millie
Judy	78	Widowed	Shop worker	Arthritis in knees, hand problem	recruited by Millie
Cynthia	84	Widowed	Insurance secretary	Osteoporosis	recruited by Judy
Sarah	72	Re-married	Administrator	Osteoporosis	recruited by Judy
Caroline	67	Re-married	Nurse	Sleep problems and Hypoglycaemia-unknown cause, basal cell carcinoma, rotating cuff problem	via poster on parish council noticeboard.

Table 6: demographic profile and health status of participants

### 3.14 Ethics

The four ethical principles of autonomy, non-maleficence, beneficence and justice described by Beauchamp and Childress (2001) have been considered and guided this study. To ensure the application of these principles the following issues around informed consent, minimization of harm, guaranteeing anonymity and assurances of confidentiality are central obligations. These principles are explored and framed within this study.

#### 3.14.1 Ethics and Ethics committee

Ethics approval was gained from the University of Hertfordshire Faculty of Health and Human Sciences Research Ethics Committee for nursing, midwifery, social work, criminal justice and counselling in December 2009 (reference number: NMSCC/11/09/5/A). A few minor amendments were necessary, which included giving participants a list of potential support providers (See appendix 7), as the ethics committee felt this was a good way of

providing choice for the participants. The original ethics approval was for focus groups, so an ethics amendment was requested and approval granted in February 2010.

### ***3.14.2 Respect for autonomy***

#### **3.14.2.1 Informed consent**

In social research ethics, consent is a key principle (Oliver, 2010). Consent is an agreement made by a person to participate in research, once they have had explained to them what is involved and it ensures that the person is not misled (Silverman, 2011). The participants should be made aware of the reasons for the study, the type of information that will be explored and how the researcher intends to use the research (Ryan et al., 2007). Information giving within grounded theory can be problematic as the researcher may not know exactly what it is they specifically want to find out (Glaser & Strauss, 1967). An informed decision to participate was facilitated by the provision of a participant information sheet (see appendix 4 and appendix 8) and verbal information was provided to support this. Those who indicated that they wished to participate were given at least one week to consider if they wanted to take part and were encouraged to speak to others about the study.

I experienced an ethical dilemma when the following situation occurred. This included the decisions made when I contacted a diarist after two months. When I telephoned her she said that her husband had died the previous night. She had consented to be part of the study but whilst she had been writing her diary her husband had been unwell. In these circumstances, it was apparent that she may find it distressing to discuss this period of time, but it could not be assumed that she no longer wished to participate. I wrote a letter of condolence, identifying that she would be re-contacted in one month's time to see if she wished to continue in the study, reinforcing that she could withdraw at any time. Before I contacted her, she left a message for me stating that she wished to withdraw from the study.

Participants should give informed consent with regard to their participation in the study and this should be on-going and renegotiated throughout the research process (Oliver, 2010). As highlighted by Denscombe (2010) the commitment from a participant can change and questions whether the original agreement stays valid and relevant throughout the process, advocating that consent be reviewed. This was particularly relevant during the first phase of

the study, as data collection was undertaken over a number of months. Initial written informed consent (see appendix 9) was obtained prior to diary commencement. Prior to each interview, participants were asked if they wished to continue with the study and informed that they were free to withdraw if they wished. Prior to interviews in the second phase, informed consent was reviewed. I also considered that I should be aware that during the interview, the participant may inadvertently reveal personal information that may have been an uncomfortable experience or that they did not mean to reveal. Polit and Beck (2006) identify that process-consent is a useful tool which involves continuous negotiation with the participant, to ensure that they are comfortable to continue with the study. Indeed, during one interview the diarist identified that she wanted some personal information removed as she felt that her family would not approve of her revealing it to me.

#### **3.14.2.2 Non Maleficence**

Although vulnerable subjects are not the focus of this study, older people are often perceived to be vulnerable and this means that care has to be taken to ensure that any people who are considered to be vulnerable are identified and treated appropriately. This study does not address particularly difficult or sensitive issues, however two participants became upset when they spoke about their husbands' illnesses, I offered to stop the interview but they insisted that they wished to continue. Participants were given information about possible sources of support via the information sheet, in the event they were needed (see appendix 7).

#### **3.14.2.3 Confidentiality and anonymity**

Guaranteeing anonymity and assurances of confidentiality is a central obligation (Oliver, 2010). This is achieved by not including real names or places, using pseudonyms and explaining to the participants the procedures that are in place to protect the individual's right to confidentiality.

Wengraf (2001) discussed different degrees of anonymity ranging from changing certain details so that people unknown to the interviewee would not recognise them, to changing the account to such an extent that the interviewee would not recognise themselves. Clearly, it would depend on the amount of information that is changed, as if there are too many radical

changes this could affect the end result of the research. Participant's names and NHS Trusts were anonymised, using a code known only to the researcher.

Personal information was requested from the participants, such as their name and contact details, and this information was stored in a locked cabinet. No personal data was stored on the computer and the digital recordings were destroyed once analysis was complete.

### **3.15 Data management**

This section identifies the ways that data were recorded, transcribed and managed.

#### ***3.15.1 Digitally recording the interviews***

Recording the interview allows the researcher to focus on the topic, the interactions within the interview (Kvale, 2007) and provides an accurate account of the interview (Bryman, 2004). All participants completed and signed the consent form giving permission for the interview to be recorded. Although the interview was digitally recorded, this does not record the non-verbal communication that occurred or the environment. Rubin and Rubin (2005) advocate taking notes, as it makes the interviewer listen carefully and allows him/her to write down potential questions as the interview progresses. Notes were not made during the interview as it would be too distracting and would not enable me to maintain eye-contact with the participants. When I left, I reflected on the interview, the recording was listened to as soon as possible, and a record made of anything significant that had occurred during the interview as field notes, of course there are limitations with relying on memory in this situation.

#### ***3.15.2 Transcription***

I transcribed all the phase 1 participants' diaries and interviews and ten of the phase 2 interviews, but for the rest of the interviews an external transcribing service was used. I did not have the typing skills, felt that I was mechanically typing the data which did not facilitate immersion and I was not focusing on the stories that were being told to me. The external transcriber understood the need for confidentiality, provided a data protection certificate and was not local to the area data was collected, which meant it was unlikely that participants

would be recognised. For these, I checked the accuracy of transcription by listening to the recording and reading the transcripts at the same time.

### ***3.15.3 Computer assisted qualitative data analysis software***

There has been some debate over the use of computer assisted qualitative data analysis software. Some scholars have suggested that using software may guide the research in a certain direction, could distance the researcher from the data (Charmaz, 2013; Welsh, 2002) and could result in the adoption of a narrow approach to data analysis (Seale, 2010).

Weitzman (2000) argues that using software does not reduce familiarity, it changes the researchers closeness to the data and argues that for some researchers it can help them get to know their data better than when analysing without it. Additionally, if used appropriately it can aid the researcher in the data handling and analysis process and can aid transparency, by allowing others to view the coding process (Hutchisona et al., 2010).

A computer assisted qualitative data analysis software programme NVivo (QSR version 9) was used. This computer package allowed text to be coded and retrieved. NVivo helped me to organise and find my data and allowed similar themes to be grouped together. NVivo was used as an organising tool to store all memos, field notes and reflective diary, which made them easily accessible (Miles et al., 2013).

### **3.16 Process of data analysis**

The next section outlines the methods of data analysis. Compared to other approaches to grounded theory (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990) constructivist grounded theory is flexible in the methods used to analyse data. It takes into account the role of the researcher, allows them to adopt a flexible and open approach to the data, which can facilitate new insights into the health information seeking behaviour of older people (Charmaz, 2006). In grounded theory analysis there are many tools that can be employed; these are using codes, categories, constant-comparison, memos, and theoretical sensitivity. These are discussed in the next section.

There appeared to be confusion within the literature with regards to the use of ‘code’, ‘category’ and ‘concept’, despite these terms being central to grounded theory methodology. Within this study they are defined as follows (see table 7):

<p><u>Concepts</u> are ideas that are descriptive explanations of the phenomena (Holloway, 2008).</p> <p><u>Codes</u> capture themes and patterns and they are clustered under a title (Charmaz, 2006).</p> <p><u>Categories</u> are higher level codes that evolve in abstraction and complexity, therefore incorporate other codes (Corbin &amp; Strauss, 2008).</p> <p><u>Sub category</u> is a sub division of a category (Birks &amp; Mills, 2011).</p> <p><u>Core category</u> incorporates the processes which are evident in the categories, encapsulating and explaining the grounded theory as a whole (Birks &amp; Mills, 2011)</p>
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Table 7: Terms defined

### ***3.16.1 Initial coding***

The first stage within the coding process recommended by Charmaz (2014 p116) is initial coding which allows the researcher to ‘remain open to exploring’ the data.

Once a diary had been returned, analysis commenced, following Corbin and Strauss’ (2008) recommendations, each diary was read all the way through, as this helped enter the diarists’ lives, feel their experiences and identify what was being said. The diaries that were handwritten were transcribed which again assisted with familiarisation. The raw data from each diary was initially analysed using line-by-line coding, as this breaks down the data, allows the researcher to remain focused on the participant’s views of their realities (Charmaz, 2000b) and ensures that the researcher remains focused on the collected data (Charmaz 1990). Using this form of coding can be problematic as each line may have no meaning or many meanings that can not be labelled by one code (Sandelowski, 1995) and can result in word overload (Heath & Cowley, 2004). This was experienced within this study as when line-by-line coding the participants did not raise one issue per line. Coding can be conducted by sentence or even paragraph, once the researcher becomes more familiar with the data and concepts (Strauss & Corbin, 1990). However, Glaser (1978) supports coding each sentence and does not advocate only using the “overview approach”, claiming it is not thorough and

leads to researchers focusing on certain themes, instead of letting the themes emerge from the data. Despite these problems with line-by-line coding, Sandelowski (1995) states that whichever approach is used, it must be consistently applied. To avoid concept spotting, to be detailed enough to capture the participants' own meanings as concisely as possible, it was decided to look at each line of the data to try and make sense of what was being said and to identify patterns. Each line of the data was labelled identifying when participants had highlighted key terms (see table 8), and this continued to be completed with each data set to identify themes and concepts.

<b>Diary data to be coded</b>	<b>Examples of codes</b>
<p>Thursday 17 March</p> <p>pick-up a copy of "mens health" after swim &amp; sauna. didn't learn anything new only a couple of abs exercises and reinforcement of dietary advice from Tuesday's talk</p>	<p>Picking up information- informal source</p> <p>Not learning new information</p> <p>Reinforcing prior knowledge</p>
<p>Friday 18 March</p> <p>visit to doctor for regular 6 monthly b.p. check. has come down to "normal" levels. i also had him look at discolour-ation on lower left leg where there is some redness. he said continue with diplobase and report if any change. re b.p. no change in medication</p> <p>picked up useful booklet on ageing and where to go for various services. "a guide for older people" from ddd</p>	<p>Surveilling-formal</p> <p>Changing bodies/triggering</p> <p>Being aware of symptoms</p> <p>Picking up information- formal source</p> <p>Learning new information</p>
<p>Saturday 19 March</p> <p>inquired of training buddy, who is a cardiologist how one can have high b.p. yet low, resting heart rate? the two are not really linked as high bp is more to do with smaller blood vessels low heart rate is a measure of "fitness"</p>	<p>Selecting informal source</p> <p>Informal 'expert'</p> <p>Learning new information</p>

Table 8: Example of initial coding-excerpt from Tony's diary

Coding in this way led to the generation of a large number of codes and these needed to be reduced. There were some elements that were coded which were not helpful, descriptive and

needed to be amalgamated into a higher level code, for example ‘family’ and ‘friends’ were coded and this was placed into a code labelled ‘seeking support from social networks’. Each code and the data within it was re-examined and it was identified that some data and codes could be amalgamated, so for example, ‘using over the counter medication’ and ‘using home remedies’ could be combined as they were addressing similar issues.

Some of the actual words used by the participants were used as codes, as this helped to ensure that the meanings of the participants are preserved (Charmaz, 2006). Gerunds were also used whenever possible, as by coding for actions by using gerunds (verbs ending in ‘ing’) emphasises processes and actions (Charmaz, 2013). The use of gerunds, enables the researcher to see processes, make links between the codes, keeps the analysis emergent and ensures that the participant’s experiences remain at the forefront (Charmaz, 2013). This made it possible to gain a fresh insight into the health information seeking behaviours of the participants, by highlighting these ‘actions’. Also, I was aware of my impact during this process of coding, as it was my choice which words were coded.

After each diary and interview had been read through, a brief account was written, which included some paraphrasing and other comments that stayed close to the data as suggested by Sandelowski (1995). This helped me to gain a sense of what was being said by the participants. Another strategy that was adopted to gain a sense of the whole, was to create a storyline about the participants which involved reading the transcripts, standing back and identifying the key messages and themes from each participant.

### ***3.16.2 Intermediate coding***

#### **3.16.2.1 Focused coding**

The next stage was to undertake focused coding. Again, various terms for coding are used by different authors; ‘intermediate’ (Glaser & Strauss, 1967), ‘selective’ (Glaser, 1978), ‘axial’ (Strauss & Corbin, 1990) and ‘focused’ (Charmaz, 2006, 2014). Focused coding is used in two ways; to further develop individual categories by connecting sub-categories and develop the ‘properties and dimensions of a category’ (Charmaz, 2006 p60), and to link these categories together. It serves to bring the data back together in a different way (Strauss & Corbin, 1990) and examines the relationship between the sub-categories and categories. This

stage involves using the codes that are most significant and frequently used to explain larger amounts of data (Charmaz, 2006, 2014). It involved me making decisions regarding the initial codes and deciding which ones made the most ‘analytical sense’ (Charmaz, 2006 p58). As previously discussed an analytic frame was not used as suggested by Strauss and Corbin (1990), but the categories were compared with each other and the relationships between them questioned. Contexts and the settings of health information seeking behaviour were also considered, who sought health information, where, how and why they sought health information from, their responses to health information and what were the consequences of this. This assisted in the process of exploring the experience more completely and clarifying the components or properties of health information seeking behaviours in this study. The codes needed continuous reorganisation, involved me going back and forth between the codes and at this stage, memos were found to be invaluable. Key codes were extracted such as those that were used frequently and these were grouped together. For example in the excerpt above, I selected the codes ‘picking-up information’, ‘changing bodies’ and ‘being aware of symptoms’, which were close to the data and felt to capture the main themes in this set of data.

After each data set had been coded, previous codes and data were compared. By comparing the data, a focused code can be developed, with the next stage being a comparison of data to the codes, which assists in refining them. In the above example, situations were compared in which participants had become aware of symptoms which triggered a response to gain health information and when this had not led to information seeking. At first, the code only represented when they became aware of symptoms. As more data was gained, it was identified that an awareness of symptoms did not always lead to health information seeking. This code became a sub-category called ‘recognising disruptions’ as there may be the acknowledgement of symptoms, but a decision to do nothing.

### ***3.16.3 Advanced coding***

#### **3.16.3.1 Theoretical coding**

Theoretical coding is used in the later stages, with their purpose to move the ‘analytic story in a theoretical direction’ (Charmaz, 2006 p63). Theoretical coding follows the codes that were selected when undertaking focused coding and specify relationships between categories

(Charmaz, 2006). Using theoretical coding allows categories to be organised, the relationships between each category are clarified, links are developed between them and the theory is explained (Glaser, 1978). It is cyclical with coding occurring at several levels; moving between initial, intermediate and then theoretical coding (McCann & Clark, 2003a). Once the core category has been developed through this process, attempts need to be made to establish a link between this and other categories (Charmaz, 1990). Theoretical coding occurs when the core category is saturated and explores relationships between saturated categories and the core category. To assist with this process, Glaser (1978) provides examples of theoretical codes which are formal and highly abstract concepts and suggests the use of a 'coding family', as they can help to develop links between the codes. In this study, Glaser's (1978) coding families were not used to the extent that was intended as I believe that using these would lead to forcing of categories and would inhibit emergence. However, certain questions of the data were asked to explore the relationships between the categories and to facilitate emergence (Glaser, 1978): What is going on in the data? How does this relate to the research question? How do the categories relate to each other? How can they be explained? What is it that is helping older people to seek health information?

#### ***3.16.4 Coding example***

Using Tony's diary as an example it is possible to illustrate the development of these codes from initial to advanced coding (see table 9). From his diary entry on March 19<sup>th</sup> initial codes included: selecting informal source, informal 'expert' and learning new information. These codes at the focused coding stage became subcategories called: Seeking support, expanding knowledge and establishing credibility. Tony selected an informal source, from within his social network, as he was a retired cardiologist who was perceived to have valuable information and would provide medical expert knowledge specifically about blood pressure and heart rate. By making this choice, Tony believed he was approaching a credible source that was able to meet his particular information needs regarding his blood pressure, thus expanding his knowledge regarding his health. These intermediate codes were developed into the theoretical code 'self-mobilisation'. I asked what is going on here? How does this relate to my research question? What is it that was helping older people to seek health information? It became clear that a variety of information sources were mobilised by participants to fulfil information needs and this was incorporated within this category. Crucial to this process was health information seeking from personal informal sources, which was highlighted by Tony

when he wrote his diary. Tony approached an expert friend who he perceived would be able to assist him meet his health information needs relating to a concern he had regarding his health. At interview, Tony elaborated on his retired cardiologist friend who was a swimming partner and provided the explanation he had been given, although he also stated:

*...Even he said nobody's totally clear about this...*

Interview: Tony, 66, retired salesman

Excerpt from Tony's diary	Initial coding	Intermediate coding	Theoretical code
Saturday 19 March inquired of training buddy, who is a cardiologist how one can have high b.p. yet low, resting heart rate? the two are not really linked as high bp is more to do with smaller blood vessels low heart rate is a measure of "fitness"	Selecting informal source Informal 'expert' Learning new information	Seeking support Establishing credibility Expanding knowledge	Self-mobilisation

Table 9: initial coding to theoretical code

### 3.16.5 Constant comparative analysis

The process of constant-comparison guides the development of theory by continuing to build and substantiate emerging categories, during analysis the researcher looks for similar and differing opinions and aims to seek explanations for these (Appleton & King, 1997). The purpose is to view the data to see if it supports emerging categories. It is threefold and involves comparing incidents to incidents, emergent concepts with incidents, and then emergent concepts are compared (Holton, 2007). As this process continues a core category emerges. As analysis progresses, the recurrent themes are followed up during subsequent data collection and if the themes occur at a later stage by using constant-comparative analysis, this allows the researcher to return to previous accounts (Charmaz, 1990). Constant comparison is

ongoing and involves returning to the data to facilitate this process. Using this process enables the researcher to make comparisons between data, codes and categories. For example, 'doing nothing' about seeking health information was coded and then compared with examples of the code 'seeking information'. Diary and interview data was then re-examined to identify examples of avoiding, comparing and contrasting these with examples of actively seeking, which helped to identify the important characteristics of the phenomenon.

### ***3.16.6 Memos***

During the process of coding and constant comparison, memos were written to identify potential patterns in and between codes. The function of memos is to organise thinking as to how the data fits together and helps with the articulation of patterns and emerging possible links between codes (Glaser & Strauss, 1967).

Memo writing has been described by Birks et al. (2008) as a reflective process which not only aids memory, but also allows the researcher to question and analyse their data. They continue by claiming that this should be done throughout the research process which identifies the researcher's starting point as well as their impact. Memos also provide an audit trail of the decisions that are made and the conclusions that are drawn. With this in mind, at the start of the study memoing was commenced, this was undertaken within the reflective journal and proceeded to memo-writing when data collection started and continued throughout the research process. Writing memos allowed me to build upon and explore new ideas, to reflect on the codes that had been developed, assisted me to examine what each participant was saying and thoughts were recorded about issues that were raised within the interviews. They helped me to extract the meaning of what the participants were saying about health information seeking behaviours, about their lives and how this impacted on their information seeking.

### ***3.16.7 Theoretical sensitivity***

Charmaz (2006) suggests that theoretical sensitivity is acquired by the researcher stopping and thinking, comparing, considering multiple viewpoints, by following leads and building on these ideas. She suggests that using gerunds facilitates this process as it helps the researcher to see sequences and make connections. Strauss and Corbin (1990) identify

different ways to enhance theoretical sensitivity. The first is for the researcher to read the literature. As previously discussed, a preliminary literature review was undertaken prior to data collection and analysis and although this allowed me to familiarise myself with the literature about the subject area, it did not influence my emerging theory. A further source used to develop theoretical sensitivity is the researcher using their professional and personal experiences. Again I have previously reflected on my background as a healthcare professional and my personal experiences and this helped me to identify how the participant's experiences were similar or different to my experiences. The final source of theoretical sensitivity is the analytic process which Strauss and Corbin (1990) later call 'analytic tools' (Corbin & Strauss, 2008; Strauss & Corbin, 1998), which aim to increase the researcher's sensitivity to any potential constructs appearing in the data. Birks and Mills (2011) identify that theoretical sensitivity will be raised when applying the essential grounded theory methods and to promote the development of this memoing can be a valuable tool.

#### ***3.16.8 Theoretical saturation***

The aim in grounded theory is to ensure that theory is generated from the data (McCann & Clark, 2003a) and the researcher constructs theory as a result of their interpretations of the stories told by the participants (Mills et al., 2006b). Theoretical saturation occurs when the categories are fully developed or 'saturated' and no new theoretical insights are gained through gathering further data, which is important as the data forms the foundation of the theory (Charmaz, 2006, 2014). A judgement is made by the researcher that it is not necessary to gather further data (Wiener, 2007). When undertaking a grounded theory study, there are a set of processes that the researcher needs to follow, and by using these, it allows the researcher to ensure a robust exploration of the areas being studied which will help uncover the multiple realities held by the participants. By utilising a thorough sampling strategy this can facilitate the discovery of a variety of constructions and will help to discover the phenomena being studied (Appleton & King, 1997). Whilst it was difficult to select participants for this study according to their views on health information seeking behaviour, the setting of older people living in the community meant that I recruited a broad range of participants who varied in characteristics. These included gender, age, and marital status. During analysis, memos and field notes were kept to record my reflections as to whether new dimensions within the categories were emerging. By interview twenty five, I concluded that

no new issues were emerging and decided that theoretical saturation had occurred. A further four interviews were conducted to ensure that no further themes emerged.

### **3.17 Criteria for evaluating research**

The researcher should demonstrate both methodological and interpretive rigour when presenting their study (Cooney, 2011). Numerous standards of rigour for qualitative research have been proposed (Glaser & Strauss, 1967; Sandelowski, 1986; Guba & Lincoln, 1989). As discussed earlier in the chapter, Glaser and Strauss (Glaser & Strauss, 1967) and Corbin and Strauss (2008) adopt different criteria for evaluating research. Additionally Charmaz (2006, 2014) emphasises the importance of applying criteria which evaluate purpose and content and refers to four criteria; credibility, originality, resonance and usefulness. I have decided to select Beck's (1993) criteria credibility, auditability and fittingness to demonstrate rigour in this study as they provide direction in defining criteria for a grounded theory study. These criteria are explored in the following section.

#### ***3.17.1 Credibility***

Credibility refers to the trustworthiness of the study and aims to establish credibility of both the process and the product the researcher needs to demonstrate evidence of good practice. The study should also provide descriptions that allow for the reader to recognise these from their own experiences (Guba & Lincoln, 1989). It has been suggested that a prolonged engagement in the field can establish credibility, as this facilitates rapport, helps build trust to uncover participants' constructions, facilitates immersion and aids with understanding of the context (Guba & Lincoln, 1989). Twenty-nine participants were recruited; with contact being made with them on at least two occasions. The interviews varied in length, but on average they lasted an hour which allowed for an exploration of areas of relevance to the participants and covered a broad range of topics. Consideration was given to the researcher's stance, as to what exactly the relationship was between the participants and me and how close I was to the data. In this study, I was analysing the data and picking out themes so I would also be influencing the data, and to ensure these themes were important to the participant two strategies were employed. Firstly, when interviewing the participants who had completed diaries, I identified what I viewed as the key points from their diary entries and they were asked if my understanding of their perspective was accurate. Secondly, at the end of each

interview, the key points were summarised to ensure that these were indeed relevant and viewed as an accurate account. This is a way that credibility can be established and safeguarded (Chiovitti & Piran, 2003), which involves sharing what has been found and allows for confirmation from the participants that these are indeed accounts of their experience (Cooney, 2011).

Additionally, to enhance credibility, it is suggested that participants should guide the process and the interview guide should be modified accordingly (Chiovitti & Piran, 2003). According to Charmaz (2006) concurrent data collection and analysis, using constant comparative analysis and theory development which is grounded in data, adds credibility within grounded theory. I also immersed myself in the data during transcription and analysis which allowed me to get as close to the experience as possible, with decisions being kept in detailed field notes and a reflective diary. It is important that dependability is demonstrated, the study and its findings should be auditable, with a clear visible decision trail which indicates research decisions throughout the study (Sandelowski, 1986).

The purpose of member checking enables participants to access the data collected and for the researcher to gain feedback from the participants with regard to the interpretations of this (Sandelowski, 1993). Member checking can be informal or formal, provides the participants with the opportunity to correct any misinterpretations, offers them the opportunity to add further information, allows the researcher to summarise the data and provides a chance for the participant to confirm agreement (Lincoln & Guba, 1985). However, member checking can cause conflict, where participants search for themselves and their reality in the accounts, whereas the researcher is representing multiple-realities with Sandelowski (1993) highlighting that sometimes, the participants are more interested in descriptions of their own experiences rather than the abstract that includes them with other's experiences. For this reason, member-checking was not undertaken within this study. However, each participant was asked if they wished to review the transcripts, which would allow them to add or remove anything if they wished. None of the participants requested their transcripts.

### ***3.17.2 Reflexivity***

A key aspect of constructivist grounded theory is that the researcher should be reflexive and consider how they contributed to the theory (Charmaz, 2006). Therefore the researcher is not

considered to be ‘neutral’ during the research process. When identifying relevant data, the researcher plays a role in coding this (Charmaz, 2006). I reflected upon and considered my role in the gathering of data, with regards to interview questions, coding and analysis. The participant is viewed as the key informant, although I ask the questions and identified areas that I wished to be explored. Therefore, my role is integral to the data analysis process and the emerging data. The emergent theory is therefore a ‘construction’ developed between the researcher and their participants (Charmaz, 2009). Reflexivity is the process of critically reflecting on ‘the self’ as researcher (Guba & Lincoln, 2005). Indeed, I have learnt the importance of self-critiquing and self-appraisal through every aspect of the research process and how I can impact on the process. For example when undertaking qualitative interviews the researcher and their personal biography can affect the research (Kvale, 2007). Due to this, I must also be aware of how previous research, my own values and beliefs and life experiences, including being a Health Care Professional and someone with older relatives, can impact on the process. Keeping a reflective research journal has helped me self-evaluate and reflect on how I might have had an impact on the research process. It also helps a researcher develop insight and guides future actions (Birks & Mills, 2011). An example in the following excerpt from my journal (see table 10), demonstrates how I was feeling when I undertook this particular interview, how important the follow up interview is and how I felt some of the literature may be impacting on the interview process:

27<sup>th</sup> July 2011.

‘The interview went well, really worked hard on not speaking too much-although my mood was quite low due to dads biopsy results which I think did affect my feelings during the interview, as I really didn’t want to be there-but I tried to remain professional and focus on the diary and what the man said during the interview. The interview really helps clarify things that are written in the diary e.g. I wondered why he was interested in Wiels disease as there had been a lot of interest in local press and I wondered if that had influenced his search-no it was due to his swimming outdoors. ....He also mentioned about monoclonal antibodies whilst he was in hospital-turns out he read it on a display in the hospital and it wasn’t related to his own personal health problems-if I hadn’t had the opportunity to explore this with him I may have been barking up the wrong tree! So I think the two methods are definitely essential to ensure a thorough understanding of what is written.

The other thing that stood out to me during this interview is that because of the recent piece of written work that I completed as part of the doctoral programme, I am now more aware of some of the literature and research around lay health and illness beliefs and I did think that this has influenced some of the interviews and questions that I have undertaken more recently-mainly the last lady and this

gentleman for example-when I asked about complementary therapies, hereditary and I do feel that although some of the earlier diarists did mention these things, I picked up on them and explored them further because of the literature-or was it because the other diarists had mentioned them in their diaries and at interview and here is constant comparative analysis, picking out themes and exploring them in greater depth.'

Table 10: Excerpt from reflective journal

### **3.17.3 Fittingness**

There will be a variety of views and themes that emerge and Guba and Lincoln (1989) discuss difficulties in drawing generalisations, due to the unique contexts, stating that when studying human behaviour, generalisations are meaningless as they cannot be separated from either context or time. However, Guba and Lincoln (1989) also claim that the detailed descriptions provided within the research should allow others to draw similarities, which facilitates the application of the findings to their own setting (Sandelowski, 1993). Thick description (Geertz, 1973) is key when addressing transferability and involves capturing enough detail of the context and social realities which allows the reader to transfer the results to their situation (Denscombe, 2010). Thick description involves including an extensive description of time, place, context and the culture where the research has been undertaken (Guba & Lincoln, 1989). Chiovitti and Piran (2003) suggest the setting and demographic characteristics of participants should be in enough detail to allow others to judge transferability of findings. To illustrate thick description, the findings in the next chapter present excerpts of interview narrative which provides evidence for transferability. Potential transferability can be demonstrated by highlighting any similarities that might be apparent between the findings of the study and prior literature and theory (Chiovitti & Piran, 2003). This is further explored within the discussion chapter (see chapter 5).

### **3.17.4 Auditability**

Auditability requires the researcher to record an audit-trail throughout the research process which includes keeping a thorough record of methodological decisions, including a record of data-sources, sampling and analytical decisions (Cooney, 2011). This can be demonstrated when the reader can follow the decision-trail of all decisions made by the researcher at every

stage of the research process. Chiovitti and Piran (2003) suggest methods of research practice that can address the issue of auditability. These include writing a reflective account which outlined my professional and personal background, personal beliefs, assumptions and values. They also identify that it is important to explain how and why participants were selected. As previously discussed, purposive sampling was used initially as there was no data to direct sampling. The participants were recruited in response to the information provided by previous participants and continued to be recruited until theoretical saturation was reached. Categories appeared to be saturated, as during analysis of later interviews no new themes were seen in the data.

### *3.17.5 Originality*

Originality is measured in terms of whether the research study offers new insights into the empirical area. This can be demonstrated by providing new insights into the process of the health information seeking behaviours of older people and the development of a conceptual framework. The process of health information seeking occurs in diverse ways and these findings build on existing research which is relatively limited. Health information seeking behaviours are dynamic and change over time. A conceptual framework is presented which presents the process of health information seeking behaviour, the nature of this and the contextual factors affecting this. This provides evidence of the health information seeking behaviour of older people, illustrating that this is relevant to a broad range of older people living within the community.

The following chapter discusses the study findings, which contribute to a greater understanding of the health information seeking behaviours of older people.

## **CHAPTER FOUR**

### **FINDINGS**

#### **4.0 Introduction.**

The purpose of this chapter is to present findings from the study data. The data was derived from nine diary interviews followed by twenty qualitative interviews conducted with older people. Following the principles of constructivist grounded theory (Charmaz, 2006) the major categories are inductively drawn from the participant's responses. The analysis suggests three main categories that explain the health information seeking behaviours of older people, culminating in a typology of health information seekers which contributes to developing a greater understanding of the complex nature of health information seeking behaviour. The chapter is divided into three sections to reflect the categories, followed by the typology and concludes with the overarching core category of navigating later life (Strauss and Corbin, 1990) which connects the categories.

#### **4.1 The health information seeking journey**

Multiple views of the phenomenon of health information seeking were identified, located in larger social structures and discourses. Meanings reflected individual's beliefs, with actions reflecting beliefs, discourses and social conventions. The findings suggest that in order to seek health information individuals embark on a metaphorical journey (see figure 5) which is shaped by experience and the nature of later life. Following data analysis it became clear that there were a set of stages that participants progressed through when embarking on the health information seeking journey. Three interrelated conceptual categories were identified that explain the health information seeking behaviours of older people: self-regulation, self-management and self-mobilisation.

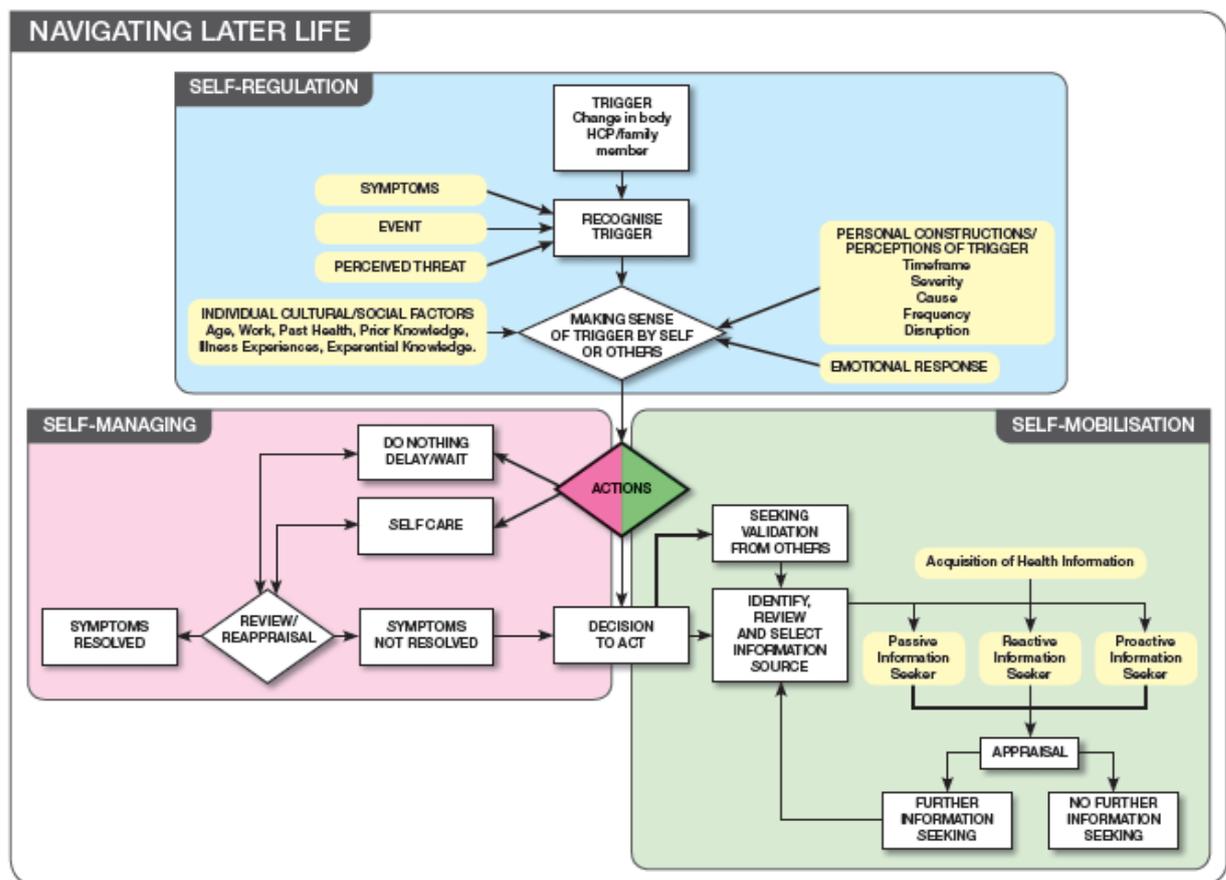


Figure 5: Health Information Seeking Journey

Events prompted information seeking behaviour being undertaken, with triggers providing the motivation to seek information. To understand the complexities of the health information seeking journey, it is important to understand what motivates and impacts on older people's decisions to seek or not seek information. To place the health information seeking journey in context and help understand the whole experience, it is necessary to identify what occurs prior to older people seeking health information. Therefore, the categories emerging from the analysis, although not directly related to health information seeking behaviour, provide the context and are necessary to build the story of the whole journey.

The health information seeking journey commenced with a period of self-regulation. In order for participants to self-regulate they needed to know their body, recognise health changes and monitor health changes. A trigger/change in their body and recognition of this started the process, which was influenced by individual cultural and social factors. Furthermore,

perceptions of the trigger affected decisions regarding the next stage of the health information seeking journey.

Despite participants experiencing health changes, monitoring these and recognising changes to their body this did not mean that health information was sought in every situation. Self-managing was a key theme that emerged, and was a moderating factor within the health information seeking journey. As illustrated within the figure, certain actions were undertaken with self-management fundamental to this stage. Within this stage participants maintained their health, self-managed health changes and self-treated. The next part of the journey depended on the outcome of these tactics and impacted on decision making and health information seeking.

Self-mobilisation describes the actions taken by participants when there was a decision to act upon a change in health. This category identified that participants build knowledge, seek support and establish credibility of information sources. It was necessary for participants to identify, review and select information sources that met their information needs. It was clear that different patterns of health information seeking behaviour emerged between participants with the acquisition of health information related to a typology of the older person as information seeker. Once initial information seeking had occurred, participants either ceased the search for information or health information seeking continued from the various sources available.

The core concept 'navigating later life' integrates the three conceptual categories and describes how participants navigate health information to negotiate later life.

The first section of this chapter will present the data that through constant comparative analysis provided evidence for the category of self-regulation.

#### **4.2 Self-regulation**

The health information seeking journey was initiated when participants experienced a trigger, for example: developed symptoms, interpreted these, made choices with subsequent actions that defined and structured the future of the illness experience. Prior to engaging in the health information seeking process, participants took part in processes involved in self-regulation.

To self-regulate participants needed to know their own body, how it worked and recognise when something was wrong with decisions based on this knowledge. This section presents these processes which are: 'knowing their body', 'recognising health changes' and 'monitoring health changes'.

#### **4.2.1 Knowing their body**

Analysis of the data illustrated that for most of the participants health information seeking behaviour happened as a result of them noticing a change in their body. By knowing their body through a process of self-regulation changes were recognised, acting as a trigger to seek information. If a change in bodily function occurred, participants noted that this could mean that there was something wrong. Changes manifested themselves in two ways, either as sensations or changes in their body's appearance. Sensations were frequently described as fatigue, loss of appetite but most commonly pain was discussed:

*Er....well pain is the body's way of telling you that there is something wrong that there may be something wrong er and its notional it's just the message going from wherever to the brain er as a warning..*

Interview: Sue, 68, retired receptionist

Recognising changes to their bodies was also common, with comparisons made to how their body normally appeared and noting alterations. Generally, when their known body altered, participants made decisions to take action to reduce health threats:

*... I always had 1 testicle which I thought was ruptured which the doctor said boys are often born like that and er it got big'*

Interview: Craig, 78, retired sheet metal worker

In everyday life, the body is experienced unconsciously and taken for granted. But when there was a health change, this resulted in an increased awareness of their body, bringing it into perceptual consciousness as the participants gaze turned inwards on their body and how it worked, or did not. The complexity of their body becomes particularly evident when experiencing a long term condition or a threat to health. Having a long term condition increased awareness of their body and any changes that occurred, which were often quite

subtle but raising it to consciousness. This presented itself as a general awareness of their body's functions:

*.. And we don't realise how complex our bodies are until you've had something like cancer. You realise what all your organs that...you know, it's incredible.*

Interview: James, 79, retired builder

For others, specific awareness of the part of their body affected by disease was described in relation to body limitations and how this was dealt with on a daily basis. When describing the malfunctioning body, participants described functional ability and restrictions, highlighting how this impacted on everyday life:

*...I've got a fold up stick that I bought years ago. And I said, I have to get that out because when I go up and down the steps, I like to be able to put that on another step and then put my leg...It's the instability of it that it doesn't want to take the weight. And it just goes and you can't take...it's hard to describe. You just can't put your weight on it because it won't take the weight. And you're conscious of it. So, I think I should do that just to make sure I've got that bit of confidence.*

Interview: Millie, 76, retired office worker

The data suggested that participants viewed some physical and sensory functions as a higher priority, adopting a hierarchical approach to decision making and health information seeking. If a change in their body was perceived as an increased threat to health and functioning then participants were more likely to seek help for this:

*... no I think this is just erm tiredness in a way I think well that's what I am telling myself but I thought no I want to go you know you don't ignore your eyes you can ignore pain can't you but erm no..*

Interview: Judy, 78, retired shop worker

There was a sense of participants knowing their body including how it performed, its idiosyncrasies and understanding its needs. If a change in health affected body function impacting on the ability to carry out activities, in these situations the participants had learnt to trust their body's messages. Judgements were made as to whether this was something familiar or perceived as a threat and further illustrates how knowledge of their body influenced information seeking:

*Very slow to start today. Whole body feels drained. Is it a bug or should I see the doctor? Hiatus hernia is playing up too. Take a pill.*

Diary: Sue, 68, retired receptionist

Whilst a pattern started to emerge of how participants knew their body, the responses are further illuminated by those who initially misinterpreted unfamiliar changes to their body. Occasionally, there was a misunderstanding of what their body was communicating with participants misdiagnosing what could have caused the changes. Their body had become unfamiliar, but the information received proved difficult to understand and open to interpretation. This could have been an avoidance tactic or hoping it was something less problematic, with a wait and see approach adopted. One man reflected on a previous symptom misinterpretation which turned out to be bowel cancer. He initially started to think of alternative explanations, finding logical 'normal' explanations for symptoms. Originally, he suspected his symptoms were due to normal illness as they made him feel unwell, but at the time had no serious features. As time progressed and symptoms persisted this prompted him to realise this was abnormal and needed intervention:

*I waited a little while which is foolish really, I waited probably two, three weeks. I thought it might have just been a bug or whatever you got going on, a virus but, and then my body was telling that there was more more to it than that.*

Interview: James, 79, retired builder

By knowing and understanding what was normal and abnormal for their body, the participants were able to recognise changes. However, some demonstrated a tacit knowledge

of their body, where there was recognition of something unusual but were unable to explain what it was:

*When I was getting these... I was getting problems. Not really breathing but I was just feeling as if everything was just draining away from me, you know. And I haven't...I got at one time, so I was a bit afraid to go into town by myself because I'd have these sort of sense. I didn't...it's difficult to explain... No pain but difficult to know how I just felt.....And feel...yeah, that you're just draining of all energy, you know?*

Interview: Erin, 77, retired secretary

One participant taking warfarin highlighted how he sensed when his International Normalized Ratio (INR) was outside his normal limits:

*Yep, you have a target between two to three, it never remains static.....I can tell when it goes over the top....Because it's the staircase, we've got 2 flights of stairs and when it's over the top I go up to the top floor I get this sort of breathlessness. So I always know when it's gone up you're sensitive to the change.*

Interview: Alan, 80, retired architect

Self-regulation was a process that occurred with the recognition of symptoms being facilitated by knowledge of their body and decisions were based on this assessment. Health information seeking behaviour and actions depended on perceptions of symptoms and the desire to gain more information about their body and changes. However, the perception of symptoms and the cause of these were also influenced by beliefs regarding the ageing process. The next section will now progress to explore the impact of explanatory causes developed by participants and focus on beliefs about ageing.

#### 4.2.1.1 Ageing bodies

Rather than attributing the cause of health problems to disease processes or infection, participants suggested that changes were often caused by intrinsic factors. They spoke about their age in relation to their health and its general deterioration. Participants attributed their body changes to ageing; the wear and tear their body had experienced over time, how this

impacted on their body in later life and how functional ability was affected. There was a general perception that their body had worn down or deteriorated with age, with symptoms rationalised as age-related deterioration. Coupled with this, there was a decreased expectation of functional ability and health in later life with some participants accepting these changes and discussing what it meant to be older in relation to their body:

*..obviously you know, of a certain age, things don't always work quite as well as they always do or used to, but uh you learn to live the fact that you can't do quite so much as you used to and physically you can't do so much*

Interview: Tom, 74, retired book keeper

There was evidence that some participants assumed pain was a normal part of ageing. This belief potentially impacts on health information seeking behaviour as symptoms attributed to normal ageing maybe less likely to be reported and receive medical treatment. Furthermore, the data suggested this and lower expectations of health older people resulted in a perception that there is no benefit from seeking health information:

*But I mean I can it just feels a little bit stiff occasionally but that's when I get up mornings. But then again age-wise you're going to get you feel aches and pains I feel.*

Interview: James, 79, retired builder

The belief that body changes were due to the ageing process was a common theme, and participants often attributed certain health problems to old age rather than disease processes, viewing health concerns and deterioration as a normal part of ageing:

*...I don't feel like I've got any shock absorbers anywhere when I do anything my whole body jars seems to jar, it's it is all like the cartilages and everything are not the same when you get older I just feel I want somebody to tip a can of oil all over me inside me and oil them all up (laughs) that sort of thing but it just happens don't it we*

*all get aches well we do all get aches and pains sometimes you get a pain in yer stomach I mean at this end of life..*

Interview: Pauline, 77, retired secretary

Participants adopted a life course approach to ageing and reflected on previous experiences which were believed to have resulted in body changes. Not only were the ageing body and previous illnesses perceived to be the cause of current health problems, but other external explanatory causes were also considered. Explanations were provided as to the impact that the work environment had on health in later life and how this affected their body:

*...and the machine in the rush hour, the machine was producing 8 decibels over the legal limit in rush over a hundred yards away and that was what did the damage..I have my ears, I am partly deaf in this ear, I can't hear when I put the indicator on, I can't hear the bleeping the fridge there the fridge it's got a very high pitched noise, I can't hear it at all..I can hear all the very low decibel's but that was machinery at work... I think that's my own opinion I just think work environment contributes a lot..*

Interview: Craig, 78, retired sheet metal worker

The cause of health problems included bad luck, however the hereditary nature of some diseases was also mentioned and how this impacted on health in later life. Being aware of family history heightened sensitivity to changes occurring in their body and impacted on the interpretation of symptoms. Others identified that there was a family history of certain medical conditions and this linked to beliefs about what caused the health problem and the perceived threat this might have on health. This was highlighted by one woman who had mild heart failure which led to her experiencing breathless and light headedness but she had also recently had previous surgery for a malignancy:

*...And heart problems are quite embedded in our family. They don't die of cancer, die of heart.' (Laughter)*

Interview: Annie, 75, retired office worker

Despite her identifying that cardiac problems led to mortality in her family, she only made a few comments about her cardiac condition, as she focused on her recent cancer experience

during the interview. However, this awareness of family history appeared to heighten her sensitivity to bodily changes which alerted her to seek further health information. This was further reinforced through the regular cardiac information magazine her husband received post his stent insertion for cardiac problems.

In other examples, rather than awareness there was suspicion of family history which also acted as a powerful trigger for information seeking. Another woman mentioned that her family tended to suffer with either cardiac or cancer, but she was unclear of her past family history as this had not been discussed openly in the family. This was further compounded by her husband's history of cardiac arrest when she was young, resulting in her ensuring that her BP was recorded and her heart was listened to on each visit to the GP.

Despite the cause of some health problems being attributed to age, some perceived symptoms as possibly serious and worrisome, resulting in information seeking. This depended on the participant's perception of their altered health status, which prompted attempts to reduce health threats. For some, the motivation to seek health information in later life was believed to be a way to address health concerns, protect health and to act as reassurance:

*I think when you get to our age; you've got to take care of yourself. And you have to be aware that you could easily get an illness. And I don't think it would be wise at this age to not go to the doctor's. Some people would pretend it will go away if they don't go to the doctor's. I don't believe in that.*

Interview: Millie, 76, retired office worker

Due to the changed circumstances in later life and the consequences of an altered health status, some participants had the attitude that it was important to carry on and make the best of the situation. As a result, adjustments were made with the reaction being one of:

*You just have to go on*

Interview: Millie, 76, retired office worker

This sentiment appeared to be reinforced by some healthcare professionals, with participants keen to follow this advice. One participant had become apprehensive about leaving his house; previously he had experienced some falls and collapsed in the City whilst shopping. The

cause of the collapse was not clear, but appeared to be cardiac in nature:

*Yes, the doctor she said “you’ve just fight it” she said “there’s nothing that I can really do it’s up to you really to get on top of it”, so I came home and said to Kate [wife] “I think I’ve got to come to terms with this” and I did make a great effort, because I got to the point where I daren’t leave the house and I wouldn’t go into town on my own because I had this absolute dread that I was going to collapse*

Interview: Alan, 80, retired architect

Self-regulation was influenced by the ideas and beliefs of health and illness in later life. Explanations regarding the cause of body and health changes and expectations were often attributed to the ageing process. Perceptions and attitudes to ageing impacted on expectations of health and functional ability and influenced decisions regarding health information seeking. This illuminates how beliefs regarding ageing can facilitate or hinder health information seeking behaviour. Furthermore, as part of coping with health changes in later life, modifications and adaptations had to be made. The following section will explore some of the coping strategies and styles used to adapt to changes in later life.

#### 4.2.1.2 Adapting self

There was an awareness of how their body had altered over the years and the impact that ageing had had on the ability to undertake activities. Learning to live with body limitations and unpredictability, participants adopted various coping strategies and styles including acknowledging that there had been changes to their body and incorporating modifications to lifestyle and activities as they became older:

*I think, well, I used to do like workouts and stuff when I was younger, doing that type of thing. No, I'm quite...I don't do a lot, do I, really? We garden and stuff like that but I mean...And then, it's just that arm. And it's...during the daytime, I forget about it*

*until I do something and think, oh, I shouldn't have done that because I've got...but it's round about 10:00 at night it starts again. Especially...well, whether it's because your body's getting tired...*

Interview: Jess, 66, retired PA to factory manager

Key to adapting self was an acceptance of how lives had changed as the result of ageing or a medical problem. Typically, accounts described the impact that declining health had on their lives, acknowledging the importance of accepting these changes and learning to live life differently. Although there was acceptance that there were a number of things they were no longer able to do, some reframed their lives to accommodate this. This process was reinforced by comparisons with contemporaries of a similar age, with suggestions that the high degree of health problems within the social network was due to old age:

*Yes. You've got to accept your own limitations. I think if you do that when you're older, then, you lead a happier life because you're not all the time bothering about, oh, years ago, I could run up the road..I think..when you get old, you can lose sight of your own body. But I think...like I know that I can't run now. So, if the bus comes, I don't try to run to get in the bus. I miss it. Because if I run with my knee, I might trip and fall. It's a waste of time. I know I can't run; I wish I could run but I can't run anymore. But you just accept it and what 76-year-old can run up the road?*

Interview: Millie, 76, retired office worker

However, some participants demonstrated that they were actively fighting to maintain and continue with activities. Often participants described everyday joint pains which limited their ability to perform daily activities. Changes to health resulted in adjustments and typically incorporated adaptations to the way that activities continued to be carried out. When the cause of the pain was known, lifestyles would be adapted to accommodate the pain, for example stopping activities until the pain subsided. The following participant had polymyalgia rheumatica which caused pain in both shoulders and she described adjustments that were made, so that she could continue to be independent and tend to her garden:

*So, if I really get stiffened up, well mind you I do push myself out there, laying slabs and things. I shouldn't be doing I know (laughs) but erm I'm moving pots and that,*

*there's no one else to do it, if you've got to move them you've got to move them. I know I do push myself in that sense and I do now have to stop and come and sit down for 5 or 10 minutes and then I have another go.*

Interview: Pauline, 77, retired secretary

For some, there was a sense of trying to take control, with self-help and being independent highly valued. This was particularly noticeable in those living alone; as there was no one available to help, they just had to get on with it. The data suggested that by knowing their body and symptoms it was possible to carry on with activities by taking medication to relieve symptoms, which was especially apparent with pain. Prevention was also a strategy with over the counter (OTC) analgesics taken to prevent anticipated pain:

*Just one paracetamol when I go bowling*

*Why is that? (Interviewer)*

*Well they are painful I'm not kidding sat here they're not but um you know when I go on me kneeler and if i do too long I struggle to get up its really hard work (laughs) but I just curse and you get up there's nobody else going to do it*

*So you just take 1 paracetamol before you bowl? (Interviewer)*

*If I'm going to bowl or I think I'm going to do something what affects my knees anything makes it easier don't it but I don't take em every hour or anything like that no no*

Interview: Judy, 78, retired shop worker

Some of the adjustments and adaptations that were made to cope with an altered health status have been explored within this section. Participants self-regulated and monitored symptoms and by having knowledge of their body, adapted to accommodate this, either by avoiding certain activities or self-administering medication is further discussed in 4.3.2. For participants, knowing their body facilitated the process of recognising health changes which is discussed in the next section.

#### **4.2.2 Recognising health changes**

Health changes in this section are defined as anything that the individual felt was impacting on their daily life. In order for participants to seek information about a specific health

concern, changes needed to be recognised. When health changes were experienced, choices were made regarding which pathway should be followed (see health information seeking journey figure 4). Health changes impacted on the participants normal identity, potentially affected the future, their independence and were perceived as a challenge; physically, socially and/or emotionally. The management of the illness required regulation of the self, especially physical and emotional states. This was influenced by perceptions of the health change; its severity, timeframe, cause, frequency and emotional response.

#### 4.2.2.1 Degree of health change

Health changes were a key triggering factor for health information seeking behaviour. The presence of a symptom alone was often not enough of a trigger to seek health information, as other dimensions of the symptoms were considered. The perceived cause was contemplated, the possible reason for these unfamiliar symptoms and the extent to which these health changes impacted on everyday life. One woman reflected on the unresolved disruptive nature of her symptoms, attempted to identify the cause of these, with the persistent nature of the symptoms prompting a visit to the GP:

*While I was keeping the diary I'd been very very tired. I could sit down there and go to sleep and it will be a case of difficulty keeping awake. This is what prompted me to go to the doctor's, the fact that I was always tired and um could nod off at the slightest thing erm but that's passed er. I think that was more stress with this family thing that was happening back then, I was doing a lot of listening*

Interview: Sue, 68, retired receptionist

Whilst recognising health changes and the impact these had, a lack of control over what was happening when undertaking activities was also a cause for concern. Again, participants tried to seek an explanatory cause for persisting symptoms with the following participant seeking health information from various sources such as the pharmacist and members of the informal social network:

*Yes, the reason for that was that sometimes when I play squash I er and I will erm and I can get that feeling of very low energy that you get when your blood sugar isn't*

*converting...I had that 2 or 3 times and for no apparent reason, in so much as my diet hadn't changed or whatever and I can go to the gym where I'm in control it doesn't bother me, I don't get but with squash you are less in control and it's more a reasoning*

Interview: Bruce, 73, retired engineer

If health changes were perceived as serious, an immediate search for information was triggered. Examples included acute declines in health being recognised or symptoms so severe that it was felt necessary to take immediate action:

*It happened when I was at the surgery and I was working one afternoon and I said to the GP I have a very strange effect in my eye, and I can't see the computer and I described it, it's very strange like a little pond, a circle which moves around wriggly and in the middle of it lightning flashes wriggling, but it will move around but stay in one eye. It was very distressing. So she was worried, so she phoned a doctor who is an eye specialist, who is a doctor at the practice I go to*

Interview: Louise, 73, retired nurse

Physically debilitating symptoms impacted on daily life with consideration given to the longevity of these. Most participants identified a perceived normal time line for the development and duration of an illness and when symptoms should dissipate. However, information would be sought if the symptoms persisted longer than anticipated or failed to respond to self-management:

*I then noticed that when I went up to the second storey of stairs, my legs got tired and I had to sit down and I was completely short of breath and this went on, I suppose, for a couple of months*

Interview: Alan, 80, retired architect

#### 4.2.2.2 Accommodating familiar symptoms

Familiar symptoms that did not change were integrated into the fabric of participant's life, over many years, and were not perceived as a cause for concern. Symptoms were often characterised as having non-serious features and were commonly gradual in onset. These included problems with mobility, hearing, eyesight and general aches and pains and were accommodated within daily life. The following woman had fallen two years ago, resulting in a fractured shoulder which continued to cause pain; she explained how she adapted her life to accommodate her symptoms:

*...so I can do all the sort of weeding. I don't let it get too bad but I do weeding and deadheading and I can plant things because I can dig a little hole with my right arm, but I have to be very careful treat this with respect...But I don't feel ill with it I just get annoyed with it...If I happened to turn a bit awkwardly which you do in bed say you're back to this side or off here you know wherever, um it makes me jump a bit but it's a momentarily thing I sort of rootle around it just gives me the impression that something is still out of place. Because I rootle around and it goes you know. (pause) So it's still literally a pain in the neck but not often you know I don't it's just my mobility effects, my mobility I can't I can't get my arm up to reach anything.*

Interview: Penny, 82, retired from working in social services

This familiarity with their body extended to those who had medically unexplained symptoms. Participants described how they adapted their life to accommodate symptoms, which despite numerous investigations and health information searching had an unknown cause. For the following participant her symptoms occurred when she was driving long distances and she fell asleep, as she had warning signs and was aware of this occurring she took certain preventative actions:

*.... I go to St Peters sleep resource centre because...I fall asleep at the wheel.*

*(Laughter)*

When you're driving? (Interviewer)

*I don't so much now. Well, I don't know because I know what to avoid. But...with this machine, actually, they had to record it all and they said it was inconclu—I also*

*went to the diabetic clinic. Inconclusive. Well it...could be narcolepsy but that's not...they haven't given a name because it's not like in the day...it's not like when I'm talking to people...But I do know I get...it's a real, it's a real horrible feeling that I get and...it's fighting that is the wrong thing... So we've got it down to a fine art. I mean, I think, if I caused an accident through falling asleep, I wouldn't forgive myself.... But I do know when it's happening. But I know—I mean, I look awful. I go white around here, I feel like death. I have a sleep, and I feel better but I mean, that's a bit like...everything else, I've learnt to manage it*

Interview: Caroline, 67, retired nurse

However, an exacerbation accompanied by an increased intensity of symptoms meant that attempts were made to make sense of the unfamiliar. An explanation and possible causes for these symptoms and health threats were explored:

*Lots of walking and my foot is extremely painful at the moment. Perhaps I should get it checked, but I've had the problem for 20 odd years. Still, it IS [her emphasis] swollen tonight which is unusual. I figure there is probably some arthritis in it now.*

Diary: Sue, 68, retired receptionist

A learned pattern of response was demonstrated when familiar symptoms were experienced which indicated that health was declining. When familiar symptoms followed a pattern, this often meant that further health information was needed. This familiarity led to a comparison of symptoms with past experiences, which highlighted their significance. One man described how he had experienced recurrent infections in his body over the past 38 years after damaging his knee in a road traffic accident. He had learnt to recognise the rapid decline in his health which he described as always presenting itself in the same way. He clustered the symptoms together to make sense of them and as a consequence this symptom recognition led to him seeking medical help:

*.....The symptoms have always been the same, I get the feeling that I've got flu coming on, joints start to ache, I get a temperature, I get bright red inflammation on all the damaged tissue and a large egg like swelling in my lymph node in my groin. Right, that has always been the case, this may happen once a year, once every five years,*

*completely out of the blue and the rapidity of it coming on literally can be quarter of an hour from being fit and well to being a quivering, shaking mess....'*

Interview: Tony, 66, retired salesman

Whilst familiar symptoms were accommodated into everyday life, if these altered or the nature changed this often triggered health information seeking behaviour. Participants continued to self-regulate and appraise symptoms and if they altered or were perceived to cause a threat then further actions were taken. In the next section, there is an exploration of participant's perceived health threats and the actions that were taken to reduce these.

#### 4.2.2.3 Perceived threats

The uncertain impact that symptoms might have for the future proved for many to be another motivating factor for seeking information. Participants reflected upon the pre-diagnosis stage of a long term condition often expressing anxiety about persisting symptoms, concerns as to whether these might be long term and the implications of this. Here a participant spoke about the perceived threats and the implications of the symptoms on future life which caused concern and motivated health information seeking:

*Yes. So, I must have been quite concerned about it....I think I must have been because I think I was finding that I couldn't turn my head. I think that worried me. Because I thought, "Oh, gosh, about driving" you know.*

Interview: Carol, 83, retired primary school teacher

Perceived threats were also considered post diagnosis and impacted on health information seeking. Once diagnosed with a long term condition, the uncertainty of the condition led to an evaluation of the changes that this would bring for the future. In an attempt to alleviate anxiety about the implications of diagnosis, health information was actively sought:

*Looked up osteomyelitis & tkr [total knee replacement] revision on google. Not comfortable with what I learned as both sound rather serious*

Diary: Tony, 66, retired salesman

External alerts also heightened awareness of perceived threats and motivated health information seeking behaviour to identify vulnerability. One man illustrated how an external alert had motivated an information search. He had been notified by the open water swimming club, to a potential threat of contracting Weil's disease which motivated a search for information. Whilst keeping his diary he noted that he had sought information about Weil's disease. During his interview he concluded although it would be rare to contract the disease, he had accepted that he may be at risk and avoided swimming in that environment:

*....and the team have suggested suddenly that I don't go in lakes any more, just at the risk, well look at me now, I did some gardening yesterday, so not withstanding now anything now with an open wound, anything could get in it, not particularly the ingestion of water would be the risk .It would be through .....Scrapes and cuts have always got. They seem to think the sea is far less risky than a lake.*

Interview: Tony, 66, retired salesman

Whilst knowing their body and recognising changes were important factors in shaping self-regulation and health information seeking behaviour, this next section will now explore how surveying the self through monitoring health changes is also a vital aspect within this process.

#### **4.2.2.3 Monitoring health changes**

By monitoring health it was possible to recognise further changes, with decisions made regarding whether to follow certain actions which included seeking health information, do nothing or self-manage the condition with self-monitoring (see figure 4). The health change usually presented itself as a symptom and participants monitored this for further changes. Sometimes these symptoms were subtle, with initial symptoms not being reported but monitoring continued; if symptoms persisted or there was further deterioration health information or medical help was sought. The following participant noticed subtle changes of

altered and deteriorating vision over a period of time; the persistence of symptoms and his perceptions of these suggested that it had become worse which eventually prompted health information seeking:

*I can't remember precisely but very luckily I have a or had an alarm clock and it had a little red light on it and I began to noticed the red light was invisible and I moved my head and I could see it...and it got worse, that little red dot, then it disappeared from my right eye and also a big black blob appeared, it got worse, that's what I have now, a big black blob, just peripheral vision in the right eye.*

Interview: Pete, 85, retired from managing car repair panel beating business

Again through self-regulation, there was a sense of knowing what was normal and abnormal for their body. Not only did the presence of a new or unfamiliar symptom lead to continued monitoring, but judgements were made as to whether health information was needed, with emotions such as fear and anxiety motivating behaviour:

*I didn't really...no, I didn't really think about that. I just thought it was a freckle that was.... I didn't really even consider it. And I had something here that was new, and I'd...and it was speckly, and I thought. "Oh, I don't much like the look of that.*

Interview: Caroline, 67, retired nurse

Recognising changes and symptoms was common and was integral to self-monitoring. There was an attempt to reflect on potential reasons for this decline in health, an interpretation of symptoms and attempts made to identify a possible cause. Again, causal attributions were assigned to symptoms where participants attempted to find logical explanations for what was occurring:

*Lay awake mulling it over and realised that although I had had my usual tea & coffee consumption in the day, I had not drunk any water. This also applied when I was away. So I got to thinking that maybe it was akin to gout and that my kidneys were not flushing properly. I shall drink more water today and take note. It is spasmodic so*

*even if this is not the cause, it will be interesting to see if it has any impact. I normally do drink water*

Diary: Sue, 68, retired receptionist

Whilst a pattern started to emerge of how participants self-monitored, the responses are further illuminated by the data provided by those who described how comparisons were made with other older people. As previously discussed, participants did compare themselves to others of a similar age in order to support the belief that health problems were prevalent in later life (see adapting self in 4.2.1). Furthermore, participants suggested that these comparisons led to changes in their own health being recognised, thus acting as a trigger. Through monitoring other people it raised awareness of how their own and others' bodies functioned, potential differences were noted, resulting in surveillance and monitoring for changes. Prior to this, changes had not been noticed, but viewing others had increased awareness that there were differences in body function:

*...think I've got prostate trouble because 2 of my friends have got prostate cancer... I went to village A to a model flying do and we all walked round the museum before we went out we went to the loo. When I came out the rest of them were half way across the airfield*

Interview: Craig, 78, retired sheet metal worker

Self-monitoring of symptoms was integral to self-regulation and was influenced by perceptions of health changes. By appraising and monitoring symptoms, participants decided upon the next actions that were perceived to be necessary to deal with changes to health.

As illustrated in figure 5, a trigger started the health information seeking process, with the interpretation of this defining and structuring the future of the illness experience and health information seeking behaviour. The process of self-regulation involved knowing their body, recognising health changes and monitoring these. However, perhaps the most significant finding within this process has been how integral it is to prompting health information seeking behaviour. As previously discussed, it is important that the context of the health information seeking journey is considered, as many factors influence the path that follows. Specifically, it was apparent that participants often attributed body changes to the ageing process. The next section focuses on 'self-managing' and the processes which are

incorporated within this category.

### **4.3 Self-managing**

Despite experiencing health changes, monitoring these and recognising changes to their body did not mean that health information was sought in every situation. During the health information seeking journey, self-managing was a moderating factor. Self-managing refers to the activities undertaken that aim to maintain, improve or restore health, or treat disease in response to a health change. This section illustrates the involvement with activities to self-manage and explores how participants engaged with this process. It presents the processes which involve maintenance of health with approaches utilised to remain healthy and self-manage health changes and discusses the role that health information seeking plays within this. The key themes include maintaining their body and self-managing health changes which incorporate strategies employed by participants to manage symptoms.

#### ***4.3.1 Maintaining their body***

Part of self-management aimed to maintain their body in response to health changes. Prior to changes in health, there was general agreement that maintaining their body throughout the lifespan was vital. Not only were there discussions about the impact ageing, family history and previous experiences had on their body, but participants reflected on the importance of caring for their body over the life course. It was suggested that looking after their body, by following a healthy lifestyle had a positive impact on health in later life:

*And I've always taken pride in being sensible about the way we live. And he [doctor] said, "Well, that's why you are as good as you are because you've looked after yourself over the years." And I felt, yes, that is quite true.*

Interview: Elsie, 85, retired social services clerical worker

Conversely, it was suggested that not maintaining their body during the life course and lifestyle choices, such as smoking and diet negatively impacted on health in later life:

*Went to a lecture, Prof Alan Raynham, Cancer research, 'Cancer DNA and Darwin'  
Excellent explanation of how cancer is a disease of damaged DNA. Having been a  
smoker for 38 years, given up 20 years ago, I realise I could still have damaged my  
DNA!!*

Diary: Bruce, 73, retired engineer

None of the participants were free from illness, injury or pain as all had diagnosed medical conditions. Maintaining their body was viewed as important as there was a desire to sustain current levels of function in order to continue with activities and remain independent. A pattern began to emerge of participants' beliefs about the importance of having a balance of exercise, diet, psychological and social contact in one's life, and was described by one man in the following way:

*I don't think of it [health] in that way I think more about well-being which is different;  
and so I think for me it's about balance – I have to have a mixture of stuff, so I've got  
to have reasonable food, I've got to live in a reasonable at a reasonable pace and do  
exercise the brain, exercise the body, so it's a whole range it's that that I look at.*

Interview: Brian, 67, retired project manager

Most discussed the importance of eating a healthy and balanced diet, viewing this as a way to maintain health. These participants adopted a health-promotion approach, which has increased in recent years. Perceptions of a healthy diet were illustrated by participants providing examples of the healthy and unhealthy foods that were eaten:

*I'm conscious of what I eat. So, if I go out I'll tend to have fish and chicken rather  
than a fatty you know. So but I think that's my way of eating healthily and trying....we  
go to a pork butcher's where they do their own curing and stuff like that.  
Hopefully...we buy health...we eat healthy anyway, don't we? We eat lots of  
vegetables and stuff like that.*

Interview: Jess, 66, retired PA to factory manager

However, some participants commented on the lack of consistency of some sources of health information. These participants suggested that mixed and confusing messages were given by

some information sources, which made it difficult to understand exactly what currently was viewed as a healthy diet (further illustrated in 4.4.3):

*Well, we get The Mail. And nearly every day there's something in there that says you should be doing this, or and or, and then the next week it's contradicted by, "You should be doing that or eating this or drinking that or not –". You know. So, I mean we treat it more with amusement, really, but.... So that's kind of really conflicting, all the stuff in The Mail. Or other papers I expect.*

Interview: Fern, 75, retired Parish Clerk assistant

Although it was generally acknowledged that it was important to eat a healthy and balanced diet, some spoke about balancing well-being. These participants identified that despite having the knowledge regarding what was a healthy diet, sometimes what was eaten might be unhealthy, but this helped maintain well-being:

*Yes, I do. I think I, you know, eat quite good, diet. I eat lots of vegetables and fruit. I love fruit and I do have fresh vegetables. Yes. I probably eat too many biscuits. I find in the evenings, is the worst time for eating things like biscuits or (Laughter) or crisps occasionally if I have a gin or something. (Laughter)*

Interview: Carol, 83, retired primary school teacher

In order to maintain their body, participants considered their health status and how this impacted on food intake. This was brought into focus when health changes were experienced, which affected the gastrointestinal tract and appetite. These health changes led to adjustments and altering diet:

*I'm very careful with diet, what happens when I have the stomach upsets, I tend to go for dry biscuits and toast and that sort of thing – vegetables and fruit so that could have an effect I imagine. Common sense tells me that I should have more.*

Interview: Louise, 73, retired nurse

Trying to keep as active as possible was another strategy employed to maintain their body. Some participants with an existing health problem discussed the importance of exercise to maintain their body. Due to deteriorating health, some experienced limited mobility, and highlighted how attempts were made to remain active and the rationale for this. One woman with a long cardiac history explained why she believed it was important to continue exercising:

*I try and go a little walk every day. I don't go far now but I try to go out every day just to have a little walk.*

*So do you think that's important? (Interviewer)*

*To keep me body going (laughs)*

Interview: Victoria, 84, retired shop worker

Whilst a pattern started to emerge of how participants maintained their body, the responses are further illuminated by those who also spoke about mental well-being. Maintaining health was not viewed as just being about the physical, for instance being active and eating the right food, it was also about mental well-being. Having a positive outlook impacted on attitudes to well-being and maintaining self. Most acknowledged the importance of remaining mentally active and having a positive attitude as a means to maintaining self:

*I do try and keep the body in by exercise which is obviously going to help and for heaven's sake that horrible thing right mental attitude is it, not quite sure, yeah, I am just positive about things.*

Interview: Tony, 66, retired salesman

One person displayed a less positive mental attitude with this being linked to the severity of his circumstances. He had recently been widowed, moved from South Africa into assisted living accommodation, had limited income and physical disabilities due to previous spinal surgery and macular degeneration:

*It's difficult for me to explain but in some ways I'm getting mentally lazy with old age. I know I've got to do something, I've had stuff here, I've been here for several*

*months, I can't persuade myself to get me round to do it and I have to clean this house, that's not too much of a problem but mopping the floors, the kitchen and the bathroom, a bit of a job. But I sit here and think I've got to do that and three days later, four days later, I'm still telling myself not to do it, it's a mental thing again.*

Interview: Pete, 85, retired from managing car repair panel beating business

#### **4.3.2 Self-managing health changes**

To be able to self-manage a number of strategies were employed including monitoring physiological measurements, taking prescribed and non-prescribed medication. Self-managing requires individuals to appraise and understand health information in order to incorporate these strategies into their lives. On a day to day basis, all were self-managing with various strategies employed to maintain this.

##### **4.3.2.1 Monitoring physiological measurements**

A strategy adopted by some was to monitor symptoms through physiological measurements. One participant had been diagnosed with type 2 diabetes and he measured his blood glucose levels at home. Physiological measurements were normally undertaken when there was a history of hypertension and involved blood pressure measurement. For some, the process of recording blood pressure was not done regularly:

*I've got a home machine, which we sometimes think of using.*

Interview: Fern, 75, retired Parish Clerk assistant

Being aware of a medical history, heightened awareness to health changes and having a medical condition resulted in measurement of blood pressure when a health change was recognised or suspected. For some the monitoring was at the request of the GP and undertaken regularly:

*So you take your blood pressure, is that right? (Interviewer)*

*If I'm not feeling well I take it, I don't want to get a thing about it but I did have a machine because I was told to keep charts.*

Interview: Erin, 77, retired secretary

Others recorded blood pressure not at the request of the GP, but as a way to self-monitor, provide evidence of recordings and act as reassurance that medication was effective:

*Did the doctor ask you to take your blood pressure at home? (Interviewer)*

*Well no I do it for my own benefit, because er when Bob [husband] was ill or when he had just died, that went off the chart and that was when I had to start taking tablets because when I went to the doctors she sort of thought it can't be that high I know she did but then she took it that didn't register on hers it was so high*

Interview: Lorna, 80, PA in insurance company

#### **4.3.2.2 Prescribed medications**

The majority of participants took prescribed medication on a long term basis for various long term conditions. Most participants stated that medications were taken as prescribed.

However, participants consulted a variety of sources and did not solely rely on doctor's advice regarding medication. Medication information was supplemented by the written medicines information provided with medications; all participants suggested this was always read. The rationale for this included having knowledge and understanding of possible side effects:

*Absolutely, all the time....Definitely I do I think I need to know about my own possible side effects go into the minutia one in ten million may suffer the following. Yes I do read them, probably read them from top left hand corner to bottom right hand corner.*

Interview: Tony, 66, retired salesman

The impact of trust in the prescriber was also discussed (this issue of trust is expanded within section 4.4.3). The majority of participants described that despite reading potential side effects, medications continued to be taken:

*Because, obviously had these things cover everything and you know, are you subject to this and that and everything else. I read them but, you know, obviously, there is nothing really that is relevant to me. Otherwise, they probably wouldn't give it to me in the first place right?..Well, you really got to the trust the doctor, haven't you?'*

Interview: Tom, 74, retired book keeper

However, one participant experienced adverse effects when taking statins. Previously, he had been given mixed messages from the two GP's in the practice regarding taking statins. As a result he stopped taking these and then informed his GP that he was not taking the medication as prescribed. Following negotiation with the GP, the dose was reduced but side effects continued and at this stage he decided to discontinue them. The undesirable effects of the medicine were so bad that he had to question whether it was appropriate to continue and decided to choose quality of life in preference to the treatment:

*I went on the statins. I think I had 6 or 7 and then I threw them in the bin because I was on 20 milligrams. Oh I had a headache for...well, it just reached a stage I couldn't...So, I was lying on the bed, and I was alright. So, right I went to see him...I said, they made me feel sick and they gave me headaches and completely killed my appetite...I don't like them, I don't want. He said, we could have reduced the dose. And I said, okay. And he said, he's a real statins man...I said, well, okay. So, he reduced them to 10 and I was on that...appetite's come and gone and always feeling sick, was generally nauseous. And I said, I don't really want them. And he kept on. And I said, what's the lowest? He said 10. I said, how about half a tablet a day. Okay. Whatever I can get into you I'll get into you. So, I've had six days of that. I've had six days of headaches, feeling muzzy, stomach's upset again. They're going. I'm not going to...I don't see why I should...*

Interview: Len, 71, retired builder

All participants had contact with the pharmacist, mainly to collect repeat prescriptions. Some participants did not find medication discussion useful, but could see the value for other people. One suggested that the reason for meeting with the pharmacist was to prevent patients from stockpiling their medications. Overall, the general perception was the medication review was part of the pharmacist role:

*...before, he took me into a little room there once and just made sure I knew what it was about*

*And did you find that useful? (Interviewer)*

*Um yes, but I thought 'well, he's obviously got a job to do and it is one of those routine things' so I just went along with it*

Interview: Tom, 74, retired book keeper

Additionally, examples were provided of situations where participants self-managed by making adjustments to their prescribed medications. Modifications were made to regimes after participants had made an assessment of symptoms and health changes. These adjustments were made in line with healthcare professional's advice and helped manage on-going health problems. This was facilitated by self-regulation and by knowing their body, monitoring and recognising health changes. Examples were provided to describe the changes that would indicate that there was a need to adjust medication. The decision making processes involved when adjusting the medication through assessment and symptom recognition were explained:

*I take one Felsartin, they send me a double lot. If I've got the stomach upset I take the double lot because I have noticed now and I thought obviously I'm not absorbing it and that is why my blood pressure goes up... when I've been to the doctor and it's been high and she said take 160 instead of 80 not at once, if you like take one in the morning and one at night and I do that when I know its high, but when I'm back to normal I don't need to so I don't and I've said that to her and she said OK I'll leave it to you.*

Interview: Louise, 73, retired nurse

All participants were on prescribed medications and received information regarding these in verbal and written form. The majority of participants said that medication was taken as prescribed, with modification made in collaboration with the prescriber. There was no evidence in the data to suggest that drugs regimes were adjusted without informing healthcare professionals, although sometimes this was done retrospectively.

The next section explores further strategies that were employed to self-manage health changes, with OTC medication often used.

#### 4.3.2.3 Self-treatment

Changes in health resulted in the majority of participants continuing to take prescribed medication, with other strategies used such as taking OTC medications to manage the accompanying symptoms. A self-treatment plan was often devised which included experimentation with non-prescribed medication; these were assessed for effectiveness and appropriateness, with beliefs impacting on this process. Some identified that non-prescription drugs would be used when symptoms were perceived to be possibly caused by either a minor health problem or one which was familiar.

Examples of how participants self-manage were provided from experiences of minor ailments such as colds, headaches and minor injuries. The behaviour and decisions made regarding the appropriate course of action were based on beliefs regarding the causes and nature of the problem. Symptoms were made sense of by self-diagnosing the illness; decisions were made about these symptoms, whether they were perceived as significant and the impact they had on daily life. A tactic commonly used was to monitor the symptoms which included assessing the effectiveness of self-management strategies. To cope with the symptoms various strategies were adopted but if symptoms persisted or were perceived as serious, this would trigger further health information seeking. This decision making process was illustrated by a woman in the example below, although there appeared to be a two week rule for this participant, this was not expressed by others:

*But I don't believe in going to the doctor's because I've got a little sore throat. But say I had a sore throat and I had it for a fortnight. And it didn't seem to be getting any better. Then, I'll go to the doctor. But if I have a sore...wake up with a sore*

*throat, I think, I've got a cold coming and I can take something for it and it goes. Fine. But I think you have to be...strike a happy balance.*

Interview: Millie, 76, retired office worker

Taking non prescribed medication was one strategy employed by participants, before or instead of consulting a healthcare professional. It became clear that, for some, the use of OTC medication was an established strategy based on previous experience:

*I go for Savlon. On that painful toe the other day and I rubbed in Savlon but...So, because that night, I just got my nail clippers you know dug it out a little bit and it was fine. Put plenty of Savlon on it and it was alright after that.*

Interview: Erin, 77, retired secretary

Often OTC treatments were used without referring to health information sources. However, occasionally reassurance was sought that the treatment was appropriate which involved checking that there were no contraindications. In the following quote, one man explored the remedies that he used post knee replacement and the health information sources that were used to check that it was appropriate to use:

*Both of them have healed well, I cheated though. Once the scar had got healed quite well I used bio oil its good but it's mainly for women stretch marks it works nice and it helps to flatten it*

*How did you know about that?* (Interviewer)

*The wife she used it and she said see if that will work the physio district nurse said don't put it on till your scars well healed give it a couple of months which I did with this one...*

Interview: Craig, 78, retired sheet metal worker

So, often, established regimes were followed, however some were not averse to searching for different and new treatments to alleviate symptoms. The following participant had fallen off his bicycle and commented on how new health information was used to self-treat:

*My wife spotted an article in a Sunday paper somewhere which referred to these almond oil....She read the article which I then read –and I thought we’ve got some almond oil, give it a go.*

Interview: Tony, 66, retired salesman

Analysis of the interview data highlighted that for many of the participants, daily joint pain was a common symptom that was self-treated by non-prescription medication (see 4.2.1.2 for further exploration of the use of OTC analgesia). However, for some there was a reluctance to take non prescribed analgesics, especially when being in pain was perceived to be normal. Reasons for this included anxiety about the side effects of the medication, how these could affect their body and fear of addiction. New or unfamiliar pain was also considered as a valid reason for seeking health information, as it was perceived to be a sign of a potentially serious problem. The following participant described how previous experiences had impacted on his beliefs regarding medication and the circumstances that would trigger health information seeking behaviour:

*I don't like medication unnecessary, I take 2, 4, 8 tablets a day, I like the body to get used to doing it itself. I did have a relative a few years ago now and took medication, medication, medication. Eventually she could not operate without medication, that psychologically put me off so I don't like taking excessive medication unless I really have to; if it's going to help me I think fair enough I'm going to have to do it. Painkillers, if it gets too bad then I'll go to the doctor the next day but the idea of just taking painkillers to take away the pain without knowing why doesn't appeal. Maybe I'm a bit funny, I don't know.*

Interview: Pete, 85, retired from managing car repair panel beating business

Caution regarding the use of non-prescription medication was also suggested as a reason to restrict its use. Some suggested a general reluctance to frequently self-administer non-prescription medication, due to fear that the medication might lose its effect and the impact this might have on future needs. The following participant also referred to her previous professional background and experience to support her beliefs:

*Yes, paracetamol, but I have to be careful, I've had a lot of joint pain lately, I've found myself taking paracetamol for that and now I'm, it's alright again, so I stopped and I do try not to because I think, you never know what's ahead of you, you don't want to, find they don't work anymore, kidneys and all the rest of it, trouble is being a nurse, you have great imagination about what can go wrong.*

Interview: Louise, 73, retired nurse

Overall, participants demonstrated involvement with the process of self-managing health changes. The data highlighted that participants adapt and adjust to changes in health, by self-managing, using various strategies. Participants self-managed long term conditions and often self-treated symptoms of ailments using OTC medication. It was clear, that the adoption of self-management strategies related to the beliefs held by participants regarding symptoms and medication use.

The health information seeking journey is not straightforward, it is complex in nature and the pathway is shaped by various factors. A variety of strategies were adopted prior to self-mobilisation, with health information seeking occurring throughout this process. Self-managing was a key theme that emerged with participants maintaining their health, self-managing health concerns and self-treating. The outcome of these tactics impacted on decision-making and health information seeking behaviour. The next section will consider the activity of 'self-mobilisation', the third category within the health information seeking journey and the three processes that are incorporated within this category.

#### **4.4 Self-mobilisation**

This final category, within the health information seeking journey (see figure 5) identified processes participants undertook to gain further health information to satisfy individual needs regarding health concerns. This depended on whether symptoms had resolved or not in the previous stage of self-management. Interview data revealed the importance of the process of self-mobilisation which was triggered by a health change. This describes the actions taken by the participants when there was a decision to act upon a change in health and engage with

self-mobilisation. This section will outline features that underpin the self-mobilisation process: building knowledge, seeking support and establishing credibility.

#### **4.4.1 Building knowledge**

Knowledge was perceived by participants to be a necessary requirement for any level of engagement with health information seeking. As discussed in a previous section, some demonstrated a tacit knowledge about their body (see section 4.2.1); however different sources of knowledge were used to create new knowledge which facilitated self-management or triggered health information seeking. Part of the self-mobilisation process involved participants reflecting on prior knowledge and building on this.

##### **4.4.1.1 Experiential knowledge**

Experiential knowledge which had been gained through personal experiences was evident. Over the years, participants became familiar with their bodies and changes in health which were deemed as normal. As discussed in ageing bodies (see 4.2.1.1), perceptions regarding the ageing process impacted on knowledge and beliefs. Drawing on experiential knowledge influenced whether further health information was perceived necessary. Commonly, familiarity with the altered health status negated the need for further information as symptoms were attributed to pre-existing medical conditions:

*Obviously 'sinus' infection as per usual!*

Diary: Louise, 73, retired nurse

However, if symptoms were perceived to be serious in nature this attitude altered. If health had significantly changed or presented in an unfamiliar way there was an acknowledgement that there could be a need for further information. This new information was sought to make sense of symptoms and identify potential causes:

*Last year I had three episodes of an infection, one was the classic, one was totally different but still associated with the damaged knee and I thought it was just an*

*inflammation but I didn't have all the shakes and things, I just had the swelling and some redness but I wasn't actually ill.*

Interview: Tony, 66, retired salesman

Participants demonstrated the ability to recall knowledge gained in previous events and were able to apply this to new situations. This was not just through experiential knowledge, but previous knowledge which had been gained through a variety of sources. This knowledge was sometimes referred to as either 'common sense' or 'general knowledge' and could be traced back through the lives of the participants, sometimes acquired through past employment:

*I think that's just general knowledge that sort of stuff I don't know I mean yes I would have learnt from an engineering point of view quite a lot about food hygiene and how you er and the microbiology no I'm no microbiologist but I would have picked up bits about..I would have picked up bits about constituents of different foods and how they react to different heat treatment and stuff like that....No that's general knowledge*

Interview: Bruce, 73, retired engineer

As discussed in self-management (section 4.3.2) regarding self-medication and OTC medication, past experiences influenced participants. This also applied to knowledge sources which went beyond personal life experience and extended to memories of other people's experiences. This health information was often acquired through direct observation:

*I use a lot of hand cream and er for dry skin on my legs because I always remember me mother in law oh as she got older when my kids were little oh her skin was so dry so obviously that comes into me head now now I'm she were younger than what I am I used to go round and rub olive oil on her legs and that's as good a thing as anything*

Interview: Judy, 78, retired shop worker

Additionally, remembering information about cause and treatment previously suggested by healthcare professionals was drawn upon. This information was reinterpreted, reshaped and

incorporated into the context of everyday life. Participants viewed information gained in this way as important, with knowledge integrated into the decision making process as to whether to seek or not seek further information. The following participant explained the rationale that had been provided by a healthcare professional for her symptoms and the possible cause of these. She accepted the explanation and concurred that symptoms worsened with weight gain:

*I do have a...I've got a flappy bit at the top of my stomach. And the doctor said, when you are overweight, it will set your stomach off. You'll get acid indigestion. And I am getting it at the moment because I am overweight...I mean, it's not all the time. It's when you're bending forward and that sort of thing. It's acid.*

Interview: Millie, 76, retired shop worker

#### 4.4.1.2 Expanding knowledge

To expand knowledge base, participants accessed other sources to supplement information about health concerns with more than one source of knowledge drawn upon. Typically, this was knowledge gained from a healthcare professional and the written medicines information which was reframed into terms that were easy to understand:

*The doctor says I've got a lazy heart so I read about the heart in that to help your heart beat he said it's like this instead of going like that (demonstrates with hands, pushing them together) it's like that you've got a lazy heart and the water tablets is far as I know is to stop me from retaining water you know that's all that's all*

Interview: Cynthia, 84, retired secretary

Generally a wide range of health information sources were used at different stages of participant's life. This knowledge evolved according to life experiences, changes in health status and when it was perceived that more health information was required. Frequently, the health information was medical and disease specific, although occasionally information on diet and exercise was also sought. A variety of sources were identified (see figure 6). The information sources were either written or verbal or a combination of the two. For most of the

participants written information was either provided as information leaflets and letters or found by the participants and used with other information. The sources chosen by the participants appear to be influenced by their availability and accessibility.

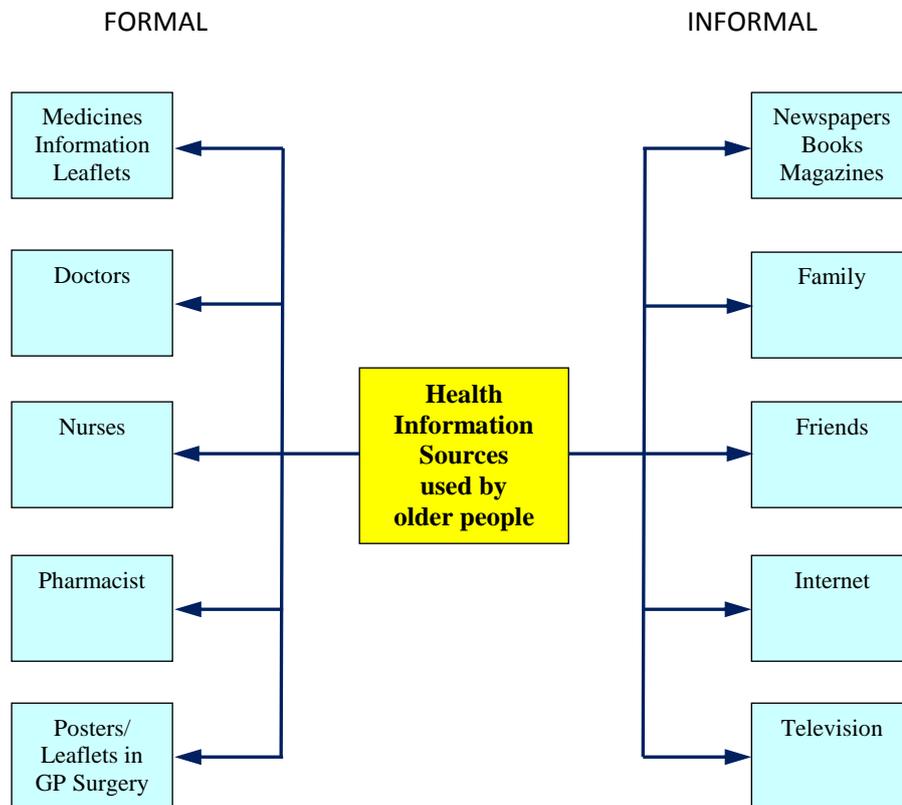


Figure 6: Sources of health information used by older people.

Participants provided examples of sources that were used to expand knowledge which often related to the type of information seeker they were. The extent of the health information search varied widely from an in depth, thorough inquiry of many varied alternatives to a selective or superficial search (see typology of information seekers in 4.5). Another dimension of the search related to the method used, which refers to the information source that was selected. The two methods most frequently used were impersonal where information was sought from sources (see table 11) such as a publication, and personal where information was sought from a person known to the participant which will be explored in section 4.4.2. A combination of both methods was frequently used and again related to the type of information seeker. Participants stated that traditional print media such as books, magazines and

newspapers were used as well as the internet, which implies that the internet has not shifted traditional media as a source of information used by some older people.

SOURCES	EXAMPLES	EXAMPLES OF EVIDENCE
Web	Internet-pre diagnosis	<i>checked on the web..and it looks like it</i> Interview: Maud <i>looked up varicose eczema on google and NHS site</i> Diary: Tony <i>If there's something I want to know about</i> Interview: Sue <i>I went for some health thing I wasn't sure about</i> Interview: Caroline
	Internet-post diagnosis	<i>I did when I had prostate cancer when I was diagnosed with prostate cancer</i> Interview: Jack <i>Solar keratosis. I looked that up on the internet</i> Interview: Erin <i>I've got a diagnosis then I might look</i> Interview: Millie <i>I did look up Allendronic Acid, yes</i> Interview: Sarah
Paper	Information sheets	<i>he downloaded a load of stuff for me, off the internet</i> Interview: Annie <i>they're printed off the internet</i> Interview: Sue
	Newspapers and magazines	<i>...in one of the papers..there was a doctor on tablets which should have been taken with water...so if you need to take them with water always do</i> Interview: Lorna <i>Occasionally there will be articles on things that we cut out and keep</i> Interview: Tony <i>..there's some thyroid problem, I'll read that because that's all, that is what I've got</i> Interview: Annie

	Books	<i>I've got a medical book, I look in that</i> Interview: Fern <i>I do like my drugs book...it's because I am interested in drugs</i> Interview: Pauline
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Table 11: Common sources identified by the participants and examples of data evidence.

Thus, it would appear that vital components to building knowledge are acquired experientially, with participants recalling knowledge gained over their life time. The building of knowledge continued with various health information sources used, although the selection of the source and method was dependent on the type of information seeker and will be further explored in the typology later in this chapter. Health information seeking was mainly undertaken as the result of a change in health; however another trigger to health information seeking behaviour was also identified.

#### 4.4.1.2.1 Non solicited triggers

It became evident that a trigger to health information seeking behaviour was not always as the result of an active change in health. At times, an apparent change in health was actually created by health information with participants perceiving that there was a cause for concern and a need to take action. This non solicited trigger was normally accessed through the media and alerted participants to seek further health information. This information was used in a variety of ways, with some using it as a trigger to seek further information when consulting healthcare professionals:

*The Mail on Sunday has quite a lot of medical chat really um and some of it's of interest and some of it isn't. This week they've got things about flat feet which I am supposed to have. I was told 20 years ago my arches had dropped er when I went to the Doctor's this time...mentioned that I was getting a lot more pain and that I was getting it further up my foot towards my ankle..*

Interview: Sue, 68, retired receptionist

New knowledge about health promotion and healthy lifestyles was also gained via non solicited triggers. However, some demonstrated that despite reading health information there was a lack of confidence in the source, impacting on whether information was considered relevant and would result in behaviour change:

*you know, we're bombarded with adverts what we should do and five pieces of fruit there and all this sort of. Drink this, drink that. But I don't go, I don't take a lot of notice of that. I identify with what they're trying to tell me, but I don't follow it, uh, you know....No, no. If I want a piece of fruit, I'd have a piece of fruit. If I don't have a piece of fruit, I'm probably told, "I should eat more fruit. I should eat this, I should eat more of that." But I do what I personally feel that I need to do and want to do, really...I'm not overly influenced by adverts.*

Interview: Tom, 74, retired book keeper

Crucial to the process of self-mobilisation was seeking support from personal sources, which will be explored in the next section.

#### **4.4.2 Seeking support**

As previously indicated, various impersonal and personal sources of health information were used which provided knowledge regarding health. Social networks influenced virtually all stages of the health information seeking journey from recognising health changes, lay referral system and validating health information seeking behaviour. Not only did participants seek to validate that there had been a health change and there was a need for health information seeking behaviour, but support was provided by personal sources, mainly from people within participant's informal network. Patterns emerged about the significance of the people within the participant's informal network as a provider and source of support and information. It was common for support to be sought when changes to health were experienced, this was often to gain further health information and to receive emotional support regarding concerns. Various people within the social network were consulted, but commonly these were family and friends:

*You see, if I did, there are so (Pause) many people around who I could say, ask. I mean, I'm just...I'm looking over there because I've got a neighbour over there. And she's a...I call her a frustrated nurse because she...she says to me, Oh I love illness. And if...and I feel if I did, I could go to her, Jenny, I don't know. What is so and so, so and so? If she didn't know, she'd look it up and we'd talk about it...She's got books...yeah, she's got books. She'd look it up on the internet and the books, yes. But I'd have her to talk about it too...*

Interview: Millie, 76, retired office worker

Support was provided by the exchange and provision of information with additional help requested when there was a perceived gap in knowledge. Often this was sought from family members who would seek and provide information, which had been normally sourced from the internet:

*If I was really concerned and something kept on and on, I had shingles once and Jenny [daughter] got information off the internet about shingles but erm only because I wanted to know all the ins and outs of it*

Interview: Pauline, 77, retired secretary

The importance and significance of having local family impacted on information sharing. Whilst all participants had access to a pool of friends who they would consider using for support, it would appear that lacking local family support did have an impact. For those participants this lack of availability of local family support impacted on information sharing, with health concerns communicated after the episode. There was a sense that there was a wish not to burden others, especially offspring when they did not live locally:

*...Not until after the event. (Laughter)*

*Why would you do that? (Interviewer)*

*I wouldn't want to worry him. Although, he said, something happened to me, "Why didn't you tell me, Mother!" "Oh I haven't thought of it." Because I was managing it. Whatever it was. And he couldn't do anything being up there.*

Interview: Sarah, 72, retired administrator

Availability of an informal network was important for participants at all stages of the health information seeking journey. Significantly members of the network provide and shared health information when a health change occurred. The processes of seeking support to build knowledge were further enhanced by establishing credibility which is explored in the next section.

#### ***4.4.3 Establishing credibility***

The final process within self-mobilisation is establishing credibility and relates to how valuable knowledge was perceived to be. Participants searched for credible sources to meet their unique needs, with new information integrated into their knowledge base, thereby providing participants with their own stock of knowledge so they were able to conceptualise and give meaning to their health problem. When establishing credibility of information sources, participants discussed the importance of the sources' credibility. Credible informal sources were identified as those with some medical knowledge; these were either family members or people from their social network. Often these sources were consulted after a change in health and further information was deemed necessary to provide clarification. The following participant had been diagnosed with prostate cancer and he had asked his granddaughter, a Doctor, about treatment options as he did not understand the information provided by healthcare professionals:

*I know that when Eve come home a few weeks back and I said I don't she said "ah that's so and so granddad". I didn't understand what it was about, she knew straight away, well she should do she's a damn doctor, you hope she does*

Interview: Jack, 82, retired police officer

Health information was evaluated to determine whether new knowledge was adequate, useful and relevant. When it did not fulfil these criteria, further health information sources were explored to complete knowledge. Another described how the limited explanation from the GP had triggered him to gain a more in depth understanding from a friend who happened to be a retired cardiologist:

*Inquired of training buddy, who is a cardiologist how one can have high blood pressure yet low, resting heart rate?*

Diary: Tony, 66, retired salesman

*If you ask the doctor he just says yes well you've just got high blood pressure.*

Interview: Tony, 66, retired salesman

Others actively sought information from friends who were perceived to be credible and an important source of knowledge about certain health issues. Their credibility as someone who had previously or were currently experiencing similar health concerns, meant that they might be able to provide new insights from the lived experiences of having the condition. These lived experiences meant that participants were able to gain insight into others perspectives. These sources were perceived to offer the right type of information and support:

*I've had 2 friends die with prostate. I go to the aero club with one who's had it spread to his hand but they kept that under control. Now the cancer spread from to his hand and the prostate. And I will talk to him because he will say to me have you had your check-up is it any worse. No. when you go to the toilet. He said watch if there's any blood go straight to the doctor*

Interview: Craig, 78, retired sheet metal worker

Additionally, credibility of other sources of information including its trustworthiness and expertise were reflected upon, with a judgement being made concerning this. This was highlighted when one discussed the nurse specialist and described him as a specialist in the field, knowledgeable, gave clear explanations and showed her the scan images which she found useful.

Despite the use of various information sources, participants reported they depended on traditional sources of information, notably healthcare professionals. Overall, the majority viewed healthcare professionals as credible sources of information, often referred to as the experts. They were credited as useful, informative sources and perceived to be the most

appropriate source to validate information. One participant who used the internet to look up terms that he was unfamiliar with concluded that Doctors:

*...are the experts, I let them fix me*

Interview: Bruce, 73, retired engineer

Perceptions of the source providing information were important with previous experiences impacting on engagement with health information seeking. This was evident when the source provided information that appeared to be less than useful and suggested using other sources of information:

*...I don't find the chemist, the pharmacist particularly. I wouldn't say they're not helpful, but I found they're not really willing to give decisions, particular decisions. Though perhaps like say a cream, if you've got something like here. But then, you know, "Well it might be so and so" or you know? "If it doesn't heal, go and see your doctor." ...Because there's been a lot hasn't there about going to the pharmacist first, hasn't there? And they'll tell you what to do, give you advice. I mean, I haven't been...or, had the need to go a lot. But the 2 or 3 occasions I've been, I thought, "You know, really. I might just as well have gone to the doctor first." ...And she said, "I really don't know, you know. It could be allergy, it could be sweat, perspiration, that..." And I think she suggested some cream. And I think I'd already been using it.*

Interview: Carol, 83, retired primary school teacher

Sometimes there was uncertainty regarding which appropriate source should be accessed. Despite some participants being aware of the changing role of the community pharmacists, some still perceived the pharmacist as a dispenser of medications and would not consider that they had a role to play in providing health information:

*You wouldn't go to the chemist? (Interviewer)*

*No*

*Why is that? (Interviewer)*

*Well they dish medicine out don't they (pause) it's never arisen really its (pause)...It's*

*never arisen I suppose if it's bad enough generally I've got good health its bones I don't think chemist can do out for bones do you?*

Interview: Judy, 78, retired shop worker

As previously identified, impersonal sources of health information were also accessed with the quality appraised. The credibility of these sources was discussed, including how judgements were made when evaluating the trustworthiness of information sources:

*I really use the web, the web is really good, but I'm not very keen on um the (pause) American because they bring it in from all over the world the Americans always seem to over egg the pudding...I usually just look at one of our own health links and the NHS one is reasonably good.....I usually do it chronologically like it how it happens the symptoms erm the treatment err and the prognosis...you can ask questions.*

Interview: Maud, 66, retired newspaper reporter

Participant's perceptions of credibility were further illuminated when conflicting information from various sources had been provided. This inconsistent information was evaluated, had led to confusion and indicated a lack of confidence:

*..I had my bloods taken and I am due to go back next month. Cholesterol, I don't know how high is high, they change their minds about it, sometimes they say its high sometimes they say it isn't, they're not sure are they really about this cholesterol business.*

Interview: Louise, 73, retired nurse

Additionally, when establishing credibility, consideration was taken about the applicability of the information to self. Within discussions about which health information sources were used, if the information was personal and applicable then this was viewed as valuable and helpful. Some of this information had been provided by healthcare professionals:

*He [Doctor] gave her about 3 or 4 sheets, wasn't it? About three sheets, wasn't it?*

*Yes. But it was helpful because it hit the nail on the head exactly as to what I was feeling, you know... It was very helpful.*

Interview: Elsie, 85, retired clerical worker & Anton, 87, retired waste management worker

Establishing credibility also meant that decisions were made about information that was not perceived to be applicable or was too general. In these situations, the credibility of the information was evaluated and decisions were made about its usefulness. These judgements were often informed by past experiences, were relevant to self and perceptions of particular sources of information influenced this:

*I've looked up medical things on there [Internet]. Because quite truthful they're blanket coverage and I've learnt through life's experiences that no particular thing applies to, to, to people. Everybody's different. You know. Everyone is different and I learned that through my wife's illness. And you know one person can have it and die very quickly. Another one can have it and fight it for another year, so whatever I read is only blanket coverage. It's not applicable to the person in question. So therefore I don't read it, because you could read into it so much, you'd make yourself probably ill. (Laughs) To put it bluntly..... Worrying about what you might have and what you might not have. And no two people are the same.*

Interview: Tom, 82, retired book keeper

Rather than enabling the participants to cope with changes in health, some sources were perceived to provide too much information which resulted in increased anxiety levels. This meant that some sources of information were actively avoided in an attempt to reduce anxiety about potential problems:

*I said what is it, he said ocular rosacea, ever heard of rosacea, lumps over your face, look it up on the computer, I don't look anything up on the computer, you see the very, very worst, it gives you heart failure just to see what people look like, if I'm going to get like that I don't want to know.*

Interview: Louise, 73, retired nurse

This section, has explored the tactics that participant's employed when establishing credibility of health information. Key to this was perceptions held by participants with regards to the credibility of the information source, the evaluation and applicability of the information. Participants explained how information was evaluated and decisions made regarding information seeking, including avoidance.

Clearly, the health information seeking journey is a complex, multi-stage process with various sources of health information accessed at different parts of the journey. These sources impact on decision making and the route that is followed. The first stage is dependent on the interpretation and perception of symptom meaning and these are self-regulated with decisions reflecting individual's perceptions of these. As highlighted in section 4.1.2, there were variations in health information seeking behaviour depending on the participant's perceptions of the cause of symptoms, including age. Self-management was evident within the journey, where participants adopted strategies to maintain, improve or restore health, or treat symptoms in response to a health change. Participants devised a self-treatment plan undertaken within the home, and monitored for health improvements or deterioration. Depending on whether symptoms resolved or not, self-mobilisation followed, exploring various avenues to build and support understanding of health changes. Not only were lived experiences variable amongst participants, but also different patterns of health information seeking behaviour emerged. The following section will present a typology of the older person as information seeker.

#### **4.5 Typology of health information seekers**

The focus in this section will be an exploration of the specific elements of the information seeker which underpins a typology of the older person as health information seeker. There were different patterns of behaviours between participants when seeking health information which captures variations in information seeking (see table 10). These were either: proactive, reactive or passive information seekers. A brief summary of three participants will be used as emblematic cases to illustrate the different patterns of information seeking.

#### *4.5.1 Proactive health information seekers*

Proactive information seekers actively gained health information from various sources. There was a commitment to intense and in depth information seeking both for self and others, often motivated by a desire to make informed choices. The proactive seeker acted as both a resource for people who were in their social network and information was sought and provided to them from their network. Information seeking was intentional, often accompanied by a search for a diagnosis for health problems as well as to supplement information gained through other sources. The internet and other informal information sources were used for self-diagnosis, which was usually undertaken prior to consulting formal sources. Also, information was sought post diagnosis and this information used to expand knowledge. There was a desire for more information than had been gained from healthcare professionals about health concerns. Proactive information seekers engaged with online sources in a more inquiring way and used their skills to evaluate the information that had been gained. Proactive seekers felt comfortable with using the internet, which was used regularly and had become integrated into these participants' lives.

Additional information was sought about health concerns, but for the majority the main motivation to seek information was due to unexplained medical symptoms. It seemed that the reason for engagement was to try to find a reason for symptoms with the search for further information, helping with understanding and as a way to cope with health problems. For one participant the reasons for engagement with further health information seeking were slightly different. Further health information was sought due to not feeling fully informed, believing this was due to some healthcare professionals not having enough time to provide complete information.

Tony was married; his children lived abroad and he had experienced recurrent infections in his body over the past 38 years after damaging his knee in a road traffic accident. The reason for the recurrent infections was unknown. He actively engaged with health information seeking, by using various sources of information to explore potential reasons for health concerns. The internet was the main source, he responded to threats to his health by seeking further information on the internet. Additionally, he used other sources to complement this information, for example he used information that had been gleaned from the newspaper to manage health. The information was analysed and decisions were made regarding their

appropriateness to his health concerns. When he attended medical appointments he informed the healthcare professional that he had searched for information. His search for information was not just for self but for other people and he acted as a source for them.

Box 1: Example of a proactive information seeker

#### ***4.5.2 Reactive health information seekers***

Reactive information seekers were those that were more focused regarding the search, which usually related to a health problem or concerns about self. There was a purpose to the searching and once this was fulfilled there was a decision to cease looking. Normally, the search was post diagnosis so information was used to derive meaning and apply to self. The search for information was often prompted if they were unfamiliar with particular words or wanted to find out further information about their health. People within social networks were spoken to about health concerns but the reactive seeker did not perceive that they acted as a source for others.

Some reactive health information seekers had on line access and viewed it as a valuable resource, but it was rarely used for health information in the way that the proactive information seekers did. The search was purposeful with the majority of internet users finding out what was perceived to be needed to expand knowledge and once this was completed the searching ceased. By accessing the internet for health information this had led to an increased level of understanding, facilitated shared decision making and satisfied needs at that time. For the reactive seeker, information seeking needs changed over time and this was illustrated by those who had occasionally accessed specific information about health problems, but the search for health information was undertaken inconsistently. Having on line access, did not always lead to the internet being used for health information seeking. Previously some had used the internet to find out about a health problem but now this source was avoided. Reasons for this included that the information was too generic and increased anxiety levels. This demonstrates that the increased availability of information can sometimes hinder health information seeking and deter some from searching and using the information in a meaningful way.

For those reactive seekers who did not have access to on line information, other sources of information to increase knowledge were used. Family members acted as an information source, sometimes using the internet on their behalf. They searched for information about the health problem and provided the participant with information either in verbal or written form. Some participants had access to books, mainly general medical books and medical encyclopaedias that had been purchased. Books were referred to, either instead of searching on line or to help with understanding medical terms that had been used by healthcare professionals. These books concisely summarized most of the information that was perceived to be needed. Therefore books were often considered as valuable sources because they provided essential information about topics that were being searched. Some of the books might not provide the most current information, but appeared to be useful in providing information, in an easy to understand way.

Millie was widowed and her family lived away from her. There was a sense that she wanted to have knowledge about her health concerns and engagement with health information fluctuated depending on perceived need. She sought health information post diagnosis to glean more knowledge about health concerns and used this information to support what she had been told by healthcare professionals and to help with management and adaptation. Her main sources were the internet and people within the informal support network that she consulted. Previously her family had provided her with information about health concerns.

Box 2: Example of a reactive information seeker

#### ***4.5.3 Passive health information seekers***

For passive information seekers there was limited active engagement with information seeking. Minimal sources of information were used and these were mainly healthcare professionals and written medication information. Once information had been received from a healthcare professional or written medicine instructions had been read it was unlikely that any further information was sought. The passive information seeker stated that they were satisfied with the information they had been provided with. A paternalistic approach to decision making was often sought by the passive information seeker. Only a few sources of information were consulted, as it was perceived that there was sufficient information about health concerns, to be able to make sense of what was going on with health, to be able to

manage this and monitor for changes.

Some explained that sometimes they avoided information as it made them feel uncomfortable. These information seekers had never used the internet for health information, but were aware of their health problems and had sufficient knowledge about this. These participants did not give the impression that they were disinterested in their health problem; it was just accepted and integrated into their biography. Although some of these seekers had informal networks, these were not as extensive as they were for the other information seekers and discussions with them about health appeared to be more sporadic.

Pete was a widower who lived in independent living with assistance accommodation. He had no contact with his son who lived locally, but had contact with his step family who all live abroad. There was an acceptance that the information that was provided to him via healthcare professionals was adequate and there was no need to seek further information or gain further knowledge about health concerns unless he recognised a decline in his health. He knew what he was supposed to do with regards to self-management strategies and the information he had received from healthcare professionals was personal to him. His attitude to his deteriorating health was that he believed that he had to just get on with it, with a feeling that this was not really in his control.

Box 3: Example of a passive information seeker

#### ***4.5.4 Summary of typology of health information seeker***

The table below (table 12) summarises the various approaches adopted by each health information seeker and highlights their motivation, timing, pattern, style, information sources commonly consulted, focus and decision making within this process.

	PROACTIVE	REACTIVE	PASSIVE
MOTIVATION	Supplement other sources. Gain more knowledge about various health concerns, act as a source, search for diagnosis for Medically Unexplained Symptoms	Understanding illness. Derive meaning and apply to self	Need to know basis, gaining enough knowledge about specific health concern
TIMING ON MEDICAL TRAJECTORY	Self-diagnosis, pre-diagnosis, post diagnosis	Mainly post diagnosis	Post diagnosis
INFORMATION SEEKING PATTERN	Supplementary and intense	Complementary	Minimal, limited
STYLE	Interrogating, inquiring, assessing and evaluating, consistent, on-going	Purposeful, application to self, inconsistent	Minimal, avoidance
SOURCES	Multiple-mainly internet	Various-some internet, books	Minimal-provided by healthcare professional
FOCUS	Self and others	Self	Self
DECISION MAKING	Informed choice decision making	Shared decision making	Passive decision making

Table 12: Typology of health information seeking

This section has described a typology of information seeker and provided examples of participants located within each pattern of behaviour. The typology of information seekers demonstrates the complexities of information seeking within an ever changing world and the navigational tools that were used by each type. To make sense of the situation, strategies that the participants employed to construct meanings and actions were diverse, depending upon the type of information seeker. The following section explores the core category.

#### **4.6 The core category: Navigating later life**

This chapter has presented the three interrelated conceptual categories which form the basis of the emergent theory called ‘navigating later life’. Each category has been reported separately with extracts of data used to illustrate this. It was evident that participants followed different patterns of information seeking and a typology has been developed to explain this. The relationship between the three conceptual categories: self-regulation, self-managing and self-mobilisation which were examined discretely in the previous sections are made explicit. These three categories describe how participants navigate health information and attempt to negotiate later life.

This final section explores the core concept which integrates the three concepts into a logical and understandable whole and is the organising thread of the theory. During the analysis of the data and development of categories a pattern began to emerge and this related to the process of navigation. The typology of information seekers explains the different navigation styles that were adopted by participants. Navigation was evident throughout the life course, but was particularly relevant when considering later life and some of the challenges this brought.

Although growing older presents many opportunities for growth and advancement, it can also present challenges. Ageing brought life changes such as retirement, loss of function and bereavement requiring navigation. Additionally, potential threats in later life were identified and when these were recognised and acknowledged this meant that actions were adopted to address these. Seeking health information helped reduce threats, and was often motivated by the wish to be informed not only about present health, but also about the future. The rationale for health information seeking behaviour was often cited as: ‘*wanting to know*’. Additionally, seeking health information was described in terms of acting as a coping mechanism:

*I like to know what’s going on with my body and then that helps me cope*

Interview: Sue, 68, retired receptionist

Whilst participants identified the rationale for health information seeking, as previously highlighted there were various sources that were available which required navigational skills to follow the most appropriate path. The following section explores how sources were navigated and the barriers that impacted on health information seeking.

#### ***4.6.1 Navigating sources***

Commonly, health information seeking was self-initiated and often due to participants recognising an alteration to health, which presented as a change in their body. Usually, participants self-monitored and waited to see how health changes developed before mobilising resources. This involved making judgements as to whether further health information was needed to assist with navigation through the health change. Self-treatment strategies were frequently employed within the home to manage symptoms, which were often conducted independently without referral to new information sources. However, when it was perceived that there was a need for further information, participants selected sources and retrieved information which depended on the availability of resources. A previous section (4.4.1.1) identified that health knowledge was gained throughout the life course experientially, by use of information sources and from observation of others. Travelling through later life requires older people to navigate between known and unknown terrain, where comparisons are made. Not only did participants compare themselves to others (section 4.2.1.2, 4.2.2.3), compared previous health concerns (section 4.2.1), but they also compared information sources and the knowledge gained from these. Participants explained that frequently one source was not used in isolation, with multiple sources being consulted to provide further explanations:

*pick up a copy of “men’s health” after swim and sauna. Didn’t learn anything new only a couple of abs exercises and reinforcement of dietary advice from Tuesday’s talk*

Diary: Tony, 66, retired salesman

During the selection of different sources of knowledge, various paths were followed which were influenced by the perceived credibility, applicability and the availability of the source (as described in 4.4.3). This was not always seamless with the route sometimes blocked or

requiring a change in direction. Occasionally the direction could lead to a dead end, for example when the knowledge was impersonal or perceived as irrelevant:

*Sometimes the leaflets aren't user friendly...When I think about it the doctors surgery is, there are posters all over the place about do this do that go here go there, if you are you know while you're there read this stuff as long as it's there you can pick it up. I must admit I don't particularly look at it to be honest*

Interview: Bruce, 73, retired engineer

Not only was relevance important, but it became apparent that participants needed to be interested in the health information with timing on the medical trajectory also impacting on knowledge:

*it's what you already know or what you've been told by the various nurse practitioners...I do read it only read the bits I want to read...I don't take an interest in anything I don't want to know about...but if I'm not interested in it I don't take notice of it*

Interview: Jack, 82, retired police officer

Whilst the navigation of various sources was required, some obstacles were presented which are explored in the following section.

#### 4.6.1.1 Navigating barriers

Navigating services and information was an active process, not always straight forward and at times required participants to be persistent, which could be draining of energy, exhausting and proved challenging. The following quote illustrated the perception that later life can affect the ability to be resourceful which impacted on this participant's well-being:

*But I don't think I am as resourceful as I used to be (laughs)*

*Why do you think that is? (Interviewer)*

*I think I should have demanded a doctor the first night and I can't imagine why I didn't really...yer I am feeling absolutely shattered, I don't feel very perky at the moment I mean I'm fine but (pause) just worn out by it...it's depressing*

Interview: Maud, 66, retired newspaper reporter

Additionally, barriers to understanding health information presented as challenges inhibiting the acquisition of new knowledge. These barriers were often due to the way that information was presented and related to inadequate and poor communication, particularly from healthcare professionals. Often, participants suggested that the terms and language used proved difficult to understand. The following participant reflected on a conversation with his GP who telephoned with the results of cardiac investigations, he did not understand the terms used but realised they were significant as he was referred to a cardiologist:

*Dr rang and told me the results, it was called leaking. I don't know what that means. I don't understand anything medical really because I'm not that way but erm obviously enough for me to be seen...*

Interview: Alan, 80, retired architect

Despite admitting there was a lack of understanding of terms, at times this motivated others to seek further clarification in order to complete understanding. To reduce these barriers to understanding, various sources were accessed to find additional information, thereby increasing knowledge. New knowledge was sometimes provided by healthcare professionals, with this participant describing how and why she questioned the GP:

*So I think I'm a bit of pain in the neck with him [GP] because I want to know what's happening to my body, I want to know why he's doing this and he'll tell me you know I know he will tell me he better had (Laughter)*

Interview: Penny, 82, retired from working in social services

However, when additional information was not provided by healthcare professionals, participants explained how they overcame these barriers to understanding. In order to

facilitate understanding, other sources were navigated within the home setting, in an attempt to establish meaning:

*I might do something, again come up with a word and I didn't understand it, I might look it up in the dictionary....*

Interview: Tom, 74, retired book keeper

In situations where it was viewed that the information did not meet the necessary requirements, there was a change in direction and a different path would be navigated. This change in direction meant either returning to previous sources that were familiar or selecting new sources that were believed to provide the necessary information and help. Some described accessing private health care when waiting lists were too long. For others, a change in direction led to exploring complementary and alternative medicine (CAM) as conventional treatments had offered little and using CAM helped with managing symptoms:

*I thought it was my shoulder but I went to Len's [husband] chiropractor and she said, no. It's that there that is caused by this muscle across the back and also your neck. And so, I go there...but it just aches towards the end of the day, it's like toothache, you know.*

*But did you go to the doctor about it in the first place? (Interviewer)*

*They don't want to know. They said there's nothing wrong with it really. But it is what she said, it's water in the muscle. That, no, you see, they don't recognise osteopaths and chiropractors, do they, very much anyway.*

Interview: Jess, 66, retired PA to factory manager & Len, 71, retired builder

Participants navigated between conventional and complementary care with CAM used in conjunction, not in lieu of conventional care. Several factors led to the decision not to commence CAM, its discontinuation and these related to beliefs and judgements about its efficacy:

*Have you ever used complementary and alternative medicines? (Interviewer)*

*No I haven't, I did consider erm I had very bad sciatica and I did consider. I was in excruciating pain and i did consider acupuncture but didn't go ahead with it because someone had had it and it hadn't worked for them so I didn't bother.*

Interview: Cynthia, 84, retired secretary

Despite these barriers, participants navigated through health information, using the resources that they had available to them. Commonly, certain individuals such as healthcare professionals and members of the social network played a key role in supporting participants when health changes were experienced. The following section explores the role and significance of these supporting individuals as the older person navigates later life.

#### **4.6.1.2 Navigating health changes-the significance of co-navigators**

Overall, there was a perception that later life had brought with it obstacles which needed to be overcome, in order to maintain a sense of independence. Health changes as a result of the ageing process, acted as such obstacles, impacting on daily life and to overcome these participants adapted to the changes. To assist with navigating later life and seeking information, resources were mobilised which often included family and other members within the social support network who acted as co-navigators. These co-navigators provided emotional, physical and informational support. The importance of providing information support has been previously highlighted in the section 'seeking support' (see section 4.4.2). By providing information support, tailored to individual needs, co-navigators can help smooth the path and overcome obstacles faced by older people in later life.

As explored within the typology of information seekers (section 4.5) the depth of knowledge perceived to be necessary by information seeker varied. Often for the passive seeker there was a need to have just enough information that focused on essential information and was tailored to individual needs. The importance of the co-navigator providing the right amount of information is reflected by the following statement:

*She [GP] was good. She discussed the whole thing in great detail and then said was going to put me on these heart failure tablets and I said how long for and she said wait until you go to the teaching hospital*

Interview: Victoria, 84, retired shop worker

For the more inquisitive information seeker they expressed a desire for more in-depth information. A co-navigator for these information seekers needed to provide more information to fill a perceived gap in knowledge. As previously suggested in section 4.4.3, participants consulted various co-navigators including informal sources with some medical knowledge, as well as healthcare professionals. By accessing various sources this helped to provide a different perspective, translated health information and aided navigation through health problems. Sometimes, despite healthcare professionals acting as co-navigators and providing extensive explanations, proactive health information seekers continued to explore the minutiae to gain answers regarding health concerns:

*I absolutely found the explanations [from healthcare professionals] helped me, I still have one confusion which I haven't got to the bottom of, what's the difference between infection and inflammation, can't get my head round that at all. I have gone on the internet and I'm probably not much wiser, I've not actually asked Google what's the difference between infection and inflammation because they are related but I've not actually asked Google that, I might do that today.*

Interview: Tony, 66, retired salesman

Furthermore, as highlighted within the typology (section 4.5.1), proactive information seekers focused information seeking on self and others. Sometimes these participants described their role as co-navigator within the information seeking situation, acting as a health information resource for others. The following participant described a scenario in which she perceived that the GP had not provided enough information to her husband and her role as co-navigator consulting various information sources:

*Pitted it's cellulitis you know*

*How do you know that? (Interviewer)*

*Well really from what Jenny Lewis whose husband has it, said to me and then I checked on the web, as you do and it looks like it you know and then you read it what the symptoms are and you think oh you know this isn't just bruising*

Interview: Maud, 66, retired newspaper reporter

Interaction with co-navigators from within the social network provided additional information and shaped the pathway followed by some participants. The following reactive information seeker illustrates the impact that a conversation had on managing her health problem:

*One of the bridge players, Frances...She's in her eighty's, she told me and this is interesting for my immune system I should take betaglucan, every heard of betaglucan? So I wrote it down. And when I was in town I went into Boots and there it was, £20, so this is all since I've had the blood tests with the low neutrophils*

Interview: Louise, 73, retired nurse

The co-navigators role also included accessing sources for participants when there was a gap in knowledge. As previously highlighted in section 4.4.2, family and friends acted as co-navigators by providing information from the internet to aid understanding regarding health concerns. This was often for reactive information seekers when they did not have access to the internet. Other participants also gave examples where healthcare professional's provided additional written information from the internet:

*Are you ever given any information leaflets? (Interviewer)*

*Yes, yes they're printed off the internet and they print it off and give it to you to take it away*

*Do they give you any websites that you could go to? (Interviewer)*

*No*

Interview: Sue, 68, retired receptionist

Whilst the support provided from members of the social network has been presented above, participants also suggested that other co-navigators are available to support navigation. As previously highlighted (4.4.3), healthcare professionals were generally perceived as credible sources, often played a supporting role and therefore might also act as co-navigators throughout later life. This was demonstrated when informational support was required, helping the participants to navigate changes and maintain health and is highlighted below:

*Brought some Brewer's Yeast tablets-the chemist recommended for immune system-(having finished probiotics) will see if they help!*

Diary: Louise, 73, retired nurse

Again, health information needs varied with differences between the information seekers apparent. When acting as a co-navigator it is important that healthcare professionals are aware of the health information needs of each individual. The following participant, a proactive seeker, suggested that she would ask for further information if she did not understand anything:

*How would you describe the explanations and information they [healthcare professionals] give you? (Interviewer)*

*Good, yes, if I didn't understand what they were talking about, I would ask*

Interview: Sue, 68, retired receptionist

By translating information, co-navigators would be able to ensure that older people are more informed regarding their health. This was illustrated by participants when discussing their understanding of their health problems. The following participant, who was a passive information seeker, was taking oral anticoagulants and had regular INR tests, demonstrated his gap in knowledge:

*I'm never quite sure about the bruising, what sorts of bruises that they mean whether you bang yourself or you just get a bruise out of the blue.*

Interview: Alan, 80, retired architect

As identified earlier, a barrier to health information seeking was poor communication by healthcare professionals. The importance of good interpersonal skills, kindness and a caring attitude was noted by many of the participants as a key attribute for healthcare professionals. By adopting this approach, healthcare professionals have a significant role as the older person's co-navigator:

*District nurse is brilliant. Oh, she's lovely. The others were, yeah...They come in, like you're sitting here talking to me. There's no authority as such, you know, .... Well, I suppose, I've been through the RAF, you know. We—we work to, you know come on you know you jump around everything has to be at.... It's, I suppose they've got a special interest in what they're doing. That's a big thing it's not like going through a supermarket where some of them are yawning and shove the stuff here and there. But when they come through that door that kind of say don't knock you come straight in. And there's no airs or graces; it just flowed through. Wonderful, wonderful*

Interview: James,79, retired builder

To navigate later life, skills acquired throughout the life course were used. When threats in later life were experienced, having knowledge of their body and recognising health changes facilitated navigation. Despite challenges, participants demonstrated that they had managed to navigate through unknown terrain and overcome barriers with health information aiding this. Co-navigators such as healthcare professionals, family and friends can also provide assistance; support and information during later life which can help maintain the equilibrium. In order to achieve this, the ideal co-navigator from the older person's perspective should be framed as to where they are on the typology, to ensure information needs are appropriately met.

#### **4.7 Summary**

This chapter has presented the main findings of the study, exploring the health information seeking behaviours of older people. In a quest to seek health information, older people undertake a metaphorical journey which is shaped by many factors. Strategies of health information seeking behaviours are not necessarily fixed, but may be subject to change over

time. The major categories have been inductively drawn from the participant's responses and three categories have been identified to explain the health information seeking behaviours of older people. Throughout the chapter, a constructivist approach has been adopted to indicate the complexities of the older person's worlds, views and actions. A typology of health information seekers has been developed, identifying that differential health information seeking behaviours exist among older people. The chapter has concluded with the presentation of the overarching core category, arguing that older people continue to develop navigational skills throughout later life and demonstrates how older people cope, adapt and manage changes in health and sustain well-being.

The discussion chapter develops an explanation for these findings arguing that the context of ageing is changing and impacting on older people's health information seeking behaviour. To navigate later life, older people acquire strategies that are embedded in everyday life.

## **CHAPTER 5**

### **DISCUSSION**

#### **5.0 Introduction**

By adopting a constructivist approach, the aim of this study was to explore the complexities of the older person's worlds, views and actions. This was achieved by focusing on the experiences of participants and exploring their views, values, actions, beliefs, feelings, assumptions and ideologies. The constructivist view assumes an ever-changing world whilst recognising diverse local worlds and multiple realities (Charmaz, 2008), hence constructivists are concerned with their social realities that are constructed by individuals as they try to make sense of situations, communications, events and other people (Lincoln, 2005).

Findings from the study suggest that older people embark on an health information seeking journey (see figure 7) requiring navigation. The pathway is shaped by experience, perceptions and the nature of later life with self-regulation an integral part of this. Illness perceptions were associated with coping, self-management, well-being and health information seeking behaviour. Triggers to health information seeking were often as the result of a change to health, symptoms were interpreted and decisions made as to what followed; however non-solicited information also acted as a trigger.

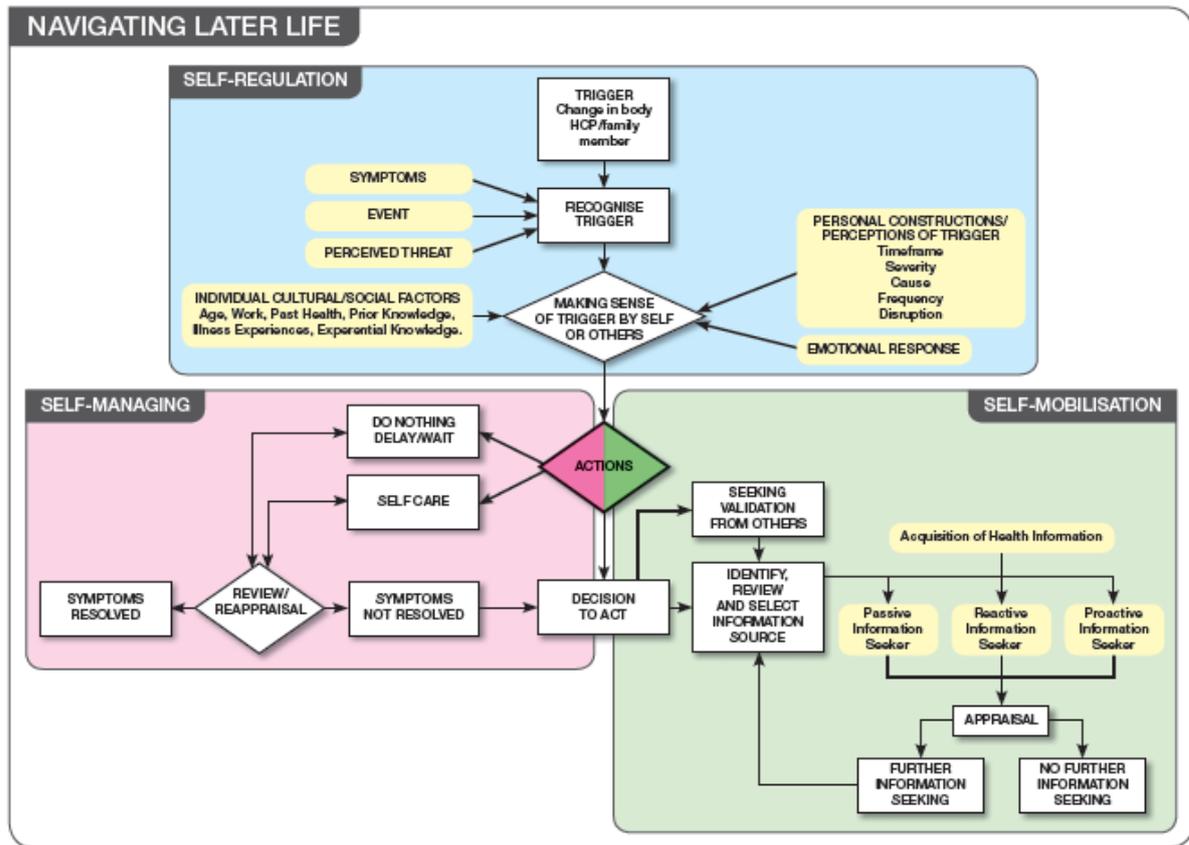


Figure 7: Health information seeking journey

This study mirrors previous theoretical frameworks, for example; Wilson (1999) and Leventhal et al.'s (1984), however these can be extended and applied to the health information seeking behaviours of older people. Wilson's (1999) study was generic and explored information seeking for all age groups, whereas the current study focused on older people and their health information seeking behaviour. Furthermore, this study demonstrates how Leventhal et al.'s (1984) model can be extended in light of the altered landscape experienced by older people. In this chapter, Leventhal et al.'s (1984) and Wilson's (1999) theoretical frameworks will be discussed with findings further interrogated and used to compare and contrast these frameworks and other literature.

In this chapter a case is argued for the following concepts: First, shifts in knowledge have occurred as the result of an altered landscape, with older people adopting strategies to navigate a complex pathway in an ever-changing world. Second, there is a typology of health information seekers. Third, health information seeking is undertaken at various stages of the medical trajectory. Fourth, much ill health is contained within the home with older people

being self-reliant and contributing to their own healthcare, supported by people within the informal social network. Fifth, health information is located by accessing various sources, these are used to build and create new knowledge, often used in tandem with knowledge acquired from healthcare professionals. Finally, despite going beyond the medical establishment for health information, the general perception is that healthcare professionals head the hierarchy of expert knowledge therefore influencing the health information choices made, with trust and credibility of sources impacting on usage.

## **5.1 Setting the scene**

Today's older people experience significant political, cultural, social and technological changes (Pond et al., 2010). Medical advances have meant that life expectancy is increasing with older people living with comorbidities and the disease burden shifting from predominantly acute to life limiting conditions (Victor, 2010). Consequently, the contemporary older person has to learn to navigate through a world of more choice, multiple sources of knowledge, an increasingly complex patchwork of services, changed healthcare roles, and an expanding self-care role undertaken within the home. This changing landscape is explored within the discussion, the impact on the older person's life, and how it has led to a complex pathway being navigated to seek health information.

### **5.1.1 Modern world**

The passage of time has meant a changing world, with older people previously experiencing a world with traditional routines and institutions, and the interaction between the medical profession and 'patients' being central (Blaxter, 2004). When reviewing research, it has become clear that academic understanding of decisions about seeking help were previously based upon a relatively simple framework. This was particularly evident when Zola conducted his study in 1973 and identified non physiological factors or triggers to action, these being perceptual, interpersonal, temporising and family induced triggers which prompted the individual's decision to seek (or delay) health care. Furthermore, Suchman's (1965) model of the decision to seek medical help identified five stages which included 'symptom experience', 'assumption of the sick role', 'medical care contact' 'dependent-patient role' and 'recovery'. Both Zola (1973) and Suchman (1965) described a pathway that was relatively straightforward and uncomplicated, usually resulting in the patient navigating a pathway to a medical professional. These models possibly reflect a period where

healthcare was characterised as curative, and once the pathway had led to the medical professional, a classic sick role relationship (Parsons, 1951) was entered into with the doctor informing the passive patient what was wrong and what they had to do to get better.

Functionalism views social relations in the healthcare setting as products of a consumerist society, where social order and harmony are maintained by individuals performing defined roles and undertaking certain activities. The functionalist school of thought emphasised the requirement of the passive patient and dominant doctor to ensure an efficient running state. The concepts of the sick role, patient and doctor roles were the product of a distinct phase of the superiority of the biomedical model, where behaviour was viewed as a response to the biomedical state of disease. Parson's (1951) functionalist approach shaped in a modernist society clearly identified the boundaries of expertise and the role of medicine within society to validate the sick role. Parsons symbolised patients as compliant, passive and grateful with his account of the professions reflecting the dominant values of the profession itself, as doctors being universally beneficent, competent and altruistic. To return to being a productive citizen, an individual submits to the medical profession, and complies with treatment. If returning to productivity was not possible, then the doctor would verify the sickness and the individual became exempt from productivity responsibilities. The functionalist approach has been critiqued by commentators with regards to medical status, arguing it is less about communal altruism and more about social advantage (Freidson, 1970). Furthermore, the concepts of cultural differences in illness perception, self-care and the use of Complementary and Alternative medicine (CAM) have been excluded from the sick role model.

Illich (1977) challenged and questioned the superiority of medical knowledge and expertise identifying that individuals had become deskilled and were dependent on medical experts. Illich (1977) argued that the monopoly of medicine in diagnosis and treatment promoted the passive consumption of healthcare and by transforming health issues into technical problems, medicine had eroded the potential of individuals to be autonomous when dealing with health conditions. Later research undertaken by Kleinman (1980) asserted that it was far more complex and discussed three spheres of a healthcare system that operated in conjunction with each other and consisted of lay, folk or professional sector, with the lay sphere playing the largest part. This study was not conducted in the NHS economy, but in one-where there was a consumerist model where various medical practitioners, for example folk healers and temple medicine men were consulted. Kleinman's (1980) research demonstrated the diverse local

worlds that individuals live in, highlighting the importance of understanding the beliefs and behaviour from the individual's perspective and the impact that culture and context might have on this. The findings have highlighted the importance of considering health information seeking behaviour from the individual's perspective and the impact of context is explored later in the chapter. Kleinman's model is over 30 years old and during this period, the distinction between and within the three sectors (professional, popular and folk) has become progressively blurred. Indeed, the findings from this study suggest that all three sectors are relevant for older people when navigating later life and seeking information about health.

### *5.1.2 Navigating the changed landscape-the new paradigm of healthcare*

Many participants in this study described the trigger to seek help and health information as the result of knowing their body and recognising changes (see 4.2), with these interpretations often structuring the future illness experience, for example making decisions regarding symptom management. The rhetoric around the biomedical model is increasingly challenged by a new paradigm of healthcare which reflects the changing nature of health and medical care (Nettleton, 2006). The postmodern world is shaped by challenge to expertise with a philosophical shift away from viewing the patient as a passive, objectified, differential person conceptualised in the sick role and recipient of care, with the emergence of a service user as an expert in their own condition and one who knows their own body. The service user of today is increasingly well-informed challenging medicine's claims to an exclusive knowledge base (Haug, 1988). The variety of help seeking strategies that are available are numerous and increasingly diverse (see 5.3.1) as the conceptualisation of patient roles shift. This has resulted in a change in relationship between healthcare professionals and lay people and will be explored more fully in 5.3.2.4 and 5.3.2.5.

Thus, the changed landscape in the postmodern world has both impacted on where information is sought and the experience of later life. The later life that is lived today has been transformed and contrasts with the one experienced by previous cohorts. Health and life expectancy have improved as medical technology has become effective in the prevention of disease, management of chronic illness and the increase of disability-free life expectancy resulting in diseases with a poor prognosis for older people becoming responsive to healthcare intervention (Patient Information Forum, 2013). However, the reality of later life in the postmodern world is complex, with older people living longer with more healthcare

needs. The navigational model within this significantly different landscape can increase understanding regarding the choices made by older people, specifically concerning health information seeking and the facilitators and barriers involved within this process. Within this context, the discussion explores Leventhal et al.'s (1984) theoretical framework and how illness representations shape behaviour directed at managing disruptions.

## **5.2 Self-regulation**

When participants experienced symptoms, these were interpreted, choices made and actions followed with decisions impacting on how individuals defined and structured the future of the illness experience. Recognition of these symptoms was facilitated by knowledge of their own body, with decisions based on this assessment. Participant's knowledge of their body triggered health information seeking behaviour if it was perceived that health changes acted as health threats. The self-regulation model (Leventhal et al., 1984) potentially increases understanding of the many aspects of older people's health information seeking and aids understanding of individual experiences and behaviours when a health threat materialises. This study demonstrates how Leventhal et al.'s (1984) model can be extended, not only incorporating health information seeking but including strategies undertaken when experiencing a disruption, embracing emotional representations, with its use being applied to broader areas of self-management. However, misinterpretation of symptoms can also impact on health information seeking, potentially leading to a delay in addressing health threats (see 4.2.1).

It was evident that the commonly held belief amongst most participants that health changes and illness were normal in later life impacted on behaviour and health information seeking, and will be further explored within section 5.3.2. In my study and as identified in Leventhal et al.'s (1984) model, the individuals understanding of the disease (both the label and symptoms) impacted on illness management. This was apparent for some participants who had medically unexplained symptoms and experienced uncertainty, who searched for information in an attempt to find a diagnosis (see 4.5.1 and 4.5.4). Indeed, Cooper (1997) explored the struggles experienced by participants with an unknown illness as they attempted to gain a label in order to achieve a legitimate move into the sick role.

### *5.2.1 Motives and coping*

Motives as a reason for health information seeking were discussed by participants. Passive information seekers suggested that they were satisfied with the information that had been provided to them, and some explained that sometimes they avoided information as it made them feel uncomfortable. As previously discussed, Wilson's (1999) model also identified different types of information seeking: passive attention, passive search, active search and ongoing search. Parallels to this can be identified within the current study and will be discussed in following sections (see for example 5.5.2). Indeed it was clear that participants did seek health information in the way Wilson (1999) described; however the typology of information seeker within this current study develops this further. This study identified that it was also important to consider other factors which impacted on health information seeking. Within this study, these included motivation (see 5.2.1), timing (see 5.5.1), pattern (5.5), style (5.5), information sources commonly consulted (see 5.3.1), focus and decision making within this process (see 5.3.2.5).

As previously identified within Leventhal's (1984) self-regulation model (see 2.3.1.1); fundamental to self-regulation theory is the relationship of illness representations to coping responses. Furthermore, Wilson's (1999) model identified that motives and coping were factors that affected information seeking. Seeking information may act as a coping strategy and allows the individual to feel they have control over their medical condition (Broom, 2005). However, Case et al. (2005) argue that assumptions have been made that individuals actively seek information, but for some, avoidance is used but is rarely explored by researchers. The present study identified how anxiety and perceived threats to health on health information seeking impacted on motivation resulting in individuals, either seeking or avoiding information. According to Maslow (1963), individuals either seek information to reduce anxiety regarding the threat or they avoid knowing by not seeking additional information. There was a split in the sample in this study on whether anxiety associated with the disruption led to information searching or not. Anxiety motivated some participants to seek health information in order to address concerns, whereas for others heightened anxiety reduced information seeking with participants actively avoiding information, in order to reduce anxiety.

Previously, information seeking styles have been characterised by the terms of either monitoring or blunting (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Monitors survey the environment for threats and are active in information seeking, whereas blunters have a tendency to avoid information that is potentially threatening or use distraction to avoid it (Miller, 1979). Of course, distraction can work effectively, but this could be dependent on the degree of disruption and could prove challenging with significant disruption. Information seeking in this study went beyond the dichotomy of monitoring and blunting and fluctuated depending on perceived need. For example, some participants restricted searching according to need and as the illness experience unfolded, with variations clustering into patterns. Although monitor and blunting styles were evident within this study, they were not as distinct as research has previously suggested. Similar to other studies on monitoring (Gaston & Mitchell, 2005; Miller, 1995), proactive seekers wished to gain information about their health concerns and that of others. But, monitoring, as presently described within the literature, does not encapsulate the differences suggested within the reactive and passive patterns of information seekers. For example, some participants within this group, purposefully avoided some information, but also limited searches related to other aspects of health and illness. These findings corroborate those of Lambert et al., (2009a) regarding cancer information seekers, suggesting that variations in style do exist. Health information seeking was a strategy employed at various stages of the disruptive experience as participants attempted to provide explanations and increase knowledge. Reactive information seekers actively searched for information, but with information searchers varying in their approach.

### ***5.2.2 Burden of treatment and minimally disruptive medicine***

Leventhal et al.'s (1984) self-regulation model is useful when reflecting on health information seeking behaviour in this study. Leventhal et al.'s (1984) model has provided good explanations for some of my findings, but there are new emerging areas of thinking that can build upon and develop this theory further which were applicable to the participants within this study. Illness perceptions may not be the only reason for following regimens as the burden of treatment can also impact on decisions made regarding treatment (see section 5.2.4). Perceptions of treatment necessity are bound up with representations of the illness, once it has been decided that treatment is necessary, decisions are made as to whether this is the appropriate treatment by the individual. These evaluations are influenced by social and cultural norms, past experiences and information gained from various sources (Horne, 2003).

Living with and managing a long term condition in later life involves hard work as individuals seek to cope, adapt and minimise the physical, psychological and biographical impacts of the disease (Corbin & Strauss, 1985; Bury, 1991). Management of long term conditions requires routine work to avoid exacerbations, to monitor for recurrence and prevent disease progression (May et al., 2014). Additionally, navigating healthcare services and information sources, communicating with healthcare professionals and following treatment regimens similarly creates work and result in disruptions to individual well-being and functioning (Eton et al., 2012). With the recent move towards self-management, these changes have shifted the work of healthcare professionals towards patients and their families (Dabrth et al., 2015) and represent a significant burden for them (Sav et al., 2013). May et al. (2014) argue that this shift adds a further dimension to the experience of living with a long term condition; the burden of treatment. The burden of treatment is experienced alongside the burden of illness and healthcare regimens that include taking medication, monitoring health, exercise, diet and keeping appointments with healthcare professionals (Eton et al., 2012). An increasing body of literature (May et al., 2009; Eton et al., 2012) suggests that part of the solution to solve the problem of treatment burden is the need for minimally disruptive medicine. Minimally disruptive medicine is designed to advance healthcare goals with the least burden by tailoring treatment regimens to the daily lives of the individual. By adopting this approach, it could improve the quality and care of the life of patients by acknowledging patient complexity and considering individual preferences (May et al., 2014).

### ***5.2.3 Rationalised non-adherence***

A factor impacting on adherence is the burden of treatment. To reduce the burden of treatment, only one participant admitted to non-adherence to their treatment regime which was unrelated to disease causation but was in relation to taking prescribed statins and the undesired side effects he experienced (see 4.3.2.2).. Rationalised non-adherence, describes the intentional, partial or complete non-adherence to treatment recommendations which aims to minimise disruptions, and has been reported in other studies (Jordan et al., 2006; Johnston & Nobel, 2012; Sav et al., 2013). Medication use was found to be one of the key sources of treatment burden within a study by Sav et al. (2013) resulting from side effects, polypharmacy and stigma. A systematic review by Demain et al. (2015) revealed that most rationalised non-adherence was undertaken by individuals in isolation, without discussion with healthcare professionals and was often actively concealed. The review (Demain et al.,

2015) also identified that when rationalised non-adherence was disclosed, healthcare professionals expressed disapproval or disappointment and attempted to persuade adherence. This has resonance with the current study, as the participant who followed this route of rationalised non-adherence described the discussions and negotiations that his GP underwent with him to persuade him to continue with his statins. Non-adherence to statins has been highlighted within the literature as a common problem (Mann et al., 2010) with concerns about or experiences with adverse events cited as the commonest cause of statin discontinuation (Fung et al., 2010). The perceived severity of the illness also impacts on adherence to statins, for individuals with coronary artery disease and minimal symptoms tending to have lower adherence rates to individuals with symptomatic heart disease (Benner et al., 2014). Adherence to treatment of a symptomless condition presents a challenge to healthcare professionals and their patients, with Turin et al. (2015) suggesting that adherence is influenced by the patient-healthcare professional relationship with communication key to this. Indeed, for Fung et al. (2010) a dominant theme within their study was dissatisfaction with the amount of information gained regarding statins from both doctors and pharmacists, with these participants gathering further information from other sources. However, healthcare professionals should acknowledge that some are unable to tolerate statins and should suggest alternative interventions such as therapeutic lifestyle changes (Maningat et al., 2013), thus reducing the burden of treatment.

### **5.3 Developing knowledge**

#### ***5.3.1 Lay knowledge***

Participants constructed knowledge through the lived experience of health and illness and social interactions with others. Multiple sources of knowledge (see figure 8), including written, verbal or a combination of the two, were drawn upon by many of the participants resulting in a complex pathway being navigated.

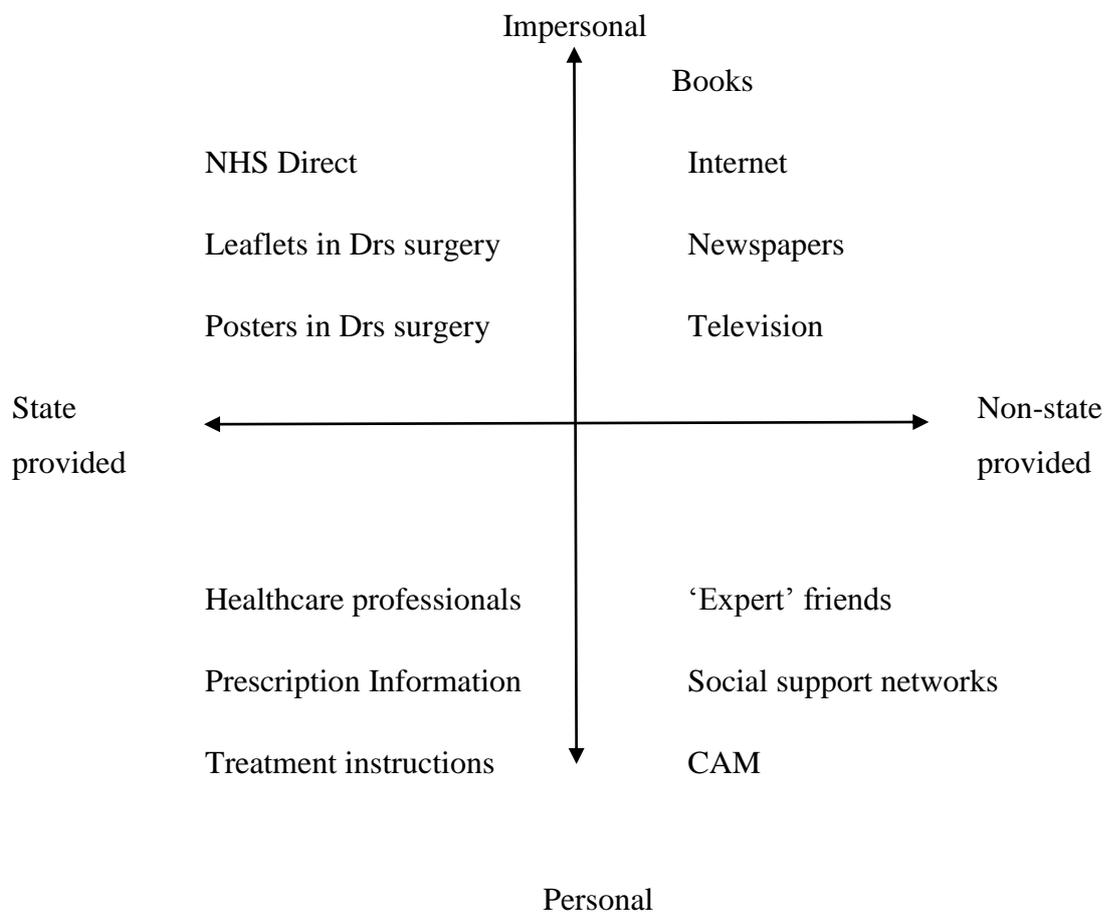


Figure 8: Information sources used by older people

Knowledge was constructed using diverse forms of information which had become entwined and used to inform participants about health and illness. The knowledge was acquired experientially, through the lived experience of ageing and by expanding knowledge via other sources, with anecdotal information gained from family, friends and neighbours. Health changes impacting on participant's daily lives motivated further information seeking in an attempt to make sense of the situation and to identify potential causes. Personal reflections on problems were often shaped by a person's biological and biographical experiences. While this is true for all age groups (Attfield et al., 2006), older people have a larger repertoire to draw on, gained over many years. Some may be better informed, influenced by their professional background; however, this could lead to potential problems as the knowledge may have become out of date or inaccurate as health interventions have advanced. Lay health

and illness beliefs are socially embedded in the context of the person's lives are structured by an individual's culture, no matter where they are in the life course (Hodgins et al., 2006a).

### **5.3.1.1 Sources of health information**

Consistent with Hunt et al.'s (1989) study, the present study found that information was gained from different sources. These sources were utilised to build and create new knowledge, often used in tandem with the knowledge acquired from healthcare professionals. The various sources accessed for medical knowledge included the internet, books, media, and past experiences including medical consultations were all used to build a picture of the situation. Views about cause and treatment held by lay people are commonly drawn from the medical establishment, these are reinterpreted and integrated into the belief systems of the lay person and incorporated in the context of everyday life (Pill, 1991). This is often undertaken within the home where medical knowledge is reinterpreted, reshaped and applied to the individual's needs and health concerns (Dew et al., 2013).

Often the sources used by participants depended on the type of information seeker and the information sources available. All the proactive information seekers used multiple sources to gather information about their health; they had access to and mainly used the internet to gain health information. They also used other informal sources in their quest to gain as much health information as possible to meet their information needs. For reactive information seekers, the sources to seek health information were more varied, for example they used medical books. Some had on line access but rarely used this for health information seeking in the same way that it was used by proactive information seekers. The search was purposeful, and once information had been gained searching stopped. For those who did not wish to seek health information via the internet or did not have access to on-line information, other sources such as books were used. As previously identified, passive information seekers only used a minimal number of sources to fulfil information needs which were mainly healthcare professionals and written medicine information. Passive information seekers perceived that they had acquired enough information about their health concerns.

In the process of navigating through the vast amounts of information now available, it was evident that participants became experience-based experts regarding their own health problems, thus weakening the division between professional and lay expertise. Experiential

knowledge of their bodies, together with available information sources to find out health information, helped expand knowledge. In order to enhance understanding of personal health and illness, knowledge was adapted to meet individual needs. With more information becoming available to the layperson, the divisions in knowledge between lay and professionals could potentially converge, with much research (for example Prior, 2003) exploring the dichotomy between medical and lay understandings of disease and illness. Within this study, it was apparent that some constructed a medical diagnosis, which was self-diagnosed, by assessing their symptoms and labelling these with a diagnosis. It was common for information to be gathered with conclusions made as to whether a healthcare professional was needed for further help, for example to treat symptoms. Even when asymptomatic, unsolicited triggers activated health information seeking behaviour. It was also evident that the construction of a diagnosis has moved outside the traditional biomedical domain, with some circumventing the doctor altogether, for example those who consulted CAM to receive a diagnosis (see 5.7.2).

Traditionally, it has been viewed that the doctor's and lay person's perspectives are completely different (Lehtinen, 2007). The beliefs that individuals hold influence perceptions about health and illness (Thompson & Gifford, 2000), and are important as lay knowledge and beliefs impact perceptions of risk of disease and whether health information is needed for prevention. Lay knowledge is gained via two avenues which are scientific or professional knowledge and public or lay belief (Davison et al., 1991). These various bodies of knowledge differ as professionals are concerned with disease processes, with lay people more focused on personal experience (Brown, 1992) and are experts in their own health problems (Barker & Galardi, 2011). Prior (2003) has argued that lay knowledge is limited to personal interests and does not move beyond the self, with lay people able to recognise changes in the body, but not in the underlying pathology. Indeed, the ability to construct a medical diagnosis from a complaint and symptoms, defines the doctor from the lay person (Freidson, 1971). This reflects the dichotomy between medical and lay knowledge, with lay people acquiring an expert body of knowledge which is different, but personal to them. Furthermore, there has been a tendency to privilege clinical expertise over subjective knowledge (Wilson et al., 2007). Popay and Williams (1996) assert that due to life experiences, lay people have an 'expert' body of knowledge, which they identify is different but equal to healthcare professionals. However, the altered landscape has impacted on this, with open access to information previously restricted to doctors. The dichotomy between lay and professional

knowledge is diminishing with the traditional, paternalistic patient-provider relationship beginning to shift towards a more dynamic model as individuals have become more knowledgeable. Nettleton (2004) argues that health and medical knowledge has been transformed into information no longer confined within medical institutions, with the flow and exchange of information facilitated by more information sources being available and accessed by service users.

### *5.3.2 Navigating ageing*

It was necessary for participants to navigate a changing and complex healthcare system, in tandem with navigating the experience of later life. Participants used experience and knowledge, with consideration given to social and contextual factors. Individuals create mental representations of illness based on available abstract and concrete sources of information (Diefenbach & Leventhal, 1996). Sources of information are constantly updated, with each influencing the interpretation and perception of the symptom (Aasen et al., 2012), whilst potentially impacting on the path that is navigated. Representations of illness are formed from information gained from culture, personal experiences of the illness and social exchanges with significant others such as healthcare professionals (Leventhal et al., 1980; Leventhal et al., 1984). These information sources and interpretations contribute to the individual making sense of the condition and results in help seeking, employing a coping strategy or undertaking an illness management regime (Bishop & Converse, 1986; Diefenbach & Leventhal, 1996). Interpretations of symptoms were often viewed as a consequence of ageing and affected the pathway navigated by participants and is further explored in section 5.3.2.1.

Furthermore, the representations of disease and treatments are influenced by beliefs about the self and cultural views about illnesses and treatments (Leventhal et al., 1999; Ekdahl et al., 2010). These influence the individual's illness representations by the provision of linguistic labels for categorising and differentiating many events that represent illness and determine whether the experience is normal (Leventhal et al., 2003). This impacts on all facets of the self-management of illness, ranging from the identification and labelling of symptoms to deciding to seek medical care, use CAM, and to make lifestyle changes in order to manage illness (Leventhal et al., 2004). For instance, if a participant believed a natural consequence of ageing was to experience pain then this impacted on decisions regarding management.

Therefore, an individual's decision to act upon a symptom by adopting a self-care strategy or seek help to cope with illness is likely to be shaped by life course and socio-cultural factors, with the decision to seek professional help promoted or delayed by social factors (Zola, 1973; Lawton et al., 2005; Backett-Milburn et al., 2010; Suziedelyte, 2012).

As participants tried to make sense of the situation, perceptions regarding symptoms impacted on the route navigated and were shaped by prior experiences and knowledge. The lay person's disease perceptions and understandings are focused on the context in which they live and are the product of the individual's social history (Blaxter, 1983). Indeed, this was demonstrated by participants who believed previous employment had impacted on their health in later life. In addition, these understandings are gained through past knowledge of family history and from wider society throughout the life course (Pound et al., 1998), with an awareness of family history resulting in an increased awareness of potential vulnerability to medical conditions. Finally, contextual factors such as the individual's position in the life course determine and impact on disease perceptions (Pound et al., 1998).

#### **5.3.2.1 Ageing perceptions**

Symptoms were often perceived as an inevitable consequence of ageing with the illness integrated into the fabric of their being. Perceptions of ageing related declines were found to impact on motives for health information seeking behaviour. For some participants, a heightened awareness of ageing related body changes meant that they perceived a need for further information and held the belief that seeking this might prevent further decline. However, some participants, who perceived that the decline in health was related to ageing, suggested there was an inevitability about this which did not motivate health information seeking. Indeed, the interpretation of symptoms can be influenced by 'normative conceptions of the body' (Kleinman, 1988). Poor perceptions of age can affect an individual's beliefs, with older people having low expectations of health, anticipating that healthcare will be of little benefit to them, or believing the condition to be a normal part of ageing (Victor, 2010). Therefore, it could be argued that due to the prevalence of long term conditions in later life (Office for National Statistics, 2013b), the presence of a long term condition could be perceived as normative.

A common finding in research is that older people have low expectations attributing symptoms to normal ageing (Sarkisian et al., 2002; Kim, 2008; Shaw et al., 2008; Prasanna et al., 2013). Sanders et al (2002) research on older people with osteoarthritis, suggested that older people tended to perceive the disease as a normal part of the ageing process. However, while age is a prevailing risk factor for osteoarthritis, not all older people develop osteoarthritis and is not an inevitable consequence of later life (Yeom, 2013). As lay concepts are culturally influenced, an older person's view of health is shaped by society's attitude towards ageing. Studies have provided evidence that older people have ageing-stereotyped beliefs including attributing health problems to inevitable consequences of the ageing process (Locher et al., 2002; Heidrich et al., 2006; Yeom & Heidrich, 2009).

#### **5.3.2.2 Self-efficacy and health beliefs**

In addition to perceptions of ageing, Wilson (1999) identified that some needs prompted information seeking more than others. Indeed, the decision to seek information could be affected by the participant's perception of their degree of control over events; their self-efficacy. Bandura (1986) developed the concept of self-efficacy which is the belief in one's ability to achieve an action and is a central construct within social cognitive theory. Self-efficacy is linked to outcome expectation; the predicted consequences of taking action. Most individuals might avoid tasks such as information seeking if it is perceived to be beyond their capabilities, or if the expected result would not generate enough reward for the amount of effort that is put into the activity. Therefore, if an individual does not believe that having more information will facilitate a change, then it is less likely that information will be sought. Conversely, if the perception is that a problem might be solved this is likely to motivate a search for a way to do this, which includes seeking information (Johnson et al., 2001). This is particularly relevant in later life, if there is a belief that health changes are a result of the ageing process, it may be perceived there is nothing that can be done about ageing changes with little value in seeking further information. For participants in this study, perceptions of altered health as a result of ageing influenced health seeking behaviour in two ways, either prompting or not, participants to find out information. Therefore, it could be argued that the decision to seek health information is affected by the older person's perception of their degree of control over their health as they age.

The Health Belief Model (Rosenstock, 1974) postulates that an individual is more likely to take a health-related action if it is believed a negative health condition can be avoided, has a positive expectation and a recommended health action will be successful. Furthermore, the likelihood of visiting a healthcare professional can be determined by elements of the Health Belief Model such as beliefs about the severity of the situation, individual knowledge about the significance of symptoms, perceived barriers and beliefs about the value or efficacy of medical attention (Rosenstock, 1974; Vebrugge & Ascione, 1987). This model developed to explain the health-related behaviour of individuals, can be applied to health information seeking behaviour, with these elements considered when deciding to seek information. Fundamental to this, was the importance of individuals self-monitoring and applying previous knowledge to the situation, which triggered a response to action, for example seeking health information.

Within the present study, once ill health had been diagnosed, the majority of participants (see section 5.2.3) reported that they did adhere to treatments regardless of the perceived cause of this. Individuals actively constructed and reconstructed understanding of illness, which is consistent with their own concepts about health and illness and their bodily experiences (Hunt et al., 1989; Health and Social Care Act, 2012). Indeed, many referred to ageing, the changes that had occurred and how this impacted on health, illness and the body along with the adaptations that had been made to accommodate these. Health promoting activities were followed with reference made to the importance of protecting and maintaining health through diet and exercise, suggesting participants were attempting to remain as healthy as possible, despite negative perceptions regarding ageing. Modifications to lifestyle, such as physical activity and a healthy diet can facilitate healthy ageing, improve quality of life (Davies, 2011) and help preserve cognitive function (Lee et al., 2009). Research has suggested that many older people do not appreciate the benefits of health promoting behaviours (Pascucci et al., 2012), in contrast to this participants within the current study described health promoting strategies undertaken to maintain health and adjustments made.

### **5.3.2.3 Ageing expectations impacting on health information seeking behaviour**

Attributing changes to health and reduced function to the ageing process, impacted on health information seeking. Hwang and Jeong (2012) identified that decision delays related to social context and lack of knowledge, with not seeking help potentially being detrimental to health

in the long term contributing to delays for serious conditions. Indeed, Mechanic (1995) cautions that although ageing is associated with increased chronic illness and reduced function, the two processes are separate and it is important that reduced function is not always attributed to the ageing process, when the cause could be disease. Healthcare professional's should consider ageing-related stereotypes and the messages conveyed to older people as they can be harmful and impact on engagement with health promotion behaviours (Yeom, 2013). Unfortunately, the myth that ageing is synonymous with disease can be reinforced by healthcare professionals (see 4.2.1.1), as older people are the population group most frequently told that their condition is due to their age (Conway & Hockey, 1998). Within mental health literature, 'diagnostic overshadowing' is described as a process where physical conditions are incorrectly attributed to mental illness (Jones et al., 2008). Parallels may be drawn between this phenomenon and the experiences that older people described. This was demonstrated by some participants who delayed seeking health information and others who had falls and did not seek further help. Understanding older people's expectations regarding ageing and how these influence information seeking, helps to identify situations in which older people needlessly miss opportunities to seek healthcare for modifiable conditions. Furthermore, it is important to consider that there could be value in seeking healthcare for common problems related to ageing and highlights the importance of educating older people that many age-associated conditions are modifiable or preventable with medical care. Thus, healthcare professionals hold a unique position and play a pivotal role in facilitating fitting attitudes towards the ageing process for older people (Yeom, 2013).

#### **5.3.2.4 Changing relationships**

Experiencing health changes caused participants to construct meaning, make decisions and follow actions in response to this (see figure 4). These events were seen as a challenge or a threat depending on past experiences, timing in life and the amount of unpredictability or uncertainty they brought. When responding to this, individuals both managed the problem and regulated their response which involved gaining information and seeking help. As a result of the changed landscape and diffusion of health knowledge, the present study found that as participants sought information from different sources the relationship between health care professional and lay person has altered. The findings support other research (for example Kav et al., 2012; Rood et al., 2014) regarding individuals preferring to receive health information from healthcare professionals. However, participants did not just rely on

healthcare professionals for health information, as other sources were used (see figure 7). Indeed, to make sense of the situation, it was common that participants used other strategies before engaging with healthcare professionals (especially the doctor) for information. Participants provided examples of actions that had been taken to gain information about health and illness, which were often complex and embedded in the social context. The availability of a vast array of information sources has extended the access to information that can be used to assess whether or not further professional help was necessary. It was apparent that sources were used that were familiar and previously used to access information, such as the written information supplied with medication, although they were not averse to exploring other sources. Knowledge acquisition was not always straightforward due to the plethora of sources of information and advice that were available which meant that it often proved challenging to know where to seek information.

#### **5.3.2.5 Shifts in knowledge**

This study has shown parallels can be drawn between the typology of information seekers and decision making patterns. Similar to findings by Genuis (2012) and Lambert et al., (2009a, 2009b) variations were found in involvement with decision making. Those information seekers, who were proactive, adopted an informed-choice decision making approach. These participants viewed healthcare professionals as providers of formal health information, which was then utilised in the decision making process. They regularly used other sources, to make sense of this information before making decisions regarding health management. Reactive information seekers adopted more of a shared decision making approach. Whilst they looked to the healthcare professional for their expertise, they described being open to information sought from other sources and collaborated in decisions made. Passive information seekers assumed a traditional paternalistic approach to decision making, providing consent for treatment often based on trust in the main source of information, the healthcare professional.

Freidson's (1984) conception of professional dominance claims that healthcare professionals continue to have a monopoly on some elements of medical knowledge. However, the contemporary doctor-patient relationship is based on sharing; decision making is shared, and information is shared by the doctor and is accessed and produced by the patient (Hunt et al., 1989). In the postmodern world, the relationship between patient and doctor has altered, with

the relationship being perceived as a ‘meeting between experts’ (Tuckett et al., 1985), where there is an expectation that patient’s will participate actively in the medical decision making process (Brashers et al., 2000).

The traditional imbalance of power between healthcare professionals and lay people results from the knowledge gap between the two. The knowledge gap between healthcare professionals and the general public is being reduced and challenged by the access to, and availability of information. Indeed, Hardey (1999) characterised the internet as a technology that facilitates its users to challenge medical expertise. New knowledge has altered the relationship between healthcare professionals and users, with individuals encouraged to seek health information, with the intention that they will become more actively involved in their healthcare. It has been suggested within sociological literature that healthcare professionals (mainly doctors) control of knowledge is at the heart of their dominance (Light & Levine, 1988) with the exclusive access to ‘expert knowledge’ being central to medical autonomy (Giddens, 1991). This shift in control is central to the deprofessionalisation thesis proposed by Haug (1988), which claims that the diffusion of health knowledge previously reserved for healthcare professionals weakens their control, with the level of trust being eroded and healthcare professionals authority being challenged. A further challenge to the erosion of this control is the emergence of self-help groups and other alternative ways to seek information, which results in experiential knowledge being exchanged and for some is an attractive alternative to medical knowledge. Experiential knowledge occurs when lived experiences, of both body and illness provide a personal insight that facilitates the individual to cope with disability and illness and by sharing this, surpasses the borders of individual experiences (Caron-Flinterman et al., 2005).

#### **5.4 Shifts in policy**

The nature of health care is evolving; for example, individuals are now more active participants in their care and as healthcare roles and relationships become more complex, a complicated pathway was often navigated prior to appropriate information being acquired which satisfied needs. A shift in the policy paradigm has impacted upon and transformed the context of ageing and decisions made by older people when disruptions are experienced. This shift in policy has been triggered by the ageing population and rise in long term conditions. The literature review explored the policy agenda surrounding the informed patient, promoting

self-care and reducing utilisation of unscheduled care and how this relates to health information (see 2.5). These changes aim to facilitate individuals to make informed choices and focus on individual responsibility to be an active participant regarding health and illness. Despite this policy focus, it remains clear that, although not exclusively, healthcare professionals retain a pivotal role in shaping decisions and providing health information to the current older population.

#### ***5.4.1 Engaged patients***

It was evident that participants engaged in health information seeking behaviours to varying degrees, with all seeking additional health information specifically about their long term conditions, other than that provided by healthcare professionals. This demonstrated their motivation to have information about their illness and to remain as healthy as possible by self-managing, monitoring disruptions, preventing further deterioration and avoiding hospitalisation. Participant's use of healthcare services was prompted by past experiences, what was believed to be the correct pathway to navigate and influenced by members of the social network.

Within the UK, the provision of health information is firmly embedded in health policy, including the NHS Constitution (Department of Health, 2012b) and the Health and Social Care Act (2012). It has been suggested that a healthcare approach centred on values promoting and maintaining health is less expensive than the management of disease (Porter, 2009). Potentially, new knowledge increases independence, making individuals less reliant on healthcare professionals, thus reducing frequency of consultations and costs. By ensuring availability of quality information this should enable individuals to understand, better manage health and wellbeing and facilitates confident, fully informed decisions about health, care and treatment. By providing access to health information with support on how to use it, suggests that patients and the public are engaged and take control of their health and wellbeing. However, alone, access to good quality information does not result in increased understanding as it would appear that further searching for information is sometimes necessary to seek clarification. This was evident when health information was provided by healthcare professionals which resulted in further health information seeking by all participants. This often involved participants navigating sources that were available to them; frequently family members or people from within the social network were consulted, as well

as the media. Occasionally, healthcare professional's provided additional written health information, to reinforce and supplement verbal information, which participants found useful and understandable.

Engagement is important as it improves knowledge, satisfaction and experience, through self-care and self-management, reduces costs with services used more appropriately and results in adherence to treatment and improved health behaviours (Patient Information Forum, 2013). In order to engage, not only is it necessary for individuals to find and use health information to increase understanding, but also support is needed to undertake skills to improve and manage health. Motivation to want to be an active participant and thus access the resources available is also a key element. Additionally, active participation does presume that the individual will have all the necessary information, which often requires access to appropriate sources. The reality of health information seeking for some participants was that access to multiple sources of information was limited; however they made use of the sources that they had.

### **5.5 Discerning information, judging quality and trusting sources**

While health care providers remain the most trusted source for health information and could not be substituted by the internet, this study has shown that the internet is a rich alternative. The internet has become increasingly important as a source of health information regardless of people's age (McClinchy et al., 2011). Some participants constructed meanings, evaluated the worthiness and quality of internet information with judgements made as to the applicability to their situation. These information seekers adopted an interrogating and inquiring style in a quest to gain continuous health information about their own and others health and illness. Literature suggests that healthcare professionals underestimate how well the public can evaluate media and web information. Some have suggested that lay people lack the ability to understand medical information accessed via the internet (McMullan, 2006), do not have the expertise and are therefore unable to assess the reliability and quality of such information (Hirji, 2004). Here it can be seen that an individual's health literacy comes into play as access to health information can be affected by health literacy (Baker et al., 2007), which can impact on an individual's health and his or her ability to perform daily activities (Wolf et al., 2005). As discussed within the literature review (see 2.1.5.3), health literacy focuses on the ability to perform health related tasks that requires reading and reflects

the cognitive abilities and social skills to understand, analyse and apply health information in health related decision making (Gregory et al., 2012). The on-going health policy focus around choice about treatment and partnership with health care providers (Department of Health, 2004), emphasises that adequate health literacy is important for patient involvement in their healthcare (Tian et al., 2012) and is essential for patients to make optimal choices.

However, not all of the participants used the internet for locating health information, either through choice or not having access. These participants (usually passive information seekers) tended to rely on the healthcare professional to provide health information. There were two underlying reasons; the perceived credibility of the healthcare professional and as a coping style. The criteria for judging expertise included track record, qualifications and experience (Collins & Evans, 2007). Whilst specialist knowledge was valued, there was also an element of trusting the source of information. Dew et al. (2013) highlight individuals determine which healthcare professionals to trust, finding that often there was a hierarchy of professionals, relating to their role and who were perceived to be the most appropriate to seek help from. If health information was not understood or further clarification was required then the healthcare professional was often returned to. It was suggested that the healthcare professional was the most appropriate source to validate information, due to the perception that they were the 'expert'. It is important to be aware of where older people gain information about their health as the findings suggest that a variety of sources are used and these are ordered hierarchically. Although, participants went beyond the medical establishment for information the findings suggest older people continue to perceive the professional as heading the hierarchy of expert knowledge, revering doctors in particular, which influences the health information choices made by them (Henwood et al., 2003; Dickinson et al., 2011).

A further consideration impacting on trust is the professional status of the healthcare professional with cultural and societal norms influencing this (Wilson et al., 2012). Previous research (Redsell et al., 2007) found expectations were clearly linked to the social status of the healthcare professional, with social status being a predictor of influence that an individual has over another (Oldmeadow et al., 2003). It has been suggested that trust in healthcare is being challenged as a result of societal changes that have led to increased patient autonomy and access to health information (Tarn et al., 2005). Regardless of the type of information seeker, this theme of trust persisted amongst participants regarding healthcare professionals. However, the participants were raised before this period of challenge towards the medical and

scientific community with the perception that healthcare professionals were to be trusted. Therefore, this perception may become eroded in the future, as representation of alleged errors fuel views of professional fallibility, resulting in lay people questioning the validity of medical knowledge and potentially the trustworthiness of the healthcare professional and the healthcare system (McClellan & Shaw, 2005) . It has been suggested, that as a result individuals take control of their health, through the active choice over certain aspects of technology (for example, the growth of CAM) or by taking matters into their own hands (for example self-care) (Giddens, 1991).

### ***5.5.1 Information seeking patterns***

Differential information seeking patterns existed, with proactive seekers investing much time in this activity, compared to passive seekers who used information that was readily available. By accessing various sources, participants demonstrated a desire to have more information and be involved in their treatment and decisions; in order to self-manage an individual needs to appraise and understand health information and to be able to incorporate strategies into their lives. There was an element of participants assessing and appraising the usefulness and quality of the information that was read, with active decisions made as to when enough information had been acquired to meet needs. Due to the increasing amounts of information available this might prove challenging and potentially results in information overload. Hardey (1999) identified that consumers protected against information overload by actively deciding when enough information had been read to meet their needs. Nettleton and Burrows (2003) claim that the utilisation of internet information rests on the reflexive capacities of users to interpret, discern and use in their favour. Despite the proliferation of information, the sheer volume and multiple forms of information that are available cannot be assimilated, let alone considered reflexively resulting in a misinformed society (Lash, 2002). Lee et al. (2014) identify that consumer's not only wish for healthcare professionals to guide them to reliable and relevant online information, but need reassurance of its accuracy.

### ***5.5.2 Timing of searches***

The typology of information seekers (see 4.5) identified that health information seeking behaviours varied with regards to when the information was sought. Timing of information seeking was along the medical trajectory, either pre diagnosis to find a reason for the

symptoms or post diagnosis to provide further explanations. Participants timing of searches depended upon the type of information seeker. The proactive information seeker intentionally sought information, searching for a diagnosis for health concerns as well as to supplement information post diagnosis. For reactive information seekers the timing of the search was generally post diagnosis to derive meaning and apply to self. Once information had been gained from a healthcare professional or written medicine information, the passive information seekers were unlikely to search for further information to provide further explanations. Laing et al. (2010) found that health information sources were explored at various stages of the individual's illness journey, due to specific events and the accessibility of professionals. Attfield et al. (2006) found that their participant's rationale for information seeking was to identify a possible diagnosis, although Laing et al. (2010) identified that patients usually look for information post diagnosis. This was supported by findings from research focusing on older adults (people over 55 years old) who identified that the primary motivator for seeking health information was following the diagnosis of a new medical problem (Hardt & Hollis-Sawyer, 2007). Often research studies investigate information seeking which occurs after diagnosis so this may have impacted on results found by these studies. Through using these strategies, the responses from participants reflected a proactive approach to knowledge building and taking control over health and care. Information may provide needed knowledge about the health concern, treatment and self-management. At the same time it may facilitate coping by mediating anxiety and uncertainty (Afifi & Weiner, 2004).

### ***5.5.3 Non-solicited information***

While Zola (1973) identified key triggers for information seeking, it was evident within this information rich world that the information itself was now providing a trigger for further information seeking. This information was sometimes non-solicited which was gained in a (serendipitous) passive way generating a trigger that created a disruption. Prior to gaining this information, participants were unaware that they needed this information until they picked it up from these sources. This information was often gained through surveying information sources with the intention of being generally informed about health issues. The resulting feeling of 'something not being quite right' and to make sense of this, caused participants to go to seek further information. Indeed, to make sense of the situation, non-solicited information which related to participants specific health concerns seemed to increase contact

with healthcare professionals. For some, the knowledge that was gained in this way led to excessive levels of anxiety for the participant. Furthermore, it creates resource implications as the 'worried well' (Garfield, 1970) were consulting healthcare professionals for help when it may have been unnecessary, although it did act as reassurance. More non-solicited information was gained that related to general wellbeing, although participants commented on the inconsistency of this information and suggested that there was a lack of confidence in the source (usually media). The acquisition of non-solicited information also highlights that information seeking should not be assumed to be always actively sought with this study revealing that individuals come across useful information serendipitously. Indeed, the current study supports findings by Wilson (1999) which suggested that individuals gained information through passive attention without intentional seeking. Wilson (1999) also identified that information was found coincidentally when searching for other information. Furthermore, the current study supports McKenzie's (2003) findings which suggested that individuals receive information without actively seeking it, describing this as gathering incidental information.

## **5.6 Self-reliance in later life**

Set against policy changes, with the emphasis on self-care, participants were self-reliant and contributed to their own healthcare, with much ill health often contained in everyday life and not reaching medical attention. Strategies were employed that occurred within the home, either alone or in combination with professional care. When symptoms were experienced, health information was often sought with alternative strategies employed rather than contacting a healthcare professional. As illustrated in figure 7, a key theme within the health information seeking journey was for participants to self-manage health concerns and monitor these strategies prior to seeking health information. Indeed, Hunt et al. (2004) observed that encounters with the medical establishment only constitute a small segment of patients' lives. Last (1963) noted that there was a considerable pool of illness which never comes to the healthcare professional's attention, known as the 'illness iceberg'. Much of the clinical iceberg of morbidity of minor ailments was dealt with by individuals undertaking self-care strategies within the home. This is often ignored in debates about health policy, which lean towards an overemphasis of the input of formal health services and down play the individual's role in self-care. When describing the 'symptom iceberg' Hannay (1979) suggested that individuals self-treat the majority of symptoms, with 'iceberg' cases

outnumbering the trivial reasons for seeking professional help. It has been suggested (Coulter, 2011) that individuals consult healthcare professionals more frequently than when Hannay undertook his research in the 1970's; however the illness iceberg remains, with possibly a greater proportion of it being seen by healthcare professionals than previously. More recently, Elliott et al. (2011) concluded that the majority of illness episodes were never presented for medical attention and therefore remained in the submerged part of the illness iceberg.

Participants adopted multiple levels of self-reliance including behaviours related to prevention, promotion, minor illness and treatment of injuries, chronic disease care and rehabilitation. Strategies were used to avoid contact with healthcare professionals, with information accessed from beyond the medical establishment. Participants reconstructed their lives with symptoms monitored and illness accommodated by adjusting and simplifying tasks. To be able to self-care, an individual needs to feel that they have control over their illness, and having adequate information is part of this (Rosenstock, 1974), with participants navigating various sources to facilitate this. Self-reliance extended to some searching for health information to maintain health, with others satisfying curiosity about queries regarding health concerns. Information seeking allowed individuals to assess whether they needed to seek medical advice or self-manage their condition.

Self-reliance was evident for those who were self-managing long term conditions. On a day to day basis, all were self-managing and various strategies were employed to maintain, improve or restore health, or treat disease in response to a disruption. These were undertaken to either help prevent further deterioration of health or to improve well-being. Self-management was deeply embedded in everyday life with individual self-management strategies followed which related to how they lived their lives and in turn tackled the problems and challenges linked to it. This reflects the altered pattern and nature of health and illness, with medical intervention treating conditions which are more life limiting with individuals needing to incorporate prolonged regimes of self-management into their everyday lives (Fitzpatrick, 1984). However, it has been suggested that despite self-management giving the individual control over their lives, too much self-reliance could result in symptoms being ignored which may need investigations and possible treatment (Lloyd, 2012). This unintended consequence on self-management can potentially result in increased service use as shown in the pathway below (figure 9).

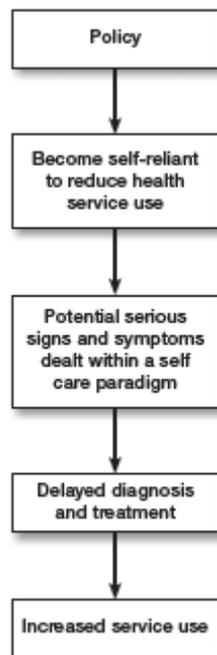


Figure 9: Unintended consequence of self-management pathway

## 5.7 Integrating additional external health information sources

As previously highlighted, within this changed landscape knowledge was constructed using several forms of health information via various sources (see 5.3). Specifically within the present study, participants identified that there had been a shift in direction as they tended to utilise the services of pharmacists and CAM, rather than seeking health information from one source. The section concludes with an exploration of the significance of social support networks within the health information seeking journey.

### 5.7.1 Pharmacists as information source-the rhetoric and reality

All participants had contact with pharmacists to collect repeat prescriptions, medication reviews and for advice about OTC medications and minor ailments. Pharmacists are ideally placed to bridge the gap between lay and professional networks and deliver health information as they can provide an important and central venue for purchasing and seeking methods of health maintenance. Over the last two decades, the role of the pharmacist has changed with retail pharmacy embarking on a transformation journey, away from the traditional role as supplier of medicines to become an integrated provider of clinical advice

and care (Anscombe et al., 2012). A recent community pharmacy report highlighted that a key part of the pharmacist's role is to provide front-line care which along with the traditional role includes promoting a healthy lifestyle and self-care (Anscombe et al., 2012). This shift reflects the retail pharmacist as part of the everyday social world in which older people live and experience health and illness, which is of importance as medicine taking is undertaken in the home away from the gaze of the formal world of healthcare providers. Previous research has suggested that pharmacists view their role as involving patients in care decisions, working in partnership as well as being a valuable source of information (Benson et al., 2009).

Within a hierarchy of health professionals, pharmacists can be regularly used as information providers with qualifications and expertise being recognised by service users (Dew et al., 2013). Indeed, the community pharmacy can play a key role by promoting healthy lifestyles, identifying and managing health problems and 'making every contact count' (Department of Health, 2012a). Additionally, the UK government's strategy of encouraging more self-care in relation to health has been addressed through the promotion of the use of pharmacies and reclassifying a number of medicines from prescription to prescription free (Ferner & Beard, 2008; Rutter, 2012). However, pharmacist's perceptions of operationalising the elements of self-care support were identified as being medicines focused, depended on services provided and opportunistic rather than proactive and patient focused (Ogunbayo et al., 2015). The reality within the present study was that interactions and information were perceived as of little value when the query related to treatment of ailments, as the pharmacist redirected the participant to other sources or no new suggestions were made.

#### **5.7.1.1 Perceptions of role of pharmacist shaping utilisation**

Participants perceptions about the role of a healthcare professional, factored into the decision about which resources were used and often shaped by what was previously familiar. Integral to this are the individual's beliefs and knowledge about health and illness, past use of services and personal experiences of illness. So, the nature of the condition, the individual's beliefs of the pharmacists' healthcare role and the need for medicines all influence the use of community pharmacies in the UK (Hassell et al., 2000 ). The general public's perception of the pharmacist is that they are drug experts and not experts in health and illness, resulting in the underutilisation of pharmacy services (Anderson et al., 2005; Saramunee et al., 2012).

Anderson et al., (2005) called for actions to extend the public's awareness and acceptance of the pharmacist's role in giving advice as crucial. Other studies (for example Krska & Morecroft, 2010; Eades et al., 2011) have also suggested that there is a general lack of awareness by the public of the pharmacists' public health roles, resulting with these services being underutilised. Livingstone (1995) noted that older people's belief in the GP as the only healthcare professional with the expertise to diagnose and treat may explain why there was a reluctance to use pharmacies as a primary healthcare resource. Hassell et al., (2000 ) concluded that a robust belief in medical practitioners resulted in a lower utilisation of pharmacies, which was further supported by research undertaken by van Geffen et al., (2011). However older people with complex health problems may have a greater need for medical attention, so the pharmacist maybe limited in what they can offer beyond signposting to other services. Despite these general beliefs about the expertise of the GP, some did mention that they did not want to 'bother' the GP with minor conditions, so the notion of inappropriate use of GP's was also shaping pharmacy utilisation. It has also been suggested that to increase utilisation, GP's should promote the services of the pharmacist to their patients and engage in joint working (Saramunee et al., 2012). Furthermore, as the pharmacist's role develops, individual's preferences and expectations may change particularly if they experience quality care delivered by the pharmacist. By providing useful information the pharmacist can be an integral part in facilitating involvement and active participation in decisions about health and illness, and aid navigation for the older person in later life.

Furthermore, the role of the pharmacist with regards to medication review has evolved, becoming more focused on improving patient's knowledge. Pharmacists provided information to participants during the medication review, although this was often viewed to have limited value with little new knowledge being gathered in relation to the management of medicines. Reasons for this could be that the participants were well informed and experienced long-term users of medicines with a frequently used source of medication information being the written information supplied with medicines. Salter (2010) found that participants gained little new knowledge during the medication review, which has resonance with this study. Some participants implied that the medication review was convoluted and impersonal, also highlighted by Salter (2010) who suggested that there are difficulties if communication with service users is protocol driven and appears impersonal. Additionally, care can become fragmented when processes associated with ordering and obtaining repeat

prescriptions are protocol driven, which could impact on the patient experience and relationship between pharmacist and the older person (Wilson et al., 2013).

### **5.7.1.2 Over the counter medications**

A strategy adopted by participants was choosing to self-treat a wide range of illnesses with non-prescribed medication which were usually over the counter (OTC) medications. It was apparent that participants decided what was considered to be appropriate ways to treat illness. Over the counter medicine use, was either as a temporary approach to treat symptoms and illness, to attempt to stabilise these or for longer term treatment of symptoms. Use of OTC medicines has been at the forefront of the policy (Department of Health, 2005a, 2005b) to encourage individuals to treat ailments with OTC under the guidance of the pharmacist. This has been considered as a way to reduce costs to the NHS and decrease the use of GP services. However, as previously discussed, knowledge of the pharmacist's role needs to be extended and trust established between the pharmacist and individual seeking information, advice and treatment options for this strategy to work in the long term.

A self-treatment plan was often devised which involved self-prescribing, experimenting with medication, assessing its effectiveness and appropriateness, and drawing on advice from other members within the social network, as well as healthcare professionals. Self-medication is often used as an alternative to seeking help from a healthcare professional (Russell et al., 1991), however the efficacy of self-treatment relies on the appropriate self-diagnosis of symptoms. Regimes were developed with participants combining their past experiences and own understandings to make diagnoses and treatment plans. There was also receptiveness to new treatments, with some participants demonstrating that strategies had been followed as the result of new information gained from sources. Beliefs impacted on self-medication with some suggesting that there was a reluctance to self-medicate, due to these beliefs and a wish to find the underlying cause for symptoms. Posey (2003) notes that in illness an individual's belief system contributes to the decision making process, with the sources of information recruited to inform the decision including those both external and internal to the individual.

### ***5.7.2 Integrating Complementary and Alternative Medicine (CAM) into later life***

An integral part of health self-management practised by some, was the use of Complementary and Alternative Medicine (CAM). Complementary and Alternative Medicine incorporates a variety of healthcare approaches that fall outside the boundaries of conventional medicine. Integral to CAM usage is knowledge of treatments, beliefs about cause and controllability of symptoms and knowledge of health. The Self-Regulation Model (see 2.3.1.1) (Leventhal et al., 1984) suggests factors that affect the process of incorporating CAM into health self-management regimes, which consist of older peoples knowledge of CAM, understanding of symptoms and self-perception of health. Several participants discussed CAM, but stated they did not use it due to beliefs about efficacy and not experiencing a significant change in health after its use (see 4.6.1.1). Participants used CAM as a component of the treatment of symptoms and for illness prevention and health promotion as they perceived that CAM would enhance or maintain current health status. As predicted by the Self-Regulation Model, participants commenced and discontinued CAM use for pragmatic reasons. CAM users instigated its use with the hope of treating symptoms for long term conditions, for illness prevention or health promotion. If the participants, judged that CAM usage produced a favourable result, then they continued, but it was discontinued if judged ineffective.

#### **5.7.2.1 Changing direction towards CAM**

A consistent finding within the literature has been that older adults are less likely to use CAM than young or middle aged people (Office for National Statistics, 2013b; Ho et al., 2014). However, research demonstrates that increased levels of chronic conditions are associated with higher CAM usage (Bell et al., 2006; Cheung et al., 2007), suggesting that social processes play a key role in shaping the use of CAM. Indeed, Grzywacz et al (2007) noted that the decision to integrate CAM into one's self-management strategy is likely to be shaped by socio-cultural factors and the life course. It has been suggested (Schnabel et al., 2014) that due to the lack of conventional care during childhood, many older people have a lifetime experience with home remedies and herbal medicines. Beliefs about the causation of ill health differ by age, as older people tend to attribute ailments as the inevitable sign of ageing, compared to younger people who interpret ailments as due to disease or illness (Light & Levine, 1988). If there is a tendency to attribute ailments as a sign of a legitimate illness reducing with age, then it is possible that older people would be less likely to treat these with

CAM. This is supported by evidence which indicates that older people regularly wait for symptoms to disappear and only commence self-care activities when symptoms become worse (Rees-Jones & Higgs, 2010). When older people decide that a symptom is becoming more severe and to reduce the threat of this symptom, they move management responsibilities to healthcare professionals (Cutchin, 2005; Rowe & Kahn, 1987). Previously, it has been suggested that this transference is due to older people's beliefs in the value of consulting the healthcare professional (Bryant et al., 2001) and because they have little experience with CAM (Peel, 2004). However, this situation may be changing with the increased popularity of CAM, older people living with more chronic conditions, and decisions to turn to CAM being made, once conventional treatments are deemed unsuccessful.

With new opportunities created for freedom and choice, the use of CAM demonstrated that this had been embraced by some participants. Participants explained that choices were made as to specific types of practitioners that were consulted for particular problems. Indeed, Thomas et al. (2001) found that the majority of visits to CAM, were for musculoskeletal problems, with more recently Elliot et al. (2011) identifying that back and joint pain were the symptoms most commonly presented to CAM. This has resonance with this study, as commonly CAM was used for these conditions. Furthermore, the use of CAM can be linked to the changing landscape in which the individual takes greater responsibility for health, with the availability of choice impacting on this. There has been the promotion of the choice agenda within UK health services, with multiple sources of knowledge facilitating choice in new ways. This extends to individuals being prepared to purchase the service that they wish to have, rather than exclusively relying on the advice and treatments of healthcare professionals. Research undertaken in the USA, discovered that CAM was a lower cost alternative to conventional care (Bowling, 2006), although this would not be the rationale for individuals using CAM in the UK. The rationale for choosing CAM was perceived as a way to self-help with participants attempting to find solutions to symptoms, where conventional medicine had offered little or had been ineffective.

### *5.7.3 Navigating social support networks*

As previously discussed, in their quest to gain further health information, participants went beyond the medical establishment for health information. Indeed, some lay people rely on their own resources rather than professional help (Lloyd, 2012), with anecdotal and

experiential information about illness and disease often gained and shared with partners, family members, friends and neighbours (Phillips et al., 2010; Lloyd et al., 2013). This study found that some of the health information seeking undertaken for older people originated from family members, especially from partners and close family members. Partners and close family tended to be involved in meeting all types of health information needs. However, findings also suggested that participants accessed and mobilised a diverse set of relationships with contributions from different kinds of members of a network varying.

The main focus of illness representation research has been on the individual and although social context is considered (Leventhal et al., 1999) with self-regulation dependent on the input of others and shaped by the social environment (Leventhal et al., 2003), it has been contended that the impact of the social context needs further exploration (Weinman et al., 2003). This study found a strong theme relating to the key role the social network played in supporting participants in the health information seeking process. The lay network was often the first port of call when seeking health information about illness and its treatment with it either eliminating the need for professional support or encouraging the search for further help. In order to make sense of, and to develop an understanding of disruptions, often the participant discussed health concerns with others including family and friends, with these discussions often acting as a trigger to seek further information.

Social support networks were varied, complex and used in a variety of ways and at various stages of the health information seeking process. Although critical moments and the subsequent biographical disruption have been identified as major catalysts for network dynamics (Perry & Pescosolido, 2012), this study has identified that participants consulted with members of the social network for information at various stages of the health information seeking process. This health information seeking extended beyond the circumstances of a crises or acute deterioration in their condition, which require mobilisation of short term help and commitments from others (Parsons, 1951). Informational support was required over a longer period and included the dimensions of social support. Cutrona and Russell (1990) identified common dimensions of social support and this has been adapted to reflect social support provided during later life to meet health information needs (see table 13).

<b>DIMENSION</b>	<b>CONTENT</b>
Emotional Support	Individual receives psychological support from another person
Comparison support	Share experiences and make comparisons
Peer support	Share understanding and feeling of affiliation
Informational support	Someone provides information and possible solutions
Appraisal support	Provides help in decision making
Practical support	Individual receives concrete, instrumental support, for example transport to healthcare professional

Table 13: Dimensions of social support in later life within the context of health information seeking (adapted from Cutrona and Russell, 1990)

### 5.7.3.1 Shared understandings

By communicating with people within the social network, individuals exchanged information about themselves or others on various topics. This information exchange included experience of symptoms, diagnosis, treatment options, evidence from various sources, experiences with healthcare professionals and views about their quality. Social networks were used as comparisons and to share experiences. This resulted in participants being able to gain insights into others perspectives which can be valuable when gaining information. However, this may impact on perceptions of symptom severity and influence decisions as to what actions should be taken. When trying to make sense of the situation, shared understandings of ageing were developed through interactions with other older people perceived to be in a similar situation. Indeed, lay people construct their state of health as part of their on-going identity in relation to others (Radley & Billig, 1996). Certainly, the lived social world has great saliency in the construction of illness explanations, with pre-existing ideas and bodily experiences drawn on to build understandings about health and illness (Hunt et al., 1989; Health and Social Care Act, 2012). Additionally, by sharing experiences and knowledge this can offer individuals with a sense of not being alone and provides an opportunity to gain and underpin existing knowledge (Miller & Davis, 2005; Sparud-Lundin et al., 2010). According to the self-regulation model, a number of heuristics or rules are involved in transforming stimuli into representations with age-illness rules, impacting on decisions as to whether one is ill or not (Leventhal et al., 2003). Furthermore, the perceived severity of symptoms are reduced when it is believed that the symptom is prevalent among others (Croyle & Jemmott, 1991) which

has implications for older people who exchange information and compare symptoms with contemporaries. Hunt et al. (1989) explored the impact of extra-medical social information, concluding that the interaction with the medical profession was not central to the construction of the illness experience, as individuals often held fairly elaborate prior constructions of their condition.

When the symptoms were obscure or not readily recognisable others in the social network were consulted, to decide the significance of what had happened and what to do about it. Although family and friends were most frequently consulted, if the individual experiences an unfamiliar problem, then a lay person with expertise is often sought and consulted (Kadushin, 1987). Indeed, access to various types of social network members provides access to a wider range of support and information sources (Vassilev et al., 2014). Owing to the high prevalence of chronic conditions within the ageing population (Victor, 2010), it can be easy for older people to navigate towards potential lay experts among their acquaintances. Participants within this study had a pool of friends to choose from and the decision to select one person over another, reflected this availability and perceived expertise of the friend. A similar concept to this was identified by Vassilev et al. (2014) who described this as ‘network navigation’, which is when an individual identifies and connects with existing relevant resources in a social network. However, informal social networks are not universally available, so this has implications for those who are socially isolated. Indeed, it has been suggested that there is a strong association between limited social network support and poorer health outcomes (Petrou & Kupek, 2008).

Relationships can be characterised by the ‘Convoy Model’ suggesting that individuals maintain a convoy of support during the life course (Antonucci et al., 2009). According to the Convoy Model (Kahn & Antonucci, 1980), the quality, function and structure of the social convoy contributes to well-being in later life, acting as a protective layer who encircle the individual and assist in the successful negotiation of life's challenges (Antonucci & Akiyama, 1987). Furthermore, Kahn and Antonucci (1980) identify a wide range of social network types may exist for older people due to variations in family histories, historical context and changes resulting from gains and losses. Additionally, this convoy shifts depending where in the life course one is, with age being an important factor that shapes the social convoy. The loss and acquisition of friends is a dynamic process with friends often being replaced in later life (Higgs, 1995; MacKichan et al., 2011). The model identifies the importance of

reciprocity, with individuals storing up ‘credits’ and using them when they feel it is necessary. Participants used these ‘credits’ when experiencing a decline in health and there was a perceived need that support was required. Vassilev et al.’s (2014) qualitative meta-synthesis discusses the negotiation and renegotiation of relationships that occurs and concluded that approaching social network members for help was not exclusively based on their knowledge with other factors, such as autonomy and independence, featuring more highly over a need for help.

### **5.7.3.2 The significance of the co-navigator in later life**

The lay referral system remains an important aspect of health information seeking which was inevitable, as many illnesses were identified and accommodated within the informal context. Despite social networks and social relations in later life diversifying, it would appear the importance of the social network has not altered with the changed landscape. Specifically, the co-navigator acted as someone who assisted participants with decisions regarding the use of healthcare and seeking further information. Previously, Suchman (1965) discovered that three quarters of his respondents reported discussing symptoms with another person before seeking formal care with Zola (1973) including the influence of others as a key trigger. The structure and composition of lay referral networks can influence decisions to seek medical help. Scambler et al. (1981) identified that large friendship networks reduced levels of formal service use. More recently, it has been recognised that social network members can shape the behaviour of individuals and facilitate action (Vassilev et al., 2014). Reeves et al.’s (2014) findings indicated that support from members of the social network substituted formal care, which has some resonance with this study. However, it has been proposed that social network members can create barriers to resources due to their lack of understanding about specific conditions or by creating obstacles to individuals, such as raising expectations (Jones et al., 2008a; Sparud-Lundin et al., 2010).

The changed landscape has impacted on the sources of health information available to older people. As previously discussed, a broad range of health information sources were accessed by participants to meet health information needs. People within the social network often acted in the role of co-navigator, which included providing emotional, physical and informational support (see table 11). This was particularly evident for those who did not have access to some information sources such as the internet, with co-navigators often providing a rich

source of information as they gathered new information from this source. Co-navigators also accessed other sources to gain new and different health information for participants. Co-navigators consulted with health advisors and acquaintances that were perceived to have expert knowledge, with this information communicated to the participant.

Not only were members of the social support network utilised for informational support, but they supported participants with the self-management of long term conditions, particularly with drug regimes. This support was particularly noticeable with those cohabiting with the person with a long term condition; although when this was not available others stepped into this gap. This supports findings by Vassilev et al. (2013) and Sintonen and Pehkonen (2014) who found that family members and spouses provide high input in the self-management of long term conditions and this facilitates independent living. Research (Rogers et al., 2011; Pickard & Rogers, 2012; Vassilev et al., 2013; Blickem et al., 2014) on self-care, demand and social networks has highlighted the importance of networks, not merely in providing social support, but in delivering and allocating important practical work around care. Whilst literature (Vassilev et al., 2014) on informal care explores the contribution made by significant others to the care of those with a long term condition and for those requiring high levels of support, less focuses on the development of an understanding of the type of work informal social networks undertake to support self-care in the wider social context. This study has identified the informational support provided by members of the social network as being important to support older people in self-care.

There is considerable variation between individuals regarding their ability to cope with treatment workload which Dabrh et al. (2015) suggests depends on social support systems. Furthermore, it is well established that a person's ability to pursue treatments and engage with healthcare professionals can be shaped by factors such as social support (Rogers et al., 2011) and health literacy (Furniss et al., 2014). Indeed, often the burden of treatment and symptoms impacts on not only patients but their families and extended social network (Mair & May, 2014). It has been suggested that for self-management to be effective, it is equally important that carers are supported, as well as the person with the long term condition (Berzins et al., 2009). As members of the social network play a pivotal part for some people living with long term conditions, it would appear appropriate that access to health information should be extended to include them.

## **5.8 Navigating later life**

Later life brings a time of challenge, with unfamiliar territory needing to be navigated in order for the older person to be resilient and adapt to different situations. The ability to develop and sustain resilience required participants to make realistic plans and follow these through, utilising decision making skills regarding the use of healthcare alongside self-management. As the conceptualisation of the patient role has changed, it can be seen that later life has become a period of choice and self-care. The navigational model within this context can facilitate health information seeking by having awareness of individual needs and providing appropriate signposts directing older people into a suitable direction. Participants navigated their way through disruptions, by adopting individualised strategies to cope with symptoms and their impact on everyday life, with health information seeking playing an integral part of this. Commonly, key individuals such as healthcare professionals and members of the social network supported this, with shared understandings developed through social interaction. They also acted as co-navigators and supported navigation when disruptions were experienced. This was particularly evident when the co-navigator provided health information that was perceived to be credible, applicable and useful. The co-navigator also deciphered information, translating information which made it easier to understand. Often, familiar sources were used, such as the written information supplied with medications, although some explored other avenues in a quest to gain further health information.

### ***5.8.1 Healthcare professional as navigator***

The role of healthcare professional as navigator has been highlighted in the literature reviewed. Within healthcare, it has been suggested that navigators play a reactive role (Dohan & Schrag, 2005), assume a barrier-focused approach which concentrates on a specific disease, population or setting (Wells et al., 2008). A systematic review examining navigation roles supporting older people with long term conditions when experiencing healthcare transitions, found some evidence that coordinated and integrated care directed by a navigator was beneficial (Manderson et al., 2012). Within the community setting, it has been proposed that this role is fulfilled by the community matron who manages care for individuals with complex needs by providing psychosocial support and advocacy, facilitating the access of services and co-coordinating health and social care (Williams et al., 2010). Although, the participants within this current study did not have such complex health needs, they still

required information to help them manage their health. As identified, participants tended to trust healthcare professionals to have accurate knowledge which suggests that even when an individual does not have complex needs, healthcare professionals can adopt a navigational role.

### *5.8.2 Navigation-relevance for typology of information-seeking styles*

The study findings add to the theoretical understanding of health information seeking behaviour by highlighting the rationale and decisions that older people make regarding this. Common to all participants in the typology, was the ability to navigate within the altered landscape. How they differed was the amount, type, sources and how information was utilised. Variations were also identified within the sample regarding timing, pattern, style and what health information was sought. Furthermore, participant's motivation for health information seeking significantly impacted on the route that was followed. This was evident regarding beliefs about ageing and self-efficacy, which shaped the navigated route and affected motives for information seeking. Individual responses to health information seeking were often related to participants coping strategies, which either acted as a barrier or facilitator during the journey.

There is much debate surrounding whether health information increases or decreases contact with healthcare professionals. By making health knowledge available to the public, new knowledge may make the individual more concerned about health which could lead to an increase in contact with healthcare professional's (Suziedelyte, 2012). However, there is no consensus within the literature as to whether health information either substitutes or complements health care. The findings demonstrated that further information seeking both supplemented information provided by healthcare professionals, but also additional information sometimes increased encounters. Increased contact was evident for the proactive information seekers, as they were most likely to obtain health information from sources for self-diagnosis, usually prior to seeking additional information from formal sources. However, for reactive seekers the motivation to seek information was to bridge a gap in knowledge and to make sense of acquired health information often gained post diagnosis, information was sought which appeared to reduce contact with the healthcare professional. Consequently, the type of information seeker and timing on medical trajectory clearly impacted on actions taken as to whether information needs were satisfied, or further interaction was required with the healthcare professional.

Navigational tools (see table 14) related to perceptions and interpretations of ill health and disruptions which often acted as a trigger and impacted on the route navigated. The tools that were relied upon to facilitate this varied and were the basis of differing navigational strategies employed.

- Their body
- Understanding and interpretation of disruption and impact of ageing
- Past experiences and previous events
- Prior knowledge
- Formal information sources
- Informal information sources

Table 14: Summary of navigational tools

The management of health and illness in later life can be a complex process (Lindsay, 2009) which requires monitoring and maintenance. This study identified that participants were self-reliant, contributing to their healthcare within the home, with experiential knowledge providing participants with tools to aid this process. Participants visualised different routes to plan how to get from where they currently were to another place, in order to build knowledge regarding health. Furthermore, the type of information seeker tied in with the route that was adopted. Passive information seekers tended to use a one directional navigational strategy, which involved recognising a disruption and navigating towards the healthcare professional, a reliance on this information source was evident. A more multidirectional strategy was adopted by reactive and proactive information seekers, who consulted various sources prior to, and after consultation with a healthcare professional. For these information seekers, changes in direction occurred when it was believed that information was not valuable, with the complex patchwork of services and information sources available sometimes facilitating this. In order for these changes in direction to take place, it was important that participants were aware of, and trusted these information sources for their effective utilisation. Participants navigated between conventional and complementary care with CAM being used in conjunction, not in lieu of conventional care.

## 5.9 Conclusion

The new context of ageing required older people to navigate a healthcare system that expects a service user, who is active, makes choices and takes responsibility. The world that older people live in today is full of complexities, is ever-changing and in order to make sense of these, older people use multiple strategies to adapt and cope. Leventhal et al.'s (1984) self-regulation model considers the social and cultural factors which often shape the decision to act when disruptions materialise. Central to the experience of later life, are the perceptions and beliefs held by the older person which are shaped by the social and cultural context. Strategies were employed to construct meaning including selecting information sources based on previous knowledge, trust, experiences and perception of disruption. Self-reliance has become embedded in everyday life which incorporated self-treatment, consulting various sources of information beyond the medical establishment and seeking support from people within the social network. There were different patterns of behaviours between participants which captured variations in information seeking; these informed the development of a typology of health information seekers. During later life, it is necessary for older people to hold onto and acquire new tools that can aid navigation, with healthcare professionals and members of the social network playing an integral part and acting as co-navigators. Furthermore, the navigation model provides a potentially valuable tool for policy makers when considering the support older people require to self-care. The next chapter will explore the implications of the study and makes recommendations regarding how the issues might be addressed.

## CHAPTER 6

### CONCLUSION

#### 6.0 Summary

This study has explored the health information seeking behaviours of older people. The philosophical shift to service user as expert in their own condition and one who knows their body has impacted on the experience of later life; and this has been accompanied by key policy initiatives. Older people have had to navigate a world of more choice and sources of knowledge, an increasingly complex patchwork of services, changed healthcare roles and increasing self-care undertaken within the home (Pond et al., 2010).

In the following sections, the key findings are summarised, with the chapter structured around the research questions. Implications for policy and practice, limitations and suggestions for future research are included. The chapter concludes with a personal reflection.

#### 6.1 Research questions

The chapter will now turn to the research questions and examine how this study has provided answers to these. The final research question is explored within section 6.2.

##### *6.1.1 What are the health information seeking behaviours of older people?*

In order to seek health information individuals embark on a metaphorical journey (see figure 7) which is shaped by a life-time of experience. There were a set of stages that participants progressed through when embarking on the health information seeking journey. Three interrelated conceptual categories were identified that explain the health information seeking behaviours of older people: self-regulation, self-management and self-mobilisation. The core concept 'navigating later life' integrates the three conceptual categories and describes how participants navigate health information as they negotiate challenges to their health in later life.

Older people adopted a range of approaches to health information seeking and discussed the ways they took responsibility for managing their health. The typology developed within this thesis has demonstrated that information seeking varies with the older person's health information seeking behaviour being individual to them. Information seekers can be differentiated in several ways and these are summarised later within this chapter (see section 6.1.2., 6.1.5).

### ***6.1.2 What motivates older people to access health information?***

Health information seeking was often triggered following a change in health and provided individuals with a greater understanding of these changes. For some, the motivation to seek health information was an active way to address health concerns, protect health and provide reassurance about present and future health. Health information seeking employed at various stages of the illness experience in order to provide explanations and increase knowledge about altered health status. Decisions were made about health information seeking, with perceptions and beliefs about the significance of symptoms clearly impacting on this process. Uncertainty about the course and impact of the illness motivated individuals to search for an explanation. However, this impacted on motivation in two ways, either seeking or avoiding health information.

All participants were involved in decisions about the type, amount, and sources of health information that were used to meet their needs. Leventhal et al.'s (2001) self-regulation model proposes that illness behaviour depends on the individual's perception or representation of the illness. Conceptualising health information seeking behaviour as a self-regulatory strategy highlights that according to an individual's representation of their illness, there is a continuum of motives to engage in health information seeking. To conceptualise health information seeking in this way highlights that seeking information is more diverse than previously suggested (Germeni & Schulz, 2014) and recognises nuances in health information seeking behaviour undertaken by individuals.

### ***6.1.3 What enables older people to access health information?***

There were factors that facilitated or acted as barriers to health information seeking behaviour. Knowledge, self-regulation, self-efficacy and health beliefs (Mann et al., 2013)

have been found to impact on decisions regarding health information seeking behaviour and shaped the route navigated. Individual responses to health information seeking were often related to participants' coping strategies, which either acted as a barrier or facilitator during the journey.

Access to, and availability of relevant sources of information affected how older people found health information. All participants had access to a range of information sources, although the extent to which each source was used by individuals varied. Regardless of location within the health information seeking typology, participants made assessments regarding trust and credibility of the different information sources.

Navigational support from healthcare professionals and people within the informal social network facilitated the information seeking process for older people and enabled older people to access health information (see section 6.2.3.2 and 6.1.5). Beliefs regarding ageing and declines in health are summarised in the following section (section 6.1.4).

#### ***6.1.4 What barriers to accessing health information exist for older people?***

Perceptions of age related declines were found to impact on motives for health information seeking behaviour. For some participants, a heightened awareness of age related changes to their body prompted searches for information relating to prevention of further decline. However, a reduced motivation for health information seeking could be seen for those who perceived the decline in health to be inevitable. For older people and healthcare professionals', ageist attitudes and beliefs that poor health was inevitable, interventions ineffective and improved outcomes not valuable are common (Centre for Policy on Ageing, 2009). Healthcare professionals' attitudes towards ageing and illness can impact on information giving, and subsequent health management strategies made available to the older person. Beliefs about ageing and related body changes influenced health information seeking behaviour acting as a trigger or inhibiting health information seeking.

Poor understanding of health information presented challenges and inhibited the acquisition of new knowledge. This was related to inadequate and poor communication, particularly from healthcare professionals.

### ***6.1.5 Which sources of information do older people use to gain information about their health?***

Information about health was drawn from three main information sources. The sources used by participants depended on the type of information seeker and the information sources available. The first source of information was gained experientially and through the current experience of changed health status, such as somatic experiences and symptoms. The second source was the general pool of information that had previously been assimilated. The third source was information gained externally from personal sources such as healthcare professionals, members of social networks and impersonal sources including the internet and other media. There was evidence that healthcare professionals were often used to obtain health information; an area that is summarised later in this chapter. Whilst older people continued to perceive the healthcare professional as an expert and main information provider, a number of alternative sources were used. Informal social support was found to be very important for older people in helping to meet health information needs. The social network was often called upon when older people embarked on the health information seeking journey and provided a convoy of on-going support throughout the care seeking process (Pescosolido, 1992).

Some participants move beyond the traditional health system to complementary and Alternative Medicine (CAM). However, participants used CAM in conjunction with, not *in lieu* of conventional care. Some lay people relied on their own resources rather than professionals (Lloyd, 2012) and anecdotal information about illness and disease was often gained from family members, friends and neighbours (Phillips et al., 2010). If the person experienced an unfamiliar problem, then a lay person with expertise in similar signs and symptoms was often sought and consulted (Kadushin, 1987).

## **6.2 Implications for policy and practice**

The study provides important insights for healthcare professionals and has implications for developing strategies aimed at improving older people's access to appropriate health information. The navigation model offers a potentially valuable tool for policy-makers who are considering the support older people require to self-care.

### **6.2.1 Policy**

The growing use of health information seeking and its potential contribution to the goals of prevention, promotion and protection in health-enhancing strategies have made health information seeking an important issue for policy makers. A number of key health policy initiatives (Department of Health, 2006, 2008a) encourage individuals to make informed choices drawing on a rhetoric of rights and control over health and healthcare. Within this context, people are encouraged to self-care, manage diseases, and make decisions and choices about healthcare in an informed way (Department of Health, 2010a, 2012c). The findings build upon this policy work, which sets out to support those with long term conditions to self-care and illustrate that learning about health information seeking behaviour is a key element of living with and managing a long term condition. Health information seeking was undertaken at various stages of the illness experience in order to provide explanations and increase knowledge about altered health status, which suggested that older people were endeavouring to self-care and manage symptoms within the home. However, despite a policy agenda focused on self-care (Department of Health, 2000a), shared decision making (Department of Health, 2010a) and reducing utilisation of unscheduled care (Department of Health, 2005c), the role of health information influenced by the social and cultural context is currently absent and should be considered in future policy documents. Furthermore, policy documents should consider the dynamic nature of health information seeking behaviour in supporting individual's self-care strategies as this may change over time.

The findings emphasise that the health information seeking behaviours of older people are variable and may have an important role in healthcare change in the NHS. A key goal for policy-makers should be to develop and implement new strategies that consider these variances within the ageing population. Furthermore, healthcare professionals need to face the challenges related to health information seeking, particularly in light of the increasing number of informed patients. Health information seeking can affect the doctor-patient relationship, as patients become more informed. The doctor-patient relationship is altering in terms of the medical decision-making process. Overall, the patient's role is shifting from compliant and passive, to the patient who wants to make their own decisions and being active in their own health. Therefore, it is important that healthcare professionals are aware of health information seeking behaviours which inform decisions and shape healthcare usage. This study found that health information seeking is not universal and did not influence the use of

healthcare, indeed it cannot be assumed that health information seeking is generally undertaken by older people on an everyday basis. Equal access to health information and health literacy cannot be taken for granted and should be tailored to individuals. Communication and information should be developed by considering information seeking behaviours, health literacy and the information requirements of older people. Policy-makers should prioritise health literacy and interventions to develop health literacy in all older people.

One important goal for policy-makers should be to develop and implement new strategies to deliver appropriate health information to older people. Guidance should be provided regarding health knowledge, its organisation and collection by selecting quality patient-centred health-related information available to older people. Older people need help to find information, to make sense of this healthcare professionals will have to develop an information intermediary role including signposting individuals to appropriate sources of health information, helping to filter out irrelevant information and supporting the use of applicable information. Healthcare professionals should be aware of what resources are available and accessed, provide guidance for older people who identify an active and proactive approach to information seeking and direct them to accurate and reliable sources. This approach can be effective in promoting a genuine partnership between healthcare professionals and the older person. Furthermore, enabling individuals to make sense of health information and critically assess it should be a central theme of any health strategy. However, this will prove challenging given the time limitations imposed during a medical consultation which limits time available to discuss information. Furthermore, impersonal health information is often generic, but older people are not a uniform group with the same health information needs. If older people are to be empowered to use information about health then the content should be appropriate and designed to meet diverse needs, it must be accessible and different ways to disseminate the information should be available to enable all to make use of the information. Therefore, it is necessary to consider different ways of delivering non-generic health information to older people. Individual health information leaflets could be designed which focus on the older persons unique health concerns. A telephone helpline could provide health information and would be useful for those who are socially isolated and have reduced mobility. Health information could be provided via touch screen kiosks which could be located within GP waiting rooms, libraries or pharmacies. If the older person was shown how to use the kiosk and encouraged to do so this may promote usage. The kiosk

could be multi-purpose and focus on various aspects to meet older people's needs, as well as delivering health information.

### ***6.2.2 How can healthcare professional's best facilitate health information seeking behaviours for older people?***

Implications for healthcare professionals who are working to address the health information needs of older people are summarised within the table below (Table 15).

<p><b>Holistic assessment</b></p> <ul style="list-style-type: none"><li>➤ Identify needs</li><li>➤ Identify individual's triggers to information seeking</li><li>➤ Be aware of perceptions</li><li>➤ Be aware of beliefs, values and fears</li><li>➤ Observe for changes in service users condition</li><li>➤ Establish where located in typology</li></ul> <p><b>Communication</b></p> <ul style="list-style-type: none"><li>➤ Establish robust relationships</li><li>➤ Partnership working</li><li>➤ Question and listen to service user</li><li>➤ Reinforce messages</li><li>➤ Join the older person's convoy and act as co-navigator</li><li>➤ Identify other co-navigators</li></ul> <p><b>Education and information</b></p> <ul style="list-style-type: none"><li>➤ Tailor information to individual</li><li>➤ Check new knowledge is acquired</li><li>➤ Be clear who has access to internet</li><li>➤ Signpost patients to appropriate information</li></ul>
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Table 15: Recommendations and implications for healthcare professionals

New systems of health and social care are more focused on prevention, early diagnosis, intervention, and managing long-term conditions to prevent deterioration, (Select Committee on Public Service and Demographic Change, 2013) and should be person-centred, with individuals engaged in decisions about their care and supported to manage their conditions in

their own homes. Furthermore, with the philosophical shift to service user as expert in their own condition, there is an emphasis on the importance of communication and partnership working. The key within this process is good communication skills, identifying information seeking behaviours and patient education.

As key providers of care for older people, healthcare professionals are well placed to support health information seeking. Older people gained health information from various sources which were used to build and create new knowledge which was often used in tandem with information gained from healthcare professionals. Additionally, they utilised their own hierarchies of trust for developing self-reliance. This study supports other research by authors such as Feinberg et al., (2015) which identified that healthcare professionals continue to be perceived as the most trusted source of health information.

Healthcare professionals should undertake an individualised, holistic assessment of the older person, which ensures person-centred care and facilitates partnership working. When adopting this approach the Royal College of General Practitioners (2014) recommends that quality evidence-based information is provided. However, despite the increased availability of health information some individuals do not have the confidence, skills and knowledge to undertake an active role in their health management (Hibbard & Gilbert, 2014). To achieve this, Hibbard and Gilbert (2014) suggest a number of cultural changes in the roles of healthcare professionals and patients. Firstly, healthcare professionals need to change focus from deliverer of information to one who enables patients to be more active in their own healthcare. Secondly, individuals must have a sense of control over their health and some degree of ownership. This represents a shift for healthcare professionals and requires greater understanding of the changing patient role, collaboration and good communication skills.

It is essential for healthcare professionals when communicating with individuals to consider how they would like to participate in making treatment decisions about healthcare. Although the majority of participants wished to be involved in decision making and have access to information, for a few this did not apply. An awareness of the typology would enable healthcare professionals to locate individual preferences to aid the process and facilitate the tailoring of health information. Indeed, participants who had been provided with additional written health information from healthcare professionals found this useful. Healthcare professionals are encouraged to find ways of providing health information while respecting

individual preferences for the type and amount of information desired. Passive information seekers may benefit from written information that provides only the necessary information in an understandable way.

An important goal for healthcare professionals should be to develop and implement strategies to ensure individual health information needs are met for older people in later life. New insights regarding the health information seeking behaviour of older people, identified within this study, should be used within the education of healthcare professionals to facilitate this process. Education would increase healthcare professionals awareness of the complexities of information seeking within an ever changing world and the navigational tools used by older people. By adopting a patient-centred curriculum and involving older people directly as teachers would highlight to healthcare professionals the complex nature of later life.

#### **6.2.3.1 Implications for future workforce-pharmacists as emblematic**

With the current financial pressures on healthcare services it has been recognised that service users must use health services effectively. The study concurs with other studies which identified that pharmacist services were underutilised (Saramunee et al., 2012). Despite older people having regular contact with pharmacists (to obtain prescriptions), they often selected GP's for health information, with this decision based on past experiences and a lack of knowledge and understanding regarding the role of the pharmacist. An increased awareness by the public regarding treatment options and service availability could redirect patients to pharmacists. Expanding the role of community pharmacists will facilitate coordinated care delivery (Mossialos et al., 2015). Pharmacists are ideally placed to deliver health information, promote a healthy lifestyle and facilitate self-care. More recently, the role of the pharmacist has expanded with policy makers encouraging pharmacists to play an increased role in improving health (Department of Health, 2000b; Holland et al., 2005) and the promotion of community pharmacists as the preferred setting for the management of minor ailments (All Party Parliamentary Group on Primary Care and Public Health, 2008). To further expand their role requires education of the public and increased confidence in the ability of pharmacists. The development of health education leaflets for older people and other lay people involved in their care regarding accessing health information and useful resources may benefit this client group. GP's could direct their patients to the pharmacist.

The NSF for older people (Department of Health, 2001) recommends annual medication reviews to decrease medicine related problems, with the NHS Plan proposing pharmacists play a key role in this (Department of Health, 2000b). It is important for patients to have medication information (Hamrosi et al., 2014), however this study found that needs varied regarding medication review. Therefore, pharmacists need to adopt a tailored approach to ascertain individual patient preferences so that appropriate, relevant information is provided. The medication review has potential to provide a basis for pharmacists to develop their role as health information provider and aid navigation for older people and build a relationship with patients, thereby positively impacting on health information seeking behaviour and ‘making every contact count’ (Department of Health, 2012a).

#### **6.2.3.2 Navigational support**

The use of the navigational model can be extended to other areas of healthcare. This study suggests that formalised navigational support could be of value for older people both when accessing healthcare and to support health information seeking. As healthcare services continue to grow in size and complexity, older people may need support in navigating this. When a trigger was experienced, co-navigators often guided the older person in the right direction. Navigational support would be valuable in a variety of settings to help with access to healthcare. In my area of clinical practice as a community nurse, this would be valuable for those patients who are socially isolated and living with long-term conditions.

Within the cancer care context, patient navigation was implemented to address health disparities and to support those at risk of delaying care within marginalised groups such as ethnic minority and low income populations (Freund et al., 2014). Trained lay community members support navigation through cancer care services in the USA and have been found to address confusing, fragmented, and uncoordinated care (Carroll et al., 2010). The navigator acts as a link between two different worlds and was perceived as having an in-depth knowledge of the healthcare system and having a robust relationship with the patient. The potential use of volunteers to fulfil the role of lay navigator to support and guide older people in the right direction when seeking health information appropriate to their needs, could be valuable. Sprague (2012) suggests that the introduction of lay health workers can help with increasing access to healthcare. Located within general practice or community centres, lay navigators could provide a single point of access for a variety of good quality information.

Health and social care alongside voluntary organisations such as AgeUK could be involved in training and developing the role of lay navigator, with information other than health being incorporated to support older people in later life.

### **6.3 Limitations and future research**

#### ***6.3.1 Limitations***

A number of limitations of the study must be acknowledged. The study was conducted in a non-densely populated, urban setting in the south-east region of the UK, and the study should be extended to more densely populated areas and other regions and countries to explore the impact that location might have on health information seeking for older people. Various strategies were utilised in an attempt to recruit a wide range of participants who would provide rich, dense and focused information on the research question. However, the participants were a self-selecting sample, who it could be argued chose to participate in a study about health information seeking and had a particular interest in this and may not be typical of all older people. This study focused on the health information seeking behaviours of older people and participants reflected on their experiences. The study did not capture the perspective of actual and potential information providers such as family members and healthcare professionals. Incorporating these information providers would provide further insight into the role played by these actors in meeting older people's information needs. Participants in this study have mainly held professional jobs, so would be considered to be well educated. Despite these limitations, the study provides an insight into the factors and responses to health information seeking by older people.

#### ***6.3.2 Future research***

Further research is required to explore the experiences of those of different socio-economic groups, literacy levels and those with poor or no understanding of the English language.

##### ***6.3.2.1 eHealth***

Many participants used the Internet as a navigation tool to seek information about health concerns. Indeed, the internet and other digital technologies are becoming increasingly essential to many people's day to day lives and can potentially change the way in which people interact with health services (Royal College of General Practitioners, 2014).

Continued evaluation of the sources from which older people seek information is necessary to track potential shifts in sources of information used by older people in a climate of increasing information access. Some participants described how information found on the internet met their health information needs; these findings suggest the importance of determining not only from where health information is obtained but also the accuracy of this information as this might affect health outcomes. This study did not focus on the quality of information found online. However, concerns remain about the quality of information available on the Internet. Further research regarding the quality of on-line health information is necessary to evaluate the evidence-based information accessed by older people.

The NHS has been slow to appreciate the potential of new digital technologies to enhance patient care with the use of health Apps to facilitate self-care limited (Royal College of General Practitioners, 2014). There are a considerable amount of health Apps available, but so far there has been little regulation or guidance for patients or healthcare professionals regarding efficacy, quality or safety (Armstrong, 2015). Further research is required to explore the effectiveness of eHealth, quality of health Apps and their use by older people and the impact these have on the experience of later life.

#### **6.3.2.2 Health information seeking: a self-perpetuating cycle**

There has been limited consideration of health information seeking behaviour undertaken in health and when asymptomatic. As a result there is an incomplete understanding regarding patterns of health information seeking behaviour in the different stages of health and illness. I have argued that health information seeking clusters into patterns according to health concerns, both when experiencing symptoms and asymptomatic. Work to comprehensively understand the impact of the contemporary information-based culture on information seeking when asymptomatic is required.

#### **6.3.2.3 Typology of health information seekers**

While there were many similarities with younger people, there are some key issues that are more relevant and specific to older people which have been explored. For example, older people need health information to help them make decisions about their health and its maintenance and self-care. I have presented the typology of the older person as health

information seeker. The findings indicated that for older people, seeking health information could become a quest. Different types of information seekers have been identified within research by Wilson (1999), with the current study highlighting that factors such as motivation, timing pattern, style, information sources, focus and decision making impact on health information seeking. Further in-depth research is merited to test the typology further with people of other age groups, as this would further illuminate health information seeking and decisions made regarding health.

#### **6.4 Personal viewpoint**

As described in chapter three, this study was triggered by a series of events that occurred in my personal life. I based my decisions to undertake this study on anecdotal evidence from family and friends. When I started this study, I was an academic involved in educating nurses and I was able to relate theory in my teaching. However, in the past year I have returned to working in clinical practice as a Community Staff Nurse. Many of the patients I encounter are older people with long-term conditions, are confined to their own homes, and are often socially isolated, reliant on family, friends and neighbours for social contact. I believe that I fulfil the role of co-navigator in two ways; professionally and in my personal life and I reflect in this final section on what being a co-navigator actually means to me in these two areas.

Undertaking this study during my changing professional role, has provided opportunities for me to observe older people's health information seeking behaviour in my everyday interactions and to draw on and experience the typology in the real world of clinical practice. My increased knowledge ensures that in my clinical practice I can act as a co-navigator supporting patients through the complex healthcare systems they are required to navigate. To support health information seeking the provision of signposts to appropriate information sources and assistance with the navigation of barriers to gain health information is an important role. The older people that I meet in my day-to-day work vary in their information needs and place within the typology and this helps me critically reflect on my role as a healthcare professional. It is important to me that patients have enough information to be active participants in decision-making. As a healthcare professional, I listen to the meanings patients express, try to understand the process they have followed; provide health information that is tailored to individual needs which reflects information requirements. In order to achieve this, I believe that it is important to work in partnership with patients and families.

This study has highlighted the significance of the informal social network and the part they play as providers of health information. I realise that the health information people have, can impact on decisions made by individuals and it is important that sources used are identified and research-based. Indeed, when I visited a patient who required a flu vaccination, he told me he did not require one this year, having read an article in the Guardian newspaper (Boseley, 2015) based on two research studies (Black et al., 2015; Omer et al., 2015) which suggested taking statins impacted on the effectiveness of the flu vaccination. However, he had not considered the limitations of the studies or that due to his heart disease he was at greater risk of heart failure if he had flu. To me, this added further weight to the findings, in that older people access many information sources and that these sources might contain confusing or conflicting information that differs from public health recommendations.

Personally, it is now as I come to the end of my study that I am able to reflect on my own health information seeking behaviour. I am able to reflect on how the typology of the health information seeker, which I would suggest is the unique contribution to knowledge that this study offers, relates to me. In the past few years, I have had a need to seek health information that mainly relates to my family and I can identify turning points when I transformed from a reactive to proactive information seeker. Due to my professional background, I have often been turned to as a health information source and in order to fulfil this role I have utilised many information sources to help inform others. Having reflected upon my personal experiences of health information seeking behaviour and the findings of this study, I have experienced that older people seek health information in various ways, at different times and use diverse strategies to do this.

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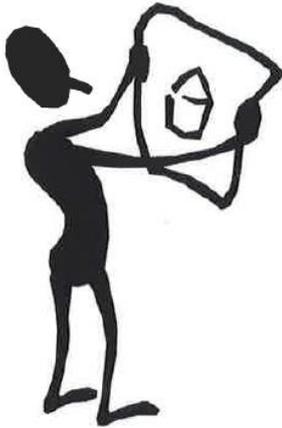
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## APPENDICES

## **APPENDIX 1**

**Poster for recruitment**

## ARE YOU OVER 65 YEARS OLD?



If so, would you be interested in taking part in a study which is seeking to identify where people over the age of 65 find out information about their health and what they do with this information?



This would involve keeping a diary for 2 months, and then an interview after you have completed the diary.

All information collected from you during the course of this research will be kept strictly confidential.

The study has been approved by the University of Hertfordshire Ethics Committee.

**If you would like more information, please contact the researcher: Gill Hurst.**

Email: [REDACTED]

Telephone number: [REDACTED]



## **APPENDIX 2**

### **Interview schedule post diary**

1 to 1 interview post diary

INTERVIEW TOPIC GUIDE

- To start with, tell me a little about yourself
- Can you tell me a bit about your health? Pick out themes when asking this question
- In your diary you write about (specific to person), how do you decide on which one to use?
  - are these sources of health information useful-why?
  - are these sources of health information not useful?-why?
- What would make it easier to find out information about your health?
- Have you experienced any difficulties in finding out information about your health?
- Within the 2 months, was there anything that hindered your search for health information?
- Within the 2 months, was there anything that helped your search for health information?

## **APPENDIX 3**

### **Diary instructions**

## **Instructions for filling out the diary**

Thank you for agreeing to take part in this study. Here are a few points that you need to consider when filling in this diary. I am interested in hearing about how you find out more information about your health.

Remember that this is your diary. I am interested in finding out as much as possible about where you find out about your health over a two month period. So please tell me as much as you can about yourself, no matter how unimportant it may seem. If you are not sure whether to write about something or not, please include it. I would prefer to have too much information rather than too little. If you wish, you can include any leaflets/newspaper clippings that have given you some information about your health.

Try to fill in the diary every evening over the next two months. If you are not able to make an entry for a particular day, then you can fill it in the following day. If you do not have anything to write about on that day, just write that in the diary.

If you find that you have missed out a few days, please do not give up doing the diary. Just start again on the day that you are able to fill in.

Please fill in the date on each page of the diary.

Please don't worry about spelling and grammar, but try to write as clearly as you can, using a pen. If you would find it easier you could use the computer.

Once the two-month period has been completed, I will collect your diary, photocopy it and then return it to you. If you have any questions about the diary, please phone Gill Hurst on [REDACTED] and I will phone you back.

## **APPENDIX 4**

### **Participant information sheet for diary and interviews**

**STRATEGIES IN SEEKING HEALTH INFORMATION FOR THE OVER 65  
YEAR OLDS.**

University of Hertfordshire  
Hatfield, Hertfordshire  
AL10 9AB  
UK

Switchboard 01707 284000  
Fax 01707 284115  
www.herts.ac.uk

**DIARY AND INTERVIEW INFORMATION SHEET. NMSCC/11/09/5/A**

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

The purpose of the research is to see why and where older people find out information about their health and what they do with this information. At the moment there is very little known about this.

**Why have I been asked to take part?**

I am asking approximately ten over 65 year olds to take part in this part of the study.

**Do I have to take part?**

It is up to you to decide whether to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do wish to take part, you will need to complete the contact sheet at the end of this information sheet and return it to me. I will contact you by telephone so that we can arrange a convenient time and place for me to go through how the diary needs to be completed.



01/10/2010

A Charity Exempt from Registration  
under the Second Schedule  
to the Charities Act 1993

**What will happen to me if I take part?**

You will be asked to keep a diary for two months before the interview. The diary will be used to identify if you have sought any information about your health, where you got this information from and what you do with this information.

Once the diary has been completed and I have looked at it, you will be interviewed by me and there will be discussion on sources of information about your health. The interview will take approximately one hour to complete. If you agree, the interview will be tape-recorded but no reports of the study would identify you in any way.

**What are the possible benefits of taking part?**

You may not benefit directly from the study. However, the findings may be of use in developing information that is easier to find and understand.

**What are the possible disadvantages and risks of taking part?**

The only possible disadvantage is the time element required from you when completing the diary. Some people may feel tired during or following the interview. You can withdraw from the study at any time

**Will my taking part in this study be kept confidential?**

All information collected from you during the course of this research will be kept strictly confidential. The information you provide will be made anonymous by removing any personal details so that you cannot be recognised from it. All data will be secured in a locked filing cabinet in a locked office. All the data will be kept on a secure computer only accessible to the research team with password protection. All data storage and use will comply with the Data Protection Act (1998).

The study has been approved by the University of Hertfordshire Ethics Committee for Nursing, Midwifery, Social Work, Criminal Justice and Counselling.

01/10/2010

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### **What if there is a problem?**

If you have any questions about the way you have been dealt with during the study, please contact Dr. Patricia Wilson, Senior Lecturer & Research Lead- Patient experience and Public Involvement. CRIPACC, University of Hertfordshire, Hatfield Campus, College Lane. AL10 9AB. Telephone number:

[REDACTED]

**Contact details for the researcher: Gill Hurst.**

Email: [g.hurst@hertsm.ac.uk](mailto:g.hurst@hertsm.ac.uk)

Telephone number: [REDACTED]

**DIARY AND INTERVIEW RESPONSE FORM**

University of Hertfordshire  
Hatfield, Hertfordshire  
AL10 9AB  
UK

Switchboard 01707 284000 <sup>UK</sup>  
Fax 01707 284115  
[www.herts.ac.uk](http://www.herts.ac.uk)

**Yes, I am interested in keeping a diary and attending the interview.**

**Name (please print)**

**Address (please print)**

**Telephone number**

**Signed**



A Charity Exempt from Registration  
under the Second Schedule  
to the Charities Act 1993

## **APPENDIX 5**

### **Interview schedule for phase 2**

## 1 TO 1 INTERVIEWS

### INTERVIEW SCHEDULE

To start with, tell me a little bit about yourself (age, background information e.g. living alone, past employment, family living nearby)

Can you tell me a bit about your health?-pick out themes when asking this question

If you were to find a red patch on your hand about the size of a 5 pence piece and it seems to be getting bigger, what would you do?

So you want to find out about the red patch-how do you decide where to get the information from?

Thinking about (the internet, book or whatever they suggest) how easy is it to find information in this way?

Do you always get useful information from the xxx?

Do you find other sources of information less useful?

Can you give me an example of where you have found it difficult to find something out about your health?

Is there anything that you wish to add?

## **APPENDIX 6**

### **Individual descriptors of participants**

## PARTICIPANT INFORMATION

Maud, 66 years old, a retired journalist. She was divorced and had re-married. She had three children, all who lived locally and she was regularly in touch with them. She had access and used the internet on a regular basis to look up health information.

Bruce, 73 years old, a retired freelance engineer, was divorced and lived alone. He had one son who did not live locally. He had a large group of friends. Had access to internet, which he used on a regular basis to seek health information.

Bob, 67 years old who was married. He was a retired project manager. He had two children who both lived abroad, and his mother was still alive. He had access to the internet, which he used occasionally to seek health information.

Louise, 73 years old, was divorced and had previously worked as a nurse. She lived in an independent living complex. She had three children, two children lived locally. She had internet access but did not use this to access health information.

Pete was 85 years old who had lived abroad for many years. He was widowed and had previously run his own car repair business. He had no contact with his family who lived locally, but had contact with his step daughter living abroad.

Alan, 80 years old was a retired architect who lived with his wife. He had four children who all lived locally, who he saw regularly. He did not have internet access, did not watch television and listened to the news on the radio.

Tony was 66 years old, a married retired salesman; his children lived abroad. He used the internet regularly and gained health information from various sources including internet, media and medical books.

Sue, 68 years old lived with her second husband. She had retired as a receptionist. She had three children; one son lived locally and two lived away. She regularly used the internet and newspapers to seek health information.

Lorna, 80 years old had been widowed for nearly 15 years, and then she had a partner who died in a few years ago. She was a retired PA. Her daughter lived abroad, but visited regularly.

Pauline was 77 years old and had been widowed for many years. She had worked as a secretary and she had two daughters who lived locally. One of her daughters had internet access and provided information as requested. She also had a drugs book which she regularly referred to for information.

Craig, 78 years old and had been recently widowed. He was a retired sheet metal worker. He only had one daughter who he had no contact with. His sister in law lived close by who he saw her regularly. He had a medical book which was his wife's that he used occasionally.

Erin, was 77 years old and had been widowed for many years. She had previously worked as a secretary. She had two children who did not live locally. She used the internet and occasionally looked up health information and was used Facebook to stay in touch with her grandchildren.

Carol, 83 years old had been widowed for a few years. She was a retired school teacher. She had two sons who lived locally but did not like to worry her family so did not speak to them about her health. She did not have internet access but was planning to go on the internet in the near future.

James, 79 years old, retired from working in the building trade. He was widowed a few years ago. He had a son who lived locally and a granddaughter who visited regularly. He had other family who lived close by who he saw regularly. Had internet access, but did not look up information about his health, any information he needed he referred to a medical book.

Penny, 82 years old who was widowed a few years ago, she had worked in social services. She had a son who did not live locally who she spoke to daily on the telephone and a brother who lived locally. She had no internet access.

Sarah was 72 years old and following the divorce from her first husband had re-married. Prior to her retirement she was an administrator. She had one son from her first marriage who lived a distance away who she spoke to occasionally. She was an occasional user of the internet but not for health information.

Caroline, a 67 year old retired nurse. She was divorced and had re-married a few years ago. She had a son and daughter who did not live locally. She did have internet access which she used to look up health information, also had BNF and Nurses dictionary which she also used for health information.

Victoria, 84 years old, retired from shop work, who had been widowed for many years. She had one daughter who lived locally. No internet access.

Millie was 76 years old and had been widowed for a few years. She had previously worked in an office. Her family lived away from her. She had internet access which she used occasionally to look up health information.

Elsie was 85 years old. She was married and interviewed with her husband Anton. They had a daughter who lived locally. She previously worked doing clerical work. Elsie and Anton did not have internet access. They had a medical book which they recently updated.

Anton, 87 years old was married and interviewed with his wife Elsie. They had a daughter who lived locally; he had retired from his job working for the Council.

Jess, 66 years old was married and interviewed with her husband Len. She had retired as a PA. She had three children who lived locally. She had internet access which she used to look up information.

Len was 71 years old was married and interviewed with his wife Jess. He was a retired builder. His wife looked up information but he did not.

Annie, 75 years old, who was a retired office worker. She had re-married and had two daughters, one lived locally and the other lived overseas. She had internet access but did not use it, had referred to her husband's magazines for health information.

Cynthia, 84 years old, who had been widowed for a few years. She was a retired secretary. She had two children who lived locally. She had internet but had never used it to look up information about her health.

Jack was married and 82 years old. He was a retired Police officer. He had two children who live locally. He had internet access which he never used for health information and had a medical book.

Tom was 74 years old and was widowed a few years ago. His son lived at home with him and daughter lived locally. He had access to the internet which he never used for health information, if he needed to know what a word meant he would use a dictionary.

Fern was 75 years old and was a retired clerk assistant. She was married and had three children who did not live locally. Used the internet to access health information occasionally, but also had a medical book.

Judy was 78 years old who had been widowed for a few years. She was a retired shop worker. She had a laptop in the cupboard which she never used. She had three children with one living locally.

## **APPENDIX 7**

### **List of potential support providers**

## POTENTIAL SUPPORT PROVIDERS

If you have identified to the researcher that you have experienced some distress when discussing your health information seeking behaviours, you could contact your GP. Also, the following list of contact details of some groups/organisations that you can contact for further support may help.

Age concern. Telephone number: 01354 696650. [www.ageconcern.org.uk](http://www.ageconcern.org.uk)

BBCiHealth. [www.bbc.co.uk/health](http://www.bbc.co.uk/health). Provides features on general health issues.

CambridgeshireUK. [www.cambridgeshire.nhs.uk](http://www.cambridgeshire.nhs.uk). Gives details of local services, and there is a health advice section.

CamDoc. Telephone number: 01223 464242. Provides out of hours care for many GP practices in Cambridge.

Citizens Advice Bureau. Telephone number: 0844 848 7979. OFFERS INDEPENDENT ADVICE.

Help the Aged. Telephone number: 0207 278 1114. [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

NHS Direct. Telephone number: 0845 46 47. Provides confidential health advice and information.

NHS Choices: your health, your choices. [www.nhs.uk](http://www.nhs.uk). This website provides information on all aspects of health and healthcare.

## **APPENDIX 8**

### **Participant information sheet for interviews**

**STRATEGIES IN SEEKING HEALTH INFORMATION FOR THE OVER  
65 YEAR OLDS.**

University of Hertfordshire  
Hatfield, Hertfordshire  
AL10 5AB  
UK

Switchboard 01707 264000  
Fax 01707 284115  
www.herts.ac.uk

**INTERVIEW INFORMATION SHEET. NMSCC/11/09/5/A**

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

The purpose of the research is to see why and where older people find out information about their health and what they do with this information. At the moment there is very little known about this.

**Why have I been asked to take part?**

I am asking approximately twenty over 65 year olds to take part in this part of the study.

**Do I have to take part?**

It is up to you to decide whether to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do wish to take part, you will need to complete the contact sheet at the end of this information sheet and return it to me. I will contact you by telephone so that we can arrange a convenient time and place for me to interview you.



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**What will happen to me if I take part?**

You will be asked to be interviewed once. You will be interviewed by me and there will be discussion on sources of information about your health. The interview will take approximately one hour to complete. If you agree, the interview will be tape-recorded but no reports of the study would identify you in any way.

**What are the possible benefits of taking part?**

You may not benefit directly from the study. However, the findings may be of use in developing information that is easier to find and understand.

**What are the possible disadvantages and risks of taking part?**

Some people may feel tired during or following the interview. You can withdraw from the study at any time

**Will my taking part in this study be kept confidential?**

All information collected from you during the course of this research will be kept strictly confidential. The information you provide will be made anonymous by removing any personal details so that you cannot be recognised from it. All data will be secured in a locked filing cabinet in a locked office. All the data will be kept on a secure computer only accessible to the research team with password protection. All data storage and use will comply with the Data Protection Act (1998).

The study has been approved by the University of Hertfordshire Ethics Committee for Nursing, Midwifery, Social Work, Criminal Justice and Counselling.

**What if there is a problem?**

If you have any questions about the way you have been dealt with during the study, please contact Dr. Patricia Wilson, Senior Lecturer & Research Lead-Patient experience and Public Involvement. CRIPACC, University of Hertfordshire, Hatfield Campus, College Lane. AL10 9AB. Telephone number: [REDACTED]



11/06/2012

A Charitable Incorporated Organisation  
under the Companies Act 2006  
11153789

**Contact details for the researcher: Gill Hurst.**

Email: 

Telephone number: 

**INTERVIEW RESPONSE FORM**

**Yes, I am interested in attending the interview.**

**Name (please print)**

**Address (please print)**

**Telephone number**

**Signed**



11/06/2012

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## **APPENDIX 9**

### **Consent form**

**CONSENT FORM**

**Title of project: Strategies in seeking health information for the over 65 year olds. NMSCC/11/09/5/A**

**Name of Researcher: Gill Hurst**

**Please initial box**

1. I confirm that I have read and understand the information sheet dated 11.06.2012 for the above study. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
  
3. I understand that the interview will be audio taped with possible use of verbatim quotation from this and I agree to this.
  
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of participant                      Date                      Signature

\_\_\_\_\_  
Name of researcher taking consent      Date                      Signature