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Exploring the facilitators and barriers to meeting older adults' health literacy needs in clinical practice

by

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<u>ABSTRACT</u>

FACULTY OF HEALTH SCIENCES

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EXPLORING THE FACILITATORS AND BARRIERS TO MEETING OLDER ADULTS' HEALTH LITERACY NEEDS IN CLINICAL PRACTICE

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Background and aim

Health literacy is a term used to describe the ability of individuals to access, understand and use health information. Lower health literacy levels are associated with increased mortality and morbidity, and are more prevalent in older adult populations. UK NHS policy advocates meaningful patient engagement in healthcare. Vital health information is often inaccessible and older adults are not always sufficiently supported by healthcare providers to meaningfully engage with healthcare decisions. There is little research in this area. This research aimed to identify facilitators and barriers to meeting older adults' health literacy needs in clinical practice, from patients' and healthcare providers' perspectives.

Methods

This research comprised two discrete but interconnecting phases; the findings from the first phase led to the development of the second. The first phase involved conducting semi-structured interviews with nine older adults (aged 65 years and over) attending a falls clinic in the South of England. Participants' health literacy was measured using the Rapid Estimate of Adult Literacy in Medicine and the Newest Vital Sign-UK. Interviews explored older adults' views and experiences about access to the service, provider-patient interaction and self-management. Interpretative phenomenological analysis was used to interrogate the data. The second phase involved four focus groups with 22 healthcare providers working

with older adults, and explored views about meeting older adults' health literacy needs. Framework analysis was applied to the focus group data.

Findings

Both phases of the research revealed the importance of building relationships and trust, tailoring healthcare information to individuals' needs and social support when meeting older adults' health literacy needs. Limitations or concerns about the use of health literacy screening were also identified in both phases. All older adult participants emphasised the importance of clear and simple communication; contrastingly, the healthcare providers expressed strong reservations about using 'universal precautions' with all patients. Healthcare providers also had low awareness about health literacy and appeared to shift the responsibility for development of health literacy onto public health and education sectors.

Conclusion and implications for clinical practice

The findings corroborate other research emphasising the essential role of face-to-face interactions in meeting older adults' health literacy needs and recognising health literacy as an interaction between individuals' personal capabilities and the demands of healthcare systems. This research uniquely identifies issues with the transference of the holistic health literacy concept to a UK healthcare setting, such as healthcare providers viewing health literacy as a static risk and shifting responsibility for development of health literacy onto public health and education sectors. This is the first study to qualitatively compare health literacy screening and universal precautions from healthcare providers' and older adults' perspectives, revealing practical and emotional issues with both approaches. The research also reinforces the importance of trust, tailoring interactions to older adults' unique attributes and goals and preferred learning and communication styles and social support. To engage older adults meaningfully in their healthcare, healthcare providers need support to develop their skills to meet their patients' health literacy needs. The findings also highlight that further research is needed to develop effective health literacy interventions for older adults and to ascertain the acceptability and utility of using health literacy screening or universal precautions with older adult patients.

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DECLARATION OF AUTHORSHIP

I, Charlotte Brooks declare that this thesis and the work presented in it is my own and has been generated by me as the result of my own original research.

Title of thesis: Facilitators and barriers to meeting the needs of and development of health literacy in an older adult population.

I confirm that:

1. This work was done wholly while in candidature for a research degree at this University;

2. Where I have consulted the published work of others, this is always clearly attributed;

3. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

4. I have acknowledged all main sources of help;

5. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

6. Some of the work of this thesis has been published in part in peer review conference presentations and journals. See Appendix A for full list of dissemination activities, including peer reviewed publications and conferences.

Signed:...

Date: ....

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Definitions and Abbreviations

Definition of terms

Community-dwelling older adult

An individual who lives in the community, and not in a residential or nursing home.

Critical health literacy

The capacity to use more advanced cognitive, literacy and social skills to critically analyse and use health information to gain increased control over own healthcare and other health situations (Nutbeam 2000, 2015).

Critical literacy

'More advanced cognitive skills which, together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations' (Nutbeam 2000, p.264).

Falls clinic

'A facility based in either primary or secondary health care that administers services to individuals with the purpose of preventing falls, and involves qualified health professionals' (Lamb et al. 2007, p.10).

Functional health literacy

The ability to apply basic health literacy skills (including reading, writing, basic knowledge and understanding) to a limited range of prescribed activities (Nutbeam 2000, 2015).

Functional literacy

'Sufficient basic skills in reading and writing' (Nutbeam 2000, p.263).

Healthcare provider

Individual providing healthcare in a clinical capacity.

Health literacy

'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' (Nutbeam 1998, p.357).

Interactive health literacy

The ability to use more advanced cognitive, literacy and social skills to contribute actively to healthcare, derive meaning from different forms of healthcare communication and to apply new information to changing circumstances (Nutbeam 2000, 2015).

Interactive literacy

'More advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances' (Nutbeam 2000, p.263).

Literacy

'The ability to read and write' (Oxford Dictionaries 2015a)

Older adults

Adults 65 years or older.

Secondary care

Refers to healthcare services offered by healthcare providers who generally do not have the first contact with a patient.

Self-management

'Day-to-day decisions and activities that patients, with the help of loved ones, engage in to live with and control their illnesses' (Paasche-Orlow and Wolf 2007a , p.23).

Abbreviations used in thesis

AAHLS – All Aspects of Health Literacy Scale (health literacy measurement tool)

HLQ – Health Literacy Questionnaire (health literacy measurement tool)

GP – General Practitioner

IPA – Interpretative Phenomenological Analysis

NHS – National Health Service

NVS – Newest Vital Sign

NVS-UK – Newest Vital Sign United Kingdom

REALM – Rapid Estimate of Adult Literacy in Medicine (health literacy measurement tool)

SILS – Single Item Literacy Screener (health literacy measurement tool)

SSQ – Single Screening Question (health literacy measurement tool)

TOFHLA – Test of Functional Health Literacy in Adults (health literacy measurement tool)

UK – United Kingdom

US – United States

Chapter 1: Background and rationale for this research

1.1 Introduction

This thesis explores the facilitators and barriers to meeting older adults' health literacy needs in clinical practice and contains two discrete but interconnecting research phases; exploring this area from both older adult patients' and healthcare providers' perspectives.

In recent years, the concept of health literacy has been gaining momentum: literacy and health literacy have been given increasing recognition in NHS guidance documents and influential Government reports (National Institute for Health and Care Excellence 2012; Public Health England 2015). NHS England have sponsored health literacy meetings, with the aim of facilitating discussions regarding health literacy amongst healthcare providers (Royal College of General Practitioners 2014). Furthermore, the number of research papers published about health literacy has increased exponentially over the last ten years (Sørensen et al. 2012; Nutbeam 2015). There are many definitions of health literacy; however all the definitions in current use have at their core the ability to access, understand and use information for health (Sørensen et al. 2012). For the purpose of this thesis, health literacy will be defined as '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' (Nutbeam 1998, p. 357).

In this chapter, the development of interest in the topic of health literacy from a clinical and personal perspective is explored initially. Following this, the concept and importance of health literacy is introduced, and health literacy in the context of older adults and clinical healthcare services is examined. The chapter closes with a summary section and an overview of what is included in each chapter. Throughout the thesis, the author will be referred to as 'the researcher'. Users of the NHS will be defined as 'patients', individuals working clinically with patients will

be described as 'healthcare providers', and those participating in research as 'participants'. The 'present research' will refer to the research conducted for this thesis. This is to assist with distinguishing between this research and the body of research in the health literacy area, but where appropriate the present research may also be described as 'this research'.

1.2   Development of interest in health literacy from a clinical and personal perspective

The researcher undertook a clinical academic doctoral fellowship; working two days a week as a community occupational therapist and three days a week as a doctoral student. Clinical academics engage in clinical practice and research concurrently, developing skills in both areas and providing clinical and research leadership (Department of Health 2012a). The researcher began on this pathway following attainment of an occupational therapy degree. The opportunity to develop clinical academic skills simultaneously was what initially attracted the researcher to this post. Additionally, previous experience of working as a healthcare assistant with prison populations ignited the researcher's interest in the effect of low literacy and social inequalities on health outcomes. As a clinical academic student, the researcher aimed to develop clinically relevant research questions and disseminate and implement research findings into the clinical setting (Latter et al. 2011). The Association of UK University Hospitals non-medical clinical academic careers group suggests a central feature of clinical academic research is that it 'aims to inform and improve the effectiveness, quality and safety of healthcare' (Department of Health 2012a , p.3).

This clinical academic fellowship was a collaboration between the University of Southampton and an NHS Trust; research priorities and aims had to be agreed between both parties. To enable collaborative working, the researcher met regularly with both clinical and academic representatives. The topic of health literacy was identified by the primary PhD supervisor and occupational therapy manager as a relevant and timely area for investigation within an inner city NHS population with a high percentage of lower socioeconomic groups represented. The concept of health literacy was seen as a relevant fit for occupational therapy services and one that neatly dovetailed into current service provision, but also an

area that to date had received no attention within the NHS Trust involved. However, the research question and target population was later refined with the researcher and her academic and clinical representatives; this was primarily guided by reviewing the literature, the researcher's observations from clinical practice and discussions with clinical colleagues.

Working as an occupational therapist within community healthcare, the researcher observed patients experiencing difficulties accessing, understanding and using health information. These issues appeared to be particularly apparent in older adults. The researcher initially reflected that this possibly results from sensory and cognitive impairments and multiple complex conditions. Subsequently, the researcher ruminated over whether these difficulties result from a combination of older adult patients' lower health literacy levels and how information had been presented to these individuals. Equally, as a result of reading in the health literacy area, the researcher utilised recommended health literacy communication strategies with patients (Schwartzberg et al. 2007; Weiss 2007; DeWalt et al. 2010) which produced positive results, including patients expressing their satisfaction about the provided communication. Although not an exhaustive list, communication strategies used included asking patients about their literacy and educational requirements, using simple language, designing accessible information, encouraging patients to ask questions with an open-ended approach and checking understanding during clinical encounters. During clinical assessments, patients sometimes spontaneously disclosed a perceived lack of confidence when interacting with healthcare providers and commented on the complexity of the healthcare system. As a result, the researcher began to consider how health literacy needs could be met and skills developed within clinical practice. On occasion, the researcher observed patients or their carers appearing to develop health literacy skills; patients would mention obtaining information on the internet or questioning a healthcare provider. However, primarily patients appeared to be overwhelmed by the complexity and sometimes conflicting nature of health information.

During conversations with academic supervisors, it was suggested that a single clinical encounter has the potential to help develop a patient's health literacy; the researcher became interested in this idea and grew to believe it is the

responsibility of all healthcare providers to meet their patients' health literacy needs. When observing other clinical colleagues working with patients, the researcher was unable to discern the use of the recommended health literacy communication strategies described above. Furthermore, conversations with clinical colleagues revealed a lack of prior awareness about health literacy as a concept. As a result, the researcher became increasingly interested in how patients' health literacy needs can be met within clinical practice.

The concept of health literacy originated from public health, but has also been developed within clinical care. However, much of the research into health literacy conducted in clinical settings has focussed on reducing the 'risks' of low health literacy through measurement of patients' health literacy and tailoring of education accordingly (Nutbeam 2008). It follows that this research explores the transferability of health literacy as a holistic concept into a clinical setting.

1.3 Literacy and health literacy as distinct but interconnecting concepts

It is important to understand the concept of literacy before one considers health literacy because they are different but interconnecting concepts (Nutbeam 2009). Literacy itself is a complex and evolving concept and understanding this provides useful context when examining the conceptual development of health literacy. The evolution of the concept of literacy is reflective of the changing economy from agricultural to industrial to information-based (Berkman et al. 2010). For instance, the level of literacy required is a socially constructed phenomenon and dictated by current societal expectations (Cook-Gumperz 2006); effective participation in society and the economy has required different literacy skills at different times and participation in the current information-based economy requires much higher literacy skills than ever before. Thus, literacy is context-specific; varying in different social, economic and cultural contexts. Interpretations of literacy differ widely; literacy is most frequently defined and conceptualised as reading and writing abilities (UNESCO 2006). However, UNESCO (2005, p.21) proposed a more complex operational definition of literacy as, 'the ability to identify, understand, interpret, create, communicate and compute, using printed and written materials with varying contexts. Literacy involves a continuum of learning in enabling

individuals to achieve his or her goals, develop his or her knowledge and potential, and participate fully in the community and wider society'. The multitude of different skills described in this definition demonstrates the complexity of the subject. Furthermore, this conceptualisation of literacy places emphasis on what literacy enables individuals to do (Nutbeam 2000). Literacy skills even at the most basic level assist an individual to function more fully in society. An illiterate individual cannot read or write at all, whereas low functional literacy would affect an individual's ability to apply basic reading, writing or numeracy skills to everyday situations such as reading a medicine or nutritional label, filling out a job application form and working out the correct change at a supermarket (World Literacy Foundation 2012). Interactive and critical literacy levels have also been described (Freebody and Luke 1990). Interactive literacy involves more advanced literacy and cognitive skills and critical literacy includes the most advanced literacy, cognitive and critical analysis skills utilised to exert greater control over life events. For the remainder of this thesis, when 'literacy' is referred to, the abilities will relate to functional literacy.

Given the potential impact of low literacy levels on an individual's daily life, it corresponds that low literacy levels are linked to a range of poor health outcomes, including increased morbidity and mortality, increased risk of hospitalisation and reduced use of preventive health services (DeWalt et al. 2004; Berkman et al. 2011). Low literacy levels are common in the UK: in a large survey, 15% of adult participants (aged 19-65) were performing at a national school curriculum equivalent of aged 11 or below (Harding et al. 2011). Resulting from these issues, there has been a great deal of focus on reducing the negative impact of low literacy through modified communication (Nutbeam 2009).

Despite the clear impact of literacy on health outcomes, health literacy is seen as a distinct concept. For instance, there are multiple domains of context-specific literacies emerging, including media literacy, financial literacy and health literacy (Nutbeam 2009). As a result, an individual with advanced interactive or critical literacy abilities may not be able to apply these skills in a healthcare context (Nutbeam 2008, 2009). Barriers to an individual accessing, understanding and using health information may include lack of healthcare experience, stresses associated with medical situations and the way in which healthcare services are

organised and delivered (Speros 2005; Nutbeam 2008). This means an individual's ability to access, understand and use health information may fluctuate according to changing contexts (Mårtensson and Hensing 2012). To understand the difference between health-related literacy and a more complete conceptualisation of health literacy, Nutbeam (2009) suggests combining an advanced understanding of literacy with an understanding that health literacy is content and context-specific.

1.4 Differing definitions of health literacy and the definition chosen for this research

According to Ratzan (2001), the term health literacy was first employed by Scott Simonds in 1974 in a school education context. Simonds argued that the school curriculum should aim to improve the health literacy of pupils, alongside more conventional subjects such as English and maths. The term was subsequently applied to healthcare contexts, and evolved from narrow definitions of health literacy as the ability to read and write in a healthcare context to more complex definitions including more advanced cognitive and social skills used for empowerment and increased control.

There are many definitions of health literacy: Sørensen et al. (2012) identified 17 explicit definitions within their systematic review. Nearly all of these definitions focus on a narrow conceptualisation of health literacy relating to individual abilities (Sørensen et al. 2012). The definition of health literacy as individual capabilities recognises that being health literate is not simply the ability to read and write; it requires application of many different skills in a healthcare context, including cultural and conceptual knowledge, memory, numeracy, navigation, comprehension, listening and interacting, analytical and decision-making abilities (Sørensen et al. 2012). However, this 'individual-level construct' tends to focus on reactive rather than preventive healthcare and does not fully take into account socioeconomic and systemic factors. Reactive healthcare occurs when an individual has already become ill or disabled; contrastingly, preventive healthcare involves acting to prevent or delay the onset of health conditions through the promotion of independence and healthy behaviours (Howse 2012; Windle 2015).

Increased preventive healthcare is a key UK Policy (Department of Health 2010c, d).

Health literacy can also be viewed as an interaction between the demands of the health systems and the skills of individuals (Ishikawa et al. 2008; Ishikawa and Yano 2008; Sørensen et al. 2012). Only one definition from Sørensen et al.'s review (2012) appears to include systemic considerations: 'an individual's possession of requisite skills for making health-related decisions. This means that health literacy must always be examined in the context of specific tasks that need to be accomplished... it is important to underscore the importance of a contextual appreciation of health literacy' (Paasche-Orlow and Wolf 2007a, p.20). The World Health Organization (2015, p.12) recently defined health literacy as 'the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health'. This definition also considers the 'social resources' which may be needed to be health-literate, thus appears to conceptualise health literacy as an interaction between individuals' abilities and the resources made available to them. The argument for conceptualising health literacy is this way is that a patient's health literacy may be higher if health-related materials and communication were more accessible (Berkman et al. 2010). In agreement with this definition, when exploring the meaning of health literacy, patient participants in Jordan et al.'s study (2010) identified a range of factors affecting their abilities to access, use and understand health information including patients' individual skills, healthcare providers' communication abilities and broader considerations at both the healthcare system and community level. Despite the merits of this alternative conceptualisation of health literacy, health literacy is more than making health-related decisions, as Paasche-Orlow & Wolf's (2007a) and the World Health Organization's (2015) definitions suggest.

Many of the health literacy definitions described in Sørensen's review (2012) neglect the rights of individuals to make poor but informed decisions: to be health-literate, individuals are expected to make 'appropriate' or 'sound' decisions about their health (Institute of Medicine 2004; Kickbusch et al. 2006; Adkins and Corus 2009; Yost et al. 2009). Furthermore, some of the definitions are entirely focussed on health literacy within either a clinical or public health setting (Ishikawa and

Yano 2008; Freedman et al. 2009). No single definition was identified which recognises that health literacy involves healthcare maintenance activities in addition to making decisions, considers individuals' specific health literacy abilities and contextual demands and also recognises individuals as having the capability to take responsibility for their own decisions (whether these are viewed as healthy or not).

The definition of health literacy used in this thesis (Section 1.1) goes beyond individual abilities in reading and writing in a healthcare context, and includes social skills and motivation. Including the promotion and maintenance of good health, this definition also integrates clinical and public health approaches to health literacy. However, this definition is centred around individuals' abilities; therefore in alignment with conceptualisations of health literacy as an interaction between individual abilities and the demands of the healthcare system, the researcher also recognises that improved health literacy may result from enhanced communication by healthcare providers and reducing the demands of the healthcare system. The researcher's choice of health literacy definition will be referred to throughout this thesis, given that it impacts on how research is interpreted. Understanding the concept of health literacy has important implications for the way in which health literacy research is conducted. The lack of consensus about the definition and conceptual dimensions of health literacy may be one explanation for the wide variety of different health literacy measurement tools being developed (Jordan et al. 2011; Haun et al. 2014) and why health literacy has not been mentioned in recent health White Papers (Department of Health 2010a, c).

1.5 The health literacy framework and model chosen for this research

As with literacy, health literacy can be categorised as functional, interactive or critical (Nutbeam 2000, 2015). These three levels of health literacy have been classified as:

- Functional health literacy: The ability to apply basic health literacy skills (including reading, writing, basic knowledge and understanding) to a limited range of prescribed activities.
- Interactive health literacy: The ability to use more advanced cognitive, literacy and social skills to contribute actively to healthcare, derive meaning from different forms of healthcare communication and to apply new information to changing circumstances.
- Critical health literacy: The capacity to use more advanced cognitive, literacy and social skills to critically analyse and use health information to gain increased control over one's own healthcare and other health situations.

Kanj and Mitic (2009) describe functional health literacy as relating to an individual's ability to perform a limited number of prescribed tasks, such as reading consent forms, medicine labels and healthcare information, and understanding and adhering to written and verbal instructions. In addition to reading and writing abilities, numeracy has also been included in functional health literacy definitions (Kickbusch and Maag 2008). Health education based around meeting functional health literacy needs involves the transmission of factual health information regarding health risks and navigation of the health system. The outcome of this type of education involves improved knowledge and compliance with instructions (Nutbeam 2000). Functional health literacy can lead to increased adherence to medical instructions, awareness of risks and knowledge of health services (Muir et al. 2006; Macabasco-O'Connell et al. 2011).

Interactive health literacy is grounded in health promotion theory, emphasising skill acquisition to enable an individual to take increased control over their existing health conditions whilst simultaneously developing skills for preventive health (Manafo and Wong 2012). Chinn and McCarthy (2013) suggest that interactive health literacy consists of two separate components: information seeking and processing skills and interactive skills necessary for communicating with healthcare providers. Interactive health literacy can lead to an improved ability to act independently and to successfully interact with healthcare providers and the healthcare system (Sørensen et al. 2012; Smith et al. 2013a).

Through her review and critical analysis of the concept, Chinn (2011) identifies information appraisal, understanding the social determinants of health and collective action as the constituent domains of critical health literacy. However, some authors have focussed on information appraisal abilities as the key component to critical health literacy (Steckelberg et al. 2007; Ishikawa et al. 2008). Given that the present research is focussing on health literacy within clinical services, patients' ability to understand the social determinants of health and collective action may not be as relevant; therefore information appraisal will be the main emphasis. Recognising the rights of an individual to make their own decisions (regardless of how those decisions are viewed by healthcare systems), Rubinelli et al. (2009, p.309) propose critical health literacy 'reflects an individual's capacity to contextualise health knowledge for his or her own good health, to decide on a certain action after a full appraisal of what that specific action means for them "in their own world"'. This aligns with the researcher's view about respecting patients' abilities to make poor but informed decisions, but does not include social skills and therefore Nutbeam's definition will be used for this thesis (2000, 2015). Critical health literacy can result in personal empowerment and resilience to social and economic adversity (Sørensen et al. 2012).

Progression through the health literacy levels appears indicative of increasing personal empowerment and autonomy (Nutbeam 2000, 2008), which is a key public health goal (Department of Health 2010a, c). This classification system has the benefit of incorporating cognitive and social skills. Application of this health literacy framework in a clinical setting may involve clinicians supporting patients to actively participate in healthcare decisions and gain skills to manage their conditions (Royal College of General Practitioners 2014). However, this framework also has the potential to shift the balance of power toward the public and the focus of healthcare provision toward more preventive healthcare (Royal College of General Practitioners 2014). Health literacy definitions have developed from a public health approach, and transferring this concept, with its focus on preventive healthcare, to clinical settings may bring challenges, which are explored throughout this thesis.

Multiple papers have examined the associations between functional health literacy and a range of health outcomes (Berkman et al. 2011). Individuals with lower

functional health literacy are more likely to have poor health outcomes and increased morbidity (Schillinger et al. 2002; DeWalt et al. 2004; Wolf et al. 2005a; Berkman et al. 2011), increased risk of mortality, especially in older persons (Baker et al. 2007; Bostock and Steptoe 2012), and greater likelihood of hospital admissions (Baker et al. 1998; Baker et al. 2002; Mitchell et al. 2012; Omachi et al. 2013). As a result, there are clear cost implications for society; healthcare charges are higher for individuals with lower functional health literacy levels (Howard et al. 2005; Eichler et al. 2009; Herndon et al. 2011). It has been proposed that health literacy is a more accurate predictor of health status than age, income or employment (Weiss 2007). However, lower functional health literacy is also strongly associated with demographic factors such as low income, low levels of education attained, occupation, employment, income, older age and minority populations (Kutner et al. 2006; Bostock and Steptoe 2012). Health literacy may partially explain the observed relationships above (Howard et al. 2006; Curtis et al. 2012; Adams et al. 2013). Individuals with lower health literacy may also have increased difficulty in locating providers and services, filling out complex health forms, providing medical histories, seeking preventive healthcare, knowing the connection between risky behaviours and health, managing long-term conditions and understanding directions on medications (Baker et al. 1996; Gazmararian et al. 2003; Schillinger et al. 2003; Lindguist et al. 2012; Easton et al. 2013). Despite the observed relationships between functional health literacy and socioeconomic status, it has also been proposed that low health literacy levels can be present in any individual (Nutbeam 2009). This may be partially because individuals with advanced functional literacy skills may not be able to apply these abilities consistently (Nutbeam 2015), but equally they may not have developed more advanced health literacy abilities (i.e. interactive and critical) to be able to function effectively in a healthcare context. As such, health literacy is the main focus of the present research, as opposed to socioeconomic status.

The relationship between interactive/critical health literacy and adverse health effects or patient outcomes is less clear than the relationships identified with functional health literacy. However, interactive and/or critical health literacy have been positively associated with decreased haemoglobin A1c levels, understanding of diabetes care, self-efficacy and some aspects of self-management, such as taking medications, perceived participation, making decisions and perceived ability

to organise care, interact with healthcare providers and perform self-care (Ishikawa and Yano 2011; Inoue et al. 2013; Lai et al. 2013; Heijmans et al. 2015; Van der Heide et al. 2015). Despite the important findings from these studies, the majority of published research to date has focussed on functional health literacy (Berkman et al. 2011). The interactive and critical levels require further research to determine their relationship to clinical outcomes, transferability to the NHS healthcare system and effect on patient experiences. Nutbeam's (2000) tripartite health literacy framework (and the definitions used within it) will be used to inform the literature review and subsequent data collection and analysis for this research.

A model which was developed using available research findings to identify the causal pathways linking health literacy to health outcomes, will also be used for this research (Appendix B) (Paasche-Orlow and Wolf 2007a). This model suggests a range of patient, provider and system factors which may affect health literacy, such as patient knowledge and provider communication skills. In contrast to Nutbeam's health literacy framework (2000), this model does not consider the development of health literacy. However, it is a useful model when considering factors influencing health literacy and the tailoring of information to patients' specific needs. This model is also used to influence data collection and analysis in this research. This was chosen in preference to Baker's conceptual model linking individual capacities, health-related print, and oral literacy and health outcomes (2006): the focus on written and verbal information is narrow and individual characteristics such as vision, hearing and memory which may affect older adults are not included in this model. It was also felt that Zarcadoolas' model (2005) which characterises four different literacy types (fundamental literacy, science literacy, civic literacy and cultural literacy) would not easily transfer to a clinical research study; this model may be useful for considering health literacy more broadly. Similarly, the Institute of Medicine's health literacy model (2004) suggests health literacy can be affected by the health system, education system, and culture and society; it was not used given the specific focus of this research being on the healthcare system.

When considering theoretical models and frameworks, it is important to recognise that these models may not always transfer easily to clinical practice. Implementation of models within clinical practice may be complicated if the model

does not accurately reflect patients' situations within clinical practice. This issue is considered within the thesis.

1.6   Different conceptualisations of health literacy

It is imperative to consider the different conceptualisations of health literacy, because this impacts on how health literacy is defined, measured and implemented within clinical practice (Berkman et al. 2010).

1.6.1   Health literacy as a static clinical 'risk'

Health literacy can be conceptualised as a clinical 'risk' or as a personal 'asset'. Both conceptualisations will be described, and then compared in terms of their application within clinical practice. First, Nutbeam (2008) argues health literacy can be perceived as a clinical risk factor; this approach suggests the healthcare system necessitates assessing for and adapting to an individual's prior health literacy status. Using this conceptualisation, health literacy is considered as static; it only needs to be measured once. This is more consistent with consensus regarding literacy levels; literacy abilities are considered to be relatively fixed unless intensive interventions such as adult educations classes are used (Berkman et al. 2010). This stance fits with the overwhelming majority of previous health literacy research, which has focussed on the risks and management of low health literacy (DeWalt et al. 2004; Berkman et al. 2011). It appears indicative of aiming for patient adherence to healthcare providers' recommendations and medication (Nutbeam 2008). This approach fits with a functional health literacy definition (Nutbeam 2000) and the causal model linking health literacy with health outcomes (Paasche-Orlow and Wolf 2007a).

1.6.2   Health literacy as a dynamic 'asset'

The second conceptualisation which has derived from public health is health literacy as a personal 'asset' or skill which can be developed over time (Nutbeam 2008). Conceptualised in this manner, health literacy is viewed as dynamic (Zarcadoolas et al. 2005). Applying this approach takes health literacy beyond

health-related reading and numeracy skills and the healthcare system; health literacy skills can be fostered in other areas such as school education, adult learning and community development programs (Nutbeam 2008). This approach aligns with the three-tiered functional, interactive and critical health literacy framework, and Nutbeam's (2000, p.263) argument that health literacy is not just about literacy abilities, but 'what it is that literacy enables us to do'.

1.6.3   Implications of framing health literacy as a static clinical risk or dynamic asset for clinical practice

Although distinctive concepts with differing research methods and applications, both the risk and asset conceptualisations rely on fundamental literacy and numeracy skills. Adopting the static risk approach has the practical advantage of generating clear guidelines, easily implemented in policy and busy clinical practice (Nutbeam 2008). This is because the healthcare provider could test an individual's health literacy once and tailor healthcare to their needs after this; this may not be too time-consuming. When applying the risk approach, it is proposed that improved clinical outcomes such as adherence will result from tailored healthcare delivery (Nutbeam 2008). However, this approach does not consider individuals who are not currently accessing healthcare services and does not include the many healthcare decisions which individuals make on a daily basis outside of the healthcare environment (Peerson and Saunders 2009). Furthermore, when utilising the risk approach, healthcare providers do not seek to improve patients' health literacy which is suggested as a method of empowering patients to be partners in their healthcare (Nutbeam 2008). Contrastingly, distinguishing health literacy as a dynamic asset is more aligned with health promotion and preventive healthcare. Implementing the dynamic asset approach may be more beneficial in the long term, linking with 'health empowerment' and informed choice principles (Department of Health 2010a, c; National Institute for Health and Care Excellence 2012), and may provide rationale for an alternative patient approach; health literacy could be incorporated into patient education programmes as a potential desired outcome. For instance, success of a patient education program could be partially measured using dynamic health literacy measurement tools. It is argued that this preventive approach could reduce pressures on the NHS long-term (Peerson and Saunders 2009). However, this approach may be incompatible with

goal oriented healthcare resulting from the person-centred flexible approach. For instance, when conceptualising health literacy as an asset, healthcare providers tailor their provision of information, communication and education to individuals' needs, and seek to improve patients' health literacy skills, engagement and participation based on this (Nutbeam 2008). However, currently many conventional self-management programmes within the NHS focus on goal oriented tasks expected by doctors and nurses, such as managing medication (Greenhalgh 2009). Both the risk and asset approaches involve tailoring of information based on a prior understanding of individuals' abilities. Therefore, when adopting either approach, healthcare organisations can initially ensure their environment is sensitive to individuals' health literacy needs. Moving beyond this and beginning to develop individuals' health literacy abilities may involve a change in the policy and culture of healthcare services (Edwards et al. 2012).

In this thesis, the researcher conceptualises health literacy as a dynamic asset; development of health literacy skills is seen as possible through education and healthcare experiences. However, health literacy will also be considered from the risk perspective. Research questions developed for this thesis needed to be clinically relevant and applicable to NHS healthcare settings. From the researcher's clinical observations and the limited research exploring UK healthcare providers' views and awareness of health literacy (Salter et al. 2014), health literacy appears to be currently viewed primarily from a risk perspective within the NHS (Nutbeam 2015). As a result, it was deemed necessary to evaluate the current state of affairs before considering novel approaches to healthcare delivery. Although considering health literacy as a personal asset and 'important life skill' may eventually result in minimised use of healthcare services, this impact may not be seen for many years. In the meantime, there are many patients currently struggling to access, understand and use health information (Shaw et al. 2009). It may be necessary to reduce the possible risks for patients with lower health literacy before considering the potential of asset building initiatives. However, the researcher is also interested in exploring the transferability of the dynamic asset approach to the NHS. Adoption of the asset conceptualisation may be pertinent, given the NHS is required to increase patient involvement in healthcare and provide more patient-centred healthcare to increasing numbers of

people with finite resources (Department of Health 2010a; Royal College of General Practitioners 2014).

1.7   Relevance of health literacy in an older adult population

The UK has an ageing population (Office for National Statistics 2009). The number of people in the UK over 65 years old is forecasted to double by 2050 (UK Parliament Website 2010). This has clear implications for the cost of public health services with retired households costing the NHS double the amount compared with non-retired households (UK Parliament Website 2010). The ageing population is a consequence of the 'baby boom' years after the second world war and during the 1960s and increased life expectancy (Office for National Statistics 2005; UK Parliament Website 2010). However, healthy life expectancy has not risen at the same rate, with the number of people in England with a long-term condition predicted to rise from 1.9 million in 2008 to 2.9 million by 2018 and costing the NHS a predicted additional £5 billion (Department of Health 2012b). Multi-morbidity is more prevalent among deprived populations (The King's Fund 2014), where lower literacy levels are also more common (Kutner et al. 2006).

Supporting individuals to be more informed and involved, take control of their health and engage in self-management activities is advocated by the Government (Department of Health 2010c, b, a; National Institute for Health and Care Excellence 2012). Self-management skills may be necessary to manage a range of health conditions in older people and can be defined as 'day-to-day decisions and activities that patients, with the help of loved ones, engage in to live with and control their illnesses' (Paasche-Orlow and Wolf 2007a, p.23). Healthcare providers can actively support self-management by encouraging partnerships with patients and by facilitating informed decision making (Imison et al. 2011). Poor self-management has been associated with lower health literacy levels in older adults (Federman et al. 2014a).

If self-management goals are to be realised, older adults need to be adequately equipped to access, use and understand health information and apply this information, promoting self-management and informed choices. Older adults are also more likely to have low health literacy levels than younger adult populations

(Gazmararian et al. 1999; Kutner et al. 2006; Bostock and Steptoe 2012; Wu et al. 2013); this likelihood also increases with age (von Wagner et al. 2007). In Federman et al.'s study (2013), 34% of older adults aged 60-64 had low health literacy, in comparison to 40% of older adults aged 70 and over.

Low health literacy has been associated with a range of poor outcomes in older adults, including worse physical and mental health (Wolf et al. 2005b; Mõttus et al. 2014), increased morbidity (Sudore et al. 2006; Omachi et al. 2013), increased rates of mortality (Bostock and Steptoe 2012), medication errors (Lindguist et al. 2012) and increased risk of admission to hospital (Federman et al. 2014b). Poor inhaler technique, reduced adherence to medication and physical activity guidelines, low knowledge levels relating to conditions and medications and incorrect health beliefs have also been associated with low health literacy levels in older adults (Mosher et al. 2012; Federman et al. 2013; Burke et al. 2014; Federman et al. 2014a; Geboers et al. 2014).

Health literacy involves a complex set of skills, including cognitive, social and literacy skills (Nutbeam 1998, 2000). However, older adults often have physical and psychological barriers which may affect their ability to access, understand and use health information (Speros 2009), thus further justifying exploration of health literacy in the context of older adults. Hearing, visual and cognitive impairments are common among older adults and they may also experience high levels of fatigue, pain, anxiety or depression (Speros 2009). Many older adults have reduced mobility, long-term conditions and multiple co-morbidities (Speros 2009).

Older adults experience age-related cognitive decline, where cognitive skills gradually deteriorate over time (Salthouse 2009). This may affect their ability to retain information, maintain focus, process messages, manage multiple messages and understand abstract concepts (Speros 2009). Low health literacy has been associated with cognitive decline in older adults (Boyle et al. 2013; Nguyen et al. 2013; Serper et al. 2014). One study revealed that older adults' health literacy significantly decreased over a period of two years (Morris et al. 2013). Furthermore, lower health literacy has been associated with worse recall of medical instructions in older adults and the general risk of poor recall increases with age (McCarthy et al. 2012c).

Visual impairments are also common in older adults; it is estimated one in five people aged 75 and over have sight loss (Royal National Institute of Blind People 2015). Common conditions include cataracts, glaucoma and macular degeneration (Speros 2009). However, as many as 62% of older adults have presbyopia (an inability to focus at near distances) (Patel and West 2007). This has a huge impact in a healthcare system where reading and writing tasks are regularly necessary. Individuals with visual impairment may be more likely to take medication incorrectly or miss appointments (Muir et al. 2013). They may also have difficulties with increasing their knowledge levels through accessing written information. It is estimated that more than 70% of older adults aged above 70 have a hearing impairment (Action on Hearing Loss 2015). These difficulties may result in reduced confidence in accessing healthcare information and communicating with healthcare providers.

If health information is inaccessible and older adults are not enabled and supported to develop their health literacy abilities, the unintended exacerbation of social inequalities is possible (Protheroe et al. 2009). Given the complex physical and psychological difficulties older adults frequently experience which may inhibit their health literacy abilities, exploring ways in which older adults' health literacy needs can be met could assist with meeting the health literacy needs of the general population. Chapter Two explores older adults' health literacy views and experiences by critiquing available research. The focus of this research is on older adults, not sensory impairments; highlighting the possible additional barriers which older adults may face when accessing health information is crucial. This is because health literacy issues could get confused with sensory impairments: an individual with sensory impairments may have high health literacy if information was tailored to their sensory needs.

1.8 Meeting older adults' health literacy needs in clinical practice

1.8.1 'Risk' based approaches to meeting older adults' health literacy needs in clinical practice and whether these needs are being met

This thesis views health literacy as an interaction between individuals' abilities and the demands of the healthcare system (Section 1.4). As such, the abilities of both patients and healthcare providers are considered. Two of the regularly recommended but conflicting strategies for meeting patients' health literacy needs are measuring health literacy (screening) and tailoring information accordingly, or using evidence-based communication strategies ('universal precautions') with patients of all health literacy levels, including patient-centred and clear health communication, confirmation of patient understanding and multimodal education delivery (Baker 2006; Paasche-Orlow and Wolf 2007b; Sudore and Schillinger 2009; Jordan et al. 2011; Haun et al. 2014). These strategies will be explored further in Chapter Two while this section explores the complexity of the healthcare system, justifying further exploration of how healthcare providers meet older adults' health literacy needs.

Guidance from the National Institute for Health and Care Excellence (NICE) recommends providing patients with both oral and written information (National Institute for Health and Care Excellence 2012). Provision of verbal information alone has the potential to disempower patients; information may be forgotten and cannot be referred to again (Johnson et al. 2008). Therefore, it is noteworthy that numerous studies indicate that printed healthcare materials are not meeting recommended reading levels (Bennett and Gilchrist 2010; Fitzsimmons et al. 2010; Todhunter et al. 2010; Cronin et al. 2011; Brooks et al. 2013). Although, readability is one quality indicator for printed information, it does not consider legibility, layout, use of pictures, personalisation and content and does not measure whether the information will be understood or accepted by readers (Meade and Smith 1991; Redish 2000; DeWalt et al. 2004; Sudore and Schillinger 2009).

Equally, oral communication is not always meeting patients' needs. Clear health communication may include utilising lay language and avoiding jargon, slowing down speech and avoiding overloading patients with information (Sudore and Schillinger 2009). Medical jargon and complex language is frequently used by healthcare providers (Castro et al. 2007; Deuster et al. 2008; Koch-Weser et al. 2010; McCarthy et al. 2012b; Howard et al. 2013; Al Sayah et al. 2014). This is despite healthcare providers reporting that they use plain language (Howard et al. 2013). Schwartzberg et al. (2007) conducted a survey with 307 healthcare providers exploring their self-reported use of communication techniques with patients with lower health literacy. The results demonstrated the most commonly reported communication techniques were more basic in nature: using simplified language, administering printed materials and speaking more slowly. Less commonly used strategies, which are currently recommended by health literacy experts (Protheroe et al. 2009; Royal College of General Practitioners 2014), included strategies to assess patients' understanding, such as the 'teach-back' technique where the patient is asked to explain what they have been taught in their own words (Paasche-Orlow et al. 2005b; Kripalani et al. 2008). Schwartzberg et al.'s findings (2007) are also supported by several other studies (McCarthy et al. 2012a; Howard et al. 2013; Al Sayah et al. 2014; Vargas et al. 2014). Assessing patients' recall and comprehension has been shown to have positive health benefits, for instance a reduction in haemoglobin A1c levels in diabetic patients (Schillinger et al. 2003). Furthermore, ensuring a patient has understood the information provided is recommended by recent guidance in the UK (National Institute for Health and Care Excellence 2012). Tailoring communication to individuals' needs is beneficial: initially establishing patients' knowledge on a topic may assist with this (Kripalani and Weiss 2006; Royal College of General Practitioners 2014).

1.8.2 'Asset' based approaches to meeting older adults' health literacy needs in clinical practice

If health literacy is conceptualised as a dynamic asset within clinical practice, healthcare providers will need to go much further than tailoring communication to individuals' prior health literacy status and a shift away from the standard model of health education is needed. Nutbeam (2008) suggests that conceptualising health

literacy in this manner draws on adult learning principles and has clear implications for provision of healthcare education.

Pedagogy refers to the theory and practice of teaching individuals and is primarily focussed on the transmission of knowledge to learners, especially children (Knowles 1970). Within this teaching style, the teacher takes responsibility for the recipient's learning and knowledge and experiences are gained from the teacher's knowledge (Knowles 1970). A pedagogical approach to learning may be suited to meeting patients' functional health literacy needs or adopting a risk approach to health literacy; information is transferred from healthcare providers to patients and understanding is checked. This approach to education was criticised for adult learners, who did not respond well to this method of education, therefore Knowles (1970, p.42) developed the concept of andragogy, defined as a 'model of assumptions about learners'. In contrast to pedagogy, andragogy involves more proactive engagement from learners and aims to increase autonomy. This approach is clearly more suited to developing patients' interactive or critical health literacy abilities and conceptualising health literacy as a dynamic asset. Andragogy also focusses on experiential learning, drawing on adults' wide range of experiences to make learning more meaningful.

Neither pedagogy nor andragogy are aimed at older adults specifically. Speros (2009) suggests using principles of gerogogy when working with older adults. Gerogogy is based on Knowles' adult learning theory (1970), but takes into consideration older adults' specific education requirements. Speros (2009) proposes a number of educational strategies based on the principles of gerogogy including speaking clearly and slowly, limiting content, repetition of main points, using pictures, providing accessible written information, assessing understanding using the teach-back technique, allowing additional time for processing, using concrete terms, inviting family members to attend appointments and creating an open environment where the older adult can comfortably acknowledge areas they have not understood. Many of these recommendations focus on information provision (and thus seem to be more aligned with pedagogy), although it is also suggested to encourage older adults' participation and link learning to past experiences, aligning with andragogy. Most of the above principles appear to be more aligned with the risk based approach to health literacy and are not focussed

around developing interactive and critical health literacy abilities. These principles also do not consider the subtle differences which older adults may have in their learning styles and preferences. Giuse et al. (2012) revealed greater knowledge gains when information was tailored to both the participants' assessed functional health literacy level and preferred learning style preference as opposed to just their health literacy level. They used the VARK questionnaire, tailoring information based on whether the individual preferred to learn using visual, aural, reading/writing or kinaesthetic methods (Fleming and Baume 2006). Older adults may also prefer to learn by thinking (reflective learning), watching (observational/learning from others), doing (experiential learning), or by learning from other people's experiences (vicarious learning) (Kolb 1984; Bandura 2011). There are a wide range of different approaches to learning. However, to promote effective learning in older adults, it is necessary to ensure patient education is tailored to individuals' needs. Therefore, consideration of older adults' preferences in terms of learning approaches and whether healthcare providers deliver education according to pedagogical/andragogical/gerogogical principles and consider patients' learning styles is needed when aiming to develop health literacy abilities and/or when encouraging patients to participate more actively in their healthcare. These principles will be referred to throughout the thesis. However, the successful implementation of health literacy strategies (either risk or asset based) within clinical practice is dependent on many factors, which are described next.

1.8.3   Factors affecting the integration of health literacy into clinical practice

To integrate health literacy into clinical practice, Levasseur and Carrier (2012) suggest healthcare providers should be informed about and recognise health literacy, standardise their practice to accommodate the health literacy needs of their patients, make information accessible, interact optimally with clients, and intervene and collaborate to increase patients' health literacy. These suggestions appear to be congruent with both conceptualising health literacy as a risk and a dynamic asset. Possible influencing factors such as healthcare providers' knowledge, awareness, and perceptions of health literacy are considered in Chapter Two. As discussed earlier, the implementation of health literacy in clinical practice may also be influenced by how easily health literacy models transfer to

clinical practice. To address the health literacy needs of older patients, responsibility lies with all healthcare providers, guidance and policy makers and public health and education sectors (Parker 2000). To make meaningful and wide-spread change within clinical practice, health literacy needs to be recognised nationally and locally as a health policy priority. Stakeholders would need to be involved from all these areas (World Health Organization 2013). However, without health literacy being recognised in policies, it is unlikely that healthcare systems would incorporate health literacy training into mandatory schemes or that managers of clinical teams would ensure employees routinely consider health literacy. If health literacy is included in policies, healthcare providers would be held responsible for meeting patients' health literacy needs through audits and universities would be encouraged to include health literacy within the curricula for healthcare related degrees. To justify inclusion of health literacy (and specific strategies associated with it) within policies, there needs to be a strong evidence base (Peerson and Saunders 2009), justifying further research in the area.

1.9   Overview of the thesis

Having provided the background and rationale for this research, an outline of the remainder of the thesis is provided. Following this chapter, there are eight chapters:

Chapter Two comprises the literature review. Literature is explored and critiqued relating to meeting older adults' health literacy needs in clinical practice.

Chapter Three is the methodology chapter. The researcher's epistemological and ontological positions, use and quality of qualitative research and methodological approaches are discussed.

Chapters Four and **Five** detail the methods and findings from the first phase of the research respectively.

Chapter Six provides an overview about how the findings from the first phase of the research influenced and led to the development of the second phase of the research.

Chapters Seven and **Eight** outline methods and findings from the second phase of the research respectively.

Chapter Nine includes the discussion, implications of the findings for clinical practice, strengths and limitations of the research, future directions for the research and conclusion.

1.10   Summary

This chapter has introduced health literacy as an interconnecting but distinct concept from literacy. Health literacy has been defined as emerging from an interaction between individuals' skills and the demands of the healthcare system. This definition fits with the health literacy framework (which recognises health literacy as an asset which can be developed over time) (Nutbeam 2000) and model (which considers patient, healthcare provider and system factors which could affect health literacy outcomes) (Paasche-Orlow and Wolf 2007a) chosen for this research. Both risk and asset perspectives are considered in this thesis to assist with exploring the transferability of the concept to a UK healthcare context.

Justification was provided for focussing on an older adult population: there is an ageing population, increasing number of older adults with multiple and complex healthcare conditions, rising expectations for patients to take control of their own healthcare and a higher prevalence of low health literacy in older adults. By itself this has clear cost and healthcare provision implications, but it is also possible that meeting older adults' health literacy needs could assist with meeting the health literacy needs of a wider population. This chapter also demonstrated that healthcare providers are not always meeting older adults' health literacy needs in clinical practice; this may only be possible through changes in policy based on research evidence. Therefore, the present research focussing on exploring the facilitators and barriers to meeting older adults' health literacy needs in clinical practice is fundamental. The following chapter explores and critiques research in the area.

Chapter 2: Literature review

2.1   Introduction

This chapter presents and critically reviews research evidence surrounding health literacy and older adults, including how health literacy needs can be met in clinical practice. Initially, the aims and methods of the search strategy for the literature review are outlined. Following are three key sections: literature is reviewed in relation to older adults' health literacy views and experiences, the suitability of using health literacy screening or 'universal precautions' with older adults in clinical practice and healthcare provider factors affecting the implementation of health literacy strategies within clinical practice. The chapter concludes with a summary of the literature review and the research aims and objectives are outlined.

2.2   Aims of the literature review

- To examine and critically review research relating to older adults' health literacy views and experiences, considering the influence of sensory impairments, assessed health literacy levels/other proxy indicators and social support.
- To explore and critique research about using health literacy screening or universal precautions with older adults in clinical practice.
- To critically review research relating to healthcare provider factors affecting the implementation of health literacy strategies in clinical practice, with a particular focus on perceptions about, awareness and understanding of health literacy.
- To review the literature identified in terms of whether it applies to a UK healthcare context.

2.3   Search strategy

To fulfil the aims of the literature review, three separate but overlapping searches were undertaken, aiming to answer the following questions:

- What are older adults' health literacy views and experiences?
- Is the use of health literacy screening tools or universal precautions suitable with an older adult population in clinical practice?
- What healthcare provider factors could affect the implementation of health literacy strategies in clinical practice?

The details of the searches are included in full in Appendix C, including the databases and search terms used, dates of searches, and number of papers identified and included within the final review. A flow diagram (Appendix D) provides an overview of the literature searched. The following databases were utilised to search for literature with justification (Table 1):

Electronic Database	Justification
MEDLINE	- Includes life sciences literature.
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	- Includes Nursing and Allied Health literature.
PsycInfo	- Includes psychology articles.

Table 1   Electronic databases searched with justification

A mixture of thesaurus terms and keywords were developed in the search. Additional keywords were included by exploring relevant systematic reviews following preliminary searches (DeWalt et al. 2004; Berkman et al. 2011). Full details of search terms used are included within Appendix C. Additionally, relevant papers identified by colleagues and cited in other papers were incorporated in the review. The general inclusion and exclusion criteria for literature are detailed in Table 2.

Inclusion criteria	Rationale	Exclusion criteria	Rationale
Material published in the last ten years (2005-2015).	Relevant and current literature.	Not written in English language.	Difficulties analysing and may not be accurately translated.
All research methodologies which answer the literature review questions.	All study designs potentially applicable.	Papers focussing on health literacy of children, or parents of children, or pregnant women.	Not relevant to the area of health literacy and older adults. Different health literacy needs.
Papers which include older adults, but are not specifically focussed around older adults.	Very little research identified which focusses specifically on older adults and health literacy.	Papers focusing on dental health literacy or mental health literacy, defined as 'knowledge and beliefs about mental disorders which aid their recognition, management or prevention' (Jorm 1997, p.182).	Dental health services are separate from healthcare services and the present research is focussed on physical health, not mental health.

Table 2   Inclusion and exclusion criteria for literature review

To critique the evidence, the Critical Appraisal Skills Programme (CASP) tools (2012) were used. These tools were chosen since a range of checklists for different research methods are provided. Critical appraisal tools provide researchers with a structured framework to critically evaluate the quality of published research evidence, enabling the researcher to be more explicit about their judgements (Dixon-Woods et al. 2007). Given that this literature review was not intended to be a systematic review, research papers which made insightful contributions to the field, but had methodological limitations were included (Katrak et al. 2004).

2.4 Part One: Older adults' health literacy views and experiences

Older adults are more likely to have low health literacy and may experience physical and psychological barriers when accessing health information (Section 1.7). The following sections describe and critique the papers revealed from the literature review which explore older adults' views about and experiences of accessing, understanding and using health information. Given the large amount of papers examining health literacy prevalence and the associations between health literacy and health outcomes (Sections 1.5; 1.7), it is essential to explore patients' perceptions to develop evidence-based health literacy interventions (Corrigan et al. 2006). Very few research papers were identified examining older adults' health literacy perceptions, therefore papers are included which do not specifically focus on older adults' experiences, but have included older adults in the sample.

2.4.1 Older adults' health literacy experiences and the influence of sensory impairments

Older adults may experience difficulties accessing, understanding and using health information due to hearing and visual impairments (Section 1.7). Sensory impairments could be mistaken for poor understanding, resulting in false identification of low health literacy, and may cause a barrier to older adults' health literacy at the functional, interactive and critical levels. As a result, these impairments are considered within the review as an issue particularly relevant for older adults accessing, understanding and using health information. However, the present research does not focus specifically on sensory impairments, but instead considers these factors as possible barriers to health literacy. Chapter One highlighted that cognitive impairment can also be a barrier for older adults accessing health information, but research exploring this area in the context of health literacy experiences was not revealed through the literature review.

Several studies were identified that qualitatively explored the health literacy experiences of patients with sensory impairments (Harrison et al. 2010; Harrison et al. 2012; Napier and Kidd 2013). These studies revealed some important findings. Napier and Kidd (2013) revealed that few participants (deaf individuals

who use Auslan – Australian sign language) felt confident in their English literacy and experienced substantial barriers to accessing health information as a result, exacerbated by information not being provided in Auslan. Similarly, participants with visual impairments in Harrison et al.'s studies (2010; 2012) reported barriers to accessing health information which the participants attributed to how healthcare systems managed their visual impairments, such as being treated as incapable of self-management; information not being provided in alternative formats; healthcare providers not offering them help with filling out forms and violating their privacy by reading out forms in the presence of others and not having the time to support them. Individuals with lower literacy have also reported difficulties filling out forms and having to ask for help with this (Baker et al. 1996), indicating that individuals with either low health literacy, or sensory impairments, or both, may experience some similar barriers to accessing health information.

Despite the important findings which have implications for meeting older adults' sensory and health literacy needs (due to the additional barriers), there are a number of limitations to the studies. Both Harrison et al. studies (2010; 2012) were conducted in the US and Napier and Kidd (2013) in Australia. However, the focus was not on older adults in any of these studies: in Napier and Kidd (2013), only 19/72 participants were over the age of 65; Harrison et al. (2010) interviewed individuals aged 44-79, but did not report the mean or standard deviation when describing the sample and Harrison et al. (2012) interviewed individuals aged 40-88 (mean 61). Findings may be more transferable to an older adult population than the previous Harrison et al. study (2010) as a result of this age range, but none of these studies considered any differences in findings by age. Furthermore, Napier and Kidd (2013) focussed on the experiences of deaf individuals who use Auslan (Australian sign language) and Harrison et al. (2010; 2012) explored the experiences of blind individuals. Very few participants had other disabilities in Napier and Kidd (2013) and all of these studies primarily included females: Harrison et al. (2010) focussed entirely on women's experiences; only 11% of participants were male in Harrison et al.'s study (2012) and only 37.5% of participants were male in Napier and Kidd's (2013) study. Therefore, the findings in these studies may not be transferable to male populations, or older adults with mild or moderate visual and hearing impairments, or other disabilities, in the UK.

Health literacy was not assessed in any of the above studies and participants had high education levels: 13/15 participants were educated to a degree level in Harrison et al. (2010); 73% had a college degree in Harrison et al. (2012) and this was not reported in Napier and Kidd (2013). As such, it is possible that the participants had higher health literacy levels and findings may not be transferable to individuals with lower health literacy levels. This is further evidenced by the participants in Harrison et al. (2010; 2012) having higher access to healthcare and tending to identify a preference for high levels of information and participation in their healthcare. Previous research has indicated that individuals with higher health literacy are more likely to actively participate in patient-provider interactions (Ishikawa and Yano 2011).

This section has revealed important barriers (these may be similar for individuals with low health literacy) which individuals with visual and hearing impairments may experience when accessing, understanding and using health information. However, the participants were predominantly highly educated and health literacy levels were not measured. Contrastingly, whilst the present research does not focus specifically on sensory impairments, the methods used ensure individuals with lower assessed health literacy are included within the sample.

2.4.2 Older adults' health literacy experiences as differentiated by their assessed health literacy levels or socioeconomic status

One large qualitative study was identified (Baker et al. 1996) which explored the experiences of participants with low functional literacy levels, as assessed by the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al. 1991). This study was published 20 years ago; therefore findings may no longer be relevant. However, the research has been widely cited and has revealed some important findings: participants reported feeling 'tremendous shame' about their literacy difficulties, with few informing their healthcare providers about this. This finding was corroborated by Easton et al. (2013) who qualitatively explored the views of adults with low functional literacy. Participants in Easton et al.'s (2013) study were recruited from a UK adult learning centre; findings may be more transferable to a UK population. However, in contrast to Baker et al.'s (1996) study, health literacy was not assessed, and no older adults were included in this study. No information

was reported on the age or gender of the sample in Baker et al. (1996); it is impossible to ascertain whether the findings are relevant for an older adult population. Participants in both studies reported difficulties with written communication and felt things were not always explained to them in a way which they can understand. These findings provide evidence that it may be helpful to consider health literacy as an interaction between patients' abilities and the demands of the healthcare system (Section 1.4). They also suggest care should be taken when conducting research with participants who have low literacy levels, an area the researcher endeavours to address in the methods for this research.

Despite Baker et al.'s (1996) useful contributions, there are some limitations which need to be considered, especially in relation to reporting of the research. The authors did not justify the use of interviews or focus groups, or the decision to use them in conjunction. Further, little detail was provided about what questions were included within an interview schedule/topic guide and the analysis methods. The data appears to have been analysed deductively. As such, the researchers may not have been able to explore the participants' experiences in such an in-depth and explorative manner as other qualitative analysis methods allow (Pope and Mays 2006). Given the lack of adequate reporting of this research, it is difficult to ascertain the transferability of the findings. As discussed in the next chapter, the researcher aims to be transparent about methodological decisions to enhance trustworthiness and the researcher's epistemological position aligns with more explorative approaches and inductive analyses.

Baker et al.'s (1996) and Easton et al.'s research (2013) focussed entirely on the experiences of patients with low functional literacy, and concentrated on the impact of literacy issues on healthcare experiences and not health literacy issues. Given the earlier assertion about highly literate individuals not necessarily being health literate, the present research includes individuals with higher health literacy and research in this area is considered next. Other studies have sought to qualitatively compare patients' views and health literacy preferences according to their assessed health literacy levels (Shaw et al. 2009; Gaglio et al. 2012). Shaw et al. (2009) assessed participants' health literacy using the Rapid Estimate of Adult Literacy in Medicine (REALM) and Gaglio et al. (2012) used the Test of Functional Health Literacy in Adults (TOFHLA). Both were part of larger

quantitative studies. The majority of the sample had adequate health literacy in both Shaw et al.'s (2009) and Gaglio et al.'s (2012) studies (77.6% and 85.9% respectively). This is problematic when the authors are making comparisons between the groups, but this may be indicative of the number of adults in the population with low functional health literacy levels (Paasche-Orlow et al. 2005a). Furthermore, the use of a functional health literacy measure may mean the findings do not apply to individuals with high interactive or critical health literacy levels. Neither studies were focussed on older adult populations: the mean age of Shaw et al.'s sample was 64 years and Gaglio et al.'s was 57.8; the age range is not reported in either study. Findings may be more relevant for an older adult population in Shaw et al.'s study due to the higher mean. However, findings are not differentiated by age in either study. Furthermore, individuals with sensory impairments were excluded from participating in both studies. Therefore, the findings may not accurately represent the views of older adults with visual and hearing impairments.

Despite Shaw et al. (2009) being conducted in the UK and Gaglio et al. (2012) being carried out in the US, these studies revealed similar findings: participants identified a preference for face-to-face interactions and simple and clear written and verbal healthcare information regardless of their assessed health literacy levels. The authors also discussed how both individuals with low and adequate health literacy found health information worrying or confusing. These findings are noteworthy when many health literacy experts recommend the use of universal precautions to communication (Section 1.8.1). Additionally, although these studies did not focus on older adults, older adults were included, and other research has revealed that older adults have a preference for healthcare providers communicating clearly and openly whilst also considering individual preferences for information and participation (Bastiaens et al. 2007). Face-to-face interactions were emphasised by participants in Shaw et al.'s (2009) and Gaglio et al.'s (2012) studies due to the ability to ask questions; feeling comfortable during these interactions was also an important facilitating factor for this.

The above two studies' environments and procedures could have influenced the findings. Shaw et al. (2009) conducted the interviews at hospital bedsides and wrote responses contemporaneously: participants may not have felt comfortable

due to privacy issues, and responses may not have been recorded accurately or in sufficient depth. Participants in Gaglio et al.'s (2012) study needed to travel to the research site; this may have deterred older adults or individuals with low literacy, possibly partially explaining the high proportion of individuals with high functional health literacy levels in this study. Individuals with low literacy may find it difficult to navigate to research sites and older adults are often deterred from participating in research due to time burdens and lack of transportation (Paasche-Orlow and Wolf 2007a; Shearer et al. 2010). As discussed in subsequent chapters, the researcher aims to address these shortcomings by recording interviews and conducting research in alternative convenient locations.

Both studies had a large sample size: Shaw et al. (2009) qualitatively interviewed 321 participants and Gaglio et al. (2012) completed a survey with 150 participants, and combined these findings with 28 qualitative interviews. Although Gaglio et al. reported using open-ended questions for their qualitative component, it is not clear which findings derived from the survey and which resulted from the in-depth interviews, and whether there was any difference between the two. The large sample sizes in both studies may increase the transferability of the findings. However, the structured nature of the questions in Shaw et al.'s study may have limited the spontaneity and depth of participants' answers. The researcher believes much can be learnt through in-depth exploration of individuals' experiences and seeks to address this by using more explorative qualitative methods, guided by an alternative paradigm, as discussed in the following chapter.

All of the studies discussed in this section thus far appear to consider health literacy from a 'risk' perspective and focus primarily on a narrow definition of health literacy involving functional health literacy. Contrastingly, in alignment with the researcher's conceptualisation of health literacy, several qualitative studies appear to have conceptualised health literacy as an 'asset' which can be developed over time (Edwards et al. 2012; Protheroe et al. 2012; Edwards et al. 2015). However, as with the aforementioned studies, none of these studies focussed on older adults or assessed participants' health literacy levels, justifying the need for further research specifically centred on this area. Despite this, in Protheroe et al.'s study (2012), 71% of the participants were aged 65 or over and socioeconomic status was used as a proxy indicator for health literacy; findings were compared between

participants with lower and higher socioeconomic status. A small majority of the sample had lower socioeconomic status in Protheroe et al.'s study (19/35 participants). Although socioeconomic status is associated with lower health literacy levels (Bostock and Steptoe 2012), it may not always accurately predict this, and therefore findings may not represent the views of patients with lower and adequate health literacy levels. In Edwards et al. (2012; 2015), the participants were recruited from education and self-management programmes and had primarily obtained high levels of educational qualifications; the sample is likely to have included predominantly individuals with higher levels of literacy. Additionally, only six of the participants interviewed were over 65 years old, making the findings potentially less relevant for older adult populations.

Protheroe et al.'s (2012) findings revealed differences in participation preferences between the two groups (lower and higher socioeconomic status): participants with lower socioeconomic status perceived their patient role as passive and expressed no desire to ask questions, whilst participants with higher socioeconomic status reported seeking health information from a range of sources and using their knowledge to participate in health-related decisions. Use of simple and clear communication appeared to be a facilitator for participation through increasing knowledge and understanding. Edwards et al. (2012; 2015) suggest patients' participation preferences are dependent on adequate health literacy, develop over time and are influenced by social support. None of these studies used a health literacy measure (an area addressed in the present research). However, another qualitative study, where health literacy measures were used, corroborates these findings: in Melton et al.'s study (2014), participants with higher assessed functional health literacy felt more responsible for obtaining and bringing information to their doctors, reported taking ownership of their condition, and treated the patient-provider relationship as a partnership. However, although appropriate when using interpretative phenomenological analysis (IPA) methodology (Smith et al. 2009a), the study's small sample size of four participants limits transferability of the findings. Additionally, only one participant was over the age of 65 and the participants were all African American women with asthma, therefore findings may not be transferable to men or to an older adult population in the UK with different health conditions. Despite the limitations, this was the only study revealed which used IPA methodology; the paper includes rich

description and the use of methodology (with a focus on the individual) has provided useful insights. This suggests more research using an in-depth explorative methodology would be beneficial, as discussed in further depth in the next chapter. However, the authors may have put too much emphasis on assessed health literacy scores. Given the possible issues with health literacy screening tools (discussed later in this chapter), the researcher aims not to focus entirely on these scores when analysing the data.

The findings in the studies above have not been explicitly linked to the functional, interactive and critical health literacy framework. However, they appear to have implications for developing patients' interactive and critical health literacy levels. Many of the facilitators and barriers to understanding health information revealed through the studies above related to interactions with healthcare providers, therefore all of the above studies provide further rationale for exploring how the interactions between healthcare providers and patients can inhibit or enhance health literacy. Despite the identified limitations, there is limited research exploring health literacy from an asset perspective. As a result, findings from these research studies provide valuable contributions to the knowledge base and suggest further research from an asset perspective would be beneficial.

In addition to papers exploring and comparing health literacy experiences, several research studies have also qualitatively explored the meaning of health literacy to patients (Jordan et al. 2010; Salter et al. 2014). Salter et al. (2014) explored the views of older adults in relation to this, and revealed that participants viewed health literacy as emerging as a result of 'good two-way communication'. Although it is unclear in Jordan et al.'s study (2010) how many older adults participated, and the focus was not specifically on older adults, similar findings emerged relating to health literacy resulting from the interaction between individuals' abilities and the demands of the healthcare system. Additionally, participants in Salter et al.'s (2014) study, many of whom had become expert patients over the years according to the authors, expressed frustration that the healthcare system expected them to rise to the demands, rather than adapting to meet their needs. Health literacy was not assessed in either of these studies, and most of the sample in Jordan et al.'s study (2010) had high levels of education, therefore the findings may not pertain to individuals with low health literacy. Jordan et al. (2010) obtained a large sample in

their study (48 participants), thus increasing the transferability of the findings. Despite this, a small sample size may have transferability if a rich description of findings is provided and the reader believes the situation to be similar to their own; views about assessing the quality of qualitative research are explored in the next chapter. Additionally, Jordan et al. (2010) used structured interviews which may have limited the spontaneity and depth of participants' responses and subsequent analysis (Rubin and Rubin 2012). Contrastingly, Salter et al. (2014) used open-ended questions and a flexible topic guide, but it is possible that their use of focus groups may have deterred low literate individuals from taking part due to shame associated with low literacy (Baker et al. 1996; Parikh et al. 1996; Wolf et al. 2007). Both of these limitations are addressed in the present research; as discussed in later chapters, in-depth semi-structured interview methods were chosen in preference to focus groups.

2.4.3 Older adults' health literacy experiences and the influence of social support

The sections above have revealed the importance of considering health literacy as an interaction between individuals' abilities and the demands of the healthcare system. However, health literacy is often viewed as an individual phenomenon (Section 1.4). Therefore, patients' use of social support and resources may not always be considered (Lee et al. 2004). Social support has been defined as the 'functional content of relationships' (Glanz et al. 2008, p.190) which can be categorised into four types of supportive behaviours: emotional support (empathy, love, trust and caring), instrumental support (tangible aid), informational support (advice, suggestions and information provision) and appraisal support (information useful for self-evaluation) (House 1981).

Older adults often have complex needs (Section 1.7): carers, spouses, family members and friends may be crucial in supporting them to access, understand and use health information. Older adults with low health literacy may have support with reading or filling out forms, taking medication, understanding medical information, making healthy choices and negotiating the healthcare system (Lee et al. 2004; Lee et al. 2006). It has been suggested that social support may mitigate the risks of low health literacy and reduce health service utilisation costs (Lee et al.

2004; Reeves et al. 2014). However, contrary to their hypothesis, Lee et al. (2009) subsequently revealed that social support was positively associated with health status in a high health literacy group, but not the low health literacy group. They suggest this could be due to the level of social support being inadequate in the low health literacy group. Paasche-Orlow and Wolf (2007a) suggest that the relationship between social support and health literacy is complicated given that individuals with low educational attainment are likely to be supported by people with a similar educational background. It may be necessary for healthcare providers to assess or consider the health literacy level of both the patient and their contributing social support network. Carers tend to have higher health literacy levels than the older adults they care for (Garcia et al. 2013; Levin et al. 2014). However, both of these studies had relatively small sample sizes: Garcia et al. (2013) and Levin et al. (2014) included 174 and 17 carer-patient dyads respectively. Therefore, these studies may have been underpowered and findings may not be generalisable to a larger population.

Very little qualitative research was revealed exploring health literacy and social support. However, one qualitative study revealed that health literacy is distributed through individuals' social support networks (Edwards et al. 2015). For instance, participants drew upon the health literacy skills and abilities of others to assist them to access, understand and use health information. They also acted as 'health literacy mediators' by passing their skills onto others. However, the health literacy of the participants was not formally assessed and participants were selected from education programmes; they therefore may have had high baseline literacy levels. In addition to considering patients' abilities and their own communication practices, healthcare providers should consider older adults' social support and how this can effectively be used to meet their health literacy needs. However, there are individuals who have low health literacy and lack social support; these individuals are in particular need of health and social care provider attention and support (Lee et al. 2004). Given that the focus of the present research is on health literacy more broadly, social support is considered as a possible contributing factor when patients are accessing health information. However, the focus is primarily on health literacy and social support is considered as an interrelated but distinct concept.

2.5 Part Two: Suitability of using health literacy screening tools or universal precautions with an older adult population in clinical practice

Part One revealed the significance of the interactions older adults have with their healthcare providers; it remains important to explore how healthcare providers can meet older adults' health literacy needs. This section describes two commonly recommended health literacy strategies: health literacy measurement and universal precautions (Section 1.8.1). These two different approaches are focussed on because there is disagreement regarding which strategy should be used, with some authors strongly arguing for health literacy measurement, whilst others suggest that universal precautions may be more appropriate when health literacy screening could cause shame and lacks sufficient evidence (Baker 2006; Paasche-Orlow and Wolf 2007b).

2.5.1 Suitability of using health literacy screening tools with an older adult population in clinical practice

Health literacy measurement tools can be broadly categorised as tools which directly measure individuals' abilities and self-report measures. Jordan et al. (2011) suggest that it is difficult to compare health literacy at individual and population levels resulting from the variety of different health literacy measurement tools available. Jordan et al. (2011) identified and evaluated 19 health literacy measurement tools and Haun et al. (2014) assessed 51 tools, indicating the wide range of tools to choose from. The focus of this review is on tools which have been developed in the UK or validated for UK populations; are viewed as tools which can be used in clinical practice in general healthcare and are widely used. The critique is centred on the suitability of using these tools with an older adult population in clinical practice. Table 3 provides an overview of these health literacy measurement tools.

Measure of health literacy	Objective / self-report measure	Description of tool	Country of origin	Validated in a UK population	Scoring	Health literacy dimensions measured	Administration time	Measures functional /interactive /critical health literacy
Rapid Estimate of Adult Literacy in Medicine (REALM) and short forms (Davis et al. 1991; Davis et al. 1993)	Objective	List of medical words; scored on the individual's ability to pronounce these words correctly. Administered by a researcher/healthcare provider.	US	Yes (Ibrahim et al. 2008)	Sum score (0-66) which gives a grade level (<3rd grade; 4th-6th grade; 7-8th grade or high school)	Literacy (Haun et al. 2014)	2-3 minutes (Haun et al. 2014)	Functional health literacy
Test of Functional Health Literacy in Adults (TOFHLA) and short forms, e.g. S-TOFHLA (Parker et al. 1995)	Objective	Assesses literacy, comprehension and numerical abilities using 'Cloze-style' questions, where the person replaces missing words from a text. Administered by a researcher or healthcare provider.	US	Yes (von Wagner et al. 2007)	Sum score; categorised as adequate, inadequate or marginal health literacy	Literacy, comprehension, numeracy and evaluation (Haun et al. 2014)	18-22 minutes; 7 minutes for short form (Haun et al. 2014)	Functional health literacy

Measure of health literacy	Objective / self-report measure	Description of tool	Country of origin	Validated in a UK population	Scoring	Health literacy dimensions measured	Administration time	Measures functional /interactive /critical health literacy
Newest Vital Sign (NVS) (Weiss et al. 2005)	Objective	Six questions asked relating to a nutritional ice cream container label. Administered orally; also considers memory and listening abilities.	US	Yes (Rowlands et al. 2013)	Sum score (0-6); categorised as high likelihood of limited literacy (0-1); possibility of limited literacy (2-3) and adequate literacy (4-6)	Literacy, comprehension, numeracy and application (Haun et al. 2014)	5 minutes (Haun et al. 2014)	Functional health literacy
Single screening question (SSQ) (Chew et al. 2008)	Self-report	Single survey item: 'How confident are you filling out medical forms by yourself?'	US	No, but validated in the US (Chew et al. 2008)	Likert scale from 0-4. Higher scores indicate greater problems with reading	Literacy and confidence	Not reported, but developed as a brief measure.	Functional health literacy

Measure of health literacy	Objective / self-report measure	Description of tool	Country of origin	Validated in a UK population	Scoring	Health literacy dimensions measured	Administration time	Measures functional /interactive /critical health literacy
The All Aspects of Health Literacy Scale (AAHLS) (Chinn and McCarthy 2013)	Self-report	Survey questions which measure functional, interactive and critical health literacy levels.	UK	No, but developed in the UK for primary healthcare settings (Chinn and McCarthy 2013)	Sum score	Literacy, interaction, comprehension, information seeking and evaluation (Haun et al. 2014).	7 minutes (Haun et al. 2014).	Functional, interactive and critical health literacy
The Health Literacy Questionnaire (HLQ) (Osborne et al. 2013)	Self-report	44 survey questions with 9 scales.	Australia	No	Independent scales measuring nine competencies for health literacy	Interaction, comprehension, information seeking, application and decision-making (Haun et al. 2014)	5-15 minutes (Haun et al. 2014).	Content items pertain to functional, interactive and critical health literacy levels

Table 3   Overview of health literacy measurement tools

Individuals with low literacy or health literacy may feel shameful about this; they may not disclose their difficulties to family or healthcare providers and may go to significant lengths to hide their difficulties (Baker et al. 1996; Parikh et al. 1996; Parker 2000; Easton et al. 2013). Healthcare providers also frequently overestimate their patients' health literacy (Bass et al. 2002; Seligman et al. 2005; Ensrud et al. 2007; Dickens et al. 2013). As a result, it may be important for healthcare providers to identify their patients' health literacy levels. However, the table above reveals issues which could cause practical barriers to the implementation of these tools in clinical practice: some of the measures (including the HLQ, AAHLS and TOFHLA) are lengthy to administer which may make them impractical in busy clinical settings.

The potential to cause harm through health literacy screening necessitates discussion. Wolf et al. (2007) assessed participants' health literacy using the REALM and sought their perceptions about this: whilst a majority of participants were willing to have their reading difficulties documented in medical records, 22.6% reported documentation of this would make them feel shameful or embarrassed. Similarly, Vietnamese participants completing the TOFHLA in one qualitative research study were observed to be hostile to completing the test, perceived themselves as 'too old', and one participant became upset when she did not understand the questions (Shaw et al. 2012), which is important when the present research focusses on older adults. The health literacy measures were translated into Vietnamese, but have not been validated with this culture or language. Predominantly, health literacy measurement tools are administered in English, thus they do not distinguish between language difficulties or cultural differences.

Contrastingly, several studies have revealed that most participants feel comfortable with health literacy screening and do not feel shameful (Vangeest et al. 2010; Ferguson et al. 2011). However, research participants voluntarily taking part in a study which involves assessing health literacy may be less likely to feel anxious about health literacy measurement. In Ferguson et al.'s (2011) study which assessed the acceptability of the REALM and TOFHLA, the majority of participants were over 60 years of age (53%), making the results more relevant for an older adult population. In contrast, in Vangeest et al.'s study (2011) which

evaluated the NVS, the mean age of the sample was 44 and a majority of the sample had adequate health literacy according to the NVS (63.4%); results may not apply to an older UK sample with low health literacy. Despite this, more than 99% reported screening did not cause them to feel shameful, and more than 95% of patients did not have problems with screening for health literacy within a primary care setting. In contrast, 33% of participants in Ferguson et al.'s (2011) study felt use of these tests in clinical practice would make people feel uncomfortable; the level of discomfort was not assessed and few participants in this study had particularly low literacy levels (22/150 participants scored as sixth grade or less when assessed with the REALM). The percentage of participants reporting feelings of shame in Wolf et al.'s study (2007) was greater for individuals with lower literacy; results may have differed in Ferguson et al.'s (2011) and Vangeest et al.'s (2010) studies if a greater proportion of participants had lower literacy levels. However, Vangeest et al. (2010) suggested that differences in perceptions of health literacy screening may be dependent on the measures used, which may be relevant when different health literacy measures were used in the studies described above.

All of the studies described above were exploring participants' views of health literacy screening tools used for research purposes and therefore may not relate to naturally occurring clinical settings where perceptions may differ. For instance, participants may be more amenable to health literacy screening tools when they have agreed to partake in a study assessing perceptions of these tools. However, when routine health literacy screening (using the NVS) was implemented in a breast surgery clinic in the United States, no patients refused assessment and increases in overall patient satisfaction with the clinic appointments were seen (Komenaka et al. 2013). Although this research was conducted in a naturally occurring clinical setting, satisfaction with health literacy measurement was not specifically measured, the sample was primarily younger women and individuals with visual impairments were excluded. Participants in other studies have emphasised the importance of feeling comfortable with their healthcare providers (Shaw et al. 2009), and it is possible that health literacy screening could have an impact (positive or negative) on the patient-provider relationship, but this is not known. Authors who support the use of self-report health literacy measures (as opposed to objective measures) argue they have the potential to be less

stigmatising or anxiety-inducing (Chew et al. 2008; Haun et al. 2009).
Contrastingly, other authors speculate about whether personal admission of
literacy issues, when using self-report measures, could be more stigmatising than
objective measures (Chinn and McCarthy 2013).

Through this review, no measure was identified which takes into consideration the
specific difficulties an older adult may have, such as memory, visual and hearing
impairments. When validating health literacy screening tools in a UK population
(REALM, TOFHLA and NVS), older adults, and/or individuals with cognitive or
sensory impairments have often been excluded (von Wagner et al. 2007; Ibrahim
et al. 2008; Rowlands et al. 2013). However, if used routinely in clinical practice,
individuals with cognitive and sensory impairments would presumably also be
screened. Therefore, in an older adult population, it is possible that health literacy
screening tools could confound health literacy with memory and sensory
impairments. For instance, the REALM, TOFHLA and NVS require the patient to
read text, which they may be unable to do due to memory or visual impairments.
Further, the questions in the NVS are administered orally, which may pose
difficulties for older adults with hearing and memory impairments. Older adults with
poor vision are at a greater risk of having low health literacy levels when assessed
using the REALM and Single Item Literacy Screener (SILS) (Press et al. 2013).
This may be because the REALM and SILS assess reading ability. One study
compared the performance of commonly used health literacy screening tools
(REALM, TOFHLA and NVS) in an older adult population and found that a large
percentage of older adults were unable to complete all of the measures (Kirk et al.
2011). Many older adults with visual impairments may use different strategies to
access health information (Harrison et al. 2012), which healthcare providers may
not take into consideration when tailoring information based on measures of
functional health literacy. This issue is also relevant for the self-report measures of
health literacy (inclusive of those measuring interactive and critical health literacy);
if an individual has a hearing or visual impairment, this may affect their score
depending on whether the self-report measure is interviewer or self-administered.
Patients may also answer the questions with the sensory impairment in mind.

Some of the tools described in Table 3 may only provide limited information to
healthcare providers due to focussing on a narrow definition of health literacy

(REALM, TOFHLA, NVS and SSQ). If healthcare providers assess patients' health literacy using a functional health literacy measure, they may only tailor healthcare information to patients' functional health literacy abilities. However, screening also has implications for time spent tailoring information to patients' needs: it may be less time-consuming to tailor information to patients based on functional health literacy measures, than when trying to adopt a more comprehensive measure, but this is not known. Although associative relationships have been identified between low health literacy levels and poor health outcomes (Sections 1.5; 1.7), it would be redundant to use health literacy screening tools unless implementation of such tools improved healthcare providers' communication. Seligman et al. (2005) completed a randomised controlled trial where physicians were either notified of their patients' health literacy levels or not: physicians who were notified of their patients' health literacy levels were more likely to use recommended health literacy strategies, but less satisfied with their visits and perceived themselves to be less effective. Furthermore, only 64% of intervention physicians felt health literacy screening was useful, in comparison to 96% of patients, indicating a possible barrier to routine implementation in clinical practice. It is not clear why the physicians felt less satisfied and effective; this could be due to many reasons, for instance feelings of discomfort related to screening, lack of training or a heightened awareness of health literacy issues, resulting in self-criticism.

Most research revealed exploring perceptions about health literacy screening was quantitative and derived from a positivist paradigm, suggesting more in-depth qualitative exploration may be necessary. Little is known about healthcare providers' perceptions regarding health literacy screening, suggesting that this area benefits from further exploration in the present research.

2.5.2   Universal precautions as an alternative to health literacy screening

There is uncertainty regarding whether it would be more beneficial to use health literacy screening to identify vulnerable individuals or to reduce the demands of the healthcare system for all by applying universal precautions (Section 1.8.1). Baker (2006) argued that the effectiveness of health literacy screening would be limited without more comprehensive and accurate tools and healthcare provider training. He suggested that improved communication and use of universal

precautions may render health literacy screening redundant. Additionally, Paasche-Orlow and Wolf (2007b) argue there is not enough evidence to support health literacy screening in clinical practice. One argument for using universal precautions as opposed to health literacy screening is to avoid patient discomfort which may be associated with measurement. However, there is little research which explores the acceptability of using universal precautions as an alternative.

Several papers critiqued in Section 2.4 revealed that patients prefer clear communication, regardless of their assessed health literacy levels (Shaw et al. 2009; Gaglio et al. 2012). Otal et al. (2012) developed 'plain language' materials, written at sixth grade reading level - as recommended when developing easy-to-understand materials (Brega et al. 2015). They found that participating parents, including those with low and adequate health literacy levels, were satisfied with the information. However, this study did not include older adults or compare the patient information to higher reading level material. Contrastingly, Sudore et al. (2007) conducted a randomised controlled trial where they compared a standard advance directive form (more than twelfth grade level – UK equivalent is year thirteen at school and 17-18 years old) to information redesigned to meet most adults' literacy needs (sixth grade level with pictures – UK equivalent is year seven at school and 11-12 years old). The redesigned form was rated higher for acceptability and usefulness by the participants (aged 50 and over).

Before routinely implementing either health literacy screening or universal precautions, more research is needed to ascertain the acceptability and practicalities of using either approach from both patients' and healthcare providers' perspectives, something which is explored within the present research.

2.6 Part Three: Healthcare provider factors affecting the implementation of health literacy strategies in clinical practice

2.6.1 Healthcare providers' awareness and understanding of health literacy

To meet older adults' health literacy needs, healthcare providers need to have an awareness of health literacy. Knowledge of health literacy and use of health literacy strategies have been found to be low in healthcare providers in other studies. For instance, healthcare providers have low knowledge levels about the impact of health literacy on the healthcare system (Jukkala et al. 2009; Atcherson et al. 2013). Devraj and Gupchup (2003) used a survey to assess the health literacy knowledge of pharmacists in the US. Pharmacists had low knowledge levels about the concept of health literacy and the prevalence of individuals with low health literacy. Several other survey studies have focussed on nurses' health literacy knowledge and also revealed low health literacy knowledge levels (Knight 2011; Macabasco-O'Connell and Fry-Bowers 2011; Cafiero 2013).

All of the above survey studies were conducted in the US and may not apply to other healthcare providers in different countries, who may have undertaken substantially different training. Additionally, given that much of the health literacy research has originated from the US (Nutbeam 2008; Berkman et al. 2011), it is possible that healthcare providers could have a higher awareness of health literacy than those in the UK. Furthermore, all of these studies used quantitative survey methods. Although this enabled the researchers to use relatively large samples, they were unable to explore why the healthcare providers' knowledge of health literacy was low and the impact that this has. Very few studies have qualitatively explored healthcare providers' perceptions and awareness regarding health literacy, something the present research aims to address. One study was identified using qualitative interviews to explore dietitians' engagement with health literacy in clinical practice (Wood and Gillis 2015). The dieticians in this study had an awareness of the term health literacy and conceptualised it using all three levels of health literacy (Nutbeam 2000). However, the sample of dieticians only consisted of nine Canadian dieticians. Therefore, the findings may not be

transferable to a UK population or to other healthcare providers. Similarly, in Sadeghi et al.'s study (2012), most of the healthcare providers (working in one pulmonary rehabilitation centre) had heard of health literacy through their workplace and the media. However, given that this study was conducted in only one setting in Canada, these findings may not be transferable to UK healthcare providers working in other contexts. Despite this, there was no mention in either of the above papers about healthcare providers conceptualising health literacy as an asset. Lambert et al. (2014) used interviews and focus groups to explore the perceptions of a diverse group of healthcare providers across three countries: New Zealand, Canada and Australia. They found the majority of the healthcare providers were unfamiliar with the term health literacy and conceptualised health literacy as relating to patients' individual abilities. Many did not view health literacy as an interaction between patients' abilities and the demands of the healthcare system (Section 1.4). However, this study was focussed around healthcare providers in different countries working with indigenous populations; findings may not be transferable to UK healthcare providers working with other patient populations.

Healthcare providers' low knowledge levels about health literacy may be as a result of limited training at both undergraduate and graduate level (Coleman 2011). Improvements in knowledge and intentions to use health literacy communication strategies have been observed where health literacy training has been provided (Mackert et al. 2011). None of the studies described above focussed on UK healthcare providers; more research is needed to explore this in the context of UK healthcare providers working with older adults, which the present research addresses.

2.6.2 Healthcare providers' perceptions about meeting older adults' health literacy needs

Identifying health literacy levels

One way of tailoring information to patients' health literacy levels is by using health literacy screening tools (Section 2.5.1). However, in addition to these tools requiring quick administration times and acceptance by patients, healthcare

providers also need to feel comfortable using them. Further, if used in clinical practice, health literacy screening tools need to result in healthcare being tailored to patients' abilities, which is something only healthcare providers could do. Therefore, the next section explores the available literature relating to healthcare providers' perceptions about identifying patients' health literacy levels and meeting their health literacy needs. Lack of knowledge about low health literacy, time restraints and a perception that 'good' screening tools are not available were identified as barriers to using health literacy screening in Macabasco-O'Connell's & Fry-Bower's survey study involving nurses (2011).

In several qualitative studies healthcare providers have dismissed using health literacy screening tools due to time, stigma related to literacy issues and concerns about causing offense or anxiety (Salter et al. 2014; Smith et al. 2014). Smith et al. (2014) interviewed 26 radiation oncologists in Australia, therefore this study was not focussed specifically on older adults and may not be transferable to a UK population. In contrast, Salter et al.'s study (2014) was focussed on UK healthcare providers working with older adults with musculoskeletal conditions. The corroborative nature of the findings in these studies increases the transferability to other settings. However, the issue of health literacy screening was not examined in great depth in either Salter et al.'s (2014) or Smith et al.'s (2014) study. For instance, in Salter et al.'s study (2014), they did not describe any specific health literacy tools within the focus groups, and health literacy screening was given only very brief attention within Smith et al.'s (2014) findings. Despite this, the concerns identified by the healthcare providers in both studies suggest that further exploration of the issue within the present research would be beneficial.

Instead of using health literacy screening tools, in both Smith et al.'s study (2014) and Salter et al.'s study (2014), the healthcare providers reported using subjective assessments and interpretations to form judgements about patients' health literacy levels. In Salter et al.'s study (2014), healthcare providers described 'gauging', but not directly asking about patients' understanding and need for information. They also cited embarrassment and stigma as possible barriers to identifying health literacy levels. The participants not only showed concern in asking about literacy, but also about understanding. Spending enough time with patients was considered to be the best method for identifying older adults' health literacy levels.

This section has revealed that there are a number of barriers to identifying older adult patients' health literacy levels, including an aversion to health literacy screening and concerns relating to asking patients about their literacy or understanding. As such, it is possible that healthcare providers are not correctly identifying patients' health literacy. Therefore, the next section explores healthcare providers' perceptions about meeting older adults' health literacy needs.

Facilitators and barriers to meeting older adults' health literacy needs identified by healthcare providers

A number of studies have explored healthcare providers' perceptions about the facilitators and barriers to meeting patients' health literacy needs. In addition to knowledge about health literacy, perceptions about the importance of addressing health literacy are likely to be influential for healthcare providers meeting patients' needs. Through their survey of nurses, Macabasco-O'Connell and Fry-Bowers (2011) revealed many participants felt implementing a health literacy programme for patients was a low priority (53%) and would be too expensive. Additionally, 53% of participants also felt health literacy was a low priority compared with other problems, thus causing barriers to implementing a health literacy training programme for healthcare providers. This study used a quantitative survey; it is difficult to ascertain why the nurses felt this way.

Several qualitative studies have also explored facilitators and barriers to meeting patients' needs. For instance, in Wood and Gillis' study (2015), the dieticians identified facilitators and barriers to health literacy, including complex and contradictory information, time restraints, language barriers, cultural differences and lack of organisational support to address health literacy. The healthcare providers in Sadeghi et al.'s study (2012) also identified the patients' language and culture as potential barriers to health literacy and added patients' fear of being shamed, age, cognitive ability and scarcity of resources as potential barriers too. Additionally, when discussing the communication strategies they use, the healthcare providers in Sadeghi et al.'s study seemed to be focussing on mitigating the 'risks' of low health literacy through using strategies such as repeating information and using simple language. None of the studies above were conducted with UK healthcare providers or focussed around older adult

populations, therefore the findings may not be transferable to this area. However, the UK healthcare providers in Salter et al.'s focus groups (2014) were focussing on older adults, and identified patient barriers such as older adults being reluctant to ask questions, struggling to accept their diagnoses and personal beliefs about health as potential barriers to health literacy. Additionally, the healthcare providers in this study were uncertain about how much information to give. However, Salter et al. (2014) did not explore healthcare providers' perceptions about health literacy screening in depth or examine the acceptability of universal precautions. This is addressed within the present research.

2.7   Summary of literature review

This literature review has revealed a number of common limitations in the studies: only one study focussed specifically on older adults' health literacy perceptions (Salter et al. 2014); many studies did not assess participants' health literacy, had samples with high education levels and many studies were not conducted in the UK. This limits the transferability of the studies' findings to older adult UK populations with different health literacy levels. As described in the following chapters, the present research addresses this by seeking older adults' perspectives, assessing participants' health literacy levels and conducting the research in the UK.

From a methodological perspective, many studies used quantitative methods or deductive qualitative approaches, leaving scope for further in-depth qualitative inquiry which may yield rich data and unexpected findings. The decision to use qualitative methodology within the present research is further justified in the next chapter. Furthermore, some qualitative studies used methods such as focus groups which may have deterred low health literate individuals from participating. Later methods chapters will explore how the present research aims to address this through using interview methods.

Many of the papers identified here emphasised the importance of health literacy being viewed as an interaction between individuals' abilities and the demands of the healthcare system, which fits with the conceptualisation adopted for this thesis. This also justifies further exploration of health literacy from both patients' and

healthcare providers' perspective. Only one paper was identified which compared health literacy views and experiences from both older adults' and healthcare providers' perspectives (Salter et al. 2014). However, this study did not assess participants' health literacy or explore perceptions about health literacy screening or universal precautions. This is important given that the literature review also revealed issues regarding the implementation of health literacy screening or universal precautions with older adults in clinical practice from both patients' and healthcare providers' perspectives. However, few studies were revealed which focussed specifically on healthcare providers' and patient perceptions regarding health literacy screening or universal precautions, with even less using qualitative methodology to explore this. The qualitative studies which did report on this, did so only briefly. Furthermore, no research was identified comparing views about the two different approaches concurrently, indicating this warrants further exploration within the present research, especially given the contention identified between the two approaches. Additionally, few studies were revealed which consider health literacy as an asset and no studies were revealed which consider the application of both the risk or asset perspectives in a clinical setting, another area which the present research aims to address.

In summary, the literature review revealed little research relating to the facilitators and barriers to meeting older adults' health literacy needs in clinical practice, particularly in a UK context. More research is needed to explore older adults' health literacy experiences and how healthcare providers can meet older adults' health literacy needs. Therefore, the aims and objectives of the research are outlined next.

2.8   Aims and objectives of the research

2.8.1   Aim

- To identify the facilitators and barriers to meeting older adults' health literacy needs, from both a healthcare provider and patient perspective.

2.8.2   Main objective

- To explore the facilitators and barriers to meeting older adults' health literacy needs in clinical practice.

2.8.2.1   Secondary objectives relating to older adults

- To explore and understand the views and experiences of older adults attending a falls clinic about their overall experience, access to the service, provider-patient interaction, information provision and self-management.
- To identify possible facilitators and barriers to meeting older adults' health literacy needs, guided by the older adult participants' views and experiences of attending the falls clinic.
- To explore whether older adults' experiences of attending a falls clinic may be influenced by their assessed health literacy levels.
- To explore the acceptability and practicality of the health literacy screening tools administered during qualitative interviews.

2.8.2.2   Secondary objectives relating to healthcare providers

- To explore healthcare providers' knowledge and awareness of health literacy.
- To explore healthcare providers' views about identifying older adults' health literacy levels.
- To explore healthcare providers' views about using health literacy screening tools or universal precautions in clinical practice.
- To explore healthcare providers' views about the facilitators and barriers to meeting older adults' health literacy needs in clinical practice.

Chapter 3: Methodological considerations for this programme of research

3.1 Introduction

In this chapter, the phases which constitute the programme of research are diagrammatically represented and the researcher describes her epistemological and ontological position and how this has influenced the methodological choices for this research. Describing the methodology of this research assists with providing justification for the research. Methodology includes the description, explanation and justification for the research methods but does not include the methods (techniques and tools of the research) (Carter and Little 2007), which are described in subsequent chapters. Use of qualitative research and specifically Interpretative Phenomenological Analysis (IPA) and the framework approach to analysis are then discussed. Finally, evaluation of quality in qualitative research is explored and a summary of the chapter provided.

3.2 Phases of the research

This programme of research was carried out in two distinct but interconnected phases. The diagram below (Figure 1) demonstrates how the research was conducted in an iterative manner; phase one influenced the design and analysis of phase two. Finally, the findings from phase one and two were compared, contrasted and synthesised.

Phases and aims of research	Methods
Phase one: Health literacy from older adults' perspectives Initially, the views and experiences of older adults with varying health literacy levels regarding attending a falls clinic about overall experiences of attending the falls clinic, access to the service, provision of information, provider-patient interaction and self-management were explored.	• Individual in-depth semi-structured interviews (N=9 older adult patients) • Purposive sampling • Interpretative phenomenological analysis
Phase two: Health literacy from healthcare providers' perspectives The findings from phase one influenced the questions and objectives for phase two. Healthcare providers' views and experiences regarding working with older adults' with varying health literacy levels were sought. Findings from phase one also influenced development of the framework for analysis and additional themes were added.	• Individual focus groups (4x groups, N= 22 healthcare providers) • Purposive sampling • Framework approach to analysis

Synthesis of findings After separately analysing the two phases, common themes from both phase one and two were synthesised, compared and contrasted. Themes which were unique to each phase were maintained.

Figure 1   Phases of the research

3.3   Justification of methodological approach

3.3.1   The researcher's ontological and epistemological position

Mason (2002) argues that qualitative researchers should actively engage with issues relating to their own ontological and epistemological positions. This is important because assumptions researchers make affect their approach to research. Being aware of their belief systems and prejudices enables researchers to reflect on the impact they have on the research, how they construct their research, what they view as data, the methods they employ to collect data and how they warrant their findings (Finlay and Ballinger 2006; Carter and Little 2007).

There are two main paradigms in research methodology: positivism and constructivism-interpretivism (Ponterotto 2005). A paradigm has three

components: ontology (how the nature of reality is viewed), epistemology (the researcher's approach to knowledge creation) and methodology (the researcher's research strategy) (Mason 2002).

A positivist argues that there is 'an absolute reality, which can be measured, studied and understood' (Duncan and Nicol 2004, p.453). Researchers working in a positivist paradigm may have an ontological position of realism: a belief that reality and truth exist and can be found if researchers look for them. Within the positivist paradigm, the researcher is independent of the object of study and knowledge is created through direct observation or measurements of the phenomena (Krauss 2005). Primarily, positivism is associated with quantitative methodology, and objectivity and reliability are the criteria used to evaluate research in this tradition (Madill et al. 2000). However, some qualitative researchers may have realist epistemologies; they may transfer quantitative quality criteria directly over to qualitative research and aim for representative sampling, generalisability and inter-rater reliability (Madill et al. 2000). These researchers may have large samples and use strategies such as triangulation to increase the validity or reliability of the research (Madill et al. 2000). Positivism and realism did not fit with the researcher's epistemological and ontological beliefs that there are alternative perspectives on the question of reality (Duncan and Nicol 2004). Additionally, the present research aims to understand the subjective perspectives and experiences of a small group of individuals in context. The positivist/realist position would necessarily be limited for exploring subjective experiences; if there is a single truth, researchers should be able to apprehend it themselves and subjectivity and multiple perspectives would be ruled out. The researcher rejects this, believing instead that the nature of reality is complex.

In contrast to the positivist paradigm, constructivism (or interpretivism) 'adheres to a relativist position that assumes multiple, apprehendable, and equally valid realities' (Ponterotto 2005, p.129). Unlike realist epistemologies, the researcher no longer assumes that a single reality can be unearthed when using the appropriate methodology and methods (Madill et al. 2000). Many researchers who adopt this position argue that as a distinctive paradigm, it would be inappropriate to apply quality criteria derived from a positivist paradigm (Pope and Mays 2006). An alternative ontological position of subtle realism has been proposed (Mays and

Pope 2000). Subtle realism is the researcher's chosen philosophical position. When adopting a subtle realist position, researchers endeavour to represent reality, as opposed to attempting to attain a single truth (Mays and Pope 2000). Further, although it is believed that there is an underlying social reality, it is recognised that researchers can only know this reality from their own perspective of it (Finlay and Ballinger 2006). Therefore, importance lies with the researcher reflecting on their methodological decisions and predispositions (Finlay and Ballinger 2006). This position is also suited to the present research, given that it recognises the context-specific nature of qualitative inquiry; this programme of research was conducted in one geographical area. A subtle realist may reject direct transference of quantitative quality criteria to qualitative research; they may instead argue that quality assessments should take into account the distinctive goals of qualitative research. The researcher also argues that to derive insights from qualitative research which can be applied, it is necessary to evaluate qualitative research (Pope and Mays 2006). This was particularly important to the researcher, who wished to develop clinically relevant research which could have an impact on health services. A position of subtle realism also supports a hermeneutic approach (Koch 2006), where hidden meanings can be revealed through reflection and interpretation. The researcher believes it is neither possible nor advantageous to attempt to conduct research without recognising the subjectivities and different interpretations the participants, researcher and the reader can bring (Koch 2006). Additionally, much of the research presented in the literature review derived from a positivist paradigm; conducting research from an alternative paradigm can provide unique and alternative perspectives.

3.3.2   Use of qualitative methodology in both studies

Chapter Two revealed that few studies have explored the area of health literacy and older adults qualitatively. Therefore, little is known about older adults' health literacy experiences and how health literacy is understood and managed by healthcare providers. Further, the literature review revealed inherent limitations in these studies and few studies exploring older adult patients' health literacy experiences and healthcare providers' views relating to meeting older adults' health literacy needs in clinical practice. Given the novel and extremely complex nature of the topic, an exploratory research methodology was deemed most

suitable for use in this programme of research (Flick 2009; Green and Thorogood 2009; Holloway and Wheeler 2010). In this research, a qualitative approach enables the researcher to explore the rich complexities of health literacy views and experiences from both patients' and providers' perspectives. Qualitative research is particularly appropriate when there is a lack of understanding regarding people's perspectives on an issue (Green and Thorogood 2009; Holloway and Wheeler 2010). Thus, using qualitative methodology also aligns with the researcher's philosophical position outlined above; seeking to explore and understand different perspectives fits with an understanding of reality as complex and lacking a single truth.

Quantitative approaches can also be used to elicit views. For instance, questionnaires could be used to examine health literacy views and have the potential to produce more generalisable results. However, as revealed in the literature review, little is known about older adult patients' and healthcare providers' health literacy views. Therefore, the researcher felt it would be more suitable to use qualitative methodology which aims to gather rich and in-depth responses. Questionnaires, which are often reliant on written responses, may also prove to be too challenging for individuals with lower functional literacy levels (Adams et al. 2012; George et al. 2013).

Qualitative research also enables the researcher to develop a relationship with participants, which is beneficial when exploring sensitive issues. Low literacy levels can be associated with shame and stigma (Section 2.4), therefore it was felt that a researcher sensitively asking questions and responding to participants' verbal and non-verbal cues accordingly was most suited to research including participants with low literacy or health literacy. Finally, the flexible and iterative nature of qualitative research was felt to be an asset, enabling the researcher to explore areas of interest as they emerge (Hayes 2000). For instance, the research questions can be adjusted according to participants' responses and emergent themes.

3.3.3   Justification for use of both Interpretative Phenomenological Analysis (IPA) and the framework approach

3.3.3.1   Use of IPA for the first phase of the research

Phenomenology is grounded in the belief that truth can be found in lived experience and phenomenological research studies aim to gain an understanding of participants' lived experiences (Wertz et al. 2011). This philosophical assumption that 'truth' can be found in lived experience is congruent with the researcher's subtle realist position (Finlay and Ballinger 2006). However, the researcher would argue individuals can only know 'truth' from their own perspective of it. The focus on exploring experiences initially attracted the researcher to phenomenology, since it allows research participants to tell their own story; this desire to explore other people's experiences may have derived from working clinically as an occupational therapist. Furthermore, given that the research question for the first phase of the research focussed on older adults' experiences, this approach initially appeared suitable for this phase.

Further reading in the phenomenological field revealed different schools of phenomenological thought. Whilst there are many versions of phenomenology, there are two main types: transcendental (descriptive) phenomenology, developed by Edmund Husserl and hermeneutic (interpretative) phenomenology developed by Martin Heidegger (Heidegger 1962; Husserl 1970; Lopez and Willis 2004). A researcher utilising the more descriptive transcendental phenomenological approach aims to describe the participant's lived experience without any personal biases or using any expert knowledge they may have (Lopez and Willis 2004). This usually means not conducting an extensive literature review and involves a process of 'bracketing' off any preconceptions for the duration of the research. As a result of the researcher's clinical background (which involves interpreting patients' responses) and prior reading around health literacy to identify a research question, the researcher felt unable to separate the participants' responses from the researcher's interpretations. Furthermore, the researcher agrees with the argument that personal values and interpretations are what makes research meaningful and engaging (Koch 2006). Therefore, a hermeneutic inquiry (influenced by Heidegger) which goes beyond description and recognises that a

researcher has a key role in the generation and interpretation of data (Lopez and Willis 2004), was deemed a more suitable fit.

Interpretative phenomenological analysis (IPA) is another approach to phenomenology (Smith et al. 2009a). IPA is phenomenological given that it focuses on the study of lived experiences and is interpretative since it is a derivative of the hermeneutic variant of phenomenology (Smith et al. 2009a). The primary concern of IPA is the lived experience of the participant and how they have made sense of that experience. However, given the interpretative element, the outcome is a double hermeneutic: an account of how the researcher thinks the participant has made sense of their experience (Smith et al. 2009a). As Smith (2004) describes, the three main characteristics of IPA are idiographic, inductive and interrogative. Idiographic analysis involves a detailed exploration of one case until some degree of closure is reached, before moving onto the next. Cross case analysis is only attempted when all cases have been individually interrogated. Maintaining an idiographic focus ensures variations are not lost and each participant is valued as an individual. Inductive analysis aims to allow themes to emerge from the raw data, rather than through reliance on pre-existing literature or theories. This approach was chosen in preference to deductive analysis owing to the unexplored nature of the topic and the potential to limit the inquiry and introduce analytic preconceptions. Finally, interrogating the data in a detailed and idiographic manner adds important and insightful contributions to the existing literature.

Smith et al. (2009a) suggest that the primary reason for choosing IPA should be that it fits with the researcher's epistemological position. With IPA, the researcher assumes that through carefully considered explicit methodology, excellent interviewing techniques and rigorous analysis, they are able to access an individual's cognitive inner world (Biggerstaff and Thompson 2008). From previous clinical encounters with patients, the researcher felt that to some extent an individual's thought processes can be accessed through interviewing and analysis; therefore the methodology was felt to be a good fit. Further, although designed to be used flexibly, there is clear step-by-step guidance on how to conduct IPA (Smith et al. 2009a); as a novice researcher, this was felt to be instrumental. The researcher also felt that the older adults in the first phase of the research would

have idiosyncratic experiences and views which should be valued and not dismissed as not pertaining to the majority; therefore the idiographic nature of IPA appealed. Finally, only one other study was identified which aimed to reveal health literacy experiences through the use of IPA (Melton et al. 2014); this study did not focus on older adults' experiences. Therefore, the researcher felt this novel choice of methodology would be useful to gain rich and insightful data. Benefits of using an IPA approach include that it deals with the 'unexpected' from participants and provides rich in-depth data (Pringle et al. 2011). More in-depth details about how IPA was used in relation to research design and data analysis can be found in Chapter Four.

3.3.3.2 Use of the framework approach for the second phase of the research

In contrast to the first phase of the research focussing on older adults' individual experiences of a particular situation (i.e. attending a falls clinic), the second phase aimed to explore the views and experiences of groups of healthcare providers regarding working with older adults with varying health literacy levels. Therefore, the focus shifted from an individual level to a group and organisation level. As a result, the researcher felt it would not have been true to the methodology or appropriate to use IPA for the second phase of the research, given that IPA focusses on an individual's experiences (Smith et al. 2009a). For the second phase of the research, the researcher was interested in accessing a collective response from healthcare providers within different contexts. This was achieved through using focus groups. Although some researchers have used IPA within focus group research, this has been recognised as problematic when using IPA (Smith et al. 2009a). As a result of this, the framework approach to qualitative analysis was chosen for the second phase of the research. The framework approach is not associated with a particular epistemological position and is considered a flexible tool (Gale et al. 2013); therefore, this choice of method also fits with the researcher's philosophical position. This approach involves a matrix-based method of thematic analysis (Gale et al. 2013). Using this approach, key themes, concepts and emergent categories are organised and classified using a thematic framework (Ritchie and Lewis 2013). The framework approach was

developed in the UK in the 1980s by social policy researchers for applied or policy relevant research (Pope et al. 2000; Smith and Firth 2011).

The framework approach was chosen for the second phase of the research as a result of the clearly focussed aims and objectives set prior to the research (Gale et al. 2013), and the utility of the framework for making comparisons within and between cases (Pope et al. 2000; Gale et al. 2013). In this phase of the research, the objectives derived from the findings from the first phase and from the literature on healthcare providers and health literacy. These objectives helped to formulate the interview guide; data collection tends to have a degree of structure and analysis is more strongly informed by prior knowledge in a framework approach, in comparison to other qualitative methods (Pope et al. 2000). The clear structure and guidance around using the framework approach also makes it particularly suitable for a novice researcher (Smith and Firth 2011).

Benefits of the framework approach include that it encourages in-depth exploration of data whilst simultaneously maintaining systematic analysis and a transparent audit trail (Smith and Firth 2011; Gale et al. 2013). The rigour and credibility of the findings are enhanced as a result (Smith and Firth 2011). For instance, the researcher clearly defines each code used and the framework is developed and tested over time. After the framework has been developed (a process which does not conclude until the final transcript has been analysed), it is re-applied to each transcript. As a result of the matrix-based approach, comparisons can be made within and between cases (Pope et al. 2000; Gale et al. 2013). As a result, combined with the structured nature of framework development, the approach is particularly suited to collaborative research (Pope et al. 2000). In this phase of the research, the analysis was able to be easily shared with the supervisory team. A common misconception of the framework approach is that data is analysed deductively. The framework approach is amenable to both inductive and deductive analysis (Gale et al. 2013). Further information about how the framework approach was applied in relation to research design and data analysis can be found in Chapter Seven.

3.3.4   Enhancing trustworthiness in qualitative research

Qualitative research is inherently subjective, given that it is open to interpretation and different perspectives. However, qualitative research should still be open to scrutiny and the quality of the research undertaken needs to be evaluated in some way (Madill et al. 2000). Quantitative research is usually evaluated using the following criteria: validity, reliability, generalisability and objectivity (Finlay and Ballinger 2006). Guba and Lincoln (1989) redefined the quantitative criteria as credibility, transferability, dependability and confirmability. This approach aims to ensure the findings and conclusions have derived from the data (Koch 2006). In this thesis, as a result of the researcher's subtle realist position, the reformulation of quantitative quality criteria is considered appropriate (Finlay and Ballinger 2006). The researcher argues that these criteria fit with the subtle realist position, due to the emphasis on describing the context and processes in depth (Shenton 2004). The following sections provide an overview of how each of these criteria were addressed in this research.

3.3.4.1   Credibility

Credibility is the quality criterion suggested for qualitative research instead of internal validity. Credibility assesses the extent to which the findings reflect reality (Shenton 2004). Lincoln and Guba (1985) posit credibility is one of the most important criteria for establishing trustworthiness in qualitative research. To enhance credibility, the following strategies as recommended by Shenton (2004) were used for the present research.

Firstly, it is important to reflect on the researcher's qualifications and expertise, given that the researcher is the primary instrument of data collection and analysis within qualitative research (Shenton 2004). The researcher worked clinically as an occupational therapist, thus had experience in conducting clinical interviews. However, the style of interviewing in a clinical assessment may involve a more direct line of questioning. As such, the researcher also completed Good Clinical Practice and qualitative interviewing/focus group training (Department of Health 2005). Qualitative expertise was also offered from PhD supervisors. Enhancing a researcher's qualitative interviewing skills through training supports the researcher

to raise their self-awareness when interviewing participants (Koch 2006), and they may be less likely to influence the direction of the interview. Thus, the intended outcome is that the participants' responses reflect their own reality, as opposed to being influenced by the researcher's predispositions.

To refine the research methods and design, and to access different perspectives on the research (Shenton 2004), both phases of the research underwent a rigorous peer review process before ethical approvals were sought. Scrutiny and appraisal of the research was also encouraged throughout the process by attending conferences and presenting to clinical colleagues. The researcher also developed an early familiarity with the culture of the participating NHS Trusts through clinical observations and through clinical work in one of the NHS Trusts involved. Peer scrutiny of research demonstrates a commitment to reflecting the participants' reality because it supports the researcher to challenge their own assumptions and predispositions.

It is important to take steps to ensure participants are honest and authentic when sharing their views and reflections (Shenton 2004). Participants could be concerned that their views and identity would be shared with their healthcare provider or colleagues. During both phases of the research, participants' honesty was encouraged by explaining and reiterating their rights to confidentiality, anonymity, to not take part and to withdraw. The researcher was aware that her personal position could influence participants' responses and carefully considered how to present herself to the older adult participants and healthcare provider participants. For instance, the researcher introduced herself as a postgraduate research student to the older adult participants in the first phase of the research. If the researcher had introduced herself as a healthcare provider, participants could have been concerned that she was relaying their interview responses to the healthcare providers at the falls clinic or may have tried to 'please' the researcher by giving positive responses about the healthcare system. In the second phase of the research, the researcher worked within the NHS Trust involved and therefore had to introduce herself as a clinical academic doctoral student, given that some participants were already aware of her role. The healthcare provider participants may have viewed the researcher as having high knowledge levels about health literacy. However, to enhance honesty, the researcher explained to participants

that health literacy is a relatively new concept and that she was interested in their views on this evolving concept. The researcher also aimed to develop rapport at an early stage: Participants were advised that the researcher is interested in exploring their personal views and experiences, there is no right or wrong answer and that they are able to change the direction of the interview/focus group. Respondent validation of transcriptions or findings was not used because participants' views and situations may alter over time, thus impacting the sense-making occurring at one particular time, such as within an interview context (Kitto et al. 2008). Furthermore, individuals with lower functional literacy levels may be unable to or not want to read extensive transcriptions. However, the researcher did check whether her understanding of the participants' accounts was accurate during and at the end of the interviews and focus groups. This was achieved by summarising the participants' responses, asking if they have been described accurately, whether they have anything further to add and whether they felt there was anything the researcher had not covered. This also helped to ensure that the researcher did not control the direction of the interviews or focus groups.

The researcher kept a reflexive diary to record initial thoughts after interviews/focus groups and ongoing reflections about emerging themes and any personal biases (Shenton 2004; Nadin and Cassell 2006). Immediately after data collection, this involved reflecting on any previous contact with the participants, the characteristics of the participants, the interview/focus group setup, details of any other people present (e.g. family members), length of the interview/focus group, how the participant(s) appeared during the interview/focus group, personal feelings about the interview/focus group and any initial analytical impressions. Subsequent diary entries involved reflecting on the analysis as codes and themes were generated. For both phases of the research, it was essential that the participants and their raw data was the focus of the analysis; using a reflexive diary was useful to increase the researcher's awareness of her own beliefs and predispositions which may influence the analysis (Smith et al. 2009a). To further enhance reflexivity, as recommended by Shenton (2004), the researcher had regular supervisory meetings; these meetings were an opportunity to highlight any ongoing practical or theoretical issues and to raise the researcher's awareness of other analytical interpretations, theoretical perspectives and experiences.

3.3.4.2   Transferability

In positivist quantitative research, the generalisability of results to a wider audience is often of chief concern. However, qualitative research often involves small samples within a certain context, therefore findings cannot be generalised to other audiences. Despite the unique contexts however, it can be argued that a reader of the research may believe the situation is similar to their own (Guba and Lincoln 1989; Shenton 2004; Tracy 2010). The researcher argues that qualitative research needs to have some degree of transferability to have impact (Tracy 2010), hence why transferability was focussed on within the literature review. Therefore, to enhance transferability, responsibility lies with the researcher to provide a rich and detailed description of the context. For both the interview and focus group studies, the researcher describes the contexts and setting in detail in the methods sections. As Shenton (2004) advises, information is also provided to the reader in the methods section about the number and location of participating organisations, total number of participants, data collection methods used, number and length of data collection sessions and the time period which the data was collected.

3.3.4.3   Dependability

In quantitative research, the reliability of the work is considered; this is the extent to which the same results would be produced if the research was repeated with the same methods and participants. However, the fluid and iterative nature of qualitative research renders this quality criterion redundant. Guba and Lincoln (1989) propose dependability is the equivalent criterion for qualitative research. They suggest researchers should report their research in sufficient detail to enable a future researcher to repeat the research, but not necessarily obtain the same findings. Given that a reader of research has their own interpretations and preconceptions, the researcher must ensure the reader has an understanding of why particular interpretations have been proposed, even if they do not agree with them (Koch 2006). To enhance dependability in this research, as recommended by Shenton (2004), the researcher provides a detailed description of the processes in the methods chapters. Additionally, with regards to recruitment and data collection, primarily the same processes were followed for each participant.

Any deviation from the processes are recorded in the write-up, and the impact reflected on accordingly. Finally, the transcription documents were checked by the researcher multiple times for errors.

3.3.4.4   Confirmability

Confirmability can be described as the extent to which the research findings have stemmed from the ideas and experiences of the participants, as opposed to the characteristics and views of the researcher (Shenton 2004). Confirmability is the equivalent term for objectivity in positivist research. Guba and Lincoln (1989) suggest confirmability can only be established when credibility, dependability and transferability have been achieved. This means research decisions and influences should be made clear throughout the research (Koch 2006). To enhance confirmability in this programme of research, the researcher has acknowledged personal beliefs and predispositions. For instance, earlier in this chapter the researcher reflected on her epistemological and ontological position. Additionally, alternative methodology and methods have been discussed and the reasons for favouring one approach over another have been articulated. Finally, an awareness of the limitations of certain approaches is demonstrated in the discussion chapter. Making the methodological, theoretical and analytical decisions explicit assists with development of an audit trail (Shenton 2004). To demonstrate the audit trail for this research, the researcher has reflected on theoretical decisions made about the conceptualisation of health literacy in the first chapter, methodological decisions in this chapter and clearly describes the steps taken to collect, manage, analyse and report data in subsequent chapters. Additionally, any changes to research design are discussed and the research documentation is included in the appendices (Pope and Mays 2006).

3.4   Summary

Chapter Three justified why the researcher has rejected positivism and adopted a philosophical position of subtle realism due to a belief in multiple perspectives and complexities when considering the question of reality, fitting with the researcher's decision to use qualitative methodology for the present research. This is further reinforced by the lack of previous qualitative research (possibly resulting in a lack

of understanding regarding different perspectives about health literacy which is fundamental when viewing reality as lacking a 'single truth') and the benefit of using qualitative methods when exploring sensitive issues relating to possible literacy difficulties. Use of IPA methodology in the first phase of the research was justified in terms of the researcher's beliefs; individual experiences should be valued (in-depth case analysis may contribute insights about how systems can be better organised) and interpretation is advantageous. Framework analysis was adopted for the second phase of the research due to the focussed aims and objectives derived from the first phase and the shift in focus from an individual to organisation level. Decisions about how the trustworthiness of the research was increased were also discussed. Having justified the methodological decisions to assist the reader in understanding the rationale behind choices, thus enhancing trustworthiness, the next chapter describes and justifies the methods adopted for the first phase of the research.

Chapter 4: Methods for first phase of the research involving interviews with older adults

4.1 Introduction

This chapter describes the methods for the first phase of the research. This phase involved conducting individual semi-structured interviews with older adults. Included are the aims and objectives, research design, recruitment, data collection and analytical procedures and ethical considerations. The chapter concludes with a summary.

4.2 Aim

This phase of the research aimed to qualitatively explore the views and experiences of older adults who have low and adequate health literacy levels and had recently attended a falls clinic, relating to their overall individual experience, access to the service, provider-patient interaction, information provision and self-management.

4.3 Objectives

- To explore and understand the views and experiences of older adults attending a falls clinic about their overall experience, access to the service, provider-patient interaction, information provision and self-management.
- To identify possible facilitators and barriers to meeting older adults' health literacy needs, guided by the older adult participants' views and experiences of attending the falls clinic.
- To explore whether older adults' experiences of attending a falls clinic may be influenced by their assessed health literacy levels.
- To explore the acceptability and practicality of the health literacy screening tools administered during the interviews.

4.4   Research design

4.4.1   Setting and context for first phase of the research

The decision was made to focus on a falls clinic in the South of England as an exemplar of services for older adults. Many older adults have falls: approximately one in three community-dwelling older adults fall each year (Scuffham et al. 2003; World Health Organization 2007). Individuals who fall often also have long-term conditions and multiple co-morbidities (Lord et al. 2007). Additionally, from a health literacy perspective, falls prevention is an area which can be considered from both 'risk' and 'asset' perspectives. For example, it has been suggested that a focus on self-management skills is the key to promoting uptake of and adherence to falls prevention activities (Robinson et al. 2014). Therefore, an analysis of how older adults perceive self-management of their falls and whether provider-patient interaction and information provision meets older adults' health literacy needs links with the research aims.

To gain an understanding of the setting and increase credibility (Section 3.3.4.1), prior to conducting the research, the researcher spent time observing clinical practice at the falls clinic and discussed how the falls service is organised with the manager and clinicians. These observations were completed to increase the researcher's understanding of the setting to assist with interpretation of the participants' accounts of their experiences of attending the falls clinic. The researcher spent a day observing the nurses completing assessments with patients and also observed the falls clinic doctors assessing and treating patients. The researcher also spent a day observing physiotherapy sessions at the falls clinic, including initial assessments and follow-up appointments. During all of the observations, the researcher made notes on the type of observation (e.g. initial assessment with patient), format and length of the appointments, assessments used, interactions between the patients and the healthcare providers and any reflections the researcher had. The researcher also met with two senior clinicians/managers to discuss the processes within the falls clinic, observed a patient triage meeting (where referrals to the falls clinic are prioritised) and observed a falls exercise class in the community where patients are often referred to after attendance at the falls clinic. From these observations and discussions, the

researcher was aware of the referral service, the transportation service, how patients were prioritised, the falls clinic processes, written documentation and assessments used and which healthcare providers patients might see at the falls clinic.

A falls clinic is defined as 'a facility based in either primary or secondary health care that administers services to individuals with the purpose of preventing falls, and involves qualified health professionals' (Lamb et al. 2007, p.10). Patients attending the falls clinic involved in this phase of the research are above the age of 65, have had unexplained falls and often have complex multi-morbidities. This is a strength within the study population: many older adults have complex multi-morbidities (Section 1.7); exploring these individuals' views may represent the experiences many older adults have when trying to manage their healthcare and contrasts to studies which only include participants with one health condition. As a result, within this type of service there is an element of both long-term condition care and preventive care. However, this may mean findings are less transferable to a healthier population with one or no health conditions. Given that only older adults are eligible to attend, it was considered a good service to access the views of older adults attending a service which is more likely to be tailored to the needs of older adults.

The falls clinic used in this phase of the research provides a multidisciplinary service for community-dwelling individuals, including assessment by a consultant in medicine for older people, falls nurse specialist, physiotherapist and occupational therapist. Whilst attending falls clinics, older adults may have medical investigations, vision checks, medication reviews, mobility assessments and home hazard checks (Lamb et al. 2007). They may also be offered equipment, exercise interventions and advice on preventing falls. The falls clinic involved in this research provided all of these services. As a result, the patients may see multiple different healthcare providers who are each communicating different messages. This is a strength in the study population given that many older adults with multiple co-morbidities would see multiple healthcare providers in secondary healthcare. However, findings may not be transferable to patients only seeing GPs. Patients may also attend the falls clinic for varying lengths of time, according to their needs. The falls clinic attendees are assessed/treated in private consultation rooms when

seeing the nurse/consultant, and are seen in a large therapy room with other patients whilst having physiotherapy. If required, an occupational therapist sees the older adult in their own home. Older adults may be referred to the falls clinic by their GP, a registered physician or the emergency department.

The older adults attending the falls clinic are offered hospital transport if they are unable to get to the falls clinic via their own means. Patients may attend with a member of their social support network and are offered refreshments while they are sat in the waiting room. The waiting room is a place where older adults wait to be seen or to be picked up by the hospital transport, taxis or family members. There are tables, chairs and patient education resources available.

4.4.2 Sampling

Purposive sampling is normally used in IPA studies, because of the opportunity to gain insight into particular experiences as opposed to representing a population (Smith et al. 2009a). Purposive sampling aims to sample a group of people who have certain characteristics which enables the researcher to explore the issues relevant to the research topic (Ritchie and Lewis 2013). The health literacy level of the participants is the main characteristic of interest for this phase of the research; the researcher aimed to interview individuals with both low and adequate health literacy levels. However, given that health literacy was assessed after the interviews, it was decided that if the researcher was recruiting participants from only one group (e.g. only participants with high health literacy), a brief screening question would be used during recruitment to establish the participants' health literacy levels (Morris et al. 2006). Due to the relatively small sample size (Section 4.4.3), it was decided the researcher would implement this strategy if needed after five interviews. Using this strategy, the researcher would exclude participants who had low/high health literacy when assessed using the screening question. It was decided this screening question would be asked when initially recruiting to avoid disappointing participants who would like to take part.

A relatively homogenous sample is usually aimed for in IPA studies to ensure the research questions are meaningful to the participants (Smith et al. 2009a). Smith et al. (2009a) suggest it is possible to compare the experiences of two different

groups in IPA research, but suggest ensuring group homogeneity in other areas. In this phase of the research, the sample was homogenous in terms of age and experiences - all the participants had sustained falls and attended the falls clinic. However, the researcher aimed for heterogeneity in terms of health literacy abilities by interviewing older adults with low and adequate health literacy levels due to both groups reporting difficulties understanding health information (Shaw et al. 2009). Although the researcher was not aiming to make generalisability claims, comparing two different health literacy groups for possible differences in their experiences was deemed suitable. However, this was only with the purpose of making tentative links, given that causal inferences cannot be drawn.

4.4.3　Sample size

In contrast to quantitative researchers who usually conduct research with large numbers of people to make generalisations and undertake valid statistical analyses, qualitative researchers seek to gain a more in-depth subjective understanding of how and why individuals have certain experiences or behaviours (Baker and Edwards 2012). As opposed to generalisability, qualitative researchers often aim for transferability (Section 3.3.4.2) and this quality criterion does not demand a large sample. Qualitative experts advise that a broad sample range of between twelve and sixty is used for qualitative research studies (Baker and Edwards 2012). In this report, they suggest that a sample size of between one to a hundred could be adequate depending on the research question and methodology, but recommend student projects should have approximately 12-20 participants to allow adequate time for planning, conducting, transcribing, analysing and to increase the chances of publication. Due to the depth of analysis and idiographic focus, a sample size of approximately six is suggested when using an IPA approach in a student project (Smith et al. 2009a). This is because the primary concern of an IPA approach is to provide a detailed account of an individual's experience at a case study level; meeting the requirements of the approach would be particularly challenging with a larger sample size (Smith et al. 2009a). It is suggested that smaller samples complement the amount of time and level of reflection required for a successful IPA project (Smith et al. 2009a). As a novice to both qualitative research and IPA, the researcher was committed to analysing each interview at the case study level and interrogating the data in an in-

depth manner (Smith et al. 2009a). However, the researcher also wished to gain valuable interviewing and analysing experience, which would involve interviewing more than a few participants. With these reflections and the above guidance in mind, the researcher aimed to recruit a sample of between six and ten participants. Interviewing more than five participants was essential to meet the research objectives relating to exploring the views of older adults with both low and adequate health literacy levels. However, the depth of analysis and interpretation and the idiographic focus could be lost if interviewing more than ten participants.

4.4.4   Inclusion and exclusion criteria for participants

The tables below (Tables 4 and 5) identify the inclusion and exclusion criteria with justification used for participants in the first phase of the research:

Inclusion criteria	Justification
Aged 65 and above.	Focus of research is on older adults and falls happen more frequently in older people (Lord et al. 2007).
Men and women.	Both men and women have health literacy issues and falls. However, it is more likely for women to sustain non-fatal falls (70.5%), whereas men are more likely than women to experience fatal falls (Stevens and Sogolow 2005). It is also more likely for women to experience fall-related injuries.
Individual must be community-dwelling.	Health literacy strategies may be different for individuals that are community-dwelling or in hospital. Falls prevention strategies differ for community-dwelling adults compared with institutionalised or hospitalised older adults (Gillespie et al. 2009).
Individuals with lower and adequate health literacy levels.	Both those with low and adequate health literacy feel unable to access, use and understand health information (Shaw et al. 2009).
Attended falls clinic in last 3 months.	To assist with recall of the experience.
Had a first face-to-face contact with a physiotherapist and/or occupational therapist as part of the falls clinic service.	Focus of research on self-management.

Table 4   Interview inclusion criteria and justification

Exclusion criteria	Justification
Severe cognitive impairment.	Different health literacy needs and mental capacity issues.
Individuals who do not speak English as a main language.	Interviews conducted in English and issue of translation may get confused with health literacy.
Individuals with severe visual or hearing impairment.	These individuals may have different health literacy needs, interviews will be conducted orally and health literacy measurement tools used require hearing and vision.
Participants the researcher has previously or is currently working with.	Could impact credibility as questions are exploring participants' experiences of NHS services.

Table 5　　Interview exclusion criteria and justification

4.4.5　Use of semi-structured interviews

As a method, interviewing is usually conducted in a fully structured, semi-structured or unstructured manner (Rubin and Rubin 2012). A fully structured interview usually involves a structured questionnaire and data is primarily quantitative (Rubin and Rubin 2012). The researcher felt this method would not enable an in-depth exploration of the participants' views. For an unstructured interview, the researcher usually has a general topic in mind, but specific questions are generated as the interview progresses (Rubin and Rubin 2012). This approach has been suggested as an endeavour to apply IPA's 'inductive epistemology to the fullest extent' (Smith et al. 2009a, p.70). However, it is generally suited to a more experienced IPA researcher and was deemed unsuitable in this phase of the research given that the researcher had specific questions and objectives relating to health literacy which warranted further exploration (Smith et al. 2009a). In-depth individual semi-structured interviews were employed to collect data in this phase of the research. When using principles of an IPA approach, researchers aim to explore the experiences and meaning-making activities of individual participants, therefore a flexible data collection method is necessary (Smith et al. 2009a). The flexible nature of semi-structured qualitative interviews allows the researcher to clarify meanings and probe for additional information. Meanwhile, the participant is enabled to explore their personal thoughts and exert some control over the interview direction (Holloway and Wheeler 2010). This approach is congruent with the researcher's

epistemological position; the researcher believes knowledge should be co-constructed by the researcher and participant. The researcher also wished to develop interviewing skills and have the opportunity to develop rapport with the participants.

Other qualitative methods such as focus groups were also considered, but due to feelings of shame that may be associated with lower literacy levels (Parikh et al. 1996; Wolf et al. 2007), interviews were deemed to be most suitable. Given that researchers cannot guarantee confidentiality in focus groups, this can pose difficulties when aiming to explore more sensitive topics (Hennink et al. 2011). Furthermore, social dynamics in focus groups can result in more confident individuals dominating discussions (Krueger and Casey 2009). Finally, focus groups can be problematic when using an IPA approach; focus groups generate interactive group discussions, but IPA aims to maintain a focus on an individual's experiences (Smith et al. 2009a; Tomkins and Eatough 2010). It is less likely that using a focus group would produce individual narratives and separating the group patterns/dynamics from idiographic accounts would be challenging (Smith et al. 2009a). Finally, given the focus on highlighting patients' individual views and experiences, methods such as observations were not deemed suitable.

4.4.6 Instruments and tools used for data collection

4.4.6.1 Development of the interview guide

Despite the flexible nature of semi-structured interviews and the emphasis on capturing individuals' experiences, developing an interview guide helps the researcher to consider possible difficulties with question wording or sensitive areas and guides the researcher during the interview process, allowing them to focus and respond more confidently to the participant's story (Smith et al. 2009a; Holloway and Wheeler 2010).

The interview guide (Appendix J) was developed using health literacy research and published guidance on the design of interview schedules. The list of questions was also discussed and tested for clarity and simplicity with clinical colleagues, supervisors and a public contributor (an older adult with falls experience).

Paasche-Orlow & Wolf's conceptual model of the causal pathways linking health literacy to health outcomes (2007a) (Appendix B) provided the framework for the interview guide. Through using available evidence, Paasche-Orlow and Wolf (2007a) propose that health literacy should be viewed as a patient and system phenomenon and it affects three healthcare areas: access and utilisation of healthcare, provider-patient interaction and self-care. Therefore, the interview guide incorporated questions from each of these domains and considered both patient and system factors. Furthermore, given that IPA focusses on individuals' experiences, in addition to exploring issues relating to health literacy, the researcher asked participants about their overall experience of attending the falls clinic, including what they enjoyed and did not enjoy.

The researcher was also influenced by a number of guidelines for developing interview guides (Patton 2002; Flick 2007b; Kvale 2007; Smith et al. 2009a; Holloway and Wheeler 2010; Rubin and Rubin 2012). In congruence with the model employed and guidance on the development of interview guides, questions were included relating to experiences, knowledge and feelings (Patton 2002; Paasche-Orlow and Wolf 2007a). However, given the IPA focus, questions primarily related to the participants' views and experiences. An interview guide with between six to ten main questions with additional prompts is considered optimal (Smith et al. 2009a). The interview guide for this phase of the research included twelve main questions, with follow-up questions, probes and attempts at clarifications based on each individual participant's responses (Kvale 2007; Rubin and Rubin 2012). Although longer than recommended, this number of questions was required to adequately cover the three healthcare areas in Paasche-Orlow & Wolf's model (2007a) and enable participants to describe personal aspects of their overall experience.

Predominantly, the questions were open, to encourage rich in-depth data. However, there were a few instances where closed questions were necessary. For instance, one question involved asking participants about their thoughts on the communication at the falls clinic. However, the prompt involved a closed question: 'Was any written information provided?' This is because the researcher did not want to assume that participants had received or remembered receiving written information. Questions were kept simple, brief and avoided leading the participant

in a certain direction (Flick 2007b). When avoiding leading participants in certain directions and enabling them to respond based on their own perceptions of the experience, it is possible that the resulting questions can sound quite abstract (Smith et al. 2009a). For instance, question three in the interview guide was 'can you tell me about your experience of attending the falls clinic?' This was asked to allow participants the opportunity to discuss what was important to them about their experience of attending the falls clinic. However, it is broad, and prompts such as 'what did you enjoy?' and 'what did you not enjoy?' were used to encourage participants to elaborate.

When structuring interview guides, it is advised to initially pose a straightforward question about a descriptive experience or concrete situation, enabling the participant to relax into the interview (Kvale 2007; Smith et al. 2009a; Holloway and Wheeler 2010); the initial question on the interview guide asked participants to recount the story of their fall. After this initial question, the interview guide followed a logical 'funnel' structure, by starting off with general questions and gradually working towards the more challenging specific questions (Kvale 2007).

4.4.6.2   Development of the sociodemographic questionnaire

In agreement with Paasche-Orlow & Wolf's (2007a) health literacy model (Appendix B), the following participant characteristics were collected using a sociodemographic questionnaire (Appendix K): age, level of education, race/ethnicity, occupation, employment, income, social support and language. The amount of previous falls, gender, presence of health conditions, including visual impairments, hearing impairments and long-term conditions was also information collected in this questionnaire. Collecting all of the above information was important to adequately describe the sample and provide context for analysis.

4.4.6.3   Health literacy measurement tools used within interviews

After the sociodemographic questionnaire was administered, the researcher chose to assess the participants' functional health literacy levels. Therefore, the health literacy measurement tools utilised are described and justified next. The researcher felt it was important to establish the older adult participants' health

literacy levels to inform later data analysis; the literature review revealed a lack of qualitative research papers using this approach (Section 2.4). The following validated functional health literacy measurement tools were chosen for this purpose:

1. UK version of Newest Vital Sign (NVS-UK) (Rowlands et al. 2013).
2. The Rapid Estimate of Adult Literacy in Medicine (REALM) (66 word version) (Davis et al. 1993)

The chosen tools directly test an individual's abilities, as opposed to measures which elicit a self-report of abilities. The REALM and NVS-UK were chosen because they have been validated in a UK population, are quick and easy to administer and assess different dimensions of health literacy (Section 2.5.1). This section also revealed low literacy can be a cause of shame and anxiety; care and sensitivity should be employed when using health literacy measures. Therefore, the researcher administered the health literacy measures after the interview to ensure this did not affect the participants before the interview, it was explained that the purpose of the tools is to help make sure healthcare providers are able to offer the most useful patient education materials and the researcher did not disclose the health literacy score to the participants. The instructions were followed when administering the tools.

4.4.7 Development of the recruitment documentation and recruitment strategy

Given that this phase of the research was likely to include individuals with low functional literacy levels, it was essential to develop accessible recruitment documentation tailored for these individuals. All written information was designed according to guidelines on producing clear written materials and the readability levels established (Gunning 1952; The National Institute of Adult Continuing Education 2009) (Table 6). Due to the complexity of the information included, it is recommended that participant information sheets and consent forms are evaluated using readability formulae (Knapp et al. 2009). In accordance with recommendations, there was white space between paragraphs, bullet points, font size of 14 Point and long sentences and polysyllabic words were avoided where

possible (Weiss 2007; Raynor and Dickinson 2009). The majority of polysyllabic words used were unavoidable, commonly used words and repeated throughout: for instance, 'interview', 'information' and 'communication'. The documentation was also evaluated by a public contributor (Section 4.7).

Written information	Average Sentence Length	Gunning Fog Index*	Reading age (Years)
Recruitment leaflet	13.40	7.25	12-13
Research information sheet	13.73	8.52	13-14
Consent form	11.24	8.68	13-14
Key – *Gunning Fog Index: A readability formula developed in the US (Gunning 1952). To determine the Fog Index, an online readability calculator was used - the percentage of polysyllabic words and average sentence length was calculated from a sample of randomly selected text. It is recommended that healthcare materials are written at US sixth grade or below (suitable for readers at a UK national curriculum level of age 12 or below) (Weiss 2007). Where possible, polysyllabic words should be avoided and sentences should consist of ten words or less (Centers for Disease Control and Prevention 2010). Fifteen percent of the English working-age population have literacy skills lower than US sixth grade (Harding et al. 2011).			

Table 6   Readability of written information provided to participants

Recruitment of older people can be challenging in research (Harris and Dyson 2001): deterrents may include disabilities, lack of transportation, unfamiliarity with research, concerns about safety, time commitments and lower education levels (Shearer et al. 2010). As a result of the above issues, the following recruitment strategies were developed to enhance recruitment and minimise bias:

– Research poster and recruitment leaflets (Appendix E; Appendix F) left in the falls clinic waiting area for patients to help themselves to. Potential participants would then be able to contact the researcher if interested.
– The researcher explained the inclusion and exclusion criteria to the falls clinic staff and encouraged them to offer recruitment leaflets to eligible patients. Potential participants would then be able to contact the researcher if interested.
– The researcher went into the physiotherapy sessions to recruit personally.

As a practicing occupational therapist and due to the emphasis of the research on self-management, the researcher was particularly interested in participants who had therapy input as a result of their falls clinic attendance; therefore it was

through these services recruitment took place. Participants may have had individual physiotherapy sessions or group exercise sessions run at the clinic.

Utilising different recruitment strategies in this manner has the potential to reduce bias (Hewison and Haines 2006); the research site may have been concerned that findings would reflect negatively on the service and could affect recruitment procedures. Asking administrative staff to send out information packs to all recent falls clinic attendees meeting the inclusion and exclusion criteria is an alternative, but it is likely that respondents would have been individuals with higher functional literacy levels.

4.5   Recruitment and data collection procedures

4.5.1   Recruitment procedures

To recruit, the researcher liaised with the falls clinic staff and arranged to come into the physiotherapy sessions. The researcher waited in the falls clinic for an entire morning/afternoon/day, depending on the constraints of the service, and approached consecutive patients attending the falls clinic. After confirming the potential participant was happy to learn more about the research and met the inclusion and exclusion criteria with the therapy staff, the researcher approached the potential participant, briefly explained the research and offered them a recruitment leaflet (Appendix F). If the potential participant was interested, the researcher sent further information including the invitation letter, participant information sheet and consent form (Appendices G-I) in the post to them. Participants were then given the choice of the researcher ringing them to discuss the information verbally on the phone or visiting them. When explaining the research, clear and simple language was used with participants, avoiding the use of technical research terms or unfamiliar terms such as 'health literacy' (Weiss 2007; Salter et al. 2014). Informed consent was obtained by using the 'teach-back' method to establish whether the potential participant understood the information provided (Kripalani et al. 2008). This technique involves asking the participant to explain in their own words what has been discussed.

Caution was taken to ensure the participants did not feel pressured into take part in the research since this would affect the credibility of the findings. To reduce feelings of pressure, the researcher reminded the participants their participation was entirely optional, their healthcare provider would not be informed of their decision and their decision would not affect their medical care. Additionally, to ensure participants were not influenced by financial incentives, participants were not informed about the token of gratitude (a five pound gift voucher) until after they had completed the interview. Participants were offered a minimum of 24 hours to consider their decision to participate.

4.5.2 Pilot activity

As a novice researcher, confidence was developed through conducting practice runs of the qualitative interviews with the supervisory team (Holloway and Wheeler 2010). After a favourable ethical outcome was achieved, pilot work commenced. The first three interviews conducted were considered pilot activity. The same methods were followed. Pilot studies can be used within qualitative research to identify potential practical issues, for example with recruitment and to refine data collection strategies (van Teijlingen and Hundley 2002); therefore participants were encouraged to suggest any necessary alterations to questions. Piloting is also particularly important for a novice researcher to develop their interviewing style or technique (Holloway 1997). This was facilitated by asking the participants to give feedback to the interviewer about the overall experience and how comfortable they felt. The aims for the pilot interviews were to:

1. Identify any practical issues with recruitment and participants' feelings towards recruitment strategies.
2. Develop confidence in conducting interviews.
3. Refine interviewing technique through personal reflection and obtaining feedback on this from participants.
4. Refine data collection methods, including development of the interview guide.
5. Practice use of equipment, including checking it is working.
6. Practice transcription.
7. Enhance data analysis methods.

8. Establish feelings and acceptability of the health literacy measures utilised.
9. Begin to develop reflexivity skills.

After the first three interviews, the researcher established her interviewing style as naturalistic; the researcher aimed for the interviews to feel like a relaxed conversation where the participants could exert control over the direction of the interview. It also emerged that the participants had difficulties with completing the health literacy measures. However, given that this was an important finding and no participants provided negative feedback about this, the researcher continued to use these measures to access participants' opinions about them. No other substantial issues arose as a result of the pilot activity.

Qualitative data collection and analysis is frequently considered progressive, therefore data from the pilot activity is included in the main results (van Teijlingen and Hundley 2002). No significant design modifications were necessary following the pilot activity, therefore no substantial ethical amendments were needed (Flick 2007a). Resulting from the progressive nature of qualitative inquiry, although three interviews were specifically defined as pilot activity to provide clear direction and develop confidence, the researcher continued to reflect on interviews and ask for participant feedback throughout the process (Holloway 1997).

4.5.3   Procedure for conducting interviews

Interviews were carried out in participants' homes. When the researcher arrived at participants' homes, she introduced herself as a postgraduate student at the University of Southampton. Participants were advised interviews would last approximately one hour. To develop rapport with participants and ease them into the interview process, the researcher began by making 'small-talk'. With the participants' consent, a digital audio-recorder was used during interviews; participants were advised that the purpose of using an audio-recorder is to ensure their views are accurately captured. The recording device was tested before the interview. Participants were briefed about the purpose of the research and were reminded that the interviewer is interested in their personal views and there is no right or wrong answer. They were invited to ask any questions, reminded of their

rights to withdraw at any time and asked for their written and verbal consent to continue with the interview.

The researcher then commenced the interview, using an interview guide (Appendix J) which was also shared with the participant (Smith et al. 2009a). The researcher used a conversational style when asking the questions. The interview guide was used flexibly and the researcher utilised effective body language and prompts throughout to allow natural flow of conversation and to avoid intervening too soon. The researcher accepted instances where the participant diverted away from the interview topic entirely and aimed to actively listen to the participants throughout the interview. There were also occasions where the researcher clarified meanings with the participant, but interpreting the insights was avoided during the interview. Finally, the researcher was sensitive to the participants' needs, allowing them to rest and stop the interview at any point. At the end of the interview, the researcher summarised the information provided and asked the participants if they felt this accurately described their experience and whether they have anything further to add on the topic.

After the interview, the sociodemographic questionnaire (Appendix K) was completed with participants. The anonymity of the data was emphasised at this point and the participants were given the option of filling in the form themselves or the researcher assisting. Following completion of the sociodemographic questionnaire, with consent, the participants were asked to complete two health literacy measures (Section 4.4.6.3). It was explained to participants that the tests are not about measuring their individual abilities, but about giving the researcher an increased understanding of patients' communication needs. The researcher did not disclose the health literacy score to the participants. Feelings and attitudes towards the chosen measures were sought after the interviews. Participants were also invited to choose their own pseudonym. Finally, the researcher debriefed the participants on what will happen to the data, asked for any feedback and offered them a thank you card and five pound gift voucher as a token of gratitude.

4.6   Data analysis

4.6.1   Transcription

Given the importance of capturing an individual's experiences, IPA approaches require a verbatim record (Smith et al. 2009a). To ensure no meaning was lost, the researcher transcribed all data from the recordings. Data was transcribed as soon as possible after each interview, and before the next, to aid reflection about the interviewing style used and to review the interview guide. The researcher personally transcribed all of the data from the audio-recordings verbatim, applying a naturalised standardised approach, where every utterance is captured, since it can add to the meaning (Oliver et al. 2005). This included mispronunciations, slang, grammatical errors, nonverbal sounds and background noises (McLellan et al. 2003). This research was concerned with exploring participants' views and experiences, therefore it was not necessary to transcribe the more prosodic aspects of speech, as a discourse analysis study would do. The names of individuals, organisations and settings were replaced with a substitution phrase to maintain contextual information without breaching confidentiality. A transcription protocol (Appendix L) was adapted and used to ensure that this process was standardised for each transcript (McLellan et al. 2003). Personally carrying out this procedure and rechecking the transcriptions for obvious errors, for instance misplaced punctuation which may alter the intent of participants' responses, enhances validity, reliability and increases the researcher's familiarity with the data (Bird 2005; Braun and Clarke 2006).

4.6.2   Use of computer software packages during analysis

The word processing package Microsoft Word 2010 was used for writing up field notes and transcribing data. Microsoft Excel 2010 was used to store sociodemographic data and health literacy measurement scores. This contextual information was referred to throughout the process. However, analysis of the research was conducted using the qualitative data analysis software QSR NVivo 10. Using qualitative data analysis software was chosen in preference to manually analysing the data. There has been considerable debate about the advantages and disadvantages of using qualitative data analysis software. Concerns about

using qualitative data analysis software include that creativity of analysis could be lost, the researcher may inadvertently distance themselves from the data and quantification of qualitative data is possible (St John and Johnson 2000; Welsch 2002). However, using qualitative data analysis software has a number of benefits, including the ability to manage and organise data, easily retrieve codes and have a data trail (St John and Johnson 2000). Using qualitative data analysis software has also been suggested as one way of enhancing rigour in qualitative research (Pope et al. 2000). The researcher argues that qualitative data analysis software is merely an aid for analysis and does not replace any creative thought or the interpretative process. For this research, QSR NVivo 10 was chosen for both pragmatic purposes and the functions it provides. Pragmatically, the license for this product was available at the University of Southampton and training and support is freely provided. Methodologically, use of NVivo can be tailored to the needs of the research, as described next.

4.6.3   Data analysis procedures

This phase of the research used an IPA approach (the principles of which were described in Section 3.3.3.1). Using this approach, the raw data was analysed using the participants' accounts; themes were derived from each individual's description of the experience separately, before cross-case analysis was attempted. This was to ensure that the analysis reflected the participant's individual experiences. It has been proposed that a researcher can use the principles of an IPA approach without following a rigid structure of analysis (Smith et al. 2009a). However, as a novice researcher with no previous experience of using IPA, the researcher found it useful to use the following steps:

1. Reading and re-reading the transcripts
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases

Figure 2   Steps for conducting an interpretative phenomenological analysis (Smith et al. 2009)

Smith et al. (2009a) suggest beginning by analysing the most detailed and interesting transcript. However, the researcher analysed the transcripts chronologically, to support reflection over the development of her interviewing style. The first step of repeatedly reading transcripts enabled the researcher to familiarise herself with the data. Initial analytical thoughts were recorded to 'bracket' them off for a while. Smith et al. (2009a) suggest this type of bracketing can be useful to reduce of the level of 'noise' when first analysing and remain focussed on the raw data; ideas and reflections can be returned to later. This contrasts to bracketing in transcendental phenomenology where the researcher aims to put aside their beliefs for the duration of the analysis (Laverty 2003; Chan et al. 2013). The 'memo' function in NVivo was used to facilitate this first step. These thoughts were reviewed again at a later stage of analysis.

Step two involved making detailed comments on the transcript: descriptive, linguistic and conceptual comments were made using the 'annotations' function in NVivo. Whilst simultaneously referring to the comments made in step two, every section of the transcript was subsequently coded during step three; this was to avoid reaching erroneous conclusions or focussing on aspects of interest to the researcher as opposed to reflecting the participant's lived experience. During this stage, the researcher aimed to condense and summarise the data whilst maintaining the essence of the participants' stories. In NVivo, individual 'node' (code) folders were generated for each participant to maintain the idiographic focus and annotations created in step two were repeatedly referred to.

Step four involved looking for patterns across the themes; superordinate themes were generated for the individual participant. During this step, the researcher went through analytical processes such as abstraction (clustering together similar themes to make higher order themes), polarisation (exploration of oppositional relationships or conflicts between themes), contextualisation (identifying the contextual elements within the analysis) and numeration (analysing possible level of importance by how often a theme arises or the depth in which the participant discusses it) (Smith et al. 2009a). However, care was taken not to quantify the data. During this step, the NVivo 'node' (code) folders and the raw data within them were repeatedly referred to and analytical 'memos' were used to reflect on any connections or conflicts between themes. After searching for connections

across emergent themes for the individual participant, a graphical representation of the structure of the themes was created using the NVivo 'model' function. In agreement with the idiographic focus of an IPA approach, participant portraits were developed for each individual participant. These are intended to provide an overview of the researcher's interpretation of each participant's individual experiences of attending the falls clinic and to provide contextual information to assist the reader in understanding why the participants may have made sense of their experience in a particular way. Creating idiographic 'portraits' has been suggested as a strategy by other phenomenological authors (Wagstaff et al. 2014), enabling the participant to remain a 'whole' person with individual circumstances, traits and experiences (Moustakas 1994). The researcher repeated the previous steps for the next transcript during step five.

Finally, during step six, the researcher looked at the themes arising from each individual participant's accounts and looked for patterns across cases. To support cross-case analysis, separate 'node' (code) folders which pertained to the group were generated in NVivo to avoid the individuals' narratives being lost. During this final step, the researcher maintained the individual experiences of the participants but also searched for commonalities and conflicting themes between cases. When performing the group analysis, superordinate and subordinate themes emerged.

Views offered by the participants on the use of the health literacy screening tools and researcher's observations during administration of these tools were analysed using content analysis (Robson 2011). Content analysis is a systematic and objective means of describing and quantifying phenomena (Elo et al. 2014). It was deemed inappropriate to apply IPA to this data, given that the researcher was not exploring an individual's personal experience, rather their perceptions about tools the researcher had chosen to use within the research. The content analysis was conducted inductively (Elo et al. 2014). The data were open coded, categories were created and the context considered and findings were reported using a table (Elo et al. 2014).

4.7   Ethical considerations

Following peer review, ethical approval was obtained from the Faculty of Health Sciences Ethics Committee. Given that the research involved NHS patients, it also underwent proportionate review by the NRES Committee South West – Exeter (Reference: 13/SW/0030). To ensure research governance, NHS Research and Development (R&D) approvals were also required from two participating NHS Trusts. All approvals were obtained before pilot activity and data collection commenced. Human rights principles of respect for autonomy (respecting individuals' decision making capacities), non-maleficence (avoiding causing harm), beneficence (balancing the risks and benefits) and justice (fair distribution of benefits, risks and costs) were adhered to at all times (Beauchamp and Childress 2008). The core ethical values of informed consent, protection, anonymity, rights to withdraw and debriefing were followed throughout the interviews (Department of Health 2005; Smith et al. 2009a). Table overleaf describes these.

Ethical issue	How issue was addressed in the present research
Protection from harm and anonymity	– Linked anonymity was used in this research. Using this method, complete anonymity cannot be guaranteed but the following strategies were taken to encourage it. – In accordance with the Data Protection Act (The National Archives 1998), any information identifying participants, NHS staff members or the organisation was removed from transcriptions. Participants given option of choosing their own pseudonyms for transcriptions and reports. – Interview data stored on a password protected computer. Any identifiable data including consent forms kept separately from other data in locked storage only accessible to the researcher. – Participants informed they do not have to answer any question they do not want to. – Participants informed they can stop the interview at any time. – Further information and support page provided as part of participant information sheet (Appendix H). – Regular support and supervision for researcher provided. – Researcher adhered to lone working policy as required by the Faculty of Health Sciences.
Informed consent	– Recruitment leaflet, invitation letter, participant information sheet and consent form (Appendices F-I) provided to potential participants. – Information provided in both verbal and written formats. – A minimum of 24 hours given to participants to decide if they want to take part. – Teach-back technique used to confirm participants' understanding (Kripalani and Weiss 2006). – Consent form signed before interviews commenced (Appendix I).
Rights to withdraw	– Detailed in participant information sheet and consent and confidentiality form. – Participant made aware throughout research of rights to withdraw at any point without providing a reason.
Debriefing	– Participants debriefed at end of interview about what will happen to data collected. – Findings sent to participants and to the falls clinic after data analysis (Appendices N-O).

Table 7   Ethical considerations for first phase of the research

Involving the public in research is integral for conducting ethical research, emphasising democratic principles; those affected by research have a right to contribute to the development of publicly funded research (INVOLVE 2012). The researcher spent two hours with a public contributor, an older adult with falls experience. The purpose of this meeting was to obtain a different perspective and improve the quality of the research by reviewing the language and content of research documentation and assessing the acceptability and sensitivity of the chosen methods. The researcher made amendments to the following based on the public contributor's advice: recruitment materials (including the recruitment leaflet and poster, letter of invitation, participant information sheet and consent forms) and the interview guide.

4.8   Summary

This chapter has described the methods chosen for the first phase of the research. The decision to use in-depth qualitative interviews and IPA enabled the researcher to explore the individual participant's views and experiences of the falls clinic, with a particular focus on access to the service, information provision, interaction with healthcare providers and self-management. This guided the researcher to identify facilitators and barriers to meeting older adults' health literacy needs, grounded in participants' lived experiences of attending a specific service. The assessment of participants' health literacy using validated health literacy screening tools enabled the researcher to consider assessed health literacy levels within the analysis and to explore the acceptability and practicality of the health literacy screening tools administered during the interviews. The following chapter explores the findings, each of which is linked to the research objectives for this phase of the research (Section 4.3).

Chapter 5: Findings from first phase of the research involving interviews with older adults

5.1   Introduction

This phase aimed to qualitatively explore the views and experiences of older adults who have low and adequate health literacy levels and had recently attended a falls clinic about their overall individual experience, access to the service, provider-patient interaction, information provision and self-management. The objectives of the research are described in Section 4.3. Three superordinate themes with eleven corresponding subordinate themes are explored and the chapter concludes with a summary section.

In this chapter, the term 'healthcare providers' relates to falls clinic staff members providing clinical care (e.g. nurse, doctor, physiotherapy assistant); the term 'auxiliary staff' describes falls clinic staff members providing supportive services (e.g. receptionists, catering staff, transport staff) and 'other falls clinic attendees' is used when referring to other patients attending the falls clinic.

5.2   Participant characteristics and acceptability/practicality of the health literacy screening tools administered during interviews

5.2.1   Participant characteristics

Nineteen adults were approached to discuss the research. Nine older adults were interviewed, nine declined participation and one individual was excluded due to severe cognitive impairment. Recruitment and data collection took place between the 13th June 2013 and the 6th September 2013. The interview length ranged between 20-87 minutes, mean 42 minutes (SD 22.1).

All participants had experienced at least one fall. All were white British. Nearly all of the participants were widows (seven participants), and primarily they were female (seven participants), lived alone (eight participants) and were independent (seven participants). No participants reported having completed higher education, and all had left school at age 16 or below. The age range was 75-99 years, mean 83 years (SD 6.7). Issues arose with the income question in the sociodemographic questionnaire (Appendix K); many of the participants were retired and could not remember how much they had previously earned or the amount described was irrelevant due to differing currencies. Therefore, this data is not included in the findings. Most of the participants had a self-reported hearing impairment (six participants) and five out of nine participants had a self-reported visual impairment. All of the participants reported having at least one other long-term condition. Table 8 overleaf shows the characteristics of each participant, in alignment with the IPA approach, which values the individuals' experiences. Within Tables 8 and 9, and the following sections, participants are identified using the pseudonyms they were invited to choose for themselves.

Participant pseudonym	Age	Gender	Marital status	Living status	Level of independence	Highest level of education	Previous occupation(s)	REALM score /66	NVS-UK score /6	No. of falls	Visual impairment (self-reported)	Hearing impairment (self-reported)	Presence of other long-term conditions (self-reported)
Daisy	99	Female	Widow	Alone	Family support	Age 16	Retail	64	-	4+	No	Yes	Musculoskeletal
Faye	80	Female	Widow	Alone	Independent	Age 16	Retail and office work	66	3	3	Yes	Yes	Musculoskeletal
Rebecca	81	Female	Widow	Alone	Carers	Age 14	Nurse, catering, office work	66	0	4+	Yes	No	Cardiovascular and renal
Priscilla	75	Female	Widow	Alone	Independent	Age 16	Catering, factory, gardening, retail	51	1	1	Yes	Yes	Musculoskeletal, neurological, endocrine
Janet	79	Female	Widow	Alone	Independent	Age 16	Office work, textiles	59	1	4+	Yes	No	Musculoskeletal
Dylan	80	Male	Widow	Alone	Independent	Age 14.5	Carpentry, media manager (hospital)	65	0	4+	No	No	Musculoskeletal, respiratory
Grace	85	Female	Widow	Alone	Independent	Age 14	Cleaning, waitressing, catering	56	1	3	No	Yes	Respiratory, cardiovascular, endocrine
Ermintrude	84	Female	Divorced	Alone	Independent	Age 16	Finance	66	2	4+	Yes	Yes	Musculoskeletal, cardiovascular, neurological
Phillip	84	Male	Married	With partner	Independent	Age 15.5	Dockyard worker	61	1	4+	No	Yes	Musculoskeletal, respiratory, cardiovascular

Table 8   Participant characteristics for first phase of the research

5.2.2 Acceptability and practicality of the health literacy screening tools administered during the interviews

One of the research objectives was to explore the acceptability and practicality of health literacy screening tools administered during the interview; this section addresses this objective. The NVS-UK (Rowlands et al. 2013) and the REALM (Davis et al. 1993) were used as the health literacy measurement tools for this phase of the research. The content of both of these tools were described in Section 2.5.1. Individual scores are presented in Table 8 above, but the REALM range was 51-66, mean 61.6 (SD 5.3). According to the REALM, a score of 45-60 indicates that an individual is likely to have difficulties with most patient education materials, and a score of 61-66 suggests the individual will be able to read most patient education materials. The NVS range was 0-3 and the mean was 1.1 (SD 1.0). When assessed using the NVS-UK, it is suggested that a score of four or more would identify all individuals with adequate health literacy, a score of 2-3 would suggest a possibility of low health literacy and a score of 0-1 would indicate low health literacy.

As the scores in Table 8 reveal, there is a discrepancy between the health literacy scores participants had on the REALM when compared with the NVS-UK: all of the participants had low health literacy according to the NVS-UK (with one participant scoring 2 and another scoring 3, indicating a possibility of low health literacy), but only three out of nine participants had low health literacy according to the REALM. The sample for this research is too small to make generalisations about this finding, but this discrepancy is considered when discussing differences in the main IPA findings presented below. As a result of this discrepancy, it was difficult to accurately ascertain whether the participants had high or low health literacy. Resulting from this and the researcher accessing participants with both low and adequate health literacy according to the REALM, the original sampling strategy, which involved asking participants a single screening question if the researcher was only accessing individuals with low or high health literacy was not used. As such, no results were obtained or reported from this measure. Additionally, when administering the health literacy measurement tools, issues emerged when using the NVS-UK tool which may have affected the scores, and a content analysis was conducted, the methods of which are detailed in Section 4.6.3). Table 9 details the

observations made by the researcher and comments made by participants whilst they were completing the NVS-UK. These comments were recorded by the researcher immediately after the interview.

Acceptability and practicality of using NVS-UK during phase one (themes identified from content analysis)	Total number of participants (out of 9)	Examples
Issues with administration, possibly relating to memory, hearing and visual impairments, or health literacy difficulties.	3/9	– Unable to administer NVS-UK to Daisy due to self-reported hearing impairment. – Priscilla asked for several questions to be repeated and advised this was due to her hearing impairment. – Faye asked for a piece of paper to write things down on. This was offered but then declined by the participant. Faye then repeatedly asked researcher to repeat/clarify questions, possibly due to self-reported visual and hearing impairments, or possibly memory or health literacy difficulties.
Participants' difficulty with NVS-UK items involving numeracy skills; completion of the numeracy items appeared to make participants feel apprehensive.	3/9	– Phillip commented that the NVS-UK felt like mental arithmetic, which he advised he had not done since being at school 80 years ago. – When Ermintrude first saw the NVS-UK, she asked the researcher, 'you're not going to make me do percentages are you? I'm terrible at them!' – Dylan advised he has difficulties with numeracy whilst completing the NVS-UK.
Participants appeared to perceive health literacy measurement as being like a test.	4/9	– Phillip advised the researcher he felt like he was back at school and doing a test. – Janet apologised to the researcher for not performing very well at the NVS-UK. – Whilst completing the NVS-UK, Grace informed the researcher she did not understand any of it and after completion, she advised the researcher she felt like she had not done very well. – Rebecca advised that she is reluctant to complete 'tests and measurements' but then decided that she was happy to go ahead.

Acceptability and practicality of using NVS-UK during phase one (themes identified from content analysis)	Total number of participants (out of 9)	Examples
Difficulty with metric measurements used in the NVS-UK resulting from unfamiliarity with these measurements.	1/9	– Grace advised the researcher that she does not work in calories and grams, and normally uses ounces and pounds, which she identified as a reason why she felt she had not performed well.
Participants made comments about not knowing much about dieting / food containers, appearing to identify this as a reason for why they were finding completion of the NVS-UK difficult.	2/9	– Janet informed the researcher that she does not know much about calories or dieting. This also appeared to link with her providing a reason for why she perceived she had not performed well. – Phillip advised the researcher that he and his wife do not usually look at food containers or count calories.
Confusion resulting from the allergies question (Q5: Imagine that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream?). The nutritional label has peanuts included in the ingredients, but participants appeared to have difficulties understanding that this question was not about them personally or did not relate to pre-existing knowledge.	3/9	– Phillip advised that he is allergic to peanuts, and normally eats ice cream. As a result of this, he informed the researcher it would be safe to eat. – In response to this question, Dylan advised that someone with diabetes would have to be careful about eating ice cream. – Priscilla stated that she was answering the question about allergies from her knowledge of ice cream labels and knowing that they mostly contain nuts, rather than looking at the label in front of her. She also advised that she had not looked at the label. This was the only question which Priscilla answered correctly; it is possible that Priscilla was trying to hide low literacy levels.

Table 9   Content analysis of issues relating to the acceptability and practicality of using the NVS-UK within this research

5.3   Participant portraits

Participant portraits were developed to help maintain an idiographic focus by describing each individual participant's overall experience of attending the falls clinic (Appendix M).

5.4   Overview of superordinate themes

Three superordinate themes were identified through the analysis. In alignment with the IPA approach, themes which were interpreted as having the most noteworthy impact on the older adult participants' individual experiences were focused on. This impact was established through participants' prolonged attention to these areas and use of language to emphasise their importance. The researcher was committed to enhancing the credibility of the findings, aiming to present the participants' reality in terms of how they made sense of their experience, whilst recognising that this is a double hermeneutic whereby the researcher is interpreting the participants' interpretation of their experiences. Throughout the following sections, the researcher attempts to distinguish between ideas which have resulted directly from the raw data and those which have resulted from interpretation. Each superordinate theme is initially introduced, represented using a diagram and explored using examples from the participants' accounts. Resulting from the idiographic focus of IPA, in addition to synthesis of findings, in-depth evidence and interpretation is presented from individual participants to support each theme (case within theme) (Smith et al. 2009a). When writing up IPA research importance lies with presenting a substantial and discursive account to assist the reader to understand the researcher's interpretation of the participants' sense-making (Smith et al. 2009a). Figure 3 represents the three superordinate themes.

Superordinate themes

Relationship building and trust as a facilitator to meeting older adults' health literacy needs

Tailoring of education and healthcare to older adults' needs and preferences as a facilitator to meeting older adults' health literacy needs

Use of social support to manage health
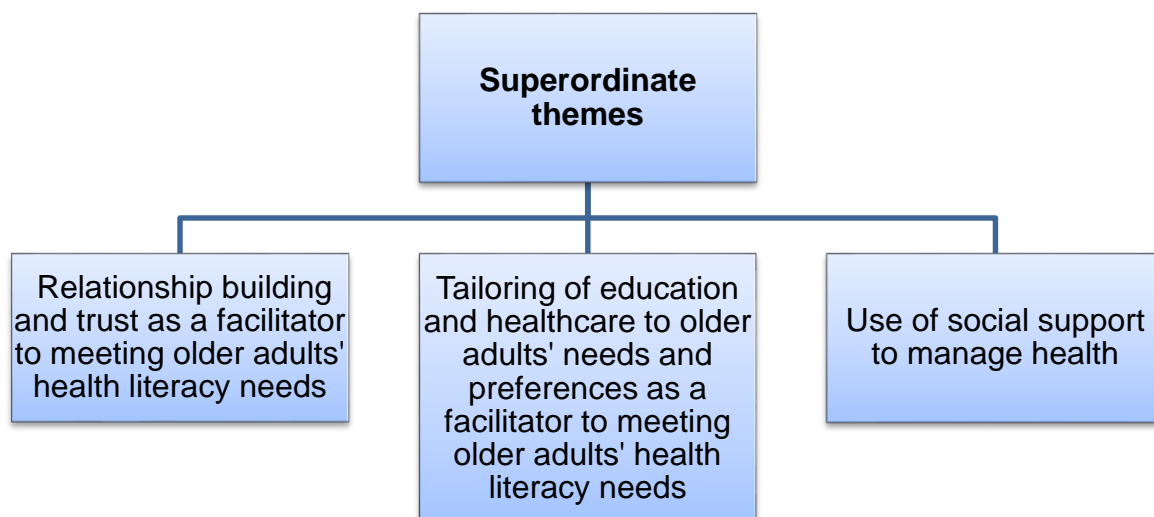
Figure 3   Superordinate themes for first phase of the research

5.5   Superordinate theme one: Relationship building and trust as a facilitator to meeting older adults' health literacy needs

The following sections present the four subordinate themes relating to the superordinate theme of relationship building and trust for older adults. This theme relates to the research objective about exploring older adults' views and experiences of attending the falls clinic to identify possible facilitators to meeting health literacy needs (in this case relationship building and trust) and references are made to participants' assessed health literacy levels.

In this research a patient-provider relationship was understood as an 'interpersonal process that develops over time' (Gantert et al. 2008, p.24); how this connection developed and was built over time through interactions and behaviours is considered in the analysis. The development of positive relationships is viewed as something which both healthcare providers and patients may contribute to. Therefore, relationship building can be seen as a collaborative process, influenced by how each 'party' within the relationship responds to each other. Within the

analysis the researcher considered how the participants discussed relationship building, and whether they viewed this as self-initiated, instigated by healthcare providers or a collaborative process.

The participants' perceptions about the relationships they developed while attending the falls clinic are explored. Whilst participants discussed the social support from and interactions/relationships they had with family/friends/neighbours, the researcher assumed these relationships had primarily developed prior to the participants' attendance at the falls clinic, therefore this is considered separately. Intrinsically linked to the concept of relationship building is 'trust'; relationships are often built on trust, thus justifying including the two concepts within this superordinate theme. This research conceptualised trust as having confidence and belief in the reliability, truth, abilities and intentions of another person (Gilson 2003; Oxford Dictionaries 2015b).

Building relationships and trust appeared to enhance the experiences of the older adults attending the falls clinic. Both of these factors appeared to be beneficial for all participants regardless of their health literacy level. The researcher interpreted relationship building as being particularly important; when participants were trying to make sense of what they enjoyed about their experience of attending the falls clinic many of them implicitly referred to the effective relationships they had with the healthcare providers and auxiliary staff members. As the excerpts in the following sections illustrate, building relationships with the healthcare providers and auxiliary staff members appeared to relax participants, improve their mood and instil in them confidence that staff members were acting in their best interests. These beneficial outcomes seemed to positively affect the participants' overall experience of attending the falls clinic. Resulting from this and the participants suggesting that they were keen to attend the falls clinic due to their appreciation of these outcomes, the researcher felt that relationships developed may have influenced participants' motivation to access and be receptive to the service and the healthcare messages delivered within it. Development of relationships may have also positively influenced the growing trust between the participants and healthcare providers, as perceived by the researcher. The researcher hence noted that trust and the development of positive relations with healthcare providers may

have improved the participants' receptiveness to accessing health information in a face-to-face format, thus possibly influencing participants' health literacy.

Participants described developing positive relationships with auxiliary staff (such as transport and catering staff), building effective relationships and trust with healthcare providers and cultivating relationships and friendships with other falls clinic attendees. Each of these areas are explored individually. Subordinate themes in this section are organised in the chronological order which participants would have met different healthcare providers in the falls clinic; this illustrates how the participants experienced relationship building during the course of their treatment. An overview of the first superordinate theme is provided in Figure 4.

Relationship building and trust as a facilitator to meeting older adults' health literacy needs

Subthemes

- Relationship building involving transport staff

- Relationship building involving catering staff

- Relationship building and trust involving healthcare providers

- Relationship building involving other falls clinic attendees
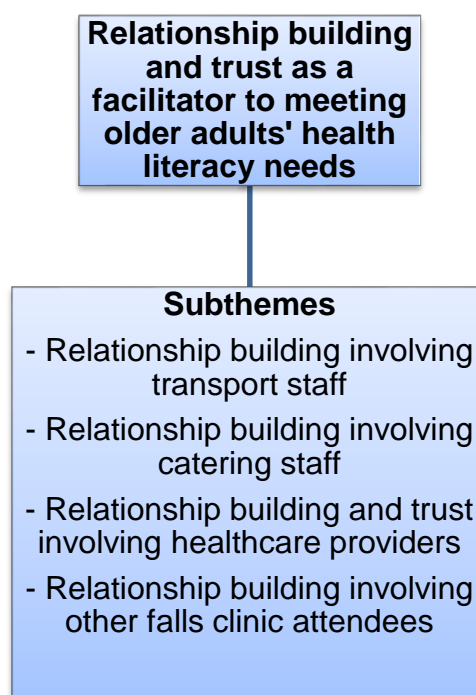
Figure 4   Superordinate theme one for first phase: Relationship building and trust as a facilitator to meeting older adults' health literacy needs

5.5.1   Relationship building involving transport staff

For participants using the hospital transport, this would have been the first face-to-face interaction they experienced with the falls clinic, therefore this is explored initially. Dylan and Rebecca discussed the impact of using the hospital transport on their experience of attending the falls clinic. The other participants either accessed the falls clinic by public transport or family and friends drove them. Falls clinic attendees are offered hospital transport if they are unable to get to the falls clinic. The transportation service has regular drivers and staff who assist patients onto the vehicles and picks up both falls clinic attendees and patients accessing other departments within the hospital site.

Although time spent on the transportation service was not directly part of their clinical treatment at the falls clinic, both Dylan and Rebecca reflected on their positive experience in depth. Whilst they expressed gratitude about being offered the transport service on a practical level, Rebecca and Dylan primarily discussed the relationships they had developed with the transport staff and interactions they had with other falls clinic attendees on the transport service. The researcher interpreted relationship building in this context as being primarily facilitated by the transport staff. For instance, the participants discussed how the transport drivers sang to music, were jovial, provided explanations if they were late and knew the participants well enough to use their nicknames. This positive tone appears to have been set by the transport staff members; Rebecca described how she would rather have this experience than just sit quietly on the ambulance. The researcher felt this implied Rebecca may be guided by the actions of the transport staff; if they had not been outgoing, she may have deemed it more appropriate to sit quietly and not interact with the transport staff or other falls clinic attendees. Rebecca was very positive about her experience of the hospital transport; this experience appeared to have improved her mood and relaxed her to the extent that she felt able to talk to other patients using the service.

> *…some of the drivers are really funny, they're, they're well oldish people, you know say in their fifties and er they sing along to the music on the thing, and you're all sitting there huddled up and everything, and before you know where you are, you're laughing at them, and then you start talking… and it*

makes a big, big difference to how you feel. Rather than just sit there, you know in an ambulance. So… but yes, it's people like that that you need, it is. People that, you know, you can laugh with (Rebecca, age 81, lines 299-306).

Later in the transcript, Rebecca described how she went into the falls clinic sessions feeling relaxed, without apprehension and was pleased with what the healthcare providers had taught her. The researcher interpreted the positive experience on the transportation service as playing a substantial role in relaxing Rebecca prior to her sessions, thus putting her in the right frame of mind when arriving for her clinical appointments. Rebecca's responses indicated she was very receptive to the healthcare information provided at the falls clinic; the researcher felt the overall falls clinic experience (including time spent on the transportation service) may have supported this.

Throughout his interview, Dylan was very positive about the transport staff and described how he had developed a friendly relationship with them. The quote below suggests that Dylan knew the staff members well enough for them to use his nickname. Dylan may have asked the transport staff to use his nickname, given that he requested this when introducing himself to the researcher and he emphasised the importance of someone doing this. For instance, in the quote below the researcher felt Dylan was connecting use of his nickname with how well someone may know him. This may be because use of a nickname can be perceived as more personal, and further, the transport staff remembering to use this may have been appreciated by Dylan. In this situation, the transport staff may have made efforts to develop personal relationships with patients accessing the service through remembering their preferences and tailoring their communication to this.

I can't emphasise just how nice those ambulance crews are… male, female, I know them all very very well, y'know, got to know them all very well, they're all on [insert participant's nickname] terms. You know, [insert participant's first name] if they're being formal with me (laughs) (Dylan, age 80, lines 118-22).

Dylan was also impressed by how attentive the transport staff were when supporting other passengers onto the vehicles, describing them 'as good as gold' and saying that he couldn't 'really fault them'. Although he described how on occasions they turned up late to his house, he did not appear concerned about this; he seemed to understand why and described how the transport staff promptly apologised and explained their reasons. The prompt apology and explanation may have supported relationship building. Additionally, as described above, Dylan appeared to value the use of his nickname; the transport staff using his nickname in this situation may have helped to reduce any feelings of grievance.

> *I think the longest I waited was an hour and a half. And the first thing was the crew, the… driver, and he was on his own that day, er… came over and said to me, y'know, said 'I'm really sorry [insert participant's nickname]', he says, 'I've been to [insert place]', I says, 'say no more' y'know (laughter) (Dylan, age 80, lines 125-28).*

The researcher interpreted that Dylan understood why the transportation was sometimes late because he also discussed road traffic issues and how patients may not be ready when the transportation arrives. Dylan also discussed how he did not mind waiting a long time whilst being on the transportation, because he was 'chatting all the time'.

5.5.2 Relationship building involving catering staff

Dylan and Ermintrude discussed how they had built relationships with the catering staff at the falls clinic. Ermintrude discussed how being offered a cup of tea, coffee, or anything else she wanted relaxed her and improved her mood. Dylan described how after several days the catering staff were already aware of his favourite dessert and he felt that he knew the 'hostess' very well. The researcher felt Dylan's emphasis on the catering staff knowing his favourite dessert was similar to his appreciation of the transport staff using his nickname. This is because it is another example of the falls clinic staff members remembering his preferences, tailoring their approach to this and treating Dylan as an individual. Dylan also appeared to value the hostess attending to him immediately on arrival, indicating that he appreciated them acknowledging his arrival and being attentive

to him. Similarly to the theme relating to relationship building with transport staff, it is possible that the personable atmosphere created by the catering staff assisted the patients in feeling relaxed before their sessions. This may have assisted the patients to feel more ready to access health information. The examples above are also indicative of a non-clinical approach which may have made the experience of attending the falls clinic feel more familiar and less threatening.

> *The minute you sit down in there, again I know her very well, the hostess as they call 'em comes along, 'would you like a cup of tea? We've got so and so, so and so sandwiches, we've got two choices of soup', er… and after a couple of days she'd say, 'I've got your favourite, mince tart with custard' (laughter) (Dylan, age 80, lines 137-41).*

5.5.3   Relationship building and trust involving healthcare providers

Relationships which participants developed with the healthcare providers at the falls clinic appeared to have a positive effect on their experience of attending the service. This appeared to be important for participants with lower and adequate health literacy levels according to the REALM. However, whilst participants with higher health literacy reflected on this extensively, those with lower health literacy often stated that the healthcare provider was 'nice' or 'friendly' but did not elaborate further on this. Participants were primarily overwhelmingly complimentary about the healthcare providers they had seen in terms of their interpersonal skills. For instance, they discussed how the healthcare providers were friendly, positive, humorous and attentive to their needs. The interview guide (Appendix J) did not include questions relating to relationship building; this finding emerged spontaneously throughout many of the interviews and also when participants were asked about their experience of attending the falls clinic in a broad and open manner. The researcher interpreted this as possibly resulting from the older adults' emphasis on the relationships they had built with healthcare providers, which led to them wanting to evaluate and discuss this.

Participants also appeared to trust in the healthcare providers' abilities and intentions, which seemed to have been fostered through interpersonal relations. Given that participants indicated a willingness to participate in their rehabilitation

and adhere to exercise regimes at home (and some participants discussed feeling motivated by knowing they will see the healthcare provider the next week), the researcher interpreted relationship building and trust as possible facilitating factors for participants' adherence.

Relationships developed with healthcare providers through humour and positivity

Some participants described their relationship with the healthcare providers as humorous and positive, which they appeared to value when describing their experiences. Dylan described how he felt like he had formed friendships with the healthcare providers. From Dylan's account below, he appeared to have played a part in relationship building; he described how he personally is 'always skylarking' with the healthcare providers. However, Dylan appeared to have connected his 'skylarking' with why he would miss the healthcare providers after finishing treatment. Therefore, the healthcare providers may have played a part, or reacted positively to Dylan's 'skylarking', hence supporting relationship building. This suggests the healthcare providers fostered an environment which felt non-threatening and open to Dylan, thus creating a more balanced relationship between the healthcare provider and patient.

> *I said to her 'well I'm gonna miss you when I finally finish here' y'know. I said, 'well I really enjoy', cause I'm always skylarking with them y'know (Dylan, age 80, lines 262-63).*

Similarly, Priscilla described personal interactions she had with the physiotherapist as one of the aspects she enjoyed about attending the falls clinic. From Priscilla's excerpt below, the physiotherapist appeared to facilitate relationship building by being jolly, making the sessions fun and sharing aspects of her personal life. Priscilla appeared to respond to this by joking with the physiotherapist and 'having a laugh with her'. This is similar to where Dylan describes 'skylarking' with the healthcare providers above. In Priscilla's situation, the relationship building may have been initiated by the healthcare provider but was positively reinforced by Priscilla's reactions. Priscilla also appeared to attribute this mutually constructed relationship as having a positive impact on her day, and thus on her experience of

attending the falls clinic. Later in the transcript Priscilla discussed appreciating the healthcare providers counting with her, claiming that she would be unable to remember to do this. Priscilla had lower health literacy according to the REALM; the researcher felt that the combination of relationship building achieved through use of both positivity and attentiveness to individual difficulties may have increased the likelihood of Priscilla engaging with the healthcare providers' recommendations.

> *Interviewer: What do you enjoy about going to the falls clinic?*
> *Participant: Everything. Meeting the physio, going through the exercises with her, having a laugh with her, she's very jolly. She makes it fun, we have a laugh over it, and she tells me what she did the night before, her exercise boxing or whatever she does, and I look at her and say, 'well you don't really need it you know'. And we 'ave a laugh, it brightens the day up (Priscilla, age 75, lines 285-91).*

Given that the above excerpt was from Priscilla's perceptions, it would not be possible to ascertain whether the physiotherapist was using this style of interaction consciously as part of therapeutic engagement or subconsciously.

Relationships built with healthcare providers through perceived level of attentiveness

Regardless of their assessed health literacy level, many of the participants appeared to perceive the level of attentiveness shown towards them by healthcare providers as an aspect of the falls clinic which they valued. Participants seemed to infer attentiveness based on the healthcare providers' actions such as recognising when they might be feeling unwell or need assistance and responding to this accordingly. When interpreting the participants' accounts, in addition to participants directly referencing attentiveness, the researcher felt use of adjectives such as 'thoughtful', 'helpful' and 'kind' implied attentiveness when used directly after describing certain actions taken by the healthcare providers. Therefore, the researcher felt the participants appeared to value general kindness and the 'emotional intelligence' shown by the healthcare providers. Emotional intelligence can be defined as 'the ability to engage in sophisticated information processing

about one's own and others' emotions and the ability to use this information as a guide to thinking and behavior' (Mayer et al. 2008, p.503). The healthcare providers' emotional intelligence seemed to make the participants feel safe and may have supported with the development of trust; the researcher interpreted the healthcare providers' attentiveness as encouraging the belief that the healthcare providers were acting in their best interests.

One example of attentiveness which nearly all of the participants mentioned as an aspect of the falls clinic they enjoyed was being offered a cup of tea or coffee. Some participants also described how healthcare providers attended to their physiological needs when they felt unwell. The quote below demonstrates how Priscilla found this attentiveness to be very thoughtful.

> *And if you feel a bit under the weather… they'll [the physiotherapists will] say would you like a cup of tea? And I usually say, 'no a cup of water will do'. So they're very thoughtful (Priscilla, age 75, lines 117-18).*

In addition to offering her a cup of tea, Grace valued how the falls clinic staff members helped her by moving her chair.

> *They make you a cup of tea and they're ever so nice you know, and she [the physiotherapist] always helps me, she moves the chair, 'cause the chairs are quite heavy down there you know (Grace, age 85, lines 450-52).*

Participants also described how the healthcare providers encouraged them to achieve as much as they could but did not push them beyond their limits. Phillip described the healthcare providers as 'attentive' and felt that they looked after him. The researcher interpreted this as also possibly linking with trust, given that Phillip seemed to feel safe, and trusted that the healthcare providers knew his limits.

> *They try to push you, but they don't go over the top, and if they see it's too much for you… they make you sit down… You know the people there, that run the clinic… they're really attentive, and they look after you (Phillip, age 84, lines 308-11).*

This notion of feeling looked after was reinforced when Phillip also discussed the healthcare providers 'putting themselves out' to help him when he suggested something and feeling as if he is having a one-to-one session with the physiotherapist even whilst in a group with other patients.

Relationship building through personalisation of healthcare and recognising patients as individuals

Some participants discussed how they valued written information which recognised them as an individual with personal interests and qualities. For instance, Phillip was very pleased that a letter sent to his GP had described him as a 'lovely gentleman', and asked his wife to find this and read it out to the researcher. Similarly, Dylan was impressed that his interest in carpentry was mentioned in a letter to his GP. The quote below demonstrates how the healthcare provider may have tried to engage with Dylan's personal interests to build an effective relationship with him. Dylan seemed to value the healthcare providers knowing him as an individual and acknowledging his unique skills.

> *Even things like… she put down on the thing about the… models y'know… 'he's a big interest in carpentry and things like that', and she says, 'and has promised that he will bring the models in to show me' (Dylan, age 80, lines 108-10).*

The researcher's interpretation was that participants felt like they were being treated as individuals, which was reinforced when participants described feeling like they were a name and 'not just a number'. This is illustrated by Faye's quote below where she compares the falls clinic to her experiences of an acute hospital. This may link in with the amount of healthcare appointments an older adult may have and a concern that their experiences and skills which have been developed over many years are recognised.

> *You know you're not just a number over there, you're a name. And they call you by your like, [insert participant's first name], Edna, whatever (Phillip, age 84, lines 584-5).*

…you know sometimes when you go up to [insert other hospital's name] you think, oh god I'm in a big crowd or whatever, but they're [healthcare providers at falls clinic] all very, sort of, um, what, how can I say? You feel as if you, they've seen you before, you've seen them before, and it's all sort of on a very friendly basis (Faye, age 80, lines 224-27).

Building trust

In addition to building positive relationships, many of the participants emphasised the importance of having trust in their healthcare provider. The participants did not directly use terms such as 'trust', but the researcher inferred trust when interpreting the participants' accounts in terms of the conceptualisation of trust used for this research. For instance, the participants appeared to believe in the good intentions of the healthcare providers and had faith in their interpersonal abilities and knowledge, as illustrated through the quotes in this section. Development of trust appeared to positively impact the participants' beliefs about the healthcare messages being delivered. For instance, Ermintrude explained in her interview that she was initially very sceptical about the falls clinic, describing how she was adamant that she would not learn anything new. During her first session at the falls clinic, Ermintrude discussed how she was 'bemused' about how the physiotherapist was telling her what to do, and what not to do, in an authoritarian manner.

Yet, yes, at the back of my mind I knew, I knew she knew exactly what she was talking about. But so yes, I think I was bemused that she should speak to me like that. It was almost like going back to school… um… and then… because I'm not you know, I'm not so stubborn, er… I thought well you know open mind Ermintrude, you know… do what she asks and see. And then… when I realised it worked, then… no problems after that. It-it… I-I know it sounds strange but I suppose it was… I needed to be shown that it worked. Just her telling me was no good… but when I realised that what she was saying actually worked… that was it. Then I would accept anything she said after that (Ermintrude, age 84, lines 407-15).

Ermintrude's account above indicates that she developed trust in her physiotherapist after she tried out what was suggested and saw that it worked. This could also be an example of Ermintrude learning by doing (experiential learning). However, the excerpt above suggests Ermintrude had some initial trust that the physiotherapist knew what she was talking about. Ermintrude advised this was at the 'back of [her] mind', and this suggests that although she was initially affronted by the communication style, she had some trust in the content of what was being delivered. Further, despite reporting feeling initially sceptical she advised the researcher that she went back to her second session feeling less sceptical, indicating that trust had developed rapidly. Subsequently, Ermintrude described how after this initial trust was built, she was willing to follow anything the physiotherapist suggested, which appeared to have impacted her readiness to adhere to recommendations and engage in physiotherapy, thus possibly influencing her likelihood of 'accessing' and 'using' health information as per the health literacy definition used for this thesis.

> *…by that time I was well and truly under her thumb (laughter). Er… I went back and just followed whatever she wanted to do with her exercises (Ermintrude, age 84, lines 438-40).*

Rebecca discussed how she felt that the physiotherapist knew what she was talking about, indicating possible trust in the physiotherapist's knowledge levels. However, she also added that the physiotherapist also understood her and acted upon her concerns. This suggests Rebecca felt the physiotherapist actively listened to what she was saying, and responded by taking action, suggesting trust was possibly built through a belief that the physiotherapist was acting in Rebecca's best interests. The excerpt below may also indicate that Rebecca had confidence that the healthcare provider was tailoring the treatment approach to her as an individual. Further, given the positive response from the healthcare provider, this incident may have increased Rebecca's confidence in interacting with healthcare providers, which is crucial for interactive health literacy.

> *She [the physiotherapist] knew what she was talking about. You tell her what was wrong and she knew what you were talking about… and she did something about it… (Rebecca, age 81, lines 523-24).*

Another example of a participant feeling that the healthcare providers listened to him and acted upon his suggestions was when Phillip described the following incident:

> *Philip: 'I'm gonna be cheeky.' She said, 'well what now?' I said, 'you know you gave me a stick the other day'. She said, 'yes'. I said, 'can you change that one to marry up with this one?' I said 'because this one's thinner and shorter… on the holes, you know the adjustments… and you couldn't do it'. I said 'if you went up one, then I'll be higher'. 'Ah yes, lemme have the other one'. She went over, she got the left-handed one, and stuck 'em there together, married 'em up perfect. I'm okay now.*
> **Interviewer: So now you've got two matching sticks.**
> *Phillip: So matching sticks. You know they put themselves out. You know they don't argue or anything like that. They don't say 'oh no, we can't do that, 'cause you've gotta go through OT an' all'. No (Phillip, age 84, lines 339-48).*

The researcher felt Phillip had trust in the healthcare providers' intentions, and felt that if he made a suggestion, it would be listened to and the healthcare providers would act upon this. However, this may have been influenced by Dylan's confidence in making suggestions (possibly indicating interactive health literacy abilities), which was revealed throughout his transcript when he described occasions where he mentioned ideas to his GP, and these were responded to. Phillip had higher health literacy according to the REALM and this may be one indicator of this.

Participants' trust also seemed to be built through an emerging confidence that the healthcare providers were competent. Dylan appeared to trust in the healthcare providers' abilities; throughout the transcript he spoke highly of the healthcare providers' abilities when communicating and perceived all of the healthcare providers to have the same ability when explaining things to him and other patients. This may have been partly about his appreciation of the healthcare providers' abilities to explain things clearly, but also possibly trust in their knowledge, as he also discussed how he had learnt a lot about preventing falls whilst attending the falls clinic.

And I had this little coloured girl, she was a lovely girl. And er… and they were all so good, once they started explaining things to you, y'know, all really the same ability, and such a mixture in the ages and everything, of the nursing staff there, y'know. But er… super… they really are (Dylan, age 80, lines 395-98).

They always explained everything. Yeah, always explained everything, very well explained in simple form y'know, without making people feel like idiots y'know (Dylan, age 80, lines 383-85).

Dylan had higher health literacy according to the REALM and also appeared to have high knowledge levels, as revealed through his use of complex medical terminology in his transcript. Dylan also appeared to have high health information preferences; he was often asking questions and wanted things explained to him. However, as the second quote above reveals, he still indicated a preference for clear communication. It is notable that he emphasised that this communication was delivered without 'making people feel like idiots', suggesting the manner in which clear explanations are delivered is crucial. The researcher felt this linked in with both relationship building and trust; relationship building may have occurred through well-delivered, clear explanations and this may have been supported by the development of trust. Further, Dylan also discussed what he had learnt about causes of falls whilst attending the falls clinic and advised that he felt the 'study of falls must be really interesting'. It is possible that the way in which the healthcare providers communicated with Dylan using both humour and well-delivered clear explanations helped to make falls seem accessible and interesting to Dylan. This may have increased his motivation to learn about falls prevention strategies, and adhere to recommendations, thus possibly affecting his motivation to access and use health information.

Repeated explanations were also emphasised as important to participants. In the excerpt below, Grace discussed how the healthcare providers did not leave her 'dangling' when she had not understood things and were willing to explain things again, which may have assisted with her understanding of the information. Similarly to Dylan's account above, this may have assisted with relationship building and trust.

Grace: You know they explain things to you, you know. They don't leave you dangling, and you don't understand what they're talking about, you know. If I say to them, well what does that mean, she'll tell me again you know.
Interviewer: Oh okay. So they explain it, and then explain it again if-
Grace: Yes, they will do yes. They're very, very nice (Grace, age 85, lines 195-99).

The excerpt above suggests that Grace's 'understanding' of health information was enhanced through her confidence to ask questions and the healthcare provider's interpersonal communication abilities; this appeared to be something which she valued.

5.5.4 Relationship building involving other falls clinic attendees

Irrespective of their assessed health literacy level, many of the participants discussed how cultivating friendships and interacting with other falls clinic attendees enhanced their experience. This appeared to take place in an unplanned and unstructured manner, such as in the falls clinic waiting room or on the transport service, and seemed to be initiated by participants. For most participants this appeared to centre around having company and meeting new people; it did not necessarily involve discussing falls. This is another key area where participants valued aspects of attending the falls clinic which are non-clinical. For instance, Phillip described how he enjoyed having general conversations with other falls clinic attendees about the weather or about the transport service.

There's you know maybe er… a couple of ladies who come up, come there on the… to the clinic, or another gent. You know, and you talk to one another… whether it's about the weather… or whatever, or about their transport… But yeah, it's something different, something to moan about (Phillip, age 84, lines 512-15).

In contrast to Phillip's excerpt above, Dylan emphasised the benefits of discussing falls and sharing falls-related experiences with other falls clinic attendees and described this aspect of attending the falls clinic as 'the most important thing'.

Given that the question the researcher posed to Dylan before his response was asking about what he had learnt whilst attending the falls clinic, the researcher interpreted that the most important things Dylan felt he had learnt whilst attending the falls clinic was what he had learnt from other attendees. In the excerpt below, Dylan described an interaction he had with two falls clinic attendees; he discussed how sharing similar falls experiences led to another falls clinic attendee feeling relieved.

> ***Interviewer: You say you've learnt a bit about the vision side of things, and the hearing, what else do you feel that you've learnt?***
>
> *Dylan: I think the most important thing really is people's personal experiences of er… things that might have caused falls, y'know I mean you see the patients come in every day, people you've been going with for… 2 months, 3 months, and some of them will turn up and they'll look like an owl, y'know (laughter), black face and just little white eyes, er… and y'know for them, they just can't understand. It was only last week that I was sat there listening, and this… woman said y'know, she said 'I just fell'… she said, 'I just can't understand it', and she'd had stitches in the back of 'er 'ead and one side of her face was all… and this woman said to her, 'well I've been doing that for a while', she says, 'I've had a face like yours several times'… and I said y'know, I said, 'well I'm the same, I've looked like an owl on several occasions', y'know, I said, 'and broke several bones'. 'Have you really?!' she says, 'that's almost a relief to hear that', y'know. Yeah, er, er, amazing, amazing (Dylan, age 80, lines 188-99).*

Dylan was the only participant who explicitly referred to learning from other patients' experiences whilst attending the falls clinic. The researcher felt he may have made sense of his time spent at the falls clinic in a different way, viewing it as an opportunity to learn from and share experiences with others. Dylan's positive experience above appeared to take place in the waiting room, initiated by Dylan and other falls clinic attendees, as opposed to being led by healthcare providers. Therefore, although having had a positive effect on Dylan's experience, it could be seen as coincidental that he was sat with other people who were willing to engage in this type of conversation. Some of Dylan's other responses indicated a preference for active involvement with his healthcare; he used medical terms

throughout, reported questioning providers and described feeling responsible for taking control of his healthcare. Many of his responses during the interview indicated possible higher interactive health literacy levels; Dylan may have had higher confidence and motivation to initiate conversations with other falls clinic attendees around sharing experiences and knowledge. In addition to knowledge gained, the extract above suggests that Dylan and his fellow falls clinic attendees may have also found comfort in shared experiences. Although Dylan does not explicitly state this impact on himself, he described the experience of sharing experiences as 'amazing'. Additionally, later in his interview Dylan discussed how his neighbour understands him given that she also experiences pain and has a disability. Dylan also discussed interacting with other patients on the transportation service and explained that he enjoyed attending the falls clinic for the female company, which he missed greatly having lost his wife. Therefore, the researcher felt Dylan enjoyed the company and cultivating friendships, in addition to the opportunities to learn from others.

> *I enjoy going to the clinic… y'see… a lot of females, cause the one thing I do miss is female company (Dylan, age 80, lines 312-13).*

When discussing what she enjoyed about attending the falls clinic, Janet also referenced the 'company' of other falls clinic attendees. Rebecca discussed how interacting with other patients on the transport service had a positive impact on how she felt and relaxed her.

In contrast, Ermintrude advised that she did not like interacting with people and preferred the company of her daughters. However, she advised that activities involving social interaction would not be a barrier to her attendance if she perceived them as beneficial to her health. Ermintrude had higher health literacy according to the REALM; the researcher felt that many of her responses indicated a motivation to learn and a preference for active involvement in her healthcare, thus indicating possible motivation to access and use health information. Therefore, it is possible she would be more willing to engage in health-related activities, regardless of the format, if healthcare providers placed emphasis on the health benefits.

5.6 Superordinate theme two: Tailoring of education and healthcare to older adults' needs and preferences as a facilitator to meeting older adults' health literacy needs

The next superordinate theme relates to the tailoring of education and healthcare. This theme relates to the research objective about exploring older adults' views and experiences of attending the falls clinic to identify possible facilitators and barriers to meeting health literacy needs (in this case tailored interactions) and references are made to participants' assessed health literacy levels.

For this research 'tailoring' is conceptualised as adapting and modifying healthcare delivery to meet an individual's preferences and requirements. The participants discussed aspects of healthcare delivery which did or did not meet their individual preferences and needs. However, it is not always clear whether or not the healthcare providers were deliberately and consciously tailoring education and healthcare to individuals' needs. Therefore, this theme is about the researcher's interpretation of what aspects of their healthcare the older adults appeared to value being tailored. Tailoring of education and healthcare delivery to participants' individual needs and preferences appeared to enhance the older adults' overall experience of attending the falls clinic. The older adults also discussed occasions when they were disappointed about information not being tailored to their needs and preferences, as revealed later in this section. This superordinate theme also links with the first theme of relationship building and trust, because in many instances tailored healthcare supported relationship building and trust. For instance, when the information was delivered according to the older adults' communication and learning style preferences, they appeared to have confidence in the healthcare providers' interpersonal abilities and knowledge levels.

The following section presents five subordinate themes applicable to this superordinate theme. The subordinate themes are focussed around different aspects which the older adults felt were important to be tailored to them as individuals. This included written documentation and verbal interactions. Figure 5 provides an overview of the superordinate theme.
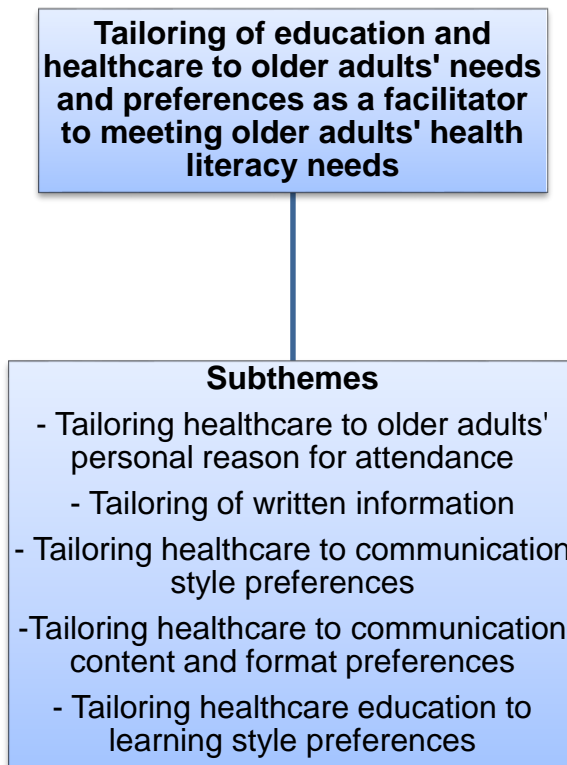
Figure 5   Superordinate theme two for phase one: Tailoring of education and healthcare to older adults' needs and preferences as a facilitator to meeting older adults' health literacy needs

5.6.1   Tailoring healthcare to older adults' personal reason for attendance

Regardless of their assessed health literacy levels, nearly all of the participants identified a personal reason for attendance to the falls clinic which was important to them. It was not clear whether or not the participants had informed the healthcare providers about this. The participants' personal reasons for attendance appeared to motivate them to continue with the sessions and their exercises, therefore this potentially increased their likelihood to access and use health information. Although the participants did not explicitly discuss the importance of the healthcare providers being aware of their personal reason for attendance, they described how paramount it was for them. This may indicate that they would value healthcare providers demonstrating an awareness of their personal motivators, and tailoring healthcare delivery to this by engaging with their personal goals, linking with the earlier section where older adults valued their personal strengths and individual qualities being recognised. Being aware of and tailoring the

approach to a patient's personal reason for attendance may also assist with relationship building. For example, a healthcare provider may initially tailor their approach to someone's personal motivators and this may ultimately result in relationship building and trust.

Grace discussed her motivation to exercise at home as a result of a scheduled holiday to visit her daughter. Given how important this was to Grace, being aware of it and tailoring the approach accordingly may be an opportunity for healthcare providers to maximise motivation for engagement with rehabilitation.

> *I do them [the exercises] when I'm here, 'cause I try walk up and down the hallway there you know. Trying to get myself fit for Florida. Cause of getting the insurance, see, I've got to get insurance, so. And if I've got too much wrong with me they won't give me one (Grace, age 85, lines 161-65).*

Phillip and Ermintrude appeared to be motivated by a desire not to be a burden on their family.

> *I want very much… to be able to go out on my own. I want that very much and I do feel that at some time in the future I hope and pray that with my rollator I can go out on my own. Which means, which means that I'm not so dependent on my daughters, because their, their whole lives now are around me (Ermintrude, age 84, lines 315-19).*

Other participants appeared to be motivated by wanting to see improvements in their abilities. For instance, Dylan discussed how he was driven by aspirations of being fit and healthy. This may indicate that Dylan would be more motivated to access, understand and use health information, and engage in preventive health as a result of his goals for being healthy. Participants also described how pleased they were when they saw improvements in their abilities. Dylan discussed how he was eventually able to perform a balance exercise with just his fingers touching the bar for stability:

> *And I could do that with fingers just touching the bar eventually, so, really good (Dylan, age 80, lines 338-39).*

Some participants were also keen to see a reduction in any barriers to their abilities: Rebecca discussed a strong desire to see a reduction in her pain levels whilst Faye described having lost her confidence and wanting to see increases in this.

Some participants advised that they had not informed the staff about their personal reasons for attendance or goals. This may be especially pertinent given the fact they felt they had positive relationships with the healthcare providers; demonstrating an awareness of these goals could further enhance these relationships.

5.6.2   Tailoring of written information

When reflecting on the written information they had received at the falls clinic, many participants identified a clear preference for information tailored to them as an individual. Some participants were satisfied that information provided at the falls clinic had been tailored to them as an individual. Participants seemed to value health information which was tailored to their individual health needs, and as discussed later in this section, participants did not always seem satisfied that this had occurred.

Most participants advised that they were pleased when copies of letters were sent to their GP, but also addressed to them. However, this was the only comment about tailoring of written information that individuals with lower health literacy made. It was primarily the individuals with higher health literacy according to the REALM who reflected further on this. For instance, Dylan advised that he felt it was important for letters to be addressed to him because it was his responsibility to take control of his healthcare. The researcher interpreted this as empowering for Dylan, and felt that this may be another indicator of Dylan's higher health literacy levels and motivation to engage in self-management.

> *…you're the most responsible person, you're the one that can do something about it. Yeah. And so why not write to me, and they did, the letter was to you, copied to so and so, and so and so (Dylan, age 80, lines 102-105).*

Dylan had not finished his treatment at the falls clinic, but discussed how he would like a personalised discharge summary, with information about what he initially found difficult and which areas he had improved upon. Dylan was still attending the falls clinic and had not received a discharge letter. In contrast, Ermintrude was disappointed with a letter which she had received after being discharged from the service. Ermintrude suggested this letter was very medical in content and did not use any glowing terms to describe her. This contrasts to many of the examples described earlier where participants appeared to value the non-clinical aspects of their experiences, as seen with Philip's appreciation of the letter which described him as a 'lovely gentleman'. Given that Ermintrude felt that she had developed a positive relationship with her healthcare providers whilst attending the falls clinic, it is possible that she felt affronted that this was not recognised when she was discharged from the service. However, when the researcher probed, Ermintrude struggled to fully articulate why she had not liked the letter, but speculated that she may not have understood the letter. As such, Ermintrude may have also been implicitly suggesting the information was not tailored to her knowledge or literacy levels.

> *Perhaps I wanted more glowing terms you know. She's absolutely marvellous. I don't know. I really don't know but I mean she is speaking in medical terms and is a… and er… maybe I didn't quite comprehend what she was getting at, I don't know. I know when I looked at it I thought ooh (laughs) is that all? (Ermintrude, age 84, lines 705-10).*

Ermintrude also critiqued an advice sheet on how to get up from a fall and suggested it could have been more tailored to her individual needs. She advised that she had spent time writing feedback on the advice sheet about which parts were not relevant to her personal situation, but stated she had not discussed this with the healthcare providers. Priscilla also discussed her disappointment at not receiving a written outcome of her initial assessment which described 'her personal results' of the assessment.

It was only the participants with higher health literacy according to the REALM who critiqued information and reflected about whether or not it was tailored to their individual needs, possibly indicating critical health literacy abilities. This may be

because participants were asked about their views on the written information and verbal communication received at the falls clinic, but were not explicitly asked to critique information.

5.6.3 Tailoring healthcare to communication style preferences

Janet, Rebecca and Ermintrude all described the use of a direct or authoritarian style of communication used by the healthcare providers at the falls clinic. The first two participants were positive about this communication style, appearing to view this as a facilitator. However, given that no other communication styles were discussed, it is possible that this was the only style used by the healthcare providers at the falls clinic, and may not have been tailored to participants' preferences. Despite this, the participants placed emphasis on their preferred communication style, therefore tailoring to this may be important.

Considering that Rebecca had higher health literacy according to the REALM and Janet had lower health literacy according to the REALM, this finding did not appear to relate to participants' assessed health literacy levels. The quote below illustrates how Rebecca preferred healthcare providers being direct with her. However, later in the transcript she discussed how this preference may have derived from her previous occupation as a military nurse, where strictness was usual.

> *I prefer people that say 'you don't do it that way, you do it this way!' Well as far as I would say, she knew what her job was, and she knew what she was doing by the way she was telling you… you know she was telling you what to do, and she expected you to do it. Really, you know, properly. I don't mind anybody doing, when they're doing a job like that, doing it right you know (Rebecca, age 81, lines 90-94).*

Janet described how she was told what to do in a direct manner by the healthcare providers, but felt this was 'useful' and delivered in a 'nice way'. In contrast, Ermintrude appeared to be initially bemused or offended by the direct manner of communication. Whilst the use of an authoritarian style of communication appeared to help facilitate trust with Janet and Rebecca, it appeared to be an

initial barrier for Ermintrude. However, later in the transcript Ermintrude described a realisation that the healthcare providers' messages were logical and beneficial to her and therefore became less resistant to the messages. Despite this, Ermintrude never expressed a preference for this style of communication.

> *…after I'd done the walking one foot in front of the other… then to be said oh now turn round… no you've done that all wrong… you know my face, well my face was a picture, wasn't it? (Ermintrude, age 84, lines 102-5).*

5.6.4 Tailoring healthcare to communication content and format preferences

Although participants discussed different communication style preferences, most participants emphasised the benefit of the healthcare providers using clear and simple explanations and language. This finding was irrespective of the participants' assessed health literacy level. For instance, although Dylan described how he felt most of the falls education was 'obvious' due to his previous medical background, he appeared to value the information being delivered in an accessible format. However, crucially, he emphasised that the manner in which the healthcare providers delivered the simplified information did not make people feel inadequate, as discussed in the first superordinate theme. Other participants discussed valuing the information being delivered in a clear and easy-to-understand manner, as evidenced by Grace's quote in the first superordinate theme where she discussed healthcare providers clearly explaining things she had not understood.

Aside from where Ermintrude discussed healthcare providers using overly medical terms in her discharge summary, the participants did not refer to any unclear information that was provided in either verbal or written formats. It is possible that healthcare providers had communicated very clearly with the participants. Alternatively, the participants may have found it difficult to reflect on the complexity of information without having actual examples of written information or opportunities to reflect immediately after a clinical encounter. The participants' self-reported memory impairments could have also influenced this. The

participants appeared to value clear communication, accessible information and repetition, which are all principles of gerogogy.

5.6.5   Tailoring healthcare education to learning style preferences

Dylan, Rebecca, Ermintrude and Phillip all reflected on their learning style preferences. Dylan appeared to value learning by doing (experiential learning) and learning through watching others (observational learning), but identified vicarious learning (learning from others' experiences) as 'the most important thing'. Phillip's preference appeared to be for observational learning, since he described enjoying watching other people exercising and comparing this with his own performance. The researcher interpreted this as indicative of a possible competitive element.

> *And you do the exercises… then you sit down and then you watch the others do it. You thought, did I mess up like that? Or did I do better than that? (Phillip, age 84, lines 658-60)*

Ermintrude and Rebecca appeared to value reflective learning. For instance, they discussed reflecting on the content of falls clinic sessions at home. For Ermintrude, this reflective period seemed to facilitate processing of the information. Ermintrude also discussed the benefits of experiential learning. Her trust in the healthcare providers' messages appeared to have been fostered through a combination of experiential and reflective learning.

> *…but [the falls clinic] was the turning point. It made me… come home and think about what they said and… it then… opened my way of thinking to encompass everything else that didn't come from [the falls clinic], but it did come from [there] if you follow me (Ermintrude, age 84, lines 432-35).*

> *And… although I had the resistance… when I went to the first er session… after I got home and sat and thought about it… I could see that that was sense (Ermintrude, age 84, lines 184-86).*

After reflecting on the session, Ermintrude decided to try out what she had been taught (experiential learning), and described how it was only after seeing it worked

that she was able to accept it. None of the individuals with lower health literacy according to the REALM reflected on their personal learning styles or preferences. However, this may be because the interview guide did not explicitly include questions on this, given that the researcher did not want to lead participants in certain directions. Additionally, those that did discuss how they learnt implicitly reflected on their learning styles, and never explicitly used terms such as 'reflective' learning. Instead, they discussed learning styles by describing what they did, and how it helped, such as how Ermintrude described going home and thinking about what she had been told. This may be because the participants were not aware of different learning styles or were not used to reflecting about their 'learning' and how education is delivered; on various occasions participants were confused when the researcher asked them about their views on communication/information and what they had learnt whilst attending the falls clinic.

5.7   Superordinate theme three: Use of social support to manage health

This theme relates to the research objective about exploring older adults' views and experiences of attending the falls clinic to identify possible facilitators to meeting health literacy needs (in this case social support) and references are made to participants' assessed health literacy levels. House's social support typology (1981) (Section 2.4.3), which includes emotional, instrumental, informational and appraisal support is also considered here. In addition to discussing aspects directly relevant to the older adults' experiences of attending the falls clinics, participants reflected on input from their social support networks and how this linked with management of their health. For instance, older adults appeared to use social support as a strategy for managing their health, and this included support with accessing, understanding and using health information. On many occasions this also linked in with their experience of attending the falls clinic. The following sections focus on the two subordinate themes in connection with the use of social support to manage health; these relate to participants' feelings about their social support and the assistance they have from their social support. Figure 6 provides an overview of this superordinate theme.
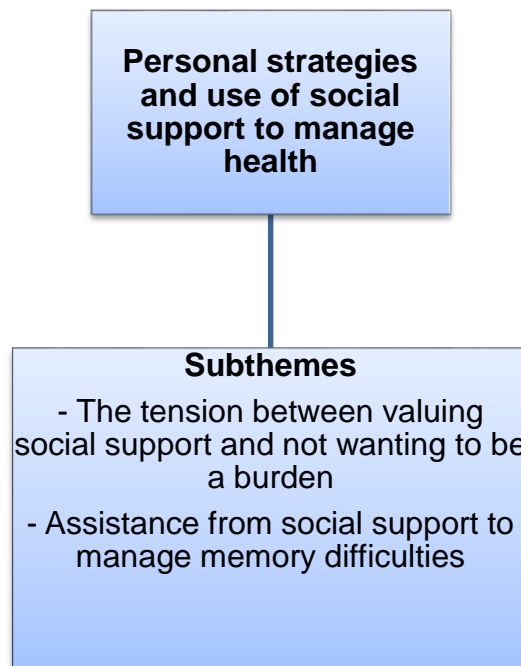
Figure 6   Superordinate theme three for the first phase: Personal strategies and use of social support to manage health

5.7.1   The tension between valuing social support and not wanting to be a burden

Regardless of their assessed health literacy level, all of the participants described social support (including friends, neighbours, family and spouses) as being integral to their ability to manage issues relating to their health. Some participants' social support networks assisted with all aspects relating to their health, including attending all medical appointments, assisting the individual to fill out forms and being actively involved in education and monitoring or encouragement of healthy behaviours such as exercise. Other participants discussed their family members encouraging them to exercise more (informational support). It is possible this is related to decreased motivation to exercise which may have been affected by their lack of understanding about the benefits of preventive behaviours, as revealed through the transcripts. Other participants described their social support primarily assisting with practical tasks such as driving them to appointments (instrumental support). Nearly all participants spoke positively about their social support. For instance, Dylan discussed how his neighbour provided emotional and practical/instrumental support to him.

She has been an absolute god send. She used to come in 'ere, and she said to me I never knew what I'd find… could be laid in the kitchen with your head bleedin', or you'd ring me up, I'd come over and you'd fallen and hit yer head on the side there… er… and as I say I don't think I'd be alive if it wasn't for [insert neighbour's name] quite honestly, y'know. The other thing is, she understands me, 'cause she's in so much pain and such herself (Dylan, age 80, lines 438-43).

Furthermore, participants who had limited social support reflected about how this made them feel. For instance, after the interview Priscilla discussed how she felt unhappy when she attended the falls clinic alone because everyone else had a family member with them. This appeared to be about her comparing herself to others.

Despite valuing social support, some participants also expressed a desire to be less reliant on their family members. This appeared to be linked to concerns about being a burden on their family members. Ermintrude discussed feeling motivated to do exercises to help reduce her reliance on her daughters; one of her personal goals was to be able to go outside independently to limit the burden on her daughters.

5.7.2 Assistance from social support to manage memory difficulties

Most participants referred to the impact of memory difficulties on their ability to function in a healthcare setting. This finding was irrespective of participants' assessed health literacy level. Participants described experiencing difficulties in remembering appointments; when to take medication; written information; staff members' names; the route and outcome of referrals; to use their mobility aid and to wear their falls alarm. To manage their memory difficulties, many of the participants described having support from their spouses/family members. Ermintrude, Phillip and Daisy's spouses/family members discussed attending their medical appointments to ensure information was not forgotten (informational support). Philip described how his wife attended appointments as a result of memory issues relating to residual memory difficulties from a previous stroke. Ermintrude's daughter advised she was able to remind Ermintrude about taught

falls prevention strategies as a result of her attendance. Inviting family members to attend appointments is a principle of gerogogy; these excerpts reveal the older adult participants used social support to assist with managing their health.

> *Yeah I went with all, so if there was anything I could do, so I know what mum should be doing, and then I can help her and say, you know, 'hang on mum you're not quite right with that, you've gotta do this, you've gotta do that' (Ermintrude's daughter, lines 272-74).*

Although the quote above was Ermintrude's daughter's account of the situation, it demonstrates how Ermintrude's daughter supported her, and Ermintrude agreed with the description of support given by her daughter.

Priscilla described how her daughter suggested strategies for remembering to take her medication (informational support) and bought her a 'Dossette box' to assist with medication recall.

> *I did forget them the second week, so I started on the Monday, Tuesday and Wednesday. Normally my daughter advises me to take 'em Friday, Saturday and Sunday so I'd remember (Priscilla, age 75, lines 183-85).*

5.8   Summary

This chapter has explored the findings from the first phase of the research. Relationship and trust building, tailored interactions and social support were identified as facilitating factors for meeting older adults' health literacy needs. These factors were revealed as important to participants regardless of their assessed health literacy level, suggesting it was beneficial to include participants with both low and adequate health literacy levels. However, issues were also identified with the health literacy screening tools, including participants having different health literacy levels according to the different tools used and acceptability and practicality issues. The next chapter explores how the findings from the first phase of the research led to the development of the second phase in an iterative manner.

Chapter 6: Iterative process between phase one and phase two of the research

6.1   Introduction

Three superordinate themes emerged from the first phase of the research. The following sections will consider each of these in turn, and how the researcher's interpretations of each theme influenced the development of the second phase of the research. The chapter concludes with a summary and conclusion.

6.1.1   Relationship building and trust

Relationship building and trust emerged as important when older adults were making sense of their experiences of attending the falls clinic. This appeared to be primarily about relationship building and trust with the healthcare providers, but also extended to relationships with auxiliary staff and other falls clinic attendees. Relationships with healthcare providers were particularly important and the next phase of the research focusses on healthcare providers' views, therefore this section concentrates on this area. From the participants' accounts, it appeared that effective relationships were built by the healthcare providers through use of positivity, humour, attentiveness, clear communication, sharing aspects of their personal self and personalised healthcare. However, in addition to having an effective relationship, the researcher felt that many participants also needed to trust the healthcare provider before becoming receptive to the healthcare information. Participants' level of trust appeared to be influenced by numerous factors, including whether or not they felt the healthcare provider was knowledgeable, the healthcare providers' communication abilities and whether they had any success after trying to implement healthcare providers' suggested strategies. Additionally, the healthcare providers' emotional intelligence, attentiveness, listening skills and personal qualities such as being caring appeared to be important. It seemed that older adults wanted to feel like they were being listened to and treated as an individual, not just a number within a system. Trust appeared to influence the participants' readiness to accept and implement the healthcare messages and their motivation to attend the falls clinic. Linking this

finding back to Nutbeam's health literacy definition (2000), relationship building and trust may have influenced the participants' motivation and ability to access, understand and use health information. It is possible that without positive relationships and trust, the participants may have been less motivated to attend the falls clinic and less likely to be receptive to the healthcare information, possibly influencing their 'understanding' and 'use' of this information. Further, when considering this finding in terms of Nutbeam's (2000) health literacy framework, relationship building and trust with healthcare providers may be paramount when considering 'interactive health literacy'. When viewing health literacy as resulting from an interaction between individuals' abilities and the demands of the healthcare system (Ishikawa et al. 2008), it follows that the interactive abilities of the healthcare providers are also key. The importance of healthcare providers communicating health information in a comprehensible and accessible manner has been previously documented (Section 1.8). However, there has been little focus in the health literacy field on how healthcare providers can improve patients' understanding whilst simultaneously increasing their receptiveness to new knowledge and health information, through building relationships and trust.

Additionally, although the originally devised aims and objectives of the first phase of the research did not seek to explore views about health literacy screening tools, unexpected issues were identified with the use of health literacy screening tools during the research. The researcher felt this unexpected finding was of substantive importance to the health literacy field and warranted further exploration. Several of the issues identified by the participants during the health literacy assessment centred on feeling as if they were being tested, apologising for underperforming and being reminded of their past school education experiences. Consequently, the researcher began to consider the possible impact of using health literacy screening tools with older adults in clinical practice, and the risk that this could damage the relationships and trust clearly emphasised as important by older adult patients.

Little is known about healthcare providers' perceptions about the acceptability and utility of health literacy screening in clinical practice. The researcher felt this warranted further exploration and that it would be beneficial to explore whether

and how healthcare providers feel relationship building and trust is important when meeting older adults' health literacy needs in the next phase of the research.

6.1.2   Tailored interactions

The older adults in this phase of the research valued information being tailored to their needs and preferences. The older adults described instances where they valued written information which was tailored to their individual circumstances and health literacy needs. When considering this finding in terms of the health literacy framework, this may relate to functional health literacy, which tends to focus on written information. However, fundamentally most of the literature on functional health literacy focusses on general guidance around the accessibility of written information (Weiss 2007; DeWalt et al. 2010). Although this is important, few older adults in this research made reference to these issues and instead emphasised the tailoring of the information to them as an individual. In addition to written information, the older adults also appeared to place importance on information being delivered according to their preferred learning or communication styles. The researcher reflected on how this finding may apply to the use of health literacy screening tools or universal precautions.

Another issue identified relating to the health literacy screening tools was that all of the participants had low health literacy according to the NVS, but only three of the participants had low health literacy according to the REALM. Hypothetically, if the NVS had been administered with this specific patient group in clinical practice, healthcare providers may have deemed low literacy written materials necessary and simplified their verbal interactions with all of these older adults. Given that many participants in this research who had higher health literacy according to the REALM expressed a preference for clear and simple communication, even when they had high health knowledge levels, they may still accept the lower literacy materials. However, these functional health literacy measurement tools would not take into consideration individual preferences, a patient's preferred communication or learning style, or any other aspects relating to their interactive health literacy.

In view of these findings, the researcher felt it would be pertinent to explore healthcare providers' perceptions regarding the utility of health literacy screening

tools (such as the REALM and NVS), how use of these tools may impact on the delivery of healthcare and if and how tailoring would result in the second phase of the research. The researcher also felt it would be beneficial to explore whether healthcare providers felt tailoring of healthcare to older adults' health literacy needs is important, and if/how they achieve this.

6.1.3   Use of social support to self-manage health

The final superordinate theme identified during the first phase of the research related to how participants described their social support networks as integral to support them to manage their health and in assisting them to access, understand and use health information whilst attending the falls clinic. For many participants, input from social support appeared to be instrumental (e.g. transportation) or informational, for instance focussed around reducing the risks of memory impairments through using strategies such as having spouses/family members attend healthcare appointments and reminding participants to take medication as prescribed/exercise. As a result, the researcher felt it would be advantageous to explore whether/how healthcare providers consider older adults' social support, in the context of health literacy, in the second phase of the research.

6.2   Summary and conclusion

Based on the above findings relating to older adults' health literacy experiences and views, the researcher felt it would be beneficial to explore healthcare providers' perspectives on the following areas:

- How healthcare providers develop health literacy in, communicate with and educate older adults with varying health literacy levels, including their views on relationship building, trust, tailoring of information and use of social support to manage health literacy needs.
- Healthcare providers' perceptions regarding using health literacy screening tools and universal precautions in clinical practice.

Exploring the above areas from the perspective of healthcare providers was deemed especially pertinent given the importance that older adults placed on the

interactions they had with healthcare providers. This was also essential in meeting the aim of the research: to identify the facilitators and barriers to meeting older adults' health literacy needs, from both patients' and healthcare providers' perspectives. The importance of both patients' and providers' perspectives was also highlighted in the literature review. Qualitative research is commonly conducted in an iterative manner (Kuper et al. 2008). As such, the researcher devised the focus, research questions and objectives and initial analytical framework for the second phase of the research based on the findings from the first phase of the research. Despite this, the researcher wanted to see whether concepts such as trust, relationship building and tailored interactions emerged organically within the healthcare providers' accounts. Therefore, care was taken not to explicitly frame phase two's objectives around these concepts, as can be observed in the next chapter.

Chapter 7: Methods for second phase of the research involving focus groups with healthcare providers

7.1 Introduction

The following chapter describes the methods of the second phase of the research. This phase involved conducting focus groups with healthcare providers. The aims and objectives, research design and specifics of the recruitment, data collection analytical methods are outlined; concluding with ethical considerations and a summary of the chapter.

7.2 Aim

The first phase of the research informed the aims and objectives for this second phase. This phase of the research aimed to qualitatively explore the views and experiences of healthcare providers working with older adults with varying health literacy levels.

7.3 Objectives

- To explore healthcare providers' knowledge and awareness of health literacy.
- To explore healthcare providers' views about identifying older adults' health literacy levels.
- To explore healthcare providers' views about using health literacy screening tools or universal precautions in clinical practice.
- To explore whether or not healthcare providers identify relationship building, trust, tailored interactions and social support as important factors when considering health literacy in older adults.
- To explore healthcare providers' views about the facilitators and barriers to meeting older adults' health literacy needs in clinical practice.

7.4 Research design

7.4.1 Setting and context for second phase of the research

There was one NHS Trust involved in this phase of the research, which is in the South of England and is the NHS Trust the researcher works for. The NHS Trust is not explicitly named within this thesis to assist with protecting the anonymity of participants. This setting was chosen partially because the NHS Trust involved funded the researcher's clinical academic post and had identified an interest in improving their health literacy practices. The NHS Trust involved is a secondary care provider and specialises in community health services. This is important given that this research considers older adults' health literacy needs outside of acute hospital care. For instance, older adults' ability to self-manage their conditions at home is considered. The NHS Trust involved serves a population with high levels of poverty. This is a strength of the study given the associations between sociodemographic status and lower functional health literacy levels (Howard et al. 2006), but there are no data stratified by English regions about health literacy levels.

7.4.2 Sampling

Purposive sampling was used for this phase of the research. Purposive sampling aims to sample a group of people who have certain characteristics which enables the researcher to explore the issues relevant to the research topic (Ritchie and Lewis 2013). This type of sampling allows for systematic comparison (Barbour 2007). In this phase of the research, the researcher was interested in sampling a range of different healthcare providers who work with older adults in different areas of clinical practice.

7.4.3   Sample size and focus group composition

7.4.3.1   Number of focus groups

The number of focus groups the researcher decides to conduct is determined by the comparisons they want to make (Barbour 2007). For these focus groups, the researcher wished to make comparisons between healthcare providers working in different clinical areas, but all working with older adults. Therefore, prior to commencing the research, it was decided that the researcher would carry out a minimum of two and a maximum of ten focus groups. Conducting more than one focus group is important to ensure any patterns or differences revealed are not just a feature of a one-off group (Barbour 2007). Equally, the researcher was aiming for transferability as opposed to generalisability and therefore it would not have been necessary to conduct the number of focus groups needed to represent a population (McLafferty 2004; Kitzinger 2006). Recruiting for focus groups ended when data saturation (where no new understanding would be generated through further groups) had been reached; it has been suggested that between three and six focus groups are usually adequate to reach data saturation (Krueger 1994; Morgan 1997).

7.4.3.2   Number of participants in each focus group

The researcher aimed to conduct focus groups with between four and eight participants (Kitzinger 2006; Barbour 2007): a focus group with less than four participants may risk generating fewer concepts and one with more than eight participants group may inhibit contributions from all members and may be difficult to moderate, transcribe and analyse (McLafferty 2004; Freeman 2006; Barbour 2007). The researcher was interested in capturing in-depth views and experiences; it would be more difficult to seek clarification and explore any differences in views with a particularly large group (Barbour 2007)

7.4.3.3 Group composition

When designing focus group research, it is important to consider the group composition, in terms of who is participating in each group. Homogeneity in group composition in terms of background, but heterogeneity in terms of experience was aimed for in this research (Kitzinger 2006; Barbour 2007; Ritchie and Lewis 2013). The researcher was not solely interested in making comparisons between different professions, but instead wished to explore healthcare providers' views and experiences in context (Freeman 2006). Therefore, clinical teams who usually work together and have similar experiences as a result were invited to participate. Conducting heterogeneous focus groups with pre-existing groups has the advantage of members already feeling comfortable with one another and more closely relating to the experiences of other participants (Kitzinger 2006). For instance, participants in this phase of the research were able to share experiences of working with specific patients known to the entire team. However, issues of hierarchy can also arise when using pre-existing groups; Krueger and Casey (2009) suggest heterogeneous groups can result in some participants being reluctant to disclose information. However, consideration was given to this during the data collection and analysis (Freeman 2006; Kitzinger 2006). Information on strategies used to mitigate this risk can be found in Section 7.5.3.

7.4.4 Inclusion and exclusion criteria for sample with justification

The tables below (Tables 10 and 11) identify the inclusion and exclusion criteria with justification used for participants in this phase of the research:

Inclusion criteria	Justification
Healthcare provider (from any clinical background) works within the NHS Trust involved.	Research and development approvals obtained for this NHS Trust.
Healthcare provider works clinically with older adults.	Research question focussed around older adults.
Healthcare provider works in physical health.	First interview study which supported development of focus group study was focussed around physical health. There may be different health literacy requirements in mental health services.

Table 10   Focus group inclusion criteria and justification

Exclusion criteria	Justification
Individuals who do not work clinically with older adults, for instance receptionists.	Research aims and objectives focussed around the clinical interactions between healthcare providers and older adults.
Individuals who work in mental health.	Research topic focussed around physical health.
Individuals who work in the same clinical team as the researcher.	Conducting a focus group with close clinical colleagues could introduce bias, as these individuals have become familiar with health literacy. Also, potential participants may feel pressured into participating.

Table 11   Focus group exclusion criteria and justification

7.4.5   Use of focus groups

The researcher was interested in gaining a range of different perspectives in this phase of the research and identifying group norms whilst also explicitly using interaction as part of the method (Kitzinger 2006; Barbour 2007; Hennink et al. 2011); therefore focus groups were considered the most suitable method. Kitzinger and Barbour (1999, p.20) define focus groups as any group discussion where the 'researcher is actively encouraging of, and attentive to, the groups' interaction'. Focus groups exploit group dynamics by allowing participants to comment on other members' experiences and points of view and to qualify and modify their opinions (Freeman 2006; Kitzinger 2006). This style of interaction can elicit rich experiential data (Barbour 2007). Similarities and differences in opinions can be drawn out using the interaction inherent in focus groups (Freeman 2006). The following guiding principles of focus groups were followed when designing this phase of the research:

- Encourage group interaction; this is what makes focus groups distinct from a group interview, which aims to ask each participant the same list of questions in turn (Barbour 2007; Redmond and Curtis 2009). It is not essential to cover all of the questions during a focus group; it is important that all participants are given an opportunity to explore the main topic areas (Bloor et al. 2001; Redmond and Curtis 2009).

- The role of the moderator is to facilitate; they should emphasise that they are not an expert on the topic, they are interested in the participants' views and there is no right or wrong answer (Hennink et al. 2011).
- Careful consideration of the topic guide and group composition to stimulate interaction between the participants and not with the moderator (Barbour 2007; Hennink et al. 2011).
- Exploration of differences in opinion (Kitzinger 2006; Redmond and Curtis 2009).
- Emphasising confidentiality within the group, since this cannot be guaranteed by the researcher (Barbour 2007).

Health literacy is a complex area; there is much contention regarding the definition, differing conceptualisations and how it should be implemented within healthcare (Nutbeam 2008; Sørensen et al. 2012). As a result, the use of focus groups provided a platform for healthcare providers to explore and debate these issues in a way which would not be as accessible using other methods (Kitzinger 2006; Hennink et al. 2011).

When developing this phase of the research, the researcher also considered other methods such as interviews and questionnaires. Interviews are useful for capturing individual experiences but do not elicit the multiplicity of different views within a group context as focus groups do (Flick 2007b). Questionnaires are useful for accessing a large sample, but would not provide rich in-depth qualitative data (Maltby et al. 2013).

7.4.6   Instruments and tools used for data collection

7.4.6.1   Development of the focus group topic guide and justification for materials used to facilitate discussion

A focus group topic guide was developed (Appendix T) as recommended when using a framework approach to analysis, and when conducting focus groups (Hennink et al. 2011; Smith and Firth 2011). The topic guide included questions which were developed with the aim of answering each research objective.

Although the same areas were covered in all focus groups, the focus group topic guide was used flexibly, allowing participants some degree of control over the direction of the focus group discussion (Hennink et al. 2011).

When developing the topic guide, the researcher was influenced by a range of guidance on focus group topic guides (Morgan 1997; Barbour 2007; Hennink et al. 2011). As recommended by Hennink et al. (2011), the researcher developed the topic guide with a logical funnel structure in mind; the guide begins with broad opening questions, progresses to more specific questions and finishes with closing questions. It is also recommended to use factual and non-threatening questions initially to put participants at ease (Barbour 2007; Hennink et al. 2011). The topic guide began with a question exploring the meaning of the term 'health literacy' to participants. Although this could be perceived as a challenging question, the researcher wanted to explore participants' initial responses, conceptualisations and understandings about health literacy. This is because the researcher's clinical experiences and the literature review had revealed that healthcare providers lack understanding or knowledge about health literacy. To reduce the risk of participants feeling any discomfort about this question, the moderator reminded them that the term and concept is relatively new. The questions were primarily open, to encourage rich in-depth discussion and to avoid leading the participants in a certain direction (Barbour 2007). However, on occasion closed questions were used to avoid making assumptions. For instance, question three: 'have you ever worked with an older adult that you felt had difficulties understanding health information?' was asked to avoid assuming the participants had worked with, or perceived that they had worked with a patient with low health literacy levels.

The topic guide was also designed and structured around the functional, interactive and critical framework and explored issues relating to health literacy from both the 'risk' and 'asset' perspectives (Nutbeam 2008): questions were included relating to meeting the needs of individuals with lower health literacy levels and development of health literacy. As with the first phase of the research, questions were also guided by the causal model linking health literacy to health outcomes (Appendix B); the focus group topic guide developed for this research considers patient, provider and system factors when conceptualising health

literacy (Paasche-Orlow and Wolf 2007a). For instance, the topic guide included a question on what abilities patients need to have to access, understand and use health information (question two; patient factors); how healthcare providers can help patients develop their health literacy abilities (question eight; provider factors) and whether there are any barriers to implementation of health literacy strategies (question nine; system factors). The topic guide also used findings from the first phase of the research to inform development of the questions. For instance, older adults in the first phase of the research identified tailored information, development of a relationship and trust with the healthcare provider, consideration of learning and communication styles and social support as important factors when making sense of their experiences. To avoid leading the focus group participants in a certain direction, the researcher included these factors in the topic guide as prompts as opposed to main questions. The researcher wanted to see if healthcare providers would spontaneously bring up these factors before asking about them. Additionally, as part of the topic guide, the following health literacy screening tools were utilised to facilitate discussions regarding health literacy screening:

- The Rapid Estimate of Adult Literature in Medicine (REALM) (Davis et al. 1993)
- The Newest Vital Sign-UK (NVS-UK) (Rowlands et al. 2013)
- The Single Screening Question (SSQ) (Chew et al. 2008)
- The All Aspects of Health Literacy Scale (Chinn and McCarthy 2013)

Printed paper copies of these tools were taken to the focus group discussions and passed around. Use of group exercises are suggested as a tool for encouraging focus group participants to engage with one another as opposed to the moderator and to explore their different perspectives in a more natural way (Kitzinger 2006). It was beneficial to use health literacy screening tools for this purpose because the use of health literacy screening has been recognised as a contentious issue (Section 2.5). The specific tools listed above were chosen because they are widely used in the literature and assess different components of health literacy (Jordan et al. 2011). The first two screening tools in the list above directly test patients' abilities and were used in the first phase of the research. Issues were identified

with the use of these two tools in in Section 5.2.2, which was another reason for inclusion of them as stimuli for discussion. As discussed in Chapter Six, the researcher wanted to explore whether any similar issues were identified with the use of these tools by the healthcare providers. The bottom two tools in the list are self-reports of abilities, which were included to see whether or not healthcare providers had a preference for self-report measures or tests of ability. Permissions were obtained to use these tools. The Test of Functional Health Literacy in Adults (Parker et al. 1995) is also a widely used health literacy screening tool, but it is lengthy to administer and the researcher was unable to gain access to it for the research. As a point of comparison, participants' views were also sought on the use of universal precautions as an alternative approach to health literacy screening.

The focus group topic guide was piloted with two clinical colleagues who were not participating in the focus group and an academic colleague. The wording and order of certain questions were checked and altered as a result of feedback.

7.4.6.2   Development of the sociodemographic questionnaire

To enable the researcher to adequately describe the sample and to inform analysis, a sociodemographic questionnaire was developed and used (Appendix U). The questionnaire included basic information on the participants, such as gender, job title, type of clinical team, NHS Agenda for Change pay band (Health Careers 2016), total amount of years in clinical practice and length of time in current post. The Agenda for Change pay band information was collected as opposed to age given that age does not necessarily denote experience, whereas the Agenda for Change grade provides information about whether or not the healthcare provider has a healthcare degree, and provides an indication about their level of experience. Total years in clinical practice and length of time in current post provided further information about amount of experience, which may influence participants' views and experiences about health literacy.

7.5   Recruitment and data collection procedures

7.5.1   Recruitment procedure

Participants were recruited from the NHS Trust the researcher works for in the South of England. To adequately purposively represent the sample, information about specific clinical services was obtained through the website for the NHS Trust involved. Given that the main characteristic of interest was clinical experience of working with older adults, a range of clinical teams were initially identified as likely to work with older adults. The areas of clinical practice and team compositions were then considered. For instance, teams which had a variety of different healthcare providers within them (e.g. occupational therapists, physiotherapists, nurses etc.) were decided upon.

The researcher then contacted managers or gatekeepers of the identified teams. If they agreed to allow their team members time to participate, they were asked to share an E-mail with their teams (Appendix P). The E-mail briefly introduced and described the research, detailed inclusion criteria and provided the contact details of the researcher. Participants decided whether they were eligible to participate themselves. When there were limited responses to the E-mail, one reminder was sent out and/or a telephone call was made.

Potentially interested healthcare providers were sent the participant information sheet (Appendix Q) and were given the opportunity to ask any questions and discuss the research further with the researcher before agreeing to take part. Participants were made aware that their participation is optional and caution was taken to ensure individuals did not feel pressured into taking part.

Given that focus groups took place during normal working hours where participants were being paid, financial remuneration was not offered. However, to optimise recruitment, health literacy resources were provided at the end of focus group sessions and participants were offered a free health literacy workshop run by the researcher. The health literacy resources provided included a list of useful health literacy references, guidance on how to produce clear written materials

(The National Institute of Adult Continuing Education 2009) and the Suitability Assessment of Materials (a checklist to evaluate written materials) (Doak et al. 1996). The health literacy workshop had been delivered previously to healthcare providers, undergraduate students and at conferences (Appendix A) and has received positive feedback. It is tailored to the needs of the attendees, but usually includes a quiz on health literacy, background to the concept and importance of considering health literacy and various interactive activities such as practical exercises using the 'Teach-Back' technique, case studies, group discussions about how medical terminology can be simplified and discussions about how health literacy fits within the workshop participants' daily clinical practice. Potential participants were also informed of the opportunities to critically reflect on their own practice, which aligns with 'Continuing Professional Development' goals (Barbour 2007).

Recruitment of healthcare providers for the focus groups ended when a point of data saturation was met; this was achieved when the researcher could accurately predict the themes which would arise during analysis of the next focus group, and no new codes were being added to the coding framework.

7.5.2 Pilot focus group

The first focus group conducted was considered a pilot group. As a novice researcher, this provided an opportunity to develop moderating skills through obtaining feedback from participants (Holloway and Wheeler 2010). Additionally, responses to the structure of the session, questions used and use of the stimulus materials were elicited (Barbour 2007). During the first focus group, the researcher used a case vignette to facilitate discussion (Barbour 2007; Cutilli and Schaefer 2011). Although the participants did not express negative comments about use of this, the researcher felt that it hindered the natural flow of conversation and therefore did not use it for the remaining three focus groups. Participants in these later groups provided feedback about the focus groups feeling like a natural conversation; removing the case vignette may have assisted with this. The case vignette was originally positioned after question one on the topic guide (see Appendix S for focus group topic guide used for the pilot focus group). As such,

the participants had already begun discussing their views regarding health literacy in a more natural and conversational manner. The case vignette may have been better situated at the beginning of the topic guide, but the researcher specifically wanted to ask participants about their understanding of the concept of health literacy first to get a response which was uninfluenced by lengthy discussions, questions asked or materials provided. Additionally, as a result of the pilot focus group, the researcher was able to prioritise questions based on which ones elicited the most in-depth responses and interaction. Prioritisation was necessary because staying within the scheduled timeslot was identified as important by participants during the pilot focus group. This need for prioritisation was another reason why the case vignette was removed: the case vignette was time-consuming and seemed to produce responses relating to the healthcare providers' understanding of health literacy, which was already being covered within the first question. Questions six and eleven (Appendix S) were removed from the topic guide after the pilot focus group. Question seven focussed on confidence in identifying individuals; it was unnecessary to ask this since responses relating to confidence emerged spontaneously when the moderator asked about how the healthcare providers identified individuals' health literacy levels. Question eleven which was centred on assisting self-management was not focussed around health literacy specifically, and responses pertaining to health literacy and self-management naturally arose in conversations.

Resulting from the progressive nature of qualitative inquiry, although one focus group was specifically defined as a pilot focus group to provide clear direction and develop confidence, the researcher continued to reflect on each focus group and asked for participant feedback throughout the process. Feedback was sought about the overall focus group experience and questions used in the focus group topic guide. All feedback was positive and did not require any further modifications to research design or procedures. Data from the pilot activity is included in the results section.

7.5.3   Procedure for conducting focus groups

For the participants' convenience and to reduce the impact on clinical time, the researcher conducted the focus groups at the participants' office sites. The researcher/moderator and note taker arrived fifteen minutes before the participants to prepare the equipment and room. The note takers differed between focus groups and included two occupational therapists and one physiotherapist. To optimise interaction, the positioning of the participants, moderator and assistant were considered. Participants were positioned in a circle or around a table to facilitate interaction. Where possible the note taker was sat in a separate area of the room behind the participants to avoid distracting the participants. Refreshments were provided to promote a relaxed atmosphere and show gratitude to the participants. The note taker was briefed and trained; their duties were to take notes on the order which participants speak during the focus group to assist later transcription and to distinguish between individual voices to assist comparisons in the analysis.

When the participants arrived, the moderator introduced the purpose of the research and facilitated introductions. The moderator explained the aims and guiding principles of focus groups (Section 7.4.5). Participants were briefed about the use of audio-recording equipment to allow verbatim analysis. To reduce the risk of losing data, this equipment was tested before the groups and measures were taken to ensure data was audible.

The moderator advised participants that the focus group would last approximately an hour and asked about any time constraints they had prior to commencing. Participants were advised that they were able to have comfort breaks and to help themselves to refreshments. Participants were then invited to ask any questions, asked to sign a written consent form and fill in the sociodemographic questionnaire (Appendix U).

The moderator began recording the focus group. A topic guide (Appendix T) was used flexibly to allow natural flow of conversation. Groups commenced with an opening question for everyone to answer to relax and engage participants.

Progression to more detailed introductory questions and then towards transition and ending questions driven by the focus of the second phase of the research ensued. Sessions aimed to achieve a balance between directed discussions surrounding questions that the researcher selected prior to commencing the groups and open-ended discussion of aspects of interest to the participants. If participants disagreed with one another during the focus group, the moderator tactfully probed and explored differences in opinion to ascertain why the participants felt that way. If a group member was silent, the moderator offered them opportunities to engage and was perceptive to their non-verbal cues. If one group member was dominating the discussion, the moderator asked each individual for a response. However, this tactic was used in moderation to avoid stifling interaction. A balance was struck between ensuring the focus groups finished on schedule and providing the participants with an adequate opportunity to express their views about each area.

The moderator debriefed participants after the focus group, allowing an opportunity for participants to raise any concerns and advising participants about what will happen to the findings. Health literacy resources were provided and participants were offered the opportunity of a health literacy workshop at a later date. A contact number for future queries was also provided.

7.6   Data analysis

7.6.1   Transcription

Verbatim transcription was immediately carried out by the researcher to ensure that full immersion in the data was possible (Gale et al. 2013). The transcription procedure utilised for the first phase of the research was also followed for this phase of the research (Section 4.6.1), including use of the transcription protocol (Appendix L). The only deviation from this was that in this phase of the research all transcripts were prepared before analysis was commenced. This is because the framework approach does not have the same idiographic and inductive considerations that IPA has.

7.6.2　Use of computer software packages during analysis

Similarly to the first phase of the research, Microsoft Word 2010 was utilised for writing up field notes and transcribing data. Participants' actual names and codes were also entered into a password protected Word document. Microsoft Excel 2010 was used to detail sociodemographic data and to generate the thematic frameworks. Separate worksheets were created within the spreadsheet to accommodate the entire second phase of the research and enable easy cross referencing. Analysis of the second phase of the research was conducted using the qualitative data analysis software QSR NVivo 10. Justification for use of computer software as opposed to manually analysing the data can be found in Section 4.6.2. Table 12 describes how computer software was used for each stage of the analysis; these stages are described in greater detail in the next section.

Stage of analysis	Type of computer software used
Transcription	• Microsoft Word used to transcribe audio-recordings
Familiarisation with the interview	• Windows Media Player used to listen to audio-recordings • NVivo's Annotations function used to write initial impressions or notes
Coding	• QSR NVivo 10 (Nodes) used to code the data • Microsoft Word used to generate a coding schedule
Developing a working analytical framework	• Framework developed in Microsoft Excel
Applying the analytical framework	• QSR NVivo 10 (Nodes)
Charting data into the framework matrix	• Data entered into framework in Microsoft Excel
Interpreting the data	• Viewing matrices in Microsoft Excel • Viewing coded transcripts in QSR NVivo • Memos in QSR NVivo 10

Table 12　Use of computer software for framework analysis

7.6.3   Data analysis procedures

The framework approach was utilised to analyse the data from this phase of the research, combining inductive and deductive approaches to analysis (Gale et al. 2013); the framework included pre-identified issues which the researcher wanted to explore from the first phase of the research and also from the available literature. However, the researcher was also flexible to new themes emerging. Figure 7 details the procedure for analysis which was followed:

Stage 1: Transcription

Stage 2: Familiarisation with the interview

Stage 3: Coding

Stage 4: Developing a working analytical framework

Stage 5: Applying the analytical framework

Stage 6: Charting data into the framework matrix

Stage 7: Interpreting the data

Figure 7   Steps for conducting framework analysis (Gale et al. 2013)

The first stage (transcription) has already been detailed (Section 7.6.1). Stage two (familiarisation with the interview) involved re-listening to the audio-recording and making notes on any initial impressions. During stage three, the researcher coded each section of the transcripts within QSR NVivo 10. Initially, this was completed inductively, but certain codes based on the research objectives were later incorporated. An initial coding schedule was devised where each generated code was given a definition; this ensured content was coded in a systematic manner.

To increase the credibility of the research and enhance reflexivity, one member of the supervisory team with extensive qualitative experience independently coded two of the transcripts. This part of the process contributed to developing the final coding schedule. For instance, some of the initial codes developed by the researcher were too conceptual in nature; the researcher was able to reflect on this and ground the codes more fully in the raw data. Having initially coded all of the transcripts, stage four involved developing the final coding schedule (Appendix

V). This was developed and refined through reflection, feedback from supervisors and emergent codes. Codes were then grouped together using mind maps, to enable the researcher to see connections between different codes. Using this information, a working analytical framework was generated. Stage five entailed applying the framework to the transcripts using the existing codes and categories. Additional codes were added if any data did not fit with the existing categories. Stage six involved extracting the data from QSR NVivo 10 and entering it into the matrix in Microsoft Excel 2010. Each main theme was 'charted' in the matrix; a row was allocated in the matrix to each participant and the columns were used to represent each subordinate theme. Data were summarised by each category and representative quotes were entered for subsequent interpretation. An example of a matrix representing the second main theme (identifying older adults' health literacy levels) can be seen in Appendix W. Finally, the data in the matrix were interpreted during stage seven; analytical memos were used to assist the researcher to move beyond description to interpretation. The researcher looked for differences and similarities between opinions in the focus groups. Possible reasons for differences in opinion were considered, such as type of healthcare provider, area of clinical practice and level of experience/knowledge. Throughout the analysis, the impact of group dynamics were considered and the researcher aimed to distinguish between individual opinions and the group consensus (Kitzinger 2006).

7.7 Ethical considerations

The same procedure was followed for gaining ethical approval as described in Section 4.7 (University of Southampton ethics reference number: 12154). Research and Development Approvals were required from one NHS Trust and no patients were involved, therefore NHS ethical approvals were not required. All approvals were obtained before pilot activity and data collection commenced.

The methods used in the first phase of the research to protect participants from harm, maintain anonymity and obtain informed consent were also followed for this phase of the research (Section 4.7). The only differences from the ethics procedure described for the first phase of the research were that participants were given a code to protect their anonymity (as opposed to choosing their own

pseudonyms) and ground rules were set regarding confidentiality at the beginning of the focus groups. Participants also signed a confidentiality agreement as part of the consent form (Appendix R). Additionally, the Teach-Back technique was not formally used to assess understanding; it was assumed that all healthcare providers would have an adequate level of literacy, but the researcher did ensure participants were given information in a verbal and written format to ensure informed consent. Research documentation related to gaining informed consent for the second phase of the research can be found in Appendices P-R. Participants known to the researcher were not excluded; the researcher knew three of the participants. However, the researcher did not work directly with any of the participants and the same protocol was followed for all participants, no coercive methods were used for recruitment and confidentiality principles were adhered to by the researcher. Finally, a summary of the research findings was sent to the healthcare provider participants (Appendix X).

7.8   Summary

This chapter has described the methods chosen for the second phase of the research. Changes were made to the focus group topic guide (including removing the case vignette and prioritising questions). The decision to use focus groups and framework analysis enabled the researcher to explore structured aims and objectives derived from the first phase of the research. This allowed the researcher to identify group norms, consensus and encourage discussion about areas relating to the research objectives such as knowledge and awareness of health literacy, identifying older adults' health literacy levels and perceptions about the use of health literacy screening or universal precautions. Through facilitated interaction, the researcher was able to identify healthcare providers' views about the facilitators and barriers to meeting older adults' health literacy needs in clinical practice, and to compare healthcare providers' perceptions about the importance of relationship and trust building, tailored interactions and social support. The next chapter explores the findings from this phase in depth.

Chapter 8: Findings from second phase of the research involving focus groups with healthcare providers

8.1　Introduction

This chapter describes the findings from the second phase of the research, involving exploring the views and experiences of healthcare providers in relation to assisting older adults to access, understand and use health information. The functional, interactive and critical health literacy framework was considered during the analysis. Health literacy was conceptualised from both 'risk' and 'asset' perspectives. The researcher aimed to identify facilitators and barriers to meeting older adults' health literacy needs.

The participant characteristics are presented and five main themes with corresponding sub-themes are explored using illustrative quotes. During this chapter, the term 'healthcare providers' relates to NHS staff working with patients in a clinical capacity (e.g. physiotherapist, occupational therapy assistant). The chapter concludes with a summary.

8.2　Participant characteristics

Eleven teams were invited to take part in this phase of the research. Three teams advised they were unable to participate due to clinical time restraints and/or low staffing levels, including the falls clinic from the first phase of the research. Another team did not reply to the researcher's attempts to invite their participation. Data were collected using four focus groups. Recruitment and data collection took place between the 28th January 2015 and the 24th March 2015. The focus group length ranged between 51 minutes and 74 minutes, with a mean of 62 minutes (SD 11.7).

Chapter 8

Seven different clinical teams from one NHS Trust participated in four focus groups. These included the palliative care service, community neurological service, in-patient neurological service, chronic fatigue service, chronic pain service, home oxygen service and the pulmonary rehabilitation team. All of the groups involved teams who normally work together. These clinical teams work with a diverse patient group, but all work with older adults.

Table 13 shows the participants' characteristics divided by each focus group and Table 14 details the overall participant characteristics for all four focus groups. Details of individual participants are not included given that this phase primarily focussed on groups as opposed to individuals and to assist with maintaining confidentiality.

Focus group number	Team	Focus group composition by gender	Focus group composition by profession	Focus group composition by Agenda for Change grade* (Bands 3-8)	Number of years of clinical experience (years)	Number of participants in focus group
1	Palliative care service	6 females; 1 male	5 nurses; 2 occupational therapists	5 Band 6s; 2 Band 7s	Range: 13-38 Mean: 24.9 SD: 10	7
2	Community neurological service and in-patient neurological service	5 females	2 occupational therapists; 1 clinical psychologist; 1 physiotherapist; 1 occupational therapy assistant	3 Band 6s; 1 Band 8; 1 Band 3	Range: 4.5-9.5 Mean: 6.6 SD: 1.9	5
3	Chronic fatigue service and persistent pain service	7 females	3 clinical psychologists; 2 physiotherapists; 1 occupational therapist; 1 exercise rehabilitation instructor	3 Band 8s; 2 Band 6s; 1 Band 7; 1 Band 5	Range: 4-16 Mean: 11.3 SD: 5.6	7
4	Pulmonary rehabilitation and home oxygen service	2 males; 1 female	2 physiotherapists; 1 occupational therapist	3 Band 6s	Range: 6-13 Mean: 9.7 SD: 3.5	3
Key ***Agenda for Change Grades** (Health Careers 2016) - Band 3: £16,800-£19,655 (roles include occupational therapy assistants); Band 4: £19,217-£22,458 (roles include associate practitioners); Band 5: £21,909-£28,462 (roles include newly qualified nurses, exercise rehabilitation instructors, occupational therapists and physiotherapists); Band 6: £26,302-£35,225 (roles include more experienced nurses, occupational therapists and physiotherapists); Band 7: £31,383-£41,373 (roles include advanced nurses, physiotherapists and occupational therapists, specialist clinical psychologists) and Band 8: £40,028-£82,434 (roles include highly specialist clinical psychologists and other highly specialist healthcare providers).						**Total:** 22

Table 13   Participant characteristics for second phase of the research involving focus groups with healthcare providers

Characteristic	Proportion of sample
Ethnicity	100% white British
Gender	86% female
Agenda for Change Grade	Range: 3-8 Mean: 6.3 SD: 1.1
Number of years in clinical practice	Range: 4-38 Mean: 14.3 SD: 9.8

Table 14   Overall participant characteristics in all focus groups

8.3   Overview of main themes

Five main themes were identified through the analysis, with 12 corresponding sub-themes. Each theme is explored in depth in this chapter, using illustrative quotes. The researcher aimed to go beyond individual cases and provide possible explanations for what was happening in the data (Gale et al. 2013). This contrasts with the focus in the previous IPA phase on the individual and their unique experiences. Therefore, the write-up focusses less on individual cases and more on patterns across the focus groups and the culture within clinical teams.

To provide context for each quote provided, the researcher identifies which focus group it derived from (e.g. FG1: focus group 1; FG2: focus group 2), the participant number within the focus group (e.g. P1: Participant 1) and the profession of the participant (e.g. physiotherapist). Figure 8 provides an overview of the main themes which emerged from the analysis.
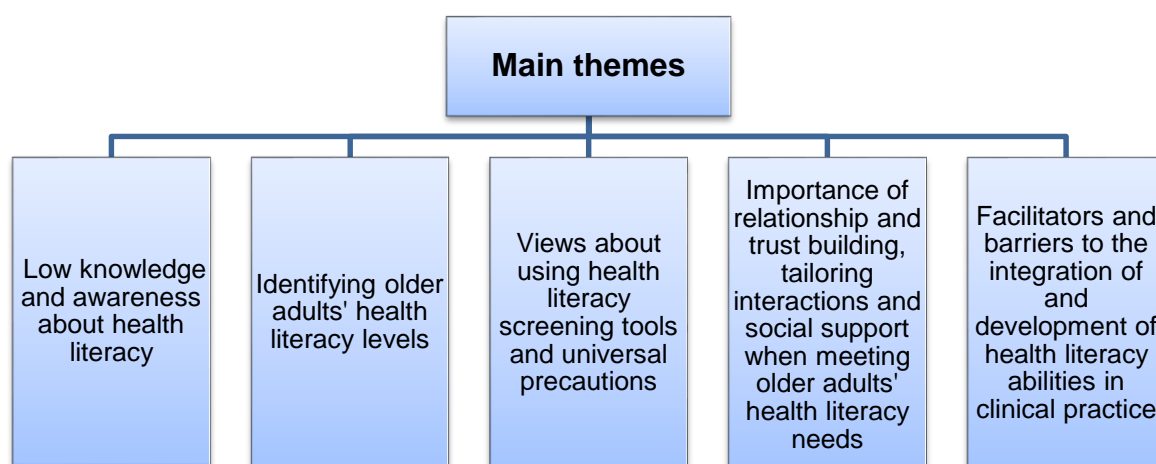
Figure 8   Main themes for second phase of the research

8.4   Theme one: Low knowledge and awareness about health literacy

The first research objective for this phase was to explore healthcare providers' knowledge and awareness of health literacy. To understand healthcare providers' conceptualisations of health literacy before asking more in-depth questions, the first question in the topic guide (Appendix T) was about the meaning of health literacy to the participants. Given that the healthcare providers' levels of prior knowledge and awareness about health literacy could have influenced their responses in the focus groups, this could have impacted on their understanding of health literacy, and consequently their responses to questions exploring their views about recommended health literacy strategies. Considering the possible impact on other themes, this theme is explored initially. Healthcare providers' prior knowledge and awareness of health literacy is considered by exploring their perceptions about their knowledge of health literacy and also the researcher's interpretations about their knowledge levels. Subsequently, the healthcare providers' understanding of health literacy as a concept is explored. This is compared and contrasted with the conceptualisations of health literacy adopted for this research (Sections 1.4; 1.6). Figure 9 provides an overview of this theme.
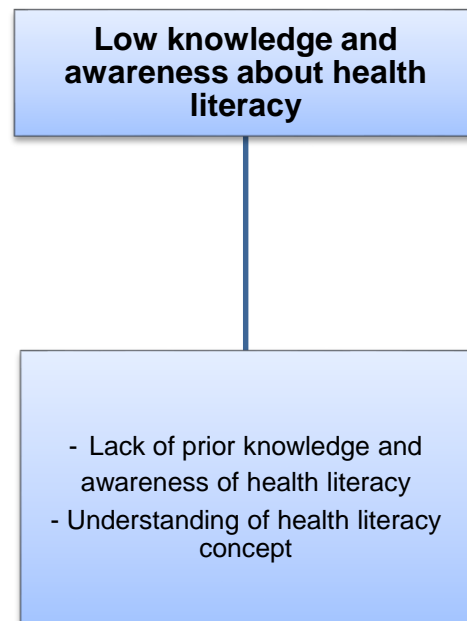
Figure 9   Main theme one for phase two: Low knowledge and awareness about health
            literacy

8.4.1   Lack of prior knowledge and awareness of health literacy

Healthcare providers' perceptions about their knowledge levels

Participants in all four focus groups advised that prior to the focus group they had
a lack of knowledge about health literacy. Several participants advised that they
had not come across the term before: 'I haven't heard the term, like health literacy
really before today' (FG2, P3, physiotherapist, lines 702-3). The participant below
(chronic fatigue service) readily acknowledged that she had looked up the term
when asked to participate in the research.

> *Well if I am really honest, I, when you, when I got the E-mail about it I kind of*
> *thought, what, what's that? And it wasn't really something I had even thought*
> *that much about, so I did have to look it up (laughter) to see whether I*
> *understood it or not (FG3, P1, occupational therapist, lines 7-9).*

In contrast, one senior nurse in the palliative care focus group gave a fairly
comprehensive definition of health literacy when the researcher asked about what
the participant understood health literacy to mean:

To me it's um… about patients understanding not only the jargon that um… is used within the NHS and healthcare services, um… but navigating their way around the services… finding out who does what, where, where it happens… um… the… communication skills, or lack thereof within the professionals that they see… both written and verbal (FG1, P2, nurse, lines 8-12).

Despite giving a definition of health literacy which corresponds with some of the risk-based perspectives of health literacy, the researcher noted that the participant whispered to a colleague that he had looked it up on the internet. The participant may have experienced social desirability bias; it is possible that he was keen to show a certain level of knowledge in the focus group, which may have been influenced by his level of seniority within the team (Band 7 nurse). Both excerpts above revealed that participants were uncertain about health literacy before being invited to participate in the research and keen to ensure they had understood the term correctly by looking it up. The first participant was the healthcare provider which the researcher initially contacted; it is also possible that she wanted to understand the concept before discussing the research with her colleagues.

Healthcare providers' levels of knowledge about health literacy

Participants in the focus groups also revealed a lack of knowledge of health literacy, as interpreted by the researcher, by making comments about health literacy which are not supported by the literature. For instance, one participant in the neurological service focus group (Participant 3, physiotherapist) discussed an example of an individual with low literacy and advised that this was her 'only experience' of working with an older adult with low literacy. Given the high prevalence of low literacy (Section 1.3) and the fact this participant had worked clinically for six years, it seemed unlikely that this was the physiotherapist's only experience. This belief may have resulted from not being attuned to identifying individuals with low literacy levels: in this participant's example, the patient's family had disclosed the patient's literacy issues. In contrast, a participant in the pulmonary service focus group demonstrated some health literacy awareness by suggesting that sociodemographic factors may influence health literacy levels within certain patient groups.

> *I think it's also different from one client group to the next as well, that's my understanding of it. For instance, in COPD… the sort of health literacy levels of those patients might not um, might not achieve the same as another cohort of patients with a different disease, or with a different condition… Um… possibly due to sociodemographic reasons. So um… areas of um social deprivation, perhaps where there's higher instances of certain conditions and poor access to health er… poor access to education, and those kinds of things (FG4, P1, physiotherapist, lines 17-24).*

8.4.2   Understanding of health literacy concept

The way in which healthcare providers understood and conceptualised health literacy within the focus groups may have been influenced by their prior knowledge of health literacy and the discussions with other participants in the focus groups; this is explored next.

Primarily, participants focussed on functional literacy abilities, written information and basic understanding of this information; akin to the functional health literacy definition. Despite the researcher using a more broad definition of health literacy when asking questions, the participants often discussed patients' 'reading', 'writing' and 'literacy' skills. For instance, one participant discussed how sometimes it is not important to know about a patient's literacy abilities when doing certain activities with them:

> *And sometimes it doesn't matter if you don't know, because what you're doing doesn't impact on whether they can read or write (FG1, P7, occupational therapist, lines 477-49).*

The participant above focussed on reading and writing abilities throughout the focus group, suggesting she may have conceptualised 'health literacy' as only being about functional literacy.

Participants also emphasised the importance of healthcare providers' skills in providing information to patients, thus appearing to recognise health literacy as an interaction between patients' skills and the demands of the healthcare system.

Despite this, participants frequently described health literacy as being about 'providing information' to patients, as opposed to education being a collaborative process. Their understanding of health literacy appeared to be more aligned with a pedagogical style of healthcare education.

> **Moderator: What kind of abilities do you think that someone needs to have to fully access, understand and use health information?**
> *I suppose reading. Because we give a lot of written information to people so being able to read… and to understand that as well. I suppose that's up to us to present it at a level that is appropriate to that person. If people can't read, then it's up to us to find an alternative way of presenting it (FG3, P1, occupational therapist, lines 40-43).*

The participant above stated it is 'up to us' to find alternative ways of presenting information, indicating she perceives it as her responsibility to provide information in a helpful format, but possibly suggests the patient may not be included in this process. Further, the excerpt below demonstrates that another participant had some awareness that patients may have different levels of health literacy, but she used terms such as 'we're providing' and the patient is 'receiving' which suggests the healthcare provider may be inadvertently perceiving her role as an information provider and patients as passive recipients of health information.

> *We started this sort of little debate just a while ago, thinking what was it? And the understanding of it… so my understanding is about how we're, how we're providing information and how the patient or client is receiving that information and their level of understanding… about whatever we're trying to put across to them. Um… and I suppose that is on a spectrum as well, so kind of understanding where that person might be… and how to pitch the information (FG4, P2, occupational therapist, lines 7-12).*

The excerpt above also reveals that the participant had a prior lack of knowledge about health literacy. This 'debate' may have resulted from the invitation to participate in the focus group.

One participant discussed how an individual with low functional literacy levels may be able to develop coping strategies to effectively manage their health, and mitigate the risks of low literacy levels. This demonstrated some understanding that illiteracy may not necessarily mean that someone cannot manage their health. However, the focus in the example below appears to relate to a patient managing their functional health literacy needs in terms of medication management, and does not consider whether or not the patient understands why they are taking certain medications. Although the healthcare provider does allude to possible interactions with the patient where she perceived that the patient understood what she had told him, this also indicates that the patient is a passive recipient of health information.

> *Some people that we see who haven't got literacy of any kind, but it doesn't, but it doesn't mean that they don't, but they still can understand what you're telling them, and they can identify medicines and so forth by their colours and shapes (FG1, P1, nurse, lines 42-44).*

Although most participants appeared to perceive health literacy as being about functional literacy abilities, the psychologist in the neurological service focus group discussed health literacy as relating to the ability to discriminate between good and bad quality information: a definition more similar to the concept of critical health literacy. The participant in the example below also discussed how patients may seek information independently of their clinical appointments.

> *I think for me, really what the core point is to discriminate between good quality and bad quality information. I think a lot of the time people will say to you, 'I've been on this forum' or 'I've joined this group' or something [P4: yeah or Facebook or something] and they're maybe a little bit concerned about… the accuracy, or the reliability, or the… usefulness of that information really. So I think beyond the kind of the cognitive ability and the… the computer literacy… it's about making… assessments of the information they're reading and knowing how evidence-based it is (FG2, P1, psychologist, lines 115-22).*

The researcher felt the neurological psychologist's emphasis on information seeking and the critique of health information may have derived from her focus on assessing cognitive skills and the culture of self-management within this team. Despite this, the psychologist remained primarily focussed on written information. Health literacy was rarely conceptualised as an asset which can be developed in patients over time. Although the psychologist recognised the importance of critical analysis abilities, she did not make suggestions for improving patients' abilities. However, one participant in the pulmonary service alluded to the possibility that patients' health literacy can be developed.

> *…actually that's part of what will affect what people can take on board information wise, is what their baseline is. What is their initial understanding of something? And then, how does that build and that grow? (FG4, P3, physiotherapist, lines 499-501)*

Similarly to the neurological team, the pulmonary service team appeared to place emphasis on self-management of conditions and therefore this could have influenced the physiotherapist's understanding of health literacy as a concept.

Healthcare providers' lack of prior knowledge and awareness of health literacy appeared to have an impact on their suggested strategies for identifying older adults' health literacy levels. Additionally, an older adult's health literacy needs may only be able to be met in clinical practice when the healthcare provider has some awareness of their health literacy levels. Therefore, identification of older adults' health literacy levels is explored next.

8.5   Theme two: Identifying older adults' health literacy levels

The second research objective was to explore healthcare providers' views about identifying older adults' health literacy levels. The healthcare providers identified a range of strategies and their perceived facilitators and barriers to identifying older adults' health literacy levels in clinical practice. These areas are explored in the subsequent sections. Figure 10 provides an overview of this theme.
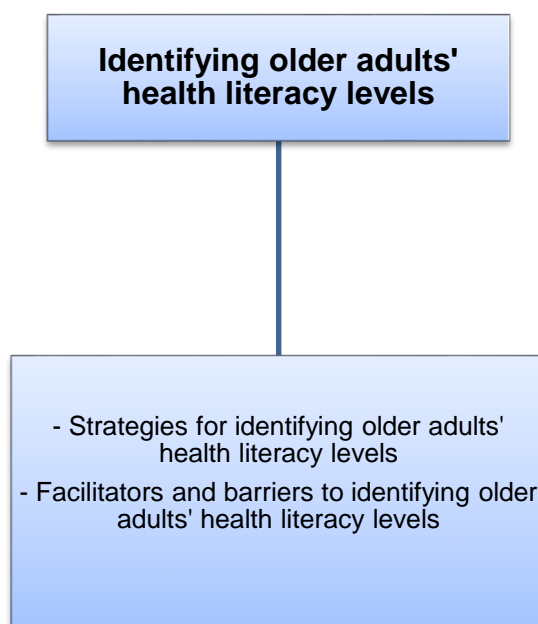
Figure 10   Main theme two for phase two: Identifying older adults' health literacy levels

8.5.1   Strategies for identifying older adults' health literacy levels

Strategies suggested by participants for identifying older adults' health literacy levels varied according to individual participants, professions and teams; there was no standard practice. None of the participants reported using any formal measures of health literacy. This may be because healthcare providers had low knowledge and awareness of health literacy. This low knowledge could also be another reason why the healthcare providers primarily focussed on identifying functional literacy abilities.

Picking up verbal and non-verbal indicators

Many healthcare providers discussed using verbal and non-verbal indicators that older adult patients have low health literacy levels. The researcher interpreted these verbal and non-verbal indicators as tacit cues about health literacy, inferred during interactions with patients, as opposed to resulting from directly asking patients or completing formal assessments. Picking up indicators was suggested as a strategy within all four focus groups; participants described specific observations they made which they felt indicated a patient has low functional literacy or low health literacy.

Some of the indicators directly resulted from healthcare providers' assessments. For instance, the psychologist in the neurological service focus group discussed making assumptions from patients' education and occupation history, obtained during the initial assessment. However, as illustrated in the quote below, these indicators were used alongside formal assessments of patients' abilities, reinforced where the psychologist discussed using educational and occupational history to 'build up a bit of a picture':

We do all sorts of things like school or educational and occupational history. Um… and I suppose you do make certain assumptions on the basis of that. You know, someone says to you, you know, 'yes I went to University' or you know, 'I've worked in certain jobs', you start to build up a bit of a picture about the level someone might have been functioning at before their illness (FG2, P1, psychologist, lines 394-97).

Some of the nurse participants described picking up on cues regarding patients' reading ability during medication reviews.

I think that us nurses, because we always go through the patient's drug list. Um… then that's a very big indicator… um… that the patients can't read or… have very poor reading skills (FG1, P2, nurse, lines 457-59).

When asking about identifying health literacy levels, the researcher used a holistic definition of health literacy, but the excerpt above indicates that this nurse was primarily considering identifying patients with low functional literacy abilities. The nurses may have been using this strategy as a way of seamlessly building literacy assessments into their standard assessments; a medication check is perhaps an assessment which patients would expect from their healthcare provider. Similarly, participants in the persistent pain and chronic fatigue service focus group discussed picking up indicators about patients' health literacy when observing them filling out forms, which is part of their normal treatment processes.

But I think because we have a fair amount of form filling, in, um… that it becomes quite evident quite quickly if they have difficulties with reading and writing. Um… because we will give them forms in the session, um… to

> *complete, so like outcome measure questionnaires and things like that, I*
> *guess is the first thing that they get. So we tend to pick up on it, fairly early*
> *(FG3, P3, physiotherapist, lines 525-29).*

Similarly to the palliative care focus group, the excerpt above reveals the
healthcare providers in the persistent pain service/chronic fatigue service focus
group were primarily discussing identifying individuals' lower functional literacy
abilities. This team delivered treatments in groups; patients may feel
uncomfortable if they have to disclose literacy issues in front of others as a result
of being unable to fill in the forms.

The participants also inferred their patients' health literacy levels from verbal
interactions. One participant in the neurological service discussed identifying an
older adult patients' health literacy difficulties through his use of simple language.

> *I think it was evident in his speech, that he was using very simple English*
> *language (FG2, P4, occupational therapist, lines 270-71).*

Patients' level of responsiveness to information and interaction during education
sessions was also seen as an indicator of lower health literacy. The psychologist
in the persistent pain service suggested this may not necessarily indicate that the
individual has not understood and discussed how the patient may in fact not agree
with the information. However, it is possible patients may have low confidence
when interacting in groups; using this strategy could lead to the incorrect
identification of lower health literacy in patients.

> *…if someone sits and I suppose there's not as much interaction, you kind of*
> *get a sense for, have you got that? Or maybe it's just that they don't agree*
> *(FG3, P6, psychologist, lines 464-66).*

In addition to levels of interaction, participants in the chronic fatigue and persistent
pain service focus group described using non-verbal indicators of low health
literacy such as body language and facial expressions.

…if they're not looking engaged, then you probably know they're not getting everything. Um… and obviously if they drop out of groups, they certainly aren't. So um… I think that's yeah… and if you can do assessments and sort of ask and check. But it's more just a looking [another participant: yeah] [participant 005: you can tell]… if they've sort of got a frown, or you know [another participant: yeah] whatever, then you know (FG3, P4, psychologist, lines 454-59).

Although the participant in the quote above acknowledged that healthcare providers can do assessments and check understanding, through her use of language, it seemed that she was more reliant on picking up cues based on an individual's body language and facial expressions. This participant did not discuss how frowning or not looking engaged could indicate disagreement, boredom or high levels of pain or fatigue, and may not necessarily be indicative of low health literacy. However, another participant in this focus group discussed how using these types of indicators can sometimes result in healthcare providers reaching erroneous conclusions about a patient's health literacy status.

And there's often surprises because there are often people, I know I've been aware of that I've looked at the way they've sort of, their body language [another participant: mm] or their facial expressions and been thinking they're not, they're just not with me at all on this [another participant: yeah]… but then when you have the discussion with them over the phone, they, they can say all the right things. So there can sometimes be a mismatch there between what you think from the person's body language to the reality of the situation (FG3, P3, physiotherapist, lines 496-502).

The participant's example above relates to patients having understood information when the healthcare providers had perceived that they had not from their facial expressions. It is possible that levels of understanding of patients who appear to have understood during sessions would not have been checked in this same way.

Finally, participants discussed patients avoiding certain activities as another indicator of low health literacy. This included behaviours such as avoiding form filling, dropping out of groups and requesting phone calls.

You pick up cues when they're very reluctant to ever do anything, like they say, 'oh always phone me yeah, there's no point sending me a letter'. Or they, you know a form comes round, and they say, 'well this is, this is far too long, I can't possibly do this' (FG1, P7, occupational therapist, lines 141-43).

Asking older adult patients about their functional literacy abilities

This section relates to participants directly asking older adults questions about their functional literacy abilities. In the neurological service focus group, healthcare providers described asking patients about their reading/writing abilities as part of a formal assessment of patients' abilities.

…you'll always say, 'oh how is your reading and writing?' It's part of the assessment (FG2, P4, occupational therapist, lines 103-105).

Within the neurological service focus group, it may have been deemed more acceptable for healthcare providers to ask about functional literacy abilities given that it is part of the standardised assessment, therefore it is something that the healthcare providers 'always' do. Healthcare providers may be more likely to assess areas of a patient's ability included in a standardised assessment, given that this is expected by managers. In the other focus groups, asking about literacy levels in this manner did not appear to be standard practice. For instance, participants in the chronic fatigue and persistent pain service advised they do not ask patients about their functional literacy levels: 'I mean we don't ask specifically' (FG3, P3, physiotherapist, line 525). Similarly, one participant in the palliative care focus group reported she had not come across healthcare providers asking about literacy abilities before. Other participants in both the chronic fatigue/persistent pain service and palliative care focus groups followed up these statements by suggesting they pick up cues instead of asking. Additionally, in contrast to the example in the neurological service focus group, it is possible that routinely asking about literacy abilities was not part of the standardised assessments within these teams, therefore less likely to be considered. Further, the healthcare providers' lack of knowledge about health literacy may mean they are less likely to consider health literacy on a daily basis, or they may feel uncomfortable asking about functional literacy abilities. For instance, one participant in the pulmonary service

described avoiding directly asking about literacy abilities by asking patients if they require assistance or if they require reading glasses.

> *I always wonder when we're asking our patients to fill in our questionnaires, whether they can actually read it. Um… so I usually curb the subject of simply asking them, 'can you read?' by asking them, 'do you need reading glasses?' Rather than just simply ask, because I feel there's an embarrassment (FG3, P2, physiotherapist, lines 27-30).*

The excerpt above suggests the participant felt uncomfortable about asking patients directly about their literacy abilities. The participant suggests that he adopts this strategy due to concerns about patients' embarrassment, which links in with his possible preconceptions relating to how someone may feel about their functional literacy abilities. It is also possible that an individual with literacy difficulties would feel relieved if someone asked them about this. Given that a high proportion of older adults use reading glasses due to visual impairments, the participant may have been using this strategy as a way of allowing participants to open up about their functional literacy abilities if they desire.

Assessing knowledge and understanding

This section relates to the healthcare providers assessing older adult patients' knowledge and understanding as a means to understanding their health literacy abilities. In addition to the sub-theme about picking up indicators of low health literacy, this is about directly asking patients questions relating to their knowledge and understanding, and making inferences about their health literacy based on this.

The healthcare providers in the palliative service focus group described gaining information about patients' knowledge levels from asking them about their understanding of their diagnoses.

> *Um… asking them what they understand by their diagnoses as well… you can get quite a lot from that conversation too (FG1, P6, nurse, lines 72-73).*

The healthcare providers in the palliative service focus group reported that asking about patients' understanding of their diagnosis is a question they ask patients during initial assessments. It is possible they felt asking this question can be easily integrated into their routine care and that it is a question which patients may expect to be asked, given that the service focuses on patients with palliative diagnoses. The nurses in the palliative care focus group reported using medication reviews as a strategy to assess understanding in connection with how the medication is supposed to be taken. Similarly to asking about diagnoses, this may be a strategy for identifying health literacy which the nurses felt they could easily incorporate into their standard assessments. Participants in the chronic fatigue and persistent pain service described checking patients' understanding of sessions during one-to-one interactions and follow-up phone calls. However, it was not clear how patients' understanding was checked.

> *I think we do that quite well, after the education sessions when we phone the patients, we sort of ask them, 'what did you take from the education session or what was your understanding of duh-duh-duh-duh?' (FG3, P2, exercise rehabilitation instructor, lines 479-81).*

Although a different strategy from the participants in the palliative care focus group, the participants in the chronic fatigue/persistent pain service focus group indicated that the follow-up phone call is standard practice within their team. Healthcare providers who described assessing understanding appeared to be endeavouring to seamlessly integrate this assessment into their standard care. However, given their self-identified lack of health literacy knowledge, it is also possible that the healthcare providers may not have been consciously aware that they were implementing these strategies partially to assess comprehension levels. Assessing understanding using the teach-back technique is a gerogogical principle; no participant mentioned this strategy by name or discussed the tailoring of information resulting from assessing understanding.

Formal assessment of abilities

The final section within this sub-theme relates to healthcare providers formally assessing patients' abilities. Only participants in the neurological service focus

group described using formal assessments of patients' abilities to assist with identifying individuals' health literacy levels. The participants were not using recognised health literacy measures, rather using knowledge gained from cognitive assessments, which include a functional literacy component.

> *I think the situations that I've experienced most times have been where… um… so I might have done a, a formal cognitive assessment with someone. And I know that their comprehension is very good, and I know that their, their spoken… language is quite good, um… but I also found out from the assessment that their reading is maybe below you know average. Um… and I've moved on to doing small work with um you know I've also looked at memory and they've got poor short-term memory (FG2, P1, psychologist, lines 280-85).*

Given that the neurological service focussed on issues relating to the brain, it is possible that they approached the topic of identifying health literacy levels in a different way because it may be more routine practice and therefore more readily accepted to use formal measures. As such, the healthcare providers may be more able to infer a patient's possible health literacy through literacy and comprehension assessments they use as standard practice.

8.5.2 Facilitators and barriers to identifying older adults' health literacy levels

Having explored the ways in which healthcare providers described identifying older adults' health literacy levels, it was pertinent to examine the facilitators and barriers to doing so. Participants focussed more on barriers than facilitators to identifying individuals' health literacy levels. This may be indicative of the healthcare providers' low knowledge and awareness about health literacy. In many instances, healthcare providers suggested they were not routinely considering health literacy within their practice, which may have resulted in them being less able to reflect on the facilitators.

Facilitators to picking up indicators of low health literacy

Participants identified possible facilitators to picking up the indicators of low health literacy. These facilitators were primarily identified within the palliative care focus group where the healthcare providers appeared to discuss picking up indicators of low health literacy as their main strategy. One participant in this focus group felt that if a healthcare provider had extensive clinical experience they would pick up the indicators of low health literacy. It is possible that this comment could have resulted from this healthcare provider having had 21 years of clinical experience.

> *And I think, as…when you've got, when you're experienced you hopefully… there's questions you ask and the way you assess people, that you would pick it up (FG1, P5, nurse, lines 595-96).*

Another participant in the palliative care focus group felt that having a bit more time with patients or actively making more time with patients assisted with making the 'clues' more obvious.

> *We tend to have a bit more time… or make a bit more time with the patients. And we do talk a bit more and in-depth and look at different areas… and the clues can be more… obvious (FG1, P7, occupational therapist, lines 474-76).*

The facilitators that healthcare providers suggested appeared to be focussed around provider factors. The next sections explore the barriers which healthcare providers identified. Some of the examples were explicitly identified by healthcare providers as barriers to identifying older adults' health literacy levels. Others were more implicit and interpreted as barriers by the researcher.

Barrier: Uncertainty about identifying older adults' health literacy levels

Participants in all four focus groups appeared to be uncertain about identifying older adults' health literacy levels. This uncertainty appeared to result from a combination of healthcare providers not knowing how to identify older adults' health literacy levels and not being confident about their interpretation of health literacy levels. Primarily, participants did not directly and personally express

uncertainty regarding this and instead described the uncertainty which healthcare providers may have more broadly. However, one participant in the pulmonary service focus group personally expressed uncertainty about this.

> *I wouldn't know how we'd identify that someone struggles. I mean part of me thinks, part of me is aware of the fact that it is a, it is something that we need to be aware of, and um… to change our intervention accordingly. But… is it actually going to really change how we treat our patients? We're still offering the same things to them, regardless of literacy levels anyway (FG4, P1, physiotherapist, lines 69-73).*

The physiotherapist in the excerpt above appeared to lack confidence in being able to identify older adults' health literacy levels. Despite this, throughout the transcript he mentioned strategies he used such as asking patients about their baseline understanding of their condition. Further, the uncertainty extended to whether or not identification of health literacy issues would actually make a difference to how patients are treated. However, this could be influenced by his lack of knowledge about managing health literacy within clinical practice.

Participants also appeared concerned that their health literacy interpretations may not be correct. Participants in the chronic fatigue and persistent pain service argued that it is more difficult to identify individuals struggling to understand in a group setting. As discussed earlier, participants in this focus group also discussed reaching erroneous conclusions from using indicators of low health literacy.

> *…you can often in a group have two or three people who are quite vocal and do a lot of the talking, and a lot of other people that are sitting back, and for a variety of reasons, it might just be that they're not comfortable speaking out, but they're you know, taking it all in and are on board with it, or it could be that they don't, they don't get it, or that they don't believe that you know, it's relevant to them. Um… so, and it's harder to check that out in a group (FG3, P3, physiotherapist, lines 469-75).*

Barrier: Embarrassment or shame associated with lower health literacy levels

This section on barriers to identifying health literacy levels relates to healthcare providers' perceptions about embarrassment and shame which patients may feel about their health literacy levels. Participants suggested embarrassment/shame may affect patients' willingness to disclose information regarding their functional literacy levels or lack of understanding. Participants in the pulmonary service focus group discussed how they felt there was a stigma, particularly for older adults, in admitting any lack of understanding and the resultant effect of this.

> *I think there's a certain amount of stigma for some of the older patients to admit if there's a lack of understanding on their part and so they will just follow the advice given by professionals (FG4, P1, physiotherapist, lines 531-33).*

The same participant also suggested it might be 'taboo' to ask a patient about their literacy abilities and expressed concern about their reaction.

> *I think it's a bit of a taboo thing to ask someone as well. Um… it can cause them embarrassment too (FG4, P1, physiotherapist, lines 73-74).*

The healthcare providers' perceptions about the embarrassment and shame associated with lower health literacy levels may be one reason why some of them expressed reluctance to ask patients about their literacy abilities. The healthcare providers' uncertainty and lack of confidence in identifying health literacy levels may be one reason why they were concerned about causing embarrassment and shame by asking.

Barrier: Reliance on patients or family members disclosing functional literacy issues

The following section refers to occasions in the transcript where the researcher inferred that the healthcare providers appeared somewhat reliant on patients or family members disclosing functional literacy issues, without explicitly asking the

patients or family members themselves. This reliance may be related to the healthcare providers' uncertainty about identifying health literacy levels and their concerns about any embarrassment or shame patients may feel. This may also link in with the section earlier discussing how healthcare providers do not always ask about patients' literacy or health literacy abilities. Reliance on patient or family member disclosure was inferred through the language which the healthcare providers used, as described below. This was not interpreted as a healthcare provider strategy for identifying older adults' health literacy levels; it was rooted in the researcher's interpretation and the participants did not refer to directly asking patients or family members about functional literacy issues. For instance, the excerpt below indicates that the patient's wife revealed his literacy issues and the healthcare providers were previously completely unaware of this:

Um… and it came out [the patient's literacy issues] in a family meeting, and his wife told us, and it was quite embarrassing really that we hadn't picked, we hadn't known about that (FG2, P3, physiotherapist, lines 210-12).

To differing extents, participants in all four focus groups appeared to rely on patients or family members disclosing functional literacy issues as opposed to actively seeking the information. Participants postulated that 'some' patients disclose the information, demonstrating an awareness that many may withhold this information.

Some people are very honest and say, you know, 'I can't read it, I can't read it' (FG1, P2, nurse, lines 149-50).

The use of the word 'honest' in the excerpt above indicates a possible reliance on patients disclosing this information, given that it may imply the healthcare provider does not routinely ask patients about their literacy abilities. The quote below also suggests a possible reliance on patients' self-disclosure of literacy abilities, but the participant may also be unaware of how to identify patients' health literacy levels through other means.

…it's very difficult, it's okay if people are willing to disclose and share the information, but if they're not… you can only really act in the way that you

> *can with the information that you've got (FG4, P3, physiotherapist, lines 86-88).*

Another participant in the palliative care focus group demonstrated an awareness that participants may hide their functional literacy abilities, and therefore healthcare providers may never find out: 'And I mean some people are incredibly good at hiding it and… you may never know' (FG1, P7, occupational therapist, lines 476-77). The researcher felt this may indicate that the participant felt that to some extent it is the patient's responsibility to disclose their literacy issues. This reliance on patient and family member disclosure emerged as a finding to a lesser extent in the neurological service focus group; this may be because the healthcare providers described asking about functional literacy levels and used formal assessments of comprehension and literacy.

8.6 Theme three: Views about using health literacy screening tools and universal precautions

The third research objective for this phase was to explore healthcare providers' views about using health literacy screening tools or universal precautions in clinical practice. As discussed in the previous main theme, healthcare providers reported not using any recognised health literacy screening tools. They advised that they were not aware of any such tools prior to participating in the research. The next theme relates to healthcare providers' views about using health literacy screening tools, with reference to the specific tools used to facilitate discussions within the focus groups (Section 7.4.6). Given the debates in the literature surrounding using either health literacy screening tools or universal precautions (Section 2.5), healthcare providers' perceptions regarding using universal precautions are also explored within this theme. Healthcare providers expressed reservations and positive views about both health literacy screening tools and universal precautions. Figure 11 provides an overview of this theme.
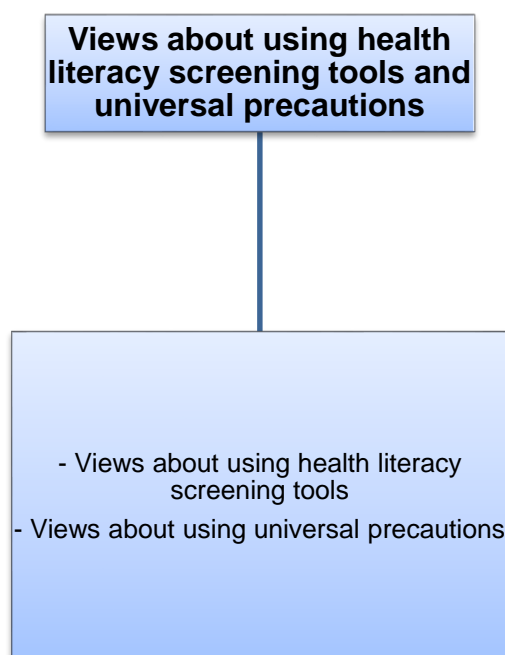
Figure 11   Main theme three for phase two: Views about using health literacy screening tools and universal precautions

8.6.1   Using health literacy screening tools

Positive view: Creating a more 'literacy friendly' environment

Positive views on health literacy screening included that it may increase disclosure of literacy issues and create a more literacy friendly environment. The physiotherapist in the excerpt below seemed to demonstrate an awareness that improvements are needed within the service to be more 'literacy friendly'. This reflection and level of awareness may have influenced the participant to feel more positive about the concept of using health literacy screening tools.

> *…if we were all using a question, a simple brief screening question like this on a more regular basis, I think actually it would make us a bit more literacy friendly anyway, and people are going to be a bit more outgoing about their literacy and their gaps in knowledge of their condition anyway (FG4, P1, physiotherapist, lines 665-68).*

Positive view: Creating an opportunity for dialogue

An occupational therapist in the pulmonary service focus group felt completing a self-report screening tool may assist with beginning a dialogue about meeting someone's health literacy needs. This is the only occasion in all four focus groups where a participant suggested having a 'dialogue' or conversation with a patient about health literacy. The quote below appears to suggest the healthcare provider may have seen the use of the self-report screening tool as a way of working together with the patient to empower them to identify their personal needs. Use of phases such as 'gauge with them', 'allow that discussion' and 'give them that opportunity' seem to implicitly suggest an aim to empower the patient. This contrasts with examples discussed earlier where participants appeared to be discussing patients as passive recipients of health information. In this example, meeting health literacy needs appears to be more of a collaborative process.

> *Yeah I like… this is good [gestures to AAHLS]. I like this… in terms of being able to… to gauge with them, and actually allow that discussion. But it could just a kind of, it's for me, kind of thinking actually I could use some of those questions. Um… you know, it's kind of beginning that dialogue with them, so in terms of when they're given information by other people… what's the question? 'How often do you think carefully about how the information makes sense in your particular situation?' You know, just having that dialogue and give them that opportunity, and start that conversation (FG4, P2, occupational therapist, lines 656-64).*

Reservation: Health literacy screening is unnecessary

In most of the focus groups (with the exception of the pulmonary service group), participants suggested that health literacy screening may be unnecessary in their service or that specific measures may not contribute anything additional. One reason why the participants in the pulmonary service focus group may not have deemed health literacy screening unnecessary is that they reflected a great deal about areas where they might not be meeting older adults' health literacy needs. As such, they appeared to be more open to different ideas. Although some

participants in other focus groups also acknowledged this at points, this was to a lesser extent.

Participants in the palliative care focus group extensively discussed the unnecessary nature of health literacy screening in their service. They felt that the nature of their patients' conditions rendered health literacy screening irrelevant and an unnecessary stress. They also suggested that they were able to gauge their patients' health literacy levels without testing.

> *I think… I guess the main message from us is that um… in the jobs that we do- [P1: We can gauge it] that, those tools can be less relevant than other professionals in different jobs, is that fair to say? (FG1, P2, nurse, lines 535-37)*

The participant in the quote above was one of the more senior members of the team. This participant summarised the 'main message' from the team collectively, thus appearing to establish a group consensus. Although an opportunity to disagree was offered, it is possible that other participants may have felt unable to disagree with this assertion due to the participant's level of seniority and dominance during discussions. Further, when the group was asked about their perceptions on health literacy screening tools, this participant immediately expressed his concerns about relevance within the team, which could have influenced the other participants' responses. The other participants agreed with this concern, suggesting screening may be more useful in other settings, but remained unsure as to whether there would be uptake.

> *P7: GP's actually in some ways might, might benefit from something like that. But I'm not sure that they would use them either (FG1, P7, occupational therapist, lines 541-42).*
> *P2: Perhaps people in um… learning disabilities, mental health, um… (pause) care of the elderly, dementia sort of things (FG1, P2, nurse, lines 543-44).*
> *P7: Where there's likely to be some obvious problem, where there's more likely to be, so that you would be… it would become more of a norm to look for that, than where in our case, it's something that we just… we are aware*

> *of, and try to, because we try to be holistic for the patient (FG1, P7,*
> *occupational therapist lines 545-48).*

Prior to making the comment above, Participant 7 (occupational therapist) had expressed concerns that the health literacy screening tools discussed would not provide a particular functional purpose. Therefore, the reference to unlikely uptake by other healthcare providers in the first quote may have resulted from her own reservations about use of health literacy screening tools. After this comment, Participant 2 (nurse) lists off services that might benefit more from using health literacy screening tools including elderly care, learning disabilities and dementia services. In a separate part of the transcript, this participant mentions working clinically with 'elderly' patients, and patients with learning disabilities and dementia, possibly indicating inconsistent views. The occupational therapist agrees with the relevance comment, revealing her perception that there would be more likely to be an 'obvious problem' in these services. This may reveal a lack of understanding about health literacy, or a perception that health literacy is not a 'problem' that needs to be considered within palliative care. She also alludes to the possibility that if identifying health literacy issues was the 'norm', this may increase uptake of screening. This links in with previous interpretations about how participants may be adopting health literacy strategies which are part of their routine assessments and treatments.

One participant in the chronic fatigue and persistent pain service felt screening involving comprehension tasks was unnecessary given that most of the information they provide is simplified and takes the form of written text. The comment below possibly indicates that the psychologist does not place emphasis on patients' comprehension of the information they provide. However, it could also suggest that the participant feels that the information they provide to patients is already delivered in way in which it would be understood universally. Her comment may have derived from not having fully understood the health literacy concept and perceiving the NVS as irrelevant.

> *We didn't think this one [Newest Vital Sign] was as relevant because it's*
> *more, I suppose it's um… there's a bit more, I suppose there's thought*
> *involved in working something out… and um… understanding kind of the*

information. Whereas, most of our information is mostly language, and it's mostly written text and it's more kind of, a lot of its probably explained in layman's terms (FG3, P6, psychologist, lines 609-13).

The psychologist in the neurological service focus group asserted that one of the health literacy screening tools (REALM) discussed during the focus group may not add anything additional to the cognitive testing she already completes, where a list of words is already used.

Because that's about their ability to read the word. Not about their understanding of it. So… I already use word list tests already, I probably wouldn't use that one because I don't think it would add anything (FG2, P1, psychologist, lines 440-42).

This participant also discussed how she thinks standardised tools are useful, but only if they are used as part of a wider assessment; when used alone, she feels they do not provide useful or accurate information. Despite other groups not reporting use of cognitive assessments, this view about the REALM not providing useful information was echoed by participants in all of other focus groups.

Reservation: Concerns about patients' reactions to health literacy screening

Participants in all four focus groups revealed concerns about how patients might react to health literacy screening. Concerns varied: some participants were worried about patients being offended or perplexed as to why the tool was being completed, whilst others were concerned about the tests causing anxiety and distress.

I feel as if they may be insulted (FG1, P1, nurse, lines 514).

It might bring up quite a lot of anxiety in patients (FG3, P2, exercise rehabilitation instructor, line 594).

> *A lot of patients are quite distressed as well… and putting this in front of them… they're already concerned that the Macmillan nurse is knocking on the door (FG1, P3, nurse, lines 563-65).*

In contrast to concerns about patients' negative reactions, one participant in the chronic fatigue and persistent pain service focus group was apprehensive about patients who do not need help requesting it as a result of being asked self-report questions. The participant did not explain why she was concerned about this particular reaction, but these concerns could relate to worries about de-skilling a patient who does not need it or concerns about using clinical time unnecessarily.

Reservation: Health literacy screening would feel like testing the patient

Participants in most of the focus groups (with the exception of the neurological service focus group) discussed how health literacy screening may feel like testing the patient. They discussed this as something they personally would 'feel', but this may have also derived from concerns about patients' reactions. Participants in the neurological service focus group may have not discussed this because as discussed earlier they already administer other tests routinely. Participants in the other groups may have felt like health literacy screening was like testing a patient as a result of their concerns about patients' reactions, which may have resulted from their perceptions that patients may feel embarrassment and shame about their health literacy levels.

> *I wouldn't want to [use health literacy screening tools]… I think I… I would feel as if I was testing them (FG1, P1, nurse, lines 510-11).*

Some participants described how completing the health literacy screening tools may be a challenge for patients.

> *…if somebody had fairly low health literacy… this would be in itself [P3: challenging] a challenge (FG4, P2, occupational therapist, lines 657-58).*

8.6.2   Using universal precautions

Providing accessible information, limiting content, speaking clearly, assessing understanding and using pictures are all principles of gerogogy and universal precautions strategies. Participants identified a number of reservations about the concept of universal precautions, but some participants commented on the possible benefits of this approach, which are explored initially.

Positive view: Utilitarian approach to providing healthcare

A utilitarian approach to healthcare dictates that the moral action produces the greatest good for the greatest number of people: 'the Greatest Happiness principle' (Mill 1863, p.9). Two participants suggested that simple information is desired and required by most patients. One of these participants (pulmonary service) appeared to suggest that universal precautions could be a utilitarian approach to healthcare; he discussed how providing simplified information could benefit the majority of people and may only upset a minority. This participant also argued that increased patient use of healthcare information may result from providing accessible information to all.

> *You can argue you've got the potential that's going to be a handful [individuals offended by provision of accessible information] whereas all the rest of your patients can access that information and understand it. So actually… if that's a consequence of upsetting a few (FG4, P3, physiotherapist, lines 706-8).*

Reservation: Concerns about patients' reactions

Many participants expressed concerns about some patients being offended by simplifying or providing accessible information to all patients. In particular, they suggested that they would feel uncomfortable about providing simplified information to their more highly literate patients. They were concerned that these individuals would feel patronised or offended and would construe provision of this information as demeaning. Participants used terminology such as 'childlike' when

referring to simple and clear messages; they appeared to be concerned that patients would perceive written information in this way if it was simplified.

> *And… you know I know they say the average reading age of the adults is about 6 years or something and… the sun readers. Um… I know we've got to put all of our um… literature through the um… is it the communications team? [Another participant: yeah] Whatever team it is. Um… sometimes when it comes back I'm thinking it's a bit almost offensive to some people. Because we do have some intelligent and literate patients and I would be uncomfortable perhaps giving some things to them (FG1, P2, nurse, lines 737-40).*

Although the healthcare provider in the excerpt above appeared to be concerned about 'literate' patients' reaction to the written information, he also reported personally feeling uncomfortable. This may result from his concerns, but he may perceive that information provided is reflective of his own abilities. Furthermore, the physiotherapist in the excerpt below appeared to have concerns about patients questioning his professional status and knowledge levels if information is simplified.

> *Um… but then I think there could be a detriment for people who have quite a good understanding, when you start to simplify a lot of the information. They could start to think, why is this physio here? He doesn't know anything (FG4, P1, physiotherapist, lines 869-71).*

Whilst agreeing with this sentiment, the other physiotherapist in the pulmonary service focus group also reflected that the risk of upsetting patients with higher health literacy could be reduced by managing expectations about the level of information and signposting to further information if required.

Reservation: One size fits all approach will never work

Many participants felt universal precautions would not be suitable because a strategy intended to suit everyone will not achieve a favourable outcome. Participants in the focus groups used similar language to articulate this, and

justified their points by arguing that patients have different needs and information preferences and information should be tailored appropriately.

…the one size fits all approach is never going to work. If we always send out you know complicated information, that's not going to work for everyone… but if we always send out simplified information, I think that would, you know, some of our patients would feel quite offended (FG2, P1, psychologist, lines 486-89).

We don't treat them all the same, in terms of you approach every patient differently, and this is just an extension of the treatment that you are offering them. So I don't think it could be one size fits all (FG2, P2, occupational therapist, lines 493-95).

Both quotes above indicate that the participants perceived the concept of using 'universal precautions' as incongruent with their treatment approaches and principles, which relate to treating patients as individuals with varying preferences and needs.

8.7   Theme four: Importance of relationship and trust building, tailoring interactions and social support when meeting older adults' health literacy needs

The third theme revealed that participants primarily appeared to have reservations about using health literacy screening tools and universal precautions. Overall, the participants did not seem to have a preference for either and focused more on their reservations, than positive views, about both. Therefore, the next section explores what healthcare providers felt was important when addressing health literacy needs, and supporting patients to develop their health literacy abilities. The healthcare providers appeared to emphasise relationship and trust building, tailoring interactions and use of social support when meeting older adults' individual health literacy needs. These themes were also revealed as important by older adult patients during the first phase of the research (Sections 5.5; 5.6 and 5.7), and are conceptualised in the same way as described in the previous phase. Exploring whether or not healthcare providers identified these factors was the

fourth research objective, resulting from the importance placed on these areas by the patients in the first phase. Figure 12 provides an overview of this theme.
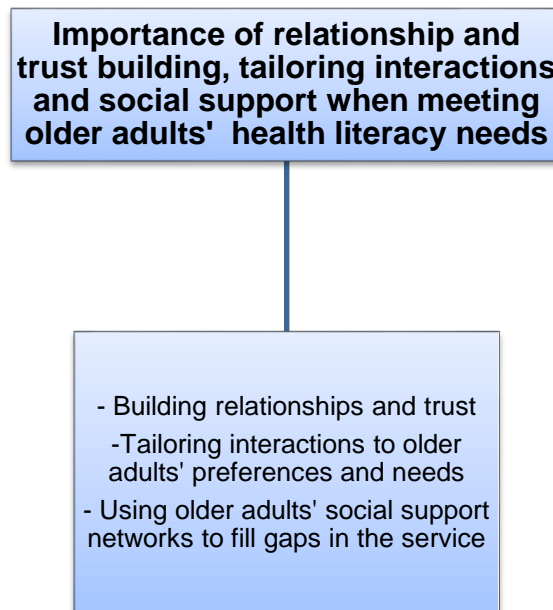
Figure 12   Main theme four for phase two: Importance of relationship and trust building, tailoring interactions and social support when meeting older adults' health literacy needs

8.7.1   Building relationships and trust

The healthcare providers in all of the focus groups discussed how important relationship building and trust can be for older adults in terms of their access to, understanding and use of health information. Relationship building and trust are distinctive but interconnected concepts (Section 5.5). However, the healthcare providers frequently discussed the two concepts together, in particular referring to how relationship building can lead to trust. Therefore, the two concepts are discussed together. The healthcare providers appeared to primarily identify relationship building and trust as a facilitator for meeting health literacy needs. However, they also discussed how the relationships and trust which older adults have with their healthcare providers can have negative impacts on their healthcare; this concern is explored initially.

Relationship and trust building as a barrier for health literacy

Focus group participants discussed how the level of trust older adults often have in healthcare providers could be a possible barrier to them accessing, understanding and using health information. It was proposed that older adults frequently have extremely high levels of trust in doctors and that they will believe anything the doctor tells them without question. Questioning and critical analysis abilities are considered interactive and critical health literacy skills. Therefore, it is possible that the healthcare providers felt older adults' high trust levels may have an impact on their abilities to access, understand and use health information at the interactive and critical health literacy levels. However, this is inferred by the researcher, given that participants may not have had knowledge and awareness about 'interactive' and 'critical' health literacy levels.

One participant described an occasion where an older adult's high level of trust in her GP's advice ultimately led to a medication error.

> *I've also now suddenly thought of a medicine situation where a lady was told by the doctor 'you take one of these tablets um… and that will make you feel', she was suffering from nausea… so she was told to take one tablet. Well um the prescription was for 2.5. Well clearly the pharmacist didn't have 2.5, he had 10s. Well, so on the outside of the box it said take a quarter of a tablet. But… the doctor had told them to take a tablet. So they took a whole tablet. It wiped them out for a couple of days. But actually… that kind of misunderstanding… because the pharmacist hadn't checked that she'd, whoever was picking it up knew what to do with the tablet. It just said on the outside take a quarter which was right… would have given you the right level of medication. But that wasn't what the doctor had told her to do. So, she trusted the doctor more to do what they were told than they would anyone else (FG1, P7, occupational therapist, lines 662-71).*

In the above example, levels of trust seem to have impacted on the patient's health-related actions. The patient may have chosen to trust the advice without questioning or reading the prescription, but could have also put this level of trust in her doctor as a result of having poor functional literacy levels. The healthcare

providers in all the focus groups suggested the high levels of trust older adults have in doctors may link with patients already having a relationship with their doctor, but may also result from older adults having more respect for seniority and hierarchy. The excerpt below indicates that the physiotherapist in the pulmonary service focus group felt that older adults are less likely to listen to the messages from less senior clinicians. This suggests an impact on interactive health literacy, but is a view that could have been influenced by the physiotherapist's perception about his position in the 'pecking order'.

> *It's the esteem that they hold with the GP, 'well the GP says I should do this'. And that's generally what I've found across my years, is actually those older patients generally will do what they are told by the more senior clinicians. Um… whereas, perhaps down the pecking order, they're not always so likely to be inclined to listen and reason with you (FG3, P3, physiotherapist, lines 523-27).*

Similarly, participants in the chronic fatigue/persistent pain service focus group discussed how older adult patients are often inclined to unequivocally believe the first thing they are told by their doctor about their pain. The participants felt this also had an impact on older adults' abilities to engage interactively with other healthcare providers, such as themselves.

> *From what they've said about their GP or what other doctors have said to them, 'oh well the doctors have told me it's this, therefore it must be this'. And I think that often when we're explaining pain to people, we expand on, expand quite a lot on probably the information they've been given already… they might have been told already they've got sort of degenerative changes or something like that, and we'll expand on that quite a lot to encompass how… it, the changes within the nervous system and all that type of stuff. But if that information… the focus can sometimes then be on the information that's given in the first instance by that by the doctor whose given me that information (FG3, P3, physiotherapist, lines 126-34).*

It was also suggested in the pulmonary service focus group that levels of healthcare provider hierarchy may influence older adult patients' trust in

information provided, regardless of the length of relationship. For instance, Participant 3 (physiotherapist) discussed how older adults may believe a consultant they have seen for 'five minutes' above a healthcare provider they have worked with for months. The same participant also discussed how when older adults are given conflicting advice from different healthcare providers, they sometimes make personal judgements on the person based on their relationship, as opposed to weighing up the evidence.

> *The difficulty is, again, okay it's great going out and getting information but of course then they get two people, they're asking the professional for their opinion which is based on the professional's experience and knowledge… and then of course then they're finding, well hang on, the two of them don't match up. And it's then very difficult for them to then determine, hang on, who do I listen to? They don't necessarily take away the fact and think well actually this has been their experience, compared to this other clinician… and then they make the judgement calls, and then actually then they start to make probably sometimes um actually quite um… personal judgement calls on the professional… rather than looking at their knowledge base (FG3, P3, physiotherapist, lines 288-96).*

The quote above appears to relate to patients' critical health literacy skills, in terms of their ability to evaluate conflicting advice. The participant later discussed how this might relate to the 'rapport' the patient has built with one healthcare provider. Finally, this participant also suggested that trust can be difficult to build if a patient has previously been informed of something by a certain physiotherapist or occupational therapist, and the message turned out to be inaccurate. However, as discussed earlier, this may also link in with hierarchy issues within the healthcare system as perceived by patients; an older adult patient may trust a doctor more than a healthcare provider who has had less years of training.

Relationship and trust building as a facilitator for health literacy

Building relationships and trust was considered to be an important factor by the healthcare providers to enable them to meet older adults' functional and interactive health literacy needs in all four focus groups. Trust and relationship building was

seen as integral to enable patients to open up about their health literacy needs. Being respectful and creating an environment where an older adult is comfortable in acknowledging the deficits in their knowledge base is a gerogogical principle, one which healthcare providers appeared to support. Participants seemed to link relationship and trust building with their perceptions about patients feeling embarrassed and shameful about their health literacy issues.

> *Um, and um… we had to build a good rapport with him to start as a kind of a basic, as a you know to start with, because he, he was very cagey about… he didn't want to kind of admit that he had literacy problems. And it was you know it was a lot of things that he wasn't doing, he was getting himself into debt, he didn't fill out these forms correctly, and it was, it was about… really building that rapport initially was vitally important for this chap. Um… before he could then open up (FG2, P4, occupational therapist, lines 247-52).*

The quote above suggests the participant was primarily referring to building rapport in order to enable an older adult patient to open up about his functional literacy levels. However, the participant below also appeared to speak more broadly about using rapport building to understand gaps in patients' knowledge.

> *Yeah. And it kind of… we've talked about rapport already, and I think building rapport with patients is really key for understanding where the gaps in their knowledge are (FG4, P1, physiotherapist, lines 867-69).*

The quotes above reveal that relationship building may also be a possible strategy used by healthcare providers to assist with identifying individuals with low health literacy.

In contrast to the possible negative effects of an older adult having unwavering trust in their GP described above, the healthcare providers also suggested that this trust in the GP may have a beneficial impact on attendance to their services and adherence to continued attendance and treatment recommendations. Participants referred specifically to their own services; they suggested that if a GP was positive about their service, the older adult patient may be more likely to attend and adhere to healthcare providers' recommendations. The quote below

suggests that the physiotherapist perceived that long-lasting positive outcomes in terms of access, adherence and self-management can result from a referrer being positive about the service. The physiotherapist subsequently contrasted this with an example of when a patient might dislike their GP, and therefore not attend services.

> *'What has the GP said about pulmonary rehab?' Nine times out of ten, they suddenly say, 'well nothing, they just said I should go'. And um… but we know that if, from that initial contact, if the referrers are positive about the service that they're referring to, the patients are going to adhere to it, they're going to go to the initial assessments, they're going to complete the fourteen sessions, complete the seven weeks and might go on to maintenance (FG4, P1, physiotherapist, lines 507-12).*

Participant 3 agreed with Participant 1 about this, and suggested that this relates to the 'esteem' in which the older adult holds their GP. The effect of trust on adherence was also discussed in the chronic fatigue and persistent pain service focus group. Participants in this group discussed an example where a patient with learning disabilities was refusing all treatments due to loss of trust which resulted from treatments completed without fully explaining them, and this had to be built up again to enhance adherence.

Finally, the importance of relationship building and trust was deemed as essential to enable effective tailoring of communication and education. For instance, participants in the chronic fatigue and persistent pain service focus group discussed how it is only possible to challenge a patient's beliefs after building a relationship and trust with them.

> *…you might be slightly more explicit with something the more you get to know them. And you know if they [another participant: yes] you know, have a bit more understanding of the basics, you can be that bit more explicit or if you're challenging some of their beliefs or you know, querying things (FG3, P6, psychologist, lines 742-45).*

The participant above appears to be inadvertently discussing how a patient may progress through the health literacy levels; she mentions how she can be more explicit with a patient after a relationship has been established, but also after they have understood the basics (functional health literacy). The psychologist also appears to be discussing being able to tailor her communication style to a more direct one based on the patient's level of knowledge.

8.7.2 Tailoring interactions to older adults' health literacy preferences and needs

As iterated earlier, many participants rejected the concepts of health literacy screening and universal precautions. Instead, participants argued that information should be tailored to older adults' needs and preferences. However, the healthcare providers also discussed how there can be barriers to tailoring interactions, which will be addressed first.

Barriers to tailoring interactions to older adults' health literacy needs and preferences

Participants generally emphasised the importance of tailoring interactions to older adults' individual needs. However, participants identified group work as a possible barrier to tailoring interactions. For instance, several participants in the chronic fatigue/persistent pain service focus group described pitching their sessions at what they felt was the average recipient's ability, in the hope that this would satisfy most patients.

> *I guess we tend to work on the average, don't we? [Another participant: yeah] We kind of, we're delivering it for what we hope at least is the majority, and that the majority of people are understanding that. And I'm thinking particularly group work when you can only really, well obviously you can still do it in different ways like we talked about, but I think that you're using a bit of a broad brush there [several participants' agreement] and hoping that you capture most people with the middle-of-the-road approach really. So there's always going to be some people who benefit*

from it more and some people maybe that aren't getting that bit [several
participants' agreement] (FG3, P3, physiotherapist, lines 967-74).

The excerpt above reveals that the participant was aware that adopting a 'middle-of-the-road' approach might result in some patients not understanding all of the information. In subsequent discussions, two different participants discussed how this may result in patients not attending groups or not being referred in the first place, suggesting a possible level of acceptance of patients not benefitting from or accessing groups as a result of their low health literacy levels. Similarly, participants in the pulmonary service also discussed how it is more difficult to tailor information in a group setting where patients all have different abilities and preferences.

…it can be less tailored to the individual as well when you're in a group
setting. Um… you're sort of delivering the information by prescription really
[Participant 003 (Pulmonary): yeah] rather than looking at someone's
individual needs, and addressing those individual needs at a level which is
pitched suitably to them, rather than in a group (FG4, P1, physiotherapist,
lines 108-12).

Both the pulmonary service and chronic fatigue/persistent pain services used group work as part of their standard treatment pathway; this may be why it was highlighted as an issue.

A participant in the chronic fatigue/persistent pain focus group suggested that although it would be 'nice' to, there is no time to assess each individual's learning style preferences and abilities. Instead, she suggested that as a team they try and provide information in a range of different formats to meet different people's needs.

It would be nice if we had the time to assess each person's learning style
[several participants' agreement] and level of kind of literacy and ability. But
feasibly I don't think we do, so I think it is more just about trying to have
information in different formats [another participant: mm] so that some of it's

>*verbal, some if it's written and with pictures (FG3, P5, clinical psychologist, lines 693-96).*

In the excerpt above, when discussing different formats of information, the focus appears to be primarily on the simple provision of verbal and written information, thus possibly not considering a patient's interactive and critical health literacy levels fully. Furthermore, when discussing tailoring to learning style preferences, healthcare providers tended to focus on visual or auditory preferences; this appears to be more aligned with a pedagogical education style.

A participant in the palliative care focus group felt having a variety of different options when providing information was not feasible from either a time or cost perspective. This appeared to be somewhat conflicting with this healthcare provider's aversion to universal precautions and strong emphasis the healthcare providers placed on tailoring interactions, as explored next.

The importance of tailoring interactions to older adults' health literacy needs and preferences

As discussed earlier, participants appeared to highlight that older adults have varying information preferences and a one size fits all approach will never work. The healthcare providers aimed to treat patients as individuals and discussed how they might do this. Primarily, this appeared to be about establishing an older adult's literacy abilities and finding an alternative way of presenting the information. Healthcare providers also described occasions where patients have personally disclosed their functional literacy issues and asked for tailored written information, which the healthcare providers have then offered. However, in an example like this, it is unclear whether or not the healthcare provider would have established this preference had the patient not voluntarily disclosed information about their functional literacy issues, linking with Section 8.5.2 where participants discussed their reluctance to ask patients about their functional literacy and health literacy needs.

In the palliative care focus group, participants discussed asking patients about their information needs.

> *So… every consultation that I have with a patient, I will then ask, 'do you*
> *have any further questions?' Um… and through the, you know visits and*
> *things and the assessment, is, you know… 'do you have enough*
> *information about your condition?' 'Would you like to know anything*
> *more?' (FG1, P2, nurse, lines 578-82).*

In the example above, the healthcare provider appears to be giving the patient an opportunity to request further information but appears to be using closed questions to establish this, which may limit the patient's response. When other participants explored how they tailor information to patients' individual needs, some of them felt that the tailoring resulted from a 'gut feeling'.

> *I know I probably do modify my explanations based on the person in front of*
> *me… and I will go with a gut feeling of what I think is going to be helpful for*
> *them… and then I guess respond to how they're reacting and then modify it*
> *further, depending on how they're reacting or… you know, or what they're*
> *saying, or what they fed in (FG3, P3, physiotherapist, lines 722-26).*

The excerpt above indicates that tailoring might be more a subconscious thing which the healthcare provider does without realising. Further, the tailoring also appeared to be linked to her inferences about how the patient is reacting to the information, which may link with how participants tended to identify patients' health literacy levels through using subtle indicators.

8.7.3   Facilitator: Using older adults' social support networks to fill gaps in the service

Participants in all four focus groups discussed a number of ways which older adults' social support networks (including family and spouses) mitigated the risks of low health literacy or supported older adults accessing healthcare. The healthcare providers described the support network helping in the following ways: managing medication, attending appointments, communicating with healthcare providers, disclosing literacy issues, providing support to access the internet or

other written healthcare materials and providing emotional encouragement to accept or adhere to treatments/interventions.

The healthcare providers identified time constraints as a barrier to fully meeting older adults' health literacy needs.

…and then the pressures of the NHS, and time creep in [several participants: yeah], and you know as much as you might, in an ideal world I would record this session for this person and I would then do a verbal summary, and I will, then… (sigh) (FG2, P1, psychologist, lines 300-304).

The quote below illustrates how the participant felt restricted by not always being able to provide information in alternative formats. To manage this, she reports using input from the patient's family.

If I'm not able to provide an audio recording or something like that, I would usually maybe involve the family in and maybe more significant others [another participant: mm], even more so, to try and involve them and use their [two participants: yeah] input (FG2, P1, psychologist, lines 318-21).

Another participant discussed how an older adult patient's wife would spend additional time reading through written materials with a patient with low literacy outside of the educational sessions. However, this healthcare provider also discussed how this was challenging for the wife, also an older adult.

…a lot of our handouts we've got pictures on, so we can use the pictures with him during the session but then his wife will go away and she will read the handouts and then they can talk about them (FG3, P1, occupational therapist, lines 281-84).

The healthcare providers discussed the vulnerability of some individuals who do not have social support. Additionally, healthcare providers in the palliative care focus group perceived social support as a barrier to providing information to patients in some instances when families do not want to know about the patient's conditions or wish to prevent the patient from knowing all of the information. No

other healthcare providers in the other focus groups perceived social support as a barrier, but this may be indicative of the type of patients the healthcare providers in the palliative care service are working with, where families may be deeply distressed.

8.8 Theme five: Facilitators and barriers to the integration of and development of health literacy abilities in clinical practice

The final theme in this chapter relates to the facilitators and barriers to the integration of and development of health literacy in clinical practice. Exploration of healthcare providers' views about the facilitators and barriers to meeting older adults' health literacy needs in clinical practice was the final research objective. Figure 13 provides an overview of the theme.
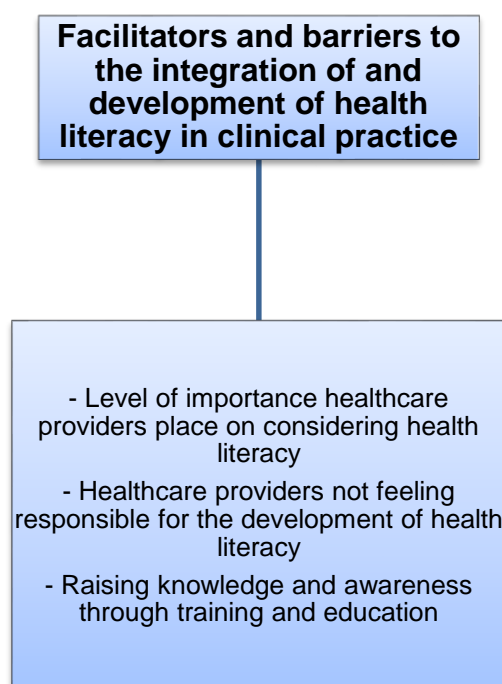
Figure 13   Main theme five for phase two: Facilitators and barriers to the integration of and development of health literacy in clinical practice

8.8.1 Facilitator/barrier: Level of importance healthcare providers place on considering health literacy

Some participants in the focus groups appeared to argue or imply that health literacy may not always need to be considered. This was particularly in reference to the identification of health literacy issues, as discussed in Section 8.5. Where participants seemed to argue that health literacy was not important to consider, or irrelevant within their service, this appeared to be related to their understanding of health literacy as relating to functional literacy abilities. For instance, participants discussed how sometimes it is not necessary to know whether or not someone can read and write, because the activity may not require this.

Many participants also expressed a view that health literacy is important to consider. Primarily, this was discussed in relation to literacy levels or in terms of information provision to patients. One participant appeared to reflect on the importance of health literacy through recognising the consequences of low literacy and healthcare providers not recognising it. However, prior to this realisation, this participant had expressed a belief that experienced healthcare providers (such as herself) would identify an individual with low health literacy.

> *So we didn't, we didn't actually pick up on it straightaway. It didn't… the impact was that he didn't attend his hospital appointments… so obviously that is important (FG1, P5, nurse, lines 614-16).*

Participants in the neurological service focus group also reflected on the consequences of low health literacy and how other services such as learning disabilities teams are more attuned to engaging with patients regarding their health literacy. Another participant (chronic fatigue/persistent pain service focus group) who had appeared to be initially somewhat defensive about the topic later reflected on the redundancy of healthcare providers' input if the patients do not understand it.

> *…it is really important because if people can't understand the information you're giving them, then you might as well not be there, and they might as*

well not come, so it is really important, isn't it? (FG3, P5, psychologist, lines 963-66).

It is possible that the experience of taking part in the focus group allowed participants the time to reflect; this may be why some healthcare providers appeared initially resistant to or hesitant about the concept of health literacy, and later appeared to recognise the importance of it. This indicates that training and discussions around health literacy may alter healthcare providers' perceptions.

8.8.2 Barrier: Healthcare providers not feeling responsible for the development of health literacy

When asked about how health literacy could be developed, the participants in all four focus groups suggested a range of strategies. Many of these strategies revolved around solutions outside of the healthcare system. For instance, participants advised they felt the development of health literacy is a wider societal issue and responsibility instead lies with media, school education and literacy courses. This appeared to be a partial shifting of responsibility and could also be linked to the participants primarily conceptualising health literacy as being about functional literacy abilities.

> *That's a big question, isn't it? Maybe through more starting right from schools [several participants' agreement] and public health. I think… I think that's a wider question (FG3, P5, psychologist, lines 780-82).*

However, participants also discussed steps which healthcare providers or the healthcare system could take to assist health literacy development, such as creating an open environment, creating accessible health files for patients, supporting vulnerable patients to navigate the healthcare system and encouraging patients to take responsibility for independent learning. Participants in two focus groups also suggested that a health literacy advisor post would be beneficial and could provide health literacy support to both patients and healthcare providers.

8.8.3 Facilitator: Raising knowledge and awareness of health literacy through training and education

Many participants identified a need for training around health literacy. This included some of the participants who felt they were automatically using health literacy strategies. Additionally, despite this perception, some healthcare providers admitted providing 'reams' of information to patients, which they later suggested needing support with knowing how to modify.

> *…it's reams of paper, well three sides, but it's just, just kind of [participant 001: blocks of texts], it's kind of overload (FG4, P2, occupational therapist, lines 821-22).*

Participants discussed how health literacy is not currently part of mandatory training and there is not a focus on it. One participant in the neurological service focus group also felt that training on health literacy had not been provided as part of her undergraduate training.

> *…it's something that… I like to think that it's something that I think about with each patient, but like in my degree, I don't ever remember this being, something quite specific about how are you giving this information [Participant 1: yeah] to patients? How are you checking that they've understood? Um… and then within like our training in the Trust, it's not really something that, even though it's obviously very important, um… there's no like training on it, or there's no, it's not measured (FG2, P2, occupational therapist, lines 692-97).*

One participant in the pulmonary service admitted that he would not know how to identify an individual with low health literacy and another participant suggested that knowing how to provide adequately tailored care after identification is also crucial. Participants also felt training in sensitively broaching the subject of health literacy would be important, linking with the aforementioned concerns about causing a bad reaction when asking about functional literacy levels.

So yes, okay you can ask the question, and you can find out the answer, but then how do we then act on it as best as we can? And then of course that then adds on additional… probably learning needs for the professionals, which isn't a bad thing (FG4, P3, physiotherapist, lines 685-88).

The participant in the excerpt above appears to be suggesting that health literacy screening would be redundant if healthcare providers are not able to provide meaningfully tailored information as a result.

8.9   Summary

Each of the five main themes presented in this chapter related to one of the research objectives (Section 7.3). The first three themes identified that healthcare providers have low knowledge and awareness about health literacy, are uncertain about identifying older adults' health literacy levels and have strong reservations about the use of health literacy screening tools and universal precautions. Instead, healthcare providers placed emphasis on relationship and trust building, tailoring interactions to older adults' health literacy needs and preferences and using older adults' social support networks to meet the gaps in the service. The final theme revealed that healthcare providers are undecided about how important it is to consider health literacy and shift the responsibility for the development of older adults' health literacy abilities onto other services/sectors. Finally, the healthcare providers personally identified a need for further health literacy training. The next chapter explores and synthesises the findings from both phases of the research, whilst comparing these to the existing literature.

Chapter 9: Discussion and conclusion

9.1   Introduction

This chapter discusses the research findings, exploring similarities and differences between the findings from both phases of the research, and comparing these with previous research. In accordance with the aims of the thesis, the implications of the findings for clinical practice are highlighted throughout. The researcher reflects on methodological decisions, strengths and limitations of the research are discussed, key recommendations for meeting older adults' health literacy needs are suggested and the thesis concludes by suggesting future directions for research and summarising the main contributions of this research.

9.2   Overview of findings

Understanding patients' and healthcare providers' perspectives through qualitative research provides useful insight for the development of future health literacy interventions. The first phase of the research employed an IPA approach, which enabled an in-depth exploration of older adults' individual views and experiences of attending the falls clinic, including access to the service, provider-patient interaction, information provision and self-management. Using this approach, the researcher was able to identify idiosyncratic experiences and similarities across the group of older adults with varying health literacy levels. The second phase of the research utilised a framework approach to analysis, allowing the researcher to explore healthcare providers' views about health literacy and the implementation of health literacy strategies in clinical practice at an organisation level.

An overview of the findings suggests that the interactions older adults have with their healthcare providers are important in enabling them to access, understand and use information for health purposes. This supports the view proposed by some health literacy experts that health literacy emerges as an interaction between the demands of the health system and the skills of the individual (Ishikawa et al. 2008).

Older adults in the first phase of the research emphasised the relationships and trust they have with their healthcare providers, the benefit of tailored information and the importance of their social support networks in assisting them to manage their health. As such, health literacy is not just an interaction between the patient and the healthcare system, but also an interaction between the patient and their social support networks. The first phase of the research also revealed practical and emotional difficulties when assessing older adults' health literacy. The second phase of the research revealed healthcare providers' low knowledge and awareness about health literacy, uncertainty about identifying older adults' health literacy levels and concerns about using health literacy screening tools and universal precautions. By contrast, the healthcare providers placed emphasis on relationship and trust building, and tailoring interactions to older adults' individual health literacy needs. Facilitators and barriers to the integration of and development of health literacy in clinical practice were also revealed. The main findings are discussed in further depth in the next sections.

9.3   Discussion of main findings

9.3.1   Knowledge and awareness of health literacy in clinical practice

One objective of the second phase of the research was to qualitatively explore healthcare providers' awareness and understanding of health literacy. The healthcare providers frequently commented on their lack of prior knowledge about health literacy, referencing their uncertainties around identifying individuals' health literacy levels. Many of the healthcare providers admitted to not having heard the term health literacy before and no participants had seen the health literacy screening tools prior to the focus group. When healthcare providers grappled with the concept, they predominantly conceptualised it according to limited functional health literacy definitions and as a static concept (Sections 1.5; 1.6.1). These findings are similar to another qualitative study involving healthcare providers from New Zealand, Canada and Australia (Lambert et al. 2014) which revealed a lack of familiarity around the term health literacy. The findings from the present research also corroborate quantitative research which reveals that healthcare providers have low knowledge of health literacy (Devraj and Gupchup 2003; Knight 2011; Macabasco-O'Connell and Fry-Bowers 2011; Mackert et al. 2011; Cafiero 2013).

However, this contrasts with findings from other studies revealing healthcare providers' awareness of the term, good understanding about health literacy and implicit knowledge about interactive and critical health literacy levels (Smith et al. 2013b; Wood and Gillis 2015). It should be noted that these studies were based in Australia and Canada and this issue has not been previously explored for UK healthcare providers; there may be more familiarity regarding health literacy in countries where there is more research in the area (Section 2.6.1).

Despite the self-identified lack of knowledge, many of the healthcare providers felt that they were using health literacy communication strategies automatically. This conflicts with many of the healthcare providers' accounts where they admitted to providing reams of complex written healthcare information to patients, expressed uncertainty about identifying individuals with low health literacy levels and discussed occasions where they have not identified individuals with low literacy levels. Furthermore, the healthcare providers revealed a lack of knowledge about the prevalence of low health literacy. Social desirability bias and conformity pressures could have influenced responses (Hollander 2004). The healthcare providers may have felt reluctant to fully admit to a lack of consideration of health literacy within their daily clinical practice. This admission may have implications for their professional identity. The healthcare providers did suggest different strategies for communicating with individuals with low health literacy, such as finding alternative methods of providing information. However, there appeared to be no consensus or standardisation of techniques employed. Suggested strategies tended to be more basic in nature (Schwartzberg et al. 2007) and were usually aligned with a risk-based approach to health literacy and did not focus on developing skills or abilities (Nutbeam 2008). This is congruent with Lambert et al.'s (2014) findings. This means that healthcare providers may not be empowering patients to take control of and self-manage their conditions through fully engaging with the more holistic health literacy concept.

Of primary concern is the level of awareness healthcare providers have regarding health literacy. This is essential because healthcare providers' knowledge and awareness of health literacy may impact on their abilities to identify patients' health literacy levels, meet patients' health literacy needs and begin developing health literacy. This may also have an impact on how health literacy is conceptualised by

healthcare providers. Healthcare providers may need more training in health literacy at an undergraduate level and as part of their ongoing professional education. To facilitate this, training would need to be integrated into the curricula of all healthcare providers' degrees and incorporated into mandatory clinical training programmes.

9.3.2 Identifying older adults' health literacy levels in clinical practice

Exploring healthcare providers' views about identifying older adults' health literacy levels was a research objective. Similar to a previous study's findings, the healthcare providers' strategies for identifying individuals' health literacy appeared to be shaped by their understanding of health literacy (Smith et al. 2014), which links in with the issues identified regarding healthcare providers' low awareness of health literacy. When the healthcare providers discussed strategies for identifying individuals with low health literacy, there was no consensus, standard practice or use of health literacy measurement tools across the four groups. The healthcare providers suggested a range of different strategies they used to identify individuals' health literacy levels. Many of their suggested strategies are not supported by advice in the health literacy field. Recommended strategies include assessing understanding during medication reviews and through using the 'Teach-Back' technique (where the patient is asked to describe what they have been taught in their own words), obtaining a detailed social history including asking questions about how easy the patient finds reading and writing and using health literacy measurement tools (Weiss 2007). The healthcare providers strongly relied on picking up subjective indicators of low health literacy: these included verbal and non-verbal cues such as language used by older adults, level of engagement in sessions, facial expressions and body language. These findings are congruent with another qualitative study exploring levels of awareness regarding health literacy in Australian oncologists (Smith et al. 2014). However, the healthcare providers in the present research also demonstrated an awareness that this strategy sometimes resulted in drawing erroneous conclusions about patients' health literacy levels.

Some of the healthcare providers felt that they had both underestimated and overestimated health literacy levels at times. Previous literature has revealed that

healthcare providers often overestimate and rarely underestimate their patients' health literacy levels (Dickens et al. 2013). Healthcare providers also discussed tacitly observing indicators of low health literacy during medication reviews, when patients are filling out forms and making assumptions based on education levels, occupations and when patients exhibited avoidance behaviours, such as dropping out of groups or requesting phone calls. Many of the strategies which healthcare providers suggested for identifying health literacy levels seemed to be ones which could be seamlessly integrated into their clinical practice or were already expected as part of their standard assessments. It is possible that seamless integration of health literacy strategies is necessary at a time when the NHS is under great pressure to make cost efficiency savings (Department of Health 2010a) and time-limited appointments are common (NHS Choices 2014). Conversely, this may also be the most challenging time to implement new strategies and approaches, as evidenced by the healthcare providers in this study and other studies citing time as a barrier to identifying health literacy issues and meeting related needs (Macabasco-O'Connell and Fry-Bowers 2011; Lambert et al. 2014; Salter et al. 2014). However, routine integration of these strategies may increase the likelihood of them being used, particularly if managers support such integration. However, policy changes may be needed to obtain management endorsement.

Another of the research objectives was to explore the acceptability and practicality of using health literacy screening tools. In phase one, qualitative content analysis revealed practical difficulties with administration of the NVS-UK (possibly relating to memory, hearing or visual impairments), which may increase the administration time with older adults. If implemented in clinical practice, it is also possible that health literacy issues may get confused with memory, hearing or visual impairments. Although phase one of the research had a small sample, six out of nine participants had a self-reported hearing impairment and five out of nine participants had a self-reported visual impairment. It was discussed earlier how cognitive and sensory impairments are prevalent in older adult populations (Section 1.7). Unless health literacy screening tools were routinely administered as part of a broader assessment including visual, hearing and memory assessments, it is possible that healthcare providers would not be able to adequately tailor information to their patients' needs based on health literacy scores. For instance,

patients may have low scores resulting from their visual impairment which simplified written information may not resolve.

Older adults' cognitive and sensory impairments may also increase the time taken to administer health literacy screening tools. The health literacy screening tools used in both research phases have comparatively quick administration times (Haun et al. 2014). However, Patel et al. (2011) revealed that it took an average of 11 minutes to administer the NVS to their older African American patient cohort, much longer than the 2.9 minute administration time with a younger population. This research did not measure the administration time, but the NVS-UK was unsuitable to be administered to one older adult participant due to her hearing impairment and other participants requested multiple repetitions of the questions. The administration time of health literacy screening tools is of crucial importance, given that healthcare providers in the second phase of the research were concerned about screening being time-consuming. This builds on previous research findings where healthcare providers identified time restraints as barriers to implementing health literacy screening (Macabasco-O'Connell and Fry-Bowers 2011; Salter et al. 2014). Longer measures such as the TOFHLA were not included in the focus group discussions for the second phase, but based on the findings it can be reasonably assumed that healthcare providers may have issues with this measure too, based on administration time.

The healthcare providers in this research also added that health literacy screening would be an administrative burden. Participants discussed how you can easily find out an older adult's health literacy score, but this is redundant unless healthcare is meaningfully tailored to their needs. Therefore, it is not just health literacy measurement tool administration times which need to be considered: knowing an older adult's health literacy score would undoubtedly have further implications for time spent tailoring information and interventions. Further, whilst one healthcare provider recognised that a single health literacy screening question (Chew et al. 2008) would be most practical for use in clinical practice in terms of being quick and easy to administer, he also felt it would not provide enough information. Healthcare providers in all of the focus groups were concerned that the REALM would not provide enough information. Participants in the neurological service focus group reported already using tests of reading ability, justifying this as the

reason why they felt the REALM would not contribute anything new. However, the healthcare providers in the other groups did not use health literacy screening measures or any proxy measures and still held a similar view.

In addition to practical issues relating to the use of health literacy screening tools, emotional issues also need to be considered. The healthcare providers in this research revealed an awareness that patients may go to significant lengths to hide their literacy issues and identified stigma, embarrassment and shame as possible reasons for this (Baker et al. 1996; Parikh et al. 1996; Wolf et al. 2007; Easton et al. 2013). Possibly resulting from an awareness of this stigma, the healthcare providers expressed a reluctance to discuss or ask patients about literacy issues. The healthcare providers appeared to perceive using health literacy screening tools or even asking patients about their literacy levels and understanding as potentially embarrassing, stigmatising or offensive. This barrier to identifying individuals' health literacy levels has also been reported in previous studies (Gillis 2009; Salter et al. 2014; Smith et al. 2014). The shame felt by patients with low literacy and the resulting discomfort healthcare providers feel about addressing the issue clearly causes a barrier to meeting health literacy needs. This builds upon Smith et al.'s findings (2014) that healthcare providers would be concerned about offending patients or causing anxiety by using health literacy measurement tools. However, this also seemed to be partially about the healthcare providers not feeling confident in identifying and managing health literacy issues in a sensitive manner, further evidencing the need for more training.

A unique contribution of this research is the finding of health literacy screening feeling like a 'test', in both phases of the research. Whilst completing the NVS-UK, the older adults made comments about feeling like they were back in school, doing a test or that they struggle with numerical skills. Other older adult participants commented about not doing very well on the test despite the researcher not disclosing the health literacy score to them. The comments about tests and feeling like being at school were not made when completing the REALM; participants may have perceived completing the REALM as less challenging. It is conceivable that provoking feelings of being back at school and failure in tests may cause anxiety and have a negative impact on older adults. This could plausibly exacerbate any shame felt about low health literacy or affect the relationship built with their

healthcare provider. Other researchers have discussed how care needs to be taken when administering health literacy screening tools and have also chosen to not disclose health literacy measurement scores to participants (Smith et al. 2009b). However, it may be different when patients' health literacy is being assessed in a clinical setting as part of their treatment, as opposed to as part of research participation; patients may expect results to be shared with them. Indeed, participants in phase one seemed to desire results from the falls clinic assessments being shared with them. The health literacy screening conducted as part of the interviews did not take place in a natural clinical setting, but it is possible that similar issues could arise in clinical practice. The concept of health literacy screening being a test of patients was also evident in phase two of the research: the healthcare providers were concerned that health literacy screening would feel like testing a patient and expressed concerns about offending patients or causing anxiety. The healthcare providers were shown both tests of individual abilities and self-report health literacy measures during the focus groups, but did not distinguish between the two when discussing their concerns about health literacy screening feeling like a test. It is possible that using a self-report measure may induce less anxiety given that the patient is given the choice about disclosure of any difficulties. Despite this, some healthcare providers expressed concerns that patients would not be honest if self-report measures were used. Discrepancies between actual tests of ability and self-report measures of health literacy have previously been observed (Lee et al. 2013). However, some healthcare providers did see the possible benefit of health literacy screening, to begin a dialogue with older adults around their health literacy needs and to create a more literacy friendly environment.

These findings are important given their novel contributions: the literature review did not reveal any other studies exploring healthcare providers' perspectives regarding specific health literacy measures. Additionally, previous studies describing healthcare providers' perceptions about health literacy screening tools have not explored this in depth (Salter et al. 2014; Smith et al. 2014). There is huge interest in the use of health literacy screening in clinical practice (Section 2.5.1) and multiple different measures have been developed (Jordan et al. 2011; Haun et al. 2014). However, there remains little evidence of the benefit of using health literacy screening and there is potential to cause shame or harm (Paasche-

Orlow and Wolf 2007b). This research has also revealed the need for more exploration into the implications of screening. For instance, it is imperative to be clear about the purpose of health literacy screening and whether or not individualised tailoring or general tailoring of information would be the end result. Being clearer about the purpose would make it easier to select appropriate measures for use in clinical practice, and may support with engaging healthcare providers with the tools.

9.3.3 Using universal precautions as an alternative to health literacy screening

The concept of universal precautions was introduced in Sections 1.8.1 and 2.5.2 as an alternative to health literacy screening. The older adult participants in this research valued both verbal and written information being presented in a clear and simple manner. This finding was irrespective of their assessed health literacy level or medical knowledge and supports previous research findings which indicate patients with low and adequate health literacy levels desire clear and accessible health information (Smith et al. 2008; Shaw et al. 2009; Gaglio et al. 2012). These findings appear to further support the use of universal precautions in older adult populations. However, the findings also indicated that the way in which universal precautions are delivered is crucial. Clear and simplified information should be provided in a way which makes people feel comfortable, as evidenced by the older adults valuing the healthcare providers delivering information simply and in a respectful manner. However, only participants' functional health literacy was assessed in this research. Although some possible indicators of interactive and critical health literacy were revealed through the interviews, we cannot assume that any of the older adult participants had interactive or critical health literacy. Therefore, it is possible that individuals assessed as having high interactive or critical health literacy levels may have different views.

Contrastingly, healthcare providers unanimously expressed discomfort about providing simplified information to patients, concerned about the potential of offending or patronising some of their highly literate patients. They felt simplified information could be construed as 'childlike' and some also suggested using universal precautions may result in patients questioning their professional status

and knowledge levels. This is an important finding which suggests that patients with higher health literacy may appear somewhat threatening to healthcare providers; healthcare providers may feel that they need to provide high-level information to satisfy these individuals and avoid their knowledge being questioned. Healthcare providers may need further training to feel confident in engaging with highly health literate patients who may require a different approach, involving managing expectations of information received and signposting to further information. Additionally, healthcare providers may need to be made aware that highly literate patients may not have high levels of health literacy, emphasising the content and context specific nature of health literacy.

The healthcare providers also appeared to view universal precautions as at odds with tailored healthcare communication; they advised that they treated their patients as individuals, and that one 'size cannot fit all'. Therefore, universal precautions did not fit conceptually with how the healthcare providers viewed their service provision. Alternatively, this may reflect healthcare providers' confusion about the term 'universal precautions' or indicate use of this academic term during focus groups was off-putting. For instance, the researcher used the term during the focus groups, subsequently explaining what this meant. It may have been more beneficial to just describe the meaning of the term without using the actual term. Despite the healthcare providers' reasoning behind their reservations for universal precautions, some of the healthcare providers felt that providing alternative forms of communication (i.e. meeting the needs of older adults with low and high health literacy) would not be feasible, thus revealing a possible contradiction in the healthcare providers' perception of their tailoring of information. Previous research has revealed individuals with both high and low health literacy levels have similar concerns about complex health information (Sudore et al. 2007; Smith et al. 2008; Shaw et al. 2009), thus possibly justifying use of universal precautions. The healthcare providers' concerns about providing clear and accessible information could also be linked to their lack of knowledge and awareness of health literacy issues (Section 8.4). When developing written healthcare materials, it is recommended to include patients in the design (Raynor et al. 2011; Brach et al. 2012). When doing this, it is important to include older adults and individuals with low and high literacy levels. It is possible that

healthcare providers' concerns about simplifying information could be alleviated through user-testing.

The findings from the present research revealing healthcare providers' reservations about universal precautions contrasts with Smith et al.'s findings (2014) that radiation oncologists in Australia appeared to be using universal precautions with patients and assuming a low level of baseline cancer knowledge with all patients. However, perceptions about the concept of 'universal precautions' were not explored here and this is the first research study explicitly exploring perceptions about universal precautions and qualitatively exploring and comparing health literacy screening with universal precautions in the context of healthcare for older adults. This contributes to understanding of the possible issues with implementing either approach in clinical practice. It is possible that Smith et al. (2014) chose not to specifically ask about use of 'universal precautions' to avoid the risk of the term itself being unappealing. However, within clinical practice, a conceptual term may either help or hinder implementation of any interventions associated with the term.

Similar to health literacy screening, the concept of universal precautions broadly fits with a risk based approach to health literacy, given the lack of focus on developing patients' abilities. However, it still remains unclear whether it would be more beneficial to screen individuals for lower health literacy or apply universal precautions (Baker 2006). Findings from the second phase of this research revealed that healthcare providers have concerns about using either approach. Interestingly, the older adults in the first phase appeared to value clear and simple information regardless of their assessed health literacy level, suggesting that healthcare providers' concerns may not be entirely warranted. However, this concern is evidently something which would need to be addressed within healthcare providers' health literacy training.

When considering the learning theories discussed in Section 1.8.2, using either health literacy screening or universal precautions appears to be congruent with a more pedagogical style of teaching instead of an andragogical style. For instance, both strategies primarily relate to the healthcare provider providing information using the method they think will deliver the best results for the patient. This

contrasts to viewing delivery of healthcare information as a collaborative process with the patient, where the patient is empowered to discuss their health literacy needs. However, it may be pragmatic, and ultimately easier, to implement either one of these approaches within healthcare policies and busy clinical areas, especially considering the emphasis healthcare providers have placed on time pressures. The present research suggests it would be beneficial for universal precautions advocates to place more emphasis on how the needs of individuals with higher health literacy levels could be met, for instance through signposting and managing expectations. It may be more useful to consider universal precautions as providing clear and easy-to-understand information to all patients universally, whilst also considering opportunities to extend knowledge and engagement with patients who are capable and willing. Presenting universal precautions in this manner may also help to allay healthcare providers' concerns and perceptions about providing simplified information to all patients.

9.3.4   Relationship building and trust, tailored interactions and social support

Relationship building and trust

Regardless of their assessed health literacy levels, the older adults in the first phase of the research strongly emphasised the importance of relationships and trust with non-clinical staff, their healthcare provider and other falls clinic attendees. Relationship building and trust appeared to be particularly important when participants were learning new concepts and seemed to affect participants' desire to attend the service, adherence to recommendations and receptiveness to health information.

The impact of non-clinical staff, such as transport and catering staff, was highlighted in the first phase of the research. When accessing the falls clinic, patients often encountered non-clinical staff first: the relationships built through positive interactions and kind gestures (such as being offered a cup of tea) appeared to relax participants in preparation for their clinical sessions, thus seeming to increase their receptiveness during sessions and enhancing their overall experience. The importance of non-clinical staff should be given more

attention; a patient's overall experience may affect their motivation to access and optimally use the healthcare services available.

Some of the older adults were initially resistant to the concept of a falls clinic and falls prevention, but as a result of trust in the referrer or a growing trust in the healthcare providers at the falls clinic, their receptiveness to the information appeared to increase. Effective relationships appeared to be built through healthcare providers being friendly, positive, sharing aspects of themselves, recognising the patient as a unique individual and being attentive. Being treated as individuals appeared to make the older adults feel like they were being acknowledged as an individual with unique strengths and motivators. These are simple and straightforward attributes which, if used successfully, can make a big difference to patients' experiences. They are also opportunities for healthcare providers to design healthcare programmes that maximise motivators for engagement with rehabilitation. Interpersonal skills and human kindness shown by clinical and non-clinical staff may foster an environment which is open, non-threatening and conducive to learning.

Trust appeared to be built through the patients' belief that the healthcare providers had their best interests at heart and were demonstrating caring attributes and emotional intelligence, but also confidence in the healthcare providers' communication abilities and knowledge levels. Healthcare providers' clear communication, willingness to explain and repeat and respectfully listening to the older adult's concerns before then acting upon them appeared to be beneficial. Feeling like suggestions would be listened to seemed to increase patients' confidence to make suggestions. Additionally, having confidence that the healthcare provider is tailoring the treatment or approach to the older adults as individuals seemed to be important. Many of these factors may link with interactive health literacy; trust appeared to be built when patients interacted with their healthcare providers and positive results were produced. The human qualities discussed may be central to caring and supporting patients to engage with self-management messages. This important finding links the present research to prior research on the importance of trust for optimal healthcare provision, patient satisfaction and adherence to medication or recommendations (Baker et al. 2003;

Piette et al. 2005; Berry et al. 2008). Additionally, this finding may need further consideration in a health literacy context.

The older adults also developed relationships with other falls clinic attendees in the waiting area and reported both valuing meeting new people and learning from one another. Such knowledge acquisition seemed to occur organically, but this indicates healthcare systems could benefit from incorporating psychosocial interventions and vicarious learning in their treatment plans.

In summary, these findings highlight the vital component of the non-medicalisation of healthcare, the value of human kindness and personalised approaches, all mediators in helping to support and develop health literacy and enhance the experiences of older people.

The healthcare providers in the second phase of the research also perceived relationship building and trust as important factors when meeting older adults' health literacy needs, but primarily focussed on how relationships and trust can enable older adult patients to be upfront about their health literacy levels and any gaps in their knowledge. Some healthcare providers felt that a patient's health literacy can only be truly understood by developing a relationship and building trust with them over time. Another study suggested that healthcare providers felt spending enough time talking to patients is the best way to identify patients' health literacy needs (Salter et al. 2014). Some authors have suggested that health literacy screening tools should only be used after trust has been established (Reyes 2010). In the first phase of the research, relationships and trust appeared to be influenced by tailored interactions, although it may be difficult to tailor interactions without building up an understanding of an individual's health literacy. Furthermore, if understanding about a patient's health literacy has already been built through interactions before using health literacy screening tools, it may not be necessary to use a screening tool.

The healthcare providers also discussed how older adults may be more likely to access services and adhere to recommendations when a trusted doctor who they have good rapport with refers them and is positive about the service. Whilst attending the falls clinic, the older adults inferred trust in the healthcare providers

and discussed being willing to follow their recommendations as a result. Relationships and trust built with healthcare providers may increase the likelihood of older adults attending services, and adhering to recommendations as a result. Therefore, relationship building and trust may be important when considering health literacy.

Previous research has revealed that older adults trust their physicians significantly more than younger adults (Rodriguez et al. 2013). As such, trust may be important when meeting older adults' health literacy needs. Trust and effective provider-patient interactions have previously been found to be essential for fostering therapeutic encounters and to have a positive effect on health outcomes, including increased glycaemic control in diabetic patients (Stewart 1995; Hall et al. 2001; Mancuso 2010). Trust in healthcare providers has been known to influence patient satisfaction, perceptions about the quality of provider-patient interactions, adherence to recommendations and patient utilisation of healthcare services (Sheppard et al. 2004; LaVeist et al. 2009). One study found no relationship between literacy (as assessed by the REALM) and trust (DeWalt et al. 2007). Contrastingly, another study found that individuals with lower health literacy (as assessed by the TOFHLA) were more likely to have greater physician trust (White et al. 2013). Further, one qualitative study revealed that individuals with both lower and adequate health literacy identified trust as having an important influence on involvement in decision-making (Smith et al. 2009b); another study revealed low trust and older age are associated with suboptimal shared decision making (Barton et al. 2014). Whilst it is unclear whether low functional health literacy levels influence a patient's likelihood to have trust in their healthcare providers, it may be relevant for meeting patients' interactive health literacy needs.

Despite the positives, it is unclear whether or not high levels of trust might impair an older adult's interactive or critical health literacy abilities; the healthcare providers in this research felt trust could cause a barrier to older adults' questioning abilities. Seeking to improve patients' interactive/critical health literacy may alter trust dynamics; an individual with higher health literacy may have different expectations which need to be met before trust is established. In this situation trust may be more conditional and dependent on aspects such as

effective communication, provision of information and signposting and use of research evidence (Rowe and Calnan 2006).

There has been little attention in the literature to the relational aspects of communication when considering health literacy, with health literacy clinical guidance documents not mentioning relationship building or trust (Weiss 2007; Brega et al. 2015). This has implications for the future development of health literacy interventions and suggests that trust needs to be considered when exploring patients' 'access to' and 'use' of health information. This research has uniquely contributed that relationship building and trust may be imperative factors when identifying older adults' health literacy levels and trying to increase access and receptiveness to health information. Previous research has revealed patients prefer to receive information during face-to-face encounters, and within these interactions they need to feel relaxed to be able to ask questions (Shaw et al. 2009; Gaglio et al. 2012). The older adults in the first phase of the research emphasised the relationships with their healthcare providers and participants reported asking healthcare providers to explain things again, indicating they felt relaxed enough to ask questions. Relationship building and trust may have implications for older adults' interactive health literacy. This finding also raises important questions about the most effective delivery method of health information to older adults at a time when web-based interventions are increasing exponentially (Wantland et al. 2004).

Tailoring of information and interactions

Ensuring information is tailored to an individual and directed towards the patient is consistent with the empowerment principles of health literacy (Kickbusch 2001). If healthcare delivery is adapted to older adults' individual needs, tailored information could meet older adults' functional, interactive and critical health literacy needs. The importance of tailored information was revealed through both phases of this research.

The older adults in the first phase of the research identified a personal reason for their attendance at the falls clinic, which was often linked to their personal goals. These personal reasons for attendance and goals appeared to have positively

impacted the older adults' motivation to attend the falls clinic and their subsequent adherence to recommendations, thus possibly influencing their access and use of health information. To increase older adults' receptiveness to health information, it may be necessary for healthcare providers to discuss and engage with the older adults' reasons for attendance and goals. Collaborative goal-setting is suggested as a strategy for addressing health literacy needs and previous research indicates participation in goal setting is important for patients and underused by therapists (Baker et al. 2001; Paasche-Orlow et al. 2006). However, no other health literacy research was identified which emphasised the importance of discussing personal reasons for attendance and goals with patients.

The older patients in the first phase of the research also described a preference for information tailored to their individual needs and preferences, including written and verbal information. Patients with both low and adequate health literacy levels have previously expressed frustration at receiving generic information and desire tailored information instead (Gaglio et al. 2012). NICE guidance (2012) recommends that healthcare services are tailored to individuals' needs and preferences. However, whilst this is clearly important for patients' experiences, this may be challenging at a time when the NHS is expected to make cost-efficiency savings and is under mounting pressure, with waiting times and an ageing population (Department of Health 2010a; Office for National Statistics 2012; Department of Health 2015).

When discussing both health literacy screening and universal precautions, the healthcare providers in the second phase of the research appeared to reject such approaches in preference of tailoring education, information and healthcare to older adults' individual needs. However, although appearing to favour tailoring of information, this seems to be at odds with the healthcare providers' reluctance to ask patients about or assess their health literacy requirements. The healthcare providers identified a number of barriers to doing this including time constraints, difficulties identifying needs within group sessions and the shame and embarrassment patients may feel about low health literacy. This is despite potential difficulties tailoring information without knowing about an individual's health literacy needs. In both the risk and asset approaches to health literacy, Nutbeam (2008) suggests the healthcare provider needs to have an understanding

of a patient's capabilities before being able to tailor information to their needs. The healthcare providers in this research felt they could estimate a patient's health literacy through verbal and non-verbal indicators, but some reflected on occasions where they had been incorrect in their judgement, and research indicates that healthcare providers often overestimate patients' health literacy abilities (Dickens et al. 2013). It is possible that the healthcare providers view tailoring information as the ideal, but do not currently have the skills or knowledge to do this. Further, their knowledge about the specifics of universal precautions may be limited. For instance, it is possible to use both universal precautions and tailor information to an individual's specific information needs (Protheroe and Rowlands 2013; Smith et al. 2013b). This could be achieved by providing accessible information to all, but asking patients about their information preferences and either having more in-depth information on offer to individuals with high information needs, or signposting them to where they can access more information.

The findings also suggested that tailoring healthcare delivery to older adults' preferred communication and learning styles may be beneficial when meeting older adults' health literacy needs. This type of tailoring appears to be more congruent with a more andragogical style of healthcare education. Many of the older adult participants identified preferred styles of learning, such as observational, reflective, experiential and vicarious (Bandura 1971; Kolb 1984). Previous research has demonstrated that tailoring health information to both literacy level and learning style preferences improves patient understanding of hypertension (Giuse et al. 2012). However, in relation to health literacy, the patient perception regarding this has not previously been documented and therefore this finding contributes to the health literacy field. Healthcare providers could consider older adults' preferred learning and communication styles and initiate conversations regarding this, which would enable more personalised tailoring of information. Although, this may be most viable in patient education programmes where learning outcomes are considered.

The healthcare providers did not discuss tailoring information to the learning styles described above and instead discussed different types of learning such as visual or auditory (Fleming and Baume 2006). This type of tailoring may fit more with a pedagogical style of education, where information is provided to patients by

healthcare providers. However, this research has revealed that healthcare providers are not aware of different learning styles such as reflective and vicarious learning. This contribution to the field suggests it may be challenging to implement asset based approaches to health literacy without further training.

Some of the healthcare providers felt that there is not enough time to consider or assess individual patients' preferred learning styles, and that they try and meet their patients' needs by applying a 'middle-of-the-road' approach. This is noteworthy considering the healthcare providers' strong aversion to the concept of universal precautions and identified preference for tailoring information. Additionally, many of the healthcare providers indicated that their tailoring of information resulted from a 'gut feeling' and therefore appeared to be performed subconsciously. As a result, it may be necessary for healthcare providers to have further training on tailoring information to patients' health literacy.

Social support

The older adult participants' accounts revealed a crucial role for their social support networks in assisting them to manage their health needs. This included tangible support (e.g. transportation, managing medication and help with forms and communicating with healthcare providers) and informational support (e.g. providing advice and encouragement). Health literacy was found to be distributed through participants' social networks in Edward et al.'s study (2015). Asking if a patient would like a family member present at healthcare appointments is a recommended health literacy communication strategy, but is not consistently used (Schwartzberg et al. 2007). The healthcare providers in the second phase of the present research recognised the role older adults' social support has in meeting their health literacy needs, and some discussed involving family members or friends in their consultations. However, very few healthcare providers mentioned asking patients specifically if they would like someone to attend appointments with them. This is something simple which could be easily implemented routinely, and incorporated into clinical guidelines, such as the NICE guidelines.

Additionally, some healthcare providers felt that a patient's social support network could cause a barrier to information provision, particularly when dealing with

sensitive issues. Healthcare providers should be educated about using social support to mitigate the risks of low health literacy. It is probable that most healthcare providers have had some experience of carer or family members' beliefs impacting on patients' responses to advice, but also possible that healthcare providers may allow one or two difficult experiences to overly influence subsequent encounters. However, caution is advised because patients struggling to understand health information may be more likely to have social support from individuals who also have lower education levels (Paasche-Orlow and Wolf 2007a). Whilst this may provide opportunities for developing the health literacy of both parties, there are also vulnerable individuals who have inadequate or no social support who need to be considered.

The findings from the present programme of research are further evidence that it is important to consider the individuals' abilities and the demands of the healthcare system (Ishikawa et al. 2008). However, it is not just the demands of the healthcare system which should be considered, but also the quality of the interactions between the healthcare provider and the older adult patient, the relationship and trust between the provider and patient and the extent of tailoring. These factors could be considered facilitating factors for creating a positive 'health literacy environment', and could be included within checklists which promote the health literacy environment (Rudd and Anderson 2006). For instance, actions such as offering patients a drink, asking about their social support and considering patients' unique goals and attributes could easily be integrated into guidance. To enable meaningful tailoring, the present research suggests it may be necessary for healthcare providers to initiate these conversations since patients may not have the confidence to articulate their preferences. The conceptualisation of health literacy as an asset may be important here. However, patients must be willing and able to both engage and participate in their healthcare if these health literacy strategies are to succeed (Protheroe et al. 2012).

9.3.5   Facilitators and barriers to meeting older adults' health literacy needs in clinical practice

This Chapter has highlighted that healthcare providers have low knowledge levels about health literacy, which may affect their ability to meet older adults' health

literacy needs. Qualitative exploration of the issue enabled participants to elaborate and provide explanations for their perceived lack of health literacy knowledge. For instance, the healthcare providers identified a need for further training in the area; many felt health literacy was not focussed on during their undergraduate degree training or within mandatory clinical training. Increased training in health literacy has previously been identified as a need for the healthcare workforce in the US (Coleman 2011). There has been little focus on increasing health literacy training within undergraduate training in the UK, but the Royal College of General Practitioners have recently emphasised the importance in a report on health literacy (2014). Providing health literacy training to healthcare providers has resulted in improvements in their perceived health literacy knowledge (Mackert et al. 2011) and the present research reveals that UK healthcare providers working in the NHS may be receptive to the idea of training. This research has also revealed that healthcare providers have different approaches and views about identifying patients' health literacy levels and meeting patients' health literacy needs according to their professions (e.g. nurse) and the type of treatment which they offer to patients. For instance, the nurse participants discussed using medication reviews to identify patients' health literacy levels, the neurological service focus participants discussed including literacy assessments as part of their broader cognitive assessments and focus group participants who used group work as part of their standard treatment pathway discussed how this can be a barrier to identifying patients' health literacy levels. Given these differences, it would be beneficial to provide a tailored approach to educating healthcare providers about health literacy which considers the needs of individual professions and teams.

Healthcare providers' low knowledge levels may also affect their perceptions about how important it is to consider health literacy within daily clinical practice. The second phase of the research revealed that healthcare providers had varying opinions about how important health literacy is to consider. Some of the healthcare providers felt that health literacy does not always need to be considered, but this may have been influenced by their primary understanding of health literacy as relating to functional literacy abilities. Again, this perception may be addressed through increased training.

The second phase of the research also revealed some important findings in connection with healthcare providers' perceptions about development of health literacy. Many of the healthcare providers appeared to shift the responsibility for health literacy development onto schools, public health and literacy programmes. This was evident when the healthcare providers appeared perplexed when asked about how a patient's health literacy abilities could be developed and often described this as a wider societal issue. The healthcare providers' perceptions about the development of health literacy could have been influenced by a range of factors. For instance, the healthcare providers' understanding of health literacy appeared to primarily align with functional health literacy definitions. However, this may have resulted from confusion about the term 'health literacy': the researcher rarely used the term during the focus groups, and instead opted to ask questions relating to the definition of health literacy. In clinical practice, it is possible that using the term 'health literacy' with healthcare providers could increase the likelihood of them then using recommended communication strategies. In contrast, use of this academic term itself could be off-putting or cause confusion resulting from inclusion of the word 'literacy' within it. Although the researcher used the term 'health literacy' and the full definition, the healthcare providers often perceived it as pertaining to functional literacy abilities. The healthcare providers' self-identified lack of awareness, knowledge and confidence regarding health literacy could have impacted both their conceptualisations of health literacy and their views about development of health literacy. The healthcare providers were keen to discuss their role in providing health information to patients and usage of strategies to enhance patients' understanding of information provided. This appears to align more with a pedagogical style of healthcare education delivery.

The healthcare providers did not necessarily view health literacy as 'static', given that they identified methods for developing health literacy outside of the healthcare system. However, their approach to meeting older adults' health literacy needs did seem to align with viewing health literacy as static within the healthcare system. For instance, healthcare providers discussed an individual's existing functional literacy abilities or information requirements, and how healthcare could be tailored to meet these needs. This is obviously important, especially when older adults often experience personal and permanent barriers affecting their information requirements, such as hearing, visual and memory impairments (Speros 2009).

It has been suggested that school education and adult literacy/education programmes can be used to develop health literacy, but these strategies are more attuned to preventive and public health (Leger 2001; Nutbeam 2008). It is arguably beneficial to increase children's health literacy abilities through school education. If children are equipped with critical appraisal abilities which they can apply to healthcare, this may result in more health-aware and capable older adults. From a public health perspective, the aim would be for children to make healthier choices throughout their lives. However, education is a lifelong process and the provision of healthcare changes and evolves at a rapid rate. If these strategies are used alone, there would be potential for individuals to forget skills over time and only a certain proportion of the population would attend low literacy programmes. Further, health literacy changes over time – what someone needs to know as a child may be different to their information requirements as a parent, or adult, or older adult. Additionally, as discussed in Section 1.8.2, adult education is often successful when it is deemed to be relevant and based on personal experiences. As a result, some individuals may be more inclined to seek health information and wish to develop their health literacy abilities when they are receiving current treatment for a condition. It is argued that health literacy is equally important in both healthcare settings and in the public sphere (Pleasant and Kuruvilla 2008). The researcher argues the development of health literacy is the responsibility of all sectors; but in a healthcare context, each clinical encounter should be viewed as an opportunity to develop a patient's health literacy abilities. Furthermore, the development of health literacy can be incorporated as an explicit aim of existing patient education groups and self-management courses. Health literacy development programmes could also be developed; health and social care organisations could take responsibility for both identifying suitable individuals to attend and running these types of courses.

Healthcare providers' low health literacy knowledge levels, perceptions about the importance of considering health literacy and shifting of responsibility for developing health literacy, are further evidence for increasing health literacy training for healthcare providers. Additionally, further education and training may support healthcare providers to engage in debates about how to determine older adults' health literacy and whether to use health literacy screening or universal

precautions. If healthcare providers opt not to use health literacy screening or universal precautions, they need to be supported and educated in identifying health literacy and meaningfully tailoring healthcare to older adults' health literacy needs.

9.4   Reflections

To enhance confirmability, it is necessary for the researcher to reflect on the reasons for choosing one approach over another and any weaknesses in the techniques used (Shenton 2004). The researcher outlined how the trustworthiness criteria were met in Section 3.3.4. The following sections discuss the methodological decisions made and how they influenced the research.

9.4.1   Use of Patient and Public Involvement and designing research according to health literacy principles

A public contributor was included in the development of the first phase of the research (Section 4.7): this individual had a high level of educational attainment and literacy abilities. Therefore, in the development of the research, the views of older adults with low functional literacy were not represented. This may have impacted on the choice of health literacy measures and on the questions used in the interview guide. In future health literacy studies, it would be beneficial to include individuals with lower functional literacy abilities in the development of research.

Strategies were used to make the research accessible to individuals with low literacy levels (Section 4.4.7) and in general, were well received. Given that there was a large amount of information to cover, it would not have been realistic to use the Teach-Back technique on every aspect of the participant information sheets. As a result, understanding was assessed at the end, and therefore it was difficult to ascertain if the entire participant information sheet was understood. Furthermore, participants' perceptions about the use of the Teach-Back technique to assess understanding were not sought. In future, collecting this information would be useful. The Teach-Back technique is widely recommended

(Schwartzberg et al. 2007), but little is known about the acceptability of using it with patients or research participants.

9.4.2   Use of two different qualitative approaches

IPA was used for the first phase of the research in this thesis, exploring the health literacy experiences of older adults attending falls clinics. Aspects of the IPA approach which were compatible for the data set included the methods used, an idiographic approach and detailed interrogation of the data. For instance, the semi-structured interviews enabled the participants to reflect on their personal experiences and have some control over the direction of the interview. This may have assisted in the production of rich in-depth data. The idiographic approach enabled the researcher to focus on each individual participant's experience before attempting cross case analysis, which ensured an in-depth analysis and valued the experiences of the individual. This is congruent with the researcher's epistemological position of subtle realism; the researcher believes that it is possible to access an individual's cognitive inner world through explicit and careful analysis. Analysing the data inductively and in such depth initially allowed themes to emerge, some of which may not have when using a less idiographic or deductive approach. However, in order to add meaningful contributions to the health literacy field, the researcher then applied personal knowledge of health literacy to the analysis, thus analysing the data through a health literacy lens. Therefore, although the researcher focussed on aspects of the experience which the participants emphasised as important, some of the researcher's predispositions may have influenced the analysis.

Using IPA for the first phase of the research enabled the researcher to develop the research objectives and topic guide for the second phase of the research, which were grounded in the views of the older adult participants. Given that the goal of the second phase of the research was to identify group norms and explore health literacy in clinical practice, as opposed to explore an individual's experience, it was deemed inappropriate to use IPA for the second phase of the research. However, using two analytical methods in this manner has drawbacks. Firstly, using different methods and samples makes it more difficult to draw comparisons between the two sets of data. For instance, if older adults and healthcare providers were

recruited from the same place, asked similar questions and interviewed using the same techniques, it would be easier to compare and contrast their accounts. However, health literacy affects all service providers and patients and therefore it is also useful to interview diverse groups and check for similarities and differences.

9.4.3 Utility of the health literacy framework and model used in thesis

The conceptual model linking health literacy to health outcomes (Paasche-Orlow and Wolf 2007a) guided the development of this research and the analysis of findings. This model enabled the researcher to consider health literacy as both a patient and system issue which is influenced by personal and social determinants (Paasche-Orlow and Wolf 2007a). For the first phase of the research, this model was useful to guide the collection of sociodemographic data and guide the development of the interview guide. The model was used less explicitly for the focus groups, but assisted with framing health literacy as an interaction between older adults' health literacy abilities and the demands of the healthcare system in the topic guide (Paasche-Orlow and Wolf 2007a; Ishikawa et al. 2008). For both phases of the research, consideration of issues relating to access, provider-patient interaction and self-care was useful to explore health literacy experiences and facilitators and barriers to meeting health literacy needs. However, this model is relatively static, in that it considers the factors which may affect an individual's health literacy, but does not suggest a pathway for development of health literacy or focus on development of skills. Additionally, this research has primarily focussed on patient and provider factors (system factors primarily relating to healthcare providers and their interpersonal abilities), whereas the model considers extrinsic factors (such as media and technology) and system demands, such as the organisation of services. Further research may benefit from more in-depth exploration of these areas.

Use of Nutbeam's functional, interactive and critical framework (2000) was invaluable for considering the development of health literacy and how health literacy is conceptualised in clinical practice. This framework was used to structure the topic guide for the focus groups and the data analysis. To be useful in clinical practice, Nutbeam's health literacy framework (2000) may need expansion to include the variables which affect health literacy at a functional, interactive and

critical health literacy level. However, to expand this framework, further research would be necessary to ascertain facilitators and barriers to the development of interactive and critical health literacy. Manganello's model (2008) endeavours to make links between the functional, interactive and critical health literacy framework, factors influencing health literacy such as individual traits and health outcomes. However, this model focusses on adolescent health literacy and does not specify which factors may facilitate development of health literacy at each level. A model focussing on the specific variables and how health literacy develops in older adults would be beneficial.

This research also raises important questions about the transferability of Nutbeam's tripartite framework (2000) into a clinical setting. The majority of theoretical and colloquial data argues that functional and interactive health literacy skills need to be present before critical health literacy emerges (Sykes et al. 2013). However, some health literacy experts oppose this view arguing reading and writing skills are a 'building block' but not an absolute requirement (Nutbeam 2000; Sykes et al. 2013). The analysis from the present study may suggest that progression through the health literacy levels is not entirely linear. Several participants in this research had low health literacy scores according to the NVS-UK but exhibited indicators of interactive and critical health literacy (such as when one participant appraised a written document during an interview in phase one of the research). Additionally, some patients may have difficulties reading and writing, but may have high confidence levels in interacting with their healthcare providers. Whilst the health literacy tripartite framework may be useful when considering how to structure educational programmes, it is important to remember that within clinical practice it is often more complicated and theoretical models/frameworks do not always apply to the reality of patients' situations.

9.4.4 Utility of health literacy screening for first phase of the research

Many of the qualitative research studies focussing on health literacy have not used health literacy measurement within the methods (Jordan et al. 2010; Edwards et al. 2012). However, other studies have included health literacy measurement within the design (Smith et al. 2009b). The present research opted to use health literacy measurement to inform data analysis and make comparisons between the

groups with low or adequate health literacy. However, a discrepancy between participants' assessed levels and their responses was observed. For instance, participants' responses indicated varying health literacy levels and abilities in different areas. This may be because functional health literacy measures were used and it may be more insightful to use measures which include the interactive and critical abilities (Chinn and McCarthy 2013; Osborne et al. 2013). Additionally, practical and emotional issues were identified relating to using health literacy screening with older adults. These findings were important and justify use of the measurement tools for the purpose of this qualitative research while suggesting care needs to be taken if routinely using measures in research or clinical practice. Furthermore, future research may benefit from incorporating more holistic health literacy measures within the designs. The AAHLS was used to facilitate discussion during the focus groups with healthcare providers, but other measures such as the HLQ were not included. Future research with healthcare providers could entirely focus on screening tools, and thus include more within the design.

9.5   Strengths and limitations of the research

Firstly, as described in Chapter Three (section 3.3.4), steps were taken to enhance the trustworthiness of the research (Shenton 2004). This helps to ensure that the contributions to the evidence-base are credible and grounded in the participants' accounts as opposed to being influenced by the researcher's predispositions. On reflection, few barriers were identified to meeting older adults' health literacy needs in the first phase of the research; in the context of the falls clinic, there were few observable threats to positive relationships and trust. This may indicate that the participants were trying to 'please' the researcher by reporting what they thought was wanted. However, steps were taken to enhance participants' honesty (Section 3.3.4.1) and participants compared their positive experiences of relationships, communication and trust at the falls clinic to less favourable experiences in acute hospitals. Participants also discussed instances where they felt information was not tailored to their needs. Therefore, it is possible that this was an accurate representation of the participants' experiences, but also that participants who had negative experiences of the falls clinic chose not to participate.

Although qualitative methodology was congruent with the researcher's epistemological position of subtle realism, it was also deemed the most appropriate method to answer the question and few published studies have explored health literacy issues in the context of older adults using qualitative methodology (Sections 2.4; 2.5 and 2.6). As such, qualitatively exploring the views and experiences of both older adults and healthcare providers has provided rich, in-depth and insightful data which a quantitative study may not have generated. Considering this issue from both patients' and healthcare providers' perspectives enabled the researcher to compare findings, illuminating similarities and differences in the way patients and healthcare providers may think about information provision. This research contributes novel findings about the facilitators to meeting older adults' health literacy needs, including relationship building and trust, tailoring healthcare delivery to older adults' individual health literacy needs and preferences and consideration of social support. Additionally, the literature review revealed no other research comparing healthcare providers' perceptions about the use of universal precautions or health literacy screening. This research raises further questions about which method is more effective or acceptable for older adults, and there has been little research in this area (Section 2.5). Low knowledge and uncertainty about the relevance and significance of health literacy was revealed in the second phase of the research: the healthcare providers were participating in a health literacy focus group in a voluntary capacity; they may have had relatively higher interest in and awareness of health literacy as a concept. It is possible that other healthcare providers not voluntarily participating in focus groups may have less interest and awareness about the area. This may mean that the barriers and reservations revealed by healthcare providers in this research could be even more pronounced in other healthcare providers.

Through completion of this clinical academic doctorate, a range of practical contributions have been made to the NHS Trust involved. Firstly, the researcher has assisted in raising healthcare providers' awareness of health literacy. This has been achieved through healthcare providers' participation in focus groups, delivering health literacy workshops with the NHS Trust and providing a health literacy consultancy service. Additionally, the findings were shared with the healthcare providers and research participants (Appendices N, O and X). Despite this, after receiving the summary of the findings, neither the healthcare providers

within the falls clinic or the focus group participants engaged in further conversations with the researcher about meeting patients' health literacy needs or opted to participate in a health literacy workshop. The findings were shared by E-mail and the researcher reflected that more creative measures may assist with continuing a dialogue regarding meeting patients' health literacy needs. In future research, the researcher could present the findings at a team meeting and encourage group discussions about the findings. It may also be beneficial to send reminders to focus group participants about the health literacy workshops. The implications for clinical practice (Section 9.6) which directly derived from the data will also provide useful insight for healthcare providers considering setting up health literacy or patient education programmes.

Although there are many strengths and worthwhile contributions of this research to the evidence-base, a number of limitations need to be discussed to enhance transparency and confirmability (Shenton 2004). Firstly, both the interview and focus group studies were conducted in one geographical area, in a community setting. As such, findings may not be transferable to other NHS Trusts, in particular those which provide hospital care. Furthermore, views relating to health literacy may be influenced by a country's culture and the healthcare system. As a result, findings may not be transferable to other countries where patients' and providers' perceptions about healthcare may be different. As with literacy, health literacy is a social construction and different cultures and societies may have different expectations about what it means to be 'health-literate' (Institute of Medicine 2009). However, detailed reporting of the research context and sample enables readers of the work to assess the transferability to their own situation (Shenton 2004).

Although acceptable for the methods used, both the interview and focus group phases of the research had relatively small sample sizes. The interview phase used an IPA approach, where a small sample size is advised due to the depth of analysis (Smith et al. 2009a). As a result, only older adults with low health literacy according to the NVS-UK were interviewed and individuals with particularly high health literacy levels were not represented. However, according to the REALM, six out of nine participants had adequate health literacy, therefore it is difficult to accurately ascertain whether the participants had high or low health literacy. The

original sampling strategy, which involved asking participants a single screening question if the researcher was only accessing individuals with high health literacy, was therefore not used. Future qualitative research which endeavours to make comparisons between individuals with high and low health literacy may benefit from having a larger sample and using one carefully chosen comprehensive health literacy measure. Additionally, recruitment only occurred through the researcher on specific days; it may have been more beneficial if healthcare providers also recruited. Although they were asked to do this originally, this did not happen due to the healthcare providers' time constraints. A larger sample size was used for the focus groups (N=22), but this is still considered relatively small for focus group research (Millward 2000).

The focus groups were conducted with a range of different clinical teams who work with older adults in the community. The teams included involved healthcare providers specialising in a certain area or health condition. A wide variety of healthcare providers were included by using pre-existing groups including nurses, occupational therapists, physiotherapists, psychologists, an occupational therapy assistant and an exercise rehabilitation instructor. However, a number of professions were not represented, including doctors and pharmacists. These professions do not work directly within the participating teams, but findings from the second phase of the research may not be transferable to these healthcare providers working in similar settings. Resulting from the small sample sizes in both phases of the research, the factors identified as affecting older adults' ability to access, understand and use information may not be transferable to other populations, for instance a younger population, less frail older adults, other settings, other healthcare providers and different areas of clinical care. Additionally, the focus groups with healthcare providers focussed on a more diverse clinical population than falls prevention alone. This is a strength given the similar findings which emerged, indicating that these findings may not just apply to falls prevention. Also, the healthcare providers involved worked with both younger and older adult populations; at times they did not make a distinction between the two groups or commented that their younger adult patients were treated in the same way or had similar concerns. However, the healthcare providers were working in long-term condition management, whilst the falls clinic was focussed around preventive healthcare. It may be beneficial to conduct research with

patients in long-term condition management and healthcare providers in preventive healthcare.

There were only two male older adults interviewed and three males participated in the healthcare provider focus groups. However, this is reflective of less males attending falls prevention programmes and participating in falls research (Yardley et al. 2006; Vind et al. 2009; Walker et al. 2011), and more females being in clinical healthcare professions (NHS Employers 2015).

Each focus group consisted of specific clinical teams who normally work together. The alternative would have been to conduct separate focus groups with different healthcare professions, for instance a focus group for nurses and a different group for occupational therapists. However, it was felt that 'naturally occurring' groups would be more comfortable with one another and richer data would result (Freeman 2006). Using this method, a range of different healthcare providers participated in each group. The importance of encouraging and being attentive to interaction within focus groups has been discussed (Section 7.4.5). Whilst there were differences in opinion, primarily this emerged between groups as opposed to between individuals within a group. It was particularly evident in the third main theme (comparing health literacy screening tools and universal precautions) that there was group consensus, primarily involving reservations about these approaches. It is possible that this consensus resulted from hierarchical issues within the team; a senior healthcare provider within the team would often express reservations and the other team members would agree. It is noteworthy that there appeared to be more conflicting opinions within the fourth focus group where the participants were on the same Agenda for Change pay band. This group was also small; therefore, participants may have felt more confident to express their views. Naturally occurring clinical teams normally have some levels of hierarchy within them; this may reflect how teams would react if a manager was negative about a proposed new intervention, which provides useful insight into another possible barrier to implementing health literacy strategies. Further, the use of pre-existing teams made it easier to make inferences about whether existing health literacy strategies are embedded within the individual team's culture.

The final limitation relates to the researcher's lack of prior experience in conducting qualitative interviews. As discussed in Section 3.3.4.1, in qualitative research the researcher is the primary instrument for data collection and analysis. Prior to conducting the first phase of the research, the researcher had no experience of conducting qualitative interviews. IPA research is intended to be conducted in an iterative manner (Smith et al. 2009a), involving making changes to the interview guide and analysing using non-linear and iterative methods. However, the researcher felt that her skills in actively listening to participants, probing further about participants' experiences during interviews and in interpreting data evolved over the years of doctoral study. As a result, the interview guide for the first phase of the research did not change during the data collection period. After several iterations of analysis, the researcher was subsequently able to pick out the salient points within the participants' accounts. It would have been beneficial to follow-up on these points within the interviews. However, it was apparent that the researcher's qualitative research skills developed, given that she was able to make changes to the focus group topic guide and use probes more effectively within the second phase of the research.

Despite the limitations, the findings provide novel contributions and valuable insight into the facilitators and barriers to meeting older adults' health literacy needs.

9.6 Implications of findings for meeting older adults' health literacy needs in clinical practice

Having highlighted the possible limitations to the research, based on the research findings, the researcher has developed a number of recommendations for clinicians about meeting older adults' health literacy needs (Table 15). However, improving the health literacy experiences of older adults is not just an NHS issue; these recommendations are also relevant for integrating health literacy into the undergraduate and postgraduate curricula for healthcare subjects and could contribute to evidence-based guidelines on delivering effective healthcare in the UK, such as NICE guidelines.

	Factor for healthcare providers to consider	Recommendations and section(s) in thesis where evidence can be found to support
Factors relating to identifying older adults' health literacy levels in clinical practice	Identifying older adults' health literacy levels	- Create an open and shame free environment where the older adult is enabled to talk freely about any gaps in their understanding (8.5.2; 8.7.1; 8.8.2). - Consider the impact of embarrassment / stigma associated with low literacy or health literacy levels (8.5.2). - Build a positive relationship and trust with the older adult (8.7.1). - Assess older adults' baseline understanding (8.5.1). - Consider identification strategies which can be routinely implemented into clinical practice (8.5.1). - Train healthcare providers in identifying health literacy (both practical strategies and equipping healthcare providers to sensitively handle this), and meaningfully tailoring healthcare as a result of identification (8.8.3).
	Using health literacy screening tools or universal precautions	If using health literacy screening: - If using a health literacy screening tool, ensure this is accepted by the older adults accessing the service by asking for their feedback (5.2.2; 8.6.1). - Choose a health literacy screening tool which best suits the purpose of assessing health literacy. It may be helpful to choose a tool which enables meaningful tailoring of information based on the individual's needs (5.6). - Consider the impact of sensory and cognitive impairments when using health literacy screening tools (5.2.2). - If using an individual test of patients' abilities, ensure the older adult does not feel anxious/shameful or feel like they are being tested whilst having their health literacy measured. It may be preferable to use a self-report of abilities where the patient has the option to disclose their difficulties if they wish to (5.2.2; 8.6.1).

	Factor for healthcare providers to consider	Recommendations and section(s) in thesis where evidence can be found to support
		- Consider a tool which allows meaningful dialogue with the older adult about collaboratively meeting their health literacy needs (8.6.1). If using universal precautions: - Obtain feedback from older adults (with both low and high health literacy levels) about written information developed (8.6.2). - Ensure written healthcare information is designed according to health literacy principles (Weiss 2007), but provide options for further information/signpost individuals to further information if they want it (8.6.2). - Discuss the level of information the older adult would prefer to receive (8.6.1; 8.7.2).
Meeting an older adult's health literacy needs in clinical practice	Conceptualisation of health literacy	- Health literacy should be considered as an asset which can be developed over time and both a patient and system issue, which is influenced by personal and social determinants (Chapters 5 and 8).
	Healthcare providers' awareness and understanding of health literacy	- Provide training on health literacy to healthcare providers. This should include training on identification of health literacy and meeting older adults' health literacy needs (8.4; 8.8.3). This training should be tailored to the individual needs of different healthcare professions and teams (9.3.5).
	Relationship building and trust	- Consider how relationships and trust can built through the patient's entire journey through the service, e.g. with auxiliary staff members and healthcare providers, on transportation and with other patients attending the service (5.5). - Attend to older adults' physiological needs before beginning a session and be attentive at times when they may require assistance or feel unwell (5.5.3).

	Factor for healthcare providers to consider	Recommendations and section(s) in thesis where evidence can be found to support
		- Treat the older adult as an individual (5.6; 5.5.3). - Use the patient's preferred name (5.5.1). - Positivity, use of humour, a personalised touch and sharing aspects of yourself can assist with relationship building (5.5.1; 5.5.3). - Use clear communications and give the older adult opportunities to ask questions (5.5.3; 5.6.4). - Attentively and respectfully listen to the older adult, providing opportunities for them to discuss their issues and try to act upon their concerns (5.5.3).
	Tailoring of information	- Consider the older adult's personal reason for attending a service, and personal goals, and tailor healthcare to this (5.6.1). - Tailor information (both written and verbal) to the older adult as an individual (5.5.3; 5.6). - Consider learning style preferences, e.g. observational, reflective, experiential and vicarious. Linking new knowledge to past experiences can facilitate learning. Consider andragogical and gerogogical styles of teaching (5.6.5). - Consider communication style preferences (5.6.3).
	Does the older adult have adequate social support to meet their health literacy needs?	- Ask the patient whether they would like a family member/spouse/friend to attend appointments (5.7.2; 8.7.3). - Consider level and type of social support the older adult has (5.7.2; 8.7.3). - Consider the health literacy abilities of the older adult's social support (8.7.3). - Consider how health literacy needs can be addressed for individuals with low health literacy and inadequate social support (8.7.3). - Consider whether psychosocial benefits can be incorporated into service, e.g. groups. Emphasise the health benefits for those who may not normally value social interaction (5.5.4).

	Factor for healthcare providers to consider	Recommendations and section(s) in thesis where evidence can be found to support
	Time factors	- Consider allocating more time to clinical appointments with older adults who have difficulties with understanding health information (8.5.2; 8.7). This may result in less time spent overall and could be achieved through identifying vulnerable individuals using health literacy measurement tools and policy changes. Alternatively, consideration of how the patient's social support network could assist with meeting health literacy needs could be beneficial (8.7.3).

Table 15   Recommendations for meeting older adults' health literacy needs in clinical practice

9.7   Suggested future directions for research

Interest in health literacy research is currently gaining momentum (Section 1.1), and exploration of the area in the context of older adults was revealed as relevant and timely. The present research has raised a number of issues which warrant further exploration.

Firstly, the research has made contributions to the debate about whether it would be better to use universal precautions or health literacy screening in clinical practice. However, further in-depth qualitative exploration of the issues focussing on the issue from both patients' and healthcare providers' perspectives would be beneficial. Additionally, quantitative research could examine the differences between using both approaches, and how this impacts on patient satisfaction and outcomes, such as perceptions of relationships and trust. Universal precautions could also be expanded to consider individuals with higher health literacy levels. Based on the findings from these studies, there is also clearly a need for a health literacy measure which takes into account older adults' specific needs such as sensory and cognitive impairments. A measure for older adults which would be accepted by healthcare providers and patients is necessary. It is possible that this could be a self-report measure which supports the healthcare provider to engage with the patient as a collaborative process around their health literacy, sensory and cognitive needs. The findings of this research also suggest a questionnaire or measure directed at carers may be beneficial given their important role in enabling access, understanding and use of health information.

The research also unearthed a wide range of facilitators and barriers to meeting older adults' health literacy needs. Using these findings and other available literature, an intervention focussing on increasing the health literacy abilities of older adults could be developed using qualitative methods and tested within a randomised controlled trial. There are currently very few intervention studies focussing on older adults and these are primarily based on US populations (Manafo and Wong 2012). This research suggests that consideration of relationship building, trust, tailored interactions and social support may be

necessary when developing health literacy interventions aimed at older adults. It was discussed that few barriers were identified during the first phase (Section 9.5): further research identifying barriers to positive relationships and trust would also be advantageous.

This research explored the views and experiences of healthcare providers about meeting older adults' health literacy needs. However, there is often a difference between what individuals say they do and what they actually do (Ritchie and Lewis 2013). As a result, future work could use qualitative interviews in conjunction with observation techniques to explore healthcare providers' use of health literacy strategies in clinical practice. Triangulation of research methods can enhance the credibility of research (Shenton 2004). Although suitable for this programme of research, the sample sizes for both the interview and focus group phases of the research were relatively small. Therefore, future research could qualitatively explore the health literacy views and experiences of younger adults or older adults with different conditions, and in different settings, such as hospitals. It is rare for similar research studies to be conducted in different environments, but this can enhance transferability (Shenton 2004). Additionally, greater representation of individuals with higher health literacy levels could be achieved by using recently developed health literacy measures which include interactive and critical health literacy abilities (Chinn and McCarthy 2013; Osborne et al. 2013). Furthermore, questionnaires could be used in order to access a larger sample and test some of the findings generated from this research (Gillham 2007). Whilst this method may be appropriate for healthcare providers, care would need to be taken when administering questionnaires to individuals with low literacy levels.

The researcher also suggests a future health literacy model could be made more clinically relevant by expanding Nutbeam's functional, interactive and critical framework (2000) to include variables which affect health literacy at each level. This could also be tailored to an older adult population. However, further qualitative and quantitative work would be necessary to ascertain which variables should be included at each level. Quantitative research could explore the relationships between health literacy (using a comprehensive measurement tool) and positive relationships, trust, tailored interactions and social support and

qualitative research could explore these areas in further depth and with different patient populations.

9.8   Conclusion of thesis

A huge proportion of previous health literacy research has focussed on the development of health literacy screening tools and relationships between functional health literacy and health outcomes. The purpose of this qualitative research was to explore the facilitators and barriers to meeting older adults' health literacy needs in clinical practice. To do this, two distinct but interconnecting research questions were explored using interviews and focus groups:

- – What are the views and experiences of older adults with low and adequate health literacy levels attending falls clinics about access to the service, provider-patient communication and self-management?
- – What are the views and experiences of healthcare providers working with older adults about meeting their health literacy needs?

Findings from exploration of the first research question explicitly led to the development of the second phase of the research in an iterative manner. Findings from both research phases revealed that health literacy is not an individual patient problem but should rather be considered as an interaction between the individual's abilities and the demands of the healthcare system, whilst also considering the patient's social support.

This research has uniquely contributed that, in order to meet older adults' health literacy needs and enhance overall experiences of healthcare services, healthcare providers should build relationships and trust (through positive interactions, non-clinical approaches and treating the older adult as an individual with idiosyncratic attributes and preferences), tailor information and consider input from the older adult's social support network. Healthcare providers need to consider older adults' abilities and preferences, and tailor their practice according to this.

More support and training should be given to healthcare providers to identify older adults' health literacy levels and meet their related needs. Altering systems to meet the health literacy needs of older adults with varying health literacy levels is fundamental. Working in the NHS can be busy, but small changes could make a substantial difference. Providing more effective and tailored education could both mitigate the risks of low health literacy whilst also aiming to develop individuals' health literacy abilities. Given their complex health needs, considering older adults' health literacy needs has the potential to aid in addressing the health literacy needs of younger populations.

Appendix A List of dissemination activities

Publications

Brooks C, Adams J and Ballinger C (2015) Reading between the lines. Nursing Older People 25(7): 11

Ballinger C and **Brooks C** (2014) Preventing falls with older people living in the community, Age UK Later Life Publication. Available from: http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Services-what_works_spreads.pdf?dtrk=true

Adams J, Lowe W, **Brooks C** and Ballinger C (2014) Poster: Training health professionals in health literacy: use of the hospital audit tool. Available from: http://www.southampton.ac.uk/assets/centresresearch/documents/wphs/JAWPHS%20IPLU%20HLJAWLCBLB(2).pdf

Brooks C, Ballinger C, Nutbeam D and Adams J (2013) Literacy levels required to understand regularly accessed falls prevention websites aimed at the public. Journal of Physical Therapy and Health Promotion 1(1): 8-14

Brooks C, Adams J and Ballinger C (2013) Abstracts for the College of Occupational Therapists Annual Conference. British Journal of Occupational Therapy 76(supplement 1): 101

Ballinger C & **Brooks C** (2013) An overview of best practice for falls prevention from an occupational therapy perspective. Available from: http://patientsafety.health.org.uk/resources/overview-of-best-practice-fallsprevention occupational-therapy-perspective

Brooks C, Adams J, Ballinger C & Nutbeam D (2012) Abstracts for the 8th World Congress on Aging and Physical Activity. The Journal of Aging and Physical Activity 20 (supplement):1045

Brooks C (2012) Case Study, postgraduate directory. Postgraduate Prospects. Available from: http://viewer.zmags.com/publication/3a0db2ed#/3a0db2ed/75

Brooks C (2012) The exciting and stimulating experience of a dual role. Occupational Therapy News. May issue, p.31

Conference papers / posters presented

March 2016
Oral presentation: Healthcare providers' views about how to develop health literacy in an older adult population
4th UK Health Literacy Conference: Health literacy at the deep end: Addressing health inequalities

July 2015
Workshop presentation: Health literacy - implications for practice
Solent NHS Trust conference: Demonstrating the value of research, evaluation and clinical audit via clinical impact

March 2015
Oral presentation: The experiences of older adults with varying health literacy levels attending a falls clinic: An interpretative phenomenological analysis
RCN Older People's form and BGS joint conference, 'making integrating care a reality'

February 2015
3MT oral presentation: PhD research
Innovative and Essential Care Research Seminars

January 2015
3MT oral presentation: PhD research
Clinical doctoral research fellow welcome event

June 2014
Oral presentation: The development of occupational therapy clinical academic career pathways
World Federation of Occupational Therapists Conference, Yokohama, Japan

June 2014
Workshop presentation: Improving accessibility, understanding and use of consumer health information
World Federation of Occupational Therapists Conference, Yokohama, Japan

March 2014
Oral presentation: The experiences of older adults with low and adequate health literacy levels attending falls clinics
Research and clinical audit conference, Solent NHS Trust

January 2014
Oral presentation: The experiences of older adults with low and adequate health literacy levels attending falls clinics
Primary Care and Population Science: PhD research presentation half day

January 2014
Oral presentation: 3MT presentation: PhD research
Clinical Academic Welcome Event, QA Hospital

December 2013
Oral presentation: 'clinical academic doctoral pathway: progress to date and next steps'
Research and clinical audit strategy day, Solent NHS Trust

November 2013
Poster presentation: Reflections on the validity of the NVS-UK for use with older adult populations Worldwide Universities Network Conference on health literacy, Sydney, Australia

October 2013
Oral presentation: 'clinical academic doctoral pathway: progress to date and next steps'
Research and Development Committee Meeting

July 2013
Poster presentation: 'Literacy levels required to understand regularly accessed falls prevention websites aimed at the public'
Postgraduate Research Conference, University of Southampton

June 2013
Oral presentation (seminar): 'Using health literacy communication skills with service users'
COT annual conference, older person's specialist section

March 2013
Poster presentation: 'Literacy levels required to understand regularly accessed falls prevention websites aimed at the public'
Evidence informed practice conference, Solent NHS Trust

August 2012
Oral presentation: 'The readability of English language falls prevention websites aimed at the public
World Congress on Active Ageing, 15th August, Glasgow UK

April 2012
Poster presentation: 'Clinical academic careers'
Research in primary and community healthcare settings: showcasing the patient benefit, Solent NHS Trust

Appendix B   Model of the causal pathways linking health literacy to health outcomes (Paasche-Orlow & Wolf 2007)
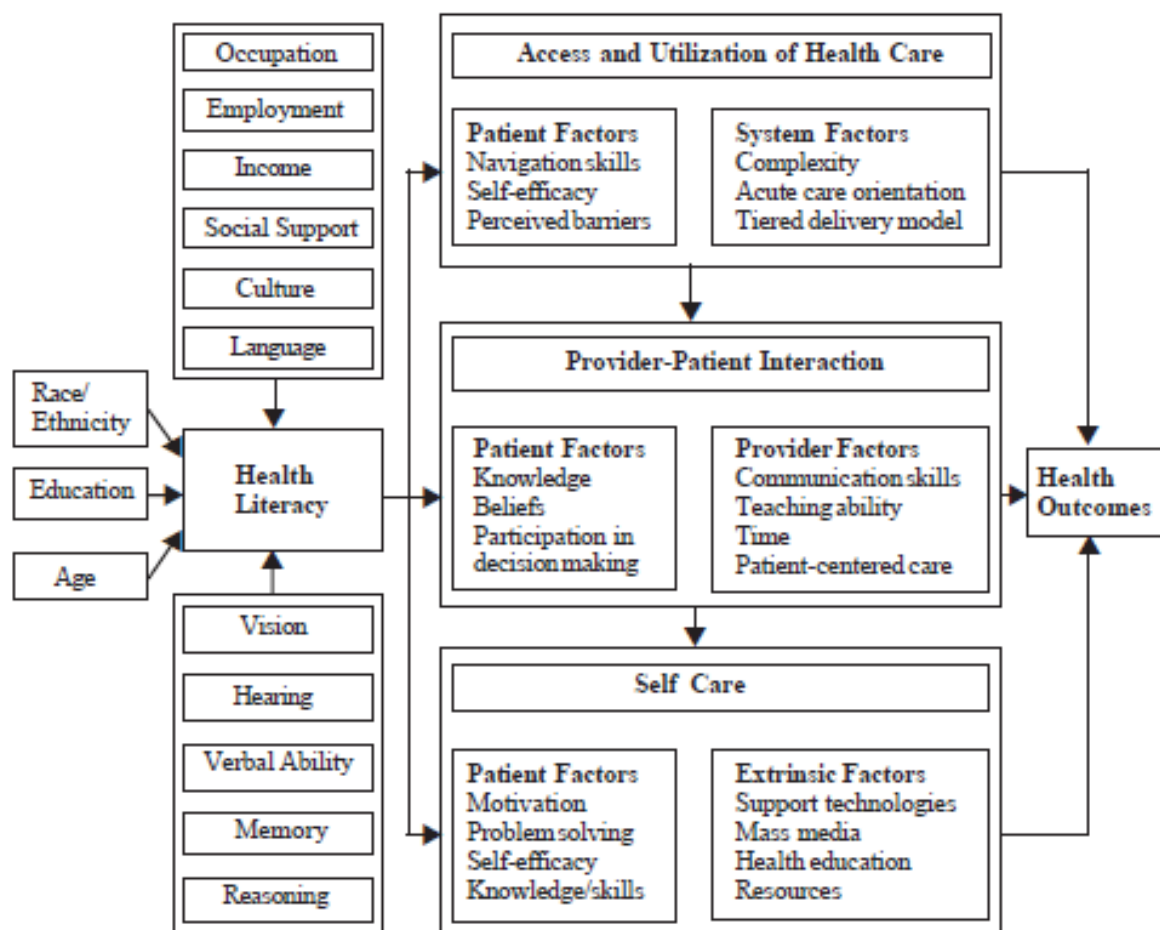
Appendix C Search strategy for literature review

First search performed:

Search question	What research is available on health literacy and older adults?
Which literature review questions is this search relevant to?	- What are older adults' health literacy views and experiences? - Is using health literacy screening tools or universal precautions suitable for use with an older adult population in clinical practice? - What healthcare provider factors could affect the implementation of health literacy strategies in clinical practice?
Databases	Medline, CINAHL, PsycInfo,
Date search completed	23/11/2015
Keywords	'Health literacy': 10,767 results
Limiters	- Health literacy as a major heading: 2896 results - Age 65+ years: 488 results - Academic journals: 486 results - English language: 468 results
Number of results reviewed	468 results
Which papers included?	- Salter et al. (2014) - Melton et al. (2014) - Napier et al. (2013) - Osborne et al. (2013) - Rowlands et al. (2013) - Chinn et al. (2013) - Dickens et al. (2013) - Edwards et al. (2012) - Gaglio et al. (2012) - Haun et al. (2012) - Harrison et al. (2012) - Ferguson et al. (2011) - Jordan et al. (2010) - Harrison et al. (2010)
How many papers included in final review identified from search?	14 papers included in review.
Exclusion reasons	Not answering any of the literature review questions

Appendix C

Second search performed:

Search question	What qualitative research is available on health literacy relating to patients' and healthcare providers' views and experiences about health literacy?
Which literature review questions is this search relevant to?	• What are older adults' health literacy views and experiences? • Is using health literacy screening tools or universal precautions suitable for use with an older adult population in clinical practice? • What healthcare provider factors could affect the implementation of health literacy strategies in clinical practice?
Databases	Medline, CINAHL, PsycInfo,
Date search completed	2/12/2015
Keywords	'Health literacy': 10814 results
Limiters	- Health literacy as a major heading: 2,904 - Qualitative research methodology: 199 results - Academic journals: 175 results
Number of results reviewed	175 results
How many papers included in final review identified from search?	- Smith et al. (2014) Duplicate papers already identified and included from first search: - Salter et al. (2014) - Melton et al. (2014) - Gaglio et al. (2012) - Harrison et al. (2012) - Jordan et al. (2010)
How many papers included in final review?	1 (excluding duplicate papers already identified)
Exclusion reasons	Not answering any of the literature review questions

Third search performed:

Search question	What research is available on health literacy relating to patient' and healthcare providers' views/experiences?
Which literature review questions is this search relevant to?	- What are older adults' health literacy views and experiences? - Is using health literacy screening tools or universal precautions suitable for use with an older adult population in clinical practice? - What healthcare provider factors could affect the implementation of health literacy strategies in clinical practice?
Databases	Medline, CINAHL, PsycInfo,
Date search completed	2/12/2015
Keywords	'Health literacy': 10,814 results - Health literacy as a major heading AND experience\$ OR view\$ OR opinion\$ OR perception\$ OR attitude\$ OR patient satisfaction: 733 results
Limiters	- Date limiters 2005-2015: 667 results - English language: 642 results - Age limiters: Only 18+: 429 results
Number of results reviewed	429 results
Which papers included?	- Vargas et al. (2014) - Smith et al. (2013) - Protheroe et al. (2013) - Howard et al. (2013) - Sadeghi et al. (2013) - Macabasco-O'Connell et al. (2011) - Vangeest et al. (2011) - Seligman et al. (2005) Duplicate papers already identified and included from first or second search: - Salter et al. (2014) - Melton et al. (2014) - Smith et al. (2014) - Napier & Kidd (2013)

	- Dickens et al. (2013) - Harrison et al. (2012) - Edwards et al. (2012) - Jordan et al. (2010) - Harrison et al. (2010)
How many papers included in final review identified from search?	8 (excluding duplicate papers already identified)
Exclusion reasons	Not answering any of the literature review questions

Appendix D   Flow diagram for literature review

Databases searched:
MEDLINE, CINAHL, PsycINFO

Number of searches: 3

Dates of searches:
23/11/2015 – 2/12/2015

Inclusion criteria: Published in last 10 years (2005-2015), include older adults within sample, all research methodologies

Exclusion criteria: Not English language, focus on children/maternal health literacy, focus on mental health, not answering the research question

Total number of articles assessed for eligibility (n=1072)

Number of results screened from first search (n= 468)

Number of results for first search (n= 468)
- Not meeting inclusion criteria (n= 454)
- **Included in final review (n= 14)**

Number of results screened from second search (n= 175)

Number of results for first search (n= 175)
- Not meeting inclusion criteria (n= 169)
- Duplicate articles already included from first search: 5
- **Included in final review (n= 1)**

Number of results screened from third search (n= 429)

Number of results for third search (n= 429)
- Not meeting inclusion criteria (n= 412)
- Duplicate articles already included from first search: 9
- **Included in final review (n= 8)**

Total number of articles included in literature from three literature searches:

(n= 23)

Appendix E   Recruitment poster for first phase

Would you like to be part of a research project?

I need your help.

I need to talk to people who are aged 65 and above and have been to a falls clinic.

I want to find out more about older people's views and experiences of falls clinics and their supporting services.

The aim is to improve NHS services.

If you would like to know more, please contact:

Charlotte Brooks, Chief Investigator

Tel: 02380 594319

E-mail: lotty.brooks@soton.ac.uk

Appendix F   Recruitment leaflet for first phase

Solent **NHS** NHS Trust   **Southampton** UNIVERSITY OF

Portsmouth Hospitals **NHS** NHS Trust

To take part or to find out more please contact:

Charlotte Brooks

PhD student

Faculty of Health Sciences

University of Southampton

Building 67

Highfield Campus.

SO17 1BJ

Telephone: 02380 598442

E-mail: Lotty.Brooks@soton.ac.uk

Thank you for taking the time to read this leaflet. I look forward to hearing from you.

Funded by Solent **NHS** NHS Trust

Southampton UNIVERSITY OF

Research Team

Researcher:

Charlotte Brooks,

PhD student

Research supervisors:

Dr. Jo Adams,

Dr. Claire Ballinger

Professor Don Nutbeam

Solent **NHS** NHS Trust   **Southampton** UNIVERSITY OF

Portsmouth Hospitals **NHS** NHS Trust

I need your help

>> **I need to talk to people who are aged 65 and above and have been to a falls clinic.**

Be part of this research project.

I want to find out more about older people's views and experiences of falls clinics and their supporting services. The aim is to improve NHS services.

Please read this leaflet to know what the research is about and how to contact me. I look forward to hearing from you.

Recruitment leaflet version 2.0., 25/01/2013

What is the research about?

- I am looking at whether falls clinics are meeting the information and communication needs of patients.

- I would like to know more about your views on the information, both verbal and written given to you at the falls clinic. This may be about your treatment or advice about preventing future falls.

- It is important that information is given in a clear and useful way to help you prevent future falls.

What am I asking you to do?

- I (Charlotte Brooks) would like you to take part in an interview. This is for part of my PhD (postgraduate degree).

- If you think you might like to take part, please contact me (details on the back). I will then come to your house, or a place of your choice, to explain the study further. You will be given some time to decide if you want to take part.

- Then, at a time and date of your choice, we will meet again to do the interview.

- I will ask questions about your views and experiences of the falls clinic.

- The interview will last for about one hour.

- If it is okay with you, I would like to record the interview. This is to make sure I have got all the main points.

What are the benefits of taking part?

- There is no direct benefit to taking part. You will be giving useful knowledge, which may improve NHS services and help others.

What will happen to the results of the research study?

- I want to make sure your views are heard, as they can help to develop better services. Your identity will be protected and anonymous.

- I will let you and the falls clinic know the results.

- The results will also go towards my PhD and may be presented or published.

Recruitment leaflet version 2.0., 25/01/2013

Appendix G Letter of invitation to participants for first phase

Dear Mr/Mrs/Ms/Miss xxxx

Thank you for contacting us to say that you may like to take part in my study. This is an interview looking at your views on the information and communication given to you at the falls clinic and / or by supporting services.

I have put a copy of the Research Information Sheet in this letter. This gives you more details about the project. Before you look at this, I would like to point out:

- You do not have to take part. It is your choice.
- I will not tell anyone about your decision.
- Anything you tell me will be confidential.
- You are able to leave the study at any time. You do not have to give a reason.
- To take part, you must be over 65 years old and living in your own home.

Please ask any questions at any time during the study.

Yours sincerely,

Charlotte brooks

Appendix H   Participant information sheet for first phase

Study Title: What are the views of older adults who have been to a falls clinics about information and communication given by the clinic and supporting services?

Researcher's Name: Charlotte Brooks   **Study number:** 95606

Ethics number: 13/SW/0030
Contact details: Building 45, room 0059, Faculty of Health Sciences, University of Southampton, Highfield Campus, SO17 1BJ. Tel: 02380 594319

I would like to invite you to take part in a research study. Please read this information before deciding to take part in this research. Please ask me if you are unclear about anything or you would like to know more. Talk to others about the study if you wish, e.g. family, friends or your doctor. If you are happy to take part you will be asked to sign a consent form.

What is the research about?

- This research is part of my PhD (postgraduate degree). I am working towards this at the University of Southampton. I am looking at the views and experiences of older adults who have been to a falls clinic. I would like to know more about your views on the information and communication, both written and verbal you received at the falls clinic and from their supporting services, e.g. occupational therapy and physiotherapy. It is important that information is given in a clear and useful way to help you prevent falls. I would like you to take part because you were referred to a falls clinic. A maximum of thirty people will be interviewed.

Do I have to take part?

- It is up to you whether you would like to join the study. I will describe the study and go through this information sheet with you. I will give you time to ask questions and decide. If you would like to take part, I will ask you to sign a consent form. You are free to leave the study at any time, without giving a reason.

Choosing not to take part or leaving the study will not affect the medical care you receive.

What will happen to me if I take part?

- You will be asked to take part in an interview. This will last about an hour in total. The researcher (Charlotte Brooks) will come to your house at a time of your choice to do this. If you would prefer to do the interview somewhere else, please let me know and I can arrange this. Your travel costs would be covered. If you would like a relative or carer to be at the interview, please let me know.
- The interview will be recorded, written out line by line and analysed. You may stop the interview at any time. You do not have to answer anything you do not want to. The interview data will only be used for this study.
- After the interview, if you are happy to, you will be asked to complete two health literacy forms. This will take about ten minutes. This is not to test you but is to give the researcher a better understanding of patients' communication needs. This will not take long and the results will be kept confidential and will not be discussed with you. If you want feedback from this, the researcher will go through the questions at a later date. Finally, I will ask you to complete a short survey. This will take about five to ten minutes to complete. This will involve a few questions about your personal situation (age, housing, health etc.). This will not have your name on it and you do not have to do this if you do not want to.

Are there any benefits in my taking part?

- There is no direct benefit to taking part. However, the information we get from this study will provide useful knowledge which may improve services. This may help others in future.

What are the possible harms of taking part?

- There are no real harms linked with taking part in an interview. It is possible that you may become upset when talking about your experiences. I will be sensitive to this and will have details on where you can get help if you need it. There are details about support groups at the end of this information sheet.

Will my taking part be anonymous?

- You will be asked to choose a different name from your own for the study. This can be your own choice or from a list.
- I will make sure that no clues to your identity appear in any reports, publications or the PhD papers.
- Interview data will be kept on a password protected computer.
- Any data protection information will be kept in locked storage for ten years. This is in line with the Faculty of Health Science's data protection policy.

What happens if I change my mind?

- You are able to leave the study at any time you want to. Your legal rights or routine care as a patient would not be affected.

What will happen to the results?

- If you wish, I will send you a brief report of the findings of the full study after it is finished.
- The falls clinic will be told about the results, but they will not know that you took part.
- The results will be presented in my PhD papers. The study may be also be presented at conferences and published in a research journal. If you are happy for me to, I will use anonymous quotes from your interviews in these reports.

Who is organising and funding the research?

- Solent NHS Trust is funding the study. The research sponsor is the University of Southampton.

Who has reviewed the study?

- To protect you, all research in the NHS is looked at by a Research Ethics Committee. This study has been reviewed and accepted by South West - Exeter Ethics Committee. Please ask if you would like to know more about this.

What happens if something goes wrong or I have a complaint?

If you have a concern or a complaint about this study you should contact [insert name], Head of the Governance Office, at the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ. Tel: [insert number].
Email: rgoinfo@soton.ac.uk. If you remain unhappy and wish to complain formally [insert name] can provide you with details of the University of Southampton Complaints Procedure.

Where can I find out more?

If you want to know more, please contact me on:-
Telephone number: [insert number]. You can leave an answer phone message and I will get back to you if I am not in.

Thank you for taking the time to read this. Please ask any questions if you need to.

Information and support

- Please contact your GP if you have any concerns about your health. They will be able to advise you about support groups for your needs.

- The charity Age UK can provide advice on falls and other issues.

  Telephone: 02392 862121 (Portsmouth) / 0800 169565 (Advice or information nationwide)
  Website: http://www.ageuk.org.uk/

- For more information on taking part in research, the national advisory group INVOLVE can help.

  Telephone: 02380 651088
  Website: http://www.invo.org.uk/

Appendix I Consent form for first phase

Study title: What are the views of older adults who have been to a falls clinics about information and communication given by the clinic and supporting services?

Researcher name: Charlotte Brooks   **Study number**: 95605

Ethics reference: 13/SW/0030

Contact details: Building 45, room 0059, Faculty of Health Sciences, University of Southampton, Highfield Campus, SO17 1BJ. Tel: 02380 594319

Please initial in the boxes if you agree:

I understand and have had the reasons and nature of the above study explained to me. I have been given the information sheet (25/01/2013, version 2.0.).

I have had the chance to ask questions about the study.

I know that I do not have to take part in the study. I understand that I can leave the study at any time. My legal rights and medical care will not be affected.

I understand that my data will be made anonymous.

I understand that the interviews will be audio-recorded.

I am happy for you to use anonymous quotes from the interviews in the findings. This may be in final reports, PhD papers, conferences and in research journals.

Name of Participant (print):   **Date**   **Signature**

_____   _____   _____

Name of person taking consent (print):   **Date**   **Signature**

_____   _____   _____

Appendix J   Interview guide for first phase

1. Can you tell me the story of your fall?
   - What happened afterwards?
   - Did you go to hospital?
2. When you were asked to come to the falls clinic, what were your first thoughts?
   - How did you feel about it?
   - What were your expectations?
   - What did you think the purpose of the falls clinic was?
3. Can you tell me about your experience of attending the falls clinic?
   - What did you enjoy?
   - What did you not enjoy?
4. Did you receive any information before you attended the falls clinic?
   - What was this?
   - What were your thoughts about this?
   - What did you expect to get?
5. How did you get to the falls clinic?
   - How was that?
   - What were your thoughts on the directions?
6. Who did you see at the falls clinic?
   - What type of healthcare provider were they? E.g. Nurse, doctor, OT, physio
   - What did you do with them?
   - Can you tell me more about that?
7. What did you think about the communication at the falls clinic?
   - Was any written information provided?
   - What were your thoughts on this?
   - What did you think about the verbal communication?
   - How did that feel?
   - Can you tell me more about that?
8. What did you learn about preventing falls whilst at the falls clinic?
   - What about whilst getting treatment in the community?
   - How did you feel about how that was communicated to you?
9. What decisions were made about your treatment whilst going to the falls clinic?
   - How did you feel?
   - How included did you feel in the decision?
   - What helped you to make that decision / what would help you to make that decision?
10. What was the outcome of your assessment at the falls clinic?
    - How was it given it to you?
11. Were you given any written information to help you prevent future falls?
    - Do you use it?
12. What do you think you can do to reduce your risk of future falls?
    - What might help you to do this?
    - What would prevent you from doing this?

Closure

- Researcher provides summary of what was discussed.
    - Do you think that summarises your experience?
    - Do you think there is anything I have missed out in the questions?
    - Have you got anything to add?
    - Do you have any other comments?

Appendix K Sociodemographic questionnaire for first phase

The following questions ask you some details about your life. This will help me have a better understanding of what you are saying in the interviews. It has some questions about your life and some about your health. You do not have to answer anything you do not want to. This information will be confidential.

Part 1: Personal situation

1. Age _____ years

2. Gender (please tick)

Male ☐   Female ☐

3. What is your marital status?

Single ☐

Married ☐

Divorced ☐

With partner ☐

Widowed ☐

4. Which best describes your current living situation?

Live alone ☐

Live with partner ☐

Live with family ☐

Live with friends ☐

Other _____

5. Which best describes your ethnicity?

White ☐

Asian ☐

Black ☐

Mixed race ☐

Chinese ☐

Other European ☐

Other _____

7. What was your highest level of education?

None ☐

Primary (age 4 – 11) ☐

Secondary (age 11-18) ☐

Higher education college / university ☐

Further education / professional qualification ☐

Other _____

8. What is your current or past employment / job(s), if any?

_____

_____

9. If you had a job, how much did you get paid?

Less than £5,000 ☐

£5,000 – £19,999 ☐

£20,000 - £49,000 ☐

More than £50,000 ☐

Don't know ☐

Would rather not say ☐

Part 2: Health Questions

10. How many times have you fallen in total?

Once ☐ Twice ☐ Three times ☐ More than three ☐
times

11. Do you have any disabilities (you may tick more than one)?

Visual problems ☐

Hearing problems ☐

Physical problems ☐

Other ☐

If so, please describe:
_____

12. Do you have a long term condition (you may tick more than one)?

Respiratory disease (breathing problems) ☐

☐

Heart disease

☐

Diabetes

Parkinson's / multiple sclerosis / motor neuron disease ☐

☐

Bone problems

☐

Muscle problems

If so, please describe: _____

11. How do you manage on a day to day basis?

I am independent ☐

I have carer support ☐

I have regular visits by a healthcare professional ☐

I receive tele-care / tele-health ☐

I attend day care ☐

Appendix L   Transcription protocol used for both phases of the research

General instructions

The Transcriber will transcribe all interviews using the following formatting:
- Arial 12 point font
- Paragraph: 1.5 spacing
- Margins: One-inch top, bottom, right and left
- All text to begin at the left-hand margin (no indents)
- Entire document to be left justified
- Interviewer's questions in bold
- Insert page numbers at the bottom right hand side of the page
- Include everything the participant and interviewer says, including the interviewer's back channel utterances, no exceptions
- Do not alter grammar

Labelling interview transcripts

The following labelling information will be at the top of the document, left justified:
Participant ID:
Interview location:
Date and time of interview:
Age of participant:
Titles of other people present:
Name of Transcriber:
Version number:

'P' – Participant
'I' - Interviewer

Audiotape changes

- Indicate when interview is recorded on a new tape and include information verifying the second side of the audiotape is blank as well as the total number of audiotapes associated with the interview.

End of the interview

- To indicate when the interview session has finished, type END OF INTERVIEW in capital letters.

Spelling

- UK spelling to be observed

Appendix L

Content

- Transcribed verbatim (word for word, exactly as said, including all non-verbal and background sounds).
- No 'cleaning up' of text - Mispronunciations, slang, foul language, grammatical errors all included.
- Filler words should be transcribed
- Repetitions included
- If a word is cut off, a hyphen is to be inserted at the end of the last letter or audible sound

Non-verbal sounds

- Examples of non-verbal sounds: Laughter, sighs, coughs, claps, snaps finger, pen clicking, car horn and sneeze.
- Put these in parentheses (circular brackets)
- One person laughing: (laughs/laughing); several laughing: (laughter).

Hesitation words

- Um
- Er (short hesitation)
- Erm (longer hesitation)
- Ah
- Oh

Legal fillers

- Eek
- Eh?
- Euh
- Hm?
- Huh?
- Mm
- Mm-hm
- Ooo!
- Ouch!
- Oops!
- Phew
- Shh
- Uh-huh
- Uh-uh
- Whoa!
- Whoosh
- Wow
- Yeah
- Yup
- Yes

- Yay

Pauses

- Use an ellipsis (…) if there is an audible silence, i.e. for pauses up to 2 seconds.
- For pauses between 2-3 seconds, use (pause)
- For a longer pause, i.e. more than 4 seconds, write (long pause)

Inaudible information

- [Inaudible: 2 minutes of interview missing]

Interruptions

- If someone's speech is broken off midsentence, use a hyphen (-) at the point where the interruption occurs, e.g. What do you –

Overlapping speech

- Use: (overlapping), and include the speech of the other person

Sensitive information

- If participant identifies themselves, replace name with their pseudonym.
- If participant identifies another individual, such as healthcare provider, replace with [insert physiotherapist's name]

Emphases

- Indicate an emphasis on a word or phrase by putting it in capital letters
- To indicate an exclamation of surprise, shock or dismay, use the standard exclamation mark.

Participant's tone

- Include in circular brackets, i.e. (sounds angry)

Grammar

- Do not correct grammar for either the interviewer or the participant (Oliver et al. 2005).

Appendix M Participant portraits for first phase

Daisy

Daisy had recently been discharged from the falls clinic when she was interviewed with her daughter present. She had also previously attended the falls clinic. Daisy did not have a formal diagnosis of dementia but appeared to the researcher to have difficulties remembering her experience of attending the falls clinic, which impacted on her responses to questions. Daisy advised that she was nearly 100, and therefore could not remember much about her experience. Daisy also had a hearing impairment. As a result, it was difficult to explore Daisy's experience fully, given that primarily her daughter responded to the interview questions. Daisy had difficulties in remembering why she had fallen, what happened after this and what she did or did not enjoy about attending the falls clinic. Daisy did discuss how she felt the experience of attending the falls clinic was 'quite pleasant'; she felt the falls clinic staff were encouraging and spoke nicely to her. She was also pleased that they gave her a cup of tea. Daisy's daughter reported attending all of her healthcare appointments, communicating with healthcare providers, providing encouragement and emotional support and assisting with memory recall and implementation of falls prevention strategies.

Dylan

Dylan was currently attending the falls clinic when he was interviewed, but had not finished his treatment. Overall, Dylan described greatly enjoying his experience of attending the falls clinic and felt that there was nothing he wished to complain about. Dylan described this experience as 'positive from the word go'. Dylan had worked in a medical unit as part of his employment in the Navy and had subsequently worked as a media resources manager in a hospital; he felt that this medical experience may have impacted on his experience of attending the falls clinic, in particular in relation to his motivation to be healthy and his understanding of health information. Dylan described support from his neighbour in terms of

managing his falls and general health as invaluable, and felt that he may not be alive if his neighbour had not been there to help him.

Ermintrude

Ermintrude had been recently discharged from the falls clinic when she was interviewed with her daughter present. Ermintrude had recently been diagnosed with dementia; to the researcher, she did not appear to have any substantial memory impairments, given that she was able to reflect on her experience in depth. Overall, Ermintrude appeared to enjoy her experience of attending the falls clinic and explicitly stated that there was nothing she wished to complain about. She described feeling initially resistant to the concept of falls prevention and learning new things, and felt that she would not learn anything at the falls clinic. However, she discussed feeling 'amazed' and pleased to have learnt a great deal from attending the falls clinic. Ermintrude described how her mind was 'opened' to new ways of doing things, which on multiple occasions she attributed to attending the falls clinic and described 'extending' what she had learnt at the falls clinic to her whole way of life. Ermintrude appeared to be particularly motivated by her desire to not be a burden on her daughters, and was pleased when she was able to attain her goals.

Faye

Faye was currently undergoing treatment at the falls clinic when she was interviewed. She had also previously attended the falls clinic, before needing to stop due to health reasons. Overall, Faye appeared to enjoy her experience of attending the falls clinic, and advised that she had no complaints about the service. She reported feeling both surprised and pleased that actions were taken to refer her and that she was not 'left hanging' after her fall. Throughout the interview, Faye described feeling concerned about her therapy input continuing. She described seeing her therapist on a regular basis as a particularly motivating factor. Faye also cited her loss of confidence as another reason why she wanted to continue attending the falls clinic. Faye also reported focussing on improvements and getting better as opposed to the falls prevention aspects. The

support Faye had from her friend who took her to the falls clinic and her daughter who encouraged her to exercise also appeared to be important to Faye.

Phillip

Phillip was currently undergoing treatment at the falls clinic when he was interviewed with his wife present, and had only attended several sessions. On the whole, Phillip appeared to be positive about his experience of attending the falls clinic, and felt that there was 'nothing' he did not enjoy. He was initially unsure what a falls clinic was and what might happen. Phillip felt that the name 'falls clinic' was strange and did not accurately describe the service. Phillip discussed how his wife attended all of his appointments because he forgets the information, as a result of a previous stroke. Phillip also described his concerns that his slow walking pace affected his wife; his desire to not be a burden on his wife and to continue improving his strength seemed to motivate him to continue exercising and attending the falls clinic.

Rebecca

Rebecca was currently undergoing treatment at the falls clinic when she was interviewed. Overall, Rebecca appeared very positive about her experience of attending the falls clinic. She advised that she was pleased that she was invited to attend the falls clinic because she was experiencing high levels of pain, and was glad that actions were being taken to help. Rebecca discussed how she had experienced pain for a long time without seeing improvements; she was motivated to do anything which might help alleviate the pain. Rebecca also suggested that the pain motivated her to continue with her exercises at home whilst attending the falls clinic. Rebecca had a previous background of working as a Nurse in the RAF, which she thought may have impacted on her preference for strict communication by healthcare providers. Rebecca discussed having a supportive daughter who provided her meals daily. However, she advised that she did not want to be too reliant on her daughter who had a disability.

Appendix M

Janet

Janet was currently undergoing treatment at the falls clinic when she was interviewed. Janet appeared to have mixed feelings about her experience of attending the falls clinic. She was initially unsure who referred her, and asked about this when she first attended. Janet advised that the falls clinic had cancelled a number of sessions which were no longer needed, as a result of Janet's improved ability. Janet discussed how she was pleased about this because she felt it was too much of a time commitment due to the travel time, having no set appointment time, and sometimes having to wait a long time to be seen. She also perceived herself as healthy and active, and although she thought the concept of the falls clinic was helpful, in terms of her abilities, she felt she was not 'as bad' as a lot of the other attendees. Despite this, Janet also advised that she found attending the falls clinic helpful; she learnt how to walk, what things not to do and reported having an increased awareness of the impact of her actions. Janet advised she was motivated to attend the falls clinic in the hope that it would benefit her. Janet discussed how her son took her to the falls clinic appointments.

Grace

Grace was currently undergoing treatment at the falls clinic when she was interviewed. Grace described her experience of attending the falls clinic as enjoyable and advised that there was nothing that she did not enjoy. She discussed feeling pleased about being invited to the falls clinic; she felt unsteady on her feet and wanted to do something about this. Grace appeared to be motivated to attend as a result of the progress she had made, and explained that she wanted to improve further to enable her to visit her daughter in Florida. Grace described how her son regularly took her to the falls clinic, but that she did not like relying on him too much, because of being an independent person. She also discussed how her daughter regularly phoned her from Florida to encourage her to eat well and exercise.

Priscilla

Priscilla was currently undergoing treatment at the falls clinic when she was interviewed. When Priscilla was initially invited to the falls clinic, she reported arguing with the referrer, since she perceived falls clinics to be for 'old people' and did not perceive herself to be old. After the purpose of the falls clinic was explained to her, she advised she was willing to try it. She discussed how there was nothing she did not enjoy about attending the falls clinic, except that she found the first morning too long. Priscilla discussed how she has difficulties with her memory, and how her daughter has supported her to develop coping strategies to manage this. However, she also expressed sadness that her family were not able to attend the falls clinic with her; she advised that all of the other falls clinic attendees she had seen had family with them.

Appendix N Summary of research findings sent to falls clinic

Research Summary
What are the views and experiences of community-dwelling older adults attending falls clinics with lower and adequate health literacy levels about access, use and follow-up from these services?
Charlotte Brooks; Dr Jo Adams; Dr Claire Ballinger and Prof Don Nutbeam

Introduction

Study location: Participants who had attended the [insert NHS Trust name] were interviewed.

Study dates: Participants were interviewed between the 13th June 2013 and 6th September 2013.

Background: Health literacy is the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy emerges as an interaction between an individual's abilities and the demands of the health system. Lower health literacy levels are associated with increased mortality and morbidity and lower health literacy is prevalent in older adult populations.

Type of health literacy	Definition
Functional health literacy	Basic skills in reading and writing applied to healthcare situations
Interactive health literacy	More advanced cognitive and literacy skills, capacity to actively participate, derive meaning and apply new information quickly to changing circumstances
Critical health literacy	Most advanced cognitive and literacy skills, critical analysis of information, ability to use information to exert greater control over life events and situations

Appendix N

Methodology: In-depth semi-structured interviews were used.

Data analysis: An Interpretative phenomenological analysis (IPA) approach was used

Participants: 9 participants interviewed, age range: 75-99 years (mean: 83 years)

The participants' health literacy was measured:
- Most participants (7/9) scored as having a high likelihood of lower health literacy when assessed using the Newest Vital Sign measure.
- 6/9 participants scored as 'high school' (will be able to read most patient education materials) when assessed using the Rapid Estimate of Adult Literacy in Medicine. 3/9 participants scored as '7th – 8th grade' (will have difficulties with most patient education materials).

Main Findings

10 key recommendations for falls clinic to meet health literacy needs of attendees
1. **Provision of accessible written information**
2. **Invite spouse or family member to attend appointments**
3. **Consideration of patient's sensory and cognitive impairments, and the impact on their learning as a result**
4. **Use of clear and simple language**
5. **Interventions which aim to improve the patient's knowledge levels**
6. **Interventions which aim to improve the patient's confidence and self-efficacy levels**
7. **Consideration of the patient's communication style preferences**
8. **Consideration of the patient's learning style preferences, e.g. encouraging vicarious learning**
9. **Confirming the patient's understanding**
10. **Encouraging the patient to ask questions, e.g. asking 'what questions do you have', rather than asking 'do you have any questions?'**

Development of functional health literacy	
Facilitators	**Barriers**
Practical factors affecting access: - Hospital transportation - Being taken to falls clinic by family members	Practical factors affecting access: - Timing of hospital transport - Personal time restraints - Structure / length of sessions can be too long - Times of sessions
- Patient aware of route or reason for referral to falls clinic	- Patient unaware of route or reason for referral to falls clinic
- Basic knowledge of purpose of falls clinic	- No expectations or unsure what to expect from falls clinic
- Self-management strategies to assist recall, e.g. visual reminders, aids, family member/spouse attending appointment	- Impact of visual, cognitive and hearing impairments
Written information: - Good selection of educational materials in the waiting area - Use of personal touch on letters - Use of illustrations - Addressing written documentation to patient personally - Sharing written documentation with GP	The use of or accessibility of written information provided: - Memory difficulties - Difficulties reading long passages - Lack of clarity on photocopies - Lack of personal touch - Lack of tailored information - Confusion over different letter headings - Lack of clarity regarding the purpose of falls clinic on letters - Not receiving the outcome of assessment letter - Use of medical terminology / jargon
Being attentive to the patient's physiological needs: - Food, water, rest	
Environment: - Good signage - Disabled access, e.g. lifts	

Development of interactive health literacy	
Facilitators	**Barriers**
Knowledge levels: - Previous medical background or experience - Understanding of medical terminology and knowledge of health - Understanding about cause(s) or risk factors for falls - Ability to risk assess situations - Understanding purpose of investigations and interventions - Knowledge of falls prevention strategies	Knowledge levels: - Not understanding cause(s) or risk factors for falls - Not understanding purpose of investigations or interventions - Lack of knowledge about falls prevention strategies
Confidence levels / social interaction factors: - Confidence to ask questions and make suggestions to healthcare provider	Confidence levels / social interaction factors: - Lack of confidence to ask questions and make suggestions to healthcare provider
Motivation levels and self-efficacy: - Personal reason to attend falls clinic - Seeing an improvement in abilities / reduction in pain - Psychosocial benefits of attending falls clinic, e.g. meeting new friends and social interaction - Personally setting goals - Ensuring a long-lasting impact of interventions, e.g. continuation of exercise	Motivation levels and self-efficacy: - Perception of falls as an insignificant or inevitable event - Concerns about healthcare professional input ending
Staff members' communication: - Use of clear and simple language - Consideration of communication style preferences, e.g. direct - Repetition of key information - Trust and relationship building with healthcare provider - Use of humour	Staff members' communication: - Style of communication used not preferred - Not confirming understanding of information - Conflicting messages from healthcare provider
Consideration of learning style preferences by healthcare providers.	

| - Experiential learning – learning from own experiences
 - Vicarious learning – learning from other people's experiences
 - Observational learning – watching others
 - Reflective learning – reflecting on learning | |

Possible indicators of critical health literacy
A few participants (3/9) revealed some possible indicators of critical health literacy. This included critical appraisal of written information, critical comparison and evaluation of health services and making suggestions for improvement. However, more research is needed to establish how critical health literacy is developed in individuals.

Implications of this research for rest of PhD
The research to date has raised some important questions regarding the concept and measurement of health literacy.   Next steps: - Using the research findings from this study, the next steps will involve conducting focus groups with healthcare providers working with older adults.   - The focus groups will explore facilitators and barriers to the development of health literacy in older adult populations from a healthcare provider perspective.

| For further information on this research or for guidance on meeting the health literacy needs of your service users, please contact the principal investigator (Charlotte Brooks):

 E-mail: Lotty.Brooks@soton.ac.uk   Telephone: 02380 594319 |

Appendix O Summary of research findings sent to older adult participants in first phase

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Research Summary
Research title: What are the views of older adults who have been to a falls clinic about information and communication given by the clinic and supporting services?

Charlotte Brooks; Dr Jo Adams; Dr Claire Ballinger and Prof Don Nutbeam

</div>

Introduction

- Thank you very much for taking part in an interview for the research study above.
- Your views have been shared with the falls clinic to help develop their services.
- Your views have also helped the researcher to develop the next research project.

Main Findings

Based on your interview answers, these guidelines have been given to the falls clinic, to help future patients:

- Use clear written information which is suitable for my needs
- Ask me if I would like to invite someone to the appointment
- Think about how my hearing, visual or memory problems may affect me
- Use clear language when speaking to me
- Help me to improve my knowledge about falls prevention
- Help me to improve my confidence for falls prevention
- Think about how I like to be communicated with
- Think about how I like to learn
- Check that I have understood the information you have given me
- Ask me if I have any questions

<div style="border:1px solid black">

For further information on this research or for a full report, please contact the principal investigator (Charlotte Brooks):
E-mail: Lotty.Brooks@soton.ac.uk Telephone: 02380 594319

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Appendix P Recruitment E-mail sent to healthcare providers in second phase

Invitation to take part in a focus group

Title of study: What are the views and experiences of healthcare professionals about assisting older adults to access, understand and use information for health? I am a clinical academic PhD student at the University of Southampton. My PhD focusses on health literacy and older adults and I work as an occupational therapist within [insert NHS Trust's name] community team. I am conducting a research study which will form part of my PhD project.

Purpose of the study

- To explore the views and experiences of healthcare professionals working with older adults with lower and adequate health literacy levels.
- Health literacy is the ability to access, understand and use information for health.
- Lower health literacy levels are associated with increased mortality and morbidity, and are common in older adult populations.

Who can take part?

- Healthcare professionals working within [insert NHS Trust's name]
- Healthcare professionals with professional registration, working clinically with older adults and in physical health

Why take part?

- Your views and experiences are extremely valuable to help inform development of health literacy initiatives and future NHS services.
- Useful opportunity for Continuing Professional Development.
- A health literacy resource pack will be provided at the end of the focus group.
- Focus group participants will be offered a free health literacy workshop if interested.
- Light refreshments will be provided during the focus group for your comfort and convenience.

What does the study involve?

- Taking part in a focus group with other healthcare professionals, lasting approximately 1-1.5 hours. Please discuss your participation with supervisors/line managers where appropriate. The time and venue will be agreed with you. Focus groups will take place during work hours and on Trust premises.
- You will be asked about your views and experiences in working with older adults who may have difficulties accessing, understanding and using information for health. At present, we do not know enough about healthcare

professionals' views on health literacy, including interventions and assessment tools. You do not need to know about health literacy to take part; you only need to have experience of working clinically with older adults.

- Your data will be anonymised; within the transcripts of the focus groups you will be identified with a code.

I would be very grateful if you would be willing to take part in my study. If you are interested please contact me:

Lotty.Brooks@soton.ac.uk, 02392 437983 (Mon/Tues) or 02380 594319 (Wed, Thurs, Fri)

If you do so, you will have the chance to find out more about the study before reaching any decision.

Many thanks,
Lotty Brooks
Clinical Academic PhD student
Faculty of Health Sciences
University of Southampton
Building 45, Room 0059
Highfield Campus
SO17 1BJ

E-mail: Lotty.Brooks@soton.ac.uk
Phone numbers: [insert number] (Mon/Tues) or [insert number] (Wed, Thurs, Fri)

Supervised by Dr Jo Adams (ja@soton.ac.uk), Dr Claire Ballinger (C.Ballinger@soton.ac.uk) and Prof Don Nutbeam.

Appendix Q Participant information sheet for healthcare providers in second phase

Participant Information Sheet

Study title: What are the views and experiences of healthcare professionals about assisting older adults to access, understand and use information for their health?

Researcher's Name: Charlotte Brooks

Supervisors: Dr Jo Adams, Dr Claire Ballinger and Prof Don Nutbeam

Ethics reference: 12154

Contact details: Building 45, room 0059, Faculty of Health Sciences, University of Southampton, Highfield Campus, SO17 1BJ. Tel: 02380 594319

You are invited to take part in a study as we are interested to find out more about your views and experiences about assisting older adults to access, understand and use information for their health.

Please read the following information carefully before deciding to take part in this research. If you have any questions, please do not hesitate to ask. If you decide to take part you will be asked to sign a consent form.

Part 1

What is the purpose of the study?

- The research is part of a PhD research project at the University of Southampton. The purpose of the research is to explore the views and experiences of healthcare professionals working with and communicating health messages to older adults with lower and adequate health literacy levels. Health literacy is the ability to access, understand and use information for health. Individuals with low and adequate health literacy levels find health information concerning. Lower health literacy levels are associated with increased mortality and morbidity, and are common in older adult populations.

Why have I been invited?

- You are invited to take part in this study because you are a health professional working clinically with older adults within [insert NHS Trust's name]. Your views and experiences are extremely valuable to help inform development of future NHS services.

What will happen to me if I take part?

- We will invite you to join a small group of other healthcare professionals to take part in a focus group interview.
- You will be asked to come back at a separate time to take part in the focus group. A suitable time and venue for participants will be agreed with you. Focus groups will take place during work hours and on Trust premises. You will also be asked to sign a written consent form before beginning the focus group. The focus group will last about 1.5 hours and will be audio-recorded and transcribed.
- In the focus group you will be asked for your views and experiences working with older adults with low and adequate health literacy levels. We are interested in both how we can tailor health information to individuals' health literacy needs and how we can develop individuals' health literacy abilities.

What are the possible benefits of taking part?

- It is possible that you will learn more about health literacy and helping your clients to access, understand and use the information you give them. Reflecting on your own practice and learning from others could serve as a useful opportunity for Continuing Professional Development. Additionally, at the end of the focus group health literacy resource packs will be provided and a free health literacy workshop will be offered to those interested. We cannot promise the study will help you. However, the information we get from this study will help us to understand how we can communicate with clients with both low and adequate health literacy levels.

What are the possible harms of taking part?

- There are no real harms associated with taking part in the focus group. Any complaint about the way you have been dealt with during the study will be addressed and is detailed in Part 2.

Part 2

Do I have to take part?

- You do not have to take part in this study. If you decide not to take part your employment will not be affected in any way.

What happens if I do not want to carry on with the study?

- You are free to leave the study at any time without any consequences. However, as this is a group discussion it will not be possible to exclude individual data once the session has commenced.

How will my confidentiality be protected?

- At the beginning of the focus group session the researcher will ask participants to respect the confidentiality of the group. However, the maintenance of confidentiality by other group members cannot be guaranteed.
- All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you will have your name removed so that you cannot be recognised.
- Within the write up of the focus group you will be referred to with a code and according to your profession. The list of codes will only be accessed by the chief investigator and will be kept in a password protected document on a password protected computer. Anonymised data will be seen for research purposes by the research team. Anonymity will be encouraged through these methods, but cannot be guaranteed.
- After finishing the study, audio-files will be deleted and the paper data will be kept for 10 years and then disposed of securely. The electronic data files will also be deleted after 10 years.

What will happen to the results?

- You have the opportunity to receive the summary of the research findings if you would like to.
- The results will be presented in my PhD papers. The study may be also be presented at conferences and published in a research journal. If you are happy for me to, I will use anonymous quotes from your interviews in these reports.

Who is organising and funding the research?

- Solent NHS Trust is funding the study. The research sponsor is the University of Southampton.

Who has reviewed the study?

- This study has been reviewed and approved by the Faculty of Health Sciences ethics committee and Research and Development within [insert NHS Trust's name].

What happens if something goes wrong or I have a complaint?

If you have a concern or a complaint about this study you should contact the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ. Tel: 023 8059 5058; Email: rgoinfo@soton.ac.uk. If you remain unhappy and wish to complain formally the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.

Appendix Q

Further information and contact details

If you want to know more, please contact me on:-
- E-mail address: Lotty.Brooks@soton.ac.uk Telephone number: 02380 594319. You can leave an answer phone message and I will get back to you if I am not in.

Thank you for taking the time to read this. Please ask any questions if you need to.

Appendix R Consent form for healthcare providers in second phase

Study title: What are the views and experiences of healthcare professionals about assisting older adults to access, understand and use information for their health?

Researcher's name: Charlotte Brooks
Contact details: Building 45, room 0059, Faculty of Health Sciences, University of Southampton, Highfield Campus, SO17 1BJ. Tel: 02380 594319

Please initial in the boxes if you agree:

1. I have read and understand the information sheet dated (18/12/14, version 2.0.) for the above study. I have had the opportunity to consider the information and ask questions.

2. I understand that my participation is voluntary and that I may withdraw at any time without giving any reason and without my legal rights being affected.

3. I understand that my data will be made anonymous.

4. I understand that the focus group will be audio-recorded.

5. I am happy for you to use anonymous quotes from the interviews in the findings. This may be in final reports, PhD papers, conferences and in research journals.

6. I agree to take part in the above study.

7. I would like a summary of the findings when the research has been completed:

    Yes / No (please circle)
    If you would like a copy of the findings, please write your address/email address clearly here:

Data Protection and Confidentiality
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous. I understand that all group members will be asked to keep what we talk about private but that this cannot be guaranteed.

Name of Participant (print):   **Date**   **Signature**

_____

Name of person taking   **Date**   **Signature**
consent (print):

_____

Appendix S   Focus group topic guide (used for pilot focus group) in second phase

1. What does the term health literacy mean to you?
2. **CASE STUDY DISCUSSION – HYPERTENSION**
   - What do you think happened here?
   - What do you think was the issue for the patient?
   - What do you think was the issue with Dr H's communication?
   - How do you think Dr H could have communicated better?
3. What abilities does a person need to have in order to access, understand and use health information to make informed decisions?
4. Have you ever worked with an older adult that you felt had difficulties understanding health information?
   - What made you think they had difficulties with this?
   - How do you think their difficulties affected them?
   - Can you describe what kind of difficulties they had?
   - Did they have any coping strategies?
   - What was your experience of working with this person?
   - Did you use any strategies to help their understanding?
5. Have you ever worked with an older adult that you felt was particularly good at understanding health information?
   - What made you think they were very capable?
   - What was your experience of working with them?
6. How do you think we can identify individuals who struggle to understand health information?
7. How confident do you feel in being able to identify individuals who struggle to understand health information?
8. **HEALTH LITERACY MEASUREMENT TOOL DISCUSSION**
   - What do you think about using tools to measure our clients' abilities to access, understand and use health information? Show tools to facilitate discussion.
   - What do you think about using clear and simple communication with all of our clients to ensure information is fully understood?
     - Establish views on using tools versus universal precautions.
9. What do you think is important when providing health information to older adults struggling to understand and use health information?
   - What do you think is important when communicating verbally?
   - What do you think is important when providing written information?
10. How do you think we as healthcare professionals can help someone to develop their health literacy abilities?
    - How important do you think it is to consider trust?
    - How important do you think it is to tailor information to individuals' needs?
    - How important do you think it is to consider communication / learning style preferences?
    - How important do you think it is to consider social support?
11. How do you think we can help someone to self-manage their conditions better?

12. How easy do you think it is to use communication strategies to assist older adults who have difficulties using health information?
    - What, if anything, makes this easier?
    - What, if anything, makes this more difficult?
13. How important do you think it is to consider our patients' abilities to understand and use health information within daily clinical practice?
    - What, if anything, makes this easier?
    - What, if anything, makes this more difficult?

Closure and debriefing:
- Summarising what has been said
- Asking for any additional comments
- Thanking participants for participation
- Provide health literacy resource packs
- Ask participants to put name and contact details down for health literacy workshop if interested

Appendix T   Focus group topic guide (version used after pilot focus group) for second phase

1. What does the term health literacy mean to you?
2. What abilities does a person need to have in order to access, understand and use health information to make informed decisions?
3. Have you ever worked with an older adult that you felt had difficulties understanding health information?
    - What made you think they had difficulties with this?
    - How do you think their difficulties affected them?
    - Can you describe what kind of difficulties they had?
    - Did they have any coping strategies?
    - What was your experience of working with this person?
    - Did you use any strategies to help their understanding?
4. Have you ever worked with an older adult that you felt was particularly good at understanding health information?
    - What made you think they were very capable?
    - What was your experience of working with them?
5. How do you think we can identify individuals who struggle to understand health information?
6. **HEALTH LITERACY MEASUREMENT TOOL DISCUSSION**
    - What do you think about using tools to measure our clients' abilities to access, understand and use health information? Show tools to facilitate discussion.
    - What do you think about using clear and simple communication with all of our clients to ensure information is fully understood?
        - Establish views on using tools versus universal precautions.
7. What do you think is important when providing health information to older adults struggling to understand and use health information?
    - What do you think is important when communicating verbally?
    - What do you think is important when providing written information?
8. How do you think we as healthcare professionals can help someone to develop their health literacy abilities?
    - How important do you think it is to consider trust?
    - How important do you think it is to tailor information to individuals' needs?
    - How important do you think it is to consider communication / learning style preferences?
    - How important do you think it is to consider social support?
9. How easy do you think it is to use communication strategies to assist older adults who have difficulties using health information?
    - What, if anything, makes this easier?
    - What, if anything, makes this more difficult?
10. How important do you think it is to consider our patients' abilities to understand and use health information within daily clinical practice?
    - What, if anything, makes this easier?
    - What, if anything, makes this more difficult?

Appendix T

Closure and debriefing:
- Summarising what has been said
- Asking for any additional comments
- Thanking participants for participation
- Provide health literacy resource packs
- Ask participants to put name and contact details down for health literacy workshop if interested

Appendix U   Sociodemographic questionnaire for second phase

Participant information

Please fill in some basic information about yourself and your job. This will help me to have a better understanding of what you are saying in the interviews. This information will be anonymised when writing up the research.

Name	
Gender	
Job title	
Team/department	
Agenda for Change grade	
Total amount of years of clinical practice	
Length of time in current post	

Appendix V   Coding schedule for second phase

Code	Definition
Facilitators to identifying individuals	Participant suggests things which may make identifying individuals' health literacy levels easier.
Barriers to identifying individuals	Participant suggests things which may make identifying individuals' health literacy levels more difficult.
Strategies for identifying individuals	Participant discusses how they would identify an individual's health literacy levels.
Perceptions regarding health literacy screening	Participant expresses their views (positive, reservations or neutral) on health literacy screening. They may also critically analyse a specific tool or discuss the implications of screening.
Perceptions regarding use of universal precautions	Participant expresses an opinion about using evidence-based communication strategies with all patients. Their responses are categorised as positive, reservations or neutral.
Patient factors	Participant refers to any patient factors which may affect a patient's health literacy level (both facilitators and barriers).
Provider factors	Participant refers to anything a healthcare provider might do which may affect the patient's health literacy.
Societal factors	Participant refers to societal factors which may affect a patient's health literacy. This includes media, stigma, stereotypes, sociodemographic factors, internet etc.
Support network	Participant refers to how a patient's support network may be a facilitator or barrier to information provision.
System factors	Participant refers to factors relating to the healthcare system which may affect information provision or the patient's health literacy.
Perceptions regarding the importance of considering health literacy	Participant makes a comment which indicates how important or unimportant it is to consider health literacy.
Understanding, awareness and confidence regarding health literacy	Participant reveals their level of knowledge or understanding about health literacy, or describes how confident they feel in meeting patients' health literacy needs.

Appendix V

Code	Definition
Suggestions for improving practice	Participant suggests something which could be done to improve practice in relation to health literacy.
Suggestions for development of health literacy	Participant suggests strategies or ideas about how patients' health literacy could be developed.
Functional health literacy	Participant refers to basic reading and writing skills applied to a healthcare situation and factors which may affect this. Also, basic functioning in a healthcare situation.
Interactive health literacy	Participant refers to more advanced health literacy skills and abilities. Also, participant may discuss interpersonal healthcare provider skills.
Critical health literacy	Participant refers to patients they perceive as having very high health literacy levels. Participant may also discuss how they manage working with patients who they perceive to have very high health literacy levels.
Relationship building and trust	Participant refers to healthcare providers building 'relationships', 'rapport', or 'trust' with patients.
Tailoring interactions	Participant refers to modifying their communication/education/healthcare delivery to meet an individual's needs.

Appendix W Example of a framework matrix for second phase relating to the second main theme (identifying older adults' health literacy levels)

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
Participant 001 (Palliative Care); Nurse; band 6	**Picking up clues/checking understanding** we go through the medications with every patient that we meet, so… and I think some people declare it.	**Reliance on patient disclosure** 'and I think some people declare it.'		**Negative - feels like testing / concerns about patient reaction** 'I wouldn't want to. I think I would feel as if I was testing them' 'As if you're testing them and… I feel as if they may be insulted'	**Tools not assessing specific areas relevant to team** 'they don't need to understand everything, the whole realm of all of these um… you know medical health terms' [REALM]
Participant 002 (Palliative Care); Nurse; Band 7	**Picking up clues** 'no books and no newspapers in their house' **Asking about abilities** 'I suppose it's also making sure that they actually can read or write' [N.B. P6 advised afterwards she has not come across this before] **Checking understanding/picking up clues** 'because we always go through the patient's drug list. Um… then that's a very big indicator that the patients can't read'	**Reliance on patient disclosure** - 'Some people are very honest [another participant: yeah] and say, you know, 'I can't read it, I can't read it.''		**Negative - Unnecessary for our service** - 'I guess the main message from us is that in the jobs that we do, those tools can be less relevant than other professionals in different jobs.' **Concerns about patient reaction** - Reference to how patients still find the MMSE offensive. **Positive - does serve a purpose**	

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
Participant 003 (Palliative Care)				**Negative - concerns about patient reaction** 'A lot of our patients are quite distressed as well. And putting this in front of them'	
Participant 004 (Palliative Care); OT; band 6					
Participant 005 (Palliative Care); Nurse, band 6	**Picking up clues (from clinical experience)** - 'We assume that they've got… and then, and then you pick up cues'	**Uncertainty about identifying individuals** 'So we didn't, we didn't actually pick up on it straightaway' **Reliance on family member disclosure** - 'you know got his family involved and his daughter was actually the one who told us that he couldn't'	**Clinical experience** 'And I think, as…when you've got, when you're experienced you hopefully… there's questions you ask and the way you assess people, that you would pick it up'	**Negative - Unnecessary as you would pick it up from clinical experience Negative - burden** 'it would be… another hurdle to try and get through when you go and do an assessment.' 'another bit of paperwork, maybe to put on RIO'	
Participant 006 (Palliative Care); Nurse; band 6	**Asking about knowledge** - 'asking them what they understand by their diagnoses as well... you can get quite a lot from that conversation too.'	**Uncertainty about identifying individuals** - 'Um… so whether that's related to what their understanding is literacy wise… or not' **Embarrassment** 'Yeah shame, and a fear that they have to			

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
		divulge that information.'			
Participant 007 (Palliative Care); OT; band 7	**Picking up clues (avoiding form filling, requesting phone calls, having time to explore issues)** - 'you pick up cues' - 'oh always phone me yeah, there's no point sending me a letter.' - 'Or they, you know a form comes round, and they say, 'well this is, this is far too long, I can't possibly do this…''	**Uncertainty about identifying individuals / reliance on patient disclosure** 'There might be a problem. But I mean you sometimes never really figure it out.' - 'And I mean some people are incredibly good at hiding it and… you may never know.'	**Making or having more time to pick up clues** - 'We are also quite lucky in that we tend to have a bit more time… or make a bit more time with the patients. And we do talk a bit more and in-depth and look at different areas… and the clues can be more… obvious.'	**Negative - feels like testing** 'As if you're testing them' 'It might be, that… I might ask verbally what… some of the questions ... rather than give them a piece of paper to ask… because that feels like um… testing them, and there's a pass or fail in that' **Negative - Unnecessary / lacking functional purpose** 'things like the mini mental assessment, you're doing for a particular functional reason' **Negative - May be more relevant for other professionals** **Negative - Less relevant as we verbally communicate with our patients**	No I am not saying you shouldn't do them. But I, I don't think at the moment that they're the thing that would make me… particularly something with a list of words would not necessarily be something I would think of giving to someone' [REALM]

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
				Negative - concerns about patient reaction - 'the people that we are working with have got so much going on that you don't overload them with anything more than seems appropriate at the time' **Negative - burden** 'It's another little thing for us to think about'	
Participant 001 (Neuro); psychologist; band 8	**Picking up clues (education and occupation history)** - 'we do all sorts of things like school or educational and occupational history. Um… and I suppose you do make certain assumptions on the basis of that.' **Asking about knowledge** - 'before I signpost to information, I will always ask someone… you know how much they know already, … what sort of things they're interested in finding out… how have they accessed that information' **Formal ax of abilities** - 'um… so I might have done a, a formal cognitive assessment with someone. And I know that			**Negative - Unnecessary** - 'Because that's about their ability to read the word. Not about their understanding of it. So… I already use word list tests already, I probably wouldn't use that one because I don't think it would add anything.' **Positive - standardised tools can be useful** - 'I think as part of a broader assessment, standardised tools are really useful. Um… but they're probably on their	Standardised tools are only useful if done as part of a broader assessment'

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
	their comprehension is very good, and I know that their, their spoken… language is quite good, um… but I also found out from the assessment that their reading is maybe below you know average'			own not going to tell you a huge amount.'	
Participant 002 (Neuro); OT; band 6	**Formal ax of abilities** 'in the MOCA assessment, um… I can't quite remember, but they ask what age they were when they left school'	**Uncertainty about identifying individuals** - 'I think what can sometimes happen is you can mistake hearing impairments for cognitive impairments' **Embarrassment** 'I imagine there's probably embarrassment around literacy levels.'	**Building trust** 'to actually truly understand what the person's literacy level is… you need to develop a relationship with them that there's some element of trust, so that they'll share that information with you.'	**Positive - would identify that individual needed help** 'if people were being honest, this would, this one, the 'All Aspects of Health Literacy Scale' would identify that you needed help.'	'you could easily get a high score in, say you don't need any help without having to prove, or it's not really testing, it's just asking them if they need help or not' [CHEW]; 'if people were being honest, this would, this one, the 'All Aspects of Health Literacy Scale' would identify that you needed help. But only if you were honest'
Participant 003 (Neuro); physio; band 6		**Uncertainty about identifying individuals / reliance on family member disclosure** - 'Um… and it came out in a family meeting, and his wife told us, and it was quite embarrassing really that we hadn't picked, we hadn't known about that' **Information needs not recorded**	**Reducing embarrassment by not specifically asking about literacy (NVS)**	**Concerns about patient reaction when asking about literacy levels Positive - NVS can be used functionally as part of shopping trip**	Agreement regarding honesty issue [CHEW]

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
		- 'I suppose it's really rare actually to see like an older person in their past medical history, for it to say like dyslexia' **Embarrassment** 'and also then it wouldn't, there probably might not be so much embarrassment'			
Participant 004 (Neuro); OT, band 6	**Picking up clues (complexity of spoken language, not filling out forms)** - 'I think it was evident in his speech' 'he's not filling out forms' **Formal ax of abilities / asking about abilities** - We're quite often asking, it's part of the assessment, we'll quite often ask them to do some form of… you know writing or reading, potentially. And, and kind of as part of that, you kind of… as part of the questions, you'll always say, 'oh how is your reading and writing?'	**Embarrassment / reliance on patient disclosure** 'he didn't want to kind of admit that he had literacy problems.'			
Participant 005 (Neuro); OTA; band 3					Agreement regarding honesty issue [CHEW]

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
Participant 001 (CFS); OT; band 6		**Patients not being honest** - 'Well yeah, or they might say, 'oh yeah, yeah, I'm fine' but actually they might not be.'		**Negative - feels like testing** 'It's a bit like a test' **Negative - concerns about patient reaction** 'It might be that actually they're perfectly capable of doing it [another participant: but now we've asked them], but now we've asked them, they want us to help them'	Doesn't tell you much, does it?' [REALM] - Patients may not be HONEST [Brief Screening question] 'It might be that actually they're perfectly capable of doing it [another participant: but now we've asked them], but now we've asked them, they want us to help them…'
Participant 002 (PPS); exercise instructor; band 5	**Checking understanding** - 'after the education sessions when we phone the patients, we sort of ask them, 'what did you take from the education session or what was your understanding of duh-duh-duh-duh?''	**Not asking about literacy needs** 'No, we don't ask, no.' **Reliance on patient disclosure** 'Sometimes people tell us, don't they?'		**Negative - concerns about patient reaction** 'It might bring up quite a lot of anxiety in patients.'	
Participant 003 (PPS); physio; band 7/8	**Picking up clues (recognition that you can reach erroneous conclusions and observations of reading ability)** 'but when you have the discussion with them over the phone, they can say all the right things. So there can sometimes be a mismatch there between what you think from the person's body	**Uncertainty about identifying individuals** See quote for 'picking up clues' **Harder to identify in a group setting** - 'It's harder in a group setting' **Not asking about literacy needs / reliance on patient disclosure**		**Concerns about patient reaction** 'They'd wonder why we were asking. Why's this relevant?'	It's about pronunciation of the words, rather than whether they understand what that word really means' [REALM]

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
	language to the reality of the situation.' 'It becomes quite evident quite quickly if they have difficulties with reading and writing. Um… because we will give them forms in the session' **Checking understanding** 'I guess it's around having the sort of individual conversations with them when you can have them to kind of check in where they're at, you know where they are at with things.'	- 'I mean we don't ask specifically.'			
Participant 004 (PPS); psychologist; band 7	**Picking up clues (level of engagement, facial expressions and behavioural indicators)** - 'if they're not looking engaged, then you probably know they're not getting everything' - 'obviously if they drop out of groups, they certainly aren't' - 'if they've sort of got a frown' **Checking understanding** - 'you can do assessments and sort of ask and check.' Vague.				I don't know how useful that would be' [REALM when discussing with P3]
Participant 005 (CFS); psychologist; band 8		**Time** 'It would be nice if we had the time to assess each person's learning style [several participants' agreement]			

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
		and level of kind of literacy, and ability. But feasibly I don't think we do'			
Participant 006 (PPS); psychologist, band 8	**Picking up clues (less responsive, less interaction)** - 'They probably don't respond as much' **Checking understanding** - 'Or maybe it's just that they don't agree. But actually, to check that out with them… to see whether… is it that they're not getting it? Or, is it the case that they just have a different opinion?'	**Uncertainty about identifying individuals** - 'I think it's harder when someone seems to be on board with stuff [Participant 003 (PPS) yes] and they're not' **Harder to identify in a group setting (didactic ones)** - 'The other sessions are slightly more discussion based and slightly more interaction, and more opportunity for checking out if they're understanding.'		**Negative - Unnecessary / not relevant for our service** - 'Whereas, most of our information is mostly language, and it's mostly written text and it's more kind of, a lot of its probably explained in layman's terms.' - 'I mean it is that more you have to work it out [another participant: yeah], which I suppose does get a better, a better sense of their understanding, but probably not in our service' **Concerns about patient reaction (agreed with P3)**	Often people can tell you what medication they're on [another participant: yeah], but they've no idea what it's for, or what it does' [Discussing REALM]
Participant 007 (CFS); physio; band 6					
Participant 001 (Pulmonary); physio, Band 6	**Asking about abilities (sidestepping)** - 'Um… so I usually curb the subject of simply asking them,	**Uncertainty about identifying individuals** - 'I don't, I wouldn't know, I wouldn't know	**Training to identify individuals** - 'I think also dealing with, training to deal	**Concerns about patient reaction** 'some of those words might be quite	

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
	'can you read?' by asking them, 'do you need reading glasses?' Rather than just simply ask, because I feel there's an embarrassment'	how we'd identify that someone struggles.' - 'Um… I don't know how we can assess for it really.' **Embarrassment / stigma** - 'Um so yeah, I think it's a bit of a taboo thing to ask someone as well. Um… it can cause them embarrassment too.' - 'I think there's a certain amount of stigma for some of the older patients to admit if there's a lack of understanding on their part' **Reliance on patient disclosure (advises one or two people have voluntarily disclosed information re: literacy)**	with someone you think might have um… poor literacy levels, and how you sort of broach that subject with that person… or if you're using the correct terminology, if you're being politically correct when you're asking about their literacy levels'	evocative' **Need to consider implications of screening** But… is it actually going to really change how we treat our patients? **Positive - increases disclosure and makes environment more literacy friendly** 'I think if we were all using a question, a simple brief screening question like this on a more regular basis, I think actually it would make us a bit more literacy friendly anyway… and people are going to be a bit more… outgoing about their… literacy and their gaps in knowledge of their condition anyway. Just thinking of the bigger picture…'	
Participant 002 (Pulmonary); OT; band 6	**Picking up clues (lack of retainment)** 'And you're usually kind of picking up where there is an issue, that maybe you've done a session and you've talked	**Reliance on patient disclosure (advises no patients have ever disclosed)**		**Positive - Begins the dialogue** 'you know, it's kind of beginning that dialogue with them'	

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
	about a certain topic and then that patient will come and say, 'now what about…? And you're like, really? We've just talked about that, like two minutes ago." **Asking patient if they need help with form filling** 'I will give them the option… you know, 'are you okay to go ahead and do that, or would you like some help with it?''				
Participant 003 (Pulmonary); physio; band 6	**Picking up clues (lack of retainment)** 'Yeah. I think that shows it, doesn't it? It's that, it's really that retainment'	**Embarrassment** - 'Actually is it a case of actually they're not able to, and actually it's that embarrassment thing that they don't want to highlight that to us directly? And actually it's just easier to decline doing that.' **Reliance on patient disclosure** - 'So it's very difficult, it's okay if people are willing to disclose and share the information, but if they're not… you can only really		**Negative - Concerns about patient reaction** 'I think that's so outside the box and so random, that people will potentially turn around and say, 'well what's this relevant to anything?'' **Need to consider implications of screening** - 'I think the question is really, is with all of this is… is it something that you would do with those that perhaps you	However, you can always argue, actually does that give you enough information?' [CHEW]

Identifying individuals	HCP strategies for identifying individuals	Barriers to identifying individuals	Facilitators to identifying individuals	Perceptions of health literacy screening	Analysis of specific tools
		act in the way that you can with the information that you've got.'		question and think hang on, what's your literacy like? Or… actually, is it something that we look to routinely do with everybody and gauge that?' - 'And then it's not just okay well we've gauged that, now what do we do as a result of that?'	

Appendix X   Summary of research findings sent to focus group participants in second phase

Research Summary

Title: What are the views and experiences of healthcare providers about assisting older adults to access, understand and use information for health?

Charlotte Brooks; Prof Jo Adams; Dr Claire Ballinger and Prof Don Nutbeam

Introduction

Study location: [Insert NHS Trust's name].

Background: Health literacy is the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy emerges as an interaction between an individual's abilities and the demands of the health system. Lower health literacy levels are associated with increased mortality and morbidity, and lower health literacy is prevalent in older adult populations.

Method: Four focus group discussions were used.
Data analysis: Framework analysis was applied to the data.
Participants: 22 healthcare providers working in 7 different clinical teams.

Main Findings

Identifying older adults' health literacy levels

Strategies healthcare providers identified	Facilitators	Barriers
- Picking up verbal and non-verbal indicators - Asking patients about their literacy abilities - Assessing patients' knowledge and understanding - Formal assessment of abilities, e.g. cognitive assessments	- Clinical experience - Having enough time with patients to pick up the indicators	- Uncertainty about identifying health literacy levels - Embarrassment or shame - Not asking older adults about their health literacy abilities (resulting from the above two points)

Views about using health literacy screening tools to identify individuals with low health literacy

Positive views	Reservations
- Could create a more 'literacy friendly' environment - Could create an opportunity for dialogue with patients about health literacy	- May not be necessary in all situations - Concerns about health literacy screening causing anxiety/distress - Concerns that health literacy would feel like testing the patient

Views about using universal precautions (using evidence-based communication strategies with patients of all abilities)

Positive views	Reservations
Would meet the needs of most patients, and may only upset a minority	- Concerns about patients' reactions, e.g. feeling offended or patronised - One size fits all approach will never work

Importance of relationship and trust building, tailoring interactions and social support when meeting older adults' health literacy needs

Building relationships and trust	Tailoring interactions	Social support
- Older adults' high levels of trust in their GP may facilitate/hinder interactions with other healthcare providers - Integral to enable patients to open up about their health literacy needs - May increase adherence - May assist with being able to challenge beliefs	- Challenges with tailoring to the individual in group situations - Asking about patients' information needs but may also happen subconsciously - May not always be possible due to time or cost issues	- May help to meet older adults' health literacy needs, e.g. attending appointments, communicating with healthcare providers, support with internet access or other written materials and disclosing literacy issues - May support with meeting health literacy needs which are difficult to meet due to NHS pressures

Facilitators to the integration of health literacy in clinical practice

- Standardise practice to health literacy, e.g. incorporate identification of health literacy strategies into routine care.
- Incorporate health literacy in clinical guidelines and policies.
- Raise knowledge and awareness of health literacy through training and education at undergraduate level and within clinical practice.
  - Frame health literacy as an interaction between the individual's abilities and the demands of the healthcare system and a skill which can be developed over time.
  - Raise awareness about the prevalence of low health literacy, how to identify health literacy levels and how to meet health literacy needs.

For further information on this research or for guidance on meeting the health literacy needs of your service users, please contact the principal investigator (Charlotte Brooks):

E-mail: C.Brooks@soton.ac.uk

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