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# Health Literacy and Chronic Health Management among Older Adults

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# Abstract

## Health Literacy and Chronic Health Management among Older Adults

Health literacy is an expanding area of health research which focuses on individuals' ability to "access, understand, appraise and use information to make decisions about health." (1) Research has shown the impact health literacy can have on patient morbidity and mortality. Despite efforts to link health literacy with health outcomes (2) (3) there is still a lack of understanding over how health literacy impacts on health outcomes, with specific assessment of the impact of health literacy on the management of chronic health in older people. A systematic review of the current evidence surrounding several proposed mediating factors (Access and Utilization of Health Care; Attitudes; Motivation; Self-Efficacy) was undertaken. This identified limited and inconsistent evidence linking health literacy with all of the proposed mediating factors. Following the systematic review a qualitative study was undertaken to gain a greater understanding of the experiences of older peoples' access to healthcare, experiences and attitudes to the management of health problems, and how these are influenced by early life experiences. The study also looked to assess barriers older people perceive that prevent them from obtaining healthcare and the views of older people on health problems in later life. Seventeen people were recruited for the study and took part in semi-structured interviews. The thematic analysis of this data identified three key factors that impacted on how participants viewed both health and healthcare: Candidacy, Resilience, and Attitudes. Assessment of these factors demonstrated the influence health literacy

had in each area. The findings also demonstrated discrepancies between the results of the Newest Vital Sign score of participants and apparent health literacy of individuals. The findings strengthened our knowledge of the mediating factors between health literacy and health outcomes, however more work is still required.

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## List of Abbreviations

AHL: Adequate Health Literacy

AIDs: Acquired Immunodeficiency Syndrome

AOR: Adjusted Odds Ratio

A&E: Accident and Emergency

CI: Confidence Interval

CINAHL: Cumulative Index to Nursing & Health Literature

CRC: Colorectal Cancer

DHBM: Diabetes Health Belief Model

EMBASE: Excerpta Medica dataBASE

ERIC: Education Resources Information Center

FOBT: Faecal Occult Blood Test

GP: General Practitioner

HbA1c: Glycated Haemoglobin ( A measure of diabetic control)

HIV: Human Immunodeficiency Virus

IHL: Inadequate Health Literacy

LTC: Long Term Conditions

NVS: Newest Vital Sign

NHS: National Health Service

OR: Odds Ratio

PAM: Patient Activation Measure

PDSM: Perceived Diabetes Self Management Scale

REALM: Rapid Estimate of Adult Health Literacy

s-TOFHLA: Short Test of Functional Health Literacy in Adults

TOFHLA: Test of Functional Health Literacy in Adults

UK: United Kingdom

UK-TOFHLA: Test of Functional Health Literacy in Adults (UK Version)

US: United States

USA: United States of America

WHO: World Health Organisation

WRAT-R: Wide Range Achievement Test- Reading

# **1 Chapter One: Background**

## **1.1.Introduction**

The health of older people is a key area of modern day healthcare. People are living longer and the number of people living with multiple chronic conditions is rising. It is projected that the impact of the ageing population in the UK and increased prevalence of long term conditions may result in an increase in health and social care cost of £5 billion by 2018 (4).

Health literacy has emerged as an important health inequality that has implications for health management and service provision. Research has shown the impact health literacy can have on health outcomes and some of the difficulties people with inadequate health literacy can have with regards to their healthcare. This will be discussed in more detail later in the chapter but include issues of vaccination uptake, screening programme involvement, and correct medication usage (2). Problems with lower health literacy are seen at all ages but are more prevalent in older people (5). Additional research has attempted to identify which factors mediate the associations that have been demonstrated between health literacy and health outcomes (3).

This thesis aims to explore health literacy and the impact on health outcomes in older people. This will include a systematic review of the current evidence that looks to explain the relationship, and new qualitative research into the experiences of health of older people with different levels of health literacy. It is

expected that this work will add to the current literature and further the understanding of the interactions between health literacy and health outcomes in older people.

Specific objectives of this thesis are to:

1. Identify potential mediating factors between health literacy and health outcomes by assessing the current literature and models
2. Examine the evidence for these mediating factors in the literature with specific reference to older people
3. Explore the experiences and beliefs of older people with regards to their health and healthcare using semi-structured interviews

This introductory chapter will begin with a definition of health literacy and the impact of this on health inequalities. There will also be a discussion of the proposed impact health literacy has on health outcomes and suggested models that link health literacy to health outcomes.

## **1.2 Literacy and Health Literacy**

Whilst it is difficult to define literacy as it is a culturally specific concept (6), it is a general term that has developed over time. It used to describe knowledge or education but this started to change in the late nineteenth century when it came to refer to the abilities to read and write (7). In this traditional sense, literacy is deemed as important to the acquisition and use of information in day-to-day life.

The description of literacy has continued to evolve over the twentieth century with multiple different disciplines, including psychology and philosophy, developing the concept in numerous different directions. Among the definitions of literacy are those that propose that literacy can be described as a set of tangible skills, such as reading or writing (7). This is a fairly simplistic definition that focuses on core skills without placing them in context. In contrast, other descriptions focus on the ability of skills to enable access to knowledge and information as well as considering what this enables the individual to do. The argument for this would be that it is more useful to identify what people are able and unable to do with the literacy skills that they have. This has led to some suggesting that a more useful concept of literacy is one that splits it into multiple forms that are context specific (8). Those that believe in this approach argue that literacies are situated (9). By this they mean that the use of language is context specific. By defining literacy by the context in which skills are applicable it is possible to understand everyday implications in far more detail. Examples of this include information, media, technological and health literacy. Further weight has been given to this argument through work that has shown that “many who are labelled illiterate are found to make significant use of literacy practices for specific purposes in their everyday lives” (7)(p151). By using these later definitions it is possible to be more focused on issues of literacy and place them in context. Failing to look at the implications of literacy by using non-contextual measures could result in the under identification of individual difficulties. For the purpose of this discussion then, the term traditional literacy will be used to contrast to context specific forms of literacy.

One aspect of this approach to viewing literacy is health literacy. This term has been used in the literature for at least 40 years (Ad Hoc Committee on Health Literacy, 1999). Much as with the definition of literacy, there remains much debate over the definition of this term. The issues over defining health literacy draw several parallels with that of standard literacy also. A recurring theme in the differing definitions is that health literacy involves a set of skills that allow people to manage their own health and navigate health systems. An example of such a definition is:

“health literacy as a constellation of skills that constitute the ability to perform basic reading and numerical tasks for the functioning in the health care environment and acting on the health care information”  
(10)(p1).

A criticism of this definition is that it parallels the traditional conceptualisation of literacy described above with focus on reading and numeracy. Although basic skills may be a pre-requisite for the more complex ones, simplistic definitions fail to address the range of skills and characteristics that are likely to contribute to health literacy. The rationale for claiming that there is more to health literacy than just reading, writing, and numerical skills is seen in health campaigning attempts in the 1960s and 70s (11). The focus of these campaigns was based on the transmission of information to enhance patient knowledge. These attempts failed to elicit the improvements in health that were expected and it was not until health campaigns embraced the social context and behavioural decisions that people made that the desired improvements were seen.

There has been a move, therefore, towards more complete definitions of health literacy that draw on psychosocial characteristics in addition to the traditional skills. For example, Baker (2006) discusses the importance of the health system in facilitating health literacy in conjunction with a collection of individual capacities (12). Referring back to the importance of cultural context, this review of the definition of health literacy addresses the role health services have in setting health cultures. There is a responsibility of health professionals and services to set a culture where information and resources are accessible and not only to those with high literacy skills. Through their actions or inactions healthcare authorities can have enabling or disabling effects on patients' health literacy (12).

The World Health Organization (WHO) has recently published a new definition of health literacy that incorporates the role of social resources:

“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” (1).

Returning to work on traditional literacy, it has been conceptualized that this skill can be divided into groups of progressively more complex proficiencies (6). For example, the most basic level describes a general ability to successfully read and engage with written script. Freebody et al (1990) suggest that as people



develop greater abilities they pass through several more complex stages until they reach a point where they are able to undertake critical reading.

Nutbeam suggests that this premise may be echoed in health literacy (11). He builds on the approach taken to defining literacy to develop a definition of health literacy that proposes three levels of health literacy:

- **Basic/Functional Literacy-** This is broadly compatible with earlier definitions of health literacy that focus on the reading, writing and numeracy skills of individuals.
- **Communicative/Interactive Literacy-** A more advanced set of cognitive and literacy skills which, combined with social skills, allows participation in everyday activities, extract and derive meaning from information. The ability to apply new information to changing circumstances is also covered at this level.
- **Critical Literacy-** More advanced cognitive and social skills that can be used to critically analyse and utilize information.

This newer description of health literacy, and the fact that Nutbeam goes on to state that health literacy is context dependent, can provide explanations for the documented differences between the literacy skills of individuals and their ability to engage in healthcare. For example, the Institute of Medicine noted the importance of not only the possession of adequate skills but also the ability to implement them (13). They stated “even well-educated people with strong

reading and writing skills may have trouble comprehending a medical form or doctor's instructions regarding a drug or procedure" (14). This is in contrast to the majority of work in the United States (US) that focuses on the relationship between literacy levels and the ability to comply with prescribed therapeutic regimen and fails to appreciate the psychosocial elements (11).

In summary, health literacy is a developing term whose definition is still the subject of much debate. It is a key area for health promotion and includes practical skills such as reading and writing as well as social and environmental factors. The increasing number of definitions, unfortunately, act as a distraction from the issue and impact of health literacy, and has the potential to act as a barrier to the advancement of knowledge in this area. The problematic nature of varied definitions is discussed by Baker who suggests that the reason for the continued disagreement over the meaning and measure of health literacy lies in the fact that researchers are simply looking at different aspects of the same, larger concept (12). In doing so this introduces some of the issues surrounding the current quantitative measurement of health literacy.

### **1.3 Measures of Health Literacy**

Measuring health literacy is important to not only identify prevalence, but also to allow researchers to assess outcomes between different levels of health literacy. With uncertainty over comparability of general measures of individual reading,

vocabulary and knowledge with the same health-related measures (12) there is a need for more sophisticated measuring tools.

An ideal assessment of health literacy would evaluate general skills, such as reading and writing, in relation to health relevant information as well as psychosocial and environmental influences. Unfortunately there are currently no assessment tools that evaluate such comprehensive dimensions. It is unlikely that there will ever be such a comprehensive assessment tool as it would likely be impractical to implement due to its expected complexity (12). Measurements can be taken objectively using quantitative measurement tools and using proxies for health literacy such as educational attainment. Alternatively a subjective assessment can be used, such as self-reported questionnaires or a qualitative assessment of individual skills.

A variety of objective measures of health literacy have been developed which have been used across the literature. The most commonly used tools are the Rapid Estimate of Health Literacy in Adults (REALM) (15) and the Test of Functional Health Literacy in Adults (TOFHLA) (16)

#### 1.3.1 Rapid Estimate of Health Literacy in Adults

The REALM is a tool that measures word recognition and pronunciation. This consists of a 66-item test and assessing the number of correct responses. As such it is a test of vocabulary and pronunciation and has been shown to be significantly associated with educational attainment (17). Individuals are scored

based on the number of correct responses given. Individuals are then grouped based on US grade

- Scores between 0-18: 3<sup>rd</sup> Grade (Equivalent to Year 4 in UK (18); 8-9 years of age)
- Scores between 19-44: 4<sup>th</sup> to 6<sup>th</sup> Grade (Equivalent to Years 5-7 in UK (18); 9-12 years of age)
- Scores between 45-60: 7<sup>th</sup> to 8<sup>th</sup> Grade (Equivalent to Years 8-9 in UK (18); 12-14 years of age)
- Scores of 61 and above: 9<sup>th</sup> grade (Equivalent to Year 10 in UK (18); 14-15 years of age)

People who can read at a 9<sup>th</sup> grade level “should be able to read most patient education materials” (19)(p807). Those with a 7<sup>th</sup> to 8<sup>th</sup> grade reading level “may struggle with most currently available patient education materials”. People who score less than 61, and hence have a less than 9<sup>th</sup> grade reading level, are considered to have limited literacy. It benefits from being an easy to apply and simple assessment. Its widespread use in health literacy research (20) (21) (22) also allows for better comparison between studies.

Despite the inclusion of several medical terms in the scale, the drawback of the REALM is that there is no assessment of comprehension. As mentioned above, this renders the assessment as a measure of vocabulary and it has been validated as instrument of reading ability with high correlations with traditional reading assessments (2). In spite of this it remains one of the most commonly used tool

for assessing health literacy and is often used as a reference by which newer measures of health literacy are compared (23). It is important to consider how accurately the REALM identifies broader health literacy in comparison to educational attainment. Only if we assume that this assessment is an accurate measure can we confidently use it as a reference for assessing other tools for evaluating health literacy. The benefits of such a measure is the ease at which it can be applied and the wide use in the current literature. The use of the same measure across numerous studies allows more accurate comparisons between the studies and, therefore, greater evidence for the findings.

#### 1.3.2 Test of Functional Health Literacy in Adults (TOFHLA)

Like the REALM, the TOFHLA assesses the ability to read text. In contrast, however, the TOFHLA also tries to assess comprehension of the text and assesses numerical ability . This is done by a cloze procedure (2). Individuals are presented with health-related prose and numerical information and are asked to fill in blank spaces. Scores are calculated range from 0-100 and people with scores of less than 59 are considered as having inadequate health literacy; those with scores of 60-74 have marginal functional health literacy and people with score of 75 and over are considered to have adequate functional health literacy.

A shorter version (s-TOFHLA) (24) of the test was later developed and comprised of fewer reading and numeracy questions. This reduction in items resulted in a reduction in time to complete from 22 to 12 minutes making it far more practical for use in both healthcare and research.

Both tests have been validated, with the original TOFHLA correlating with both the REALM and the revised Wide Range Assessment Test (WRAT-R) (16). The WRAT-R is an achievement test that measures the ability to read and spell words, comprehend sentences, and solve maths problems (25). Again it is important to consider what this test has been validated against. The REALM has already been discussed and doubts over its suitability as a measure of comprehensive health literacy described. The WRAT-R is a revised version of the original wide range achievement test that was developed to assess cognitive performance. It has undergone several further revisions and it was not until the most recent version (WRAT4) that sentence comprehension was included (25). The ability of the WRAT-R to be used as a comparison to validate comprehension is questionable, therefore, although the use of cloze procedures would imply the need to comprehend the health text to be able to supply the missing words.

Both of these tools are the most commonly used against which other, newer assessments are measured (23). It is understandable that comparison would be made with these measures of health literacy given that they are so commonly used in the work on health literacy. It is important to link new tools with those developed previously so that new research using the more progressive measures can be compared to that which has already been done. A number of more comprehensive measures of health literacy have been developed to further investigate, not only general literacy skills, but the ability to use these skills in health-related situations. By doing so they are starting to try and assess more communicative/interactive and critical health literacy skills rather than simply functional skills.

### 1.3.3 Newest Vital Sign

One such example of these more recent health literacy measures is the Newest Vital Sign (NVS). The NVS is based on a nutrition label for ice cream. Individuals are asked to read the label and then answer 6 questions, an example of which is to calculate the total number of calories that would be consumed if the whole container of ice cream were eaten. By doing this the test is moving away from simple comprehension of words on the ice cream label to being able to interpret the information to answer health related questions. The test takes 3 minutes to complete and as such is a much faster tool when compared to TOFHLA and REALM. Validation has also been shown for this test through comparison with the TOFHLA (26).

The NVS also provides an example of how several health literacy assessments are being adjusted for cultural reasons. With the NVS originating in the US, researchers have developed and validated a version for use on people within the United Kingdom (UK) in keeping with previous work validating the REALM and TOFHLA for UK populations (27) (28). This adheres to the statement of Freebody and Allan (1990) discussed earlier in this chapter that literacy must be culturally specific. In developing a UK version, Rowlands et al have made sure that this measurement is appropriate for use with a UK population and in so doing, reduced the possibility of underestimating health literacy (29).

These measures of health literacy provide an insight into the different approaches taken to assessment. However they highlight the lack of a tool that addresses all of the components of health literacy. By reviewing the current

WHO definition we can see how each of the current assessment tools miss some of the aspects of health literacy.

Any use of such tools, therefore, must acknowledge the limitations that comes with them. Studies are likely to focus on one section of health literacy rather than the whole breadth of the concept. For example, the use of TOFHLA may be completely appropriate for the assessment of ability to read and comprehend therapeutic information. It may, however, be less likely to differentiate people who can critically assess the information and so may be less appropriate in a study of how people decide to use the therapeutic information they have read.

As well as the objective measure of health literacy there are a number of subjective measures emerging which look to assess a wider range of skills believed to be involved in health literacy. Examples of these include the Health Literacy Questionnaire (HLQ) and the Ishikawa tool. As with the objective measures there are benefits and limitations to each of these.

#### 1.3.4 Health Literacy Questionnaire

This tool for assessing health literacy involves the use of a 44 item questionnaire which has questions covering 9 areas which the authors identified as forming part of health literacy. The questions assess numeracy, prose, and comprehension as well as application of this knowledge. The authors argue that the range of items in the measurement tool allows identification of more subtle health literacy difficulties. By having a range of items of varying complexity and covering different areas of health literacy this measurement looks to cover the



different levels of health literacy proposed by Nutbeam and described previously in this chapter. One of the benefits of such an approach is that this tool is likely to have a greater sensitivity for identifying inadequate health literacy and, arguably, provide a more complete assessment of health literacy when compared to more limited objective measures. It does not, however, provide assessment of all areas of health literacy and there are certain aspects, such as 'practicalities of accessing the health system', that are not covered in the final questionnaire. A further limitation of self-reported questionnaire measures, such as this, is the subjective nature of individual's responses. Being a relatively new tool there is also need for studies to be undertaken to confirm applicability in specific cultural settings.

#### 1.3.5 Ishikawa

Ishikawa et al developed two health literacy measurement tools for use in their work (30) (31). They both took a subjective approach and covered areas of functional, communicative and critical health literacy. One of the two tools was developed to be used in the area of diabetic care with the other developed for general health promotion. As with the Health Literacy Questionnaire there are clear benefits to assessing health literacy with areas covering different domains of health literacy with varying levels of complexity. There are several limitations to the Ishikawa tools. As with the Health Literacy Questionnaire there would need to be robust assessment of the applicability to non Japanese cultures. Questions also need to be raised over the development of the tools with both tools being developed in small, single communities and one of the tools excluding

all women. The generalisability of the tools is therefore questionable and more evidence would be required to overcome these concerns.

With an increasing number of measurements available and a continued call for both more comprehensive and more practical measures (12), there is a greater scope for assessing skills that are implicit in health literacy. Researchers and clinicians have to make sure, however, that they chose a measurement that evaluates the skills that are appropriate for the work they are doing as at present each of the tools is a proxy or partial measurement rather than a full assessment of health literacy.

#### **1.4 Prevalence of Health Literacy**

Due to the relative complexity of measuring health literacy it is not surprising that there are not many countries that have prevalence figures (32). In the UK estimations of health literacy have been extrapolated from surveys of traditional literacy and numeracy. Although not a direct measure of health literacy, traditional literacy can be used as a proxy which, due to the increased complexity of health related problems, will tend to underestimate the prevalence.

In 2003 and again in 2011, the Skills for Life Survey assessed the literacy and numeracy skills of UK adults between 16 and 65 (33). In total, 7,230 interviews were conducted with literacy levels being established in 5,824 and numeracy level in 5,823 individuals. Interviews of two out of three skills (literacy,

numeracy, and ICT) were performed for each individual that lasted, on average, 70 minutes. This was preceded by a 20-25 minute questionnaire that was sent to identified households. The survey found that 14.9% of people had literacy skills at an entry level 3 or below. (34) This is a definition from the UK National Qualification Framework which describes sequential stages of educational outcomes and skills (35). People with this level of literacy are able to:

- Understand short straightforward texts on familiar topics
- Obtain information from short documents, familiar sources, and signs and symbols (34); for example write short messages or describe health symptoms.

The survey also found that 49.1% of people had numeracy levels at an entry level 3 or below. People with this level of numeracy are able to:

- Understand information given by numbers, symbols, diagrams and charts used for different purposes and in different ways in graphical, numerical and written material (34); for example, understand price labels or pay bills but unable to understand more complex numerical instructions such as those contained with national bowel cancer screening kits (36)

These statistics again suggest that nearly 1 in 7 people in the UK are likely to struggle with obtaining information from unfamiliar topics or sources. With health-related issues being considered more complex it is reasonable to extrapolate that at least 1 in 7 people in the UK struggle with obtaining health

information. A study by Rowlands et al examined the congruity between population skill levels as described in the Skills for Life Survey and the complexity of currently available health materials in the UK (36). This study showed that health information is too complex for 43% of people aged between 16 and 65 years and that this figure rises to 61% when the information also requires maths skills.

The U.S. Department of Education's National Center for Education Statistics has undertaken two assessments of English literacy among adults aged 16 years and older. After the 1992 National Adult literacy Survey, 19,000 adults took part in the National Assessment of Adult literacy of 2003. This second survey was the first large-scale national assessment of U.S health literacy (37). The report on health literacy levels determined that 14% of adults had below basic health literacy with a further 22% only having basic health literacy (38). With regards to these definitions the report stated that adults with below basic literacy ranged from those that were non-literate in English to having the following abilities:

- Locating easily identifiable information in short, commonplace prose texts
- Locating easily identifiable information and following written instructions in simple documents (e.g charts or forms)
- Locating numbers and using them to perform simple quantitative operations (primarily addition) when the mathematical information is very concrete and familiar.

When reviewing the health literacy of different age groups, those aged 65 years and older had lower health literacy than the younger age groups displaying a greater burden of low literacy at this age. From these figures we can see that just over 1 in 7 US adults have literacy levels that could preclude them from obtaining and critiquing the complex information that is often required to allow adequate health management.

Other assessments of the prevalence of health literacy include the European health literacy survey (39). This survey was conducted in eight European countries and demonstrated that at least 12% of participants had insufficient health literacy and 47% had limited health literacy. There was also evidence that certain subgroups within populations had higher proportions of limited health literacy including older people.

The UK survey is likely to have underestimated the prevalence of inadequate health literacy as it required more highly developed skills to obtain an adequate score. A further important consideration in the UK Skills for Life Survey is the exclusion of people aged over 65 years. Health literacy has been shown to be markedly lower in older age groups. This was seen despite adjustment for possible memory loss with a decline of 1.4 points in TOFHLA score for every additional year (5) (39). By excluding this age group where inadequate health literacy is most prevalent any estimation of health literacy prevalence will be too low. Whether these values are true reflections of the prevalence of inadequate health literacy, there is unquestionably a significant proportion of the population

that have inadequate skills to both navigate the health system and manage their health issues.

## **1.5 Impact of Limited Health Literacy**

Despite some research undertaken in the UK, much of the current literature on the impact health literacy has on health outcomes has been done in US where there has been a huge drive to assess the literacy of the US population. The following section will demonstrate some of the range of outcomes that have been researched. Unless otherwise stated it should be assumed that the following research on the effects of health literacy is drawn from US research.

### **1.5.1 Rates of Hospitalisation**

Hospitalisation is an important outcome as it has both personal and societal implications. On an individual level, hospitalisation is associated with acute deterioration in health and higher morbidity. The impact on society is seen in the cost of hospital care. As such it is important to minimize the need for hospital care. Having lower health literacy has been shown to be associated with an increased rate of hospitalisation. For example, Baker et al (40) looked at the association between patient literacy and hospitalisation in an emergency department population in the US. They found that patients with inadequate literacy, as determined by the TOFHLA, were twice as likely to be hospitalized compared to individuals with adequate literacy. A second paper by Baker et al also investigated the risk of hospital admission with regards to functional health literacy (41). They found that the crude relative risk for hospital admission for

individuals with inadequate health literacy when compared to adequate health literacy was 1.43. In multivariate analysis, the adjusted relative risk was also statistically significant at 1.29 (CI=1.07-1.55). The findings from these studies were reflected in the correlation performed by Cho et al. (42). In their analysis they correlated the rates of hospitalisation with health literacy as assessed using the S-TOFHLA. In a study of 489 US patients they found a direct and negative correlation between health literacy and hospitalisation ( $\beta=-0.35$ ) suggesting lower health literacy was associated with higher rates of hospitalisation.

This research suggests a greater risk of hospitalisation for patients with inadequate health literacy. With the personal and societal costs as discussed above it is clear that unplanned admissions to hospital are undesirable outcomes in health management. Work that can look to address the impact of health literacy may be able reduce unnecessary hospital admissions.

### 1.5.2 Mortality

Mortality is often used as an endpoint of health research due to the clarity of measurement and comparability between studies. It is an obviously unwanted final outcome in the measurement of health outcomes. In the UK, Bostock and Steptoe found that the hazard ratio for all cause mortality for participants with low health literacy was 1.40 (43). This mirrored the previously discussed earlier study by Baker et al. (44). As with their previous work they investigated an elderly population as the burden of poor health literacy has been shown to be higher in this group (45). They found that after adjustment for other confounding factors, including age and self-reported physical and mental health,

that the hazard ratio for all-cause mortality when comparing inadequate and adequate health literacy was 1.52.

Further research in the US by Sudore et al also looked at possible links between health literacy and mortality (19). They found that even after adjustment for demographics and confounders, limited health literacy, defined as a score indicating less than a 9<sup>th</sup> grade reading level, was independently associated with mortality (Hazard Ratio 1.75; 95% CI: 1.27-2.41).

Both of these studies show clear evidence that health literacy is a strong independent predictor of mortality in the elderly population and again therefore an important area to look at reducing discrepancies in mortality rates.

### 1.5.3 Emergency Department Use

In addition to having higher rates of hospitalisation and mortality the use of emergency departments has also been shown to be higher in those with lower health literacy. In a US study of the use of outpatient services there was an analysis of the rate of emergency department visits (41). An assessment of 3260 participants who had their health literacy measured using the S-TOFHLA showed individuals with inadequate or marginal health literacy were more likely to have visited the emergency department in the first 12 months following enrolment in Medicaid. These findings are complemented by the work done by Howard et al. into the medical cost of patients enrolled in the social health care plan, Medicaid (46). This study involved the assessment of 3260 non-institutionalised, elderly people in the US. Health literacy was again assessed using the S-TOFHLA and this



showed that people with inadequate health literacy incurred significantly higher emergency department costs.

#### 1.5.4 Information and Medication Use

Away from the use of services, research has also been undertaken to assess how health literacy may effect chronic condition management. A UK study assessed literacy and numeracy skills required to understand commonly used English health information materials. The results found that there was a mismatch between the skills of the English adult population and the complexity of medical information (36). This suggests that people with low health literacy are likely to struggle with many available health information materials.

Successful use of medication is a further area of research that has demonstrated the impact of health literacy. This has included work that looks at overall adherence to medication as well as those that investigate understanding of medication. Kalicham et al (47), assessed the adherence of 145 participants to HIV medication. This was done through unannounced pill counts done over the phone. They found that people with lower health literacy demonstrated poorer adherence. In the assessment of medication knowledge and understanding Paasche-Orlow et al. measured the asthma medication knowledge and inhaler technique of patients discharge from hospital in the US following a severe exacerbation of their asthma (48). They found that those with inadequate health literacy had poorer knowledge of asthma medication and poorer inhaler technique.

This evidence was synthesised in a large systematic review published in 2011 (2). For this review, studies that related to the impact of health literacy on health care service use and health outcomes were included. Research involving literacy and numeracy assessment were both included and papers from 2003 to 2010, and 1966 and 2010 were included respectively for these. The purpose of this review was to update a previous review of health care services and health outcomes related to health literacy. The main findings from this review were in keeping with the evidence presented above. They found that lower health literacy levels were associated with hospitalisation, greater emergency care use, and poor medication taking. In addition they also identified research that linked health literacy to screening programme use, influenza vaccination, and overall health status.

With mounting evidence demonstrating the negative influence of poor health literacy on health outcomes it is clearly important that research looks to see what resources and interventions can be implemented to reduce the inequalities that have been seen. For this to occur our understanding of what is involved in health literacy needs to be expanded and what, if anything, can be done to improve the patient and healthcare factors of health literacy must be identified. A greater understanding of the factors that link an individuals health literacy to health outcomes is also important and this will be discussed in more detail later in this chapter.

## **1.6 The Role of Health Literacy in Health Outcomes**

With an increasing body of work surrounding the relationship of health literacy and health outcomes some researchers have examined how this association is produced, as will now be explored. Rather than directly affecting health outcomes, health literacy is thought to influence a number of patient and health service factors that together contribute to health outcomes. The identification of these intermediate factors, and the effect of different levels of health literacy on them, is important to allow a focused approach to interventions and policies to improve patient outcomes.

In their 2011 review, Berkman et al suggested a possible pathway linking health literacy to health outcomes to allow them to identify papers for their review (Figure 1.1) (2). In 2007, Paasche-Orlow and Wolf proposed a causal pathway that linked health literacy to health outcomes via numerous intermediate factors (Figure 1.2) (3). As discussed in work by Sørensen et al (49) the current models of health literacy are not thought to be sufficiently detailed to properly cover the scope of factors that are involved in health literacy. In their work they reviewed the currently available logic models and developed their own model (figure 1.3). This model outlines the main dimensions of health literacy, the proximal and distal factors which impact on health literacy, and the pathways linking health literacy to health outcomes. The model also illustrates the role of these factors on both individual and population levels. The scope of this model is far greater than the other US models mentioned above and, similarly to the Berkman et al model

was borne out of a systematic review of the available literature on health literacy.

Research has started to investigate the legitimacy of significant associations between health literacy and some of these factors. For example, Gazmararian et al (50) looked at the relationship between health literacy and patient knowledge of their chronic condition. Interviews of 653 participants with a chronic condition were analysed. 24% of participants had inadequate health literacy and they found that people in this group were significantly less likely to correctly answer 8 out of 20 asthma questions, 5 of the 11 diabetes questions, 4 of the 16 chronic heart failure, and 8 out of the 25 hypertension questions. Adjusted regression coefficients again showed significant associations between health literacy, measured by s-TOFHLA, and asthma, diabetes, chronic heart failure, and hypertension knowledge. Similar findings were demonstrated in a cross-sectional study by Williams et al (20). This study looked at associations between literacy measured by the Rapid Estimate of Adult Literacy in Medicine and asthma knowledge. They found that asthma knowledge was significantly and directly related to reading levels.

The systematic review of 2011 by Berkman et al (2) looked at some of the evidence for the intermediate factors between health literacy and health outcomes. Some of the factors they investigated and the strength of evidence identified can be seen below in Table 1.1

**Table 1.1 Examples of Intermediate Factors Investigated by Berkman et al.**

<b>Outcome</b>	<b>Strength of Evidence</b>
<b>Access to Care</b>	Insufficient (Evidence inconsistent)
<b>Asthma Self-Care</b>	Low (Evidence Suggests negative relationship to health literacy)
<b>Diabetes Self-Management</b>	Low (Evidence Suggests positive relationship to health literacy)
<b>Emergency Care Visits</b>	Moderate (Evidence suggests increased use with lower health literacy)
<b>Self-Efficacy</b>	Insufficient (Evidence inconsistent)

The current evidence suggests that there is still a large gap in the understanding of why and how health literacy affects health outcomes. More research is needed to investigate which factors are important in producing health outcomes, and the impact that health literacy has on these factors. At present there is a lack of evidence in both of these areas that means that any interventions and policies aimed at improving outcomes in those with inadequate health literacy may fail to accurately address the challenges these individuals face.

Figure 1.1. Logic Model Proposed by Berkman et al. (2)

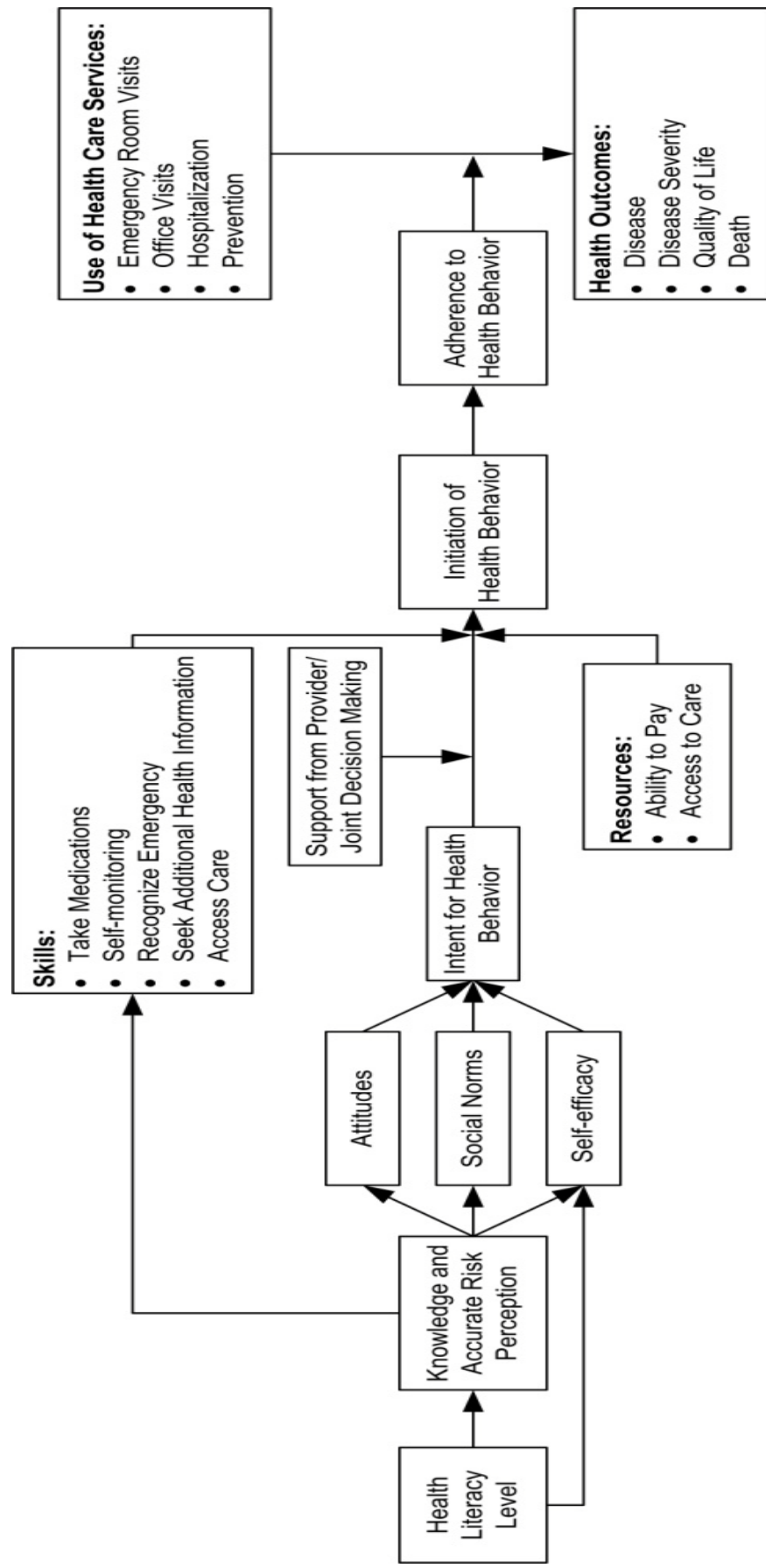


Figure 1.2. Causal Model Proposed by Paasche-Orlow and Wolf (3)

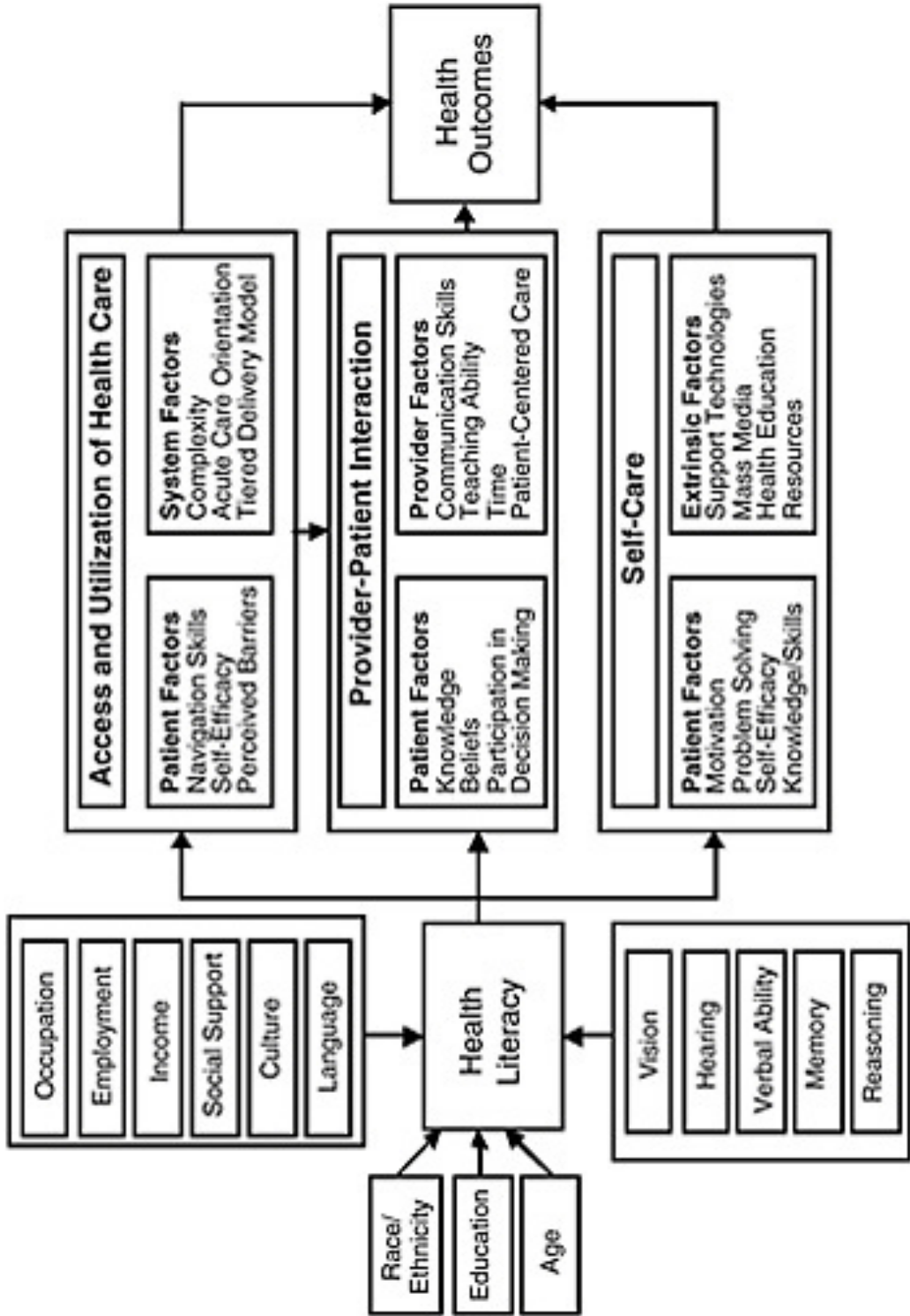
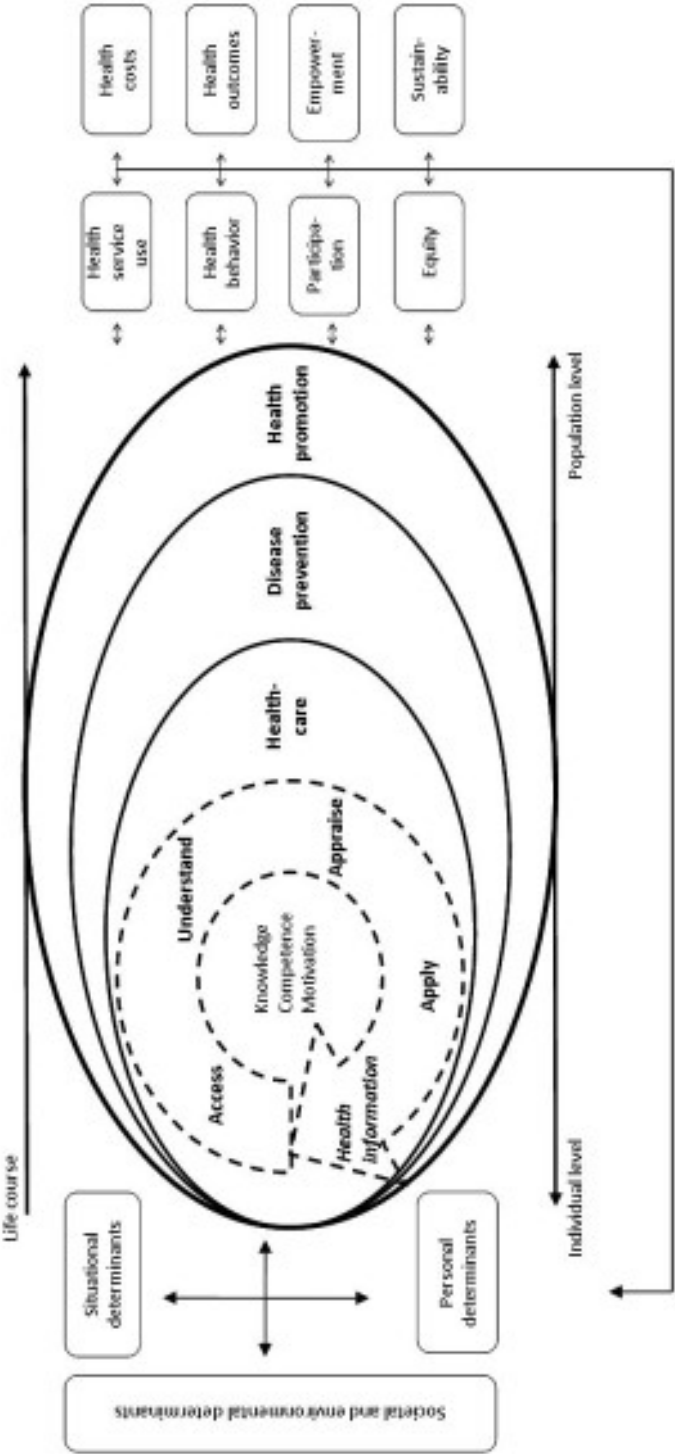


Figure 1.3. HLS-EU Conceptual Model of Health Literacy (49)





## **1.7 Chronic Conditions**

Chronic conditions have been defined as “illnesses that are prolonged in duration, do not often resolve spontaneously, and are rarely cured completely” (51)(p5). This includes a large number of different conditions, including chronic heart disease which affects 1 in 4 men aged 75 and over (52). Hypertension is another prevalent chronic health condition with approximately 2 in 3 men and 3 in 4 women having the condition by the age of 75 years. Common to all these conditions, as the definition would suggest, is the need for continued input and management. The Department of Health’s “Long Term Conditions Compendium of Information” (53) reports that 58% of people over 60 have at least one long term condition. There is also evidence that the prevalence of several common conditions has increased with an 11% increase in hypertension sufferers and a 45% increase in chronic kidney disease between 2006-7 and 2010-11. The report also highlights how people with long term conditions are more intensive users of the health service with particularly greater use of the most expensive services. This is reflected in the average health and social care cost per person per year. People with no long term conditions (LTC) have an average yearly cost of £1,000 per person. People with one LTC have an annual cost of £3,000/person, people with two LTCs have an annual cost of £6,000/person, and those with three or more LTCs having an average annual cost of just under £8,000/person. When looking at service usage, people with LTCs consume 50% of all GP appointments, 64% of outpatient appointments, 70% of all inpatient bed days, and 70% of all health spending in England. As life expectancy increases

and the population ages, the number of people with multiple LTCs is projected to increase to approximately 2.9 million in 2018 (4.4% of projected population (54)) from 1.9 million in 2008 (3.1% of population).

**Table 1.2 Use of NHS Resources by Number of Long Term Conditions**

Number of LTCs	Average annual health and social care cost (per person)	Percentage of GP appointments	Percentage of outpatient appointments	Percentage of inpatient beds used	Percentage of health spending
0	£1,000				
1	£3,000	50%	64%	70%	70%
2	£6,000				
3	£8,000				

### **1.8 Links between Health Literacy and Chronic Conditions**

With such a burden on the healthcare system there is a growing body of research looking into the impact of health literacy on chronic conditions. As discussed above, inadequate health literacy has been linked with poorer knowledge of chronic conditions. Research has, however, also looked at the effect of health

literacy on specific chronic conditions outcomes. Particular interest has focused on diabetes management and outcomes. Schillinger et al (55) examined the association between health literacy and diabetes outcomes. They performed a cross-sectional observational study of 408 people with diabetes looking at health literacy, measured by s-TOFHLA score, and most recent HbA<sub>1c</sub>. They also measured self-reported diabetes complications. Their analysis showed that there was a significant increase in HbA<sub>1c</sub> with lower scores on the s-TOFHLA and that patients with inadequate health literacy were less likely to achieve tight glycaemic control (adjusted odds ratio, 0.57; 95% confidence interval: 0.32-1.00; p=0.05). They were also more likely to have poor glycaemic control, defined as HbA<sub>1c</sub>≥9.5% (adjusted odds ratio, 2.03; 95% confidence interval: 1.11-3.73; p=0.02). Finally they found that people with inadequate health literacy were more likely to report having retinopathy, a serious complication of diabetes (adjusted odds ratio, 2.33; 95% confidence interval: 1.19-4.57; P=0.01). Similarly Powell et al assessed the link between health literacy and HbA<sub>1c</sub> as well as diabetes knowledge. They too found that people with lower literacy levels had higher HbA<sub>1c</sub> levels and also had lower scores on the Diabetes Knowledge Test (56) (56).

Assessment of other chronic conditions has occurred which has shown that low health literacy has been associated with poor self-care. Kalichman et al (57) assessed medication adherence in HIV-seropositive men and women (n=182). They found that health literacy significantly and independently predicts 2-day treatment adherence. This group were also more likely to miss treatment doses. These findings were seen again in further work by Osborn et al (58) in 2007 who

found that literacy was a significant independent predictor of non-adherence (adjusted odds ratio=2.12, 95% confidence interval= 1.93-2.32).

Research by Williams et al. (20) looked into the effects of health literacy on asthma self-care. Their cross-sectional survey looked at self-management in terms of ability to use a metered dose inhaler (MDI). They assessed how many of the 6 required steps could be done correctly and found that reading level, as assessed by REALM, was strongly correlated to the number of steps performed correctly ( $p<0.01$ ).

## **1.9 Summary**

Health literacy is an expanding area of health research that is providing fundamental knowledge about the challenges people have with understanding their health and consequently how best to assess and manage it over time. Moreover, the current evidence seems to suggest that health literacy has a vital role to play in the management of general and chronic health problems. This is likely to occur through influences on numerous personal and service factors that link health literacy to health outcomes. With an ageing population and an increasing number of people living with chronic conditions the need to optimize health and health outcomes is becoming more and more important. Failure to address issues in health management will result in greater levels of morbidity and mortality and increased cost of care for both patients and health services.

At present there is a gap in the knowledge of what factors determine health outcomes and the impact health literacy has on these factors. Further work is required to address these discrepancies so that health services and policy makers can produce plans to combat the negative outcomes that have been documented. The next chapter will present a systematic review that looked to identify the current evidence surrounding the intermediate steps linking health literacy to health outcomes. After the level of the current evidence was assessed a qualitative study was performed which will be outlined in Chapter Three. The findings from this study will be presented in Chapter Four with discussion and conclusions being presented in Chapter Five.

## 2 Chapter Two: Systematic Review

### 2.1 Introduction

Chapter One outlined how the field of health literacy has developed and evolved. Clear evidence has been presented that demonstrates how people with limited health literacy suffer from negative health outcomes and encounter greater difficulties in managing healthcare issues. As was also mentioned, there has been some research exploring the pathways that link health literacy to health outcomes. However, despite this, there is still a dearth of convincing evidence to support the proposed mediating factors. This chapter will, therefore, describe a systematic review performed with the intention of identifying the evidence for some of the proposed mediating factors discussed in Chapter One.

### 2.2 Identifying the Mediating Factors to Review

Mediating factors to explore in this review were identified from the causal model described in Chapter One developed by Paasche-Orlow and Wolf (2007), see Figure 1.2. This causal model was used instead of the ones proposed by Berkman et al. (2) or Sorensen et al, (49) as this will build on previously published research examining this model (59). The decision was made to focus the systematic review on a limited number of these factors in order to allow a more detailed analysis within the time constraints of the project. Some of the factors have also already been assessed through research such as that done by Berkman et al. described previously (2). It was therefore decided that the

systematic review described in this chapter would focus on previously un-assessed factors from within the three core areas described within the Paasche-Orlow and Wolf causal model (Access and Utilization of Health Care, Provider-Patient Interaction, and Self Care).

### 2.2.1 Access and Utilization of Health Care

Access and Utilization of Health Care was partially assessed by Berkman et al (2011) who reviewed the evidence surrounding the use of health care services and health literacy. They found five studies that supported increased hospitalisation and nine studies that demonstrated greater emergency care use in people with lower health literacy. They did not, however, assess the use of primary care services despite this being the area of healthcare with the greatest number of clinical contacts. This may be due to the fact that the studies were done in the US where primary care is very different to that found in the UK. In the UK in 2012/13 there were 15.1 million hospital admissions (60) and 21.7 million accident and emergency department attendances (61). In comparison, in 2013 there were 340 million general practice consultations (62). With over nine times the number of patient contacts, primary care is the main point of contact between doctors and patients in the UK. One of the functions of primary care is preventative medicine with the aim to reduce the need for referral to secondary care. Work has shown that primary care helps prevent illness and death and, in comparison to specialty care, is associated with a more equitable distribution of health in populations (63). It is important, therefore, to determine if people with inadequate health literacy have difficulty accessing primary care. Not only would this be an important area for possible intervention but it could also explain some

of the increased use of emergency departments and hospitalisation seen in other studies. Research conducted by Ionescu-Ittu et al (64) found that having a primary care physician was associated with decreased emergency department use by older people. For these reasons the evidence for the impact of health literacy on access to primary care will be assessed in the review.

### 2.2.2 Provider-Patient Interactions (Attitudes)

On reviewing the factors described in this section of the Paasche-Orlow and Wolf model it was decided that patient attitudes appeared to allow an assessment of both patient beliefs and patient participation in decision making. An attitude is “a relatively enduring organization of beliefs, feelings, and behavioural tendencies towards socially significant objects, groups, events or symbols” (65)(p150) . Identifying work that investigates patient attitudes, therefore, should provide an insight into both the beliefs and tendencies of patients which Paasche-Orlow and Wolf suggested may be implicit in the pathway between health literacy and health outcomes.

It has been suggested that there is a hierarchical relationship between attitudes and beliefs with the latter being a narrower, more specific aspect of attitudes (66). This way of considering attitudes and beliefs suggests they vary not by definition but more by specificity. As ‘Attitudes’ covers a wider range of factors, including tendencies, it was decided that this was a better factor to review. For these reasons the term attitude will be used from this point on in this thesis instead of beliefs.



### 2.2.3 Self Care (Motivation)

Research by the Department of Health (67) demonstrated a strong link between different attitudes and motivations to health. One example of this was that individuals that held fatalistic notions (or beliefs) about their health were less likely to engage with health behaviours and tended to hold negative perceptions of a healthy lifestyle (67). Consequently motivation was chosen as an appropriate factor from the 'Self Care Box' of the Paasche-Orlow and Wolf model to investigate in the systematic review.

### 2.2.4 Self Efficacy

Self efficacy was a factor identified by Paasche-Orlow and Wolf in the Self Care Section of their proposed causal model. It has been reviewed previously by Berkman et al but it was decided to include this in the systematic review as it has strong links with attitudes and motivation. Self-efficacy was first described by Albert Bandura (1998) as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives." (68)(p71) He discussed how self-efficacy is implicit in how we act in many varied situations and how it impacts on motivation. The theory suggests that those individuals with a high degree of self-efficacy see personal challenges as tasks to be mastered. People who lack self-efficacy or perceive poor personal self-efficacy view difficult tasks as "personal threats. They have low aspirations and weak commitment to the goals they choose to pursue."(p71) Bandura also postulates that this group of people will tend to dwell on their deficiencies, barriers to achieving a goal, and a multitude of adverse events rather than

focusing on the task in hand. People with poor self-efficacy are slow to recover and quick to give up.

Bandura further discusses the role of self-efficacy in motivation. He discusses three different forms of cognitive motivators involved in the motivational process. These are causal attributions, outcome expectancies, and cognized goals and self-efficacy is involved in all three of these motivators. The cognitive processes surrounding human functioning are clearly impacted by perceived self-efficacy and indeed those with higher levels set higher goals and are more committed to achieving them.

Due to this relationship between self efficacy and both attitudes and motivation, which have already been identified as factors to be reviewed, self efficacy will also be investigated as part of the systematic review

## **2.3 Search Strategy**

The systematic review aimed to identify research papers relating to patient attitudes, motivation and access to care in relation to patient health literacy. An example of the search terms used is shown in Box 1. This is not an exhaustive list. The format of the terms used differed between databases due to the differences in terminology adopted by the databases themselves.

**Box 2.1: Example of search terms used**

"Health Literacy"
Health adj2 literacy
"Educational Attainment"
TOFHLA
"Test of Functional Health Literacy in Adults"
REALM
"Rapid Estimate of Adult Literacy in Medicine"
Elderly
Aged
Attitude
Motivation
Access adj2 healthcare
"Family practice" AND access

Electronic searches were performed on ERIC, PsychINFO, CINAHL, EMBASE, and MEDLINE with references being uploaded to RefWorks, an online reference management system.

**2.3.1 Inclusion and Exclusion criteria**

Inclusion and exclusion criteria were developed a priori to assist in the initial selection of papers. A list of these can be seen in Box 2. These criteria were applied to all the titles and those that failed to meet the criteria were excluded. The abstracts of the remaining papers were then reviewed with the same criteria to identify the papers that would continue to full review

## Box 2.2. Inclusion and Exclusion Criteria

<b>Inclusion Criteria</b>
<b>Population Factors</b>
All races, ethnicities and cultural groups
Adults (>18 years)
Validated measure of Health Literacy, literacy or numeracy
Studies in the developed world
<b>Time Scale</b>
1980-November 2014
<b>Publication Criteria</b>
Published Studies
Full text available
English Language

<b>Exclusion Criteria</b>
Case Reports
No original data (including reviews)
Studies of patients with mental health issues

Papers were only included if they focused on adult populations (18 years and older). It was felt that people under 18 years could have unidentified confounders that could influence access to care and attitudes and motivation, such as reliance on parents and parental decision-making on health decisions. This has been discussed in terms of individual development of self efficacy (68). The paper discussed how people acquire and develop their self-efficacy over their lifespan and how children and adolescent self-efficacy develops and the additional considerations and variables in these age groups. Consequently, it was felt that research into the self-efficacy of this group would not offer a reasonable comparison with those of adults. It was decided, however, to include studies that investigated health literacy and variables in parents in relation to the care of their children. This was felt appropriate as it still linked health literacy in an adult with the desired outcomes of access to care, attitudes and motivation.

A second inclusion criteria was studies in developed countries only as defined by the MSCI list of developed countries (69). The rationale behind this was that there are fundamental differences in access to care and health in developing countries compared to developed countries (70).

Studies were searched for that were published between 1980 and November 2014. This was done to limit the papers identified to the most recent available. Papers that included patients with mental health conditions were also excluded as there can often be issues with motivation in these individuals. A common example of this is people with depressive episodes. The Diagnostic and Statistical Manual of Mental Disorders (DSM) (71)(p164) states “many individuals (with

major depressive episodes) report impaired ability to think, concentrate, or make decisions.” This confounding factor in analysis of motivation in association with health literacy means it would be difficult to ascertain the presence, or absence, of a relationship. It is for this reason that these studies have been excluded from this review.

### 2.3.2 Quality Assessment

Once full texts had been identified for review, reference checking was performed on these papers. The final collection of papers was then reviewed again with the aid of a quality assessment tool. The tool used was adapted from a Critical Appraisal Skills Programme (CASP) toolkit. Adjustments were made to fit the purpose of the review. The toolkit also had an additional section to check the presence of acceptable measures of health literacy. Sections looking at types of study were also removed, as we were not focusing on any one type of study (i.e Cohort or case control). A copy of the quality assessment template can be seen in appendix 1.

### 2.3.3 Changes to search terms

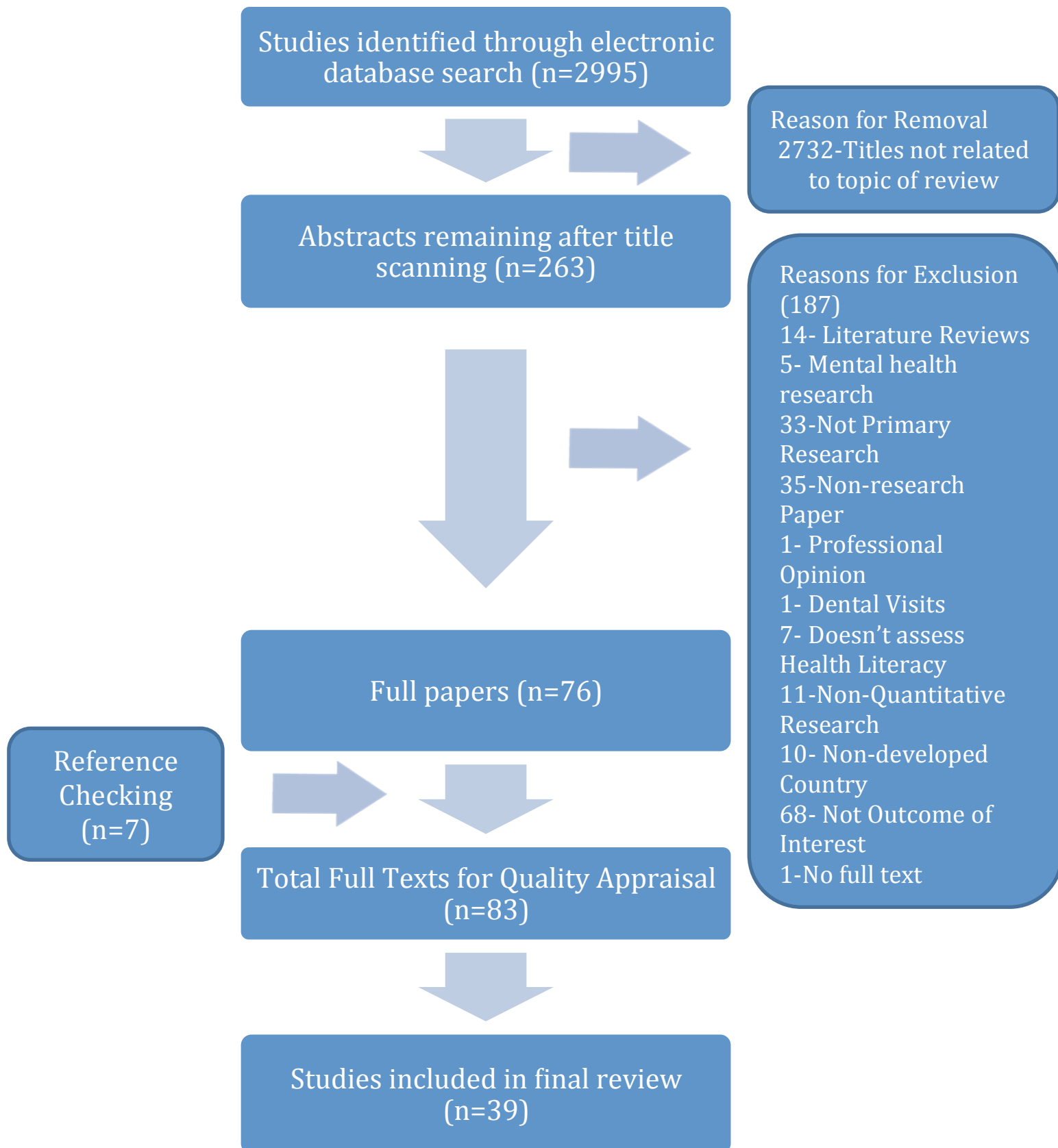
After completion of the initial search and review of the full texts a paper was identified through reference checking that should have been identified by the initial search. This resulted in a review of the search terms used and it was noted that the wording of the terms relating to self-efficacy resulted in the paper being missed. It was therefore decided to revise the search terms and also review the other terms to identify other possible oversights. This resulted in the addition of ‘self-efficacy’ and “self efficacy” as individual terms with the withdrawal of

perceived as a qualifier. The search was then re-run and additional full texts were added to the final review. The flow chart in diagram 2.1 shows the final selection of papers on the second search with inclusion of the new terms for self-efficacy.

## **2.4 Results**

The following section will discuss the findings from the literature review. Figure 2.1 demonstrates the selection process undertaken in the systematic review. 2995 papers were identified on initial searches after removal of duplicates. On reviewing the titles of the papers 2732 papers were removed and a further 187 were excluded on more detailed assessment of the abstracts. Reference checking of the remaining 76 papers identified a further 7 papers all of which were then appraised for quality. This resulted in 39 papers being included in the final review.

**Figure 2.1 Flow Chart of Paper Selection Process**





#### 2.4.1 Access to Primary Care

Seven papers were identified that looked at differences in access to primary care with relation to health literacy. The main outcomes in these studies were whether people could get to see their community physician, how often they had seen him or her, and reported barriers to accessing community healthcare. Five of the papers assessed actual access to community services with one finding a link between this and health literacy and the other four failing to find a significant association.

Schumacher et al (72) interviewed 492 patients attending an emergency department. They assessed health literacy using the rapid estimate of adult literacy in medicine (REALM), scoring patients as either having limited or adequate health literacy. During the interviews they measured self-reported health service use during the preceding 6 months. They found that those with inadequate health literacy were significantly more likely to report never being able to obtain care from a doctor's office or clinic as soon as they felt care was needed (Odds Ratio [OR]= 1.57, 95% Confidence Interval [CI] 1.02-2.43). This would support the theory that patients with low health literacy have difficulty obtaining community care. The other four papers identified, however, produced results that contradicted these findings.

Two papers by Baker et al (73) (74) looked at the use of physician visits and time to first visit after enrolling in a social healthcare programme. They measured health literacy using the short test of functional health literacy in adults (s-TOFHLA). In one of the papers (73) they found no difference in the time until

first physician visit after enrolment between adequate and marginal and adequate and inadequate health literacy groups (Adjusted Odds Ratio [AOR] 0.89, 95% CI: 0.78-1.00,  $p=0.06$  and AOR:0.94, 95% CI:0.84-1.04,  $p=0.22$ ). They also found no difference in number of physician visits. Their other paper (74) was performed over two sites with slightly differing results. Analysis in the Los Angeles site showed no difference in the number of physician visits in the last 3 months whilst in Atlanta they actually found people with inadequate health literacy were more likely than those with adequate literacy to have seen a doctor in the preceding 3 months (69.4% vs. 61.2%;  $p=0.014$ ). Both these papers showed no evidence of increased difficulty in accessing care and if anything could suggest an increased use of primary care services in those with lower health literacy.

The other two papers by Hardie et al (75) and Tecu et al (76) similarly found no evidence to support difficulties in accessing primary care services for those with low health literacy. Hardie et al found that office visits were similar across health literacy groups. Tecu et al looked at the time between first noticing symptoms of cervical cancer and presentation to a doctor and again found no difference between literacy groups. This again suggests that there is no difference in difficulties in accessing community services.

Two of the papers focusing on access to care looked at barriers to accessing care services. These both found that patients with lower literacy perceived greater barriers to healthcare. Mancuso et al (77) performed a cross-sectional study measuring health literacy, using the test of functional health literacy in adults

(TOFHLA), and its associations with asthma patients' assessments of care. In their analysis they found that people with marginal or inadequate health literacy were more likely to report difficulty accessing care for non-asthma medical conditions. It should be noted, however, that after correspondence with the author there were no limits in this study on the type of care accessed and therefore these results do not solely reflect primary care access. Meanwhile Yin et al (78) looked at the beliefs of adults with regards to the care of their children. They assessed health literacy using s-TOFHLA and interviewed 823 parents asking about perceived barriers to care. They found that parents with low health literacy were more likely to perceive barriers to care including trouble reaching their care provider at nights or at the weekend 64.9% vs. 49.6%, ( $p < 0.001$ , AOR: 1.7, 95% CI 1.2-2.4) and difficulty in traveling to their child's primary care centre 15.3% vs 8% ( $p = 0.004$ , AOR 1.8 95% CI 1.1-3.0).

In summary seven papers were identified that focused on the role of health literacy in access to care. There was no conclusive evidence to support the hypothesis that patients with low health literacy struggle to access primary care services. It should be noted, however, that all of the studies were based in US where there are fundamental differences in healthcare. Four of the five papers that assessed actual access to care used physician contact as their outcome measure. This includes all appointments outside of the secondary care setting and so includes specialist advice, which can be accessed in US without the need to see a primary care physician. As has been discussed previously the context of the healthcare system itself is important in health literacy and it must be considered that system factors present in US are likely to be different from those

in other countries, including the United Kingdom. We can conclude that there is limited evidence to support poorer access to primary care in people with low health literacy but this may be due to insufficient evidence or system factors in the country of research.

With regards to patient perceived barriers to accessing healthcare there is more, but still limited, evidence to support a higher perception of barriers. Both (77) (78) studies identified supported this hypothesis.

#### 2.4.2 Patient Attitudes

Papers that looked specifically at patient beliefs including perceived susceptibility, severity, seriousness of disease and perceived barriers and benefits to treatment and management will be discussed next. There were several measures used to assess these variables including patient fatalism. This has been described as “an attitude of resignation in the face of some future event or events which are thought to be inevitable (79).” There were two papers that looked at this outcome and interestingly they interpreted them differently, with one discussing fatalistic views on cancer and cancer prevention whilst the other using it as a measure of motivation. This again highlights one of the issues of the systematic review as different measures were used when investigating the same outcomes, and some measures were used to investigate different outcomes. This makes comparison of papers more difficult and questions the accuracy of conclusions drawn from this review.

Five papers looked at outcomes relevant to perceived susceptibility. Two showed evidence that people with lower health literacy had higher perceived risk scores. Morris et al (80) looked at the attitudes and beliefs of 1,013 participants of whom 111 (10.3%) were classified as having low health literacy (Cancer Message Literacy Test-Reading and Listening). They explored risk vulnerability by asking how strongly they agreed with the statement “I have very little control over risks to my health”. They also assessed cancer fatalism, which consisted of responses to three questions on attitudes to getting cancer. They found that those participants with low health literacy had more fatalistic views on cancer and cancer prevention ( $p < 0.01$ ) and that they felt they had less control over risks to their health ( $p < 0.001$ ). This was in keeping with the findings of Brewer et al (81) who presented 163 female breast cancer survivors with hypothetical risk results for genomic tests and asked them to estimate risk of recurrence. They found that those participants with lower health literacy (REALM) gave higher mean estimates of recurrence risk ( $p < 0.001$ ). In contrast to these studies, published work by Peterson et al (21) and Guerra et al (82) showed no association between health literacy (REALM AND S-TOFHLA respectively) and perceived susceptibility (risk) of colorectal cancer. The remaining paper by Dolan et al (83) found that people with limited literacy (REALM) were more likely to believe they were at average-to-high risk of developing colorectal cancer. This suggests that those individuals with lower health literacy had a greater susceptibility to cancer irrespective of previous history cancer history. It is also possible that those with low health literacy have less positive views on cancer prevention, which could impact on participation in screening and avoidance of risky behaviours.

Four papers looked at perceived seriousness. Guerra et al (82) found that when they assessed attitudes and beliefs to colorectal cancer screening there was no difference in perceived seriousness of colorectal cancer between different literacy groups (S-TOFHLA) with most believing that it is harmful ( $p=0.94$ ). In the 2004 paper by Dolan et al (83) also found that there was no difference in perceived severity of colorectal cancer. Questions must be asked about the investigation of perceived severity with regards to cancer. Cancer is a well publicised condition with a large amount of public interest and a clear message of severity. It may be better to assess perceived seriousness in other, less commonly publicised conditions which are less commonly viewed as potentially fatal. The other two papers did look at an alternative condition by assessing asthma beliefs. Both papers were published by Federman et al (84) (85) and looked at the beliefs of asthma patients aged over 50 years and 60 years respectively. They found that those patients with inadequate health literacy (S-TOFHLA) were more likely to have suboptimal health beliefs including the belief that having no symptoms meant having no asthma, that asthma can be cured, and that medication work better if not used all of the time. These findings suggest that those individuals with inadequate health literacy saw their condition as less serious than it actually is.

Perceived barriers and benefits were assessed in eight studies. Three of these looked principally at medication beliefs. Aikens and Piette (86) assessed the beliefs about necessity and harmfulness of people taking antihyperglycaemic ( $n=803$ ) and antihypertensive ( $n=573$ ) medication. They found that there was

no significant association between health literacy and necessity of either type of medication but that those with lower health literacy had greater concern over harmfulness of both types of medication. These findings suggest no evidence for a difference in perceived benefit but a greater perceived barrier to taking the medication, in the form of perceived harmfulness. These findings were echoed in work by Federman et al (85) which also looked at asthma medication beliefs (n=420). They also found that patients with lower health literacy had greater concern over medication use but they did recognise the necessity of the medication, again demonstrating the presence of perceived barriers but no lack of perceived benefit to treatment. These findings were not replicated by work published by Shone et al (87) in 2009. This work again looked at medication beliefs of parents (n=499) of children with asthma. This study found that parents with low health literacy (REALM) had lower treatment expectations but had higher perceived need for medication and there was no difference in concerns over medications ( $p=0.84$ ). Again there is conflicting evidence in this field. Much like the work of Pulgaron et al discussed earlier into self-efficacy questions the comparability of assessment of attitudes in an individual and in a carer or parent as both of these studies have conflicted with the hypothesised associations. Clearly more research is needed to determine if this is true.

Five of the studies assessed cancer related beliefs into perceived barriers and benefits of healthcare (22) (82) (88) (21) (83). They looked at perceived benefits and barriers to screening of colorectal cancer and mammography. Three of the papers found no association between perceived barriers and health literacy in multivariate analysis. Peterson et al (21), however, found that people with

limited literacy (REALM) did perceive more barriers to FOBT ( $p<0.001$ ) and colonoscopy ( $p=0.009$ ). In 2004, Dolan et al (83) found that those with limited literacy (REALM) were more likely to perceive FOBT as too embarrassing and were more worried that FOBT is inconvenient. They also found that patients with limited literacy were more likely to put off having a flexible sigmoidoscopy ( $p=0.007$ ). Two of the studies looked at the participants perceived benefits of screening for colorectal cancer with Peterson et al finding no association between health literacy and perceived benefits of screening, while Arnold et al found those with low literacy (REALM) were less likely to believe colorectal cancer screening was very helpful in finding colorectal cancer early (74.5% vs. 91.9%,  $p<0.0001$ ) and also less likely to believe having a FOBT would decrease their chances of dying from colorectal cancer (77.1% vs. 83.7%,  $p=0.0156$ ). This is an interesting finding with regards public health. As has been discussed above cancer is a well publicised condition with screening programmes to detect early breast, cervix, and bowel cancer (89). It is concerning that this study would appear to suggest a lack of confidence in bowel screening in those individuals with low literacy. Work is needed, therefore, to determine if this link is consistent and how belief in screening programmes can be improved.

In summary there were twelve papers that looked at the impact of health literacy on different components of patient beliefs and perceptions (Perceived Susceptibility, Perceived Seriousness, Perceived Barriers and Benefits, Cancer Related Beliefs). There were five papers that looked at perceived susceptibility. Three of these showed a possible relationship between low health literacy and higher perceived risk. Two, papers, however, showed no association. There were



four papers that assessed perceived seriousness of conditions. Two of these looked at cancer and found no difference between health literacy groups. This may be due to a general understanding of the seriousness of such conditions. The other two papers that looked at perceived seriousness focused on asthma. These papers did suggest that those with lower health literacy perceived asthma to be less serious. It is interesting to compare the research into these two different conditions as the findings may suggest that public education, through awareness programmes and advertisement, can overcome possible discrepancies in perceived seriousness in conditions.

Eight of the studies looked at perceived barriers and benefits. Of the three that looked predominantly at medication beliefs, they all found that health literacy did not affect individual's attitude towards necessity of medication. There was some suggestion, however, that people with lower health literacy had greater concerns over potential harm from medication. Five of the studies looked at perceived barriers and benefits with regards to cancer. There was limited evidence to support health literacy had much impact, however, two of the studies did find that people with lower health literacy perceived more barriers to undertaking cancer screening.

#### 2.4.3 Motivation

Finally the evidence concerning patient motivation will be discussed. Six papers were identified that assessed the role of health literacy in relation to motivation. Results were again equally split between those that demonstrated no association between the two variables and an association between higher literacy and higher

motivation and activation. Three papers that found an association between activation and health literacy all used the same outcome measure and similar measures of health literacy. Lubetkin et al (90), Smith et al (91), and Greene et al (92) all measured Patient Activation Measure (PAM) on their participants. "Patient activation is a behavioural concept. It captures a number of core components of patient involvement, each of which is important for active engagement and participation" (93) (p7). The PAM was developed in 2004 by Hibbard et al (94) and received further validation by Fowles et al (95) in 2009. The higher the score achieved the higher the activation for the person.

Three studies assessed patient motivation using PAM and all three of the studies found that health literacy was linked to patient activation and that those with adequate health literacy were more activated than those with low literacy. In the other studies Vassy et al (96) measured motivation by recording their responses to different hypothetical genetic risk results. They found low literacy (REALM) patients described higher motivation to change in response to low risk results and no difference in motivation between groups in response to high-risk results. Whether this represents an inappropriate motivation to low risk groups or simply no link is hard to determine. Equally the results of this study must be interpreted carefully as there were only 14 participants with low health literacy out of the 174 participants (8.0%). Osborn et al (97) used diabetes fatalism as their measure of motivation and found no link between it and health literacy (REALM). As previously discussed the interpretation of fatalism is debatable and whether it is a measure of motivation or not must be considered when reviewing the literature. Powe and Weinrich defines fatalism as " a complex psychological

cycle characterized by the perceptions of despair, hopelessness, worthlessness, meaningless, powerlessness, and social despair.” (98) This would seem to include aspects related to motivation such as powerlessness, however the fact that this definition also covers despair and worthlessness would suggest it would be useful to determine concurrent depressive symptoms to exclude depression as a confounder in the analysis. As discussed earlier, papers that failed to exclude participants who suffered from mental health problems were excluded from the study. A primary reason for this is that feelings of worthlessness and lack of motivation are common symptoms in depression, and it would be sensible in all assessments of motivation to exclude depression from the analysis to more accurately reflect the relationship between health literacy and motivation. Finally the 2007 paper from Powell et al (99) used the Diabetes Health Belief Model (DHBM) scale based on the Health Belief Model to determining readiness to take action. When analysed against REALM score they found that there was no significant association between health literacy and DHBM scale score ( $p=0.30$ ).

#### 2.4.4 Self Efficacy

As discussed in section 2.2 self-efficacy refers to an individual’s perceived ability to perform an action. In total eighteen papers were identified that investigated this possible positive link between health literacy and self efficacy. Eight of these papers supported the hypothesis of a link, with nine demonstrating no evidence of an association and one paper finding the reverse with greater self-efficacy with lower health literacy.

One of the first papers to look at the relationship between health literacy and self-efficacy was published in 2007 by Peterson et al (21). They interviewed 99 people and performed a health literacy assessment using the REALM tool. Patients were asked questions about colorectal cancer (CRC) screening. They found that in their sample there was no association between health literacy and self-efficacy to complete a Faecal Occult Blood Test (FOBT) or undergo a colonoscopy. Further studies have looked at health literacy and self-efficacy in the field of colorectal cancer screening. In 2009 Von Wagner et al (100) also assessed self-efficacy for participating in colorectal cancer screening with relation to health literacy level as measured by the UK version of TOFHLA (UK-TOFHLA). In contrast to Peterson et al's study, they found that those patients with lower health literacy had less self-efficacy for CRC screening ( $b=0.61$ , 95% CI: 0.09-0.131) when asked questions such as "If I received the FOB test, I would feel able to complete it" with answers on a 5-point scale. A third paper published by Arnold et al (22) found mixed results for associations between health literacy and self-efficacy. They measured REALM in 975 patients in eight health centres. They asked patients if they were confident in obtaining an FOBT kit, in completing a FOBT kit at home and in returning the test. They found that health literacy was significantly associated with confidence in obtaining a kit in multivariate analysis ( $p=0.04$ ) but not with the other two questions and that generally self-efficacy in both literacy groups was high.

When considering the current evidence of self-efficacy for CRC screening it is clear the evidence is inconsistent. One of the problems with self-efficacy is that an individual will likely not have a single level of self-efficacy as this will be

different for different tasks. As can be seen in the work by Arnold et al (22) the scores for self efficacy for both literacy groups (REALM) was high. A failure to demonstrate a link between health literacy and self efficacy may, therefore, be due to an overall high level of self efficacy for certain health problems. The papers that have been discussed look at self efficacy related to cancer screening which is a process that has a high level of support from healthcare organizations. There is also a lot of media attention surrounding these problems and people are also called for screening reducing the necessary skills required by the participant. These factors may lead to higher levels of self-efficacy but not truly assess the general health related self efficacy levels of participants.

Of the remaining papers, six looked at self-efficacy in the context of diabetes. Evidence was split with three papers showing evidence of an association with health literacy and three showing no link. Three of the papers used the same variable measure for self-efficacy with the use of the Perceived Diabetes Self Management Scale (PDSMS), although measures of health literacy varied. Osborn et al (101) found that when they measured self-efficacy in a group of 398 diabetic patients, both health literacy (REALM) and patient numeracy were associated with diabetes self-efficacy ( $r=0.14$ ,  $p<0.01$  and  $r=0.17$ ,  $p<0.001$  respectively) although when both combined in the same study only numeracy remained significant ( $r=0.13$ ,  $p<0.05$ ). The 2008 paper by Cavanaugh et al (102) had previously also found that people with higher diabetes related numeracy were more likely to have greater perceived efficacy for diabetes self management. This conflicts with data from the final study by Pulgaron et al (103), which compared parental numeracy ability with their perceived self-

efficacy for their child's diabetes management. They found that there was no correlation between numeracy and perceived self-efficacy. This may draw into question whether personal self-efficacy or self-efficacy for others are comparable although there is insufficient data to draw a conclusion on this.

Papers by DeWalt et al (104) and McCleary-Jones (105) found no evidence of an association between health literacy (REALM) and self-efficacy. The final paper discussing diabetes related self-efficacy by Inoue et al (106) compared this to three different types of health literacy: functional, communicative, and critical. They found that there was a significant association between self-efficacy and both communicative and critical health literacy ( $\beta = 0.365, 0.369$  respectively,  $p < 0.001$ ) but not functional health literacy. This is an interesting assessment of associations between different types of health literacy as discussed in Chapter One. It may be that the more complex forms of literacy, and in this study the mean scores for functional health literacy were highest and for critical health literacy lowest, are better assessments for predictors of poor self-efficacy.

One paper by Osborn et al (59) looked to link health literacy to behaviour and health status and provided evidence for the conceptual causal model linking health literacy to health proposed by Paasche-Orlow and Wolf (107). In this study they asked patients about self-efficacy to manage high blood pressure but found no significant association with health literacy (S-TOFHLA). No link between health literacy (Cancer Message Literacy Test-Listening) and self-

efficacy, in this case in terms of obtaining medical information, was found in a 2013 paper by Morris et al (80).

Reported self-efficacy regarding hormone therapy in post-menopausal women was investigated by Torres and Marks (108) in 2009. They found a significant positive relationship between health literacy, measured using sTOFHLA and self-efficacy ( $r=0.69$ ,  $p\leq 0.01$ ). Further positive correlation between health literacy and self-efficacy was identified by Donovan-Kicken et al (109) when they interviewed 254 people with the intent to determine if, among other outcomes, health literacy correlates with self-efficacy. They asked participants to self-report the potential hazards of a medical procedure and make an informed decision. When comparing these responses in association with scores from the Newest Vital Sign (NVS) test of health literacy they found that health literacy predicted self-efficacy with higher health literacy being associated with higher self-efficacy. Similar results were seen in the 2011 Macabasco-O'Connell et al (110) paper into self-efficacy to manage heart failure. They found that individuals with adequate literacy had higher self-efficacy ( $p<0.01$ ).

The results above are consistent, however two papers looked at patient self-efficacy for medication taking and showed mixed results. Colbert et al. (111) looked at medication self-efficacy in HIV/AIDS and found that there was no link to functional health literacy, although the sample investigated were found to have a relatively small number of people with lower health literacy (9.9%). In contrast Wolf et al (112) found that patients with lower literacy (REALM) were more likely to report lower self-efficacy for taking their medications as

prescribed. This contradicts the work by Colbert et al and it is important to note that when comparing the two studies the latter had a far greater proportion of people with lower health literacy with 11.3% having low literacy and 20.1% scoring marginal literacy.

Work published by Dominick et al in 2012 (113) looked to explore the influence of health literacy (S-TOFHLA) on changes in physical activity self-efficacy. As part of their analysis they assessed self-efficacy at baseline and found that patients with higher health literacy actually had lower reported self-efficacy. This finding is in complete contrast to the other papers which have shown either a positive correlation or no association. One of the reasons why this may differ from other pieces of work include the fact that the study is investigating a Latina population. Assessment of the social norms of different cultures would be important to determine if studies of different populations can be compared or if there are fundamental differences in the beliefs and norms of the groups. Similar work by Ussher et al (114) assessed self-efficacy by asking participants to rate their confidence in five questions regarding managing treatments. When they were adjusted for ethnicity, gender, age, and education, none of the variables remained significant.

In conclusion, there is a growing body of work surrounding the role of health literacy in patient self-efficacy. The current evidence has explored a broad range of skills and the results have been mixed. There is convincing evidence of links between limited health literacy and reported self-efficacy but these findings have so far been inconsistent. As with other areas of health literacy research,



questions must be asked over the comparability of the different studies that use differing measures of health literacy. Care also has to be taken when comparing, different studies surrounding self-efficacy as patients reported self-efficacy will vary depending on the task in hand and condition in question. An example of this could be someone who is confident with undertaking colorectal cancer screening but not with the management of living with a diagnosis. Conclusions from these studies must, therefore, be taken cautiously but do suggest that health literacy does impact on certain areas of self-efficacy.

In summary, the evidence available for links between health literacy and measures of patient attitudes and motivation are inconsistent. There are several studies that have shown statistically significant evidence of associations with the variables previously described but these are balanced against a similar number of studies that fail to show a significant association. Interpretation and comparison of the data is troublesome due to the varied measures of outcomes with several cases of more consistent association demonstrated when the same outcome measures are used.

## **2.5 Conclusion**

There is an increasing body of research that examines the role of health literacy on health outcomes with a focus on the possible mediators in the causal pathway between them. Research has looked to investigate associations with patient access, attitudes and motivation but have found inconsistent evidence to link health literacy with any of these variables. Even when we compare studies on

more specific outcome measures, such as self-efficacy and perceived barriers, there is limited evidence to confidently propose a causal pathway. Despite the lack of convincing evidence found there are sufficient papers reporting statistically significant results to give credibility to their proposed role in the linking of health literacy to health outcomes. There are several possible reasons why there have not been more consistent results supporting the hypothesis that health literacy is linked with measures of attitude, motivation, and access to primary care.

Firstly the measure of health literacy must be consistent. The studies reviewed use several different tools that varied in the skills that they tested. These ranged from assessment tools that focus solely on reading comprehension, to tools that look to assess an individual's ability to use their skills in a medical context, such as the Newest Vital Sign. The study by Inoue et al (2013) is an example of the importance of this. They demonstrated both statistically significant and non-statistically significant associations with self-efficacy when using different measures of health literacy. This builds on concerns raised in Chapter One about the quality of tools to measure health literacy. That two different results can be found when analysing associations using two validated assessment tools, suggests that at least one of them fails to assess the varied skills involved in health literacy. This raises concerns over the use of purely quantitative measures in the research of health literacy. Given the complexity of health literacy a more nuanced, mixed-methods approach might be more appropriate in future research (115).

Secondly the outcome measures used in research should be standardised where possible. This review found evidence of similar measures being used to assess different intended outcomes. For example, fatalism was used to assess two different outcomes in the papers identified. In one study, fatalism was used to investigate patients' perceived control over the outcome of cancer. In another study it was used as a measure of patient activation and motivation. As we have seen in section 2.2 of this chapter the terminology surrounding issues of attitudes and motivation are complex. It is important, therefore, that researchers are clear in their language and look to be consistent not only throughout their work but with work within the same field.

Thirdly, the understanding of the factors that mediate health outcomes, irrespective of the influence of health literacy, is poorly understood. Without knowing which factors affect health outcomes in the general population, assessing the impact of health literacy on possible mediating factors is pointless as it is not possible to conclude that any of the findings actually influences health outcomes. There is a gap in the current knowledge to explain these factors and more work needs to be done in this area to identify these and then the subsequent impact health literacy has on them.

## **2.6 Summary**

This chapter described a systematic review into four proposed mediating factors linking health literacy to outcomes. Despite a thorough review it is clear that there remains limited and inconclusive evidence to produce models to predict

the pathways by which health literacy impacts on health outcomes. More work is needed on this theoretical understanding so that research can be focused appropriately. The following chapter will describe a qualitative study that was undertaken to try and provide greater knowledge on the factors involved in the formation of health outcomes in older people and the impact health literacy has on them.

## **Chapter Three: Qualitative Study: Methods**

### **3.1 Introduction**

This chapter outlines the qualitative project undertaken to explore the factors involved in the management of health in older people and the impact of health literacy on these factors. It is intended that the findings from this study will enhance our understanding of what mediates the observed associations between health literacy and outcomes. An explanation will be provided of the methods used including recruitment methods and topic guide.

As has been discussed in Chapter One there is clear evidence supporting an association between limited health literacy and health care and health outcomes in people, particularly in an older population. Examples of this include increased rates of hospitalisation (40), and increased overall mortality (116). We have also seen suggested logic models that have tried to describe the factors that explain the association between health literacy and outcomes. We saw in Chapter Two, however, that there is still a lack of convincing evidence to validate these models, with inconsistent evidence linking health literacy with patient access, attitudes, and motivation. It is therefore important that work is done to further investigate how we can improve our understanding of the role that health literacy has in the determination of peoples' health outcomes.

### **3.2 Study Aims**

To explore the views and experiences of older people of their chronic health care management.

Objectives of this study are to understand:

1. The experiences of older peoples' access to healthcare
2. Older peoples' experiences and attitudes to the management of health problems
3. Older peoples' attitudes and how these are influenced by early life experiences
4. The barriers older people perceive that prevent them from obtaining healthcare
5. The views of older people on health problems in later life

### **3.3 Qualitative Research**

A major challenge is identifying how best to enhance our understanding of health literacy. Qualitative research aims to investigate social phenomena as well as being helpful in the study of human and social experience, expectations, attitudes and processes (117). Qualitative research has been used to understand human experience with papers looking at motivation (118), attitudes to drug use (119), and delay in reporting symptoms (120). In contrast to quantitative work, qualitative research does not focus on numbers and proving or disproving theory. The aims of such research is to develop concepts and hypothesis

regarding social phenomena in a natural environment (121) (122). There have been several criticisms of qualitative research. Included in these is that qualitative research is difficult to generalise and difficult to replicate, in large part because of researchers failing to adequately explain their methods and how they have arrived at their results and conclusions (123). This criticism will be reviewed later when discussing the methods of the project.

With qualitative research methods being better suited for both the exploration of the views of groups of individuals as well as the assessment of beliefs and assumptions (124), it is better suited to the proposed research question described here. There will now be a more detailed explanation of how the project will be undertaken. In the following pages I will outline the ontological and epistemological position of the research. The method will then be described which will be used for the study. As was mentioned, a lack of transparency has been a major criticism of qualitative work. By clearly setting out the processes undertaken in the study the work will have far greater transparency which will allow replication of the work and, therefore, improve generalizability

### **3.4 Theoretical Positioning**

When undertaking qualitative research there are several key concepts that the researcher must make clear. The philosophical perspective of the researcher and the way in which knowledge can be legitimately gained will affect the outcome of any work (115). Lincoln and Guba (125) discuss paradigms and the importance of defining these before undertaking investigations. Primarily the

philosophical perspective of the researcher and the way in which knowledge can be legitimately gained need to be discussed as these will affect the outcome of any work (115). Ontology is concerned with the researcher's philosophical perspective on the nature of reality and what is actually thought to exist. Epistemology is concerned with what can be known and how knowledge is generated, and observed. Therefore epistemology describes an individual's position on what can be investigated and involves the impact the observer has on this investigation. The methodological question asks how the inquirer goes about obtaining the knowledge about what they believe to be true. The varying assumptions are encompassed by a spectrum of paradigms from positivism to constructivism.

A positivist paradigm has a realist ontological position. Realism assumes that the world is both "real" and "apprehendable" (125). In other words, realism views entities as truly existing independent from either our perception of them or theories about them. Sim and Wright (115) describe positivism as the existence of a single objective reality which is viewed as the same for everyone, irrespective of personal beliefs, attitudes or perception. Epistemologically positivism has a dualist and objectivist stance meaning that the investigator and the object of interest are independent. The investigator, therefore, has no impact on the object under investigation and so can observe it without fear of researcher bias.

At the other end of the spectrum is constructivism. In a contrast to the views seen in positivist and post-positivist paradigms, constructivism views reality as



being socially constructed and that entities have no absolute truth but are relative to the individual. This form of ontology is known as relativism and “assumes multiple, apprehendable and sometimes conflicting social realities that are the products of human intellects” (125)(p111). With regards to an epistemological position, constructivism views the interaction between the investigator and the object of investigation to be interactive and inextricably linked.

A further explanation of constructivism is given by Michael Patton who explains “because human beings have evolved the capacity to interpret and construct reality the world of human perception is not real in an absolute sense but is ‘made up’ and shaped by cultural and linguistic constructs” (126)(p121). In Chapter Two we looked at both patient attitudes and motivation as possible mediators of the impact of health literacy on outcomes. As has already been stated, the evidence for these concepts is lacking and as such will form some of the basis of investigation. Sociocultural influences have been shown to affect people’s attitudes (127) (128) (129), and are thought to influence motivation (130). Despite obvious benefits of this paradigm there are, however, several critiques of constructivism.

Firstly it is argued that social constructivism has many positions and several definitions of what is meant by both ‘construction’ and ‘social’ (131). There is also the issue that social constructivists believe the only thing worth investigating is how the construction of reality occurs. This fails to assess the consequences of the constructions themselves. In keeping with criticism of

positivist approaches, constructionism is also considered too superficial and non-theoretical in its research methodology (131). Finally, data that is analyzed from a constructionist framework does not allow focus on motivation (132). As a key component of my project this makes constructionism an inappropriate paradigm.

Between these two extreme approaches lies a form of post-positivism called critical realism. Proponents of this viewpoint believe that the world is real but that the social world can not be fully comprehended and this must be taken into account. The primary purpose of enquiry for a critical realist is the investigation of underlying causal mechanisms (133). As such I feel that this philosophical position is one that I identify with the most and is best suited to my research. Having identified my ontological and epistemological standpoint I will now go on to discuss the qualitative analysis that I will use.

Unlike quantitative analysis, there are no clear-cut rules about how qualitative data should be analyzed (123). Several theories about how data should be analyzed have been developed. One that is well suited to my research is thematic analysis. Another commonly used analytical method, thematic analysis is a “rigorous, yet inductive, set of procedures designed to identify and examine themes from textual data in a way that is transparent and credible” (134) (p15). At its core, thematic analysis involves the detailed review of data to identify patterns or themes. It is similar to grounded theory in adopting inductive approach to analysis and development of themes through coding of data. However there is not the necessary pre-requisite for the researcher to suspend

any prior knowledge of the situation under investigation. Another benefit of thematic analysis is that it is very flexible and can be used across a range of theoretical approaches (132). This means that it will adapt well to the theoretical position that we have discussed above.

### **3.5 Background**

#### 3.5.1 Participants

This study was undertaken in the North Staffordshire area with participants from Newcastle-under-Lyme, Stoke and Biddulph. In the 2011 census it was found that Staffordshire had a 24.5% increase in the population aged 65 and over, the largest increase in any county in the United Kingdom (UK) (135). The burdens associated with an aging population are therefore more apparent in this location and as such this is a key area in which to examine discrepancies in health outcomes. Aside from the aging population of the region, Stoke-On-Trent has a high level of limited health literacy. A recent survey found 52% of the people in Stoke-On-Trent have limited health literacy (136). Even though, as discussed previously, there are not national figures for health literacy in the UK, the 2011 Skills for Life Survey (137) found that 14.9% of those aged between 15 and 65 had literacy levels at entry level 3 or below. If this is taken as a proxy for low health literacy it can be compared to the findings from the above survey into the health literacy of the Stoke population. In the Stoke survey 28.5% scored low health literacy and a further 23.5% scored marginal health literacy. It can be seen that the level of low health literacy is higher in Stoke when compared to the national figures, however it is likely to be partly explained by the fact the 25.5%

of those in the Stoke survey were aged over 65 years. Other evidence to support the hypothesis that Stoke has an above average level of limited health literacy can be found when reviewing the American National Adult Literacy Survey (138). This study found that 14% of adults had below basic health literacy and a further 22% having only basic health literacy. Again the difference in the populations must be considered when comparing these figures with those found in Stoke. However, even accounting for this, it is likely that there is a far greater burden of limited health literacy in Stoke-On-Trent. North Staffordshire is, therefore, an ideal area to recruit for a study focusing on health literacy in an older population.

### 3.5.2 Sampling

Purposive sampling was used to recruit patients to the project. This is a commonly used form of sampling often used in qualitative research (134). This form of sampling allows the selection of participants with desired demographic features that are pertinent to the study. This form of sampling is appropriate for research where there is an *a priori* body of evidence (139), such as in this study. Miles and Huberman set out a set of criteria for sampling that can applied to the development of a sampling strategy (140). They argued that the sampling needs to be relevant to the question and that the phenomena of interest needs to be able to appear in the sample. The sampling plan needs to enhance generalizability of the findings and produce believable descriptions and explanations. They also argue the sampling plan needs to be feasible and ethical to be considered appropriate.

Participants were recruited from two social groups run by Age UK and a local forum for older people. There is no universally agreed cut off for defining someone as older or elderly. The United Nations have a non-official agreed cutoff of 60 years to define older people (141) and so this cut off was used in this project. Age UK is the country's largest charity dedicated to the wellbeing of the over-60s (142). As part of their work they run activity groups in the community. Through discussions with the organizers of the local groups it was agreed that I would attend two meetings, one for women and one for men, to discuss the project and recruit participants. I also attended a city wide forum called the Fifty+ Forum which is set up so that people aged over fifty can give their views on local services directly to the organizers (143). The project was again discussed and participants were recruited directly from the meeting. In targeting the sampling to these groups and explaining the study, including the need for participants over the age of 60, I was able to sample a group of participants that have the desired characteristics for the study. In order to allow the recruitment of participants that were as generalizable as possible to the larger population the inclusion and exclusion were produced to allow as broad a selection as possible. Recruitment continued until saturation was seen in the analysis.

### **Inclusion Criteria**

Aged over 60 years

Suffering with a long-term health condition: defined as any condition that is persistent whether controlled or otherwise

Capacity to give informed consent

## **Exclusion Criteria**

Unable to complete an interview

Non-English speaking

### 3.5.3 Interviews

There are multiple ways of obtaining qualitative data. Interviews are the most commonly used research tool in qualitative methodology. They “allow us to enter into the other person’s perspective” (126) (p341). Through interviews we are able to access areas that are not directly observable, such as attitudes and experiences as well as previous actions, allowing us to explore the experiences and beliefs of the individual.

There are two main types of interviews used in qualitative work. (123) These are unstructured and semi-structured interviews. Unstructured interviews are akin to a conversation. The interviewee is allowed to respond freely to a very limited number of questions. This results in a very flexible interview process that can produce a diverse set of data. This type of interviewing facilitates spontaneity and responsiveness to the situation and individual, allowing the participant to focus on issues of primary concern to them (126).

The second type of interview seen in qualitative research is the semi-structured interview. In contrast to the unstructured interview, the semi-structured interview is guided by a set of specific topic areas, and particularly useful where

an a priori body of work exists, as in this study. The interviews are more comparable and are more similar in the data they collect as questioning is led by an interview guide that provides key questions and prompts. Although more scripted, semi-structured interviews allow flexibility with the interviewer able to adjust the questioning in response to the answers received. Semi-structured interviews are more appropriate for studies where there is a clear focus of the topic of interest (123).

The findings of the systematic review informed the focus of the discussions, and formed the basis of a semi-structured interview schedule (appendix 2).

#### 3.5.4 Interview Schedule

Interview schedules are used to ensure that the same basic line of enquiry is maintained throughout the interviews (126). A standard interview schedule or guide will provide topics and questions for the interviewer to use with prompts to attempt to obtain greater detail if required. I produced an interview schedule that covered the four areas investigated in the systematic review discussed in Chapter Two. Within the initial schedule I included a section on experiences of healthcare in childhood and growing. This approach takes some aspects for life history interviews which invites the interviewee to explore their experiences over their entire life (123). The aim of such an approach is to look at how experiences in an individual's earlier life have shaped their view of the world and how they interpret it. I wanted to briefly explore whether early life experiences had impacted on future actions in healthcare. This led to a section of the

interview being dedicated to the experiences of healthcare in childhood and their views on parental approaches to healthcare.

As will be discussed in more detail later in this chapter the analysis of the data was iterative. After completing seven interviews it became evident that there was no significant data being obtained from the life history section of the interview. A revised interview schedule was therefore produced which allowed a greater amount of time to be dedicated to other areas.

#### 3.5.5 Socio-demographic Information

Several socio-demographic features were collected for each participant. During the recruitment process the verbal explanation provided to potential participants set out the requirement for people to be aged 60 years or older. Collection of the socio-demographic factors outlined in table 3.1 was intended to allow comparison of the responses given by participants including comparison between literacy groups as determined by the Newest Vital Sign. Scores greater than, or equal to 4 were deemed to represent adequate health literacy. This cut off has been suggested as an appropriate level to differentiate between adequate and inadequate health literacy (Rowland, Khazaezadeh, Oteng-Ntim, Seed, Barr, & Weiss, 2013). Choosing this cut point has been shown to have a sensitivity of 100% and a specificity of 40%. Although selecting a lower score can increase specificity, the sensitivity of the test falls off dramatically. One of the demographics was the abbreviated mental test score. This is a simple screening tool for the evaluation of mental impairment. It is a ten question test that has been shown to be accurate at identifying individuals with mental impairment.



The general cut off for an abnormal result is either less than 7 or 8 out of ten (144). So that cognitive impairment could be identified and its impact on results be discussed if necessary it was decided that a cut of for mental impairment would be a score of less than 8.

**Table 3.1: Socio-demographic Features**

Demographic Feature	Rationale
Age	Allow comparisons between age groups
Sex	Allow identification of potential gender specific issues
Highest Educational Attainment	For consideration as confounder in analysis
Abbreviated Mental Test Score	Brief assessment to exclude cognitive impairment
Newest Vital Sign Score	To assess participants health literacy and allow comparison between health literacy levels in analysis

### 3.5.6 Data Recording and Transcription.

The interviews were audio recorded and then transcribed verbatim. It is usual for interviews to be recorded as this allows for the limitations of human recall and note-taking to be circumnavigated (145). The audio files were then transcribed verbatim into anonymised text. Transcription is a key process in

qualitative research but can vary greatly depending on the study and aim of the analysis. No single transcription method is universally correct, but it is important that the right transcription method for the study in question is chosen and this is decided before starting the process (146). Due to the variability in style of transcription it is important to make the process clear and explicit (134). In her seminal work on transcription, Elinor Ochs claimed “transcription is a selective process reflecting theoretical goals and definitions” (p.44) (147). She also said that “a transcript that is too detailed is difficult to follow and assess” (p.44) (147). For this study a simple transcription model was thought to be the most appropriate for the needs of the research question.

#### 3.5.7 Ethics

Ethical approval was obtained from Keele University prior to commencement of the study. The original approval was obtained in December 2011 (appendix 3) prior to my involvement. This was because the study was initially developed before I joined the project. Adjustments to the study protocol were agreed once I joined and as such an amendment was submitted for approval. This involved changes to the proposal and participant information sheet. These amendments were accepted in March 2014 (appendix 4). I will now outline some of the ethical considerations taken into account for this study.

Confidentiality is a cornerstone of any research project and is a fundamental ethical consideration. This is a particular concern when audio recordings are being taken, as this is another level at which confidentiality could be compromised. To maintain confidentiality the audio recordings were stored on a

single computer with password protection. Unique anonymous identification numbers were used for the recordings and the only data that contained both the participant details and name was on the consent form. These consent forms are stored securely at Keele University. Transcriptions were also identified with the same unique numbers, and pseudonyms were used for participants and other identifiable individuals (such as healthcare professionals). The transcribed data was again stored electronically under password protection. Participants were informed about the issues of confidentiality on recruitment as well as in participant information leaflets and when obtaining consent prior to the interviews. Participants were also informed that the audio files would be archived for 10 years before being destroyed. Consent was taken by the primary researcher prior to the interview. The consent form was discussed with the participant and any questions were answered. If anyone else who was not directly part of the study were present they were also consented to avoid issues if they were to speak during the audio recording. The consent forms are also stored securely at Keele University.

As part of the recruitment process potential participants were provided with information sheets outlining key points of the study (Appendix 6). This contained information on the aims of the study as well as what would be required if they chose to get involved. Contact details were provided to provide a contact to both the primary researcher and the University's research governance officer if there were any concerns. After the original ethical approval it was decided that it was important to consider the possible literacy levels of potential participants. An assessment of the readability of the original

participant information sheet was made leading to changes to the original text based information sheet and the production of a simplified, picture based supplementary information sheet. Evidence suggests that the use of pictures and cartoons can significantly increase the amount of information that people retain when compared to text only information (148) (149). The supplementary information sheet consisted of short sentences covering the major points of the main text sheet with accompanying cartoon pictures (Appendix 6). The readability of the supplementary sheet was also evaluated to make sure that it was appropriate for as many potential participants as possible. The final information sheet had a Flesch-Kincaid grade level of 3.6 and a Flesch reading ease score of 86.7%. This defines the text as easy to read and appropriate for a grade 3 student in the US. Converting this level of education to the UK system would mean the text is appropriate for a child in year 4 (8-9 years old).

### **3.6 Data Analysis: Thematic Analysis**

As with any form of qualitative analysis there are several steps that are taken to allow a full assessment of the data. This is often not made explicit and as such it is more difficult to judge the quality of the process undertaken (150). Braun and Clarke (132) describe six phases of thematic analysis which I will now outline as a description of the methodology I have undertaken.

#### Phase 1:

The initial phase of analysis is familiarization with the data. For this study this began with collection as I conducted all of the interviews and also transcribed each interview. Undertaking the transcription myself provides a good starting point to become more familiar with the data set (151). Indeed it has been described as “a key phase of data analysis within interpretive qualitative methodology” (152)(p227). To completely immerse in the data further reading is required and so all of the transcripts were actively re-read to search for meaning and patterns. At this stage notes were kept about ideas on the data but it will not be annotated.

#### Phase 2:

During the first phase notes were taken on the data that provided some ideas about the possible areas of interest. At this stage preliminary codes were produced for the data. These initial codes were basic and general, providing a simple description of the data.

#### Phase 3:

This part of analysis began once an initial list of codes had been produced in the preceding phase. The aim of this section was to move from the narrow codes that have been generated to the broader themes that they represent. There are two main types of themes that developed at this stage. Firstly there are overarching themes that describe larger parts of the data and then there are several subthemes that subdivide these larger themes.

#### Phase 4:

At this stage in the analysis there was a need to refine the themes that were developed. This phase started with a meeting between myself and my supervisors to discuss the codes and themes. This allowed a discussion over the coding of the data to ensure that codes were not missed and that the analysis of the data had been complete. The codes and themes were then assessed across the transcriptions to check for a good fit. After this discussion I re-read all of the transcriptions again to reassess the coding, and add and adjust the coding in keeping with those agreed on between my supervisors and myself. A thematic map was produced which connected and described the themes identified in the data.

#### Phase 5:

This phase involved the refinement and defining of the themes to determine the “essence” of each theme (132). This involved consideration of the themes individually and in relation to one another. This allowed identification of any overlap between themes. Subthemes were again looked for in this phase, to give structure to large or complex overarching themes.

#### Phase 6:

The final phase of analysis involves the final analysis and write up, which will be outlined in Chapter Five. This involved a concise and coherent description of the themes with examples lifted from the data. Included in Chapter Five there is a reflection on the expected impact health literacy has on the findings. This was done by assessing the skills and views expressed and describing how these fit

with the current definitions of health literacy as outlined in Chapter One. There is also a comparison of the findings from participants with NVS scores below four and equal to or above four. The aim of this was to see if the expected differences can be identified with a standard health literacy assessment tool.

### **3.7 Conclusion:**

This chapter has outlined the methodological approach that will be used for a qualitative study into the impact of health literacy on chronic health management in older people. The philosophical standings of the primary researcher have been stated by explaining both the epistemological and ontological stance. This affects the way in which data will be collected and analysed and explains the decision regarding the adoption of thematic analysis. The steps that were taken to ensure that the thematic analysis was undertaken in a clear and defined manner were also described, in order to ensure that it is possible to identify how the themes have been identified and allow for a critical appraisal of the results by the reader. The following chapter will discuss the findings of the analysis.

## **Chapter Four: Findings**

### **4.1 Introduction**

This chapter will present the findings from the thematic analysis outlined in Chapter Three. Firstly, the demographics of participants will be presented and individual demographics and pseudonyms described. These pseudonyms will be used throughout the chapter so as to maintain anonymity. The main findings from the analysis will then be discussed with reference to the impact of health literacy.

### **4.2 Participants**

Interviews were conducted between August and December 2014. Three participants were recruited from a female knitting group organized by Age UK. Three were recruited from a men's group that was also organized by Age UK. Eleven other participants were recruited from a local forum for those aged over 50 years. This resulted in seventeen individuals being recruited for the interview stage. Two of the individuals were married and wished to conduct their interview with their partner, therefore this was counted as one interview. Additionally, one of the interviewees wished for her partner to be present for her interview and he was therefore also consented for the interview, but this was still analysed as one interview. The final number of interviews for analysis was sixteen.



#### 4.2.1 Demographics

Demographics for the group are shown in Table 4.1.

**Table 4.1 Participant Demographics**

Gender	
Male	7
Female	10
Age Range (years)	
Mean [SD]	
Male	65-89 78.14 [8.71]
Female	64-76 71.8 [5.81]
Newest Vital Sign Score (* 1 Participant Unable to Complete due to Visual Impairment)	
Inadequate (<4)	9
Adequate ( $\geq$ 4)	7
Highest Educational Level	
No Higher Education	12
Higher Education	5
Abbreviated Mental Test Range	8-10

As can be seen, the participants were a mix of men and women with a range of educational attainment and health literacy scores. Educational attainment ranged from leaving school at 14 years to a university degree. Newest Vital Sign scores ranged from 0/6 to 6/6. As can be seen in the above table, all of the participants had abbreviated mental test scores of 8 or higher indicating that there was no evidence of cognitive impairment.

A summary of some of the characteristics of the participants is shown in Table 4.2. This includes pseudonyms that will be used in quotations to protect participant anonymity.

**Table 4.2 Participant Characteristics and Pseudonyms**

Interview Number	Pseudonym	Age (years)	Gender	Health Literacy: Adequate (AHL) Inadequate (IHL)*	Number of People living with participant
1	Ella	76	Female	IHL	1
2	Tracy	74	Female	AHL	0
3	Dianne	75	Female	AHL	0
4	Gerald	83	Male	Unable to Complete NVS	0
5	Toby	89	Male	IHL	0
6	Frank	83	Male	IHL	0
7	Laura	69	Female	IHL	0

8	Frances	65	Female	AHL	0
9	Craig	83	Male	IHL	1
10	Lianne	84	Female	IHL	1
11	Holly	70	Female	AHL	1
12a	Timothy	65	Male	AHL	1
12b	Georgina	64	Female	AHL	1
13a	Tabetha	71	Female	IHL	1
13b**	Richard	58	Male	IHL	1
14	Luke	75	Male	AHL	1
15	Eva	70	Female	IHL	1
16	Leonard	69	Male	IHL	1

\*: AHL defined as Newest Vital Sign score of 4 or greater

IHL defined as Newest Vital Sign score of less than 4

\*\* : Not part of study but present at request of participant 13a (partner)

### 4.3 Analysis Summary

The initial analysis produced a wide list of codes. Reliability was checked through independent analysis (JP and BB) of a random selection of three transcripts , and codes were compared to determine accuracy. Several themes were identified and refinement of these through discussion led to the development of three core themes:

Candidacy

Resilience

Attitudes

These themes were constructed out of several sub themes (Appendices 5 and 6), which in turn reflected the lower level codes. These sub themes tended to impact on several aspects of healthcare and defined how individuals view their health, healthcare and needs. The themes identified were present across the interviews of participants both with adequate and inadequate literacy. It is therefore likely that these themes may be a feature of the actions of older people in general, with health literacy impacting on the effectiveness and scale of the prevalence of the themes. A description of the main themes will be presented after which the impact of health literacy will be proposed.

With the sub themes being pervasive throughout the themes of candidacy, resilience, and attitudes they will be discussed as part of these themes. This is done to prevent confusion and unnecessary jumping between themes.

#### **4.4 Candidacy**

One of the main themes from the analysis of the interviews surrounded how people viewed their own health and consequently, how they legitimized accessing health services. This was described under the overarching theme of candidacy. Candidacy is a term that describes individuals' perceived eligibility for healthcare (153). It is a complex construction that is developed through the

continued interactions between an individual and the health professionals and organizations. As such the nature of candidacy is agreed between these two parties and is therefore dependant on factors from both of them. Not only does the patient need to identify themselves as a candidate for healthcare, but so do health professionals and organizations and society in which they live. It has been proposed that there are seven domains that are involved in the construction of candidacy (153). Six of these factors; Identification of candidacy, operating conditions, navigation, adjudication, permeability of services, and appearances at health services were all present in the data and will be described below with offers and resistance being the final proposed domain that was not present.

It was common for participants in the study to express concerns over the worth of their problems and they described how they felt like a burden on health professionals:

“I feel I'm wasting their time. What am I going for, I'm able to do what I want. Unless it's something really bad I wouldn't go”

(Laura, 69. NVS<4)

“It doesn't put you off but you think about it, they'll probably say, "there's nothing up with you, what's up with you woman," you know, "go away." That's the only thing I think, ‘Oh do they think I'm mithering or do they think I'm being silly for this little symptoms that I think I've got’”

(Frances, 65. NVS $\geq$  4)

Here both Laura and Frances voice their doubts over the validity of their symptoms for seeking the assessment of their doctor. The slight difference in Frances' view is that she does not believe her doubts over validity affect her actual health seeking behaviour. In contrast Laura concludes that her symptoms are not worthy of seeing the doctor. This may suggest that there is a general doubt among older people about the worth of their need to see the doctor and it may be that health literacy could be an important factor in determining the need to seek assistance and therefore the ability to identify candidacy.

As highlighted by the quotations from Laura and Frances, there were similar expressions of candidacy concerns by participants with NVS scores above and below 4. Comparing all of the interviews, there was also no obvious difference between genders or across the age range of the participants.

These examples show how participants could struggle to legitimise visiting their General Practitioner (GP). This resulted in them waiting until they had symptoms which they perceived as sufficiently bad to validate their attendance in general practice. This highlights the first issue encountered by the participants in identifying their candidacy: assessment of symptoms. One of the skills that has been suggested is needed for people to identify candidacy is the ability to recognise and evaluate their symptoms (153). Participants presented examples of failing to recognise symptoms as markers of a medical problem. Alternate explanations were given which demonstrated deficiencies in the early identification of medical problems:

"when I had that angina attack, it's like wind...I thought it was wind and I had run out of ginger beer. I used to keep a bottle in there for wind. Take a glass of ginger beer and you're belching and that was it. But it didn't work ...The doctor came and he says..." you've been going up and down on all fours and you've got a heart attack." I says, " I didn't know it was a heart attack, I thought it was wind."

(Toby, 89. NVS<4)

The ability to assess symptoms and identify problems would be expected to require adequate health literacy skills. Toby's failure to identify his symptoms as a potential heart attack demonstrates a lack of these health literacy skills which is in keeping with his NVS score. During the passage of this interview he states how he didn't contact the doctor himself suggesting that he may have not taken any further action on his symptoms if it was not for someone else, therefore requiring specific operating conditions for the development of candidacy. This is a point that will be returned to later in this chapter.

The importance of symptom recognition is clear. Remaining in a state of ignorance to the medical nature of problems has a fundamental impact on developing candidacy. The initial identification of issues is essential to subsequent evaluation of the problem in the process of legitimizing access to health services.

A factor that was seen to be important in the ability to identify medical problems by the participants was their expectations for their health. Problems in health

were identified when there was a move away from the level of health that the individuals perceived as acceptable. This target level is therefore important in defining satisfactory health for the individual. Among the participants there was a tendency to have low expectations for health. Their expectations were often linked to what they were able to do in spite of health problems rather than whether they had health problems or if any problems were well controlled. Often low targets for health were set with participants definitions of 'being healthy' frequently being framed in terms of being able to get up each day and continue with their lives:

“Waking up in the morning and saying “O geeze I've got another... I've beaten um”. (Laughs) I get up and, I'm happy in the morning”

(Toby, 89. NVS<4)

In this case, Toby's expectations for his own health are summarised in his pleasure at living to see another day. When asked about what being healthy meant to them, the primary response was to remain active and continue in their day-to-day lives. There was a lack of discussion about health in biomedical terms with a preference to reflect on the psychosocial impact of health.

By having psychosocial expectations for health and being satisfied with the ability to continue in life on a day-to-day basis, there is a requirement for significant deteriorations in health to occur before a problem will be recognized. Only when symptoms reach a point where they impact on daily functioning



would participants view them as problematic and identify candidacy for possible health assessment.

Even if candidacy was identified there was discrepancy in the abilities to evaluate the severity and navigate the health system to access the most appropriate service. This represents the next step of symptom assessment and failings at this stage by the participants resulted in underestimation of problem leading to late presentation and/or presentation to an inappropriate access point to health services. The example below shows how an inability to evaluate the severity of a problem led to a delay in seeking healthcare assessment and presentation to the incorrect service:

“Luke: Even when I had my heart attack we didn't call anybody. We went off ourselves to the open surgery.

Interviewer: So why, in those situations...what made you choose to go to the...open surgery or the relief doctor as your first port of call?

Luke: Because people like us are reluctant to hit 999 because you don't know what's going on. Kirsten [wife]...when I had the heart attack, Kirsten was quite suspicious of it. Me, I always thought it was like the films, O and over you go. It isn't”

(Luke, 75. NVS $\geq$  4)

Here Luke provides an example of a situation where he has failed to evaluate the symptoms of a heart attack. His expectations of more dramatic symptoms negatively impacted on his ability to evaluate his medical needs. Sufficient

concern was raised that medical attention was required but there was a failure to identify the correct health service to access. Despite scoring well on the NVS this may demonstrate a lack of health literacy skills in terms of symptom evaluation. This discrepancy between scores on the NVS and the demonstration of health literacy skills within this qualitative project is a feature that will be repeated throughout this chapter and raises questions over the use of such tools in the investigation of the role of health literacy in research. Although such measurements may have an important role in certain areas of health literacy assessment they may not be sufficiently nuanced to accurately determine the presence or lack of complex health literacy skills. Other explanations for an approach such as the one demonstrated by Luke here may lie in a more general issue of reluctance of older people to use emergency services or the expectations of symptoms of certain conditions, such as heart attacks, as portrayed in media outlets such as films and TV.

Navigation of services was further complicated for several of the participants by their poor ability to relate the severity of their symptoms to the terminology used in the health service. Within general practice it is common for certain appointment slots to be allocated as 'Emergency Appointments'. This term led to confusion among participants and an underestimation of their medical complaints. Even when the need for medical attention was established by the individual, they did not consider the problem an emergency. In this process the involvement of health services in the construction of candidacy can be seen with the impact of penetrability of services. By using the term 'emergency', health services are informing patients what constitutes a legitimate reason for booking

such an appointment. In doing so there is a reduced penetrability of services which has a negative impact on candidacy. Below are two examples of such an issues:

"I said to him, " just ring and get an appointment this morning because your chest infection has kept me awake all night." That's how sure I was that he'd got a chest infection... So he said he rang up and they said, " is it an emergency?" Now to him, and probably to lots of old people, if you're not actually having a stroke or a heart attack, it ain't necessarily an emergency. So he said no and that was it"

(Holly, 70. NVS $\geq$  4)

This is an interesting example that exposes some of the barriers people have to overcome to develop candidacy. Holly is the participant in the study discussing an occasion where her husband had become unwell. She demonstrates health literacy skills by identifying the problem and severity sufficiently to instruct her husband to seek medical attention. The measured health literacy score of the husband is unknown as are the exact details of why he failed to make an appointment. What is highlighted here is that despite the identification of candidacy and an attempt to seek medical assessment there was a barrier to this process that prevented an appointment being made.

Possible explanations for this include disagreement over terminology used by health services. It appears that the use of the term emergency was key to the decision to make an appointment. By asking patients if they feel their problems

are an emergency health services ask them to evaluate their problems. This only works if there is an agreement over what is an emergency between the patient and health service and if the patient is able to evaluate their symptoms. It is possible that health literacy skills are important in this evaluation, however, opinions over what constitutes an emergency may differ equally by age or sex. Below is a further example of such a problem of terminology:

“Like me Achilles’ heel. Er. I would never have bothered the doctor with that, you know, but I couldn’t walk, and er, it was a Saturday morning, well the surgery was closed so I got that, er, emergency number and I said, "well it’s not an emergency."

(Toby, 89. NVS<4)

Here it can again be seen that participants were reluctant to class their problems as emergencies. In this example we have more details of the thought process and it appears that Toby takes a psychosocial view to assessing his problems. It is not the physical injury itself that appears to concern Toby but the impact on his ability to walk that prompts him to seeking a review. Even then, however, Toby demonstrates a reluctance to class the problem as an emergency. It is difficult to determine if health literacy is involved in this process and it appears likely that this opinion may be more a reflection on the views of an older generation. Clearly this impacts on participant evaluation of problems and determination of candidacy and is an example of the many factors that interact in the formation of candidacy. Some, but not all, of these factors will be influenced by health literacy

but all of them must be considered when determining why older people have issues surrounding candidacy and ultimately health decisions and outcomes.

Concerns over penetrability or accessibility of services was also raised with discussion over perceived barriers to accessing care. This was a perpetual concern and covered areas of making appointments, time to being seen, continuity of doctors seen, and out of hours care.

"I press five and get a...recall. But if you don't do that, by the time you get through, all the appointments have gone, then you've got to start the same, the same thing the next day, and the next day, and after a while you, "awww, I'm not gonna bother." So really, erm, that is one thing that erm, could be dangerous because you might think "aw, I'm not gonna bother", and you know, the condition that you thought you'd got might get worse without you realising. So I think, I think there ought to be a better way of making appointments."

(Dianne, 75. NVS  $\geq 4$ )

Here we see how the experience of difficulty in accessing healthcare has resulted in Dianne forming a negative attitude towards access. Her belief that there must be a better way of doing things demonstrates her frustration and there is also a demonstration of how this barrier has resulted in giving up on seeing their doctor.

Not only was making appointments seen as a problem but it even questioned the candidacy of certain individuals by suggesting they seek advice elsewhere.

“Because I'd tried to phone up, and, er it was blummin hopeless. In fact the first time I phoned up, it said press one, press two, press three and if you don't get that press four. And so I pressed one and I get a big list of all the things I couldn't go the doctor with.”

(Frank, 83. NVS<4))

“You ring up at half past eight in the morning. You can ring twenty times, they are constantly engaged. If you ring before half past eight it's there answer phone of course, which is useless. So after half past eight you can ring for about half an hour until you eventually get through and then all the appointments have already been made”

(Lianne, 84. NVS<4)

A further influence on participants' evaluation of their symptoms and identification of candidacy was how they felt their health compared to others. It was common for participants to compare the symptoms they have and their perception of the severity of the symptoms with other people. If participants felt that their symptoms were less severe or debilitating then other they would display low levels of candidacy.

“Not at the moment, no. 'Cos it's [arthritis] just there and I know it's there but, no it doesn't... I'm not crippled with it like some people. I suppose if it got worse yes I would but at the moment no.”

(Frances, 65. NVS $\geq$  4)

Even without another person to directly compare symptoms with, participants expressed concern that by visiting their GP they would be preventing access to someone else with greater need. This resulted in participants having reduced candidacy for seeking healthcare as they perceived that there would be someone with a greater need than their own. This perception that there is generally someone in a worse situation is another barrier that must be overcome by the participants as they need a sufficiently severe deterioration in health so that they see their need as greater than that of others.

“As regards to the doctors I don't go, I suppose I think at the back of my mind, suppose someone was really ill... and trying to use that phone system, or someone, I'm a bit forgetful sometimes but I know there are people a lot worse than me.”

(Frank, 83. NVS<4)

The role of ageing played a key role in how participants evaluated their health problems and the need for health assessment and intervention. The ageing process was often alluded to with participants suggesting that certain problems were to be expected given their age. This idea that natural decline in health and development of 'age-accepted' problems was normal invalidated any thought of

candidacy. This affected the expectations of the participants by creating a group of chronic conditions that the participants would not identify as legitimate cause for seeking the assessment of health services:

“No, I've got arthritis and I suffer from those but I mean that's, when you get to my age you expect that kind of thing”

(Tracy, 74. NVS $\geq$  4)

“You know, life's just slipping away, what bit of life's left in your eighties, it's something you've got to expect I suppose”

(Gerald, 83. Unable to complete NVS)

The impact of participants' life journeys was not just limited to perceptions of ageing and the belief that certain medical conditions were a natural part of this process. The experiences individuals had acquired over their life course also had a profound impact on the development of candidacy. These experiences spanned a range of different interactions from those with the health service to social interactions on health matters. A particular finding from the interviews was how participants reflected on experiences of approaches taken towards healthcare by family when they were younger. This often consisted of self-management within the family unit. Avoidance of healthcare professionals in childhood would tend to reduce the perceived candidacy for seeking professional assistance in later life:

“Somebody cut their foot open in our house. Messing about with something, I can't remember what it was. And, my uncle, who had



rheumatoid arthritis and things like that, he stitched his foot up. With black thread. I can see it now, uncle Henry in the shed. Just my uncle, and he was about fifteen and we all stood round watching him do it, because I can't remember if it was his foot or his leg, I think it was his- here somewhere. And he stitched it up, because you couldn't- "you're not going to the doctor with that."

(Laura, 69. NVS<4)

Here Laura reflects on how her family would avoid doctor interactions with problems they felt they could manage on their own. It is important to note that Laura grew up in Ireland where health care was not free. Cost is a factor that plays a vital role in the decision to seek out the healthcare in countries that do not have a system that is free at the point of access, such as the UK (154).

Further examples of the role of past experiences were seen where participants discussed previous illnesses and times of hardship. This draws on theories of life course such as that of work on unequal aging. This field looks at why there are differences in treatment and outcomes between different groups of older people as well as between older and younger people. One explanation for the unequal aging focuses on life courses and experiences because, "older people first of all carry into retirement and, on and on, into late old age a position in their socio-economic structure that is forged at earlier stages in their lives." (155)(p143) This suggests that experiences individuals have throughout their lives impact on their opinion and position in later life.

All the participants had experienced ill health at some point in their life and their experiences of how this was managed and the recovery from these problems continued to influence how similar issues were approached in the present day. Through experience of ill health and hardship but managing to overcome these led to the strengthening of their conviction that self-management was appropriate for many health issues. This draws on the concept of resilience, which will be revisited in more detail later in this chapter. Successful self-management reinforces its role and leads to greater implementation of this approach in future periods of ill health. This reduces the development of candidacy to access health care through health services in favour of self-management.

“But if my dermatographia, I, I self-medicate, because I’ve had it for so long, that...I know more about it than the doctors do and if it starts to flare up I just start to take more antihistamines, so I self-medicate there.”

(Dianne, 75. NVS $\geq$  4)

Appearances at health services and adjudication by health professionals had both enabling and disabling effects on future candidacy. Positive experiences would reinforce the benefits of seeking health care as well as the candidacy for the condition in question. Receiving treatment acted as a legitimization of their appearance. This is further evidence of the role of health services in agreeing candidacy with patients. In adjudicating, health professionals can demonstrate the eligibility of the patient seeking their advice. The result of this is that, when confronted with comparable issues, patients will act similarly:

“I’ve had cystitis, quite a few times. You’ll have to go because with some antibiotics it clears up so quickly and it’s a very painful thing. Yes I do go for that”

(Lianne, 84. NVS<4)

Here Lianne has experienced the same symptoms several times and as such has developed the ability to confidently assess recurrences and seek health care. This shows that despite her NVS score of 3, she has developed a level of health literacy specific to this problem.

“I had to have two mammograms because they thought something was there and they were both negative fortunately, so that made me go. Straight away. Having been a radiographer I know. I know they’re both diagnostic and therapeutic. I know all the consequences”

(Lianne, 84. NVS<4)

In this example, Lianne discloses her previous work as a radiographer. It may be expected that people that have worked in the health service would have good health literacy. This is at odds with Lianne’s NVS score of three. Whether this represents a failure of the quantitative measures of health literacy to assess the nuances of such a complex construction is therefore debatable. Later in the quotation, however, Lianne speaks of the ‘therapeutic’ benefit of mammography possibly demonstrating a failure of understanding of the investigation. This

suggests that health literacy could be problematic even for those that have exposure to health care.

In contrast to these positive experiences, negative experiences with health services had harmful consequence on future candidacy and likely actions. There was a focus on negative experiences with health services which suggested a strong influence for these episodes. Further evidence is provided in these descriptions to the key role of health services in constructing patient candidacy. Candidacy can only be created if it is supported by health professionals. A failure to demonstrate to a patient that their reason for attendance was appropriate left participants with a belief that they were wrong to seek advice from medical services. Participants described feeling let down and the result of this was to infer that they should not be seeking health assessment for the reasons they had.

“I was tired all the time. I could go bed at night as normal and I could stay in bed till four o'clock the next day... I don't know whether it was a part of depression or what...he [GP] said, "if you're still like this in a fortnight come back and we'll see if there's anything else we can think of. But, just put it down to being tired...It was just fobbed off in a sense wasn't it?”

(Timothy, 65. NVS $\geq$  4)

Consequently participants would explain that this would reduce the chances of future attendances as their candidacy was reduced through the invalidating effects of healthcare workers:

“So it was pointless so we walked out and said that was pointless. I won't do it again. I'll probably have a break down before I'll even think of doing it again because there's no point to it.”

(Timothy, 65. NVS  $\geq$  4)

Another important factor in how participants formed their candidacy was the role of social networks. Interactions in social groups provided participants with a wide range of shared experiences that provide an operating condition for candidacy. The positive experiences of others were seen as legitimisation of seeking review in the same way that personal positive experience were seen to reinforce candidacy above. Being able to access the experience of others allowed for decisions to be made about conditions and symptoms that the individual may not have personal experience in:

“One of our WI ladies, she went in, she was out the next day and she's told us all about how wonderful this is so that's the WI network”

(Holly, 70. NVS  $\geq$  4)

Participants were also able to draw on the knowledge and skills of others to assist in their assessment of new problems. Participants often turned to members of their social networks to seek advice regarding medical problems. This was most commonly from family members, particularly if there was someone who was deemed to have some medical knowledge. Asking the opinion of friends or family allowed participants to confirm a problem existed and, once this had been established, to determine the legitimacy or not of accessing health

care. In this manner, social networks acted to overcome issues of poor symptom assessment and facilitate the appropriate evaluation of symptoms. In doing so a shared understanding was reached which aided in the development of the participants candidacy.

“My daughter's a practice nurse so something we're not sure of, we run through her first. So she can look it up and tell us yes or nay. If it does want investigating or not.”

(Eva, 70. NVS<4)

Here Eva is seen to have an NVS score of 2 indicating inadequate health literacy. However, within her social network there is a distribution of health literacy allowing her to overcome potential barriers to symptoms assessment as discussed earlier in this section?

Social networks also enhanced symptom and condition awareness. The exposure to conditions in other members of the group allowed participants to recognize the symptoms in themselves. When others in the same group have also sought medical advice and been diagnosed this further promotes the validity of health seeking behaviour and again aids the development of candidacy.

“And, like if it was... a friend of mine was diagnosed with prostate cancer so straight away all blokes, "Oh, I better go and get this checked”

(Luke, 75. NVS $\geq$  4)

The ability of individuals to legitimize health seeking behaviour has been demonstrated to be achievable through several pathways. Some participants were able to internally validate their symptoms as needing care. Others had their symptoms legitimized by the actions of social networks. A final area of legitimization was described by participants, which involved the influence of health services themselves. Earlier in this section it was seen how the terminology of health services such as 'emergency' influenced the decision making of participants. In addition to this, health services were able to enable candidacy in participants by inviting them to seek healthcare. Invitations to attend the GP practice were seen as a valid reason to visit the doctors. This dependency on the action of health professionals is in contrast to the participants who were able to determine the need for health assessment individually or within a social group.

"I am happy to go if they [GP] send for me but I don't like going if I want to, if I need to. I don't know why, don't ask me why. I think I look around and think, 'O my goodness, what am I doing here.' You know."

(Laura, 69. NHS<4)

Here, it is only the actions of her GP that result in Laura's attendance at the surgery. Without this external influence the participant would not have sought the same care. It is possible that individuals with lower health literacy skills may find it harder to develop the necessary level of candidacy to engage in such actions and Laura's NVS score of 1 reflects this. Alternatively this may represent a further example of differences in expectations of the participants and health

professionals. It may be that some people feel it is the responsibility of health professionals to make decisions over health including timing of reviews in a relatively paternalistic fashion. Equally there may simply be a lack of understanding in the expectations of what is wanted by the patient and the doctor.

In summary the participants described the process by which they developed candidacy through acknowledging and evaluating symptoms, and legitimized seeking of health care. There were numerous influences on this process that tended to reduce the perceived candidacy, in particular previous experiences over the life course. This suggests that some older people have low expectations for their health and view many health problems as a natural part of aging. Experiences of older people have both positive and negative impacts on the development of health literacy, although negative experiences were described in far greater detail, suggesting a stronger influence for these exposures. The findings build on the work of Dixon-Wood et al (153) describing the seven domains of candidacy. The only domain that was not clearly present was that of 'Offers and Resistance' with participants being universally accepting of services once offered.

#### 4.4.1 Impact of Health Literacy on Candidacy

This section has looked at how the participants in the study identified and assessed their health and developed candidacy to seeking health care. The impact health literacy may have on these factors was also introduced. By exploring the impression of candidacy in each transcript it was possible to



determine the general view of personal candidacy that each participant had for healthcare. Through this process it was seen that a far greater proportion of participants with an NVS score of less than four perceived their candidacy as poor (78% Vs 43%).

Within the limitations of the size of the study it is not possible to draw any firm conclusions over the impact of health literacy on the development of candidacy and, indeed there were expressions of positive and negative influences on candidacy in those with a NVS score equal to and above 4 and those with a score below 4. There were, however, several differences noted in data between these two groups that suggests an influencing role for health literacy on candidacy. Issues over identification of candidacy were seen in both groups with concerns rose over the legitimacy of their health needs, however it appears that those with higher health literacy scores were less affected by these concerns. Difficulties navigating the health system were also seen across both groups but appeared to have greater impact on those individuals with lower health literacy with penetrability of services seemingly worse for those with inadequate health literacy as identified by the NVS score. The use of social networks in candidacy development was also seen across the group of participants. It was more common for individuals with a NVS score of less than 4 to develop candidacy as a result of the influence of other members of their social networks, demonstrating the need for this operating condition to allow development of candidacy through shared health literacy.

## 4.5 Resilience

The following section will discuss the importance of resilience in the approach older people take to healthcare. Patient resilience is an expanding area of health research. It evolved from work in child development and has come to describe the attribute of being able to remain resilient in the face of health adversities (156). This concept was apparent across the interviews and had both positive and negative implications for the participants. Like candidacy, resilience is another characteristic that is formed of multiple factors. The ability to self-manage and the impact of previous experiences and social networks again play important roles in the formation of this characteristic.

The participants recognised the importance of self-management and regulation of their own health, and tended to demonstrate a preference to this course of action. Rather than seeking the advice of doctors, people tended to initially look after themselves and find ways to manage their own problems. Reasons for this ranged from a desire to not be seen as a nuisance to maintaining their own independence. This self-management covered a range of different methodologies, some arguably more clinically appropriate than others. Many participants showed a preference for this approach and would manage themselves, including self-medicating, to maintain their health.

“And you wouldn’t believe what alternative stuff I take as well. I take garlic for me heart, one garlic tablet every morning. And I take umpteen tablets, for different things. For me arthritis, I take three tablets a day”

(Toby, 89. NVS<4)

Even when new health problems were recognized there was a preference for self-management with seeking the assistance of doctors being seen as a last measure. This delay in health seeking behaviour was not down to a lack of identification of a problem but due to the desire to remain independent and a belief in their own management abilities.

“I wouldn’t go to the doctor to start off. If I thought my blood pressure was going up, I would erm... look up on the net to see what you could take, you know, what sort of healthy diet you could have, to keep it down. That's what I'd do”

(Dianne, 75. NVS $\geq$  4)

Here Dianne demonstrates health literacy skills in this situation as she explains how she would access information to allow her to manage her own health. This is in keeping with her NVS score and displays the benefit of health literacy skills in developing resilience and managing health problems.

In some circumstances there was further suggestion that seeing the doctor should only be done after exhausting all other approaches. This hierarchy of health seeking behaviour with resilient actions taking preference over accessing formal healthcare also links with patient candidacy. Individuals with higher resilience will tend to see less need for the involvement of others and so will only turn to this measure after trying all other measures:

“Because when I go the GP I feel I need to go. Er,...again it's,...it's, I've got to want to go. I've got to think I've got to the point where I can't do any other, I've got to go and see the GP. Like I say, I've been the chemist, or Georgina's [wife] been the chemist and that hasn't worked”

(Timothy, 65. NVS $\geq$ 4)

Again there is demonstration of the ability to access information and resources to assist in the self-management of health problems. These health literacy skills are also in keeping with Timothy's NVS score, which suggests the benefit of adequate health literacy in development of resilience. This may suggest the quality of people's resilience may differ depending on the skills that they have. Those with better health literacy skills may develop a resilience that is better placed to allow successful self-management and overcoming of health adversities.

This approach to management of health problems led, in some instances, to long delays in seeking advice from professionals. Self-management and resilience is an important characteristic that can allow the management of health problems that do not need professional intervention. However, in some instances professional help may be more appropriate and the resilience demonstrated by some participants allowed problems to be accepted for extended periods. Only when a crisis point was reached or the symptoms had become “so bad” that the individual was no longer able to self manage the problem do they seek the

professional assessment that may have been accessed much earlier. In the example below a participant discusses his management of haemorrhoids:

“I suffered with them for ten years I should think.

Interviewer: And, what changed or what made you finally go and get something done about them?

Craig: It was getting so bad. Every time I went to the toilet it was a big problem getting them back in and making a mess of everything. Awful

Interviewer: So up until that point was it something you were coping with?

Craig: Coping with yeah. Because when you got them back in then you're alright for twenty four hours or so. And then you've hopefully forgotten about them until the next time. “

(Craig, 83. NVS<4)

Comparing the resilience demonstrated by Timothy above and Craig here we can see the difference in approaches taken to self-management. Timothy's approach to self-management was to seek out information and attempt to access other resources. In contrast Craig, in keeping with his NVS score of less than 4, failed to demonstrate any skills to facilitate self-management. He simply waited until his symptoms had deteriorated sufficiently so that he developed candidacy to seek professional assessment. In doing so Craig's resilience represents his ability to cope with problems rather than an ability to develop active self-management plans as demonstrated by Timothy. It may be, therefore, that health literacy skills

allow individuals to develop resilience that constitutes active self-management rather than passive perseverance.

Resilience tends to result in longer delays in seeking healthcare advice. Only after exhausting their own self-management plans or upon reaching a point where the symptoms were deemed severe would participants seek the input of healthcare professionals. Despite allowing the patient to persevere despite medical issues, resilience can, therefore, have a negative impact on healthcare if unnecessary delays result.

As discussed in the candidacy section of this chapter, previous experiences were shown to have a contributing affect on people's resilience. As implied by its definition, resilience is developed out of successfully overcoming or coping with periods of adversity. All of the participants had experiences of ill health in their past. How these periods of ill health had been managed and the outcomes of these events had a clear impact on the current views the participants had about health and healthcare. Some recalled hardship in their lives but were able to reflect on the fact they were still alive and inferred that they must be acting correctly to have achieved this. By drawing the conclusion that managing to endure through self-management was a marker of success, these individuals showed how these experiences aided the development of their resilience:

"I've had a very, very, very hard life. An extremely hard life. You know being deaf and painful ears and painful rheumatism and painful arthritis and all sorts of things that have gone wrong. And plus the circumstances

of my life, I've had a very hard life, but I'm still here, I'm still fit, I'm still well so something must be going right mustn't it"

(Dianne, 75. NVS $\geq$  4)

Further examples of the way participants reflected on successful navigation of ill health showed how individuals were happy with the fact they had survived ill health. This reflects the expectations older people have for health in that survival and continued functioning is viewed as successful. Managing to survive, therefore, promotes individual resilience which improves the likelihood of further self management and healthcare avoidance.

"I'm breathing, you know. With all the injuries I've had and all the trouble I've had, er I'm luck, you know. At my age I'm, er, I cannie expect any more, you know. I still have trouble with, occasionally with me aches and me pains but I don't let that stop us, you know. I keep doing me jobs."

(Toby, 89. NVS<4)

There were also examples of resilience forming out of previous experiences where a stoical approach to care previously had resulted in no harm. Situations where individuals have looked to monitor health problems rather than seeking review had strengthened their approach to self management as they found that their health had improved without the need for professional intervention. This reinforcement of self-management builds resilience and reduces the perceived need for accessing care. This is generally a positive attribute promoting the self-management of minor health problems. Issues can arise, however, when

participants look to self manage and take a stoical approach in situations where seeking professional assessment would be recommended:

“I fell over the day before we went away in May. And, er, hurt the side of me face, several things on this side of me body, and, erm, I’m sure I probably broke, did some damage to this hand. And, er, I kept on putting it off and putting it off, I went away the next day, too late to make an appointment, kept putting it off and, eventually cures itself more or less”

(Tracy, 74. NVS $\geq$  4)

Personal experience of chronic health conditions was common among the participants. These experiences provided participants with a greater knowledge of these specific conditions and enhanced their confidence in future management. It would be expected that health literacy would be enhanced for these situations. The findings from the study suggested this was not always the case however. While experience of conditions did improve participants’ confidence in self-management there were differences in how appropriately this was done. Below are two examples of participants who had experience of self-management.

First, Timothy, who is known to suffer from angina, suggests he takes a self-management approach to chest pains. Despite having angina and a high NVS score, it would appear that his knowledge of the condition is inadequate and his approach to self-management is inappropriate:



“I think if I had an accident, cut me finger, you know, cut meself cutting the hedge or run over me foot with the lawn mover then obviously A&E. But for, erm...if I get pains in me chest I tend, again it's self management.”

(Timothy, 65. NVS $\geq$  4)

In contrast Leonard, who has an NVS score of less than 4, demonstrates how his experiences of asthma management has enhanced his skills so that he can successfully self-manage future exacerbations as well as recognised when he needs to seek professional assistance:

“Get the chest infections that draw me down a bit with me asthma. Er... But I mean once, once that start- I've got me own peak flow monitor so if I'm feeling, you know, I feel as though I'm out of puff I do my peak flow several times during the day and if it's obviously markedly below what my normal is, my normal average is, erm... the first thing I do is increase me inhalers and if that doesn't work I make an appointment with the doctors”

(Leonard, 69. NVS<4)

Comparing these two examples it is interesting to note that the more developed self-management was seen in the participant with the lower NVS score. It is possible that Leonard has developed health literacy specific to asthma while his general health literacy remains low. However, it is difficult to explain why Timothy fails to demonstrate the same level of competence for a condition where he has experience if the NVS score is an accurate reflection of his health literacy

skills. This would provide further evidence to suggest that the NVS is an insufficiently detailed measure of health literacy. Not only do measurements such as this fail to assess the range of skill involved but also do not account for the situational nature of health literacy.

Interactions with healthcare workers also led to the development of resilience. Participants in the study tended to remember specific interactions with healthcare professionals and place a high level of importance on what they are told. We have seen how this affects candidacy and there is a similar, linked, affect on resilience. When people have interacted with health services in their past, a failure to develop a clear management plan and a lack of legitimization from the health professional for their attendance resulted in a personal questioning over the need for future attendance. We have already discussed the negative role this plays in candidacy. However, alongside this it results in the development of the patient perception that such problems can be self-managed and hence increases individual resilience.

"I went to the GP because I had a bad chest and, I've got asthma, and she says, "you're not managing your asthma very well... I'll send you to the nurse"...I went to the asthma nurse and I says, she says, "What are you doing here?" I says, "ah, I've been sent to yer because I'm not sorting out my asthma very well." And she says, "What does she want me to do?"

(Georgina, 64. NVS $\geq$  4)

Here we see how Georgina attended a review as requested but the asthma nurse queried the need for this. The implication of this was that the patient questioned the need for asthma reviews so long as she herself was happy with the control of the problem. It is possible that this will mean that changes to the management of this patient's chronic health that could prevent acute deteriorations in the future are missed. The result of this could mean a greater level of morbidity and mortality are experienced.

Similarly to the influence of healthcare professionals there was a recurrence of the impact of social groups on patient resilience. The support of friends and family was evident and participants discussed reliance on these individuals to maintain health. This suggested a level of "distributed resilience" where the contribution of a number of individuals in an individual's social group can help to develop their personal resilience. Within groups and networks there is the ability to access skills and resources that would not be available otherwise and in doing so allowed distribution of health literacy also. Through these means the social networks acted as a proxy to health services and there were descriptions of the ways people were supported through these networks:

"I'd like to say, it's the social, it is. Because we've got, not just these, we've got two gentlemen who's wives recently have had to go into homes with Alzheimer's and dementia and those gentleman, without our help and supporting them, talking to them freely and them talking to us, I don't think Isaac would be here today, would he?

(Georgina, 64. NVS  $\geq$  4)

Aside from direct support of members of the group, social networks also enhanced access to opportunities for patients to develop their personal skills. This provides evidence for the role of social groups in enhancing both patient knowledge and subsequently resilience. A sharing of knowledge allows people to increase their awareness of services that they may not have known about otherwise. This enhances the ability of the participants to control their own management and access appropriate resources. This ability to direct their own management allows for a more tailored healthcare plan to be produced that are not reliant on the external actions of health professionals.

“Me daughter, erm, she's a...practice nurse at Stoke. She fetched some papers to me, said, "because you're worrying, take these and see if they'll put you on the course." Well when I saw X, the nurse up here, he didn't hesitate. He just, he just went on the computer and, and, you know, put us down on the waiting list to go on it. And, I do like going on these sort of things so I can get the information and I know...you can read so much but I...it's nice to go on these things and have, have people go through it and talk it through with yer. And people are going to listen to you. “

(Leonard, 69. NVS<4)

Not only is self-management being enhanced through the increase in knowledge, but Leonard's health literacy is also being improved. This is being facilitated by the actions of his daughter and the practice nurse who provide access to resources of information. The benefit of having someone go through the

information on a course is also apparent and this further facilitates the ability to understand information that is a requirement of adequate health literacy.

The distribution of abilities demonstrates benefit to those in the social group but also raises concern over how the individuals will cope if and when the social network is disrupted or lost. There were suggestions that people would not be able to cope without their social network, which possibly represents the dependence on these systems and the lack of development of a personal resilience when there is a distributed one in the group.

“I would not be good at all. No, I rely on my wife quite a lot.”

(Craig, 83. NVS<4)

Social groups and networks are a beneficial resource for the distribution of skills and knowledge to enhance the resilience of their members. A concern would be whether this distributed resilience is dependant on continued membership of the network. While continued membership will maintain the resilience and benefits associated with it, it may be that such dependence could have a detrimental effect on the individual resilience. If individually there is no drive to enhance personal skills due to the ability to use the skills and knowledge of others, problems will inevitably be experienced if the social network is disrupted and access to the skills and knowledge to which they have been reliant is lost.

The final factor that was identified as contributing to the resilience of the participants was how they sought out knowledge. Being directed to information

by others engaged the participants in enhancing their knowledge of health problems. By doing this they were able to increase their confidence in their health issues and develop an ability to better manage these.

“He did a prescription and he gave me a website to go on. And he said, "go and, go and read this." He says, and it'll give you more information on the gout. The sort of things you can do to, er, ease it off at that." You know. And I found that really useful”

(Leonard, 69. NVS<4).

Here we again see the benefit that Leonard experiences from being directed to information. A previous example highlighted how the input of his daughter had put him in a position to enhance his knowledge through access to a course. In this example, Leonard again is directed to sources of information rather than identifying them himself. It may be that people with lower health literacy need to be directed towards sources of information, however, below we will see examples of people with both high and low NVS scores actively seeking information that would tend to refute this claim, or add further evidence suggesting that the NVS is not a sufficiently detailed measure of health literacy. These situations allowed individuals to try and determine for themselves if problems needed any further input or if they could be self managed. Resilience was developed in this way by being able to determine the likely actions needed for health problems without the involvement of health professionals.

“Interviewer: OK. When you get new symptoms or you develop any symptoms of being unwell...what will you tend to do?”

Laura: I think I'd go on the- get on the- go on the Internet and have a look see what I've got... and then, if I thought- I already knew Xavier had scleroderma before he was diagnosed. Because I went up to the library and checked it up”

(Laura, 69. NVS<4)

“I used to work in a library- so I tend to go the library and have a look. Like books of cholesterol and books on, like for Jeremy I got books on, you know, high blood pressure and things like that, you know. yeah I do.”

(Frances, 65. NVS $\geq$  4)

Both of these examples demonstrate the ability of some of the participants to seek out information to guide their own health management. This ability to act independently in the seeking of knowledge both develops and is part of the individual's resilience. By acquiring health information participants should be better equipped to self manage their health and as such develop their resilience. Seeking, evaluating, and using information is a key component of health literacy and therefore it would be expected that differences would be seen in the data between those with high and low NVS scores. As can be seen in these two examples, however, there was evidence of information seeking in both groups and assessment of the interviews showed no clear gender difference. What is not fully determined here is whether there is a difference in evaluation and implementation of the knowledge that is sought.

#### 4.5.1 Impact of Health Literacy on Resilience

Resilience was a common feature across all of the interviews and would appear to be a characteristic of all the participants. This suggests that older people in general have resilience but there is a suggestion that health literacy may affect how an individual's resilience develops and how successfully the resilience aids the management of their health.

Participants with both high and low NVS scores demonstrated a preference to self-management with no real difference between the two groups. Doctors would be avoided wherever possible as participants looked to care for themselves. The main difference that was seen between the two groups was how health information was sought and evaluated. Participants in both the low and high NVS score groups sought out health information although one of the participants in the low NVS group described how he would have to be told what information to look at in comparison to other participants who would seek information on their own.

“I wouldn't go on the internet unless it was one that recommended because I think the Internet can be dangerous”

(Leonard, 69. NVS<4)

This may suggest that those with lower NVS scores require external influences such as social networks to allow them to improve their knowledge. In addition to



the access to information there was some suggestion that those in the high NVS group were able to better evaluate the information:

“You’re not thick and you, you, you know what is important and you follow those instructions and, someone a bit...you know, a bit, unnecessary. For example there’s a book up there, yes there is, with things that you should do and shouldn’t do. And you know you go through it and, you know, you, you pick things that’s appropriate to you.”

(Tracy, 74. NVS $\geq$  4)

If people with lower NVS scores do have difficulties both accessing and evaluating medical information, which would be expected with a low health literacy score, these participants may have resilience made up of less developed skills compared to those with higher NVS scores. This may impact on how effectively the resilience facilitates health management in older people. To highlight this, there were examples of people with low NVS scores delaying health seeking to the detriment of their own health, as was seen when Craig ‘suffered’ for years with his health due to his resilient behaviour.

A final point about information seeking is the impact this would be expected to have on health literacy. It would be expected that people who have sought health information would develop their health literacy skills. If this were the case it would be expected that there would be a greater number of participants with higher NVS scores who had expressed previous information seeking, as this would have resulted in their improved health literacy. As has been mentioned

above there was equal number of participants from the high and low NVS score that discussed previous information seeking. This again suggests the limitations of the NVS as a tool to assess the nuances of health literacy.

#### **4.6 Health Attitudes**

A further theme that developed from analysis of the data was that of health attitudes. Attitudes describe the way people think about things and the beliefs they have, in this case, with regards to health and healthcare. There was overlap between this theme and those of both candidacy and resilience as the health attitudes of participants played a key role in determining how they approached their health and healthcare. The data did, however, show evidence for the importance of health attitudes in their own right and this will now be presented.

People held various beliefs about health and healthcare and these were demonstrated across the key areas of accessibility, healthcare expectations and specific health beliefs. There were examples of both positive and negative connotations for these factors which both appear to enable and disable people to manage their health problems.

Experience of poor accessibility was shown to shape the attitudes of participants when considering how they will access future care. Once people have decided that they needed to access care an important consideration for them was being seen in a timely fashion. People were not happy to wait for any extended period

of time and this was evident in the use of other services showing that their belief that being seen immediately was more important than seeing their usual doctor.

“Tabetha: You see, you see, you're faced; you're faced with anything up to a three week wait to see your GP. So then you toddle off to the walk in centre. You spend four hours sitting in the walk in centre...

Richard: Depending which one you go to.

Tabetha: Well all right, three, four, anything. I mean you're not going to walk in through the door and see somebody straight away. So you've got a couple of hours wait at the walk in centre. And, quite often you've told, "well really you shouldn't be up here, you'd have been better off at A&E."

So the general consensus is I'll go straight to A&E in the first place”

(Tabetha, 71, NVS<4. Richard, 58, NVS<4)

Aside from accessibility experiences there was also evidence of other experiences impacting on future service use. Participants attitudes of health services were shaped by their first hand experiences as well as those of friends and family. Poor experiences led to belief among the participants that future use of the service would not be worthwhile. These attitudes towards health services led to the avoidance of healthcare even if a need arose.

“And I went down again [Out of Hours Doctors] and...I saw a lady doctor, she was lovely but she was, er, spoke very good English but I think she was Swedish or German, she wasn't English anyway...she gave me some medication that you give to people with shingles. And I took it and it

didn't seem as if it did anything. I still had the pain. So I had a phone call Monday morning, eight o'clock. "Can you come down to the surgery? You've had these tablets." And I think she'd given me a quarter of the dose I should have been on... So I lost, although they were fantastic, I lost...when I had me bad chest, because they [GP] put me on...steroids straight away for a week. And over the weekend...I got worse on Saturday and worse on Sunday, I wouldn't phone 111[NHS 111 service]. I didn't trust them. So what I did, I waited till Monday and then I had to have strong antibiotics, on Monday. But really I needed them on Saturday. And I wouldn't have needed such strong antibiotics but I didn't trust the doctors on the emergency"

(Georgina, 64. NVS  $\geq$  4)

Several assumptions and expectations were held regarding healthcare. The monitoring of chronic health problems was discussed with the participants. Assumptions were made about how healthcare professionals monitored conditions on behalf of patients. A number of the participants' attitude towards the management of chronic health was that the doctor should be taking responsibility for the process. In doing this they demonstrated a passive approach to healthcare that negated the need for them to make decisions over monitoring and healthcare.

"M: It'd be nice to know someone was following it up

I: Mm-hmm

M: But presumably they just following it up from the results that come up on the computer I imagine”

(Tracy, 74. NVS  $\geq 4$ )

Other concerns were raised regarding what the consequences of accessing healthcare would be. There was a belief that something wrong was identified when going to see the doctor. It was interesting to observe a concern over problems being identified suggesting an attitude that people in this group would rather not know of problems which led to doctor avoidance. This would fit with some of the issues surrounding health aims that have already been discussed where participants were more concerned with being able to function. If people have a simple desire to be able to continue with their life on a day-to-day basis then identification of chronic problems may not be important to them.

“I much rather keep away from them, every time you go the doctor, they find something wrong with you.”

(Dianne, 75. NVS  $\geq 4$ )

Adding to the possible explanation that participants were not concerned by problems that do not affect their day-to-day functioning can be seen where participants questioned the issue of problems that did not cause symptoms. This group of people questioned the need for medical intervention for problems that did not cause immediate problems and suggested waiting until physical issues arose before seeking a review. In doing so the participants display an attitude that health can be defined by physically apparent issues only, which may be in

contrast to the attitudes of health professionals. This adds further weight to the possibility that healthcare was accessed to manage symptoms and acute issues rather than to manage longer term problems. These were either accepted as normal for the patient or left to the doctors to monitor.

"Why should I go on it if I've got no symptoms, why should I go on statins? Dr L said " Oh well I'll put you on 10". I think she done it because Mr G, or Professor G, whatever his title is, I'm not sure, whether he's put it one the report on the computer and she's taken his advice I don't know. But she said " I'll put you on 10". But I, er, it's old cliché, if it's not broke don't fix it, if I don't feel, if I feel well enough why should I take tablets?"

(Gerald, 83. Unable to complete health literacy assessment)

It appears that Gerald's attitude towards medication is that it is started in response to noticeable symptoms. A lack of understanding of the preventative role of certain medication suggests a lack of health literacy. The role of the doctor in this situation must be highlighted though, as there appears to be a failure to properly inform the participant about the reasons for starting a statin. As the expert in the interaction the doctor should be supporting the participant to allow them to make informed decisions. It is not possible to know if Gerald would have thought differently had the doctor discussed the reason for starting a statin fully but it is seen how, given the current lack of information, that Gerald's opinion is "if it's not broke don't fix it."

“Well I don't really understand what it's [cholesterol] all about. And until it effects me or something goes wrong I don't know why I should”

(Frank, 83. NVS<4)

Here Frank demonstrates a similar attitude that healthcare is accessed in response to something going wrong. He freely admits that he doesn't understand the issues surrounding cholesterol but rather than seeking advice and preventative measures he feels that there is no problem if there are no physical manifestations.

Specific beliefs were held on medication and there were many individuals who held negative beliefs on the consumption of medication. This was offered as a further reason why people tended to avoid accessing healthcare. Participants disliked medication and felt that this was the most likely outcome from consultations. This was used as a reason for avoiding such interactions and reducing access to care

“One thing I don't want is more tablets and that's what you get off them and I don't want that. A tablet that'll do it, 'cos a tablet wont do it, it's you that'll do it”

(Tabetha, 71. NVS<4)

As discussed participants have several assumptions about healthcare both in terms of accessibility and the likely results of interactions. These are seen to

influence the participants' attitudes and suggest a barrier to the timely review of health problems.

Aside from priorities between health aims and acceptable interventions there were other conflicts between health and personal life issues. In the following example, even after identification of health problems, the presence of life events superseded health needs as her role as a carer affected her ability to access her own health support:

“So I cancelled it and they gave me one for May the 8th but I had to cancel that as well as he was still... I couldn't leave him for a minute because his breathing was so bad. He was in and out of the hospital all the time and they never took any notice of what I was telling them”

(Laura, 69. NVS<4)

There was also evidence that people looked to prioritising health problems. Having one health complaint that took priority over another meant that people would ignore other issues to focus on the care of their main problem. As with other reasons for presenting, the main priority was usually a problem that affected day-to-day living.

“Something was wrong and I wouldn't ring the doctors for that reason because I was waiting for the hospital and I thought I might have to go in [Awaiting eye operation] so I didn't ring my GP, somewhat that's gone



now anyway. But that was it stopped me ringing. Not the GP, I just though,  
No suppose I ring and er, I can't go for my eyes”

(Gerald, 83 Unable to complete health literacy assessment)

A recurring theme in the data surrounded the locus of control. There was a mix between individuals who felt they had control over their health and those that did not. We have seen how some were more than happy to allow doctors to take control for the monitoring and care of health problems whereas others like to maintain control. Despite this variance in perceived locus of control, a common feeling amongst interviewees was that presentation to healthcare professionals signalled a point where significant amounts of control were devolved to the healthcare professional. Giving up control to others can be difficult and may represent a reason for delaying presentation.

“If I like to take em is a different matter, I'm just, I'm following instructions”

(Gerald, 83. Unable to complete health literacy assessment)

“When they tell me come back in a week or two weeks if it doesn't disappear, I will go back if it doesn't disappear. I'll do what they tell me in their view is best”

(Lianne, 84. NVS<4)

In both these cases there is a demonstration of the deference given to the advice and knowledge of the doctor. There is no evidence of any evaluation of the issue

on the part of the participant with avoidance of using any health literacy skills. Without being able to evaluate the situation effectively, individuals with low health literacy skills are left to either accept the word of the doctor or refuse the treatment as demonstrated previously at the potential risk to their long term health.

There were further examples of participants needing to put their trust in the healthcare providers. This was seen as part of the requirement to allowing the locus of control to be given up.

“Well, when you go into hospital and you're in bed with all being wired up and everything else you think, they know what they're doing. Or you hope they know what they're doing, and you've got to put all your faith in them.”

(Craig, 83. NVS<4)

We have discussed above how some individuals trust in healthcare providers has been lost through previous experience with the result of a future reluctance to allow the locus of control to be passed onto them. This is further evidence to show the impact that poor experiences can have on long-term healthcare.

Another area of discussion focused on what people expected from their health service. There was often a difference between what was being offered and the health system desires of the individuals. A prime concern was that patients felt pressured into only presenting one problem a time at consultations. There was a

desire among some to have an “MOT” where they could ask about multiple small problems. In addition to this the perceived reluctance of GPs to do this led some to question the worth of their attendance, building on the candidacy concerns discussed previously. With a request from GPs to only have one issue per consultation there was a trivialisation of the multiple smaller problems that people often had.

“To complain about one particular set of symptoms, you know, what about all the rest...I had the usual 6 month blood tests last week and I did say to the nurse, you know don't wa- don't doctors do MOTs on older people? You know what I mean? If y- you made an appointment once a year or something like that to.. check things. All kind of, you know, small things”

(Tracy, 74. NVS  $\geq 4$ )

Here Tracy demonstrates an attitude towards healthcare held by several of the other participants also. By suggesting a desire to take a list of problems to the doctor on a regular review basis there is a demonstration of the lack of an ability to assess each of the problems and determine which need review. Instead of seeking healthcare when needed the participants would take all of their problems to the doctors so that the doctor can determine which need further action. Although Tracy has an NVS score of 5, this would suggest inadequate health literacy skills in this area.

Further to the desire to have regular health reviews, there was a questioning of the hours worked by GPs, with a feeling that there should be longer opening and 24 hour on call access. This may demonstrate a misunderstanding of service availability, as there is 24 hour access to care in the UK. Alternatively this may be evidence of the expectations of older people who want their 24 hour care to be provided by their own GP. Comparisons to how health services were run previously was common in this respect and people would often compare the current health service to one they were accustomed to previously.

“I think the doctors are not working right anymore. I think a doctor should be on twenty-four hours. A medical centre should be open twenty-four hours and care twenty-four hours a day. That'll take the...brunt off the accident and emergency unit. People are getting fed up of just going in uncertain times. Now it's not very good for you is it? But then again we had to do, when I was working we had to do days and nights, so why shouldn't the doctors?”

(Laura, 69. NVS<4)

It is clear how these factors have affected the approach to healthcare that participants have taken. In addition to these there were more examples of the way people approach healthcare and health services. Examples of both active and passive approaches to healthcare have been discussed. There were further cases of the ability of those with an active approach to healthcare being able to plan reviews of their health. This ability to consider the possible difficulties in

accessing care in the future demonstrated a resourcefulness that allowed for timely review of health problems, and suggests a higher level of health literacy.

“Now, if the weekend is coming up and I think, well I can't do anything Saturday and Sunday, I'll make an appointment on the Friday if it's really, if it's bad, to make sure. I do not want to be the whole weekend feeling really, really bad and not be able to get an appointment maybe until Tuesday or something so yeah, yeah I do”

(Lianne, 84. NVS<4)

Similarly a number of participants took responsibility for their own health and accepted an active role in the seeking of assessments and review. These individuals felt that it was up to them to accept responsibility for accessing services rather than wait on the intervention of the providers. This meant that they were not dependent on the actions of others to maintain their health.

“No, because I can be equally stubborn really. No, I mean it's no good me complaining if I say I wouldn't bother because of, you know, erm. It's my responsibility. My health is my responsibility as much as anybody else's. The doctors down, down in Newcastle they're not mind readers and say, "Ooo, we haven't seen her for a while, perhaps she isn't very well." So I do think it's mine, it's our responsibility as a family to, erm, to go and, when we have to.”

(Holly, 70. NVS ≥ 4)

In comparison there was a significant group of individuals who had a more passive approach to healthcare and had decided that they would wait for healthcare professionals to initiate reviews. The issues in these situations are that maintenance of health is being trusted to an assumption that someone else is actively monitoring the situation.

“P: See the doctor does then best they can do with you. I mean normally if they do need you they do ring you don't they?

L: Yeah

P: Our doctors. They'll say, "It's about time you came in, had a word you know."

(Tabetha, 71, NVS<4. Richard, 58, NVS<4)

In some cases there was even a frustration that the patient was asked to take responsibility for reviews. It was felt that this should be done for the patient for fear of them forgetting.

“But, er, at the moment we have to rely on ourselves remembering when our next check up is due. We have a problem where they don't bother to let you know... when you have one review they tell you when your next one's due. But they never send you a reminder that it's due. If you don't come home and put it on the calendar, then it's missed”

(Eva, 70. NVS<4)

Other individuals also suggested a need to be prompted to take healthy life choices. It was suggested that without the input of a health professional there was no impetus to change despite implying a desire to make alterations to health behaviours:

“I wish somebody would say to me, you know, you really need to lose, 2 stone we’ll say, and then you’d work on it, but whilst it’s- you’re just in limbo. So you don’t really bother”

(Tracy, 74. NVS  $\geq 4$ )

The final area of discussion that was raised by the participants surrounded the impact of support and external influences on health behaviour. We have already seen how the social networks formed by participants have impacted on their candidacy and resilience. We have also discussed how health literacy may impact and be distributed along these networks. Further evidence for this was seen within the context of attitudes towards managing health and accessing healthcare with some of the participants directly benefiting from having a social contact that was able to enhance their ability to recognise and manage health problems and therefore increase their health literacy:

“I mean we didn’t know it was a PE (pulmonary embolus) but Kirsten had got a good idea what was going on. Probably because of me wife I’m all... I’m alive really”

(Luke, 75. NVS  $\geq 4$ )

“I had the most awful, awful cough and I didn't know that I'd got it. And my friend- we were speaking at a WI thing and when we were going she said, " are you going to be alright with that cough?" And I hadn't noticed it but it went on and on and on for the whole of December”

(Holly, 70. NVS  $\geq 4$ )

Wider than this, however, was the information and advice that was sought from external sources. Experiences of others within a social group influenced the beliefs of the participants and affected their own likelihood of implementing healthcare:

“I know me stepson, he lives in Ireland, Gary, and he was taking them [tablets], sta..., well there was a programme last year or a couple a years ago or something about the side effects and I thought I'm glad I don't take.”

(Gerald, 83. Unable to complete Health Literacy Assessment)

Information passed on through social groups provided the patient with a degree of information. The ability to determine the worth of that information varied with some disregarding certain parts whereas others took everything on board. This acquisition of knowledge was then used to shape their healthcare and in some instances was again passed on to others, showing a perpetuation of adjustment of health behaviours in a social group:



"Well I have prostate trouble. And er, I had me prostate done, and, then I was told I was, a friend that was working in Germany. He was here on holiday. And he said, "P, they're don't operate for prostate in Germany." He says, " Only for if it's cancerous." He say, " They use tablets." I says, "what sort of tablets." He says, "You can buy them." Any rate, er, when the son got on the phone one time and he says, " I think I've got prostate problems," I said, " don't go the doctor, come to me.""

(Toby, 89. NVS<4)

There have been several examples of the beneficial effect of distributed knowledge and health literacy in social groups. Here, however, Toby provides evidence for the detrimental effect of such distributed knowledge. If individuals share incorrect information or inadequate skills the recipient of the information will be no better off and potentially receive worse healthcare. It cannot be expected, therefore, that being part of a social network will invariably lead to a better distributed health literacy, as it is dependent on the people within the social group.

A further example of the dissemination of information in social groups is seen below. Here the possible enabling affects of social groups and how discussions in these circles have the potential ability to break down barriers to healthcare in the community are displayed:

"I think it's handy when men do talk about problems... it's like prostrate problems, one or two of them started with that. And they're embarrassed.

They do want do about it so I- if they come to me I just tell em, you know, how I was checked out and what they did with me and everythin'... I said, "well, you know. It's, it's your life and your health as you're thinking about." I mean, it's like the bowel cancer screening. The number of people down there when they've had em have said, "Oh, I don't fancy this. I'm better not knowing." I said, "well not really. The sooner you know, the better." "Well, well would you do it?" I said, "I, I've been doing it for a while." "Oh, well I'll think about it."

(Frank, 83. NVS<4)

#### 4.6.1 Impact of Health Literacy on Health Attitudes

There were three main areas within health attitudes that were seen to be influenced by health literacy skills. These were the attitudes towards accessibility of healthcare and the ability to navigate the health system, whether participants had a reactive or proactive attitude to healthcare, and the role of distribution of skills and information among social networks in shaping participant attitudes towards health and healthcare. As seen in the discussion of candidacy and resilience there was sometimes a mismatch between what is expected of participants with regards the accepted definitions of health literacy and their NVS scores. This further suggests the limitations of the NVS as a measure of the range of skills involved in health literacy.

In keeping with the expected differences in attitudes towards accessibility discussed above, there were differences in the perception of accessibility between participants with high and low NVS scores. Generally, participants

found the phone systems obstructive and for some this resulted in either going down to the surgery or accessing other healthcare services. Of the six interviews of participants with high NVS scores four suggested an ease of accessibility with only one suggesting a difficulty in accessing care. These participants also demonstrated abilities to overcome potential barriers to accessing care. One discussed the use of emergency appointments, one discussed using a recall system when calling to negotiate the phone booking system and a third discussed his use of online appointment booking. The one participant with an high NVS score who viewed access as a problem had found a way to arrange an appointment if required by suggesting to the receptionist that they would need a home visit if no appointments were available. In comparison, eight of the nine participants with low NVS scores had a negative attitude towards accessibility with the remaining participant having neither a positive or negative attitude. These participants also provided less evidence that they had ways to overcome the perceived inaccessibility of healthcare services. This suggests that a common attitude held amongst the participants towards barriers to healthcare. However, those with higher NVS scores demonstrated an ability to overcome the barriers, while the inability of those with low NVS scores to overcome these barriers suggests that the attitudes that they have formed are a barrier to healthcare in themselves.

#### **4.6 Summary**

This chapter has described the findings from the qualitative study of chronic health management in older people and the impact of health literacy. Candidacy,

resilience, and attitudes were found to be important factors in how the participants viewed both the health and healthcare. Assessment of these themes and the factors that make them up showed the influence health literacy would be expected to have on them. It appears that health literacy is an important factor in determining how people form candidacy and resilience and also impacts on the health attitudes that are acquired. Interestingly the expected differences could not be identified by comparing participants based simply on their NVS score. The possible reasons for this and a discussion of the findings and implications will be presented in the following chapter.

## **5. Chapter Five: Discussion**

### **5.1 Overview**

The previous chapters have looked at the impact of health literacy on older people's management of health problems. This has shown how there is still a large gap between what has been observed in terms of poor health outcomes and the understanding of how this relationship is facilitated. Models have been proposed that suggest possible factors linking health literacy to outcomes, however there is currently a lack of convincing evidence to substantiate the claims. The study discussed in Chapters Three and Four describes factors developed by older people as they age that influence how they approach health and healthcare. Overarching themes of candidacy, resilience and attitudes were identified in Chapter Four and these will be discussed here along with the importance of social networks and support which had a strong presence across all of these themes. Evidence of the impact of health literacy on these factors was also demonstrated and provides a new avenue for further research and policy to improve outcomes in older people.

This chapter will summarise these findings and compare them with the current literature, including that of successful ageing. Overall strengths and limitations of the thesis will be considered, and the implications for clinical practice and potential future research are discussed. There will also be personal reflection on the project and a final summary to conclude.

The aim of this thesis was to investigate the impact of health literacy on the management of chronic health in older people. This was achieved through an initial systematic review followed by a qualitative study. This study focused on interviewing older people to investigate their attitudes, beliefs and experiences surrounding health management, access to care and motivation. Health literacy was measured using the Newest Vital Sign (26) and was used to compare the responses of individuals from different literacy groups.

The systematic review showed that there is still a lack of understanding of the factors mediating the association between health literacy and health outcomes. There was evidence to support the association between health literacy and patient motivation as well as a positive effect on patient attitudes. The impact on access to care was mixed, however, with no clear conclusions possible. This suggested the need of further theory building research to improve the understanding of the pathways between health literacy and outcomes.

There were several interesting findings from the qualitative study. In general older people exhibited resilience in coping with chronic conditions but there was also a suggestion that this could impact on candidacy and access of healthcare. The impact of measured health literacy was least convincing in this theme with all individuals demonstrating resilience to a greater or lesser degree. The findings did, however, support the possibility that social networks were important to improve health literacy skills by the distribution between members. This may allow those with inadequate individual skills to overcome and

supplement their own health literacy. However whether these skills are maintained when contact with social networks is disrupted was not assessed.

Patient candidacy was another key theme identified and related to the individual perception of eligibility for healthcare. The impact of experience and health literacy in this area was stronger. Those with inadequate health literacy tended to need an external legitimizing factor, such as an invitation from their GP, to produce sufficient candidacy. In contrast, individuals with adequate health literacy were more capable of internally validating the need for accessing care. This demonstrates the possible effect health literacy has on being able to rationalise and prioritise health and their health needs. Again social networks were seen to be ways for skills to be shared and provide external validation for candidacy in its members.

The final main theme was on patient attitudes. There were numerous attitudes discussed including attitudes toward communicating and ageing. Evidence to support the ideas of successful aging and social roles were apparent and add to previous work in this field. The most prominent attitudes within the study surrounded attitudes and beliefs about access and perceived barriers to this. Health literacy again appeared to play an important role here with those individuals with adequate levels having a more positive view and an ability to overcome barriers to access. In comparison, individuals with inadequate skills found access more challenging and were unable to demonstrate evidence of their ability to conceptualize ways to overcome the barriers they had identified.

## 5.2 Successful Ageing

In Chapter Four we saw how older people have developed characteristics and beliefs that shape how they approach their health and healthcare. This has occurred over the course of their lives and formed part of their ageing process. Research has examined 'successful ageing' which has most commonly been defined by the biomedical aspects of aging. Rowe and Khan defined successful ageing in terms of low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life (157). The focus in definitions such as these marginalises the psychosocial components of what constitutes successful ageing. The primary concern of successful ageing in this definition would be to avoid the development of ill health and minimize the adverse physical effects from disease that might occur. The lack of lay perspectives in these definitions has led to criticism from sources that suggest the social influences that shape ageing has been neglected (158). Attempts have been made to develop the concept of successful ageing to incorporate other factors. A systematic review published in 2013 aimed to synthesise the evidence for lay perspective of successful ageing (159). The findings from this review added to the literature by including lay perspectives of successful ageing, demonstrating how this contrasts with the previously discussed definition. Of the studies they found, all of them included psychosocial components in comparison to only 76 % of studies including biomedical components. The psychosocial components that were identified included resilience, maintenance, social roles, independence, and quality of life. This wider definition is similar to the WHO definition of "active ageing" which has been described as the "process



of optimizing opportunities for health, participation and security in order to enhance quality of life as people age” (160). Acceptance of ageing was also seen as successful. This may give us some explanation of why older people have a lower perceived eligibility for healthcare for certain problems, i.e. lower candidacy.

Further literature on aging and sick roles (161) looked at the perception of older people with joint pain who reported regarding themselves as being healthy. The intention was to examine views of health in spite of chronic pain. They concluded that the key to wellness was the ability to continue with everyday activities and roles. Complicit in this was the perception that physical decline is a normal part of the aging process and so long as this does not interfere with the ability to continue with their life and roles, it is not perceived as a problem. This belief is echoed in the work of Moore et al who described how successful aging was driven by the concern of losing independence (162).

These concerns resonated with the findings in Chapter Four. People from the study discussed how they saw health as being able to carry on and that seeing a new day and being able to get up and continue with their lives was seen as a primary aim. This definition of success from the participants reflects the literature discussed above and provides both further evidence for the theory of successful aging and demonstrates the similarity between the study group and those observed in other studies.

The priority of maintaining a desirable lifestyle and independence over the avoidance of illness gives an insight into priorities of older people and allows us to contrast this to previously developed theories on sick roles. The seminal definition of illness identity and the sick role were developed by Talcott Parsons in the 1950s. He defined illness as “the breakdown of the general capacity for the effective performance of valued tasks.” (163)(p4) Parson’s sick role looked at the importance of individuals contributing to society. Entering a period of illness, he argued, negatively affects the ability to contribute and as such patients are afforded a permitted deviance. During this phase they are not expected to contribute but are expected to seek to regain their health and normal functioning. This definition has received criticism as health issues have evolved and chronic illness has become increasingly prominent (164) (163). The original theory fitted well with acute illness but is arguably less applicable to chronic conditions where a full recovery is not expected. A return to normal functioning after illness is dependent on what is considered normal. Normal functioning for both older people and those with chronic conditions are different from the baseline set out in sick role theory. Those with chronic conditions are not expected to reach the level of health they had before developing their condition. A new “normal” level of functioning is developed with exacerbations resulting in acute deteriorations in health. A similar picture is seen with older people. As mentioned above there is an acceptance among older people that physical decline is a normal part of aging and this was also seen in the study described in this thesis. Further to natural decline there are health problems that are also considered part of the aging process, such as osteoarthritis (165). Symptoms of conditions such as these are seen as a nuisance and simply a disease of the

elderly (166). With older people seeing these as an inevitable part of the aging process they are normalised and not seen as worthy reasons to take on a sick role and seek healthcare. It is evident, therefore, that what is 'normal' for older people differs from that of younger populations. The inclusion of chronic illnesses in this definition of what is considered 'normal' provides an obvious explanation for the reasons why older people do not develop candidacy for these issues.

Additional work with people who are living with pain provides further explanations for the actions of older people with regards their health. Blomqvist and Edberg explored how older people experienced and handled chronic pain (167). They found that there was often a prioritisation of independence as a health aim. They also identified four distinct groups of individuals who had different views of health and healthcare. One of these groups was titled "Competent and proud" and these people were proud of their self management. Coupled with this was an unwillingness to be a nuisance. Another group named "Confident and serene" demonstrated satisfaction in spite of suffering with pain. These two groups contributed to nearly fifty percent of the study population. A significant proportion of older people, therefore, demonstrate a preference to self management and healthcare avoidance or are satisfied with problems. This is in keeping with the findings of the study in this thesis which showed the preference of participants to self manage their problems and avoid healthcare access due to a desire to not be seen as a nuisance. The remaining individuals were either grouped under the title "Misunderstood and disappointed" or "Resigned and sad". The occupants of the former of these two groups felt unfairly

treated and believed that older people were discriminated against by health care services. It could be argued that with this viewpoint that such individuals would perceive greater barriers to accessing healthcare, which may impact on their service use. The remaining individuals belonging to the final group were resigned to pain and feeling sad. The authors commented how the pain experienced by the individuals often “restricted them and made them feel as if they were a bother to others” (167)(p302). This description of being a nuisance further demonstrates the difficulties faced by some older people in developing their candidacy for healthcare.

Parson’s sick role (1951), which focused on the impact on society of individuals suffering from illness, could be extrapolated to take account of these actions. In the ‘sick role’ illness is described as deviant behaviour and requires the individual to take certain actions to return to normal functioning. We have already discussed how the concept of normal functioning has evolved in an older population and is no longer consistent with that suggested in the sick role theory. The concept of deviance, however, does provide us with a possible understanding of the actions of older people. It is possible that older people feel their role in society is defined by their age. Indeed there has been work that shows older people assess health in terms of what might be expected for someone of their age (161). Other work has shown how older people are very sensitive to being perceived as unwelcome burdens (168). If we accept that older people believe that ill health is to be expected as part of the ageing process and that they should accept this without being a nuisance we can postulate how they view their role in society. These factors may lead them to define their role in

society as one that includes chronic ill health and subordination to younger populations as normal. In doing this, accessing care for chronic conditions and using time that could be made available for others may, from such a perspective, be deemed inappropriate behaviour. This would fit with the evidence presented from the study in this work which suggests an unwillingness to access care unless faced with a crisis in health. Work has also shown how older people are keen to maintain these identities that they create within society (169) and will avoid actions that have the potential to disrupt this such as help seeking. This links in to one of the main themes from the study in this thesis, that of candidacy.

### **5.3 Candidacy**

Candidacy is a term that has gained increasing interest in the field of medical research. This is in part due to the observations that “neither service availability nor the presence or absence of illness is sufficient to explain use of services.” (168)(p34) It describes the eligibility patients consider themselves to have for accessing medical care and has been shown to be influential in presentation to health care and acceptance of treatments (170) (171) (172). It is generally accepted that older people have a lower level of candidacy and that this impacts negatively on issues of access and management. As has been discussed in the findings this was again reflected in the study population with a widely held belief that they were not candidates for healthcare unless certain criteria were met. With a higher threshold for acquiring sufficient candidacy to engage with healthcare, older patients will naturally accept greater levels of ill health. This is

in keeping with the previous discussion over successful aging and sick roles where older people look to normalise ill health as part of aging.

Previous research has examined the influences that are involved in the construction of individual candidacy, and it is thought that there are numerous factors. Among these are the influences of information, knowledge and beliefs; confidence in self diagnosis and self management; and social support (168). Seven domains of candidacy have also been proposed (153) and as was discussed in the previous chapter these were areas identified through the analysis of the interviews from the study in this thesis. We saw how people identified their candidacy, navigated the health services and appeared at health services and also the role that health professional adjudication, penetrability of services, and operating conditions in the form of social networks had candidacy development.

The importance of knowledge in help seeking and candidacy has been highlighted in several studies. Some have looked at the knowledge of services (173) as an important determinant of use. There has also been work looking at knowledge of disease and symptoms as a key contributor to help-seeking behaviour (174) (175) (176) (177) (169). These studies looked at a variety of areas including correlations between knowledge of cancer symptoms and help seeking and linking knowledge to assess the significance and seriousness of symptoms. This is reflected in the study in this thesis with individuals often showing evidence that they were unable to assess the seriousness of problems. In one case a gentleman whose NVS score indicated inadequate health literacy,

incorrectly assessed his symptoms of cardiac chest pain as trapped wind, missing the potential serious nature of these symptoms. On a further occasion he failed to identify the potential seriousness of a wrist injury and delayed presentation as a result. Studies have shown that people with inadequate health literacy, irrespective of their educational attainment, have lower levels of written medicine information seeking (178) (179). In the study described in this thesis there was fairly comparable evidence of knowledge seeking behaviour between individuals whose NVS scores indicated adequate and inadequate health literacy. What did emerge, despite the small study size, was that it was apparent that those with NVS scores indicating adequate health literacy were better at appraising and utilizing the information which is consistent with the findings from the other studies discussed. There was also evidence of the benefits of improving health literacy by knowledge seeking in the assessment of symptoms and enhancement of candidacy. One lady whose NVS score indicated inadequate health literacy discussed how she was able to identify the cause of her husband's symptoms through reading at her library. This, in turn, led to the access of care and so was a direct influence on candidacy. Adding to the current evidence for the benefits of knowledge, therefore, it is seen that reinforcing knowledge seeking behaviours and facilitating the access to this knowledge could act to overcome issues of poor candidacy in those with inadequate health literacy.

As mentioned above, confidence in self diagnosis and management was another theme that was encountered in the review on vulnerable groups and access to care (168). This was seen in the study in this thesis and tended to delay identification of candidacy and presentation to primary care as people

demonstrated confidence in caring for themselves. This reflects work in the wider literature that found that patients will often look to self manage and that increased confidence in this process will lead to avoidance of help seeking until a later stage in their illness (180) (181) (182). The scope of this phenomenon appears to spread across age groups with younger people and parents showing the same characteristics of self confidence and management. It is likely, however, that the interactions between confidence and other factors such as wider candidacy issues result in a more pronounced effect in older people. The greater life experience of older people is also likely to play a role in their self management preferences. These individuals are not only more likely to have had or seen a greater number of health problems, they will have also seen recovery from problems leading to an increased confidence in the success of self-management. Many participants in the study in this thesis had been through periods of great hardship, such as the Second World War, and the experiences of these times had further enhanced the importance of self management. For these reasons it is probable that older people may be more resistant to efforts to reduce their 'inappropriate' self-management. Tools to improve inadequate health literacy may be a way to assist with this. Educational programmes have been shown to be effective in enhancing diabetes outcomes through self-management (183). As has been described above, knowledge seeking has been shown to improve the timing and appropriateness of help seeking behaviour. As such targeting health literacy will aid in this and is likely to also improve the appropriate use of self management while increasing candidacy for problems that need medical assessment.



We saw in the findings from the study that there was a difference in how individuals legitimise accessing healthcare. Those with inadequate health literacy tended to need an external legitimizing factor to overcome issues surrounding low candidacy. In comparison the adequate health literacy group demonstrated a greater ability to internally justify help seeking. This is described in the literature as ways of presentation. How people present to health services is key establishing candidacy. The manner in which this is done, however can vary and has been described as 'Appearances' and 'Invitations' (168). An appearance requires the individual to appear to health services independently by their own actions. Examples of this would include independent attendance for acute health problems. In contrast, invitations can be sent by health service providers and patients simply need to respond to this. A common example of this would be screening programmes for certain cancers. These invitations are external legitimizing factors and were often preferred by people with inadequate health literacy in the study in this thesis. There were indications that people felt that more health monitoring, promotion and prevention should be initiated by health service providers and as such showed a desire for a further shift from personal action to invitation. With the study demonstrating a greater acceptance of the need for personal legitimization in adequate health literacy groups it would appear likely that interventions to enhance health literacy would be able to readdress the balance of responsibility for chronic health management and identification of candidacy between the individual and services.

A prominent feature from the findings and in the wider literature is the influence of social support and networks. It is one of the most frequently researched

psychosocial forces and has been shown to be a strong influence in occurrence and recovery from life problems (184). The influence of social networks as an operating condition in the study were prominent and featured in several of the themes. People expressed how discussions with family, friends, and extended social groups formed part of their everyday lives. Discussions over health were common and advice was disseminated through these social networks. The literature contains several descriptions of the ways that social networks interact with health literacy and influences health. When confronted with a health problem people often look to the advice from social networks prior to seeking professional advice (185). This may be due to issues over shame and stigma associated with low health literacy (186) (187). Although this avoidance of professional sources acts as an initial barrier to accessing care it is thought that the social support provided in these encounters may have an enhancing effect in the long term. It is possible those feelings of shame are reduced after support within social circles and that these can work to overcome the initial issues of candidacy that this can produce. The role of social networks will be reviewed further in subsequent sections to demonstrate the scope they have in health and healthcare.

## **5.4 Resilience**

The concept of resilience has developed significantly from its initial origins in paediatrics. It was first used to describe how children were able to overcome hardship before later being used to describe the “process whereby people bounce back from adversity and go on with their lives.” (188)(p276). It can be

thought of as a protective mechanism for dealing with difficulties and minimising harm. It also allows a return of functioning after periods of stress and enhances the ability of individuals to adapt. In doing so it is suggested that it forms part of the process of successful ageing (189). The development of resilience rests on both experiencing adversity and recovering. It follows that those that have experienced more adversity have a greater potential and need for enhancement of their resilience. I believe that older people, therefore, are likely to have more opportunity to develop strong resilience as part of their ageing process.

How resilience is experienced by older people is another area that has been explored in the literature. A qualitative study described how older people view resilience and described how participants would count their blessings and focus on the “good things in life” (190)(p419). They also discussed how important it was to be able to maintain a social role and continue in desired activities. This was a feeling that was also repeatedly seen in the study in this thesis. Participants would explain how they were content with being able to get up in the morning and carry on their lives. This acceptance of maintenance as a health aim plays an important role in how older people will view ill health. As discussed in the sections on successful ageing and candidacy, what individuals consider normal will influence when they consider their health to be sufficiently abnormal for their age to acquire candidacy and poses a sense of eligibility for healthcare. If older people, through their resilience, aim for the ability to carry on with their lives over medical optimization, there will naturally be a discrepancy between their targets for health and the management of chronic illness, and those of the health care professionals. This focus on health as a means to continue with life

rather than avoid illness offers a possible factor for outcomes in older people. By not feeling candidacy older people may be more likely to suffer acute issues and as a result of not always acting on deteriorations there will be an increased risk of more serious presentations with worse associated outcomes.

Interestingly, despite the suggestion that resilient older people may not address health issues in a timely fashion, there is evidence to suggest the long-term benefits of such resilience. In older people, resilience has been shown to be associated with longer lives as well as increased satisfaction (191).

As found in Chapter Four there was no convincing evidence of measured health literacy impacting on the presence of resilience in older people, however there was some suggestion that health literacy may be involved in how successfully resilience is developed. A possible explanation for this is that resilience is a characteristic that is developed through encountering and overcoming adversity. It could be expected that those with better health literacy should be better placed to overcome individual periods of adversity by looking at the differences in outcomes with different health literacy levels. Resilience is not, however, defined by a single episode and is constantly being developed through subsequent periods of difficulty. In older people the number of adverse periods is likely to be high and so the probability is also high that they have successfully overcome sufficient episodes that they have developed resilience independent of their health literacy level. Variations in perception of normality may also be involved in the development of resilience. It is possible that people with lower health literacy have a lower target for recovery and as such have a lower

threshold for measuring recovery from adversity. Through this mechanism people with lower health literacy perceive a successful navigation of periods of difficulty that may not be deemed sufficient by those with adequate health literacy. This hypothesis would mean that people with adequate and inadequate health literacy both develop resilience, although the level of medical recovery and the ease at which adversity is overcome differs and may be inferior in those with inadequate health literacy.

A further potential contributing factor to explain the lack of difference in resilience identified between literacy groups was that health literacy can be distributed through social groups. Through this mechanism skills are shared between members of the group and allow those initially without certain abilities to navigate situations that they may not have otherwise been able to. This will be discussed in more detail later on in this chapter in the section on social support.

## **5.5 Attitudes**

Opinions and attitudes formed by people are often complex and developed through numerous pathways. We saw in Chapter Four how participants in the study discussed previous experiences and encounters that had affected future interactions with healthcare. Looking at those factors that appeared to be influenced by the individual's health literacy the issue of attitudes towards accessibility to healthcare was identified.

Access to health has been the subject of inquiry in the field of health literacy and has resulted in several papers that have looked to describe possible associations. Synthesis of the data found limited and insufficient evidence to support a link between health literacy and access to care (192). The two studies that were identified were set in the U.S. and found utilization of services was not linked to health literacy (193) (194). There are two factors about these studies which questions the generalizability to older people in the UK. Firstly the studies, as mentioned, are both U.S. based. The barriers encountered by individuals trying to access care are therefore different to those in the UK. This is made apparent in one of the studies that describe the barriers. Some of these were financial and linked to the differences in payment of health services between the U.S. and UK. Other barriers mentioned included arranging of childcare and it is questionable whether this is a realistic barrier for older people. The other factor that needs to be addressed is on the actual measure of access to care. These studies looked specifically at utilization rather than attitudes towards access and barriers to access. This might be a significant difference as it may explain the observation that people with inadequate health literacy may delay seeking care (195).

Dixon-Wood et al discussed the concern over measuring access through utilization in their 2006 synthesis of the literature (153). They highlighted the problem with measuring access by measuring units of healthcare such as consultations or procedures. It can be argued that a simple measurement of units of healthcare used fails to assess the ability of people to access care at the point that it is required. There is a failure to consider the process by which individuals undertake to gain access and a failure to consider the perceived and

actual physical and psychological barriers that are encountered. As we discuss the process of gaining access there are similarities to the process of candidacy that we encountered earlier in the chapter. This is a connection that was also made by Dixon-Wood et al (153) who argued that a better approach to considering access was through investigation of candidacy, a term which they produced as part of their synthesis. I would agree that issues of access are greater than an assessment of the actual number of healthcare contacts. The findings from the study in this thesis suggest a clear difference between health literacy groups with regards the perceptions of access and barriers as well as the ability to overcome these barriers. If the finding that those with inadequate health literacy *perceive* access of healthcare as more difficult and identify more barriers is generalizable, it could explain delays in presentation and the consequent deterioration in health. The inability to conceptualise mechanisms to overcome perceived and actual barriers will also, undoubtedly, mean delays in accessing care. It may therefore be that a main issue is not the difference in actual number of health care appointments between health literacy groups but the differences in delays to seeking health care.

## **5.6 Social Networks**

Support from participants' social networks was encountered throughout the analysis of the data from the study in this thesis. It was seen as a support system to participants and was often used as an arena to gain knowledge and enhance candidacy. Ideas and information were shared among social networks and people often gained key input from these sources. Current research suggests a

“robust relationship in which social... support from others can be protective for health” (196)(p201). This has been demonstrated in the literature with papers showing that the presence of high quality and a high number of social networks is associated with lower mortality (197). As reported by Zhang et al, for example, having a medium or high level of support was associated with a 41% and 55% lower risk of death respectively in those with diabetes (198). Similarly, others have discussed how social isolation was identified as an independent major risk factor for all cause mortality (199). Aside from mortality there is evidence of the positive influence of social networks on health behaviours. Chouinard and Robichaud-Ekstrand reported the positive effect of social support on attempts at smoking cessation (200). Not only can others in a social group support other members there is support for a subtler impact of social networks on individuals. For example, Martrie and Franks identified two themes in their review of the recent research into social networks in adult health (201). The first of these was that “connections with close others and interactions with these ties likely promote health through shaping daily health behaviour choices” (p 8). It was also described how behaviour choices would often mirror those of close social partners in a natural process which would not necessarily require active intervention.

The importance of social networks on behaviour and health is highlighted by studies that look to use these support systems as means to improve health and health behaviours. A dyadic study, in which pairs of individuals are examined, by Sorkin et al is an excellent example of this (202). In this study mothers with diabetes who had overweight or obese daughters were investigated. They were



either put onto a dyad-based, involving both the mother and daughter, lifestyle intervention or a control. The participants on the dyad-based intervention lost significantly more weight and reported a significant increase in health-related social support and control. From this we can see that the influence of social networks has implications for health interventions and policy changes.

A further finding from the study in this thesis was the sharing of health literacy skills within social groups as was mentioned in the section on resilience. This distribution of health literacy has been described in the literature previously and has been postulated to assist in the healthcare of a number of those with inadequate health literacy (203). An explanation of this is provided by Wagner et al who claimed that several individuals could possess some of the skills required for literacy but not all, but through sharing of these skills within the group may function as a more fully literate individual (204). This theory has been seen in studies including the qualitative study by Edwards et al that looked at the role of social networks in people with long-term health conditions (203). They found that participants often drew on the health literacy skills of others which helped that seek out, understand and use health information. They also described health mediators who were members of the group that distributed their knowledge and skills and facilitated the enhancement of health literacy in others. Through these actions there was also evidence that the distribution of health literacy allowed other members of the group to “manage their health, become more active in health-care decision-making processes, communicate with health professionals and come to terms with living with a long-term condition” (203)(p 1).

Social groups are accessed by patients at all levels of personal health management. When an individual's health deteriorates the first source they usually contact will be a member of their social group (187). Friends and family may then take on a role of responsibility and act as a 'surrogate decision maker'. This shows how people with low health literacy can access the skills of others to facilitate their health management and make health decisions. A further example of this phenomenon is seen in the work of Tim Rapley (205). He discussed the concept of a 'collective patient' and asserted that "decisions are routinely distributed 'over' people, they emerge, transform and solidify in and through multiple interactions with multiple others, significant or otherwise, over a period of time" (p 8).

As can be seen in the literature, and added to by the findings from the study in this thesis, social networks provide a large system of support for patients. They are sources of knowledge and skills that can enhance health literacy as well as other factors associated with health management such as resilience and candidacy.

## **5.7 Measure of Health Literacy**

The Newest Vital Sign (NVS) was the health literacy assessment tool used during the qualitative research project within this thesis. It was chosen for its ease of use and the fact that there is a version that has been validated for use in the UK (36). On analysis of the data there was evidence that assigning health literacy based solely on NVS score was not sensitive enough. There were a number of

instances where people were displaying adequate health literacy skills in their interviews but were classed as having inadequate health literacy and vice-versa. This suggests that the NVS may not be sufficiently nuanced to distinguish between individuals with certain differing health literacy skills. This may have been avoided by using alternative measures of health literacy, although these too would have had their own strengths and limitations.

## **5.8 Summary**

The findings from the study in this thesis reflect the evidence that is starting to emerge in the wider literature. The existing literature identifies issues of poor health outcomes in older people with inadequate health literacy. The study in this thesis has shown evidence for some intermediate factors that may explain this relationship. The first conclusion from the study is that the management of ill health and chronic health conditions is very important in older people. They carry a greater burden of disease and as such are a key population at which to aim health-improving interventions. There are likely numerous reasons why older people currently have worse health outcomes, some of which we have seen in the study in this thesis. The beneficial effects of resilience have been discussed throughout the literature and is a characteristic demonstrated by a large number of older people. In the study in this thesis all of the participants demonstrated resilience with both positive and negative consequences. An argument can be made that despite the positive effect resilience can have in coping with the adversities of older age; there are also several negatives to possessing this characteristic. Firstly the findings from the study suggested resilience was

associated with a strong desire to self manage health problems. This is a positive aim in healthcare generally but its success is dependent on the ability of the individual to monitor and manage their health appropriately. Evidence from the qualitative research detailed in Chapter Four provided examples of how people were not always able to accurately assess medical problems and seek appropriate and timely medical assessment. The influence of health literacy is likely to be important in this issue with those with inadequate levels being at a disadvantage in terms of assessing health problems and managing chronic conditions. Interventions to help people improve these skills would possibly reduce the morbidity and mortality seen in older people.

The second conclusion, which expands on the work of others, is the impact of patient candidacy in older people. People in the study had low levels of perceived candidacy and, linked to their high resilience, were less likely to seek medical assessment. There were intriguing findings in comparing those in different health literacy groups with those with adequate scores showing an ability to internally validate accessing healthcare. In comparison those with inadequate scores were more likely to require an invitation to attend. This opens up a potential avenue for further research and interventions to enhance the candidacy of older people. Work to enhance health literacy and educate older people to understand both the range of services and the criteria for their use may enable older people to access care at an early stage when management may be more straightforward.

There was also evidence that older people, as in the general population, have a variety of attitudes towards their own health and healthcare in general. This ranges from their expectations of their own health to their perceptions of access to services. Low expectations for health were associated with being content with poor health so long as it didn't interfere with day-to-day functioning. This impacts on the classic sick role description and, in turn, effects candidacy and use of health services. Concerns over access to care and the perception of actual and perceived barriers showed a further hurdle older people face when managing their own health. Issues of accessibility further reduce interactions between older people and health professionals even when candidacy is identified. This problem was exaggerated and more pronounced in those with inadequate health literacy who not only perceived more obstacles to attaining access but found it harder to consider ways to navigate these barriers.

Finally the evidence for the importance of social networks and support across a wide range of health management issues was clear. The influence of social groups was pervasive and impacted on every stage of healthcare, from the development and normalisation of health behaviours and social roles to the enhancement of candidacy and resilience. As discussed social networks are often the first contact for people with health issues and as such are a key target for investigation and intervention. The ability of members of social groups to act as health literacy mediators and share skills with others is of great importance to those with inadequate literacy. This allows facilitation of the assessment and management of their health problems. Rogers et al suggested that research of social networks should be of upmost importance as it will allow the

identification of the hidden roles played by the people within them on the management of long term conditions within the group (206) and the work in this thesis would echo the importance of such research. Work that furthers our understanding of the complex interactions within groups will allow interventions that assist in the process of skill sharing and make sure that accurate and contemporaneous knowledge is provided so that the sharing of poor quality or inaccurate information is limited.

This work adds to the conceptual work done by Paasche-Orlow and Wolf in the formulation of their logic model described in Chapter One and on which the themes in the systematic review and subsequent research project were based. The findings in this thesis point towards a far more complex interaction of skills and factors linking health literacy with outcomes. Some of the factors presented in the original model are complicit in the themes of candidacy and resilience identified in this thesis but the findings in this study would suggest that there are a far greater number of factors involved and that there may be a greater number of stages between health literacy and outcomes. Given the small scale of the research in this study it is likely that the findings have only uncovered a small amount of the potential intermediary factors and it is clear that more work is required to examine the theory behind the pathway linking health literacy and health outcomes. It may be that a mixed methods approach will need to be undertaken so that tangible quantitative results can be used along side the rich qualitative data in developing what will be a complex logic model.

The findings from this study also demonstrate the need for further work in the field of health literacy and its impact on the management of health in older people. Health literacy is a promising area for promotion of health and healthcare through areas, not limited to, candidacy, attitudes, resilience, and social networks. With evidence clearly demonstrating the poor outcomes in those with inadequate health literacy it is of upmost importance that we develop strategies and methods to reduce the impact it has and improve the health and management of these patients

## **5.9 Strengths and Limitations**

Undertaking a broad and systematic review of the current literature at the start of the thesis allowed the identification of gaps for future research to focus on. This allowed the subsequent study detailed later in the thesis to focus on areas where current knowledge is lacking. By choosing mediating factors to review from the existing proposed Paasche-Orlow model, the review built on existing work and allowed a focused addition to the current knowledge base. One of benefits of using the Paasche-Orlow model is that it is simple linear model, which facilitates investigation. There is also an early body of research that has looked to examine the links in this proposed model and so further research will help to develop this concept further. The simplicity of the model is also one of its drawbacks, however. There has been more recent research producing models that have a much wider concept. The European Health Literacy Survey (HLS-EU) (39) investigated health literacy across several countries in the European union. They identified a more complex construction of health literacy while also

identifying variations across different populations, including different counties and across social gradients. This suggests that the Paasche-Orlow model may not be sufficiently nuanced to address the impact of health literacy on outcomes, however for the context of the study in this thesis it provided a good background on which to investigate the links between health literacy and outcomes. The identification of variation across countries found in the work by Sørensen et al (39) also brings into question the use of a model in the UK that was developed in the USA. More work needs to be done to assess the reasons for observed differences across countries to determine how models in one country can be applied to others. At the time of planning and undertaking the study in this thesis the data from the HLS-EU had not been published, however if further work were to be undertaken a more detailed consideration of the model used to underpin the work would be needed.

However, when undertaking the systematic review papers that included people with mental health problems were excluded. This could be a significant confounder in the determination of factors that mediate health outcomes. Work has been done exploring why older people with depression fail to seek primary care advice (170). This suggests that the inclusion of mental health conditions in the review may have influenced the findings and as such provides validation for the decision to exclude this population. However, other work has demonstrated the importance of mental health literacy (207) suggesting that the exclusion of these individuals from an assessment of the impact of health literacy is inappropriate. It was found that current evidence suggests that mental health literacy is associated with help-seeking attitudes and is likely to be important in



promoting these attitudes. As was seen in the findings from the qualitative analysis in this study, attitudes are an important part of patient health decision making and so it appears that health literacy may have important implications in mental health. Whether these are additive factors or if one is simply a mediator for the other is not clear and so more research is needed in this area. Due to the evidence discussed on the effects of mental health on access and interactions with healthcare it was decided to not exclude patients with mental health problems from the qualitative study. If this project were to be repeated, however, studies that contained individuals with mental health problems would not be excluded from the systematic review. A sub analysis of those that excluded mental illness may be possible and useful but complete exclusion is likely to have missed valuable information.

Looking at the design of the main study there are also several strengths and limitations. Firstly there is the limitation of what can be drawn from qualitative studies. There are many strengths to qualitative research, which was why it was chosen as the research method for this thesis. Principally qualitative research allows the acquisition of rich data that facilitates the exploration of difficult concepts, such as attitudes and motivation, in great depth. The use of face to face interviews also allow for sensitive issues to be raised. As has been discussed previously the opportunity to interview individuals as well as measure health literacy quantitatively allowed for an assessment to be made over the validity of such tools. This has raised questions over the accuracy of such measurements in identifying health literacy. The findings from the study gave evidence that such tools primarily assess functional health literacy rather than more complex skills

such as communicative and interactive literacy which, as has been seen in the study, may be of more importance for individuals in social groups for example. Despite this, the nature of such research does not allow for causality to be established. As such it is not possible to say if any of the themes that were identified are associated with either health literacy or health outcomes. By undertaking such work and comparing with current evidence it is possible, however, to develop theories that can drive future work. Consequently the findings from this study support the need for further research on health literacy in older people and associations with attitudes and candidacy, as well as the role of social networks.

The selection of participants for the study also raises issues of the validity of the findings. Targeted sampling was used from community groups. This was done to support selection from the desired population of those over 60 years. Although it facilitated the selection of appropriate participants there are concerns over the generalizability of such a population to the wider older population. Those that attend social groups have demonstrated a degree of motivation and personal action to identify and attend a social gathering. It is likely that these individuals will have a different set of attitudes and likely demonstrate different degrees of candidacy and resilience to those people who are more isolated in the community. One of the groups attended particularly is likely to have contained individuals with an interest in promoting and enhancing the care of older people. The ENGage forum is run to allow people over 50 to give their view on service provision in the Stoke-on-Trent region. It is questionable whether the views of the individuals recruited from this forum have the same views and perceive the

same barriers to health as others. An improvement in the study could be achieved through a wider form of recruitment. If the study were to be repeated then employing tactics to engage the more disadvantaged and less social active members of society would be beneficial to gaining a better understanding of the issues surrounding health literacy and health management. This could include house bound older people as well as those with poor chronic health management to allow for discussion of the issues surrounding healthcare in this key group.

### **5.10 Personal Reflection**

I would finally like to reflect on my own involvement in the study. As an Academic Clinical Fellow undertaking research whilst completing my general practitioner vocational training, my workload consists of both academic and clinical practice. Key to the analysis of the qualitative data is the ability to allow themes to be built from the data rather than preconceived ideas. Through my work in primary care as a clinician I have cared for and seen the problems faced by older people. Frequent apologies over “wasting my time” from older people will have naturally formed beliefs in me that older people see their attendance in primary care as a nuisance. The need for clinicians to undertake regular “admission avoidance” meetings also produces emotions and ideas on the issues of older people. The purpose of these meetings is to discuss the unplanned attendance of any individual who is determined to be ‘at risk’ of secondary care. The aim is to determine possible ways these admissions could have been avoided and how future attendances could be prevented. My experience of these meetings has been that they are focused on the clinical issues surrounding health

and fail to fully address psychosocial issues. This has implications on both the interview process as well as the analysis. An a priori belief of the issues of older people and the predilection to look at the clinical problems has the potential to influence my production and conduction of the interviews as well as effecting the identification of themes within the data. I feel, however, that the finding from the study and the fact that they correlate well with the current literature demonstrates that the potential interviewer and analysis bias were likely minimized. I suggest this as I had no prior knowledge of candidacy or resilience before undertaking the study. These themes developed as I analysed the data and the subsequent review of the literature enhanced my understanding of these concepts. I believe the fact that I identified these without prior knowledge suggests that they are reliable representations of the data. A benefit of my experience is that I have first hand experience of the care of older people and am aware of the issues they have surrounding care. I am also in an excellent position to relate the findings from the study to practice. The benefit of this is the ability to make sense and purpose out of the findings and relate them to possible real world challenges.

The fact that participants knew that they were being interviewed by a doctor could also have affected the responses they gave. Some individuals may have been reluctant to be truthful over their health beliefs and self-management. If the study were to be repeated, blinding the participants to the occupation of the interviewer and having more than one researcher undertaking the interviews may reduce this potential bias. Finally it is important to acknowledge that this was the first systematic review and qualitative study that I have undertaken. As

such the techniques and skills required were new and are unlikely to be as refined as those that have undertaken several studies. Through out the project I kept a diary of my thoughts and a recurring theme was of the changes I would make in future research and reflections on the new skills I was undertaking. Among these was my underestimation of the time required for several steps, including transcribing. I also reflected on how my confidence in interviewing progressed over the course of the project and how I found them much easier to perform as my experience grew. If I were repeating the study I now feel that my skills in qualitative research are improved and as such would find the process easier and more fulfilling. I am not convinced the overall findings would change substantially but I may be able to get a wider range of information on the important topics.

## **5.11 Conclusion**

This thesis has investigated the impact of health literacy on the management of chronic health in older people. An initial systematic review demonstrated the lack of literature on the mediating factors that link health literacy with health outcomes. This resulted in the undertaking of a qualitative study of older people focusing on health management and experiences. There were several interesting findings surrounding resilience, candidacy and attitudes. The role of social groups was also highlighted and suggested an important role for these relationships. The final important finding surrounded the use of health literacy measurement tools. The study provided evidence that there was a discrepancy between the results of the NVS and the apparent health literacy of individuals as

demonstrated by the actions and answers given in the study. This suggests that consideration must be taken when undertaking research on health literacy as to how health literacy is measured.

The findings have strengthened the understanding of the mediating factors between health literacy and health outcomes. This may have a number of implications for practice and policy within healthcare. On an individual level healthcare professionals must be aware of the difficulties patients may have in understanding medical information and being able to use information they are provided with to make health decisions. Adjusting approaches to patient education and discussions to take into account differences in health literacy will allow all patients to have the chance to be actively involved in an informed discussion about their health. Hospital and general practices must look to how they communicate with their patients and make sure that consideration of health literacy inequalities is reflected in the information they provide and the accessibility of their services. Policy makers will also need to consider how their work will be applied to those with lower health literacy and ensure that barriers are not created by policies that are only accessible or understandable by a proportion of their intended audience. I do not feel there is a single aspect of medical services that is not influenced by health literacy. It would be easy to ignore such a complex issue that has, at present, a limited although growing body of evidence when compared to other health research areas. Anyone who has worked in healthcare will have experienced health literacy and will undoubtedly have seen the impact it has. At present, however, we have only begun to understand the far-reaching impact of this issue and more research is needed to

expand the knowledge and breadth of the factors which influence health literacy, test them for causality and determine how healthcare is affected by differences in health literacy. As this is being done it is important that is undertaken to see what interventions may be possible to reduce the effect of health literacy and enhance the skills of older people with the aim of improved health outcomes.

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## Appendices

### Appendix 1: Quality Assessment Tool

Did the study address a clearly focused issue?	
Were participants recruited appropriately?	
Are the outcomes related to review question?	
Worth Continuing?	
Acceptable measure of health literacy?	
Acceptable and accurate measure of outcome?	
Have confounders been identified?	
Does the design/analysis take account of confounders?	
Keep in final review?	

## Appendix 2

### Interview Schedule (First)

Questions	Rationale
<p>Can you tell me how healthy you feel you are at the moment?</p> <p>-Can you explain why you feel like that?</p> <p>-Possible discussion over particular conditions and what makes them feel well controlled/managed</p> <p>Do you mind if I ask if you have any long term health problems?</p> <p>-How well do you feel these are controlled</p> <p>-Can you tell me what control you have over the control of your health</p> <p>-Who else is involved in looking after your health</p> <p>-How much control do you think they have over your health.</p> <p>What do you feel are the most important things when it comes to looking after your health?</p> <p>Can you tell me what you do to look after your health in a normal day?</p> <p>-Are there any things you have been advised to do but don't do (give prompts if necessary- i.e. exercises/diet etc.)</p> <p>-If there are- can you tell me why you don't do these/do you feel these will make any difference to how you feel</p> <p>If you weren't to do any of these things how do you feel your health would be?</p> <p>When you feel that you are unwell, can you tell me what you normally do?</p> <p>Can you tell me about your parents' health?</p> <ul style="list-style-type: none"> <li>- What would they tend to do when they were unwell</li> <li>- Can you tell me what they did to look after you when you were unwell</li> <li>- Are there any examples of when you were ill as a child?</li> </ul>	<p>Introductory question: gain background and belief on level of health</p> <p>Beliefs about important aspects of health</p> <p>Leading question with view to discussing barriers to management/attitudes and self efficacy</p> <p>Attitude to approaching health management</p> <p>Assessment of life-story with possible identification of passage of information between generations</p>



<p>Do you feel how you view your health has been effected by your parents?</p> <p>Can you tell me what your personal views are on doctors -What do you feel their main concern is?</p> <p>What do you feel your GP practice can do for you?  <ul style="list-style-type: none"> <li>- Can you tell me what services they can provide</li> <li>- If you had problems coping at home do you feel your GP could help?</li> </ul> </p> <p>What would make you decide to go to see your doctor?</p> <p>Do you feel confident knowing when to see your doctor with regards your long term health issues? -Can you give me an example?</p>	<p>As above</p> <p>Attitudes towards health professionals</p> <p>Understanding of health service and different available services provided</p> <p>Assess triggers for accessing healthcare and attitude towards own health and when feels needs assistance- ? over or underuse</p> <p>Looking at self-efficacy around long term healthcare in terms of both knowledge of condition and access to primary care services</p>
<p>Can you talk me through what you do when you decide you need to see a doctor -Can you give an example of when you have tried to see a doctor? -Do you find it difficult to get in to see your doctor- discuss difficulties</p> <p>Are there any things that put you off seeing your GP?</p> <p>If you have become unwell at the weekend what do you do? -Have you ever used the out of hours GP services? If so can you tell me about you experiences with this? -What did/would make you decide to use this service?</p> <p>How do you feel about hospitals? -Can you tell me what you think they are there for? -Have you ever had to go to hospital</p>	<p>As above with further assessment of potential barriers to healthcare access and assessment of ability to overcome these barriers</p> <p>Further review of barriers and possibly negative beliefs about healthcare/doctors.</p> <p>As above but looking at out of hours services</p> <p>As above but with assessment of secondary care</p>

<p>(outpatient/inpatient)- if so how did you find the experience?</p> <p>Have you ever needed to go to accident and emergency department?</p> <p>-Can you tell me what you think they are there for?</p> <p>-What would make you decide to go here?</p> <p>-If so can you tell me about you experiences</p> <p>If been to A&amp;E/OOH/WIC- did you consider going to see your GP first</p> <p>-What stopped you</p> <p>-Why not?</p> <p>What do you feel could be done to make your healthcare better?</p> <p>-Could your doctors do anything differently?</p>	<p>As above</p> <p>Looking at possible ways to improve access/healthcare but also assessing understanding of feasibility of health services/constraints</p>
<p>How do you feel about the advice and information you get when you see a doctor?</p> <p>When they give you advice do you always trust it and follow it or are there things that make you doubt or disagree with what they say?</p> <p>Can you tell me what you have done if you have ever disagreed with what your doctor has said?</p> <p>Has advice of friends and family/experiences of friends/family ever effected you decisions over health</p> <p>-Has it stopped you from doing something advised by a doctor?</p> <p>How do you feel about medication?</p> <p>-Do you have any concerns about taking medication?</p> <p>-What extra information or advice do you seek out (friends etc.)?</p>	<p>Attitude to health advice and interaction with doctors and also ability to use information/understanding</p> <p>Confidence in own beliefs and ability to actively participate in a joint decision making process</p> <p>Attitudes and beliefs on medication and barriers to taking.</p>

### Interview Schedule (Revised)

#### Attitudes and Belief

Can you tell me how healthy you feel you are at the moment?

What determines if you feel healthy or unhealthy?

What sorts of things make you feel healthy or unhealthy?

Do you have any long term health problems?

How do you feel these are controlled?

What do you do to look after these conditions?

Is there anything more that you feel needs to be done?

How do you monitor these problems?

Do you get any problems from these conditions?

What control do you have over your health?

Can you tell me about the last time you went to see the doctor?

What did you want from the consultation?

What is the most important thing when seeing a doctor?

If you feel unwell- what do you do?

What makes you think about seeking review?

What motivates you to seek review?

What would put you off seeking a review?

How long do you wait to be seen?

What has to change/occur to prompt a review

If you can't get in to see your doctor, what would you do?

How would this be different if it was at the weekend?

Follow up?

After seeing a doctor/healthcare provider, how will you follow this up?

Who do you think is responsible for monitoring response to treatment plans?

Monitoring health?

Do you ever think about having health checks?

What do you think about screening tests?

If you notice new symptoms what would make the difference between putting up with them or seeing how things go and making and seeking a review?

Discuss the difference between trivial and serious issues?

How do you feel about taking regular medication?

Do you take any medication?

How do you feel about these?

Are there any medications you wouldn't take?

What about those for conditions that cause no symptoms?

Do you speak to anyone about your medication

Including doctors

How important is the advice of friends and family?

Any examples?

How do your family and friends help you to look after your health?

What would you do if they weren't around?

I would like to ask you about your views on healthcare?

What do you think of GPs?

Do you find them easy to use?

Do you find them helpful?

Do you get frustrated about them?

Have you had any problems?

What do you think about hospital doctors and specialists?

Do you find them helpful?

What have been your experiences going to the GP?

Any particular problems?

Does anything put you off going to see the GP?

How do you find the appointment system?

Do you feel there are any barriers that stop you getting the service you would like?

Do you use the OOH services?

What have your experiences been?

What do you think about these services?

Would you use these services?

When?

What have your experiences been speaking with members of the NHS?

Doctors?

Nurses

Do you feel that there has been good communication?

What have you done if there has been poor communication?

How does it make you feel speaking with doctors?

How much information do you want to be given?

How involved in decision making do you want to be when seeing a doctor?

Has the information you've been given in the past make sense?

Do you look for information or advice from places other than your doctors?

What importance do you place on this?

## Appendix 3: Original Ethics Amendment Approval



Keele  
University

RESEARCH AND ENTERPRISE SERVICES

3<sup>rd</sup> September 2013

Emee Estacio  
School of Psychology  
Dorothy Hodgkin Building

Dear Emee,

**Re: 'Health literacy and chronic health management among older adults'**

Thank you for submitting your application to amend study for review. I am pleased to inform you that your application has been approved by the Ethics Review Panel.

If the fieldwork goes beyond the date stated in your application (1 March 2015) you must notify the Ethical Review Panel via the ERP administrator at [uso.erps@keele.ac.uk](mailto:uso.erps@keele.ac.uk) stating ERP2 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP2 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on [uso.erps@keele.ac.uk](mailto:uso.erps@keele.ac.uk) stating ERP2 in the subject line of the e-mail.

Yours sincerely

A handwritten signature in black ink, appearing to read 'DB Bartlam', with a long horizontal flourish underneath.

**Dr Bernadette Bartlam**  
**Chair – Ethical Review Panel**

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK  
Telephone: + 44 (0)1782 734466 Fax: + 44 (0)1782 733740

## Appendix 4: Approval of Ethics Amendments



Keele  
University

RESEARCH AND ENTERPRISE SERVICES

20<sup>th</sup> March 2014

Christopher Williamson  
Arthritis Research UK Research Centre  
Keele University

Dear Christopher,

**Re: 'Health literacy and chronic health management among older adults'**

Thank you for submitting your application to amend study for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel.

The following documents have been reviewed and approved by the panel as follows:

Document	Version	Date
Summary Proposal	2	20/03/2014
Information Sheet	2	14/03/2014

If the fieldwork goes beyond the date stated in your application you must notify the Ethical Review Panel via the ERP administrator at [uso.erps@keele.ac.uk](mailto:uso.erps@keele.ac.uk) stating ERP2 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP2 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on [uso.erps@keele.ac.uk](mailto:uso.erps@keele.ac.uk) stating ERP2 in the subject line of the e-mail.

Yours sincerely

**Dr Bernadette Bartlam**  
**Chair – Ethical Review Panel**

CC Supervisor

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK  
Telephone: + 44 (0)1782 734466 Fax: + 44 (0)1782 733740

## **Appendix 5: Summary of Themes**

### **Candidacy**

- Social Influences
  - Social Support
  - External Influences
- Health and Healthcare Beliefs
  - Health Perception
  - Perception of Aging
  - Comparison with others
  - Perceived Accessibility
  - Stigma
- Healthcare Competence
  - Symptom assessment
  - Self Management
- Experiences
  - Previous life experiences
  - Previous Health Experiences
- Preferences and Personality
  - Locus of Control
  - Approach to Healthcare (Active Vs. Passive)

### **Resilience**

- Social Influences
  - Social Support
- Health and Healthcare Beliefs
  - Medicine Beliefs
  - Health Expectations
  - Perception of Aging
- Healthcare Competence
  - Self Management
- Experiences
  - Previous Health Experiences
- Preferences and Personality
  - Knowledge Seeking
  - Locus of Control
  - Priorities

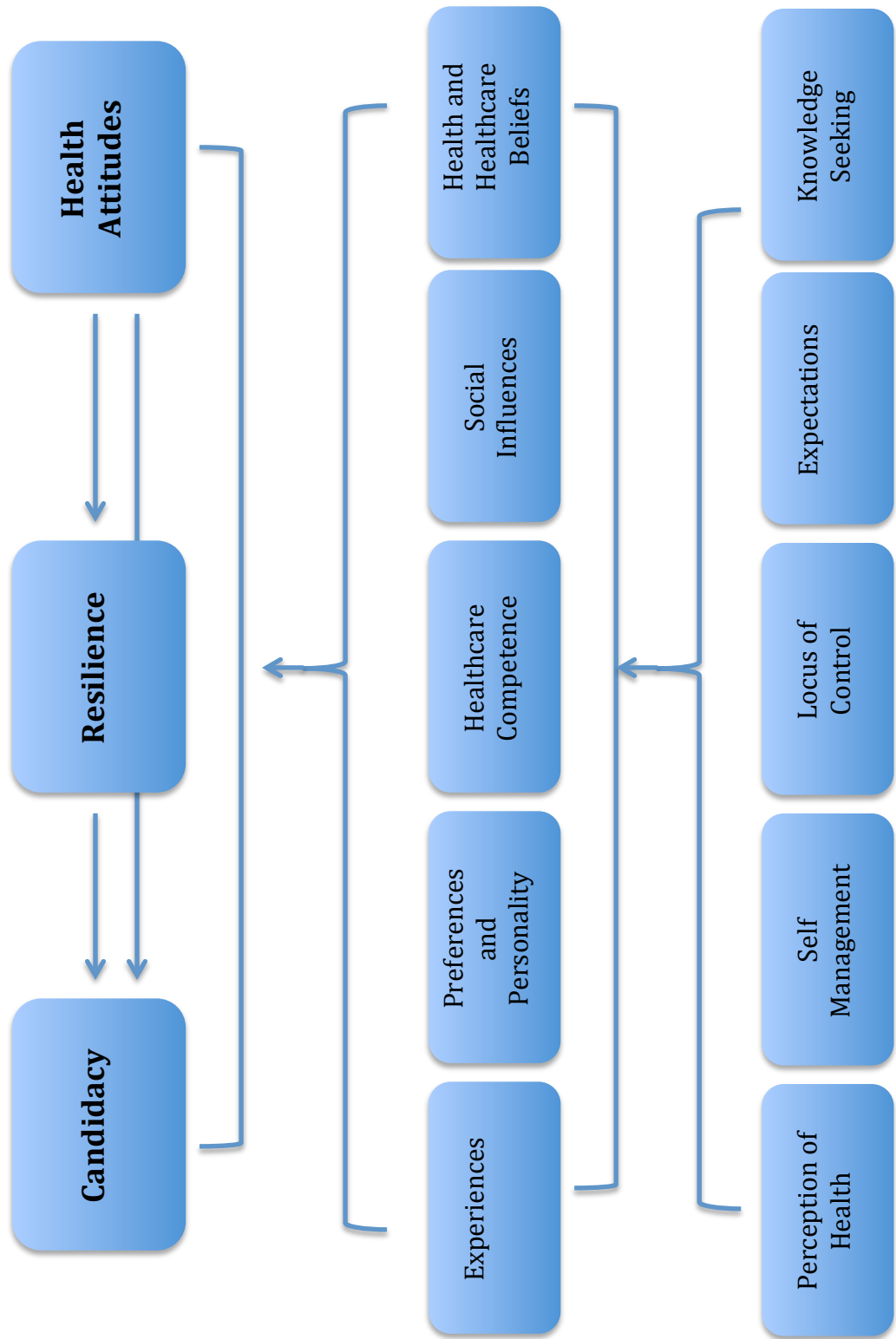
### **Attitudes**

- Social Influences
  - Social Support
  - External Influences
- Health and Healthcare Beliefs
  - Health Expectations
  - Perceived Accessibility
  - Healthcare assumptions
  - Perceived Barriers

- Medicine Beliefs
  - Self Management
- Healthcare Competence
  - Symptom Assessment
- Experiences
  - Previous Healthcare Experiences
- Preferences and Personality
  - Locus of Control
  - Knowledge Seeking
  - Approach to Healthcare (Active Vs. Passive)
  - Priorities



Appendix 6: Thematic Map



## Appendix 7: Participant Information Leaflets

### INFORMATION FOR PARTICIPANTS

We would like to invite you to help us in our research. Please read this information sheet before you decide. If anything is unclear, you can contact us at telephone number 01782 733332. You may discuss this information sheet with friends or relatives if you wish.

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**Why have I been invited?** You are someone living with a chronic or long-term health condition who is over 60 years old.

**What do you mean by long-term condition?** This is any health condition that requires on-going management over a period of years. For example, heart disease, asthma or diabetes.

**Do I have to take part?** You are free to decide if you want to take part or not. It's your choice.

**What will happen if I decide to take part?** We will invite you to take part in an interview to talk about how you manage your health. We are especially interested in the skills that you use to help you deal with everyday life. This interview could last between 45 minutes to an hour. We will ask for your permission to record the interview. You are free to say no if you are uncomfortable with this.

**What are the benefits of taking part?** Although this research may not directly influence clinical care, your participation can help inform others about what it is like to manage a long-term health condition at old age.

**What are the risks of taking part?** Talking about your health condition could make you feel upset. If this happens, please let the researcher know. You may stop the interview whenever you wish.

If you feel upset, you may contact Age UK Advice for support 0800 169 6565 or get in touch with your local GP.

**What if I say 'yes' and then decide later that I don't want to take part?** You are free to leave any time. You don't need to explain why.

**What will you do with the information from this research?**

We will write a report to share the findings with relevant groups

so they will have a better idea on how they can support people like you. We will also write articles about the project. We will not use any real names and we will leave out anything that may identify you. We will also give you a copy of the report if you wish.

**What will happen to the information collected after the research?** Everything will be kept strictly confidential. The information will be kept at Keele University for ten years. It will be destroyed after that.

**How can I let you know that I would like to take part?** You can call us at telephone number 01782 733332 or email at [e.v.g.estacio@keele.ac.uk](mailto:e.v.g.estacio@keele.ac.uk)

**Who should I contact if I have any questions or concerns?**

**Dr Emee Vida Estacio**

Project leader

Centre for Psychological Research, Keele University, ST5 5BG

Email [e.v.g.estacio@keele.ac.uk](mailto:e.v.g.estacio@keele.ac.uk)

Tel. 01782 733332

**If you remain unhappy and want to make a complaint, you may contact:**

**Nicola Leighton**

Keele University Research Governance Officer

Research and Enterprise Services, Keele University, ST5 5BG

Email [n.leighton@uso.keele.ac.uk](mailto:n.leighton@uso.keele.ac.uk)

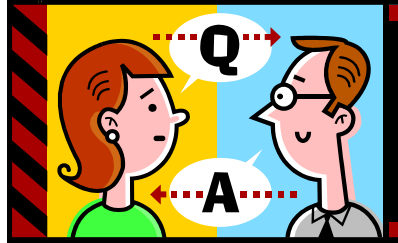
Tel. 01782 733306

The project is funded by Stoke Healthy City Partnership.



## Information About Interview On Health Management

We would like to talk to you about how you deal with your health.



We would like to tape-record the conversation.



We may also write some notes.



The conversation will last about 45 minutes to 1 hour.



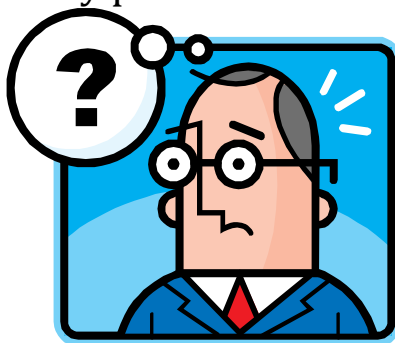
You are free to say no at any point.



You are welcome to discuss taking part with your friends and family



If you have further questions you are welcome to speak with us by phone.



## Appendix 8: Consent Form

### Study of role of health literacy in the management of long-term health problems

#### Qualitative Interviews

#### Research participant consent form

If you are happy to take part, **please initial each of the boxes, then sign and date this form.**

Please **INITIAL** each

box

1. I confirm that I have read and understand the information sheet for the study that was provided to me and had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical or legal rights being affected
3. I agree to take part in the above study
4. I agree to the interview being voice recorded
5. I understand that when this research is complete the audio file will be retained and securely archived for a period of 10 years. This archive can only be accessed by the request from the research team and all files will be destroyed at the end of that period
6. I understand that some quotes from the interviews may be used in publications but my name and personal details will not be used in these publications and all information will be anonymised

----- --/--/-----  
Name of patient (BLOCK CAPITALS)      Date      Signature

----- --/--/-----  
Name of person consenting (CAPITALS)      Date      Signature

FOR COMPLETION BY RESEARCHER ONLY. ID:  
When completed: 1 copy for researcher, 1 copy for participant

## Appendix 9: Summary of Papers in Systematic Review

Author	Year	Title	Methodology	Key Finding (All direct quotes from papers)
Osborn CY, Paasche-Orlow MK, Wolf MS.	2011	The Mechanisms Linking Health Literacy to Behaviour and Health Status. American Journal of Health Behaviour	Path analytic models tested the pathways linking health literacy to physical activity and self-reported health N=330	significant paths from health literacy to knowledge ( $r=0.22$ , $P<0.001$ ), knowledge to self-efficacy ( $r=0.13$ , $P<0.01$ ), self-efficacy to physical activity ( $r=0.17$ , $P<0.01$ ), and physical activity to health status ( $r=0.17$ , $P<0.01$ )
Schumacher JR, Hall AG, Davis TC, Arnold CL, Bennett RD, Wolf MS, et al	2013	Potentially Preventable Use of Emergency Services: The Role of Low Health Literacy	Cross Sectional Study N=492	Participants with limited health literacy reported fewer doctor office visits [odds ratio (OR)=0.6; 95% confidence interval (CI), 0.4-1.0], greater ED use, (OR=1.6; 95% CI, 1.0-2.4), and had more potentially preventable hospital admissions (OR=1.7; 95% CI, 1.0-2.7) than those with adequate health literacy
Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, et al.	2004	Health Literacy and Use of Outpatient Physician Services by Medicare Managed Care Enrollees. Journal of General Internal Medicine	Cohort Study N=3260	Inadequate health literacy was not independently associated with the mean number or visits of the time to a first visit
Baker DW, Parker RM, Williams MV, Clark WS,	1997	The Relationship of Patient Reading Ability to Self-Reported Health	Cross Sectional Study N=2659	Patients with inadequate functional health literacy were more

Nurss J		and Use of Health Services		likely than patients with adequate literacy to report their health as poor. Literacy was not related to regular source of care or physician visits
Hardie NA, Kyanko K, Busch S, LoSasso AT, Levin RA	2011	Health Care Spending and Utilization in a Consumer-Driven Health Plan.	Cross Sectional Study N=4130	Better health literacy was associated with lower total health care spending
Tecu NJ, Potter P	2012	Relationship of Health Literacy with Women's Cervical Cancer Knowledge and Health Behaviors.	Convenience sample	Majority of women did not think their symptoms were indicators of cancer
Mancuso CA, Rincon M	2006	Asthma Patients' Assessments of Health Care and Medical Decision Making: The Role of Health Literacy	Cross-sectional study N=175	Lower literacy was associated with less satisfaction with asthma status and worse assessment of quality of care. Also more likely not to participate in decisions about their care
Yin HS, Dreyer BP, Vivar KL, MacFarland S, van Schaick L, Mendelsohn AL	2012	Perceived Barriers to Care and Attitudes Towards Shared Decision-making Among Low Socioeconomic Status Parents: Role of Health Literacy	Cross sectional analysis N=823	Patients with low health literacy were more likely to report barriers to care, have trouble reaching providers at nights/weekends, and not feeling like a partner
Peterson NB, Dwyer KA, Mulvaney SA, Dietrich MS, Rothman RL	2007	Influence of Health Literacy on Colorectal Cancer Screening Knowledge, Beliefs and Behavior	Convenience Sample N=99	Limited or inadequate health literacy was significantly associated with less knowledge and more reported barriers to



				colorectal cancer screening
von Wagner C, Semmler C, Good A, Wardle J	2009	Health Literacy and self-efficacy for participating in colorectal cancer screening: The role of information processing	Cross Sectional Study N=96	Lower health literacy was associated with less information seeking, greater effort in reading and less self efficacy to colorectal cancer screening
Arnold C, Rademaker A, Cooper Bailey S, Esparze JM, Reynolds C, Liu D, et al.	2012	Literacy Barriers to Colorectal Cancer Screening in Community Clinics	Randomized Clinical Trial N=975	Participants with low literacy were less likely to be aware of advertisements promoting colorectal cancer screening or believe it was very helpful to find colorectal cancer early
Osborn CY, Cavanaugh K, Wallston KA, Rothman RL	2010	Self-efficacy Links Health Literacy and Numeracy to Glycaemic Control	Cross Sectional Study N=383	Health literacy and numeracy were each associated with greater diabetes self efficacy with was associated with lower A1C levels
Cavanaugh K, Huizinga MM, Wallston KA, Gebretsadik T, Shintani A, Davis D, et al	2008	Association of Numeracy and Diabetes Control	Cross Sectional Survey N=398	Lower literacy was associated with lower median Diabetes Numeracy Test (DNT) score. Lower DNT was associated with poorer HbA1c levels, and hence diabetic control.
Pulgaron ER, Sanders LM, Patino-Fernandez AM, Wile D, Sanchez J, Rothman RL,	2014	Glycaemic control in young children with diabetes: The role of parental health literacy	Cross Sectional Study N=70	Parental diabetes related numeracy was inversely correlated with the child's glycaemic control.

et al.				
DeWalt DA, Boone RS, Pigone MP	2007	Literacy and Its Relationship With Self-efficacy, Trust, and Participation in Medical Decision Making	Cross Sectional Survey N=268	No relationship was found between literacy and trust or self efficacy. Low literacy was associated with less desire to participate in medical decision making and less diabetes-related knowledge
McClearly-Jones V	2011	Health Literacy and Its Associations with Diabetes Knowledge, Self-Efficacy and Disease Self-Management Among African Americans with Diabetes Mellitus	Correlational Study N=50	Bivariate associations were identified for health literacy including diabetes knowledge and self efficacy which were both found to be independent predictors for dietary self-care activities
Inoue M, Takahashi M, Kai I	2013	Impact of communicative and critical health literacy on understanding of diabetes care and self-efficacy in diabetes management: a cross-sectional study of primary care in Japan	Cross-sectional observational study N=326	Communicative and critical health literacy were positively associated with understanding of diabetes care and self efficacy respectively.
Morris NS, Field TS, Wagner JL, Cutrone SL, Roblin DW	2013	The Association Between Health Literacy and Cancer-Related Attitudes, Behaviors, and Knowledge	Cross Sectional Study N=1013	Adults with low health literacy were more likely to report avoiding doctor's visits, to have more fatalistic attitudes toward cancer, to be less accurate in identifying the purpose of cancer screening and

				more likely to avoid information about disease they did not have
Torres RY, Marks R	2009	Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self-Efficacy, and Decision-Making Among Postmenopausal Health	Exploratory study N=106	Positive relationship between health literacy and knowledge about hormone therapy and self efficacy regarding hormone therapy
Donovan-Kicken E, Mackert M, Tollison AC, Breckinridge B	2012	Health Literacy, Self-Efficacy, and Patients' Assessment of Medical Disclosure and Consent Documentation	Cross Sectional Study N=254	Lower health literacy predicted lower self efficacy
Macabasco-O'Connell A, DeWalt DA, Broucksou KA, Hawk V, Baker DW, Schillinger D, et al	2011	Relationship Between Literacy, Knowledge, Self-Care Behaviors, and Heart Failure-Related Quality of Life Among Patients With Heart Failure	Secondary Analysis of baseline data collected for a randomized controlled trial N=605	Patients with adequate literacy had higher general heart failure knowledge and higher prevalence of key self care behaviours
Colbert AM, Sereika SM, Erlen JA	2013	Functional health literacy, medication-taking self-efficacy and adherence to antiretroviral therapy	Cross sectional, secondary analysis N=302	Functional health literacy was not significantly related to either medication adherence or self-efficacy beliefs
Wolf MS, Davis TC, Osborn CY, Skripkauskas S, Bennett CL, Makoul G	2007	Literacy, self-efficacy, and HIV medication adherence	Structured patient interview N=204	Low literate patients were 3.3 times more likely to be non-adherent to their antiretroviral regimen
Dominick GM, Dunsiger SI, Pekmezi DW, Marcus BH	2013	Change in Physical Activity Self-efficacy Among Sedentary Latinas	Secondary analysis of data from a randomized controlled trial	Higher health literacy scores were associated with lower baseline physical activity self efficacy. Higher

			N=89	health literacy scores at baseline also predicted greater changes in physical activity self efficacy at 6 months
Ussher M, Ibrahim S, Reid F, Shaw A, Rowlands G	2010	Psychosocial Correlates of Health Literacy Among Older Patient with Coronary Heart Disease	Cross sectional survey N=321	Lower health literacy was significantly associated with reports of increased difficulty understanding health information, less knowledge of heart problems, increased discomfort in asking for explanations, and less support with discussing health problems
Brewer NT, Tzeng JP, Lillie SE, Edwards AS, Peppercorn JM, Rimer BK	2009	Health Literacy and Cancer Risk Perception: Implications for Genomic Risk Communication	Cross Sectional Study N=163	Women with lower health literacy gave higher mean estimates of recurrence risk for a hypothetical group of women with early-stage breast cancer
Guerra CE, Dominguez F, Shea JA	2005	Literacy and Knowledge, Attitudes, and Behavior About Colorectal Cancer Screening	Cross Sectional Survey	Health literacy was not an independent predictor of colorectal cancer screening knowledge, beliefs, attitudes, or behaviour
Dolan NC, Rosario Ferreira M, Davis TC, Fitzgibbon ML, Rademaker A, Liu D, et al.	2004	Colorectal Cancer Screening Knowledge, Attitudes, and Beliefs Among Veterans: Does Literacy Make a Difference	Cross Sectional Survey N=377	Men with lower literacy were 3.5 times as likely not to have heard about colorectal cancer, 1.5 times as likely not to know about screening

				tests, and were more likely to have negative attitudes about faecal occult blood testing
Federman AD, Wisnivesky JP, Wolf MS, Leventhal H, Halm EA	2010	Inadequate Health Literacy Is Associated With Suboptimal Health Beliefs in Older Asthmatics	Cross Sectional Survey N=100	Those with inadequate literacy were more likely than those with adequate or marginal literacy to have suboptimal beliefs: no symptoms-no asthma
Federman AD, Wolf M, Sofianou A, Wilson EAH, Martynenko M, Halm EA, et al	2013	The association of health literacy with illness and medication beliefs among older adults with asthma	Cross Sectional Survey N=420	Health literacy was associated with beliefs of not having asthma all the time and that asthma can be cured. Patients with low health literacy were also more likely to be concerned about medication use
Aikens JE, Piette JD	2009	Diabetic Patients' Medication Underuse, Illness Outcomes, and Beliefs About Antihyperglycaemic and Antihypertensive Treatments	Cross Sectional Survey N=1376	Low health literacy was associated with concern over antihyperglycaemic and antihypertensive medication
Shone LP, Conn KM, Sanders L, Halterman JS	2009	The role of parent health literacy among urban children with persistent asthma	Cross Sectional Survey N=499	Low parent health literacy was independently associated with greater parent worry, parent perception of greater asthma burden, and lower parent-reported quality of life
Davis TC, Arnold C,	1996	Knowledge and Attitude on	Cross Sectional	Lower reading ability correlated

Berkel H, Nandy I, Jackson RH, Glass J		Screening Mammography among Low- Literate, Low- Income Women	Survey N=445	significantly with less mammography knowledge
Lubetkin EI, Lu WH, Gold MR	2010	Levels and Correlates of Patient Activation in Health Center Settings: Building Stratergies for Improving Health Outcomes	Cross Sectional Survey N=527	Patients with adequate health literacy were more activated than their counterparts
Smith SG, Curtis LM, Wardle J, von Wagner C, Wolf MS	2013	Skill Set or Mind Set? Associations between Health Literacy, Patient Activation and Health	Secondary Analysis of Baseline Cross Sectional Data N=697	The relationship between health literacy and patient activation was weak, but significant. Lower health literacy was association with worse physical health and depression
Greene J, Hibbard J, Tusler M	2005	How Much Do Health Literacy and Patient Activation Contribute to Older Adults' Ability to Manage Their Health?	Cross Sectional Survey N=293	Health literacy was positively related to Medicare decision making and engagement in health-care related behaviours, healthy behaviours, and chronic disease management behaviours.
Vassy JL, O'Brien KE, Waxler JL, Park ER, Delahanty LM, Florez JC, et al.	2011	Impact of Literacy amd Numeracy on Motivation for Behavior Change After Diabetes Genetic Risk Testing	Cross Sectional Survey N=175	Higher levels of health literacy, genetic literacy, and health numeracy were associated with an anticipated decrease in motivation for lifestyle modification in response to low- risk results
Osborn CY,	2010	Health Literacy,	Cohort Study	No direct

Bains SS, Egede LE		Diabetes Self-Care, and Glycaemic Control in Adults with Type 2 Diabetes	N=130	relationship was observed between health literacy and diabetes self-care or glycaemic control. Health literacy had a direct effect on social support
Powe BD, Weinrich S	1999	An intervention to decrease cancer fatalism among rural elders	Randomized Controlled Study N=70	People who viewed the intervention video had a greater decrease in cancer fatalism scores and a greater increase in knowledge of colorectal cancer scores than in the control group