EXAMINING THE ROLE OF HEALTH LITERACY IN ONLINE HEALTH INFORMATION

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Nuffield Department of Primary Care Health Sciences

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Abstract

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The internet has radically changed the way people obtain and interact with information about diseases, treatments, and conditions. Yet, our understanding of how people access and use health information to make decisions- in other words, their health literacy- has not progressed. The overall aim of this thesis is to assess the extent to which health literacy is a valid and useful construct for policy and practice related to online health resources.

A mixed-methods research programme of five studies was undertaken, influenced by realist evaluation methodology. First, to ascertain engagement with user-generated online health content (UGC) in the UK, analysis of a large European survey was undertaken. Then, the uncertainty regarding the relationship between health literacy and outcomes was addressed by a systematic review and qualitative analysis of health literacy measures. Results of these two studies informed interviews carried out with 13 'key informants': policymakers and primary care clinicians in the UK with a particular interest in health literacy and/or online information. A systematic review, incorporating a traditional narrative review and a realist review, evaluated existing trials addressing how effects of online resources vary by health literacy level. Finally, data were analysed from a feasibility randomized controlled trial, comparing usage and outcomes of accessing a 'personal experiences'- based asthma website (representing curated user-generated content) versus a 'facts and figures'- based website. Participant health literacy was assessed using an index identified from the systematic review of measures, and website usage was tracked.

Approximately 25% of UK internet users engage with UGC at least monthly. The most frequent users were younger, more likely to be male, and to be carers for someone with a

long-term illness. Three themes were identified from health literacy measurement: ‘appropriate health decisions’, ‘ability to obtain healthcare services’, and ‘confidence’. Key informants noted the lack of clarity about how health literacy influences outcomes, and suggested that personal preferences and digital access and skills may be more relevant than health literacy for policy and practice. Existing trials of online resources in which participant health literacy was measured were mostly at high risk of bias; some possible explanations of how these interventions should work in people with low health literacy were that they may experience higher data entry burden related to chronic diseases, and that they may prefer simulated face-to-face communication. Finally, there were no differences between health literacy groups in the feasibility trial regarding usage or outcomes related to either the ‘facts and figures’ or ‘personal experiences’ websites.

Taken together, these results question the validity and appropriateness of health literacy as a key objective or consideration in the development or use of online resources. While health literacy has value as a general idea, this thesis demonstrates that it may no longer be the right construct to guide intervention development and implementation to improve health outcomes.

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Little high plains town

the high school's goin' online

some kids are gonna ride

across the digital divide

out into the blue cyberspace

leave this lonesome prairie

Maybe they'll come back

save us from the wind

-Ian Tyson, *Live at Longview* (1)

Chapter 1: Introduction

1.1 Background and overall aim

Health literacy was conceptualized to capture an individual's ability to use health information to make decisions related to healthcare. When health literacy was developed in the early- to mid-1990s, people generally obtained health information from the doctor or nurse, and the amount of information available on the internet was insignificant.(2, 3) At that time, it was identified that most people did not understand the information provided to them.(4) It was subsequently recognized that those who scored low on measures of health literacy had worse outcomes than those who scored higher.(5-7)

How people access and use information has radically changed in the past two decades as a result of several developments, including the consumer health movement, the rise of shared decision-making as a (putatively) core component of evidence-based medicine, and widespread policy objectives promoting patient empowerment.(8-10) Since the 1990s health information has become progressively democratized, in large part due to the growth of the internet.(11) People are now able to go online and access information that used to be only available from professionals. Yet research into what constitutes health literacy for the modern era, and how people's health literacy affects their use of these new information resources, is limited. While study after study continues to demonstrate that low health literacy is associated with poor health outcomes (noting that the role of confounding in this relationship is often underexplored in these studies), the way in which people get their information has dramatically changed. Therefore, available conceptualizations of health literacy may no longer be useful to guide intervention development and evaluation. The multimedia, tailored, interactive nature of websites means that engaging with them is very different from reading a leaflet. As a result, an online resource can be accessed at multiple

levels rather than entirely designed for a specific reading or health literacy capacity. This has become even more relevant with the rise of user-generated content, as the internet shifts from ‘Web 1.0’ to ‘Web 2.0’.(12)

Therefore, this thesis aims to assess the extent to which health literacy is a valid and adequate construct in today’s world of readily accessible, interactive health information on the internet. It is comprised of five studies, guided by a realist evaluation approach, which seek to evaluate the role of health literacy in the use and outcomes of online health information.

1.2 Specific objectives

In order to fulfil the overall aim, the following research objectives were identified and addressed:

- To quantify UK internet users’ engagement with user-generated online health content.
- To examine the theoretical underpinning of health literacy as a construct by examining how it has been operationalized in measurement indices.
- To explore professional key informants’ beliefs and views regarding the relationship between health literacy and health outcomes when people access online information, and their perceptions of opportunities and barriers regarding the development and dissemination of online health resources.
- To identify how the effects of existing online and multimedia health education resources vary by health literacy level, and possible mechanisms by which these resources exert their effects.

- To investigate, in a feasibility randomized controlled trial (RCT), the usage and effects of a novel health experience-based online patient education resource, and describe how usage and effect varies by health literacy level.
- To draw conclusions about how, in whom, and in what circumstances online interventions may have various effects in people with different health literacy levels.
- To refine and update health literacy as a construct accounting for the way in which health information is currently obtained and shared on the internet.

1.3 Structure of the thesis

In order to answer these research questions, the thesis is structured through mixed-methods data collection and analysis, informed by realist evaluation. The content of each chapter is as follows:

Chapter 2: Methods

This chapter describes the ontological and epistemological assumptions underpinning the programme of research reported in this thesis. It outlines the selection of methods for each study.

Chapter 3: Background and literature review

Chapter Three introduces the key concepts addressed in the thesis. First, it introduces the concept of health literacy, and the relationship between health literacy and health

outcomes. Then, it reviews literature on health information in general, and online health information in particular. The rise of user-generated content is highlighted, specifically as it relates to textual narrative accounts, videos, and ratings of services. The consumer health movement, shared decision-making, and patient empowerment are discussed. The relationship between health literacy and information policy objectives in the UK and North America is reviewed. Finally, this chapter sets out the rationale for studying this topic and how this thesis contributes to the existing literature on online health resources and health literacy. The literature reviewed is interdisciplinary, and includes primary and secondary research, as well as grey literature and policy documents in epidemiology, public health, sociology, and education theory.

Chapter 4: Who engages with user-generated online health content? Survey of UK Internet users

This chapter reports a secondary analysis of a survey of UK internet users, drawing on responses to a major European survey of the use of Information and Communication Technology (ICT) for health. Taking the proliferation of user-generated online health content as a key development in health information use in current times, it explores who accesses and shares these resources in the UK. Analyses are conducted by comparing the sociodemographic and health characteristics of those who access and share these resources by the frequency with which they do so. Key findings are discussed in the context of the literature on general online health information seeking behaviour. The conclusions of this chapter inform the data analysis in Chapter 5 as well as the interview schedule employed in Chapter 6.

Chapter 5: Conceptualization and measurement of health literacy: Systematic review

Chapter Five reports the results of a systematic review of existing health literacy indices. Analyses of characteristics associated with their administration, and in-depth qualitative exploration of themes underpinning the items contained within the measures are reported. Conclusions are drawn through the identification of underlying conceptual models of health literacy, which are then interrogated in Chapters 6, 7, and 8.

Chapter 6: How might health literacy influence outcomes of online health information? Qualitative interview study

For this chapter, semi-structured interviews were carried out with 'key informants': policymakers, researchers and primary care clinicians with a particular interest in health literacy and online health information. The interview schedule was developed from the conclusions of chapters 3, 4, and 5. This chapter outlines respondents' views on health literacy, online resources, and UK policy.

Chapter 7: Do the effects of online and multimedia resources vary by health literacy level? Systematic and realist review

In this chapter, existing online and multimedia health resources are systematically reviewed. The specific components that constitute these resources are determined, and the effects of the interventions are reported. In particular, any evidence supporting or refuting differential effectiveness of these interventions between participants with different health literacy levels is discussed. Then, in order to ascertain possible mechanisms of how these interventions influence outcomes in the context of varying health literacy levels, a realist

synthesis of included studies is reported. The relationship between health literacy level and intervention effect relating to online health information more generally is explored.

Chapter 8: Health literacy and online health information: Analysis of data from a randomized controlled trial

This chapter investigates the role of health literacy in people's online health behaviour. Adults with asthma were recruited in primary care and randomized to one of two password-protected health information websites: one comprised of 'personal experiences' (representing 'curated' user-generated content) and the other of 'facts and figures' information. Participant health literacy was measured at baseline and usage data was obtained, including number of logins, number of pages viewed, and length of time spent on the websites. Participants completed baseline and follow-up questionnaires, including self-reported health outcomes. Analyses are reported comparing characteristics of people with different levels of health literacy, and usage and outcomes between these groups.

Chapter 9: Conclusions

Chapter Nine synthesizes findings from these five studies in the context of the literature review. It reviews potential mechanisms by which online health information influences outcomes in the context of different levels of health literacy. It discusses how the findings fit into and build upon existing research in the field, as well as their implications for policy and practice, and recommendations for future research.

Table 1.1 Abbreviations used in this thesis

Abbreviation	Description
ACA	Patient Protection and Affordable Care Act (United States)
ACT	Asthma Control Test
ADHD	Attention Deficit Hyperactivity Disorder
ANCOVA	Analysis of covariance
ASQ-e	Asthma Screening Questionnaire- electronic
A & E	Accident and Emergency
BP	Blood pressure
BMI	Body Mass Index
CARDES	Cardiovascular Dietary Education System
CDSEQ	Chronic Disease Self-Efficacy Questionnaire
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CONSORT	CONSORT
CPHA	Canadian Public Health Agency
DHHS	Department of Health and Human Services (United States)
eHIQ	eHealth Impact Questionnaire
EXPERT	Experiences Evaluated in a Randomized Trial
HbA1c	Haemoglobin A1c
HDL	High density lipoprotein
HL	Health literacy
HLQ	Health Literacy Questionnaire
HLSI	Health Literacy Skills Instrument
ICMJE	International Committee of Medical Journal Editors
iPEX	Internet Patient Experiences project
ISRCTN	International Standard Randomized Controlled Trial Number
LDL	Low density lipoprotein
MAR	Missing At Random
MI	Multiple imputation
MNAR	Missing Not At Random
MOS	Medical Outcomes Study
MS	Multiple sclerosis
NASA TLX	National Aeronautic and Space Administration Task Loading Index
NCD	Non-communicable diseases
NIHR	National Institute for Health Research (United

	Kingdom)
NHS	National Health Service (United Kingdom)
NVS	Newest Vital Sign
OSOP	One Sheet Of Paper
PCA	Principal Components Analysis
PHLAT	Parental Health Literacy Assessment Test
PIH	Partners In Health
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RAMESES	RAMESES
REALM	Rapid Estimate of Adult Literacy in Medicine
REAL-G	Rapid Estimate of Adult Literacy in Genetics
REALM-Teen	Rapid Estimate of Adult Literacy in Medicine-Teen
REAL_VS	Rapid Estimate of Adult Literacy in Vascular Surgery
SD	Standard deviation
SDM	Shared decision making
STOFHLA	Short Test of Functional Health Literacy in Adults
TAIMI	Test of Ability to Interpret Medical Information
TOFHLA	Test of Functional Health Literacy in Adults
UK	United Kingdom
WHO	World Health Organisation

Note: A full list of abbreviations of all health literacy measures from studies included in this thesis is available in Appendix C.1 (page 258).

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Chapter 2: Methodology and methods

2.1 Ontology, epistemology, and the overall approach

In this chapter, I describe the overall methodological approach that ties together all the studies comprising this thesis. Each subsequent chapter contains a description of the specific method(s) selected for each individual study. After the results are described and discussed, each chapter contains a section outlining the limitations of the methods used in that chapter.

It is a truth (almost) universally acknowledged that there is substantial definitional uncertainty in health literacy.(1, 2) Health literacy is complex, and is inherently socially constructed and mediated, as is the use of online health information. In designing the programme of research that comprises this thesis, it was assumed that one of the fundamental reasons why little progress has been made producing successful interventions to improve health literacy is that understanding of the construct itself has not changed with the times. As discussed in Chapter 1, it is obvious that many people access their health information in vastly different ways than in the early 1990's, yet our understanding of what capabilities and capacities are required to get the most out of health information today has not progressed in step.

Many studies demonstrate that lower health literacy is associated with poorer health outcomes.(3, 4) Various interventions have been developed to improve health literacy, yet with little evidence of success. The response to unsuccessful interventions has generally been to develop alternatives, and to test them in randomized controlled trials. It has been repeatedly noted that it is unclear how online resources, including patient education information, cause effects.(5-8) Yet few authors have taken a critical approach to the construct of health literacy to question what, if anything, has changed about health

information access and use that may account for the outcomes (success or failure) of these interventions.

In order to investigate this issue, an ontological position of "critical realism" was adopted.(9) Critical realist ontology holds that reality cannot be measured objectively or definitively, but that progress can be made towards developing a better understanding of the causal mechanisms relating interventions to outcomes. Although there is some debate about the importance of causal mechanisms in Evidence-Based Medicine (EBM) (10), the fact that there has been no progress updating knowledge about health literacy suggests the potential usefulness of this mechanism-focused approach. It draws on the work of Ray Bhaskar (11) and others, such as Edgley (12), Collier (13), and Campbell.(9) Critical realism sits between positivism, which holds that the real world can be observed and measured directly, and constructivism, in which there is no objective reality and that as a result it is impossible to know the nature of the real world. Its inherent epistemology is incremental; objective truth cannot be known, but progress can be made towards a deeper understanding of the real world[1].

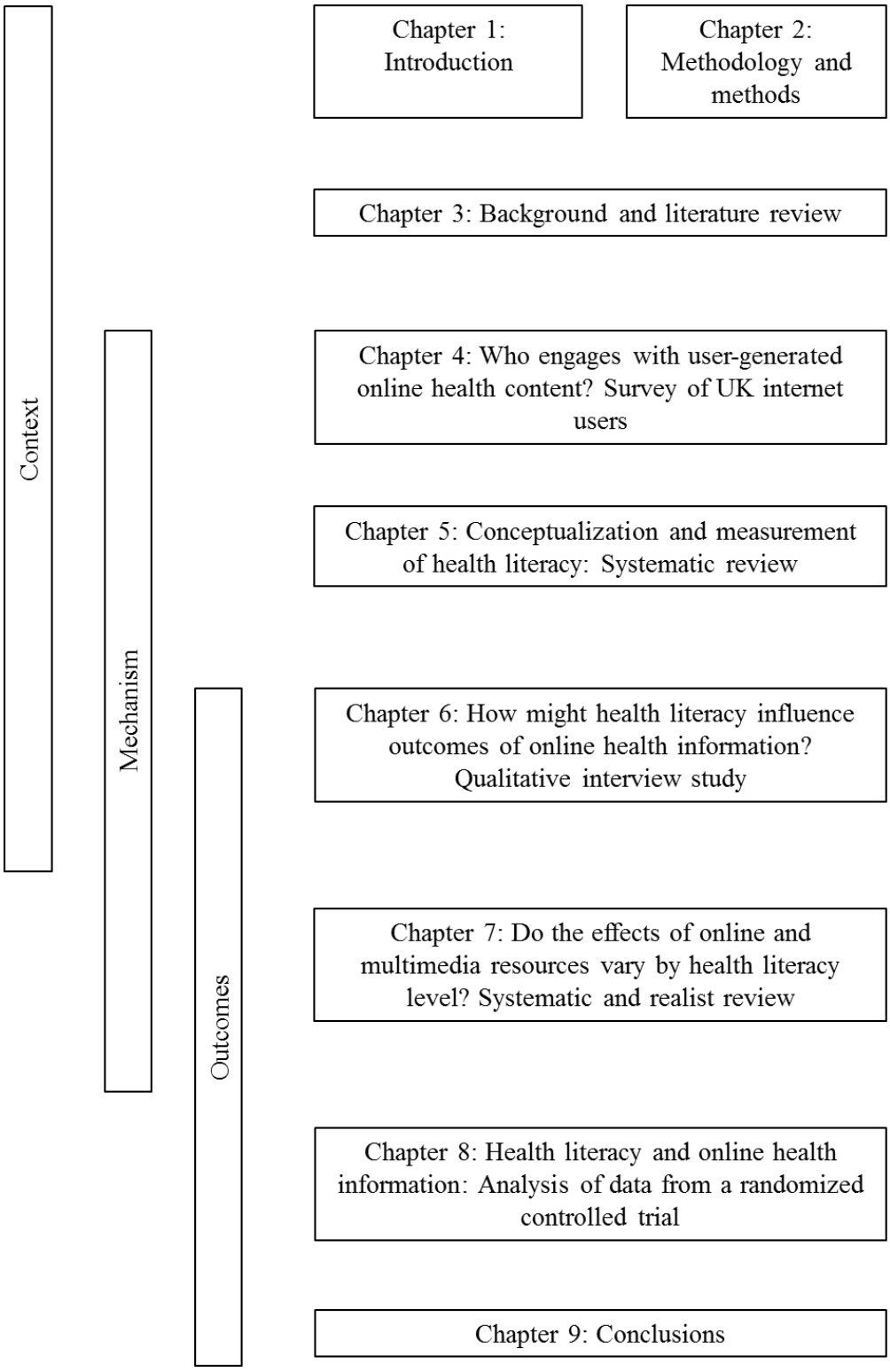
The realist approach develops understanding of how interventions relate to outcomes through 'generative causality'.(14) Instead of discovering knowledge through the application of experimental control, a realist approach attempts to account for the relationship between mechanism and context, and the outcomes that follow. Whereas the positivist approach seeks to control context to prove or disprove hypotheses about *intervention-outcome* relationships, a realist approach accepts that context varies, and that

[1] The idea of critical realist ontology having an 'inherent' epistemology differs from the Bhaskarian conceptualization of critical realism (which he called "transcendental realism") (7), in which ontology and epistemology are kept separate. This thesis follows Pawson (14) in adopting Campbell's 'post-positivist critical realism'.(9) Pawson holds that "criticism is something that scientists apply to each other" and that "competitive cross-validation" is how progress is made towards the truth. Ontology and epistemology are therefore interrelated. He also notes that to fully explain the differences between Bhaskar's and Campbell's critical realism "would require a festschrift." Further elaboration is therefore considerably outside the scope of this thesis.

the *mechanism-outcome* relationship depends on accounting for this variation in context. (Critical) realism holds that everything is socially embedded in systems. Human behaviour is a central component influencing outcomes. Interventions are therefore non-linear and are subject to adaptation and revision when implemented. Rather than 'control' for these differences as would happen with a positivist approach, it is accepted that "social systems are the product of literally endless components and forces."(14)

In this thesis, the realist approach is operationalized by treating health literacy as context, and online resources (such as health education websites, and online patient records, but excluding email) are the interventions which act in context. Outcomes that result from accessing online resources are defined broadly, and have included morbidity and mortality, as well as patient satisfaction and self-efficacy. Each study is designed to address some aspect of context (unpacking how health literacy is conceptualized) mechanism (addressing how online resources might act differently between health literacy levels) and outcomes (what is affected by online resources, and whether user characteristics and outcomes differ between health literacy levels). Figure 2.1 demonstrates the overall relationship between studies in the thesis, and what aspect of the 'context-mechanism-outcome' (C-M-O) relationship each chapter addresses.(15)

Figure 2.1 Thesis overview diagram



2.2 Methods

2.2.1 Overview

I selected a mixed-methods approach, ensuring that that the contribution of each specific method was carefully considered with respect to the overall aims.(16, 17) In keeping with realist ontology and incremental epistemology (14, 15), multiple methods allow for the development of a progressive and generative causal understanding of the phenomenon under study.

Mays and Pope have argued that multiple methods can be used erroneously in the hope that "the weakness in one method can be compensated for by the strengths in another."(18) The rationale for using multiple methods in this thesis was to address a complex issue from several different perspectives. In accordance with a central principle of EBM - that the highest quality of evidence for any given component of a study depends on the nature of the specific question being asked (19) - I have selected each method to ensure the conclusions of the project are useful and applicable.

2.2.2 Specific methods

One key component of an influential agenda to eliminate "research waste" is that existing literature should be reviewed as the first stage of any research project.(20) Therefore, this thesis includes two systematic reviews of available literature, each following established standards for the conduct and reporting of systematic reviews.(21) In line with the diverse methodological orientation underpinning the work, I analysed data from these systematic reviews both quantitatively and qualitatively. This allowed the same data to be examined

asking two types of questions: both “how effective is this”, and “what is the relationship between mechanism and outcome” across different contexts.

Qualitative research is considered appropriate for exploring social phenomena, particularly when the aim is to conduct exploratory research allowing for emergent, as well as anticipated, analytic themes.(22-24) Therefore, in addition to the qualitative components of both systematic reviews, I carried out semi-structured interviews with key informants. These allowed me to explore the findings of the reviews, and to unpack ideas about mechanisms relating health literacy to outcomes, as well as the general usefulness of the construct. These interviews also facilitated stakeholder engagement, which is a key feature of realist inquiry.(15)

Finally, I analysed data from a randomized controlled trial to investigate people’s online health information use and related outcomes. While this trial was originally designed as a feasibility study to evaluate the effectiveness of a health experience-based website, I analysed data relevant to the exploration of relationships between health literacy level and website usage and outcomes. Just as there is some tension between EBM and the realist approach (25), there has been some debate regarding the appropriateness of RCTs in realist inquiry.(26, 27) I took the position that using data from an RCT was appropriate to inform this type of inquiry, since it allowed the opportunity to study the characteristics and online behaviour (what people do as well as what they say they do) in association with the trial. Thus, this was not a case of using data from an RCT to answer merely ‘what works’, but rather to develop knowledge about how health literacy may relate to website usage and outcomes.

2.2.3 Ensuring research 'quality'

While there are several well-established standards for research conduct and reporting in quantitative health research, such as the CONSORT guidelines for randomized controlled trials (28, 29); the STROBE guidelines for observational studies (30); and the PRISMA guidelines for systematic reviews (21, 31), there is somewhat more debate about how to define quality in qualitative research. Multiple paradigms exist, including that of 'trustworthiness' (32), 'rigour' (33), as well as adaptations of those terms more commonly associated with quantitative research such as 'reliability' and 'validity'.(34) I have adopted the position of Seale, noting that all these paradigms have some value, and what is most important is to be transparent about what was done and the potential limitations of chosen methods.(35)

In this thesis, data are collected and analysed according to the established principles of each selected methodology. The overall approach is iterative and reflexive; rules are followed by default, but deviated from when there is a clear, defensible reason to do so. Systematic reviews, for example, have been conducted in accordance with the Cochrane Collaboration guidelines (21), and the PRISMA guidance for reporting is followed in both Chapters 5 and 7.(31) In the latter part of Chapter 7 involving a realist synthesis of included studies, the recent RAMESES guidelines are mostly followed, but were deviated from as a result of a discussion I had with a member of the guideline development committee (see section 7.6.2).(36)

2.3 Conclusions

Throughout the course of this thesis, the primary objectives (as outlined in section 1.2) are addressed. The final chapter summarizes the results pertaining to the specific research questions reported in section 3.7 related to these objectives. This thesis furthers an understanding of the relationship between health literacy, online health information, and health outcomes. It provides guidance for developing online health information and incorporating it into practice and policy, and suggests areas for further research.

A note regarding terminology:

The word "online" is used variably throughout available literature. The Oxford English Dictionary (OED), for example, defines it as "controlled by or connected to a computer."(37) In this thesis, it is taken to mean any state in which a desktop, portable, or handheld computer that has the capacity for connectivity with other electronic devices is used as the medium by which health-related content is accessed or shared. This includes accessing the internet through a desktop or laptop computer, through a smartphone or tablet, as well as the use of an "application" or "app" on a handheld device. Although the use of "apps" does not necessarily require connectivity at the time at which they are being used, for the purposes of this thesis, they are included as a component of "online" resources. While email is an "online" function, it is excluded from consideration in this thesis.

"Information" is an even more variously defined term. The OED provides several definitions, but two are of particular relevance to this thesis: "the imparting of knowledge in general" and "knowledge communicated concerning some particular fact, subject or event" (38). These two definitions sit at either end of a spectrum; whereas the former can

be criticised for over-inclusiveness, the latter is too narrow, implying that there is always an active process of information provision and that it is predominantly factual in nature. Neither is quite appropriate to describe health information, particularly in the context of user-generated content, which can be experiential and may be iteratively shared and accessed. The former definition is closer to being appropriate for this thesis, with the caveat that information is socially constructed and consumed, and this social influence is of primary importance when studying health information.

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Chapter 3: Background and literature review

> *In the new electric Age of Information and programmed production, commodities themselves assume more and more the character of information.*
>
> -Marshall McLuhan, 1964 (1)

> *This is an age in which there is more information, more knowledge, and more material purporting to be knowledge, much of it generated by university research, more available than ever before.*
>
> -Donald Markwell, 2012 (2)

3.1 Overview

Research into the impact of health literacy on outcomes, and the development of interventions to improve the health status of people with low health literacy or to improve health literacy itself, constitute important areas of inquiry. The proliferation of online health information has expanded availability and modified delivery of health information, and there is a growing body of literature regarding these resources. I undertook a literature review to explore and synthesize research on health literacy and online information, and to identify relevant gaps in the literature to be addressed in subsequent chapters of the thesis.

In order to carry out this literature review, I started by identifying key grey literature reports on health literacy by using Google search. Subsequent to this, I searched in three databases, accessed through the Ovid interface (Thomson Reuters): Medline, PsycINFO, and Embase. Initially I focused on the phrase "health literacy", as well as a parallel search for "health information" but soon realized that focusing solely on the biomedical literature excluded important literature in education and the social sciences that had often been excluded in other studies of health information. Therefore, I expanded my search to

include the ‘Google Scholar’ interface, which references a variety of multidisciplinary databases. I scanned reference lists of relevant identified papers, and conducted periodic ‘update’ searches using the Ovid interface with the aforementioned three databases. This review covers the following areas:

- History and development of health literacy (section 3.2)
- Health information, the internet, and changing information ecologies (section 3.3)
- Patient empowerment, the consumer health movement, and shared decision-making (section 3.4)
- Health literacy and health information policy (section 3.5)

3.2 History and development of health literacy

3.2.1 Origins and development

The concept of health literacy had its genesis in early 20th century research on what literacy level was necessary for successful employment.(3, 4) An individual was considered ‘functionally literate’ if he or she possessed the skills necessary to carry out daily activities in employment and social life. Educational programs were designed to ameliorate deficits through education and skills training. The emphasis on these early educational curricula, operationalized through formal schooling for the masses, was on the spread of functional literacy through promoting individual achievement.(5) Alongside this recognition of the importance of reading ability for participating in society, it was recognized in the United States in the 1940s that the health-related material being provided to soldiers returning from World War II was unreadable by most.(4)

The phrase “health literacy” was first used in 1974, in a paper entitled ‘Health Education as Social Policy’ (6), although it has been suggested that its use in that publication was more of an “accident of English” than any deliberate attempt on the initial author’s part to define a new concept.(7) Indeed it was not until the early 1990s that research started in earnest relating literacy to health. Constant progress in this area started when a group of clinician researchers determined that a significant proportion of their patients were unable to read or understand the health information given to them in clinical settings.(8)

Initially, ‘health literacy’ was conceptualized relatively narrowly as an individual’s skill in reading and understanding health information.(8) Although the general literacy and education literature had adopted a more comprehensive view of pedagogy as empowerment decades earlier, influenced in large part by Paulo Freire’s 1970 *Pedagogy of the Oppressed* (9), these concepts- described by Scribner as ‘literacy as power’ (10)- were not taken up in the initial development of the concept of health literacy. At first, health literacy was focused specifically on individual deficits in being able to use health information to make decisions. From this initial narrow definition, several authors expanded the concept to encompass more complex and nuanced use of health information, exemplified by two influential models that divided it into sub-constructs: basic, communicative, and critical health literacy (11); and fundamental, science, civic, and cultural literacy.(12, 13)

3.2.2 Early programmes to promote health literacy

One of the first national-level approaches to health literacy was established in 1994 by the Canadian Public Health Agency (CPHA). The National Literacy and Health Program

established collaborations between 27 national partners to improve health services for people with literacy difficulties.(14)

The next prominent national programme on health literacy was developed in the United States in 1999 with the American Medical Association's establishment of the 'Ad Hoc Committee on Health Literacy' for its Council on Scientific Affairs. It established a definition of health literacy as the "constellation of skills, including the ability to perform basic reading and numerical tasks, required to function in the health care environment."(15)

Research into the epidemiology and determinants of health literacy was further supported by the Institute of Medicine's 2001 report 'Health Literacy: A Prescription to End Confusion.'(16) This was the first study undertaken to identify the prevalence of low health literacy at a national level, and estimated that 90 million United States citizens had low health literacy. This report provided several recommendations for how to improve health literacy, including coordinated efforts by the education system, media, and health systems, as well calling for increased effort by consumers.

3.2.3 Definitions of health literacy

Although several indices to measure health literacy were developed during the early and mid-1990's (17-20), the first widely disseminated definitions were not developed until late in that decade. The first, published by the World Health Organisation in 1998, defined health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health."(21)

It was not until 2000 that the first comprehensive definition of health literacy was published, taking into account research identifying the increasing complexity and diversity of the construct. (11) To develop this definition, Nutbeam applied existing literature on general literacy that defined three levels - 1) 'basic/functional', 2) 'communicative/interactive', and 3) 'critical'- that enable use and understanding of progressively more complex information.(22)

According to this model, 'basic/functional' literacy provides sufficient basic skills in reading and writing to be able to function effectively in everyday life. 'Communicative/interactive' literacy refers to more advanced cognitive and literacy skills that combine with social skills to be able to apply new information to varied circumstances. 'Critical' literacy, the highest level, combines more advanced cognitive skills to be able to critically analyse information and to use it to exert control over life events. In a 2008 follow-up, Nutbeam expanded on this concept to distinguish two streams of health literacy research: one characterizing it as an 'asset', versus regarding an absence of it as a 'risk'.(23)

Existing definitions of health literacy can be found in Table 3.1. One review found 13 definitions of health literacy (3): eight "individual-static" definitions (11, 15, 16, 24, 26-29); two "individual dynamic" definitions (13, 30); two "individual/system" definitions (25, 31) and one "public health" definition.(32) Another review published two years later (33) added six additional definitions.(34-39) That review reported six clusters from a content analysis underpinning these definitions: (1) competence, skills, abilities; (2) actions; (3) information and resources; (4) objective; (5) context; (6) time. Additional review of these documents and review of reference lists resulted in finding five additional definitions.(27, 35, 56, 58, 96) This definitional heterogeneity and uncertainty has been noted as an important barrier to progress in health literacy research.(38, 40, 41)

Table 3.1: Definitions of health literacy and health numeracy, in chronological order by year developed

Number	Author (year published)	Definition
1	World Health Organization (WHO) (1998) (34)	The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health.
2	American Medical Association Ad Hoc Committee on Health Literacy (1999) (15)	The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment, such as the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials.
3	Ratzan and Parker (2000), in Institute of Medicine (2006) (16)	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
4	Selden *et al.* (2000) in Lee, Arozullah, and Cho (2004) (24)	The capacity of individuals to obtain, process, and understand the basic information and services needed to make appropriate health decisions.
5	Nutbeam (2000) (11)	The cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health.
6	'Healthy People 2010' (2000) (25)	Dependent on individual and system factors, including communication skills of lay persons and professionals, lay and professional knowledge of health topics, culture, the demands of the healthcare and public health systems, and the demands of the situation/context.
7	Bernhardt, Brownfield, and Parker (2004) in Schwartzberg (2004) (27)	An individual-level construct composed of a combination of attributes that can explain and predict one's ability to access, understand, and apply health information in a manner necessary to successfully function in daily life and within the health care system. Functional health literacy: the skills and ability to successfully function and successfully complete health related tasks. Individual-level attributes include abilities in prose, document, and

		quantitative literacy; ability to engage in two-way communication; skills in media literacy and computer literacy; motivation to receive health information; and freedom from impairments and/or communicative assistance from others.
8	Golbeck *et al.* (2005) (28)	Health numeracy is the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistic, and probabilistic health information needed to make effective health decisions. Health numeracy is considered to be not simply about understanding (processing and interpreting), but also about functioning (communicating and acting) on numeric concepts in terms of health.
9	Kickbusch, Wait and Maag (2005) in European Commission (2007) (35)	The ability to make sound health decision(s) in the context of everyday life - at home, in the community, at the workplace, the healthcare system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility.
10	Zarcadoolas (2005) (13)	The wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life.
11	Nutbeam (2006) (26)	Personal, cognitive, and social skills that determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health. These include such outcomes as improved knowledge and understanding of health determinants, and changed attitudes and motivations in relation to health behavior, as well as improved self-sufficiency in relation to defined tasks. Typically these are outcomes related to health education activities. Health literacy is conceptualized as one domain in a conceptual model of health promotion.
12	Kwan *et al.* (2006) (96)	The degree to which people are able to access, understand, appraise and communicate information to engage with

		the demands of different health contexts to promote and maintain health across the life-course.
13	Baker (2006) (31)	The ability to function in the health care environment and depends on characteristics of both the individual and the health care system. An individual's health literacy is context specific (dynamic) and may vary depending upon the medical problem being treated, the health care provider, and the system providing care.
14	Paasche-Orlow and Wolf (2006) (56)	An individual's possession of requisite skills for making health-related decisions, which means that health literacy must always be examined in the context of the specific tasks that need to be accomplished. The importance of a contextual appreciation of health literacy must be underscored.
15	European Commission (2007) (35)	The ability to read, filter and understand health information in order to form sound judgments.
16	Australian Bureau of Statistics (2008) (39)	The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.
17	Mancuso (2008) (58)	A process that evolves over one's lifetime and encompasses the attributes of capacity, comprehension, and communication. The attributes of health literacy are integrated within and preceded by the skills, strategies, and abilities embedded within the competencies needed to attain health literacy.
18	Pavlekovic (2008) (36)	The capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health.
19	Rootman and Gordon-El-bihbety (2008) (37)	The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.
20	Ishikawa and Yano (2008) (38)	The knowledge, skills and abilities that pertain to interactions with the healthcare system.
21	Freedman *et al.* (2009) (32)	Public health literacy is the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health

		decisions that benefit the community.
22	The National Network of Libraries of Medicine (2009) (30)	Varies by context and setting and is not necessarily related to years of education or general reading ability.
23	McCormack (2010) in Berkman (2010) (29)	The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions.
24	Sørensen *et al.* (2012) (33)	Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.

These definitions were published between 1998 and 2012, and encompass a wide variety of skills, motivations, and related concepts regarding the use of health information. Sørensen *et al.'s* 2012 review (which developed definition 24, Table 3.1) was the only one that attempted to systematically review all other prior definitions before developing a new one. These definitions chronicle a gradual shift from an emphasis on passively understanding what has been provided by a healthcare professional (see, for example, definition 2) to a more active process of being able to contextualize information gained through various means (such as in definition 10). Yet there are important differences between them: note, for example, that the Australian Bureau of Statistics definition (definition 16) was the first to mention 'first aid', as well as 'drugs and alcohol' directly. The concept of 'sound' or 'appropriate' health decisions is repeated throughout these definitions (such as in definitions 3, 4, 9, 15) with little guidance on what constitutes a 'sound' (or, for that matter, 'unsound' or 'inappropriate') decision. There is only one definition available that specifically addresses "health numeracy" (definition 8); most others do not distinguish between use and understanding of words versus numbers. In general, health literacy and numeracy have been dealt with separately in the literature,

although several available ‘literacy’ indices [e.g. the Test of Functional Health Literacy in Adults (TOFHLA) (19) and the Newest Vital Sign (NVS) (42)] incorporate aspects of numeracy as well. Muir Gray noted in ‘Better Doctors, Better Patients, Better Healthcare’ that statistical illiteracy is a problem faced by a majority of patients and practitioners alike, and suggested that a lack of understanding of medical statistics should be considered a priority area for health promotion.(43) The evidence linking health numeracy to outcomes is unclear.(44)

3.2.4 Health literacy measurement

The first measurement index developed to measure reading ability as related to health was published in 1964.(45) Although the first use of the phrase "health literacy" was in 1974 (6), it was only in 1991 with the publication of the Rapid Estimate of Adult Literacy in Medicine (REALM) (46) that the first index described as measuring "health literacy" was available. Subsequent indices attempted to more adequately measure the construct in its entirety [e.g. Test of Functional Health Literacy in Adults (TOFHLA) (19)] or parsed health literacy into condition- or specialty-specific constructs [e.g. Nutrition Literacy Scale (NLS) (47); Rapid Estimate of Adult Literacy in Vascular Surgery (REAL_VS) (48)]. A recent systematic review of 19 indices noted psychometric weakness and lack of comprehensiveness amongst many available measures limiting their usefulness and generalizability.(49) Other reviews on diabetes-specific indices (50) and indices for eHealth applications (51) came to similar conclusions. Several articles have promoted research agendas on improving health literacy measurement, including calling for more 'basic' research about the construct itself (52, 53), improving representation of the health literacy skills and abilities required to maintain and promote health in non-medical settings (54), and developing a comprehensive unified conceptual framework.(55)

3.2.5 Relationship between health literacy and health outcomes

3.2.5.1 Theoretical frameworks linking health literacy and health outcomes

Research into the theoretical relationship between health literacy and outcomes lagged behind the development of indices to measure the construct, measuring its prevalence, and determining the quantitative relationship between measured health literacy and outcomes. In a 2005 review of the progress of health literacy research in Canada, Rootman and

Ronson reported a conceptual framework for literacy and health developed in 2002 as part of a national research programme on health literacy.(14) They reported actions involved in health literacy- communication; capacity, community, and organizational development; and policy- as well as determinants such as education, early child development, and personal capacity. Their framework posits that actions and determinants feed into general, health, and other (scientific, cultural) literacy, which act iteratively to provide direct and indirect effects. Direct effects include medication use and health safety practices, whereas indirect effects include use of health services, lifestyle, income, and quality of life. In this model, all these direct and indirect effects support improvements in health status.

One of the most highly cited theoretical frameworks was developed by Paasche-Orlow and Wolf (56) in which they suggested health literacy influences three points along the continuum of healthcare access and use: 1) access and utilization of healthcare; 2) patient-provider relationships; and 3) self-care. In this model, health literacy facilitates accessing necessary health services, optimizing the patient-provider interaction while accessing services, and engaging in appropriate self-care after consultation.

A 2011 study attempted to validate the self-care pathway in the Paasche-Orlow and Wolf model through the use of structural equation modelling of data from hypertensive patients attending safety net primary care clinics in the United States.(57) This study found paths between health literacy and knowledge, from knowledge to self-efficacy, from self-efficacy to physical activity, and from physical activity to health status. It found that education, race, and age were directly related to health literacy and were unrelated to other variables; whereas health literacy was not directly related to self-efficacy, self-efficacy was not related to health status, and knowledge was not related to self-care behaviour. They found no direct relationship between health literacy and health status. It should be noted that this study used exclusively self-reported measures, and given the disease-

specific patient population from which data was obtained, the results are of limited generalizability.

Drawing on a wide range of related literature in the health and social sciences, Mancuso (58) described a theoretical framework in which the development of health literacy required six antecedent competencies: 1) autonomous, 2) contextual, 3) operational, 4) interactive, 5) cultural and 6) informational. The consequences of these antecedents are described as communication, capacity, and comprehension. In turn, the individual and society work iteratively to influence outcomes in the context of these antecedents and consequences.

Another theoretical framework was developed by von Wagner and colleagues in 2009, which focused on the relationship between health literacy and health actions such as use of and access to healthcare services, patient-provider interactions, and self-care.(59) Navigation of health services features in both the von Wagner *et al.* and Paasche-Orlow and Wolf models, although von Wagner *et al.* note that there is a lack of empirical research demonstrating deficient navigation amongst people with low health literacy (such as, for example, the relationship between health literacy and 'inappropriate' Accident and Emergency service use in the UK, which has not been investigated). They also note that navigation may encompass a broader set of skills including navigating media (such as television and newspaper stories) as well as the ability to choose appropriate services. Von Wagner *et al.* conclude suggesting that health literacy is a "combination of cognitive skills, knowledge, and experience attained throughout the lifespan" and that "motivation based and skill based" processes mediate the relationship between health actions and health literacy.

3.2.5.2 Epidemiologic evidence linking health literacy and outcomes

Two decades of research into the relationship between health literacy and health outcomes, mainly in the United States, has demonstrated associations between low measured health literacy and poorer health outcomes. There is moderate to high quality evidence for the relationship between low health literacy and health status in elderly persons (60-67), interpreting labels and health messages (68-71), obtaining mammography (72, 73), and appropriate medication use.(74-79) Moderate evidence also exists for increased emergency care use in the United States (60, 62, 80-86) and hospitalization (60, 62, 81-84) amongst individuals with low health literacy. It has been noted, however, that these associations are not always present, and that the "quality and inconsistency" of existing evidence lead Baur and Ostrove to suggest that "health literacy researchers who are interested in the association between chronic disease and health literacy should pause to rethink their research strategies, including the value of conducting more theory-driven research."(87)

These studies, which are either cross-sectional or cohort studies, address bias and confounding in variable ways. Appendix A.1 contains details of each of the 27 studies in the above paragraph: their purpose, design and participants, the health literacy measure used in the study, a brief statement of results, as well as how confounding was addressed. While bias was addressed in most of these studies (n = 23), either through controlling for covariates in regression modelling or path analyses, five studies described 'adjustment' but did not specify covariates.(62, 73, 76, 79, 85) A further four did not report any method of reducing bias through adjusting for covariates, or for exploring possible influence of confounders.(60, 71, 81, 88)

3.2.6 Prevalence of different levels of health literacy

Using available assessment indices, a high prevalence of low health literacy has been reported in in both population-representative (89) and patient samples.(90, 91) The largest survey conducted on the health literacy of a population was undertaken by the United States Department of Health and Human Services in 2003. Using the Ratzan and Parker definition of health literacy (definition 3, Table 3.1), it identified that 53% of adults had "intermediate health literacy" while 12% were found to be "proficient". A further 22% of the population was characterized as having "basic health literacy", whereas 14% had "below basic" health literacy.(92)

The next largest health literacy study was the European Health Literacy Survey, involving 8000 adults from 8 European Union countries [Austria, Bulgaria, Germany (limited to the state of North Rhine-Westphalia), Greece, Ireland, the Netherlands, Poland, and Spain].(93) This study used the Sørensen *et al.* definition of health literacy (definition 28, Table 1). It found that overall, 47% of people in the study had "inadequate" or "problematic" health literacy. This estimate varied from 29% in the Netherlands to 61% in Bulgaria. It further characterized the specific deficiencies people had with health information: 40% of people had difficulties in health settings; 42% had difficulties with disease prevention information; and 49% had challenges associated with health promotion (such as food packaging, and interpreting how political changes may affect their health).

Comparatively, there has been less research into the prevalence of different levels of health literacy in the United Kingdom. Three studies have been conducted in the UK: von Wagner and colleagues found in a 2007 study (in which they did not specify what definition of health literacy they used) that 11.4% of participants in their UK population-representative sample had 'marginal' or 'inadequate' health literacy.(94) In a 2012 study

of 7857 older adults across the UK (the English Longitudinal Study of Aging, which used the Ratzan and Parker definition), Bostock and Steptoe found a 12.5% prevalence of 'low' health literacy; 20.3% prevalence of 'medium' health literacy; and 67.2% prevalence of 'high' health literacy (95). This estimate is in stark contrast to that obtained by the US study using the same definition outlined above.(92)

3.2.6.1 Varying prevalence of health literacy between studies

The extent to which the wide variation in the prevalence of different health literacy levels between studies is due to heterogeneity in measurement or in the 'actual' differences in prevalence of health literacy levels amongst populations is unclear.(96) It has been suggested it is to some degree a combination of both, given that there is variability in health literacy levels in studies using the same measurement tool in all populations.(89, 93, 96)

Several studies exist in which health literacy has been measured using different indices in the same population. In an Australian sample, Barber *et al.* (89) found a varying prevalence of 'low' health literacy based on their use of three separate assessment measures: between 6.8% [measured by the Test of Functional Health Literacy in Adults (19)] and 26.0% [measured by the Newest Vital Sign (42)]. The European Health Literacy Survey included the United Kingdom version of the Newest Vital Sign (97) in addition to a new measure developed specifically for that study, the HLS-EU-Q (98), to determine correlations between the existing validated measure and the new measure. Whereas 47% of respondents in the survey had 'limited' health literacy as measured by the HLS-EU-Q, 21% had a 'high likelihood of limited literacy' as measured by the NVS. The report authors note that the NVS "only explains a moderate amount of variation of the HLS-EU's

general HL index," suggesting that there are differences in the latent constructs measured by these instruments, despite that they are both stated to measure health literacy.

Similarly, in a study of predominantly white older females in the United States, Shigaki and colleagues (99) found 55% of participants had a 'perfect' score on the Rapid Estimate of Adult Literacy in Medicine (18, 100) whereas 32% had a 'perfect' score on the Newest Vital Sign.(42) This study reported differences in REALM score by education but not age, while NVS scores varied by both education and age. Again, this variability suggests differences in the latent constructs measured by these respective instruments.

3.2.7 Explicit uncertainty in health literacy as a latent construct

It is perhaps unsurprising, given that the rapid development and use of measurement indices across multiple conditions and contexts occurred prior to intensive theoretical elucidation of the construct, that there is substantial uncertainty in what health literacy 'is'. The most highly cited indices used to measure health literacy (18, 19, 100, 101), for example, were all developed prior to the first comprehensive description of health literacy by Nutbeam in 2000.(11) They were also developed prior to the publication of the most widely cited definition of health literacy: "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions" (definition 3, Table 3.1).(102)

Indeed, it has been acknowledged by Pleasant *et al.* that the "lack of a broadly shared understanding about the causative structures underpinning the process of using health literacy to make informed decisions and the relationship between health literacy and behaviour change" is one of the most significant issues in health promotion research.(52) Furthermore it has been suggested that the variability in how health literacy is measured

and operationalized represents “underlying conceptual disagreements about health literacy.”(40)

Health literacy has been described as “old wine in new bottles” (103) and it has been suggested that it means different things to different people and has to some extent become a source of confusion.(31) More recent publications have acknowledged criticism that it may add little to existing concepts of health promotion, such as patient education.(104) In a 2008 publication reviewing progress in health literacy research since his influential 2000 description, Nutbeam noted the existence of continued uncertainty as to whether health literacy is a derivative of general literacy or a distinct latent construct.(23) Multiple authors have suggested the existence of several ‘health literacies’ acting at different levels in different contexts (23, 105) while it is acknowledged by others to be a ‘multidimensional’ concept.(106) Results of one study investigating whether low health literacy influences outcomes through a threshold or gradient effect suggested that the nature of the relationship between low health literacy and poorer health outcomes depends on the outcome of interest.(107) Overall, it is clearly apparent that there are many levels of uncertainty regarding health literacy as a construct.

3.3 Health information and the internet

3.3.1 Health information

Health information for patients has been a component of medical care throughout the course of Western medical history. This can be traced at least as far back as the Hippocratic corpus. ‘The Sacred Disease’, for example, described the importance of providing information to patients and the general public that a disease characterized by

frequent seizures- today known as epilepsy- was due to physiological abnormalities and not divine retribution.(108)

It has long been suggested that well-informed patients have better health outcomes as a result of engagement in decision-making and self-care.(45) To this end, the provision of health information to patients in order to educate about diagnosis, treatment, and conditions is a dominant aspect of modern medical care. In this thesis, "health information" is defined as any health-related content that is either provided or available to patients or the general public. It can be provided in leaflet form or on the internet, and can be provided or indicated to during a consultation, but does not include the basic interaction that occurs during a consultation for diagnostic or treatment purposes, and is therefore supplementary to the content of the consultation. It has been identified that health information is an essential aspect of healthcare that matters to patients.(109)

3.3.1.1 Motivations and functions of health information

Given the importance of information to health education and promotion, there has been a great deal of research regarding motivations and functions of health information. It has been identified that patients want more information than they are currently provided, and that practitioners frequently overestimate the amount of information they provide.(110)

One review described seven motivations for patients seeking health information (111):

1. For reassurance that their doctor has listened and understood and applied his or her expert knowledge.
2. To enable patients to make the necessary mental adjustments to their condition.
3. For patients to learn what agents should be avoided that would cause/worsen their symptoms/illness.

4. To enable people to contribute to their own treatment and care through following treatment regimes.
5. For people to interpret the significance of their symptoms and know who to consult.
6. To allow individuals to plan their social and economic functioning around their symptoms and treatment; and access material and financial assistance.

Another review suggested the following additional reasons why patients seek health information (112):

1. Understand what is wrong.
2. Gain a realistic idea of prognosis.
3. Make the most of consultations.
4. Understand the processes and likely outcomes of possible tests and treatments.
5. Assist in self-care.
6. Learn about available services and sources of help.
7. Provide reassurance and help to cope.
8. Help others understand.
9. Legitimise seeking help and their concerns.
10. Learn how to prevent further illness.
11. Identify further information and self-help groups.
12. Identify the 'best' healthcare providers.

Health information can be accessed at different stages in the course of interacting with healthcare. It may be accessed prior to a consultation (for patients to obtain knowledge about a forthcoming interaction with a healthcare service), as an adjunct to a consultation, or in place of a consultation.(113, 114) It can be used by patients to confirm treatment

options that have been presented, as well as to critically appraise diagnostic or treatment information that has been provided by a clinician.(115) Health information can also support self-management of long-term conditions.(116-118)

3.3.1.2 Sources of health information

There are several ways in which health information is provided to patients or is available to them, including leaflets, websites, and interactive computer-based tools.(119, 120) Patients either access information independently of any recommendation, or are provided suggestions from a clinician. These recommendations may be provided *ad hoc* or come in the form of an 'information prescription'.(121, 122) While leaflets provided as an adjunct to the clinical encounter were previously the predominant source of health information for patients, now, health information is often actively provided as well as accessed independently through multiple media.(119, 123)

An important shift has occurred in the last two decades along with the rise of the internet as a ubiquitous source of information in society, in which health information has become widespread. Previously privileged information, formerly available only when provided by a healthcare practitioner, is now widely available on the internet. It is estimated, for example, that 70% of UK residents access online health information at least monthly.(124, 125) Furthermore, the proliferation of user-generated online health information has further expanded the breadth of resources available to patients and the general public, including the ability to share their own information (113, 126), although engagement with these resources has not been investigated previously in the UK (see Chapter 4).

3.3.1.3 User-generated online content

One of the most important differences in how health information is developed and accessed today as opposed to in the early 1990's is the rise of user-generated online health content. It is clear that the production of health information has begun to shift from commercial organizations to healthcare users themselves. People increasingly go online to access information others have posted and to share their own health and illness experiences. Whereas traditional online health content (developed by businesses, health systems, governments, or charities) has predominantly consisted of numerical data related to the diagnosis or prognosis of a condition, user-generated health information, by virtue of its often informal development and dissemination, is a broad concept and incorporates anything that a patient or carer posts online for others to see. Entwistle *et al.* suggested that online health information can be broadly divided into two categories: 'general facts' and 'personal experiences'.(127) While these categories are not mutually exclusive, the differences have important implications. General facts consist of (often numerical) information about particular conditions, treatments, or services, and are intended to be broadly applicable to many people interested in the same topic. Personal experiences may also provide information about conditions, treatments, or services but are often in narrative form and portray an individual's experience of undergoing a particular treatment or of living with a long-term condition. People tend to draw on both general facts and personal experiences, depending on the issue involved: whereas 'general facts' are regarded as obviously essential for general health decision-making, 'personal experiences' are used to recognize decisions and identify and appraise options, and to support coping strategies.(127, 128)

3.3.1.4 Functions and motivations of health experience-based information

Few studies investigate the function of user-generated health experience-based information, or what outcomes might be influenced by accessing this increasingly prevalent type of information. Ziebland and Wyke reported seven domains through which accessing patients' experiences might influence health: 1) finding information; 2) feeling supported; 3) maintaining relationships with others; 4) affecting behaviour; 5) experiencing health services; 6) learning to tell the story; and 7) visualizing disease.(129) In a study of YouTube videos depicting the 'effectiveness' of a controversial treatment for multiple sclerosis (the 'liberation' procedure or venoplasty), O'Neill *et al.* (130) described the potential role of user-generated content (in this case, patient-generated videos) to influence policy and research agenda setting. There are similarities between domains from these two studies and the motivation domains elucidated by Olszweski and Jones (111) but four of them (maintaining relationships, learning to tell the story, and visualizing disease, as well as policy and research agenda setting) are novel and may be uniquely influenced by health experiences. It is therefore apparent that there are domains influenced by user-generated content (such as people's own health experiences) that have not been addressed in more traditional conceptualizations of motivation towards using health information.

3.3.2 Healthcare, the digital divide, and 'expert patients'

In 'The Rise of the Network Society', Manuel Castells described a future in which vertical hierarchies of social organization would be progressively replaced by participation in a relatively horizontal social structure called the 'Net'.(131) At the time the first volume of 'The Network Society' was published in 1996, just 20 million adults in the United States had access to the internet.(132) Today, 85% of US residents (around 254 million people)

and 78% of UK residents (around 49 million people) have access.(133) There can be little doubt that the internet has transformed interactions between colleagues and friends. It has profoundly impacted commerce, education, and health.

Early work on the availability of health information on the internet portrayed a degree of moral panic about the consequences of patients coming in to see physicians with reams of printouts from websites of dubious quality.(134) It was suggested that the deprofessionalization of previously privileged knowledge might set up a struggle over who holds health expertise.(135) Indeed, the spread and use of online health information has paralleled (and in turn supported) the development of the "expert patient". Those in favour of the increased availability of health information online advocated that 'expert patients' would transform healthcare systems by reducing costs (136), while others worried this move towards increasing patient autonomy might increase the workload of already busy practitioners without improving outcomes.(137) At the same time, the potential consequences of online health information for patients were characterized in similar uncertain ways, as 'celebratory', 'concerned', or 'contingent'.(138) Some assumed that online resources would be essential components of making patients 'expert', although whether the consequence would be empowerment, as opposed to more medical dominance, was unclear.(139) More recent work has noted that many programs designed to educate expert patients have not met their initial promise and suggest that embracing holistic models of how people live and interact in communities, rather than merely providing health information to patients, may be more valuable.(140)

A central theme of internet research is the extent to which there is a 'digital divide' based on inequalities in how people can access and benefit from the internet. In contrast to the frequent conceptualization of the digital divide as whether someone has a computer and internet connection, Van Dijk and Hacker define it in terms of four barriers: 1) lack of

elementary digital experience (“mental access”); 2) no possession of computers and network connections (“material access”); 3) lack of digital skills (“skills access”); and 4) lack of usage opportunities (“usage access”).(141)

One of the predominant places in which user-generated content is accessed and shared online is in the context of virtual support groups, for particular conditions as well as individual treatments. The heterogeneity of online support group membership has been reported in several publications; these groups consist of some people who post occasionally and some who are frequent, prolific posters. Those who post have been described as ‘key players’ (142), ‘active users’ (143), and ‘caretakers’.(144) Most people who visit support groups do not actively post. In a study of people accessing an online smoking cessation group, 84.7% of those who had registered and accessed the resource at least once never posted.(145) This is likely to be contextual and people’s behaviour may vary between sites if they visit several. Adams (146) has suggested that people may be more motivated to add their own commentary if they feel that their experiences are not covered by others’ accounts of, for example, adverse drug effects. Since the content on these websites is generated by a small proportion of the people who use it, the concept of the ‘superuser’ (147) of user-generated online health information- that is, that minority of people who post information online- is highly important.

3.3.3 eHealth literacy

Norman and Skinner developed the concept of “eHealth literacy” in response to the proliferation of online health information, an understanding of health literacy as an important factor in use of health information, and recognition that there is unequal access to online resources by various groups in society.(148) eHealth literacy consists of six

components: 1) computer literacy, 2) traditional literacy, (3) information literacy, (4) media literacy, (5) health literacy, and (6) scientific literacy. Norman and Skinner suggested that these six literacy types "combine to form the foundational skills required to fully optimize consumers' experiences with eHealth." Then, they developed and validated an eHealth Literacy Scale (eHEALS) (149) consisting of 12 questions generated from their initial conceptual model.

Subsequent studies investigated the relationship between online health behaviour and eHealth literacy in low-income homebound older adults (150); Japanese adult support group members (151); Japanese internet users (152); patients with long-term conditions accessing a government health website (153) and low-income parents.(154) One study in adolescents reported that eHealth literacy increased after exposure to a credible source of online health information.(155) A study in older adults reported increased eHealth literacy after undergoing an online skills training course (156), although it should be noted that the sensitivity to change of the eHEALS has not been validated (see Chapter 5).

Further work attempted to characterize eHealth literacy demands and barriers.(157, 158) van der Vaart *et al.* found a weak relationship between eHEALS score and internet use to validate a Dutch-language version of the eHEALS.(159) In addition, associations that would have been expected to exist between eHEALS score and age, education, and performance on internet tasks were not present.

In 2011, Norman revisited the initial eHealth literacy concept, noting that it failed to account for the rise of user-generated content and 'Web 2.0'.(160) While eHealth continued to proliferate, they suggested their initial six component model may no longer be valid as a result of rapid shifts in how people access and share health information

online. Therefore, they suggested that a new conceptualization of literacy in the context of accessing online information may be required, but did not go on to complete this.

3.4 Patient empowerment, engagement, and shared decision-making

3.4.1 Empowerment, engagement and the consumer health movement

Freire's 1970 move away from the traditional characterization of the teacher-learner relationship as primarily a translation of information from teacher to learner supported a redefinition of education as the co-creation of knowledge.(9) One of the important concepts contained within was a move away from 'basic' or 'functional' literacy towards a conceptualization of literacy as emancipatory and enlightening, enabling people to do what they want in the world.(161)

While literacy-as-empowerment began to spread throughout the education literature, only to influence health education and information use much later, another influential work from 1977 created space for a movement towards increased autonomy and patient choice. Ivan Illich's 'The Limits of Medicine' argued that comprehensive medicalization of normal life had taken hold as a result of Western medical practices.(162) Illich suggested that patients had been turned into uncritical, passive consumers of health services. His proposed solution involved a "laicisation of the Temple of Aesculapius" and a reassertion of the "will to self-care". The progressive development of the consumer patient movement in the United States and Europe since the 1970's has brought with it the rise of the "expert patient" (see section 3.3.2) as well as an increasing imperative for patients to become actively engaged in decision-making.(163)

There is an important tension between this "patient as policy factor" discourse (164), which seeks to involve the end-users of healthcare in clinical and policy decision-making, and the capability and/or motivation of patients to engage in these domains. Patient empowerment itself is variously defined as either an outcome or a process.(165, 166) It has been suggested that adequate health literacy may be essential to patient empowerment (167, 168) and, in turn, engagement with self-care and policy.(123, 169)

3.4.2 Shared decision-making

Closely related to patient empowerment and engagement, as well as health literacy, is the concept of shared decision-making (SDM). In part as a result of the consumer health movement previously discussed, it came to prominence in the late 1990's.(170) Although definitional uncertainty has existed since its inception, shared decision-making has nonetheless become a widely discussed concept. A key report supporting SDM expanded on the 2000 Salzburg Statement in which the guiding principle of healthcare in the fictional nation of "PeoplePower" was described as being "no decision about me without me."(171) SDM has featured prominently in the academic health promotion literature since, including in a more recent Salzburg Statement.(172) SDM is currently considered a key policy objective in the NHS.(173-175)

Research into SDM has facilitated the development of patient decision-aids, which are tools that provide assistance for patients and clinicians to engage in SDM.(176) Decision aids consist of two primary components: 1) a presentation of what decisions are available, and 2) a presentation of evidence-based information about those decisions.(177, 178) There are a myriad of decision aids available for a variety of contexts and conditions, and many have been shown to be effective at improving SDM and health outcomes.(119, 179,

180) It has been increasingly recognized that patient experience information might be beneficial. While it has been suggested that adequate health literacy may be a necessary condition for successful shared decision-making (123), it has been noted that having what is currently characterized as “adequate” health literacy may be insufficient to support decision-making in the context of online health information.(168)

3.5 Health literacy and online information policy

Health literacy features prominently in governmental and non-governmental policy in the United Kingdom as well as in international organizations. The World Health Organization (WHO) has repeatedly focused on health literacy as both an outcome of health promotion services as well as a necessary capacity required for people to make appropriate health decisions. In a recent overview, the WHO proposed a “whole-of-society” approach to addressing health literacy, involving multiple sectors and actors to improve health literacy and to make it easier for people to navigate environments to promote health.(181) Health literacy is conceptualized as a key health determinant, while insufficient health literacy is seen as an obstacle to development.

Health literacy has also been a central policy focus for the UK Department of Health in recent years. The 2012 report ‘The Power of Information: Putting us all in charge of the health information we need’ (182) set out various policy proposals for improving access to and use of health information in the UK. Drawing on recommendations from the NHS Future Forum, it placed improving health literacy as a key objective for programmes and services that provide and support patients and the general public in accessing and using health information. In 2013, NHS England set out their ‘Transforming Participation in Health and Care’ strategy (183), partnering with the Tinder Foundation to support the

development of ‘digital health literacy’ by training 100 000 people in ‘basic online skills’.(184)

In Scotland, a National Health Literacy Action Group has been established to implement the results of their 2009 scoping study on the definitions, measurement, and policy implications of health literacy.(185) A similar report was produced in 2011 for the Welsh Government (186), with policy recommendations including improving access to health information and increasing health literacy levels in the general population.

Several prominent non-governmental organizations in the UK have also focused on health literacy in recent years. The Patient Information Forum, for instance, published its own guidance on health literacy, drawing on a UK-wide survey of information producers and providers.(187) Their report suggests that addressing health literacy issues is a key part of addressing challenges related to consumer health information. It suggests that the majority of information producers see health literacy issues as a universal concern, rather than something that only affects specific subgroups of the population. Their report calls for the development and dissemination of “practical guidance” and examples of good practice regarding the development of clear, simple, appropriate health information to be provided to organizations that develop and distribute health information across the UK.

3.5.1 ‘Improving’ health literacy?

A common theme amongst the policy literature reviewed in this chapter is the emphasis on ‘improving’ (182, 184, 188) or ‘increasing’ (37, 186) health literacy. There is scant evidence that health literacy can be improved through interventions; a PubMed search undertaken on 20 May 2014 with the phrase “improving health literacy”, for example, returned 65 references, only 13 of which make any explicit reference to strategies for

enhancing health literacy. Conclusions of these studies are almost universally of the 'more research is needed' type, such as that of Barry *et al.* ("considerable gaps in the evidence exist regarding the most effective population-level health literacy interventions") (188), the former US Surgeon General Regina Benjamin ("health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life") (189), and Davis *et al.* ("a more comprehensive approach to the delivery of health information is needed").(190) Despite the almost universal focus of online health resource policy on improving health literacy, it is apparent that there is very little evidence of how to do this, or for whom it is possible. There is an unresolved, fundamental debate about whether health literacy is a static or dynamic construct.(3, 13)

3.6 Conclusions: what is not known and what questions remain unanswered?

Improving health literacy and making online health information relevant and accessible to all is a key research, practice, and policy objective. It is well established that lower health literacy is related to poorer health outcomes (44, 191). Most of this research, however, was conducted before the proliferation of online health information. In particular, as has been demonstrated above, most was conducted before the widespread availability of user-generated content. Attempts to 'update' the construct of health literacy and to establish causal relationships between the use and understanding of online health information and health outcomes have been acknowledged to lack sensitivity to user-generated content, and to modern information ecologies.(158, 160) There is therefore a lack of evidence regarding the most effective way to develop and disseminate internet health information for people with different levels of health literacy. Furthermore, it is uncertain to what extent online

information should be developed differently for different levels of health literacy. The characteristics of existing resources that make them effective and/or compelling to patients and the general public are not well established.(192-194)

Any solution to improve health information access for all must therefore consider how leaflets and online health information are dissimilar, in dimensions such as the ability to tailor and target information to people's needs and preferences. In addition, online information facilitates the incorporation of multimedia such as video and audio, as well as personal experiences alongside traditional textual 'general facts' information. It is not known for whom or in what circumstances these various components of online information are desirable or effective in relation to different levels of health literacy. Needs and preferences may be different for those who are not ill, seeking 'wellness' rather than 'illness' information.

Therefore, in the context of the available research reviewed in this chapter, and the overall paucity of information regarding the role of health literacy in the use and effect of online health information, the following research questions were identified:

- Who engages with user-generated online health content most frequently in the UK, and how do characteristics of these people compare with known sociodemographic characteristics of people who have 'high health literacy?
- What can be determined from health literacy measurement about the relationship between this construct and outcomes?
- What are UK stakeholders' views about the relationship between health literacy and outcomes related to online resources (as developed in the first two studies), and what are the possible policy implications of these findings?

- Is higher health literacy associated with greater use of and attitudes towards online resources, and is it related to better outcomes as a result of accessing these resources?

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Chapter 4: Who engages with user-generated online health content? Survey of UK Internet users

4.1 Background

In Chapter 3, I argued that there can be little doubt that the internet has changed the way we experience health and illness. People routinely use the web to learn about the meaning of symptoms, tests, diagnoses and treatments and to find out how others have rated doctors and hospitals.(1) Over two thirds of UK residents go online to obtain health information.(2) The availability of high-quality information has been considered a key policy objective by the UK Department of Health (3) and NHS England.(4) Whereas the internet once provided information that could be accessed and viewed but not easily modified, patients increasingly go online to share information and to access information others have put on the internet, including their own experiences. Although this is a widespread practice, especially in long term conditions (5), relatively little is known about the characteristics of people who share and access user-generated content (UGC) online. This is in contrast to general online health information seeking behaviour, which has been extensively studied.(2, 6, 7)

Available literature demonstrates that those with lower educational attainment, who are members of ethnic minority groups, older people, as well as those with poor health status, are more likely to score low on health literacy measures. Conceptual work (reviewed in Chapter 3) suggests these individuals are less able to access and effectively use health information, but this has primarily been defined as print health information provided by professionals. Since one of the main differences between modern health information available on the internet, as opposed to health information available in the early 1990s, is

the rise of UGC, it is therefore relevant to the issue of health literacy and online information to identify who engages with this content.

This chapter draws on a major European survey to explore who shares and accesses UGC in the UK.

4.2 Aims and objectives

The primary aim of this chapter is to investigate behaviour related to UGC amongst UK internet users. It aims to establish if there are differences in the sociodemographic and health characteristics of people who engage with this content with different frequencies, and how these characteristics relate to descriptions of those currently thought of as 'health literate'.

The objectives are as follows:

- To report the proportion of UK internet users who access and share UGC at varying frequencies.
- To identify characteristics of individuals who frequently access and share UGC, as well as those who rarely or never do so.
- To explore the relationship between accessing and sharing UGC and self-reported health status.

4.3 Methods

4.3.1 Survey instrument and ethics

The study reported in this chapter came about as a result of meeting Francisco Lupiáñez-Villanueva, who was at the time the principal investigator of an international project: the "Citizens and Information Communication Technology for Health" survey. The Institute for Prospective Technology Studies of the European Commission's Joint Research Centre carried out the original survey under his direction. The survey aimed to understand and characterize European citizens' use of information and communication technology (ICT) for health, and was translated into native languages in 14 European Union (EU) member countries. It included questions on a range of triggers, motivations, and behaviours. This analysis examines a subset of questions related to UGC. The full questionnaire is available at http://ftp.jrc.es/EURdoc/JRC71142.pdf (8).

I reviewed the survey after discussing the possibility of collaborating on analyses dealing with user-generated content. Although this issue was comprehensively addressed in the original survey, UGC was not its primary focus. The survey contained pertinent questions about the use of UGC amongst UK residents, an issue central to this thesis and for which there were no other data available. Across a series of discussions with my supervisors as well as Dr Lupiañez-Villanueva, I independently developed a statistical analysis plan based on the relevant literature in UGC for health, and selected data available from the survey (a full list of questions included in analysis is available in Appendix B.1). Dr Lupiañez-Villanueva carried out the analysis in Seville, Spain (the raw data could not be shared as a result of EU data protection regulations) according to my statistical analysis plan. We corresponded frequently throughout the analysis process via Skype (as he was based in Seville). This chapter draws on a paper published (with Francisco Lupiañez-

Villanueva, Sue Ziebland, and Jose Valderas) in the Journal of Medical Internet Research (Appendix G.1).

Technical, methodological and legal considerations were addressed while designing and implementing the survey. These considerations ensured anonymity and confidentiality of individual responses.(9-11) The survey was conducted in accordance with European Society for Opinion and Marketing Research ethical guidelines.(12) This chapter reports a secondary analysis of survey data.

4.3.2 Sample and data collection

The sample for the UK section of the survey consists of 1000 respondents who completed an online survey in 2011 covering a variety of domains regarding the use of ICT for health.

An online invitation to participate in the survey was sent to 7291 randomly sampled individuals between 16 to 74 years of age who were recruited through online advertisements. The data were collected between 20 July 2011 and 1 August 2011. Simple random sampling was carried out by the software provider who administered the survey (Cint: Barcelona, ES). Then, quota sampling was used to accurately reflect the demographic composition of UK residents. (13) (This was done to facilitate international comparisons; limitations are described in section 4.5.2.) (2410 responses (4881 non responses) were obtained, of which 1320 were out of quota and 90 were excluded due to missing data. The average length of time to complete the survey was 20.5 minutes (standard deviation not available).

Over half (57%) of the respondents were employed; nearly all (90%) had completed upper secondary or tertiary education. This is broadly comparable to the characteristics of the

UK population, although it should be noted that this sample is more highly educated than the general UK population.(13)

Table 4.1 Demographic composition of sample: % (n)[2]

Age group (years)	Female, n (%)	Male, n (%)	Total, n (%)
16-24	103 (10.3)	106 (10.6)	209 (20.9)
25-54	297 (29.7)	295 (29.5)	592 (59.2)
55-74	98 (9.8)	101 (10.1)	199 (19.9)
Total	498 (49.8)	502 (50.2)	1000 (100.0)

4.3.3 Statistical analyses

Initially, we calculated descriptive statistics about the characteristics of the study participants. After this, in order to determine the extent to which the four behaviours studied represent an underlying composite variable, we employed principal components analysis (PCA). In carrying out PCA, we a priori defined components explaining adequate amounts of variability in the data as those that have an eigenvalue greater than 1.00.(14) Results of the PCA suggested that all four behaviours could be explained by one underlying component. For further analysis this was treated as a single composite variable: "accessing and sharing user-generated health content online."

We then used non-hierarchical k-means cluster analysis to characterize respondents based on their reported frequency of accessing and sharing UGC online. We determined differences between the frequency groups by carrying out ANOVA and chi-square tests for categorical and continuous variables, respectively. Data were examined to determine if they met assumptions for the univariate and multivariate statistical tests carried out, and all

[2] All tables in this chapter are reproduced from: O'Neill BG, Ziebland S, Valderas JM, Lupiañez-Villanueva F. User-generated online health content: a survey of Internet users in the United Kingdom. *J Med Internet Res*. 2014 Apr 30;16(4):e118 (see Appendix G.1).

assumptions were met. Statistical analyses were performed using SPSS version 20.0 (IBM Corporation). Although I discussed the overall approach and the general analysis plan with Dr Lupiañez-Villanueva, I made all final decisions related to carrying out the analyses reported in this chapter.

4.4 Results

4.4.1 Frequency of engaging in individual study behaviours

The demographic composition of the sample is reported in Table 4.1. About a quarter of all respondents participated in online support groups (27.8%), and health-related social networking sites (23.8%) (Table 4.2). A similar proportion reported describing a medical condition or problem online in order to get help from other online users (23.1%) and disclosing medical information on social networking sites (16.7%).

Less than 10% of respondents reported engaging in any of the study behaviours weekly or more. About 10% of respondents reported being unaware that it was possible to engage in these behaviours online.

Table 4.2 User generated content behaviours

Regarding health, wellness, and the Internet, how often have you...	Frequency, n (%)					
	Never	Less than once a month	At least once a month (but not every week)	At least once a week (but not every day)	Every day or almost every day	Not aware of it
Participated in an online support group for people who are concerned about the same health or medical issue	588 (58.8)	145 (14.5)	66 (6.6)	46 (4.6)	21 (2.1)	134 (13.4)
Participated in social networking sites talking about health and wellness	629 (62.9)	106 (10.6)	54 (5.4)	53 (5.3)	25 (2.5)	133 (13.3)
Described a medical condition or problem online in order to get advice from other online users	628 (62.8)	119 (11.9)	64 (6.4)	25 (2.5)	23 (2.3)	141 (14.1)
Disclosed medical information on social networking sites	660 (66)	72 (7.2)	40 (4)	33 (3.3)	22 (2.2)	173 (17.3)

4.4.2 Characterizing predictors of accessing and sharing user-generated content

Applying cluster analysis to the "accessing and sharing user-generated health content online" composite variable resulted in a three-cluster solution. After excluding those who did not know that these resources were available (excluded because they have different reasons for non-use than those who are aware of the possibility and choose not to engage) (15) we were left with 778 responses for further analysis.

Most respondents (612; 78.7%) were 'rare users' who reported that they never or very rarely access and share user-generated health content (Table 4.3). 'Users' who go online and engage in these behaviours infrequently (i.e. weekly or monthly, but not daily) accounted for just over 10% (108; 13.9%) of respondents. A further minority (58, 7.5%) were clustered as 'superusers' who access and/or generate UGC daily.

4.4.3 Who are the 'rare users' and the 'superusers'?

Comparing the 3 groups, superusers were more likely to be male than users or rare users (Table 4.3). Those in the 16-24 years age group were more likely to be superusers than users or rare users, whereas those in the 55-74 years age group were generally rare users, as opposed to superusers or users. Superusers were more likely to be employed (57.8%, 33/58) than unemployed (9.3%, 5/58), students (19.0%, 11/58), or retired/inactive in the labour force (24.0%, 13/58). The groups did not differ on level of education.

Regarding household composition, respondents with children (1-parent, 2-parent, or extended family households) were less likely to be superusers than they were to be users or rare users. There were no differences between the groups based on the number of children younger than 16 years in the household. More rare users and superusers reported that they

lived in intermediate areas, as opposed to densely or thinly populated areas, whereas users were more likely to report living in densely populated areas.

Table 4.3 Sociodemographic characteristics of respondents

Sociodemographic characteristics	Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Gender				.02
Male	301 (49.3)	61 (56.5)	38 (67.2)	
Female	311 (50.7)	47 (43.5)	20 (32.8)	
Age (years)				<.001
16-24	89 (14.7)	39 (36.1)	25 (43.1)	
25-54	370 (60.6)	63 (58.3)	32 (55.2)	
55-74	151 (24.7)	6 (5.6)	1 (1.7)	
Level of education completed				.99
Primary or lower secondary education (ISCED 0-2)[a]	70 (11.4)	14 (13)	7 (12.1)	
Upper secondary education (ISCED 3 or 4)[a]	261 (42.6)	45 (41.7)	26 (44.8)	
Tertiary education (ISCED 5 or 6)[a]	281 (45.9)	49 (45.4)	25 (43.1)	
Occupation				<.001
Employed or self-employed (including family workers)	354 (57.8)	72 (66.7)	31 (53.4)	
Unemployed	57 (9.3)	6 (5.6)	11 (19.0)	
Student (not in the labor force)	54 (8.8)	21 (19.4)	11 (19.0)	
Other not in the labor force (eg, retired, inactive)	147 (24.0)	9 (8.3)	5 (8.6)	
Type of locality				<.001
Densely populated area (cities and large towns)	186 (30.4)	52 (48.1)	18 (31.0)	
Intermediate area (towns)	308 (50.3)	43 (39.8)	36 (62.1)	
Thinly populated area (village and rural)	118 (19.3)	13 (12)	4 (6.9)	
Number of members in the household				.13
1	81(13.2)	11 (10.2)	7 (12.1)	
2	224 (36.6)	36 (33.3)	12 (20.7)	
3	123 (20.1)	22 (20.4)	19 (32.8)	
≥4	184 (30.1)	39 (36.1)	20 (34.5)	
Number of children under 16 years				.08
None	436 (71.2)	67 (62)	32 (55.2)	
1	92 (14.9)	23 (21.3)	12 (22.4)	
2	74 (12.1)	14 (13.0)	10 (17.2)	
>2	11 (1.8)	4 (3.7)	3 (5.2)	
Household composition				.02

	Single person ≥65 years	14 (2.3)	1 (0.9)	0 (0)	
	Single person <65 years	67 (10.9)	10 (9.3)	8 (13.8)	
	2 persons, ≥1 aged ≥65 years	69 (11.3)	6 (5.6)	2 (3.4)	
	2 persons, both <65 years	148 (24.2)	26 (24.1)	8 (13.8)	
	Single person with child(ren) <16 years	7 (1.1)	5 (4.6)	1 (1.7)	
	2 persons with child(ren) <16 years	161 (26.3)	34 (31.5)	20 (34.5)	
	2 persons ≥65 years	27 (4.4)	2 (1.9)	3 (5.2)	
	Extended family (<16 + 16-64 + <65 years)	6 (1.0)	3 (2.8)	3 (5.2)	
	≥3 adults <65	113 (18.5)	21 (19.4)	13 (22.4)	

[a]International Standard Classification of Education (16)

4.4.4 Health characteristics

There were no differences between groups in terms of health status, undergoing long-term medical treatment, or number of visits to the doctor in the last 12 months (Table 4.4). Amongst superusers who reported having someone close to them currently experiencing long-term illness or disability, 64.3% (37/58) reported taking care of them. This contrasts with the rare users, 37.1% (227/612) of whom have someone close to them in this situation.

Table 4.4 Health characteristics of respondents

Health characteristics		Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Health status reported					.63
	Very bad	3 (0.5)	1 (0.9)	1 (1.7)	
	Bad	45 (7.4)	7 (6.5)	6 (10.3)	
	Neither good or bad	115 (18.8)	24 (22.2)	6 (10.3)	
	Good	297 (48.5)	53 (49.1)	28 (48.3)	
	Very good	152 (24.8)	23 (21.3)	17 (29.3)	
Long-standing illness or health problem reported					.57
	Yes	263 (42.9)	41 (37.5)	25 (43.9)	
	No	349 (57.1)	68 (62.5)	33 (56.1)	
Undergoing a long-term medical treatment					.74
	Yes	215 (35.1)	35 (32.1)	18 (31.6)	
	No	397 (64.9)	73 (67.9)	40 (68.4)	
Visit a doctor during the past 12 months					.29
	Yes	512 (83.7)	95 (88.0)	52 (89.7)	
	No	100 (16.3)	13 (12.0)	6 (10.3)	
How many times did you visit a doctor during the last 12 months?					.64
	None	100 (16.3)	13 (12)	6 (10.3)	
	1-2 visits	216 (35.3)	31 (28.7)	21 (36.2)	
	3-4 visits	118 (19.3)	27 (25.0)	11 (19.0))	
	5-6 visits	70 (11.4)	15 (13.9)	8 (13.8)	
	>6 visits	108 (17.6)	22 (20.4)	12 (20.7)	
Is someone close to you currently experiencing long-term illness or disability?					.01
	Yes	227 (37.1)	56 (51.5)	29 (50.0)	
	No	385 (62.9)	52 (48.5)	29 (50.0)	
Are you taking care of such a person?					.02
	Yes	234 (38.2)	39 (35.8)	37 (64.3)	
	No	378 (61.8)	69 (64.2)	21 (35.7)	

4.4.5 Internet activity

Almost all UGC superusers (94.8%) reported engaging in 11 or more internet activities (such as online banking, keeping a blog, and looking for travel information), whereas only about a quarter of rare users reported the same engagement with other internet activities (Table 4.5). Similarly, nearly three quarters of superusers (74.1%) reported accessing the internet through three or more devices (such as a home computer, work computer, and smartphone), which contrasts with less than a third (29.4%) of rare users doing the same.

Table 4.5 Internet activities and devices

Internet activities and devices	Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Breadth of internet use (number of Internet activities)				<.001
1-5	109 (17.8)	2 (1.9)	1 (1.7)	
6-10	340 (55.6)	25 (23.1)	2 (3.4)	
≥11	163 (26.6)	81 (75)	55 (94.8)	
Breadth of internet access (number of Internet devices)				<.001
1	203 (33.2)	15 (13.9)	7 (12.1)	
2	229 (37.4)	27 (25.0)	8 (13.8)	
≥3	180 (29.4)	66 (61.1)	43 (74.1)	

4.5 Discussion

4.5.1 Main findings

This chapter describes the results of a secondary analysis of UK data from a major European survey. It describes the prevalence and frequency of accessing and sharing user-generated online health content, and compares the sociodemographic characteristics of those who do so with different regularity.

As has been repeatedly shown in studies of online health support groups, a majority of participants do not actively post their own content, but they read what others have written.(17-21) Although it is not possible to measure directly the activity of these 'lurkers', they represent such a large proportion of those engaged with UGC that this should be seen as "normal" online behaviour. Further exploration of the motivations and usage of UGC by these passively engaged individuals is required. It would be erroneous to assume from these results that 'lurkers' are not obtaining benefit (or not being subject to harm) from these resources. This finding raises some uncertainty regarding what constitutes 'health literate' behaviour while accessing or sharing UGC: are there differences in the online skills or motivations regarding health between these groups?

These UGC superusers are predominantly male. Respondents in the youngest age category (16-24 years old) are more likely to be superusers, whereas those in the oldest age category (55-74 years old) are generally rare users. Superusers also carry out more varied activities on the internet, such as online banking and booking travel, than the users and rare users. Despite these differences, this analysis found that there are no differences in health status or health service use between the superusers and the other two groups. This is, to our knowledge, the first explication that user-generated content does not appear to be associated with self-reported use of health services. They are however more likely to be the caregiver for someone close to them with a long-term condition or disability, so it is possible that their frequency of use may relate to their caring responsibilities, rather than to their own health. Given the strong relationship between health literacy and outcomes, this finding raises important questions about people who frequently engage with UGC: are they indeed more 'health literate', or is this just a preference they have developed as a result of an interest in or proclivity for engaging with websites? Given that these superusers also engaged in more internet activities, perhaps it is more the latter than the former.

Another issue is that the study did not distinguish between the use of information that provides guidance for a diagnosis or treatment of a health condition, and information shared or accessed by people who are healthy and either seeking or offering lifestyle advice. Several possible mechanisms by which UGC, and in particular others' experiences, may affect health have been identified, such as finding information, feeling supported, and experiencing health services.(22) The results of this chapter are congruent with the "contingent model" of health information use, which suggests that health information is one important component of a health care experience, rather than as something that displaces or reduces use of health services.(23)

It was surprising that 10% of participants were unaware of the availability of UGC, particularly as this was a sample of Internet users. This could relate to the specific questions asked; perhaps they were generally aware that online support groups exist, but not of a specific "online support group for people who are concerned about the same health or medical issue." The outcomes of user-generated content are unclear. Further research should focus on reasons for which these individuals, who have access to the Internet and are motivated to complete a health survey, may be unaware of the availability of these resources. It could be that they are generally uninterested in learning about UGC, or that they are unaware of *specific* sites for exchanging UGC (e.g. they may be unaware that there is health content on YouTube) (24), and may want to engage with these resources if they were made aware of them.

Previous studies of health seeking behaviour on the internet have found that females more commonly access health information on the internet then males.(5, 25) However in the present study, superusers were more likely to be male. It has been suggested that men rate their self-assessed online skills higher than women, which is one possible explanation for higher reported use of these complex online resources by men.(26) Although the survey

data did not provide an opportunity to examine this issue further, it is an important area for future research.

4.5.2 Limitations

The survey used in this study was administered online. This enables rapid data collection, reduces administrative burden, and is cost-effective. It may cause selection bias as those who do not have Internet access or adequate digital skills are excluded.(27) In this study, rare users in particular may have been excluded due to lack of digital skills. Those with chronic illness may also have been less inclined to participate in an online survey or excluded due to fatigue or disability. Another limitation is the use of quota sampling (this was done to facilitate international comparisons in the overall survey), which reduces the generalizability of the results of this analysis to the overall population when compared with a true random sample. While the sample was selected to be representative of UK internet users, subsequent studies with different designs should sample purposively for superusers to explore their behaviour and motivations more fully. Further research focusing on smaller age categories, and going deeper into some of the life stage variables that may affect use of online health information (such as parenting or retirement), would be useful as well.

In addition, this chapter reports a secondary analysis of a larger survey on people's use of the internet for health. The original study contained questions that were appropriate to investigate this issue, but was not specifically designed to investigate UGC in depth. Secondary analysis has many advantages and efficiencies, but one of the inevitable disadvantages is that some variables of interest may not have been explored in the data. Some potential areas of inquiry relevant to UGC were not included in the original survey,

such as its use to obtain social support and to select health services based on others' experiences.(22) It would be valuable to address when people access information for themselves or others, and whether there are differences in the content they access or share in these varied situations. An important limitation regarding the main objective of assessing the role of health literacy in online information is that respondents did not complete a health literacy questionnaire during this survey. Although it was possible to compare sociodemographic characteristics of superusers with those from existing literature on people with different health literacy levels, it would have been useful to compare frequency of accessing and sharing UGC with health literacy directly. Finally, this study reports cross-sectional data, which precludes determining causal relationships. It is intended to be exploratory, and to compliment other data collected in this thesis.

4.6 Conclusions

This chapter reported a secondary analysis of the UK-specific findings of a major European survey of internet users regarding ICT for health. The findings focused on characterizing accessing and sharing increasingly popular user-generated health content. It found that UK Internet users who were aware of the availability of UGC could be divided into three broad groups: those who rarely or never access it (rare users), those who do so infrequently (users), and those who do so daily or almost daily (superusers).

The most frequent UGC users, the 'superusers', were more likely to be male, to be younger, and to live in densely-populated areas. This contrasts with other surveys that have suggested women are more likely to go online for health information (which could either be an artefact of this sample, or a novel finding). Superusers were more likely to report caring for someone close to them with a long-term disability, and their use of information

may be related more to this role than to their own health. Taken together, these findings suggest that changes may be occurring regarding who accesses online health information, as well as what resources they access. These results have implications for the role of health literacy in online information: the demographics of those who frequently access health information may be changing. The nature of the postings and interactions in which people engage online may be less related to traditional conceptualizations of health literacy. These issues will be investigated further in following chapters.

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Chapter 5: Conceptualization and measurement of health literacy: Systematic review

5.1 Introduction

It has already been acknowledged that significant definitional uncertainty exists regarding health literacy (see Table 3.1 for a comprehensive list of definitions). To further understand how health literacy impacts outcomes (such as morbidity and mortality), it is necessary to develop an enhanced understanding of the construct and the mechanisms by which it may influence these outcomes.

In part because of the lack of consensus about its definition (1-4), there are many available instruments to assess health literacy. The diversity represented by existing measures has been demonstrated in a systematic review.(5) This review described a classification scheme, dividing measures into three categories: those that directly test an individual's abilities; questionnaires that elicit self-report of abilities; and proxy measures of health literacy in the population. In addition, these authors identified variable content and construct validity amongst existing measures, suggesting they may be measuring different constructs or dissimilar content. However, this review did not include all available measures, nor did it explore underlying conceptual models of health literacy, despite identifying variable content and construct validity.

The heterogeneity and psychometric deficiencies identified in health literacy assessment, the wide range of prevalence estimates depending on which measure is used, as well as the established uncertainty of how health literacy affects health outcomes, suggest the importance of examining the constructs and models underlying health literacy measurement.

5.2 Aims and objectives

The aim of this chapter is to explore health literacy as a construct through an examination of conceptualizations underpinning existing measures. It explores various perspectives on health literacy through an in-depth examination of the ways in which it has been measured, which is a method for exploring the latent content of a construct that has been used elsewhere in the literature.(6, 7)

The specific objectives are as follows:

- To search for and obtain all available health literacy assessment indices.
- To report characteristics associated with their administration and their psychometric properties.
- To elucidate tacit assumptions about mechanisms underpinning the relationship between health literacy and health outcomes.
- To identify a suitable health literacy measure to be administered in a randomized controlled trial of online information (reported in Chapter 8).

5.3 Methods

5.3.1 Search strategy

In order to carry out this study, I undertook a systematic review of available health literacy assessment indices. This chapter begins by summarizing the administration characteristics and psychometric properties of existing measures, and then moves on to present results of qualitative content analysis of these measures.

I conducted systematic searches of the following electronic databases: Medline (1946- September 2012), Embase (1980- September 2012), PsycINFO (1987- September 2012) (all accessed through the OVID interface), and CINAHL (1981- September 2012). These searches were undertaken on 11 September 2012, and all references were imported into EndNote X4 (Thomson Reuters, 2011).

The search strategy was developed with a specialist librarian (Nia Roberts), with an emphasis on sensitivity to identifying studies reporting the development of condition- and specialty-specific health literacy measures (which were underrepresented in the Jordan *et al.* review), in addition to measures of general health literacy. Search terms used included literacy, health, assessment, indices, and measurement. The search strategy can be found in Appendix C.2. Database searches were augmented by 'snowballing' (8) from the reference lists of key identified papers to identify further relevant instruments for inclusion. This chapter complies with PRISMA reporting guidance.(9)

5.3.2 Inclusion criteria

I included studies that reported the development and/ or validation of a novel measure of health-related literacy. Generic measures as well as those focusing on more specialized health literacy such as "nutrition literacy" (10) and "eHealth literacy" (11) were included (Appendix C.1). All indices published in the English language were included, even if the measure itself was not in English. One key reference was included for each measure (usually the first to report on a particular measure).

5.3.3 Exclusion criteria

Studies that reported the development or validation of literacy measures that were not specifically related to health, such as measures of general literacy used in educational settings, were excluded. In addition, those that reported solely on "numeracy" were excluded, since the relationship between numeracy and health outcomes in the absence of literacy assessment remains somewhat unclear.(12)

5.3.4 Selection procedure

I conducted the search and scanned titles and abstracts. Two postdoctoral researchers (Daniela Gonçalves, Ignacio Ricci-Cabello) scanned abstracts and selected titles for full-text screening and inclusion in the review. I scanned all abstracts and selected titles; Drs Gonçalves and Ricci-Cabello each independently completed half of the references and we met together to discuss inclusion and to resolve disagreements.

5.3.5 Data extraction and synthesis

I designed a structured form to extract relevant information from each article, and extracted data from each included reference into this form. Another colleague independently extracted data from each reference (again, Drs Gonçalves and Ricci-Cabello each completed extraction of half of the references while I completed all of them). Disagreements were resolved by consensus.

Means and standard deviations were calculated using Microsoft Excel. I extracted data on the following characteristics of the instruments: breadth of construct (general vs. condition- or specialty- specific health literacy), whether it was an original instrument or a

derivative, country, language, time for completion, self-administration, interface for administration, setting (clinical vs. research), as well as evidence for validity. I extracted data relevant to assessing the face validity (the extent to which an index appears to measure what it is supposed to), content validity (how far items of which the index is comprised reflect the concept to be measured), and construct validity (the extent to which the index as a whole measures what it is supposed to) of included measures.(13)

After identifying all available measures, I attempted to obtain the health literacy index source material (that is, the individual items comprising the measure, with directions for how to administer it) wherever possible. In the initial stages of this research I contacted three authors attempting to obtain indices; one did not reply after repeated attempts, and two others indicated that their measure was available, but only at substantial cost. Upon investigating further, I identified that many measures were only available through purchase, and as I did not have funding for this, I used whatever was freely available, performing internet searches (using Google Search) when this information was not available in the original publication. I decided to not continue to contact authors, as I believed the yield would be minimal. When it was not possible to obtain the full set of items for a measure, I included in the analysis whatever information I could obtain (full measure or sample items).

My search identified six indices in languages other than English or Spanish (14-19) and I included these when English translations of sample items or the full measure were available. Four further indices were available in English and Spanish.(20-23) One was only available solely in Spanish (24) and was excluded. After all exclusions were made, 32 health literacy assessment indices remained for which I had some or all the items contained within the measures. These constituted the data included in qualitative analysis.

In order to plan the qualitative content analysis, I initially read all the included studies, and considered what characteristics of the measures were reported, and how these related to existing literature on the relationship between health literacy and outcomes as reviewed in Chapter 3. Three characteristics seemed particularly relevant from this initial literature scoping, and as a result I extracted data relevant to these features: the content of the items comprising the measure, its mode of administration (whether self-administered or administered by a researcher or clinician), and the directions provided for how to administer it.

Qualitative analysis proceeded thematically to identify underlying concepts and models from health literacy indices. Themes were developed through discussion with my supervisors, who independently read the relevant data. Iterative review of the source material at a series of meetings enabled us to reach consensus. I employed a qualitative data analysis method known as the 'One Sheet of Paper' or 'OSOP' method, which involves writing down codes on a single sided sheet of paper, linked to the source from which they came, then looking for a pattern or 'string' connecting the codes conceptually.(25) This technique was originally developed for qualitative analysis of patient interviews, but is ideally suited to the purpose of unpacking and exploring the apparent assumptions underlying items in assessment indices. I did not contact study authors to engage in respondent validation of the identified themes (see section 5.7.2 for a description of why I decided to not do so).

5.3.6 Ethics

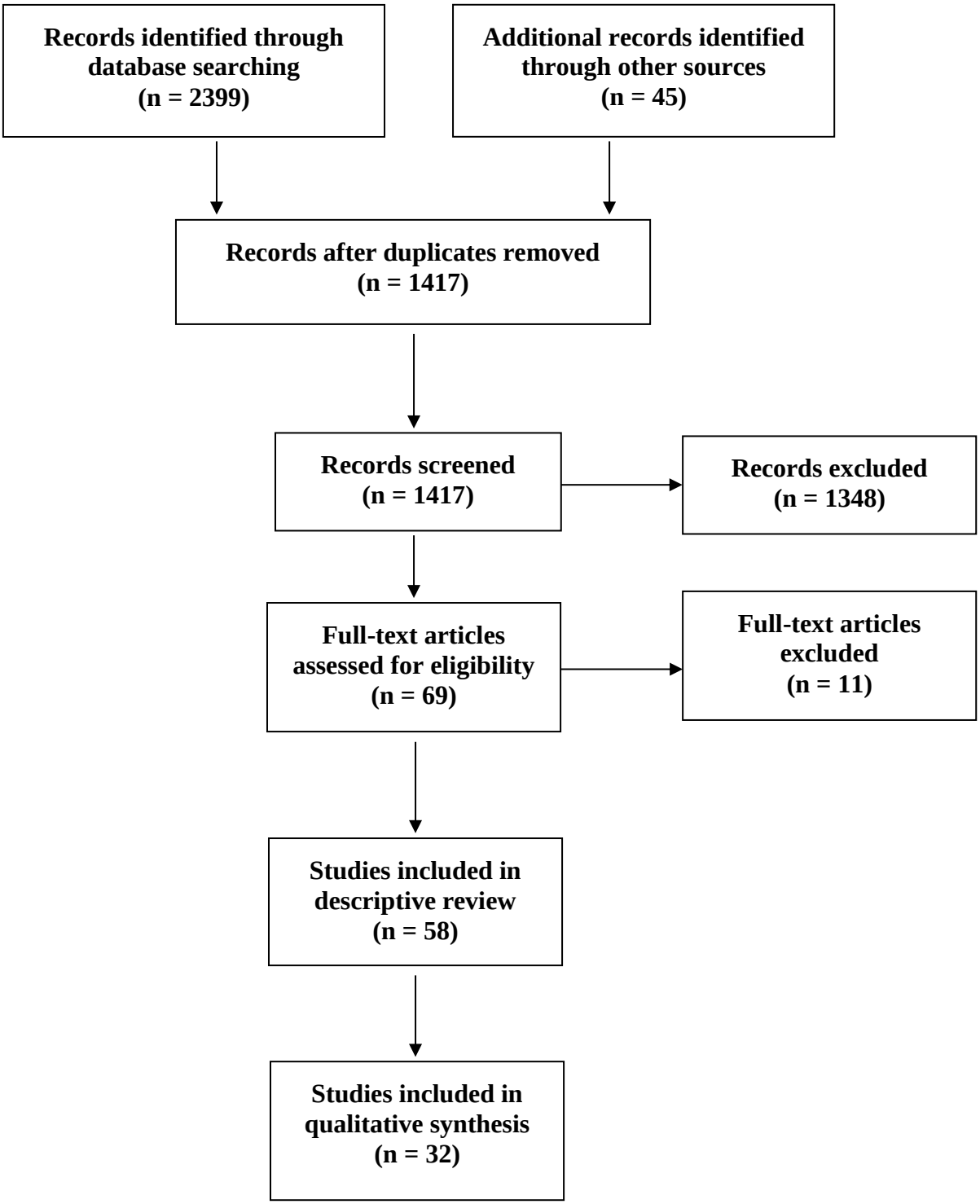
Ethical approval was not required for this element of the study.

5.4 Results

5.4.1 Overview

The initial database search identified 2399 references. Hand searching of reference lists of included papers resulted in an additional 45 references. After removing duplicate references, 1417 abstracts were scanned for inclusion and 1348 were excluded. 69 full-text articles were obtained for review, of which 11 were excluded because upon full-text review they did not report the development of a novel or newly validated health literacy measure. Thus, 58 articles reporting the development and/or validation of a health literacy instrument were included (Figure 5.1).

Figure 5.1 PRISMA flow diagram for included/excluded studies

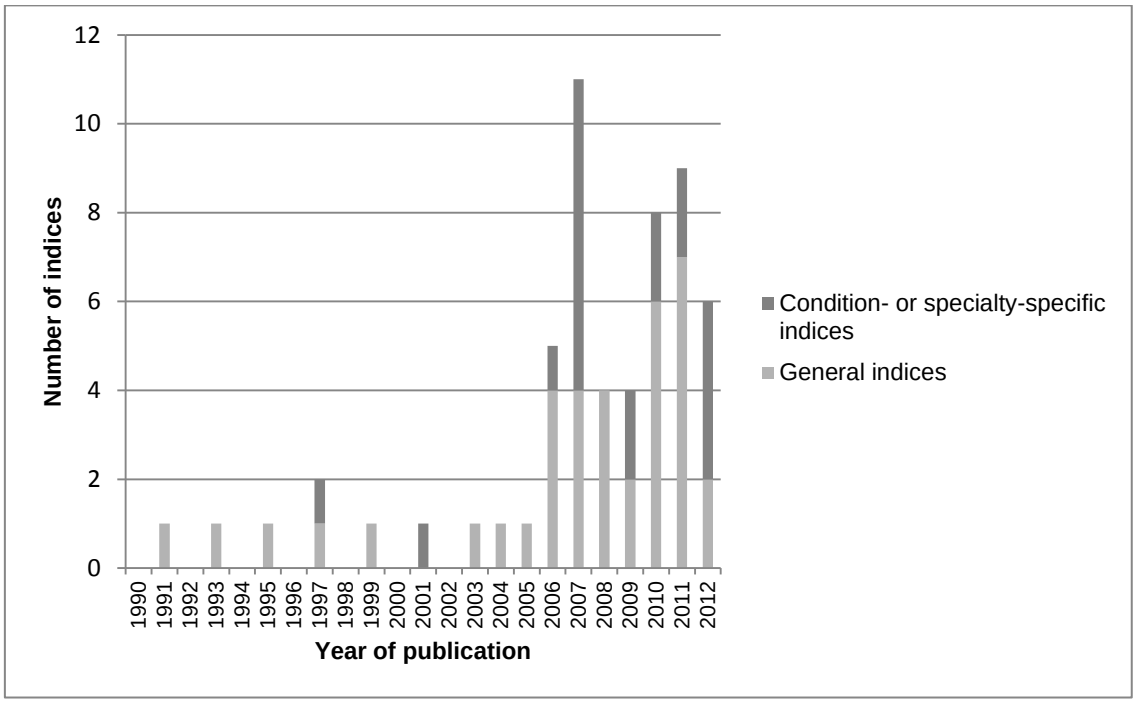


5.4.2 Characteristics of measures reported in included studies

5.4.2.1 Type of measure

Of 58 instruments included in the review, there were 39 original instruments (39/58; 67.2%) and 19 derivative instruments (19/58; 32.8%), which were either modifications or short-form versions of original instruments (Appendix C.1). I classified the measures into two groups: general (stated as measuring "health literacy", or literacy and its implications for generic use of health information); and condition- or specialty- specific [stated as measuring "literacy" with a health-related prefix, such as "oral health literacy" (26, 27) or "vascular surgery literacy" (28)]. Most measures were classified as general (39/58; 67.2%), while the remainder (19/58; 32.8%) were classified as condition - or specialty specific. Although the first health literacy measure included in this review was developed in 1964 (29) it was not until 1991 with the development of the Rapid Estimate of Adult Literacy in Medicine (30) that steady progress in the development of general indices commenced (Figure 5.2). The first condition or specialty-specific measure was developed eight years later: the Cardiovascular Dietary Education System index.(10)

Figure 5.2 Health literacy measures by year of publication



Note: One measure (Mohammed 1964) (29) is excluded from the figure.

5.4.2.2 Country of origin

Most of the available instruments to measure health literacy have been validated in the United States (42/58; 72.4%), with Canada and Japan being the next most frequent country of origin of health literacy indices (both contributed 3/58; 5.2%) (Appendix C.1). All studies before 2006 (n=16) reported measures developed in the United States.

5.4.2.3 Language

The indices in this review are available in five languages. The majority of these measures are in English (48/58; 82.8%). There are four measures (4/58; 6.8%) in Spanish; two each

(2/58; 3.4%) in Japanese and Mandarin Chinese, and one each (1/58; 1.7%) in Korean and Hebrew (note that none of the non-English indices are included in the qualitative analysis).

5.4.2.4 Setting

All included studies reported the setting from which participants were recruited for validation. Almost half of the instruments were validated in populations recruited from secondary and specialty care settings (25/58; 43.1%), while a quarter of studies recruited in primary care settings (15/58; 25.9%). The remainder recruited from diverse non-clinical settings (18/58; 31.0%), such as schools, prisons, and shopping malls. One study reported validating a generic health literacy measure (the Test for Ability to Interpret Medical Information; TAIMI) (31) through an online survey and did not provide information about the characteristics of the subjects recruited.

5.4.2.5 Intended use

24/58 (41.4%) indices were recommended for both clinical and research purposes. A quarter of indices were developed for clinical purposes only (15/58; 25.9%), and 19/58 (32.8%) were reported as being valid for research purposes only.

Combining the ‘clinical only’ indices with those that are reported as valid in both settings (i.e. all those purported to be for clinical use) resulted in 39/58 (67.2%). Similarly, when the ‘research only’ was combined with all those purported to be for research use resulted in 44/58 (75.9%).

5.4.2.6 Psychometric characteristics

I assessed the face, content, and construct validity of included measures, according to the definitions established by Portney and Walkins.(13) Most measures had adequate face, content, and construct validity (39/58; 67.2%). A further 17 (29.3%) had adequate face and content validity, but construct validity was not established. Finally, two indices (3.5%) [CARDES (10) and TAIMI (31)] established face validity only. None of the included studies reported that sensitivity to change in health literacy level over time could be measured using the instrument (Appendix C.1).

5.5 Qualitative content analysis

From 58 health literacy indices identified and described above, I was able to obtain adequate items and administration descriptions to carry out qualitative analysis on 32 indices[3]. I identified three underlying themes in this qualitative analysis: 'confidence', 'the ability to obtain healthcare services', and '"appropriate" health decisions'.

5.5.1 Confidence

The connection between feelings of shame and low health literacy is well established. Parikh *et al.* (37) explored this in a qualitative study of 202 African-American patients and found that 40% of the patients who had trouble reading (in the study) reported experiencing shame as a result. Wolf *et al.* hypothesized that experiencing shame could cause patients to externalize the discomfort it brings on, leading to impaired communication and service access.(32) This situation is easy to imagine: an exasperated

[3] Due to copyright restrictions, I have been unable to include items from several indices that are described in the text of this section. I have included the original items when allowed, and described the items as much as possible when I could not include them.

patient, alone in an unintelligible system, becoming frustrated with an equally exasperated health care professional. In order for effective communication to occur, a patient must be able to ask questions to a practitioner. Confidence in one's ability to communicate may be a necessary (but not sufficient) condition for an effective clinical encounter to occur. Some health literacy indices may, by their content, measure confidence as it relates to communication. The eHealth Literacy Scale (11) asks about confidence directly:

10. I feel **confident** in using information from the Internet to make health decisions

1) ❑ Strongly Disagree
2) ❑ Disagree
3) ❑ Undecided
4) ❑ Agree
5) ❑ Strongly Agree

Several indices including the REALM (33, 34) and its derivatives are administered by asking patients to pronounce progressively more complex health-related words until they are unable to continue. The Rapid Estimate of Adult Literacy in Medicine-Teen (REALM-Teen) (35) addresses words that have some purported relevance to adolescents, and are thought to be relevant when an adolescent has to communicate with a health care practitioner. Context-specific indices, such as the Cardiovascular Literacy Assessment (CARDES) (10), the Rapid Estimate of Adult Literacy in Genetics (REAL-G) (36), and the Rapid Estimate of Adult Literacy in Vascular Surgery (REAL_VS) (28) are word recognition tests in the style of the REALM that test recognition of words that are commonly used in certain clinical settings. The REAL-G was developed by recording consultations between patients and genetic counselors and including words that were most

often used in these consultations. All of these aforementioned indices are administered by asking a patient to read aloud a list of words, and when they reach a word in ascending order of difficulty that they feel they cannot pronounce, they are instructed to skip past it and continue on.

What is most striking about these indices is the tacit (or, in the case of the eHEALS, explicit[4]) notion of *confidence*; that is, by asking patients to repeat aloud words until they reach a level of clinical vocabulary too challenging for them to pronounce, what is being tested may be patients' confidence in communicating in the clinical setting. The REALM contains words that could be considered sensitive ("rectal" and "incest" must be pronounced out loud in succession during the test, for example), which could heighten the importance of confidence in being willing to say these words and complete the examination. (One might also conjecture that this willingness may be measuring something other than either health literacy or confidence.) The assumption is that confidence in reading/pronouncing words equates with the ability to communicate in clinical settings. Therefore, if a patient in clinic cannot (or will not, as there is no facility within the measure to distinguish between inability and refusal) say a certain word, it is suggested that this may result in adverse outcomes.

Presenting to medical attention can be an intimidating process, and is significantly more so for individuals with low health literacy.(37, 38) Indices such as the REALM and other word recognition and vocabulary tests are designed to provide a fast assessment of literacy level, but what they also do is require the participant to 'speak up' and demonstrate their vocabulary in front of an authority figure. This may be akin to testing someone's confidence, and could be particularly distressing if the setting is a clinical one and the

[4] Another tacit assumption is that these measures are 'literacy neutral' – that is, in the case of the eHEALS, for example, it is assumed that everyone filling in the measure understands what "confidence in using information" means.

authority figure is the patient's clinician. Chief amongst experiences of health services that matter to patients is that people want to be treated with respect and dignity and that they want to feel they are heard by their caregivers.(39) Supporting patients in having confident, non-intimidating interactions with practitioners is therefore a necessary goal of health service provision.

5.5.2 The ability to obtain health care services

Several health literacy assessment instruments included in this chapter contain items relating to a person's ability to navigate specific aspects of health system and obtain health services. The TOFHLA reading comprehension section (22) contains sentences from an application form for Medicare, which is the United States national health insurance programme for seniors and those with low income. The section is based on the Cloze procedure (40) which requires the person taking the test to fill in a blank word in a sentence from a list of several possible choices. Although the index does not directly measure knowledge of the Medicare application procedure, its use of this as a relevant 'real-world' stimulus suggests that this type of application is fundamental to health care access in the United States. The question "How confident are you filling out medical forms by yourself" (41) addresses both confidence and the issue that healthcare access may be predicated upon the necessity of 'filling out forms'. The Health Literacy Skills Instrument (HLSI), developed in the United States where health care often needs to be paid for at the point of access (42, 43), contains items that test an individual's ability to calculate payments for specific services from a table providing this information.(42) If someone can calculate what insurance will pay for a service, it is implied they will be better able to access these services. If not, their health may suffer. These items suggest that those with

low health literacy who are consequently unable to navigate the healthcare system would experience poorer health outcomes as a result.

5.5.3 'Appropriate' health decisions

The restrictive nature of acceptable responses to items in health literacy assessment indices was striking. Many of the myriad of health literacy definitions include a reference to 'appropriate' or 'informed' decisions as the end goal of having health literacy. While on the surface this seems like an important goal, it nevertheless reflects, at least to some degree, the dominant biomedical orthodoxy on which most health literacy definitions are based. This is not merely a definitional problem, either, since many health literacy assessment indices are based on the idea that people's correct responses as defined by the authors of the study represent the optimal decision in each case. The Parental Health Literacy Activities Test (PHLAT) (44), for example, contains an item that asks if a caregiver would call their paediatrician given that they have been instructed to do so if their child's temperature rises above a certain level. In the item, the temperature is displayed as if it is from a digital thermometer printout, and has not reached the 'critical' level at which the caregiver has been told to contact the doctor. There is no opportunity for the caregiver being administered the PHLAT to suggest that they might call the paediatrician anyway because they are worried about their child even though the temperature has not yet reached the pre-established threshold. It is unclear from this measure the extent to which, given freedom to do so, the participant being assessed would make decisions consistent with their own conceptualization of good health, because they are forced to report that they would make decisions congruent with the test authors' definition of the right course of action.

A related situation is included in the 'Test of Ability to Interpret Medical Information' (TAIMI) (31), in which people are provided the following prompt, with related questions:

> *Suppose that you had a strong interest in dieting, and a company advertised "weight loss pillows." The advertisement claimed that "just sleeping, without any effort would result in losing 20kg" and you could "slim down, sleep well, and change your life." It costs 7800 yen. Would you buy it?*
>
> (1) I would buy it
>
> (2) I would buy it, if I could get a 20-30% discount
>
> (3) I would buy it if my family member or my friend recommended it
>
> (4) I would buy it after checking the feedback of the other buyers by using the Internet
>
> (5) I would not buy it
>
> (6) I have no interest in this type of product
>
> (7) Other

In this example, the only 'correct' answers are (5) and (6); the authors of this instrument have decided what is and is not an appropriate decision in the context of purchasing health-related products. A decision to do anything other than that which is endorsed by the authors is considered 'health illiterate'.

Finally, the 'Brief Estimate of Health Knowledge and Action-HIV version' (BEHKA-HIV) (45) includes a series of statements, such as "I don't take my medicines when they make me feel bad" and "I don't take my medicines when I am feeling down or low". Participants are asked to rate whether they "agree", "disagree", or are "not sure" regarding

these. As in the previous example, there are 'right' and 'wrong' answers to these questions as determined by the instrument's authors, obviating the influence of any personal beliefs or judgment in these situations[5].

The assumption that people want to follow advice but are prevented by *their* misunderstanding of the *correct* answer fails to account for the complexity of people's use of health information, as well as their interactions with clinicians. The determinants of adherence are complex (46, 47) and physicians are inaccurate at estimating which patients are adherent and which are not.(48) While it is tempting to suggest health literacy assessment may represent another way in which to indirectly measure a patient's adherence, it should be cautioned that several studies have failed to show a relationship between health literacy, self-reported adherence, and outcomes.(49, 50) There are obvious counterfactuals, such as that physicians are not perfectly compliant people despite their high health literacy[6]. It is currently understood that in order to assist patients to improve adherence, individualized modalities are required, developed through an understanding of individual patients' needs and motivations.(51, 52)

5.6 Selecting a measure for the EXPERT study

In order to fulfil one of the primary aims of evaluating the usage and outcomes of online information amongst people with different levels of health literacy, an established measure was incorporated into the Experiences Evaluated in a Randomized Trial (EXPERT) study. The characteristics of an 'ideal' measure to be administered to participants were discussed

[5] This is particularly ironic given the rich history of patient activism in HIV and AIDS research and treatment, an excellent account of which can be found in Randy Shilts' 'And the Band Played On'.(53)
[6] Relevant examples of this are too numerous to describe; reading the General Medical Council's reports on those struck off would be a good place to start. To do so would obviously require more than a festschrift.

at a series of meetings prior to starting the trial, and the steering group decided on the following attributes:

- Self-administered through an online survey
- Established face, content, and construct validity
- Minimal time/administration burden

Therefore I selected the '3 question' index (41) to be included in the baseline data collected from participants in EXPERT. Analyses from that study are reported in Chapter 8.

5.7 Discussion

5.7.1 Main findings

Low health literacy is significantly related to worse health outcomes (12), and has been described as a major contributor to health disparities.(54) In order to improve the provision of healthcare for patients with low health literacy, it has been suggested that it is necessary to have valid indices to measure individual or population health literacy.

This chapter reports the administration characteristics and validity of 58 health literacy measures, as well as the qualitative analysis of 32 of these measures. It explored tacit themes underpinning existing health literacy measures. One of the key objectives was to select an appropriate index to be included in the trial in Chapter 8.

There is a clear trend towards the development of more measures in recent years. The instruments identified in this review are mostly intended for adults (with only three available for paediatric populations) and have been primarily tested in secondary care settings, with a range of instruments available for research and clinical settings. It has been

identified that most instruments take less than 5 minutes to complete (although this ranges from less than 1 minute to 70 minutes), and that there is a range of choices regarding whether the instrument is self-administered or whether it requires a trained examiner.

While it is understandable that no single assessment measure has been able to represent a complex and multifaceted construct such as health literacy, there are additional aspects to the construct itself that are inherent to the way in which it is assessed. As one of the central tenets of a proposed agenda for health literacy is to encourage "basic research" and theory development (55), our discussion of these underlying concepts and models provides clarification to what theory already exists in health literacy research.

Most health literacy measures have been developed in the United States, a country in which it has been suggested that only 50% of basic care is actually obtained by those who need it.(56) Others may receive more healthcare than they need, as a consequence of unwarranted variation in the provision of care.(57) The identification of the 'ability to obtain health services' as a key tacit theme relating health literacy to outcomes raises the importance of ensuring information resources support people to obtain the care they need. Of course, information is only useful when other key barriers have already been addressed.

It is increasingly regarded as important to take into account people's diverse experiences and beliefs when recommending or developing health information or providing services, which this chapter has identified is at odds with health literacy measures. The development of individualized patient reported outcome measures, where people nominate the domains that are important to them, is an example of this movement.(58, 59) The health literacy measures included in this study do not attend to individuals' autonomy in making the best decision in their own particular context, given their own experiences and beliefs.

5.7.2 Limitations

Given that new measures are being developed and published frequently, other measures may have been developed and published since the search was carried out (in September 2012) which have not been included (see section 9.1.2). In addition, given the clinical heterogeneity and diversity of health literacy measurement, it is possible that relevant studies available at the time the search was carried out have not been retrieved.

Despite conducting a comprehensive electronic database search to identify all available health literacy measures, I was unable to obtain the actual items from the measures for 26 of these, due to copyright restrictions and fees. There may be additional important themes underpinning these measures I was unable to elucidate as a result. In addition, I did not engage in respondent validation of the qualitative analyses by contacting the original authors of the measures, although since these were 'tacit' constructs, the authors may not have been aware of or recognized them. While their reflections might have been interesting, this was a relatively small aspect of a larger body of work in this thesis, and these themes were investigated further with 'key informants' in Chapter 6.

5.8 Conclusions

This chapter reports the results of a systematic review of health literacy measurement indices, and a qualitative content analysis of the items contained within these measures. In September 2012, there were 58 health literacy measures available, validated in a variety of contexts and intended for diverse applications. After two decades of research developing health literacy measurement indices, several critiques have emerged, including those related to definitional uncertainty and varying prevalence estimates. New measures continue to be developed, which are of variable quality. However, there is no evidence that health literacy screening improves outcomes (60), and no clear evidence that measurement leads to improved outcomes. In light of the results of this chapter, I believe the drive to develop new measures may be misguided. There is a growing evidence base on patient engagement (61), and one could argue that it is more appropriate to implement effective interventions (while paying attention to effects in different populations) than develop further refinements to a construct that rests largely on its face validity.

What has not been addressed in this chapter, however, is how this underlying heterogeneity in health literacy as a construct impacts people's use of *online* health information. Therefore, in order to further explore the findings of the present chapter (and Chapter 4), the next chapter reports analyses of interviews carried out with UK 'key informants' – health information policymakers, researchers, and clinicians – in which these themes are interrogated.

5.9 References

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Chapter 6: How might health literacy influence outcomes of online health information? Qualitative interview study

6.1 Introduction

Several possible relationships between health literacy level and usage and outcomes of online information have been suggested by the research conducted so far in this thesis. Given the focus on tailoring information by health literacy level in UK government and non-governmental organization policies (1, 2), it is essential to obtain stakeholders' views on how health literacy relates to health outcomes of online information, and on the findings of the thesis to this point. A key component of realist inquiry is the involvement of stakeholders in generating and refining conclusions.(3-5) This chapter presents the results of a qualitative study conducted to explore the views of UK 'key informants'- policymakers, clinicians, and researchers interested in and experienced with the topic of health literacy- on the relationship between health literacy and health outcomes.

6.2 Aims and objectives

The overall aim of the research reported in this chapter was to determine key informants' views on health literacy, patients and public use of online health information (such as user-generated content, patient education information, health service quality reports, and personal health data), and how this may relate to health outcomes.

The specific objectives were:

- To explore how health literacy is conceptualized by UK key informants.
- To explore proposed pathways between health literacy and health outcomes.

- To understand key informant perspectives on how and why people use online health information.

6.3 Methods

6.3.1 Study design

Given the exploratory nature of the study and the uncertainty surrounding the relationship between health literacy and health outcomes, qualitative research was most appropriate since it is useful for exploring participants' views on anticipated and emergent issues.(6) I considered it necessary to go beyond published literature to explore key informants' views on the construct and on the results of the thesis thus far. The use of semi-structured, rather than open-ended interviews, allowed the results of previous chapters to be interrogated while allowing participants to raise previously unidentified issues.(7)

6.3.2 Participants, sampling, and recruitment

Clinicians, policymakers, and researchers with particular expertise in online health information and health literacy were purposively sampled. These 'key informants' were identified as a result of their leadership within relevant national policy organizations, their publication record, or their known expertise regarding health information and health literacy. At the conclusion of each interview, I asked participants to suggest other participants (chain referral/'snowball' sampling). This method has been established as appropriate when seeking to identify views of a group of professional respondents.(8) Sampling was guided by emerging themes during data analysis, as recommended by Charmaz in the context of a modified grounded theory study.(9)

After obtaining ethics approval, I identified and contacted potential participants by email or phone. I provided a brief description of the study and asked if they would like to take part. The study information form was also provided (Appendix D.2). Interviews were conducted face-to-face when possible (in Oxford or in London), but Skype or telephone were used when preferred by the participant.

I planned to continue data collection until theoretical saturation was reached.(10) While there is much debate regarding how to ascertain when data saturation is reached, the procedure suggested by Francis *et al*. was followed, in which 10 interviews were initially planned, and 3 further interviews were to be conducted after one interview in which no additional themes emerged.(11) However, it became increasingly difficult to identify and recruit 'key informants' who would have adequate knowledge and experience to provide relevant insights. Therefore, I decided to stop recruitment at 13 participants. Although few new themes were emerging by the conclusion of the 10th interview, some as yet unexplored themes emerged in the final interview, suggesting data saturation may not have been reached. The impact of this on the findings is discussed in section 6.5.3.

6.3.3 Interview schedule

I conducted all the interviews after completing the following training: a 5-day module on Qualitative Research Methods, run by the Health Experiences Research Group, University of Oxford. In order to develop the interview schedule, I reviewed the key findings of Chapters 4 and 5, in addition to the evidence gaps identified in the literature review. Sue Ziebland read and commented on initial drafts of the schedule. This led to alterations in the question order, as well as the suggestion to include prompts to probe further after receiving responses. The interview schedule is available in Appendix D.1.

Interviews were conducted between March 2013 and February 2014. They lasted between 35 and 60 minutes.

The interview started with an open-ended question about the definition of health literacy. Then, successive questions focused on findings from previous chapters. This allowed the exploration of the following key areas of inquiry:

1. Defining health literacy.
2. Online health information.
3. Ideas about mechanisms linking health literacy to health outcomes, such as morbidity and mortality.

At the conclusion of the interview, participants were asked a final open-ended question, allowing them to raise any topics or issues they deemed relevant but which had not yet been addressed. Following the constant comparative method as outlined by Pope *et al*. (10), newly identified issues were incorporated into the interview schedule used with subsequent participants, since analysis progressed in parallel with interviews. For example, an early interview participant raised the issue of patient access to online medical records in relation to health literacy; questions were asked about this in subsequent interviews.

Participants were reassured that they could withdraw their consent at any time. All participants gave signed consent to participating in the interview and being audiorecorded.

6.3.4 Data collection and management

Interviews were audiorecorded using an Olympus digital recorder and then transcribed. Interview audio files were stored in the .wav format and labeled with a randomly generated unique ID number corresponding to the participant's name. These numbers linked the

digital interview file to the paper invitation letter and consent form, and were stored in a password-protected Microsoft Excel file. Consent forms were kept in a locked filing cabinet. I had sole access to participants' personal data.

I transcribed the first seven interviews; a professional transcriber completed the remaining six. I assessed the accuracy of those transcribed by the transcriber by reading the text of interviews while listening to the audio file.

Transcripts included hesitations "[um]" and long (> 5 second) pauses, because these might denote some degree of uncertainty or hesitation, which would be potentially relevant to the analysis. Quotes found in the results section (section 6.4) have these features excluded for brevity.

6.3.5 Analysis

I used a qualitative interpretive approach, combining thematic analysis with constant comparison.(12, 13) This approach was originally developed by Glaser and Strauss in 'The Discovery of Grounded Theory'.(12)

It has been suggested that grounded theory as it was initially founded is "imbued with positivism."(14) In their initial formulation, Glaser and Strauss laid out a systematic process to guide inductive reasoning and further data collection and analysis through the course of a project.(12)

Over time, however, Glaser and Strauss moved the method in conflicting directions. While Glaser moved towards emphasizing emerging theories through an inductive examination of the data (15), Strauss increasingly supported the systematic use of defined, specific validation criteria.(16, 17) Given the emphasis on establishing a realist (as opposed to

positivist) understanding of the role of health literacy in online health information, this study has adopted a predominantly Glaserian approach to analysis. In line with this approach, my analysis has been influenced by a constructivist grounded theory approach in which it is acknowledged that data are co-constructed by researchers and participants.(9, 18)

I uploaded each transcript into NVivo 9 (QRS International) qualitative data analysis software. Computer-aided qualitative data analysis software has become increasingly popular, since it allows the data to be accessed and organized quickly, and is easily searchable. It has been suggested that this can impair the researcher's familiarity with the data which is important for thorough, reflexive analysis. In order to limit the possibility of this happening, previous transcripts were read and re-read frequently as new ones became available, ensuring that theories arose equally from all sections of the data.(6)

In the first instance, transcripts were read and considered without prior assumptions of what will emerge. This is known as *open coding*. This was carried out in NVivo 9 by highlighting text and coding it at 'nodes'. Textual annotations were made (as 'memos' in NVivo) and stored alongside these nodes to describe thoughts or considerations emerging from this open coding process.

Each subsequent transcript was read as it became available, identifying emergent codes and re-reading and coding previous transcripts as appropriate. This is known as the constant comparative method (19) in which continually emerging conceptual categories are refined as they are compared to previous data. Deviant cases were sought and compared in order to further refine these categories.(20)

Analysis took place in parallel with interviews, and where appropriate based on emerging codes or themes, the interview schedule was modified to explore these emergent themes.

This meant that later interviews were informed by previous findings, to explore new areas of interest as they arose.(21)

Once I had transcribed, read, and coded the first six interviews, codes and emerging themes were discussed with a supervisor (SZ). This discussion facilitated development of a series of thematic codes that encompassed the existing open codes into groups of categories. According to the Glaserian approach this is known as 'theoretical coding'[7].(15) Subsequent transcripts were then coded in accordance with this theoretical coding framework.

Once all interviews had been coded, I used the "OSOP" or "one sheet of paper" analysis technique (22) to collect key anticipated and emerging issues on a single sheet of paper, labelled with the participants' ID number. Then, these issues were combined into overall themes, which are reported in section 6.4.

6.3.6 Interviewing 'elites'

This chapter reports the results of a study in which professional 'key informants' were interviewed. There is no clear-cut definition of 'elites' (23) in the context of qualitative research (or, for that matter, in any other field). Much of the available literature comes from interviewing political or public service elites.(24) They are variously defined as 'highly-skilled' or 'professionally competent' individuals.(25) Others have described them in relation to either the researcher or compared to the 'average' person in society.(26) Another set of definitions posits elites as those who hold strategic influence in important social networks or organizations.(27, 28)

[7] Corbin and Strauss describe the equivalent analysis step as 'axial coding'.(17)

I considered respondents interviewed for this study as ‘elites’, and as a result, the aforementioned literature was used to guide the design of the interview schedule, communication with participants, and conduct of interviews. Two fundamental considerations are having thorough knowledge of the subject area, and increased flexibility in interview questions and timing.(29) Other guidance suggests the importance of gaining the participant’s trust through transparent explanation of one’s own educational and professional background, dressing professionally, asking open- and closed- ended questions, and ensuring the length of the interview is carefully managed.(23)

Following this guidance, I started the interviews by describing my status as a postgraduate student completing a DPhil and as a medical student on educational leave of absence to complete this degree. Professional attire was worn. Interviews consisted of open- and closed- ended questions, and were kept to less than one hour. They were concluded by asking the following open-ended question: “Is there anything else you consider important about this topic about which I have not asked you during the interview?”

6.3.7 Ethics

The study was reviewed by the University of Oxford’s Medical Sciences Division Interdisciplinary Research Ethics Committee and obtained clearance under reference MSD-IDREC-C1-2013-18. Data were collected and stored in accordance with the University of Oxford’s policy on academic integrity.

6.4 Results

6.4.1 Characteristics of participants and interviews

Fifteen individuals meeting the inclusion criteria were contacted to take part in the study. One person declined as they did not believe they knew enough about the topic to be an effective participant, and another did not respond after three attempts to contact. Therefore, thirteen 'key informants' took part (Table 6.1).

Table 6.1 Description of participants

Sex	**n**
Female	5
Male	8
Age	
20-40	2
40-60	7
>60	4
Professional designation	
Policymaker	7
Researcher	3
Clinician	3

Interviews lasted between 35 and 60 minutes. 10 interviews were carried out face-to-face, either in Oxford or London. Two were completed using the telephone and Skype was used for one.

Analysis results can be broadly divided into two main themes: 1) defining health literacy and 2) health system responsibilities. A description of the main themes and sub-themes now follows. All quotes from interview participants are given in italics. Sections of

superfluous text that have been removed are indicated with (…). Participants are identified at the conclusion of each quote by an ID number (e.g. R1, R2, etc.), and where appropriate, additional identifying features.

Table 6.2 Anticipated and emerging sub-themes

Key theme	**Anticipated**	**Emerging**
Defining health literacy	"Appropriate" health decisions	Prior experience
	Confidence	Social support
Health system responsibilities	Navigation	Communication from the health system to patients
	Personal experiences versus general facts	Personal health records

6.4.2 Defining health literacy

While respondents were familiar with existing definitions of health literacy, several reported scepticism or uncertainty at how these have been operationalized. In particular, some suggested that although it is clear that there is a high prevalence of 'low health literacy' as it has been measured, that the relationship between health literacy and outcomes can be "quite confusing" (R11), or that "because health literacy has such broad definitions, that it becomes more complex than it needs to be." (R12) Participants discussed three main sub-themes regarding definitions of health literacy: (1) 'appropriate' health decisions; (2) prior experience with conditions or treatments; (3) social support.

6.4.2.1 'Appropriate' health decisions

While discussing definitions of health literacy and their application to the use of online information, participants frequently brought up the importance of clinicians attending to personal values and beliefs. Often these were characterized in terms of religious or cultural characteristics influencing what constitutes an 'appropriate' healthcare decision for a certain patient:

> *One of the most health literate people I ever met was an 87 year old Pakistani man who didn't speak English, and who had valvular heart disease, and through his son I was explaining that if he had an operation, there was quite a high chance that he would die. And if he didn't have the operation, there was a certainty that he would die within a year. And he just smiled and looked at me and his son and his son said 'he doesn't mind'. And that was the interaction. I think you know that I suppose you know many of us will have that philosophy at the age of 87, particularly if we happen to be Muslim, but they, that seemed to be an absolutely sound way of responding. And so the decision went to me, and he had his operation, and he lived another five years, and then his son was very pleased because he died praying, at home, five years down the line. (R5)*

In the above quote, the respondent (a general practitioner) employed a tacit hierarchy of health literacy in describing that patient as the "most health literate" they had ever encountered, suggesting that what constitutes high or low health literacy is in part defined by the clinician. This seemed to refer to the *clinician's* own individual values and beliefs about what constitutes a good decision; several participants noted the primacy of *patient's* individual values and beliefs in defining what is appropriate:

> *You say 'appropriate', I say good. The good decision is for the patient… I think the use of the word appropriate sounds very totalitarian, doesn't it, you know, has definite overtones of appropriate meaning that you do make a decision in mind of what you want, of what we want you to decide. Whereas I think a good decision is based on a patient who is fully informed, that takes into account the pros and the cons of whatever treatment it is we're talking about and also their own individual values and preferences. (R9)*

> *I suppose my problem would be the high and low [health literacy] there, I would say different groups have different understandings of health, and those may or may not be appropriate, to their community. So if I give you a very simple example, from an area that I happen to know a lot about, so dementia and Alzheimer's disease, if you're, if you're an older person in a village in India, and you have dementia, it's very unimportant in terms of your health and wellbeing, because certainly in the early stages, because there's very little danger that you can come to, everybody knows you, if you wander off, people will bring you back, you can still take part in the community, there's- the impact on your social life and your wellbeing in a broad sense is very minor in relation to the disease. But someone with the same level of disease in a Western urban environment would be at high risk, so the knowledge that you'd need in each community to manage that particular aspect of health is completely different. (R8)*

One participant offered another interpretation of the idea of 'appropriate' use of health services, suggesting that there are clear situations when navigating the health system, in which there are appropriate and inappropriate things to do:

> *I mean I'm very focused at the moment on appropriate use of services. I think that's because, you know we've just had the Easter holiday period and we've just had a lot of difficulties introducing the new NHS service. A lot of that is around people having a health problem over the period when services are less available and knowing the appropriate place to go. So that is about navigation and it is about the use of health services so you know the… I suppose that navigation and use aren't exactly the same, but you know navigation is an essential precondition to use. (R7)*

6.4.2.2 Prior experience

One of the distinguishing features between traditional, established definitions of health literacy, and what participants reported was that prior experience with health conditions or with healthcare services were deemed relevant. It was suggested that patients with 'low health literacy' (that is, those likely to score low on a health literacy measure) may develop, over time, competence with information as a result of their experience with the health system. Since health service navigation is quite system specific, it stands to reason that previous experience might be more useful than 'reading age' in this regard.

> *So I would put experience with the health service as certainly, and I haven't looked at this literature for some time, but you know sort of assumptions around reading*

> *age, you know, are pretty irrelevant with health care information, and so you know you can have people with very poor scores for reading, or low scores for reading, but because they've had to navigate health systems for maybe a parent or a child, they're well able to read above their sort of average reading age, so that's why I think the experience with the health service is quite important. (R2*)

One participant, describing a conversation they had with a patient who often accesses online resources, suggested that as a result of experience, that over time people may become 'expert' patients:

> *They want to go and read everything, they want to tell their friends about stuff, they want to be experts, they want to pass stuff on… I think she said something like, "I had breast cancer ten years ago and I'm all clear but I know it might come back. So I read your website regularly so that if it does come back I know what to talk to my doctor about. (R1)*

As one participant put it,[8] "the longer we would spend in a foreign country, the more likely we are to understand the language and culture of that country" (R11). In contrast, it was noted that assuming people automatically gain knowledge and skills through the course of an illness might be detrimental, as people might be assumed to be more knowledgeable or capable than they are, potentially leading to poor outcomes.

6.4.2.3 Confidence

Respondents primarily discussed the role of confidence in the context of clinical encounters. It was taken as a necessary but insufficient condition to be able to manage one's own illness, facilitating decision-making in consultation with practitioners:

> *And yet we and we know that some of that sort of self-management has to be about being able to go into your consultation and start to make decisions with a provider, with a clinician as opposed to just sort of be told what to do. You're not likely to self-manage if you, if you don't, if you're not encouraged to be responsible for some of that yourself. And if you feel unconfident you're very unlikely to be able to have the*

[8] After Susan Sontag's 'Illness and Its Metaphors' (30).

sort of conversation with your clinician that allows you to put something about your sort of, you know. (R10)

They can't, they find it very difficult to grasp new concepts and so for a start, they lack confidence in acquiring new skills and knowledge. So they will immediately say or say to themselves, "Oh this is, you know, I'm not, I'm never going to be able to understand this. This is far too complex." And then they either completely ignore it or they will just submit themselves to a very passive role in their relationship with their healthcare providers. So there's the confidence to, lack of confidence to acquire new skills and knowledge but then that, in turn, will affect their confidence to engage generally with healthcare. (R11)

Two GPs raised the idea that if people have difficulty pronouncing the names of their drugs during clinical encounters, they may lack confidence to try to say them and miscommunication could result (perhaps to some extent reflecting a concern that medics have about whether they are mispronouncing unfamiliar words as well):

So if you cannot read something or pronounce it, it matters enormously as to how you're then going to be able to use yourself in terms of, you know, being an advocate for yourself. You can't, you can't say the name of the drugs. That's not, not good. (R10)

And it makes you feel pretty self-conscious, and, and you may be unwilling to engage in a discourse that's going to show you up in that sense. And I think some patients certainly may feel that others of course go boldly ahead and sort of mispronounce happily, and in fact in many cases we don't know the 'correct' pronunciation of drug words, for instance, which are purely arbitrary. (R12)

Only one participant described a potential solution to assist those who lack confidence while communicating with clinicians [an experience described as "difficult" (R3) and "challenging" (R1)]. This policymaker noted that online resources might be particularly useful to help those with less confidence:

There's all sorts of people with certain mental health problems, social phobias, you know, learning disabilities who find it very difficult to get out the house and engage face to face with a healthcare professional but find it very safe to actually interact anonymously disguised as an avatar in these 3D virtual worlds. And what's more, it seems to be increasing their confidence to engage in the real world, which is fascinating. (R11)

The same respondent went further to suggest that exposure to 'personal experiences' information may build confidence more than 'facts and figures' – type information,

suggesting that “they’re hugely powerful and particularly addressing the problem of confidence as well as sharing knowledge.”

Not all participants agreed that confidence was related to health literacy; one researcher mentioned that discussing confidence as a component of health literacy “muddies the water a bit, and we don't necessarily have the evidence to support that” (R4), and a policymaker suggested, “it’s understanding as opposed to confidence.” (R2)

Two respondents (both non-clinicians) noted that when clinicians perceive that patients portray confidence, that this may be detrimental to the care they receive:

> *If you presented in a GP consultation with a high level of social confidence and you were middle class and you were like a peer of that GP. They may assume a higher level of health literacy and may explain things in a way that assumes a greater knowledge than you already have actually, so could actually potentially be a barrier to communication. (R7)*
>
> *Most patients and people go out of their way to actively hide their lack of ability and, as a result, healthcare professionals, as a rule, completely over estimate people’s skills and capabilities and confidence levels. (R11)*

6.4.2.4 Social support

Another key issue was the idea that access to social support would help people understand and use health information. Family and friends were taken to be essential resources in interpreting information:

> *I think [outcomes are] obviously affected by individuals’ characteristics at the point of access and services for patients, I think that people around the patient if you like- families and friends and other community groups- can contribute to health literacy. (R12)*

One respondent, a non-clinician involved in developing online health information, told a personal story about how they had used text messaging to provide health information to their ill parent in hospital:

> *So I Googled the Wikipedia article on Crohn's disease, copied and pasted the first eight or nine paragraphs into a series of texts which I sent my mum in her hospital bed. And when the nurse came back to see her six hours later, my mum was equipped to ask her questions about what sort of Crohn's disease, how many patches on her gut did they suspect. And the nurse was just like, 'How the hell did you get access, you haven't left your bed!' (R1)*

However, there were some apprehensions about relying on family and friends. In particular, there were concerns regarding confidentiality, suggesting that it would be detrimental for clinicians to assume that people who have difficulties with health information would be able to "rely on others to support their health literacy, or improve or mitigate it… you can't assume that because someone's got a helper, that that's enough." (R12)

6.4.3 Health system responsibilities

6.4.3.1 Communication from the health system to patients

Respondents discussed the role and responsibilities of the health system to communicate health information to patients. This was conceptualized broadly, and included patient education resources provided before and after consultations, information about where and when to present to medical services, and information about the effect of treatments. All participants thought that the quality of communication from the NHS to patients was generally poor. Currently, one of the most common ways the NHS communicates with patients is through sending letters; one respondent (a senior non-governmental organization policymaker) described that "the letters that the health service writes to people are ridiculous" (R8). A senior NHS policymaker indicated the scale of the opportunity to improve communication, and how the internet might facilitate this:

> *So, each year the health service in England sends out a billion and a half letters, and I've never seen useful information about the internet in one of them. So let's*

start- when we sent out a letter, or email to somebody, let's provide what we think is best current evidence, and send a link to say 'a bit of NHS Choices, that would have links to patient groups in it', then of course immediately the person will go and use Google and look for something else. So we have to compete with the internet, and the time we compete will be when we send letters and lab reports to people. (R13)

A general practitioner described their own experience as a patient of receiving information from the NHS when undergoing a routine screening procedure:

Halfway through it then tells me, "Do not follow the manufacturer's instructions" on the packet of stuff that they've already sent me, "Do this instead." Okay, so I didn't, I only read it by accident because I wasn't going to bother to read the booklet. And I was bored, I don't know why I read it, you know, because I thought I sort of know that stuff. So when people turn up with inadequate preparation, which means they cannot complete the investigation, it is their fault. That is not, that is nothing to do with the patient's health literacy. Because even as a health literate person, what they sent me was just poor. (R10)

6.4.3.2 Navigation

An important issue in relating online health information to outcomes was the idea that resources should facilitate appropriate navigation, and service choice. This issue is closely related to the development of knowledge and ability about particular health systems gained through prior experience (see section 6.4.2.2). Clinicians in particular suggested there is a major deficiency in what is available for people who are trying to decide whether to attend general practice versus accident and emergency (A & E):

So I mean take an example of people… often use accident and emergency services inappropriately and that might be because they're lazy or stupid, or it might be just that they don't understand how to navigate the system. They don't understand what's an appropriate thing to take to an A&E department, or they don't know how to register with their GP or whatever. So I think system navigation - navigation of service options and what's the appropriate place to go to - is a really key part of health literacy. (R7)

In addition to deciding between general practice or A & E, one respondent discussed the importance of information helping people know when *not* to present to health services. It

was suggested that high quality online information could support self-management, and reduce unnecessary use of services:

> *It may actually make it the other way, it may make them not go and seek, you know, health seeking behaviour because they do have an understanding of the condition they might may realize it will get better on its own. (R2)*

6.4.3.3 'Personal experiences' versus 'facts and figures'

Several respondents discussed different types of patient education information that the health system could use to communicate better with patients. In general it was suggested that "there's an awful lot of personal preference for the way you get your information in addition to the health literacy aspect of it" (R9), and that "some people will be intimately more, infinitely more evidence and data driven and other people will be experience driven and you've got to find a way to cater for both" (R1).

One respondent described how this principle might fit into NHS communication to patients:

> *If you want to see the evidence, from the Cochrane reviews, for example, and then the relation of the evidence to the individual patient is probably still better done by human beings, then Healthtalkonline and the values, we'll reflect on the values. So I think people need both, and I think we can deliver both. (R13)*

Concerns were raised about the representativeness of online resources generally, and personal experiences were identified as "potentially misleading" (R6). A specific case that arose during the course of this study was that of the American actress Angelina Jolie, who wrote an op-ed in the New York Times in May 2013 describing her decision to have a prophylactic bilateral mastectomy to prevent breast cancer as a result of testing positive for a BRCA mutation. One study participant, involved with developing online information for a UK-based NGO, described the conflict their organization had as a result:

> *Which meant our phones rang quite a lot for a couple of weeks. And no one would ever force a celebrity to reveal, you know, she was absolutely right to not reveal more detail than she wanted to. But just the knock-on effects, on the one hand massively positive, on the other, on the other hand negative. And that's because you've got a single experience. Whereas data gives you the whole picture. (R9)*

That is, while there were general concerns about personal experiences, this respondent noted that their particular issues resulted from the widespread discussion of a "single

experience", rather than having available multiple people's experiences about the same condition[9].

6.4.3.4 Personal health records

One of the most prominent issues raised by respondents was the proliferation of people having online access to their own health record, which has been set out by the Department of Health as a major policy objective to be achieved by 2015 (31). Few respondents were concerned about people seeing what doctors had written about them; in contrast, they suggested the widespread availability of personal health records would encourage doctors to write more clearly (and appropriately). One respondent, quoting from an article on the topic, suggested that "if pathologists wrote their reports for patients, maybe other doctors would actually understand them" (R13). Regarding the issue that patients might be 'overwhelmed' by the information they received, it was generally noted that it might offer an opportunity for clarification in the context of a consultation, as opposed to people going away without fully understanding their condition.

In contrast, one respondent (a GP working in a 'deprived' community) noted concerns regarding confidentiality:

> *So I could imagine the rights of my patients coming to me telling me about their domestic violence and about if their husband logs on to their health record. So are they going to tell me in future about their domestic violence? (R9)*

Furthermore, one of the key issues with providing people access to their health records online was suggested to be the format in which information is currently provided. It was

[9] This is one of the primary differences between the 'curated' collections of experiences available on websites such as Healthtalkonline (32) and the information from multiple users available on online fora, versus the selected 'testimonial' or the individual personal blog.

noted that in general, if patients were merely provided an online version of their currently available health record, that this might be at best confusing, and at worst harmful:

> *The other thing that we also need to do is, we need to provide information in meaningful formats. So if we are sharing results, I don't think we should necessarily be providing patients with their, with numbers, you know, numbers don't mean anything, BMIs, blood pressures, haemoglobin A1c's, they're all numbers and the don't really mean anything to patients but if you actually can present that data in sort of a traffic light system or a more visual way, that would be more meaningful and I think patients would understand that and engage with it. (R1)*

There were concerns that current mandates to provide access to an online health record may, at least in the short term, exclude those who most need them:

> *I just think the whole connection between health literacy and digital literacy is just so important, really. And we're not going to, increasingly we're not going to empower people in health care environments if they haven't got a level of digital literacy skills as well as a level of health literacy skills, because all these things are predicated on digital as the solution. You know, access to your health record, you know the idea of that is your online health record really. (R7)*

While there is a distinction between online records that are accessible but not modifiable by patients, and those into which patients themselves can enter information, no one discussed the issue of patient-generated data in the context of online health records. One GP working in maternity care spoke about their own practice's use of a 'patient-held record', describing patients' perceptions of the benefits they receive from this service:

> *In maternity, the mothers carry their notes with them. And there's been some research done on that, you know, a lot of them just don't complete the bits they're meant to complete because they struggle to know what to complete. I mean that is an example of a form, if you like, that they are expected to fill in certain things, and they struggle with, with, knowing what so often the purpose of the notes is not fulfilled. Because they don't fill stuff in that they should. (R3)*

6.5 Discussion

6.5.1 Main findings

This chapter reported results of a study in which 13 UK-based 'key informants' were interviewed about the relationship between health literacy and outcomes, particularly in the context of online information. In general, participants expressed uncertainty about how health literacy relates to outcomes. It was suggested that a focus on a top-down approach to 'appropriate' health decisions as an outcome of health literacy, as inferred from how it has been operationalized, may limit autonomy and the importance of personal values and beliefs in decision-making. The availability of social support was considered a primary facilitator of better health outcomes, and that it may mitigate some of the challenges faced by people with 'low health literacy'. However, it should not be assumed that social support can mitigate these challenges; recall in Chapter 4 that those frequently accessed UGC were more likely to have caring responsibilities. Those being cared for may benefit from social support in part because it facilitates access to useful health information through the internet.

Respondents characterized the quality of much NHS communication with patients as poor, and offered solutions, such as enhancing the availability and diversity of online resources. Making patient education information available in both 'personal experiences' and 'general facts' formats was posited as an important aspect of revamping these resources in the UK, and it was noted that the main driver of whether people use one or the other is personal preference. By allowing people to "find their own level" (R13), respondents thought it would be possible to make health information more generally accessible and useful in the UK.

6.5.2 Anticipated 'tacit' themes from Chapter 5

I asked specific questions in these interviews about the three 'tacit themes' – 1) 'appropriate' health decisions; 2) confidence in clinical encounters and 3) obtaining health services – reported in Chapter 5. Participants were highly critical of the idea that an 'appropriate' health decision is identifiable (in many situations), and the importance of eliciting personal values and beliefs was considered a key component of healthcare decision-making. Confidence in clinical encounters was suggested as potentially valuable for enhancing shared decision-making, but it was also noted that if clinicians assume people understand because they portray confidence, impaired communication may result. A health services researcher described a study in which it was noted, that "the stigma associated with [study participants'] low literacy affected their confidence and their ability to ask questions, and in social situations as well as health situations" (R12). Another respondent suggested health literacy is more about "understanding as opposed to confidence" (R2). One researcher was concerned about the extent to which interrogating the relationship between health literacy and outcomes in this way might obfuscate existing knowledge:

> *There is this thing called health literacy and you can measure it… when we start moving into the realm of putting confidence and efficacy and, um, other behavioural medicine type constructs into health literacy definitions, I think then that muddies the water a bit, and we don't necessarily have the evidence to support that, at the moment I don't think. (R4)*

Finally, the last of the three 'tacit themes', obtaining health services, was raised as a central issue across most of the themes identified in this chapter, but was interpreted in this chapter to be about navigation, rather than access *per se*. This likely reflects differences in access between the UK's single payer system, and the US private insurance-based model, since most of the indices from which these tacit themes were derived were developed in the US. Navigating the health system was discussed in the context of health decision-making, as well

as a central aspect of health system responsibility to provide patients with adequate resources to be able to make a decision about where and when to present to services. It was suggested that high quality information could both increase access of services where required, as well as supporting better self-management, which could decrease inappropriate use of services such as A & E. It has recently been identified that A & E attendance for conditions that could have been appropriately addressed in primary care has been rising in the UK.(33)

6.5.3 Limitations

The problem of ascertaining when data saturation is reached is one that continues to be debated widely. Broadly, it is acknowledged that it is a matter of judgement (34) and that either informational redundancy (35) or theoretical saturation (17) is the goal. While it has been suggested that a grounded theory study may require a specific number of participants (such as 30 to 50) (36), others have taken a more inductive approach, which is what was followed in this chapter. Upon reflection, it is unclear whether data saturation was reached, given that new themes continued to emerge from the last conducted interview. However, since these interviews serve to refine and contextualize findings, I do not believe it strongly limits the overall conclusions as reported in Chapter 9, given the incremental nature of the studies comprising the thesis.

I sought to obtain a diverse, rather than numerically representative sample during recruitment. When discussing this project with my department thesis committee (consisting of professors and senior researchers) after having recruited and interviewed 7 participants, a concern was identified that the individuals recruited may not be the 'right' participants; that is, they might not have adequate knowledge of health literacy to be able to provide informed perspectives on the construct. While care was taken to ensure that

participants were aware of available definitions and literature on health literacy, there was clear variation in their familiarity with the academic literature. This may have limited the extent to which responses were grounded in existing evidence, but could also be considered an advantage as well, as it enabled the critical examination of the construct from a slightly different perspective than what has been reflected in published literature. Furthermore, participants varied in the extent to which they had vested interests in 'health literacy'; without this variability, some of the more measured, sceptical reflections on the practical usefulness of health literacy may not have been uncovered.

6.6 Conclusions

There was a general, but not ubiquitous, belief amongst those interviewed that the relationship between health literacy and outcomes remains unclear. Respondents criticized the emphasis on 'appropriate' health decisions, noting that different decisions are right for different people. The quality of some NHS patient information was criticized as poor, and several suggestions were posited, such as making available a variety of different types of information (such as 'general facts' and 'patient experiences'), while helping people to identify and find what suits their own preferences (and, hopefully, facilitating recognition of the difference between collections of personal experiences and one-off personal narratives). The next two chapters build on these results by reviewing (Chapter 7) and developing (Chapter 8) evidence regarding the relationship between health literacy and outcomes from quantitative studies, in order to compliment these qualitative observations.

6.7 References

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Chapter 7: Do the effects of online and multimedia resources vary by health literacy level? Systematic and realist review

7.1 Introduction

This thesis has already identified that online health information policy guidance in the UK strongly supports the assertion that health literacy is a key area of interest (1), and that tailoring online resources by health literacy level is an important aim.(2) Despite this, no study has investigated the extent to which existing online interventions have different effectiveness across health literacy levels.

The internet facilitates information delivery through multimedia, as well as the use of online assessments, tailoring, and structured feedback.(3) The evolution between early computer- or personal digital assistant- based patient education interventions, to today's sophisticated Internet-based multimedia resources (which may be interactive, and may include curated- and non-curated UGC), has been transformative. A body of literature already exists about the effects of non-online multimedia interventions (such as DVDs and audiorecordings) and I considered it useful to review this 'older' literature when evaluating modern Internet-based interventions.

Therefore, given the challenges identified by other authors in determining clear patterns of effects amongst (offline) interventions to mitigate the detrimental effect of low health literacy on health outcomes, I undertook a systematic review of online and/or multimedia patient education interventions. In accordance with the underlying realist ontology adopted in this thesis, the "Cochrane-style" systematic literature review reported in this chapter is complimented by a realist synthesis of the same literature. Authors' considerations regarding the design and implementation of these resources, as well as their effects on

primary and secondary outcomes, were recorded. Conclusions shed light on possible mechanisms that may operate to result in certain outcomes in specific contexts.

7.2 Aims and objectives

The primary aim of this chapter is to investigate the relationship between health literacy level and the effectiveness of online and/or multimedia interventions as reported in existing peer-reviewed literature.

Equal importance has been attributed to both sections of the review reported in this chapter. Therefore, there are two primary objectives:

- For the systematic review: To assess the extent to which the effectiveness of online resources for patients varies by health literacy level.
- For the realist review: To report considerations associated with the development and implementation of these resources, and authors' statements regarding reasons for the success or failure of these resources to result in specific health outcomes.

Results of the systematic review are reported first (section 7.4), followed by results of the realist review (section 7.5). Then, the conclusions of both studies are discussed together in section 7.6 and 7.7.

7.3 Systematic review of the effectiveness of multimedia and online interventions by health literacy level

7.3.1 Methods

For this review, Cochrane Collaboration guidelines were followed to identify studies for inclusion, assess their validity, and extract and summarize data as outlined in the Cochrane Handbook for Systematic Reviews of Interventions.(4) Although Cochrane recommends that more than one person extracts data (section 7.6.2 in the Cochrane Handbook), due to resource constraints, I completed this independently. With the exception of independent data extraction, this systematic review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.(5)

7.3.1.1 Systematic review search strategy

A systematic literature search was undertaken of three electronic databases, to identify articles reporting the evaluation of the effectiveness of online interventions for patients *whose health literacy was also measured*. Three databases were searched: Medline (1946-present), PsycINFO (1987-present) (both accessed through the OVID interface) and the Cochrane Central Register of Controlled Trials (1948-present), using terms related to literacy and multimedia or online/web-based informational interventions, adapted from two existing systematic reviews of multimedia and online interventions.(6, 7) A full list of search terms used can be found in Appendix E.3. Terms were combined with Boolean operators where appropriate, and where Medical Subject Heading (MeSH) terms were not available, the corresponding free text term was searched instead. The search was conducted on 6 September 2013.

EndNote X4 (Thomson Reuters, 2011) was used to manage citations. Microsoft Excel was used for data extraction and analysis.

7.3.1.2 Inclusion criteria

Databases were searched for studies in adults with any medical condition, in any country, age >18 years old, in any language. Included study designs were: randomized controlled trials (RCTs), and clinical controlled trials (CCTs; also referred to as quasi-randomized trials). Studies were included if they reported the evaluation of a multimedia, online or web-based health information intervention, including those that reported the use of mobile device applications. A broad definition of health-related outcomes was used: interventions were included that were designed to influence health outcomes such as all-cause mortality and quality of life, as well as those designed to influence patients' healthcare experiences such as electronic web portals or forms. These criteria were used in order to as fully as possible capture the potential influence of health literacy on any outcome that would impact patients' experiences of health and health services.

Initially, only studies reporting interventions delivered online were to be included. After preliminary searching it was evident that literature meeting these criteria were limited, and this would have excluded offline-administered interventions that share some characteristics with Internet-based ones, such as audio and video components (specifically, those that were not entirely text-based). Therefore, I decided to include studies reporting computer-based multimedia interventions as well, subject to other inclusion criteria.

Multimedia was defined as the delivery of information using more than one format incorporated into the same intervention. In accordance with existing literature (8), these formats were divided into: 1) text, graphics or photographs; 2) animation or video; 3)

audio. Studies were included if they evaluated interventions delivering content in at least two different formats.

Studies were only included if they reported the health literacy level of participants, as measured by any available validated assessment index. (Chapter 5 was used as a reference for including studies in the review reported in this chapter.) Studies were not included or excluded on the basis of the comparison interventions, which included usual care, paper pamphlet-based information provision, or audiobooklet information provision. Included studies reported interventions administered in any setting, whether clinical, educational, or at home.

7.3.1.3 Exclusion criteria

Those studies reporting the evaluation of interventions to improve people's computer ability, without evaluating a specific online health intervention, were excluded. Similarly, studies reporting the evaluation of text-message based reminder systems, without any additional internet component, were excluded. In addition, studies were excluded if participant health literacy was not measured using a validated index. Protocols and pilot studies were excluded, as these would not have provided adequate data from which to develop adequate quantitative conclusions. Conference abstracts and dissertations were also excluded. One group pre-test/post-test studies, literature reviews, and studies incorporating solely qualitative methods were excluded.

7.3.1.4 Selection procedure

Following the database searches, I imported identified studies into EndNote X4. After the removal of duplicates, I reviewed titles and abstracts, and excluded studies that did not

meet the inclusion criteria. I read candidate full text articles and extracted data from papers that met the inclusion criteria. I scanned the reference lists of the five papers included from the database searches to identify additional papers for inclusion, and as a result one more study was included. Therefore, six studies are included in this review. Figure 7.1 reports the flow of papers through the review process.

7.3.1.5 Data extraction and synthesis

A bespoke data extraction form was developed. This was based on the aims and objectives as well as existing literature on the components present in online resources (6), their complexity (3), and their intended outcomes.(9)

For the quantitative portion of the review, data were extracted on aspects of the studies relevant to health literacy, health information, and intervention effectiveness. Primary and secondary outcomes were recorded. Any adverse outcomes reported in included studies were extracted. The validity of studies were appraised according to the guidelines set out by the Cochrane Collaboration. Clinical heterogeneity in outcomes between studies precluded statistical pooling, therefore meta-analysis was not undertaken.

Data were extracted regarding the constituent components of included interventions, in order to explore relationships between effectiveness and characteristics of the interventions. The following data were extracted from published studies: whether the interventions included video; personal experiences of health, illness, or treatments; peer-to-peer interaction; patient-practitioner interaction; additional “in-person” (i.e. not online) interaction; and additional phone/SMS/telehealth interaction. Table 7.1 provides an overview of the primary outcomes of included studies.

7.3.1.6 Validity assessment

For randomized controlled trials, validity was assessed based on the following criteria: randomization (methods used as described in the publication, comparison of baseline characteristics between groups), blinding (whether the participants, care providers, and outcome assessors were blinded), qualitative description of the intervention, the degree to which the intervention was consistently delivered, and generalizability (to clinical practice across a variety of settings).(4) Where information was unclear or unavailable, this was recorded. Authors were not contacted to obtain information about risk of bias; the Cochrane Handbook is equivocal about whether this is necessary (4), and it has been suggested that author-provided information often confirms that certain criteria were not met, thereby downgrading the risk of bias.(10) Since in this study, 'unclear' risk of bias for individual criteria often resulted in studies being rated at 'high' overall risk of bias, it is probable author contact would not have changed the overall ratings.

No clinical controlled trials met the inclusion criteria, so validity assessments were not applied to this type of study.

Studies were judged as being at "low", "high", or "unclear" risk of bias for each criterion. Then, based on this assessment, each study was given an overall "low", "moderate", or "high" risk of bias across these criteria. Main findings were interpreted in the context of this quality assessment. A summary of the risk of bias assessment for included studies can be found in Appendix E.2.

7.3.2 Ethics

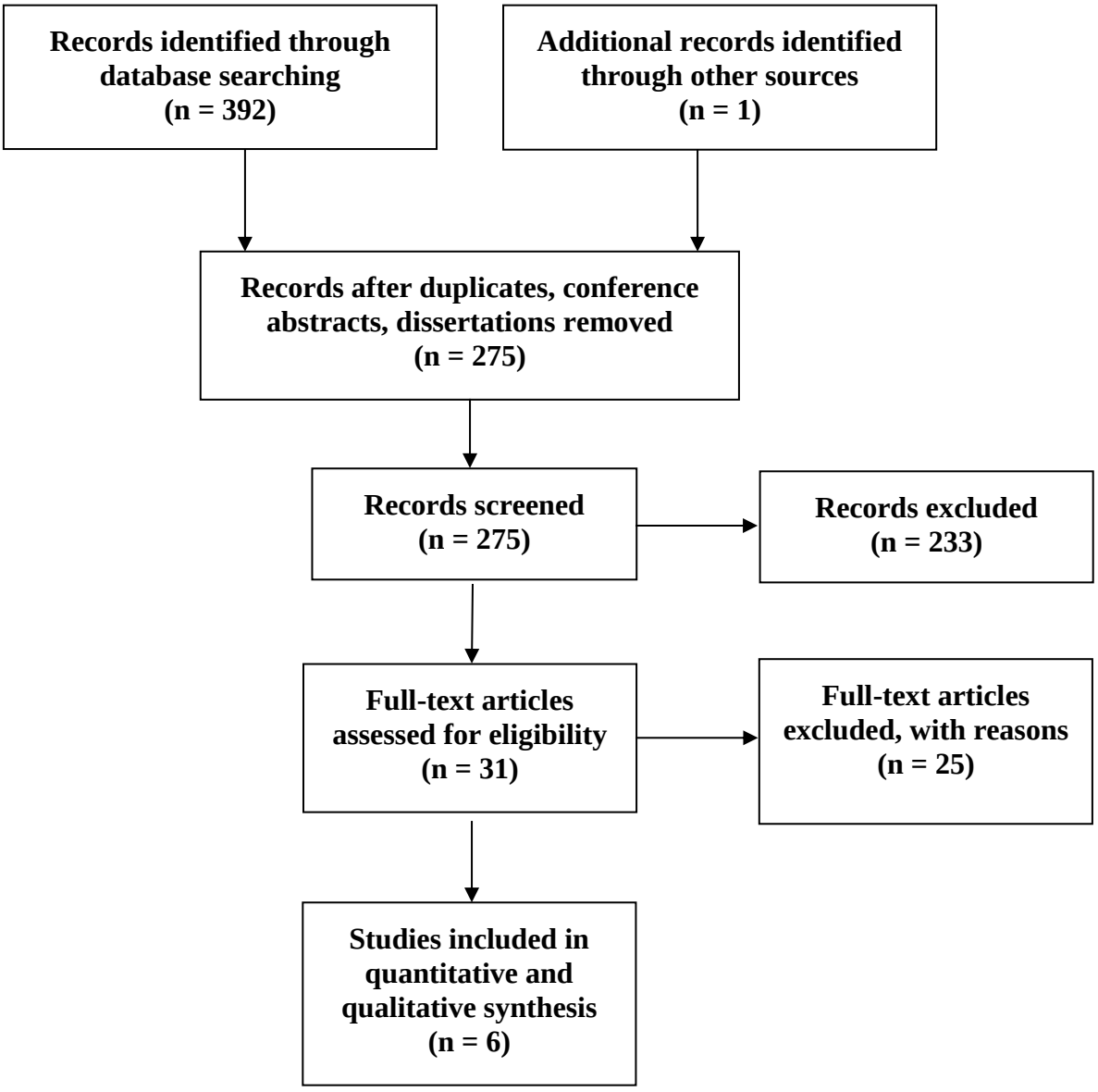
Ethical approval was not required for this element of the study.

7.3.3 Results

7.3.3.1 Characteristics of included studies

392 candidate studies were identified from database searching. 275 remained after removing duplicates. Titles and abstracts of these studies were screened, and 30 were selected from the database search for full-text review. From 30 studies reviewed at full-text level, 25 studies were excluded because they did not meet the inclusion criteria. Five studies meeting the inclusion criteria were identified from the database search. The reference lists of these studies were scanned for relevant studies, resulted in one additional paper to be included.(9) Therefore, 6 RCTs were included in this review. These 6 studies evaluated 8 interventions, and included 1513 participants. All of the included studies were undertaken in the United States. A flow diagram is available in Figure 7.1.

Figure 7.1 Flow diagram of included studies



7.3.3.2 Risk of bias of included studies

None of the six included studies were judged to be at low risk of bias. Two studies (9, 11) were judged at moderate risk of bias. The remaining four (8, 12-14) were judged to be at high risk of bias, as a result of their unclear random sequence generation and allocation concealment, lack of blinding of outcome assessors, and for not analyzing data according to intention-to-treat principles. Generally, quality criteria were not met due to lack of information, rather than due to explicit reporting of inadequate methods; this led to downgraded risk of bias. It has been suggested that incomplete reporting- represented in this chapter as 'unclear' risk of bias for each criterion- has been associated with overestimates of treatment effect.(4) Figures 7.2 and 7.3 give an overview of the risk of bias assessments; Appendix E.1 provides narrative descriptions of the risk of bias ratings.

Figure 7.2 Risk of bias presented as judgments for each item for each included study

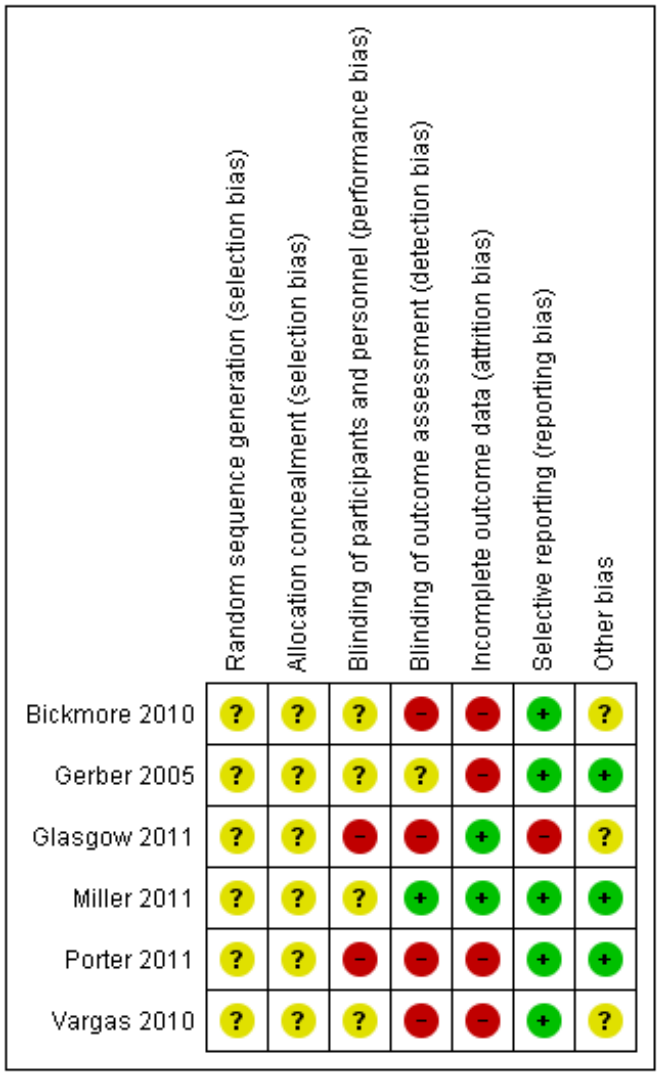


Figure generated using Review Manager (Cochrane Collaboration, 2011)

Figure 7.3 Risk of bias presented as percentages across all included studies

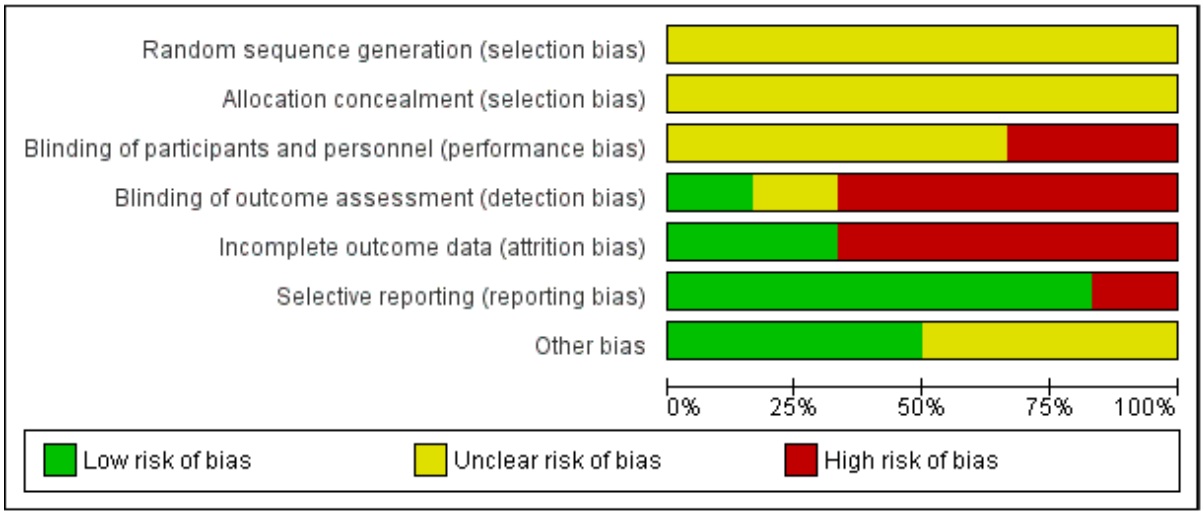


Figure generated using Review Manager (Cochrane Collaboration, 2011)

7.4 The relationship between health literacy level and intervention effects

Five of the six included studies commented on the relationship between participant health literacy level and the effectiveness of the evaluated interventions, thereby providing information to fulfil the primary objective of this chapter. One study (14) did not stratify results by literacy level, therefore it was not possible to examine quantitative evidence of differential effectiveness. Details of primary outcomes and intervention effects are available in Appendix E.2. What follows in this section is a brief description of each study, and any available information regarding how intervention effects varied by health literacy level.

Gerber *et al.* evaluated a series of computer-based multimedia self-management lessons in English and Spanish for patients with type I and II diabetes.(8) This intervention was provided in a primary care clinic waiting room, and included a series of knowledge-based questions for reinforcement after each lesson was completed, and narrative instruction as

well as testimonials from other patients with diabetes. The control group completed a different multimedia intervention consisting of multiple-choice quizzes, without any narrative instruction or testimonials. Health literacy was measured using the STOFHLA.(16) The primary outcome was change in HbA1c over the study period (one year). Secondary outcomes included BMI, blood pressure, self-efficacy, knowledge, medical care, and change in perceived susceptibility to complications.

All outcomes were reported as the absolute change in means stratified by health literacy level, but no interaction tests were carried out to determine if a true subgroup effect was present. There was no difference in outcomes by health literacy level in all but one primary or secondary outcome; they found that HbA1c significantly improved in the intervention group amongst low health literacy participants, but not high health literacy participants, who had poor control at baseline (defined as HbA1c $\geq$ 9.0%).(8)

Porter *et al.* compared 'task burden' related to use of a computer-based versus paper-based questionnaire for parents with ADHD.(11) This questionnaire allowed parents to enter medical information about their child in a clinical record, and consisted of identical questions in both the computer-based and paper-based groups. Participants were allowed to undertake the intervention in a location of their choice (at home or in the clinic). Health literacy was measured using the TOFHLA.(15) The primary outcome was 'task burden' experienced while completing the questionnaire, which was measured using a validated scale (the National Aeronautics and Space Administration Task Load Index; NASA TLX). They found an inverse relationship between health literacy and 'task burden', noting that "subjects who scored adequate [on the health literacy measure] had a lower but nonsignificant difference in burden score than those who scored marginal/inadequate for literacy (decrease in score of 0.68 SD, $p = .11$)". The primary outcome was reported using means and standard deviations, therefore it was possible to calculate an overall effect size:

the standardized mean difference between intervention and control was 0.35 (95% CI = 0.06 - 0.65). Whether these results mean that the computer-based questionnaire was more effective at reducing task burden amongst ‘marginal/inadequate’ health literacy participants than amongst ‘adequate’ health literacy participants is unclear, since the stratified effect sizes are not reported.

Another study also evaluated an intervention using a multimedia-based data entry system.(14) Vargas *et al.* evaluated an electronic version of the Asthma Screening Questionnaire (ASQ-e) compared with a paper-based version. The intervention was administered during visits to a mobile asthma clinic. Parents were asked to fill out either the electronic or paper version of the questionnaire. Then, they were asked the same questions verbally in a follow-up interview immediately afterwards. Health literacy was measured using the STOFHLA.(16) The primary outcomes were concordance of the questionnaire responses with verbal responses in the interview, as well as usability and satisfaction with the questionnaires. The paper reported that there was 68% concordance in the intervention group versus 54% concordance in the control group ($p < 0.01$), but did not provide enough information to calculate an effect size. Usability and satisfaction was only reported for the intervention group: 95.8% of participants "found it simple to use, felt comfortable responding to questions, and found the screens and instructions clear and easy to understand." There was a significant correlation between individual health literacy scores and years of education (Spearman rho = 0.47, $p < .01$), but no correlation between health literacy level and concordance. There was however a correlation between years of education and concordance. (Spearman rho not reported, $p < .05$). Other outcomes were not reported between health literacy levels, precluding any other conclusions.

Bickmore *et al.* (13) reported preliminary results of two trials of multimedia interventions designed specifically for people with low health literacy. One trial ("A RCT to Reduce Cardiopulmonary Rehospitalization"), was carried out with 417 participants, but only 143 completed necessary measures and were included in analysis. Health literacy was measured using the REALM.(17) The intervention, an 'Embodied Conversational Agent' (ECA), consisted of a computer wheeled to the bedside which interactively provided medication information prior to discharge from hospital. The authors did not report results stratified by health literacy level numerically, but gave the following narrative description: "In the few measures in which there were significant or near-significant differences on health literacy, these were mostly in favor of patients with inadequate health literacy, indicating that ECAs may be even more acceptable to this population than to patients with adequate health literacy." Again, it is not possible to ascertain the effect size, or to compare the effect size between groups of participants with different health literacy levels.

Within the same publication, a second trial was reported ("Computer Agents to Promote Walking in Older Adults with Low Health Literacy"), which aimed to "promote walking in older adults." Patients ≥ 65 years old were recruited from an ambulatory clinic and were given pedometers and a linked tablet personal computer, and were asked to interact with this version of an "Embodied Conversational Agent" daily for two months. Health literacy was measured using the TOFHLA.(15) The comparator was usual care. As in the previous trial, results were not reported numerically (despite recruiting 88 participants into the trial, data was only analysed and reported from 33 participants, all of whom were in the intervention arm), but it was suggested that "participants with inadequate health literacy completed fewer home-based conversations with the ECA compared to participants with adequate health literacy ($p < 0.05$)." Regarding attitudes towards the computer agent, respondents scored "well above the Likert scale midpoint," and "differences on a few of

the individual items in the scale reached significance, indicating a greater degree of personification of the agent (mutual understanding) and a lower level of understanding of the technology (thinking the agent would discontinue use if the participant said the wrong thing) by participants with inadequate health literacy." Whether these differences were clinically or statistically significant is unclear.

Glasgow *et al.* evaluated an online/multimedia intervention called "My Path to Healthy Life/Mi Camino a la Vida Sana", a computer-assisted self-management intervention designed to improve healthy eating, physical activity, and medication adherence.(12) This study was a three-arm randomized controlled trial in which this intervention alone was evaluated in one arm, along with a control arm of usual care. The third arm evaluated this intervention plus social support through a computer-based telephone system, which provided prompting and reminders if aspects of the computer intervention were not completed. Health literacy was measured using the STOFHLA.(16) The primary outcomes were medication adherence, exercise, and food choices, gathered through self-report. The outcomes were reported as correlations with usage of the intervention, precluding calculation of an effect size for either the computer or computer plus social support interventions. It was narratively reported that "participants who had moderate to lower health literacy, or who had little baseline computer use were as engaged with the website as other participants," but no numerical representation of this engagement was provided.

Miller *et al.* evaluated a web-based intervention to increase colorectal cancer screening.(9) This intervention, called 'CHOICE' (Communicating Health Options through Interactive Computer Education), was designed to be "accessible to low-literacy patients by using easy-to-understand audio segments, video clips, graphics, and animations" (although these participants were not involved in intervention design). It was administered during clinic visits at a community-based internal medicine clinic. Health literacy was measured using

the REALM (17). The primary outcome of interest was receipt of colorectal cancer screening within 24 weeks of study enrolment. Outcomes were reported stratified by literacy level: for the primary outcome, the adjusted odds ratio for those in the limited literacy group was 1.7 (95% CI 0.69, 4.4) versus 1.9 (95% CI 0.70, 5.0) in the 'adequate' literacy group. They also reported that "average viewing time did not differ by literacy level ($p = 0.91$)." In general, there was "no significant interaction between CHOICE [the intervention] and literacy level," and "the intervention showed similar effects in limited-literacy and adequate-literacy patients."

7.4.1 Components and sophistication of included interventions

Data were extracted to attempt to ascertain if there were discernible patterns between the effects of interventions and the components of which they were comprised, as well as their degree of sophistication. All but one included study (11) evaluated interventions incorporating videos. The content of these videos varied between studies; this included videos that described features of action plans (12), demonstrated implements used in colorectal cancer screening (9), incorporated narrative descriptions (8), reviewed discharge medications (13), and asked questions in order to elicit questionnaire responses.(14) Gerber *et al.* included personal experiences of health and illness, in the form of narrative descriptions from people with type I or II diabetes about symptoms, treatments, and complications.(8)

One study (12) evaluated an intervention which included, in addition to a computer-based support programme, an offline component in the form of interactive voice response phone calls, containing motivational messages and action plan reinforcement. This study also

included dedicated patient-practitioner interaction as part of the intervention, as well as invitations to attend group visits with other participants in the same study condition.

Two of the interventions provided information without any capacity for interactivity and were classified as having no sophistication.(11, 14) One intervention (9) incorporated online assessments. A further five interventions, reported in three studies (8, 12, 13) were classified as having moderate sophistication, including online (or computer-based) assessments and tailored feedback. No interventions were deemed to have high sophistication (i.e. complex tailored health programmes).

Due to the diversity of components and outcomes reported in these studies, it was not possible to establish any clear patterns of effectiveness based on the components or level of sophistication of the interventions. In particular, it was not the case that there were specific components or degree of sophistication which were more effective for low or high health literacy groups.

7.5 Realist review

7.5.1 Rationale and methodology

A number of reviews have attempted to use ‘conventional’ systematic review methodology to shed light on the relationship between interventions to mitigate the effects of low health literacy on outcomes. Their conclusions have been universally uncertain, noting that their findings “do not give a clear picture about which type of initiative is most likely to be effective” (18); that they provide “insufficient information to conclude whether interventions for health literacy can attract the target population, achieve an effect that is sustainable, or be generalized outside of clinical settings” (19); and that “evidence for the

effects of other interventions on other outcomes was either limited or mixed, precluding conclusions."(20)

Therefore, I addressed the following question: How does health literacy level affect the outcomes of multimedia and online patient education interventions? More specifically: What are the possible mechanisms explaining the successes or failures of the interventions reported in included studies? How does health literacy as a contextual factor influence the mechanisms by which interventions exert their effects?

In order to address these questions, I selected realist review, as it is an appropriate methodology for ascertaining the relationship between context, mechanism, and outcomes of complex interventions.(21-23)

7.5.2 Study selection, data extraction, and synthesis

All six studies included in the systematic review were included in the realist review. Following guidelines for conducting a realist review (22), studies were selected for inclusion on the basis of their relevance to the primary objective (evaluating the relationship between health literacy level and intervention effects) and rigour. Although the available literature has been demonstrated in this chapter so far to be of moderate to high risk of bias, given the paucity of available studies, all those included in the systematic review were also included in the realist review.

Included studies were read and re-read, and passages were extracted that provided specific information to develop "theories of change" (24) regarding how the interventions exert effects. In turn, this was used to explore how health literacy level may impact on the success or failure of interventions.

The following data were extracted in order to develop these "context-mechanism-outcome" relationships (23): authors' explicit conceptual models of how the intervention should work; any theories or mechanisms postulated by the study's authors to explain the success or failure of the programme; and explanations of the relationship between health literacy level and intervention effectiveness. Where this was not explicitly available, it was inferred from the assessment measures they used or how they stratified groups within the study. Microsoft Excel was used for the extraction and organization of data and relevant passages.

The scope of this work was to identify information from a narrowly-selected group of included studies to fulfil specific research objectives. Taken alone, this is inconsistent with the broader exploration of a body of literature identified through iterative searching, which constitutes a formal realist review.(25) In November 2013, I contacted one of the members of the 'Realist And Meta-narrative Evidence Syntheses: Evolving Standards' (RAMESES) steering group (Henry Potts, University College London), and discussed whether it was necessary to engage in iterative searching if relevant literature had already been obtained and reviewed in the context of carrying out a thesis. He suggested that the RAMESES guidelines could be considered a 'work in progress', and that it would be acceptable to review studies obtained in the context of a conventional systematic review if the limitations of this approach were identified and discussed. I decided on the basis of this discussion to proceed with undertaking 'realist review' of the same RCTs included in the complimentary systematic review. As suggested, the limitations of this approach are detailed in section 7.6.2.

The results of this chapter are reported in the form of 'process factors', which explain the success or failure of particular interventions. These are derived from the authors' explicit ideas about how interventions exert specific effects differently between health literacy

groups, as well as tacit explanations identified through how interventions were developed and implemented, and whether or not they were successful.

7.5.3 Theories on why multimedia/online interventions may have different effects between people with different levels of health literacy

7.5.3.1 People with lower health literacy may experience disproportionately higher data entry burden

Two included studies evaluated interventions designed to reduce the effort or burden experienced by health care users entering clinical data: one in parents of children with ADHD (11) and another in parents of children with asthma.(14) The latter study did not report results stratified by health literacy level so it was not possible to ascertain quantitative evidence, but the authors explicitly noted that the intervention was designed to "minimize the parents' need for reading and writing skills in providing accurate information about their children's asthma symptoms." Given that the electronic questionnaire intervention in the study yielded better concordance of responses with a follow-up interview than when participants were asked to fill out the same questionnaire on paper, this suggests that data accuracy improved as a result of reducing burden associated with data entry.

The other data entry study (11) reported that amongst people in the computer intervention group, there was a smaller difference in task burden between people of lower and higher health literacy than in the paper control condition.

This conclusion suggests the possibility that accessing these particular computer interfaces reduces task burden in people with lower health literacy. It suggests that in the context of low health literacy, computer interfaces may be somehow easier to use for people with lower health literacy, leading to improved data accuracy.

7.5.3.2 People with lower health literacy may prefer simulated face-to-face communication

In their study reporting preliminary results of two RCTs of computer interventions, Bickmore *et al.* suggested that both interventions were designed to mimic face-to-face communication with a practitioner.(13) Narrative results from that study demonstrated that for usability outcomes in which there were differences between intervention and control by health literacy level, those patients with 'inadequate' health literacy derived greater benefit from the interventions. This suggests that one way in which these interventions may have different effects is that those with lower health literacy may be more amenable and/or receptive to simulated face-to-face communication. This may lead to the outcome of higher perceived usability.

7.5.3.3 Exposure to personal experiences may enhance perceived susceptibility to complications

Although Gerber *et al.*'s evaluation of a multimedia intervention for people with type II diabetes found no significant differences between intervention and control groups in most of the measured outcomes (HbA1c, weight, blood pressure, knowledge, self-efficacy, or self-reported medical care), they did find an increased effect of the intervention on HbA1c in low health literacy patients who had poor diabetes control (defined as HbA1c

>9.0%).(8) They suggested that in this patient population, perceived susceptibility to complications may be low at baseline, as a result of lack of knowledge or understanding of the pathophysiology and prognosis of the condition if left inadequately managed. Consequently, use of narrative descriptions from patients who had experienced severe complications such as amputation and vision loss may have enhanced perceived susceptibility to complications, leading to improved self-management and disease parameters.

7.5.4 Theories on why multimedia/online interventions may not have differential effectiveness between people with different levels of health literacy

7.5.4.1 Essential barriers to care other than health literacy need to be addressed first

In a study of a prostate cancer decision aid, it was found that the intervention increased patients' expressed readiness to undergo colorectal cancer screening.(9) Despite this, only one third of patients who wanted immediate screening went on to order a test. This suggests that there were further limitations than a lack of appropriate decision support to patients obtaining screening; the authors proposed "lack of time and competing priorities" (that is, individual barriers) as two reasons why people did not obtain screening. (Of course, this could also be related to people giving what they perceive as the 'desired' response to the question posed by the researchers, without actual intent to undergo screening.) Therefore, it is suggested that online interventions cannot be effective unless they address additional barriers to implementation of the desired behaviour, or that these other barriers are addressed in conjunction with the online intervention. These barriers can be individual, as suggested in the study, but there are a myriad of other ways in which

inequality in access occurs. In these situations it is not possible for any participant, regardless of health literacy level, to access the care they require which in turn would improve outcomes, unless access barriers are addressed first.

7.5.4.2 Adherence to optimal design principles may result in an intervention that is acceptable to everyone regardless of health literacy level

In a trial of a multimedia computer-based patient support intervention for type I and II diabetes with and without additional social support (12) the intervention was taken up equally by participants regardless of health literacy level. In addition, there were no differences in the results (reported as correlations between website usage and various outcomes such as medication adherence, physical activity, and HbA1c) between groups with respect to health literacy. The authors suggest that one of the reasons for this may have been "that efforts made during website development to address issues of literacy, cultural appropriateness, patient-centeredness, and personal choice and to maximize initial success served to make the program engaging to a broad variety of patients". Therefore, one of the factors that may influence the impact of health literacy on intervention effectiveness may be the degree to which an intervention has been designed with varied, engaging content. One potentially important feature of the intervention evaluated by Glasgow *et al.* is that people can access different aspects of the intervention (video, audio, etc.) based on their own preferences, rather than having to undertake the entire intervention as a whole.

7.6 Discussion

7.6.1 Main findings

In this chapter, literature was reviewed on the impact of health literacy level on the effectiveness of multimedia and online interventions to improve health outcomes. The available peer-reviewed literature includes interventions to improve data entry (11, 14), to reduce rehospitalisation and to increase walking amongst elderly patients (13), to increase knowledge of colorectal cancer screening (9), and to support self-management amongst those with type I (8) and type II (8, 12) diabetes.

Given the diversity of interventions reported in included studies, it was not possible to ascertain clear patterns between studies. A realist review was undertaken to describe the mechanisms by which these interventions may affect outcomes, and any role that is discernable for health literacy level in influencing the intervention design, outcomes, or programme theory.

7.6.2 Limitations

Despite developing a comprehensive search strategy and translating it for use in three databases, it is possible that relevant studies may have been excluded. The reference lists of included studies, as well as available systematic reviews of interventions to improve the health of people with low literacy, were scanned, but this did not result in any additional studies to be included in the review over those that were found in the database search.

As stated in section 7.3.3.2, quality criteria were generally not met due to lack of information, rather than due to explicit reporting of inadequate methods. Although it has been suggested that contacting study authors may be of benefit in this situation (4) it has

also been noted that this may lead to overly positive answers.(26) This was not undertaken; quality assessment may have been different if I had done this.

Finally, it is acknowledged that having one author select studies for inclusion and extract data increases the risk of bias (4), but this was not done for this review. Since the review reported in this chapter was undertaken primarily as a component of a doctoral thesis, resources were unavailable to employ a second person to extract data.

As discussed in 7.4.2, further iterative searching was not undertaken beyond the systematic database search used to obtain studies for the systematic review. While this deviates from recently established guidance on the conduct and reporting of realist reviews (25), I decided to take this approach because it allowed me to directly compare and contrast the findings of the 'conventional' narrative systematic review and the realist approach. The limitation of this decision is that potentially relevant studies (for example, qualitative research) were not included in the description, which may have added additional contextual information to the findings.

7.7 Conclusions

The key findings of this chapter are as follows:

- Existing literature evaluating the impact of health literacy level on the effectiveness of online and multimedia interventions is of poor quality, at moderate to high risk of bias.
- No high quality evidence exists supporting the assertion that the response to online and multimedia patient education resources differs by health literacy level.

- Several possible underlying theories of what might be expected to work, and why, were elucidated:
    - People with lower health literacy may experience disproportionately higher data entry burden.
    - People with lower health literacy may prefer (simulated) face-to-face communication.
    - Exposure to accounts of other people's personal experiences may enhance perceived susceptibility to complications amongst people with lower health literacy.
- Several possible mechanisms were put forward to explain when intervention effects do not differ by health literacy level, including:
    - Essential barriers to care other than health literacy should be addressed first.
    - Adherence to optimal design principles may result in an intervention that is acceptable to everyone regardless of health literacy level.

Although it has been suggested that it is necessary to develop interventions that specifically address the needs of people with low health literacy, the studies included in this review did not provide convincing evidence to support this assertion. In fact, given the results of this chapter, the suggestion that it could be 'harmful' or inappropriate to provide the same resource for people with low and high health literacy (20) should be questioned. This conclusion needs to be placed in the context of the moderate to high risk of bias of the included studies.

The realist review provides suggestions to be addressed in further research, including addressing the scope of what interventions can be effectively provided online in place of being provided as an 'in-person' service. One promising area raised in this chapter is the suggestion that exposure to personal experiences (recall from Chapter 4 that their

availability and use is increasing with the proliferation of user-generated content) may enhance perceived susceptibility to complications, possibly influencing people to engage in improved self-management. This was one of the few positive results identified from this review.

Although it has been shown that increased sophistication of online resources is associated with higher medication adherence (3), the online resources included in this review, which were all designed to attend to the health literacy limitations of various populations, did not demonstrate any gradient of effect along with sophistication. More research is needed to explore this relationship. This must be considered in the context of questioning the necessity of tailoring different online resources to people with low and high health literacy. Perhaps it is the case that the general design of online resources contributes more to their effectiveness than the extent to which they have been designed for individuals with low health literacy, as was suggested by the authors of one study in the present review.(12)

Finally, no clear relationships were noted between the specific components that made up interventions included in this review and their effectiveness. One possibility to be addressed further is that the most effective interventions are those comprised of components that address specific, pre-identified needs of the population. It was also identified that when other barriers to accessing essential services exist, such as in the case of colorectal cancer screening, online and multimedia interventions will not be effective since they do not ameliorate the most important barrier. It is essential to consider the contexts in which online interventions are likely to be beneficial, and to thoroughly characterize all the barriers to accessing necessary services prior to developing an intervention.

7.8 References

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Chapter 8: Health literacy and online health information: Analysis of data from a randomized controlled trial

8.1 Introduction[10]

As established in Chapter 7, there is limited experimental data on the relationship between health literacy level and usage and outcomes related to online health resources. What few studies exist are of low quality, and at moderate to high risk of bias.

In order to investigate this issue further, data were analysed from an existing (feasibility) trial - EXPeriences Evaluated in a Randomized Trial (EXPERT) (International Standard Randomized Controlled Trial Number: ISRCTN29549695) - investigating the use of novel health websites, comparing 'facts and figures' and 'patient experience' websites (the latter website representing a proxy for curated user-generated content). The available data enabled me to compare usage and outcomes related to both trial websites. Specifically, I undertook analyses to evaluate the baseline characteristics, attitudes towards health websites, and usage between groups of participants with differing health literacy levels. I undertook exploratory analyses of self-reported health outcomes to assess the extent to which health literacy level was related to outcomes of online information.

Six novel password-protected websites were developed for the EXPERT study: two for people with asthma, two for people interested in smoking cessation, and two for carers of people with multiple sclerosis (MS). The analyses reported in this chapter are based on data from the 'asthma' arm of the study. I decided to focus on asthma because it is a

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prevalent non-communicable disease in the UK and around the world.(1) Asthma self-care is complex, and it has been identified that people with asthma have high unmet information needs (2, 3), making it an ideal exemplar condition to investigate usage and outcomes of patient education websites. In addition, the asthma data was complete and available at the time at which I carried out these analyses, while the 'smoking cessation' and 'MS carers' data were not yet complete.

I had the opportunity to include a health literacy measure in the EXPERT study. I selected the measure (4) on the basis of its favourable administration and psychometric characteristics as determined in Chapter 5. At the time, another doctoral student (Laura Kelly) was developing a novel measure to be included in the trial (the eHealth Impact Questionnaire) (5), and was conducting cognitive interviews to evaluate the suitability of questions being included in the measure. Since the measure I chose had not been used before in the UK setting, I asked Laura to include the three questions from the Chew *et al.* measure in her cognitive interviews. In particular, I was concerned that the question "How often do you have someone help you read medical forms" would be confusing for UK participants, as the volume of documentation required to access NHS services is considerably less than what is often required to access healthcare in the US, where the measure was developed and validated. Results of these cognitive interviews suggested that this question- and the entire measure- would be acceptable for the UK setting.

Chew *et al.* '3 question' health literacy measure

Question	Scoring (one choice allowed for each question)
1. How often do you have someone help you read hospital materials? 2. How confident are you filling out medical forms by yourself? 3. How often do you have problems learning about your medical condition because of difficulty understanding written information?	0 = Never 1 = Occasionally 2 = Sometimes 3 = Often 4 = Always

8.2 Aims and objectives

The aim of this chapter was to evaluate the role of health literacy in use and outcomes of online health information. The specific objectives were:

- To assess the health literacy level of participants recruited into a trial of online resources for asthma.
- To investigate the relationship between health literacy level and various baseline characteristics, such as age, educational attainment, internet usage, and asthma control.
- To assess the relationship between participant health literacy level and the usage of two novel health websites.
- To explore possible health literacy subgroup effects on self-reported health outcomes related to the use of these websites.

8.3 Methods

8.3.1 Participants and trial design

Participating general practitioners in the Oxfordshire, Berkshire, Wiltshire, and Gloucestershire areas identified patients in their own practice who met the trial eligibility criteria, and contacted them to ask if they wanted to take part in a study about online health information. The onus was on patients to respond if interested based on study information sent to them through the post. Eligible patients were men and women over the age of 18, who had a clinical diagnosis of asthma recorded in their primary care record, and who had been prescribed inhaled corticosteroids for at least 3 months in the previous year. Those who were terminally ill, who could not understand English, and who had previously entered the study (in the 'smoking' or 'MS carers' arms) were excluded. Informed consent was obtained from patients and they were provided with login information and a detailed information sheet. Each user was provided with a distinct username and password, and was sent an email containing a hypertext markup (HTML) hyperlink, which allowed access to the trial portal. Participant blinding was achieved by providing information that the purpose of the trial was to explore use of health websites; participants were not told about any hypotheses regarding the different websites. Participants were randomized by automatic computer allocation (facilitating allocation concealment) in a 1:1 ratio to receive either the 'facts and figures' (control) website, or the 'patient experience' (intervention) website.

Participants completed baseline questionnaires prior to viewing the trial website for the first time. Then, they obtained access to the trial website, and had a two week period in which they had unlimited access to the website. At the conclusion of the two week period, they were sent an email with a link to follow-up questionnaires (section 8.3.5).

Participants were free to use the website *ad libitum*. If participants had not logged onto the website in the first week, they were sent an email reminder at the conclusion of that first week to do so. They were free to drop out of the trial at any time, and were provided with information on how to access health services if required during the trial period.

8.3.2 Sample size

This trial was a pilot/feasibility study; given the paucity of evidence regarding this type of intervention, the principal investigator (John Powell) and the research team assessed that two weeks would provide sufficient time for participants to view the website, but not so much that they would subsequently forget their experience of it, or that the initial effects would have subsided. A target sample size of 50 in each arm (100 total in the asthma condition) was calculated based on the trial primary outcome (acceptability judged by engagement). I did not complete my own sample size calculation prior to analysis for two reasons: 1) the overall sample size was calculated prior to my involvement in the trial, and I could not change it; 2) the paucity of available evidence on health literacy subgroup effects made any *a priori* sample size calculation a presumption at best. Furthermore, packing up information as if it is provided in a specific 'dose' (and basing a sample size calculation on the suspected effect of a particular dose) is an inherently artificial approach, and does not account for how people view, digest, and revisit information. In lieu of this, I completed post-hoc power calculations (see section 8.5.1.2 for limitations of this approach) to ascertain what sample size would have had adequate power to reliably detect the effect sizes identified in this chapter.

8.3.3 Trial websites

This chapter focuses on the two websites developed for the asthma condition: one 'facts and figures'- based website , representing standard health information, and one 'health experiences'- based website, as a proxy for curated user-generated content. Both websites had equivalent information about asthma epidemiology and treatment, and provided evidence-based self-management advice. Each included a video of a health professional talking about asthma and self-management. Care was taken to ensure the websites had the same look and feel, components, and level of sophistication. Screenshots of the trial websites are available in Appendix F.1.

8.3.4 Data management

Data were obtained directly from the trial websites, and was stored on secure servers at the University of Oxford. Trial data was provided to me from the Clinical Trials Unit in a password-protected .csv (comma separated values) file. This file was kept in a password-protected folder contained on my personal computer. Access to this folder was available through two-step authentication on my personal computer, which was located in the Nuffield Department of Primary Care Health Sciences.

8.3.5 Baseline and outcome measures

Health literacy was measured using the '3 question' measure developed by Chew *et al*.(4) In accordance with existing literature (6, 7) total health literacy scores were dichotomized into a group with those reporting that they have had problems with health information (a value of ≥ 1, described as 'some health literacy limitations'), and a group reporting that they never have problems with health information (a value of 0, described as 'no health

literacy limitations'). Participant age, ethnicity, educational attainment, and general internet attitudes and ability were recorded at baseline.

The Asthma Control Test (ACT) was completed at baseline, which is a validated 5-item measure of symptom severity and control, with each item scored from 1-5. Total scores on the ACT range from 5-25, with a total score <20 indicating "poor" asthma control.(8) Three validated indices were completed at baseline and at 2-week follow-up: the Partners in Health (PIH) scale, the Chronic Disease Self-Efficacy Questionnaire (CDSEQ), and the eHealth Impact Questionnaire (eHIQ). PIH is a validated 12-item scale, with each item scored from 0-8 (total score 0-96, mean score 0-8), which measures general principles of long-term condition self-management.(9) CDSEQ is a validated 6-item scale, with each item scored from 1-10 (total score 6-60, mean score 0.17-10), which measures self-efficacy in managing long-term conditions.(10)

The eHIQ is divided into two independently administered and scored parts: eHIQ Part 1 (baseline) and eHIQ Part 2 (outcomes).(5) The eHIQ Part 1 consists of 14 items regarding an individual's general attitudes towards health-related websites, divided into two subscales: 1) 'Attitudes towards health information'; 2) 'Attitudes towards sharing health experiences online'. The eHIQ Part 2 consists of 34 items that ask about an individual's views regarding a specific health-related website, divided into three subscales: 1) 'Confidence and identification'; 2) 'Information and presentation'; 3) 'Understanding and motivation'. All items in Part 1 and Part 2 consist of five point response categories, which range from 'Strongly disagree' to 'Strongly agree'.

8.3.6 Statistical analysis

I designed and performed all the analyses reported in this chapter. Data were analysed using the 'R' statistical package (R Foundation for Statistical Computing, Vienna, Austria). My intention was to be blinded to allocation while conducting these analyses, but I became accidentally unblinded in the course of data transfer.

8.3.6.1 General principles

Baseline characteristics of all participants were summarized by health literacy level ('no health literacy difficulties' versus 'some health literacy difficulties'), including gender, age, ethnicity, educational attainment, and current internet use and ability. Categorical variables were summarized as frequencies and proportions, including missing values; continuous variables were summarized as means with corresponding standard deviations. Skewed continuous data was summarized as medians and interquartile ranges. Comparability was not assessed using hypotheses tests between intervention and control groups, since by definition any baseline differences are due to chance as long as randomization is adequate.(11, 12)

Quintile-quartile plots were interpreted to assess for normality. Parametric tests [t-test, Chi-squared, Analysis of Covariance (ANCOVA)] were used to analyse normal data. The Wilcoxon Rank-Sum test was substituted for the independent t-test to analyse skewed data. No other non-parametric substitutions were required. The significance level for all analyses was set at 0.05; no correction was made for multiple comparisons, which should be considered when interpreting the results of this chapter.

Retention rate was calculated based on the proportion of individuals who completed all baseline and follow-up measures, randomized to either intervention or control arm. This was compared between health literacy levels using independent t-tests.

Logistic regression was used to assess the degree to which baseline variables predicted health literacy level. The significance of individual predictors was assessed with two-tailed p values, as well as the Chi-squared and R^2 statistics for the overall model.

Usage was compared between intervention and control, within health literacy groups, using the Wilcoxon Rank-Sum test. Between-group comparisons were also performed using the Wilcoxon Rank-Sum test. There was no missing usage data; other analyses were performed using all available data (see section 8.3.6.2).

Unadjusted changes in PIH and CDSEQ total scores between baseline and two weeks were summarized using means and 95% confidence intervals, with corresponding p-values. Exploratory subgroup analyses (PIH, CDSEQ) were undertaken using ANCOVA, adjusted for baseline scores. An interaction term (health literacy level and website allocation) was included in the models; the significance of this interaction term (assessed with two-tailed p values) as a predictor of the outcome was used to assess for subgroup effect, as suggested by Altman and Bland.(13) These exploratory analyses were undertaken with complete cases only.

8.3.6.2 Missing data

I assessed that data could be considered "Missing At Random" (MAR); that is, that missing values may be related to other observed variables. Initially, I undertook descriptive analyses of the data, reporting what data was available as well as frequencies of missing data for each variable.

Although it has been widely noted that available case analysis may introduce bias in the context of MAR data (14), Altman and Bland have suggested that "in general, it is

advisable not to include in an analysis any variable that is not available for a large proportion of the sample."(15)

There were two main options for addressing the risk of bias associated with analysing outcomes of MAR data: complete case analysis, or imputation. Given that adequate data were not available regarding relevant covariates, it was not possible to develop an appropriate multiple imputation model. Furthermore, it is acknowledged that "MI [multiple imputation] is not always better than CC [complete case analysis] for missing covariate problems."(16) Therefore, all baseline analyses were undertaken with available data unless otherwise specified, and exploratory outcomes analyses were undertaken only with complete cases (n = 88). The sample size for the number of cases involved in each analysis is reported in conjunction with the analysis (denoted by NA = x).

8.3.7 Ethics

Ethical approval was obtained prior to commencement of the trial through the National Research Ethics Service North West – Liverpool East, under reference number 13/NW/0162.

8.4 Results

8.4.1 Recruitment and retention

Analyses in this chapter are based on the data available on 1 April 2014. Between July 2013 and January 2014, 200 patients with asthma were contacted by their general practitioners and invited to take part, of which 150 were initially recruited. Two

participants did not complete any baseline measures and were therefore not randomized, leaving 148 participants randomized to view either the intervention or control websites.

Figure 8.1 summarizes the numbers of patients recruited and followed up. There were no adverse events reported in either group. 59.5% (88/148) participants completed all baseline and follow-up measures. The trial statistician, who will remain blinded to all treatment allocations, will perform the final analysis on the full asthma dataset of 148 participants, since the analyses reported in this chapter represent a subset of the total analyses being performed on the data for the EXPERT trial.

8.4.2 Baseline characteristics and health literacy

148 participants were randomized and included in the final analyses. 85 (57.4%) had 'no health literacy difficulties', while 63 (42.6%) had 'some health literacy difficulties' (Table 8.1). There was no missing health literacy data. The groups were broadly comparable with respect to gender, age, ethnicity (Table 8.1), and educational attainment (Table 8.2).

A logistic regression model was fit to the data, assessing the strength of all baseline variables as predictors for health literacy difficulties. Health literacy level was not strongly predicted by gender ($p = .611$), educational attainment ($p = .747$), or ethnicity ($p = .932$), but was related to age (older age associated with higher health literacy; $p = .01$) (overall model characteristics: Chi-square = 20.6, $p = .08$, total $R^2 = .175$).

Figure 8.1 Participant flow diagram

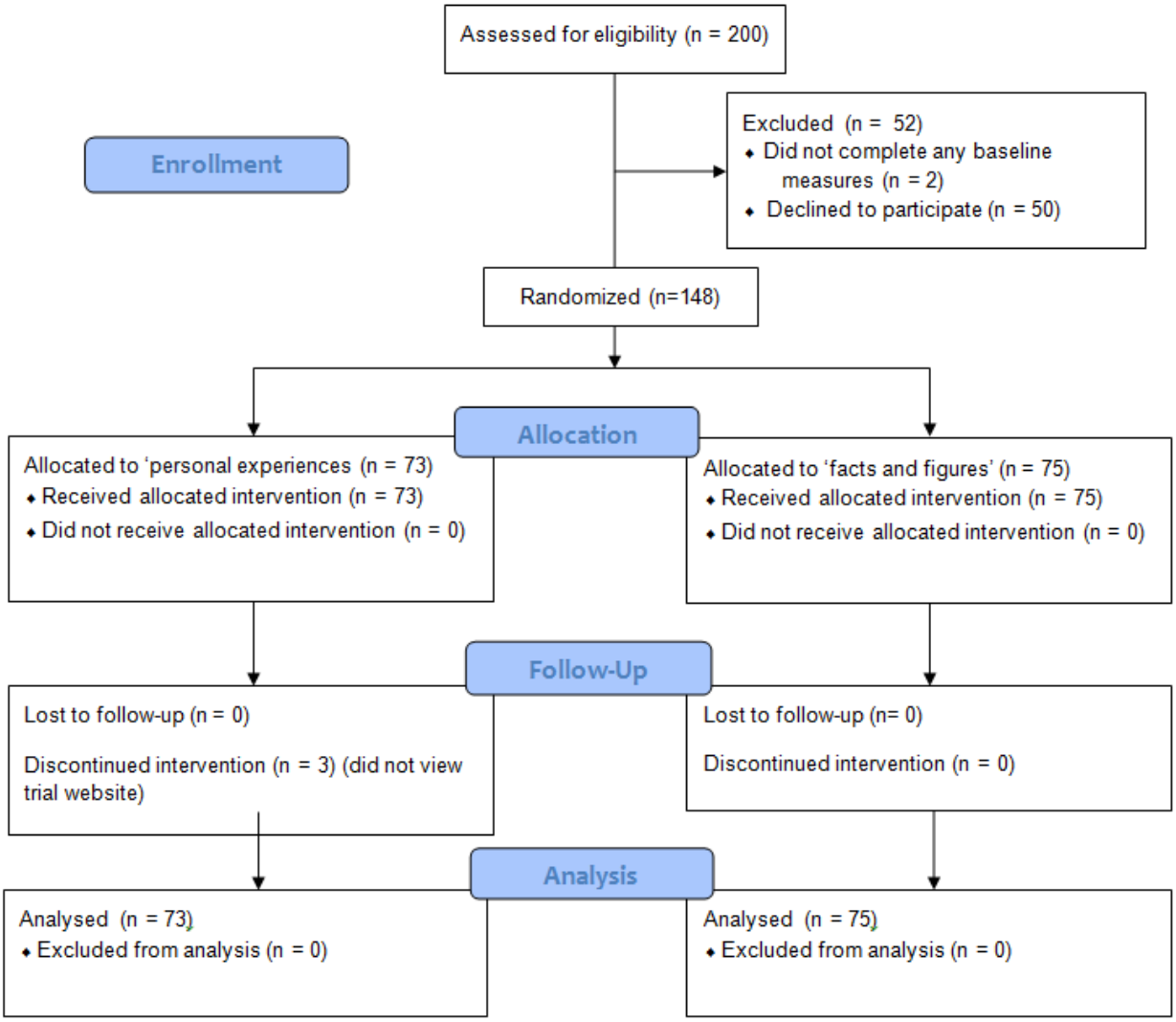


Table 8.1 Baseline characteristics by health literacy level

	Overall n (%) or (SD)	**No HL difficulties n (%) or (SD)**	**Some HL difficulties n (%) or (SD)**
Gender			
M	61 (41.2)	32 (21.6)	29 (19.6)
F	87 (58.8)	53 (35.8)	34 (23.0)
Age	57 (12.9)	59 (11.0)	55 (14.9)
Ethnicity			
White - English / Welsh / Scottish / Northern Irish / British	132 (89.2)	78 (52.7)	54 (36.5)
White - Any other White background	5 (3.4)	2 (1.4)	3 (2.0)
Mixed - White and Black African	1 (0.7)	1 (0.7)	0
Asian - Indian	3 (2.0)	1 (0.7)	2 (1.4)
Black - African	1 (0.7)	0	1 (0.7)
Black - Caribbean	1 (0.7)	0	1 (0.7)
NA	5 (3.4)	3 (2.0)	2 (1.4)
Total	148	85	63

Note: the denominator for the % reported in this table is the total study population (n=148)

Table 8.2 Educational attainment

Educational Attainment		Overall n (%)	No HL difficulties n (%)	Some HL difficulties n (%)
Do you have any educational qualifications for which you received a certificate?	Yes	135 (91.2)	79 (53.4)	56 (37.8)
	No	13 (8.8)	6 (4.1)	7 (4.7)
(If 'no' above) Do you have any professional, vocational or other work-related qualifications for which you received a certificate?	Yes	5(3.4)	3 (2.0)	2 (1.4)
	No	8 (5.4)	3 (2.0)	5 (3.4)
Was your highest qualification?	At degree level or above	63 (42.6)	42 (28.4)	21 (14.2)
	Another kind of qualification?	77 (52.0)	40 (27.0)	37 (25.0)
	NA	8 (5.4)	3(2.0)	5 (3.4)
Total		148	85	63

Note: the denominator for the % reported in this table is the total study population (n=148)

8.4.3 Usage

Three usage variables were measured: total number of logins, total website usage duration (in minutes), and total number of webpages visited. Overall, the median number of logins was 2, the median duration of usage was 16 minutes, and the median number of webpages visited was 14. There were no statistically significant differences within health literacy groups with respect to usage of the facts or personal experiences websites (Table 8.3), nor between health literacy groups.

Table 8.3 Website usage

Usage	**No HL difficulties (n=85)**			**Some HL difficulties (n=63)**		
	Facts and figures median (IQR)	*Patient experience median (IQR)*	*Significance*	*Facts and figures median (IQR)*	*Patient experience median (IQR)*	*Significance*
Total number of logins to study site	2 (1 - 3)	2 (2 - 3)	p = .87	2 (1 - 3)	3 (2 - 4)	p = .62
Total website usage duration (mins)	16 (5.00 - 34.00)	16 (4.00 - 45.25)	p = .90	21 (8.75 - 41.50)	14 (3.50 - 40.50)	p = .45
Total number of webpages visited	12 (5 - 26.5)	12 (3 - 25.5)	p = .45	15 (7.25 - 25.5)	14 (6.5 - 27)	p = .47

8.4.4 Health literacy and self-reported health outcomes

Three health status questionnaires were analysed: the Asthma Control Test (ACT), Chronic Disease Self-Efficacy Questionnaire (CDSEQ), and the Partners in Health scale (PIH). There were no differences in baseline asthma control between those with some and no health literacy difficulties (p = .11) (Table 8.4). However, there were differences at baseline on both PIH (unadjusted mean difference = 0.60, p <.001) and CDSEQ (unadjusted mean difference 0.93, p = .001) between health literacy groups at baseline. Although there are no established criteria for clinical significance on the PIH, it is doubtful that a difference of 0.60 constitutes a clinically important difference. The difference between groups on the CDSEQ is however considered clinically significant, although the

magnitude of this difference (as well as that between groups on the PIH) may not be significant if multiple comparisons correction had been undertaken.(17)

There were no significant differences between baseline and 2-week follow-up in PIH or CDSEQ scores within health literacy groups between intervention and control (Tables 8.5, 8.6).

There were no significant health literacy subgroup effects on PIH ($p = .404$, $F = .703$, sum of squares = 38.87, adjusted $R^2 = .556$), and CDSEQ ($p = .770$, $F = 0.086$, sum of squares = 2.161, adjusted $R^2 = .666$).

Table 8.4 Asthma Control Test scores

	Overall (n = 148) mean (SD)	**No HL difficulties (n=85) mean (SD)**	**Some HL difficulties (n=63) mean (SD)**	**Unadjusted mean difference, significance**
Baseline total score	20.49 (4.19)	20.96 (3.90)	19.84 (4.49)	1.12, p = .11

Table 8.5 Partners in Health scores

	No HL difficulties (n=85)		**Some HL difficulties (n=63)**	
	Facts and figures (n = 39)	*PEx (n = 46)*	*Facts and figures (n = 36)*	*PEx (n = 27)*
Baseline score[1]	7.17 (0.63) NA = 2	6.88 (0.80) NA = 1	6.43 (0.93) NA = 1	6.38 (0.96) NA = 0
2-week follow-up score[1]	7.32 (0.44) NA = 12	7.03 (0.76) NA = 8	6.64 (1.25) NA = 8	6.55 (0.96) NA = 4
Unadjusted change from baseline to 2-week follow-up[2]	0.15 (-0.01 – 0.31)	0.15 (-0.04 – 0.34)	0.21 (-0.09 – 0.51)	0.17 (-0.25 – 0.42)
Unadjusted within-group difference[3]	0.00 (-0.17 - 0.34) p = .51 NA = 20		-0.05 (-0.15 - 0.04) p = .59 NA = 12	

[1]Presented as mean (SD) with frequency of missing data (NA = x).

[2]Presented as mean difference (95% CI) with frequency of missing data (NA = x). Positive mean difference indicates an improvement in PIH score from baseline to 2-week follow-up.

[3]Presented as mean difference (95% CI), (p value) with frequency of missing data (NA = x). Positive mean difference indicates greater improvement in intervention group than in control group.

Table 8.6 Chronic Disease Self-Efficacy Questionnaire scores

	No HL difficulties (n=85)		**Some HL difficulties (n=63)**	
	Facts and figures (n = 39)	*PEx (n = 46)*	*Facts and figures (n = 39)*	*PEx (n = 46)*
Baseline score[1]	8.56 (1.22) NA= 1	8.66 (1.11) NA = 0	7.83 (1.79) NA = 2	7.50 (2.05) NA = 0
2-week follow-up score[1]	8.77 (1.21) NA = 10	8.70 (1.03) NA = 7	8.08 (1.73) NA = 8	7.52 (1.46) NA = 6
Unadjusted change from baseline to 2-week follow-up[2]	0.21 (-0.10 – 0.52) NA = 10	0.04 (-0.16 – 0.24) NA = 7	0.25 (-0.15 – 0.65) NA = 8	0.02 (-0.43 – 0.47) NA = 6
Unadjusted within-group difference[3]	-0.17 (-0.62 - 0.14) p = .22 NA = 17		-0.22 (-0.87 - 0.39) p = .46 NA = 14	

[1]Presented as mean (SD) with frequency of missing data (NA = x).

[2]Presented as mean difference (95% CI) with frequency of missing data (NA = x). Positive mean difference indicates an improvement in CDSEQ score from baseline to 2-week follow-up

[3]Presented as mean difference (95% CI), (p value) with frequency of missing data (NA = x). Positive mean difference indicates greater improvement in intervention group than in control group.

8.4.5 eHealth Impact Questionnaire

Almost all participants (n = 145, 98.0%) completed the eHIQ Part 1 (at baseline). Those with some HL difficulties scored higher (p = .03) than those with no difficulties on 'Scale 2'; that is, people in that group had more positive attitudes towards sharing experiences online. There were no differences on Scale 1, or on the overall score (Table 8.7).

118 participants (79.7%) completed the eHIQ Part 2 (at 2-week follow-up). Independent of website allocation, those with some HL difficulties scored higher on the 'confidence and identification' subscale (Scale 1) of Part 2. There were no differences on Scales 2-3, or on the overall score (Table 8.8). There were no differences within groups between those

allocated to different websites (not displayed). As with the differences between groups at baseline on PIH and CDSEQ scores, multiple comparisons correction was not undertaken for these analyses, and it should be noted that these differences might not have been significant if this had been done.

Table 8.7 eHealth Impact Questionnaire Part 1

	Overall mean (SD)	**No HL difficulties (n = 85) mean (SD)**	**Some HL difficulties (n = 63) mean (SD)**	**Unadjusted mean difference (95% CI), significance**
Scale 1 (*Attitudes towards online health information)*	59.70 (16.22)	59.24 (15.46)	60.32 (17.29)	1.08 (-4.36 – 6.52) p = .69
Scale 2 (*Attitudes towards sharing health experiences online)*	62.01 (17.94) NA = 3	59.29 (18.14) NA = 2	65.66 (17.13) NA = 1	6.37 (0.54 – 12.20) p = .03
Overall Part 1	61.11 (17.94) NA = 3	59.37 (18.14) NA = 2	63.43 (17.13) NA =1	4.06 (-0.75 – 8.87) p = .10

Table 8.8 eHealth Impact Questionnaire Part 2

	Overall mean (SD)	**No HL difficulties (n = 85) mean (SD)**	**Some HL difficulties (n = 63) mean (SD)**	**Unadjusted mean difference (95% CI), significance**
Scale 1 ***(Confidence and identification)***	59.25 (15.8) NA = 30	56.67 (15.4) NA = 18	62.64 (15.8) NA = 12	5.97 (-3.27 – 7.44) p = 0.04
Scale 2 ***(Information and presentation)***	75.31 (10.95) NA = 27	75.41 (10.7) NA = 16	75.18 (11.4) NA = 11	-0.23 (-4.26 – 3.81) p = 0.91
Scale 3 ***(Understanding and motivation)***	64.14 (14.4) NA = 27	63.24 (13.6) NA = 16	65.33 (15.6) NA = 11	2.09 (-3.27 – 7.44) p = 0.44
Overall Part 2	66.56 (11.8) NA = 30	65.39 (11.2) NA = 18	68.11 (12.6) NA = 12	2.72 (-1.70 – 7.15) p = 0.22

8.5 Discussion

8.5.1 Main findings

148 adults with asthma were recruited from general practices, and were randomized to view either a ‘facts and figures’ – based asthma education website, or a ‘personal experiences’- based website. 85 (57.4%) had ‘no health literacy difficulties’, while 63 (42.6%) had ‘some health literacy difficulties’. While there were no differences between the groups with respect to gender, age, ethnicity, or educational attainment, there were statistically significant differences on the PIH scale and the CDSEQ. The difference between groups at baseline on CDSEQ was clinically significant as well, although these differences, as well as those between groups on the eHIQ, might not have been significant if multiple comparisons correction had been undertaken. There were no differences within or between health literacy groups in website usage.

As demonstrated in Chapter 6, no high-quality evidence exists from randomized controlled trials supporting the assertion that website usage or outcomes of online interventions differ between those with varying health literacy. That finding is supported by this chapter; 'expected' patterns of usage (that is, people with health literacy difficulties would use the website less) were not seen. Furthermore, there were no subgroup (interaction) effects between health literacy score and website allocation. In their study of patients with type II diabetes in California, Sarkar *et al*. found that usage of an online patient portal varied by health literacy level (those with low health literacy used the online portal less), as did diabetes control.(6) Their study, due to its cohort design, could not assess the effect of the online resource on outcomes. Although the results of this chapter differ, they are perhaps not surprising; viewing a patient education website is a relatively low intensity/complexity behaviour when compared with accessing and entering one's own data into a patient portal. What is striking, however, is that usage was *no less* amongst those with some health literacy difficulties.

Furthermore, eHIQ scores provided some suggestion that attitudes towards health resources were different. Those with some difficulties had more positive attitudes towards sharing personal experiences online at baseline; they also had more positive attitudes regarding their own confidence in managing their health condition after viewing either website. The baseline finding is supported by a growing body of psychological literature suggesting that narrative information may be processed differently from factual information. The theory of 'transportation' suggests that narrative information facilitates identification with a story, thereby increasing its salience.(18) This may be one reason why people with health literacy difficulties have more positive attitudes towards narrative experience-based information, as reported in this chapter.

The trial websites were designed according to specific best practices developed by colleagues in Northumbria for developing health experience-based information on the internet, involving gating, engagement, and outcomes.(19) However, these websites were not specifically designed for people with low (or high) health literacy. Yet those with health literacy difficulties had generally equal attitudes towards viewing websites as those with no difficulties; again, this contradicts policy guidance that websites need to be tailored by health literacy level. This may suggest, more generally, that websites developed using current best design principles, containing multimedia components and options about how to view and engage with content, are suitable for participants regardless of health literacy level. (Recall from section 7.5.4.2 that Glasgow *et al.* suggested the reason why their intervention for people with type I and II diabetes was taken up equally by participants regardless of health literacy level was that it was designed to be generally accessible and engaging for everyone.) Taken together with the equivalent usage between groups, this supports the assertion that health literacy level may not be a critical factor in using or obtaining information from health websites.

8.5.2 Limitations

EXPERT was designed primarily to assess 'feasibility'; that is, in the main trial, the primary outcome measures were the number of people who completed baseline and follow-up measures and viewed the website. As a result, the trial was likely underpowered to detect differences in some of the outcomes presented here. To test this, a post-hoc power calculation was carried out for the Asthma Control Test [11] which suggested that a sample size of about 200 in each group would have been necessary to adequately detect

[11] The concept of a 'post-hoc' sample size or power calculation is a contested one. (20, 21) Since it is merely another way to represent the p-value, I have taken the approach that it can be useful in exploratory work, but I believe it would be inappropriate to do this on a non-significant value in an appropriately-powered trial.

differences between health literacy groups of the magnitude identified in this chapter. Although an attempt was made to blind participants, it is possible they recognized the study hypotheses and behaved differently as a result. I was not blinded during analysis; although this deviated from trial best practices, I do not believe it had a discernible effect on the results, as the outcomes were measured objectively, and there were no deviations from the original statistical analysis plan. The Chew *et al.* measure used in this chapter has not been properly validated in the UK setting. Although I made an attempt to ascertain its suitability by including it in cognitive interviews, it may not adequately capture health literacy amongst UK residents for some reason, impairing the external validity of the findings.

8.5.3 Strengths of this study compared to existing evidence

In contrast to studies included in the systematic review in Chapter 6, this trial was rigorously conducted and can be assessed at low risk of bias. Participant health literacy was measured using a validated index, and the prevalence of people reporting that they have health literacy difficulties in this study was greater than that reported in another UK-based observational study of health literacy (22), but similar to a survey of health literacy amongst older adults in the UK.(23) This suggests that the study population did not experience a ceiling effect on the measure, and that the population recruited for the trial had varied enough health literacy to make between-group comparisons valid. In addition, EXPERT was the first trial of a health website that measured people's actual, rather than self-reported usage, while comparing this by health literacy level.

8.6 Conclusions

This chapter reported results of the analysis of a feasibility trial comparing use and outcomes of two novel asthma self-management websites. There were no differences within or between groups with differing health literacy levels with respect to website usage. Exploratory analyses of outcomes related to disease self-management demonstrated no significant health literacy subgroup effects. Although some differences between groups in attitudes towards the use of health websites were identified, these are of uncertain clinical or practical significance. In general, these results question the assertion that health literacy is an important differentiating factor in either the use of health websites, or outcomes related to them. Further work should examine what outcomes may be amenable to modification from viewing health websites, and what specific components of these websites may be effective at improving outcomes.

8.7 References

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Chapter 9: Conclusion

> *So much for endings. Beginnings are always more fun. True connoisseurs, however, are known to favour the stretch in between, since it's the hardest to do anything with.*
>
> -Margaret Atwood (1)

9.1 Summary

In this chapter, I summarize the findings from each section as they relate to the research objectives set out in Chapter 1. Then, I discuss the limitations of the approach, and the impact of carrying out this programme of research through realist inquiry versus other possible approaches I could have selected. I set out implications of thesis findings for policy, research, and practice. Finally, I discuss what I believe should come next for research in this area, and provide some final thoughts.

9.1.1 Why did I start?

At the beginning of this programme of research, while the relationship between measured health literacy and outcomes was strong, there was a clear deficiency in what was known about the nature of this relationship. It was readily apparent that health literacy had been conceptualized differently by different authors. After determining that there were at least 20 disparate published definitions, I became interested in attempting to unpack this 'black box' connecting health literacy to health outcomes.

Substantial changes in how people access and use health information have occurred over the past two decades. This came first as a result of the widespread availability of the internet, and has more recently incorporated the rise of user-generated online health content, as well as 'curated' patients' experiences. Despite these changes, before this thesis

was conducted, the extent to which health literacy was still an appropriate or valid construct in today's modern information ecologies was not known. Online health resources represent an increasingly prominent part of UK healthcare at the policy and practice level, yet the evidence base for their development and implementation remains limited. Thus, exploring the role of health literacy in usage and outcomes of online information represented an interesting and important problem, and one that had been under-researched to date.

9.1.2 Have things changed since I started in 2011?

Despite the identification by Berkman *et al.* in 2010 that the lack of theoretical understanding about the relationship between health literacy and outcomes was leading to a "potentially unstable foundation" (2), little progress has been made in this area. Policy documents continue to be published asserting the importance of tailoring information by health literacy level (3, 4), without the corresponding development of an evidence base to support these assertions. New health literacy measures continue to be published, with scant attention paid to the tacit assumptions made in their development or validation. In order to quantify this, I re-ran the search from Chapter 5 on 8 April 2014, and determined that at least 40 new measures (in several languages) had been developed since the original search was conducted in September 2012.

Rather than include all these new measures in Chapter 5, I briefly reviewed them to determine if anything notable had been discerned that might relate to the research questions underpinning this thesis. One notable exception to the undiscerning development of health literacy measures is the Health Literacy Questionnaire (HLQ), developed by Osborne *et al.* in 2013.(5) This measure includes nine "conceptually distinct areas of

health literacy." It represents the most comprehensive attempt to develop a measure that encompasses all the domains included in health literacy; three of these domains ('ability to engage with healthcare practitioners', 'navigating the healthcare system', and 'having sufficient information to manage my health') are closely related to the findings of Chapters 5 and 6 from both 'tacit models' and key informant perspectives ('confidence', 'navigation', and 'communication from the health system to patients'). That the domains identified in this thesis relating health literacy to outcomes match closely with domains identified in developing the HLQ provides some degree of external validity to the findings of this thesis.

9.1.3 Principal findings

There were four primary research questions set out at the conclusion of the literature review. In this section I briefly review the specific findings relating to each question and how they inform understanding about the role of health literacy in online health information (Table 9.1).

Table 9.1 Principal findings by initial research questions

Research questions (from section 3.7)	Main findings	Implications for the relationship between health literacy and outcomes
Who engages with user-generated online health content most frequently in the UK, and how do characteristics of these people compare with known sociodemographic characteristics of people who have 'high health literacy?	• Approximately 25% of UK Internet users access UGC at least monthly. • Those who do so most frequently – superusers – are younger and have equivalent self-reported health status and health service use to those who access these resources less frequently or not at all. • These highest users of UGC have different characteristics than those 'traditionally' thought of as high health information users.	The rise of UGC is exposing younger, healthy people to health information. This may provide an opportunity to reach previously disengaged people with preventive information, independent of their health literacy status. In particular, UGC is accessed more frequently by carers; these people may prefer or benefit more from this type of resource for reasons not yet understood.
What can be determined from health literacy measurement about the relationship between this construct and outcomes?	• 58 existing health literacy measures were found, with variable conceptualizations of health literacy and variable validity. • Three tacit models of health literacy were identified: (1) 'appropriate' health decisions; (2) obtaining health services; (3) confidence.	These tacit models represent possible pathways between health literacy and outcomes; investigated further during interviews (see below).
What are UK stakeholders' views about the relationship between health literacy and outcomes related to online resources (as developed in the first two studies), and what are the possible policy implications of these findings?	• Attending to personal values and beliefs – and having information available that is suitable for varied perspectives on health decisions – was considered generally more useful than 'health literacy'. • Communication from the NHS to patients was characterized as	The concept of 'appropriate' health decisions was strongly criticized, while shared decision-making was emphasized as the key driver of improved outcomes. It was suggested that 'true' confidence could improve clinical encounters, whereas practitioner misperceptions could impair quality of care provided.

	generally inadequate, with little reference made to the availability of online resources.	Obtaining services was reconceptualised as 'navigation', support of which was suggested to be an essential role of health system communication to patients.
Is higher health literacy associated with greater use of and attitudes towards online resources, and is it related to better outcomes as a result of accessing these resources?	• No high quality evidence exists supporting differential effectiveness of online resources between health literacy levels in patient data entry, screening uptake, or hospital discharge. • There were no differences in usage or self-management outcomes between health literacy subgroups when people with asthma were randomized to view either a 'facts and figures' education website, or a 'personal experiences' website.	Available evidence does not support the existence of a quantitative relationship between health literacy level and usage of online information, or outcomes related to its use.

9.2 Reflecting on the methodological approach

9.2.1 Was realist inquiry the most appropriate approach?

I first learned about 'realist inquiry' in the early stages of designing this thesis and came to the conclusion it offered a promising opportunity to explore this inquiry from a novel perspective. Despite several attempts over the past 15 years (6-11) to identify the relationship between health literacy and outcomes, none have been able to validate proposed pathways. It has been argued that this lack of theoretical understanding has contributed to an "unsteady foundation" (2) in health literacy research. Investigating the pathways between context (health literacy), mechanism (how they exert their effects), and outcomes (such as self-efficacy, morbidity, and mortality) therefore promised to move

beyond existing conceptualizations. A realist-informed research programme had never before been conducted on health literacy. I drew on methodological literature in realist inquiry (12-14) as well as general literature on complex intervention evaluation (15, 16) and systematic reviews of interventions to mitigate the effects of low health literacy (17-19) to design this thesis. Reflecting on the overall approach, I still believe it was the most appropriate way to 'unpack' health literacy.

The decision to inform data collection and analysis through realist inquiry meant that the findings from successive chapters were combined using the principle of 'generative causation', which means that findings from earlier studies informed data collection and analysis in later ones. This contrasts with a thesis designed according to a positivist framework, in which each chapter may have tested one sub-component of a larger hypothesis, which would then be supported or falsified at the end. I did not know what I was going to find when I started; the process of developing the literature review (Chapter 3) identified an overall gap in the literature (best described "the role of health literacy in outcomes and usage related to online information"), but which did not set out a particular hypothesis. Successive chapters then progressively addressed context, mechanism, and outcome.

If I had designed this thesis according to a 'conventional' mixed-methods approach (for example, by strictly following the MRC guidance on evaluation of complex interventions) (15), I might have started with a systematic review of existing interventions to improve the health of people with low health literacy, then moved on to the development and evaluation of a novel intervention specifically designed for this population. I decided not to pursue this approach for the following main reasons:

1. It became apparent early on while developing the literature review that there is an extensive, two-decade body of research developing (largely ineffective and un-scalable) interventions for this outcome.
2. Existing conceptualizations of health literacy were highly varied, and almost entirely neglected to take into account the existence of online health information and how its use might be different from that of offline information or standard pamphlets.

Taken together, these two main issues strongly suggested that developing *yet another* intervention would be superfluous, and that what was required instead was an enhanced theoretical and practical understanding of conceptualizations of health literacy, and how these relate to online information.

9.2.2 Main limitations of the overall approach

The primary limitation of the realist approach is that it sacrifices experimental control in favour of generating a more contextualized understanding of how interventions exert effects. If this thesis had been designed around the development and evaluation of a website for people with low health literacy, for example, it would have been possible to directly follow the development of each component of the intervention, and to control for variables that may confound the relationship between health literacy and outcomes.

More generally, a limitation of the particular data sources I chose is that two of them – the survey analysed in Chapter 4, and the RCT of asthma information websites in Chapter 8 – were originally designed for different purposes. While it is increasingly recognized that secondary analysis of available data can be an efficient, valuable source of research (20), it raises the concern that these data may not have been 'fit for purpose'. Certainly, there are

aspects regarding the use of UGC (Chapter 4), such as its use to obtain social support and to select health services based on others' experiences (21), which were not included in the original survey and would have been relevant to this thesis.

Furthermore, the trial in Chapter 8 was not originally designed to evaluate the role of health literacy as it relates to usage and outcomes. Whereas Chapter 4 would clearly be strengthened by the inclusion of these domains, I believe the fact that the websites were originally designed for a different purpose can be seen as a benefit. The emphasis in this thesis has been on developing 'real-world' understanding of conceptualizations of health literacy and of online information; if the websites had been designed specifically to be appropriate for people with different literacy levels, they would be less representative of what is currently available. Since the websites were designed according to current best practices, including recent work on how people engage with personal experiences information (22, 23), this means that these websites represented the latest evidence on design and implementation. Therefore, the conclusion that health literacy level was not related to usage or outcomes suggests that if these 'best practices' continue to be followed and refined, health literacy will likely continue to be less relevant than personal preferences, as has been concluded. Still, the results may have been different if the websites had been developed specifically for the purpose of assessing usage between populations with different health literacy levels.

9.3 Participants, perspective, and possible implications

There were three main groups of participants included in this study: UK internet users (Chapter 4); policymakers, researchers, and clinicians with a special interest in health literacy and online information (Chapter 6); and asthma patients in primary care (Chapter

8). Since the purpose of Chapter 4 was to investigate internet use behaviour, that offline participants were excluded is not a limitation; however, it should be acknowledged that the population of internet users who is interested and willing to spend 20 minutes filling out a survey about health information may be different in some unmeasured way from 'general' internet users. Thus, the findings of that study in isolation should be considered somewhat limited in their external validity.

One concern is that the 'key informants' recruited for interviews in Chapter 6 may not have had adequate knowledge of health literacy and therefore may have answered questions about the construct without appropriate background information. Most of the participants had published or written about health literacy (whether in academic or grey literature), but several respondents had never done so, and were identified by being recommended for the study by other participants. This is both a strength and limitation; although the concern about insufficient background knowledge is valid, it is also the case that these participants may have been more able to challenge dominant orthodoxy about what health literacy *is*, or the extent to which it is a *useful* construct. Researchers focused on the health literacy field would have had a vested interest in maintaining its prominence (and measurement); if the sample had been dominated by health literacy experts, it would not have been a sufficiently diverse sample.

The aim of Chapter 6 was to obtain a varied sample of stakeholder views; if anything, another criticism is that additional relevant participants may have been excluded, such as practitioners working in A & E, or in secondary care. This is particularly relevant given the emphasis placed on health system navigation as a key issue related to health literacy. All the clinicians interviewed were general practitioners, who may have different perspectives on navigation than those working in hospital or emergency settings (whether allied health professionals or physicians).

Patients were not interviewed in this thesis. This was done for two main reasons: 1) practitioners' subjective views on health literacy conceptualizations have not been explored before, while patients' perspectives have; and 2) patient data featured prominently in other chapters. The patient perspective on health literacy was addressed by Jordan *et al*. (24), who interviewed 48 patients in Australia. Two of the 'key abilities' they identified - 1) 'knowing where and when to seek health information' and 2) 'assertiveness'- relate to key themes from this thesis such as 'communication from the health system to patients' and 'confidence'. However, their primary conclusion – that "more comprehensive measures to assess patient's [sic] health literacy are needed" – was not supported by the findings of Chapter 5.

The participants in Chapter 8 were asthma patients identified and recruited into the study by their GPs. This procedure had two main sources of bias: 1) GPs may have attempted to recruit patients they perceived to already be more engaged with online health information than other patients; 2) those who agreed to be enrolled may have been more (or less) satisfied than others with the care currently provided. Randomized participants may have differed from those who were not approached or those who declined to take part on some fundamental unmeasured characteristic. They may have been patients who had a longer and more satisfactory relationship with their GP, or who trusted that their GP would provide high quality resources, thereby excluding participants who are critical of their practitioner and who may use the internet for different reasons, such as to question information they were provided. There were no items included in the baseline or follow-up questionnaire addressing these issues, which would have been helpful to determine what people's motivations were for accessing these resources. Despite being instructed to view the website *ad libitum*, since patients were only told that the study was about designing better health information (thereby preserving blinding), it is possible they went through all

the pages in each website more closely than they would have normally. As long as the distribution of participants who took this approach to viewing study websites was equal between randomized groups, it should not affect comparisons between intervention and control websites. This might explain some of the usage findings: perhaps patients with some health literacy difficulties were more likely to adopt this strategy, artificially raising their usage to match that of those with no health literacy difficulties. Since participants were not asked about their baseline internet use *for health* (they were only asked how often they go online), it is not possible to discern whether use of study websites differed from baseline use of health websites.

9.4 Implications for policy and practice

9.4.1 Implications for policy

One of the primary findings of this thesis is that 'health literacy', as it is currently measured and operationalized, does not predict usage or outcomes related to online information. Therefore, a primary policy implication is that the focus on 'health literacy', as exemplified in many documents including the NHS England 'Transforming Participation' framework (25) and the Department of Health 'Power of Information' strategy (26), should shift towards the development and implementation of a variety of different online resources, for various personal preferences. Rather than attempting to 'improve health literacy' – since it has been shown in this thesis that there is no available evidence that this is possible – supporting the development of digital access and skills may be more useful for patients and the general public. Interview respondents suggested that the NHS (and other organizations that develop and disseminate health information) should 'compete' with existing online resources, and take advantage of the rising popularity of

user-generated content to provide health information to new populations, such as younger people interested in obtaining lifestyle and preventive advice. In particular, it was identified that the NHS has many points of contact with patients, from information websites (such as NHS Choices) (27), to outpatient letters. One interview participant (a senior policymaker who had access to this data) estimated the NHS sends out 1.5 billion letters each year, very few of which provide any guidance regarding online health resources. Given the finding that personal preferences may be a better predictor of whether people use and are satisfied with online resources, it is suggested that one option would be to include in these letters the uniform resource locator (URL) for a few relevant evidence-based online resources. These could take the form of 'information prescriptions' (as described in Chapter 3) relevant to specific conditions (28, 29), or could be more general, referring to a site such as NHS Choices, from which people can search to find what they require.

This thesis suggests that making resources more widely available is likely to be more important than ensuring they are tailored or targeted to health literacy levels. It argues that tailoring should be focused on ensuring there is a mix of 'personal experiences' and 'facts and figures' information available, and that people have the opportunity to discuss it with a practitioner if required. The lack of time available in clinical practice is, however, often cited as a reason why more discussion of online information cannot be included in consultations, and may contribute to clinicians' unwillingness to engage when patients present information found on the internet.(30-32) Another potential implication related to this finding is that if access to online resources is to be prioritized, clinician remuneration and scheduling might need to be reformed with this function in mind. While this thesis has not addressed the use of email for communicating with patients, this has been suggested as

one option for dealing with routine matters for over a decade (33), although the evidence base remains underexplored.(34)

9.4.2 Implications for practice

Usage and outcomes related to online resources, as investigated in this thesis, do not differ by health literacy level; therefore it seems unlikely that screening or routine measurement would be beneficial. Instead, patients might routinely be asked whether they access online resources and, if so, should be offered an opportunity to discuss what they have found. Practitioners should engage with online resources and be able to provide recommendations of available evidence-based resources that are widely applicable across different patient preferences.

While it is increasingly considered a *fait accompli* that patients should gain (online) access to their medical records - an idea strongly endorsed by several participants in Chapter 6 - there is nevertheless some concern about possible harms. Recall from section 6.4.3.4 that a general practitioner working in a ‘deprived’ community noted the possibility for vulnerable patients, such as those experiencing abuse, to have their records accessed by an abusive partner. This concern has persisted for nearly a decade (35), demonstrating there is still much to be done to address these issues. This thesis does not offer guidance on the extent to which these privacy and security issues relate to health literacy, other than the practical suggestion that some people will engage strongly with online records, and some will always remain uninterested. It will therefore be incumbent upon practitioners to provide some degree of guidance, and to avoid taking a normative view of engagement with online records, to instead support patients whether they want to engage or not. How to best do this, however, is a question for further research. The same is true for preferred

online resources: some people will engage with ‘general facts’, while others will prefer ‘patients’ experiences’, and practitioners should provide similarly supportive guidance. How this is best incorporated into clinical practice has yet to be determined.

9.5 Recommendations for future research

It is unclear the extent to which additional health literacy measures are necessary other than those which already exist. Rather than measuring health literacy, it is suggested that resources should be developed based on the best available design principles to be suitable for everyone, regardless of health literacy level. Identifying which components of online interventions might be effective (which was attempted in Chapter 6 but with insufficient evidence to support any claims in that regard) would be particularly valuable, improving the extent to which these resources could be scalable.

There is a pressing need to ensure that resources are developed and implemented to be appropriate for all users, and that attention is paid to the information and design needs of those with low digital skills and access, as well as those for whom English is not their first language. This is in contrast, to some extent, to policymakers’ often fervent enthusiasm for the putatively transformative goals of large-scale eHealth interventions.(36) Therefore, there is a large unmet need for evaluating online resources prior to their adoption, which is a function best served by the research community. Results of this thesis suggest that in order to move forward, these goals might be better achieved by focusing more on the development and evaluation of flexible, multi-media and multi-level online interventions, rather than tailoring for health literacy level. As one interview participant said, if the right resources are developed and made available, people are often able to “find their own level”. In addition to health literacy measure development being of increasingly marginal

benefit, a potential conclusion of this work is to raise the question of whether health literacy has served its purpose in general. Now that it is well-established that there is a high prevalence of low health literacy across many countries[12] (37), this thesis argues the focus should switch to developing and evaluating online interventions in order to achieve better outcomes.

Therefore, this thesis has identified the following questions for further research:

- What are the effective components of online resources, and does the effectiveness of different online resources vary between people with different characteristics (such as particular health conditions, duration of experience with illness, or whether someone is a carer)?
- How does engagement with user-generated online health content affect outcomes (such as patient satisfaction as well as morbidity and mortality), and are there differences in these outcomes based on whether people access or share user-generated content?
- What are the most (cost-)effective interventions for enhancing digital access and skills amongst those interested in using online resources?
- What is the most effective way to incorporate direction to and discussion of online resources into clinical practice? In particular, do these interventions enhance patient engagement and shared decision-making?

[12] Recall from section 3.2.6.1 that prevalence estimates of different levels of health literacy vary widely, even in the same population, depending on which assessment measure is used.

9.6 Final thoughts

In the early 1990's, when the concept of 'health literacy' was first developed, health information (whether educational materials about conditions or treatments, or one's own health records) was mostly held by practitioners, and meted out when perceived necessary. Today, the internet has made it possible for people around the world to go online twenty-four hours a day, and to obtain a variety of health information on any condition. As McLuhan anticipated in 1964 (38), information is now one of the key commodities in Western societies.(39) This thesis suggests that it should be considered as such in the context of a health service.

One of the key arguments of this thesis is that health literacy is a less useful concept today because so much information is available; the democratization of health information through the internet has created innumerable opportunities for people to find what suits them. Clearly, not everyone has access to a computer, or to the internet, or the skills necessary to find what they are looking for; it is therefore incumbent upon governments (perhaps in conjunction with the voluntary or private sector) to prioritize digital access. Accessing online health information is now a nearly ubiquitous behaviour in the UK.(40) The idea that we can predict health website usage and outcomes by dichotomizing people into the health literate and health illiterate (or, for that matter, measuring degrees on a scale instead) has not been supported by the findings of this thesis.

Websites are not just the online equivalent of pamphlets. They comprise an almost limitless variety of personal preferences, values, and beliefs regarding one's own health, influenced by prior experience, ethnicity, religion, and a host of other features. It is an impossible task for health systems to develop the 'right' resources for everyone; some people will immediately engage with a certain health website, for example, and some will

have no interest. With online resources, the dilemma of trying to develop the 'right' resource is less acute, since different people can interact with the same online materials to different degrees, in ways that suit their personal information needs and preferences.

In developing new (online) resources, it is now important to question the relevance of the concept of health literacy as a guiding principle. As a general concept, health literacy has obvious value. It can be measured, and scores on measurement indices predict a variety of outcomes. However, the way people access and use health information today is radically different from the way it was when the concept was first developed two decades ago. This thesis has shown that health literacy may no longer be the right construct to guide intervention development and implementation for better health outcomes.

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Appendices

Appendix A: Chapter 3 – Literature review

- Appendix A.1: Characteristics of studies investigating the relationship between health literacy and outcomes[13]

[13] References for the studies included in this appendix are available in the reference section of Chapter 3 (section 3.8, page 70).

Appendix A.1: Characteristics of studies investigating the relationship between health literacy and outcomes

First author, year of publication	Study aim	Study design; description of study participants	Country in which study conducted	Health literacy measure used	Main findings	How did authors address bias and/or confounding?
Gazmararian, 1999	"To determine the prevalence of low functional health literacy among community-dwelling Medicare enrollees in a national managed care organization."	Prospective cohort; 3260 Medicare patients 65 years of age and older.	United States	Short Test of Functional Health Literacy in Adults (STOFHLA)	33.9% of English-speaking and 53.9% of Spanish- speaking respondents had 'inadequate' or 'marginal' health literacy. Study location, race/language, age, years of school completed, occupation, cognitive impairment associated with inadequate or marginal health literacy.	"To analyze data across study locations, we conducted weighted analyses using 'SUDAAN' software to adjust for differences at each location in number of eligible members, sample size, and response rate." Weighted analyses were similar to unweighted so only reported latter.
LeVine, 2004	To "address the question of whether literacy could be mediating the relationships of schooling to maternal health behavior in	Mixed-methods, cohort; 167 urban and rural mothers of school-aged children in Lalitpur District of the Kathmandu Valley of Nepal.	Nepal	Semi-structured interviews, reading test	27.6% of participants who claimed they could read, tested zero on a reading test administered several months later. Results suggests "that literacy is a pathway through	No specific measures were taken.

	populations undergoing demographic transition."				which the Nepalese women's schooling had affected their health behaviour, pointing to the likelihood that the effects of schooling on reproductive and health behavior suggested in prior surveys of the district were mediated through literacy skills."	
Estrada, 2004	To "examine literacy and numeracy skills among patients on warfarin and explored their association with anticoagulation control."	Prospective cohort; 143 patients on warfarin 50 years of age or greater attending an anticoagulant management clinic.	United States	Rapid Estimate of Adult Literacy in Medicine (REALM)	The INR variability was higher among patients at lower literacy levels (r = -0.22, P = 0.009). Similarly, the INR variability was higher among patients with lower numeracy skills (r = -0.24, P = 0.004). After adjusting for age in the exploratory analyses, the time in range was similar among patients at different literacy (P = 0.71) or numeracy levels (P = 0.35).	Linear regression adjusted for age.
Baker, 2004	To "determine whether inadequate functional health	Prospective cohort; 3260 new Medicare enrollees 65 years of	United States	STOFHLA	Participants with inadequate and marginal health literacy were	Multivariate logistic regression adjusted for age, gender,

	literacy adversely affects use of physician outpatient services."	age or older.			more likely to have an emergency department visit than participants with adequate health literacy (30.4%, 27.6%, and 21.8%, respectively; P = .01 and P < .001 for comparison to those with adequate health literacy, respectively… "After adjusting for the worse health status of participants with limited health literacy and the other covariates listed above, participants with marginal health literacy averaged 0.80 fewer visits (95% CI, −2.41 to 0.82), and those with inadequate health literacy averaged 0.59 fewer visits (95% CI, −1.91 to 0.72) than participants with adequate health literacy."	race/ethnicity, primary language (English or Spanish), income, years of school completed, health behaviours, body mass index, number of chronic diseases, self-reported physical and mental health, depression, study site, total months of enrolment. Income was imputed.
Hope, 2004	To study "the association of medication adherence,	Cohort study; 61 patients with CHF in 'usual care' arm of trial of pharmacy-based	United States	Measured ability to read medication	"Lower medication adherence ($p < 0.001$) and an inability to read standard prescription	"We then extended this analysis to multivariate log-linear regression,

	knowledge, and skills with emergency department (ED) visits by patients 50 years of age or older with congestive heart failure (CHF)."	intervention		labels (bespoke scale)	and auxiliary labels (p = 0.002) were associated with an increased number of cardiovascular-related ED visits. Knowledge of the prescribed dose was associated with CHF-specific ED visits (p < 0.001)."	including the predictors of primary interest, as well as important covariates as identified by the univariate analysis." Authors did not specify what these variables were.
Howard, 2005	To "examine the impact of low health literacy on medical care use and costs."	Prospective cohort; 3260 Medicare patients 65 years of age and older.	United States	STOFHLA	When compared to those with adequate health literacy, emergency room costs were significantly higher ($108; 95% CI: $62 to $154; P <0.0001) among those with inadequate health literacy, while differences in total ($1551; 95% CI: −$166 to $3267; P = 0.08) and inpatient ($1543; 95% CI: −$89 to $3175; P = 0.06) costs were marginally significant. Total costs were higher in the marginal health literacy group, but the difference was not	Logistic regression controlled for: age, sex, race/ethnicity, income, education, tobacco and alcohol consumption, and self-reported comorbid conditions.

					significant ($596; 95% CI: −$1437 to $2630; P = 0.57).	
Guerra, 2005	To "explore the association between functional health literacy and the knowledge, beliefs, attitudes, and behaviour about mammography and self-breast examination in a sample of Latinas attending community health clinics in Philadelphia."	Cross-sectional; 245 female Latina patients waiting to see primary care providers in Philadelphia clinic.	United States	STOFHLA	70% of population had 'inadequate' or 'marginal' functional health literacy. Functional health literacy was weakly associated with knowledge, and not associated with beliefs and attitudes about mammography. Functional health literacy was associated with having ever had a mammogram (OR 1.14, 95% CI = 1.02-1.27).	Logistic regression adjusted for education, age, acculturation (measured using the 'Short Acculturation Scale for Hispanics'), insurance status.
Paasche-Orlow, 2005	To examine "the relationship between inadequate health literacy and difficulties learning and retaining instructions about discharge medications and appropriate MDI [metered dose	Prospective cohort study; 73 adults hospitalized for severe asthma exacerbations at two inner-city hospitals.	United States	STOFHLA	"Before instruction, inadequate health literacy was associated with lower asthma medication knowledge (5.2/10 vs. 7.2/10, $p < 0.001$) and worse MDI technique (3.2/6 vs. 3.9/6, $p = 0.03$). However, inadequate health literacy was not associated with	"Results were similar in multivariable models adjusted for demographic characteristics and asthma severity indicators."

	inhaler] technique."				difficulty learning (p =0.33) or retaining (p =0.35) instructions about the discharge regimen."	
Sudore, 2006	To "determine the relationship between health literacy, demographic, and access to health care."	Prospective cohort; 2512 community-dwelling adults in Memphis, Tennessee and Pittsburgh, Pennsylvania.	United States	REALM	Mean age 75.6; 24% had limited health literacy. Associations between limited health literacy and being male, black, having low income and education, diabetes mellitus, depressive symptoms, fair/poor self-rated health (p <.02). Older people with a sixth-grade reading level or lower were twice as likely to have indicators of poor healthcare access (OR = 1.96, 95% CI = 1.34-2.88).	Logistic regression: demographic variables (age, sex, race, income, study site) were "included in model if they were associated with literacy in bivariate analyses." Stratified analyses also undertaken to determine proportion of people with lower health literacy within each demographic stratum.
Davis, 2006	To "examine patients' abilities to understand and demonstrate instructions found on container labels of common prescription	Cross-sectional; 395 English-speaking adults in 3 primary care clinics in Louisiana, Michigan, and Illinois.	United States	REALM	19.0% of patients had low health literacy; 28.6% had marginal health literacy. Low health literacy associated with older age, African-American race, less education.	Multivariate analyses were adjusted for: age, sex, race, education, number of medications currently taken daily.

	medications."				46.3% of participants were unable to read and correctly state 1 or more label instructions on 5 common prescriptions. Rates of misunderstanding were higher among patients with marginal and low literacy, yet 37.7% of patients with adequate literacy misunderstood at least 1 of the label instructions.	
Rothman, 2006	To "explore patient comprehension of food labels was examined, along with the relationship of comprehension to their underlying literacy and numeracy skills."	Cross-sectional; 200 primary care patients in Tennessee. 18-80 years of age.	United States	REALM; Nutrition Literacy Scale (NLS); Wide Range Achievement Test (WRAT-3)	While 75% of patients reported at least a high school education and 77% had 9th-grade literacy skills, only 37% had 9th-grade math skills. On average, patients answered 69% (standard deviation, 21%) of the food-label questions correctly. Higher comprehension of food labels was significantly correlated (all p values were less than 0.001) with higher income (rho=0.39),	Multiple linear regression was used to identify factors independently associated with NLS scores; age, gender, race/ethnicity, income, insurance status, presence of a chronic illness, education level, diet status, label-reading frequency.

					education (rho=0.49), literacy (rho=0.52), and numeracy (rho=0.67).	
Raehl, 2006	To identify screening tools to predict elderly patients' intended medication adherence that are suitable for primary-care settings and community pharmacies.	Cross-sectional; 57 people ≥ 65 years of age from "diverse socioeconomic backgrounds", recruited from retirement communities	United States	REALM, STOFHLA	"REALM word-recognition pronunciation test, along with age, number of OTC drugs, and 2 socioeconomic questions, predicted the intent of seniors to correctly take their own prescribed oral medications."	Multivariate regression, adjusted for age, gender, and "covariates with a p value less than 0.2" on the univariate analyses (not specified).
Baker, 2007	To determine "whether low health literacy levels independently predict overall and cause-specific mortality."	Prospective cohort; 3260 Medicare patients, 65 years of age and older. Interviewed in 1997, then main outcome measures (all- and specific-cause mortality) were followed through 2003.	United States	STOFHLA	"The crude mortality rates for participants with adequate (n = 2094), marginal (n = 366), and inadequate (n = 800) health literacy were 18.9%, 28.7%, and 39.4%, respectively (P < .001)… The hazard ratios for all-cause mortality were 1.52 (95% confidence interval, 1.26-1.83) and 1.13 (95% confidence interval, 0.90-1.41) for participants with inadequate and marginal	Linear and logistic regression: analyses adjusted for demographic characteristics, socioeconomic status, health behaviours, number of chronic medical conditions, self-reported physical and mental health. Annual income imputed on the basis of age, sex, race/ethnicity, past occupation, health status for 16.2% of

					health literacy, respectively, compared with participants with adequate health literacy. In contrast, years of school completed was only weakly associated with mortality in bivariate analyses and was not significant in multivariate models. Participants with inadequate health literacy had higher risk-adjusted rates of cardiovascular death but not of death due to cancer."	participants who refused to report income.
Wolf, 2007	To examine the "nature and cause of patients' misunderstanding common dosage instructions on prescription drug container labels."	Cross-sectional; in-person cognitive interviews with 395 primary care patients in Louisiana, Michigan, Illinois.	United States	REALM	19% of patients with low literacy, and 29% with marginal literacy. 46% of patients misunderstood one or more dosage instructions.	No specific measures were taken.
Yin, 2007	To assess whether low caregiver health literacy was associated with health outcomes.	Cross-sectional; 292 caregivers presenting to an urban pediatric emergency room	United States	TOFHLA	23.3% reported use of nonstandardized liquid dosing instruments; 67.7% were unaware of weight-based dosing.	Linear regression adjusted for: child age, health care experiences, and caregiver

					Inadequate/marginal overall health literacy was associated with lack of knowledge of weight-based dosing (adjusted odds ratio [AOR] 2.3; P = .03), whereas lower reading comprehension was associated with both lack of knowledge (AOR 2.0; P = .03) and reported use of nonstandardized instrument (AOR 2.4; P = .007).	acculturation and education.
DeWalt, 2007	"To determine whether parental literacy is related to emergency department visits, hospitalizations, and days of school missed for children with asthma."	Retrospective cohort; 150 children with a diagnosis of asthma between 3-12 years of age and their parents recruited from a university paediatric clinic.	United States	REALM	Children of parents with low literacy had greater incidence of emergency department visits (adjusted incidence rate ratio [IRR] 1.5; 95% CI 1.1, 2.1), hospitalizations (IRR 3.2; 1.4, 7.3), and days missed from school (IRR 2.5; 2.1, 3.0) even after adjusting for asthma-related knowledge, disease severity, medication use and other socio-	Analyses (reported as "incidence rate ratios") were carried out unadjusted as well as adjusted for selected covariates: child age, household income, parental race, parental asthma knowledge, parental tobacco use, asthma severity classification, controller medication use, site of care.

					demographic factors.	
Cho, 2008	To explore intermediate factors that may link health literacy to health status and usage of health services such as hospitalization and emergency care.	Cross-sectional; 489 Medicare patients who had at least one outpatient visit in one of two Chicago hospitals 65 years of age and older.	United States	STOFHLA	Path analyses indicated health literacy "tended to have direct rather than indirect effects on health outcomes" and no variable of interest (disease knowledge, health behaviour, preventive care, medication compliance, health status, health care utilization) was "found to be [sic] significant mediating factor"	Path analyses: reported that three sociodemographic variables (race/ethnicity, gender, educational attainment) were "included in the analysis as controls". None were found to be significantly associated with health literacy, so were excluded from final analyses.
Bennett, 2009	To assess "whether health literacy contributes, through mediation, to racial/ethnic and education-related disparities in self-rated health status and preventive health behaviors among older adults."	Prospective cohort; 2668 people 65 years of age and older from 2003 National Assessment of Adult Literacy.	United States	National Assessment of Adult Literacy health literacy scale (NAAL HL)	"The findings from this study provide evidence that one component of health literacy, namely, health-related print literacy, significantly mediates racial/ethnic (black vs white) disparities in self-rated health status and receiving an influenza vaccination, as well as contributes to the education-related disparities in self-rated	Multiple regression controlled for: age, household income, nativity (whether born in the U.S.), marriage status.

					health status and utilization of influenza vaccination, mammography, and dental care services."	
Kim, 2009	To "investigate the relationships of health literacy to chronic medical conditions and the functional health status among community-dwelling Korean older adults."	Cross-sectional; 103 community-dwelling Korean older adults.	South Korea	Korean Functional Health Literacy test	"Individuals with a low health literacy had significantly higher rates of arthritis and hypertension. After adjusting for age, education and income, older individuals with low health literacy had higher limitations in activity and lower subjective health. In a model adjusting for age and income only, older individuals with low health literacy were more likely to report lower levels of physical function and subjective health and higher levels of limitations in activity and pain."	No specific measures were taken.
Lee, 2009	To examine "whether social support interacts with health literacy	Cross-sectional; Medicare patients 65 years of age and older in Chicago, Illinois.	United States	STOFHLA	51% of subjects classified as having 'low' health literacy. "Low health literacy	Logistic regression: adjusted for age, gender, race, educational

	in affecting the health status of older adults."	Sample size not reported.			was significantly and negatively associated with self-reported general health and was not significantly associated with physical and mental health status. Social support was significantly and positively associated with all three health status measures."	attainment, marital status, income.
Waldrop-Valverde, 2009	To test the relation of health literacy (reading comprehension) and numeracy to one's ability to manage a "mock" HIV regimen and whether men and women differed in these abilities.	Cross-sectional; participants recruited from HIV care clinics in Florida, or Florida Department of Health pharmacies serving those enrolled in AIDS Drug Assistance programme.	United States	TOFHLA; Applied Problems subtest of the Woodcock-Johnson – III Tests of Achievement	"Women were less able than men to follow medication instructions and answer questions about the mock regimen. Numeracy mediated the relationship between gender and medication management."	Path analysis: adjusted for years since HIV diagnosis. Multiple regression: adjusted for years of education, time since HIV diagnosis, gender, health literacy, numeracy.
Murray, 2009	To determine "the factors associated with exacerbation of heart failure, using a cohort (n = 192) nested within a randomized trial at a university-	Prospective cohort study; 192 patients over 50 years of age with heart failure from the 'usual care' arm of a randomized controlled trial of medication	United States	STOFHLA ; non-validated prescription reading label test	"In multivariable analysis, prescription label reading skills were associated with a lower incidence of heart failure–specific emergency care (incidence rate ratio,	No specific measures were taken.

	affiliated ambulatory practice."	management intervention.			0.76; 95% confidence interval (CI), 0.19–0.69), and participants with adequate health literacy had a lower risk of hospitalization for heart failure (incidence rate ratio, 0.34; 95% CI, 0.15–0.76)."	
Yin, 2010	To "assess parents' liquid medication administration errors by dosing instrument type and to examine the degree to which parents' health literacy influences dosing accuracy."	Cross sectional; 302 parents of children presenting for care at a public paediatric hospital.	United States	Newest Vital Sign (NVS)	"In adjusted analyses, cups were associated with increased odds of making a dosing error (>20% deviation) compared with the oral syringe (cup with printed markings: adjusted odds ratio [AOR] = 26.7; 95% confidence interval [CI], 16.8-42.4; cup with etched markings: AOR = 11.0; 95% CI, 7.2-16.8). Limited health literacy was associated with making a dosing error (AOR = 1.7; 95% CI, 1.1-2.8)."	Multiple regression; repeated measures analyses. Adjusted based on "a priori inclusion of potential confounders."
Murphy, 2010	To investigate "HIV positive adolescents' health	Cross-sectional; "Adolescents in this study were	United States	STOFHLA plus 4 items from the	"Among adolescents health literacy was not significantly associated	Regression modelling: testing health literacy as a

	literacy and whether factors associated with health literacy in HIV-positive adults are associated with health literacy among HIV-positive adolescents."	behaviorally and perinatally HIV-infected youth (N = 186) from five U.S. cities. Participants had a mean age of 20.5, and 49.5% were male."		Numeracy section of the original TOFHLA	with: medication adherence adjusting for age and education level; viral load; or self-efficacy to adhere to medication regimens. The only significant association was of health literacy with medical care received."	predictor of adherence, adjusting for age and education level.
Pagan, 2012	To "analyse the role of functional health literacy on mammography screening behaviour and adherence of Hispanic women."	Cross-sectional; 722 Mexican American women 40 years of age and older.	United States	STOFHLA	51% of respondents had inadequate or 'marginally functional' functional health literacy. Women with adequate health literacy were more likely to report having had a mammogram (OR = 2.92, 95% CI = 1.62-5.28), to have had a mammogram within the last 2 years (OR = 1.70; 95% CI = 1.14–2.53) or to have had one within the last year (OR = 2.30; 95% CI = 1.54–3.43), compared to women with inadequate or marginally adequate	"All the other demographic and socioeconomic variables included in the models" (not specified).

					functional health literacy levels.	

Appendix B: Chapter 4 – Survey of UK Internet users

- Appendix B.1: Questions from the "Citizens and Information Communication Technology for Health" survey included in analysis

Appendix B.1: Questions from the "Citizens and Information Communication Technology for Health" survey included in analysis

The full survey, including those questions excluded from Chapter 4 analyses, is available at http://ftp.jrc.es/EURdoc/JRC71142.pdf.

Overall instructions:

We are currently conducting an International research study on behalf of the Institute for Prospective Technological Studies (IPTS), one of the seven scientific institutes of the European Commission's Joint Research Centre (JRC). The objective of the study is to analyze the use of Information and Communication Technologies (ICT), specially the Internet, for healthcare purposes. In this regard, we would like to ask for 20 minutes of your time to complete this survey. We would very much appreciate your opinion.

Please rest assured the survey is anonymous and the data gathered strictly confidential.

Survey questions:

Block A: Health status and health care and social care services use

A1. How many times did you visit a doctor during the last 12 months? (include hospitalisation or visits to the outpatient department; do not include visits to the dentist)

***Number:*_____** A1

A4. How is your health in general?

	A4
Very good	5
Good	4
Neither good or bad	3

Bad	2
Very bad	1

A5. Do you have any long-standing illness or health problem?

	A5
Yes	1
No	2
Don’t Know	99

A6. Are you undergoing a long-term medical treatment?

	A6
Yes	1
No	2
Don’t Know	99

A7. Over the past 6 months, to what extent, if at all, have you been limited in activities people normally do, because of a health problem. Would you say you have been…?

	A7
Severely limited	1
Somewhat limited	2
Not limited at all	3

A9. Is someone close to you, currently experiencing long-term illness or disability?

	A9
Yes	1
No	2
Don’t know	99

If A9 = 1 -> A10

If A9 =2 or A9 =99 -> A11

A10. Are you taking care of such a person?

	A10
Yes	1
No	2

Block C: Internet and Information and Communication Technologies

C1. Could you tell me if…?

	Every day or almost every day	At least once a week (but not every day)	At least once a month (but not every week)	Less than once a month	Never	
You use the Internet in your home	5	4	3	2	1	C1_1
You use the Internet at your	5	4	3	2	1	C1_2

place of work						
You use the Internet somewhere else (school, university, cyber-café, etc.)	5	4	3	2	1	C1_3

C2. Which of the following Internet related activities have you already carried out?

	Every day or almost every day	At least once a week (but not every day)	At least once a month (but not every week)	Less than once a month	Never	
Use a search engine to find information	5	4	3	2	1	C2_1
Send e-mails with attached files (documents, pictures, etc.)	5	4	3	2	1	C2_2
Post messages to chatrooms, newsgroups or an online discussion forum	5	4	3	2	1	C2_3
Use the Internet to make telephone calls	5	4	3	2	1	C2_4
Use peer-to-peer file sharing for exchanging movies, music, etc	5	4	3	2	1	C2_5
Create a web page	5	4	3	2	1	C2_6
Use websites to share pictures, videos, movies, etc.	5	4	3	2	1	C2_7
Use a social networking site	5	4	3	2	1	C2_8
Purchase goods or services online / online shopping (e.g. travel & holiday, clothes, books, tickets, films, music, software, food)	5	4	3	2	1	C2_9
Keep a blog (also known as web-log)	5	4	3	2	1	C2_10
Instant messaging, chat websites	5	4	3	2	1	C2_11

Do home banking	5	4	3	2	1	C2_12
Use online software	5	4	3	2	1	C2_13
Use the Internet through your mobile phone	5	4	3	2	1	C2_14
Online gaming and/or playing games console	5	4	3	2	1	C2_15

Block D: Health related use of Information and Communication Technologies, and the Internet

D1a. Regarding health, wellness and the Internet, how often have you….?

	Every day or almost every day	At least once a week (but not every day)	At least once a month (but not every week)	Less than once a month	Never	I was not aware of it	
participated in an online support group for people who are concerned about the same health or medical issue	5	4	3	2	1	9	D1a_4
participated in Social Networking Sites talking about health and wellness	5	4	3	2	1	9	D1a_5
described a medical condition or problem online in order to get advice from other online users (peers)	5	4	3	2	1	9	D1a_9
disclosed medical information on Social Networking Sites	5	4	3	2	1	9	D1a_13

For each reply where D1a_x=1 or 9 do the same for D1b_x

If D1a_1 = 1 and D1a_2= 1 -> D10

If D1a_1 = (2 to 5) or D1a_2 = (2 to 5) ->D2

Block E: Socio demographic profile of participants

E1. Gender

	E1
Male	1
Female	2

E2. How old are you?

*Age:*_____ E2

E5. What is your highest level of education completed?

	E5
Primary or lower secondary education [ISCED 0,1 or 2]	1
Upper secondary education [ISCED 3 or 4]	2
Tertiary education [ISCED 5 or 6]	3

E6. Which of these descriptions best describes your situation or applies to what you have been doing for the last month?

	E6
Employed or self-employed (incl. family workers)	1
Unemployed	2
Student (not in the labour force)	3
Other not in the labour force (retired, inactive, in compulsory military service, etc.)	4

If E6= 1 -> E7

If E6 = (2 to 4) -> E8

E9. Type of locality:

	E9
Densely-populated area (Cities and Large towns)	1
Intermediate area (Towns)	2
Thinly-populated area (Villages and Rural)	3

E10. Number of members in the household?

Number:_____ E10

E11. Of which, number of children under 16 years?

Number:_____ E11

E12. Of which, number of members over 65 years?

Number:_____ E12

Appendix C: Chapter 5 – Health literacy measurement review

- Appendix C.1: Health literacy indices identified in the included studies (in ascending order by year of publication)[14]
- Appendix C.2: Search strategy

[14] References for the studies included in this appendix are available in the reference section of Chapter 5 (section 5.9, page 122).

Appendix C.1: Health literacy indices identified in the included studies

First author, year	Name of measure	Original or derivative measure?	Country	Time required to administer: minutes (standard deviation)	Validity (Face, Content, Construct)	What type of measure is it? (General; Condition or specialty specific)
Mohammed, 1964	No name	Original	United States	18.2 (5.9)	Face, Content	General
Davis, 1991	Rapid Estimate of Adult Literacy in Medicine (REALM)	Original	United States	Not reported	Face, Content	General
Davis, 1993	Rapid Estimate of Adult Literacy in Medicine (REALM)	Derivative (REALM, 1991)	United States	Not reported	Face, Content	General

Parker, 1995	Test of Functional Health Literacy in Adults (TOFHLA)	Original	United States	22	Face, Content, Construct	General
Hanson-Divers, 1997	Medical Achievement Reading Test (MART)	Original	United States	Not reported	Face, Content	General
TenHave, 1997	Cardiovascular Dietary Education System (CARDES)	Original	United States	5	Face	Condition or specialty-specific
Baker, 1999	Short-Test of Functional Health Literacy in Adults (S-TOFHLA)	Derivative (TOFHLA)	United States	12	Face, Content, Construct	General
Nath, 2001	Literacy Assessment for Diabetes (LAD)	Original	United States	10	Face, Content, Construct	Condition or specialty-specific
Bass, 2003	Rapid Estimate of Adult Literacy in Medicine, Revised (REALM-R)	Derivative (REALM)	United States	< 2	Face, Content, Construct	General

Chew, 2004	3 questions	Original	United States	Not reported	Face, Content, Construct	General
Weiss, 2005	Newest Vital Sign (NVS)	Original	United States	3	Face, Content, Construct	General
Agre, 2007	Stieglitz Informal Reading Assessment of Cancer Text (SIRACT)	Original	United States	10 - 20	Face, Content	Condition or specialty-specific
Davis, 2006	Rapid Estimate of Adult Literacy in Medicine-Teen (REALM-Teen)	Derivative (REALM)	United States	3	Face, Content, Construct	General
Kutner, 2006	National Assessment of Adult Literacy, Health Literacy (NAAL HL)	Original	United States	Not reported	Face, Content	General
Lee, 2006	Short Assessment of Health Literacy for Spanish Adults (SAHLSA-50)	Derivative (REALM)	United States	3 - 6	Face, Content, Construct	General

Morris, 2006	Single Item Literacy Screener (SILS)	Derivative (3 questions)	United States	Not reported	Face, Content, Construct	General
Norman, 2006	eHealth Literacy Scale (eHEALS)	Original	Canada	3	Face, Content	Condition or specialty- specific
Arozullah, 2007	Rapid Estimate of Adult Literacy in Medicine-Short Form (REALM-SF)	Derivative (REALM)	United States	Not reported	Face, Content, Construct	General
Baron-Epel, 2007	Hebrew Health Literacy Scale (HHLS)	Original	Israel	Not reported	Face, Content	General
Diamond, 2007	Nutrition Literacy Scale (NLS)	Original	United States	Not reported	Face, Content, Construct	Condition or specialty- specific
Gong, 2007	Test of Functional Health Literacy in Dentistry (TOFHLiD)	Derivative (TOFHLA)	United States	Not reported	Face, Content, Construct	Condition or specialty-specific

Lee, 2007	Rapid Estimate of Adult Literacy in Dentistry (READ-30)	Derivative (REALM)	United States	Not reported	Face, Content, Construct	Condition or specialty-specific
Erby, 2007	Rapid Estimate of Adult Literacy in Genetics (REAL-G)	Derivative (REALM)	United States	1	Face, Content, Construct	Condition or specialty-specific
Richman, 2007	Rapid Estimate of Adult Literacy in Dentistry (READ-99)	Derivative (REALM)	United States	5	Face, Content, Construct	Condition or specialty-specific
Rudd, 2007	Health Activities Literacy Scale (HALS)	Original	United States	Not reported	Face, Content, Construct	General
Wolf, 2007	No name	Original	United States	Not reported	Face, Content, Construct	General

Hanchate, 2008	Demographic Assessment of Health Literacy (DAHL)	Original	United States	Not reported	Face, Content, Construct	General
Ishikawa, 2008	Functional, Communicative, Critical Health Literacy Scale (FCCHL)	Original	Japan	Not reported	Face, Content, Construct	General
Ishikawa, 2008	Communicative and Critical Health Literacy Scale (CCHL)	Original	Japan	Not reported	Face, Content, Construct	General
Tang, 2008	Chinese Short Test of Functional Health Literacy in Adults (Chinese S-TOFHLA)	Derivative (TOFHLA)	China	Not reported	Face, Content, Construct	General
Lee, 2009	Korean Health Literacy Scale (KHLS)	Original	Korea	20	Face, Content	General

Sabbahi, 2009	Oral Health Literacy Instrument (OHLI)	Original	Canada	20	Face, Content, Construct	Condition or specialty-specific
Steckelberg, 2009	Critical Health Competence Test (CHC)	Original	Germany	90	Face, Content	General
Wallace, 2009	Rapid Estimate of Adult Literacy in Vascular Surgery (REAL_VS)	Derivative (REALM)	United States	< 1	Face, Content, Construct	Condition or specialty-specific
Atchison, 2010	Rapid Estimate of Adult Literacy in Dentistry (REALM-D)	Derivative (REALM)	United States	2	Face, Content, Construct	Condition or specialty-specific
Emmerton, 2010	No name	Original	Australia	Not reported	Face, Content	General

Kumar, 2010	Parental Health Literacy Assessment Test (PHLAT)	Original	United States	21	Face, Content, Construct	General
Lee, 2010	Short Assessment of Health Literacy in Spanish and English (SAHLS & E)	Derivative (REALM)	United States	3	Face, Content, Construct	General
McCormack, 2010	Health Literacy Skills Instrument (HLSI)	Original	United States	38	Face, Content, Construct	General
Osborn, 2010	Brief Estimate of Health Knowledge and Action (BEHKA-HIV)	Original	United States	Not reported	Face, Content, Construct	Condition or specialty-specific
Rawson, 2010	Medical Term Recognition Test (METER)	Original	United States	2	Face, Content, Construct	General

Wu, 2010	No name	Original	Canada	Not reported	Face, Content	General
Yost 2010	Talking touchscreen	Original	United States	18	Face, Content, Construct	General
Galesic, 2011	Graph literacy	Original	Germany United States	10	Face, Content	General
Hahn, 2011	Health Literacy Assessment using Talking Touchscreen Technology (Health LiTT)	Derivative (Talking touchscreen)	United States	18	Face, Content, Construct	General
Ishikawa, 2011	Communicative Health Literacy (CHL)	Derivative (FCCHL)	Japan	5 - 10	Face, Content	General
Levin-Zamir, 2011	Media Health Literacy (MHL)	Original	Israel	Not reported	Face, Content	General
Rubin, 2011	Measure of Interactive Health Literacy (MIHL)	Original	United States	7	Face, Content, Construct	General

Scior, 2011	Intellectual Disability Literacy Scale (IDLS)	Original	United Kingdom India Hong Kong Singapore	Not reported	Face, Content, Construct	Condition or specialty-specific
Stucky, 2011	Two-Stage Rapid Estimate of Adult Literacy in Dentistry (TS-REALD)	Derivative (REALM)	United States	Not reported	Face, Content, Construct	Condition or specialty-specific
Takahashi, 2011	Test for Ability to Interpret Medical Information (TAIMI)	Original	Japan	Not reported	Face	General
Tsai, 2011	Mandarin Health Literacy Scale (MHLS)	Original	Korea	25	Face, Content	General
Begoray, 2012	No name	Original	Canada	Not reported	Face, Content, Construct	General

Diviani, 2012	Cancer Literacy Score (CLS)	Original	Switzerland	Not reported	Face, Content, Construct	Condition or specialty-specific
Kim, 2012	High Blood Pressure- Health Literacy Scale (HBP-HLS)	Original	United States	15	Face, Content, Construct	Condition or specialty-specific
Mazor, 2012	Cancer Message Literacy Test-Listening; Cancer Message Literacy Test-Reading (CMLT-L/CMLT-R	Original	United States	70	Face, Content	Condition or specialty-specific
Pendlimari, 2012	Assessment of Colon Cancer Literacy (ACCL)	Original	United States	Not reported	Face, Content, Construct	Condition or specialty-specific
Yin, 2012	PHLAT-Spanish	Derivative (PHLAT)	United States	Not reported	Face, Content, Construct	General

Appendix C.2: Search strategy

MEDLINE search strategy

1. health literacy.mp.
2. assessment.mp.
3. measure*.mp.
4. tool.mp.
5. indices.mp.
6. instrument.mp.
7. 2 or 3 or 4 or 5 or 6
8. 1 and 7

PsycINFO, Embase, and CINAHL search strategies

1. health literacy/
2. assessment/
3. measure/
4. tool/
5. indices/
6. instrument/
7. 2 or 3 or 4 or 5 or 6
8. 1 and 7

Appendix D: Chapter 6 – Qualitative interview study

- Appendix D.1: Health literacy and online health information interview schedule
- Appendix D.2: Interview study information form
- Appendix D.3: Interview study consent form

Appendix D.1: Health literacy and online health information interview schedule

Preamble: I want to start by asking you some general questions about health literacy and health information. As we go through this interview, I may ask questions that sound like I am testing your academic knowledge of the construct. But this is not what I am trying to do; instead, I am interested in your perspective, from your own experience. If you are not sure about an answer, please do not hesitate to say so.

Part One

Defining health literacy

1. What does the term "health literacy" mean to you?
2. To what extent do you see health literacy as a characteristic of individuals or populations? Does it relate to people or to health systems or both?
    a. *To what extent do you think it is about:*
        i. *People's ability to pronounce words, such as drug names?*
        ii. *Confidence during clinical encounters?*
        iii. *Something to do with the ability to obtain health services?*
        iv. *Communication with practitioners?*

        If participant responds 'yes' to any of these, ask "Can you say a little more about that?"

    b. *Do you think clinical interactions are intimidating to average people? If yes, what aspects of them are intimidating?*
3. Which groups in society do you think of as being likely to have high health literacy? Low health literacy?
    a. *Doctors? Journalists? Scientists? Patients who have had a long-term condition for a long time?*
    b. *How would you know if they have high or adequate health literacy? Through measuring it, or through something they do or say?*
    c. *Do you think you can you tell through how people present themselves?*
4. How does health literacy influence people's health outcomes?
    a. What does it 'do' for people, to have this capacity called health literacy?
        i. Are they able to understand better what a practitioner tells them? Is it that they are able to follow directions better and this improved compliance results in better health?
        ii. Are they better able to engage in self-care?

Part Two

Use and outcomes related to online health information

5. What are the most significant barriers to people getting the most out of health information?
    a. For example, lack of understanding of technology?
    b. To what extent is this due to the length of clinical encounters?

    c. *Do you think it is necessary for people to discuss information with their practitioners to get the most out of it?*
6. What does health information do for people?
    a. *For example, does it improve their ability to take medications properly?*
    b. *Does it help them to feel more in control of their care?*
    c. *What other effects does it have?*
7. What is the role of online health information, from the perspective of the health system?
    a. *Does it support the shift of responsibility from the health system to the patient? How about from the practitioner to the patient?*
8. If we assume that a lack of health literacy makes it more difficult for people to understand health information, to what extent do you think providing information as health experiences, rather than general facts, is valuable?
    a. What concerns, if any, do you have about this approach, particularly related to people's skill in understanding or using health experience information to make decisions, about their own health or others?
9. Personal health records- where patients are in control of their own health information or at the very least have access to it (as in an electronic health record that is also available to the patient)- are currently a popular topic for discussion. They have been suggested to have the potential to improve health and self-care and reduce costs.
    a. It is often suggested that this might be dangerous for patients as a result of their lack of understanding of 'complex medical jargon' or 'frank language' used to describe medical conditions. To what extent do you believe this to be true, and if so, can you suggest ways to deal with this?

Part Three

Conclusion

Thank you for taking the time to answer these questions. Before we finish the interview, thinking back on all the questions I have asked, is there anything else you would like to add about the relationship between health literacy, online information, or health outcomes?

Appendix D.2: Interview study information form

Study title:
Health literacy and online health information: Experts' views

Name, position and contact address of Researcher:
Braden O'Neill, DPhil Candidate
Department of Primary Care Health Sciences, University of Oxford
New Radcliffe House, Radcliffe Observatory Quarter
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braden.oneill@univ.ox.ac.uk
+44 (0)7502 313384

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?
This study aims to understand experts' conceptualization of health literacy and views on how and why lay people and patients use health information (including patient education information, health service quality reports, and personal health data), and how this relates to health outcomes. It will involve one interview.

Why have I been invited to participate?
You have been selected due to your relevant expertise and experience regarding health literacy and/or health information and/or health services research, policy or practice.

Do I have to take part?
It is up to you to decide whether or not to take part. You can ask questions about the study before deciding to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. There is no penalty if you withdraw from the study.

What will happen to me if I take part?
The principal investigator will conduct a digitally recorded interview using a structured guide designed for the study, which will last approximately one hour. You will be asked to answer a series of questions and provide your opinions and viewpoints regarding the relationship between health literacy, patient information and health outcomes. The interview will take place in a location of your convenience.

What are the possible benefits of taking part?
By taking part, you will support a thesis project that aims to understand and improve access to efficacious health information for people with a variety of conditions, and further understanding of health literacy and how it affects health outcomes.

Will what I say in this study be kept confidential?
Data generated by the study will be retained in accordance with the University's policy on academic integrity. The data generated in the course of the research will be kept securely in electronic form for a period of ten years after the completion of the research project. Identifiers will be removed and data reported in such a way as to protect your identity. The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research. If you agree to participate in this project, the research will be written up as a component of a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published with open access, which means that it will be available to every Internet user.

What risks are involved in the study?
There are no known risks to taking part in the study.

What if there is a problem?
If you have a concern about any aspect of this project, please speak to the researcher concerned who will do his/her best to answer your query. If you remain unhappy and wish to make a formal complaint, please contact the Research Ethics Committee at the University of Oxford (ethics@medsci.ox.ac.uk; Medical Sciences Inter-Divisional Research Ethics Committee, Medical Sciences Divisional Office, Level 3 John Radcliffe Hospital, Oxford, OX3 9DU, UK).

What should I do if I want to take part?
Email the principal investigator at braden.oneill@univ.ox.ac.uk or call at +44 (0)7502 313384. You will be sent a consent form to sign and return, and the principal investigator will arrange a time and location for the interview at your convenience.

What will happen to the results of the research study?
The results will be written up for publication in a peer-reviewed journal and will also be included in the principal investigator's thesis. A copy of the final results will be made available to you at the conclusion of the study.

Who is organising and funding the research?
The researcher is conducting this study as a component of a DPhil in Primary Health Care at the University of Oxford.

Who has reviewed the study?
This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.

Date 2 February 2013

Appendix D.3 Interview study consent form

Study title: Health literacy and online health information: Experts' views

Name, position and contact address of Researcher:
Braden O'Neill, DPhil Candidate
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What is the purpose of the study?
This study aims to understand experts' conceptualization of health literacy and views on how and why lay people and patients use health information (including patient education information, health service quality reports, and personal health data), and how this relates to health outcomes. It will involve one interview.

	Please initial box
I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions, and that I have received satisfactory answers to these questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without penalty.	☐
I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
I understand that personal data will be kept securely in an electronic format for 10 years after it is collected, and that any personal data included in publications or in the principal investigator's thesis will be fully anonymized.	☐
I understand the process by which to raise a concern and make a complaint if this becomes necessary.	☐
I agree to take part in the above study.	

	Please tick box	
	Yes	No
I agree to the interview being audio recorded.	☐	☐
I agree to the use of anonymised quotes in publications.	☐	☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix E: Chapter 7 – Systematic and realist review

- Appendix E.1: Quality assessment of included studies[15]
- Appendix E.2: Primary outcomes and effects on other outcomes by health literacy level[15]
- Appendix E.3: Search strategy

[15] References for the studies included in this appendix are available in the reference section of Chapter 7 (section 7.8, page 183).

Appendix E.1: Quality assessment of included studies[16]

First author, year of publication	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessors (detection bias)	Incomplete outcome data (attrition bias)	Incomplete / selective outcome reporting (reporting bias)	Other bias (e.g. sample size calculated and met)	Risk of bias
Miller, 2011	Unclear: method not reported	Unclear: method not reported	Unclear: method not reported	Low: outcome assessors were blinded	Low: analysis according to ITT principles	Low: all outcomes reported	Low: sample size calculated and appropriate number of participants enrolled	Moderate
Glasgow, 2011	Unclear: method not reported	Unclear: method not reported	High: reported that participants and personnel not blinded	High: reported that outcome assessors	Low: analysis according to ITT principles	High: all outcomes reported, but reported as correlations with usage data	Unclear: no description of calculation	High

[16] Each study received a judgment of "low" "high" or "unclear" risk of bias for each criterion. Quality score was based on overall uncertainty or evidence of bias, resulting in a judgement of "low" "moderate" or "high" risk of bias for each study.

Gerber, 2005	Unclear: method not reported	Unclear: method not reported	Unclear: method not reported	Unclear: method not reported	High: participants lost to follow up (25%; 61/244) excluded from analysis	Low: all outcomes reported	Low: sample size calculated and appropriate number of participants enrolled	High
Porter, 2011	Unclear: method not reported	Unclear: method not reported	High: reported that participants and personnel not blinded	High: reported that outcome assessors	High: reported as "intention to treat" analysis, but excluded one randomized participant from analysis	Low: all outcomes reported	Low: sample size calculated and appropriate number of participants enrolled	Moderate
Bickmore, 2010	Unclear: method not reported	Unclear: method not reported	Unclear: method not reported	High: reported that outcome assessors	High: participants lost to follow up not included in analysis	Low: all outcomes reported	Unclear: no description of calculation	High
Vargas, 2010	Unclear: method not	Unclear: method not	Unclear: method not	High: reported that	High: participants lost to	Low: all outcomes	Unclear: no description of	High

	reported	reported	reported	outcome assessors were not blinded	follow up (1/48; 2.1%) excluded from analysis	reported	calculation	

Appendix E.2: Primary outcomes and effects on other outcomes by health literacy level

First author, publication date	Name of intervention	Health literacy measure used	Primary outcome(s)	Overall results for primary outcome(s)	Did it work for people with low HL?	Did it work for people with high HL?
Miller, 2006	No name	Test of Functional Health Literacy in Adults (TOFHLA)	Receipt of colorectal cancer screening within 24 weeks of study enrolment	Adjusted OR 1.7 (95% CI= 0.88 - 3.2)	Yes; improved odds of reporting a test preference [adjusted OR 3.9 (95% CI 1.7, 8.7)] and readiness for screening [adjusted OR 4.9 (95% CI 1.4, 16.4)	Yes; improved odds of reporting a test preference [adjusted OR 9.8 (95% CI 3.0, 32.4)] and readiness for screening [adjusted OR 5.7 (95% CI 1.1, 30.2)
Glasgow, 2011	"My Path to Healthy Life/Mi Camino a la Vida Sana" with + without social support (two interventions)	Short Test of Functional Health Literacy in Adults (STOFHLA)	Medication adherence (outcomes reported as correlations with website use)	r = 0.11, no p value reported	Unclear; "participants who had moderate to lower health literacy, or who had little baseline computer use were as engaged with the website as other participants"	Unclear; "participants who had moderate to lower health literacy, or who had little baseline computer use were as engaged with the website as other participants"
			Physical activity	r = 0.00, no p value	See above	See above

			(outcomes reported as correlations with website use)	reported		
			Dietary fat intake (outcomes reported as correlations with website use)	r = -0.31, p < .01 (negative correlation indicates higher fat intake)	See above	See above
			Eating behaviours (outcomes reported as correlations with website use)	r = 0.20, p < .05 (positive correlation indicates improved eating behaviours)	See above	See above
Gerber, 2005	No name	Short Test of Functional Health Literacy in Adults (STOFHLA)	HbA1c	-0.2 (SD 2.0) in low health literacy group; 0.3 (SD 1.6) in high health literacy group (where negative change indicates reduction in	Yes; those in low health literacy group had significant improvement in HbA1c	No significant improvement in any outcome

				HbA1c)		
Porter, 2011	No name	Test of Functional Health Literacy in Adults (TOFHLA)	NASA TLX total weighted score	Standardized mean difference= 0.35 (95% CI= 0.06 - 0.65)	Yes; computer intervention had lower 'task burden'	Yes; computer intervention had lower 'task burden'
Bickmore, 2010	Embodied Conversational Agent (ECA) (evaluated in trial: "A RCT to Reduce Cardiopulmonary Rehospitalization")	Rapid Estimate of Adult Literacy in Medicine (REALM)	Usability	78% of participants scored 7/7 (with 7 = "very satisfied")	Unclear; authors suggested that "differences… indicated that [the intervention] may be even more acceptable to this population than to patients with adequate health literacy"	Unclear; authors suggested that "differences… indicated that [the intervention] may be even more acceptable to this population than to patients with adequate health literacy"
			Attitudes toward the agent	Scored "well above the Likert scale midpoint" on overall mean "Working Alliance Bond" subscale scores	Unclear; see above	Unclear; see above
	Embodied Conversational Agent (ECA)		Usability	Participants with 'inadequate'	No; see description at left	Unclear; see description at left

	(evaluated in trial: "Computer Agents to Promote Walking in Older Adults with Low Health Literacy")			health literacy completed fewer home-based conversations with the ECA compared to participants with 'adequate' health literacy ($p<0.05$)		
			Attitudes toward the agent	Scored "well above the Likert scale midpoint" on overall mean Working Alliance Bond subscale scores	No; respondents scored "a greater degree of personification of the agent (mutual understanding) and a lower level of understanding of the technology (thinking the agent would discontinue use if the participant said the wrong thing) by participants with inadequate health	Unclear; these results were not reported

					literacy”	
Vargas, 2010	Asthma Screening Questionnaire-electronic (ASQ-e)	Short Test of Functional Health Literacy in Adults (STOFHLA)	Concordance	68% concordance in intervention group versus 54% concordance in control group (p <0.01)	Yes; outcomes presumed to be equivalent in both health literacy groups	Yes; outcomes presumed to be equivalent in both health literacy groups
			Usability and satisfaction	95.8% of participants in intervention group "found it simple to use, felt comfortable responding to questions, and found the screens and instructions clear and easy to understand"	Yes; outcomes presumed to be equivalent in both health literacy groups	Yes; outcomes presumed to be equivalent in both health literacy groups

Appendix E.3: Systematic review search strategies

MEDLINE search strategy

1. health education/

2. consumer health information/

3. patient education as topic/

4. health promotion/

5. counseling/

6. information dissemination/

7. information services/

8. (inform* adj5 (patient* or client* or consumer* or user* or carer* or caregiver* or care giver*)).tw.

9. or/1-8

10. exp educational technology/

11. communications media/

12. medical informatics/

13. information systems/

14. exp computers/

15. software/

16. online systems/

17. user computer interface/

18. computer graphics/

19. Internet/

20. (Internet or web or website*).tw.

21. video recording/

22. computer assisted instruction/

23. (computer adj (assisted or based or mediated or generated)).tw.

24. computeri#ed.tw.

25. (interactive adj3 (program* or software or online or on-line or media or technolog* or communication or health*)).tw.

26. video games/

27. (multimedia or multi media or video* or dvd* or film? or television or cd-rom* or animation or audiovisual* or audio visual*).tw.

28. ((audio* or cassette* or tape? or compact dis* or cd or cds or radio or smartphone? or phone? or telephone? or iphone? or helpline*) and (visual or print* or written or text or pamphlet* or leaflet* or flyer* or brochure* or booklet* or publication* or card? or graphic* or picture* or image* or pictorial* or pictogram* or illustrat* or computer* or software or program* or online or on-line or email* or mail* or letter*)).tw.

29. telemedicine/

30. (e-health or ehealth).tw.

31. or/10-30

32. literac*.mp.

33. randomized controlled trial.pt.

34. controlled clinical trial.pt.

35. randomized.ab.

36. placebo.ab.

37. drug therapy.fs.

38. randomly.ab.

39. trial.ab.

40. groups.ab.

41. or/33-40

42. exp animals/ not humans.sh.

43. 41 not 42.

50. 9 and 31 and 32 and 43

CENTRAL search strategy

#1

“health education”:kw

#2

((patient or client) next education):kw

#3

“health promotion”:kw

#4

counseling:kw

#5

((patient or medical or health) next information):kw

#6

(information next (service or dissemination)):kw

#7

(inform* near (patient or client or consumer or user or carer or caregiver or care-giver)):ti,ab

#8

(“medical information” or (health next (education or information or communication or promotion))):ti,ab

#9

((educat* or instruct* or advis* or advice* or counsel* or teach* or train* or coach* or learn*) and (patient or client or consumer or user or carer or caregiver or care-giver)):ti,ab

#10

teaching:kw

#11

learning:kw

#12

“education program”:kw

#13

MeSH descriptor Educational Technology explode all trees

#14

((communication or telecommunication or mass or instructional) next media):kw

#15

((information or online or on-line) next system):ti,ab,kw

#16

“medical informatics”:kw

#17

MeSH descriptor Computers explode all trees

#18

“computers”:kw

#19

MeSH descriptor Software, this term only

#20

(internet or web or website):ti,ab,kw

#21

“computer assisted instruction”:kw

#22

(computer next (assisted or based or mediated or generated)):ti,ab

#23

computeri?ed:ti,ab,kw

#24

(interactive near/3 (program or software or online or on-line or media or technolog* or communication or health*)):ti,ab

#25

((video or computer) next games):ti,ab,kw

#26

((audio* or cassette* or tape? or compact dis* or cd or cds or radio or smartphone? or phone? or telephone? or iphone? or helpline*) and (visual or print* or written or text or pamphlet* or leaflet* or flyer* or brochure* or booklet* or publication* or card? or graphic* or picture* or image* or pictorial* or pictogram* or illustrat* or computer* or software or program* or online or on-line or email* or mail* or letter*)):ti,ab,kw

#27

(telehealth or telemedicine or e-health or ehealth*):ti,ab,kw

#28

#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12

#29

#13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27

#30

Literac*:ti,ab,kw

#31

#28 and #29 and #30

PsycINFO search strategy

1. health education/

2. client education/

3. health promotion/

4. counseling/

5. information dissemination/

6. information services/

7. (inform* adj5 (patient* or client* or consumer* or user* or carer* or caregiver* or care giver*)).ti,ab,id.

8. or/1-7

9. exp audiovisual instruction/

10. instructional media/

11. exp audiovisual communications media/

12. communications media/

13. exp electronic communication/

14. exp human computer interaction/

15. exp information systems/

16. exp computers/

17. computer software/

18. exp computer assisted instruction/

19. (internet or web or website* or portal*).ti,ab,id.

20. websites/

21. (computer adj (assisted or based or mediated or generated)).ti,ab,id.

22. (interactive adj3 (program* or software or online or on-line or media or technolog* or communication or health*)).ti,ab,id.

23. (multimedia or multi media or video* or dvd* or film? or television or cd-rom* or animation or audiovisual* or audio visual*).ti,ab,id.

24. ((audio* or cassette* or tape? or compact dis* or cd or cds or radio or smartphone? or phone? or telephone? or iphone? or helpline*) and (visual or print* or written or text or pamphlet* or leaflet* or flyer* or brochure* or booklet* or publication* or card? or graphic* or picture* or image* or pictorial* or pictogram* or illustrat* or computer* or software or program* or online or on-line or email* or mail* or letter*)).ti,ab,id.

25. telemedicine/

26. (telehealth or telemedicine or telepharmac* or e-health or ehealth or e-pharmac*).ti,ab,id.

27. or/9-26

28. literac*.mp.

29. random*.ti,ab,hw,id.

30. trial*.ti,ab,hw,id.

31. placebo*.ti,ab,hw,id.

32. ((singl* or doubl* or trebl* or tripl*) and (blind* or mask*)).ti,ab,hw,id.

33. (cross over or crossover or factorial* or latin square).ti,ab,hw,id.

34. (assign* or allocat* or volunteer*).ti,ab,hw,id.

35. or/29-34

36. 8 and 27 and 28 and 35

Appendix F: Chapter 8 – Randomized controlled trial

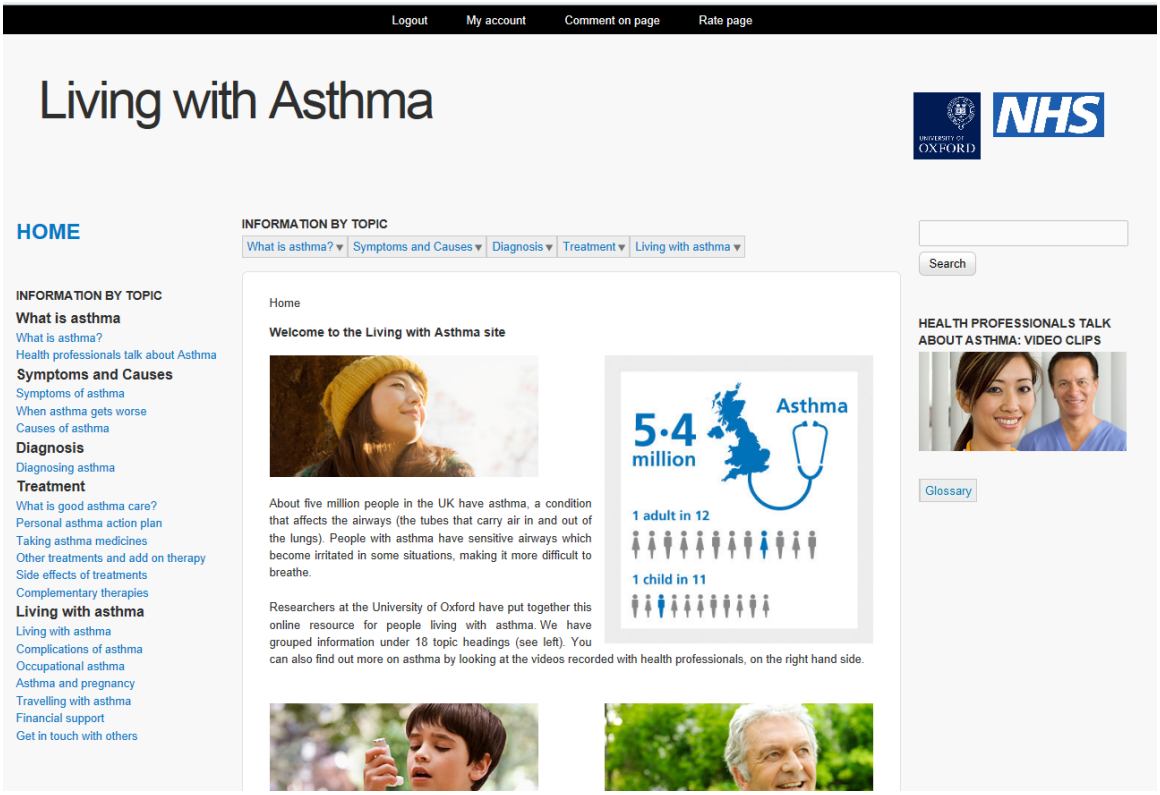
- Appendix F.1: Trial website screenshots

Appendix F.1: Trial website screenshots

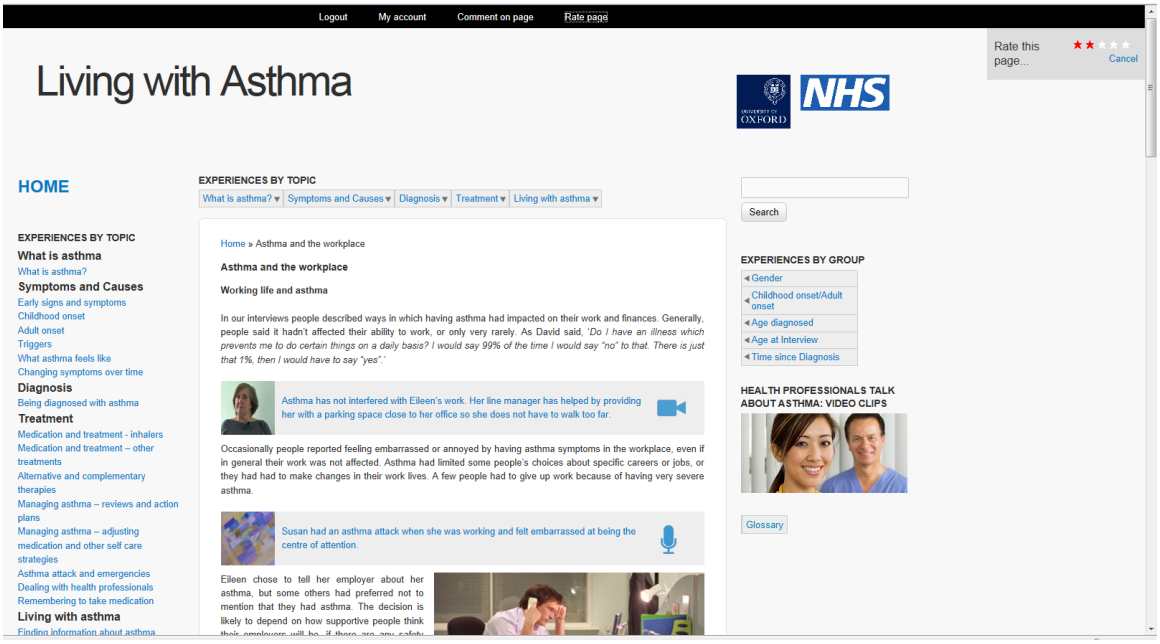
1. ‘Personal experiences’ (intervention) website main page



2. ‘Facts and figures’ (control) website main page



3. ‘Personal experiences’ website rating page



Appendix G: Publications from thesis

- **O'Neill B**, Ziebland S, Valderas JM, Lupiañez-Villanueva F. User-generated online health content: a survey of Internet users in the United Kingdom. J Med Internet Res. 2014 Apr 30;16(4):e118.

Original Paper

User-Generated Online Health Content: A Survey of Internet Users in the United Kingdom

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Abstract

Background: The production of health information has begun to shift from commercial organizations to health care users themselves. People increasingly go online to share their own health and illness experiences and to access information others have posted, but this behavior has not been investigated at a population level in the United Kingdom.

Objective: This study aims to explore access and production of user-generated health content among UK Internet users and to investigate relationships between frequency of use and other variables.

Methods: We undertook an online survey of 1000 UK Internet users. Descriptive and multivariate statistical analyses were used to interpret the data.

Results: Nearly one-quarter of respondents (23.7%, 237/1000) reported accessing and sharing user-generated health content online, whereas more than 20% (22.2%, 222/1000) were unaware that it was possible to do this. Respondents could be divided into 3 groups based on frequency of use: rare users (78.7%, 612/778) who accessed and shared content less than weekly, users (13.9%, 108/778) who did so weekly, and superusers (7.5%, 58/778) who did so on a daily basis. Superusers were more likely to be male (P<.001) and to be employed (P<.001), but there were no differences between the groups with respect to educational level (P=.99) or health status (P=.63). They were more likely to use the Internet for varied purposes such as banking and shopping (P<.001).

Conclusions: Although this study found reasonably widespread access of user-generated online health content, only a minority of respondents reported doing so frequently. As this type of content proliferates, superusers are likely to shape the health information that others access. Further research should assess the effect of user-generated online content on health outcomes and use of health services by Internet users.

(J Med Internet Res 2014;16(4):e118) doi:10.2196/jmir.3187

KEYWORDS

eHealth; consumer health information; patient education; health education; health promotion; social media; superusers

Introduction

Background

There can be little doubt that the Internet has changed the way that people experience health and illness. People routinely use the Web to learn about the meaning of symptoms, tests, diagnoses and treatments, and to find out how others have rated doctors and hospitals [1]. In the United Kingdom, more than two-thirds of residents use the Internet to obtain health information [2], and the UK Department of Health considers

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availability of high-quality information a key policy objective [3]. The Internet once provided information that could be accessed and viewed, but not easily modified. Patients increasingly go online to share information and to access information others have posted on the Internet, including their own experiences. Although this is a widespread practice, especially for long-term conditions [4], relatively little is known about the characteristics of people who share and access user-generated content (UGC) online. This is in contrast to general online health information-seeking behavior which has been extensively studied [1,3,4]. In this paper, we draw on a major European survey to explore who shares and accesses user-generated health content online in the United Kingdom.

User-Generated Health Content

User-generated health content is presented in many different ways across different types of websites [5]. Traditional, commercially produced online health content (developed by businesses or health systems or governments) has predominantly consisted of facts and figures, such as numerical data related to the diagnosis or prognosis of a condition. User-generated health information, by virtue of its distributed, often informal development and dissemination, is a broad concept and incorporates anything that a patient or carer posts online for the purpose of others seeing it. Entwistle et al [6] noted that online health information can be broadly divided into 2 categories: general facts and personal experiences. Although these categories are not mutually exclusive, the differences have important implications. General facts consist of information about particular conditions, treatments, or services, and are intended to be broadly applicable to many people interested in the same topic. Personal experiences may also provide information about conditions, treatments, or services, but are often in narrative form and portray an individual's experience of undergoing a particular treatment or of living with a long-term condition. People tend to draw on both general facts and personal experiences, depending on the issue involved [6,7]. It has been noted that adequate information is an important aspect of health care delivery that matters to patients [8].

General health information sites often provide UGC in the form of curated experiences selected by the site's developers and the ability for site users to post their own comments. There are sites exclusively devoted to interview-based research on health experiences; for example, the UK's Healthtalkonline has been available for more than a decade and now has many counterparts in other countries [9]. Blogs enable people to post their stories over time and provide the facility to embed video and links to other content, including peer-reviewed journal articles where applicable. Social networking sites enable patients to post content (both facts and experiences) and have pages devoted to specific conditions and treatments. Online forums host pages for specific conditions and facilitate patients coming together who have similar diseases or have undergone similar treatments. Some sites include crowdsourcing: "an approach to accomplishing a task by opening up its completion to broad sections of the public" [10]. For example, the website PatientsLikeMe aggregates data provided by site users. Patients can compare their data with aggregated input from other site users, and data obtained through crowdsourcing can be used for research [11]. Finally, there are those sites that enable a health service user to write and read reviews of specific hospitals, doctors, or health systems [12]. Increasingly, websites include several different ways of incorporating content from patients and the public. What all these disparate sources share is that their content depends on people posting, sharing, and comparing health information, whether about themselves or those for whom they care.

Use and Nonuse

One of the predominant places where UGC is accessed and shared online is in the context of virtual support groups for particular conditions as well as individual treatments. The heterogeneity of online support group membership has been reported in several publications; these groups consist of some people who post occasionally and some who are frequent prolific posters. Those who post have been described as key players [13], active users [14], and caretakers [15]. Most people who visit support groups do not actively post. In a study of people accessing an online smoking cessation group, 84.7% of those who registered and accessed the resource at least once never posted [16]. To explain this distribution, the "1% rule" has been adapted from marketing literature to the use of health social networks, suggesting that 90% of actors observe but do not participate, 9% rarely contribute, and 1% create most of the content [17]. This is contextual, and people's behavior may vary between sites if they visit several different sites. Adams [18] has suggested that people may be more motivated to add their own commentary if they feel that their experiences are not covered by others accounts (eg, adverse drug effects). Because the content on these websites is generated by a small proportion of the people who use it, the concept of the "superuser" [17,19] of user-generated online health information—the minority of people who post information online—has received recent attention. This has not been characterized within the United Kingdom.

The Aim of Our Research

The purpose of this paper is twofold. First, we identify characteristics of UK Internet users who access and share UGC online. In this study, we use UGC to denote 4 specific behaviors about which questions were asked in the survey: (1) participating in an online support group for people who are concerned about the same health or medical issue, (2) participating in social networking sites talking about health and wellness, (3) describing a medical condition or problem online to get advice from other online users, and (4) disclosing medical information on social networking sites.

Second, we investigate the frequency with which respondents engage in the aforementioned study behaviors, paying particular attention to those who do so most frequently because these users predominantly generate the content that others view. By grouping respondents according to how frequently they go online to access and share UGC, we aim to characterize the differences between these groups. We aim to determine areas for further research to support the effective and beneficial use of online health information.

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Methods

Survey Instrument and Ethics

We analyzed United Kingdom data from the Citizens and Information Communication Technology for Health survey, a project undertaken in 2011 by the Institute for Prospective Technology Studies of the European Commission's Joint Research Centre. This online survey was developed from a theoretical framework of the social determinants of information and communication technology (ICT) for health, translated into native languages in 14 European Union (EU) member countries. The survey was developed to understand and characterize European citizens' use of ICT for health. It included questions on a range of triggers, motivations, and behaviors. This analysis examines a subset of questions related to user-generated online health content. The full questionnaire is available in Multimedia Appendix 1 [20].

Technical, methodological, and legal considerations were carefully addressed in the context of designing and implementing the survey. These considerations ensured anonymity and confidentiality of individual responses [21-23]. The survey was conducted in accordance with European Society for Opinion and Marketing Research ethical guidelines [24]. At the time the survey was carried out, one of the authors (FLV) was employed by the European Commission.

Sample and Data Collection

The sample consisted of 1000 respondents from the United Kingdom who completed an online survey in 2011 covering a variety of domains regarding the use of ICT for health. We randomly sampled people aged 16 to 74 years who had used the Internet in the 3 months before the survey to obtain the sample.

An online invitation to participate in the survey was sent to 7291 individuals. The data were collected between July 20 and August 1, 2011. Simple random sampling was carried out by the software provider who administered the survey (Cint), then quota sampling was used to accurately reflect the demographic composition of UK residents [25]. We obtained 2410 responses (4881 nonresponses) of which 1320 were out of quota and 90 were excluded because of missing data. The average length of time to complete the questionnaire was 20.5 minutes.

More than half (57.00%, 570/1000) of respondents were employed and nearly all (90.00%, 900/1000) had completed upper secondary or tertiary education (Table 1). This is broadly comparable to the characteristics of the UK population, although it should be noted that this sample is more highly educated than the general UK population [25].

Table 1. Demographic composition of sample.

Age group (years)	Female, n (%)	Male, n (%)	Total, n (%)
16-24	103 (10.3)	106 (10.6)	209 (20.9)
25-54	297 (29.7)	295 (29.5)	592 (59.2)
55-74	98 (9.8)	101 (10.1)	199 (19.9)
Total	498 (49.8)	502 (50.2)	1000 (100.0)

Statistical Analysis

Initially, we calculated descriptive statistics about the characteristics of the study participants. After this, to determine the extent to which the 4 behaviors studied represent an underlying composite variable, we employed principal components analysis (PCA). In carrying out PCA, we a priori defined components explaining adequate amounts of variability in the data as those that have an eigenvalue greater than 1.00 [26]. Because the results of the PCA suggested that all 4 behaviors could be explained by one underlying component, for further analysis we treated this as a single composite variable, which we called "accessing and sharing user-generated health content online."

We then used nonhierarchical *k*-means cluster analysis to characterize respondents based on their reported frequency of accessing and sharing UGC online. We determined differences between the frequency groups by carrying out ANOVA and chi-square tests for categorical and continuous variables, respectively. Data were examined to determine if they met assumptions for the univariate and multivariate statistical tests carried out, and all assumptions were met. Statistical analyses were performed using SPSS version 20.0 (IBM Corp, Armonk, NY, USA).

Results

Frequency of Engaging in Individual Study Behaviors

We found that approximately one-quarter of all respondents participated in online support groups (27.80%, 278/1000) and health-related social networking sites (23.80%, 238/1000) (Table 2). A similar proportion reported describing a medical condition or problem online to get help from other online users (23.10%, 231/1000) and disclosing medical information on social networking sites (16.70%, 167/1000).

Less than 10% of respondents (4.80%, 48/1000 to 7.80%, 78/1000) reported engaging in any of the study behaviors at least or more than once a week. Approximately 20% of respondents (22.20%, 222/1000) reported being unaware that it was possible to engage in these behaviors online.

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Table 2. User-generated content behaviors.

Regarding health, wellness, and the Internet, how often have you...	Frequency, n (%)					
	Never	Less than once a month	At least once a month (but not every week)	At least once a week (but not every day)	Every day or almost every day	Not aware of it
Participated in an online support group for people who are concerned about the same health or medical issue	588 (58.8)	145 (14.5)	66 (6.6)	46 (4.6)	21 (2.1)	134 (13.4)
Participated in social networking sites talking about health and wellness	629 (62.9)	106 (10.6)	54 (5.4)	53 (5.3)	25 (2.5)	133 (13.3)
Described a medical condition or problem online in order to get advice from other online users	628 (62.8)	119 (11.9)	64 (6.4)	25 (2.5)	23 (2.3)	141 (14.1)
Disclosed medical information on social networking sites	660 (66.0)	72 (7.2)	40 (4.0)	33 (3.3)	22 (2.2)	173 (17.3)

Characterizing Predictors of Accessing and Sharing User-Generated Content

Applying cluster analysis to the "accessing and sharing user-generated health content online" composite variable resulted in a 3-cluster solution. After excluding those who did not know that these resources were available (excluded because they have different reasons for nonuse than those who are aware of the possibility and choose to not engage) [26], we were left with 778 responses for further analysis.

Most respondents (78.7%, 612/778) were rare users who reported that they never or very rarely accessed and shared user-generated health content. Users who went online and engaged in these behaviors infrequently (ie, weekly or monthly but not daily) accounted for more than 10% (13.9%, 108/778) of respondents. A further minority (7.5%, 58/778) were clustered as superusers who accessed and/or generated UGC daily.

Sociodemographic Characteristics

Comparing the 3 groups, superusers were more likely to be male than users or rare users (Table 3). Those in the 16-24 years age group were more likely to be superusers than users or rare users, whereas those in the 55-74 years age group were generally rare users, as opposed to superusers or users. Superusers were more likely to be employed (57.8%, 33/58) than unemployed (9.3%, 5/58), students (19.0%, 11/58), or retired/inactive in the labor force (24.0%, 13/58). The groups did not differ on level of education.

Regarding household composition, respondents with children (1-parent, 2-parent, or extended family households) were less likely to be superusers than they were to be users or rare users. There were no differences between the groups based on the number of children younger than 16 years in the household. More rare users and superusers reported that they lived in intermediate areas, as opposed to densely or thinly populated areas, whereas users were more likely to report living in densely populated areas.

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Table 3. Sociodemographic characteristics of respondents (N=778).

Sociodemographic characteristics	Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Gender				.02
Male	301 (49.3)	61 (56.5)	38 (67.2)	
Female	311 (50.7)	47 (43.5)	20 (32.8)	
Age (years)				<.001
16-24	89 (14.7)	39 (36.1)	25 (43.1)	
25-54	370 (60.6)	63 (58.3)	32 (55.2)	
55-74	151 (24.7)	6 (5.6)	1 (1.7)	
Level of education completed				.99
Primary or lower secondary education (ISCED 0-2)[a]	70 (11.4)	14 (13)	7 (12.1)	
Upper secondary education (ISCED 3 or 4)[a]	261 (42.6)	45 (41.7)	26 (44.8)	
Tertiary education (ISCED 5 or 6)[a]	281 (45.9)	49 (45.4)	25 (43.1)	
Occupation				<.001
Employed or self-employed (including family workers)	354 (57.8)	72 (66.7)	31 (53.4)	
Unemployed	57 (9.3)	6 (5.6)	11 (19.0)	
Student (not in the labor force)	54 (8.8)	21 (19.4)	11 (19.0)	
Other not in the labor force (eg, retired, inactive)	147 (24.0)	9 (8.3)	5 (8.6)	
Type of locality				<.001
Densely populated area (cities and large towns)	186 (30.4)	52 (48.1)	18 (31.0)	
Intermediate area (towns)	308 (50.3)	43 (39.8)	36 (62.1)	
Thinly populated area (village and rural)	118 (19.3)	13 (12)	4 (6.9)	
Number of members in the household				.13
1	81(13.2)	11 (10.2)	7 (12.1)	
2	224 (36.6)	36 (33.3)	12 (20.7)	
3	123 (20.1)	22 (20.4)	19 (32.8)	
≥4	184 (30.1)	39 (36.1)	20 (34.5)	
Number of children under 16 years				.08
None	436 (71.2)	67 (62)	32 (55.2)	
1	92 (14.9)	23 (21.3)	12 (22.4)	
2	74 (12.1)	14 (13.0)	10 (17.2)	
>2	11 (1.8)	4 (3.7)	3 (5.2)	
Household composition				.02
Single person ≥65 years	14 (2.3)	1 (0.9)	0 (0)	
Single person <65 years	67 (10.9)	10 (9.3)	8 (13.8)	
2 persons, ≥1 aged ≥65 years	69 (11.3)	6 (5.6)	2 (3.4)	
2 persons, both <65 years	148 (24.2)	26 (24.1)	8 (13.8)	
Single person with child(ren) <16 years	7 (1.1)	5 (4.6)	1 (1.7)	
2 persons with child(ren) <16 years	161 (26.3)	34 (31.5)	20 (34.5)	
2 persons ≥65 years	27 (4.4)	2 (1.9)	3 (5.2)	
Extended family (<16 + 16-64 + <65 years)	6 (1.0)	3 (2.8)	3 (5.2)	
≥3 adults <65	113 (18.5)	21 (19.4)	13 (22.4)	

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[a]ISCED: International Standard Classification of Education [27].

Health Characteristics

We did not identify any differences between groups for health status, undergoing long-term medical treatment, or number of visits to the doctor in the past 12 months (Table 4). Among superusers who reported having someone close to them currently experiencing long-term illness or disability, 64.3% (37/58) reported taking care of them.

Table 4. Health characteristics of respondents (N=778).

Health characteristics	Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Health status reported				.63
Very bad	3 (0.5)	1 (0.9)	1 (1.7)	
Bad	45 (7.4)	7 (6.5)	6 (10.3)	
Neither good or bad	115 (18.8)	24 (22.2)	6 (10.3)	
Good	297 (48.5)	53 (49.1)	28 (48.3)	
Very good	152 (24.8)	23 (21.3)	17 (29.3)	
Long-standing illness or health problem reported				.57
Yes	263 (42.9)	41 (37.5)	25 (43.9)	
No	349 (57.1)	68 (62.5)	33 (56.1)	
Undergoing a long-term medical treatment				.74
Yes	215 (35.1)	35 (32.1)	18 (31.6)	
No	397 (64.9)	73 (67.9)	40 (68.4)	
Visit a doctor during the past 12 months				.29
Yes	512 (83.7)	95 (88.0)	52 (89.7)	
No	100 (16.3)	13 (12.0)	6 (10.3)	
How many times did you visit a doctor during the last 12 months?				.64
None	100 (16.3)	13 (12)	6 (10.3)	
1-2 visits	216 (35.3)	31 (28.7)	21 (36.2)	
3-4 visits	118 (19.3)	27 (25.0)	11 (19.0))	
5-6 visits	70 (11.4)	15 (13.9)	8 (13.8)	
>6 visits	108 (17.6)	22 (20.4)	12 (20.7)	
Is someone close to you currently experiencing long-term illness or disability?				.01
Yes	227 (37.1)	56 (51.5)	29 (50.0)	
No	385 (62.9)	52 (48.5)	29 (50.0)	
Are you taking care of such a person?				.02
Yes	234 (38.2)	39 (35.8)	37 (64.3)	
No	378 (61.8)	69 (64.2)	21 (35.7)	

Online Health Information and Health Behavior

Superusers were more likely than users or rare users to report that the information they accessed affected the way they care for themselves and the way they eat or exercise (Table 5). They were also more likely to report that after accessing health information on the Internet, they subsequently talked to a doctor or nurse about what they found. Finally, superusers were more likely to report accessing information for their children than users or rare users.

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Table 5. Online health information and health behavior of respondents (N=778).

Online health information and health behavior	Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Looking for health and/or wellness information for...				
Yourself	531 (86.7)	102 (94.4)	56 (96.6)	.01
Your child	152 (24.9)	32 (29.6)	26 (44.8)	.004
Parent	158 (25.8)	48 (44.4)	27 (46.6)	<.001
Another relative	194 (31.7)	41 (38.0)	24 (41.4)	.19
Some else	155 (25.3)	39 (36.1)	24 (41.4)	.005
Did you later talk to a doctor or nurse about the information you got online?				<.001
Yes	234 (38.3)	65 (59.8)	43 (74.1)	
No	378 (61.7)	43 (40.2)	15 (25.9)	
Overall, how useful was the health information you got online?				.02
Not at all useful	15 (2.5)	2 (1.9)	0 (0)	
Not too useful	55 (9.0)	5 (4.6)	1 (1.7)	
Somewhat useful	400 (65.3)	71 (65.7)	33 (56.9)	
Very useful	142 (23.2)	30 (27.8)	24 (41.4)	
Did the information you got online affect any of your decisions about health treatments or the way you take care of yourself?				<.001
Yes	201 (32.8)	56 (51.9)	38 (65.5)	
No	411 (67.2)	52 (48.1)	20 (34.5)	
Did the information you got online affect the way you eat or exercise?				<.001
Yes	171 (28.0)	56 (52.0)	40 (69.8)	
No	441 (72.0)	52 (48.0)	18 (30.2)	

Internet Activity

Almost all superusers (94.8%, 55/58) reported engaging in 11 or more Internet activities (eg, online banking, keeping a blog, and looking for travel information), whereas approximately one-quarter of rare users (26.6%, 163/612) reported the same engagement with other Internet activities (Table 6). Similarly, nearly three-quarters of superusers (74.1%, 43/58) reported accessing the Internet through 3 or more devices (eg, a home computer, work computer, and smartphone), which contrasts with less than one-third (29.4%, 180/612) of rare users doing the same.

Table 6. Internet activities and devices of respondents (N=778).

Internet activities and devices	Rare users, n (%) n=612	Users, n (%) n=108	Superusers, n (%) n=58	*P*
Breadth of Internet use (number of Internet activities)				<.001
1-5	109 (17.8)	2 (1.9)	1 (1.7)	
6-10	340 (55.6)	25 (23.1)	2 (3.4)	
≥11	163 (26.6)	81 (75)	55 (94.8)	
Breadth of Internet access (number of Internet devices)				<.001
1	203 (33.2)	15 (13.9)	7 (12.1)	
2	229 (37.4)	27 (25.0)	8 (13.8)	
≥3	180 (29.4)	66 (61.1)	43 (74.1)	

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Discussion

Principal Findings

Within the past few years, a rapid expansion of technologies that people can use to generate their own Internet content has provided novel opportunities for members of the general population to share and access health information. Social media have facilitated this ever-growing shift from the production of health information online being in the hands of commercial enterprise and health systems, to being led by users themselves. This study, the first to investigate user-generated health content on the Internet in the United Kingdom, sought to understand this growing trend through people's responses to survey questions. One of the more striking findings in this study is that one-quarter of this sample of UK Internet users reported accessing and/or posting user-generated health information online. Because this is the first study of its kind in the United Kingdom, there are no equivalent data from which to study trends.

As has been repeatedly shown in studies of online health support groups, most participants do not actively post their own content, although they read what others have written [13-17]. Although it is not possible to directly measure the activity of these "lurkers," they represent such a large proportion of those engaged with UGC that we should see this as "normal" online behavior. Further exploration of the motivations and usage of UGC by these passively engaged individuals is required. By grouping responses to this survey according to the frequency with which people reported accessing and sharing UGC, we sought to understand the characteristics of people who are highly engaged in these behaviors—the superusers. Although our data do not provide information on the effects of UGC, our findings characterizing the 7.5% of respondents classified as superusers is valuable in describing the group who may be generating the content that others are viewing.

These superusers are predominantly male. Respondents in the youngest age category (16-24 years) are more likely to be superusers, whereas those in the oldest age category (55-74 years) are generally rare users. Superusers carry out more varied activities on the Internet, such as online banking and booking travel, than the users and rare users. Despite these differences, our results suggest that there are no differences in health status or health service use between the superusers and the other 2 groups. This suggests that people who are well may be as responsible for producing our online health content as people who are ill. To our knowledge, this is the first explication that UGC does not appear to be associated with self-reported use of health services. This study did not distinguish between the use of information that provides guidance for a diagnosis or treatment of a health condition, and information shared or accessed by people who are healthy and either seeking or offering lifestyle advice. Several possible mechanisms have been identified by which UGC and, in particular, others' experiences may affect health, such as finding information, feeling supported, and experiencing health services [5]. Therefore, our results are congruent with the contingent model of health information use, which suggests that health information is one important component of a health care experience, rather than as something that displaces or reduces use of health services [28].

It was surprising that about 20% of participants were unaware of the availability of UGC on the Internet, particularly as this was a sample of Internet users. The outcomes of UGC are unclear; therefore, we would not necessarily recommend interventions to increase access. Further research should focus on reasons why these individuals, who have access to the Internet and are motivated to complete a health survey, are unaware of the availability of this increasingly ubiquitous content.

Previous studies of health-seeking behavior on the Internet have found that females more commonly access health information on the Internet than males [1,4]. However, in the present study, superusers were more likely to be male. It has been suggested that men rate their self-assessed online skills higher than women do, which is one possible explanation for higher reported use of these complex online resources by men [29]. Although our data did not provide an opportunity to examine this issue further, it is an important area for future research as it guides content development and implementation.

Limitations

The survey used in this study was administered online. Administering a survey in this way enables rapid data collection, reduces administrative burden, and is cost-effective. It may cause selection bias because those who do not have Internet access as well as adequate digital skills are excluded [30]. In this study, rare users may have been excluded because of a lack of digital skills. Those with chronic illness may also have been less inclined to participate in an online survey or excluded because of fatigue or disability. Another limitation is the use of quota sampling (done to facilitate international comparisons in the overall survey), which reduces the generalizability of the results of this analysis to the overall population when compared with a true random sample. Although the sample was selected to be representative of UK Internet users, subsequent studies with different designs might sample purposively for superusers to explore their behavior and motivations more fully. Further research focusing on smaller age categories and going deeper into some of the life-cycle variables that may affect use of online health information (eg, parenting or retirement) would be useful as well. Furthermore, this study reports a secondary analysis of a larger survey on people's use of the Internet for health. Some potential areas of inquiry relevant to UGC were not included in the original survey, such as its use to obtain social support and to select health services based on others' experiences [5]. Finally, this study reports cross-sectional data, which precludes determining causal relationships. Because this is the first study of its kind in the United Kingdom, it is exploratory in nature and does not evaluate effects of UGC.

Conclusions

This study reports results of the first representative sample of UK Internet users that investigates accessing and sharing user-generated health content online. Within the context of available surveys from other countries, our results suggest that

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UGC may be increasingly popular among those who are healthy and who have chronic conditions alike, and that a minority of people who frequently access and share may be primarily responsible for generating the majority of content that others view.

The potential benefits of ICT for health are vast, but it is likely that some online resources are effective and desirable for some people and they are not for others. Understanding the contexts in which they are helpful is important to be able to support individual patients, public health initiatives, and to develop information policy and strategy in clinics and health systems. Through understanding characteristics of those who already participate in accessing and sharing user-generated health content online, as well as the differences between groups of users based on the frequency with which they do so, the results of this study bring clarity to this important issue regarding use of ICT for health information. These findings inform an agenda for further research to identify why people access and share UGC, what the impact is on health behaviors and outcomes, and if expanding engagement with user-generated health content online is likely to be beneficial.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

"Citizens and Information Communication Technology for Health" survey.

[PDF File (Adobe PDF File), 6MB - jmir_v16i4e118_app1.pdf]

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Abbreviations

EU: European Union
ICT: information and communication technology
PCA: principal components analysis
UGC: user-generated content

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